



Chai Lifeline

Fighting Illness With Love

A Volunteer's Guide to Stem Cell Donation.

preface

In an effort to address the most common concerns of potential bone marrow donors in the Jewish community, in 1998 Chai Lifeline published *A Volunteer's Guide to Bone Marrow Donation*. The guide was designed to take potential volunteers through every step of the bone marrow donation process in which transplanted donor stem cells generate the growth of potentially life-saving new marrow in the patient.

Since the guide was published, however, donation techniques using stem cell sources other than bone marrow have become viable options for many people considering donation. Where it was once possible to talk only about bone marrow donation, a comprehensive discussion of transplantation today would more appropriately go under the heading of “stem cell” donation. This revised edition of the volunteer's guide — which fully explores all the donation options currently available — has therefore been renamed, *A Volunteer's Guide to Stem Cell Donation*.

There may be any number of reasons why you are considering becoming a stem cell donor.

Perhaps your heart has been touched by the plight of someone like Chaim, a young father of four who has been diagnosed with leukemia and whose only hope for survival is to receive a stem cell transplant.

Or maybe you're thinking about it because of someone like four-year-old Sara — a beautiful little girl who suffers from a disorder of the immune system that, if left untreated, will almost certainly prove fatal.

Or perhaps your reason does not have any particular name or face attached to it — it simply reflects your desire to increase the odds that one of the thousands of individuals diagnosed with a life-threatening blood disease will be given a second chance.

Whatever your motivation, you are thinking about donating stem cells because, as a Jew, you feel a strong desire — indeed, a responsibility — to give of yourself to help another.

Understandably, though, you may be a little apprehensive about making the commitment to become a stem cell donor. There are so many questions running through your mind: What are the risks involved in donating stem cells? Is there much pain? Will my stem cells be going to another

Jew? Why is the identity of the patient not revealed at the time of donation? If called upon to donate, can I refuse to go ahead with the process?

To answer these questions and others typically of concern to prospective donors, Chai Lifeline — a worldwide organization dedicated to helping individuals and families cope with medical crises — has published *A Volunteer's Guide to Stem Cell Donation*. While at Chai Lifeline we recognize that many people have legitimate reasons for not becoming stem cell donors, many others hesitate to take the step only because they don't know enough about the process. This guide has been designed to help those people — people like you — get the facts they need to make informed decisions about stem cell donation.

If after reading this guide you still have questions about the transplantation process, please feel free to contact Chai Lifeline. In our goal to educate members of the Jewish community about this vital, life-saving procedure, we stand ready to serve as an information and support center both for prospective volunteers and for those who have already been tested as donors.

So please read this guide carefully.

The facts are all here.

The decision is up to you.

“I just felt it was the right thing to do.”

For Reuven Green, the decision to become a stem cell donor was an easy one.

He had first been tested in 1989 at a drive for Jay Feinberg — a young Jewish man who had been diagnosed with leukemia. Although Reuven did not prove a match for Jay, two years later he received a call informing him that he was a potential match for yet another desperate patient, one whose identity he did not know.

“I was fairly certain my marrow would go to another Jew,” says the 27-year-old Brooklyn resident. What Reuven had learned when researching the marrow transplantation proce-

How does the national registry system work?

Each year, approximately 30,000 new patients are diagnosed with leukemia, aplastic anemia and other life-threatening diseases. Many of these patients could be cured with a stem cell transplant using stem cells from another person — a donor. Donated stem cells — which are found in the donor’s bone marrow, the donor’s blood stream (peripheral blood) or in cord blood (a more detailed discussion of cord blood donation begins on page 17) — allow new marrow to grow in a transplant patient. Marrow produces three major blood components: red blood cells, white blood cells and platelets responsible for clotting. These are the main agents of the body’s immune system.

In a stem cell transplant, the closer the match in what is known as Human Leukocyte Antigens (HLA) type between the donor and recipient, the

greater the chance the transplant will be successful. Because these antigens are inherited, just like eye or hair color, a patient’s best possible match is another blood-related family member, generally a sibling.

