

**DKMS** X

WE DELETE BLOOD CANCER



# DONOR HANDBOOK

TOGETHER AGAINST BLOOD CANCER

CODY STRULL,  
PBSC donor





# WHY WE NEED BONE MARROW DONORS

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Blood cancer is the third leading cause of cancer deaths and kills more children than any other disease in the U.S. A bone marrow transplant can be a lifesaving treatment for blood cancers like leukemia & approximately 70 other diseases, including aplastic anemia and sickle cell disease.

*From left to right:*

**NAMAN BHUSHAN, JAKE WHITSON,  
and JASMINE LYNN BURT**  
DKMS supporters



# WELCOME

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Dear Friend,

DKMS started with my family's search to find a bone marrow donor for my mother. At the time, there were only 3,000 registered donors in our native country, Germany, and the situation seemed hopeless for us. My father however, was determined to make the impossible, possible. Together, with family, friends and volunteers, he registered 68,000 potential lifesavers in just one year.

Despite our best efforts, my mother ultimately lost her hard-fought battle when I was only fourteen. Before her passing, my mother made my father promise that we would not stop this fight until every patient had a matching donor and a potential second chance at life. My mother motivated us to do everything we could to prevent other families from suffering the loss that we did.

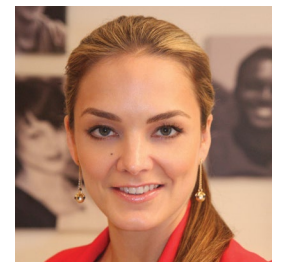
In 2004, I helped my father expand the life-saving work of DKMS to the U.S., where we register new potential donors everyday to increase the chances of saving more lives. As you are about to find out, we also provide those who become donors with the best possible support and care during their donation journey.

In the coming weeks, you will get to know many of us by name as we guide you through this life-saving experience. We will do all we can to ensure it is a positive and powerful experience that leaves you feeling like the lifesaver you truly are. When you registered as a bone marrow donor, you gave hope to so many patients. Now, you have the chance to give a patient a second chance at life.

With gratitude and appreciation,

*Katharina Harf*

KATHARINA HARF,  
Co-founder, Chairman of DKMS US



Matene donated her stem cells to Marcus and met him for the first time at the 2018 DKMS Gala





**KENZA,**  
transplant recipient

# THERE ARE SURVIVORS ONLY BECAUSE THERE ARE LIFESAVERS

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# WHY A PATIENT NEEDS YOU

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There are approximately 5 major groups of blood disorders, many of which are cancers: leukemia, lymphoma, myeloma, anemia and myelodysplastic syndrome. These disorders disrupt the production of healthy red blood cells, white blood cells and/or platelets, resulting in a life threatening illness. A bone marrow or stem cell transplant is a potentially lifesaving treatment for patients fighting various forms of these blood disorders.

## How does a transplant work?

Blood stem cells are responsible for producing healthy red cells, white cells and platelets. With a transplant, your healthy blood stem cells will replace the patient's diseased cells.

In preparation for a transplant, the patient receives high dosages of chemotherapy, possibly even radiation therapy, to completely destroy all the diseased cells in their body and repress their immune system. This is done to decrease the risk of their body rejecting your donation.

Soon after these series of treatments, the donated cells are infused into the patient and moved through their bloodstream to settle in the bone marrow, where it begins

to grow and produce new healthy blood cells and platelets in a process called engraftment.

In many cases, patients have undergone other treatments that have been unsuccessful. A stem cell transplant not only can save their life, but it is also their last hope at survival. Approximately 70% of blood disorder patients must rely on the generosity of registered donors, like you, for a second chance at life.

**“I just hope that people know that when they swab their cheeks and sign up for the registry, they are going to change a family’s life forever.”**

**KATHLEEN HOGAN,**  
mother of aplastic anemia survivor, Owen





# THE DONATION JOURNEY

From just matched to just donated—there are many steps that come between being called as a potential match to resuming life after donation. DKMS will be by your side the entire way. Though you'll work with different people as you move through the process, you'll experience how we're all united in making sure you always get the best personalized care and support.



“It could be me one day, or a family member, or a friend, who is sick. I can only hope someone would do the same.”

NATASHA BOUKNIGHT, bone marrow donor



# YOU ARE A MATCH!

Less than 1% of all registered donors ever donate.

## HOW YOU WERE SELECTED

You may remember swabbing your mouth with something that looked like extra-long Q-tips. By swabbing, you collected a sample of your cheek cells which were sent to our Life Science Lab to determine your Human Leukocyte Antigen (HLA) typing. HLA are protein markers on your cells that help your immune system recognize cells that do or don't belong in your body.

Once we determined your HLA type, it was listed anonymously on the national registry for transplant centers to access globally. When a patient is in search of a lifesaving transplant, their doctor performs HLA testing to determine the patient's typing. Then the medical team searches the national database to identify possible donor matches based on the HLA profile and sends out donor requests. The closer the match, the less likely it is for the patient's immune system to identify the donated cells as foreign threats.

We are contacting you because a doctor has found your HLA typing to be a close match to that of a patient in need of a lifesaving transplant. You may be a good match but for the safety of you and your patient, further testing is required to determine if you are medically fit to donate.

