Donor Handbook
Information about bone marrow and stem cell donation
Dear Friends,

My life changed forever when my mother, Mechtild, was diagnosed with an acute form of blood cancer. We were told that a bone marrow transplant could save her life if we could find her a matching donor. With the odds of finding a match ranging from one in 20,000 to one in millions, having only 3,000 donors available in Germany at the time made the situation seem hopeless.

Determined to make the impossible, possible, my father made it his mission to find my mother a donor. With the help of family, friends and volunteers, he worked tirelessly to recruit 68,000 donors in only one year. Sadly, my mother lost her hard-fought battle with blood cancer when I was only fourteen.

My mother’s death shaped my life in many significant ways. It motivates me to continue the lifesaving work that my father began in 1990. I fight so other blood cancer patients can defeat this disease. No family should have to endure the pain and loss my family suffered.

Very few registered donors will ever match a patient. You are one of these rare individuals. I hope this handbook helps you on your lifesaving journey. Together we can delete blood cancer!

Sincerely,

Katharina Harf
Co-Founder
Delete Blood Cancer DKMS
Contents

WHY AM I BEING CONTACTED? ........................................... 3
1. Peripheral blood stem cell (PBSC) donation ................................. 3
2. Bone marrow donation .................................................. 3

CONFIRMING YOU ARE A MATCH .................................... 4
1. Become informed ......................................................... 4
2. Submit the health history questionnaire & consent form ................. 4
3. Provide a blood sample (confirmatory typing) .............................. 5
4. Keep us updated & be ready ............................................. 5

GENERAL INFORMATION ABOUT
PERIPHERAL BLOOD STEM CELL (PBSC) DONATION ............... 6
Peripheral blood stem cell donation ......................................... 6
Before, during and after PBSC donation .................................... 6
Side effects and recovery .................................................... 7

GENERAL INFORMATION ABOUT
BONE MARROW DONATION .............................................. 8
Bone marrow donation .................................................... 8
Before, during and after bone marrow donation ............................ 8
Side effects and recovery .................................................... 9

PREPARING FOR YOUR DONATION ................................ 10
1. Information Session ..................................................... 10
2. Physical exam .......................................................... 10

AFTER YOU DONATE .................................................. 12
Donor follow-up ............................................................ 12
Updates about the patient .................................................. 12
Communicating with the patient ........................................... 12
Sharing with care ......................................................... 13

FREQUENTLY ASKED QUESTIONS .................................. 14
Why am I being contacted?

When you registered with Delete Blood Cancer DKMS, you submitted a cheek swab sample that was tested to determine your tissue type. Less than 1% of registered donors are ever found to be a match. You are part of this rare 1%, because your tissue type is very closely matched to a specific patient’s. The patient’s doctor requested you for additional testing to determine if you can donate. If this testing indicates that you can donate, you will be asked to donate in one of two ways:

1. **Peripheral blood stem cell (PBSC) donation**
   A non-surgical, outpatient, apheresis procedure where your blood is removed from one arm and passed through a machine that separates out the blood stem cells. The remaining blood is returned through your other arm.

2. **Bone marrow donation**
   An outpatient surgical procedure, performed using anesthesia. Blood stem cells are collected from the back side of your pelvic bone, not your spine.

This booklet will help you navigate through the donation process and explain your next steps. Please review the information in the booklet carefully and contact your Coordinator to discuss the rest of the process and ask any questions you may have.
Confirming you are a match

1. Become informed
Call us today so we can explain the process, answer your questions and help you make an informed decision. Review this booklet to learn about the two ways to donate:
- Peripheral Blood Stem Cell (PBSC) Donation
- Bone Marrow Donation

2. Submit the health history questionnaire & consent form
- The health history questionnaire provides us with information regarding any medical conditions that may prevent you from donating.
- The consent form allows us to move forward with your additional blood work.
- After you submit these forms, we will call you to review the information.

Your health and safety are our top priorities. Any medical condition is thoroughly reviewed by our medical staff. If donating poses any additional risk to you, you will not be asked to proceed as a donor. If you are concerned about your ability to donate, please contact your Coordinator and they will carefully assess your eligibility with you before proceeding. Depending on your health status, it is possible that you may be temporarily unavailable to donate, or need to be permanently removed from the registry.

Donating is a serious commitment to the patient. We cannot schedule your blood tests unless you are 100% committed to moving forward with the donation.
3. Provide a blood sample
(confirmatory typing)

- We will schedule an appointment for you at a local lab.
- The blood samples will compare your tissue type with the patient’s and test for infectious diseases.
- We will inform you of any unexpected results.
- All test results are strictly confidential.

