# 2020 WBMT PROGRESS REPORT







# Worldwide Network for Blood and Marrow Transplantation

(WBMT)

**Progress Report** 

Calendar Year 2020

wbmt.org

Headquarters: Laupenstrasse 37, Postfach 7951, CH 3001 Bern, Switzerland

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## **1.0 INTRODUCTION**

The Worldwide Network for Blood and Marrow Transplantation (WBMT) was formally created in 2007 by leaders from major hematopoietic cell transplantation (HCT) societies and donor registries across the world, culminating in consensus on Bylaws and an organizational structure in 2009. With the interest and strong support of the World Health Organization (WHO), these leaders shared a mutual vision of combining efforts towards improving standardization in the global application of HCT, cellular therapy, and related fields as well as broadening the scope of data sharing. This "Federation of Societies" began with 17 international organizations now numbering 22, all with substantial interest in HCT (**Appendix A**). The WBMT was incorporated as a non-profit organization for educational, scientific, and philanthropic purposes under the laws of Switzerland with headquarters in Bern. Funding support has been solicited from relevant industry plus income from educational activities.

Description of the earliest years of WBMT activity is available in previous Progress Reports available on the WBMT website (<u>wbmt.org</u>). They contain information on how WBMT developed, its structure and charter, its notable achievements, and its future aims and goals. This report focuses on the accomplishments of WBMT during the calendar year 2020.

The calendar year 2020 was different than previous years. As it was not possible to organize a face-toface meeting, the planned WBMT workshop could not take place. The focus of WBMT was on COVID-19 prevention for the patients receiving cellular therapy, their caregivers and also the stem cell donors.

## 1.1 Early Development

The four founding Member Societies of the WBMT are the Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Center for International Blood and Marrow Transplant Research (CIBMTR), European Society for Blood and Marrow Transplantation (EBMT), and World Marrow Donor Association (WMDA). Representatives organized themselves in 2007 to help identify goals and to communicate them to all other interested societies in HCT or related fields. They recognized:

- HCT is a global endeavor.
- More could be accomplished if the different societies active in this field collaborated.
- An international organization could support and even influence thoughtful, local policy and legislation from a global perspective.

It was concluded that the WBMT required a unique organizational structure to fulfill its goal of coordinating HCT, stem cell donor, and cellular therapy activities worldwide. It was also important not to duplicate decades of successful efforts by other established organizations in the field; the result was the current and continuing Federation of Societies structure.

# **1.2** Current Status with the WHO

The WHO played a critical role in the WBMT from its inception by providing substantial interest in and support of this new initiative. The collaborative relationship with the WHO led to the current status as non-government organization (NGO) in official relations, approved in January 2013. The WHO Executive Board reviewed the report of the relations and collaboration at its 144<sup>th</sup> session in January 2019 and decided to maintain WBMT in official relations with the WHO. In January 2022 the Executive Board will review the implementation plan again.

The WHO strongly supported the WBMT's early collaborative and unifying efforts. WHO representatives continue to attend meetings as observers, assist in planning activities, and participate as forum presenters on a variety of relevant topics. Since acquiring *NGO in official relations* status, the WBMT provides a set of deliverables to the WHO in pursuit of its educational, scientific, and philanthropic mission (**Section 4.4**).

#### 2.0 COMMITTEE STRUCTURE

#### 2.1 Board

The WBMT Board leads decision-making for all WBMT activities. The Board includes elected Executive Committee officials (Section 2.2 and Appendix B) as well as Co-Chairs of the Standing Committees (Sections 2.3 and 3.0). Each committee is permitted a single vote. The WBMT Board includes a primary and alternate representative from each Member Society. Each Member Society is permitted a single vote, either by the primary or the alternate representative. Find below an overview of the member society representatives.

WBMT BOARD: Primary and Alternate respresentatives					
Primary Representative	AABB	David	McKenna	July 1, 2022	End of first term
Alternate Representative	AABB	Details requested by WBMT on Feb 11, 2021			
Primary Representative	ABMTRR	Sam	Milliken	July 1, 2022	End of first term
Alternate Representative	ABMTRR	Duncan	Purtill	July 1, 2022	End of first term
Primary Representative	AfBMT	Alaa	Elhaddad	July 1, 2022	End of first term
Alternate Representative	AfBMT	Bazuaye	Nosa	July 1, 2022	End of first term
Primary Representative	APBMT	Shinichiro	Okamoto	July 1, 2022	End of first term
Alternate Representative	APBMT	Alok	Srivastava	July 1, 2022	End of first term
Primary Representative	ASTCT	Damiano	Rondelli	July 1, 2024	End of first term
Alternate Representative	ASTCT	Corey	Cutler	July 1, 2022	End of first term
Primary Representative	ASFA	Joseph	Schwartz	July 1, 2022	End of first term
Alternate Representative	ASFA	Laura	Connelly Smith	July 1, 2022	End of first term
Primary Representative	ASHI	Marcelo	Fernandez Vina	July 1, 2022	End of first term
Alternate Representative	ASHI	E. Victoria	Turner	July 1, 2022	End of first term
Primary Representative	CIBMTR	Marcelo	Pasquini	July 1, 2022	End of first term
Alternate Representative	CIBMTR	Mary	Horowitz	July 1, 2022	End of first term
Primary Representative	EBMT	Nicolaus	Kröger	July 1, 2022	End of first term
Alternate Representative	EBMT	Mohamed	Mohty	July 1, 2022	End of first term
Primary Representative	EFI	Steven	Marsh	July 1, 2022	End of first term
Alternate Representative	EFI	Mats	Bengtsson	July 1, 2022	End of first term
Primary Representative	ELN	Rüdiger	Hehlmann	July 1, 2022	End of first term
Alternate Representative	ELN	Dietger	Niederwieser	July 1, 2022	End of first term
Primary Representative	EMBMT	Amir Ali	Hamidieh	July 1, 2022	End of first term
Alternate Representative	EMBMT	Syed Osman	Ahmed	July 1, 2022	End of first term
Primary Representative	EMDIS	CarlHeinz	Mueller	July 1, 2022	End of first term
Alternate Representative	EMDIS	Evelyne	Marry	July 1, 2022	End of first term
Primary Representative	ESH				
Alternate Representative	ESH				
Primary Representative	Eurocord	Eliane	Gluckman	July 1, 2022	End of first term
Alternate Representative	Eurocord	Vanderson	Rocha	July 1, 2022	End of first term

WBMT Progress Report 2020					
Primary Representative	FACT	Paul	Eldridge	July 1, 2022	End of first term
Alternate Representative	FACT	Phyllis	Warkentin	July 1, 2022	End of first term
Primary Representative	ICCBBA	Paul	Ashford	July 1, 2022	End of first term
Alternate Representative	ICCBBA	Monica	Freire	July 1, 2021	End of first term
Primary Representative	ISBT	Mickey	Koh	July 1, 2022	End of first term
Alternate Representative	ISBT	Peter	Horn	July 1, 2022	End of first term
Primary Representative	ISCT	Edwin	Horwitz	July 1, 2022	End of first term
Alternate Representative	ISCT				
Primary Representative	JACIE	John	Snowden	July 1, 2022	End of first term
Alternate Representative	JACIE	Jane	Apperley	July 1, 2022	End of first term
Primary Representative	LABMT	Gregorio	Jaimovich	July 1, 2022	End of first term
Alternate Representative	LABMT	Belinda	Pinto Simões	July 1, 2022	End of first term
Primary Representative	WMDA	Jeff	Szer	July 1, 2022	End of first term
Alternate Representative	WMDA	Lydia	Foeken	July 1, 2022	End of first term

At the end of 2020, WBMT had 22 Member Societies. Each Member Society reviewed and confirmed the individuals serving as their representatives on the Board on an annual basis.

The Board meets annually in person, alternating between the February Transplantation and Cellular Therapy Meetings in the US and the March - April European Society of Blood and Marrow Transplantation Meeting in Europe. The Board generally holds additional teleconferences, (**Appendix E**), to remain informed and to handle issues arising between the in-person sessions. Email communication is utilized as necessary between these meetings. Meeting minutes are posted on a password-protected section of the WBMT collaboration website and are available on request. Due to the pandemic no inperson meetings were possible in 2020. All meetings were video conferences. Therefore, the bylaws of WBMT has been adjusted to accommodate video conferences.

# 2.2 Executive Committee

The Executive Committee informs the WBMT Board while managing business matters between Board meetings. Membership includes the elected President, Vice-President, Treasurer, Secretary, Past President, and WBMT Representative to the WHO. The final role, WBMT Representative to the WHO, was added to the Executive Committee in 2016 and is filled by the Past President. As noted above, appointed Co-Chairs of the seven Standing Committees (Sections 2.3 and 3.0) serve on the Executive Committee. The Executive Committee conducts monthly hour-long teleconferences, and minutes of these meetings are also posted on a password-protected section of the WBMT collaboration website.

Following existing Nomination and Election House Rules (which were reviewed and revised through 2016-2018), and with input from Board members, an ad hoc Nominating Committee, including one representative from each WHO region, convenes as necessary. In 2019, the Nominating Committee was activated to fill the President, Vice President, Secretary and Treasurer position. Secretary Hildegard Greinix was elected President; this term will expire in April 2022. Mickey Koh was elected Secretary; this term will expire in April 2022. Vice President Mahmoud Aljurf and Treasurer Adriana Seber were confirmed for another term. Their next terms will expire in April 2022.

WBMT ELECTED OFFICERS - SERVE ON EXECUTIVE COMMITTEE AND BOARD					
President	Hildegard	Greinix	April 1, 2022	End of term	
Past President and WHO representative	Daniel	Weisdorf	April 1, 2022	End of term	
Vice President	Mahmoud	Aljurf	April 1, 2022	End of term	
Secretary	Mickey	Koh	April 1, 2022	End of first term	
Treasurer	Adriana	Seber	April 1, 2022	End of term	

Appendix B displays photos and contact information for all current, elected officers of WBMT.

#### 2.3 Standing Committees

Seven Standing Committees (**Section 3.0**) focus on areas of prime importance to the mission of the WBMT, as identified by the Executive Committee. Most of these committees were created in 2008. Committee leadership positions were last reviewed at the beginning of 2020. The majority of WBMT project work is accomplished by these Standing Committees:

- Accreditation [the international Alliance for Harmonization of Cellular Therapy Accreditation (AHCTA) serves in this capacity] (Section 3.1)
- Donor Issues (Section 3.2)
- Education and Dissemination (Section 3.3)
- Graft Processing and Cellular Therapy (Section 3.4)
- Global Emergencies and Nuclear Accident Management (Section 3.5)
- Patient Advocacy / Advisory (Section 3.6)
- Transplant Center / Recipient (Section 3.7)

Two or rarely three Co-Chairs lead each committee. These Co-Chairs also participate in the ongoing work and decisions of the Executive Committee as noted above.

In 2016, the Board revised the WBMT bylaws related to the Standing Committee Co-Chairs. There is now greater emphasis on committee leader expectations and reporting committee activities.

Any interested individual belonging to any (one or more) of the Member Societies is eligible to join these committees; membership is solicited and refreshed periodically.

Because all WBMT committees are project driven, they meet with varying frequency, usually by teleconference due to international participation. WBMT committees also take advantage of relevant, international HCT meetings for in-person dialog as they are attended by many of their members; these international meetings are conducted in both the US (February) and the EU (March - April) annually.

STANDING COMMITTEE CHAIRS - SERVE ON EXECUTIVE COMMITTEE AND BOARD					
Accreditation (AHCTA)	Joseph (Yossi)	Schwartz	July 1, 2023	End of second term	
Donor Issues	Nina	Worel	July 1, 2021	End of first term	
Donor Issues	Chloe	Anthias	July 1, 2023	End of second term	
Education and Dissemination	Sebastian	Galeano	July 1, 2021	End of first term	
Education and Dissemination	Yoshihisa	Kodera	July 1, 2023	End of second term	
Graft Processing and Cellular Therapy	Paul	Eldridge	July 1, 2022	End of second term	
Graft Processing and Cellular Therapy	Tom	Leemhuis	July 1, 2021	End of first term	
Patient Advocacy and Advisory	Menachem	Bitan	July 1, 2022	End of second term	
Transplant Center / Recipient Issues	Yoshiko	Atsuta	July 1, 2023	End of second term	
Transplant Center / Recipient Issues	Wael	Saber	July 1, 2021	End of first term	
Transplant Center / Recipient Issues	Dietger	Niederwieser	July 1, 2023	End of second term	
Global Emergencies and Nuclear Accident Management	Ray	Powles	July 1, 2021	End of first term	
Global Emergencies and Nuclear Accident Management	David	Ma	July 1, 2022	End of second term	
Global Emergencies and Nuclear Accident Management	Shahrukh	Hashmi	July 1, 2023	End of first term	

#### 3.0 STANDING COMMITTEE ANNUAL REPORTS AND ACCOMPLISHMENTS in 2020

#### 3.1 Accreditation Committee formerly known as AHCTA

#### **Committee Mission**

The mission of the Accreditation Committee is to recommend to the Executive Committee policies, programs, and actions pertaining to regulatory matters, practices, and codes with both national and international implications. This involves procedures related to all activities of the other Standing Committees. In its vigilance to avoid duplication of efforts, WBMT members agreed in 2009 that AHCTA would fulfil the role of the WBMT Accreditation Committee.

#### Leadership

The Chair of this committee is:

- Joseph Schwartz (Member Society, ASFA)
- Mickey Koh stepped down after one term on April 1, 2020, since he was elected as Secretary of WBMT.

#### **Meetings / Teleconferences**

The Accreditation Committee meets by videoconference at least quarterly and in person once or twice per year, as international conference attendance permits. In 2020, this committee had two committee calls and no in person meetings due to the pandemic.

#### **Completed Projects**

During 2020, the Accreditation Committee completed a multi organization project regarding the Harmonization of terminology and processes related to adverse events related to cell therapy administration. The gap arose from a blood based hemovigilance meeting at the International Society of Blood Transfusion (ISBT). A working group had been set up with participation from AABB, EBMT, ASFA, ISBT, JACIE, and WMDA.

#### **Publications**

• Adverse event reporting for cellular therapy products: current status and future directions. Loper K, Sugrue MW, Raval JS, Schwartz J, Land K, Koh M, Mengling T, Greinix H, Halter JP, Celluzzi CM, Chaudhri M. Transfusion. 2020;60(12): 2815-2827.

#### **Future Plans**

In 2021 the Accreditation Committee plans:

- Eduction effort regarding different cell therapy accreditation pathways existing world wide to include FACT, JACIE, AABB, Cord Blood Banks;
- Education effort in areas which seem to be an obstacle to achieve accredation e.g. quality programs and different quality programs in different areas of the world;
  - Webinar in conjunction with the Education and Dissemination Commitee is in planning stages.

## 3.2 Donor Issues Committee

## **Committee Mission**

The mission of the Donor Issues Committee is to recommend to the Executive Committee policies, programs, and actions pertaining to the identification of stem cell donors (bone marrow, peripheral blood, and cord blood), harvesting procedures, product transportation, donor safety practices, and outcomes / long term follow-up within a member collection center; this includes the conduct of individuals and processes related to these procedures and practices.

