

PRESS RELEASE

The European Society for Blood and Marrow Transplantation supporting the Rare Diseases Awareness Day this Saturday

Barcelona, Thursday February 26, 2015 – 2015 marks the 8th year of Rare Disease Day. The main objective of this special day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. The EBMT, the leading scientific organisation in the field of hematopoietic stem cell transplantation and cellular therapy, embraces this overall objective so that the society at large acquires a better understanding of the challenges faced by people living with rare diseases.

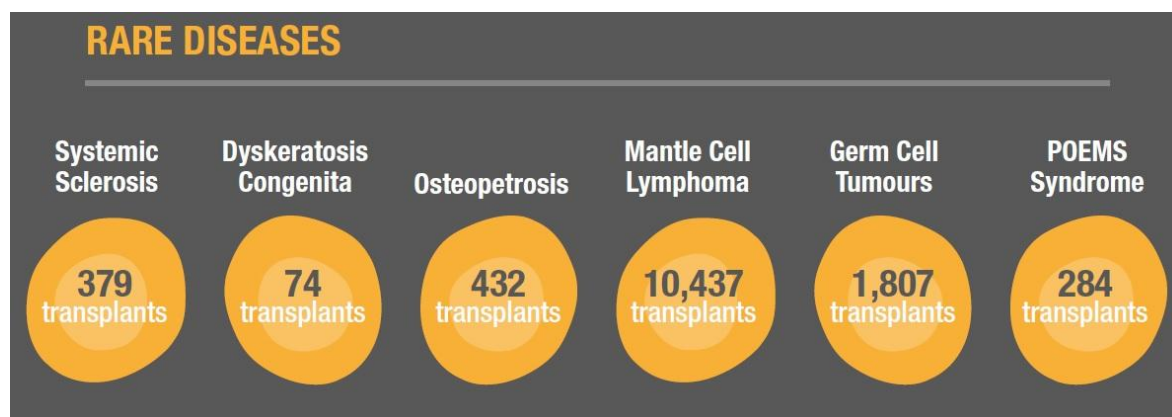
A disease or disorder is defined as rare in Europe when it affects less than 1 in 2,000 people. One rare disease may affect only a handful of patients in the European Union, and another touch as many as 245,000. In the EU, as many as 30 million people alone may be affected by one of over 6,000 rare diseases existing.

Carlo Dufour, Chairman of the EBMT Aplastic Anemia Working Party, says that "rare diseases are numerous and often very severe. We all should keep in mind that rare does not mean that these diseases do not exist, on the contrary, we, as the scientific community, should pay a particular attention to all of them".

The complex nature of rare diseases puts the patients in an even more disadvantaged position compared to those suffering from more common blood disorders (e.g. leukaemia, myeloma) since they face limited access to treatment and services. This situation puts the family members as the primary source of support and care, hence the Rare Disease Day 2015 slogan "day-by-day, hand-in-hand" with rare disease patients.

The EBMT works on a broad diversity of blood disorders and non blood disorders or diseases (such as systemic sclerosis for example), which can be treated with haematopoietic stem cell transplantation (HSCT) and / or cellular therapy. The EBMT has a genuine interest in rare diseases and aims at gaining a better scientific knowledge on the pathogenesis, the diagnosis and management of these illnesses with the ultimate goal to improve patients' lives suffering from rare blood disorders.

In fact, the EBMT provides an important added value in this respect since its worldwide registry on stem cell transplantation contains data on more than 400,000 patients, including thousand of patients with rare diseases, and more than 500,000 transplants. This EBMT registry enables intense networking, retrospective and prospective studies on critical aspects of these diseases.



EBMT Infographic August 2014

The EBMT will be part of the Twitter conversation using @rarediseaseday and #raredisease.

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

The EBMT is a non-profit organisation that was established in 1974 in order to allow scientists and physicians involved in clinical bone marrow transplantation to share their experience and develop co-operative studies. The EBMT aims to promote all aspects associated with the transplantation of haematopoietic stem cells from all donor sources and donor types including basic and clinical research, education, standardisation, quality control, and accreditation for transplant procedures.

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

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