ZKRD Zentrales
Knochenmarkspender-
Register Deutschland

ANNUAL REPORT
2021

Content

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1 Preface

The annual report for 2021 is much more than just that – it is packed with a piece of contemporary history that spans 30 years.

Let us take you on a fascinating journey into the early days of the ZKRD. Comparing the ZKRD back then with the ZKRD of today, we discover an incredible development that could never have been achieved without you!

With the support of our many donors, we have helped almost 110,000 patients in Germany and abroad over the last 30 years and in the future shall continue to give patients in need a second chance of life. Our dedicated voluntary donors are the foundation of our work. We are therefore especially grateful to them. Thanks to their support, many patients and their families have been given fresh hope.

With the support of our donor centers, we now have access to over 9.7 million potential donors in Germany when conducting a donor search. The tireless work of the donor centers from the very beginning in recruiting, registering and typing new donors means that Germany now has the highest number of registered adult volunteers and cord blood preparations and the ZKRD is thus the largest national registry worldwide. We thank them sincerely for their cooperation, wide-ranging support, and amazing commitment over the decades!

With the support of the search centers, suitable donors can be selected: Relying on their expert knowledge, the search centers select suitable candidates from the ZKRD donor lists. Today, it takes only a few weeks to find a suitable donor for 9 out of every 10 patients in Germany. Every year, we help more than 3,500 patients in Germany with the support of the search centers. We are very grateful for the many years of successful cooperation!

With the support of its staff, the ZKRD has evolved to become what it is today: a central registry with a team that often goes above and beyond, putting the interests of patients first and always giving their very best. Countless threads – often unnoticed from the outside – are woven together in the hands of the ZKRD's team members. Without them, the numerous achievements of the past 30 years would not have been possible. We are proud of our team and take the opportunity here to sincerely thank them for their commitment!

By all working together, we have established a donor search network in Germany that has become one of the most capable and efficient worldwide in this regard. This achievement was and is only possible because you have pursued the same goals and given us great support in the last 30 years. Thank you very much!

PD Dr. Joannis Mytilineos **Dr. Peter Mein**

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Prof. Dr. Karl Lauterbach
Federal Minister
Member of the German Bundestag

Welcoming address

In Germany alone, more than 12,000 people are diagnosed with leukemia every year. Many can be cured with chemotherapy, but for several thousand patients, a blood stem cell transplant offers the only remaining chance of survival. Thirty years ago, however, the transplantation of blood stem cells was still in its infancy and donors were few and far between.

The foundation for a national registry was laid at the end of the 1980s by the Ulm working group headed by Professor Shraga Goldman and Dr. Carlheinz Müller, who thus began to collect donor data from various donor centers and make it available to hospitals searching for donors.

When the Federal Ministry of Health decided in 1991 to support the establishment of a central registry, and consequently resolved to set up the German National Bone Marrow Donor Registry on April 27, 1992, the goal was to improve the situation for critically ill patients. Nobody could have imagined at the time how successful this venture would be. With the support of its partners, the German National Bone Marrow Donor Registry (Zentrales Knochenmarkspender-Register Deutschland, ZKRD) has succeeded in creating a highly efficient system for managing blood stem cell donations that is one of the best in the world!

The advantages of a central registry are obvious: Since its establishment, the ZKRD has responded to over half a million search requests, which has lead to more than 100,000 stem cell collections. Numerous patients have thus been given a second chance at life. Today, almost 40 percent of blood stem cell transplantations worldwide involve donors from Germany. Even during the coronavirus pandemic, as a central coordination office, the ZKRD and its partners were able to ensure that patients received vital blood stem cells without delay by quickly adapting the transport logistics.

We are therefore confident that, even with a view to future developments, the ZKRD and its partners will continue to provide every patient with the best possible blood stem cell transplant.

I wish to congratulate everyone at the ZKRD on its 30th anniversary. We also wish the ZKRD every success for the future and hope that it can continue its seamless and successful work as a central registry, and in doing so master the interesting challenges to come.

Prof. Dr. Karl Lauterbach

3 ZKRD – General

THEN

In 1985, many countries began recruiting volunteers as bone marrow donors with a view to improving the chances of survival for critically ill patients. At that time, Germany had several small bone marrow donor centers, none of which listed more than a few hundred donors.

In light of this, Professor Shraga F. Goldmann and Dr. Carlheinz Müller of the German Red Cross Blood Donation Service (DRK-Blutspendedienst Baden-Württemberg) in Ulm set up a program for handling search queries more efficiently, with financial support from the Stefan-Morsch-Stiftung foundation. At the same time, they offered to integrate the data from the German search centers relevant to the donor search into a centralized database in anonymized form. By 1989, the forerunner to today's ZKRD had thus already been established.

The rapidly growing number of donors and the increase in all the related activities soon necessitated the creation of an efficient organizational structure with which to effectively search for donors. In 1991, the German Federal Ministry of Health (BMG) asked the working group in Ulm to set up a central national registry of anonymized donor data and to continue developing its existing donor search system. The Central Bone Marrow Donor Registry for the Federal Republic of Germany (ZKRD) was established in April 1992 and the mission set out by the BMG was incorporated in the statutes of the ZKRD.

By the end of 1992:
150,000
German donors

8
stem cell collections

TODAY

Central

Today, the German Central Bone Marrow Donor Registry (ZKRD) is the central coordination office for bone marrow donor searches in accordance with Article 65f of the Fifth Book of the German Social Code. Acting as the hub between transplant centers, search centers, donor centers and other donor registries throughout the world, the ZKRD coordinates the activities of all involved, from searching for suitable donors to organizing the transportation of donated cells.

Innovative

By continuously enhancing its software systems, the ZKRD today provides its partners with wide-ranging support. Donor centers can manage their donor data using the software supplied by the ZKRD, and search centers can enter patient data directly into the system. The OptiMatch® matching software is one of the leading systems in the world.

Global

Today, the ZKRD responds to more than 3,500 search requests for German patients and over 30,000 search requests for patients from abroad every year. The German system has proved so efficient that almost 40 % of unrelated blood stem cell transplants worldwide originate from voluntary donors in Germany.

Up to date

Thanks to this development, a suitable donor can be rapidly found for many patients. The ZKRD has access to a database containing the data not only of German donors registered with the 26 German donor centers but also of the majority of internationally registered donors. The ZKRD's highly intelligent software application updates the database overnight, ensuring that the data available each day is completely up to date.

Competent

Thirty years' experience – as a central registry, the ZKRD offers a wide range of services today that cover every aspect of blood stem cell donation: whether A for algorithms, B for billing, or C for coordination and customs clearance.

Neutral

As a central registry, the ZKRD is a neutral coordinating body that supports all partners equally. Since its foundation, the ZKRD has striven to involve its partners with the aim of achieving the greatest possible transparency.

more than
9.7 million
donors in Germany

about
7,000 stem cell collections
per year in Germany

4 Search

THEN

In the ZKRD's early years, most of the donor search processes had to be handled manually given that only rudimentary technology was available in terms of IT.

The donor centers would send their donor data to the ZKRD on floppy disks, where it was then imported. The patient data, on the other hand, was faxed or mailed by the doctors and had to be entered into a program manually. The HLA characteristics, at least, could be matched locally using the program developed by Dr. Müller. As nobody in the team had internet access and email accounts had not yet been established, the list of donors had to be printed out and faxed to the patient's doctor. All requests and results (e.g., typing results) had to be registered manually before they could be printed out and again forwarded by fax.

On an international level, Bone Marrow Donors Worldwide (BMDW; now known as WMDA Search, Match & Connect, or WMDA SMC for short) also regularly sent updated editions of the data collection to the ZKRD on floppy disks, where it was copied and shared with the search centers. The data was then saved locally at the search centers so that it could be screened for suitable donors for a patient in the event of a donor search.

In case of an international search, a request would be sent to the European Donor Secretariat (EDS) in Paris. Given the technical limitations at the time, this could only ever take place overnight. A reply from Paris would usually arrive after three to four days depending on the speed with which the registries in other countries responded to the EDS.

TODAY

Speed

The search process is much faster today: for approx. 90 % of patients in Germany, a suitable donor can usually be identified within a few weeks. The ZKRD receives a total of more than 33,000 requests a year from Germany and abroad.

Automation

As far as possible, the search processes and the associated data exchange at the ZKRD have been automated with a view to managing the numerous requests. Search centers managing the search on behalf of a doctor with a patient requiring a transplant can record data, send requests, and view the respective results using BMDnet, the ZKRD's proprietary system. Requests from abroad and the corresponding feedback are exchanged directly via an international network, namely the European Marrow Donor Information System (EMDIS).

Efficiency

The ZKRD's proprietary matching software, Opti-Match®, not only enables lists of potentially suitable donors to be generated for each patient within a very short time but can also indicate the probability of a match for each donor. This makes the search both fast and efficient, while saving costs. Since the ZKRD can access the data of other registries during the matching phase, the donor lists will contain international donors in addition to the national donors.

Transparency

Thorough documentation of the processes in BMDnet permits the entire workflow to be checked at any time; furthermore, follow-up requests for missing results can be issued automatically. This ensures that the search status is transparent and that the entire search process can be tracked.

5

Workup

THEN

In the early years, the ZKRD's work was over once a search was stopped, irrespective of whether a suitable donor had been identified or not.

Workup – meaning the coordination of processes from the moment a suitable donor is asked to donate until collection of the stem cells – was initially handled only by the donor centers. Because many different institutions are involved in this process, various people had to be contacted during each workup while potentially having to consider the different time zones.

By establishing the ZKRD as a central point of contact, the registry originally supported its partners by forwarding the workup documents received by fax to the relevant party. Any documents or forms required had to be completed manually, a process that was very labor-intensive and prone to error. The paper records were filed manually in countless folders. As the number of requests and documents increased, so did the effort involved in handling the processes. There was also no means of accessing the data in the ZKRD systems externally, meaning that requests arising due to an emergency outside of regular working hours, for instance, usually could only be resolved on site at the ZKRD.

TODAY

Workup is a very individual, complex process. Though electronic support is available, communication is based largely on forms. Nevertheless, in many aspects the ZKRD's BMDnet software eases the burden.

Central point of contact

The workup process has developed continuously over the years and the number of partners and diverse process-related requirements has increased enormously. Partners therefore benefit from having a single point of contact to approach with all their queries and documents. The ZKRD checks and forwards the documents to the respective parties. Proactive follow-ups and reminders sent to the partners by the ZKRD team help the partners in their daily work and offer added security.

Additional quality assurance

Manual filing has been replaced by an electronic archiving system, enabling ZKRD staff to access patient files within seconds. A lot of data is recorded electronically so that the necessary forms can be pre-filled automatically with the data from the system. This not only saves a lot of time but also increases the quality. Furthermore, by applying the four-eyes principle the ZKRD team checks that the documents are complete, correct, and plausible.

National and international regulations and standards

During the workup process, many regulations now need to be considered which, moreover, often differ from country to country. The ZKRD is familiar with all national and international requirements and standards and supports its partners with this knowledge.

Workup program

Today, the workup program involves recording and documenting not only the requirements but also all the essential data and details during the workup process. Hospital partners thus always have access to updated information on the status of their workups and, thanks to pre-filled forms, can easily and efficiently forward the required documents. This electronic means of data acquisition also increases the flexibility of the ZKRD on-call service. Partners can be supplied with the information they need from anywhere and at any time.

