



Asia-Pacific Blood and Marrow Transplantation Group

SECRETARIAT OFFICE / DATA CENTER OF APBMT



Asia-Pacific Blood and Marrow Transplantation Group

(APBMT)

Annual Report

December 31, 2014

Secretariat Office / Data Center of APBMT

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Introduction

General overview for the last 2 years (from September 2012 to August 2014)

APBMT is comprised of 19 countries/ regions as of December 2014.



This Annual Report is the 7th edition. It includes useful information about APBMT including results of the 8th Activity Survey (transplantation performed in 2012). In addition, information about WBMT (Worldwide network for Blood and Marrow Transplantation) is included in this booklet.

New Executive Board members were elected at the business meeting in 2013. APBMT continues to reinforce its structure and reinvigorate its activity with the leadership of the newly organized Executive Board.

Data collection by the Activity Survey has been performed comprehensively since 2007. The result has also contributed to the WBMT Global Survey. As for the Outcome Registry, data is gradually accumulated by virtue of efforts from each country/region. In 2014, the first article from APBMT (Nutrition Support WG) was published in the journal *Bone Marrow Transplantation*.

BYLAWS OF THE ASIA PACIFIC BLOOD AND MARROW TRANSPLANTATION GROUP (APBMT)

ARTICLE 1

Name of the Group

Asia Pacific Blood and Marrow Transplantation Group, hereafter referred to as APBMT was established in 1990 to allow physicians as well as co-medicals and scientists from related companies in Asia Pacific countries and regions involved in clinical blood and marrow transplantation to share their experience and to develop co-operative studies.

ARTICLE 2

Incorporation

APBMT is incorporated as Corporate Juridical Person for scientific and educational purposes under the laws of Japan.

ARTICLE 3

Purpose of APBMT

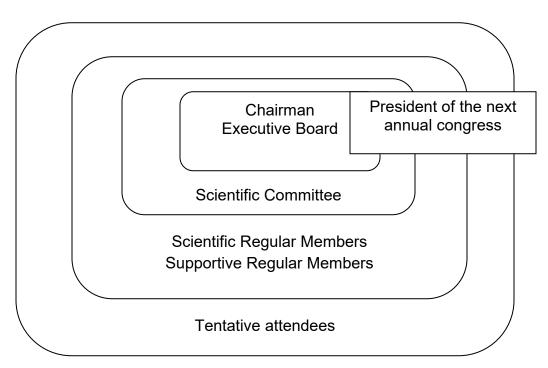
The group aims to promote all aspects associated with the hematopoietic stem cell transplantation (HSCT) in Asia Pacific, which includes:

- To know the updated status of haematopoietic stem cell transplantation (HSCT) in Asia Pacific countries and regions.
- To steer and regulate the HSCT Registry in Asia Pacific (Asia Pacific Blood and Marrow Transplantation Group Registry: APBMT Registry).
- To share current knowledge of all aspects of HSCT to promote and maintain the highest standards of care, and to work towards a set of standards and accreditation of transplant units.
- To provide training opportunities in HSCT in Asia Pacific countries and regions.
- To champion for patients and their carers to access the best healthcare services.
- To promote collaborative research in Asia Pacific Countries and regions.
- To collaborate with other international organizations related with HSCT
- To work as a core voting member of WBMT

ARTICLE 4

Organization

The schema of the organization in APBMT indicates below.



4.1 Executive Board

The Executive Board of APBMT steers the group for administration and minor decisions. The Executive Board is responsible for all running operations and decisions on behalf of the Scientific Committee. The Executive Board is consisted of seven members, with one member from one country, elected from The Scientific Committee. The Chairman of Executive Board represents APBMT.

4.2 Scientific Committee

The Scientific Committee elects the members of the Executive Board. The Scientific Committee must be consulted regarding any changes to the By-Laws. Any modifications to the decisions made by the Scientific Committee will need approval by them.

Each country can elect and nominate 1 voting member as the country representative. This right may be transferred to a designated substitute. If there is more than one nominee from one country, the Executive Board will select the voting candidate of that country. The members of the Executive Board cannot have voting right. The names of the current members of scientific committee are listed and updated annually. The Chairman of the Executive Board, who also serves as the Chairman of the Scientific Committee, has the deciding vote if the vote is otherwise tied.

New Scientific Committee members need to be recommended by the current members of Scientific Committee among the members of the Scientific Regular Members and to get approval in the business meeting. Decisions are taken by majority voting (One vote/one country).

A proposed new member must provide a brief CV up to 3 pages. The criteria to be a Scientific Committee Member include proven medical and/or scientific experience in HSCT; willingness to committee and have demonstrated as an active participant in

scientific endeavors of the APBMT; no criminal record, good ethical and moral standards as expected by professional societies (Membership Committee, see Annex 1).

The Scientific Committee has the following rights and obligations: 1) To elect Executive Board members; 2) To decide on admission of new members; 3) To decide the annual fee for APBMT membership and 4) to make final decision on APBMT policies.

4.3 Regular Members

Regular Members are consisted of the members from medical fields (Scientific Regular Members). Regular Members can elect representatives for their country into the Scientific Committee. A proposed new member must provide a brief CV up to 2 pages that includes professional qualification, current employment and place of work. Regular members must agree to abide by the regulations of APBMT, to participate in scientific endeavors of the APBMT, to have no criminal record, good ethical and moral standards as expected by professional societies

4. 4 Emeritus Members

These are members who served in previous Executive Board and accepted to be an Emeritus Members instead of Full Member. They will serve for a term of 4 years to provide advice to the Executive Board and do not have a voting right.

4.5 Associate and Affiliate Members,

Representatives of commercial companies can become an Associate member. Associate Members do not have voting right or permit to attend the Business meetings. Applicants are required to submit a brief CV.

ARTICLE 5

Membership

- **5.1 Any persons** involved in the treatment of recipients and donors. (such as physicians, nurses, pharmacists, laboratory technicians, allied health professionals, scientists and persons related to stem cell donor programs or pharmaceutical companies), who are involved in HSCT and agree with the purpose of the group can become a member (see above section). New members are admitted by submitting a membership application form to the Secretary Office. This application must include the signature of an APBMT member as a presenter. There are two different kinds of memberships; Scientific Members (physicians, nurses, laboratory technicians, persons related to stem cell donor programs) and Supportive Members (pharmaceutical companies). Previous Executive Board members who have contributed to the establishment and the development of ABPMT would become Emeritus Members (Inside of APBMT) or Honorary Members (Other registries etc.). Emeritus and Honorary Members can attend the business meeting and can give advices for APBMT.
- **5.2 Membership Fees:** All the Regular Members are required to pay annual membership fees on an individual basis (see Annex 2). The members who paid the

membership fees can receive up-to-date information including the survey data from APBMT office and also may have the advantage of discount of the registration fees at annual congress.

ARTICLE 6

Officers

- **6.1** Scientific Committee elects a) one Chairman of Executive Board, b) one Vice Chairman of Executive Board, and c) five other Members of Executive Board.
- **6.2** The function of the **Chairman of Executive Board** is to promote and coordinate all activities of APBMT. These include fund raising, coordination of Working Group activities, giving suggestions to the organizers of the annual meeting, and negotiations with other organizations on behalf of APBMT. The Chairman of Executive Board is elected by the business meeting, and serves for two years and may be re-elected for another term of two years.
- **6.3 The Vice Chairman** supports the Chairman and will perform the duties of the Chairman in the absence. The Vice Chairman serves for two years and may be reelected for another term of two years.
- **6.4 The Executive Board Members** will be appointed for a period of four years and may be re-elected for a maximum of one more terms.
- **6.5 Secretariat / Treasurer** shall oversee the maintenance of a permanent record of APBMT. The Secretariat / Treasurer shall have oversight of the budget of APBMT (see Annex 3). The Secretariat / Treasurer Office of the group is currently located at the Department of HSCT Data Management, Nagoya University, School of Medicine, and the Department of Promotion for Blood and Marrow Transplantation, Aichi Medical University School of Medicine, Japan. The Secretariat / Treasurer Office works for the development and the maintenance of the group under the collaboration with the Chairman of Executive Board, the Chairman of the next annual congress, and the members of Executive Board and Scientific Committee.

