

Asia-Pacific Blood and Marrow Transplantation Group

SECRETARIAT OFFICE / DATA CENTER OF APBMT





**Asia-Pacific Blood and Marrow
Transplantation Group
(APBMT)
Annual Report
2016**

Secretariat Office / Data Center of APBMT

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Preface

First of all, I am pleased to share with you that APBMT has kept growing in terms of the numbers of participating countries/regions and the numbers of transplantation performed, and the strength of our collaboration in 2016. One of the highlights this year is launching our own journal “Blood Cell Therapy/An Official Journal of APBMT”. Dr. Akatsuka has been assigned to the Editor in Chief of this journal, and under his outstanding leadership the preparation of the journal has progressed smoothly. We are now expecting to launch the first issue by the end of this year, and I strongly encourage you all to submit your basic as well as clinical studies/experiences to our journal.

The urgent challenge in APBMT is to increase sites to perform HSCT and the access to it. APBMT leadership team has continued to work on this issue aiming at providing emerging countries with training opportunities in HSCT and ensuring the quality of HSCT among Asia-pacific area. The leadership team is setting up the standardized step-up approach for starting transplant program while harmonizing our approaches with the materials and recommendations of WBMT. We are still facing to many obstacles, but I remain optimistic as I believe your great enthusiasm and passion for HSCT has undoubtedly contributed significantly to achieve this mission.

I would also like to mention about the activity of HSCT Registry in Asia (APBMT Transplant Outcome Registry). The activity of our registry is vital for establishing platform to design and promote clinical study and to collaborate with other international organizations related with HSCT. Thanks to Dr. Atsuta, the Chairman of Registry Committee, and the Committee members for their dedicated work on refining the data submission forms and tackling with harmonizing the regulation regarding the data submission to the registry and exchanges the data among participating countries.

Finally, as the chairman of Executive Board of APBMT, I would like to express my sincere appreciation to all of you for your dedicated support to APBMT. I would also like to acknowledge Drs. Minako Iida and Yoshiko Atsuta, and Ms. Yukari Nakao for their excellent work in preparing this annual report.

Shinichiro Okamoto, MD, PhD
On behalf of the Executive Board, APBMT

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Introduction

General overview of last year

APBMT is comprised of 21 countries/regions as of December 2016:

Australia
Bangladesh
Cambodia
China
Hong Kong
India
Indonesia
Iran
Japan
Korea
Malaysia
Mongolia
Myanmar
New Zealand
Pakistan
Philippines
Singapore
Sri Lanka
Taiwan
Thailand
Vietnam



This Annual Report is the 9th edition. It provides an update on the activities of APBMT including results of the 10th Activity Survey (transplantations performed in 2014). In addition, information about WBMT (Worldwide network for Blood and Marrow Transplantation) is included in this booklet.

The total number of registered members exceeded 200 this year. As APBMT decided to discount the annual membership fee for the health allied professionals (100 USD to 30 USD), we hope to increase new members, not only physicians but also all staff who are keen to contribute and active in this field.

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

ARTICLE 1

Name of the Group

The Asia Pacific Blood and Marrow Transplantation Group, hereafter referred to as APBMT was established in 1990 to allow doctors, other health professionals and scientists in the Asia Pacific region involved in clinical blood and marrow transplantation and therapies related to hematopoietic stem cell transplantation to collaborate and promote high quality blood and marrow transplantation in the region.

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

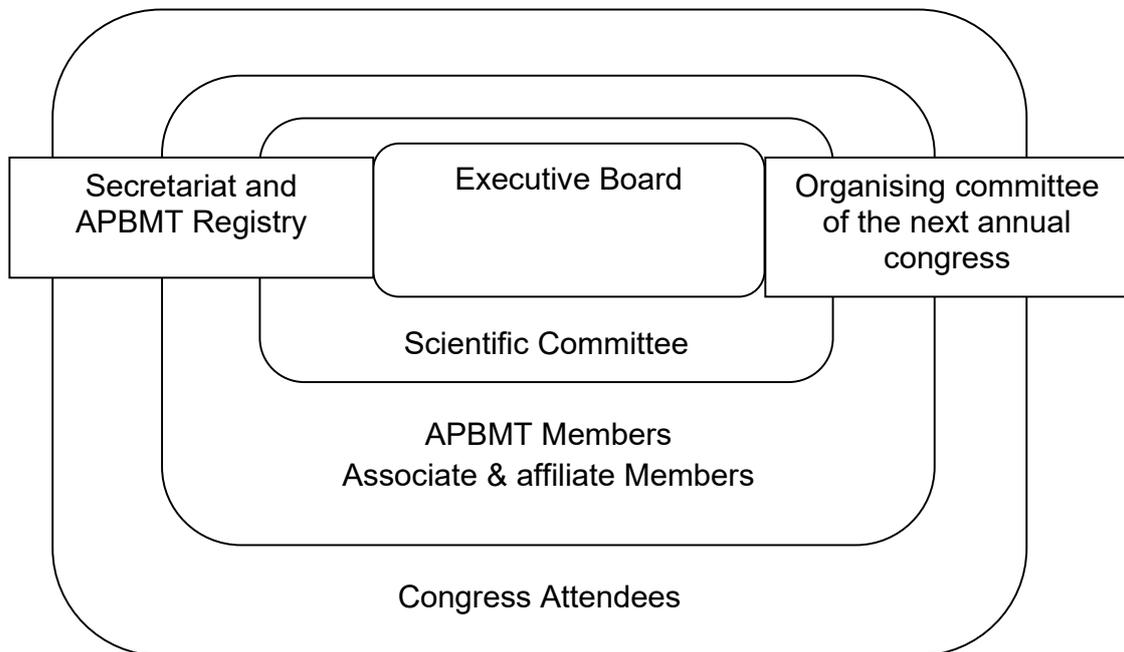
The group aims to promote all aspects associated with the hematopoietic stem cell transplantation (HSCT) and related therapies in the Asia Pacific region, which includes:

- To ascertain and provide the updated status of haematopoietic stem cell transplantation (HSCT) in the Asia Pacific region.
- To steer and regulate the HSCT Registry in the Asia Pacific region (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 the Asia Pacific region.
- To promote collaborative research in the Asia Pacific region.
- 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. Membership Any persons involved in the treatment of recipients and donors (such as physicians, nurses, laboratory technicians, 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 APBMT would become Emeritus Members (within APBMT) or Honorary Members (other registries etc.). Emeritus and Honorary Members can participate in the business meeting.

4.1 Regular Members

Regular members consist of members from medical fields (Scientific Regular Members) Scientific Regular Members can elect and can be elected Scientific Committee Members within each country. 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.

4.2 Associate & affiliate members

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

4.3 Emeritus members

These are members who served in previous Executive Board and accepted to be an Emeritus Members instead of Regular Member. They will serve as Advisory Board Members for a term of 2-3 years to provide advice to the new Executive Board and do not have a voting right.

Emeritus membership is also awarded to those who organized APBMT annual congress as a meeting president and in recognition of their outstanding contribution to the APBMT.

4.4 Scientific Committee

Scientific Committee is the supreme decision-making body in APBMT. Each country can elect and nominate 1 voting member as the country representative. The vote is casted by the country representative but this right may be transferred to a designated substitute. If there is more than one nominee from one country, the Scientific Committee can vote to select one candidate. 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 participate in scientific endeavors of the APBMT; no criminal record, good ethical and moral standards as expected by professional societies.

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.

4.5 Executive Board

The Executive Board of APBMT steers the group for administration and all decisions that need to be taken for functioning of the organization in accordance with the constitution and bylaws of the organization. The Executive Board is responsible for all running operations and decisions that are not due to be taken by the Scientific

Committee at the annual meeting. The Executive Board, appointed by the Scientific Committee, will act on behalf of all members for regular decisions during the period between Scientific Committee meetings. During this period, the Scientific Committee need not be consulted unless a decision would affect the bylaws or contravene a decision previously made by the Scientific Committee. The Executive Board consisted of regular members (only one member permitted from one country) elected from the Scientific Committee. The maximum number of members of the Executive Board is nine. The Chairman of Executive Board represents the APBMT.

4.6 Officers of the Executive Board

1 Scientific Committee elects a) one Chairman of Executive Board, b) one Vice Chairman of Executive Board, c) several other Members of Executive Board including one Secretariat / Treasurer. The members of the Executive Board is elected by the business meeting, and serves for two years and may be re-elected for another term of two years.

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.

