

A Volunteer's Guide to Confirmatory Typing



Congratulations!



Dear Friend,

The Gift of Life Bone Marrow Foundation has contacted you because you are a potential match for a patient needing a bone marrow or blood stem cell transplant. As you may recall, you registered with us at a community donor drive or through the mail using an individual testing kit.

Your tissue type has been kept on file with our registry of volunteer donors. This database is screened daily by transplant centers around the world searching for donors on behalf of the many patients who need transplants. Your identity as a donor is kept strictly confidential.

Perhaps you were tested for a family member or friend seeking a donor. Perhaps you saw a flyer or a newspaper article about a member of your community who needed a transplant. You may even have been tested at your college's Hillel or Alpha Epsilon Pi chapter. Whatever the reason for your initial recruitment, we are excited to report that you are on your way to participating in perhaps the greatest act of kindness — giving the gift of life.

The purpose of this brochure is to give you an overview of what is involved in bone marrow and blood stem cell donation, so that you can make an informed decision whether to proceed with the next step, *Confirmatory Typing*.

On behalf of the thousands of patients around the world who have been given a second chance at life because of people like you, thank you for considering this opportunity to become a donor. If you would like additional information to help make a decision, please visit our website at www.giftoflife.org or contact your donor services coordinator at 1-800-9MARROW.

Sincerely,

A handwritten signature in black ink that reads "Jay Feinberg".

Jay Feinberg
Founder & Executive Director



Giving the Gift of Life

Gift of Life is an internationally recognized organization facilitating bone marrow, blood stem cell and umbilical cord blood transplants for children and adults suffering from life-threatening illnesses. Since its inception in 1991, Gift of Life has facilitated over 1,000 transplants for patients around the world. Because tissue type is inherited, a patient's best chance of finding a genetic match lies with those of similar ethnic background. Gift of Life strives to increase the representation of Jewish donors in the registry in order to overcome the devastating effects of the Holocaust, which severed bloodlines.

The donation process is completely voluntary. We ask that you take some time now to educate yourself about becoming a donor. If you are chosen as a match, discuss this opportunity with your family so that you can be certain about your decision to proceed with the donation process.

Confirmatory Typing

You have been contacted by Gift of Life because you are a potential match for a patient who needs your help. The next step in the process of becoming a donor is called "Confirmatory Typing." At this stage, you will be asked to give a sample of blood which will be analyzed to confirm that your tissue type matches that of the patient closely enough to offer the best chance of survival.



Blood stem cell donor, Joel, during his collection.

What is being asked of me at this point?

At this stage you are being asked to consider giving a sample of blood (a maximum of 80 ml, which is less than three ounces). Your blood sample will be analyzed to ensure that you are a suitable match for the patient and screened for markers of infectious diseases including:

- HIV
- Hepatitis
- Syphilis
- CMV (cytomegalovirus)
- Other Infectious Diseases



Your blood sample will be sent to the transplant center for confirmatory tissue typing and an affiliated reference lab for infectious disease testing.

Please note that you will not be eligible to donate stem cells or bone marrow if you become pregnant. Once you agree to begin the Confirmatory Typing stage, we ask that you plan accordingly to prevent pregnancy from occurring during this time period.

When and where can I go to give my blood sample?

Your blood draw will be scheduled by a member of Gift of Life's Donor Services team at a lab that is convenient to your home or work. Due to restrictions concerning the shipping and receiving of blood products, your sample must be drawn in the morning on specific days. Every effort will be made to accommodate your schedule so that your appointment will be as convenient as possible.



Prior to your blood draw, you will need to sign a consent form authorizing the testing of your blood sample. Once you are sure you want to proceed, please sign it and return via fax to Gift of Life at (561) 988-0141. **Your testing cannot take place without returning this form to our Donor Services department.**

What happens next?

It takes an average of four to six weeks to get the results from your blood tests. Based on those results, the Transplant Center will select one of three options:

1. **You will be requested to donate.** This means you are a match! The next stage in the process is known as “Workup.” A Gift of Life coordinator will walk you through the remaining steps to becoming a donor!
2. **You will be released.** This can happen for a variety of reasons including that a more suitable donor has been found, or the patient is not ready to receive the transplant.
3. **You will be placed “on hold.”** This means that the transplant center is not ready to release you, nor do they want to request you as a donor yet. The maximum amount of time you will be placed on hold is generally three months. Your Gift of Life coordinator will contact you at least once a month to give you an update on your progress.

