



WE DELETE BLOOD CANCER

ZAID,
Sickle cell disease
patient

DONOR HANDBOOK

TOGETHER AGAINST
BLOOD DISORDERS

THERE ARE SURVIVORS BECAUSE THERE ARE LIFESAVERS

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DEAR POTENTIAL DONOR

If you are reading this handbook you have very likely been asked to donate some of your blood stem cells to someone in desperate need. Or maybe you are reading this because you are considering registering as a potential blood stem cell donor and want to find out more.

Whatever stage you are at, this handbook will help you to understand the process of blood stem cell donation and outline the support offered to you by the team at DKMS.

The DKMS organisation started in Germany in 1991 around one family's search for a donor.

This search for potential donors still goes on today for every patient in need of a blood stem cell donation. DKMS has grown to become the largest international organisation to recruit donors.

Today over 10 million potential donors have registered with DKMS and over 91,000 donations have taken place, to give people a second chance at life. New hope opens up for patients worldwide, as our international registry of donors expands both in size and ethnic diversity, meaning that currently 22 people per day get that second chance at life.

Thank you for making the commitment to saving lives. DKMS will support you at every step of your lifesaving journey



ALANA JAMES
COUNTRY EXECUTIVE DIRECTOR, DKMS AFRICA



WHY YOU ARE BEING CONTACTED

When you registered with DKMS, you submitted a cheek swab to determine your tissue type. You have now been identified as a match to a patient in need of a blood stem cell donation. This makes you very special, as you could be someone's only hope of survival.

HOW YOU ARE MATCHED

To be considered a match, the donor and patient must share similar tissue characteristics. With more than 17,000 known characteristics that can occur in millions of combinations, finding a match is challenging and requires the availability of a large number of donors.

As a potential stem cell donor, your tissue type is matched using Human Leukocyte Antigen (HLA) typing. HLA are proteins or markers found on all cells in your body.

These proteins are used by your immune system to recognise which cells belong to your body and which cells do not. If these proteins do not match, the patient's body would reject the stem cells given by the donor. A close match means that the

patient's immune system would recognise the donor's blood system as its own.

The patient's doctor will look for a matching donor within the patient's family first. However, about 70% of patients who need a transplant do not find a suitable donor within their family. In these cases, the patient's doctor will search for an unrelated adult donor.



Analysing tissue characteristics (HLA) in our labs

CONFIRMING YOU ARE A MATCH

1. GET INFORMED

We will call you to explain the process and answer any questions you may have. Donating is a serious commitment so we recommend that you discuss it with your family and friends to help you make your decision.

2. SUBMIT THE HEALTH HISTORY QUESTIONNAIRE AND CONSENT FORM

The health history questionnaire provides us with information regarding any medical conditions that may prevent you from donating. Your consent enables us to move forward with a blood test. You can submit these forms by scanning and sending them by email to ct@dkms-africa.org

Your health and safety is our top priority. Any medical condition will be reviewed by our medical team and if donating poses any additional risk to you, you will not be asked to proceed. Depending on your health status, it is possible that you may be temporarily unavailable to donate, or need to be permanently removed from the registry.

3. PROVIDE A BLOOD SAMPLE

A blood sample will be taken to compare

your tissue type with that of the patient, and to screened for infectious disease markers. This process is called Confirmatory Typing.

- We will schedule an appointment for you at your nearest pathology laboratory to take your blood sample.
- We will inform you of any unexpected results and you can request all test results from us.
- All test results are strictly confidential.

The patient's doctor will inform us if you are a confirmed match for the patient. A DKMS coordinator will then inform you of this and answer any questions you may have.

