

Friday 1 December 2023

ERN



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart

ATTENTION!

Fill in the **SURVEY** on
“accessibility to drugs for
treatment arrhythmias”
(see page 4 for details)


ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2023 NUMBER 7

ERN Webinar December on CHD

Amsterdam, 28-11-2023

The next Webinar of ERN GUARD-Heart will take place on Wednesday 20 December at 13:00 till 13:45 and will be in the field of the Congenital Heart Diseases (thematic area 4): ‘4D flow CMR in CHD: Consensus statement update, application in Fontan-patients and surgical perspectives’. There will be three interesting presentations. See the flyer below for details. Please join this webinar and encourage you colleagues to do so as well. Registration is possible using by the following link <https://forms.gle/FfjZ93C8gdNkY2Re7>. ♥



European
Reference
Network

Network
Heart Diseases
(ERN GUARD-HEART)

Invites you to attend:




The Webinar series for rare or low prevalence cardiovascular diseases

“4D flow CMR in congenital heart disease”

Speakers:
Dr. A. Roest, Leiden
Prof. Y. d’Udekem, Washington
Dr. F. Raimondi, Florence

Wednesday 20-12-2023
13:00 - 13:45

Register now to receive the Zoom link:
<https://forms.gle/FfjZ93C8gdNkY2Re7>



Grant evaluation completed

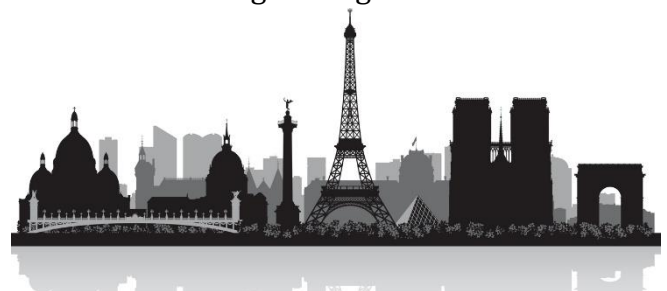
Amsterdam, 28-11-2023

The grant proposal for the direct grant to the ERNs, which provides support for the coordination, management and operational activities of the ERNs has been re-submitted, after it was cancelled due to legal problems with Ukraine-related activities. In the new application, these activities have been, as requested by the Commission, gathered into one separate work package. While the re-submitted application has received positive evaluation, major revision is required. We’re currently in the process of revision and grant preparation and hope that the agreement will be signed in January 2024. ♥

Save the date: 22 March 2024

Paris, 29-11-2023

The next hybrid board meeting of ERN GUARD-Heart will be held in Paris on Friday 22 March 2024. We would like to invite one representative per HCP to attend this meeting on site, and the dinner on the evening before. Reimbursement of the travel costs and accommodation is available. There will be a simultaneous meeting for the ePAGs of our ERN. Soon an e-mail will be sent with instructions for registering. ♥





Who are our ePAGs?

Amsterdam, 28-11-2023

One of the European patient advocates of ERN GUARD-Heart in the spotlight: **Lorraine McGlinchey** from Ireland tells her story and her active way to cope with it..

'In 1994, a devastating event changed the course of my life forever. My eldest sister Caroline, aged 33 years, died suddenly while at a local swimming pool with her husband and two young boys. At that time, her death was attributed to drowning as no other explanation was found on autopsy. Three years previously, my 16-year-old cousin Thomas died at his school while standing at a notice board. Again, no definitive answer was forthcoming on autopsy. In the years prior to this, three other young members of my extended family had died suddenly and unexpectedly.

After the death of my sister, I felt there had to be an explanation as to why so many of my family were dying at a young age. I started having myself referred for tests in the hope that something could be found that may explain what was happening. This took many years to achieve as I was met with a mixture of skepticism and lack of action by the healthcare professionals. It was only in 2006 that we found the gene responsible, Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT). Unfortunately, another young cousin (13 years old) had to die for this gene to be discovered. Her 9-years-old brother was one of the earlier deaths. This then began cascade testing in my family. My nephew, Christopher (my sister Caroline's son) was found to be positive for the gene in September 2009, however he died three months later, nine days before Christmas aged 25.

In 2007 I decided to train as a nurse with the ambition of changing the landscape for families like mine and to be an advocate for patients and their families. I have raised funds to train over 200 people in my local area in CPR and defibrillator use, while also fundraising to purchase 13 defibrillators for schools, clubs, and communities, while also raising awareness of these conditions and SADS. I have been a member of the Long QT support group and the SADS support group within the Irish Heart Foundation (IHF) since 2006. I am also a national representative on the Sudden Cardiac Death Taskforce Council (IHF).



