



MEETING OF THE LATIN AMERICAN BLOOD AND MARROW TRANSPLANTATION SOCIETY AT THE TANDEM MEETINGS IN SAN DIEGO

Saturday February 4, 2012 Room Ford A

4:30-6:00 PM

Dietger Niederwieser, president of the WBMT, welcomed all participants and explained the structure and scope of the WBMT as a federation of international societies working in cooperation with the World Health Organization (WHO) to promote excellence in stem cell transplantation, stem cell donation and cellular therapy. The WBMT has a board of 18 societies working in the field of stem cell transplantation and covering most of the WHO regions including Europe (European Group for Blood and Marrow Transplantation; EBMT), Eastern Mediterranean (Eastern Mediterranean Blood and Marrow Transplantation Group; EMBMT), Asia Pacific (Asia Pacific Blood and Marrow Transplantation Group; APBMT) and Northern America (CIBMTR) but also the World Marrow Donor Association WMDA and many other societies active in the stem cell transplantation field. Recent deliverables of the WBMT were mentioned like the annual global activity survey, the meeting in emerging countries (Hanoi Vietnam 2011) and the activities of the standing committees of the WBMT. The experience WBMT had in the local meeting organized in Hanoi was excellent. All slides are available at the WBMT website www.wbmt.org and the WBMT will prepare an algorithm for optimizing transplant activity and support within a country. The idea would be to have similar workshops in Latin America but it would be necessary first to have a local society to organize such a meeting.

He then went on to give some background information about the evolution of what has come to be called the LABMT. During the SBMTO meeting in Rio in August 2011, transplant center directors in Latin America discussed the creation of the LABMT agreeing it is necessary to build a "Latin American Blood and Marrow Transplant group". One important goal for this organization is to represent the region of Latin America within the Worldwide Network for Blood and Marrow Transplantation (WBMT) group, a non-profit scientific organization with the mission to promote excellence in stem cell transplantation, stem cell donation and cellular therapy (www.wbmt.org). The purpose of this cooperation would be to engage in scientific and educational activities and endeavours. The annual global survey is one of the activities of the WBMT.

Next there was a teleconference in January 2012 during which it was decided to organize a face to face meeting at these Tandem meetings in San Diego to move the organization of the LABMT forward. Minutes from the Rio meeting and the phone conference are available at www.WBMT.org. Dr. Niederwieser asked to approve the minutes of the last phone call. The document was approved after a few e-mail corrections.

The idea would be to have a LABMT Society with all Latin American BMT societies as affiliates. Since many Latin America countries have Hematology but do not have BMT



Societies, these Hematology Societies (e.g. in Argentina, Paraguay, Uruguay) could also be part of LABMT. And then, this regional Society, the LABMT, would be part of WBMT. WBMT associates are societies and health care authorities, not individuals.

He also introduced Paula Watry (administrative support), as well as Helen Baldomero, responsible for data collection at the global level.

The agenda for today's conference, as presented by Dr. Dietger Niederwieser, was to continue discussions of the foundation of a Latin America BMT Society (LABMT), its executive committee and elections of a president, vice president, secretary and treasurer. Dr. Dietger Niederwieser previously sent out the bylaws of the WBMT to be used as a template.

Dr. Alejandro Madrigal, president of the EBMT, confirmed his strong support in developing the LABMT further.

Dr. Marcelo Pasquini, representing the CIBMTR within the WBMT, and closely connected to the LABMT activities, explained the need to form the LABMT and to represent this region in the WBMT. Stem cell transplantation has reached a global dimension and activities are still increasing from year to year. Collaboration of scientists, physicians, but also of national health authorities, donor registries and many other groups is urgently needed and centers need to connect nationally, internationally and globally. The final aim of WBMT is to have a network between communities, regions and societies to promote access to transplant and to optimize stem cell transplantation around the world. Dr. Pasquini continued saying that there are excellent BMT programs in Latin America and attempts have been made before to bring this community together. In Latin America with a population of more than 6 hundred million people, relatively few BMT centers are available and they are too loosely integrated. WBMT would like to facilitate the integration and to have representatives from the regions in its cooperation with the WHO.

