Study Group on Peripartum Cardiomyopathy

Aims

- To establish a platform where current knowledge on peripartum cardiomyopathy based on experimental and clinical studies is summarized and regularly updated.
- To raise awareness of this uncommon but devastating problem by promoting sessions at congresses and publishing articles.
- To coordinate the collection and analysis of data internationally for better understanding of the condition.
- To meet regularly to discuss and update management strategies with a focus on novel diagnostic and therapeutic approaches.
- Provide information and contact addresses on our webpage for physicians and patients concerned about PPCM.

To initiate and be advocates for the PPCM Registry

Affiliate members:
Amam Mbakwem (Nigeria)
Long-Term Registry on Patients with Peripartum Cardiomyopathy

Executive Committee:
Karen Sliwa, Chairperson
Burkhart Pieske, Chairperson
Denise Hilfiker-Kleiner
Aldo Pietro Maggioni
Alex Mebazza
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Background on PPCM Registry
Study group highlighted in the Position Paper, published 2010, the lack of data from ESC member countries

Current state of knowledge on aetiology, diagnosis, management, and therapy of peripartum cardiomyopathy: a position statement from the Heart Failure Association of the European Society of Cardiology Working Group on peripartum cardiomyopathy

Karen Sliwa¹, Denise Hilfinger-Kleiner², Mark C. Petrie³, Alexandre Mebazaa⁴, Burkert Pieske⁵, Eckhart Buchmann⁶, Vera Regitz-Zagrosek⁷, Maria Schaufelberger⁸, Luigi Tavazzi⁹, Dirk J. van Veldhuisen¹⁰, Hugh Watkins¹¹, Ajay J. Shah¹², Petar M. Seferovic¹³, Uri Elkayam¹⁴, Sabine Pankuweit¹⁵, Zoltan Papp¹⁶, Frederic Mouquet¹⁷, and John J.V. McMurray¹⁸
Peripartum Cardiomyopathy

Study group members contributed to new knowledge advancing the understanding of the disease

MicroRNA-146a is a therapeutic target and biomarker for peripartum cardiomyopathy

Julie Halkein, Sebastien P. Tabruyn, Karen Sliwa, Denise Hilfiker-Kleiner, Ingrid Struman et al April 2013


Peripartum Cardiomyopathy as a Part of Familial Dilated Cardiomyopathy

Karin Y. van Spauldonck-Zwaart, MD; J. Peter van Tintelen, MD, PhD; Dirk J. van Veldhuisen, MD, PhD; Rik van der Werf, MD; Jan D.H. Jungbloed, PhD; Walter J. Paulus, MD, PhD; Dennis Doeljes, PhD; Maarten F. van den Berg, MD, PhD
Background

1. Proposal for a **PPCM Registry** was submitted in September 2010.
2. Subcommittee of the PPCM Study group (8 members) met at the ESC HF Winter Meeting, held 26\(^{th}\) and 28\(^{th}\) January 2011 to agree on data to be collected, proposal and CRFs.
3. All documents circulated to entire group in January 2011.
4. Group looked at a first version of ‘mock website’ at the ESC HF Gothenburg meeting (June 2011).
5. Protocol finalized and start of Registry May 2012
Access via the EURObservational Research Program or via a link though the Heart Failure Association (HFA) of the ESC website.

The front page will contain the mandatory key questions qualifying a patient as potential PPCM:

- Peripartum stage
- Signs and/or symptoms of heart failure
- Ejection fraction <45%

This will ensure that mainly patients with suspected PPCM will be entered.

Link to the Pregnancy in cardiac disease registry.

www.escardio.org
EUR Observational Research Programme

Peripartum Cardiomyopathy Registry
Recruitment status as of May 16th, 2013

71 participating centres within 35 countries

www.escardio.org
Peripartum Cardiomyopathy Registry
Recruitment status as of May 16th, 2013

64 patients enrolled within 18 countries:
EURObservational Research Programme

Peripartum Cardiomyopathy Registry
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Creating awareness for the condition and the registry

1. Promoting the registry via lectures given
2. Referring to the PPCM registry in publications
3. Please enter cases!!