



The European Group for Blood & Marrow Transplantation

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EBMT: Some Key facts:

- Established in **1974**
- The EBMT is the leading, non-profit, scientific society
- The membership currently lists **3653** members from **527** centres across **57** countries
- 360,000** Haematopoietic Stem Cell Transplantations on **309,000** Patients are currently held in EBMT Registry
- 10** specialist Educational Courses organised annually across Europe
- 100** Retrospective Studies currently underway
- 8** ongoing Prospective Studies
- 89** Transplant Centres JACIE accredited



Vision Mission & Values



To foster **excellence in science** in order to further **improve the outcomes** of Stem Cell Transplantation and **inform** all concerned, including patients and their families about **developments** in the field

This includes:

- Measuring trends in transplant activity
- Collecting and analysing patient transplant data in Europe
- Initiating pioneering prospective studies to improve clinical outcomes and advance patient care
- Networking and Educating Professionals
- Imposing strict quality standards
- Improving patient care



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EBMT: In numbers



46 Publications
in peer-review
journals in
2009

150
Retrospective
Analyses
underway

8 Prospective
Clinical Trials
underway

350,888
Transplants in
the EBMT
Registry

30,293 HSCTs
submitted to the
Activity Survey
in 2009

3612 EBMT
Members
across 57
Countries



EBMT Executive Committee



President: Alejandro Madrigal (London, UK)
Secretary: Anna Sureda (Barcelona, Spain)
Treasurer: Jan Cornelissen (Rotterdam, NL)



EBMT Working Parties



Acute Leukaemia

M Mohty (Nantes, France)

Aplastic Anaemia

J Marsh (London, UK)

Autoimmune Diseases

D Farge Bancel (Paris, France)

Chronic Leukaemias

T de Witte (Nijmegen, NL)

Immunobiology

A Velardi (Perugia, Italy)

Inborn Errors

B Gaspar (London, UK)

Infectious Diseases

S Cesaro (Verona, Italy)

Late Effects

A Ticheli (Basel, Switzerland)

Lymphoma

P Dreger (Heidelberg, Germany)

Paediatric Diseases

C Peters (Vienna, Austria)

Solid Tumours

M Bregni (Milan, Italy)



