

ZKRD Zentrales Knochenmarkspender-Register Deutschland

ANNUAL REPORT 2024

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1 Preface

In times of global crises and uncertainties, there is a force that connects us and gives us stability: SOLIDARITY.



Every day, we are wholly committed to blood stem cell donation – an act of unity and compassion. Hope is our motivation: the hope of a cure, a second chance, and a better future for those who depend on a life-saving blood stem cell donation. Yet this hope remains far from abstract. It is borne by countless donors, dedicated partners, and a strong network tirelessly committed to patient well-being.

A lot happened at the ZKRD in 2024.

One major change was the appointment of Volker Rump as Commercial Managing Director. He has been with us for many years and, alongside Dr. Joannis Mytilineos and Dr. Peter Mein, will drive the continued development of the ZKRD with the clear mission of making the organization future-proof. Furthermore, the ZKRD was again re-certified by the World Marrow Donor Association (WMDA). This certification once more confirms the ZKRD's high quality standards and reflects the effective collaboration with our partners.

Dynamic exchange is the key to a strong partnership.

The 2024 ZKRD annual conference provided a valuable platform in this regard: lectures by specialists, animated discussions and realistic best-practice examples offered in-depth insights while strengthening the bonds between the experts.

To reinforce this network, the ZKRD has been active on LinkedIn since December 2024 with its own company page. **We flourish thanks to a robust network** – and this is precisely our focus. Using this new communication channel, we aim to promote direct exchange and create momentum together.

But our year was not shaped by strategic and substantive progress alone. The figures also speak for themselves:

Yet again, the statistics clearly illustrate our collective impact and the ongoing advancements in stem cell donation. But behind these achievements are not only facts and figures – it is the people who make the difference. Advances are being made in blood stem cell donation thanks to the tireless commitment, the expertise and the determination of our partners and, above all, the donors who sign up or have already donated stem cells. They are the ones who give hope, save lives, and make the future possible. This is the true essence of solidarity in action. We are incredibly grateful for this.

Dr. Peter Mein

PD Dr. Joannis Mytilineos

Volker Rump

New management structure

For more than three decades, the ZKRD has been the central point of contact in Germany in the search for suitable unrelated blood stem cell donors. Working closely with more than 300 institutions worldwide, the ZKRD coordinates the collaborative efforts of all stakeholders, from the search for a suitable donor to the transport of donated cells. The ZKRD also guarantees seamless remuneration processes while working closely with payers at home and abroad.

To ensure that this high standard is upheld in the future and to further develop the ZKRD strategically, the management was restructured in 2024. Having been an authorized signatory at the ZKRD for many years, Volker Rump joined the management team on May 1, 2024, assuming the role Commercial Managing Director alongside Dr. Peter Mein. Together with Dr. Mein and Chief Medical Officer Dr. Joannis Mytilineos, he will drive the ZKRD forward while ensuring that future challenges are navigated with ease.

Dr. Mytilineos also stresses the importance of this development:

"Our goal is to further strengthen the ZKRD as a trusted and indispensable partner on the national and international stage. It is not only about continuously optimizing patient care, but also about setting new standards.

It is particularly important to us to address the changing needs of patients proactively so that we can make a valuable contribution to health care in the long term."

The ZKRD has benefited from Volker Rump's expertise and commitment for 28 years. He played a significant role in ensuring that the central coordination center for bone marrow donor searches was firmly embedded in the German Social Code – a decisive step that enabled the ZKRD to officially take on this important responsibility.

Volker Rump also oversees all financial transactions of the ZKRD with every partner nationally and abroad, and ensures that the business processes integrate seamlessly. With his outstanding expertise, he continuously strives for improvements in the immediate interests of patient care.

New perspectives and valuable synergies have been created by restructuring at the management level. This close collaboration enables precise analysis of current medical and economic developments and future-proofing of the ZKRD in the long term. We can therefore guarantee the continued focus on the needs of patients as well as the protection of donors.

"As a Commercial Managing Director, I aim to builc achievements while introducing fresh momentum," explains Volker Rump. "A key priority is to explore new business areas, expand our range of services and further improve patient-centered care. With the support of our dedicated team and partners, I hope to develop innovative solutions that not only meet the current challenges but also consider the future."

