EBMT Annual Meeting 12TH Meeting of the Data Management Group

We very much look forward to welcoming all participants to the EBMT Annual Meeting in London this year, where a varied programme of DATA MANAGEMENT EDUCATION SESSIONS and EBMT REGISTRY DATABASE (PRoMISe) TRAINING SESSIONS will be on offer.

EDUCATION SESSIONS are open to everyone interested in the field of Data Management. Some are aimed to assist people who are new to the field to enhance their knowledge and others have a higher scientific content of interest to everybody, regardless of background. We do encourage active participation in sessions, raising issues and requesting clarifications so that we can all learn from each other. Click here for a link to the data management programme.

Below you will find information on some of the education sessions – to give you an idea of what will be on offer:-

Why is the classification of Lymphoma such a nightmare? (Speaker: Maria Calaminici)
This will be a scientific presentation and the talk will focus on:
-Discussion of current WHO classification of lymphomas
-Subclassification : Hodgkin's Lymphoma and Non-Hodgkin's Lymphoma
-Subclassification: non-Hodgkin's Lymphomas, B and T cell origin
- How did we get to the current WHO classification: an overview of the past classifications

Study co-ordination: Pitfalls and remedies – and how you can help (including "dos and don'ts" of data confidentiality (Speaker: Steffie van der Werf)
The EBMT is performing different kind of studies; surveys, retrospective and non-interventional prospective studies and clinical trials (clinical trials will not be discussed here – please see details below for separate session on clinical trials). During the coordination of these studies we face many challenges such as unwilling centers, incomplete or missing data,

data quality, Financial Agreements and site contracts that have to be drawn up, submissions to Ethical Committees etc. However, most difficulties we can tackle with our combined knowledge and a lot of patience and most studies are successfully finished and published. During this presentation we will discuss the challenges we encounter and how **you** can help **us** and, more importantly, how **we** can help **you!** In addition, as there is no study without patients agreeing to having their data submitted to the EBMT database, **c**onfidentiality of patient data stored in the Registry is of paramount importance to the EBMT and we will inform you how to ensure the data is transferred and stored with the highest possible level of security**.**

How improved Data Quality leads to better understanding of GvHD (Speaker: Liesbeth de Wreede)
The registration of aGvHD and in particular of cGvHD can be a time-consuming and difficult procedure. In this presentation, we will give two examples to illustrate what these data are used for and why good data quality is indispensable for meaningful results.   In the first example, GvHD was studied as a predictor of future events. GvHD was taken as a surrogate marker for the Graft-vs-Leukemia effect and the differential impact on relapse of both aGvHD and cGvHD for different disease entities was assessed. In the second example, we focused on GvHD as an outcome, relevant to understand the impact of stem cell transplantations on the quality of life of the patients. The data for this study have been collected through the CLL Data Quality Initiative using a different date to assess the resolution of cGvHD.

Use of ECP in Treatment and Prophylaxis of GvHD. (Speaker: Emma Dasgupta)
Both acute and chronic graft-versus-host-disease (GvHD) represent significant causes of morbidity and mortality after allogeneic HSCT. This session will outline the role of extracorporeal photopheresis (ECP) in management of GvHD. Background information on GVHD will be provided including an explanation of acute and chronic GvHD and their treatment options. This will be followed by an explanation of ECP aimed to give an understanding of the procedure itself and how it can be used in clinical practice to treat or prevent acute and chronic GvHD.

Complexities of the Med-A (Speaker: Carmen Ruiz de Elvira)

This session will use the Med-A form as reference to highlight the essential data necessary to record an HSCT in the EBMT Registry database. We will look at areas that frequently present difficulties in recording data, notably: Conditioning, Relapse, GvHD and HLA. There will be some hints and tips to ensure your data is being accurately recorded - and how to get help when you need it! This will be an **interactive session** – please feel free to suggest any relevant queries or problems that you would like discussed in advance by e-mailing registryhelpdesk@ebmt.org. This session can be seen as a complimentary session to the EBMT Registry Database (ProMISe) Data Entry session on Monday morning, but attendance of the latter is not a prerequisite.

Disease Status evaluation in Med-B forms for Autoimmune Diseases (Speaker: Zora Marjanovic)

This presentation will give a brief explanation of the nature of Autoimmune Diseases and a clinical presentation of the different types of diseases. The evaluation parameters will be pointed out and importance of the questionnaires for these diseases will be stressed. Explanation of the EBMT consensus/guidelines will be given in order to underline the difficulties in evaluating the disease activity and outcome of patients.

