



2008 Annual Report

AUSTRIAN BONE MARROW DONOR REGISTRY

**Fonds Österreichisches Stammzellregister /
Austrian Stem Cell Registry Fund**



Introductory remarks

**Leukemia is curable.
With your help.**

Ladies and gentlemen,

This year's annual report shows that we successfully searched for histocompatible blood stem cell donors for more than 1,000 patients suffering from leukemia or other hematologic diseases. While we were merely able to find donors for a few patients at the beginning of our activities, the number increased to almost 100 in 2008. In other words: in the past year, our organisation has provided a donor for a patient every three days, giving these patients a chance to live.

We would be unable to take such good care of Austrian patients if it wasn't for all our donors who make themselves available whenever seriously ill people need them. In recent years, blood stem cell donors have proven to be highly reliable and helpful partners. Even when their initial registration dates many years back, most donors are happy to come to our tests and to donate blood stem cells as soon as requested to do so. These persons – lifesavers who volunteer to make their donation without receiving any financial compensation and without knowing the patient personally – deserve, above all, our gratitude.

In addition, we would like to thank all institutions with whom we have had excellent collaboration for many years: the Austrian Blood Banks, the Austrian Transplant Centers, Health Insurance Funds, the Austrian Agency for Health and Food Safety, the Austrian Federal Institute of Public Health Care and the Austrian Federal Ministry of Health.

We would especially like to thank those individuals who have made a great difference in our work in so many ways: by organizing blood drives, by putting on charity concerts and events, by volunteering at charity concerts or by providing financial support: a heartfelt „thank you“ to all of you!

Dr. Agathe Rosenmayr
Medical Director
Austrian Bone Marrow Donor Registry



Editha Freistädter
Administrative Director
Austrian Bone Marrow Donor Registry



Finding the matching bone marrow donor

Curing leukemia

The only remedy for curing some types of leukemia and other malignant hematologic diseases are bone marrow or blood stem cell transplants. If no matching donor is available in the patient's family, a non-related volunteer is needed whose tissue is compatible with the patient's. The search for the matching donor in the international pool of donors that includes 13 million donors requires advanced expertise, sophisticated IT systems and excellent collaboration with the laboratories in charge. All this makes the process so costly and time-consuming.

Donating blood stem cells

In order to transplant blood stem cells from a histocompatible donor, the blood stem cells are collected from the donor's blood, either by bone marrow puncture or by venipuncture, followed by apheresis at the blood cell separator. The latter is similar to an extended blood donation process.

Finding histocompatible donors

To ensure a successful transplant, the donor's blood stem cells must be fully histocompatible with the patient's. The chances that two persons are histocompatible are only one to 500,000, on average. Worldwide, 13 million donors, whose data has been stored in large international computer networks, are ready to donate. In order for a compatible donor to be found without delay, these international computer networks need to be available around the clock.

We assist in getting the histocompatible bone marrow to the patient

All donors residing in a given country are registered in the national computer system. Donor data is always kept up-to-date by the registry and is periodically fed into the international donor network or international pool of donors. In case of need, every national stem cell registry has the option of searching the international pool of donors for a donor matching the patient in question. Once a donor has been found, the donation is made in his or her own country. In Austria, the Austrian Bone Marrow Donor Registry is in charge of handling the donation, in cooperation with the Transplant Center that imports and receives the donated blood stem cells and performs the transplant on the patient without delay.



Coordinating the worldwide donor search: Andrea Mitterschiffthaler.



Telecommunication is essential for international collaboration.



The blood stem cells are delivered in a special shipping container.

Austria-wide cooperation and international IT networking

The organizational form of the Austrian Bone Marrow Donor Registry (= Fonds Österreichisches Stammzellregister/Austrian Stem Cell Registry Fund)

In order to meet its duty of finding matching donors, the Austrian Bone Marrow Donor Registry is in continuous contact with all transplant centers and all blood banks (= donor centers) in Austria.

