

About DKMS UK

Introduction

DKMS UK is a national charity and not-for-profit organisation established in the UK in 2013. The organisation works in the field of blood cancer and blood disorders, with the primary aim of recruiting potential blood stem cell donors to the UK registry, who will then be available to donate their blood stem cells to patients in need of a life-saving blood stem cell transplant.

DKMS UK is also part of an international group of not-for-profit organisations, based in seven countries and working globally in the field of blood stem cell donation and transplantation. DKMS was first established in Germany in 1991, around one family's search for a blood stem cell donor. Dr Peter Harf founded the organisation in honour of his wife, Mechtild, who had been diagnosed with leukaemia but was sadly unable to find the donor that she so desperately needed. Since then DKMS has been dedicated to creating more second chances of life by trying to find a matching donor for every blood cancer/disorder patient around the world who needs a blood stem cell transplant.

Following a decision to internationalise the organisation's work in the early 2000s, DKMS has established national organisations in USA (2004), Poland (2009), UK (2013), Chile (2017), India (2019, as a joint venture between DKMS and the Bangalore Medical Service Trust) and South Africa (2020, as a partnership between DKMS and the Sunflower Fund). The DKMS Group also has a number of other organisations that are vital to its work and mission, including world-leading, state of the art laboratories at DKMS Life Science Lab, the DKMS Cord Blood Bank and the DKMS Clinical Trials Unit (all based in Dresden, Germany), and DKMS Life (which provides patient support programmes for patients in Germany with any form of cancer).

Global reach, local impact

DKMS has grown and developed massively in its nearly 30-year history and is now the world's largest blood stem cell donor centre, having passed in early 2020 the milestone of recruiting 10 million donors globally. Since its founding, DKMS has created over 91,000 second chances of life (as of Jan 2021) from the blood stem cell donations it has arranged and supported, and we are grateful to all our stem cell donors that have made this happen.

In the UK, since founding in 2013, we have worked as part of the UK aligned stem cell registry (along with Anthony Nolan, the British Bone Marrow Registry (part of NHS Blood and Transplant) and the Welsh Bone Marrow Donor Registry). As of January 2021, we have recruited c860,000 donors to the UK registry, which account for over one-third of the 2 million+ registered donors in the UK. Since founding, we have arranged over 1,300 blood stem cell donations and are growing our work and impact at a fast pace.

Internationally, the DKMS Group provides blood stem cell donors for c40% of the UK's blood stem cell transplants.

Mission and Values

Our mission

To provide a matching donor for every blood cancer/disorder patient in need of a blood stem cell transplant.

Our organisational values

DKMS UK works to a clear set of values in everything that it does. We are:

- People-focused
- Ambitious
- Positive
- Efficient

About blood cancers, blood disorders and stem cell transplants

Blood cancer is a collective term for cancers that affect the bone marrow or the body's blood or lymphatic systems. Often the term "haematological malignancies" is used to describe blood cancers. Blood cancers affect the production and function of the body's blood cells, with the three most common forms being lymphoma, myeloma and leukaemia. These forms of blood cancer divide into well over a 100 other subtypes. Blood cancer is the fifth most common form of cancer in the UK with around 40,000 new cases diagnosed each year and around 250,000 people living with the disease.

Diagnosis, prognosis, treatment and aftercare varies according to the different forms and types of blood cancer, but will usually involve chemotherapy, radiotherapy, immunotherapy or cell/gene therapies, including stem cell transplants. Blood stem cell transplants play an important role in the treatment of blood cancer and in many cases may be the last or one of the last treatment lines for patients who have exhausted all other treatment options. Similarly, in many cases, a blood stem cell transplant will offer the only chance of a cure for someone with blood cancer.

There are two types of blood stem cell transplant:

- Autologous (where the blood stem cells are taken from the patient's own body); and
- Allogeneic (where the blood stems cells are donated to the patient by a related or unrelated donor).

Some patients receive blood stem cells from umbilical cord blood, which has been collected at birth and frozen in a cord blood bank. DKMS' work focuses primarily on allogeneic transplants involving unrelated donors, but the DKMS Group also has a Cord Blood Bank in Germany.

Allogeneic blood stem cell transplants are an important treatment option in the following forms of blood cancer (non-exhaustive list):

- Acute lymphoblastic leukaemia.
- Acute myeloblastic leukaemia.



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- Chronic lymphocytic leukaemia.
- Diffuse large B-cell lymphoma.
- Follicular lymphoma.
- Hairy cell leukaemia.
- Hodgkin lymphoma.
- Mantle cell lymphoma.

There are also a number of other conditions that are often grouped with blood cancer, but that in fact are not clinically defined as cancer, although they may over time develop into cancer in some people (but they will not always do so). Such conditions include: myelodysplastic syndromes (also referred to as MDS), myeloproliferative neoplasms (often referred to as MPN) and essential thrombocythaemia (ET). There are many others.

