

From A to Z: The fight against blood cancer

WHAT WE DO. WHAT DRIVES US.



- 05 Welcome to your second life.
Correspondence between a stem cell donor and his recipient.
- 14 After the transplant: Cured patients give us courage
- 23 We find donors. For people who could die without them.
- 24 The first step towards saving a life
- 27 We save lives. And more and more people want to help us.
- 28 A race against time. Every day counts.
- 30 For Mechtild Harf and others. How it all began.
- 32 Milestones in the history of DKMS
- 34 The importance of going global. For every single patient.
- 36 Global commitment. We're changing the world.
- 38 Working together for patients. Here and around the world.
- 40 Show you mean it! 05/28 World Blood Cancer Day
- 42 Innovation center: the DKMS Life Science Lab in Dresden
- 43 The DKMS Cord Blood Bank. Little heroes wanted.
- 44 Faster searches, more efficient support. Why quality matters.
- 46 Interview with DKMS Chief Executive Officer Dr Alexander Schmidt.
- 47 Science and research at DKMS.
- 48 Focus: young donors. An education for life.
- 50 Open wide. Mouth swab against cancer. Publicity can save lives.
- 52 Heroes: our donors. Lifesavers with a heart.
- 54 Donors and recipients: Happy encounters.
- 56 Financing: why every cent counts.
- 58 Supporters and helpers – Saving lives. A matter of honor.

From A to Z: The fight against blood cancer – What we do. What drives us.

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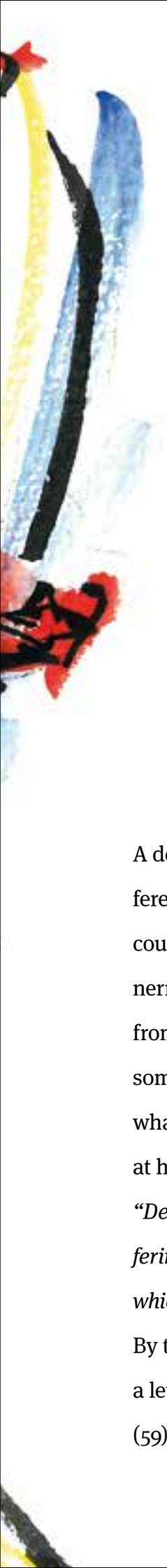
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A

**t the end of the day,
this is all about
one thing: saving
as many lives as
possible.**





Welcome to your second life

Correspondence between a stem cell donor and his recipient

A desk, a sheet of paper, a pen. Two people from completely different walks of life. Sometimes even from completely different countries or continents. They begin to write, letting their innermost thoughts and feelings flow out onto the paper, straight from their hearts. They write about something truly unique, something truly valuable: their lives. One of them describes what made him want to save a life; the other expresses his joy at having a new, second life.

“Dear donor, I’d like to tell you our story! It’s a tale of agony, suffering and illness, but also full of joy, love and hope. It’s a story in which you play one of the leading roles.”

By the time he’s strong enough to pick up a pen again and write a letter to his stem cell donor and life-saver, Hans-Peter Hambach (59) has already been through a period of extreme difficulty.

Corresponding and meeting. Here’s how it’s done:

According to German regulations, donors and patients can meet face-to-face only after a mandatory two-year waiting period that begins with the stem cell transplantation. (Some countries allow no such exchanges of addresses at all.) If they wish to make initial anonymous contact before that time, they can do so. DKMS German Bone Marrow Donor Center acts as an intermediary for anonymous contacts so they can exchange letters and gifts.

Here's how it all began. In early 2007 Hans-Peter was diagnosed with blood cancer. He received the news only a short time after he had met Maike, who is now his wife. It had been love at first sight – but for this new couple there were tough times ahead.

“The diagnosis really pulled the rug out from under our feet. I was really scared that this would be the end of it all. And I had just met the woman of my dreams! When Maike took me to the hospital I thought, ‘That’s it! I’m never going to see her again!’ But Maike stayed by my side and did everything she could to help me. Then, after a while, we got the news we’d been waiting for – the news that there was a donor. A donor – for me!”

The donor in question was Mario Schäfer (50) from Lindlar/ Germany. Mario donated some stem cells to taekwondo trainer Hans-Peter in August 2007. *“For me, it was clear from the word go that I would see this through, no matter what. I didn’t want a family to be living in fear just because I’d decided not to make my donation. I was absolutely convinced right from the start that we – the patient and I – would make it together!”*

Donors first find out about the age and nationality of “their” patient straight after they have made their donation. Three months later they can submit their first inquiry to the transplant center to learn more about the recipient’s state of health.



WELCOME TO YOUR SECOND LIFE



A moving record of a moving time

Because Hans-Peter Hambach was still too weak to write at the time, his wife documented every last detail of the all-important day of his transplantation in a letter written in pen and ink:

“We waited all day for your donation to arrive, right until the evening. It was already getting dark when the doctor finally came in carrying a bag of your stem cells: ‘Here it is,’ she said, ‘your new life.’ It’s a situation I cannot even begin to describe. Shortly afterwards she came back again, this time with your letter. I read it out to Hans-Peter as your life continued to drip into his body. He lay there for a whole two hours, as it made its way into his bloodstream, where his body, we hoped, would accept it. It’s a moment we will never forget.”

It was also the moment when two men became brothers. For two years Hans-Peter and Mario wrote to each other regularly, from ‘big brother’ to ‘little brother’. The two each became a part of the other, bonding without even knowing who the other really was, with no idea of what he might be thinking or feeling, or even what he looked like. Mario recalls: *“At some point I found out my stem cells were going to a German man who was older than me, and I thought to myself, ‘Hey, so you have a big brother now!’”*

Due to confidentiality laws, DKMS has no direct contact with patients and cannot easily pass on mail to them. To forward letters or postcards, we regularly rely on the cooperation of the hospital in which the patient is receiving treatment.

Two years after the transplant procedure, some countries allow donors and patients to exchange addresses and meet in person. This too is organized by DKMS and requires both sides to consent to their details being exchanged.

F Hans-Peter and Mario began exchanging letters detailing every step of the patient's progress, no matter how large or small, and meticulously describing the joys of everyday things. In February 2008, six months after the transplantation, a joyous Hans-Peter wrote to his donor: *"My diet is finally becoming less restricted! What a joy: my first ground pork sandwich in a year and a half. My wife no longer needs to freeze every slice of sausage or every piece of butter, and I even get to eat in restaurants. But in my mind I'm still wondering who you are."*

For Mario, every letter he receives is a sign of hope: *"I remember well when I first got a letter from Hans-Peter and Maike. My wife and I were in tears as we read it because we realized how much suffering these people had been through and how easily it could hit any one of us as well. After the letter I was absolutely convinced that, come what may, I was going to help my 'big brother'. There was no way I was going to let his god-damned cancer destroy the new-found happiness of these two people."*





WELCOME TO YOUR SECOND LIFE



As he began to return to his normal existence, Hans-Peter enthusiastically described his new lease of life, writing how he was enjoying the summer, riding his bike, meeting friends, and traveling again, at last... Since the transplantation, he has been enjoying his life in the knowledge that people like Mario exist, people who care for the well-being of others and don't expect anything in return. *"When I first met him, we just fell into each other's arms. There was so much I wanted to tell him: Thank you for being here. Thank you for doing all of this for me. Thank you for allowing me to live! It immediately occurred to me to ask Mario if he would be best man at my wedding."*

Mario agreed. *"I think we have a very special connection"*, he says. In the meantime Hans-Peter Hambach had been given the all-clear, and when Mario Schäfer was best man at his wedding in August 2009, he gave the newlyweds a card with the words *"Omnia vincit amor"* ("Love conquers all"). One week earlier Hans-Peter and Maike had had exactly those words engraved on their wedding bands – and hadn't told anyone about it ...



*“I thought
I’d never
be able to
play soccer
again.
No way!”*

TIM

Tim, age 12, comes from Spenge/Germany. Eight years ago a stem cell transplantation cured him. It was made possible by stem cells from Udo, who lives just a few miles away. Today Tim and Udo are best buddies.

*“At last I can
go on vacation
again!
I never thought
I’d be able to
do that
any more.”*

MICHELLE

Michelle, 16, from Heilbad Heiligenstadt/Germany, managed to beat blood cancer. She can now go on vacation with her family again. The teenager is promoting the DKMS’s cause because she wants to give hope to blood cancer sufferers. She’s also working to help more people join the donor register.





“My family and friends were always there for me. And we can be together in the future too – thanks to my donor.”

ARNE

Arne, 25 years old, is a student from Berlin/Germany. He was diagnosed with blood cancer in 2005, and after a relapse, he received a life-saving stem cell donation. Today he is fully recovered and enjoying life again. He likes to hang out with friends and enjoys traveling the world.

*“Finally I can
go outside again
and play and
do whatever
I want!”*

PAUL

Paul, age six, from Sanitz/Germany, was diagnosed with leukemia as a baby, when he was just seven months old. He spent the first few years of his life in various hospitals. After a successful stem cell transplantation, he now has a bright future ahead of him.



*“When it comes to
saving lives,
we’ll stop at nothing.”*

We find donors. For people who could die without them.



From left to right: Dr Alexander Schmidt, Sandra Bothur and Sirko Geist, Managing Directors of DKMS German Bone Marrow Donor Center

It's a devastating diagnosis. And it can hit anyone anywhere in the world: **blood cancer**. Around the globe, more children die of blood cancer than of any other disease, and for many patients a life-saving stem cell donation is their only chance of survival. In Germany alone, one person contracts blood cancer every 16 minutes, worldwide every 35 seconds. And still one patient in five in Germany is unable to find a donor.

Blood cancer is a malignant disease of the blood-building system. The only cure for many sufferers is to transplant healthy stem cells from a suitable donor. When it comes to finding such a donor and matching them to the patient, the non-profit DKMS German Bone Marrow Donor Center is here to help.

