

Study Group on Peripartum Cardiomyopathy

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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



Long-Term Registry on Patients with Peripartum Cardiomyopathy

Executive Committee:

Karen Sliwa, Chairperson
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Denise Hilfiker-Kleiner
Aldo Pietro Maggioni
Alex Mebazza
Marc Petri
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Katrin Walenta
J McMurray (Glasgow, GB)
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Coordinating centre:

EURObservational Research Programme
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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



European Journal of Heart Failure (2010) 12, 767–778
doi:10.1093/eurjhf/hfq120

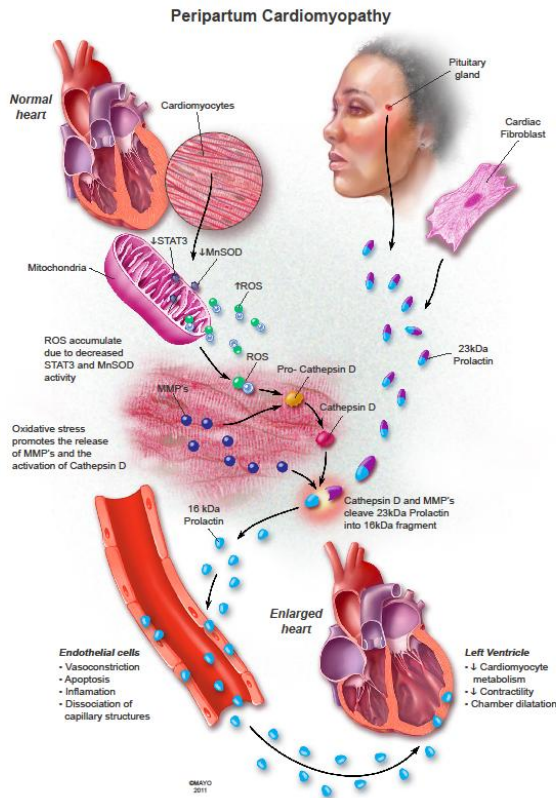
POSITION STATEMENT

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 Sliwa^{1*}, Denise Hilfiker-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



European Heart Journal Advance Access published February 3, 2012

European Heart Journal
doi:10.1093/eurheartj/ehs485

BASIC SCIENCE

Circulating microparticles as indicators of peripartum cardiomyopathy

Katrin Walenta¹*, Viktoria Schwarz¹, Stephan Schirmer¹, Ingrid Kindermann¹, Erik B Friedrich¹, Erich Franz Solomayer², Karen Sliwa³, Saida Labidi⁴, Denise Hilfiker-Kleiner⁴, and Michael Böhm¹

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JOURNAL OF THE AMERICAN HEART ASSOCIATION

Evaluation of Bromocriptine in the Treatment of Acute Severe Peripartum Cardiomyopathy: A Proof-of-Concept Pilot Study

Karen Sliwa, Lori Blauwet, Kemi Tibazarwa, Elena Libhaber, Jan-Peter Smedema, Anthony Becker, John McMurray, Hatice Yamac, Saida Labidi, Ingrid Struman and Denise Hilfiker-Kleiner

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HEART
and Education in Heart

Downloaded from heart.bmj.com on February 25, 2013 - Published by group.bmj.com

Cardiomyopathy

ORIGINAL ARTICLE

Predictors of outcome in 176 South African patients with peripartum cardiomyopathy

Lori A Blauwet,¹ Elena Libhaber,^{2,3} Olaf Forster,⁴ Kemi Tibazarwa,^{2,5} Alex Mebazaa,⁶ Denise Hilfiker-Kleiner,⁷ Karen Sliwa²

European Journal of Heart Failure Advance Access published March 23, 2012

European Journal of Heart Failure
doi:10.1093/eurjhf/ehs018

SHORT REPORT

Unexpected and rapid recovery of left ventricular function in patients with peripartum cardiomyopathy: impact of cardiac resynchronization therapy

Frederic Mouquet¹*, Meriem Mostefa Kara¹, Nicolas Lamblin¹, Capucine Coulon², Stephane Langlois¹, Christelle Marquis¹, and Pascal de Groote¹

¹Service de Cardiologie, Hôpital Cardiologique de Monroville, Hôpital Cardiologique, CHU Lille, 59037 Lille Cedex, France and ²Service de Cardiologie, Hôpital de France, CHU Lille, Lille, France

