Donor Handbook

Together against blood cancer

Your guide to becoming a stem cell donor
Thank you for being an important part of our key mission, working towards providing all blood cancer patients with a potential donor. We believe that no blood cancer patient should die because of lack of a match.
At your side on your lifesaving journey

Dear Potential Donor,

If you are reading this handbook you are very likely to have received the great news that a request has been made on behalf of a patient who needs some of your stem cells. Or maybe you are reading this because you are considering registering with us and want to find out more. Wherever you are at in your own decision making about stem cell donation, this handbook will help you to understand the processes and support offered to you by our team at Delete Blood Cancer UK.

We are part of the DKMS family of organisations that started in Germany in 1991 around one family’s search for a donor. This search for potential donors still goes on today worldwide for every single individual patient in need of stem cells/ bone marrow, and DKMS has grown to become the largest international organisation to recruit donors.

Today over 3.72 million potential donors have registered and over 36,000 donations have taken place, to give people a second chance at life. As we work in new countries, new hope opens up for all patients worldwide, as the international registry of donors expands both in numbers and across different ethnicities, meaning that currently 15 people per day get that second chance at life - because of people like you!

Your commitment to potentially save someone’s life is really important and we thank you for making this. Our commitment is to support you at every step of the way on your lifesaving journey.

Together we really can delete blood cancer.

Best wishes,

Deirdra Taylor
Head of Donor Recruitment and Communications, Delete Blood Cancer UK
There are only survivors because there are lifesavers.
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Why patients need stem cell donations

Learn about why blood cancer patients need donations of stem cells and how some of yours could save their life. This section describes the types blood cancer and what happens when someone’s blood cells become dysfunctional and their immune system stops working as a result. Their only cure at this point is a stem cell donation.

“It is wonderful to work so closely with donors who are saving lives of patients every day. They are the lifesavers!”

Prof. Gerhard Ehninger
Chairman of the Medical Board at Delete Blood Cancer, DKMS
Woher ist das vorgegebene Bild?
Patients in need of a bone marrow or stem cell donation are fighting life-threatening diagnoses such as:

- leukaemia
- lymphoma (e.g. hodgkin's lymphoma)
- myeloma
- other blood disorders

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 or bone marrow donation by an unrelated donor (allogeneic stem cell transplantation) can be a potentially lifesaving treatment option for patients who are at high risk of relapse, don't respond fully to conventional treatment such as radiotherapy or chemotherapy, or relapse after prior successful 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 destroy all the diseased cells in their body.

This high dose of treatment destroys their blood-forming cells in the bone marrow, to make room for the new stem cells and also destroys 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 body and replace patient's unhealthy blood stem cells. The donated stem cells settle into the bone marrow, where they engraft (begin to grow and produce red blood cells, white blood cells and platelets).

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, which affect the recipient, such as immune rejection of the donated stem cells by the patient (host-versus-graft-effect) 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 at the time of the transplant, the type of underlying illness and the occurrence of possible complications. In accordance with the range of these variables, for 40 to 80 percent of the transplant patients the treatment is successful.
Why am I being contacted

You’ve been identified as a match because you have the same tissue type as a person desperately in need of a stem cell donation to continue their life. This section of the booklet explains the rarity of finding a person with the same tissue type as the patient, how we confirm you are a match, and how we will support you throughout your lifesaving journey.

“It was amazing to finally meet the person that saved my life! I was very scared when I had blood cancer. I didn’t know what was going to happen and whether I’d find a matching donor to donate some of their stem cells”

Chloe, aged 13, blood cancer survivor
Chloe, aged 13, blood cancer survivor

Chloe meets her donor Ronnie for the first time
We have been notified that a patient with a blood cancer is in desperate need of a stem cell donation to save their life. When you registered with Delete Blood Cancer UK, you submitted a cheek swab sample that was tested to determine your tissue type. Your tissue type has now been found to be a close match for this patient.

→ For every donor there is a only a 3% chance that they will match a patient within the next ten years, so it is like winning the lottery. You are part of this rare figure because your tissue type is very closely matched to a specific patient.

