

Wednesday 15 February 2023

ERN



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2023 NUMBER 2

5-years Evaluation Process ERNs

Amsterdam, 9 February 2023

It is / was a lot of work: answering the self-evaluation questions for the ERN. Hopefully everyone is about to finish this now. The official deadline was postponed to 19 February. Hereafter the documental reviews, virtual interviews and on-site audits (5 HCPs are invited for this in our ERN) will follow by the independent evaluation body. We will keep you updated about the results. ♥

First Podcasts are online

Amsterdam, 13 February 2023

The first recordings of the Podcast Series have been made and the first publication on the website is available. Elena Arbelo and Angela Lopez from Clinica Barcelona did the kick-off and they were interviewed by our ERN Coordinator Arthur Wilde. Some technical improvements are under construction and the option to launch the Podcasts to Spotify as well, will be discussed during our Board-Meeting in Amsterdam. ♥

Patient-Clinical reflection meeting

Amsterdam, 9 February 2023

Prior to the ERN Board meeting 15 March in Amsterdam, there is organized a patient-clinician feedback meeting with a delegation of our EPAGs, the thematic area leaders, and the coordination team. This meeting will be moderated by Rita Francisco, patient engagement healthcare manager from Eurordis. ♥

Update about Webinar Series

Amsterdam, 13 February 2023

With two series of Webinars within the ERN, we had to conclude that there was some overlap in both programmes. That's why we will cancel the 'last Wednesday of the month' Webinar which was planned for February. Our thematic area leaders of the Congenital Heart Diseases decided to this because of the same planned topic for both planned Webinars.

The biweekly teaching Webinars organized by the Association for European Paediatric and Congenital Cardiology (AEPC), in collaboration with ERN GUARD-Heart, will continue their series as usual. In the future these sessions will possibly cover all thematic areas of our ERN. These Webinars take place biweekly on Wednesdays between 17:00-18.30. You are invited to sign up to attend these webinars!

Find out more & register here:

<https://www.aepc.org/aepc-webinars>

Until all our thematic areas are covered in the programme above, we will continue the initial Webinar programme as well, but less frequent and with the thematic areas 2 and 5 only (familial cardiomyopathies and 'other rare cardiac diseases'). This programme will be updated on the ERN website and announced as usual by e-mail. ♥



15 March 2023: ERN GUARD-Heart Board Meeting

Amsterdam, 09 February 2023

On Wednesday 15 March 2023, the ERN coordination team organizes a hybrid ERN GUARD-Heart Board meeting in Amsterdam (12:45 – 17:00) and dinner in the evening (18:30 – 21:30). Registration is completed.

BOARD MEETING

Date: Wednesday 15 March 2023

Time: 12:45 – 17:00

Agenda: see page 3.

Location: Trippenhuis, Tinbergenzaal
Kloveniersburgwal 29, 1011 JV Amsterdam (city centre)

Registration: If you would like to receive the direct online-link to this hybrid meeting, please send an e-mail request to Nynke (n.hofman@amsterdamumc.nl) **before** Tuesday 14 March.



*Trippenhuis
National monument in
Amsterdam*

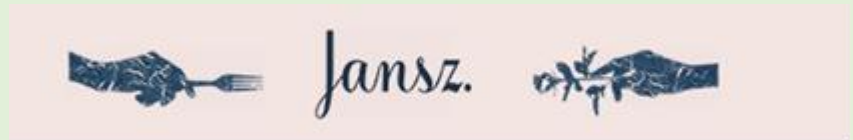
DINNER

Date: Wednesday 15 March 2023

Time: 18:30 – 21:30

Location: Restaurant Jansz (Saxenburg Room)
Reestraat 8, 1016 DN Amsterdam

Registration: completed (confirmation e-mail will follow)



SYMPOSIUM 'complex genetics of inherited arrhythmias'

Date: Thursday 16 and Friday 17 March 2023

Location: Trippenhuis, Tinbergenzaal
Kloveniersburgwal 29, 1011 JV Amsterdam

Registration: completed (confirmation was sent already to those who registered). In person tickets are sold out. Registration for online attendance on Thursday 16 March (only) is still possible.