We have a clear objective: to help people who are at risk of dying. All over the world. That's our mission. We have a global responsibility to delete blood cancer!

The first step towards saving a life

A cheek swab sample is a quick, simple and convenient way to join the donor center. Rock band Cat Ballou, from Cologne/Germany, shows us how it's done.



Across Germany DKMS organizes more than 1,100 donor drives a year to win new people for the database – in businesses, schools, clubs, houses and elsewhere. Every day some 1,600 people on average sign up. In 2013 more than 660,000 new donors around the world joined our registry. That's a record!

For us to add as many new donors to our books as we possibly can is absolutely vital – partly to increase the chances of finding a match for a patient in need and partly to keep DKMS fit for the future and working well on a permanent basis. At the same time we lose more than 30,000 donors every year because of the 61-year age limit that applies.

When it comes to finding people who are willing to support us in our work, compassion is the key – the unique motivation that makes us want to save somebody else's life.

Three ways – two methods

As a rule, any healthy individual aged between 18 and 55 years can become a stem cell donor and join the registry in one of three different ways.

There are two ways of analyzing donors' tissue: either on the basis of a blood sample or, since 2007, by means of a cheek swab.

Donor drives

Our public donor drives are always prompted by the needs of a specific blood cancer sufferer. They are organized by local initiatives working in collaboration with DKMS. On the day of the drive, potential donors provide a sample of approximately 5 ml of blood, which is taken from a vein in their arm and sent to the lab for their tissue type characteristics to be analyzed. In 2013 there were 636 public donor drives, which added 179,285 new donors to our database in Germany.

A record high – more than

660,000

new donors registered in 2013 alone.



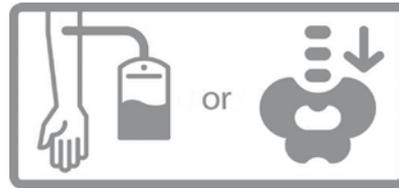
1. Register



2. Lab test



3. Health check



4. Stem cell donation or bone marrow donation

Blood typing in companies

As well as individuals, numerous businesses have joined the fight against blood cancer. They often launch typing campaigns when a co-worker falls ill or a story emerges about a patient in the local area. Many of them have also been taking targeted steps to support DKMS as part of their Corporate Social Responsibility programs. New donors are registered directly on the premises, giving everybody in the organization the opportunity to join the action. As a rule, the company carries the cost of the €50 registration fee that has to be paid for every addition to the registry.

By mail

Many people live some way away from a place in which public donor drives are held. So if they are interested in joining the registry, they will need to have a registration pack sent to their home. They can request one either online or by phone and use the swab contained in it to take a sample from inside their cheek. The sample should then be sent to the DKMS Life Science Lab in Dresden/Germany. By the end of March 2014 a total of 706,960 donors had done just that; they are now registered with DKMS. And the trend is upward: in 2013 there were 158,835 new online donor registrations.

Confidentiality

For us at DKMS, confidentiality and data security are the top priorities in everything we do. Personal data protection is a key concern, and to make sure sensitive information is treated appropriately, we have our own in-house data protection officer to ensure German data protection laws are adhered throughout. Any information DKMS transfers to the Central Bone Marrow Donors Registry in Germany (ZKRD) or the National Marrow Donor Program (NMDP) in the USA consists solely of data that is relevant for matching. This includes tissue typing, age and gender and is always transferred with the relevant donor number rather than their name.



Joining the registry: donors and assistants at a donor drive organized by DKMS partner, Delete Blood Cancer UK



Helpers at a donor drive for Kayla, a young patient in Berlin



Registration details coming into the lab are checked on arrival before being sent to typing.

Collecting stem cells from a donor in the outpatient clinic: beside him is the bag containing his life-saving donation – a second chance at life for a blood cancer sufferer somewhere in the world.



We save lives. And more and more people want to help us.

DKMS donors do great things. Each and every one of them is willing to give someone they've never even met a second chance at life – without a thought for themselves.

Together with our donors, we represent a very special community in the fight against blood cancer, linking patients' destinies with people who want to help. Together we are strong. At the time of writing, in July 2014, more than 4.5 million stem cell donors are listed in the various DKMS databases around the world. 3.4 million of them are based in Germany. The DKMS family consists of five national organizations, which together form the largest association of databases of this kind in the world. Since 1991 we have given more than 41,000 patients the chance of a new life. Every day more than 15 DKMS donors provide stem cells or bone marrow to a patient somewhere in the world.

So what exactly does a stem cell donation involve?

Once we've found the right donor for a blood cancer patient, their stem cells can be harvested in one of two different ways:

Peripheral stem cell collection (apheresis)

In about 80 percent of cases stem cells are harvested from the donor's blood stream. For five days prior to the procedure, the donor is given G-CSF growth factor to increase the number of stem cells in the peripheral blood. The cells are then taken directly from their blood in an outpatient procedure that takes about four hours to complete. In general donors can leave the hospital on the same day, although on rare occasions a follow-up collection may be required the next day. This procedure, which was co-developed by DKMS, has been in use since 1996.

Bone marrow donation

This method involves using a syringe to remove approximately 1 liter of bone marrow and blood from the pelvic bone (not the spine!). The donor is given a full anesthetic. The mix that is extracted includes about 5 percent of the donor's overall bone marrow. Their remaining bone marrow will regenerate to normal levels again within about two weeks of the procedure. Usually two small incisions towards the back of the pelvic bone are enough for the cells to be extracted. Any potential complications tend to be linked to the anesthetic rather than cell removal.

It's important to know

Providing the detailed information our donors need is a top priority at DKMS. We like to ensure they know everything they should. Our goal is to see that every one of them has the best possible understanding of the significance of their donation and what the two cell collection procedures involve. That way they will know what to expect. Detailed consultations and information for donors also make all the difference for patients: only about 4 percent of donors withdraw from the process after they have been selected, usually only because they have fallen ill themselves, are pregnant or something else is preventing them from going through with their donation.

What collection method is used depends on the patient's state of health. As a rule, donors should be willing to undergo either of the two procedures, which is why the medical checks they have beforehand are of the utmost importance. If there are any doubts about a donor's state of health, the DKMS medical team clarifies whether or not they are fit enough to go through with the procedure. Donors undergo a complete medical check-up, and when they are found to be fully suitable for the stem cell collection and consent to the procedure being carried out, they finally make their donation.

*Around the world
we have more than*

4.5 Mio.

registered stem cell donors. 3.4 million of them are based in Germany.

A race against time. Every day counts.

When it comes to finding the life-saving match needed for a stem cell transplant, time is of the essence. The sooner a suitable donor is found, the better the patient's chances of survival. And when doctors call on DKMS for support, they know they can rely on us. Our donors have a reputation among international hematologists and oncologists for being immediately available and highly motivated.

And there are plenty of good reasons for the specialists to think so. High-quality typing of HLA findings from our donors means we can find matches for patients extremely fast. In fact, more and more people are becoming actual donors within just a few weeks of registering – because we are working hard to get even faster and better at what we do. Since 2013, we have been using DNA sequencing to test not the standard five but six transplant-relevant HLA gene loci of every new DKMS donor joining our data base: HLA-A, HLA-B, HLA-C, HLA-DRB1, HLA-DQB1 and HLA-DPB1. This significantly speeds up the process of finding the right match in the database and represents

a major improvement in quality in the interests of patients.

In addition, since January 2013 the DKMS has screened every donor blood sample for cytomegalovirus (CMV), a common genus of the herpes virus, even before typing. Between 30 and 90 percent of the global population are thought to be CMV positive. In healthy people the infection is usually completely harmless. But for those with a weakened immune system the consequences can be fatal. That's why the CMV status of every donor and patient is ascertained before a transplant takes place. Thanks to the new DKMS profiles we generate for every person joining our registry, we can identify donors whose CMV status is compatible with that of the patient. That's a major step forwards in stem cell transplantation and in our life-saving race against time.

So far about

73%

of DKMS donors around the world have undergone high-resolution typing.

Our donors are always on hand

Annual donor mailshots and an online newsletter are just some of the ways we make sure our donors' addresses, phone numbers and email addresses are up-to-date – and stay that way. This enables us to contact them any time anywhere, even at short notice, whenever we think they might be a match for a patient in need.



Since 2006 the lab has been carrying out high-resolution typing on every DKMS donor as standard – a major step in improving quality.

A courier delivers blood samples to the lab





For Mechtild Harf and others. How it all began.

The DKMS story is one of change, hope and success. And it proves emotions can overcome barriers.

“If Mechtild doesn’t find a donor, she will die.”

In 1991 these words echoed around the city of Frankfurt/Germany after Mechtild Harf, a mother of two girls, had been diagnosed with leukemia. The race between life and death was on, and a bone marrow transplant was the only way of saving her. Mechtild’s husband, Dr Peter Harf, now Chairman of the Board with the DKMS Foundation for Giving Life, immediately set about searching for a suitable donor. The situation was critical. The USA and Britain both had extensive databases of potential donors already. But in Germany no more than about 3,000 people were registered.

“We’re making the impossible possible!”

Meanwhile, time was running out for Mechtild. So Peter and Mechtild’s sister-in-law, Claudia Rutt, got together with family and friends to launch the Help For Leukemia Sufferers initiative in January 1991. Two months later Prof Dr Gerhard Ehninger, one of Germany’s few bone marrow transplant specialists, joined them, and a team of helpers organized the first public donor drives.

A wave of support began to emerge, and in the space of just two months some 20,000 new donors joined the registry. On May 28, 1991, the Tübingen-based Help for Leukemia Sufferers initiative officially became known as DKMS Deutsche Knochenmarkspenderdatei gemeinnützige Gesellschaft mbH, or the German Bone Marrow Donor Center.

