

Thursday 30 January 2020

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 2020 NUMBER 1

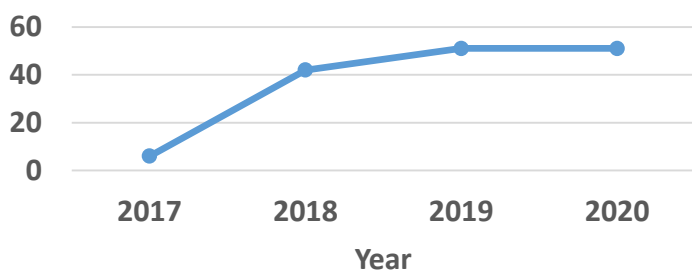
## Helpdesk news - Clinical Patient Management System (CPMS)

Amsterdam, January 2020

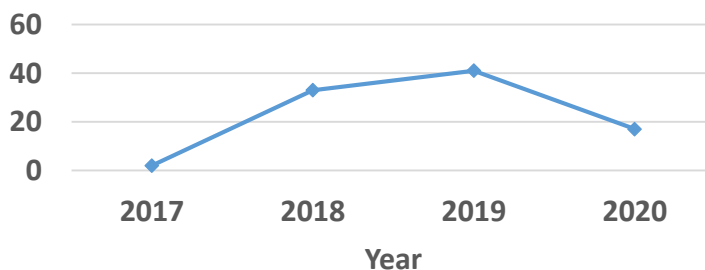
From September 2018 to September 2019, the CPMS helpdesk was available for questions about the account registration and to solve issues with regard to uploading patient cases. This implementation project has been finished now. The ERN GUARD-Heart management team is delighted to announce that Hidde Bleijendaal will continue to assist the ERN with finding solutions with regard to CPMS issues. The e-mail address for future questions on CPMS helpdesk questions is: [h.bleijendaal@amsterdamumc.nl](mailto:h.bleijendaal@amsterdamumc.nl). The mobile telephone number is not available any more. It is still possible to create new accounts on CPMS, so if there are interested colleagues in your department, who wish to upload a case, please contact us to support them. ❤

### CPMS Activity Report for ERN GUARD-Heart

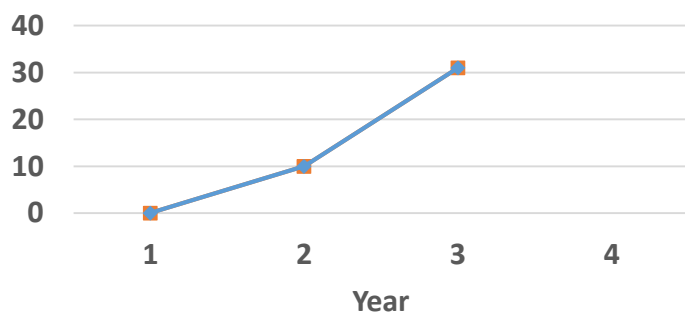
#### Registered Users



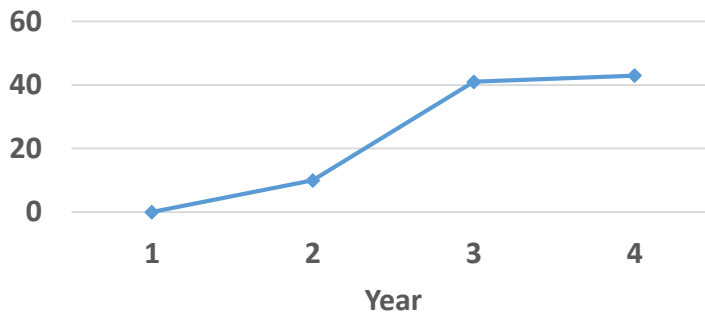
#### Active Users



#### New Panels (i.e. Cases)



#### Total Panels (i.e. Cases)





## ERN activities

### Call for national patient meetings in the next ERN year (2020-2021)

Amsterdam, January 2020

In addition to the written education materials for patients, the Network aims to empower patients and their families by organizing national topic meetings for patients with rare cardiac diseases. In the 2<sup>nd</sup> and 3<sup>rd</sup> year of the ERN GUARD-Heart's existence, several meetings were organized with financial support of the ERN, often in collaboration with patient advocacy groups. In the upcoming year, there is again financial support (max. € 4000) for national patient meetings, this time in 10 different (European) Member States. If more than one centre in a country is interested in organizing such a meeting, it can be decided to share the money for two (or three) meetings.

