



**2020**  
**ANNUAL REPORT**



**COVER PHOTO:** Andreas Quirini was born in Cologne and has been flying with Lufthansa for more than 30 years. For the last 19, he has traveled the world as a pilot with Lufthansa Cargo. During the pandemic, he and his team have been helping with the handover of boxes of stem cells. As soon as the plane lands, these special consignments are passed on to specialist couriers waiting at the airport, ready for the onward journey to the transplant center.

## IMPRINT

### DKMS gGmbH Board of Directors

Dr. Elke Neujahr (Chair), Dr. Dr. Alexander Schmidt, Sirko Geist

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\* All figures as of 31.12.2020

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## *Dear friends and supporters of DKMS.*

2020 was an extraordinary year and presented us with the greatest challenge so far in the history of our organization.

But if there's one thing that fills me with joy, it's the fact that despite all the difficulties, we succeeded in our fight against blood cancer. The number of second chances at life we helped to provide for people proves it: last year, we collected stem cells from 5,618 donors in Germany - more than ever before. 75 percent of the donations were for patients abroad.

This amazing achievement would never have been possible without the overwhelming commitment of our supporters. So I would like to say a heartfelt 'thank-you' to our donors for traveling to their collection clinics despite the difficult conditions to donate their precious stem cells to a patient in need.

Our donors are our greatest asset, and it goes without saying that we will continue to do all we can to care for and protect them as best we can throughout the donation process.

Another area where we can continue relying on the support of countless helpers is donor recruitment. To help stem the spread of the coronavirus, we quickly switched from physical to online donor drives. Our new idea proved very popular and represents an important step into the future. With over ten million potential lifesavers now on the books across all our DKMS locations, we achieved a significant milestone in 2020. Our "Team of 10 Million" is now set to grow much further to support blood cancer patients.

Over the last year, we also coined a new motto: Blood cancer doesn't stop for coronavirus. Now

more than ever, our tremendous commitment matters because countless people with life-threatening conditions still need our help, even in the pandemic. And we'll stop at nothing to make sure they get it. From closed borders and quarantine regulations to transport restrictions and all the other obstacles, in 2020 nothing was able to prevent us from getting every one of our stem cell donations to transplant clinics around the world. For example, we sent 850 shipments of stem cells as cargo in the cockpit to support patients worldwide in desperate need. We learned a lot in 2020. Off the back of the public health crisis, we optimized our processes to make them even more efficient and effective. And when it comes to digitalization, we are in a better position than ever before. Teamwork across international borders has become an even more natural part of our day-to-day work – because, after all, the ramifications of the actions of every individual can be felt far beyond the borders of their own country. We intend to continue in the same vein, bringing hope and optimism to people around the world. That's what motivates us every day.

The passion and commitment everyone brings to our organization has been palpable since day one and never fails to impress me. For me and our more than 1,000 highly motivated and skilled employees, they set the direction. Our recipe for success includes a list of essential ingredients: commitment, courage, flexibility, professionalism and, most of all, our secret ingredient: our heart and soul. Add to that our sheer persistence and constant desire to find solutions for our patients, and you soon realize every single one of us is in this with our hearts and minds.

In our 30-year history, our network with eleven subsidiaries has grown into a multifaceted, international organization that's doing all it can to delete blood cancer and other malignant blood disorders. We do so with every tool at our disposal, from donor registration and procurement through to the new therapeutic approaches being developed by our own research team and efforts to foster upcoming generations of scientists. Together, we are developing our activities clearly and consistently to offer the best possible support for patients worldwide. We want to collaborate with other countries to improve access to transplantation for patients in regions where they are difficult or impossible to obtain. And we will continue our work for as long as it takes for a world without blood cancer or blood disorders to become a reality.

This annual report provides an overview of our life-saving work. We hope you enjoy reading it.

Stay well!  
Best



Dr. Elke Neujahr  
Chair of the Board of Directors,  
Global CEO DKMS Group

# CRISIS DRIVES INNOVATION

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As a non-profit organization, in 2020 we found ourselves facing a host of new challenges. In a historically unique situation, we adhered even more closely to the credo that has been our mission since we began:

Never give up when you can help give someone a second chance at life. Not even when the world pauses due to a pandemic – because blood cancer does not stop.

Borders were closed, stem cell flights canceled, and public events like donor drives banned. In addition, we had to adapt the workflows of nearly 1,000 employees at our seven DKMS entities worldwide to keep everything running smoothly even though they were working from home... During the pandemic, we found ourselves revisiting the processes and workflows we had perfected over the years and integrating new and creative solutions so we could continue our daily work: giving as many blood cancer patients as possible a second chance at life. Our efforts proved successful. Very successful, in fact. We sent a grand total of 5,618 stem cell donations from donors in Germany to patients around the world. That's more than ever before.

We also had to think on our feet and find new solutions for donor recruitment. At DKMS, we have a special commitment to the health of those around us, so when Germany officially went into lockdown for the first time, in March 2020, all our physical donor drives had to be temporarily called off for public health reasons. So, without much ado, we simply took them online, developing a digital event format in no time. Our Virtual Donor Drives for patients in need and their initiative groups now continue to encourage as many people as possible to register as potential stem cell donors. They work by offering users a registration link with background information, which they can share as widely as possible in their own networks and via the media. The result makes us feel validated





**HANDOVER AT THE AIRPORT**  
A pilot receives a box of valuable stem cells.

in our approach: our new online format generated approximately 60,000 new registrations. In 2020 as a whole, DKMS registered a total of 415,973 new donors.

Going online turned out to be an important factor in our ability to continue working efficiently in a range of areas. Even before the pandemic, our employees had already been able to work from home, so it didn't take long for us to provide them with all the equipment they needed to work remotely for longer periods as well, and across the various locations. Suddenly, with all the new communications tools and technologies, we often felt closer than ever across our international locations, despite the physical distance between us. Our donors also set a shining

example, selflessly remaining on hand to support their "genetic twins" throughout the pandemic. In 2020, DKMS managed to continue procuring more than 15 lifesaving stem cell donations a day in Germany for transplant clinics across the globe. From donors and employees to partners and authorities, thanks to everyone involved, the chain of operations continued to run smoothly, allowing stem cell donations to be successfully procured even in the midst of a major public health crisis. "The coronavirus pandemic has fundamentally changed the way we work



at DKMS. Despite the enormous challenges, we seized the opportunities and made many positive changes. We're now even more digital and flexible than before," says Dr. Elke Neujahr, Chair of the DKMS Board of Directors.

**CREATIVE SOLUTIONS CAN SAVE LIVES**

As the impact of the coronavirus on everyday life grew in March 2020, our focus shifted more than ever to protecting the health of our donors and safely transporting their lifesaving stem cell donations to transplant clinics around the world. About 75 percent of our stem cell donations are for patients outside Germany, so when the borders suddenly closed, it was potentially life-threatening for many of them around the world. "We didn't want to risk our patients having to go without the transplants they so urgently needed," says Gabi Rall, Director of Medical Business Development at DKMS.

From that point on, our medical teams were in operation around the clock, supporting patients and getting their stem cell donations to them safely despite the ever more difficult conditions. We quickly contacted authorities, donor registries, cell collection clinics and transplant centers at home and abroad as well as international courier services, transport companies and airlines to ensure all the donations made in Germany would safely reach their recipients around the world.

The effects of our tireless background work, support at political level and our well-connected international partners could soon be felt. In the USA, for example, the National Marrow Donor Program (NMDP) was able to obtain a general exemption from travel bans signed by the director of the US Center for Disease Control and Prevention. This meant European couriers would still be able to take stem cells into the USA despite the travel ban. We also came up with a solution for couriers at European level by getting together with the World Marrow Donor Association (WMDA) and the European Commission to obtain an exemption.

To make sure all went well at German borders, we contacted the federal police, who promised their support. Every day, we worked flat out to come up with what were often very special, creative transport solutions for various countries – and we succeeded.

One example is a delivery to Lithuania, in April 2020. Faced with an emergency, the DKMS workup team came up with a masterstroke: first of all, a courier service took the stem cell products to the German-Polish border. There a Polish logistics provider took over and drove them right across the country by truck. At the Polish-Lithuanian border they were handed over to a courier, who finally delivered

them safely to the patient's clinic. "It really moves me to know we have so many people supporting us and that everything went so well," says Dr. Elke Neujahr. "Everyone worked hand in glove, no matter what the obstacles. The solidarity was – and still is – quite overwhelming."

Initially, it was "only" border closures that caused problems in transporting stem cells. But soon another challenge was added to the mix: passenger air travel was becoming more and more restricted. In addition, couriers were not always able to work, as they often had to quarantine after every visit to a high-risk area. Before passenger air travel ceased almost entirely, yet another solution was soon found. The recipe for success was Cargo in the Cockpit, which allowed stem cell preparations to be delivered to patients without onboard couriers. (See the info box on the left.)



**HELP BY CARGO**



In order to continue transporting stem cells, DKMS joined forces with time:matters, a specialist provider of global, time-critical transport services, and with the Ontime courier service. Together, we developed the Cargo in the Cockpit transport solution, in which our non-profit cooperates with freight airlines to get our valuable consignments flown either in cockpits or stowed safely in special containers right behind them. The pilots are always made aware of their special freight. Routes between the USA, South Africa, Europe, and South America, for example, were covered by Lufthansa Cargo and LATAM Cargo. In 2020, this approach allowed us to deliver a second chance at life to around 850 patients.

Since the pandemic, personal care for our donors has become even more important.



#### ADAPTING WORKFLOWS FOR MORE SECURITY

As well as delivering stem cells safely to their recipients, the health and wellbeing of our donors was very much in the focus in 2020. With every one of the 15 stem cell collections carried out every day in Germany alone, we discussed the details with the donor, with the pandemic situation in mind, and made all the necessary arrangements to ensure that they were as fully protected as possible from a potential infection. One of the issues we talked about was what mode of transport they would use to get to the donor clinic, and on some occasions, we provided them with rental cars so they would not have to use public transport. Another was organizing accommodation, and donors were granted special permission to travel and stay overnight in hotels that were closed to tourists. They were also issued with permits so they could get to the clinic despite the curfews that were in place. For security purposes, COVID-19 questionnaires were handed out to them to keep track of any safety-relevant information and pursue it if necessary. To minimize all the possible risks, we asked our donors to come unaccompanied. We remain indebted to them for accepting these and other additional measures in the clinics and showing such great understanding for the situation.

Good to know: Even when there's not a pandemic, we offer personal support and advice for our donors throughout the donation process and always do our utmost to ensure that, capacity permitting,

they can make their donation as close to home as possible. We also give every donor an emergency number, where they can reach us round the clock. This tried-and-tested method also proved helpful in the crisis. "In 2020 a total of 5,618 people made stem cell donations - more than ever before," reports Sandra Bochart, head of Workup. "The fact that we managed to achieve a record number of second chances at life in such a challenging year is of course particularly gratifying."





## “THE SUPPORT AND FLEXIBILITY WERE AMAZING”

**Interview: Gabi Rall, Director Medical Business Development, speaks about how the pandemic affected stem cell transports.**

### **2020 was a dramatic year. After almost 30 years, everything changed at DKMS...**

DKMS has experienced a number of extreme situations. 9/11, for example, and the volcano eruption in Iceland in 2010 had just as huge an impact on the way we transport stem cells. We didn't think things could get any worse – but then came the coronavirus crisis, our greatest challenge to date by far. At the beginning especially, there were new problems cropping up every day. Our medical teams at all our locations were working around the clock to make sure the stem cell donations reached their patients.

### **And they did so with huge success, even at the start of this crisis.**

Thanks to the tremendous commitment of everybody involved, we were able to provide 638 second chances at life in March 2020 alone – despite all the challenges around the world.

### **Obstacles notwithstanding, what positive experiences were there?**

The support and flexibility of the courier services DKMS works with were amazing. With every new challenge our partners – time:matters and Ontime – came up with an answer in record time. But I was also amazed at everybody's creativity as they tackled the challenges – and succeeded. When the borders to Poland closed, our Polish colleagues helped to establish a corridor between Frankfurt/Oder, on the German side of the border, and Słubice, on the Polish side. That way, the couriers could hand over the stem cell products to the neighboring country.



Gabi Rall is always finding new solutions to help patients around the world.

### **Were there any particularly scary moments?**

Yes. Interestingly, for me it was not so much the beginning of the pandemic that worried me but what came later, when we had already got all our new routines in place. The news came in that a new variant of the virus had been found in the UK, so all flights to and from there were suddenly canceled. I found myself wondering how we were going to cope. But yet again, our partner, time:matters, came up with a solution: small charter flights, the kind of scenario where the pilot will happily drive the forklift to the plane themselves. Another problem sorted!

### **Is there anything that will remain etched in your memory?**

Even at the height of the pandemic, when the situation really was difficult in some of the countries we were flying to, we always managed to find couriers who were prepared to take the stem cells to their destination. They just said, “Sure, we'll do it for you.” Their unconditional commitment to the fight against blood cancer made a huge impression on me.

**A NEW, VIRTUAL HOME FOR DONOR DRIVES**

At the beginning of the pandemic, Donor Recruitment also found themselves facing an unprecedented situation. For the first time in the history of DKMS, public donor drives were impossible. Normally, thousands of people would have flocked to these events in response to our appeals on behalf of patients who need a “genetic twin”.

On March 10, 2020, before the first official lockdown, we had to take a painful decision: to cancel all physical donor drives. This affected not only public donor drives but also those in schools, colleges, universities, companies, and sports associations all over Germany. It was a drastic but necessary step to help stem the spread of the virus.

Pre-pandemic, Donor Recruitment organized about 2,000 drives a year, leaving little room for downtimes. Now their creativity and speed were needed. Before the month was over, we moved all

our donor recruitment activities online. The new, virtual donor drive format worked in much the same way as a regular public donor drive – except almost everything was done online. (See info box below.)