EBMT Committees



Accreditation

Cord Blood

Developmental

Education

Nuclear Accident response

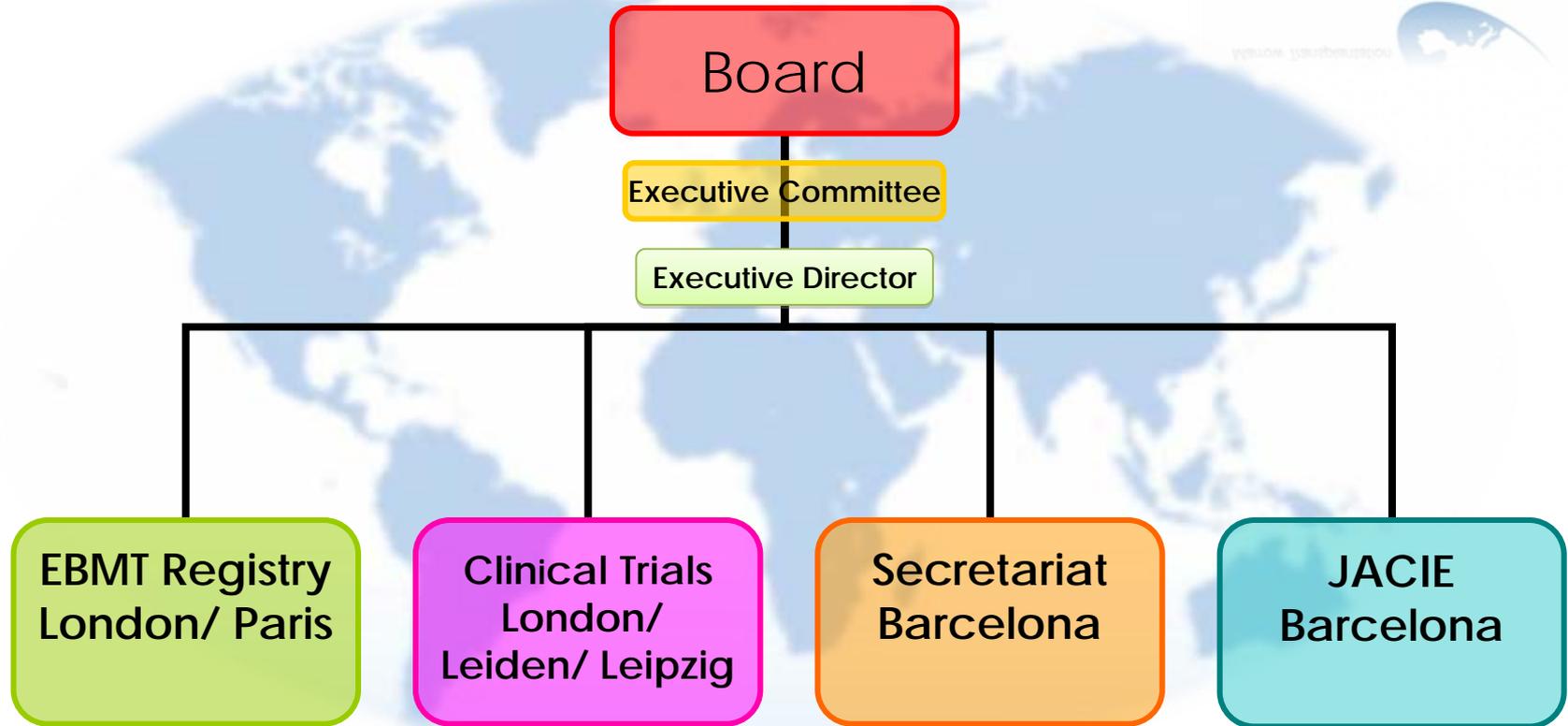
Outreach

Prospective Clinical Trials

Quality Assessment of autologous grafts

Statistical

EBMT: Operations



EBMT: Educating Professionals

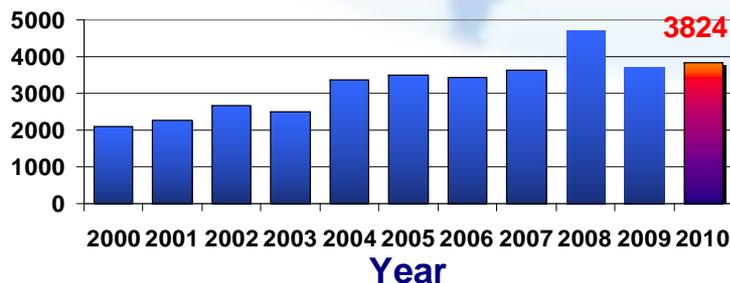
- EBMT organises the **only** annual **specialist educational course** on Blood and Marrow Transplantation in association with the European School of Haematology (ESH)
- In addition, regular courses (all CME accredited) are organised on the application of HSCT in the **treatment of specific diseases** and conditions
- Sharing the knowledge:** All courses offer a number of **outreach scholarships** to facilitate the attendance of delegates from **countries** with **lesser developed** transplantation programmes
- The ESH – EBMT Handbook on Haematopoietic Stem Cell Transplantation is the **main reference guide** for professionals working in the field. **50,000** copies are currently in circulation
- EBMT has created a public **online educational resource** with the slides from EBMT led educational programmes



EBMT: Annual Congress – Networking & Education

- The EBMT organises an annual congress for **scientific exchange** between physicians, nurses and data managers. The meeting takes place in a different European city at the end of March.
- The congress' Scientific Programme is designed to **inform** physicians, nurses, data managers, quality managers of the **cutting edge advances** in their field through a series of workshops, plenary sessions, controversy sessions, and educational sessions.

**Number of participants 2000 -
2010**



EBMT: Supporting developing transplant programmes

A programme of activities has been developed by the EBMT, in collaboration with the European School of Haematology, aimed at **supporting emerging BMT programmes** and transplant centres in countries with **limited resources** and/or **experience**.

Key objectives of the Outreach programme include:

- Facilitating **wider participation** of members in EBMT activities
- Encouraging** and **promoting collaboration**, through building **long-lasting relationships** between Blood and Marrow Transplantation developing projects to provide **training** and **support** for transplant programmes, with a view to harmonisation of BMT standards & practice across Europe and beyond
- Identifying resources** and **funding** to **support** Outreach **initiatives**



EBMT: Patients, Families, Donors and Carers

EBMT organises an annual **Patient & Family Day**. The key objectives are as follows:

- to **encourage communication** between patients, scientists and clinicians working on curing their illnesses
- to **bring together** patient associations to foster long-lasting **collaborations**
- to promote **a sense of solidarity** between patients suffering from the same disease





