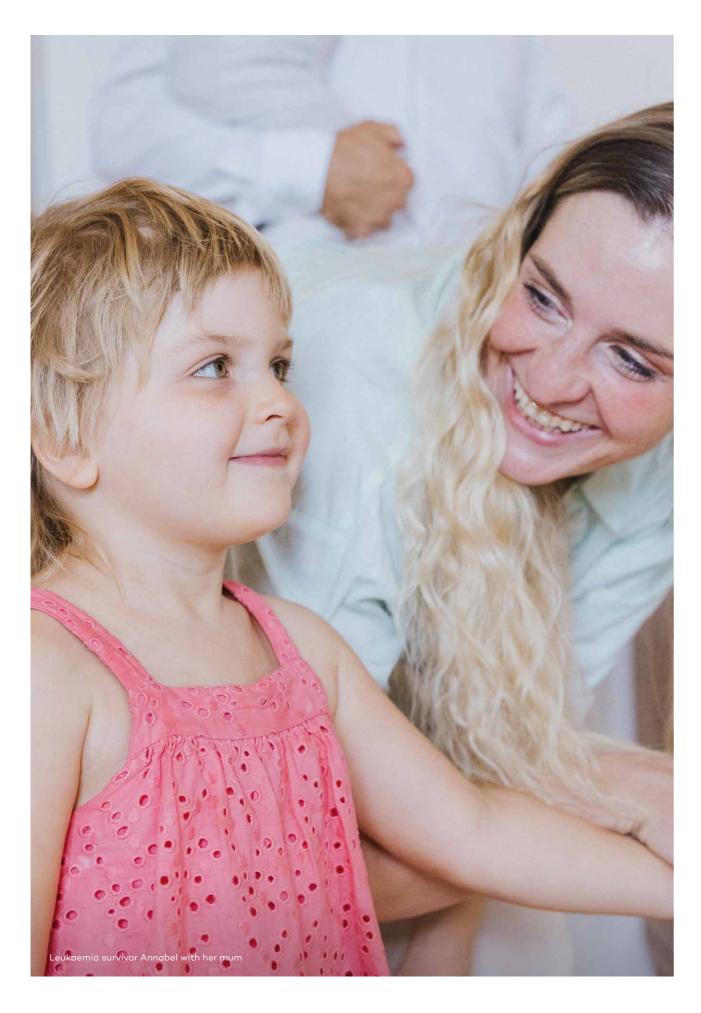


### Global Impact Report 2023

Give hope. Save lives.



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**Our Global Footprint** 

"A miracle to be alive"

Celebrating five years and counting

Chile

2023   5

Editorial Editorial



## Dear supporters and friends,

Welcome to the first edition of our DKMS Global Impact Report! In this report, we will share the global progress we have made so far in our lifesaving mission.

Since we were founded in 1991, we have achieved some remarkable milestones. What started as a private initiative in Germany – driven by the tragic fate of Mechtild Harf – is now the world's leading non-profit organisation for patients with blood cancer and other blood disorders. We are much more than a stem cell donor centre though; we are also a patient organisation that strives to improve the chances of recovery before and after transplantation.

2023 was a particularly groundbreaking year for us. With the opening of three of our own DKMS Collection Centers in Germany and Chile, we now support our donors throughout the entire donation journey: from initial information and registration of potential donors, through to high-resolution typing, actual collection of stem cells and follow-up. Often, we even build strong connections with them and stay in touch for many years after.

We also rely on Research & Development to ensure the highest quality standards and seamless processes. The same is true of our recently launched Stem Cell Bank – another significant achievement. This innovation enables us to help blood cancer patients with common genotypes even faster. We can now deliver the cryopreserved stem cells that are so urgently needed in acute cases within just 72 hours – a pivotal and globally unique breakthrough.

Thanks to our selfless stem cell donors and supporters worldwide, we have already been able to save countless lives and give hope. In 2023, we also passed the impressive milestone of 12 million registered donors! What's more, since our foundation we have been able to give over 110,000 people in 60 countries a second chance at life through a stem cell donation.

A large and diverse donor pool is crucial to our mission. To this end, we register people in seven countries on five continents, making us the largest stem cell donor database in the world. Our database also serves as a search unit for clinics worldwide, ensuring patients receive the best chance of a suitable donation.

Yet, our commitment goes much further: in 2014, we launched international aid programmes to support people in low- and middle-income countries. In 2023

alone, we gave more than 400 patients in regions with limited access to transplants a second chance at life – bringing the total since 2014 to 1,500.

We have always been bold in our approach to new topics and fields, and our DKMS entities – especially our medical-scientific units – have helped us break new ground with numerous innovations and improvements, giving hope to more and more patients in need.

Allow me to highlight just some of our achievements in R&D. Since the founding of our DKMS Life Science Lab (LSL) and DKMS Clinical Trials Unit (CTU), our expertise and know-how have earned us respect in the international haematology community. We remain committed to continuously improving transplantation and cell therapies to boost the chances of recovery for patients even further. And that's why we are proud to present the findings of our latest research in this report.

Over the years, we have matured into a unique international organisation. The success of our DKMS group is based on close cooperation between our affiliates, who stand united in pursuit of our mission. We take a holistic approach because we believe it's essential for the lives of patients. To present our endeavours in a way that makes sense, we have defined three interconnected pillars that reflect our three clear areas of impact: (1) Boost Stem Cell Donations, (2) Improve Access to Transplantation in disadvantaged regions, and (3) Advance Research & Development. This report tells you more about what we do and also presents some patients' personal stories.

We still have a long way to go, but we are well-equipped for the journey. Our Agenda 2030 sets out our ambitious goals, such as giving 12,000 patients every year a second chance at life. Our ability to overcome challenges such as the COVID-19 pandemic – and even seeing them as opportunities to develop – proves that we will remain flexible and innovative well into the future. Digital donor registration, for example, is just one of the modern options we have introduced to help us further advance our mission.

I hope you enjoy reading this report. Thanks to our donors, colleagues, supporters and partners worldwide, we are tackling blood cancer and giving people a second chance at life. This report tells you how.

Sincerely

Dr Elke Neujahr

Global CEO, DKMS Group



## Our global impact in numbers...

Our donors are at the heart of our mission

Potential lifesavers

12,202,341

registered donors
as of 31 December 2023

694,089
donors recruited in 2023

We give hope to patients worldwide

Second chances at life

114,021

since 1991

8,318

in 2023

A new record!

444 in 2023

\*includes second chances facilitated through our Access to Transplantation programmes, Cord Blood Units, family donors and non-DKMS donations facilitated via DKMS Registry searches.

Additional second chances at life\*

Constant innovation,
new opportunities

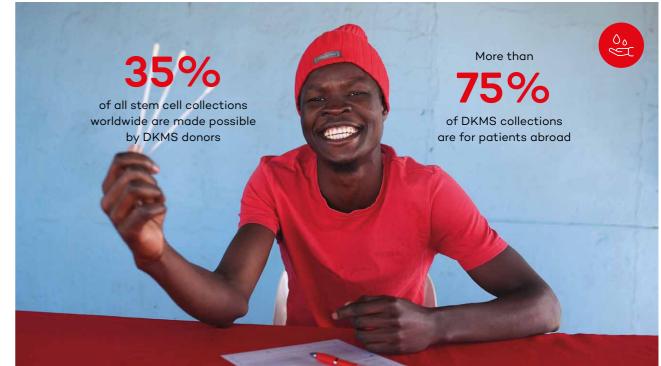
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1

where Reg online registration tool and virtual donor drives
up to 280 attendees a day at the International Donor Registry
Conference (IDRC) 2023 organised by DKMS in Hanau, Germany
of collection centres globally of of-a-kind stem cell bank and much more besides...









## World Blood Cancer Day

Happy 10th anniversary!

In 2023, we celebrated the **tenth anniversary of World Blood Cancer Day (WBCD).** Every DKMS office used this milestone as an opportunity to showcase its own unique ways of promoting our cause and our vision of deleting blood cancer. DKMS first launched WBCD on 28 May 2014 as a day to rally the public, raise awareness and show support for blood cancer patients around the world. Today, we are proud to say that WBCD has seen exponential growth, thanks to various creative public campaigns and strategic collaborations. It now plays a critical role in elevating public awareness of the struggles facing patients worldwide – and of the lifesaving potential of stem cell donations.

### Chile

After the tremendous success of WBCD in 2022, we once again invited well-known illustrators to "explain" in their own style the frequency of blood cancer diagnoses around the world and the importance of registering to save a life. We posted the illustrations on social media, engaging our audience and creating a conversation around the need for more donors.



### Germany

We celebrated WBCD at the BIKE Festival in Willingen. There, we educated attendees about our cause and offered a unique 3D audio experience called Destiny's Ride, in which visitors could experience the emotional stories of three former patients. To help spread awareness about our presence, we invited patients, volunteers, stem cell donors and a DKMS PR colleague onto the main stage to share their experiences.

### India

In India, we chose the theme #ItStartsWithYou for WBCD, highlighting unique individuals who are now role models. We were also thrilled to have over 80 passionate bikers from Bangalore enthusiastically participating in our awareness rally under the motto Two Wheels, One Mission. The presence and support of renowned motorbike influencers from Karnataka, who led the entire fleet, made this event a memorable success: more than 50 bikers registered as stem cell donors.



#### Poland

In Poland, we sent gifts to every patient we have ever worked with and hosted an incredible meeting with 52 former patients at DKMS Poland's headquarters. We also organised donor drives in five cities across the country, resulting in over 1,100 new registrations! And we cooperated with two big Polish internet companies, so their users could learn about our work via a video by Polish actor Maciej Musiał, articles and a dedicated website.



#### South Africa

We used WBCD to highlight the prevalence of blood cancer amongst South African youth. We refurbished a room called the Hope Hub for teens undergoing cancer treatment at Inkosi Albert Luthuli Central Hospital (IALCH) in Durban, creating a space where they can have fun, catch up on homework and feel at home.



#### UK

This year, DKMS UK created social media content in different languages. Using the phrase "Every 27 seconds, someone somewhere in the world is diagnosed with blood cancer", we highlighted the fact that DKMS helps people across the globe. We also ran a #MakeltRed challenge, with influencers and celebrity partners encouraging the DKMS community to turn ordinary or unexpected items red to raise awareness for our mission.



#### LISA

In the week prior to WBCD, we held a donor drive in partnership with a popular local apparel company in Charlotte, North Carolina. We spread the word through a number of activities: we installed a series of "reverse graffitis" that led people to our website to learn more about WBCD and our event. We also partnered with influencers to promote our mission and the event to their followers, and appeared on the TV show Charlotte Today.



## DKMS Collection Centers – Professional all-round support

In 2023, we achieved a new milestone when we opened our very own DKMS Collection Centers – the first in Dresden, open since April, and the second in Cologne, open since August. Towards the end of the year, we also set up a new Collection Center in Santiago de Chile, as part of DKMS Chile. Together, the three new facilities allow us to meet increasing demand and ensure the safety and wellbeing of our stem cell donors throughout their entire journey. We spoke with Sirko Geist, COO of the DKMS Collection Centers in Germany, about the impact of these new additions on the DKMS family.

### Why was it so important to run our own DKMS Collection Centers?

Sirko Geist: We're on a mission to save the lives of as many blood cancer and blood disorder patients as possible, and so securing more capacity for collections was the next logical step. It also means we can complete our donor process chain. We strive to deliver quality transplants and improve outcomes for patients, while also providing the best possible all-round support for our donors. It is important that we offer a comprehensive donor journey and are there for our donors every step of the way – from first registration and stem cell collection to follow-up care.

### What's the number one priority at the new Collection Centers?

The main focus of the Collection Centers is always transplant quality and donor protection. Our highly specialised physicians and dedicated nursing and coordination teams work with state-of-the art medical equipment to ensure the donated cells that are



Dr Elke Neujahr, CEO DKMS Group, and Dr Kristina Hölig, Medical Director, in our Collection Center in Dresden



Sirko Geist at a press conference in Dresden

supplied to transplant centres across the world are of the highest quality, above and beyond international standards. To help us fulfil this primary objective, we have a stringent quality management system in place that ensures all the relevant processes are GMP-compliant<sup>1</sup>.

### How many collections did our DKMS Collection Centers facilitate in 2023, and what are our plans for the coming years?

In 2023, we started with around 1,150 stem cell collections from unrelated donors. Having successfully invested in the Dresden site, we are currently expanding our Collection Center in Cologne to increase collection capacity even further. This will enable us to supply more than 4,000 high-quality transplants a year to patients. Bone marrow, peripheral blood stem cell and lymphocyte collections can be performed in both our German Collection Centers and are an important component in DKMS's support for blood cancer patients around the world.

### Partnering up

To maintain a sufficient supply of transplants, we will continue to work with other certified stem cell collection centres across the globe to ensure a safe, smooth donation close to home for every donor. In 2023, DKMS donors facilitated more than 8,300 stem cell collections worldwide in total – a record for our organisation.

 $^1 \text{GMP}$  stands for good manufacturing practice. The standard is monitored and coordinated by the European Medicines Agency



### The donor-patient journey

Marianne donated her lifesaving stem cells to Ricardo in 2018. It was an experience that changed both their lives. Find out more about the donor-patient journey and their thoughts on this lifesaving experience.



of the illustration please unfold this page

### "It was fantastic to meet Marianne,

and we both felt as if we had known each other for years. It's her I have to thank for the fact that I am doing well again today and can fully enjoy life with my wife and my young daughter."