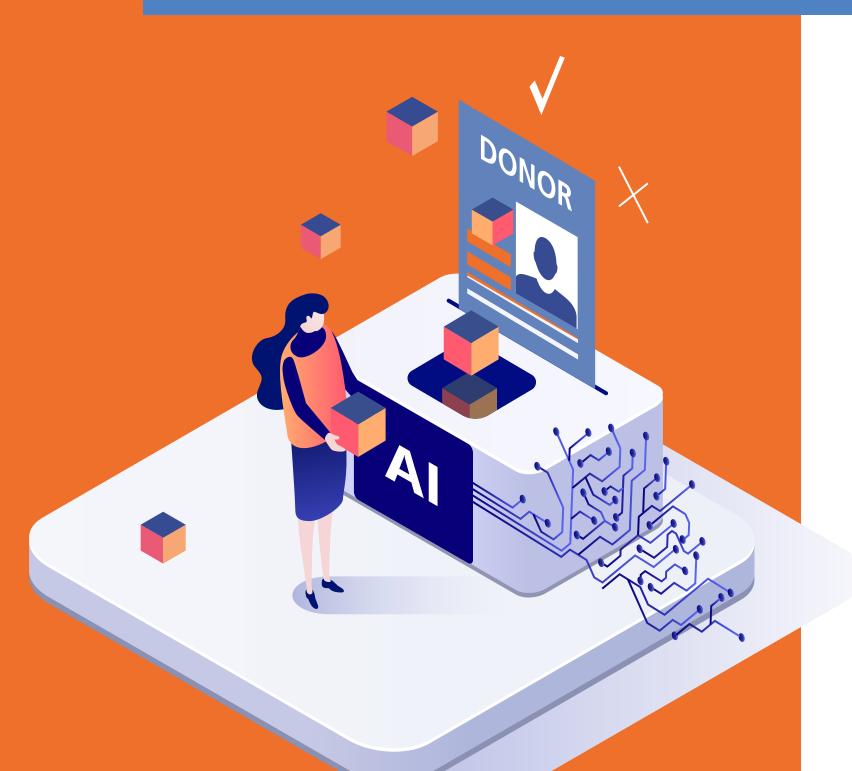
Volker Rump



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2024 ZKRD annual conference: Artificial intelligence and advances in stem cell transplantation

Medicine is constantly evolving, whereby artificial intelligence (AI) is playing an increasingly important role. It can support the diagnostic process, adapt therapeutic strategies with greater precision, and improve patient care. Its use is also opening up new possibilities in blood stem cell transplantation – especially in the search for suitable donors. These developments were the focus of the 2024 ZKRD annual conference.



AI in donor search: Novel approaches to more accurate decision-making

Dr. Janina Hegner from Charité Berlin presented an example of the use of AI in donor search. The MatchGraft.AI software application analyzes donor and recipient data, assesses potential risks such as graft-versushost disease (GVHD), and offers predictions as to the success of a transplant. This assessment could help to increase the chances of finding a suitable match.

Digital Twins technology was also presented as a promising concept: Patient data is used to create individual digital models, which can then simulate different courses of treatment. Dr. Jonas Marcello from Fraunhofer IESE in Kaiserslautern explained how such technology can help to make more targeted treatment decisions.

At the end of the AI-focused session, Prof. Manfred Spitzer (University Hospital Ulm) talked about the opportunities and challenges presented by AI-based technologies. He pointed out that although AI offers many possibilities, its use must be approached with caution. Questions concerning ethics and data privacy take on special importance here. Only if these aspects are carefully considered can AI be usefully integrated into medical practice.

Scientific developments and practical relevance

In addition to examining the role of AI, the 2024 ZKRD annual conference focused on current medical developments. Researchers and medical experts presented new therapeutic strategies, including cellular treatments for leukodystrophies and the use of CAR T cells for treating autoimmune diseases. Another key topic was histocompatibility in allogeneic stem cell transplantation, which plays a decisive role in the success of a transplant.

Practical questions were also discussed in depth. Representatives from various fields – including search centers, donor centers, transplant centers and collection centers – exchanged views on existing challenges and potential solutions. Dr. Joannis Mytilineos gave insights into current developments within the organization. In addition, he and Prof. Reiner Siebert, Director at the Institute for Human Genetics of University Hospital Ulm, provided information on the appropriate handling of genetic abnormalities in donors, which are occasionally detected as an incidental finding.

Following on from technological progress with a view to successful patient care, Dr. Alexander Platz, Director of the DKMS Stem Cell Bank, presented his opinion on the productive use of a new stem cell product, namely Adult Donor Cryopreserved Units, or ADCUs for short. These can simplify the logistical and time-consuming process of donation and facilitate more flexible patient care.

CONCLUSION: Teamwork delivers the best patient care

The 2024 ZKRD annual conference convincingly demonstrated how the collaborative efforts of research institutes, transplant centers and medical partners can drive meaningful advancements in blood stem cell donation. Sustainable solutions that improve patient access worldwide to suitable donors can only be achieved through concerted efforts and interdisciplinary teamwork.



4 ZKRD re-certified by the WMDA

In 2024, the German National Bone Marrow Donor Registry (ZKRD) reached a significant milestone: renewed certification by the World Marrow Donor Association (WMDA).

As an international umbrella organization, the WMDA coordinates the activities of blood stem cell donor registries worldwide and, by setting high standards, lays the foundation for safe and efficient blood stem cell donation. The certification confirms that the ZKRD meets the highest requirements across the board – from donor selection through data processing to cell transportation and medical care. It therefore contributes both to the safety of donors and patients and to an ethically sound and effective blood stem cell donation system.

Regular reviews of national partners

WMDA certification is a demanding process for the ZKRD. Comprehensive documentation must be presented to confirm that we fulfill our tasks and responsibilities with no exceptions.

Accordingly, we are obliged to conduct regular checks to ensure that our over 150 national partners adhere to the German standards. These standards are based on – and in some cases exceed – the WMDA's catalog of more than 200 requirements. The complex structure of the German blood stem cell donation system, in particular, and the numerous partners involved, make it a major undertaking.

Using checklists, the German donor centers, cord blood banks and search centers are evaluated comprehensively by a voluntary audit team consisting of four ZKRD representatives and ten external reviewers from partner organizations. In addition, questionnaires are used to regularly review our partners, including the collection centers and transplant centers. Given the large quantity of documents to be assessed, close collaboration between all partners and continuous process optimization are vital.