This may be exciting news for you! It might make you a bit nervous, too. That's OK. DKMS is here to support you in every way as you consider the opportunity to donate. This booklet provides you with detailed information on the next steps, as well as the two methods of donation:

1. [Peripheral blood stem cell \(PBSC\) donation](#)
2. [Bone marrow donation](#)

**"If someone was to ask me 'Would you do it again?', the answer is always 'Yes'. You're doing something that is so much bigger than you."**

**BENNETT MARANO,**  
bone marrow donor





# METHODS OF DONATION

The patient you are matched with needs a stem cell donation. This section will help you understand the two different ways in which you can donate.

For you, as a donor, there are 2 possible methods of donation: Peripheral Blood Stem Cell OR Bone Marrow.

The main difference between the two is the location from where the cells are collected. It's important you read about both methods used to collect stem cells as you will be asked to donate by **one** of these two ways.

Learn about the steps involved before, during and after each method of donation and how we will support you along the way.

## PERIPHERAL BLOOD STEM CELL (PBSC) DONATION

PBSC is a procedure similar to platelet donation, or a more involved way to donate blood. Your blood is drawn from one arm and passed through an apheresis machine that filters out the blood stem cells from the other blood cells, before returning the blood back into your body through the other arm. To increase the amount of stem cells in your blood flow at the time of donation, you will receive a 5-day course of a synthetic protein called filgrastim. Filgrastim signals your bone marrow to release more than average amounts of stem cells into your bloodstream.

PBSC is the donation method of choice more commonly requested by patients' medical teams.



### METHOD 1: PERIPHERAL BLOOD STEM CELL DONATION

#### SCHEDULING

PBSC donation will be performed at one of our accredited partner medical facilities. The procedure generally lasts one day (6-8 hours). In some cases, it may be necessary to collect over the course of two days (3-4 hours each day).

#### THE PROCESS

##### BEFORE

- Starting four days before your procedure, you'll receive once-daily injections of filgrastim. Your blood stream naturally contains some of these stem cells. Filgrastim will stimulate the release of more stem cells from your marrow into your bloodstream.
- The first injection is given in a clinical setting convenient to your home, office or school. The second through fourth injections may be administered by a nurse in your home or office, and the fifth is given at the hospital, the morning of donation.



# PERIPHERAL BLOOD STEM CELL (PBSC) DONATION

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## DURING

- You'll be seated in a reclining chair or adjustable bed.
- A sterile needle will be placed into a vein in each of your arms.
- Blood is drawn through one arm, passed through the apheresis machine, and then returned to you through your other arm.
- The machine collects stem cells, platelets, and some white blood cells.
- All of the tubing used with the machine is sterile and used only once for your donation.

## AFTER

- You'll be observed for a short time until you are physically stable and ready to go home.
- We will follow up with you two days after your donation and regularly thereafter, to ensure you are recovering well.

## COMMON SIDE EFFECTS

As a donor, you may experience some of the following common side effects:

### *Filgrastim*

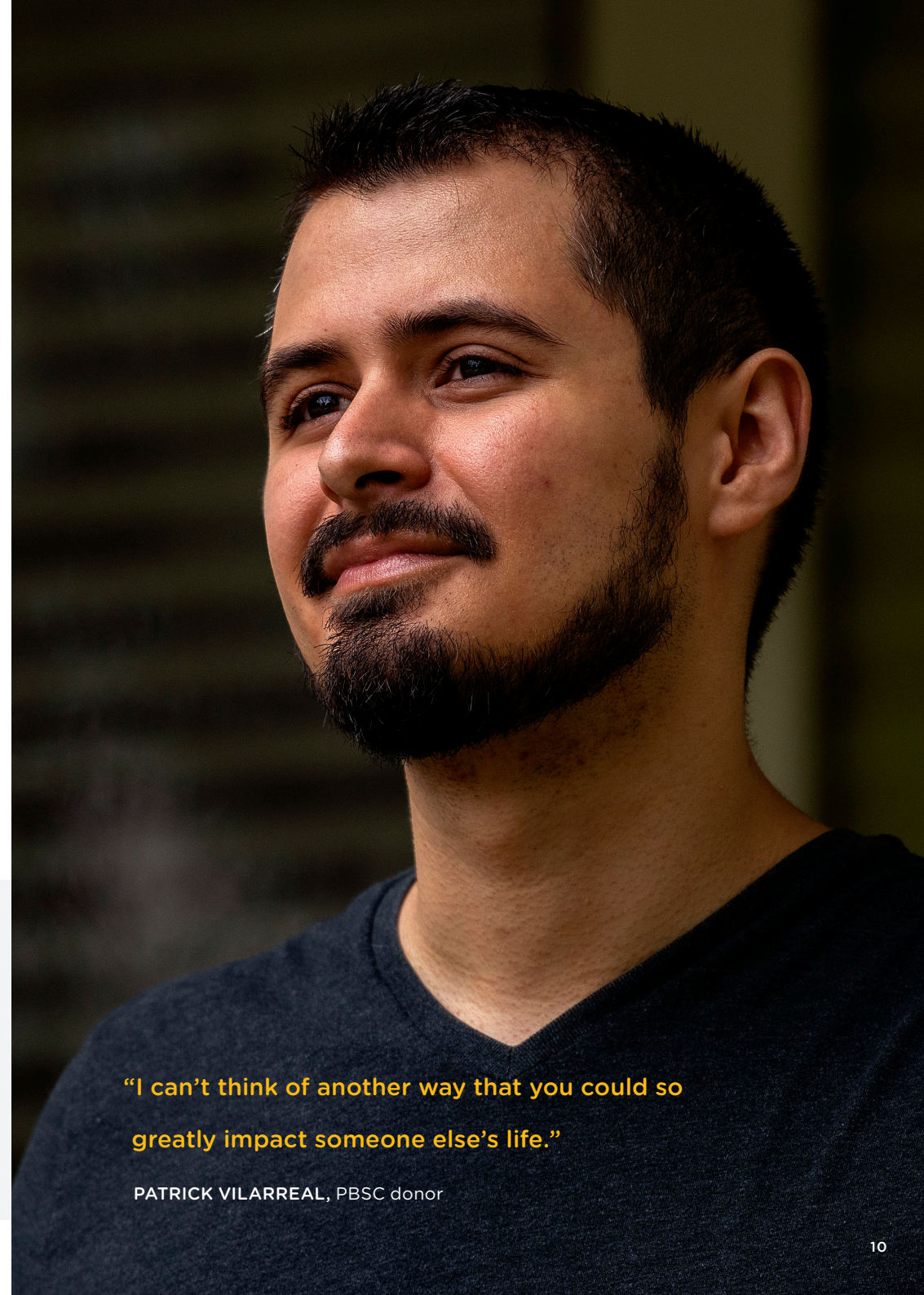
- Headaches
- Bone or muscle aches
- Nausea
- Fatigue

