

Tuesday 29 January 2019

EUROPEAN REFERENCE NETWORKS  
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

**Share. Care. Cure.**

# ERN



## GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2019 NUMBER 1

## 5<sup>th</sup> Board Meeting of the ERN GUARD-Heart

Paris (France) – 12 & 13 February 2019

### Tuesday 12 February



**Welcome Dinner (at 19:30)**

**Le Train Bleu**

Gare de Lyon, 1<sup>st</sup> Floor  
Place Louis Armand, 75012 PARIS

### Wednesday 13 February



**Board Meeting (8:30 – 15:00)**

**Hôpital Universitaire Pitié-Salpêtrière**

Room Bordeaux, 5<sup>th</sup> Floor  
105 Boulevard d' l'Hôpital, 75013 PARIS

### Hotel

**Villa Lutèce Port Royal**

52 bis rue Jenner  
75013 PARIS



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**  
Heart Diseases  
(ERN GUARD-HEART)



## ERN Board Meeting

### Agenda\* of the 5<sup>th</sup> ERN GUARD-Heart Board Meeting

*Based on the work plan for the 2<sup>nd</sup> ERN year*

**Paris, 13 February 2019**

#### **8:30 Summary on activities of the 2<sup>nd</sup> ERN year**

- Update ERN extension
- Brexit procedure
- Patient information leaflets
- Topic meetings for patients
- Cross-border patient pathways
- European patient Advocacy Groups (ePAGs)
- Patient reported outcome measures (PROMS)

#### **10:15 Monitoring of the ERN performance**

- Performance & outcome indicators
- Clinical Patient Management system

#### **13:15 Education plan for healthcare providers**

#### **13:45 Update on registries**

#### **14:15 Benchmark studies**

#### **14:30 Plans for the 3<sup>rd</sup> ERN year**

#### **15:00 Questions & Closing**

*\* The project management office has sent a detailed version of the agenda of the 5<sup>th</sup> ERN GUARD-Heart Board meeting to all the attendees.*

### List of the participants at the 5<sup>th</sup> ERN GUARD-Heart Board Meeting

*In alphabetic order*

<b>E. Arbustini</b>	.....	Pavia
<b>B. Bauce</b>	.....	Padua
<b>E. Behr</b>	.....	London ( <i>St George</i> )
<b>P. Charron</b>	.....	Paris
<b>P. Chevalier</b>	.....	Lyon
<b>E. Costafreda</b>	.....	Barcelona
<b>L. Crotti</b>	.....	Milan
<b>S. Van Dooren</b>	.....	Brussels
<b>F. Drago</b>	.....	Rome
<b>P. Garcia Pavia</b>	.....	Madrid
<b>J. Gimeno</b>	.....	Murcia
<b>T. Helio</b>	.....	Helsinki
<b>R. Jurcut</b>	.....	Bucharest
<b>J. Kaski</b>	.....	London ( <i>Great Ormond</i> )
<b>P. Lambiase</b>	.....	London ( <i>Barts Health</i> )
<b>G. Limongelli</b>	.....	Naples
<b>S. Mörner</b>	.....	Umea
<b>C. Napolitano</b>	.....	Pavia
<b>J. Pihkala</b>	.....	Helsinki
<b>G. Sarquella-Brugada</b>	.....	Barcelona
<b>E. Schülze-Bahr</b>	.....	Munster
<b>J. Sieira</b>	.....	Brussels
<b>T. Tavacova</b>	.....	Prague
<b>A. Thollet</b>	.....	Nantes
<b>E. Del Vecchio</b>	.....	Rome
<b>A. Wilde</b>	.....	Amsterdam
<b>R. Willems</b>	.....	Leuven
<b>B. Winkel</b>	.....	Copenhagen
<b>N. Hofman</b>	.....	Management Office
<b>A. Amin</b>	.....	Management Office