3 The Vice Chairman supports the Chairman and will perform the duties of the Chairman in the absence.

4.7 Secretariat/Treasurer

Secretariat / Treasurer shall oversee the maintenance of a permanent record of APBMT. The Secretariat / Treasurer shall have oversight of the budget of APBMT. 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 5

Committees and Working Groups

5.1 Committees

The APBMT will have the following Standing Committees to help with its work.

1. Membership Committee
2. Registry Committee
3. Program Committee

Each of these committees will have a specific term of reference.

5.2 Working Groups

The aim of Working Groups is to enhance research in focused areas. The Executive Board and Scientific Committee of APBMT determine the formation of Working Groups as 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). 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 in consultation with the Executive Board. 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 and the Executive Board. The chairperson should adhere to the Working Group responsibilities, which are specified separately from the bylaws.

ARTICLE 6

Meetings

6.1 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 section below).

6.2. 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.

6.3 Board Meeting

The Executive Board of the APBMT shall meet in person at the annual meeting. It is presumed that all members will attend this meeting unless there are unavoidable personal circumstances. In addition, the board will meet via conference calls every 4-8 weeks, as needed. All members are expected to attend all scheduled board meetings.

ARTICLE 7

7.1 APBMT Registry

A major activity of the APBMT will be to guide the development of national registries in each country. This data will then be collected into the combined APBMT registry in formats compatible with other international registries. Both activities and outcome data will be collected every year. The details of the registry are in Annexure 4.

7.2 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 is confidential, however, it can be quoted after written approval from APBMT and accompanied by proper acknowledgement.

7.3 Rules on the use of the Registry data

Data are restricted to publication in a scientific article and / or presentation at academic meetings. APBMT contributions must be appropriately acknowledged in all presentations and publications prior to the release of the data and analyses. Written Applications for these purposes are limited to Scientific Committee Members, Working Groups and the Data Center of APBMT for the time being. Written requests from other academic organizations or commercial companies will be assessed and if approved a cost recovery will be charged depending on the amount of work. Confidentiality of source information will be protected in accordance with the laws of individual centres and countries. An application form is attached as a separate sheet. The Registry Committee will evaluate all applications and approval made after consultation with the Executive Board.

ARTICLE 8

Finance

8.1 Membership Fees:

All the Regular Members are required to pay annual membership fees on an individual basis (see Annex). 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.

8.2 Statement of accounts of annual APBMT congress

An audited statement of accounts must be prepared by the organizing committee for each annual APBMT meeting within one year of its completion and submitted to the APBMT Headquarters and presented at the annual business meeting.

ARTICLE 9

Amendments

9.1 These Bylaws may be amended at any annual business meeting of the Scientific Committee 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 distributed to members of the Scientific Committee 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 October 1, 2009, second revision adopted on December 31, 2010, and revised in September 2015 and to be adopted by the Scientific Committee on October 31, 2015. On November 1, 2016, Annexure 6 was added after the Business Meeting in Singapore.

9.2 Annexures may be amended by the Executive Board, (with a minimum of two third majorities of the members of the Executive Board) and report to the Scientific Committee.

Annexures:

1. Committees - Terms of Reference to be determined.
2. Working Groups - Terms of Reference to be determined.
3. Annual Congress – Format of the meeting to be formulated
4. The APBMT Registry
5. Financial Issues:
6. The Scientific Committee members: In addition to the criteria to be a Scientific Committee Member described in APBMT Bylaw (4.4 Scientific Committee), the candidate must have served as a regular member for the past three years with the consecutive payment of annual membership fee.

No term limits are set for Scientific Committee Members. However, the members are required to participate in at least 2 out of 4 most recent APBMT Annual Congress, and consecutively pay annual membership fee in order to maintain their membership. In addition, their willingness of serving as Scientific Committee Members is to confirm every two years.

No limits are set for the maximum number of Scientific Committee members in each country/region participating APBMT.

Organizational tree of APBMT

Chairman

Annual Congress President

Scientific Committee
Executive Board

Nuclear Accident Management (NAM) Committee

Treasury Committee

Scientific Program Committee

Membership Committee

Registry Committee

Working Group

Aplastic anemia

AML

CML

Congenital marrow failure

Thalassemia

HLA

Late effect

Cord Blood Transplantation

Nutrition

Donor Safety

Principal member list (Dec.2017)

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)

*Scientific Committee Members (* executive board member)*

Akatsuka, Yoshiki (Japan) Alimoghaddam, Kamran (Iran) Altangerel, Otgonbat (Mongolia)
Apte, Shashikant (India) Batsukh, Khishigjargal (Mongolia) Baylon, Honorata G (Philippines)
Biju, George (India) Chandy, Mammen (India) Chen, Po-Min (Taiwan)
Chen, Yao-Chang (Taiwan) Chiou, Tzeon-Jye (Taiwan) Dong Ying, Gao (China)
Gyi, Aye Aye (Myanmar) Haipeng, Lin (Malaysia) Hamidieh, Amir Ali (Iran) *
Harada, Mine (Japan) Hariman, Herman (Indonesia) Hong, Jun Ling (China)
Huang, He (China) * Huang, Xiao-Jun (China) Hwang, Tai-ju (Korea)
Hwang, William YK (Singapore) * Issaragrisil, Surapol (Thailand) Jootar, Saengsuree (Thailand)
Khan, Mohiuddin (Bangladesh) Khattry, Navin (India) Kim, Chun Choo (Korea)
Kim, Dong-Wook (Korea) Kim, Hack-Ki (Korea) 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) Ma, David D (Australia/New Zealand) *
Miyamura, Koichi (Japan) Nguyen, Tan Binh (Vietnam) * Okamoto, Shinichiro (Japan) *
Ostadali Dehaghi, Mohammadreza (Iran) Ouyang, Jian (China) Rowlings, Philip (Australia/New Zealand)
Shamsi, Tahir Sultan (Pakistan) Shin, Hee Young (Korea) Srivastava, Alok (India) *
Tang, Jih-Luh (Taiwan) Taniguchi, Shuichi (Japan) Teh, Alan (Malaysia)
Teshima, Takanori (Japan) Tran, Van Binh (Vietnam) Tzeng, Cheng-Hwai (Taiwan)
Ungkanont, Artit (Thailand) Vikram, Mathews (India) Viswabandya, Auro (India)
Wang, Jianmin (China) Wu, Tong (China) Zhang, Mei (China)

Honorary Members

Atkinson, Kerry (Australia) Gratwohl, Alois (EBMT) Carter, John (New Zealand)
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, Patric (Singapore)
Cao, Lu Xian (China) Masaoka, Tohru (Japan) Ghavamzadeh, Ardeshir (Iran)
Kodera, Yoshihisa (Japan) Kim, Dong Jip (Korea) Lu, Dao-Pei (China)
Saikia, Tapan K (India)

Annual Meetings of APBMT

Previous Meetings

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
20 th	2015	Okinawa	Okamoto, Shinichiro
21 th	2016	Singapore	Hwang, William YK / Joo, Chng Wee / Ho, Aloysius

Future Meetings

- The 22nd meeting
October 28-30, 2017, Teheran, Iran
President: Ghavamzadeh, Ardeshir
- The 23rd meeting
It will be held in Taiwan.

