

Thursday 2 June 2022

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 2022 NUMBER 4

### Survey to collect statistics about care of Ukrainian refugees with Rare Diseases

**Strasbourg, 6 May 2022**

As announced in the newsletter of April 2022, the 24 European Reference Networks (ERNs) have launched a dedicated website and a social media campaign to collect information and help healthcare professionals to find support for the Ukrainian patients with rare diseases if needed: <https://www.erncare4ua.com/>.

In case you see one or more of such patients, it is requested to fill in the survey to keep an overview. <https://ec.europa.eu/eusurvey/runner/ERNukrainianRefugeesCare>. ♥

### 12<sup>th</sup> Board meeting of the ERN GUARD-Heart in Barcelona

**Amsterdam, 31 May 2022**

The next board meeting of ERN GUARD-Heart will be held in Sant Joan de Déu Barcelona Children's Hospital, Barcelona on Tuesday 30 August 2022, from 8.30 to 13.30. Participants could register online (one person per healthcare provider) for the meeting and the dinner on the evening before. The exact location of the restaurant and meeting room will be announced later. We are looking forward to be able to meet each other face to face again. ♥

### New ePAGs from Sweden and France on board

**Amsterdam, 3 May 2022**

The list of the European Patient Advocacy Groups (ePAGs) in ERN GUARD-Heart has been updated by renewals for their commitment. Some of the patient organizations prefer a pro-active role and others are behaving more on the background. Recently one new organization from France has joined the ePAGs in the ERN. In addition, two new organizations from Sweden will participate as supporting partners. We welcome Gaelle Marguin from Petit Coeur de Beurre ([www.petitcoeurdebeurre.fr](http://www.petitcoeurdebeurre.fr)), Catherine Jacobsson from Riksförbundet HjärtLung (<https://www.hjartlung.se>), and Katarina Hanseus from Hjärtebarnsfonden (<https://www.hjardebarnsfonden.se>).

The ePAGs are still searching for more organizations to join the ERN GUARD-Heart, particularly from EU Member States which are not represented yet with a patient organization in the ERN (i.e., Belgium, Czech Republic, Hungary, Croatia, Ireland, Poland and Portugal). Also patient organizations from Member States with an affiliated partner and Member States not yet otherwise related to the ERN are more than welcome to introduce patient representatives. For more information and/or link to the application form, please contact the project management team ([n.hofman@amsterdamumc.nl](mailto:n.hofman@amsterdamumc.nl)) or Ruth Biller ([familie-biller@gmx.de](mailto:familie-biller@gmx.de)), chair of the ePAGs of ERN GUARD-Heart. ♥





Open on May 2nd, 2022  
until June 13th, 2022

The ERN

# Research Mobility Fellowship funding opportunity

## What can be funded?

Visits of junior clinical or lab researchers aimed to acquire scientific skills and advance rare disease research performed by the ERNs

## Who can be funded?

PhD students, post-Docs and medical doctors from ERN Member/Affiliated Partner centers or other European research institutions

## Where can you go?

- To another ERN Member/Affiliated Partner center
  - To any research institution in Europe
- Either home or host institution must be a Full Member or Affiliated Partner of an ERN

## For how long can you go?

1 to 6 months



<https://www.ejprarediseases.org/ern-research-mobility-fellowship/>

The aim of the call is in compliance with the vision and goals set by the International Rare Diseases Research Consortium (IRDiRC), which fosters international collaboration in rare diseases research



## European Conference on Rare diseases and Orphan Products

Paris, May 2022

The European Conference on Rare Diseases & Orphan Products (ECRD) is recognised globally as the largest, patient-led rare disease event in which collaborative dialogue, learning and conversation takes place, forming the groundwork to shape goal-driven rare disease policies and allow for important and innovative discussions on a national and an international level to take place.

**ECRD 2022 will take place online on 27 June - 1 July.**

Leading, inspiring and engaging all stakeholders to take action, the Conference is an unrivalled opportunity to network and exchange invaluable knowledge with over 1500 stakeholders in the rare disease community – patient advocates, policy makers, researchers, clinicians, healthcare professionals, healthcare industry representatives, academics, payers, regulators and Member State representatives. This 11th edition follows a pivotal two-year Rare 2030 Foresight Study, supported by the European Parliament and European Commission, that guided a large-scale and multi-stakeholder reflection on rare disease policy in Europe through 2030.

