

## DIAGNOSIS

### Familial lymphohistiocytosis (FLH)

The Inherited Disorders Med-B form can now be used to provide Med-B data on **FLH**. The necessary navigational changes have also been made in ProMISe. We recognize that this form is not ideal for this disease, but using the [Inherited Disorders Med-B](#) form in this way does allow us to collect a substantial amount of relevant information until we can develop a more appropriate form.

### Primary Immune Deficiencies

The following categories of **SCID** under the **Primary Immune Deficiencies** heading have been given their own code in the Registry database :

**T- B- NK+ code 16**

**T- B+ NK+ code 25**

**T- B+ NK- code 26**

## AVOID USING "UNCODED" when submitting diagnosis classifications.

We would like to re-iterate to all ProMISe users to please **avoid using** "uncoded" wherever possible. If you feel that you must use "uncoded" when submitting data to the EBMT Registry database, please talk to us **FIRST**. **Please** email the Registry helpdesk for a discussion and further classification: [registryregistryhelpdesk@kcl.ac.uk](mailto:registryregistryhelpdesk@kcl.ac.uk)

## LYMPHOBLASTIC LYMPHOMA: REMINDER

**Lymphoblastic lymphomas** are not registered under **Lymphoma** but under **Acute lymphoblastic leukaemia (ALL)**. This is more in line with the WHO classification which labels them **Acute lymphoblastic leukaemia/lymphoma**

## CHEMOTHERAPY

Please **do not use** the "Other chemo" field to record the brand name of any drugs. If you do need to record the brand of the chemo or drug being given, you can do that using the field called "**Name of the brand**". This field can be seen by removing the dynamic filters.

## Please avoid using "Other" wherever possible.

If you cannot find your drug, check the current list of drug coding which appears as a pop-up when entering drugs. The same document can be viewed online at:

[http://www.ebmt.org/4Registry/Registry\\_docs/MEDAB0084.pdf](http://www.ebmt.org/4Registry/Registry_docs/MEDAB0084.pdf)

If you still cannot see the drug that you are looking for contact the Registry helpdesk

**MOVEMENT OF DATA:** There has been a significant movement of data within the EBMT Registry database over the past few months as a result of the creation of new fields for HLA and Donor as advised in the July 2010 issue of [Data Management News](#). The information stored in the old fields has been transferred whenever possible to the new fields.

In some instances data written in the old HLA fields could not be interpreted for a variety of reasons and therefore could not be transferred. If you have any queries regarding the transfer of previous data to new data fields, please contact the Registry helpdesk.

## FOLLOW UP DATA FOR PREVIOUS TRANSPLANTS

When Centres are forwarding details of second (or subsequent) transplants to their Registries or Data Office to enter, please also send the follow up form for the previous transplant. The **Date last seen** for this report should be the date of the second (or subsequent) transplant.

As already advised, another **REMINDER TO PLEASE** download the latest [Med-A](#) form from the [EBMT website](#) before submitting any new Med-A registrations.

If submitting Med-B data, download the latest [Allograft Med-B form](#) before submitting any new allograft registrations.

## Two diagnosis as indication for transplant.

In some cases, the transplant received by the patient is meant to treat more than one diagnosis. Unfortunately, the EBMT database is not yet able to deal with this situation. Until this problem is fixed, we recommend you do the following:

1. Select the diagnosis that is more complicated in terms of data entry, and complete its 1<sup>st</sup> registration using Med-A or Med-B.
2. Go back to the diagnosis record and turn the Main diagnosis into 88 (uncoded)
3. If both diagnosis were diagnosed on the same date continue with point 4. If they were diagnosed on different dates, go to point 5.
4. Within the same diagnosis record, go to the *Chapter* that contains the fields for the second diagnosis (you can use the *Chapters & Sections* location on the right of the screen) and fill in the relevant items.

**Save** the patient.

5. Create a diagnosis record manually using the "Create new record" button.
6. Label the record as "Main indication diagnosis" in the field "Type (manual input, see note)"
7. Enter the corresponding main diagnosis and subclassification.