4. Keep us updated & be ready
Once you have completed your blood work, you become an essential part of the patient’s search for a donor as well as the patient’s opportunity for a second chance at life. It can take anywhere from one week to three months to schedule the final phases of your donation. The patient’s doctor will choose the donation method that best suits the patient’s care. We ask that our donors be willing to move forward with either method of donation. If you are comfortable with only one method of donation, please notify your Coordinator as soon as possible.

MATCHING A PATIENT GIVES THEM HOPE
“My brother had the worst case of Acute Lymphoblastic Leukemia and T-Cell type Lymphoma his doctor had ever seen. I remember getting the call that the doctors had found a perfect match. Unfortunately, he never got into remission long enough to have the transplant, but I wish every day that I could contact the person who was willing to donate to my brother and let him know that we still thank him for being awesome.”
— Patient’s sister

Please contact Delete Blood Cancer DKMS if you have changes to your health, dates of availability, or contact information.
General information about peripheral blood stem cell (PBSC) donation

Peripheral blood stem cell donation is a six to eight hour apheresis procedure where your blood is removed with a sterile needle from one arm and passed through a machine that separates out the blood stem cells. Your remaining blood is returned to you through the other arm. For four days prior to the collection and on the first day of the collection, you will receive daily injections of a synthetic protein called filgrastim that increases your blood stem cell count.

Peripheral blood stem cell donation

- Is scheduled on a weekday (generally Monday–Thursday).
- Is performed at the hospital where you will have a physical exam about 2–3 weeks prior to donation.
- Donors do not stay overnight at the hospital.
- We will follow up with you regularly to check on your recovery after donating.

Before, during and after PBSC donation

BEFORE THE DONATION
In order to ensure that you are able to donate enough stem cells for the transplant, you will receive daily filgrastim injections for four days before your donation. The first injection is done in a clinical setting. The second, third and fourth injections are given by a nurse in your home.

DURING THE DONATION
- Donations are scheduled to take place over one or sometimes two consecutive days.
- A one-day donation can take up to six hours and a two-day donation can take up to four hours each day.
- You will receive a fifth injection of filgrastim on the morning of your first donation day.
• During the collection, a sterile needle will be placed into a vein in each of your arms.
• Blood is removed from a vein in one arm, passed though an apheresis machine, then returned to you through a vein in your other arm.
• The machine collects stem cells, platelets, and some white blood cells.
• All of the tubing used in the machine is sterile and used only once for your donation.

AFTER THE DONATION
You will be observed for a short time until you are physically stable and ready to go home.

Side effects and recovery

COMMON SIDE EFFECTS OF FILGRASTIM
• Headaches
• Bone or muscle pain
• Nausea
• Fatigue

COMMON SIDE EFFECTS OF PBSC DONATION
• Bruising at the needle site
• Numbness or tingling
• Chills
• Decrease in blood platelet count
• Lightheadedness
• Nausea

DURING YOUR RECOVERY
• Side effects of filgrastim usually disappear within 48 hours of donating.
• Donors can take non-aspirin products (such as Tylenol, Motrin or Advil) for discomfort.
• Most donors are able to return to work, school and most other activities within two days of donating.
• If your regular activities involve physical labor, heavy lifting or contact sports, more recovery time may be necessary.
General information about bone marrow donation

Bone marrow donation is usually an outpatient surgical procedure done under anesthesia. Doctors use a special needle to remove liquid marrow containing blood stem cells from the back of the pelvic bone.

Bone marrow donation

• Is scheduled on a weekday (generally Monday–Thursday).
• Is performed at the hospital where you will have a physical exam about 2–3 weeks prior to donation.
• Most donors are discharged the afternoon or evening of their donation.
• We will follow up with you regularly to check on your recovery after donating.

Before, during and after bone marrow donation

BEFORE THE DONATION

You will receive general anesthesia. You may be under anesthesia for one to two hours.

DURING THE DONATION

The doctor will insert a special needle through tiny incisions in the skin over the back of the pelvic bone (not your spine). The incisions are less than one-fourth of an inch long and do not require stitches.

“I went into the hospital in the morning, was put under anesthesia, and woke up an hour and 15 minutes later. When I woke up, I was more stiff than anything; like I slept in a really weird way. They asked how I felt. The pain wasn’t bad. It was a dull, achy soreness. They made sure I was ok. I went home in the afternoon and rested for a couple days. That was it.”

— Christian, Bone Marrow Donor
AFTER THE DONATION

A bandage will be placed over the incisions and you will be moved to a recovery room where you will be observed until you are fully alert and physically stable. If you had a unit of blood collected at your physical exam, this may be infused in the recovery room.

Identical twins, Keane and Ethan, received lifesaving transplants when they were only 10 months old. They were saved by Monika, a Donor who donated her bone marrow to them.

“Thanking Monika is never going to be enough because we’ll always be blessed with Keane and Ethan because of her.”

