Donating blood stem cells: What you should know
Swiss Blood Stem Cells (SBSC)

SBSC was founded in 1988 and became part of Swiss Transfusion SRC in 2011. The organization has been helping people suffering from serious illnesses by searching for matching blood stem cell donors worldwide for more than 25 years. SBSC, which is governed by the Swiss Transplantation Act, has a mandate from the Federal Office of Public Health for the following tasks: the management of the registry, the recruitment of new donors, the search for unrelated donors for Swiss or foreign patients and arranging the collection and transportation of the transplant material.

SBSC gets involved when a patient requires a blood stem cell donation and no matching donor can be found in his or her family. In such situations, SBSC launches a worldwide search for an unrelated donor. If the search proves successful, SBSC arranges the collection and transportation of the transplant material.

Blood stem cell donation is based on the following principles: solidarity, voluntary participation, non-remuneration and anonymity.

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Blood stem cells are responsible for the production of red and white blood cells and blood platelets. They are found chiefly in the bone marrow, to a minor extent they are also present in the circulating blood. For people suffering from leukemia or other life-threatening blood disorders, a blood stem cell transplantation often offers the only chance of survival. The transplantation of new blood stem cells can enable the bone marrow to recover its ability to produce blood.

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Bone marrow
Bone marrow constitutes the hematopoietic system (the system which produces blood cells) and is located primarily in the cranium, ribs, bodies of the vertebrae and pelvic bones of the human skeleton. Bone marrow and spinal marrow are not the same thing. Hence, spinal cord injuries can never occur in connection with a bone marrow donation.

‘You can do a good deed and may even save a life!’

Michael Hermann, Neuenegg
(Bone marrow donor, January 2012)
Why is your type in demand?

One essential precondition for the successful transplantation of blood stem cells is compatibility of the donor’s tissue markers (HLA markers) with those of the recipient. Since billions of combinations of HLA markers are possible, finding a matching donor is often very difficult.

The chances of finding a donor within one’s own family (usually a sibling) are between 20 and 30 percent. Patients who do not have a donor in their family, depend on finding a matching unrelated donor. Your type is needed so that we will one day be able to find a suitable donor for every patient. Every one of us has the potential to save a life. The more willing donors there are, the greater the chance of finding a matching donor in time.

Who can become a donor?

As a minimum, the following eight criteria must be met to be eligible for registration as a blood stem cell donor:

1. Age between 18 and 55
2. Very good state of health
3. Body weight of at least 50 kg
4. No hepatitis C
5. No positive test for HIV or syphilis
6. No heart or lung diseases
7. No disorders of the blood and hematopoietic system (coagulation disorder, high thromboembolic risk)
8. No cancer

Tissue markers

Human tissue displays certain antigens, called markers, which are characteristic for each individual, similar to the different blood groups. By means of these markers, known as HLA markers (human leukocyte antigens), the immune system can differentiate between foreign tissue and its own tissue. Therefore, compatibility of the donor’s HLA markers with those of the recipient is crucial for the success of blood stem cell transplantations, as it reduces the risk that the patient’s immune system will reject the donated cells.

1 You can remain on the registry until your 60th birthday.
How can you become a blood stem cell donor?

Are you healthy, between the age of 18 and 55 and well informed about blood stem cell donation? If so, you can register as a blood stem cell donor online at sbsc.ch, and you might soon save someone’s life.

A buccal swab set will be sent to you by post for the required tissue typing. The set includes instructions on how to take your own oral mucosa sample. You can then return the materials to SBSC along with the signed ‘informed consent’ form in the pre-paid reply envelope.

Once the registration process is complete, your donor profile will be encrypted and entered into our database. From then on, you will be available as a potential donor to patients throughout the world. You will receive your own personal donor card confirming your enrolment in the registry.

If you would prefer to contact a regional blood transfusion service in your neighbourhood, the health care professionals there will be pleased to provide you with information about registering.

