ERN GUARD-Heart
European Reference Network on uncommon
and rare diseases of the heart

September 2026

ERN GUARD-Heart Newsletter 2026 Nr 3

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

In this edition, we highlight recent ERN GUARD-Heart activities and meetings, bring you the latest updates on CPMS 2.0, introduce a new ePAG representative and share new scientific publications. We announce diverse open opportunities and interesting forthcoming events and collaborations across ERN GUARD-Heart🖤.

Read Online

📄 *The full newsletter is also available as an attached PDF for easy reading and sharing.*

ERN GUARD-Heart Board Meeting

European Reference Network on uncommon and rare diseases of the heart
ERN GUARD-Heart
20th Board Meeting
Munich
LMU Klinikum
Thursday, 27th August 2026
European Reference Network
Funded by the European Union
ERN GUARD-Heart

The 20th **ERN GUARD-Heart Board Meeting** took place in **Munich** (Germany) on

Thursday, 27 August 2026, just before the ESC Conference.

Meeting was organized as a hybrid event, allowing those who were unable to attend in person to still participate and contribute to the discussions.

All full members representatives were present, along with eight ePAG representatives, marking the highest in-person ePAG participation in an ERN GUARD-Heart Board Meeting to date.

SAVE THE DATE: **21st Board meeting** will take place in **Amsterdam** on **30 March 2027**
22nd Board meeting will take place in **Milan** on **26 August 2027**

Any questions **contact us** 💙

ADDITIONAL MATERIAL

Who are our ePAGs?
Francesca Musso from HCM Patient Foundation

I am a patient advocate and Patient Relationship Manager at HCM Patient Foundation, and I live with non-obstructive Hypertrophic Cardiomyopathy (HCM). I was diagnosed at the age of 24 while graduating in Physical Education. After my diagnosis, I spent several years between Australia and London, learning to understand and accept what living with a chronic heart condition meant.

I returned to Italy in 2019, where, following the progression of my disease, I received a subcutaneous implantable cardioverter-defibrillator (S-ICD). Although initially something I hoped I would never need, the device ultimately saved my life.

Living with HCM has also taught me that, despite the challenges of a chronic condition, it is possible to live a full and meaningful life, sometimes with a few adaptations and by learning to listen to and respect one's own body. For me, this means continuing to travel, pursue personal and professional goals, and enjoy everyday life while understanding my own limits and knowing when to slow down. I believe that respecting oneself does not mean putting life on hold, but finding a balance that allows you to keep living it fully.

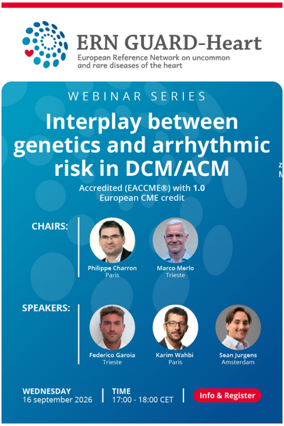
This experience became a turning point. I created my Instagram platform, Living with HCM and ICD, to share my experience and connect with people living with HCM and other inherited cardiomyopathies, as well as those facing ICD implantation. Over time, the platform has grown into a community where patients and families can find support, information, and the reassurance that they are not alone.

I am a member and patient testimonial of AICARM, the Italian Association of Cardiomyopathies, and represent AICARM as an ePAG representative within the ERN GUARD network. Through my advocacy work, I promote patient education, peer support, psychological wellbeing, and a more patient-centred approach to healthcare.

I am passionate about making sure that the patient voice is heard in healthcare, research, and policy, and about helping patients feel informed, supported, and involved in decisions about their health.

Today, I combine my lived experience with my professional role in patient relations, working to build stronger connections between patients, healthcare professionals, organisations, and the wider cardiomyopathy community.🖤

Upcoming ERN GUARD-Heart Webinar "Interplay between genetics and arrhythmic risk in DCM/ACM"



ERN GUARD-Heart
European Reference Network on uncommon
and rare diseases of the heart

WEBINAR SERIES

Interplay between genetics and arrhythmic risk in DCM/ACM

Accredited (EACCME®) with **1.0**
European CME credit

CHAIRS:
Philippe Charron Paris
Marco Merlo Trieste

SPEAKERS:
Federico Garoia Trieste
Karim Wahbi Paris
Sean Jurgens Amsterdam

WEDNESDAY 16 september 2026 | **TIME** 17:00 - 18:00 CET | **Info & Register**

We are pleased to invite you to the upcoming ERN GUARD-Heart Webinar, taking place on **Wednesday, 16 September 2026** from **17:00 to 18:00 CEST**. This expert-led session will explore the complex relationship between genetic factors and arrhythmic risks in patients with DCM and ACM. Webinar will cover key topics: **Clinical Case Presentations**: Direct insights from real-world medical cases; **Arrhythmic Risk in Genetically Determined DCM/NDLVC**: Navigating the era of risk scoring and **Arrhythmic Risk in Gene Elusive Patients**: Moving towards a personalized clinical approach.

