



# euromacs

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

## NEWSLETTER No 3. October 2012

### Euromacs Welcomes its 100<sup>th</sup> Member

**From: Roland Hetzer**

The board of Euromacs is proud to announce that its 100<sup>th</sup> member has been registered. Moreover, we are glad that, coincidentally, our 100<sup>th</sup> member is Pieter Kappetein, and we cordially welcome him to our association. During the last year, Pieter Kappetein, on behalf of the board of the EACTS, has taken the initiative to try to harmonize the modus operandi of the different registries in Europe. Most governors of these registries are EACTS members themselves. Thus, one important point in the exchange of thoughts between the registries and the EACTS has been the necessity to open up the boards of the different registries for other EACTS members, and to create greater transparency. Pieter Kappetein has been instrumental in promoting a closer relationship between Euromacs and the EACTS. It is foreseen that during our Annual Meetings, next October in Barcelona, an important step will be made in the direction of close and intense cooperation between Euromacs and the EACTS. As there is an enormous overlap

between the aims of the two organisations; specifically, when promoting scientific research, it is only natural that our associations should amalgamate. The board of Euromacs looks forward to fruitful cooperation with Pieter Kappetein.



**Prof. Dr. Pieter Kappetein**



## **Annual General Members' Meeting, October 30, 2012 during the EACTS in Barcelona**

**From: Theo de By**

This year's annual Euromacs General Members' meeting will take place during the EACTS meeting in Barcelona on October 30 (15.00 hrs in room M219 of the CCIB Congress Centre).



The General Assembly Hall has been prepared

All members are invited to take part in the meeting. The main topics on the agenda are: approval of the annual report, the budget proposal for 2013, the rotation scheme of the board members and a change in the statute.

This change of the statute is aimed at the enhancement of the democratic character of our association, as well as at enlarging the possibilities for Euromacs to intensify cooperation with other associations which are working on a non-profit basis.

The membership of Euromacs is free of charge. Each member has one vote during the Annual General Members' Meeting (see also page 1 of this Newsletter).

## **Euromacs Registry translated**

**From: Peter Walton**



Dendrite Clinical Systems, the organisation which hosts Euromacs' database, has been instrumental in providing translations of the Euromacs Registry. The database fields are now readable in French, German, Italian and Spanish.

As the patient data in the participating hospitals are basically available in the language of the countries of origin, those responsible for data input no longer have to make the translation into the English language professional terminology. Thus one can avoid errors. If the data are to be used e.g. for English language scientific publications, users can shift between languages, simply by choosing the required language from the menu, or press Ctrl. Alt. "L" at the same time. If the budget allows, translations into more languages will follow.



## **Euromacs applies for EU FP7 Grant**

**From: Paul Mohacsi**

It is my opinion that, as a European association comprised of members from over 20 countries, we have a unique opportunity to show that we can stimulate scientific insights. For this reason I have initiated the submission of a grant application in the Seventh Framework Programme for Research (FP7) of the European Union. Thanks to the assistance of Prof. Janssens, Prof, Meyns (both from Leuven, Belgium), Judith Kikhney and Theo de By we have been able to finalize the application and sent it to the European Commission.

The Euromacs database offers great possibilities to analyse the clinical course of our patients with mechanical circulatory support. This large database that is being built up by Euromacs will enable us to generate unique information about how various device types influence treatment, performance and prognosis in heart failure patient populations. In addition, socio-economic parameters can be assessed, such as quality of life after VAD implantation, the frequency and character of adverse events, patient mortality, morbidity and costs for the health care institutions.

As a result we will obtain a decision making protocol for patients with end stage heart failure for clinicians and health care workers. The study *A Heart for Assist* which has been submitted for an EU grant in the framework of FP7, will for the first time allow selection of the most effective device type for each individual patient.

By mid-December we will know whether the submitted grant application has passed the first round of “HEALTH.2013.2.4.2-2: Comparative effectiveness research of existing technologies for prevention, diagnosis and treatment of cardiovascular diseases”. The application is aimed at financial compensation for the input of data by the hospitals, as well as to build interfaces between local databases and Euromacs. But I trust that, even if Euromacs is not be eligible to receive an EU grant, the Euromacs members will continue to contribute data to the registry.



**Prof. Dr. Paul Mohacsi**

## **Euromacs in numbers**

Per the end of October 2012, Euromacs counts 107 individual members, and 35 institutional members from 25 countries. As compared to the previous year, the numbers have increased by 50%.



# Euromacs website renewed

From: Theo de By

Some members of Euromacs, as well as other visitors, have probably already noticed that the Euromacs website has been renewed. Last summer we made efforts to upgrade the website by increasing its functionalities and by providing more information to Euromacs members, to professionals who have an interest in information concerning the treatment of patients with mechanical surgical support, and to the public at large.

This renewal is considered a first step in developing the database into an every day tool to enter and to obtain data about different areas of interest related to the Euromacs Registry. Members of Euromacs who wish to get acquainted with the Euromacs registry can contact me to obtain a password with which they can enter, via the website, the test database. The password also provides you with proprietary information regarding the Euromacs Association.

On behalf of the board you are invited to visit us at [www.euromacs.org](http://www.euromacs.org) :

The screenshot shows the Euromacs website homepage. At the top, there is a search bar and navigation links for 'Registered Users' and 'New Users' with 'log-in' and 'register' buttons. The main navigation menu includes 'Home', 'About', 'Downloads', 'News', 'Patient Information', 'Links', and 'Contact'. The content area is divided into several sections: 'latest news' with two articles, a 'newsletter' sign-up form, and 'next event' information. A map of Europe is shown in the 'Anytime from Anywhere' section. The footer contains 'Quicklinks', 'About EUROMACS', and 'Contact EUROMACS' information.



## Upcoming events:



## 7th European Mechanical Circulatory Support Summit Multidisciplinary Approach. December 5-8, 2012 – Bad Oeynhausen, Germany:

<http://www.hdz-nrw.de/eums/>



5<sup>th</sup> International Congress

Aortic Surgery and Anesthesia “How to do it”

Ospedale San Raffaele - Milano, December 13<sup>th</sup> - 15<sup>th</sup>, 2012

21st Congress of the International Society for Rotary Blood Pumps  
September 26 - 28, 2012 - Yokohama, Japan <http://www.isrbp2012.org>

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## From the press:

### Czech man with no heart dies after 6 months

<http://www.bbc.co.uk/news/world-europe-19977958>

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