Data protection
Data protection has top priority at SBSC. All personal data is stored at the responsible donor center. Only data relevant for the donor searches, such as HLA markers, age and sex, is transmitted to the international search registries, where it is identified only by an assigned donor number.

Solidarity
You will be registered as a potential donor for patients worldwide. Registration for a specific recipient is not possible.
What happens if you are selected as a potential donor?

First preliminary examinations
If your tissue markers match those of a patient, you will be contacted to obtain your consent to the donation. At this point, you will be asked to decide whether you wish to serve as a donor. The likelihood that you will be shortlisted as a potential donor depends essentially on your HLA markers.

If none of the exclusion criteria for donation apply, you will be asked to go to the regional blood transfusion service of your choice to have blood drawn for confirmatory HLA typing and to test for certain infectious diseases.

Due to the complexity of the donor selection procedure, it is possible that several months will pass between initial contact and the final selection of a donor.

Before the donation
If you are selected as the best matching donor and have given your oral consent, you will be requested to attend an information session on blood stem cell donation with a specialist in the appropriate collection center (Zurich, Basel, Geneva). This will be followed by a comprehensive health check intended to ensure that the risks associated with the donation are as low as possible for both you and the patient. You will be asked to confirm your consent in writing before the actual donation procedure begins.

From the initial contact to the donation

1. The potential donor is contacted by telephone and asked to come in for a preliminary examination.
2. Blood is drawn at the regional blood transfusion service: the HLA typing is confirmed and the blood is checked for infectious disease markers (e.g. HIV, hepatitis B and C).
3. The donor is contacted and his/her consent to donate and to the type of donation is obtained.
4. The transplanting physician selects the final donor and proposes the desired type of donation (donation of bone marrow or peripheral blood stem cells).
5. Information session on blood stem cell donation.
6. Medical examination of the donor in the collection center (Zurich, Basel or Geneva) to verify his/her suitability.
7. Collection of the blood stem cells.
8. Transportation and transfusion of the collected blood stem cells within 48 to 72 hours.
Confirmatory typing
Once a potential donor is placed on the shortlist for a patient, the donor’s HLA typing is confirmed with more in-depth testing.

Donor withdrawal
Blood stem cell donation is always voluntary. You are entitled to change your mind even after you have confirmed your informed consent. Bear in mind, though, that withdrawing from an agreement to donate shortly before the collection could have serious or even life-threatening consequences for the patient.

‘When I tried to put myself in the patient’s place, the decision became clear: of course I will donate!’

Maico Bentivoglio, Zurich
(Bone marrow donor, September 2011)
I was given a new chance of life!

Just married and over the moon about the future she would share with her husband, life seemed simply perfect for Stephanie Crast. But she then received the shattering diagnosis: leukemia. In an interview with SBSC, Stephanie Crast relates how her life was suddenly turned upside down by the life-threatening disease acute myeloid leukemia (AML). Thanks to an anonymous donor, she was able to get her life back in 2012. Today, she is active in the fight against leukemia together with SBSC. She wants to do her part, to encourage more people to register as donors. After all: we all have the potential to save a life and there are still plenty of leukemia patients who are waiting to get lucky with a ‘genetic twin’.

SBSC: Mrs Crast, how did you learn that you had a serious disease?
Stephanie Crast: I went in for a medical check-up because I was feeling increasingly fatigued and my physical abilities were deteriorating. My blood counts were bad, and at first the doctors suspected an immune disease. After one bone marrow puncture had to be abandoned because the pain was unbearable, I underwent a second puncture under anesthesia. A day later I got a voice message from my doctor, asking me to call back. I knew straight away that it was leukemia, not an immune disease.

‘Because I was suffering from a very rare form of leukemia, it was clear from the beginning that I would need a blood stem cell donation.’