We developed new processes and contacted and briefed all the donor drive initiators whose events were already in planning. And from that point on, any new drives that people were initiating were set up online. We had managed to create a safe, simple, successful alternative to physical donor drives that would allow families, friends and patients themselves to do something about the helplessness they were feeling during the crisis: they could now help us grow the global pool of potential lifesavers after all. In 2020 the initiative groups and DKMS successfully carried out 459 virtual donor drives.



# Virtual donor drives: Here's how they work

Virtual donor drives were developed at the start of the pandemic and offer a digital channel by which DKMS can continue registering new stem cell donors. They are another way of signing up, besides our website at [www.dkms.de](http://www.dkms.de). Like regular donor drives, they are designed to reach out to as many people as possible, raise awareness around the topic of blood cancer, and encourage them to register as potential stem cell donors.

Anyone looking to become a donor can click on the dedicated link for the virtual donor drive they are interested in. We then match them to the relevant online drive and send a registration kit to their home address. Once we receive their sample and registration details, we add them to our registry. That way, we can see at a glance exactly how successful a donor drive has been.



Whether with a photo of the patient, a personal story or even a video, our virtual donor drives encourage limitless creativity so that users share the relevant link as effectively as possible via their own on- and offline channels. Our colleagues in Donor Recruitment offer online info packs for PR support – just like for real-world donor drives before the pandemic. Registrants joining via a virtual donor drive also receive all the documents they need. These come in the post with a swab set so they can swab their cheeks for a sample in the comfort of their own homes.



## THOUSANDS WANT TO HELP LANA AND JENS

Right at the beginning of the pandemic, eleven-year-old Lana (pictured right) proved just how effective a virtual donor drive can be at reaching out to people and encouraging them to register. Lana had blood cancer, and a public donor drive was scheduled for her for March 22, 2020. It was originally supposed to take place in Augsburg, Germany, but was then carried out online instead. The emotional appeal brought in more than 11,000 requests for registration kits. Regularly posting updates on her state of health on Instagram, Lana touched the hearts of countless people, amassing over 100,000 followers in just a year. Even celebrities like the rapper Kool Savas supported her appeal and helped her story go viral. In August 2020, Lana was given a transplant with stem cells from her mother. But in the end, her weakened body was unable to handle the side-effects of her treatment. Sadly, Lana passed away on April 18, 2021, at the age of just 12.



Lana's last wish was for as many people as possible to keep registering to give others like her a second chance at life.



The story of 33-year-old Jens (pictured left), from Grenzach-Whylen, shows the opportunities a virtual donor drive can offer. A fan of American football, Jens was diagnosed with blood cancer in September 2020. The team responsible for the TV show *Ran NFL* offered their support and promoted an online drive for him during their coverage of the league matches. This prompted more than 8,000 people to order a registration kit, and Jens finally received a transplant with cells from an unrelated donor in February 2021. By springtime he was making short trips to the mountains again.

Virtual donor drives like this one show the kinds of opportunities our new format can offer, thanks to its unlimited reach. In fact, organizing a donor drive has never been easier!

**VIDEO CONFERENCES CREATE NEW OPPORTUNITIES**

The switch from physical to virtual donor drives also changed the daily work of the Donor Recruitment department. Before the pandemic, they would visit the patient’s family, friends, and donor drive organizers for a preliminary face-to-face chat a few weeks prior to the event.

But now the discussions around planning were happening via video call. Meeting someone online certainly isn’t the same as meeting them in person, but video calling has turned out to offer other benefits instead: now, everyone involved in organizing a drive can take part, no matter where in the world they are. And for the first time, even patients themselves can take part, speaking from the hospital via their cellphones and tablets.

Not all donor drives are organized for a specific patient, though. In 2020 we also received numerous inquiries from companies, colleges, schools, and associations looking to organize donor drives for their employees, students, and members. They set up a total of 459 virtual drives, adding another 59,353 people to our list of potential donors. A further 43,292 had already signed up at 459 physical donor drives before the pandemic, up to the end of February 2020, and another 313,382 joined via the individual online registration option on our website. So, all in all we recruited 415,973 new potential donors in 2020.

Compared with the previous year, the figure was down by 35.9 percent, but thanks to our new, digital solutions, we came ever closer to offsetting the losses caused by the ban on public gatherings.

Since physical donor drives were suspended due to the pandemic, online registration has become a cornerstone of our efforts to recruit new donors. In total, 372,681 people used this method to register with DKMS – a rise of 1.2 percent on the previous year (2019: 368,081). Konstanze Burkard, Director Corporate Communications and Donor Recruitment: “As a result, we’re now planning to develop this area and are all the more committed to continuing our digitalization strategy. But at the same time, we still very much want to be able to get out and support people, no matter where they may be. So, in the future, we will have not only virtual donor drives but also physical ones in communities, schools, and colleges as well as companies and clubs.”



Video calls have replaced physical meetings across large parts of our organization.

### PANDEMIC-READY

The coronavirus crisis also prompted us to try out new processes in-house. In such exceptional circumstances, our creative, flexible organizational culture turned out to offer a strong foundation. Having already set up an interdepartmental pandemic team long before COVID-19 reached Germany, as an organization, we were able to respond especially quickly and efficiently when the crisis finally struck: responsibilities had been clarified beforehand and new decision-making systems were already up and running. On January 31, 2020, the pandemic team announced to all employees that the novel coronavirus was taking hold and hygiene measures were needed. From that point on, we regularly updated the entire workforce via the intranet and emails on the latest infection rates as well as their impact on our organization and people's personal areas of work. Our infor-

mation strategy incorporated every channel at our disposal and allowed us to keep our entire team fully up to date and aware of the situation. In the spring of 2020, we rapidly set up everything needed for people to work from home, which large parts of the organization had already been doing before the pandemic anyway. Our Information and Technology Services department were in very strong demand and duly rose to the challenge. In line with our pandemic plan, preparatory measures had already come into force by mid-February. They included the fast procurement, installation and distribution of additional IT equipment for remote working – laptops and headsets especially – and the purchase of additional software licenses so that video conferencing systems could be set up and employees trained. So, when we transitioned to remote working almost completely, in March 2020, we did so largely without difficulty.

## MEDICAL COUNCIL MEETS ONLINE



The Medical Council is the advisory body for the DKMS parent organization, the DKMS Foundation for Giving Life (see page 51). It consists of renowned figures from the world of medicine and delivers key impulses for our medical strategy as

we continue the fight against blood cancer. But the Medical Council, too, has had to adapt to the pandemic. Rather than meeting twice a year as they used to, since May 2020, they have been video-conferencing every six to eight weeks.



Thanks to the technology available, online team meetings have now become standard.

Since the switch, about 80 percent of our colleagues have worked either largely or completely from home. To help them handle both their family and professional lives in these exceptional circumstances, we extended our flextime bandwidth period from 6 a.m. to 10 p.m. to make it easier for them to see to their family commitments and so on. We also offered them more flexibility around leave, flex days, and minus hours. Wherever possible, remote working became the preferred solution for all of us.

As part of the DKMS Foundation for Giving Life and our advisory body on medical issues, the Medical Council also adapted their working methods to the pandemic situation to offer even more targeted support (see box on left).

**SUPPORT FOR EMPLOYEES**

Meanwhile, we introduced numerous in-house measures to help employees feel closer despite the physical distance between them and ensure they still feel part of our great DKMS family despite working from home. Our virtual international town hall meetings were especially helpful in this regard, often attended by more than 600 employees from seven countries across five continents. Before the pandemic, international meetings of these dimensions had not existed with us, but they now strengthen the bonds more than ever between everyone in our international community.

Mutual support was also what prompted us to set up what we call our Capacity Board. Since late March 2020, the new, virtual platform on the DKMS intranet has allowed us to chart special requirements

in areas where the crisis has led to an increased workload, and the capacity available. This has enabled colleagues to support each other across teams, departments, and locations. It's this flexibility that has ultimately helped ensure our colleagues could continue pursuing the goals of our organization, even during the pandemic – and that has enabled us to find ways of registering and taking care of our donors, and ensuring no patient has to wait for their lifesaving stem cell product.

To keep employees as up to date as possible on developments – beyond their own area of work or that of DKMS as a whole – the internal communications team provided plenty of information via our intranet news site Pulse. This presented articles on topics like how to set up an ergonomic workplace at home or maintain a good work-life balance and offered tips on how to take care of the kids. It also kept everyone up to speed on the latest developments that were relevant to DKMS.

“Looking back on the situation more than one year on, it is safe to say that the coronavirus crisis certainly presented us with innumerable obstacles and challenges in a whole range of respects. We actively rose to meet and accept and overcome them together through our creativity, innovation, flexibility, and persistence. We learned a lot of new things that will make us even stronger in the future. But throughout it all, we never lost sight of the actual goal of our work – to delete blood cancer – and I’m incredibly proud of that,” says Dr. Elke Neujahr, summarizing the situation.

# MORE THAN A DONOR CENTER

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“We delete blood cancer.”

In pursuit of our ambitious goal, we do much more than register potential stem cell donors and match them to patients. We also carry out medical research, and educate and inform people - crucial tasks in advancing the fight against blood cancer across the globe.



From left to right:  
 Dr. Geoffrey A. Behrens, Business Development Manager with the DKMS Life Science Lab, Anja Häusling, Sales Representative Liquid Handling with Analytik Jena GmbH, Michael Brehm, specialist for lab automation with the DKMS Life Science Lab

We know from our daily work that blood cancer is a tough opponent. That’s why it is so important to tackle it from every direction, with a holistic approach. Innovative research and strategic foresight are vital, but so too is the courage to try something new and venture into uncharted territory to help someone. So, our commitment extends far beyond the registration and procurement of potential stem cell donors: in 2020 we proved once again that DKMS is more than a stem cell donor center.

**INNOVATIVE RESEARCH AS A CRUCIAL FACTOR**

After a stem cell transplant, many patients can fortunately get back to their normal lives pretty quickly. But not all are cured completely and permanently. Medical specialists and scientists continue to face huge challenges around relapses and complications such as graft-versus-host disease, which can still cause life threatening rejection responses after a transplant.

That’s why we consider it particularly important to support the advance of medical science in this area as much as we possibly can. To help us do so, in 2013, we set up our own research unit the Clinical Trials Unit (CTU), in Dresden, to launch immunogenetic research projects and clinical studies. The goal of our scientific research work is to make allogeneic stem cell transplants even safer and more successful so that blood cancer patients can have the best possible chances of a cure and survival. The CTU works closely with other DKMS scientists from areas such as bioinformatics and our very own DKMS Life Science Lab. In 2020 alone, our research teams published



16 studies in renowned specialist journals. We work closely with international transplant registers, major clinics, and national and international study groups.



To us, thinking ahead and close collaboration with top scientists around the world are extremely important – because to delete blood cancer, you have to join forces with like-minded people and all pull in the same direction. To continue improving collaboration in the field of blood cancer research, in 2016, our Clinical Trial Unit launched an important cooperation project: the Collaborative Biobank (CoBi). This comprises a store of blood samples collected by participating stem cell donor registries as well as transplant and collection clinics from volunteer stem cell donors and patients. The samples and data are now available to scientists around the world to use in their research into the prevention, diagnosis, and treatment of blood cancer disorders. In 2020, the 14 existing members of the CoBi project were joined by two more: the Charité University Hospital in Berlin (a medical clinic focusing on hematology, oncology and tumor immunology), and the DRK Blutspendedienst Nord-Ost gemeinnützige GmbH (German Red Cross Blood Donor Service, Institute Berlin).

#### FULLY COMMITTED TO FINDING THE PERFECT MATCH

Another key area of our scientific work is our endeavors to enable the even more precise selection of matching stem cell donors. For donated stem cells to become properly established in a patient's body and combat infections, the HLA or tissue characteristics and certain other parameters of the donor and patient must match as closely as possible. The more we know about these parameters, the more accurately treating physicians can choose a suitable donor for a patient – and the greater the chances of transplant success. Some of our specialist departments – our Scientific Projects team and HLA Services, for example – have teamed up with our bioinformatics specialists, a scientific data analyst and other experts to systematically seek out further areas that would benefit from optimization. One of them relates to the additional immunogenetic factors that could have a positive impact on the outcomes of stem cell transplants.



## SEIZING AND EXPLOITING EVERY OPPORTUNITY

Do certain KIR-HLA combinations have a positive impact on the outcomes of stem cell transplants? Are patients less likely to suffer a relapse if their stem cells are equipped with the maximum possible activating KIRs? These are among the questions the DKMS research team is exploring in collaboration with the German cooperative transplant study group and the German register for stem cell transplants.

“KIR” is the collective term for 17 different killer-cell immunoglobulin-like receptors. These help natural killer cells to recognize and then destroy diseased cells, such as tumor or infected cells, and formed the topic of a study that retrospectively examined the different KIR-HLA combinations of 2,222 donor-patient pairs. None of the selected models allowed the scientists to prove any links between relapse frequency or other complications, so the finding was negative but still of great scientific value. It was published in the renowned specialist journal *Blood*, in January 2021.

Thanks to this research, scientists around the world now know that these selected combinations can be ruled out as factors in the future. “We still think that analyzing the impact of KIR is a promising approach and will continue our research in this area,” says Dr Johannes Schetelig, Director of the DKMS Clinical Trials Unit. “We want to seize and exploit every opportunity there is for improving therapy options for people with blood cancer.”

One of the most important partners of our Clinical Trials Unit is the DKMS Life Science Lab, a Dresden-based subsidiary of DKMS gGmbH. Every year around 160 employees there analyze approximately 1,000,000 cheek swabs from DKMS donors around the world. To mark World Science Day 2020, our lab published a film on vimeo that offers some fascinating insights into the exciting world of HLA typing. “People often ask us where their cheek swabs go and what we do with them,” explains Thomas Schäfer, one of the directors of the DKMS Life Science Lab. “We wanted this film to show DKMS donors what happens to their cheek swab samples – because what a lot of people don’t know is that it is only after the swab has done its bit that the journey really gets started!”