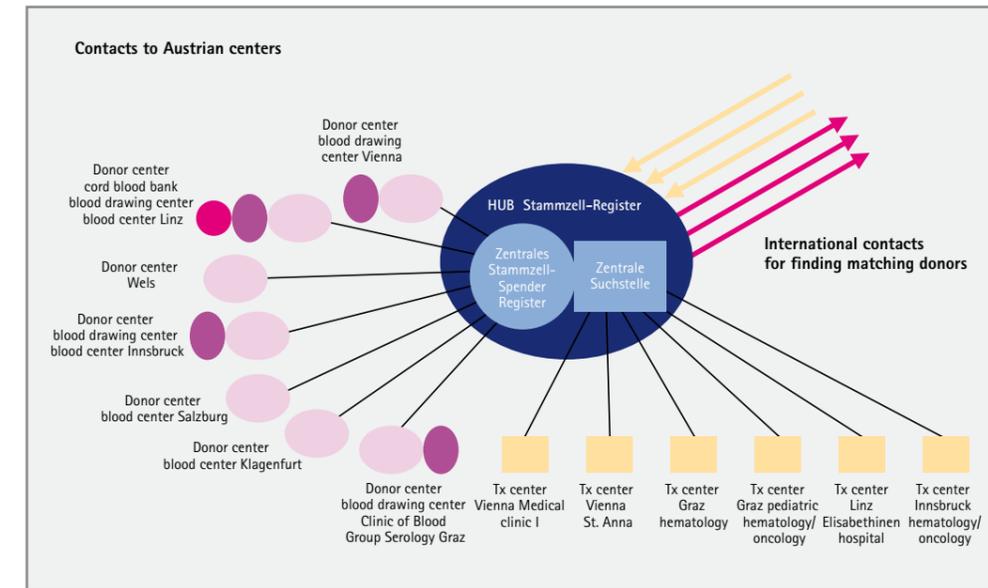


Figure 1: Overview of collaboration between Austrian centers

International integration

In order to adequately meet its duties, the Austrian Bone Marrow Donor Registry collaborates closely with international computer networks. „Bone Marrow Donors Worldwide“ (BMDW) is a centrally organized computer system that provides an updated overview of available donors at any given time. The „European Marrow Donor Information System“ (EMDIS) is an international interactive system of computers that communicate with each other, providing up-to-date information about available histocompatible bone marrow donors for patients with specific tissue characteristics upon request.

International umbrella organisation

The „World Marrow Donor Association“ (WMDA) is the international umbrella organisation of all national registries. It is an organisation which compiles recommendations and guidelines for national stem cell registries, provides quality management guidelines and is currently establishing an international quality control and accreditation system for national stem cell registries. The goal is to foster international collaboration to facilitate the exchange of high quality hematopoietic stem cells for clinical transplantation world wide and to promote the interests of donors.



Recruiting bone marrow donors and blood stem cell donors in Austria

Bone marrow donors and blood stem cell donors are recruited by Austrian donor centers and during drives organised by highly dedicated non-profit associations

In Austria, potential bone marrow donors are recruited at blood banks, where donors also receive information and a donor briefing. This aspect is essential for the continuous functioning of the Austrian pool of donors, because every year, more than 1,000 donors are removed from the pool of donors for having passed the age limit. Therefore, support provided by non-profit organisations and initiatives when it comes to recruiting donors is very important in Austria.



A staff meeting at the donor center in Vienna.

Registering new bone marrow donors in the blood banks and at institutes of transfusion medicine

In addition to providing stored blood, blood plasma and platelet concentrates to large Austrian hospitals, Austrian blood banks also provide a large number of services in the area of transfusion medicine. This includes recruiting bone marrow donors and providing all relevant information to potential donors. In addition, they are in charge of histological typing of donors. In 2008, Austrian blood banks recruited 2,066 donors and performed the histological typing.



Blood drive organised by the association „Leben Spenden - KMT“.

Bone marrow donor recruiting by non-profit organizations and initiatives

In 2008, several highly successful donor drives were organized: the largest ones took place on January 27 in Lustenau, on May 5 in Schwarzach and on May 13 in Feldkirch in Vorarlberg. Two additional large blood drives took place in Lower Austria in April 2008. Another very successful blood drive took place in Stadl-Paura/Upper Austria on March 13, 2008.

Centralized storage of donor data

All Austrian donors' medical data is centrally stored by the Austrian Bone Marrow Donor Registry. Data is transferred from participating blood banks to the national center in Austria which, in turn, periodically feeds this data into international computer networks, ensuring that all donors appear in the international system and that the latest information can be accessed from all over the world. The encryption and protection of donor data play a crucial role. In accordance with national and international guidelines, all donor data is rendered anonymous. Special security measures are used to protect the data.



Blood drive organised by the association „Geben für Leben“ Knochenmarkspende Vorarlberg.



Austrian donors saving lives

Donor centers are the place to turn to when a lifesaver is needed

As soon as a donor has been identified as a lifesaver, the person in question is asked once again if he or she is willing to proceed with the actual donation. If the donor agrees, an information session is arranged during which he or she receives extensive information about all risks and side effects associated with the donation. This is followed by a health exam and a blood analysis to ensure that the donor is healthy and does not have any infectious diseases. It is not until the donor's current health status has been assessed and that he or she has once again declared his or her willingness to donate that the actual donation process starts.