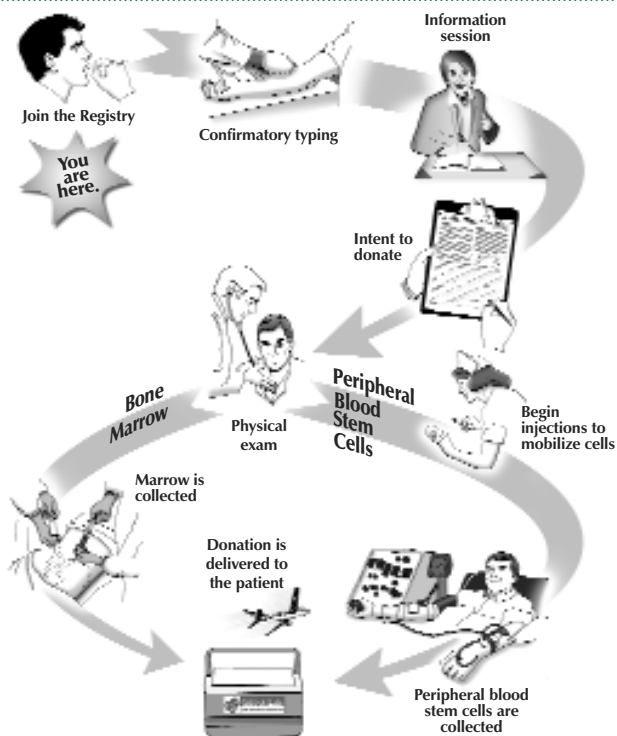
If you are requested for workup, Gift of Life will arrange an information session to further educate you on the donation process. If after your information session you agree to participate, you will be asked to sign a form indicating your intent to proceed with the donation. You will then undergo a physical exam, usually at a hospital where the donation will take place.

What will I be asked to donate?

You will be asked to donate either bone marrow or peripheral blood stem cells. Stem cells are the immature cells that produce red and white blood cells and platelets, which are the major components of blood. They are found predominantly in both bone marrow and in much smaller quantities in the peripheral blood. Patients suffering from malignant and inherited diseases, as well as immune system disorders can be treated with transplants of healthy stem cells from volunteer donors like you.



Steps to Becoming a Donor



How is bone marrow collected?

Bone marrow is found in the hollow cavities of the body's large bones. It is withdrawn from the posterior aspect of the pelvic bone, in an area called the iliac crest, under sterile conditions with needles and syringes. The procedure itself can take an average of one to two hours and is performed in a hospital operating room under either general or regional (i.e. spinal or epidural) anesthesia.

Most donors go home from the hospital on the day of their donation, although some are asked to stay overnight. Typically, donors can expect to experience soreness for a few weeks and are given a prescription for pain medication, if necessary. This is usually only needed for the first days following the procedure. Most donors are able to take Tylenol™ to help alleviate the soreness. Since marrow regenerates completely within four to six weeks, you can become a donor more than once throughout your lifetime. Donors should consider taking a couple of days off following the procedure, and must avoid strenuous activities for several days after the donation.

For more information on the process of bone marrow donation, please visit www.giftoflife.org or contact a donor services coordinator.



How are peripheral blood stem cells collected?

Though stem cells are found in the bone marrow, they can be collected from the circulating blood through a process called

apheresis. In order to mobilize the stem cells from the bone marrow into the peripheral blood, donors are given injections of a medication called filgrastim (Neupogen®). These injections are given once a day for five days prior to the collection by a nurse or physician. Side effects of filgrastim generally include symptoms such as achiness and fatigue. Some donors may also experience headache, nausea and bone pain. These symptoms subside when the filgrastim is no longer administered. Filgrastim is routinely used in normal, healthy volunteer donors, but this use has not yet been approved by the Food and Drug Administration (FDA).

On the day of the collection, the donor undergoes the apheresis procedure in a hospital. A blood collection needle is placed in each arm. The donor's blood is removed from one arm and processed through a cell-separating machine that collects the stem cells. The donor's blood is then returned through the other arm. The collection usually lasts for up to five hours on one or two days. The amount of the stem cells collected will depend upon the size of the recipient. This amount, delineated by a stem cell count, will determine whether donors will need to return for a second day of collection.

Approximately 10 percent of donors do not have veins large enough to perform the apheresis process. All donors are evaluated for venous access at the time of the physical exam. Donors who do not have sufficiently accessible veins will be counseled on the potential use of a central line, a temporary blood drawing tube inserted in a large vein in the neck.

For more information on the process of peripheral blood stem cell donation, please visit www.giftoflife.org or contact a donor services coordinator.



Can I choose whether I will donate bone marrow or peripheral blood stem cells?

The patient's transplant physician determines whether bone marrow or blood stem cells offer the patient the best chance of survival. Gift of Life has no control over which stem cell source is requested. Ultimately, the decision to proceed is entirely up to you, the donor.

What information will I be given about the recipient?

In order to protect both donors and recipients, privacy laws governing the transplant provide that the process must be anonymous. The only information you will receive is the recipient's age, sex and diagnosis. In some cases, donors and recipients are permitted to meet one year after the transplant, with mutual consent.

What if I change my mind?

After your information session, you will be asked to sign an intent to donate form. While this does not constitute a legal obligation on your part, Gift of Life considers it the donor's firm commitment. In order to receive the transplant, the patient begins a conditioning regimen to eradicate his/her disease. The conditioning destroys the patient's bone marrow. Without your stem cells, the patient would not survive. For this reason, we ask that you carefully consider the decision to proceed at this point. You should take some time to study the educational information, ask questions, and talk it over with your family. Gift of Life will be happy to put you in touch with previous donors who can tell you exactly what the experience was like for them.



