

## Exchange of Data with Donor Registries

Allogeneic centres reporting to the EBMT may also be required to submit forms to the donor registries providing them with the cells. There is noticeable overlap in data requests from the donor registries and the data that centres are already submitting to the EBMT. As part of the EBMT Registry's continuous commitment to facilitate the work of the centres, the Registry has entered in an agreement with two UK donor registries: Anthony Nolan and BBMR. The agreement allows the donor registry to see patient data submitted by the centre, so that the data only needs to be registered once. The agreement applies only to centres that have explicitly consented for their data to be accessible to the donor registry (BBMR, see [CONSENT FORM](#)) or have an existing agreement with the donor registry itself for data transfer (Anthony Nolan). Centres must ensure that patient consent is inclusive of this arrangement. At present the agreement with the Anthony Nolan Registry includes UK centres only.

The agreement includes the provision of HLA typing data directly from the donor registry to the EBMT Registry and we are pleased to announce that we have received HLA data from the Anthony Nolan and BBMR registries for all the donor patient pairs we have been able to identify.

We want to stress the importance of ensuring the donor identification and donor registry name are properly conveyed to the EBMT because identification of donor patient pairs is essential in ensuring the agreement is fruitful for all parties. (For more detailed info on how to label the donor and donor registrations please see the newsletter from July 2010 [http://www.ebmt.org/4Registry/Registry\\_docs/ProMISe%20News/DM\\_News\\_201007.pdf](http://www.ebmt.org/4Registry/Registry_docs/ProMISe%20News/DM_News_201007.pdf))

This type of collaboration is a win-win situation for the transplant community as donor registries obtain the data they need, the centres have a bit less work, and the EBMT increases the quantity and accuracy of its HLA typing data .

## Reminder: New Contact for HLA typing reports

In April we sent information regarding the centralisation of the Registry in London. The EBMT office in Paris will now dedicate itself exclusively to the coordination and analysis of studies, supporting the research carried on by the Working Parties.

In addition to the MED-AB data entry for non Promise users outside of National Registries, the entry of HLA tissue typing reports will now be carried out in London. For submission of the HLA typing report for patients already registered please use our updated [HLA Cover Page](#)

### HLA typing results of patient and donor should be attached and sent:

- *to your NATIONAL REGISTRY if you are based in The Netherlands, Switzerland, Turkey or the UK* and you normally report to your National Registry.

- to the EBMT REGISTRY OFFICE in London for any other centre:

Shelley Hewerdine  
EBMT Registry Office  
12th Floor, Tower Wing  
Guy's Hospital  
Great Maze Pond  
London SE1 9RT  
United Kingdom  
Phone: 00 44-207-188-8409 Fax: 00 44-207-188-8411  
Email: [shelley.hewerdine@kcl.ac.uk](mailto:shelley.hewerdine@kcl.ac.uk)

# Review of the Data Management Programme at EBMT 2011

*Pamela Welson*

*Data Management and Helpdesk Co-ordinator*

The EBMT Annual Meeting in Paris this year was a very happy and productive affair and the data management sessions proved once again to be popular with Data managers and colleagues. Around 140 Data Managers attended the event and participated in a wide range of Educational & Scientific sessions as well as training sessions on the ProMISe software.

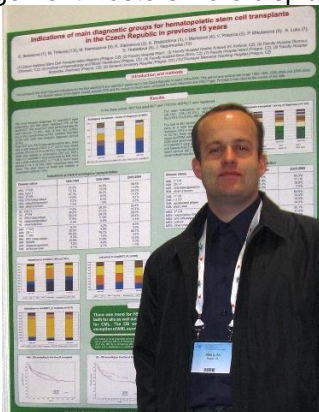
The Educational sessions for GvHD with Hildegard Greinix and for Paediatrics (Children are different) with Jacqueline Cornish proved to be very popular, as was the session by two managers from Sheffield Children's Hospital – Janet Williams, Data Manager and Sharon Barrott, Quality Manager– who outlined their experience of improving the data collection and documentation procedures at their Centre. The concept of having a Data Manager talking about their work and their Centre's experiences is relatively new and it is one which we hope to repeat in the future and to include in the programme annually (see below).

Once again, we are grateful to all our speakers for the efforts that they put into producing consistently high quality educational sessions for data managers – so thank you to all of them for the hard work which they put into their presentations :

Hildegard Grenix; Jacqueline Cornish (stepping in at very short notice); Vanderson Rocha; Francesco Lanza; Tomáš Kozák and Zora Marjanovic; Emanuele Angelucci; Erik Aerts; Carmen Ruiz de Elvira; Catherine Cordonnier; Eduardo Olavarria; Tapani Ruutu; Nicolaus Kröger; Anja van Biezen; Janet Williams and Sharon Barrott; Beate Lindner and Emmanuelle Polge.