Expert Chairs & Speakers:
The webinar will be chaired by ERN experts Prof. Philippe Charron (France) and Prof. Marco Merlo (Italy). Featured speakers include Dr. Federico Garoia (Italy), Dr. Karim Wahbi (France), and Dr. Sean Jurgens (Amsterdam UMC, The Netherlands) .

Accreditation:
This webinar is officially accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) with **1.0 European CME credit (ECMEC®)**.

Registration & Access:
Participation is free, but registration is required. Registered participants will receive the webinar access link a few days prior to the event.🖤

REGISTER **WEBINAR SERIES**

CPMS 2.0 live sessions

The DG SANTE team is hosting live walkthrough of CPMS 2.0 this autumn with 4 sessions lined up for Q4. 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. ♥

📅 **15 September 2026** | 10:00 CET
📅 **13 October 2026** | 15:00 CET
📅 **12 November 2026** | 15:00 CET
📅 **8 December 2026** | 10:00 CET

Each session covers the key CPMS 2.0 functions, including patient records and enrolment, adding files and participants, conducting discussions, scheduling meetings, user settings, and chat.

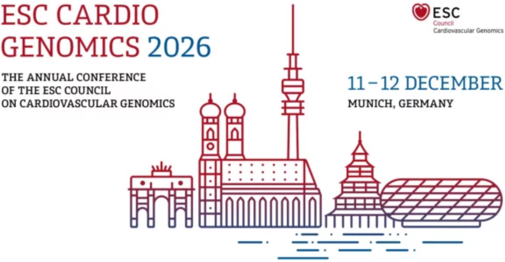
JOIN THE WEBINAR **CPMS2.0 PLATFORM** **SHORT GUIDE**

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 **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♥.

READ MORE **CPMS2.0 PLATFORM** **SHORT GUIDE**

ESC Cardio Genomics Conference 11-12 December Munich, Germany


ESC CARDIO GENOMICS 2026
THE ANNUAL CONFERENCE OF THE ESC COUNCIL ON CARDIOVASCULAR GENOMICS
ESC Council Cardiovascular Genomics
11–12 DECEMBER
MUNICH, GERMANY

The **ESC Council on Cardiovascular Genomics** will host its third in-person meeting from **December 11–12, 2026**, at the Ludwig-Maximilians University Hospital inner-city campus in **Munich, Germany**. This two-day event aims to help cardiologists, trainees, geneticists, and allied professionals integrate genetic data into daily clinical practice. Attendees will gain new insights into cardiomyopathies, amyloidosis, heart failure, channelopathies, and vascular disorders through a comprehensive program featuring limited-seating variant interpretation workshops, state-of-the-art lectures, debates, and peer abstract presentations designed to expand professional networks♥.

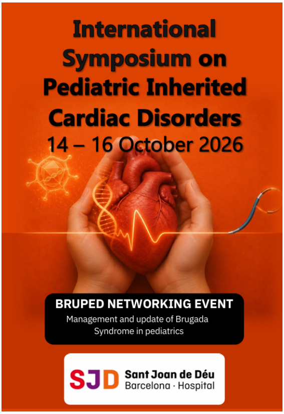
Abstract submission deadline: 14 September 2026

Early registration fee deadline: 13 October 2026.

READ MORE PROGRAMME

International Symposium on Pediatric Inherited Cardiac Disorders

Bruped Networking event


International Symposium on Pediatric Inherited Cardiac Disorders
14 – 16 October 2026
BRUPED NETWORKING EVENT
Management and update of Brugada Syndrome in pediatrics
SJD Sant Joan de Déu Barcelona · Hospital

We are pleased to share that Sant Joan de Deu Barcelona is organizing **International Symposium on Pediatric Inherited Cardiac Disorders** from **14 to 16 October 2026**. The symposium will provide an advanced, practice-oriented update on emerging therapies and ultra-rare inherited arrhythmia syndromes, with a particular focus on paediatric Brugada syndrome. The programme will bring together clinicians, researchers, geneticists, data scientists, nurses, patient representatives and early-career professionals from across Europe and beyond. Participants will have the opportunity to engage with international experts through state-of-the-art lectures, real-world case discussions, multidisciplinary panels and hands-on workshops. Key topics include advances in gene therapy and clinical trials, risk stratification, artificial intelligence, remote monitoring, genetics and precision medicine. The event will also include the first European networking event dedicated to paediatric Brugada syndrome and contribute to laying the foundations for the European BRUPED Registry and the BRUPED-RISK precision medicine initiative. The symposium is available in both **in-person and online format♥.**

Registration deadline is 13 October. For further information and registration please visit the **event webpage.**

READ MORE PROGRAMME

ERN GUARD-Heart Exchange Programme: A Week of Learning, Collaboration and Inspiration at Copenhagen University Hospital

