

Data Management Sessions: EBMT 2012 REVIEW

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The EBMT Annual Meeting held in Geneva this year was a very enjoyable event and the Data Management sessions were well attended, with some **120** Data Managers from **26** different countries - with representatives from Europe, Australia, Asia, Canada, and -for the first time- Nigeria attending the sessions.

The Educational programme included sessions on: Stem cell mobilization; Survivorship; Follow up forms; HLA; Antibodies and many others. Marie Trnkova spoke about her experience of balancing her roles as Data Manager of a Centre and of a National Registry. Prof Alessandro Rambaldi presented a very interesting session on his Centre's work on Outcome Research. There was also a very useful session presented by the JACIE staff outlining their accreditation process.

Once again, we are grateful to all our speakers for the effort that they put into producing consistently high quality educational sessions for data managers – so a special **“thank you”** to all of them for their hard work: Didier Blaise; Ilias Doxiadis; Sebastian Giebel; Simona Iacobelli; Michelle Kenyon; Beate Lindner; Silvia Montoto; Curly Morris; Alessandro Rambaldi; Carmen Ruiz; Franziska Strehle; Marie Trnkova and Isaac Yaniv.

Slides of the educational sessions from this year's meeting are now available on www.ebmt.org in Resources – [Slide Bank](#) (scroll down for the Data Management table). If you weren't able to attend the conference, it's well worth looking at these and they're worth a re-cap if you attended as well

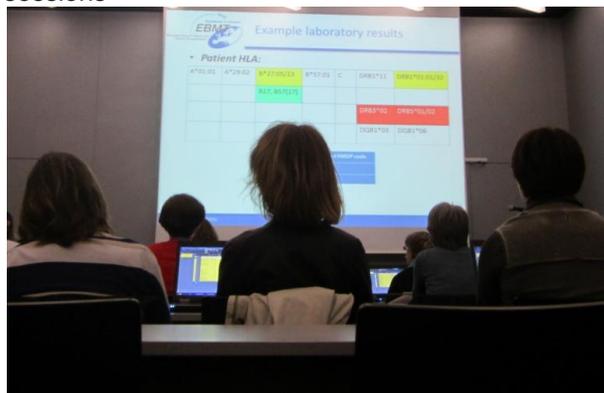
The **Data Quality** session included a quiz and the first prize was won by Evy Billen from Maastricht. This was followed by a drinks reception for Data Managers.

Feedback

Thank you to all the Data Managers who completed the Feedback forms at the Annual Meeting. These forms are very important to enable us plan the sessions for the future: if you have forgotten to send yours, please fax it NOW! A full report will be available on our website very shortly.

Registry Database Training

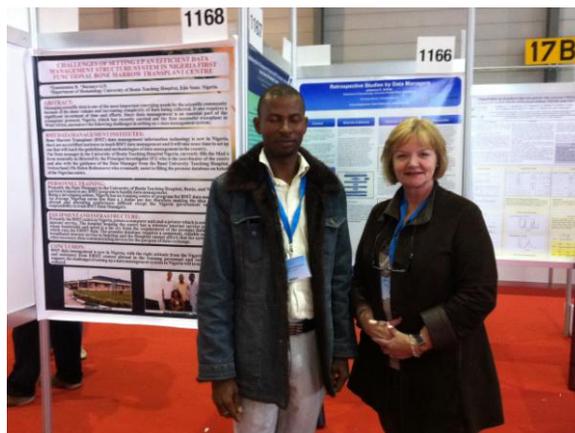
This proved popular with all courses fully attended again this year. The online booking system worked well and we plan to continue to use this system. There were new courses on HLA Data Entry and Advanced Data Entry (including Med-B). Thank you to Helen Baldomero; Agustin Cabrera; Shelley Hewerdine; Keiren Kirkland; Julia Perry, Nicole Raus and Carmen Ruiz for running these courses. Thank you also for **all** the support from volunteers from the various EBMT offices and National Registries who helped during the sessions



