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Source: EBMT February 2018
# Table of Contents

Message from the President 4  
About EBMT 5  
EBMT Structure 6  
Staff organisational chart 7  
EBMT Membership 8  

<table>
<thead>
<tr>
<th>SCIENTES</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>The scientific activity report</td>
<td>11</td>
</tr>
<tr>
<td>Severe Aplastic Anaemia Working Party (SAAWP)</td>
<td>12</td>
</tr>
<tr>
<td>Autoimmune Diseases Working Party (ADWP)</td>
<td>14</td>
</tr>
<tr>
<td>Acute Leukaemia Working Party (ALWP)</td>
<td>16</td>
</tr>
<tr>
<td>Cellular Therapy &amp; Immunobiology Working Party (CTIWP)</td>
<td>18</td>
</tr>
<tr>
<td>Infectious Diseases Working Party (IDWP)</td>
<td>20</td>
</tr>
<tr>
<td>Inborn Errors Working Party (IEWP)</td>
<td>22</td>
</tr>
<tr>
<td>Lymphoma Working Party (LWP)</td>
<td>24</td>
</tr>
<tr>
<td>Paediatric Diseases Working Party (PDWP)</td>
<td>26</td>
</tr>
<tr>
<td>Chronic Malignancies Working Party (CMWP)</td>
<td>28</td>
</tr>
<tr>
<td>Transplant Complications Working Party (CQLWP)</td>
<td>30</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Publications</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EBMT Transplant Activity Survey 2016</td>
<td>37</td>
</tr>
<tr>
<td>The EBMT Registry</td>
<td>40</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EDUCATION</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EBMT 43rd Annual Meeting</td>
<td>43</td>
</tr>
<tr>
<td>Awards</td>
<td>46</td>
</tr>
<tr>
<td>Educational events</td>
<td>49</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PATIENT CARE</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EBMT Nurses Group</td>
<td>51</td>
</tr>
<tr>
<td>JACIE</td>
<td>54</td>
</tr>
<tr>
<td>Financial highlights</td>
<td>58</td>
</tr>
</tbody>
</table>
One more year has passed, and I am delighted to introduce the EBMT Annual Report.

Since the last one, EBMT has delivered another impressive wave of scientific production, with exciting findings, analysis of new modern drugs in the context of stem cell transplantation, and a greater focus on the haplo-identical transplant activity which is currently booming everywhere. EBMT Working Parties and investigators are harnessing the power of the Registry, thanks to the great support of EBMT statisticians and data managers, in order to deliver state of the art research in many underserved medical fields. All of these achievements are reflected in this Annual Report.

I would like to express my deep gratitude to all of you, EBMT members, who voluntarily report your activity to the EBMT Registry. Through your dedication and enthusiasm, you have been the driving force behind the dynamic scientific agenda of our Society. I would like to emphasise the critical role of the EBMT Registry, which proved to be a powerful tool towards significant improvements in clinical care. However, one should bear in mind that the pace of change is accelerating. This is why I am convinced that EBMT needs to invest in the development of new statistical methods and data analysis tools. Advances in basic scientific research, fuelled by the tools of molecular biology and genomics, have generated unprecedented knowledge. Thus, many of the so-called “traditional” methods may prove to be insufficient in the near future to handle complex data combining both clinical and laboratory findings. In addition, we need to establish closer collaborations with the different disease-oriented cooperative groups in order to shape up our research agenda, integrating transplant and non-transplant approaches. Such close cooperation would also allow us to facilitate the increasingly difficult implementation of prospective clinical trials. This is a crucial endeavour in a very complex regulatory and financially stretched environment. I am confident that EBMT can make a difference in this area and play a major facilitator role across national boundaries.

Over the last few years, EBMT has grown into a truly global organisation, which is comprehensively addressing the complexities of hematologic malignant and non-malignant diseases. I eagerly encourage you to participate in EBMT scientific and educational activities. I am confident that you will always feel within EBMT a renewed sense of energy and inspiration for the benefit of the patients who put their lives in our hands.

Please enjoy reading this report, and do not forget to follow the EBMT news on Twitter @TheEBMT and @Mohty_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.

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. Membership encompasses more than 500 centres from over 60 countries, that perform or are involved in HSCT.

The EBMT holds a central role in performing co-operative studies and disseminating state-of-the-art knowledge: the aim is to increase survival rates and enhance the quality of life of patients with life-threatening blood cancers and diseases.
## EBMT structure

### Board

1. **Executive Committee, President**  
   Mohamad Mohty  
   Hospital Saint Antoine, Paris, France

2. **Executive Committee, Secretary**  
   Rafael Duarte  
   Hospital Universitario Puerta de Hierro, Madrid, Spain

3. **Executive Committee, Treasurer**  
   Jurgen Kubal  
   University Medical Centre, Utrecht, The Netherlands

4. **President Elect, Scientific Council Chair**  
   Nicolaus Kröger  
   University Hospital Eppendorf, Hamburg, Germany

5. **Scientific Council Co-Chair**  
   Arnon Nagler  
   Chaim Sheba Medical Center, Tel-Hashomer, Israel

6. **Scientific Council Education Representative**  
   Carlo Dufour  
   Institute G. Gaslini, Genova, Italy

7. **Scientific Council Registry Representative**  
   Chiara Bonini  
   Hospital San Raffaele, Milano, Italy

8. **Nurses Group President**  
   John Murray  
   Christie NHS Trust Hospital, Manchester, UK

9. **Annual Meeting President**  
   Manuel Abecasis  
   Instituto Português de Oncologia Lisbon, Portugal

### Committees

10. **Severe Aplastic Anaemia**  
    Carlo Dufour  
    Institute G. Gaslini, Genova, Italy

11. **Autoimmune Diseases**  
    John Snowden  
    Sheffield Teaching Hospitals NHS Trust, Sheffield, UK

12. **Acute Leukaemia**  
    Arnon Nagler  
    Chaim Sheba Medical Center, Tel-Hashomer, Israel

13. **Cellular Therapy & Immunobiology**  
    Chiara Bonini  
    Hospital San Raffaele, Milano, Italy

14. **Infectious Diseases**  
    Jan Styczynski  
    University Hospital, Collegium Medicum UMK, Bydgoszcz, Poland

15. **Inborn Errors**  
    Arjan Lankester  
    Leiden University Hospital, Leiden, The Netherlands

16. **Lymphoma**  
    Silvia Montoto  
    St. Bartholomew’s and The Royal London NHS Trust, London, UK

17. **Paediatric Diseases**  
    Peter Bader  
    Klinikum der Johann-Wolfgang Goethe Universität, Frankfurt, Germany

18. **Chronic Malignancies**  
    Nicolaus Kröger  
    University Hospital Eppendorf, Hamburg, Germany

19. **Transplant Complications**  
    Grzegorz Basak  
    Medical University of Warsaw, Warsaw, Poland

20. **Nuclear Accident**  
    Ray Powles  
    Cancer Center London, London, UK

21. **Statistical**  
    Myriam Labopin  
    Hospital Saint Antoine, Paris, France

22. **JACIE**  
    John Snowden  
    Sheffield Teaching Hospitals NHS Trust, Sheffield, UK

23. **Donor Outcomes**  
    Joerg Halter  
    University Hospital of Basel, Basel, Switzerland

24. **Registry**  
    Per Lyngman  
    Karolinska University Hospital, Stockholm, Sweden

25. **Global**  
    Norbert-Claude Gorin  
    Hospital Saint Antoine, Paris, France

26. **Legal & Regulatory Affairs Committee (LRAC)**  
    Christian Chabannon  
    Institut Paoli Calmettes, Marseille, France
Our members are listed according to their role within their team. They are comprised of the following distribution of roles:

- **Physician**: 2,809
- **Nurse**: 804
- **Data Manager**: 622
- **Laboratory Technician**: 141
- **Quality Manager**: 242
- **Other**: 147

**Total**: 4,765

Our members can be classified as centre members (full or associate); individual or provisional members.

---

* Commit to submitting data on all patients treated in their centre on an annual basis, and enjoy the benefits of voting rights and eligibility for JACIE accreditation.

** New members which are pending approval at the General Assembly Meeting during the upcoming EBMT Annual Meeting.

Source: ProMise Jan. 2018
Membership benefits

The benefits for those centres which are full EBMT members include the following:

- Eligibility to elect and stand as board members
- Participate in EBMT studies
- Be eligible for JACIE accreditation
- Have access to the EBMT Registry
- Be eligible for reduced fees to attend the EBMT Annual Meeting
- Receive discounts on subscriptions to the official journal of the EBMT, Bone and Marrow Transplantation.

*There are special conditions for Chinese centre/individual member applicants:
- 50% discounted membership fees for the first year
- Sponsorship with two signatures on the application form is not mandatory, only the support of the EBMT Global Committee Representative (Norbert Claude Gorin).

Joining the EBMT

Centres or independent persons that are active in the field of transplantation & cellular therapy related to any kind of haematopoietic stem cell, or any other organisation involved in the care of donors and recipients of HSCT, can become a member of the EBMT.

Our 582 members are located in 65 different countries

Top ten countries in terms of number of centres participating in the EBMT

- Germany: 56
- Poland: 20
- Belgium: 18
- The Netherlands: 15
- U.K.: 53
- France: 51
- Spain: 48
- Switzerland: 12
- Italy: 87
- Austria: 12
- Turkey: 39
### The scientific activity reports

<table>
<thead>
<tr>
<th>Working Party</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe Aplastic Anaemia Working Party (SAAWP)</td>
<td>11</td>
</tr>
<tr>
<td>Autoimmune Diseases Working Party (ADWP)</td>
<td>12</td>
</tr>
<tr>
<td>Acute Leukaemia Working Party (ALWP)</td>
<td>14</td>
</tr>
<tr>
<td>Cellular Therapy &amp; Immunobiology Working Party (CTIWP)</td>
<td>16</td>
</tr>
<tr>
<td>Infectious Diseases Working Party (IDWP)</td>
<td>18</td>
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<td>Inborn Errors Working Party (IEWP)</td>
<td>20</td>
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<tr>
<td>Lymphoma Working Party (LWP)</td>
<td>22</td>
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<tr>
<td>Paediatric Diseases Working Party (PDWP)</td>
<td>24</td>
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<tr>
<td>Chronic Malignancies Working Party (CMWP)</td>
<td>26</td>
</tr>
<tr>
<td>Transplant Complications Working Party (CQLWP)</td>
<td>28</td>
</tr>
</tbody>
</table>

### Publications

- EBMT Transplant Activity Survey 2016: 37
- The EBMT Registry: 40
The following pages of this scientific report will show you the high activity and productivity of our Working Parties and Nurses Group in 2017.

You may have noticed that in 2017 the number of the Working Parties have been reduced from 11 to 10, because the Solid Tumor Working Party has become a subcommittee within the Cellular Therapy and Immunobiology Working Party (CTIWP). Furthermore, the former Complication and Quality of Life Working Party was re-named to Transplant Complications Working Party (TCWP).

The steadily increasing number of stem cell transplantations in EBMT Registry allows the Working Parties to perform high quality retrospective Registry studies reflecting the current use and trends of autologous and allogeneic stem cell transplantation. Several Working Parties performed a “Data quality initiative”, which improved the quality of the data and allowed to focus on specific scientific projects. These manuscripts were published in high ranked peer-reviewed journals such as Journal of Clinical Oncology, Blood, Leukemia, Biology of Blood and Marrow Transplantation, Bone Marrow Transplantation and others and provide a substantial scientific contribution to the stem cell transplant community worldwide.

You will also notice the evolving challenges in cellular therapies by the increasing activities of the CTIWP. Even if CAR-T-cells are not approved in Europe yet, EBMT is prepared with the implementation of a new Cellular Therapy Registry to collect composition and outcome of cellular therapies within our Registry, which will help us to show trends and perform cellular therapy studies.

Due to the strong commitment of the Working Parties and the tireless efforts of its members numerous abstracts could also be presented in 2017 as oral communication or poster at several international meetings, such as EBMT, ASH, EHA, ASCO and Tandem (ASBMT/CIBMTR) meetings.

A second major achievement of the Working Parties in 2017 are the 22 international Educational Events, which provided the latest update and developments in the field of stem cell transplantation and cellular therapies, following our mission to disseminate the best knowledge to our members and the transplant community worldwide.