The number of attendees for each annual meeting from 2006 to 2016

2006(JAPAN)		2007(CHINA)※		2008(TAIWAN)		2009(KOREA)		2010(THAILAND)		2011(AUSTRALIA/ NEW ZEALAND) ※※		2012(INDIA)		2013(VIETNAM)		2014(CHINA)		2015(JAPAN)		2016(SINGAPORE)		
Japan	97	China	317	Taiwan	349	Korea	292	Thailand	280	Australia	637	India	118	Vietnam	375	China	646	Japan	159	Singapore	234	
Korea	30	Korea	47	Korea	46	China	65	China	100	China	178	China	66	China	82	Japan	31	China	186	China	116	
China	30	Japan	36	Japan	24	Taiwan	34	Taiwan	63	New Zealand	84	Japan	19	Korea	41	Taiwan	24	Taiwan	51	Japan	62	
Taiwan	20	Taiwan	25	Malaysia	6	Japan	33	Korea	52	Korea	57	Korea	15	Japan	32	Korea	16	Korea	41	Korea	44	
Hong Kong	5	Thailand	17	Thailand	5	Thailand	19	Japan	25	Japan	38	Vietnam	12	Taiwan	17	United States	11	Singapore	23	Taiwan	28	
USA	4	Singapore	15	Australia	5	Australia	7	Singapore	19	Taiwan	16	Australia	11	Thailand	13	India	9	Hong Kong	17	India	25	
Iran	4	India	12	Pakistan	3	Vietnam	5	Malaysia	17	Malaysia	14	Germany	8	Hong Kong	7	Singapore	9	Vietnam	16	USA	22	
Malaysia	3	Malaysia	12	Hong Kong	3	USA	4	Hong Kong	13	Singapore	14	Taiwan	7	Belgium	6	Australia	7	India	11	Thailand	21	
Pakistan	3	Other Country	12	Singapore	3	Germany	3	Vietnam	13	Thailand	12	Iran	6	Singapore	6	Mongolia	7	Thailand	11	Hong Kong	19	
Thailand	2	USA	12	USA	2	Singapore	2	Australia	9	Vietnam	10	USA	6	France	5	UK	5	Indonesia	9	Malaysia	19	
UK	2	Iran	6	Saudi Arabia	2	France	1	Iran	8	Philippines	9	Singapore	4	India	5	Hong Kong	4	USA	7	Bangladesh	15	
Vietnam	2	Indonesia	5	Philippines	2	Hong Kong	1	Italy	6	India	6	Philippines	3	Australia	4	Philippines	4	Malaysia	6	Vietnam	15	
India	2	Australia	4	India	1	Indonesia	1	Germany	4	Hong Kong	5	Bangladesh	2	Iran	4	Vietnam	4	Australia	5	Australia	13	
Australia	1	Germany	4	Vietnam	1	Iran	1	Indonesia	4	Myanmar	4	Belgium	2	United States	4	France	3	Philippines	5	Iran	11	
Germany	1	Pakistan	3	Romania	1	Malaysia	1	USA	4	Switzerland	4	France	2	Germany	3	Iran	3	UK	4	Philippines	10	
Switzerland	1	Romania	3	France	1	Philippines	1	India	3	Bangladesh	3	Hong Kong	2	Mongolia	3	Thailand	3	Germany	2	Germany	9	
Total	207	Canada	2	Total	454	Switzerland	1	Pakistan	3	Pakistan	3	Mongolia	2	Spain	3	Germany	2	Iran	2	Sri Lanka	6	
%		Czech Republic	2	%		UK	1	France	2	Fiji	2	Canada	1	Malaysia	2	Myanmar	2	Sri Lanka	2	UK	6	
Domestic	47	Saudi Arabia	2	Domestic	77	Total	472	Myanmar	2	Samoa	2	Italy	1	Philippines	2	Pakistan	2	Bangladesh	1	France	4	
Foreign	53	UK	2	Foreign	23	%		Canada	1	UAE	2	Myanmar	1	Indonesia	1	Bangladesh	1	Cambodia	1	Mongolia	4	
		Denmark	1			Domestic	62	Hungary	1	Brunei	1	Nepal	1	Ireland	1	Indonesia	1	Canada	1	Indonesia	3	
		Myanmar	1			Foreign	38	Israel	1	Cook Islands	1	Sweden	1	Myanmar	1	Lebanon	1	France	1	Ireland	3	
		Nigeria	1					Philippines	1	Indonesia	1	UK	1	Netherlands	1	Malaysia	1	Italy	1	Italy	3	
		Philippines	1					Sweden	1	Iran	1	Missing	3	Sweden	1	South Africa	1	Mongolia	1	Cambodia	2	
		unknown	1					Turkey	1	Israel	1	Total	294	UK	1	Spain	1	Myanmar	1	Myanmar	2	
		Total	543					Total	633	Kiribati	1	%		Total	736	Sri Lanka	1	Pakistan	1	Qatar	2	
		%						%		Micronesia	1			%		Total	799	Switzerland	1	Belgium	1	
		Domestic	58					Domestic	44	Papua New Guinea	1	Domestic	40			%		Missing	1	Canada	1	
		Foreign	42					Foreign	56	Slovak Republic	1	Foreign	60					Total	567	Nepal	1	
										Slovakia	1							%		New Zealand	1	
										Solomon Islands	1								Domestic	28	Spain	1
										Sri Lanka	1								Foreign	72	Switzerland	1
										Turkey	1									Total	704	
										Tuvalu	1										%	
										Vanuatu	1										Domestic	33
										Total	1115										Foreign	67
										%												
										Domestic	65											
										Foreign	35											

※APBMT 2007 with ISH-APD2007

※※APBMT 2011 with HAA-ISHPD 2011 and ISCTA

Activity Survey

Introduction of the 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 transplantations sorted by the donors' sources and diseases.

The following figure shows how the data is collected.

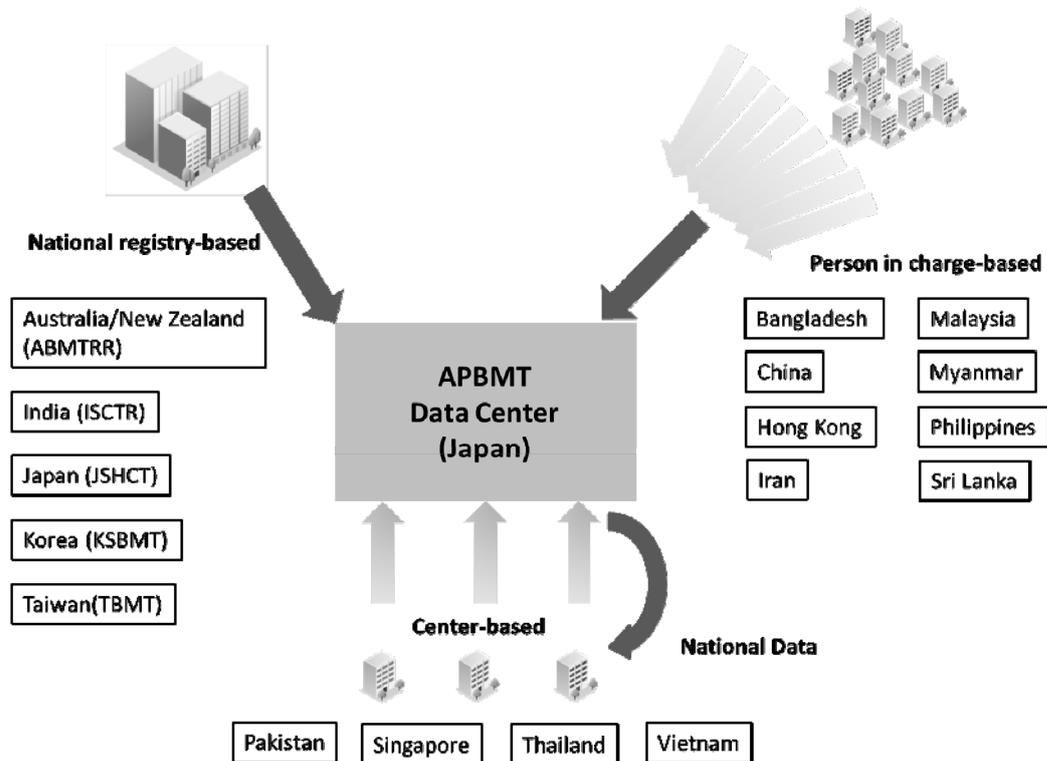


Figure: Data collection

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

As shown in the Figure above, 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 Bangladesh, China, Hong Kong, Iran, Malaysia, Myanmar, the Philippines, and Sri Lanka, 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 10th APBMT Activity Survey is to update the HSCT activity data for APBMT countries/regions — transplantations **performed by the end of 2014**. Data Center received data from eighteen out of twenty-one countries/regions participating in this survey by December 31, 2016.

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 — transplantations 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 established between APBMT and CIBMTR and between APBMT and some centers that submitted Outcome Data to CIBMTR.

To promote and accelerate the data collection, APBMT decided to establish the Registry Committee in October 2014. The Committee officially started operations in October 2015, and since then, it has held web conferences bimonthly. The first accomplishment of this committee was formulating three documents regarding data collection and usage: The Mission Statement, the Letter of Commitment and the Protocol. The Protocol was approved by the Ethical Committee of Aichi Medical University on October 24th, 2016.

