

# **Peripartum Cardiomyopathy (PPCM) Registry**

## **Study Group & Investigators meeting**

**3 Septembre 2013  
ESC Congress, Amsterdam**

## Long-Term Registry on Patients with Peripartum Cardiomyopathy

### Executive Committee:

- Karen Sliwa, Chairperson
- Burkert Pieske, Chairperson
- Katrin Bachelier
- Uri Elkayam
- Roger Hall
- Denise Hilfiker-Kleiner
- Aldo Pietro Maggioni
- John McMurray
- Alexandre Mebazaa
- Frederic Mouquet
- Mark Petrie
- Piotr Ponikowski
- Vera Regitz-Zagrosek
- Jolien Roos-Hesselink
- Maria Schaufelberger
- Petar Seferovic
- Ajay Shah
- Luigi Tavazzi
- Karin van Spaendonck-Zwart
- Dirk van Veldhuisen

### Coordinating Centre:

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# 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 up-dated.
- 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.
- To provide information and contact addresses on our webpage for physicians and patients concerned about PPCM.

**To initiate and be advocates for the PPCM Registry**



**Karen Sliwa (Cape Town, South Africa)**  
**Burkert Pieske (Graz, AT)**



**Denise Hilfiker-Kleiner (Hannover, DE)**  
**John McMurray (Glasgow, GB)**  
**Alexandre Mebazaa (Paris, FR)**  
**Mark Petrie (Glasgow, GB)**  
**Vera Regitz-Zagrosek (Berlin, DE)**  
**Maria Schaufelberger (Gothenburg, SE)**  
**Petar Seferovic (Belgrade, RS)**  
**Ajay Shah (London, GB)**  
**Luigi Tavazzi (Cotignola, IT)**  
**Dirk van Veldhuisen (Groningen, NL)**  
**Karin van Spaendonck-Zwart (Amsterdam, NL)**  
**Uri Elkayam (Los Angeles, US)**  
**Frederic Mouquet (Lille, FR)**  
**Katrin Bachelier (Homburg, DE)**

*Affiliate member:*

**Amam Mbakwem (Nigeria)**

## Background on PPCM Registry

Study Group highlighted in the Position Paper, published 2010,  
the lack of data from ESC member countries



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CARDIOLOGY®

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

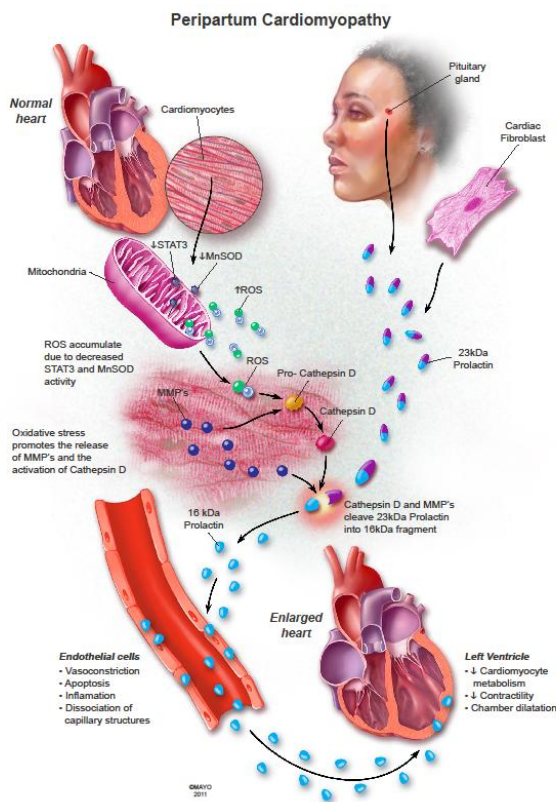
POSITION STATEMENT

### **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<sup>1\*</sup>, Denise Hilfiker-Kleiner<sup>2</sup>, Mark C. Petrie<sup>3</sup>, Alexandre Mebazaa<sup>4</sup>, Burkert Pieske<sup>5</sup>, Eckhart Buchmann<sup>6</sup>, Vera Regitz-Zagrosek<sup>7</sup>, Maria Schaufelberger<sup>8</sup>, Luigi Tavazzi<sup>9</sup>, Dirk J. van Veldhuisen<sup>10</sup>, Hugh Watkins<sup>11</sup>, Ajay J. Shah<sup>12</sup>, Petar M. Seferovic<sup>13</sup>, Uri Elkayam<sup>14</sup>, Sabine Pankuweit<sup>15</sup>, Zoltan Papp<sup>16</sup>, Frederic Mouquet<sup>17</sup>, and John J.V. McMurray<sup>18</sup>**