ARTICLE 7

Annual Congress

Any countries participating in APBMT can propose to be a host country of the Annual Congress. Host country of the future Annual Congresses will be decided by the Scientific Committee. The President of the next annual congress cooperates with the Executive Board for the year preceding the annual congress. The format of the meeting is to be standardized (see Annex 4)

ARTICLE 8

Business Meeting

The Scientific Committee will open the Business Meeting at least once a year. One of them will be held during the annual meeting. It is co-chaired by the Chairman of the Executive Board and the President of the Annual Congress. The Board may establish subcommittee / working party as the need arises.

ARTICLE 9

Working Groups

APBMT can organize Working Groups if and when required. The application of the new Working Group and its chair person is approved by the members of the Scientific Committee in the Business Meeting (see Annex 5). The chair person of each Working Group is elected for three years and may stand for reelection once. The substructure of the Working Group is defined by the chair person. Regular Members are encouraged to participate in one or more Working Groups according to their particular interests. The Working Group chair person must submit annual activity reports to the Scientific Committee. The chair person should adhere to the Working Group responsibilities, which are specified separately from the bylaws.

ARTICLE 10

APBMT Registry

The registries of patients, donors, and HSCT activities are one of the major missions of APBMT. The regulatory rules for the Asia-Pacific BMT Registry are as the followings;

- **10.1 The name of the registry** is "Asia-Pacific Blood and Marrow Transplantation Group Registry (APBMT Registry)".
- **10.2 The purposes of the APBMT Registry** are to provide documentation on the status of hematopoietic stem cell transplantation in Asia-Pacific countries
- **10.3** APBMT Registry conducts the "APBMT Activity Survey" and the "APBMT Outcome Registry".
- **10.4 "APBMT Registry Subcommittee"**: a subcommittee of the Scientific Committee steers the APBMT Registry. The members of the APBMT Registration Subcommittee are nominated and approved by the Scientific Committee of APBMT. (see Annex 6)

10.5 Operation of the APBMT Registry

10.5.1 Patient personal information

Patient names are not included among the survey items. However, to trace survival status and disease status, a unique patient number at each institute and a national registry number are included in the survey items.

10.5.2 Units of registration

The national level is the most preferable unit of registration. A national registry should be established in each country. "National" registry in this document does not mean

"governmental" registry. It is a hematopoietic stem cell transplant (HSCT) activity and outcome registry which collects HSCT data performed in the country. When it is impossible or difficult, registration from individual institutes is also possible. The APBMT Data Center gathers the registrant data by countries and returns nation-wide data to the responsible person delegated by each country.

10.5.3 Location of the data center

The data should be sent to the APBMT Data Center either by electronic means or by postal mail. Facsimile is not preferable because of difficulties in deciphering the data.

Nagakute Campus

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1-1 Yazakokarimata, Nagakute, Aichi, 480-1195, Japan.

Tel:+81-561-62-3311(Ext.12375)

Fax:+81-561-61-3180 Email: office@apbmt.org

10.5.4 Subjects of registration

All types of hematopoietic stem cell transplantations, allogeneic syngeneic or autologous transplantation, are subjects for the APBMT registry.

10.6 APBMT Activity Survey

The number of HSCT by indications, donor types, and stem cell sources will be collected annually by using "APBMT Activity Survey Sheets". APBMT Activity Sheets are sent to the APBMT Data Center for APBMT Activity Survey mainly via e-mail.

10.7 APBMT Outcome Registry

10.7.1 Survey items

APBMT Registration Subcommittee is responsible for deciding the survey items to collect. APBMT Outcome Registry collaborates with other international HSCT registries for the basic survey items.

10.7.2 Methods of registration

Data should be registered using one of the following methods.

10.7.2.1 Direct transfer of data sets

Microsoft Excel format (xls/xlsx file) output from each registry program in each country. The format for each Excel cell is decided by the APBMT Registration Subcommittee.

10.7.2.2 TRUMP Data

Use the APBMT version of Transplant Registry Unified Management Program. (TRUMP).* A transfer form at file from TRUMP, which is de-identified and code

encrypted, is sent to the APBMT Data Center for APBMT Outcome Registry either by wire or by postal mail.

*Atsuta Y et al. Unification of hematopoietic stem cell transplant registries in Japan and establishment of the TRUMP system. Int J Hernatol. 2007; 86: 269-274.

10.7.2.3 Paper forms

APBMT Registry Day 100 report forms and disease classification form are to be mailed following day 100 post - transplantation. The follow-up form is also submitted annually for surviving patients.

Electronic registration data is transferred through the APBMT home page (in cases of 10.7.2.1 and 10.7.2.2). If the file size is small enough, data can be sent by e-mail as an attached file, but this is not recommended due to security problems. Paper forms (10.7.2.3) are mailed to the APBMT Data Center for APBMT Outcome Registry.

10.7.3 Timing and units of registration

Registration can be received any time after the day 100 post-transplantation. Data can be transferred either on a per patient basis or as a series of patients on a registry basis.

10.8 Annual Report

The list of registrants and summary of analyses are published in the APBMT Annual Report of each year, which is distributed to the APBMT member and related persons / organizations. The results published in the APBMT Annual Report can be quoted freely if accompanied by adequate referral.

10.9 Rules for investigation are use

Data uses for investigation are restricted to publication in a scientific article and / or presentation at academic meetings. Applications for data usage are limited to Scientific Committee Members, Working Groups and the Data Center of APBMT for the time being. Requests from other Academic organizations or commercial companies will be charged depending on the amount of work (cost recovery). If the data usage is limited to data from each country, there are no restrictions. An application form is attached as a separate sheet. The Scientific Committee will evaluate all applications.

ARTICLE 11

Amendments

11-1 These Bylaws may be amended at any annual business meeting. Amendments to the Bylaws may be proposed in writing to the Executive Board and must be submitted at least ninety days prior to the annual meeting. In addition, the Executive Board may initiate proposed amendments to the Bylaws.

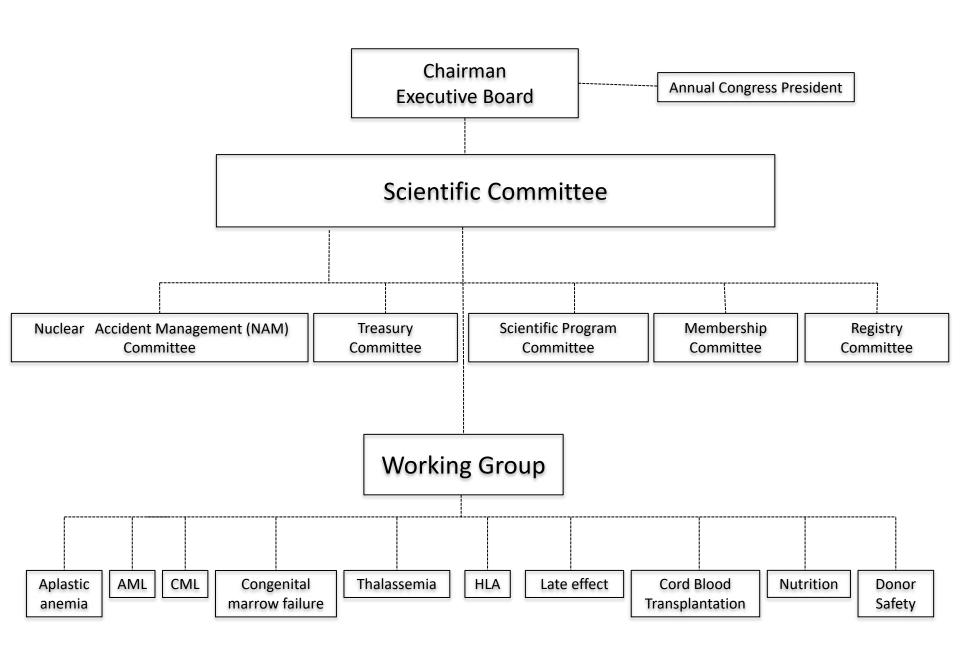
The proposed amendments, together with the Executive Board's recommendation, shall be mailed to each member country at least thirty days before the annual meeting at

which it is to be considered. To be adopted, an amendment must be approved by at least two thirds of voting at the annual meeting.