Protocol

Asia-Pacific Blood and Marrow Transplantation Group Registry

Version Number: 1.0

October 2016

1. Background
2. Purpose
3. Subjects
4. Method
5. Explanation, consent and anonymity
6. Data management
7. Ethical policy
8. Publication of results
9. Use of data and international cooperation
10. Research organization
11. Appendices
 - 1) APBMT Outcome Registry Committee Rules for Operation
 - 2) Letter of Commitment
 - 3) Survey forms: Activity Survey, Outcome Registry

Asia-Pacific Blood and Marrow Transplantation Data Center
Aichi Medical University School of Medicine
Department of Promotion for Blood and Marrow Transplantation
1-1, Yazakokarimata, Nagakute, Aichi, Japan 480-1195

1. Background

The survey and reporting on hematopoietic cell transplantation and related therapy is essential for the proper development of hematopoietic cell transplantation therapy in the Asia Pacific region. The purpose of the Activity Survey and Outcome Registry carried out by the Asia-Pacific Blood and Marrow Transplantation Group (APBMT) is to enable a full understanding of the number of transplants being carried out, as well as their outcomes, and to generate a variety of useful information for the analysis of individual factors, such as geographic distribution, transplant types, illnesses and pathology, etc. Information on the number of transplants conducted in the region, as well as a country by country count, is reported as reference information to the World Health Organization (WHO) via the Worldwide Network for Blood and Marrow Transplantation (WBMT). Information by transplantation type and information related to prognoses are used to understand the current situation in this very geographically and ethnically diverse region, and also forms part of the foundation information that will underpin future development. This survey will be able to provide information that is extremely useful to patients, physicians and other medical professionals. The Data Center is sited at Department of Promotion for Blood and Marrow Transplantation, Aichi Medical University School of Medicine in Japan. The survey was begun as the 1st Activity Survey conducted by APBMT in 2007, and has been conducted, and its report published, every year since then. Further, the Outcome Registry was started in 2010, compiling the transplantation information since 2009. With the formal launch of the APBMT Outcome Registry Committee in November, 2015, the rules regarding the collection and management of data have been strengthened, as well as the cooperation of different countries in this survey.

2. Purpose

- To collect baseline and outcome data relating to all bone marrow, peripheral blood, cord blood hematopoietic stem cell transplants and therapies related to hematopoietic stem cell transplantation performed throughout the Asia Pacific area.
- To provide data to clinicians and researchers for studies involving specific subsets of patients, or to determine the feasibility of such studies.
- To provide data to clinicians to inform patient care.
- To provide data to health administrators for resource planning and quality assurance purposes.
- To participate in international data collections by contributing summary and outcome data to enhance the global knowledge base for these types of transplants.

3. Subjects

The survey has as its target all medical institutions (hereafter, “transplantation facilities”) involved in hematopoietic cell transplantation and related therapy in Asia-Pacific region. The report subjects will

be all kinds of hematopoietic stem cell transplantation, including autologous transplantation and allogeneic transplantation (transplantation between blood relations, transplantation between non-blood relations, and transplantation of umbilical cord blood) and the related therapies. The data to be surveyed are transplant related clinical data of the patients and donors, and data related to prognoses. There will be no collection of specimens.

4. Methods

1) The Activity Survey comprises survey items on the numbers of transplants conducted from two years previous, by donor and transplantation source. The Data Center sends the APBMT Activity Survey Form every year to the Scientific Committee members of each country and region, and they then notify the transplantation facilities in their country or region. The transplantation facility then enters one year's actual performance data from the previous year into the form and submits the form to the data center within the prescribed time limit. Further, it is recommended that the data are submitted on a country basis.

2) In the Outcome Registry, the transplantation facilities register information about all transplants that they have conducted into the Least Minimum Dataset (LMD) survey item, as stipulated by APBMT. There are three types of questionnaire, i) day100_LMD sheet, ii) Disease_LMD sheet and iii) follow_LMD sheet. These forms can be downloaded from the APBMT website. For the first report, forms i) and ii) should be registered, then updated as form iii) every year subsequent to that. The Outcome Registry data are either mailed out or sent by email, depending on the situation of each country or region and transplantation facility. If the center reports its data to other registries, APBMT and a registry could agree on the data transmission or data sharing .

5. Explanation, consent and anonymity

The survey is conducted in an anonymous format in which data can only be linked back to individual patient information within the facility itself. Each transplantation facility needs to make sure that the details of the project have been fully explained to the patient before registering. Information reported to the Data Center will not contain any information that could identify individual patients, such as patient names or medical chart numbers, etc. However, sex, dates of birth, dates of transplantation and transplantation facility numbers will be reported along with the clinical data. The additional data from recipients and donors may be collected when needed for a specific study. In this case, data should be collected from their medical records, not from direct contact with recipients or donors.

6. Data management

The APBMT Data Center manages all information, including anonymous patient clinical information (with personal information removed) and names and other personal information of contact physicians

at cooperating facilities. The information is managed according to the APBMT Data Center's security policy.

7. Ethical policy

- 1) International participants in APBMT must follow their own national regulations and provide assurance to APBMT that national regulations are being followed.
- 2) The central ethical review of this protocol was approved by the Aichi Medical University ethics committee on October 24.
- 3) Where the use is intended for the purpose of evaluate, the decision will undergo an ethical review in the facility to which the researcher belongs.

8. Publication of results

The summary results will be described in outline on the APBMT website, and will be contained in the Annual Report.

9. Use of data and international cooperation

Use of data is judged by the APBMT Outcome Registry Committee, which exists within APBMT in order to manage data, and judges each data request based on its aims and scope of use. Data regarding the number of operations performed are reported to WHO every year, via WBMT, in cooperation with the effort to compile transplantation number data on a worldwide basis.

10. Research organization

The APBMT Outcome Registry is overseen by the APBMT Outcome Registry Committee and Data Center.

Chair: Yoshiko Atsuta

Vice Chair: Anthony Dodds, Aloysius Ho

Data Center: Minako Iida, Yukari Nakao

APBMT Registry Committee

Detailed Rules for the Operation of the Committee

1. General Rules

1. The following rules shall apply to the collection, management and use of data related to hematopoietic stem cell transplantations conducted in the Asia Pacific region by the Registry Committee and Data Center established within the Asia-Pacific Blood and Marrow Transplantation Group (APBMT).
2. The kinds of data gathered by the Registry Committee and Data Center are as follows.
 - 1) Activity Survey
 - 2) Outcome Registry
3. The operation of the Registry Committee is stipulated in the APBMT regulations. Further, the rules that define the procedures relating to the management and use of Registry data, as decided by the Committee, are the “APBMT Registry Committee Detailed Rules for the Operation of the Committee”.
4. The composition of the Registry Committee is as follows.
 - 1) Committee members recommended by the Executive Board or Scientific Committee (one person for each member country)
 - 2) Effective data managers appointed by the committee members of 1), above, to compile the data of each country
 - 3) APBMT Data Center staff
5. The member of the Registry Committee serves for two years and may be re-elected for another term of two years. The Chairman of the Registry Committee is elected from Registry Committee members and serves for two years. The Chairman can be re-elected for another term of two years, however, a third term is prohibited.
6. The members of the Registry Committee have the obligation to report transplantation related data from their own countries.

2. Data Registration

7. The most important element of the APBMT Registry is the data registration. Members of the Registry Committee have a duty to promote the Activity Survey and Outcome Registry registration.
8. Data registration is performed through the contact person for each country. The contact person is appointed by the committee members of the Registry Committee in accordance with the situation in each country. The designated contact person enters the data pertaining to hematopoietic cell transplantations and related therapy in their respective country into the Activity Survey and Outcome Registry in the prescribed format (paper, electric or data transmission) and sends it to the Data Center.
9. Activity Survey: A prescribed form is distributed from the Data Center. Annual data from two years prior is reported. The data contains the number of transplants, entered by transplantation type, donor source and disease.
10. Outcome Registry: The data for each patient are submitted by using three types of forms, describing the first 100 days after transplantation, information on the patient's disease, and follow-up information. There are three methods of registration as follows, depending on the situation of each country or institution.
 - 1) Paper: A paper form can be downloaded from the APBMT website and sent directly to the Data Center in PDF format or printed out and posted.
 - 2) Electirc: In accordance with the dictionary designated by the Data Center, transplantation information can be entered directly into Excel and emailed.
 - 3) Data transmission: An institution sending transplantation reports to CIBMTR signs a data transmission agreement, thereby allowing patient reports to be transmitted directly from CIBMTR to the Data Center.

3. Use of Data

11. Applications for data request
 - 1) Applications to use registry data must come from APBMT members that fulfil the following conditions.
 - Belonging to an institution, country or region that has completed registry of the Activity Survey and Outcome Registry.
 - APBMT membership for the previous year paid.
 - Other than transplant physicians, has been an APBMT member for more than one year.
 - Data use application from WG also must fulfil the conditions described above.