From a Donor

MF

Dear Friend,

Like you, I will never forget the day I received the phone call from Gift of Life. When I learned I was a possible match, a potential donor, I felt like I had won the lottery. My recipient, a 29 year old leukemia patient needed me to save her life. Looking back, I think I was the true recipient. How many people get the chance to save someone's life? She was the real donor, the donor of lessons that I will hold for the rest of my life about kindness, giving and life.

To say that becoming a donor for a cancer patient has changed my outlook on life is an understatement. I cherish the letters I received from her in the year after the transplant, and I would like to share something she wrote to me:

The tomorrow that brought my cancer with it wasn't a completely rotten day. I have learned that people come first, not your job. I appreciate the miracle of each day like our perfect match, instead of harping on the bad stuff. I celebrate, really celebrate the birthdays and anniversaries. I have no choice but to live with cancer but I have lived.

I will live the rest of my life to thank you in any way I can. You are an amazing soul to have taken that one second to decide to donate means the rest of my life and I just can't thank you enough.

The people at Gift of Life made the relatively simple procedure so easy. They took care of everything and more importantly, took great care of me. I am asked if I would be willing to donate again. I would do it a hundred times if I had to. It was a five hour procedure. Five hours of my life, and I was able to save a life. I think that is the highest paying job I could ask for. This mitzvah I did is compared to saving the entire world. What a Zechus!

Rita F...

Moshe donated blood stem cells and saved the life of a young woman from Florida named Jennifer. The two met at Gift of Life's Partners for Life Gala in New York one year after the transplant.



7 July 2004

Dear student,

many of you have taken CCR/
 emergency aid instructions to respond to a
 rare emergency and save a life.
 This greatest of mitzvot (good deed) need not
 wait for such an occasion. You can earn the
 reward of saving a life by donating stem cells
 to those already afflicted with life-threatening
 illness for which, the only cure, is a stem cell
 transplant. Torah (biblical) law obligates all
 who can save a life without risk to oneself,
 to do so. It is not to be viewed as a
 "donation". It is an ethical, moral, religious
 obligation to save a life, without regard to
 the patient's race or religion.

I pray that you will enjoy
 good health, and success in all your
 endeavors.

Moshe David Tendler, Ph.D.
 Prof. of Talmudic Law (YU affiliate)
 Sr. Prof. of Biology - Yeshiva College
 Prof. of Medical Ethics - Yeshiva University



Tzvia and Alon's Story



For six-year-old Alon and his family, life in the small Israeli town of Afula changed dramatically after learning that he had leukemia and needed a blood stem cell transplant to survive. When no one in his family was a match for him, they were forced to look elsewhere for a donor. Luckily, word came from the United States that a perfect match had been found on Gift of Life's registry of donors.

Alon's donor was Tzvia, a mother of two from Long Island, New York. Tzvia said, "When I first received the phone call that I was a match for a little boy, I was stunned. I thought these things only happen to other people, extraordinary people, not regular people like myself." To Alon, a young boy who can now look forward to a long and happy life, Tzvia is extraordinary. Gift of Life makes heroes of regular people all the time.

Tzvia's blood stem cells were flown to Israel and personally delivered to Alon's hospital by Gift of Life's Executive Director, Jay Feinberg, himself the recipient of a bone marrow transplant. According to Alon's mother, Larissa, "Tzvia now has a new son in Israel."

According to Tzvia, "Part of being an Orthodox Jew is helping each other in a time of need. So that's what I did. It was really G-d's will. To save someone's life is the greatest gift of all."

The Role of Gift of Life

Gift of Life maintains a computerized registry of potential volunteer bone marrow and blood stem cell donors, and umbilical cord blood units. Transplant centers may search the registry in order to identify potential donors who they consider appropriately matched with the patients under their care.

Gift of Life enrolls donors in its registry through recruitment drives, conducts **preliminary** eligibility screening of donors, and serves as a liaison between donors, collection centers and transplant centers. While Gift of Life coordinates these activities, it **does not** select appropriate "matches" for patients needing transplants; establish final eligibility and suitability of bone marrow, blood stem cell or lymphocyte donors; prescribe or administer medications for/to donors; or harvest marrow, peripheral blood stem cells, donor lymphocytes or umbilical cord blood. These activities are undertaken by collection centers and transplant centers.

Mission

Gift of Life facilitates bone marrow, blood stem cell and cord blood transplants for children and adults suffering from life-threatening illnesses. Since tissue type is inherited, a patient's best chance of finding a genetic match lies with donors of similar ethnicity. Gift of Life strives to increase the representation of Jewish donors in the registry in order to overcome the devastating effects of the Holocaust, which severed bloodlines.



Gift of Life

BONE MARROW FOUNDATION



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