Tuesday 6 October 2020

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES
Share. Care. Cure.

ERN GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart

ERN GUARD-HEART BIMONTHLY NEWSLETTER YEAR 2020 NUMBER 5

ERN monitoring 2020: the first six months data collection

Amsterdam, 15 September 2020

At the end of October 2020, ERN GUARD-Heart has to submit the required data for the first six months of 2020 to the European Commission through the online IT tool. All full members of the Network have been requested by e-mail to complete their data and send the forms (in PDF & Excel format) to the ERN GUARD-Heart management office before 25 October 2020. Affiliated partners will be included in the data collection process for the whole year of 2020. For this, data will be collected in February 2021. Affiliated partners will be informed about this process separately. ♥

European Commission

Assessment ERN applications

Amsterdam, 30 September 2020

The 32 applications for full membership in ERN GUARD-Heart have been assessed by the proposed delegation of the ERN board (Georgia Sarquella-Brugada, Philippe Charron, Carlo Napolitano, Eric Schülze-Bahr, and Arthur Wilde) with assistance from project managers. The opinions have been submitted to the IT assessment platform and the applicants who received un unfavourable opinion can reply within 30 days. Currently, 9 applicants have been accepted fully for the thematic areas they had applied for & 12 have been accepted partially (for part of the requested thematic areas). It is expected that the assessment procedure will be completed in the first months of 2021.

The current members who wish to apply for the new thematic areas 'congenital heart disease' and 'other rare cardiac diseases') are invited to fill in a template document which will be distributed by e-mail. The templates will be discussed by the same team as mentioned above. Indeed, the assessors will be excluded in the decision for their own centres. ♥

Transversal cross-ERNs Working Group on Pregnancy and Family Planning in rare, low-prevalence and complex diseases

Professor Marta Mosca, the coordinator of ERN ReCONNET (i.e. for Rare and Complex Connective Tissue and Musculoskeletal Diseases) from Pisa, has initiated a transversal cross ERNs working group on pregnancy and family planning in rare, low prevalence and complex diseases. The working group will take care of driving the research in this field, delivering specific clinical practice guidelines for pregnancy planning and management in rare diseases, as well as develop education and information materials for patients and healthcare professionals. ERN GUARD-Heart will be represented by Giuseppe Limongelli, Ruth Biller (EPAG), and Ahmad Amin. Isabelle Denjoy (France) and Kalliopi Pilichou (Italy) will also be involved in the project. ♥

RARE Connect (a project from EURORDIS)

Vision

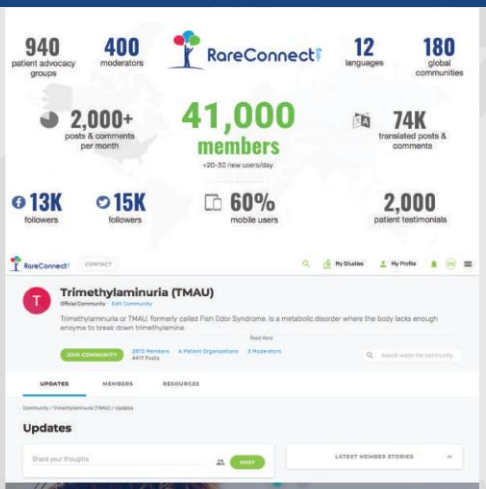
RareConnect's primary aim is to:

Reduce isolation and increase wellbeing.

Help individuals find the support and information they're looking for

RareConnect will:

- Provide patients and caregivers with a supportive and safe environment to ask questions and connect with other people with similar conditions
- Suggest other members, communities, and organizations that may be of interest
- Enable users to provide health-related information
- Eventually streamline clinical visits and lead to a better understand of the spectrum and progression of rare diseases



Translation

RareConnect fully supports 12 languages and is working to add more. Posts are automatically translated to the user's preferred language to facilitate multi-lingual communication between members.

My Studies

RareConnect Research - My Studies aims to build a rich resource database and data repository that will include patient-reported data.

Mobile friendly. Tracking measurements and completing surveys has been developed with a mobile first approach to ensure it is as easy and intuitive as possible.

It has been designed to provide researchers with a completely customizable survey/questionnaire functionality that they can push to their study participants to complete.

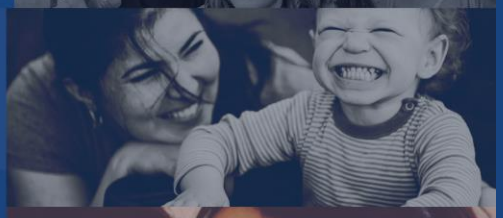
Find out more at **rareconnect.org**

RareConnect

About RareConnect

RareConnect addresses the isolation of people living with rare diseases by allowing them to connect to a support network of similar families and advocacy organizations based on the health information they provide in over 180 disease-specific communities. The communities provide a safe environment to ask questions and interact with others experiencing the same challenges. In addition, users will be able to request new communities targeted towards specific phenotypes, diseases, and genes.

