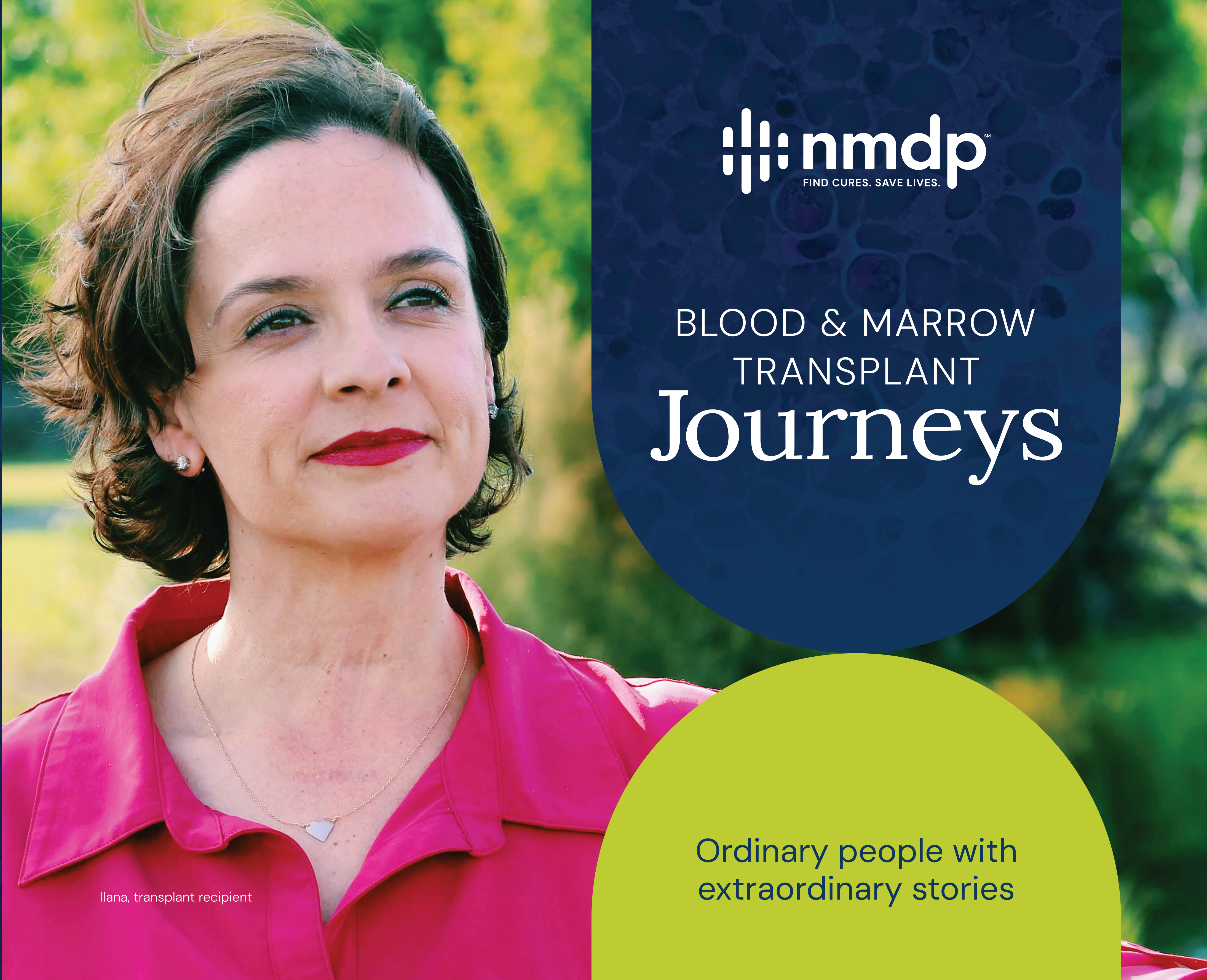
BLOOD & MARROW TRANSPLANT Journeys

nmdp

FIND CURES. SAVE LIVES.

BLOOD & MARROW TRANSPLANT Journeys

Ordinary people with extraordinary stories



Ilana, transplant recipient

Blood & marrow transplant journeys:
ordinary people with extraordinary stories

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About NMDP

At NMDP, we believe each of us holds the key to curing blood cancers and disorders. As a global nonprofit leader in cell therapy, NMDP creates essential connections between researchers and supporters to inspire action and accelerate innovation to find life-saving cures. With the help of blood stem cell donors from the world's most diverse registry and our extensive network of transplant partners, physicians and caregivers, we're expanding access to treatment so that **every** patient can receive their life-saving cell therapy. **NMDP. Find cures. Save lives**.

Every individual's medical situation, transplant experience and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.

Learn more at nmdp.org/one-on-one
or call **1 (888) 999-6743**.

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Wanda Zimmer, transplant recipient and NMDP supporter

Foreword by Wanda Zimmer

The most vivid memory of my cancer journey was when I received the date for my blood stem cell transplant. The agony of having to tell my children was overwhelming. My 16-year-old daughter asked me, "Mom, are you going to be here when I get married?" Those words made my own mortality very real as I had to tell her the honest truth: "I don't know."

My husband and I moved 7 hours away to receive my transplant. The family and friends that I could count on if I needed physical or emotional support were no longer close by. At that point, I knew if I were going to beat this, I would have to be my own advocate. I braced myself mentally for my long stay in the hospital, but the day before I was admitted, my doctor called with the dreaded words, "Go home, Wanda. Your donor backed out, and we don't have another one for you."

He was my only fully matched potential donor. My only HOPE. I took the steering wheel and drove the long journey home with my husband sobbing at my side. Something inside told me to fight on and if I wavered emotionally, I was going to lose this battle. While waiting for another donor, I ended up in a coma with septic shock. I awoke to the news that NMDP had found another donor for me—not a fully matched donor, but one that might be the key to survival. In the end, my second donor saved my life, becoming the match I needed after all. My "perfect stranger" and his family are now our family.

During my hospital stay, I learned so much about myself. I learned I was stronger than I thought. I learned compassion for others. Most of all, I learned that in the end I was the catalyst to saving my own life. I took charge of my life because I knew no one was going to be a bigger advocate for myself than me. And with that empowerment, I had **HOPE.**

When you read the stories in this book, you'll see the common thread that runs through them is **HOPE**. I'd like to share with you a written inspirational quote from Nikki Banas that carried me through the darkest of times.

"If you only carry one thing throughout your entire life, let it be hope.

Let it be hope that you can get through even the toughest of times.

Let it be hope that you are stronger than any challenge that comes your way.

Let it be hope that you are exactly where you are meant to be right now, and that you are on the path to where you are meant to be…

Because during these times, hope will be the very thing that carries you through."

—Nikki Banas

"I'm here today, living the life I could not imagine 12 years ago. When my daughter got married, I was sitting in the front row cheering her on. **Never give up on HOPE.**"

—Wanda Zimmer

Dedicated to all patients, caregivers and families.
As you venture through your own BMT journey,
we stand by you.

Dear reader,

As you prepare for a blood or bone marrow transplant (BMT), I hope you find solace, encouragement and a sense of community within these pages. While each BMT journey is unique, there are shared experiences that bind us together.

Reflecting on your experiences can be a powerful part of the healing process. But it can be challenging to know where to begin.

In this book, you'll read stories from people just like you who have walked this path before you. They're patients and caregivers who have navigated the landscape of diagnosis, treatment, transplant and the road to recovery.

Their stories span a range of emotions and perspectives, from the initial shock of a diagnosis to the triumphs and setbacks along the way. You may find echoes of your own journey or gain new insights from differing viewpoints.

What unites these storytellers is their courage to do good by sharing their experiences to help others. Here, you'll find understanding, inspiration and hope from those who have been there.

At its heart, this collection is a testament to the power of community and the comfort that comes from knowing you're not alone. We're deeply grateful to everyone who shared their story.

Please know that we are with you throughout your BMT journey. If you need support, information or resources, our NMDP Patient Support Center is just a call, text or email away. You can reach us at **1 (888) 999-6743** or **patientinfo@nmdp.org**. Our dedicated team of BMT patient navigators and social workers is here to help.

With warmth and care,

Amy Ronneberg

Amy Ronneberg
Chief Executive Officer, NMDP

Ilana, transplant recipient

CHAPTER 1:

Letters and advice

Dear 2003 Ilana,

By Ilana, transplant recipient

You will be scared. I wish that I could be there to tell you what is about to happen. I wish I could be there to hold your hand. I wish I could be there to tell you you're going to be alright.

You will be part of a community. When they first said "transplant," I know how hard that was to contemplate. Everything you knew about a transplant involved an organ. How could you possibly have a transplant? I know you are scared, you don't know anyone who has had a transplant, let alone a stem cell transplant. You are 27, alone and worried. But you aren't alone. You are making great relationships in the hospital with doctors, nurses and other caregivers, even some patients. Your family is right by your side. Down the road you will even find more people just like you.

You will be humbled. I'm not going to lie and tell you it isn't going to be hard. It is. You will feel like you're at the edge of death. The only thing I can think of that comes close to explaining how bad, is a cross between the worst hangover of your life/worst flu of your life/worst food poisoning of your life. You will probably poop your pants and throw up in bed. Luckily, you are so sick, you aren't even embarrassed. But don't worry, they will take good care of you at the hospital and not make you feel bad.

You will have pain. Sometimes they will do things to you that hurt. You can always ask if it will hurt, and they will tell you. It's ok to be afraid, and it's ok to cry. There will be a lot of needles. You won't be able to eat, your mouth will be full of sores. The doctors and nurses will help ease your pain. You will have to work on healing yourself from the trauma of cancer. And you will, I promise.

You will be changed. I know you're thinking about what is going to happen to you; are you going to die? Are you going to be able to have children? Is the cancer going to come back? Will you ever be healthy again? The best thing I can tell you, is to take each day as it comes. Do what the doctors tell you, but educate yourself, become your own advocate and take care of yourself. Your new mantra will be: "Don't worry unless they give you something to worry about."

You will be on a journey. Once you get through this there will be more obstacles. New relationships will emerge, old relationships will fail. Your health will really never be the same again. You will really never be the same again. But I'm here to tell you, it will be worth it in the end. In the future your life is amazing. I can't wait for you to experience this; have faith and never give up.

Xoxo,

2018 Ilana

Tips from a 10-year survivor

—By Greg, transplant recipient

In the summer of 2005, I was a 35-year-old married, father of 3. I started to feel run down. Looking ashen, I went to my family doctor and within a 48 hour period I was admitted to the ER with the diagnosis of acute myeloid leukemia (AML), intermediate cytogenetics. I was critically ill with a white count well over 120,000. I was 50/50 for conventional treatment vs. transplant option. Opting for the chemo route, I incurred 100+ days of hospitalization in a 5 month period. With many bumps and close calls, remission was achieved and I was home for good.

I enjoyed almost 2 years of remission before my disease came back in my body. It was discovered in my central nervous system. Second time around there were no options; I was heading towards a bone marrow transplant. I was unable to find a suitable family donor or in the registry. Ironically my 3 siblings all matched each other and not me. I underwent a double umbilical cord transplant, 2 baby cords from unknown donors. I engrafted around day 21 with the cord from a baby girl. First year or so was tough, lots of platelets and red blood transfusions and some minor health issues. Mainly just handling and recovering from the beating I had taken physically and psychologically. My GVHD has been limited to skin and gastrointestinal issues, nothing too bad. As they say "if you have some you know it's working."

My survival guide

- Be your own advocate with your medical care. If you can't, find someone who can help you.
- Confidence in your treatment is key. Get a second opinion if you have doubts; your doctors won't be offended. Your confidence that your plan is the optimal path to go is power.
- Listen to your body. "Squeaky wheel gets the grease." If you feel off let your medical team know. Be persistent, infection comes quick!
- Drink water, stay hydrated.
- Accept the help, support and kindness from others.
- Self-pity and blaming is wasted energy, focus on looking forward not backwards.
- Stay away from chat rooms and blogs, they are not validated sources of information.
- Statistics and percentages are meaningless; there is only one of you in the whole world.
- Take it day by day, give yourself a break if you are having a down day.
- Stay busy, try to move around.
- Surround yourself with things that make you happy, the people, hobbies, etc. that you enjoy.
- Time is your ally, remission buys you time and new discoveries are happening every day.

I don't proclaim that I had a plan for success or even comprehend what I went through. I do know that people go through the process and can come out on the other side. I believe in science and I believe in the technology of this treatment.

I am now heading to 10 years post-transplant and living a normal life. It's been quite a ride and I am changed from this experience forever. I am grateful for my family, friends, my medical team, and NMDP for providing me a chance at survival.

Blessing and respect and love to all my fellow BMT warriors and their families.

> "Take it day By day. Give yourself a break if you are having a down day."

Letter to pre-transplant self

By Wendy, transplant recipient

Dear Pre-Transplant Self,

I want to pass along what I've learned along the way to hopefully make your journey a little easier.

First and foremost, **YOU CAN DO THIS!**

Be patient—With yourself. With your body. With the process. With others.

Be kind to yourself—Don't beat yourself up. Give yourself grace. Get rid of all expectations. Healing will happen in its own time.

It's a marathon, not a sprint.

Breathe—Take lots of deep breaths.

Accept help—Don't rob people of the blessing of helping you. You will be blessed. They will be blessed. You will be able to see God at work.

Enjoy the good days, get through the bad days.

Laugh—Find the humor in everything you can. Even if it's not funny now, it may be funny later.

Cry—Get out your emotions. You need the release.

Pray—For yourself. For others, knowing you are not alone in your suffering. When you are too weak or too discouraged, ask others to pray for you. You will feel God's peace and presence and it will be the most exquisite thing you will ever experience.

Don't compare yourself—To others. To your pre-transplant self. It's unproductive.

Learn—About yourself. About others. About life. About death. About faith.

Teach—Teach the lessons you've learned through your journey and pay it forward.

Finally, you are not alone. There are many that have gone before you and are cheering you on. **YOU'VE GOT THIS!**

With love and encouragement,
Post-transplant self

Bone marrow transplant recipient

By Roberta, transplant recipient

I survived By doing what
I was asked: staying calm.
I had a great team.

I brought a blanket with family members' pictures on it.

Anything to increase good feelings.

SHARE your journey with others

—By Barbara, transplant recipient

The summer of 2016 was a miserably hot summer with a heat index often above 100. No surprise that I sweated profusely at our grandkids' soccer games or that I got so out of breath playing active games with them. It did bother me that, even as the weather cooled, I was still saying, "Grandma is going to have to take a break." I called the doctor for my yearly check-up, and she had an opening, of all days, on my 69th birthday—happy birthday to me! She noticed some bruising, which I had assumed came with aging, and of course, she did blood work. First thing the next morning the doctor called with my lab report. She expressed concern about my low white blood cell count (1.6). The next day's labs came back even lower at 1.2. Then she referred me to the local cancer clinic. Obviously, my concern and that of my husband moved up significantly.

A week later, the oncologist I met with was very kind, but honest, that it could possibly be cancer. He asked if I wanted to have the bone marrow biopsy right then at his facility, so I said with a shaky voice, "Yes, let's just do it." His assistant said I should hear results from the doctor in a few days. My husband and I said a prayer and went home to wait.

The next day as I pulled into my driveway from a ladies' gathering at church, my cell phone rang with the doctor's number appearing on the screen. He explained that he believed I had acute myeloid leukemia, and he felt that it would involve chemotherapy and possibly bone marrow transplant. He suggested a couple of well-known hospitals in the area and said his office would be glad to refer me, and for me to talk with my family and to let him know soon. I hung up, sat quietly, in the driveway, feeling numb. Then the thought came to me, "You just turned 69, you've had a good life, God has blessed you with a loving family, maybe it's just your time to go." Then a dreadful thought came to me, "I have to go wake my husband from his afternoon nap and tell him the news."

Slowly and gently, I woke up my dear husband of 48 years and told him exactly what the doctor told me. We cried together and called our family and friends. There was never a thought that we wouldn't share the information. No secrets here! Immediately, my husband and two adult children and their spouses began to take rapid action, as I went into a strange calm or perhaps a "daze." It was as if I were on the outside watching a fast moving project. They began to call hospitals, set up appointments, research, bring in organic foods, books on nutrition and cancer, organic clothing, natural food and skin products. The neighbors and friends from church began to pray, send cards, bring food, prayer shawls, inspirational books, and neighborhood kids made posters. I cried with each act of kindness and love. I recalled my earlier thoughts, "I'm 69 years old; maybe it's my time to go." I came out of my "daze" and realized that the outpouring of love had presented a new perspective. The new me said, "I want to fight this with all the faith and fight I've got left in me!"

Thus began the process of choosing the hospital, meeting with doctors, planning to proceed with low intensity chemo, getting into a trial study, and starting all the many medications involved. The first day of hospital labs, the nurse welcomed us to our new full-time job! We laugh about that now, because we took that nurse's comment to heart.

Did I mention that I used to have a problem accepting help? Well, that changed for me. I decided that people mean it when they offer; they really want to help. The love goes both ways.

The wait for a treatment plan was the hardest, although in hindsight, it wasn't that long. Now moving ahead to months of chemo, and with the goal of blast counts going down to fewer than 5 percent, fighting complex abnormalities, going to doctors' appointments, it became almost routine, tiring as it was. The clinics at the hospital became our "second home." Finally after about 7 months, came remission, and plans for bone marrow/blood stem cell transplant. Yes, there were several "big bumps" along the way and hospitalizations for blood clots, blockage, and fevers, and at times asking God for his mercy and receiving it. I am now 10 months out from Day 0 of my transplant. I had a wonderful, complete HLA match donor through the NMDP program, a young German donor. We have exchanged a few letters (sent through the hospital and NMDP); protocol says we remain anonymous to each other for some time. However I know already that my donor is an angel! My family and I are moving ahead with life, with hope, still seeing doctors and taking medications. The last bone marrow test and DNA FISH test showed no leukemia cells and no remaining abnormalities.

AML, like any cancer, is not an easy road, with no guarantees, but are there any guarantees in life? My main message is PLEASE share your journey with family and friends. That's my big suggestion. If people say something awkward, I figured it was well-meaning and said out of love. I was especially impressed with how many people in turn shared their cancer journey with me. Let people love you and help you! In addition, fight like crazy, and as one of our doctors said, "Find the joy in each day."

Dear future transplant patient

By Andrea, transplant recipient

The journey you are about to embark on is going to change your life in ways you never thought possible, let it!

It is going to be the wildest rollercoaster ride you have ever been on. You are going to have ups and downs, twists and turns. Through my experience, I learned that your mindset is going to determine how you view and handle your experience. Look at your obstacles as opportunities, you are an overcomer! Be kind to yourself! Let yourself have bad days, but don't stay there! Every step of the way, focus on and celebrate the positive things going on, no matter how small. On the days you don't want to get up, do it anyways! No matter how small of a step you take, you are moving in the right direction and you won't regret it!

I am 10 months post-transplant and living proof that you can make it through, hour by hour, day by day!

I have faith in you,

Andrea

Three days of truth

—By Shaun, transplant recipient

Day One: July 30, 2016

The day I learned a life-altering truth, that although modern medicine kept me from dying, saving my life was entirely up to me, whether it was a life of one day or a decade.

I strapped my IV tubes under my shirt, downed my morning meds and started a slow run up the Tahoe Rim Trail. I had arrived in the Sierra Nevada the night before from sea level, now starting at an altitude of 6000'. My destination: Martis Peak at 7800'. Even in my previous life as a mediocre runner it would be a challenging half marathon without acclimating. But that was before my year of poor-prognosis acute myeloid leukemia, brutal chemotherapy, a bone marrow transplant, and to ensure maximum loss of running ability… open heart surgery to replace a damaged aortic valve. It was before I lost my health, my livelihood, my passions and all the details of a beautiful and carefully constructed life. And it was before competent doctors bravely told me – at my request – other truths, ones that included prognostic descriptors such as “dismal” and “misery.” But two and a half hours and 2000 calories later I returned to the trailhead in disbelief. So I waited two days… and I did it again.

I had told my cardiologist and oncologist that I would only accept the surgery and transplant if I could run a marathon distance again. That was the sole determinant of my decision to continue, because if I lived to run a marathon I had a shot of resurrecting a life of value. After Tahoe I dared to hope, and by December finished my base training and officially began the hard stuff. By May I was covering brutal mileages on desert trails in the heat of Arizona, ready to run the San Diego Marathon with my cohort from The Leukemia & Lymphoma Society.

Day Two: June 4, 2017

The day I did not run the San Diego Marathon. As if a cruel universe had conspired against me, it was race day and National Cancer Survivors Day, and I was absolutely not in San Diego. Instead I was in Phoenix, undergoing diagnosis and treatment for bacterial, fungal, and viral infections. My body’s weak immune system had been bushwhacked, requiring weeks of recovery. The failure was entire, physically and emotionally, which sent me into a state of true despair… until I remembered my mantra: The doctors did their job and put me back out in the world. Saving my life was now entirely up to me. Get over it. I started training again, from the beginning.

Day Three: December 17, 2017

The day I saved my life and nobody knew. On this day I completed a notably non-prestigious small-town marathon in northern California. No cheering crowds, no swag bag or after-party. I smile now as I think how cautiously I ran, knowing that nearly three years of my life were invested in one day. Nothing failed and I crossed the finished line laughing, with a crowd of exactly one person (my brother) waiting. No matter. It was a formal redemption and undeniable statement: Whatever the future holds, I beat the supposed odds. I did this.

So here is my message:

We can create our own epic life story, and likely save our life, not by knowing what to do but by knowing why we should be living at all. After establishing purpose, we are self-propelled. I have worked at regaining a purposeful life not just for myself, but also for those who can’t, and for those who think they can’t. If I can do thing X, others should know they can do 2X. Today, two years after my bone marrow transplant, my feet take me across wild landscapes like daily pilgrimages. I am making memories of breathtaking mountain trails rather than soulless hospital beds. As much as I am daily challenged by graft-versus-host disease, I am haunted more by the images of fear and misery on the faces of my fellow inpatients. I know that some never left the hospital. Others are struggling, and a too-small fraction are doing well. Consequently, my goal is to live the true and authentic story we should have been hearing while confined for months in the leukemia ward. In fact, all of humanity needs more true and inspiring stories. We need to make this a social movement, leveraging catastrophe into our own authentic exceptional story, and make the world more civil and beautiful along the way. Those of us who did leave the hospital after losing everything but our heartbeats—we feel like a forgotten demographic. I figured that if I survived this ordeal that would be my new profession, to inspire lives beyond survival. Because I am certainly much alive and living.

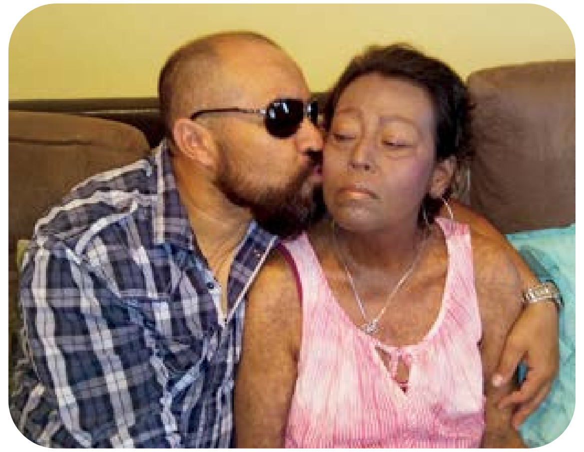
A mother’s faith

—By Patricia, transplant recipient

I’m a 50-year-old mother of a wonderful teenage boy. When I was 16, I was diagnosed with myasthenia gravis which almost killed me. I had a thymectomy and eventually, the myasthenia went into remission. In early 2016 I was diagnosed with stage 4 lymphoma while battling lupus. The lupus caused severe anemia which required me to have blood transfusions on a regular basis. When I was diagnosed with lymphoma my world collapsed and I just thought it was a death sentence. After having several chemo treatments with no lasting success, my oncologist referred me to a transplant specialist and lo and behold, I was determined to be a candidate. I had an autologous transplant in March of 2016 but by June of that same year, the lymphoma was back. I was informed that there was a matched donor and so that fall I had the donor transplant.

Who would have thought that a total stranger would be so generous to save my life? I held on to that promise that I would be ok and with the support of my family and friends, I overcame all the challenges that come with the transplant.

I firmly believe that God’s mercy and love for me has healed me. The process has been a difficult one, especially seeing my son and how my struggle has affected him, it’s been difficult.



But I never doubted that God had other plans for me. I got to meet my stem cell donor last November and it was the most amazing moment, to see his love and unselfish heart.

I’m now in remission but have GVHD and I’m still trying to find my new normal. I know I will not go back to being the woman I used to be but there is a stronger woman, with a new purpose.

I’m sharing a picture of my husband and me, not a flattering self but this picture really tells a story of the unconditional love, patience and perseverance he’s had for me throughout this phase of our life. If I could share a message with others like me, I would tell you to never give up, have faith and surround yourself with loved ones.

Living each day with gratitude

—By Judy, transplant recipient

> “Keep positive, trust your care team, keep the faith, keep reminding yourself how fortunate you are to be able to have a BMT.”
>
> — Judy, transplant recipient

I am a non-Hodgkin’s T-Cell lymphoma survivor, because I had a BMT.

A journey is thought of as traveling from one place to another. If you are reading this, you like me will be on a never-ending journey sometimes in difficult or dangerous circumstances.

From the beginning I learned a few things. One being do not believe everything you read on the internet, it will scare the heck out of you and most of it is not truthful. But do research on the best place to get care. It took me a few tries on that, but I found the best care ever, with the best people and an awesome doctor(s) that I adore.

You must keep positive thoughts and completely trust your medical team, they are experts fighting for your life. You’re not their first patient and unfortunately, you will not be their last. Just know they really care about you.

The road ahead could change you mentally and physically. You could be weak, sick, very sleepy, no appetite, lose your hair, have to wear a mask, lose some of your memory, have numb feet, and have to take medicines. You will overcome all of these. I still have some memory problems, numb feet, tired, winded. But you may not have any problems. I am out 270 days from my BMT and every day I have improvements in my problems. I am so thankful for my family, I could not have done this without them and prayers from others, my faith, and my care team.

You cannot put a price on life. It’s worth more than what I have lost with my side effects. Yes I would do it again. I will fight for my life, it is too precious not to.

Besides you will now get to have two birthdays a year!

Keep positive, trust your care team, keep the faith, keep reminding yourself how fortunate you are to be able to have a BMT.

Good luck and remember everyday it does get better and you will, too. This is your second chance at life. Remember when you were little and you were finally able to take baby steps, and when you fell down you got right back up. It took time, but you did it one step at a time.

New Year’s Eve—a memory

—By Mary Louise, transplant recipient

Dear current and future transplant recipients,

A few weeks ago I received a letter from NMDP, an organization that supports those who are going through transplants. I was asked to share something about my own experience as a transplant recipient. My first reaction was no, no. It’s over. I don’t want to go there or think about it. Then I remembered New Year’s Eve at Hope Lodge.

Hope Lodge is a place where transplant recipients can stay while they still must see their doctor frequently but live far away. I was there all through the holidays. I was still sick and very sad and homesick too. Christmas is a very special time for our family.

Then New Year’s Eve happened. We had a very supportive group on our floor at Hope Lodge, everyone in different stages of recovery. Some of the guys organized a transplant New Year’s Eve party. They went shopping, cooked food that we all could eat and I think we had apple juice for a toast. My daughter was with me at the time. So we went to the party and I played every Christmas carol I could and my daughter and I sang. Soon some other ladies came over and started to sing with us. And for a little while there I think we all felt like we were home. When it was time our host made a very nice toast and reminded us to never give up hope. Then we all sang “Auld Lang Syne”.

It was a wonderful evening and I think we all came away feeling better. To those who read this: you will feel better, and your life will normalize. So Happy New Year and don’t give up hope.

Sincerely,

Mary Louise

October—received 2nd stem cell transplant for MDS.
Doing fine.

> “You will feel better, and your life will normalize. So happy New Year and don’t give up hope.”
>
> — Mary Louise, transplant recipient

Enjoy every day

—By Gary, transplant recipient

My contribution to the NMDP project is an article that focuses on the one thing that we can control, our attitude. Our attitude for the day is up to us and I want to pass along some tactics that I have learned to stay upbeat and positive when facing a transplant or other challenge. Once the decision has been made to go ahead with the transplant I think it's important to work hard in the weeks leading up to the transplant to become as strong and focused as you can be. My doctor told me that the stronger I am heading into the transplant, the better I will do, and I have 100% confidence in my doctor and medical team. The probability is high that you will be challenged, maybe more than once during the transplant process and this is where having 100% confidence in your medical team comes into play.

In the 18 years that I have been dealing with cancer and related issues I have come to realize how important it is to stay positive. To me that includes finding some happiness in each and every day. That might include bringing some favorite photos with you to the hospital as you begin the treatment process. I enjoy the benefits of meditating and over the years have developed some mantras that help me stay strong and focused. Two of my favorite mantras are #1 If my wife and kids are doing great then I am doing great, and #2 I believe that I have the spiritual, the emotional and the physical strength to face up to this challenge. So even during difficult days my mantras help me find some happiness.

Writing has always been an important hobby of mine and it is a great tool to work through issues or challenges that I come across. On October 21, 1999 (one day after being diagnosed) I started keeping a special moments log where I record the date and the special activity that I feel blessed to have been able to experience. Reviewing my special moment log never fails to remind me of how fortunate I am to be able to enjoy these special moments after a cancer diagnosis.

As you are going through the transplant process you will find that you have a lot of down time. I think it's very important how you use your down time. I made a commitment to myself to not focus on mistakes I have made or sad times in my life. Some cancer buddies let themselves reflect on things that they will probably never experience in their life due to cancer, and I don't let myself go down that road. I take the opposite approach by truly appreciating all the things I am enjoying in life right now. One of my goals when working with cancer survivors is to help them change from that negative mindset. I believe strongly in the saying "a positive attitude might not add years to your life, but it will definitely add life to your years."

Working out has always been an important part of my life, and my plan was going to be to incorporate working out as much as possible into my recovery. Riding the exercise bike is something I look forward to doing the first thing every morning so my family ordered one for me and had it delivered to the apartment that my wife and I were staying at for 7 or 8 weeks as I was recovering from my allogeneic transplant in late January of 2016. You don't have to spend a lot of money to do this as my bike was delivered for under one hundred dollars. The bike was lightweight, easy to assemble and made a huge difference as I fought to get my strength back. I used the bike several times a day. My hope is that you will develop your own plan to get a little bit stronger each and every day...

Staying connected to friends and family is another important tool in a positive recovery. My wife has been a wonderful caregiver and she signed me up with CaringBridge on my computer. CaringBridge allows family members and friends to communicate with individuals who are going through difficult times, and certainly helped me stay positive and to feel connected. NMDP and some other organizations offer a chance to speak with individuals who have gone through transplants and can answer questions you might have. This is another opportunity to prepare yourself before the transplant, or during the process. I have benefitted for 18 years from my involvement with the Wellness House where I attend a weekly support group and have participated in many structured programs that help improve the quality of cancer survivors' lives.

In 2008, I wrote an article about how important it is to focus on the things that you can do in life, and not on the things you can no longer do. To me that is what having inner strength means. To accept the things that we cannot change is my way of appreciating the fact that I am still alive. It's up to me to make the most of all the gifts I do have. I love spending time with my wife and kids and I am able to cherish the time we have together. I feel blessed to have a wonderful extended family, and several kind and caring friends. I look forward to getting up every day and riding the exercise bike.

I honestly believe that I am the luckiest man in the world and am able to enjoy every day of my life. I hope you can learn to enjoy every day of your life.

Waiting for the clouds to part

—By Shera, transplant recipient

I have AML with Flt 3. I went into remission after chemo and had a BMT in April. It has been 2 years. A long and hard 2 years. Everything was so fast in the beginning. I was told my best chance for a cure was a BMT. So I just went with it. Later, I learned about the things that I wish I had known before. The questions I did not know to ask. Yes, I know everyone is different. Did you know that your donors DNA becomes your DNA? My donor was a male. I'm a female. Or I was by DNA standards. Your blood type changes. You may forever deal with GVHD; mild to severe. The sun becomes an enemy. Steroids heal you and make you sick. If you had asked me 6 months ago if I would still have done the BMT I would have said no. My quality of life has so drastically changed. I've been so sick. Then it was like the clouds parted and I could see the light. I feel better, things are getting back to a new normal and I do think I did the right thing. Everyone needs to make their own decision, be informed, and be your own advocate.

When hope stops working, eat the elephant

— By Ellen, transplant recipient

> "How do you eat an elephant? Well Ellen, you eat an elephant one bite at a time."
>
> — Ellen, transplant recipient, recalling advice she received from her husband

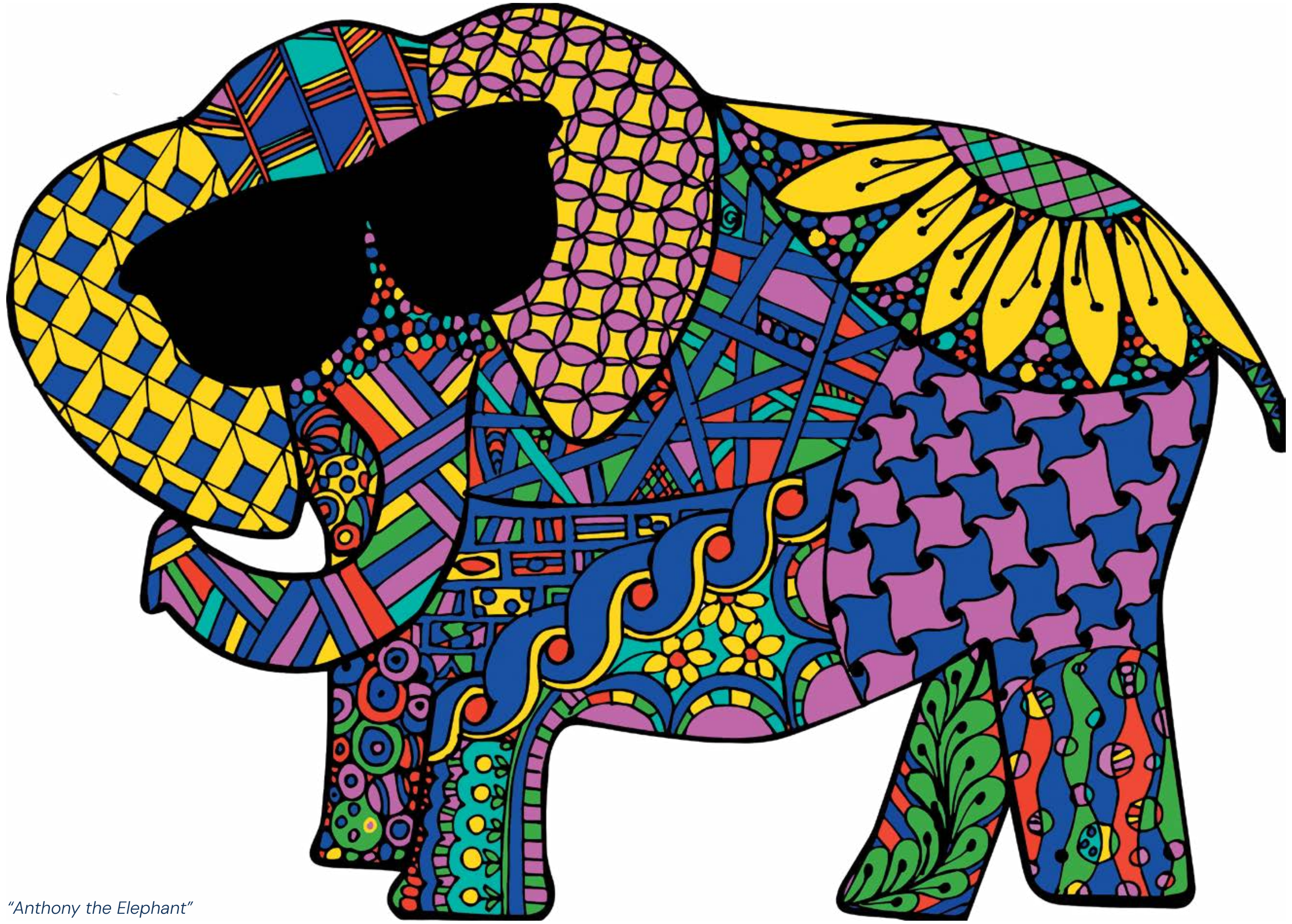
We sat across the room from the doctor and he quietly repeated what we were not ready to hear. "Enjoy each other, take a trip, spend time with people you love. It is very unlikely you will live until next winter." I was 25 years old and I was dying. It was discovered on my (then required) pre-marital blood test. I had a rare bone marrow disease, severe aplastic anemia along with a second, even rarer condition, paroxysmal nocturnal hemoglobinuria (PNH). At that time, I received a piece of advice that served me well for 30+ years. One of my doctors, took my hand, looked me right in the eye and said "Dear, you have one thing to hold on to. And that one thing is hope. Why? Because hope only goes one way and that way is forward." I followed his advice and went on with whatever life I had left.

We sat across the room from another doctor and he quietly repeated what we were not ready to hear. Again. "We have to act quickly. You are very sick". I was 55 years old. I now had a third rare bone marrow failure disease, myelodysplastic syndrome (MDS). The trifecta. How lucky was I? I lost my hope. My secret weapon, my husband of 35 years (yes, he married me anyway) knew I was angry, hurt and scared. He sat me down and he asked me "How do you eat an elephant? Well Ellen, you eat an elephant one bite at a time. And that is how we are going to do this. One bite at a time." The elephant is big and fearful. Take it apart and we can do this. And it worked. Day in and day out he'd ask me for the bite that day. It kept me focused, connected and best of all, less fearful.

This is a piece of art I created—Anthony the Elephant. Isolated for months during my transplant I took to drawing in a doodle style. I created Anthony as my visual aid to help me walk through the days.

It is my 60th birthday tomorrow. What am I doing for my birthday? I'm having a party. A "PIF" Party. To Pay It Forward. We are inviting 250+ people to help me celebrate a milestone I was not supposed to have. We are encouraging everyone who attends and helps me celebrate, in lieu of gifts to me, that they will consider giving a donation to the Andy Talley Bone Marrow Foundation—part of the NMDP network.

I am eager to give another person the chance that I got. I thought about all of the milestones that people would not be able to experience and the idea of giving those moments back to someone was so powerful and a way that I could pay it forward.



"Anthony the Elephant"
By Ellen, transplant recipient

Coping with humor

—By Adam, transplant recipient

Chicago, IL: it was mid-June when I was diagnosed with AML (acute myeloid leukemia), a blood cancer. Your diagnosis will come as a shock, but you try to rationalize that your situation will be different. You don't know it yet, but your life is about to drastically change. And then you ask yourself, "how will I cope?" It may sound strange to think of humor at a critical time in your life, but I found that maintaining my sense of humor was necessary to endure the hospital stay, tests and treatments.

Phase One: Let's kill those leukemia cells! You get the call to be in the hospital and you think the stay will be short. But then you come to learn that you are there for over a month, as they use chemo to clean out your bone marrow. It can be unpleasant, tough, and exhausting. With the repetitive routine of blood draws, daily rounds, transfusions, pain meds, wipes, and exercise, it was important to maintain a positive attitude.

To help cheer me up (as I was going to be in the hospital for my birthday), my daughter decided to decorate my room. I was born in Scotland but grew up in Canada, so my room had a Canadian theme: Canadian flags, maple leaves, family photos, get well cards, and drawings from nieces and nephews. This theme inspired me to challenge my doctor and his team on some Canadian trivia. To my surprise, my oncologist knew the name of our capital city (few Americans do), and a few other facts about our country. This made everyone in the room laugh.

The decorations brightened the room, creating a sense of hopefulness and optimism. They also prompted conversations between me, the doctors, nurses, and staff; not only about Canada, but their personal lives as well. A piece of advice: be nice to the hospital staff because they will look forward to coming to your room, and they will be there when you really need them.

Biopsies are part of the treatment, and they can be nerve-racking. My oncologist performed my first biopsy. However, when a young resident performed my second biopsy, she offered music to distract me. I asked for Pitbull. She was shocked by this request from a man in his 60's. On my next routine visit, I challenged my oncologist (from my generation) with creating a playlist for his next biopsy. He thought this was quite funny, and had no idea who Pitbull was.

Unfortunately, a negative side effect to chemo treatment is hair loss so I decided to have a hair cutting party. It was tragic to let go of my full head of hair, but I was comforted to have my favorite nurse as the barber. The family took pictures at different stages of the buzz cut, and I almost got stuck with a mohawk hairstyle.

Another distraction to pass the time was jigsaw puzzles, which helped mostly my wife while I was in and out of sleep. On one occasion, the rounding physician wondered what was so fascinating about puzzles. We decided to complete the puzzle and leave the last piece for her to insert. She got a kick out of this, making it her only puzzle action in her life.

After 35 days in the hospital, I reached my first milestone. The oncologist announced that the chemo worked and killed off all the leukemia cells. This was a very emotional day, and I was glad to have my wife there to support me (tears and all). It felt like our first victory. I was able to go home for a month to get stronger for the next phase.

Phase Two: Let's transplant those stem cells! Back at the hospital, I had befriended a nurse practitioner who came from a small town known for being the capital of the "Grumpy Old Man." Every time we saw her, we laughed about this moniker; I even offered up my brother as mayor.

While in the hospital, my cousin came to visit and brought me a Green Bay Packers cheesehead hat (knowing I am a Bears fan). I wore it while I walked the hallways and got a mix of strange looks and smiles. It was risky to display such a headpiece in a Chicago hospital.

Three months after my diagnosis, it's finally transplant day. The chemo has been intense yet tolerable, but my worst days were immediately after the transplant. Originally I thought a transplant was a more complicated procedure, but I found out that it is the same as getting a blood transfusion. I received a bag of stem cells from a young anonymous donor (who I am hoping to meet to thank in person).

With the repetitive routine of blood draws, daily rounds, transfusions, pain meds, wipes, exercises, and spirometer, it was important to maintain a positive attitude.

I was released from the hospital two weeks after the procedure. My wife and I ended up staying near the hospital (as we live 2 hours away) to shorten the commute for the almost daily follow up visits. During these 2 months, I was very uncomfortable, eating less, lethargic, and finding it difficult to sleep. I had lots of time to watch TV, and witnessed a miracle—the Cubs winning the World Series.

Phase Three: Let's get my life back! Around Thanksgiving, I was able to finally go home for good. I was grateful for so many things: the support from family and friends, incredible care from the hospital staff, and a transplant that saved my life. As I recovered for the next year, I continued with medications and doctor visits, but I could look forward to making future plans. On my 1-year transplant anniversary, I celebrated my last chemo pill with a bottle of my favorite scotch and took a photo to commemorate this event. Who has two thumbs and is in remission… this guy!

Jack, transplant recipient

CHAPTER 2:

Diagnosis, illness and transplant

About Jack

Jack was still in high school when he received a transplant for aplastic anemia. "I thought that if I could share my story, and it helped someone who's going through something similar, then I'd feel pretty good," Jack said.

"Before I got sick, I was doing normal things. I was getting certified for scuba diving. I was doing great. It was pretty crazy to go from feeling good and being active, to being so sick, so fast. That's one of the reasons I wanted to share—just how fast it can happen."

"Through the whole process, I always tried to stay positive and look on the bright side. I think that really helped me through my transplant. I always thought, 'Today might not be great, but maybe it will be better in the future.' I guess for the parents, I'd say that just being there during the transplant process helps. Even though I didn't talk to them a lot when I was really sick, it helped for me to know they were there."

"Today, I'm back to normal. I ran cross country in the fall last year. I played tennis for my high school this spring. I just finished my sophomore year. I've got a summer job, too. It's great to be back in the world."

See Jack's poem "Before" on the next page
Also see pages 158-159 for more submissions from his family

Before

—By Jack, transplant recipient

Before

A week ago I was learning,
Getting my certificate to dive,
Although I was bruising and spotting;
Heavily, but alive.

Back home and going to exercise;
I tried, but I came up surprised,
I couldn't do anything, I was out of breath,
Along with the dizziness,
I was confused and shocked to death.

But wait, I thought,
I was just diving a week ago, what has changed?
My dad said I was out of shape,
I took his comment as if I ate a sour grape.

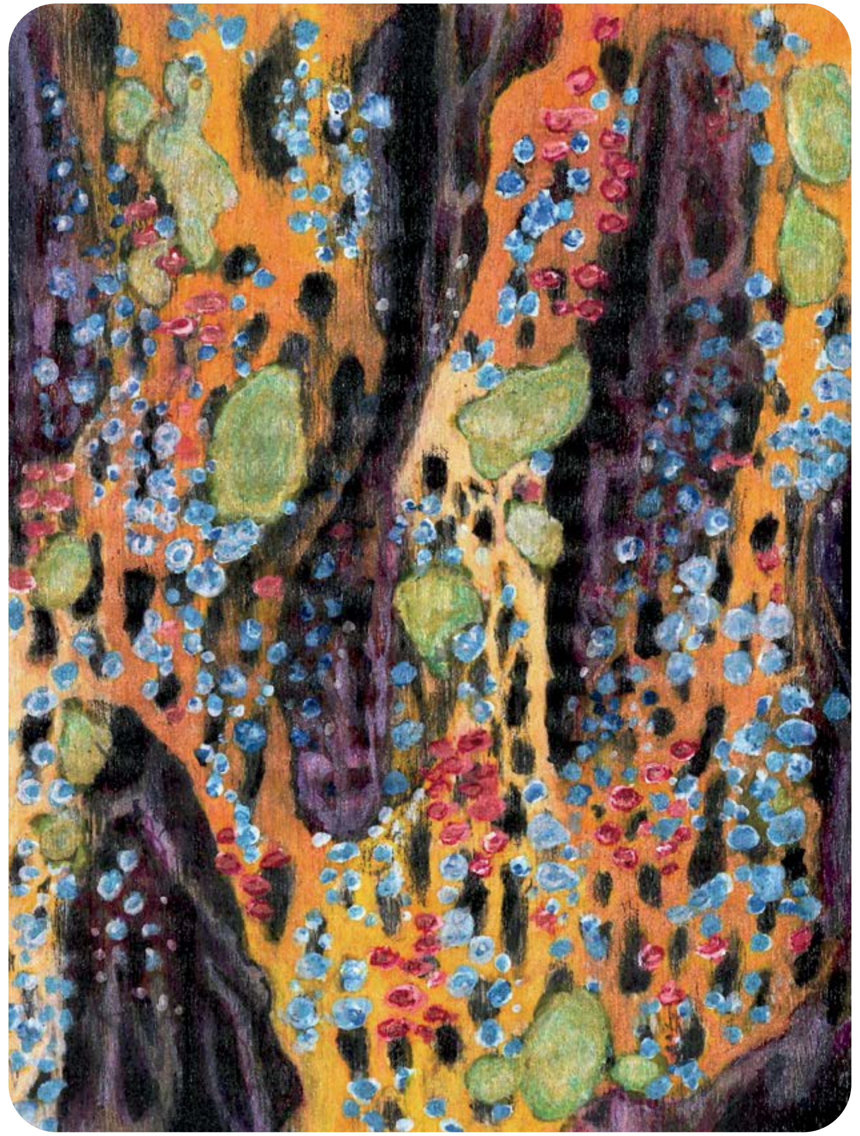
Then I get sick,
I'm on the couch for a week,
The doctors say I'm fine,
But I feel kinda bleak.
Finally I go to my primary doctor,
She looks at me concerned,
with my bruises and spots
Some blood tests get ordered,
And I'm off to the next lot.

After getting tested, I went back home,
Just to find that I have to go,
This time to the hospital,
This sounds like an oh no.

More and more tests
So many it was hard to rest,
After a long time a decision was made,
That I had aplastic anemia,
And now I was a bit afraid.

Hematopoiesis

—By Brian, transplant recipient



The Chimera

—By Courtney, transplant recipient

A two week "flu"
before the
two day coma.

Countless tubes carved
into my flesh.
Poked, punctured,
and pricked
but
apheresis keeps
my blood fresh.

Various parts
taken.

A fever ignited
a fetal yet fiery beast:
iced in my armpits,
bald and begowned,
feeble yet fearless.

I am
various parts
my mother and my father
but
also her:
a woman in the midwest
whose marrow would spawn
a chimera, naked, in the sun
not from the cave of Plato
or the tombs of Lycia,
but through golden gates
foggy with anesthesia.

Roused and renewed with
various parts
I am still
Me, but not, and
I have not met Bellerophon
just yet.

I am
various parts.

Living through guilt, determination, laughter and love

—By Kelly, transplant recipient

I picked up the phone and broke the news to family one by one. I had to be strong because if I fell apart, so would everyone else. No matter how much I tried to prepare myself before going to the hospital, my head was still spinning with the reality of my diagnoses. A million things were going through my head, but foremost was, "What do I need to do to kill this thing?" I never once thought about not doing everything I could to survive.

Later, when things calmed down, I was shocked to realize how badly I wanted to live. When my son died, my husband and I both said we wouldn't do treatment if we had cancer because we had no faith in the medical system. Sixteen years after his death, I was ready to slay the monster inside me. The guilt crept in as I asked myself why I deserved to live when our son didn't. It didn't seem right that I was fighting so hard. The feelings of failing him came rushing back.

We lost our firstborn son to leukemia complications. I felt like I was on the same train that refused to stop. I was released from the hospital on Sunday. I have no recollection of leaving that day. I'm not sure if my brain decided it just couldn't think anymore, or if I was so emotionally stunned that my brain was shutting down. All I remember is being at the hotel and waiting to hear from the doctor. We had decided I should participate in a study. After all, one more drug working to kill this "thing" was good, right? We got the call we had been waiting for. My doctor told me I had been accepted into the study. I cheered and said, "That's so awesome!" There was a brief silence, and he drily replied, "I'm glad you are so excited. Now get your butt down here now!"

> "The guilt crept in as I asked myself why I deserved to live when our son didn't."

We drove to the cancer clinic. It was a surreal experience knowing I was the patient and this wasn't going to just go away. We were pleasantly greeted and given a bunch of paperwork to fill out. They put us in a room to speak to us privately. The nurse explained the process and brought in the study nurse to tell us about the pills I would be taking on the study. She explained that I would have five rounds of chemo and that the pills were to be taken the first three days of each round. I was starting the induction phase that day.