**Patient** 

Ricardo

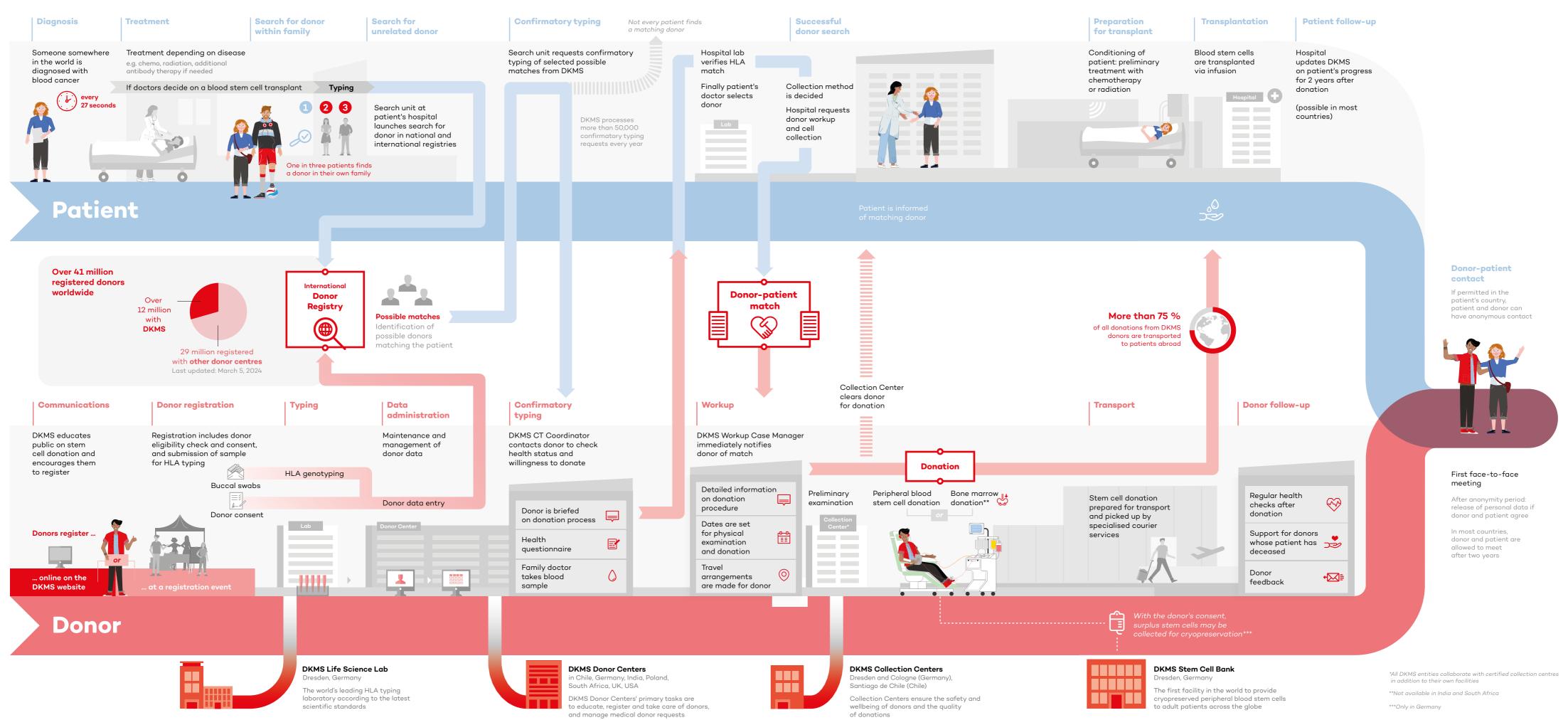


## "looking back on it, I am just grateful to have helped Ricardo.

This became even clearer to me when we met.
I've felt very close to him and his family ever since.
From the very beginning, there was a warmth between us that's impossible to describe."

Marianne

Donor





## DKMS Stem Cell Bank - Our latest innovation

#### One collection, two second chances at life

It's the morning of 1 November 2023. Lukas is a little nervous, but mostly excited as he is about to donate stem cells to save a patient's life. But there is even more: he is also about to make history as the first adult in the world whose excess stem cells will be cryopreserved in the DKMS Stem Cell Bank. Because at some point in the future, they could save another patient's life.

"I was amazed. You don't necessarily expect to be contacted because someone needs your stem cells, but I immediately knew I wanted to help. My decision to donate was already made. I think the Stem Cell Bank is a great idea because that way, a one-off effort made for one patient could save another patient as well," says Lukas.

The DKMS Stem Cell Bank in Dresden, Germany, is the first of its kind and one of DKMS's most recent innovations. To obtain the precious cells that could potentially save two lives, the Stem Cell Bank works hand in hand with the DKMS Collection Centers and other partners. All that's involved for donors like Lukas is a slightly longer apheresis.

The excess cells are collected with the donor's consent and taken to the DKMS Stem Cell Bank to be quality-checked, analysed and then cryopreserved over liquid nitrogen at minus 180°C. Knowing how many cells are immediately available is a huge advantage – and because they are cryopreserved, they can be ready for the patient faster. This reduces the time from search request to actual transplantation from around 12 weeks to just 72 hours – and can happen independently of the donor's availability.



Dr Alexander Platz, Medical Director of the DKMS Stem Cell Bank, with the first Stem Cell Bank donor, Lukas



Thick vapour of nitrogen is released when the cryogenic tank is opened to put in the stem cells

"The DKMS Stem Cell Bank
is another innovative milestone
in our lifesaving mission and
significantly increases the
chances of survival for patients
in urgent need of a transplant"

Dr Elke Neujahr Global CEO, DKMS Group

### **Precious ADCUs**

The average stem cell donor produces more haematopoietic stem cells than their recipient needs. So, with their consent, their surplus cells can be cryopreserved. These cells – known as ADCUs (Adult Donor Cryopreserved Units) – are stored in the DKMS Stem Cell Bank, ready for another patient on request.



## Access to Transplantation – Successful aid since 2014

In our mission to provide as many second chances at life as possible for blood cancer patients worldwide, our international support programmes in low- and middle-income countries are a lasting success.

When it comes to giving patients a second chance at life, we cross borders, forge international partnerships, and leave no stone unturned...

- 1,314 transplants resulting from 40,700 free patient and family HLA typings
- 621 collections resulting from 1,840 free confirmatory typings (CT) of DKMS donors for patients in India, Chile and South Africa
- 708 transplants co-funded by DKMS:
   We cover on average 36% of the
   total cost of a transplantation –
   equivalent to €4,700 per patient
- 14 new transplant beds and 3 high-dependency unit (HDU) beds funded at the Bhagwan Mahaveer Jain Hospital (BMJH) in Bangalore in memory of Mechtild Harf and at Christian Medical College (CMC) in Vellore, India
- 9 paediatric bone marrow transplant (BMT) nurses trained during a 2-year pilot programme in India and Pakistan



this report.



Zyaan (left), a thalassaemia patient, with her sister



Manuella, a paediatric patient in South Africa



Sankalp paediatric ward at BMJH in Bangalore



DKMS colleagues visit the CMC in Vellore



Extreme efficiency, fast throughput, highest quality – that's what the DKMS Life Science Lab (LSL) in Dresden, Germany, is all about. The LSL can analyse and type up to 7,000 buccal swabs a day from around the world, enabling potential donors to complete their first step towards joining the DKMS database. It also finds lifesaving matches for patients in need of a stem cell transplant.

The DKMS LSL is a hub of innovation and excellence in the mission to beat blood cancer. The primary focus is on high-resolution, sequence-based HLA typing for stem cell donor registries, and in 2023 it achieved a significant milestone by obtaining prestigious DIN EN ISO 15189 accreditation. This accreditation underscores the LSL's commitment to quality and precision in lab operations and opens new avenues in diagnostics, clinical trials and pharmaceutical research.

The LSL's state-of-the-art equipment, stringent controls and highly skilled team ensure reliable and accurate results and meet the high standards of the Deutsche Akkreditierungsstelle (DAkkS) and European Federation of Immunogenetics (EFI). The DKMS LSL also collaborates closely with the DKMS Clinical Trials Unit (CTU) and is dedicated to advancing healthcare and research for blood cancer patients. By sharing its findings with other scientific organisations, the lab plays a crucial role in reducing post-transplant complications and enhancing recov-

ery chances: the better the quality of typing and the more precise the data, the higher the chances of a successful transplantation. The dedicated team at the DKMS Life Science Lab plays a vital part in pursuing DKMS's vision: to delete blood cancer, one match at a time.

- Around 170 colleagues
- Up to 7,000 samples a day
- Around 1 million analyses a year
- 22 HLA characteristics and other parameters analysed

### HLA typing for a genetic match

Human leukocyte antigens (HLA) are crucial tissue characteristics that determine donorpatient compatibility.

To find the most suitable match, the lab examines 22 HLA characteristics and several other parameters in a procedure known as HLA typing.

### DKMS Registry – Finding the best possible donors for patients

The DKMS Registry is the backbone of our activities. With more than 12 million registered donors, it is the biggest stem cell donor registry in the world and the place where second chances at life can be found.

Our services include making pseudonymised donor data accessible to physicians, transplant centres, and other registries worldwide. This is done largely via the DKMS Registry's in-house software – Hap-E-Search and Donor Navigator – but also via the international database maintained by the World Marrow Donor Association (WMDA).

Searches for unrelated donors can be initiated 24/7 at the click of a button. Our state-of-the-art algorithm identifies potential lifesavers in minutes by comparing the HLA characteristics of patients with those of all the donors registered worldwide – not just with DKMS. It then provides a comprehensive list of potential matches. When a DKMS-registered donor is identified from among the pool, our registry coordinators launch and facilitate the donor management process, from initial donor availability checks to delivery of the final stem cell transplant.

In countries with limited access to unrelated donors, our search coordinators take additional steps, offering recommendations for suitable donors among the pool and assisting with all the other necessary steps, irrespective of the database involved. This way, our DKMS Registry provides dynamic support for the global transplantation community as both a donor and patient database – across borders and beyond our own organisation!

In 2023 alone, the DKMS Registry received 22,173 search requests for unrelated donors – an average of just over 460 searches per week. This produced the donations needed to give 4,132 patients a second chance at life.

The DKMS Registry is committed to providing top-quality, efficient services for patients across the globe, while ensuring the highest standards of donor safety. DKMS currently holds Benchmark Level 2 certification from the World Marrow Donor Association (WMDA) and is on track for full accreditation.



## Three Pillars That Give Us Direction

Every 27 seconds someone, somewhere in the world is diagnosed with blood cancer. For many, a stem cell transplantation is the only hope of survival. But the chances of finding a genetic match – or even affording such a procedure – vary across the globe. The long-term success of a transplantation also depends on many different factors, which is why we have extended the scope of our activities to pursue a holistic approach comprising three pillars:

Every 27 seconds ...







## Pillar 1 Boost Stem Cell Donations

### Our goal by 2030:

Pages 30-33

- A donor pool that is as diverse as possible, with high donor availability
- 12,000 second chances at life a year, including 1,000 p.a. via our Access to Transplantation programmes
- 200,000 second chances at life provided by DKMS since 1991

### Pages 36-39

### Pillar 2 Improve Access to Transplantation

- Free HLA Typing Programme:
   Efficient identification of related donors and support with donor search
- Patient Funding Programme: Reducing financial obstacles to transplantation
- Capacity-Building Programme:
   Enhancing treatment and care via infrastructural support and knowledge sharing



## Pillar 3 Advance Research & Development

- Improving outcomes and increasing the chances of survival for patients needing transplants through the work of our Clinical Trials Unit
- Opening the field of diagnostics
- Contributing to advanced cell therapies with our expertise, equipment and dedicated supporters

Pages 40-43

Boost Stem Cell Donations represents the heart of our activities: finding the right matches for patients with blood cancer or blood disorders and facilitating stem cell donations. This pillar underpins the activities in all seven of our Donor Centers, from awareness campaigns and donor recruitment events to the work of our DKMS Life Science Lab and the DKMS Registry.

Improve Access to Transplantation centres on supporting patients with blood cancer or blood disorders in low- and middle-income countries and has allowed us to save additional lives through international aid.

Last but not least, as we work to fulfil our mission sustainably and efficiently, **Advance Research & Development** reflects our focus on various areas of innovation, such as innovative cell therapies, to fight blood cancer from every angle. This pillar includes investments in scientific studies and clinical trials to improve patient outcomes, and opening a new field of diagnostics to enhance blood cancer treatment.



## Mandeep & Mandeep – Faces behind the figures

In 2023, DKMS proudly celebrated two major milestones in our mission to ensure a matching donor for every patient in need: 12 million registered donors worldwide and over 110,000 second chances at life facilitated. The figures are remarkable and represent not only the largest but also the most diverse donor pool in the world.

And yet, at DKMS we haven't forgotten that behind them are the unique and powerful stories of heroes who champion our cause and of the lives they have changed. What follows is one of those stories, in which two strangers in India, who happen to share the same name, meet for the first time after a successful donation and transplantation.

Mandeep, a 35-year-old farmer from Punjab, was diagnosed with chronic myeloid leukaemia in 2009. After years of fighting the disease and searching for a donor, he finally received a stem cell transplant, giving him a second chance at life in January of 2020.

In February 2023, Mandeep travelled from his remote town in Punjab to Bangalore to meet his lifesaver, a 39-year-old also named Mandeep!

On that day, Mandeep the donor sat in a restaurant, hands fidgeting and feet shuffling, hoping his recipient was okay and wondering just who they might be. Thankfully, after only a few minutes he felt a tap on his shoulder. And so, Mandeep finally met Mandeep!

As words of gratitude flowed, interrupted only by hugs and laughter, Mandeep the patient forgot all about his struggles before finding his donor. He hugged his donor's parents and thanked them for raising a true hero.

With 47 journalists attending, this incredible story was shared by media from across all platforms, including all the key publications such as The Times of India, New Indian Express, The Hindu etc. The acclaimed Indian actress Tisca Chopra also attended the event, speaking about how the touching story had led her to register as a donor and encouraging the public to do the same.



Patient Mandeep hugs his lifesaver – also called Mandeep! – with gratitude the first time they meet

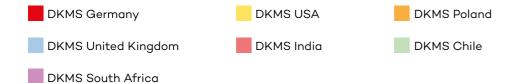
The story was ultimately so captivating that it inspired author Dr Sona Sharma to write a book, Mandeep meets Mandeep, about their story. The book went on to be widely appreciated and helped create a ripple effect that continues to inspire many to register as stem cell donors.

The story was ultimately so captivating that it inspired author Dr Sona Sharma to write a book, Mandeep meets Mandeep, about their story.

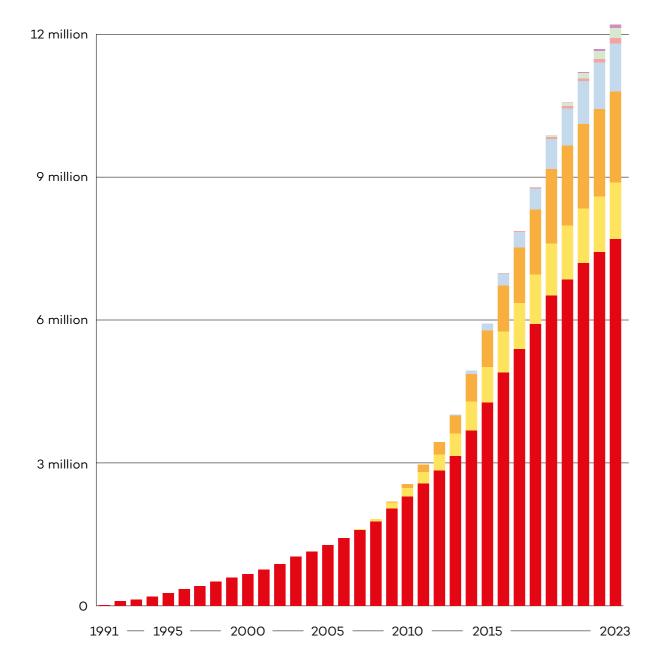


Three Pillars That Give Us Direction | Pillar 1

## Growth in donor registration numbers



As of 31 December 2023, we had registered a total of 12,202,341 potential donors!