## Leadership

The Co-Chairs of this committee are:

- Chloe Anthias (Member Society, WMDA)
- Nina Worel (Member Society, EBMT)

Bronwen Shaw (WMDA) temporarily replaced Chloe Anthias in 2020 due to Chloe's maternity leave.

#### Meetings / Teleconferences

The Donor Issues Committee did not meet in person in 2020 due to the pandemic. Two videoconferences took place for this committee.

#### **Completed Projects**

During 2020, the Donor Issues Committee completed the following projects:

- A survey on changes in HCT practices during the COVID-19 pandemic and subsequently a publication of the results (<u>link</u>).
- Donor Issues Committee E-learning: Haploidentical family donors with special respect to minors as donors on 9 July 2020 (<u>Summary</u>).
- Donor Issues Committee has sponsored four successful Donor Issue Workshops in 2009, 2011, 2013, and 2016. The workshops focused on the suitability of related donors (consensus statement of the WBMT published 2015) and donors with infectious diseases or living in areas of endemic infectious diseases. Workshop participants continue to prepare for publications outlining recommendations related to infectious diseases and HCT.

#### Publications

 Real-World issues and potential solutions in hematopoietic cell transplantation during the COVID-19 pandemic: perspectives from the Worldwide Network for Blood and Marrow Transplantation and Center for International Blood and Marrow Transplant Research Health Services and International Studies Committee (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7380217/)

#### **Ongoing Projects**

This committee continues to work on the following projects:

- Work on recommendations related to infectious diseases started during a 2016 workshop in Tel Aviv. The manuscript is being prepared for publication by the workshop participants in close collaboration with experienced colleagues working in regions with endemic diseases (e.g. Latin America and Asia), the WMDA, infectious disease specialists involved in the HCT field, and the European Centre for Disease Prevention and Control (ECDC). One important aim is to connect already available sources of information.
- Publish a summary of the webinar "Haploidentical family donors with special respect to minors as donors" held in July 2020 (currently in preparation).

#### Future Plans

The Donor Issues Committee identified the following projects for initiation during 2021:

• Work together with WMDA and EBMT on a manuscript to define standards for allogeneic donor mobilization.

#### **3.3 Education and Dissemination Committee**

#### **Committee Mission**

The mission of the Education and Dissemination Committee is to recommend to the Executive Committee policies, programs, actions and materials pertaining to the development or design of resources prepared for the express purpose of educating the populace about HCT. This committee collaborates with all partners within the WBMT - but particularly the European School of Hematology (ESH) - and assists in preparation of opinion or advisory materials for the WBMT and/or WHO. It plays an important role in Workshop program design.

#### Leadership

The Co-Chairs of this committee are:

- Sebastian Galeano (Member Society LABMT)
- Yoshihisa Kodera (Member Society APBMT)

#### **Meetings / Teleconferences**

The Education and Dissemination Committee continues to participate actively in various projects related to workshops, seminars and printed materials related to HCT. The committee had 4 videoconferences in 2020, mainly focusing on organizing webinars and future workshops.

WBMT Education Committee plans to meet by videoconference on a quarterly basis or as needed according to the ongoing projects.

#### **Completed Projects**

In 2020, the Education and Dissemination Committee completed the following projects:

- Webinar "COVID-19 and stem cell transplantation, a Worldwide perspective" (link)
- Webinar: Stem cell transplantation for multiple myeloma: a global perspective (link)
- Update of the invitation letter for countries applying to host the workshops, titled: "Call for WBMT Workshop Meeting"
- Update of the following document: "Criteria for WBMT Workshop Site Selection"

#### **Ongoing Projects**

This committee continues to work on the following projects:

- Organization of the 7th WBMT Workshop
- Host regular webinars

#### **Future Plans**

The Education and Dissemination Committee identified the following projects for 2021:

- Continue to organize Workshop/Scientific Symposia annually or as appropriate. In-person meetings/workshops will not be developed during 2021 due to the COVID-19 pandemic.
- Next WBMT Workshop is planned for March 2022 in Islamabad, Pakistan.
- Discuss financial support for future WBMT Workshops.

- Develop online training programs directed to low-middle income countries in cooperation with regional transplant organizations.
- Establish contacts and identify obstacles for setting up new transplant centers in emerging and underdeveloped countries.
- Evaluate participation in the creation of an International Continuing Medical Education (CME) accreditation plan.
- Assess long-term outcomes of previous Workshops for organizers and participants.

## 3.4 Graft Processing and Cellular Therapy Committee

#### **Committee Mission**

The mission of the Graft Processing and Cellular Therapies Committee is to recommend policies, programs, and actions pertaining to the handling of a harvested product, including: storage, preparation and manipulation, equipment, product transportation, and documentation within a cell processing center. This includes the conduct of individuals and processes related to these practices. The committee also focuses on cellular therapy, which is increasingly important in haemato-oncology, transplantation, and regenerative medicine, in relation to cellular product source, processing, and in the coming years, in relation to advanced therapeutic medicinal products.

#### Leadership

The Co-Chairs of this committee are:

- Paul Eldridge (Member Society, Foundation for the Accreditation of Cellular Therapy, FACT)
- Syed Osman Ahmed (Member Society, Eastern Mediterranean Blood and Marrow Transplantation Group, EMBMT)
- Tom Leemhuis stepped down after his first term ended due to other obligations. Mickey Koh filled in as interim co-chair until April 1, 2020.

# Meetings / Teleconferences

During 2020, the Graft Processing and Cellular Therapy Committee did not meet in person.

#### **Ongoing Projects**

This committee continues to work on the following projects:

- Partner with the International Society of Cellular Therapy (ISCT) on the *ISCT Presidential Task Force on the Use of Unproven Cellular Therapies* project (**Section 4.4.2.3**). Mickey Koh was appointed one of three Co-Chairs for this project.
- With Mickey Koh as the lead, support the Ethiopia project (**Section 4.5.1**), which aims to set up capabilities for HCT in Addis Ababa. The WBMT team assists the local team in developing an HCT program.

#### Future Plans

The Graft Processing and Cellular Therapy Committee identified the following projects for action in 2021:

- Create a list and map of cell processing laboratory facilities worldwide.
- Collate the practices and results of various centers who have dispensed with cryopreservation in autologous stem cell transplants. This relies on refrigerated, but non-frozen stem cells being stored for a finite period of time. The Co-Chairs thought it would be important to analyze the data and clinical results from this practice.
- Collaborate with the EBMT Cellular Therapies Working Party and other organizations to produce an activity survey of cellular therapies worldwide.

• Coordinate with FACT and the Joint Accreditation Committee of ISCT and EBMT (JACIE) and AHCTA Committee to introduce stepwise accreditation for laboratories (and transplant programs) in emerging regions under a joint International Accreditation Program.

# 3.5 Global Emergencies and Nuclear Accident Management Committee

This committee was first suggested in 2014 under the name Nuclear Accident Management Committee and first meetings and sessions took place in 2015. In the fourth quarter of 2015, committee leaders gave presentations during the WBMT session at the APBMT annual meeting. Highlights of this session focused on the number and types of radiologic response exercises being conducted worldwide; all emphasized the need to engage and educate the HCT community of their potential involvement in a nuclear disaster and to continue these practice exercises. In 2020 the mission and name of the committee were reviewed and updated, resulting in the current name.

## **Committee Mission**

The mission of the Global Emergencies and Nuclear Accident Management Committee is to promote worldwide awareness of public health emergencies, radiation or other disasters that may impact global HCT practice or there could be a role of HCT in the management of these emergencies. Committee objectives include the following: 1. Increase preparedness in WBMT countries, members, teams and organizations to provide assistance in the event of a massive radiation incident or a public health emergency. 2. Develop international consensus guidelines for triage and treatment of casualties that require hematopoietic support. 3. Establish coalitions within member countries to share information following radiation or other types of incidents or relevant global emergencies.

## Leadership

The Co-Chairs of this committee are:

- David Ma (Member Society, APBMT)
- Ray Powles (Member Society, EBMT)
- Shahrukh Hashmi (Member Society, ASTCT)

# Meetings / Teleconferences

In 2020, the Global Emergencies and Nuclear Accident Management Committee had two video conferences.

# Publications

Algwaiz, G., Aljurf, M., Koh, M., Horowitz, M.M., Ljungman, P., Weisdorf, D., Saber, W., Kodera, Y., Szer, J., Jawdat, D. and Wood, W.A., 2020. Real-world issues and potential solutions in hematopoietic cell transplantation during the COVID-19 pandemic: perspectives from the Worldwide Network for Blood and Marrow Transplantation and Center for International Blood and Marrow Transplant Research Health Services and International Studies Committee. Biology of Blood and Marrow Transplantation, 26(12), pp.2181-2189.

# **Ongoing Projects**

During 2020:

- Continue partnerships with EBMT, AABB, disaster task force, and other appropriate organizations.
- International Survey of BMT survivorship.

## **Future Plans**

- The Global Emergencies and Nuclear Accident Management Committee plans to review the model for how this committee operates.
- Gain recognition as a formal/affiliated member of the WHO's Radiation Emergency Medical Preparedness and Assistance Network (REMPAN).
- Write a consensus paper on the role of WBMT in radiation disasters.

## 3.6 Patient Advocacy / Advisory Committee

The first in-person session of this committee was held in December 2015. The committee addressed activities regarding: "How do we define patient advocacy? Is it personal advocacy navigating one patient through the HCT process or is it the broader concept of social and governmental advocacy towards larger numbers of patients – or both".

#### **Committee Mission**

The mission of the Patient Advocacy / Advisory Committee is to recommend to the Executive Committee policies, programs, and actions pertaining to the establishment and / or support of international patient advocacy groups and activities. This includes projects in collaboration with international disease or treatment specific organizations that are related to HCT (pre-and post-transplantation issues) particularly those with emphasis on patient, donor, family, and / or caregiver related topics. There will be mentorship and harmonization in the development and distribution of patient / public educational materials.

#### Leadership

The Co-Chairs of this committee are:

- Menachem Bitan (Member Society, EBMT)
- Cristobal Frutos (Member Society, LABMT), since July 2020

# Meetings / Teleconferences

During 2020, this committee had 3 video conferences.

#### **Completed Projects**

During 2020, the Patient Advocacy / Advisory Committee completed the following projects:

- Electing new co-Chair Dr. Cristobal Frutos.
- Three Zoom meetings.
- Participate in propagating a survey on behalf of EBMT Patient Engagement Task Force and the EBMT Patient Advocacy Group to "understand how all stakeholders stand regarding patient engagement in research and care".
- Propagate a patient survey from the EBMT among patient's groups in Latin America and South America.
- Presenting at the EBMT Patient Advocacy Group session.

#### **Ongoing Projects**

This committee continues to work on the following projects:

• Develop a survey (based on a NMDP/Be The Match survey) of needs and expectations, to be distributed to patient groups.

- Continue to expand the committee's global network of patient groups and seek relevant partnerships.
- Organise Patient Days at national or international HCT conferences.
- Application for patients on their mobile device.

## Future Plans

The Patient Advocacy / Advisory Committee identified the following projects for the future:

- Participate in patient activities during the ASTCT (formerly Tandem) Meeting and EBMT Annual Meeting, such as the Patient's Day at the EBMT Annual Meeting with an effort to make the sessions more educational and broadly informative.
- Participate in future WBMT sponsored workshops with advocacy position papers created as appropriate.
- Take part in the international group on Chronic GVHD that has been established and will also cover aspects on patients' point of views and accessibility to immunosuppressants.
- Develop a PAAC site within the WBMT website. It will include information regarding diseases and steps of transplantation. We already received information from BMT Infonet.
- Gather stories and information from patients around the world regarding their experience as SCT patients during COVID-19.

# 3.7 Transplant Center / Recipient Committee

## **Committee Mission**

The mission of the Transplant Center / Recipient Committee is to recommend to the Executive Committee policies, programs, or actions pertaining to the performance of hematologic transplantation and other cellular therapies / procedures within a member transplant center; this includes recording recipient outcomes, maintenance of records, and the conduct of individuals and processes carrying out these procedures and practices. As of 2015, this committee also administers activities related to the global transplant activity (GTA) reports and GTA data use proposal reviews / deliberations (**Section 4.1**).

#### Leadership

The Co-Chairs of this Standing Committee are:

- Yoshiko Atsuta (Japanese Data Center for HCT)
- Wael Saber (Member Society, CIBMTR)
- Dietger Niederwieser (Member Society, EBMT)

#### Meetings / Teleconferences

During 2020, this Standing Committee maintained regular video conferences every 2 months throughout the year, particularly related to the GTA, utilization and activity of autologous HCT in myeloma worldwide and in acute leukemias. Several VC were held for the WASTIMS project and for Consultation and Preparation of the program for the Global activity survey with Daniel Neumann, Ronald Brand and Helen Baldomero. Algorithm for authorship on survey publications has been developed with our member societies.

Several requests on brand mark registration of the WBMT of the WIPO (Japan, Switzerland, Australia) were answered.