Please discuss this with your national colleagues and provide us ([n.hofman@amsterdamumc.nl](mailto:n.hofman@amsterdamumc.nl)) with your plans, if you are interested in organizing a national meeting. The requests will be accepted on a first come, first served basis. However, if there already more than 10 meetings planned, the applicant will receive priority in the next year. ❤



### Special issue EJMG

Brussels, January 2020

Alain Verloes, coordinator of ERN ITHACA (*Rare Congenital Malformations & Intellectual Disability*) and editor-in-chief of European Journal of Medical Genetics (EJMG) has proposed the possibility of preparing special issues of EJMG for specific ERNs. These special issues will be planned soon. If there is interest from our Network, we should make the next steps:

- Provide the names of 2 experts from our ERN as Guest Editors with their contact details - these 2 Guest Editors will supervise the peer-review process of the articles and validate their acceptance;
- Follow a provisional deadline for the submission of papers for a first review (between mid-2020 & mid-2021).
- Provide a provisional table of contents of the issue preferably at least 4 months before deadline date.

The special EMJG issue may consist of:

- journal articles on one of the themes of the ERN
- recommendations for good practice
- patient series
- clinical trials
- results of recommended therapies
- comments, positions, or editorials
- max. 2 or 3 very selected cases reports

Eight to 15 contributions are usually necessary (depending on number of pages per submission). The articles must be related to genetic disorders (monogenic or chromosomal diseases) or to developmental abnormalities, even non-genetic (intellectual disabilities, malformations, teratogenic). Revised versions will be expected 3 months after the deadline for the 1<sup>st</sup> submission. The maximum length of articles is 15.000 words for a review, 8.000 words for other types of articles. All accepted articles are posted online after a few days. Paper versions of special issues will be available a few weeks after the validation of the last article. Please, if you are interested to discuss this further: contact ERN GUARD-Heart management office as soon as possible. We need to confirm our participation by February 15<sup>th</sup>, with contact details of 2 Guest Editors. ❤



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

**Rome, Friday 21 February 2020**



### Meeting-location and dinner

The 7<sup>th</sup> board meeting of ERN GUARD-Heart will be held in Rome, Italy, on 21 February 2020. The location of the meeting is the Parlamentino Room in Palazzo Alicorni: Via Scossacavalli 11. The meeting **will start at 8.30 AM** and will close at 14.30.

A dinner has been organized at Thursday 20 February in Restaurant Taberna de'Gracchi: Via Dei Gracchi 266. Start of dinner is at 20.00. Please inform us timely of any food allergies or special requests. Participants for whom the ERN management office has reserved a hotel room have already received a separate e-mail with details and reservation number.

### List of participants

Amin, Ahmad (*project manager*) \*

Baban, Anwar (*Rome*) \*

Bauce, Barbara (*Padua*) \*

Behr, Elijah (*London*) \*

Biller, Ruth (*EPAG Germany*) \*

Caforio, Alida (*Padua*) \*

Caiazza Martina (*Naples*)

Castelletti, Silvia (*Milan*) \*

Charron, Philippe (*Paris*) \*

Chevalier, Philippe (*Lyon*) \*

Del Vecchio, Elisa (*Rome*) \*

Drago, Fabrizio (*Rome*) \*

Gimeno, Juan (*Murcia*) \*

Helio, Tiina (*Helsinki*) \*

Hofman, Nynke (*project manager*) \*

Limongelli, Giuseppe (*Naples*)

Jurcut, Ruxandra (*Bucharest*)

Leenhardt, Antoine (*Paris*)

Napolitano, Carlo (*Pavia*)?

Pihkala, Jaana (*Helsinki*) \*

Robyns, Tomas (*Leuven*) \*

Rydberg, Annika (*Umeå*) \*

Sarquella-Brugada, Georgia (*Barcelona*) \*

Schülze-Bahr, Eric (*Münster*) \*

Sieira, Juan (*Brussels*)

Tavacova, Terezia (*Prague*) \*

Tfelt-Hansen, Jacob (*Copenhagen*) \*

Thollet, Aurélie (*Nantes*)

Wilde, Arthur (*Amsterdam, coordinator*) \*

\* Signed up for dinner





## ERN Board Meeting

### Agenda\* of the 7<sup>th</sup> ERN GUARD-Heart Board Meeting

*Based on the work plan for the 3<sup>rd</sup> ERN year*

**Rome, 21 February 2020**

- |              |  |
|--------------|--|
| <b>8.00</b>  | <b>Welcome and Coffee</b>  |
| <b>8.30</b>  | <b>Opening remarks and aims of the meeting</b>   |
| <b>8.35</b>  | <b>Extension of the Network</b> <ul style="list-style-type: none"><li>- official application &amp; assessment process for new centres to join ERNs</li><li>- list of applicants</li><li>- assessment strategy ERN GUARD-Heart</li><li>- addition of two thematic areas</li><li>- procedure for existing full members to apply for the new thematic areas</li></ul> |
| <b>9.30</b>  | <b>Integration and overview/update of Affiliated partners</b>  |
| <b>9.45</b>  | <b>Evaluation of deliverables of the 3<sup>rd</sup> year</b>   |
| <b>10.00</b> | <b>Presentation of deliverables of the 4<sup>th</sup> year (01.03.2020 – 01.03.2021)</b>   |
| <b>10.15</b> | <b>Educational Work Plan</b> <ul style="list-style-type: none"><li>- Update, progress, and publication educational videos for professionals</li><li>- Update and plans for topic meetings for patients</li><li>- Fellowship Genetics Brussels</li></ul>  |
| <b>10.30</b> | <b>Coffee-break</b>  |
| <b>11.00</b> | <b>Official monitoring</b> <ul style="list-style-type: none"><li>- collecting the indicators</li><li>- deadlines</li><li>- discussion, questions and experiences</li></ul>   |