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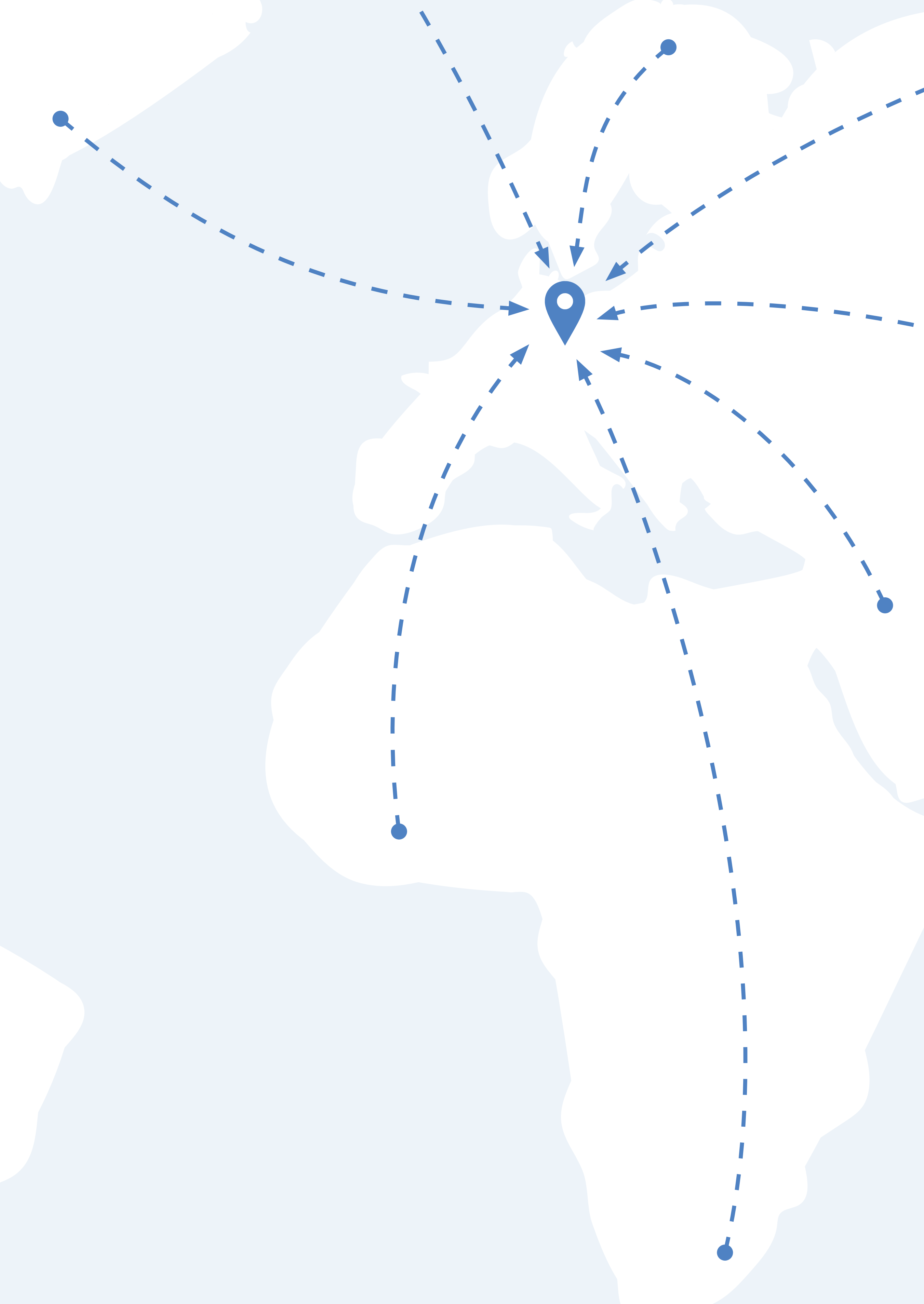


6 Transportation

THEN

In the beginning, the ZKRD was not involved in the transportation of donated blood stem cells.

Responsibility for organizing and transporting consignments lay with the respective transplant center, while the stem cell preparations were collected by hospital staff or by courier companies appointed directly by the hospital. There were no generally valid guidelines on the transportation of stem cells or training programs for couriers. Commercially available cooling bags – such as those used for camping – were frequently used for transportation purposes. Ice packs were used to keep the consignment cool, but direct contact put the cells at risk of severe damage from freezing. It was uncommon for airports or airlines to be informed in advance of a pending stem cell consignment: couriers were simply issued with a letter warning that the transport box containing the stem cells should not pass through the X-ray scanner at security. It was also difficult to provide the courier with support in an emergency outside of office hours due to the lack of access to files and IT systems.

TODAY

A safe, qualified method for transporting blood stem cells as quickly as possible is extremely important to the care of patients. Hence, the ZKRD has already supported its partners in this respect for many years, irrespective of whether the stem cells to be transported are fresh or cryopreserved.

Organizing transportation

When stem cells need to be transported, the ZKRD appoints a qualified courier service and checks its planned route to ensure that the consignment will reach the recipient according to plan. In doing so, all the regulations are considered, and the documents required for transportation are made available.

Audited courier services

To ensure the highest possible standards, only courier services audited by the ZKRD are employed. The assigned couriers receive regular training and individual briefings, moreover, on each consignment.

Validated transport boxes

Special vacuum insulation boxes are used for transportation in which the contents can be kept cool or at room temperature depending on the requirements. A data logger is enclosed for the purpose of monitoring the temperature inside the transport box and later documentation.

Registration of the consignment with airport security

The ZKRD registers the courier with the relevant airport security offices and the booked airlines before the journey begins. This helps to avoid any delays or problems at security or when boarding and ensures that, as far as possible, transportation proceeds as planned.

Customs clearance

According to customs legislation, (stem) cell preparations are classified as goods and must therefore be declared. The ZKRD assumes direct customs liability for preparations imported from or exported to a third country and therefore handles the customs declaration.

On call 24/7

In case of emergencies relating to the transportation of (stem) cell preparations, the ZKRD can now be reached all year round – 24 hours a day, seven days a week.

7 Financing and Accounting

THEN

At the end of the 1980s, when the number of transplantations involving unrelated donors began to increase, the health insurance companies would only cover the costs of transplantation but not the search for a suitable unrelated donor.

Reimbursement of these costs had to be painstakingly negotiated in each individual case with the respective insurance company. To enable the search for a suitable donor to nevertheless begin immediately, the Stefan-Morsch-Stiftung foundation would provide advance funding and subsequently bill the cost carriers in Germany and abroad.

In 1991, the Federal Ministry of Health (BMG) decided to finance the establishment of a central registry for the Federal Republic of Germany. To guarantee the transition to regular funding once the Federal funding for unrelated donor searches came to an end, the ZKRD was quick to start negotiations with the respective statutory health insurance federations. It was vital to the ZKRD that all stakeholders were involved in this process from the outset. The aim was to agree on a lump sum for a medical service for which there was no historical reference data, but which was developing at pace.

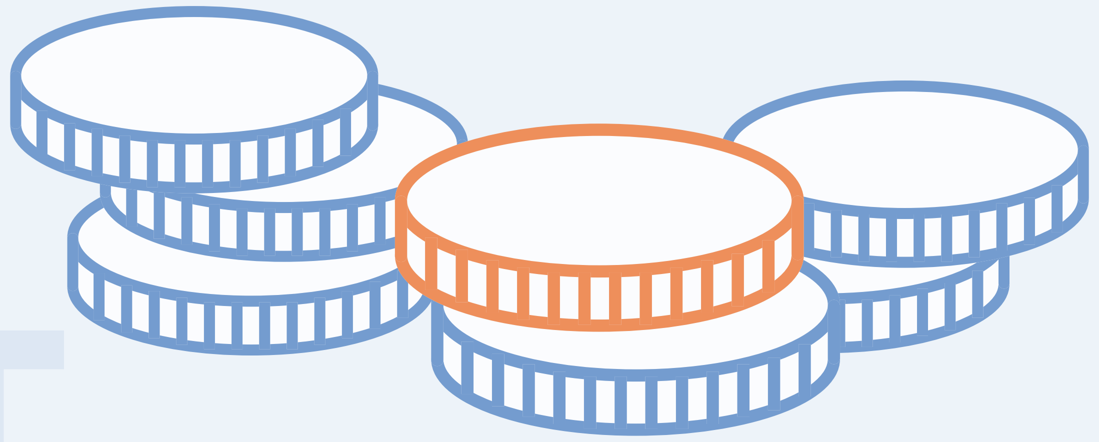
Although the ZKRD had announced in December 1991 that it would handle the entire billing process with cost carriers at home and abroad as of the following year, it was not until 1993 that the first contract (initially for patient care only) entered into force and secured funding for the search.

TODAY

The tasks of the institutions involved in a search for an unrelated blood stem cell donor and the questions concerning reimbursement of patient-related services are now regulated in detail in the statutory health insurance (GKV) agreement. In addition to offering the smoothest possible billing process, the ZKRD provides its partners with the opportunity to join framework agreements and close any insurance gaps.

Remuneration of services

As the central clearing office, the ZKRD organizes payment for more than 100,000 services connected with the search for unrelated donors and, in turn, bills the cost carriers at home and abroad for the expenses incurred. This brings major benefits to the partners involved: their invoices are settled without delay, and they do not have to chase late payments or bad debts.



Cost transparency

The ZKRD aims for utmost transparency in the billing process and therefore charges for all services based on the cost-causation principle. All those involved are thus aware of the exact costs of the search at any given time and are billed only for the services they have received.

Donor insurance

For several years, donor centers have been able to apply for insurance for their donors through the ZKRD. This insurance cover exceeds the statutory accident insurance by providing additional protection from a private accident insurance policy. Among other things, the insurance covers the donation process itself as well as later complications that may occur despite the donation having initially proceeded without incident.

Product liability

For several years, partners have also benefited from our framework agreement on product liability insurance. Such insurance mainly covers the production, preparation and circulation of blood stem cells and blood products which are delivered to third parties for the purpose of treating patients.

8 IT

THEN

From the very beginning the ZKRD relied on the digital acquisition of donor and patient data and supplied the donor centers with a software application for recording data on floppy disks.

The centers could then enter and send their donors' data to the ZKRD, where it could be read out and converted, as necessary. The worldwide donor data from the BMDW was also imported into the ZKRD system once a month from floppy disks.

Sending floppy disks, faxes and letters was a time-consuming, inefficient process that was prone to error, as the data had to be transferred manually. Another major disadvantage: the data was always a couple of days old and thus no longer up to date. With the advent of the first computer-to-computer connections, the programs could be enhanced, and data exchange could be increasingly automated. The EMDIS network and its German counterpart, the GerMIS network, could thus be expanded and, for the first time, the data held locally by the donor centers and search centers could be exchanged – fully automated and encrypted – using ISDN connections. It would still take several years, however, until all German partners were connected.

From the very beginning, all German donors registered with the central office in Ulm were also available to donate to any patient worldwide through the BMDW in Leiden and the former EDS in Paris.

TODAY

Data quality

Today, all German donor centers are connected via the national GerMIS network, ensuring that the ZKRD possesses an outstanding database of high-quality data that is updated every day. The plausibility checks conducted by the ZKRD serve as an additional quality assurance measure. These capabilities prove advantageous when it comes to searching for a suitable donor.

Inventory Exchange

The inventory exchange entails the regular exchange of complete donor inventories between registries. It goes beyond the usual exchange of patient-related match lists in EMDIS. The major advantage is that, since the entire donor inventory can be considered, search reports containing these international donors can be generated immediately upon initiating a search. Hence, there is no need to wait until messages arrive from a registry abroad with pre-selected – and therefore possibly limited – match lists, as is the case with EMDIS. The possibility for each registry to apply its own matching algorithm to this donor inventory is another positive feature in this respect.

Speed

The data of more than 12,000 patients and more than 9.7 million potential donors in Germany can be matched overnight at the ZKRD. Sophisticated algorithms such as OptiMatch® and IT solutions ensure that the data can be matched with great speed and that a donor list is swiftly generated for each patient.

About
half a million processed search requests
since foundation

BMDnet

The ZKRD provides its partners with a web-based application called BMDnet. It can be used to enter and retrieve the data required for a donor search, generate national and international donor lists, request additional information about the donors, and view the status of the respective search and the workup, as well as all results. The advantages are clear: all the necessary information and documents can always be found in BMDnet.

OptiMaS

By integrating OptiMaS (OptiMatch® as a Service) into an existing system, each registry can search its own donor pool using the OptiMatch® algorithm without having to forgo any of the applications it usually employs. The probabilities thus presented are calculated using population-specific HLA frequencies. Furthermore, the complex HLA nomenclature is updated every quarter and the ZKRD's powerful HLA software library automatically checks the HLA data of patients and donors for plausibility and consistency. The application is also ready for EMDIS integration, meaning that the prepared data can be retrieved directly and transferred to the EMDIS interfaces. So far, OptiMaS has already been adopted by various countries, including Canada, Australia, Spain, and by the WMDA.

9 HLA

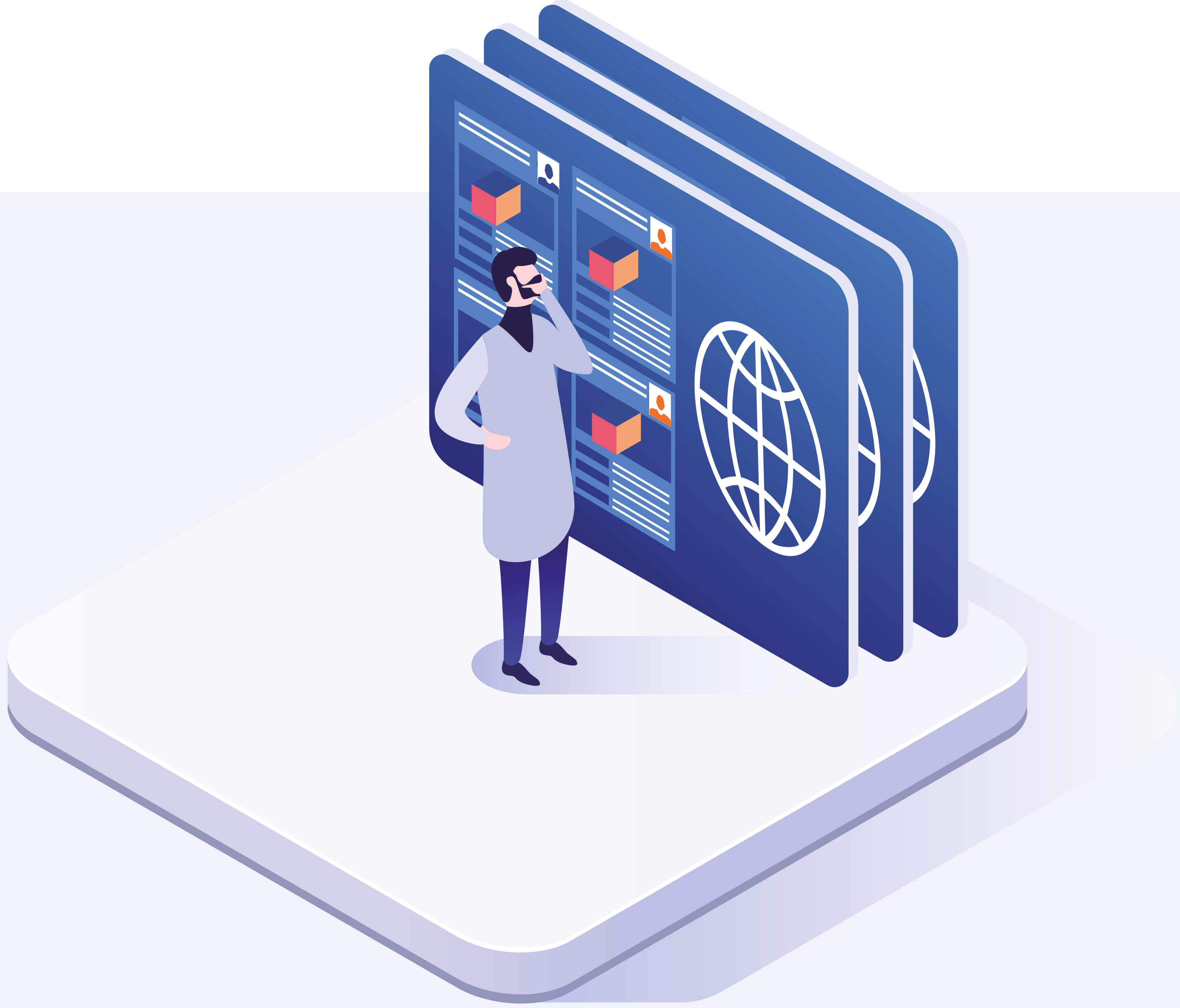
THEN

In the early days of the ZKRD, HLA characteristics were determined with serological detection methods; when determining the HLA compatibility between patients and donors, only the HLA-A, B and -DRB1 gene loci were considered.