Yet, only about 30 percent of patients have family members who can donate stem cells. The remaining patients must rely on volunteer unrelated donors and cord blood donors. Up until 1986, patients efforts to canvass the country in hopes of identifying an unrelated donor were limited to searching small, independent donor registries or organizing private bone marrow transplant drives.

Since that time, the search for unrelated donors has been immeasurably facilitated by the establishment of “national registries” of potential donors.

The national registries and the local donor centers around the country work together in the following way: After being

ture was that since some characteristics of marrow type are unique to people of specific ancestry, the most probable match from a non-relative for one Jew is another individual of Jewish descent.

Yet, Reuven was not at all deterred by the far lesser likelihood that his marrow would not go to a fellow Jew. "I didn't feel it was up to me to decide who would or would not get my help. The Ribbono Shel Olam was giving me an opportunity to help save the life of another human being — that's all the information I needed to have."

As it turned out, follow-up blood tests showed that Reuven's precise HLA-type was

tested by his or her local donor center, a potential donor's HLA type is automatically listed with one of the national registries.

While the donor center keeps a record of the volunteer's name, birth date, address and phone number, the national registries maintain no personal information other than the volunteer's assigned record number, HLA type and local donor center.

(This system has been designed to protect the identities of potential donors. See page 14.)

When a volunteer's HLA type is identified as a possible match for a patient searching the national registries (routinely, all the registries are searched by patients seeking an HLA match), the national registry that has identified the match contacts the local donor center. It is the local donor center which then contacts the volunteer.

How do I volunteer to become a stem cell donor?

The first step of the process is to have a simple blood test at a local donor center or stem cell drive site. While donor centers will usually charge for testing (prices may vary from center to center), the cost of testing at a patient-focused drive is generally covered by the patient's family or a sponsoring organization.

Recruitment drives — such as those held on college campuses or in the corporate workplace — as well as general or patient-focused drives sponsored by local community organizations, bikur cholim associations or other organizations are always conducted in conjunction with a local donor center. It is the local donor center that tests and tissue types the blood, assigns record numbers and maintains all personal identifying information.

not compatible with the patient's. Four years later, however, he was contacted again. This time he was identified as a match.

Reuven describes the actual donation experience as "much easier than expected. Beyond feeling some discomfort for about a week after the procedure, I found the whole process to be fairly painless." While donors may occasionally be required to remain in the hospital overnight for observation, Reuven — like the majority of volunteers — was able to go home later that same day. Within a few days, he was back to his normal routine.

The local donor center forwards the volunteer's record number and tissue type to the national registry where it becomes available to any patient searching the registry. If a potential match is found, the national registry will contact the local donor center who will then contact the volunteer.

What if I participate in a drive sponsored by a particular organization? Who will contact me if I prove a match?

If you take part in a general or patient-focused drive sponsored by an organization (such as Chai Lifeline or a local bikur cholim association) be aware that your HLA type and personal information are being maintained by a participating local donor center, not by the sponsoring organization. Remember, it is the local donor center that will contact you in case of a possible match, not

the organization that sponsored the drive. The name of the participating local donor center is available at the drive site.

What if my address or telephone number changes?

Since it can be devastating to the patient when a volunteer is unreachable, be sure to keep your local donor center apprised of any changes in name, address or phone number. Any changes in the state of your general health should also be reported. After your blood is tested, you will be presented with a card listing the local donor center's name and number. Be sure to keep the card in a safe place.

Should I report the changes to the national registry as well?

No.

Reuven has never regretted his decision to become a volunteer stem cell donor; if called upon to do it again, he says, he would not hesitate.

"It's hard to describe the feeling of satisfaction I got from the experience. Not only was I given the chance to make a real difference in someone's life, as an obviously Orthodox Jew willing to help an anonymous stranger, I believe I was able to create a true kiddush HaShem in the process."



Reuven Green

The national registry maintains no personal information about you other than your assigned record number, your HLA type and the name of the donor center at which you were tested.

What if I lose my card and can't remember where I was tested?

As stated earlier, it is essential that you can be readily reached in the event you prove a match for a patient. So don't simply assume that because you can't remember the name of your donor center, there is no way you can report a change of address or phone number. The following are among the steps you can take to identify the donor center at which you were tested:

- If you were tested by a donor center affiliated with the National Marrow Donor Program (one of the national registries), you are probably receiving the NMDP's newsletter, Marrow Messenger, which bears the ID number of your donor center on its cover.

