



# euromacs

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

## NEWSLETTER No 1. April 20, 2012.

**From: Roland Hetzer,  
Executive Chairman**

Dear colleagues and friends,  
It is my pleasure to announce that the Euromacs database is now ready to be filled with data from patients on a mechanical circulatory support system. From the start of Euromacs, at the end of 2010, great efforts have been undertaken to enable our Association to reach this historical milestone. I express my gratitude to all colleagues and staff who have contributed to these first results. I am also grateful to those who have donated the necessary funds with which we were able to invest in the development of specialized, professional software.  
In this first newsletter, you will be able to read how Euromacs will provide you with the necessary information and tools to upload patient data.  
I trust that, once all member clinics have contributed to the database, we will be able to perform exactly those scientific analyses for which Euromacs was created, and – for the benefit of our

patients - obtain greater insight into **the** factors that contribute to the success and failure of mechanical circulatory support systems.

Roland Hetzer



## **Database now ready to receive uploads**

**From: Evgeni Potapov**

The executive board is pleased to inform all members of EUROMACS that the database is ready for data entry. The database underwent a first test run in August 2011 and further test runs in 2012. As a result, final improvements have been made by the database provider, Dendrite.

The demonstration version of the data base is available on the website. To use it you need to register online; your password will be sent to you by e-mail within 24 hours. The demonstration version allows you to enter the data of a hypothetical or actual patient, to familiarize yourself with the database. The demonstration database and its content are open to all.

Access to the official EUROMACS database is restricted to the members of EUROMACS. The password will be provided by the firm Dendrite after approval by the executive board of directors of EUROMACS.

The necessary precondition is that the membership contract has been signed between the hospital and EUROMACS. The password is blinded to EUROMACS, which means that the EUROMACS executives do not have access to the password, and the data of each hospital are open only to the owner of the password.

As the next step, the statistical report will be created for online analysis of the data from each individual hospital in comparison to the whole database data. The analysis will be available only with the hospital password. The annual registry report will be based on pooled anonymous data and published on the website.

Since the DHZB has received approval by the ethics committee for data entry, the DHZB is starting prospective entry of the data, while data starting from January 1, 2011 will be retrospectively uploaded.

## **Progress concerning agreements between Euromacs and participating institutions**

As per mid-April, the Euromacs Association counts 75 members from 16 different countries, while 7 agreements with providing hospitals/clinics have been signed. The board expects that, now that the registry is open, the number of members, and of signed contracts will rapidly increase.



## Some useful tips from Evgeni Potapov and Neal McCann:

For those members who wish to get to know the Euromacs database before entering real data, there are two possibilities:

- 1) We can provide you with a password for the demonstration-version of the database.
- 2) The database can be approached with MS Internet Explorer, not yet with Google (Chrome) or other browsers.
- 3) Once you have that password, you can view the database, as well download the registry database form as a PDF.
- 4) If you have any questions, or suggestions to improve the database, please send an e-mail to [theodeby@xs4all.nl](mailto:theodeby@xs4all.nl)



**Dr. Evgeni Potapov (l) and Neal McCann of Dendrite Ltd**

## Berlin Ethics Committee approves Euromacs Registry

**From: Sabine Hübler and Theo de By**

On March 7, 2012, the Ethics Committee of the Charité Hospital in Berlin gave the green light for the Deutsches Herzzentrum Berlin (German Heart Institute Berlin) to start using the Euromacs Register for scientific analysis with respect to patients with mechanical circulatory support (MCS).

The fact that the Ethics Committee approved the request of the German Heart Institute is considered to be of great importance for those members who wish to seek similar approval from ethics committees or other authorities.

Summarizing the conclusions, it can be said that the Ethics Committee agreed with the



proposal of the Euromacs Association to collect and to analyze data from patients of all age categories who suffer from terminal heart failure and who receive a ventricular assist device (VAD).

The method of data collection can take place either by means of pseudonymization, or by anonymization. The data are then referred to a commercial provider of database registries, Dendrite Clinical Systems Ltd, in the United Kingdom.

Included in the approval of the Ethics Committee are the documents with which clinicians will inform their patients, or, in the case of pediatric patients, their parents.

Euromacs has translated the relevant documents into English. The English and German language versions are available for all members.

### **Theo de By appointed managing director**

On February 12, 2012, the board of Euromacs appointed Mr. Theo de By managing director of Euromacs. Now that the registry is available for all members to upload MCS patient data, it was decided that the organisation needs management on a daily basis.

Theo de By holds a Masters Degree in Executive Business Administration and has specialized in many aspects of health care management, specifically in quality management and auditing. Theo de By has previously held different management and board functions in transplantation and health care organisations.

You can reach Theo at +31653162322, or at [theodeby@xs4all.nl](mailto:theodeby@xs4all.nl).



**Theo de By**

The Euromacs board wishes him great success with his endeavors to realize the aims of the Association.

### **Upcoming events:**

- Mechanical Circulatory Support – European Training Symposium, June 28-30, Bern Switzerland. Information: [alessandra.witsch@insel.ch](mailto:alessandra.witsch@insel.ch)



## Upcoming events, continued:

- 3-Day MCS Workshop, Deutsches Herzzentrum Berlin, May 14-16
  - Decision making
  - System selection
  - Implantation
  - Patient care

Information: [mteichmann@dhzb.de](mailto:mteichmann@dhzb.de)

- EACTS Annual Congress, October 27 – 31, Barcelona. Website: [www.eacts.org](http://www.eacts.org)

## From the press:

### Three-year-old survives 251 days with artificial heart

Link to the article:

[http://www.telegraph.co.uk/health/healthnews/9195667/Three-year-old-survives-251-days-with-artificial-heart.html?goback=%2Egde\\_154079\\_member\\_108001968](http://www.telegraph.co.uk/health/healthnews/9195667/Three-year-old-survives-251-days-with-artificial-heart.html?goback=%2Egde_154079_member_108001968)

### No Pulse: How Doctors Reinvented The Human Heart

Link to the article:

<http://www.popsci.com/science/article/2012-02/no-pulse-how-doctors-reinvented-human-heart?page=all>

### Western Pennsylvania man gets latest version of artificial heart

Link to the article:

[http://www.pittsburghlive.com/x/pittsburghtrib/news/s\\_783307.html#ixzz1oWpPk3Xe](http://www.pittsburghlive.com/x/pittsburghtrib/news/s_783307.html#ixzz1oWpPk3Xe)

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