The nurse put a ham sandwich in front of me and said, "You need to eat this, or you will be sick." I groaned at the thought of being sick, but I sure didn't feel like eating. I took one bite and my appetite returned! I gobbled the sandwich up much to the delight of my husband who had been begging me to eat. She then handed me the pills. I was to take six pills twice a day for three days. They had to be taken twelve hours apart and always with food. Chemotherapy had officially begun.

When I got up the second morning, I was violently ill. I was on my knees in front of the toilet retching and feeling like my insides were going to come out of my mouth. I started to laugh at a memory that came rushing back. We were in the hospital and my son wanted to take a bath. I was running his water, and he was kneeling in the same position I currently was, vomiting repeatedly. I had felt helpless knowing there was nothing I could do to stop his pain and discomfort. Suddenly, he had stood up, wiped his mouth and said, "Is there anything else that needs fixin', ma'am? I looked at him strangely and said, "What on earth are you talking about?" He responded with, "I'm the naked plumber, ma'am, and I'm here to help." At that moment, I knew whatever I was going to go through was nothing compared to what he went through. I stood up and resolved to be brave and strong like my son.

Jacqueline's journey

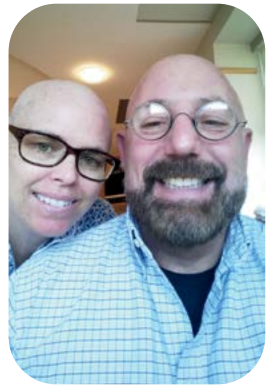
—By Destany, transplant caregiver

Pain, prayers and positivity

—By Mary, transplant recipient

At the bay

Chemo Stuff



February 2015:
In transplant

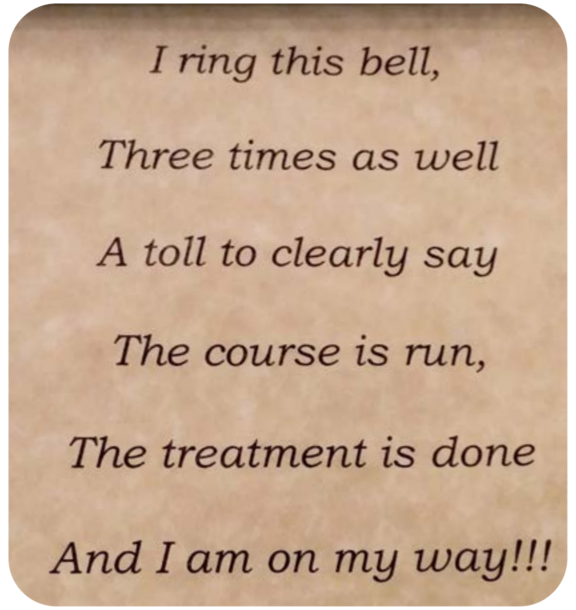
It started with shortness of breath working out at the gym in March of 2014. I was 49, working full time as a nurse, happy wife and mother of 2 wonderful children. As the lab work would uncover a strange and rare diagnosis of chronic myelomonocytic leukemia, our world would forever change. As luck was on my side, I connected with the brightest, kindest doctor close to home. He took my family and I under his care with sincerity and authority.

After managing for a few months with just monitoring, I needed to start treatment in order to keep functioning. After 2 rounds of outpatient chemotherapy my disease had other plans. I spent time in the ICU. I needed a bone marrow transplant and was looking for a match. After two potential donors didn't work out, my third donor came through and I was admitted in early 2015 to the hospital. The care from the staff was fantastic. Each day I kept my self-imposed schedule as best as I could trying not to spend time in bed unless napping. I managed through many difficult, painful experiences, but kept a positive attitude with prayers, family, friends and quotes. My matched unrelated donor cells started their slow engraftment; I ate a little and mastered my home meds so off I went. I live at the shore so that was my first stop to get a breath of fresh air after a month closed in a hospital room.

Every day since then has required lots of meds, skin care, eye care, and diligence. My transplant team has carried my along my never ending path of recovery. Three years later I am now starting to look back at this amazing science, yet personalized treatment that has saved my life. I am so blessed with life that when the struggles pop up, I take a breath to the understanding that I would not be here today if it were not for this transplant and all the care I continue to receive.

With love and thankfulness,

Mary



I ring this bell,

Three times as well

A toll to clearly say

The course is run,

The treatment is done

And I am on my way!!!

With my doctor

Family

Discharge day

June 2015

My survivor story

—By Susan, transplant recipient

I am a wife, mom, nurse and thriving bone marrow transplant warrior. This is my survivor story.

What defines a cancer survivor? It can be someone riding the tidal wave, someone who has beat cancer or someone in remission. One definition of a survivor is a person who remains alive and continues to function during and after a serious or life threatening illness. True survival is living as best as one can for as long as one can.

My survival started the day I was told I had leukemia. That day, I made the affirmation to fight and go where the detour would lead me. I like to say that I'm not just surviving—I'm thriving! I've made the choice to live like every day matters.

> "My survival started the day I was told I had leukemia. That day, I made the affirmation to fight and go where the detour would lead me."

In the early days of my illness, being a survivor simply meant carrying on with daily life. I worked for 6 months before my blood counts were at a level that treatment could start. I only shared my diagnosis with a few people because I didn't want anyone to treat me differently. The constant wondering about when I'd have to start treatment was a very difficult time. Even though I was a nurse, I knew absolutely nothing about leukemia! I made a promise to my physician not to research my disease or find out what the life expectancy for my type of leukemia was. To this day I still don't know what my life expectancy is, but then who really does?

There is much more to surviving than just physical survival. Being in the hospital for 28 days for induction, bone marrow transplant and recovery was an exercise in not just physical survival but mental, emotional and spiritual survival as well. At that point, survival was feeling empowered to make do not disturb signs for my door when I was feeling overwhelmed or too exhausted to have visitors.

Survival means having the mental energy to sort out all the financial issues that come with being a cancer patient. It's a huge challenge to sort out the pile of information that comes regarding applying for disability benefits from work as well as applying for social security disability.

They say it takes a village to walk the survival road with you. It actually takes many villages. I had my family village, work village, community village and church village. Everyone intertwined to support me and my family and carry me in my weak moments. I met people I never would have met otherwise. I've become closer than ever before to others.

Survival is a great lesson in patience. I had to learn to not only stop being the nurse and be a patient, but also learn the virtue of patience – with myself, my family and my health care team. Goal setting becomes much more basic. You celebrate the day you can drive alone for the first time, the first time you get to go on a trip, even the day you are able to go back to work. Your plate of expectations you set for yourself becomes much smaller and richer.

The newspaper obituaries often say that the person lost their battle with cancer. Did they really "lose" the battle or did they just finish the fight? Did they survive under the terms they wanted to and reach the ultimate finish line?

Somewhere along the way in your cancer journey, you will subtly go from surviving with cancer to living with cancer and being a cancer warrior. Tim McGraw sings "Live like you're dying" – I changed those words to live like every day matters. In talking to other cancer survivors, they agree that the biggest change cancer has made in their lives is that they savor and make the very best of every single moment.

Being a survivor isn't all rainbows and roses. Did I go through dark times on my journey? Most definitely! During those bad times, I embraced and acknowledged them and chose to move on and celebrate the little things.

Giving back after a life changing diagnosis is part of the survival process. It gives confirmation that life does go on and that as a survivor you can help other patients on their journey. Being able to be a mentor to new bone marrow transplant patients is part of my giving back. Being on the other side of the hospital bed has given me a whole new perspective of what a patient goes through. Using my experience, I speak to nursing and medical students and bone marrow transplant patients. This gives the students a view they wouldn't typically get in school and shows BMT patients that there is light at the end of the tunnel.

Relay for Life is an opportunity for community members to look through a small window at the impact of cancer on patients and their families. Like cancer, it can be a struggle—staying up all night and encouraging each other to always have a team member on the track. As the night darkens, a luminaria ceremony remembers those who have passed and honors those fighting and winning their war with cancer. In the wee hours of the morning when it doesn't seem it can get any darker, the walking, like the fight against cancer, continues. Just when your body is at its weakest, the sky starts to lighten up, bringing with it a new day—a day of hope, beauty and renewed strength. You celebrate surrounded By teammates and wonderful friends.

This month I'm celebrating my 4th anniversary as a thriving bone marrow transplant recipient. Looking in the rear view mirror, I can see bits and pieces of the old me, gone but not forgotten. Looking forward, I don't take anything for granted. I look for the good in the simple things, I celebrate the small stuff and give thanks for all that I have.

I AM A SURVIVOR!

> "I don't take anything for granted. I look for the good in the simple things, I celebrate the small stuff and give thanks for all that I have."
>
> — Susan, transplant recipient

Taking a proactive approach to mindful recovery

—By Jodi, transplant recipient

At the young age of 41, I was diagnosed with a Myeloproliferative Neoplasm (MPN). When I first heard the phrase I immediately thought of the 1958 Science Fiction classic "The Blob" and the image was reeling through my head. When informing me the oncologist used phrases such as; "slow growing," "minimal symptoms," "more likely to die from old age diseases," and "yes, it's a rare type of environmentally-induced blood cancer". Asymptomatic at the time, life still seemed pretty normal and I was able to function well as a parent, a wife, an employee, and volunteering in my children's school and our church community.

After 3 years, I transitioned from essential thrombocythemia (high platelets @ 1 million), to polycythemia vera (both high platelets and high hematocrit) requiring regular phlebotomies to reduce blood volume. It was at this time that I learned most patients are initially diagnosed with an MPN in their 60's, not their 40's and I began to battle frequent negative thoughts and fears. Symptoms began at this stage and I had to drop out of all volunteering and extracurricular activities. It was at this point that I started to seek out MPN experts. I started attending patient conferences learning all I could and consulting with a holistic doctor learning how to better take care of my body.

It was a good thing I took a more proactive role in my care. The holistic doctor found several other "anomalies" in my blood work and encouraged the hematologist to do my first bone marrow biopsy 4 years after initial diagnosis where I discovered I had progressed to the next phase "early myelofibrosis". My bone marrow began hardening with fibrosis, unbearable fatigue, and bone pain. Myelofibrosis is not treatable like most cancers with rounds of chemotherapy. The only cure is an allogeneic blood stem cell transplant (SCT), a very risky procedure, with about an 80% chance of success with a donor that's a 10/10 match. I had no intentions of putting neither myself, nor my family through this traumatic event and began researching right to die states—Oregon.

The next bone marrow biopsy revealed "intermediate myelofibrosis" so the "slow growing" blood cancer in my case turned out to be not so slow. This was truly depressing and a dark period in my life got even darker. The blood stem cell transplant doctor suggested I start practicing yoga to help with both physical and emotional symptoms. I began as soon as I returned home and what a life changing experience. Yoga allowed me a deep connection not only with my physical body but took my gratefulness and prayers to a whole new level. My prayer life combined with my yoga practice glorified God in so many ways the peace I felt after practice was beyond belief. I started to consider the possibility of a blood stem cell transplant ...

As symptoms continued to worsen, I decided to finally do the SCT. There was one 10/10 donor match, but they were unresponsive when contacted. My heart sank and I dropped to my knees in prayer. The 9\10 match dropped the SCT success rate from 80% to 60%—the other 40% death. I moved forward, and a good thing I did, the bone marrow biopsy prior to SCT showed I had progressed to "advanced myelofibrosis".

For an allogeneic blood stem cell transplant patients are admitted to the hospital and given a very high dose of chemo (ablative chemo) for several days knocking all my cell lines as close to zero as possible. On the next day, I was given the donor stem cells, and the battle began. I was in the hospital for about two months with a few complications requiring isolation on top of vomiting, diarrhea, and mucositis. The riskiest part is that you have no immune system so catching a cold from a visitor can be life threatening as any other type of infection. I'll be honest, it was an incredibly tough experience, but a life experience I can now share with others. Thank goodness I had plenty of meditation and prayer experience as I was able to sit in my own thoughts without a lot of movement or action for months while I was healing.

Thankfully, as of February 2018, I'm currently cancer free, although still battling graft-versus-host disease (GVHD) where the new cells that are transplanted attack the old cells. The required steroids to counteract GVHD are a temporary nuisance and my husband gives me plenty of grace! Prayers, yoga, and meditation facilitated the stressful process and taught me so much about my own body, mind and spirit. Through the years I've become a yoga instructor and in the process of establishing a Christian yoga non-profit that reaches out to the community in need. I look forward to sharing time on the mat with future yogis.

What I've learned from this experience: seek out an expert in the field for a rare illness, you ARE stronger than you think, never underestimate the love and support of a spouse and your family and friends, be kind to your body. A total stranger donated their stem cells through NMDP, without that, I may not be here to teach you how to strengthen your mind, body, and spirit through a yoga practice.

Much Love,

Jodi

> "The blood stem cell transplant doctor suggested I start practicing yoga... and what a life changing experience."
>
> — Jodi, transplant recipient

Battling boredom to achieve the impossible

—By Traci, transplant recipient

On Martin Luther King Jr. Day, 2010, my husband carried me into the ER. It had been 1½ years of tests and no one could tell me what was wrong. In the ER there was a nice surgeon who decided to do a CAT scan. Even then, he had to admit me to figure out what it was. By the end of January, I had had surgery to remove a tumor which was labeled large diffuse B-cell non-Hodgkin lymphoma. A PET scan later would reveal that I was stage 4. And so my struggle to survive had begun. I spent another 1½ years doing chemo trying to reach remission.

In late June 2011, my mom, husband, daughter and I left at 9:30 a.m. and arrived at my transplant center just in time to go have lunch. I wondered if this would be my last burger for awhile. It was. Upstairs, I unpacked, put my stuff away, and familiarized myself with my surroundings. My room was on the 10th floor and overlooked the parking lot. It was roomy and full of light. I had a bathroom with a big stand-up shower and seat. I loaded the WIFI and my daughter played on the laptop while we adults talked. At 3:00 it was time for them to leave; we hugged tightly and said our goodbyes. I started thinking about what was ahead of me and began to cry. Horrible fear washed over me. Fear of the pain, fear of the fatigue, fear of the nausea; fear that after all of this, it won't have worked. I know I have to take one day at a time. I took a big breath and thought that every time that I could get out of bed and walk the halls will be steps toward home. Scared? You bet!! But, now that I was here, I believed that I could do this!

After 4 days of chemo, I had had no bad reactions. My doctor assured me that this chemo was tame compared to previous treatments. The only reaction I did have was to the magnesium they gave me every day. During the first infusion, my head started spinning and I felt hot. I signaled the nurse. She slowed down the drip and the symptoms went away. My nurse told me that I was going to see fireworks tonight. I couldn't believe it. It wasn't even July yet. They were going to be outside my window and on television. It was awesome. The transplant nurses were very kind but firm. They wanted nothing more than for us to get out of here. They told me boredom was what gets most patients. That was an understatement. The walls began to close in on me after lunch every day. I would go out in the halls to do my laps and talk to the other walkers. There was this couple that walked/raced at least 4 times a day. It took me awhile to meet up with them. She also had had lymphoma and just finished her second transplant. We swapped war stories and exchanged phone numbers. She became my cheerleader and friend for the first few years that I was out. I miss her so much. My husband, my daughter and a friend came to visit me. It was great to see people from home. My friend came even though she just had eye surgery. I tried to talk her out of it. She would hear nothing of it. I loved seeing her even though it was for such a short time. My daughter needed some Mom time so I was glad she came with my husband. She sat and drew a couple of pictures on the dry erase board. It seemed like time just flew. After they left, I went to the window to watch them walk to the car. I stood there waving, hoping they could see me. They must have known because they both looked up to try and find me. It didn't take long for them to spot me. They waved back. Tears filled my eyes. I wanted to run out of this place and go home with them. My daughter called and asked if I could see them. I waved at her, told her I loved her, and then got off the phone quickly. I didn't want her to hear me cry. As I sat on my bed sobbing, I breathed in deeply and reminded myself that I'm here to get my life back. Some days were better than others. I just had to have patience. I was never good at that.

During the next 4 days, my body finally gave in to the nausea and I had no appetite. I managed to eat graham crackers and a breakfast drink daily. They wanted me to eat a lot more. My transplant day had arrived and the nurses referred to it as my 2nd Birthday. So we celebrated it with some total body irradiation and some freezing blood stem cells. The bag that they came in was nothing special but it was the most beautiful thing to me. To think a young man gave me his cells so I could live. I was amazed that we were a match. They were so cold. I couldn't stop shivering. Warm blankets didn't work. The physician's assistant suggested a medication. Once they administered it, I didn't remember much of the rest of the day. I can say one thing though, I slept really well. Happy Birthday to me!!

I am not going to say my transplant was a breeze. Graft-versus-host disease reared its ugly head right away. It was another fight I wasn't ready for. But I tackled it. When I finally was able to walk the halls again, I would look at the beautiful pictures and quotes that lined the walls. One in particular stuck with me.

"Start by doing what's necessary, then what's possible. And suddenly, you are doing the impossible."

Traci, transplant recipient (center), with her family

> "Start by doing what's necessary, then what's possible. And suddenly, you are doing the impossible."
>
> — Traci, transplant recipient, recalling an inspirational message

The journey

—By Noreen, transplant recipient

Bev was with me. When getting a diagnosis of leukemia, it's best to have someone with you.

It should have been like any other weekday with both of us at our respective jobs. Instead, she drove me to the hospital.

I checked in and was given an ID bracelet. I told the nurse that I was just there for an appointment with the doctor and didn't need a bracelet. She assured me that I did. I smiled at Bev and put it on as if I was getting ready for a street festival with alcohol, as I told the nurse, "I hope it's an open bar."

Bev and I met in corporate America when we were struggling and studying to get ahead. We became fast friends, going on that first vacation together to Epcot Center, where we got the idea to trade our Epcot passports for real ones. This opened us up to the world of travel and my own "Grand Tour" of Europe.

A hospital employee called out my name. We were led to the same room where I endured a bone marrow biopsy a week earlier where I ignored the pressure, pain, and fear by focusing on the idyllic beach scene framed on the wall.

I sat on the examination table and thought of my two uncles who died of leukemia three decades earlier, when they were about the same age as me. The paper shifted under me as I tried to sit comfortably.

Bev broke the deep silence by fiddling with the tongue depressors and picking up a box of latex gloves while asking, "I wonder why they left us this box of balloons?"

Each uncle died quickly, within weeks of being diagnosed. Would I be dead in two weeks?

When I didn't show any reaction to Bev who was attempting to blow up a glove into a five-fingered balloon, she asked, "Where do you want to go for lunch once this is over?"

I couldn't think about lunch, or respond. I stared at the closed door in anticipation of seeing the doctor and getting my test results.

The doctor walked into the room, in a stiff dress, wearing a stiff demeanor. She carried a clipboard filled with facts, the details of which were lost to me as all external sounds were drowned out by the pulse of my diseased blood.

"Noreen...Noreen are you listening? There is no doubt. You have acute myeloid leukemia and must be hospitalized immediately—today."

When getting this kind of news, a good friend's presence is needed. A best friend will pick up the pieces. Bev negotiated a two-day reprieve so I could get my affairs in order.

I stared at myself in the mirror. I remember having the same feeling of staring at a stranger's face, when I was six years old. At that time, I thought that my eyes were the same, but that I now had a "big girl" face.

This time I was in a hospital room after two months of chemo. It was strangely comforting to see my familiar, unchanged eyes looking back at me. My mother called them "laughing eyes."

She fell in love with my father because of those same eyes, shared by his side of the family.

There was plenty of laughter at my grandmother's house. The entire family fit around her table in her tiny kitchen. The house was filled with food, laughter and the clink of jelly jars filled with homemade wine. They laughed about interesting neighbors and people in the old county.

My bloodline hails from a southern Italian town where my grandmother learned to make a meal from the simple ingredients of the land and sea. This is also where she learned to grieve the dead when she lost her mother to leukemia.

I share that blood. It comes with laughter, love, and a lost summer of leukemia. When diagnosed, I thought of my two uncles whose stories kept the family in laughter. Their voices died along with them when they were about my age. And now I've been diagnosed with the same disease.

Leukemia is cancer of the blood.

With no operation capable of cutting away this liquid cancer my uncles and great grandmother didn't stand a chance against this enemy. I thought of their battles when it was my turn to fight the beast.

My friends tell me how lucky I am to be alive. I was diagnosed after I took a blood test – simply because I realized that I no longer had my usual wind-up toy energy level. Thanks to the Affordable Care Act I didn't have to fight for insurance coverage while fighting for my life. I was kept alive with months of continual chemo therapy while the machinations of a stem cell transplant were put into motion.

I was also relatively healthy. The protocol is to only bring leukemia patients to the brink of death if they are strong enough to live through the process of killing off all of their diseased blood so it can be completely replaced by healthy donor cells.

I packed my bags with humor books and checked into a training hospital that would do the transplant and looked forward to the cure. The staff was wonderful, which certainly helped in my recovery. The nurses even chose to hang out in my room during their breaks.

One day, two nurses danced to a Michael Jackson song blasting from a toy bear. All three of us sang along, when the Chief of Oncology walked in. The nurses stopped dancing, while our three sets of eyes riveted to the serious presence at the door. Even the stuffed bear stopped the song. I broke the silence by telling the doctor, "You'd better join them or this will really get awkward." He laughed, and broke the tension.

Fortunately, I'm a survivor thanks to medical advancements, a very generous stem cell donor, and the same joy of life that my relatives sent to me through the generations.

The swipe

—By Thomas, transplant recipient

Peggie and Anna, two nurses extraordinaire said to Tom, "you've got to swipe this special swab somewhere."

"Any suggestions?" asked Tom just out of the air.

They thought for a moment, pointed a finger and said, "You've really got to swipe way down, back there."

As he walked to the restroom he mouthed to himself, "This is really, truly and totally unfair!"

He pulled down his pants, swiped here and swiped there contemplating scrawling on the mirror over there.

No sooner had he finished he swabbed with a flair:

You, too, can swipe this way down, back there!

Author's note:

Prior to seeing BMT physicians most patients go through a series of medical diagnostic tests—blood work, vitals and other specialized tests. Among the specialized tests is one called the VRE, which tests for germs especially resistant to the vancomycin antibiotic. The test is done by swabbing the area around the rectum.

The poem was written as part of the bantering about the test that took place between medical personnel and myself.

My cancer journey

—By Michael, transplant recipient

I was extremely busy—I had a full-time job, a 6-month-old daughter and I had started taking weekend college classes—when I noticed that I was more fatigued than normal. I blamed the exhaustion on my lifestyle and didn't think anything of it until my wife recommended I see a family doctor.

When a routine blood test showed that I was somewhat anemic, my doctor referred me to a hematologist and underwent several more tests. In March 2001, after six months of testing, I was diagnosed with a rare, incurable form of non-Hodgkin lymphoma called lymphoplasmacytic lymphoma, or Waldenstrom macroglobulinemia.

I remember staring like a deer in the headlights wondering what the doctor was saying, but I wasn't willing to give up upon hearing those ugly words 'you have cancer.'

After being diagnosed, I began my 16-year cancer battle. I went through my first round of chemotherapy before going into a yearlong remission. In the spring of 2003, my cancer progressed, and I underwent another round of chemotherapy. However, my treatment was stopped after discovering I had an allergic reaction to this new drug.

Throughout the next four years, I stopped treatment and worked with my oncologist to maintain my disease. During this time, I struggled with anemia, as well as the challenge of working full time.

Daily, I remember driving home from work with exhaustion from anemia. I literally felt like I was sleep walking through life with no energy.

With the support of my wife, I made it through this difficult period and started treatment again in the spring of 2007. After six months, I went into remission. For the first time in years, I was feeling well and took the opportunity to visit close friends in Seattle with my family.

While in remission, my family and I received devastating news. My wife was diagnosed with breast cancer. Believing our family would make it through her diagnosis together, we stayed optimistic and prepared for her cancer journey.

After another round of treatment and a short remission, I started to experience neuropathy. My neurologist conducted tests and discovered that cancer cells had spread into my spinal fluid. Without delay, my neurologist worked with my oncologist to treat me. After numerous monthly treatments, my spinal fluid was cancer-free.

By the summer of 2015, my immune system was extremely weak, and a routine blood test showed I had other abnormal cells in my blood. I was diagnosed with myelodysplastic syndrome (MDS), a rare blood disorder that can develop into acute myeloid leukemia. Due to the risks of MDS, my doctor suggested I undergo a donor bone marrow transplant.

After searching the NMDP database, they found a donor: a young man from Israel who was a 100 percent match.

After a 16-year cancer battle, I received a donor marrow transplant in 2016, and am cancer-free. I now share my experiences with cancer clinic leadership, faculty and staff as a patient and family adviser.

I gave cancer the knockout punch it so deserved. I won. I'm excited to help and inspire others with cancer.

Reflecting on my journey, I credit my wife and children, for helping me survive cancer. My wife believed I would be cured, and her courage and strength helped guide me and my family through this difficult time. Sadly, after a four-year battle with an aggressive breast cancer, she died in December 2012.

My family and I have been through many challenges, but I believe my faith in God, support from friends, and compassionate care from doctors and staff at the cancer center have helped us through it all. Every day I am grateful for a second chance at life.

The unexpected journey

—By Judy, transplant recipient

What started out as a regular summer checkup turned out to be a life-changing event that no one would have expected. I was seeing a new doctor and he said I was in good shape, a healthy weight and overall good health. A few days later he called and was upset when he told me my white blood count was extremely low. I felt fine and we repeated it 2 weeks later. His next call was to tell me to go to a hematologist as soon as possible. That visit required a bone marrow test and the next call I received, as I was about to go for a walk on the beach, was to tell me I had acute myeloid leukemia (AML) and I needed to get to the hospital as quickly as I could.

That day, July 28, 2015 was one I will never forget. My best friend came to my house and took charge as I sat there in shock. She called the hospital and on July 30th my husband and I met our doctor and his wonderful team. They did another bone marrow test and spoke to us for a long time assuring me that what I had was treatable and curable but it would be a long and difficult road to get there.

I would not be able to go back to teaching until the next school year. I told them that our daughter was getting married and I would be traveling to her wedding in Las Vegas in October and they said they would make sure I was there. I entered the hospital on August 5th with my sneakers in hand and walked the 10th floor until I got all my steps in. Before I went home on September 2 we were told that my best chance to stay cancer-free would be to get a bone marrow transplant. The prospect was so scary and the thought of going back to the hospital was daunting but I trusted the doctors. I was able to travel to Las Vegas for the most beautiful wedding of our youngest daughter and I went home to wait for the call that a donor was found. I consider myself so lucky that I was back in the hospital on October 29th and had the transplant on November 5th.

> "…stay positive and surround yourself with as many loving people as you can…"

My doctor and the staff were always patient and kind and I was back home in 3 weeks. Although I was weak and tired I never doubted that I would get my life back on track and make a full recovery. Each time I went for my visits at the clinic they said I was the "rock star" who always had a positive attitude and was determined to get better. My PICC line came out November 17 and as soon as I felt up to it I began a regular morning practice of gentle yoga that I still keep up today. I began my immunizations over the summer of 2016 and returned to work full time in September before my one-year anniversary.

In October at our school's Fall Fair, I had a table for NMDP, and got 26 people to sign up for the registry. I currently teach full time and host two Chinese exchange students for the school year making for a very busy and full schedule. I am also blessed with 3 grandchildren, the youngest is just four months old. I was able to take a month off to go and help my daughter who lives in Los Angeles when he was born.

When I reflect on all that I went through it almost seems like a dream. I was able to meet my donor after a year and he is a young doctor who joined the registry just a few weeks before I was diagnosed. We had an amazing dinner together, knew some people in common, and keep in touch as he awaits the birth of his first child. We are connected for life and "family" as he says!

My advice to anyone going through this is to stay positive and surround yourself with as many loving people as you can. My family and friends supported me each step of the way and it made all the difference in my recovery.

Cancer

—By Beth, transplant recipient

"You've got cancer" spefically, acute myeloid leukemia (AML). No words you can ever imagine hearing. How could this happen to ME? I felt great, as I usually did. I was never sick, hadn't been on antibiotics for decades. Ate healthy (I've been a vegetarian for years), never smoked, moderate exercise, no family history of cancers, I was relatively young (47 years old), etc. The list went on and on.

I'm classic type A: highly organized, perfectionist, always planning and preparing to-do lists for daily tasks as well as tomorrow's dreams. Leukemia was not what I had envisioned.

I was diagnosed simply by going in for my annual physical, at my primary care physician's office. My blood work was all out of whack. After repeating tests showed my barely existent WBC and extremely low platelet count, I was referred to a hematologist. He soon became known as my oncologist.

5 days after being diagnosed, I was sitting in my hospital room, at the start of a 22 day stay, preparing to go down to surgery to have a tunneled catheter put into my chest for chemotherapy administration. I was beyond broken. HOW did I get here??? You've heard of walking nightmares? A person who's just been diagnosed with cancer, out of the blue, is simply a sleepwalker in this space we call reality. The emotional pain is unimaginable, and you contemplate that death really is right around the corner, and there is nothing you can do about it.

My husband was my biggest cheerleader. He stayed every single night in the hospital with me. Held me, reassured me, shaved my hair off when we knew there was no going back (large chunks had started falling out). Our children struggled. Our son was in college, and our daughter was just finishing up her senior year of high school. The spring/summer of 2016 was supposed to be a happy time. Proms, dance recitals, graduation, a trip to Europe. I was devastated I missed her prom, and all the excitement that the day brings. My oncologist cautiously told me I should make her graduation ceremony. Thankfully, I did.

I was hit with more devastating news, during my initial induction chemotherapy, that further genetic testing on my bone marrow revealed mutations that were very aggressive. My only hope for a complete cure and survival was a stem cell transplant. Those three words alone brought such anxiety and uncertainty, as if you were not scared enough already.

Two weeks after processing this news, I was told a match had been found. You don't know whether to cry for joy, or cry for fear, of this long road you're now about to go down.

After several weeks of pre-transplant testing, I had another port insertion, and then was finally admitted for three days of intense chemotherapy (the strongest chemotherapy drug there is, I was told), followed by my stem cell transplant. Sick cannot even begin to describe how you physically feel during this process. The days rolled into each other, and you don't think you will ever come out of this torture. The doctors basically kill you and bring you back to life. Brutal honesty, yet thankfully, they know what they are doing.

But, day by day, little miracles happen. Such as your WBC goes up 1 point. Huge victory! You kept down your breakfast. Yes! You could shower without being absolutely exhausted and having to sit down after 30 seconds. Progress!

The day that you are finally discharged from the acute care hospital, to your near by "home" for an additional two months, is pretty monumental. I remember taking that first breath of fresh air and soaking in the moment I was finally able to go outside, after the longest 21 days of my life. I cried when I heard birds singing. It's the little things.

The temporary housing we had was not "home home", but we adapted and were just grateful to be out of the hospital. Again, days roll into each other, and time seems to stand still. But, I tried to remind myself that I was not in the hospital, and that I was alive! Days were spent in bed resting and recuperating, and daily we had an evening walk around the apartment community. We became friendly with several other transplant patients and their families, who were also staying at our complex, bonding over our shared experiences and comparing notes.

Magically, the big day came that I was actually allowed to be discharged "home home." We lived 3½ hours away, and it was the longest car ride, EVER! I cried driving into our community, I cried when I saw our home; I cried when we pulled into the driveway; I cried when our daughter welcomed us; and I cried when I saw our two cats. I basically just cried! Tears of joy, gratefulness, relief, and happiness. I was on my way to true healing now.

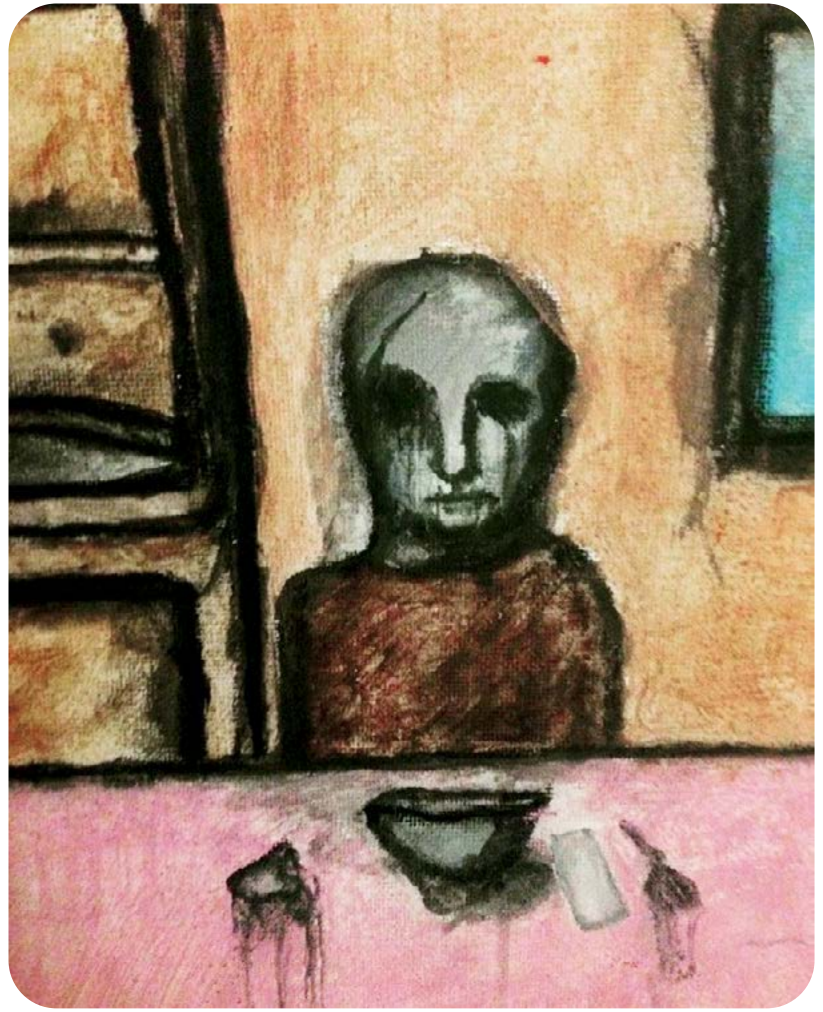
Once home, my recovery was slow and steady. I gained strength everyday just by being in my own surroundings, which brought me so much peace and inner calm. And more importantly, I felt better day by day.

As the days roll into months, I soon realized that I was actually feeling more and more like my old self. Your hopes and dreams soon come back to a reality. You will actually sing along to the radio again. You smile. And your heart is happy once more.

I am now 20 months out from my transplant. I'm in remission, some minor graft vs host, but I feel like I've been given a second chance at life. If I can do this, anyone can! Life is amazing for me, and I try not to take anything for granted. I will be eternally grateful to my donor (a young man who was a perfect match). He has chosen to remain anonymous. He is my hero and angel, and I hope he knows how much he has given me, and my family.

Time to eat

—By Jack, transplant recipient



Mackenzie's Mission

—By Mackenzie, transplant recipient

MACKENZIE'S MISSION

About amyloidosis

Amyloidosis is a rare and incurable disorder in which an abnormal protein, amyloid, is produced by plasma cells in the bone marrow. This protein is misfolded and thus the body is unable to properly discard it. As a result, the amyloid protein can deposit in any tissue or organ. Amyloidosis affects each person differently, but frequently affects the heart, kidneys, liver, spleen, nervous system, and digestive tract. Severe amyloidosis can result in life-threatening damage to these organs or even failure.

My story

In April of 2017, I was diagnosed at the age of 23 with amyloidosis. I had noticed a lump in the back of my throat that continually increased in size. After numerous visits with different ear, nose and throat physicians, I had the lump biopsied, and the results indicated the tissue had characteristics of amyloid. I was referred to a hematologist who suggested a bone marrow biopsy to confirm the diagnosis. The results confirmed the suspicion. For a second opinion, I met with an amyloidosis specialist at a recognized center of excellence. The specialist was completely baffled by my case, saying he'd never seen anything like my presentation. The "typical" amyloidosis patient is a 50 to 80-year-old male with organ involvement, whereas I was a young woman with no organ involvement whatsoever, making my case extremely unique.

My first trip to the hospital in May of 2017 involved a battery of tests to re-confirm the diagnosis. Once it was confirmed a second time, the doctor recommended I undergo an autologous stem cell transplant in concert with high-dose chemotherapy in hopes of eradicating the disease. He believed that due to my age, lack of organ involvement, and early diagnosis, the treatment would be successful. This is important, as my medical team said only about 25% of amyloidosis patients are eligible for a transplant, due in large part to their age or health.

Two months later, I returned to the clinic for my treatment. I spent a total of five weeks undergoing treatment, which included fertility preservation, autologous blood stem cell transplant, and high-dose chemotherapy. The transplant process began and my re-birthday was in July 2017. I proudly hold a certificate of my transplant in the picture above.

While treatment is typically outpatient, one of those weeks was spent inpatient due to severe esophagitis. Other than that, the treatment went incredibly smoothly. In my exit interview post-transplant (day 18), the doctor said I had a complete response to therapy and that there was no evidence of disease anywhere in my body. This was confirmed at day +100 return to the clinic. The autologous blood stem cell transplant worked and has given me a renewed chance for a long life.

I am currently day 275+ post-transplant and doing exceedingly well. I work full-time as a research assistant investigating breast cancer while preparing to apply to medical school.

Why Mackenzie's Mission

As a result of my experiences, Mackenzie's Mission (**www.mm713.org**) was created to spread awareness on the importance of early detection and raise money to support amyloidosis research. It was because of my early detection that complete remission was possible. It is my hope that by creating this foundation, increased awareness can lead to people getting diagnosed years and even decades earlier before organ involvement becomes life-threatening. Thus, greatly improving the chances of successful treatment. The entirety of every donation will be used to support the development of early detection and innovative treatment methods that are so desperately needed for others to live a longer, better quality of life.

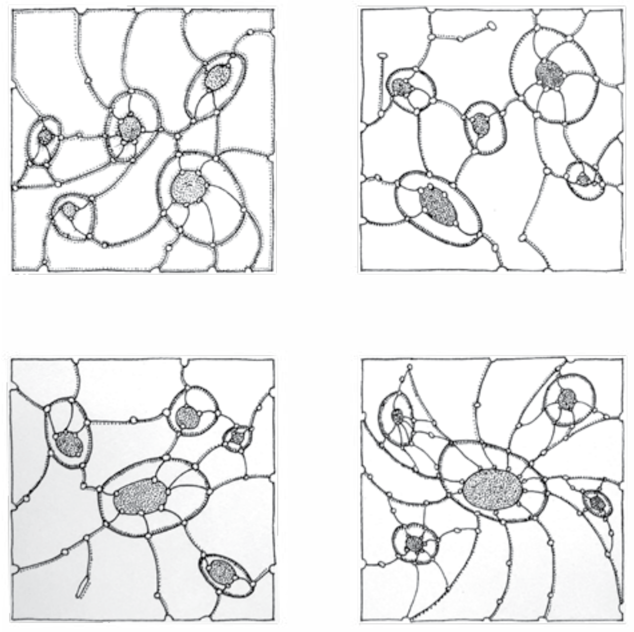
> "I spent a total of five weeks undergoing treatment, which included fertility preservation, autologous stem cell transplant, and high-dose chemotherapy."
>
> — Mackenzie, transplant recipient

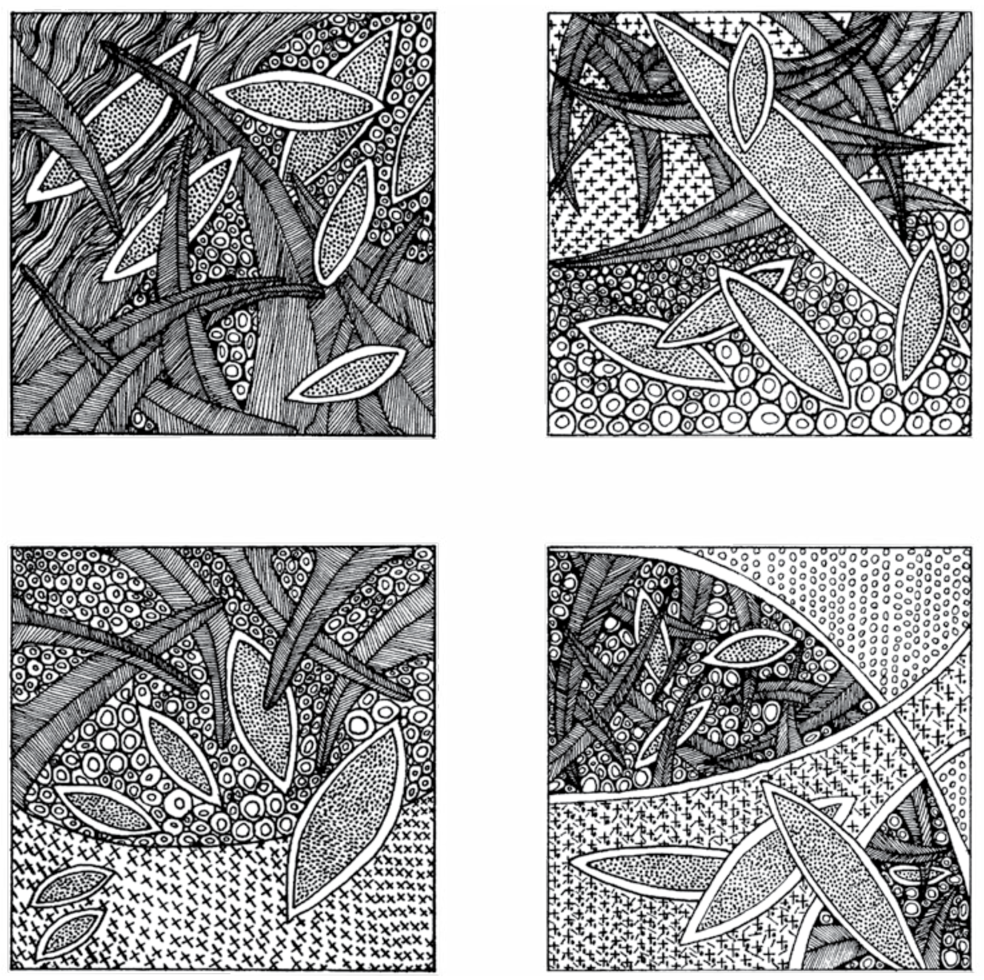
See page 146 for another submission from Mackenzie's family

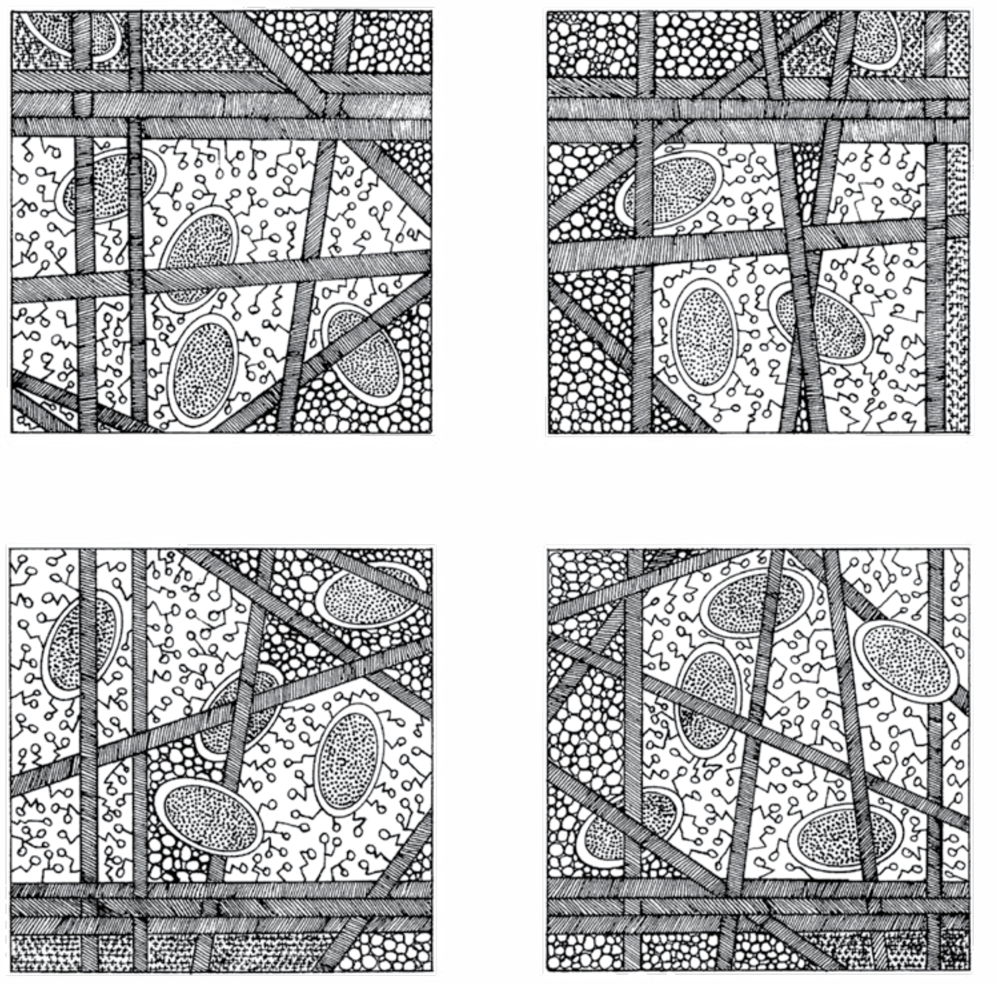
Visualizing blood stem cells

—By Michael, transplant recipient

I am an artist and art educator with an MFA, an MS, and a BFA from prestigious universities. During a recent lengthy hospitalization, I had a bone marrow transplant. During that time I produced close to a hundred drawings inspired by my interest in stem cells and the transplant process. None of my blood stem cell drawings are illustrations of blood stem cells but are interpretations of my thoughts and feelings, joys and fears surrounding my bone marrow transplant, which is a remarkable medical achievement.







Dear GVHD

(graft-versus-host disease)

—By Jenny, transplant recipient

You were cute when you were acute.
A little nausea, a rash on my arm.
A mild burn in my esophagus,
Not too bad, not much harm.

But then you decided to play with my liver,
Fatigue and a fever—you sure deliver!
You hit my knees like a baseball bat

Swinging at a home run pitch—
did I deserve that?

My lungs were next - breathing impaired,
Hard to climb just a flight of stairs.

My eyes, MY EYES, so dry they burn,

New lenses would help, I would soon learn.
My wrists and hands swelled—
couldn't wear my rings,

Chronic GVHD you didn't miss a thing.
But did you have to mess with my hair?
Cancer took it once, it's just not fair!

It's been a slow fight, as I write this letter,
Got a new drug, things are getting better.

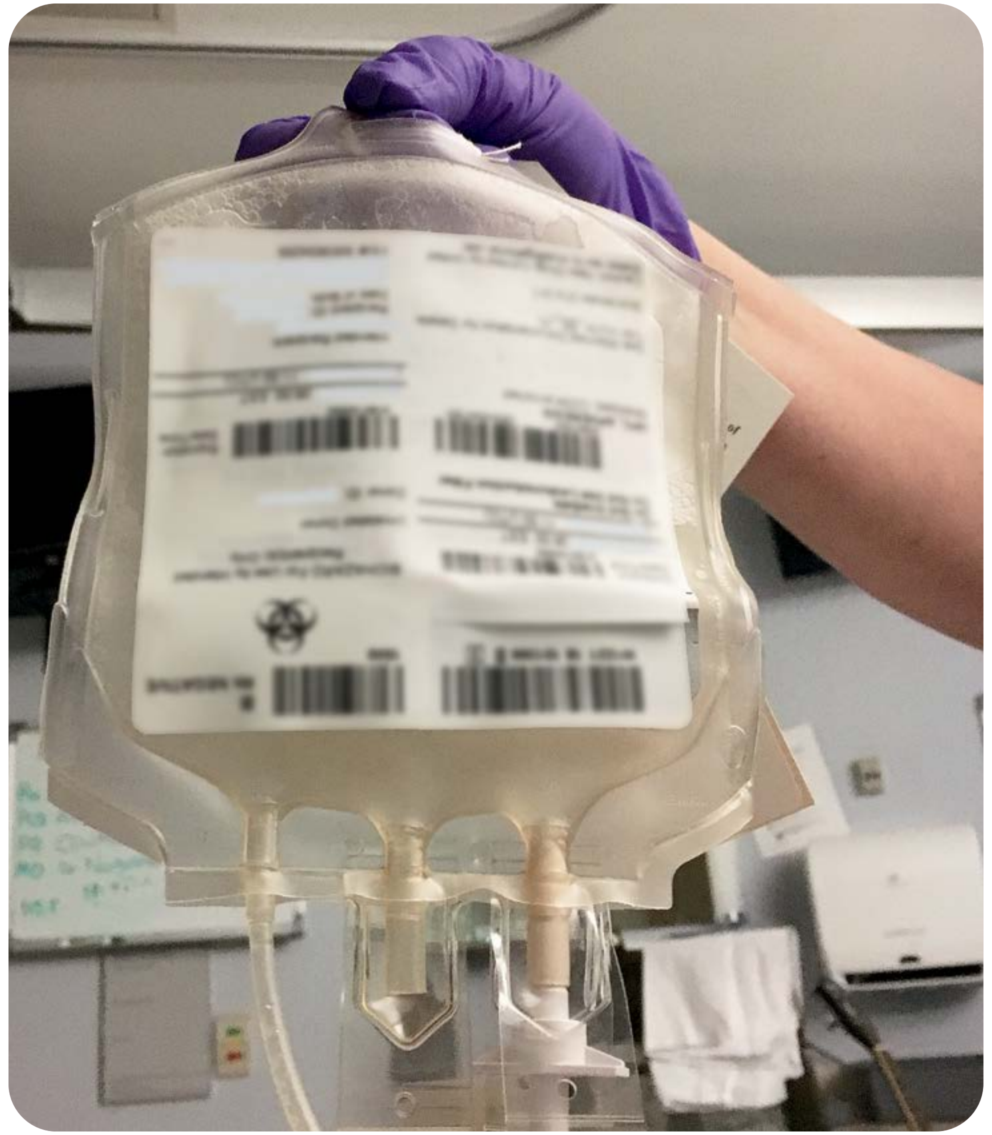
I wish you'd go away,
but you did help me to survive.

The alternative is worse—
Thank God I'm alive!

Sincerely,
Jenny

The tough get rockin'!