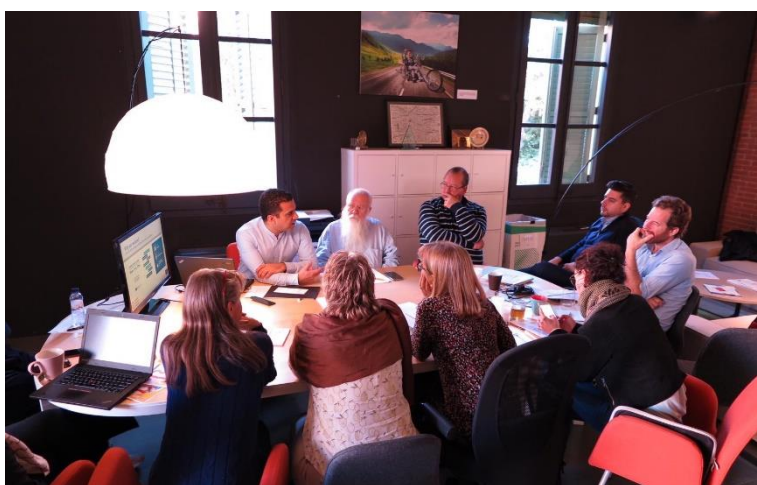
## ERN Meetings

### Patient Groups Meeting

**Barcelona, 9 December 2018**

European Patient Advocacy Groups (ePAGs) active in ERN GUARD-Heart had a face-to-face meeting in Barcelona on Sunday 9 December 2018. ePAGs represented at the meeting were ARVC-Selbsthilfe (Germany), Cardiac Risk in the Young (UK), European Congenital Heart Disease Organisation, Hart4Onderzoek & Harteraad (the Netherlands), Síndromes Arrítmicos relacionados con la Muerte Súbita (Spain), and Hjärtebarn (Sweden) (*see [ERN website](#) for details on ePAGs*). The meeting was made possible by EURORDIS. At the meeting, ePAG members discussed several topics, including their needs and expectations, tasks and responsibilities, organisation & structure of the Patient Advocacy Board of ERN GUARD-Heart, and patient journeys. The Patient Advocacy Board of the ERN GUARD-Heart aims to include at least one ePAG from each EU member state with a full HCP member in the ERN, and to have a patient representative for each rare disease covered by the ERN.

The goal of patient journeys will be to map out the journeys for rare cardiac diseases represented by the ePAGs. In other words, a patient journey will provide an overview of the sequence of care steps that a patient with a rare cardiac diseases follows from the point of entry in to the healthcare system until the end of the care process. ePAGs in the ERN GUARD-Heart will produce such patient journeys for the diseases they represent. Patients journeys will then be published on the ERN GUARD-Heart website as educational materials for the patient community. They will also serve as tools for ePAGS to engage with clinicians to highlight the needs of patients with specific rare cardiac diseases. ❤



Harteraad





## ERN News

### European Cardiac Arrhythmia Genetics (ECGen) Group of EHRA

London, 23 December 2018

As part of furthering the work of the electrical disease theme in ERN Guard-Heart, the European Heart Rhythm Association (EHRA) board was approached about establishing a professional multidisciplinary sub-group group, within EHRA, with an interest in arrhythmia syndromes & genetics of arrhythmia. This was met with great interest as EHRA would like to support and be a natural home for the field. The EHRA board agreed to a proposal to address training, education, guidelines and research opportunities and will provide a small budget to facilitate group and/or committee meetings. Hein Heidbuchel (president of EHRA) has already asked for representation in four committees and the following representation has been proposed: Elijah Behr (Board), Arthur Wilde (Guidelines), Jacob Tfelt-Hansen (Education), Pier Lambiase (Programme), and Vincent Probst (EHRA board representative to ECGen).

We would like to gather a group of interested parties, as representative of the ERN, the field and different nations as possible, to kick-off the formation of the ECGen group at the next EHRA congress in Lisbon. Unfortunately, this will be limited in size as the available meeting room only has space for 20 people. It is booked on Sunday 17 March (15:45 to 17:30). The aim will be to start fleshing out how to develop the group, how to establish a future committee and identify volunteers.

While we have based the group's mission on the ERN's objectives, these are universal aspirations and colleagues outside the ERN are included. **The only requirement is membership of EHRA.** We look forward to hearing from you and whether you can attend to support what we hope will be an exciting new opportunity. ♥

### ERN Monitoring System to assess ERN performance go-live in January 2019

Brussels, 14 December 2018

The 1<sup>st</sup> phase of the ERN Monitoring System (with 18 quality indicators) to assess the performance of ERNs has been approved by ERN coordinators, the European Commission and Board of Member States at the 4<sup>th</sup> ERN Coordinators Conference in September 2018. The final version of the 18 quality indicators have been circulated among the members of ERN GUARD-Heart and are available upon request. The IT system to support & collect the information related with the 18 indicators developed by the European Commission is about to go live in **January 2019**.

The collection of data on the 18 indicators will be organised in a two-step approach. From January to the end of February 2019, ERNs are asked to collect the data corresponding to years 2017 and 2018. From April 2019 ERNs will start to collect the information corresponding to the 1 quartile of 2019. Information should be collected at least every 3 months although it would be possible to upload the information monthly. ♥

### ERN Communication Toolkit

Brussels, 10 December 2018

There is a new set of products i.e., video clip, flyer, poster) which are specifically targeted to patients and their doctors. The video clip and the flyer are publicly available on the [ERN webpage](#). All 3 new products and other useful communication tools for ERN members are available on the [toolkit webpage](#) (reserved only to the ERN members). In the toolkit you will find the web version, as well as the printable version (flyer and poster). At the moment all 3 products are available in English. The other linguistic versions will be ready by end January/beginning of February 2019. ♥





