

Monday 3 April 2023

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

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ERN



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2023 NUMBER 3

Meetings for patients

Amsterdam, 30-03-2023

In the current (bridging) grant period, which runs until 01-09-2023, ERN GUARD-Heart has 3.000 EURO per country available for the organization of national patient meetings. Currently 10 countries used this budget (or planned to use it before the end of the grant period). For the remaining 13 countries (which are in our ERN) it is possible to ask for this national budget before the 15th of April (please contact the coordination team). Thereafter the budget will be open for all countries again (to be able to organize an extra meeting). ♥

Call for next grant period ERNs

Amsterdam, 30-03-2023

The call for the direct grant to the ERNs, which includes support for the coordination management and operational activities of the ERNs is launched. The duration of this grant period is 4 years: 01-09-2023 – 01-09-2027. The deadline of the submission is 25 May. There are 7 mandatory workpackages: coordination, dissemination, evaluation, healthcare & CPMS, Registries/ datamanagement/ analysis, training/ education, and clinical practice guidelines/ clinical decision support tools. Within the workpackages it is possible to organize preferred activities as for example a continuation of the exchange programme, fellowships, etc. We invite all our members to think about activities you would like to include. Please share your ideas as soon as possible and before the first of May. ♥

Information about registries

Amsterdam, 30-03-2023

The next ERN newsletter will be published within 2 weeks, exclusively with information about the registries. This is an important, but also quite complex topic with a lot of decisions to take and questions to answer. We would like to encourage all the HCPs to think about inclusion of their patients to the disease specific registries and maybe to find a contact person or local coordinator in your centre who can be of support in collecting and uploading the cases. ♥

PARQ 2023

Amsterdam, 03-04-2023



The PARQ Action is a pan-European network, supported by the EU-COST program, aimed at promoting research and research networks on Sudden Cardiac Arrest (SCA) in its broadest sense, including studies into the underlying causes of SCA and into the treatment of SCA. The PARQ Action is planning its 1st Training School on 15-18 May 2023 in Gargnano (Lago di Garda), Italy. This event will be held alongside the 4th PARQ Consortium Meeting. The Training School is aimed at promoting the development and research of Young Investigators. There is place for 6 trainees and 2 trainers of the ERN. Despite the tight deadline, the trainees list is complete, **but there is one place left for a trainer:** please contact the ERN projectmanagers soon if you are interested. ♥



Patient-Clinician reflection meeting

Amsterdam, 30 March 2023

At Wednesday morning 15 March a patient-clinician reflection meeting was held in Amsterdam. This was organized by the ERN-patient representatives groups (ePAGs) and Eurordis. The session was a structured and outcome-driven group forum where 3 patient representatives came together with the thematic area leaders and ERN GUARD Heart's coordination team, to assess and work on their collaboration. It was an important and inspiring meeting, with nice plans for the further implementation and involvement of the patients voice into the ERN activities. ❤





EJP-RD / ERN Symposium

Amsterdam, 30 March 2023

The Board Meeting in Amsterdam was combined with a two-day symposium (16 and 17 March) and networking event on the genetics of inherited arrhythmia syndromes. The symposium was organized by the Amsterdam UMC (Prof. Connie Bezzina and Dr. Roddy Walsh) and ERN GUARD-Heart and was partially funded by the EJP RD Networking Support Scheme.

Over 100 participants enjoyed impressive talks on cutting edge research from some of the world's leading investigators in this field. It also included discussions on developing the new and existing networks required to further progress research in this field and how to translate recent advances into clinical applicability - the development of multicentre patient registries, national and international databases and future collaborative projects and grant applications. ♥



Who are our ePAG's?

Amsterdam, 30-03-2023

A new item in this newsletter will be a short story of one of the European patient advocates groups (ePAG) This edition we have the story of the current chair : Ruth Biller:

'I founded ARVC-Selbsthilfe (a German ARVC patient organisation) together with several family members in 2013 after the sudden cardiac death of my daughter Judith at the age of fourteen. In 2018 I became chair of the registered non-profit organisation ARVC-Selbsthilfe e.V. and joined the ePAG of ERN GUARD-Heart. Since August 2019 I am ePAG chair. I am also member of the Cardiomyopathy Patient Council of Global Heart Hub, an international Umbrella Organisation for all heart diseases.

By education, I am gynecologist. Being a doctor helps me to facilitate communication between clinicians and patients. It's my big aim is to make people aware of ARVC and other genetic heart diseases and to prevent sudden cardiac death in other families.