—By Vernon, transplant recipient



The day of my diagnosis it felt like a tsunami had hit me. It was one of the darkest days of my life. It proceeded to get darker as each layer of diagnosis was received. Finally, after three days of sheer hell waiting to find out if there even **was** a treatment, I got the news. I had aggressive acute lymphoblastic leukemia (ALL), Philadelphia positive. I learned that since the disease was aggressive, my treatment needed to also be aggressive. The prognosis would be either staying in the hospital another month to get chemo, or to be able to use a chemo pill at home. My caregiver and wife, and I waited in my hospital room that third day for the doctor to come with the treatment plan. We prayed for the chemo pill at home but were prepared for the long stay. The doctor finally arrived with the news: I was going home to take a chemo pill and get the disease into chemotherapeutic remission and return in a few months for a bone marrow transplant.

The mysterious bone marrow transplant loomed over me for the next few months as the chemo pill put the leukemia into remission. I spoke to a few others who had had a BMT and learned about their experience. I was scared but the odds of beating this disease were so much better getting a transplant than not, that it was an obvious choice. My caregiver was in full support of my getting one. The die was cast and the date of the BMT was set. I was admitted to the hospital in early 2018.

The first 9 days leading up to the BMT were the hardest. The eradication chemo treatment was my first hurdle in the BMT journey. I would receive 8 days of nonstop chemo to eradicate my bone marrow to give the transplant a new home. I made it through pretty well with only a few of the usual chemo side effects, but I never felt bedridden or too sick to get up each morning and take a shower, followed by a nice walk around the quad. This activity, along with the love and support of my caregiver and family, helped me endure those 8 days of chemo. Then came "Day Zero" and my transplant had flown across the Atlantic Ocean and was at the airport.

My nurse kept me posted as my transplant landed at the airport. She predicted how long it would take to arrive at the hospital and go through the process in the lab. She assured me that since the transplant was "alive" it needed to be administered within a certain number of hours. The time kept getting pushed back. Finally, at 4:52 a.m., the transplant arrived in my room. I took a picture of it and said a prayer. The nurse hooked me up and the special stem cells from my donor, which had just flown halfway around the world, were entering my body. When the transplant was over, I fell asleep.

The next day, they told me that the transplant will take a certain amount of time before it starts showing in my numbers. On the third day after the transplant, there was a slight bump up in my white blood cell count. I asked if that was a good sign that it was starting early...the doctor wasn't sure that it was a sign. It could be normal or it might even be within the margin of error of their tests. I felt differently, though. I somehow knew this was my blood getting built up by the transplant.

Sure enough, the next day my numbers had increased again and my doctor was now willing to make the assessment that the transplant was in fact taking root in my marrow and making new blood. The next few days saw my numbers improve every day until the doctor said that I would be released about a week early because of this. The transplant had definitely begun to work. By the day of my discharge, my numbers were better than they were on my day of diagnosis. All those beautiful stem cells had somehow managed to repopulate my marrow with good, healthy blood-producing cells.

The return home and all the follow up hospital visits during the first 100 days post-transplant were the next hurdle on my journey. I've since passed the 100 day mark, and there have been very few bumps. As I await my immune system as it matures and grows stronger, I've been very aware of the great work and care that I was shown during this whole process (and still!) This has been the hardest challenge I have ever had, but the overwhelming love and support from my family and friends had been even greater than the overwhelming feeling of that first diagnosis.

Getting leukemia or any kind of cancer is not fun. It can shake up your life and your family's life just by showing up. My journey through this experience is not over. Sure, the recovery process is hard and long, and there are no guarantees. But for now, I have today. I feel great. I'm getting stronger every day. Before I got diagnosed, I began work on an album of music with my family. The fight to beat leukemia didn't stop us. In fact, it fueled the album's original songs with inspiration. We wrote many songs that came from this experience. One of them encapsulates my advice to anyone who has to face cancer, leukemia or any disease in this world:

> "When the going gets tough,
> the tough GET ROCKIN'!"

Thanks to all the great doctors and nurses, and to all my family and friends, **I hope to keep rocking!**

Grateful for a “pretty normal” life

—By Teresa, transplant recipient

In August 2016, at the age of 55, I was diagnosed with acute bilineal leukemia with the Philadelphia chromosome and cancer of the central nervous system. It was a rare and aggressive form of leukemia in which I had both AML and ALL.

They told me from the beginning I would need a bone marrow transplant. They asked if I had any siblings. I came from a family of seven children, all of which agreed to be tested. Of those six siblings, I was blessed to find out my sister, Mary, was a perfect match.

After months of chemotherapy, I was in remission and my bone marrow transplant was scheduled for late 2016. It was the day after Thanksgiving that I was admitted back into the hospital to start preparation for my transplant. I was anxious and afraid of the unknown. I went through more chemotherapy treatments and full body radiation to make sure all the cancer cells were gone.

My sister, had to start injections five days prior to the transplant. The drug used increased her white blood count, she said her body felt very heavy. The day of the transplant she was connected to a machine, through an IV, that withdrew her blood and separated the bone marrow. My sister produced more than enough stem cells. It was then brought to me and injected through my IV. I felt nothing at the time.

Afterwards, Mary felt tired but after a good night sleep she was back to her daily routine. I developed mouth sores, diarrhea, nausea, and a rash which turned out to be GVHD, and at one point I had to be fed intravenously. All of which were treated and I was made as comfortable as possible. I got through it and I was sent home 15 days later. Never to return again.

I have been undergoing treatment at the bone marrow clinic, but I haven’t had to be admitted for any reason. Treatment at the clinic started as two days a week, then one day a week, then every couple weeks, once a month and so on. I have been going to the clinic every couple months now. At each visit they adjust my medications and treat any new occurrences. I’ve had a cough, tingling in my legs, hemorrhoids, and another rash, different from the GVHD in the beginning.

I’ve had restrictions during this whole recovery process. I had to be aware of germs and bacteria that could cause infection in my body. Some of the restrictions were that I couldn’t clean my house and I wasn’t able to be around while someone else did it. I wasn’t able to drive at first, then I could. No shopping, no church, had to stay away from crowds of people. These are just some, there were more.

As time went on and as my body was accepting the transplant some restrictions were lifted. In April 2018, I received the “All Clear” from my doctor.

I am currently being weaned off my medications, including my immunosuppression medication and soon my chemo pill. I am also in the process of being immunized all over again. Every couple months I get a round of vaccinations, just like a newborn baby.

Today I am living a pretty normal life, thanks to my wonderful medical staff, a great support system, my AWESOME sister who was my DONOR, and SAVED MY LIFE, and the good Lord above that made it all possible.

Not my first rodeo

—By Trish, transplant recipient

I was diagnosed with acute lymphoblastic leukemia, Philadelphia positive in early September, 2016. I went in for what I thought was a simple backache. After ultrasounds, MRI and CT scan where done they found nothing. My ER doctor said I am going to do bloodwork. My blood pressure was like 99/47 so that worried her. I just wanted my backache to go away. I sent my husband home and said I will call you when I am done.

Around 2 a.m. my doctor came in with tears in her eyes and simply said “I am so sorry but you have leukemia or lymphoma”— my white blood count was 113,000. Normal is between 4,000–10,000. She said we are going to transfer to a different hospital. My husband texted me to see if I was ready to go home and I replied no they are transferring me and I need to see the oncology doctor. He called I am on my way. He was there in like a minute. He spoke to my doctor. All I could think is I already had cancer. And I beat it. Sorry wrong test results. Sadly it was confirmed I had leukemia. The oncology doctor said we are transferring you to yet another hospital.

It was all a whirl. My sweet husband had the difficult talks of calling our families to break the news. I am so thankful he did it because I couldn’t tell my parents. I just didn’t know how it would be compared to thyroid cancer (my first rodeo).

> “All I could think is I already had cancer. And I beat it.”

I spent 3 weeks in the hospital. My chemo started. I was given several different chemos for a week through my PICC line in my right arm. I also did oral chemo through the month. They were hopeful I would be in remission in a couple of months. However it took 5 months and a stem cell transplant! One week a month I would head to the “spa” for chemo treatments. I am a jokester. And I love to make fun of very scary situations. I had to take a leave of absence from work. My bosses were so generous and gave me a stipend to help with living expenses. I just had to worry about getting better, my job is being a nanny and I missed my kids so much. They took the news like champs. They were like take your medicines and hurry back.

I finally went into remission after 5 months. My sisters were tested to be my donors but were only 50% matches. So we had to find a donor. My donor is from Germany. Yep, I had to go international!

I am so thankful to my donor! Because of his unselfish act I am alive.

He didn’t know me or anything but he gave me a second chance. A second chance to be a better daughter, sister, friend, wife, nanny, grandma and person. He has touched so many lives By simply donating his stem cells to me. I will forever be grateful to him.

This was a tough 17 months. But it was amazing. God has blessed us with incredible family, friends and even strangers who touched our life By their concern and kindness.

Keep fighting!

Trish

P.S. Leukemia, we are not that into you!

A blood stem cell transplant story

—By Terry, transplant caregiver, on behalf of the family dog

This morning, my Mommy left again. She is going to visit Daddy. I hear his voice in our house sometimes. She tells me, "Look, it's Daddy." I don't see him. He is the cuddly guy on his chair. He is not here. Mommy tells me he is in the hospital.

This all started on July 27th. Daddy kept talking to me about being gone for a while. My Daddy is the greatest Dog Daddy in the world. He lets me sit on his lap and lick his beard. A week or so before July 27th, Daddy said I couldn't lick his beard anymore. Then, Daddy had no beard and no hair! Those grandkids came for dinner that night, and everyone hugged Grandpa.

On the morning of the 27th, my Daddy told me he loved me and that he would miss me. Mommy took a picture! I suppose we were so cute! They probably posted it on online. This is how they let people know how Daddy was doing during his hospital stay.

Mommy tells me that Daddy is doing really well. He had chemo for five days, then a "Rest Day." Then, Daddy got a stem cell transplant. He received cells from someone else, since his are not healthy and have leukemia. The idea is to kill off the bad cells and have the new person's cells take over and make Daddy healthy. I just want him to come home and for us to be a family again.

After Daddy was in the hospital for nine days, Mommy took me to see Dr. Davis. They talked about Daddy, and Dr. Davis, my vet, signed some papers. On Saturday morning, Mommy said, "Doggie, you will get a bath, then go see Daddy." I really do not like baths. Mommy kept talking about germs and Daddy, so I was cooperative. Then she said, "Want to go along?" I jumped in the air and off we went!

Mommy opened the door to Daddy's room, and I saw him sitting on a chair. I leapt right on his lap! He was so happy to see me! I couldn't lick him, but I enjoyed sitting with him. I love my Daddy!

My Daddy is okay. He still has no hair and beard, but he talks the same and still loves me. Mommy says his platelets are going down, and he wanted me to come today, as he might not feel as well in the next few days.

We talk to Daddy every night on Face Time. Daddy is having tummy troubles. Mommy brings Daddy's laundry home. He wears regular clothes in the hospital, and walks up and down the hall. Exercise is important for him. The first week, he was walking a few miles a day, but now he is supposed to take it slowly.

Daddy's doctor is surprised at how well he is doing so far. He had a headache one night, and after two weeks he is a little tired of being in the hospital. He has family and friends visit, and that makes him happy!

Mommy has been very busy cleaning the house. When Daddy comes home, his immunity will be very low, so everything needs to be very clean. Mommy has been keeping the back door closed, so I get used to that. Daddy will need to wear a mask when he goes outside.

Mommy says that what Daddy is doing is a miracle. She can't explain everything, but she says it is amazing. Daddy's white cells are down to 0.6. They need to get pretty close to zero. Then he will begin to get the cells of the donor. This should make him better. Daddy is supposed to be feeling sick, but he doesn't seem sick at all. Mommy says he is rocking this treatment. That's my Daddy!

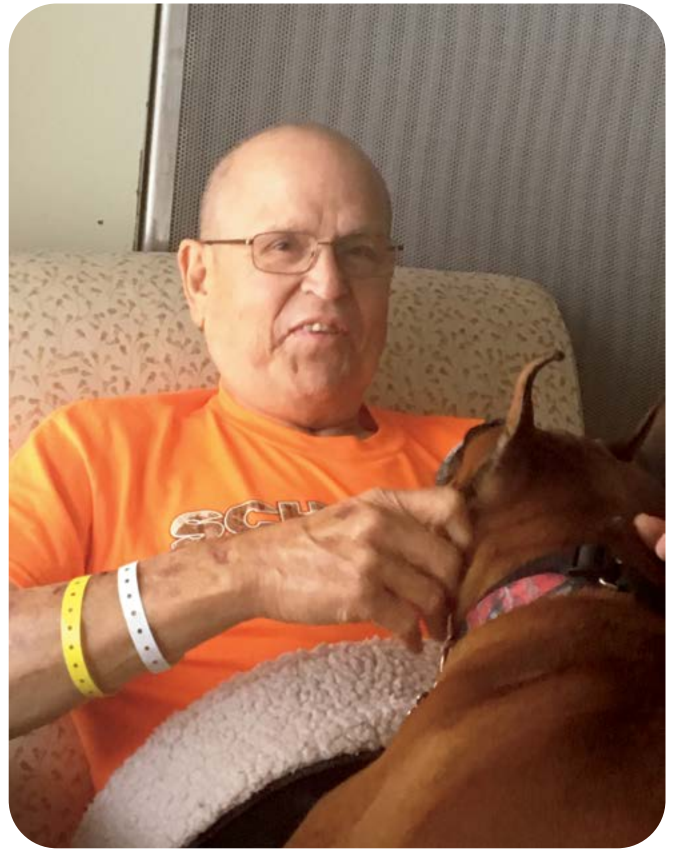
Then, Daddy came home from the hospital. He was supposed to stay four weeks, but he got out nearly a week sooner. Things have gone pretty smoothly, but there were some bumps in the road. In September, after I was just getting use to Daddy being home, he had a cold and had to go back in the hospital for a week. In January, that happened again. In February, Mommy had a cold, and she was careful to wash her hands extra and sleep downstairs. Daddy didn't get it! Mommy said he was handling germs like a champ now.

So here it is near the end of April. My Daddy is starting to have a more normal life again, but still has to be very careful. We are looking forward to the one year anniversary of his stem cell transplant and to his real birthday. Last year we couldn't really celebrate his 70th birthday, as he was in the hospital. This year will be an extra special time with two birthdays to celebrate!

We are very thankful for the NMDP, for finding Daddy such a perfect donor, and for all the medical staff for the excellent care for Daddy!

Love,

The family dog



Who am I? Ready to start a new journey

—By Shanna, transplant recipient

> “I am doing great physically and getting there mentally. When I look in the mirror I don’t look like I used to, and I have had a very hard time trying to figure out who I am now.”
>
> — Shanna, transplant recipient

I remember when I thought I was invincible, and that I would be around to grow old. I had everything I wanted: a wonderful husband and son, a wonderful life. I was going to college to be a medical assistant. Everything was perfect and I thought it would continue to be perfect. Then I started getting sick and having to go to the hospital, and they would admit me and run all kinds of tests. But they could never figure out what was causing me to stay sick.

I will never forget the day that one of my many doctors came into my hospital room and told me about an article he had read. A doctor wrote an article about a genetic disorder called GATA2, and my symptoms matched the symptoms for GATA2. So I agreed to have my blood drawn and sent to that doctor for testing. I went home from the hospital and looked up GATA2 and the doctor. I learned that the NIH is a research hospital and the doctor was doing a study on GATA2. It had only been diagnosed in 2009 so there was and still is a lot to be learned about this genetic disorder.

Then I got the phone call I definitely had GATA2. I had been feeling better and was back at work, so I put it in the back of my head and went on with life as usual. Then a few months go by and I am back in the hospital and was very sick. My doctors gave me two options. I could go to the doctor who wrote the article or I could go home on hospice. There was nothing else they could do for me here. It was very scary to hear that; I was at a very good hospital. So of course I went to the doctor.

I was not allowed to go home and pack or say goodbye. I went straight from the hospital to the airport and boarded my plane. My husband had to stay home to work and care for our son. I finally got to the hospital around 8 p.m. and after getting checked in I finally met the doctor. We immediately went over my past and current medical information. He looked me in the eyes and told me he could make me a lot better but I would never be the person I was before I got sick. Then he told me I would have to have a bone marrow transplant.

I couldn’t believe it. I never thought this could happen to me. I immediately began learning about bone marrow transplants. I learned that I would have to find a match for my transplant. None of my family was a match so my doctors told me about NMDP, and how they were a national registry. We didn’t know how long it would take to find a match or if I would even have a match. As it turns out I was blessed with several matches. So my doctors picked the best match for me.

So now it’s time to get my body ready for transplant. I had to have chemo to kill off my immune system and bone marrow. It was very hard. I got sick from the chemo and my hair fell out I also lost a lot of weight. I was finally ready for transplant and things went great.

I was about 60 days from transplant and I got to go home. I wasn’t home 30 days before I was back in the hospital with chronic graft-versus-host disease of the skin, liver, and gastrointestinal system. It took some time but my doctors got everything back under control and I was finally back at home.

April 2018 was my 2 year rebirth birthday (that’s what my family and I call it). I am doing great physically and getting there mentally. When I look in the mirror I don’t look like I used to, and I have had a very hard time trying to figure out who I am now. I will never look the way I used to and I can’t do all the things I used to be able to. I am having to find the new and improved me.

One year after my transplant I found out who my donor was, and was able to contact him. We thank God for him every day. Because without him doing the most selfless act a person could do for someone they don’t know I wouldn’t be here today. This has been the hardest and best thing I have done and that someone has done for me in my life. So just know that when this journey is ending that you will be ready and able to start a new journey.

Transplant journey

—By Mike, transplant recipient

This is the story of Mike.
Once upon a time, things were great...

Then Steve the Spleen showed up. Large and in charge–so he thought...

I was diagnosed with Myelofibrosis and needed a Bone Marrow Transplant–and a steak!

I recieved chemotherapy for my birthday that year. It was one of those things you don't want but need–like socks.

An angel in Europe sent me some of their bone marrow for Christmas. They also gave me a new life...

On Christmas Santa woke me up in the middle of the night to take blood, temperature, and blood pressure. Boy do I love my nurses!

We recieved lot's of support from friends and family. This poster was created by some dear friends children.

[redacted] is my caregiver. She visited every day and went to her job for 8hrs. She took care of me when I came home from 28 days in the hospital. I owe my life to her. One day she was so tired she wore two different shoes by mistake. We had a great laugh!

Tears of happiness when I found out I was 97% engrafted with the donor's cells. (I'm 100% now).

During the cold months I walked at the clinic.

After 28 days they sent me home. That was quite a day. Also a little scary because I felt so safe in the hospital.

100 days since my transplant.
I drank water to celebrate.

This is the day we were told we were cancer free–or it was the day I bought this shirt. It was so unbelievable!!

Around +180 days GVHD appeared on my skin, mouth and liver. They put me on Prednisone and a bunch of other pills and I started Photopheresis 2 times a week. This is the machine.

The story isn't over but I am cancer free and feeling great. We have settled into our "New Normal" for now. Things are looking up and we have hope! I'm Mike and I'm here to stay!

Michael

My story

—By Lois, transplant recipient

> “Life is not bad after all. Sometimes the road can be rough but worth the trip if it means getting to stay here a bit longer.”
>
> — Lois, transplant recipient

I was certainly not prepared to hear the words, “you are full of cancer” from the emergency room doc the night the pain got so bad we went to the hospital. I was just 2 months past my 60th birthday when I began to have stomach pains which resulted in the late night ER visit. My long-time love and I sat dumbfounded at 3:00 a.m. listening but not really hearing him tell us there was nothing he could do. I was given some pain medication and sent home. My journey was just beginning, and though terrifying and painful both physically and emotionally, I am here to tell about it.

I received no instructions from the ER doctor as to what I was supposed to do. I called the local clinic when they opened in the morning and was told they had no appointments available, perhaps one of the satellite offices had an opening. I was shuffled around and given an appointment. I was sent to an oncology clinic that day to meet with a doctor. I had a few appointments and many tests done when they realized I had large B cell lymphoma, triple hit. This is an aggressive and often deadly diagnosis. I was started on aggressive chemotherapy requiring long hospital stays.

I have little memory of anything prior to starting treatment. I was in terrible pain due to the tumors that had developed so I was heavily medicated much of the time. I vaguely remember dreading having to tell my grown children, my mother, siblings and friends of my diagnosis, not yet knowing if there was any treatment available. I remember feeling such an overwhelming love and support from everyone.

The doctors felt my best chance of survival would be a stem cell transplant. Plans were made for me to go to the hospital and By Mother’s Day I was there ready to start that process. I had high hopes that the transplant would be the answer. By the first part of August I had my stem cells harvested and I had produced such an abundance that I had enough for the transplant. I underwent the precursor to the transplant which kills everything, in theory, but you, and then underwent the stem cell transplant, my second birthday. I felt fine for a while but ended up back in the hospital with side effects.

Once I recovered, it was found that a small amount of cancer continued to grow so the next step was a transplant from a donor. Although I have 2 brothers and a sister, none were an ideal match or they had health problems that would not allow them to donate. My children all wanted to donate but they are not good matches either. I was told a perfect match was ten markers out of ten. The health care team searched the national registry for a good, even partial match. The person they found matched me 12 out of 12, a closer match than ever hoped for. His cells were flown and immediately infused into me. Now I have a 3rd birthday.

A long 100 days followed the transplant with me taking all sorts of medications to help the transplant “take.” We moved to a nearBy apartment building filled with people at various stages of transplant or treatment. I had now been gone from home about 4 months, it would end up being 8 months before I could return home. After the 100 days my transplant showed sufficient signs of being successful, I was allowed to return home taking a huge amount of medications with me and instructions to see the doctor weekly.

Some of the side effects I have experienced have ranged from strange to irritating to painful. This is called GVHD, or graft-versus-host disease. I learned that a little GVHD is good; it shows the donor cells are working. My rambunctious immune system has been very active and sometimes sees things it needs to “fix” and attacks it. I am on steroids and other meds to hold it back and keep it from attacking other organs. I had GVHD in the GI tract for which I took some pretty icky medicine suspended in corn-oil. I took that daily for several months but that has subsided and I am off that particular drug. I developed a bit of GVHD in the lungs but I think that is also improving with medication. My worst complaint has been my eyes and mouth. I am thankful to have found an eye doctor who is familiar with a special lens treatment. They correct my sight and hydrate my eyes allowing me to still work part time. Those lenses make my quality of life so much better and I have gotten quite proficient at applying them.

Until I became ill, I had only heard about the healing powers of prayer. So many people prayed for me. People I know as well as people that I have never met. I know this had a profound effect on my healing. I received shoeboxes of cards, money from friends and total strangers.

I am over 30 months post-transplant and still cancer free! I cannot say this has been without complications but the alternative is not preferable to me. I still have a terrible fear that it will come back, any pain I get causes me anxiety which I try to keep in check. I am still immune suppressed so I have to be careful to avoid crowds, sick people and grandchildren with coughs and fevers. But I get to see them! I get to be with them and with others who I love. I got to be with my mother on her 89th birthday. I get to see my children and their children flourish. Life is not bad after all. Sometimes the road can be rough but worth the trip if it means getting to stay here a bit longer.

That cold morning of late November

—By Fahmida, transplant recipient

My journey from an initial diagnosis to being fully healed took about two and a half years. There were many peaks and valleys that I had to surmount in my fight with ALL. The four part poem is my narrative from the day of my diagnosis to being finally given assurance that I will survive long term. In the past 2 years, I have met several other recipients of stem cell transplant that are enjoying a very fulfilling life. That has given me a lot of confidence in positively looking forward to a quality life for as many years as God wants me to be here.

Diagnosis

That cold morning of late November,
Of year 2014, I will forever remember.
Was clear, bright and how so beautiful,
When the loud ringer, broke my slumber.

Mrs., please come and see us now,
And do make it stat, no matter how.
Her voice was familiar, but why was it somber,
My nurse's concerned tone,
did raise my brow.

On my way there, I did call my spouse,
Informing confidently, but with a pause.
That oncologist, had summoned me stat,
To discuss further, my WBC deficit cause.

Doctor's known office, to me looked scary,
"Chaz" came in too, with a sense of hurry.
We soon got ushered into a vacant room,
Waiting to hear, my bone marrow's story.

Oncologist "Emad",
came with my biopsy report,
Quickly he sat across,
ready to render his retort.
Firmly stating, "Fahmida",
your diagnosis is ALL.
And in adults, this cancer is very difficult
to retard.

His words to us were,
a deafening bombshell,
Oh Lord, why on earth,
do I deserve this hell.
Seeing my doc announce…
my serious diagnosis,
Was akin to hearing, a tolling death bell.

My treatment

My treating oncologist,
was a man sent by God,
Who assured, he'd try fixing me,
despite all odds.
The long and gruesome,
was the lengthy care plan,
That seemed like a mountain,
but I agreed with a nod.

The induction shots of chemo,
hit me really very hard,
Portal's infections lead me,
quickly to critical care ward.
On the threshold of death,
I was playing hopscotch,
Dodging pneumonia,
septicemia and thrush so bad.

By many doctors' wisdom,
and many earnest prayers,
I made it home again,
pampered with family' care.
Slowly gaining strength,
to resume my treatment,
Ha-ha, a 42 days, consolidation,
wondering how would I fair.

That gruesome journey was quiet debilitating,
Yet, with God given strength,
I never stopped smiling.
I knew I have to fight and stay on treatment
course
Though a bald skeleton…I kept up my fancy
dressing.

My doctors and nurses,
were often amazed,
Doubting my excessive laugh,
lest was I crazed?
But it was God's peace
that I was holding on,
Knowing that my cancer,
was harnessed and braced.

Transplant

Then I was admitted,
at the hospital in Westwood,
For a stem cell transplant,
to bury ALL for good.
My care-team comprising,
Gary, Tidi, and Faysman,
Did a job akin to a feat that only God could.

A bone marrow donor, wasn't found,
Would I still make it,
such apprehension did hound.
Then a stem cell donor,
the allogeneic option,
Was tracked and found,
in Spain on foreign ground.

24 hours after the transplant,
I was a "day one" new born,
A new life infused,
to my bone marrow deep down.
My breathing skeleton body,
was intensively watched,
To see if I accepted,
a graft winning a new life crown.

Recovery

My recovery was faster than my team's
expectation,
My room was filled,
with pretty cards of congratulations.
By my new age of day 20,
I left my treatment room, Victorious.
ALL was defeated,
that's no exaggeration.

Living healthy, a year past the transplant, was
finally attained,
The journey was rough,
but problems were contained.

Through prayers
and cares of my care team,
In January 2017, all meds were stopped, since
full health regained.

For the precious life's extension,
I excitingly now rejoice,
Thanking God for his people,
working in health field by choice.
For human intellect and knowhow,
will always have a limit,
Blessed are the professionals,
who work By His voice.

Oh, God heal everyone,
suffering of whatsoever disease,
By guiding their steps,
to those epitomes of peace.
The doctors & nurses,
along their ancillary helps,
Angels serving mankind,
every opportunity they seize.

Blood stem cell miracle

—By Rita, transplant recipient

I tried to anticipate the unknown as I sat in my private room at the hospital, not knowing what the next few months would entail. My mind raced with thoughts and fears about the upcoming journey.

Since I am of German and Irish descent, the worldwide search for a match included the United States and Europe. The blood stem cells were donated by a woman in her twenties living in Europe, who matched 12 for 12 on the criteria. Neither of us had ever been pregnant, which was a major advantage. The donor remains anonymous for two years. After that time, if she chooses, I may travel to Europe to meet and thank her for her extraordinary gift.

My physician, the clinical director of the inpatient bone marrow transplant unit, was hopeful about the match. Her enthusiasm and positive attitude were contagious.

My treatment began with four days of chemotherapy, followed by one day of rest. The blood stem cell transplant occurred on day six after entering the hospital. It was 5:15 in the evening when two nurses entered the room and announced, "They're here." One nurse was carrying what appeared to be a 300 ml, clear bag of reddish-brown stem cells. She hung the life-saving bag on the intravenous pole and began to connect the tube from my upper-chest catheter to the bag. No sound was heard. The lights in the room were dim. The only additional lights came from the picture window of the twinkling city lights.

She slowed the drip from the blood stem cells so that my body could gradually absorb them. As the three of us watched them drip through the tube, the nurse caressed the bag with her hands and said, "This woman has very healthy stem cells."

I sat there hoping this life-saving treatment would cure my myelofibrosis, a form of blood cancer. I felt no pain or discomfort, just hope.

Both nurses stood by the intravenous drip the entire time. Neither took her eyes off the procedure. After two hours and 45 minutes, the bag was empty. When it was over, I didn't feel any different. I kept thinking … is that all?

Over the next few days, changes in my body began to take place, such as darkening of existing moles and blemishes on my arms and legs. New fingernails began to grow from the nail beds pushing the old nails off.

About two weeks later to my chagrin, I combed half of my medium-length, light brown hair into the garbage pail. The next day, I combed out the rest. It is expected to begin growing back in three months. Mine took about four and a half months. Six months have passed since transplant, and my hair is one-eighth inch long and growing in evenly. It's a sign of healing and of my body returning to good health.

For doctor appointments, I wear a short blonde wig with pointy bangs, and comb the sides back behind my ears, topped with a newsboy-styled hat. I feel stylish again.

The doctors say it may be a year to 18 months before I am fully recovered. I never looked long range. I took each new day and experience by itself. There were times of despair, yet the nurses counseled me and gave me new hope. They provided comfort when I felt most alone.

Yes, I would recommend a blood stem cell transplant as a means for a cure. The discomforts come gradually and are never unbearable. Each day I saw my health returning. Presently, I am able to do simple tasks that I couldn't do six weeks ago, such as a 30-minute morning walk, bake Irish soda bread, vacuum, cook meals, and most of all, type memoirs.

Thanks to the excellent doctors, nurse practitioners, pharmacists, nurses, medical technicians, aides, housekeeping staff and food service personnel at the hospital, I am healing.

Mi historia de transplante

—By Roberto, transplant caregiver

Mis nietos nacieron en el hospital un día muy especial 11-11-16. Después que fueron pasando las semanas vinieron los controles, y los llevamos al hospital por plaquetas bajas, y lo atendían dos doctoras. Después de aproximadamente 6 meses de análisis y preocupación de las doctoras, le diagnosticaron con el síndrome Wiskott Aldrich. Fue algo desconocido y preocupante, nos derivaron al hospital. Tengo conocimiento que la doctora estudio con otro doctor, con este fuimos a hablar en el hospital y su equipo, con mi nuera y mi hijo, conocimos al doctor y a sus enfermeras. Los empezaron a revisar y ver lo que harían, la resolución fue que había que trasplantar a los dos hermanos. En la revisión descubrió el doctor que no eran mellizos, que eran 99.9 gemelos idénticos, gran sorpresa para los papas y la familia. Nos explicaron al detalle cómo sería el trasplante y nos dieron un libro para informanos y en que consistía el trasplante, la medicación y sus efectos, la quimio y la duración. Las vías que llevarían en el pechito y el estómago para darles la medicación y la comida. El tubo en el estómago, era la decisión si se lo ponían de los padres. Lo recomendaba el doctor por si no tomaban la medicación oral, y porque la medicación es fuerte por la boca, dieron con detalles todas las explicaciones. El cirujano les coloco las vías del pecho y el estómago. Dieron una previa entrevista como sería la colocación de las vías y la cirugía que les harían. La preocupación del médico y su equipo era encontrar el donante y la compatibilidad en lo posible que fuese un 100%. Como abuelo que estuve junto con los papas desde el comienzo de la internación con mis dos nietos, siempre me dio seguridad el equipo de médicos. Cuando comenzó el proceso de bajarles las defensas con la quimio, a la semana me sentí muy triste al ver caérseles el pelo y hicieron fiebre, ya me lo habían explicado pero fue muy fuerte verlos quedarse sin su bonito pelo. Otra situación que me sentí mal cuando le bajaron la inmunidad para el trasplante. El verlos conectados a las vías del pecho con la medicación y muy decaídos hasta el trasplante, pero así es el proceso. Estuve presente en el trasplante de uno de mis nietos, fue una experiencia tremenda. Lo tenía agarrado de su manita izquierda. Después transcurrieron los días y le salieron llagas en la boca. Les daban cierta medicación por el tubo del estómago ya que no podían comer. Dos semanas después ya tomaban por la boca la medicación y no se usó más hasta que les salió Graft vs. Host Disease. A uno de ellos, le dio en la piel y los intestinos, lo tuvo bastante mal. Se volvió a usar el tubo del estómago 15 días más o menos para darle la medicación y ya no se volvió a usar el tubo. Fue una buena decisión la colocación del tubo en el estómago. Ahora que están en casa caminan, juegan, hablan están felices y prontos para cuando el equipo médico decida quitarles la vías y el tubo del estómago, siguen evolucionando y recuperándose. Controlados por el doctor y su equipo. Aunque siguen en su recuperación bajo la experiencia del equipo médico quienes mantuvieron su peso adecuado para mis nietos durante y después de trasplante, más que agradecido eternamente al doctor que le devolvió su vida a mis nietos y a todo el banco de donantes. También extendiendo un agradecimiento incondicional a todo el equipo de trasplante del hospital.

Sylmonia,
transplant recipient

CHAPTER THREE:

Faith and resiliency

My journey with leukemia

—By Sylmonia, transplant recipient

My new life

Who would have thought I would end up in the hospital with a blood cancer disease called B-cell ALL (acute lymphoblastic leukemia)? Who would have thought that this disease would change my life forever? Who would have thought this life changing transformation would strengthen my faith in God?

I certainly would not have thought this would ever happen to me. Why me? I believe God picked me for a reason–maybe I was dragging my feet about doing His business and this was my test. Maybe this or maybe that, whatever the reason may be, I am here now. I will hold on to God's unchanging hands and let him lead me through this journey.

I see myself as a little child, wearing my little hospital gown holding Jesus' right hand. He leads me through the hospital through the good, the bad, and the ugly. As I go through this new life, He's still holding my hand; He refuses to let my hand go. I know He will never let go my hand, because he'll never leave me.

What's wrong with me, urrrrgh I feel horrible

I will never forget that dreadful Friday evening when I received the news that I had the big "C", cancer. Oh my God, I was devastated but I maintained my composure through it all. I may have been screaming on the inside, I was pretty calm on the outside.

The entire week I felt as if I was going to die! I felt horrible! I finally convinced myself to go to the ER. This is where I received my life changing news. I was told by the ER doctor I had cancer. I cried upon hearing the word "cancer." Immediately I was rushed to the hospital to receive ongoing treatments that seemed to last forever.

My first hospital stay lasted over a month. I received my new best friend, the PICC line. This line was attached to my arm and became part of my daily life. I was pretty scared of the unknown during my first hospital stay. The doctor informed me I would go through cycles of chemo and I would have many inpatient stays.

Am I going to die?

I was still in denial, going through this huge ordeal. I was concerned with what was happening to me. I couldn't help from thinking that I was

...continued

going to die. The doctors assured me that I would be fine, as long as I kept my positive attitude. On the outside, I was very pleasant and positive. However, in my mind, I wondered if I would die. My husband, mom, children, family and friends were very supportive. They helped build my confidence as I went through this life-changing journey.

Oh my God, I have no hair!

While in the hospital I received chemo, I was told that I would possibly lose my hair. I didn't believe I would lose my hair because I had long, thick beautiful hair. Shortly after receiving chemo, my hair started to fall out like leaves on an autumn tree. Not only did I lose my hair, I also lost my appetite. After losing weight and my hair, I was bald and skinny. To my surprise, I didn't look as bad as I thought. My daughters told me I looked pretty with my bald head. What a relief.

BMT news

My very nice, very handsome oncologist informed me that I would possibly need a bone marrow transplant. I dismissed this information because he said "possibly." However, after being in and out of the hospital, my condition seemed to worsen. I wasn't able to complete all my chemo cycles due to the need to prepare for the BMT.

As reality set in, I prepared my mind for the BMT. I was told that I would need a donor for this process. Fortunately, my brother was a match. This was awesome news because there was no match on the donor registry, due to my rare blood type. My brother was extremely excited that he was a match, I was ecstatic!

Preparing for the BMT was a lengthy process. My procedure date was pushed back twice due to complications. My white blood cell count was high so back to the hospital for more chemo. Once I was cleared, I was able to start the many preparations for the transplant.

One of the treatments was full body radiation for three days. It was painless, but I wasn't prepared for the end results of the radiation. A couple of weeks after receiving the radiation, I literally went to bed one color, I woke up a totally different color. My skin was black as tar. I didn't recognize myself when I looked in the mirror.

I was a very sick person after the transplant. My body didn't adjust to the transplant very well. However, after receiving the wonderful treatment from the cancer team, the nurses, and the hospital staff, I began to feel better.

During this life-changing experience, I kept my faith. I prayed to God everyday to heal my body and allow the transplant to be successful. My strong family support helped me tremendously dealing with leukemia.

Post BMT

The first 100 days after transplant was crucial to survival. I had to be extra careful to keep from getting any type of infection. Although I ended up back in the hospital twice, I made it! I am fine today. Almost two years later, I am in remission and very thankful that the bone marrow transplant was a success. It was a tedious journey and I'm thankful everyday that I'm still here.

I'm thankful to my doctors, the hospital staff, my husband, my mom, my children, my family, and especially God!

I hope my journey helps whatever you're going through.

Sylmonia,

transplant recipient

"Who would have thought this life-changing transformation would strengthen my faith in God?"

Sylmonia received a transplant for acute lymphoblastic leukemia (ALL). "One day, you're one way, and in a matter of hours, your entire life changed," Sylmonia said. "It was a horrific experience. I wanted to share the good, the bad and the ugly. Everyone handles it differently. Because of my faith, I was able to handle it well. Just because you receive a diagnosis, it's not a death sentence."

And story

—By Mark, transplant recipient

Marathon

all my life and way before

cancer was the end

no chance

I'm still here

they are saving people now

Why me?

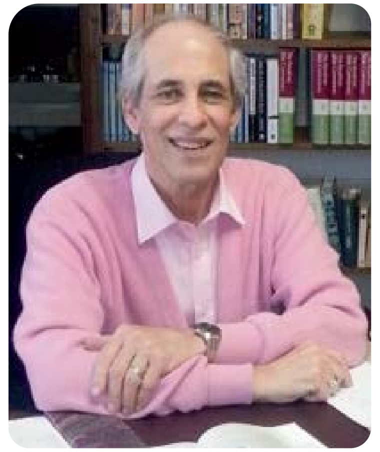
I'm feeling guilty,

much more good will come from this

that's why me.

What do you do when you are told by the doctor, "You have CANCER!"

—By Daniel, transplant recipient



What do you say? How do you feel?

A feeling of disbelief came over me! How dare my body have 'CANCER!'

I was experiencing fatigue. As time progressed, I was losing weight. Oh how much I was to learn of my condition in the future!

I scheduled an appointment with my family doctor. I was diagnosed with 'anemia.' Which is only a symptom (I learned later) of what my condition truly was! Then what happened to me in the pulpit preaching a sermon during our worship service began to reveal what was 'REALLY' taking place in my body.

Halfway during the message I fainted, pulling the pulpit down on top of my body. It took two grown men to pull it off of me. There were not any bruises or any pain in my body and I could only say 'Thank You God' that I was living! A member ran to get help and paramedics came. I asked if we could pray for those who came to help. I never want to pass up an opportunity to pray for those I may never see again this side of heaven. With the diagnosis of 'syncope' (fainting), I was to be put on a stretcher and taken to the hospital. I told them, "The only way I will be taken out on a stretcher is when God takes me home!" What I learned next was a journey of complete faith in this God I serve!

My wife put me in the car, after I walked out of church on my own. After a week of testing, nothing was determined. I needed a 'bone marrow biopsy,' which would determine if I had 'leukemia.' We had to wait over the weekend to find out the results. How hard that was to wait! Then to find out, I had acute myeloid leukemia (AML), cancer of the blood.

There was no time to waste. I was in the hospital for many rounds of chemotherapy which I never complained about. I chose to look at 'chemo' as a healing agent to get rid of this cancer in my blood, not a poison that we think of! How much my faith would be tested over the coming months!

During this time I was asked if I wanted to have a bone marrow transplant. The process would wipe out all the 'bad' cells and replace them with 'good' ones. Sounds pretty simple, right? What I experienced the next few months would simply be astounding!

Not once did I fret or fear because I "KNEW" God was with me. His hand was guiding the circumstances. I knew I needed to get better because God needed me for His work and for my wife. She needed me because we have lost everyone in both of our families. Our church needed me too!

I was in the hospital for nearly 25 days! Imagine that, I had not been a patient in the hospital since I was 8 years old and now I find myself here at 64 years of age!

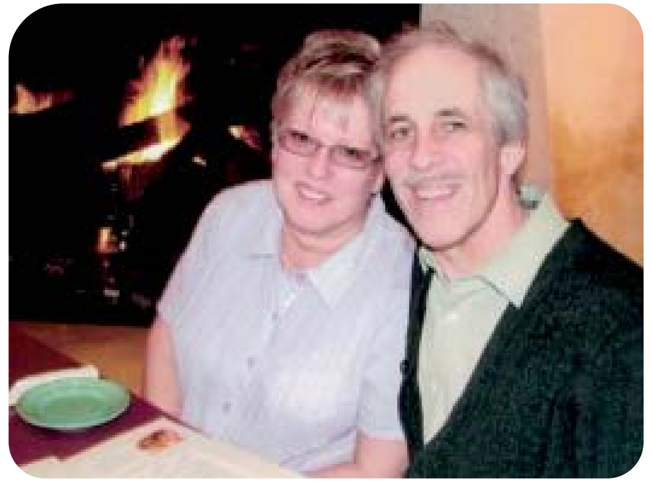
I learned that I would have a 10% chance of living with chemotherapy and up to 90% chance with a bone marrow transplant! What would you choose if you were offered that? We prayed that God would locate that "right" person to give me new life! A match was found in a young woman from Germany. Imagine that, a donor was found for me in such a short period of time I couldn't say, 'NO!'

We let the whole world know what I was to go through and asked God to use me as 'A TESTIMONY' to help other people in whatever struggle they were going through. I was 'hooked up' to a continuous drip of saline, medications and oh yes, CHEMO! At times I counted 12 bags of 'medicine' going through me! Each day my blood levels were recorded and I could see my body being wiped out of the bad cells to be replaced By the donor's good ones.

Each day I would try to find 'SOMETHING GOOD' to laugh and smile about. My laptop became a source of comfort with music. The nurses would visit my end of the hall and listen to gospel music, sermons, 'oldies and Motown music.' In my pain, I was a source of comfort for all who came to see me. A singer/songwriter in our church had written a song for me titled: 'Pastor Dan' which I played for the doctors. I knew that if I played the song before they consulted with me, I'd have their undivided attention; they had to listen before they talked with me! Pretty smart, huh? Each day we could see I was improving. The transplant director, called me his 'Model Patient'! We told him it was God who was doing the healing, all I am was a willing servant!!!

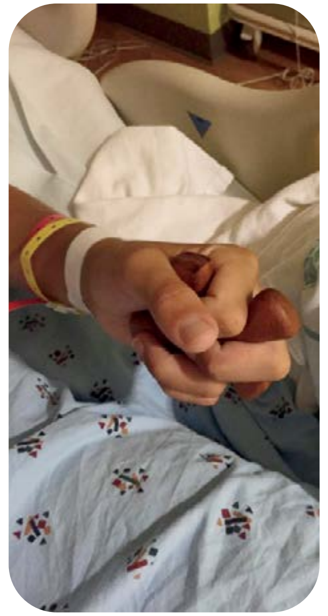
We share our faith with others in a special way when we go through severe times! If God can touch and heal my life, surely he can and will touch your life, no matter what you are going through!!! All we have to do is 'GIVE' the whole problem to him! If God can create a whole world, can't He take care of your need! That's why we are offered the greatest gift ever given, all we have to do is ask for it! The "gift of eternal life," not just going to heaven one day, but experiencing joy, peace, and comfort no matter the circumstance!

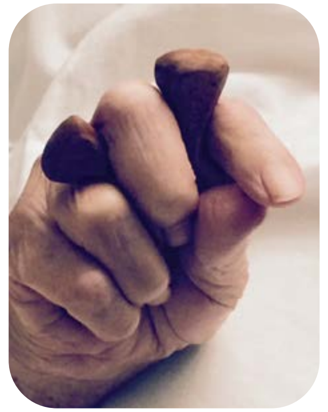
Now here I am writing my story! So much has happened, too much for me to account! The moment of truth came when my doctor asked, "Do you want to keep going through chemo with a 10% chance or do you want a transplant with up to a 90% chance?" The choice was mine. I chose to put my "TOTAL FAITH & TRUST" in this God that created me! Always remember God is good, all the time, God is good!"



The healing cross

—By David, transplant recipient





I will celebrate my 5th rebirthday on May 29, 2018. After failing to find an adult bone marrow donor, my life was saved from AML through the miracle of umbilical cord blood stem cells, generously donated by two families in New York and Texas. It is ironic, because I was an obstetrician.

My journey was hard, but through it all I felt the love and support of my friends, family and church. After my diagnosis, a close friend gave me the precious gift of a healing or clinging cross. Every day I carried, and it carried me, through every visit and treatment.

The following year, I passed it on to my sister-in-law when she suddenly and tragically lost her son in an accident. It was such a source of comfort and strength to both of us that I wanted to share that gift with others. Since then, I have created over 400 crosses and freely shared them with anyone who needed comfort.

Now, whenever I learn of someone who is facing an illness, trial or loss, my pastors or I present them and their family with this symbol of God's love and His presence. My Cross Ministry has resulted in such an outpouring of gratitude, and so many stories of its impact in their lives, that I have been truly humbled. This effort has inspired other churches and woodworkers to begin their own ministries.

Alone at my hospital window

—By Albert, transplant recipient

As I quietly sat alone at the window in my hospital room

and enjoyed the recurring bright light of the morning sun

that hid the darkness of the night filled with gloom

and for the day it would give me fun

My sick entire self was renewed like clockwork each day
like a morning flower

blooming as the rays filtered down by the wonderful light of the day.

Amazingly, two caring pigeons came to rest on the window ledge

they must have known a new life was begun by the transplant and
keeping illness at bay

A note to myself

—By Allen, transplant recipient

It's been two years and four months since my transplant. I discovered this note to myself, written during the difficult days after transplant.

Reasons to welcome each new day:

For the unexpected sight
of something beautiful.

For a chance to give encouragement and cheer.

For a shared sweet moment
with someone I love.

Strength

—By Mary, transplant recipient

> “Strength is a spiritual force and each of us has it. When the physical strength gives out then one must rely on mental strength and positive thoughts.”
>
> — Mary, transplant recipient

Strength is a powerful word. Physical strength is very obvious to the human eye. Internal strength is something different and more difficult to define. Not only is it difficult to define it is hard to determine where one finds their internal strength. It varies from person to person. When I received my diagnosis, I did not feel strong. I felt like a weak and helpless child in the face of this disease. An anonymous quote said: “When on the edge of destiny, you must test your strength.” AML with 2 BMTs put me on the edge of a new destiny—to survive at all costs.

To ensure my survival I had to find new sources of strength. Since dying was NOT an option, I decided I would need an extraordinary amount of strength to fight the orange ribbon demon. Thank God I did not fight alone. I have the most amazing family and friends who helped me every step of the way and a perfect match from my only sister. When my strength failed I could rely on them to push me forward. That’s right—I am a thief—a strength stealer. When I couldn’t put another foot forward, I would look into the eyes of someone I know with great strength and steal some of theirs to help me through. These strong people in my life, my husband, sons, my mother, sister, aunts, cousins and other family and friends shared their strength with me and gave me the ability to get up each and every day and fight this disease.

I don’t regret stealing from these wonderful people. Strength in the face of adversity is one of the true gifts of life. There were days when I was so sick and in pain I didn’t know if I could get out of bed. I would lie in bed and imagine the eyes of one of these people, and like a thief in the night, I would rob some of their strength so that I could use it to get through another day. The great thing about stealing this is that I could then pass it on to others in the same situation as I was. Now that my strength is back to the new “normal”, I can’t wait until someone looks me in the eye and steals my strength. I have a lot to give. I had many pillars of strength during my journey and now I can be a pillar for others with this disease.

Ralph Waldo Emerson said “…Spiritual is stronger than any material force … thoughts rule the world.” Strength is a spiritual force and each of us has it. When the physical strength gives out then one must rely on mental strength and positive thoughts. The key to mental survival is the key to physical survival. I made up my mind that I would win and I will. Everyone with cancer will have good and bad days. On those good days, let others steal your strength and on the bad days steal from others. Use your strength, your friends, family and even your children. Wherever you find it, and use it.

We are all strong and with the combined research and NMDP as well as awareness we can and will WIN.

My faith carries me through

—By Sharon, transplant recipient

It was spring 2015, I had always been healthy and active. I thought this couldn’t be happening to me; I can’t have acute myeloid leukemia. I told the oncologist. But I was wrong. We were told we had an hour to get things packed and be on our way to the hospital, a three hour trip. And go to the emergency room they will be waiting for me, which they were and test after test and in my room for the night. The next steps began the next morning early and continued for months of chemo, more blood tests, x-rays, bone marrows, EKGs, more chemo. The day came when my oncologist said you have 3 options. I right away said option #3. I’m a fighter; I’m on board let’s find a donor. And in a short amount of time I was told they found me a donor and he’s a perfect match. They had the date when this was going to be done; I’m getting a transplant! I stayed positive and worked hard every day to keep strong and have energy. I’m very independent and wanted to do for myself. I got lots of support and prayers from my husband, our son and family and our church. I kept setting goals for myself and that made me want to fight even harder. I never felt alone through this transplant process; I kept a journal and kept in touch with friends as much as I could. I had to retire from my job which was sad but keep in contact with the staff and many friends.

I can’t say enough about the wonderful doctors and nurses that took special care of me. For the seven months I had to spend there.

This is my story and I so often go over in my head all I had to go through— It can be lonely, but you’re not going through it alone.