WMDA

WMDA re-certification

All the documents required for the 2024 re-certification were submitted on time, and many were also translated into English. The increased requirements for IT safety and data privacy, for which even more detailed information had to be provided, were a particular challenge on this occasion. For the submission, all ZKRD documents along with national laws and guidelines as well as sample documents from partners had to be uploaded online and described accordingly. We are especially grateful in this respect to the donor centers in Göttingen, Heidelberg and Mannheim, the laboratory in Ulm, the collection centers in Mannheim and Ulm, and the cord blood banks of Erlangen and the DKMS for supplying the necessary documents. The subsequent audit in December, which was the first "onsite" audit of the ZKRD to be held remotely, enabled the auditors to inspect specific processes and documents in greater detail.

Extremely satisfied with the processes at the ZKRD, the WMDA auditors made a recommendation for re-certification. The certificate was presented to the ZKRD at the subsequent WMDA Conference in Quebec.

> "The staff with whom the review team spoke had excellent English skills, were very well informed about the procedures and their responsibilities, and were always willing to provide the requested information – primarily by sharing their screens at their workstations."

WMDA-Auditors

CONCLUSION AND THANKS

Re-certification strengthens the ZKRD in its joint mission with its partners to rapidly find the best donors for patients worldwide and in doing so maximize the chances of successful stem cell transplants.

A big thank you goes to all those involved at both the ZKRD and our partner organizations, whose untiring commitment and teamwork enable us to fulfill the highest standards of quality and safety. This not only guarantees a seamless blood stem cell donation process but also gives thousands of patients new hope for life.

5 The Quiet Force in the Background

Behind every trouble-free IT environment with smoothly functioning systems and programs lies a complex technological infrastructure. The ZKRD is no exception.

Continuous maintenance, optimization and protection are essential. Responsibility for this lies with a team that is often only noticed when something goes wrong: IT Service. As one of the team's members says: "Our work is perfect if it goes unnoticed." A proactive approach is critical here: Problems should be promptly identified and resolved, ideally before they even arise.



Working so that others can work

Servers must remain stable, and networks must be robust. Hence, regular backups, software and database updates (such as the quarterly HLA updates), as well as the establishment of new work environments, are just some of the IT team's tasks. Despite modern monitoring systems that promptly detect any warning signs, technical problems cannot always be solved before operational disruptions occur. In such cases, the Support team must be organized efficiently with a clear escalation structure: "In first-level support we handle simple requests, at the second level we take on more complex tasks such as system configurations and error analyses. If the issues are particularly problematic, such as in BMD-net or in interfaces such as GERMIS and EMDIS, we work closely with our software developers", according to a team member.

Swift and reliable

Server failures, unresponsive databases or faulty updates can prove critical, especially in centralized systems. For example, malfunctions in BMDnet, GERMIS and EMDIS require immediate action because they are essential to our operations. In such cases, the IT department delivers swift support for both internal and external partners either onsite or remotely via chat, telephone, email or online meeting. Despite automation, requests from EMDIS partners sometimes remain unprocessed or results are not provided. This often results from unexpected software behavior or divergent processes in other countries. If this is the case, we coordinate the matter directly with the administrators of the 34 registries, which we are connected to via EMDIS.

More than troubleshooting: Communication is key

The Support team not only resolves technical problems, but also advises and coordinates procedures, especially in critical situations. Working with external partners can sometimes be challenging, as error messages may be unclear. "Not everyone speaks IT – but we need to understand both sides!," says a team member. Targeted queries and precise documentation help to quickly identify the causes and efficiently share solutions. This requires technical know-how as well as good communication skills and patience. "In stressful situations, a cool head helps to approach problems from different angles."

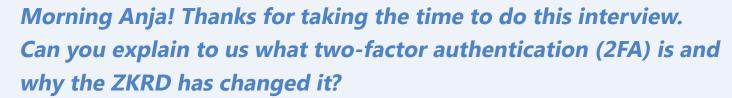
Looking forward: IT development as the key to success

As technology advances, the demands for a stable and secure IT environment rise. Automated processes help identify potential problems early on. An open error culture as well as analysis along with systematic documentation of previous disruptions help to sustainably optimize the system.

"In the long term, we aim to make the IT infrastructure more robust and efficient by investing in new technologies, regularly updating our systems, and continually optimizing processes."

Interview with an IT staff member

In this interview, IT employee Anja Siebinger offers us insights into a significant role of the IT team at the ZKRD, namely the ongoing optimization of the digital workspace based on the example of introducing a new two-factor authentication (2FA) method.



Anja: Of course! 2FA means that users must identify themselves through two independent factors. Typically, you combine something you know – a password – with something you possess, like a smartphone or special piece of hardware. A common example is a bank card that can only be used in combination with a PIN. In the digital world, password alone is often insufficient because it can be easily intercepted. The second level of security significantly increases the degree of protection.

Why is 2FA needed at the ZKRD?

Anja: It guards the entry to our BMDnet software, which is used by our partner organizations to search for donors and to generate donor lists and information on the status of the respective search.

Highly sensitive medical data is managed here, which is why security has top priority.

Why was it necessary to switch to a new method?

Anja: 2FA has been standard at the ZKRD for years, but our previous hardware token solution was outdated. We have therefore switched to a modern and more flexible method, combining a password with an app that generates time-based one-time codes. This not only enhances security but makes the process much easier for users.

What if someone doesn't have a suitable smartphone or can't use the app?