Finally a suitable donor was found for Mechtild, and her stem cell transplant was carried out on April 15, 1991, at Tübingen University Hospital. But just four months later and despite all efforts to save her, Mechtild Harf died.

Undeterred by this tragic turn of fate, the founders of the initiative continue their work to this day.

Now more than ever!

Today, what used to be a private initiative has become the world’s largest association of stem cell donor databases. In July 2014 it had more than 4.5 million donors on its books and partner organizations in the USA (established in 2004), Poland (2009), Spain (2011) and the United Kingdom (2013). In Germany DKMS relies on the services of more than 15,000 volunteers across the country, and it employs over 450 people around the world.

The non-profit organization is managed by CEO Dr Alexander Schmidt along with the CFO for Administration, HR, Finance and IT Sirko Geist, and COO for Donor Recruitment, Fundraising, Marketing and PR Sandra Bothur. *“We still have a lot to do. But we have a vision and we work hard every day to achieve it,”* says Peter Harf, now Chairman of the DKMS Foundation Board. *“We aim to give every blood cancer patient – no matter where in the world they are – another chance to live.”*

It’s a promise that began with the sad fate of Mechtild Harf but now brings hope to people all over the world.

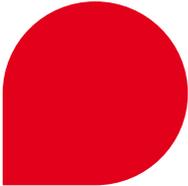
DKMS German Bone Marrow Donor Center was founded on

**May 28,
1991**

after growing from a private initiative

The fate of Mechtild Harf marks the beginning of the DKMS story.

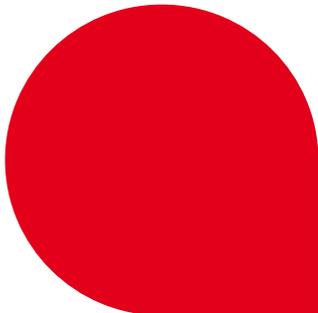
Milestones in the history of DKMS



1991

May 28, 1991: DKMS German Bone Marrow Donor Center is officially founded in Tübingen.

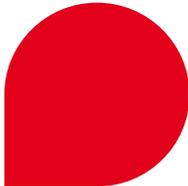
It ends its first year with a groundbreaking success: 68,000 new donors.



1995

By 1995 DKMS has grown to become the largest stem cell donor center in the world.

In May of the same year Dr Peter Harf and Claudia Rutt establish the non-profit organization Active Against Cancer, which is renamed DKMS LIFE in spring 2005. This organization forms an association with “*look good feel better*”, which offers free cosmetics seminars for women patients and is subject to the same standards all over the world.



1997

December 18, 1997: The DKMS Foundation for Giving Life is established. Initially known as the German Foundation for Giving Life, it is the parent organization of DKMS.

1997 is also the year in which DKMS German Bone Marrow Donor Center starts promoting the storage of umbilical cord blood at the University Hospital in Dresden. Since 2008 the non-profit DKMS Cord Blood Bank has been a member of the DKMS family in its own right.



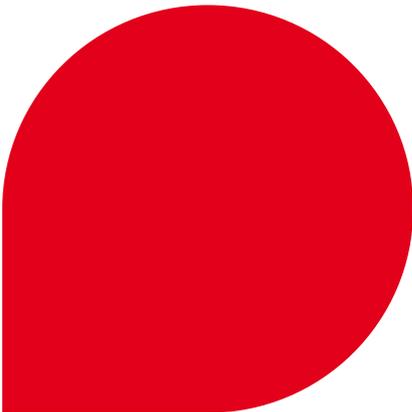
1992

In March 1992 DKMS reaches a milestone: its first donor donates bone marrow to a patient in France.



1996

1996 sees DKMS become the first donor center in the world to harvest cells from flowing blood by means of peripheral stem cell collection.

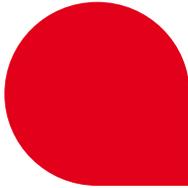


2001

May 28, 2001: DKMS proclaims the date of its foundation to be World Give the Gift of Life Day. Subsequently high-profile campaigns are held on May 28 every year to raise awareness of the fight against blood cancer.

On October 3 the first Mechtild Harf Prize is awarded in memory of Mechtild Harf and her legacy.

In November 2001 DKMS takes over the DKMS Life Science Lab GmbH in Dresden. Dresden is now one of the largest typing labs in Europe and the benchmark in lab technologies for sequencing.



2014

May 28, 2014: As the only internationally active association of stem cell registries, DKMS launches World Blood Cancer Day (WBCD). This global day of action in the fight against blood cancer is set to take place every year. Its aim is to encourage people all over the world to show their solidarity for blood cancer patients from around the world.



2011

May 28, 2011: DKMS celebrates its twentieth anniversary with a big international donor-patient meet-up in Berlin.



2004

2004: DKMS Americas, now known as Delete Blood Cancer US, is established in New York City. It is DKMS's first partner organization.

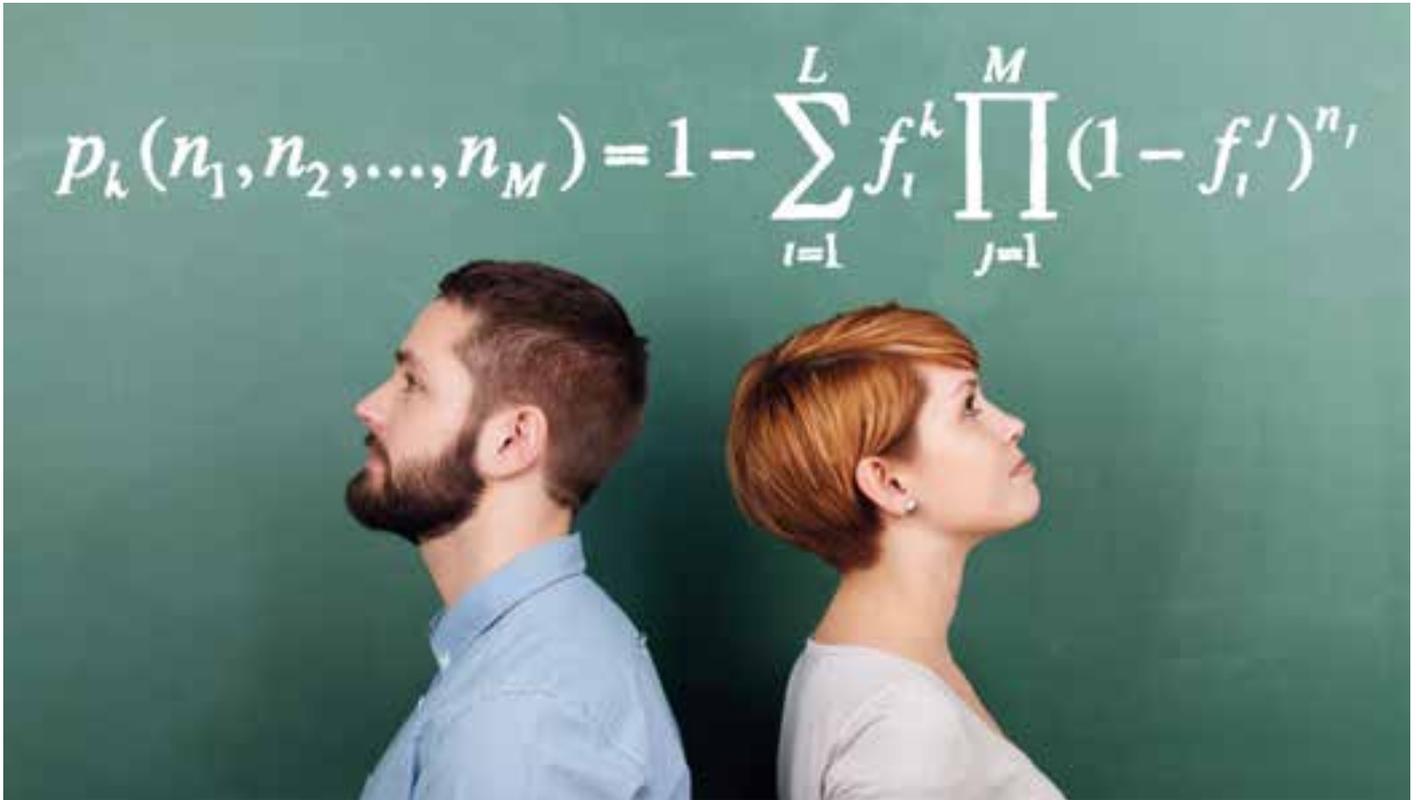
2003

July 2003: DKMS makes history by registering its one millionth donor. A breakthrough!

2013

“We will delete blood cancer”: DKMS extends its mission and establishes its own Clinical Trials Unit (CTU) in Dresden.

The importance of going global. For every single patient.



This formula can save lives. DKMS scientists use it to calculate the probability of finding suitable donors in other countries.

Research is vital. And it can save lives. At DKMS we are running a number of research projects in a variety of specialist areas to help us constantly improve our service. The question of how to increase the chances of finding a suitable donor internationally is especially fascinating – and it’s one our own DKMS scientists are pursuing with interest. If we want to increase our chances of helping even more patients, what countries do we need to register the most donors in? And how can we achieve even more matches? Are patients in one country more likely to benefit from donors registered in their own country or elsewhere?

The key: diversity

The fact is that different combinations of tissue type characteristics occur in different frequencies in different geographical and ethnic areas. Known as HLA characteristics, these pieces of information are ascertained for every single donor joining the DKMS donor center.