These bylaws started on October1.2009; 1st revision December 31, 2010; 2rd revision October 18, 2014.

Annex:

- 1. A membership committee will proceed all applications including ex-officio membership
- 2. Current Annual Membership fee is 100 U.S. dollars
- 3. Funding of APBMT activities and guideline on the use of APBMT funds: To be formulated
- 4. Format of the meeting to be standardized and there should be a program committee which will work with the local organizing / scientific committee to maintain uniform standards / format. It is to be defined in a separate document
- 5. Appointment process and Terms of Reference of a Working Group need to be defined and annual reports required
- 6. APBMT Registry Subcommittee: its role and responsibilities need to be defined.





Principal member list (Dec.2014)

Executive Board members

Okamoto, Shinichiro (Chairman, Japan) Srivastava, Alok (Vice-chair, India) Ma, David D. (Australia/New Zealand) Huang, He(China) Hamidieh, Amir Ali. (Iran) Lee, Jong Wook (Korea) Hwang, William YK (Singapore) Nguyen, Tan Binh (Vietnam) Ghavamzadeh, Ardeshir (Iran) Kodera, Yoshihisa (Japan) Kim, Dong Jip (Korea) Issaragrisil, Surapol (Thailand) Lu, Dao-Pei (China) Scientific Committee Members (\square executive board member) Alimoghaddam, Kamran (Iran) Altangerel, Otgonbat (Mongolia) Apte, Shashikant (India) Batsukh, Khishigjargal (Mongolia) Baylon, Honorata G (Philippines) Binh, Tran Van (Vietnam) Chan, Lee Lee (Malaysia) Chen, Po-Min (Taiwan) Chandy, Mammen (India) Chen, Yao-Chang (Taiwan) Chiou, Tzeon-Jye (Taiwan) George, Biju (India) Ghavamzadeh, Ardeshir (Iran) Gyi, Aye Aye (Myanmar) Haipeng, Lin (Malaysia) Hamidieh, Amir Ali (Iran) □ Harada, Mine (Japan) Hariman, Herman (Indonesia) Hiraoka, Akira (Japan) Dong Ying, Gao (China) Huang, He (China) □ Hwang, William YK (Singapore) □ Huang, Xiao-Jun (China) Hwang, Tai-ju (Korea) Issaragrisil, Surapol (Thailand) Jootar, Saengsuree (Thailand) Khan, Mohiuddin (Bangladesh) Khattry, Navin (India) Kim, Chun Choo (Korea) Kim, Dong Jip (Korea) □ Kim, Dong-Wook (Korea) Kim, Hack-Ki (Korea) Kodera, Yoshihisa (Japan) Koh, Mickey (Singapore) Kojima, Seiji (Japan) Koo, Hong Hoe (Korea) Kook, Hoon (Korea) Lee, Jong Wook (Korea) □ Liang, Raymond (Hong Kong) Lie, Albert (Hong Kong) Lin, Kai-Hsin (Taiwan) Liu, Kai-yan (China) Lu, Dao-Pei (China) \square Ma, David D (Australia/New Zealand) □ Mathews, Vikram (India) Miyamura, Koichi (Japan) Nguyen, Tan Binh (Vietnam) □ Okamoto, Shinichiro (Japan) Ostadali Dehaghi, Mohammadreza (Iran) Ouyang, Jian (China) Rowlings, Philip (Australia/New Zealand) Saikia, Tapan K (India) Shamsi, Tahir Sultan (Pakistan) Shin, Hee Young (Korea) Srivastava, Alok (India) \square Tang, Jih-Luh (Taiwan) Taniguchi, Shuichi (Japan) Teh, Alan (Malaysia) Teshima, Takanori (Japan) Tzeng, Cheng-Hwai (Taiwan) Ungkanont, Artit (Thailand) Viswabandya, Auro (India) Wang, Jianmin (China) Wu, Tong (China) Zhang, Mei (China) **Honorary Members** Atkinson, Kerry (Australia) Gratwohl, Alois (EBMT) Carter, John (NewZealand) Hill, Geoffrey (Australia) Confer, Dennis (NMDP) Horowitz, Mary (CIBMTR) Niederwieser, Dietger (EBMT) Goldman, John (EBMT) **Emeritus Members** Asano, Shigetaka (Japan) Advani, Suresh H (India) Tan, Pattric (Singapore) Cao, Lu Xian (China) Masaoka, Tohru (Japan)

Annual Congresses of APBMT

1) Previous Congresses

No	Year	City	President
1 st	1990	Beijing	Cao, Lu Xian
2 nd	1991	Nagoya	Masaoka, Tohru
3 rd	1992	Osaka	Masaoka, Tohru
4 th	1994	Fukuoka	Masaoka, Tohru
5 th	1996	Seoul	Kim, Dong Jip
6 th	1998	Taipei	Chen, Yao-Chang
7 th	2000	Bangkok	Issaragrisil, Surapol
8 th	2002	Mumbai	Advani, Suresh
9 th	2004	Tehran	Ghavamzadeh, Ardeshir
10 th	2005	Hangzhou	Lu, Dao-Pei
11 th	2006	Nagoya	Kodera, Yoshihisa
12 th	2007	Beijing	Lu, Dao-Pei
13 th	2008	Taipei	Chen, Po-Min
14 th	2009	Seoul	Kim, Chun-Choo
15 th	2010	Phuket	Jootar, Saengsuree
16 th	2011	Sydney	Ma, David / Rowlings, Philip
17 th	2012	Hyderabad	Saikia, Tapan K / Srivastava, Alok
18 th	2013	Ho Chi Minh City	Nguyen, Tan Binh
19 th	2014	Hangzhou	Huang, He / Huang, Xiaojun

Future Congresses

• The 20th Congress of APBMT

October 30-November 1, 2015, Okinawa, Japan

Congress President: Okamoto, Shinichiro

• The 21st Congress of APBMT

It will be held in Singapore.