In the following years, molecular typing methods were increasingly used and thus enabled the HLA nomenclature data to be determined based on DNA differences in individual HLA gene loci. This resulted in the parallel use of the serological and the molecular HLA nomenclature to describe the HLA characteristics. Added to this were the ambiguous designations in the form of multi-allele codes. This plethora of variables had a far-reaching impact on various aspects of the donor search.

Not only did the constantly growing number of new allele values have to be considered, but the serological and molecular values, which were possibly delivered together, also had to be checked for consistency. Since the matching algorithms at the time were based on serological factors only, this mainly affected the comparison of the HLA data of the patient and donor. Shortly after the turn of the millennium, the course was set at the ZKRD for generating match lists at the allele level.

This development also implied that the HLA information would need to be presented in a medically correct and at the same time machine-readable data format to facilitate efficient processing. In collaboration with the British Anthony Nolan Research Institute, the means were established for delivering the HLA nomenclature data relevant to the donor search process in the WMDA data format developed by the ZKRD. Rules were needed, moreover, on how to interpret such data, which had been obtained with different typing methods. Hence, the globally applicable guidelines of the WMDA on usage of the HLA nomenclature were developed with the ZKRD at the helm.



TODAY

OptiMatch®

OptiMatch® is a probabilistic algorithm based on HLA haplotype sequences which was developed by the ZKRD and has been used at the Registry since 2006 for daily donor searches. As one of the world's first matching tools, OptiMatch® could predict the probability of a donor being suitable for a patient even in the case of incompletely typed data. Time and money are thus saved. A targeted search is possible due to the diverse settings that can be adjusted depending on the patient in question. This method has proved advantageous, especially in complex cases. The ZKRD matching algorithm is regularly adapted to reflect the latest developments and thus obtain the best possible donor list for each patient within a very short time.

Assuring the quality of the HLA nomenclature for the WHO

In addition to an efficient algorithm, valid and consistent data is a prerequisite for successful matching. The WHO Nomenclature Committee for Factors of the HLA System is responsible for the naming of new HLA genes, allele sequences and their quality control. The ZKRD has long been involved in the quality assurance process relating to the quarterly updates of the HLA nomenclature. Using sophisticated programs, the ZKRD additionally checks for any possible inconsistencies in the data planned for publication. Since the official HLA nomenclature is used by registries worldwide as the basis for donor searches, it is particularly important to have accurate data.

HLAcore HLA software library

Since such rules for the application of the HLA nomenclature are only as good and useful as their practical implementation, the ZKRD has developed HLAcore, an HLA software library. Through numerous functions, this HLA base library implements the guidelines and relationships in such a way that it is now used worldwide as a reference for HLA plausibility checks. Most notably, checking the consistency of the HLA data of patients and donors is of crucial importance here.

10 Quality Management

THEN

The quality of the services provided by the ZKRD is vital to the care of thousands of critically ill patients every year.

In the early 1990s, the IT systems already included plausibility checks, every member of staff was paying close attention to quality, and the four-eyes principle was being applied. Nevertheless, there was still no formal, refined QM system in place at the ZKRD.

WMDA
matching donors • serving patients

WMDA Accredited

WMDA certifies that

ZKRD - Zentrales Knochenmarkspender-Register Deutschland
Helmholtzstrasse 10
89081 Ulm
Germany

Has been assessed by WMDA and has been found to meet the requirements of

World Marrow Donor Association International Standards for Unrelated Hematopoietic Stem Cell Donor Registries
Edition 1 January, 2017

and is granted:

Accreditation

In the following areas:

Adult Volunteer Donors and Cord Blood Units

Effective date: **25 February 2020**
Certificate expiration date: **25 February 2024**
Accredited since: 1 May 2016
Certificate number: WACC-1079/6939

Carolyn K Hurley

Jeff Szer, MD
President

Carolyn K. Hurley, PhD
Accreditation Steering Committee

Certification Body:
World Marrow Donor Association
Schipholweg 57
2316 ZL Leiden
The Netherlands

TODAY

The most important goal of the ZKRD is to find a suitable donor for each patient as quickly as possible and to ensure the safety of further processes such as workup and transportation. Hence, the ZKRD already began establishing a quality management system in its early stages with the medical well-being of patients and protection of donors as its primary focus. A further aim is to achieve a high level of satisfaction among our partners and staff.

DIN EN ISO 9001

The ZKRD's quality management system was already certified to DIN EN ISO 9001:2000 in 2004. All subsequent audits have confirmed the high standards the ZKRD achieves with its work.

German standards for unrelated blood stem cell donation

The latest German regulatory requirements relating to the donation of blood stem cells are summarized in the respective German standards for unrelated blood stem cell donation. These standards apply within the German network and are maintained by a cross-institutional panel comprising representatives of the various partners and expert committees. German donor centers, search centers, receiving units and transplant centers are regularly audited against these standards, which frequently exceed those of the WMDA. The ZKRD relies on the cooperation of these partners in further developing the standards and when conducting an audit. Thank you for the qualified support over the years!

WMDA accreditation

The ZKRD has been accredited by the global umbrella organization, the WMDA, since 2006. This demonstrates that the ZKRD not only works according to the WMDA standards but also that the partners in the German system also comply with the corresponding standards and quality requirements. It is only through this valuable collaborative network that all institutions both nationally and internationally can work together swiftly and securely.

11

Knowledge Transfer

THEN

In the early 1990s, blood stem cell donation was an innovative therapy. Though only few experts possessed the knowledge required for an unrelated donor search, this knowledge developed at pace.

Even at that time, a global network existed which enabled experts to work closely with one another. The foundation of the ZKRD gave rise to a central office in Germany where all the information on donor searching nationwide converged and which served simultaneously as a central point of contact for international inquiries. Information on innovations and developments was exchanged between the national and international partners within the scope of working groups and initial conferences.

TODAY

Blood stem cell transplantation is still associated with major risks for the patients concerned, and research in the field continues to this day.

Finding the right donor for a patient is a very complex matter, both medically and logistically, with many different partners in Germany and abroad involved in the process. In addition, national and international regulations must be considered or even harmonized. Over the last 30 years, the ZKRD has continuously built up its knowledge, for example through specialist congresses, conferences, memberships in expert committees and the continuing professional development of its staff. As a central registry, we also see it as our task to keep all partners informed of the latest developments, to promote the exchange of information and, where applicable, to develop standards which will ensure that people receive safe stem cell donations of the highest possible quality.

Up-to-date information

The ZKRD shares updates and information relevant to routine operations by sending digital circulars and newsletters to the partners concerned. Most of the information can also be found online, in the partner portal of the ZKRD website. Numerous templates, documents and forms for managing daily tasks are also to be found there. During critical situations, such as the coronavirus pandemic, armed conflicts or natural disasters, the ZKRD monitors the current situation, collects and distributes important information from the relevant institutions (e.g., PEI, WMDA, German governmental agencies), and in this way supports those partners in particular who cannot maintain regular contact with these institutions.

Sharing knowledge and experience

The ZKRD regularly offers its partners training sessions on the varied aspects of stem cell donation. Aside from purely sharing knowledge, we attach particular importance to maximizing the opportunities for exchanging experience. It is precisely in this way that participants can develop or deepen their understanding of the processes specific to the respective institutions or countries and collaboration can be nurtured.

> Workshop for transplant centers

The ZKRD organizes regular workshops for the coordinators of German transplant centers, focusing specifically on the current standards, regulations and processes relevant to workup coordination. If necessary, discussions of key topics are also included on the agenda.

> ZKRD courier training

WMDA accreditation means that all partners are obliged to ensure that couriers transporting stem cell products comply with the international WMDA standards and recommendations and that, as a result, the quality of the product is not compromised. ZKRD courier training is aimed primarily at stem cell couriers used by hospitals in place of commercial providers. The training covers the diverse aspects of the pertinent standards, such as product quality, logistics, responsibilities, and anonymity.

> Dangerous goods training

Shipping potentially infectious materials (e.g., blood samples) is subject to legal provisions. The ZKRD has developed a training course aimed specifically at blood stem cell donation which is held on an annual basis. Anyone involved in shipping blood samples can thus acquire the necessary knowledge or refresh their knowledge according to the regulations.

> ZKRD conference

The ZKRD conference, held annually by the ZKRD for its national partners, focuses on current developments as well as information exchange. The first ZKRD conference was held in Kassel in 1999. The conference now takes place once a year in Ulm. The first digital version was held in 2021 due to the coronavirus pandemic.

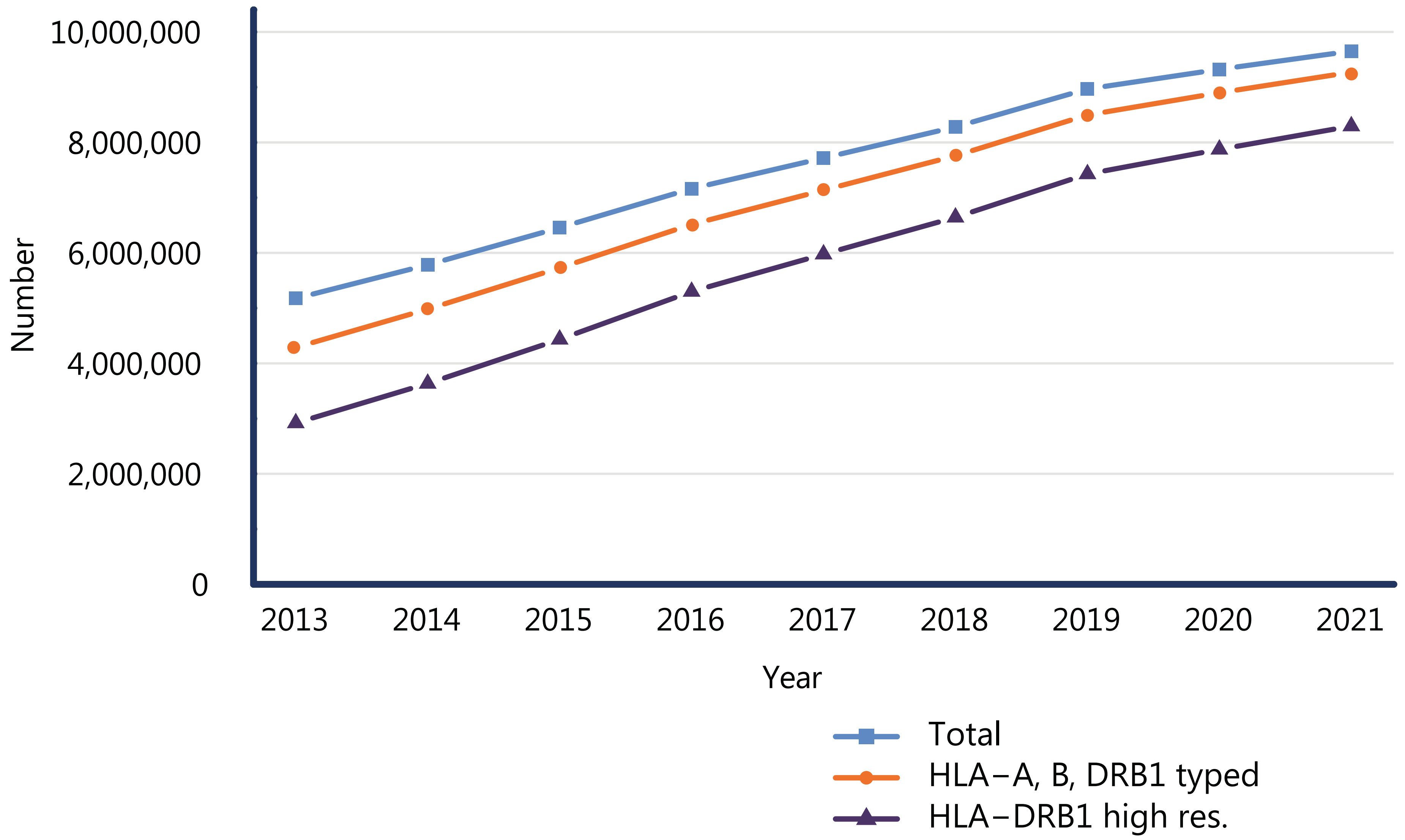
12 The ZKRD 2021 in figures

Our joint efforts enabled us to maintain patient care at the highest possible level during 2021 despite the ongoing pandemic. The statistics below provide a more detailed overview of the figures.