- 2) Persons wishing to use registry data must submit the Application Form for Using the Registry Data to the Data Center. The form must contain details of the person responsible for the data use, the purpose of the data use, the required data content, research details, information on conflicts of interest and ethical issues.
 - 3) Applications for use of data will be examined upon receipt by the Registry Committee members. If the application is approved, the applicant will be asked to sign the Letter of Commitment relating to data use, and to observe its provisions fully.
 - 4) Applicants are required, in principle, to publish their results within three years of the approval of use of data. And the Registry Committee can rescind the permission granted to this application if the applicant makes neither presentation nor publication within three years.
 - 5) In the event that the leading applicant in an application to use data has made successive applications, in principle, no new application can be made until the research that was the purpose of a previously approved application is completed, or until a paper has been submitted.
12. As regards details that appear the Annual Report, these may be quoted freely, regardless of whether the person is a full member of APBMT or not. In such cases, the Annual Report must be acknowledged as the source of the quote.

4. Reporting of Results of Analysis

13. The progress of the research, regardless of whether there is to be any formal announcement of its results, is to be reported every year to the Registry Committee. Prior to submission of a paper or academic presentation, application for co-author selection shall be submitted to the Registry Committee.

5. Other

14. The data collected in the Activity Survey and Outcome Registry are anonymous, but they should be handled with sufficient care in order to prevent accidental leakage, etc.
15. When data provided by the APBMT Registry are to be used, data use application must be made not only from an academic standpoint, but also based on ethical and moral considerations. Also, sufficient care must be given to the handling of data from the perspective of compliance with regard to conflict of interest.

16. In the event that any new intellectual property rights, commercial rights, or copyrights are generated by research and results based on used data, the parties responsible shall negotiate with APBMT at that time as regards the scope of said rights and the sharing of responsibility.

17. Any revision or abolition of this Rules for the Operation will require a decision by the Registry Committee.

Supplementary provision: This Rules for the Operation will come into effect from May 2, 2017.

The Letter of Commitment

To the Chairman of APBMT Registry Committee,

I promise to uphold the following commitments.

1. Registry data are not to be used for any purpose other than those approved by APBMT Registry Committee.
2. Data are not to be used for commercial purposes.
3. Data are to be managed under the responsibility of the applicant, and are not to be made available for viewing by, or transferred to, a third party. Viewing by co-researchers, co-authors and working group members is to be restricted to an absolute minimum, and such persons are to observe these provisions.
4. The content of data provided by the Data Center are not to be altered without permission.
5. The applicant is to report to the Data Center every year on the progress of the research.
6. Before publishing the results of any research, the title and abstracts must be submitted to the Data Center for review. As for co-author(s), the application for co-author selection shall be submitted to the Registry Committee prior to submission of a paper or academic presentation.
7. When publishing the results of the research, it is to be made clear that APBMT Registry data were used.
8. The applicant is to inform the Data Center without delay in the event of any of the following,
 - (1) discontinuation of use of the data,
 - (2) changes to the details given in the application to use data.
9. Those applying to use data shall make an effort to encourage data registration, at their own responsibility.
10. Any infringement of these provisions will result in the cancellation of the data use application approval. In that event, the applicant shall promptly return any data to the Data Center, and destroy all copied or processed data.

I certify that I have read this document and commit to fulfilling the responsibilities described herein.

Date

Institute

Name

Registry Committee member list

	Name	Country
Chairperson	Yoshiko Atsuta	Japan
Deputy Chairperson	Anthony Dodds	Australia/New Zealand
	Aloysius Ho	Singapore
Members*	Tang Yamin	China
	Alok Srivastava	India
	Amir Hamidieh	Iran
	Shinichiro Okamoto	Japan
	Tatsuo Ichinohe	Japan
	Hyoung Jin Kang	Korea
	Jih-Luh Tang	Taiwan
	Hui-Fen Chiang	Taiwan
	Po-Nan Wang	Taiwan
	Ming Yao	Taiwan
	Lallindra Gooneratne	Sri Lanka
	Chang Kian Meng	Malaysia
	Albert Lie	Hong Kong
	Mafruha Akter	Bangladesh
	Huynh Van Man	Vietnam
	Aye Aye Gyi	Myanmar
	Pheng Bora	Cambodia
	Tasneem Farzana	Pakistan
	Herman Hariman	Indonesia
	Artit Ungkanont	Thailand
Batsukh Khishigjargal	Mongolia	
Honorata Baylon	Philippines	
Data Center	Minako Iida	Japan
	Yukari Nakao	Japan

*random order

APBMT2016 Registry Committee Meeting Minutes

Time: 12:30 to 14:00, Friday, October 28, 2016

Venue: Room L2S1, The Academia, Singapore General Hospital Campus

Attendance:

Yoshiko Atsuta, Anthony Dodds, Aloysius Ho, Shinichiro Okamoto, Hyoung Jin Kang, Yamin Tan, Artit Ungkanont, Mafruha Akter, Lallindra Gooneratne, Huynh Van Man, Nguyen Hanh Thu, Mohiuddin Ahmed Khan, Sharifah Shahnaz Syed Abd Kadir

Data Center: Minako Iida, Yukari Nakao

1. Approval / amendment of agenda

All approved the agenda of this meeting.

2. Approval/modification of the minutes of the Oct.20 web conference

All approved the minutes.

3. Report of the current status of the APBMT data collection 2016

Nakao briefly showed the results of the APBMT Activity Survey 2014. In 2014, Bangladesh, Myanmar and Sri Lanka submitted data for the first time and the total number of HSCTs reached over 16,000. Detailed analyses will be put on the APBMT website and in the annual report.

4. Summary of the accomplishments of this past year

Atsuta summarized the accomplishments of the committee from November 2015 to October 2016.

- 1) We could establish the organization of the committee and have representatives from all countries / regions (as of the end of the Singapore meeting). We had 5 bimonthly web conferences.
- 2) The APBMT Registry protocol was approved by the Ethical Committee of Aichi Medical University on October 24th, 2016.
- 3) We started to collect the Activity Survey data using two types of sheets: the conventional APBMT style and the new WBMT one. Thanks to the efforts of all collaborators, two types of data were collected without any trouble.

We all agreed to have the bimonthly web conference in the next year.

5. The current situation of the Outcome Data collection and “How do we collect the Outcome Data from all countries / regions efficiently?”

Before this meeting, the Data Center sent a simple questionnaire to all countries / regions asking 1) whether there are any official HSCT databases and a national registry, 2) if they don't have any, are there any plans to build a database in the future, and 3) what are the difficulties for establishing the HSCT database and registry. Each representative reported the current status of the data collection and registry system in his / her country / region based on these questions.

Bangladesh: They would like to develop the national HSCT database and they are going to start. The Protocol will help them to build the system.

Korea: KSBMT is now remodeling their total system and will finish it this year. After getting funding for data collection and getting IRB from participating centers, they will be able to send outcome data to APBMT.

Vietnam: Two main centers in Ho Chi Minh City and Hanoi will cooperate with each other to collect data, however, as the number of doctors is substantially fewer than patients, it may take one to two years to submit it.

Japan: JSHCT submitted their outcome data annually by using the translation system from the TRUMP in Japanese to the LMD in English.

Australia: The official approval of the Protocol will contribute to the progress of ethical issues regarding the outcome data submission from ABMTRR. ABMTRR has just started to establish an electronic data submission system.

China: As it is such a big country, they don't have the national database, only by region. They will make an effort and hope to have a national database in the future.

Malaysia: They have the national registry and the web-based database, however, because of the computerized system, they can't collect full outcome data. In addition, lack of manpower makes things difficult.

Singapore: They don't have the national database, so far. However, main centers independently submit their outcome data to CIBMTR and EBMT, and it is transmitted to APBMT annually. As a matter of fact, some private hospitals perform HSCTs and they don't submit their activity or outcome data to APBMT.

Sri Lanka: They have just started HSCT in 2014, so they haven't started an official plan to build a registry and database yet. The Protocol will be of great help to get official approval for these issues. They also need database manuals and the LMD will help them.

Thailand: They would like to have their national registry and database within 2 years. They are making efforts to bring up transplantation nurse coordinators who will help data collection.

Hong Kong: They are now making the electric data collection system and will start in 2017. (Comments from the last web conference by Dr. Lie.)

Pakistan: Nobody could attend this meeting. They replied to the questionnaire by email saying that they have no official database as well as no national registry so far.

Indonesia: Nobody could attend this meeting. They replied to the questionnaire by email saying that they have a very difficult situation.