• The 22nd Congress of APBMT

It will be held in Iran

• The 23rd Congress of APBMT

It will be held in Taiwan

The number of attendees for each annual meeting from 2006 to 2014

2006(JAPAN)		2007(CHINA)*		2008(TAIWAN)		2009(KOREA)		2010(THAILAND)		2011(AUSTRALIA/ NEW ZEALAND)* *		2012(INDIA)		2013(VIETNAM)		2014(CHINA)	
Japan	97	China	317	Taiwan	349	Korea	292	Thailand	280	Australia	637	India	118	Vietnam	375	China	646
Korea	30	Korea	47	Korea	46	China	65	China	100	China	178	China	66	China	82	Australia	7
China	30	Japan	36	Japan	24	Taiwan	34	Taiwan	63	New Zealand	84	Japan	19	Korea	41	Bangladesh	1
Taiwan	20	Taiwan	25	Malaysia	6	Japan	33	Korea	52	Korea	57	Korea	15	Japan	32	France	3
Hong Kong	5	Thailand	17	Thailand	5	Thailand	19	Japan	25	Japan	38	VietNam	12	Taiwan	17	Germany	2
USA	4	Singapore	15	Australia	5	Australia	7	Singapore	19	Taiwan	16	Australia	11	Thailand	13	Hong Kong	4
Iran	4	India	12	Pakistan	3	Viet Nam	5	Malaysia	17	Malaysia	14	Germany	8	Hong Kong	7	India	9
Malaysia	3	Malaysia	12	Hong Kong	3	USA	4	Hong Kong	13	Singapore	14	Taiwan	7	Belgium	6	Indonesia	1
Pakistan	3	Other Country	12	Singapore	3	Germany	3	Vietnam	13	Thailand	12	Iran	6	Singapore	6	Iran	3
Thailand	2	USA	12	USA	2	Singapore	2	Australia	9	Vietnam	10	USA	6	France	5	Japan	31
UK	2	Iran	6	Saudi Arabia	2	France	1	Iran	8	Philippines	9	Singapore	4	India	5	Korea	16
Vietnam	2	Indonesia	5	Philippines	2	Hong Kong	1	Italy	6	India	6	Philippines	3	Australia	4	Lebanon	1
India	2	Australia	4	India	1	Indonesia	1	Germany	4	Hong Kong	5	Bangladesh	2	Iran	4	Malaysia	1
Australia	1	Germany	4	Vietnam	1	Iran	1	Indonesia	4	Myanmar	4	Belgium	2	United States	4	Mongolia	7
Germany	1	Pakistan	3	Romania	1	Malaysia	1	USA	4	Switzerland	4	France	2	Germany	3	Myanmar	2
Switzerland	1	Romania	3	France	1	Philippines	1	India	3	Bangladesh	3	Hong Kong	2	Mongolia	3	Pakistan	2
Total	207	Canada	2	Total	454	Switzerland	1	Pakistan	3	Pakistan	3	Mongolia	2	Spain	3	Philippines	4
	%	Czech Republic	2		%	UK	1	France	2	Fiji	2	Canada	1	Malaysia	2	Singapore	9
Domestic	47	Saudi Arabia	2	Domestic	77	Total	472	Myanmar	2	Samoa	2	Ita ly	1	Philippines	2	South Africa	1
Foreign	53	UK	2	Foreign	23		%	Canada	1	UAE	2	Myanmar	1	Indonesia	1	Spain	1
-		Denmark	1			Domestic	62	Hungary	1	Brunei	1	Nepal	1	Ireland	1	Sri Lanka	1
		Myanmar	1			Foreign	38	Israel	1	Cook Islands	1	Sweden	1	Myanmar	1	Taiwan	24
		Nigeria	1					Philippines	1	Indonesia	1	UK	1	Netherlands	1	Thailand	3
		Philippines	1					Sweden	1	Iran	1	Missing	3	Sweden	1	United States	11
		unknown	1					Turkey	1	Israel	1	Total	294	United Kingdom	1	United Kingdom	5
		Total	543					Total	633	Kiribati	1		%	Total	736	Vietnam	4
			%						%	Micronesia	1	Domestic	40		%	Total	799
		Domestic	58					Domestic	44	Papua New Guinea	1	Foreign	60	Domestic	61		%
		Foreign	42					Foreign	56	Slovak Republic	1		•	Foreign	40	Domestic	81
		•						•		Slovakia	1					Foreign	19
										Solomon Islands	1					•	
		※APBMT 2007 wi	th ISH	-APD2007						Sri Lanka	1						
		* APBMT 2011 wir	th HA	A-ISHAPD 2011 an	d ISC	TA				Turkey	1						
										Tuvalu	1						
										Vanuatu	1						
										Total	1115						
											%						
										Domestic	65						
										Foreign	35						

Activity Survey

Introduction of Activity Survey

The APBMT Activity Survey has been performed annually from 2007 (HSCT data from 2005). This survey is a collection of the number of transplantation sorted by the donors' sources and diseases.

The following figure shows how the data is collected.

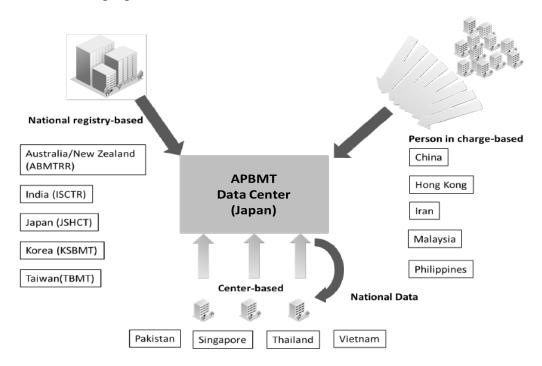


Figure: Data collection

The method of submission is different in each country/region.

As shown in Figure, data from India, Japan, Korea and Taiwan was submitted through their national registry. The Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) submitted the national data for Australia and New Zealand. In China, Hong Kong, Iran, Malaysia and the Philippines, data was collected by a particular contact person and submitted to the data center. The data center has direct contact with major transplantation centers and receives data from Pakistan, Singapore, Thailand and Vietnam. The data collected from these four countries is made available to each country/region for use as national data.

The aim of the 8th APBMT Activity Survey is to update the HSCT Activity data for APBMT countries/regions —transplantation **performed by the end of 2012**. Data Center received data from fourteen out of nineteen countries/regions participating in this survey by January 31, 2015.

Outcome Registry

About the Outcome Registry

The APBMT Outcome Registry was launched in July 2010. The original APBMT Outcome Registry Forms are identical to the EBMT MED-A or the CIBMTR TED, and the subjects for registration were the same as the subjects for the APBMT Activity Survey. However, the original forms were too burdensome for some countries/regions. To solve the problem, simplified report forms with fewer items were introduced by the APBMT Data Center: Least Minimum Dataset (LMD) forms.

The countries/regions started reporting HSCT data —transplantation performed in 2010 or 2011—according to each country/region's situation. Limited data from 2009 is also available.

The APBMT Data Center may receive HSCT outcome data from CIBMTR through data transfer agreements, which were concluded between APBMT and CIBMTR and between APBMT and some centers that submitted Outcome Data to CIBMTR.

By the end of 2014, 23,184 transplant cases from seven countries/regions were reported to the Data Center (4,757 in 2009, 6,259 in 2010, 5,396 in 2011, 6,136 in 2012, 553 in 2013 and 83 in 2014). Seven countries which submitted data were China, India, Japan, Pakistan, the Philippines, Singapore and Taiwan as described on the next page. Paper forms were used for the reports from China as well as some centers in India, Pakistan and the Philippines. Japan and Taiwan reported their data using the LMD Excel Form. From following hospitals, Data Center received their data through CIBMTR.

- ---Singapore
 - —National University Hospital
 - —Singapore General Hospital
- ——Pakistan
 - —National Institute of Blood Disease & Bone Marrow Transplantation
 - —Armed Forces Bone Marrow Transplant Centre
- ---India
 - —Cristian Medical College, Vellore

Numbers of data submission (update: 2014/12/31)

	Number of reported cases (N)						
Country	2009	2010	2011	2012	2013	2014	Follow up data (transplant year)
Australia							
China		991	10	8			
Hong Kong							
India	94	103	127	185	130	37	(1711: including multiple report)
Iran							
Japan	4,438	4,813	4,929	5,364			20,044 (2009-2011)
Korea							
Malaysia							
New Zealand							
Pakistan	47	72	51	56	31	24	196 (2009-2013)
Philippines		4	2	11	9		2 (2010)
Singapore	74	118	130	132	80	22	453(2009-2013)
Taiwan	104	158	147	380	303		521 (2009-2014)
Thailand							
Vietnam							
Total	4,757	6,259	5,396	6,136	553	83	-
No. of Activity Survey	11,078	11,961	12,685	12,873			
% of OR submission	42.9	52.3	42.5	47.7			

Working Groups

Working Groups

APBMT started the Working Groups (WGs) in 2009. The main aim of the WG activity is to participate in research and analysis of all facets of HSCT which members are interested in. Listed below are the 10 WGs which have already been approved by the Scientific Committee as of December 2014.