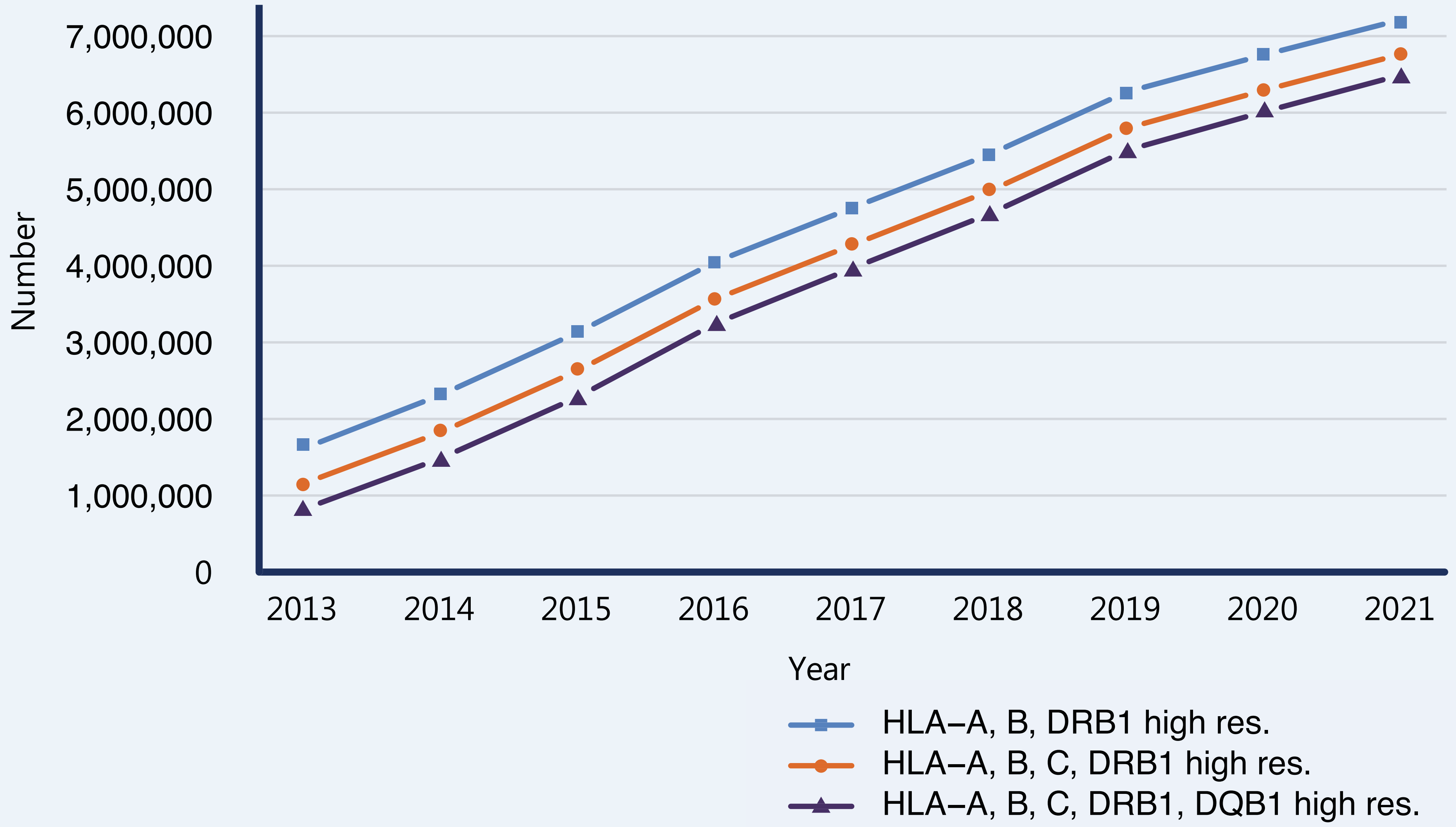
2021:
+ 330,000
DONORS

In 2021, the number of German donors increased by a good 330,000 to reach a total of roughly 9,700,000 potential lifesavers. Furthermore, continued post-typing of registered donors has helped increase the quality of the donor pool: of those currently listed in the database, donors with 5-loci high-resolution typing (HLA-A, B, C, DRB1 and DQB1) account for just over 67 %.

1. Donor numbers in Germany



2. Donors in Germany with high resolution typing

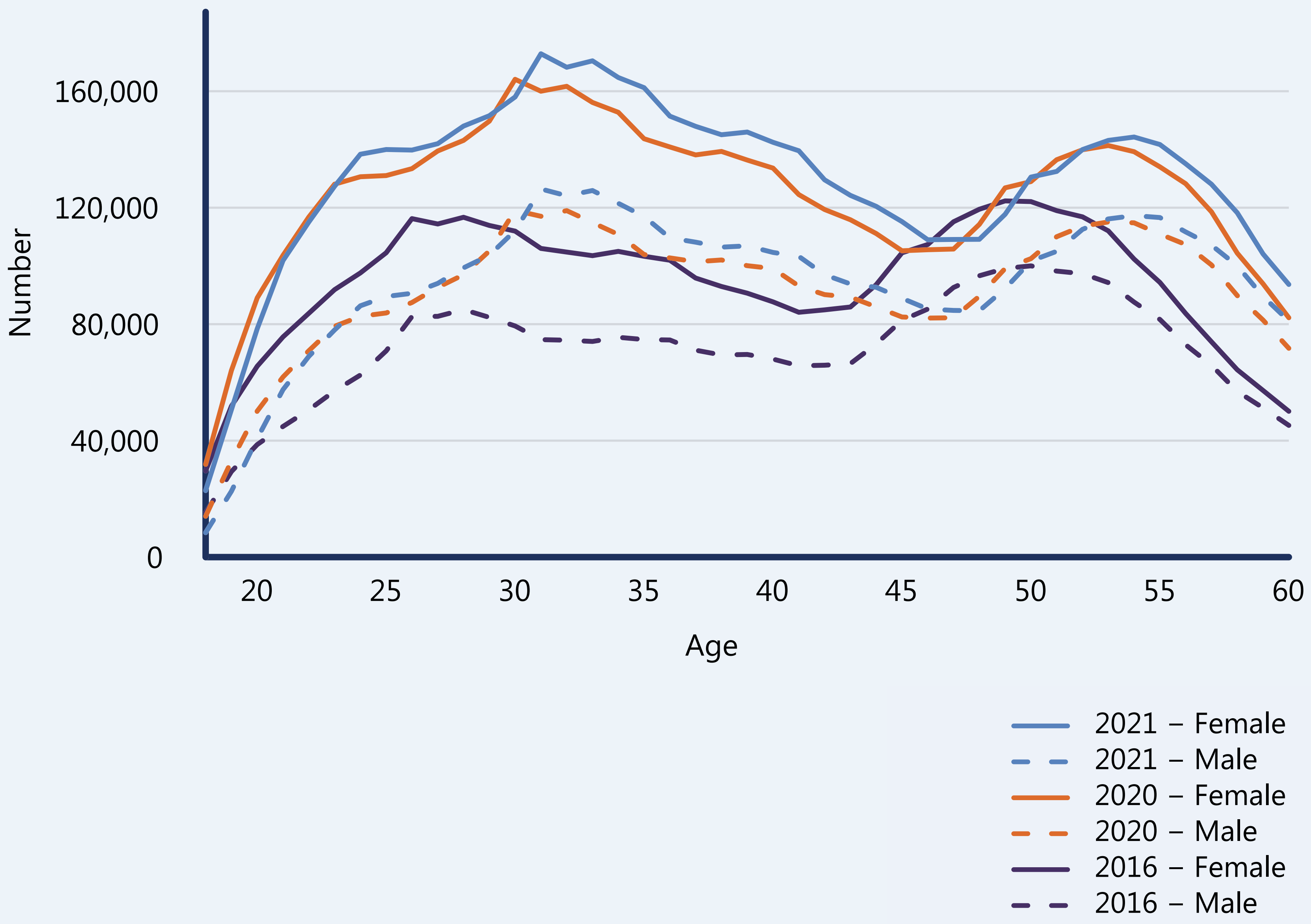


12

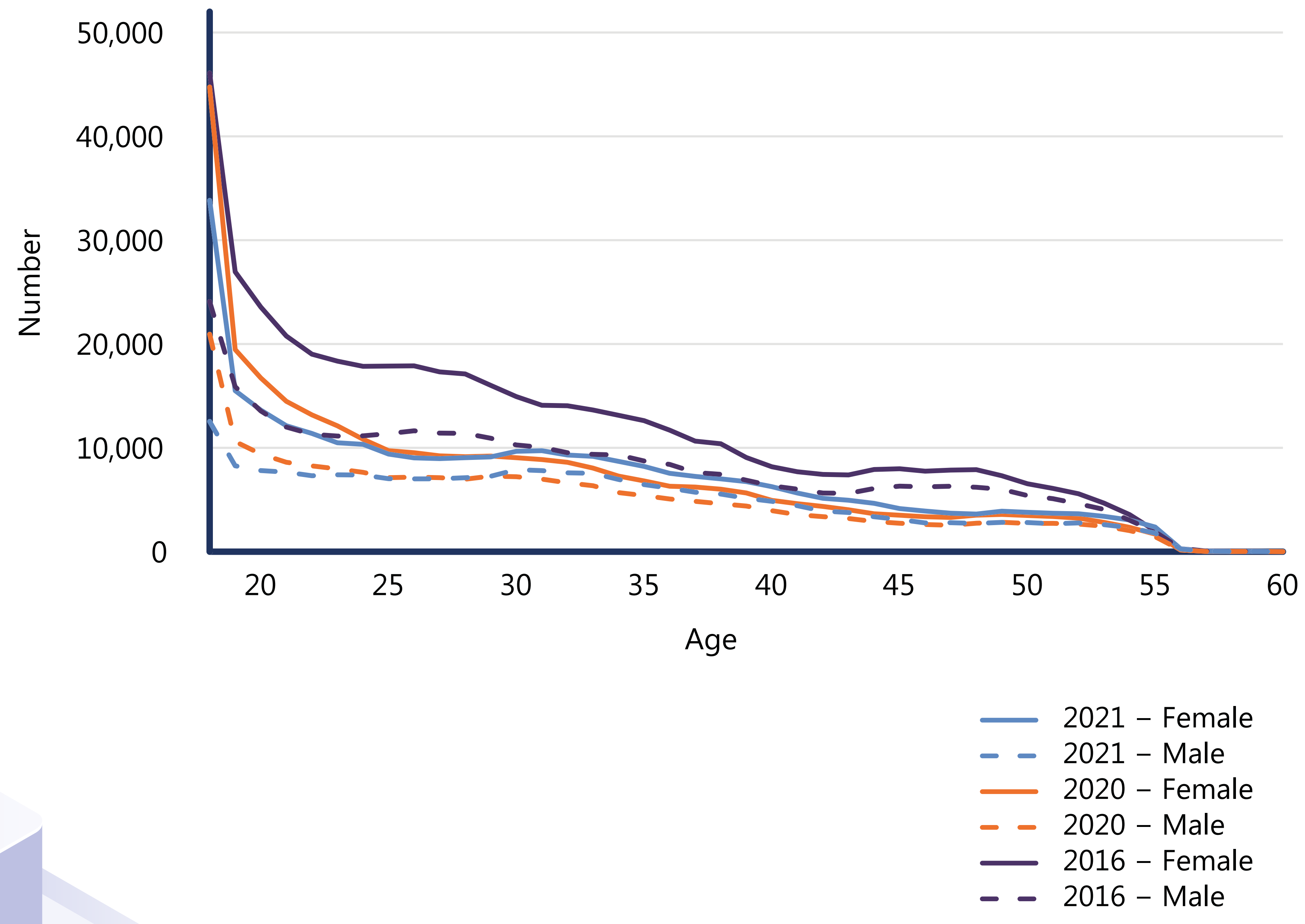
The ZKRD 2021 in figures

As in 2020, donor numbers last year generally grew at a slower pace than in previous years but still exceeded expectations in the face of the challenges posed by the coronavirus pandemic. The age distribution of new donors was also largely the same as that in the preceding years.