If you call the NMDP (1-800-MARROW) and give them the ID number, they will tell you the name and number of your donor center.

- If your blood was tested at a drive sponsored by a particular organization (like Chai Lifeline), that organization can give you the name of the donor center that conducted the testing. Call for assistance.
- Call Chai Lifeline. We will be happy to guide and assist you in your search.

Must I meet any specific criteria to qualify for testing by a local donor center ?

To qualify for testing by a local donor center, volunteers must be between the ages of 18 and 60 and in good general health. In accordance with national registry guidelines designed to protect the health of the patient and the donor, certain health conditions may make a vol-

Elaine Shapiro has never thought about becoming a volunteer stem cell donor — indeed, she knew next to nothing about what the commitment involved — until the fateful night she accepted an invitation to have dinner out with a friend.

“On the way to the restaurant, my friend asked me if I’d mind making a quick stop at a local synagogue that was sponsoring a marrow drive for Jay Feinberg,” says Elaine. “Although I certainly didn’t mind accompanying her, I never dreamed that I’d actually end up participating in the drive myself. But after talking to some of the people there and reading some of the literature on hand, I just knew I had to join.”

One of the things Elaine learned that night was that the most likely match for a Jewish patient who can’t find a compatible donor within his or her own family is an unrelated individual who is also Jewish. She realized that even if she would not prove a match for the young man she had signed on to help, simply by having her blood tested

unteer ineligible for stem cell donation. (These are usually the same conditions that would make one ineligible to donate blood in a blood bank.)

How does a stem cell transplant help the patient?

Stem cell donation helps patients with life-threatening blood disorders. It is the stem cells found in either the donor’s bone marrow or blood stream (peripheral blood) that, when transplanted, allow new and healthy stem cells to grow in a patient. These stem cells found in marrow or peripheral blood produce three major blood components — red blood cells, platelets, and white blood cells

— which are the main agents of the body’s immune system.

In a stem cell transplant, the closer the match in Human Leukocyte Antigens (HLA) type between the donor and recipient, the greater the chance the transplant will be successful. These antigens are genetically determined, just like eye or hair color. Thus siblings have a one in four chance of having the same HLA type, while other blood relatives — including parents — are considerably less likely to match, though they still have a much higher likelihood of doing so than strangers.

and her tissue type entered in the national registry, she would be increasing the odds that somewhere in the world, another Jew in need would get a second chance at life.

Almost a year later, Elaine was contacted by her local donor center with the news that she was a potential match for a patient.

"I must admit I was surprised," says the Boston resident who works as a headhunter for actuaries. "In my line of work I'm used to dealing with people who think in terms of percentages and probability. Frankly, when I joined, I thought it was pretty unlikely I'd ever be contacted."

Still, from the moment she got the call, Elaine never really doubted she'd go through with the procedure — not when there was someone out there who so desperately needed her help. With the proud support of her family, Elaine underwent follow-up testing, which confirmed that she was indeed a precise HLA match for the patient. A comprehensive information session and a thorough physical exam came next.

Outside of his or her own family, where is a patient most likely to find an HLA type match?

The chances of finding an unrelated donor vary widely, depending on the rarity of the patient's HLA type. Since some characteristics of HLA type are unique to people of the same racial or ethnic background, it is most likely that a match will come from among individuals of shared ancestry. Consequently, when someone of Jewish descent chooses to become a volunteer stem cell donor, he is contributing to the strong likelihood that a fellow Jew will find a match.

If you are ever matched with a patient in need and are unable to donate, keep in mind that

because of your shared genetic background your sibling may also be a match for the patient. You may wish to share this information with your sibling.

How are stem cells taken from the donor?

There are two ways to remove stem cells from the donor. The first, more traditional method is bone marrow donation; the second, newer method is known as peripheral blood stem cell (PBSC) donation. The patient's medical team determines whether it prefers peripheral blood stem cells or marrow. (See pages 10,11,12.)