I completed a Masters in Science in 2018, researching the views and experience of people with an inherited cardiac arrhythmia or history of SADS and their families who attend an acute hospital setting for an unrelated condition. I am currently an Adult Nurse Lecturer at Ulster University and am currently writing up a PhD thesis on my research study entitled "Healthcare professionals' knowledge and experience of Inherited Cardiac Arrhythmias (ICA), their views towards and confidence in caring for a person with an ICA in a surgical environment". I was very privileged to have my research abstract accepted to present at the European Society of Cardiology Congress in Barcelona in 2022.

I became a member of the European Patient Advocacy Group (ePAG) for the ERN GUARD-Heart in January 2023, so am new to this role. However, I feel that my unique position as a family member, a registered nurse, nurse lecturer and researcher gives me a great insight into all aspects of these conditions and as a nurse advocate have honed these skills to be able to use my voice to amplify the many voices of the families I speak for. I aim to use these skills within my role as an ePAG to collaborate with my colleagues and peers to improve the narrative into the future for people with cardiac conditions'. ♥

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lorraine.mcglinchey@hotmail.com

Website Irish Heart Foundation:

<https://irishheart.ie/>





ERN - Exchange Programme

Amsterdam, 28-11-2023

The ERN Exchange Programme has been designed to spread knowledge across the ERN GUARD-Heart and to stimulate collaboration between healthcare professionals in different European Reference Networks (ERNs).

With funding from the ERN GUARD-Heart, each exchange package will provide funds for a 5-day exchange visit to an ERN healthcare provider (HCP) center – this can be an HCP within the ERN GUARD-Heart, or potentially an HCP within one of the other 23 ERNs, if relevant and appropriate.

Per HCP, one application (as a visitor) can be accepted per year. One package includes reimbursement of travel costs (maximum of € 500,-) and a daily allowance of € 200,- (for accommodation costs, local transport and food). Travel insurance is NOT included.

A request to combine packages for a longer visit can be considered, but depends on the number of submitted applications.

There are 15 packages available per year. Visitors can come from full members or affiliated partners of the ERN GUARD-Heart (including members of their multi-disciplinary teams).

The first call for applications for an exchange visit before September 2024, is now open. The deadline for these applications is 1 February 2024.

How to apply:

Once you found your hosting hospital, you can apply for an exchange package by describing your objectives, activities and expected results. Please fill in the 'mobility agreement' (which is available on the ERN-website <https://guardheart.ern-net.eu/2023/10/30/exchange-programme-2023-2024/>) completely and send it to the ERN Coordination team (n.hofman@amsterdamumc.nl).

Please feel free to contact Nynke Hofman, ERN GUARD-Heart network manager, if you have any questions or if you would like to discuss an application. ❤️





SURVEY: accessibility to drugs for treatment arrhythmias

Barcelona, 28-11-2023

Dear colleagues,

With this **survey** the EHRA Advocacy and Quality Improvement Committee (EHRA AQIC), with the support of the EHRA Scientific Initiatives Committee (SIC), the Association for European Paediatric and Congenital Cardiology (AEPC) and ERN GUARD-Heart, would like to ask you **to state and comment on issues you experience regarding the accessibility to drugs for the treatment of arrhythmia**. The reasons for this survey are the seemingly progressive problems that many colleagues experience in Europe, both for adult and for pediatric cardiology, regarding their accessibility to treat their arrhythmia patients, whether it being supraventricular, ventricular, rare/heritable, or common arrhythmia. We would like to establish the current state of these problems, to be able to better address these problems both in national and European frameworks.

Please fill in the survey and distribute it to your peers! Many thanks for your kind cooperation, and please feel free to leave additional comments.

Kind regards on behalf of the EHRA AQIC, EHRA SIC, AEPC, and ERN GUARD-Heart,

Pieter G. Postema, MD, PhD, Amsterdam University Medical Centers, Amsterdam, The Netherlands

Elena Arbelo, MD, PhD, Hospital Clinic, Barcelona, Spain

Georgia Sarquella-Brugada, Hospital Clinic, Barcelona,

LINK TO SURVEY:

<https://www.surveymonkey.com/r/DrugAccess>

The more replies we have, the better! ♥



Dissemination of Congress programs ERN-centres

Amsterdam, 28-11-2023

We would like to invite all members and affiliated partners to send their programs (agendas) of any planned (inter)national congresses to the ERN coordination team, for dissemination on the ERN website ('future events' page) and on social media channels. In addition, it is possible to ask for ERN endorsement, by sending the congress program to the ERN coordination team. It will create a good overview of all the activities within the ERN and can be an inspiration to attend a specific meeting or to inform your colleagues about it. If the program receives ERN endorsement, we request to use the ERN-logo on the presentations and flyers.



