

June 2026

ERN GUARD-Heart Newsletter 2026 Nr 2

Welcome to the **ERN GUARD-Heart Newsletter – June 2026 Edition**

In this issue, we bring you **key updates from across the network**, including details of the upcoming **Board Meeting in Munich**, from our opportunities through the **2026 Call for Affiliated Partners**, and highlights from our *growing patient community*. We also introduce a new member of the coordination team – **Adriana Planinić** – share developments in our **biweekly CPMS case discussions**, and report on recent events and collaborations.

Finally, don't miss important **European calls and initiatives**, including the **ERDERA Clinical Trial Call** and our contribution to **EU cardiovascular health policy**.

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

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20th ERN GUARD-Heart Board Meeting 27 August 2026 in Munich, Germany

The next ERN GUARD-Heart Board Meeting will take place in **Munich** (Germany) on **Thursday, 27 August 2026**, just before the ESC Conference.

All Board members have received the invitation to register in the upcoming ERN GUARD-Heart Board Meeting. Participation is foreseen **one representative per HCP**, as well as **two ePAG Board members**. Other **ePAG representatives** are welcome to attend as **additional observers**.

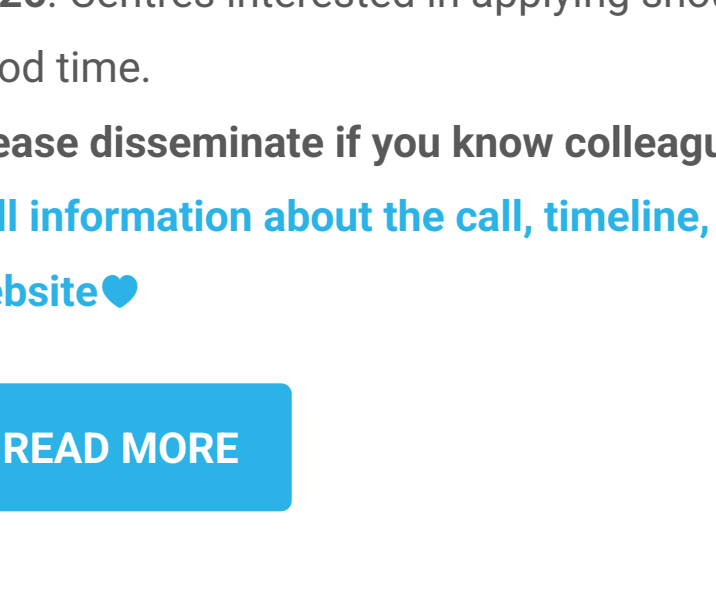
Networking Lunch will be served at **13:00**, followed by the **Board Meeting from 14:00 ending around 18:30** followed by **Social program & Diner**. For those unable to join on site, an **online option** will be available. Prior to the Board Meeting, a separate **ePAG meeting** will be held in the morning. The both meetings are hosted by and will take place at the: **LMU Klinikum- City Center Campus, Ziemssenstrasse 5, 80336 Munich**.

Any questions [contact us](#) ♥

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2026 Call for Affiliated Partners: Opportunity for European Centres to Join ERN GUARD-Heart



The European Commission has opened applications for Affiliated Partners within the European Reference Networks.

The European Commission has opened applications for Affiliated Partners within the European Reference Networks.

This is an opportunity for healthcare centres in countries without full ERN coverage, namely **Bulgaria, Cyprus, Latvia, Greece or Norway** to collaborate

with ERN GUARD-Heart and access the network's expertise in rare and complex diseases of the heart across the European Union. The deadline for applications is **1 September 2026**. Centres interested in applying should contact their National Competent Authority in good time.

Please disseminate if you know colleagues in these countries!