By March 2014 some 10,533 different HLA characteristics had been identified around the world, and more new, as yet unknown ones are being discovered all the time. This shows just how diverse the HLA system is – and how difficult it can be to find two people with identical tissue type characteristics. And yet successful matching is a prerequisite for any stem cell transplant. Between 2009 and 2013 alone, 2,127 new HLA characteristics were discovered in DKMS donors. And numbers are increasing all the time. Of all the tissue type characteristics identified so far, some 30 percent were proven for the very first time to be present in DKMS donors. The many tissue type characteristics identified in DKMS-registered donors have enabled our scientists to make a variety of calculations. These are helping them find out where exactly more new donors are needed to boost the chances of finding a suitable match for a patient significantly with as few new registrations as possible. If we explore this problem by

taking people of Spanish and German origin as an example, we will see our intuition confirmed: German patients stand to benefit most from German donors, and Spanish ones from Spanish donors – irrespective of how many individuals each country has registered and of any international stem cell donor exchanges that are already taking place (see info box).

What new registrations do patients benefit from the most?

This same evaluation model was used to assess donor statistics from the central registry of Bone Marrow Donors Worldwide (BMDW) for the 21 population groups whose tissue type characteristics are publicly available. Calculations reveal which groups stand to benefit most from an international exchange of donors. But they also show clearly that specific population groups would benefit most from an enhanced global system for new registrations. After all, despite worldwide exchanges, most patients are likely to benefit from more donors in their own population group. In many countries with only an insufficient donor base, the need for new registrations is all the more urgent to save patients' lives.

To significantly improve the situation for blood cancer patients, we need more registered donors who have undergone high-resolution typing.

So DKMS has yet another good reason to step up its international activities and establish more partner organizations around the world. In addition, the registration of donors from minority groups is particularly important in helping more patients around the world survive blood cancer. It's another area of work in which DKMS is doing more.

More than

10,000

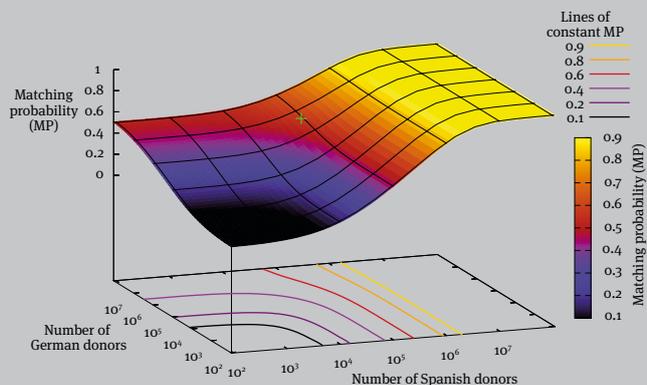
different HLA characteristics have been recorded worldwide.

Spain – A meaningful example

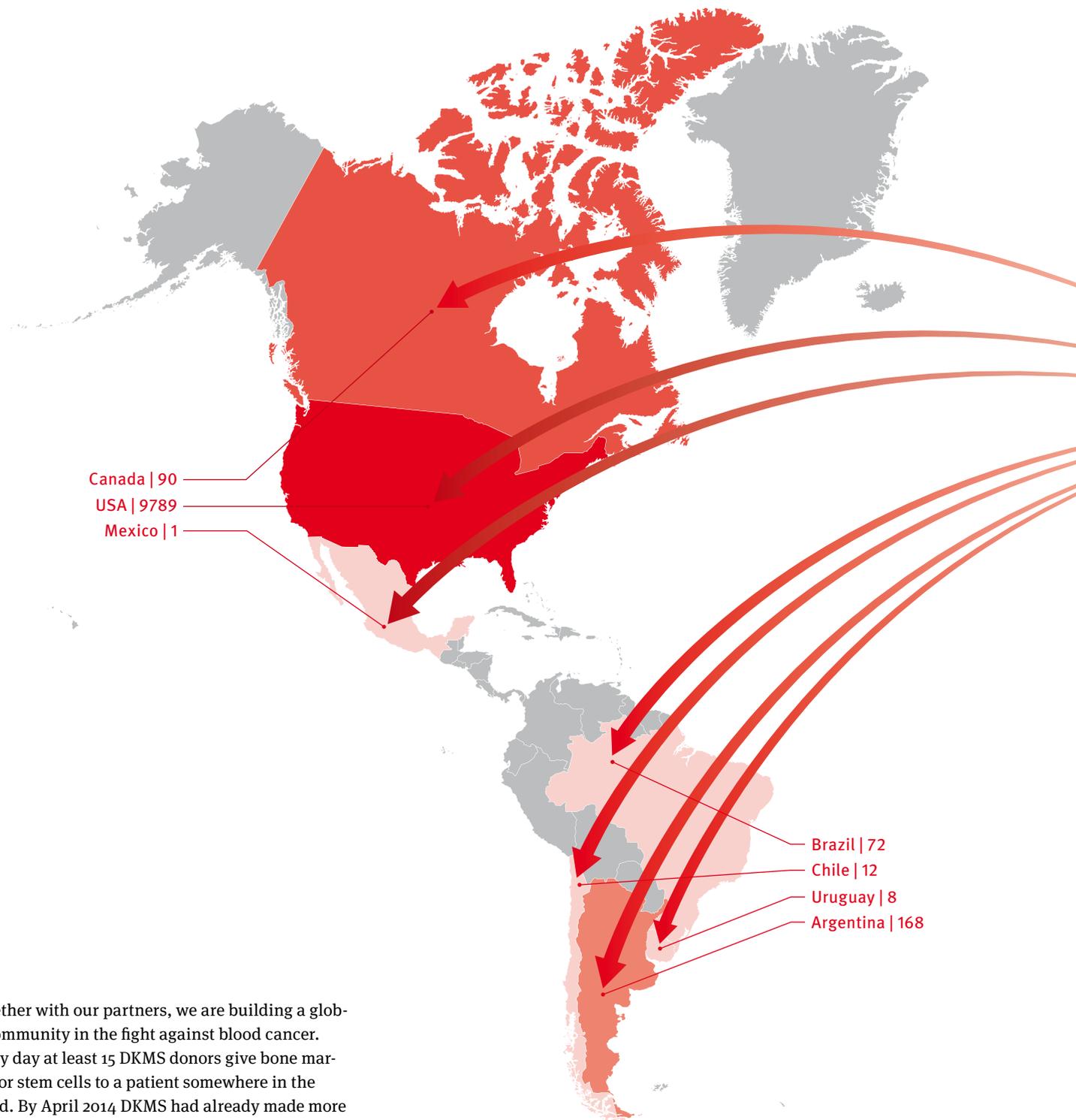
Of all the most common HLA tissue type characteristics found in donors of Spanish origin, only the top five occur more than once in every 1,000 donors. The most common combination occurs about 1.8 times in every 1,000 donors. At the moment, however, this donor group is known to have at least 1 million different characteristic combinations. Of those, some 860,000 are completely unknown among German counterparts. This means Spanish donors are highly likely to donate to Spanish patients – but don't always.

If 500,000 more people were to join the donor registry in Spain, the chances of finding a suitable match for a Spanish patient would rise from about 44 percent at present to around 74 percent. Take into account the German donors who would be willing to help as well and that figure would rise to about 77 percent. For a German patient, on the other hand, the registration of 500,000 new Spanish donors would increase the odds of success by just 0.2 percent.

If 500,000 donors joined the registry in Germany, the probability of finding a suitable match for a German patient would rise by 0.9 percent. The chances of finding one for a Spanish patient would rise by just 0.3 percent.

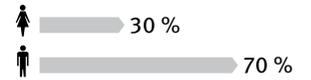


Global commitment. We're changing the world.



Together with our partners, we are building a global community in the fight against blood cancer. Every day at least 15 DKMS donors give bone marrow or stem cells to a patient somewhere in the world. By April 2014 DKMS had already made more than 41,000 stem cell transplantations possible. Most of them involved DKMS donors from Germany, as this world map shows. DKMS accounts for about 30.4 percent of stem cell donors in the world market at the moment (source: WMDA Report 2012).

In Europe:	Sweden 747	Slovakia 132
Germany 11,080	Czech Republic 666	Hungary 126
France 2729	Austria 533	Ireland 120
Italy 1895	Denmark 405	Slovenia 79
The Netherlands 1120	Greece 263	Croatia 47
Spain 986	Finland 222	Estonia 39
Poland 859	Lithuania 180	Bulgaria 19
Belgium 819	Portugal 173	Romania 12



Working together for patients. Here and around the world.

Every human life counts. No matter where in the world. Because blood cancer knows no international borders. Even today too many blood cancer patients are dying because of insufficient medical care in their home countries. DKMS wants to give people everywhere – in their own countries or elsewhere – a new chance of hope. **If we continue growing, our chances of helping blood cancer sufferers will gradually increase, one day at a time.** 80 percent of patients in Germany find a suitable match. But elsewhere the situation is far less favorable. Many countries lack potential donors in their registries, and their typing is often of poor quality due to the costs involved. It's a dilemma. And it's the reason why the global growth of DKMS is absolutely vital – now and in the future. The predicament in which many patients and transplant doctors around the world find themselves presents us with a mission: to bring genuine help to patients not only in Germany but in other countries as well.

DKMS partner organizations: Help knows no borders

Thanks to DKMS's international set-up, we have strong global links. As the largest association of stem cell donor centers in the world, we are in a position to take active steps to improve the situation of blood cancer patients. We take our responsibility extremely seriously and have already made our first steps towards a more global presence by establishing independent DKMS partner organizations. The number of stem cell donations we organize for

patients living abroad shows just how great the need is. At the moment more than 75 percent of our donations are destined for recipients outside Germany. At least 11 of the 15 stem cell collections that take place every day leave our country. At the same time about 20 percent of stem cell donations for German patients are brought in from abroad.

DKMS partner organizations are currently operating in the following countries:

- Delete Blood Cancer DKMS, New York, USA, founded in 2004
- Fundacja DKMS Polska, Warsaw, Poland, founded in 2009
- Fundación DKMS España, Barcelona, Spain founded in 2011
- Delete Blood Cancer UK, London, UK, founded in 2013

Our own DKMS International Medicine team is working to set up additional presences abroad and help run them for the longer term. Our goal is to transfer the high standards we have in Germany to all of our DKMS offices elsewhere – to deliver the same quality and level of service for all donors and patients, no matter where they may be.

