



**2018**

**ANNUAL REPORT**

**MATHIES BECKER**

When Mathies was a child, a stem cell transplant saved his life.

PAGE 10 >

# CONTENTS

---

<b>EDITORIAL</b>	<b>4</b>
<hr/>	
<b>SPOTLIGHT 2018</b>	
More than just a job: We connect people	6
Blood cancer: The figures	9
<hr/>	
<b>STORIES</b>	
Emotional beginnings, tireless research	10
Development of stem cell collections	13
<hr/>	
<b>QUALITY AND EFFICIENCY</b>	
Always on the lookout for the best donor	14
Interview with Professor Thomas Klingebiel: "It's about finding the best approach"	17
<hr/>	
<b>MEDICINE AND RESEARCH</b>	
In pursuit of a single goal: A cure	18
<hr/>	
<b>OUR DONORS</b>	
Focus on true heroes	22
<hr/>	
<b>JOINING FORCES FOR PATIENTS</b>	
Our motto: Never give up!	28
World Blood Cancer Day	30
<hr/>	
<b>GLOBAL COMMITMENT</b>	
Stem cells for the world	32
<hr/>	
<b>HELPERS AND SUPPORTERS</b>	
Volunteering can save lives	36
<hr/>	
<b>FAQs</b>	
Social media 2018	40
<hr/>	
<b>FACTS &amp; FIGURES</b>	
Financial results 2018	42
About DKMS gGmbH	45
Balance sheet	46
Income statement	48
Risk management	50
Our contributors	52
<hr/>	
<b>PUBLICATION DETAILS</b>	<b>53</b>
<hr/>	

A portrait of Dr. Elke Neujahr, a woman with long, wavy blonde hair and blue eyes, smiling warmly. She is wearing a dark blue, long-sleeved button-down shirt. Her right hand is raised to her chin, resting on her cheek, and she is wearing a large, textured silver ring on her ring finger. Her left arm is crossed over her chest. The background is a bright yellow wall with some blurred red and white elements.

**“We are deeply grateful to everyone who supports our endeavors to reach out to more and more patients with blood cancer. But we still have much more to do. Crucially, we need more young donors.”**

**DR. ELKE NEUJAHR**

As Chair of the Board of Directors, Elke Neujahr runs DKMS and its various locations in Germany and worldwide. She is convinced that a global network and collaboration with partners are needed to win the fight against blood cancer.

## Dear Reader,

In 2018, the desire to support blood cancer patients by providing the life-saving stem cell transplants they need was tremendous again, with more than 600,000 new donors joining our registry in Germany alone. In September 2019, about 9.3 million people are registered with DKMS, 6.2 million of them in Germany. Every day, an average of 20 DKMS donors provide stem cells or bone marrow for patients, and the trend is upward. Ten years ago, it was just six donations a day – way less than half of what we have now. During the course of 2018, we were able to bring hope to almost 7,500 people around the world by providing them with stem cells from one of our donors. It was made possible by the sheer and unwavering commitment of our donors, volunteers and the DKMS team.

The fundamental factor in this success is trust: our trust in our own strong DKMS team, our donors' trust in us, and our patients' trust in our typing quality. We are grateful to have such trusting relationships and would like to thank everybody who supports our endeavors to help more and more people with blood cancer.

But we still have much more to do. Illnesses know no national borders, and already 75 percent of all DKMS stem cell donations are destined for patients abroad. That's why, for many years, we have seen our mission as a global mission to help as many blood cancer patients around the world as we can. In April 2018, we were able to open our fifth DKMS site, this time in Chile, which we hope will allow us to increase the diversity and scope of our registry even further.

To allow us to do so, we will need the support of many more passionate people. We are urging young people in particular to register with us – because by staying on our records for several decades, they improve the chances of finding a matching donor for our patients.

We are grateful to everyone who helps us continue our work to support blood cancer patients.

Thank you!

Best regards



**Dr. Elke Neujahr**  
CEO

A portrait of Pamela Kölbl, a woman with curly brown hair, smiling warmly. She is wearing a white blouse and a light blue cardigan. Her hands are clasped in front of her. The background is a blurred office setting.

**“I’ve been working for DKMS for ten years and am always deeply impressed by the number of volunteers supporting us. It’s through their commitment that we are able to register even more stem cell donors and offer even more second chances at life to patients all over the world.”**

**PAMELA KÖLBL**

Pamela works in Donor Recruitment as part of the campaign team that cooperates with local initiative groups to organize public donor drives across Germany.

# MORE THAN JUST A JOB: WE CONNECT PEOPLE

When people need us, we are here to help. Families and friends of patients regularly join forces with us to find an urgently needed donor for a loved one. It's the stories of these blood cancer patients that drive us to register more and more donors - to offer more and more people a second chance at life.

When Pamela Kölbl talks about her work, her eyes light up. "I'm always fascinated by how committed people are to supporting the fight against blood cancer. They are so selfless in their support, and that's what keeps me going."

For Pamela and her colleagues, 2018 was a particularly successful year. In Germany alone, they helped to register 641,725 new donors for the DKMS registry, through over 1,300 recruitment drives and via [www.dkms.de](http://www.dkms.de). That's over 100,000 more new donors than one year earlier — and all of them are now potential lifesavers.

## **78 PERCENT OF ALL DONATIONS ARE MADE THROUGH DKMS**

Last year, DKMS registered over a million new donors across the globe — a fantastic success! It also achieved another milestone in March 2018, having eight million DKMS donors worldwide in the database. By the end of the year, the German registry had about 5.9 million donors — an impressive sign of people's strong desire to help in this country. About 70 percent of all potential stem cell donors in Germany are registered with DKMS, which was responsible for 78 percent of successful donor matches in Germany last year.

Yet one in every ten patients still cannot find a suitable donor. So, to help improve their chances, donor drives take place on a daily basis in Germany, inviting anyone with an interest to register. Whether at a local event or online, registering takes just a few minutes to do.

For Pamela, organizing public donor drives for patients means travelling almost 10,000 kilometers a year. But the donor drives are a matter very close to her heart. Like all of the team, she wants everyone who needs a stem cell transplant to have a second chance at life. The stories of individual patients touch people's hearts across entire regions, and to encourage people to register, Pamela not only develops emotional connections with them but also educates and communicates with them. Our presence in print, online, and on television, radio and social media helps raise awareness of our existence with as many people as possible.

One particularly important group DKMS is target-

ing is young men, as they are more likely to donate stem cells and are most often requested to do so. That's why we have been concentrating on schools, universities, recreational teams and fire departments as focal points for donor drives. In 2018, 139,294 of the donors we recruited in Germany were young men between 17 and 30 years of age.

#### **IMPORTANT: DIFFERENT GENETIC ORIGINS**

Another group our donor recruiters concentrated on in 2018 was new donors living in Germany with different ethnic and genetic backgrounds. We were able to recruit almost 90,000 new potential donors of non-German origin to help us support patients searching the globe for a second chance at life.

## DKMS NEWS

### DKMS IS THE MOST POPULAR DONOR ORGANIZATION

According to figures by the market research institute YouGov, DKMS continued to enjoy a positive image in every respect in 2018. The YouGov Brand Index shows promoted public awareness of DKMS in 2018 at 43.6%, relatively consistent with 43.1% one year earlier.

In a ranking of the 30 most popular donor organizations, DKMS was top among people familiar with it, increasing its lead over the next highest. Our performance in the rankings was achieved by our donors' desire to help – and that is what makes our successful work possible in the first place.

### NETWORKING IN BERLIN

Since 2010, DKMS has had a donor recruitment team based in Berlin. Last year, it adopted a new strategic focus: the establishment of a Public Affairs office. For a non-profit organization, close relationships between policymakers, civil society and government in the capital are particularly important. That's why our new department sets out to represent our strategic interests and actively position DKMS's interests within political decision-making processes.

### AWARD-WINNING NEWSROOM

In 2018 the DKMS Media Center won the German Award for Online Communication in the Portal and Newsroom category. The award was presented by 'pressesprecher' magazine in recognition of the achievements of our digital communications. The DKMS online information portal offers news, press releases and information on patient campaigns as well as images, videos, and social media posts. The details that can be found combine information with storytelling and offer comprehensive, up-to-date support for media and influencers.

In 2018, the DKMS Media Center presented a number of articles designed to develop a better understanding of the problems blood cancer patients around the world are facing, but also to explain the latest research on stem cell transplants. Campaign events such as Volunteers' Day presented an opportunity to showcase the commitment shown by our thousands of volunteers in the fight against blood cancer. In September, International Children's Day drew attention to the particular situation of seriously ill children.

The online award spurs our communications team on to continue its hard and varied work.

# BLOOD CANCER: FACTS & FIGURES 2018

## THE CHALLENGE AT A GLANCE



**Every 15 minutes** someone in Germany is diagnosed with blood cancer.

Every year more than **18,000 people** die of blood cancer in Germany.



**One in ten blood cancer patients** in Germany cannot find a suitable unrelated donor.





**“Since my transplant, I no longer need medication. I feel good and can exercise. I enjoy playing table tennis with my Dad and soccer with friends. Someday I’d like to fulfill my dream of traveling to Thailand or New Zealand for a few weeks.”**

**MATHIES BECKER**

was diagnosed with aplastic anemia in 2008. A major donor drive in Norderstedt generated about 3,500 new registrations. 66 of them have since been able to make a life-saving donation. Mathies had a successful transplant in the same year.

# EMOTIONAL BEGINNINGS, TIRELESS RESEARCH

Eleven years ago, Mathies, who is now 16, received a life-saving stem cell donation. Today he is fit and healthy. Success like this takes a lot of research but it all started with a catastrophe.

When you first meet Mathies Becker, from Norderstedt, it's hard to imagine that a teenager so full of life could have been so close to death at the age of just five. As a boy, he was diagnosed with aplastic anemia, and a stem cell donation was his only hope. A global search was launched and a suitable donor was found.

Unfortunately, not every stem cell transplant is so successful. Looking back at the history of stem cell research, the achievements of the last few decades have been huge. Scientists have known since the 1860s that bone marrow produces blood cells, but it took almost a century to find out how this knowledge might be used in the treatment of blood disorders. The discovery came after the atom bombs were dropped on Hiroshima and Nagasaki in 1945.

## **RADIATION SICKNESS TRIGGERS RESEARCH**

Weeks after the devastating explosion, countless people continued to die of the effects of radiation. Their bone marrow was no longer producing blood cells, and their previously unknown symptoms needed an explanation. At the top of the list was the question of how to replace bone marrow once it has been destroyed. Shortly after World War II, tests on animals suggested that administering bone marrow cells could help reactivate blood cell production after exposure to radioactivity. Healthy stem cells, it seemed, could renew bone marrow destroyed by radioactivity.

### FIRST TRANSPLANT ATTEMPTS YIELD ONLY LIMITED SUCCESS

The first attempts to transplant human bone marrow were carried out in the late 1950s. After an accident in a reactor in Yugoslavia in 1959, the French physician Georges Mathé made the first attempt to treat radioactivity-induced blood formation disorders with human bone marrow transplants. However, his long-term success was limited. One of the difficulties he faced was graft-versus-host disease (GvHD), in which the immune cells of the donor attack the cells of the recipient.

It was not until the discovery of HL antigens (human leukocyte antigens) that a turn of fortune came about. It was found that rejection and GvHD were caused by genes that were important for a functioning immune system. When the first transplants were carried out between twins, hopes were reignited. In 1968, more and more bone marrow transplants were carried out, initially on children with congenital immune deficiencies, using a stem cell donation from their HLA-identical sibling.

### THE RISE OF UNRELATED DONORS

In the 1970s, German teams in Ulm and Munich began to carry out bone marrow transplants. In 1974, Europe's first specialist society was founded: the European Society for Blood and Marrow Transplantation. Collaborations between German and European transplant centers enabled common treatment and control standards to be established. Bone marrow was increasingly provided by HLA-identical donors who were not related to the recipient. Transplants of cells from unrelated donors became standard practice, thanks in part to the first comprehensive registries, in the US, the Netherlands and Germany.

### DKMS IS BORN

The story of DKMS is inextricably linked with that of the Harf family. In 1991, Mechtild Harf, a mother of two girls, was diagnosed with leukemia. Determined to fight her cancer, her husband, Peter, set up an initiative called Hilfe für Leukämiekranke (Help for Blood Cancer Patients). He organized public donor drives and generated 20,000 potential donors in the space of just a few months. On May 28 of that year, the private initiative of Dr. Peter Harf became the non-profit organization DKMS gemeinnützige GmbH.