Taiwan: Nobody could attend this meeting, however, they have the TBMT and in past years, they submitted complete outcome data using the Excel form.

Cambodia / India / Iran / Mongolia / Myanmar: Nobody could attend this meeting.

Iida explained the outcome data collection system briefly: 1) paper forms (day 100, disease and follow-up sheet), 2) Excel forms with the dictionary, and 3) the Data Transmission Agreement with CIBMTR. As for the Data Transmission Agreement with EBMT, Atsuta explained that the number of centers which submitted outcome data to EBMT is so small (and some of them submitted it to CIBMTR concurrently) that it is not completed. However, if a lot of more centers submit data to EBMT, it will be more convenient for us

to develop an agreement on data transmission. To prevent duplication, if a certain country / region submits its national data to APBMT, the Data Center won't get data from the centers which belong to the country / region from CIBMTR.

6. Preparation for the Business Meeting on Oct. 29

Atsuta announced that she will report this committee's activities in the business meeting based on today's discussion.

**Worldwide Network for
Blood and Marrow
Transplantation
(WBMT)**



General Introduction

The Worldwide Network for Blood and Marrow Transplantation (WBMT) was formally created in 2007 by leaders from major hematopoietic stem cell transplantation (HSCT) groups and donor registries worldwide culminating in consensus on Bylaws and an organizational structure as early as 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 HSCT, 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 24, all with substantial interest in HSCT. The WBMT was incorporated as a non-profit organization for educational, scientific, and philanthropic purposes under the laws of Switzerland with headquarters in Bern. There is no fee for Member Societies; its funding support is solicited from relevant industry. Description of the earliest years of efforts can be found in previous Progress Reports available at www.wbmt.org as they describe how those proactive clinicians and researchers shaped the WBMT into a recognizable organization, its structure and charter, its notable achievements, and its future aims and goals. (From the 2015 WBMT Annual Report)

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. Since 2014, the previous APBMT chairman, Dr. Yoshihisa Kodera has spent the last two years as a WBMT president. After that, he became the immediate past President and Dr. Jeff Szer took over Dr. Kodera’s former position as the WBMT president. APBMT has played a more important role in the development of WBMT, such as the WBMT survey and seven Standing Committees.

WBMT officers

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**Worldwide Network for Blood and Marrow Transplantation
(WBMT)**

**Valencia, Spain
Feria Valencia Convention Center, Room 2 E
April 4, 2016
15:45-18:45**

(14 of 24 Member Societies represented at this in-person meeting)

ELECTED OFFICERS		
Present	Position	Country
Dennis Confer	(Immediate past-)Treasurer	USA
Yoshihisa Kodera	Immediate past-President	Japan
Jeff Szer	President	Australia
Daniel Weisdorf	Vice-President	USA
Hildegard Greinix	Secretary	Austria
Not Present	Position	Country
Adriana Seber	Treasurer	Brazil

BOARD MEMBER SOCIETY REPRESENTATIVES* – July 2015			
MEMBER SOCIETY		POSITION	PRESENT
<i>XXXXX = Member Society not represented</i>			
AABB			
David	McKenna	Primary	
	PENDING	Alternate	
ABMTRR			
Tony	Dodds	Primary	
Phil	Rowlings	Alternate	present
AFBMT			
Nicolas	Novitzky	Primary	present
Bazauye	Nosa	Alternate	present
APBMT			
Shinichiro	Okamoto	Primary	present
Alok	Srivastava	Alternate	
ASBMT			
A. John	Barrett	Primary	
Chris	Bredeson	Alternate	
ASFA			
Joseph	Schwartz	Primary	
Nancy	Dunbar	Alternate	
ASHI			
Marcel	Fernandez-Vina	Primary	
E. Victoria	Turner	Alternate	
BMDW			
Henny	Braund	Primary	present
Claudia	Rutt	Alternate	
CIBMTR			
Marcelo	Pasquini	Primary	present
Mary	Horowitz	Alternate	present
EBMT			
Nicolas	Kroger	Primary	
Mohamed	Mohty	Alternate	
EFI			
Steve	Marsh	Primary	
Mats	Bengtsson	Alternate	
ELN			
Rüdiger	Hehlmann	Primary	
Dietger	Niederwieser	Alternate	present

BOARD MEMBER SOCIETY REPRESENTATIVES* – July 2015			
MEMBER SOCIETY		POSITION	PRESENT
<i>XXXXX = Member Society not represented</i>			
EMBMT			
Mahmoud	Aljurf	Primary	present
Amirali	Hamidieh	Alternate	
EMDIS			
Carlheinz	Müller	Primary	
Evelyne	Marry	Alternate	
ESH			
Didi	Jasmin	Primary	
Eliane	Gluckman	Alternate	present
Eurocord			
Eliane	Gluckman	Primary	
Vanderson	Rocha	Alternate	present
FACT			
Carolyn	Keever-Taylor	Primary	
Phyllis	Warkentin	Alternate	
ICCBBA			
Paul	Ashford	Primary	
Pat	Distler	Alternate	present
ISBT			
Mickey	Koh	Primary	present
Peter	Horn	Alternate	
ISCT			
Mary	Laughlin	Primary	
Massimo	Dominici	Alternate	
JACIE			
Jane	Apperley	Primary	present
John	Snowden	Alternate	
LABMT			
Gregorio	Jaimovich	Primary	present
Belinda	Pinto Simoes	Alternate	present
Netcord			
Etienne	Baudoux	Primary	
Elizabeth	Shpall	Alternate	
WMDA			
Michael	Boo	Primary	present
Enric	Carreras	Alternate	

STANDING COMMITTEE CHAIRS PRESENT (who are not Member Society Representatives)		
Jörg Halter	Donor Issues	Switzerland
Kathy Loper	AHCTA	USA
David Ma	Nuclear Accident Management	Australia
Ray Powles	Nuclear Accident Management	EU
GUESTS PRESENT		
Yoshiko Atsuta	APBMT	Japan
Helen Baldomero	EBMT (Global Survey)	Switzerland
Reggie Belkhedim	EMBMT	Saudi Arabia
Willem Bujan Boza	LABMT	Costa Rica
Hassan El-Solh	EMBMT	Saudi Arabia
Lydia Foeken	WMDA	Netherlands
Alois Gratwohl	University of Basel	Switzerland
Fazal Hussain	EMBMT	Saudi Arabia
Minako Iida	APBMT	Japan
Tokiko Nagamura-Inoue	APBMT	Japan
Ayami Yoshimi	APBMT	Germany

Agenda Item	Discussion	Consensus	Action Item
1) Welcome/Introduction	Jeff Szer opened by welcoming all in attendance.	Seventeen (14) of twenty-four (24) Member Societies were represented on this call.	• None
2) Minutes – December 1, 2015	<ul style="list-style-type: none"> Action items were reviewed. All were completed except one which remains on Paula's task list. 	<ul style="list-style-type: none"> Minutes approved as moved by Marcelo Pasquini and seconded by Mickey Koh. 	<ul style="list-style-type: none"> Paula to pursue survey of Member Societies re: annual meetings to avoid date conflicts when planning future Workshops.