HLA Data Entry using the ProMISe system

Data Management Posters

Three were displayed – two outlined the challenges of establishing Data Management systems and structures (in Jordan and in Nigeria) under difficult circumstances. The third poster, from Basel, presented work regarding retrospective studies (inspired by the session on this topic presented at the Paris meeting)



B. Enomamien and J. Schep next to their team's posters

Other News: Data Quality

GvHD Prophylaxis/prevention and aGvHD Treatment:

We would like to remind ProMISE users to enter the drugs (immunosuppressive chemotherapy) using the given code. Unless it is coded it makes it very difficult for data analysis. This rule applies in general – please avoid using “Other” and enter the code where available. We have made minor revisions to the current MED-A form and ProMISE to make it clearer for this particular item.

AFTER HSCT

GvHD prophylaxis or preventive treatment (*Allografts only*)

No Yes

If yes: Drugs (Immunosuppressive chemo)

- ALG, ALS, ATG, ATS (*given after day 0*)
- Anti CD25 (*MoAB in vivo*)
- Campath (*MoAB in vivo; can be "in the bag"*)
- Corticosteroids
- Cyclosporine
- Cyclophosphamide (*given after day 0*)
- Etanercept (*MoAB in vivo*)
- FK 506 (*Tacrolimus, Prograf*)
- Infliximab (*MoAB in vivo*)
- Methotrexate
- Mycophenolate (MMF)
- Sirolimus
- Other monoclonal antibody (*in vivo*), specify.....
- Other agent (*in vivo*), specify.....

Extracorporeal photopheresis (ECP)

Other, specify.....

In ProMISE for example, for the patient below we have “tacrolimus, MMF, Cyclophosphamide” entered as text in “Other”. (Only Fludarabine – given for Conditioning – appears in the list of drugs in the right-hand ‘Record Locator’:

Treatment	value	label
CIC		8001 City_1 [TC1]
Patient		126 126
Treatment date	2012/02/17	2012/02/17
Treatment related to complications		
GvHD prevention & immunosuppression		
GvHD prevention in the patient		2 Yes
Drugs or chemotherapy (<i>Immunosuppression</i>)		1 No
Extracorporeal photopheresis (ECP)		
Other therapy for GvHD prevention		2 Yes
Other GvHD prevention: specify	Tacrolimus, MMF, Cyclo...	Tacrolimus, MMF, Cyclophosphamide
Treatm for failure or complications		
Treatment for aGvHD		

The correct way to enter is to put “Yes” under “Drugs or chemotherapy” and then enter the drugs as you would for conditioning, following the normal navigation, so it ends up looking like this, with drugs appearing as separate records:

Treatment	value	label
CIC		8001 City_1 [TC1]
Patient		126 126
Treatment date	2012/02/17	2012/02/17
Treatment related to complications		
GvHD prevention & immunosuppression		
GvHD prevention in the patient		2 Yes
Drugs or chemotherapy (<i>Immunosuppression</i>)		2 Yes
Extracorporeal photopheresis (ECP)		
Other therapy for GvHD prevention		1 No
Other GvHD prevention: specify		
Treatm for failure or complications		
Treatment for aGvHD		

The same is true for the drugs used in GvHD treatment. This is important as studies are being done that take into account the prophylaxis and treatment of GvHD and it is very difficult to do searches in text fields.

Donor Outcome Committee

We are pleased to inform you that a new committee has been set up to collaborate on a global strategy for the collection of donor follow up data. Through this committee, the EBMT is working together with the WMDA. More information on the Donor Outcome Project will follow in the August issue of EBMT News.

Looking forward to EBMT 2013



39th Annual Meeting of the European Group for Blood and Marrow Transplantation

7 - 10 April 2013 • London, UK

You can email us on registryhelpdesk@ebmt.org if you have any suggestions for next year's Data Management programme; if you would like to submit a Data Management poster or would be interested in presenting a session on DM work in your centre.