October 2026

ERN GUARD-Heart Newsletter 2026 Nr 4

Welcome to the ERN GUARD-Heart Newsletter – October 2026 Edition

In this edition, we share the latest network updates, upcoming events, educational opportunities and initiatives supporting collaboration in the field of rare and complex heart diseases. Discover important announcements about the secured funding for the continuation of the ERNs, 2027 ERN External Evaluation and book your calendar for Board meetings in Amsterdam and Milan, join the CPMS 2.0 training and case discussion sessions, explore upcoming scientific meetings and webinars as well as inspiring patient-led initiatives. Finally, find out about new funding and networking opportunities and the latest ERN GUARD-Heart publications.

We hope you enjoy this edition and find inspiration in the many opportunities to connect, learn and collaborate across our network. ♥

ERN GUARD-Heart 2027 Board meeting anouncements

SAVE THE DATE:

21st Board meeting will take place in **Amsterdam** on **30 March 2027** at Amsterdam UMC ♥
Preceding **Amsterdam Cardiogenomics 31 March - 1 April 2027**

22nd Board meeting will take place in **Milan** on **26 August 2027** at San Luca Hospital, IRCCS Istituto Auxologico Italiano ♥
Preceding **ESC Congress 2027 Milan 27 - 30 August**

Continuation of ERN Funding under EU4Health 2026 Work Programme

The European Commission's adoption of the 2026 EU4Health Work Programme on 19 October, 2026 secures vital financial continuity for European Reference Networks (ERNs) dedicating to rare and complex diseases.

Out of the total €680.7 million budget, a dedicated envelope of €42.25 million is earmarked specifically for ERN-related actions.

Crucially, €40 million of this budget is allocated as a direct "bridging grant" to support the coordination, management, and operational activities of the 24 ERNs for the two-year period upon the end of current grant. This funding provides a seamless bridge and operational stability for the networks as they transition out of their current four-year funding cycle (2023–2027). ♥

ERN External evaluation cycle scheduled for 2027

The European Commission has confirmed that the next evaluation cycle of the European Reference Networks (ERNs) will take place in 2027, following the adoption of the EU4Health Work Programme 2026 on 19 October 2026.

The evaluation, to be conducted by the Independent Evaluation Body (IEB), will cover approximately 620 Clinical Centres across 220 hospitals. It will focus on **Clinical Centres that joined the ERNs in 2022**. No additional ERN-level evaluations are planned for 2027.

The 2027 cycle will introduce a revised ERN Evaluation Methodology, developed in collaboration with ERN representatives and members of the Board of Member States. Key changes include:

- Three levels of evaluation: ERN, Healthcare Provider (institution/hospital) and Clinical Centre.
- Revised evaluation criteria and evidence requirements to improve clarity and consistency.
- Reduced administrative burden through streamlined requirements and measurable elements.
- Greater emphasis on continuous improvement and follow-up actions, where appropriate.

The updated evaluation manual and evaluation toolbox are expected to be finalised by the end of 2026, with the final versions planned to be shared with ERNs in January 2027.

The IEB will also provide guidance and training materials and organise information sessions to support ERNs and participating Healthcare Providers in implementing the revised methodology.

ERN GUARD-Heart members will be informed as further information on the evaluation timeline and key milestones become available.
In the meantime, please check the list of HCPs that joined the network in 2022 to see if your center is among those, potentially, scheduled for evaluation. ♥

LIST OF HCPS THAT JOINED IN 2022

Upcoming ERN GUARD-Heart Expert Webinar: Arrhythmogenic Mitral Valve Prolapse (AMVP)



Join us on **Wednesday, 2 December 2026** for the next **ERN GUARD-Heart Expert Webinar**, dedicated to **Arrhythmogenic Mitral Valve Prolapse (AMVP)**, an important and evolving topic in inherited and rare cardiovascular diseases.