Blood disorders include conditions where, for instance, the body's blood or blood system is not working in the way it should, so that, eg, red blood cells' function of carrying oxygen, or white blood cells' role in fighting infection, or platelets' role in blood clotting, is affected. Such blood disorders are included within the term "haematological non-malignancies", which indicates they are not life-threatening in and of themselves, however, in severe cases they can make patients susceptible to life-threatening infections or complications.

Blood stem cell transplants play a role in the treatment of many blood disorders, the most common ones being:

- Myelodysplastic syndromes.
- Aplastic anaemia.
- Sickle cell disease.
- Autoimmune diseases.
- Thalassaemia.

There are around 2,000 people in the UK each year who are looking for an unrelated blood stem cell transplant. Almost 25% will find a match within their family. The remaining c75% will be reliant on finding a matching donor somewhere in the world from one of the stem cell registries internationally. Of those from a North European background, about 70% will find a good match from an unrelated donor, but this drops to around 20% for patients from a black, Asian or minority ethnic background.

What we do

DKMS UK is based in Chiswick, West London and currently employs about 50 staff, as well as numerous volunteers, who carry out our work and services, as follows:

- Raising awareness of blood cancers and disorders – via online and offline campaigns, through the media and via communications initiatives.
- Blood stem cell donor recruitment – we run face-to-face/group events and online campaigns to encourage more people to register as a potential donor. Anyone aged between 17 and 55 and in good overall health is generally eligible to register, which involves a simple swab test and the provision of some personal data and health information.
- Swab testing by our DKMS Life Science Lab, as part of the HLA (Human Leukocyte Antigen)



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typing process so that potential donors can be matched with patients in need of a transplant.

- Medical care and support services – information, support, medical assessment and care relating to blood stem cell donations in one of the UK hospitals that we use for our medical services.
- Stem cell transportation – the collection and couriering of blood stem cells from one of our hospitals in the UK to transplant centres throughout the world.
- Donor follow-up and donor/patient contact – ongoing and longer-term support for donors on their health, safety and welfare, plus support with any future contact and reunion with patients.
- Fundraising – we run community and corporate events and sponsored activities as part of our programme of fundraising, which also involves support and involvement from a network of supporters and stakeholders, including grant-making trusts and foundations.

The charity's work and strategic objectives are overseen by a Board of Trustees, which is also part of an international group structure for DKMS organisations. The day-to-day operation of DKMS UK is led by the CEO, Jonathan Pearce, and a senior leadership team (SLT) comprising:

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|-----------------------|---------------------------------------|
| • Julie Roberts | Head of Customer Service |
| • Candy Stern | Head of Innovation and Improvement |
| • Helen Kelly | Head of Donor Request Management |
| • Hasnein Alidina | Head of Finance |
| • Caroline Richardson | Head of Fundraising |
| • Reshna Radiven | Head of Communications and Engagement |
| • Regina Salih | HR Generalist |

DKMS UK is part of an international group governance structure under the leadership of the Group CEO, Dr Elke Neujahr.

Financially, we are dependent on a combination of the fees we charge for our medical services, our fundraising work and intercompany funding from the DKMS Group, as part of our initial founding and establishment in the UK.

We have grown quickly since 2013 and our annual turnover in the last financial year was £10m. With the increase in the numbers of our registered donors, we know that we are on track to create even more second chances of life than previously and that this will lead to continuing growth of the organisation.

Strategic priorities

Following a strategic business planning review in 2019, DKMS UK works in line with the following strategic priorities:

1 – More second chances of life

- By 2023, to create at least 500 second chances of life per year from UK lifesavers for people affected by blood cancer and disorders in the UK and around the world

2 – Better chances for those who currently have fewer chances

- To transform the hopes and chances of people from BAME backgrounds to find a suitable match for a blood stem cell transplant

3 – The best support for the best donors

- To recruit the best-prepared blood stem cell donors and provide them with excellent services and support on their journey from joining the register to becoming a stem cell donor and beyond



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4 – Being financially self-sustaining

- For DKMS UK to be financially self-sustaining by 2023

5 – Building a community of support

- To create a community of support around DKMS UK's mission to give more people a second chance of life

6 – Being an excellent employer

- For DKMS UK to be an excellent employer

7 – Reducing environmental impact

- To reduce the amount of carbon generated by DKMS UK's work and activities

8 – Digital first

- To be a “digital first” organisation in everything we do

Our work and business plans, as well as individual and team management objectives, all link directly to the above organisational priorities.

The impact of the coronavirus/COVID-19 pandemic on DKMS UK's work

Like most organisations and the rest of society we have been affected by the Covid-19 pandemic. It has meant we have had to move temporarily to predominantly home-based working and our face-to-face/group stem cell donor recruitment events have had to stop completely. However, we have been able to continue with online registration and virtual donor recruitment events. Similarly, like many charities our community-based/events fundraising has been impacted significantly.

