## New Registry System

As announced in the last Data Management News, the EBMT has appointed Elsevier to work on our new registry system. based on the MACRO Electronic Data Capture system .An update was included in the June issue of EBMT News and you can get a full recap here. With the hosted environment in place, development of the custom forms for Data Entry is continuing apace with approximately half of the MED-AB items transferred to the MACRO e-form format. A test plan has been drafted and Registry staff have completed the first iteration of data entry testing, raising about 700 comments and suggestions.

Independently of the eForm design which is now being mostly carried out by Registry staff, the EBMT has agreed with Elsevier a series of "software drops" which all together should encompass the EBMT requirements. The first of these software drops is expected by the end of this month.

The other major development since the last newsletter is the appointment of a full-time project manager, Nigel Brook, who has a wealth of experience in pathology and disease registries. The training plan for EBMT centres is being developed. Requests for assistance in both testing and training will be made shortly. We look forward to demonstrating the power of the MACRO software to you soon. If you have any questions please contact us

## EBMT Registry is Paper free

We would like to remind all centres that the Registry can no longer accept paper forms for entry at the EBMT Registry in London. (This includes HLA typing as well as the MED-A/B forms). This policy was due to begin in January 2017 but we are still receiving some forms on paper so it has taken some time for the transition. **If you have been sending forms to the EBMT office in London, this data should now be submitted directly online**. If you need any assistance with ProMISe or training please do contact us

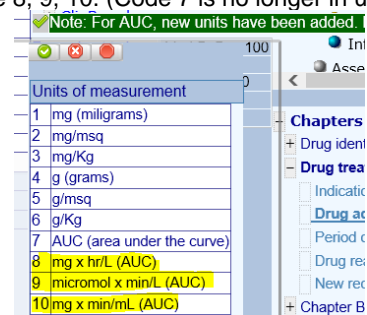## Patients treated in multiple centres

Please remember to send us a request to search the database if your patient has already had a transplant in a different centre. All data for a patient must be entered within the same patient registration, even if a patient has different treatments in different centres. We will search the database for existing records and give access to each treatment centre. Do not create a new registration for these patients unless we advise you to do so.

## Minor changes in ProMISe

1. **ECP treatment for GvHD** was included in the MED-B Allograft form and this has now been added to ProMISe. Approximately 150 existing records have been coded with Extracorporeal photopheresis (ECP). If you have any questions about this please contact us.



2. Conditioning doses: **Area under the curve (AUC)**. Specific units of measurement have been added for AUC in conditioning drugs such as Busulphan and Carboplatin. The new codes are 8, 9, 10. (Code 7 is no longer in use).



We have also added these new units in the MED-AB forms.

## Lost to follow up

We ask that centres try to enter follow up data regularly, even if it is difficult to keep in touch with patients. However, if you have tried but completely lost contact with a patient, the last status can be recorded as "lost to follow up". Note that the date of this last assessment should be the **last date that the patient was known to be alive**. It should not be the date that you decided the patient was lost to follow up.

| Last status | | |
|---|---|---|
| Patient status | | |
| Conception after transplant? | 1 | No |
| Did pregnancy result in live birth? | | |
| Survival status on this date | 9 | Lost to follow up |

## EBMT 2018

We look forward to welcoming data managers at the EBMT Congress next March in Lisbon! A full educational programme for Data Managers will take place on Monday 19th and Tuesday 20th March. Programme details will follow online at www.ebmt2018.org. (We take your feedback into account and the report of EBMT 2017 is available here)