Example: India and the Netherlands Active support abroad

Time and again international organizations and other donor centers contact DKMS to ask for our help and support. We invite them to visit us in Germany so we can train them on how to win new donors, relevant medicines, marketing and media relations. This way DKMS would like to help these countries grow

DKMS currently has

5

*partner organizations
around the world – and
numbers are set to in-
crease.*

Top: MingKhai Phan Thi and Marcel Nguyen are supporting Joon, from Korea.

Middle: Transplant coordinator Maha Lakshmi at her desk in the Christian Medical College Hospital in Velore, India

Below: 2014 saw the Fundacja DKMS Polska celebrate its fifth anniversary – birthday cake included, of course.

their own registries and raise awareness for the issue of stem cell donations. In addition, we provide intensive support for other countries as they search for matches and connect donors with patients. Since 2008 outstanding collaborations have been underway between DKMS and 28 transplant centers in Indian cities such as Velore, Chennai, Bombay, Bangalore, Calcutta and New Delhi. We are in direct contact with doctors at all of these locations. As well as visiting them, we offer consultations for hospitals and transplant units. In 2013 DKMS also launched an international cooperation with the Netherlands. We are now working even more closely with Eurodonor, the Netherlands Bone Marrow Donor Center, to help blood cancer patients around the world. In addition, our two organizations are planning some joint donor drives. Collaborations will also focus on knowledge transfer and providing extra capacity in laboratories.



Show you mean it!

05/28 World Blood Cancer Day

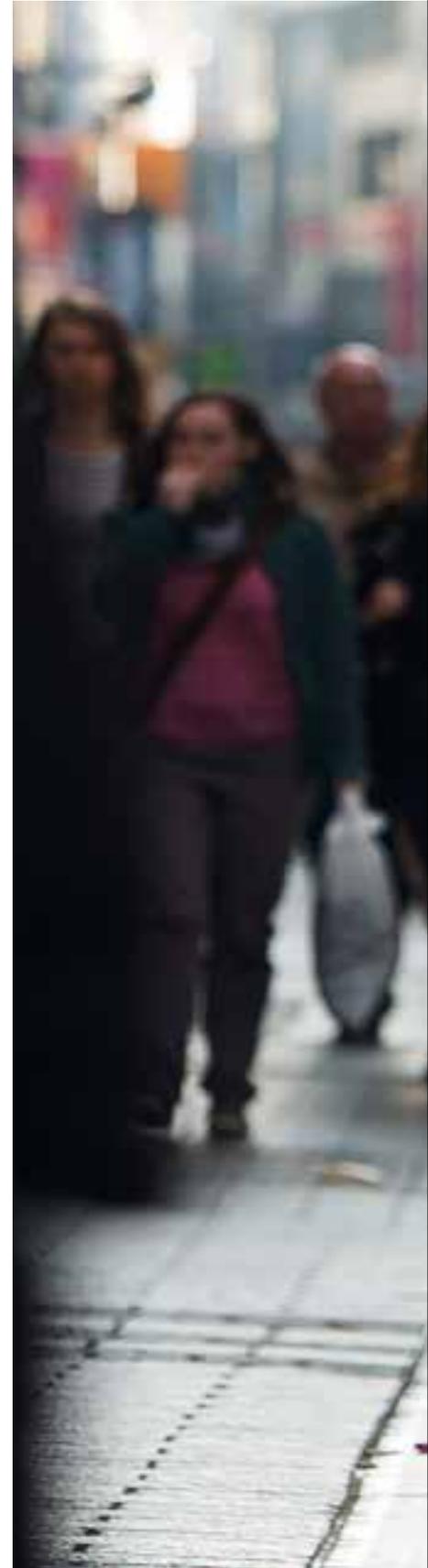
At DKMS, we want to raise awareness of blood cancer around the world and draw people's attention to the fate of patients everywhere. We also want to raise money to support progress in blood cancer research. That's why in 2014 DKMS established the World Blood Cancer Day. This global day of action will take place on May 28 every year. Stem cell donor centers, registries and databases, transplant centers, initiatives, interest groups and supporters everywhere will get active with their campaigns to win the solidarity of as many people as possible and encourage them to show their commitment to the fight against blood cancer. To support our cause, we welcome boundless creativity of any kind. On this day we want our red "&" sign to be seen everywhere. May 28 is of special importance to DKMS because on that day in 1991 we were founded. DKMS is now the world's largest association of stem cell donor centers.

To find out more visit:
www.worldbloodcancerday.de

*World Blood Cancer Day
was launched in*

2014

*From Germany, the USA,
UK, Poland and Spain, it
has advanced around the
world.*



Show you mean it! Two students, Jana and Tim, are doing just that by sending out a clear message from downtown Cologne to the rest of the world.



Innovation center: the DKMS Life Science Lab in Dresden.



The DKMS Life Science Lab uses liquid handling robots for typing.

The DKMS Life Science Lab GmbH (LSL) is the largest HLA typing lab in Europe and a subsidiary of DKMS German Bone Marrow Donor Center. It is based in Dresden/Germany and currently employs about 70 people. Established in 1997, it has been a part of the DKMS family since 2001. It's our most state-of-the-art lab and works with cutting-edge technology.

High-throughput typing

The DKMS Life Science Lab uses a number of DNA sequencing reactions to determine the HLA characteristics of potential donors joining our registry. It also carries out initial and confirmatory typing for patients, family members and unrelated donors. The DNA sequences it produces are then converted into HLA findings by software in a process that is getting faster and faster all the time. Thanks to its high throughput, the lab can carry out nine cycles per day, each one typing 384 blood or cheek samples from donors. In total, that means 3,456 samples from new donors can be processed there daily. In 2013 alone effective process enhancements meant we were able to type 365,526 new donors, and our LSL now has 2,220,434 sets of results. The number of typing operations carried out in our own DKMS lab is

In 2013 the lab typed

365,000

new donors.

rising further. In the first quarter of 2014 alone we typed 195,468 samples from new donors. That's more than half of all the new donor samples we analyzed in the whole of 2013!

Enhanced performance

This immense increase in output is attributable to the fact that we continuously enhance our methods. In fact, we have a designated team especially for the job. In 2011 and 2012 they achieved a major breakthrough: they came up with their own reagents and primers, which they took from the development stages right through to routine implementation. In 2013 we had another groundbreaking success: we started using next-generation sequencing (NGS) for our HLA typing. This cutting-edge sequencing method was rolled out very quickly, catapulting the DKMS Life Science Lab to the forefront on an international level. Together, these advances have made us considerably more efficient and drastically cut our costs – even though our profiling was extended to a total of six HLA loci, CCR5 genotyping and blood grouping.

Our own search team

The DKMS Life Science Lab is also the home of our own in-house search team, which is one of 17 in total that are currently operating in Germany. Each day, they receive search requests for unrelated stem cell donors to be found for patients around the world. Sometimes there is only incomplete data for donors available, especially if they were typed by “older” methods or are registered in non-DKMS databases. In cases like this, the team starts by arranging further typing. But because our DKMS donors have been typed to outstandingly high resolution, we can often ask them to come in for confirmatory typing immediately.

The DKMS Cord Blood Bank. Little heroes wanted.



A donation of cord blood unit is processed in a clean-room lab.



Left: Cord blood units are cryopreserved in special freezer boxes at -180°C and stored in tanks.