We’ll be in touch regarding making an appointment with your GP to go and give a blood sample, which will be sent to the patient’s doctor to verify if you are actually a suitable match for the patient. This process is called Confirmatory Typing (CT). We will also test your blood to rule out any infectious diseases, such as hepatitis. We will explain the blood test and the next steps of the process, and thereafter any test results can be sent to you upon request. The decision as to whether you are a perfect match can be made at short notice by the patient’s doctor. You may be asked to donate within a few weeks of that decision, depending on the patient’s condition.

→ If the results of this test indicate that you are a suitable match you will be asked to consider donating stem cells in one of two ways. Donation is entirely voluntary and the final decision on the method of how you donate will be made by you. Having made it you can still withdraw your consent at any time, up until the patient is medically prepared to receive your stem cells.

**Donor care: we’ll be at your side**

Giving you the right information from now on is most important to us, to ensure you get the best care possible. The first step will be a detailed information session with the co-ordinator of our team to start the Confirmatory Typing process, see Chapter “Confirming you are a match”. After that we will have to wait a few weeks to hear back from the patient’s doctor regarding whether you are the best match. Before you go to the hospital to actually donate your blood stem cells you will do a medical assessment at the same hospital where the donation will later take place. This will either be arranged by a Delete Blood Cancer UK co-ordinator or by a staff member of Anthony Nolan, who runs the 'UK Aligned Registry'. This registry lists our donors in an anonymous format and Anthony Nolan co-ordinate some donations on our behalf, as they also do for registered stem cell donors of the British Bone Marrow Registry. The medical assessment usually takes two hours, plus travelling time and is important since it will also ensure that the actual stem cell collection will not involve any risk for you. If you are eligible as a donor and consent to proceed, the patient will be prepared to receive your stem cells. For more information please see chapter 3.
Why am I being contacted

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 in your body and which cells do not. If these proteins do not match, the patient’s body would reject the given stem cells of the donor. A close match means that the patient’s immune system would recognise your blood system as its own. With more than 8,500 known characteristics that can occur in millions of combinations, finding a match is extremely rare.

The patient’s doctor will look for a matching donor within the patient’s family first. However, approximately 70% of patients who need a transplant do not have a suitable donor and rely on the register to find an unrelated donor. In these cases, the patient’s doctor will search for an unrelated adult donor, or alternatively for a cord blood donation. To be considered a match, the patient and donor must have at least 8 out of 10 tissue characteristics in common, but ideally should have 10.

How am I matched?

Confirming you are a match

Confirming you are a match

Donating is a serious commitment to the patient who is in desperate need of the stem cells that will potentially save their life. This decision is a personal one and it is up to you. One important thing you need to know is that once you have re-consented at the medical assessment, the patient is then prepared medically to receive their stem cell donation from you. Withdrawing at that time would pose a serious risk to that person’s life.
01. Get informed
Why not call us today so we can explain the process, answer your questions and help you with the next steps? You can also review this guide to understand more about the two ways to donate: peripheral blood stem cell (PBSC) donation and bone marrow donation.

→ Talk to your family and friends, as they can help you think it through. If you would like to talk to somebody who has already donated some stem cells, we can put you in touch with someone, so you can hear about their experience.

02. 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 your additional blood tests.
- You can submit these forms via fax or you can scan and send them by email.

Your health and safety is our top priority and we want you to be informed at every step of your journey as a stem cell donor. Any medical condition will be thoroughly reviewed by our medical team and if donating poses any additional risk to you, you will not be asked to proceed as a donor. 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.

03. Provide a blood sample
Your blood sample will be sent to the patient’s hospital and to our labs for further testing to double check that you are able to donate. This is called Confirmatory Typing (CT).
- We will be in touch regarding scheduling an appointment with your GP.
- The blood samples will compare your tissue type with that of the patient, and test for infectious diseases.
- We will inform you of any unexpected results and you can request all test results from us.
- All test results are strictly confidential.

DID YOU KNOW?
There are currently around 1,600 people in the UK waiting for a stem cell donation and 37,000 worldwide. Please support us to find a donor for every patient who is in need.
The patient’s doctor will inform us if you are a confirmed match for the patient and we will then inform you of this special news. The Delete Blood Cancer UK co-ordinator will always be on hand to discuss both methods of stem cell collection and to answer any questions.

**04. Keep us updated and be ready**
Once you have completed your blood tests, you will have already become an essential part of the patient’s search for a donor and may well represent their only opportunity for a second chance at life. It can take anywhere from one week to three months to schedule the final phases of your donation.