# 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 Walenta<sup>1</sup>\*, Viktoria Schwarz<sup>1</sup>, Stephan Schirmer<sup>1</sup>, Ingrid Kindermann<sup>1</sup>, Erik B Friedrich<sup>1</sup>, Erich Franz Solomayer<sup>2</sup>, Karen Sliwa<sup>3</sup>, Saida Labidi<sup>4</sup>, Denise Hilfiker-Kleiner<sup>4</sup>, and Michael Böhm<sup>1</sup>

\*Klinik für Innere Medizin III, Kardiologie, Angiologie und Internistische Intensivmedizin, Universitätsklinikum des Saarlandes, Homburg 66421, Saar, Germany; <sup>1</sup>Klinik für Frauenheilkunde, Geburtshilfe und Reproduktionsmedizin, Homburg, Saar, Germany; <sup>2</sup>Faculty of Health Sciences, Hater Cardiovascular Research Institute, University of Cape Town, Rondebosch, South Africa; and <sup>3</sup>Klinik für Kardiologie und Angiologie, Medizinische Hochschule Hannover, Hannover, Germany

Received 26 May 2011; revised 4 December 2011; accepted 8 December 2011

# Circulation

American Heart Association  
*Learn and Live*

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

Circulation 2010, 121:1465-1473; originally published online March 22, 2010  
doi: 10.1161/CIRCULATIONAHA.109.901496  
Circulation is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75234  
Copyright © 2010 American Heart Association. All rights reserved. Print ISSN: 0009-7322. Online ISSN: 1524-4539

# 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,<sup>1</sup> Elena Libhaber,<sup>2,3</sup> Olaf Forster,<sup>4</sup> Kemi Tibazarwa,<sup>2,5</sup> Alex Mebazaa,<sup>6</sup> Denise Hilfiker-Kleiner,<sup>7</sup> Karen Sliwa<sup>2</sup>

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

European Journal of Heart Failure  
doi:10.1093/eurjhf/hfr021

**SHORT REPORT**

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

Frederic Mouquet<sup>1</sup>, Meriem Mostefa Kara<sup>1</sup>, Nicolas Lamblin<sup>1</sup>, Capucine Coulon<sup>2</sup>, Stephane Langlois<sup>3</sup>, Christelle Marquie<sup>1</sup>, and Pascal de Groote<sup>1</sup>

<sup>1</sup>Service de Cardiologie, Pôle Cardio-vasculaire et Pneumologie, Hôpital Cardiologique, CHRU Lille, 59037 Lille Cedex, France and <sup>2</sup>Service de Cardiologie, Hôpital Pasteur, Université de Strasbourg, CHRU 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](http://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

# PPCM Registry

The electronic Case Report Form will be accessed through the website of the EURObservational Research Programme (EORP):