Anja: We purposely chose a flexible solution that works on different devices. Especially in hospitals, the circumstances vary – not everyone has a cell phone specifically for work or has permission to install software. We are therefore relying on a standardized procedure with several options: in addition to the app, there are free software programs for computers. We can therefore offer a wide range of solutions that can be adapted to the varying needs of our partners.

Were there any challenges when it was launched?

Anja: The diversity of our roughly 250 partners was in fact the biggest challenge. Some were already using compatible systems, while others required a solution for the software installation first. Nevertheless, the changeover went surprisingly well: Within three months, over 98% of the users had been successfully migrated. It was certainly a lot of effort, but I'm delighted that we have now achieved a very high level of protection for our data – which is a tremendous benefit for all involved. It was an exciting project, and I would like to thank all the partners who were deeply committed to making the transition a success!

It sounds like a great achievement. Thanks for telling us about it, Anja.

The ZKRD on LinkedIn – Strengthening the network and promoting dialogue



In December 2024, we launched our official company page on LinkedIn, opening a new chapter to enhance transparency and make it easier for anyone interested in the ZKRD to stay informed. Through this platform, we regularly share updates on current developments, projects, and key topics related to blood stem cell donation. Our LinkedIn page is designed not only to address potential donors and partners, but also to spotlight the needs of patients requiring life-saving transplants.



linkedin.com/company/zkrd

The importance of a robust network

The ZKRD's work is based on a robust network – and we are committed to expanding it even further. Our presence on LinkedIn creates a platform for intensive exchange with experts, partner organizations and interested parties. We focus not only on our own projects, but also on our partners' activities and the latest industry developments. Because only by working together can we achieve even more.

Opening initiatives on LinkedIn

Since the ZKRD was founded, our central mission has been to raise public awareness of the importance of blood stem cell donation and to highlight the life-saving impact that donors can have. We aim to continue pursuing this mission on LinkedIn.

Among the first posts shared is information on World Cancer Day and the latest statistics on the registration of new blood stem cell donors as well as the collections that took place in 2024. These figures provide a clear overview of the progress we have made in the past year and illustrate the ongoing urgency of blood stem cell donation.

Promoting dialogue and collaboration

Our LinkedIn page is intended to be more than just a source of information – it should be a hub for engaging dialogue, networking and collaboration. We invite everyone to become a part of this network and to join forces in the fight to save the lives of patients worldwide. We look forward to meeting you there!

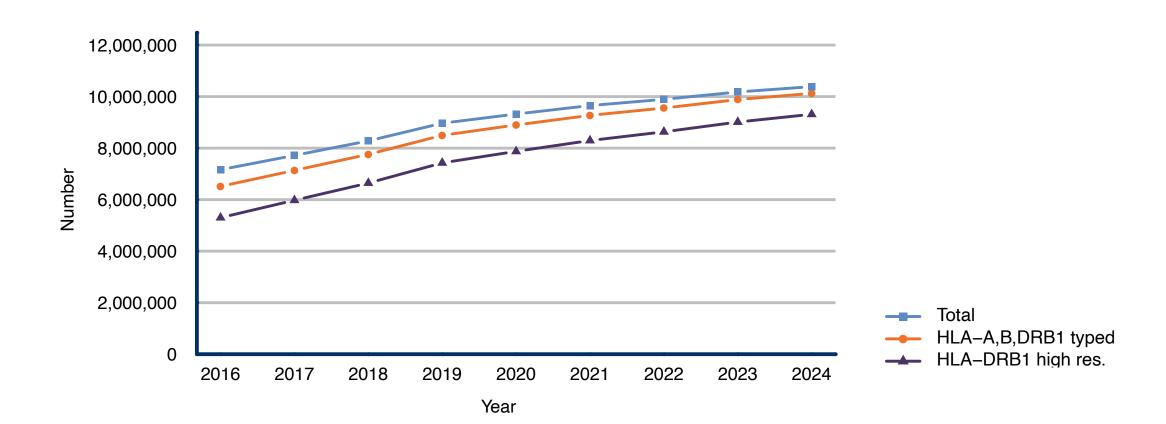




The 2024 Annual Report again provides a concise overview of the key statistical developments.

This figure represents an increase of almost **206,000 donors** over the previous year. While this is the lowest annual increase in Germany in the last 20 years, it is still roughly twice that of Poland for 2024: With an increase of around 105,000 new donors compared to 2023, Poland ranks second behind Germany.