3. Age distribution of German donors



4. Age distribution of newly recruited donors



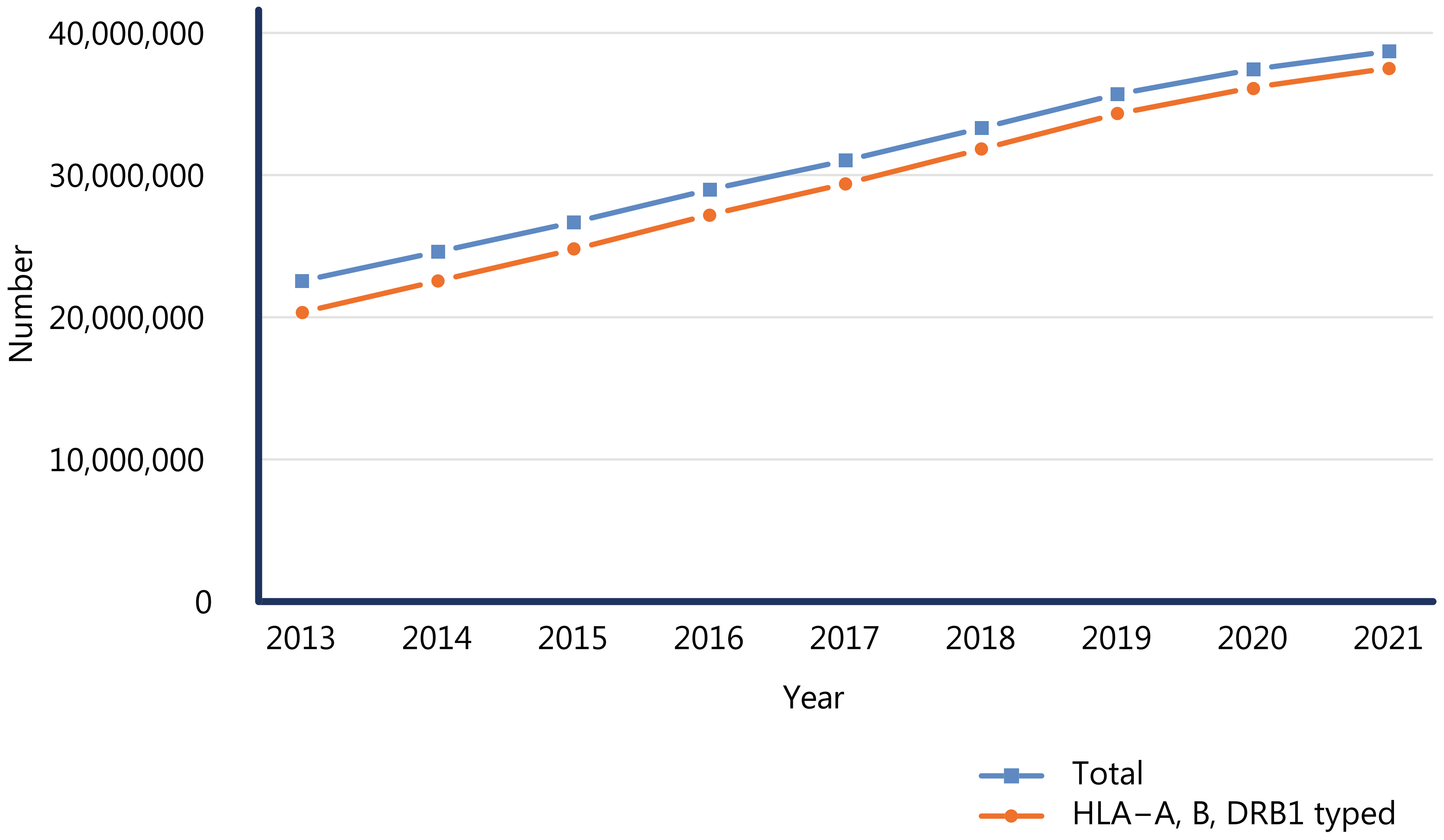
12 The ZKRD 2021 in figures

The huge success in recruiting German donors is evident from the international comparison: there has been an increase of almost 1,300,000 donors, with German donors accounting for an incredible 25 %.

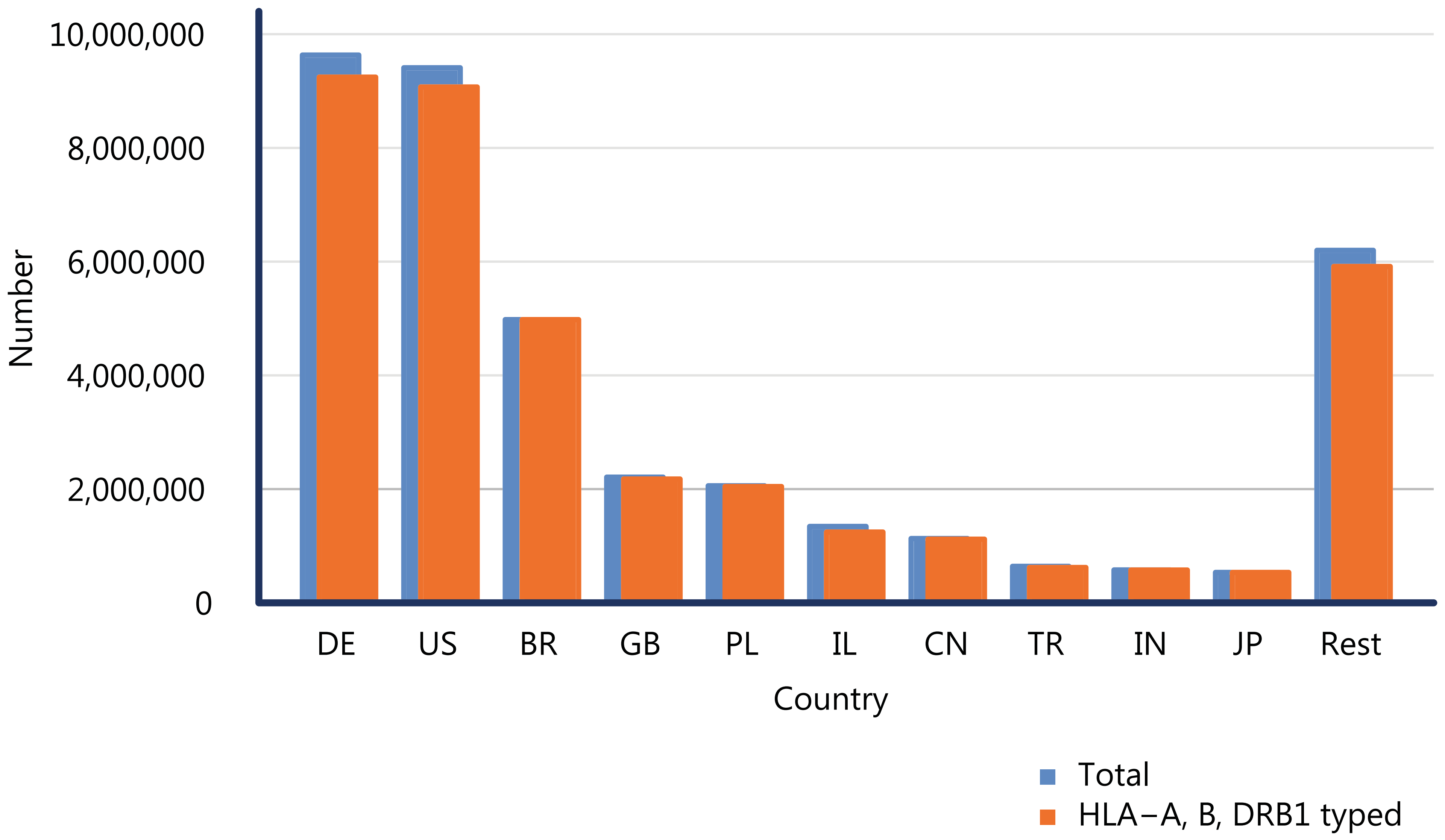
Hence, the ZKRD is now the world's largest national donor registry.

Many thanks go to all our partners for this amazing joint achievement!

5. Donor numbers worldwide (according to WMDA)



6. Distribution of donors worldwide (according to WMDA) in 2021



12 The ZKRD 2021 in figures

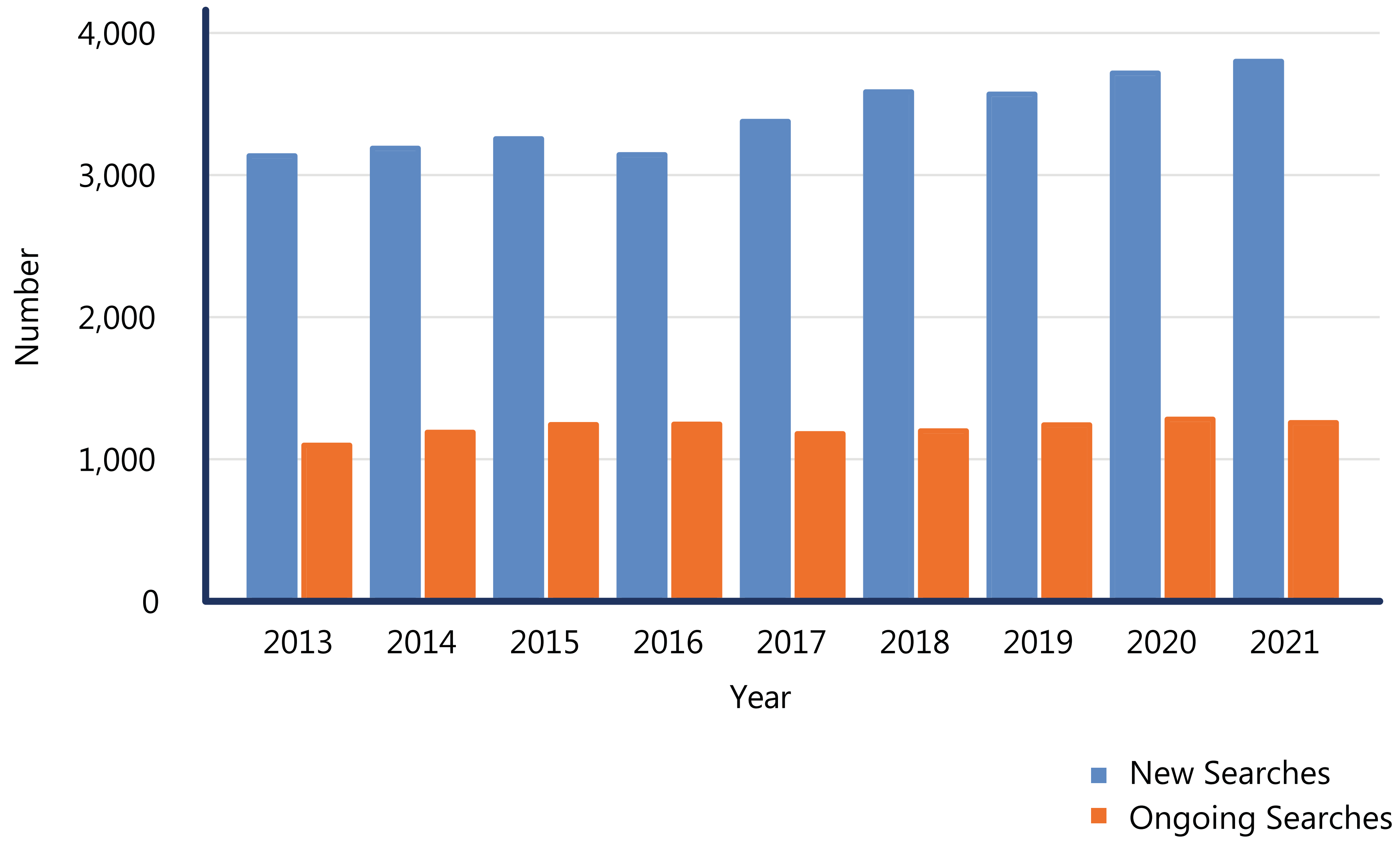
A total of 3,800 new searches for German patients were initiated in 2021 – the highest number since the ZKRD came into existence.