Through the ERN GUARD-Heart Exchange Programme, MUDr. Silvia Elisabeth Henrich, a Resident Physician at the Institute for Genetics of Heart Diseases (IfGH) at University Hospital Münster (UKM), spent a week at the Inherited Cardiac Condition Clinic at Copenhagen University Hospital. The visit offered her valuable insights into Denmark's high-volume care, nationwide research registries, and multidisciplinary workflows. She observed specialized patient management across the cardiac arrest unit, outpatient clinics, and a detailed autopsy session. A major highlight for her was seeing how complex genetic findings were communicated to families with remarkable clarity and compassion. The visit also offered valuable perspectives on real-time documentation and close collaboration between physicians, technicians, and specialised nurses. These experiences provide new perspectives that may complement existing structures and inspire further development of patient pathways and genetic testing processes at UKM. Ultimately, the exchange demonstrates the value of European collaboration: by sharing expertise, approaches, and experiences across centres, both sides can learn from each other and contribute to continuously improving care for patients with inherited cardiac diseases♥.

READ MORE

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. The deadline for all submissions is the end of September. Send your photos **here** ♥.

EURORDIS 2027 Open Academy X ERDERA Schools

Applications are now open for the **2027 EURORDIS Open Academy x ERDERA Schools from 7-10 June in Barcelona**. Two in-person training courses for 80 members of the rare disease community are available this year. The **School on Medicines Research and Development** is aimed at rare disease patient advocates and researchers interested in areas such as therapeutic development, clinical trials, regulatory pathways, health technology assessment and patient engagement. The **School on Scientific Innovation and Translational Research** is designed for patient advocates and early-career researchers, including PhD candidates and researchers within two years of completing their PhD, with a focus on areas such as diagnostic care pathways, translational research, genomics, ethics and patient-generated data♥.

Application deadline is 16 October.

READ MORE

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 **explicitly acknowledge ERN GUARD-Heart**:

1. Postema PG *et al* Essential antiarrhythmic drug accessibility worldwide: A multi-survey study and comprehensive evaluation of access and supply challenges. *Europace.* 2026.

2. Hauptmann L *et al* Prognostic Thresholds of Tricuspid Regurgitation in Transthyretin Amyloid Cardiomyopathy. *JAMA Cardiol*. 2026.
3. Sarquella-Brugada G *et al* Diagnosis and management of very rare primary arrhythmia syndromes in children and adults: a Clinical Consensus Statement of the European Heart Rhythm Association of the ESC and the Association of Cardiovascular Nursing & Allied Professions of the ESC, endorsed by the Association for European Paediatric and Congenital Cardiology. *Europace*. 2026.
4. Peretto G *et al* Workup and management of rhythm disorders in myocarditis and inflammatory cardiomyopathy: a clinical consensus statement of the European Heart Rhythm Association and the Heart Failure Association of the ESC, the ESC Working Group on Myocardial & Pericardial Diseases, the European Association of Preventive Cardiology of the ESC, the Heart Rhythm Society, the Asian Pacific Heart Rhythm Society, and the Latin American Heart Rhythm Society. *Europace.2026.*
5. Mara P *et al* Erosion and embolization after transcatheter atrial septal defect closure: Findings from a multicenter international survey. *Int J Cardiol.* 2026 Aug.
6. Sepehri Shamloo A *et al* Mortality reduction with implanted defibrillator for primary prevention of sudden death after Myocardial Infarction: temporal trends in the PROFID study. *Eur Heart J.*
7. Drapier N *et al* Ajmaline or flecainide testing in Brugada syndrome: influence of SCN5A variants. *Eur Heart J.*
8. Mora-Ayestarán N *et al* Left Ventricular Hypertrabeculation and Prognosis in Dilated Cardiomyopathy. Circulation. 2026 .
9. Schwerzmann M *et al* Triggers for Serious Illness Conversations in Adults With Congenital Heart Disease: A Delphi Consensus Study. *JACC Adv*. 2026.
10. Costantino A *et al* Multidisciplinary and Personalized Molecular Diagnosis to Solving Sudden Death During Sport. *Mol Diagn Ther*. 2026.
11. Underwood JFG *et al* Timothy syndrome and CACNA1C-Related Disorder: first international language and management guidelines consensus statement. *Eur J Hum Genet*. 2026.
12. Perotto M *et al* Variant Site-Specific Natural History of Titin-Induced Cardiomyopathy: An International Multicenter Registry. *Circ Genom Precis Med*. 2026.
13. Haissaguerre M *et al* Prominent T-wave induced by Valsalva maneuver associated with a RYR2 loss-of-function variant. *Heart Rhythm*. 2026.
14. Sumitomo N *et al* Current Topics of Progressive Cardiac Conduction Disease. *J Arrhythm*. 2026.
15. Dollfus H *et al* Crisis readiness for rare disease populations: learnings and recommendations by the European Reference Networks. *Lancet Reg Health Eur*. 2026. Cross-ERN collaborative article.

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

PUBLICATIONS

PROJECT MANAGEMENT OFFICE

Arthur A.M. Wilde

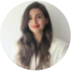
Network Coordinator

Ahmad S. Amin

Registry Manager

Mari Murel

Network Manager



Adriana Planinić

Project Manager

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