

Confidentiality Guidelines

Why is it so important to maintain patient and donor confidentiality?

- The NMDP is mandated to do so by U.S. law and federal contract.
- To avoid the possibility of outside coercion and/or undue pressure put on potential donors to donate now or in the future.
- Anonymity ensures donors and patients do not receive unwanted publicity.
- To avoid a potentially adverse impact on other patient searches. If potential donors fear their personal information won't be kept confidential, fewer people will be willing to donate – which could ultimately make it more difficult for patients everywhere to find a match.

Providing facts in media stories

- Never reveal the location of the donor or recipient.
- Do not reveal the actual collection or transplant date. For example, *"... the donor donated marrow several weeks ago..." is appropriate, but "the donor donated marrow last Tuesday..." provides too much information.*
- Recipient and donor ID numbers should never be revealed, photographed or filmed.
- Use generalities about the age and sex of the patient or donor, and the disease of the transplant recipient. *For example, "...a teenager with leukemia..." is acceptable, but "...a 17-year-old boy with chronic myelogenous leukemia..." is too revealing.*

Filming the donation or transplant process

- If the collection of stem cells or their arrival is being filmed, film only at the collection center or hospital itself. Media coverage of a transplant should not begin until the stem cells have arrived at the transplant center.
- Do not capture place names or landmarks on film that may identify the city/location (e.g., hospital building that includes hospital name, well-known public site or building).
- Never film information that identifies the patient or donor such as donor/recipient names or ID numbers. Marrow address tags and labels should be concealed if the camera is filming the marrow bag or cooler.
- Do not capture items indicating the date such as a wall calendar.
- Do not follow the courier to the airport. Instead, here are some optional filming opportunities:
 - the courier leaving the hospital with the marrow (if possible, do not identify the courier on film)
 - lab shots showing marrow preparation
 - marrow leaving the operating room
 - a nurse or a physician leaving the operating room with marrow bags