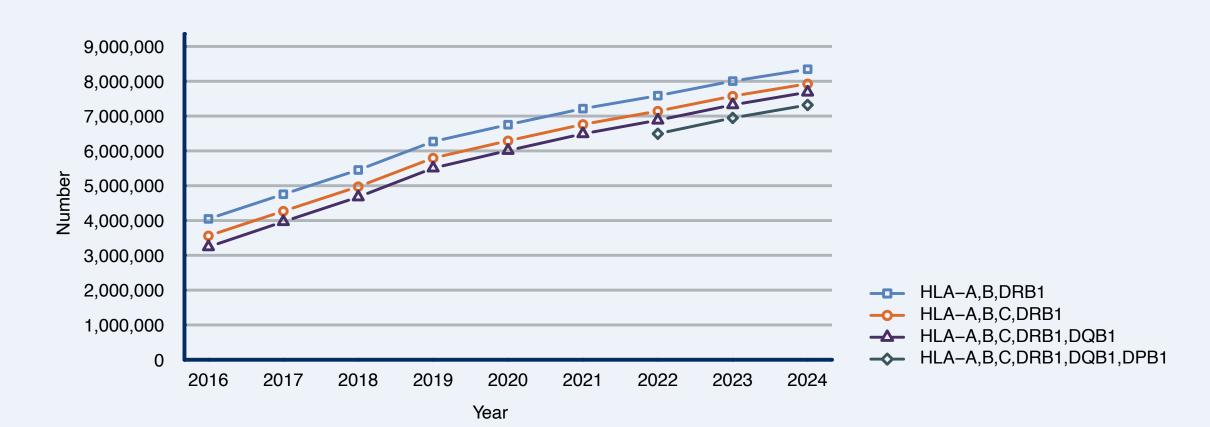
Donor numbers in Germany





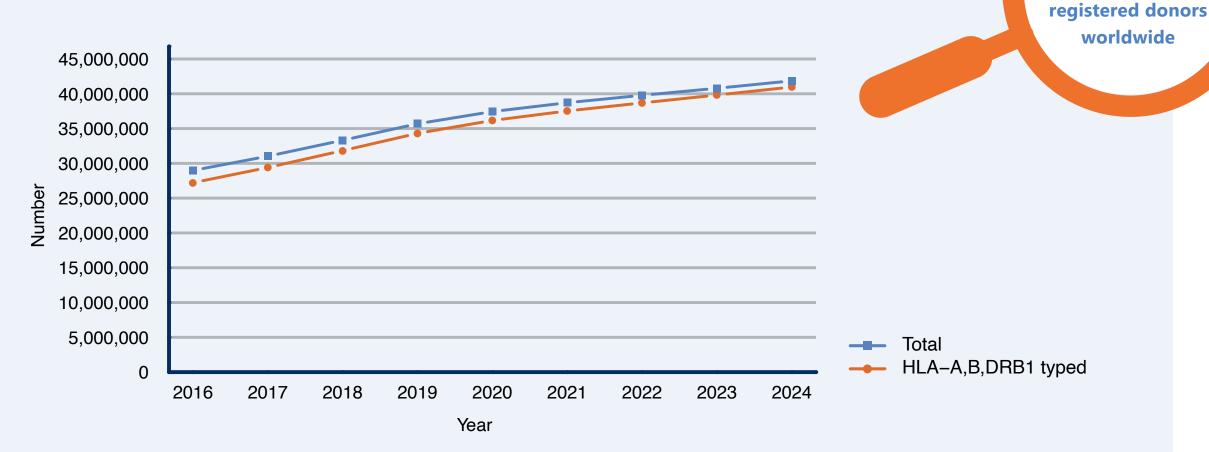
Furthermore, the proportion of donors with high-resolution typing across **five gene loci** (HLA-A, -B, -C, -DRB1, and -DQB1) rose once again and now accounts for almost 74% of the total German donor pool

Donors in Germany with high-resolution typing

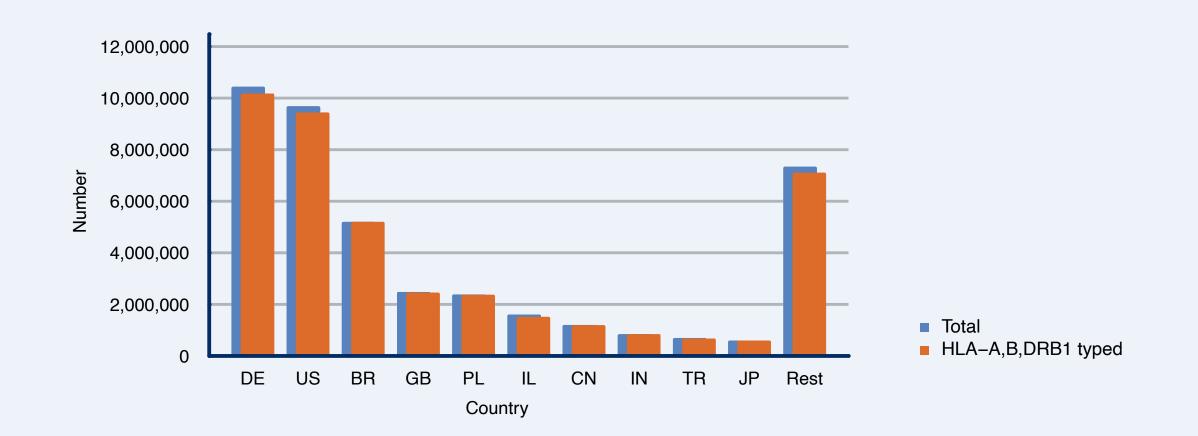


Over the last three years, the number of newly registered donors worldwide has increased by around one million annually. In contrast, between 2013 and 2019 more than two million new donors were recruited per year. Percentage-wise, Israel achieved the largest growth in its donor base with an increase of 5.7%, while the USA recorded a rise of 0.5% whereas Portugal's donor pool decreased by 2.7%.