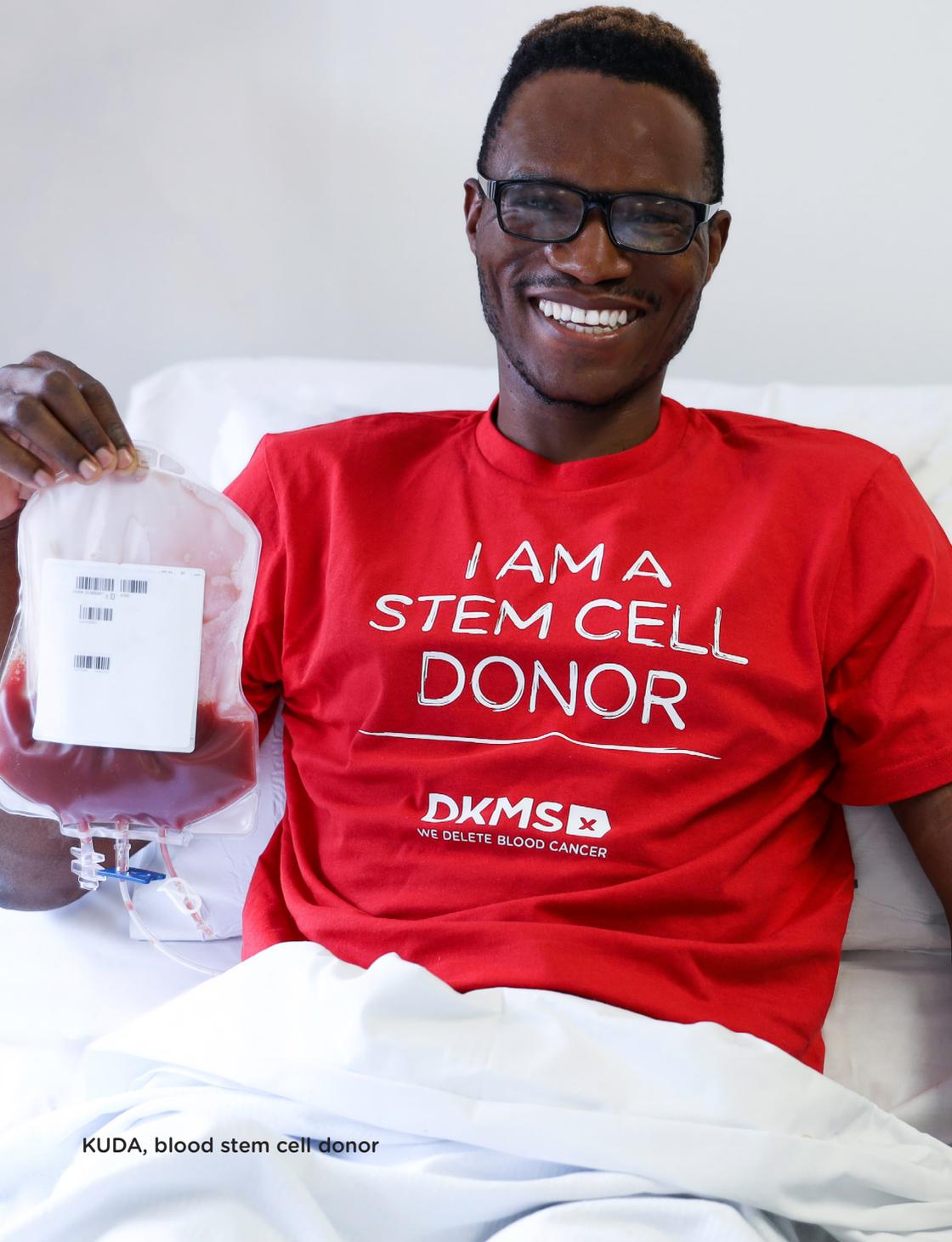
4. KEEP US UPDATED AND BE READY

Once you have completed your blood tests, you become an essential part of the patient's treatment. It can take up to three months to schedule the final phases of your donation. But don't worry, we will keep you informed as soon as we hear anything.

“

I would do it again! Without any hesitation - it's important to help save a life.”

KUDA, blood stem cell donor



I AM A
STEM CELL
DONOR

DKMS
WE DELETE BLOOD CANCER

KUDA, blood stem cell donor

THE CONFIRMATORY TYPING PROCESS AT A GLANCE



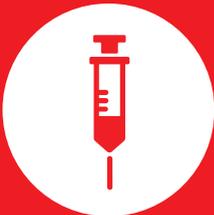
1. FIRST CONTACT

We will contact you to confirm your availability and willingness to proceed, discuss what it means to be a shortlisted match and ensure you are of good medical health.



2. PAPERWORK

We will ask you to complete and return a comprehensive health history questionnaire and consent form.



3. BLOOD TEST

We will arrange for the closest pathology laboratory to take a blood sample.



4. BLOOD ANALYSIS

Your blood sample will be confirmed as an HLA match and screened for infectious disease markers.



5. WAITING

It can take up to 12 weeks before we hear from the patient's transplant team as to how they would like to proceed.



