



REGISTRIES SUB COMMITTEE (RSC)

Minutes of the meeting held on 29th of March at the EBMT 2008 Annual Meeting.

Participants: *Carmen Ruiz (Chair); Sandra Allgaier; Helen Baldomero; Virginie Chesnel; Sunil de Souza; Dilek Dursen; Nabila Elarouci; Hervé Finel ; Nathalie Fortin-Robertson; Anja Henseler; Chantal Kenzey; Beate Lindner; Jian Jian Luan, Helga Neidlinger; Emmanuelle Polge; Bénédicte Samey; Keiren Towlson; Marie Trnkova; Henk Jan van der Wjick.*

1. Members Project

Sunil de Souza , EBMT Central Registry Office, London, UK

Sunil de Souza, Database Manager at the EBMT Registry Office, informs us that more people have now requested access to the Members Project. Nabila, from the Paris Data Office has been using it as well to contact centres. In general, users are relatively satisfied with the MDB and are finding it very useful to retrieve member's details to contact with centres. Carmen explained that you can get listing of centres by type of transplants as well. Since the meeting, we have been able to complete the update of the Members database so we now have a centralized platform to manage all contacts throughout the EBMT Centres.

2. Med-B Forms

Carmen Ruiz, EBMT Central Registry Office, London, UK

Most of the Med B forms are now updated and now manuals are going to be updated to reflect the changes in the forms. All the updated forms and manuals have been uploaded on the Registry section of the website.

3. Data Retrieval -Train the Trainer sessions

Carmen is preparing a new Data Retrieval Train the Trainer session this year and it is agreed that the sessions should take place at the time of the RSC Meeting this autumn. Carmen is hoping to make changes in the way Data Retrieval is given. More emphasis on programs and software to retrieve data will be given as well as how to teach Data Managers to use the Excel Macros.

We asked participants to check with their institutions for computer rooms' availability and Marie Trnkova, from the Czech Registry as kindly offered to host the RSC Meeting/ Train the trainer at the end of October 2008. More information about the venue and dates will be given in further communications from the Central Registry Office.

4. Data Management Programme at EBMT 2008/Preparing EBMT 2009

Our meeting in Florence this year has been very busy with the new Promise Open Learning Centre taking its first steps as a new component to the Data Management Programme. After a shy start on Monday it did really get busy and it wouldn't have worked without all the volunteers, mainly from the National Registries and also the participation of Ronald, who gave a demonstration on how to import to SPSS. We are very pleased with the outcome and wish to renew the experience in Goteborg.

We have received some of the Data Management Feedback questionnaires and hopefully more are to come following the Registry Article in the next issue of EBMT NEWS. We will compile the feedback and suggestions made by the participant in order to help us fine tune the Data Management programme for next year's annual meeting. If some of the participants belonging to your respective registries would like to give their input, you can inform them that we have put the questionnaire in the Registry section of the EBMT Website.

At present time, we need to start organizing next year's Educational Sessions, Promise Data Entry & Retrieval as well as the Open Learning Centre. Please let us know of any ideas and suggestions you may have and inform Nathalie, from the EBMT London Registry Office.

5. Follow-Up Procedures

Carmen Ruiz, EBMT Central Registry Office, London, UK

We provisionally agreed on the following Guideline to be implemented:

- Annually for transplants performed less than 10 years ago
- Every 2 years for transplants performed between 10 and 20 years ago
- Every 5 years for transplants performed more than 20 years ago

This will be reflected in the Registration Summary that is sent to the centres bi-annually.

6. Data Quality

Carmen informed the meeting on the curation process that the CIBMTR is doing. The National Cancer Institute (NCI) has a site where medical terminology and definitions are curated with every concept being defined. The CIBMTR is going through a slow and painful process of curating every single term used in their forms. They have started with the Med-A/TED. This is of great interest to us since it is the stated aim of the EBMT to harmonize our data collection as much as possible, not only with the CIBMTR, but with any other organisation collecting similar data (donor registries, for example).

Helen Baldomero has proposed to create a PowerPoint presentation to put on the web with step-by-step instructions on how to enter a Med-A form.

7. Excel Macros

Keiren Towlson, from the British Registry and Henk Jan van der Wjick, from Leiden, have been working at writing a manual/helpfile for people who wish to use the Excel Marcos. This is still being worked on and will be posted on the website as soon as it is completed.

7. Encryption Software

Beate Lindner, from the Austrian Registry, made a presentation on an Encryption Software, which would enable a more secure way of sending files with sensitive information. The presentation and the software itself were very interesting and it gave everyone the opportunity to discuss the security and confidentiality issue. The software itself seems easy to use and to install. However, a lot of people working on stricter networks like hospital ones would find it difficult to use at their workplace. We would like to thank Beate for putting together this presentation.

9. Any Other business

As previously announced, Nathalie Fortin-Robertson will be stepping down from her post at the EBMT Central Registry Office later in the year. A new person has joined the EBMT Registry Office, Judith Aben has started her appointment as the new Registry Assistant. Nathalie has been seconded to Shelley Hewerdine's post for a few weeks until she leaves.