Dr. Kodera, the vice president of the WBMT and president of APBMT, explained that he has been part of WBMT now for 5 years. He thinks that APBMT is a very good model for LABMT because there has been no competition between societies, CIBMTR and EBMT. APBMT was formed in 1990 and encourages the report of small experiences and exchange of information between the Asian Pacific countries. Every year the APBMT has an annual meeting and the first topics are always country reports: it shows that each country member is important, that the experiences are interesting and it gives them good information about the other countries. He encourages LABMT to do the same, to build a good communication and to perform an activity survey in the region. The captured data must be solid and informative for each country. Then, LABMT can move to outcomes registries but it has to be a step-by-step development.

Last year, the WHO proposed to the WBMT to start a promotion for stem cell transplantation in the Asia Pacific area for countries without a stem cell transplant program or with low activity according to the activity survey published in JAMA. The result was the



Workshops organized by WBMT in Hanoi, Vietnam with the participation of politicians and physicians and was very successful in understanding the problems and need of the countries.

Dr. Luis Bouzas reinforced that the mission of WBMT is to promote excellence in stem cell transplantation and cellular therapies at a global level. He thinks that it would be very good for the Latin American region to have more contact within the continent, but also to represent the region. Africa and Latin America are the only continents without representation in the WBMT. His impression was that the persons representing the ten countries in Rio were excited about this idea and committed to work together. One of the goals of a new group might be the collection of stem cell transplantation activity data in Latin America in order to have a right reflection on the important contribution the Latin American programs are giving to the global activity, but also to support the needs of individual transplant programs. LABMT should promote relationships between the transplant centers to help to advance the scientific development in the region, to protect the patients and to create a regulatory environment in the region. Each society or group (nation) with special interest in BMT should have a representative. Dr. Luis Bouzas has talked previously to Gustavo Milone, both are interested in being part of the LABMT, although they are not at this meeting.

Dr. Niederwieser explained that a section was created in the WBMT webpage in order to temporarily allow LABMT to include minutes and documents of interest during developmental stages. Dr. Alejandro Madrigal and Dr. Niederwieser suggested to the group to identify the national BMT or Hematology Societies in Latin America, to aim for a model of primary/secondary representatives from each country in Latin America and to build an interim Board composed of members of national societies or individual in countries without national societies.

Next Dr. Niederwieser reviewed a list of countries, representative names, levels of activity, and presence of BMT or Hematology Societies. They are summarized as follows:

Argentina has a Hematology Society and a chapter of BMT within the society led by Dr. Juliana Martinez Rolon, present at the meeting together with Dr. Gregorio Jaimovich and Dr. Gustavo Kusminki - and invited to take part in LABMT. Argentina already has National Donor Registry that works with BMDW and WMDA.

Bolivia has no BMT activity yet.

Brazil has the Brazilian Bone marrow Transplantation Society (SBTMO) and a National Donor Registry – REDOME.

Chile has very active physicians, Dr. Julia Palma, Dr. Francisco Barriga, Dr. Claudio and Sandra Elgueta; they have a BMT group within the Hematology Society. More than 400 transplants are performed per year.



Colombia has a National Hematology Association and they are thinking of starting a transplantation chapter within it.

Costa Rica has Dr. Bujan and Dr. Oscar Porras, pediatrician. Dr. Bujan offered his help to organize this task and his experience from previous activities.

Ecuador has two groups performing BMT: Dr. Patricio and Dr. Bouzas has his e-mail.

Panama Dr. Ernesto says Dr. Fanilla is very active. He was already contacted previously and his response was positive.

Paraguay does not have a BMT program yet.

Peru has a Hematology Association (can not be called a Society due to local legal issues), one BMT unit and they are looking forward to establish two more.

Republica Dominicana has no BMT activity yet.

Mexico has a Hematology Society with 400 members; a group with special interest in BMT is being organized; Dr. David Gomez-Almaguer suggested contacting the president to indicate a representative.

Uruguay, Dr. Ricardo Pasquini reported considerable activities with more than 70 transplants per year. There is a Hematology Society and Dr. Milka Bengochea Sindome (from the Instituto Nacional de Donación y Trasplante de células, tejidos y órganos - INDT - Ministerio de Salud Pública – Uruguay) is in the address list of the LABMT; there is a national fund to finance all transplants, National Registries that work with BMDW and WMDA and they have all the data of what is performed in the country.

