

Monday 03 January 2022

ERN



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2022 NUMBER 1

New full-members on-board

Amsterdam, 01 December 2021

On Friday 26 November 2021, the ERN Board of Member States (BoMS) approved by consensus 620 applicants to join the 24 currently existing ERNs. The ERN membership of these newly approved HCPs started 1 January 2022 and the Networks will progressively welcome them (timeline is however Network dependent). ERN GUARD-Heart is happy to welcome and introduce 23 new full members, who will be active in 3 existing thematic areas (familial electrical diseases in adults and children, familial cardiomyopathies in adults and children, and special electrophysiology conditions in children) and in 2 new thematic areas (congenital heart diseases and other rare cardiac diseases). A complete list of all the participants in different thematic areas is available on page 2. By this expansion, ERN GUARD-Heart will consist of full member HCPs from 16 EU Member States (the newly added States are Portugal, Poland, Ireland, Hungary and Croatia). On top of this, ERN GUARD-Heart is proud to have affiliated partners from Austria, Lithuania, Slovenia, Slovakia, Estonia, Malta and Luxembourg. So currently there are 23 of 27 EU Member States actively involved in the ERN. Missing States are Bulgaria, Cyprus, Greece, & Latvia.



Affiliated partners

Amsterdam, 1 December 2021

With the introduction of new full members in an ERN, it is possible that the status of a HCP as an affiliated membership has to be terminated. This is because affiliated partners are only allowed to be active in an ERN, when there is not a full member from the same Member State present. In ERN GUARD-Heart there were 11 affiliated partners (9 Associated National Centres and 2 Coordination Hubs). Two of these affiliated partners had applied to become full members of the ERN and their applications have been approved by the BoMS: the University Hospital Centre in Zagreb (Croatia) and the University of Szeged (Hungary). So, these two HCPs will continue their activities in the ERN as full ERN members. ❤



List of full members in the ERN GUARD-Heart from 1 January 2022

No.	Representative	City	Country	Thematic area
1	Arthur Wilde	Amsterdam	Netherlands	1, 2, 3, 4
2	Georgia Brugada	Barcelona	Spain	2, 3, 4
3	Philippe Charron	Paris	France	1, 2, 3, 4, 5
4	Carlo Napolitano / Silvia Priori	Pavia	Italy	1
5	Pablo Garcia	Madrid	Spain	2, 5
6	Vincent Probst	Nantes	France	1
7	Jaana Pihkala	Helsinki	Finland	1, 2, 3, 4, 5
8	Jan Janousek/ Josep Veselka	Prague	Czech Republic	1, 2, 3, 4
9	Rik Willems	Leuven	Belgium	1, 2, 4, 5
10	Fabrizio Drago / Anwar Baban	Rome	Italy	2, 3, 4, 5
11	Annika Rydberg/Stellan Mörner	Umea	Sweden	2, 3
12	Jacob Tfelt-Hansen	Copenhagen	Denmark	1, 2, 4
13	Juan Ramon Gimeno	Murcia	Spain	1, 2, 3
14	Eric Schulze-Bahr	Munster	Germany	1, 2, 4
15	Philippe Chevalier	Lyon	France	1, 2
16	Ruxandra Jurcut	Bucharest	Romania	2, 5
17	Giuseppe Limongelli	Napoli	Italy	2, 5
18	Peter Schwartz	Milano	Italy	1, 2, 3
19	Eloisa Arbustini	Pavia	Italy	2
20	Carlo DeAsmundis	Brussel	Belgium	1, 2
21	Sabino Iliceto	Padova	Italy	1, 2, 3, 4, 5
22	Henrik Kjærulf Jensen	Aarhus	Denmark	1, 2
23	Johan Saenen	Antwerp	Belgium	1, 2
24	Elena Biagini	Bologna	Italy	2, 5
25	Gianfranco Sinagra	Trieste	Italy	2, 5
26	Frederic Sacher	Bordeaux	France	1
27	Rui Anjos	Lisboa	Portugal	4
28	Maria Joao Baptista	Lisboa	Portugal	2
29	Fatima Pinto	Lisboa	Portugal	2, 4
30	Pastora Gallego	Sevilla	Spain	4
31	Jolien Roos - Hesselink	Rotterdam	Netherlands	2, 4
32	Massimo Massetti	Roma	Italy	4
33	Elena Arbelo	Barcelona	Spain	1,2,5
34	Francisco Fernández-Avilés Diaz	Madrid	Spain	2
35	Jose Rodriguez Palomares	Hebron	Spain	2,4
36	Alica Krebsova	Prague	Czech Republic	1,2
37	Massimo Chessa	Milano	Italy	4
38	Stefan Kääh	München	Germany	1,2
39	Ingrid Krapels	Maastricht	Netherlands	1,2
40	James Galvin	Dublin	Ireland	1, 2, 3, 4
41	Katarzyna Mizia-Stec	Katowice	Poland	2
42	Robert Sepp	Szeged	Hungary	1, 2
43	Davor Miličić	Zagreb	Croatia	2, 4
44	Annette Baas	Utrecht	Netherlands	1, 2, 5