Although a donor was found, Mechtild died four months after her stem cell transplant – but the founders of DKMS continued undeterred. Peter Harf had a vision. He wanted to fulfill his wife's greatest wish: to prevent other cancer patients and their families from suffering the same fate.

## THE HISTORY OF STEM CELL TRANSPLANTATION

### MILESTONES

- **1869** Scientists discover that blood cells are produced in the bone marrow.
- **1957** British scientists identify an anti-leukemic effect in a study of mice that had received bone marrow transplants after being exposed to radiation.
- **Late 1950s** First attempts are made at transplanting bone marrow in humans – but with limited long-term success initially.
- **1958** Jon van Rood and others discover HLA markers.
- **Late 1960s** For the first time, physicians in the US successfully treat immune defects, aplastic anemia and leukemia with bone marrow transplants.
- **1967** Jon van Rood establishes the organ donation organization Eurotransplant.
- **1970s** Transplant teams in German hospitals start to carry out bone marrow transplants.
- **1974** The European Society for Blood and Marrow Transplantation (EBMT) is established to support the exchange of knowledge about stem cell transplants and to advance clinical studies.
- **1987** The first successful transplant with an unrelated donor is carried out in Germany.
- **1988** Bone Marrow Donors Worldwide (BMDW) is established, which regularly collects data from donors across the globe.
- **1991** Peter Harf and his family and friends establish the leukemia support organization Hilfe für Leukämiekranke (Help for Leukemia Patients), which later becomes DKMS.
- **By the end of 2018**, DKMS has a total of 8.6 million registered donors worldwide, 5.8 million of them in Germany. In its 27 years of existence, it has provided over 75,000 second chances at life to patients around the world.

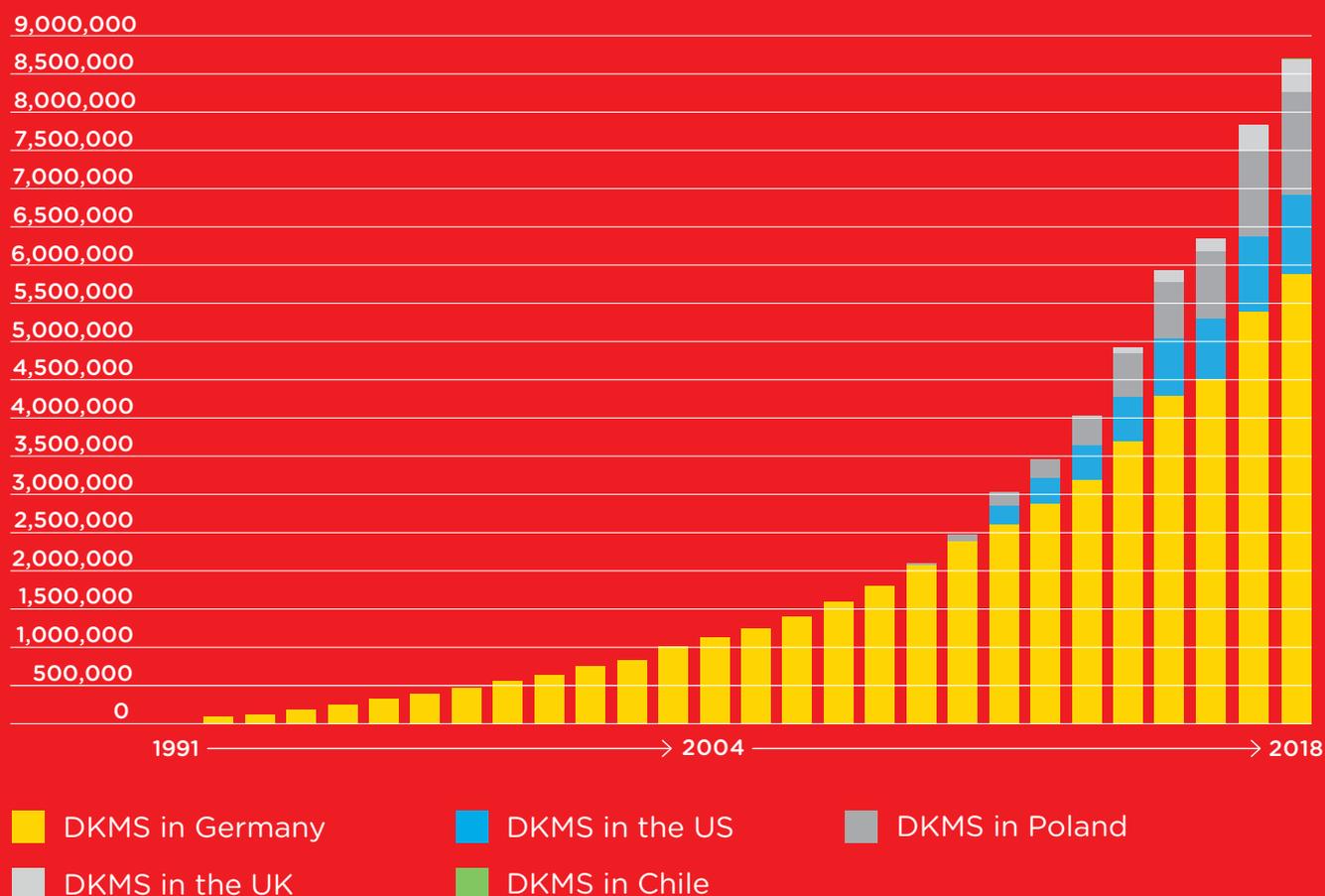
## DEVELOPMENT OF CELL COLLECTIONS

AVERAGE NUMBER OF DKMS STEM CELL DONATIONS IN GERMANY PER DAY



## DEVELOPMENT OF DKMS DONOR NUMBERS

Figures as of: December 31, 2018



A portrait of Heike Fischer, a woman with long blonde hair and glasses, wearing a blue floral patterned top. She is smiling and has her hands clasped on a wooden surface. The background is a wood-paneled wall.

**“2018 was a special year for us at DKMS because we succeeded in determining cytomegalovirus statuses by buccal swab. We were able to persuade almost a quarter of a million donors to send us another sample for follow-up typing to increase their chances of becoming a donor.”**

**HEIKE FISCHER**

graduated in biology and has been a HLA specialist with the HLA Service department of DKMS in Tübingen for the last 10 years. Her main focus is on projects to enhance the quality of donor data and checking incoming data. In her free time, she loves to play table tennis.

# ALWAYS ON THE LOOKOUT FOR THE BEST DONOR

When it comes to the chances of survival, selecting the best stem cell donor and ensuring their immediate availability are crucial. We work tirelessly to enhance our donors' profiles and achieve the best possible transplant outcomes.

Heike Fischer (38) knows that for patients, every day counts. For many of them, the search for a suitable stem cell donor starts as a race against time. Finding a match is often their only hope. A key factor determining the success of a transplant is the degree of the match between the HLA markers (tissue markers) of donor and recipient. "The more markers we can analyze when donors register, the faster we can find and connect matches for patients," says the biologist. She and her colleagues work constantly to define new approaches and optimize existing ones to improve the quality of donor data.

## COMPREHENSIVE TYPING TO THE HIGHEST STANDARDS

DKMS types samples to the highest standard and works tirelessly to optimize donor selection based on the latest scientific findings. Today, typing is already very comprehensive with samples undergoing high-resolution analyses of seven HLA gene loci with 14 tissue characteristics. Other crucial criteria for donor selection are also examined, such as CMV status, blood type (ABO and Rh.), KIR receptors, the CCR-5 receptor and MIC-A and MIC-B receptors.

Heike explains: "HLA stands for human leukocyte antigens, which are a group of molecules on the surface of almost every cell that are vital to a functioning immune system. Our HLA data is of such high quality that we can often tell immediately whether or not we have a match in our database."

### **BUCCAL SWAB SAMPLES NOW MORE RELIABLE THAN EVER**

In 2018, one challenging project explored the development of a test that would allow the cytomegalovirus (CMV) status of donors to be identified via their buccal swabs. CMV is widespread around the world and a member of the herpes family, but in stem cell transplant patients with a compromised immune system, it can cause potentially fatal complications. Last year, the DKMS Life Science Lab successfully developed an antibody test that determines CMV statuses using buccal swabs rather than blood samples, as was previously required.

### **OVER 546,000 DONORS INVITED TO SUBMIT SECOND BUCCAL SWAB**

Analyses by our scientific project team showed that the probability of being selected as a stem cell donor increases when a donor's CMV status is noted in the search list. This information is particularly important for male donors up to 35 years of age and females up to 25 who have already been typed for five or six HLA markers: both of these groups have a higher chance of making a donation if their CMV status is known. "That's why, in 2018, we got together with teams from several departments to write to more than 546,000 donors in this group and invite them to send us a second buccal swab," Heike says. Their efforts were hugely successful: 49 percent of the donors they wrote to ordered a swab set. Of those, 84 percent submitted a further sample. By the end of the year, more than 218,000 samples had been successfully tested for CMV. The best news is that, since then, almost 2,600 registered donors taking part in the project have been identified as a potential match for a patient and 607 of them have already donated their stem cells.

### **EUR 1.13 MILLION FOR BETTTER DATA QUALITY**

Determining donors' CMV status is just one of many projects initiated by DKMS to increase typing quality. In 2018, we invested more than EUR 1.13 million in total in upgrading the data of previously registered donors. The funding was used not only to enable follow-up CMV status checks but also to locate substitute donors in the database and carry out addi-



## **COTTON BUD WITH A DIFFERENCE**

Three 'cotton buds' – or buccal swabs – are all you need to become a DKMS donor and potentially save a life. The special swabs are a medical product made of high-tech fibers that pick up and retain genetic material, in this case epithelium cells from inside the mouth. The samples offer a sufficiently high concentration of DNA for us to determine a potential donor's HLA and other markers, giving us all the information we need for a successful search for a matching donor. Since October 2017, DKMS has also been determining the CMV status of all new donors, purely with the help of the third buccal swab.

# “IT’S NOT ABOUT MORE THERAPIES BUT ABOUT FINDING THE BEST APPROACH”

Professor Thomas Klingebiel MD is the director of the Clinic for Pediatric and Adolescent Medicine at Frankfurt University Hospital and a member of the Foundation Board and Medical Council of DKMS Foundation for Giving Life. In this interview, he talks about the development, success and future of stem cell transplants and blood cancer therapies.

## **PROFESSOR KLINGEBIEL, THE SIDE-EFFECTS OF STEM CELL TRANSPLANTS ARE LOWER TODAY THAN EVER BEFORE, AND MORTALITY RATES CONTINUE TO FALL. WHY IS THAT?**

Nowadays, clear treatment concepts and well-founded insights from studies on transplants mean we know exactly when an allogenic stem cell transplant makes sense. Another key reason is that we have optimized our donor selection process through methods such as high-resolution typing. And then there are the ongoing scientific studies that are expected to deliver even more improvements. The system here in Germany allows us to find well-typed donors at short notice who are ready to do their part – thanks to DKMS, among others. This has helped us to cut mortality rates dramatically.

## **WHAT CHALLENGES IN STEM CELL TRANSPLANTS REMAIN UNRESOLVED AT THE MOMENT?**

The main challenge facing us all at the moment is to prevent the most acute and chronic forms of rejection, or graft-versus-host disease (GvHD), wherever we can while keeping relapses to a minimum.

## **DO YOU SEE ANY PROMISING APPROACHES THAT COULD HELP US RESOLVE THIS PROBLEM IN THE FUTURE?**

Looking ahead, I see a whole range of other exciting challenges. For instance, we are just in the process of integrating antibodies, or ‘small molecules’, into therapies and clinical studies, and developing new drugs. We are also concentrating on new genetic diagnostic procedures. So, it’s not necessarily about ‘more’ therapies or new drugs but about finding the best approach.

## **HOW ELSE CAN NON-PROFIT ORGANIZATIONS SUCH AS DKMS SUPPORT THE FIGHT AGAINST BLOOD CANCER?**

Networks and knowledge transfer are crucial, and DKMS is a key contributor. It awards scholarships to outstanding young scientists so they can implement



Prof. Dr. med. Thomas Klingebiel

their ideas. Their scientific insights will then help us to improve therapies. In addition to this, DKMS supports the clinical studies that underpin our decisions. Clinical studies are the only way we can really validate our strategies.