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

The Journal of Clinical Investigation. More information at www.jci.org/articles/view/64365

Peripartum Cardiomyopathy as a Part of Familial Dilated Cardiomyopathy

Karin Y. van Spaendonck-Zwarts, MD; J. Peter van Tintelen, MD, PhD;
Dirk J. van Veldhuisen, MD, PhD; Rik van der Werf, MD; Jan D.H. Jongbloed, PhD;
Walter J. Paulus, MD, PhD; Dennis Dooijes, PhD; Maarten P. van den Berg, MD, PhD



ESC HFA PPCM Registry

Start May 2012

N=1000 patients

European Society of Cardiology Members Countries

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 26th and 28th 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 through 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



The screenshot shows the homepage of the EURObservational Research Programme. The header includes the program name and navigation links: Welcome, My Account, Upload, and Download. A sidebar on the left features a globe and a 'Survey' dropdown menu. The main content area is titled 'Webcasts from the ESC Congress 2011:' and contains a table with columns for Date, Title, and Presenter. Below the table, there is a section for 'Important information' and a note about submitting topics for publication.

	Date	Title	Presenter
Open	30 Aug 2011	EORP: what and why.	L Tavazzi (Cotignola, IT)
Open	30 Aug 2011	General Registry: Heart Failure.	A P Maggioni (Florence, IT)
Open	30 Aug 2011	Sentinel Registry: Ablation in Atrial Fibrillation.	J Brugada Terradellas (Barcelona, ES)
Open	30 Aug 2011	Special Registry: Pregnancy in Cardiac Disease.	J W Roos-Hesselink (Rotterdam, NL)
Open	31 Aug 2011	General Registry: Chronic Ischaemic Heart Disease.	R Ferrari (Ferrara, IT)
Open	31 Aug 2011	Sentinel Registry: Transcatheter Valve Treatment.	C Di Mario (London, GB)
Open	31 Aug 2011	Special Registry: Cardiomyopathies.	P M Elliott (London, GB)
Open	31 Aug 2011	Ancillary to Heart Failure Registry: Peripartum Cardiomyopathy.	K Sliwa-Hahnle (Cape Town, ZA)

Important information:

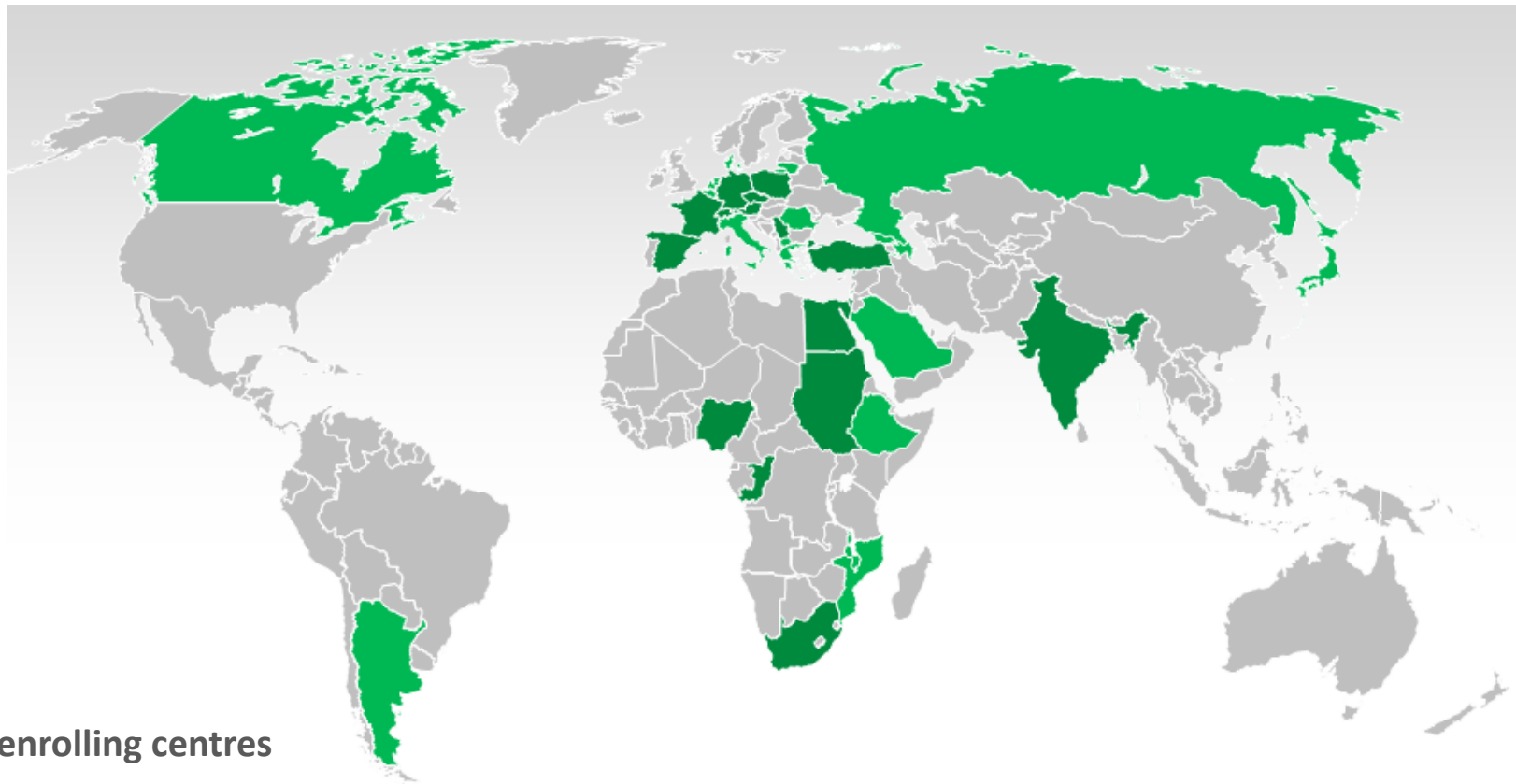
Participants are welcome to [submit a topic for publication](#) according to the [EORP publication policy](#) and to [request statistical analyses](#) on the databases.