## Reaching young audiences at festivals

Recruiting donors is and always will be a core activity at DKMS. Every year, more and more donors leave the database as they reach the age of 60. Last year alone, 145,000 potential lifesavers dropped out of the donor pool as they were no longer eligible to be a match for a patient. For medical reasons, DKMS can only accept donations up to the age of 60 and has to remove older donors from its registry.

The younger a donor is at registration, the longer they will be available as a match for a patient. That's why, to keep on saving as many lives as possible in the future, we need our donors to be as young as possible. Another reason young people are so important is their health: they tend to have fewer potential complications to prevent them from donating and are therefore more likely to go ahead when asked. This is precisely why DKMS has stepped up its efforts to approach young people at schools, universities, sports clubs and so on.

Our focused outreach work is also taking new approaches. In Germany, India, Poland and the UK, for example, we run donor recruitment events at festivals, where we attract plenty of young people. Our red tents at the Pol'and'Rock festival welcomed more than 1,000 new donors who had come to sign up to the sounds of pop, disco, techno and rock. As well as introducing our organisation, we got to meet actual donors we hadn't seen for a long time and patients who had lived to tell the tale, thanks to their transplants. Meetups and donor recruitment events like these are a source of huge inspiration and drive us to continue our work.

#### Pol'and'Rock Festival in Czaplinek, Poland



The younger a donor is at registration, the longer they will be available as a match for a potential patient in need

### GLÜCKSGEFÜHLE Festival in Hockenheim, Germany



Another example is our charity partnership with the GLÜCKSGEFÜHLE Festival at the Hockenheimring in Germany, which was a complete success. In perfect summer weather, more than 1,000 visitors registered to join the fight against blood cancer. Our unmistakable red DKMS tents and the 3D audio experience Destiny's Ride were located between the two main festival stages and were well attended throughout. The number of people taking up our invitation to "Share your happiness – become a stem cell donor" exceeded our expectations by far. Around 70 percent of the newly registered lifesavers are under 31 and belong to a generation that is particularly important for our work.

Our festival work was supported by several young volunteers. Among them was 23-year-old Julian from Mannheim, who used to have cancer himself. He knows exactly how important other people's support was to his own recovery. "I really enjoyed working at the festival to find more stem cell donors for the future," he says. Campaigns like this also show that young people want to get involved and save lives.

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Collaborating for Impact

## Collaborating for impact -

## Three questions for Dr Matthew Seftel

The World Marrow Donor Association, WMDA, was founded in 1994 to ensure reliable provision of lifesaving cells as well as the care and safety of both patient and donor. Today, it is an association of organisations and individuals striving for a world where all patients have access to lifesaving therapies and donors' rights to safety are protected. As one of the WMDA's member organisations, DKMS talked to Dr Matthew Seftel, WMDA President and Medical Director of Canadian Blood Services, about the impact we are having together:



The WMDA is the central database for volunteer stem cell donors from various registries around the globe and promotes patient and donor care. In a few words, tell us about the latest achievements you see in terms of accessing lifesaving cell therapies.

Matthew Seftel: The WMDA facilitates access to a growing global database of unrelated cell sources. Our database currently comprises 41,648,775 adult volunteer donors and 794,625 cryopreserved cord blood units.<sup>2</sup> Crucially, search coordinators and transplant physicians can access data from 57 countries in a matter of seconds – because time-to-transplant really matters when it comes to providing lifesaving cells. To ensure the transplant centres have access to fresh data at all times, the registries update their information several times a day. We are also seeing an expansion in clinically relevant donor-related data, such as their latest contact information, CMV status, or availability status of the donor.

## DKMS is one of the longest-standing members of the WMDA. Why is it important to have an organisation like ours on board? What is it that makes our cooperation mutually enriching?

WMDA and DKMS are partners with established working relationships on every level. DKMS is an inspiration to many WMDA member organisations, allowing the community to benefit from lessons learned, especially around donor recruitment and retention. On the operational level, as a registry, DKMS plays a key role in the development of Search, Match & Connect<sup>3</sup>. They are also an expert on how we, as a global community, can organise our ICT landscape efficiently to reduce the administrative load of many registries.

"Search coordinators and transplant physicians can access data from 57 countries in a matter of seconds"

On a strategic level, DKMS is a key stakeholder, and together we have successfully worked on the development of the new EU SoHO legislation<sup>4</sup> to protect the role of donor recruitment organisations and promote the WMDA's valuable work in biovigilance<sup>5</sup>.

### In 2023, we organised the International Donor Registry Conference (IDRC) in Hanau. What were the key takeaways for you?

DKMS was a wonderful organisation to collaborate with. We shared a clear understanding of what we wanted to achieve: Engage and Empower for Excellence. My key take aways were:

- Implement innovative approaches to expand access to care: mismatched unrelated donor and cord blood therapies are a viable option for patients who cannot find a fully matched donor.
- 2. Educate transplant centres to start an unrelated donor search as soon as possible.
- Team up with recruiters to explore ways of engaging with donors who could be invited to donate for purposes other than a conventional stem cell transplant – for cell and gene therapy, for example.











Impressions from the IDRC 2023 in Hanau, Germany. Picture at bottom: From left to right: Christian Schenk (time:matters), Dr Elke Neujahr (DKMS), and Lydia Foeken and Dr Matthew Seftel (both WMDA)

<sup>&</sup>lt;sup>2</sup> As at 15 August 2024

<sup>&</sup>lt;sup>3</sup> The global WMDA database and service to find a matching unrelated stem cell donor worldwide

<sup>&</sup>lt;sup>4</sup> In 2022, the European Commission presented a proposal for a regulation to enhance the safety and quality of substances of human origin (SoHO) intended for human application. Mandatory for all EU member states, the SoHO Regulation aims to provide guaranteed access for EU citizens to the highest standards of safety and quality for essential products, such as blood products

<sup>&</sup>lt;sup>5</sup> Biovigilance refers to a system that helps monitor the safety and quality of substances of human origin (SoHO)



### Help where it's needed

In 2014, we launched our international support programme Access to Transplantation for patients in low- and middle-income countries.

When it comes to gaining access to a potentially lifesaving treatment, patients in poorer regions of the world face major challenges. In many low- and middle-income countries (LMICs), comprehensive stem cell treatment is unavailable, due to a lack of medical infrastructure, trained healthcare professionals and financial resources. In our view, removing the socio-economic and infrastructural obstacles to accessing potentially lifesaving therapy is crucial in parts of the world that are under such constraints. That's why, in 2014, we initiated three patient support programmes that continue to evolve. So far, patients in various countries have benefitted from them, in India, South Africa, Chile and elsewhere.

#### In 2023...

- ... **409 patients** received a second chance at life under Improve Access to Transplantation.
- ... our DKMS Life Science Lab determined the HLA characteristics of more than **9,700 patients** and their family members free of charge, resulting in **313 transplants**.
- ... **nine nurses** successfully completed a two-year training program funded by DKMS.

### Sparing no effort:

### Our three programmes

In many LMICs, patients who need a stem cell transplantation face the challenge of accessing HLA typing. Testing facilities are scarce, and the costs are high.

Our **DKMS Free HLA Typing Programme** aims to ease the hardship facing these patients in their search for a donor by covering the costs of HLA typing for them and their family members. And if they can't find a suitable donor within their own family, we support unrelated donor searches as well. When a matching donor is found, many families face the next daunting obstacle: the cost of the transplantation and the medical care involved.

This is where the **DKMS Patient**Funding Programme comes in. To help patients overcome the financial challenges, we work closely with other nonprofit organisations and cover part of the cost of a stem cell transplantation for patients who would otherwise not receive adequate treatment. You will find some of the success stories on pages

51 and 60 of this report.



Another important aspect of our work is our support for nonprofit hospitals and organisations in countries with limited medical infrastructure.

Our **DKMS Capacity-Building Programme**helps to advance treatment and care
through infrastructural support and
knowledge sharing. This includes
providing financial assistance and
training medical staff to improve
the level of care.

-3-



Three Pillars That Give Us Direction | Pillar 2

### Synergy in action

Collaboration and the support of dedicated local partners are essential to the sustained success of our Access to Transplantation programmes. In India, we work closely with the nonprofit Sankalp India Foundation. Based in Bangalore, Sankalp was founded in 2007 to help young thalassaemia patients access an appropriate standard of care, such as safe, regular blood transfusions. Sankalp has since expanded the scope of its activities and today operates two bone marrow transplantation units for children, on a nonprofit basis. Rajat Kumar Agarwal, one of its founding members, shared his thoughts on the collaboration with us.

### Why is it so important to help young thalassaemia patients in India?

Rajat Kumar Agarwal: India is the thalassaemia capital of the world. We already have about 200,000 patients living with the disease, and another 12,000 join them each year. A cure – and a transplantation especially – not only helps the patient but also has a much larger positive impact on their whole family and community. When one child is cured, it gives hope to the other patients around them.

How are Sankalp and DKMS connected?

After Sankalp decided to expand into stem cell transplantation, we were immediately confronted with the first burden: the costs of HLA typing in India. Families had to go to specialised centres for testing, often far away from home. Sankalp was working with very underprivileged patients who could never afford all of this.

It was at this time that DKMS met Dr Lawrence Faulkner, Medical Coordinator of Cure2Children, an international NGO from Italy. Dr Faulkner was also aware of our work in India, and together, they decided to support Sankalp. With the financial support of DKMS, we started offering free HLA typing for patients in need. It was a real gamechanger, because suddenly we knew if someone had the option of a cure. With this first initiative we realised that Sankalp and DKMS share the same mission, and since then we've been working together as a team.

Not only the costs, but also the infrastructural capacity and availability of qualified nurses are important factors. How are Sankalp and DKMS working on that?

In the course of our work, we realised that with a much better and bigger transplant unit, we would be able to support even more patients. Together, we turned these thoughts into a plan: we opened a state-of-the-art BMT unit, a bone "We realised that with a much better and bigger transplant unit, we would be able to support even more patients. Together, we turned these thoughts into a plan."

marrow transplant unit, at the nonprofit Bhagwan Mahaveer Jain Hospital in Bangalore in 2021 – in memory of Mechtild Harf. The ward consists of ten beds for patients, an intensive care unit, an isolation room, a nursery, a training facility and a laboratory. This was an enormously important step toward being able to help more patients with higher-quality care. By the end of 2023, we were able to treat over 209 children in the BMT unit.

Another problem we face in India, as well as in other countries, is the shortage of qualified healthcare professionals. Again, DKMS, Cure2Children and Sankalp came together and implemented a pilot training programme for nurses. It's called EMPACT, which stands for EBMT middle-income countries paediatric advanced care train-





Rajat Kumar Agarwal, a founding member of Sankalp



A mother and daughter at a family typing event in Rajpur, India

ing, and is organised by Cure2Children, funded by DKMS, and endorsed by the EBMT – the European Society for Blood and Marrow Transplantation. The pilot ended in 2023 and we are elated that nine nurses from India and Pakistan successfully completed the two-year training programme.

### What motivates you to carry on working for thalassaemia patients every day?

A few days ago, I was walking through the corridors when I happened to peek down at the play area. There were mothers sitting in the corner, kids were playing, swings were moving around. Watching the scene, I could see happiness, joy and a bright future. And that's what drives us to come back and work harder every day.

### **Thalassaemia**

**Thalassaemia major** is a hereditary blood disorder that causes severe anaemia and requires lifelong blood transfusions.

In India alone, over 12,000 children are born with it every year. The severe form of thalassaemia is life-threatening, and many sufferers do not live past the age of 20. But they can be cured – by a stem cell transplantation.

"Since the start of our Access to Transplantation programmes, we have been facilitating lifesaving treatment for many patients in regions with limited resources. To help even more patients in the future, we are constantly expanding our activities.

One innovation we are proud of in 2023 is the successful pilot training programme for paediatric BMT nurses in India, and we look forward to providing these training opportunities again in 2024. As with all our Access to Transplantation programmes, we are very grateful for the valuable collaboration with our local partners, which we plan to build on further over the coming years."

Dr Alexander Schmidt Global Chief Medical Officer DKMS Group





## Where brilliant minds meet state-of-the-art science to save lives

The only way to achieve a world without blood cancer is through innovative research and new scientific approaches. We work with medical experts to foster scientific progress and increase the chances of success during and after treatment so that patients have the best possible prospects of long-term survival.

#### Celebrating ten years of clinical trials

Since 2013, we have been operating our own clinical research unit. Our Clinical Trials Unit (CTU) in Dresden, Germany, currently employs more than 30 colleagues. Together, they work constantly to optimise our activities, conduct our own studies and invest in international research projects that will make stem cell transplantation a lasting success for patients. We work closely with the DKMS Life Science Lab to run the Collaborative Biobank (CoBi), where samples from stem cell donors and patients are processed and stored, with their consent, for use in research projects worldwide. Our research mainly focuses on improving cell therapy and transplantation.

### First DKMS clinical trial with practice-changing results

One of our many research projects is the ASAP trial, in which we tested a scenario where a stem cell transplant was facilitated as soon as possible. Supported by the Study Alliance Leukemia (SAL), Cooperative German Transplant Study Group, and the Gert and Susanna Mayer Foundation, ASAP took seven years of meticulous work by researchers at the University Hospital Carl Gustav Carus Dresden, the National Center for Tumor Diseases Dresden (NCT/UCC), and the University Hospital Münster, all of which are based in Germany. This culminated in our first clinical trial – with groundbreaking results. The study challenged the timing of current stem cell transplantations and received international recognition.



"In countries with less comprehensive healthcare, stem cell transplantations are often not performed, sometimes because complete remission has not been achieved, sometimes for cost reasons. Eliminating this expensive intermediate step could make stem cell transplantations more accessible to AML patients worldwide. For many of them, a transplant is the only hope of a cure."