All these achievements are only feasible by the continuous support of the EBMT centers who provide the data by hard working data managers and physicians and the work of voluntary Working Parties members and the help of excellent statisticians. Last but not least, special thanks go to the patients, without their help in providing their data to EBMT, all these studies would not have been possible.

I encourage you to keep your commitment to EBMT for further progressing and improvement towards our mission.

Nicolaus Kröger
Scientific Council Chair
Major achievements

Progression of two prospective randomised clinical trials:

1. The RACE study that compares standard immunosuppressive treatment (IST) (ATG+CsA) plus Eltrombopag vs Standard IST alone. This EBMT study financially supported by GSK, Pfizer and Alexion Pharmaceuticals. 118 patients enrolled up to mid December 2016. The closing number of 200 is predicted to be reached in next fall.

2. The Moderate Aplastic Anaemia (MAA) study that compares Cyclosporin A (CsA) plus placebo vs. CsA plus eltrombopag in MAA. This study is sponsored by the University of Ulm (Germany) and financially supported by GSK Germany. Sixteen EBMT centres from six countries (France, Germany, Italy, Switzerland, The Netherlands and the UK) will recruit patients. German centres have been opened and 26 patients have been enrolled up to early December.

Publication of the text book: "Congenital and Acquired Bone Marrow Failure”, First Edition

This book is EBMT/ESH cooperation and is divided in two parts:
- Part I: Acquired Aplastic Anemia
- Part II: Congenital Bone Marrow Failure Syndromes

The book includes 21 chapters with a total of 274 pages and covers all aspects of bone marrow failure both in paediatrics and adults and also areas of supportive care; these are topics of great interest to physicians working with infectious diseases and also those involved in transfusion services. eBook ISBN: 9780128041758

Data quality Initiative

This initiative aims at improving the quality and follow up data of patients receiving Stem Cell Transplant and the number of registration and the quality of data from undergoing exclusive Immunosuppressive (IS) treatment.

The SAAWP data managers along with the Chair and the Secretary revised the data collection form (Med B) for transplanted patients and prepared a new one for those undergoing only IS. These forms were further revised by expert members of the SAAWP and afterwards a survey has been initiated among all EBMT centres to assess willingness to participate in either one or both initiatives.

So far the SAAWP has received the completed files from 39 centres for a total of 724 patients. Data are expected from 46 other centres who accepted to participate for a predicted total of 1,865 patients.

Newsletter

The Newsletter was launched in order to better inform the SAAWP members and the EBMT community and raise awareness of the numerous WP’s ongoing activities and also to get contribution for new study ideation from anyone willing to be active in the marrow failure field.
**Principal research studies**

1. Autoimmune phenomena post HSCT for AA. Collaboration with ADWP. PI: P. Miller
2. Survey on rabbit ATG. PI: A. Bacigalupo
3. Long Term side effects of G-SCF in AA. PIs: A. Tichelli, R. Peffault de Latour
5. Outcome of SCT in Congenital Dyserythropoietic Anemia. PI: M. Miano

**Key publications**

Major achievements

In 2016, John Snowden was elected as ADWP Chair and Tobias Alexander became Secretary. They have continued to build on the achievements of the previous chairs, Dominique Farge, Riccardo Saccardi and Alan Tyndall.

Over the past 20 years, the ADWP has developed the largest database worldwide for HSCT in autoimmune diseases with around 2,500 cases reported from all over the world. As reflected in the current EBMT activity survey, autoimmune diseases (ADs) are now the largest growing indication for HSCT, reflecting a significant change in transplant practice and the active role of many EBMT centres that have developed an interest in this field.

In association, the ADWP continues to add to the evidence-base with prospective studies, Registry-based studies and guidelines written with other professional groups outside of haematology. Our collaborations also now robustly extend outside of Europe, including North and South America and Australia.

The clinical efficacy of autologous HSCT for some indications AD is now becoming well established. The future challenge is to further optimise transplant protocols to maximise safety and efficacy of this procedure. Health economic considerations and implementation science will also be essential to define how to deliver HSCT best in the context of biological and other modern therapies. Immunologic studies in the field are ongoing and provide novel aspects in the understanding of the underlying mechanisms that promote long-term, medication-free remissions by HSCT in ADs.

Sustained positive clinical results and enhanced ADWP activity in otherwise refractory AD patients continues to attract patients, clinicians, and healthcare providers in the field. However, the future of this treatment will depend on quality care. Therefore, we continue to update guidelines for HSCT in specific autoimmune disease groups and delivery of HSCT in AD by JACIE accredited centres.

Finally, in 2017 the ADWP organised a joint meeting with the IEWP in November where we explored the interface between autoimmunity, auto-inflammatory disease, Immunodeficiency and other inherited disorders.

Principal research studies

1. Autologous HSCT for Crohn’s disease: a retrospective survey of the ADWP.
3. Allogeneic HSCT for Autoimmune Diseases (AD), with IEWP.
4. Comparison of Cyclophosphamide/ATG vs BEAM/ATG conditioning regimens in autologous HSCT for Multiple Sclerosis.
5. Outcomes after autologous hematopoietic cell transplantation for rapidly progressive systemic sclerosis (Joint EBMT/CIBMTR study).
6. HSCT in myasthenia gravis.
7. Guidelines and reviews: Guidelines for HSCT in Neurological diseases, EULAR initiative: recommendations for HSCT in SSC, Guidelines to patients travelling overseas for HSCT in AD and invited reviews to J Autoimmunity (general) and Frontiers in Immunology (Crohn’s disease).
Key publications
2. Cardiopulmonary assessment of patients with systemic sclerosis for hematopoietic stem cell transplantation: recommendations from the European Society for Blood and Marrow Transplantation Autoimmune Diseases Working Party and collaborating partners. Farge D, Bone Marrow Transplant. 2017 Nov
4. Long-term Outcomes After Autologous Hematopoietic Stem Cell Transplantation for Multiple Sclerosis. Muraro PA, JAMA Neurol. 2017 Apr 1

Major educational courses
1. Joint educational meeting of the EBMT Autoimmune Diseases and Inborn Errors Working Parties - 3 November 2017 in Newcastle upon Tyne, UK
2. Education session “Transplant in non-hematological disorders” at the EBMT Annual Meeting 2017 in Marseille, France
3. Meet the expert session “Autologous transplant for Crohn’s disease” at the EBMT Annual Meeting 2017
4. Invited educational session at ASBMT-CIBMTR Tandem Meeting “Autoimmune Disease and BMT”, presenters Snowden (Chair & MS), Rovira (Inflammatory Bowel Disease) and Alexander (Rheumatological Diseases and immune Reconstitution) - 23 February 2017 in Orlando, Florida, USA
Major achievements

The ALWP had a very successful 2017 year. Acute leukaemia continues to be the number one indication for allogeneic stem cell transplantation (allo-SCT) in Europe accounting for 55% of all transplantation procedures. The leading indication is Acute Myelogenous Leukemia (AML) - 39% (early AML - 21%; advance AML - 12% and transformed AML - 6%) to be followed by Acute Lymphoblastic Leukemia (ALL) - 16%.

According to the recent Transplant Activity Survey of the EBMT, 9,413 transplants are for AML and 1,597 for ALL. Notably, there is a constant increase in numbers of transplants for acute leukaemia with no saturation; in last year report the number of transplants for acute leukaemia increased by 8%. Unrelated donors are the leading donor type but the most impressive increase is in the Haploidentical transplants (Haplo-SCT) and especially of the T cell repletion (T-replete) Haplo-SCT with post-transplant cyclophosphamide (PTCy) with close to 300% increase in the Haplo-SCT numbers in one decade. For this reason, one of the ALWP main areas of interest in 2017 continues to be Haplo-SCT as part of our alternative donor subcommittee chaired by Dr Fabio Ciceri. We took advantage of the large Registry data and performed several retrospective Registry studies trying to address open issues in the field of Haplo-HSCT including comparison to HSCT from unrelated, cord blood and sibling donors; the type of graft BM vs PB; conditioning RIC vs MAC, TBF and low dose TBI; GVHD prophylaxis with PTCy vs ATG and donor related issues like age, blood type, CMV status, HLA disparities on the unshared Haplotype and the potential role of KIR mismatching. Specifically, T cell–replete Haplo-HSCT were compared with cord blood transplantation in acute leukaemia to address the topic of alternative donor transplants (Ruggeri A, Leukemia 2015). Similarly, in 2 separate studies, T cell–replete Haplo-HSCT has been compared with matched and mismatched unrelated allo-HSCT (Piemontese S, JHO 2017; Versluis J Blood Advances 2017). Theoretically, there was the idea that the broad HLA disparity involved in haplo-HSCT would result in a stronger graft-versus-leukemia effect in comparison with HLA-matched transplants. This question has been addressed in another study from the ALWP comparing relapse rate post Haplo-HSCT to HSCT from siblings (Ringden O, Leukemia 2016). Other studies have researched myeloablative versus reduced-intensity conditioning (Rubio MT, JHO 2016); and GVHD prophylaxis with PTCy vs ATG (Ruggeri A, Hematologica 2017). As for donor selecting issues we assessed the impact of HLA disparities on the outcomes after haplo-HSCT (Lorentino F, Blood Advances 2017), the role of blood groups (Canaani J; Hematologica 2017), donor age (Canaani J; Am J Hematol 2017) and CMV status (Crocchiolo R; BMT 2017). We tried to summarise all in a recent position statement on Haplo-HSCT for AML, we published in Hematologica 2017. New studies in the Haplo setting will be presented in the coming international meetings including the impact of molecular markers like FLT3 and minimal residual disease (MRD) status on results of Haplo-HSCT. Of note the PTCy that was pioneered as anti GVHD prophylaxis in the Haplo arena is being increasingly used also for GVHD prophylaxis post HSCT from sibling and unrelated donors and Dr Ruggeri A will present our recent study in this regard in the coming ASH.
**Principal research studies**

1. **CBT**: Although it seems that numbers are decreasing the ALWP together with Eurocord performed some important studies focusing on CBT in 2017. Baron F assessed CB failures (Oral at ASH) and revisited the topic of graft vs leukemia effect (GVL) in CBT (IJM 1017). Dr Shouval on behalf of the ALWP in collaboration with Eurocord used the random survival forests technique identifying overall survival (OS) predictors and related interactions in CBT (Shouval R, Clin Ca Res 2017).

2. Defining AML-related cytogenetics and molecular markers and dissecting their influence on allo-SCT outcome continues to be one of ALWP’s main efforts led by Dr. Jordi Esteve leading to 2 frontal presentations at ASH 2017.

3. Dissecting the pre-transplantation conditioning continue to be one of the ALWP main topics of interest orchestrated by Dr Bipin Savani with the comparison of the TBF versus FB by Francesco Saraceni as one of the examples (Oncotarget in press, 2017). As for the autologous setting Pr Claude Gorin the head of our Autologous subgroup compared Bu/Cy to Bu/ Mel in AML patients undergoing Auto-SCT (Am J Hematol 2017) and in high risk patients (Frontal presentation at ASH).

4. Allo-SCT for ALL: Results of allogeneic transplants from both siblings and moreover unrelated transplants are improving significantly over the last decade and this important finding in view of the recent development of novel antibiotics and cellular therapies (CAR) for ALL was published by Sebastian Giebel the chair of the ALL subcommittee and the secretary of the ALWP in Hematologica 2017.

5. Immunotherapy is one of the leading approaches to combat relapse which is still the major obstacle for successful HSCT. Dr Christoph Schmid the head of our immunotherapy subgroup concentrated on prophylactic and preemptive DLI with interesting results (Oral Tandem 2017).

**Key publications**


5. Outcomes of UCB transplantation are comparable in FLT3+ AML: results of CIBMTR, EUROCORD and EBMT collaborative analysis. Ustun C, Leukemia. 2017 Jun

**Major educational courses**

1. Master Classes in Transplantation and Hematology (MATH®): Advances in Immunotherapy - 20 January 2017 in Paris, France

Major achievements

In recent years, scientific breakthroughs and major biotechnological advances have boosted the field of cellular therapies that are now moving from the experimental phase to the stage of real-life in several medical areas, including onco-haematology and inherited diseases. The successful and long-lasting experience gained through the clinical application of HSCT represents the basis for many current and future developments in cellular therapy. The CTIWP aims at understanding and exploiting the biological, including immunological, events occurring upon HSCT at large, and to implement modern cellular therapies based on cell and gene engineering approaches to improve transplantation outcomes. CTIWP has recently designed a dedicated arm of the Registry, to collect data on patients treated with cellular therapy approaches. The recent merging of the previously existing Solid Tumor Working Party within CTIWP, offers the opportunity to further expand our ability to capture the expanding field of cellular therapy and of its clinical indications in the solid tumors area.

