

Friday 22 July 2022

ERN



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2022 NUMBER 5

## ERN GUARD-Heart Webinars

Amsterdam, 20 July 2022

ERN GUARD-Heart starts a Series of Webinars for professionals. All interested (multidisciplinary) colleagues from the Full-Member and Affiliated Partner hospitals are invited to register for general information and announcements about these Webinars.\*

During each Webinar 1 or 2 cases will be discussed by anyone who wants to discuss a case and will be evaluated by 1 or 2 ERN-expert(s). Thereafter all participants will be encouraged to ask questions and to discuss the cases. Each webinar will cover one specific thematic area, and will take no more than 45 minutes. All webinars will be recorded, and will be available on our YouTube channel, and the cases will be included within the CPMS system.

Currently, about 150 participants registered already. The first Webinar will be held next **Wednesday 27 July from 12:00 – 12:45**. It will be a 'Thematic Area 1' topic (familial electrical diseases in adults and children) entitled: "Workup of a young Sudden Cardiac Arrest case and how to interpret RyR2 variants". The speaker is Prof. dr. Arthur Wilde from Amsterdam UMC, coordinator of ERN GUARD-Heart.

For each Webinar, a flyer will be send to the Webinar-email-list with the topic, title, and name of the speaker and a registration link. A separate registration per Webinar is needed. Thereafter the link to the meeting will be shared.

\* Registration to the Webinar email-list is possible via this link:

<https://forms.gle/6KZjrnsECvJncbwK9> . ♥

## Last packages for Exchange Programme available

Amsterdam, 21 July 2022

The ERN Exchange Programme is running until the end of the year and at this moment 26/34 of the available packages are reserved or already used. It is a very nice opportunity to visit one of the expert centres in the ERN for a 5 days (or somewhat longer, up to 30 days). It works on a the 'first come, first served' basis. Please contact the ERN Projectmanagers for the procedures and forms. Since the exchanges have to take place before 31th of December it is important not to wait too long anymore. ♥



European  
Reference  
Networks

Exchange Programme  
2021-2022

ECORYS

Answering  
tomorrow's  
challenges  
today



# ERN-dinner and Board Meeting in Barcelona

**Amsterdam, 21 July 2022**

Monday-evening 29 August 2022, a dinner is organized for the ERN GUARD-Heart members, affiliated partners and patient representatives in Barcelona (one participant per centre). We look forward to meet all of you who registered for this dinner. This newsletter and the agenda for the meeting will be send to all the registrated colleagues.

## Dinner

**WHEN:** Monday 29 August 2022

**WHERE:** Restaurant Dos Torres

**TIME:** 20:00 h

**ADDRESS:** Via Augusta, 300, 08017 Barcelona



## Board Meeting

The Board Meeting will be held on Tuesday 30 August

**WHERE:** Auditori Plaza, Hospital Sant Joan de Déu

**TIME:** 8:30 – 13:30

**ADDRESS:** Passeig Sant Joan de Déu, 2  
08950 Esplugues de Llobregat, Barcelona.



Please, inform us when your availability has changed or if someone else from your centre attends the meeting. After the meeting there will be a lunch available (to go for those who have to leave to the airport).♥





# ERN GUARD-Heart Network Agreement

**Amsterdam, 21 July 2022**

The European Commission has provided the European Reference Networks (ERNs) 5 years ago with a uniform draft Network Agreement. The Network Agreement formalises the relationship of the members within the ERNs. The Network Agreement is a private and voluntary agreement between partners (HCP's, members of the Network) to set out common rules and obligations among themselves. The Agreement is solely meant to support working arrangements between members of the Network. Although the Network Agreement does not involve the European Commission, and neither the Commission nor any person acting on Commission's behalf may be held responsible for the use which may be made of the information contained in the draft Network Agreement, it is important to realize that the EU legal texts are the only authentic legal reference.

This Network Agreement for the members of ERN GUARD-Heart has been updated now and on behalf of the thematic area leaders it will be shared separately with the agenda of the Board Meeting. During the Board Meeting this document will be presented and there will be time for questions. Thereafter the document has to be signed by the representative members of the HCP or an official from the HCP, whatever is deemed appropriate. ♥

## NETWORK AGREEMENT

For members of the European Reference Network on Rare Diseases of the Heart

**ERN GUARD-HEART**

Amsterdam, 1 March 2022



European  
Reference  
Network

Heart Diseases  
(ERN GUARD-HEART)

**Save  
the  
Date** ♥

**EJPRD Networking Symposium:  
“Complex genetics of inherited  
arrhythmias – moving from the  
research lab to the clinic”  
16 and 17 March 2023 in  
Amsterdam.**

**and**

**ERN GUARD-Heart Board Meeting  
on the day before: 15 March 2023.**





Invites you to attend:

**The Webinar series for rare or low prevalence cardiovascular diseases**

"Workup of a young Sudden Cardiac Arrest case and how to interpret RyR2 variants"



Prof. Arthur Wilde

Wednesday July 27th 2022

12:00-12:45

Digital

Register now to receive the Zoom link

<https://forms.gle/coSPey7xfxGSotkKA>

See page 1 from this  
Newsletter  
for more information  
about  
the ERN GUARD-Heart  
Webinars

**Latest ERN GUARD-Heart Publication(s)**

- 1. Arrhythmic risk prediction in arrhythmogenic right ventricular cardiomyopathy: external validation of the arrhythmogenic right ventricular cardiomyopathy risk calculator.** Jordà P, Bosman LP, Gasperetti A, Mazzanti A, Gourraud JB, Davies B, Frederiksen TC, Moreno Weidmann Z, Di Marco A, Roberts JD, MacIntyre C, Seifer C, Delinière A, Alqarawi W, Kukavica D, Minois D, Trancuccio A, Arnaud M, Targetti M, Martino A, Oliviero G, Pipilas DC, Carbucicchio C, Compagnucci P, Dello Russo A, Olivetto I, Calò L, Lubitz SA, Cutler MJ, Chevalier P, Arbelo E, Priori SG, Healey JS, Calkins H, Casella M, Jensen HK, Tondo C, Tadros R, James CA, Krahn AD, Cadrin-Tourigny J. Eur Heart J. 2022 Jun 29;ehac289. doi: 10.1093/eurheartj/ehac289. Online ahead of print. PMID: 35766180.
- 2. Importance of genotype for risk stratification in arrhythmogenic right ventricular cardiomyopathy using the 2019 ARVC risk calculator.** Protonotarios A, Bariani R, Cappelletto C, Pavlou M, García-García A, Cipriani A, Protonotarios I, Rivas A, Wittenberg R, Graziosi M, Xylouri Z, Larrañaga-Moreira JM, de Luca A, Celeghin R, Pilichou K, Bakalakis A, Lopes LR, Savvatis K, Stolfo D, Dal Ferro M, Merlo M, Basso C, Freire JL, Rodriguez-Palomares JF, Kubo T, Ripoll-Vera T, Barriales-Villa R, Antoniadou L, Mogensen J, Garcia-Pavia P, Wahbi K, Biagini E, Anastasakis A, Tsatsopoulou A, Zorio E, Gimeno JR, Garcia-Pinilla JM, Syrris P, Sinagra G, Baucé B, Elliott PM. Eur Heart J. 2022 Jun 29;ehac235. doi: 10.1093/eurheartj/ehac235. Online ahead of print. PMID: 35766183.

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