Prof Dr Johannes Schetelig, Head of the CTU and the Department of Stem Cell Transplantation at the University Hospital Dresden

### The ASAP Trial

- >> Procedure: 276 adult patients with relapsed or refractory acute myeloid leukaemia (AML) were randomly divided into two groups. As is standard practice, the patients in group one received high-dose chemotherapy to suppress all their cancer cells and achieve complete remission prior to transplantation. These patients were transplanted after about 8 weeks. Patients in group two received the stem cells as soon as a compatible allogeneic donor was found. In preparation for the transplant, they received lower doses of medication for around 12 days.
- >> Results: The treatment achieved equally good results in both groups, even though group two patients had spent only half the time in the hospital on average and had reduced exposure to chemotherapy.
- >> Potential impact: Immediate transplantation without attempting complete remission beforehand could not only reduce side-effects and shorten hospital stays but also give more patients access to this potentially lifesaving therapy.

Three Pillars That Give Us Direction | Pillar 3

Three Pillars That Give Us Direction | Pillar 3



Prof Carl H June receives the Mechtild Harf Science Award 2023 from Katharina Harf, Chair of the DKMS Foundation Board

## **DKMS Mechtild Harf Science Award 2023**

### For outstanding scientific achievements

In 2023, the DKMS Stiftung Leben Spenden (Foundation for Giving Life) presented Prof Carl H June with the DKMS Mechtild Harf Science Award for his outstanding achievements in the field of cancer immunology. Throughout his distinguished career, the physician-scientist has made significant contributions to the field of immunology, including his pioneering work on the use of T cells in cancer. He was instrumental in the development of chimeric antigen receptor (CAR)-T cell therapy, which has proven remarkably effective in treating patients with relapsed and refractory leukaemia and lymphoma.

His work has not only brought about a paradigm shift in the treatment of blood cancers; it also has the potential to improve treatment options for solid cancers, chronic infections and autoimmune diseases. Numerous preclinical and clinical trials are already underway that hold great promise not only for the scientific community but

most importantly for all affected patients and their families.

The annual DKMS Mechtild Harf Science Award is named after the late wife of DKMS founder Peter Harf. It is presented in recognition of the outstanding scientific achievements of internationally renowned physicians and scientists in the field of stem cell transplantation and cell therapy.



Prof Carl H June

### DKMS John Hansen Research Grant 2023

## Supporting young scientists



John A Hanser

The DKMS John Hansen Research Grant 2023 was awarded to four young scientists who all share a common goal: improving medical care and outcomes for blood cancer patients worldwide.

The researchers will receive a total of 240,000 euros each over a three-year period

to support their promising projects in the field of cell therapy and stem cell transplantation.

The DKMS John Hansen Research Grant – known until 2019 as the Mechtild Harf Research Grant – was launched in 2015 and was renamed in honour of John A Hansen, the outstanding oncologist and immunogeneticist who dedicated his life's work to the causes of graft-versus-host disease and the fight against it.

Hansen himself received the DKMS Mechtild Harf Science Award in 2015 in recognition of his land-mark research into the efficacy of stem cell and bone marrow transplants as lifesaving therapies for blood cancer patients. From 2015 until his passing, John A Hansen was a member of the DKMS Foundation Board and DKMS Medical Council



Ivan Cohen

PhD, from the University of Pennsylvania

Ivan is developing an enhanced version of the existing (CAR)-T immunotherapy to help avoid severe immunosuppression. CAR-T cell therapy is a promising approach to treating diseases of the haematological system.



### Eiko Hayase

MD, PhD, from the University of Texas MD Anderson Cancer Center

Eiko aims to establish new treatment strategies to prevent intestinal graftversus-host disease (GvHD).



Andri Lemarquis

MD, PhD, from the Memorial Sloan Kettering Cancer Center in New York

Andri is focused on improving the reconstitution of the immune system after transplantation.



### Eliana Ruggiero

PhD, from the University Vita-Salute San Raffaele in Milan

Eliana aims to develop innovative targeted and combined therapeutic strategies that can establish or restore tumour immunosurveillance and prevent cancer relapse.

Fundraising Fundraising



## Fundraising for a brighter future for patients

In achieving DKMS's goals, we rely on many things: passionate employees and supporters, innovative scientific and medical research, and the essential funds we raise. For most businesses, the ultimate goal and sign of success is profit, but for an organisation like ours, money is not the goal but rather a means to an end. That end is to bring hope and health to the patients we serve and end blood cancer.

Fundraising is critical to our DKMS mission because it fuels our ability to expand our operations, adapt to the needs of the patients, and foster awareness for our mission to achieve our ultimate dream of a world without blood cancer. To better understand the importance of fundraising for DKMS's work, we spoke to the Chair of our Foundation Board, Katharina Harf:

### Getting straight to the point, why is fundraising so crucial for us?

Katharina Harf: Like all nonprofits, DKMS relies on fundraising to finance its activities. We depend on financial support, mainly in the form of donations from private individuals and companies, to expand our mission and save more lives. We refuse to accept the status quo as enough for the patients we serve and strive to continue developing and expanding our operations in pursuit of our ultimate goal.

From funding for research and clinical studies on long-term care to our Access to Transplantation programmes that break down infrastructural and financial barriers for patients who would otherwise not receive treatment – DKMS has always operated under the view that when it comes to patients, we cannot take no for an answer. That's why it is critical for DKMS to increase the monetary donations we receive so that we can continue to meet the needs of blood cancer patients.

### Do you have any specific examples of R&D projects we have been able to finance, especially thanks to our fundraising?

There are numerous examples of the impact fund-raising has had on our ability to improve care for patients, both today and in the future. We currently have a clinical trial and a scientific study that both focus on learning how to prevent one of the most common post-transplant issues faced by patients: graft-versus-host disease, or GvHD. GvHD is a potentially serious post-transplant complication, so the ability to address and alleviate it would drastically improve the quality of life and long-term outlook for blood cancer patients. Additionally, thanks to our fundraising efforts, we have been able to invest in the support and recognition of young scientists, with our John Hansen Research Grant, for example. Grants like this ensure that, as a community, we gain a better



From left to right: Peter Harf, Katharina Harf, Viktoria von Wulffen, Sue Nabi and Dr Elke Neujahr at the DKMS UK Gala

"DKMS has always operated under the view that when it comes to patients, we cannot take no for an answer"

> Katharina Harf Chair, DKMS Global Foundation Board

"As an international nonprofit organisation of our scale, we have a sound and sustainable financing concept that allows us to continuously enhance our support for patients with blood cancer and blood disorders. We are truly grateful to have so many generous supporters by our side, joining our fight for such an important cause."

Bernd Weinel Global Chief Financial Officer DKMS Group

Fundraising Fundrais

understanding of the diseases blood cancer patients suffer from to create a future with more efficient and effective treatment options.

### How do you see fundraising evolving in the next 10 years?

The fundraising landscape is changing radically: mobile technologies continue to evolve, social media is gaining influence by the day, and campaigns, actions, and causes are becoming increasingly diverse. Our mainstays – such as galas and traditional initiatives – will always be a core part of nonprofit fundraising, and small dollar donors will remain critical to the

success of our mission. But we must be able to adapt our approaches and rise to the challenge of meeting our audience wherever they are.

In an age where potential donors are getting more and more information across more channels from more and more organisations, it is incumbent on us to stand out and find ways to truly connect them with our mission. But although we may need to use additional platforms or avenues of outreach, the message at the heart of our DKMS mission remains as universal as it is timeless: together, we can overcome all odds and bring hope to those facing their darkest times.

## Fundraising income

24,714,300 €

in 2022

24,395,900 €

in 2023

### Galas

UK Gala 1,500,000 GBP (around 1,727,340 euros)<sup>6</sup>
US Gala 4,550,000 US Dollars (around 4,115,940 euros)<sup>6</sup>

from all entities

<sup>6</sup> As at 31 December 2023; Source: Currency calculator at https://bankenverband.de/service/waehrungsrechner; accessed on 13 September 2024



Olympic champion Tom Daley with a gift from DKMS - knitted stem cells at the UK Gala









Joachim Creus, Chief Executive Officer, JAB:

"It has been, and still is, a great honour to be a longstanding partner and supporter of DKMS and its lifesaving mission. As a leading global investment firm, we hold a deep responsibility to give back to society and help make the world a better place. By supporting DKMS in its mission, we are not only investing in a brighter future for patients battling a life-threatening disease but are also part of a vital movement that offers countless people a second chance at life. The remarkable work DKMS does every day inspires us, and we are proud to contribute to their global impact."

## A huge thank-you to our supporters and partners

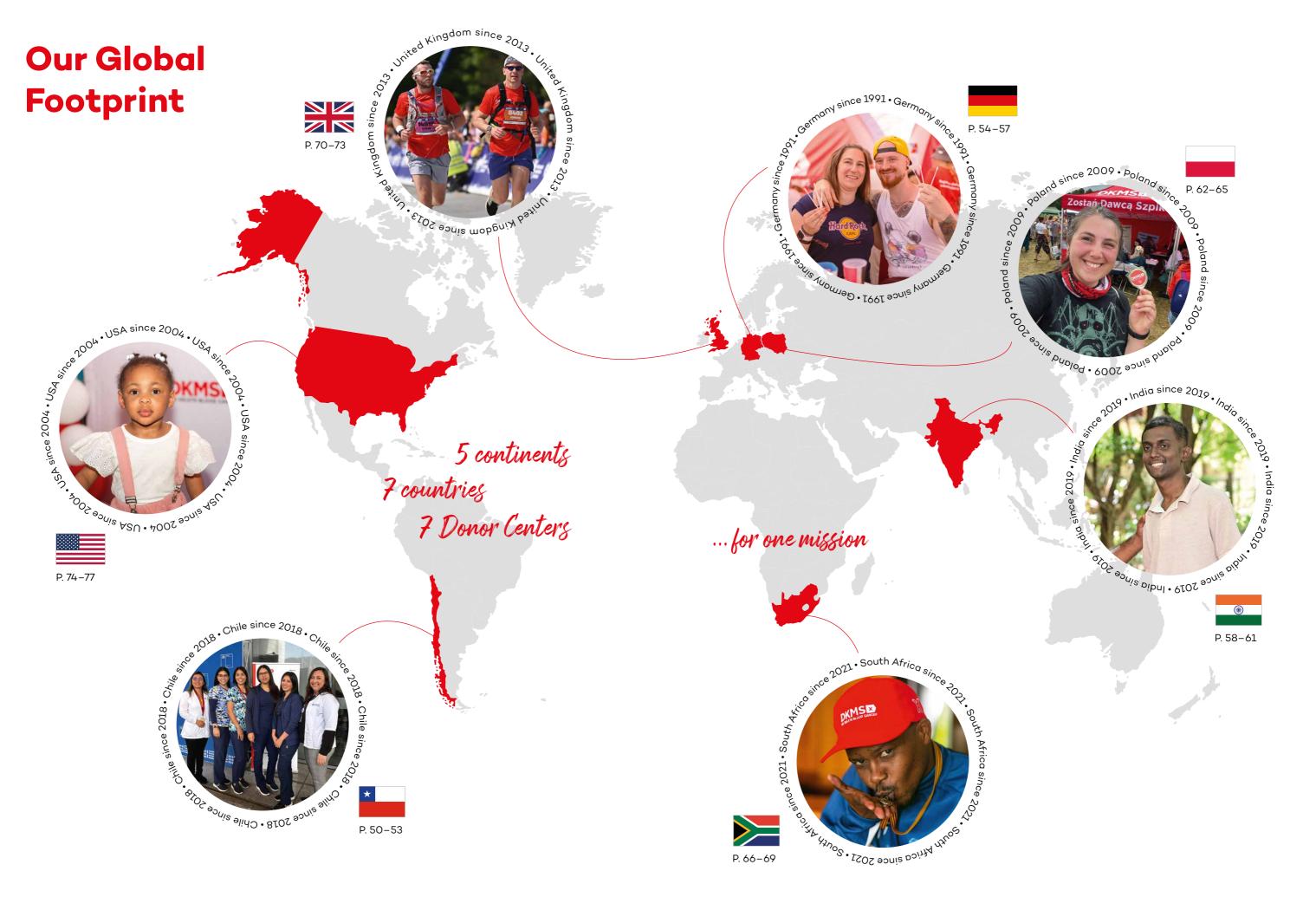
The money we raise is a testament to the incredible impact we can make when we stand united for a common cause. Thanks to the generosity of our financial donors and supporters in the business world, DKMS can not only provide lifesaving transplants to patients in need but also work actively towards making our dream of a world without blood cancer a reality. Our supporters may not be as publicly visible as our stem cell donors, but their contributions ensure that DKMS can continue fighting for every patient, overcome every obstacle or challenge, and refuse to take no for an answer.

Sue Nabi, Chief Executive Officer, Coty:

"We are proud of Coty's partnership with DKMS. Spanning over three decades, it's a reflection of our joint dedication to catalysing positive transformations through scientific advances and empowering communities worldwide. As Coty celebrates its 120th anniversary, we look back on our journey from a small fragrance house to a global beauty leader. In doing so, we pay tribute to DKMS's remarkable evolution into a pivotal nonprofit organisation dedicated to fighting blood cancer. We remain committed to making a positive impact alongside DKMS in the years and decades to come."



Our Global Footprint



Our Global Footprint | Chile



Emotional donor-patient meeting in Santiago de Chile at festivities marking five years of DKMS Chile

## Celebrating five years and counting

In 2018, Cristina and Iván learned of their 9-year-old son Martín's leukaemia diagnosis. "It all started when they told us DKMS was coming to Chile," says Cristina. "That was the first time we heard of stem cell transplants. We wanted to get involved and launch an appeal for donors with DKMS."

In March of that year, DKMS Chile launched its first donor recruitment campaign for a patient, in Puerto Varas. More than 700 people registered in Martín's honor, and the event became one of the biggest campaigns in the country to date.

In the end, Martín found his genetic twin via a registry in another country, but the campaign that was started in his name quickly grew into something greater than the family could ever have imagined. His story touched thousands of Chileans, and what began in Puerto Varas continues to this day.

Many of the donors recruited in those donor registration events turned out to be compatible with other patients. People like Guillermo, Eduardo, César, Juan

Antonio, Francisca, Myriam and Catalina registered to help Martín but ended up being able to save the lives of other patients. And so, one boy's story created a ripple effect that inspired hundreds to get involved and saved many lives. This is the beauty of DKMS's success: we inspire the compassion and love that unites us all.

Five years later, DKMS Chile has over 215,000 registered donors and has given more than 329 patients in Chile and around the world a second chance at life. Chilean stem cells have saved lives across the Americas and Europe, and even in Africa and Asia.