<http://www.eorp.org>

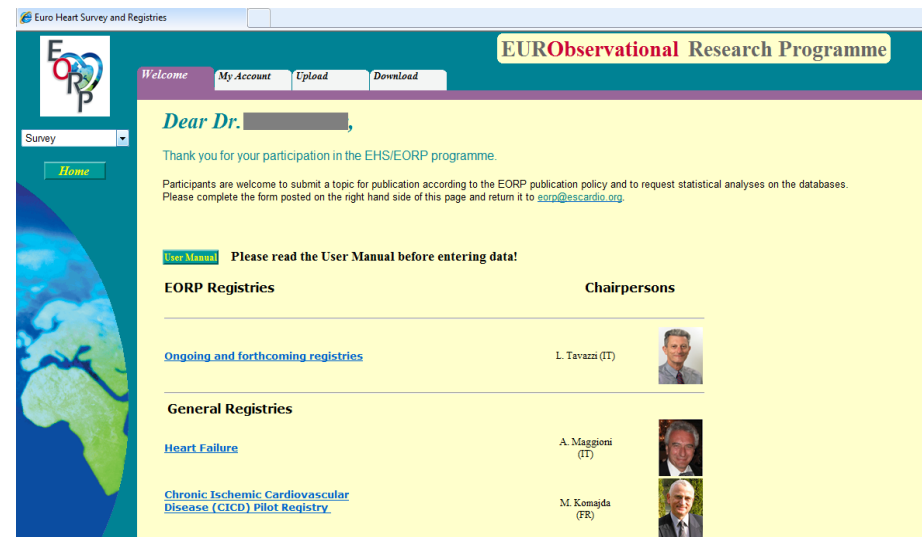
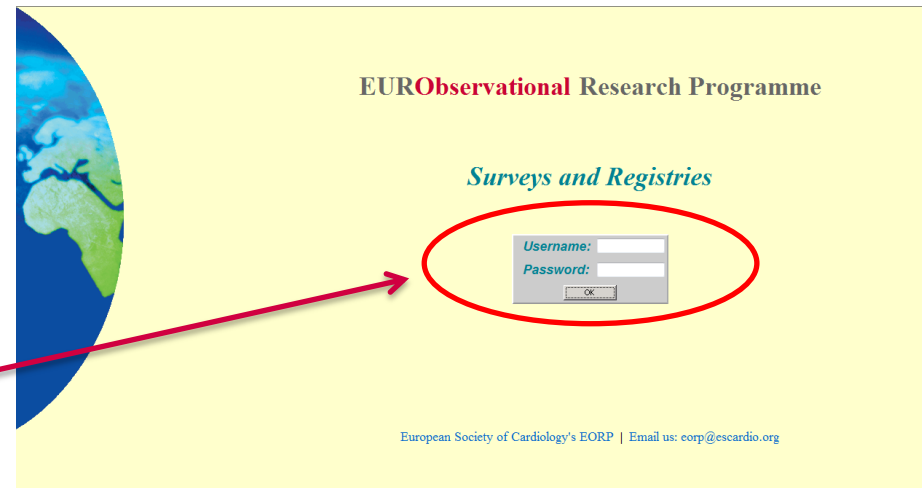
To register and obtain login codes to access the EORP website, please contact the EORP department:

[eorp@escardio.org](mailto:eorp@escardio.org)

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

1. Peripartum stage
2. Signs and/ or symptoms of heart failure
3. Ejection fraction <45%
4. Other causes of heart failure excluded