Chaired by **Prof. Alice Krebsová** and **Prof. Elena Arbelo**, the webinar will feature a state-of-the-art lecture by **Prof. Kristina Haugaa** on *"Arrhythmogenic MVP/MAD: diagnosis, current risk stratification and management."* The programme also includes two clinical case presentations from the **IKEM** team, highlighting imaging, ventricular arrhythmia, genetic aspects, and experience from the IKEM cohort, followed by an interactive panel discussion.

This webinar is intended for cardiologists, clinical geneticists, electrophysiologists, fellows, researchers, and other healthcare professionals involved in the care of patients with rare and low-prevalence cardiovascular diseases.

Accreditation:
The European Accreditation Council for Continuing Medical Education (EACCME®) accreditation will be sought for this webinar.

Registration & Access:
Participation is free, but registration is required. Registered participants will receive the webinar access link via email prior to the event. ♥

REGISTER HERE | WEBINAR SERIES

CPMS 2.0 live sessions

The DG SANTE team is hosting live walkthrough of CPMS 2.0 this autumn with two more sessions lined up for Q4.

12 November 2026 | 15:00 CET
8 December 2026 | 10:00 CET

Each session is led by European Commission trainers and lasts about an hour: 30 minutes of training and 30 minutes for Q&A. These sessions are recommended for anyone who hasn't used the CPMS 2.0 before and needs a guided session to help them get started.

Each session covers all key CPMS 2.0 functions, including: general overview of the platform; registration for clinicians, assistants and guests; patient records and enrolling new patients; adding files and participants; opening and running a panel discussion; scheduling a meeting and user settings and the chat function.

Don't miss this chance! ♥

JOIN THE WEBINAR | CPMS2.0 PLATFORM | SHORT GUIDE

Biweekly CPMS ERN GUARD-Heart Case Discussion

ERN GUARD-Heart has launched biweekly CPMS online case discussions as of May 2026, held on the **first and third Monday/or Wednesday of each month at 17:00 CET**. Each one-hour session brings together ERN centres to discuss **up to three pre-submitted clinical cases**, supported by expert input shared in advance via CPMS. Case preparation and chairing rotate across centres (see list), encouraging broad participation and knowledge exchange.
Upcoming meetings:

- **10th CPMS Case discussion session**
  2 November 2027
  Amsterdam UMC Sport cardiology
- **11th CPMS Case discussion session**
  16 November 2027
  Erasmus MC: University Medical Center Rotterdam

If you still havent created your personal CPMS account, please explore CPMS Guide or reach out to us for additional support: contact@guardheart.ern-net.eu. ♥

READ MORE | CPMS 2.0 PLATFORM | SHORT GUIDE

ERN GUARD-Heart Exchange Programme: From forensic findings to genetic diagnosis: bridging the gap after sudden cardiac death



Through the ERN GUARD-Heart Exchange Programme, clinical geneticist Saskia van der Crabben (Maastricht UMC+) visited the team at Copenhagen University Hospital – Rigshospitalet to learn from the Danish approach to sudden cardiac arrest, sudden cardiac death and postmortem diagnostics.

During the exchange, Saskia met with Jacob Tfelt-Hansen, Bo Gregers Winkel and Kristine Boisen Olsen and explored different parts of the diagnostic pathway. Together with Bo Gregers Winkel, she focused on how the clinical diagnostic work-up of survivors of out-of-hospital cardiac arrest (OHCA) is organised, including the role of inherited cardiac disease and genetic evaluation. With Jacob Tfelt-Hansen and Kristine Boisen Olsen, the focus shifted to the postmortem pathway and the close connection between forensic medicine, postmortem diagnostics and subsequent cardiogenetic care for relatives.

The Danish approach provides an inspiring example of how clinical and forensic pathways can be connected to improve the identification of inherited causes of sudden cardiac arrest and death. The exchange provided valuable inspiration for ongoing initiatives in the Netherlands aimed at closing the "post-forensic loophole": ensuring that potentially relevant findings from forensic investigations reach the clinical setting and can lead to appropriate cardiogenetic evaluation and care for families. Ultimately, this may help prevent another sudden cardiac death within the family.