In Chile, the impact has been tremendous. Since DKMS arrived, the probability of a Chilean finding a 100-percent compatible unrelated donor has increased from 30 to 50 percent, helping to break down an important barrier to accessing transplantations. DKMS Chile has also been able to support the health system and transplant centres, helping reduce costs and waiting times while increasing the means of medical teams to give more patients a second chance at life.

### "A miracle to be alive"

Lorena's life changed when she was diagnosed with bone marrow aplasia. Her only hope of survival was a stem cell transplant from an unrelated donor. Only a few health centres in Chile perform the procedure, but Lorena was lucky: she was able to undergo a transplant made possible by the DKMS Patient Funding Programme.



DKMS Patient Funding Programme

In November 2019, Lorena found herself facing an uncertain horizon. Hospitalised for low red and white cells and platelet counts, she waited desperately to find out what would happen. Finally, in February 2020, the doctors determined that she had medullary aplasia and would need immediate treatment.

After months of repeated blood transfusions that did little to stop the progression of the disease, Lorena's haematologist told her there was only one option left: a stem cell transplant from a 100-percent compatible donor. But without a matching donor in her family, she would have to find an unrelated donor somewhere in the world.

Incredibly, her medical team conducted a search and found a genetic twin, but unfortunately the public health system in Chile does not cover transplants from unrelated donors for adult patients. With her future hanging in the balance, Lorena reached out to DKMS, hoping for a miracle.

"I wanted to live, I have three daughters, my husband, my home"

Lorena

The DKMS Patient Funding Programme was created for this very purpose: to ensure that those without guaranteed health coverage or the financial resources they need can still have a transplant – fast. DKMS ensures patients get the transplants they need by contributing toward the cost.

"I wanted to live! I have three daughters, my husband and my home," Lorena explains. "At the Foundation they told me they would contribute toward the treatment costs. It was a hope, at least. I believe in

God, and I think he gave me the blessing of coming to DKMS to continue living, the blessing of finding a donor so that I would still be here."

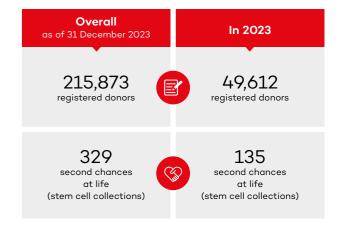
Lorena was treated at the Hospital Clínico UC, one of the centres in Chile that performs transplantations from unrelated donors in adult patients. Today, she is healthy and enjoying her second chance at life with her family.

The Patient Funding Programme is part of the international DKMS Access to Transplantation Programme (see p. 36).



Celebrating five years of DKMS Chile

### **Key Figures Chile**



Our Global Footprint | Chile

## New hope for patients in Chile and worldwide

At the end of 2023, DKMS Chile opened its own stem cell Collection Center to help increase transplant capacity and respond fast when donations are needed by patients in Chile and around the world. The Collection Center's first donor was Camila, who describes registering as a donor with DKMS as her "first adult decision".

DKMS Chile now has its own Collection Center which specifically serves unrelated donors, with the goal of speeding up transplant times for patients who find a match in Chile. Thanks to this unique facility, DKMS now has the capacity to ensure patients receive their transplants as soon as possible and have a better chance of a successful outcome.

At the end of 2023, with the Collection Center newly opened, we contacted Camila, who had registered just a few months earlier. Delighted to be called as a match, Camila was excited to be the inaugural donor at the centre and overjoyed to be giving a blood cancer patient a second chance at life.

### "My first adult decision"

On her 18th birthday, Camila decided to register as a stem cell donor. "I registered on 5 June 2023 and a few months later they had already called me to let



Camila at the official inauguration celebration

me know I was a match," she says. "It was very exciting, because I knew I could help someone."

After her experience, Camila felt it was important for everyone to know how easy it is to donate – and how big the potential is to save a life. "Donating doesn't hurt at all. It's just a pinprick," she explains. "I was connected to the apheresis machine for just over 3 hours, but the time flew by as if nothing had happened. It was super comfortable and I still believe that having DKMS and medical staff there for support makes the whole process a personal growth experience as well, because you get to meet different people. It's a really simple procedure, and at the end you have the satisfaction that – without even knowing who – you are helping someone. You are saving someone."



Official inauguration of the DKMS Collection Center in Chile









## To save lives, we go the distance

There are more than 4,000 kilometres between the extreme north and south of Chile, and one of the challenges we face has been to reach every corner so that we can add new donors who are willing to help a blood cancer patient. In 2023, for the first time, we managed to reach the remotest corners of the country.

Throughout the year, we made it to the regions of Arica,
Tarapacá, Atacama, Aysén and Magallanes, where we added more than 2,000 people as stem cell donors.



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Our Global Footprint | Germany



In 2017, professional footballer Willi Orbán registered as a stem cell donor. Six years later he would become a lifesaver

### Support from all directions

For DKMS Germany, 2023 was another year packed with moving moments and emotional appeals. Thanks to the selfless commitment of our fantastic community, we came together to create countless highlights – some of which we would like to share with you here.

With more and more people wanting to become potential lifesavers, 2023 saw a total of **411,247 new registrations with DKMS Germany** (compared with 371,716 the previous year). Of those, 162,893 were between 17 and 25 years old, showing that with our approach, we are on the right track and our local public donor recruitment campaigns are being well received.

As many as 36 percent of new registrations came in response to physical campaigns; the remaining 64 percent registered online In 2023, we even managed to set a new record in terms of stem cell donations: thanks to the selfless efforts of donors in Germany, we were able to provide 5,919 second chances at life all over the world (compared with 5,368 the previous year). Let us tell you a little more about one of those donors now ...

#### Professional footballer donates stem cells

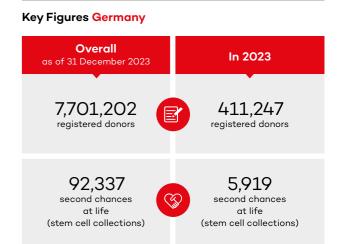
Back in 2017, RB Leipzig's defender Willi Orbán registered with DKMS during a donor recruitment campaign organised by his football club. In 2023, he finally received a call: the first-division professional was a match and his stem cell donation would give a patient a second chance at life. "Of course, I was a bit surprised when I first got the news that I could donate," recalls Willi, who also plays for the Hungarian national team. "But I knew in an instant that I wanted to do it." His club backed the decision too, giving their captain the green light to miss a league game and proceed with the lifesaving donation. "It's a clear reminder that there are more important things in life than football," explains his coach Marco Rose, who had already donated for a patient himself. "We are very proud of his commitment."

On the day of his donation, the 31-year-old was already thinking about the possibility of meeting his recipient. "I would be really thrilled to meet them one day – and it might even encourage other people to register." DKMS greatly appreciates Willi's dedication as well as that of all the other professional athletes who have registered, as it really does show that absolutely anyone can help!

#### Annabel meets her lifesaver

The professional footballer from Leipzig is looking forward to an experience that others have already had: the moving moment when donor and patient finally meet. One young family from Berlin, for example, had been through many years of worry – and hope – before relief finally came. Their daughter Annabel had been diagnosed with leukaemia in the autumn of 2020 at just 13 months old, and they had been told she would need a stem cell transplant. Thankfully, the news finally came in that a global search had identified a match. Meanwhile, in 2021, when Fabian got the call inviting him to donate stem cells, he didn't hesitate for a second.

After her lifesaving transplant, Annabel got a little better every day. In July 2023, she was able to celebrate her fourth birthday and have one of her greatest wishes come true: to finally meet her donor and hero Fabian. It was an unforgettable moment with tears of joy, warm hugs, and happy faces. There could truly be no better gift. "It's moments like these that keep us going in our lifesaving mission," says Dr Elke Neujahr, Global CEO of the DKMS Group. "It makes me so happy and fills me with joy to witness these meetings. The story of Fabian and Annabel is a perfect reminder of just how much you can achieve by registering with DKMS: it keeps families together and could give a terminally ill little girl the gift of a future."





Annabel and her lifesaver Fabian

Our Global Footprint | Germany

### Record-breaking TV appeal

In 2023, two well-known German TV presenters -Joko Winterscheidt and Klaas Heufer-Umlauf – kept the entire country in suspense with a thrilling treasure hunt. Their spectacular campaign also drew attention to the topic of stem cell donation and the work of DKMS. Their appeal set a historic DKMS record for the most registration requests ever generated by a **single appeal.** "A huge thank-you to Joko and Klaas for their fantastic commitment to DKMS and stem cell donation. 38,000 requests for registration kits within 72 hours is a record for humanity!" exclaimed Stephan Schumacher, COO of DKMS Germany. "They also generated countless shares, likes and comments on social media that helped spread the word about the appeal for donors. We are thrilled that so many people have taken part - for the direct benefit of blood cancer patients."

Media coverage is a key driver for successful donor recruitment more generally, and in 2023 we were able to maintain a considerable presence in the national media despite the many – often overlapping – political and social news. By keeping the public informed, we were able to raise awareness and grow our reputation. All in all, we were delighted to see over 8,670 media reports mentioning DKMS – compared to around 5,300 in 2022.



From left to right: Klaas, former patient Stella, and Yoko raise awareness for our DKMS mission on prime-time German TV

In 2023, our communications reached a potential audience of 707.2 million people, up from 416.2 million in 2022



German Country Managers Dr Deborah Buk, Dr Elke Neujahr (Chair) and Stephan Schumacher

In 2023, our communications reached a potential audience of 707.2 million people, up from 416.2 million in 2022. This represents a year-on-year increase of 65 percent in the number of posts, and around 70 percent in reach. On average, each person in Germany came into contact with us and our topic around eight times via traditional media alone (TV, radio, print, online). The majority of articles (88 percent) appeared in regional media, primarily because of the many patient appeals and successful communications by our Donor Recruitment department.

### Focusing on Our Core Activities

Since 31 May 2023 the DKMS Donor Center has been operating as a subsidiary of the DKMS Group in Germany. This step marks an important turning point in the development of the DKMS family. By spinning off the Donor Center in Germany into a separate organisation – equal to the donor centres in the other six countries – we can focus our activities in Germany more clearly and better meet the needs of our donors.

The Donor Center is primarily responsible for donor registration, donor care and facilitating donations and consists purely of the departments required for its core operational activities. These are: Donor Recruitment, Corporate Communications, Data Management, Fundraising, Confirmatory Typing, Workup, Physicians Team, Donor-Patient Contact, and Postal & Logistics Service. The Management Board consists of Dr Elke Neujahr (Chair), Dr Deborah Buk, and Stephan Schumacher.







## Continuing to grow with fundraising

Fundraising is an important pillar of financing and supports the dynamic pursuit of our mission, both nationally and internationally.



Thanks to our many volunteers and supporters, we were able to generate almost 14 million euros in donations in 2023.

For our fundraising department, it is always great to see not only private individuals donating money for a good cause, but also companies and event organisers showing their social commitment.

Among the corporate fundraising efforts of 2023 was a product-sharing cooperation with the food retail chain EDEKA. For every bottle of a specific fruit drink purchased, 10 cents went to DKMS. This raised a total of 400,000 euros, which will help us to invest even more in giving patients in need a second chance at life. We also benefitted from the fantastic support of our long-standing partner B2Run, who raised over 55,000 euros for DKMS at their company runs. Since

2019, B2Run have also donated a share of the entry fees for their nationwide running events to DKMS. Whether one euro or ten thousand: any and all support is welcome and helps patients in need! Over the years, we have been able to reduce our donor registration costs significantly, but registering still costs money, and financial donations remain critical to our mission.

In 2023, we were reminded once again that despite the many success stories, our mission is far from over. Blood cancer can affect anyone at any time – and so we will continue to do everything we can to give people affected a second chance at life.

Our Global Footprint | India Our Global Footprint | India

### Our record campaigns 2023

#### Women's Day Campaign - #SelfLoveJourney



Many female followers embraced our #SelfLove Campaian. with their own social media posts

### ... a strong community of female influencers

For International Women's Day on 8 March 2023 we ran a campaign for female audiences called #SelfLoveJourney. Self-love is about focusing on one's own wellbeing and happiness, especially when it comes to health and lifestyle. It's a concept that has gained significant traction among modern women in India, especially on digital platforms, and empowers them to express and share how they show self-love.

The goal of our campaign was to join these ongoing conversations and present our own unique twist on the idea of self-love: what a greater acknowledgement of one's own worth is there than saving another person's life? By tapping into this audience on our social media platforms and showcasing the stories of female donors and patients, we generated more registrations and helped build a strong community of female influencers and supporters.

As well as creating our own content for the threeweek campaign, we teamed up with female influencers to produce reels, and featured the story of Kriti, which can also be seen on SheThePeopleTv, a women-centric platform that has over 1.3 million subscribers. The platform is famous for highlighting unconventional women's stories, and Kriti, a young woman whose life and aspirations are likely familiar to the audience, inspired a large spike in registrations when her story was shared. The 26-year-old has been battling with chronic myeloid leukaemia for more than half her life, yet despite waiting for a lifesaving stem cell transplant, she remains cheerful and hopeful. She aspires to become a fashion designer with her own boutique one day.

#### Collaboration with Getsetfly SCIENCE

In December 2023, we teamed up with Getsetfly SCIENCE, one of India's biggest science channels with over 7.33 million subscribers. Together, we set out to do a video on how stem cell transplants can provide a second chance at life for patients with blood cancer or blood disorders. By highlighting successful examples from India, we were able to ensure audiences understood how close to home the problem was, and that they could directly impact the lives of those in need.

The video was released on the Getsetfly SCIENCE YouTube channel, receiving more than 1.5 million views and leading to a record-breaking 5,000 kit requests!

By joining forces with a known and trusted partner, we were able to reach out to and educate new audiences to great success. This story is a wonderful reminder of the effectiveness of a core part of the DKMS ethos:

Collaboration is key. knowledge-sharing is power, and we can only move forward when we move together.



GetsetflySCIENCE b... Ø







### From soldier to lifesawer

Often, soldiers are seen as heroes for what they do to protect and uphold the values of their country. But for Sandipan and Harsh – two dedicated army personnel - heroism came elsewhere. The two men donated their stem cells to save blood cancer patients. They had registered as potential stem cell donors back in 2019, at a donor registration campaign at their base, organized by DKMS-BMST Foundation India.