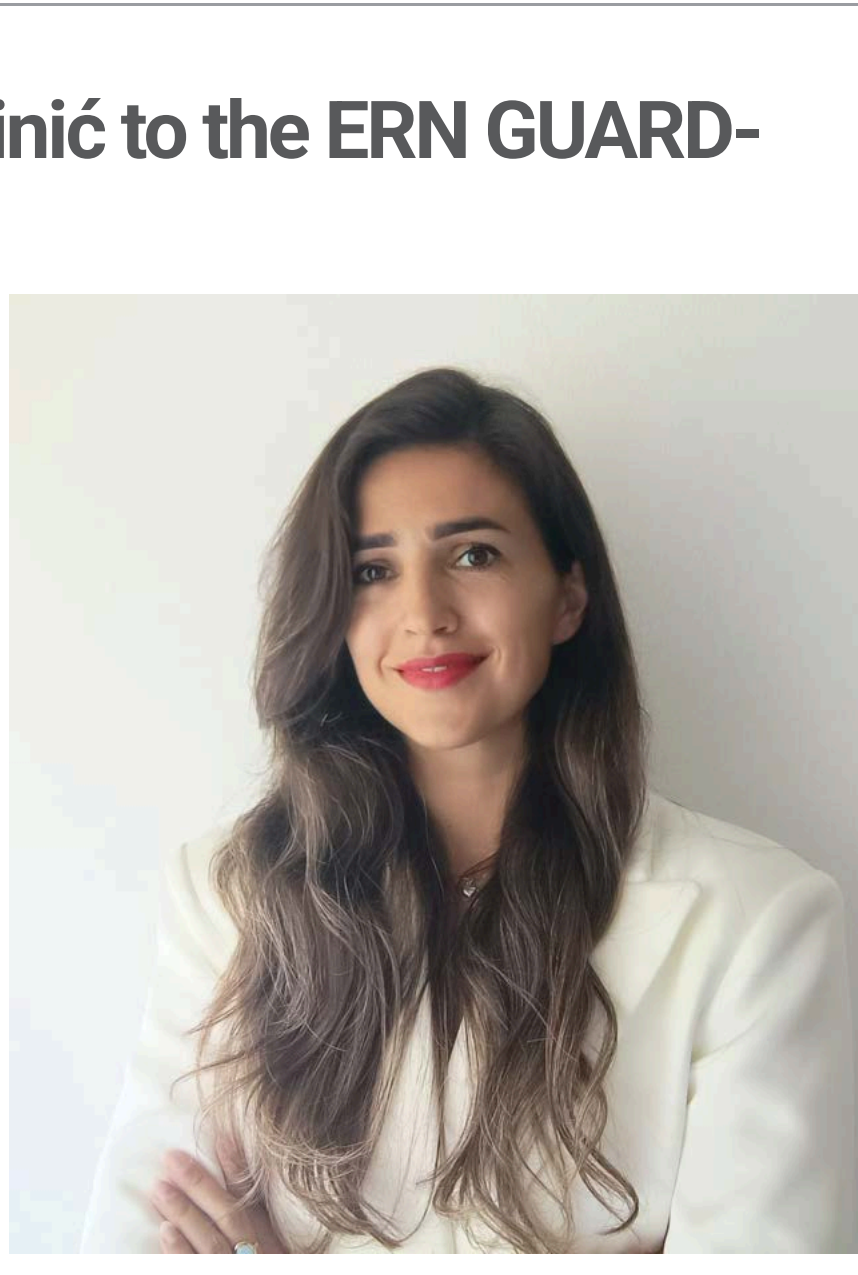
[Full information about the call, timeline, and application procedure is available on our website](#) ♥

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Who are our ePAGs? CardioGen Romania: From a Family Diagnosis to National Support

Founded in 2021 following a personal diagnosis of hypertrophic cardiomyopathy, **CardioGen Romania** has grown into a key patient organisation supporting people living with genetic cardiac diseases. Driven by lived experience, the organisation provides education, community support, and advocacy, while working closely with clinicians to improve access to diagnosis and care.

