

PRESS RELEASE

The European Society for Blood and Marrow Transplantation (EBMT) launches a new database including donor outcome follow-up

Barcelona, Thursday September 17, 2015 – On the occasion of the World Marrow Donor Day, that will be celebrated this Saturday the 19th of September, the EBMT would like to emphasize the establishment of the EBMT donor outcome database that enable to obtain robust data on donor safety and follow-up.

Since the first bone marrow transplant performed in the 1950s, over a million patients have received a haematopoietic stem cell transplantation (HSCT) for the treatment of a wide variety of blood cancers including leukemia, lymphoma, sickle cell disease and other diseases of the blood and bone marrow such as aplastic anaemia, myelodysplastic syndrome, inherited immune deficiency disorders and inherited metabolic disorders. Today every year more than 10,000 transplants in Europe become possible because a related or unrelated donor volunteers to donate blood stem cells for a patient. The increasing number of allogeneic HSCT has only become possible because of the ongoing willingness of more than 25 million registered unrelated volunteer donors to undergo a stem cell collection procedure.

Donor safety and follow-up have become an integral part of the allogeneic HSCT process and it is already mandated by law in some European countries, hence the utmost importance to collect internationally donor outcome data. Since 2013 EBMT offers the possibility to enter donor follow-up data as well for related as for unrelated donors. These data are crucial to ensure maximum donor safety and availability.

The Registry is the single data source of its kind in Europe. It has data on more than 500,000 HSCT procedures including disease, transplant type, donor type and stem cell source. It contains data not only on patients that have undergone an HSCT but also on patients receiving immunosuppressive therapies or other cell therapies. The Registry underpins a large proportion of European research that translates into changes in clinical practice leading to improvements in patient outcome and care. Including donor follow-up data to the EBMT patient database is an innovative step and emphasizes the importance of the donor in the whole donation and transplantation process.

The EBMT and the WMDA invite transplant and collection centres and donor registries to participate in reporting donor outcome data in the EBMT Registry. Jörg Halter, Chair of the Donor Outcome Committee highlights that “many centres and registries have already answered positively to this initiative. Motivation of the teams is high - the challenge is to get the resources needed to collect the donor outcome data. While unrelated donor registries collect locally donor follow up data since many years, this is still new for many teams caring mainly for related donors of all age groups. Nevertheless, some of them had already started to enter donor follow up data.”

More than 50 years after the first successful blood stem cell transplantation the main focus remains unchanged: the wellbeing of both, the patient and the donor.

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About the European society for Blood and Marrow Transplantation (EBMT)

The EBMT is a not-for-profit medical and scientific organisation established in 1974. It is dedicated to fighting life-threatening blood cancers and diseases and improving patients' lives. The EBMT Members - more than 4,000 physicians, nurses, scientists and other healthcare professionals - participate in a unique collaborative network of peers involved in haematopoietic stem cell transplantation (HSCT) and cellular therapy research. The membership encompasses at least 500 centres who are performing or involved in HSCT in more than 60 countries. The EBMT holds a central role in performing co-operative studies and disseminating state-of-the-art knowledge aimed at increasing survival rates and enhancing the quality of life of patients with life-threatening blood cancers and diseases.

For further information about the EBMT, please visit the website: www.ebmt.org and follow us on Twitter: [@TheEBMT](https://twitter.com/TheEBMT)

About the WMDA

Worldwide, over 50,000 patients per year are looking for a matched donor outside their family. Nearly 50% of the patients that find a donor find his or her perfectly matched donor in another country. WMDA works towards a global standardization by establishing an accreditation programme for registries. The accreditation programme ensures that the involved organisations protect the welfare of the donors and that high-quality stem cells products are delivered to patients worldwide.

About WMDD

World Marrow Donor Day takes place on the third Saturday of September each year and will have its first edition in 2015. The day will be celebrated in 52 different countries throughout the world reaching hundreds of thousands of people and resulting in a great deal of media coverage. The main objective of World Marrow Donor Day is to raise awareness among the general public and decision-makers about being a stem cell donor and the impact of blood stem cell transplantation on patients' lives. This years theme is 'thanking 25 million donors' to celebrate the occasion of reaching 25 million registered volunteer stem cell donors worldwide.

To learn more about WMDA or WMDD, visit: www.wmda.org or www.worldmarrowdonorday.org or www.facebook.com/worldmarrowdonorday

Press contacts

EBMT

Mélanie Chaboissier

Phone : +34 93 453 8570 – E-mail : melanie.chaboissier@ebmt.org

WMDA

Lydia Foeken

Phone : +31-71-568 5367 – E-mail : foeken@wmda.info