<p>3) Outgoing President's Address</p>	<ul style="list-style-type: none"> • Dr. Kodera reported that: <ul style="list-style-type: none"> ○ WHO "official relations" have been renewed for 3 years as indicated in a Feb 19 letter from WHO office. We continue to appreciate the support of our primary contact, Dr. Jose Nuñez. ○ The application for the Princess of Asturias award was submitted earlier than required. WBMT was nominated by the Duke of Saxony and the Ambassador from Spain. It is "looking positive" but we don't know when we'll be informed. ○ The group is reminded of the EBMT/WBMT Joint Session tomorrow with major topic of "Global Changes in Transplantation - haplo HCT". • Dr. Kodera read a gracious, personal message expressing sincere thanks for all support. He is pleased with the 3rd Workshop (in Cape Town) during his first year and noted new ventures in, and visits to, Myanmar, Vietnam, Indonesia and Mongolia during his 2nd year. This includes training exchanges. He states there is still much to be done though as he handed the telescope symbol to Jeff. • Jeff thanked Yoshi for his years of successful service 	<ul style="list-style-type: none"> • N/A 	<ul style="list-style-type: none"> • None
<p>4) Financial Report and Outgoing Treasurer Address</p>	<ul style="list-style-type: none"> • A detailed financial report was provided in advance – dating back to 2011 when the account was opened with 72,636.94 €. No information is available prior to then. • The new report format presents data in fiscal years April 1-March 31. • Each year of this new format also documents gratis Society and Institutional support. • Dennis reviewed a summary document for 2015 only. <ul style="list-style-type: none"> ○ Opening balance = 23,326.29€ ○ Revenue total (Corporate Memberships, MCI payment and Bank Interest)=31,701.43€ ○ Expenses total (teleconferences, personnel, miscellaneous, bank charges)=28,311€ ○ Closing balance = 26,716.39€ • Dennis also indicated his pleasure in serving his 3 term tenure as the organization has grown; he will communicate with Adriana in relinquishing his duties to her. An important task ahead is to continue solicitation of additional funding sources. The Princess of Asturias award, if granted, will be a temporary cushion only – WBMT needs more sustainable funding. • He leaves the books "in order" now that Dr. Kodera and Dietger's office worked so hard to prepare the new report format. • Dietger reminded that: <ul style="list-style-type: none"> ○ WBMT still owes money to CIBMTR for previous support. ○ There was an anonymous personal donation of \$30,000 USD to help fund the Salvador Workshop. ○ There was a recent (in new, current fiscal year) 40,000€ donation from JAZZ, Celgene and Viopharma. ○ Companies tell him they remain interested in supporting regularly scheduled Workshops. • Dennis reminded the group of his fondest memory; this was paying tribute to his dead brother and the trip to Hanoi permitting him to meet the people in the village where his brother's plane crashed in the 1960's. • Dennis also acknowledged the full retirement of Paula at year's end. 	<ul style="list-style-type: none"> • The financial report was accepted; there was no further discussion. 	<ul style="list-style-type: none"> • None

<p>5) WHA Side Event</p>	<ul style="list-style-type: none"> • Dietger reported that WHO “likes us” and invited us to present a 90 minute session during the May 2016 General Assembly. – it is our opportunity to “show off” to country politicians. • A Program is prepared (is not a scientific focus) with the help of several including Mary Horowitz; the application was submitted recently. There were 19 applications; 5 will be chosen. 	<ul style="list-style-type: none"> • We need to alert select politicians and invite as many as possible whom we wish to influence; should target country policy makers. • Alois reminded all that WHO does not provide money – that these opportunities are meaningful and we should take advantage. • We need a list of countries we feel are needed to hear our message. • We need 1 page “talking points” including our accomplishments. 	<ul style="list-style-type: none"> • If our proposed program is selected, we will notify our WBMT representatives so message gets to governments. • Dietger to obtain country list from WHO so can identify those most in need of invitation. • Who to prepare talking points???
<p>6) Riyadh Workshop</p>	<ul style="list-style-type: none"> • Mahmoud Aljurf reported details of current status: <ul style="list-style-type: none"> ○ January 15-17, 2017 when temperature will be warmer than original fall dates ○ Venue decision in progress (hotel vs KFSHRC) – depends on targeted number of participants (400-600) and cost. ○ 14 countries selected for regional report. ○ Speakers (50 internationals, ~15 local/regional) ○ Travel grants will be made available to less resourced countries. • Program Chairs are identified (Mahmoud, Hassan ElSolh, Hildegard Greinix and Dan Weisdorf) • Country reports to include accreditation status (or how plan to achieve); the new JACIE criteria will be covered • 2 days with no parallel sessions • Focus on special issues related to HCT in EMRO region: socioeconomic and logistics, infections, disease indications, donor availability. • 1 day Symposium – program to cover neoplastic and non-neoplastic diseases highly prevalent in region (e.g., hemoglobinopathies, marrow failure, immunodeficiency, etc) 		
<p>7) Annual Survey</p>	<ul style="list-style-type: none"> • Dietger asked Helen to address current issues re: survey; is a “big project”. • Helen reported that despite an electronic database, it is difficult to identify all centers accurately; actual numbers not always exact – she will maintain/clean up as best as possible; but best way is to assign very long, but unique, center numbers. • She reminds the group that Roland Braund designed the Transplant Activity Survey (TAS) database; it is the same database that LABMT will use for its new registry. • The real problem is that centers are not reporting to a registry. 		<ul style="list-style-type: none"> • Gregorio Jaimovich to provide proper list of reporting centers to Helen.
<p>8) Ethiopian Project Report</p>	<ul style="list-style-type: none"> • Mickey Koh reviewed the December 2015 WBMT team (including AfBMT rep) onsite visit and all steps over 1 year up to that point. They had WHO data in advance of their trip. <ul style="list-style-type: none"> ○ See “Brief and Scope” slide posted with these minutes once approved. 	<ul style="list-style-type: none"> • Next 6 months will determine if really serious about recommended changes to infrastructure. 	<ul style="list-style-type: none"> • WBMT to post full report on website.

	<ul style="list-style-type: none"> • A stable Ethiopian delegation is in place. Their blood transfusion program was part of the review as well as the proposed legislative document for regulation. • Complete report prepared and submitted in January (already shared with WBMT Exec Cmte). They project 2 year timeline; WBMT group feels at least 3 given infrastructure issues in particular. • There's a substantial number of malignant diseases (and are likely under-reported) • Findings include: <ul style="list-style-type: none"> ○ Black Lion Hospital is a tertiary institution with a medical school; 600 beds ○ Disease workload: haem malignancies vs haemoglobinopathies (both adult and peds) ○ Some chemo/antibiotics available (issues of age, fitness and cost) ○ Haematology and onc/radiotherapy: both med and nursing with decreased manpower ○ Infrastructure(both ward and hospital) in poor repair ○ Infection control and diagnostic capacity a challenge. ○ There is an ICU and lab service. • Positive aspects: <ul style="list-style-type: none"> ○ Strong government commitment ○ High medical team enthusiasm (including med school Dean) ○ Blood service improving ○ Existing renal transplant Programme ○ Other groups already engaged (PEPFAR, ICCBBA, WHO, Toronto based twinning programme), South African engagement for both blood and BMT programme. • Moving forward: <ul style="list-style-type: none"> ○ Committee firmly established ○ Fortnightly meetings planned ○ National coordinator identified ○ Continuing support from MOH ○ Continuing support from medical school ○ Training opportunities -?Toronto? ○ ?new premises at Black Lion ○ National Cell and Tissue Regulation in place • Open discussion led to question re: who is driving the plan – this is Director of Blood Services who is the Chief Medical Officer (and classmate of MOH). 	<ul style="list-style-type: none"> • This group feels if/when start HCT – should start with multiple myeloma. • Though enthusiastic, only 2 hematologists trained in Toronto – need more. • During first 6-12 months, should focus on training of both nurses and hematologists. 	
<p>9) Honorary Member Bylaws Changes</p>	<ul style="list-style-type: none"> • Hildegard reviewed the new text recommended by the Nominating Committee • Mary Horowitz clarified that the <u>election</u> Nominating Committee be the same as the “new” <u>Honorary Member</u> Nominating Committee and we simply call the one committee the “Nominating Committee”. • She also clarified that in the document provided, it is not clear if the honorary member must be related to WBMT activities or not – what should it be, if not “a WBMT person”? • The committee felt the text needed to be more explicitly clear so they recommended further changes today (e.g. – even if the party meets criteria, are contributions sufficient enough?). The group agreed the nominee might still not be the right person even though meets criteria. • Lastly – the bullet that states the nominee can attend all Board level discussions should also be rewritten to state that the President has the ability to invite an Honorary Member to attend Board level discussions. 	<ul style="list-style-type: none"> • The group agreed the lines of discretion are still not clear. • The first step is to rewrite this text one last time and circulate to Board members via email. • Once final recommended text is approved by the Board, the current nominee name can be taken back to the Executive Committee. 	<ul style="list-style-type: none"> • Paula to rewrite the text with the recommendations presented today, then circulate to Board.
<p>10) Unproven Therapies Project</p>	<ul style="list-style-type: none"> • Mickey Koh reviewed the history of WBMT involvement with the ISCT project on what was first called “cellular tourism”, now “unproven cellular therapies”. 	<ul style="list-style-type: none"> • Group agreed should not deter those with approved trial protocols 	