## RECOVERY

- The side effects of filgrastim generally improve within 48 hours of donation.
- Most donors return to work, school and most other activities within two days of donating.
- Allow more recovery time if your regular activities include physical labor or contact sports.
- Alert family, friends and supervisors that you might need to alter routines for a bit, i.e. shorter workdays or less intense activities.
- Your stem cells will completely replenish themselves within three to six weeks.

### *PBSC*

- Bruising at needle sites
- Numbness or tingling
- Chills
- Lightheadedness
- Nausea
- Temporary decrease in platelet count



**“I can’t think of another way that you could so greatly impact someone else’s life.”**

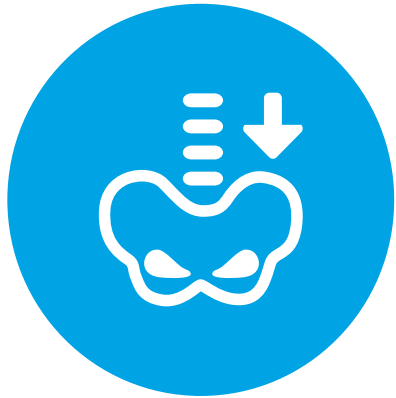
PATRICK VILARREAL, PBSC donor



# BONE MARROW DONATION

Bone marrow donation is an outpatient surgical procedure performed under general anesthesia. Doctors use a special syringe to collect a volume of bone marrow, which stores blood stem cells, from the iliac crest of the hip bone.

Bone marrow donation is more commonly requested by patients' medical teams to treat pediatric cancers and certain forms of anemia.



**METHOD 2:**  
BONE MARROW DONATION

## SCHEDULING

Bone marrow donation is performed at one of our accredited partner hospitals. The procedure lasts about one to two hours. Most donors are discharged the same day.

## THE PROCESS

### BEFORE

- Once you arrive at the hospital, you'll check in with your doctors to review the procedure and discuss any questions you may have. An anesthesiologist will administer the anesthetic medication through an IV tube into a vein in your arm or hand. Once you are asleep, a breathing tube will be used to aid respiration.

### DURING

- The doctor makes tiny incisions (typically just two) in the skin over the back of your iliac crest (not the hip joint or spine). For reference, put your hands on your hips in a superman/superwoman pose. Where your thumbs rest in the back is the approximate site of the incisions. A syringe is inserted through these incisions to collect a very small sample of your marrow from inside the bone.

**“It’s probably the biggest change or influence you’ll have on someone else’s life.”**

**SANDRA OLIVEIRA,**  
blood cancer  
patient



### AFTER

- Incisions are less than a quarter inch; no stitches needed. A bandage is placed over the incisions.
- You will be moved to a recovery room where you will be observed until you are fully alert and physically stable once the anesthesia wears off.
- Most donors are released the same day or the next morning

### RECOVERY

- It's normal to experience some pain, bruising and stiffness during the first two to three weeks after donation.
- Most donors return to work, school and any other non-strenuous activities within a few days.
- You should avoid physical labor, heavy lifting, bending and strenuous exercise for about two weeks after donation.
- Alert family, friends and supervisors that you might need to alter routines for a bit, i.e. reduced travel, lighter duty tasks or more assistance caring for children.
- Your bone marrow will completely replenish within three to six weeks.

### COMMON SIDE EFFECTS

As a donor, you may experience some of the following common side effects:

#### *Donation*

- Lower back pain
- Fatigue
- Mild stiffness when walking
- Bleeding from incisions

#### *Anesthesia*

- Sore throat (from the breathing tube)
- Mild nausea and/or vomiting
- Decrease in blood pressure
- Grogginess



# TALK IT THROUGH, THINK IT OVER

This is A LOT of information to take in at once. You might be experiencing a lot of conflicting emotions like excitement, fear, uncertainty. THAT IS COMPLETELY NORMAL. But DKMS is here for you! We urge you to come to us with all your questions and concerns BEFORE you make a decision.