**Save** the patient.

Please contact me at [registryhelpdesk@kcl.ac.uk](mailto:registryhelpdesk@kcl.ac.uk) if you have any queries regarding the content of this edition of *Data Management News*. Pamela Welson EBMT Registry helpdesk Co-ordinator

## CHANGES TO ProMISE LOG-ON SCREEN - MAIN ENTRY TO PROJECT MEDAB

We will shortly be making a change to the default entry to the ProMise system. This will mean that the current default form:

**MED-A: All diseases --- MED-B: All malignancies except CLL and CPL**

will be changed to:

**MED-AB: All diseases.**

Therefore, in future, unless you **actively** select one of the other Med-A or Med-AB form options, you will be logging in to the whole database. The only difference will be an increased burden on your computer's memory. We hope that this change will facilitate the entering of data for the majority of users – however we will monitor the situation so please email [registryhelpdesk@kcl.ac.uk](mailto:registryhelpdesk@kcl.ac.uk) if you experience any particular difficulties

Med-A: All diseases –Med-B: All Malignancies except CLL and CPL =  
TO BE REMOVED

The screenshot shows the ProMISE version 2.2.05 log-on interface. It includes a 'username' field, a 'password' field, and a 'Start Session' button. A 'MEDAB' button is highlighted with a red box. Below the login fields, there is a 'Scope of this session' dropdown menu. The menu is open, showing several options: 'Med-A: all diseases +Med-A Appendix', 'Med-A: All diseases --- Med-B: All malignancies except CLL and CPL', 'Med-AB: Acute leukaemia (AML, ALL, etc.), only primary', and 'Med-AB: All diseases'. The 'Med-AB: All diseases' option is selected and highlighted. Below the dropdown, there is a 'Type of this Session' dropdown menu with options: 'All programs', 'Data Reports only', 'Predefined Reports', and 'DEMO session'.

Med-AB: All diseases  
NEW DEFAULT

## IMPROVING DATA QUALITY



The EBMT is currently focusing on new ways to improve Data Quality and to empower Centres to take responsibility for the quality of their own data. A series of straightforward **Data Quality Reports** have been developed which can be regularly run by Centres to correct some of the errors which occur in the data. The details were circulated to Data Managers recently and the new manual: [Guide to Producing Data Quality Reports in the EBMT Registry Database using ProMISe](#) is available on the EBMT web site.

The Data Quality Reports can highlight, for example: invalid data, missing data, duplicate information, incorrect diagnosis, error messages, conflicting information etc. Inconsistencies in data can occur when for example changes are made manually or when data is converted to new formats etc. The errors highlighted in the Data Quality Reports can be corrected directly in the Registry database or alternatively forwarded to the EBMT Office in Paris for amendment. Centres who do not enter data directly themselves and whose data are entered by the EBMT Office in Paris can also run Data Quality Reports to check and verify their data. Centres who have a National Registry Office, may want to discuss with them prior to running these Data Quality Reports, because the National Registry may already have set up a Data Quality Report plan/schedule which includes the Centre.

The Data Quality Reports can be used to:-

- Monitor your own data entry work (or that of others within your Centre)
- Check on the quality of the data from the Centre(s) for which you have responsibility
- See what data are missing
- Check where data are wrongly entered
- Edit the data directly in the EBMT Registry database
- Make a note of the required amendments and use these to submit the corrections to the EBMT Paris Office or your national registry via fax or email.

***We recommend*** that the Data Quality Reports are run and the corrections are made to the EBMT database regularly – approximately once every 2 – 3 months (depending on the size of the Centre and how many transplants are carried out). We would like to encourage Data Managers to download this [new guide](#) and run the reports following these guidelines and to give us feedback regarding the usefulness of this document and the Data Quality reports.

### There is an exciting Data Management Group Education Programme lined up for the EBMT Annual Meeting in Paris (3<sup>rd</sup> to 6<sup>th</sup> April 2011).

We will again be running training sessions for the ProMISe system for Data Managers – a Data Entry session for beginners on how to enter MED-A registration and a Data Retrieval session for more experienced users focusing on obtaining data listings, frequencies and running reports. Please note that you will need to enrol for these sessions in advance following the link in the [congress registration form](#). This is because in previous years people who have booked places have failed to attend the session or have shown up on the wrong day. This is very disruptive for everyone and may mean that people with a genuine interest are denied access as the number of places is restricted. Note that your Institution may be charged for the full cost of the course (150 Euros) if you book a place but fail to show up on the day you are booked for. Facilities for cancelling a booking are available following the same link.

In addition, there will be a varied programme of educational, scientific and training sessions especially suited to Data Management professionals of all levels and interests. Including sessions on Med-A and Med-B forms; scientific sessions for example GvHD, Harvesting and Engraftment; sessions on Paediatrics, Cord Blood, the role of Nurses in transplantation as well as sessions regarding the role of data in Quality Management and the use of data in studies. **You can see the programme by following the links on the web site to the Scientific Programme: Data Management Group on the left side.**

**If you have any suggestions regarding particular issues you would like to be addressed within the topics listed in the programme, please email the Registry helpdesk with your ideas.**

There will be a social gathering where you can meet and chat to colleagues. In fact, there will something for everyone at the EBMT Annual Meeting. We would like to encourage as many Data Managers as possible to attend. So book up now! - visit <http://www.congrex.ch/ebmt2011/> and follow the **Registration** links – and join us in Paris for this exciting programme!