These lessons will feed directly into ongoing work within the Dutch CardioVascular Alliance (DCVA) Working Group on Postmortem Genetic Diagnostics and PhDs within PRECISE-DETECT, which aim to improve postmortem diagnostic pathways after sudden cardiac death in the Netherlands. By bringing together expertise from cardiology, clinical genetics, pathology and forensic medicine, these initiatives seek to create a more integrated pathway from sudden cardiac arrest or death to diagnosis and family care.

The visit provided a valuable basis for continued exchange of expertise and, hopefully, future collaboration between the Dutch and Danish teams. ♥

READ MORE | EXCHANGE PROGRAME 2024-2027

XV Jornada de Cardiogenética, Murcia Spain



The **XV Jornada de Cardiogenética**, endorsed by the ERN GUARD-Heart network, will take place on **27–28 November 2026** in a hybrid format, combining in-person and online participation. Organised by the University Hospital Virgen de la Arrixaca, a full member of ERN GUARD-Heart, the event will bring together healthcare professionals, researchers, geneticists and patients to exchange knowledge and discuss advances in hereditary cardiac diseases. The programme will feature expert debates, practical workshops on artificial intelligence and genetic variant interpretation, and sessions addressing diagnostic, prognostic and therapeutic developments. Registration is free, offering an opportunity for the wider community to engage with current developments in cardiogenetics. ♥

PROGRAME | REGISTER HERE

Expressions of Interest - Complimentary Registrations for ESC Cardio Genomics Conference 11-12 December Munich, Germany



ERN GUARD-Heart, in collaboration with the ESC Council on Cardiovascular Genomics, is offering **complementary registrations** for the ESC Cardio genomics conference in Munich to the ERN GUARD-Heart members.

Our primary aim is to enable participation from ERN full member and affiliated partner centers to enhance genetic and genomic literacy and, ultimately, improve patient care.

If demand exceeds the available places, we will:

- Prioritize early-career scientists and healthcare professionals, and
- Distribute complimentary registrations as evenly as possible across ERN centers.

The offer also applies to eligible ERN members who have already registered. Please note that only the registration fee is covered; travel, accommodation, and subsistence are not reimbursed.

If you are interested in complementary registrations to attend the conference contact us not later than **15 November**. ♥

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Focus meeting: Hot topics on cardiovascular management in pediatric patients with neuromuscular disorders



ERN GUARD-Heart is supporting organisation of the Focus meeting **"Cardiac Care in Neuromuscular Disorders"** organised by Full member **Hospital Sant Joan de Deu Barcelona** on **28-28 January, 2027.** This symposium brings together internationally renowned experts to share the latest advances in the cardiac care of neuromuscular disorders, including Duchenne muscular dystrophy, LMNA-related disease and TANGO2 deficiency disorder.
Each block combines cutting-edge insights, up-to-date clinical protocols and real-world case discussions, with dedicated Q&A sessions that encourage open and generous exchange among clinicians. It is a unique opportunity to learn, exchange and shape the future of care for patients and families.

