

Monday 6 October 2025

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

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# GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2025 NUMBER 4

## Save the date: 19-03-2026 next board meeting in Bucharest



**Bucharest, 01-10-2025**

The next ERN GUARD-Heart board meeting will be held in the afternoon of 19-03-2026 in Bucharest, the day before the 10<sup>th</sup> edition of the Hereditary Cardiovascular Diseases course. Please, save the date. ♥

## 10<sup>th</sup> Hereditary Cardiovascular Diseases course in Bucharest

**Amsterdam, 01-10-2025**

On March 20-21<sup>st</sup> 2026, Bucharest will host the 10<sup>th</sup> edition of the Hereditary Cardiovascular Diseases course. This will represent a fantastic opportunity to discuss with top experts in the field, to present your cases in the abstracts and e-posters sessions and to meet other cardiogenetics enthusiasts. With an internationally faculty, the course will be open to cardiologists, geneticists, and pediatric specialists. The language will be English. For the program and registration information, check the course website:

<https://www.curs-cardiogenetica.ro> ♥

## 'Summerschool' 14 - 15 November in Prague

**Prague, 19-09-2025**



The team from Motol University Hospital in Prague prepared a very nice program for an ERN-Summerschool course. This course: **CRT in paediatric and congenital heart disease: A practical guide to diagnosis, indication and implementation** will be held at 14 and 15 November 2025. Team-members from the full-member and affiliated member hospitals from ERN GUARD-Heart can subscribe. There is place for 20 participants.

Registration is open, information is sent by e-mail. Please, check the instructions and reimbursement rules before registration.





## 7-8 November 'Summerschool' Padova: biopsy-proven pediatric and adult myocarditis from diagnosis to tailored aetiology

**Padua, 26-09-2025**

The team of Prof. Alida Caforio, ERN full-member and thematic area leader of thematic area 5 (other rare cardiac diseases) in ERN GUARD-Heart, organizes a very interesting Summer School in Padova. The program information is sent by e-mail to all contact persons of the ERN GUARD-Heart members and affiliated partners. Registration is open!



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Thematic Area 5:  
Other rare cardiac diseases  
in adults and children

**SUMMER SCHOOL**

**BIOPSY-PROVEN PEDIATRIC  
AND ADULT MYOCARDITIS  
FROM DIAGNOSIS TO  
TAILORED AETIOLOGY-  
DIRECTED THERAPY**

**NOVEMBER 7<sup>th</sup>, 2025**  
AULETTA DI CARDIOLOGIA,  
Policlinico Universitario  
Padova

**NOVEMBER 8<sup>th</sup>, 2025**  
AULETTA DI ESERCITAZIONI  
DELL'ANATOMIA PATOLOGICA,  
Azienda Ospedale  
Università di Padova





## Sudden Cardiac Death – leaflet for the family (template)

**Amsterdam, 23-09-2025**

The ERN GUARD-Heart ePAG-s created an informative letter to send to family members following the sudden cardiac death of loved ones. This letter is reviewed and approved by ERN-members and thematic area leaders (1-3). The letter is written from the perspective of patients who have experienced sudden cardiac death in their family. You are welcome to translate it into your local language. Please keep the ePAG and ERN logos as it is now, but you are welcome to add the logo of your own hospital/organisation. Many thanks to Peter P., member of ARVC-Selbsthilfe Deutschland, who provided the graphics for free. The letter can be adjusted with local national links and addresses and distributed to hospitals, emergency physicians, paramedics, coroners, pathologists, family doctors, paediatricians, and anyone else involved in sudden cardiac death in the young. The template is available on the website: <https://guardheart.ern-net.eu/experts/tools/>. Final translated versions can be directed to the ERN managers to add to the patient information-section of the ERN website. ♥

## Help Shape ERN Research: Participate in the ERDERA Survey

**Amsterdam, 01-10-2025**

ERN GUARD-Heart encourages all members active in research to take part in the ERDERA Survey on Clinical Research in ERNs, developed by Work Package 25 – Task 4.

This short survey aims to gather insights into the current state of clinical research across ERNs and the involvement of ERN-affiliated Health Care Providers (HCPs) in the ERDERA project. The results will support the development of the ERN Living Lab, a platform designed to foster collaboration between researchers and clinical experts. Here is the link to the survey:

<https://forms.office.com/pages/responsepage.aspx?id=T4wExFTdvUyASVRXqs0vuKe40vldqo9IINdKTc4qLh5UOFVaU041M0dFNVMwSFQ1WkxEQ1RXOFhLNC4u&route=shorturl> ♥

## ERN GUARD-Heart Submits Feedback to EU Cardiovascular Health Plan

**Amsterdam, 25-09-2025**

ERN Guard-Heart has officially submitted feedback to the EU Cardiovascular Health Plan (Initiative 14755), a strategic initiative by the European Commission aimed at improving cardiovascular health across Europe. The plan addresses prevention, early detection, treatment, and rehabilitation of cardiovascular diseases — the leading cause of death and disability in the EU — and encourages stakeholder input to shape inclusive and effective policies.