"I'd never been hospitalized, so for me the idea of going into an operating room was the scariest part of the whole thing," remembers Elaine. "But the medical personnel involved with the transplant were wonderful; they kept me fully informed, explaining what would happen every step of the way. In the end, it was all so much easier than I'd ever imagined. There was no real pain to speak of, and the recuperation was fast and uneventful."

At the time of the donation, Elaine was given virtually no information about the identity of the patient. A month later, though, she was told by her local registry that the recipient was a teenage girl. But the really exciting news was that the patient was doing well. Elaine was to receive equally encouraging updates at the six-month and nine-month marks.

But it was not until a little over a year later that Elaine actually learned the name of the young girl to whom she had given the gift of life — Maital Cohen, a 15-year-old living in Florida. Elaine describes their first phone conversation as "unbelievable". But it

What happens during the bone marrow collection procedure?

In bone marrow donation, marrow is removed from the donor's lower back by a needle aspiration.

Typically, the donor enters the hospital on the day of the donation. After the donor receives general or regional (spinal or epidural) anesthesia, the marrow is removed from the rear of the pelvic bone (in the lower back) with a special needle and syringe. This process usually lasts 60 minutes. The marrow is then processed and transfused directly into the patient's blood stream. Healthy marrow cells travel to the patient's bone cavities where they begin to grow and replace the old marrow.

After the marrow collection, the donor remains in the hospital for several hours or, in some cases, overnight.

The amount of marrow taken from the donor depends on the weight of the recipient and is completely replenished in 4-6 weeks.

Does it hurt to donate marrow? Is the recovery difficult?

Because anesthesia is used, donors don't feel any pain during the marrow collecting procedure. For several days following the procedure, a donor may feel some soreness in the lower back. Other symptoms may include fatigue, pain at site of donation, pain with walking,

would pale in comparison with their first face-to-face meeting at a Chai Lifeline dinner held a while later in Miami.

"It was so emotional for everyone involved," recalls Elaine. "As for me, I was just in awe. All along I'd been imagining what it must be like for the patient to have gotten a new lease on life. I hadn't really thought much about what an impact it would have on her family and all the other people who love her.

"They were all so thankful, so happy — just looking at their faces, I knew that I'd made the best decision of my life."



Maital Cohen and Elaine Shapiro

low back pain, sore throat, pain with sitting, nausea and light-headedness.

Despite these symptoms, results of donor surveys indicate that 91% of donors would donate again if asked, and less than 2% would decline future donations.¹

Are there any serious risks to the donor in bone marrow donation?

The marrow collection process is itself essentially without risk. Problems that have been reported include infection at the needle insertion site, a rare complication which is easily treatable with antibiotics. Because blood loss can also occur, donors routinely store two units of their

own blood to be given during and after the procedure.

While there is a minimal amount of risk associated with the administration of anesthesia, donors' concerns about anesthesia reactions are generally allayed by the knowledge that spinal or epidural anesthesia can be used instead of general.

What happens during PBSC collection?

Since the number of stem cells found in peripheral blood is much smaller than in marrow, the donor is given a growth factor medication to increase the number of stem cells in the blood stream. The growth factor is injected daily for four or five consecutive days.

Maital Cohen was not quite seven-years-old when she was diagnosed with ALL (Leukemia).

In the years that followed the diagnosis that nearly devastated the Cohen family, Maital was in and out of remission. By the time she was 14, her doctors had concluded that her only hope for survival was a bone marrow transplant. Maital was so sick at that point, however, not a single hospital the Florida family contacted was willing to undertake the procedure.

The injections are usually administered by a medical professional and may be given at the donor center or at a designated clinic near the donor's home. In some cases, a home health nurse or a family member may administer the injections.

Stem cells are collected through a procedure called "apheresis", which is generally performed at a blood donor center or hospital outpatient unit. In apheresis, blood is removed with a needle inserted in one arm and sent to a machine that separates out the stem cells. The remaining blood is returned through a tube and needle inserted in the donor's other arm. The collection procedure requires approximately 4 1/2 hours. If the stem cells cannot be collected using the veins in the donor's forearm and a needle, a plastic tube, called a central line, is placed in a large vein. (Recent studies indicate that between five and ten percent of PBSC donors may

require a central line.) The number of apheresis collections is dependent on the size of the stem cell recipient.

