



euromacs

European Registry for Patients with
Mechanical Circulatory Support e.V.



NEWSLETTER No 5. September 2013

The importance of international data accumulation

From: Professor Jean-Noel Trochu

Medical Director of the Institut du Thorax, CHU Nantes, France

As a cardiologist, I'm specifically interested in advanced heart failure patients, heart transplantation and assist devices. Faced with a limited number of donor organs and a lack of pharmacological innovations, the prevalence of advanced heart failure is expected to grow in the coming years. LVADs have been shown to prolong survival and improve symptoms and quality of life in bridge-to-transplant and destination therapy. European guidelines clearly acknowledge the importance of VAD therapy but the use of VADs is less widespread than in the USA and varies widely across Europe.

This is due to differences in national regulations on the reimbursement of the costs of the procedure, follow-up, center experience and the organization of care for advanced heart failure patients.

In this context a more accurate evaluation of the European mechanical circulatory support (MCS) population is essential for building knowledge and improving quality of care. Implementing a European MCS registry will contribute greatly to improving the situation. Experience in the US has demonstrated the growing importance of the availability of up-to-date information on MCS therapy for determining the overriding factors relating to patient survival and for improving clinical decision-making as well as the function and functionality of the assist devices.

Given the small number of MCS devices on the market, and the high proportion of centers with limited numbers of implantations, there is an urgent need to gather data from different centres.

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Prof. Jean-Noel Trochu



Although generating statistics on a national level is of great benefit, far more will be achieved by gathering data on an international level. Being able to provide a breakdown of the number of transplant candidates on MCS as a bridge, as well as the total number of patients on destination therapy, will allow physicians and decision-makers to adjust or adapt their policies to suit the needs of their patients. A European registry will provide feedback to teams submitting information to the dataset, allowing them to compare their own population at both national and European level. It will also allow a cross-sectional view of multiple clinical and demographic aspects and provide information on the utilization of resources, changing VAD population patterns, and impacts on outcomes for the entire registry population or for defined subgroups. Moreover, registries are important platforms for developing guidelines and disseminating good clinical practices. They can propose algorithms, create reminders and help to generate hypotheses for clinical studies.

National data can be useful for identifying trends and potential imbalances e.g. in heart transplantation, and health authorities can use these data to influence unwanted, or to anticipate future developments. However, in most countries the numbers are too small to provide significance for scientific analyses.

From my point of view, local and national MCS patient databases have become both a reality and a necessity. Given that Euromacs offers the possibility to upload local data as well as to download data from the registry, I plead for making maximum use of these opportunities.

Election of board (EACTS-Euromacs committee) members

In the e-mail with which the convocation for the general members' meeting on October 6, which was sent to the members, it was explained that according to the agreement with the EACTS, and according to our own statute:

- A. Three board members will step down as of January 1, 2014.
- B. We will elect 2 executive board members, ex § 7.1 of our statute (the maximum is five)
- C. As there was no quorum in Montreal, we will confirm the election of Bart Meyns (B), Finn Gustafsson (DK) and Luigi Martinelli (I) as members of the extended board, ex §11 (maximum is seven). Two of them may also choose to be a candidate to become a board member, ex §7.1
- D. Candidate board members to be elected on October 6, are Pascal LePrince (F), Ivan Netuka (CZ) and Antonio Loforte (I)



Pascal LePrince



Ivan Netuka



Antonio Loforte



Software Uploads, Real Time Statistics, how to obtain Downloads

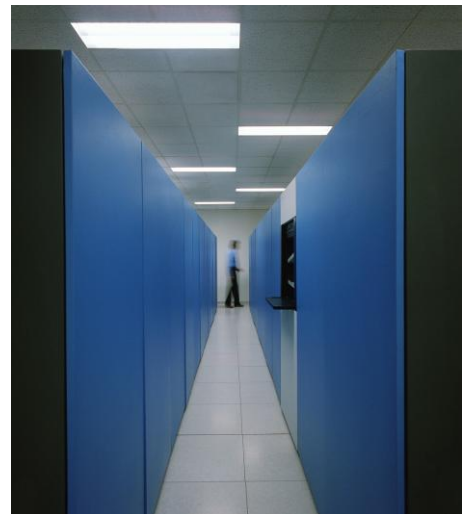
From: Theo de By

In this issue of the Euromacs Newsletter we inform you about the increasing possibilities the registry offers for its members.

Primarily, the Euromacs members are interested in:

- Storage of patient data;
- Follow up analyses of their patient data;
- Comparison of their own clinical data, and pump data, with the data of all other members;
- Specified scientific studies.

As the Euromacs database has now entered into a phase of growth and international expansion, the articles in this issue elaborate these subjects so that members, and potential members, get a better understanding about the possibilities and working methods of Euromacs.



Mainframe computer

“Upload my Data” software available.

By Andy Smallman and Neal McCann

Upload-My-Data (UMD) is a new web-based data collection system, which allows authorized users to upload and submit their data to the Euromacs database. Users will have been provided with their individual login details and the website for accessing the system.

A manual has been designed to aid users in this process by outlining the various steps that need to be undertaken to complete a successful data submission.

Contributors wishing to use the UMD must first produce an output data file from their local system in the required format. The specification can be obtained from Andy Smallman. Email: asmallman@e-dendrite.com

Downloads from the Euromacs database.