The concluding recommendation of Rare2030 was the need for a new European policy framework on rare diseases with measurable and actionable goals. Current actions at Member State level alone, or legislative changes in specific areas are not enough. We need a new European collective strategy for rare diseases to bring Member States' commitment to rare diseases under a common umbrella and mark a step forward in the post-COVID world. This ECRD will be a critical opportunity for all stakeholders to consider how to transform this exhaustive review of the strategy on rare diseases into a proposal of concrete actions ultimately creating the ecosystem required to address the unmet needs and persisting inequalities across Europe. ❤

**See the full ECRD programme:** <https://www.rare-diseases.eu/programme/>

**ECRD REGISTRATIONS ->** <https://www.rare-diseases.eu/register/>







# Update of the ERN-Exchange Programme

**Amsterdam, 31 May 2022**

The ERN-exchange programme is still open and exchange visits are possible until the end of this year. Several members and affiliated partners requested for one of the packages and until now 20/34 packages are reserved (see table 1, page 6).

Three of these visits took place in April. One to Umeå and two to Amsterdam. The experiences of these 3 visitors are reported on page 5 of this newsletter.

The official closing date for the exchange visits under this Programme is 31 December 2022. *So there are 8 months left to organize and implement exchanges.*

## The packages

Each package provides compensation for 5 working days and includes travel arrangements and a daily allowance of 200 EURO for local transport, accommodation and food. It doesn't include any costs incurred by the hosting healthcare provider.

## Goal of exchange visits

The exchange programme is meant to meet goals and strengthen capacity on the network level by sharing expertise, experiences and highly specialized knowledge under the scope and frame of the 24 ERNs. It is not meant for research nor for individual development (though this may be a secondary effect of the exchange programme). The thematic scope includes medical practice and skills but also organizational aspects of a network.

## Possible options for exchange visits

One (or more) healthcare professionals go on an exchange to enhance their clinical skills. The evaluations of visitors in these exchange visits are very positive.

Group meetings/visits are eligible as long as the proposed exchanges are in line with the goal of the contract as described above. ❤

## Changes in the utilisation of packages

The experiences of the organisation of exchanges before the suspension, have been evaluated and demonstrated opportunities to further improve the programme. In consultation with HaDEA, the funding agency, Ecorys, the contractor that manages the organization of the exchange programmes, agreed on the following adjustments:

- Besides individual exchanges, group meetings or visits are still encouraged as long as the proposed exchanges are focused on sharing expertise, experiences and, highly specialised knowledge under the scope and frame of the 24 ERNs.
- Last-minute visits are easier to arrange now; if the signed Mobility Agreement cannot be shared 2 months before the visit, visitors can arrange the travel themselves and be reimbursed for the costs (up to a maximum of 300 Euros for flights and 200 Euros for train tickets). If the Mobility Agreement is shared 2 months in advance, Ecorys can arrange the travel.
- The maximum duration of an exchange visit has increased from 3 to 6 weeks, in order to better meet the varying needs of the ERNs.
- Daily allowance (DSA) is now also applicable for weekend days for exchanges with a duration of multiple weeks. The weekends in between will be covered with DSA. ❤





# Evaluations of exchanges

**Who:** **Fabrice Extramiana, Cardiologist**

**From:** Assistance Publique - Hôpitaux de Paris, Hôpital Bichat-Claude Bernard, Paris, France

**To:** Departments of Cardiology and Clinical Genetics, Amsterdam University Medical Centers, location AMC, Amsterdam, The Netherlands

**Experience:** I have had the opportunity to participate to the Exchange project by going to the Amsterdam University Medical Centre. Over a few days, I could observe and discuss the different facets of the organization of the inherited arrhythmia clinic as well of the organization of the link between the arrhythmic clinic and basic science programs. All the team members have been very available and friendly. Meeting together has been a privilege and will definitely strengthen ongoing collaborations and facilitate future collaborative research programs. It has been also very fruitful to better understand and discuss the organization at the ERN level.

My visit at the Amsterdam UMC inherited arrhythmia clinic will inspire changes in our local organization and facilitate the improvement and development of our clinic to next step level. This ERN exchange program should be praised, continued and extended. ♥

**Who:** **Saskia vd Crabben, Clinical Geneticist**

**From:** Department of Clinical Genetics, Amsterdam University Medical Centers, location AMC, Amsterdam, The Netherlands

**To:** Center for Cardiovascular Genetics (CCG), Heart Center, Umeå University hospital, Umeå Sweden

**When:** Monday April 25th until Friday April 29th 2022

**Main goal:** Learning from Swedish counseling process focusing on communicating class 3 variants not back to patients and studying other counseling differences between the two centers and leaning from mutual experiences.

**Experience:** Being in Umeå, learning from each other, talking about the differences in the work we are all so passionate about while also enjoying Swedish culture in one word has been fantastic!! The colleagues hosting me were ever so kind and fun to be with. We made plans for additional visits both ways and we made plans for a joined publication on VUS-es. I brought back the knowledge from Umeå to Amsterdam and we have active discussion on implementing the things I learned from my colleagues in Umeå.