## **LOOKING BACK, WHAT HAS REVOLUTIONISED STEM CELL TRANSPLANTS IN THE LAST 30 OR 40 YEARS?**

As a physician and oncologist, I have experienced some of the most exciting periods in this field of medicine. Over the last few decades, our commitment and successful partnerships – and, most importantly, our clinical studies and study networks – have enabled us in many cases to turn an incurable disease into a curable one. When I see what we have been able to achieve and how many patients have been able to carry on living, I think we have been incredibly lucky. Fundamental insights into transplant biology have been a key factor in all of this, as have improved donor selection and the availability of volunteer donors in large donor registries to support so many people from different backgrounds. Another significant point was the development of new drugs and cell therapies. Clinical studies to validate our treatment strategies have also been crucially impor-

A full-length portrait of Professor Michael Albert, a man with short brown hair and glasses, smiling warmly. He is wearing a light blue long-sleeved button-down shirt, a brown leather belt, and dark blue jeans. He has his hands in his pockets and is standing in front of a wall made of vertical wooden slats. The lighting is soft and even.

**“As a doctor, my work is first and foremost about successfully curing my young patients. I know that for many of them, a stem cell transplant is their only hope of returning to good health. That is why it is so important to have as many donors as possible. Increasing donor numbers is a key focus at DKMS and one I wholeheartedly support.”**

**PROFESSOR MICHAEL ALBERT**

is a senior physician at the Pediatric Hematology, Oncology and Stem Cell Transplantation unit of the Dr. von Hauner Children’s Hospital at the University of Munich. His specialist areas include the treatment of children and young people with a congenital immune deficiency.

# IN PURSUIT OF A SINGLE GOAL: A CURE

When it comes to treating children with blood disorders, Professor Michael Albert knows the bright sides as well as the darker ones. He is one of the physicians and scientists who have devoted themselves wholeheartedly to the fight against these diseases - and he understands the importance of research for creating a better future.

“Children with congenital immune or other genetic deficiencies who have had a stem cell transplantation often have a better chance of being cured than those with other types of blood cancer. We perform transplant surgery even on newborns and have a success rate of over 90 percent with some forms of the illness,” says Professor Albert. However, he is well aware that “for some patients, such as those from ethnic minority backgrounds, it can be much more difficult to find a matching stem cell donor because too few people around the world are registered. Stem cell transplant therapy can sometimes fail, leaving us with no way to cure the patient. A setback like that can be really tough.”

Cure. It’s a big word, but how high are the chances of it happening to a patient with a stem cell transplant? In Germany alone, over 18,000 people die of cancers of the blood every year. In half of these cases, a transplant fails to deliver what the doctors really want: complete victory over their illness. Relapses, severe infections and life-threatening rejection cases remain a major challenge.

#### **DKMS SUPPORTS BLOOD CANCER RESEARCH**

DKMS has long been committed to scientific research in the field of stem cell donation. Since 2013, we have even been running our own Clinical Trials Unit (CTU). However, many questions still remain unanswered around the treatment of blood cancer and other disorders of

the blood-forming system. The CTU works actively to drive scientific advances in the treatment of leukemia by launching and supporting innovative, life-saving research projects. In 2018, we invested more than EUR 2.8 million in this area of work.

Research focuses primarily on allogenic blood stem cell transplants, which use donor cells, rather than autologous procedures, which use the patient's own stem cells. It is an area of work that is of little interest to the pharmaceutical industry and therefore tends to be underfunded. The CTU is set up for international collaboration within Europe but also reaches out to the US. It collaborates with international transplant registries as well as national and international study groups in pursuit of its goal.

### **THE SEARCH FOR BENIGN 'KILLERS'**

A current research project at the CTU examines the role of natural killer (NK) cells. These immune cells are found in human blood and play an important role in fighting viral infections – but they may be able to make the crucial difference in the fight against cancerous cells as well. The cell surface proteins on NK cells prevent them from killing other body cells, but unfortunately, the relevant key for this signal is also frequently found on leukemia cells, which may therefore escape natural destruction. A treatment that interrupts the spread of the signal from leukemia cells to immune cells would leave the leukemia cells unprotected and allow them to be killed.

The DKMS research project in this area is designed to monitor and compare the development of the NK cell repertoire in transplanted cells at various timepoints. In the future, the insights gained in this way could help to improve the selection of suitable blood stem cell donors.

### **COBI. A BANK FOR LIFE**

One of the CTU's key tasks last year remained the administration of the Collaborative Biobank (CoBi), established in 2016. CoBi is a shared scientific platform that provides resources worldwide for medical research projects investigating blood cancers. The partners that work with it are transplant and stem cell donation centers as well as donor registries. A particular characteristic of CoBi is that it offers an archive of samples and data of matched stem cell donors and recipients – a service that had previously only been available from very few databases around the world. Participating centers and research groups across the globe can use the samples and data concerned to support their research on the prevention, diagnosis and treatment of blood cancers. By the end of 2018, the CoBi team had welcomed nine more transplant and donation centers in Germany to the platform.

A number of important research projects have already been made possible by the resources of the biobank, such as an investigation to confirm the advantages of donor selection based on killer cell

## **DKMS LIFE SCIENCE LAB WINS HLA AWARD 2018**

DKMS Life Science Lab (LSL) achieves tremendous success: In May 2018, the HLA typing lab of DKMS won the HLA Award 2018 at the European Federation for Immunogenetics and Histocompatibility Congress (EFI). It was presented to Vivian Albrecht of the LSL team, who published the most influential scientific paper in the HLA journal the previous year. Her prize-winning treatise explores the full genetic characterization of a total of 1,056 new and confirmed HLA alleles.

Every year, the DKMS Life Science Lab types over 1.2 million samples from potential stem cell donors, frequently discovering new alleles never seen before. An allele can be defined as a gene variant that is found on a specific part of a specific chromosome (gene locus). A special department of the lab analyzes these new alleles more closely, making a vital contribution to the enhancement of the global HLA allele database. Overall, the LSL has already discovered new HLA alleles in over 25,000 donor samples (as of February 2019). Knowledge of new alleles is important in achieving the best possible match between the tissue types of patients and donors.

We are working actively to drive scientific progress in the fight against blood cancer, and to launch and support innovative, life-saving research projects.

immunoglobulin-like receptors (KIRs). KIRs play a key role in this regard because they influence the activity of natural killer cells. In addition, further research projects were initiated in 2018 to optimize donor selection for allogeneic stem cell transplants from unrelated donors.

**RESEARCHERS SUPPORT RESEARCHERS**

DKMS is not just contributing its own scientific work to help improve the outcomes of blood stem cell transplants; it also supports relevant projects by external research groups, in part by offering opportunities to DKMS stem cell donors to participate in promising projects. These primarily consist of studies of no commercial interest and often with limited funding. In 2018 alone, DKMS received over 170 external requests for sample material, from the US, Germany, Canada, Austria, Italy, Australia, and the UK.

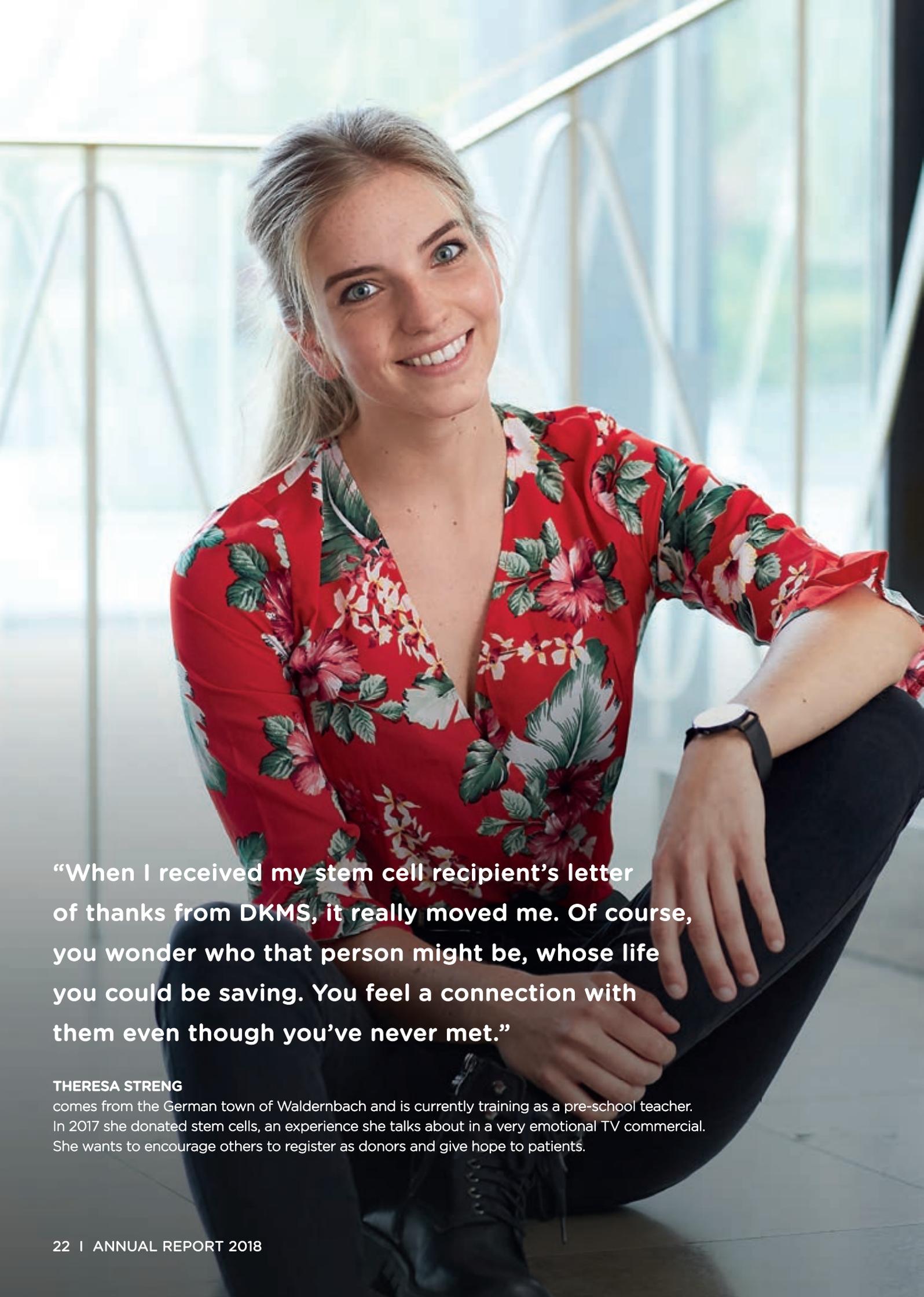


Award-winner Professor Yair Reisner (left) with Richard Champlin, MD, who delivered the prize-giving speech.

**DKMS FOUNDATION HONORS SCIENTISTS**

In 2018, the Mechtild Harf Science Award of the DKMS Foundation for Giving Life went to the Israeli immunologist Professor Yair Reisner. It was presented to him in recognition of his outstanding work in the field of transplant immunology, and in particular for his research into the role of immune-tolerance mechanisms in stem cell transplants. “The findings of numerous research projects at the Weizmann Institute of Science have been successfully translated into clinical success. This has already benefited many patients and will continue to do so in the future,” said Dr. Alexander Schmidt, chief medical officer with DKMS, speaking at the award ceremony. The Mechtild Harf Science Award has been presented annually since 2001 on the fringes of the conference of the European Society for Blood and Marrow Transplantation (EBMT). It honors the endeavors of internationally renowned medical practitioners and scientists in the field of blood cancer research and stem cell transplantation.

The DKMS Foundation also presented two Mechtild Harf Research Grants. In 2018, the scholarships went to Dr. Pietro Crivello of the University of Essen and Dr. Elke Rücker-Braun of the Dresden University Hospital. Their research focuses on gaining a deeper understanding of treatment complications relating to stem cell transplants and cellular therapies for malignant hematological diseases. Mechtild Harf Research Grants are presented annually to applicants from around the world and provide three years of financial support.



**“When I received my stem cell recipient’s letter of thanks from DKMS, it really moved me. Of course, you wonder who that person might be, whose life you could be saving. You feel a connection with them even though you’ve never met.”**

**THERESA STRENG**

comes from the German town of Waldernbach and is currently training as a pre-school teacher. In 2017 she donated stem cells, an experience she talks about in a very emotional TV commercial. She wants to encourage others to register as donors and give hope to patients.