Table Legend

Thematic area 1: Familial electrical diseases in adults and children

Thematic area 2: Familial cardiomyopathies in adults and children

Thematic area 3: Special electrophysiology conditions in children

Thematic area 4: Congenital heart diseases

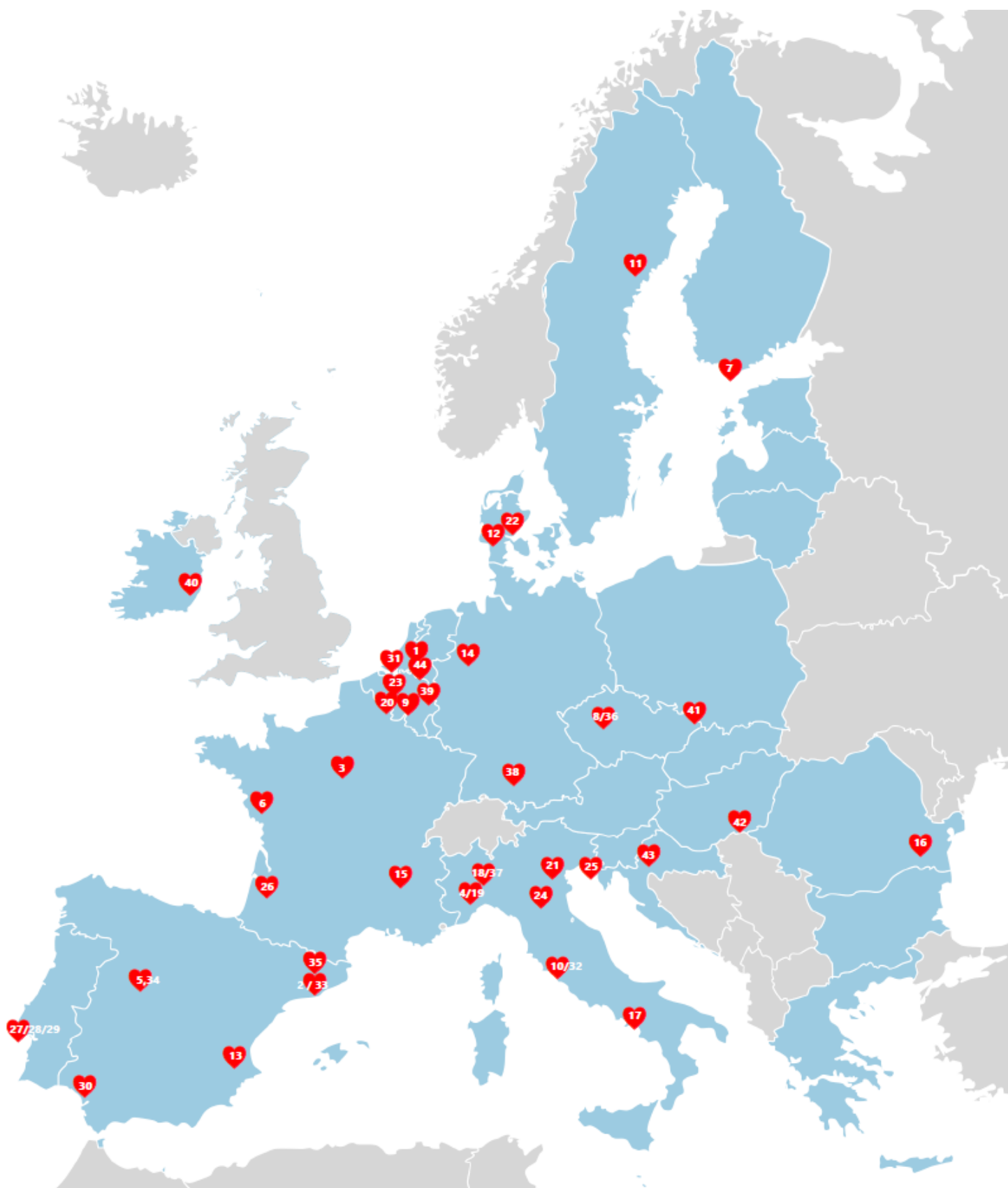
Thematic area 5: Other rare cardiac diseases