Donor Numbers Worldwide (according to WMDA)

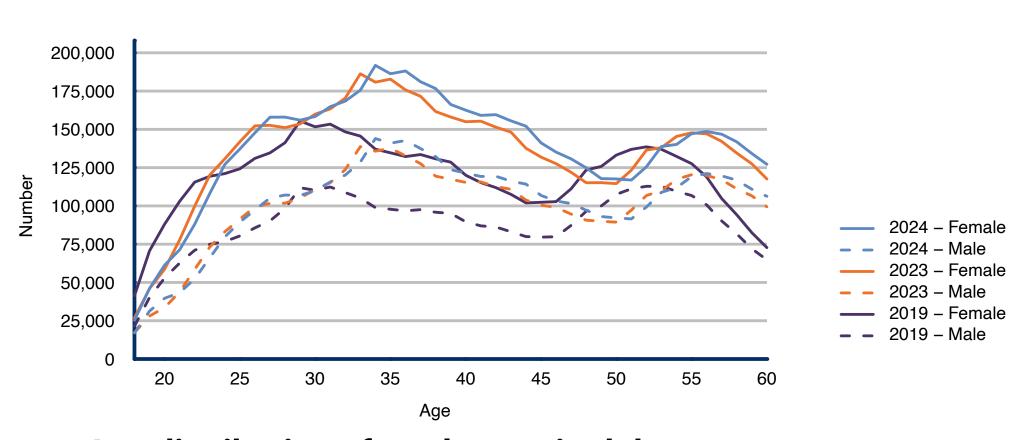


Distribution of Donors Worldwide (according to WMDA) in 2024

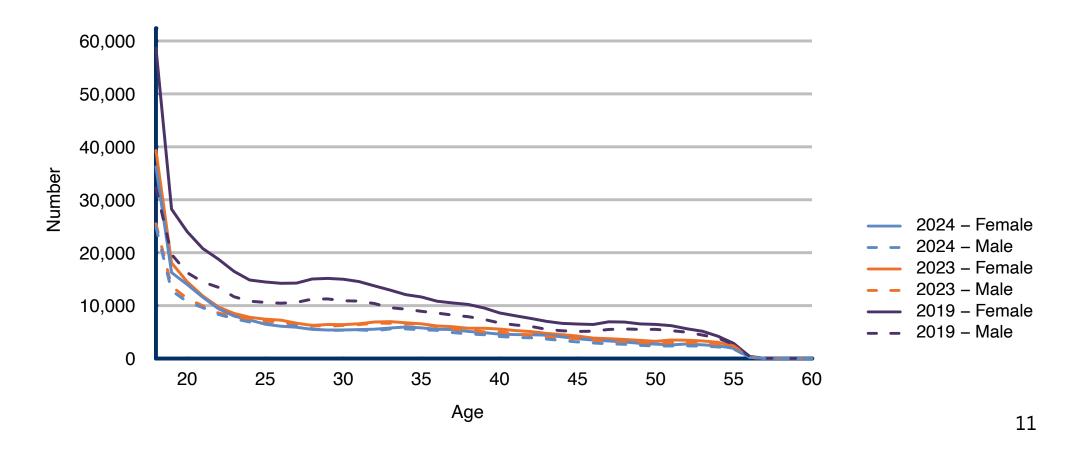


The age distribution of the donors, as observed in previous years, continues to show a rightward shift in the peak of the age group of 50 to 60 years. Hence, over the next five years, the number of donors leaving the donor pool due to exceeding the maximum age will continue to grow. This will have a negative impact on the total number of donors in our database. We therefore need to stay on the ball to counteract this trend. Recruiting young donors of both sexes has proved to be an effective solution that continued to reap rewards in 2024.