Working Groups	Chairs
Severe Aplastic Anemia	Seiji Kojima
AML	Vikram Mathews
CML	Dong-Wook Kim
Congenital Marrow Failure Syndrome	Biju George
Thalassemia	Suradej Hongeng
HLA	Yasuo Morishima
Late Effect	Shinichiro Okamoto
Cord Blood Transplantation	Satoshi Takahashi
Nutrition Support	Sung-Won Kim
Donor Safety	Yoshihisa Kodera

Table: Working Groups in APBMT as of December 2014

Working Group chairs and members' responsibilities

- Each WG should have at least one in-person meeting per year, including in-person meetings during the APBMT annual meeting
- All meeting minutes should be submitted to the APBMT secretariat within 2 months of the meeting
- All WG members should be a member of APBMT
- WG members shall contribute to outcome data registration within their countries/regions
- Currently, no financial supports are available for APBMT WG activities
- For more information, refer to our website

Working Group Accomplishment

[Publication]

Severe weight loss in 3 months after allogeneic hematopoietic SCT was associated with and increased risk of subsequent non-relapse mortality.

S. Fuji, T Mori, N Khattry, J Cheng, YR Do, K Yakushijin, S Kohashi, T Fukuda, S-W Kim on behalf of the Nutritional Support Working Group of the Asian Pacific Bone Marrow Transplantation

Bone Marrow Transplantation

Advanced online publication 6 October 2014

[Conference presentation]

Implementation of international guideline for screening and preventive practice guideline for long-term survivors after hematopoietic transplantation. APBMT Late Effect Working Group survey report.

Y Atsuta, D Ma, S Jootar, OY Jian, A Lie, W Hwang, HV Man, S Taniguchi, A Butler, S Takahashi, J Szer, S Okamoto, for the APBMT Late Effect Working Group The 19th Congress of the APBMT, 17 October 2014, Hangzhou China

Severe weight loss in 3 months after allogeneic hematopoietic SCT was associated with an increased risk of subsequent non-relapse mortality.

S Fuji, T Mori, N Khattry, T Fukuda, S Kobashi, S-W Kim

The 36th Annual Meeting of the Japan Society for Hematopoietic Cell transplantation March, 2014, Kanazawa Japan

Additional information: Nuclear Accident Management (NAM) Committee

Chairperson: Dr. David Ma (Australia)

Deputy Chairperson: Dr. Alok Srivastava (India)

Consensus: (1) It is valuable to have NAM committee within APBMT

(2) APBMT has a co-ordinating role in the region to:

- Facilitate co-operation within our region, with other societies in other regions such as EBMT and ASBMT, WBMT
- Establish an APBMT NA registry
- Establish a training programme
- SOPs for handling of NA in our region

Worldwide Network for Blood and Marrow Transplantation (WBMT)



General Information

The WBMT is a nonprofit scientific organization with the mission to promote excellence in stem cell transplantation, stem cell donation and cellular therapy. WBMT cooperates with many related-organizations around the world and engage exclusively in scientific and educational activities and endeavors. The annual global survey is one of the activities of the WBMT. Publications of the WBMT are available on the website (http://www.wbmt.org).

The WBMT engages in a variety of activities to further its mission, including:

- An annual global survey of hematopoietic cell transplantation (HCT) activity
- Scientific and educational conferences
- Development of consensus guidelines for optimum delivery of HCT services and accreditation of HCT facilities

From April 2014, the following were achieved:

- Preparations of WBMT research guidelines by a Board mandated Task Force
- Publications by several WBMT Standing Committees
- WBMT attendance and contribution to the meetings for Medical Products of Human Origin organized by WHO
- Publication of the annual report of WBMT
- Working with transplant centers in developing countries with more established transplant centers
- The organization and convening of the African Workshop in Cape Town

APBMT is one of the first founding societies of WBMT and has made great efforts to organize WBMT in collaboration with other member societies such as CIBMTR, EBMT and WMDA since 2007. In 2011, WBMT had the first Workshop and Scientific Symposium in Hanoi for the development of HSCT in Asia-Pacific countries/regions. After the Workshop, a lot of supports to establish and operate HSCT were provided from leading countries to advancing countries/regions in this area. In 2014, the previous APBMT chairman, Dr. Yoshihisa Kodera was elected as a new WBMT president and APBMT has played a more important role in the development of WBMT, such as the WBMT survey and five Standing Committees.

WBMT officers

President

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Past President

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Secretary

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Treasurer

Dennis Confer National Marrow Donor Program and Be The Match 3001 Broadway Street N. E. Suite 100, Minneapolis, MN 55413-1753 Tel: +1 612 362 3425 Fax: +1 612 845 0882 dconfer@nmdp.org

Worldwide Network for Blood and Marrow Transplantation (WBMT) In-person Meeting

Salt Palace Convention Center, Salt Lake City, UT, Room 254 A-B

February 13, 2013, 4:45 PM – 7:45 PM US CMT

Present	Position	Member Society	Country
Executive Officers			
Dietger Niederwieser	President	·	Germany
Yoshihisa Kodera	Vice President		Japan
Dennis Confer	Sec'y/Treasurer		USA
Hildegard Greinix	President-Elect/Placeholder		Austria
Mahmoud Al-Jurf	Primary Board Member	EMBMTR	Saudi Arabia
Helen Baldomero	Member	Activity Survey	Switzerland
Michael Boo	Primary Board Member	WMDA	USA
Luis Fernando Bouzas	Primary Board Member	LABMT	Brazil
Jorg Halter	Standing Cmte Chair	EBMT	Switzerland
Amir Ali Hamidieh	Alternate Board Member	EMBMT	Iran
Mary Horowitz	Alternate Board Member	CIBMTR	USA
Carolyn Keever-Taylor	Primary Board Member	FACT	USA
Steve Marsh	Primary Board Member	EFI	UK
Carlheinz Müller	Primary Board Member	EMDIS	Germany
Marcelo Pasquini	Alternate Board Member	CIBMTR	USA
Donna Regan	Primary Board Member	AABB	USA
Doug Rizzo	Standing Cmte Chair	CIBMTR	USA
Vanderson Rocha	Alternate Board Member	Eurocord	UK
Adriana Seber	Alternate Board Member	LABMT	Brazil
Dan Weisdorf	Primary Board Member	ASBMT	USA
Guests/Staff			
Yoshiko Atsuta	Guest	APBMT	Japan
Minako Iida	Guest	APBMT	Japan
Ana Grace Barrantes Ramirez	Guest	LABMT	Costa Rica
Menachem Bitan	Guest	EMBMT	Israel
Willem Bujan-Boza	Guest	LABMT	Costa Rica
Antonio Carrasco-Yalan	Guest	LABMT	Costa Rica
Jessica Gillis-Smith	Guest	CIBMTR	USA
Yachiyo Kuwatsuka	Guest	APBMT	Japan
Mariela Moreno	Guest	LABMT	Costa Rica
Satoshi Nishiwaki	Guest	Ministry/Health, Labour and Welfare	Japan
Luc Noël	Guest	WHO	Switzerland
Ricardo Pasquini	Guest	LABMT	Brazil
Paula Watry	Staff	CIBMTR	USA

<u>WELCOME & INTRODUCTIONS</u>:
Dietger Niederwieser opened this 15th meeting of the WBMT Board by welcoming all in attendance.

His first announcement was about the January 30th Press Release regarding the 1 millionith HCT worldwide; he explained that the count may actually be higher but WBMT is confident about the process in which it determined this information. All Member Societies are encouraged to disseminate the Press Release information and to contact him if there are questions.

His second announcement was to describe the past 2 year process while in "working relations" with the World Health Organization (WHO) and the recent formal approval by the WHO Assembly of the WBMT as an "NGO" partner.