Donating blood stem cells: the venipuncture.

Assisting donors before, during and after the donation

After a donor has ultimately been chosen for a donation, he or she receives comprehensive assistance and care during every step of the process. Before, during and after the donation, a staff member of the donor center, i.e., the blood bank where the donor has been registered, will personally assist the donor at all times. Donors can ask questions and request additional information at any point during the process.

The donation process itself

Blood stem cells are donated at the blood bank where the donor has been previously registered. In case the blood bank lacks the required technical equipment, e.g. for blood stem cell pheresis, the donation process is carried out at a close-by blood bank that does have this equipment. In rare cases, the donation might require general anesthesia. In that case, the donation is done in a fully equipped hospital that is closest to the donor's residence. Today's way of donating – i.e., blood stem cell donations – is by far the most popular approach.



Donating blood stem cells: a few hours on the cell separator.

Long-term follow-up care for donors

Following international standards, donors are periodically interviewed about their health status and blood analyses are performed on them every year after the donation. This follow-up care for donors is provided at donor centers. Many donors are also asked to share their experiences about the donation process itself in interviews made before, during and after the actual donation process. Many of these volunteers say that the donation meant a lot to them and that they would do it again anytime. Oftentimes, they would be delighted to hear from „their“ patient and learn about his or her recovery.



Tired but happy after the donation.



Financial report

Balance sheet and profit and loss statement of the Austrian Bone Marrow Donor Registry

The Austrian Bone Marrow Donor Registry's profit and loss statement shows that subsidies provided by health insurance funds, the federal government and regional governments account for 14% of the organisation's total income, while funds raised at charity concerts and donations account for 5% of the total income, thus securing the organisation's financial survival and the performance of its activities. A large part of the organisation's funds are proceeds from the provision of bone marrow and blood stem cell preparations to countries around the world. Expenses at the Austrian Bone Marrow Donor Registry are mostly related to the international donor search, overhead, human resources and expenses for donor typing.

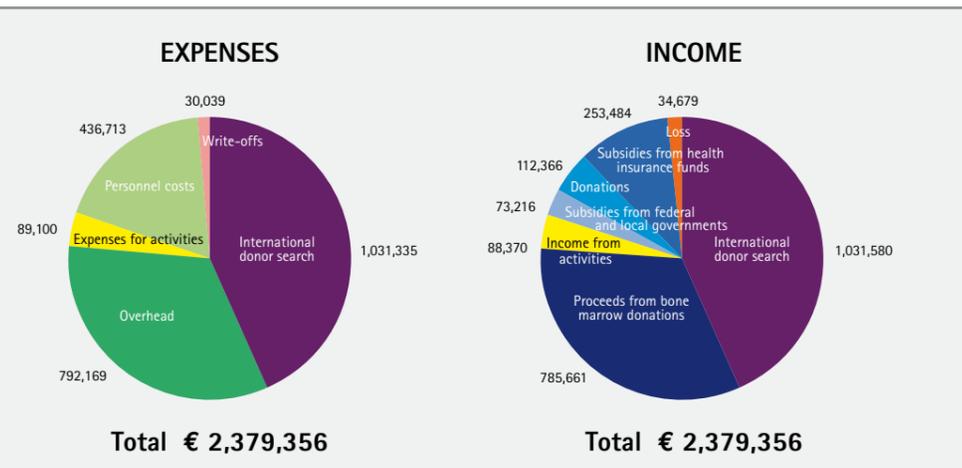


Figure 15: Receipts and expenses of the Austrian Bone Marrow Donor Registry in 2008.

Seal of approval for charities

The Austrian Bone Marrow Donor Registry has been awarded the Austrian seal of approval for charities.

This seal of approval is awarded annually and is valid for one year. It follows the close examination of the financial management by an auditor, which is subsequently approved by the Chamber of Auditors.

Tax deductibility of donations

Donations to the Austrian Bone Marrow Donor Registry are eligible for income tax deductions: donations made to our organisation are always deductible for income tax purposes as part of the blanket allowance for special expenses.



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Legal form

The Austrian Bone Marrow Donor Registry is a non-profit fund pursuant to the Foundations and Funds Act.

The name of the fund is as follows: Fonds Österreichisches Stammzellregister

Establishment

Established in 1988 as a platform; was a non-profit association from 1991 to 2002; has been a non-profit fund since May 2002.



Bank accounts for donations

Erste Bank, bank identification code 20111,
bank account number 096-04642
PSK, bank identification code 60000,
bank account number 90.209.000