

Donating blood stem cells: What you should know



TOGETHER AGAINST LEUKEMIA



BLUTSPENDE SRK SCHWEIZ
TRANSFUSION CRS SUISE
TRASFUSIONE CRS SVIZZERA



SWISS BLOOD STEM CELLS
BLUTSTAMMZELLEN
CELLULES SOUCHES DU SANG
CELLULE STAMINALI DEL SANGUE

Who we are

Swiss Blood Stem Cells (SBSC), a division of Swiss Transfusion SRC, acts on a mandate from the Federal Office of Public Health to manage the registry for blood stem cell donors in Switzerland, carry out global searches for unrelated donors for patients and arrange the collection and transport of transplant material. The SBSC is subject to the provisions of the Swiss Federal Transplantation Act and the Federal Act on Data Protection. In addition, the SBSC recruits new donors.

The mission of the SBSC is to find a suitable donor for every patient who needs blood stem cells.

Four principles for blood stem cell donation

The lifesaving donation of blood stem cells is based on four principles:

- **Solidarity**
Registered persons are available as potential donors for patients all over the world. It is not possible to register only for one specific recipient.
- **Voluntary participation**
Blood stem cell donation is always voluntary. A donor can withdraw his or her consent at any time.
- **Anonymity**
Donor and patient remain anonymous at all times, and the two cannot meet face-to-face.
- **Non-remuneration**
Donors do not incur costs of any kind. At the same time, the donation of blood stem cells does not give rise to any entitlement to financial remuneration. Ethical concerns dictate that no one should benefit financially from the donation of blood stem cells.

COVER PHOTO

Lisa Steffen, who suffered from acute lymphoblastic leukemia, is still alive thanks to a blood stem cell donation.

Your registration gives hope

Every day, children and adults are diagnosed with life-threatening blood diseases like leukemia. Many of these patients could be helped through the transplantation of blood stem cells. The probability of finding a suitable donor outside of a patient's family is very low, however. This means that every single person who registers as a blood stem cell donor gives patients hope for a cure.

The essentials at a glance

Thinking about registering but haven't quite made up your mind? Or perhaps you are already in the register and would like to deepen your understanding of blood stem cell donation? In this brochure you will find the most important information relating to blood stem cell donation:

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Thank you very much for registering – suddenly one day it might be your blood stem cells that match those of a patient somewhere in the world, and you may help to save life.

Vital role of blood stem cells

Blood stem cells are responsible for the production of red blood cells, white blood cells and blood platelets. Though found chiefly in bone marrow, they are also present in low concentrations in the blood.

A blood stem cell transplant often represents the only chance of a cure for people suffering from leukemia or another life-threatening blood disorder. The transplantation of new blood stem cells can enable a patient's bone marrow to start carrying out its blood-producing function again.

Bone marrow

Making up the haematopoietic system (the system which produces blood cells), bone marrow is concentrated primarily in the axial skeleton, i.e. in the bones of the skull, the pelvic bones, the ribs, and the bodies of the vertebrae. Bone marrow and spinal marrow are not the same thing. Hence, no injury to the spinal cord can result from a bone marrow donation.

Why you are needed

For a blood stem cell transplant to be successful, the tissue markers (HLA markers) of the donor must closely match those of the recipient. HLA markers are inherited. There are billions of different combinations of HLA markers, so it is difficult to find suitable donors for patients.

The probability of finding an ideal donor within the patient's family is between 20 and 30%. Patients who do not have a donor in their family must hope that a donor will be found somewhere in the world.

The more people who register and are willing to donate, the greater the chance of finding suitable donors for patients in time.

Key tissue markers

Human tissue displays certain markers that are characteristic for each individual. These markers are called human leukocyte antigens, HLA markers for short. They enable our immune system to distinguish between foreign tissue and our own tissue.

A close match between the donor's HLA markers and those of the recipient is therefore crucial for the success of a blood stem cell transplant, as it reduces the risk that the patient's immune system will reject the donated cells.



«There are going to be more and more patients who need blood stem cell transplants.»

Dr. Grazia de Nicoloso de Faveri,
Chief Medical Officer, Swiss Blood Stem Cells

Who is eligible to register

To be eligible to register as a donor, you must be between the ages of 18 and 55, be in good health and have health insurance in Switzerland.