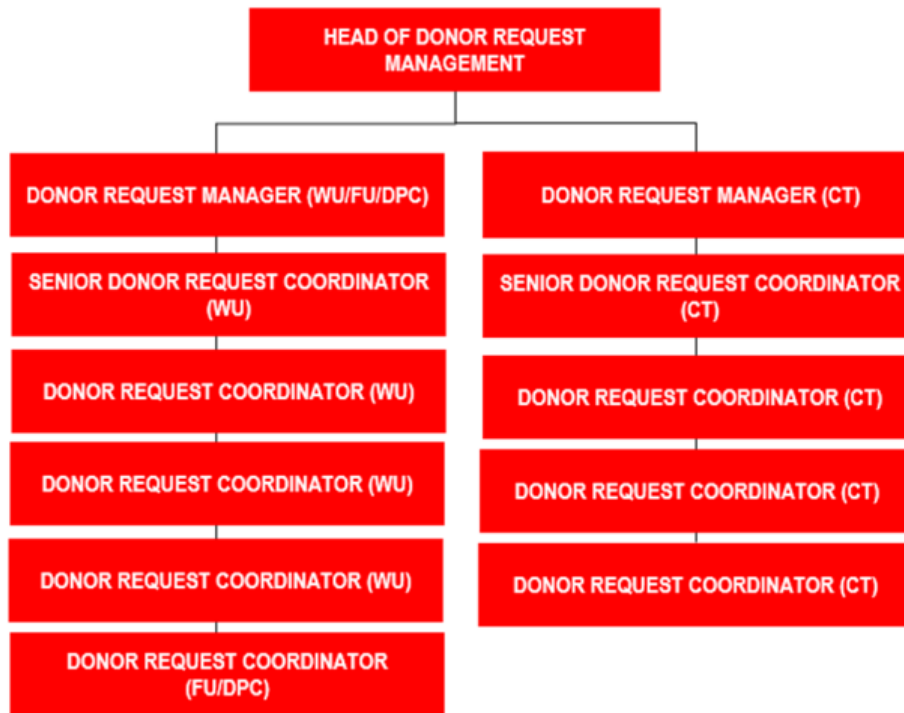
As an organisation we are privileged and fortunate enough to be part of the healthcare system, where blood stem cell transplants are still desperately needed and stem cell donors are categorised as key workers. Although we have seen a small reduction in the number of blood stem cell transplants during the pandemic (due to treatment deferral or delays, and which has had some impact on our finances, along with a small reduction in our fundraising income), the majority have continued, albeit in difficult circumstances. We have continued to work with our stem cell donors so that they can continue to donate safely and we have managed to keep transporting stem cells around world, despite the extreme challenges presented by international transport and logistical systems.

Like many organisations working in the pandemic, we have reviewed our working practices to ensure we are as efficient as we can be, but we are also fortunate that the nature of our work means we have not had to furlough staff. The pandemic has also forced us to think more innovatively about how we recruit and register our blood stem cell donors, resulting in a much more digital approach, which in turn has led to a decision to merge our Donor Recruitment Department with our Marketing and Communications Department, which we hope will create new synergies, be more efficient and maximise our impact. This has led to a limited reorganisation and restructure of roles within those teams to create a new Communications and Engagement Department.

As of early 2021, we maintain a limited number of staff in the office (working under a detailed health and safety assessment and the application of stringent safety policies and procedures), in order to carry out essential functions. The staff group as a whole (with the exception of those classed as extremely clinically vulnerable) share out this work and these duties on a weekly rota system. The situation will be kept under review and, when it is safe to do so, we will begin increasing the numbers of staff who can return to the office. When the lockdowns are lifted, we are

planning to move to a much more flexible working system, with a stronger balance between home and office working. We are currently consulting with staff on the exact details of this system.

The Donor Request Department



The Donor Request Management Department is responsible for liaising with, and providing support to, our blood stem cell donors who have been identified as a potential match for a blood cancer or blood disorder patient in need of a blood stem cell transplant. They guide and advise the donor at all stages and coordinate the communication between all international and national parties involved in the process.

The department specifically covers the three stages in the process of matching potential stem cell donors with patients. The Confirmatory Typing (CT) stage confirms potential donors' HLA typing (Human Leukocyte Antigen) and confirms donors' medical eligibility to donate and proceed to the Workup stage. The Workup (WU) stage includes the preparation and organisation of a blood stem cell donation and the transport of stem cells to patients both based in the UK and internationally. The final stage, Follow up/Donor Patient Contact (FU/DPC), provides support to donors after their donation and facilitates donor and patient contact, be it via anonymous correspondence or face-to-face meetings. The Donor Request Management Department uses a bespoke database system to manage all three stages of the donor journey and works predominantly by phone, email and post to communicate with donors.

Since 2013 the Donor Request Management team has grown significantly, with a team of 12 staff

now supporting over 250 donors each year. In addition, the team is responsible for the donor enrichment programmes which involve improving the quality of the medical information and data we have on donors that are most likely to be match with a patient, as well as maintaining more regular contact with them. In the future the department will create even more second chances of life by supporting more donors with the aim of delivering up to 500 blood stem cell collections each year by the end of 2023. As part of achieving this ambitious goal, the department is working on developing new partnerships across the NHS and within the private healthcare sector and engaging with healthcare professional in the field of blood cancers and blood disorders..