As in bone marrow donation, the body naturally replaces the donated stem cells within a few weeks.

Is the recovery from PBSC donation difficult?

Recovery from PBSC donation is generally rapid. Side effects of the growth factor, which may include muscle and bone aches, headaches and fatigue, diminish within two days after the last dose is given.

Less often, nausea, vomiting, insomnia and irritability may occur.

Is there any discomfort associated with the PBSC process?

Because calcium levels sometimes drop during PBSC

Finally, the doctors at Memorial Sloan-Kettering Cancer Center in New York agreed to do the transplant.

“From the start, the doctors there made it clear to us that they held out very little hope,” recalls Maital’s mother. “They told us there was a less than 10 percent chance that Maital would leave the hospital.”

The search for a donor whose HLA type would be compatible with Maital’s yielded miraculously quick results; within just a few weeks, a donor was identified through the

donation, the donor may experience dizziness and a tingling sensation in the hands and feet. Tums relieves these temporary symptoms.

Are there any serious risks to the donor in PBSC donation?

Since anesthesia is not used during the PBSC collection process, there are no serious risks associated with the donation procedure.

Though no long term data is yet available regarding risks associated with the blood cell growth factor medication, several studies report no adverse effects on donors up to five years after donation.²

How are the stem cells transplanted into the patient?

The stem cell transplantation process is the same for bone marrow and PBSC donation.

After undergoing rigorous treatment to wipe out the diseased cells, patients receive the donated stem cells intravenously — much like a blood transfusion. Once the donated stem cells enter the patient’s circulatory system, it takes approximately two to four weeks to see the first evidence of a “graft”, meaning that the marrow has begun to work and is producing new blood cells. A noticeable rise in the patient’s white blood cell count is the first sign that a graft has occurred.

Will I know the identity of the patient who is receiving my stem cells?

At the time of donation, the volunteer donor is not given any identifying information beyond the age and gender of the recipient and the nature of the disease. For at least the first year after the transplant, the donor and recipient may communicate only in anonymous writing through the national registry.



national registry. While Maital's parents could not be told the identity of the stranger who had agreed to help their child, they did not doubt for a moment that it was someone kind and wonderful.

That conviction was confirmed a little over a year later when, at a Chai Lifeline din-

AN EMOTIONAL MEETING.
Maital and Elaine meet for the first time at a Chai Lifeline Dinner in Miami.

If donor and patient both wish to meet after that time, national registry coordinators and the local donor center may assist in the process.

Why won't they tell me the identity of the patient? Are they trying to hide something from me?

Rest assured, the purpose of anonymity in stem cell donation is protection, not deception.

Since revealing the names of donors and patients might encourage unscrupulous individuals to engage in the unlawful buying and selling of stem cells, the stem cell donation process, like that of organ donation, has been designed

to preserve and safeguard the integrity of the system.

Remember, too, that the policy of anonymity works both ways. Because your identity is kept confidential as well, you can be certain that you will never be directly contacted by a patient, patient's family or patient's medical doctor during the decision-making period.

Why should I go ahead with the procedure if I don't even know who I'm doing it for? *

That is a question that, in the end, only you can answer.

Perhaps, though, it might be beneficial in making the decision to consider the things you do know, rather than those you don't.

* This question and answer segment has been reviewed and approved by leading halachic authorities. For more information, contact Chai Lifeline. Please also refer to the introduction section of this guide.

ner in Miami, the Cohens finally met the woman whose act of generosity had changed their lives.

"Elaine Shapiro is an angel," says Maital, today a happy, healthy high school student.

"She's a great lady," says Mrs. Cohen in a tone that leaves little room for argument.

She remembers that during one of their early conversations, Elaine told her that she did not have any children of her own. Mrs. Cohen's response was immediate and heartfelt.

"Well, now you do. Now you have a daughter."

Consider, for example, that stem cell donation is essentially a risk-free process.

Consider the great personal satisfaction of knowing that by making the choice to donate you are offering the gift of hope to another human being, most likely another individual of your racial and ethnic background.

And, finally, consider that the worldwide effort to help save lives is a great kiddush HaShem (glorification of G-d's name), bringing people of all races and backgrounds together under the banner of friendship and goodwill.