On Independence Day 2023, the two men displayed their compassion again, urging the public to register as stem cell donors to help blood cancer patients

"When I registered as a stem cell donor with DKMS-BMST, I was initially unfamiliar with the profound impact I could make on a person's life," says Harsh. "However, as I delved deeper, my heart swelled with emotion as I realized that even my modest contribution could be a beacon of hope and give someone a precious second chance at life. When I received the call from DKMS-BMST telling me I was a match, it was a great moment and an indescribable feeling. Knowing that I could save someone's life made me feel special. It's truly amazing how a simple act like donating stem cells can make a big difference for someone else."

Sandipan, a devoted father, loving husband, and passionate soldier hailing from the Latur district of Maharashtra, India, displayed unwavering commitment to his donation, even amid the uncertainty caused by the pandemic. Though concerned about his loved ones, Sandipan felt it was his duty to journey from Latur to Bangalore to donate his blood stem cells.

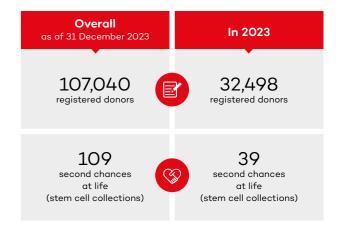
"A phone call from DKMS-BMST changed my life," Sandipan explains. "I learned that I had been identified as a possible match for a patient in need. Despite the initial reluctance of friends and family, I recognized it was my moment to embody the hero within me, driven by my duty as army personnel to aid those in need. Becoming a stem cell donor has truly shown me the incredible courage and determination of individuals battling blood cancer. I consider it a privilege to provide them with an opportunity for a second chance at life."



Soldier and DKMS lifesaver Sandipan

"I recognized it was my moment to embody the hero within me, driven by my duty as army personnel to aid those in need. Becoming a stem cell donor has truly shown me the incredible courage and determination of individuals battling blood cancer."

#### **Key Figures India**



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Our Global Footprint | India

## Giving hope where there was none

Every five minutes someone in India is diagnosed with blood cancer or a blood disorder such as thalassaemia or aplastic anaemia. Thalassaemia patients are mostly children whose only treatment option is painful and continued blood transfusions that merely delay the progression of the disease. For hope and a true cure, these patients need a stem cell transplantation, ideally at an early age.

Our **DKMS-BMST Thalassaemia Programme** supports underprivileged patients by covering the cost of searching for suitable stem cell donors, whether from within their family or – if necessary – from outside. We collaborate with local NGOs and transplantation clinics to organise so-called thalassaemia camps. Paediatric thalassaemia patients and their families travel from faraway places – sometimes from very remote areas of India – to attend the camps, learn about the disease, and identify whether they are a suitable donor for their child. The cheek swabs taken at the camps are analysed in our DKMS Life Science Lab in Dresden.

When it comes to accessing treatment in India, guidance on treatment options and potential sources of financial support are the most critical factors. The **DKMS-BMST Patient Funding Programme** addresses these challenges by offering partial financial support for stem cell transplant patients from lower socioeconomic backgrounds in India. We help cov-

We collaborate with local NGOs and transplantation clinics to organise so-called thalassaemia camps



Puneeth with his brother, who turned out to be his lifesaving match



Buccal swabs at a thalassaemia camp in Delhi

er part of the cost of the treatment when financial resources, including government and other funding support, are not sufficient.

The efforts of this programme have illuminated the path towards a brighter future for many patients, providing them with the prospect of a healthier life. In 2023, the program supported 90 patients.

Puneeth is one of those patients. At the age of eight, in 2008, he was diagnosed with thalassaemia. After receiving blood transfusions for several years, his family became aware of a thalassaemia camp in Bangalore. Puneeth and his brother were tested, and the family was relieved to find out that the two were a perfect match. But their joy was soon extinguished, when the parents found out how much the transplantation would cost. The family could not afford it. Puneeth's parents applied for various grants, and finally, in April 2022, they received the good news that a part of the transplantation costs would be covered by the DKMS-BMST Patient Funding Programme. Puneeth received his brother's stem cell donation and has been living a healthy, happy life ever since.

The DKMS-BMST Patient Funding Programme and the DKMS-BMST Thalassaemia Programme were initiated under the umbrella of DKMS's international Access to Transplantation programme. Read more about the initiatives on pages 36–39.









### Highlights of 2023

- 105 thalassaemia camps
- 5,932 free HLA typings for patients and their families
- 114 transplantations from family donors
- 16 partnerships with NGOs/hospitals

Our Global Footprint | Poland

## Five years that changed the world of patients and Polish haemato-oncology

We envision a world in which haemato-oncological patients receive quick diagnoses and stem cell transplantations, optimal care throughout their treatment, even after they have been discharged home, and appropriate support for their relatives. In this world, patients are left in no doubt about the next steps of their treatment and receive timely medical and rehabilitative support that's tailored to their needs, whether psychological, physical or nutritional. It is also a world where properly prepared, trained volunteers and patient organisations provide assistance and recreation. With its Programme for

the Development of Polish Transplantology and Patient Support, DKMS Poland has been helping to build such a world and offering help where it is needed the most since 2018.

Since the programme's inception, we have allocated more than 27,000,000 Polish sloty (around 6,200,000 euros<sup>7</sup>) to it. In 2023 alone, our initiatives supporting patients and hospitals in Poland and promoting the development of haemato-oncology generated a total of 6,093,240 Polish sloty (around 1,402,523 euros<sup>7</sup>).

### The programme is based on four pillars:







Patient Support



Cooperation with Patient Organisations



Science, Knowledge & Education

Values as at 31 December 2023; Source: Currency calculator at https://bankenverband.de/service/waehrungsrechner; accessed on 6 September 2024

#### We stand for and with patients

The patients we serve are our inspiration and driving force. It is through them that we witness the immediate and devastating impact a sudden diagnosis has and how it changes the course of people's lives forever... Their stories also provide support for those who are at the beginning of their journey in fighting a disease. That's why we want to share Piotr's story with you, which was also the starting point for our Rehabilitation Project, launched in 2023.

At the age of 61, Piotr received a diagnosis of myelodysplastic syndrome. Based on his level of physical activity and rehabilitation experience, he developed a programme to prepare for the effects of his illness and upcoming transplant. During this difficult time, the support of his family and friends, who had registered as stem cell donors, was invaluable to Piotr, giving him energy and optimism. Three months after being discharged from the hospital, Piotr regained his full motor coordination and fitness by following the rehabilitation programme he himself had developed. He then began working on his own project, explain-

"Today, step by step,
we are building a new
and better world for patients
and changing their lives during
their hospital stay"

Natalia Bursiewicz



Piotr with his grandson

ing its benefits to us with joy and excitement. We immediately recognised its potential and knew that together we could provide support for other patients!

Sadly, due to a relapse, Piotr passed away in 2021, but his legacy remains. His project helped create a peri-transplant rehabilitation programme covering the stages before hospitalisation, during therapy and during the recovery period after discharge, and his daughter Natalia has taken over as President of the Active Recovery Foundation that Piotr founded. We are proud to be partner of this project and help fulfil Piotr's biggest dream...

"Dad's illness and passing was a very difficult time for me," explains Natalia Bursiewicz, President of the Active Recovery Foundation. "However, somewhere deep inside there was still a spark and a will to fight to realise his plans. Rehabilitation has been overlooked and forgotten in Polish hospitals for years. Today, step by step, we are building a new and better world for patients and changing their lives during their hospital stay. During my dad's illness I received a great deal of support from DKMS, and I am extremely happy to be working on patient rehabilitation with them today."

### **Donating knows no borders**

## A story of genetic twins

It sounds like a script for a Hollywood movie, but this story actually happened – and came to a happy end. In 2017, Maciej donated stem cells to Brian, from the USA. But that's not the end of their story by far – because together Maciej and Brian's parents prepared a surprise for Brian at his wedding...

#### Patient call

"Your genetic twin is battling blood cancer," said a phone call from DKMS to Maciej in 2017. When asked if he was still willing to help, Maciej agreed without hesitation. "To be honest, the whole process of collecting stem cells is quite boring," Maciej recalled. "For about six hours your blood is filtered and you just sit in a chair. But that's nothing compared to the purpose of doing it."

### You just have to be there!

One day, long after the donation, Maciej found out that his recipient was alive and the transplant had been successful. Unforgettable news. Then, in November 2022, he received a message from Brian's dad: "Hi, we would like to invite you to Brian's wedding. This is a secret for him, of course," Brian's father wrote, "but we cannot imagine you not being there."

Maciej did not hesitate this time either. "Brian was born in America, but his parents are from Jamaica," Maciej explains. "They have the blood of many cultures and nationalities running through their veins, so the house and wedding party probably included family from all over the world. They are amazing people



Lifesaver Maciej (right) at his genetic twin Brian's wedding

and welcomed me like a family member. Everyone at the wedding wanted to say hello to me and thank me for what I had done. It was the kind of moment when even the biggest tough guys well up with emotion!" The wedding was in 2023.

#### Transplant anniversary on the Vistula

At the end of 2023, Brian and his wife Madeline flew to Poland to visit Maciej – and mark a very important anniversary: exactly six years earlier, Maciej had given Brian a second chance at life.

Today, Brian is doing well. He has finished his education and is now working in the IT industry. His loved ones say that after the transplant, it was not just his blood type that changed to Maciej's but his habits as well. Before his illness, Brian had not been a foodie,

Our Global Footprint | **Poland** 

and nor did he enjoy cooking. Now, he not only appreciates good cooking, but enjoys preparing fancy dishes himself!

"Maybe I passed on a part of my personality to him, because I am a chef by vocation," laughs Maciej, who comes from Pruszków. "What's certain is that we became genetic brothers and I gained a family overseas." The story of Maciej and Brian is a wonderful reminder that the lifesaving powers of donation are not contained by borders. It is also an example of how one person can change the fate of an unfamiliar – yet so similar – person.



Maciej and Brian at the DKMS office in Warsaw

## 2023 - The year of young donors

Wow! We rock! In 2023, we carried out numerous events and initiatives that we are truly proud of. Under the slogan "Full speed ahead", we travelled all over Poland visiting secondary schools, universities and festivals. With unwavering enthusiasm, our staff and volunteers spread the word about stem cell donation far and wide to win new potential donors.

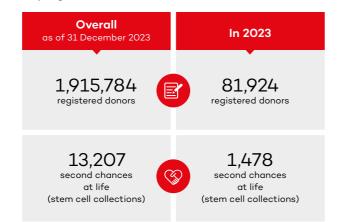
During the summer holidays, we attended festivals large and small to reach out to young people (see Reaching Young Audiences at Festivals, page 33). We also reached out to school communities in 2023, educating them about stem cell donation, training volunteers and organising events. That year also marked the end of the first edition of the nationwide Teachers for Life Competition.

Open to all secondary school teachers, the competition is part of the Cellmania project #KOMÓRKOMANIA and invites teachers to organise donor recruitment campaigns and awareness initiatives with their high school students

"Taking part in the #KOMÓRKOMANIA campaign is an invaluable experience for young people, as they see that their actions can save someone's life. What surprised me most was that the whole group of student volunteers were well-organised, followed the schedule and worked efficiently, as if they had been doing it for years. Not only can they be proud of themselves, I am proud of them too! Through their participation, they learned valuable skills such as teamwork and project work," says Małgorzata Kujawska, teacher and initiator of the #KOMÓRKOMANIA campaign.

"I am totally in favour of promoting stem cell donation. I learned about DKMS when I was at school. In April 2018, I registered as a stem cell donor during a donor recruitment event, and in March 2023, I had the opportunity to give someone a second chance at life. I am proud to have been able to help someone fight their blood cancer by giving them a part of myself. The day of the stem cell donation will forever be imprinted on my memory," says Paulina, a successful stem cell donor.

#### **Key Figures Poland**







### **#KOMÓRKOMANIA**

After 10 years collaborating with the academic community, we celebrated our anniversary with 138 events, attracting 12,559 new recruits to the DKMS database in Poland!

It was all made possible by the commitment of our student leaders, thousands of volunteers, and nearly 100 universities across the country.



Shudufhadzo Musida, Miss South Africa 2020, hands DKMS gifts to a patient

### We've come a long way

South Africa is a country with more than 250,000 nonprofit organisations, a multitude of major social issues and a very politically active population. Amid this complex environment, we faced a critical question before we even began operations here: how can we forge a space to discuss an intersectional topic like stem cell transplantation?

In 2021, DKMS Africa was launched against the backdrop of COVID-19. Like much of the world, South African society faced myriad issues beyond the pandemic itself, including a dramatic rise in misinformation around health topics.

Confronting this reality, it was critical for us to stand firm in disseminating factually correct information about blood cancer and blood disorders, focusing particular attention on the importance of education and awareness.

What started as a slow integration into the fabric of the cancer-aligned nonprofit community has turned into a beautiful development characterised by the spirit of ubuntu, an ancient African philosophy highlighting the universality of our humanity and the necessary nature of compassion and cooperation. When we first opened our doors, we knew we would need to appeal to a robust and proactive community that was not laissez-faire about matters they hold dear. DKMS Africa stepped into a landscape where people were hungry for knowledge, understanding that what they learned could help them make informed decisions about their own health.

In the years since we opened, we have managed to dramatically grow our donor database and now have over 70,000 strong individuals standing ready, willing and able to help current and future patients.

In South Africa, our goal for 2024 alone will be to register 38,000 new potential lifesavers from ethnically diverse backgrounds. Over the last couple of years, we have managed to significantly alter the composition of the South African database, and currently over 50 percent of our donor pool is Black, mixed ethnicity, Asian and/or Indian. What this has shown us is that, despite our concern that other social demands might eclipse our efforts, South Africans across all backgrounds have proven receptive to our message and are excited to join our mission. Equally uplifting is the number of relationships we have been able to build with civic society groups including universities, colleges, corporations and other organisations.

South Africans clearly don't just talk the talk; they walk the walk too. Our expansive education and awareness efforts show that, when called upon, South Africans have an untapped ability and limit-less potential to rally behind a cause.

## Debunking myths

One of our most important goals in South Africa was to ensure communities understand that blood cancer and blood disorders don't just affect the white community. This meant filling the information gap and correcting a major misunderstanding: white South Africans have better access to knowledge and healthcare, so they get diagnosed more often and the incidence rate is higher.

It was also important for us to debunk the highly problematic notion that stem cell donation was akin to giving away an irreplaceable organ – a practice that is not easily welcomed in Africa. To address this, we had to emphasise the fact that stem cell donation is non-invasive for the donor and that, ultimately, because of their treatment prior to donation, donors are actually giving away excess stem cells.

To help us launch this cultural conversation, we engaged a South African traditional healer and founder of Sangoma Society, Makhosi Nomabutho, who registered as a donor. She hoped her decision and public promotion of the cause would influence other traditional healers and her clients to do the same. "I do not want to be in the position that a lot of people find themselves in of not knowing where they will get a donor. Because there's no amount of money or influence that can change a person's diagnosis. The only thing that can is more donors of African descent," Makhosi explains.

