

## Remedy Informatics selected for New Registry in 2013



We are delighted to announce that EBMT will be working together with Remedy Informatics to develop a new IT system for the Registry this year, with a **go-live** date planned for **9<sup>th</sup> December 2013**.

Remedy's solution combines BMT content expertise with superior technology. The platform has been used to develop over 120 registries including BMT. It is intuitive and user friendly for both data entry and analysis and requires no installation.

"Our registry has been an important tool for BMT researchers throughout Europe for decades, and we have recognised the need to upgrade our registry to better meet the evolving needs of our member centres, scientists and collaborating institutions. In our search for new registry technology for our upgrade initiative, we were very impressed with the flexibility and ease of use of Remedy's registry software. Having a registry that incorporates reporting interfaces, user-friendly data visualisation and analytical tools will enable us to deliver substantial benefits to our member BMT researchers and clinicians looking to improve patient outcomes"

**Professor Alejandro Madrigal, EBMT President**

"The EBMT Registry has been a valuable resource for BMT researchers for more than four decades and we are confident that the power and versatility of our registry software will aid EBMT as they work to expand further the size and value of their HSCT database. Ultimately, the entire European BMT community will benefit as EBMT member centres, collaborators and outside groups use our software to tangibly, measurably, and permanently improve the effectiveness of their care and patient-centred research."

**Gary Kennedy, founder and CEO of Remedy Informatics**  
 Click [here](#) to read the full press release

We will keep you informed of developments throughout the year. Training on the new system is planned for this Autumn, before go-live. Additional web-based training will also be available. During the [EBMT 2013 congress](#) there will be an overview presentation of the new system. (NB: ProMISe training will go ahead as planned so that centres can continue to enter data and do not fall behind with their registrations).

## Donor Follow Up going live on Monday 14th January

In collaboration with Swiss Transfusion SRC and the [Donor Outcomes Committee](#) chaired by Jörg Hälter, the EBMT Registry will be ready to accept registrations on donor outcome from next week. This is an important and integral part of allogeneic HSCT which will allow provision of data on short and long term donor safety and help to develop recommendations for donor eligibility, selection and outcome follow up based on donor health characteristics.

Reporting of **Donor outcome Data** is done through two data collection forms:

- Report on donation procedure and up to 30 days after
- Long term follow up report after last donation procedure

Both forms, together with this manual, can be downloaded from the Data collection forms section of the Data management page of the EBMT website, at: <http://www.ebmt.org/Contents/Data-Management/Pages/Data-Management.aspx>

Transplant centres should report outcome of related donors only. Responsibility for the unrelated donor outcome lies with the Donor Registry.

We strongly recommend that you have a look at the manual for this form before you get started. As always please contact the [Registry Helpdesk](#) if you have any questions.

ProMISe users can enter a 30 day donor outcome using code 7 and a long term follow up using code 8:

Patient data	
Form information	
Form about to be entered	
7	Donor donation procedure and 30 days
8	Donor follow up
9	Cell Therapy Med-A registration
10	Cell Therapy Follow up
11	HSCT MED-A registration
12	HSCT MED-B registration
13	HSCT MED-A Follow up
14	HSCT MED-B Follow up
15	HSCT Day 0 Registration (Modified MED-A)