Over

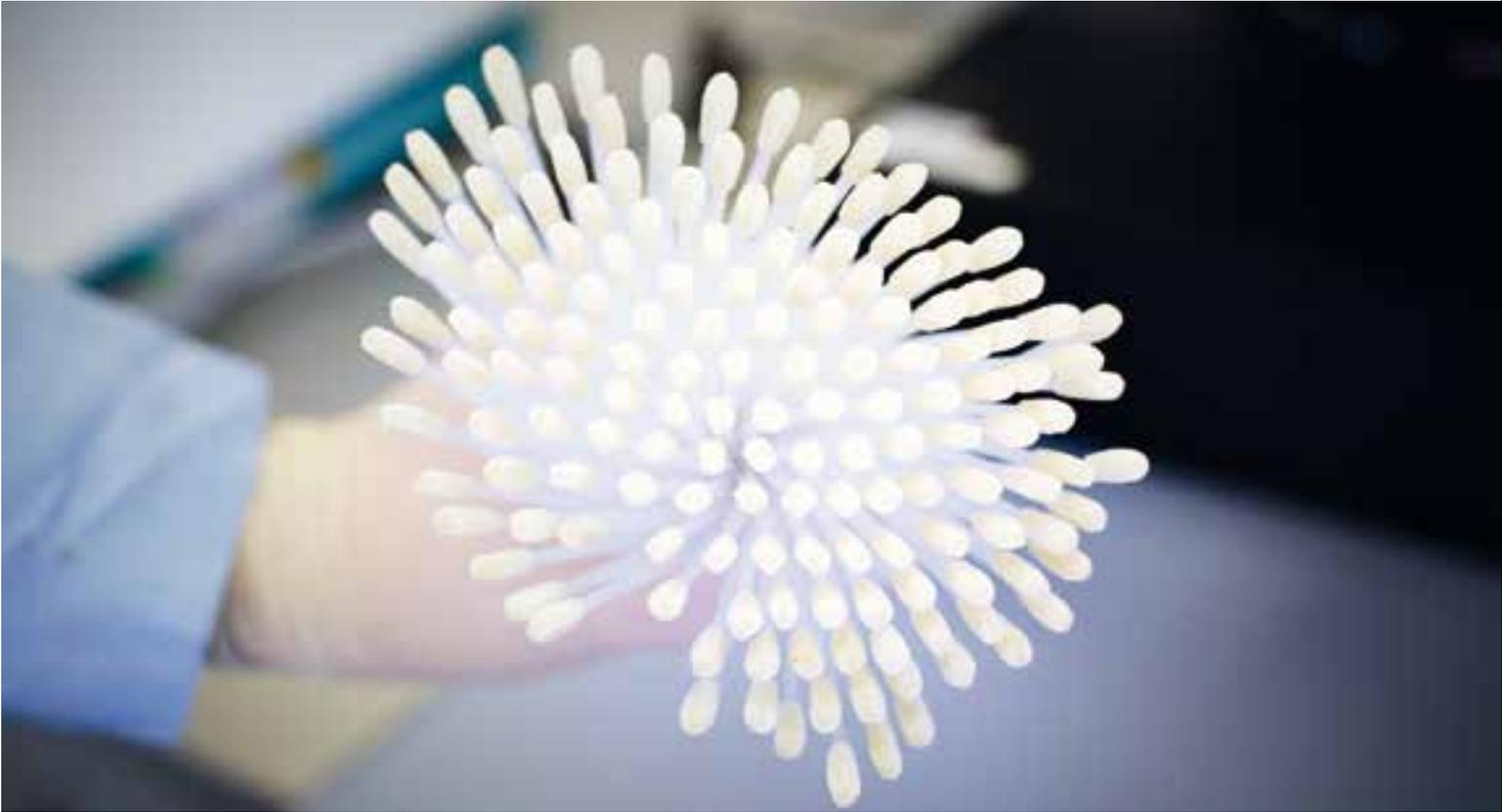
8,300

cord blood donations are already in storage and ready to go to patients at any time.

Some 1,700 babies are born in Germany every day. But in 97 percent of cases the blood that remains in placentas and umbilical cords after they have been cut is disposed of unused. The DKMS Cord Blood Bank wants this to change. In fact, DKMS has been working to promote the preservation of cord blood at Dresden University Hospital since 1997. The Cord Blood Bank is based in Dresden and has been a DKMS subsidiary in its own right since 2008. It appeals to expectant parents to donate the cord blood of their baby for the greater good. Many people are unaware that cord blood can work wonders – and probably even give the blood cancer patient a second chance at life! Along with bone marrow and flowing blood, cord blood is a valuable source of stem cells. Collected and preserved straight

after birth, these life-saving cells could be used without delay – for a stem cell transplant in a blood cancer patient. At present co-operation is underway with more than 90 partner hospitals whose specially trained staff collect cord blood donations. In the first quarter of 2014, the facility had more than 8,305 cord blood units in storage. DKMS Cord Blood Bank pays the full cost for collecting, transporting, preparing and storing them, meaning the expense for parents is absolutely zero.

Faster searches, more efficient support. Why quality matters.



Every single buccal swab containing a cheek sample from a donor is another chance of survival.

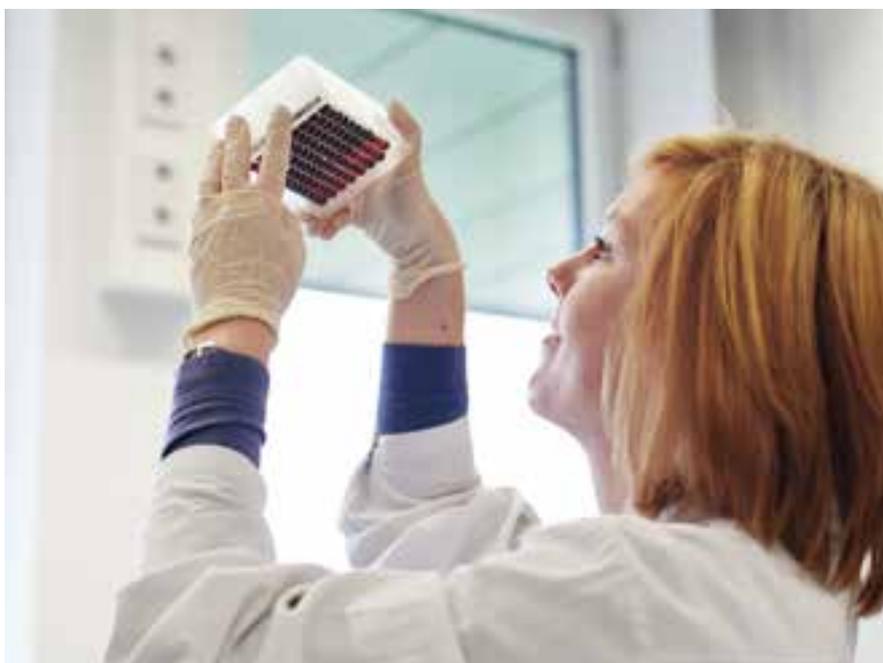
Continuous improvements and enhancements to the DKMS database are not just important; they're a matter of life or death. The more efficient we are, the faster we can deliver on patients' needs in the race against time. Enhancing the quality of donor data is all-important and it's our top priority at DKMS. The DKMS's HLA service team in Tübingen/Germany is going all out with a single aim in mind: to keep on improving the quality of the tissue type characteristic data of more than 4.5 million registered donors around the world and using it more efficiently. The more details we have, the faster we can find out if a donor might be a potential match for a patient. To help this happen, our experts have set up a special quality program designed to increase the chances of connecting matches faster and better.

New search algorithm

DKMS has managed to improve the quality of its database significantly by developing its own search algorithm: the HAP-E Search (haplotype enhanced search). This special software program makes it easier to find suitable donors by using patients' results. It works by flagging up not only matches but also potentially suitable mismatched donors (whose tissue type characteristics do not coincide completely with those of the patient). It also enables automated searches and requests to support quality projects and calculates probabilities for incomplete HLA findings, making it easier and simpler to identify the best donors.

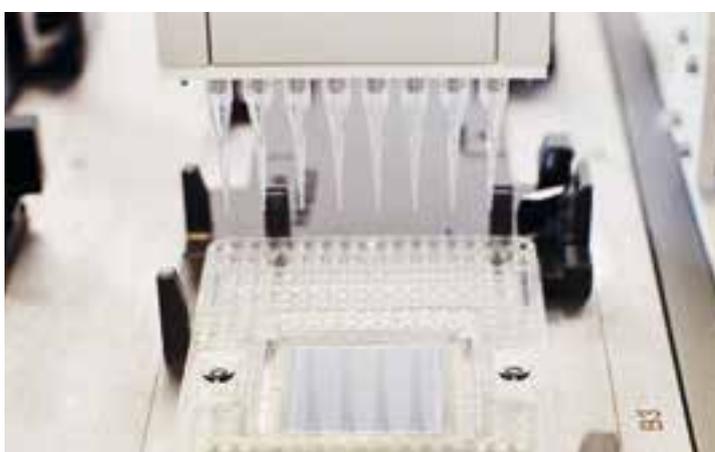
Prospective typing

In a bid to bring donor profiles up to the latest standard, DKMS funded and launched its own campaign to contact almost 270,000 German-based donors for further typing in 2013.



Left: A lab technician checks fill levels on a plate of blood samples.

Below: Donor samples are prepared for sequencing on special plates.



This approach means donors who have long been registered in our database are gradually undergoing high-resolution typing. Each donor will have 12 transplant-relevant HLA characteristics determined, and their profiles will be updated to current scientific standards.

Replacement donor program

Since 2001 the Replacement Donor Program has been working towards a clear goal: to find at least one replacement donor, or ‘twin’, for each donor making a donation. The replacement should have the same HLA characteristics and be typed to the same high degree of resolution. The advantages of this approach are obvious: if a donor is unable to make their donation, perhaps because they are ill when they have been found to match a patient, a fall-back solution will be quicker to find.

Ancestry program

In an attempt to win donors with rare combinations of tissue type characteristics, we set up our Ancestry program. We stand a better chance of finding additional donors with rare and unique HLA characteristics if we search among the close relatives of those already on our database.

Retrospective follow-up project

To make sure donors do not suffer any adverse effects from their donation, DKMS carries out standard examinations on each one before and after collecting cells. So far results indicate

that there are no risks linked to stem cell donations and no causes for concern over the longer term. As well as keeping a record of the donor’s state of health for many years after their donation, we keep a note of whether or not they would be willing to do the same again. A hugely significant 98.7 percent of those we asked said they would.

Matched pair follow-up project

Despite all efforts to the contrary, many people still view the idea of donating stem cells with fear and concern. To help break down their negative perceptions, DKMS has been carrying out a long-term study of potential and actual donors since the end of 2009. When one of our donors has given away some of their cells, we search our database for another potential donor (who has not yet done so) who matches them as closely as possible in terms of age, gender and tissue type characteristics. These donor pairs are regularly surveyed about their state of health over a period of several years and findings are medically evaluated.

In 2013 DKMS funded and initiated further typing for almost

270,000

donors.

Our objective: active support for medical advances.

Interview with DKMS Chief Executive Officer Dr Alexander Schmidt



DKMS Chief Executive Officer
Dr Alexander Schmidt

Alexander Schmidt, DKMS works hard to continuously improve the quality of its service. Why is that so important?

“Because the improvements we make have a specific impact on patients’ chances of survival. The DKMS Life Science Lab, for instance, has adopted a new technology called next-generation sequencing for typing new donors. We were one of the first HLA labs in the world to do that, possibly even the first. That means now we can determine donors’ tissue type characteristics in higher resolution as well as analyzing their blood group. This information makes it easier to find the right donor for patients as soon as possible.”

What are your goals?

“We want every patient in need of a stem cell transplant to have the best possible donor. Over the last few years, things have improved dramatically, thanks to the commitment of our donors. But we’re still a long way from finding a suitable match for every patient who needs one. The situation is especially difficult for many people from ethnic minorities, but also for patients whose parents come from different ethnic groups. Another thing we want to do is help support clinical studies and carry out similar studies of our own. That way we can continue increasing the likelihood of a stem cell transplant succeeding. It’s also the reason we’ve just established a new department, our Clinical Trials Unit (CTU).”