To Learn More Visit:
rareconnect.org



RareConnect

RareConnect

CONNECTING
RARE DISEASE PATIENTS GLOBALLY

Affiliated partners

Amsterdam, 25 September 2020

ERN GUARD-Heart welcomes 11 Affiliated Partners from 9 EU Member States. All bilateral agreements between the ERN GUARD-Heart and the Affiliated Partner have been signed. The integration of the Affiliated Partners into the ERN has been described in an official document, designed by the European Commission, revised by the ERNs, and approved by the Member States. This document will be available on the website of the ERN GUARD-Heart soon. ♥

Robert Sepp
Albert Szent-Györgyi Health Centre
University of Szeged
Szeged - Hungary

Raili Ermel
Tartu University Hospital
Tartu - Estonia

Karin Writzl
University Medical Centre
Ljubljana - Slovenia

Iveta Simkova
Grown-up Congenital
Heart Disease Center
Bratislava - Slovakia

Egle Ereminiene
Hospital of Lithuanian
University of Health Sciences
Kauno Klinikos
Kaunas - Lithuania

Gerhard Pölzl
Medical University
Innsbruck - Austria

Bojan Biocina
University Hospital Centre
Zagreb - Croatia

Kerstin Wagner
Hospital Center
Luxembourg
National Coordination Hub

Jūratė Barysienė
Vilnius University Hospital
Santaros Klinikos
Vilnius - Lithuania

Ina Michel-Behnke
Medical University Vienna
Vienna - Austria

Melanie Burg & Tiziana Felice
Mater Dei Hospital Malta
National Coordination Hub

EJP-RD Research Training Workshop Call

European Joint Programme on Rare Diseases (EJP RD) ERN-RD training and support program Research Training Workshop Call.

The aim of this call is to identify the most suitable topics for the organization of research training workshops targeted to the ERNs. Selected research training workshops will have to train ERN researchers and clinicians in ERN relevant innovative training themes. Training themes may include innovative research methodologies, diagnostic research methodologies, interdisciplinary treatment approaches, such as gene therapy and transplantation, etc. Moreover, workshops will be aiming to provide a cross-ERN added value.
The call opened on 31 August 2020. The deadline for application is 12 October 2020. The links to the electronic application form, as well as this call document (pdf) can be found at the EJP RD website. ♥

Application form:
https://forms.office.com/Pages/ResponsePage.aspx?id=AcQ6OB2ia0KAcl90w2twk8f8TO5199dFvKkSOEEBdRlUNFAyQTdOVE5ZTVZCNDdUVFlTWDlJWlpHNS4u

Call document:
https://www.ejprarediseases.org/index.php/trainingandempowerment/erntrainings/

EJP-RD Research Mobility Fellowship

The call for Research Mobility Fellowships aims to financially support PhD students and medical doctors in training affiliated to ERN Full Members or ERN Affiliated Partners to undertake short scientific visits (secondments) fostering specialist research training outside their countries of residence and within one of the ERN host institutions. Applicants who will receive fellowships for Research Mobility should acquire at their host (secondment) institution new competences and knowledge related to their research on rare diseases and with benefit to their ERN. Call open: 1 October and closes 13 November.

Applicants/Application profile:
•PhD students with a minimum of one year of research experience OR physicians having finished their first year of specialist training
•Be affiliated to an ERN Full Member or to an ERN-Affiliated Partner Institution from one of the 24 **ERNs** at the time when the application is submitted, as well as during the proposed period of the training stay
•The host (secondment) institutions must be Full or Affiliated Member of an ERN at the time when the application is submitted, as well as during the proposed period of the training stay
•Added value to ERN of the mobility stay ♥

Application form:
https://forms.microsoft.com/Pages/ResponsePage.aspx?id=AcQ6OB2ia0KAcl90w2twk2IqTVIYWZFGrQTKKrr6cotUMkxFWkc3VUo1OVNWN004MVRUM0hBUURaNS4u

Call document:
https://www.ejprarediseases.org/wp-content/uploads/2020/10/EJP_RD_FELLOWSHIP_CALL_TEXT.pdf

ERN educational activity (online) – Murcia -Spain

IX Jornada de Cardiogenética

Viernes 27 noviembre 2020, 8:30 horas.

ERN GUARD-HEART

IMIB Instituto Murciano de Investigación Biosanitaria

Hospital C. Universitario Virgen de la Arrixaca

European Reference Network
for rare or low prevalence complex diseases

Network Heart Diseases (ERN GUARD-HEART)

PROMS-PREMS meeting: first workshop 29 October 2020

Brussels, 6 October 2020

The Heart Rhythm Management Centre (HRMC) and Centre for Medical Genetics (CMG) of the University Hospital of Brussels, UZ Brussel, in collaboration with ERN GUARD-Heart, would like to invite you to four online workshops in our joined attempt to assess the specific psychosocial issues individuals undergoing (genetic) counselling for inherited cardiovascular disease encounter.