## **Completed Projects**

During 2020, this Standing Committee completed the following projects:

- The Global State of Hematopoietic Cell Transplantation for Multiple Myeloma: An Analysis of the Worldwide Network of Blood and Marrow Transplantation Database and the Global Burden of Disease Study. Publications on Myeloma by Cowan et al.(1) Oral presentation at ASH 2019.
- Real-World Issues and Potential Solutions in Hematopoietic Cell Transplantation during the COVID-19 Pandemic: Perspectives from the Worldwide Network for Blood and Marrow Transplantation and Center for International Blood and Marrow Transplant Research Health Services and International Studies Committee. Algwaiz G, Aljurf M, Koh M, Horowitz MM, Ljungman P, Weisdorf D, Saber W, Kodera Y, Szer J, Jawdat D, Wood WA, Brazauskas R, Lehmann L, Pasquini MC, Seber A, Lu PH, Atsuta Y, Riches M, Perales MA, Worel N, Okamoto S, Srivastava A, Chemaly RF, Cordonnier C, Dandoy CE, Wingard JR, Kharfan-Dabaja MA, Hamadani M, Majhail NS, Waghmare AA, Chao N, Kröger N, Shaw B, Mohty M, Niederwieser D, Greinix H, Hashmi SK; WBMT and the CIBMTR Health Services and International Studies Committee.Biol Blood Marrow Transplant. 2020 Dec;26(12):2181-2189. doi: 10.1016/j.bbmt.2020.07.021. Epub 2020 Jul 24.PMID: 32717432
- Bridging the gap using telemedicine: optimizing an existing autologous hematopoietic SCT unit into an allogeneic hematopoietic SCT unit in Paraguay with the help of the WBMT. Frutos C, Enciso ME, von Glasenapp A, Quiroz A, Batista J, Niederwieser D.Blood Adv. 2019 Dec 6;3(Suppl 1):45-47. doi: 10.1182/bloodadvances.2019GS121781.PMID: 31809552
- Worldwide Network for Blood and Marrow Transplantation (WBMT) perspective: the role of biosimilars in hematopoietic cell transplant: current opportunities and challenges in low- and lower-middle income countries. Muhsen IN, Hashmi SK, Niederwieser D, Kroeger N, Agrawal S, Pasquini MC, Atsuta Y, Ballen KK, Seber A, Saber W, Kharfan-Dabaja MA, Rasheed W, Okamoto S, Khera N, Wood WA, Koh MBC, Greinix H, Kodera Y, Szer J, Horowitz MM, Weisdorf D, Aljurf M.Bone Marrow Transplant. 2020 Apr;55(4):698-707. doi: 10.1038/s41409-019-0658-2. Epub 2019 Sep 4.PMID: 31484992 Review.
- Worldwide Network for Blood and Marrow Transplantation (WBMT) recommendations for establishing a hematopoietic stem cell transplantation program in countries with limited resources (Part II): Clinical, technical and socio-economic considerations. Aljurf M, Weisdorf D, Hashmi SK, Nassar A, Gluckman E, Mohty M, Rizzo D, Pasquini M, Hamadani M, Saber W, Hari P, Kharfan-Dabaja M, Majhail N, Gerges U, Ali Hamidieh A, Hussain F, Elhaddad A, Mahmoud HK, Tbakhi A, Othman TB, Hamladji RM, Bekadja MA, Ahmed P, Bazarbachi A, Adil S, Alkindi S, Ladeb S, Dennison D, Patel M, Lu P, Quessar AE, Okamoto S, Atsuta Y, Alhejazi A, Ayas M, Ahmed SO, Novitzky N, Srivastava A, Seber A, Elsolh H, Ghavamzadeh A, Confer D, Kodera Y, Greinix H, Szer J, Horowitz M, Niederwieser D.Hematol Oncol Stem Cell Ther. 2020 Mar;13(1):7-16. doi: 10.1016/j.hemonc.2019.08.002. Epub 2019 Aug 20.PMID: 31449781
- Worldwide Network for Blood and Marrow Transplantation (WBMT) recommendations for establishing a hematopoietic cell transplantation program (Part I): Minimum requirements and beyond. Pasquini MC, Srivastava A, Ahmed SO, Aljurf M, Atsuta Y, Doleysh C, Galeano S, Gluckman E, Greinix H, Hale G, Hari P, Hashmi SK, Kamani N, Laughlin MJ, Niederwieser D, Seber A, Szer J, Snowden JA, Van Biesen K, Watry P, Weisdorf DJ, Apperley J.Hematol Oncol Stem Cell Ther. 2020 Sep;13(3):131-142. doi: 10.1016/j.hemonc.2019.08.001. Epub 2019 Aug 20.PMID: 31449780
- Worldwide Network for Blood and Marrow Transplantation Recommendations for Establishing a Hematopoietic Cell Transplantation Program, Part I: Minimum Requirements and Beyond. Pasquini MC, Srivastava A, Ahmed SO, Aljurf M, Atsuta Y, Doleysh C, Galeano S, Gluckman E, Greinix H, Hale GA, Hari P, Hashmi SK, Kamani N, Laughlin MJ, Niederwieser D, Seber A, Szer J, Snowden JA, Van Biesen K, Watry P, Weisdorf DJ, Apperley J.Biol Blood Marrow Transplant. 2019 Dec;25(12):2322-2329. doi: 10.1016/j.bbmt.2019.05.002. Epub 2019 May 6.
- Worldwide Network for Blood and Marrow Transplantation Recommendations regarding essential medications required to establish an early phase Hematopoietic Cell Transplantation Program Running Title: required medications for an early phase HCT program. Riad El Fakih, Hildegard Greinix, Mickey

Koh, Bronwen Shaw, Mohamad Mohty, Mohammad Al Nahedh, Wael Saber, Mohamed A Kharfan-Dabaja, Miguel-Angel Perales, Bipin N Savani, Navneet S Majhail, Jakob R Passweg, Anna Sureda, Syed Osman Ahmed, Eliane Gluckman, Marcie Riches, Areej El-Jawahri, Damiano Rondelli, Alok Srivastava, Lawrence Faulkner, Yoshiko Atsuta, Karen K Ballen, Walid Rasheed, Shinichiro Okamoto, Adriana Seber, Nelson Chao, Nicolaus Kröger, Yoshihisa Kodera, Jeff Szer, Shahrukh K Hashmi, Mary M Horowitz, Daniel Weisdorf, Dietger Niederwieser, Mahmoud Aljurf. Transplantation and Cellular Therapy. Volume 27, Issue 3, March 2021, Pages 267.e1-267.e5

• One and a half million hematopoietic stem cell transplants worldwide: An analysis of Trends in Activity and Access up to 2016 from the Worldwide Network for Blood and Marrow Transplantation (WBMT.) Submission to The Lancet Haematology

#### **Ongoing Projects**

This Standing Committee continues to work on the following projects:

- Continue to lead the Research Data Activities Task Force, including overseeing review of incoming proposals for use of GTA data (WASTIMS project).
- Letter of intent for funding the project by the Leukemia Society has been submitted. Agreement between the societies has been presented to the EC and protocol finalized
- Reviewed and approved a study request for use of GTA data to describe the global state of HCT for multiple myeloma including outcome.
- Transplants of acute myeloid leukemia worldwide and utilization of autologous and allogeneic HCT.
- Agreement for the AML study (not outcome, but only survey data) has been organized and will be sent to the registries.
- Encourage use and further analyses of GTA data more broadly.
- Intervention for drug shortage in Latin America by Pierre Fabre together with WHO.

#### Future Plans

This Standing Committee has identified the following projects for the future:

- Implementation of an internet based database for TC's to submit their transplantation data.
- Develop an annual report from the GTA in the form of a slide set to be available to all member societies on the WBMT website.

## 4.0 WBMT ACTIVITIES AND ACCOMPLISHMENTS IN 2020

The WBMT engages in a variety of activities including:

- An annual global survey of HCT activity (Section 4.1);
- Conducting scientific and educational conferences (Section 4.2);
- Developing consensus guidelines for optimum delivery of HCT services and accreditation of HCT facilities (Section 4.3);
- Collaborating and consulting with the WHO to promote excellence in HCT, stem cell donation, and cellular therapy (Section 4.4);
- Supporting other global HCT activities (Section 4.5);
- Maintaining a Website for broad communication (Section 4.6);
- Establishing research guidelines within this global HCT community, particularly as related to use of the Global transplant activity data.(Section 4.7).

#### 4.1 Annual Global Survey

WBMT leaders agreed in early formative years that a first initiative should be to conduct annual global surveys of HCT activity performed by transplant centers (**Appendices C1 and C2**); a minimal yet essential level of activity information is requested of participating centers. The annual survey displays volume of, and main indications for, allogeneic (related, unrelated, and graft source information) and autologous HCT activity. Disease indications for HCT include main- and sub-class categories. Reporting these global data has become an obligation to the WHO (Section 4.4.1).

The WBMT survey reporting sheet is available on the WBMT website; it is accompanied by the disease indications classification codes to assist in completing the survey.

The WBMT continues to promote the annual survey by publishing findings biannually and presenting results at least once annually at international meetings (**Appendix F**); The WBMT encourages other, growing and developing groups (e.g., LABMT and AfBMT) to form their own registries to participate in the survey, and a WBMT representative presents at each Workshop and Symposium (**Section 4.2.2**), describing the activity data, including the collection process, and encouraging all teams to report their activity data. These data are also provided to the Global Observatory for Donation and Transplantation (**Section 4.4.2.4**).

The Transplant Activity Survey (TAS) was designed several years ago for the WBMT. This tool allows the reporting of transplant activity via the web using a simple, user- friendly input form being provided to WBMT via a regional transplant society, national registry, or individuals at the team / center level. Activity data can be entered at either the country or center level and supplement data provided to the WBMT through the international outcomes registries.

These data do not represent an outcome registry, but the TAS is a mechanism by which each country's annual data can be registered with the WBMT and also used by the reporting organization.

These activity data can be used at the team level for those countries / societies that do not have an existing data collection system (e.g. LABMT, AfBMT). If a new regional or national outcome registry were to be developed, it could potentially use the TAS to identify the activity in those countries that are outside other data collection systems (e.g., CIBMTR, EBMT, etc.), providing a mechanism for follow-up.

The WBMT has guidelines for research using these data (**Appendix D1**). Member Societies can request use of these data for research purposes with signed Data Transmission Agreements (**Appendix D2**). Proposals for the use of these data are reviewed and approved by the WBMT Transplant Center / Recipient Committee (**Section 3.7**).

# 4.2 Scientific and Educational Conferences

## 4.2.1 Joint Scientific / International Symposia

Scientific conferences are an important activity of the WBMT for communicating with other clinicians and researchers. WBMT conducts an annual 90-minute Scientific / International Symposium at one or two major HCT conferences. The Symposium is most often presented during the US-based Transplantation and Cellular Therapy Meetings [sponsored by the CIBMTR and the American Society for Transplantation and Cellular Therapy (ASTCT)] each February. Additionally, the WBMT presents a similar or modified program at the annual EBMT meeting in March – April. The focus during the WBMT presentations is on topics of global interest. **Appendix F** lists annual Symposia programs since WBMT began coordinating them in 2009.

Planning for the 2021 WBMT sessions at the ASTCT and EBMT meetings occurred during 2020 and are focused on transplantation during a world wide crisis.

## 4.2.2 WBMT Workshops and Scientific Symposia

The WBMT sponsors Workshops and Scientific Symposia in various world regions; often those with constrained resources to encourage expansion of existing transplant programs or new programs. The WBMT leverages the skills and expertise of its member Societies along with the Education and Dissemination Committee along with all other Standing Committees in planning these programs. Since 2011, the WBMT conducted six Workshops and Symposia: in Hanoi, Vietnam, in 2011 (Section 4.2.2.1); Salvador, Brazil, in 2013 (Section 4.2.2.2); Cape Town, South Africa, in 2014 (Section 4.2.2.3), Riyadh, Saudi Arabia, in 2017 (Section 4.2.2.4); Casablanca, Morocco, in 2018 (Section 4.2.2.5) Beijing, China, in 2018 (Section 4.2.2.6; and Asuncion, Paraguay (Section 4.2.2.7).

#### 4.2.2.1 2011 Hanoi, Vietnam

In late 2011, the WBMT conducted its first two-day Workshop and associated one-day Scientific Symposium in Hanoi, Vietnam, in cooperation with the WHO and in partnership with the APBMT and a local Vietnamese Organizing Committee.

The Hanoi Workshop concluded that WBMT should conduct training programs for physicians who lead transplant programs abroad. Since then, several teaching fellowships materialized during 2013 and increased in number through 2015. Trainees included practitioners from Vietnam (Hanoi and Ho-Chi-Minh City), Mongolia, Qatar, the Philippines, and Cambodia cross-training in Japan, Korea, Belgium, and Germany. This Workshop also enhanced networking across the globe. For instance, representatives from Myanmar, Indonesia, and Bangladesh established an HCT program under the guidance of WBMT 2011 Workshop participants.

#### 4.2.2.2 2013 Salvador, Brazil

With a commitment by the WBMT Board to support the LABMT, a new WBMT Member Society in 2013, and strong interest from a local organizing committee, the WBMT hosted a two-day Workshop and oneday Scientific Symposium in late 2013 in Salvador da Bahia, Brazil. Participants indicated this was a successful and valuable collaborative venture, but the most visible measurement of success has been the high level of regional organization and productivity since the Workshop.

The LABMT now holds regular monthly and annual meetings and continues to actively develop standing committees modelled after WBMT committees. Within two years of the Workshop, LABMT investigators published in peer-reviewed journals and presented oral abstracts at the prestigious American Society of Hematology (ASH) meetings.

## 4.2.2.3 2014 Cape Town, South Africa

The WBMT held its third Workshop and Scientific Symposium in November, 2014, in Cape Town, South Africa, in collaboration with the WHO, the African Society of Blood Transfusion and a local, South African planning committee. With the largest audience yet, attendees represented 34 countries, 20 of which were African. More than 200 individuals registered for the Workshop, and providing primarily positive responses and sound suggestions for improvements to future Workshop programs.

The WBMT customized the scientific program to address blood transfusion safety, a special problem on the continent, and included more open dialog time than in previous Workshops.

As was true for both previous Workshops, a broad spectrum of expert planners and presenters were from Europe, the Far East, Mediterranean region, and the US, augmenting a cadre of regional speakers.

Similar to the LABMT and the Workshop in Salvador, Brazil, the WBMT encouraged and strongly supported a more formal structure and activity level of the AFBMT. The WBMT received and approved a formal application for status as a WBMT Member Society in February 2015, and the AFBMT hosted a business meeting with newly elected officers in Istanbul in March 2015.

## 4.2.2.4 2017 Riyadh, Saudi Arabia

The fourth Workshop and Symposium, this one co-organized with the EMBMT, took place in Riyadh, Saudi Arabia, in January 2017. WBMT Officers and Standing Committee Co-Chairs participated along with the Riyadh-based Planning Organization. An extended program included longer, open discussion periods, as suggested on prior program evaluation forms. More than 1,000 individuals from 34 countries participated in the Workshop. Representatives from 12 different countries provided regional presentations. A summary of the presentations was published (**Appendix G**).

#### 4.2.2.5 2018 Casablanca, Morocco

In April 2018, the WBMT and AFBMT hosted a Workshop in Casablanca, Morocco, in association with the Moroccan Society of Hematology. The scientific program focused on setting up and enhancing HCT programs in Africa, including adapted conditioning regimens and focusing on diseases affecting regional populations. JACIE offered a workshop regarding establishing an accreditation program in low-middle income countries. A summary of this meeting was published.

#### 4.2.2.6 2018 Beijing, China

The 5th Annual WBMT / WHO Workshop and Scientific Symposium in collaboration with the Chinese Hematopoietic Stem Cell Transplantation Committee and the Chinese Medical Association was held at Beijing Kuntai Hotel, Beijing, China from September 19-21, 2018, focusing on the development of a HCT global outcome registry and advanced technology for HCT in emerging countries. The attendees were approximately 500 and most of the domestic attendees were relatively young physicians and other medical professionals. They concluded that it was a successful workshop and that they learned that different regions and differing times require different approaches to the challenges of HCT internationally. The scientific, social and organizational parts were outstanding. Following the pattern of the other meetings of the WBMT; we developed some new scientific aspects of importance.

Congratulations were offered for the extremely well-arranged 5th WBMT workshop. Most important was the very high-quality program and lectures and the large number of local and international speakers. This is in addition to the exceptional arrangements of logistics including venue, lecture room, audiovisuals, exhibit, registration, meals and many others. It was encouraging to note that the Central Administrative Office, WBMT and the Local Administrative Office communicated well each other. This was a model for the preparation of future workshop/scientific symposia sponsored with the WBMT.

## 4.2.2.7 2019 Asuncion, Paraguay

The 6<sup>th</sup> WBMT Workshop and Symposium was held September 2-4, 2019 in Asuncion, Paraguay. With the participation of 13 countries from Latin America sharing the current situation of HCT from the key players to an audience of 20 different countries as well as the Paraguayan Minister of Health, representatives from PAHO and WHO. Debate and discussion was vigorous. Everyone wanted to share what they were doing, express their weaknesses, ask how other countries had gotten through common barriers including access to medication and funding for HCT.

With over 300 colleagues, a list of essential medication was brought forth by the WBMT, discussed by all those present, and a commitment was secured by WHO representatives to make every effort possible to ensure easy access to these drugs.