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

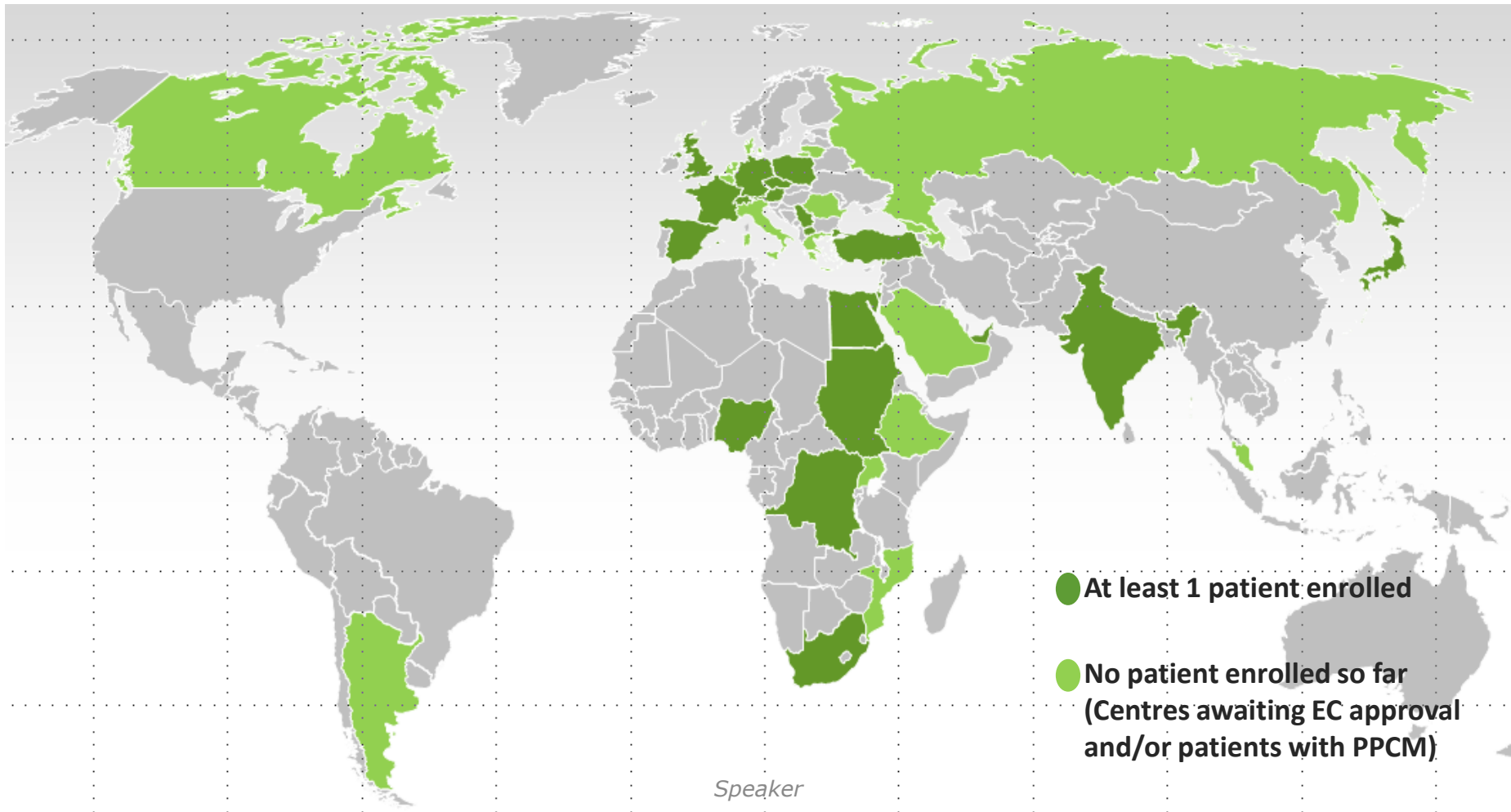