Dietger also took this moment to thank Dr. Rudy Schwabe and his team in Basel for their support of the WBMT Website. There is now archive capability on the site and recent death notices and the Press Release are posted.

I. MINUTES:

Draft minutes of the teleconference WBMT Board meeting held on October 19, 2012 were provided in advance for review. Dennis reviewed action items and the minutes were accepted/approved as written.

II. TREASURER'S REPORT:

The report was displayed for all to see and Dennis reviewed the current balance at 44,000 €. There were questions regarding the revenue for the Hanoi workshop and the "donations" source of income; these donations were essentially funds raised by the APBMT for the workshop. There is also an expense item, "statistical analysis" and this is described as fees for the services of Helen Baldomero for the annual Activity Survey. The report was approved unanimously.

III STANDING COMMITTEE REPORTS:

Dietger noted that along with NGO status comes deliverable requirements to the WHO including an Annual Progress Report. The Executive Committee wants to include an activity report from each of the Standing Committees in this Progress Report.

A) <u>Donor Committee</u> (reporting Chair, Joerg Halter)

There have been 2 in-person meetings, one in San Diego and the other in Geneva. Committee accomplishments included establishing the Minimum Data Set for unrelated donor follow-up; this was published this month and EBMT already implemented them in past weeks.

Ongoing projects include working with the AHCTA group and their "Essential Elements" project and this committee will complete their contribution by end of this month. Then they will work on follow-up issues for related donors.

In the future the committee intends to work in collaboration with Michael Pulsipher on a data set for donors mobilized using Plerixifor as well as on eligibility recommendations for unrelated donors. Dietger noted that there should be a collaboration of this project and that of the broader Biovigilance project; he will discuss this with our WHO representative. He reported also that the next Biovigilance group is meeting next week in London.

B) Transplant Center/Recipient Committee (reporting Chair, Doug Rizzo)

There was a single in-person meeting in Geneva and this committee has completed its contribution to the ongoing Hanoi manuscript project. The group is still considering future topics of interest but participated in thoughts about the Research Committee (later on agenda).

There was reconciliation of center numbers but will be due again this year. This lead to a brief discussion regarding the Global Transplant Center Number (GTCN). A plan proposed last year would require resources and would include an interactive map with easy functionality for posting on the WBMT site; centers could access independently and maintain their center identification data there.

There was pre-meeting discussion between Dietger and Doug and they have agreed on a different approach which was not defined.

- C) Education and Dissemination Committee: there were no committee Chairs in attendance for reporting.
- D) Graft Processing Committee: (reporting Chair, Carolyn Keever-Taylor)

There was a single in-person meeting in Geneva and 2 teleconferences. This group feels their role is more as a teaching resource and to this end worked on a *Basic Elements* document for cryopreservation. A draft is circulating for second version editing. This document will be made available on the Website.

A second project in progress is development of a *Frequently Asked Question* document. It is under committee review at this time and will also be made available on the Website.

E) AHCTA: (reporting for Chair, Donna Regan)

This group has been especially active with 5 projects in progress or under consideration. These are:

- Laboratory training survey; drafted results and will submit for publication this month;
- Consensus paper also drafted description and recommendations for training cell collection staff and will submit in March;
- Essential Elements Project completed description of necessary steps for developing programs; is
 working in collaboration with the Donor Issues Committee as must insert their relevant
 components. These are considered a platform for preparation for accreditation and will be posted
 to both the AHCTA and WBMT websites on March 1st;
- Developed cell processing survey of training practices; will draft in collaboration with Carolyn Keever-Taylor. This project is near completion;
- Updated resources on website <u>www.ahcta.org</u>.

This group will continue to work with other committees to plan and develop the training program for the WBMT Workshop scheduled for later this year.

F) Nuclear Accident Committee: (reporting for Chair, Yoshihisa Kodera)

Dr. Kodera reported that during the APBMT Congress in India (October 2012), the group decided to form a Nuclear Accident Management Committee within the APBMT and Drs. David Ma and Alok Srivastava were chosen as co-Chairs. There were various presentations including one by Dietger regarding the role of the WBMT and regional societies in developing approaches to handling this type of disaster globally.

It was further suggested there that this APBMT NAM committee collaborate with the existing Radiation Injury Treatment Network (RITN) in the US and the EBMT Nuclear Accident Committee (NAC) under the umbrella of a single WBMT Nuclear Accident Committee. The WBMT Board already approved this approach during a teleconference later in 2012.

To expand the project, others will be invited to join so that there is truly global involvement; though Brazil and Mexico already participate, the LABMT and the AFBMT groups should be invited to join in this collaboration for complete global participation.

G) Research Standing Committee:

In follow-up to last year's discussion in Geneva, Drs. Yoshiko Atsuta and Marcelo Pasquini proposed formation of a new Standing Committee – that of a Research Committee. The idea was that the WBMT needs to address how to handle both internal and inter-registry collaborations as well as requests for data and/or research studies.

Their proposal was for this committee to promote – not perform – research and to build a platform on which research activities can occur within the WBMT. This committee would develop guidelines for how to manage survey data in particular and would provide leadership with well-developed responsibilities regarding global research focused on transplant issues. Dr. Marcelo asked if there is interest and, if so, how would membership be determined.

There was open discussion with all in agreement that WBMT needed procedures for both analyzing data and guiding research studies. This committee could provide oversight, governance, proposal review and handling questions about sharing data worldwide.

All agreed we need structure and processes but some felt there would be overlap of existing committee activities and there was also some resistance to formation of another Standing Committee. It was finally decided to form a Task Force first with representation from all international transplant outcome registries (5). This Task Force will decide how best to move forward with establishing House Rules for research activity. Yoshiko and Marcelo will lead the Task Force and Paula will draft a letter inviting each of the major registries to appoint a representative to the Task Force.

H) Other:

Dietger and Helen Baldomero took this moment to inform the group of a new tool (Transplant Activity Survey; TAS) designed for the EBMT Activity Survey that permits coding of new transplant center numbers. It also permits display of registry aggregate data.

The tool allows the reporting of transplant activity via the web using a simple user friendly input form that is similar to the reports (easy, single page record) provided to WBMT via a regional transplant society, national Registry or at the team/center level – and mathematical calculations are performed automatically avoiding human error. Activity data can still be entered at either the country or center level.

These data do not represent an outcome registry but the TAS is a new tool by which each country's annual data can be registered to the WBMT (in the format of the survey sheet that WBMT has been using) and put to further use within the organization. It can be used at the team level for those countries/societies (e.g. LABMT) that do not have an existing data collection system. If an 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) providing a mechanism for follow-up.

IV. ELECTION RATIFICATION:

Hildegard Greinix, Chair of the Nominating Committee, reported the results of the recent election for President Elect. Drs. Kodera and Weisdorf were the nominees and Dr. Kodera won with the majority of votes. All present agreed with the motion to ratify the election results.

This presents a new issue as now the Vice-President post will be vacant until another election occurs (scheduled for next December with ratification in spring). Options are not clearly defined in the House Rules and this is felt to be an unusual situation. The Executive Committee put forth the recommendation that Dan Weisdorf serve in the Vice-President position until the next election. Dan is willing and agreed to serve for this one year.

V. WORKSHOP UPDATE:

Dietger described that the Workshops will be a biannual event and that he has been in contact with MCI to inform them that the Executive Committee chose them to work with in coordinating the October 2013 Workshop/Scientific Symposium in Salvador, Bahia, Brazil. He invited Dr. Luis Bouzas, interim President of the LABMT, to address ongoing plans.

Dr. Bouzas first noted that the LABMT is convening its 5th meeting tomorrow and that many countries within, representing 160 centers, have begun reporting HCT activity to the EBMT survey during this past year since the 1st formal LABMT meeting in San Diego (Feb 2012).