Our highly qualified lab experts also support the research work of the Clinical Trials Unit and other scientific institutions, as well as working on their own studies and supporting medical advances.

In 2020 alone, the lab provided the international reference database with about 1,300 previously unknown HLA characteristics to facilitate donor-patient alignment. This benefits not only medical specialists

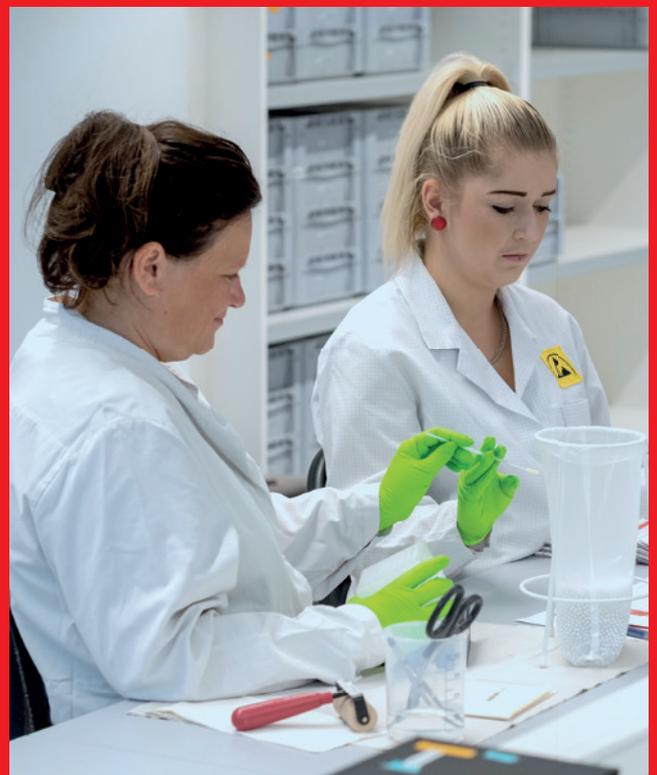
and scientists but also - and most importantly - patients across the globe.

In 2020 the DKMS Life Science Lab was presented with the Analytik Jena Science Award in the category for Molecular Biology, in recognition of its outstanding research on identifying cytomegalovirus (CMV) in cheek swab samples. Cytomegalovirus is a member of the herpes virus family and can cause considerable complications after stem cell transplants, especially if donor and recipient have different CMV statuses. Our lab developed a procedure by which CMV statuses can be ascertained quite simply, from cheek swab samples rather than from the blood samples that had previously been required. The DKMS Life Science Lab’s highly acclaimed paper was published in February 2020, in the Journal of Infectious Diseases.



## WHERE DO CHEEK SWABS GO?

- As soon as a sample comes in, the barcode on the registration kit is scanned so that each sample can later be allocated to its owner. Before being saved, however, all the data is pseudonymized.
- Next, the swabs are removed from their sticks and placed onto a plate of 96 cotton “buds”. The DNA samples they contain are then released by applying a special solution. As soon as the DNA is isolated, the actual analysis begins.
- The most important component in all of this is those strands of DNA that give an indication of HLA characteristics. These strands are multiplied several times over, by polymerase chain reaction, to create several million identical DNA sequences
- These sequences are then read by machine to deliver the basic data our lab employees need to determine the exact HLA characteristics of individual donors.



First of all, the samples are scanned in the lab and their HLA characteristics are determined.

**THE COVI-DO STUDY:  
ON THE TRAIL OF THE CORONAVIRUS**

When typing donors, our DKMS Life Science Lab analyzes the immunogenetic information (HLA, KIR, MICA/B, CCR5 and ABO/Rhesus blood groups) that is relevant for matching stem cell donors to blood cancer patients. But as the pandemic unfolded, the question soon arose as to whether these immunogenetic factors might affect the risk and development of a COVID-19 infection? Some indications seemed to suggest they did, so we set up a large-scale study to take a closer look. Our goal was to gain a better understanding of COVID-19 so that at-risk groups could be better protected, and patients would receive more effective treatments.

First of all, a DKMS research team surveyed around five million German-based, DKMS-registered stem cell donors online, asking if they had been tested for the virus, received a positive result, and if there were any underlying factors that might put them at greater risk if they contracted the disease. “The response was overwhelming,” says a delighted Dr. Alexander Schmidt, Chief Medical Officer at DKMS. In total, 924,557 donors took part in the study, of whom 7,948 had tested positive for a SARS-CoV-2 infection.

Next, with the respondents’ permission, of course, the COVID-19 information they had voluntarily provided was linked to the data already held about their HLA characteristics and other immunogenetic factors. The study revealed that, contrary to

the expectations of many experts, HLA characteristics relevant to donor selection had no bearing on the development of COVID-19 infections. However, the DKMS research team was able to confirm that familiar risk factors – such as higher ages and body weights, and conditions like diabetes and high blood pressure – did indeed affect the risk of infection and the development of the disease. Our study also showed that frequency of infection in people with blood group A was slightly higher than for those with blood group O, although blood group was not found to have any discernible effect on the development of the disease.

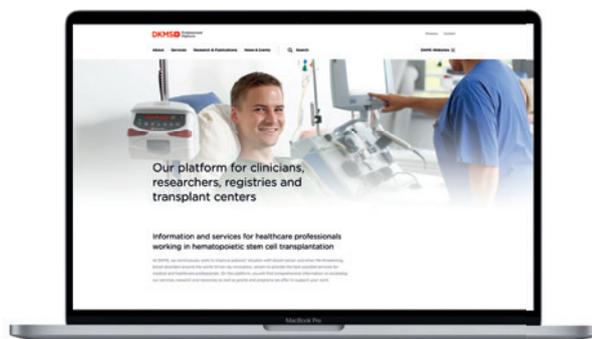
“We would like to say a heartfelt thank-you to everyone who took part in our study, for their trust and their support in helping us combat the pandemic,” says Schmidt, adding that the findings are also very constructive in the fight against blood cancer. “The study is helping us gain an even better understanding of how the immune system works – and the immune system plays a crucial part in the selection of matching donors for patients,” adds Prof. Dr. Johannes Schetelig, Head of the Clinical Trials Unit and leader of the Covi-Do study. “Also, the findings are helping make stem cell transplants even safer and more successful.” In summer 2021 the research team launched another survey, this time on the potential long-term effects of a COVID-19 infection. The findings are not yet out.



## NEW DKMS ONLINE PLATFORM FOR MEDICAL SPECIALISTS

Sharing knowledge and supporting medical advances in the field of stem cell transplants was also the goal behind the development of our online platform for medical specialists in 2020. Since early 2021, doctors, healthcare professionals and scientists have been able to find all the most important information on hematopoietic stem cell transplants at [www.professional.dkms.org](http://www.professional.dkms.org). The website provides a clear overview of the work carried out by the various DKMS departments and offers comprehensive insights into the scientific studies and publications of our

non-profit organization. It also offers access to services, grants, and funding programs available from DKMS.



### A MILLION EUROS FOR SCHOLARSHIPS

One part of our commitment to research and education is especially close to our hearts: the long-term funding of upcoming generations of scientists. Every year the DKMS Foundation for Giving Life presents the John Hansen Research Grant to as many as four young candidates. Each grant is worth €240,000 and supports promising international research projects in the field of blood stem cell transplants and cell therapy. Here, too, the aim is to significantly increase the chances of recovery and survival for blood cancer patients.

In 2020, the grants were awarded to: Dr. Cynthia Perez of the Centre Hospitalier Universitaire Vaudois in Lausanne (Switzerland), Dr. Andrea Schmidts of the Massachusetts General Hospital Cancer Center in Charlestown (USA), Dr. Youli Ktena of the renowned Johns Hopkins University in Baltimore (USA), and Dr. Mirjam Belderbos of the Princess Máxima Center for Pediatric Oncology in Utrecht (Netherlands).

“It’s a huge honor and a privilege to receive this research grant,” said Dr. Youli Ktena. “It will allow me to continue pursuing my research. My goal is to make stem cell transplants even safer and more successful for patients who need this effective and often lifesaving therapy.”

Besides the John Hansen Research Grant, the DKMS Foundation for Giving Life presents the annual Mechtild Harf Science Award, also in recognition of outstanding achievements in research by medical experts of international renown. In 2020 the prestigious award went to Prof. Dr. J. H. F. Falkenburg, from the Netherlands. The professor of hematology is deputy head of the Department for Hematology at the Medical Center of the University of Leiden (LUMC) and one of the most prominent researchers in the field of immunotherapy of hematological diseases. Professor Falkenburg’s achievements include groundbreaking contributions to the treatment of leukemia with donor T-cells. He donated his €10,000 prize money to the charitable trust of the Department for Hematology at the Medical Center of the University of Leiden.

### ONE DONATION, TWO LIVES SAVED

Keeping an open mind and venturing into uncharted territory is not just important in research. It is also essential in practice. In 2020, we introduced a new organization that specifically benefits our patients: the DKMS Stem Cell Bank gGmbH. Here, the primary focus is on speed, because the faster a stem cell transplant is carried out, the greater the chances of survival and recovery for many patients. So, to support patients even more, we intend to keep a store of stem cells from DKMS donors with especially



Award-winner in 2020: Prof. Dr. J. H. F. Falkenburg

common HLA characteristics. This has the advantage that patients whose HLA characteristics match those found in a donation in our store can receive their transplant directly, without having to wait. The cells they need are already available and ready for transplant almost immediately.

To build up the DKMS Stem Cell Bank, we are requesting the support purely of DKMS donors who are already donating stem cells through peripheral donation anyway. On occasions, far more cells are collected than the patient actually needs. Whenever we expect this to be the case, we ask the donor if they would be prepared to extend the donation procedure and donate their “excess” cells to our bank. Except for the slightly longer time it takes, there are no disadvantages at all for the donor, nor any health implications. With their permission, their extra stem cells are cryo-preserved in the Stem Cell Bank at -180°C - and could soon provide a transplant that could save the life of another blood cancer patient.



### THE DKMS REGISTRY - ANOTHER MILESTONE

About one in three patients who need a stem cell transplant find a matching donor within their own families. But what many people don't realize is that the rest depend on stem cells from unrelated donors. In 2020, this was the case for about 63,000 patients worldwide. In instances like these, the search for a suitable stem cell donor is coordinated by what are known as donor registries. These are organizations that administrate databases containing the HLA characteristics of all potential stem cell donors. The

data is pseudonymized beforehand so that it cannot be directly traced back to the owner. Although most donor registries are national, they are linked to other registries around the world to help the treating doctors at transplant clinics find a suitable donor for their patient.

To continue improving the search process, on August 1, 2020, we established the DKMS Registry, an independent and globally active subsidiary of DKMS. Based in Tübingen, Germany, the DKMS Registry allows us to present the typing profiles of



## DKMS DIRECTOR THILO MENGLING APPOINTED TO WMDA BOARD



Thilo Mengling has been Director of International Medical Science at DKMS since 2019.

The pandemic has been an urgent reminder to us all of the importance of international collaboration on many levels in the fight against blood cancer. The World Marrow Donor Association (WMDA) is dedicated to precisely this issue. Its mission is to promote global collaboration and the sharing of best practices for the benefit of stem cell donors and patients. It is controlled by the WMDA Board, which consists of international experts on the various aspects of donor searches and stem cell extraction and transplantation.

The work of the WMDA is divided into 4 pillars: Search, Match & Connect, Global Development, Donor Care and Quality. At the begin-

ning of January 2021, Thilo Mengling, Director of International Medical Science with DKMS, started contributing his expertise to the WMDA Board as head of Promoting Donor Care. He has been a member of this area of work for more than 10 years, focusing on donor acceptance criteria and medical standards, among other things.

Thilo Mengling is delighted to be appointed to the WMDA Board. "I am looking forward to seeing what new opportunities will arise. As an organization, we will be able to broaden the scope of our work so far and play an active part in shaping and advancing international collaboration in the WMDA."



Highly motivated: the DKMS team in South Africa

our donors in full to support global donor searches. Previously, this had not always been possible at short notice because DKMS typing profiles exceed the standard, and some typing parameters that only we establish were difficult to display in existing registries. Under the new arrangement, transplant clinics can now look for an even more exact “genetic twin” for their patient – because the closer the match, the better the chances of a stem cell transplant being successful in the long term. The DKMS Registry holds the details of about 25 percent of registered donors worldwide. “We are proud to represent so many donors and be able to procure the right one when the need arises,” says Dr. Julia Pingel, CEO of the DKMS Registry. But the DKMS Registry doesn’t just procure DKMS donors for patients worldwide; in Chile and India it also acts as the first point of contact and as a search unit for clinics. “Our professional search coordinators search the global pool of almost 40 million registered donors to find the best match for patients in Chile and India and help clinics procure the stem cell products they need,” Dr. Julia Pingel explains. “Our work makes a vital contribution to increasing access to stem cell transplantation in these countries.”

### **ETHNIC DIVERSITY SAVES LIVES**

Our mission – and passion – is to procure donors across the globe and help patients worldwide. Working with foresight, we are already devoting our attention today to the needs of patients tomorrow whose

lives will depend on our work. As we do so, we are keeping continuing globalization firmly in mind – because in order to offer as many people as possible from different ethnic backgrounds a second chance at life, we need our stem cell donor center to be as diverse as it possibly can. That’s why we are doing more and more to grow our organization internationally.

But why does all this matter so much? In each ethnic population, certain combinations of HLA characteristics are particularly common, so the chances of finding a “genetic twin” within your own ethnic group are considerably higher than elsewhere. But as yet, many of these specific combinations of characteristics are hugely underrepresented in donor centers around the world. In Germany, nine out of ten patients find a suitable donor; worldwide only six in every ten do. In addition, as society becomes ever more globalized, the combinations of genetic characteristics are becoming increasingly diverse and complex. For patients from mixed ethnic backgrounds especially, this complexity can make finding a matching donor particularly challenging.