Age distribution of German donors

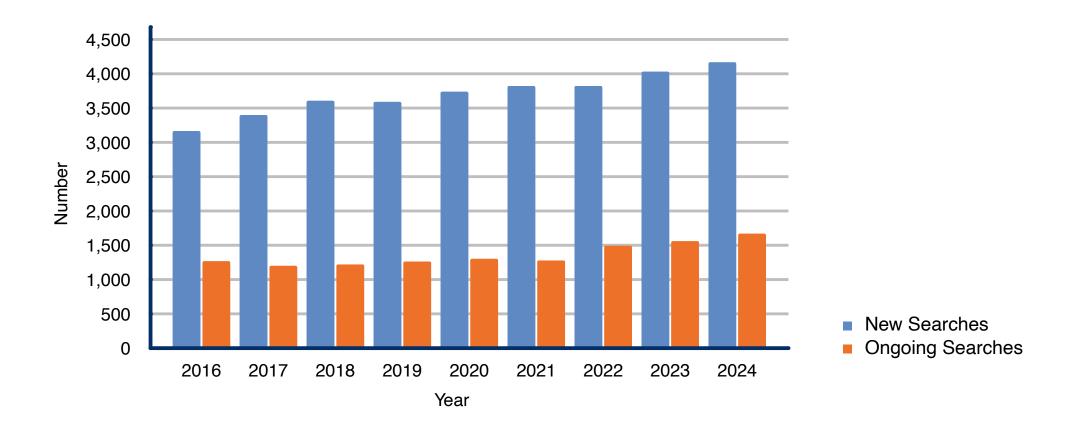


Age distribution of newly recruited donors

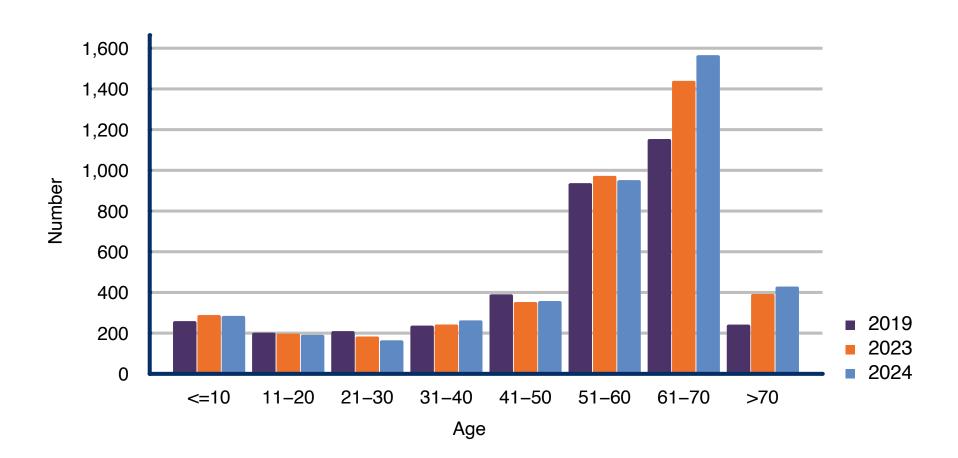


In 2024, searches for German patients increased by 3.4%, reaching 4,146 cases in total. Compared to the previous year, this increase was observed almost exclusively in patients over 61 years of age, while there was no notable change in the younger age groups

Donor Searches for German Patients



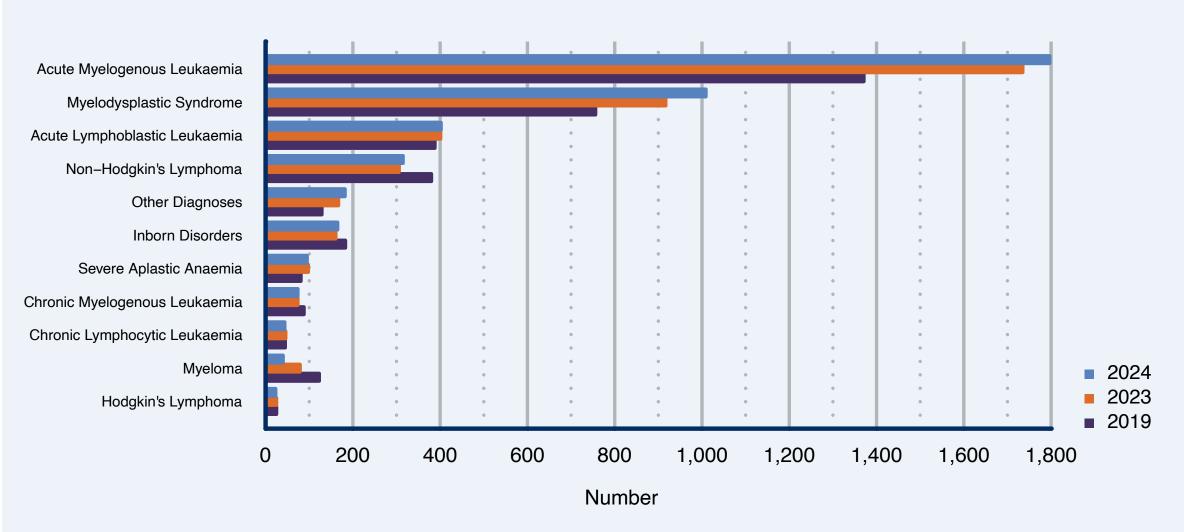
Distribution of German Patients by Age





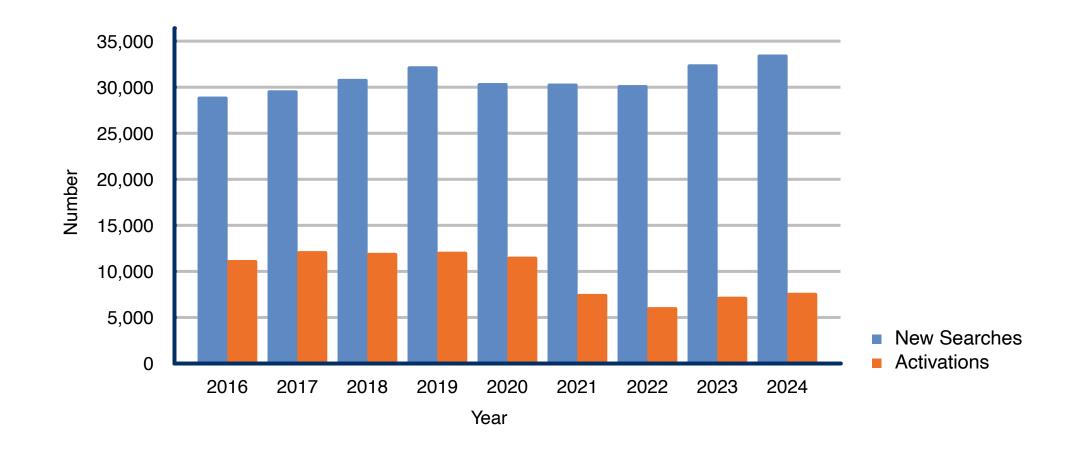
Corresponding to shifts in the age distribution, searches for patients diagnosed with AML and MDS, diseases that commonly occur at an older age, are also being increasingly diagnosed. In contrast, a distinct reduction has been observed in cases of multiple myeloma, though this decrease of approximately 30 cases does not have a statistically significant impact on the patient numbers.