Stephanie Crast, Hagenbuch (recipient of blood stem cells in 2012) with her godchild Valentina
What went through your head at that moment?
I knew very little about leukemia at that point in time. When my doctor confirmed the diagnosis of ‘acute leukemia’, I remembered Andy Hug (a Swiss martial arts champion) who died at the age of 35 within a few weeks of his diagnosis of leukemia. So then I asked her if I was going to die in five weeks as well.

When did it become clear that you would need a blood stem cell donation?
Because I was suffering from a very rare form of leukemia, it was clear from the beginning that I would need a blood stem cell donation. In the whole world, there are only six to nine known cases of Blastic Plasmacytoid Dendritic Cell Neoplasm, a form of acute myeloid leukemia.

How did the people around you react?
My relatives were even less able to cope with the situation than I was. My husband’s whole world fell apart and I had to convince him that everything was going to be all right and that I would win this fight.

Did you ever lose hope of recovering?
No, I never gave up hope! Not even when the doctors told me that my chances of survival were absolutely zero without a matched donor. I was just convinced that a matching blood stem cell donor would be found somewhere in the world. I did not start feeling afraid until just before the transplantation. I put everything at home in order beforehand for that reason – in case something went wrong and I didn’t come home.

The preparation I received was excellent and I was looking forward to the day of the transplantation with great hopes.

Was it a very emotional moment when you heard the news that a donor had been found?
I burst into tears and thanked God. At the same time, though, I was afraid of getting my hopes up too high because I knew that the donor could still withdraw consent at any time. So I tried to suppress my elation.

Were you well prepared for the transplant procedure and what did you feel while it was going on?
The preparation I received was excellent and I was looking forward to the day of the transplantation with great hopes. The moment when the foreign blood stem cells finally started flowing through my body was a very emotional one. Knowing that they were my only chance for a new life, my feelings alternated between joy and fear. But I was panic-stricken too: what if my body rejected the transplanted cells?
Acute myeloid leukemia (AML)
AML is a malignant disease of the hematopoietic system that causes abnormal changes within the hematopoietic precursor cells. There are many different forms of leukemia. For most of them, their origin is not clearly established.

Is there anything you would like to say to potential blood stem cell donors?
It doesn’t take much effort to save a life. Apart from bone marrow collection, it is also possible to collect peripheral blood stem cells. This procedure does not require the donor to stay in hospital for several days. Find out more, because you could be the only hope of survival for a patient.

‘It doesn’t take much effort to save a life.’

Since her recovery, Stephanie Crast has joined SBSC in their fight against leukemia.
How are blood stem cells collected?

Blood stem cells can be collected directly from bone marrow or from blood. In Switzerland, the collection of peripheral blood stem cells (80 percent of all donations) is much more frequent than bone marrow donations. The doctor responsible for the transplantation decides on the type of donation depending on the patient’s diagnosis. The final decision is taken by the physician in agreement with the donor.

Donating peripheral blood stem cells
A few days before the actual donation, the donor is given growth factors (G-CSF) to stimulate the proliferation of blood stem cells in the bone marrow and their release into the blood (known as mobilisation). G-CSF is injected into the subcutaneous fatty tissue (e.g. thigh) during four to five days prior to donation.

The collection of blood stem cells proceeds as follows: peripheral venous access is obtained on both arms, allowing blood to flow from one arm through a medical device called a cell separator and, from there, back into the body via the tube in the other arm. The cell separator removes white blood cells and blood stem cells from the blood; the remaining blood components are returned to the donor. There is hardly any loss of blood.

The procedure takes between three to six hours. A second collection procedure may be required on the following day, if the quantity of blood stem cells collected in the first procedure is insufficient. The donor can leave the hospital on the day of the procedure and is generally able to return to work the following day.

Should the patient’s healing process after transplantation not be satisfactory, the donor may be asked to donate again for the same patient.