JACIE

The European Group for Blood and Marrow Transplantation

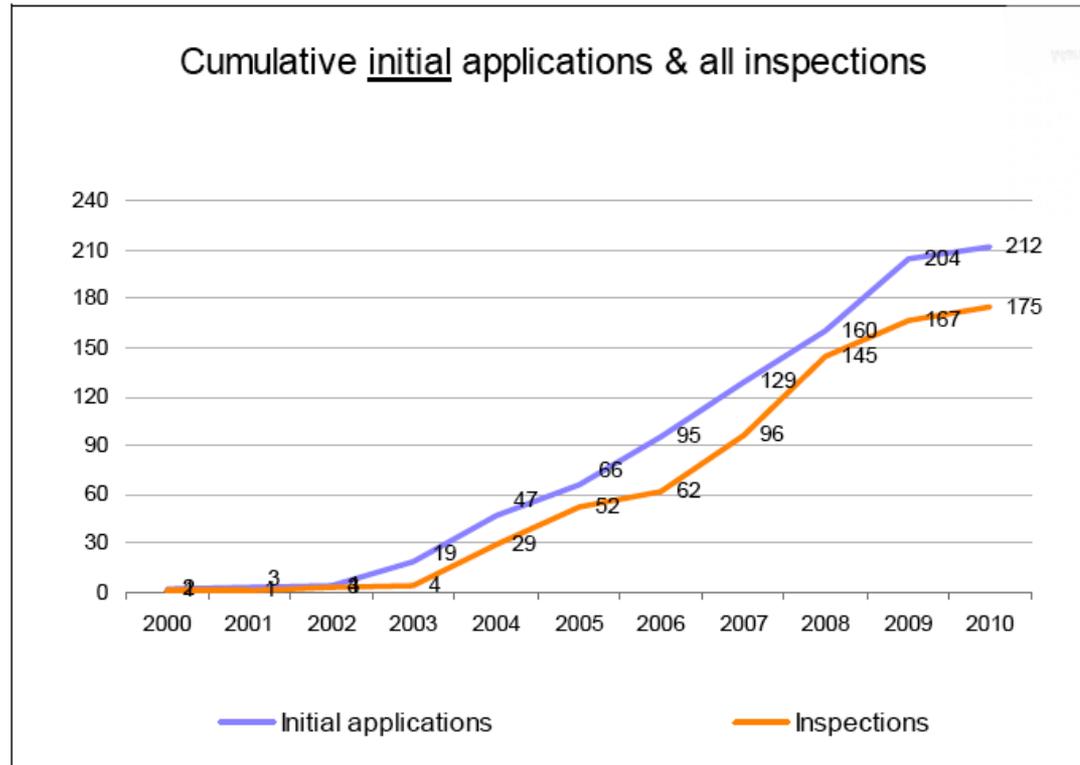


EBMT: JACIE (Joint Accreditation Committee-ISCT & EBMT)