# FOCUS ON TRUE HEROES

**What motivates people to do good? There are many fascinating questions around the issue of motivation and altruism, and in 2018 DKMS launched a campaign to find out more.**

Focus on True Heroes is a DKMS campaign launched in 2018. It sets out to raise awareness of the all-important topic of blood cancer and stem cell donation, and asks direct questions that give us food for thought. The aim is to convince as many people as possible to register as potential donors. The focus of the campaign is on people who do great things: DKMS donors whose altruistic deeds make them the true heroes of our patients.

As part of the campaign, DKMS produced two TV commercials that both work with an element of surprise. To make sure the people seen in them gave authentic answers, we let the cameras roll without telling them. They thought they were at a casting. Only afterwards did they find out what was actually going on!

To get them thinking, the casting team asked the candidates various questions: What good things have you done? Would you save someone's life? And even: Why don't you save someone's life? The answers they received ranged from "I offered my seat to an elderly gentleman on the bus one day" to "I bought a copy of Big Issue" and "I carried my neighbor's shopping up to the fourth floor of our apartment complex". But the last person in the commercial to answer the question links memorably to our own work, at DKMS: it was Theresa Streng, who has in fact saved someone's life - by donating stem cells to a blood cancer patient.

## **AWE-STRUCK**

When the DKMS commercial was first broadcast, Theresa and her family were all geared up in front of the TV. Several of her friends contacted her immediately afterwards, completely unaware that she had made the donation. They were in awe of what she had done. "I had some really amazing responses and was surprised by how many people saw the commercial and registered as donors because of it. That really motivated me to carry on supporting DKMS."

## OUR DONORS

### FACE OF THE CAMPAIGN: THERESA AS A ROLE MODEL FOR OTHERS

Since then, Theresa's face is familiar to the German TV audience, and her answer touched many people. She originally registered with DKMS online at the end of 2016 and received a message six months later inviting her to donate some stem cells to help a patient. "I was overwhelmed to be able to help someone," she recalls. The preparations and the donation itself were no problem at all. She now knows that her donation went to a patient in the Netherlands, who is recovering from her illness and is expected to return to a normal, healthy life - thanks to Theresa's stem cells.

Modest through and through, Theresa certainly does not consider herself a hero. What matters to her is that as many people as possible learn about the work of DKMS, just like she did. Always ready to help out, Theresa finds it important to connect to other people and support social causes. "That's how I was brought up," she says - and it is also the reason she has been an active member of the Volunteer Fire Services since the age of 10.

### YOUNG PEOPLE ARE PARTICULARLY VALUABLE AS DONORS

To help give blood cancer patients around the world a second chance at life, as many potential donors as possible need to register. DKMS is primarily appealing to those most likely to actually make a stem cell donation: young people aged between 17 and 30, people like Theresa, who exemplifies the fantastic altruism of donors around the world.

Registered DKMS donors who go on to actually donate their stem cells are on average only about 30 years old, six years younger than the average of all potential donors registered in our database. Young men are a particularly important group: a comparison shows that, even though women account for 59 percent of our potential stem cell donors and men for 41 percent, men account for roughly two thirds (71 percent) of actual stem cell donations made. However, DKMS still welcomes everybody who would like to register as a potential donor and offer their support.

### EVELYN: OUR FASTEST DONOR IN 2018

Fast, faster and Eve(ly)n faster. In 2018 Evelyn Kerber was Germany's fastest DKMS donor. From the time she registered until the moment she made her stem cell donation, just 79 days had passed.

Last year, Evelyn, a senior in high school at the time, not only had her last exams to write but also a test of a very different kind to pass: a stem cell donation. After registering, Evelyn joked with her friends that it wouldn't be long before it was her turn. Little did she know that the phone call from DKMS was just about to come in. When it did, she was overjoyed at the prospect of helping a seriously ill person, in this case a woman from Germany.

Evelyn is one of fewer than 20 percent of donors whose stem cells are extracted from the bone marrow in the back of their iliac crest. "The pain wasn't too bad. I thought it would be worse," Evelyn recalls.

The junior bank teller is the only donor among the alumni of her high school. To motivate more students to register, she has committed to support forthcoming campaigns in schools.

In 2018, DKMS Germany matched 5,460 stem cell donors to patients around the world. Of those, 646 had been registered with us for a year or less. 24 of them were like Evelyn, able to make a donation within the first hundred days of being in our database.



Evelyn Kerber

## DKMS DATABASE: UPDATING RECORDS TAKES TIME AND EFFORT

Choosing the best possible stem cell donor and being able to contact them quickly can save lives. That is why, as soon as a request comes in, we need to be able to get in touch with our donors. To help us – and with the permission of those concerned – we sometimes work with local registration offices, who provide us with donors' new addresses after they have moved house, for example. In 2018, DKMS Data Management in Germany submitted and processed 87,150 requests for local registration offices to provide information. We also updated the addresses and contact details of about 500,000 additional people who informed us of the changes via our website, or by phone or email.

At DKMS, data protection is a top priority. We make sure that we strictly follow and adhere to the latest EU General Data Protection Regulation (EU GDPR).

### MOTIVATION THROUGH INFORMATION

Irrespective of age, sex or origins, our donors all share an incredible desire to help, a sense of humility, and most of all the fact that, given the opportunity, the vast majority would do it all again. According to a survey, 94.8 percent of all DKMS donors would provide stem cells again. They feel well informed and cared for and want to remain on the record in order to help others. So that we can contact them quickly, we need to make sure their contact details are up-to-date at all times, because efficiency is key: from the beginning of the workup to the actual stem cell donation takes on average 44 days. The fastest workup in 2018 took just four days to complete.

### WELL-INFORMED DONORS ARE RELIABLE DONORS

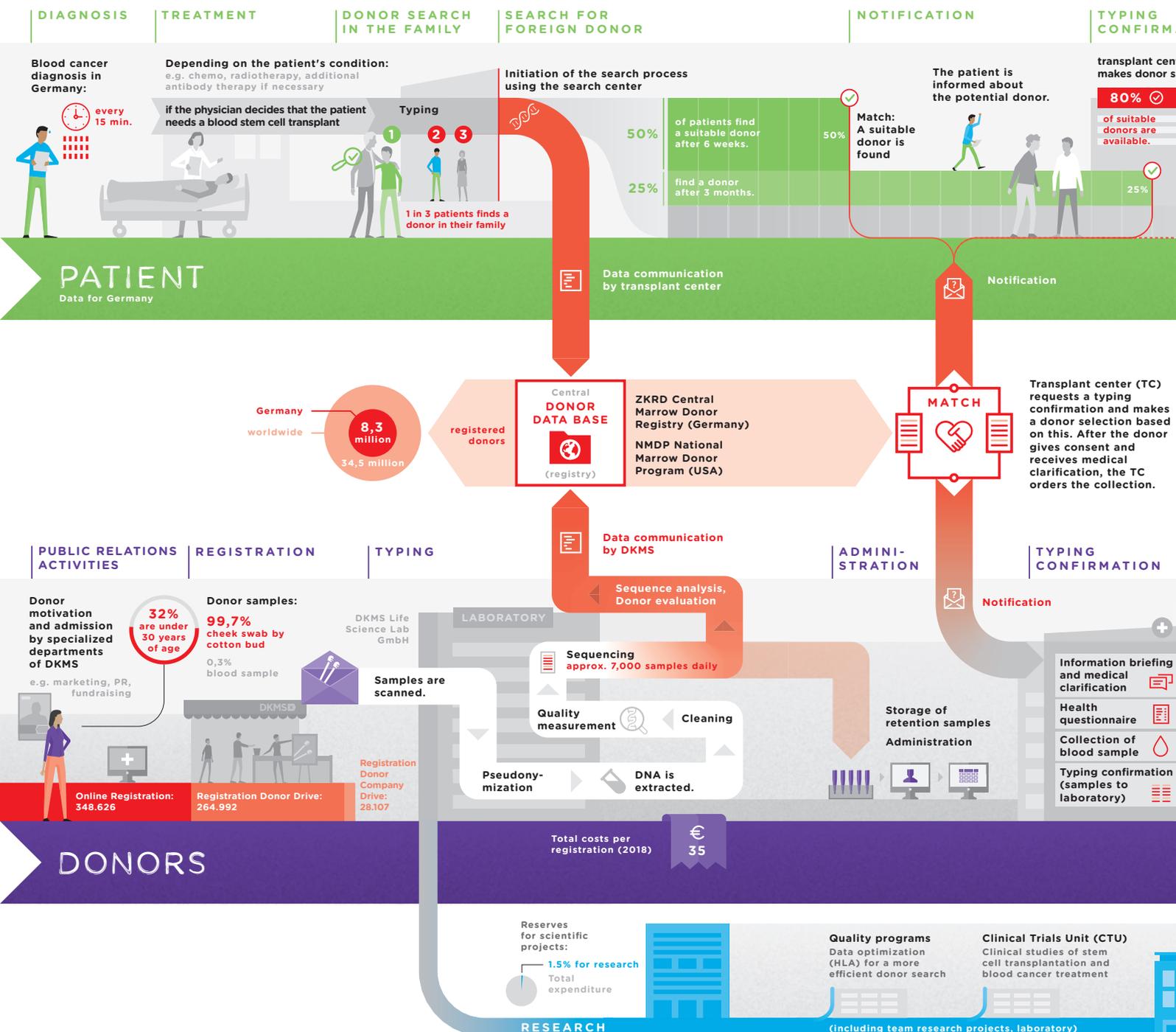
Our annual mail outs and email newsletters to stem cell donors help us to ensure all the contact details we have are up-to-date. The patients' chances of survival also depend on something else: the fact that our donors make an educated decision. Fewer than four percent of potential DKMS donors withdraw from making their donation, the vast majority because they are sick themselves, or pregnant, or have other issues that prevent them from doing so. In cases such as these, where a donor cannot deliver, we need to find an alternative fast and our Donor Replacement Program is one of the options that helps us find the substitutes we need. Launched in

2001, it sets out to identify at least one 'twin' for as many donors as possible. With the same HLA markers in the same resolution, 'twins' can act as stand-ins for donors, so if a chosen donor cannot deliver, perhaps for their own health reasons, we will have an alternative at hand. Where donors are identified who might potentially match the required profile but have not yet been sufficiently typed, we invite them for further typing. So, if, for example, a second request for this HLA type comes in, we will have a fully typed substitute ready and waiting. In 2018, we invited 13,592 donors for further typing as part of the Donor Replacement Program.

### HOW DONORS AND RECIPIENTS COME TOGETHER

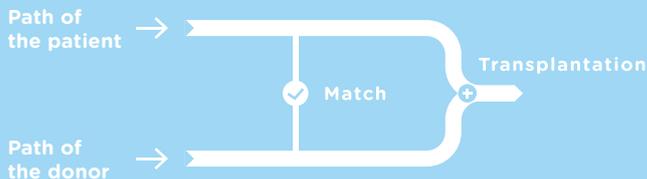
Many donors have a strong desire to know whether the stem cells they donated have performed as hoped in the body of the recipient. To help them find out, the team in our Donor-Patient Contacts unit provides information about patients from most countries to update donors on developments. The team also manages anonymous correspondence between the two, exchanges their contact details on request, and sets up a first face-to-face meeting, generally at least two years after the transplant. In 2018, we were able to organize a number of emotional meetings all over the world.

# WE FACILITATE STEM CELL TRANSPLANTS



There are many individual steps on the road from developing blood cancer to receiving a transplant. This infographic shows you the most important stages of our work.

## READING GUIDE:



76% of donations are requested by foreign transplant centers.

### PATIENT FOLLOW-UP

- Information on the health status of the patient over 2 years (not in all countries)
- Disclosure of the outcome data to collection clinics for quality assurance purposes.

### DONOR-PATIENT CONTACTS

When there is mutual agreement, contact is immediately possible by means of an anonymous letter exchange.

DKMS facilitates and supports contact between patients and donors if desired.

Becoming acquainted with one another in person is possible in Germany after 2 years.

### DONOR FOLLOW UP

- Service for grieving donors, if patient does not survive
- Blood test (4 weeks after donation), questionnaire (6 months after donation, then annually)

### WORK-UP

- Information briefing and preliminary screening
- Final consent
- Organization of time and type of sample collection at request of the responsible clinic
- Medical clearance

### COLLECTION

Collection from blood (peripheral stem cell donation)  
General anesthetic

17,5% 82,5%

2 days with hospital stay  
3-5 hours  
Max. 2 days + 5-day pretreatment

### TRANSPORT

Courier with transplant in special transportation box  
Max. 72 hours cooled

**TRANS-PLANTATION**  
Stem cell administration by means of infusion

Recovery

DKMS Life Science Lab GmbH, head office in Dresden is one of the largest and most efficient HLA typing laboratories in the world.