In 2017, we implemented the new Registry forms, designed to capture the details on the nature and sequence of administration for all kinds of cell products and cellular therapies received by registered patients. This new feature is integrated within the EBMT Registry, designed to capture data on the most innovative cell and cell-based gene therapy approaches that are rapidly entering the clinical arena. Preparation of this new form was coordinated with CIBMTR, and lays the basis on which to collaborate with pharma companies and with European competent authorities to organise long-term follow-up of patients treated with innovative cellular and gene therapies that are now reaching the European market. Concomitantly, CTIWP leaders have established contacts with EU bodies (see below) and with major pharma companies that are close to marketing cellular or gene therapies with applications in the field of haematology and oncology.

We completed two retrospective studies and one multicentric prospective transplant immunobiology study, aiming to identify biomarkers that could be predictive of post-transplant outcome. One of these studies is at the stage of a manuscript due for 1st revision.

We implemented 4 retrospective studies on HSCT applied to solid tumors.

Several surveys on various aspects of transplant practices within EBMT centers were completed or launched. We completed a survey on graft storage procedures in Europe (manuscript recently accepted for Publication in Cytomtery), a survey on immune monitoring post transplantation (submitted to Bone Marrow Transplantation, currently in revision), and a third one on manufacturing of Mesenchymal Stem Cells in Europe.

Together with other WP members and EBMT governance, we established and consolidated contacts with European bodies (EC, EMA, IMI), in order to position EBMT as one of the important stakeholders in the field of cell transplant and cellular therapies, either alone or in the context of consortium with other professional associations interested in overseeing various fields of cell or tissue transplantation such as the SoHO (Substances of Human Origin) consortium.

Last, one of the most important missions of the CTIWP is to disseminate and discuss scientific results. See below our major educational activities.
**Principal research studies**

1. Identification of immunological biomarkers predictive of clinical outcome after haplo-identical SCT.
2. The role of parent/child and haplo-identical siblings immune interactions (IPA/NIMA vs NIPA/IMA mismatching in GvH vs HvG directions) on clinical outcomes in haplo-identical transplantation.
3. Non-interventional prospective study on the role of donors vs recipient NK cell allo-reactivity in haplo-identical SCT.
4. A Survey on policies of immunological monitoring of patients undergoing allogeneic HSCT.

**Key publications**

1. Single- or double-unit UCBT following RIC in adults with AL: a report from Eurocord, the ALWP and the CTIWP of the EBMT. Baron F, J Hematol Oncol. 2017 Jun 21

**Major educational courses**

1. Activities during the EBMT Annual Meeting 2017 in Marseille, France:
   - 6th Cell Therapy Day designed with the local organising committee, and the CTIWP Scientific Symposium provided attendees with practical, regulatory and scientific background information for the optimisation of cell transplant and the development, evaluation and implementation of innovative cellular therapies.
   - Jon J. Van Rood Award 2017
   - ISCT-EBMT Joint Session
2. ISCT Annual Meeting - May 3-4 2017 in London, UK

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**Impact factor**

*Cell Therapy & Immunobiology*

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<td>Oral Presentations</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>7</td>
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<td></td>
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<td></td>
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Major achievements

The mission of the IDWP is to share experience and develop cooperative studies to increase education in the field of diagnosis, prophylaxis and treatment of infectious complications in HSCT patients.


IDWP recent achievements were published in Clinical Infectious Diseases, Haematologica, Journal of Antimicrobial Chemotherapy, Bone Marrow Transplantation and Journal of Infection.

Principal research studies

1. Role of CMV, EBV, ADV, JCV, HHV6, HHV8 and HIV on outcomes of HSCT
2. Causes of deaths after HSCT
3. Infections with toxoplasmosis, tuberculosis and legionella after HSCT
4. The incidence of gram-negative bacteremia, risk factors and resistance to antibiotics: a prospective study
5. Anti-infective prophylaxis and antibiotic use in patients undergoing HSCT
6. Impact of candidemia on transplant outcome
7. Impact of pre-existing invasive aspergillosis on allo-HSCT outcome: prospective non-interventional study
8. Risk factors and outcome of pneumocystis pneumonia (PcP) infection in HSCT: prospective non-interventional study
9. Treatment approach for patients with HCV infection and who underwent HSCT: prospective non-interventional study
10. Infections of CNS after HSCT
Key publications


5. Comparable survival using a CMV-matched or a mismatched donor for CMV+ patients undergoing T-replete haplo-HSCT with PT-Cy for acute leukemia: a study of behalf of the infectious diseases and acute leukemia working parties of the EBMT. Cesaro S, Bone Marrow Transplant. 2018 Jan 12

Major educational courses

1. 20th “State-of-the-Art” Educational Course of Infectious Diseases Working Party and 25th Anniversary of IDWP, special lectures were given by IDWP former Chairs - 12 October 2017 in Poznan, Poland

2. 7th ECIL (European Conference on Infections in Leukemia) – 22-23 September 2017 in Sophia Antipolis, France
Major achievements
In 2017, IEWP has been very active both at scientific and educational level. In terms of publications, six manuscripts (of which four accepted in 2017) were published in 2017 in high impact journals. In addition, several manuscripts on IEWP studies, performed in close collaboration with the EBMT data office, are in preparation. In 2017, the interaction with the EBMT data office has been intensified to further improve the execution of studies by IEWP and its international partners. IEWP contributed with dedicated sessions at the EBMT Annual Meeting and European Society of Immunodeficiencies Meeting in Edinburgh (Sep 11-14). In addition, IEWP took part in a joint educational meeting with the PDWP and EBMT Paediatric Nurses Group in Copenhagen (June 8-10). The IEWP Autumn meeting in Newcastle (Nov 3-5) was very well attended with 140 delegates. The first day of the meeting was a joint educational meeting organised by IEWP and ADWP entitled “Interface between autoimmunity and PID’ with a keynote by Mario Abinun. The IEWP meeting included excellent sessions on metabolic diseases, DNA repair disorders, primary immune disorders, hemoglobinopathies, gene therapy and haplo-identical transplantation strategies. The keynote lecture was given by Georg Hollander from Oxford. An IEWP expert meeting was held in Leiden (Mar 16) to discuss and revise guidelines for haplo-identical SCT in PID. A first workshop on malignancy in PID was organised with representatives for ESID, IEWP and I-BFM (June 20, Leiden).

We look forward to an exciting 2018 with several educational and scientific meetings scheduled.

Principal research studies
1. Allogeneic HSCT in chronic granulomatous disease
2. Outcome and immune reconstitution in SCID HSCT 2006-2015: a joint IEWP-SCETIDE study
3. HSCT in Wiskott-Aldrich syndrome comparing Bu-Flu and Treo-Flu conditioning: a joint IEWP-SCETIDE study
4. Long term outcome of HSCT for SCID: a joint SCETIDE-IEWP-PIDTC study
5. Outcome of LAD HSCT 2008 – 2015: a joint IEWP-PDWP study
6. Domino HSCT for PID: joint IEWP-PIDTC study
7. Cord Blood SCT for HLH (with Eurocord)
8. HSCT for Erythropoietic Porphyria: a joint EBMT-CIBMTR study
9. HSCT in Inherited Metabolic Diseases with focus on immune cytopenia: a joint IEWP-Eurocord study
10. HSCT fin LAL-Wolman’s disease
Key publications


Major educational courses

1. 6th Training Course for Paediatricians and Paediatric Nurses on HSCT in Children – 8-10 June 2017 in Copenhagen, Denmark

2. IEWP session during the Meeting of the European Society for Immunodeficiencies (ESID) focusing on the theme of Autoimmunity and Inflammation in primary immunodeficiency diseases (PID) - 11-14 September 2017 in Edinburgh, Scotland

3. Joint educational meeting of the EBMT Autoimmune Diseases and Inborn Errors Working Parties - 3 November 2017 in Newcastle upon Tyne, UK

4. Inborn Errors Working Party Annual Conference - 4-5 November 2017 in Newcastle upon Tyne, UK

Impact factor (Inborn Errors)

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Major achievements

The past year has continued to be a busy and industrious time for the LWP with new operational developments and a successful year of research and education. The Working Party is chaired by Silvia Montoto and supported by Stephen Robinson (Scientific Secretary), Ariane Boumendil (statistician), Hervé Finel (data management) and newly appointed Irma Khvedelidze (data manager). Additional support is provided by a panel of experts in the field of transplantation in lymphoma. Operating procedures for processing new study proposals and their subsequent delivery have been recently developed. Membership of the Working Party is entirely open and we actively encourage junior and senior members of the EBMT to submit their research proposals. We currently manage a portfolio of 30 ongoing studies and have successfully published 4 manuscripts this year, with 2 more papers recently accepted and 3 pending minor review. The LWP has established strong links with the CIBMTR Lymphoma Sub-committee and is collaborating on several projects with other EBMT Working Parties and pharma colleagues. The LWP meets three times each year and additional fortnightly teleconferences are conducted to oversee the research portfolio.

The LWP is strongly committed to educational activities and successfully hosted the 13th Educational course in Prague this year and next year’s course will be held in Majorca on 26-28 September 2018. Members of the LWP also actively engage in educational activities at the EBMT Annual Meeting and other international conferences. We are currently developing international consensus guidelines regarding stem cell transplantation in Waldenstrom’s macroglobulinemia (jointly with the European Consortium for Waldenstrom’s Macroglobulinemia –ECWM– and the International Waldenstrom’s Macroglobulinemia Foundation –IWMF–), conditioning regimens for transplantation in lymphoma and maintenance therapy post transplantation (both jointly with the CIBMTR).

Principal research studies

1. EBMT LYM1 long term follow up of a randomized trial
2. Efficacy and toxicity of donor lymphocyte infusions following allogeneic SCT for lymphoma
3. Impact of donor characteristics on the outcome of haploidentical stem cell transplantation for lymphoma
Key publications


3. Radioimmunotherapy-augmented BEAM chemotherapy vs BEAM alone as the high-dose regimen for autologous stem cell transplantation (ASCT) in relapsed follicular lymphoma (FL): a retrospective study of the EBMT Lymphoma Working Party. Bento L, Bone Marrow Transplant. 2017 Aug

Major educational courses

1. 13th education course of the Lymphoma Working Party - 20-22 September 2017 in Prague, Czech Republic
Major achievements

The PDWP, the IEWP and the Paediatric Nurses held their joint educational meeting in Copenhagen, Denmark, in June 2017. Marianne Iversen and her team from the Paediatric SCT and Immune Deficiency Unit of the University Hospital Rigshospitalet welcomed nearly more than 100 nurses, physicians and medical students to the wonderful midsummer Capital of Denmark.

Mary Slatter explained and discussed current principles of the modern donor and graft selection hierarchy, which is one major backbone of this fascinating treatment option. Anita Lawitschka updated the audience on the most important side effect of modern HSCT, which still is an often-unsolved problem: GvHD. She focused on the long-term burdens of chronic GvHD, its classification and treatment options.

Of course CAR T-cell therapy is a “must” of an up-to-date HSCT-educational: Jochen Buechner updated the audience with promising current results and developments of the worldwide multicenter single-arm open-label ELIANA trial to treat children with relapsed and refractory B-precursor ALL using the fascinating genetically modified chimeric-antigen-receptor (CAR) T-cells.

Taken together Marianne Iversen and her team represented a perfect host for this important and up-to-date PDWP and IEWP-driven educational event.

A trilogy, handling the issue of fertility preservation (FP), represents three key PDWP publications in Bone Marrow Transplantation in 2017 (see below the key publications)

One more time the know-how of the PDWP in the field of VOD was proven by the paper “Diagnosis and severity criteria for sinusoidal obstruction syndrome/veno-occlusive disease in pediatric patients: a new classification from the EBMT”.

Finally, the PDWP driven study ALL SCTped 2012 FORUM (“For Omitting Radiation Under Majority Age”) is successfully running, recruiting patients from the whole of Europe and overseas.