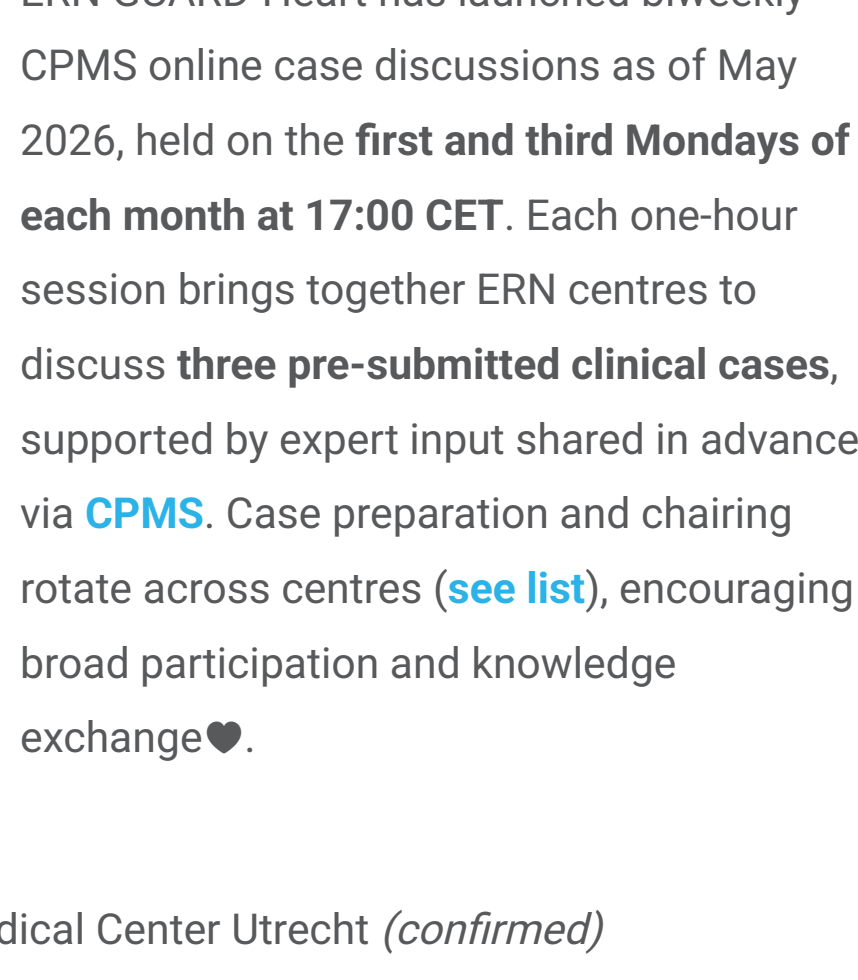
Despite the devastating loss of its president in 2024, CardioGen has demonstrated remarkable resilience—continuing its mission through patient webinars, national meetings, awareness campaigns, and the distribution of patient guides across Romania. Looking ahead, CardioGen is focusing on expanding psychological support, improving the patient journey, and strengthening collaboration across Europe ♥



[READ THE FULL STORY HERE](#)

Introducing Adriana Planinić to the ERN GUARD-Heart Coordination Team

We are pleased to welcome **Adriana Planinić**, an experienced research management professional with a strong background in rare diseases, to the **ERN GUARD-Heart coordination team**. With a PhD in Biology and extensive expertise gained at the St. Anna Children's Cancer Research Institute in Vienna, she has been actively involved in major EU initiatives such as **ERICA** and **EJP RD**, supporting collaboration across European Reference Networks.