The first day of the Workshop closed on a high note with the official launch of the Paraguayan Donor Registry and the presence of the Orchestra Band of Cateura, a local band composed of children from Asuncion that make their instruments out of the salvaged garbage -- a true testament of their resilience.

Day 2 began with meet the experts session followed by a Pediatrics HCT round table that finished with the commitment of all Heads of Services of Pediatric Centers to work together towards harmonizing treatments and sharing facilities. Common HCT debates included discussion of cryopreserved vs refrigerated grafts for autologous HCT; matched unrelated donor vs Haploidentical donor; and bone marrow vs cord blood with detailed presentations.

Patients emphasized the challenges of living after HCT. They formed a patient association and came to give their thanks to the WBMT for their assistance in the development of the HCT Program in Paraguay.

During the Gala Dinner that was held the second day of the meeting the President of the National Social Security Insurance assured those present he would expedite processes to have a HCT Center built with international standards by seeking the help of the WBMT.

Parallel to these events, the first JACIE-FACT Workshop was held on the 1<sup>st</sup> of September, a Nurses Satellite meeting took place coordinated by the Nurses Group of the LABMT and EBMT and the LABMT held an assembly where officers were elected, charges were distributed and work was outlined for the next two years.

Follow-up to the success of the workshop led to expressions of thanks to the WBMT. It was stated that the meeting "truly shattered all our expectations".



#### 4.2.2.8 Future Workshops and Symposia

Due to the ongoing COVID-19 pandemic WBMT has not committed to any future workshops. There are preliminary discussions with representatives of Pakistan and Russia and formal inquiries from other sites can be received for consideration.

## 4.3 Consensus and Guideline Initiatives

The primary purpose of the WBMT is to serve as a collective venue and voice – at a global level – for HCT and related issues. With the support of its Board, the WBMT publicizes its findings on controversial or critical matters on its website and collaborates with other groups. Previously WBMT positions have been published on: standardized product labelling; rejection of financial reimbursement for donation of cellular products. These have been published and reported on the WBMT website.

More recently, current and previous Standing Committees authored substantial work, either independently or collaboratively, on standardization of practice topics (minimal requirements for a HCT program, training best practices and other topics) (Section 3.0 and Appendix G). The Transplant Center / Recipient Committee; in 2017 and 2018 created a table of minimal requirements for establishing a new HCT program. All elements were rated, then reviewed by committee volunteers and later published. This fundamental information was used, in part, by a WBMT group who visited Ethiopia in December 2015 to assess their existing situation and to document what might be required for their five-year HCT plan. A final report was created in the second quarter of 2016 and provides the basis for the ongoing work in Ethiopia.

In 2020 a statement on COVID-19 and adverse event reporting have been published.

## 4.4 Collaboration with the WHO

As noted previously, a WHO representative has been involved with WBMT activities since the earliest concept development meetings. The WBMT maintained a working relationship with the WHO for almost four years before being officially invited to apply for *NGO in official relations* status with the WHO. The WHO approved the WBMT's initial application as of January 2013 and approved this continued status in January 2019. This status provides the WBMT with the opportunity to continue its work in partnership with the WHO in promoting global excellence in HCT, stem cell donation, and cellular therapy. This partnership brings with it additional responsibilities, including participation in other WHO initiatives, in pursuit of mutual educational, scientific, and philanthropic missions. Because of the importance of this collaboration, the WBMT created in 2016 a Board position, generally the past-President, specifically designated to represent the WBMT to the WHO.

# 4.4.1 Platform for WBMT Collaborative Projects

The 2012 NGO status application process recognized those collaborative projects already in progress and continues its work on specific identified projects.

Those activities which form the foundation of WBMT's continued work are:

- Work with the Global Observatory on Donation and Transplantation (Section 4.4.2.4).
- Promote access to HCT stem cell donation (Section 4.2).
- Develop a donation guidance document (Section 4.3).
- Promote access to HCT stem cell transplantation (Sections 4.2-4.5).
- Provide technical and scientific input on safety and quality of HCT (Sections 4.2-4.4).
- Provide global consultation on ethics, safety, and access to HCT (Sections 4.2-4.4).
- Contribute to the initiative for global vigilance and surveillance of adverse reactions and events (Section 4.4.2.1).
- Provide consultation services (Section 4.0).

The WBMT works in collaboration with the WHO as an NGO and WBMT is engaged in the following projects:

## 4.4.2 Collaborative Projects

## 4.4.2.1 NOTIFY Project

WBMT members have participated in the NOTIFY Project since a first meeting in Bologna in 2011. The NOTIFY Project, a vigilance initiative, was launched as a joint venture by WHO and the Italian National Transplant Center. Also, in collaboration with the European SOHO V&S project (Vigilance and Surveillance of Substances of Human Origin), this global initiative was organized to support the vigilance and surveillance of substances of human origin (organs, tissues, and cells for transplantation and assisted reproduction). A sub- project of the broader NOTIFY Project is referred to as BIG V&S (Bologna Initiative for Global Vigilance and Surveillance), coordinated by the WHO and the Italian National Transplant Center. Adverse reactions associated with MPHO can be reported to this group.

An important accomplishment of the NOTIFY group of experts was the development of the NOTIFY Library, a large database launched in 2013, which provides global access to reports of adverse outcomes. WBMT was in a unique position to make important recommendations to this group, including changes in cell type taxonomy data items and keywords specificallyrelated to cellular therapies. WBMT representatives also recommended improving website navigation processes and the formation of an editorial board including more specialists in hematopoietic progenitor cell therapies. Experts in this Blood Working Group will eventually join existing editorial working groups, and, as the work develops, an Editorial Group will be established for Transfusion Reactions.

# 4.4.2.2 Medical Products of Human Origin

WBMT is one of four WHO NGOs assigned to the MPHO project. A paper produced by these four NGOs is completed and awaiting publication. The WHO circulated another draft paper, entitled "Principles of donation and management of MPHOs", to the WBMT for comments. This paper focuses on donor concerns, including development of an overarching set of guiding principles to ensure ethical and safe practice in management of donors of MPHO and derived products. The principles will cover the different aspects of donation and MPHO management to the point of product allocation and should include: safety, ethics, transparency, traceability, and informed consent. It is anticipated that these principles will be a central plank for future regulation of MPHO. Publications prepared relevant to these topics include:

- <u>Cell, tissue and gene products with marketing authorization in 2018 worldwide.</u>
   Cuende N, Rasko JEJ, Koh MBC, Dominici M, Ikonomou L. Cytotherapy. 2018 Nov;20(11):1401-1413.
- <u>Science, ethics and communication remain essential for the success of cell-based therapies.</u> Dominici M, Nichols KM, Levine AD, Rasko JE, Forte M, O'Donnell L, Koh MB, Bollard CM, Weiss DJ. Brain Circ. 2016 Jul-Sep;2(3):146-151.

# 4.4.2.3 Unproven Cellular Therapies

In 2020 a position paper entitled "Unproven Cellular Therapies" was submitted to the WHO for endorsement. The information in the paper was assembled and reviewed by over 100 experts in the field of stem cell based therapies. The aim of the paper is to educate both the public and the medical community regarding the appropriate use of cellular therapy and the importance of engaging in clinical trials as most of these novel cellular therapies are still investigational products. Under Mickey Koh's guidance and leadership a final version of the position paper was submitted to the WHO. Endorsement by the WHO is pending.

Mickey Koh was invited to present his work on "unproven therapies" to the WHO Expert Advisory Committee on Developing Global Standards and Oversight of Human Genome Editing. This was followed by a discussion and interactive session with the panel on how Genome editing is within the remit of Unproven Therapies and the relevant points raised by the doucment prepared by WBMT. This was followed by work looking at various clinical scenarios worldwide involving human genome editing including unscrupulous entrepreneurs and Unproven Stem Cell Clinics.

## 4.4.2.4 Global Observatory on Donation and Transplantation

Data on international use of HCT procedures are gathered inconsistently across the globe but usually by registries and professional societies. The Department of Essential Health Technologies of the WHO and the Spanish National Transplant Organization (Organización Nacional de Transplantes) established the Global Observatory on Donation and Transplantation (transplant-observatory.org) in 2007. These collaborative activities help to meet the requirements of the 2004 57<sup>th</sup> World Health Assembly Resolution WHA57.18. This resolution suggested the collection of global data on the practices, safety, quality, efficacy, and epidemiology of transplantations as well as their global availability for all those concerned, including professionals, patients, politicians, and the general public, are recognized as a prerequisite for global improvement of, and better access to, transplantations [Organs, Tissues and Cells, (2), 91-94, 2007]. One goal of the Observatory is the development of a global database on donation and transplantation. WBMT Member Societies, particularly the WMDA, contributed substantially by providing unrelated donor information from their own databases to this Observatory databank.

The WBMT provided its first HCT activity contribution to the Global Observatory in 2012 with Global Survey data from 2006-2008 and now updates these data as they become available. The 2014 data were provided by the WBMT in the first half of 2017 and updated and refreshed in late 2017. The summary of Global Transplant Activity is now updated by the WBMT every 2 years.

## 4.4.3 Ongoing Collaboration between WHO and WBMT

Specific collaborative projects proposed by WBMT have included both a WBMT workplan (below) and ongoing discussions to establish a Global Framework for further collaboration in Hematopoietic Cell Transplantation. The workplan includes:

# 4.4.3.1 Defining Essential medications for transplantation:

WHO maintains a list of essential medications for other medical uses.

Since WHO currently monitors shortages; WBMT will propose a joint plan for monitoring pricing and availability or procurement practices of transplant essential drugs. This activity may also provide regular surveys to capture information on drug (or device) shortages in various world regions. Establish a warning tool and communications plan for monitoring and responding to HCT related drug/device shortages. This could include a list of alternatives (e.g. biosimilars, generics, patent-free drugs etc) to be shared through WHO to regulatory authorities in various regions to ensure availability and affordability of drugs/devices.

Encourage regular discussions with political authorities and practitioners along with scientific organizations and pharmaceutical industry representatives to sustain access to essential medications and innovative therapies.

# 4.4.3.2 Cost Saving Practices

Highlight and promote low cost practices that may be best applicable in Low/Middle Income Countries (LMIC) or across the world. Examples are: (haplo vs MUD; Use the same catheter for stem cell collection and infusion; generic plerixafor for PBSC collection efficiency).

Establish good practices through survey and interviews from LMIC BMT experts.

# 4.4.3.3 Disaster planning

Integration with WHO in disaster management; especially in radiation or nuclear accidents where the HCT community has capability and specific expertise.

# 4.4.3.4 Communication with local and regional authorities

Acknowledgment from WHO that guidelines and procedures having international recognition could help centers and other institutions establish and expand transplant activities. This WBMT activity is fitting with the goals of WHO, but at present is not a joint WBMT-WHO activity.

# 4.5 Supporting Other HCT Global Activities

# 4.5.1 Ethiopia – A New HCT Center

The WBMT assists in establishing new HCT programs of high quality. In November 2014 representatives from Ethiopia (a Minister of Health office representative, individuals representing blood banks, hematologists, and others) met with WBMT leaders and requested support and technical assistance in establishing an HCT program in their country. These preliminary discussions led the WBMT to create a task force of interested parties to assess and assist in this venture. As at that time Co-Chair of the WBMT Graft Processing and Cellular Therapies Committee, Mickey Koh, was identified as the WBMT Project Leader and he maintained frequent communication with the Ethiopian team throughout 2015. Planning became more focused in the second half of 2015, and a comprehensive onsite visit by four WBMT HCT clinicians (some with substantial blood transfusion expertise) followed in December 2015. In the first part of 2016, the team prepared a full report, which was approved by the WBMT Executive Committee and distributed to the Ethiopian clinician team as well as the Dean of the adjacent medical school and the Minister of Health. Throughout the year, Mickey Koh conducted regular discussions via email with the Ethiopian team, and this project continued in 2018. Though challenges exist (recent political instability), the WBMT is impressed with the eagerness and engagement of local planners who are strongly supported by their current government.

Since then-Mickey Koh has continued with regular teleconference calls to assess the progress of this initiative all though 2016 and 2017. There were encouraging signs of continuing governmental support and concrete plans were being drawn up for building works. There was also planning done for training of Ethiopian staff in HCT. Unfortunately, the domestic and political situation changed in Ethiopia about 2018 and there has been little progress since. The political situation has worsened with fighting in the country and Covid-19 has put further strain on the country and its resources.

This project is currently on hold. Mickey Koh intends to touch base with the Ethiopian team sometime in 2021 if the Covid situation improves.

# 4.5.2 Regional HCT Societies

As previously mentioned, (Section 4.2.2.2) the WBMT has been instrumental in supporting the development of the now highly successful LABMT. The LABMT first met as an integrated group in 2013; now it has a Board and bylaws, and it holds regular monthly and annual meetings. The WBMT continues to support this organization, and the LABMT continues to actively develop, including creating standing committees modelled after WBMT committees.

Similarly, the WBMT was very supportive of establishing the AFBMT (**Section 4.2.2.3**). A small, interim Executive Committee existed early in the building process; elected officers are now in place. The WBMT approved the AFBMT's formal application for Member Society status in February 2015 and continues to place high focus and expectations on this organization; it represents the single remaining continent that has not uniformly reported transplant activity or outcome data. In April 2018, the WBMT and AFBMT hosted a Workshop in Casablanca, Morocco, in association with the Moroccan Society of Hematology (Section 4.2.2.5).

Both of these groups are encouraged to commit to participation in the WBMT annual global survey of HCT activity (**Section 4.1**). After the Workshop in Latin America, several new transplant centers started providing activity data to this survey. This is an important step forward in addressing the current gap in acquisition of data from these regions.

The WBMT remains heavily engaged with the EMBMT following the Workshop and Symposium in Riyadh, Saudi Arabia, in January 2017 (**Section 4.2.2.4**). The EMBMT wis proactive and well organized. They led the design of the scientific program and fund raising; they also handled most of the logistics, including making arrangements for ancillary activities.

# 4.6 Website

The first WBMT website was launched in 2010. Identifying itself via the internet was an important first step in the evolution of WBMT branding. In 2020 a new version of the website was launched: <u>wbmt.org.</u> Substantial effort is continually placed on posting current documents, information regarding Workshops and Symposia programs, and important newsworthy items (e.g., one millionth transplant announcement in early 2013, consensus statements, latest versions of the Bylaws and Houserules, etc.).

# 4.7 Research Data Task Force

The WBMT Board mandated development of a Task Force in 2013 for the purpose of developing guidelines for management and use of the WBMT GTA data as well as guidelines for how research should be managed with collaboration amongst WBMT Member Societies. These documents (**Appendices D1 and D2**) were approved in 2015, and all Member Societies signed data transmission agreements in early 2016. Since 2015, the Transplant Center / Recipient Committee (**Section 3.7**) administers all activities related to the GTA survey, including providing reports and reviewing proposals for use of these data.

# 4.8 Administrative support

Administrative support is outsourced to members of WBMT. WMDA took on this responsibility per July 2019.

# 4.9 Updated Bylaws and Houserules

In 2020 the WBMT <u>Bylaws</u> and <u>Houserules</u> were updated. The most recent versions are available on the WBMT website (by clicking the links).