My organisation provides presentations, Q&A sessions and peer-to-peer support for patients and their families to raise awareness and to educate patients.

As chair of the ePAGs, I want to bring the patient perspective and the patients' unmet needs to clinicians and by building a strong network of HCPs and patient representatives add value to patients and their families'. ♥

German speaking HCPs are very welcome to attend our next ARVC day in Munich 17 June 2023.

More information:
www.arvc-selbsthilfe.org

Contact:
info@arvc-selbsthilfe.org



ERN-Board Meeting and dinner in Amsterdam

Amsterdam, 30 March 2023

On Wednesday 15 March, the ERN Board members, affiliated partners and representatives from the European patient advocacy groups participated in the 13rd ERN Board Meeting, which was organized in the Trippenhuis in Amsterdam. With 41 physical attendees and about 20 online, each HCP could attend. It was a nice meeting and it is more and more interactive and an important Network meeting. There was a joint dinner with the faculty of the EJP RD/ ERN symposium speakers (large overlap) at restaurant Jansz in the impressive 'Saxenburg Room'. Thanks to all the attendees for their active participation. ♥





SAVE THE DATE

Cardiogenetics, the evolution of a discipline

and a celebration of the academic career of Arthur Wilde

Keynote speakers:

- Dan M. Roden, Vanderbilt University Medical Center, Nashville (TN, USA)
- Michael J. Ackerman, Mayo Clinic, Rochester (MN, USA)

Click for more information and registration:

<https://registratie.roijecongressen.com/cardiogenetics>Amsterdam UMC
Universitair Medisch Centrum

August 24th, 2023

Felix Meritis | Amsterdam

1st European
Loeys-Dietz Syndrome

Patient and Research Networking Conference

Gruauwzusters, Antwerp, Belgium

Presentations by Bart Loeys & Harry Dietz

For patients, families and health care providers:

- Patient perspective
- LDS: the basics and genetics
- Research update
- Managing quality of life
- Cardiovascular imaging & treatment
- Gastro-intestinal & immune issues
- Orthopedic issues

Break out sessions for patients and families:

- Aortic surgery, Children, Pregnancy, Sport,
- Nutritional issues, Psychosocial challenges

Hof van Liere, Antwerp, Belgium

For clinicians and scientists:

World Café Brainstorm for setting
the Research Agenda25th June 2023Scan me to register on
<https://ngs.uantwerpen.be/ldsday2023/>Centrum Medische
Genetica AntwerpenUniversiteit
Antwerpen

Dear colleagues,

I would like to share with you that on June 24 and 25, 2023 we will organize the first European Loeys-Dietz Patient and Research Networking Conference in Antwerp, Belgium. The first day is oriented towards patients, families and health care professionals; so please spread the word to interested patients and colleagues. The second day is dedicated to clinical and basic researchers who are interested to join us for a brainstorm on the future of LDS research.

Programme and registration (both for day 1 and day 2) are available via <https://ngs.uantwerpen.be/ldsday2023/>

Sincerely,
Bart Loeys

Latest ERN GUARD-Heart Publication(s)

- Eriksson P, Pihkala J, Jensen AS, Dohlen G, Liuba P, Wahlander H, Sjöberg G, Hlebowicz J, Furenas E, Leirgul E, Settergren M, Vithessonthi K, Nielsen NE, Christersson C, Sondergaard L, Sinisalo J, Nielsen-Kudsk JE, Dellborg M, Larsen SH. Transcatheter Intervention for Coarctation of the Aorta: A Nordic Population-Based Registry With Long-Term Follow-Up. JACC Cardiovasc Interv. 2023 Feb 27;16(4):444-453. doi: 10.1016/j.jcin.2022.11.007. PMID: 36858664.
- Christiansen MK, Kjær-Sørensen K, Clavsen NC, Dittmann S, Jensen MF, Guldbrandsen HØ, Pedersen LN, Sørensen RH, Lildballe DL, Müller K, Müller P, Vogel K, Rudic B, Borggreffe M, Oxvig C, Aalkjær C, Schulze-Bahr E, Matchkov V, Bundgaard H, Jensen HK. Genetic analysis identifies the SLC4A3 anion exchanger as a major gene for short QT syndrome. Heart Rhythm. 2023 Feb 15:S1547-5271(23)00148-0. doi: 10.1016/j.hrthm.2023.02.010. Epub ahead of print. PMID: 36806574.

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