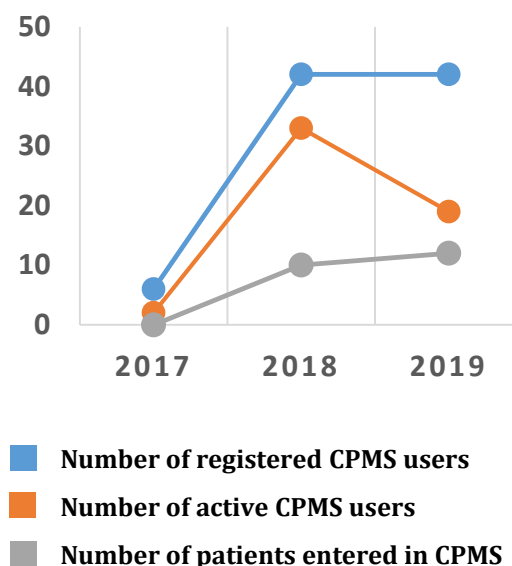
## ERN SURVEY

### Activity of the ERN GUARD-Heart members in the CPMS

Amsterdam, 24 January 2019

The Clinical Patient Management System (CPMS) is a EU-provided secure online consultation tool for 2<sup>nd</sup> opinion service in ERNs. Using CPMS, experts can discuss their patients within the ERNs, and can be invited to provide their 2<sup>nd</sup> opinion advice. Each participating centre within the ERN GUARD-Heart will be assessed by the European Commission (EC) with regard to its activities within the CPMS. In fact, the activity of each ERN centre within the CPMS is a quality indicator used by the ERN Monitoring System of the EC (*see page 4 of this Newsletter*) to assess the performance of the ERN in general and of each HCP in the ERN in particular. It is of extreme importance that all ERN GUARD-Heart members have an CPMS account and use the CPMS for patient consultation. So far, 11 of the 24 ERN GUARD-Heart member centres have entered at least one patient in the CPMS. All ERN members can contact the CPMS Helpdesk of the ERN for any assistance regarding the use of CPMS. ♥

Fig. 1: CPMS Activity in ERN GUARD-Heart



## ACTION – REQUEST

### Publications 2018 for annual reporting

Amsterdam, 25 January 2019



The end of the official second year of ERN GUARD-Heart is approaching, and we the project management office has to write and submit some deliverables and annual reports to the European Commission. In order to complete the annual reports on “*research projects, clinical trials & publications*” and on “*Benchmark studies*”, you are requested to send the project management office an overview of:

- all your publications related to one of the thematic areas in scientific journals (2018)
- all your publications related to the ERN in lay-journals (2018)

This is not just about the ‘ERN publications’ (with contribution of at least two ERN GUARD-Heart members), but it includes also the publications, including single-centre publications or publications of an ERN centre in collaboration with centre(s) that are not part of the ERN. A summary list is sufficient and it is not necessary to send the PDFs of the publications.

**Please send your list before Thursday 31 January 2019 to Nynke Hofman (n.hofman@amc.nl). ♥**



## UPCOMING EVENTS

<b>Acute Cardiovascular Care</b> .....	02.03.2019 – 04.03.2019 ...	<b>Malaga – Spain</b>
<b>EHRA</b> .....	17.03.2019 - 19.03.2019 ...	<b>Lisbon – Portugal</b>
<b>EuroPrevent</b> .....	11.04.2019 - 13.04.2019 ...	<b>Lisbon – Portugal</b>
<b>EuroCMR</b> .....	02.05.2019 – 04.05.2019 ...	<b>Venice – Italy</b>
<b>Heart Rhythm Society Sessions</b> .....	08.05.2019 – 11.05.2019 ...	<b>San Francisco – California</b>
<b>27<sup>th</sup> Nordic-Baltic Congress of Cardiology</b> (see banner below) .....	10.06.2019 – 12.06.2019 ...	<b>Helsinki – Finland</b>
<b>Basic Science Summer School</b> .....	16.06.2019 – 20.06.2019 ...	<b>Sophia-Antipolis – France</b>
<b>European Society of Cardiology</b> .....	31.08.2019 – 04.09.2019 ...	<b>Paris - France</b>

## CPMS Helpdesk

### Support documents provided by CPMS Helpdesk

Amsterdam, 28 January 2019

Evelien van der Schaaf and Hidde Bleijendaal, our CPMS Helpdesk team, created three support documents based on frequently asked questions:

1. **First login CPMS;**
2. **A CPMS quick reference card, and**
3. **An adapted workflow inviting panel members.**

These documents are attached separately to the email together with this newsletter, and will be added to the website as well.

Furthermore they recommend to consider using WhatsApp when you have questions (+31 645153319). ❤



### 27th NORDIC-BALTIC CONGRESS OF CARDIOLOGY

June 10-12, 2019  
Finlandia Hall, Helsinki/Finland

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