Distribution of Diagnoses of German Patients



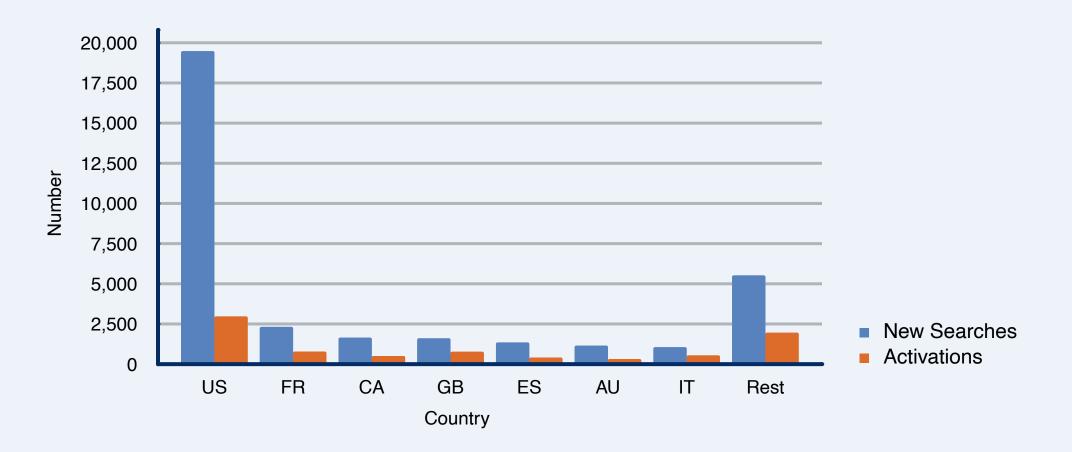
The number of searches for international patients also reached a further high, with over 33,000 search requests in 2024 compared to 32,316 the previous year. As in the past, the USA was again the country with the most requests, at 58.1%, followed by France (6.7%) and Canada (4.7%). We wish to extend our heartfelt gratitude to all the voluntary donors for their willingness to donate blood stem cells and all our partners for their unwavering commitment to provide a suitable donation for each patient worldwide.

Donor Searches for International Patients



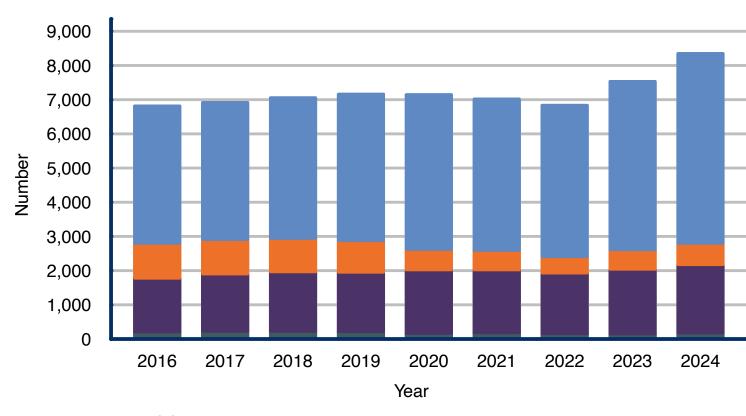


Origin of Searches for German donors in 2024



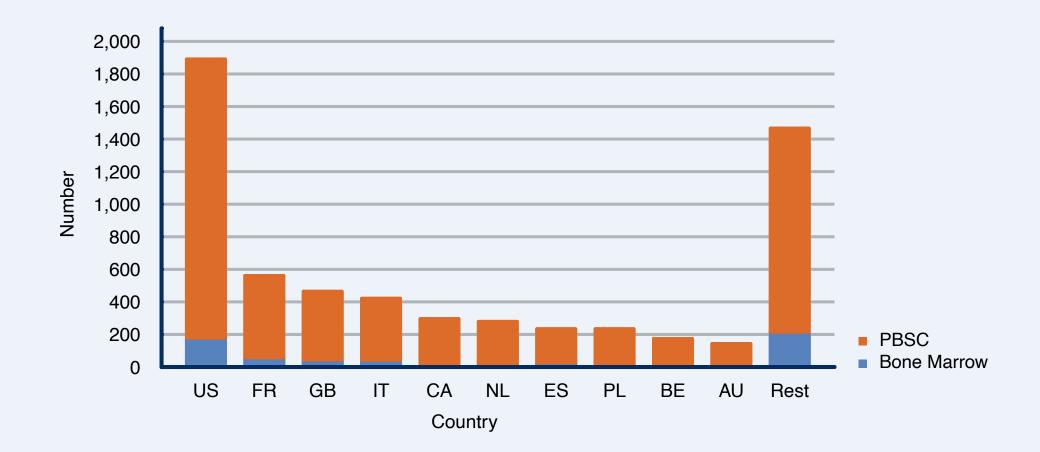
One last record figure we would like to share with you for 2024 is **8,349: the number of people in Germany who donated.** Compared to the previous year, in which a new record had been set, this represents an increase in collections of around 6.5% for domestic patients and almost 12.5% for patients abroad. This is truly impressive!

Blood Stem Cell Donations from all German Donors



- PBSC int. Patient
- BM int. Patient
- PBSC German Patient
- BM German Patient

Distribution of Donations from all German Donors for International Patients in 2024



about
11% more
collections
from German
donors

8.349
collections from
German donors in
2024

