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