What specific things can people do to support the fight against blood cancer?

“Join the DKMS Bone Marrow Donor Center! But we’re also asking people to make an active contribution by donating money – because every cent we receive helps us recruit new donors. We also need support for the important work of our CTU to actively drive forward our fight against cancer. That way we will be able to make effective improvements to patients’ chances around the world.”

Fighting blood cancer on every front. Science and research at DKMS.

DKMS has long been doing its own research as well as supporting clinical research projects into allogeneic stem cell transplants, which involve cells from donors who are related or unrelated to the patient. We want to help improve patients' chances of survival for good. But we also want to make the processes involved in donating stem cells more effective and safer for donors so as to minimize any side effects.

Over the years DKMS has already implemented a number of different projects. In 1996, for example, our involvement in science and research made us the first stem cell donor center in the world to use peripheral stem cell collection – to extract stem cells from blood rather than bone marrow, in other words. Today the method is standard, and it's carried out in an outpatient procedure. 80 percent of all stem cell collections are performed in this way.

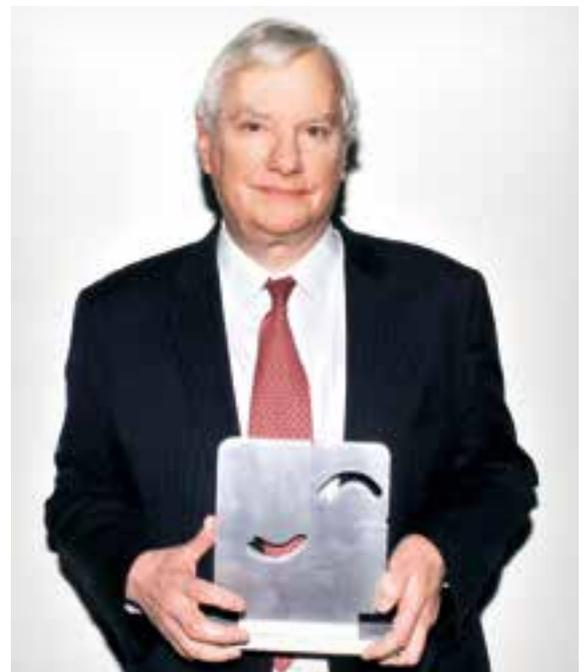
The most recent enhancement in science and research at DKMS consists of the establishment of our very own Clinical Trials Unit (CTU). This was also our most far-reaching change in organizational terms. The CTU officially opened for business in 2013.

The department organizes and supports studies into stem cell harvesting and transplantation. Work with major stem cell donor centers, for example, is currently exploring ways of further reducing the side effects arising

from donations. Specifically, this joint study focuses on avoiding taking bone marrow from donors whose previous peripheral procedures failed to deliver sufficient numbers of stem cells.

Every year DKMS underscores its objectives by presenting the DKMS Mechtild Harf Science Award. Linked with prize money of €10,000, the accolade is presented in recognition of outstanding research achievements in the fight against blood cancer for the benefit of patients and donors around the world. In 2014 the DKMS Mechtild Harf Science Award went to Richard J. O'Reilly, MD. The US researcher was honored for his essential insights in the field of transplant immunology and cell therapies.

Richard J. O'Reilly, MD,
winner of the DKMS Mechtild
Harf Science Award 2014



Focus: young donors. An education for life.



DKMS often works with committed students like those pictured here from the vocational schools in Syke/Germany. Together, we organize regular school campaigns to win more younger donors for the registry.

More than

135,000

students and young adults aged 18 and over have registered with DKMS as potential donors.

At DKMS we invest heavily in upcoming generations – because motivating younger donors is immensely important to us. That’s why we have made it a very special concern. It’s in the nature of things that younger people will be available for a longer time if we need to call on their services. They are a popular choice for stem cell collection centers. In 2013 donors under 26 years of age made up of 35 percent of the total number on our database. But we want that number to rise.

Young donors are immensely important

Since 2004 DKMS has been working under the patronage of Education Secretaries of the various German federal states to launch annual

appeals in high schools that will encourage young people aged 17 and over to join the fight against blood cancer. As part of the DKMS’s *Leben spenden macht Schule* schools project, we are working to get students, parents and teachers to engage actively with the issue of giving life and support our efforts to find donors and extend our database further. And we’ve been very successful: so far, 289 schools in Germany have joined the DKMS schools project, and more than 39,000 students have signed up on our registry. 533 of them have already been able to donate stem cells to help a blood cancer patient.

The many students we have been working with also remind us time and again just how

An info talk tells students at a vocational college all they need to know.

Students at the vocational college join the registry.

A roaring success: the universities project by DKMS Polska

Joining forces for DKMS: these students have just taken part in a successful school campaign.



many exciting and creative ideas there are for introducing people to the topic of stem cell donation, from project days, lessons and charity events to sponsored walks and donor drives. The educators' classes in the vocational schools of Syke/Germany, for instance, collaborated with principal Horst Burghardt to come up with something truly amazing: a three-day registration campaign with nine lectures to introduce students to the idea of donating stem cells. The event was held in March 2014, and with the help of more than 100 volunteers, it attracted the interest of some 3,100 students. An incredible 1,061 of them subsequently joined the registry, financed by external sponsors and proceeds from a bake sale. The team at Syke certainly set an outstanding example! What's more, besides this particular project, a number of other educational institutions are also campaigning to support DKMS. In fact, over the years some of them have been active on a regular basis. Their campaigns have generated more than 96,000 new donors. 1,407 of them have already been able to give a patient a new chance at life.

Universities project

"Students' checklist – Save a life. Register as a stem cell donor." That's the slogan on a flyer that is currently being used to raise awareness among young students at colleges and universities. Between 2009 and 2013 a total of 198 DKMS registration campaigns were held at educational establishments of this kind across Germany. 63,170 young people joined our donor database as a result.

The same universities project is also running with our partner organization, DKMS Polska – also with considerable success. In October 2013 the Polish DKMS team recruited more than 17,000 new donors at over 100 universities in 43 towns and cities in Poland. Six months later, in April 2014, a total of 220 volunteers spent two days campaigning at 104 universities in 46 towns. They recruited another 13,509 new donors. That's a record!



Open wide. Mouth swab against cancer. Publicity can save lives.

*Almost half the people
in Germany*

47%

*know about the work
of DKMS.*

We promote life. Every day. We tell people the facts about blood cancer – on a regional, national and, increasingly often, on an international level. But there’s one thing every one of our messages has in common: their emotional core. Behind every public campaign is the fate of a blood cancer patient and their family – and our desire to help them.

Our communications are geared fully towards our target group. We want our striking media campaigns to motivate increasing numbers of people to register or make a monetary donation. And we are succeeding more and more often.

Market research findings confirm our success

In May 2013 a telephone survey by market research institute IMAS International GmbH revealed that almost half of all people of German origin are familiar with DKMS. The vast majority of those surveyed have a positive or very positive image of DKMS, and almost one in three say they have seen or heard about the database quite recently.

Making ourselves heard

Our publicity activities include working with TV, radio and print media to produce reports of a high editorial standard. We also do a variety of traditional advertising, such as nationwide billboard campaigns and movie theater and TV commercials. In 2013 and 2014 activities like these increased the reach of DKMS significantly. From the pro bono airing of commercials on channels with extensive reach, which triggered an avalanche of registrations, to features – no other media can spread our message as quickly and widely as television.

Trending on social media: saving lives online

Online social networks are a new and interesting trend in donor registration and have enormous potential to mobilize large sections of the population. In 2013 in Germany alone more than 160,000 new DKMS donors were prompted to join our donor center online by posts appealing for help on Facebook and other such platforms. In the first quarter of 2014 some 90,000 did the same, ordering their registrations sets via the internet. And the trend is upwards. DKMS is also attracting rising numbers of Facebook fans. In the first quarter of 2014 we had 350,000, making DKMS one of the largest German non-profit organizations on Facebook. Individual posts often generate more than 250,000 ‘Shares’.

The redesigned DKMS website, www.dkms.de, is also enjoying increasing popularity. On average 350,000 users a month visit our pages to find out more about what we do.

Top: Blood cancer survivor Tim Lissel was saved by a stem cell transplant. He is pictured here talking to TV presenter Steffen Hallaschka. Stern TV’s report about Tim’s inspiring story prompted more than 30,000 people to request registration sets.

Below left: Actress Sila Sahin lost a friend to blood cancer and is now committed to supporting DKMS.

Below right: Making ourselves heard: reports and films about stem cell donations are being produced almost daily.



Heroes: our donors. Lifesavers with a heart.



Matthew Heath Voss donates stem cells.



Zane Staab next to a poster of blood cancer patient Owen

Since 1991 more than

41,000

DKMS donors around the world have been able to donate stem cells or bone marrow.

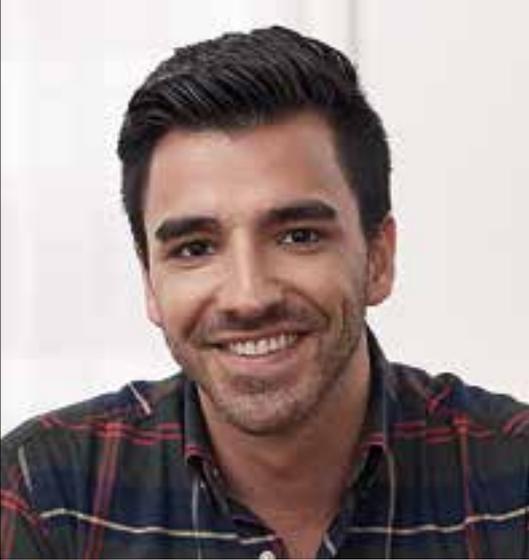
Without our DKMS donors, our successful work would be worthless. Every single one of them does great things, helping complete strangers without a single thought for themselves. Each one represents a potential chance of survival for a blood cancer patient.