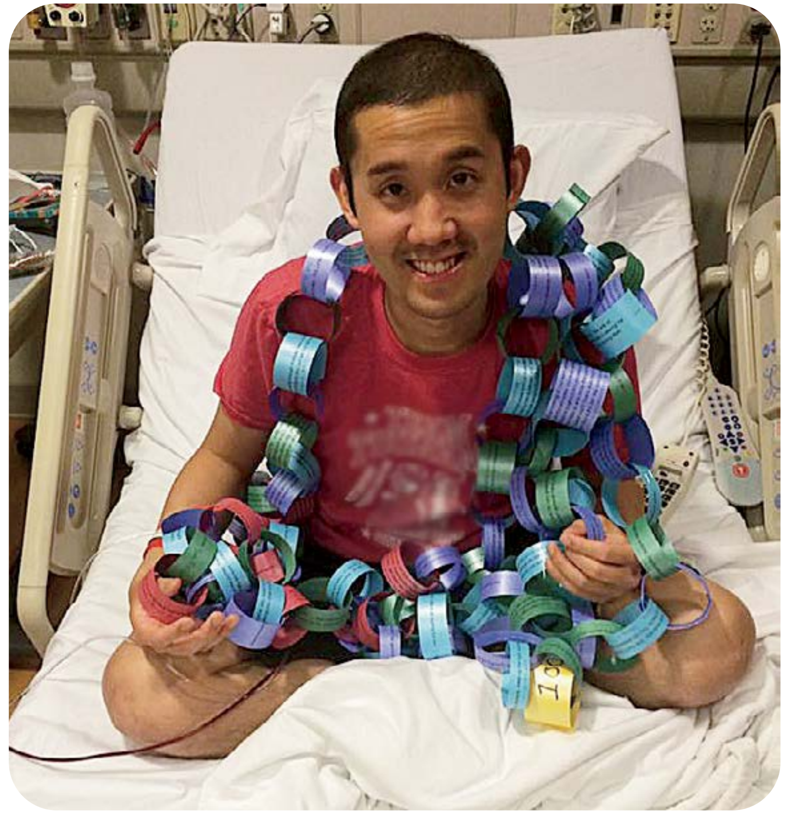
“I can do all things through Christ who strengthens me.”

Philippians 4:13.

Sharon

My daisy chain

—By Matt, transplant recipient



Here is a picture of me with my daisy chain which was a collection of short notes and inspirations from different people in my life. One of my friends collected quotes, stories, and funny sayings from my friends and family and put this chain together. I would open up one each day and read it out loud to help me get through the first 100 days post-bone marrow transplant. It was something for me to look forward to each day and would always put a smile on my face and help me get through the difficult day. Small things like this can make all of the difference!

Never give up hope

—By Barbara, transplant recipient

It was a Sunday in March and I was heading into church services when my friend said I looked pale. I was the healthiest woman in her 70s you ever wanted to meet. Never a hospitalization, no health issues. I told my friend that I was feeling a little tired and had a few mouth sores but figured it was nothing important. She, a retired nurse, was concerned and called 911 and in minutes I was on my way to the hospital. I felt it was totally unnecessary but she insisted. While in the ER they took some blood and came back looking very alarmed. The ER doc asked me if I had "blood issues." I said no and he said "well, you're running on half a tank and we're admitting you for a transfusion." I was shocked and petrified. My hemoglobin was super low. Once I got the transfusion, I felt fine and asked to be discharged. By then a neighbor had brought over my husband (who was 20 years my elder and in declining health), and I heard my daughter and two brothers were on their way from out of state. That made me really nervous, why all this fuss? Finally a doctor came in to tell me I had leukemia. I was convinced they had the wrong patient. A week later, I was home and a week after that on my way to the local cancer center.

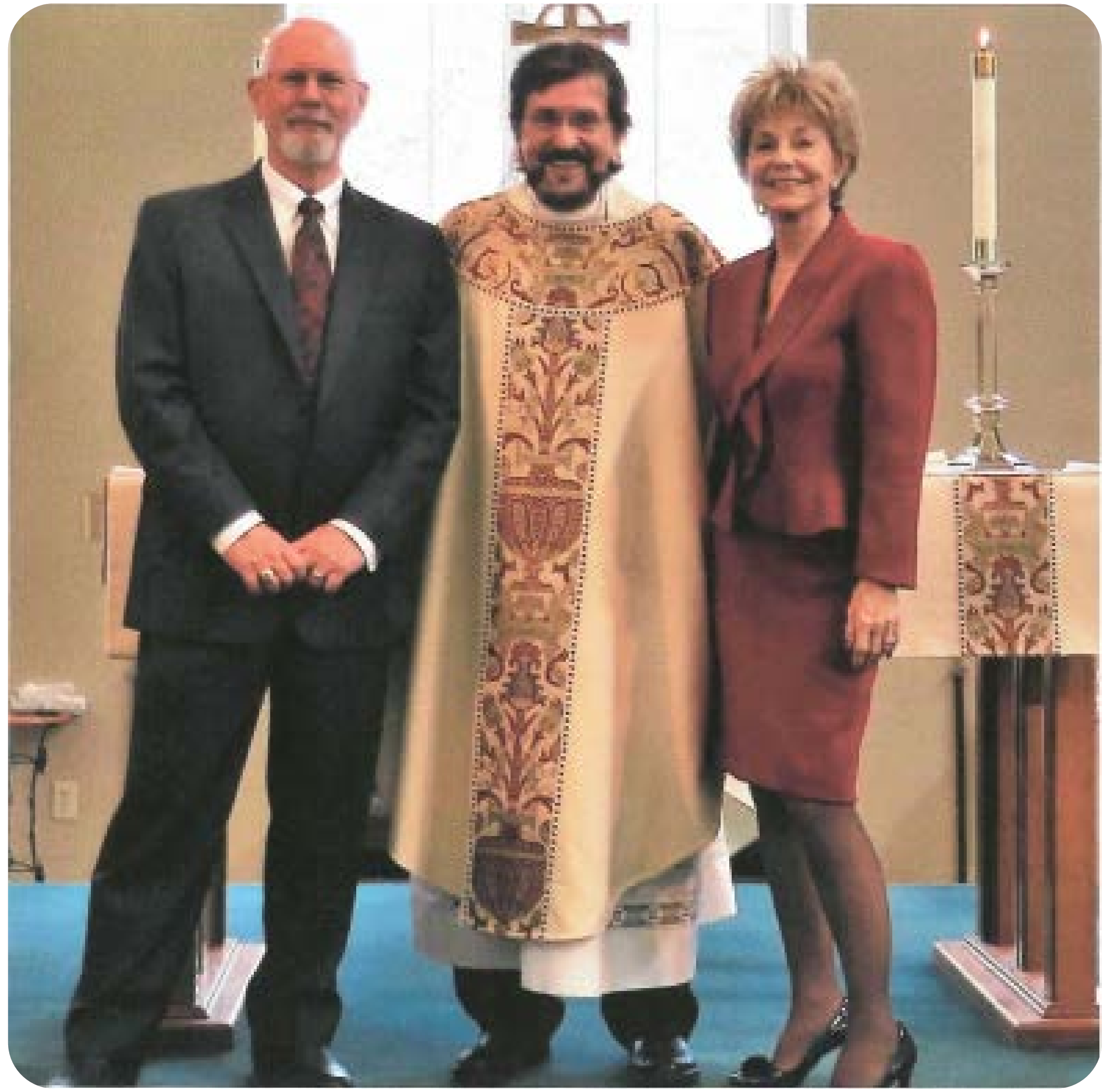
I was being admitted for chemo and to see if they could get me stable to prepare me for my "options." I spent three weeks in the hospital getting chemo and losing 16 lbs and feeling pretty awful. Then one day, they came in and told me I was being discharged and had an appointment with the hematologist to hear more about "where we go from here." My visit with him sent me over the edge. He said my best "hope" was a bone marrow transplant but even at that they refused to tell me I would be cured… just that it was the best "hope." They also said my disease was called AML which was further complicated with a mutant gene called FLT3. The news sounded bad, really bad.

I went home to talk to my family and determined based on how scary the BMT sounded that I would not do it and instead just try more chemo and "hope" I got a little more time. My family and church friends convinced me I was stronger than I thought I was, that I should do whatever gave me the best chances at some more years. I finally reluctantly agreed. Then came some more chemo while they went to nmdp.org in search of a donor. I knew nothing about the process but in two weeks was told they found a perfect match. I was so excited. Only 2 weeks later I found out the donor didn't pass his physical and could not be a donor. Four more weeks went by and I was called in where they explained they found another match, not a perfect match but pretty close. They said with time running out, it was their recommendation to accept this donor. I didn't know what the heck to do but since I knew less than they did, I agreed. It appeared to be my only real hope.

I got my BMT in October… all I know is donor was a young man. I am grateful to him wherever he is and hope someday to make contact. The BMT wasn't a cake walk but honestly it was nowhere near as bad as some people said it would be. I recovered in an apartment 10 minutes from the cancer center with round the clock caregivers (friends and family) and with daily visits for blood draws, transfusions, and infusions. I learned a lot in the process and my team could not have been kinder. I was there 8 weeks and then home just in time for Christmas. Sadly, while I was going through the BMT process, I lost my husband who died in a nursing home (one of my biggest regrets was not being there for him.)

Christmas was quiet but to my shock a friend of mind from church who had driven me over the summer to every medical appointment (2 hours round trip and there must have been 85 trips)…asked me if I'd like to spend Christmas at his house instead of alone in my house. I was thrilled at the chance not to be alone. I still go for weekly blood draws and quarterly biopsies and it is now almost April 2018. So far I'm still in remission but this FLT3 gene does cause concern that the cancer could return. I've learned however to live one day at a time and although I now and then still have a good cry, in general I am grateful for family, friends and the team at the cancer center, my donor, and God. Oh, and if you are reading this and going through the BMT process, let me tell you, just when you think you can't go on, the next day can provide a totally new outlook… so NEVER GIVE UP HOPE…remember the man I told you about from my church who was my driver…well as of February 2018, he's now my husband and I could not ask for a better man in my life.

> "Just when you think you can't go on, the next day can provide a totally new outlook … so NEVER GIVE UP HOPE."



FEAR … False Expectations Appearing Real

—By Lori, transplant recipient

When I was told my options for treatment in 2007 after being diagnosed with stage 4 follicular lymphoma (a non-Hodgkin disease), it included a blood stem cell transplant in my future. My kind response was "No, not having one! Ever!" My mind was made up. That word, "transplant," struck fear in me.

For many years, I endured several different kinds of chemo regimens with varying results and side effects. It was when my only remission lasted just 21 months that the word "transplant" was tossed around again. And the fear and wall around me came back in a heartbeat. And again, my kind response was "NO! I am not having one!"

By this time in my cancer journey, we were intermittently traveling 1,500 miles to a different cancer center for advice and treatment. Both my oncologists wanted me to have the transplant. I thought I knew what was best for my husband and me and after a lengthy discussion, I opted for one of the last chemo regimens available to me.

Plans were being set to begin this treatment when one day I was working in my kitchen at home and a little voice inside of me said "You know, Lori, your husband's late wife had a different kind of cancer and a different kind of blood stem cell transplant and she had it done in the 90's." Those words jarred me to my soul and I felt a sense of peace like I have never known before.

All that day, I continued with my daily plans, but those words were in the forefront of my mind. And I still felt peace.

I prayed about it when I went to bed that night and when I woke, the peace was still there. The underlying fear that had been festering for so many years surrounding that word "transplant" had been lifted. After breakfast, I told my husband about what happened and he said that it was an answer to his prayer. Although he understood my reasoning, he had asked God to change my mind and proceed with the transplant as recommended. That was my confirmation that the voice I heard so loudly the day before was from the Holy Spirit. I knew that a stem cell transplant was God's will for me.

That afternoon, I sent my oncologist an email and told him that I wanted to proceed with the transplant recommendation. Apparently, he must have thought that the email was a joke because he called me immediately to verify that I had actually sent it to him. He couldn't believe it!

Things were progressing and my sister was tested for a possible match. It was amazing that she matched 100%. Unfortunately, two weeks before we were to leave for the transplant, she was diagnosed with a very rare aggressive cancer and was placed in hospice the next day. My oncologist told us to still come down and they would find a match for me.

With total faith in our hearts, we left town to head south and it was one of the hardest and most emotional days in my life as I said goodbye to my sister knowing that shortly, she would be passing away. As we got on the road in our RV, I prayed to God to please let my transplant journey be more than just about me. Please let me touch someone, somewhere, somehow and make a difference. All this emotional pain had to have a purpose and I was putting it in God's hands to show me.

My sister passed away shortly before the transplant. Even though I was unable to attend her funeral, I had to keep concentrating on the fact that she was no longer in pain, was in a much better place and that I would see her again for sure. I promised her that I would fight very very hard to beat this cancer in her honor and memory. And I have! And God's plan is so perfect that my donor was a better match than my own sister. He also was a 100% match; but he had the four optional matches which my sister did not.

Without a shadow of a doubt, my prayer that day has been answered tenfold. The "God moments," as I call them, were presented to me one right after another. The peace I felt continued throughout the entire transplant process and still is with me today, some four years later. And the "God moments" continue and he has shown me that I have made a difference, one person at a time through His "moments."

I may not be alive today to share this with you if I had continued to let "fear" rule my life. Little did I realize that the fear I felt when I was first diagnosed continued to slowly grow in me, just like the cancer did. I finally realized that the devil had me in his grips and if I continued to make decisions based on his fear, I was worshipping the wrong person. I am so grateful that the Holy Spirit was able to jar me loose from the devil's grip and realize that my husband's late wife, was a totally different situation than I was. She had been in a Phase 1 clinical trial for breast cancer for which a blood stem cell transplant had never been tried before.

I am so grateful that I do not let fear rule my life any longer and that Peace has taken its place.

Don't be afraid. There is a plan for you and it is a good one. Trust and believe and don't let **false expectations appear real**. Your mind is a very powerful tool in this journey. Guard it with care.

New Blood

—By Sarah, transplant recipient

This piece is called "New Blood". It's the first work I've done since receiving my BMT in December. It reflects how I feel now that I've been given back my life.

The best day of my life

—By Sandra, transplant recipient

The best day of my life was during my 9 month hospital stay. I am an acute myeloid leukemia survivor. To say I have a best day is to summarize the worst day. After feeling so bad, my symptoms kept me from doing my favorite thing, from working, and led me to go to an after-hour clinic and blame my medications. I was finally able to get a simple blood test, and was told to go to the emergency room immediately due to extremely low blood counts. There my family and I heard my diagnosis, the severity, treatment needed, etc. It all started right then.

Having been told I would need a bone marrow transplant if the first round of chemo didn't get me into remission. It did not. Sibling match tests were sent out, and my sister was a match. She flew in from out of state. During her work up it was discovered she had cancer herself, "What about Sandy?" was what she said after she was told she couldn't be my donor. A donor was found through the donor registry. Preparation started for the transplant. I had been in and out of hospitals the last two years, the longest was for 9 months. I had the beginning signs of graft-versus-host disease, on the skin and it internalized into my gut. Without going into detail about my conditions etc., the following is a brief summary. As you might know, some of these were done numerous times: infusion, lab work, high dose chemo, bone marrow biopsies (19), radiation pill, colonoscopies, scans, X-rays, mouth sores, no food intake, nutrition bag, steroid and antibiotic therapy, body swelling, sodium toxicity and drops, delirium, vents, breathing tubes, BiPAP, blood pressure instability, sepsis, immune suppression, physical therapy. A daily medical journal was created just before my transplant in 2011. It continues through 2012 with current entries. There are a lot of photos and detail of my conditions and progress.

As I said before I had a best day, during my 9 month stay, I had an especially bad day. It was a Friday, my husband was there to spend the night with me. It was late, he was asleep in the chair next to me. Let me testify that I never questioned why I had been given this disease. Why this or why that. I am a follower of Christ Jesus. Throughout my entire illness there was no bitterness, bad attitudes, or lack of faith on my part. Looking in from somewhere outside of myself I resolved that there would be plenty of fight in me, to mend all the sorrow my family had been enduring. So the following morning, as my kids came in and my husband was waking up, it was very apparent and real that mom looked different. Something definitely had happened, for I looked aglow with renewed health. I couldn't wait to tell them that God enveloped me the night before with His healing, and I heard him say: "I'm going to heal you." I have been blessed with His healing in my life. I was a rare case; there were so many extreme moments, but the best day of my life was when Lord God Almighty brushed across me with His healing touch.

Sandra, transplant recipient, in 2012 and 2014

The climb

—By Sally, transplant recipient

What's it like to recover from a bone marrow transplant? Now, I am not a rock climber, I'm a senior citizen. I enjoy water aerobics, the occasional game of mini golf, sitting in a comfy chair watching "Downton Abbey." Yet I imagine my recovery is something like climbing El Capitan in Yosemite National Park in California. I've never been to El Capitan with its 3,000 vertical feet of sheer rock granite but I've seen photographs of climbers pitted against the monolith of unforgiving stone, inching their way up, one miniscule toehold, one thin finger hold at a time. It is a very challenging climb, one that requires large personal resources of strength, stamina, skill and patience.

Like El Capitan itself, leukemia is a force to be reckoned with: formidable, implacable. It is the challenge that I did not choose. I had no preparation for it. The great imposing wall simply presented itself to me one day, indifferent to the particulars of my life. My only choice was—and is—to go forward, trusting in the doctors and nurses who generously offer their considerable skills and expertise. But they cannot make this climb towards recovery for me. It is mine alone and requires every ounce of grit and stamina I possess.

After several set-backs with various chemotherapies and a round of radiation the long-awaited day of the transplant finally arrived. My blessed donor is a stranger to me, a twenty something female from Poland. The courier flew back from there carrying the small, precious bag of blood stem cells.

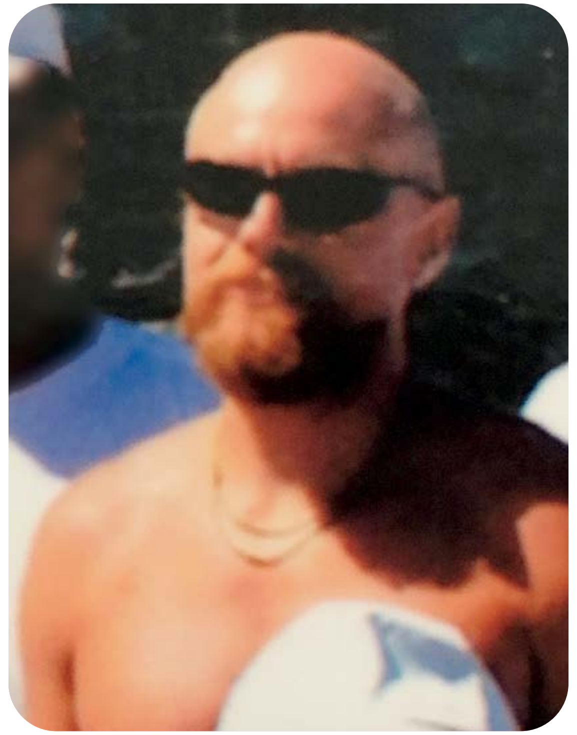
It was about 10:00 p.m. when the cells were brought into my hospital room. The chaplain, nurse, my husband and daughter were gathered around my bed. I 'lit' a small battery operated candle; this was sacred space. In the dim light the chaplain offered a blessing on these treasured cells. The nurse hung the bag on my IV pole and soon the hope-giving, life-saving cells were flowing down the tube. The nurse showed me how to see the cells, which clumped together to a size no bigger than a grain of sand. I watched as they moved quickly down the tube and into my port. Into me. I loved them dearly, welcomed them into my body, did my best to make them feel at home.

After the transplant I started my new life feeling like a newborn, only able to take one small step at a time. At first I managed to walk for five minutes and then I slowly added to that, knowing each push forward would drain my small supply of energy but prepare me for the next step. Although the side effects of the chemo were unpleasant my transplant doctor reassured me, "it will get better." His words, and every prayer offered by friends, every word of encouragement, every gesture of love and support, every positive test result, every reduction in medication was like a handhold that helped me move forward.

I have not reached the top of my personal El Capitan but there have been many small celebrations along the way: the day I walked from the parking lot to my transplant doctor's office without needing a wheelchair; the day I climbed the stairs in my house; the day I kept food down all day; the day I walked for 20 minutes. I'm only half way up the mountain at this point. There are more tests ahead that will monitor my progress, more small victories to achieve. But I've learned the immense healing powers of laughter, gratitude, prayers, music, and small gestures of kindness. It's a long, hard climb requiring every ounce of courage and fortitude I possess. I grow in guarded confidence and trust that I will reach the top where I expect the view of my new life will be exhilarating in its very dear and treasured ordinariness. There is so much more life for me to live. And I plan to live it.

The way out is through

—By Anonymous, transplant recipient



I am 36 years old. I was diagnosed with Hodgkin lymphoma seven years ago in 2011. I have had chemo after chemo but the cancer returned. These are the things that have happened to me.

1) Six months of ABVD,
2) Six months of ICE chemotherapy (had a seizure after the first treatment),
3) Two months of light chemo,
4) Bone marrow transplant, autologous,
5) Eight months of chemo (anaphylactic shock after the 2nd treatment),
6) Bone marrow transplant, allogeneic (developed graft-versus-host disease and lost 44 pounds in two weeks),
7) Six surgical procedures,
8) Three PICC lines,
9) 15 plus PET scans.

My last treatment was an allogeneic bone marrow transplant in 2016. NMDP found me a match and I am still cancer free. It wasn't an easy road. I had severe graft vs host disease complications. I dropped to 129 pounds, couldn't eat and was hospitalized for two and one half months.

What I feel makes my story interesting is I did all of this from inside prison. I've been locked up since 2002. I have had to endure some of the harsh conditions of prison while battling cancer. Being shackled for hours while chemo sickness kicks in, ice cold holding cells, long van rides in shackles and getting car sick from not being able to see out of the van. Waiting outside in the pouring rain to receive my medication for hours.

This whole process strengthened my soul. It created a resilience of character. I am truly thankful to have a second chance at life from receiving donor cells from NMDP. I am grateful for all I have in my life even though I am locked up. I feel if I endure and be who I truly am, that my life will never be wasted.

Check yourself
Awareness
No excuses
Chemo
Empathy
Responsibility

Digging for the inner shift

—By Marianne, transplant recipient

It's been a little over a year now since my BMT, and I am both happy and thankful to say I'm doing well. Made it, I'm thinking as I write this.

I knew going in that the experience of undergoing a bone marrow transplant would be a long and difficult journey, but the extraordinary team of medical professionals prepared me for the journey, and then they pulled me through. I'm here today because of my donor and hospital, and I'm so grateful to them all.

My husband of 34 years, my caregiver, my rock who's been by my side every step of the way, can attest to how tough it's been. My sister, my champion and my inspiration, who visited or called every single day, knows too. My friends and my family helped in a hundred ways. Cards and emails, rides and errands, visits, phone calls, books, pots of soup, a poem or a quote, something funny in the mail—and they might tell you those things were no big deal, but to me they were. Each one, big or little, was a life raft that helped get me through that day, that hour.

Yes, I knew it would be difficult—yet what a gulf lies between knowing a fact and experiencing its truth. Impossible to grasp beforehand how much grit and determination I'd need to make it through the hardest days—far more than I'd ever dreamed. And neither my husband, my sister, my family, my friends, nor all the doctors and nurses in the world could find my strength for me; I had to do that myself. There was loneliness as well, despite all that care and support—there's that gulf again. The human experience in a nutshell, perhaps; we can all sympathize, but we can't all relate.

So, it was difficult, but that's no surprise, right? Yet there was a surprise waiting for me: finding my inner strength led me to what I can only describe as an inner shifting. People often talk about the way life-changing experiences have a way of changing one's perspective, and I think it's true. For me, it opened me to other kinds of healing I didn't know I needed as unnecessary worries and defenses that no longer served me burnt to nothing, and floated away like ash.

I am more open to the world now. I am braver, freer, and bolder. I am a truer version of me. Making small talk with a stranger is a good example. My thoughts are on that person, their words, their smile or expression. Small talk is easier now because I'm easier. Driving in the city or in heavy traffic on the highway doesn't faze me the way it used to; I've done tougher things than that. Another shift, and I felt my creativity return from hiding after many years' absence. Creativity brings me joy now, simply because that little voice—do you know the one I mean, the voice that whines at the sight of a blank page or a white canvas?—is no longer in charge.

> "I am more open to the world now. I am braver, freer, and bolder. I am a truer version of me."

One morning I sipped my coffee, daydreaming as I flipped the pages of a travel magazine. I turned another page, paused, flipped back and read it again. Wouldn't that be amazing, I thought—and there it was again, another little shift. In one exhilarating moment I flew right past my 'what if' daydream and landed smack on 'I think I'll go there'. I remember giggling.

My grit, my strength was waiting—I just had to dig for it. I'm strong, I know that now, and learning that I am has helped me heal. Looking back, I can't help wondering if there's something crucial about the digging process itself, like spring water rushing in to fill a well that begins with a hole in the dirt. Where next? I don't know, but my journey has just begun and I can't wait to see what lies ahead.

48 hours to live

—ByJohn, transplant recipient

I had never really been sick, never spent a day in hospital and never seriously thought about death or dying. In my mid-60s, living and working in Greece for 5 years, a nagging sore throat forced me, reluctantly, to see a hospital-based general practitioner. From that moment God, the Universe or whoever you believe in stepped firmly into my life. He was worried enough to send me for blood tests. The laboratory was so worried about the results that they referred them immediately to their hematologist consultant. She in turn was so worried that she asked me to see her that evening in her consulting rooms close to where I lived in Athens. Accompanied by one of my Greek friends, Nicki, the doctor saw me after midnight and broke the news to me that I had leukemia and she needed me in hospital the next day for further tests. The next day, and a week before I was due to fly back home to Ireland, a barrage of tests were completed and she broke the news to me that I had 48 hours to start chemotherapy and other treatments or I would die very shortly.

> “I had 48 hours to start chemotherapy and other treatments or I would die very shortly.”

The world of good health and a very busy working life disappeared and a new world of leukemia, of chemo, of blood transfusions, of bone marrow, of hospitals, doctors and nurses opened its doors to me. To say that I was totally unprepared for any of this was an understatement. I understood nothing of what was involved and how my life and above all else my attitude to life and appreciation of health, friends, family and health professionals was going to change and change dramatically in a short space of time.

The doctor and her wonderful nurses became my angels and friends very quickly as treatment started and I faced into my first Christmas away from home and hanging on to life by a thread. My Greek friends were amazing and rallied round me and became rocks in my life. Rocks that I clung to as the stormy waters of chemo and other medications washed all over me. Without them I would have drowned, nothing surer. But I was determined from the start that I was going to get better, dying wasn’t on my agenda. There were times during the first three months of treatment, the bulk of it spent in hospital that this resolve was fully tested. The first doses of chemo did not put me in remission but my good blood cells had gone from only 12% in December to 90% by mid-February. A victory as far as I was concerned, not so said my doctor, we need 95% to say you are in remission and so another round of chemo and blood and platelet transfusions started.

The worst day of the treatment and when resolve did crack was when I developed an allergic reaction to a platelet transfusion. The sickness, the shaking, the uncontrollable cold, and the fever are some things I will never forget. But neither will I forget the wonderful care of the nurses who spent hours with me, covering me in blankets, caressing me, talking to me or my doctor who made frequent visits to my room and put up with my bad language and frustrations.

Contrast this with the many, many good days especially on St. Patrick’s Day, 2016 when the results of another bone marrow aspiration showed that I was finally in remission. Such wonderful feelings of relief and gratitude and lots of hugs with doctors and nurses. I even managed a little Irish jig!!!

But no sooner had I reached this plateau of joy and happiness that I was brought crashing back to earth by the prognosis that I needed a bone marrow transplant. A new mountain to be climbed, a mountain that I knew nothing at all about. I couldn’t understand why I needed one. I was in remission, would I not stay in remission? No, said my doctor, I needed one or the leukemia would return in time.

And so a consultation was arranged with another Greek hematologist who was in charge of transplants. My youngest daughter and my first doctor came with me for this crucial meeting to see if he would accept me into the Greek transplant program. He did and so began the transplant journey.

Everything is going to be ok

—By Jeff, transplant recipient

I had been fighting polycythemia for about 12 years when my condition began to morph into something more serious. In a small percentage of polycythemia cases, it can transition into myelofibrosis. Myelofibrosis is a scarring of your bone marrow. Untreated, my bone marrow would eventually stop working and we know what happens with that. I was informed that I needed a bone marrow transplant which was extremely hard to hear as I felt great. I told my doctor that I had a young daughter and that dying was not an option for me.

My wife and I considered two hospitals for treatment. I knew that I stood the best chance of fighting from my home base and I also knew that my family would have the most support if I didn’t survive the transplant. The decision was made and the NMDP Registry was contacted by the transplant team. I needed an angel. Five individuals were contacted and four responded. Of those four, three were perfect matches for me. The doctors had a choice. In January of 2016, I received stem cells from my German angel donor. I spent approximately 7 weeks in the hospital and then daily after treatment for months. My numbers did not rebound as planned and it was determined that my enlarged spleen was devouring the new cells being produced.

As we were contemplating the removal of my spleen, I had a brain bleed due to low platelets and spent 2 weeks in neuro ICU. The spleen decision was made for me. It was removed in July 2017 and my numbers rebounded immediately. It looked like there was light at the end of the tunnel. There was. The light was a train. While my immune system was suppressed, some melanoma cells decided that they wanted to attack. Two surgeries and 20 days of radiation followed. I am into month 3 of 12 months of immunotherapy. I am doing great.

Warriors fight and that is what I do. There have been times when I have felt hopeless, but never faithless. God always has my back. He did when I was a policeman and he does today. When I needed an angel, he sent me NMDP.

In our kitchen, there is a plaque and it says “Not to spoil the ending, but everything is going to be OK.” That is what God showed me, and that is how I live every day.

Angel of hope

—By Terry, transplant recipient

Life is a continual journey and when I was diagnosed with a form of acute leukemia 5 years ago after numerous blood tests followed by a bone marrow biopsy, my family and I asked "why me?" I soon accepted my illness and began the fight for a normal life.

After several rounds of chemo and my condition getting worse, a stem cell transplant was the next option. It became apparent that my condition had worsened and with prayers from numerous family members and friends, my personal relationship with God became stronger than ever.

A search for a donor began and was quickly completed with a match agreeing to donate. I knew that a new journey in my life was about to begin. I daily thanked God for my life and asked for strength to continue. I also felt that a steel angel I had cut out had become my guardian angel and would help me through the process.

The blood stem cell transplant process was long and difficult but I had numerous people helping that included a great medical team, my wife, family and many friends also assisting me along the way. Not only did I pray for myself, but also prayed for strength to be given to my wife, who spent almost every day and night with me in the hospital.

For the most part, I kept a positive attitude and exercised daily, including walks around the hospital ward.

Today I lead a relatively normal life for a 69-year-old man. I still have regular blood tests and monthly doctor appointments. Most days though are spent enjoying life with family and friends. I enjoy outside activities including shooting sports, fishing and walks with my Labrador retriever, Jake.

After waiting the required time after my transplant, I requested to contact my donor and with his approval, we exchanged email addresses. My first email to him was to deliver my sincere thanks to him for being a major part in saving the life that I enjoy today. We continue to exchange emails and photos that we both enjoy. We will probably never see each other in person because he is from a distant country but who knows what the future will hold for both of us. My wife and I want to work with NMDP to inform and encourage people to donate blood stem cells. Most people do not realize how simple the process is to save someone's life.

Almost daily I thank God and my angel, the medical team, wife, family and friends and my donor for the wonderful life I enjoy.

My angel and star are ¼ inch steel plate that I hand-cut using the oxygen-acetylene process. I then sanded the steel to smooth silver surface. Next the angel and candle holder were welded to the star base. Finally, I used a torch to heat blue and color the piece followed by several coats of clear lacquer to protect the angel. In low light, the candle can be lit and light will flicker through the slots that are cut into her dress.

I hope you enjoy my angel and if you have cancer, stay hopeful and continue to fight. I pray you have God and angel with you on your journey.

The harder you fight, the stronger you get

—By Christopher, transplant recipient

Hi family, my name is Christopher. My journey started when I heard the words, "you have cancer" in February 2016 as a young man in my 30s. Diagnosed with acute lymphoblastic leukemia, Philadelphia chromosome positive one month before I was going to marry my partner in Puerto Rico. During my first round I thought I wasn't going to make it, but if it wasn't for faith, love from family and friends and my own will to survive I would have struggled with staying positive. I am naturally a positive person but it's different when you are fighting for yourself and cheering yourself on as you fight.

After completing eight rounds of hyper-CVAD chemotherapy, I was told I needed a blood stem cell transplant. The news was difficult to hear and process, but after connecting with people from all over the world and reading about their experience on social media the news became a lot easier to accept and understand. I am thankful to live in a time where technology and information is readily available by people putting themselves in vulnerable situations speaking out about their journeys. Probably why I feel so inspired to share my story because I remember how beneficial it was for me when I received the news for the first time.

Six months after my eighth round of chemotherapy and being told that I was in complete medical remission I began preparation for my allogeneic stem cell transplant. I matched with one person out of 25 million on the donor registry. The donor was woman in her 40s and matched me 10/10. The news was life changing. Thank you, NMDP, for providing this service, and thank you to my donor for the selfless act that someday you may save a life. I am and will always be incredibly grateful to you for a second life.

In March, I celebrated my Stem Cell-iversary. What I've learned through this experience is that the fight gets easier on the soul when you believe in the possibilities of thriving. What keeps you focused on beating cancer is the mind set and faith, whether it is God, the universe or a higher self. The mindset is a valuable asset. Always have faith, positivity and optimism no matter how scary the truth may be.

I also learned that I can accomplish more in life. I've beat cancer, overcome a broken heart, thrived from having a blood stem cell transplant and strengthened my body, mind and soul. This year, I set goals to be more active, eat healthier and get yoga certified. I walk, swim, go to the gym, eat healthier and gained more muscle. In April, I passed the written and teaching portion of my yoga exam. This will be official late summer. The journey has been transformative. Looking forward to the day I'll be yoga certified. Setting goals during treatment and recovery helped me become more active, focused, present and ALIVE.

> "I am proud to be a part of the cancer community that is accepting and resilient."

Looking forward to teach yoga to my peers and also be of service to a community that I call family. I am proud to be a part of the cancer community that is accepting and resilient. A community that embraces all people with open arms. Strangers was never who we were, always friends from all over the world. We inspire, embrace and support one another other. Thank you, I am blessed and have so much admiration for all of you.

Cheers

Passage to survival

—By Michael, transplant recipient

You know when you know something isn't right;
You're not ready for reality or the truth to come to light.

Uncontrollable doubts consume your heart and your mind.
Trying steadily to convince yourself that everything is fine.

You start holding your breath each time the phone rings;
Unprepared emotionally for results a call brings.

You're talking to professionals whose advice you trust,
But, the future of your health is now urgently rushed.

Unfamiliar terminology begins to fill your head space.
Searching websites continually to keep up with the pace.

Yearning to stay ahead of the beast living within,
You start dismissing your family, your neighbors, your friends.

A silver-lining arises in the mist of a dark cloud;
Medical technology is ready to fight cancer out loud.

Is your armor ready? Are your reinforcements in place?
Are your daily prayers for God's Amazing Grace?

The needles, the meds, the blood and your gut,
Will be constant reminders that you can never give up.

A stranger's face starts staring back in the mirror;
It's hiding the truth of your weakness and fears.

Then one day you'll wakeup with very small pain;
Nothing about this life will ever feel the same.

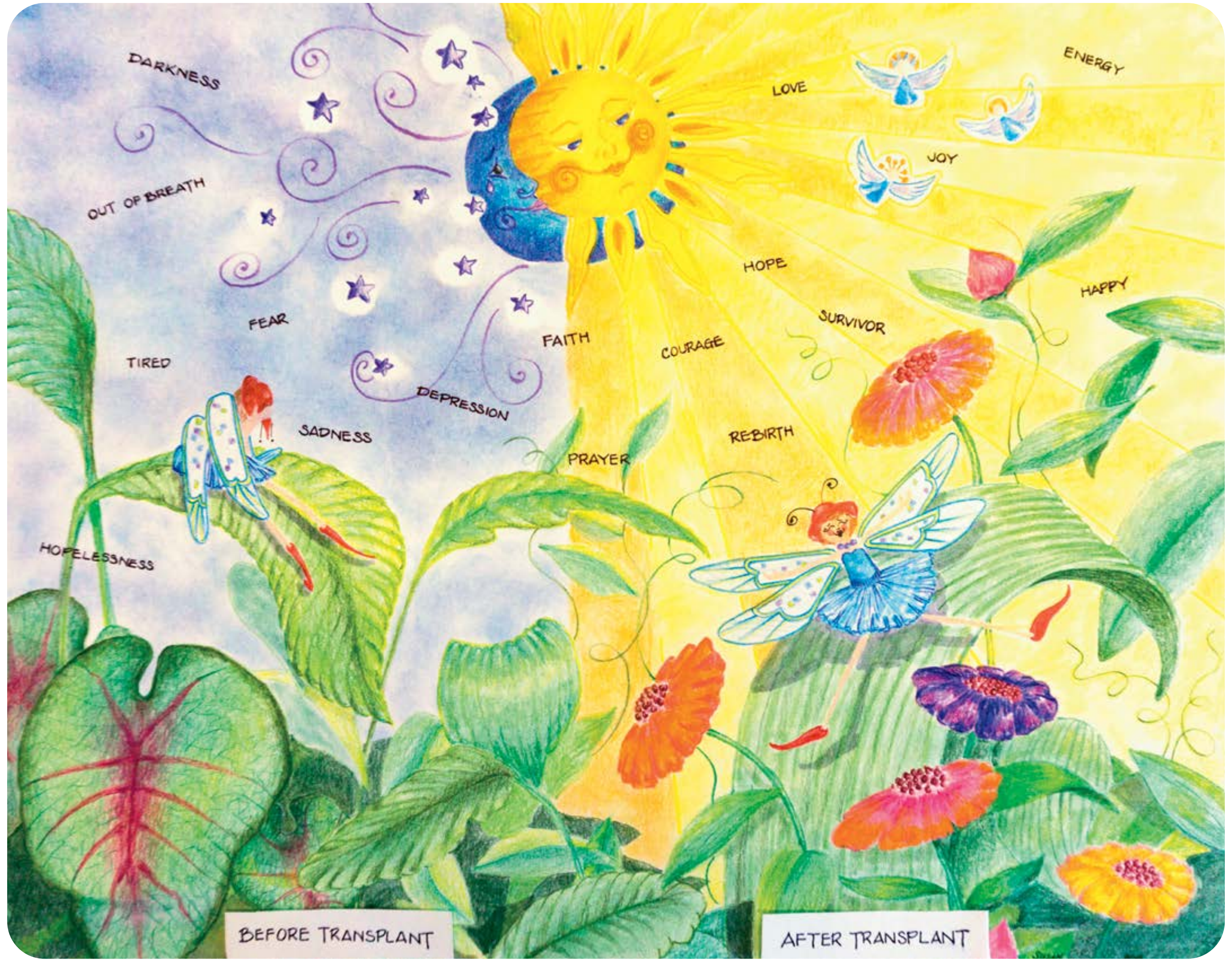
How did you get here – the other side of the fight?
This passage of survival – this future with light.

Be grateful for your donor, a caring silent friend.
Count your blessings daily as they endure to the end.

You felt this journey was yours alone to be strong;
Only to discover you were so very wrong.

Before & after

—By Susan, transplant recipient



My drawing reflects my feelings before and after my transplant.

The rivers of ancestry: her blood is my life

—By Robin, transplant recipient

As a health professional, I immediately understood the serious implications of the blood test that showed gravely low levels of all my body's blood cells (pancytopenia). But I was not prepared for what came next as I began to absorb the meaning those implications. At first, it was like the ground not only had moved (we're in earthquake country after all!), but that the earth had opened up in front of me and I was tumbling into an abyss. Over the next few days, there was a moment when I felt like there was suddenly a brick wall in front of my face and I was smothering. It was at that moment that I said, emphatically, "I don't want to die," and then I was breathing again.

I knew I was strong, but I had no idea about the inner strength that I would discover as time went on and one challenge emerged on top of another. My breathing, and the assurance that the next breath would come, became an immense source of comfort, and confidence. While I could not know if I had a future, or if the treatment would be successful, or that the pain would ever go away, I did know that I was there in that moment, and that I would be in the next. Strength from other people came in many forms, and was embodied in my husband Robert's steadfastness, devotion, humor, energy, patience, and love. I found that my anxiety was immensely soothed by creating email "updates" about my situation, and sending these out to a list of friends and family. These notes not only allowed me to draw on their strength, but also helped them stay connected with me, and kept them from being too fearful to approach me in my sickness.

I have now a second family in Germany. I matched with no one close by—my two brothers matched each other!—or even on my continent, until NMDP found my one 10:10 donor in Europe.

Two years after the transplant, we made contact, and through emails and texting, began making plans for my husband and I to visit Germany to meet Sarah and her family. I wanted to thank her in person. In September of 2015, when we met in the lobby of a hotel in Hamburg, we looked at each other unbelievingly, and collapsed into a long embrace. She and her husband drove us to their home in northwest Germany, where we stayed with her family, and welcomed as beloved family. It was there that I learned about the other half of the transplant experience: Sarah's story. I discovered that though the transplant came at an inconvenient time in her life—she was getting married, and the transplant was scheduled for the week before her wedding!—and she was scared, Sarah's commitment was matter-of-fact, "What else is there than to help another human?"

> "I spend less time worrying about small things, I laugh more, and I take myself less seriously."

I am no longer the same, through this experience. I, like many others, found myself allowing aspects of my life that were not meaningful, to slip away. Relationships are richer, I spend less time worrying about small things, I laugh more, and I take myself less seriously. At the same time, having had an experience living very close to death, I am more passionate about life than ever, and find fulfillment in studying (I'm working on a PhD), art, music, friends, community involvement, family, the natural world, pets..... I view my illness experience with bone marrow transplant as a gift of transformation.

Devastation to hope

—By Amy, parent caregiver

Devastation is how this parent felt when I first heard that my daughter had relapsed with acute myelomonocytic leukemia just one year after her original diagnosis. She needed a bone marrow transplant. Siblings were not a match. We were dependent on strangers. Hope is what I found when they put my daughter's information into the NMDP Registry and found the perfect match for her. Gratitude is what I felt when the potential donor said yes. I was in awe as my daughter laid there having someone's stem cells enter into her body. As she was sleeping her second chance was flowing into her. Then we rejoiced 11 days later when the transplanted blood stem cells started to grow. She had engrafted. All these emotions and more were felt on our pediatric cancer journey. **Bone marrow transplant saved her life.**

Fishing for a cure

—By Anonymous, transplant recipient

I am an optimist, or so I consider myself. Actually, I never heard of anyone as optimistic as what I am. I think it is partially a function of being somewhat of a force of nature and partially a separate gift. My original DNA and apparently that of my donor, have left me an overabundance of the optimism gene. To me, the glass is not only half full, but the stuff it contains tastes pretty good. I am an optimist and probably no one who has ever come to know me would question that. But admittedly, they do sometimes use colorful adjectives to describe it to my face.

The blessing of what I am, has never served me better than in my recent struggles with health issues, specifically a type of cancer (MDS) requiring a bone marrow transplant. For purposes of this treatise I will offer one quote concerning the nature of the disease, treatment and consequences. “We save your life, but we put a monster inside you.” Doc was right on as it turns out, and probably devastating to those not fortunate enough to be inherently optimistic. But I, like some other fellow chimeras, are just optimistic by nature. And isn’t nature the most optimistic thing there is. Unsure of that? One word for you then: Spring. So an optimist understands things like monster insertion in no uncertain terms. I do not deal with the monstrous inside, it falls with the monster to have to deal with me.

The old time bank robber Willie Sutton once said he would gladly spend two thirds of his life in prison to enable him to spend one third doing whatever he wanted. The optimist that I am has a naturally themed passion that also involves banks, river banks in my case. I am an angler. Fishing feeds and complements my optimism, part and parcel of who I am. It is why the monster won’t win, at least not yet. I’ve got some fishing to do.

If you spend a couple of months a year in a hospital, and a significant amount of time convalescing at home, “quality of life” and “new normal” are a few of the terms that start getting bandied about. Seems quite vexing, but not so much for an optimist and his positive attitude. We all understand that just as the wind and tide wear down the coast and mountains, the world can grind away at our resolve and joy unless we do something about it. An optimist such as myself, well I go fishing. It is something I’ve always loved, and now it is an act of small rebellion against the monster(s). The country song refrain “I ain’t as good as I once was, but I’m as good once, as I ever was” pretty much sums it up. There are numerous days of more or lesser degrees of wellbeing that allows this optimist to wade joyously in his pursuit of angling adventure, roaring in mirth like Beowulf at any monsters that think they have attained an upper hand.

My fishing simply is enough to outweigh, with its inherent optimism, the inherent negativism of disease. I fish therefore I am, monsters do not, therefore they are not. A life worth living is a life where fishing can be embraced. And I suppose it is the infinite possibilities of the pursuit of fish that have kept things so fresh and exciting after all these years, all those casts. While fishing can be a simple and a universal diversion in its basic form, it can be as intriguing and multi-faceted as any endeavor on earth. Izaak Walton wrote famously that “Angling is so much like mathematics, that it can never be fully learned.” So true, for no matter how much you delve into any one aspect, how much time and energy and pleasure you derive, there is always more.

The blending of the familiar with the constantly changing and different is the heady essence one inhales while fishing. No two days are ever the same, rarely two casts. The weather, water, fish, the mechanics of the cast, the quest, thousands of other factors are interacting to keep the angling lifestyle constantly amazing. And it often is played out in some of nature’s most beautiful venues. Whether in the Florida Keys, Montana, Lough Swilly, Cabo San Lucas, and all points between, the sport of fishing involves you with beautiful nature. And it is not all exotic locations that are the key, it is the ability of an optimist to readily perceive the beauty wherever fish exist. And more often than not, it is not exotic and far.

Very near the hospital where my transplant was performed, there was a stream that would satisfy the mind of any angler. And I can show you things like drainage ditches, outflow pipes and swamps that have beauty, fecundity and joy far beyond their initial comprehension. An optimist can ask for no more than to have gained the sight to see this.

So you catch a bad break and end up dealing with things you didn’t know existed three years ago, and the ever unknown future becomes an even murkier present. What to do? Well, for this optimist, that one was a no brainer. Either continue to fish, or fish more. It is what I have done and will continue to do. The monster has no say in this, and no way to escape its own fate, inexorably linked to mine as it is. And monsters don’t fish as I mentioned. So my joyous fishing life, and the peace and serenity it affords the balance of my existence, including my medical struggles, will continue to be swept along by an optimistic nature. Come along, you might enjoy the ride.

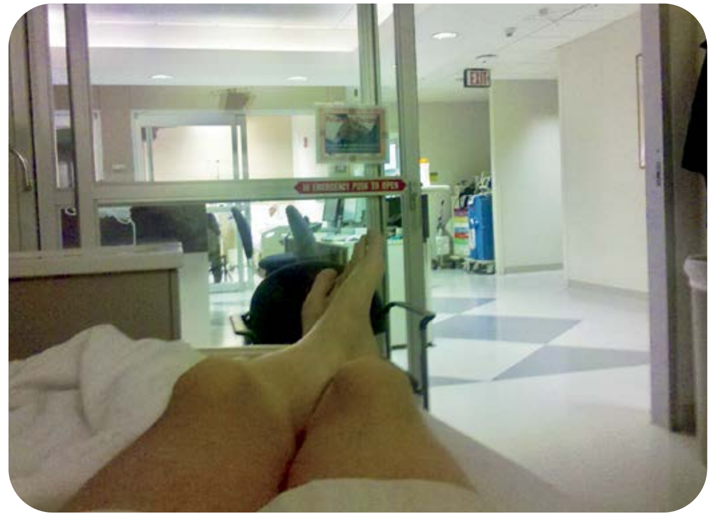
Rebirth

—By Darla, transplant recipient

“Would you like to hold them?” the nurse had asked.
My donated blood stem cells were here!
A perfect fit in the palm of my hand;
I prayed with a few silent tears.
How could I not be moved in this moment?
A real hero in the making.
Why would a stranger care to sacrifice?
His own price and pain forsaking.
A rush of excitement, coupled with fear,
New cells intertwining with old.
The parallels to the Gospel of Christ
Indisputably must be told.
These blood stem cells increased my chances of life;
The remaining length is unsure.
But the blemish-free blood that Jesus shed
is an absolute, guaranteed cure.
Not of the physical life you see now,
Time naturally withers and fades.
But my soul is secured for heaven’s home,
Having trusted in Jesus who saves.
With much gratitude I say a huge thanks
To the man whose cells now are my own.
And with eternal thanksgiving and awe
To the One whom my sins did atone.

What a difference a year makes

—By Steve, transplant recipient



Bone Marrow Transplant Center, July 2013

Home Sweet Home British Columbia, July 2014

My initial bout of Hodgkin lymphoma was detected soon after I retired in the fall of 2011. Standard chemotherapy lasted until mid-2012 postponing our long-held plan of retiring to British Columbia (BC) by a year.

Six months after chemo ended, in the midst of planning our cross-continental move, the cancer was back. Treatment would require high-dose chemotherapy and an autologous stem cell transplant. Again, BC would have to wait.

Months of pre-transplant preparation, five weeks of transplant treatment and hospitalization in Nebraska, and several months of home recuperation followed. Thankfully, six months after the transplant, the cancer was nowhere to be seen. Life was finally returning to normal, and our long-awaited retirement could begin at last.

Almost five years later, healthy and happily settled in BC, I discovered these two remarkably similar photos that I took almost exactly a year apart. The first was shot as I received one of many brutally potent chemotherapy infusions as part of my transplant. The second was shot, one year later, as I relished a perfect summer afternoon at our beautiful Canadian home. Side by side the photos' symbolism was clear: what an extraordinary impact modern medicine, dedicated doctors, and loving caregivers can have on one's life. AND...what a difference a year makes.

Weathering the storm

—By Linda, transplant recipient

A hospital room can be a lonely, forlorn habitat especially when as a patient you have just received yet another round of bad news instead of a hopeful diagnosis. On this particular day, a thunderstorm was raging outside my room and pelting the windows with treacherous raindrops and small hail. My doctor just informed me that the traditional chemotherapy treatment for AML was not being effective in my case. The blood cancer was not in check and surely would return in force and ravage my body. He suggested I explore the possibility of a bone marrow transplant, which would be risky for someone my age and at this time, and did not have an outstanding rate of success. To complicate matters more, the doctor just received the report that confirmed the swelling in my arm was indeed a blood clot at the insertion of the PICC line. At this time, the medical team was unsure how they would proceed with the problem.