Venezuela the group knows a few names from prior meetings as Dr. Carmem Milanez, Dr. Francisco Ramirez, Dr. Socorro and Dr. Somoza.

In addition to the national activities, there is already an important support by the following health organizations, which were involved in previous meetings and were invited to the San Diego Meeting.

ONT: Eduardo Martín-Escobar; -Gregorio Garrido; -Mar Carmona; Mattesanz
WHO: Malhi Cho Calidad en la Atención y Seguridad del Paciente; Luc Noel; WHO; Geneva

An interim board for LABMT would involve representatives from each country with two persons (one leading representative and one alternate). These persons should organize a telephone conference in March and discuss about bylaws of the LABMT using those of the WBMT (see homepage) or the SBTMO bylaws as template. Ideally the representatives should have the mandate of the stem cell transplant society of their country, but this may not be



feasible since many countries do not have such a society or not even a Hematology association. Therefore the idea was to establish an interim board of individuals of these 13 countries. This interim leadership should start the activities and thereafter the leadership should be elected. This interim committee should be defined today and should work until the next meeting.

Dr. Bouzas offered the infrastructure of the Brazilian Society (SBTMO) for LABMT to start its activities – the location, secretary, computer and internet access. LABMT should get organized to have bylaws and to rotate the leadership between the partner societies every couple of years. The group can also count on help from Paula Watry and Dr. Marcelo Pasquini.

A proposal was discussed to organize an annual scientific meeting (ideally together with other meetings in the region). It was suggested that LABMT should meet during the *Highlights of ASH* in Latin America next May 18-19 in Foz do Iguaçu, Brazil and continue the process of bylaws development and activity planning.

Dr. Kodera suggested to move forward step-by-step. If there are special topics to be discussed, a separate meeting can be arranged. One of the activities of WBMT is the creation of a global transplant center number. In order to proceed with this task, WBMT will need a list of transplant programs from each country and the information about reporting of the center. Each BMT Center will eventually receive a WBMT Global Center Number to avoid duplications.

He suggests that the initial LABMT members should be representatives of each country and must be active in BMT, not necessarily the most important names. In many countries hematopoietic stem cell transplantation groups belong to Hematology/Oncology Societies. LABMT should involve BMT physicians but must also involve nurses, and other professionals. This helps to bring the HSCT teams stronger and more active.

It was further suggested that each participant, if not already fully reporting to the CIBMTR, could download the brief activity report form from the WBMT webpage and try to collect information on their country. Ideally there should be only one page per year per country. The form is very easy to fill in, does not need a data manager because only totals are included. This report does not substitute reporting to the CIBMTR or EBMT. The WBMT reports can be sent to Dr. Bouzas and copied to Helen Baldomero so it will not be counted twice. A common email address will be designed by the SBMTO to which all reports can be sent for forwarding to Helen.

Dr. Marcelo Pasquini reported a survey conducted by the International Studies Working Committee of CIBMTR with 50 centers answering the questionnaire. But there may be much more data available. The global activity survey currently being evaluated by the WBMT is the 2009 – 2010 and information from LABMT is still needed. The survey has been obtained from the reports of the CIBMTR, the EBMT, the APBMT and the EMBMT. The SBTMO provided data from Brazil. Data from centers reporting to these societies have their activity included.



The WBMT activity report is different from CIBMTR or EBMT reports because it involves only a single sheet (available at the WBMT website to download). The idea for the global survey is to present data by country and region – not by teams.

Helen Baldomero reviewed the activity survey process and showed that Latin America is under-represented. This should be one of the first tasks of the LABMT. It was explained that there are two levels of activity reports: first the simple one involving one single sheet/year, where every transplant program can report in a very easy way the number of transplants and indications for each team; second the CIBMTR TED or EBMT MED A form, where every patient is reported in detail including the 100 days outcome. For the global survey just the first report is needed for those teams not reporting yet. This is not time consuming and usually reported by the physician and not data managers. It was suggested that each participant not reporting already to one of the board member societies of the WBMT could consider completing these annual activity reports. These reports do not substitute reporting to the CIBMTR or EBMT.

