



## PRESS RELEASE

### **The EBMT introduces its upgraded patient Registry to meet the needs of haematopoietic cell transplantation and cellular therapies**

**Barcelona, 3 October, 2023** - After one year and a half of work, the EBMT launches its new and improved patient Registry database, co-funded by the European Union in a grant called EuroTraCTOR.

The EBMT Registry, established in 1974, is the backbone of the EBMT's research and educational activities, providing a pool of data to haematopoietic cell transplantation (HCT) for healthcare professionals to perform studies, assess new developments, and ultimately improve the care of patients with haematological malignancies and other life-threatening disorders.

For more than 20 years, the EBMT has worked with ProMISe, a data-entry and registry solution. Because of the licence expiration at the end of 2023, EBMT had to search for a new solution that meets future data collection and retrieval needs and adjusts to innovative treatments and associated legal and technical requirements.

#### **The new EBMT Registry**

Today, the EBMT has established the next generation software, a successor to ProMISe, that will significantly improve the level of science and facilitate studies.

The EBMT Registry holds data on over 700,000 patients that have undergone HCT and have received immunosuppressive therapies or cellular therapies. This clinical data has been migrated to the new platform. This process will continue after the launch of the new database to manage the heavy load of patient data built up for more than four decades.

Mirjam Steinbuch, EBMT Executive Director, explains: "At EBMT, we understand the importance of staying at the forefront of medical advances. Upgrading and re-designing our Registry system will lead to better health decisions, study design and improved patients' outcomes and care." She adds: "Dr. Anna Sureda, EBMT President and respected haematologist who has made significant contributions to the fields of haematopoietic stem cell and cellular therapy, has been very engaged and supportive in the implementation of this incredibly complex project and has backed the team during all the steps of the project. Having a more advanced tool for HCT researchers and healthcare professionals to access and utilise clinical data effectively was critical. Today a major milestone has been achieved under Dr Sureda's leadership."

#### **Partnership**

To deliver this new data-entry and registry solution, EBMT partnered with edenceHealth, Studio Hyperdrive and De Cronos Groep.

Freija Descamps, Managing Partner edenceHealth: "we have been able to design and deliver a next-generation EBMT data-entry and registry solution that fits the requirements of the EBMT. The flexible data-entry web application is connected to a live application database. Designed to be fast and responsive, this live database will enable many users to concurrently enter and retrieve data."



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### About the EBMT

The EBMT is a non-profit medical and scientific organisation established in 1974 which hosts a unique patient registry providing a pool of data to perform studies and assess new developments in cellular therapies and stem cell transplantation. We aim to be the connection between patients, researchers and other stakeholders to anticipate the future of cellular and stem cell-based therapies. Our community of healthcare professionals is focused on innovation, research and the advancement of these fields to save and improve the lives of patients with blood-related disorders. Visit [www.ebmt.org](http://www.ebmt.org) to learn more about membership, JACIE accreditation, educational opportunities and how to get involved.

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### About the EBMT Registry

The EBMT patient Registry was established in the early 1970's. It is one of the biggest data sources of its kind in Europe. The data is submitted continuously by EBMT centre members, including those from outside Europe. The Registry has data on haematopoietic cell transplantation (HCT) and cell-therapy-associated procedures including details on diagnosis and disease, first-line treatments, transplant type, donor type and stem cell source, complications and outcome. It contains data on patients that have undergone HCT and also patients receiving immunosuppressive therapies or cellular therapies. The Registry also offers the possibility to enter donors' follow-up data, which is crucial to ensure maximum donor safety. The Registry underpins extensive European research that translates into changes in clinical practice and improvements in patient outcome and care.

In 2019, EBMT received a regulatory qualification from the European Medicine Agency (EMA) on the use of its patient registry to support novel CAR T-cell therapies. Currently several Post Authorisation Safety studies based on secondary use of their registry data are ongoing at the EBMT.

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