

NATIONAL MARROW DONOR PROGRAM®

Creating Connections. Saving Lives.™



Opportunity to Participate in the
NMDP Research Sample Repository

An Opportunity to Participate in Research

Advances in medicine occur when carefully designed research studies determine that a new type of treatment works better than an existing one. The existing treatment is then replaced by the newer, better one.

In the field of stem cell (peripheral blood stem cells, marrow and umbilical cord blood) transplantation, researchers are continually evaluating factors that might improve the outcomes of stem cell transplants. Through these studies, researchers can learn which pre and post transplant factors lead to better results.

Why is the NMDP asking for a research sample?

To encourage research into stem cell transplantation, the NMDP asks both donors and transplant recipients to provide a research sample to be stored in the NMDP's Research Sample Repository. The NMDP then allows qualified researchers access to the samples to conduct research designed to make stem cell transplantation more successful for future recipients.

Some of the factors being studied include the degree of match between the donor and recipient; the type of stem cells collected from the donor; and the type of pre and post transplant treatment received by the recipient.

What kind of research is done on the samples?

The NMDP Research Sample Repository contains more than 10,000 sample pairs donated by donors and recipients of NMDP transplants. Each transplant pair is unique. At any given time several dozen research studies are using the samples from the Research Sample Repository or data generated from them in previous studies.

It's important to note that should you donate a research sample, it will most likely not have any benefit for you. However, research using the samples from the NMDP Repository may benefit future donors and recipients of stem cell transplants.



Research samples have been used on studies designed to:

- Improve the methods of matching donors and recipients.
- Determine which factors are most important when matching donors and recipients.
- Look for characteristics that can help predict transplant complications or failures.
- Determine the association between specific diseases and tissue types.
- Develop better treatment plans specific to certain diseases.
- Compare different sources of stem cells: peripheral blood stem cells, marrow and umbilical cord blood.



How does the NMDP assure privacy and confidentiality?

The NMDP follows strict rules to ensure that studies using research samples are conducted confidentially, ethically and scientifically. When used in a study, research samples are never associated with the names of the persons who donated them. To protect your privacy, your sample in the Repository is identified by a number, not your name. No publication or presentation based on research using research samples will include your name.

The NMDP has an Institutional Review Board (IRB) that reviews any research study involving NMDP donors, recipients and their samples. The IRB is a committee made up of scientists, ethicists and people from the community. The IRB is responsible for ensuring that the rights of people who participate in research are protected. The NMDP follows all guidelines set forth by the institutions that oversee research using human subjects.

Your rights as a participant in the NMDP Research Sample Repository

Participation in the NMDP's research program is entirely voluntary, and your decision on whether or not to donate a research sample will not affect your relationship with the NMDP – your donor center or your transplant center – in any way.

If you donate a research sample, you may at any time direct the NMDP to remove the sample from the Repository and destroy it.

Please feel free to discuss any concerns you may have about donating a research sample with the individual who is making this donation request.

If You Choose To Participate

If you agree to donate a sample to the NMDP Research Sample Repository, two tablespoons of blood will be collected from a vein in your arm. It's similar to having blood drawn for medical tests.

Your research sample will then be sent to the Repository where it will be processed and stored for possible study.



For a list of recent articles that used samples from the NMDP's Research Sample Repository, visit the NMDP Research Web site at www.nmdpresearch.org

For more information about your rights as a Research Sample Repository participant, please contact:

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