Our 40,000th donor

Our 40,000th donor was Matthew Heath Voss (34), from Krampe/Germany. Born in Lancaster/UK, Matthew is a milestone donor. In December 2013 he donated stem cells for a 41-year-old British mother. For him it seemed the most natural thing in the world to do. The father of a four-year-old boy had registered with DKMS a year and a half earlier. *“When I got the message from DKMS, I immediately knew I would help. I’d do the same again any time!”*

We’ve now passed the four million mark. A fantastic success.

In December 2013 a Delete Blood Cancer donor drive on Staten Island/USA saw the four millionth donor in the DKMS family sign up: twenty-one-year old Zane Staab, from New York City. When he heard about the campaign to help two blood cancer patients, he didn’t hesitate for a moment. *“It would be great if I could help someone,”* he says. *“Registering is quick and easy – yet you could change so much by doing it!”* Today DKMS has more than 4.5 million donors from around the world in its database network.



Donors and recipients. Happy encounters.



We can never get enough of these stories – because every time a stem cell donor meets “their” cured patient in person for the first time, their hearts are filled with joy and emotions. Every single meeting is unique, moving and inspiring – not only for us but for many other people as well. That’s why we want to initiate more such stories, to witness them and share them with others – because a second life is the most beautiful gift a person can give.

JENNIFER – MAXIMILIAN

Langenfeld – Hamburg | 2011

- Jennifer (36)
- Maximilian (7)

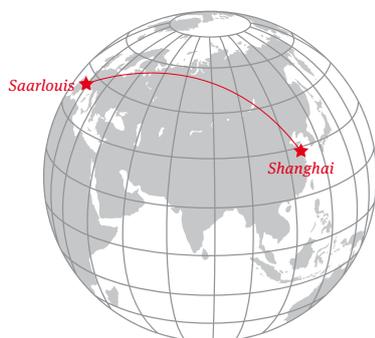


Maximilian can grow up! That’s the best news in the world. After being diagnosed with acute lymphatic leukemia in 2011, the little boy from Hamburg/Germany battled his way through five rounds of chemotherapy, none of which really brought lasting success. Help finally arrived in the shape of doctor’s assistant Jennifer, from Langenfeld/Germany, who donated bone marrow for him. “When I heard my donation had worked and he would get well again, it was sheer euphoria,” says Jennifer. Two years after the donation, Jennifer and Max met for the first time along with their families. It was a very special moment. As for Max, he’s growing and growing all the time and thinks the lady who saved his life is “really nice”!

Around

10 %

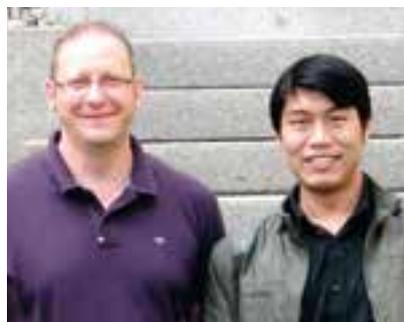
of all DKMS donors and their recipients swap addresses after a successful transplant and when the two-year waiting period is over because they want to get in touch.



MARTIN
—
CHEN GONG

Saarlouis – Shanghai | 2006

- **Martin (41)**
- 📌 **Chen Gong (30)**



“Without you I’d be dead now,” said Chen Gong (29) when he first met his donor, Martin. In 2006 Chen Gong moved from Shanghai/China to Stuttgart/Germany to study computer sciences. One year later he was diagnosed with blood cancer. A worldwide search for a donor began and the tissue characteristics of Martin from Saarlouis/Germany were found to match those of the young Chinese student. After the transplant things began to look up. Chen Gong made a full recovery, and his dearest wish – to meet his donor – came true. The two men are even traveling to China together and now have family ties too: Chen Gong is godfather to Martin’s little girl.



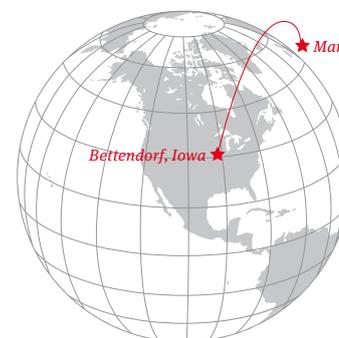
MELANIE
—
CHRIS

Pulheim – Cape Town | 2013

- **Melanie (37)**
- 📌 **Chris (57)**



Hello Africa! In September 2013 DKMS donor Melanie (37) from Pulheim, near Cologne/Germany, traveled to South Africa full of excitement and anticipation. Ten years earlier she had given South Africa’s Chris Mattinson (57) a new life through her stem cell donation. When they finally embraced in Cape Town/South Africa, Chris was so happy he didn’t want to let her go. Along with their families the two are spending time together and gradually getting to know each other. “Now all I have to do is learn German so I can talk to her even better,” says Chris. Their next reunion is already in planning.



MICHAEL
—
LORI

Marl – Bettendorf, Iowa | 2013

- **Michael (31)**
- 📌 **Lori (43)**



Michael Henke (31) from Marl/Germany, is a hero in the USA – ever since he donated stem cells for American Lori McFate (43). Exactly 2,747 days after the transplant, the two met up for the very first time, in December 2013 – and found their encounter deeply emotional. “It was moving. Lori and I hugged straightaway at the airport. I knew immediately this would be a lifelong friendship,” says Michael, who received a joyous welcome from Lori’s friends and family. In the small town of Bettendorf, Iowa/USA, where Lori lives, a big welcome committee awaited the lifesaver from Germany. “There were people everywhere giving me a vociferous welcome, holding up signs and so on. I was showered with joy,” recalls Michael, still moved.

Every donor matters. So every cent counts.

DKMS is a non-profit organization and is registered as such in the German register of companies. That means we are verified and officially recognized as serving a charitable purpose. We can use our funds only according to strictly defined rules – for the fight against blood cancer.

But being a non-profit doesn't mean we don't care about money. On the contrary, the fight against blood cancer doesn't come cheap. Tissue typing and registering potential stem cell donors still requires costly lab analyses. Moreover, from quality assurance and scientific research programs right through to setting up partner organizations abroad, developing our organization comes at a cost. There are also a number of strict regulations we must adhere to, and registering donors has become much more complex as well. We want and need to work particularly cost-efficiently to use our resources as wisely as possible.

Back in 1991, just after the DKMS was founded as a purely private initiative, one thing soon became clear: even though we very quickly managed to cut the lab costs per registration from 600 Deutschmarks to 75 dollars and had volunteers helping us enormously with our infrastructure and organization, we knew we would not get far on private donations alone. Initially public bodies and large organizations came to our rescue. The Federal Ministry of Health granted us immediate aid to the tune of DM 1 million, and German Cancer Aid, who very much welcomed our work, even gave us DM 5 million so we could set up the database. With this funding we were able to establish a principle that still applies today, namely that private donations are spent not on administration or growth but solely on registering new donors. In 1994 our start-up funding from Ger-

man Cancer Aid and other development funds from the Federal Ministry of Health ran out. Since then we have been financially on our own and reliant on our donors to help us with the registration costs.

From setting up and expanding our database, to scientific projects, marketing and internationalization – the costs for these and other projects are financed solely from generated funds, and especially from the lump sums we receive from healthcare systems for finding stem cell donors for patients.

Nevertheless, as a non-profit organization we continue to depend on donations. Registering our stem cell donors is costly, but it's also an urgent requirement, not least to replace the 30,000 people a year who are removed from our database for reasons of age. These costs are not covered by health insurance companies. Instead we publicly ask for donations so that we don't have to fund them all by ourselves.

Our fundraising department selectively approaches private individuals, companies (who might want to organize a donor drive among their staff, for example), authorities, courts (such as fine-payment offices) and associations who may like to support us by funding the registration of new stem cell donors.

Registering a donor is considerably more expensive today than it was just a few years ago. Regulations are now much tougher, and material expenditure is rising. In addition, tissue typing of our donors is now essentially high-resolution and once again high above the usual standard. For patients this makes finding a matching stem cell donor much faster. But for us it means registration costs remain comparatively high, despite all the technical advances.

*Every new donor we tissue
type costs the DKMS*

€50

Nonetheless, we remain firmly convinced that these costs are absolutely justified. After all, they have enabled us to register over 3.4 million donors in Germany. And because our financial supporters absorb (part of) the registration costs, we are free to fight blood cancer on a much broader front today than we could in 1991.

Volunteers collect cash donations at a donor drive because every new registration costs the DKMS €50.



Saving lives. A matter of honor

Our supporters and helpers set new records in humanity

The invaluable help of DKMS's many supporters is diverse and often quite awe-inspiring. Time and again we are deeply touched and full of gratitude when we see how people go out of their way to actively support blood cancer patients and help publicize the life-saving issue of stem cell donation.

Year after year more than 15,000 volunteers are in action behind the scenes for DKMS. In their free time they organize donor for patients, take blood samples non-stop, collect monetary donations and, with their heart and soul, exemplary commitment and limitless ideas, they set new records in humanity. Without this network of willing helpers, DKMS's successful work would simply not be possible. To acknowledge the voluntary commitment of people to our cause, we present our DKMS Volunteer Award once a year. This award honors the outstanding commitment and personal dedication of individuals to DKMS.

There are also many organizations, associations and companies that support us, both practically and financially. Our partners include Ford, Daimler, VW, Deutsche Telekom and the German Dental Association, to name just a few.

To every single one of our supporters we say from the bottom of our hearts: THANK YOU!

Each year the DKMS has the support of more than

15,000

volunteers throughout Germany.







**Real is what we need in our
fight against blood cancer!
Our story, which began
with the fate of one person,
laid the foundation for a
global campaign to delete
blood cancer. We need
committed people like you!**



