

# An Overview of Donation

A quick review  
of what's  
happened....



Some time ago,  
you provided a  
swab or blood.



Your de-identified  
data was listed on  
the Registry.



A patient got sick  
and the patient's  
doctors...



searched the  
Registry and  
picked you.

## Important now:

- ⇒ You are the best donor for this patient.
- ⇒ We want to quickly but carefully move along the path towards donation.
- ⇒ We're trying to identify potential issues so that we have time to find solutions.



## Next Steps



### Communication



If you haven't already, contact your Coordinator as soon as possible. Your Coordinator can help with all kinds of issues – fears, questions your Command or family may have, childcare concerns, scheduling conflicts, etc. The secret to an easy donation is honest and timely communication.



### Health History & Info Session

By phone, you will complete an information session and health history questionnaire with your Coordinator. Your Coordinator will work around your schedule to find adequate time to complete both.



### Consent Forms

Your Coordinator will send you a number of consent forms for different aspects of donation. Read, sign, and return them as soon as possible. If you do not understand the forms or have any questions, contact your Coordinator – it is his/her job to make sure you are well informed and have had a chance to have all of your questions answered.

## Arrangements



Your Coordinator is tasked with making all of the necessary arrangements for your donation, including locating healthcare providers and arranging travel. We understand that every donor has unique needs and circumstances and we will attempt to accommodate your needs. Be clear with your Coordinator about your needs and your preferences.

We will arrange and pay for all of the health exams and tests, donation itself, all required travel (including transportation, hotel, and food while traveling), and any required medications. We will provide documentation to your Commanding Officer or employer to arrange leave (TAD/TDY for active military). We can assist with child- and pet-care while you are absent.



## Physical Exam & Blood Testing

In order to ensure that donation would not present any special risk to you or your patient, we provide a very thorough physical exam. This may take place at one of our partnering facilities or at a qualified physician's office close to your location.

At or near the time of the physical exam, you will also be asked to submit blood samples for additional testing. Some of the blood will be used for infectious disease testing, some for testing requested by the Transplant Center (the patient's representative).



## Clearance

Once your physical exam and blood test results have been reviewed, you will be "cleared" to donate. This means two doctors agree that it is safe for you to donate.

## Important to Remember

At this point, it becomes crucial that the process not be interrupted. Your patient will begin what is called a "preparatory regimen". Basically, the patient's diseased bone marrow is destroyed using chemotherapy or radiation. Think of it as cleaning out space that your own cells will then occupy. Once that regimen begins, it is absolutely critical that the patient receive donated cells. Without them, the patient will most likely die.

If you have any doubts or concerns about donating, it is vital that you express these prior to the start of the preparatory regimen. While you always have the option of dropping out of this volunteer program, once the regimen has begun, you need to understand the consequence of this decision.

## Donation

While we often use the term “bone marrow”, a more accurate phrase is “hematopoietic stem cells” or HPCs. HPCs are the cells that live inside the marrow of your bones and produce other types of blood and immune cells.

There are currently two ways to collect these cells from donors – marrow collection and peripheral blood stem cell (PBSC) collection. Typically it is the patient’s disease type that determines which method of collection is requested, as the different methods yield slightly different treatment effects. However, your health history may disqualify you from being able to safely donate by one method. If you are unwilling to donate by one method, please alert your Coordinator as early in the process as possible.



The first method of collecting HPCs for transplant is by drawing the cells directly from a rich marrow source, the hip bones. Special, strong needles are used to create tiny holes in the crest of the hip bone and remove a portion (no more than 5%) of the soft, soupy marrow inside. Multiple needle insertions are made on each of the hip bones, near where you find the top of the back pocket on a pair of jeans. This procedure is performed under anesthesia, and typically takes 1-2 hours.

Depending upon the amount of marrow you have been asked to donate, you may have a unit of your own blood that was collected prior to donation returned to you now. This is called an autologous unit (or “auto unit”) of blood, and your Coordinator will make all of the arrangements for its collection at a convenient blood bank.