## NEXT STEPS

- ✓ **Make a list.** After reading through all this information, you are likely to have some questions. Organize your thoughts and write it down in one place.
- ✓ **Contact us.** You should find the contact information for your designated coordinator in the “You’re A Match” email and/or letter that came with this booklet. This coordinator is ready to take you through the next steps, answer any questions you may have, be a great sounding board as you consider moving forward with donation, and be your expert guide through the process. If you want, we can also connect you with a “veteran” donor who can share their first-hand experience with you.
- ✓ **Talk to friends and family.** Donating is a serious commitment. It’s important to reach out to the people you trust the most to talk through your decision to donate and what it means for you physically and emotionally. Moving forward is entirely up to you. We do ask that you be 100% committed to donation prior to agreeing to the additional testing.

### ✓ **Complete a health history questionnaire and consent form.**

This initial screening will help us determine if donating is safe for you and give us permission to conduct further testing. Please be as detailed and honest as possible. Your health is our priority!

✓ **Look at your calendar.** Inform your coordinator of any upcoming dates in the next three months you may be unreachable or unavailable to donate. If you move forward, you may need to travel. This may mean taking time off from school or work on a short notice. Begin to think about the support you may need if moving forward.

✓ **Provide additional testing sample (blood or cheek swab)** Your coordinator will schedule you for a blood draw at your nearest lab. This will be to further analyze how close of a HLA match you are to the patient and screen for any possible communicable infectious diseases. This will be at no cost to you and all results are strictly confidential. If you are confirmed as the best match, you’ll likely be asked to donate. If you are not, you will stay on the registry and be available to other searching patients.

✓ **Wait to hear back.** While it may take up to a week, at most, to receive the results of your infectious disease test, the patient’s medical team may take as long as three months (sometimes longer) to make the final decision on if and when you’ll be donating. This is determined based on various factors, with the two major ones being HLA match and the patient’s prognosis. Your coordinator will check in with you periodically during this wait time.

## Talk to Your Personal Support Team

It’s important to discuss your decision to donate with the family and friends closest to you. It’s likely that they won’t know much about bone marrow donation and may be surprised to learn you registered as a potential donor.

This guide is a good starting point for explaining the basics—what bone marrow donation is, the two ways to donate and how a bone marrow transplant from a healthy person like you can save a life. Your coordinator can also provide other print and digital resources.

It’s important for family and friends to know the personal side of your decision—your motivations and convictions—so they can provide better support. Some good ways to do this include:

- Explaining what inspired you to register
- Discussing why you are committed to donating.
- Sharing how astounding it feels to match with a stranger on a biological level
- Opening up about your fears and hopes about donating



“What it could mean to someone is so, so big. And it’s not just someone—it’s their whole family.

“I became their adopted son, almost. Yeah, I now have a new family. To this day, it is the thing I am most proud of—and it wasn’t hard.”

**JOHN CONCADO,**  
bone marrow donor



## WHILE YOU WAIT

We are sure you're anxiously waiting to hear back about the possibility of donating. This wait can feel very long but think of it as time to organize should you be found as the best possible match for the patient.

Just remember, **DKMS is here for you.** If you have any questions or concerns, reach out to your coordinator immediately.

It is also very important that you inform your coordinator about any changes in your health as it could result in risks for exposure to infectious diseases for both you and your recipient.

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**“DKMS, when I look at it, means a second chance at life.”**

**HENNA DURANI,**  
mother of transplant recipient, Kenza



### Contact your coordinator immediately if any of the following occurs:

- You are diagnosed with a new medical condition
- You suffer a physical injury that may affect your ability to donate
- There is a change to any of your current medication(s) or you will start on new medication(s)
- Possible exposure or diagnosis of West Nile Virus, HIV or hepatitis
- Are diagnosed with or traveled to Zika or Malaria risk areas
- Recent body piercing or tattoo
- Receive a blood transfusion or any type of transplant
- Have a positive test or received treatment for syphilis
- Use a needle to take drugs not prescribed by a physician
- Receive an accidental needle stick or come in contact with someone else's blood through your mouth, eyes, an open sore or wound
- Are held in a jail or prison for more than 72 consecutive hours
- You plan to receive a vaccination (especially smallpox)
- You experience any signs or symptoms of an infection or other medical problems:
  - Fever or sore throat lasting more than 2-3 days
  - Fatigue or body aches consistent with the flu
  - Chest pains
  - Unexplained headaches, weight loss, night sweats, or persistent diarrhea
  - Abdominal pain, nausea, or vomiting
  - Long-lasting spots or sores in your mouth
  - Persistent cough or shortness of breath
  - Lumps in your neck, armpits or groin
  - Swollen lymph glands
  - Skin rash on trunk of the body

#### FEMALES:

You cannot donate if you are pregnant. Please avoid the possibility of becoming pregnant. This could impact the recipient's life because of delayed timing and locating another possible donor. If you think you may be pregnant contact your DKMS coordinator as soon as possible.



# PREPARING FOR DONATION

Once you've been confirmed as the best available match for the patient, you'll take the next steps toward donating. In most cases, you will donate one to three months after confirmation, depending on the health of the patient.

## INFORMATION SESSION

One of our coordinators will contact you to schedule an hour-long telephone information session. During this call, you will:

- Find out whether you will be donating peripheral blood stem cells or bone marrow.
- Learn details about the donation process and have the opportunity to ask questions.
- Review and sign the consent forms for donation.
- Schedule a physical exam and donation.
- Start planning travel arrangements for you and a companion of your choice with the help of your coordinator. Although we try our best to keep it to a minimum, you may have to travel by car, train or airplane.