Please use the form posted on the right hand side of this page and return the completed form to eorp@escardio.org

Peripartum Cardiomyopathy Registry

Recruitment status as of May 16th, 2013

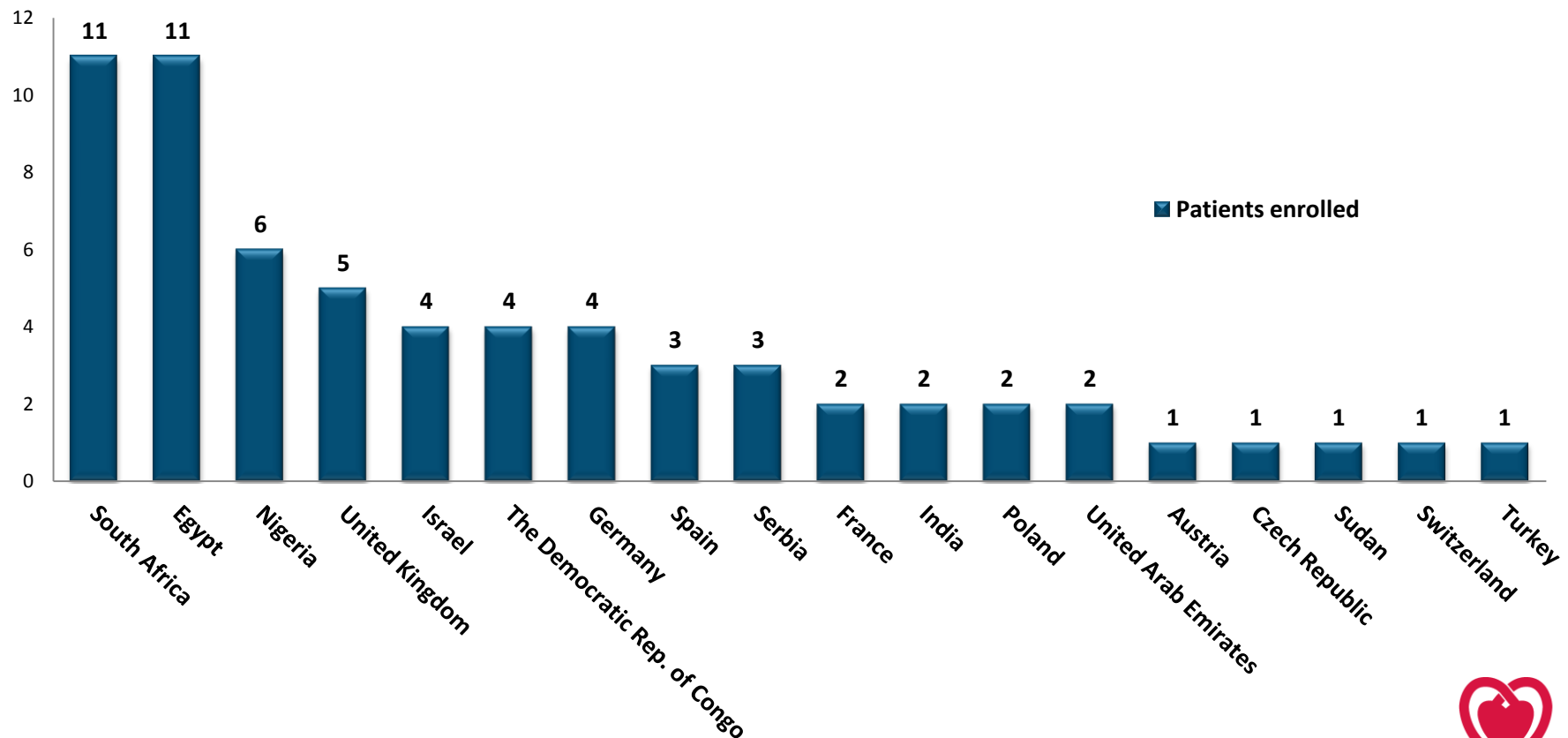
71 participating centres within 35 countries