New Searches for German patients

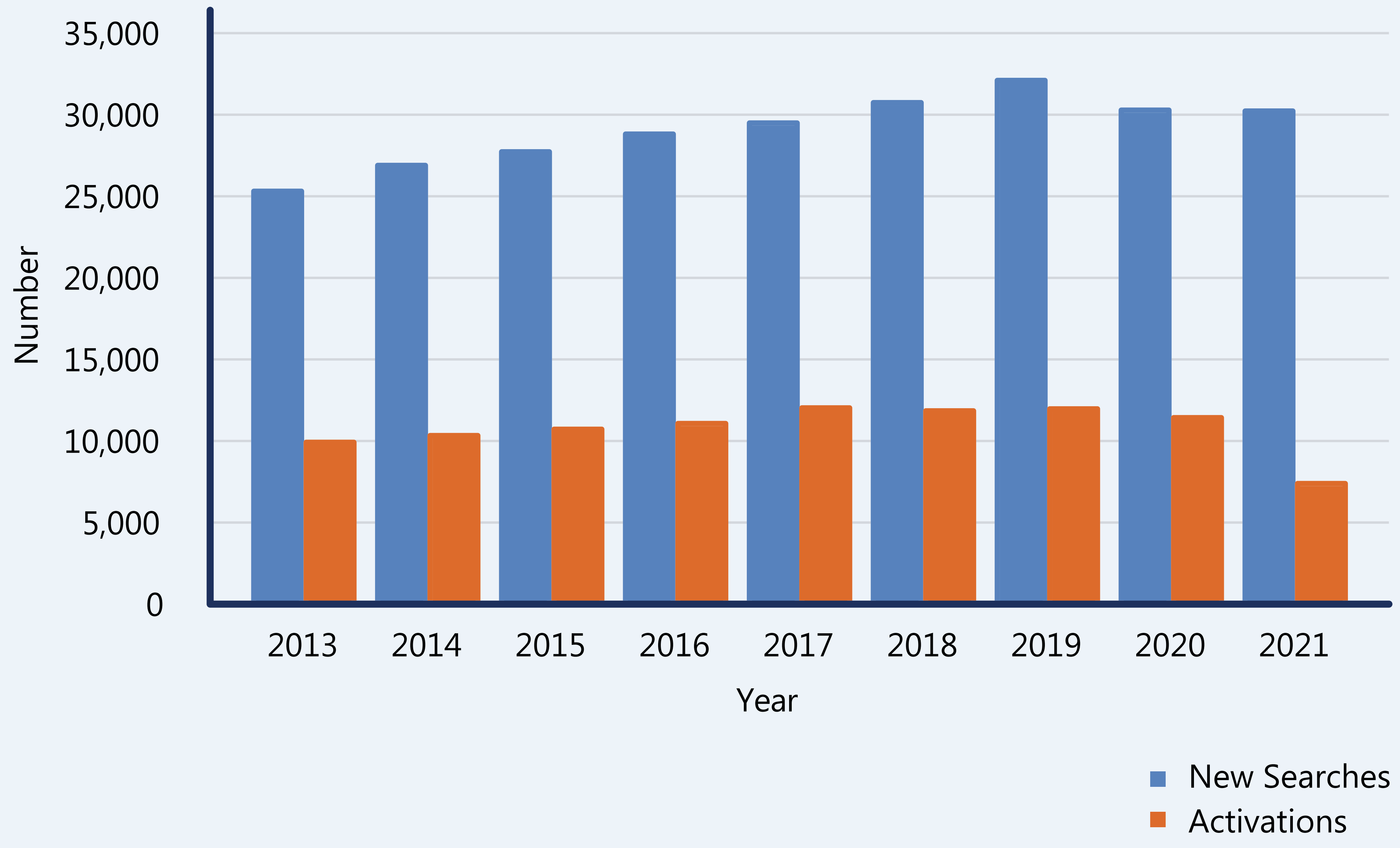
3,800

The ZKRD receives a total of more than 33,000 requests a year from Germany and abroad.

7. Donor searches for German patients



8. Donor searches for patients abroad



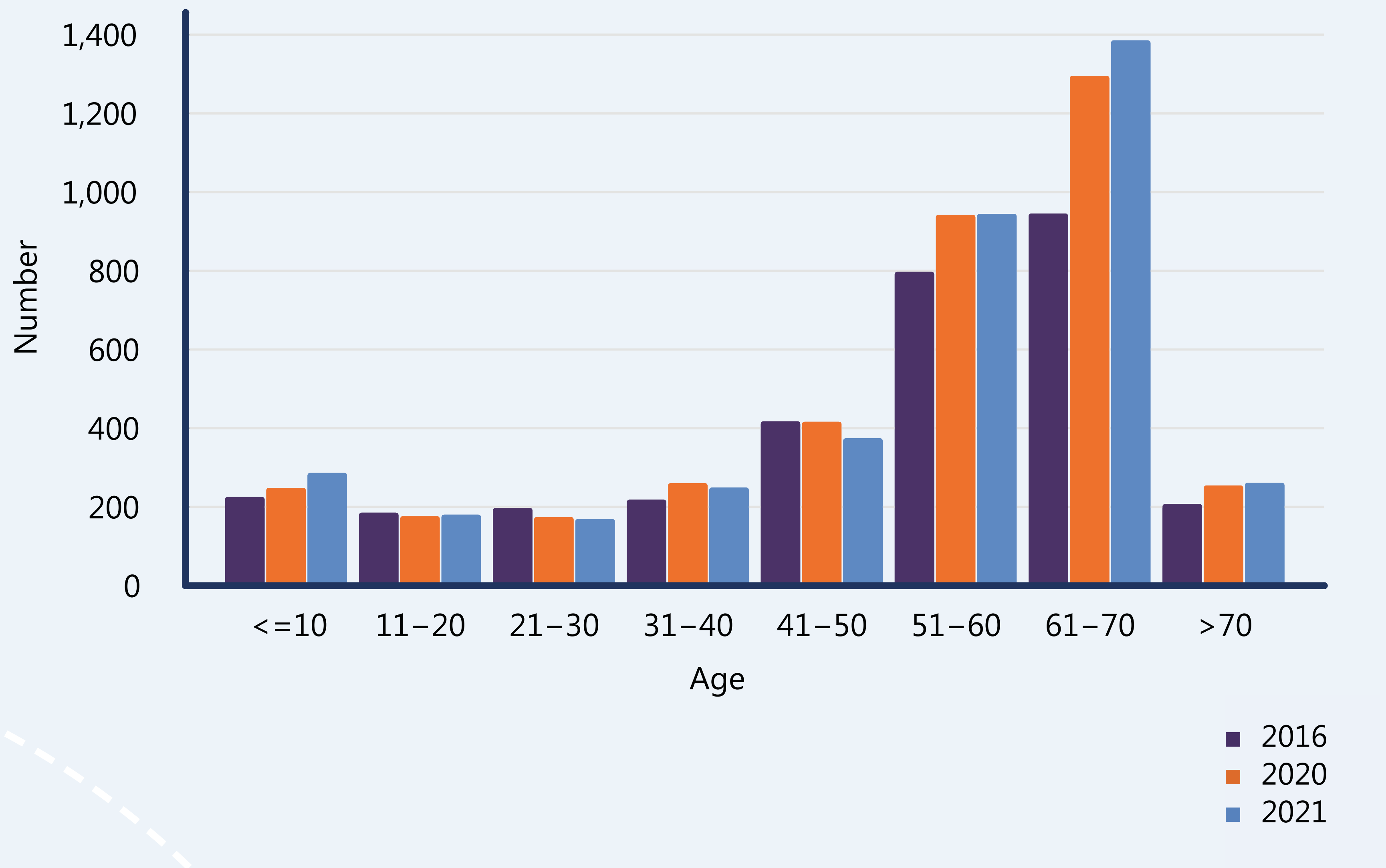
12

The ZKRD 2021 in figures

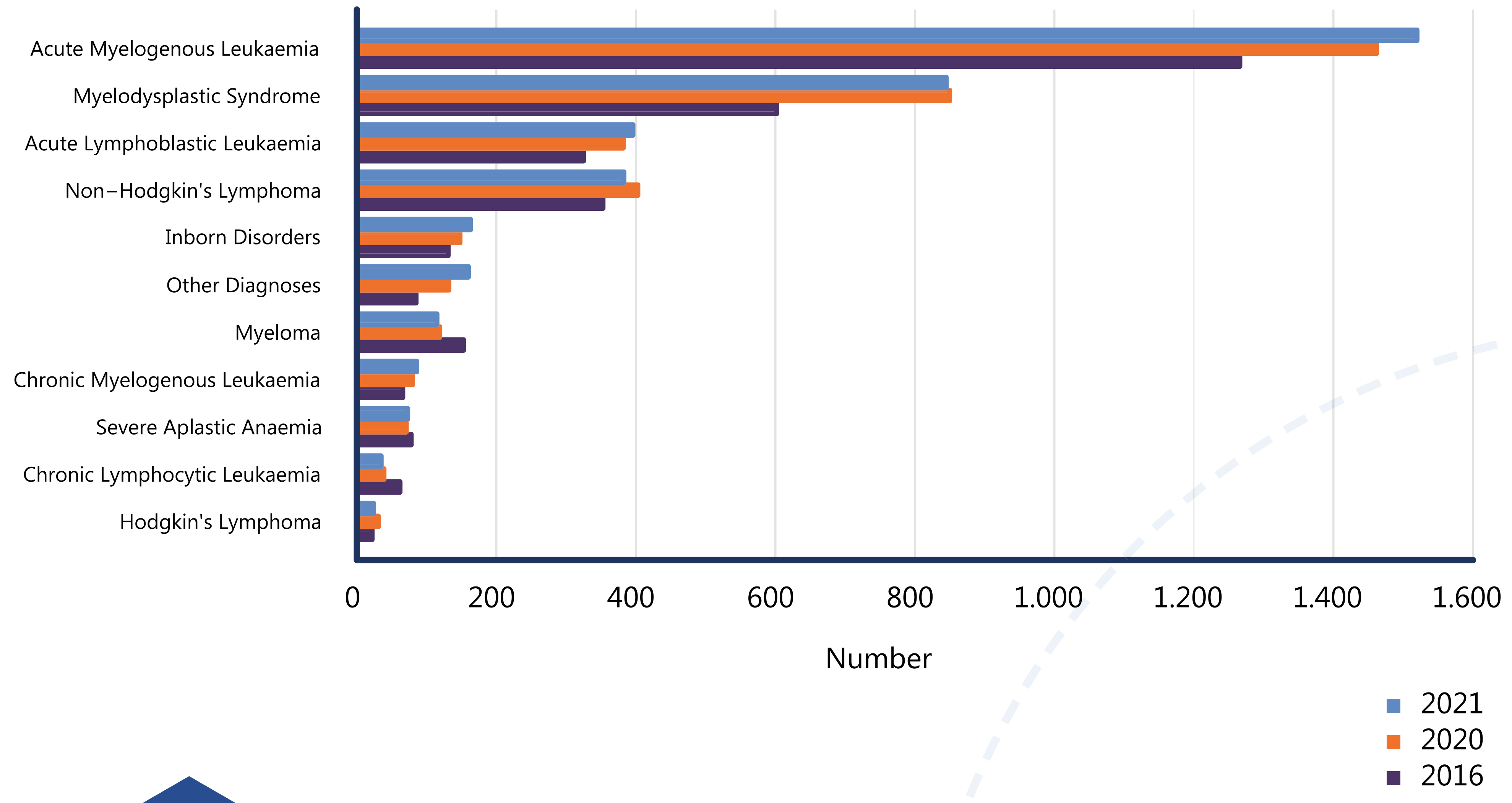
Compared to the previous year, search requests for German patients increased mainly in the age groups < 10 years and 61–80 years. The number of very young patients in particular, i.e., under 10 years of age, was 16 % higher than in the previous year.

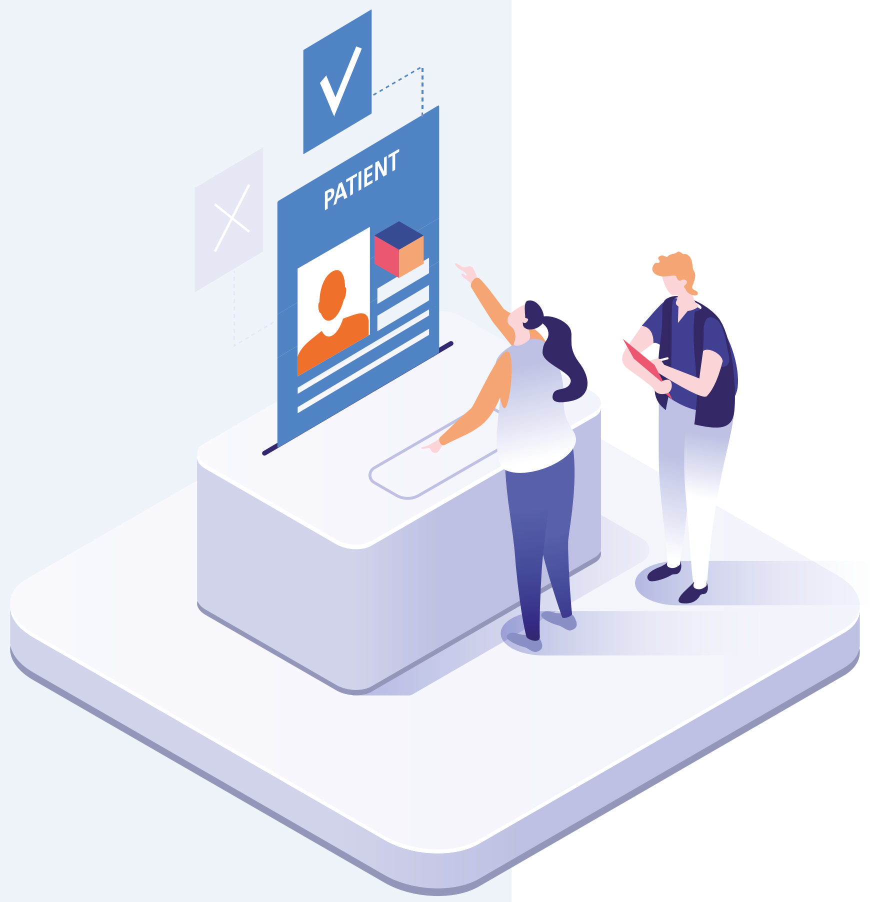
This is reflected in the diagnoses, with increased rates of AML and MDS, both of which are age-related conditions.