## PHYSICAL EXAM

This is a comprehensive exam to make sure donation is safe for you. The physical exam includes:

- **Lab work:** urinalysis, blood tests, and pregnancy test for women. If you are pregnant, you will not be allowed to donate.
- **A vein assessment for PBSC donors** to confirm that your blood can safely be drawn through your arms. In less than 10% of cases, a central line may be needed.
- **For marrow donors only, a unit of blood may be collected** to have available for transfusion after the procedure, if needed. This is called an autologous unit and it is reserved just for you.

## AFTER THE EXAM

We'll review your results and notify you of any unexpected outcomes. If the findings pose a risk to you or the patient, you will not be able to donate.

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## SCHEDULING

The physical exam is held on a weekday, two to three weeks prior to donation, and is typically conducted at the hospital where you will donate. It takes approximately three to four hours, but you should plan to commit a full day.

Once you are medically cleared for donation, the patient's transplant center will be notified and final preparations for the patient's transplant will be made, including the preparatory regimen to destroy all diseased cells and repress their immune system.

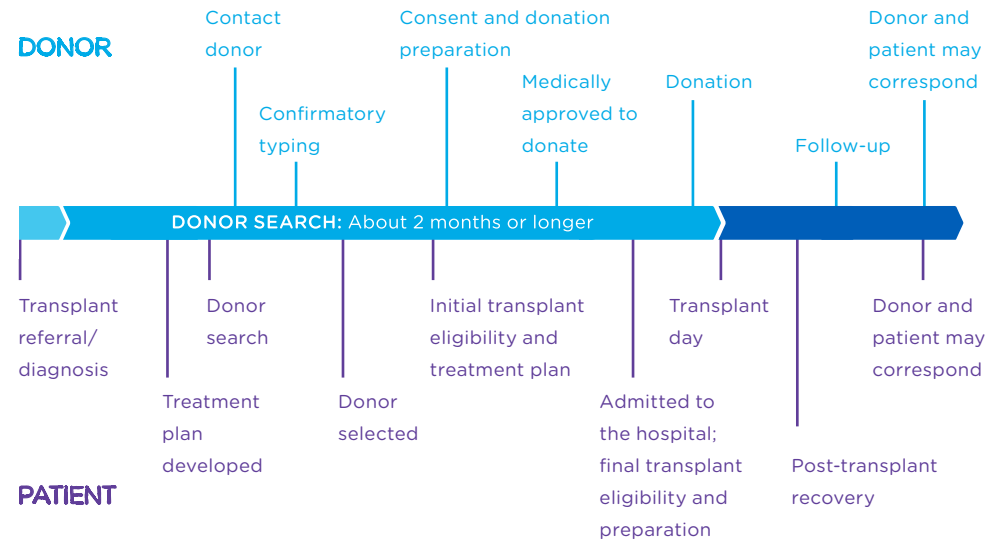
It's important to note that once a patient begins this treatment in preparation for the transplant, it leaves them highly susceptible to infections that can become life-threatening.

## TIME AND TRAVEL

The time commitment for donation is generally 20-30 hours over a three to six week period. In rare instances it can extend longer. You will likely need to miss a few days of work or school for your donation as well as recovery. Depending on the donation method and the nature of your work you may need to take additional time before returning to any physically strenuous activities. We can provide documentation to your employer or school to verify the medical nature of your absence(s).

Many donors will have to travel to one of our partner hospitals for the physical exam and donation. We arrange and pay for all transportation and accommodations for you and, on the day of donation, also for a friend or family member. We also cover childcare costs on the day(s) of your donation.

## Donation and Transplant Timeline





# NOTES

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Questions \_\_\_\_\_

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Thoughts \_\_\_\_\_

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# NOTES

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Reminders \_\_\_\_\_

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# 10 THINGS TO DO WHILE DONATING

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- Binge watch a TV series
- Watch a movie or two
- Grab a book
- Make new friends
- Catch up on sleep
- Listen to music
- Destress & day-dream
- Meditate; rest your mind
- Take selfies
- Talk to family and friends
- Document your journey



**“There was a lot of communication between DKMS and myself. They answered all of my questions and soothed my fears.”**

EMILY McMONOGALE, bone marrow donor



# AFTER DONATION

## THE PATIENT GETS THEIR TRANSPLANT

The cells you donated will be infused into the patient within one to two days of your donation. The stem cells move into the patient's bone marrow where they begin growing and producing new blood cells. The patient will stay in the hospital between 30-100 days until their blood counts approach normal levels and their immune system rebuilds.

## ANONYMOUS COMMUNICATIONS

Communicating with your patient is subject to hospital policies. During the first year after donation, many centers allow anonymous written communication facilitated through the national registry and DKMS.

## DIRECT CONTACT

After a year or more, some transplant centers allow direct contact between donors and patients. This is arranged only if both you and the patient consent to it.

Some centers may not allow any communication—anonymous or direct—which can be disappointing. Your coordinator will let you know what to expect.

## PATIENT UPDATES

You may be eager to hear about your patient's progress, but updates are subject to the policies of your patient's hospital (often referred to as a "transplant center"). While some centers provide updates during the first year after transplant, others have confidentiality policies that don't allow for release of any patient information. Your coordinator will let you know what to expect.