Principal research studies

1. ALL SCTped 2012 FORUM (“For Omitting Radiation Under Majority Age”)
2. Evaluation of practice guidelines for the assessment and surveillance follow-up of pediatric hematopoietic stem cell donors
3. Pregnancy rates and pregnancy outcomes after HSCT performed during childhood
4. Transfer from SCT- to ICU-unit in the context of allogeneic SCT
5. Subsequent allogeneic SCT in paediatric patients: indications, procedures and outcome
6. Outcome of children developing grade III-IV acute graft-versus-host-disease after allogeneic haematopoietic stem cell transplantation
Key publications


5. More chronic GvHD and non-relapse mortality after peripheral blood stem cell compared with bone marrow in hematopoietic transplantation for paediatric acute lymphoblastic leukemia: a retrospective study on behalf of the EBMT Paediatric Diseases Working Party. Simonin M, Bone Marrow Transplant. 2017 Jul

Major educational courses

1. 6th Training Course for Paediatricians and Paediatric Nurses on HSCT in Children and Adolescents - 8-10 June 2017 in Copenhagen, Denmark
Major achievements

The CMWP is a disease-orientated Working Party covering diseases such as chronic myeloid and lymphocytic leukaemia, myelodysplastic syndromes and secondary leukaemia, myeloproliferative neoplasms, multiple myeloma, and other plasma cell disorders such as amyloidosis. The mission of the CMWP is to contribute significantly to an improved outcome of stem cell transplantation in chronic haematological malignancies.

In January 2017 Marie Robin hosted in Paris a symposium on “New insight into pathogenesis and treatment of MDS”. In September 2017 Matjaz Sever invited us for the business meeting and an educational event in Ljubljana in Slovenia. The event was titled: “Impact of Molecular Mutation on Transplant Decision?” which highlighted the increasing importance of molecular genetics in order to select proper treatment decisions including stem cell transplantation”.

A major achievement in 2017 was the publication of the randomized EBMT study “Dose-Reduced Versus Standard Conditioning Followed by Allogeneic Stem-Cell Transplantation for Patients With Myelodysplastic Syndrome: A Prospective Randomized Phase III Study of the EBMT (RICMAC Trial)” in the JCO.

In 2017 we provided in Blood guidelines on allogeneic hematopoietic stem cell transplantation for MDS and CMML.

Many important contributions in the field were published by studies from data derived from a “Data Quality Initiative” in CLL and MDS, which provide a better data quality and thus a more in depth insight in outcome after transplantation. Special thanks to all the centers who worked hard on collecting and providing these additional data. Many new studies derived from the CALM study in myeloma patients are ongoing.

This high activity and scientific productivity of the CMWP are reflected by 30 manuscripts in peer-reviewed journals such as Journal of Clinical Oncology, Blood, Leukemia, Haematologica, British Journal of Haematology, Bone Marrow Transplantation, Biology of Blood and Marrow Transplantation, etc, resulting in a cumulative impact factor of more than 200 in 2017. At international meetings such as ASH, EHA, and EBMT, active and highly motivated members of the CMWP presented more than 34 oral or poster presentations.

Principal research studies

1. 5-Azacytidine vs Allogeneic Stem Cell Transplantation in elderly MDS patients (Vidaza-allo Study). A prospective, randomized EBMT-labelled study

2. Data Qualitative initiative in MPN, MDS and CMML

3. Multi-state model to develop outcome after sequential therapies (e.g Myeloma)

4. Life expectancies of long term survivors after allograft for CLL, MDS and MPN in comparison to normal population
Key publications

1. Dose-Reduced Versus Standard Conditioning Followed by Allogeneic Stem-Cell Transplantation for Patients With Myelodysplastic Syndrome: A Prospective Randomized Phase III Study of the EBMT (RICMAC Trial). Kröger N, J Clin Oncol. 2017 Jul 1

2. Allogeneic hematopoietic stem cell transplantation for MDS and CMML: recommendations from an international expert panel. de Witte T, Blood. 2017 Mar 30


4. Melphalan 140mg/m² or 200mg/m² for autologous transplantation in myeloma: results from the Collaboration to Collect Autologous Transplant Outcomes in Lymphoma and Myeloma (CALM) study. A report by the EBMT Chronic Malignancies Working Party. Auner HW, Haematologica. 2017 Dec 7

5. Centre characteristics and procedure-related factors have an impact on outcomes of allogeneic transplantation for patients with CLL: a retrospective analysis from the European Society for Blood and Marrow Transplantation (EBMT). Schetelig J, Br J Haematol. 2017 Aug

Major educational courses

1. CMWP Business Meeting and Educational Event “New insight into pathogenesis and treatment of MDS” - 20-21 January 2017 in Paris, France

2. Educational event of the Chronic Malignancies Working Party “Impact of Molecular Mutation on Transplant Decision?” - 23 September 2017 in Ljubljana, Slovenia
Major achievements

Three major fields are addressed by TCWP: 1) Science – in order to perform top quality research of non-infectious transplant complications by exploiting existing retrospective data, performing prospective, non-invasive studies based on reports from interested centers and by investigating current practices with performing EBMT surveys. 2) Education – in order to provide top educational courses and position statements covering a broad spectrum of post transplant complications including rare and controversial ones. 3) People – in order to provide a platform for investigators from EBMT centers and other Working Parties for an efficient and quick project development.

Following the 2017 elections, Grzegorz W. Basak (Poland) became the new Chair and Zinaida Peric (Croatia) the Secretary of the TCWP. The latter consists of three subcommittees: Regimen-related toxicity and supportive care (T. Ruutu), Graft-versus-host disease (H. Greinix), Late Complications (N. Salooja) and a Nurse Lead (Diana Greenfield). Since 2017, TCWP collaborates with the EBMT Paris Office.

In September 2017, the Complications and Quality of Life WP was renamed into Transplant Complications Working Party, in order to better explain its field of interest, which includes all non-infectious causes of post transplant morbidity and mortality, in particular VOD, microangiopathy, acute and chronic GvHD and late complications.

In 2017, we focused on the finalisation of ongoing studies, which resulted in five ASH abstracts and a number of pending manuscripts. We developed the WP strategy with clear definition of mission, goals and tasks. Recently we developed a significant number of new studies chosen by the criteria of actual clinical importance and in order to address the most burning issues. The list stays opened for further innovative projects.

The clear benefit of performing studies within TCWP is to access to a substantial body of retrospective data from the EBMT database, the possibility to officially approach EBMT centers with new ideas, supported by experts in the field, full-time data manager and statistician. We encourage you to contact us with new projects and we will do our best to accomplish your goals.

Principal research studies

1. EASIX Score to predict outcomes of alloHCT (O. Penack, T. Luft) – validation and further investigation of new and easy score based on LDH, platelets and creatinine.
2. Complications of CTX-based haploidentical stem cell transplantation (G. Basak) – noninvasive prospective study
3. Incidence and mortality of acute GvHD over time (N Kroger, H Greinix)
4. SFAST: A cross-sectional study on the sexual function of adult survivors and their partners 3 and 15 years post allogeneic stem cell transplantation (C Eeltink)
Key publications


2. The EBMT-ELN working group recommendations on the prophylaxis and treatment of GvHD: a change-control analysis. Ruutu T, Bone Marrow Transplant. 2017 Mar

3. Health-care professionals’ perspective on discussing sexual issues in adult patients after haematopoietic cell transplantation. Eeltink CM, Bone Marrow Transplant. 2017 Dec 15

4. Metabolic syndrome and cardiovascular disease following hematopoietic cell transplantation: screening and preventive practice recommendations from CIBMTR and EBMT. DeFilipp Z, Bone Marrow Transplant. 2017 Feb

Major educational courses

1. Crash course on recommendations on diagnosis and treatment of noninfectious complications after HCT - 19-20 October 2017 in Granada, Spain
# Publications 2017