## ERN Board Meeting

### Agenda\* of the 7<sup>th</sup> ERN GUARD-Heart Board Meeting

*Based on the work plan for the 3<sup>rd</sup> ERN year*

**Rome, 21 February 2020**

- 11.20 European Patient Advocacy Groups (EPAGs) – R. Biller**
- update on EPAGs
  - patient journeys
  - integration of EPAGs into GUARD-Heart's activities
- 11.50 Cross-cutting action groups**
- overview of existing groups
  - plans and activities
- 12.15 Lunch**
- 13.15 CPMS**
- activities and experiences
  - helpdesk and contact addresses/numbers
  - uploading cases
  - LQT-cases evaluation and improvement
- 13.45 Update on guidelines, research and registries**
- Overview of ERN publications
  - Overview of current registries
  - Registry grant
  - Plans for registries
  - ERN policy document – managing conflict of interest
- 14.30 Questions and closing**





## ERN monitoring: complete 2019 year data collection

Amsterdam, 20 January 2020

At the end of February 2020, ERN GUARD-Heart has to submit the required data for the year 2019 to the IT-tool of the European Commission. All full members of ERN GUARD-Heart are requested by e-mail to complete their data and send the forms (in PDF and Excel format) to the ERN GUARD-Heart management office before 20 February 2020. The Affiliated members will be included in the data collection of 2020. They will be informed about this soon. ♥

## Assessment ERN applications

Amsterdam, 20 January 2020

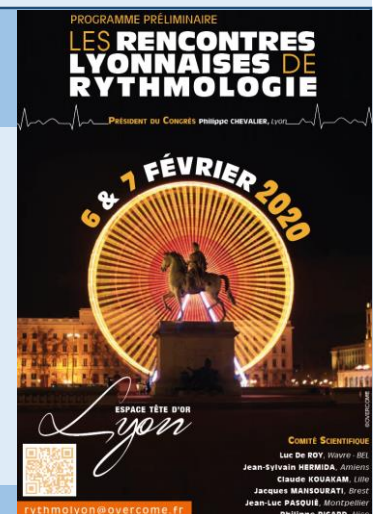
The call for HCPs to join existing ERNs was closed on 30 November 2019. Initially, there were 32 applications for the ERN GUARD-Heart. The European Commission is currently performing an eligibility check of all the applications. Thereafter, the proposed delegation of ERN GUARD-Heart Board (Arthur Wilde, Silvia Priori/Carlo Napolitano, Georgia Sarquella-Brugada, Philippe Charron, Eric Schülze-Bahr and project managers) will assess the applications and provide an official opinion. The complete procedure will take about one year. ♥

## Latest ERN GUARD-Heart Publications

1. Roberts JD, Asaki SY, Mazzanti A, Bos JM, Tuleta I, Muir AR, Crotti L, Krahn AD, Kutyla V, Shoemaker MB, Johnsrude CL, Aiba T, Marcondes L, Baban A, Udupa S, Dechert B, Fischbach P, Knight LM, Vittinghoff E, Kukavica D, Stallmeyer B, Giudicessi JR, Spazzolini C, Shimamoto K, Tadros R, Cadrin-Tourigny J, Duff HJ, Simpson CS, Roston TM, Wijeyeratne YD, El Hajjaji I, Yousif MD, Gula LJ, Leong-Sit P, Chavali N, Landstrom AP, Marcus GM, Dittmann S, Wilde AAM, Behr ER, Tfelt-Hansen J, Scheinman MM, Perez MV, Kaski JP, Gow RM, Drago F, Aziz PF, Abrams DJ, Gollob MH, Skinner JR, Shimizu W, Kaufman ES, Roden DM, Zareba W, Schwartz PJ, Schulze-Bahr E, Etheridge SP, Priori SG, Ackerman MJ. An International Multi-Center Evaluation of Type 5 Long QT Syndrome: A Low Penetrant Primary Arrhythmic Condition. Circulation. In Press.

### Upcoming Cardiology Events 2020

Rythmo-Lyon	6-7 February	Lyon - France
ERN Board meeting	21 February	Rome - Italy
Cardiovascular Genetic Diseases Course	3 April	Bucharest - Romania
Face to Face meeting EPAGs	21 April	Amsterdam - Netherlands
European Society Cardiology	29 Aug - 2 September	Amsterdam - Netherlands



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