What is the procedure after a match is established?

If you are found to be a preliminary match, your donor center will contact you and schedule follow-up blood tests to further determine compatibility. Should additional testing confirm

precise HLA-compatibility, counselors from your center will provide a detailed information session about the donation process. At this point, you will be told which type of stem cell donation the transplant physician is seeking. If you agree to go ahead with the donation, you will also receive a thorough physical examination.

Can I say "no" at this point?

At no time in the donation process are you under any legal obligation to continue. Your decision to decline a stem cell request (either bone marrow or PBSC) does not affect your future relationship with the national registry.

Still, while the decision of the matched donor to decline is always respected, it is probably best to delay making the commitment if you have serious doubts about actually going through with the donation

When the mother of 31 year-old M.Z. says of her son, “good deeds are in his blood,” it’s a pretty literal assessment.

Responding to a call from the national registry of stem cell donors, the young father of six underwent a surgical procedure to donate bone marrow to a desperately ill patient. Because the national registry maintains a strict policy of patient-donor anonymi-

procedure. For a patient desperately awaiting stem cell transplantation, the refusal of a matched donor to proceed is enormously disappointing.

What is the “Intent to Donate” form? What are the implications of actually signing the form?

If you decide to become a donor, you will be asked to sign an Intent to Donate form.

Once the Intent to Donate form has been signed, the patient undergoes a treatment of chemotherapy and/or radiation to wipe out all disease. Because the treatment destroys the immune system, the patient will most likely die if he or she does not receive a stem cell transplant at this stage of the process.

It is crucial, therefore, that the potential donor be certain about the decision to donate stem cells before signing the intent form.

Who pays for the transplant?

The patient or patient’s medical insurance pays all the donor’s medical expenses relating to the transplant. Although many employers offer paid time off to donate marrow, some donors have found it necessary to take unpaid time off from work or to use vacation time.

What special accommodations are donors required to make during the immediate pre-donation period?

Donors who pass the physical are not required to make any changes in diet, work or social habits before the stem cell donation. However, to ensure that both donor and recipient are in the best possible physical condition for the transplant, during the period the patient is undergoing the pre-transplant regimen donors are asked to refrain from taking any unnecessary risks which could lead to

ty, M.Z. knew nothing about the recipient of his marrow other than age and gender. That he would be performing this selfless act for a total stranger never once gave him pause.

Clearly, the propensity to “do unto others”, is part of M.Z.’s genetic make-up, passed down to him along with his eye color and hair texture. His grandparents, he recalls, were always involved in charitable activities, and their homes were always open to anyone

illness or injury. They are also asked not to take any medication without the approval of the transplant center physician.

Cord Blood — A Promising New Source of Stem Cells

What is cord blood?

During pregnancy, oxygen and essential nutrients pass, via the placenta and umbilical cord, from the mother’s blood to the baby’s. A newborn’s blood can also be found in the umbilical cord and placenta after birth. This placental blood contains large numbers of blood stem cells.

How is cord blood collected?

After the baby’s birth, the umbilical cord is clamped, breaking the connection between infant and placenta.

The small amount of blood remaining in the umbilical cord — typically 3 to 5 fluid ounces — is drained and taken to a cord blood bank where it is frozen. The stem cells in frozen cord blood remain available for transplantation for many years.

Who will get the baby’s cord blood?

For a variety of reasons, parents may wish to store blood exclusively for use within their own family. They may do so because another family member has a disease or a medical history that indicates an increased risk of disease that may be treatable with a stem cell transplant. Or they may simply choose to bank their newborn’s cord blood as “insurance” for their family, however small the chances of their needing it.

Others, however, may choose to donate cord blood for possible transplantation in an unrelated patient.

who needed a meal or a place to stay. As a child, M.Z. remembers helping his grandfather collect the thousands of dollars he distributed in tzedaka every year.

Unlike certain inherited traits, chesed did not skip a generation in the Z family. For a number of years, M.Z.'s mother has been a Chai Lifeline volunteer. Aside from her regular weekly hospital visits, the Brooklyn housewife and mother of eight frequently prepares

Does the cord blood collection process pose a risk to the baby?