Could this day and its outcomes get any gloomier? Before my mind had an opportunity to go racing to negative thoughts, I decided I needed to get my mind and spirit quiet and spend time with God meditating on His Word. Typically, I am a high energy, overachiever juggling multiple activities at the same time. However, this was not the time to begin searching the internet. This was a time to "Be still and know that I am God." Psalm 46:10. As I patiently sat quietly and prayed, a peace about what I was to face came over me and I began to read. A passage from the Old Testament suddenly jumped off the page to me. Jeremiah 29:11 "For I know the plans I have for you, declares the Lord, plans to prosper you and not to harm you, plans to give you hope and a future." This is my overreaching banner of faith that carries me beyond the agonizing moments. I know I have a future and a hope that will someday culminate in a celebration.

I decided that worry and anxiety can crowd out the ability to hear God's voice, so I'm throwing them out. At that moment, the sun suddenly appeared. Out of my hospital window I saw three rainbows. Look closely, there are three! I am claiming this as God's promise for a future, not one of illness but of prosperity.

That night as I continued to read, I picked up a book by Linda Benz Kovarik titled "It's Cancer." In the first chapter she shares that with cancer we become surrounded by a dark cocoon of stressful change, invoking a striking alteration of our physical appearance, our personal character, and our lifestyle circumstances. Remember the metamorphosis of the worm and know that God can supernaturally work in your circumstances transforming His love to give you wings of hope, lifting you up for new vision and purpose beyond cancer.

> "I decided that worry and anxiety can crowd out the ability to hear God's voice, so I'm throwing them out."

Four months after that dreaded day, I received a bone marrow transplant. Yes, there were some challenges along the way, but today, I have no trace of cancer in my body and my energy has almost returned to normal. My journey in life post-transplant will be different from my previous life. It will be something new, less stressful and more peaceful, making every moment count. I will not walk and run but soar through each new day of the year with God by my side.

Events along the way

—By Don, transplant recipient

As my journey continues, I look back at some events along the way and think about what this experience means:

The day my doctor gave me the results of the bone marrow biopsy, and my wife and I learn I have myelodysplastic syndrome (MDS) caused by a defective chromosome 7. It was December 23rd.

The day I was admitted to the hospital to begin the transplant procedure, my birthday, September 27th.

The day my perfect donor cells were administered! October 7th.

The day we went to Hope Lodge, October 21st, where we met several transplant recipients who will be lifelong friends.

We celebrated Christmas and the New Year at Hope Lodge with our transplant family.

The day we finally got to go home on January 14th. Wow!!!

Feeling well enough to ride my bicycle over 1,000 miles before October 7th, thanks to my new blood stem cells!

The day I contacted my very special perfect donor (Terra!!!), November 9th. We have since shared many holiday and birthday messages. I look forward to the day we can meet.

These moments and many others are what led to my second chance at life. Learning you have a blood disease, learning what the treatment is, dealing with the recovery, you wouldn't expect to say how rewarding the experience can be.

From the great fortune of being matched with a perfect donor, to appreciating the unselfish nature of a total stranger that gave part of herself, to the unbelievable doctors and medical care at the hospital, to the hospitality and undying friendships from Hope Lodge, and to the love and support given by my wife and family. I truly appreciate how fortunate I am.

I don't wish this on anyone. And regardless of what happens as this journey continues, I do see the great goodness that can exist in the world and I do see the true caring and love individuals are capable of. With that, I know that this thing called cancer can't beat us.

God's miracle

—By Nancy, transplant recipient

The end of May 2014 at age 74 I received bad news
I was diagnosed with AML leukemia & I had no clues
I started treatment ASAP, I had no choice
That was when God did hear my voice

My faith and hope was always clear
That someday I would be able to cheer
I was advised I had 8–12 months to live
I was told chemo treatment would not be worth the time to give

Two weeks later in a hospital I blew up like a balloon
I needed emergency help and not too soon
My son drove me 2 hours to St. Louis with an oxygen tank to keep me alive
I had fungus pneumonia and God helped me survive

I had to get out of bed and walk the halls and pray
I walked 16 laps down 4 halls rectangle in 20 minutes 3 times a day
I regained my strength more and more
As I continued to walk the halls on my floor

I received chemo, platelets and blood 2–3 times a week
Hoping for a cure I prayed to seek
I was told the chemo would make sick each day
But I never got sick and continued to pray
I received a letter I was in a donor bank and I had no fear
They said it may take months before I would hear
I called the same day—they already had 2 donors for me
How blessed could I be to someday be free

God worked his miracle, his plan that day
As both donors were a full match they did say
I was scheduled for a stem cell transplant June 2015 from the first donor that day
But the day before they had to reschedule for the 2nd donor—why they did not say

I spent 3 months 4½ hours from home at Hope Lodge St. Louis come what may
Lab work and doctors appointments every day
I was still feeling good and never ill—so blessed
My recovery and transplant proved to be a success

I pass on to others to always keep the faith and hope in their heart
They go hand in hand and never apart
Remember God will always have the last say
Please remember to pray now and every day

The enemy within

—By Mike, transplant recipient

> “She was a stranger who was kind to me and connected in a way I didn’t understand. This was a turning point in how I perceived myself.”
>
> — Mike, transplant recipient

The enemy within

There is, of course, a biological explanation for cancer as an abnormal growth of cells, uncontrollably spreading throughout the body. It doesn’t think or intend to hurt anyone. I have always believed in science and I am living proof that it saves lives. But after traveling fourteen hundred miles for eight and a half months of treatments while sharing my body with this dreadful disease, I found some relief by relating to my cancer as an evil being with a mind, a plan and a goal.

Typically, enemies can be seen. They have a physical form that we perceive as the “bad guy.” Cancer attacks from the inside, without a face or visual presence, and from a closeness that is completely personal. I saw it as a struggle to claim ownership of myself. I had to decide, was the disease going to dictate my mood and outlook on life or would I be in charge? It seemed a question of identity. Was I primarily a cancer patient or was I a person with a life and history who happens to have cancer? From that point on, I chose to be in control.

An elderly lady covering baldness with a scarf limped to the check-in counter. Walking the short distance appeared difficult for her. At the counter, she looked up, smiled and spoke with a purposeful cheer, “Hello there, how was your weekend?” When I witnessed her inspiring attitude, I realized she just beat cancer! She is in control.

Even though disease will attack my body, it will never control me. I do have cancer but cancer doesn’t have me.

Haircut

Since I was about to lose my hair, I needed to get it cut very short. I found a discount haircutting business just five minutes away. There were three stylists. One of them was a stern-looking lady with a very modern haircut. She didn’t smile and looked somewhat intimidating. I hoped to get one of the other two stylists.

My goal was to just get a quick buzz cut. It would take about five minutes. I could do it myself if I had the right tool. My name was called by the no-nonsense stylist. She sat me down in her chair and asked what I wanted. I didn’t plan to mention the cancer but I found myself explaining that I would lose my hair within a week or two so I wanted a simple crew cut. She was curious, so I found myself telling her about the cancer. It was first time that I shared or admitted my disease to a stranger. She pulled out her clippers and added an attachment. Then, it hit me. I’m starting to look like a cancer patient. Maybe I’ve been in denial for a few months. That was going to change. Soon, I wouldn’t be able to hide behind a normal head of hair.

She completed the buzz cut in even less time than I predicted. I was having trouble with the idea of people looking at me differently but more importantly, I was having trouble seeing myself as a cancer patient. The reality was starting to sink in. I thought of the silliness that a simple haircut would be such a turning point. I spent a lot of time in a hospital but just getting a haircut was turning out to be a traumatic experience. It was a ridiculous notion and I decided at that time to accept the new look and just get through it.

When I thought she was done, she was really just getting started. After the quick cut with electric clippers, she pulled out her scissors. She started to clip stray hairs and trimmed sections she didn’t like. She bobbed her head around looking for imperfection. Her extreme care for my haircut confused me. Didn’t she remember that my hair would be gone in a week or two? What difference does it make if it’s not perfect? She went on for several minutes like an artist with intense focus. She seemed to truly care that my hair was perfect and that my appearance mattered. It was a display of kindness from a stranger that was making me feel uncomfortable. I could feel some of my guards against showing emotion start to falter. I wanted to get out of there.

She finally handed me a mirror and asked if the back of my head was okay. I said “It’s fine” before I could even see it. After a careful sweep of my neck and adjustments to my collar, she removed the apron and approached the register. Her “simple haircut” turned into caring for me beyond what was necessary. I was very uncomfortable with the feeling that I needed special care, that I was sick, that I even had cancer.

I realized that I was living two lives. While at the hospital, I was a patient, even a cancer patient. Everyone knew it and I was comfortable in that setting. But outside, I could blend in. Just as I pulled out my wallet to pay she looked into my eyes smiled and said with complete certainty, “You’ll be fine.” It was as if she knew something about me that I didn’t even know about myself. I was certain that she saw my pain and confusion but her statement gave me momentary peace. I knew she was right. I was going to be fine. Then she added, “No charge.” I was having difficulty processing what had just happened. I pulled out some cash, put it on the counter, said thanks and somewhat rudely raced out the door.

She was a stranger who was kind to me and connected in a way I didn’t understand. This was a turning point in how I perceived myself. I changed from a patient who just knows he has cancer to a full blown cancer patient. This new perception of myself was a truer version of reality, a reality that I could no longer avoid.

New journey

—Anonymous, transplant recipient

In June, the day after my 23rd wedding anniversary, the results of my most recent bone marrow biopsy were presented to my husband and me. The clear diagnosis was myelofibrosis: a blood cancer which destroys the marrow by scarring its tissue. I barely spoke the words, “New journey, huh?”

My doctor’s serious eyes and guarded half smile indicated, “Bone marrow transplant.” I simply released a low breath.

Facing movement through dangerous and difficult circumstances chartered a path into my unknown. Would I be strong, healthy, and peaceful enough to endure chemotherapy? What would happen to my body when my immune system is wiped put? Would my body sustain itself? What about my family and their needs? Could I meet these excruciatingly powerful expectations? Where do we get the blood? Help!

Where do I go? I went to God.

I began praying and at first asking God for advice, then asking Him to show me the path. I prayed for Him to fill me with the right questions, to surround me with strong educated experts, and pleaded for courage. I begged for love and mercy over my entire family. I cried out for my friends and care providers.

My answered prayers began to unfold. I was offered the best doctors, nurses and support system. My case became a personal promise to me, the patient and my frightened family. We were welcomed into a cocoon of hope which had a well-oiled plan; a sustainable location of mercy for my weakened body. As a team we planned. We discussed the process as well as the recovery. We located a donor and then days prior to admittance to the hospital we lost the donor. That day was a Friday and I went back to God. I began to feel peace as my friends and family were sparked to move. Meals, crowd fundraising, apartment hunting, household chores, basic nursing care classes and general fellowship became their occupation. With a surge of urgency, they became overnight heroes.

On Monday, I learned my prayers were further answered. A British national would be my donor. I discovered he was willing to donate by undergoing a bone marrow donation. Praise God!

In the following days, my central line was surgically implanted. On the morning I entered the hospital, I wore a dress, full make up and did my hair. As exhausted as I was, I wanted to smile and face this “destroyer of life; myelofibrosis” with strength. by early afternoon I was introduced to my adversary; a liquid chemotherapy drug which immediately began flowing into my central line. Not wanting to sit quietly, my husband and I walked the hospital immunosuppression floor. Movement and talking really helped me to not focus on the fact that I was actively destroying my immune system. By the end of the day I felt exhaustion tugging at my body and mind. This process continued for five days. On the sixth day we rested.

I felt God’s promise had guided me to work hard for several days, then rest. The midnight prior to transplant, my donation arrived on an international flight. A nurse accepted the transfer and ensured it was safely processed throughout the night. The next day, which was called day zero, the long-awaited bone marrow transplant occurred with its phenomenal entry into a winding tube and into my central line.

AMEN!

The following days were rough. My husband tells me I was physically sick and in and out of consciousness. I have memories of waking to alarms and glowing numbers on the beeping IV machine.

As I slept, I struggled. Devastating conflicts overwhelmed my existence. With my dear life as the ultimate prize, my unconscious inner self descended into battle. My mind faced a deeply darkened being whose force threw me into the walls of my church chapel. Crumbling plaster pulled me into its crevices. I clawed my way through the rubble only to be thrown into the overturned pews. I felt my crushing bones roll to a stop at the entry door of the chapel. Blinded, I crawled through the dust to the steps of the altar. I gazed upward to view Jesus peering down from the cross. His smile began in the crinkles of his eyes and illuminated downward showering me with light. I began to cry as a tear cleared a path down my ashen cheek. That trail guided me back to my hospital bed, dampened face and moist night clothes. Opening my eyes, I felt a calmness and silence.

Dawn began radiating the corners of my room as I pulled myself up. Carefully, I stood on unrecognizably wobbly legs, walked to the side table and collapsed into the chair. I just wanted to order food.

As I dialed, the morning nurse arrived and began her duties. Once I was done, I greeted her. Without looking up from her computer my nurse asked if “she” was in the bathroom. I looked at her puzzled and asked, “who?”

“The patient,” she stated.

I laughed and said ,”No I’m right here.”

She paused and looked at me. Her genuine smile replaced the shocked stare as she spoke, “Well good morning! You’ve been so sick especially when I was your nurse the other day.”

Then I looked surprised and flashed a weak smile,
“Really? What is your name?”

Time had been lost and replaced with my internal wrestling of emotions and health. My reality had become skewed. Yet, I had witnessed the smile of Jesus! I was so humbled and inspired. I knew I could succeed. My nurse’s similar powerful smile assured me I could.

> “I was so humbled and inspired. I knew I could succeed. My nurse’s similar powerful smile assured me I could.”
>
> — Anonymous, transplant recipient

Fight

—By Teddy Joe, transplant recipient

As a bone marrow transplant recipient and cancer survivor, I know firsthand the physical and emotional toll that cancer and cancer treatment can take on one's body and mind. Do not let cancer take your will to fight, or your will to live.

Fight is a visual representation of the mental battle that comes with cancer. This piece illustrates multiple soldiers standing together fighting the single orange soldier representing leukemia.

The multiple soldiers signify the importance of support from family and friends in addition to ones will to survive. The three soldiers exemplify Faith, Hope, and Love, and the healing power they possess. Faith in God's power to heal. Hope for the strength to battle on. Love for, and from others to get you through. Always remember...**NO ONE FIGHTS ALONE! Stay strong, and battle on!**

One hundred percent-i.e.

—By Roy, transplant recipient

We live in a world of percentages
A chunk are below the poverty line
The select few are the one percent-ies
So many go to college
A big chunk are married, a growing portion are not

Me—I just want to be 100%
I'm tired of taking pills, measuring liquid meds
Keep trying to run the old distances, somewhere near the old paces
It's a tough climb to be whole again

Even so, being 100% becomes variable over time
Full strength may not be the same as it used to be
What I could do then may no longer be what I can do now
And that's only if I feel good, feel right

When I've been taken down several notches, the road back is much harder
There are gains and losses
Two steps forward, five steps back, three sideways
It's partly a patience game, the other piece a relentless drive

I constantly need to recalibrate what is full capacity for me
But whatever it is, I just want to be 100 percent.

A whole new me

—By Roy, transplant recipient

Sitting in a coffee shop with the usual clamor
Hip-hop blasting from the speakers, baristas barking from the bar
It's both sunny and snowing all at the same time
This is why I'm still here, to experience it all
I can run on a track, fly on a plane
Do anything I want
I'm still here

A year ago I couldn't be sure
Weeklong toxic attacks pounding my body
Six months ago I started wearing the shield of someone else
Hoping it wouldn't make me disappear

But I'm still here
As good as ever
My hair is fluffier, my smile still bright
I can enjoy the people I know, delight in new people I'll meet

I can reinvent myself into anybody or anything I want
Who will it be? What will be?
It's a whole new me

The gift of life

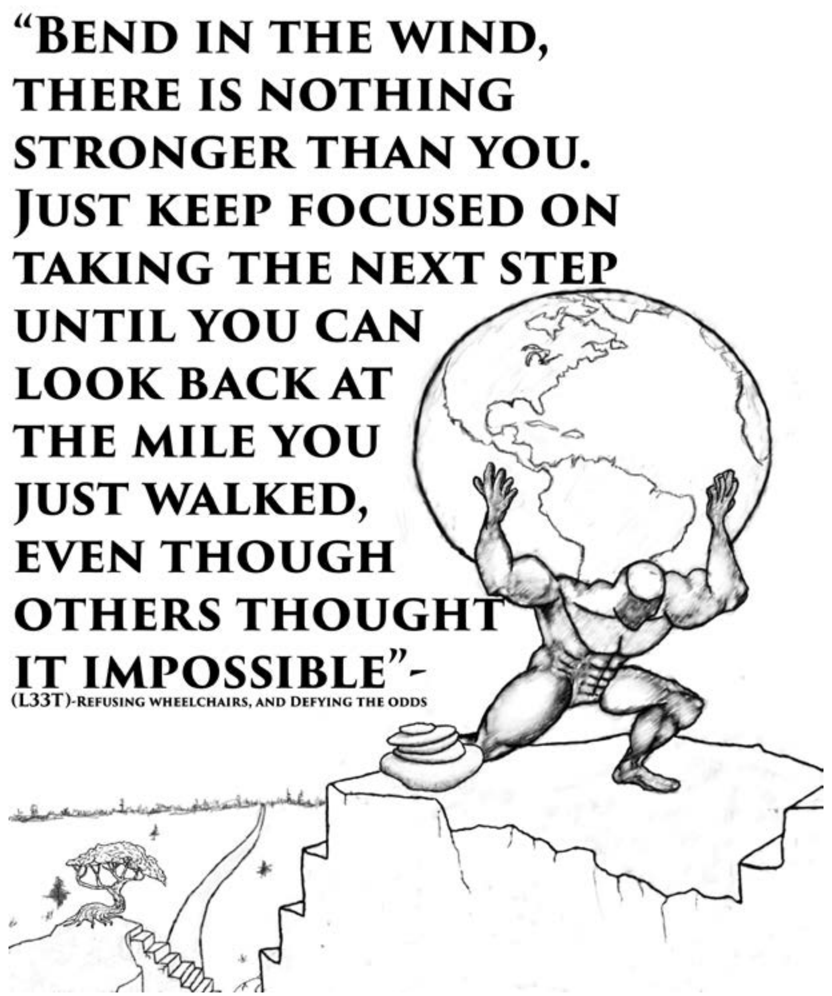
—By Ann, transplant recipient

Bend in the wind

—By Leaton, transplant recipient

When I got sick, I wanted to believe it was just a nasty bug or infection and I would get over it. After further tests, my doctor walked into my hospital room wielding a war-hammer of despair of unfathomable proportions disguised as a clipboard of results that I was NOT prepared for. I instantly became overwhelmed, like a wild animal lashing out I regretfully wasted the next few hours losing my composure and compassion with the staff and family around me.

Mentally drained and exhausted. I felt like Atlas holding the world, and finally I shrugged. Then took a deep breath, and looked across into the fear manifesting in the eyes of the person who was my best friend, "now wife", and reason I am still alive. I said, "Don't worry. It's going to be OK. Death will need more than cancer to make me depart this world before I decide I'm ready to go. It has challenged the toughest S.O.B. there is."



"BEND IN THE WIND, THERE IS NOTHING STRONGER THAN YOU. JUST KEEP FOCUSED ON TAKING THE NEXT STEP UNTIL YOU CAN LOOK BACK AT THE MILE YOU JUST WALKED, EVEN THOUGH OTHERS THOUGHT IT IMPOSSIBLE"-

(L33T)-REFUSING WHEELCHAIRS, AND DEFYING THE ODDS

My journey

—By Oben, transplant recipient

“With the new day comes new strength and new thoughts.”

— Oben, transplant recipient, recalling wise words of Eleanor Roosevelt

My aplastic journey began on March 13th, 2013. While preparing for school on that morning, I fainted. I was rushed to the hospital where it was discovered in the lab work that I had aplastic anemia. The idea and knowledge of aplastic anemia was new to me and my family. Lack of familiarity with the disease put my parents on edge with fear about my health and well-being. However, I was optimistic and hopeful.

While in the hospital, my parents and I learned more about aplastic anemia. We learned its history, and how it could affect an individual for years without them noticing. The doctors told us that aplastic anemia occurs when the body stops producing enough new blood cells and it can happen at any age. Also, it could occur suddenly or slowly and grow worse over time. Unfortunately for me, I fell into the latter category. Treatment for aplastic anemia includes medications, blood transfusions and bone marrow transplant. I was told that because of the severity of my condition, my treatment options were limited to receiving a bone marrow transplant.

The idea of a bone marrow transplant seemed daunting to me. I had to undergo a bone marrow biopsy, an analysis of the bone marrow. Getting a matching donor was not a problem because my twin brother offered to give me the blood stem cells required for the transplant. Next, I underwent chemotherapy and radiation. The final step was the infusion of my brother’s bone marrow into me. The above mentioned procedures spanned over a few months, and I recovered gradually. During my recovery, I showed no signs of rejecting the bone marrow transplant, so I was discharged immediately.

During the first few weeks of coming back home, I was very restricted in my daily activities. I had to avoid close contact with people, crowded areas and avoid wood-burning fireplaces, since the wood contains fungus. These restrictions were placed on me because all bone marrow transplant patients had to undergo a 100 day isolation period after their procedure. After clearing up my follow-ups for the following months, I was finally able to return to school. I returned to the 10th grade without any issues and for the remainder of my high school career, I was able to play sports, dance, and live life normally as if nothing had happened. But all of a sudden that changed.

In July of 2017, I fainted and was once again rushed to the hospital. I was taken to the hospital, where the doctors discovered a resurgence of aplastic anemia. I was transferred to the children hospital, and the medical staff decided to do another transplant. As with my first transplant, I spent a lot of time in the hospital and at home during recovery.

The second transplant and its toll on me were greater than the first. During the first transplant, I was high school student in the 10th grade. The high school curriculum was set up in a way that students can catch up the work if they have been out of school for a long time. So the first transplant did not affect my academic career too much. However, the second transplant halted my academic career as a college student. The second transplant occurred when I had just finished my freshman year of college. I was unable to take classes during the summer and fall semesters. The structure of college courses do not allow leeway when it comes to the completion of a course. The summer session classes go on for five weeks, meanwhile the fall semester is sixteen weeks long. All of this time equates to the time I spent in the hospital and at home recovering. For those reasons, I was only able to resume school during the spring semester of 2018.

I remain optimistic about accomplishing my goals of becoming an automotive engineer. Despite all these setbacks, I look forward to continuing my education and successfully completing my program of study. I plan on accomplishing these goals by obtaining an associate degree in engineering and science, and transfer to a four year college where I would obtain a bachelor’s degree in automotive engineering.

The only difference

—By Laura, transplant recipient

I lay in the tall wet grass
Reached up to hold the sky in my hand
I begged the rain to pierce my eyes
To feel something real again

But the rain washed away my skin
My hope
My ignorance
My pain

Into acceptance

And an angel came to kiss my eyes closed
And to tell me that everyone is dying
The only difference is I know

And I wish from every hidden corner of my soul
That I never knew the beauty of this world
Or the pain
And that leaving didn’t hurt like this

I wrote this poem the day I was told that I needed a bone marrow transplant. The gravity of the situation hit me for the first time and I felt the weight of the world placed upon my life. After this, I researched and found the amazing recent discoveries and advancements with BMT, and began to develop much hope. I still have a lot of hope through this process, but I wanted to share how scary it can be for a patient at diagnosis and that they are not alone with these heavy emotions.

Faith when you need it most

—By Julia, transplant recipient

When my own parents passed, many years ago, each of them gave me the same advice, completely separate from each other. At each parent's death bed, I asked them "How do I have faith like you?" Each of them responded identically: "You will have it when you need it." This story is about my faith, and how I found it when I needed it most.

The summer of 2015, I noticed that I had been getting weaker. I approached my doctor about it, and he passed it off as my body fighting off a virus. My family attributed it to me reaching 60 and getting older and "slowing down". But I knew something was wrong. Then, suddenly, I began itching all over my body–my scalp, my stomach, all over – but with no rash or apparent cause. Naturally, I went to the local walk-in clinic to find out what was happening. After performing some blood tests, I found out that my white blood cell count was through the roof. A normal human being has a white blood cell count of between 4,500 and 10,000. Mine was over 138,000. The doctors ran another test because they thought the machine was broken. Another test confirmed that my white blood cell count was really at those high levels. The doctor sat me down to tell me the news. "Julia, you are a very, very sick woman. You have leukemia." At that time my son was out-of-town, my daughter in Connecticut doing clinicals to become a physician's assistant, and my husband overseas. But I didn't feel alone— I felt the presence of Jesus picking me up and carrying me and taking away ALL my fear. It was as if the diagnosis had taken away my uncertainty, and faith rushed in to fill the void.

The next few days were a blur. I remember being driven to the hospital by my neighbors. I remember the hysterical sobs of my daughter when I called her about the diagnosis. I remember waking up to the sight of my son's shoes after he rushed home. I remember the nurses asking me about my living will and medical power of attorney. Several months of testing and treatment followed, with my leukemia eventually settling in to what's known as the "blast phase." My doctors told me I had 6 months to live, and would need a bone marrow transplant in order to survive. For my family, there was no question about whether or not to pursue treatment. For myself, I had faith that all would work according to God's plan.

One of my greatest concerns was losing my hair. I thought my family would not love me anymore. I confessed my fears in a Sabbath-school class, and received words of wisdom from an unlikely place. One of our church members was a marine in his younger years, and he shared the story of when he joined the Marines: "When I joined the Marines, we were all lined up and they shaved our heads, because we were preparing for war. You losing your hair? That's you going to war. That's you preparing to fight this disease." Once again, as my parents promised, I found my faith restored. I asked the attending nurse to shave my head for me, and he willingly agreed. Afterwards, I was struggling to look in the mirror, continuing to feel ashamed of losing my hair. The attending nurse and my son forced me to look, reminding me that even with a shaved head I looked beautiful. And when I looked in the mirror, I saw they were right, but I also saw something more: I saw the face of a warrior, I saw my face prepared for battle with this disease.

One of my cousins crocheted me a beautiful prayer shawl to wear during my recovery, another crocheted me a beautiful cap with a scarf to match, lots of volunteers crocheted colorful caps for people like me going thru chemo treatment but I will never forget the look of the warrior I saw in the mirror that day, just as I will never forget the feeling of Jesus lifting me up in his arms and taking away all of my fear when I was first diagnosed.

I was in the hospital for one month. I was then transferred to Hope Lodge which was one mile from the hospital. I stayed there for two more months. My doctor was amazing! He was caring, kind, and compassionate. He gave me the greatest advice. The rule was, that I would not look online, medical journals, etc. about my disease. My job was to focus on exercise by walking a mile each morning and afternoon also some exercises in bed which the nurses taught me. My thoughts and prayers were on strength and recovering. My doctors' job was to help make me well with all this new amazing technology.

I cannot tell you how blessed I was. My daughter spent the first week with me along with my sister. She was off from work for a week and spent every day with me, and my son came each day for a few hours. I had five days of chemo, a rest day, and then my blood stem cell transplant. My stem cells were donated by a young man from Germany. What a great blessing it was that this young man saved my life. While I was receiving my stem cell transplant by IV my son, daughter, sister, doctor, and three nurses were surrounding me. God is so good! The nurses and doctor were exceptional in the care that I was given. I cannot thank them enough, and my son, who stayed the next three weeks in the hospital with me. When I moved to Hope Lodge my wonderful husband along with my son took care of me.

I am now two years in remission thanks to my Heavenly Father, a family that loves me so much, church members, and friends that prayed for me so much over the past two years and the medical staff who worked endless hours treating me with CML with Philadelphia chromosome.

May this story bless you and give you strength.

Dena, caregiver, with her husband, David, transplant recipient

CHAPTER FOUR:

Gratitude

Dear donor,

—By Dena, transplant caregiver

It was April of 2012 and excitement was in the air. Our nephew was getting married. This was the first traditional wedding among the kids and we were going to celebrate! It was also the first time our immediate family would be together in a while. Our youngest was still at home but the older two had left the nest years earlier and now lived in different states.

David was helping me prepare for the kid's visit. He was my rock. I leaned on him for everything and he always delivered. He had recently started complaining of his shoulder hurting and being extremely tired. I didn't think much of it. He was a hard worker and had many injuries in the past. Not only was his job physically demanding, he did a lot of projects around the house. He recently had a full physical and was given a shot in the shoulder to ease the pain. A CAT scan was scheduled and I was happy the doctors were going to get to the bottom of it.

The night of the reception we laughed, sang, danced and toasted to the future! It was an unforgettable evening, little did we know in more ways than one. It would be the last time our family would know what life was like before David had cancer.

The prognosis was devastating. A rare cancer called histiocytic sarcoma. Four aggressive growing tumors. Terminal. Three months. David and I cried together. We talked about the kids, the trips we had taken and the beautiful moments we had shared. We talked about our firsts. We hoped and prayed like never before. That is when David confessed when we slow danced at the reception a few short weeks before, during the intimate moment we had shared in a room full of people, he couldn't shake the feeling that it may be our last dance and he had cried. We talked about our lasts.

Through prayer, faith, speaking the positive, good doctors and a series of treatments including tandem autologous stem cell transplants, we experienced what most would consider a miracle! I was so in awe and grateful for a second chance with my husband. More trips. More moments. More firsts. David was my hero, but God was now my rock. Eventually things settled into a new normal.

Fast forward to November 2016. David was once again diagnosed with cancer. This time stage 4 B-cell lymphoma throughout his bone marrow. It was so aggressive it was multiplying while viewed under a microscope. Our doctor said his PET scan lit up like a Christmas tree.

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I was scared. I was angry. I had lost my beautiful mom to leukemia over six years earlier, almost lost my husband over four years earlier and now I might lose him again. However, once again prayer, faith, David's perseverance, good doctors and many treatments, set him up for another transplant. This time it would call for an allogeneic transplant. He would need a donor.

> "I was scared. I was angry. I had lost my beautiful mom to leukemia over six years earlier, almost lost my husband over four years earlier and now I might lose him again."

Months later we had another first. The first slow dance after yet another long cancer battle. I once again found myself grateful beyond belief. Grateful for more time. Grateful to be sharing an intimate moment with my husband in a room full of people. Grateful that there was a donor out there who was willing to give selflessly of himself to give someone he didn't know yet another chance and experience even more firsts.

The photographer for a wedding we were attending candidly caught our first slow dance after cancer journey number two on film. It is our pleasure to share it.

Dear donor ... thank you for the dance.

Dena was a caregiver to her husband, David, who received an unrelated transplant for lymphoma. "I was scared," Dena said. "I was angry. I had almost lost my husband over four years earlier, and now I might lose him again. Months later, during a slow dance with David at a wedding reception, I found myself grateful beyond belief. Grateful that there was a donor out there, grateful for more time."

Lifelong dream comes true

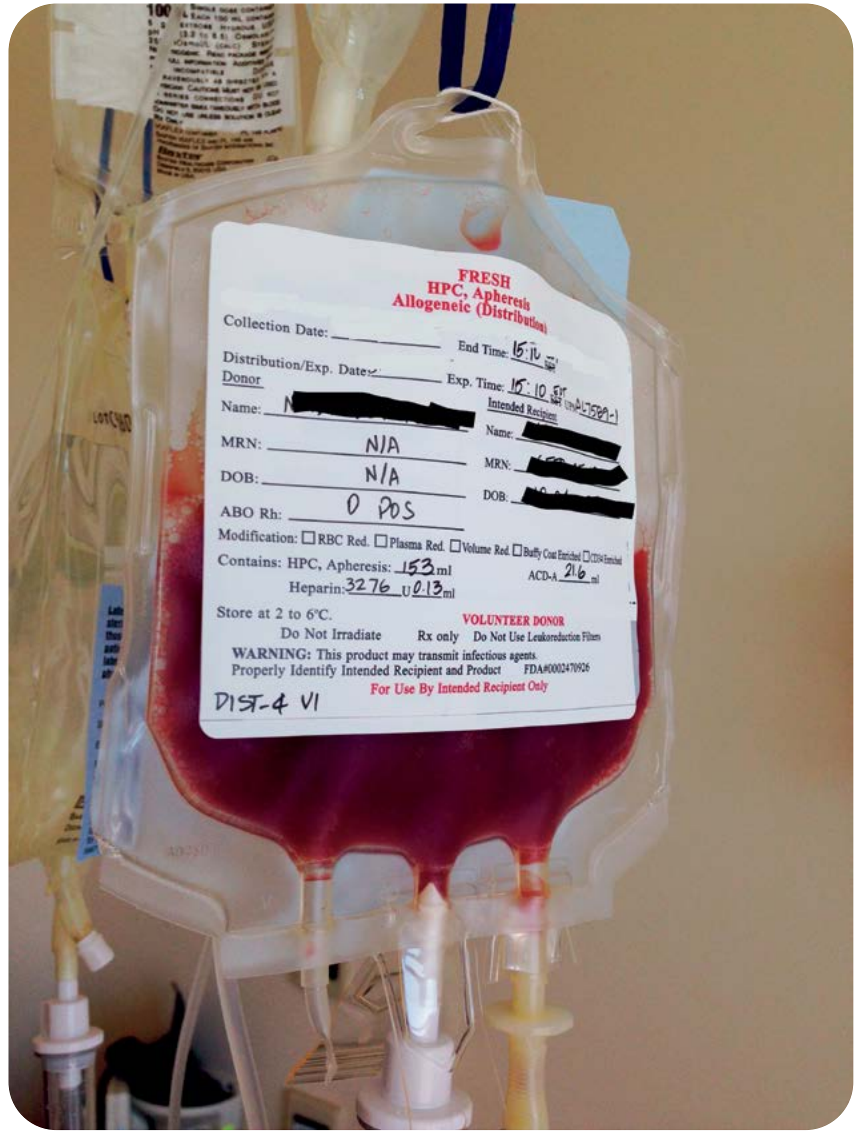
—By Lester, transplant recipient

Photo from left to right: blood stem cell donor Jon and wife Sarah as Best Couple, transplant recipient Lester, Husband and Caregiver, Carlos, Best Friends and Caregivers Carol and Elizabeth.

Thanks to NMDP, this photo of our lifelong dream was possible. We have been in a committed relationships for 36 years and were finally able to get legally married in San Marino, CA in January 2017, after my bone marrow transplant on September 8, 2015. It is so hard to express thanks to someone who saved your life, but I strive to say thanks at every opportunity, and encourage any eligible adults to register with NMDP. You will never know how many lives you will touch with your generous donation.

This little bag

—By Gloria, transplant recipient



FRESH
HPC, Apheresis
Allogeneic (Distribution)

Collection Date: ____ End Time: 15:1L
Distribution/Exp. Date: ____ Exp. Time: 15:10 (ALT5891-1)

Donor
Name: [redacted]
MRN: N/A
DOB: N/A
ABO Rh: 0 POS

Intended Recipient
Name: [redacted]
MRN: [redacted]
DOB: [redacted]

Modification: ☐ RBC Red. ☐ Plasma Red. ☐ Volume Red. ☐ Buffy Coat Enriched ☐ CD34 Enriched
Contains: HPC, Apheresis: 153 ml ACD-A 21.6 ml
Heparin: 3276 U 0.13 ml
Store at 2 to 6°C.
VOLUNTEER DONOR
Do Not Irradiate Rx only Do Not Use Leukoreduction Filters
WARNING: This product may transmit infectious agents.
Properly Identify Intended Recipient and Product FDA#0002470926
For Use By Intended Recipient Only
DIST-4 VI

This little bag saved my life.

This little bag was my only hope for survival.

This little bag is donated bone marrow from a man who put in the time, the energy and the effort to save a stranger's life.

This little bag made me realize
that there are good people out there, really good people.

This little bag put me in remission from leukemia.

This little bag gave me a new lease on life.

This little bag gave me a new appreciation for the small things.

This little bag is proof that good things
do come in small packages.

This little bag makes me cry, it makes me cry everyday
with tears of overwhelming joy.

For if it wasn't for this little bag
I would have died in my birthday month.

This LITTLE BAG saved my life.

True heroes

—By Gloria, transplant recipient

True heroes are volunteers.

True heroes are people like you and me with busy lives.

True heroes may have a family, a job or go to school.

They may be overwhelmed by all their responsibilities.

BUT

True heroes do not let this stop them
from helping someone in need.

True heroes may never get to see the fruits of their labor
or get compensated in any way.

True heroes may never get praise for a job well done
or hear the words "thank you."

BUT

True heroes know that somewhere someone
will be forever grateful.

I KNOW A TRUE HERO

He is a man I never met.

But his blood runs thru my veins every day and every night.

He is a volunteer who took a cheek swab one day.

He is a man that found out sometime later that he is a match for someone who has leukemia and needs a bone marrow transplant.

He is a person just like you and me with a busy life who might have a family, a job or go to school.

He is a man who might be overwhelmed by all his responsibilities.

BUT

He is a man who did not let this stop him
from helping someone in need.

He is a stranger who paused his life to go to the hospital for five consecutive days to get injections and then on a sixth day spent up to 8 hours in the hospital to be hooked up to a machine so that it could collect his bone marrow.

This stranger is my true hero.

PLEASE KNOW, MY TRUE HERO

I hope to meet you one day so that you could hear me say the words "thank you."

PLEASE KNOW, MY TRUE HERO

I will be forever grateful.

We are family!

—By Lori, transplant recipient

Michael is not my brother, cousin, uncle, or any other family member. But we are "family" because we have the exact same DNA, blood type, bone marrow. I am alive because he swabbed, because he said yes, because he donated life-saving bone marrow!

On June 22, 2006, Michael gave me the gift of life! He donated his bone marrow; a "perfect match" at a very critical time for me. A "perfect stranger", donated "perfect marrow"!

I'd been on chemotherapy and radiation for years, finding myself without any option but a bone marrow transplant. Unfortunately, there was no family member or registered donor that matched. I felt very desperate, wondering if I would live long enough to find a match. By the grace of God, Michael came onto the international registry just when I needed him and agreed to be my "perfect match" donor!

Thanks to Michael's good health, unselfishness, willingness, and compassion I am alive today, able to live a healthy life! I am able to work full-time for the Department of Defense (ARMY); I was able to raise my son Matthew (now 22 years old), and I enjoy every aspect of life: church, family, friends, jazzercise, volunteering, working, and running. Without Michael, my life would have had a different outcome. Thanks to God, my amazing doctors, and my donor, I've been able to accomplish some amazing things since transplant like Abrams Tank Commander Training, obtaining my motorcycle license, earning my Master's Degree, and running several marathons. Thanks to Michael, I truly look forward to a great future! Every day is a GIFT, a BLESSING!

However, every day since transplant hasn't been easy. My doctors explain that I traded one disease (cancer) for another disease (GVHD). Five years post BMT (2011), I experienced life-threatening Graft vs. Host Disease (GVHD). I had to be airlifted from Detroit, Michigan to Omaha, Nebraska where my cancer/transplant doctors are located. Angel MedFlight (AMF) Worldwide Air Ambulance Services provided the flight, a doctor, a nurse, a pilot and a co-pilot. I never asked "Why me, God?" I have lived firmly rooted in the belief that I have the faith and family to FIGHT; something others may not have!

I spend every moment being GRATEFUL for this one life, knowing it was God, my amazing doctors, and my donor that made that happen for me. I don't have a bucket list, but I did have one wish! I wanted to meet Michael face-to-face and THANK HIM for giving my son back his mother (10 years old, at the time of my bone marrow transplant)!

> "I spend every moment being GRATEFUL for this one life, knowing it was God, my amazing doctors, and my donor that made that happen for me."

I had communicated with Michael since September 2008 via email. He was very young at the time he donated. Since my bone marrow transplant, he had gotten married. Not only has Michael saved a life, he has created two beautiful children. He is a full-time employee, husband, and father. For both of us, it was a dream to meet, but financial resources prevented that from occurring, until I learned that two years after airlifting me to Omaha, AMF was hosting a "Home for the Holiday" contest. I submitted my transplant story and my plea for them to bring Michael from Germany! Without that need for a life-saving flight from Detroit to Omaha, I wouldn't have known about AMF; I wouldn't have been in their email database and I wouldn't have gotten the email telling about their "Home for the Holiday" contest. I never ask "Why Me, God?" because he always has a PLAN greater than I could ever understand, even on my deathbed!

Once I submitted my story and plea, along with many, many others I was notified by AMF that I was one of the Top 5 stories submitted and it would go to online voting to determine the winner.

GAME ON! For several days, I watched my story get aired on local TV and radio stations, written in local newspapers, and shared on Facebook/Social Media around the world. I watched as strangers shared my story, encouraged their friends to vote! I watched votes climb and climb for "our story" to WIN!

Then, it happened! AMF announced that I had won the "Home for the Holiday" contest and they would be bringing my donor Michael from Germany to Iowa, USA!! Then the party planning began! Lots of family and friends, and local businesses in small-town Iowa (and the surrounding area) wanted in on planning!

On Saturday December 28th, 2013 a small plane landed at Quad City International Airport. On that plane was Hans, a German pilot, two staff members from AMF, and Michael, my donor from Germany. MY LIFE FOREVER HAD BEEN CHANGED. Hundreds of airport employees, family and friends, and strangers crowded the airport to catch a glimpse of me meeting my life-saving donor in person, for the very first time.

My wish had been granted, God's plan fulfilled!

Thankful for you

—By Robert, transplant recipient

As I went to sleep last night
I thought about how you changed my life
I can't imagine where I'd be
Without you here right beside me
And I know I've told you this before
But I want to tell you just once more
I'm thankful for the life
That you've given me
And all the love you give
So unselfishly
I'm thankful for the dreams that you made come true
But more than anything
I'm thankful for you

Dedicated to my doctor
and the entire BMT team

Day 0: to the person saving my life...

—By Jennifer, transplant recipient

> "I hope you read this and realize just how grateful I am. Your incredible generosity went to someone who desperately needed it and who will never waste another day of her life because you've given me life."
>
> — Jennifer, transplant recipient

My name is Jennifer. I have to wait a whole year to send you a thank you card and two years to meet you, but I want you to know me now and am hoping this will somehow reach you. I hope that when you read about how I received a stem cell transplant in August, you'll pause and think, "I donated blood stem cells around then!" I'm hoping when you read where my transplant happened, you'll say, "that's where my blood stem cells went!" I hope that the universe finds you, the young man from somewhere in the U.S., who just happens to be the perfect match for me. I hope you read this and realize just how grateful I am. Your incredible generosity went to someone who desperately needed it and who will never waste another day of her life because you've given me life. You've saved my life. I promise you this was a good investment.

So who am I?

I am a daughter. I was raised by two amazing parents. Two people very different from each other, but whom I reflect perfectly, good and bad. My dad had tremendous work ethic. He came from poverty and built a beautiful life with my mom. He was funny and kind and generous with his talents. He was also temperamental and quick to react emotionally. Stubborn, impatient...totally me. My mom is a strong woman, and the type that sees a challenge and just pushes ahead. She has gotten our family through tough time after tough time. My dad was diagnosed with lung cancer in 2009 and passed that same year. Cancer is just part of our experience. What woman should have to lose her husband to cancer and watch her kids fight it though? Six months after losing dad, my son was diagnosed with a rare disease, changing my life forever. Two years later my brother's twins were born at 24 weeks gestation and spent three months in the hospital fighting to live. I think my strength comes from watching mom be strong year after year. I know my mothering nature comes from watching her take care of everyone else.

I am a mother. I found my purpose in life when I became a mom. My daughter is a miniature version of me in many ways. She's creative, struggles with math and has a heart that's bigger than her abilities. She'd help everyone if she could. She has a mouth on her too. The "I hope you have a kid just like you when you grow up" sort of happened. She's helped me realize a lot of my faults, forced me to confront them and adjust my attitude. I grew up after having her, and every day she shows me the type of woman I aspire to be. My son, as I mentioned, has a rare disease so he's developmentally disabled. He's my soulmate. I know most people associate that phrase with romance, but I don't. My son makes me whole. No one understands him the way I do, and oddly enough, no one probably understands me the way he does. Because of him, I figured out my purpose.

I am a wife. "Opposites attract" has never been truer than when it comes to my husband and me. I'm loud. He's quiet. I'm emotional and temperamental. He is calm and level. I don't do spontaneity...he doesn't plan anything. We balance each other perfectly though. When I need to slow down and relax, he helps me do that. When he needs to find his way out of a paper bag, I draw the map. Kidding. He's learned that by now. He's a good man. A steady man. He has fulfilled my dreams.

I am many other things too. A sister, an aunt, a niece, a cousin and a friend. I'm a sports fan (oh god...what if you're a fan of my rival!?), and a person with a dark sense of humor (cancer gives you loads of joke material). I'm a woman who lives life loudly and with passion for the things that matter to her. I could go on and on and tell you about the things that make me Jennifer, the woman who you matched, but thanks to you, I can now say that I'm a survivor. Thanks to you, I have a chance to take care of my mom as she grows older. I have a chance to see what my kids accomplish in life. I have a chance at many more years with a man whom I have loved for almost 20 years. I have a chance. Before you, I had none.

I hope the universe pays you back in full and gives you an incredible life. I may never know you, but I will never forget you. You will be in my thoughts every day for as long as I live.

Sincerely,
Jennifer

"Day zero", January, 2017

—By Jessica, transplant recipient

January, My Day Zero
On this day my life changed forever
When a stranger became my hero.

I don't know who he is
I have never seen his face
But he will forever hold a place in my heart
That can never be replaced.

I know nothing of him but his age
And that he does not live nearby
I have to wait two years
Before I can ever meet this guy.

I wonder if he's heard my story
Or the pain that I've endured
That I would have left three kids behind
That because of him for now I'm cured.

It may not last forever
The cancer may return
But every day I have with my kids
Is one less that they will mourn.

So thank you to my donor,
My angel and my hero
I hope I finally get to meet you
Two years from my day zero!
-Jessica

To my life donor

—By John, transplant recipient

My life donor,

My name is ________________, I live in ________________ a great town with many friendly people. I wish to tell you that ________________ who is my companion and life partner truly the love of my life is very grateful for your gift.

My greatest joys are my children and grandchildren, my two daughters,________________ and ________________ have blessed me with four grandchildren. ________________ who attends college with aspirations of becoming a doctor and had a 4.0 GPA in her first year, ________________ and will move into middle school this year is an honor student and very musically talented; she plays the violin and vocally gifted. The next in line is ________________ also an honor student as well as an excellent soccer player, he is going to soccer camp this summer and I get to take him. The youngest is ________________ and such a loving child. She too is an honor student and very involved with athletics and of course being the youngest is the most spoiled!

As for me I am in my mid 60’s and semiretired from owning and operating my own businesses since my early 20’s. I have been blessed through the years to have seen many parts of the world while meeting many interesting people, it has been a wonderful ride through life, although not without the ups and downs which was what made life so very interesting. My interests are very diverse from boating, flying, computers, military history, volunteering and fundraising. It has always given me great pleasure to “give back” as a firefighter for 12 years and a member of the military for 21 years the sheer pleasure and excitement of these careers again kept life very interesting.

I’m not sure, other that you are in your 20s, anything about you except we now have a bond of genetic tie which has provide me a “new birthday” and a continuance of life. The day I received your cells into my blood stream we would “brothers from another mother” and I will until my last breath be eternally thankful for your generosity.

It is such a magnificent gift you have given, God saw this through, my medical staff, family and friends were guided by love, compassion and expertise.

It is so amazing to now awaken and can look forward to having my children text or call me. My soulmate tell me she loves me. My grandchildren, well because of you, I could enjoy buying them some new outfits yesterday and sharing dinner on Memorial Day. The soccer camp would have happened without me but now I get to be part of the experience. The concerts will go on but I now get to see her perform and the little one will compete and come up with some of the craziest ideas without me but now I get to be part of her life.

This is all because of you!

It I so difficult to for me to fully express my sincere gratitude and appreciation for what you have done for me and my family. Someday I would look forward to meeting you but until then always remember there are many people that owe a big hug and thank you!

“At times, our own light goes out and is rekindled by a spark from another person. Each of us has cause to think with deep gratitude of those who have lighted the flame within us.” Albert Schweitzer

Thank you and God bless you!

Sincerely,

____

Dear diary

—By Walter, transplant recipient

Dear Diary,

Jim Valvano said, “If you laugh, you think, and you cry that’s a heck of a day.” Today I did just that in a matter of minutes when I heard news my hemoglobin was 11.7.

Why? Three days ago my hemoglobin was 7.9. Two days ago my hemoglobin was 8.3. Yesterday it was 8.9, and today I was 11.7. What does this mean? Normal is between 13.5 and 17.5. The closest to normal I have been is in the 12’s, but that was the first day I got rushed in, and they gave me 3-4 bags of blood and 2 bags of platelets. Today was the highest I have been by myself. I also have been .1 on my white blood count for two consecutive days. So, today, I, Walter have officially began to engraft, and am on my way to becoming healthy.

Last June, was when I first got rushed into the hospital for my anemia. Then we didn’t know what I had. Someone had said there was a possibility I had leukemia. Nobody took this worse than my dad. He was frantically pacing back and forth, and for the 3rd time in my life I saw him in tears. I knew in that moment I had to be stronger than ever before. I knew I had to say something to relax him a little. So, I looked at him and said, “Dad look at me…no matter what it is I will get through it.” I had seen my dad cry just twice before that moment. Since that moment I don’t know how many times I’ve seen him cry because he was scared for me.

Now, back to today. As we were getting my counts back I was thinking about that moment, laughing because I could finally tell him, “I did it.” I then had my emotions move me to tears of joy. Why? My dad could finally stop crying because he was scared for me. The only tears he would cry now are ones of joy.

My relationship with my dad has completely changed over the last year. It is stronger than ever, because he has helped me out the most. He helped open my eyes, and never wanted to miss an appointment, no matter how hard we tried to tell him he doesn’t have to. He has been there every visit, besides when we force him out. I am officially on the road to recovery, but the day doesn’t belong to me. He was in the hospital with me on Father’s Day so, this day’s for you dad. I don’t know how I’ll ever be as great of a dad as you one day.

The matchmaker

—By Richard, transplant recipient

It was hard to like my doctor. He was always the bearer of bad news. He confirmed that my white blood count was indeed going through the roof when I was admitted into the ER. He informed me that I needed chemotherapy right away while awaiting a matching donor. For those reasons alone, he is forever disqualified from my favorite person list.

