

## NEWSLETTER No. 8, April 2015

**Dear readers,  
In this newsletter you can read about:**

- EUROMACS First Annual Report published in press
- VAD Coordinators Education Course, May 23-25
- General Members' meeting, on April 16 in Nice, France
- The Importance of EQ5D data to measure patients' quality of life
- Board Composition as per January 1, 2015

### **EUROMACS 1<sup>st</sup> Annual Report** **From: Prof. Dr. Jan Gummert**

The first Annual Report of our Registry has been accepted for publication in the European Journal of Cardio-Thoracic Surgery (EJCTS), and is now in press. The Board of EUROMACS acknowledges the representatives of all participating VAD implantation centers for their contribution. Thanks to their consistent input it has been possible to provide a first analysis of data from the Registry.

With this first annual publication, and with the second report in preparation, the EUROMACS Registry has come of age. We have now come to a phase in which, apart from producing accumulated overviews of the results of all cases, the data enables us to generate bespoke statistics. This service can be provided to those clinicians and scientists who wish to either benchmark their own data against the (anonymous) data of all other centers participating in the EUROMACS Registry, or carry out studies that are aimed at analyzing outcomes of treatment with mechanical circulatory support.

Presently, 27 VAD implanting centers are contributing data internationally, and



**Euromacs Chairman Prof. Jan Gummert**

three centers are in the process of engagement.

The annual report shows that our database opens unique possibilities to get a better insight in the clinical results. I invite all colleagues, who haven't already done so, to join EUROMACS, to contribute data and to use those data in for the improvement of clinical care of our patients.



## VAD Coordinators Course 28-30 May, 2015 Berlin

Theo de By

The management of patients with MCS requires care from multi-disciplinary teams. EACTS and EUROMACS have taken the initiative to set up a Training Course for VAD co-ordinators and aspiring VAD co-ordinators. The VAD co-ordinator is the spider in the web of the multi-disciplinary network of health professionals, and is the first in line to communicate with patients with a VAD. Presently there is the need for VAD co-ordinator education. Although the function differs from one hospital to another, there are many similarities between these functions in the hospitals. The main task of the VAD co-ordinator is setting priorities, based on the knowledge of the roles of all these disciplines as well as of the departments in the hospital. The VAD co-ordinator often functions as an anchor for medical specialists as well as for patients, and watches over an established process of the patients through the internal and external system of health care.



The Coordinators course includes hands-on training

The course will provide attendees with a detailed understanding, knowledge and skills in all aspects of end-stage heart failure and the application of assist devices.

Subjects include such items as:

- Anticoagulants: current practices
- Wound management
- Inclusion criteria for patients
- Psychological aspects
- Fluid management of LVAD patients
- Weight management
- Treatment of infections

At the end of the course, attendees will have a firm knowledge base of the subject, will know how patients are assessed, who will have an operation and how, and which other treatment options are available.

The faculty consists of experienced scientists from different clinical fields and with vast experience in the treatment of patients with mechanical circulatory support. Moreover, the latest information from the industry will add insight to the functionalities of the devices.

### The VAD Coordinators course Organisation and Registration

The VAD Coordinators course is organized by EACTS in collaboration with the Deutsches Herzzentrum Berlin and EUROMACS.

It will take place in the academy of perfusion

Course information and registration, please is available at [www.eacts.org](http://www.eacts.org)



## Committee and General Members' meeting

**16 April 2015 Nice, France**

The next meeting of the committee, the board, and members of Euromacs will be held on 16 April 2015 during the ISHLT Meeting in Nice, France. The meeting will take place in Room Calliope from 12:45 pm - 2:15 pm. EUROMACS members will receive an invitation and an agenda.

### **The Importance of providing EQ-5D data to the EUROMACS Registry.**

**From: Theo de By**

While composing the 2014 annual data overview from the EUROMACS Registry, it became apparent that data with respect to the well being of patients, the so-called EQ-5D data, are unfortunately, often ignored.