6. THUMBS UP!

An official request for donation is received. You are on your way to being a lifesaver!

YOU HAVE BEEN SELECTED TO DONATE

1. DONATION METHOD

Once it is determined that you are a match for a patient, a DKMS coordinator will contact you to schedule the next steps. You are allowed to bring your companion with you at every step. Please note: this might not always be possible due to covid restrictions.

2. MEDICAL ASSESSMENT

This will take place at the hospital that will carry out your donation and will take one or more days, including travel time. Its purpose is to assess your suitability as a donor and includes:

- Medical history
- Thorough physical examination
- Blood tests including virological and bacteriological testing
- Ultrasound of the abdomen ECG;
- Chest X-ray
- Consultation and information regarding the donation of blood stem cells via apheresis
- Your consent as a donor

The physician will review the donation procedure and the consent forms with you prior to obtaining your consent to donate. If you have any concerns or doubts about proceeding, you should advise the physician or DKMS of this and not sign the consent form.

It is essential that you assure yourself that you definitely do wish to proceed with the donation before the patient begins his or her pre-transplant conditioning treatment. The patient is dependent on the infusion of

donor blood stem cells to engraft and start producing the necessary blood cells to carry oxygen and fight infection. Without this source of new cells, the patient may not get a second chance at life.

Your peripheral veins (ie in the arms and hands) will also be assessed to see if they are suitable for peripheral blood stem cell collection. If not, a central line catheter (a thin plastic tube placed into a large vein) may be discussed as a final option.

If you are a female of childbearing age you will be asked to take a pregnancy test before receiving G-CSF, and you must use reliable contraception until the G-CSF course is finished and for at least one month after. It is not known whether G-CSF would harm an unborn baby as insufficient studies have been undertaken to date, so this is a safety precaution.

After the medical assessment, your results will be reviewed. If you are medically cleared to donate and you still wish to proceed, the patient will be prepared to receive your stem cells.

If you have any concerns please speak to your DKMS coordinator as soon as possible as the patient is at serious risk if you decide not to continue once they have been medically prepared.

THE DONATION PROCESS

This section will help you to understand the donation process. You can learn about the steps involved before, during and after the collection and how we will support you along the way.

Method:

Peripheral Blood Stem Cells (PBSC) collection

AT A GLANCE



PERIPHERAL BLOOD STEM CELL COLLECTION

1

Preliminary medical assessment of the donor in collection centre
duration: 1 day including travelling

2

WAITING PERIOD

After the preliminary assessment,
duration: generally 14-21 days

3

PREPARATION

Stimulation of the stem cells with the naturally occurring growth factor G-CSF
duration: 4 days

POSSIBLE SIDE EFFECTS:

Headaches, Bone or muscle pain, Nausea , Fatigue, Skin rash

COLLECTION

Further single injection of G-CSF in the morning. Peripheral stem cell collection, procedure not ambulant - donor in a bed procedure in collection centre
duration: 1-2 days

POSSIBLE SIDE EFFECTS:

Slight bruising at the needle site, numbness or tingling, chills, a temporary decrease in blood platelet count, light-headedness, nausea

4

RISKS

- Infections of the puncture sites
- At the current state of research there are no long-term side effects documented

RETURNING TO WORK:

Usually within two days



PERIPHERAL BLOOD STEM CELL COLLECTION (PBSC)

PBSC is an apheresis procedure, meaning your blood is removed with a needle from your arm and passed through a machine that separates your blood stem cells. Your remaining blood is returned to you through the other arm. In some cases you will be called back for a second day, if enough blood stem cells are not collected on the first day.

BEFORE THE COLLECTION

In order to ensure that you are able to donate enough blood stem cells for the transplant, you will receive/administer daily G-CSF (granulocyte-colony stimulating factor) injections for four consecutive days before your donation. Your injections are administered in either the arm, stomach or thigh.

G-CSF is a naturally occurring growth factor that encourages your stem cells to move from your bone marrow, which is where they usually live, to your blood. G-CSF also stimulates the overall production of stem cells in the bone marrow of the donor.

DURING THE COLLECTION

Blood is removed from a vein in your arm which passes through a machine that collects your blood stem cells. The remaining blood components are returned to you through a vein in your other arm (apheresis).

A donation takes about four hours, a second consecutive donation day could be necessary depending on the mobilisation of your blood stem cells. A stay over in a hotel would then be arranged by DKMS if required.