## 5.0 FUTURE AIMS

The WBMT continues to evolve and available resources and time from the Society leaders and committee members constrain the selection of projects for its portfolio. In addition to the plans identified by each Standing Committee, the Executive Committee regularly assesses priority activities.

They are to:

- Establish a more durable mechanism for soliciting and sustaining high level financial support. In 2020 WBMT member societies have contributed via a voluntary fee. The letter stating this request has been added (**Appendix J**).
- Continue the close collaboration with the WHO on global projects relevant to HCT and fulfilling WBMT responsibilities as an NGO in official relations with the WHO, including the ongoing WHO-sponsored project, the ISCT Presidential Task Force on Unproven Cellular Therapies (**Section 4.4.2.3**).
- A WHO Task Force has been created (Section 4.4).
- Continue to offer Workshops and Scientific Symposia in regions with constrained resources and willing to establish new or expand existing HCT programs.
- Continue efforts in support of AFBMT and LABMT (Section 4.5.2).
- Continue support of transplant center twinning and/or other cross-training activities;
- Continue the mission of the Research Data Task Force to oversee proper procedures for research coordinated by the WBMT (Section 4.7).
- Sustain the WBMT Global Emergencies and Nuclear Accident Management Committee (Section 3.5) in collaboration with existing nuclear accident committees.
- Further develop the WBMT Patient Advocacy / Advisory Committee (Section 3.6) to mentor patient groups and harmonize patient educational materials across the globe.
- Continue collection of global activity data by new and userfriendly database and its publication.
- Work on ways to collect and analyze global outcome data.

## APPENDIX A: MEMBER SOCIETIES

Member Society	Description
American Association of Blood Banks (AABB) <u>aabb.org</u>	AABB is the global leader in standards development, accreditation and implementation of quality systems in transfusion medicine and cellular therapies. AABB has an unwavering focus on donor and patient safety. This is accomplished by translating knowledge into solutions that shape the field of transfusion medicine and cellular therapies. AABB brings together those engaged in transfusion medicine and cellular therapies. AABB creates a unique learning environment, including an Annual Meeting, that inspires and enables research, innovation, discovery and excellence.
African Blood and Marrow Transplantation Group <b>(AFBMT)</b> <u>https://www.wbmt.org/member-</u> <u>societies-of-wbmt/AfBMT/</u>	In order to encourage activity in the medical and scientific field of blood and marrow transplantation in Africa, AFBMT has been established with the support of the WBMT. The main objectives are to improve awareness among health workers, to improve the skills of healthcare teams through sharing experiences and adapt the knowledge and potential of HCT therapy to local resources and needs.
American Society for Apheresis (ASFA) apheresis.org	ASFA is the premier organization of physicians, scientists, and allied health professionals whose mission is to advance apheresis medicine for patients, donors, and practitioners through education, evidence-based practice, research, and advocacy. ASFA creates guidelines for the appropriate use of apheresis techniques, provides education for apheresis practitioners, and promotes research in apheresis medicine, as well as information for patients regarding apheresis procedures.
American Society of Transplantation and Cellular Therapy <b>(ASTCT)</b> <u>https://www.astct.org/home</u>	ASTCT is an international professional membership association of more than 2,200 physicians, investigators and other health care professionals from more than 45 countries. It is dedicated to improving the application and success of stem cell transplantation and related cellular therapies. It strives to be the leading organization promoting research, education and clinical practice in the field.
American Society for Histocompatibility and Immunogenetics <b>(ASHI)</b> <u>ashi-hla.org</u>	ASHI is a not-for-profit association of clinical and research professionals including immunologists, geneticists, molecular biologists, transplant physicians and surgeons, pathologists and technologists. As a professional society involved in histocompatibility, immunogenetics and transplantation, ASHI is dedicated to advancing the science and application of histocompatibility and immunogenetics; providing a forum for the exchange of information; and advocating the highest standards of laboratory testing in the interest of optimal patient care.

WBMT Progress Report 2020					
Asia Pacific Blood and Marrow Transplantation <b>(APBMT)</b> <u>apbmt.org</u>	APBMT is an international organization which is involved in hematological stem cell transplantation, sharing their information and cooperating with basic and clinical research in Asia-Pacific countries. APBMT is comprised of 22 countries/regions (Australia, Bangladesh, Cambodia, China, Hong Kong, India, Indonesia, Iran, Japan, Korea, Malaysia, Mongolia, Myanmar, Nepal, New Zealand, Pakistan, Philippines, Singapore, Sri Lanka, Taiwan, Thailand and Vietnam) and is expanding its activities through the annual congresses, registration systems and working groups under the collaboration with the member societies of WBMT.				
Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) <u>abmtrr.org</u>	ABMTRR was established in 1992. Operating under the auspices of the Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), it records details of bone marrow, peripheral blood and cord blood stem cell transplants throughout Australia and New Zealand.				
Center for International Blood and Marrow Transplant Research (CIBMTR) cibmtr.org	CIBMTR <sup>®</sup> is a research collaboration between the National Marrow Donor Program <sup>®</sup> (NMDP)/Be The Match <sup>®</sup> and the Medical College of Wisconsin (MCW). CIBMTR collaborates with the global scientific community to advance hematopoietic cell transplantation and cellular therapy worldwide to increase survival and enrich quality of life for patients. CIBMTR facilitates critical observational and interventional research through scientific and statistical expertise, a large network of transplant centers, and a unique and extensive clinical outcomes database.				
Eastern Mediterranean Blood and Marrow Transplantation <b>(EMBMT)</b> <u>embmt.org</u>	EMBMT was established in 2008 as a cooperative platform for physicians, scientists and healthcare workers from institutions in the WHO designated Eastern Mediterranean area with the goal of sharing experience, initiation of cooperative trials and establish common strategy to achieve optimization in the field of HCT. The group's aim is to promote all aspects of patient care, academic and research activities associated with HCT in the region which includes knowledge of the trends, patterns and status of HCT in Eastern Mediterranean countries.				
Eurocord <u>eurocord-ed.org</u>	EUROCORD is a non-profit organization affiliated to the University Paris Diderot and to the Assistance Publique des Hopitaux de Paris (APHP). It has strong links with the University Institute of Hematology (IUH) at the Saint-Louis hospital, and the French Agence de la biomédecine. Located within the campus of Saint Louis hospital in Paris, EUROCORD is a clinical research group dedicated to study cord blood transplantation and innovative therapy in both malignant and non-malignant diseases, and to develop new indications for stem cell therapy.				

WBMT Progress Report 2020				
European Federation for Immunogenetics <b>(EFI)</b> <u>efiweb.eu</u>	EFI is a European society of workers in the field of immunogenetics, histocompatibility testing and transplantation. EFI supports the development in Europe as a discipline in medicine and promotes research and training in this field.			
European Society for Blood and Marrow Transplantation <b>(EBMT)</b> <u>ebmt.org</u>	EBMT is a collaborative peer network of professionals working in centres and as individuals in the field of clinical stem cell transplantation and cellular therapy. Members contribute to and benefit from the collective knowledge that the EBMT has accrued, with the ultimate goal of saving the lives of patients with blood cancers and other life-threatening diseases.			
European Leukemia Network <b>(ELN)</b> <u>www.leukemia-net.org</u>	The objective of the ELN is to integrate the leading leukemia trial groups (CML, AML, ALL, CLL, MDS, CMPD), their interdisciplinary partners (diagnostics, treatment research, registry, guidelines), industry and SMEs across Europe to form a cooperative network for advancements in leukemia-related research and health care and cure.			
European Marrow Donor Information System <b>(EMDIS)</b> <u>emdis.net</u>	EMDIS defines an open specification of a protocol for the electronic communication among registries. Therefore, EMDIS is implemented as an asynchronous peer-to-peer network connecting distributed, heterogeneous databases.			
European School of Hematology (ESH) <u>esh.org</u>	ESH is a non-profit institution for continuing education that promotes and facilitates access to research in hematology and related disciplines in Europe, North America, North Africa, and the Middle East. ESH also develops tools for continuing education produced in collaboration with international experts in the field.			
Foundation for the Accreditation of Cellular Therapy <b>(FACT)</b> <u>factwebsite.org</u>	FACT is a non-profit organization that establishes standards for high-quality medical and laboratory practices in cellular therapies for the purposes of voluntary inspection.			

International Council for Commonality in Blood Banking Automation <b>(ICCBBA)</b> <u>iccbba.org</u>	ICCBBA is a not-for-profit, tax exempt, NGO responsible for management of the ISBT 128 Information Standard for Blood and Transplantation, a global standard for the terminology, identification, labeling, and information transfer of human blood, cell, tissue, and organ products across international borders and disparate health care systems. It ensures the highest levels of accuracy, safety, and efficiency for the benefit of donors, patients, and ISBT 128 licensed facilities worldwide. The system features a unique, highly flexible, and comprehensive coding method for every collected product and provides international consistency to support the transfer, transfusion, or transplantation of blood, cells, tissues and organs.
International Society of Blood Transfusion <b>(ISBT)</b> <u>isbtweb.org</u>	ISBT is an international professional society that facilitates knowledge about transfusion and transplantation science and medicine.
International Society of Cellular Therapy <b>(ISCT)</b> <u>celltherapysociety.org</u>	ISCT is a global association that promotes cellular therapies research by fostering international translational research, driving commercialization strategies, and providing education.
Joint Accreditation Committee – ISCT (Europe) & EBMT <b>(JACIE)</b> jacie.org	JACIE is a non-profit organization that assesses and provides accreditation in the field of HCT. Its primary aim is to promote high-quality patient care and laboratory performance in hematopoietic stem cell collection, processing and transplantation through an internationally recognized system of accreditation. It partners with EBMT, ISCT, and FACT.
Latin American Bone Marrow Transplantation group <b>(LABMT)</b> <u>https://www.wbmt.org/member-</u> <u>societies-of-wbmt/labmt/</u>	The purpose of this group is to provide a mechanism through which Latin American Blood and Marrow Transplant and Hematology groups can collaborate and engage in scientific and educational activities and endeavours to promote excellence in stem cell transplantation, stem cell donation, cellular therapy and hematologic practices. Activities include data collection and sharing outcome information.
World Marrow Donor Association (WMDA) worldmarrow.org	WMDA is a global association whose mission is to assure that high-quality stem cell products are available for all patients in need, while maintaining the health and safety of volunteer donors. WMDA now incorporates all functions previously undertaken by Bone Marrow Donors Worldwide and Netcord.

#### APPENDIX B: EXECUTIVE COMMITTEE ELECTED OFFICERS





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Vice-President Mahmoud Aljurf, MD, MPH King Faisal Specialist Hospital & Research Center P.O. Box 3354 Riyadh 11211 Saudi Arabia <u>maljurf@kfshrc.edu.sa</u>



**Treasurer** Adriana Seber, MD Hospital Samaritano Rua Domingos Augusto Setti, 21, São Paulo, SP 04116- 070 Brazil Tel: +55 11 99614 3210 <u>adrianaseber@gmail.com</u>



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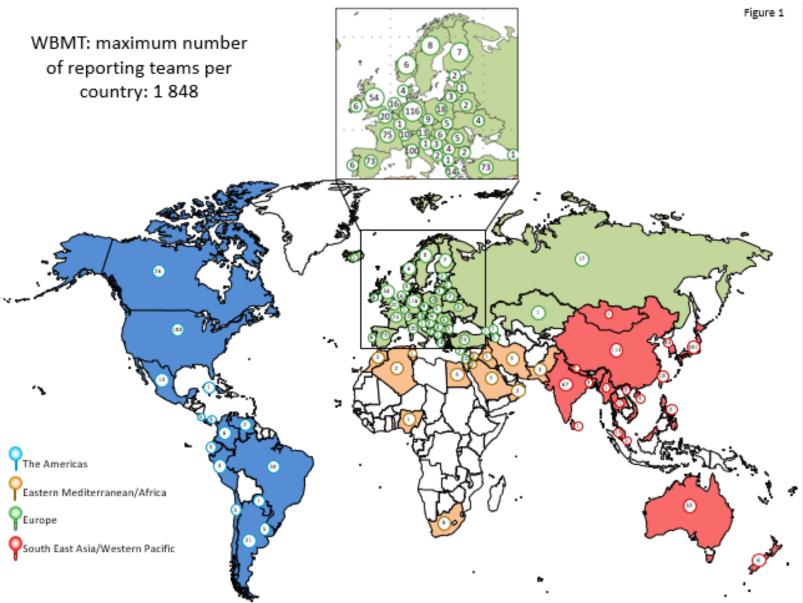


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#### APPENDIX C1: CENTER SITES THAT CONTRIBUTE DATA TO THE ACTIVITY SURVEY

# APPENDIX C2: COUNTRIES THAT HAVE CONTRIBUTED DATA

WHO Region	Country	Max. N Teams in any survey year
EMR/AFR	Algeria	2
AMR/PAH	Argentina	24
EUR	Armenia	1
SEAR/WPR	Australia	42
EUR	Austria	13
EUR	Azerbaijan	1
SEAR/WPR	Bangladesh	4
EUR	Belarus	2
EUR	Belgium	20
AMR/PAH	Bolivia	1
EUR	Bosnia and Herzegovina	2
AMR/PAH	Brazil	45
EUR	Bulgaria	2
AMR/PAH	Canada	26
AMR/PAH	Chile	5
SEAR/WPR	China	114
AMR/PAH	Colombia	6
AMR/PAH	Costa Rica	3
EUR	Croatia	3
AMR/PAH	Cuba	5
EUR	Cyprus	2
EUR	Czech Republic	9
EUR	Denmark	4
AMR/PAH	Ecuador	3
EMR/AFR	Egypt	3
EUR	Estonia	2
EUR	Finland	7
EUR	France	75
EUR	Georgia	1
EUR	Germany	116
EUR	Greece	14
SEAR/WPR	Hong Kong	3
EUR	Hungary	6
EUR	Iceland	1
SEAR/WPR	India	77
SEAR/WPR	Indonesia	3
EMR/AFR	Iran	3
EMR/AFR	Iraq	1
EUR	Ireland	6

EUR	Israel	10
EUR	Italy	100
SEAR/WPR	Japan	381
EMR/AFR	Jordan	2
EUR	Kazakhstan	1
EMR/AFR	Kuwait	1
EUR	Latvia	1
EMR/AFR	Lebanon	2
EUR	Lithuania	3
EUR	Luxembourg	1
EUR	Macedonia, FYR	1
SEAR/WPR	Malaysia	13
AMR/PAH	Mexico	31
SEAR/WPR	Mongolia	1
EMR/AFR	Могоссо	2
SEAR/WPR	Myanmar	2
SEAR/WPR	Nepal	1
EUR	Netherlands	16
SEAR/WPR	New Zealand	6
EMR/AFR	Nigeria	1
EUR	Norway	6
EMR/AFR	Oman	2
EMR/AFR	Pakistan	3
AMR/PAH	Panama	3
AMR/PAH	Paraguay	2
AMR/PAH	Peru	5
SEAR/WPR	Philippines	6
EUR	Poland	18
EUR	Portugal	6
EMR/AFR	Qatar	1
EUR	Romania	5
EUR	Russian Federation	17
EMR/AFR	Saudi Arabia	7
EUR	Serbia	4
SEAR/WPR	Singapore	5
EUR	Slovak Republic	5
EUR	Slovenia	1
EMR/AFR	South Africa	9
SEAR/WPR	South Korea	45
EUR	Spain	73
SEAR/WPR	Sri Lanka	4
EUR	Sweden	8
EUR	Switzerland	10

	92	1848
SEAR/WPR	Vietnam	3
AMR/PAH	Venezuela	2
AMR/PAH	Uruguay	5
AMR/PAH	USA	198
EUR	United Kingdom	54
EUR	Ukraine	4
EUR	Turkey	73
EMR/AFR	Tunisia	1
SEAR/WPR	Thailand	12
SEAR/WPR	Taiwan	18

#### APPENDIX D1: WBMT RESEARCH GUIDELINES

#### WBMT RESEARCH GUIDELINES

This document is developed by the Worldwide Network for Blood and Marrow Transplantation (WBMT) and outlines the guiding principles of research performed directly by this entity through the global survey data or indirectly by fostering collaboration among member societies with the intent of dissemination of information for advancement of the hematopoietic cell transplantation field.