Clinical Trials - general talk (Speaker: Liz Clark)

Ever wondered what is involved in a clinical trial? What are the rules and regulations that govern their conduct? Why is so much documentation needed? If so, please come to Liz Clark's (EBMT Clinical Trials Operations Manager) informal talk about clinical trials to get an overview of why we run clinical trials, how they should be run and what you can do to help a clinical trial run smoothly. Even if your Centre does not participate in clinical trials, you might find this talk useful as it's important for all Centres to know what is involved in clinical trials and data collection.

Med-B CLL (Speaker : Johannes Schetelig)

In patients with chronic lymphocytic leukemia (CLL) allogeneic stem cell transplantation is usually administered late in the course of the disease. As a consequence, most patients have received multiple lines of pre-treatment and the documentation of previous chemo-immunotherapies is a major challenge in the documentation of patients with CLL. Moreover, additional treatment opportunities with kinase-inhibitors will arise in CLL in the next years. Assessment of pre-treatment will thus be discussed thoroughly. Further, remission assessment in CLL at various levels and problems with the definition of progressive disease will be shown. Alluding to the data quality initiative which has been accomplished last year, first results of this

major effort will be presented and the scope of MED-A and MED-B forms in CLL will be discussed.

Complications after HSCT (Speaker: *Alicia Rovó*)

Hematopoietic stem cell transplantation (HSCT) is the treatment of choice and the only option for cure for defined malignant and non-malignant hematological disorders. During the last decades the introduction of new transplant strategies, including less intensive conditioning regimens, have increased the number of candidates for an HSCT. Thus older patients, as well as patients with comorbidities, can now be considered for such a therapy. A stem cell transplant poses many risk of complications; some life-threatening. The risk depends on many factors, including the primary disease, the type of stem cell transplant, preparative regimen, the strength of the tissue match between the donor and recipient and the age and health of the recipient. Complications include the toxicities of the high dose of chemoradiotherapy given as preparative regimen which can cause organ damage, as well as the risks of infection and bleeding associated with the marrow aplasia. Ultimately, however, GVHD and its therapy are the major factors in determining the outcome in allogeneic HSCT. Relapse remains a relevant matter after any type of transplantation; it represents a challenge to rescue patients in such a situation. A number of innovative pre-emptive or salvage therapies have been developed during the last years.

In addition there will also be education sessions on: - *CHIMERISM, HLA Mismatches, EBMT Transplant Activity Survey, "Holistic" Overview of blood cells; Chemotherapy complications and late effects*

For details of session times, please refer to the Data Management programme which is available on the EBMT web site

HOT OFF THE PRESS

As highlighted in the January issue of Data Management News, the EBMT Registry Upgrade Project of the new IT system has now started with a go-live date scheduled for 9th December 2013.

*We would be pleased to count on your presence at the **official presentation** of the new **EBMT Registry System** at the **Annual Meeting on Tuesday 9th April** (9.00am to 10.30am)*
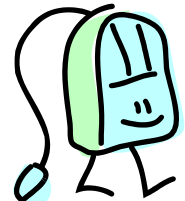
We will also be offering the following practical workshop training sessions for EBMT REGISTRY DATABASE (ProMISe) training. Please register in advance for these sessions – some spaces are still available and registration details are on the Data Management Education section of the EBMT web page.

Data Entry: introductory session for **new users** to EBMT Registry Database (ProMISe) illustrating how to enter a MED-A registration, subsequent transplants and patient follow-ups.

Data Retrieval: focusing on obtaining data listings, frequencies, report running. The session is open to all users but **not** recommended for people who are absolute beginners.

HLA Data Entry: explaining on how to enter HLA typing reports for those users who want to do it themselves. This session is aimed primarily at **experienced** users.

Advanced Data Entry (including MED-B): Med-B data entry with examples of complex data including adding: missing data, follow ups, subsequent diagnoses and transplants.

And don't forget, on Monday evening 8th April (17.00-18.00) there will be an opportunity to socialise with colleagues at the Data Manager's reception – look out for further details at the conference!

We very much look forward to welcoming you to the **12TH Meeting of the Data Management Group in LONDON** and hope to see you there!