**“It was incredibly moving to meet my donor. The first thing I did was thank him with all my heart. He saved my life – just like that and he wanted absolutely nothing in return.”**

**KARL KAPAHNKE**

is now looking forward to a bright future after his successful stem cell transplant. His dream job? Doctor, preferably an oncologist.

# OUR MOTTO: NEVER GIVE UP!

**Every human life counts. That is why we support blood cancer patients all over the world. The best part of our job consists of giving people hope and a healthy future to look forward to.**

“Blood cancer has made me stronger. It has made me who I am,” says Karl Kapahnke. At 18, Karl, from Schildow in northern Germany, is about to graduate from high school. He was first diagnosed with leukemia at the age of six and spent almost a year in hospital, where he had chemotherapy. After leaving, he had regular checkups, and after no concerns were raised for a while, he was finally given the all clear. However, in April 2016, he was diagnosed with leukemia again. “My back hurt and I had no energy whatsoever, so my mother insisted I go to the doctor,” he recalls. “When he told me I had blood cancer – not a relapse but a different type – my world just fell apart.”

#### **CHEMOTHERAPY ALONE WAS NOT ENOUGH**

Once again, Karl found himself fighting to survive. Initially, he was given another round of chemotherapy, but it soon became clear that he would need a stem cell transplant. A global search for a donor was launched. Fortunately, a match was found and the long-awaited transplant was carried out with his parents by his bedside. A few weeks later, the doctors told him that his new stem cells were working well and had started producing new blood cells. Karl was relieved: “The first time they let me out of hospital, I went for a short walk and just enjoyed the cold winter air,” he recalls.

Not long ago, Karl experienced a very special moment: he met with his donor for the very first time. “I found it incredibly moving, and the first thing I did was thank him with all my heart,” he says. He is now looking forward to a bright future and has big plans: he wants to be a doctor, preferably an oncologist.

**OUR WORK CONTINUES - ON BEHALF OF KARL, JANA AND MANY OTHER PATIENTS**

Every 35 seconds, someone somewhere in the world is diagnosed with blood cancer. In Germany, it is every 15 minutes. Blood cancer accounts for more than nine percent of all newly diagnosed cancers and almost 50 percent of cancers in children. 11-year-old Jana, from Leverkusen, is one of them. In 2017, a donor drive under the motto Heroes Wanted was run for Jana, which generated over 600 new registrations. Unfortunately, however, none of them was suitable for her, and in 2019, she died from her serious condition. For her family and friends and everyone who knew her, the news was absolutely devastating.

At DKMS, we are continuing our work on behalf of Jana, Karl and all the other blood cancer patients around the world. We are working flat out to recruit as many new donors as we can and our efforts are paying off: in 2018 alone, around 1,800 people in Germany registered with us every day - more than twice as many as five years ago. By the end of 2018, about 65,000 stem cell donors from DKMS Germany had given a blood cancer patient the hope of a healthy future. Every day, an average of 15 DKMS donors in Germany provide stem cells or bone marrow for transplants. In 2018, a total of 5,460 donations were made. Of those, 82.5 percent were peripheral stem cell donations, and 17.5 percent were bone marrow.

**SOLIDARITY ACROSS THE GLOBE ON WORLD BLOOD CANCER DAY**

Part of DKMS's work consists of raising awareness of blood cancer and stem cell donations among the general public, in part through events such as World Blood Cancer Day (WBCD) on May 28 every year. Launched in 2014, WBCD is a global day of action in which people around the world show their solidarity with blood cancer patients. In 2018, a special DKMS train traveled Germany north to south and east to west for an entire week to raise awareness of the disease and encourage people to register. On the side of it was the slogan "Jetzt bist Du am Zug - Setz ein Zeichen gegen Blutkrebs!" ("Be a part of it and make your mark against blood cancer!").





## WORLD BLOOD CANCER DAY 2018

For one week in May 2018, a special DKMS train traveled all over Germany bearing a message of support for World Blood Cancer Day. Written on the side of it was the slogan: "Jetzt bist Du am Zug - Setz ein Zeichen gegen Blutkrebs!" ("Be a part of it and make your mark against blood cancer"). The train stopped at Munich, Stuttgart, Cologne, Leipzig, Hamburg and Berlin. Donor drives at the various stations generated 700 new recruits for the DKMS registry. Countless more people made enquiries or donated money. On board the train was the pianist and composer David Ianni, who performed at each station on his red Piano of Hope (below, left). In Berlin, the DKMS campaign was supported by congressman Cem Özdemir (The Greens) and State Minister for Health Dilek Kolat (below, center). In addition, a young patient called Marie got to meet her donor, Ionna, and gave some very professional-looking interviews (bottom, right).





**“Being a stem cell courier is potentially addictive! Handing someone a second chance at life is the most incredible feeling. I wish I had time to do the job more often.”**

**PATRICIA SCHEER**

is a volunteer stem cell courier. Her daughter, Rinah, who had blood cancer, was cured thanks to a stem cell donation from a woman in America. Out of gratitude, Patricia became a stem cell courier and delivers to patients around the world.

# STEM CELLS FOR THE WORLD

**When it comes to giving patients a second chance at life, our endeavors know no bounds. We leave no stone unturned. Working as a global network, we are currently establishing new locations and increasing the genetic diversity in our database.**

“I wanted to give something back,” says Patricia Scheer full of conviction. In 2015, her daughter, Rinah (15), received a stem cell donation after a worldwide donor search on her behalf. The right match was finally found in the US.

The fact that it is just a matter of hours to get stem cells to donors anywhere in the world is something Patricia finds inspiring. When her daughter recovered from blood cancer, she applied to be a courier. Her application stirred up memories of her daughter’s illness as well as powerful emotions, but the interview was a success. “I knew how it felt to be the person who’s waiting,” she recalls.

On her first courier trip, a thousand thoughts raced through her mind. She called the office on several occasions just to make sure she was doing everything right, but all’s well that ends well: the stem cells reached their recipient safely and on time.

## **NEVER JUST ROUTINE**

Now, Patricia’s courier trips are not quite so emotional any more. “It was only on my first trip that Rinah was constantly on my mind, and that was a good thing, but this job will never be routine for me. I feel nervous every time. It’s a huge responsibility. The best part is always when you send the final code to the courier service. That’s when I know I have done my best. The tension just falls away at that point,” she says.

It is people like Patricia and our thousands of other supporters who make international stem cell donations possible at all. All of them are part of a united global system of solidarity that organizes donors for people in countries that have only limited registered donors of their own. In these countries, the number of blood cancer patients who die remains high.

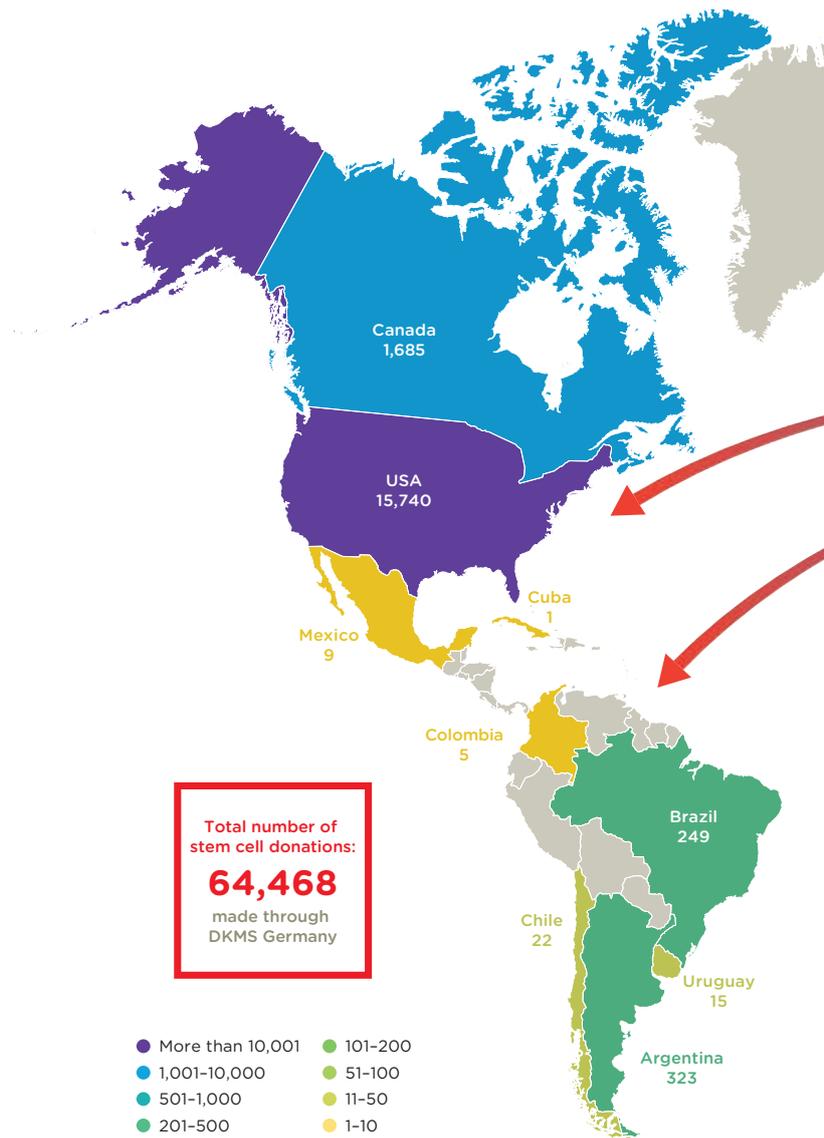
## GLOBAL COMMITMENT

Our commitment in the US, Poland, the UK, Chile and India, allows us to continue working to improve the situation for blood cancer patients around the world. By registering as many people as possible with different HLA characteristics, we will be able to achieve our goal.

The latest figures confirm the success of our international operations. 76 percent of DKMS stem cell donations are sent to patients in other countries. We supply cells to about 600 hospitals in 56 nations around the world. In 2018, 24 percent of our donations went to the US; 52 percent went to other countries, primarily France (13.6 percent), the UK (11.2 percent), Italy (9.3 percent), Turkey (6.1 percent) and the Netherlands (5.6 percent). 27 percent of stem cell donors worldwide are registered with DKMS, and we account for 39 percent of all stem cell donations.

### PROGRAMS FOR PATIENTS IN NEED

The DKMS high-risk program enables typing for particularly difficult cases, such as patients with rare tissue types and donor searches that have to be carried out with little or no funding. In 2018, the program contacted 2,147 donors. It also supported hospitals needing to type family members living abroad and organize stem cell donations. In 2018, we dispatched 227 typing sets to people in 46 different countries. We also run a patient aid program that supports stem cell transfers to patients who cannot afford a transplant. In 2018, it helped patients in South Africa, India, Chile, Iran, and elsewhere.