Bone marrow donation
During a bone marrow collection procedure, bone marrow is collected from the pelvic bone using a needle and syringe. The donor is under general anesthesia during the procedure, which is performed in an operating theatre. The amount of blood lost during the operation can be relatively high (10 to 20% of total blood volume, corresponding to between 0.4 and 1.3 litres of blood). The procedure takes around two hours. After the procedure, the donor receives a transfusion of his or her own blood if necessary. The donor can leave the hospital on the following day, but generally receives a medical prescription to stay off work for a day or two. The bone marrow regenerates fully within four weeks.

Growth factors (G-CSF)
G-CSF is a substance which is physiologically present in small quantities in the human body and which influences the production and development of blood stem cells.

Transplantation
Patients receive the blood stem cells intravenously in a sterile transplantation room. The transplantation should be carried out within 48 to 72 hours of the blood stem cell collection procedure.
What are the side effects and risks?

**Donating peripheral blood stem cells**
- **Preparation**
  - Stimulation of blood stem cell proliferation with the growth factor G-CSF during four to five days
- **Side effects**
  - Flu-like symptoms such as headache, aching limbs or fever
- **Collection**
  - Collection of peripheral blood stem cells on one or two successive days in sessions lasting three to six hours, outpatient procedure in a collection center
- **Side effects**
  - Dizziness
  - Sensation of coldness
  - Burning in the mouth
  - Tingling in the mouth
  - Bruising at the puncture sites
- **Risks**
  - Infection at the puncture sites
  - Formation of thromboses
  - No evidence of long-term side effects according to the current state of research
- **Temporary disability**
  - Three to four days (in total)

**Bone marrow donation**
- **Collection**
  - Bone marrow collection (takes 1 ½ to 2 hours) in a collection center, kept in as an inpatient for two to three nights
- **Side effects**
  - Pain at the collection sites for several days
  - Bruising at the collection sites
  - Nausea and vomiting caused by the anesthesia
  - Tiredness
- **Risks**
  - General anesthesia
  - Infection at the collection sites
- **Temporary disability**
  - Five to six days (in total)
‘I was a bit apprehensive about the donation, but the strong feeling of being able to help someone prevailed.’

Diego Rossi, Camorino
(Bone marrow donor, August 2012)

Who bears the costs?

You will incur no costs associated with your donation. The patient’s insurance covers the costs of the hospital stay or the outpatient collection of peripheral blood stem cells. SBSC bears any additional expenses related to the donation. These include, for example:

- Loss of income
- Travelling expenses
- Costs for child care

Should any complications arise, the associated costs will be covered by your obligatory accident and health insurance. SBSC will cover the deductible and retention fee.

No entitlement to financial remuneration is associated with the donation of blood stem cells. As it is the case for blood donations, ethical concerns dictate that no financial reward should be received for blood stem cell donation.

What happens after the donation?

Shortly after you donate blood stem cells, our medical team will ask about your state of health and will also take a blood count. Your health is important to us! This is why we will continue to enquire about your well-being at regular intervals for some time.

Anonymity

The donor and patient always remain anonymous and are not permitted to meet face to face. After the donation, a single, anonymous exchange of letters is allowed via the registry.
How else can you get involved?

Help us to raise people’s awareness about leukemia and blood stem cell donation and attract more donors. Every single one of us has the potential to save someone’s life. The more willing donors there are, the greater the chance of finding a matching donor in time. We’ll show you how: request our brochure ‘Together against leukemia – how you can help’ and get active!

Your monetary donation can save lives too! With a voluntary donation you can help us enrol new donors in our registry and increase patients’ chances of a cure. Tissue typing is a complicated process performed in high-tech laboratories. The average cost of a new donor profile is around 220 Swiss francs. Request your deposit slip at sbsc.ch.

With your help, we are getting closer to our common aim every single day: to find a matching donor for every patient. Thank you for your commitment.

‘It doesn’t take much to save a life.’

Thomas Schweingruber, Rafz (Peripheral blood stem cell donor, December 2011)