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<td>A comparison between allogeneic stem cell transplantation from unmanipulated haploidentical and unrelated donors in acute leukemia.</td>
<td>Piemontese S</td>
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<td>A risk factor analysis of outcomes after unrelated cord blood transplantation for children with Wiskott-Aldrich syndrome.</td>
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<td>ABO incompatibility in mismatched unrelated donor allogeneic hematopoietic cell transplantation for acute myeloid leukemia: A report from the acute leukemia working party of the EBMT.</td>
<td>Canaani J</td>
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<td>Administration of high-dose chemotherapy with stem cell support in patients 40 years of age or older with advanced germ cell tumours: a retrospective study from the European Society for Blood and Marrow Transplantation database.</td>
<td>Necchi A</td>
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<td>Allogeneic hematopoietic cell transplantation for primary refractory acute lymphoblastic leukemia: A report from the Acute Leukemia Working Party of the EBMT.</td>
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<td>Allogeneic hematopoietic stem cell transplantation for MDS and CMML: recommendations from an international expert panel.</td>
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<td>Allogeneic Stem Cell Transplantation for Myelodysplastic Syndrome Patients with a 5q Deletion.</td>
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<td>Allogeneic stem cell transplantation in adult patients with acute myeloid leukemia and 17p abnormalities in first complete remission: a study from the Acute Leukemia Working Party (ALWP) of the European Society for Blood and Marrow Transplantation (EBMT).</td>
<td>Poiré X</td>
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<td>Allogeneic stem cell transplantation benefits for patients ≥ 60 years with acute myeloid leukemia and FLT3 internal tandem duplication: a study from the Acute Leukemia Working Party of the European Society for Blood and Marrow Transplantation.</td>
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<td>Alloreactivity: the Janus-face of hematopoietic stem cell transplantation.</td>
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<td>An Integrative Scoring System for Survival Prediction Following Umbilical Cord Blood Transplantation in Acute Leukemia.</td>
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<td>Anti-thymocyte globulin as graft-versus-host disease prevention in the setting of allogeneic peripheral blood stem cell transplantation: a review from the Acute Leukemia Working Party of the European Society for Blood and Marrow Transplantation.</td>
<td>Baron F</td>
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<td>Association of aplastic anaemia and lymphoma: a report from the severe aplastic anaemia working party of the European Society of Blood and Bone Marrow Transplantation.</td>
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<td>Autologous haematopoietic stem cell transplantation for systemic lupus erythematosus: time ready for a paradigm shift?</td>
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<td>Autologous stem-cell transplantation in treatment-refractory Crohn’s disease: an analysis of pooled data from the ASTIC trial.</td>
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<td>Autologous haematopoietic stem cell transplantation for treatment of multiple sclerosis.</td>
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<td>Baseline Characteristics Predicting Very Good Outcome of Allogeneic Hematopoietic Cell Transplantation in Young Patients With High Cytogenetic Risk Chronic Lymphocytic Leukemia - A Retrospective Analysis From the Chronic Malignancies Working Party of the EBMT.</td>
<td>van Gelder M</td>
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<td>Cardiopulmonary assessment of patients with systemic sclerosis for hematopoietic stem cell transplantation: recommendations from the European Society for Blood and Marrow Transplantation Autoimmune Diseases Working Party and collaborating partners.</td>
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<td>Centre characteristics and procedure-related factors have an impact on outcomes of allogeneic transplantation for patients with CLL: a retrospective analysis from the European Society for Blood and Marrow Transplantation (EBMT).</td>
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<td>Comparison of matched sibling donors versus unrelated donors in allogeneic stem cell transplantation for primary refractory acute myeloid leukemia: a study on behalf of the Acute Leukemia Working Party of the EBMT.</td>
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<td>Diagnosis and severity criteria for sinusoidal obstruction syndrome/veno-occlusive disease in pediatric patients: a new classification from the European society for blood and marrow transplantation.</td>
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<td>Donor age determines outcome in acute leukemia patients over 40 undergoing haploidentical hematopoietic cell transplantation.</td>
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<td>Dose-Reduced Versus Standard Conditioning Followed by Allogeneic Stem-Cell Transplantation for Patients With Myelodysplastic Syndrome: A Prospective Randomized Phase III Study of the EBMT (RIOMAC Trial).</td>
<td>Kröger N</td>
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<td>ECIL-6 guidelines for the treatment of invasive candidiasis, aspergillosis and mucormycosis in leukemia and hematopoietic stem cell transplant patients.</td>
<td>Tissot F</td>
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<td>Evolution, trends, outcomes, and economics of hematopoietic stem cell transplantation in severe autoimmune diseases.</td>
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<td>Factors Associated with Long-Term Risk of Relapse after Unrelated Cord Blood Transplantation in Children with Acute Lymphoblastic Leukemia in Remission.</td>
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<td>Fertility preservation issues in pediatric hematopoietic stem cell transplantation: practical approaches from the consensus of the Pediatric Diseases Working Party of the EBMT and the International BFM Study Group.</td>
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<td>Fluoroquinolone prophylaxis in haematological cancer patients with neutropenia: ECIL critical appraisal of previous guidelines.</td>
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<td>Handling, processing and disposal of stem cell products in Europe: A survey by the cellular therapy and immunobiology working party of the European Society for Blood and Marrow Transplantation.</td>
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<td>Hematopoietic stem cell transplantation in patients with gain-of-function signal transducer and activator of transcription 1 mutations.</td>
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<td>High dose chemotherapy and autologous stem cell transplantation in nodular lymphocyte-predominant Hodgkin lymphoma: A retrospective study by the European society for blood and marrow transplantation-lymphoma working party.</td>
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<td>High-Dose Chemotherapy for Adult-Type Ovarian Granulosa Cell Tumors: A Retrospective Study of the European Society for Blood and Marrow Transplantation.</td>
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<td>How I manage patients with Fanconi anemia.</td>
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<td>Impact of ABO incompatibility on patients' outcome after haploidentical hematopoietic stem cell transplantation for acute myeloid leukemia - a report from the Acute Leukemia Working Party of the EBMT.</td>
<td>Canaani J</td>
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<td>Impact of CTLA4 genotype and other immune response gene polymorphisms on outcomes after single umbilical cord blood transplantation.</td>
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<td>Impact of FAB classification on predicting outcome in acute myeloid leukemia, not otherwise specified, patients undergoing allogeneic stem cell transplantation for acute myeloid leukemia in first complete remission conditioned with a fludarabine iv-busulfan myeloablative regimen: a report from the EBMT Acute Leukemia Working.</td>
<td>Canaani J</td>
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<td>Impact of in vivo T cell depletion in HLA-identical allogeneic stem cell transplantation for acute myeloid leukemia in first complete remission conditioned with a fludarabine iv-busulfan myeloablative regimen: a report from the EBMT Acute Leukemia Working.</td>
<td>Rubio MT</td>
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<td>Improving results of allogeneic hematopoietic cell transplantation for adults with acute lymphoblastic leukemia in first complete remission: an analysis from the Acute Leukemia Working Party of the European Society for Blood and Marrow Transplantation.</td>
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<td>Incidence of Second Primary Malignancies after Autologous Transplantation for Multiple Myeloma in the Era of Novel Agents.</td>
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<td>Intravenous Busulfan Compared with Treosulfan-Based Conditioning for Allogeneic Stem Cell Transplantation in Acute Myeloid Leukemia: A Study on Behalf of the Acute Leukemia Working Party of European Society for Blood and Marrow Transplantation.</td>
<td>Shmoni A</td>
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<td>JACIE accreditation for blood and marrow transplantation: past, present and future directions of an international model for healthcare quality improvement.</td>
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<td>Jon van Rood (1926-2017).</td>
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<td>Long-term Outcomes After Autologous Hematopoietic Stem Cell Transplantation for Multiple Sclerosis.</td>
<td>Muraro PA</td>
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<td>Long term impact of hyperleukocytosis in newly diagnosed acute myeloid leukemia patients undergoing allogeneic stem cell transplantation: An analysis from the acute leukemia working party of the EBMT.</td>
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<td>Long Term Outcomes of Cord Blood Transplantation From an HLA-Identical Sibling for Patients with Bone Marrow Failure Disorders: a Report From Eurocord, Cord Blood Committee (CBC-CTWP) and Severe Aplastic Anemia Working Party (SAAWP) of the European Society for Blood and Marrow Transplantation.</td>
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<td>Metabolic syndrome and cardiovascular disease following hematopoietic cell transplantation: screening and preventive practice recommendations from CIBMTR and EBMT.</td>
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<td>Occurrence of graft-versus-host disease increases mortality after umbilical cord blood transplantation for acute myeloid leukaemia: a report from Eurocord and the ALWP of the EBMT.</td>
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<td>Outcome after relapse of myelodysplastic syndrome and secondary acute myeloid leukemia after allogeneic stem cell transplantation: a retrospective registry analysis on 698 patients by the Chronic Malignancies Working Party of European Society of Blood and Marrow Transplantation.</td>
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<td>Outcomes of haploidentical stem cell transplantation for chronic lymphocytic leukemia: a retrospective study on behalf of the chronic malignancies working party of the EBMT.</td>
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<td>Outcomes of UCB transplantation are comparable in FLT3+ AML: results of CIBMTR, EUROCORD and EBMT collaborative analysis.</td>
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<td>Pneumocystis jirovecii pneumonia: still a concern in patients with haematological malignancies and stem cell transplant recipients-authors’ response.</td>
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<td>Relatively favorable outcome after allogeneic stem cell transplantation for BCR-ABL1-positive AML: A survey from the acute leukemia working party of the European Society for blood and marrow transplantation (EBMT).</td>
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<td>Revised diagnosis and severity criteria for sinusoidal obstruction syndrome/veno-occlusive disease in adult patients: a new classification from the European Society</td>
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<td>Salvage high-dose chemotherapy in female patients with relapsed/refractory germ cell tumors: a retrospective analysis of the European Group for Blood and Marrow Transplantation (EBMT).</td>
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<td>Salvage High-Dose Chemotherapy for Relapsed Pure Seminoma in the Last 10 Years: Results From the European Society for Blood and Marrow Transplantation Series 2002-2012.</td>
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<td>Sickle cell disease: an international survey of results of HLA-identical sibling hematopoietic stem cell transplantation.</td>
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<td>Single- or double-unit UCBT following RIC in adults with AL: a report from Eurocord, the ALWP and the CTIWP of the EBMT.</td>
<td>Baron F</td>
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<td>State-of-the-art fertility preservation in children and adolescents undergoing haematopoietic stem cell transplantation: a report on the expert meeting of the Paediatric Diseases Working Party (PDWP) of the European Society for Blood and Marrow Transplant.</td>
<td>Dalle JH</td>
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<td>The Association of Combined GSTM1 and CYP2C9 Genotype Status with the Occurrence of Hemorrhagic Cystitis in Pediatric Patients Receiving Myeloablative Conditioning Regimen Prior to Allogeneic Hematopoietic Stem Cell Transplantation.</td>
<td>Uppugunduri CRS</td>
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<td>The survey on cellular and tissue-engineered therapies in Europe and neighboring Eurasian countries in 2014 and 2015.</td>
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<td>The impact of HLA matching on outcomes of unmanipulated haploidentical HSCT is modulated by GVHD prophylaxis.</td>
<td>Lorentino F</td>
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<td>Thiotepa-based conditioning versus total body irradiation as myeloablative conditioning prior to allogeneic stem cell transplantation for acute lymphoblastic leukemia: A matched-pair analysis from the Acute Leukemia Working Party of the European Society for Blood and Marrow Transplantation.</td>
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<td>Transplant results in adults with Fanconi anaemia.</td>
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<td>Treatment of severe forms of LPS-responsive beige-like anchor protein deficiency with allogeneic hematopoietic stem cell transplantation.</td>
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<td>Unmanipulated haploidentical stem cell transplantation in adults with acute lymphoblastic leukemia: a study on behalf of the Acute Leukemia Working Party of the EBMT.</td>
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<td>Unrelated matched versus autologous transplantation in adult patients with good and intermediate risk acute myelogenous leukemia in first molecular remission.</td>
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<td>Use of defibrotide to treat transplant-associated thrombotic microangiopathy: a retrospective study of the Paediatric Diseases and Inborn Errors Working Parties of the European Society of Blood and Marrow Transplantation.</td>
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<td>Use of haploidentical stem cell transplantation continues to increase: the 2015 European Society for Blood and Marrow Transplantation activity survey report.</td>
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<td>Validation of the acute leukemia-EBMT score for prediction of mortality following allogeneic stem cell transplantation in a multi-center GITMO cohort.</td>
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<td>Validation of the revised IPSS at transplant in patients with myelodysplastic syndrome/transformed acute myelogenous leukemia receiving allogeneic stem cell transplantation: a retrospective analysis of the EBMT chronic malignancies working party.</td>
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<td>What is the outcome in patients with acute leukaemia who survive severe acute graft-versus-host disease?</td>
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In 2016, a total of 43,636 transplants were reported in 39,313 patients (first transplant) from 679 teams in 40 European and 9 affiliated countries. Of these, 17,641 HCT (40%) were allogeneic and 25,995 (60%) autologous. When compared with 2015, the total number of transplants increased by 3.5% (2.0% allogeneic HCT and 4.5% autologous HCT). In addition, there were 4,323 second or subsequent transplants (1,134 allogeneic and 3,189 autologous). In patients receiving their first transplant in 2016, allogeneic HCT increased by 3.0%, in which a 6.2% increase was seen for pediatric patients and 2.1% increase for adult patients. Autologous HCT increased by 5.6%.

The main diseases were myeloid malignancies (AML, CML, MDS and MPN): 9,547 (24% of total; 96% of which were allogeneic); lymphoid malignancies (ALL, CLL, HL, NHL and PCD): 25,618 (65%; 20% allogeneic); solid tumors: 1,516 (4%; 2% allogeneic); non-malignant disorders: 2,459 (6%; 85% allogeneic) and others: 173 (0.4%) (Table 1, figure 1).

Observations and trends include the use of allogeneic HCT for CML, where, after the major decrease due to the introduction of tyrosine kinase inhibitors in 2000, there is a stable number of approximately 400 patients reported annually since 2008. For MDS, it appears that the use of allogeneic HCT has been levelling off since 2014 but continues to increase in MPN. For lymphoid malignancies, a mixed picture is seen, with increasing numbers for NHL and decreasing numbers for PCD and HL. In CLL, an increase of 8% is seen in allogeneic HCT, after the major decrease of 49% seen between the years 2011 and 2015. Trends in autologous HCT continue to show an increase for PCD but less so for NHL and a levelling off in HL. In AID, a sharp increase is seen over the last 5 years, driven mostly by autologous HCT for multiple sclerosis in specialized centers.

One interesting observation in this year’s survey is the remarkable growth of unrelated donor HCT seen between 2004 and 2015, with annual growth rates of >16%, appears to be slowing down. In consequence, it would be of interest to check whether such growth rates will remain similar in the next few years. To look whether sibling, unrelated and haploidentical HCT were used differently according to available resources, transplant rates over the last 5 years in three income groups; very high, high and upper middle income defined as GNI in USD per capita according to World Bank criteria were considered (table 2). The rates of haploidentical HCT were highest in the high income group when compared to the very high income group and argues in favor of haploidentical HCT use over unrelated HCT, possibly based, in part, on economic considerations. In the very high income groups, rates of alternative donor HCT were equally low, when compared to sibling donor HCT, possibly pointing towards restricting HCT technology to the best possible donor in situations where resources are limited.

**Cellular therapy use**

2,879 patients received donor lymphocyte infusions. 1,153 patients received other forms of cellular therapy, most commonly mesenchymal stromal cells (n=491), mainly to treat graft versus host disease. The second most common indication was expanded / selected T lymphocytes to treat infections (n=157) or malignancy (n=35). Only very few (n=36) cellular therapies using genetically modified allogeneic or autologous T-lymphocytes were reported.

The activity survey reports the most recent trends in stem cell transplantation and is an essential tool for health care planning and health policy makers. It reflects the culture of sharing information and data prevalent within the EBMT.