<https://www.eventbrite.com/e/ejprd-networking-symposium-complex-genetics-of-inherited-arrhythmias-tickets-399392793597>

*Complex genetics of inherited arrhythmias:
moving from the research lab to the clinic*





15 March 2023: ERN GUARD-Heart Board Meeting

Agenda:

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|----------------------|---|
| 12.45 | Welcome with coffee & lunch in the foyer |
| 13.30 | Opening remarks and aims of the meeting |
| 13.35 | Updates from the Network <ul style="list-style-type: none">- Network agreement- Next grant (period)- Podcasts- Webinar Series for professionals- Evaluation Exchange Visits Programme- Update and plans for national topic meetings for patients |
| 14:00 | Update on guidelines, research and registries <ul style="list-style-type: none">- Overview of ERN-adopted guidelines- Overview of current registries- Registry grant – Heart CORE registry- Data sharing agreement and data access policy- Plans for disease specific registries |
| 15.15 | <i>Coffee-break and group-picture</i> |
| 15.30 | CPMS updates and plans <ul style="list-style-type: none">- number of accounts and activity- helpdesk- uploading cases- update LQTS Sports Project |
| 15.50 | European Patient Advocacy Groups (EPAGs) <ul style="list-style-type: none">- update on EPAGs |
| 16.20 | Official monitoring <ul style="list-style-type: none">- collecting the indicators- deadlines- discussion, questions and experiences |
| 16.45 – 17.00 | Questions and closing |



ERICA WP4 Webinar 28-02

Amsterdam, 15 February 2023

In the ERICA WP4 Clinical Trial Support webinar '*Essential requirements before thinking about a clinical trial*' there will be an overview what should be done at the very least before starting a clinical trial in a study site. All the requirements will be discussed according to the role that an investigator may have in the trial. Some guidance and sources will be also provided.

Speaker: Viviana Gianuzzi, Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus

Date: 28-02-2023 from 12:00 – 13:00 (CET)
Organised by ERICA in collaboration with EJP RD and ERN BOND.

Additional information and registration

<https://erica-rd.eu/event/erica-wp4-webinar-essential-requirements-before-thinking-about-a-clinical-trial/> ♥



EJP RD Retreat Meeting in Paris

Amsterdam, 15 February 2023

Within the context of the European Joint Programme on Rare Diseases (EJP RD), Work Package 20 (WP 20) aims to accelerate the validation, use and development of innovative methodologies tailored for clinical trials in RDs.

WP20 leaders, Rima Nabbout and Ralf-Dieter Hilgers, are organizing a face-to-face Retreat meeting on April 13th and 14th 2023 in Paris. This meeting will bring together key stakeholders from across the RD research community working and implicated in the state-of-the-art innovative methodologies to foster collaboration in this area and advance in rare diseases clinical trials' conduction, interpretation, and dissemination.

The WP20 leaders will be delighted to have representatives from the different ERNs for participation in the meeting. It is asked to have already some expertise in innovative Clinical Trials methodologies. If you are interested, please contact Nynke. The preliminary agenda for the meeting is available on request as well. (n.hofman@amsterdamumc.nl) ♥

Latest ERN GUARD-Heart Publication(s)

- Long QT Syndrome, a Diagnosis That Warrants Expert Opinion and Expert Centers.** Wilde AAM, Schwartz PJ. J Am Coll Cardiol. 2023 Feb 7;81(5):487-489. doi: 10.1016/j.jacc.2022.11.037. PMID: 36725177
- Reevaluation of ambiguous genetic variants in sudden unexplained deaths of a young cohort.** Martinez-Barrios E, Sarquella-Brugada G, Perez-Serra A, Fernandez-Falgueras A, Cesar S, Alcalde M, Coll M, Puigmulé M, Iglesias A, Ferrer-Costa C, Del Olmo B, Picó F, Lopez L, Fiol V, Cruzalegui J, Hernandez C, Arbelo E, Díez-Escuté N, Cerralbo P, Grassi S, Oliva A, Toro R, Brugada J, Brugada R, Campuzano O. Int J Legal Med. 2023 Mar;137(2):345-351. doi: 10.1007/s00414-023-02951-0. Epub 2023 Jan 25. PMID: 36693943

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