



About Us

DKMS is an international non-profit organization dedicated to the fight against blood cancer and other blood disorders. Founded in Germany in 1991 by Dr. Peter Harf, DKMS and our over 1,000 employees have since relentlessly pursued the aim of giving as many patients as possible a second chance at life.

With over 11.5 million registered donors worldwide, we have succeeded in doing this more than 105,000 times to date by providing blood stem cell donations to those in need. This accomplishment has led to DKMS becoming the global leader in the facilitation of unrelated blood stem cell transplants.

Our Story

Our story began with one family fighting to save someone they loved. When Mechtild Harf was told that the only treatment for her leukemia was a blood stem cell transplant, she had no matching family members. Motivated by the need to find his wife a donor, Mechtild's husband Peter founded DKMS, and in our first year of operations we managed to expand the registry from 3,000 donors to 68,000.

Unfortunately, despite the Harf family's best efforts, Mechtild ultimately did not survive. However, before she passed away she made Peter promise her that he would not stop fighting until every patient had a matching donor and a potential second chance at life. By 1995, DKMS had already become the world's largest network of donor centers and ever since we have worked tirelessly to fulfill our mission - **to provide as many patients as possible with a second chance at life**.

We have offices in Germany, United States, Poland, United Kingdom, Chile, and South Africa. In India, DKMS has founded the joint venture DKMS-BMST together with the Bangalore Medical Services Trust. International expansion and collaboration are key to helping patients worldwide because, like DKMS itself, blood cancers and disorders know no boarders.





What Does The Abbreviation DKMS Stand For?

DKMS stands for 'Deutsche Knochenmarkspenderdatei'. which means "German Bone Marrow Donor Center" in German. But as we grew internationally and extended our mission to include the United States, Poland, the United Kingdom, Chile, India, and South Africa, we moved to give ourselves a standard identity. In 2016 we decided to use the same name everywhere - DKMS - to make us identifiable as a single organization that operates under a single name.



What We Do

We are dedicated to the fight against blood cancer and blood disorders by:



Creating awareness of blood cancer and other blood disorders.



Recruiting blood stem cell donors to give those in need of a transplant a second chance at life.



Facilitating blood stem cell and bone marrow donations to make saving a life as easy as possible for our donors.



Engaging with the public as well as companies to organize donor registration events.



Helping improve blood cancer treatment - through our own research and state-of-the-art technology in our laboratory.



We also support patients from day one of their diagnoses, providing family and friends with a positive way to get involved by organizing stem cell donor drives that can enhance the chances of finding a lifesaving match, rally community support, and provide hope.

Why Our Work Matters

Blood stem cell transplants can be the best or only treatment for patients fighting blood cancers like leukemia, lymphoma and myeloma as well as approximately **70** other conditions including sickle cell disease, severe aplastic anemia, immune system disorders and inherited metabolic disorders.



Only **30%** of patients in need find a matching donor within their family, the remaining **70%** must rely on finding an unrelated donor.



30% FAMILY MEMBER DONOR In the United States, there are over **17,000*** new patients each year who will need to find a matching unrelated donor.



How Is A Match Found?



A common misconception is that matching is based on blood type, but **matching is actually based on the donor and patient's human leukocyte antigen (HLA) tissue**

characteristics. HLA are proteins - or markers - found on most cells in your body. Your immune system uses these markers to

recognize which cells belong in your body and which do not. The closer the donor and patient's HLA match, the better the chances the patient's body will accept the donated cells and allow them to grow and make new healthy cells.

When a potential donor joins the DKMS donor pool, they swab their cheeks. Those swabs are tested for the potential donor's HLA tissue type and added to the global donor pool, where doctors can search to find a matching donor for their patient. If a potential donor's HLA type is found to be a match for a patient in need, they will then be contacted by DKMS to begin the donation process.

Ethnic Diversity On The Registry

Matching is linked to ethnicity because certain HLA markers are more common among specific ethnicities. It is more likely, although not guaranteed, that patientdonor matches will happen between those who share the same ancestry. Unfortunately, patients from backgrounds that are underrepresented in the global donor pool are less likely to find a match.

DKMS is working hard to increase the representation of diverse ethnic backgrounds in the global donor pool to ensure that all patients have a second chance at life.

How Donation Works?

There are two methods of donation, **Peripheral Blood Stem Cell Donation** and **Bone Marrow Donation**, which method a donor does is determined by the patient's medical team. For both methods, DKMS covers all donor costs related to donation, including but not limited to medical costs, transportation costs, accommodation costs, food costs, and lost wages.



Stem cells are collected from the blood stream in a process similar to plasma donation. For four days prior to the donation, donors receive injections to increase stem cell count in the blood stream. On the day of collection, the donor's blood is removed from one arm and passed through a machine that separates out the blood stem cells. The remaining blood is returned to the donor through the other arm. This is an outpatient procedure that takes about 6-8 hours over one day. This method is used for around **85%** of donations in the U.S.



Marrow cells are collected from the backside of the pelvic bone (not the spine) using a special syringe. Donors receive general anesthesia so no pain is experienced during the procedure. This is a 1-to-2-hour, outpatient surgical procedure. This method is used for around **15%** of donations in the U.S. CHANCES OF FINDING A MATCHING UNRELATED DONOR BY ETHNICITY*











*National Marrow Donor Program, 2021

FAQs



HOW DO I REGISTER?

There are two ways to register: at an in-person donor registration drive or online at **<u>dkms.org</u>**. DKMS does not charge anyone to register. Registration includes an eligibility and health screening, filling out a form, and swabbing each cheek to collect cells for use in matching with a patient.



WHO CAN REGISTER?

To be eligible to register, a person must be:

- Between the ages of 18 and 55
- 🖌 In general good health
- Willing to donate to any patient
- Willing to do either method of donation
- Not already registered
- Not an active member of the armed forces
- Living permanently in the U.S. and willing to travel to donate, if needed

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WHO PAYS FOR DONATION?

The patient's insurance generally covers the cost of the donation procedure or related testing or doctor's appointments. There is no cost to the donor to donate nor is there a cost to sign up. DKMS covers any of the donor's costs related to their donation, including but not limited to transportation, lodging, meals, and lost wages.



CAN I REGISTER FOR A SPECIFIC PATIENT?

All DKMS potential donors are part of the global donor pool and can be called to save the life of any patient searching for a matching donor. If you would like to register only for a specific patient, contact their medical team directly.

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WILL I PERMANENTLY LOSE MY BONE MARROW OR 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.



I REGISTERED A LONG TIME AGO. DO I NEED TO RE-SWAB TO STAY REGISTERED?

No, once you've registered and received confirmation that you are in our database and on the national registry, you're all set. Once registered, you will remain on the registry until age 61, unless you ask to be removed earlier.



CAN I REGISTER AS A DONOR IF I'M PART OF THE LGBTQ+ COMMUNITY?

Sexual orientation does not make people ineligible to register as a potential bone marrow or blood stem cell donor and it is not part of our eligibility criteria. You can register if you are part of the LGBTQ+ community.



New York, NY • Charlotte, NC Dallas, TX • Washington, MO



For stories or press inquiries <u>pr@dkms.org</u> <u>dkms.org</u>

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