Individuals with any of the following are not eligible for registration:

- Blood disorder or haematopoietic system disorder (bleeding disorders, high risk of thrombosis)
- Severe heart or lung disease (e.g. heart attack, severe bronchial asthma)
- Severe neurological or psychological disorder
- Autoimmune disease (e.g. rheumatism)
- Severe transmissible infectious disease (e.g. HIV, hepatitis C)
- Cancer
- Body weight of below 50 kg
- Substantial excess weight, with BMI >40

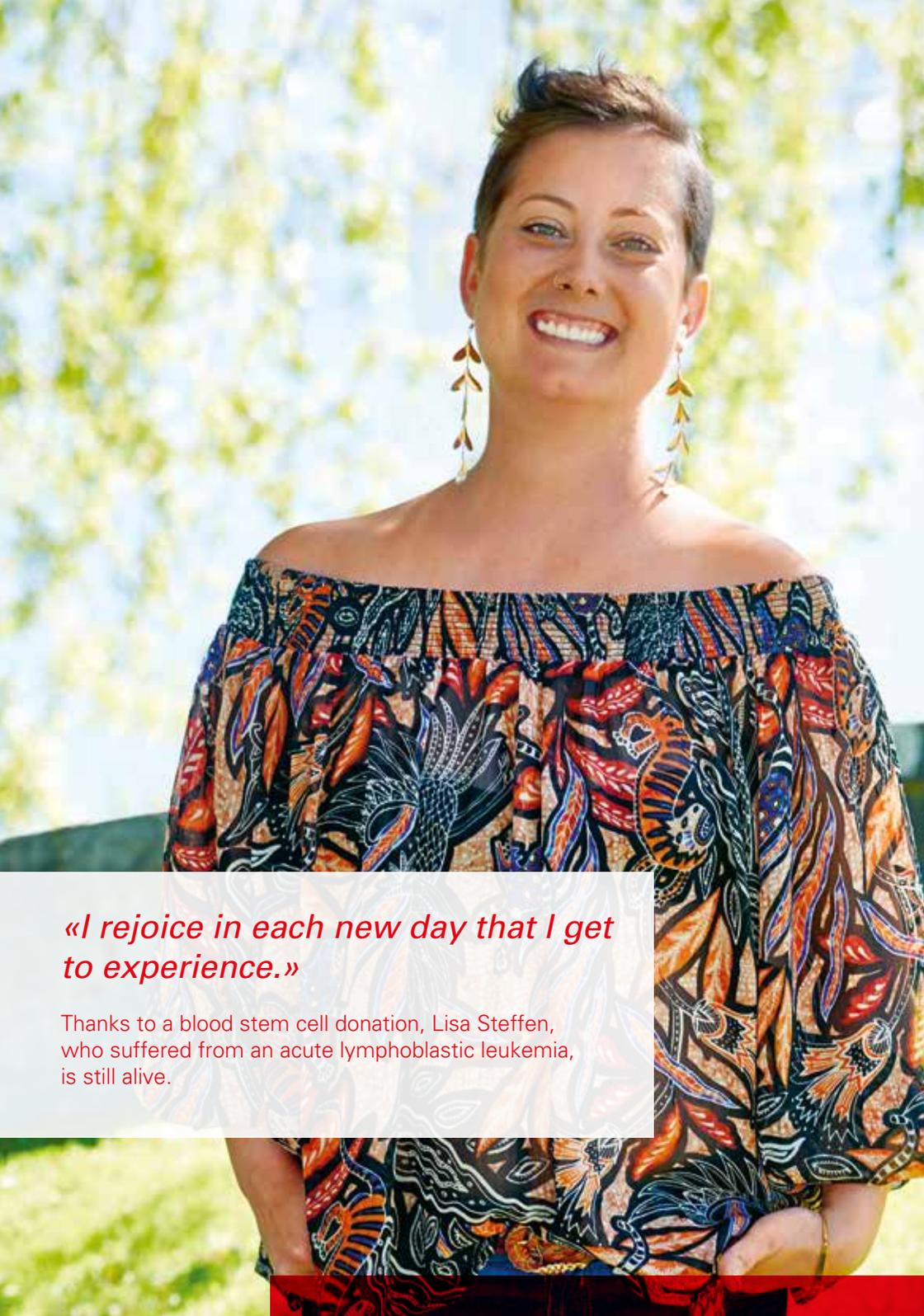
You will receive a donor card upon successful completion of the registration process, and your donor profile will be encrypted and entered into our database. From that time until your 60th birthday, you will be available as a donor to patients throughout the world.