We also chose to speak to communities in their own language, ensuring audiences gained a deeper understanding of the issue and felt a greater sense of respect and representation in our cause

Finding a matching donor is one of the most difficult challenges for people with blood cancer – and for Black Africans especially, given the small pool of donors from this population. "Just as the work of traditional healers is God's work, so too is medical science," Makhosi says. "If someone with blood cancer or a blood disorder were to come see me, for instance, I would try to help them access an oncologist so they

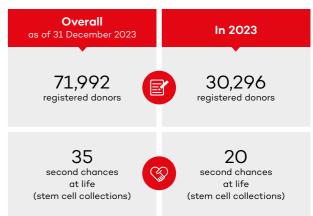
can start the appropriate treatment. At the same time, I would work with them on the spiritual element of their disease"

Our breakthroughs in these communities relied critically on the use of language and representation. Through joint online and offline efforts with digital influencers, individuals and groups in various spaces we were able to target and reach out to different demographics. We also chose to speak to communities in their own language, ensuring audiences gained a deeper understanding of the issue and felt a greater sense of respect and representation in our cause. Through carefully planned engagements, events and activities, we have been able to grow from strength to strength in regard to the number of people of colour represented on the registry.



Healer Makhosi Nomabutho

### **Key Figures South Africa**



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Our Global Footprint | South Africa

## Running the race for DKMS Africa

In an effort to increase the understanding of our mission in South Africa, DKMS Africa has launched a number of activities around the marathon that have been highly successful for our awareness-raising. We have participated in some of South Africa's biggest races, which draw both local and international crowds. Our presence at the marathon expos has ensured our education efforts are seen in different spaces, showcasing our cause for new audiences and allowing us to target healthy, active individuals to sign up to become potential lifesavers.

In the same vein, many of the individuals we have partnered with for the marathons have been directly touched by the devastation of a blood cancer diagnosis. One example is the runners and volunteers who participated in the Comrades Marathon in honour of former blood cancer patient Gugu.

In May 2023, we published Gugu's story and called for people to register as stem cell donors so that she could live to raise her two children. We were able to find four matching donors – but none of them were willing to commit when contacted, and Gugu ultimately passed away. Yet, her memory lives on in those who knew and loved her, such as her sister Cebo and her best friend Lindokuhle.

Since her sister's passing, Cebo has registered as a DKMS Africa volunteer and, much like DKMS founder Peter Harf, has used her love for her sister as motivation to ensure that other families have hope for a second chance at life. In addition to the monumental task of looking after her sister's children, she dedicates her time to DKMS activations to help increase



DKMS at the Sanlam Marathon in October 2023



Media partner Cape Town TV films an insert for a segment after the shakeout run

Since her sister's passing,
Cebo has registered as a DKMS
Africa volunteer and, much like
DKMS Founder Peter Harf, has used
her love for her sister as motivation
to ensure that other families have
hope for a second chance at life

the number of available donors for patients in need. Likewise, Lindokuhle chose to run the Comrades Marathon as a tribute to Gugu, hoping to inspire something beautiful from the tragic loss of his best friend's life.

These stories are a heart-warming reminder that the lifeblood of our organisation and the success of our mission stems directly from the commitment and passion of all those volunteers, supporters and donors who fight on in the name of those they loved for those who have yet to be saved.







## From pilot to successful programme with impact



Our **DKMS State Patient Support Programme** supports paediatric patients from South Africa suffering from blood cancer or life-threatening blood disorders such as severe aplastic anaemia. South Africa's public healthcare system fully covers the cost of stem cell transplantations for patients who have found a matching donor within their family – but those who rely on an unrelated donor are faced with two major challenges: finding a matching donor and covering donor-related costs.

DKMS supports paediatric state patients without private medical insurance who cannot afford these donor-related costs – no matter which donor centre the selected donor is registered with.

We collaborate locally with three hospitals of the public sector: the Red Cross War Memorial Children's Hospital in Cape Town, Steve Biko Academic Hospital in Pretoria and Inkosi Albert Luthuli Central Hospital in Durban.

Having started with a pilot in 2022, we successfully continued the programme in 2023 and were able to support three patients.

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Our Global Footprint | United Kingdom

### A record year in the UK

2023 was a particularly special year for DKMS in the UK, as we celebrated our tenth anniversary. During the year, we made significant progress in our mission by continuing to expand and diversify the stem cell database and offering crucial support to patients with blood cancer and blood disorders.

Throughout the year, we focused on raising awareness of the stem cell database and registering more potential lifesavers across the UK. Our efforts facilitated critical stem cell transplants, profoundly affecting hundreds of lives both nationally and globally. Moreover, our fundraising campaigns led to significant corporate partnerships that further amplified our mission.

Moving forward, we are intensifying our efforts, with a special focus on registering donors from minority ethnic communities to ensure everyone has the same opportunity to find a lifesaving stem cell donor. The recent growth in our staff enhances our ability to support this mission.

The stories presented on these pages illustrate the vital impact DKMS UK had in 2023 on the lives of our supporters, stem cell donors and patients with blood cancers or disorders.



Volunteer Gilly at a DKMS donor recruitment event

"For me, it's something you have to act upon, if you get called and asked if you will be a donor. I thought, 'Let's get it done!'."

At the start of the donation process, Joe went for medical checks at Scotland's new stem cell collection centre, launched in August 2023 by the Scottish National Blood Transfusion Service.

"DKMS's medical team explained everything, and once I was given the OK to go ahead, I went in to donate with the help of the amazing nursing staff." DKMS UK is committed to working with heroes like Joe and empowering more people from ethnic minority communities to make an informed choice about joining the stem cell donor pool.

"In our community, there can be a lot of stigmas around going to the hospital for anything: due to historical precedence, people from a Caribbean background can fear that you will go into hospital and not come out, or that procedures will be done and not properly followed up on. We need to break down these sorts of barriers and I'm happy to be an example

for people from my community of someone who completed the process of registering and donating my stem cells.

I was able to give someone a second chance at life. This made me feel humbled and honored to have the opportunity to do my small part in this ever-changing society. Hopefully my experience will encourage others to step up and get registered."



Joe, a proud DKMS stem cell donor

### **Our work with donors**

Our Confirmatory Typing (CT) team grew significantly this year to accommodate the increased volume of CT requests, thus boosting DKMS's commitment to eliminating blood cancer. The CT team works quickly and effectively in time-sensitive situations, often making a potentially lifesaving difference for patients in need of a stem cell transplant.

In 2023, the UK CT team handled an impressive 3,941 CT requests, which is a significant increase from previous years (296 more than in 2022 and 856 more than in 2021) and more than double the number of requests since 2018. This growth illustrates our dedication and efficiency in meeting the rising demand for stem cell donors. Another key achievement was successfully turning this record number of CT requests into 359 collections – a remarkable conversion rate.

As the first point of contact for potential donors, the CT team plays a crucial role in the donation process, ensuring donors are well-prepared to provide the best possible results for patients. By prioritising donor safety, we aim to achieve the best outcomes for patients, while maintaining the highest level of care for our donors as well. The stories of donors like Joe highlight the incredible lifesaving potential that stem cell transplants can have.

### Empowering people to become stem cell donors: Joe's story

As a passionate outdoorsman, Joe knows the beauty that can be found in life. This is why he is determined to encourage people from his community to register as potentially lifesaving stem cell donors, especially after becoming a donor himself.

"I registered with DKMS as a stem cell donor back in 2017, after a friend and colleague of mine in the Royal Navy needed a stem cell transplant," explains Joe. "He is from St Vincent and he needed a specific genetic match with someone from a Caribbean background. I'm from Trinidad and Tobago, so I wanted to help.

There aren't enough people from our community registered, and this simple act can give someone a second chance at life. So, I organized a series of events at Royal Navy bases across the UK to encourage more colleagues to join the database. I was delighted that over 1,000 people signed up! If I can play a part, then I want to help all I can. Thankfully, my friend found a match and he is much better today."

In 2023, Joe received a call from DKMS to say that he was a matching donor.

### **Donor recruitment**

In April, we had nearly 10,000 kit requests thanks to patient appeals in Northern Ireland. This helped DKMS UK build relationships with local businesses and create future partnerships for 2024.

Families were a main theme in 2023 – from helping them find a stem cell donor for their loved one to mothers who donated their stem cells.

In 2023, our Donor Recruitment team passed the milestone of one million registered stem cell donors in the UK

#### Inspiring others to register: Jo's story

Jo's son Oti received a stem cell transplant after being diagnosed with acute myeloid leukaemia in 2022. Today, at three years old, he is healthy and thriving. "I am forever grateful to Oti's donor," Jo says. "Oti now tells people he has 'magic blood.' Watching him loving life inspired me to encourage more people to join the stem cell donor pool."

In September 2023, as part of Blood Cancer Awareness Month, Jo decided to organise a swabbing event at a restaurant near where she lives in Essex. Working with DKMS to spread the word locally about the event and about how a stem cell transplant had given Oti a second chance at life, she helped people make an informed choice.

"So many gave up their precious Sunday morning. It was the busiest and best day and felt like such a celebration," exclaims Jo. "Over 200 people signed up there and then, with even more people going online afterwards to request a swab kit from DKMS. Even better, one of the people who came that day has



Jo with her family

Our Global Footprint | United Kingdom

already been found as a match for a patient needing a stem cell transplant and been called to donate. That could mean the world to someone!"

After Jo's success in registering new potential donors, she has continued to support DKMS UK by sharing her story with journalists and playing a key role in developing our partnership with the UK nonprofit organisation Battle Cancer. Her message for anyone thinking of hosting a stem cell registration event themselves? "One: go for it. Two: you will be completely supported. Three: you can't fail. If you manage to get one person on the database, that person could be a match for someone with a blood cancer or disorder. It's made me feel so incredible about humanity and what we can do for each other."

# Overall as of 31 December 2023 1,007,051 registered donors 46,610 registered donors 2,265 second chances at life

(stem cell collections)

**Key Figures United Kingdom** 

(stem cell collections)

### Volunteering - For years to come

In 2023, volunteering played a critical role in achieving DKMS UK's mission. We have over 116 active volunteers, who:

- organise or support donor recruitment campaigns across the UK
- help raise vital funds through fundraising events
- raise awareness about blood cancer and blood disorders.

With five volunteering hubs already, in 2023 we launched our East Midlands Hub as well. Our hubs in the West Midlands, Scotland, Bedford, South West England and West London had exciting milestones in 2023:

- Students vs Blood Cancer: we increased the number of universities and colleges running donor recruitment events organised by student volunteers.
- Annual Volunteer Fundraising Day: 2023 was the first year we established a collective fundraising day for our volunteers, raising over 5,000 GBP (around 5,700 euros<sup>8</sup>) for DKMS UK.
- Fundraising events organised by volunteers, including a charity dinner that raised over 34,000 GBP (around 39,000 euros<sup>8</sup>).

### Leading community action: Manj's story

"It all began when I signed up with DKMS as a potential donor because my cousin's son needed a match," explains Manj. "I was uneducated on stem cells and transplants at the time, so I checked out the DKMS

website and contacted them to ask if I could help in any way. I was put in touch with a local volunteer and went for training on how to swab and register people. Then I set up my first donor recruitment campaign at my local Gurdwara, and I've since helped with many DKMS events.

I've also witnessed the devastating impact of cancer on my own family, losing two special people in my life: my husband Raj and my mother. I've seen first-hand the urgent need for a diverse donor pool, and it has made me determined to help others have a chance at survival. I couldn't save my special people, but I can try to help other people's special people. We need more donors from Asian and other ethnic minority communities.

In October 2023, I was delighted to join with other West Midlands Hub volunteers to organise a charity event at Birmingham's Manor Grove banqueting hall, where we welcomed 400 guests. They joined us in celebrating having registered more than 500 people as potential donors over the past year – predominately from the Asian community – and highlighting the need for even more people to sign up. I was so thrilled that the evening also raised a magnificent 34,000 GBP (around 39,000 euros<sup>8</sup>) to support DKMS's lifesaving mission.

The best part of my volunteer work, though, is hearing that a patient has found a stem cell match and knowing that we have been part of the process in potentially saving their life. That is priceless."







"I've seen first-hand the urgent need for a diverse donor pool and it has made me determined to help others have a chance at survival.

I couldn't save my special people, but I can try to help other people's special people. We need more donors from Asian and other ethnic minority communities."





Manj with DKMS UK volunteer manager Ian Corpuz

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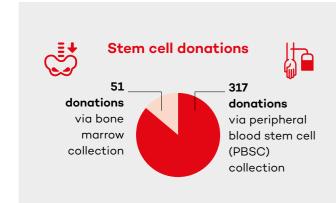
<sup>&</sup>lt;sup>8</sup> As at 31 December 2023; Source: Currency calculator at https://bankenverband.de/service/waehrungsrechner; accessed on 6 September 2024

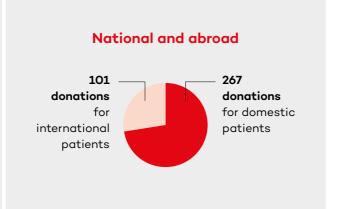
Our Global Footprint | USA

### From hope to healing

In 2023, DKMS US continued its efforts to expand and diversify the donor pool and provide donors for patients around the world. By keeping our focus local, we were able to build our brand awareness, forge new partnerships and see results that had a global impact. Ultimately, our US team contributed to DKMS's role as a leading source for global donations and saw our work rewarded both in the number of transplants facilitated for international patients and through the recognition of like-minded organisations in providing grants to further our mission.

### Here are some examples of the success we saw in 2023:





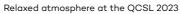


DKMS US colleagues Maya, Corey and Nafi at the Queen City Saves Lives (QCSL) event in September 2023

### **Local events**

In September, DKMS hosted the first Queen City Saves Lives (QCSL) event in Charlotte, North Carolina. A lively mission-driven evening filled with music, raffle prizes and of course an in-person swab station, QCSL offered over 100 locals the opportunity to directly interact with the DKMS family, including employees, avid volunteers and stem cell donors. 42 percent of the attendees registered that same evening to become a potential lifesaver!







vent check-in

### Jan & Ben - A Bond for life

Ben's life changed forever in 2010 when he was diagnosed with T cell lymphoblastic lymphoma, a form of blood cancer. He quickly underwent extensive chemotherapy that required weeklong hospital stays. Finally, Ben achieved remission, but it wasn't long before he learned that the cancer had come back and he would now need a stem cell transplant. For that to happen, he would first need to find a matching donor.