### NEW HOPE FOR BLOOD CANCER PATIENTS WITH AFRICAN BACKGROUNDS

The only way we can rise to these challenges is by working across international borders and at a global level. That's why DKMS currently operates in seven countries – Germany, the USA, Poland, the UK, Chile, India, and South Africa – on five different continents. As we continue to grow, we constantly develop valuable partnerships with local donor centers worldwide. In May 2020, DKMS joined forces with South Africa's Sunflower Fund, a non-profit organization that has been fighting blood cancer for more than 20 years. The Sunflower Fund brings to the partnership its extensive knowledge and a wealth of experience in the registration of potential stem cell donors from South Africa, Namibia, Ghana, and Nigeria. It also runs a support fund for patients who cannot afford a transplant. "Increasing the diversity of the donor pool is absolutely crucial," says Alana James, Country Executive Director DKMS Africa. "We believe our partnership with DKMS offers us a fantastic opportunity to integrate not only South Africa but also other African countries and bring new hope to patients there." In March 2021, 'The Sunflower Fund Partnered by DKMS' became a member of the global DKMS family: DKMS Africa.

### HELP FOR PATIENTS IN POORER PARTS OF THE WORLD

The fact that blood cancer knows no borders is already well established. But the same is also true of other blood disorders, such as thalassemia and sickle cell anemia. Both are caused genetically, so they often affect small children. For patients like these, a blood stem cell transplant is their only hope of a healthy life. But obtaining the often lifesaving treatment is especially challenging in poorer parts of the world. Patients and their families often find themselves confronted with medical costs they simply cannot afford and that are also not covered by their health insurance, if they have any, or the health system.

"When it comes to giving people a second chance at life, we collaborate across borders at a global level. In our quest to help, we leave no stone unturned. Anyone whose life depends on a stem cell transplant deserves to have one," says Dr. Elke Neujahr, Chair of the Board of Directors, DKMS gGmbH.

To advance this cause, in 2020, we developed several programs primarily for patients in low- to medium-income countries:

- Giving the hope of a healthy life: Our **patient-support program** means we can help cover the costs of blood stem cell transplants for patients who would otherwise have no access to this lifesaving treatment. Between 2018 and 2020, our fund helped us enable 191 transplants.
- Finding the perfect match: Our free **HLA typing program** means we can support people seeking a donor within their own family to give them the stem cells they need for a transplant. We type both the patient and their family members free of charge. And if they can't find what they need that way, we support them in the search for an unrelated donor.
- Building a better future: As part of our **capacity-building program**, we support projects to increase transplant capacity so that more patients can receive the lifesaving therapy they so urgently need. We also support training programs for doctors and healthcare professionals to sustain capacity once it has improved.

In addition, we partner with local transplant clinics and other non-profit organizations fighting for the same goal as us: better access to blood stem cell transplantation. The main ones include the Sankalp India Foundation and Cure2Children. Both of these benefit from our free HLA typing program, meaning they can invite patients and their families to what are known as thalassemia camps for typing. Countless patients – usually small children – travel to these camps with their families, often from far away, to provide cheek swab samples so that we can find out if a family member could be the stem cell donor that's needed. Their samples are then HLA-typed at our DKMS Life Science Lab, the cost of which is covered by our organization. Between 2018 and the end of 2020, a total of 9,037 people were typed in this way, most of them from India and Pakistan. 2,066 were typed in 2020 alone. This has allowed us to find 712 potential related donors to give patients the hope of survival and a healthy life.



## JOURNEY INTO A NEW LIFE



Jishan, a patient, and his little sister, who donated her stem cells to him

By the end of 2020, our financial support had enabled 191 sick children to receive a stem cell transplant. One of them is Jishan, from Vijapur, a small town in India. Jishan was just four months old when his parents received the devastating diagnosis: their little boy had thalassemia. Thalassemia is a widespread hereditary disease, and every year, more than 10,000 children in India are born with it.

Although they knew little about this life-threatening form of anemia, Jishan's parents stopped at nothing to ensure their little boy could be treated. He received his first blood transfusion in Vijapur – but it wasn't long before his parents found out that from now on, Jishan would need hours and hours of the same time-consuming treatment every month. Unable to afford private healthcare for him, his parents decided to have Jishan treated in a state hospital. This meant undertaking a grueling journey every three weeks, taking several hours to get there from where they live.

On one of their visits to the hospital, they heard about a non-profit organization called the Sankalp India Foundation. As a partner organization of ours, the Sankalp India Foundation is dedicated to providing easier access to reliable, suitable medical treatment for children with life-threatening conditions like thalassemia. They also offer free blood transfusions in nine clinics across the country.

The family's first visit to the Sankalp Center offered them a new glimmer of hope when they learned that a blood stem cell transplant could cure their son for good. In conjunction with our free HLA typing program and the non-profit Cure2Children, Sankalp arranged for Jishan and his family to attend a thalassemia camp. These typing events attract many families from across the land, who come in the hope of a healthy life for their children. Jishan's family swabbed their cheeks for samples to see if any of them were a matching donor for the boy, and their swabs were sent to the DKMS Life Science Lab in Dresden for analysis. Finally, there was good news for the young parents: Jishan's little sister had turned out to be an identical HLA match to her brother. This meant she could become his donor and save his life.

But the question the family now faced was how to pay for the upcoming stem cell transplant? Jishan's parents were in no position to cover the costs themselves, and so they did all they could to organize the necessary funding. In the end, DKMS, the Cipla Foundation, the Jalaram Abhyuday Trust and Chief Minister's Relief Fund all contributed to the cost of the treatment, paving the way for the lifesaving transplant. It was carried out at the CIMS Hospital in Ahmedabad, where the transplant unit is directed by Sankalp and Cure2Children.

Since his stem cell transplant in October 2020, Jishan has made a great recovery. We are very pleased and grateful to have worked with Sankalp, Cure2Children and a wealth of other helpful individuals and organizations to give Jishan the chance of a healthy future.



## SHARING EXPERIENCES THROUGH THE GLOBAL COLLABORATION GRANT



As the world's leading stem cell donor center, sharing our knowledge, experience and resources with international partners and organizations is a matter very close to our hearts and the reason we issued our second Global Collaboration Grant, in 2020. This is awarded to support the work of international registries and donor centers that share our goal of giving as many blood cancer patients as possible a second chance at life. The prize includes free HLA typing at the DKMS Life Science Lab for 5,000 samples, about 50 hours of training for employees, and €25,000 for materials to support public relations work and donor retention.

Before the training courses, the winners first define what they would like to focus on. Potential issues include quality management, process management, and medical topics. The courses are then delivered by DKMS colleagues working at one of our seven locations. Afterwards, the trainer and group work together to develop constructive communication measures that will allow them to reach out as successfully as possible to the public and registered donors in their country. Due to the pandemic, all of the training courses were delivered online, with the advantage that significantly more participants were able to join than if we had carried out the courses physically.

In 2020 the Collaboration Grant went to the Russian-based charitable fund Karelian Registry of Unrelated Hematopoietic Stem Cell Donors, and to the Ukrainian Bone Marrow Donor Registry, a charitable foundation based in Ukraine.

### KNOWLEDGE CAN SAVE LIVES

Familiarizing young people with the topic of blood cancer, stem cell donations, and what they can do to help is vital and should happen as soon as possible – because when our donors turn 61, we remove them from our records, partly to protect them and partly because of their age. To maintain the chances of finding a donor, we urgently need young people to sign up. For this reason, alongside our activities in medicine and the sciences, we have added education and information to our statutes and strengthened our focus on this area of our work.

Over the last few years, we have already been steadily developing our activities at schools. By the time the pandemic struck, more than 100 info events a year across Germany were raising awareness and were educating school students about the opportunity to register as a stem cell donor. To offer the best possible support to teachers as they tackled this important topic, we presented them with visually attractive folders containing modular lesson materials. Our lesson plans for biology, religious education, ethics, German, and social science lessons combine a variety of different measures to support independent learning.

In 2020, we added an online biology lesson to our analog training program, primarily to deal with the changing school situation caused by the pandemic. “Our many conversations with teachers showed very clearly just how challenging the situation in schools is and how grateful staff are for support,” reports Svenja Ebbing, responsible for education communication in our Donor Recruitment department. Our innovative online lesson takes DKMS one step closer to digitalization and provides online content for students and teachers to access anytime, anywhere. The lesson can be easily adjusted to suit the group and delivered at the class's own speed. The materials are intuitive to use and teach with. The 45-minute session gives young people a basic understanding of the circulatory system, blood cancer and stem cell donation, so they can make their own confident, well-thought-out decision as to whether to register as a stem cell donor.

### SPECIAL AWARD: THE DKMS SCHOOL CERTIFICATE

“We stayed in contact with schools the whole time they were closed or students rotated to reduce class sizes. This allowed us to communicate closely and directly with teachers and pupils and respond quickly to the latest developments,” explains Marina Miller, head of the DKMS schools project. “Our team tailors its solutions for schools wanting to integrate our work into their lessons or carry out a donor drive, to suit their situation and possibilities as closely as possible.”

Over the years, many schools have started making donor drives a regular event. By the end of 2020, 3,536 school donor drives had been carried out, bringing in 451,618 new registrations. Of those, 5,739 donors actually went on to donate stem cells. To publicly express our gratitude to these schools for their longstanding commitment, we introduced the DKMS School Certificate, which we first awarded in the 2020/2021 school year. The special accolade is presented to schools that have carried out three or more donor drives. In 2020 it was presented to three schools in the German state of North-Rhine-Westphalia and three in the state of Hesse, who received it on behalf of numerous grammar and comprehensive schools, and vocational colleges. The DKMS School Certificates were presented at special press events, by the North-Rhine-Westphalian Minister for Schools, Yvonne Gebauer, and Hesse's Minister for Education, Prof. Dr. R. Alexander Lorz. Further similar events are currently being planned with the Ministers for Education and Senators of other federal states as well.

Dr. Elke Neujahr: "Education and information, medicine and science, and a stronger international commitment are essential in the fight against blood cancer." For this reason, she adds, DKMS has significantly increased its field of activity as a stem cell donor center over the last few years. "These are important cornerstones of our work, and we intend to continue developing them in the future - because to accomplish our mission, we have to think holistically and dare to try something new," she emphasizes.

**PRESS EVENT**

With the headmasters of the award-winning schools (from left to right): Dr. Peter Luetke (Paderborn), Yvonne Gebauer (Minister for Schools and Education in North-Rhine-Westphalia), Marco Lohmann (Cologne), Dr. Elke Neujahr (CEO of DKMS), Mathias Gehle (Warburg).



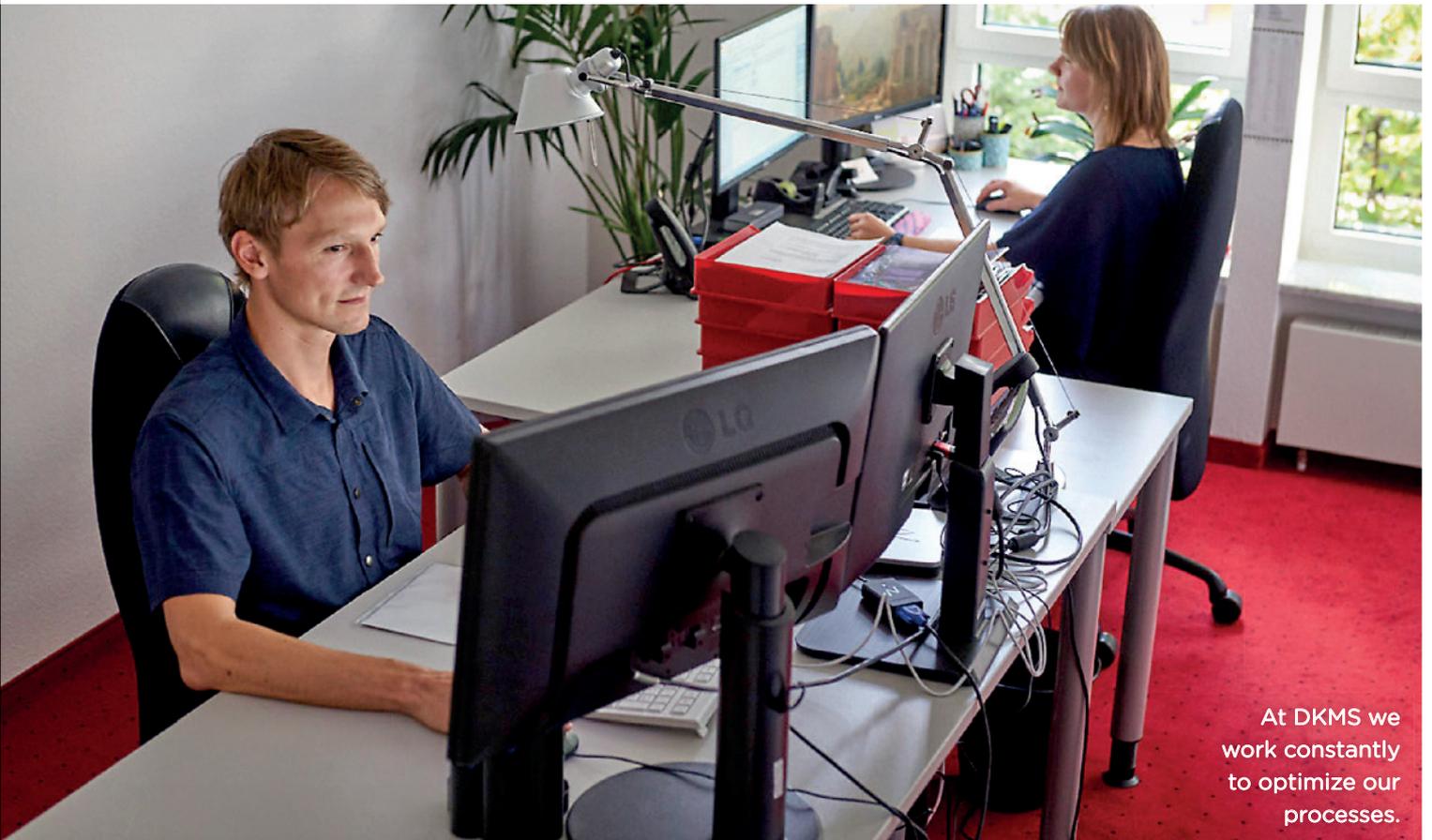
# QUALITY IS OUR STANDARD

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We want to give as many blood cancer patients as possible worldwide a second chance at life through a stem cell donation and permanently increase their chances of survival. That's why our investments reach beyond new areas of work and into the field of quality. When it comes to steadily improving our existing processes and implementing innovative, new solutions, we do all we can to be even more efficient and successful.

