

Monday 7 February 2022

ERN



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2022 NUMBER 2

Monitoring numbers of 2021

Amsterdam, 4 February 2022

For the ERN monitoring system, we have to collect – as previously - the activities of ERN members for 2021 (complete year). Although the online system for data collection is not open yet, we expect that we have to submit our ERN activity before 1 March 2022. This week, we will send an e-mail with the requested indicators to the 'existing' members (i.e. members <2022) and the Affiliated Partners. Please provide your files in time. The 'new' members don't have to deliver their activities and number of new patients yet. ♥

Online meeting new full members ERN GUARD-Heart.

Amsterdam, 26 January 2022

On the 26th of January, a first online meeting was held for the new full members of ERN GUARD-Heart. With a short summary of the start and the first 5 years of the ERN programme the new members hopefully feel comfortable to join the current ERN activities and find their way to the project management and other full members.

21 of the 23 new HCP's were online and all the centres received the slides of the presentation afterwards in their mailbox. ♥



ERNs under 2022 Annual Work Programme

Brussels, 27 January 2022

The European Commission presented the plans for the future ERN grants and at 27 January there was an online meeting with to present details and timelines for the grant writing process. After enlargement of the 24 ERNs, there are currently 1466 full members + ~200 Affiliated Partners = ~1600 HCP units. Now it is important to manage the ERN expansion and to consolidate the ERN system for clinical collaboration (including IT infrastructure and the new CPMS). Future ERN goals are the support to ERN knowledge generation, training and dissemination actions and research activities, to integrate ERNs into national healthcare systems and to demonstrate the added value of the ERNS, and evaluation (2022-2023) and continuous monitoring. Currently, ERNs receive the following grants: ERN coordination grants, ERN registry grants (both under 3rd Health Programme) and grants for IT-related activities implemented under Connecting Europe Facility (CEF). A long-term goal is to streamline ERN funding by bringing the various funding sources together in the new multiannual direct grants. An issue here is the diverse expiration dates of the different grants. The chosen solution is to start with a 1,5 year bridging grant to ensure business continuity until most of the current grants expire and thereafter continue with a multiannual direct grant (encompassing 3,5 years) integrating all previous grant activities. Although the grant writing is ongoing at this moment (deadline march 1st), we are happy to share this positive news: hopefully we are able and allowed to make plans for ERN GUARD-Heart, for at least another 5 years. ♥



The position of the coordinator and the leaders of the thematic areas in ERN GUARD-Heart

Amsterdam, 2 February 2022

With the inclusion of two new thematic areas in ERN GUARD-Heart, we need two new thematic area leaders (one for Congenital Heart Diseases and one for the Other Rare Cardiac Diseases). The new areas started at 1 January 2022, after the new members were approved by the Board of Member States (BoMS) and could officially join the ERNs. For the existing members (in thematic areas 1, 2, and 3, who also applied for the new disease areas), the final approval by the BoMS is still pending and hopefully this will be established at the next meeting of the BoMS in the beginning of April. However, we think it is important to start activities with the complete group and therefore we would like to invite all (potential) members from all thematic areas to participate at the next ERN board meeting: 8 March 2022. During that meeting, we would like to vote for the leadership of the two new thematic areas (information about the online voting software will follow, along with the agenda for the meeting). In the run-up to that we will send an e-mail to all the representatives of thematic areas 4 and 5 with the question if they would like to be candidate for this position. As soon as the candidates list is complete it will be disseminated by e-mail.

Furthermore, we will ask the current leaders of the first three thematic areas if they would like to continue their work as thematic leaders. And last but not least, we would like to ask all members whether they wish to support the continuation of the coordination of the ERN GUARD-Heart project by the current coordinator after the bridging grant, which ends at the 1st of August 2023. ♥

Save
the
Date ♥

**The next ERN GUARD-Heart
board meeting will be held
online on
Tuesday 8 March 2022
from 9.00 – 12.00 a.m.**

ERN Extension

Inclusion of existing members in the new thematic areas

Familial
Electrical Diseases



Carlo
Napolitano

HELLO!

New Members!

Familial
Cardiomyopathies



Philippe
Charron

HELLO!

New Members!

Special
Electrophysiology
Conditions

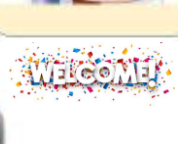


Georgia
Sarquella-
Brugada

HELLO!

New Members!

Congenital
Heart Defects
(2022)



WELCOME!

Other rare
diseases
(2022)



WELCOME!



European
Reference
Network





Update and continuation ERN - Exchange Programme

Amsterdam, 2 February 2022

The ERN Exchange Programme 2021-2022, funded by the European Commission, aims to promote the sharing of knowledge and collaboration between the healthcare providers in the ERNs. For ERN GUARD-Heart, there are 34 so-called 'packages' available.