None of these behaviors can be attributed to be misdeeds of his own, moreover, he possesses quite a number of redeeming qualities. For one, he always wears a smile on his face. It was unmistakably the smile of the famous Mona Lisa. It seems he has that stitched to the corners of his mouth. It was there every time he visited me, even when he was about to hand down the harshest verdicts. For the care I received in the most inhospitable circumstances, I promised myself that I'll repay him one day if he makes me healthy again.

Even with the cavalier attitude that I had toward treatment, I cannot say I was unfazed. They made radiation sounded like a session at the tanning salon. But when you were the last person left in the room, draped in nothing but a thin hospital gown, you started thinking about the frailty of human nature instead of getting a nice skin tone. I used the pictorial technique I learned from my counselor to keep my thoughts straight. I tried to imagine myself on a tropical island. That did not work for long as the AC encroached on my scantily clad body. I lost focus, paralyzed by the rice bags which held me firmly in place, disallowing even the slightest movements.

I began to have second thoughts. Perhaps I should not be so gung-ho about day zero, hoping the donor cells would find my hollow bone marrow and make their home there.

The image of my doctor's smile floated in front of me. In times of tribulation, his smile calmed me. For sure, we maintained our proper doctor/patient decorum, but I was able to pry with the curious personality that I am.

"Tell me, how come with all your credentials you're still single?" I asked him as casually as I could after he finished examining me.

"Oh, I just don't have time to meet people." He gave me the standard reply. "And my parents are going to arrange a wife for me when the time comes." He added.

"Don't tell me you still go for that in this time and age!" I exclaimed.

"Believe it or not, it's our tradition. And it works better than any dating apps." He said half-jokingly.

"It may be." I said, "But I would hate to leave such an important matter up to the whims of our parents."

"Don't worry. Our parents always take good care of us and make sound decisions." He finished listening to my lungs through his stethoscope.

I was flabbergasted by his unwavering trust in his parents' judgement. I wondered how someone in a profession which represents the epitome of logical thinking, could relegate his own future to chance. I think of how hard it has been for me to find a matching donor. Even my siblings have only a 25% chance of providing a satisfactory match for my genetic markers. On the other hand, a 10 out of 10 match doesn't guarantee me recovery either. This led me to the conclusion that when it comes to our daily lives, some black magic is nevertheless still an unavoidable ingredient.

I searched the back of my mind for a suitable match for my doctor. I already have somebody in mind that would match his outstanding character. Someone whose XX chromosomes will soon enter my body and cohabitate with my XY chromosomes. The thought brought a smile to my heart, even though it was hard to laugh at anything on the eve of my transplant.

No doubt, he would try to assure me that everything will be okay. Could I trust a life and death moment in the hands of someone who did not even care to be in control of his own destiny?

"You should try going out with someone you like." I tested him again when he came for my final check-up before transplant.

"I'm in no hurry to marry." He replied in his usual fashion. "You're thinking too much. All my patients get antsy before transplant." He tried to deflect.

"So, we're in this together?" I asked.

"Till death do us part." He answered.

It was unclear to me whether he meant he would be complicit with my plan. His words did give me a unsettling feeling. Death is definitely a possibility, and I have yet to make a contingency plan. Sometimes, it may be better to leave certain things up to fate. At this stage of the game, our options are limited. We need a touchdown and a two point conversion.

Back in the huddle, I already know what my doctor will say. He will say that I would be bald for some time, but that my hair will grow back; that I would feel nausea and fevers would be common as my army of resistance was wiped off en masse by the controlled demolition. I rehearse our plan over again. I don't know if I'd trust the quarterback or the receiver more, I just know that the ball must not be dropped.

It's not easy to like someone who brings you bad news all the time. But we understand each other, we're both matchmakers in our own ways. More importantly, we're on the same side of the field. Secretly, I told myself: if he thinks he can win me over so easily with his Mona Lisa smile, then I'll set him up with someone who will nag him for the rest of his life. That will be my sweetest revenge.

Of course, the transplant worked. It wasn't an easy feat. Call it a touchdown. Now, the two point conversion.

Donor

—By Deb, transplant recipient

Gives of his body

He; unnamed, unseen, unknown

Love and Compassion

A miracle match

—By Rob, transplant recipient

In the spring of 2015, I was diagnosed with high-risk myelodysplastic syndrome, or MDS. At the moment of diagnosis, I knew my life, and the lives of my wife and children had changed forever. This is not the story of my illness, however. It is the story of my match. I am not by nature an emotional person. But as I write, thinking about my match, I am on the verge of tears.

I required an external donor, and having no siblings, I didn't know where that donor would come from. I was told early in my treatments that the NMDP Registry had identified some possible donors, one of whom was a perfect match. Many things had to be coordinated including the donor's travel to a large city and my treatments. This was made much more complicated because the potential donor was in Europe. The many unknowns made me very anxious.

One day the good news came through: the donor had agreed and a schedule had been set; the donated blood stem cells would travel by courier from Europe to San Francisco. On the given morning, a nurse walked into my hospital room carrying a small cooler. Inside were two small bags of brownish-red liquid – my donor's blood stem cells. Several hours later the transplant was finished and, miraculously, the blood stem cells were already on their way to my bone marrow. My new immune system was born.

Who was this person from thousands of miles away who had given me such a gift? A number of months later I began to find out. My wife and I were at the clinic for my regular check-up when the transplant coordinator came in and handed us a letter handwritten in Polish. The three of us broke into tears. When the nurse practitioner arrived, she thought something terrible had happened. And then she started crying too.

This is the translation:

"Dear Recipient [hand-drawn heart],

"If you are reading this card, then you know that I want to help you so much from the bottom of my heart and soul. When they called me for the first time from ____________ to say that I could help you, I agreed without a moment of hesitation and I was happy; everyone congratulated me, although there is nothing to congratulate, as everyone would do the same if they were me. I was so happy that I could help you that I went to see the priest to give me his blessing.

"Despite the fact that I don't know you and I don't know where you are from, it doesn't matter at the moment—the most important is that I can help you, which I want from the bottom of my heart.

"I wish you (my brother or sister) lots of health, so that my help will shine as the sun in the sky.

"May God be with you.

"See you.

[hand-drawn smiley face]"

> "I wish you (my brother or sister) lots of health, so that my help will shine as the sun in the sky."

Who is this person with such a deep well of generosity and caring? We now could exchange letters: "Dear Donor, ……with deepest gratitude, Recipient." Over the next year and a half we learned a bit more. She was a 21-year-old woman with a 2-year-old son living somewhere in Poland. And, despite the restrictions that governed our communication, her fundamental beauty as a human being shined through. The details of who she was, and how she came to be a perfect genetic match for me, were the subjects of endless conversations with my family and friends.

Two years after the transplant, I filled out a form giving my consent to share my personal information with my donor. We were told that a similar consent form had been sent to her. Yet, after several months of not hearing anything, I was worried. Maybe she had moved and couldn't be contacted? Perhaps something was keeping her from taking this step? One day, with no warning, I received a copy of my donor's consent form. There it was, on the computer screen: Angelika, from a town in northeastern Poland. All her contact information was included. In several minutes our daughter found her Facebook page. Two days before my transplant, Angelika had posted a photo of herself lying in a hospital bed hooked up to the machine that was spinning stem cells out of her blood to send to me. Looking at her picture, I found myself sobbing. Seeing her photo triggered the release of a lot of emotion I had locked up about the ordeal I had been through.

I immediately sent a message to my friends and family, letting them know about Angelika and asking if anyone knew of a Polish speaker who could translate for me. More quickly than I could have imagined, I was put in touch with a Polish friend of a friend who was more than happy to translate. I was then able to send my first letter, and to receive hers. One of my first questions was, what was it that led you to register as a donor? Her answer was simple: "I was 19, taking a walk, and passed a booth for a European bone marrow registry. It seemed like a good idea, so I registered." I learned later that it was a more difficult decision for her to actually be a donor. She had to travel to Warsaw and remain there for a period for the procedures leading up to the apheresis process.

We are now getting to know each other, a twentysomething Polish woman and a 70-year-old American man. I suppose one could call us friends, but the relationship is much deeper and more unique than that. Her blood runs through my body. There are really no words to describe how I feel about her.

Perhaps some day I will meet Angelika in person, but right now, that doesn't matter. What is important, and this thought never leaves me: because of Angelika I am alive. What more profound gift could someone give?

Thank you,

Angelika

How can I say "thanks?"

—By Christopher, transplant recipient

In late May 2015, after days of testing to try and figure out what was wrong, what was causing me these uncontrolled chills, hot flashes, overall weakness; what was making me feel like I had been dragged through a briar patch and left for dead? Did I have some sort of exotic disease? Where were these tests going to lead? Then a doctors comes in to tell me that they have run every type of test they can to determine what sort of infectious disease I might have, but came up empty. And now it was time to look at other possibilities. Her name badge had her name, M.D., and the department was hematology/oncology. Now I was really nervous. It was then that I learned what a bone marrow biopsy was. It was then that I realized we were looking at something I had never imagined—you know, the type of thing that only happens to folks you hear about on T.V. or fundraisers for kids. Not me. I have been fairly healthy all my life.

Two days later a couple of doctors with the same Hematology/Oncology on their name badges, came to tell me that I had a form of blood cancer known as acute myeloid leukemia (AML). When I asked them what that meant as far as if I was going to die from this and they said that without treatment I had about 6 months to live – but that with treatment they could (or was it "would"?) not be able to tell me but that it would prolong my life... how long, or what condition I would be in was uncertain. They also told me not to Google AML since these things tend to scare people and that everyone responds to treatment differently. Wow.

I don't know about you, but when I'm issued a warning like that it is almost impossible to actually take that advice and not look up whatever I can. So I did. And of courses they were absolutely right. I should not have (for the record: at the time the charts were showing I had a 24% chance of surviving 5 years).

The story of treatment through chemo and a blood stem cell transplant has been told and while I would not recommend the process I can honestly say it helped me come to grips with a lot of things. Months of isolation, weeks of chemotherapy, months of pain, lost weight/appetite, could not answer why it was that a complete stranger found it within himself to respond to a call asking him to donate stem cells to save my life. He was a 10 point match... none of my family came close. A person who took the time, discomfort, and distraction (in this day and age) to donate to someone he never met. He didn't know anything about me. Just that someone out there needed something that only he could offer.

> "A person...took the time, discomfort, and distraction...to donate to someone he never met."

I was told after the transplant that I could reach out to him and try to communicate assuming that was something he wanted to do... but I had to wait a year to be given the contact information—if and only if he was willing to give it.

So I sent him an anonymous email letter hoping to get a bit of information back and to thank him. But I never got a response.

After all the time, pain and effort of going through this process I was not going to get a response? Nothing?

It's been a year since that email and after thinking about my disappointment I do believe that some don't do things like this in order to get thanks, or praise or to answer questions as to why they did something good. I think many people do things like this because it is the right thing to do, the only thing to do and therefore MUST be done. There are no choices when it comes to saving a life.

All my adult life I gave blood a few times a year as I always thought it was the least I could do to help people. But in that case (giving blood) I never knew where the blood was going or if it would be used for someone in crisis or someone getting plastic surgery or what. But when it comes to giving stem cells the facts are crystal clear: you are saving someone's life. Period. There are no ifs ands or buts about it.

The biggest regret I have now almost 3 years since my diagnosis is that I can no longer give blood or stem cells or anything like that due to my experience with AML.

But if you are out there and you are the one who saved my life by being selfless and giving, I know no other way to thank you.

The letter we sent to our donor

—By Douglas, transplant recipient, and family

We were told that we could send a thank you note, as long as it was anonymously. So here it is, but after a year, if you wish to make contact to see how we are doing, please do so. It would be a delight.

We have been trying to figure out how to say Thank YOU. The words seem so empty and come so easily. We can't easily describe how deeply we feel—deep into the very core of our beings. To say we are grateful, does not say enough. You have done a most special and huge thing for us, for him and our entire family.

Your generous donation of bone marrow—a life giving substance—brought hope back into our lives. The day we learned that we had a perfect match 10/10 match, we were so relieved and happy. The day we learned you actually showed up to perform your donation, we danced for joy. The day we learned that the bone marrow was heading our way, we had a celebration dinner. The day it arrived at the hospital, where we were waiting patiently, we broke down and cried for joy. We called all of our friends and family and they cried and celebrated with us. We felt like singing from the top of a mountain—HE WILL LIVE.

You gave life to him, how can we be grateful enough? We will always think, in the face of many doubts, that goodness can prevail. His bone and body with your marrow, is a testament in favor of humans and humanity and their best endeavors. We were lost. You gave him life. We are found, and we can now move forward. He would not have had a future without your life saving actions.

So, from our family to your family, you have done a great thing, and **we will forever be GRATEFUL. THANK YOU**.

Thank you to my donor

—By Woody, transplant recipient

> “It is beyond my writing ability to put words together that thanks you enough”
>
> — Woody, transplant recipient

December 25, 2017

To my brave, caring, beautiful donor,

I know donating to me involved personal sacrifice. Thank you. You are the one that put a light back into my life. You gave me hope.

The morning in January 2016 was very exciting. I awoke to a bold sign on my board, it wished me a happy birthday; today would be my new birth date. The nurses were very respectful of your stem cells. They let me know when they landed at the airport and when they arrived at the hospital. Anticipation and the unknown were very high. Two hospital chaplains, my wife and a friend were with me when your precious stem cells arrived. The nurse hung the small red bag and connected it to my IV. As your life saving gift flowed into me the chaplains started a ceremony personal to me and giving blessings to you. At the conclusion they lit a candle. The whole atmosphere was one of HOPE. Ten days later lab tests showed my body was accepting your stem cells and I was soon discharged from the hospital, at about three months post-transplant lab tests showed my blood was one hundred percent donor and my blood had changed from type A to O.

Having been diagnosed with AML and receiving your blood stem cells has been a challenge physically and mentally. I have had many challenges over the last two years. My doctor is smart, intuitive and very pretty. She along with my new immune system have gotten me through all setbacks. Lab tests show no return of AML.

Because of your gift I have a life. I am home with my wife and our Boston terrier. I am a vascular ultrasound tech and I have returned to part time work. I swim ten to twelve miles a week. Christmas of 2016 we started skiing again. We have done some traveling and plan to do more. We spend time with family and friends.

It is beyond my writing ability to put words together that thanks you enough for giving me a new immune system, new blood and a new chance to live. It is your gift that has made all things possible again. You saved my life. I will respect what you have given me. It is my opinion that you are the most awesome person on the planet. I wish you health and happiness.

Thank you, Thank you, Thank you.

Lovebirds

—By Carol, transplant recipient

My husband, Bob, and I shared everything, including leukemia. Fortunately, we both were taken care of by the same doctor at the same hospital. We were lucky enough to find bone marrow matches and were able to spend additional time with each other. My husband received his transplant first. Later I was diagnosed with leukemia and a match was found for me also. During my bone marrow transplant, I wrote the following poem:

I'm in love with birds and water—and Bob!

My husband and I ended up
sharing everything!

Diseases, sharing the cancers,

Each of us receiving a kind donor, then
resting by the blue waves

of water in our lake, which made us so
much better!

I am an artist. My paintings are often water oriented. Lake Champlain holds a special place in our hearts and I paint it often. We spent a lot of time together and with our family on the lake and it was our recovery place.

After my husband's death, I painted the love birds.

8 is our lucky number

—By Polly, transplant caregiver

Miracles pulled out of thin air—our amazing Calstar Air Medical Services crew flew us to our hospital for a bone marrow transplant.

Celebrating 2 years post-BMT

Life unexpected

My husband was at work when he got the call that would turn our lives upside down. He had leukemia and needed to be admitted immediately. We spent the next 7 months in hospitals. I say "we" because, except for a few nights, I was there by his side. For me, there was no other choice.

As an advocate, a caregiver, and a wife, I had to face some impossible challenges, but they were nothing compared to what my husband faced as he fought for his life.

Digging deep

When our family insisted on flying out to say their weepy goodbyes, we said no, we were not done fighting. When one transplant center said they couldn't treat him, we found one that would. When the oncologists, infectious disease specialists, and pulmonary surgeons could not find the antidote for my husband's respiratory infection, we kept trying different options. When clinical trial after clinical trial rejected my husband as too risky, we didn't give up. When each round of chemo couldn't knock him into remission, we kept researching for another way. When there were no related matches, we knew that there would be a donor out there somewhere who would step up. And he did.

True hero

When we see others face life's most difficult challenges, it's hard to know what to say or do. That's something that makes the anonymous donor's gift all the more special. Clearly, he knew exactly what to do—help selflessly. It's a rare thing, and we are forever grateful.

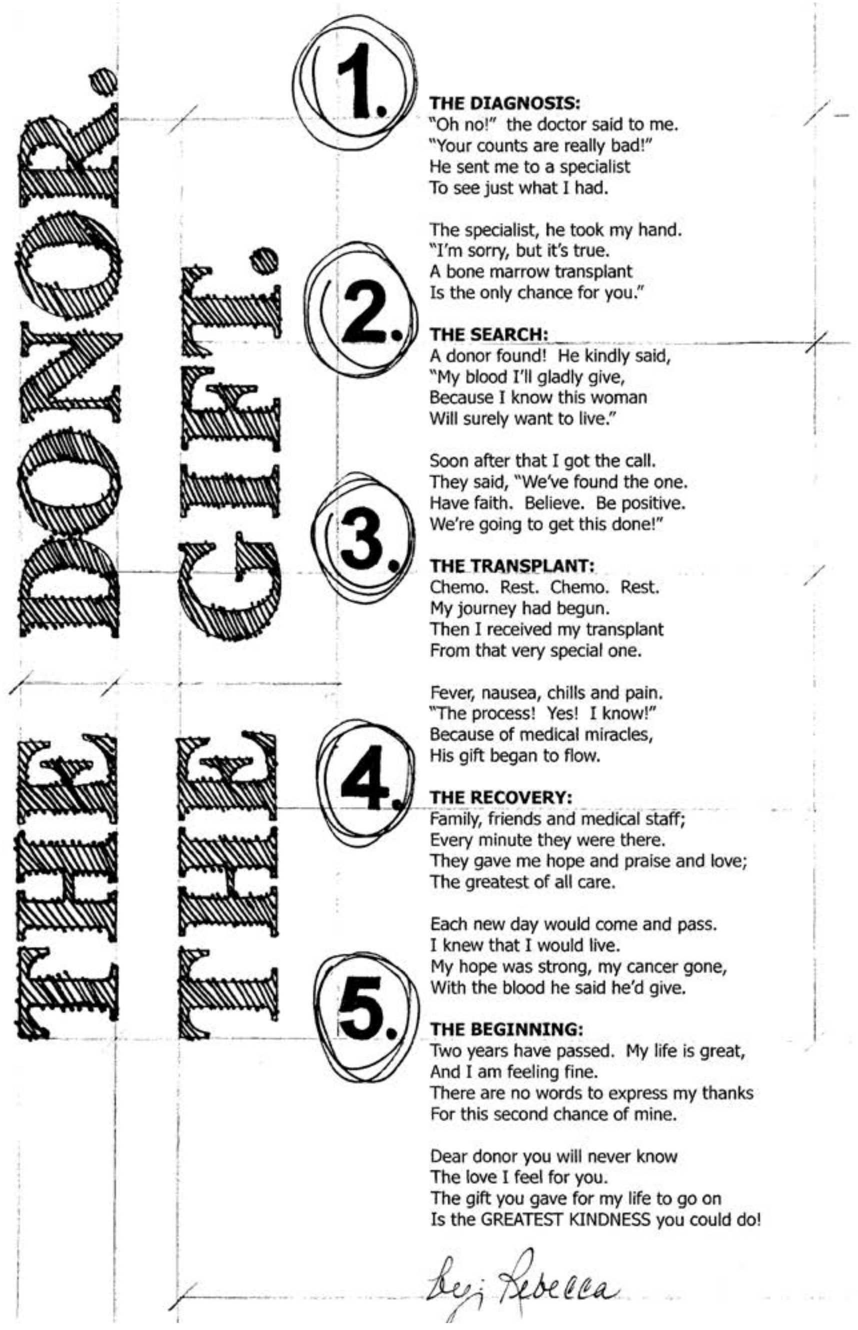
Always enough

Cancer has given us perspective. All too often we say, "There's not enough money to go on vacation. There's not enough time to call my friend." Surviving cancer, and a bone marrow transplant, is a wake-up call. It's a reminder to find the money and to make the time, because those opportunities are too precious to pass up. So we're striking "not enough" from our vocabulary.

The number 8 is good luck because in Chinese the word sounds like the word for prosperity. An anonymous donor unselfishly gave 8.8 million blood stem cells that have saved my husband's life. Now is not the time to dwell on what has been or what could be; we have decided to focus instead on the abundance we have been granted.

The donor the gift

—By Rebecca, transplant recipient



THE DONOR.
THE GIFT.

1.
THE DIAGNOSIS:
"Oh no!" the doctor said to me.
"Your counts are really bad!"
He sent me to a specialist
To see just what I had.

The specialist, he took my hand.
"I'm sorry, but it's true.
A bone marrow transplant
Is the only chance for you."

2.
THE SEARCH:
A donor found! He kindly said,
"My blood I'll gladly give,
Because I know this woman
Will surely want to live."

Soon after that I got the call.
They said, "We've found the one.
Have faith. Believe. Be positive.
We're going to get this done!"

3.
THE TRANSPLANT:
Chemo. Rest. Chemo. Rest.
My journey had begun.
Then I received my transplant
From that very special one.

Fever, nausea, chills and pain.
"The process! Yes! I know!"
Because of medical miracles,
His gift began to flow.

4.
THE RECOVERY:
Family, friends and medical staff;
Every minute they were there.
They gave me hope and praise and love;
The greatest of all care.

Each new day would come and pass.
I knew that I would live.
My hope was strong, my cancer gone,
With the blood he said he'd give.

5.
THE BEGINNING:
Two years have passed. My life is great,
And I am feeling fine.
There are no words to express my thanks
For this second chance of mine.

Dear donor you will never know
The love I feel for you.
The gift you gave for my life to go on
Is the GREATEST KINDNESS you could do!

by; Rebecca

One of one

—By Dave, transplant recipient

I'm unique, but aren't we all? My BMT doctor calls me one of one, so I'll believe it. What makes me one of one?

My journey started in May 2012 with a rare cancer, histiocytic sarcoma. I had tumors inside my liver, spleen and the lymph cluster between those organs. I was told I lost the cancer lottery and given at best three months to live. At my worst one of the two tumors buried inside my liver grew to a whopping 17 centimeters. By the miraculous grace of God Almighty, the efforts of many inside and outside the medical community, and my faith family, I survived. Thankfully my own bone marrow wasn't cancerous and my blood stem cells were harvested to perform tandem autologous stem cell transplants in 2013. The transplants were spaced six months apart. The chemotherapy for both transplants were grueling, bringing my blood counts and immune system to zero.

I was encouraged by the love and support of my wife, my children and countless others to persevere. I BELIEVED I WOULD GET BETTER AND I DID! November of 2013 I was declared cancer free! I'm still in awe of the way everything was orchestrated. By using growth factors, harvesting my stem cells, storing the blood stem cells and ultimately reintroducing them back into my body I survived. Histiocytic sarcoma cancer, which at my disease progression, had not been previously survivable.

I began to write about my journey. With a background in construction, not writing, the task proved challenging. As I made my way through the process I came to the part of my story most difficult to put into words, a time filled with pain, anxiety and fear. As I recounted those experiences I began to physically feel familiar pains. Was I appropriating the manifestations of my previous battles? The pain could not be dismissed. I was experiencing deep bone and back pain, fevers and chills. In November of 2016, I was diagnosed with stage four B-cell non-Hodgkin's lymphoma, riddled throughout my bone marrow and lymphatic system.

I questioned "Why me?"

I was reminded of my beautiful mother-in-law, who had succumbed to leukemia in the same hospital six years earlier. She once said, "People want to know if I ever ask why me? I say why not me?" The picture of grace and dignity, I looked to the standard she set. I resolved to not complain or give up until the Lord takes me by the hand and says, "It's time."

I underwent chemotherapy and spinal chemotherapy requiring months in the hospital. With the strength of God, I was able to weather the storms of double vision, blood infections, a brain bleed and a platelet count of one. The cancer was sent into remission but my bone marrow was spent. I was unable to produce blood cells needed for survival without regular transfusions. My only hope for long term survival was an allogenic transplant.

Without a full blood sibling, the best related donor we could hope for was a 5 of 10 match. My BMT team sent my data to the bone marrow registry, NMDP®. We prayed and anxiously awaited news about an unrelated donor. A donor was found! A young man almost half my age who was not only a 10 of 10 match but also met two additional criteria! Praise God! An incredible match!! My transplant was scheduled for May.

Two days before transplant while undergoing chemotherapy conditioning, I contracted the paraflu virus. It was too late to postpone the transplant; the wheels were in motion. Complications followed. I developed deep vein thrombosis (DVTs), which traveled to my pulmonary artery causing a saddle embolism blocking over 85% of the blood flow to my lungs. An IVC filter was placed and a regimen of blood thinners prescribed. Then came the CMV virus and the excruciatingly painful BK virus. Yet through all of these complications our faith remained unwavering. God brought me this far for a reason!

My issues are continually resolving and closely monitored. Neuropathy affects my hands and feet. I live with a new normal. But yes, I live! In December after the results of a questionable bladder biopsy came back benign, I was once again declared cancer free!!

I reflect often on the sacrifice made by an unknown stranger. A young man who carved out time and gave a part of himself that I could no longer provide. I was a man who fixed and built things most of my life but I was unable to fix my bone marrow. By the grace of God, only my donor, an individual who is in his own right "One of One," could fix. With grateful tears I see the world afresh. I see my beautiful wife, children and grandchildren. I see the beauty of God's awesome creation and will hopefully one day look my donor in the eyes and express a gratitude that words alone could never say.

To my donor, the NMDP team, my BMT team and all the prayer warriors under the direction of God's mighty hand, **THANK YOU FOR SAVING MY LIFE!!** I hope I make you proud!

Gratefully,

Dave

My team of angels

—By Hollie, transplant recipient

My Journey with cancer started back on 03/31/2010 when I was first diagnosed with Hodgkin lymphoma. Since then my cancer has come back four different times and is now considered to be non-Hodgkin follicular lymphoma. I have had radiation, chemo, an autologous stem cell transplant (with my own cells) and an allogenic stem cell transplant (with a non-related donor). I am now over 182 days post-transplant.

I couldn't have made it through without my support system by my side. My boyfriend, my mom, my sons, sister, family, and friends. Everyone was there by my side through most of it. But my boyfriend and mom saw me through the worst days. And there were many. It's not an easy thing to go through for anyone, patient, family or friends. It's difficult to see a loved one go through something like this. I am grateful to have such an amazing group of people in my life to support me.

I am so grateful for my donor. A stranger that was willing to go through a procedure to give his blood stem cells to a stranger. It's amazing, he is my guardian angel. He was 100% of a match to me which also amazes me.

And my friends have become like family to my boyfriend and me. Sending cards, gifts, thoughts and prayers our way during these difficult times. This family has also helped us raise money over the past 3 years for LFR (Lymphoma Research Foundation) a foundation to help find a cure for lymphoma, and help patients and families touched by this horrible disease.

I am still fighting and will probably always be fighting my cancer but having all these people in my corner sure does help make it a little bit easier. Makes me want to fight that much harder.

Nurses dispense more than medicine

—By Jennifer, transplant recipient

Nurses. The lifeline of hospitals. Maybe we picture a women in a starched white uniform, a little cap resting gently on her hair, perhaps dispensing medicine. But this is not accurate. Not all nurses are women. Most do not come in a set uniform, but wear varied scrubs, designed to bring a smile to the children they serve. Some, as you will read, do not have hair to place a cap on. Nurses, though, dispense so much ....

They dispense medicines. I can't imagine how hard it must be to administer chemotherapy, knowing what it is going to do to the one you are giving it to. Yet, these nurses do it, always double and triple checking with other nurses dosing, medicine and patients, to try to eliminate human error.

They dispense empathy. Some shaved their heads, in support, raising money for childhood cancer while empathizing with the children they serve. I remember their lovely long hair. I was always sad to see their shaved heads, but I always felt special knowing that while I lost my hair, they had the love to voluntarily cut theirs.

They dispense care for the body. It's chemo. You throw up-A LOT. I've sat puking my guts out countless times, only to suddenly find a nurse behind me, with a wet towel, rubbing my back and speaking comfort until I'm done, then taking the dish from me. I was always amazed at how quickly a nurse would come when I was sick. It's like they have a 6th sense that they are needed ...

They dispense care for the spirit. They don't just care for patients physically, but also emotionally. One day I was alone and upset after a doctor left. My nurse appeared out of nowhere, and kindly spoke to me, and comforted me, even though I refused to say a word. Her gesture of kindness helped me through that long day. On bad days, nurses have spoken so many words of encouragement, on how well I had done, or how I was nearing the finish line.

They dispense laughter. They dress up, clown around, and do countless other things to bring a smile to a hurting ward. Laughter isn't a sound that usually echoes through the walls of oncology; but when it does, there's usually a nurse or two or three behind it!

They dispense love. Nobody fills the place of a mom. There are times when we need dads and brothers and sisters, but I think that when we are sick, we need the love of a mother most. However... my mom wasn't always with me. My nurses have so often filled that void, whether it has been physical or emotional support and help, or simply a little extra love.

They dispense kindness. Little gestures mean so much. My nighttime nurses worked to coordinate all my vital measurements, blood sugar readings, medicines, weights to be at the same time, so they could minimize when they woke me up. They worked their best to schedule everything so that I could maximize my sleep. They always worked as noiselessly as possible, to achieve their mission. I would never wake when they entered or exited; they only thing that would wake me was the taste as they flushed my line, or the pain when they pricked my finger. No matter when I asked, they would cheerfully change my sheets, or bring me a drink or snack, or fetch my sweater. Little gestures that make a difference.

They dispense encouragement. I ate a cracker. Cheering. I ate my pills. A hug. I only was toting half my IV pole. Congratulations from everyone I meet. The nurses were always cheering me on, no matter how big or small the milestone. They were always so genuinely excited, sometimes over seemingly insignificant details. I was discharged. Dancing, clapping, hugs and tears, a ruckus.

They dispense hope. Cancer is a tough thing to deal with. When you are in the midst of everything, it's really hard to see the light at the end of the tunnel, to imagine yourself healthy and well. Many of these nurses have been here for years, and have seen hundreds of patients. They have encouraged me and filled me with hope that one day it will be over.

It's not easy being a nurse – especially an oncology nurse. I've rarely seen them sit; usually they are constantly on their feet, as they rush to silence one beeping IV after another. There have been kids who simply scream to summon their nurse, but they always respond. They are always available. A simple press of a button would bring one to my side. Most work 12 hour shifts. They have to deal with incredible sadness, as not every patient will make it. They're in it for the long haul. I've come to realize that most of them regard it not as their occupation, but as their calling. Some have gone on to become certified oncology nurses, devoting their entire career to bringing hope and comfort to kids with cancer. My oncology nurses showed me so much love and kindness through my journey, and I'm indebted to each one.

I remember my very first visit to oncology. It was late in the evening, I was tired and hungry, and told I needed to be admitted. It was an emergency decision, and I was really scared. My nurse stayed well past her scheduled hours, sharing comfort, love, and kindness to my parents and me. She has never stopped being a tremendous support to me. She has often given me advice when I'm at a crossroad, hope when I'm lost, and love when I'm hurting. It was on Ceci's shoulder that I first cried about my relapse, and called to cry about grades, scans, and more. She has so often counseled me and loved me like her own daughter. I'm so blessed and proud to be able to call her my nurse!

Thank you to each of my wonderful nurses!!

> "My oncology nurses showed me so much love and kindness through my journey, and I'm indebted to each one."
>
> — Jennifer, transplant recipient

Communal living, post-transplant

—By Craig, transplant recipient

When my myelodysplastic syndrome took a turn for the worse three years ago, my wife and I were faced with a decision: when, if ever, should I proceed with a stem cell transplant (SCT)? We sought advice from three specialists and got three different opinions about the urgency and/or advisability of an SCT, based on my age and the severity of my disease. The doctor who urged me to proceed without delay was the most convincing. I was now transfusion dependent, and whereas the outcome of an SCT was fraught with uncertainty, the option of waiting while pursuing other dubious treatments brought with it the certainty that I would continue to decline, further limiting any chance of extending my life. With the decision made, I was introduced to the process of seeking a donor, for which I am immensely grateful to NMDP with its monumental database of potential donors. The other looming decision was where to have the procedure done. Fortunately, on this topic all the doctors were in agreement: the status and success rate of the hospital was of less importance than the support I would receive during my recovery. In short, they advised, go where I have family.

On this basis we chose a hospital. Here we have extended family consisting of my brother and his wife (an emergency room doctor) and my wife's sister and her husband. Fortuitously, my youngest daughter, after fourteen years living in Scotland, had just arrived in the U.S. to pursue graduate work, and had been accepted at the university. She and her family needed a place to live, and so did we. The idea of combining our resources and living communally in a single home had instant appeal to all of us. We rented a modest-sized three bedroom home in a nice area between the hospital and the university. Within easy walking distance was a city park with a playground, and unknown to us until later, a fitness center.

We had no illusions about the potential challenges of our living situation. I would be recovering from one of the most difficult medical procedures one can experience. My wife was on the threshold of a long and demanding stint as my caregiver. My daughter's husband is British, and would be adjusting from life in a modest-sized Scottish town to the role of stay-at-home dad in a large American metropolis, while my daughter would be pursuing full time graduate studies at the university. Their children would be at home for several months until it was appropriate to put them in daycare.

The most difficult time, not surprisingly, was the first couple of months after I came home from the hospital. My recovery was slower than average; for a period of several weeks I was without appetite and what little I ate was mostly the result of continual exhortations from my wife. I was listless and reluctant to engage in the most rudimentary exercise, such as walking around the block, I was depressed and socialized very little, spending most of my waking hours curled up on the cough reading from a book or tablet. Contrary to the scenario I had envision, I had little interaction with my grandchildren. Although I was grateful for everyone's efforts to make me comfortable and cheer me up, I am sure I could have done more to express my gratitude. Now I realize, more so than I was capable of at the time, what challenges my needs, not mention my slothful presence in the household, presented to my housemates, most of all my wife and caregiver.

One of the greatest challenges was accommodating a household with five different diets and schedules. My son-in-law was vegan and gluten free; one grandchild was deathly allergic to dairy, nuts, eggs, and soy; the other was terribly picky, and I was for all purposes a non-eater. Almost all the foods I had loved in the past were tasteless if not revolting. My wife went to great lengths to provide me with nutritious food that I could get down, chiefly bone broth soups, custards, and milkshakes. The difficulties in preparing meals to fulfill all these requirements were compounded by having to negotiate a very small kitchen with a not-so-large refrigerator. With three or four people involved in various stages of food preparation, serving, and cleanup, the kitchen was a potential disaster zone!

Living conditions improved markedly when I became more ambulatory and could take advantage of the fitness equipment at the nearby recreation center. At the beginning I had to be driven the three blocks to the center, and could only work out for short periods without becoming exhausted. Over time my strength built up and five months after my transplant I was exercising rigorously. Until much later, this was the one thing that helped me feel better.

Over time, our mutual living situation became easier. The children began spending some time in day care, and my wife and I were able to get out for the house for short excursions. After three months we had all agreed to renew the experiment for another three, and at six months we agreed to three more. The experience, in retrospect, was one whose rewards ultimately far outweighed the difficulties. Credit is due to all of us for seeing this through, but especially my wife, whose responsibilities exceeded others' tenfold. My daughter is the soul of equanimity and her comforting presence, not to mention a great deal of domestic duty while maintaining straight A's in her course work, was huge in my recovery. I must also give credit to our cat, whom I could count on to sprawl on my lap when others were probably at their wit's end wondering what they could do for me, which often was nothing.

> "The idea of combining our resources and living communally in a single home had instant appeal to all of us."
>
> — Craig, transplant recipient

Welcome, with love

—By Keri, transplant recipient

On November 28, 2014, my life changed forever. After a diagnosis of acute lymphoblastic leukemia only four months before, I underwent a life-saving blood stem cell transplant, in an attempt to kill this cancer once and for all. I checked into a beautiful (for a hospital) room overlooking the Mississippi one week earlier to start the process of essentially killing my immune system, in preparation to receive another.

The lovely doctors and nurses gave me what they called an atomic bomb of chemotherapy and two-a-day rounds of total body radiation. The day of my transplant was honestly uneventful. The effects of the chemo and radiation hadn't fully hit yet, so I was feeling ok and very excited to move on to this next phase of treatment. A Buddhist nun came to my room and performed a blessing ceremony with my husband and me. My whole family was with me when the new cells arrived. My donor cells were from a single umbilical cord—a boy born in 2012. A nurse came to get everything set up, but the set up wasn't much, and the bag of cells smaller than I'd imagined. We joked beforehand about how the cells would taste like cream corn because of the preservative (they did) and how I could never be caught for previous crimes because my DNA, my blood type, my whole immune system will eventually, hopefully, change into my wonderful donor. She hung the small bag and let gravity do its work, while I nervously hoped for the best and tried to welcome this new part of me with love.

Right as the transplant started, I looked out the window in a moment of profound gratitude – for my donor, for my family, for this amazing opportunity that not all people get, and in that moment a huge bald eagle flew by my window, only about 30 feet out. What an auspicious sign! I turned to my husband and we looked at each other in amazement. I knew in that moment that everything was going to be alright.

I wish

—By Mitchell, transplant recipient

I am writing from a hospital room, hooked up to a machine that delivers multiple chemo drugs into my veins. The dosage is high enough to kill my leukemia cells before they kill me. The problem is, that level of chemo also stops the "stem cells" in my bone marrow from supplying me with fresh blood cells. My blood counts will soon drop to near zero. This puts me into a non-survivable situation.

But I still expect to walk out of here in a few weeks. What will save me is an infusion of stem cells from an anonymous donor, somebody in a database who is a fortuitous ten-for-ten match with my cell type. This person has taken time out of his (or her) life to undergo repeated testing and get injected with medication to step up the production of his blood stem cells. By now my donor has spent a few hours hooked up to a machine that extracts the surplus blood stem cells, which will soon be couriered to my bedside—all to save the life of a person whose name he is not allowed to know.

I fervently wish I could tell my donor how much his contribution means to me. It is not likely he reads my blog. But other donors probably do, and their patients are as deeply thankful to their donors as I am to mine. Here in the hospital, patients talking about their donors almost always tear up in gratitude.

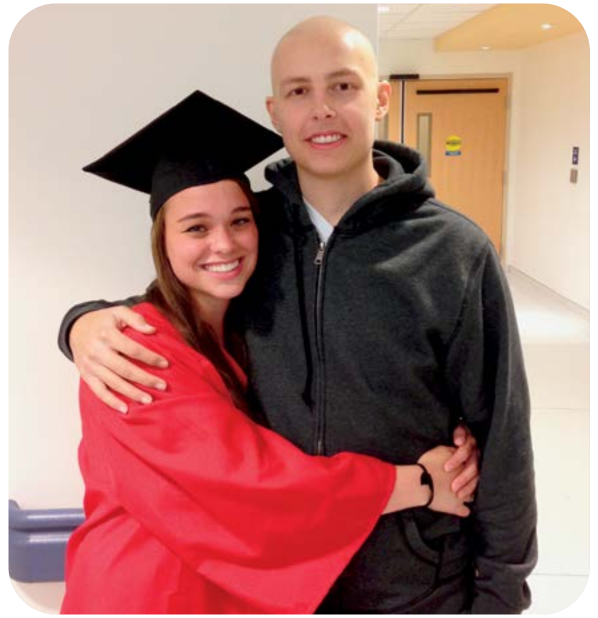
I am lucky; not every patient who needs a matching donor has one. Possibly you could be the donor who saves the life of a total stranger, with no compensation except the inconvenience. There can be no greater gift one human can give to another. To my own donor, whoever and wherever he is: I'll never be able to pay you back, but I sure wish I could try.

International donor

—By Michael, transplant recipient

Beating cancer

—By Alex, transplant recipient



Life can get hard,
It'll be unfair and tough.
But remember that without peanut butter,
You wouldn't appreciate the fluff.

Back in high school,
Before graduation,
I was hit with some news
That left me wishing for vacation.

My doctors told me
That I had a disease.
Leukemia; it could be beat,
But not with much ease.

Now that's in the past,
It was all said and done.
I had won the fight,
And was back to the fun.

But life got worse
At the end of 2015.
And I thought to myself,
"Man, life can be mean."
I was told I had relapsed.

Once again I had cancer.
I couldn't respond,
I didn't know how to answer.

All I could say was:
"Alright let's do this."
And again I'd fight;
A survivor never loses.

I decided to train
For my upcoming battle,
Because this fight would be different;
I couldn't hop on the same saddle.

I had family with me,
Supporting me without pause.

And there were lots of friends too,
Doing their part for the cause.

I learned what was important,
And who was truly there for me.
I learned what I was made of,
And what I can be.
And along my journey,

I picked up a few scars.
But I also got to meet,
A ton of pro sports stars!

It wasn't just me,
That this challenge effected.
A common misconception,
That should be quickly corrected.

My girlfriend, my Gram---Gram,
My siblings and parents;

They all helped so much,
They were all so caring.

They helped me keep up my weight,
Made me exercise too.

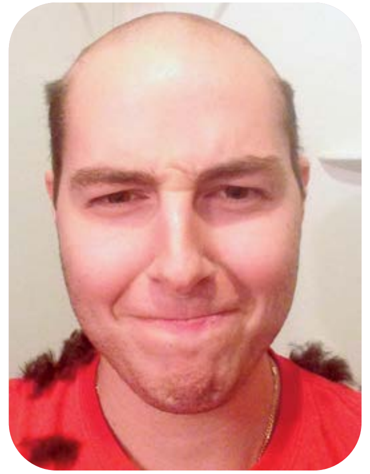
They even got me through c-diff,
With all my bloody poo.

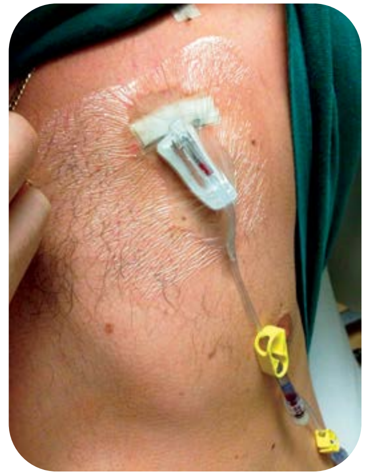
Impossible to forget,
Were the doctors and nurses.

To describe all that they did,
Would take endless verses.

And all those around me,
Reaching out helping hands.
People I didn't even know,
Being such supportive fans.

I think of all that I have,
And for that I thank God.
My family, my new marrow,
And a kind German woman abroad!





How I found happiness

—ByJoyce, transplant recipient

My life—oldest of seven children, good parents, and great home life. Married my high school sweet heart, graduated from college with a degree as a Home Economist, had a job I loved as a high school teacher, gave birth to two wonderful children a boy and a girl, seemed like I had it all.

I was proceeding through life and most things were going as I planned. I was happy. Although many times I wondered what people felt like when they said, "I am so happy." I knew I was satisfied with life but there was no exhilarating emotional sensation to happiness as I imagined it would be when I was growing up.

When I was 40 life was interrupted—a stroke and two heart episodes. What was happening? No one had any answers. I recovered and was later diagnosed with essential thrombocytosis. Had a wonderful next 20 years until I was 60 with no real sign that essential thrombocytosis was affecting my life. My doctor 20 years later told me that they now know that the strokes and heart episodes were the disease starting to present itself.

In the year 2015 my daughter and I were planning her wedding, a nice affair in a field by the ocean in August in Maine. We made most of the decorations and were decorating for the ceremony when I felt I did not have the usual energy. Shortly after the wedding a new school year began. The first day of school I sat at my desk and my body said, "no more" I could not function. I was admitted to the hospital and received 12 pints of blood. I was diagnosed with myelofibrosis. Little did I realize at the time that this disease would end my 42 year teaching career, my life as a very active person, and a wife and mother that my children and husband thought you couldn't keep down.

I survived the next four months by having transfusions. It was discovered that I had the JAK 2 gene. The whole world was turned up-side down. I felt sorry for myself. Why me? I did everything I was expected to do in the life from being the best child, wife, mother, and educator I could be. I didn't drink to excess, do drugs, or mistreat my body in any way. I was mad like I had never experienced mad before. This wasn't fair!

One day as I sat on the front porch of my home on a fall day in 2015 waiting and hoping for a match I suddenly started to really hear the wind, watch the birds fly, and the trees swing. I was happy, truly happy in a way I had never been before. I had discovered what feeling happy really was. I had been so busy with life and trying to be perfect in every way for all people in my life I had never stopped to appreciate the world around me. I began to think about other people I knew that were worse off than myself. I then thought "why not me" in this journey of life.

In December of 2015 I was blessed with a match through NMDP. A special young man was willing to donate. He was an 8 out of a 10 match. Unexpectedly I was at the hospital ready to have a transplant and surrounded by my supportive husband and children. When I was entering the building to check in an older man with twinkling eyes was being discharged as his eyes danced and he smiled he gave me the Thumbs-Up and I knew I would be OK whatever way things went. As I was having the transplant my daughter, who was pregnant, and her husband asked if they could name their daughter after me. Through the daze I was in I could hear what they were saying. It gave me the fight to go on as did the support of my son, his fiancé, my husband, and family. I gave my cares and worries up to God and asked him to take care of my husband and children.

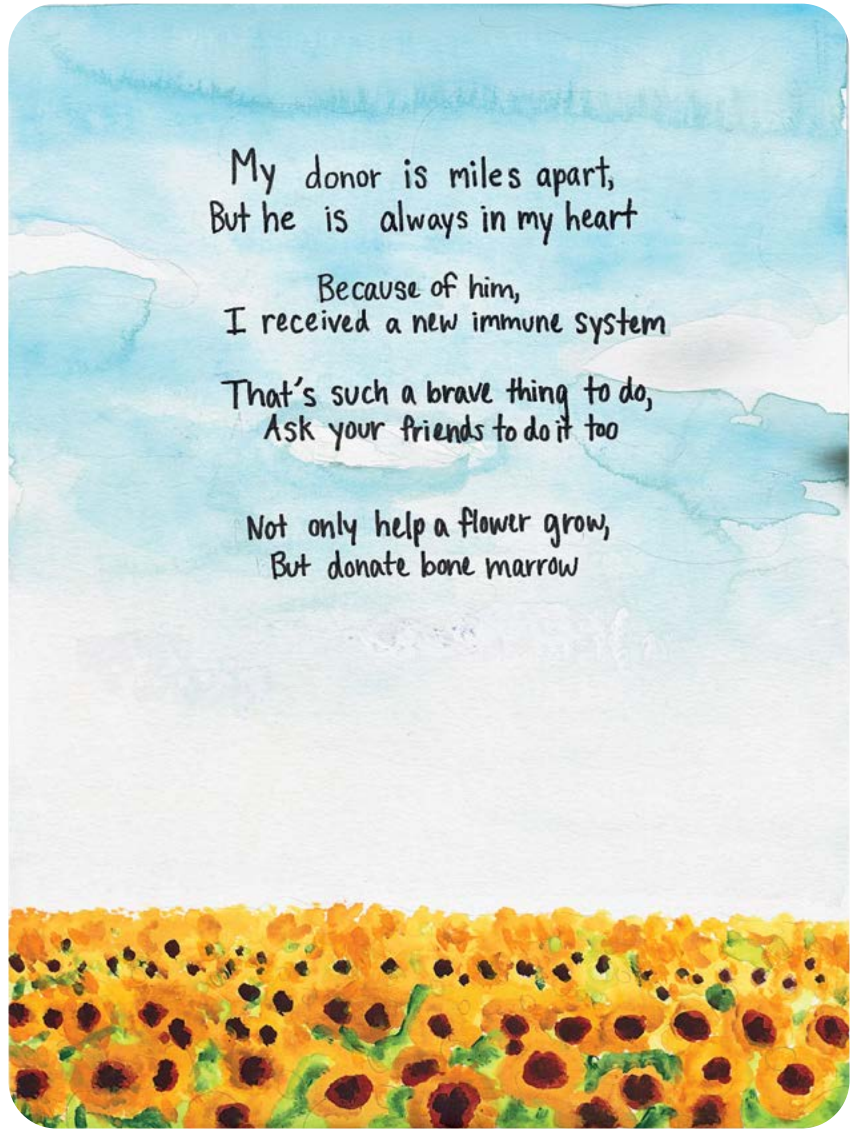
As the days in the hospital went on I watched the counts in my blood go up and my hopes that I would survive and my will to fight improved. As I slowly improved I began to realize what true happiness was—the smile of my son, the touch of my daughter's hand, the jokes my husband would make. When I left the hospital and on the drive home to Maine I saw everything in a new light. The beauty in life was all around me. The house I thought I would ever see again was still there, my family was with me, I was truly blessed and happy.

> "My donor will never realize how much he has done. He allowed me to see my first grandchild born, my son get married, and to enjoy all the daily positive things about life."

The three years that have followed have been full of my "new normal" as they call it with pains, setbacks, complications, pneumonia, ups and downs of all kinds. Through it all I have known true happiness. I now feel good most days, a little tired at times, some setbacks now and then, but I have a full life filled with love, acceptance, and peace of mind. I have graft-versus-host disease because of the allogenic transplant and that accounts for most of my discomforts. I have more good than bad days and for that I am thankful. My donor will never realize how much he has done. He allowed me to see my first grandchild born, my son get married, and to enjoy all the daily positive things about life. Wherever he is I hope his life is full and happy.

My favorite flower

—By Elise, transplant recipient



What a bone marrow donor can do

—By Deborah, transplant recipient

Transplant Day.
I include this picture because the day was not scary or painful. It was restful, and hopeful.

I received a bone marrow transplant from an unrelated donor in 2013. Throughout the early days of my physical and emotional odyssey with leukemia, one feeling came to the forefront: gratitude. I learned on the day of my diagnosis that the only way to save my life was through a bone marrow transplant. Why did I feel grateful? Because many cancer patients have a multitude of decisions to make for their treatment and care, all in the midst of the extreme emotional stress of a life-threatening diagnosis. My path to a cure was clear. There was only one way. I was grateful that I had so few decisions to make, and it helped me concentrate on staying as well as possible. Implicit in this is the hope that NMDP provides. Bone marrow transplant in so many cases is a cure, not just a treatment. Patients need only the ingredient, which is healthy cells and marrow from a donor. This is why the NMDP Registry is so vital.