9. Age distribution of German patients



10. Distribution of diagnoses among German patients

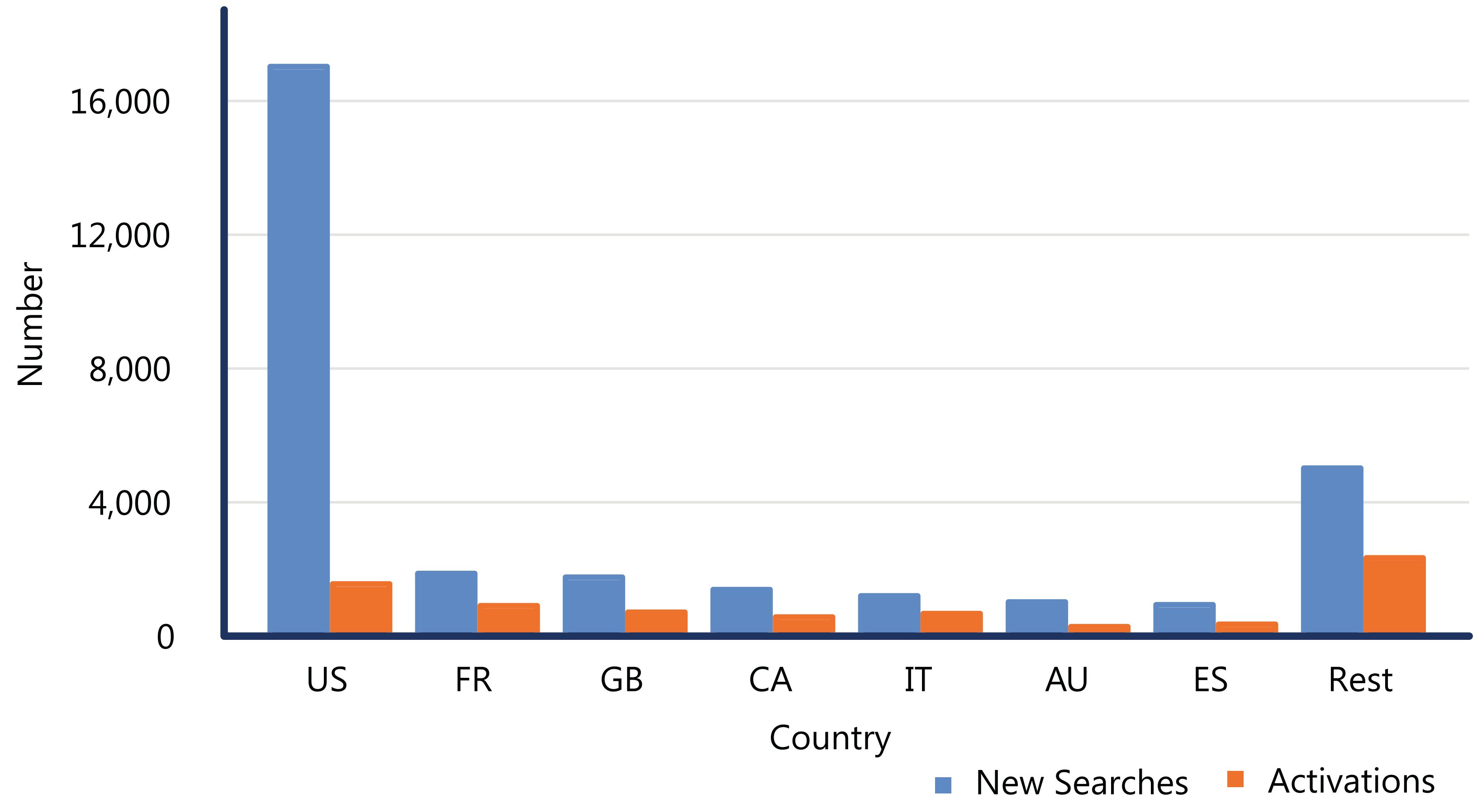




12 The ZKRD 2021 in figures

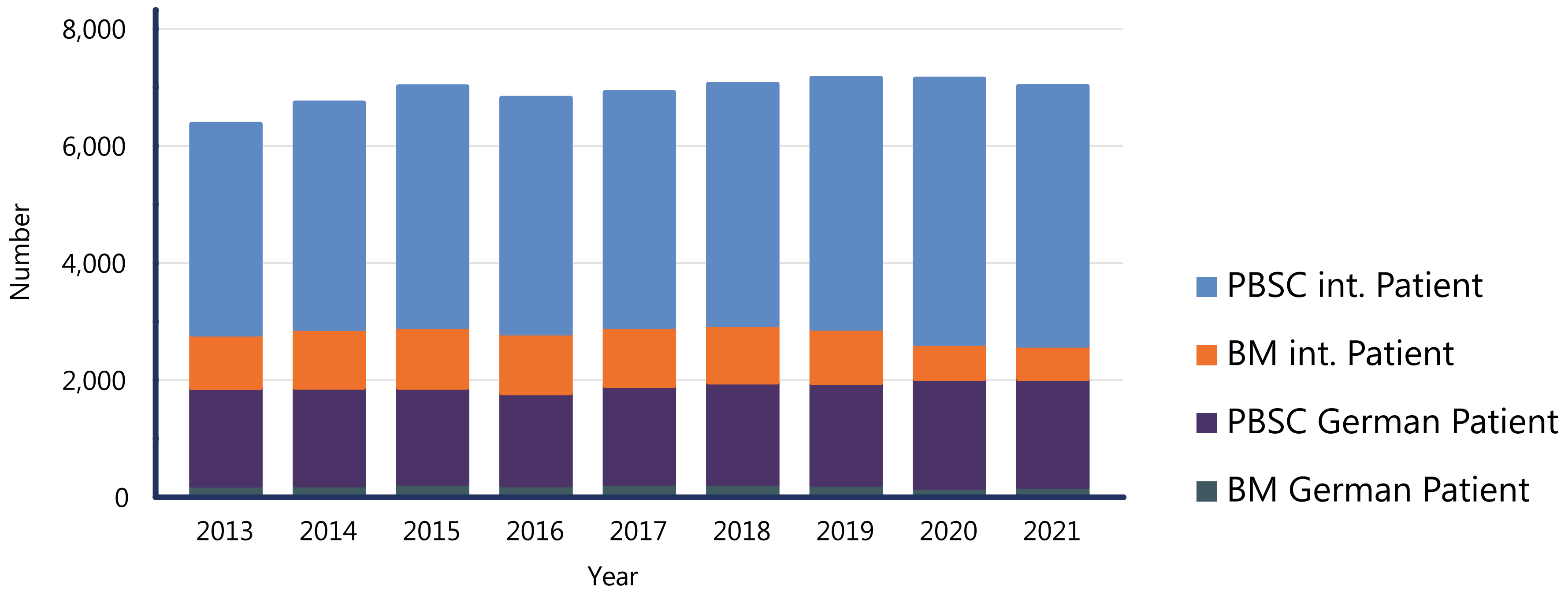
Most search requests from abroad originated in the USA, followed by France, Great Britain, and Canada. The number of orders placed by these countries was much lower, however, than the number of requests.

11. Origin of search requests for German donors in 2021

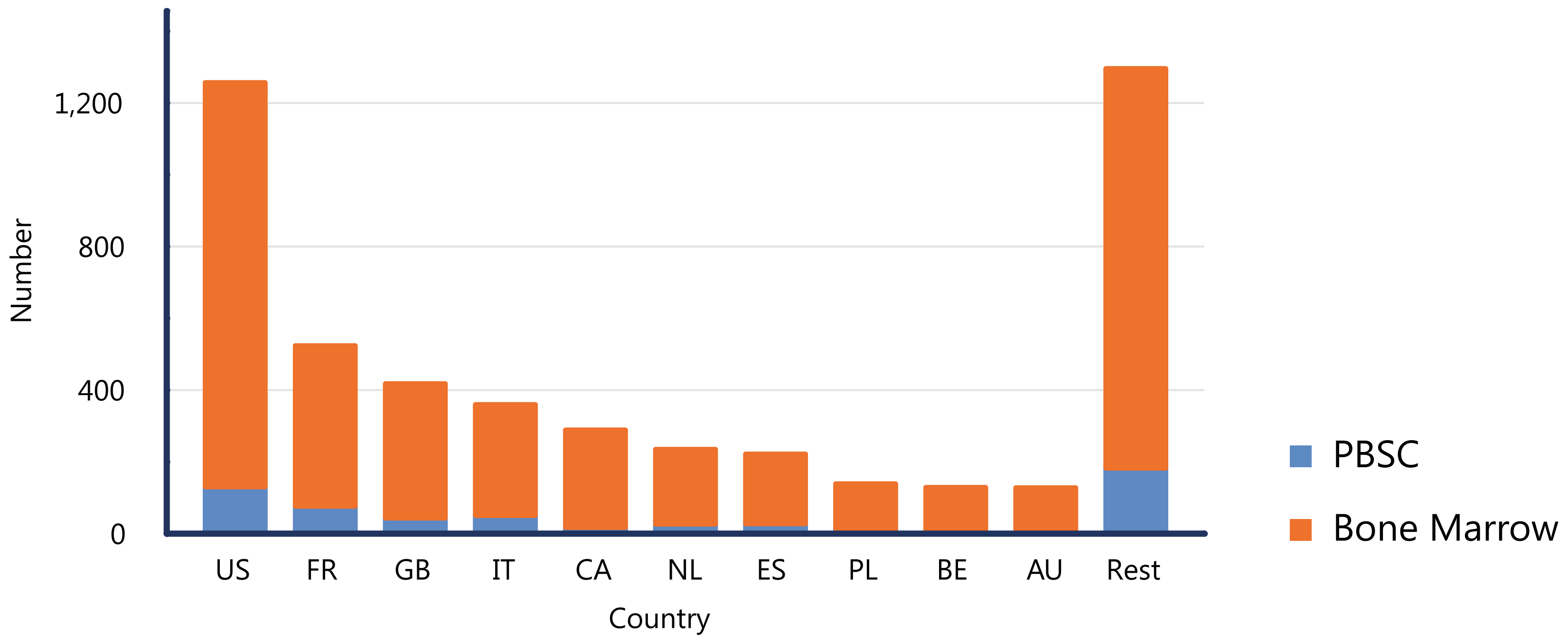


In 2021, blood stem cells were collected from a total of 7,109 German donors.

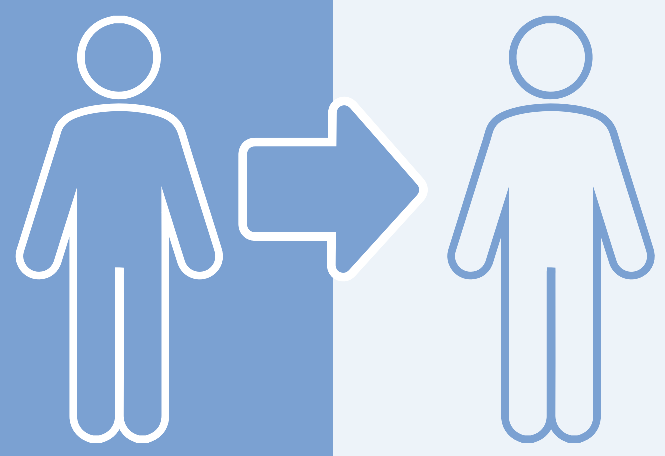
12. Collections of blood stem cells from German donors



13. Distribution of stem cell collections from German donors for patients abroad in 2021



Since its inception, the ZKRD has identified suitable donors in Germany for almost 110,000 patients at home and abroad.

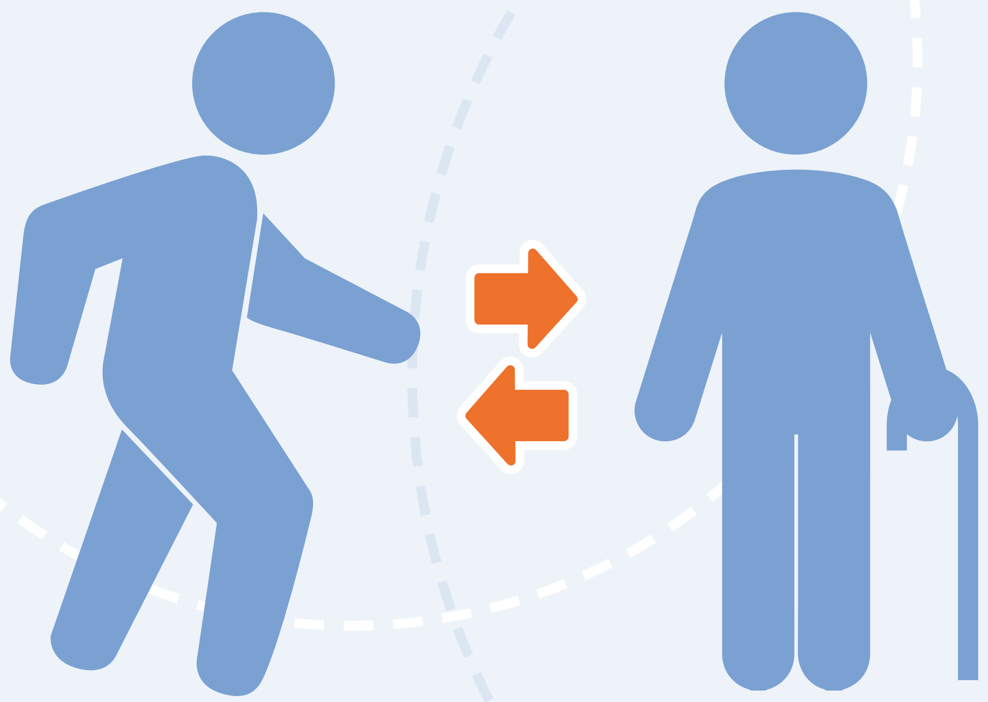


As with the search requests, most of the stem cells donated for patients abroad are destined for the USA. Yet France, Great Britain and Italy also frequently request donors from Germany.