A single package provides:

- compensation for 5 working days for 1 person;
- travel arrangements;
- and 200 EUROS per working day (for the cost of accommodation, travel insurance, food and local transport).

Currently, one visit has been completed, and 5 have been approved (see table below). Besides that, several members and Affiliated Partners have requested for the proposal template to write a plan. For your reassurance: this template is compact and requests for the objectives, planned activities and expected results. The thematic scope of the Exchange Programme includes medical practice and skills but also organisational aspects of a Network. Healthcare professionals working in ERN centres are eligible for this programme – this includes all disciplines related to the relevant expertise areas of the ERN. Hosting centres should be approved ERN members as well. Exchange visits to (members) of other ERNs are allowed. Visits to centres outside the EU27+Norway are not foreseen. At the end of November 2021, the ERN Exchange Programme was suspended because of the COVID-19 pandemic. The last update is that it is still the idea to re-start the activities from the 1st of March on. So, please: if you or one of your colleagues would like to visit one of the other ERN-centres for a couple of days, this is possible with help of the Exchange Programme.

Please contact the project management (n.hofman@amsterdamumc.nl) if you have a suggestion for an exchange plan. The general information of this programme is available on the website of the ERN GUARD-Heart: <https://guardheart.ern-net.eu/experts/ern-exchange-programme/>. ❤

From	Participant	To	Status
University Hospital Brussels	Saar van Pottelberghe	Amsterdam UMC	Completed
Amsterdam UMC (cardiology)	Virginnio Proost	University Hospital Münster, Germany	Approved (delayed)
Amsterdam UMC (genetics)	Dr. Saskia vd Crabben	University Hospital of Umeå, Sweden	Approved (delayed)
Paris (l'hôpital Bichat)	Prof. Fabrice Extramiana	Amsterdam UMC	Approved
Motol University Hospital Prague	Terezia Tavacova	Amsterdam UMC	Approved
Motol University Hospital Prague	Dr. Karel Koubsky	Bambino Gesù Children's Hospital IRCCS, Rome	Approved

Table 1: Completed and approved exchange - visits



Joint press release on Accelerating Clinical Trials in the EU

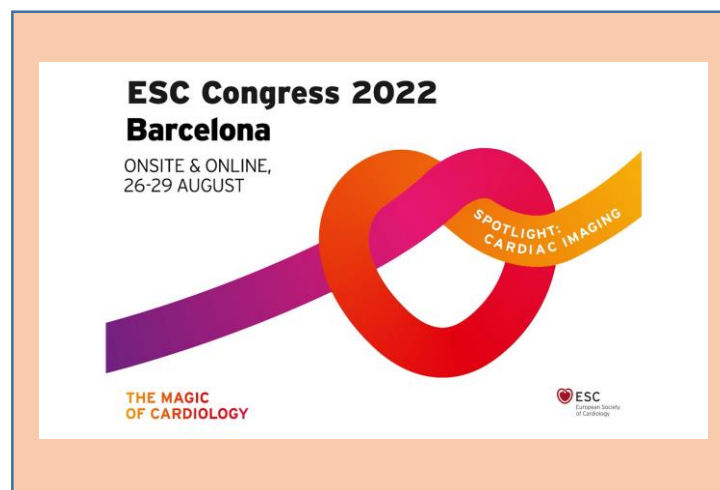
Brussels, 14 January 2022

The European Commission (EC), the head of Medicines Agencies (HMA) and head of the European Medicines Agency (EMA) are coming together to optimise the environment for clinical research in Europe by launching Accelerating Clinical Trials in the EU (ACT EU).

This initiative will use the momentum created by the implementation of the Clinical Trials Regulation and the launch of the Clinical Trials Information System (CTIS) on 31 January 2022, to further promote the development of high quality, safe and effective medicines.

One of the initiative's priority actions will be to establish a multi-stakeholder platform, where all voices, including those of ERNs can contribute to enabling better clinical research. More detailed information on all priority actions is available in the following document:

https://www.ema.europa.eu/documents/regulatory-procedural-guideline/accelerating-clinical-trials-eu-act-eu-delivering-eu-clinical-trials-transformation-initiative_en.pdf ♥



Latest ERN GUARD-Heart Publication(s)

1. **Clinical and Functional Characterization of Ryanodine Receptor 2 Variants Implicated in Calcium-Release Deficiency Syndrome.** Roston TM, Wei J, Guo W, Li Y, Zhong X, Wang R, Estillore JP, Peltenburg PJ, Noguer FRI, Till J, Eckhardt LL, Orland KM, Hamilton R, LaPage MJ, Krahn AD, Tadros R, Vinocur JM, Kallas D, Franciosi S, Roberts JD, Wilde AAM, Jensen HK, Sanatani S, Chen SRW. JAMA Cardiol. 2022 Jan 1;7(1):84-92. doi: 10.1001/jamacardio.2021.4458. PMID: 34730774.

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