You may or may not be kept overnight in the hospital after the procedure. This decision is made on a case-by-case basis and depends upon the collection center/hospital policy and how you are feeling.

Common side-effects of marrow donation include soreness, especially at the hips and lower-back, and fatigue. Pain medications will be provided. We ask donors to rest and take it easy for about 2 weeks after the procedure.

Risks for this collection method include the normal risks of using anesthetic, bleeding, and muscle, bone, and/or nerve damage. They are rare, but can occur.



The second form of collecting HPCs is called peripheral blood stem cell (PBSC) collection. Donors are given five days of injections of a drug called filgrastim (Neupogen®) that causes the bones to release extra HPCs into the blood stream.

Injections are given around the same time each day, typically in the arm. Some donors travel to the Apheresis Center for all five days of the injections – others have the first few injections locally and then travel at the mid-point. You will be assessed daily to see how you are feeling. Common side-effects of filgrastim include body aches, fatigue, headaches, and nausea. These may vary from mild to significant, but typically resolve within a few days of donation. You can contact your Coordinator any time you have questions or concerns.

On the 5<sup>th</sup> day, you will undergo an apheresis procedure. Blood is removed from a needle placed in one arm, screened by an apheresis machine, the HPCs are removed and collected, and the rest of the blood is returned through a needle in your other arm.

The apheresis procedure itself can take anywhere from 3-6 hours. During that time, you will be awake and laying in a bed or chair. You must remain still, but you can watch television or eat a snack.

Risks for this collection method include rare but serious side-effects of filgrastim, such as spleen enlargement or rupture. We ask donors to limit their physical activity while taking filgrastim and for two weeks after to avoid injury. If the veins in your arms are insufficient, a line may be placed by a trained physician in one of your larger veins.

*Does it hurt? There is discomfort associated with either type of donation, but it varies greatly between people and experiences. Most donors report being very happy with their donation experience and are willing to repeat it.*



## Your Donated Cells

Immediately after they have been collected, your donated cells will be hand-carried by a specially-trained courier to the patient's Transplant Center. Your cells are given to the patient, typically within 48 hours.

The goal of this whole process is "engraftment" – the infused cells will travel to the patient's bones, where they will settle in and begin creating an entirely new immune system. Unfortunately, there are a lot of ways that things can go wrong for the patient, such as the cells may fail to engraft, the new immune system may be too weak to fight off normal infections, the original disease may return, or the new immune system may be too strong and cause "graft vs. host disease".

Beyond providing cells, donors cannot control the success of a transplant, so it is important that you do not feel personally responsible for its outcome. There are no guarantees of success.



## Recovery

The vast majority of donors recover completely within about 2 weeks of donation. We ask that you take it easy for the period of time recommended by your physician. This means no strenuous exercise or heavy lifting. Your HPCs will replenish themselves within about 6 weeks. Your Coordinator will call you regularly to see how you are doing after you donate.



## Reimbursement

Travel, hotel, and all medical expenses are paid directly by our program. If you need to pay out-of-pocket for anything related to donation, we will reimburse you. Written directions will be provided by your Coordinator.

## Future Contact

Most donors are extremely curious about their patients, but protecting both donor and patient privacy is important. Please keep in mind:

⇒ Transplant Centers located inside the U.S. are supposed to provide updates about your patient at the one-month, six-month, and one-year points. Internationally-located Transplant Centers follow different rules and may allow only limited information or no information at all. Your Coordinator will discuss with you what you can expect regarding updates on how your patient is doing and if future contact is allowed.

Be careful what information you post on social media about your donation experience to protect both your privacy and the patient's. For more information, see NMDP's resource (<https://bethematch.org/socialmediaguidelines/>).

## Delays & Cancellations

Only very sick patients need transplants. Changes in the patient's health status may cause delays or cancellation. We will contact you as soon as we are aware of changes in plans.



It is our pleasure to work with you towards donation. Our team will do everything we can to make this experience a positive one.