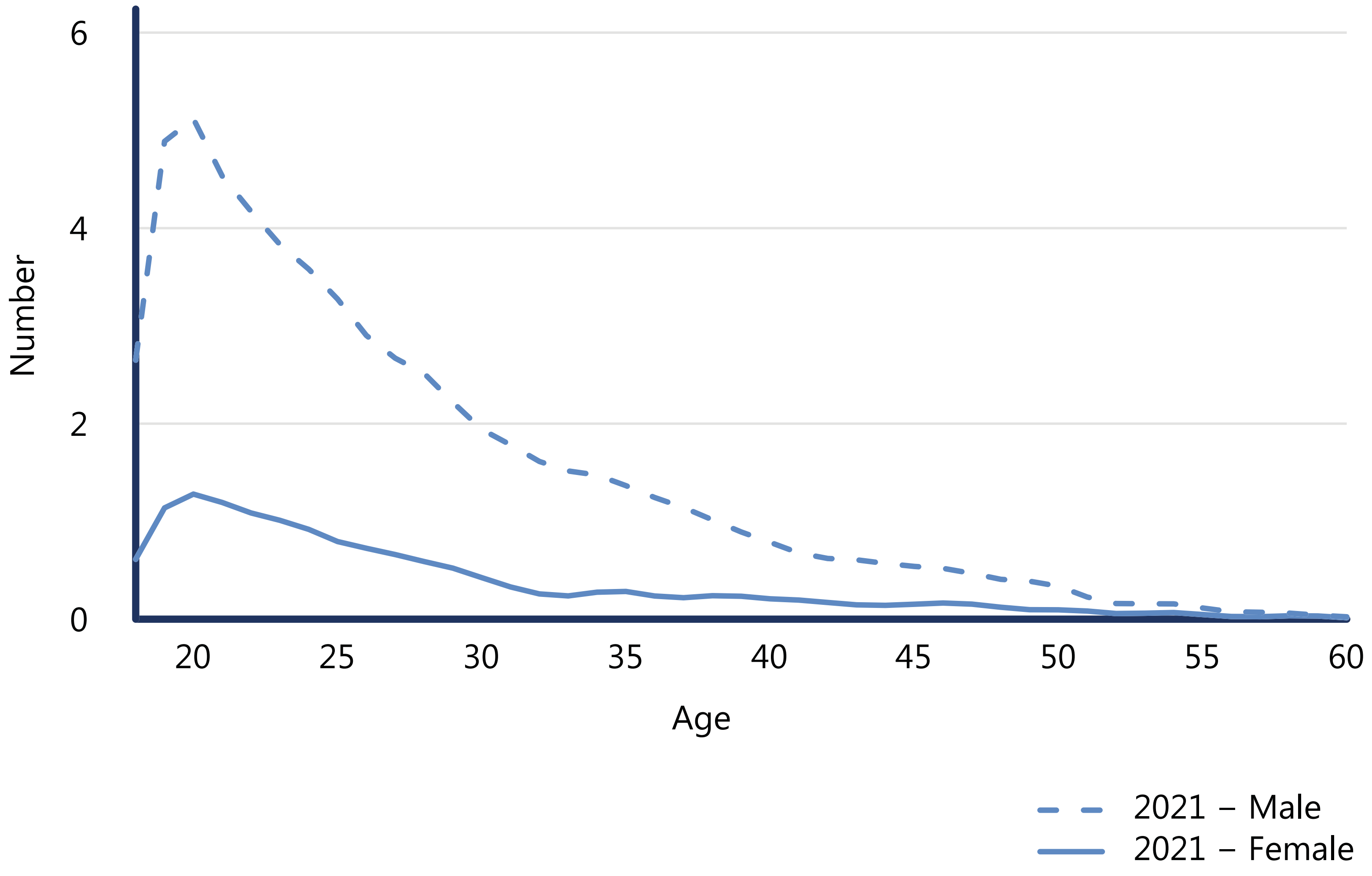
As a central point of contact, the ZKRD supports its partners across the board – from searching for an unrelated stem cell donor through coordinating the workup and transportation, to customs clearance and billing.

The ZKRD 2021 in figures

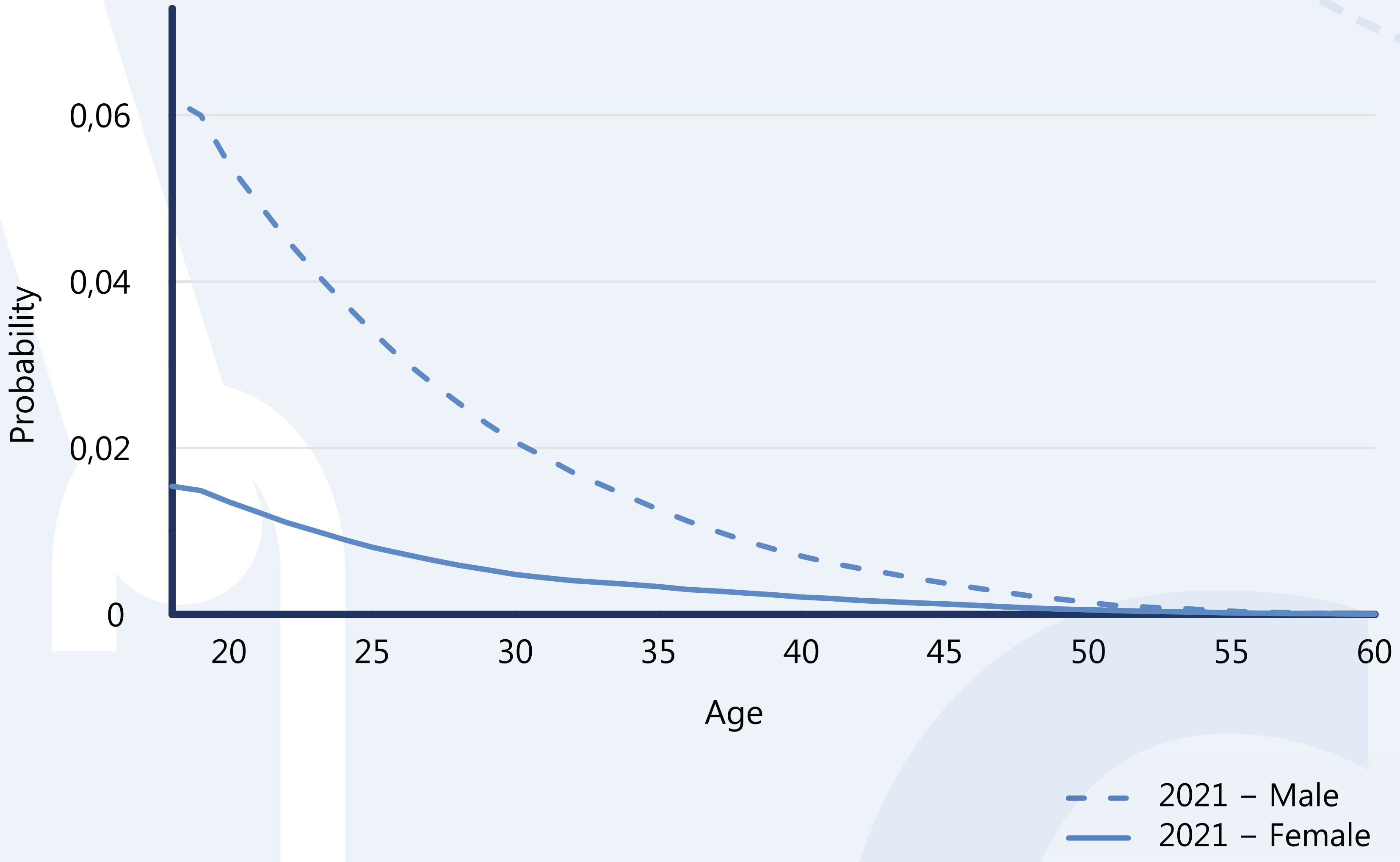
When considering the chances of selection as a stem cell donor at a certain age, the following charts demonstrate that the probability decreases with increasing age and that it is mostly young men who are asked to donate.

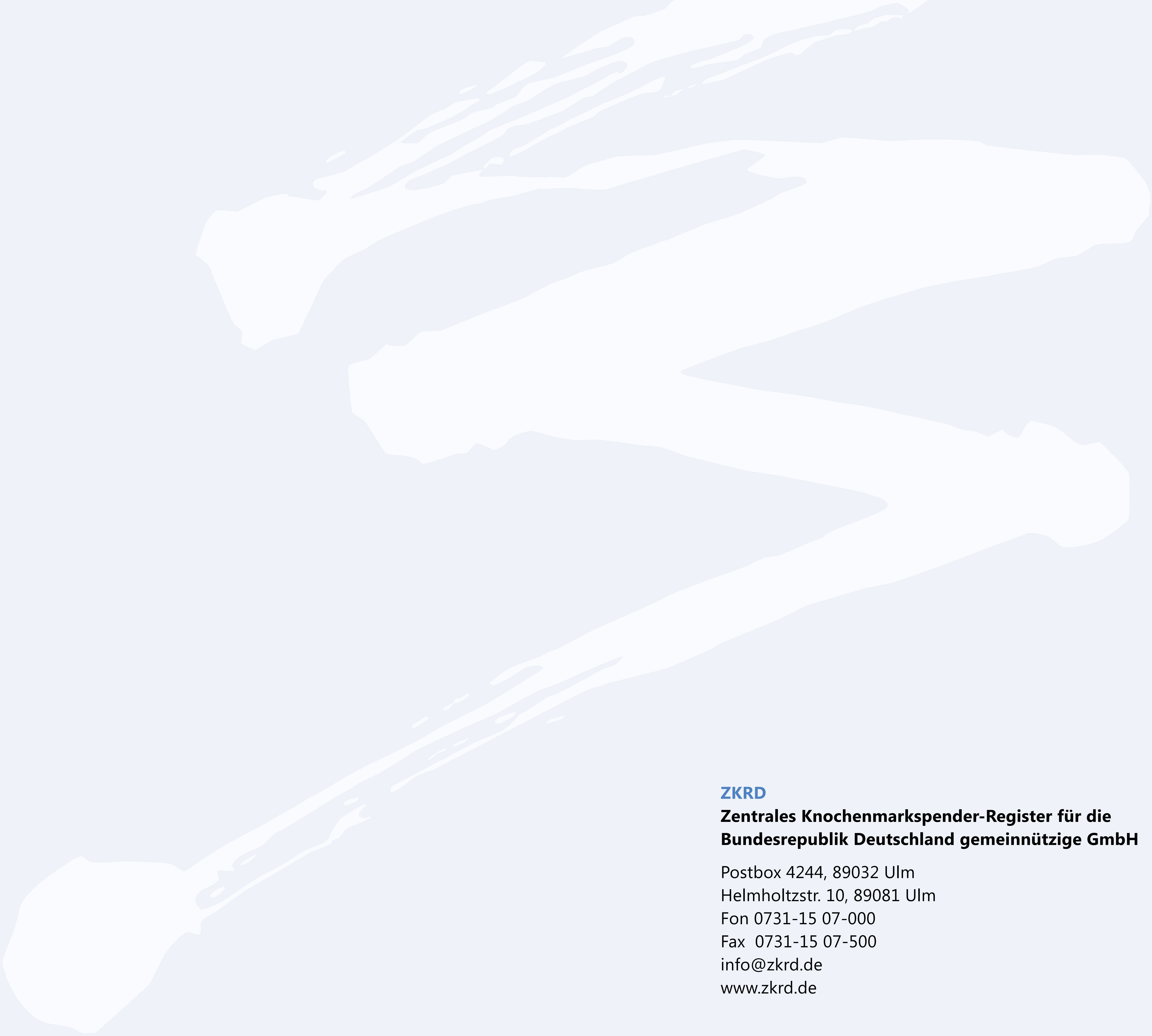


14. Collections per 1,000 donors



15. Probability of donation up to the age of 60 years





ZKRD
Zentrales Knochenmarkspender-Register für die Bundesrepublik Deutschland gemeinnützige GmbH

Postbox 4244, 89032 Ulm
Helmholtzstr. 10, 89081 Ulm
Fon 0731-15 07-000
Fax 0731-15 07-500
info@zkrd.de
www.zkrd.de