The registration will open in the coming weeks. ♥

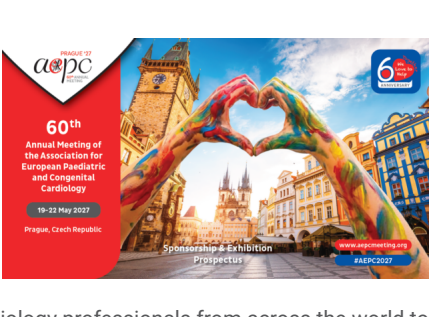
Amsterdam Cardiogenomics Symposium



The Cardiogenomics Symposium will take place on March 31- April 1 2027 in Amsterdam, the Netherlands. This international symposium unites researchers, clinicians, biotech, patient advocates and policymakers to share advances in cardiogenomics and shape new initiatives in diagnosis, risk prediction and treatment of inherited cardiac conditions. Two days of cutting-edge science and clinical progress will be paired with dedicated opportunities to build new collaborations. Sessions will focus, amongst others, on registries, data harmonization and access, emerging genetic therapies and clinical trials, innovative research approaches to novel therapies, large scale genomic studies, risk stratification, and patient engagement in research. The symposium is being organized under the auspices of a portfolio of European Innovation Council-funded projects working in this domain (DCM-NEXT; Nav1.5-CARED, Impact and CardioRepair) as well as ERN GUARD-Heart. Attendance is free, but registration is required. ♥

REGISTER HERE

60th Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC 2027)



ERN GUARD-Heart will support the **60th Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC 2027)**, that will take place on **19–22 May 2027** at the Prague Congress Centre. Marking the 60th anniversary of AEPC, the meeting will bring together paediatric and congenital cardiology professionals from across the world to exchange knowledge, share the latest scientific advances and strengthen international collaboration. The scientific programme will cover all aspects of paediatric and congenital cardiovascular medicine, with opportunities to present original research and a strong focus on interactive sessions and the involvement of young scientists.
The meeting will also feature a children's art exhibition and networking opportunities. ♥

Abstract submission deadline**: 23 November 2026**
Early registration deadline: **1 March 2027**

READ MORE | PROGRAME

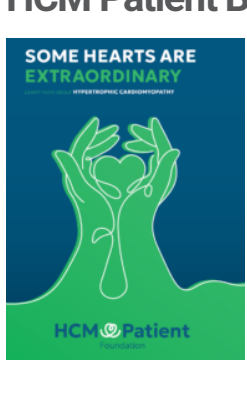
The Sudden Cardiac Death Letter: An ERN GUARD-Heart Patient-Led Initiative



Ruth Biller and Lia Crotti (ERN Guard-Heart) were guests in the Episode 10 of EURORDIS' **ERNs ON AIR podcast** where they talked about patient-led initiative of writing the *Sudden Cardiac Death Letter* to inform family members following the sudden cardiac death of a loved one. The letter is written from the perspective of patients who have experienced sudden cardiac death in their family.
The initative was led by ePAG members: Ruth Biller, Ester Costafreda, and Lorraine McGlinchey, and supported by ERN GUARD-Heart experts Lia Crotti, Alice Krebsova, Elena Arbelo, Philippe Charron, and Georgia Sarquella Brugada who have reviewed the text and approved the final version.
The letter can be distributed to hospitals, emergency physicians, paramedics, coroners, pathologists, family doctors, paediatricians, and anyone else involved in sudden cardiac death in the young. ♥

LISTEN TO PODCAST | READ MORE

HCM Patient Brochure



HCM Patient Foundation, member of European Patient Advocacy Groups, developed an HCM Patient brochure.

The brochure is designed to provide patients and their families with clear, accessible information about hypertrophic cardiomyopathy, helping them better understand the condition and navigate their journey with HCM. It is part of our commitment to improving patient education and support.

Learn more about the HCM Patient Foundation here. ♥

HCM PATIENT BROCHURE

Meet our ePAG supporting partner SZÍVSN: National Patient Association from Hungary

SZÍV·S·N ORSZÁGOS BETEGEGYESÜLET

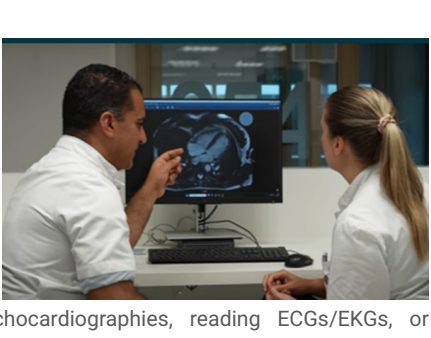
The **SZÍVSN National Patient Association** is Hungary's largest patient organisation dedicated to supporting people living with heart disease and their families. Founded in 2011 at the Városmajor Clinic of Semmelweis University, the association brings together patients, healthcare professionals and volunteers to improve access to reliable information, practical support and a strong patient community. Its work is particularly relevant to people affected by complex cardiovascular conditions, including rare heart diseases.