The following section of the handbook will discuss what happens if you are confirmed as a match.

**I’ve been selected!**

**Preparation for your donation**

**01. You are the match**
Once it is determined that you are the best match, a Delete Blood Cancer UK co-ordinator will contact you to prepare a time schedule, explain the next steps and may refer you to a co-ordinator at Anthony Nolan.
- You will find out whether you will be requested to donate bone marrow or peripheral blood stem cells (PBSC). The patient’s doctor will suggest one method according to best treatment and the patient’s care. The final decision on the procedure to be used will be made by you and we will consult with you on this.
- You will receive information to understand the details specific to both donation methods.
- Once you have agreed, we will begin scheduling your stem cell collection.

**02. Medical assessment**
The medical assessment will take place at the hospital that will carry out the collection of stem cells. The purpose of the medical is to assess your suitability as a donor and includes:
- counselling on donation methods (including information on the risks of both methods)
- donor consent
- physical examination including health history check
- an electrocardiogram (ECG) to check your heart
- a chest x-ray
- lab work (urinalysis, blood tests, pregnancy test for female donors)
→ **PBSC Donors:** You will also have a vein assessment to see if your veins will be a suitable vehicle for the peripheral blood stem cell method of collection. If not, a femoral line may be discussed as an alternative method for collecting your stem cells.

After the medical, your results will be reviewed and you will of course be notified of any unexpected results. If any findings show a risk to you or to the patient, you will not be asked to donate. If everything proves suitable and you still wish to proceed the patient will be prepared to receive your life saving stem cells. If you have any concerns please let us know as soon as possible as the patient is at serious risk if you decide not to continue once they have been medically prepared.

**DID YOU KNOW?**

Today over 3.72 million potential donors have registered across all the countries in which DKMS operates and over 36,000 donations have taken place, to give people a second chance of life.
Two ways to donate your stem cells

This section will help you to understand the donation process. It’s important to read about the two methods used to collect stem cells as you will be asked to donate in one of these two ways. Learn about the steps involved before, during and after each method of collection and how we will support you along the way.

Method one → peripheral blood stem cells (PBSC) collection
Method two → bone marrow collection
At a glance

### Bone marrow collection
- Preliminary medical assessment of the donor in collection centre
duration: 1 day including travelling
- Waiting period
  After the preliminary assessment,
duration: 14-21 days
- Preparation
  Stimulation of the stem cells with the naturally occurring growth factor G-CSF (injected daily by a professional nurse)
duration: 3 days
- Collection
  Bone marrow collection in collection centre
duration: 1-2 days
  Possible side effects of anaesthesia:
  - Sore throat (caused by breathing tube)
  - Mild nausea and vomiting
  - A decrease in blood pressure
  - Headache
  Possible side effects of marrow collection:
  - Lower back pain
  - Fatigue
  - Stiffness when walking
  - Slight bleeding at the site of incision
- Risks:
  - General anaesthesia
  - Infections of the puncture sites
- Returning to work:
  Usually within one week
- Collection
  Further single injection of G-CSF
  Peripheral stem cell collection, ambulant 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
- 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
- Preliminary medical assessment of the donor in collection centre
duration: 1 day including travelling
- Waiting period
  After the preliminary assessment,
duration: 14-21 days
- Preparation
  Stimulation of the stem cells with the naturally occurring growth factor G-CSF (injected daily by a professional nurse)
duration: 3 days
- Collection
  Bone marrow collection
- Possible side effects of anaesthesia:
  - Sore throat (caused by breathing tube)
  - Mild nausea and vomiting
  - A decrease in blood pressure
  - Headache
- Possible side effects of marrow collection:
  - Lower back pain
  - Fatigue
  - Stiffness when walking
  - Slight bleeding at the site of incision
- 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
“It feels good to be a lifesaver. Donating some of my stem cells was so easy. It was a bit like giving blood”.

Friederike, stem cell donor
Peripheral blood stem cell (PBSC) collection

**General information**
Peripheral blood stem cell collection is a four to six hour apheresis procedure where your blood is removed with a sterile needle from one arm and passed through a machine that separates out the blood stem cells. Your remaining blood is returned to you through the other arm.