# Peripartum Cardiomyopathy Registry

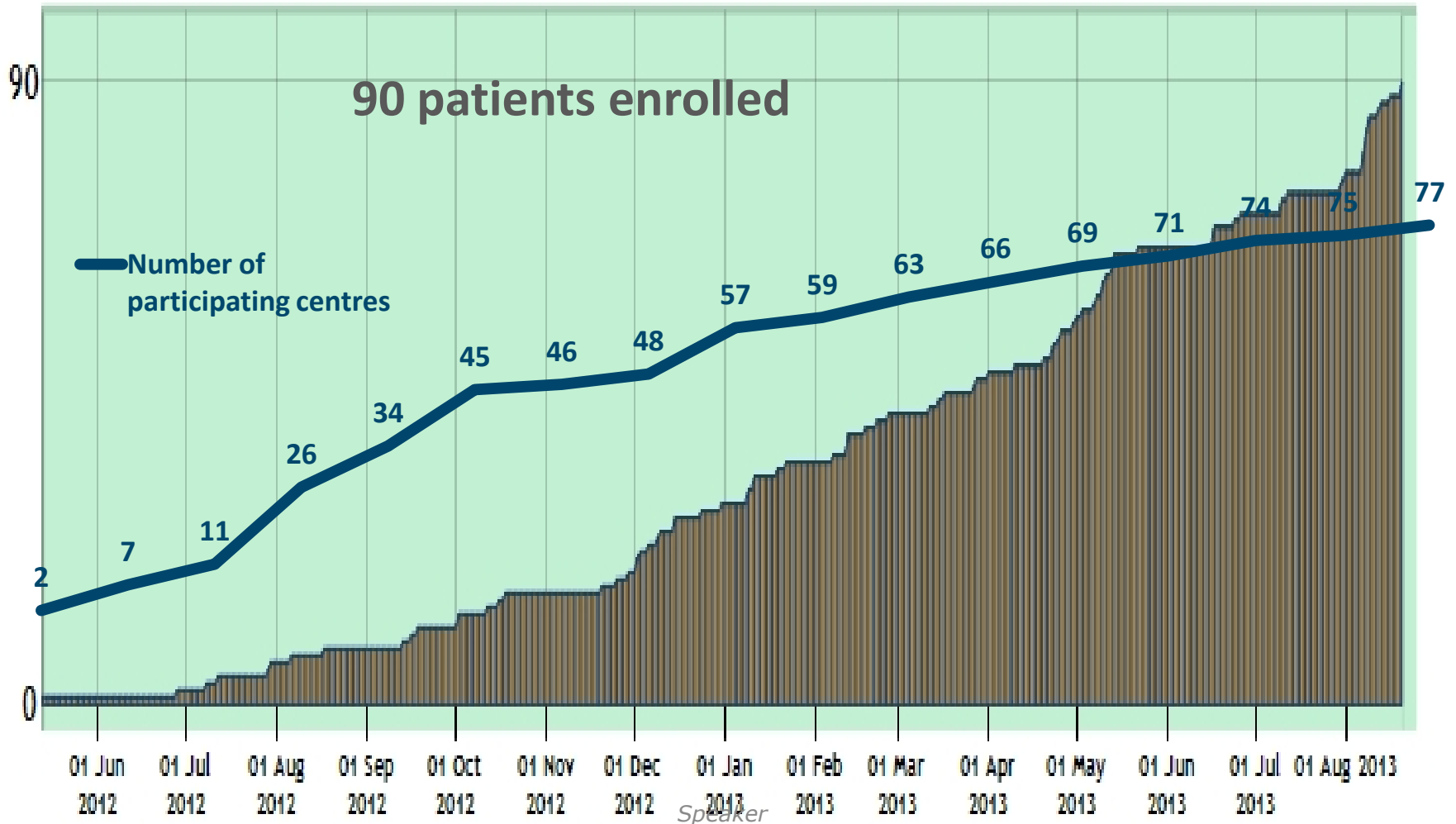
Recruitment status as of August 21<sup>st</sup>, 2013