#### **BACKGROUND:**

The idea of creating guidelines for research endeavors generated by WBMT Member Societies laterally, or on behalf of the parent organization (WBMT), was first presented during the 2013 annual, in-person Board meeting in Salt Lake City, USA. The Board agreed that guiding principles for the conduct of research by or within the WBMT was an important topic to be explored and formed a Research Activity Task Force to 1) develop a guidelines document on developing, conducting, and disseminating results of studies involving data and/or investigators from multiple Member Societies and 2) promote collaboration among the WBMT Member Societies / registries through the establishment of a framework for the conduct of research.

During the deliberations of the Research Activity Task Force, it was decided to cover this topic of research in two different fronts, first to develop the guiding principles of collection, presentation, dissemination, and sharing of the Global Activity Survey data, herein defined as Global Transplant Activity data. Second, the Research Activity Task force would develop guiding principles to provide general guidelines for the conduct of international collaborative research, with the intent to serve as reference for research procedures and for fostering collaboration among member societies.

#### SECTION 1: OVERARCHING WBMT GUIDING PRINCIPLES OF RESEARCH

#### Overarching Guiding Principle #1

The Worldwide Network for Blood and Marrow Transplantation (WBMT) has the responsibility to collect, store, and disseminate information related to global hematopoietic cell transplantation activity. This is done through the annual global activity survey. WBMT will be responsible for safe keeping of this data and oversight of its utilization.

#### Overarching Guiding Principle #2

The WBMT shall not duplicate or compete with research actively being conducted by its Member Societies and/or registries. Each WBMT Member Society conducts research in its unique manner, independent from the WBMT.

#### Overarching Guiding Principle #3

The WBMT will foster collaboration through its member societies for the development of collaborative research to address global questions in transplantation, encourage the analysis of regional differences, and offer a global perspective on transplantation. Furthermore, this collaborative research shall fulfill the WBMT mission, including increase global awareness of the importance of transplantation, improve access to transplant, optimize safety for patients and donors, and improve the quality of all activities associated with hematopoietic cell transplantation.

### SECTION 2: GLOBAL TRANSPLANT ACTIVITY (GTA)

#### Global Transplant Activity Guiding Principle #1

The WBMT is required to survey transplant activity globally in an annual basis to maintain its Non-Government Organization (NGO) status with the World Health Organization (WHO).

#### Commentary on GTA Guiding Principle #1

Since the January 2013 award of NGO status by the WHO, there are important and continuing obligations for the WBMT. One such criterion is referred to as "*Global Database on Donation and Transplantation*". The WHO, along with the Spanish National Transplant Organization established the Global Observatory on Donation and Transplantation and one of several goals is the development of a global database on donation and transplantation. WBMT has facilitated access to its global survey data for input into this Observatory database since 2006 and remains an ongoing project.

The current process for collecting these Global Activity data is performed by a WBMT paid consultant. All GTA related communication (e.g., requests to centers and registries) is managed by this individual. The data is collected through a survey and represents the number of first transplants performed by a center during a calendar year. Data for a particular year activity is collected from November of the subsequent year through February. For example, submission related to the activity for 2013 will be due starting November 2014 through February 2015. This data will be compiled and released to the WHO and to the public by the last quarter of 2015.

Any transplant center is eligible to provide data to the WBMT through its Member Society. The only requirement for participation is that each Member Society has a standing agreement with the WBMT to share transplant activity data. The WBMT will have the autonomy in using these data according to its mission and share with third parties for specific projects (Guiding Principles #2 and #3).

One important exception in the relationship between the WBMT and a Member Society involves transplant activity data from regions were the regional Member Society is still in development. In these instances, direct communication from a transplant center and the WBMT is allowed, condition upon having a standing agreement in place. The transplant center is required to include in the survey whether or not it has an active affiliation (i.e. data reporting) with an outcomes registry (APBMT, CIBMTR, or EBMT). Additionally, the regional Member Society in question needs to be aware of this direct relationship between its transplant center and the WBMT. In case of data being shared from a transplant center directly with the WBMT, the WBMT will share this activity information with the regional Member Society.

WBMT Global Transplant Activity data reports (Insert 1) capture disease indications (malignant and nonmalignant) for allogeneic (related and unrelated) and autologous stem cell transplantation, donor type, and stem cell sources. They do not include outcome data. Data are provided to the WBMT by transplant program sites, national, and/or outcome registries.

The data from an outcomes registry member society (APBMT, CIBMTR, EBMT, EMBMT, and ABMTRR as well as, in the future, LABMT and AFBMT) that are shared with the WBMT can be utilized by the same Member Society for other uses without restrictions.

Collection forms are available on the WBMT website (<u>wbmt.org</u>) and may be submitted in paper format or electronic mail.

### Global Transplant Activity Guiding Principle #2

The WBMT will be responsible for the dissemination of the Global Transplant Activity report.

#### Commentary on GTA Guiding Principle #2

The responsibilities with the GTA include report annually to the WHO and share the activity with Member Societies. A summary slide set, updated annually, outlining annual and cumulative activity will be uploaded to the WBMT website for public use. Activity reports in the form of a manuscript will be published at least once every other year.

### Global Activity Survey Guiding Principle #3

The WBMT has ownership of the GTA data and any use needs to be approved by the WBMT. This includes data requests and proposals for scientific studies that seek to utilize these data for analysis.

### Commentary on GTA Guiding Principle #3

The GTA consists of transplant center level data on volume of transplant activity indications and donor and stem cell sources. These data, in aggregate, demonstrate important trends in activities and practices globally. Additional uses of these data are possible by any WBMT Member Society. In addition to annual reports of global activities, any individual on behalf of a Member Society can request specific information by contacting the WBMT data consultant. If the use is for research purposes, the proponent is required to complete a proposal form (Insert 2), which needs to be approved by his or her Member Society Representative before it can be submitted to the WBMT. This proposal will then be reviewed by the Transplant Center / Recipient Standing Committee before the data can be released. When a proposed study is approved, any Member Society that provided data to be used for that study will be notified by the approval committee. For data requests outside of Member Societies, GTA data can only be released with approval from the WBMT Board. In these situations, charges may apply.

Data from a Member Society that are shared with the WBMT can be utilized by the same Member Society (which also has ownership of its data) without restrictions.

### Insert 1: Sample from the Transplant Activity Survey document (wbmt.org)

С	Country:						WBMT Global Transplant Activity (GTA) 2018													
No No	o. Teams reporting: o. Teams known to transplar	nt but (	do not	report																
						NUMBER OF PATIENTS RECEIVING FIRST TRANSPLANTS ONLY														
	WBMT						Allog	eneic								Autologo	ous	Total		
		Family HLA - id sibling non - id*		twin		Family total		Jnrelate		Unrelated total			Allo auto To		Total					
	Indication	BM	PBSC	Cord	BM	PBSC	Cord	BM	PBSC		BM	PBSC	Cord		BM	PBSC	Cord			
	Total Leukemia Total AML																			<u> </u>
	AML 1st CR																			
	non 1st CR																			
	Total ALL																			
	ALL 1st CR																			
nias	non 1st CR																			
euker	Total CML																			
Le	CML 1st cP																			
	not 1st cP																			<u> </u>
	Other Leukemia																			<u> </u>
	Total MDS/MD/MPN																			
	MDS or MD/MPN																			
	MPN (old MPS)																			
	CLL incl. PLL																			
	Total LPD																			f T
	Total Plasma Cell Disorder																			<u> </u>
	PCD - Myeloma																			<u> </u>
	PCD - other																			<u> </u>
G	Total Lymphoma																			
	HD																			
	NHL																			<u> </u>
	Other LPD																			
-	Total Solid tumors																			
																				<u> </u>
lors	Germ cell tumor																			<u> </u>
d tum															<u> </u>					<u> </u>
Solid	Breast Cancer														-					
	Ewing																			
┝	Other solid tumor																			<u> </u>
	Total Non-malignant dis.																			<u> </u>
60	Total Bone Marrow Failure																			<u> </u>
orders	BMF - SAA																			└──
nt diso	BMF - other																			-
്ല	Hemoglobinopathy																			<u> </u>
- Ma	Primary Immune Deficiency																			<u> </u>
Nov	Inherited Dis of Metabolism																			<u> </u>
	Auto Immune Disease																			
L	Other Non Malignant Disease																			
	Other																			
	TOTAL PATIENTS (1st. HSCT)																			
	TOTAL NUMBER OF TRANSPLA	NTS P	ERFOR	MED TH	IIS YEA	AR: inclu	udes 1s	t, 2nd,	Brd. etc		ALLO:				AUTO	:		TOTAL:		

EBMT CIC No. / CIBMTR Code / APBMT (if member):.....

Please return to Helen Baldomero; Fax: 00 41 61 265 2735, E mail: Helen.Baldomero@usb.ch, post: Helen Baldomero, Hematology, University Hospital Basel, CH-4031 Basel, Switzerland.

#### Insert 2: Global Transplant Activity (GTA) Study Proposal Form

Prepare a brief description of the proposed study as you envision it. This should be no more than three pages, using standard  $8\frac{1}{2}$ " X 11" paper with 1" margins. Use the outline below and send your description to the WBMT administrative office or a known Executive Committee Officer.

#### I. Study Title

Include the name(s) and institution(s) and WBMT Member Society of the individual(s) proposing the study.

#### II. Specific Aims

State the primary purpose(s) of the study as concisely and clearly as possible. A reader should have a clear idea of the purpose for which the data will be analyzed.

#### III. Scientific Justification

Summarize the rationale of the study, citing relevant previous work. This should convey the importance of the intended study.

#### IV. Study Design (Scientific Plan)

Describe how the specific aims would be addressed using information from the WBMT. It should include the specific statistical methodology planned, with discussion of limitations, if relevant.

### SECTION 3: COLLABORATIVE INTERNATIONAL RESEARCH IN HCT WBMT Reference Document

#### General Research Guiding Principle #1

Any collaborative research is required to follow all basic principles for ethical conduct of research in addition of being inclusive to all participating parties, being fair, minimize bias, avoid conflicts of interest, and strictly adheres to the WHO guiding principles on cell, tissue, and organ transplantation.

#### Commentary on General Research Guiding Principle #1

International collaborative research is herein defined as biomedical research that includes sharing of data or biologic specimens ("biospecimens") among different organizations or groups that are located in separate countries.

The rules and guiding principles for collaborative research are no different from any biomedical research, as the majority of biomedical research requires some level of collaboration. This guiding principle mostly apply to complex collaborative, involving different organizations situated in different countries that abide to similar but not equal rules and regulations towards the practice of research. This first guiding principle is broad and applies to biomedical research involving human subjects. The ethical principles of conduct of research are derived from the Belmont Report (<u>hhs.gov/ohrp/humansubjects/guidance/belmont.html</u>) and include respect for persons, beneficence, and justice. The inclusiveness to all participating parties is an essential component for the conduct of international collaborative research in order to acknowledge all who are involved. This statement would apply when the collaborative parties are large complex organizations or when the number of collaborative parties is large. Fairness applies to all levels of research, development, conduct, interpretation, and dissemination. Additionally, this guiding principle is referring to fairness among the collaborative parties. Bias is inherent in research, and minimizing bias strengthens research. Finally, conflict of interest at any level, from commercial to self-promotion, is deleterious to research as it clouds the conduct and manipulates the message or conclusion of a project.

International collaborative research in hematopoietic cell transplantation is necessary for the success of this field. The guiding principles are meant to be a general reference document for the conduct of research and assist investigators in promoting the betterment of the practice of transplantation, advancing the field by improving access and outcomes of patients, and safeguarding the health of volunteer donors.

#### General Research Guiding Principle #2

The process of international collaborative biomedical research requires several steps to ensure its efficiency and fairness at the same time safeguarding the patients' data.

#### Commentary on General Research Guiding Principle #2

Biomedical research process applied to specific collaborative projects can be stratified into several phases: concept development, project development, data sharing, analysis, results interpretation, dissemination and conclusion. In general, these phases can be distinct or combined depending on the project, however consideration of each of these steps are relevant in order to organize the procedures and requirements.

This guiding principle proposes general procedure in each phase of a collaborative project that could be considered.

#### Concept Development

The inception of a project starts with the concept or idea. The concept often focuses on the hypotheses of interest to be tested in the project. This step can be part of the project development. However, often in the collaborative international research, the concept or proposal is often a necessary step for recruiting collaborators, obtain approval or to better describe a project that is intended. Understanding the availability of data already in existence or procurement of such data can also be considered in the step of the research process.

#### Project Development

The development of the project requires detail information on the objectives, background, population and requirement of informed consent, data sources and analyses being done. This *a priori* exercise sediment the proposed activities and anticipates all potential pitfalls. The most common procedure in this phase is the development of a protocol that includes all the components of the project. The development of the protocol should be a collaborative effort that ensures that all participating parties are aware of the project details.

Additionally, this phase of the project development needs to address the safeguard of the data, the protection human subjects, funding information, shared responsibilities plan and authorship guidelines, results review process and dissemination plan. Each of these components might not apply to all projects, but if presented upfront might help avoid delays during the life cycle of the project.

The section below outlines each component with proposed format and content.

1. <u>Protocol Document</u>: Describes in detail all the proposed scientific activities to be done with in the project. The protocol document should include the objectives of the project in a succinct and direct language; background that justifies the study and or hypotheses; description of the population of interest and the sources of data; description of the outcomes being tested; detailed of the proposed statistical analysis; relevant references and any additional information

that is relevant for the understanding of the project (i.e. demographic table, surveys, etc.). If the study involves additional informed consent of recipients, this document would be to be referenced or added to the protocol document.