The slides of the educational sessions from this year's meeting are being published in the [EBMT 2011 Slide Bank](#)

Four Data Management Posters were displayed.



Aleks Luks by the Czech national registry poster: Indications of main diagnostic groups for HSCT in the Czech Republic in the past 15 years

The ProMISe Training courses proved popular again this year with the Data Retrieval courses fully attended. The online booking system worked well and we plan to use the same system again next year. Thank you to Helen Baldomero; Keiren Kirkland; Nicole Raus and Steven Tran for running these courses with support from other volunteers who helped them on the day (too many to mention I'm afraid!).



Data Retrieval Training

We also trialed some "workshop type" sessions and these appear to have been well received – we hope to build on these again for next year. A summary of the Q&A session is on the following page.

This year as part of our social programme we were pleased to hold a joint drinks reception for Data Managers & Quality Managers

## Future meetings

If you have any suggestions for topics which you would like to see included in the Data Management Education programme for next year, please email [registryhelpdesk@kcl.ac.uk](mailto:registryhelpdesk@kcl.ac.uk) and we will see if we can incorporate these.

Similarly, we would be interested to hear from you if you think that you could undertake a presentation at next year's Annual Meeting. If you would like to share any examples of your work with Data Management colleagues e.g. innovative Data Management practices; systems for improving data quality at your Centre, please email them to us.

## 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 very shortly.

We really hope to see as many of our Data Managers again next year at the EBMT Annual Meeting in Geneva: 1 – 4 April 2012 – save the date!

<http://www.congex.ch/ebmt2012>

## **EBMT 2011: Issues you have raised (Workshop session)**

Below we have included a brief summary of the Workshop session at the congress on Tuesday 5<sup>th</sup> April as this may be of interest to all data managers:

**Q: Do we have to answer 'yes' to conception in every follow up?**

A: We only want to know whether the patient conceived after transplant yes / no. If it 'yes' then the status will always be 'yes' and you do not have to register this each time.

**Q: How does this work with relapse/progression after transplant?**

A: The question we ask is "First relapse/progression after transplant" so we only need to know the **first** date of relapse/prog after transplant. In the database this question will be automatically skipped in subsequent follow ups for that transplant if you already entered 'yes' relapsed. If there is a subsequent progression of the disease, or a subsequent CR, this information will be recorded when answering the question "disease presence/detection at last contact".

**Q: How do I register a case where the status at transplant for acute leukaemia is CR1 and at some point, during follow up, there are still no blasts in the BM, but molecular markers are present?**

A: first relapse is yes and it is molecular

**Q: If cause of death was related to cell therapy, how do I register this?**

A: The option "Cell therapy related death" is already available in the database and we plan to add it to our forms.

**Q: When reporting acute GvHD, how do I report Overlap Syndrome?**

A: This has not been added explicitly to the MED-A but is in MED-B and it is reported by ticking both the aGvHD and the cGvHD for the same dates. It can also be done in Med-A, using the same system, although the aGvHD will be entered while entering the First report form, and the cGvHD will be entered while entering the Follow up form.

**Q: If a patient was included in a study but withdrew from the study before the transplant, should I record this?**

A: Yes. Please register that the patient was in a study because analysis will be based on the intention to treat.

**Q: Can I record CR in the status at transplant for Myeloma patients with:  
Immunofixation - negative  
BM – not evaluated  
Haematological disease detected – no**

A: No. If BM was not evaluated, the status at transplant must be recorded as "not evaluated"

**Q: Is Prednisone for Acute Lymphocytic Leukaemia (ALL) an induction therapy?**

A: Prednisone is not an anti-cancer drug, therefore this data is not collected in MED-B

**Q: Where do you record mesenchymal stem cells MSC given as gvhd prophylaxis?**

A: Please register as GvHD Prophylaxis –Other  
or Additional Treatment inc Cell Infusion – Type of Cells: Mesenchymal – Indication: GvHD Prophylaxis (code 10)

**Q: Should a boost plus additional infusion be registered as a subsequent transplant?**

A: If allo stem cells are infused this is always reported as a transplant. If DLI, please complete a DLI registration. If it is an 'augmented DLI' (Donor CD3+CD34 infusion, mobilised) please register this as a transplant.

**Q: How do we count auto transplants in myelomas for accreditation if we are doing 2 transplants per patient but there is only one collection of stem cells?**

A: They should be reported as 2 separate transplants in the EBMT Registry. For JACIE, please ask the JACIE office.

We recommend that you also consult our [MED-AB manual](#) which includes the definition on HSCT and advice on how many registrations to complete per patient for the Registry