I would like to thank ERN for facilitating these exchanges and would recommend these exchange visits to everyone as they will bring you things in every way you simply can not learn from courses or congresses. My special thanks again to Stellan Mörner, Annika Rydberg and Anna Lundström for having me and making me feel so warmly welcome! ♥

**Who:** **Terezia Tavacova, Resident in Pediatric Cardiology**

**From:** Motol University, Prague. Czech Republic

**To:** Departments of Cardiology and Clinical Genetics, Amsterdam University Medical Centers, location AMC, Amsterdam, The Netherlands

**Experience:** Thanks to the ERN Exchange Program, I got the opportunity to visit ERN GUARD-Heart team in the Netherlands. In the course of these two weeks, I was able to observe the management of adult and paediatric patients with cardiovascular diseases, especially with inherited primary arrhythmia syndromes and congenital heart defects. I visited not only the Cardiology and Paediatric Cardiology Department in Amsterdam, but also the Paediatric Cardiology Centre in Leiden with the focus on electrophysiology procedures in children. During the whole stay in Netherlands, I got the chance to discuss our patients' findings with health care professionals specializing in different kinds of rare diseases in the field of cardiology. ERN Exchange Program is definitely a great way to get in touch with medical specialists from different countries. It opens up new possibilities for easier collaboration and knowledge sharing to provide the best healthcare for patients suffering from rare diseases. ♥



## Overview of planned/reserved exchange-visits

Package number	Host	Visitor	Planned Date
6.	Germany (Munster), Eric Schulze-Bahr	Amsterdam – <b>Virginnio Proost</b>	(delayed) Oktober 2022
7.8.	Rome – Antonio Amodeo	Prague - <b>Karel Koubsky</b>	1-10 June 2022
9.	Munster	Slovakia (affiliated partner)	?
10.	Amsterdam – Arthur Wilde	Murcia - <b>Juan Gimeno</b>	27 June – 1 July 2022
11.	Amsterdam – Arthur Wilde	Murcia - <b>Maria Sabater</b>	27 June – 1 July 2022
12.	Copenhagen – Jacob Tfelt-Hansen	Vilnius – <b>Neringa Bileisiene</b>	15-19 August 2022
13.	Rotterdam – Jolien Roos	San Donato, Massimo Chessa (co-worker of)	?
14.15.	Amsterdam UMC – Arthur Wilde	Barcelona - <b>Núria Díez Escuté &amp; Patricia Cerralbo</b>	20-24 June 2022
16.	Leuven – Tomas Robyns	Tartu Estonia – <b>Kai Muru</b>	First week July 2022
17. 18.	Utrecht Medical Centre (to be requested)	Szeged - <b>Lidia Hategan &amp; Beata Csanyi</b>	?
19.	Madrid, Majahonda – Pablo Garcia Pavia	Vilnius - <b>Dovile Jancauskaite</b>	12- 16 December 2022
20.	Paris, Philippe Charron	Rome - <b>Anwar Baban</b>	20-24 June 2022

Table 1. Planned exchange visits. ERN GUARD-Heart has 34 'packages' available. The first five were already used.

## Latest ERN GUARD-Heart Publication(s)

- Three-dimensional printing, holograms, computational modelling, and artificial intelligence for adult congenital heart disease care: an exciting future.** Chessa M, Van De Bruaene A, Farooqi K, Valverde I, Jung C, Votta E, Sturla F, Diller GP, Brida M, Sun Z, Little SH, Gatzoulis MA. Eur Heart J. 2022 May 24;ehac266. doi: 10.1093/eurheartj/ehac266. PMID: 35608227
- Familial Recurrence Patterns in Congenitally Corrected Transposition of the Great Arteries: an International Study.** Tortigue M, Nield LE, Karakachoff M, McLeod CJ, Belli E, Babu-Narayan S, Prigent S, Boet A, Conway M, Elder RW, Ladouceur M, Khairy P, Kowalik E, Kalfa DM, Barron DJ, Mussa S, Hiippala A, Temple J, Abadir S, Le Gloan L, Lachaud M, Sanatani S, Thambo JB, Gronier CG, Amedro P, Vaksman G, Charbonneau A, Koutbi L, Ovaert C, Houeijeh A, Combes N, Maury P, Duthoit G, Hiel B, Erickson CC, Bonnet C, Van Hare GF, Dina C, Karsenty C, Fournier E, Le Bloa M, Pass RH, Liberman L, Happonen JM, Perry JC, Romefort B, Benbrik N, Hauet Q, Fraisse A, Gatzoulis MA, Abrams DJ, Dubin AM, Ho SY, Redon R, Bacha EA, Schott JJ, Baruteau AE. Circ Genom Precis Med. 2022 May 12;101161CIRCGEN121003464. doi: 10.1161/CIRCGEN.121.003464. PMID: 35549293

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