In our field of work, human lives are at stake. That's why patients and donors are the focus of everything we do and at the heart of our highly complex processes. To us, success means helping as many people as possible - and that takes extreme care and excellence in every respect. Since we were founded, optimizations and groundbreaking innovations have allowed us to constantly improve our processes. Going forward, the same approach will remain crucial for our continued success and fundamental to our ability to save as many lives as possible.

We carry out targeted quality campaigns to regularly evaluate our tried-and-tested procedures and take efficiency and effectiveness to new levels. The establishment of quality standards and processes ensures the same high standards across all of our DKMS organizations and is fundamental to our corporate culture and everything we do. Standard processes that apply across international borders are one example: in 2020 we began to set up and develop a global quality management system that not only meets but exceeds the highly discerning standards of our



At DKMS we work constantly to optimize our processes.

industry in many areas. We are guided in our work not only by branch-specific standards but also by the internationally recognized ISO 9001: 2015 regulations. This way, we can be sure to deliver on our promise of quality anytime, anywhere, and at any DKMS entity – the promise we make to our patients and donors, collaboration partners in science and research and, not least, to our 1,000-plus employees around the world.

Our process quality and expertise are two things we very much like to share with others. For this reason, DKMS has decided to apply for World Marrow Donor Association (WMDA) accreditation for our new DKMS Registry (see page 22), our existing offices in Chile and India, and our DKMS UK and DKMS Poland donor registries. We submitted our application in 2020 and, to our delight, the response was positive.

The WMDA is committed to promoting global collaboration and the exchange of best practices to benefit stem cell donors and transplant patients. The regulatory framework for these endeavors is the international standards for stem cell donations from unrelated donors. These were established by the WMDA and are regularly updated. They include specifications around donor information, consent, and medical and data security processes.

In donor searches, donors who are registered with a qualified or accredited registry or database are identifiable as such by a symbol that appears in the listing. This offers transplant doctors and search units certainty that the donor is registered with an organization which meets the WMDA's discerning standards.

To qualify, databases and registries must prove that they work to certain standards. Going forward, we are already preparing parts of our organization to take the next step: WMDA accreditation. This will involve meeting all the relevant standards in full, and our DKMS Registry will apply for accreditation in late 2023.



**DATA QUALITY IS CRUCIAL**

With more than seven million registered donors in Germany alone, keeping everybody's data fully up to date is a constant challenge. Responsibility for importing and consistently updating donor data in our software systems lies with our Data Management department, whose task is to ensure the best possible data quality. We also handle numerous questions around the registration process before we even create a data set for a donor. A look at the figures shows just how much data our data managers have to keep track of:

Once a day, we import the data of new donors registering online and order registration kits to be printed and sent out to them. To ensure the best possible quality of data even at this early stage, their details are automatically verified several times over, and any errors are immediately taken care of. These can include details such as incorrect addresses, or missing information or signatures, which we obtain by contacting the individual concerned. On occasions, we also have to advise new donors that, unfortunately, we cannot add them to our listings because they do not fulfill certain medical criteria. And sometimes, when their cheek swabs cannot be fully analyzed in our lab, we immediately organize for a second sample to be taken. We do all we can to

## THE NUMBERS\* AT A GLANCE



40.000

**DONOR CARDS** issued every month.



154.000

**INFORMATION REQUESTS** are sent out to local authorities every year (e.g. when mail comes back undelivered or we cannot reach the donor we need).



2.200

**REGISTRATION KITS REQUESTED** a day from new donors.



108.000

**DONOR EXCLUSIONS** processed in 2020 (e.g. for medical or age reasons, or because consent was withdrawn).



1.560

**PHONE AND EMAIL ENQUIRIES** a month from (potential) stem cell donors.



20.000

**ADDRESSES CHANGED AND 450 UPDATED** (e.g. owing to changes of name) every month.

\* Numbers are rounded

ensure we are fast, our donors are ready to donate at short notice, and data is always of the highest quality. Our goal throughout is for our donors to be made available to the search registries as soon as possible, once they have registered. Only then can they be found and identified as potential lifesavers in national and international searches on behalf of patients.

Given the importance of this goal, we also made another major step in 2020: we switched to an even faster, more secure data collection method for our printed consent forms. By introducing our DKMS Data Entry app and involving a new service provider, we have been able to reduce the maximum time required to register a new donor from about six weeks to just under three. As a result, donors joining our registry can now be included in searches even faster.

Our data, then, is the foundation for successful donor procurement, and that's why we keep it up to date at all times. One way we do this is by comparing forwarding information from the German postal service Deutsche Post with the donor data we hold. Many of our donors actively inform us of a change of name or contact details, and some tell us themselves that they are not available to donate, for example because they are moving abroad either temporarily or permanently, pregnant, or ill, or because they wish to withdraw their consent. Comparing and correcting this information can save lives – because every time we can't contact a donor we need, it's another missed opportunity for the patient.

**SPEED SAVES LIVES**

Strong demand for DKMS donors, and their selection at transplant centers are essentially based on two factors: high data and typing quality, and their desire and availability to help as soon as they are identified as a possible match for a patient. At DKMS, our typing results include not only all the regular HLA tissue characteristics – which should match as closely as possible between donor and patient – but also other parameters such as blood group (ABO, RhD), CCR5, and KIR, as well as CMV serostatus. These are analyzed as soon as donors are registered as they play a crucial role in the selection process. And our enhanced data quality really speeds up the selection process. At DKMS, we constantly extend and optimize the quality of our typing profiles (see page 19) to continue ensuring we can provide donors for patients that need them.

When it comes to procuring a stem cell donation, speed is of the essence as it can actually save lives. That's why our quality projects consist partly of asking all the donors we contact to fill in a health questionnaire. This way, we will know as soon as possible about their current state of health and

times when they may not be available to donate, for instance because they suffer from an illness that prevents them. In 2020, we contacted 212,702 donors as part of this project.

Before donating stem cells, most donors undergo confirmatory typing (CT). To begin with, they are contacted by our CT team (which consists of 40 employees) and offered a detailed consultation. Based on this and on their health questionnaire, we then clarify whether there are any medical issues that might prevent them from donating. In 2020, we contacted 30,235 donors for CT purposes.

With some donors, we already have all the transplant-relevant data we need, and since March 2020, they no longer need to undergo routine CT testing. They can instead be typed as they prepare



Mirco Gehlken, one of our more than 90,000 donors





## WE CONNECT PEOPLE

Since late 2019, we have been surveying our donors on their satisfaction levels throughout the donation process, from the moment they joined our data pool through to the follow-up they receive after donating. Their responses are evaluated every six months, and with return rates of well over 40 percent, the survey is highly satisfactory. Donor feedback remains very positive and confirms that we are doing the right thing. But we also value any suggestions that prompt us to revisit our processes and continue optimizing our communications. This helps us to keep improving what we do so that our donors and patients can benefit.

Since 2013, the Donor-Patient Contact department has been handling the concerns of donors after their donations. The team step in as soon as cell extraction is complete and seamlessly pick up where the Workup team left off. For us, a key priority is to be there for our donors even after they have given their cells and keep them posted on developments. The first follow-up discussion takes place within the first few days after the procedure and is an opportunity for us not only to inquire about the donor's well-being but also to answer any questions they may have, as far as possible, about their recipient and ways of contacting them.

In some countries, donors and patients are permitted to meet after a mandatory waiting period of at least two years. Where this is the case, we support those who wish to do so as they first make contact and meet face to face. Elsewhere donors and patients are allowed to contact each other anonymously, by letter. Here, we help them write their first letters and check what they have written for any anonymity issues. We then get them translated, if necessary, and forward them to the appropriate people. In countries where donor and patient can get in direct contact after the mandatory two or more years of anonymity have elapsed, we are happy to exchange addresses if both sides request it.

In 2020, we received, read, processed and, where necessary, translated a total of 3,894



Two years after her transplant, Sidney (left) and her donor, Leonie, were able to meet for the very first time.

letters before forwarding them to their recipients. We also enabled donors and recipients to exchange addresses on 763 occasions: 311 involved patients in the USA, 293 were within Germany, and 159 were with recipients based in other countries around the world.

“Our work is often the foundation for a unique encounter,” explains Deborah Buk, head of Donor-Patient Contacts. “The stories that emerge from them are always one of a kind. And often, these first encounters turn into friendships for life.”

to donate. If a transplant clinic wants this to happen, they can request a Health and Availability Check (HAC) before commissioning the donation to be coordinated. So, rather than providing a blood sample at the beginning, donors now do so during their preliminary check as this saves money and offers them additional protection. This new approach had already been in preparation at DKMS for quite some time but was then launched at short notice and more quickly than originally planned. In the first wave of the pandemic, it proved very helpful as many donors still wanted to donate but couldn't – or preferred not to – go to the doctor's beforehand because of the restrictions that were in place.

### IN DEMAND ACROSS THE GLOBE

One of the biggest departments at DKMS is the Workup team, which consists of 54 colleagues. When the preliminary examinations by the CT team are complete, Workup take over, offering personal support for donors and coordinating the various steps to prepare them for their bone marrow or peripheral stem cell donation. Every day, the Workup team organize 20 extractions on average, with each case manager taking personal care of their donor across the entire process. They contact them and clarify any questions they may have about the procedure. We then schedule appointments for a preliminary medical examination and for stem cell or bone marrow removal.

For us, intensive donor support is at the heart of what we do and matters a great deal. To make sure the cell removal procedure is completed quickly and smoothly, we offer our donors an emergency telephone number so they can contact us at any time of day or night. Along with foresightful organization and careful checks on scheduling, it is absolutely essential that all the relevant information is documented fully and clearly so that we can keep all the internal and external people involved in the process up to date at all times.

In 2020, new challenges, emotional moments, and success stories had a considerable impact on our Workup department.

Since March 2020, the task of coordinating the extraction and transportation of stem cells has been significantly more complex than usual, largely because of the contact and travel restrictions, which vary from place to place and are changing all the time. But the Workup team stopped at nothing to meet the increasing need of donors for relevant information with maximum flexibility. Time and again, we were relieved to see that, when faced with the difficult circumstances, our donors were extremely understanding and positive. Their desire to donate stayed as strong as ever and is evidence of how

important the topic of stem cell donations is to those who are registered with us. Despite all the obstacles, we were able to post a new record number of removal procedures, extraction stem cells and bone marrow from 5,618 donors – a rise of 0.3% compared with the previous year (5,603).

### SUPPORT BEYOND OUR OWN BORDERS

Highly efficient and effective, our IT infrastructure not only provides the essential basis we need in every area of our work but also enables processes to be intermeshed across departments and locations. This is particularly true of DKMS offices in other countries, where the same quality requirements have applied since day one, both in-house and externally. That's why, when we set up a new facility – like we did in Chile in 2018, India in 2019, and South Africa in 2020 – we involve our Information and Technology Services (ITS) department in setting things up from the beginning.

The latest addition to our family – DKMS Africa – is a good example. Born from a partnership with the Sunflower Fund, DKMS Africa administrates its donor database with dedicated DKMS software. To deal with this, our IT specialists started by adjusting these software systems to suit the local specifics and requirements. Next, the servers in our data center were configured and the data migrated from the old system of the Sunflower Fund into our new, specially adapted systems. In addition, we integrated our local offices in South Africa into our in-house DKMS network. So now, if our colleagues in South Africa ever run into IT problems, our central IT support team will be on hand to help.

"This allows us to ensure our employees worldwide can use technologies that are compatible with each other. And above all, it enables them to collaborate and deliver the same high quality as usual," explains Stephan Dötsch, Director Information and Technology Services. "DKMS Africa is benefiting from the opportunities and experience we have gained from our entities over decades. Ultimately, this will boost the acquisition of new donors and benefit the patients who need their help."



### INNOVATION IS OUR DAILY BUSINESS

One area where innovation is our daily business is in bioinformatics. “We seek out the best software for resolving biological questions,” explains head of department Jan Hofmann. “When DKMS is looking at software solutions with a medical or biological background, it’s us they turn to. We may not have much direct contact with donors, but we do know what our work achieves.”

It all started in 2013, when the DKMS Life Science Lab in Dresden took the “neXtype” software on stream as it switched to a state-of-the-art, high-throughput sequencing technology called next-generation sequencing (NGS). At that time, there was no software tool available to map the application of the NGS for high-resolution HLA typing, so we came up with our own: an in-house application that can compile the HLA findings needed for a search on the basis of raw data.