Kodera suggests that the initial LABMT board should consist of representatives of each country and should be persons active in BMT, not necessarily the most important names. In many countries hematopoietic stem cell transplantation groups belong to Hematology/Oncology Societies. LABMT should involve BMT physicians but must also involve nurses, and other professionals. This helps to bring the HSCT teams stronger and more active.

An interim committee should be defined today and should work until the next meeting; SBMTO and WBMT infrastructures can be used, and the group can also count on help from Paula Watry and Dr. Marcelo Pasquini.

The representatives present at this meeting from Brazil (Luis Bouzas and Adriana Seber), Argentina (Juliana), Peru (Murillo and Antonio), Mexico (Guillermo, David or Ovillo), Colombia (Karduss, Alleio) and Costa Rica (Bujan) were indicated as interim board and should be in contact with other participants and sending a letter to other counties inviting their participation. This list is still incomplete, but represents a starting point for the teleconference in March. It was mentioned also that the LABMT should not be too restrictive. People motivated can join and are more than welcome to work on this idea. They may also want to participate on the standing committees of the WBMT.

For the virtual meeting in March, Cho Malhi, the WHO representative for Latin America, has offered their web service (<http://new.paho.org/> and the illuminate system www.paho.org/virtual/PatientSafety) free of charge. An e-mail list for LABMT will be created.

WBMT can also be very helpful to the HSCT centers. For example, ~~in~~ Japan once faced the possible shortage of bone marrow collection kit from one company because of the discontinuation of supply of that company. The WBMT/APBMT office immediately had contacts with the members of WBMT/APBMT and they found another company which



produced similar devices avoiding real shortage. WBMT helped also to contact BMT teams in Japan during the Fukushima accident because nobody knew if they were alive or dead. It would be interesting to understand the laws in each region.

Another resource available at the WBMT webpage is the presentations of the Hanoi meeting; they address important issues in setting up a BMT program and how to optimize a BMT program. Training of primary physicians was identified as the major issue for a successful program. WBMT will develop a program on this issue in the near future. Participants can use these presentations for their own presentations at home, for politicians, etc. and are invited to ask questions to the executive committee or board of the WBMT.

Dr. David Gomez–Almaguer offered a room at the World Congress of Hematology Meeting in Cancun, Mexico. He has led another LA group that has presented and published data but the group faced many problems and one of them was to depend on other meetings to get together. He reinforces that LABMT must have its own meetings and its own identity.

Dr. Niederwieser thanks everyone in attendance and is positive for the future of the LABMT.

Attendees:

All participants introduced themselves and signed in:

Dietger Niederwieser – president of the WBMT; Paula Watry – CIBMTR; Luis Fernando Bouzas – Brazil; Adriana Seber – Brazil; Yoshisha Kodera – chairman of the Asian Pacific BMT; vice-president of WBMT; Juliana Martinez Rolon – Argentina; Gregorio Jaimovich – Argentina; Helen Baldomero – Switzerland –data collection WBMT; Goumar – Canada e India – centers not reporting to CIBMTR and came to hear about the initiative; Ricardo Pasquini – Curitiba, Brazil; Maria Moreno – Lima, Peru; Alessandra – originally from Venezuela, works in the US with patient services at NMDP; Alejandro Madrigal – Mexican, president of EBMT; Roberto Ovilla – Mexico; David Gomez – Mexico; Juan Argueles – Mexico; X? - Monterey Mexico; Bitar – Israel; - Spanish group VMT; Cancelado – Colombia; Cardoso – Colombia; Carmem – Colombia; Amado Karduss – Colombia; Virginia Abello – Colombia; Claudia Souza – Colombia; Vaneuza Funke – Curitiba, Brazil; Marcelo Pasquini – CIBMTR; Lima – Peru – partial report; Antonio Carrasco – Peru; Sergio Murilo – Peru; - NCI; Nanci Difeferozo – NHLI – NIH; Carmem Bonfim – Curitiba, Brazil; Willen Bujan - Costa Rica

Attachment 2: Proposal for the LABMT Bylaws

Adriana Seber
Louis Bouzas