Two years after my transplant I had the honor and pleasure of meeting my donor for the first time. There are few words to describe the intensity of the experience. It is acquiring new family. It is meeting your other self. The night of our meeting I told my donor, "Own your act of human care and kindness, and keep it in your thoughts throughout your life. When you are having a bad day say to yourself, 'yes, but I saved someone's life'. When you are having a good day, say, 'yes, and I saved someone's life'. What I also keep in mind almost daily after five years of health, is that my donor could have said no, but did not. This is the foundation of my extreme gratitude to him. This also is what drives my perspective as I volunteer for NMDP. My donor did not say no, and I will not say no.

> "Two years after my transplant I had the honor and pleasure of meeting my donor for the first time. There are few words to describe the intensity of the experience."

It is too simplistic to simply say donors save lives. They save all the components of those lives. For me, I am here to support my son through college and see what he becomes. My donor saved my mind as well as my body, so I can think, read, work, and contribute. Thank you, NMDP.

A reason to go on

—By Laila, transplant recipient

I never dreamed that I would ever need a BMT after my first go round with leukemia. After my first diagnosis in 2006, I had no sign of the disease for almost 9 years. Then, in spring of 2015 during my second trimester of pregnancy, I found out the leukemia had returned! After months of treatment, it was decided that my best chance at survival was a BMT after the baby was born.

I cried my eyes out. It wasn't anything I was prepared to do. Never mind having to leave my newborn son. My team was very supportive and even allowed for my son to visit me while in the hospital. He was my reason for soldiering on. Every day I was in the hospital was one day closer to being home with him, my husband and our pets.

Once home, I thought I'd be back to normal within a few months. I was pretty healthy before the transplant, so I figured I had that on my side. Actually, recovery took much longer than I thought. About 2 years. But once I started to feel like myself again, I felt the chains drop off of me. I felt like I could get myself back again. But eventually, I realized that I may never be myself again.

Cancer and a BMT changes a person. Both physically and mentally. It took me a while to come to terms with that.

It's not an easy recovery. Some have it better than others. But it does help a person realize what's really important in life. Some things just aren't so important anymore and some things are so much more important. Like quality time with your family, helping others, eating well, exercise, laughing etc.

I feel lucky today. Having to have a BMT was terrifying for me, sometimes infuriating. But, I am still here to talk about it and with my 2.5 year old amazing son. He brings me more joy than I ever thought possible. He is a miracle in itself, but that's another story. I have never been this happy in my life. I have a team of doctors and a BMT to thank for that. I believe as time passes I may feel other things or the memory will fade (hopefully), but I will always be grateful for the opportunity it gave me to survive.

> "My team was very supportive and even allowed for my son to visit me while in the hospital. He was my reason for soldiering on."
>
> — Laila, transplant recipient

It’s a good question

— By Janie, transplant recipient

> “About 90 days later, my hematologist called to give us the news we’d prayed for: My blood cells were 100% Jack’s.”
>
> — Janie, transplant recipient

If you could volunteer for a safe, relatively painless medical procedure involving a few big needles and some small residual aches, an action that could save another person’s life, why wouldn’t you?

It’s a question Jack asked himself when as a college freshman he pondered registering as a donor for NMDP while pledging to his university fraternity.

Along with other fraternity brothers, Jack signed up. The odds were slim he’d be called on to donate his blood stem cells—only 1 person in 430 is a match.

But Jack got the call from NMDP in March 2016. A hospital was looking for the perfect match for a woman with acute myeloid leukemia (AML), and he was among nine potential donors. Was he ready?

He was. So was I.

A punch in the gut

When I was diagnosed in February 2016 with AML, one of the toughest strains of blood cancer, I thought it was a cruel joke. Or some mistake.

I was the one who ate salad every day for lunch and eschewed soda, diet or otherwise. I could count on one hand the number of times I’d been hospitalized—for my birth, my tonsillectomy and the births of our three children. I was rarely ill.

Until I was, sidelined with a virus that felt different and hit hard, first at Christmas and returning with a vengeance—with a screaming sore stomach—for Valentine’s Day. A trip to the ER showed I was nearly depleted of white blood cells because of the leukemia. Two days later, a hematologist who couldn’t tell me where, when and how I got the disease, reassured my husband and me that 1) Our sons were at no greater risk for contracting it, and 2) It was curable. Other certainties: I’d start the first of several rounds of chemotherapy days later, and I’d need a bone marrow transplant.

When my two older sisters were ruled out as matches for me, the hospital’s stellar bone marrow transplant team accessed NMDP. Within a month, Jack was found.

How he did it

Jack’s mom, Jennifer, remembers getting word that her only child was a go.

“In college, you hope your kids will seek out activities that will help them grow as a person,” Jennifer said. “When Jack called to say he was a match for a patient and that he was excited at the prospect of perhaps saving a life, I could not have been more proud.”

Jack wasn’t fond of needles, but that didn’t stop him from having the requisite blood work to verify his good health and several injections to increase his blood-forming cells or blood stem cells.

He then visited his local blood center. For four hours, he sat watching ESPN’s SportsCenter while his blood was withdrawn with a big needle in one arm, passed through a machine that collected only the blood-forming cells, and returned through a big needle in his other arm.

Alongside him was Jennifer who has since joined the NMDP Registry.

“My mom is the most compassionate person I’ve ever met. I’ve learned how to be more compassionate from her,” Jack said. “If this was to happen to my mom, I’d be devastated. But I’d want to know that someone was there who was willing and able to save her life.”

His cells were transported to me, and we greeted it as Magenta Polenta, the victorious name in a contest my husband and sons—all SportsCenter fans—held. I was 60 at the time, Jack was 19.

By then I’d already had four rounds of chemotherapy, a handful of bone marrow biopsies and lumbar punctures and considerable side effects. About 90 days later, my hematologist called to give us the news we’d prayed for: My blood cells were 100 percent Jack’s.

Moving ahead, one day at a time

NMDP protects the privacy of patients and donors for one year following transplant, and the parties may only learn about each other if both agree in writing. We did.

On July 23, 2017, I opened this email:

> Hi Jane,
>
> My name’s Jack, and I just recently found out you’re the person I donated to through NMDP. I just wanted to check in and see how you’re doing. Feel free to give me a call if you want, my number is …
>
> Best Wishes,
>
> *Jack*

We spoke on the phone the next day. Since then, our sons have signed up for NMDP and have inspired others to do the same.

In May, Jack will graduate from the university. He plans to pursue law school. Seven days later I’ll celebrate my second transplant anniversary, a second chance at life, thanks to God, my family, my medical team, Jack and NMDP.

Audrey, wife and caregiver to George, transplant recipient

CHAPTER FIVE:

Caregivers

Dear MDS

(myelodysplastic syndrome),

—By Audrey, transplant caregiver

You came into our lives and changed everything.

We never wanted to know what myelodysplastic syndrome was or to learn what you were doing to George's cells and platelets and blasts.

We never wanted to have to come up with ways to make chemotherapy infusions fun while we battled you or to worry if our insurance would cover all "this."

At no time would we have thought to worry if there might be a donor somewhere in the world willing to save George's life!

We never imagined we would need to learn about bone marrow transplants and special diets and making our home the most germ-free home north of Boston.

We never wanted to learn to fear your consequence... GVHD and to have to research clinical trials into the wee hours of the morning.

And we never wanted to know our way around the hospital blindfolded or to have connected with the most brilliant, compassionate and devoted team of doctors, nurses, technicians (and parking attendants anywhere)! Though I am so very grateful for every single one of them.

But get acquainted we did. Until George's diagnosis of MDS, he and I were a formidable team of two. The marriage vows say: "For better or for worse, for richer or for poorer, and in sickness and in health." However, we were smart enough to know you don't get to choose. We had put our vows to the test and had come through a stronger and more resilient couple.

Then you, MDS, came into our relationship and we became a three-some. Everything was about to change. You became the captain of our lives. You steered our ship, and we had no choice as to where it would end. This was our journey and we were in this together.

I've heard that if you've grown from an unpleasant situation then you can be grateful it happened. There's no way I will ever be grateful for that diagnosis. No way I can be thankful for your intrusion in our lives. Yet MDS, as we fought your existence, you transformed me. You opened my heart and my eyes to things I never would have experienced or seen if you hadn't forced yourself into our lives.

continued>

...continued

There were the cherished friendships in the most unlikely places ... during chemotherapy infusions, long hospital stays, and exhausting weekly appointments. Allies, also fighting you, with whom we shared life's highs and lows.

MDS you shaped me. You made me stronger, more patient for my husband and for my family. You wouldn't let me remain shy, wouldn't let me sit back and wait for things to happen. You made me fight and you would not let my fear win. MDS you needed to come into my life for me to be who I am.

> "You taught me to be thankful for things I once might have taken for granted..."

Having you in our lives forced us to rely on the generosity and compassion of others with the ultimate humanity coming from a stranger who consented to donate the "gift of life" to George. How amazing!

You taught me to be thankful for things I once might have taken for granted... family, friends, co-workers. How had I not realized what a valued gift they were before?

Though I fought with you MDS, I realize now that you were more than a horrid disease that came into our lives. You were, if I looked honestly, an opportunity. An opportunity that allowed me to be George's caregiver. I remember how hard that was, but being his caregiver was the most important thing I will ever do in my life. And more importantly it allowed me to show George how loved he was and that, despite everything I would be okay. Being a caregiver shaped who I was to become and gave me the strength I need now to live life.

So MDS, I don't want to write about you, and I will never forgive you, and you will never be a friend. I will not miss all the havoc, chaos and heartache you caused. But I also know I cannot change what has happened in my life and I need to make peace with you, for ultimately you let me give the very best of me to someone I loved.

In honor of George

Audrey was a caregiver for her husband, George, who received an unrelated transplant for myelodysplastic syndrome (MDS). He later passed away of heart failure due to GVHD complications. "Being a caregiver was the hardest thing I ever did, but it was also the best thing," Audrey said. "It proved to me that I could do anything. I never thought I'd be published. I thought, 'Oh my God, George would be so proud of me!' I wrote it for the two of us and because NMDP is part of our lives."

Caregiver Experience

—By Bonnie, transplant caregiver

Barry and I married in 1968. In July 2005, after 37 years of marriage, Barry was diagnosed with (CLL) chronic lymphocytic leukemia. Things started to move fast, with treatment decisions, health crises, two blood stem cell transplants, and a changing marriage—he the patient and I the caregiver.

Barry died Feb. 1, 2014, eight and a half years after his diagnosis. Not all of that time was difficult. We had many rich experiences and often a rewarding quality of life. We traveled to Turkey for our 40th anniversary and took a long-wished-for trip cross-country, visiting family and friends.

From the start, we both felt compelled to write about our experiences from our different points of view. Barry posted transplant stories on his website; I began to write mass emails to my large network of family and friends. I wrote to process what was happening, and to avoid painful phone conversations. It helped me cope.

In 2011, after his second transplant and my retirement, Barry suggested that we turn our writings—his journal entries, my emails, interspersed with narrative—into a book. After he died, I finished the (mostly completed) book and published Dancing with Cancer: Maladies and Miracles in Stem Cell Transplantland.

It was very challenging emotionally, but it has given me strength and I am pleased that I completed our project.

I am still in touch with Barry's angel (unrelated) donor. When he needed her second donation, she put off a pregnancy. She now has three healthy boys.

Some things I learned about caregiving

- No one knows the patient like you do, so it's important to communicate your observations to the doctors and nurses. You are a member of the team of experts. At the hospital, I found that you will get honest responses and lots of time and caring as long as you ask for it.
- Ask for what you need from health care professionals. What would make your life easier? Support groups? Informal links to other caregivers?

The hardest and most rewarding time in my marriage was caregiving for Barry. It was a time for a different kind of intimacy and love. I felt grateful and honored to be by his side and to be his fierce advocate and partner.

A mantra I learned and try to live by:

JUST THIS
DON'T KNOW
PRESENT MOMENT
ONLY MOMENT

Being a caregiver during my daughter's transplant

—By Anonymous, parent caregiver

In April 2017 my world changed.

My daughter, Mackenzie, was diagnosed with a rare and incurable disease.

Mackenzie and her doctor explored treatment options. Because her case was unprecedented, we were in uncharted territory. They discussed two options, each on the far end of the treatment spectrum. Option one was to do nothing and monitor the disease, acting if and when the status changed. Option two was to proceed with an aggressive "guns a blazing" approach with the hope of eradicating the disease. Mackenzie was legally an adult and made the decision, in concert with the specialist, for option two.

Perhaps it is worth mentioning what kind of person Mackenzie is, of course from a parent's point of view. She has always been mature beyond her years, responsible, and empathetic towards others. She beats to her own drum, has just a few close friends, and isn't swayed by the crowd. I so admire her strength to be herself.

Back to the story. With the decision made regarding the way forward, our next step was to mobilize the caregiver coverage and put the wheels in motion for the long list of items to do in preparation for the four-to-six-week treatment. Our objective was to assemble a team of caregivers that brought different skill sets and could be there for the duration. We were extraordinarily fortunate. My husband and I were both retired, and our son (Mackenzie's brother) had the summer off from college, so we immediately had a team of three. In addition, Mackenzie's aunt who is an oncology pharmacist, made arrangements to also join us for the duration of the treatment. So now our caregiver team of four was assembled. Next was to assign roles and responsibilities to each of us caregivers. It was clear that there was much to do, and so our thought was to organize the assignments around our strengths. Here's how it broke down, in general.

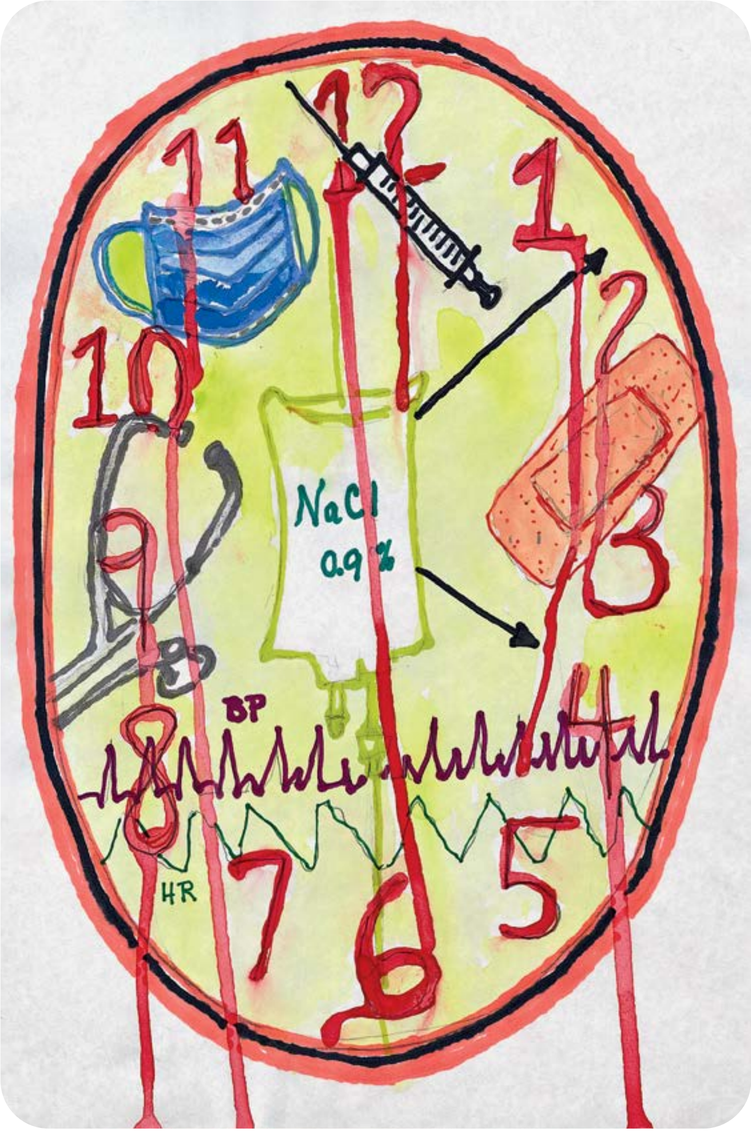
- My husband was in charge of room and transportation. We needed a place to stay for five for up to six weeks (we found a fantastic transplant-friendly house). We needed transportation and how best to get around during our stay (a combination of fly and drive so that we had a car).
- Mackenzie's aunt was in charge of administering all drugs, monitoring food and fluid intake, and taking Mackenzie's temperature throughout each day.
- Our son was our fitness coach. Knowing it was important for transplant patients to walk and exercise daily, he would walk steps with her and offer wonderful encouragement. In addition, he would remind us other caregivers regularly about the need for our own exercise to help alleviate the stress we all felt. Walks, whether around the neighborhood or in the halls of the hospital, went a long way. In addition, for a very small fee we were able to join a fitness club to get the sweat up.
- My role was administration and operations given my strong organizational skills. Insurance and all paperwork was my responsibility. In addition, I developed the list of items we needed for the rental house, such as food, sanitizing and laundry items, an air purifier, and all of the items suggested by the healthcare team for Mackenzie. I also thought about recipes to take, as well as items for the house (e.g., pictures, comforting items, aromatherapy items). Then, determine where and when best to acquire all of the items.

In hindsight, I think being so organized and having the luxury of a team of caregivers made the experience go pretty smoothly. Of course, there are always unforeseen bumps in the road. But we seemed to figure out the bumps as we went.

See page 42 to learn more about Mackenzie and "Mackenzie's Mission"

Time warp

—By Anna, parent caregiver



What is time?

Waiting for time to pass.

Waiting for blood counts to rise.

Waiting for procedures.

Time moves so slowly.

Waiting for complete healing.

Stuck in a time warp.

Wait, transport, wait!

—By Anonymous, transplant caregiver

Hands:

Just the reassuring hands of Mommy and Daddy. Nothing else needed to go to and fro.

Bike basket:

To transport my toys, and then my grownup tools consisting of two pocket folders, crayons, pencils, papers, and my jacket on warm afternoons following cold morning starts.

Backpack:

To transport my school books, the mandatory red jumpsuit (shorts, not pants!) for gym class that snapped up the front, pens, notes from friends, the single binder with subject tabs, a lunch bag… and report cards.

New, bigger backpack:

To transport thicker, heavier books, multiple 3-ring binders, a slide rule that was later replaced with a calculator, a small purse … and report cards.

Later, a worn out backpack with foreign literature and other books, a few spiral notebooks, some pens and a purse.

Purse:

No tools to transport for years. Just my purse to shove into my desk drawer because a big desktop computer stayed in my office. Then my purse morphed outside of office hours into a diaper bag or another backpack full of necessities for little girls.

Briefcase:

Evolution required transporting again. A desktop computer left in my office became a heavy "portable" laptop with cords; then it changed to lighter laptops, still with cords. Add in a gadget with ever-changing passwords for VPN access. Then a little Palm Pilot replaced the clumsy Franklin Calendar planner, then a cell phone replaced that. More and more passwords cluttering my memory, and some paper manuals or printouts. Briefcase no longer worked.

Backpack needed again:

To transport everything—but not to transport life.

Suddenly, no more reassuring hands, bike basket, backpack or briefcase.

Tote bag:

To transport my purse, jacket for cold rooms, water bottle, an apple for a snack, sometimes a packed lunch, and my list of questions and a pen/pad to take notes during time with the doctor.

AND a book to distract while **WAITING**….

…while **WAITING** for someone to change an IV bag,

…while **WAITING** to be called into the lab, exam room or infusion room.

…while **WAITING** for a procedure to be finished.

…while **WAITING** for test results.

Or, for pretending to read while watching him sleep, or pretending to read when he stares blankly into space.

But most importantly, my tote bag TRANSPORTS one to four pages of paper… usually three…the day's lab reports. Data. A printout of Numbers. For the Doctor, the Numbers are key for the required next step. For me, the Numbers are something I can see in an invisible world hidden inside of blood. These Numbers have no plot like a book … but I **TRANSPORT** the numbers home to plot them on an Excel file. I create a graph to show multiple days-months-years of labs. My graphs are something tangible to visualize the invisible. Data, more data. Patience, more patience.

As I **TRANSPORT and WAIT** with my tote, I remain hopeful that our doctor, staff and the stem cells of three donors have, and will, **TRANSPORT** us back to life. **WAIT!** It will happen.

It must.

Wait, Transport, Wait!

Our little warrior

—By Anonymous, parent caregiver

James' BMT journey of healing from severe combined immunodeficiency

Sawyer's journey

—By Anonymous, parent caregiver

It was February, we made an appointment to see my son's doctor. She took a strep test and some blood. We went home not thinking much about it. At about 6 p.m. the doctor told us to take him to nearest ER, now we are worried. I asked what the tests said, and she said just go. So, we initially went to the closest hospital. We were told that there was a good chance that he had leukemia. We were sent to a different hospital that night and we saw another doctor. Our son Sawyer was bleeding from his teeth at first. He was almost two years old. Our son spent the next three days there and they performed a bone marrow biopsy and determined it was aplastic anemia. Neither one of us knew what was going to happen to our child.

After that they recommended that he be admitted to the hospital, they gave him immune suppressive therapy. This condition he had was a blood disorder which usually happens to teens and older people. Him having this was a very rare case, like 1/million.

After some time, we felt that they were not doing the best they could to fix our son, so we decided to transfer him to a different hospital. They knew what to do right away. His neutrophils and platelets were extremely low. They started him on ATG and after some time we noticed that it wasn't working. They suggested to do a bone marrow transplant and after a short time we decided to do that. We were lucky to find a 9/9 donor. The donor was ready to do everything she needed to donate and was even willing to give actual bone marrow, which is much harder than just giving blood.

We almost lost our son many times. He had to have chemo but since he had no immune system already they gave him a very low dose. He was so thin. We celebrated his second birthday there at the hospital and even though he wasn't as happy as he could be, we were all together for him and we were hopeful for a recovery. In the next 2 weeks he would have the procedure done and then we would watch for any issues, which later turned out to be minimal.

It was very hard to watch our son go through all of this but after he got the transplant he became a normal kid again. He was in bed for 1 year and couldn't leave the room because if he was in contact with someone sick it would be very bad for him. Family would come all dressed in the outfit you have to wear so he won't get sick. We were surprised at the amount of help that my aunt gave. She helped us out so much. We were by his side every day and night for him.

Our son is now 3½ years old and even though he needs physical therapy and must take a bunch of medication he is our son again. He goes to the park and the library and plays with other kids. Even though it was a battle that I would've wanted to take, he was a trooper. We never gave up and had faith which was so hard. We could play games with him in his crib. He loved movies especially shows like the *Price is Right*.

He is loved and is happy and laughing all the time. I know that this might sound like a horrible thing to go through, but we made it out on the other side. After having gone through this experience, we believe that faith is key to survival. We accepted help when it was offered. We ferociously advocated for our son By asking questions about everything; procedures, medications, everything. We learned that staying in the moment was the best remedy for us, for our own well-being, when we were there for our son.

A letter to my daughter on the eve of your second birthday

—By Jennifer, parent caregiver

To My Baby Girl:

Happy (almost) birthday, baby! This time two years ago, your daddy and I (and a bunch of family members) were at the hospital waiting for my labor to progress so we could finally meet you. And, like usual, you decided to make things interesting and keep us (and the nurses) on our toes until the anxiety and anticipation was too much to handle and we decided for a cesarean. It wasn't the way your planner mommy planned for things to happen but you were perfect nonetheless. You were everything I imagined and more. That first year with you wasn't always easy as we were all learning (I appreciate you being patient with your daddy and I while we figured it all out) but it was such an amazing year and I learned so much from you. You taught me strength, sacrifice, self-acceptance, flexibility and the true meaning of life and love. I would often find myself thinking, "How did I get so lucky? Is this all just too good to be true? What would I do without this perfect little person in my life?" Becoming your mommy was the best thing to ever happen to me.

This time one year ago, I was watching you on the monitor as you slept, excited about your big birthday party with our closest family and friends without a care in the world. I went to bed thinking, "Is she going to like the cake we got her? Do you think we'll have time to squeeze in a nap before the party? What shoes should I wear to the party?" And, while that day will be one I will never forget, it pales in comparison to the days/weeks/months that followed. I remember holding you against my chest while you slept in the hospital, bruises all up and down your arms from the failed IV attempts needed to deliver the poisonous drugs that would ultimately save your life, thinking, "How did we get here? How can this possibly be happening? Is my baby going to be ok?" And again thinking, "What would I do without this perfect little person in my life?" Those were some dark times, Peanut. But through it all, you remained so strong, so graceful and so brave. You kept it together for all of us. This past year you taught me that life is, indeed, very short and can change in an instant. You taught me to live in the moment and never, ever take things for granted. You helped me feel emotions that I didn't know were even possible. You taught me that a hug makes everything a little better. And you taught me that even in the toughest of times, there's always something to smile about. You were amazing, baby, and I can't thank you enough for being you.

And now here we are, on the eve of your second birthday, and I'm once again watching my "baby" sleep, thinking to myself, "How did I get so lucky?" But this time I'm wondering, "What does this next year hold for us? What kind of toddler will you be? Will you remember any of those tough days?" There isn't a day that goes by that I don't look at you and think about what could have been but you made it, kiddo. You made it to your second birthday and I couldn't be more proud of you. Tomorrow is YOUR day. It's going to be a different kind of celebration this year than last but celebrate we will. I love you more than you could ever know, Peanut, and I look forward to SO many more birthdays with you.

Thanks for letting me be your momma.
Sweet dreams, my baby.

Jennifer

(Audrey's Mommy)

Audrey – BMT Recipient (February, 2016) for hemophagocytic lymphohistiocytosis (HLH)

Alone

—By Tami, parent caregiver

> "I wanted so desperately for him to not go through this alone."
>
> — Tami, parent caregiver

It was one week after my 15-year-old son's bone marrow transplant for aplastic anemia. He hadn't noticed until I offered to change his pillow case, that he was losing hair. He questioned me then, wondering what would happen if he grabbed his hair and pulled. His shock and disgust filled the room when he sat there with a handful of hair. It was an expected part of the process, but not a welcome one.

The following day, I helped him to the bathroom where he wanted to be by himself 'to pull out' the rest of his hair. I was standing on the other side of the door, feeling so helpless. All I could do was scream silently. I wanted so desperately for him to not go through this alone.

Finally, I knocked on the door and through the door, offered my help if I get a razor. He agreed.

When I opened the bathroom door, I found him sitting on a chair with his head down over the garbage can, his silent tears falling on the pile of hair. Only a few scattered patches of defiant hair clung to his scalp. Still with his head down, I shaved what remained. Not once did he raise his head up. I couldn't convince him that this was the easy part, that it's only hair, it's painless, and it will grow back. When his head was bare, he asked me to leave him again. He was still sitting with his head down over the garbage, alone with his grief and a stocking cap.

My son's hair loss was one aspect of the bone marrow transplant that he did not want me to share on his *CaringBridge* site. As far as most people knew, it never happened. It was generally not a topic for conversation, though my son did bring it up at times. That was usually when he found a longer hair on a blanket and he would playfully reprimand me, "Mom, I know this one isn't mine." People only saw my son, or pictures of him, with his stocking cap on. Not I, or even his father or three brothers ever saw him without his stocking cap while he was bald. It was something he only shared with the bathroom mirror.

79 days after I helped my son shave his head, he offered me the chance to see him again without his stocking cap. Careful not to seem too eager, I nonchalantly agreed. He took his stocking cap off and took my breath with it. He had the most beautiful, precious wisps of baby hair. And then he let me feel it …

My son was pushing 6 feet, 5 inches tall, and weighed 165 pounds before transplant. He lost about 30 pounds throughout the transplant process, but I hadn't seen the weight loss clearly until he took his stocking cap off for me that day. Reaching up to feel his new hair and seeing how gaunt his face was, I started screaming silently again. It was then I realized just how much he'd gone through, alone.

Being parent caregivers

—By Kris and Terry, parent caregivers

Our only son was diagnosed with AML in November of 2013, a very frightening day for all of us. He was 22 years old and this was his second cancer, having had testicular cancer at age 16. After being told he would need a blood stem cell transplant he began round 1 of 3 of chemo. Each subsequent round of chemo brought new challenges, different side effects from hair loss to skin burning, etc. Through it all he remained hopeful and prayerful.

Upon admission to the hospital to begin the pre-transplant chemo he was frightened and nervous. The pre-transplant chemo brought him down quickly with things like vomiting, mouth and throat sores, fatigue, sadness, being very despondent. He had absolutely no interest in anything whatsoever. It was very difficult, as parents, to watch our son go from being outgoing and witty to crawling within himself and not caring about anything or anyone. Because our son is an only child he did not have a match and was put on the donor list to find one. That alone was a very scary time hoping and praying that a match would be found and, indeed, a donor was found.

Once the transplant had taken place things were still tough. Spending a great deal of time in a hospital bed can really drag you down, it's as much of an adjustment on your mind as it is your body. We did everything we could think of to help bring him out of his depression, going for walks, playing board games, computer games, getting mail and gifts, having visitors. When all you want to do is feel better and be home it seems like that time will never come.

As parents we tried to stay positive and hopeful, and we were always prayerful. If we were having a difficult time ourselves keeping our emotions intact we'd leave the room and go for walks, get outside and try to regroup. We tag-teamed our care, dad being at home during the week so he could work and then switching off with me, mom, on the weekends when I'd come home for a couple of days. We lived about 2 hours from the hospital and we tried to make it so that our son always had someone there with a "fresh" head about them. After about 30 days in the hospital we moved to an apartment very close to the hospital transplant center and recovery continued.

After transplant there were still a lot of ups and downs, a lot of visits to the doctor, labs, various tests, etc., but it was so good not to be in a hospital room. It was still difficult to watch him have little appetite and have vomiting with everything he did eat, this took a long time to resolve and he lost a lot of weight.

Watching your child go through a transplant and all that goes with it is a tough walk but as parents you both want and need to be there. We wished so badly that we could take his place; that it was one of us going through this and not our son but, of course, we couldn't do that.

We learned a lot throughout the whole cancer/transplant process, we learned about white cells and T cells and platelets and blood counts, etc., but we also learned about graciousness and humility and absolute goodness and kindness from everyone including doctors, nurses, friends and family. Most of all, we relied on God to get us through some very difficult days and nights.

> "…we learned about graciousness, humility, absolute goodness and kindness from everyone…"

To anyone reading this and anticipating a transplant for someone you love we wish you only good and wonderful thoughts. Stay positive, stay strong!

Solar eclipse to sunny day

—By Joe, transplant caregiver

Total solar eclipses are memorable days for many people. They are fairly rare events in nature. In times past, people often viewed this event as a bad omen. My wife had her post bone marrow biopsy diagnosis of an aggressive case of multiple myeloma confirmed on the day of a total eclipse. She received this diagnosis from her caring oncologist in a calm and graceful manner. Sitting next to her, I was wondering what this diagnosis would bring us in the future.

My wife had been complaining about a pain in her lower back that persisted after a road trip to see relatives earlier that summer. She then contracted pneumonia which lead to blood tests and x-rays. It was the results of these tests that lead us to the oncology center. New words (and numbers) became part of our daily life: hemoglobin, platelets, white blood cells, plasma, M-spike, and light chains.

Her back pain became more severe which we learned was caused by her disease. She had great pain trying to do everyday things like getting out of bed or dressed. It reached the point that she needed a wheelchair. This was not something I had contemplated would happen so soon. She still maintained a great attitude. Fortunately, as the doctors predicted, the chemo regimen helped eased the pain and she progressed to a walker and later walked on her own.

She next faced the challenge of being dehydrated and having overall numbness. This lead to receiving intravenous fluids (and a "blood transfusion" or two along the way).

We have made numerous trips to the doctor/clinic/lab and saw that we were clearly not the only ones facing the challenges of cancer. Going into the treatment room for the first time was an eye-opening experience to see so many patients. It was a feeling of sadness mixed with strength and courage in the room. Angels directed the room as the nurses did their work.

As I learned my new role of "caregiver" I didn't know always what to say, but she said that my mere always "being there" was helpful. I put together a "victory plan" chart to help keep track of her various medicines. Also, under her "armchair" supervision, I began developing some basic cooking and homemaking skills (skills that she had perfected and performed for decades for our family).

Part of the new role involved handling her "media" information on what to share and how often with family and friends. Just as everyone's disease is different, the way you (and the patient's desires) handle the updates of this information may vary. I most often used text messages. When sharing my wife's story, I discovered that a couple individuals I knew had family members with multiple myeloma. It was helpful to hear their stories.

My wife is a sound reader of information about the disease. At first, I did not want to read about multiple myeloma but finally realized it was not going away and I needed to learn more for her and me. (I also later attended a conference by The Leukemia & Lymphoma Society, which was helpful and encouraging given the ongoing research with immunotherapy and CAR-T therapy as to a cancer that was estimated to have about 30,000 new cases in 2017 or 1.8% of all new cancers in the U.S.)

After a few "rounds" of her chemotherapy we prepared for her "blood stem cell transplant" (autologous) procedure (often called "bone marrow" transplant) at the cancer clinic. This involved insertion of PICC lines in her arm and neck (she later said it was an easier process than she had anticipated), the removal of blood stem cells from her blood, some heavy-duty chemo right before the transplant, and the injection of her stem cells. The process, including the blood stem cells being removed from a freezing container (cryopreserved) with its white mist was like science fiction. My dear wife through it all has handled the process with a calm and confident attitude.

She was able to come home immediately after the transplant. I was nervous about exposure to germs given her vulnerable immune system. She did fine for the first week but developed a fever (which is not unusual) and we went to the ER with our "VIP" card and she was immediately admitted to the cancer care unit. She was in the hospital for about a week. During this time, she started losing her hair. (My wife had already planned ahead, as usual, by ordering several cute caps and beanies).

She came back home and over time developed more energy to walk on the treadmill or go outside in our backyard (her favorite activity is gardening—which she could not do during her first 100 days post-transplant!)

My wife has now resumed her post-transplant chemo regimen. We go for her treatment (an injection) once a week. It is sometimes a bit daunting to realize this routine may always be the case, but it has become the "new normal." We are fortunate to have the encouraging services of great doctors, nurses, technicians and assistants.

We just received the results of her post-transplant biopsy and the transplant doctor said she has had a "very great response" and even "better than he had hoped." Our next milestone date will be a year after the transplant and then we'll evaluate further treatment options.

After receiving this report, we left the clinic and it was a sunny crisp March day. The challenges remain for us but so does the hope and confidence.

> "As I learned my new role of 'caregiver' I didn't know always what to say, but she said that my mere always 'being there' was helpful."
>
> — Joe, transplant caregiver

Relay for Life caregiver speech

—By Mary Ann, transplant caregiver

I want to share with you the speech that I wrote for our local Relay for Life event. It was a bit nerve-racking being in front of so many people delivering my speech, but I made it through.

Rosalyn Carter said it best: There are only four kinds of people in the world:

1. **Those who have been caregivers**
2. **Those who are currently caregivers**
3. **Those who will be caregivers**
4. **And those who will need caregivers**

This has stayed with me ever since the first time I saw it in one of the many books I scoured early on. I didn't set out to be a caregiver but when my husband was suddenly diagnosed with a life-threatening illness, for me it was a natural response to stay focused, take charge and start out with the mindset that we were not only going to get through this but we were going to beat this disease. I didn't hesitate, I just went into survival mode and instincts took over.

Having a loved one diagnosed with a life-threatening illness needless to say is terrifying; it's the scariest and hardest thing that my family has ever gone through. We needed all the help and support that we could get.

In February 2011, my husband Neil was diagnosed with the blood cancer, chronic myelogenous leukemia. He underwent a clinical trial. He would undergo 2 more chemo regimens while a massive search was underway to find an unrelated stem cell transplant donor as he was not fortunate enough to have a sibling or other family member match. Our prayers were once again answered when on that fateful day the call came that Neil had a match. In August 2011, Neil underwent his stem cell transplant and today he is in remission and doing very well.

My role as caregiver throughout our journey really started at diagnosis, continued through 3 chemo treatments, 3 hospitalizations and all the way through discharge from the transplant process; which required us to relocate for 3 months. Even today, I still have a few responsibilities but I am happy to report that it is minimal by comparison. The caregiver is asked to not only be the emotional support for the patient, but also be the backbone when times get really tough. A caregiver is charged with so many different responsibilities.

- To be a liaison between doctors and nurses, dissecting and trying to understand what's being said and asking questions to ensure that you understood their direction or explanation. I educated myself in Neil's disease so I would understand what we were up against. I came into this process with very little medical knowledge but by educating myself I was able to be Neil's voice.
- To be a nurse as I administered shots, IVs and dispensed a multitude of medication. This was one of the scariest parts as you are forced to quickly acquire expertise in being a healthcare provider, whether you are prepared or not.
- To be the encourager and believer of hope and faith which is so hard when there are so many dark and scary days ahead.
- To be the reporter as you try and find a way to disseminate information to keep your friends and loved ones updated with the latest because they cannot be there with you. Thankfully, technology has helped in this aspect. We had a webpage where I was able to post updates.
- To be the mother when you have to put your children aside for the first time in their lives, all the while hoping that they are being taken care of in your physical and emotional absence. This was one of the hardest parts for us, especially being away from them for 3 months.
- To sacrifice as you put all of your energy in taking care of your patient and nothing else matters, sometimes not even yourself. It is critical for the caregiver to take time away for themselves although it is the hardest thing to do. I had to remember that I had to take care of myself in order to be able to have the strength to take care of Neil.

From the beginning of our journey, Neil didn't want to read up on his disease. He told me that he relied on me to know what was needed as I read everything that was available to me. Although I was okay with that, I wondered as I continued to read that Neil really needed to be part of his recovery process. I tried to get him to read a couple of key books but he was not interested. He later told me that he would get through this with our strength and confidence and that reading all the worst that could happen was not what he wanted to dwell upon. It took me quite a while to realize that we both had our own jobs per se and that our jobs worked; mine was to learn everything that I could learn and he would just deal with whatever was presented to him, which he did very well throughout his entire ordeal.

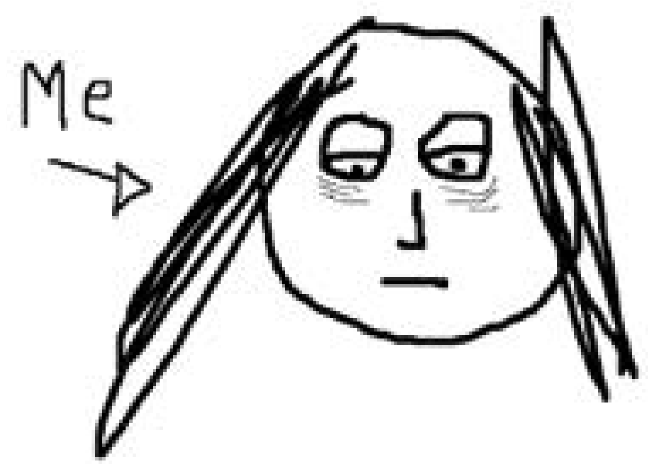
It has been a long road and one that has been an emotional rollercoaster in so many aspects. There are many decisions that must be made. Fighting and beating cancer takes teamwork and just like any team each player has an important role to play.

There are many community resources now available to caregivers. There is a wealth of educational, psychological and emotional support at arm's length. It is important to know that seeking help when needed is a sign of strength, not weakness, and from someone who has recently walked in those shoes I know the struggles as well as the rewards of the caregiver role in terms of personal growth, family cohesion, a new appreciation of priorities and for life itself.

Thank you for letting me share my perspective on the invaluable role of a caregiver with you.

Tired mom

—By Christina, parent caregiver



I drew this self-portrait on my computer after a few nights of my infant daughter receiving TPN. After mucositis made it difficult for her to eat, she needed to receive total parenteral nutrition (TPN) to supplement what little food she was eating. The TPN was thick in the IV tubes and set off alarms and needed to be adjusted every 20 minutes or so. No one got sleep those nights.

Everything

—By Deborah, parent caregiver

I want to remember everything.

How I sat in the bright orange chair
and gazed at you.
My love stripped down to a laser beam
of light.

How I would wake up early,
Tip-toeing past you on my way to
morning coffee,
each time shocked anew
by the tangle of IV lines
that lay heavy on your bony chest.
I want to remember
all the times you looked across the room
and through your pain, smiled at me.
A flood of light bursting through
the wdarkness.

The doctors, with their hushed voices
and muffled steps,
who never wanted to carry bad news
through the door,
but nevertheless did.
And the way their faces sprung open
when the news was good,
even if only just a little.

I want to remember
the magnificent container ships,
stacked with brightly colored boxes,
inching their way across the
San Francisco Bay,
reminding me that there were things
outside our window that needed to
be carried.

How one thousand times a day
I cleaned the nooks and crannies
of your IV pole with a potent disinfectant.
A mother's ache to do something
when nothing can be done.

And the way you slept, still as the moon,
while bone marrow from
your matching angel in Australia
flowed through a thin tube into your
waiting veins.
Hope and fear collided,
folding into one.
I wished for one thing—
Give us this. Give us your life.

I want to remember
the silly dance you did in bed, as you sang,
"My counts are coming up,"
the day we learned your new cells
were starting to set up house
deep inside your bones.

I want to remember every moment
that pulled us forward
and brought us to this one,
where you are alive and thriving—
a teenage boy with an unmade bed
and too much homework.

And most of all,
I want to remember that we are here.

Barbeque, interrupted

—By Deborah, parent caregiver

Jack, transplant recipient, with Deborah, his mom and caregiver

My husband is flipping
chicken thighs on the barbeque.
He doesn't know yet.

Inside, our son is learning
"Staying Alive" on the piano.
The song sputters along like
a rickety old cartoon truck.

The doctor's words are
spare and piercing.
I catch only bits and pieces.
Already, my brain has shattered.

"You need to get your son to
the hospital, fast."
"It's probably cancer."

Outside, a universe away,
my husband whistles
through a cloud of smoke,
safe in a world of burning chicken.

I burst through his smoky bubble,
and everything falls away
except the pinpoint of this
broken moment.

I toss PJ's, toothbrushes,
a beloved stuffy
into a yellow overnight bag.
(Is this what people bring on
sleepovers with cancer?)

Outside, dusk's muted sky teases us
with a last magnificent taste of
the ordinary.
We load ourselves into the car
and race toward the unknown world.

From the back seat,
still tethered to the everyday,
our son asks,
"What about dinner?"

Also see pages 22–24
for more from this family

Take care of Yourself

—By Allison, transplant caregiver

"Don't forget to take care of yourself,"
they say,
looking pityingly into my dark circle-ringed eyes.

I see their
Concern
Sincerity
Worry.

But I wonder,
Do they think
it was a reminder I needed?

That it was
lack of memory
that has caused me to spend the last
seventeen days
sitting
by his bedside
at the hospital
watching, waiting, worrying
eating cafeteria food, drinking cafeteria coffee

going home only to
sleep and shower
and even then,
worried throughout that I am missing something
and/or
being missed?

"Oh yes!"
(I might say.)

"Self-care!"
(I slap my forehead with sudden remembrance.)

"You know, I had the feeling I was forgetting something!"

(I shake my head, exasperatedly.)
"Silly me."
(bashful grin)

"Thanks for the reminder. What would I do without you?"

I know that these folks are brimming with
Concern
Sincerity
Worry.

I know that they mean well.

AND

I know that my self-care is

so

far

down

the list

that its letters are
unable to be seen.

I've heard about the oxygen masks.

"If you don't put on your own oxygen mask first, you won't be able to help your husband with his."
they say, complete with knowing looks and finger wags.

AND

The store where they sell oxygen masks for caregivers is on the other side of the world.

To get to this store, heaven and earth must first be moved.

For they stand in the path
Between here and there.

To move heaven and earth, one needs
Energy
Stamina
Grit.

Without my oxygen mask, I have none.

Perhaps you see the problem.

Does a teacher leave, mid-spelling test, walking out of the classroom to leave 23 first graders behind, to take a nap?

Does a chef put down her knife in the heart of the dinner rush, leaving to get a massage and a Frappuccino?

Why then am I expected to, commanded to, leave my watch, my position?

It is unthinkable to leave the children or the hungry customers

and yet
I am told to
leave my husband.

"Go to the store where they sell oxygen masks!"
they say.

"You need it!"
they say.

They're quite convincing
and also
I want them to leave me alone.

And so, I go.

I pull myself away from my post, from my love.

I move heaven and earth to get to the store.

I buy a mask with a gift card someone has pushed into my hand.

I put the mask on

and

I inhale.

The air feels amazing! Life-giving! Fresh! I realize that I haven't actually fully inhaled or exhaled in weeks! And now it's all I want to do! I want to breathe this fresh, clean, hospital-free air…the hospital where my husband is lying…the husband who has no choice but to be there…who cannot decide to "take a break,"…for whom the oxygen mask store is too far for him to travel.

I run.
Back to the hospital.
I take my mask with me.
After all, I've already paid for it

and

I am hoping to hold onto its effects even as I cross back over
heaven and earth.

But by the time I reach the hospital
I realize that I have lost the mask
along the way.

Somewhere between the store and this hospital room,

I dropped it.

I glance behind me, but it is nowhere to be seen.

Which makes me wonder as I take my familiar place once again at the bedside:
Did that happen?
Did I actually leave?

But then I see the doctors' notes from visits I missed,

Catching me up on test results, procedures scheduled, plans made.

I see the look of relief on my beloved's face,

As if he's been holding his breath the entire time I was gone,
worried I wouldn't return.

I feel the extra fatigue from the trip I've just endured
and I realize

it happened.

I "took care of myself."

And I wonder,
Why didn't that work for me?
Why don't I feel so much better now?

Oh, that's right.
It's not part of the job description.

Celebrating our victory

—By Nicole, parent caregiver

Our daughter was diagnosed with juvenile myelomonocytic leukemia in 2014. She was four months old, and as far as we knew she was absolutely perfect! By most standards, she was normal. During her previous well-checks, she looked like any other infant her age.

There were many signs that we missed, now that we look back. Hindsight is always 20/20, right? After her one month checkup, where she received a round of vaccinations, she developed strange bruises on her legs. They were unlike any bruise I had ever seen, not fluid and black and blue, but spotted and purple. I thought the nurse had simply held her legs too tight. It was obvious, the bruises were the shape of her hand. I talked myself down from storming into the doctor's office and given them Hell for hurting my child. If I had, we would have been on this journey three months earlier.

We started to notice how abnormally large her belly was becoming. And then later, we watched a strange mass come and go around her belly button. We learned that was her spleen, later on. It should have been hidden behind her ribs, but instead it was sitting comfortably near her pelvic bone.

We brought it up to the doctor during her four-month well-check, hoping he would have some insight. She was obviously teething and definitely not sleeping through the night anymore. We were desperate for some help.

48 hours later, she was diagnosed with leukemia. Less than 12 hours after that, we learned how absolutely rare she was. There are about 50 cases of JMML every year in the United States, with a 50% survival rate. JMML is unique because it doesn't respond to chemotherapy. The only known cure, is a bone marrow transplant.

When we were going through treatment plans after her diagnosis, I had no idea what a bone marrow transplant was. They told us we were being transferred to another pediatric hospital in our city—the only one in the state that has the ability to perform bone marrow transplants. I thought we were going to get there the following week, get the bone marrow, and go from there. I had no idea what we were facing.

Let me use this moment to say this: Whatever the diagnosis, by all means, Google should be off limits. None of the stories I found, were helpful or relevant. No one story is the same and no one outcome should be used to measure what you are facing.

We quickly learned how intense the process was. We were at the mercy of an anonymous person, somewhere in the world, to save our daughter. In that moment, I realized there was absolutely nothing I could do to help her. Being the Type A personality that I am, I had a hard time with that realization. I am a problem solver, but this was a problem that I couldn't solve.

You either go absolutely insane in that moment, or your dive full force into your faith in a higher power.

We've been told that situations like this—life-changing, heart-breaking, soul crushing—will either make you or break you. Facing the reality that your daughter may not make it, likely won't see her first birthday, changes the way you perceive the world.

Suddenly, you no longer seem to care what anyone else thinks; we were facing some criticism for being over protective of her, but it was our only job. It was the one thing I could control. We did not go anywhere, no one came over. Seclusion in the highest form. And in that seclusion, our relationship with each other grew stronger than we could have ever imagined. We were the only ones that could really understand what we were facing and experiencing. Even our closest friends and family could not fully comprehend the pain and exhaustion we were quickly becoming acquainted with.

Is it weird to say that her diagnosis was possibly the best thing that could have happened to us? Yes, absolutely. However, we've said it many times over. We were blessed that I was able to stay home. Financially, we were somewhat prepared and able for me to take almost two years off of work. And my job was waiting for me when she was healthy enough for me to come back.

> "Is it weird to say that her diagnosis was possibly the best thing that could have happened to us? Yes, absolutely. However, we've said it many times over."
>
> — Nicole, parent caregiver

Her transplant was four months after diagnosis. Day 0. The mix of hope and despair is so strange. There is hope in the cure, but fear in the unknown. So many of the stories we followed and the families we "met" through Facebook, had not gone well.

The transplant itself was simple, like a blood transfusion. We sat four hours; napping, watching Frozen, and soaking up the snuggles. It's the days and weeks following, that are most trying. She slept for what felt like two weeks straight. She vomited, stopped eating, developed VOD. Her crib was at an incline, because she was having trouble breathing. Keeping her pain under control was one of the most difficult obstacles we faced; she was eight months old. She couldn't tell us what hurt, and that made managing pain very hard to do. Once we figured out what medication worked for her, we then had to slowly wean her off of it. A double-edged sword!

Our little girl just celebrated her third rebirthday! Her cancer and transplant is part of who she is—and who we—are as a family. We never want to go back, but we celebrate the victory every year! The stories we read were nothing like what we faced. We are so grateful to be able to create our own story, separate from everything we expected. She is medication free and basically lives with very few complications. She will be four years old this summer! She is happy and healthy, and that's all we could ever ask for.

Song for mom

—Submitted by Carolina, parent caregiver

My son was diagnosed with myelodysplastic syndrome when he was 16. A little over a year later he had a bone marrow transplant. That experience was the toughest thing I had ever had to encounter. It changed my life, my son's life and our family dynamic entirely. My son is 20 now and he developed graft-versus-host disease that affects his joints, but overall he is doing very well. After he came back home and was feeling better, he went through a rebellious phase and I did not know how to handle it, he had missed so much and suffered so much! Things calmed down a little and now he is 20, still trying to figure what to do with his life, but he is ok.