Thousands of miles away, Jan had registered to be a potential lifesaver with DKMS in Germany. Having watched his childhood friend battle and ultimately lose the fight against cancer, Jan didn't hesitate when he was asked to donate his stem cells to a stranger: he knew it could mean a second chance at life for the person on the receiving end.

Fast forward to 2023: Ben proposed to the love of his life and knew he had to ask Jan to help him once more, this time as his best man. "Without him, I wouldn't be here to marry the woman of my dreams that God has placed into my life," says Ben on asking donor Jan to be best man at his wedding.

"Without him, I wouldn't be here to marry the woman of my dreams"

Ben



Ben and Jan

Our Global Footprint | USA

## Abby & Emily -Transforming lives together

In 2015, former Duke football player Abby had the chance to coach a young girl named Emily at a Duke football camp. Emily was later diagnosed with leukaemia and treated at Duke Hospital System, where she ended up undergoing a bone marrow transplant from her sister.

Emily's fight inspired Abby to register as a stem cell donor herself in 2016 and eventually seek a career in medicine. Six years later, Abby, now a second-year medical student at Duke, got a call from DKMS that she was a match for a patient in need. When asked if she would donate, she immediately said yes and in April of 2023, Abby donated her stem cells to help. She now hopes that sharing her story will help inspire others to register as potential donors.

"Almost 10 years after my initial cheek swab I got an email that I had matched. For me it was a no-brainer! I knew I was going to do whatever it took to move the process forward."



Abby and Emily at football camp in 2015

## Local Funding and Family Typing



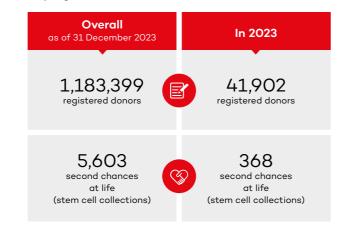
### The William G Pomeroy Foundation

In 2023, the William G Pomeroy Foundation graciously awarded DKMS US with a grant for 300,000 US dollars (around 270,000 euros°) to build awareness within communities, grow and diversify the donor pool, and offer free high-resolution typings for potential lifesavers who could not easily afford support. Grants like this help us get closer to our dream of every patient in need being able to get the second chance at life they deserve.

The Free Family Typing
Programme facilitated
236 typings for 70 patients!

We understand the great financial burden of a cancer diagnosis and the complexities of the healthcare system, which is why we believe in simplifying the processes and supporting patients in their time of need. Through the Free Family Typing Programme, we can cover the costs associated with offering highresolution HLA typing to family members of patients, relieving them of one of the many burdens they face.

### Key Figures USA



<sup>°</sup> As at December 31, 2023; Source: Currency calculator at https://bankenverband.de/service/waehrungsrechner, accessed on September 6, 2024





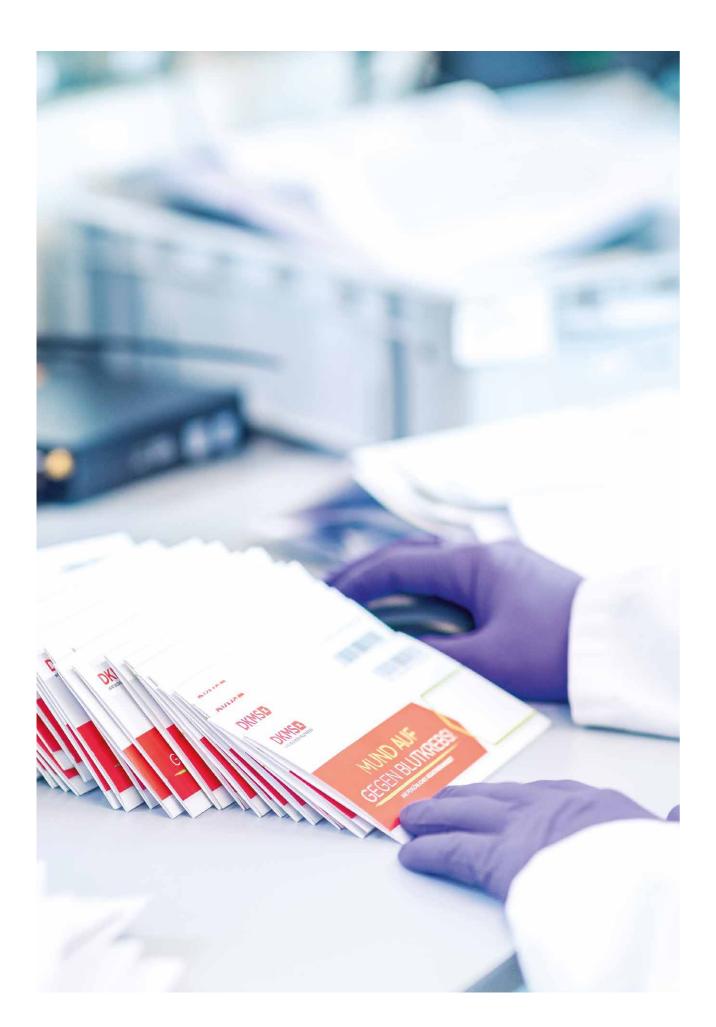


In 2023, the William G
Pomeroy Foundation
graciously awarded
DKMS US with a grant for
300,000 US dollars.

Thank you!



Our international family



### Our international family

In 2023, DKMS comprised 14 entities working hand in hand to achieve our joint mission: to give as many blood cancer patients as possible a second chance at life.

Since our first DKMS entity was founded in Germany in 1991 and the umbrella foundation DKMS Stiftung Leben Spenden (Foundation for Giving Life) was created in 1997, our organisation has grown exponentially – both in capacity and impact. Today, we run the world's largest and most diverse stem cell donor database. With Donor Centers in Chile, Germany, India, Poland, South Africa, the UK and the US, DKMS

is a global leader in the fight against diseases of the haematopoietic system, impacting the lives of people in more than 60 countries in 2023.

The DKMS Group gGmbH is the international organisation that oversees the operation of our seven Donor Centers around the world, as well as the German-based medical and scientific entities that further the treatment of blood cancer and blood disorders. These include the DKMS Life Science Lab, DKMS Collection Centers, DKMS Stem Cell Bank and DKMS Registry.



### **DKMS** family worldwide

Global operations:

Stiftung Leben Spenden

DKMS Group

Cologne,
Tübingen, Dresden

DKMS Life Science Lab

DKMS Registry

DKMS Stem Cell Bank

Tübingen

Tübingen

Tübingen

Dresden

Local operations:

**DKMS Collection Center Germany** Cologne, Dresden **DKMS LIFE** Cologne **DKMS Africa** Cape Town, Johannesburg, Durban **DKMS Chile** Santiago de Chile **DKMS Germany** Cologne, Tübingen, Berlin, Dresden DKMS-BMST India Bangalore **DKMS Poland** Warsaw **DKMS UK DKMS US** New York, Charlotte, Dallas

Our history Our history

# MENSCHEN DIE HE RETTU EN NOT 122













## Our history - A fate that continues to save lives today

Anyone who has watched a loved one battle a life-threatening disease knows the overwhelming feeling of helplessness it brings. I was only 13 when my mother was diagnosed with leukaemia, but I remember the surge of emotions: fear, sorrow and a deep frustration that there was nothing I could do to save her. We guickly found out she would need a stem cell transplant to survive, but with no matches in the family and only 3,000 unrelated donors on the German registry, there seemed to be no hope. My father Peter, however, refused to simply accept this and began recruiting family and friends to help register new donors across the country. In one year, we added 65,000 new donors to the registry. Sadly, my mother ultimately passed away from her disease in 1991, but before leaving us, she made my father promise that he would continue fighting until all patients could receive a second chance at life. From our personal tragedy, the beauty of DKMS was born and today we continue to honour my mother's legacy, fighting for patients across the globe.

"I was only 13 when my
mother was diagnosed with
leukaemia, but I remember the
surge of emotions: fear, sorrow
and a deep frustration that
there was nothing I could
do to save her"

With the simple fact that every 27 seconds someone, somewhere in the world is diagnosed with blood cancer, DKMS knew that we needed to establish international operations to better serve the needs of the global patient population. That is why I founded the US branch in 2004 and continue to serve as the Chair of our DKMS Foundation Board and as Global Ambassador for our DKMS mission ever since. The DKMS family continued to expand its international footprint in the following years, opening Donor Centers in Poland (2009), the UK (2013), Chile (2018) and India (2019, alongside our partner BMST), with the most recent office established in South Africa (2021). Our global approach is why DKMS is one of



Peter and Mechtild Harf with their first daughter Viktoria

the most diverse donor databases in the world, with over 12 million registered potential donors as at 2023. As we continue to expand and diversify the global pool of donors, we are also exploring new avenues for aiding those we serve. Whether through the work of our clinical trials and medical research teams or due to the efforts of our capacity-building and patient-focused programmes, DKMS is constantly striving to find new ways to alleviate the burdens faced by patients and improve their access to life-changing medical care.

Although we work in many languages and across many cultures, the core of who we are has never changed: DKMS is an ever-expanding movement, and within our walls we share in all aspects of our life's journey. The successes and failures, the moments of joy and sorrow, the fear of what may come, alongside the hope of knowing what may be – we are all in this together.

Katharina Harf
Chair of the DKMS Global
Foundation Board



(atharina Harf

Looking to the future



As an international nonprofit organisation of our size, it is inevitable that we must make plans, improving and expanding upon our dreams, to ensure patients, donors and our employees have the best possible prospects.

Looking ahead, we envision a world without blood cancer and life-threatening blood disorders. To achieve this, we will follow our holistic approach with its three pillars (see pages 28–43), expanding our impact in new regions and fields to guarantee hope for every patient in need.

Following a year that set records on many levels, we aim to reach even higher in the years to come. Our goal by 2030 is to have facilitated 200,000 donations since our foundation and offer 12,000 second chances at life a year, including 1,000 through our Access to Transplantation and Registry activities.

As this report makes clear, our international support programmes in low- and-middle income countries and our scientific research initiatives will play a crucial role in realising our ambitions and improving patient outcomes worldwide. We will focus particularly on cell therapies to raise the chances of ultimately curing blood cancer for good and minimising life-threatening progression of the disease.

These areas will form the nucleus of our fundraising, for which we are currently building a new strategy to

better showcase the broad array of our activities and our holistic and sustainable three-pillar approach in fighting blood cancer.

Today, the digital sphere is a significant part of our lives. Although not necessarily new, it has grown dramatically in the last decade. And that's why we intend to further increase the ambitious efforts of our Digitalisation Programme for process excellence – because that way, we can enable outstanding donor journeys and manage our organisational growth by enhancing and developing our talents and teams.

Growth is the only way forwards, and we will not be content with the status quo. As long as there are still patients with blood cancer or blood disorders whose lives could be saved, we will fight on and forge new roads to help them.

Thank you for being on this journey with us, for your support big or small, and for the hope that we, together, bring to all blood cancer and blood disorder patients.

Dr Elke Neujahr Global CEO, DKMS Group "As long as there are still patients with blood cancer or blood disorders whose lives could be saved, we will fight on and forge new roads to help them."

DKMS global leadership DKMS global leadership

### **DKMS Global Foundation Board**

#### Chair



Katharina Harf

**Vice Chair** 



van den Brink

The Foundation Board and Global Executive Team shape the future of our international DKMS Group with their extensive knowledge and experience

### **DKMS Medical Council**

Chair



van den Brink

**Vice Chair** 



Klingebiel

The Medical Council advises the DKMS Foundation Board on medical issues, monitors developments in the relevant medical fields and initiates scientific programmes



Laurence David Atlas



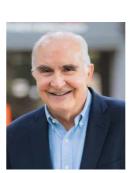
Prof Carl H June, MD



Kamenetzky-Wetzel



Niren Chaudhary



Dr Marcelo Fernández-Viña



Prof Dr Katharina Fleischhauer



Stephen J Forman,



Prof Dr Dr Dieter Hoelzer



Prof Dr Dr Dieter Hoelzer



Prof Dr Thomas Klingebiel



Alejandro Santo Domingo



Prof Emma Morris

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### DKMS Global Executive Team







Dr Julia Pingel Global CIO



Bernd Weinel Global CFO

### Leadership of DKMS subsidiaries

DKMS Collection Center gGmbH	Dr Elke Neujahr, CEO Sirko Geist, COO
DKMS Life Science Lab gGmbH	Dr Vinzenz Lange, CTO Thomas Schäfer, COO
DKMS Registry gGmbH	Dr Julia Pingel, COO
DKMS Stem Cell Bank gGmbH	Dr Alexander Platz, CMO Thomas Schäfer, COO

Donor Centers		
DKMS Africa	Erna West, Country Manager	
	Chandré Phillipus, Country Manager	
Fundación DKMS Chile	Ignacia Pattillo Garnham, Country Manager	
	Anette Giani, Country Manager	
DKMS Donor Center gGmbH	Dr Elke Neujahr, CEO	
	Dr Deborah Buk, Country Manager / COO	
	Stephan Schumacher, Country Manager / COO	
DKMS BMST Foundation India	Patrick Paul, Country Manager	
Fundacja DKMS Poland	Ewa Magnucka-Bowkiewicz, Country Manager	
	Agnieszka Wodzinska, Country Manager	
DKMS UK	Hasnein Alidina, Country Manager	
	Peter McCleave, Country Manager	
DKMS USA	Katharina Harf, Executive Chair	

All leadership positions as of December 2024

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DKMS Stem Cell Bank gGmbH Enderstraße 94, Building C 01277 Dresden Germany

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## Data privacy and information security

The protection of personal data is of the utmost importance for us.

We ensure that all data protection regulations are complied with and regularly adapt our guidelines to new legal and technological developments.

Our employees are trained in handling (personal) data, and we use modern security standards to ensure the confidentiality and security of information.

We see data protection as a fundamental obligation toward our donors, patients, employees, and business partners.

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#### **Publisher**

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### A heartfelt thank-you

To all who have supported us over the years – whether as a lifesaver, a registered donor, through monetary contributions, or by offering your time and effort – we extend our deepest gratitude.

Every contribution, no matter how large or small, has been vital in helping us fulfill our mission, and is genuinely appreciated by all of us at DKMS. We are truly honored to be part of such a dedicated and compassionate community, united in the shared vision of a world free from blood cancer and blood disorders.

Thank you for being a part of our journey.

**DKMS** Group gGmbH Kressbach 1 72072 Tübingen Germany

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