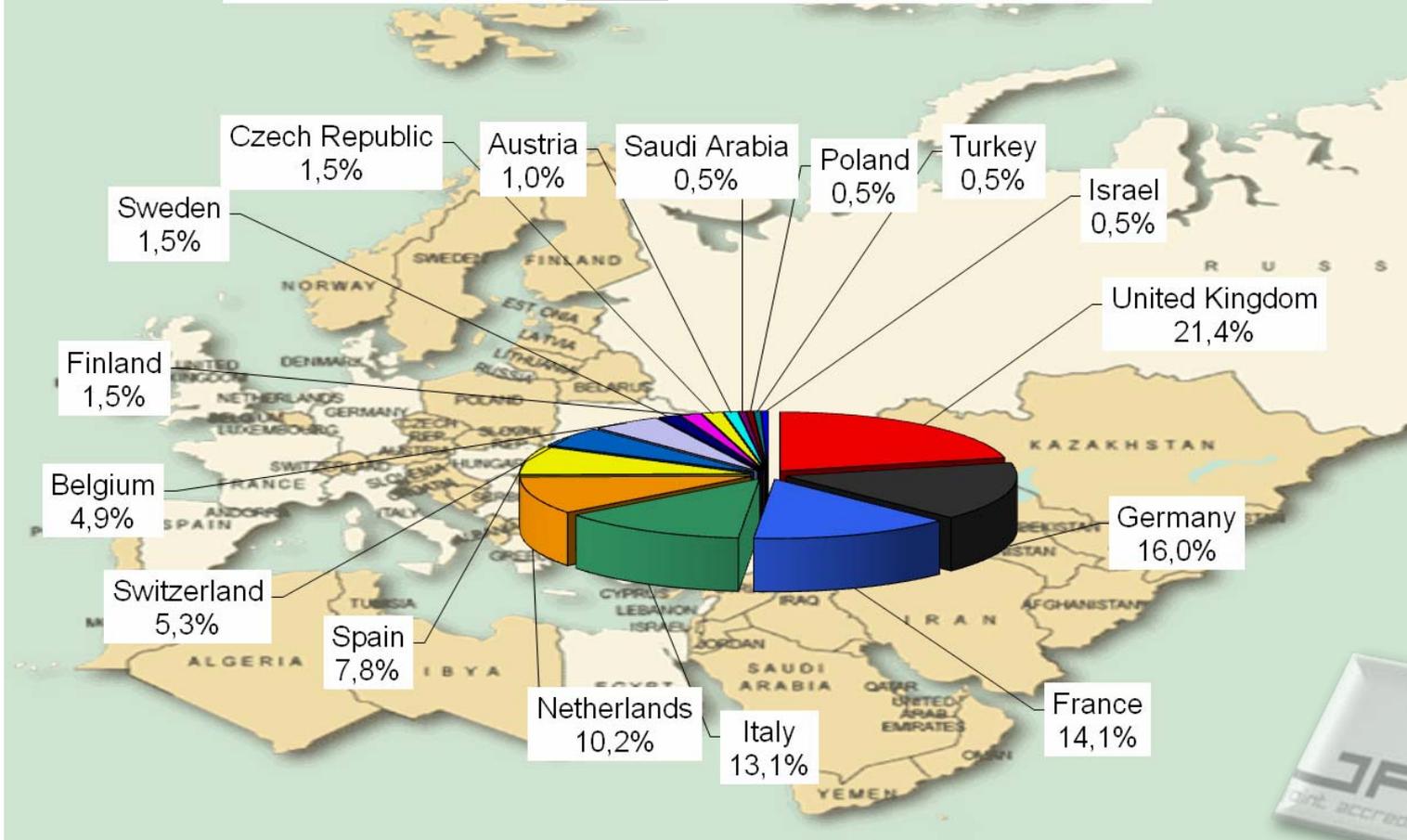
- The Joint Accreditation Committee-ISCT & EBMT is a non-profit body established in 1998 for the purposes of **assessment and accreditation** in the field of haematopoietic stem cell (HSC) transplantation.
- The funding to establish JACIE under the EBMT was achieved through a successful EU grant application
- JACIE's primary aim is to **promote high quality patient care** and laboratory performance in haematopoietic stem cell collection, processing and transplantation centres through an internationally recognised system of accreditation.
- 200 transplant centres have already applied for JACIE worldwide and JACIE accreditation is fast becoming **a necessary standard** for transplant centres to achieve