To go directly to
online registration:
sbsc.ch/registrierung



Data protection

Data protection has top priority for us. Your personal data is stored at SBSC. Only data relevant to donor searches is transmitted to the international search registries, i.e. the donor number, HLA markers, age and sex.



«I rejoice in each new day that I get to experience.»

Thanks to a blood stem cell donation, Lisa Steffen, who suffered from an acute lymphoblastic leukemia, is still alive.

When you are identified as a potential donor

If your tissue markers match those of a patient, we will contact you to request your consent for further testing and a possible donation. At this point, you should decide whether you intend to make yourself available as a donor. Whether or not you will then actually be put on the shortlist of potential donors will be determined primarily by the results of the detailed analysis of your HLA markers.

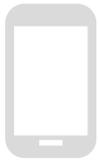
If none of the exclusion criteria for donation apply, a medical professional will take samples of your blood at the regional blood transfusion service of your choice for the purposes of verifying your HLA markers (confirmatory HLA typing) and testing for transmissible diseases.

If you are selected as the blood stem cell donor, you will be requested to meet with a specialist for an in-depth informational session. This session will take place at the responsible collection centre, i.e. in Zurich, Basel or Geneva. Afterwards, you will undergo an extensive physical examination to minimise the risks associated with collection and transplantation for both you and the patient.

The actual donation procedure will not begin until you have issued written consent.

Note: Due to the complexity of the donor selection procedure, several months may elapse between initial contact and the actual donation.

From the initial contact to the donation



1 Potential donor is called with a request to come in for further testing.



2 Blood samples taken at the regional blood transfusion service: analyses performed to confirm HLA typing and test for infectious diseases.



3 The transplanting physician selects the donor and proposes the desired type of donation: bone marrow or peripheral blood stem cell donation.*



4 Donor is notified and issues consent to the donation itself and to the type of procedure.

* For details on types of donation see p.12f.



5 Donor attends informational session on blood stem cell donation in responsible collection centre (Zurich, Basel or Geneva).



6 Health check: medical examination of the donor in the collection centre.



7 Collection of blood stem cells.



8 Preparation, transport and transplantation of collected blood stem cells within a maximum of 72 hours.

Donor withdrawal

The donation of blood stem cells is always voluntary. Even after you have issued your informed consent, you are still entitled to change your mind.

Please note: Deciding not to donate shortly before the collection procedure can have serious or even life-threatening consequences for the patient. Patients undergo powerful chemotherapy and sometimes also radiation to prepare them for transplants. This process destroys the patients' blood stem cells, and their own immune defences and haematopoietic systems no longer function.

Two different collection procedures

Blood stem cells can be collected either directly from the blood using the peripheral collection method or from bone marrow. Currently, the peripheral collection method is used in 80 % of the blood stem cell donation procedures performed in Switzerland, collection from bone marrow in 20 %.

The doctor performing the transplant will determine which collection method is most appropriate for his or her patient. The definitive decision is then made by the doctor responsible for the collection of the blood stem cells, together with the donor.

Peripheral blood stem cell donation

For a few days before the donation, the donor receives growth factors (G-CSF). G-CSF stimulates the proliferation of blood stem cells in bone marrow and their release into the blood. The G-CSF is administered through multiple subcutaneous injections over a period of four to five days before the donation procedure.

For the donation procedure itself, a short thin tube (cannula) is inserted into a vein in each of the donor's arms. Blood flows from one arm into a machine called a cell separator and then back from there into the body via the second cannula in the other arm. The cell separator removes blood stem cells and white blood cells from the blood; all of the other parts of the blood flow back into the donor. Blood loss is therefore minimal. The procedure lasts three to six hours.

In rare cases, the first procedure does not yield a sufficient quantity of blood stem cells. In such cases, a second collection procedure is necessary on the following day.

The donor can leave the hospital on the day of the procedure and is generally able to return to work on the following day.

Bone marrow donation

In a bone marrow collection procedure, bone marrow is collected from the hip bone through insertion of a needle at multiple sites. This procedure is performed in hospital with the donor under general anaesthesia. The blood loss involved can be relatively high, at 10 to 20% of total blood volume, which is quite safe for a healthy donor.

The collection procedure lasts about two hours. As a rule, the donor is able to leave hospital on the following day. The responsible doctor issues a medical statement advising that the donor will be unfit for work for two or three days. The bone marrow regenerates fully within four weeks.