**Helen Baldomero, Jakob R Passweg**

EBMT Activity Survey Office, Hematology, Department of Medicine, University Hospital, Basel, Switzerland

### Table 1

Numbers of HCT in Europe 2016 by indication, donor type and stem cell source

<table>
<thead>
<tr>
<th>Indication</th>
<th>Allogeneic</th>
<th>Unrelated</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Myeloid malignancies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute myeloid leukemia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st complete remission</td>
<td>272</td>
<td>1825</td>
<td>2097</td>
</tr>
<tr>
<td>not 1st complete remission</td>
<td>185</td>
<td>1166</td>
<td>1351</td>
</tr>
<tr>
<td>AML therapy related</td>
<td>68</td>
<td>438</td>
<td>506</td>
</tr>
<tr>
<td>AML from MDS/MPN</td>
<td>3</td>
<td>62</td>
<td>65</td>
</tr>
<tr>
<td>Chronic myeloid leukemia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>chronic phase</td>
<td>32</td>
<td>102</td>
<td>134</td>
</tr>
<tr>
<td>not chronic phase</td>
<td>13</td>
<td>51</td>
<td>64</td>
</tr>
<tr>
<td>MDS or MD/MPN</td>
<td>86</td>
<td>419</td>
<td>505</td>
</tr>
<tr>
<td>MPN</td>
<td>6</td>
<td>167</td>
<td>233</td>
</tr>
<tr>
<td><strong>Lymphoid malignancies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute lymphatic leukemia</td>
<td>263</td>
<td>734</td>
<td>997</td>
</tr>
<tr>
<td>1st complete remission</td>
<td>158</td>
<td>537</td>
<td>695</td>
</tr>
<tr>
<td>not 1st complete remission</td>
<td>105</td>
<td>197</td>
<td>302</td>
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<tr>
<td>Chronic lymphocytic leukemia</td>
<td>5</td>
<td>92</td>
<td>97</td>
</tr>
<tr>
<td>Plasma cell disorders - MM</td>
<td>5</td>
<td>145</td>
<td>190</td>
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<tr>
<td>Plasma cell disorders - other</td>
<td>2</td>
<td>12</td>
<td>14</td>
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<tr>
<td>Hodgkin’s lymphoma</td>
<td>17</td>
<td>134</td>
<td>151</td>
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<tr>
<td>Non Hodgkin lymphoma</td>
<td>42</td>
<td>378</td>
<td>420</td>
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<tr>
<td><strong>Solid tumors</strong></td>
<td>0</td>
<td>3</td>
<td>3</td>
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<tr>
<td>Neuroblastoma</td>
<td>1</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Soft tissue sarcoma/Ewing</td>
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<td>1</td>
<td>2</td>
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<tr>
<td>Germinal tumors</td>
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<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Other solid tumors</td>
<td>3</td>
<td>3</td>
<td>6</td>
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<tr>
<td><strong>Non malignant disorders</strong></td>
<td>640</td>
<td>245</td>
<td>885</td>
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<td>Bone marrow failure - SAA</td>
<td>193</td>
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<td>312</td>
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<tr>
<td>Bone marrow failure - other</td>
<td>82</td>
<td>26</td>
<td>108</td>
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<tr>
<td>Thalassemia</td>
<td>138</td>
<td>50</td>
<td>188</td>
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<tr>
<td>Sickle cell disease</td>
<td>78</td>
<td>20</td>
<td>98</td>
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<tr>
<td>Primary Immune deficiencies</td>
<td>116</td>
<td>27</td>
<td>143</td>
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<tr>
<td>Inh. disorders of Metabolism</td>
<td>28</td>
<td>2</td>
<td>30</td>
</tr>
<tr>
<td>Auto immune disease</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Others</td>
<td>21</td>
<td>15</td>
<td>36</td>
</tr>
<tr>
<td><strong>TOTAL NUMBER OF PATIENTS</strong></td>
<td>1391</td>
<td>4291</td>
<td>5682</td>
</tr>
<tr>
<td><strong>TOTAL NUMBER OF TRANSPLANTS</strong></td>
<td>1432</td>
<td>4503</td>
<td>5935</td>
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Ref: Passweg et al. Bone Marrow Transplantation Dec. (in press)
Table 2:
Transplant rates per 10 million inhabitants during the years 2012 and 2016 by donor choice and income group

<table>
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<th>Income group</th>
<th>Identical Sibling</th>
<th>Haploidentical family</th>
<th>Unrelated</th>
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<tr>
<td>Very high (GNI: &gt;41,000 USD)</td>
<td>390</td>
<td>77</td>
<td>978</td>
</tr>
<tr>
<td>High (GNI: 8,200-41,000 USD)</td>
<td>283</td>
<td>106</td>
<td>321</td>
</tr>
<tr>
<td>Upper middle (GNI: 2,080-8,200 USD)</td>
<td>102</td>
<td>16</td>
<td>16</td>
</tr>
</tbody>
</table>


Figure 1:
Relative proportion of disease indications for HCT in Europe in 2016

Figure 1a: allogeneic HCT

Figure 1b: autologous HCT

Abbreviations:
Registry milestone

In January 2017, the EBMT Registry database reached the milestone of half a million patient registrations.

EBMT Communications and the Registry worked together to create an explainer video. With this video, viewers understood the importance of the Registry and how it has contributed to advances in blood stem cell transplants. In addition, the EBMT took the opportunity to thank all the parties involved; the collaborative work of the 500 plus member centres of EBMT and national registries resulted in this milestone of 500,000 registered patients.

New registrations

15,717 allografts and 22,341 autografts were registered during 2017.
Cell therapy

During 2017, the new Cell therapy forms were finalised and implemented in the database. Training on how to complete these forms was done during the Annual Meeting and a manual has been uploaded to the Data Management web pages to help users with the forms. Feedback from centres has highlighted the need to better customise the different scenarios presented by the complexity and variation between the different types of cell therapies. The Registry is gathering this information and, in collaboration with the CTRWP, is using it to streamline the data entry flow in the implementation of the forms in the new Registry system.

End user engagement

In Autumn 2017, a Demo of Macro was provided to the EBMT Data Registries Group. Further demos are planned to take place in the first quarter of 2018, at the BSBMT Data Manager Training Day (UK) and at EBMT 2018 as part of the Data Management sessions. During the EBMT Annual Meeting we will also provide preliminary training on MACRO. We look forward to offering delegates a taster of the new system and receiving their feedback. In addition, we hope to open a demo site online, for centre data managers to visit and gain some appreciation of the software before it goes live.

Timeline

As the development programme takes shape we have been able to set some targets. Software development is only part of the project. The provision of adequate documentation and training are just as important. Our aim is to create a sufficient buffer so that end dates need not be changed even if some activities end up being delayed. Key project workstreams are shown below.

Initial testing of Macro

Staff at the EBMT Registry Office have been involved in the initial testing of the Registry Design. They reported a user-friendly experience in Data Entry with simple screens. They found more flexibility in the data structure. For example, reporting more than one diagnosis at a time with separate tests and assessments for each disease, and the possibility to enter multiple drugs or results into tables instead of creating separate records.

Data Management features for identifying missing data or clarifying data will also improve efficiency for many users. Now that the Registry design is nearing completion, we are in the process of widening our pool of testers and a number of National Registry staff and centre data managers have volunteered to devote some of their time. We are very grateful for their support.
## Education

<table>
<thead>
<tr>
<th>Infographic EBMT 43rd Annual Meeting</th>
<th>43</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awards</td>
<td>46</td>
</tr>
<tr>
<td>Educational events</td>
<td>49</td>
</tr>
</tbody>
</table>
The EBMT Annual Meeting is the Society’s flagship event. It brings together scientists, physicians, nurses, data managers, patients, quality managers, statisticians, pharmacists, biologists, technicians and psychologists from Europe and all over the world. The exciting scientific programme is designed to cover the key issues relating to hematopoietic stem cell transplantation and cellular therapy research.

43rd Meeting of the Physicians

33rd Meeting of the Nurses Group

16th Meeting of the Data Management Group

11th Patient, Family & Donor Day

9th Meeting of the Quality Management Group

6th Cell Therapy Day

6th Paediatric Day

2nd Pharmacist Day

1st Psy Day

5,047 delegates from 85 countries
1,083 abstracts submitted

156 sessions presented by 365 speakers

North America 10%
Europe 85%
Middle East 3%
Asia 2%
Australia / Oceania 1%
Delegates gave the Annual Meeting a rating of 7.5 out of 10
(EBMT 2017 delegates' survey - 559 respondents)

Digital activities

510 people sent 4,234 tweets to the Twitter wall generating 7,127,764 potential impressions

7,193 page views of the EBMT-TV online

3,136 downloads of EBMT 2017 App

2,058 delegates registered and are using the E-materials portal
Awards

Van Bekkum Award
The Van Bekkum Award for the best abstract submitted to the physician’s programme, sponsored by the EBMT, was presented to Peter Bader for the abstract entitled: Impact of MRD before and after Allogeneic Hematopoietic Cell Transplantation (HCT) of Childhood ALL By FC and RQ-PCR: A Retrospective Study on Behalf of COG, the PBMT, the i-BFM the PDWP of the EBMT, and the Westhafen-Intercontinental-Group.

Basic Science Award
The Basic Science Award, sponsored by Cryostem, was presented to Attilio Bondanza for the abstract entitled: Monocytes/macrophages are required for both optimal anti-leukaemia efficacy and the cytokine release syndrome by CAR-T cells.

Honorary Membership
Honorary Membership awarded to Dean Buckner (US) and to Axel R. Zander (Germany)

Clinical Achievements
The Clinical Achievement Award awarded to Dominique Maranich (France) and to Ljiljana Tucik (Serbia)
The Jian-Jian Luan Award
The Jian-Jian Luan Award for Lymphoma Transplant, sponsored by the EBMT, was presented to Carmelo Carlo-Stella for the abstract entitled: Haploidentical transplantation for Hodgkin lymphoma relapsed after autologous transplant: reduced incidence of relapse and of chronic GVHD compared to HLA-identical related donors.

The Jon van Rood Award
The Jon van Rood Award for the best paper in the immunobiology of allogeneic hematopoietic transplantation, sponsored by EBMT, was presented to Sarina Ravens (Germany) for the paper entitled: Human gamma delta T cells are quickly reconstituted after stem cell transplantation and show adaptive clonal expansion after viral infection.

The Joint ISCT-EBMT Award
The Joint ISCT-EBMT Award for the best abstract in cellular therapy was presented to Arpad Szoor for the abstract entitled: Two-pronged Cell Therapy: Engineering NK cells to target CD22 and redirect bystander T cells to CD19 for the adoptive immunotherapy of B-cell malignancies.

Best Young Abstracts
The Best Young Abstract Awards for the best abstracts submitted for Oral and Poster presentations, sponsored by the EBMT, were presented to 13 young investigators:
1. Zhihui Li (China) B379
2. Michael Medinger (Switzerland) A399
3. Zhanna Shekhovtsova (Russia) B230
4. David Jacobsohn (USA) B168
5. Isabelle Krämer (Germany) B265
6. Sachiko Seo (Japan) A372
7. Cheng Juan Luo (China) Oral Abstract
8. Su-Peng Yeh (Taiwan) B211
9. Maximilian Doppelhammer (Germany) B232
10. Daria Pagliara (Italy) B171
11. Sabrina Giammarco (Italy) B253
12. Samia Harbi (France) A166
13. Anna Barata (Spain) A439

Nature Publishing Poster Awards
The Best Clinical Poster Award, sponsored by Nature Publishing Group, was presented to Francesca Bonifazi (Italy) for her poster A440 entitled: Significant Improvement of QoL by using ATG as part of the conditioning regimen followed by HLA-identical peripheral stem cell transplantation in acute leukemia patients. Results from a prospective, randomized phase III study (ATG Family Study).

The Best Science Poster Award, sponsored by Nature Publishing Group, was presented to Zhanna Shekhovtsova for her poster B174 entitled: Results of hematopoietic stem cells transplantation with TCR +/CD19+ -depletion from matched unrelated and haploidentical donors in pediatric acute myeloblastic leukemia patients in complete remission.

The Best Poster Award was presented to Michelle Taylor, Vicky John, Jasmin Hebdon (Macmillan Haematology Clinical nurse specialists, UK) for the poster NP42 entitled: Implementing and improving the holistic needs assessments for autologous stem cell patients.

The Best Original Research was presented to Annika Kisch (Sweden) for her abstract entitled: “The core of sibling stem cell donation - a prospective grounded theory approach”.

The 9th Distinguished Merit Award was presented to Eugenia Anjona Trigoso (Spain).

The Best Oral Presentation Award was presented to Fabienne Colledani (France) for the presentation entitled: Nursing care in gastrointestinal GvHD.

The Best Poster Award was presented to Carmelo Carlo-Stella for the abstract entitled: Haploidentical transplantation for Hodgkin lymphoma relapsed after autologous transplant: reduced incidence of relapse and of chronic GVHD compared to HLA-identical related donors.

The Best Original Research was presented to Annika Kisch (Sweden) for her abstract entitled: “The core of sibling stem cell donation - a prospective grounded theory approach”.