- 2. <u>Data Safeguards</u>: This description could be incorporated in the protocol or in a separate document. However a safeguard plan would requirement agreements between parties if data are being exchanged. The important components for the safeguard plan include description of the data needed in the study, the expected transferring plan, who will be the responsible parties to oversee this exchange or transfer and how the transferred data will be stored, including security details, for how long and the procedures that will take place once the project is completed. In case of data, a description on whether personal health information (PHI, i.e. date of birth, gender, social security or other unique identification number among others) is required for the study and the type of PHI needs to be included. Also, if the project requires data from different databases to be merged, a description of this data merger should include the variables used for the merger, identification on ce the project is completed.
- 3. <u>Protection of Human Subjects</u>: any biomedical research that utilizes data requires appropriate informed consent, which authorizes the utilization of data for a particular use or research in general. Ethical committee oversight is a vital component of biomedical research to assure that human subjects are not being harmed. The rules of ethical committee engagement vary in different countries which makes a protection of human subjects document important in collaboration international research. The components of this document should include, the type of data being utilized in the project, whether the patients or individuals who consented for the specific project in question. In case of sharing dataset that include PHI, additional oversight might be required to overview that the process is appropriately set to avoid data breeches or losses. For studies that required additional informed consent, the document should include how the consent procedure will take place.
- 4. <u>Funding Sources</u>: studies that are done as part of funded projects may require a document that outlines any restriction that the funding agent might impose on the project. Additionally, the funding plan might require multiple sources which should be outlined accordingly.
- 5. <u>Shared Responsibilities</u>: It is important to develop a leadership plan that outlines the responsibility of each member of the project and that all members are in agreement with this plan. This document should also include authorship guidelines for any publication that results from this project. The authorship guidelines might be a detailed list of each member of the project and their position in a manuscript or general rules that will be considered to choose authors and their respective position on any manuscript from this project.
- 6. <u>Results Review and Dissemination Plan</u>: some of the components of this section can be included in the protocol document. A detailed plan for how the results will be reviewed and disseminated might be necessary in studies that involve different outcomes databases or research groups. This includes timeline for completion of the analysis, presentation in conferences or meetings and other public dissemination.

### Project Analysis

Once the project is developed with approved documentation and agreements, data can be transferred. If the project requires separate informed consent, enrollment of participants may be initiated. Prior to analyses, verification of the data for errors, outliers and follow up is important to avoid misinterpretation of results. Analyses results when completed should follow the results review and dissemination plan outline above.

#### Completion of the Project

Once the study is completed, which in some instances might be upon the publication of results or otherwise determined procedures for returning, destroying shared data or left over samples, or indefinitely storage should take place. Additional studies that include any data used in the original project need to be discussed among the original owners of the data before proceeding. This will initiate another project cycle and some of the steps described above may apply.

\*This document is posted on the WBMT website (wbmt.org).

#### APPENDIX D2: WBMT MEMBER SOCIETY REGISTRY DATA

#### WBMT MEMBER SOCIETY REGISTRY DATA TRANSMISSION AGREEMENT

This Data Transmission Agreement ("**Agreement**"), effective[*Date*], is entered into by and between the Worldwide Blood and Marrow Transplant Network ("**WBMT**"), a non-government organization with the World Health Organization and \_\_\_\_\_\_\_("**WBMT Member Society**"), each a "**Party**" and collectively, the "**Parties**".

The purpose of this Agreement is to set forth terms by which the WBMT will facilitate its member societies in data submission related to the Global Transplant Activity ("**GTA**") for public dissemination and research purposes.

First and foremost, and following WBMT Guiding Principle #3, "The WBMT has ownership of the GTA data and any use needs to be approved by the WBMT. This includes data requests and proposal for scientific studies that seek to utilize these data for analysis" and "The data from a Member Society that is shared with the WBMT can be utilized by the same Member Society (which also has ownership of its own data) without restrictions."

#### Section 1. Data Collection and Records

- <u>Global Transplant Activity Data</u>: The WBMT member society shall submit information related to transplant activity from the transplant centers that are within the region of the member society or has an established relationship with the member society to provide this data. Transplant activity data collected in the Global Activity Survey Form ("**GAS**") includes the volume of first transplants per patients performed at a transplant center in one year with accompanied information related to the indication, graftsource and donor type.
- <u>Data Collection</u>. The WBMT Member Society shall compile all annual transplant activity data from their participating transplant centers and provide to WBMT with GAS compiled for the specific region as requested by the WBMT within the time frames and in the manner specified by the WBMT. The timeline for submission of the compiled regional GAS is from November to February in reference to the activity of the prior year. The GAS should be submitted directly to the WBMT offices during this specified period.

#### Section 2. Informed Consent

• The GAS does not include any patient specific identifiers. It represents the number of transplants performed at a given transplant center. The volume per center is not provided to the WBMT, the GAT includes the number of active centers in a particular region and the number of transplants performed annually. Informed consent is not required for collection or submission to WBMT.

#### Section 3. Term

• This Agreement shall commence on its effective date referenced in the first paragraph above and shall continue in force until terminated by either Party at any time, with or without cause, upon thirty (30) days written notice to the other Party. During the thirty (30) day period after such notice is sent, the Parties shall continue to act toward each other in good faith.

#### Section 4. Miscellaneous

- <u>Compliance with Laws and Regulations</u>. The WBMT Member Society shall comply with all applicable statutes and regulations specific to that country, including, but not limited to, those regarding the safeguarding of donor and patient records, privacy regulations and human subjects protection.
- <u>Assignment and Subcontracting.</u> The WBMT Member Society may not assign this Agreement or any of their respective rights and responsibilities under this Agreement, without the WBMT's prior written consent. No responsibilities under this Agreement may be subcontracted without the prior written approval of the Parties.
- <u>Amendment.</u> Except as otherwise provided for in this Agreement, this Agreement may not be amended except by written instrument duly signed and delivered by the WBMT and the WBMT Member Society.
- <u>Non-Assumption of Liabilities</u>. Neither the WBMT nor the WBMT Member Society shall be liable for any of the prior existing or future obligations, liabilities or debts of the other Party.
- <u>Governing Law.</u> This Agreement and all transactions contemplated by this Agreement shall be governed, construed and enforced in accordance with the laws of Switzerland.
- <u>Independent Contractors</u>. Nothing in this Agreement is intended to create an employment or agency relationship between the Parties. Neither Party shall be deemed or construed to be an employee or agent of the other.
- <u>Notice</u>. Any notice required to be <u>gi</u>ven by this Agreement shall be in writing and sent by:
   1) mail, registered or certified, as evidenced by a delivery receipt; 2) with a private delivery service as evidenced by a shipping receipt; or 3) by electronic mail return receipt requested.
- <u>Prior Agreement.</u> This Agreement constitutes and contains the entire Agreement between the Parties with respect to the subject matter hereof, including but not limited to the terms and conditions relating to the maintenance and transmission of data, and supersedes any prior oral or written agreements.

- <u>Force Majeure</u>. Neither Party shall be considered to have failed in the performance of this Agreement if such failure arises out of causes beyond the control and without the fault or negligence of the Party failing to perform, except that the WBMT Member Society shall not be excused from strict compliance with this Agreement under this clause due to errors, omissions or failures by its independent contractors or lowertier subcontractors.
- <u>Successors.</u> This Agreement shall be binding on and will inure to the benefit of the Parties and their respective successors and assigns.

This Agreement is executed by individuals who are duly authorized to enter into the Agreement and legally binds their respective parties to be effective on the date stated in the first paragraph above. "Duly authorized" includes the WBMT President, a registry leadership representative or a center representative as is designated by that center.

Ву:	WBMT	Ву:	[Registry WBMT Member Society]
By:		By:	
			Authorized Signature
		-	(Typed/Printed Name)
Title:	Current WBMT President	Title:	
Date: _		Date:	

## APPENDIX E: HISTORY OF MAJOR MEETINGS AND INTERNATIONAL WORKSHOPS

WBMT Board Business Meetings	WBMT Participant Meetings
2020	
Video conference (June)	
Video conference (March)	
2019	
Houston, US (February)	
	Asuncion, Paraguay (September)
	Busan, Korea (September)
2018	
Teleconference (December)	
Teleconference (July)	
	Casablanca, Morocco (April)
	Beijing, China (September)
Lisbon , France (March)	
	Taipei, Province of China (November)
2017	
Teleconference (December)	
Teleconference (July)	
	Regensburg, Germany – Sickle Cell Disease Cure and Prevention Consortium (June)
	Geneva, Switzerland – WHO (May)
Orlando, FL, US (February)	
2016	
Teleconference (December)	
Teleconference (July)	
	Geneva, Switzerland – WHO (May)
Valencia, Spain (April)	
2015	
Teleconference (December)	Addis Ababa, Ethiopia – On-site visit by select WBMT representatives (December)

	Okinawa, Japan – Nuclear Accident Management
	Committee (October)
Teleconference (July)	
	Regensburg, Germany – Sickle Cell Disease Cure and Prevention Consortium (June)
San Diego, CA, US (February)	
2014	
Teleconference (December)	
	Geneva, Switzerland – MPHO NGO meeting (September)
Teleconference (July)	
Milan, Italy (March)	
2013	
	Brasilia, Brazil – WBMT / NOFITY (December)
Teleconference (November)	
Teleconference (July)	
	Geneva, Switzerland – WHO (May)
	London, UK – Standing Committees (April)
Salt Lake City, UT, US (February)	
2012	
	Atlanta, GA, USA – WBMT / LABMT (December)
	Rome, Italy – WBMT / NOTIFY (November)
Teleconference (October)	Hyderabad, India – APBMT (October)
	St. Petersburg, Russia – WBMT / Russia (September)
	Lagos, Nigeria – WBMT / AFBMT (September)
	Manila, Philippines – WBMT / Philippine Society of Hematology (August)
Teleconference (June)	
Geneva, Switzerland (April)	
	San Diego, CA, US – WBMT / LABMT (February)
2011	

Teleconference (December)	
Teleconference (September)	
	Rio de Janeiro, Brazil – SBTMO / LABMT (August)
Teleconference (June)	
Teleconference (April)	
	Paris, France – Standing Committees (March)
Honolulu, HI, US* (February)	
2010	
	Phuket, Thailand – APBMT (November)
Vienna, Austria (March)	
	Brussels, Belgium – WHO (February)
2009	
Minneapolis, MN, US (November)	
	New York, NY, US – UN (October)
Nagoya, Japan (April)	
Goteborg, Sweden (March)	
2008	
Minneapolis, MN, US (October)	Geneva, Switzerland – WHO (October)
Firenze / Florence, Italy (March)	
	Tampa, FL (February)
2007	
Minneapolis, MN, US (October)	
Lyon, France (March)	

\*1st elected Board meeting

#### APPENDIX F: HISTORY OF INTERNATIONAL SCIENTIFIC SYMPOSIA

#### 2020

<u>August, EBMT, video conference</u> International access to HCT drugs: Impact on transplant practice and patients

- Chair: D Weisdorf (United States) Causes of drug shortages
- Chair: G Stemer (Austria) How can pharmacists help the HCT team in drug shortages and cost of medications
- Chair: H Greinix
   Successful models of cooperation to offer essential drugs in the care of HCT patients: Role of WBMT
   <u>February, ASTCT, video conference</u>
  - Chair: Emily Thakur Identifying the Root Causes of Drug Shortages and Finding Enduring Solutions
  - Chair: Zahra Mahmoudjafari Drug Shortages: The Role of the Pharmacist on the HCT Team
  - Chair: H Greinix Successful Models of Cooperation to Offer Essential Drugs for the Care of HCT Patients: WBMT

#### 2019

### March, EBMT Frankfurt

Efficiency and Effectiveness of New Models for Transplant Care Delivery

Chair: D Weisdorf (United States)

- Remote health development, consultation from a distance in Nepal (D. Rondelli, Nepal)
- Choosing wisely for haematopoietic cell transplantation (D Weisdorf, United States)
- Telemedicine for Remote Consultations (D Niederwieser, Germany)

### February, BMT Tandem Meetings (Houston)

*Efficiency and Effectiveness of New Models for Transplant Care Delivery* Chair: D Weisdorf (United States)

- Home Delivery Model of Video Conferencing with Patients (J Nelson, United States)
- Remote Health Strategies in Development of Global BMT (D. Rondelli, Nepal)
- The Cure2Children-Sankalp India Foundation Experience in Affordable Bone Marrow Transplantation for Children with Severe Thalassemia in India (L Faulkner, Italy)
- Telemedicine for Remote Consultations (D Niederwieser, Germany)

### 2018

### February, BMT Tandem Meetings (Utah)

How the best donor can improve transplant outcomes?

Chair: D Weisdorf (United States)

- Introduction and recent trends (J Szer, Australia)
- Assessing donor suitability beyond HLA (H Yang, Australia)
- How regional haplotype frequencies influence the success of finding the best unrelated UCB or volunteer donors (L Bouzas, Brazil)
- Cost and morbility consequences of different donor choices (M Pasquini, United States)

### 2017

#### February, BMT Tandem Meetings (Orlando)

# Do stem cell transplants need to be so expensive? What is really necessary?

Co-Chairs: Y Kodera (Japan) and J Szer (Australia)

- WBMT introduction (J Szer, Australia)
- Introduction to the topic of cost (D Weisdorf, US)
- The Mexican experience (D Gomez-Almaguer, Mexico)
- The Indian experience (A Srivastava, India)

### 2016

### April, EBMT Meeting (Valencia)

### Global Challenges in Transplantation

Co-Chairs: Y Kodera (Japan) and J Kuball (Netherlands)

- Economic stresses in transplantation: How are these challenging existing and new programs? (D Weisdorf, US)
- Quality measures: How to incorporate quality into existing and new sites? (HGreinix, Austria)
- EBMT-JACIE accreditation: 10 years of success (J Snowden, United Kingdom)

## February, BMT Tandem Meetings (Honolulu)

Haploidentical HCT – A Global Overview: Comparing Asia, EU, and US Co-Chairs: Y Kodera (Japan) and J Szer (Australia)

- Introduction
  - WBMT Global Activity Survey (D Niederwieser, Germany)
  - o Trends in Haplo HCT (J Apperley, United Kingdom)
- The Asian Experience (X-J Huang, China)
- The EU Experience (A Nagler, Israel)
- The US Experience (E Fuchs, US)

### 2015

### April, EBMT Meeting (Istanbul)\*

\*During these meetings, the WBMT participated in a plenary session in lieu of a traditional Joint Session. *PLENARY: Access to Stem Cell Transplantation in the 21st Century: An EBMT-WBMT Joint Session* Co-Chairs: Y Kodera (Japan) and T Damirer (Turkey)

- Lessons after one million transplants (A Gratwohl, Switzerland)
- Which AML patient should not be transplanted in 2015? (F Appelbaum, US)

## February, BMT Tandem Meetings (San Diego)

Global Donor Selection Challenges: Clinical efficacy and cost performance Co-Chairs: Y Kodera (Japan) and D Weisdorf (US)

- Introduction (Y Kodera, Japan, and D Weisdorf, US)
- Medical Products of Human Origin / World Health Organization (MPHO / WHO WBMT / TTS / ISBT / ICCBBA) Project: Regulatory recommendations for MPHO (J Nunez, Switzerland)
- Haplo-HCT without T-cell depletion vs. unrelated vs. related (post-transplant cyclophosphamide) for developing countries (D Niederwieser, Germany)
- Regional cost differences of matched, haploidentical, and cord blood HCT (S Giebel, Poland)
- Report from regional group LABMT (A Seber, Brazil)