Thanks to scientific progress, new alleles and markers are constantly being discovered that are relevant for donor selection, and DKMS is adapting its software all the time to reflect that. But our specialist teams develop tailor-made software solutions for much more than just lab results: bioinformatics also supports HLA Services, our new, independent DKMS Registry, and various other departments. One of the key goals is to enhance the search software so the best possible match for a patient can be found as quickly as possible. For this to work, the software has to recognize certain information about donors, such as their HLA characteristics and CMV status. This data is then passed on to national and international search registries such as the WMDA or the German National Bone Marrow Donor Registry (ZKRD), who can access the pseudonymized findings directly, and quickly pinpoint any exact donor-patient matches.

Given the wide range of processes that run in the background, it is important for systems to be automated. Some of the biggest challenges in this regard are the speed of technological development, the connection to external interfaces, and the increasing number of DKMS locations around the world.

In bioinformatics especially, employees contribute new ideas and help shape developments. “In order to work to maximum effect, our harmonization processes are short,” emphasizes Jan Hofmann. “That makes us particularly innovative and efficient.”

### WE NEVER STAND STILL

At the heart of our success in quality management and elsewhere are our highly qualified and committed employees. In 2020 the team continued to grow significantly, even during the pandemic, increasing from 654 to 679 employees, German-based subsidiaries included. As coaches, trainers and first points of contact, our managers have a special responsibility. That’s why, to make sure our non-profit organization can continue rising to the challenges of the future, they took part in several workshops in 2020. These set out to explore the management culture and values of DKMS – because to succeed together in the interests of our patients and donors, our employees have to be able to rely on a clear, shared understanding of our mission, values and goals in everything they think and do. We want to be clear, open bold and fair – to each other and to the people we deal with.

Solidarity and cohesion are hugely important to the professionalism of DKMS, and a look at the story of how we were founded proves it. DKMS was established in 1991 and is the result of a personal story. Back then, our founder, Dr. Peter Harf, had promised his wife Mechtild that he would continue his fight against blood cancer for as long as it takes for a “genetic twin” to be found for every patient – and with them the chance of a cure. Sadly, Mechtild, who suffered from blood cancer herself, passed away, but the mindset of her family forms the core of our culture to this day: “We are the DKMS family”.

As we work to keep the promise of our founder, our international organization constantly looks to the future and continues to evolve. To develop our employees, we offer a wide range of training courses, personal learning opportunities, and knowledge transfer formats. And by sharing our ideas and expertise in workshops and attending webinars and online courses, we all continue to learn and develop.



## Gold and silver in the Stevie Awards

**Most Exemplary Employer, Most Valuable Non-Profit Response and Manager of the Year – DKMS scooped not one but three coveted German Stevie Awards 2021, plus two additional international awards. Confirmation of our expedient work, even in times of crisis.**

The category of Most Valuable Non-Profit Response focused on outstanding projects by non-profit organizations in response to the challenges of the pandemic. The jury particularly emphasized DKMS’s significant value-add for society, praising the skillful adaptation of all our processes so we could continue operating despite the situation. They also highlighted our DKMS mindset.

In addition, DKMS did well in the category for Most Exemplary Employer, which honors the special commitment of organizations that remunerated employees in full and offered them the greatest possible security despite the pandemic. In particular, the jury were inspired by our clear, effective crisis management, honest, empathic, appreciative dealings with employees, and measures to increase confidence.

And last but not least, the Stevie Award for Manager of the Year went to Dr. Elke Neujahr, who was confirmed as demonstrating an empathic and values-based leadership style, coupled with foresight and a profound understanding of risk management. “I’m incredibly pleased that we at DKMS took Gold in not one but three categories and I dedicate this award and my sincere gratitude to all our teams, every one of our employees, and all of our supporters,” said Dr. Elke Neujahr, Chair of the Board of Directors, DKMS gGmbH and Global CEO. “I see this award as a fantastic confirmation of our successful work, especially in these challenging times.”

The German Stevie Awards are a prestigious business award in the German-speaking countries of Europe and were presented for the seventh time this year. More than 400 companies and organizations applied for the awards and were put through their paces before the most innovative solutions were filtered out.

DKMS also scooped two international Stevie Awards, being chosen from among 3,700 applicants for Gold in the category for Most Valuable Non-Profit Response and Silver for Most Exemplary Employer. The awards are a sign of appreciation and recognition for our global collaboration as an international organization.



Dr. Elke Neujahr, Thilo Mengling and Daniel Knoll express their delight on behalf of the whole organization.



## “SURE, WE TALK ABOUT MONEY!”

The DKMS Fundraising team consists of 17 employees, whose daily work is to organize financial support for our mission. Their mission: to find and retain financial donors.



Heike Müller-Jungbluth,  
head of Fundraising

### Why is the topic of money so important for the work of DKMS?

Idealism is all well and good – but to provide effective help and win the fight against blood cancer, we need money. So, it’s actually quite important to talk about it. Every year, we are delighted to welcome hundreds of thousands of new donors to our database, each of whom costs us €35 to register. In 2020 alone, this required funding of around €15 million, which we have to draw from our own resources. These costs are not covered by the health insurance companies, and our many young donors especially – who deserve our deepest gratitude – often lack the money to cover these costs themselves. It’s these financial resources that Fundraising takes care of.

### What else are money donations spent on?

We also use the money we receive on other important fronts in the fight against blood cancer: to support science and research, improve access to stem cell transplants worldwide, and offer international support for the development of new donor registries and transplant clinics.

### How does DKMS inform its supporters about these projects?

Through regular progress reports on our work. Our regular mailshots, for example, tell them what we are achieving with people’s donations and where we still need to improve. In 2020 we sent out some 1.5 million letters and, to our delight, our appeals for donations brought in around €4.4 million – for which we’re truly grateful.

### How do our supporters benefit from their donation?

First of all, they get to feel good about having helped and contributed to the fight against blood cancer. But they also get to enjoy being part of a great movement to save lives. In our experience, people often find they need help to be able to offer help. So we’re happy to advise and assist. We want to educate, support, and foster lifelong partnerships.

### When are people particularly interested in donating?

In the run-up to Christmas. It’s a time of year when people often look back and feel they want to give something back to society or help others who are less fortunate than themselves. About 50 percent of our annual donations come in from October on, so that’s a time we particularly look forward to. But another important factor that often gets people donating is a personal link to blood cancer – a patient in the family, at school or work, in a club, city or region.

### So, what conclusion would you draw from that?

Every euro counts. Large donations from various sources give us a great deal of planning security, of course, and allow us to finance things like our schools project. But we’re particularly touched by people who don’t have much income themselves but still donate €10 – and then apologize for it being so little! And yet we’re so grateful to have it. And our supporters also give us far more than “just” money: they sacrifice their valuable time. In these fast-paced times, that’s something truly special and we’re always absolutely delighted. In 2020 one supporter of ours crossed the Alps on foot. It took him 16 days, but the physical effort was worth it, and DKMS was presented with an amazing €2,500, which he had raised from his family and sponsors.

## Feedback from our financial donors

In 2020, we contacted our supporters directly and invited them to take part in an online survey. We were very keen to find out how satisfied they were after they had donated money to us. Going forward, we want to respond even more purposefully to the wishes and needs of our donors. The response rate to the survey was overwhelming, and the positive results give us plenty of reason to be happy:

 **93 %**

**OF THOSE SURVEYED SAY THEY FEEL GOOD ABOUT DONATING TO DKMS.**

 **86 %**

**GIVE A POSITIVE ASSESSMENT OF THE PERSONAL APPRECIATION WE SHOWED AND OF THE WAY OUR MONETARY DONATIONS SERVICE HANDLED THEIR DONATION.**

 **90 %**

**WOULD RECOMMEND DKMS AS A WORTHWHILE PLACE TO DONATE TO.**

 **98 %**

**OF OUR REGULAR MONEY DONORS INTEND TO CONTINUE DONATING MONEY TO DKMS.**

 **31 %**

**WOULD LIKE TO LEARN MORE ABOUT THE DKMS LIFE SCIENCE LAB.**

 **26 %**

**WOULD LIKE TO LEARN MORE ABOUT THE SCIENTIFIC RESEARCH BEING CARRIED OUT BY THE DKMS CLINICAL TRIALS UNIT.**



### Online money donations are on the rise

Online donation has been a growing trend for quite some time now – and the pandemic has accelerated it. The AmazonSmile charity shopping program alone brought in donations worth €477,317.82 in 2020 – a rise of 122 percent compared with 2019. Great news for us! The many creative fundraising campaigns on Facebook were another highlight, with wonderful people raising €706,051 to support our mission.



### DKMS has the Ethics Signet

Quality and trustworthiness are the fundamental principles of our work and the focus of what we do. Since 2020, we have held the Ethics Signet of the German Fundraising Association. This means we are fully committed to complying with the 19 Basic Rules for Good, Ethical Fundraising Practice. The signet is confirmation of integrity, fairness, data protection, and transparency.



# WE CELEBRATE LIFE

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The DKMS “Club of Life” campaign in 2020 was all about togetherness. And the goal was to reach out to as many potential young donors as possible.



In late 2020, posters in cities across Germany raised awareness of our mission



Lars Penke beat blood cancer after a stem cell transplant and was an active supporter of our campaign

In the autumn and winter of 2020/21, we launched a nationwide campaign to highlight the importance of community in the fight against blood cancer. The primary aim was to reach out to young people with our all-important message: patients need lifesavers, even during a pandemic. And because young donors are in particular demand from transplant doctors, we decided to call on them to sign up.

The message we reached out to them with was: Join the club that celebrates life every day – a motivating appeal to encourage more young people to commit to helping blood cancer patients together. For many people affected by the disease, a sense of solidarity and feeling that they are not alone are more important than ever during the crisis.

“Special times call for special measures, and that’s why we decided to take this bold step and send our positive and clearly life-affirming message out to the public. We didn’t want to wait until the pandemic was over. After all, blood cancer doesn’t wait – it comes along when you least expect it,” says Dr. Elke Neujahr, Chair of the Board of Directors at DKMS.

The Club of Life campaign deliberately emphasized the importance of solidarity, and the idea of community became the focal point of our communications. Our extensive DKMS community includes patients, donors, doctors, researchers, all of our DKMS colleagues, and, above all, our many supporters. All of them care about others and want to support our fight against blood cancer together.

This attitude to life was also expressed on a website accompanying the campaign and publicised among other things through a video with real stem cell donors and a recovered patient, Lars Penke, pictured above. Conveying this message, the 28-year-old could hardly have been more authentic and likable. Online and off, we were able to raise awareness of our issue through TV commercials, out-of-home advertising, and social media. Between October 10, 2020, and February 28, 2021, we received 81,511 requests for registration kits from people under 30. A fantastic result!

## Building solidarity with cancer patients

With its “Cancer Doesn’t Stop”-campaign and the online charity event dreamday the DKMS subsidiary DKMS LIFE strives to make sure that serious illnesses such as cancer are not forgotten in the public awareness, even during the pandemic. Their encouraging message to those affected is: You’re not alone!



The German fashion designer and TV personality Guido Maria Kretschmer is a supporter of DKMS LIFE.

Since the pandemic, much has changed. But one thing that hasn’t is cancer. In Germany alone, about 500,000 people a year are still diagnosed with the disease. They find themselves battling a life-threatening condition – and the additional risks posed by the novel coronavirus. Many are forced into isolation for months on end as the pandemic makes their disease even more difficult to handle, in all kinds of ways. From having someone to accompany you to a doctor’s appointment, to taking care of everyday errands, or even just finding reassurance in a hug from someone you are close to, the pandemic makes everything much harder.

The coronavirus brought many things to a standstill – but it didn’t manage to stop cancer. And that’s why, in 2020, DKMS LIFE launched a comprehensive campaign to raise awareness of this all-important topic, under the motto CANCER DOESN’T STOP. Ruth Neri, a director at DKMS LIFE, explains: “We want our campaign to remind patients that they

are not alone – despite their social isolation at the moment, we are still here to help. We want to give them courage, hope, and a new joy of life. DKMS LIFE has been doing just that for the last 25 years, with the “look good feel better” program for patients. This campaign is generating donations for the program, but we are also calling on all patients to go for cancer screening – because cancer screening saves lives.”

The official symbol of the campaign is the crossed-out “pause” symbol, represented by the parallel index and middle fingers of one hand, crossed by the index finger of the other. Many users on social media responded to the campaign by posting their photos under the hashtag #krebsmachtkeinepause (cancer doesn’t stop) to raise awareness of the campaign and show their solidarity with patients during the coronavirus pandemic.

## Colleague and hero

DKMS’s very own Emrah Kilic, from Cologne, was also asked to donate stem cells

Thanks to his job in Corporate Communications at DKMS, Emrah Kilic deals with the topic of stem cell donations every day. But the news that it was his turn to donate came as a complete surprise. The 43-year-old had registered in May 2013, and his peripheral stem cell donation happened in April 2020, in Cologne. The recipient of his cells is an adult patient from France – although their contact has been purely anonymous so far.

Emrah Kilic recalls: “After two-and-a-half hours of having stem cells removed, I felt a little bit weak, but after all the donors’ stories I had read, seen, and heard over the years, I was elated to be writing my own at last. Personally, I found donating stem cells incredibly enriching and positive, and I’d do it again anytime. It also reinforces what I think and do and makes me want to sensitize even more people to the importance of our work.”



Emrah Kilic donates stem cells



#TEAM 10 MILLION

STRONGER TOGETHER

## A new milestone: 10 million donors

For us, 2020 was also a year of celebration, as we reached a truly major milestone: from 1991, the year DKMS was founded, to the end of May 2020, our registry had attracted over ten million potential donors who all wanted to help. It's a record result that would never have been possible without the commitment of our countless supporters around the world. Together, we have further increased the chances of even more people receiving a stem cell transplant and, with it, a second chance at life. All ten million of our donors are now available for global searches – a far cry from the mere 3,000 registered donors in Germany in 1991, the year we started our work.

“Ten million registered donors is an overwhelming result. But for our DKMS family and me, this will never be all about numbers,” says Dr. Elke

Neujahr, Chair of the Board of Directors at DKMS. “This is about each and every donor and patient, and about everyone who is affected by one of these life-threatening diseases. Our fight against blood cancer continues.”