Patient advocacy is an important part of SZÍVSN's mission. The association provides health screenings, weekly online lectures with medical experts, lifestyle education and support for patients navigating diagnosis, treatment and recovery. Through its nationwide network of coordinators and international collaborations, SZÍVSN works to ensure that patients and their families are better informed and more actively involved in managing their health.
Recently, SZÍVSN participated in **Cardiomyopathy Patients Day**, held in Szeged as part of the World Heart Day activities. The association's rare disease patient advocate, **Péter Kovács** who lives with oHCM, delivered a presentation, highlighting the importance of patient perspectives and advocacy in the field of cardiomyopathies and rare heart diseases.
The association's commitment to patient empowerment has also gained international recognition: **SZÍVSN is among the finalists in this year's Global Heart Hub competition**, reflecting the importance of patient-led initiatives in improving cardiovascular care and support.

Learn more about SZÍVSN: szivsn.hu ♥

READ MORE ABOUT CARDIOMYOPATHY PATIENTS DAY

Call for photographs - share your cardiology related medical imagery for our new ERN GUARD-Heart Website!



Help us showcase the real face of our network by contributing your clinical photos to the new ERN GUARD-Heart website. We are inviting all full members and affiliated partners to submit high-resolution images that feature our actual experts actively engaged in identifiable cardiology work, such as performing echocardiographies, reading ECGs/EKGs, or collaborating in the clinic. By sharing your photos, you will help us highlight the true expertise, diversity, and dedication within our network. Please ensure all submitted images comply with your institution's patient privacy and consent regulations.
We have extended the deadline for submissions to the end of November. Please send your photos here. ♥

ERDERA Network Support Scheme Proposal round number 3 is open!



ERDERA has opened third round of it's competitive funding instrument for networking events to share knowledge on rare diseases and rare cancers.

The **Networking Support Scheme (NSS)** within ERDERA invites the rare disease and rare cancer community to unite across borders, disciplines and sectors.

Through this open call, ERDERA supports the organisation of **transnational networking events** that promote knowledge sharing, research uptake and collaborations among clinicians, researchers, and patients/patient advocacy organizations (PAOs).

These events aim to **strengthen new or expanding research networks** on rare diseases and rare cancers in general and promote the inclusion of typically underrepresented countries (UCs) in European rare diseases and rare cancers networks in particular.

With funding of **up to €30 000 per networking event**, the scheme is offering a flexible framework for building the connections essential to meaningful knowledge sharing in rare disease research.

The new collection date will be **January 28, 2027** at **12.00 (CET)** ♥

READ MORE

EURORDIS Black Pearl Awards 2027



EURORDIS-Rare Disease Europe is hosting its **16th annual Black Pearl Awards** on **15 February 2027 at the Cardo Hotel in Brussels.** Since 2012, the annual EURORDIS Black Pearl Awards have brought together the international



rare disease community to celebrate the achievements of individuals and organisations.

Registration for on site and online participation will open in **early November,** while Photo submissions for the **EURORDIS Photo Award 2027** are already open! This annual competition is open to all experiences, nationalities, and rare disease affiliations highlighting everyday experiences, special moments, and unique perspectives within the rare disease community. Photographs are shortlisted by award-winning photographer Marcus Bleasdale, then this selection is put to public vote and the winner will be announced at the Black Pearl Awards Ceremony. The photo award offers an important opportunity to raise awareness, share stories, and possibly win one of the three prizes. ❤️

PHOTO AWARD | READ MORE

New project announcement: Rare disease prioritization framework for Advanced Therapy Medicinal Products (ATMP's)

The **Rare Disease Prioritisation Framework for Advanced Therapy Medicinal Products (ATMPs)** is an initiative within the European Rare Diseases Research Alliance (ERDERA), aiming to identify rare diseases that could benefit most from the development of advanced therapies, including gene, cell and RNA-based therapies. With approximately 8,000 rare diseases identified, and limited resources available for therapeutic development, a systematic, evidence-based approach is needed to help direct research and innovation towards areas of greatest potential benefit to patients.