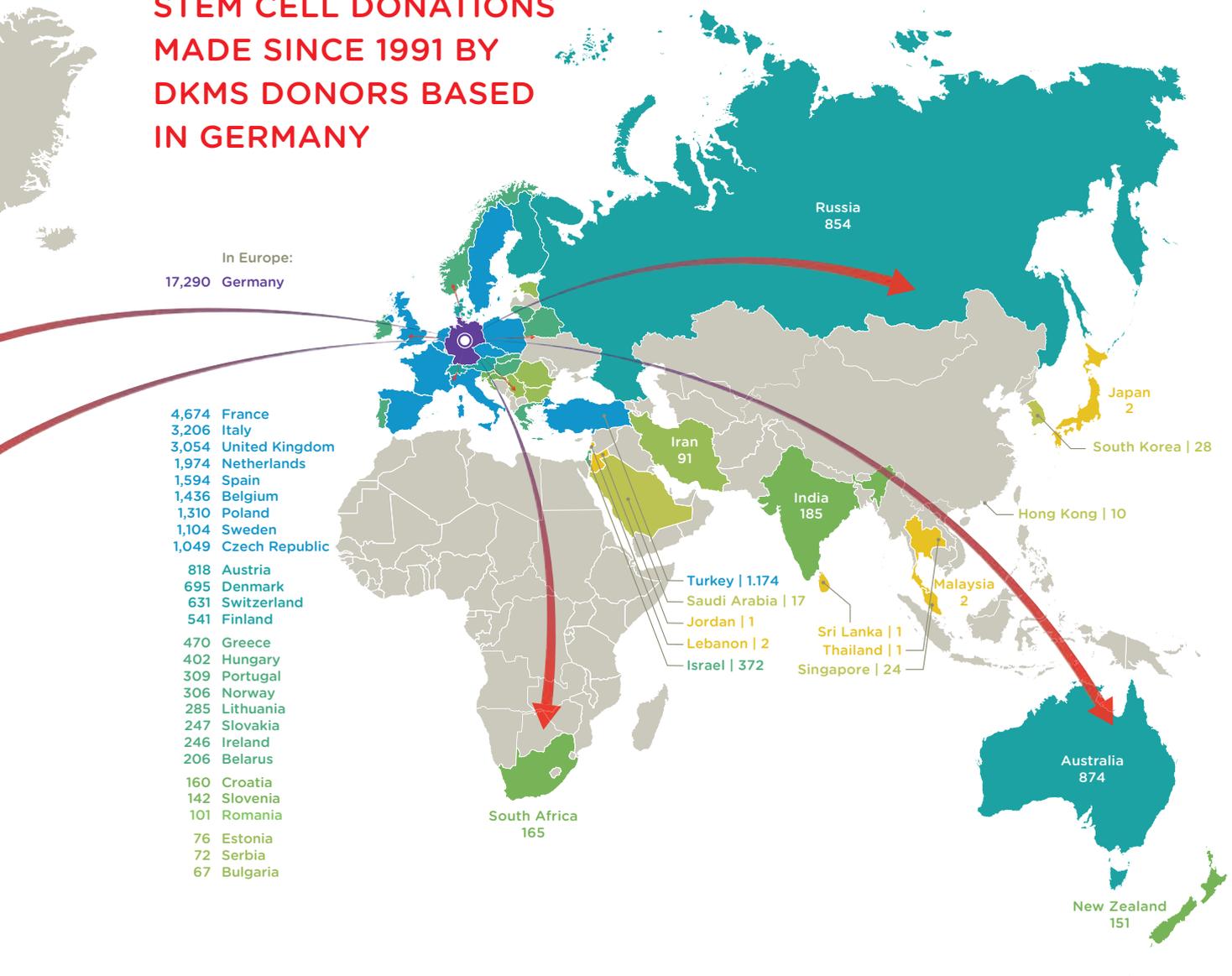
## DKMS LAUNCHES SUCCESSFULLY IN CHILE

A further milestone in the history of DKMS brings new hope to blood cancer patients across Latin America and beyond. Since April 11, 2018, people in Chile have been registering with DKMS as potential stem cell donors. By setting up an office in Santiago de Chile, we want to increase the genetic diversity in our database and help even more blood cancer patients around the world. The opening event of our new Chile office reached a particularly emotional climax: five-year-old Juan Patricio Carreño, from Chile, met his donor. The meeting was an impressive

symbol of international solidarity and 26-year-old Tatjana Tröger had travelled from Stuttgart especially for it.

In its first year of operation, DKMS Chile already delivered promising results. More than 16,300 potential donors signed up either online or in person at one of the 171 donor drives. In the second half of the year, a successful transplant using stem cells from a Chilean donor was carried out for the very first time.

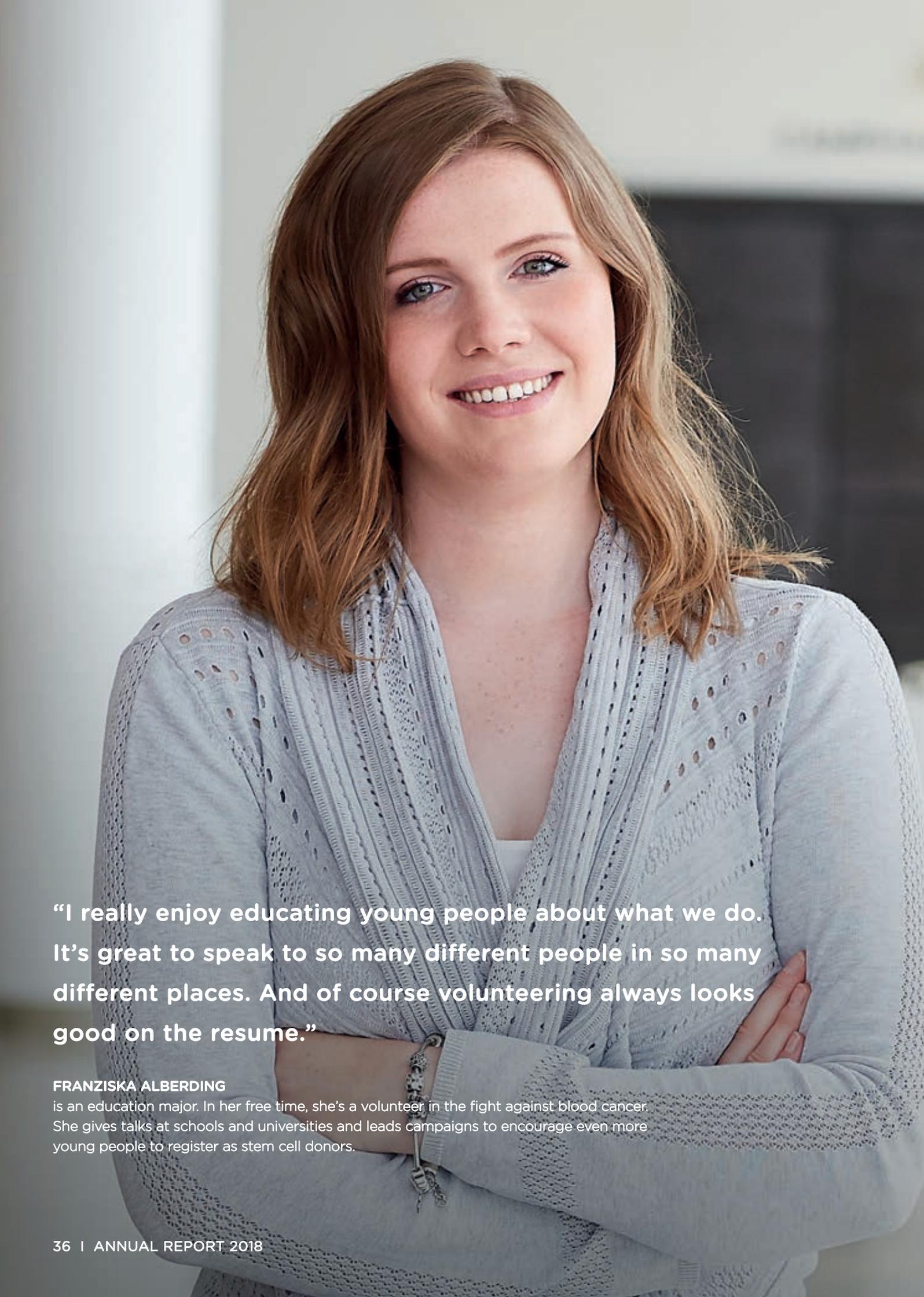
## TOTAL NUMBER OF STEM CELL DONATIONS MADE SINCE 1991 BY DKMS DONORS BASED IN GERMANY



## THALASSEMIA: HELP FOR CHILDREN IN INDIA

Since early 2018, DKMS has been supporting numerous hospitals in India. One of them is the People Tree Hospital in Bangalore, where children with thalassemia receive stem cells or bone marrow from a matching sibling or parent. Thalassemia is a severe genetic disorder of the red blood cells and can be fatal. In countries such as India, low-income families have no access to reliable medical therapies, so DKMS is working to help them. DKMS works closely with the international aid agency Cure2Children as well as the Sankalp India Foundation – Let’s Give Life a Better Chance. Cost-efficient, low-tech transplants

are carried out to the best possible quality in hospitals with only the most basic equipment. However, more help is urgently needed, as almost every hospital has a waiting list. In 2018, DKMS subsidized transplants for 100 patients with funding of €300,000. Between April and October 2018 alone, 60 young patients in India received transplants. A further seven in Pakistan and four more in Ghana also received life-saving stem cell transplants – therapies they would never have been able to access without financial support. DKMS also supports Thalassemia Camps in India by funding the HLA typing of severely ill children and their siblings.



**“I really enjoy educating young people about what we do. It’s great to speak to so many different people in so many different places. And of course volunteering always looks good on the resume.”**

**FRANZISKA ALBERDING**

is an education major. In her free time, she’s a volunteer in the fight against blood cancer. She gives talks at schools and universities and leads campaigns to encourage even more young people to register as stem cell donors.

# VOLUNTEERING CAN SAVE LIVES

**Without the unparalleled commitment of our many supporters, we would be unable to carry on winning more and more new people to join the fight against blood cancer. Our volunteers play a key role in our efforts, often working to convince younger people in particular.**

Franziska Alberding — or Franziska, as her friends call her — is an education major in her junior year at the University of Vechta. Aged 24, she has been a volunteer with DKMS since 2018. In her free time, she organizes campaigns at schools and universities, and gives talks to educate young people on donating stem cells and signing up with DKMS, potentially to save a life. DKMS introduced its volunteer program to encourage younger people to sign up at school and university campaigns.

Franziska's first contact with DKMS was when she was helping out at a campaign one time — an experience she thoroughly enjoyed. She then joined a workshop in Cologne with a group of other interested volunteers and learned how to organize campaigns. "I enjoyed it right from the start. I feel more and more confident with every event and learn so much every time," she explains. "This work really means a lot to me."

## **SHARING POSITIVE EXPERIENCES**

In January 2016, Franziska became a stem cell donor herself. "I found out about a campaign at a local high school on Facebook and went there to register. A few months later, I was told there was a patient I might be able to help. Making the donation was a fantastic feeling. It was a day I'll never forget."

Encouraged by her own experience as a donor, Franziska became a volunteer with DKMS and now motivates others to give patients around the world the hope of a second chance at life. In 2018, DKMS ran 511 school campaigns, attracting around 57,000 students to register. 74 of them have already made donations.

**EVERY LITTLE BIT HELPS**

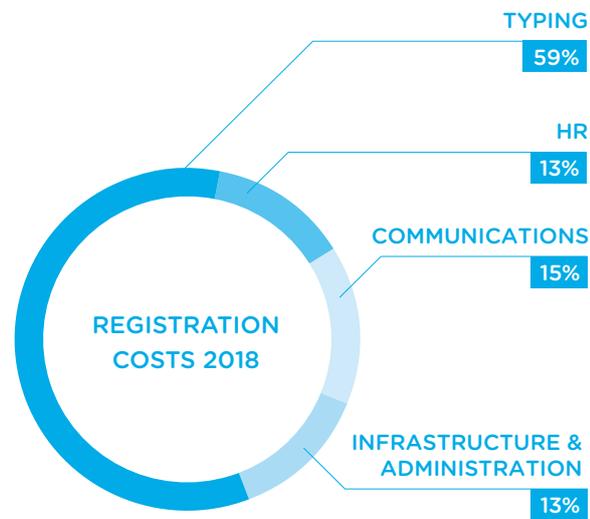
The work of volunteers like Franziska is both important and multifaceted, ranging from donor drives and talks to corporate campaigns and PR events. At DKMS, we are in a position to give so many people the hope of a second chance – and have our many thousands of volunteers to thank for it. We do all we can to support blood cancer patients in their fight against life-threatening illness and to improve their chances of recovery. Our supporters and stem cell and financial donors are helping us to succeed. We would like to thank each and every one of them for their trust. We are grateful for every ounce of moral as well as financial support.

There are many ways of supporting DKMS, such as organizing a donor drive, fundraising and motivating friends to sign up as stem cell donors. Every single initiative has an impact and helps us to improve the outlook for patients around the world. Many companies also raise money or cover the costs for their own in-house donor drives.

**FINANCIAL DONATIONS HELP US TO REGISTER NEW YOUNG DONORS**

In 2018, we generated revenues totaling EUR 18.5 million from donations, the proceeds from sales of donated items and allocations from court-ordered fines. We received 250,000 individual donations of money, the largest amounting to more than EUR 100,000. Every cent is used to help us fulfill our mission according to our statutes.

When we register a donor, we cannot pass on the costs to healthcare providers. Instead, we do the same as all other stem cell donor registries in Germany: we fund our registration costs ourselves from donations. Many donors pay for their own registration costs or support us with a financial donation when they register. That's something we by no means take for granted, because the young people we are targeting and so urgently need are often trainees or students at school or university and do not have the means to donate anything more than their stem cells.



In 2018, each new donor cost EUR 37 to register. Even though the cost continues to rise owing to improved typing quality, DKMS still asks for a donation of EUR 35 per registration.

