

## Procedure for Obtaining Post-Transplant Consent to Release Personal Information

### Introduction

The donor's and recipient's decision to release their personal identifying information is an individual one. Some will want to do this, while others will not.

The Transplant Amendment Act of 1990 defines penalties for anyone who discloses the content of a donor record (identity, address, HLA type, managing donor center, etc.) without prior written consent from the donor with respect to whom the record is maintained. To comply with the Transplant Amendment Act, both the donor and recipient must provide signed consent before specific personal information can be released to their corresponding donor or recipient.

Per S00336, *Confidential Information Standard Operating Procedure (Unrelated Donor/Patient Confidentiality)*, it is required that all post-transplant requests to release personal information between donors and recipients be facilitated through the National Marrow Donor Program® (NMDP) Coordinating Center. Donor center staff and transplant center staff should not contact each other directly until after these consents have been signed and exchanged by the NMDP Coordinating Center assigned staff.

If a donor or recipient requests his/her/their identity be released to their corresponding donor/recipient, each individual must be informed of the risks involved in such a disclosure. The NMDP consent form, F00776, *Post-Transplant Consent Form to Release Personal Information*, addresses the risks and the benefits, and allows these individuals to specify exactly what personal information they choose to disclose.

Consent is only required if the donor or recipient wishes to release his/her/their personal information. The existence of this consent, and the procedure for obtaining consent from each party, should be discussed with the donor at workup during the Informational Session and with the recipient during the Pre-Transplant Education sessions.

It is important to understand the rules of the respective center/registry before initiating a request allowing donors and recipients to release personal identifying information with one another. It is NMDP Policy that no donor/recipient personal information be released to the other party until at least twelve months have passed since the stem cell transplant. However, some transplant centers and donor registries have unique policies regarding donor-recipient contact. You can find this information on the NMDP Network website, [International Policies Regarding Post-Transplant Communications between Donors and Recipients](#).

Instructions on how to correctly expedite consent requests through the NMDP are detailed in this document.

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### **Network Center Responsibilities to Counsel the Donor/Recipient PRIOR TO the Donation & Transplant:**

1. During the donor's Information Session or the recipient's Pre-transplant Education Sessions, discuss the NMDP's policy of not exchanging personal identifying information until at least twelve months after the transplant.
2. If the transplant center or donor registry is located outside the United States, check the [International Policies Regarding Post-Transplant Communications between Donors and Recipients](#) on the NMDP's Network website to learn the center's unique policy for donor-recipient contact before discussing the possibility of exchanging personal information with your donor or recipient.

### **Procedure to INITIATE a Request to Exchange Donor-Recipient Personal Information**

1. Review and complete the consent form (F00776, *Post-Transplant Consent Form to Release Personal Information*) with the donor or recipient if ALL of the following criteria are met:
  - a. The donor/recipient expresses interest in exchanging their personal information with the other party.
  - b. It has been at least 12 months after transplant (or the required timeframe has passed).
  - c. The other international center/registry allows post-transplant contact between donors and recipients.
2. Answer any questions the donor/recipient may have about the consent. Both the donor and recipient are free to accept or decline providing this consent.
3. If the donor or recipient chooses to disclose personal information, the associated center coordinator must ensure that the donor/recipient reads and understands all sections of the consent. The donor/recipient will then:
  - a. Designate what personal information they wish to release, and write exactly how the information should be presented. Any information provided on this form is considered acceptable for release.
  - b. Sign and date the consent. Signatures are those of the donor or recipient and a witness.
  - c. A contact name and phone number at the donor center or transplant center should also be provided at the bottom of this form.
4. Forward recipient/donor's signed and completed consent form (F00776, *Post-Transplant Consent Form to Release Personal Information*) to [connections@nmdp.org](mailto:connections@nmdp.org).
  - a. Upon receipt, the NMDP Patient Support Center will review the consent form for accuracy and inform the other center. The other center is considered the "Responding Center."

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- b. The NMDP-Patient Support Center will inform the Initiating Center of the outcome upon hearing back from the other center. If the recipient/donor at the responding center agrees to have direct contact, the TC/DC will forward the signed and completed consent form to [connections@nmdp.org](mailto:connections@nmdp.org).
  - c. Upon receipt of both signed consent forms at the NMDP, the NMDP-Patient Support Center will exchange consent forms with the respective centers. The NMDP will then consider this request as closed.
  - d. It is the responsibility of both the donor center and transplant center to maintain copies of all signed consents at their center.
5. If the Responding Center is unable to obtain a decision from their donor/recipient, they should communicate this with the NMDP Patient Support Center Post-Transplant team at [connections@nmdp.org](mailto:connections@nmdp.org). The NMDP Patient Support Center Post-Transplant team will allow up to 3 follow-up attempts, then determine if the request should be closed. The NMDP will communicate the closure in writing to both the initiating center and responding center.

**NOTE:** See the section titled *Special Circumstances* for additional details on when it is allowable to reopen a closed request.

### Procedure to RESPOND to the NMDP's Request to Exchange Donor-Recipient Personal Information

1. TC or DC receives an email from the NMDP Patient Support Center Post-Transplant team informing the Responding Center that the recipient/donor is interested in having direct contact with their recipient/donor.
2. The Responding Center Coordinator informs their donor/recipient that the other party wishes to exchange personal information.

**NOTE:** There may be circumstances when the responding center coordinator deems it inappropriate to inform their donor/recipient about the Request for Consent at that particular time. See the section titled *Special Circumstances* within this document for additional details.

3. If the donor/recipient expresses interest in exchanging personal information with the Initiating party, review and complete the consent form (F00776, *Post-Transplant Consent Form to Release Personal Information*) with your donor/recipient, and forward this consent to the NMDP Patient Support Center at [connections@nmdp.org](mailto:connections@nmdp.org).
  - a. When both signed consent forms have been received, the NMDP Patient Support Center will exchange consent forms with the respective centers. The Request for Consent will then be considered closed.
  - b. It is the responsibility of both the donor center and transplant center to maintain copies of all signed consents at each respective center.

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4. If the donor/recipient declines exchanging personal information, inform the NMDP Patient Support Center by indicating this decision by email to: [connections@nmdp.org](mailto:connections@nmdp.org) or by fax: 612-627-8195.
5. If you are unable to obtain a decision from your donor/recipient, you can inform the NMDP of the reason (e.g., unable to contact, unable to locate, donor/recipient not responding to our inquiries, etc.) by email to: [connections@nmdp.org](mailto:connections@nmdp.org) or by fax: 612-627-8195.

**NOTE:** See the section titled *Special Circumstances* for additional details on when it is allowable to re-open a closed request.

### **Special Circumstances:**

1. In the event the recipient dies a special consent form has been created titled F00778, *Post-Transplant Consent Form to Release Personal Information after Recipient Death* which the donor or recipient's family member should complete to provide their contact information and signatures. The transplant center and donor center coordinators should still submit a request using the F00778, *Post-Transplant Consent Form to Release Personal Information after Recipient Death* to the NMDP.
2. If the donor center or transplant center has specific concerns about allowing release of personal information between the donor and recipient, the center coordinator should consult with the NMDP Patient Support Center or NMDP Donor Advocacy Program for guidance on how to proceed with this request.
3. It is possible to re-open a closed Request for Consent if you later learn that your donor/recipient IS willing to exchange personal information with their transplant partner.

### **Exception:**

If contact between the donor and recipient is not reciprocated or maintained after the NMDP has provided copies of the consents to each associated center, the NMDP will not attempt to reinitiate contact with either the donor or recipient in the future.