Growth factors (G-CSF)

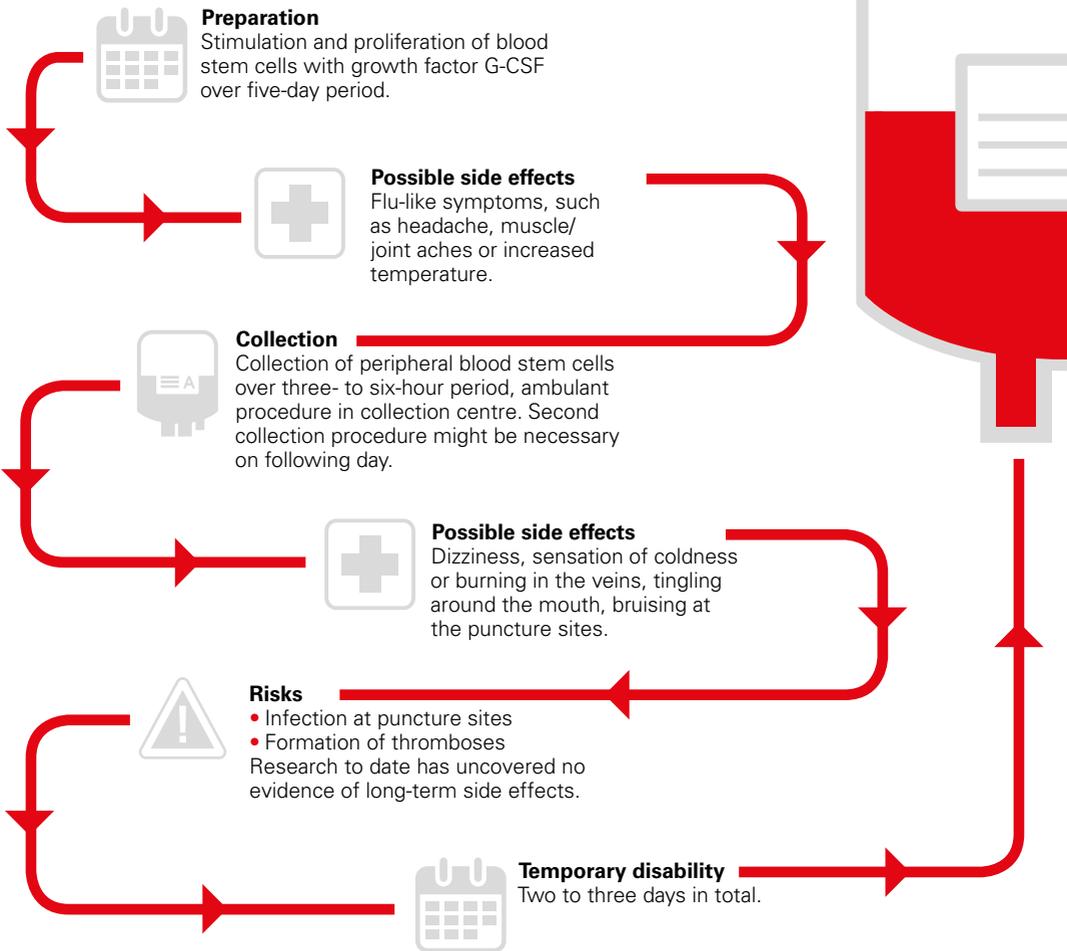
Physiologically present in small quantities in the human body, G-CSF is a substance that influences the production and development of blood stem cells.

Lifespan of blood stem cells

Collected blood stem cells have a maximum lifespan outside of a human body of 72 hours. It is therefore essential that they be transported under refrigeration to the patient and transplanted as quickly as possible. The blood stem cells are passed into the patient intravenously in a sterile isolation room.

Donation process – possible side effects and risks

Peripheral blood stem cell donation





Bone marrow donation



Collection

Bone marrow collection in collection centre under general anaesthetic; procedure lasts one and a half to two hours; two- to three-day inpatient stay.



Possible side effects

Soreness at collection sites for a few days, bruising at puncture sites, anaesthesia-induced nausea, tiredness.