Salvador, Bahia is in the NE quadrant of Brazil where there are significant problems and barriers to transplant. He further described geographic and population details in this region. The organizing committee is also meeting tomorrow. Initial dates were established for the third weekend in October but a major conflict, the NMDP Council meeting, was established. There were conflicts with other dates as well and it was clear this required further consideration/discussion and will be left to the Workshop Organizing Committee.

VI. ADMINISTRATIVE MATTERS:

A) LABMT/Member Society

The LABMT formally requested Member Society status in the form of a letter (Attachment to meeting materials). All present agreed; WBMT should post the logo on its website and LABMT is to identify both a primary and alternate representative to the Board.

B) Bylaws/House Rules revisions

A variety of recommendations were put forth by the Executive Committee for revisions to both the Bylaws document as well as House Rules governing the nomination/election process. Most are minute text detail changes and do not change practices substantively.

Two issues required consensus of the Board:

- frequency of Board meetings; it was agreed that 3 meetings each year are sufficient 2 teleconferences and the annual in-person meeting.
- handling of an Executive Committee vacancy when an executive officer is elected/ratified to a different position on that same Committee; in such cases, the Board will identify an interim designee to fill the vacancy until the next election cycle/ratification.

See attachments to this document for red-line and clean copies of the detailed, approved revisions.

C) Skype for future Board meetings

Teleconferences have been pricey for the WBMT and the group would like to attempt using Skype as a more cost efficient means of communicating. It was agreed that the WBMT Executive Committee will try using Skype on several monthly calls before attempting a bull Board teleconference using this technology in this manner.

With no further business, the meeting was adjourned at 7:30 PM.

SUMMARY OF ACTION POINTS ARISING FROM THIS MEETING

- Dietger will discuss with Luc Noël a possible collaboration between the Biovigilance project and the Plerixifor (mobilizing unrelated donors) project that the Donor Committee is undertaking.
- The Executive Committee will invite the LABMT and AFBMT groups to participate in the WBMT Nuclear Accident Committee collaboration to ensure global involvement.
- Paula will draft a letter inviting each of the major registries to appoint a representative to the Task Force that will consider the implications of forming a Research Standing Committee.
- The Workshop Organizing Committee will identify fall dates that are not in conflict with other major meetings.
- LABMT will provide names of their Primary and Alternate Board Representatives to the Executive Committee; Dietger will post the LABMT logo on the website.
- Paula will prepare red-line and clean copies of revised Bylaws and House Rules as approved during this meeting.

Respectfully submitted for Dennis Confer (Secretariat), Paula Watry.

Worldwide Network for Blood and Marrow Transplantation (WBMT) In-person Meeting

MiCo; Milano, Italy

March 30, 2014

Present	Position	Member Society	Country
Executive Officers			
Dietger Niederwieser	President		Germany
Yoshihisa Kodera	Vice President		Japan
Dennis Confer	Treasurer		USA
Hildegard Greinix	Secretary		Austria
Mahmoud Al-Jurf	Primary Board Member	EMBMTR	Saudi Arabia
Michael Boo	Primary Board Member	WMDA	USA
Pat Distler	Alternate Board Member	ICCBBA	USA
Eliane Gluckman	Primary Board Member	Eurocord/ESH	France
Jorg Halter	Standing Cmte Chair	EBMT	Switzerland
Amir Ali Hamidieh	Alternate Board Member	EMBMT	Iran
Mary Horowitz	Alternate Board Member	CIBMTR	USA
Gregorio Jaimovich	Alternate Board Member	LABMT	Venezuela
Mickey Koh	Standing Cmte Chair	APBMT/ISBT	Singapore
Kathy Loper	Standing Cmte Chair	AABB/AHCTA	USA
Steve Marsh	Primary Board Member	EFI	UK
Carlheinz Müller	Primary Board Member	EMDIS	Germany
Marcelo Pasquini	Alternate Board Member	CIBMTR	USA
Donna Regan	Primary Board Member	AABB	USA
Doug Rizzo	Standing Cmte Chair	CIBMTR	USA
Vanderson Rocha	Alternate Board Member	Eurocord	UK
Adriana Seber	Alternate Board Member	LABMT	Brazil
Phyllis Warkentin	Alternate Board Member	FACT	USA
Guests/Staff			
Yoshiko Atsuta	Guest	APBMT	Japan
Helen Baldomero	Member	Activity Survey	Switzerland
Luis Fernando Bouzas	Guest	LABMT	Brazil
Minako Iida	Guest	Member/staff	APBMT
Yuichiroh Tanaka	Guest	JMDRPC(Japan Marrow Donor Registry Promotion Conference)	Japan
Masamitsu Nomura	Guest	JMDRPC	Japan
Nicolas Novitzky	Guest	AFBMT	South Africa
Juliana Martinez-Rolon	Guest	LABMT	Venezuela
Nishiwaki Satoshi	Guest	MHLW(Ministry of Health, Labour and Welfare) of Japan	Japan
Paula Watry	Staff	CIBMTR	USA
Ayami Yoshimi	Guest	APBMT	Japan

	Agenda Item	Discussion	Consensus
1)	Welcome, Introductions;	Introductions were made around the	n/a
	Outgoing President's Report	table. 2013 Progress Reports were	
	(slide set available on website)	distributed to all.	
		Dietger listed the achievements over	
		past 4 years including acquisition of	
		NGO status by the WHO. He thanked Board members and drew attention to	
		www.wbmt.org . He identified a	
		major threat (lack of funding for last	
		workshop) and stated goals for the	
		future. The major achievement is the	
		accomplishment of the WBMT	
		mission itself.	
		D 1 d A d d G	
		Regarding the Activity Survey:	
		• 4 continental regions	
		• Latest data is from 2011 (77 countries, 534 teams	
		• Latest pub: 2010 data; awaiting	
		author comments	
		• Collecting 2011 (>60,000); 30%	
		increase.	
2)	Minutes – November 22, 2013	Yoshi reviewed 2 completed Action	Approved as written
	·	Items. Minutes available on website.	11
3)	Treasurer's Report (slides	Dennis reviewed details of the 2012,	n/a
	available on website)	2013 and 2014 financial statements.	
		Balance $12/31/13 = 41,159 \in 27/14$	
		= 35, 610 €.	
		\$20,000 US owed to CIBMTR –	
		payment next week. 2 annual sponsors (Celgene (10,000 €;	
		Gentium $20,000 \in 0 - 2014$ still due.	
4)	Research Activity Task Force	Marcelo Pasquini reviewed the	Who owns these data? Provider of the
-,	(TF) Report (slides available on	history of this task force (mandated	data? – Board must decide.
	website)	by Board Feb 2013) – essentially to	
		address "how to deal with activity	Group favors system that people can use,
		data and research projects"; 2	need simple mechanism – "not too
		objectives – prepare guidelines	bureaucratic"; maintain an inventory.
		document and establish framework	
		for the conduct of research.	Need a single, simple data agreement for collection and access that permits WBMT
		2 TF activites:	to use data and to make it publicly
		Facilitate research within	available.
		Member Societies	No barriers – even if centers,
		Standardize activity survey	rather than registries or
		(obligation to WHO, reduce	Societies, provide data –
		workload of Helen Baldomero,	"whoever gives WBMT the
		other uses?)	data" should sign the data use
		TE C (11 E 1 2014)	agreement first.
1		TF Consensus (call Feb 2014)	Until process defined and approved
		Craft a guiding principles document	Until process defined and approved, Board should approve any data requests
		documentAvoid duplication or competition	to use Global Activity Survey data.
		within Member Society research	to accountioning our vey data.
		Document based on available	Single document should describe
		documents from member	How WBMT receives the data
Щ		accamento nom momon	<u> </u>

registries

RE: Global Activity Survey:

- Required by WHO
- Annual HCT activity by country and transplant type
- Current use
 - Biennial publications
 - Comparisons of epidemiologic and macro economic factors

Should these data be used for research?