No. The cord blood is collected from the placenta after delivery and would normally be discarded. Still, cord blood can't be collected and stored without the permission of the baby's mother on behalf of her child.

What are the advantages of using cord blood as opposed to bone marrow or peripheral blood stem cells?

The use of cord blood in stem cell transplantation offers a number of advantages. Cord blood stem cells — which have the ability to treat the same diseases as bone marrow with fewer side effects and a lower rate of rejection — are easily obtained without risk to the mother or infant. Because there is less stringent HLA matching required for use in transplantation, cord blood offers hope to many individuals

(especially ethnic minorities) who are unable to locate bone marrow donors. Finally, banked cord blood has the advantage of being immediately available to the HLA-matched patient.

Are there any costs involved in storing cord blood?

For a fee, several cord blood banks in the United States will collect and store cord blood that is reserved for private use. This fee is not covered by insurance.

The cost of unrelated cord blood donation is covered by the donor cord blood bank, which will also arrange for the collection procedure. Although cord blood banks are springing up throughout the U.S., cord blood donation is currently not possible in many locales. For information about the location of cord blood banks within or close to your community, call the National Marrow Donor Program at 1.800. MARROW-2.

food for patients and their family members — everything from sandwiches to baked goods to full-course meals. Like her eldest son, Mrs. Z, her husband and all her children over the age of 18 have been tested as stem cell donors. So far, only M.Z. has proven a match for a patient.

M.Z., like many people who are tested as potential donors, first signed up in response

What is the procedure for matching the patient with the donated cord blood?

Cord blood cells are HLA-typed when they are placed in storage. When the cord blood HLA type is identified as a possible match for a patient searching the national registry, the national registry contacts the donor cord blood bank.

How do patients receive stem cells?

Like all other stem cell transplants, cord blood stem cells are administered directly into the patient's blood stream.

Will I know the identity of the patient?

Like in marrow and PBSC donation, no identifying information is exchanged between a cord blood donor and cord blood recipient. The identity of the donor is kept confidential at the cord blood bank.

-
1. Butterworth V, Simmons R, Bartsch G, Randall B, Schimmel M, Stroncek D. Psychosocial Effects of Unrelated Bone Marrow Donation: Experiences of the National Marrow Donor Program. *Blood* 1993;81:1947-1959.
 2. Sakamaki S, Matsunaga T, Hirayama Y, Kuga T, Niitsu Y. Haematological Study of Healthy Volunteers 5 Years After G-CSF. *Lancet* 1995;346:1432-1433.
Stroncek D, Clay ME, Herr G, Smith J, Ilstrup S, McCoullough J. Blood Counts in Healthy Donors 1 Year After the Collection of Granulocyte-Colony-Stimulating Factor-Mobilized Progenitor Cells and the Results of a Second Mobilization and Collection. *Transfusion* 1997;37:304-308.

to a campaign to find a match for a specific individual in the Jewish community. While he wasn't a match for that particular young man, M.Z. has in the intervening years twice been identified by the national registry as a possible match for other critically ill patients. A follow-up blood test showed his precise HLA-type to be incompatible with the first patient's; he turned out to be a perfect match for the second.

at a glance

- To qualify for testing at a local donor center, you must be between the ages of 18 and 60 and in good general health.
- After being tested at a local donor center, your tissue type (HLA) and record number are automatically entered in a computerized national registry of potential volunteer donors. All personal information, such as your name, address and phone number are kept on file **only** at the local donor center. See pages 5-6.
- Should you prove a potential match for a patient, the national registry will notify your local donor center, which will then contact you.
- If you joined the registry as the result of a drive sponsored by an organization (such as Chai Lifeline), be sure you know the name of the local donor center that will be keeping your personal information on file. If you prove a possible match, you will be contacted by the local donor center, **not** the organization that sponsored the drive. See page 6.
- Notify your local donor center of any change in name, address or phone number. This ensures that you can be contacted if you are identified as a possible match. The center should also be apprised of any changes in your general state of health.
- To preserve and safeguard the integrity of the donor system as well as to protect the privacy of volunteers who might otherwise be directly contacted by patients or their families, stem cell transplantation is an anonymous process. See page 14.