AFTER THE COLLECTION

You will be monitored by a healthcare professional until you are physically stable and ready to go home.

PBSC

- Will be scheduled on a weekday (usually Monday - Thursday).
- It is carried out at the hospital where you had your medical assessment.
- You can go home the afternoon of the donation if it is a one-day procedure.
- We will follow up with you regularly to check on your recovery after donating.

POSSIBLE SIDE EFFECTS OF PBSC

PBSC is a very safe procedure. However, there are possible side effects which can vary from person-to-person. The donor will be able to contact the CC physician in case of emergency.

DURING YOUR RECOVERY

The possible side effects of G-CSF are comparable with flu-like symptoms. They usually disappear within 48 hours of donation. To ease any discomfort you can take painkillers such as Paracetamol or Ibuprofen (please do not use aspirin as it may have an effect on the G-CSF). Most donors are able to return to usual activities within two days of donating. If your usual activities involve physical exertion, more recovery time may be necessary – possibly up to one week.

POSSIBLE SIDE EFFECTS OF G-CSF

- Headache
- Bone or muscle pain
- Fatigue
- In rare cases nausea and skin rashes have been reported

POSSIBLE SIDE EFFECTS OF APHERESIS

- Bruising at the needle site
- Numbness or tingling
- Chills
- Temporary decrease in blood platelet count
- Light-headedness
- In rare cases nausea has been reported



FREQUENTLY ASKED QUESTIONS

Here you will find all the questions we regularly get asked by potential donors. If you can't find the answer in this booklet, please feel free to call our donor support team on 0800 12 10 82.

1. WHERE WILL MY STEM CELLS BE COLLECTED?

Your blood stem cell collection will be scheduled at a stem cell collection centre in South Africa

2. WHO COVERS THE EXPENSES?

There will be no cost to you. When a donor is a confirmed match with a patient, DKMS will cover the costs (including any travel, meals, or accommodation expenses that may be necessary). While it is rare to require follow up care, if it is ever needed, the donor's costs will also be covered by DKMS. Other than that we are not legally allowed to make any payments for the provision of donations including blood stem cells for transplantation.

3. WILL I PERMANENTLY LOSE MY BLOOD STEM CELLS?

No. The amount of blood stem cells collected is only a fraction of the body's total amount. Your immune system is not weakened and your stem cells naturally replenish themselves within four weeks.

4. WHEN WILL MY DONATION TAKE PLACE?

In most cases you would be asked to donate one to three months after the confirmatory blood test. We will usually try to give you four to six weeks' advance notice. If there are any important dates when you cannot donate, we will always try to accommodate your schedule.

5. WILL I BE ASKED TO DONATE AGAIN?

Sometimes the patient requires a second donation, e.g. because the immune system does not accept the new donor cells. If this happens we might contact you again to consider a second donation, or a donor lymphocyte collection, which for the donor is similar to the peripheral blood stem cell procedure, but without the stem cell stimulation injections.

KUDA'S STORY

When I received a letter from the doctors that I was going to be a stem cell donor, I was excited because the process was going to help save my father's life.

I really was deeply glad to help. As I'd watched this disease take its toll on him. I'd wished I could do more for this man I love so much. Now, I could.

I didn't know anything about the whole process and I was curious but excited. The process started with blood tests to check for mostly infectious and other diseases. This was then followed by self-injections for 4 days after which I then went to hospital for the donation.

My initial thoughts were that the process was going to be complicated, I was going to be taken to theatre and undergo some kind of operation and that there would be side effects in the future.

However, the process wasn't painful or scary at all, just a little longer than I expected. The whole medical team, led by Erna was very supportive and available for anything that I may needed. The process was over in no time.

I would do it again! Without any hesitation - it's important to help save a life.

I definitely would recommend anyone to donate, it's not a difficult process and as long as it saves a life - it is a deed worth doing. You never know, you might possibly need similar help in future.

DKMS Africa plays a very pivotal role in society, the registry that they keeps helps to identify donors in the quickest possible time and as such the transplant will be done timeously.

I believe every patient should have an equal opportunity to find a match, regardless of their ethnicity.

This is something I am so proud to say I have done. Looking back, I would do it again in a heartbeat.

KUDA, blood stem cell donor



CAN I CONTACT THE PATIENT?