## SHARE WITH CARE

We know donation can be a powerful experience. You're doing one of the best things you could ever do by helping give someone a second chance at life. You may want to share the news with friends and family, and may turn to social media 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 exact age and diagnosis of the patient. It's simply too easy for other parties to piece together clues and possibly generate unwanted publicity for the patient.

### Example of How to Share

*"I'm donating bone marrow soon to help a child beat blood cancer."*

### Example of How NOT to Share (too specific):

*"I'm donating bone marrow this Wednesday in Washington, D.C. to a 10-year-old boy with Myelogenous Leukemia."*

FU



**"This bone marrow donation was a defining moment for me."**

**COREY SULLY,**  
bone marrow donor



## A HEARTFELT THANK-YOU FROM A PATIENT'S FAMILY TO THEIR UNKNOWN LIFESAVER

“

Dear Donor,

We are so overjoyed to be writing you this letter. The words “THANK YOU” do not do justice to what you have given to us. Your selfless act has saved our 5-year-old's life. Our son has been battling AML Leukemia since he was 3 years old. When he relapsed and we were told he needed a bone marrow transplant to live, we were devastated. Then we heard that they found a perfect donor match for him. You gave us hope, hope for a future with our little boy. As for our son you have given him a chance at life, a real chance. I was thinking of you when he was receiving the transplant, crying happy tears. We still think of you a lot. Every night that we get to kiss our son good night and every morning we get to wake up to him, we thank you. There is not that much that I can share with you through our initial correspondence, but I can say that he is doing well and we are home. He loves life and laughing and captures the heart of everyone he meets with his big smile and infectious laugh.

It is amazing how life works, from you signing up to the registry, to you being a match, saving our son's life, and us writing you this letter. You are a blessing to our family. Thank you for who you are and what you did. I hope that this is just the start in our correspondence with each other! When time permits we would love to meet you.

We were told that we are allowed to send you a gift and I wanted to send you something very close to me. It represents some of the struggle that our son has gone through over the past three years. I have compiled some of his [Beads of Courage](#) for you. We have acquired beads over the years and would like for you to have a piece of him. The white beads each represent a chemotherapy treatment, the stars are surgeries, the red beads are blood transfusions, and the textured beads are bumps along the road to recovery. Also we wanted to give you a pin that represents childhood leukemia. ”

Warmest regards,  
Tatianna Dudrick, James' mom



James Dudrick received a lifesaving bone marrow donation at the age of 5. He has been home and leukemia-free since 2017.

# FREQUENTLY ASKED QUESTIONS

## WHAT IS DKMS?

DKMS leads the fight to save lives by working with families, communities and organizations to recruit more bone marrow donors and provide more patients with lifesaving transplants. It started with one family's search for a bone marrow donor and is today the world's largest bone marrow donor center with branches in the United States, Germany, the United Kingdom, Poland, Chile, India and South Africa.

Every person we register as a potential bone marrow donor is listed on the national Be The Match Registry® operated by the National Marrow Donor Program (NMDP). DKMS donors make up 35% of this registry. During the course of the donation process, DKMS donors will encounter paperwork from Be The Match® and the NMDP, however the entire procedure will be coordinated with care by DKMS.

## DONATION

### Can I choose the donation method?

The donation method is selected by the patient's doctor based on which procedure they believe is best for the patient. That is why we ask that you be comfortable with the prospect of both PBSC and bone marrow donation. If you are not willing to donate through one of these methods, please notify your coordinator immediately.

**Does bone marrow donation involve my spine?** No. The marrow is extracted from the back of your pelvic bone using a special syringe.

### Will I permanently lose my stem cells?

For either donation procedure, the amount of stem cells collected is only a fraction of your body's total. Your donation does not weaken your immune system and the cells will naturally replenish 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.

## LOGISTICS

### When will I donate?

In most cases you will be asked to donate one to three months after the confirmatory blood test. We will always try to give you three to four weeks notice. If there are any important dates during which you cannot donate, we will make every effort to accommodate your schedule. Please keep in mind the timeframe for transplant heavily depends on the patient's prognosis. Our goal is to move as quickly as possible to give your patient a second chance at life.

### Where will I donate?

We work with a number of hospitals across the country. Although we try to schedule our donors at the hospital closest to their home, often times donors must travel by car, train or airplane.

DKMS will arrange and pay for your transportation and accommodations. In most cases, you will donate at the same facility where you will have your physical exam.

### Will my donation date change?

Donation depends on both your health and that of the patient. Delays are common—in the time it takes for you to go through testing and the physical exam, the patient's health can take a turn, either postponing or even canceling donation. This can be very disappointing, but please know that the patient is grateful that you were willing to help them.

### Who covers the expenses?

The patient's insurance and DKMS cover all medical, travel, lodging and meal expenses related to donation. DKMS will also cover the costs for a companion to travel with you for the donation procedure. There is no cost to you and your insurance will never be used. Donation-related, out of pocket expenses will be reimbursed.

### Will I be compensated for the time I take off from work?

If your employer does not provide paid time off for donation, DKMS has a financial assistance program for lost wage compensation. If you qualify for assistance, your coordinator will give you more information about applying for aid.

## MATCHING

### What makes a good match?

Doctors generally look at ten specific HLA markers to determine a match. The closer the match, the better the chances that the patient's immune system will recognize donated cells as its own and allow them to grow and make new healthy blood cells. We generally don't find out exact patient-donor HLA match ratios.