Although he has learned that the recipient of his bone marrow did not survive, M.Z. doesn't regret his decision to donate. Not surprisingly, he maintains that were he asked to donate again, he would do so without hesitation.

"It's not something I even have to think about. It's just the right thing to do."

And that sentiment bespeaks more than just a personal point of view. It attests to a long and proud family tradition.

- The chances of finding an unrelated donor vary widely depending on the rarity of a patient's HLA type. Since some characteristics of HLA type are unique to people of shared ancestry, the most likely match for a patient — outside of his or her own family — is someone from the same race or ethnic group. Therefore, an individual of Jewish descent will be the **most likely** recipient of marrow donated by another individual of Jewish descent.
- If you are ever matched with a patient in need and are unable to donate, you may wish to inform your sibling(s). Because of the genetic background you share, your sibling has a 30 percent chance of also being a match.
- After being successfully matched with a transplant candidate, a potential donor will be told which type of stem cell donation (marrow or peripheral blood stem cell) the transplant physician is seeking. Like at any point in the process, the potential donor may, without any legal ramifications, decline a stem cell request (either bone marrow or peripheral blood stem cell donation) should he or she decide against it.
- Most volunteers describe the stem cell donation experience as simple and fairly painless. 91% of donors report that they would donate marrow again if asked to do so.

NATIONAL REGISTRIES OF BONE MARROW DONORS

National Marrow Donor Program

3433 Broadway Street NE- Suite 500
Minneapolis, Minnesota 55413
(800) 526- 7809, Fax (612) 627-5899
www.marrow.org

The American Bone Marrow Donor Registry

P.O. Box 224
Mandeville, Louisiana 70470
(800) 745-2452, Fax (504) 626-7414
www.abmdr.org

The Caitlin Raymond International Registry

UMass Memorial Health Care
55 Lake Avenue North
Worcester, Massachusetts 01655
(800) 726-2824, Fax (508) 334-8972
www.crir.org

Gift of Life Foundation

(formerly the Jay Fienberg Foundation)
4740 Yardarm Lane
Boynton Beach, Florida 33436
(800)9-MARROW or (561) 638-8876
Fax (800) 707-5343
www.hlamatch.org

For the names and numbers of donor centers in cities outside of New York, contact one of the national registries listed above. While the national registries do not maintain personal information about individual donors, they can provide you with a listing of donor centers throughout the country.

LOCAL DONOR CENTERS IN THE NEW YORK AREA

New York Blood Center

310 East 67th Street
New York, NY 10021
(212) 570-3210 Fax (212) 249-2395
(800) NY Blood- ext. 2
www.nybloodcenter.org

The HLA Registry Foundation

70 Grand Avenue
River Edge, NJ 07661
(201) 487-0883 Fax (201) 487-2456
www.hlaregistry.org

For questions regarding any information included in this guide or general information about stem cell donation, call Chai Lifeline at (212) 465-1300 or (877) CHAI-LIFE.



Chai Lifeline is an international non-profit organization that provides vital services to seriously ill Jewish children and their families. Through its regional offices in New York, New Jersey, Florida, Los Angeles, Chicago and Detroit, Chai Lifeline maintains a wide network of psychosocial support programs that includes medical referrals, insurance support services, emotional support groups, homebound tutorial programs, special trips and holiday festivities, toy drives, bone marrow drives, family retreats and a celebrated summer camping program — Camp Simcha, in memory of Dr. Samuel Abraham. Most recently, Chai Lifeline established the Stella K. Abraham Respite Center — a country getaway for Jewish families coping with catastrophic illness.

Helping the child, the family and the community.

Published by



Chai Lifeline

Fighting Illness With Love

151 West 30th Street, New York, NY 10001

(212) 465-1300, (212) 465-0949 fax

www.chailifeline.org

For more copies, please call or fax.

© Copyright 2000, Chai Lifeline.

No part of this publication may be duplicated or reproduced without the express permission of Chai Lifeline.

8/00



Chai Lifeline

Fighting Illness With Love

151 West 30th Street
New York, NY 10001

NON-PROFIT
ORGANIZATION
U.S. POSTAGE

PAID

CHAI-LIFELINE/
CAMP SIMCHA