### 2014

### April, EBMT Meeting (Milan)

Hematopoietic Stem Cell Transplantation: Access and Affordability

Co-Chairs: D Niederwieser, Y Kodera, D Confer, D Weisdorf, H Greinix

- Non-Government Organization (NGO): Status significance and opportunities of an NGO (J Nunez)
- Cost of non-transplant therapy for hematologic malignancies (J Apperley)
- Alternative donor selection
  - Haploidentical donor (L Luznik)
  - Cord blood stem cell transplantation (M Eapen)

### February, BMT Tandem Meetings (Dallas)

Hematopoietic Stem Cell Transplantation: Access and Affordability

Co-Chairs: D Niederwieser, Y Kodera, D Confer, D Weisdorf, H Greinix

- Non-Government Organization (NGO): Status significance and opportunities of NGO (J Nunez)
- Cost of non-transplant therapy for hematologic malignancies (J Apperley)
- Alternative donor selection
  - Haploidentical donor (X-J Huang)
  - Cord blood stem cell transplantation (D Weisdorf)

### 2013

### April, EBMT Meeting

*The Legacy of E. Donnall Thomas: One Million Hematopoietic Stem Cell Transplants* Co-Chairs: D Niederwieser, Y Kodera, D Confer, H Greinix

- E. Donnall Thomas: From Cooperstown to Global (R Storb)
- Challenges to Future Growth: The Transplant Center Perspective
  - Europe (M Mohty)
  - Eastern Mediterranean (M Aljurf)
  - Africa (N Novitzky)
- Challenges to Future Growth: The Donor Registry Perspective (D Confer)
- Challenges to Future Growth: The WHO Perspective (L Noël)
- Improving Research Collaborations to Move Forward (M Horowitz)

### February, BMT Tandem Meetings

*The Legacy of E. Donnall Thomas: One Million Hematopoietic Stem Cell Transplants* Co-Chairs: D Niederwieser, Y Kodera, D Confer, H Greinix

- E. Donnall Thomas: From Cooperstown to Global (F Appelbaum)
- Challenges to Future Growth: The Transplant Center Perspective
  - North America (R Champlin)
  - Central / South America (C Bonfim)
  - Asia-Pacific (A Srivastava)
- Challenges to Future Growth: The Donor Registry Perspective (D Confer)
- Challenges to Future Growth: The WHO Perspective (L Noël)
- Improving Research Collaborations to Move Forward (J Apperley)

## 2012

### WBMT Scientific Session

Chair: D Niederwieser

- WBMT Update (D Niederwieser)
- The Macroeconomics of Hematopoietic Stem Cell Transplantation (A Gratwohl)
- A Global View of Cord Blood Transplantation (V Rocha)
- The Fukushima Nuclear Accident The Transplant Team Experience (S Taniguchi)

### 2011

WHO and WBMT: A Model for Optimal Collaboration Between Scientists and Health Institutions Co-Chairs: D Confer, Y Kodera, D Niederwieser

- Update on WBMT Activity (D Niederwieser)
- Global HCT Activity Survey 2007-2008 (H Baldomero)
- Report from the APBMT Congress: HCT Activity and Plans for a Vietnam Meeting (Y Kodera)
- Harmonizing Standards in BMT Improving Outcomes on a Global Scale (K Loper)
- WHO and WBMT a Model for Optimal Collaboration Between Scientists and Health Institutions (L Noël)

### 2010

Worldwide Network for Blood and Marrow Transplantation (WBMT) Session Co-Chairs: D Niederwieser, M Horowitz

- Update on Progress of WBMT (D Niederwieser)
- Challenges in Establishing HCT Outcomes Registries in Developing Countries Asia- Pacific BMT Group (Y Atsuta)
- Eastern Mediterranean BMT Group (M Aljurf)
- Ethical Issues in Donation of Hematopoietic Stem Cells (A Capron)

## 2009

WBMT International Session (Supported by THERAKOS, Inc.) Co-

Chairs: D Niederwieser, S Davies, Y Kodera, M Oudshoorn

- Overview of Unrelated Adult and Cord Blood Donation: the WMDA Annual Survey (M Oudshoorn)
- Unrelated Donor Outcomes and Plans for Assessing Related Donor Outcomes: A Report from the NMDP / CIBMTR (D Confer)
- Related Donor Outcomes from the Japanese Registry: The Importance of Preregistration (Y Kodera)
- Proposal for an EBMT Donor Outcome Registry (J Halter)

### APPENDIX G PUBLICATIONS LIST

WBN	WBMT Publications			
#	Citation	Credited to		
Publ	ished in 2020			
39	Mhamed Harif, Daniel Weisdorf, Nicolas Novitzky, Jeff Szer, Lahoucine Mahmal, Malek Benaklif, Tarek Ben Othman, Nosakhare Bazuaye, Eoin McGrath, Paul W Eldridge, Lamia Torjemane, Abdellah Madani, Redouane Ahmed Nacer, Reguia Belkhedim, Walid Rasheed, Syed O.Ahmed, Yoshihisa Kodera, Mahmoud Aljurf, Asmaa Quessara. <b>Special report: Summary of the</b> <b>first meeting of African Blood and Marrow Transplantation (AfBMT) group,</b> <b>Casablanca, Morocco, April 19–21, 2018 held under the auspices of the</b> <b>Worldwide Network for Blood and Marrow Transplantation (WBMT).</b> Hematology/Oncology and Stem Cell Therapy,Volume 13, Issue 4, December 2020, Pages 202-207.			
38	Worel N, Shaw BE, Aljurf M, eds. Changes in Hematopoietic Cell Transplantation Practices in Response to COVID-19: A Survey from the Worldwide Network for Blood & Marrow Transplantation. Transplantation and Cellular Therapy. 2020 Nov 24. DOI: <u>https://doi.org/10.1016/j.jtct.2020.11.019</u>	WBMT		
37	Kathy Loper, Michele W. Sugrue, Jay S. Raval, Joseph Yossi Schwartz, Kevin Land, Mickey Koh, Thilo Mengling, Hildegard Greinix, Jörg P. Halter, Christina M. Celluzzi, Maysum Chaudhri. <b>Adverse event reporting for cellular therapy</b> <b>products: Current status and future directions</b> . First published: 16 October 2020 <u>https://doi.org/10.1111/trf.16062</u>			
36	Ibrahim N. Muhsen, Shahrukh K. Hashmi, Dietger Niederwieser, Nicolaus Kroeger, Samir Agrawal, Marcelo C. Pasquini, Yoshiko Atsuta, Karen K. Ballen, Adriana Seber, Wael Saber, Mohamed A. Kharfan-Dabaja, Walid Rasheed, Shinichiro Okamoto, Nandita Khera, William A. Wood, Mickey B. C. Koh, Hildegard Greinix, Yoshihisa Kodera, Jeff Szer, Mary M. Horowitz, Daniel Weisdorf & Mahmoud Aljurf . Correction: Worldwide Network for Blood and Marrow Transplantation (WBMT) perspective: the role of biosimilars in hematopoietic cell transplant: current opportunities and challenges in low- and lower-middle income countries. Bone Marrow Transplantation volume 55, page837(2020). Published: 15 October 2019			
35	Andrew J. Cowan, Helen Baldomero, Yoshiko Atsuta, Nicolaus Kroeger, Daniel Weisdorf, Dietger Niederwieser. <b>The Global State of Hematopoietic Cell</b> <b>Transplantation for Multiple Myeloma: An Analysis of the Worldwide</b> <b>Network of Blood and Marrow Transplantation Database and the Global</b> <b>Burden of Disease Study.</b> Published:August 23, 2020DOI:https://doi.org/10.1016/j.bbmt.2020.08.018			
34	Ram V Nampoothiri 1, Vivek Kumar 2, Joyita Bharati 2, Sheetal Lad 3, Kajal Arora 1, Pankaj Malhotra 1, Deepesh Lad 4. <b>Hematopoietic stem cell donor</b> <b>with IgA nephropathy: Challenges and management algorithm.</b> 2020 Aug;59(4):102781. doi: 10.1016/j.transci.2020.102781. Epub 2020 May 8. PMID: 32409153 DOI: 10.1016/j.transci.2020.102781			

33	Algwaiz G, Aljurf M, Koh M, eds. Real-World Issues and Potential Solutions in Hematopoietic Cell Transplantation during the COVID-19 Pandemic: Perspectives from the Worldwide Network of Blood and Marrow Transplantation and Center for International Blood and Marrow Transplant Research Health Services and International Studies Committee. Biology of Blood and Marrow Transplantation. 2020 Jul 24. DOI:https://doi.org/10.1016/j.bbmt.2020.07.021	WBMT and CIBMTR
32	Koh M, Aljurf M, eds. <b>Position paper on Unproven Cell-Based Therapies:</b> <b>Current Global Status and Recommendations to the World Health</b> <b>Organization.</b> 2020 June (submitted to the WHO for endorsement)	WBMT
31	M.Aljurf, D.Weisdorf, K.Hashmi, A.Nassar, E.Gluckman, M.Mohty, D.Rizzo, M.Pasquini, M.Hamadani, W.Saber, P.Hari, M.Kharfan-Dabaja, N.Majhail, U.Gerges, A.Ali Hamidieh, F.Hussain, A. Elhaddad, H.K.Mahmoud, D.Niederwieser. Worldwide Network for Blood and Marrow Transplantation (WBMT) recommendations for establishing a hematopoietic stem cell transplantation program in countries with limited resources (Part II): Clinical, technical and socio-economic considerations. Hematology/Oncology and Stem Cell Therapy. Volume 13, Issue 1, March 2020, Pages 7-16.	
30	Koh M, Aljurf M, Greinix H, and Weisdorf D. <b>Coronavirus and Haematopoietic</b> <b>Stem Cell Transplantation.</b> WBMT website, 2020 Feb. 24, <u>https://www.wbmt.org/wp-content/uploads/2020/03/WBMT_COVID-19-2.pdf</u>	WBMT
29	Ram V Nampoothiri, Vivek Kumar, eds. Hematopoietic stem cell donor with IgA nephropathy: Challenges and management algorithm. Transfusion and Apheresis Science 2020 May 8; 102781. doi: 10.1016/j.transci.2020.102781 https://pubmed.ncbi.nlm.nih.gov/32409153/	
Publi	ished in 2019	
28	Frutos C, Enciso ME, eds. Bridging the gap using telemedicine: optimizing an existing autologous hematopoietic SCT unit into an allgeneic hematopoietic SCT unit in Paraguay with the help of the WBMT. Blood Advances. 2019 Dec 6;3(suppl 1): 45-47. DOI: <u>10.1182/bloodadvances.2019GS121781</u>	
27	Aljurf M, eds. Worldwide Network for Blood & Marrow Transplantation (WBMT) special article, challenges facing emerging alternate donor registries. Bone Marrow Transplantation, 54, 1179-1188 (2019)	WBMT
26	Muhsen I, Correction: Worldwide Network for Blood and Marrow Transplantation (WMBT) perspective: the role of biosimilars in hematopoietic cell transplant: current opportunities and challenges in low- and lower-middle income countries. Bone Marrow Transplantation (2019) https://doi.org/10.1038/s41409-019-0658-2	
25	Pasquini M, Srivastave A, eds. Worldwide Network for Blood and Marrow Transplantation recommendations for establishing a hematopoietic stem cell transplantation program in countries with limited resources (part I): minimum requirements and beyond	WBMT
24	Biology of Blood and Marrow Transplantation (2019), 25 (2322-2329) Aljurf M, Weisdorf D, eds. Worldwide Network for Blood and Marrow Transplantation (WBMT) recommendations for establishing a hematopoietic stem cell transplantation program in countries with limited resources (part II): Clinical, technical and socio-economic considerations	WBMT

Epub 2019: https://www.sciencedirect.com/science/article/pii/S165838761930055X?via% 3Dihub	
Published in 2018	
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#### APPENDIX H: WBMT PRESIDENTS

2007-2009: Founder and chair of initial working party – Dietger Niederwieser

President	Year
Dietger Niederwieser	2010-2014
Yoshihisa Kodera	2014-2016
Jeff Szer	2016-2018
Daniel Weisdorf	2018-2020
Hildegard Greinix	2020-2022

### **APPENDIX I: TERMS AND ABBREVIATIONS**

Term / Abbreviation	Definition
AABB	American Association of Blood Banks
ABMTRR	Australasian Bone Marrow Transplant Recipient Registry
AFBMT	African Blood and Marrow Transplant Group
АНСТА	Alliance for the Harmonization of Cellular Therapy Accreditation
APBMT	Asia-Pacific Blood and Marrow Transplantation Group
ASTCT	American Society for Transplantation and Cellular Therapy
ASH	American Society of Hematology
BIG V&S SARE	Bologna Initiative for Global Vigilance and Surveillance of Adverse Reactions and Events
BMT	Blood and marrow transplantation
CIBMTR	Center for International Blood and Marrow Transplant Research
CME	Continuing medical education
EBMT	European Society for Blood and Marrow Transplantation
ECDC	European Centre for Disease Prevention and Control
ELN	European Leukemia Network
ESH	European School of Hematology
FACT	Foundation for Accreditation of Cellular Therapy
GTA	Global transplant activity
НСТ	Hematopoietic stem cell transplantation
ICCBBA	International Council for Commonality in Blood Banking Automation
ISBT	International Society of Blood Transfusion
ISCT	International Society of Cellular Therapy
LABMT	Latin American Blood and Marrow Transplant Society
МРНО	Medical products of human origin
NGO	Non-government organization
NMDP	National Marrow Donor Program
RITN	Radiation Injury Treatment Network
SOHO V&S	Vigilance and Surveillance of Substances of Human Origin
TAS	Transplant Activity Survey
TTS	The Transplant Society
UK	United Kingdom
UN	United Nations
WBMT	Worldwide Network for Blood and Marrow Transplantation
WHO	World Health Organization
WMDA	World Marrow Donor Association

#### APPENDIX J: LETTER VOLUNTARY FEE WBMT MEMBER SOCIETIES





# worldwide network for blood and marrow transplantation

NGO in official relations with the World Health Organization (WHO)

WM/TL c/o Barupenae Stit Mowee AD, Laugerestrator ST, Parkfach, CH 2001 Bank - Switzerland

Since the beginning of the WBMT, financial support was provided by corporate sponsors (Jazz, Clinigen, Celgene), satellite symposia during our workshops, grants from industry, and support from our members. These incomes may not be available or not to the same extent in the future. To cover our annual costs (administrative support, global survey, IT support, website) we asked our membership during our last Board meeting for a voluntary fee to be donated annually by member societies, if possible, to contribute to our core activities, namely educational and scientific activities.

We are aware that many societies have their highest revenue from the annual meetings, and that due to the cancellation of these during the COVID-19 pandemic the financial situation can be difficult for many of you. Nevertheless, we would like to ask for the annual voluntary fee of 2,500 Euro to be paid soon for this year's support to allow continuation of the most important WBMT activities. We very much appreciate your support and we are open to discussion in case the current situation does not allow you to transfer this fee.

Finally, I would like to thank WBMT Executive Committee members and staff in the Leiden and Basel office for all their hard work at this very testing time. Thank you all for your generous support and looking forward to talking to you during our next board meeting on 30 June 2020.

With best regards and stay safe and healthy!

Prof. Hildegard Greinix WBMT President



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