### Am I the only match?

It is possible for a patient to find multiple potential matches, however that information is known only to the patient's doctor and not to us. The doctor will select the best donor based on how close the HLA match is, and will also consider the donor's age, sex, BMI, health history, and availability along with other factors. If you are contacted as a potential match, but not selected for donation, we will inform you. You will remain on the registry to be available for other searching patients.

### Do ancestry and ethnicity affect matching?

Heritage is a very important factor. Like hair and eye color, your HLA type is inherited, so the best matches generally happen between patients and donors who share the same ethnicity.



# ADDITIONAL RESOURCES

- 30 CONFIDENTIALITY GUIDELINES
- 33 DONOR EXPENSE/REIMBURSEMENT GUIDELINES
- 37 FAMILY/FRIENDS, PARENTS, EDUCATORS, and EMPLOYERS
- 39 SHARE YOUR STORY

# CONFIDENTIALITY GUIDELINES

## DO...

- ✓ **Take** pictures or video of your donation (But DO NOT post day of donation!). Make sure the pictures or video don't identify the center, center staff/personnel, donor ID, location, date, label on product, or your recipient. The best practice is to post a few days or weeks later, but be vague about your actual donation date.



- ✓ **Wear** your DKMS shirt on the day of donation.
- ✓ **Keep** information about your patient vague.

## DON'T...

- ⊘ **Post** on the day of donation. This not only includes photos or videos, but also Insta-stories, Facebook Live, Periscope, and Snapchat.
- ⊘ **Talk** to the media on your day of donation. This includes radio, television, web sites, newspapers etc. Contact DKMS if you want to speak to the press after you donate.
- ⊘ **Share** the location of your donation (city, hospital, medical center, etc).
- ⊘ **Share** the patient's age, location, gender, or diagnosis.
- ⊘ **Share** the actual donation date.
- ⊘ **Share** the names or social handles of any medical provider, such as a nurse or doctor.

## HOW TO SHARE



♥ 204 likes

[@DKMSsample](#) Recently, I participated in one of the most rewarding experiences of my 26 years. I registered myself as a bone marrow donor this past August after a drive at Bonnaroo. In February, I received "the call" that I was a match for someone in need and they wanted to move forward with the donation.



♥ 180 likes

[@DKMSsample](#) I WAS A MATCH! I am honored to say i donated my stem cell cells to a cancer patient. 5 yrs ago [@DKMS\\_US](#) swabbed my cheek and then I got the call.

[#life](#) [#donate](#) [#donateblood](#) [#realtalk](#) [#love](#) [#give](#) [#foodforthought](#) [#DKMS](#) [#iwasamatch](#)



**John Doe**

I was super excited to donate my bone marrow at Mount Sinai hospital last Tuesday. I would like to thank Janis and Mark, the two nurses who helped me through this procedure. Super happy to save the life of a 19-year-old boy with aplastic anemia.

[Like](#) · [Comment](#) · 9 minutes ago



**John Doe**

I was super excited to donate my bone marrow to a patient that needs my help. Thanks to the nursing staff who helped through this procedure. Super happy to save the life of a young man with this awful blood disorder.

[Like](#) · [Comment](#) · 9 minutes ago



**Richard Roe**

My best friend Jackson is donating his bone marrow today. His donation will go to a six-year-old patient suffering from acute lymphoblastic leukemia.

[Like](#) · [Comment](#) · 9 minutes ago



**Richard Roe**

My best friend is donating marrow for a little boy with blood cancer.

[Like](#) · [Comment](#) · 9 minutes ago

### WHAT'S WRONG WITH THIS POST?

- Named the donation center
- Named the nurses
- Gave the age and diagnosis of the patient
- Gave the date of donation

### WHAT'S WRONG WITH THIS POST?

- Shared patient's age and diagnosis
- Shared date of donation



# DONOR EXPENSE AND REIMBURSEMENT GUIDELINES AT DONATION

Great! You've made the first step to help your patient. We want to make your PE and donation trips as seamless as possible.

## We've got you covered

Your DKMS coordinator is going to make your travel arrangements for you including your flight/train and hotel. We'll even get an Uber for you. Check! If this is your donation trip, we will also hook up your companion. Major expenses like flights and hotels are covered upfront, however there are other expenses like meals that will need to be reimbursed. We will reimburse travel expenses related to donation activities as outlined in this section:

Travel Expenses	PE	Donation
Planes, Trains and Automobiles (luggage too)	✓	✓
Hotel	✓	✓
Ground Transportation <ul style="list-style-type: none"> <li>To and from airport</li> <li>To and from medical appointments</li> </ul>	✓	✓
Taxis/cabs to and from restaurants	⊘	⊘
Personal Vehicle Mileage @ IRS-approved Rate Parking Fees Tolls	✓	✓
Rental cars	⊘	⊘
Gasoline for personal vehicle	⊘	⊘
Meals	✓	✓
Alcohol	⊘	⊘
Excessive tipping (more than 15% gratuity)	⊘	⊘
Companion (1) Travel	⊘	✓
Extra friends and family at dinner (sorry!)	⊘	⊘

Travel Expenses	PE	Donation
Physical Examination	✓	—
Other Medical Appointments	✓	✓
Donation Procedure	—	✓
Donation-related, over-the-counter and/or prescription medications	✓	✓

**NOTE:** Unfortunately, medical billing errors may occur. We want to ensure that they are corrected quickly. If you receive a medical bill/invoice for any donation activities:

1. Forward a copy of the bill immediately. If you have received a medical bill, it means it was not routed to the correct party.
2. Alert your DKMS coordinator.