He wrote this song for me. It is a happy song but it makes me cry each time I listen to it.

Man I'm more than just a voice on this beat making noise
Tryna make my momma proud
See a smile filled with joy
Living life pretty fast, growing up not a boy

No matter how long it's been, or what you been through
Momma comes round again just to defend you
Pick you back up when you're down like a senzu
Love so strong yea it cuts like a ginsu
Feeling kinda blue she is your number one go to

Mama, I really love you
Man I swear I really love you
Mama, I really love you
Man I swear I really love you

It went from walks at the park
To when you bought my first car
Went to every single game
I was your number one star
And you're always right beside me
Yeah you're never too far
Always here in my heart no matter where you are
You shaped me as a person and you made me who am
Just look at your big strong healthy man
No need to hold my hand, but if u want u can
Yeah this life gets tough it never goes as planned

Bone marrow transplant, man I could barely stand
But you never gave up yea u never ran
You kept cheering me on, you were my biggest fan
It's kinda hard to see, but I think I understand
And I say thank you,
Thank you mama

Thank you,
Thank you mama x3
Sorry for the things I do, and everything I've done
Know it's not fun having a prodigal son
But we've had a good run and know there's more to come.
And our love sticks out just like the sorest thumb
And I know I act dumb from time to time
But when time gets ruff yea you're right beside me
Never been alone, no, you're right beside me
Any choice I make, yeah you're right beside me

Ninguna situación es para siempre

—By José, parent caregiver

Mi nombre es José y quiero compartir la historia de mi hijo que le detectaron leucemia mieloide aguda en 2015.

Fue un día muy triste para mi esposa y para mí, por nuestras mentes paso lo peor, que nuestro hijo se nos iba a morir, muchas preguntas hacía a los doctores.

Mi hijo inició con quimioterapia el mismo mes.

Durante seis meses aproximadamente o más recibió 4 quimioterapias y luego vino otro golpe duro para nosotros, la doctora nos informó que no iba a realizar la quinta quimioterapia, la razón porque las anteriores no habían obtenido los resultados que esperaban (fue un día difícil) la doctora nos dijo que mandaría el caso de mi hijo para trasplante (y ver si aceptaban el caso).

Fuimos a la clínica de trasplante, el doctor habló con nosotros y dijo que si iba a aceptar el caso de nuestro hijo, pero que el trasplante de medula ósea, puede ser pronto o demorar hasta un año o más.

Lo primero que hizo el doctor de trasplante fue ver al hermano y nosotros los padres si éramos compatibles. Y ser nosotros los donantes, pero resulto que no fuimos compatibles.

Bueno dijo el doctor, no se asusten, a veces así pasa la familia no es compatible un porcentaje alto, hay que esperar.

Recibimos una llamada de la clínica de trasplante.

Mi hijo volvió a nacer al recibir el trasplante de medula ósea,

Fue un día de mucha alegría porque esperábamos que con la ayuda de Dios el trasplante iba a funcionar.

Los días venideros fueron difíciles para nosotros, porque como esposo tenía que ir a trabajar 5 días, 6 horas y el fin de semana cuidaba a Pablo en el hospital. Mi esposa cuidaba a Pablo en el hospital de lunes a viernes y el fin de semana se venía a descansar.

Lo que nos ayudó muchísimo a mi esposa y a mí fue mantenernos trabajando como equipo, unidos, no quejándonos.

Nuestro hijo está muy bien, ya casi todo volviendo a la normalidad.

Gracias por invitarnos a participar

Jenny y José padres

It’s truly in the blood

—By Cayce, parent caregiver

Our son’s story

It’s not what happens to you, it’s how you respond to it that matters. I will never forget that day in 2015.

Our son was sick. Really sick. After one seemingly benign illness following another, a simple blood test and he was diagnosed with acute myeloid leukemia, a deadly blood cancer. The minute he went to the emergency room, little did we know, he would not check out of the hospital for 25 days, and God forbid, maybe never. We spun into one of the worst nightmares two parents who love their child more than life, can experience. Ironically, the hospital that treated him was the same place he was born in. We hadn’t been there in years. We had no idea that first night if he would be going on in the same place he had come into the world.

Fortunately, after traveling every single day back and forth to the hospital, with much pleading and prayer, vowing that if possible we would gladly trade places with him, he was in remission. He came home to heal from the protocol harsh round of chemotherapy on Mother’s Day and my birthday. What a gift to me, to us. But this was far from over.

In order to keep him in remission and to keep the leukemia from relapsing, we were told he would need a bone marrow transplant. A very dangerous procedure. Once again, we found ourselves spinning out of control in this nightmare trying to accept what is and live in each little moment being thankful for blessings and miracles so far. Taking one baby step forward at a time when our hearts were broken wide open was not an easy task.

Our son would be home for three months and another two rounds of maintenance chemotherapy to keep him in remission while the worldwide search for compatible bone marrow commenced. His sister, who would have been the first choice was not a match. Our almost 6 foot tall son came home on a 116 pound frame looking ninety years old, bent over and weak, moving at a snail’s pace, but sure enough slowly began to heal, grow back hair and put on weight in the beautiful mountain summer.

Then the next miracle happened. A perfect HLA match, based on a person’s heredity, was found in the registry, in a young man living in the UK who turned out to be just a few months younger than our son. His transplant date was set. My heart continued to break amidst hope and trust, seeing him have to go in for the “test dose” of a very harsh chemo that would all but rid him of his own flawed bone marrow and subsequently bring him back to death’s door in order for his body to accept the new cells. This was our baby, in the body of an independent able bodied man… but doing a hero’s duty. It was almost too much for us to bear. As he bravely packed his bags to enter the hospital environment for the next 120 or so days, it was silently excruciating to us. He had gotten so much healthier over the summer and seemed healed. Normal. It all seemed a cruel joke. We had no idea what the future would bring. Did we all make the right choice? I just had to depend on the miracles and blessings that had happened continually up until now. I had to continue to trust, no matter what. I am learning more about this process that I ever wanted to know.

The young donor met the schedule set for transplant. Another miracle. Sometimes patients are held at the mercy of the donor’s schedule and have to continue maintenance chemo and they sometimes lose remission status, subsequently disqualifying them for transplant. The type of donation our son needed would not be of the simple kind if there is such a thing. Some donations require the harvesting of blood stem cells after a round of shots to pump up the number and viability of the donor cells. Our son needed actual blood stem cells. The donor would be required to be sedated and bone marrow harvested from his hip bones on two sides. I am still not at the point where I can describe this without tears. Who does this for a complete stranger on the other side of the ocean?

After a month in the hospital and three months in hospital housing to be near the 4 times weekly doctor’s appointments, our son is now almost 3 years post-transplant and doing well. Back to work full time, receiving promotions, getting to see his big sister get married. The biggest miracle.

The post-traumatic stress and the pain in our hearts is getting a little better. If there is anything this experience has taught us, it’s that we have learned that we must make the plans, and we must not put off our dreams a single moment longer, for those moments as is this life, are never promised to us. I for one, will carry all the way, an energy of gratitude for this life we get to experience, good and bad, each and every step.

If anyone has been touched by the bone marrow donation information, I implore you to get on the list to be a bone marrow and/or blood stem cell donor. All you have to do is a simple cheek swab. Also you can donate blood stem cells from your baby’s umbilical cord. Cord blood also saves lives in this same way for many different blood cancers. It gets thrown away otherwise. I wish I had known this before when I could have helped in this way. I would have in a heartbeat.

One day at a time

—By Shaylyn, transplant caregiver

Haiku 俳句

One day at a time
By: Shaylyn

Cold hospital room
A mother looks upon child
Hopeful for today

A cord blood pioneer's journey

—By Anonymous, parent caregiver

Our 11-month-old son Adam was diagnosed with a fatal genetic disease on 01/13/1994. Adam's older brother Erik was diagnosed with the same disease on 01/31/1994. The disease was unstoppable for Adam and he passed away in May of 1995. Erik was eligible for a bone marrow transplant if it could be done very quickly. Only 6 BMTs had been done for this disease, globoid cell leukodystrophy, and 4 of those patients had died. No adult donor match was found in the NMDP registry. Cord blood transplants were just starting to be done and there were very few donor cords available at the time, only about 7,000. A 4 out of 6 HLA match was found in the available stored cord blood units. This would not be good enough in a bone marrow transplant but was thought to be good enough with cord blood. Only 5 unrelated cord blood transplants had been done up to this point and none for Erik's disease. We really had no choice so Erik was scheduled for an experimental cord blood transplant in July of 1994.

Erik came home after 26 days in the hospital. After a careful year Erik was pretty much back to normal daily activities and he entered kindergarten on schedule.

Erik was fully able to participate in all the usual kid activities growing up and he graduated from high school and college. He works full time in the IT department of a Fortune 500 company. As a cord blood pioneer, Erik has been profiled in a number of cord blood publicity events for the hospital's cancer research fund. Erik participated in congressional lobbying effort that resulted in the establishment of a national cord blood bank for the United States.

Top row from left: *Erik, Dec. 1991; Adam, Feb. 16, 1993.* **Middle row:** *Erik's first time out of the hospital; in the hospital, July 1994, transplant day: July 29, 1994.* **Bottom row:** *Erik in the hospital; college graduation with parents and brother Nate; Erik today.*

To my daughter

—By Kala, parent caregiver

To my daughter, to the next to come, to the doctors, nurses and donor,

You have accepted challenges since the day you were born, you've overcame more than I or anyone probably will go through in a lifetime. Your courage is admirable, your strength is commendable. Since the day you were diagnosed with severe congenital neutropenia we were all so confused and afraid. Since that day you have shown us that this battle is one that you will defeat. You have shown me how to be a better mother and have shown your dad how to be a better father, to love through the hard and the easy. I thank you for that. I thank you for being so strong. You've spent a lot of time these past years in hospitals, in and out of clinic visits and a lot of time away from your siblings. As I said before, you've taken these challenges and made the best of them. You've smiled your way through the worst of it, you have left the doctors and your family speechless so many times. You had just gone over yet another bump in the road, but this bump was different. It was a bump with a bunch of little bumps and some stop signs. This may be the end of this battle and the start of a new battle but whatever comes your way please remember, everything in life is temporary until you make it permanent.

To those after you, to the many more to come who will need a bone marrow transplant, keep your strength, be resilient, and battle your way through this as hard as you can. You have a whole beautiful life left and you all deserve to live your life as healthy as possible.

To the doctors and nurses who chose this as their life career, thank you for dedicating your lives to giving our children a second chance at life. No words can truly express how I feel.

To the donor(s), thank you for giving a piece of you to my child. Words will never be enough to thank you. As a donor you were able to do something for my child that I was unable to do. You're a special kind of person and many blessings will come your way.

This bone marrow transplant my child received is saving her life and none of this would have been successful without any of you.

With Love,

Kala

> "...keep your strength, be resilient, and battle your way through this as hard as you can."
>
> — Kala, parent caregiver

Brody's story

—By Anonymous, parent caregiver

In February of 2015, our lives were forever changed...I took my son into the doctor's office for them to do bloodwork because I was worried about some things that I noticed on his body. By that afternoon I received a phone call that will be forever stuck in my mind.

After multiple bone marrow biopsies and a long stay in the hospital we learned Brody had a blood disease called severe aplastic anemia. The doctor told us we had a long road ahead and that we were now going to be lifelong partners...our heads were spinning. How was this happening to our little boy?

After months of keeping Brody in a bubble, long hospital stays, weekly clinic visits, multiple drug treatments, weekly blood and platelet transfusions, and a laundry list of meds it was determined that the only hope for my son was a bone marrow transplant. So we began our search for the perfect match.

By summer of 2015, our perfect match was found and that fall we were about to begin his transplant journey. It was definitely not a normal life for our son, but we did what we had to do to get him better.

And it did get better. We spent about a year and a half after transplant trying to live life to the fullest, granted we still were in the clinic at least 1–2 times per week for lab work and check-ups. Brody was able to go to Disney World (thanks to Make A Wish), we took a beach trip, we visited museums, he went back to school, he had an actual birthday party, he participated in sports, he was able to go swimming, and he just really enjoyed life. He was once again finally able to participate in the activities a child his age should get to experience. We were beyond excited and never thought in a million years we would have to relive this nightmare again.

In May of 2017, Brody became sick again and we found ourselves back in this roller coaster of a battle. By June, it was determined that the disease had officially relapsed. The dreaded disease was back with a vengeance.

The majority of June-December 2017 we were in the hospital. That fall, he had his second transplant. We were fortunate to find a donor the second time around as quickly as we did. The donor who helped Brody in 2015 graciously stepped up to the plate one more time for him. We met Brody's donor a little over a year after his first transplant and what an angel she has been to our family. She had signed up for NMDP in hopes of saving the life of another little girl who was battling leukemia and was searching for a donor. Unfortunately, the little girl passed away. Coincidentally, on the same day of her passing our donor received a phone call that she was the perfect match for a little boy. She ended up saving Brody's life not only once but twice.

After our 80 day stint in the hospital, Brody's counts were finally strong enough that he was able to head home with a lot of precautions, but at least we were home. We spent about 28 days at home before the dreaded GVHD hit him hard. The doctors worked to treat his symptoms and by January he was feeling better and was able to come home again.

Currently, we are still at home and back together as a family of four. Although Brody's life continues to consist of weekly clinic visits, IVs, oral meds, central line dressing changes, lab work, platelet transfusions, bone marrow biopsies, and confinement to our bubble all over again; we are thankful to all be home together. It is so hard to separate your family while one parent lives at home taking care of one child and the other lives at the hospital, it makes the world seem like such a better place when we are all under the same roof.

We hope and we pray that he will eventually get back to a more stable life with normal counts so he can do what every other kid his age is doing but for now we endure this daily fight for him!

Needless to say, our lives have been completely uprooted to a whole new world. We have watched so many families come in and out of the pediatric oncology and hematology clinics. We have met friends for life and I have learned that the kids that battle these awful diseases fight harder than anyone I've ever met; their spirits aren't broken even when they probably should be. I've watched Brody smile and laugh while getting treatments, sing and dance with the staff, and make the most of every situation he is faced with during this battle. I am so proud of Brody and how he handles this daily fight. Don't get me wrong there are for sure bad days, there are days when we all want to scream and cry but I have to push through that for Brody and continue to encourage him that everything is going to be alright. This disease has been hard for all of us, it's changed all of our lives, but we will keep fighting this battle as long as we have too.

I share this story with you to offer anyone out there who hears this, encouragement and hope. Whether it is for yourself or someone you love who has been diagnosed with a lifelong disease, I hope that you will have brighter days ahead and I hope that your strength will help you overcome the daily struggles that you must face. Each day I tell Brody and myself, "There is always something to be thankful for," and I truly believe that. Brody is so strong and pushes through all of these hurdles with a HUGE amount of strength, bravery, and courage. Brody has truly been a picture of strength and determination.

Life is busy!

—By Jane, transplant caregiver

What? We don't have time for this? Life is busy! Learn, learn more, ask questions, ask more questions. Reach out. Reach in. Tell people. Keep it a secret as you don't know who should know and how much. How do you tell your 12-year-old what is about to happen when you don't understand yourself? People help. Medical people are awesome and available. How do they do this every day? A donor … on top of everything else we have to think about an anonymous donor—a match. How does that work. NMDP is a miracle thing—a group of souls we don't ever even meet help us find our miracle. They do! A woman from another country will do this for my husband? How can I question anything with this miracle about to happen. Hospital admission. What if the snow messes up the flight? I am too tired to worry—that can really happen. It comes and goes in. Our pastor prays over those beautiful two bags. So many hospital days with so many things happening. How can this miracle be? It is. We go through so much. Words, emotions can't be described yet. Still too much and too new even though we have been going through this since February. Seems like yesterday and what were we like before. Don't remember that yet as don't have time for that. **Life is busy!**

Daryl, transplant recipient,
with Janice, his wife and caregiver

CHAPTER SIX:

Live life every day

Janice was a caregiver for her husband during his BMT journey. Asked about her photo submission, Janice said, "I felt sad when I took that picture. We were in the hospital, so our family couldn't do any of our holiday traditions, like going to the mall and looking at holiday lights. I took the photograph on the day he was admitted. He was going to start the chemo. We were right at the start of the whole transplant process."

"We just had to get out of the room, even if it was only for 20 minutes. Our goal was to try to find a place that brought joyful thoughts. That was it. We had to wait until after hours, then we went down to see the Christmas trees, just the two of us. In that moment, it was a little oasis. Just to feel that little bit of Christmas spirit. That's what inspired me to take the picture. I decided to share the photo and caption because I know how hard it is taking care of someone throughout this experience."

"Even now, when doctors say my husband is doing well, we're still surprised. We thought the recovery would be quicker, but this has been so long. I've heard from others that it's a long recovery, so I'm holding on to that fact. It's long, but we'll get there. I hope my photo might help someone else who can identify with the feeling. It's my little, tiny way to give back."

See Janice's submission "Hospital Holidays"
on the next page >

Hospital holidays

—By Janice, transplant caregiver

Find your oasis even if this moment feels like a desert of despair.

My Journey

—By Lorayne, transplant recipient

My journey, as I like to call it, began in October, 2011. I had a blood draw on a Friday because I was experiencing symptoms of being lightheaded, having shortness of breath, and extreme fatigue. I was a teacher at the time and had just dismissed my class of kindergartners and was told by the school office to call my doctor right away. Apparently, my blood counts were extremely low, I was seriously anemic, and I was to go straight to the hospital. My doctor said I needed a blood transfusion.

In my mind, I would complete that transfusion, get those iron supplements my doctor was recommending, be home later that evening, and back at work the next day. That did not happen. I did not go home and I never was able to go back to work. I was admitted to the hospital that night. Two days later, I was given a diagnosis of acute myeloid leukemia. I was taken by ambulance to another medical center on that Friday and entered into their Hematology & Transplant Unit. I did not go home until six weeks later just before Thanksgiving. During that time, I received my first round of what they call induction chemotherapy and it lasted eight full days. The remaining time I spent waiting for my blood levels to recover. I returned to the transplant center for my second round of consolidation chemotherapy in December and came home three weeks later.

It was during my first stay at the hospital that I was told that my best chance for survival was a blood stem cell transplant, whereby the stem cells of a matched donor would replace my own. My sisters would be tested first but they were not a match. By the beginning of January, 2012, a search had begun to find a donor for me. I was so blessed in that a donor was found within the next two months. He would be a 10 out of 10 point match. In March, I was back at the transplant center for eight weeks that began with a week-long regimen which consisted of chemotherapy, many infusions, and other medications to get my body ready for the transplant. In the early morning, a very wonderful young man from Germany donated his blood stem cells. They were flown immediately, with a nurse, to the transplant center and arrived in my room at about 8:30 in the evening. By a little after 10:00 that night, the transplant was completed and I began the long process of recovery of which I am still in. Recovery is filled with peaks and valleys but through it all I remind myself I have life!

Being given a second chance at life has impacted me in a profound way. When I was in the hospital, I set a goal to give back in gratitude all that was done for me. I reached out to both NMDP and The Leukemia & Lymphoma Society to be a volunteer.

During my lengthy stays at the transplant center, I encountered many compassionate and caring medical staff who helped me to have hope and to endure the many treatments. From my doctors, nurses, support staff, and social workers, to the incredible chaplains, I was surrounded by people who truly sought to get me through transplant and into remission. They inspired me to never give up, to maintain a positive attitude, to take one day at a time, to keep walking that mile every day, and to realize life is a precious gift. My volunteer work has allowed me to give hope to other transplant patients as well as raise money for research.

In closing, I want to quote Stephen Endelman, a writer of music for film & TV, who had a stem cell transplant approximately eight years ago. I had the pleasure of meeting him at my transplant center's Celebration of Life event for their hematology and transplant patients.

He said: "I'm often asked what I've learned through my health experience. It's quite simple—there are only two things for sure—we're born and then we die. What's important are the lessons we learn in between and living life as fully as possible every single day." That truly sums up what I have learned through my leukemia journey.

> "They inspired me to never give up, to maintain a positive attitude, to take one day at a time..."
>
> — By Lorayne, transplant recipient

The polka dot jersey

—Essay and poems by Neil, transplant recipient

Introduction

In some ways
Long term survivorship
Can be strange and unsettling.
Time goes by
And
Many of your stories seem to be forgotten
by everyone
Except yourself.
Once you were a hero
Something extraordinary
Now
"You're yesterday's news."

Or are you?

It all depends
On how you see
Your own reality.

Persistence—perseverance—courage

To this very day I experience patterns from my years during and after the transplant experience.

There was a ceiling fan in the bedroom of our apartment where we had taken up temporary residence. In the evening, at bedtime, I would lie in bed, watch the fan and breathe very deeply. The days were often chaotic and stressful as medical reports came in and things changed. I would always think to myself while drifting off to sleep, "I am warm. I'm safe and I have no pain."

Upon awakening, I was always first aware of my body and that I often had no pain and then I would think, "Thank you God for giving me one more day." These mantras have continued now without fail for over 9 years. Gratitude.

I was as determined as a person could be. Maybe even more that you could imagine. Maybe, it was my dream of being healthy again and riding my bike. Maybe it was my dream to see my grandson celebrate his first birthday. Maybe it was because I really believed that I would beat this cancer and survive this transplant. But, mostly it was the bike.

I had brought my bike to Philadelphia and set it up on a trainer in our apartment and I would look at it every day when my isolation ended and I moved there. In the hospital, you would have been amazed to see me in isolation. I had them bring in a small stationary bike and I rode it every day which I could. IV lines, Jello in hand, Colnago cycling cap on backwards. I DID it. Just me and my hero at the time, Lance Armstrong. I had videos of every Tour he won. He was a cancer survivor and a cyclist. So was I. We were brothers. No matter that I couldn't ride for real. No matter. And six months later, while still in Philadelphia, two months after the PICC line came out, I took my Spectrum out of the apartment and rode to the Schuylkill river walk and back up Chestnut Street. I was making my dream become a reality.

Never, never, never give up!

The Holiday Season

I was so sick and tired
Of being "The Patient"
Endless treatment
And never getting better
I remember when
The lab tests showed
That the doctors
Were out of ammunition
Precision treatment
Was tossed to the winds
And they
The gods of my world
Started the shot gun approach
It all failed
And then
It was time
To think
About the transplant

I walked out of her office
Determined
Never to have it done
I was afraid of
The enormity
Of it all
Life and death
But a year later
I had no other choice
It was time

Show time

You walk into
The casino
And the barker
Calls out
Everything must be put
On the table
No holding back
Everything
And so
You put
Your life on the table
Red and black
Black and red
Life and death
One spin at a time
You will either
Live or die
You take a deep breath
The roulette wheel spins
And
You wait

A Truth

It was a bad day
You know what I mean
One of those days
Where I couldn't
Get out of the bed
In walked my wife
And
She just looked at me
Not a word
She shut the blinds
And shut the door
She looked at me again
And turned on the music
Took my hand
And gently led me from the bed
And she danced
With me
I often say
That Arielle
My stem cell donor
Saved my body
But
My wife Linda
Saved my soul

The flip side

My transplant was done in 2009. There was a failure to successfully integrate to 100% and so I required a donor lymphocyte infusion over a year later. The good news was that it was successful. The bad news was that I experienced acute GVHD of my liver. The good news was that the inflammation subsided and that I survived.

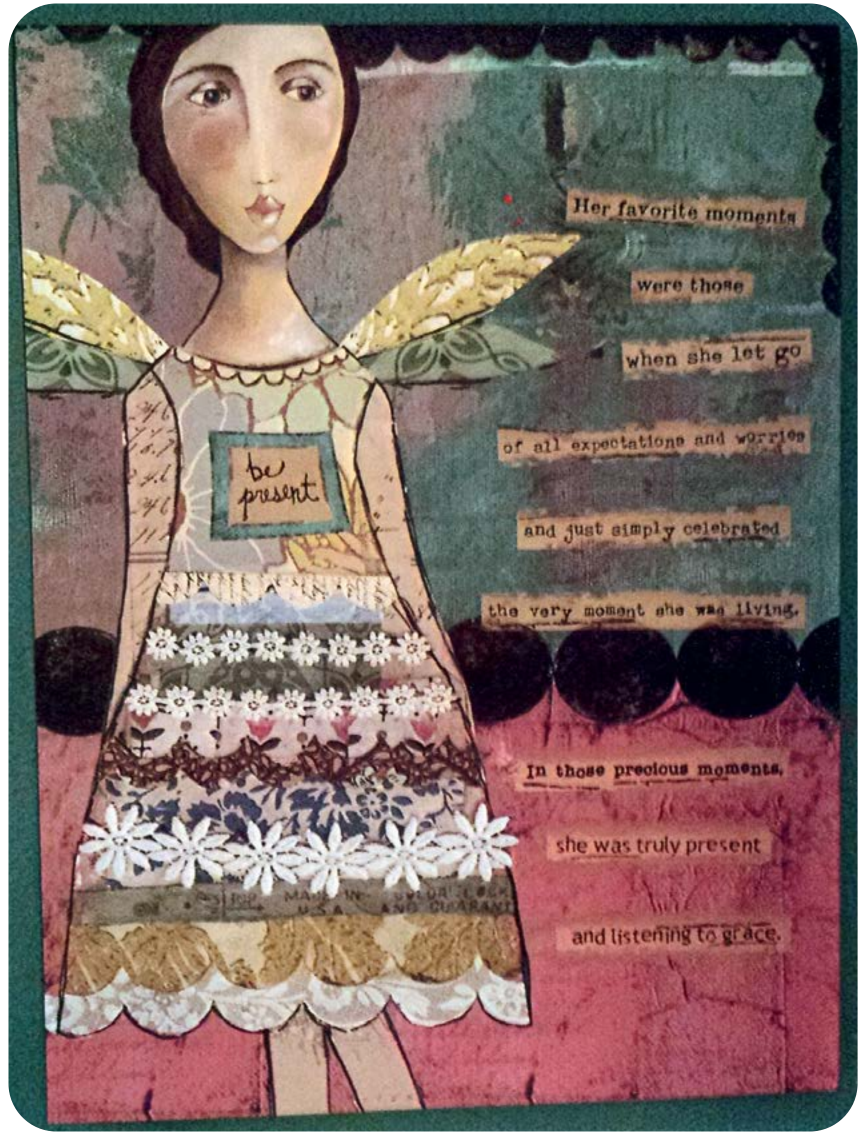
My life has been nothing short of a miracle. I've spoken to industry about my cancer and have been a motivational speaker for the Cutaneous Lymphoma Foundation, the Gift of Life Bone Marrow Foundation and NMDP. I believe that my efforts have been far reaching and have helped many people.

I've seen two grandchildren begin their lives and have had the gift of time with my family and friends. Has it always been easy or a walk in the park? Of course not.

But, here I am. My cycling friends still call me the Polka Dot Jersey. The Hill Climber. It's who I am and it's the story of my life.

Be present

—By Jill, transplant recipient



While I was getting prepared for my bone marrow transplant I came across this print, by Kelly Rae Roberts. It truly spoke to me. I purchased it and hung it where I would see it every day.

It states:

> "Her favorite moments were those when she let go of all expectations and worries and just simply celebrated the very moment she was living. In those precious moments, she was truly present and listening to grace."

I have lived by this through all the difficult times that only a transplant patient can understand. When I opened my day planner to schedule the 1 year bone marrow biopsy and port removal the heading for the month was "Be Present." I have learned to accept positive signs when they are given!

Living in the moment and being positive of all outcomes has gotten me through! I am truly blessed!

Routine

—By Teresa, transplant recipient

Midnight.

In a hospital bed.
Alone.
Anxious thoughts running through my mind.
I need to sleep. To heal.

IV pump humming.
I tell myself to relax. Breathe slowly. In and Out.
Let the wave of calm wash away my worries.
Relax. Breathe. In and Out.
Sleep finally comes.

4 a.m.

In a hospital bed.
The kind nurse is sorry for waking me.
The ritual begins.
Name and birthdate.
I open my mouth and extend my arm.
Thermometer, cuff, oximeter.
Temperature, blood pressure, O-2 saturation.
Another blood sample.
The results will dictate my day.
What will it be? Red Cells? Platelets? Magnesium? Antibiotics?
The nurse flushes my port, thanks me, leaves.

4:15 a.m.

In a hospital bed.
Alone.
Anxious thoughts running through my mind.
I need to sleep. To heal.
Relax. Breathe. In and Out.

Life

—By Randy, transplant recipient

As I approach my one-year anniversary of my stem cell transplant it's hard to believe the reality of it all.

In April of 2014 a standard physical and blood test raised suspicion of a potential problem.

After many tests and to my surprise I was diagnosed with MDS which quickly moved to AML.

To say the least it was a shock to me and my family. I have always been relatively healthy and active.

I started treatment in January of 2017 to prepare me for a blood stem cell transplant later that year.

After 36 years of working at my company it was hard to visualize being disabled for at least a year during the process.

I had different feelings about going through with it. I thought maybe this is just my time. Does God really want me to do this? Is it outside the natural order of things?

Then I looked to my family who were suffering through this too. I realized how much I meant to them and how much they really meant to me.

Shortly thereafter, I had a revelation that God would want me to try and that the medical technology was here to give me a chance for a longer life.

At that time so many people were praying for me and I believed in my team of doctors.

I realized I had a lot to live for and would give it my best effort during the treatment and transplant period. I must admit it was a little scary. The unknown always is.

It was not always easy to stay disciplined during the process. I was fortunate to have a good support group in my family, friends, medical team and of course my donor. This along with a strong religious faith got me through the first year. Thanks to the efforts of my medical team, I could attend my daughter's wedding during the treatment period. They timed it out perfectly.

Completing months of treatment and recovery and with all the support I had received, I am now back to work and doing well. I am planning to stay as active as I can and continue to pursue outdoor activities I enjoy doing with my family, especially fishing.

There is good and bad in the world. I am aware that the "bad guys" tried to get me but I believe the "good guys" are winning.

Sometimes I joke when someone asks me how I am doing and how did I get through it? I answer, "With all the prayers that God must have heard, he did not want to disappoint all those people." Maybe there is more truth in this than we realize.

I don't know what the future will bring but right know all I can try to do is live one day at a time and keep the faith.

For all that are going through or about to go through a comparable situation, I wish you all the best and God's blessings.

Randy

On opposite page: the sunrise scene in a spot where my son and I like to fish. It reminds me of a new day we can enjoy together now and in the future

World turned upside down

—By Edna and Eduardo, parent caregivers

Transplant is as rewarding, as it is terrifying. In our case, as first time parents to twins, we knew things could not go wrong, always staying positive and having a strong faith in God and to keep our boys safe, to guide the physicians in the treatment for our boys through this long journey.

Our sons are identical twin boys, at birth they were diagnosed with thrombocytopenia, low platelets, which puts them at risk for internal bleeding. They were referred to hematology, where at a few months of age received many platelet transfusions. At 6 months of age they were diagnosed with a rare genetic disorder that affects only males with symptoms of low platelets, recurrent infections, eczema and are at increased risk for developing cancer, good thing they found it early in time for transplant.

The only cure is bone marrow transplant. Our world turned upside down, completely heartbroken to see our children having to go through so much so young, not enjoying a normal life. We were then transferred to another hospital, where we received great care from the bone marrow team. They explained everything so well to us to the point where we felt safe with the whole procedure, including the dietitian, who was always as concerned as us to make sure they kept a good weight during and post-transplant.

Unfortunately we weren't a match for our boys; thank God they were able to find an unrelated umbilical cord within a few months. The worst and most terrifying part about transplant began with the surgery for placement of a catheter and G-tube for feeding, one week of chemotherapy and on Oct. 2, 2017 they had the bone marrow transplant.

Side effects were terrible from mouth sores, darkening of skin, nails and hair falling out, unable to eat by mouth, weight loss, weak and tired, muscle weakness, some minor infections which caused them fever, problems with the G-tube and they also suffered from graft-versus-host disease (GVHD) of the skin and gut.

Everything was so overwhelming seeing them go through so much; we wish we could take all their pain away. We prayed every night for a quick recovery to see them being themselves again, happy, playful, active, full of energy and together again since they had to be in separate rooms for infection reasons. God heard our prayers they recovered quickly, their blood counts increased day by day, soon out of isolation, they were soon eating by mouth again, and feeling better, they responded well to medication for the GVHD.

They were discharged 3 months after transplant; we continue to go to clinic within weekly basis for treatment and some other complications that may arise post-transplant where they do get admitted when needed but in all its ups and downs transplant gave them a second chance at life and that just made them and us stronger, they managed to get through and continue to push through, they survived transplant under 1 year of age, they inspire us every day, they always put a smile on their face regardless of the setbacks after transplant, they recover and come back stronger.

It was not easy and we know it will still take a few more times until they are completely over the setbacks but with hope and faith in God everything is possible. We as parents are greatly thankful to the people who register to donate, it is life changing. Without the cord our children received they wouldn't be where they are today. As well, we are greatly thankful to the hematologist and to the bone marrow teams.

The most precious gift

—By David, transplant recipient

My life these days couldn't be more different from two years ago. Back then I was a hi-tech exec working 10-12 hour days, training for marathons and enjoying time with my children and grandchildren. Now I'm pretty much house bound as we try to avoid any situations that might expose my immune system to a virus, fugus or bacteria. No crowds, no work, no grandchildren visits, no stores, no movie theaters, and no restaurants. Yet I find myself starting each day with the same sense of enthusiasm and carefree love of life as I did in the summers when I was 9 years old.

I'm not alone. I spend some time with pediatric cancer patients. I see the same sense of attitude and perspective among the children who are struggling with cancer. In many cases they face years of treatments yet they are quick to show you their latest project or accomplishment with an enthusiasm for life that rivals the happiest of children.

My goal these days is to try and adopt their attitude. Let's face it, part of me is just thankful to be here to wake up each morning but I've also made a conscious attitude shift to find as much joy and wonder in the little things as I can. Given a choice, I picked loving life over just living it.

I have so many people to thank for my life. My bone marrow transplant team, my bone marrow donor, NMDP for helping me find my ideal donor, my family and friends who supported me and my very special wife who acted as both my advocate and caretaker. I can never repay all their kindness. They have given me the most precious of gifts; time. Time to spend with my precious grandchildren, time to let the important people in my life know how much they are loved, and time to do those unfinished things that are on the bucket list but kept getting pushed off.

Life in a bubble: Crosby's story

—By Anonymous, parent caregiver

"40 to 100 babies are diagnosed with SCID in the United States per year," I said to my husband as I held our newborn against my chest. "There's no way, right? There's no way he's one of them."

Only a few hours earlier we received a call from our pediatrician. Crosby's newborn blood screening came back abnormal. It showed an absence of T cells. We were told this could be anything from a false positive to severe combined immunodeficiency (SCID), a rare and potentially fatal genetic disorder where there is a combined absence of lymphocyte functionality. We were told not to Google it. That we would learn more at our appointment the next morning.

We spent the entire night holding our baby. And Googling everything we could about SCID.

The following morning was a blur, yet I remember every detail. It took everything in my power to hold back tears as we told our 1 year old daughter to "just kiss Crosby's feet today," not knowing what our future would hold. Not knowing that it would be months before she would see or kiss her brother again.

At six days old, it was confirmed that Crosby had virtually no T or NK cells. He was diagnosed with X-linked SCID. Without a working immune system, even the common cold could become fatal, and so, he was placed in hospital isolation immediately. Until we learned more, we had to gown, glove and sometimes mask just to hold our newborn. I had to immediately stop nursing him, and because our daughter was a germy toddler, she wasn't allowed to visit him. The immense joy we had felt just days earlier was instantly replaced with fear, anxiety and sadness.

Currently the only treatments for X-linked SCID are bone marrow transplants and gene therapy trials. Since sibling donors are ideal, our first step was to test our daughter. She was a 9/10 match, which put her on the table but more testing (and more waiting) needed to be done. Ultimately, it was decided that daughter was not a viable option. We opted for an unrelated donor.

I don't know if I've ever gone through more complex emotions than I did determining the treatment path for our child. While we wanted so badly for our daughter to be our son's donor, we also questioned putting our daughter through that without her consent. When she was removed from the table, I cried tears of sadness but also felt relief that we wouldn't have to make that decision. Deciding between gene therapy and an unrelated donor was a bit easier, but as a parent in this journey, I easily questioned every move we made. At 7 months post-transplant, I still have moments where I question if we made the right decisions.

After three months of testing and waiting, we found our perfect donor and Crosby began the prep work for transplant. He received his new cells at four months old.

Everyone told us how underwhelming the procedure would be. While yes, the procedure itself is underwhelming, watching donor cells enter our child's body, was anything but underwhelming. These cells given so selflessly by a complete stranger were our child's second chance at life. And yet, they weren't a guarantee. We wouldn't even know if they were successful for another three to four months.

As the days, weeks and months passed us by, we prayed for glimmers of hope, signs that the transplant was working—but those signs didn't come. We just had to be patient, they told us. It just takes time. But time is hard to wait for when all you want is to know that your son is going to be ok, for your family to be whole, and for your world to start moving again.

From the beginning, we were told that if the transplant was successful, engraftment would take between 100-120 days to occur. This timeline was due to the non-chemotherapy preconditioning we chose. While we were never given false hope that we would know anything sooner than that, nothing can prepare you for how that time feels. Isolation is isolating. While everyone's lives moved forward around us, we lived in an emotional rollercoaster of a Groundhog Day that included multiple medications multiple times a day, more blood draws than I can count and a number of blood transfusions that, for Crosby, were only necessary because of the amount of blood we had to draw. We kept a strict routine that kept us sane, and yet the routine itself would make anyone crazy. My husband and I became two ships passing in the night, going about our lives as essentially two single parents, living two half lives. I wanted so badly to cherish every moment I had with each of my children, because we would never get those days back. Yet, I couldn't help but wish time away because all I wanted was to hold both of my children in my arms at the same time and to finally feel like we were in the right place. To this day, I often look back at pictures and wonder where the time went and if I truly was present enough during those days.

Just as we were told, Crosby's T cells did start to engraft around day 100 post-transplant. And after 233 days in hospital isolation, we finally got to bring our baby home. While Crosby's journey is far from over, his immune system continues to get stronger. He continues to become more adventurous and our isolation precautions are slowly becoming less strict, allowing our boy's bubble to become a little bit bigger with every passing day. We look forward to the day that we can introduce him to more family and friends, more people and places, and hopefully, one day, the woman that gave our boy the opportunity to be just that—a little boy.

First christmas two months after transplant

—By Ted, transplant recipient

As foresters, we facilitate the cutting of billions of trees annually so the world can sit in wooden chairs at wooden tables, thumb the pages of a *Fifty Shades of Grey* paperback, live in wooden houses, and stretch out a daily hand for a fistful of Charmin. We grow trees, we cut trees, they grow back … we grow trees, we cut trees, they grow back. Unfortunately, the hospital's strict compliance orders of "No live plants of any sort" applied to fresh-cut Christmas trees as well. For the very first time in my life, a 6-foot tall artificial semblance of Douglas Fir would grace our living room. There would be no evergreen scent permeating the air, no sticky pitch on the wall, no gentle forearm needle-pricking.

On Christmas Eve night, surrounded by the glow of a sparkling Seattle skyline, my family and I strolled a short two blocks to an old Lutheran church, a wooden relic tucked within bustling city streets. We climbed the decaying concrete steps and entered into candle-lit warmth. We melted into the gentle ambience, a quiet pool of old, young, rich, homeless, white, black, Asian, healthy and sick souls all seeking peace. We sang the hymns, lit the candles, and wept openly during the best rendition of Silent Night I have ever witnessed. We returned to the apartment, poured some eggnog, gathered together beneath that beautiful artificial Christmas tree and shared tears. How on Earth had I made it this far?

Cradling my grown baby girls in my arms with my wife at my side, that tranquil, artificially treed, citified Christmas shines to this day without compare. I drifted off to sleep that night in peace, nestled in the comfort that another brave man, born this very night so many years ago, suffered pain and misery just like me, but rose from it all triumphant.

Storytelling as a transplant survivor strategy

—By Steve, transplant recipient

In the spring of 2016, routine lab work revealed that I had abnormally low white blood cell counts. My doctor referred me to a hematologist who recommended a bone marrow biopsy. I followed their advice but was not overly concerned since I had been in good health my entire life and had no symptoms. My biopsy was on a Monday. The next day, I swam my normal fifty laps, saw a chiropractor, did some shopping, and ate dinner out. On Wednesday morning, I played in my weekly poker game with some retired guys and lost ten bucks. That afternoon, I was informed by phone that I had acute myeloid leukemia. On Thursday, I was admitted to a hospital. On Friday, I started chemotherapy. I thus went from feeling perfectly healthy to a life-threatening diagnosis and a chemo cocktail in the space of a few days.

Despite this frightening beginning, my story got better. I spent six weeks in the hospital recovering from induction chemotherapy that achieved a temporary remission. After researching my options, I received a double cord blood transplant in October of 2016. One cord engrafted within three weeks, launching me on a lengthy recovery. As of this writing, I'm eighteen months post-transplant and cancer-free.

Back to that frightening beginning. As if my sudden diagnosis and treatment were not surreal enough, the day after I was first hospitalized my wife was admitted to the same hospital with a fractured femur. She underwent surgery to repair the leg, spent seven days in "our" hospital, and then was discharged to a transitional care unit for another three and a half weeks. When it became apparent that our home would be unoccupied for a month or more, I sent an email to a small group of neighbors to inform them of our status and ask them to keep an eye on our house.

I quickly realized that this was an efficient way to keep not only neighbors, but family, friends, and colleagues informed about our status. Within a couple weeks, the list of recipients grew to a dozen, then two dozen, and eventually fifty or so recipients. Over the succeeding weeks and months, these missives grew to over sixty "reports from the front lines" detailing my cancer odyssey.

These reports were thus composed for a known audience. I was highly conscious that I was writing for others, and I deliberately included some wit and humor to lighten the impact of my otherwise dire news. One of the great benefits of writing for others was the supportive feedback I received from so many of my correspondents who responded with kind words, timely advice, heartfelt prayers, and good wishes.

It eventually dawned on me that these reports had become a kind of memoir telling the story of my treatment and reflections on being a cancer patient. It also occurred to me that on a more profound level, I was writing for and to myself. It seemed that each day in the hospital brought a new and dizzying array of personnel, medications, tests, side-effects, cautions, and complications. While I received excellent care, it was an overwhelming initiation into the world of cancer treatment that left me feeling highly vulnerable and utterly dependent on the care of strangers.

The best way I could make sense out of it was to write about it. Writing became my therapy. It allowed me to take the chaotic threads of my lived experience and weave them into a coherent story of what was happening. In short, composing these reports became a psychic survival mechanism. It was many months later that it dawned on me that there could be a wider audience for the story I had been telling. As a result, my memoir titled "How Steve became Ralph: A Cancer/Stem Cell Odyssey (with Jokes)" will be published.

In a preface to the emails that comprise the core of the book, I discuss lessons learned and coping strategies I used. They included mindfulness, meditation and yoga, being a pro-active patient, doing as much physical activity as possible, and maintaining an unrelenting sense of humor. Along with some excellent medical care, these strategies got me through some challenging times.

Important as they were, I know in retrospect that telling my story was central to my healing. Toward the end of my recovery, I came across a wonderful book titled *The Wounded Storyteller* by Arthur Frank. When I read it, I felt as if he had been looking over my shoulder during my entire cancer odyssey.

Arthur Frank contends that storytelling by ill persons plays a crucial role in shifting them from a passive to an active role in their illness. While doctors may insure the patient's biological survival, storytelling maintains the person's existential integrity.

Stories can be told in many ways, but the crucial point is that however we do it, storytelling allows ill persons to be active agents even as medical professionals tend to their sick bodies. In the best-case scenario, modern medicine saves bodies, but storytelling sustains selves. Among the many lessons I took away from my illness, the importance of telling our stories in whatever fashion suits us is the most valuable one of all.

Write about your own experience

—By Ted, transplant recipient

Reflective writing is a way to explore your experiences. It can be a form of expressive therapy that helps you transform a deeply difficult emotional experience.

Reflective writing has many benefits. It can help you:

- Affirm your experience
- Find meaning
- Gain perspective
- Cope with illness and treatment

Why I write

"My primary motivation for capturing this story is personal. I had come to a point in my life where the memories of and lessons learned from my struggle began to fade. I did not want them to. Revisiting those days and subsequently writing this seems the best way to "re-ground" myself. I also cling to the hope that these words may provide solace and inspiration to those in need, even transcending the cancer world."

Ideas to spark your creativity

- Reflect on your diagnosis and treatment. Think about what challenged you and what inspired you.
- Consider writing about the details of one impactful day.
- Did music inspire you? Write lyrics to your favorite melody.
- Think about a theme, like friendship, hope, fear, GVHD or caregiving, and write about that theme as it relates to your transplant experience.
- Make a collage out of images and photographs that conveys your experience.
- Did a person inspire you? Write a tribute to someone who helped you through the process.
- Draw a cartoon about a day in the life of a transplant recipient.
- Write an open letter to a future transplant patient.
- Describe a meaningful or stressful day in a "Dear Diary" format.

Support for you and your family

Get help

Whether you're a patient, caregiver or family member, you can get free support, information and resources from a patient navigator in our Patient Support Center.

- Discover how we can help: **nmdp.org/one-on-one**

Get emotional support

Your BMT journey may impact your emotional and mental health. Our free NMDP Patient and Caregiver Emotional Support (PACES) program can help. Talk one-on-one with a BMT social worker over the phone as you cope with emotions through illness, treatment, transplant and recovery.

- Access support: **nmdp.org/PACES**

Talk to someone who gets it

No matter where you are in the transplant process, BMT recipients and caregivers are available to talk by phone or email, sharing their experience and tips. Through NMDP Peer Connect, we do our best to find someone who most closely matches your situation.

- Request a connection: **nmdp.org/PeerConnect**

Contact the Patient Support Center

CALL: 1 (888) 999-6743 Monday through Friday, 8:00 a.m.–5:00 p.m. Central Time

Email: **patientinfo@nmdp.org**

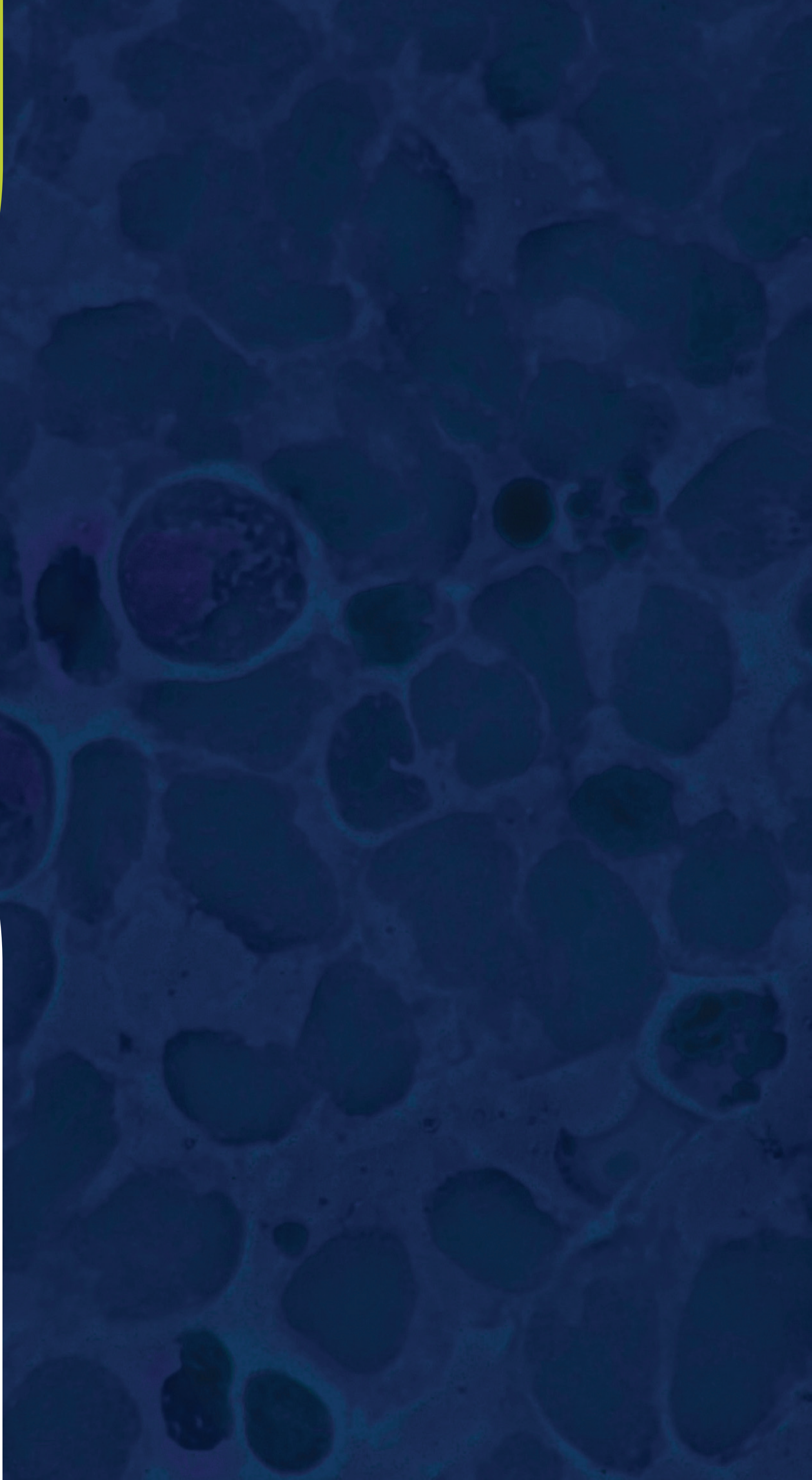
Contacte al Centro de apoyo al paciente

Llame al: 1 (888) 999-6743 De lunes a viernes, de 8:00 a.m.–5:00 p.m. Horario central

Correo electrónico: **pacienteinfo@nmdp.org**

Index

The essays, poems, letters and art in this book cover many overlapping themes, experiences and emotions. This index highlights some of the themes, but it is not all inclusive. The list here may be a starting point to explore the book, but we're certain you will find more emotion and expression in this book than could be outlined here.



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