We often get asked by donors if they can meet the person they have donated to. Find out how you can stay informed about the patient's progress and if you will be able to contact them.



“

I can finally see a future for myself, a future not confined to a hospital bed, now I can finally live!”

ZYAAN, Thalassemia Survivor

UPDATES ABOUT THE PATIENT

The patient's doctor can provide up to three updates within the first year after the donation. We will contact you once an update is available. It is important to note, because of confidentiality requirements codependant on the country, some transplant centres cannot provide patient updates. You should be prepared for the possibility that you may not receive any updates on the patient's recovery. Your DKMS coordinator can provide further information on the policies of the country where the patient you are supporting is being treated.

COMMUNICATING WITH THE PATIENT: THE FIRST TWO YEARS

Communication with the patient is managed by DKMS. Before the patient receives your blood stem cell donation, details of both parties will remain anonymous. After the patient has received your stem cell donation you are able to request some of the patient's details, e.g. age group, gender

and country the patient received their treatment in. During the first two years after your donation, some transplant centres may allow you to send anonymous letters to the patient. This communication should not include any self-identifying information such as your name, address, city, or any other contact information. We can also supply you with social media guidelines on how to talk about your donation online.

COMMUNICATING WITH THE PATIENT: LONGER-TERM

Three years after the donation, some countries may allow direct contact with the patient. Contact may only occur if both you and the patient agree to communicate. Some countries do not allow any communication, so you should be prepared for the possibility that you might not learn the patient's identity or have any contact with them. Your DKMS coordinator can provide further information on the policies of the country where the patient is being treated.

19 YEAR OLD MEETS HER LIFESAVER FOR THE FIRST TIME

Zyaan Makda, a South African patient who in 2007 was diagnosed with Thalassaemia meets her Polish donor.

When Zyaan was told that she would need a blood stem cell donation in order to survive, her whole life stood still: "I couldn't see the end of the road, I had given up. When I got the news that a match was found for in the worldwide search, I got renewed hope and I started fighting again. I knew that this was

my only chance to survive and that's why I went forward even though I was terrified".

Following a worldwide search for a matching donor, Zyaan received a lifesaving blood stem cell donation from a Polish donor, 2018. When she and her family met her donor, virtually, they battled to hold back their motions and tearfully expressed themselves by reading out letters they had each written.

Sitting alongside her mother, younger sister and father, Zyaan, now 19 years old and back in school, told 29-year-old Marta that since her new lease on life, she was able to do more things, including resuming her studies and playing with her sisters – something she could have only dreamt of doing before.

Nearly four years after her blood stem cell transplant, Zyaan and her family got to meet her donor via a virtual online meeting.

Zyaan's mother summarised her heartfelt feelings to the donor:

"I have thought about you for many years, what I would say to you, how I would thank you and words don't seem adequate enough. We had given up hope but we decided to try one late time and there you were, your selfless act saved my daughter's life'

"You are part of our family now," continued Zyaan's mom.

Marta, Zyaan's donor signed up in 2015 and three years after registering, she received the call to donate "when I was called to donate, it was a very special day, I have never won a competition in my life," she said, "and when I got the call to meet you, I was overwhelmed – who would not want to meet their genetic twin!"

Marta's husband, who was her fiancé at the time of donating continued. "the start of Zyaan's journey for a second chance at life was the start of our journey together as well. Marta has a huge heart and I'm so happy she can share that with you."

About meeting her lifesaver, Zyaan said: "When that day came, the day I got the call that a match was found, it was the beginning

of my journey. Thank you for choosing to become a donor, thank you for your selfless act and above all, thank you for saving my life."

"No words can describe to you how grateful I am to you. I can finally see a future for myself, a future not confined to a hospital bed, now I can finally live!"

DKMS aims to educate and raise awareness about the need for stem cell donors, as well as the importance of recruiting to build and maintain a registry of committed donors to help as many patients like Zyaan.



WHY PATIENTS NEED BLOOD STEM CELL DONATIONS

Learn about the different types of blood disorders and what happens when someone's blood cells become dysfunctional, why blood cancer patients need donations of blood stem cells and how some of yours could save their life.

“

A blood stem cell transplantation is still the only real hope for many patients.”