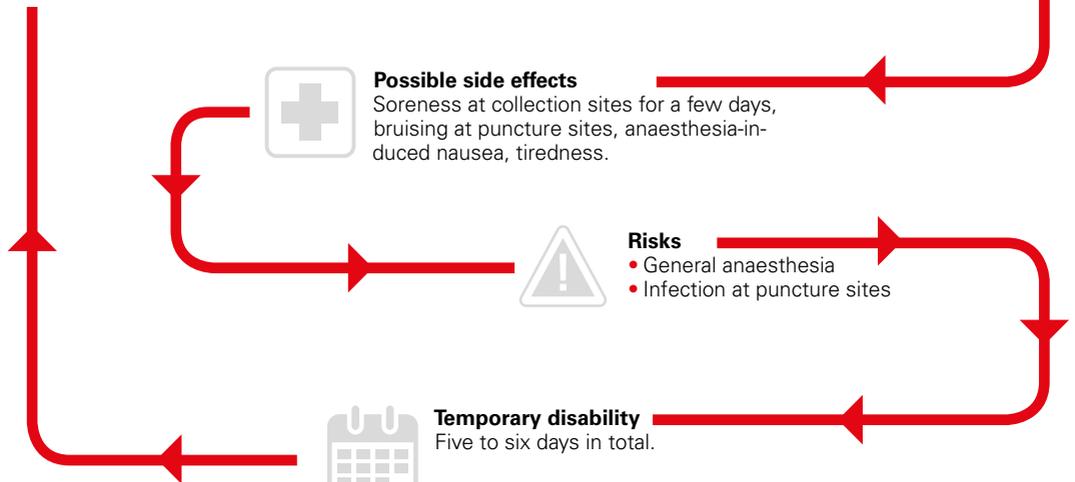
Risks

- General anaesthesia
- Infection at puncture sites



Temporary disability

Five to six days in total.





*«Leukemia can affect anyone.
That is why I'm a blood stem
cell donor.»*

Thomas Hadorn donated blood stems and hopes that many people will register.

What happens afterwards

You will be asked to come in for a health check shortly after the blood stem cell donation procedure. You will be asked questions about your health, and a blood count will be carried out. Your health is important to us, so we will keep checking back with you at regular intervals to ask about how you are feeling.

Both donor and patient remain anonymous at all times, and the two cannot meet face-to-face. After the donation, one single, anonymous exchange of letters via SBSC is allowed.

No costs for donors

Donating will not involve any costs for you. The patient's insurance will cover all of the expenses for the outpatient collection of peripheral blood stem cells or for your hospital stay if a bone marrow collection procedure is performed. The same applies for all expenses associated with preparatory measures and the follow-up medical checks.

SBSC covers all additional donation-related expenses. These include demonstrable loss of income, travel expenses and childcare expenses.

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.

The donation of blood stem cells does not give rise to any entitlement to financial remuneration. Ethical concerns dictate that no one should benefit financially from the donation of blood stem cells.

While you are in the registry

You will receive a donor card once the registration process is complete. From that time until your 60th birthday, you will be available as a donor to patients throughout the world.

Some day you may get a phone call from SBSC asking you to come in for further testing in connection with a possible donation. This might happen very soon after you register, or it might happen many years from now – or it might never happen at all. Suddenly one day, though, it could be your blood stem cells that match those of a patient somewhere in the world, and you may help to save a life. In Switzerland, 40 to 50 people donate blood cells annually.

We are here for you

For as long as you are registered with us as a blood stem cell donor, we will stay in touch: you will receive our biannual magazine «Together», aimed at all blood stem cell donors in Switzerland, which contains informative articles about patients and new developments.

Interesting information
is always available on our
website www.sbsc.ch



Feel free to contact us at any time if you have any questions.

Note: Please notify us of any change in your address to ensure that we can contact you quickly if a request comes in.

Contact address: **donorcenter@sbsc.ch**

What else you can do

Aside from registering as a blood stem cell donor, there are other opportunities to take action on behalf of people battling serious diseases: hosting an informational event, organising a drive for an affected individual, or raising funds. You can get involved as a private individual, a business or an association – here's how:

- **Organise a drive**

Information is the first step towards registration. Occasions involving the provision of information, usually lectures, are eminently well suited for this purpose. At a registration drive, people can register as blood stem cell donors right on the spot. Extensive information provision and planning are the key to a successful registration drive. Please contact us: **engagement@sbsc.ch**

- **Raise funds**

We need financial support to expand the donor registry because medical examinations and tissue typing are expensive. Every monetary donation helps us to enter new blood stem cell donors into the registry. There are many fundraising possibilities, a benefit, for instance, such as a company event, an event hosted by an association or a private fundraising event. We would be happy to provide assistance: **fundraising@sbsc.ch**

It would be a pleasure to hear from you, and we would be happy to provide you with advice or assistance.

TOGETHER AGAINST LEUKEMIA

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