



euromacs

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

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A new and important registry has started; we are all looking forward to its scientific use

From: Prof. Dr. Jan Gummert

As the Euromacs database went live on April 20, the registry is now being rapidly filled with patient data. The clinical data of patients who have received an assist device since January 1, 2012 are to be uploaded. Moreover, some centers have chosen to enter data as far back as January 1, 2011.

For those colleagues whose hospitals have signed an agreement with Euromacs, a new era with great possibilities to follow-up their patients with a mechanical circulatory support system (MCS) has started. From now on, they can follow the patients on a day-to-day basis, both with a clinical purpose, as well as with the perspective of a longer-term scientific analysis.

With respect to the possibilities to register, the board of Euromacs has chosen unrestricted data entry. The participating centers and colleagues can enter both pediatric and adult patients. The number of mechanical circulatory support systems which can be entered is unlimited; the basic characteristics of all assist devices presently on the market are part of the Euromacs standard dataset. In the future, new devices can be added.



Prof. Jan Gummert with Theo de By



The advantages are clear: Time and energy are saved, since the dataset is the same for all participants. As a result, the statistical outcome of multi-center analyses is optimized and comparable with respect to the functionality of the assist devices.

I personally have lengthy experience in organizing and analyzing cardiovascular surgery data¹. It is therefore very satisfactory to determine that Euromacs has been able to structure the database in such a way that it facilitates clinical input on the one hand, while combining the possibilities for short as well as long-term clinical and scientific analyses on the other hand.

In our institution, the Herz- and Diabeteszentrum (HDZ) North Rhine Westphalia, we have accumulated experience in treating patients with end stage heart failure by means of MCS. Now that Euromacs has become operational, its registry will enable us to compare our results with the anonymized data of our colleagues. We intend to file for the approval of the Euromacs scientific advisory committee later this year. As the number of registered MCS patients grows, all participating centers will be enabled to analyze the clinical performance of assist devices, comparing these against such a quantity of data that significant conclusions may be drawn, based upon which scientific publications can be generated.



**The Heart and Diabetes Center
North Rhine Westphalia in Bad Oeynhausen**

¹Gummert JF, Funkat AK, Beckmann A, Ernst M, Hekmat K, Beyersdorf F, Schiller W. Cardiac surgery in Germany during 2010: a report on behalf of the German Society for Thoracic and Cardiovascular Surgery. *Thorac Cardiovasc Surg.* 2011 Aug;59(5):259-67. Epub 2011 Jun 10. PubMed PMID: 21667446.

² Aissaoui N, Hakim-Meibodi K, Morshuis M, Gummert J. Recurrent thrombosis after mechanical circulatory support. *Interact Cardiovasc Thorac Surg.* 2012 Feb 20. [Epub ahead of print] PubMed PMID: 22350773.



Why is Euromacs so attractive for clinicians and researchers and what difference does Euromacs make?

From: Theo de By

As managing director of Euromacs, I am frequently asked by representatives of hospitals to explain the advantages of our Registry. Often clinicians who are member of Euromac, need to explain to their board, or to their legal department, why it makes sense to join Euromacs and to register patients with an assist device in our European Database. For your convenience, I give you here a summary of arguments about the attractiveness and the unique characteristics of Euromacs:

- The data in the Euromacs Registry are owned by the hospitals. Euromacs has no access to these data.
- The registry fulfills international legal criteria with respect to data protection.



Euromacs is a result of unique cooperation between cardiovascular hospitals in many countries

Progress of Euromacs in numbers

As per July 1, 2012, the Euromacs Association counts 91 members from 18 different countries.

- Euromacs has been built up to address all clinical aspects of implantation, follow-up and registry of complications of assist device recipients. Thus, it saves the trouble of building local databases.
- Provides immediate access to patient data and provides specific reports.
- The data in Euromacs are pseudonymized and anonymized; thus they can be used for your scientific analyses.
- Web-based registry can be accessed at any time and from anywhere.
- Track all your procedures, complications and follow-up.
- ALL contributors to the registry will receive a FREE annual report (the first annual report is expected in 2013).
- Last, but not least, participation in the Euromacs Registry and membership are free of charge.