DKMS today plays a crucial role in the global transplant community. More than a quarter of the world's 38.5 million potential donors are registered with us. “It's a fantastic achievement,” says Lydia Foeken, CEO of the World Marrow Donor Association (WMDA), “that would never have been possible without the passion and commitment of DKMS employees and supporters across the globe.”

But still tens of thousands of patients with blood cancer or other blood disorders are waiting for a matching donor – some of them in vain.

## TOTAL NUMBER OF DONORS AT OUR INTERNATIONAL ENTITIES\*

Germany

6,847,170

Poland

1,664,947

USA

1,136,344

UK

784,084

Chile

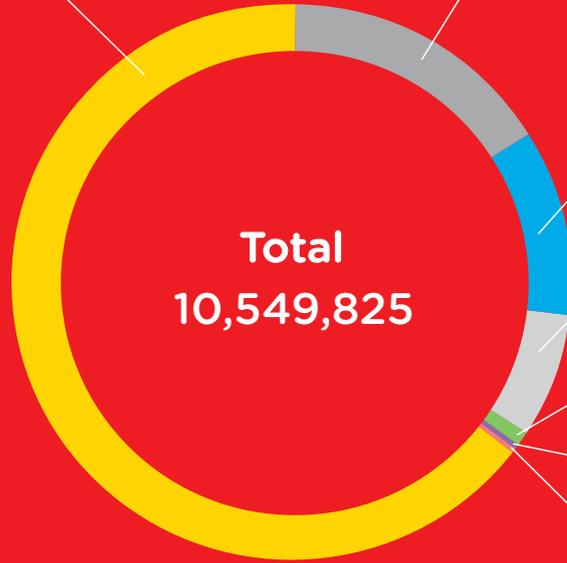
68,399

India

43,100

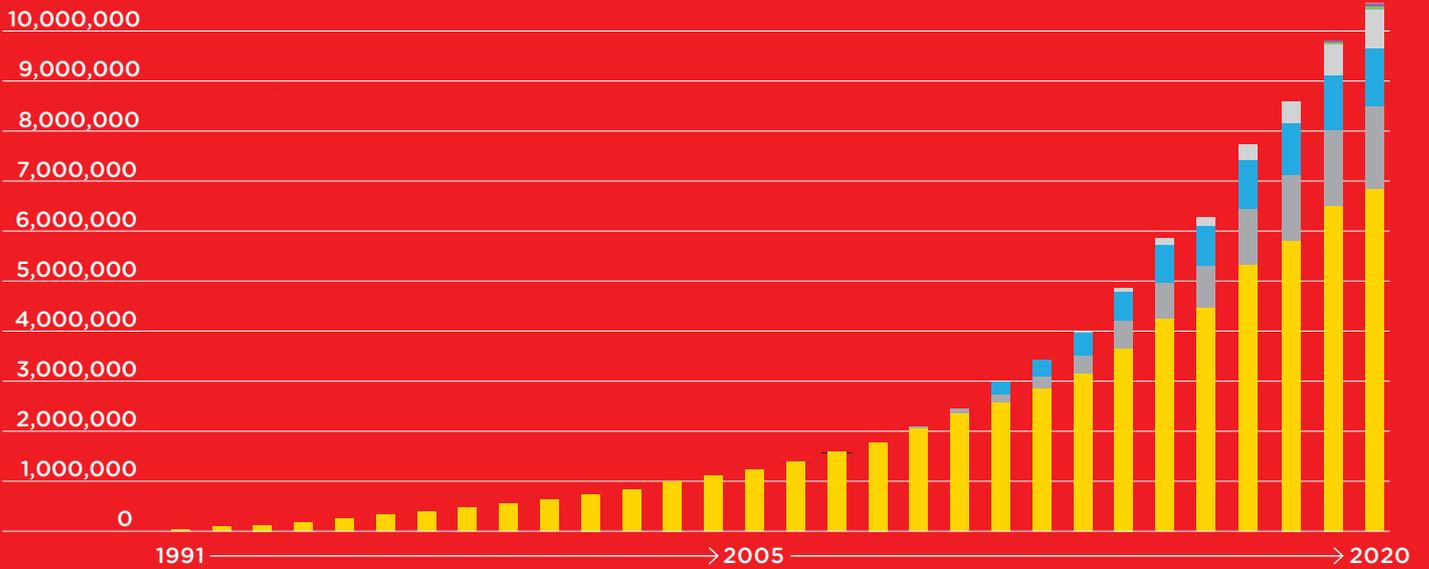
South Africa

5,781



\* Active donors

## DEVELOPMENT OF DONOR NUMBERS OVER THE YEARS



DKMS in Germany

DKMS in the USA

DKMS in Poland

DKMS in the UK

DKMS in Chile

DKSM BMST Foundation India

DKMS in South Africa (including the Sunflower Fund)

# THE CHALLENGES



**One in 10 blood cancer patients** in Germany cannot find a matching stem cell donor.



**Every 12 minutes**, someone in Germany is diagnosed with blood cancer..



Every year, around **19,500 people** in Germany die of blood cancer.

# FINANCIAL RESULTS 2020

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Despite the spread of the SARS-CoV-2 coronavirus and the challenges it posed, DKMS gGmbH can look back on a successful 2020. Our organization is in a position to continue its fight against blood cancer, independently of government grants.

The primary focus of DKMS gemeinnützige GmbH (referred to as “DKMS” in the following) is on recruiting well-informed volunteers as stem cell donors. Their personal desire to support patients with leukemia or other blood disorders by donating stem cells by either peripheral blood stem cell collection (PBSC) or bone marrow harvesting (BMH) is of the utmost importance. Part of DKMS’s work consists of actively supporting the development and maintenance of systems and databases that facilitate and expedite donor searches both nationally and, increasingly, internationally. Support with donor selection for blood cancer patients and the procurement and provision of stem cells for transplantation round off the DKMS service spectrum.

As DKMS goes ever more global, donor recruitment remains the core of its long-term strategy. For the last 20 years, DKMS has been promoting and funding the establishment of legally independent, foreign-based donor organizations, both in the EU and beyond,

that cooperate closely with DKMS in Germany. Since 2020, DKMS has been active on five continents, striving throughout to enable stem cell transplants for patients of any ethnicity with blood cancer or other disorders of the hematological system. This is done by finding the best possible matching donors for them – which is key to increasing the chances of survival for patients worldwide, no matter where they live or what their background.

Our brand image, public popularity, and donor satisfaction levels are fundamental to our success. We intend to continue focusing on these aspects so that we can continue recruiting volunteers as donors in the future.

DKMS also conducts research into the effectiveness of hematopoietic stem cell transplants with unrelated donors. Other activities include supporting fundraising by other organizations working to promote public healthcare and research and science.

Being a non-profit organization, DKMS has a minimum essential goal: to cover the necessary costs of its own business operations. It is refinanced primarily by proceeds from cost reimbursements by public health systems at home and abroad as well as donations from individuals and businesses.

Since mid-2016, DKMS has also been operating as a register, i.e. as an intermediary between transplant clinics and donor databases. On August 1, 2020, it set up an independent subsidiary to take care of this part of its business, DKMS Registry gGmbH, Tübingen. This was the only major change to the DKMS business model over the last financial year.

### Research and development:

DKMS has long been committed to scientific research around stem cell donation. Studies by its Scientific Projects department mainly investigate donor selection and methods for specifically increasing diversity within the donor database so that matches can be found for as many patients as possible. At the Clinical Trials Unit (CTU) the primary focus is on the performance and promotion of clinical research around blood cancer therapies.

To support the fight against the COVID-19 pandemic, we also carried out a survey of DKMS-registered donors in Germany. In the late summer of 2020, we asked them if they had contracted COVID-19 and, if so, how the disease developed. More than 920,000 donors took part in the survey, making it one of the largest population-genetic studies on COVID-19 to date.

In 2020, R&D costs totaled €3,716k, accounting for a 3.7 percent share of our revenue.

### Income statement:

#### 1. Financial result

2020 – the year of the pandemic – was extremely challenging for every area of DKMS. So, the fact that we were able to post an annual profit of €2,769k (compared with €7,359k in the previous year) was welcome news and much higher than forecast yet again. The deviation of almost €13m above plan was enabled by lower HR and marketing costs and a significant drop in other operating expenditure, mainly attributable to project delays caused by the pandemic.

With revenues of €99,888k, DKMS was once again able to lay the foundation for a clearly positive result. Despite a slight fall of 1.5 percent, the figure

is slightly higher than forecast (€98,390k), thanks to the sustained development of stem cell removals carried out in 2020. Other operating income amounted to €17,926k, significantly less than in the previous year owing to the pandemic and in particular to falling revenues from money donations (./ €. 4,685k)

#### 2. Donor recruitment

DKMS is one of 26 organizations in Germany dedicated to recruiting and procuring volunteer stem cell donors. With 6,847,170 potential donors as at December 31, 2020, we are by far the largest donor database in the country. Compared with the previous year, the number of donors rose by 5.4 percent, with 415,973 new registrations in total in 2020. Although we were unable to match the 649,417 new registrations of the previous year, the number of new donors entering our listing was still far higher than the number leaving for age, health, or other reasons.

The main reason for the significant drop in new registrations in 2020 was the increasing spread of the novel coronavirus. This led to palpable restrictions in public life, which severely impacted our donor recruitment work. DKMS was very quick to respond, adopting a highly responsible approach: we canceled all public donor drives for the protection of everyone involved. But to make sure as many people as possible could continue to register as potential stem cell donors, we soon developed online alternatives. Our Virtual Donor Drives ultimately helped offset a significant share of the losses we had sustained by having to cancel physical events.

Another strategic business area in the field of donor recruitment is the acquisition of young donors, who are very important for enhancing the quality of the DKMS donor database. In 2020 DKMS reached out specifically to this group, resulting in 239,441 young donors between 17 and 30 years old registering with us (compared with 355,869 the previous year). As a result, in the first year of the public health crisis, young donors accounted for approx. 58 percent of all new registrations. This represents a remarkable 3 percent rise in the share of young donors compared with the previous year. 85,222 of these newly registered donors were young males, who made up around 21 percent of new registrations overall in 2020.

#### 3. Donations and recipients organized

In 2020 DKMS organized 5,618 stem cell donations by either bone marrow or peripheral stem cell removal, marking a rise of 0.3 percent on the previous year (5,603). However, there was a significant

shift between the share of bone marrow removals and peripheral stem cell donations. Compared with 2019, the number of bone marrow donations dropped by 5.4 percent to account for 11.2 percent of procedures. In the remaining almost 90 percent of cases, peripheral stem cell donation was used. Bone marrow donations had already been falling for quite some time, but the trend was further magnified by the coronavirus pandemic and is attributable in part to the sometimes limited capacity available for bone marrow removals.

#### 4. Fundraising

In 2020 the pandemic posed an extraordinary challenge to DKMS's fundraising endeavors. Fundraising is a key and permanent contributor to the realization of the organization's purpose.

From mid-March the pandemic put an end to donor drives and community fundraising channels. Across the community fundraising channels and company donor drives alone, revenues dropped by almost €3m in 2020 and could not be offset by developing new, online solutions.

In 2020 revenues from financial donations totaled €14,262k (compared with €18,947k the previous year). Of that, €13,202k came from money donations (2019: €17,737k); €574k from fines imposed by German courts (2019: €624k); and €485k from material donations (2019: €587k). Even in the pandemic, financial donors clearly felt a strong sense of loyalty to DKMS, often because they are registered as donors as well.

#### 5. Material costs

In 2020 material costs were lower than in the previous year, totaling €2,876k. The main cause for the drop was the almost 36 percent fall in typing numbers. However, the effect of this saving is significantly reduced by a contractually agreed, retrospective price increase for lower volumes of typing.

#### 6. Personnel costs

Even during the crisis, DKMS continued to grow fast as an organization. This is evidenced by the rise in personnel costs from €24,691 in 2019 to €26,020 as at the end of 2020. The average headcount rose from 371 the previous year to 417 in 2020.

Throughout the business year, the workforce continued to grow in certain areas. This trend is expected to continue into 2021 as DKMS becomes increasingly international to be able to meet its strategic goals. For this reason, investments in boosting IT have been particularly strong, and further significant funding has been channeled into the development and expansion of DKMS's medical expertise.

#### 7. Other operating expenses

Other operating costs amounted to €36,012k in 2020 - considerably more than in the previous year (€34,141k). Expenditure on licenses, foreign currency losses and project support rose sharply while spending on freelancers and travel dropped. In 2020 price losses amounted to €1,832k (compared with €147k in 2019). Of that amount, €1,373k was accounted for by unrealized currency losses (compared with €55k the previous year).

# INCOME STATEMENT

|   | 2020, in €k   | 2019, in €k    |
|---|---------------|----------------|
| <b>Sales proceeds</b>                     | <b>99,888</b> | <b>100,100</b> |
| Other own work capitalized                | 525           | 0              |
| Change in inventories of work in progress | -174          | 35             |
| Other operating income                    | 17,926        | 21,568         |
| Cost of materials                         | -48,712       | -51,588        |
| Personnel expenditure                     | -26,020       | -24,691        |
| Depreciation                              | -4,783        | -6,112         |
| Other operating expenditure               | -36,012       | -32,141        |
| <b>EBIT</b>                               | <b>2,638</b>  | <b>7,171</b>   |
| Financial result                          | 150           | 203            |
| <b>Pre-tax profit</b>                     | <b>2,788</b>  | <b>7,374</b>   |
| Profit tax and other tax                  | -19           | -15            |
| <b>Annual profit</b>                      | <b>2,769</b>  | <b>7,359</b>   |
| Withdrawals from retained earnings        | 51,361        | 51,663         |
| Appropriation to retained earnings        | -53,630       | -57,563        |
| <b>Net retained profits</b>               | <b>500</b>    | <b>1,459</b>   |

**Balance sheet**

In 2020 the equity ratio remained unchanged at 91 percent, and on December 31, 2020, liquid funds amounted to €52,207k, including holdings of USD worth €16,854 (2019: €6,706k). This means the liquidity situation at DKMS remains outstanding, so the organization can continue pursuing its non-profit goals over the longer term. However, the earnings situation was significantly impacted by considerable fluctuations in the USD-EUR exchange rate, which affected revenues in USD as a consequence of the continuing high levels of stem cell collections for the US region. But because DKMS does not need to sell its USD holdings, the management expects to be able to offset a significant part of the unrealized foreign currency losses in the coming business year.