— Carrie, The boys’ mom

Side effects and recovery

<table>
<thead>
<tr>
<th>COMMON SIDE EFFECTS OF MARROW DONATION</th>
<th>COMMON SIDE EFFECTS OF ANESTHESIA</th>
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<tbody>
<tr>
<td>• Lower back pain</td>
<td>• Sore throat (caused by breathing tube)</td>
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<tr>
<td>• Fatigue</td>
<td>• Mild nausea and vomiting</td>
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<tr>
<td>• Stiffness when walking</td>
<td>• A decrease in blood pressure</td>
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<tr>
<td>• Bleeding at the collection site</td>
<td>• Headaches</td>
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DURING YOUR RECOVERY

• It is normal to experience some pain, bruising and stiffness during the first two to three weeks after your donation.
• You should avoid heavy lifting, bending and strenuous exercise for about two weeks after donating.
• Most donors are able to return to work, school and any other activities within a few days. If your job involves physical labor or heavy lifting, more recovery time may be necessary.
Preparing for your donation

The following section of the handbook will discuss what happens if your blood work (confirmatory typing) confirms that you are a match.

1. Information Session

Once it is determined that you are the best match, a Coordinator will contact you to schedule an information session. During this one hour phone conversation, you will:

- Find out whether you will be asked to donate bone marrow or peripheral blood stem cells (PBSC).
- Learn the details specific to your donation.
- Review and sign the consent form to donate.
- Begin scheduling your donation.

2. Physical exam

The physical exam assesses your suitability as a donor and includes:

- An electrocardiogram (EKG) to check your heart.
- A chest x-ray.
- Lab work (urinalysis, blood tests, pregnancy test for female donors).
- PBSC Donors: You will also have a vein assessment to see if your veins are suitable for donation. If not, a central line may be discussed as an alternative method of collecting your cells.
- Bone Marrow Donors: You may need to donate a unit of blood to yourself (also called an autologous unit) in case you require a transfusion after your donation. PBSC donors do not need a transfusion.

THE PHYSICAL EXAM

- Is on a weekday, typically 3–4 weeks before the donation.
- Is at the hospital where you will donate.
- Takes approximately 3–4 hours, but plan to commit a full day. After the physical exam, we will review the results and notify you if any additional testing is necessary. If any findings show a risk to you or the patient, you will not donate.
Caitlin donated her cells to save the life of 8-year-old Jaz. Recently, they met for the first time to celebrate Jaz’s 10th birthday.

“Jaz is the hero and she’s inspired me every day since I found out I matched her. I feel so thankful for registering as a donor when I did.”

“Donating feels good. But it feels even better that this is going out for a good cause. This is actually helping somebody out there who needs it. Somebody who’s dying of leukemia. It’s a very important thing to do.”

Being a bone marrow donor is more than just a cheek swab — it is a commitment to help save a life. Your decision is important.
After you donate

Donor follow-up
Delete Blood Cancer DKMS cares about your safety and wants to know about the details of your recovery. We will contact you on a regular basis after your donation to ask about your physical condition. It is important to report any symptoms you experience. You should expect a phone call two days following your donation and then weekly until you report a full recovery. As part of your longer follow up, you will be contacted one month and six months after your donation.

Updates about the patient
The patient’s doctor may provide up to three updates within the first year after the transplant. We will contact you once an update is available. It is important to note that, because of confidentiality requirements, some transplant centers cannot provide patient updates, so you should be prepared for that possibility. Your Coordinator can provide further information on the policies that are in place at the specific hospital where your patient is being treated.

Communicating with the patient
Communication with the patient is facilitated through Delete Blood Cancer DKMS and the patient’s transplant center. During the first year after your donation, some transplant centers may allow you to send anonymous letters to the patient. This communication should not include any self-identifying information such as your name, address, city, state or any other contact information.

One or more years after the donation, some transplant centers may allow direct contact with the patient. Contact may only occur if both you and the patient consent to it. Some centers may not allow any communication, so you should be prepared for the possibility that you might not learn your patient’s identity or have any contact with him or her. Your Coordinator can provide further information on the policies that are in place at the specific center where your patient is being treated.
Sharing with care
We know donation is a powerful experience. You’re doing one of the best things you could possibly do by giving of yourself to help give someone a second chance at life. You may want to share the news with friends and family, and may turn to social media like Facebook and Twitter to do so. For reasons of confidentiality and privacy, we ask that you do not share the exact date or location of donation or the age, gender, and specific disease of the patient.

“Overall my experience with the injections was good. I had some of the normal side effects, mostly bone aches in my sternum and hips. I was able to continue with my normal home and work routines throughout the injections.

The donation started early; around 7 AM. Everything was ready to go and we started as soon as I arrived. I was on the apheresis machine for about 5 hours, most of which I was comfortable. Towards the end of the procedure my arm with the needle became very sore, but not so bad that I couldn’t continue. After the procedure I was tired and still a little sore in my arm, but it felt better a few hours later. I had some bruising on my arms that lasted about a week.