1,2,3,4,5 Fully approved for this thematic areas (this applies only for new full members)

4,5 Existing members have been approved for this thematic areas by the ERN board, and this has yet to be confirmed by the Board of Member States (this is because the timeline for assessment of the existing members by the BoMS and the Commission is different than for the new full members)



List of full members in the ERN GUARD-Heart from 1 January 2022



Each heart represents a HCP (a full member) in the ERN GUARD-Heart.



Information update website

Amsterdam, 16 December 2021

As already requested by e-mail: for the update of the website (<https://guardheart.ern-net.eu>) of the ERN GUARD-Heart with information of the new members of the Network, the project management office would like to receive the following information:

1. A picture of the hospital of each new member
2. A general text about the hospital/ department
3. A picture of the representative member of the hospital in the ERN.

Please, send the required information/documents - if yet not done - to Nynke Hofman as soon as possible (n.hofman@amsterdamumc.nl).♥

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

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Reception and use of the logo

Brussels, 20 December 2021

The official HCP-specific ERN logo's will be provided by the European Commission as soon they are produced. Please remember that the logo is a registered trademark of the European Commission, licensed to the networks. New members have to sign a bilateral sub-licensing agreement with the network to be able to use the logo(s). This will be explained during the introduction meeting.♥

Online meeting for new full ERN members

Amsterdam, 16 December 2021

The project management office of the ERN GUARD-Heart will organize an introductory meeting for the new HCPs included as full members, with general information about the ERN and opportunity to ask questions and provide ideas. This meeting will be held at Wednesday 26 January 2022 (16.00 – 18.00) and all the new members will receive a link for it by e-mail. ♥

Registration of new members in the EC database

Brussels, 20 December 2021

The European Commission requested the ERNs to confirm, correct, and/or complete some details from the new ERN members. In the first week of January you will receive an e-mail from the project managers with these data and a request to check and reply as soon as possible. Once the European Commission has completely confirmed the data, they will be able to create all the required authorisations (on IT level) for the new centres. This is necessary, for example, for using the clinical patient management system. ♥

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**ERN GUARD-Heart
Project
Management
Office**



Arthur A.M. Wilde
Network Coordinator
Academic Medical Center
Amsterdam, Netherlands
Email: a.a.wilde@amc.nl
Phone: +31205662904



Nynke Hofman
Project Manager
Academic Medical Center
Amsterdam, Netherlands
Email: n.hofman@amc.nl
Mobile: +31622046435



Ahmad S. Amin
Project Manager
Academic Medical Center
Amsterdam, Netherlands
Email: a.s.amin@amc.nl
Mobile: +31614471713