DKMS can service its running costs fully from its operative, free cash flow, and measures can still be financed without borrowing from credit institutions. Financial obligations of €18,956k exist that are not reported or recorded in the balance sheet but are important for the assessment of DKMS’s financial position. They include €2,332k which are due within one year. The year-on-year rise in other financial obligations is mainly due to the establishment of a long-term lease agreement for DKMS’s Cologne base.

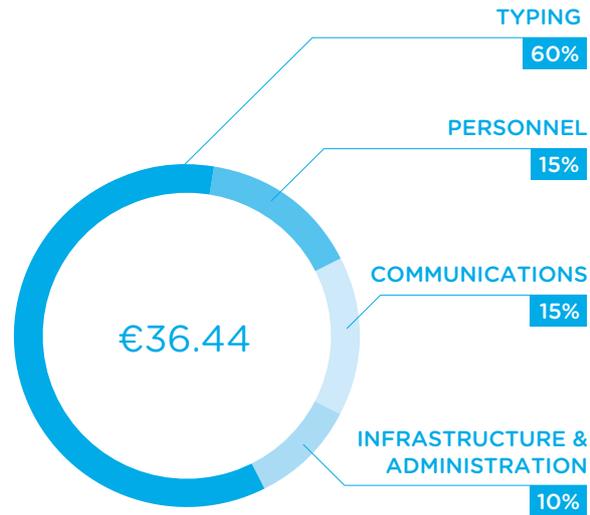
In 2020, DKMS invested €19,683k in new registrations to expand the donor database (compared with €23,666k in 2019). Of that amount €5,995k was not financed by donations (2019: €5,374k) but covered entirely with funds generated by DKMS itself, as in the previous year. The decline in investments to expand the donor database was caused mainly by contact restrictions due to the pandemic and the resulting cancelation of donor drives.

Reserves for scientific projects to combat leukemia amounted to €6,347k in 2020 (compared with €6,640k in the previous year), while reserves for quality improvement projects amounted to €2,510k (compared with €2,219k in 2019). In the past financial year, €2,297k (previous year: €3,232k) was spent on financing scientific projects, and €729k (previous year: €863) on quality improvement projects.

Financial support for foreign DKMS organizations and funded projects amounted to €11,529k in 2020, up slightly from €11,068k in the previous year. Of this amount, €4,140k went to DKMS Stem Cell Bank gGmbH (formerly DKMS Cord Blood Bank), €3,483k to the company in the UK, and €850k to DKMS LIFE

gGmbH. €698k went to the parent company, the DKMS Foundation for Giving Life, €689k to DKMS Registry gGmbH, and €387k to the Sunflower Fund Partnered by DKMS. €1,282k went into support for external partners outside the DKMS Group.

## Registration costs



In 2019 registration costs amounted to €36.44 per new donor, but in 2020 they rose noticeably due to the pandemic. At the moment, we are still working on the assumption that this will remain a one-off effect that continues for a limited time only, so calculations from 2019 continue to apply. Even though better-quality findings from typing have meant an increase in the cost, DKMS still asks its supporters to donate only €35 per registration.

# BALANCE SHEET

| <b>ASSETS</b>   | <b>2020, in €k</b> | <b>2019, in €k</b> |
|---|--------------------|--------------------|
| <b>A. Fixed assets</b>                                |                    |                    |
| I. Intangible assets                                  | 7,869              | 8,750              |
| II. Tangible assets                                   | 3,294              | 3,301              |
| III. Financial assets                                 | 68,271             | 62,398             |
| <b>Total</b>  | <b>79,434</b>      | <b>74,449</b>      |
| <b>B. Current assets</b>                              |                    |                    |
| I. Inventories  | 1,335              | 1,227              |
| II. Receivables and other assets                      | 13,529             | 12,530             |
| III. Cash on hand and bank balances                   | 52,207             | 55,766             |
| <b>Total</b>  | <b>67,071</b>      | <b>69,523</b>      |
| <b>C. Prepaid expenses</b>                            | 1,313              | 1,271              |
| <b>TOTAL ASSETS</b>                                   | <b>147,818</b>     | <b>145,243</b>     |
| <b>EQUITY AND LIABILITIES</b>                         | <b>2020, in €k</b> | <b>2019, in €k</b> |
| <b>A. Equity</b>                                      | <b>133,916</b>     | <b>132,606</b>     |
| <b>B. Provisions</b>                                  |                    |                    |
| I. Tax provisions                                     | 1                  | 1                  |
| II. Other provisions                                  | 3,209              | 5,936              |
| <b>Total</b>  | <b>3,210</b>       | <b>5,937</b>       |
| <b>C. Liabilities</b>                                 |                    |                    |
| I. Liabilities from conditionally repayable donations | 0                  | 100                |
| II. Deposits received on incoming orders              | 212                | 204                |
| III. Liabilities from goods and services              | 5,372              | 4,042              |
| IV. Liabilities for services based on statutes        | 1,900              | 0                  |
| V. Liabilities to affiliated companies                | 2,690              | 1,978              |
| VI. Other liabilities                                 | 518                | 376                |
| <b>Total</b>  | <b>10,692</b>      | <b>6,700</b>       |
| <b>TOTAL LIABILITIES</b>                              | <b>147,818</b>     | <b>145,243</b>     |

# OUR 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.**

The business activities of our 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:

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

**§ 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;

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

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

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

**§ 6** Provision of vocational training measures in the field of bone marrow or stem cell transplantation, in particular to support medical specialists, healthcare workers, search coordinators, donor center and registry staff, scientists, geneticists, medical ethics experts and lab staff, e.g. by organizing congresses;

**§ 7** 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.

## EXECUTIVE DIRECTORS OF DKMS GGMBH



**DR. ELKE NEUJAH**  
Chair of the Executive Board,  
Global CEO DKMS Group



**DR. DR. ALEXANDER SCHMIDT**  
Chief Medical Officer (CMO)



**SIRKO GEIST**  
Chief Financial Officer (CFO)

## FOUNDATION BOARD



**PROF. MARCEL VAN DEN BRINK, MD, PHD,  
CHAIR (PICTURED FAR LEFT)**  
Katharina Harf (Deputy Chair, pictured left)  
Laurence Atlas  
Prof. Dr. Dr. h.c. Dieter Hoelzer  
Anna-Lena Kamenetzky-Wetzel  
Prof. Dr. Thomas Klingebiel  
Sebastian Lombardo  
Alejandro Santo Domingo  
Patrice de Talhouët  
Alexandre van Damme

## MEDICAL COUNCIL



**PROF. THOMAS KLINGEBIEL  
(CHAIR, PICTURED)**  
Prof. Marcelo Fernández-Viña  
Prof. Dr. Katharina Fleischhauer  
Dr. Stephen J. Forman, MD  
Prof. Dr. Dr. h.c. Dieter Hoelzer  
Marcel van den Brink, MD, PhD  
Dr. Dr. Alexander Schmidt (DKMS)  
Prof. Dr. Johannes Schetelig (DKMS)  
Dr. Peter Harf (founder of DKMS and permanent guest)

# 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 our 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

## Management and employees

- Monthly Executive Board meetings; regular management meetings for internal coordination, optimization, and risk assessment
- Regular training on incident and crisis management as well as data protection

## Tax Compliance Management System

- Production of an overall framework offering an overview of all measures to ensure legal compliance with regard to tax liabilities; quarterly updates of the risk matrix included in the framework

## Cooperation with internal and 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 to Executive Board, 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. mailshots)
- Examination of legality of receipts issued for donations

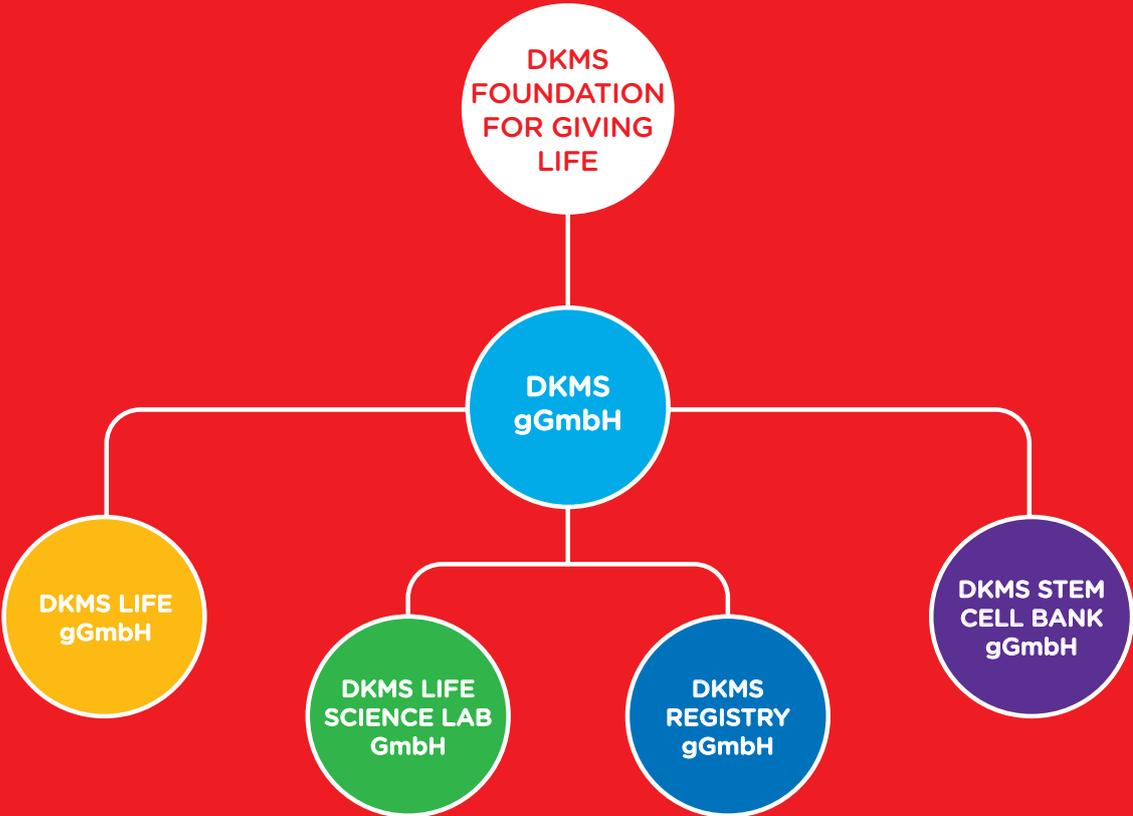
## Annual accounts

- Annual audits by an independent external auditor as the 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

# STRUCTURE OF DKMS



# DKMS ENTITIES WORLDWIDE





## We protect our donors' data

At DKMS, we handle highly sensitive personal data and do all we can to ensure it is adequately protected. To us, compliance with data protection law and absolute data security are crucial.

Personal data protection is fundamentally important to DKMS. Data protection in general is an integral part of the right of every citizen to informational self-determination, which guarantees them the right to determine for themselves which elements of their personal data – and consequently their personal privacy – may be disclosed and used.

As the largest stem cell donor registry in the world, DKMS has a particular responsibility to protect the highly sensitive, personal medical data of its registered donors. But it also processes the personal data of employees, business customers, money donors, and volunteers – with equal diligence and in compliance with data protection law.

To ensure we meet the stringent requirements around data protection, DKMS has issued in-house guidelines that primarily cover the following:

- Ensuring data security within the organization
- Protecting the personal data of data subjects
- Employee training

In addition, DKMS's third-party data processing contracts stipulate that cooperation partners and other service providers must abide by the standards of the Data Protection Regulation (GDPR). According to the GDPR, external parties may only receive and process data on behalf of DKMS and in accordance with DKMS instructions. Besides our data protection regulations, DKMS is currently setting up a DKMS-wide data security management system, which will continue to enhance data security, focusing consistently on risk.

### How are these regulations implemented day-to-day?

DKMS does not share any information about the personal data it has processed with other individuals, organizations or authorities. Any search-relevant data is pseudonymized, as agreed with the data owner, and passed on to other registers in Germany and beyond, purely for global donor searches. The recipients of this data use it to support their searches but cannot trace it back to its owner. The identity of the owner is known only to DKMS.

To ensure that all personal data is kept fully secure, DKMS regularly monitors and updates its technical and organizational measures and its encryption methods especially.

DKMS's work is governed not only by the GDPR and the German Federal Data Protection Act but also by the following regulations pertaining to data privacy law, with which DKMS regularly aligns its own in-house guidelines:

- The German Standards for Unrelated Blood Stem Cell Donations issued by the German National Bone Marrow Donor Registry (ZKRD)
- The guidelines of the Food and Drug Administration, regulations of the Health Insurance Portability and Accountability Act
- Standards of the World Marrow Donor Association (WMDA)

# THANK YOU!

We would like to express our heartfelt thanks to everyone who has supported us in the fight against blood cancer over the years.

With your help and support, we have so far been able to offer some 90,000 patients around the world a second chance at life. We couldn't have done it without you.

But our mission still isn't accomplished – because we want to find the right donor for every patient.

We appreciate your continued support.  
The only way we can delete blood cancer is together.

**Yours,  
DKMS**



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