**Peripheral blood stem cell collection**
- It is scheduled on a weekday (generally Monday - Thursday).
- It is collected at the hospital where you had your medical.
- Donors go home the evening of their donation if it is a one-day apheresis.
- We will follow up with you regularly to check on your recovery after donating.

**Before, during and after PBSC collection**

**Before the collection**
In order to ensure that you are able to donate enough blood-forming cells for the transplant, you will receive daily G-CSF injections for four consecutive days before your donation. On the first three days, your injection will be given to you by a nurse at your home or work. The fourth injection will be given to you at the hospital prior to donation. GCS-F (granulocyte-colony stimulating factor) is a naturally occurring growth hormone that stimulates the production of stem cells in the blood of the donor before collection.

**During the collection**
- Donations are scheduled to take place during one day or sometimes two consecutive days.
- A one-day donation takes approximately four hours, depending on how your stem cells have mobilised, a second 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 us.
- During the collection, a sterile needle will be placed into a vein in each of your arms.
- Blood is removed from a vein in one arm, passed through an apheresis machine, then returned to you through a vein in your other arm.
- The machine collects blood-forming cells, platelets and some white blood cells.
After the collection
You will be monitored by a medical professional until you are physically stable and ready to go home.

Common side effects of G-CSF
• Headache
• Bone or muscle pain
• Nausea
• Fatigue
• Skin rash

Common side effects of PBSC donation
• Bruising at the needle site
• Numbness or tingling
• Chills
• Decrease in blood platelet count (temporary)
• Light-headedness
• Nausea

During your recovery
• Side effects of G-CSF usually disappear within 48 hours of donating.
• Donors can take non-aspirin products (such as Paracetamol, Ibuprofen) for discomfort.
• Most donors are able to return to work, college and most other activities within two days of donating.
• If your regular activities involve physical labour, heavy lifting or contact sports, more recovery time may be necessary.

Donor follow-up
We will provide on-going support after the collection process as we care about the details of your recovery. We will contact you on a regular basis after your donation to check the status of your physical condition and it is also important to contact us directly if you have any concerns, or wish to discuss any symptoms you experience.
You should expect a phone call on the day following your donation and then weekly until you report a full recovery. As part of your long-term aftercare, we will be in contact with you on occasion for the next ten years.
“I’d do again if it meant I could save another life.”

Ronnie, bone marrow donor
Two ways to donate your stem cells

**Bone marrow collection**

**General collection**
Bone marrow collection is an inpatient surgical procedure carried out under general anaesthetic. Doctors use a special needle to remove liquid marrow containing blood stem cells from the back of the hip bone (not the spine). This is a 1-2 hour medical procedure. Some donors experience some short-term pain, bruising and stiffness after the procedure. Within a week of donating, most donors are able to return to work or college and resume usual activities.

**Bone marrow collection**
- It is scheduled on a weekday (generally Monday - Thursday).
- It is collected at the hospital where you had your medical. You will arrive in the evening before the day of collection and stay one night after donation in the hospital after the collection.
- We will follow up with you regularly to check on your recovery after donating.

**Before, during and after bone marrow collection**

*Before the collection*
You will have a general anaesthetic and may be under anaesthesia for one to two hours depending on the time needed for the collection of the stem cells.

*During the collection*
The doctor will insert a special needle through two tiny incisions in the skin over the back of the hip bone (not your spine). The incisions are less than one-fourth of an inch long and usually do not usually require stitches. The collection itself takes round about 60 minutes, and you will be positioned lying on your front. Doctors use sterile needles to remove liquid marrow containing blood stem cells, roughly one litre, which is round about 5% of your bone marrow. Two weeks after donation, your bone marrow will have recovered fully, and the hip bone will have properly healed within six weeks.

*Donor follow-up*
We will provide on-going support and advice as we care about the details of your recovery after the collection process. We will contact you on a regular basis after your donation to ask about your physical condition and it is also important to contact us directly if you have any concerns or wish to discuss any symptoms you experience. You should expect a phone call on the day following your donation and then weekly until you report a full recovery.
As part of your long-term aftercare, we will be in contact with you on occasion for the next ten years.