- Now since 2006
- 74 countries/1500 centers
- Who owns? WBMT does!
- Can others use these data?

Data capture process reviewed; labor intensive.

- Web based collection/WBMT
 - New TAS system developed by Promis (Dr. Brand)
- Should decentralize responsibility

How use data?

- Place on website available to all
- Design process to oversee proposals and data release
- Major Question is data agreement with Member Societies necessary to allow use of survey data?

Next steps:

- Guiding Principle document this year for distribution to Board.
- Global Survey
 - O Slide set available June 2014
 - Oversight to Transplant Center/recipient Standing committee for now

 Then agreement between WBMT and the party from whom WBMT receives the data.

If paper written – must recognize whomever provided the data to WBMT.

5) Workshop Updates a. Brazil

BRAZIL:

Marcelo reported that this was a Brazillian and Panamanian collaboration and was successful but not without problems. He reviewed the contribution of each of the WBMT committees and their contributions to the program. We still want more discussion time in the Program structure.

Other comments:

Luis Bouzas commented that early funding was a problem due to meeting competition in Brazil; no other LA country offered contributions. Braillian gov't did provide funding, but the Bahia state presented a problem with "promised" money.

All agreed we need to assess exactly what services are provided by MCI for the

- Too few politicians attended
- 19 countries total; 11 Latin American, 8 others. Cuba and Uroguay not represented.
- Costs; 123,00 USD (including a generous private donation)
- Problems:
 - Lack of funds
 - MCI issues despite local office support
 - o Communication issues
- Achievements:
 - o 1st time LABMT members talking/collaborating
 - LABMT leadership now firm and active
 - Consideration of "Data Back to Center" approach to LABMT centers wishing to report data.
- Lessons learned:
 - Must start earlier!
 - Need engaged co-chairs locally
 - Need better communication
 - Need accessible venue (not resort model)

Hildegard was thanked for her efforts in securing financial support from Therakos for the Satellite Symposium.

Lastly – DRAFT copies of Worskhop Evaluations and of a Post-Workshop Report template were distributed in advance. These are for use in all future Workshops. If comments, contact Paula.

SOUTH AFRICA:

Nicolas Novitzky reported the various challenges to HCT in South Africa and Africa generally. He reminded the group that his center has reported outcome data to the EMBMTR since 2008.

He also addressed issues related to securing the hotel venue for the Workshop and that congress notices have been distributed to appropriate pharma (40) already.

He outlined both scientific content and policy making content and emphasized numerous points that costs incurred.

There was further discussion about the need for an organizing company such as MCI but some thought it may be cheaper to hire a development person to seek funding for WBMT. No resolution.

• All agreed invitations should go to a complete list of African countries and that, regarding persistent budget issues, we must identify Workshop sites and begin planning earlier to provide sufficient time for fund raising.

b. South Africa

c. Workshop Mileage Grant Report	should generate much participant discussion. Transplanters should be the primary stakeholders with emphasis on how to get patients to HCT faster. He feels strongly that "hubs" should be invited and centers surrounding those hubs as well – that networks should be established to facilitate HCT on the continent. WORKSHOP MILEAGE GRANT: Mr. Nomura from the Japanese Marrow Donor Registry Promotion Conference (JMDRPC) described the role of this Japanese volunteer group that supports the marrow donor registry. Their contributions have helped save many lives over the years and he was delighted to report that	
	they, in collaboration with Delta	
	Airlines, are pledging to provide 10	
	million flight miles in support of the	
6) Election Ratification	South African Workshop.	There were no chications: all ammers I
6) Election Ratification	Yoshi presented the results of the December 2013 election; Dan	There were no objections; all approved election results.
	Weisdorf as Vice-President, Dennis	
	Confer as Secretary/Treasurer.	
7) Administrative Matters	BYLAWS REVIEW: 7 proposals:	
a. Bylaws Amendments Proposals	1. Should committee chairs be permitted to vote on all matters?	Yes – but only one chair per committee.
1 Toposais	2. Should we separate the	Commuce.
	Secretary/Treasurer position into	2) Yes – agree to appoint Hildegard
	2 separate roles?	until full election in December.
	3. Who should oversee Standing	3) Leave to committee itself.
	Committee membership? 4. How to handle non-elected terms such as committee Chair	4) Designate term changes on April 1 st of year of change; Central office to
	positions and Board members?	distribute "renewal" notices every 3 years (starting 2014) asking Member Societies to review their representation on our Board. 5) Next or last April 1st closest to
	5. When assign term onset of NEW Member Society reps?	approval date (either previous or following April). 6) Vess keep as is If get "off
	6. Should Primary and Alternate Board rep terms be identical?	 6) Yes – keep as is. If get "off schedule", maintain 3 year cycling. 7) First proposed in 2013; already approved but must add to bylave
	7. How acknowledge an Honorary Member?	approved but must add to bylaws. Suggestion: craft participation guidelines
	Dietger reviewed highlights of the WBMT website and asked that if	for how to handle non-participation.
b. Website;	anyone has ideas for improvement,	
improvements?	contact him. He again acknowledged	

		T
	the Swiss Stem Cell Bank and Dr.	
	Rudy Schwabe for their continued IT	
	support on our behalf.	
8) Standing Committee Reports	Brief Standing Committee reports were provided by respective co-Chairs. Essentially all referred to detailed achievements, publications and ongoing projects in the recent 2013 Progress Report (which will be posted on website).	AHCTA's report re: translation of "Essential Elements" website materials for the LABMT generated discussion in favor of exploring finding resources for good translation of HCT materials as this remains a barrier to outcome registries. WBMT would like to move in future towards collection of outcome in addition
	There is one new committee – the	to activity data.
	Nuclear Accident Committee (NAC) with new co-Chairs David Ma, Ray	
	Powles and Cullen Case. The EBMT group meets tomorrow and soon the WBMT Chairs will be brought	
	together to plan structure, function and mission of this WBMT committee.	
	Mickey Koh expanded his Graft Processing report to include recent	All agreed this is an appropriate subject for WBMT and agree with the approach of working with the ISCT and the Task
	activity re: cellular tourism.Becoming more lucrative and crossing boarders	Force.
	Valid clinical trials preferredWhy WBMT involved?	
	 Member Society ISCT initially very involved; accepts partnership with 	
	WBMT for broader approach – now invited to participate in	
	"presidential Task Force" to define standard, experimental	
	and clinical trial therapies WBMT already	
	involved with NOTIFY/biovigilance	
	project – already a "fit" and framework exists. Luc Noel stated WBMT has a	
	responsibility to speak as "single voice" - all Member Societies are at forefront.	
9) Incoming President's Address	First Yoshi noted his/our appreciation	
,	to Dietger for many years of	
	dedicated efforts in the formation and	
	development of WBMT to the	
	recognized organization it now is; a gift was presented.	
	He reported his continued	
	commitment to the global survey, the	
	standing committees and Task Force	

	as well as our relationship with WHO and future Workshops. His goals for the future are to strengthen the Executive Committee and to bolster acquisition of funding capabilities for a more sound financial position. He strongly supports the NAC (see above) and proposes to change our annual Joint Sessions to include topics that can be presented at other annual regional meetings in addition to Tandem and the EBMT meetings.	
	He supports a long term plan with the WHO that will focus more on regions rather than full continents.	
	The Board and Executive Committee calls are "keys to success"; he asks all	
	to support these calls by engaging and participating more fully.	
10) Other Business	There was no time remaining for further business. The meeting adjourned at 17:00.	

Respectfully submitted for Secretary, Hildegard Greinix.

Paula Watry, Executive Administrator

Workshop of the WBMT in collaboration with the WHO

Salvador-Bahia, Brazil, 3rd & 4th October 2013



Cape Town, South Africa, 14th & 15th November 2014



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