National meetings for patients

Amsterdam, 29-11-2023

In the new grant period, there is budget available (per country and per year) for the organization of national patient meetings by the full members, affiliated-partners and ePAGs. As requested by ERN members, the budget will depend on the number of HCP's per EU Member State:

Number of HCPs per country	Budget per country per year
1	2000 EURO
2	3000 EURO
3	4000 EURO
≥4	5000 EURO

In January 2024 the ERN coordination team will send a survey to identify your planned meetings before 1 October 2024, where after the budget (for the first year of the grant) can be divided equally among the planned meetings and the corresponding organizers. If a country will not use the budget, it can be re-distributed to other EU countries. ♥



Monitoring data 2023

Amsterdam, 30-11-2023

In January 2024 the collection of the monitoring data will start again. The European Commission is building an online platform where HCPs of all ERNs in the future can upload their numbers and activities by themselves. This will be mandatory in 2025. At least a main part of the data of 2023 will be collected in the same way as previously (direct files by e-mail to the ERN coordination team). Detailed instructions and requirements will become available soon and we will inform you about them by e-mail. ♥



Presentations ERICA and EJP-RD joint conference available

Amsterdam, 30-11-2023

The European Rare Disease Research Coordination and Support Action- ERICA and European Joint Programme of Rare Diseases (EJP RD) Joint Conference took place on 21st November 2023 in Amsterdam University Medical Centers.

Main topics were examples of synergies between both projects (ERICA & EJP RD), collaboration of ERNs and non-ERNs researchers, and preparing the path to the European Rare Diseases Research Alliance (ERDERA).

The full programme and an overview of all presentations is available on ERICA's website: <https://erica-rd.eu/presentations-erica-ejp-rd-joint-conference-available/> ♥

Latest ERN GUARD-Heart Publications

1. Bergeman AT, Lieve KVV, Kallas D, Bos JM, Noguer FRY, Denjoy I, Zorio E, Kammeraad JAE, Peltenburg PJ, Tobert K, Aiba T, Atallah J, Drago F, Batra AS, Brugada R, Borggreffe M, Clur SB, Cox MGJ, Davis A, Dhillon S, Etheridge SP, Fischbach P, Franciosi S, Haugaa K, Horie M, Johnsrude C, Kane AM, Krause U, Kwok SY, LaPage MJ, Ohno S, Probst V, Roberts JD, Robyns T, Sacher F, Semsarian C, Skinner JR, Swan H, Tavacova T, Tisma-Dupanovic S, Tfelt-Hansen J, Yap SC, Kannankeril PJ, Leenhardt A, Till J, Sanatani S, Tanck MWT, Ackerman MJ, Wilde AAM, van der Werf C. Flecainide Is Associated With a Lower Incidence of Arrhythmic Events in a Large Cohort of Patients With Catecholaminergic Polymorphic Ventricular Tachycardia. *Circulation*. 2023 Oct 27. doi: 10.1161/CIRCULATIONAHA.123.064786. Epub ahead of print. PMID: 37886885.
2. Hascoët S, Benthall JR, Giugno L, Betrián-Blasco P, Kempny A, Houeijeh A, Baho H, Sharma SR, Jones MI, Biernacka EK, Combes N, Georgiev S, Bouvaist H, Martins JD, Kantzis M, Turner M, Schubert S, Jalal Z, Butera G, Malekzadeh-Milani S, Valdeolmillos E, Karsenty C, Ödemiş E, Aldebert P, Haas NA, Khatib I, Wählander H, Gaio G, Mendoza A, Arif S, Castaldi B, Dohlen G, Carere RG, Del Cerro-Marin MJ, Kitzmüller E, Hermuzi A, Carminati M, Guérin P, Tengler A, Fraisse A; EUROPULMS3 investigators. Outcomes of transcatheter pulmonary SAPIEN 3 valve implantation: an international registry. *Eur Heart J*. 2023 Oct 24;ehad663. doi: 10.1093/eurheartj/ehad663. Epub ahead of print. PMID: 37874971.
3. Brida M, De Rosa S, Legendre A, Ladouceur M, Dos Subira L, Scognamiglio G, Di Mario C, Roos-Hesselink J, Goossens E, Diller G, Gatzoulis MA. Acquired cardiovascular disease in adults with congenital heart disease. *Eur Heart J*. 2023 Nov 14;44(43):4533-4548. doi: 10.1093/eurheartj/ehad570. PMID: 37758198.

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