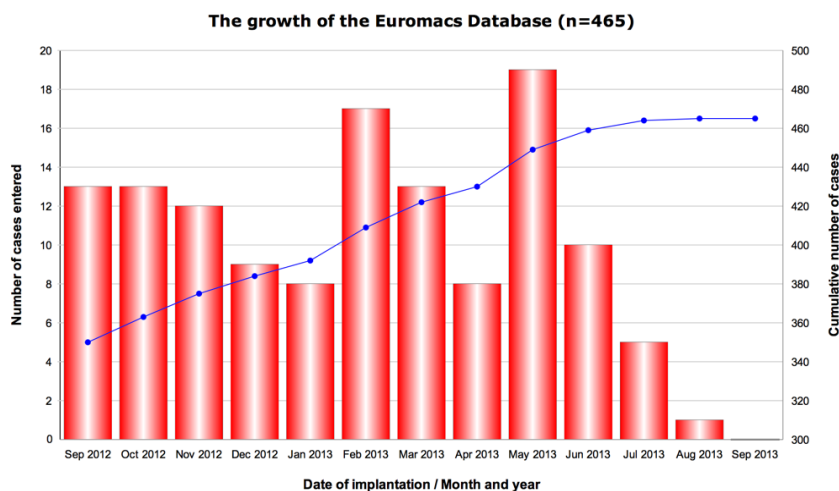
Every center that contributes to the Euromacs registry can download its own data from Euromacs at any time. After login into Euromacs, the user is offered the choice to download its registered data into a spreadsheet. A separate link is offered to download follow-up data of the patients of the center itself. Thus, the data can be used to produce statistics.

If a center would want to do a study with data from all the other Euromacs contributors, a study proposal can be sent to theodeby@euromacs.org.

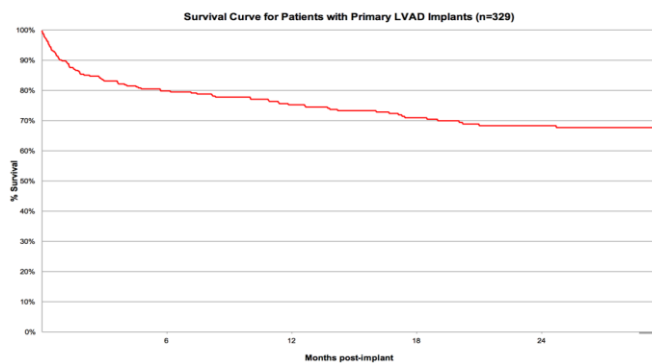


Dashboard installed on member's website

Recently, the first version of the Euromacs dashboard has become available on the members part of the website. The dashboard is meant to give members a quick glance at some general statistics in real time. Derived from the Euromacs database these statistics serve as a frame of reference. If one would want to use data for scientific purposes, a simple request can be addressed to the Euromacs board. It is Euromacs' intention to expand the real time statistics on the members' part of the website, e.g. by comparing graphs of local data with the data of the entire registry.



Actuarial Survival, Primary LVAD Implants



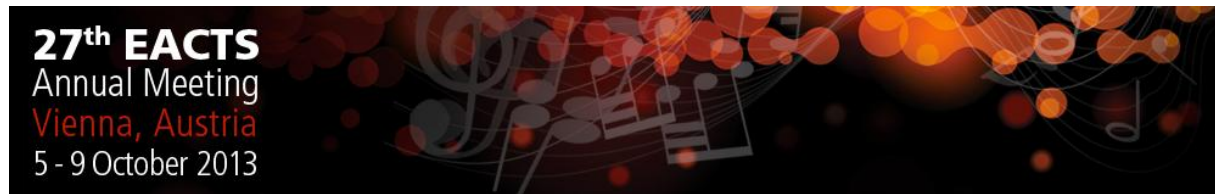
Euromacs in numbers

As per September 23, 2013, Euromacs has 137 individual members and 40 institutional members from 28 countries. Compared to the previous year, the numbers have increased by 50%. The registry contains data of patients who, in total, received 465 implanted devices.



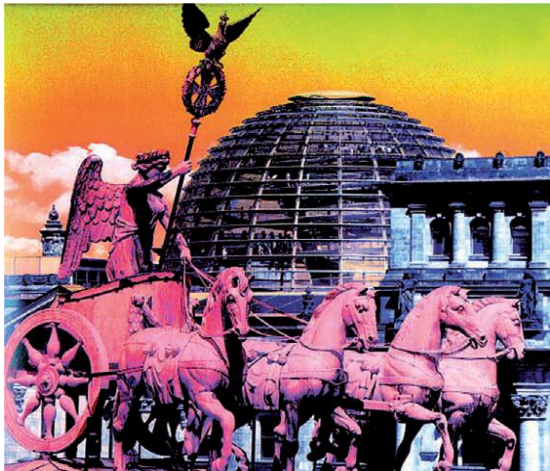
Upcoming events

21st Congress of the International Society for Rotary Blood Pumps
September 26-28, 2013 - Yokohama, Japan www.isrbp2013.org



www.eacts.org

8th Biennial Mechanical Circulatory Support symposium of the Deutsches Herzzentrum Berlin, November 8-10, 2013. Information: mcs@dhzb.de, Dr. S Hübler, tel. +49 30 4593 2201



Mechanical Circulatory Support

- * In any kind of acute heart failure
- * Towards myocardial recovery
- * In children
- * For permanent use

EUMS, European Mechanical Support Summit - Paris, France, December 4-7, 2013.
<https://www.congressecurity.net/form/abstract-eums-2013/>

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