**SPORTY COOPERATION**

In the 2018/2019 soccer season, the 1. FC Köln Foundation was a strong partner with DKMS. We were involved with them throughout the season, and their campaigns and extensive communications helped to raise awareness of DKMS among fans. A highlight of the season was DKMS game day, when the team's players wore the DKMS logo on their jerseys. Other sporting cooperations with national leagues and teams also received a great deal of publicity. The German Table Tennis league and its clubs across the country launched the claim 'Game. Set. Swab.

United against blood cancer!'. Meanwhile, in Düsseldorf, professional athletes of all sports, from soccer, ice hockey and table tennis to basketball, handball and football, joined forces under the slogan 'Shoulder to shoulder against blood cancer!' The Westphalian Shooting Club ran the motto which was called 'Sights set on fighting blood cancer', and the national-league tennis team Blau-Weiss Neuss Tennis Club positioned DKMS in the world of top-flight German tennis with the slogan 'Match Point against Blood Cancer'. Many other national-league teams also joined the campaign.

In 2017, we managed to reduce the cost of registering new donors significantly, from EUR 40 to EUR 35 per person. In 2018, however, the costs rose again, to EUR 37. The extra EUR 2 per registration, which we cover ourselves, arise from the inclusion of CMV status in sample typing (see pages 15–16). CMV, or cytomegalovirus, is widespread around the world and can cause major complications after a transplant. To prevent the life-threatening occurrence of an infection and increase the chances of transplant success, both patient and donor ideally need to have the same CMV status.

**EVERY CENT HELPS PEOPLE WITH BLOOD CANCER**

DKMS is a recognized non-profit organization. Unlike commercial enterprises, our revenues are used

entirely to support social or scientific causes. We receive financial donations primarily from private individuals and companies as well as through pro-rata amounts from healthcare providers. The money is mainly used to fund the registration of new donors, but we also use it to keep addresses and contact details of existing donors up to date so we can be sure to reach them if we need to — because in the search for a matching donor, every day counts. In addition, we support blood cancer research and work continuously to improve the typing quality of our registered donors so patients will have a better chance of finding a match. Last but not least, we use the money to finance new international locations so we can help even more people across the globe.

**GOLD FOR LIFE**

During the Winter Olympics 2018 in Pyeongchang, South Korea, DKMS was the charity partner of the German House. It was our second Olympic partnership, after Rio 2016. The nationwide campaign ‘Gold For Life – Team DKMS Needs Support’ raised public awareness of blood cancer and encouraged people to join the star athletes and Olympians in registering as potential DKMS stem cell donors. The DKMS booth welcomed not only numerous Olympic competitors but also Germany’s President Frank-Walter Steinmeier, and Bodo Ramelow, Governor of the state of Thuringia.

German President Frank-Walter Steinmeier and his wife, Elke Büdenbender, at the DKMS stand



Wacken fan, former blood cancer patient, and DKMS supporter Nils Haarhues

**WACKEN AND DKMS: THAT ROCKS!**

In 2018, DKMS joined the **Wacken Open Air Festival** for the fifth time and partnered with the **blood donor center of Itzehoe Hospital** to carry out a donor drive on the festival grounds. The festival organizers have been supporting DKMS since 2014, following the death of Melissa, the daughter of a Wacken production manager, who needed a stem cell donation. In addition, 70 women in the town of Wacken have been actively running the ‘**Wacken helps**’ initiative, with a bake sale on the grounds over the festival weekend. The proceeds, which have totaled EUR 40,000 so far, were donated to DKMS. Since 2017 festival-goers have also been able to join our registry at the DKMS stand. The result so far has been fantastic, with 7,300 metalheads joining us. 29 of them have already donated stem cells.

# SOCIAL MEDIA 2018: 180,875 COMMENTS AND POSTS

At DKMS, social media is an important and much-used channel of communication. In 2018 alone, we answered a question on social media every three minutes. We have more than 1.1 million followers on Facebook, over 100,000 on Instagram, and many more on Twitter, YouTube, and so on.

## WHAT IS THE PROBABILITY OF BEING INVITED TO MAKE A STEM CELL DONATION?

Statistically, about one percent of the people in our database are called to make a donation. The chances of being contacted within a year of registering is about 0.2 percent, but this figure can vary, depending on your age and sex. Young men are most likely to be contacted about making a donation.

## CAN I DECIDE FOR MYSELF HOW MY STEM CELLS SHOULD BE REMOVED?

The way the cells are removed depends on the illness of the patient concerned. So the patient's doctor will probably decide on the best way of making the donation. With the doctor's agreement, it may be possible to take the donor's wishes into account.

## CAN I FIND OUT WHO RECEIVED MY STEM CELLS?

In Germany, the Standards for Unrelated Blood Stem Cell Donations stipulate that the identities of both donor and recipient must be protected for a mandatory period of two years. They can find out each other's sex, age and country of origin after a transplant, but their anonymity must be guaranteed. After the two-year anonymity period has expired, a meeting can be arranged, provided both sides agree. Regulations differ from country to country.

## THE DOG HAS EATEN MY SWAB SET. CAN YOU SEND ME ANOTHER ONE?

Interesting! Our swabs not only save lives but clearly go down well with our furry friends as well ;-). We will be happy to send you another one. Just give us a call and the team will put one in the mail for you. Important: Please don't order another set via our website, as our system would recognize that you already have one and prevent it from being sent.

## WHEN WILL I GET MY DONOR CARD?

Before we can send you your card, our lab has to determine your tissue characteristics. That is quite a long process and takes four to six weeks. Once we finally have a full set of data from the lab in our system, we can issue your donor card. To save money, we print and send our donor cards once a month.

## WHAT ARE THE RISKS OF DONATING STEM CELLS?

The hospital taking the stem cell donation is responsible for informing donors about any potential risks. They also carry out a preliminary examination to ascertain whether the donor is suitable: they assess you for possible previous illnesses (anamnesis), check your physical fitness and analyze the lab results. When all of these examinations have been successfully completed, you can donate your stem cells. As yet, there is no evidence of long-term side effects or delayed effects of making a stem cell donation.

## CAN I DONATE STEM CELLS EVEN THOUGH I'M TATTOOED AND SMOKE CANNABIS FROM TIME TO TIME?

Tattoos are not a major issue, as long as they were applied in sterile conditions, but if you are shortlisted to make a donation, we will check you over nonetheless. Occasional marijuana/cannabis use also has no effect – although the emphasis here is on “occasional”. If you are a regular user of drugs of any kind, it could impact your reliability – and if you don't want to endanger a patient's life, reliability is crucial. The important point for us is to know what substances you have used and how long you have been using them. If you are a long-term user, it may be better not to register with us, but if you can still quit at any time, we would love you to sign up.

As of December 31, 2018



5,869,356

people in Germany were registered with DKMS.

DKMS employs



349

people in Germany.



5,460

DKMS donors in Germany donated stem cells or bone marrow in 2018.

# FINANCIAL RESULTS 2018

**DKMS refuses to give up hope and let pessimism take hold in the fight against blood cancer! That is why every Euro is invested where it will be most effective at creating second chances at life.**

The non-profit DKMS gGmbH is primarily devoted to recruiting informed volunteers who are willing to donate stem cells for transplantation to patients with leukemia or other blood disorders. Their cells are removed either via peripheral blood stem cell collection (PBSC) or via bone marrow harvesting (BMH). To support this goal, DKMS actively promotes the development and maintenance of systems and databases that simplify and accelerate the search for suitable donors, both in Germany and, increasingly, abroad. It also plays a part in selecting donors for blood cancer patients, and securing and preparing stem cells for transplantation.

DKMS's success in recruiting potential donors depends, among other things, on the awareness and popularity of the organization in general. This is automatically linked to the satisfaction of donors on the register.

DKMS is one of almost 30 organizations in Germany dedicated to recruiting and connecting volunteer stem cell donors. With 5,869,356 potential donors (as of December 31, 2018), it is by far the largest donor center.

Thanks to a marked increase in donor recruitment in 2018, DKMS was able to add to its database a particularly large number of donors who are high-resolution typed to the latest medical and lab standards. High-quality data is just one of the reasons DKMS donors are often the preferred option in searches - because the comprehensive human leukocyte antigen (HLA) typing that is undertaken when they join the global search systems saves further time-consuming typing later on. Unlike many other donor registers, which only partially type donors for the characteristics needed to establish a match, DKMS's detailed typing crucially speeds up the work of transplant centers and search coordinators and gets treatment to patients faster. However, an increasing number of national and international databases now contain high-quality typing results.

## FACTS & FIGURES

At the end of 2018, a total of 5,869,356 donors were registered in Germany (compared with 5,391,393 the previous year), marking an increase of 8.9 percent. With 641,725 new registrations, the previous year's figure of 541,370 was easily exceeded, more than fulfilling the Board's expectations. Moreover, the number of new potential stem cell donors again noticeably exceeded the number of people who left the register for reasons of age, ill health, etc.

Since mid-2016, DKMS has been expanding its business activities beyond the function of a donor center to become active as a register. This means that it now uses specially developed software to link transplant hospitals with donors from other databases as well.

The register function is part of DKMS's internationalization strategy and fits in seamlessly with its existing activities. For example, for several years DKMS has been promoting and financing the establishment of legally independent donor centers in Europe and beyond that cooperate closely with the organization in Germany. This forms part of the endeavor to provide patients with blood cancer or other disorders of the hematopoietic system with the best possible donor match for a stem cell transplant. The register function is available to donor centers in countries that do not yet have established public register organizations. By way of example, the register department is currently in the process of ensuring that the donors of two Indian stem cell donor centers are available to transplant hospitals worldwide.

Furthermore, DKMS is dedicated to researching the effectiveness of hematopoietic stem cell transplants with non-related donors. It is also raising funds to pass on to other organizations working to promote public health care or science and research.

The attractiveness of DKMS-registered donors is essentially based on two factors: the high quality of typing results in the database and the fast availability of donors when they may be able to help. At DKMS, typing results comprise not only the HLA characteristics, which must match between donor and patient, but also other parameters such as blood group (ABO, RhD), CCR5, and KIRs, as well as CMV serostatus (optional). These parameters are also determined directly with every new donor that is added, as they play a key role in matching and help to speed up the selection process.

DKMS's efforts to ensure that fundraising provides ongoing support for its mission were very positive over the last business year. As registration costs have decreased in recent years, revenues in registration-related channels (such as public and company-specific registration drives and mail donors) have fallen. However, thanks to income channels, fundraising has been able to offset the decline, contributing substantially to the overall growth of revenues.

2018 presented DKMS with a number of challenges, such as staff cuts, restructuring in the business unit, reduced registration costs in fall 2017, and the implementation of new CRM software (Salesforce). Nonetheless, fundraising revenues increased 15.2 percent year-on-year.

# THE DKMS GGMBH STATUTES

The DKMS statutes are the heart of the organization – they determine the actions of every one of our employees in the fight against blood cancer.

## OUR STATUTES

The business activities of the organization include the altruistic support of people who are dependent on the assistance of others due to their physical condition, the promotion of public health care and the promotion of science and research, in particular:

**Section 1:** The recruitment of informed volunteers who are prepared to donate bone marrow or stem cells for the purpose of transplantation;

**Section 2:** The development and maintenance of systems that simplify and accelerate the search for donors in this group of volunteers as well as in international groups of donors with the goal of finding compatible donors for stem cell transplants;

**Section 3:** The study of the effectiveness of hematopoietic stem cell transplants from unrelated donors, test methods of histocompatibility as well as donor motivation;

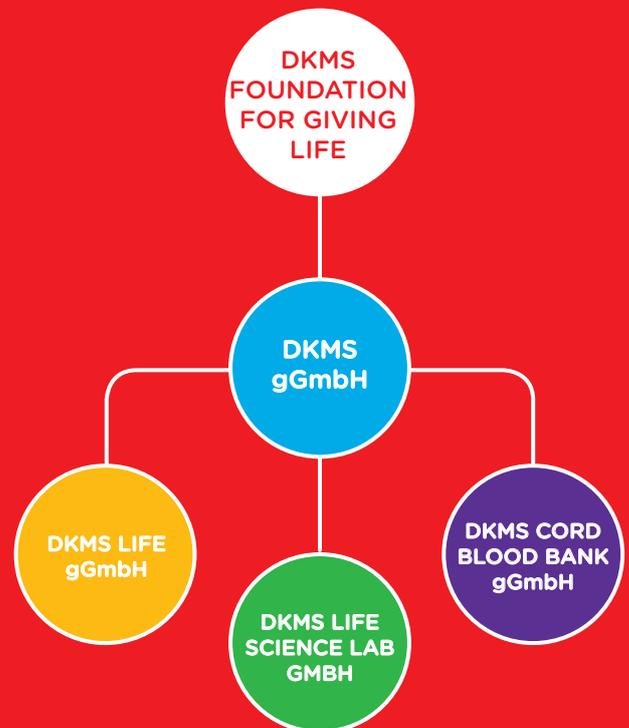
**Section 4:** Personal support for blood cancer patients, with the goal of providing personalized assistance to overcome any problems they encounter during their hospital stay;

**Section 5:** Cooperation in the selection of donors for blood cancer patients as well as the procurement and preparation of the transplant;

**Section 6:** The procurement of resources to pass on to other organizations whose purpose is the altruistic support of persons who are dependent on the assistance of others due to their physical condition, the promotion of public health care or the promotion of science and research.

