

Monday 20 November 2017



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2017 NUMBER 4

3rd Meeting of the Network Board



Amsterdam – The Netherlands

Wednesday 20 December 2017 09:30 – 16:00

20 November 2017 – Amsterdam, Netherlands

The third official Board Meeting of ERN GUARD-Heart will be held on Wednesday 20 December 2017 in Amsterdam, the Netherlands.

The meeting will be held from 9:30 till 16:00 at the Conference Centre 'The Bazel' in Amsterdam city centre. All participants have been invited to attend a welcome

dinner on Tuesday 19 December 2017 (from 19:15) at restaurant 'D'Vijf Vlieggen' (The Five Flies) and to have an overnight stay at hotel Le Coin. In this Newsletter (pages 1-3) we provide details about the Meeting.

All participants are kindly requested to bring their EU Login to the Meeting. For any questions before or on the day of the Meeting feel free to contact the management office (*mobile numbers on page 5*).



3rd Meeting of the Network Board 20 December 2017

List of participants (in alphabetical order)

Carlo de Asmundis	University Hospital Brussels
Anwar Baban *#	Bambino Gesù Children's Hospital
Christina Basso *#	Padua University Hospital
Elijah Behr *#	St George Healthcare NHS
Alida Caforio	Padua University Hospital
Philippe Charron *#	AP-HP Pitié Salpêtrière Hospital
Philippe Chevalier	Louis Pradel Cardiovascular Hospital
Lia Crotti *#	Istituto Auxologico Italiano IRCCS
Fabrizio Drago *#	Bambino Gesù Children's Hospital
Juan Gimeno *	University Hospital Virgen Arrixaca
Ruxandra Jurcut *#	Emergency Institute for Cardiovascular Diseases
Juan Kaski *	Great Ormond Street Hospital NHS
Giuseppe Limongelli *#	AORN dei Colli – Monaldi Hospital
Jaana Pihkala *#	Helsinki University Hospital
Silvia Priori *	Clinical Scientific Institutes Maugeri
Georgia Sarquella-Brugada	Sant Joan de Déu Barcelona Children Hospital
Eric Schulze-Bahr	University Hospital Münster
Jacob Tfelt-Hansen *#	Copenhagen University Hospital Rigshospitalet
Aurelie Thollet *#	Nantes University Hospital
Patricia Vlasman #	Hart4Onderzoek
Arthur Wilde	Academic Medical Center Amsterdam
Rik Willems	University Hospitals Leuven

* Participants staying at Hotel Le Coin. # Participants attending the welcome dinner.

The Meeting will be held in the Italian Room at 'De Bazel' Conference Centre.



The Bazel Conference Centre.

Address: Vijzelstraat 32, 1017 HL, Amsterdam, The Netherlands.



The Italian Room.

Draft agenda of the Meeting

1. Opening remarks and aims of the meeting

2. Notes 2nd Board meeting (27.08.2017 Barcelona)

3. General information and (technical) updates

- 'CEF Telecom' Call (selection decision Feb.2018)
- Update on grant results - Rare LQT
- Rare disease European Joint Programme Cofund

4. Updates Thematic Areas

- Meetings
- Future activities
- Outcome and/or performance indicators

5. Second opinion service set up (training session)

- IT platform
- Clinical Patient Management System (CPMS)

6. Patient and family participation

- Update ePAGs, participation, plans, meetings
- Update patient information materials

7. Research and Registries

- Updates current projects
- New projects

8. Education strategy and plans

9. Extension of the ERN in 2019

10. Definition of the 2nd year work plan under FPA

11. Cross-cutting action groups

- (1) Data management & E-health, (2) Teaching & E-learning, (3) Research & Funding, (4) Knowledge Management, (5) Ethics & Policy Issues
- Tasks and responsibilities
- Group sessions

12. External communication

- Collection of publications and press releases

13. Questions and closing



Welcome Dinner 19 December 2017



Restaurant 'D'Vijff Vlieghen' (The Five Flies)

Address: Spuistraat 294-302, 1012 VX Amsterdam
(Feel free to arrive anytime between 19:00 and 19:30)

Hotel for 19 December 2017



Hotel Residence Le Coin

Address: Nieuwe Doelenstraat 5, 1012 CP Amsterdam
(<http://www.lecoin.nl/>)



 Conference Centre 'De Bazel'

 Hotel Residence Le Coin

 Restaurant 'D'Vijff Vlieghen'

Directions by public transport

From Schiphol Airport to Central Station Amsterdam: train to Amsterdam on platform 1 or 2.

From Central Station Amsterdam to Hotel Le Coin: 20 minutes-walk or tram (from Eastside of Central Station) 4 or 9 and stop at Spui (Rokin) or tram 24 and stop at Muntplein.

From Central Station Amsterdam to Conference Centre 'De Bazel': 25 minutes-walk or tram (from Eastside of Central Station) 2 and stop at Koningsplein, 4 or 9 and stop at Spui (Rokin) or tram 24 and stop at Muntplein.

From Hotel Le Coin to Restaurant D'Vijff Vlieghen: 8 minutes-walk (Rokin to Spui to Spuistraat)

From Hotel Le Coin to Conference Centre 'De Bazel': 6 minutes-walk (Muntplein to Vijzelstraat). ♥



Third Meeting of the ERN Coordinators Group

11 October 2017 – Brussels, Belgium

The third meeting of the ERN Coordinators Group was held on 11 October 2017 Brussels. On behalf of ERN GUARD-HEART, **Arthur Wilde**, the Coordinator, and **Ahmad Amin**, the project manager of the Network, participated at the meeting.