The framework combines an evidence-based literature review, structured stakeholder interviews and a comprehensive assessment of 22 criteria across three domains: Unmet medical needs (4 criteria), Psychological and societal impact (9 criteria), and Research and system readiness (9 criteria).

The initiative is led by **ERN-ERKNet**, the European Reference Network for rare kidney diseases, which has already completed the assessment within its network. **ERN GUARD-Heart** has volunteered to become the second ERN to participate in this important initiative. In collaboration with ERN representatives, approximately 100 diseases within our network's scope have been selected for assessment.

We are now preparing to involve experts from across ERN GUARD-Heart and invite **both clinicians and basic scientists** to contribute their expertise to the evaluation of these diseases. Broad participation will help ensure that the assessment reflects the knowledge and experience of our clinical and scientific community.

The call for expert participation will open soon. In the meantime, you can find an overview of the project in the slides presented at Board meeting in Bucharest (**see the slides**).

As an additional incentive, each participating HCP can earn **up to 100 extra monitoring points for the internal annual monitoring,** with 25 points allocated per participant.

We encourage all eligible experts to consider taking part and helping shape a more evidence-based approach to identifying future opportunities for advanced therapies in rare diseases. ❤️

Latest ERN GUARD-Heart Publications

Here is an overview of the latest ERN GUARD-Heart publications. The list includes peer-reviewed articles obtained from the **PubMed database**. All publications that fall within the ERN's scope, involve **contributors from at least two Member States**, and e**xplicitly acknowledge ERN GUARD-Heart**:

1. Lipov A *et al* Whole-genome sequencing implicates rare, low-frequency and structural non-coding variation at the *SCN5A* locus in Brugada syndrome. *medRxiv* [Preprint]. 2026
2. Ramos-López N *et al* Arrhythmic Risk Stratification According to LGE Corridors and Genetics in Nonischemic Dilated Cardiomyopathy. *Circulation.* 2026
3. Balakrishnan ID *et al* Atrial Fibrillation in Genotyped Dilated Cardiomyopathy: Epidemiology, Risk Factors, and Outcomes: Insights From the SHaRe Registry. *Circ Heart Fail.* 2026
4. Jacobsen SB *et al* Diagnostic and therapeutic challenges in Andersen-Tawil syndrome. *Heart Rhythm.* 2026
5. Júdez-Serrano A *et al* Spanish founder variant in MYBPC3: implications of diagnostic criteria, clinical phenotype, and prognosis. *Rev Esp Cardiol.* 2026
6. Muller SA *et al* Optimizing Screening Intervals for At-Risk Relatives of Dilated Cardiomyopathy Carrying a TTNtv. *Circ Heart Fail.* 2026
7. Hauptmann L *et al* Definition and Prognosis of Mitral Regurgitation in Transthyretin Amyloid Cardiomyopathy: A Multicenter International Cohort Study. *Circulation.* 2026
8. Fortuna I *et al* Tracking Active Fibroblast-Mediated Tissue Remodelling in Cardiomyopathies: Translational Insights from FAPI PET Imaging. *Int J Mol Sci.* 2026
9. Deissler PM *et al* Electromechanical Window Negativity and Arrhythmic Risk in Arrhythmogenic Mitral Valve Prolapse. *JACC Cardiovasc Imaging.* 2026
10. Lerchner T & Heymans SSR. Genetic cardiomyopathy-associated myocarditis. *Nat Rev Cardiol.* 2026

Full publication details, including PubMed IDs and complete author lists, are available on our website. ❤️

PUBLICATIONS

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Project Manager

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