77 participating centres across 38 countries



# Peripartum Cardiomyopathy Registry

## Progression of recruitment as of August 21<sup>st</sup>, 2013

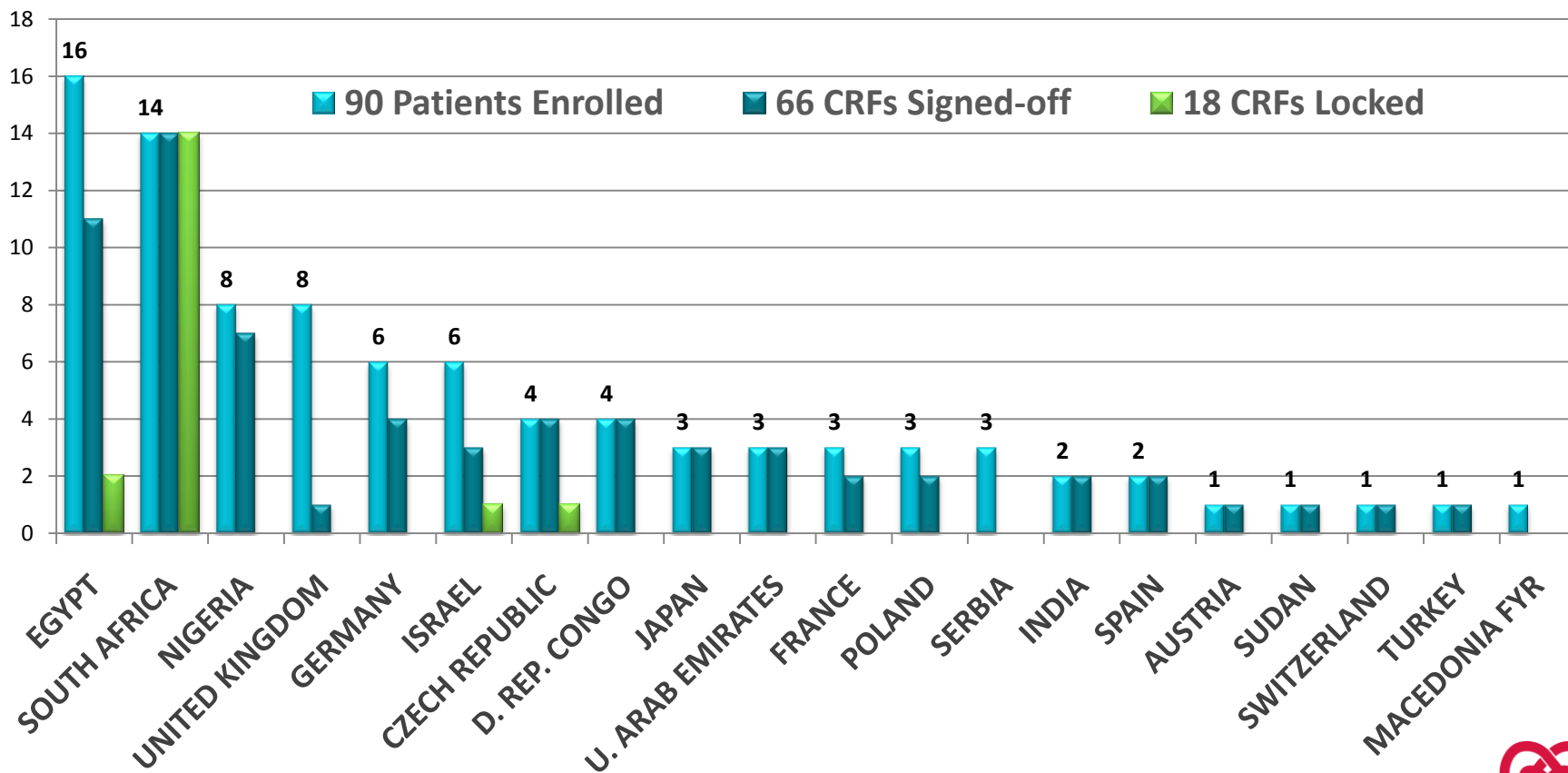




# Peripartum Cardiomyopathy Registry

Recruitment status as of August 21<sup>st</sup>, 2013

90 patients enrolled by 32 centres across 20 countries



# Peripartum Cardiomyopathy Registry

## Baseline Characteristics -assessed at day of diagnosis (1)

Item	n	All	n	ESC	n	Non ESC
Age	89	30.5±0.7 Median=30.1 Q1=25.8, Q3=34.6	54	30.4±0.8 Median=30.1 Q1=25.8, Q3=34.6	35	30.5±1.2 Median=30.3 Q1=25.4, Q3=35.3
Parity: Gravida	47	2.9±0.2	24	2.8±0.2	23	2.9±0.3
Parity: Para	47	2.6±0.2	24	2.4±0.2	23	2.7±0.3
Diabetic (%)	87	1.2	52	1.9	35	0
Smoking Current + Former (%)	87	11.5	52	19.2	35	0
HIV status YES (%)	86	3.5	51	0	35	8.6
Hypertension during current pregnancy: Yes (%)	86	24.4	51	33.3	35	11.4
Pre-eclampsia: Yes (%)	85	14.1	50	20.0	35	5.7
NYHA class I and II (%)	81	39.5	46	34.8	35	48.8
NYHA class III and IV (%)		60.5		65.2		54.3
Dyspnea (%)	82	85.4	47	83.0	35	88.6
S3 gallop (%)	82	45.1	47	31.9	35	62.9
JVP>6cm (%)	82	47.6	47	40.4	35	57.1

# Peripartum Cardiomyopathy Registry

## Baseline Characteristics/Echocardiography and Medication (2)

Item	n	All	n	ESC	n	Non ESC
Heart Rate (ECG)	77	103.6±2.5	42	103.4±3.8	35	103.9±3.1
Left Ventricular End Systolic dimension (mm)	68	51.8±1.3	34	49.9±1.9	34	53.6±1.6
Left Ventricular End Diastolic dimension (mm)	76	61.6±0.9	42	61.0±1.2	34	62.4±1.4
Ejection fraction - %	66	31.8±1.4	35	33.3±2.0	31	30.0±2.0
Ejection fraction 2. visual estim. (EF2) - %	65	29.8±1.3	35	30.2±1.6	30	29.4±2.2
Mitral regurgitation (%)	82	54.9	47	53.2	35	57.1
Haemoglobin (g/dL)	71	11.5±0.2	39	11.5±0.2	32	11.5±0.3
Beta-blockers (%)	19	57.9	6	33.3	13	69.2
Bromocriptine drugs (%)	19	21.1	6	0	13	30.8
Diuretics oral (%)	19	63.2	6	50.0	13	69.2

## Peripartum Cardiomyopathy

# Creating awareness for the condition and the registry

- Promoting the registry via lectures given
- Referring to the PPCM Registry in publications

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

**Please enter cases!!!**