The entire experience from start to finish is something that I’ll never forget. All the people involved were great and very helpful all the way through. I would definitely do it all over again, as many times as needed.”
Frequently Asked Questions

Am I the only match?
It is possible for a patient to find multiple potential matches. The patient’s doctor will select the best donor based on tissue type, age, sex, size, health history, availability and other factors. If you aren't selected, we will inform you, and you will remain on the registry to be available for other searching patients.

When will I donate?
It is hard to say exactly when your donation will take place because it strongly depends on how the patient is feeling. In most cases you would be asked to donate 1–3 months after the confirmatory blood test. We will always give you 3–4 weeks advance notice. If there are any important dates that you cannot donate, we will try to accommodate your schedule.

Where will I donate?
We work with a network of hospitals across the country. However, there are instances when the closest hospital is not available and you will have to travel. All travel is arranged and paid for by us. There is no expense to you.

Can I choose the method of my donation?
There are two possible ways you may be asked to donate. The method is determined by what the doctors believe will be best for the patient. We ask our donors to be comfortable with both methods of donation. If you are not willing to donate through both, you must notify your Coordinator, so they can let the patient’s doctors know.

Who covers the expenses?
There is no cost to you. When a donor is matched with a patient, the patient’s insurance and Delete Blood Cancer DKMS will cover the costs (including any travel, meals, or lodging expenses that may be necessary). Delete Blood Cancer DKMS will also cover the costs for a companion to travel to the donation. A donor’s insurance will never be used.
Will I be compensated for the time I take off from work?
If you are not covered by your employer, Delete Blood Cancer DKMS has a financial assistance program for lost wage compensation. If you are found to be a match and qualify for assistance, your Coordinator will give you more information about applying for aid.

Is the marrow extracted from my spine?
No, the marrow is not extracted from your spine. It is extracted from the back of your pelvic bone.

Will I permanently lose my stem cells?
For either procedure, the amount of stem cells donated is only a fraction of the body’s total. The amount donated does not weaken your own immune system. The stem cells naturally replace themselves within a few weeks.

Will my existing medical condition prevent me from donating?
We take the health and safety of our donors very seriously. All donors are required to complete a health history questionnaire before proceeding. Any medical concerns you raise are reviewed by our medical staff to fully assess your ability to continue as a donor. If you are concerned about your ability to donate, please contact your Coordinator and they will carefully assess your eligibility. Depending on your health status, it is possible that you may be temporarily unavailable to donate or need to be permanently removed from the registry.

How am I matched?
Donors are matched with patients using human leukocyte antigen (HLA) typing. HLA are proteins or markers found on all cells in your body that aid your immune system by identifying cells that do and don’t belong in your body. They are inherited, so doctors will look for a matching donor within a patient’s family first. However, 70% of patients do not find a suitable donor in their family. In these cases, the doctor will search for an unrelated donor. You were selected as a potential match because your HLA is similar to that of a patient.
What makes a best match?
Most doctors require at least a 9 out of 10 HLA match for a transplant, but a 10 out of 10 is best. A close match means that the patient’s immune system will recognize donated cells as its own and allow them to grow and make new healthy blood cells.

Example A shows the patient’s antigens (A, B, DRB1, C and DQ) all match the donor’s antigens. A 10 of 10 match means that there is a perfect match at A, B, DRB1, C and DQ.

Example B shows that one of the patient’s A antigens does not match one of the donor’s A antigens. Therefore, this is a 9 of 10 match.

Do ancestry and ethnicity affect the matching?
Heritage is a very important factor. Like hair and eye color, your HLA type is inherited, so the best matches happen between patients and donors who share the same ancestry.
Why do patients need transplants?
A blood stem cell or bone marrow transplant is a potentially lifesaving treatment option for patients fighting blood cancers like leukemia and lymphoma or other blood disorders. A transplant replaces the patient’s unhealthy blood stem cells with healthy ones from the donor. Prior to transplant, a patient undergoes high dosages of chemotherapy and possibly radiation therapy to completely destroy all the diseased cells in their body and well as their immune system so that it can't attack the donated cells after transplant. Donated cells are infused into the patient and move through the bloodstream to settle in the bone marrow, where they engraft (begin to grow and produce red blood cells, white blood cells and platelets).

What is Delete Blood Cancer DKMS?
Delete Blood Cancer DKMS started with one family’s search for a bone marrow donor and is today part of the world’s largest bone marrow donor center. We have helped register more than 3.5 million potential donors and facilitated over 35,000 lifesaving transplants around the world. But we’re not stopping there. Every day we lead the fight against blood cancer by working with families, communities and organizations to recruit more donors and provide more patients with second chances at life.
Notes and Questions