Governance of ERN Board of Coordinators

Following the election of **Maurizio Scarpa**, Coordinator of MetabERN, as the Chairman of ERN Coordinators Group on 21 June 2017, at this meeting Franz Schaefer, coordinator of ERKNet was elected as the Vice-Chair.

Board of the Member States Meeting

At the ERN Coordinators Group, a short summary was provided about the meeting of the Board of the Member States. Important points for discussion were 1) the legal entity of ERNs, 2) the sustainability of ERNs, and 3) the integration of ERNs with the National Health Systems. A working group of ERN Coordinators will be established to write position papers on these three topics on behalf of the ERNs to present to the European Commission and the Board of Member States.

Other topics

Other agenda points at the 3rd ERN Coordinators Group meeting were:

- update of the activities of the different Working Groups (i.e., Ethics, Research, IT & data sharing, Cross-border healthcare & business continuity, Knowledge generation, and Monitoring and quality improvement),
- update on the IT platform and CPMS,
- update on the new call for HCPs to join existing ERNs.

These agenda points are discussed in more detail in other sections of this newsletter. ♥

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

Share. Care. Cure.

Teleconference with thematic area leaders



31 October 2017, Amsterdam, Netherlands

In October 2017, three teleconferences took place between **Arthur Wilde** and the leaders of the three thematic areas, i.e. **Silvia Priori & Carlo Napolitano** (familial electrical diseases), **Philippe Charron** (familial cardiomyopathies), and **Georgia Sarquella-Brugada** (special electrophysiology conditions in children).

Agenda points included:

- preparation for the 3rd ERN Board Meeting
- collaboration strategies with other European academia entities, e.g. ESC, EHRA, AEPC, and ESHG
- approach to the extension of ERN GUARD-Heart
- outcome and performance indicators.

Minutes of these teleconferences will be presented at the 3rd ERN Board Meeting on 20 December 2017 in Amsterdam. ♥

Horizon 2020 Work Programme 2018-2020



SC1-BHC-04-2018: Rare Disease European Joint Programme Cofund

31 October 2017, Amsterdam, Netherlands

The objective of this is to design and implement a Rare Disease European Joint Programme (EJP) Cofund, which contains future Horizon2020 transnational calls for research projects. This means that in the current Call only funding bodies in national Member States can participate to implement the EJP Cofund and determine the content of the future calls and the amount of money involved per call.

However, ERNs can act as partners to contribute to the application writing process (to contribute to the content of Horizon2020 future calls for transnational research on rare diseases). In this context, ERN GUARD-Heart will also participate in the advisory panel to assist in the application writing process. ♥



Extension of ERN GUARD-Heart

20 November 2017, Amsterdam, Netherlands



The call for new full Members to join existing ERNs is expected to be announced in December, open in March 2018 and close in June 2018. For ERN GUARD-Heart this means not only that the number of healthcare providers (HCPs) per thematic area will increase, but also that new thematic areas will be included.

Formal representatives of Grown-up Congenital Heart Disease (GUCH) community (i.e. of the ESC and AEPC) have sent an official request to join ERN GUARD-Heart. In addition, several expertise centres across Europe

have approached the Network to obtain information about the future inclusion criteria.

At this moment, the ERN GUARD-Heart is in the process of defining and evaluating specific criteria for the HCPs that will establish the 'new' thematic area GUCH. These specific criteria, together with the criteria for the HCPs that aim to enter the currently existing thematic areas, will be discussed at the third Board Meeting of the ERN GUARD-Heart on 20 December. ♥

IT Collaborative Platform



This is a restricted online space for communications and administrative document management with the ERNs. Each ERN has a specific work space for its Members. ERN GUARD-Heart members should follow the next steps to access the IT Collaborative Platform:

1. Create an EU Login using the link:
<https://webgate.ec.europa.eu/cas/>
2. Go to the link:
<https://webgate.ec.europa.eu/ern/>
and use your EU Login to enter the Platform
3. Click 'Access/request access to my network'

Requests for membership will be authorized by the ERN Coordinator.

It is of utmost importance that all ERN members gain access to the IT Platform, as the numbers of access requests and document views will be used as a key performance indicator by the European Commission to assess the ERNs. So far, 11 GUARD-Heart members have requested access. ♥

Clinical Patient Management System



CPMS enables medical and non-medical specialists from ERNs to exchange information to diagnose and treat patients. **The European Commission (EC) will release the 1st version of the CPMS on 20 November 2017.** This means that from this date ERNs are able to use CPMS to transfer patient files between the different HCPs within the ERN to diagnose or treat patients (as a second opinion service). Multiple ERN specialists can contribute to the assessment of patient files (ECGs, echocardiograms, microscopy files, and radiology files) through comments, formal contributions, and reviews of the outcome documents. Participation is possible through written comments or panel meeting via live video conferences. When cases are closed, they can be anonymized for research.

Patients have no direct access to CPMS. The EU Login system will be used for authentication. Patient data will be pseudonymized before entering CPMS. A patient consent form, designed by EC in collaboration with the ERNs (for both care and research) will be required for patient data uploads. ♥

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