Other Support	PE	Donation
Childcare / Pet Care <small>(ask your representative about different options we can assist with for childcare/pet care)</small>	✓	✓
Donor Lost Wages <small>(see Donor Financial Assistance Application)</small>	✓	✓

## NOTES

Date \_\_\_\_\_

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# FAMILY/FRIENDS, PARENTS, EDUCATORS AND EMPLOYERS

## SOMEONE YOU KNOW IS A MATCH!

- A friend, family member, student, or employee has the chance to save a life! He/She has been chosen as the best genetic match for a patient suffering from a life-threatening blood disease. Finding a match is difficult, and a transplant is likely the patient's only hope for a second chance at life.
- Throughout the donation process, support from family, friends, co-workers and the school community is especially important.

## BE PROUD

The fact that someone you care about is willing to help another person suffering from a life-threatening blood cancer shows true generosity, kindness and compassion.

## HOW ARE MEDICAL COSTS COVERED?

All medical, travel and lodging costs related to the donation are covered by DKMS or by the transplant recipient's insurance.

- There is no cost to the donor and their health insurance will never be used.
- Donation-related, out-of-pocket expenses will be reimbursed.
- Many donors will have to travel to one of our accredited partner hospitals for the medical exam and donation.
- DKMS will also cover the costs for a companion to travel with the donor for the procedure.

## DONOR SAFETY

At DKMS, the health and safety of our donors is our top priority:

### MEDICAL CLEARANCE

A complete medical exam, including diagnostic testing, is conducted to ensure that the donor is healthy enough to donate.

### DONOR ADVOCATES

Our coordinators will closely guide your loved one through the process and follow up until a full recovery is achieved. We follow up at 2 days, 1 week, 1 month, 6 months, and 1 year after donation, and more frequently if needed.

## WILL A DONOR MISS WORK OR SCHOOL?

While we do our best to work around their schedule, donors will likely have to miss some work or class for the medical exam and donation.

- The time commitment for the entire process from medical exam to donation, including travel, is about 30-40 hours over a 4-6 week period.
- We are happy to provide letters of explanation to employers and universities.
- If a donor's employer does not provide paid time off for donation, and if he or she is eligible, DKMS has a financial assistance program for lost wage compensation.

## WHAT HAPPENS DURING DONATION?

There are two ways to donate:

### Peripheral Blood Stem Cell (PBSC) Donation

A non-surgical, outpatient procedure similar to donating platelets. Blood is drawn through one arm and passed through a machine that filters out the blood stem cells, and returned through the other arm. This procedure can take up to 8 hours. Prior to donation, injections are given to boost stem cell production. This is the more commonly requested method.

### Bone Marrow Donation

A 1-2 hour surgical procedure performed under general anesthesia. Marrow cells are collected from the back of the pelvic bone using a syringe.

## HOW LONG DOES IT TAKE TO RECOVER?

Most donors are discharged the same or next day. Donors give about 3% of their marrow, which completely replenishes in a few weeks.

Within a few days to a week, a donor should be well enough to return to work, school and many activities. Physical labor, heavy lifting, bending and strenuous exercise should be avoided for at least two weeks. Common side effects include lower back pain, fatigue, nausea, stiffness or soreness for the first 2-3 weeks.



## HOW CAN I HELP?

### FAMILY AND FRIENDS

While recovering, your loved one may not be able to do household chores or other errands. Assisting with chores, childcare and other tasks will be very helpful—especially in the days immediately following the donation.

### EMPLOYERS

In addition to supporting your employee during their donation journey, you can join us in the fight against blood cancer. From hosting registration drives to raising crucial funds, our team will work with your business to help us provide hope to more patients in need, while giving you the opportunity to showcase your commitment to corporate social responsibility.

### EDUCATORS

You can join us in the fight against blood cancer. Holding a bone marrow donor registration drive on your campus is an amazing and rewarding experience for students and the entire school community. We've already teamed up with hundreds of schools across the country with amazing results: more than 167,000 registrations, nearly 6,000 matches and over 600 donations from college drives.

### RESEARCH PROVES THAT CELLS FROM YOUNGER DONORS LEAD TO BETTER LONG-TERM SURVIVAL FOR PATIENTS AFTER TRANSPLANT.

(SOURCE: NATIONAL MARROW DONOR PROGRAM)

# SHARE YOUR STORY

Each of our donors has a story to share. YOU have one, too. Your story can help save the lives blood cancer patients around the world. Please help build our inspiring collection of stories by sharing your journey to donation.

There are no rules or requirements for your story. This is an opportunity for you to share YOUR story in your own words!

Your submission can be anonymous if you wish, but we also love to feature you and your donation photo on our website and social media channels.

There is no required length or limit to your story—it can be as short or long as you want it to be.

You may choose to dedicate your story to someone who has inspired you, touched your life or helped you through this process.

If you are not sure where to begin, here are some questions to consider in telling your story, but certainly not requirements:

- How/when did you first learned that you were a lifesaving match for someone?
- What is your most memorable moment throughout this process?
- Why did you register to be a potential lifesaver?
- Encourage others to do so.

Once you are comfortable and ready to share, you can send us your story to [press@dkms.org](mailto:press@dkms.org)

## NOTES

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# THANK YOU

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