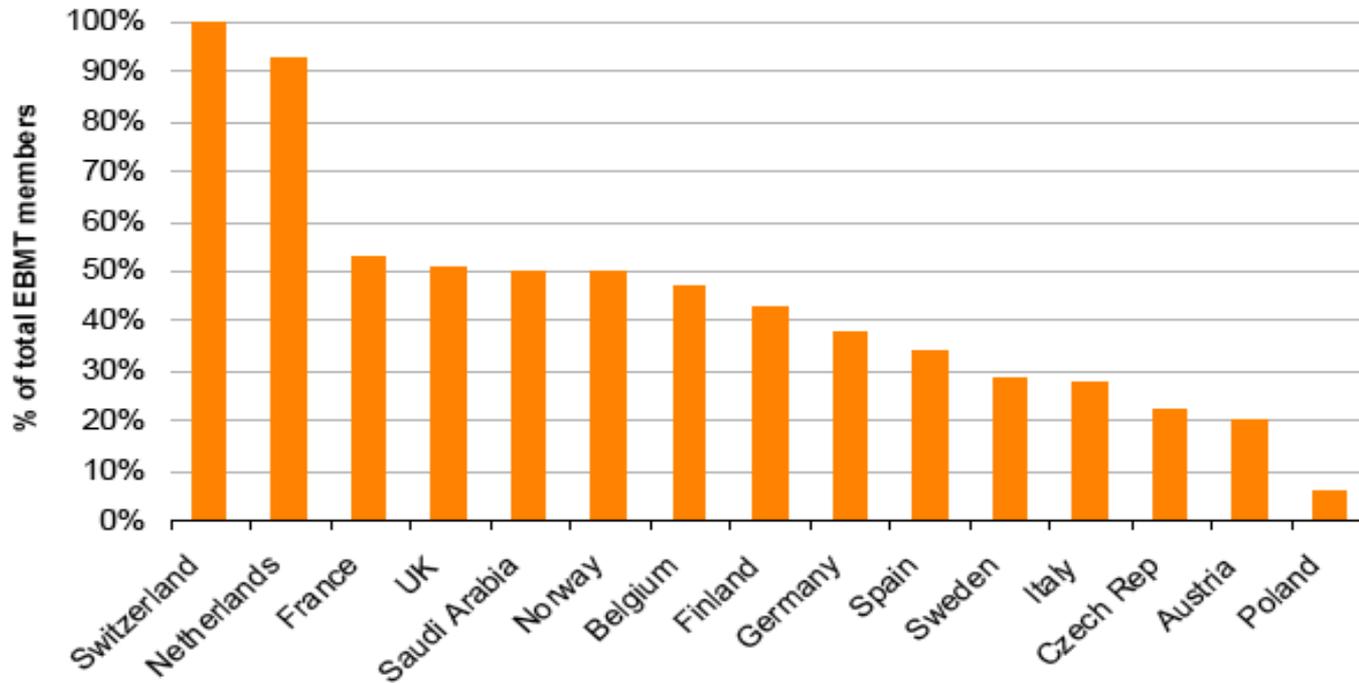
2. JACIE Accreditation



% distribution of initial applications by country



JACIE registrations as % of EBMT members by country





EBMT Registry

EBMT: Registry - A Foundation for Cutting-Edge Research



The EBMT Registry uses a central data management system to collect data on patients treated with a haematopoietic stem cell transplant (HSCT) according to indication (type of disease), donor type (allogeneic/autologous) and stem cell source (bone marrow/peripheral blood/cord blood).

- The Registry stores data from over **360,000 transplants** with over **26,000 new transplants reported each year**, and is accessible to EBMT members, representing the **largest transplant database** available to them today
- From this database, studies investigating predictive factors for transplantation, outcomes of diseases, frequencies of stem cell transplantation and the **outcomes** of different transplantation techniques can be **analysed**.
- The information available can be used **to simulate** a stem cell transplant based on the **experience** gained over the past 30 years. The database also enables **progress** in stem cell transplantation over the past three decades to be **tracked** and is used for **quality control** purposes.



EBMT: Registry



- A number of **collaborative registry studies** have been published with the CIBMTR (Center for International Blood and Marrow Transplant Research) in the **USA**
- **Data Sharing agreements** with **donor registries** and other databases of other groups are currently in progress with the objective of **facilitating data reporting** to centres, **providing a service to donor registries** for their regulatory requirements, **enlarging the scope**, and **maximizing data quality** in the Registry
- The data held in the EBMT Registry is becoming increasingly interesting for the the official agencies responsible for **national health programmes**.



EBMT: Megafile, current status



Acute leukaemias: AML	43.779	47.995
Acute leukaemias: ALL	27.342	29.447
Acute leukaemias: other/unknown	1.513	1.686
Chronic leukaemias: CML	19.389	20.879
Chronic leukaemias: CLL	4.221	4.676
Chronic leukaemias: other/unknown	435	477
Lymphomas: NHL	61.618	68.194
Lymphomas: Hodgkins	21.084	23.789
Lymphomas: other/unknown	1.483	1.611
Multiple myeloma/Plasma cell disorders	58.731	79.960
Solid tumours	32.426	42.896
Myelodysplastic/myeloproliferative	15.564	17.577
Aplastic anaemias	7.248	8.015
Primary immune deficiency	2.402	2.745
Inborn errors: other / unspecified	1.534	1.735
Histiocytic	633	695
Autoimmune diseases	1.158	1.190
Haemoglobinopathies	3.546	3.746
Other/unknown	582	692
Total	304.688	358.005



The EBMT Membership



EBMT members are mainly centres active in the transplantation of haematopoietic stem cells. Membership is also open to individuals, companies and other organisations actively involved in the care of donors and recipients of haematopoietic stem cells.

The membership lists **3612** members from **536** centres in **57** countries

Central Registry and **13** affiliated registries (**11** national, **2** others)

The EBMT is sponsored by **17** Corporate Patrons





Clinical Trials

EBMT: Initiating pioneering prospective studies to improve clinical outcomes and advance patient care



- Academic prospective clinical trials form a key part of patient-oriented clinical research, and create the basis for continuously improving patient care
- As treatment outcomes for many hematological diseases have progressively improved, it has become necessary to conduct larger and larger trials to demonstrate meaningful improvements in the standard of care
- With this background, the EBMT established several years ago the PCTC and the Clinical Trials Office (CTO), with the aim to allow for a pan EBMT commitment to opening and running large prospective clinical trials.



EBMT: Plans for the future



- Improve Med B submission
- Include more patients in clinical studies
- Change in clinical study philosophy
- Non-interventional studies
- Define optimal treatment from diagnosis
- Interaction members and the board
- Interaction with disease related scientific groups