- enrolling centres
- registered centres

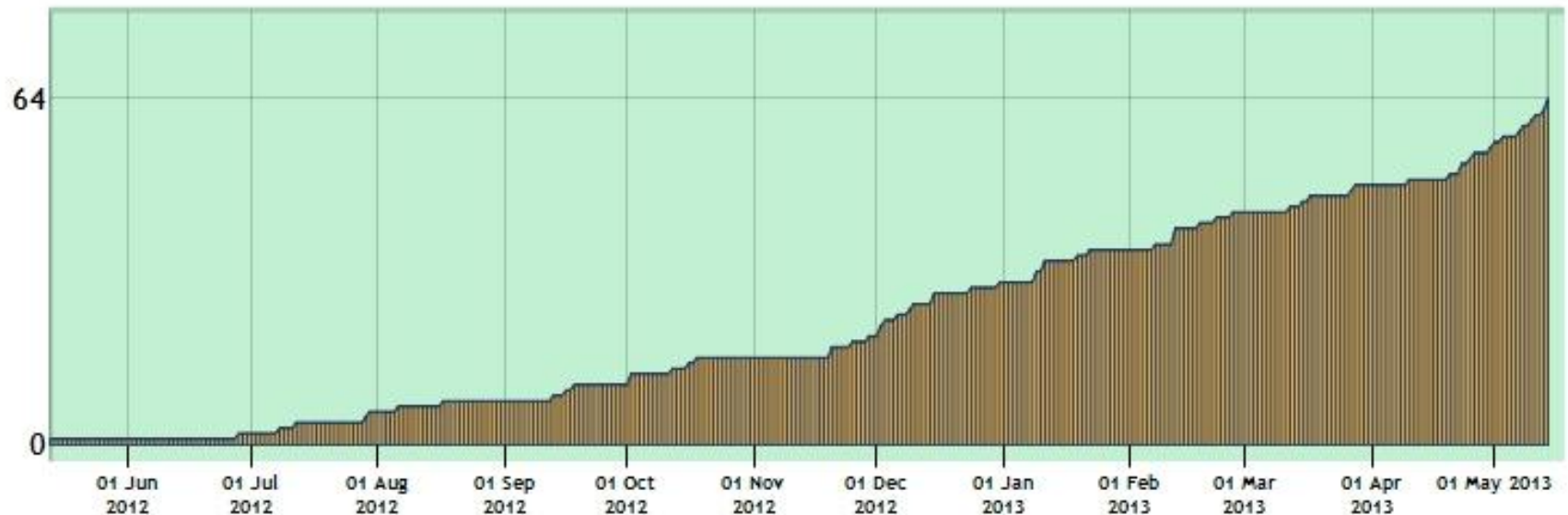
Peripartum Cardiomyopathy Registry Recruitment status as of May 16th, 2013

64 patients enrolled within 18 countries:



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

Enrolment



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!!

<http://www.escardior.org/communities/JFA/committees/peripartum-cardiomyopathy/Pages/welcome.aspx>