**Side effects and your recovery**

**Common side effects of anaesthesia**
- Sore throat (caused by the breathing tube)
- Mild nausea and vomiting
- A decrease in blood pressure
- Headache

**Common side effects of marrow collection**
- Lower back pain
- Fatigue
- Stiffness when walking
- Slight bleeding at the site of incision

During your recovery
- It is normal to experience some pain, bruising and stiffness during the first two to three weeks after your donation.
- You should avoid heavy lifting, bending and strenuous exercise for about two weeks after donating.
- Most donors are able to return to work, college and any other activities within a week. If your job involves physical labour or heavy lifting, more recovery time may be necessary.

“I registered as potential stem cell donor at a public donor recruitment event in my hometown in Germany in 2005. A colleague told me a young woman had leukaemia and was looking for a stem cell donor. I couldn’t help this particular woman as I wasn’t a match for her tissue type, but in 2008 I was really pleased to receive a letter informing me that I was a match for another patient in need. They did some medical tests and in 2009 I donated some of my stem cells through the bone marrow collection process. It was a lot easier than I expected and I’d do it again if it meant that I could save another life. My stem cells replenished within 2-3 days and I didn’t lose a thing. I’ve only gained the amazing experience of saving a little girl’s life.”

Ronnie, bone marrow donor
Frequently asked questions
Here you will find all the questions we regularly get asked at Delete Blood Cancer UK. If you can’t find the answer to your question here, or elsewhere in this booklet, please feel free to call our donor support team on 020 3176 7660.
01. Can I choose the method of my stem cell collection?
There are two possible ways you may be asked to donate your stem cells. The method of your collection is determined by what the doctors believe will be best for the patient and your individual choice. If you are not willing to donate through either method, you should notify your Delete Blood Cancer UK co-ordinator, so they can let the patient’s doctors know that you are only comfortable proceeding with one method. The final decision on the method of collection will always be made by you, as donation is entirely voluntary.

02. Where will my stem cells be collected?
Your stem cell collection will be scheduled at a hospital in either Sheffield or London, depending on where you live and we will cover all of your travel expenses.

03. Who covers the expenses?
There will be no cost to you. When a donor is matched with a patient, Delete Blood Cancer UK will cover the costs (including any travel, meals, or lodging expenses that may be necessary). Delete Blood Cancer UK will also cover the costs for a companion to travel with you to the hospital. A donor’s insurance will never be used. Whilst it is extremely rare to require follow up care, if it is ever needed, the donor’s costs will also be covered by Delete Blood Cancer UK. Other than that we are not legally allowed to make any payments or rewards for the provision of tissues, including bone marrow or blood stem cells for transplantation.

04. Is the marrow extracted from my spine?
No, the bone marrow is not collected from your spine. It is collected from the back of your hip bone.

05. Will I permanently lose my stem cells?
For either procedure, the amount of stem cells collected is only a fraction of the body’s total bone marrow. The amount donated does not weaken your own immune system. Your stem cells naturally replace themselves within a few weeks.

06. Will my existing medical condition prevent me from donating?
We take the health and safety of our donors very seriously. All donors are required to complete a health history questionnaire before proceeding. Any medical concerns are reviewed by a doctor to fully assess your ability to continue as a donor. Depending on your health status, it is possible that you may be deemed temporarily unavailable to donate, or need to be permanently removed from the registry.
07. Will I be compensated for the time I take off from work?
If you are not covered by your employer, Delete Blood Cancer UK has a financial assistance programme that deals with lost wage compensation. If you are found to be a match and qualify for assistance, your co-ordinator will provide more information on this.

08. Does ethnicity affect finding a match?
Ethnic heritage is a very important factor. Patients are most likely to match a donor of their own ethnicity, because people from the same ethnic group are more likely to have the same tissue traits. With more than 8,500 known characteristics that can occur in millions of combinations, finding a match is already extremely rare. Patients of more diverse ethnic backgrounds also tend to have more diverse HLA types, making it even more difficult to find a match.

09. When will my donation take place?
It is hard to say exactly when your donation will take place because it strongly depends on the patient’s condition. In most cases you would be asked to donate 1-3 months after the confirmatory blood test. We will always give you 3-4 weeks advance notice. If there are any important dates when you cannot donate, we will always try to accommodate your schedule.