EBMT, European Society for Blood and Marrow Transplantation
47
The EBMT acknowledged the work that stems from the pioneering observations made by E. Donnall Thomas, also known as the father of bone marrow transplantation and who received the Nobel Prize in Medicine in 1990. For over 60 years Thomas’ colleagues and fellows, not only in the United States but also in Europe and worldwide, have worked relentlessly in preclinical and clinical research to develop innovative treatments that improve the outcome and quality of life for cancer patients.

At the Opening Session, Rainer Storb from the faculty of both, the Fred Hutchinson Cancer Research Center and the University of Washington School of Medicine, gave a keynote lecture entitled, “60 years of HSCT: progress from bone marrow transplantation to the first cellular and gene therapies.”

A short movie was also presented to the attendees highlighting the pioneers and the milestones over the last sixty years in the field of stem cell transplantation (this video is available on the EBMT YouTube Channel).
## Educational events 2017

<table>
<thead>
<tr>
<th>Location</th>
<th>Date</th>
<th>Event Description</th>
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<tbody>
<tr>
<td></td>
<td>18 attendees</td>
<td></td>
</tr>
<tr>
<td>Barcelona, Spain</td>
<td>1-2 June 2017</td>
<td>JACIE Inspector Training Course</td>
</tr>
<tr>
<td></td>
<td>18 attendees</td>
<td></td>
</tr>
<tr>
<td>Copenhagen, Denmark</td>
<td>8-10 June 2017</td>
<td>PDWP / IEWP 6th Training Course for Paediatricians and Paediatric Nurses on HSCT in Children and Adolescents</td>
</tr>
<tr>
<td></td>
<td>120 attendees</td>
<td></td>
</tr>
<tr>
<td>Barcelona, Spain</td>
<td>8-10 September 2017</td>
<td>EBMT 2nd EBMT International Transplant Course (ITC)</td>
</tr>
<tr>
<td></td>
<td>120 attendees</td>
<td></td>
</tr>
<tr>
<td>Prague, Czech Republic</td>
<td>20-22 September 2017</td>
<td>LWP 13th education course of the Lymphoma Working Party</td>
</tr>
<tr>
<td></td>
<td>51 attendees</td>
<td></td>
</tr>
<tr>
<td>Ljubljana, Slovenia</td>
<td>23 September 2017</td>
<td>CMWP Educational event of the Chronic Malignancies Working Party “Impact of Molecular Mutation on Transplant Decision?”</td>
</tr>
<tr>
<td></td>
<td>55 attendees</td>
<td></td>
</tr>
<tr>
<td>Barcelona, Spain</td>
<td>5-6 October 2017</td>
<td>JACIE Inspector Training Course</td>
</tr>
<tr>
<td></td>
<td>18 attendees</td>
<td></td>
</tr>
<tr>
<td>Manchester, UK</td>
<td>5-6 October 2017</td>
<td>NURSES GROUP 9th EBMT Nurses International Study Day and 1st EBMT Research Nurses International Course</td>
</tr>
<tr>
<td></td>
<td>135 attendees</td>
<td></td>
</tr>
<tr>
<td>Poznan, Poland</td>
<td>12 October 2017</td>
<td>IDWP 20th “State-of-the-Art” Educational Course of Infectious Diseases Working Party</td>
</tr>
<tr>
<td></td>
<td>139 attendees</td>
<td></td>
</tr>
<tr>
<td>Granada, Spain</td>
<td>19-20 October 2017</td>
<td>TCWP Crash course on recommendations on diagnosis and treatment of noninfectious complications after HCT</td>
</tr>
<tr>
<td></td>
<td>70 attendees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>93 attendees</td>
<td></td>
</tr>
<tr>
<td>Newcastle Upon Tyne, UK</td>
<td>3 November 2017</td>
<td>ADWP / IEWP Joint educational meeting of the EBMT Autoimmune Diseases and Inborn Errors Working Parties</td>
</tr>
<tr>
<td></td>
<td>125 attendees</td>
<td></td>
</tr>
<tr>
<td>Newcastle Upon Tyne, UK</td>
<td>4-5 November 2017</td>
<td>IEWP Inborn Errors Working Party Annual Conference</td>
</tr>
<tr>
<td></td>
<td>140 attendees</td>
<td></td>
</tr>
<tr>
<td>Warsaw, Poland</td>
<td>23-24 November 2017</td>
<td>JACIE Inspector Training Course</td>
</tr>
<tr>
<td></td>
<td>18 attendees</td>
<td></td>
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### Key Acronyms

- **ALWP**: Acute Leukaemia Working Party
- **IEWP**: Inborn Errors Working Party
- **TCWP**: Transplant Complications Working Party
- **LWP**: Lymphoma Working Party
- **SAAWP**: Severe Aplastic Anaemia Working Party
- **IDWP**: Infectious Diseases Working Party
- **CMWP**: Chronic Malignancies Working Party
- **PDWP**: Paediatric Diseases Working Party
- **ADWP**: Autoimmune Diseases Working Party
- **CTWP**: Cellular Therapy and Immunobiology Working Party
- **NG**: Nurses Group
- **JACIE**: JACIE Inspector Training Course
Patient Care

EBMT Nurses Group  51
JACIE  54
EBMT Nurses Group
Haematology and HSCT Nursing

The EBMT Nurses Group (NG) is committed to patient care through education, research and international network collaboration.

The EBMT NG is one of the leading groups in the field of haematology and HSCT nursing. It is dedicated to improving the care of patients receiving HSCT and promoting excellence in and through evidence-based practice.

The NG’s mission is to enhance and value the nursing role all over the world, supporting and sharing knowledge through communication, advocacy, research, training and education.

Education

The nurses and allied health care professions programme at EBMT 2017 in Marseille was a great success from the first session on Sunday 26th through to Wednesday 29th March, celebrating ‘New frontiers - 60 years of Transplant’. Grants to attend EBMT 2017 were given to three nurses enabling them to join 250 nurses on Sunday and 500 nurses over the course of the next few days from across Europe at our 33rd nurse meeting. Sunday is our stand alone educational day and all of the presentations can be found through the nursing section of ebmt.org.

Over the 4 days of congress there were many stimulating and inspiring sessions focussed on the patient journey. Covering the many complications our patients face from diagnosis to their initial treatment and through and beyond the transplant process.

This year we had 3 satellite symposiums throughout the conference, supported by Jazz Pharmaceuticals, Mallinckrodt and Molmed that were extremely well attended and gave good feedback.

Educational Scholarship 2017

Mardin Mazhar from Sulaymania Iraq was a successful applicant to the Educational Scholarship and spent two weeks in Monza (Italy) in the department of paediatric haemat-oncology (Fondazione MBBM).
Paediatric Training Days

The 6th training course for Paediatricians & Paediatric Nurses on HSCT in Children and Adolescents was held on 8-10 June in Copenhagen, Denmark, themed as ‘Developing Aspects and Future Directions with Emphasis on Immune Therapy and Toxicity’.

Forty eight nurses attended the scientific program. The program included nurses’ sessions as well as joint sessions with the physicians. The nurses program focused on a large variety of topics such as improving quality of life, CAR-T cells, and ECP. Joint sessions included talks on the history of BMT, donor and graft selection.

A grant to participate in the meeting was provided by the EBMT nurses board to a nurse from Romania to attend this well run and informative educational.

International Nurses training Day and Inaugural Research Nurses day

Annually EBMT (UK) NAP provides an autumn education meeting. 2017 saw the 48th meeting shared with the main EBMT Nurses Group Committees to host the 9th EBMT Nurses International Study Day. The International Study Day was the first of a 2 day event, taking place in Manchester, 5-7 October 2017 attracting senior nurses from across Europe.

The International Study Day was followed on Friday 6 October by the Inaugural Research Nursing Study Day. Presentations for both days can be downloaded from http://ebmt.co.uk/meetings/

New Nurses Accepted to the Medical Working Parties

New for 2017 was the introduction of a nurse member to the medical working parties. The aim is to perform collaborative nursing/medical projects for patient benefit. The nurses and WP are;

1. Infectious diseases WP - Iris Agreiter (Italy)
2. Lymphoma WP - Erik Aerts (Switzerland)
3. Acute leukaemia WP - Elisabeth Wallhult (Sweden)
4. Paediatric diseases WP - Eugenia Trigoso Arjona (Spain)
5. Severe Aplastic Anaemia WP - Nana Benson-Quarm (UK)
6. Autoimmune Diseases WP - Helen Jessop (UK)
7. Transplant Complications WP - Corien Eeltink (Netherlands)
8. Cellular therapy & Immunobiology WP - Olga Samsonova (France)

Updated Veno-Occlusive Disease (VOD) Learning Programme

The newly updated active management of VOD Learning Programme is available on www.ebmt.org.

What’s new?

- Interactive PowerPoint format with further details in information popups, easy navigation between modules, and links to external resources.
- Self-assessment questions at the end of each module.
- Interactive case studies applying the new EBMT diagnosis and severity grading criteria for VOD in adults.
- Information on risk factors for VOD.
- You can now download the updated VOD learning programme in both Italian and German.
Global Educational Committee

The constitution of the Global Educational Committee in the EBMT NG was formally introduced. The Global Educational Committee in collaboration with the EBMT NG other Committees and various Nurse Groups, aims to coordinate and organise outreach meetings in cooperation with other non-profit associations with the same mission. Together they coordinate and provide a range of educational activities for nurses and allied health professionals within the field of Haematology and HSCT. On 8-9 December 2017 the committee visited Myanmar and gave lectures over 2 days to more than 100 nurses.

Day one incorporated lectures on evidence based quality of care in BM transplant, principles of conditioning, nutrition control, BMT complications management and infection control.

December 9th had a practical course on central venous devices management, particularly focused on peripherally inserted central lines (PICC), with a large participation from doctors from different hospitals across the country.

Nursing Research Committee

There are several projects currently recruiting or about to be launched by EBMT nurses research group.

S-FAST (Collaboration with TCWP) - Ethical approval has been given for various European countries and data collection continues

Nutritional Surveys (Collaboration with TCWP) – Data analysis is underway, and manuscript due to be completed in spring 2018

NG Paediatric committee (Collaboration with PDWP) – Questionnaire looking at improving collaboration between BMT units and paediatric ICU’s, communication during the transfer of patients from SCT unit to ICU

EBMT / WHO collaboration – Infection Control questionnaire for LMIC; questionnaire sent out January 2018

Cutaneous cGvHD QoL questionnaire – Assess current position with regard to impact of cutaneous cGvHD on morbidity / QoL in adult and paediatric population, collaborative project with ASBMT nurses SIG

The Textbook for Nurses

Release: March 2018

The EBMT nurses Group is proud to announce a unique collaboration with Springer Publishing to produce a comprehensive and informative guide covering all aspects of transplant nursing, from basic principles to advanced concepts.

This textbook for adult and paediatric nurses takes the reader on a journey through the history of transplant nursing, including essential and progressive elements to help nurses improve their knowledge and benefit the patient experience, as well as a comprehensive introduction to research and auditing methods. To be launched during EBMT 2018 Annual Meeting.

The EBMT Nurses Group is now on Twitter

The EBMT Nurse Group twitter account went live late September 2017. Up to now, we have 42 followers and we aim to expand this number significantly in Lisbon 2018. Follow us now for instant updates on what’s going on in the world of nursing:

https://twitter.com/TheEBMT_Nurses.

The EBMT NG has a wealth of nurses dedicated to improving knowledge and sharing this with its members. It can be seen from the variety of activities generated in 2017 that this vibrant team is moving the nursing agenda forward and improving patient care.

John Murray
President EBMT Nurses Group
Inspections 2017

53 inspections (10 first-time and 43 reaccreditation) (see figure 2).

Applications 2017

75 applications (15 first-time and 60 reaccreditation) received (see figure 1).

Accreditations 2017

51 accreditations (13 first-time and 38 reaccreditation) awarded (see figure 3).
Work on preparing the 7th edition of the FACT-JACIE Standards started in June 2017 with a meeting of the FACT and JACIE teams in Barcelona. Through the second half of 2017, the standards sub-committees worked on their respective sections of the Standards. One significant development for this edition is that a dedicated Quality Management sub-committee has been incorporated into the process which will bring more focus to these standards and bring to bear the experience of quality managers.

The 7th edition will be published on 1 March 2018.