The purpose of these workshops is to work out a guideline or E-tool that will aid patients' decisional process in clinical and genetic testing, treatment and rehabilitation for inherited cardiovascular diseases.

SAVE THE DATES (2020 – 2021):
Workshop 1: 29 October: 10.00 – 12.00
Workshop 2: 17 November: 15.00 – 17.00
Workshop 3: 8 December: 12.00 - 14.00
Workshop 4: 12 January: 12.00-14.00

WORKSHOP 1: 29 October 2020
Theme: Health-care professional centric.

Objective: What are the tools health care professionals use in cardio-genetics to measure patients' psycho-social needs? (and presentation of results of the survey).

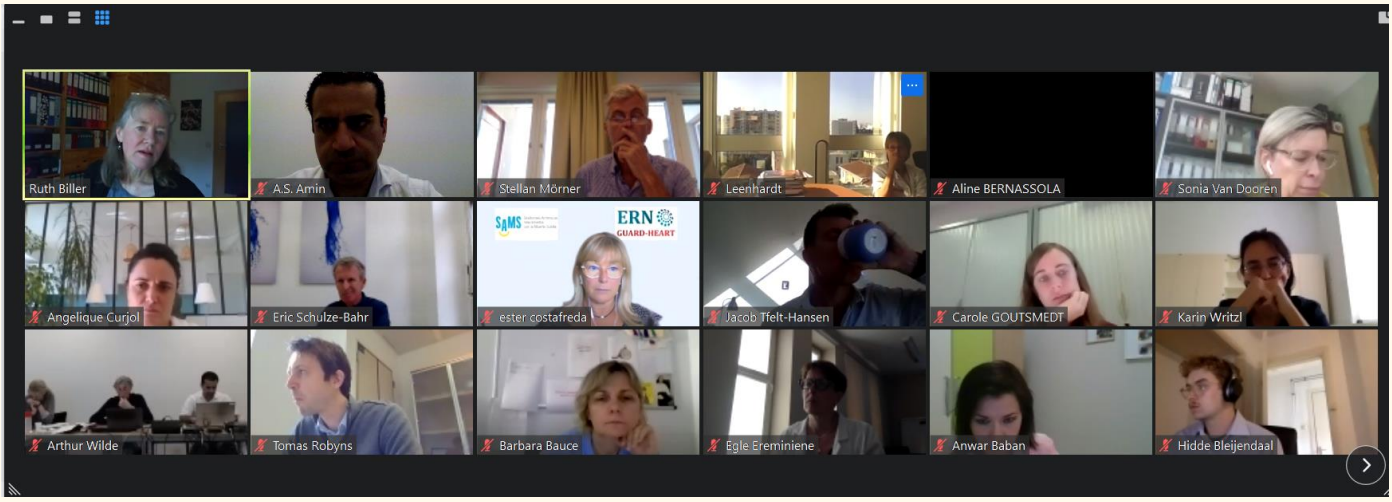
Speaker: Prof. dr. Nina Kupper, PhD, Associate Professor, Head of the Behavioral Physiology Lab (GO-LAB), Department of Medical & Clinical Psychology, Tilburg, The Netherlands

Very soon detailed information of every workshop will be sent to you and then you will be able to register for these workshops via the website of ERN GUARD-Heart.

If you have any questions, do not hesitate to contact Sarah van Pottelberghe (saartje.vanpottelberghe@uzbrussel.be) or the projectmanagement of ERN GUARD-Heart. ♥

8th ERN GUARD-Heart Board Meeting 01-09-2020 Online

Participants: there were 47 participants registered: 22/24 fullmember HCP's were present, representatives from 6/11 affiliated partners, and patient advocacy groups from 5 different countries + a representative from Eurordis. The notes will be soon available on the IT-platform. ♥



Latest ERN GUARD-Heart Publications

1. Tiina Heliö , Perry Elliott, Juha W. Koskenvuo, Juan R. Gimeno, Luigi Tavazzi, Michal Tendera, Juan Pablo Kaski, Nicolas Mansencal, Zofia Bilińska, Gerry Carr-White, Thibaud Damy, Andrea Frustaci, Ingrid Kindermann, Tomas Ripoll-Vera, Jelena Čelutkienė, Anna Axelsson, Massimiliano Lorenzini, Aly Saad, Aldo P. Maggioni6, Cécile Laroche, Alida L.P. Caforio2, Philippe Charron and on behalf of the EORP Cardiomyopathy Registry Investigators Group. ESC EORP Cardiomyopathy Registry: real-life practice of genetic counselling and testing in adult cardiomyopathy patients. ESC Heart Failure (2020) DOI: 10.1002/ehf2.12925.

2. Peter J. Schwartz, Michael J. Ackerman, Charles Antzelevitch, Connie R. Bezzina, Martin Borggrefe, Bettina F. Cuneo and Arthur A. M. Wilde. Inherited cardiac arrhythmias. Nature Rev Dis Primers 2020; 6:58.

Follow ERN GUARD-Heart on:
(click on logo to proceed)

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