10. Will I be asked to donate again?
Sometimes the patient relapses, e.g. because the immune system does not accept the new donor cells. If this happens we might get in contact with you again to consider a second donation, or a donor lymphocyte infusion, which for the donor is similar to the PBSC procedure, but without the stem cell stimulation process.

DID YOU KNOW?
You don’t actually lose your stem cells when you donate them to a blood cancer patient in need - you only donate some of them. Your stem cells are very clever and completely replenish themselves between 2-3 days.
Meeting the patient you have saved

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

Contact has been made possible for so many people worldwide. We continue to facilitate *magical moments* just like the those featured throughout this handbook, between survivor Chloe and her donor Ronnie...
“I am incredibly happy to see Tim enjoying life and playing football”
Saving Tim

“I decided to register as a potential stem cell donor as I saw it as a great opportunity to help to support people who are unwell. When I got the surprising phone call that I could really donate some stem cells, I knew that I had the once in a lifetime chance to save someone’s life. At the same time I felt a little worried because of the process ahead of me, since I was chosen to donate bone marrow. Despite my concerns, the idea of being able to save someone’s life outweighed everything else.

Anyway, my fears were proven unfounded in the end as it was very straightforward, and I am very glad that I donated bone marrow. Shortly after my donation I found out that my stem cells were to help a little boy. During the two years after the donation I kept thinking about this little boy, whether he was doing okay and if he was really going to make it. When I was finally able to meet Tim I did not know what to say. The meeting was really emotional and I experienced an intense feeling of happiness and pride to see a healthy active boy in front of me. Since we do not live that far apart I see him and his family on a regular basis and we have become very good friends.”

Udo, bone marrow donor

Updates about the patient

The patient’s doctor may 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, 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 Delete Blood Cancer UK co-ordinator can provide further information on the policies that are in place at the specific hospital where the patient you are supporting is being treated.

Communicating with the patient: the first year

Communication with the patient is managed by Delete Blood Cancer UK. Before the patient receives your stem cell donation, details of both parties will remain completely anonymous. After the patient has received your stem cell donation you are able to request some of the patient’s details, e.g. the country they live in, their age, and the type of blood cancer they were being treated for. During the first year 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, state or any other contact information.
Communicating with the patient: Longer-term

Two years after the donation, some transplant centres may allow direct contact with the patient. Contact may only occur if both you and the patient consent to communicate. Some centres may not allow any communication, so you should be prepared for the possibility that you might not learn of the patient’s identity or have any contact with them. Your Delete Blood Cancer UK co-ordinator can provide further information on the specific policies that are in place at the hospital where the patient is being treated.

A source of inspiration

Contact between stem cell donors and the patient they have supported has been happening worldwide in recent years. We are sometimes able to facilitate magical moments just like the one featured earlier in this handbook, between survivor Chloe and her bone marrow donor Ronnie. Chloe is a true survivor, a source of inspiration that drives us forward as we continue to register people as potential stem cell donors. We hope that you find their story a truly wonderful source of inspiration too.

Chloe aged 13, blood cancer survivor
On April 26th 2008 Chloe was diagnosed with acute myeloid leukaemia when she was just 9 years old. Chloe was told that she was going to need stem cell treatment (in the form of a bone marrow donation). Chloe said; “I remember just crying non-stop. I thought that my life was over, but it wasn’t. I just sat cuddling my mum and dad, not letting go”.

Imagine having to go through this at just nine years of age. Fortunately for Chloe and her family, they then received the amazing news that a 100% match had been found.

Chloe had her stem cell treatment on the 5th of February 2009. Chloe’s lifesaver was a 46 year-old man called Ronnie from Germany. In February 2013 we facilitated the first meeting of Ronnie and Chloe, who met in London so she could thank her lifesaving donor in person for the very first time. It was what can only be described as a very emotional meeting, as the image on page 10 illustrates.

On Chloe’s 12th birthday her Mum said: “Our wee girlie is now 12. I’m so thankful for this day, as three years ago we never thought this day would come. Chloe has come through so much and thanks to Ronnie our little girl has had a second chance at life. We will be eternally grateful.”
Together we really can save lives!
TELL US ABOUT YOUR JOURNEY
Your journey is just as inspiring as Chloe and Ronnie’s for other potential lifesavers. Please get in touch with us if you would like to share your story at engage@deletebloodcancer.org.uk

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