ERN Guard-Heart calls for the explicit inclusion of rare cardiovascular diseases in the Plan. These conditions — such as inherited arrhythmias, cardiomyopathies, and congenital heart defects — are life-threatening and require specialized expertise and care.

Recommendations include:

- Dedicated recognition and funding for rare cardiac diseases.
- Integration of ERN expertise, including digital tools like CPMS and ERN Registries.
- Equitable access to specialized care across all Member States. Including rare diseases ensures the Plan addresses all patient needs and fosters innovation in care and research. ♥

## Orphan Drug Congress Europe Complimentary Passes for ERNs

**Amsterdam, 01-10-2025**

ERN GUARD-Heart is invited to attend the World Orphan Drug Congress Europe 2025, 27-29 October in Amsterdam. It is the largest global event focused on orphan drugs and rare diseases which brings together stakeholders from across the rare disease and orphan drug landscape — including patient organisations, clinicians, regulators, and industry — to share insights and foster collaboration. Several ERNs are already joining, and complimentary tickets are available for ERN GUARD-Heart members. Members can apply for complimentary passes here: <https://www.terrapinn.com/WODC/2025/Guest/ERNGuardHeart> ♥





# 1 September 2025: ERN GUARD-Heart board meeting in Madrid

**Madrid, 1 September 2025**

ERN GUARD-Heart's board meeting was organized the 1<sup>st</sup> of September in Madrid. The hospitable team of full member HCP Gregorio Marañón organized a nice conference room in the Maternal & Child Hospital, and welcomed the group with a Spanish lunch. We are grateful to the local organizers for providing this excellent opportunity. All together there were 36 clinical on-site participants, 5 ePAGs and 9 online participants.

The slides and summary will be send separately by e-mail.





## New Video Tutorial for Patient Representatives involved in Care Pathways Development

Luxembourg, 25-09-2025



JARDIN has published an update highlighting the active role of patient representatives in co-developing care pathways for rare diseases within ERNs. A new video tutorial created specifically for patient representatives involved in the development of care pathways as part of the JARDIN Joint Action. This tutorial will help you understand:

- What care pathways are
- The model process proposed by JARDIN
- Your role as a patient representative at each stage of the model process. The video also highlights why lived experience and the link to the wider patient community are essential in developing care pathways.

Watch the full tutorial

<https://youtu.be/YJRorjtMgyE> ♥

## ERDERA's Networking Support Scheme



Luxembourg, 7-2025

The European Commission's ERDERA Networking Support Scheme is a funding initiative designed to foster collaboration and knowledge exchange on rare diseases and rare cancers across Europe.

This continuously open call invites proposals from researchers, clinicians, patient advocates, and research managers. Eligible events must involve participants from at least three ERDERA countries and focus on rare disease or rare cancer research. Meetings can be held in person or in hybrid formats to maximise accessibility.

Applicants may request up to €30,000 per event to cover costs such as travel, meeting logistics, and digital platforms. The first assessment round will follow the 7 October 2025 deadline, with new rounds every six months until April 2029 or until the budget is fully allocated.

Full details, including guidance notes, evaluation criteria, and the list of eligible countries, are available on the [ERDERA website](#). ♥

## Shaping the future of global rare disease research: Join the 2nd International Conference on Clinical Research Networks

Heidelberg, October 2025

ERN GUARD-Heart is pleased to highlight the upcoming 2nd International Conference on Clinical Research Networks (CRNs) for Rare Diseases, organised by ERDERA in collaboration with Rare Disease International and IRDiRC. Building on the success of the inaugural edition, this conference will bring together global experts — researchers, clinicians, patient advocates, industry, and policymakers — to strengthen collaboration in rare disease research.

Key themes include:

- Advancing Real World Evidence and data collection
- Emerging technologies in diagnostics and clinical trials
- Strategies for multi-stakeholder engagement
- Models of care and global research across income settings

Clinical Research Networks (CRNs) play a vital role in overcoming fragmentation by pooling patient populations, harmonising protocols, and sharing high-quality data. This event offers a unique opportunity to explore scalable, inclusive solutions for rare disease research worldwide.

ERN GUARD-Heart encourages participation from its members and stakeholders to ensure rare cardiac conditions are well represented in these global discussions.



Date: 9–10 December 2025



Format: Hybrid (online & in-person)



Event details & registration

<https://erdera.org/news/shaping-the-future-of-global-rare-disease-research-join-the-2nd-international-conference-on-clinical-research-networks/>





## Latest ERN GUARD-Heart Publications

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# HEREDITARY CARDIOVASCULAR DISEASES

Course Directors:

**Ruxandra Jurcut**  
**Elena Arbelo**  
**Iacopo Olivetto**

March 20-21, 2026  
Bucharest



[curs-cardiogenetica.ro](http://curs-cardiogenetica.ro)

Course organized by the Romanian Society of Cardiology endorsed by the European Reference Network GUARD-Heart

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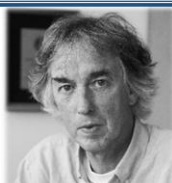
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