“Dendrite Clinical Systems is delighted to be working in collaboration with Euromacs on this exciting project.”

From: Peter K.A. Walton, MA MB BChir MBA(Lond) FRCP

“We are a specialist supplier of clinical databases and analysis software, consultancy and publishing services for the international healthcare sector. Over the last 19 years, we have built a global client base across >250 hospitals with >90 national and international databases in more than 40 countries. We are also one of the leading suppliers of clinical software to hospitals and institutions in the world and have software installations in all the major European countries, as well as the United States, the Middle and Far East and Australia.



Peter Walton

We work in conjunction with many of the leading international healthcare societies and associations, and our international client list includes: the European Association for Cardio-Thoracic Surgeons (EACTS), the European Society for Vascular Surgery, the Cardiovascular and Interventional Radiological Society of Europe, the Saudi Heart Association and the American Venous Forum.

Our award-winning national and international database reports include the EACTS Adult Cardiac Surgical Database series of reports. The 2010 edition included over one million cardiac surgical operations from 366 hospitals based in 29 countries. We also publish the National Adult Cardiac Surgical Database reports in collaboration with the Society for Cardiothoracic Surgery in Great Britain & Ireland, which was awarded the British Medical Journal Group Award for the Best Quality Improvement in 2010.

In addition, we are currently hosting the largest global disease registry involving 55,000 atrial fibrillation patients, the GARFIELD (Global Anticoagulant Registry in the Field) Registry.

As a company, we believe that this web-based registry will facilitate improved decision-making for physicians and healthcare providers by providing much needed clinical data. We look forward to working with physicians and centers and producing a comprehensive mechanical circulatory support report in the future.”



Euromacs receives support

Statement by the Friede Springer Heart Foundation, Board of Directors and Trustees

“Euromacs e.V. is receiving support for its work from our Foundation because the importance of this transnational registry can hardly be overestimated. The internationally organized exchange of patient data will lead to new, broad-based knowledge, and this will be of great significance for the treatment of individual patients. In addition, the efficiency of the latest technical developments in medicine and new methods of treatment can be evaluated and studied. We consider this innovatory approach worthy of our support.”

“Since its inception in 2004, the Friede Springer Heart Foundation has sponsored a number of preventive health projects at hospitals in Berlin (Deutsches Herzzentrum, Charité), Münster (University Hospital), Heidelberg (University Hospital), Cologne (Porz am Rhein Hospital) and Bad Oeynhausen (Heart Center North Rhine Westphalia). Financial support by the Friede Springer Heart Foundation has also been given to the Registry for Congenital Heart Disease and the supporting association of the Berlin Myocardial Infarction Registry. Information on the individual projects sponsored is to be found on the homepage of the Foundation (<http://www.friede-springer-herzstiftung.de/foerderprojekte.htm>).”



Friede Springer agrees with Tolstoi:

*„In the heart of an individual rests
the beginning and the end of all
Matter.” (Leo Tolstoi 1828-1910)*

Friede Springer initiated this Foundation in 2004 as heart and circulatory diseases belong to the most frequent causes of death.

The aim of the Foundation is to support developments of endeavours which improve the diagnostic and therapeutic care of patients. Friede Springer started this Foundation also in memory of her husband, Axel Springer, who, in the absence of refined therapeutic methods, died of a cardiac disease in 1985.



Upcoming events:

20th Congress of the International Society for Rotary Blood Pumps
September 20 - 22, 2012 - Istanbul, Turkey <http://www.isrbp2012.org/index.php>



7th European Mechanical Circulatory Support Summit Multidisciplinary Approach. December 5-8, 2012 – Bad Oeynhausen, Germany:
<http://www.hdz-nrw.de/eums/>

From the press:

Bambino Gesù Hospital: Smallest Artificial Heart Baby
<http://todaynewsgazette.com/bambino-gesu-hospital-smallest-artificial-heart-baby/>

Can you build a bionic body? The heart
<http://www.bbc.co.uk/news/health-17131259>

UM Cardiovascular Center Performs 500th Heart Device Implant
<http://detroit.cbslocal.com/2012/06/03/um-cardiovascular-center-performs-500th-heart-device-implant/>

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