**Educational events**

Three well-attended JACIE training courses were held: two in Barcelona, (Spain) and another in Warsaw (Poland) with 63 participants in total. In addition, a joint event was held in Buenos Aires (Argentina) in May at the LABMT congress with 50 attendees. Furthermore, a series of FACT-JACIE Spanish-language webinars were run for South American centres. JACIE was also represented in several other events and projects throughout the year (See figure 4 above).
Advocacy and institutional relations

In recent years EBMT has established good relations with DG SANTÉ (Public Health Commission) and the European Medicines Agency (EMA). JACIE coordinates EBMT’s interactions with European bodies.

**DG SANTÉ**

DG SANTÉ is relevant to EBMT because it issued the Directives on safety and quality of tissues and cells. The Public Health Programme funded JACIE in its early stages and EBMT is a participant in a number of projects and joint actions supported by DG SANTÉ.

EBMT is considered a stakeholder organisation interested in participating in ad-hoc meetings with representatives of members of the Competent Authorities on Substances of Human Origin Expert Group. Furthermore, EBMT is a member of the Common representation of Substances of Human Origin’s (SoHO) (CoRe SoHO) which brings together EBMT, European Association of Tissue Banks (EATB), European Eye Bank Association (EEBA) and European Blood Alliance (EBA).

EBMT experts have met with Commission staff to help inform discussions around the revision of the Directives. These contacts have also helped to bring specific issues in cell therapy to the attention of the Commission leadership. Summaries of these meetings are published on the DG SANTÉ website.

**European Medicines Agency (EMA)**

In 2015 EBMT responded to the EMA Patient Registry Initiative providing details of the Registry. This led to further contacts and an invitation to present at the EMA Patient Registries Initiative meeting in October 2016. In parallel EBMT was also present at the EMA ATMP workshop in May 2016.

EMA is also very interested in the EBMT Registry and its utility for patient follow-up following treatment with CAR-T cells. EBMT participated in the EMA Patients Registries Initiative: CAR-T Cells workshop on 9 February 2018.

**Innovative Medicines Initiative (IMI)**

Innovative Medicines Initiative (IMI) is one of the biggest EU funding envelopes. It is based on bringing together stakeholders from the public and private sectors in pursuing different objectives around medicines. Finance is provided by the EU (through HORIZON 2020) while industry makes in-kind contributions e.g. know-how, access to production facilities etc. EBMT’s current connection to IMI is as a contributor to the HARMONY Project (Healthcare Alliance for Resourceful Medicine Offensive against Neoplasms in Hematology) which aims to use ‘big data’ to deliver information that will help to improve the care of patients with these diseases.

In 2016 EBMT responded to the IMI Advanced Therapies Consultation and also attended the annual IMI event in Brussels. Contacts were made with IMI in 2017 as a ‘get-to-know-you’ effort so that they were aware of our activities although there is nothing of specific interest to EBMT in the current funding calls.

**Health Technology Assessment (HTA)**

In late 2017, EBMT opened contacts with a number of national HTA agencies to make them aware of the EBMT Registry.

**Other**

The JACIE website recorded 20,875 users compared to 19,609 in 2016, a 6% rise over the previous year. The JACIE Twitter account @JACIE_EBMT grew to 635 followers.
We would like to express our appreciation and admiration for the Medicines and Healthcare (EDQM) which was published in 2017.

Joint Action (www.arthiqs.eu). JACIE experts contributed to the new guide to the Quality and safety of tissues and cells for human application published by the European Directorate for the Quality of Medicines and Healthcare (EDQM) which was published in 2017.

We would like to express our appreciation and admiration for the Medicines and Healthcare (EDQM) which was published in 2017.

Institutions awarded accreditation in 2017

Zentrum Blutspendedienst NSTOB Institut Bremen-Oldenburg (Oldenburg, Germany); Bayerische Stammzellbank gGmbH (Gauting, Germany); Einrichtung für Transfusionsmedizin am Universitätsklinikum Hamburg-Eppendorf (Hamburg, Germany); Staatliches Klinikum Karsruhe, Germany; Universitätsklinikum Magdeburg A. o. R (Magdeburg, Germany); Klinik für Kinder- und Jugendmedizin – Pädiatrische Hämatologie und Onkologie- Universitätsklinikum Münster (Münster, Germany); NMR-Blutspendedienst NSTOB Institut Bremen-Oldenburg (Oldenburg, Germany); Azienda Ospedaliera Papa Giovanni XXIII (Bergamo, Italy); Azienda Sanitaria dell’Alto Adige (Bolzano, Italy); Azienda Ospedaliero Universitaria di Ferrara (Ferrara, Italy); Klinik für Kinder- und Jugendmedizin – Pädiatrische Hämatologie und Onkologie- Universitätsklinikum Münster (Münster, Germany); NMR-Blutspendedienst NSTOB Institut Bremen-Oldenburg (Oldenburg, Germany); Azienda Ospedaliera Papa Giovanni XXIII (Bergamo, Italy); Azienda Sanitaria dell’Alto Adige (Bolzano, Italy); Azienda Ospedaliero Universitaria di Ferrara (Ferrara, Italy); Klinik für Kinder- und Jugendmedizin – Pädiatrische Hämatologie und Onkologie- Universitätsklinikum Münster (Münster, Germany); NMR-Blutspendedienst NSTOB Institut Bremen-Oldenburg (Oldenburg, Germany); Azienda Ospedaliera Papa Giovanni XXIII (Bergamo, Italy); Azienda Sanitaria dell’Alto Adige (Bolzano, Italy); Azienda Ospedaliero Universitaria di Ferrara (Ferrara, Italy); Klinik für Kinder- und Jugendmedizin – Pädiatrische Hämatologie und Onkologie- Universitätsklinikum Münster (Münster, Germany); NMR-Blutspendedienst NSTOB Institut Bremen-Oldenburg (Oldenburg, Germany); Azienda Ospedaliera Papa Giovanni XXIII (Bergamo, Italy);
Financial Report and Highlights 2017

Jürgen Kuball
EBMT Treasurer

For the third consecutive time, EBMT has obtained an “unqualified opinion”. This demonstrates that the EBMT is maintaining its high standard of modern management, improving its financial stability and provides assurance that money is spent and allocated according to our mission.

Change of auditors to further improve our processes

Within EBMT’s policy, we have the option to reevaluate relationships with our main suppliers including our auditors. After some very positive years with EY, EBMT has decided, after an open selection procedure, to start working with Baker Tilly Berk, with the objective to bring a new perspective when looking at our accounts and further improve our processes. Baker Tilly Berk ranks among the top ten audit firms worldwide and we are looking forward to a fruitful collaboration with them.

EBMT has closed for a 4th consecutive year with a positive result

The improvement of our financial outcome during the last years is mainly due to:

- Optimising processes within the organisation, such as educational event organisation and clinical trial and non-interventional study activities.
- Joint efforts of the Working Parties to maximise the outcome with existing recourses.
- Conservative but also pro-active budgeting of all potential risks, opportunities, and upcoming activities.
- Accepting only very low financial risks in portfolio managements and consequently very modest return rates.
- Creating with the EBMT board “closed business cases” for all new activities like the upcoming benchmarking initiative for JACIE-accredited centers and novel study proposals.
- Increased income from the Annual Meeting as a consequence of more efficient processes due to the “in-housing” of many activities and optimising sponsorship structures.
- Improved capacity of the organisation to be in full control of new activities and follow up on ongoing activities.

A new plateau of our yearly income has been reached and consolidated

The financial reorganisation and professionalisation of the Society during the last three years allowed a substantial increase in the current and expected future annual income of the society (approximately 1.2 million per year when compared to budgets before 2014). However, we also assume that without new pillars of income a plateau has been reached for our annual income, which needs to be taken into consideration for all novel ideas and initiatives.

Spending our money on our missions

Our increasing annual income has been used to mainly further work towards our mission as well as to partially improve the executive structure of EBMT. As a consequence EBMT increases in 2017 the proportion of expenses allocated to our main missions from 82% to 92% (studies, Registry, accreditation and education including the Annual Meeting) and we could further reduce the allocated relative budget needed for management (8% board and executive office expenses). Main novel activities are in line with Project 2020.

Project 2020 is a priority list of strategic activities, which has been endorsed by the board during the last years. All new incomes have been mainly used to support these strategic choices. Choices include but are not limited to:

1. New EBMT Registry

Our aim is to have a functional and professional Registry ready to go live by May 2019. Training for all EBMT centres is planned for the 3rd quarter of 2018. The new state-of-the-art IT system with our partner Elsevier/Macro will allow strengthening data quality procedures and full documentation of the Registry processes. Considering the major resources needed to support and update existing registries also after implementation, the board decided to earmark 200k per year even far beyond 2020 for keeping the new Registry also during the next decade competitive and innovative.

2. Increase of staff in all our offices to support other strategic decisions

In addition to the more efficient use of existing manpower in our different offices in Leiden, London, Paris, and Barcelona, EBMT has opened ten new positions in key strategic areas. These positions are needed for supporting the Registry upgrade and implementing a data safety officer in order to meet requirements for all new European laws for data protection. In addition we have empowered our statistical expertise needed for the new EBMT-initiated benchmarking system and other scientific activities. We have also consolidated staff needed for our educational events from managing from small meetings, midsize events to the Annual Meeting. In addition, we have further professionalised our financial office where I would like to take this opportunity to congratulate for providing such an excellent financial overview and keeping track of the challenges arising from the rapid growth and increased complexity of the organisation during the past years.

3. Investing in “structural innovation”

From 2016 the board has decided to annually earmark 300k € from the yearly results for the continuous development of novel ideas. For the time being this earmarked money was and will be used to mainly support the Registry update in terms of IT and implementation among all members. Once the implementation of the Registry is complete, the “structural innovation budget” will be used to facilitate the early phase of novel projects until these projects will be able to maintain themselves such as unique educational tools and the new cellular therapy Registry.
4. Stay connected with EBMT

During 2017 EBMT upgraded its website and worked on the new VOD App. These two projects will be launched during the Annual Congress in Lisbon 2018. We hope that you will like it – please feel free to send us further suggestions for improvement.

5. Strengthen EBMT interaction with the European Commission

The board decided to also strengthen our interaction with the European Commission to create “a voice” within Europe for professionals, which is key in the guidance regarding harmonisation and well-balanced new legislation for e.g., cellular therapies as well as the potential role of our new cellular therapy Registry for novel living drugs like CAR-T. To support this the board created the new Legal and Regulatory Affairs Committee (LRAC). To professionalise this process the board has decided to financially support interactions with all stakeholders such as the EMA as well as pharmaceutical companies through a new staff position.

**Financial conclusion**

The very positive financial development of the organisation during the last few years has allowed EBMT to further build on its strategic goals. Current highlights are the website update, Registry upgrade and the development of the EBMT-based benchmarking system which could all be initiated in 2017 and will be further developed during the next few years. Despite all these substantial strategic financial key investments in 2017 for IT and staff, EBMT will be closing the year 2017 with a total positive result of €1,397 k (expenses of €7,962 k and a total income of €9,359 k). A total of 500 k will be earmarked in line with the board decisions for structural innovation (300 k) and Registry implementation (200 k). The residual budget of 897 k will be returned to our reserves and will therefore be used to further secure our key staff positions and main strategic projects in case of any unforeseen financial serious adverse event.

### Source of income during 2017

- **€583,000** 6% **EBMT Members donations**
- **€457,000** 5% **Scientific Sponsors donations**
- **€6,527,000** 70% **Annual Meeting financial result**
- **€1,338,000** 14% **Grants for Studies, Clinical Trials & Education**
- **€454,000** 5% **Standards & Accreditation (JACIE)**

### Destination of resources during 2017

- **€1,869,000** 23% **Scientific Studies**
- **€887,000** 11% **EBMT Registry**
- **€3,721,000** 47% **Annual Meeting**
- **€340,000** 4% **Educational Activities**
- **€472,000** 6% **Standards & Accreditation (JACIE)**
- **€7,289,000** 92% **EBMT Total Mission Cost**
- **€673,000** 8% **Management & Administration**
- **€7,962,000** 100% **Total Expenses**
Thank you to Professor Manuel Abecasis and his team from Instituto Português de Oncologia (IPO Lisboa) in Lisbon, Portugal for providing the necessary permission and organising the photoshoot.
The new and refreshed EBMT website is live! Take a look: 
www.ebmt.org