In this annual report, we provide an insight into the use of funds for the purposes specified in the individual statutes of our charter.

## STRUCTURE OF DKMS



## DKMS ORGANIZATIONS AROUND THE WORLD



# BALANCE SHEET

## BALANCE SHEET AS OF DECEMBER 31, 2018

<b>ASSETS</b>	<b>2018 in T€</b>	<b>2017 in T€</b>
<b>A. Fixed assets</b>		
I. Intangible assets	12.875	13.181
II. Tangible assets	3.685	3.602
III. Financial assets	61.756	62.812
<b>Total</b>	<b>78.316</b>	<b>79.595</b>
<b>B. Current assets</b>		
I. Inventories	917	1.304
II. Receivables and other assets	10.953	11.513
III. Cash on hand and bank balances	48.966	39.230
<b>Total</b>	<b>60.836</b>	<b>52.047</b>
<b>C. Prepaid expenses</b>	1.628	1.273
<b>TOTAL ASSETS</b>	<b>140.780</b>	<b>132.915</b>
<b>EQUITY AND LIABILITIES</b>	<b>2018 in T€</b>	<b>2017 in T€</b>
<b>A. Equity</b>		
I. Subscribed capital	1.000	1.000
II. Revenue reserves	124.246	118.131
III. Net retained profits	1.130	1.130
<b>Total</b>	<b>126.376</b>	<b>120.261</b>
<b>B. Provisions</b>	<b>6.660</b>	<b>5.751</b>
<b>C. Liabilities</b>	<b>7.743</b>	<b>6.892</b>
<b>D. Deferred income</b>	<b>1</b>	<b>11</b>
<b>TOTAL LIABILITIES</b>	<b>140.780</b>	<b>132.915</b>

Intangible assets mainly comprise software, the largest part of which was capitalized in 2018. Because go-live was not until November 2018, there was little amortization to deduct.

Tangible assets received no major investment in 2018.

The change in financial assets amounted to EUR 1,056 thousand and is largely attributable to the repayment of a loan granted to the DKMS Life Science Lab GmbH. EUR 573 thousand of that amount was a planned repayment; EUR 500 thousand was a special repayment. A further capital increase of EUR 17 thousand came from the Indian joint venture.

In the business year 2018, EUR 478 thousand was spent on raw, auxiliary and operating materials (compared with EUR 595 thousand the previous year). The decline is mainly due to the increase in new registrations during the business year. Unfinished services mainly related to bone marrow/stem cell collection cases in progress. These have been recorded automatically since 2017 and amounted to EUR 429 thousand in 2018 (compared with EUR 503 thousand the previous year).

Receivables and other assets amounted to EUR 10,953 thousand at the end of the business year, EUR 560 thousand less than one year earlier. This development was largely due to an increase in receivables by the reporting date that was evenly distributed across the domestic and foreign receivables as well as receivables from affiliated companies.

The EUR 9,737 thousand increase in cash on hand and bank balances to EUR 48,966 thousand is essentially attributable to higher revenues from donations.

Equity rose by EUR 6,115 thousand year-on-year, reaching EUR 126,376 thousand at year-end. This reflects the positive business development throughout the year. Reserves for purposes set out in the company statutes increased by EUR 6,115 thousand, from EUR 118,131 thousand to EUR 124,246 thousand at the end of the business year. The development, composition and intended use of reserves is detailed in the attached document.

Other provisions amounting to EUR 6,660 thousand were mainly used for bonus payments to employees (EUR 1,894 thousand), outstanding invoices (EUR 1,651 thousand) and outstanding donor stem cell collection costs (EUR 1,263 thousand). The remaining provisions were used largely for staff provisions (EUR 1,690 thousand) and financial statement costs.

Liabilities rose during the course of the business year to EUR 851 thousand, owing mainly to the increase in liabilities from unused donations for specific purposes. On the reporting date, these totaled EUR 456 thousand.

In the business year 2018, EUR 25,857 thousand was invested in expanding the donor database through new registrations (compared with EUR 19,489 thousand the previous year). EUR 8,333 thousand of that amount was not financed through donations (compared with EUR 4,588 thousand the previous year). As in the year before, this amount was fully covered by DKMS-generated funds. Reserves for scientific research projects to fight blood cancer amounted to EUR 11,352 thousand, while those for quality improvement projects stood at EUR 4,493 thousand. EUR 2,876 thousand was used to fund scientific projects last year and EUR 1,815 thousand was spent on quality improvement projects. Grants to DKMS organizations outside Germany and support for sponsorship projects amounted to EUR 8,202 thousand compared with EUR 8,092 thousand the previous year.

# INCOME STATEMENT

	2018 in T€	2017 in T€
<b>1. Income</b>	<b>118.971</b>	<b>113.975</b>
1.a Income from reimbursements of expenses/other sales proceeds	96.197	95.347
1.b Changes in inventories	-74	353
1.c Own work capitalized	692	664
1.d Other operation income	22.156	17.611
<b>2. Expenditure</b>	<b>-111.726</b>	<b>-101.060</b>
2.a Cost of materials	-50.262	-44.540
2.b Personnel expenditure	-25.679	-23.637
2.c Depreciation and amortization	-3.705	-1.917
2.d Other operating expenditure	-32.431	-31.361
2.e Financial result	369	418
2.f Taxes	-18	-23
<b>3. Net income/loss for the year</b>	<b>7.245</b>	<b>12.915</b>
<b>4. Withdrawals from revenue reserves</b>	<b>48.725</b>	<b>43.507</b>
<b>5. Appropriation to revenue reserves</b>	<b>-54.840</b>	<b>-55.292</b>
<b>6. Net retained profits</b>	<b>1.130</b>	<b>1.130</b>

As a non-profit organization, DKMS has the minimum goal of covering its own necessary costs through business operations. It refines itself mainly through reimbursements from public health care systems in Germany and abroad and financial donations from private individuals and companies.

DKMS's income of EUR 96,197 thousand again provided the foundation for a very positive performance. The slight rise in income was the result of the sustained development of stem cell donations realized throughout the business year. Other business revenues amounted to EUR 22,156 thousand, marking a clear increase of EUR 4,545 thousand on the previous year. The rise is mainly attributable to increased donations, revenues from the dissolution of provisions for contingent losses, and a clear rise in foreign currency gains.

The cost of materials increased by EUR 5,722 thousand on the previous year, primarily because of a 15.6% rise in the number of typing cases.

Personnel costs rose again, this time from EUR 23,637 thousand to EUR 25,679 thousand. The increase reflects special effects relating to salary structure composition and increased management costs owing to a growing number of managing directors.

Personnel costs amounting to EUR 692 thousand were capitalized for the in-house development of IT systems. By the end of 2018, the number of employees had fallen from 364 to 344.

Other operating expenditure totaled EUR 32,431 thousand, slightly more than in the previous year (EUR 31,361 thousand). The significant rise in expenditure on public relations work — which had dropped sharply the year before — contrasts with a reduction in expenditure arising from exchange losses, project funding and advisory expenses. Exchange losses totaled EUR 153 thousand in 2018, compared with EUR 2,624 thousand the previous year.

# RISK MANAGEMENT

**Risk management serves the systematic analysis, evaluation, documentation, communication, controlling, and monitoring of risk-bearing activities at DKMS and is an integral part of the business, planning, and control processes.**

**The individual risk management measures are:**

**Supervision of corporate bodies**

- Rules of procedure, including a detailed description of the tasks and authority of the bodies
- Half-yearly meetings with the management board of the parent organization

**Executive management**

- Annual target agreements between management, division managers and employees; continuous monitoring of target achievement
- Approx. biweekly management meetings; regular executive personnel meetings for internal coordination, optimization and risk assessment

**Cooperation with external partners**

- Written contracts to safeguard agreements
- Tax assessment and evaluation of potential risks to non-profit status

**Asset investment**

- Guidelines for asset investment specifying the composition of the investment portfolio and limits on portfolio structure (e.g. equity share)
- Regular reporting, ad-hoc measures if risk structures change

**Financial planning**

- Annual budgeting including staffing and personnel expenditure for three financial years
- Half-yearly reviews and necessary budget adjustments according to guidance
- Monthly reporting on target/actual performance, including analysis of key performance indicators

**Cost management**

- Expenses and cost guidelines with regulations and limits on travel expenses and hospitality/gifts
- Monitoring by accounting and tax departments to ensure appropriate use of funds
- Established limits on signatory authority for invoices for each employee group
- Centralized purchasing

**Donation management**

- Cost-benefit analyses of measures to acquire donations (e.g. mail-shots)
- Examination of legality of receipts issued for donations

**Annual accounts**

- Annual audits by an independent external auditor as annual financial statement is prepared

**Data protection**

- Technical and organizational measures to ensure compliance with requirements of the European Union's General Data Protection Regulation

# OUR CONTRIBUTORS



**NEVENA BEBIC BIALOWAS** has been with DKMS Corporate Communications since 2016. She holds a degree in German Studies and has experience in radio and film.



**LISA ERNSTING** has been co-developing DKMS's new Public Affairs section since 2018. Based in Berlin, she is responsible for relationship management with supporters from politics and civil society.



**RICARDA HENKEL** has been with DKMS since 2007. She creates DKMS content in two of her favorite media: photo and film.



**SIMONE HENRICH** has been with DKMS Communications since 2007 and is particularly devoted to the annual World Blood Cancer Day.



**CHRISTIAN KHALIL** has worked for TV production companies and headed up the online editorial team of an association. He joined the team at DKMS Corporate Communications in 2016.



**EMRAH KILIC** has been with DKMS since 2013. As a public relations manager, he reports mainly on issues relating to donor recruitment and fundraising.



**SONJA KROHN** was previously an editor with various daily newspapers and has been working for DKMS since 2007. She is head of Public Relations with DKMS Corporate Communications.



**MARC KRÜSEL** has been with DKMS since 2007. As editor-in-chief, he manages the newsroom. Before that, he worked in public broadcasting for many years.



**KARSTEN MEIER** is public affairs manager responsible for collaborations. He coordinates support of DKMS through celebrities, influencers, sports teams and associations.



**JULIA RUNGE** joined DKMS in 2008 and brings to the job a wealth of TV experience. She is responsible for external communications, focusing in particular on the stories of donors and patients.

## **PUBLICATION DETAILS**

### **DKMS gGmbH Management**

Dr. Elke Neujahr (CEO)  
Dr. Dr. Alexander Schmidt  
Sirko Geist

### **Title**

DKMS Annual Report 2018

### **Published by**

DKMS  
gemeinnützige GmbH  
Kressbach 1  
D-72072 Tübingen  
Germany

T 07071 943-0  
F 07071 943-1499  
post@dkms.de

dkms.de

### **Editorial Office**

DKMS gGmbH  
Corporate Communications

### **Design and layout**

MALZKORN Kommunikation & Gestaltung GmbH

### **Consultancy, copy-editing, proof-reading**

Goerke Public Relations GmbH

### **Photo credits**

Peter Godry (front cover, pages 4, 6, 10, 14, 18, 22, 24, 26, 30, 34)  
University Hospital Frankfurt (page 17)  
DKMS (pages 21, 28, 29, 37, 50)  
Florian Büh (page 28, 29)  
Bert Spangemacher (page 50)

We would like to express our special thanks to the Chamber of Industry and Commerce (IHK) in Cologne for allowing us to use their offices for photoshoots.

**DKMS gGmbH  
gemeinnützige GmbH  
Kressbach 1  
72072 Tübingen**

**T 07071 943-0  
F 07071 943-1499  
post@dkms.de**

**dkms.de**