Dr David Brittian. Consultant haematologist and medical advisor to DKMS

Patients in need of a blood stem cell donation are fighting life-threatening diagnoses such as:

- leukaemia
- lymphoma
- myeloma
- bone marrow failure
- sickle cell anaemia
- immune deficiencies

The patient's disease affects the formation and functioning of their blood cells. Blood cells are categorised into red blood cells, white blood cells and platelets. Patients with leukaemia, lymphoma or other blood disorders have a high number of immature or dysfunctional blood cells. In most cases it is their white blood cells that disrupt the normal production of cells.

A blood stem cell donation by an unrelated donor (allogeneic stem cell transplantation) can be a potentially lifesaving treatment

option for patients who don't respond fully to conventional treatments such as radiotherapy or chemotherapy or who relapse after prior treatment. Before the patient can receive the donated stem cells, they will receive high dosages of chemotherapy and possibly radiation therapy in order to completely remove all the diseased cells in their blood system.

This high dose of treatment removes their blood-forming cells in the bone marrow, to make room for the new stem cells and also weakens the patient's immune system so it cannot attack the donated stem cells.

The donated stem cells move through the bloodstream to where they belong in the bone marrow and replace the patient's unhealthy blood stem cells. The donated stem cells settle into the bone marrow, where they begin to grow and produce red blood cells, white blood cells and platelets (engraftment).

Because the immune system and the blood system are closely linked and can't be separated from each other, allogeneic transplantation means that not only the donor's blood system but also their immune system is transferred. As a result there could potentially be some adverse effects for the recipient, such as immune rejection of the donated stem cells by the patient or immune reaction by the donor cells against the patient's tissues (graft-versus-host-disease).

The individual survival rate after a transplant depends on the age and health of the patient, the illness and the occurrence of complications. Between 40 to 80 percent of the transplants are successful.



GOING FORWARD

Never be a stranger:

We want to ensure your donation is a positive experience. After all, you have given someone a second chance at life. A member of our team will get in touch afterwards to see how you're doing. We welcome your feedback. Our team will stay in touch for ten years after you've donated. As well as complying with international regulations, it's a way of showing you our appreciation.

Sharing your story

We rely on publicity to gain support for our cause. We'll never pass on your contact details, but if the media get in touch and you'd like to speak to them, please call a member of our team and they'll guide you as we have to be careful about anonymity and accuracy. As a potential lifesaver, you'll become very popular!

Staying on our registry:

We will reserve your name on our registry after you've donated. You'll be reserved for subsequent donations that your recipient might need, but you don't have to donate again.

There are two reasons we might ask you to donate again.

- The first donation fails or the patient needs more stem cells.
- The recipient needs white blood cells (lymphocytes).

Now it's your turn...

Thank you for taking the time to read our guide. We hope that you feel well informed about what happens before, during and after donation. The next part is up to you. If you have any questions, please call your coordinator whose details are on the accompanying letter or email. At this stage, every second counts for the patient. So whatever you decide, please get in touch

SOCIAL MEDIA GUIDELINES FOR DONORS

Aim of policy

DKMS encourages donors to share the facts about donation by sharing a photo or update from donation on social media, or by speaking to their local media. This can be a powerful way of raising awareness and encouraging new donors to sign up to the register and potentially save a life.

Donors should not include any personal information (E.g. Location, age, gender) about their recipient. For donors and recipients in direct contact then they may share this information, providing permission has been given by both the donor and recipient to do this. Our anonymity policy protects both the donor and recipient in accordance with South African regulations.

2. DONORS CAN:

Share the time and date of their donation (and can therefore potentially live Tweet)

Mention @dkms_africa in your twitter posts so that we can follow your story

Post a photo and your reason for joining the registry to our Facebook page and let us know if you're happy for us to share it.

3. DONORS SHOULD NOT SHARE UNDER ANY CIRCUMSTANCES:

- Their patient's location, age or gender
- Any other details about their patient which may have been given to them by their collection centre
- Photos of their stem cell bag (as it contains patient information)
- Anonymous correspondence with their patient.

4. EXAMPLES:

4.1 Donor who has donated stems cells:

I donated stem cells to a stranger, potentially saving their life! Sign up today through @dkms_africa #. [pic of donation]

Didn't think it would be this easy to donate stem cells and potentially save a life. Thanks @dkms_africa [pic of donating]

4.2 Donor who is a match:

"I've come up as a possible match on the @dkms_africa registry. So excited to be a potential lifesaver #giveblood

GET IN TOUCH WITH US

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