	<ul style="list-style-type: none"> ○ ISCT started 6 years ago eventually preparing white paper – WBMT invited to comment; wanted more details-slow progress; more progress recently including new “President’s letter...” published in <i>Cytotherapy</i>. ○ ISCT committed to pursuing topic with aim of highlighting risks/benefits and need for pre-treatment research (e.g., educating health care stakeholders, patient associations and individuals). • Some unproven therapies under clinical trial format/protocols globally (>2000 in US alone) – in various stages of development for variety of indications; others NOT under trial protocol. • Characteristics of these therapies: <ul style="list-style-type: none"> ○ Unclear scientific rationale ○ Lack of understanding ○ Insufficient data ○ Lack of standardized approach ○ Inadequate information disclosed to patients (e.g. questionable informed consent) ○ Non-standardized or non-validated methods ○ Uncontrolled experimental procedures in humans • Current Situation: <ul style="list-style-type: none"> ○ Increased numbers; increasing number of countries ○ Many are legitimate ○ Is an unmet need ○ Regulations differ ○ Cell materials paradoxically relatively easy (CD34 cells, MSCs, medical devices vs cells) ○ Questionable safety/efficacy data ○ Patient choice and right to seek treatment ○ Patient Advocacy Groups resistant ○ Overall should discourage patients from seeking, but if they do choose – should be informed • Changing attitudes: <ul style="list-style-type: none"> ○ Less judgmental ○ More emphasis on project commencement than completion ○ Source of information – highlighting need for scientific rigor ○ Consensus on need for open document/open dialogue ○ More and effective communication with healthcare stakeholders, patient groups, individuals. ○ Involvement of bioethics experts, WBMT and patient associations • Latest proposal – more formal partnership between ISCT and WBMT: Mickey Co-Chair project team with ISCT president, Massimo Dominici <ul style="list-style-type: none"> ○ WBMT Graft Proc committee to draft/revise documents and papers ○ New subgroups: <ul style="list-style-type: none"> ▪ Scientific, regulatory, patient affairs ○ WBMT Member Societies become more involved (review documents; approve) ○ Help disseminate information to Member Societies ○ Further engagement? (will WHO engage?; to follow-on the MPHO project??) • Compare successful cell therapies with unproven therapies <ul style="list-style-type: none"> ○ Are there standards of care? ○ Which make false promises? ○ Exemption/compassionate use should still require efficacy/safety data and informed consent 	<ul style="list-style-type: none"> • Aim should be information re: “state of the art” with some level of biovigilance. • Use 3rd grade level when translate materials. • Should try to influence patient advocacy groups – have them “demand” right to know full information, risks, etc. • Prepared documents/materials should be reviewed annually by task force • Real question – appropriate for WBMT to be involved? <ul style="list-style-type: none"> ○ Those in attendance – “yes” 	
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	<ul style="list-style-type: none"> ○ Should include adverse event reporting/vigilance ○ Should involve GCP labs/practices • Need more people involved 		<ul style="list-style-type: none"> • Mickey to invite participation of interested individuals from WBMT Member Societies.
11) Branch Office Concept	<ul style="list-style-type: none"> • Dr. Kodera re-read the original idea that he proposed last year – as generated after the Brazil workshop. He supports development of a “registry based” network of regional representatives willing to support administrative tasks. • Paula noted that we now have a volunteer name from each of the registries who is willing to support this idea. • Except for Workshop related tasks/activities, it remains uncertain exactly how to use this network. 	<ul style="list-style-type: none"> • All in attendance agreed a central office should be maintained for high level oversight of this Network. • We should rely on regions to help with bi-directional communication. • 	
12) DTA Documents	<ul style="list-style-type: none"> • Paula reported that we now have DTA documents signed by registry representatives except EBMT. 		<ul style="list-style-type: none"> • Paula to pursue obtaining Mohammed Mohty signature on EBMT original copy of DTA.
13) Adjournment	The meeting adjourned at 17:40		

SUMMARY OF ACTION ITEMS

Action Item

- Paula to pursue survey of Member Societies re: annual meetings to avoid date conflicts when planning future Workshops. **NOT DONE**
- If our proposed WHA side event program is selected, WBMT to notify WBMT representatives so message gets to right governments.
- Dietger to obtain country list from WHO so can identify those most in need of invitation to WHA side event.
 - Who to prepare talking points?? **NOTE: WHA/WBMT EVENT APPLICATION DENIED; MAY BE INVITED NEXT YEAR AND WOULD PROPOSE SAME PROGRAM**
- Gregorio Jaimovich to provide proper list to Helen. **PENDING**
- WBMT to post full Ethiopian site visit report to website. **DONE**
- Paula to rewrite the Honorary Member Bylaws text with today’s recommendations, then circulate to Board for final vote. **DONE**
- Mickey to invite *Unproven Therapies Project* participation of interested individuals from WBMT Member Societies. **PENDING**
- Paula to pursue obtaining Mohammed Mohty signature on EBMT original copy of DTA. **DONE**

Respectfully submitted for Secretary, Hildegard Greinix
Paula Watry, Executive Administrator

Appendix



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Blood Cell Therapy is the official journal of Asia-Pacific Blood and Marrow Transplantation Group. We will publish it from October 2017 and issue quarterly.

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- Translational research
- Transplantation immunology
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HISTORY OF INTERNATIONAL SCIENTIFIC SYMPOSIA

2016

October, APBMT

WBMT Programme- ASBMT/EBMT/APBMT Joint Session

Co-Chairs: Y. Kodera, MD; J. Szer, MD

- Future of Hematopoietic Stem Cell Transplantation & Cellular Therapy
Modern Conditioning Regimens Prior to allo – HSCT (M. Mohty)
- Hematopoietic Cell Transplant Activity in the United States (CN. Bredeson)
- Design the Future of Hematopoietic Stem Cell Transplantation: APBMT
Perspectives (S. Okamoto)
- WBMT – Who Are We, What Have We Done and What Will We Do? (J. Szer)

February, BMT Tandem Meetings

Stem Cell Transplantation for Bone Marrow Failure

Co-Chairs: S. Kojima, MD; SA. Giralt, MD

- Hematopoietic Stem Cell Transplantation in Adult Patients with Acquired
Aplastic Anemia: Asian Perspectives (JW. Lee)
- Bone Marrow Failure in Children (S. Kojima)
- Poor Graft Function Post-Transplant – Time to Take this Seriously (SA. Giralt)

2015

October, APBMT

Global Trend of HSCT and the Future Role of APBMT (WBMT/APBMT Joint Session (I))

Co-Chairs: Y. Kodera, MD; S. Okamoto, MD

- Medical Products of Human Origin WHO Project: Regulatory
Recommendations for MPHO-WBMT (JR. Nunez)
- Global Trends in Hematopoietic Stem Cell Transplantation (HSCT) (D.
Niederwieser)
- Starting New HSCT Program in Emerging Countries in Asia-Pacific Area (D.
Ma)

Working together with Emerging Countries in HSCT in Asia (WBMT/APBMT Joint Session (II))

Co-Chairs: TK. Saikia, MD; AA. Hamidieh, MD

- Report from Mongolia (B. Khishigjargal)
- Report from Sri Lanka (L. Gooneratne)
- Report from Myanmar (AA. Gyi)
- Report from Indonesia (H. Hariman)
- Report from Philippines (HG. Baylon)
- Report from Bangladesh (MA. Khan)
- Report from Cambodia (B. Pheng)

Future in Hematopoietic Stem Cell Transplantation (ASBMT/EBMT/APBMT Joint Session)

Co-Chairs: S. Okamoto, MD; W. Hwang, MD

- Hematopoietic Cell Transplantation in 2015: How the ASBMT is Facing the Challenges (C. Bredeson)
- Challenges in Hematopoietic Stem Cell Transplantation: The EBMT Perspective (M. Mohty)
- Future of Hematopoietic Stem Cell Transplantation – Asia Pacific perspective (A. Srivastava)

Global Alliance for Nuclear Accident Management in the Field of Hematopoietic Stem Cell Transplantation

Co-Chairs: D. Ma, MD; Y. Kodera, MD

- The Current Status of the Asia-Pacific Blood and Marrow Transplantation Group (APBMT) in the Management of Nuclear Accident (D. Ma)
- The Contribution of EBMT to the Global Response of a Large Number of Radiation Victims (R. Pawles)
- Radiation Injury Treatment Network: Hematologists and Oncologists Preparing for a Radiological Disaster (C. Case)

March, EBMT

Innovations in Cancer: A Joint EBMT-EHA-APBMT Session

Co-Chairs: M. Mohty, MD; C. Chomienne, MD; AA. Hamidieh, MD

- New drugs in hematology (M. Mohty)
- Leukemic stem cell heterogeneity: how to monitor and eradicate (C. Chomienne)
- Pediatric HSCT: challenges in the Asia-pacific region (AA. Hamidieh)

APBMT Annual Report 2016

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