The basis of the EQ-5D is the holistic view of health, which includes the medical definition, as well as the fundamental importance of independent physical, emotional and social functioning. The concept of health in EQ-5D also encompasses both positive aspects (well-being) and negative aspects (illness)<sup>1</sup>.

The EQ-5D data in the EUROMACS Registry may be used to assess the relationship between the EQ-5D index, the various patient characteristics and outcomes. Using studies from a range of clinical scenarios, scientists can assess relationships between the EQ-5D index and other variables at different cardiac disease stages and in different treatment groups. A patient-level analysis has substantially more power than other methods<sup>2</sup>.

As the discussion about the quality of the life sustaining therapy by means of mechanical circulatory support versus heart

transplantation intensifies, the provision of EQ-5D data is of increasing importance<sup>3</sup>. Presently, data comparisons concentrate on actuarial graft and patient survival, or freedom of adverse events. As information with respect to outcomes increases, and the results of both therapies improve, the quality of life experience from individual patients must be expressed in objective parameters such as EQ-5D.

On the occasion of the consolidation of EUROMACS data (below, under 5) the reason for not providing such data, given by centers was that patients were referred by cardiologists and peripheral hospitals. While clinical data was communicated, EQ-5D data was often missing.

### **The EUROMACS board stresses the importance of submitting EQ-5D data to interested scientists**

After all, such data in the EUROMACS registry may be used to evaluate the results of either therapy.

<sup>1</sup>. Gusi N, Olivares PR, Rajendram R. The EQ-5D Health-Related Quality of Life Questionnaire. Handbook of Disease Burdens and Quality of Life Measures 2010, pp 87-99

<sup>2</sup>. Goldsmith K, Relationship between the EQ-5D index and measures of clinical outcomes in selected studies of cardiovascular interventions. Health and Quality of Life Outcomes 2009, 7:96

<sup>3</sup>. Relationship between functional capacity and quality of life in heart transplant patients



## Consolidation of data in the EUROMACS registry

The participating EUROMACS members are kindly requested to update their patient data per 31 December, 2014. Specifically, an update, by positive confirmation in the Registry's database is needed for those patients who are alive on December 31<sup>th</sup>. Additionally, all clinical events through December 31<sup>st</sup> are to be updated. And, finally, **please add EQ-5D data!!**

The next update will be next 30th June. The data to 30th June 2015 will be presented at the EACTS Annual meeting, in Amsterdam. (3-7 October 2015)

## Board Composition 1 January 2015.

On 4 December 2014 the General members' meeting confirmed the election of several board members.

Professor Ivan Netuka was elected as member of the executive board. Professors Jan Gummert and Paul Mohacsi were re-elected as members of the executive board. Other members of the executive board are Professors Bart Meyns and Luigi Martinelli.

Drs. Kadir Caliskan, Evaristo Castedo and Professor Thomas Krabatsch were elected to the extended board alongside existing members Professors Pascal Leprince and Finn Gustafsson.

During the members' meeting it was proposed to nominate Professor Roland Hetzer, who stepped down on 31<sup>st</sup> December, as honorary chairman of the association. The board and members expressed their gratitude for the initiative Professor Hetzer had taken to start the Registry and his continuous efforts to make it an international success.



*Professor Hetzer receives a symbolic chairman's hammer during the general members' meeting in Bad Oeynhausen*



## Forthcoming Meetings

35th ISHLT Annual Meeting and Scientific Sessions

15-18 April, Nice, France

[www.isHLT.org](http://www.isHLT.org)

The 23<sup>rd</sup> Conference of the International Society for Rotary Blood Pumps

27– 29 September, 2015 Dubrovnik, Croatia

Abstract Submission Deadline 31 May 2015

<http://isrbp2015.org>

The 29<sup>th</sup> EACTS Annual Meeting, Amsterdam, The Netherlands,

3-7 October, 2015

Abstract Submission Deadline 30 April 2015

<http://www.eacts.org/annual-meeting.aspx>

**29<sup>th</sup> EACTS**  
Annual Meeting  
Amsterdam, The Netherlands  
3-7 October 2015



The 10<sup>th</sup> EUMS, European Mechanical Support Summit

2-5 December 2015

Paris, France

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