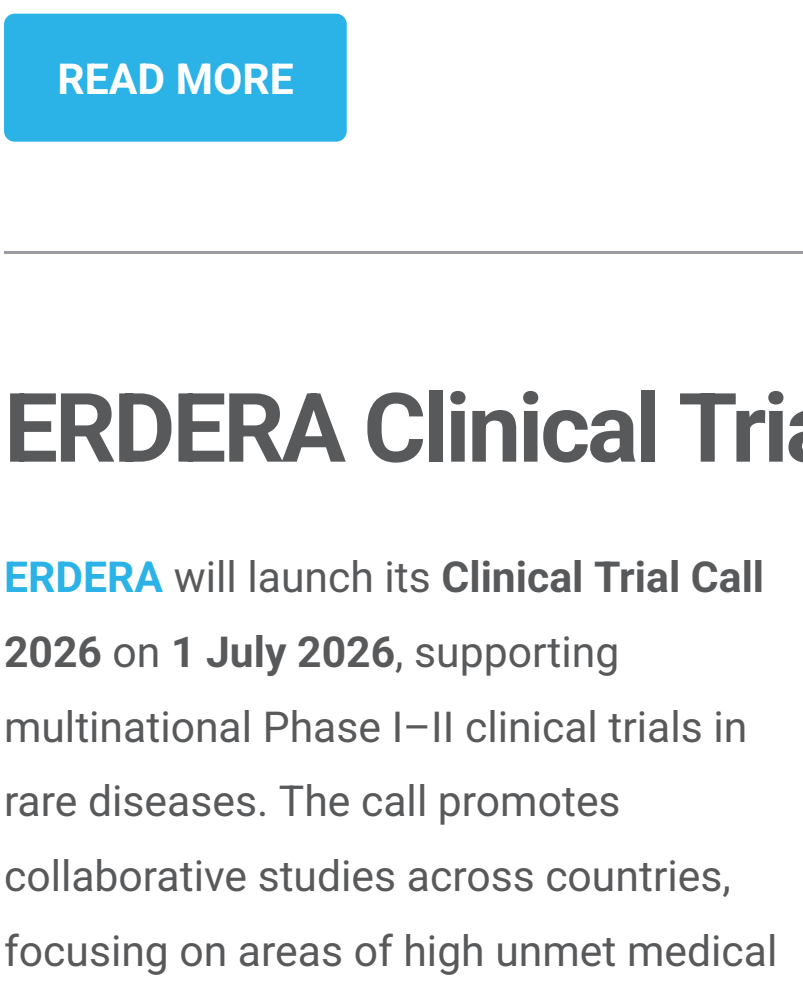


Adriana brings strong leadership and project coordination experience, with a focus on capacity building and education. In her new role, she will support collaboration between clinical centres, communication and dissemination, CPMS management, and knowledge exchange through educational activities ♥

[READ THE FULL STORY HERE](#)

[ERN COORDINATION TEAM](#)

Biweekly CPMS meetings launched



ERN GUARD-Heart has launched biweekly CPMS online case discussions as of May 2026, held on the **first and third Mondays 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 ♥.

Upcoming meetings

- **Monday 22 June 2026** – University Medical Center Utrecht (*confirmed*)
- **Monday 6 July 2026** – Antwerp University Hospital (*not yet confirmed*)
- **Monday 20 July 2026** – Umeå University Hospital (*confirmed & panel opened*)

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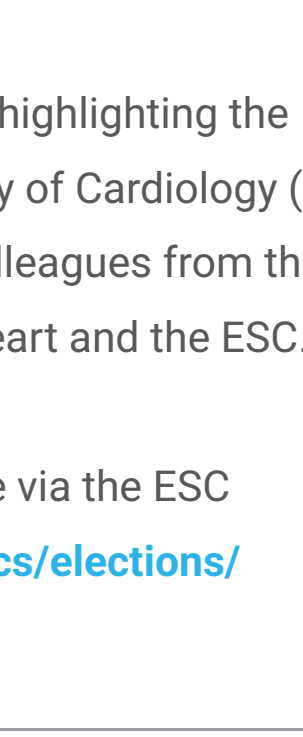
[CPMS2.0 PLATFORM](#)

[SHORT GUIDE](#)

Heart Porto Association Meeting – 29 May 2026

On 29 May, the **1st Heart Porto Association Meeting on Sudden Cardiac Death in Cardiac Muscle Diseases** brought together patients, families, and healthcare professionals for a day of learning and exchange. The event raised awareness of cardiomyopathies, prevention strategies, and the importance of early diagnosis and support networks, complemented by a hands-on Basic Life Support workshop.

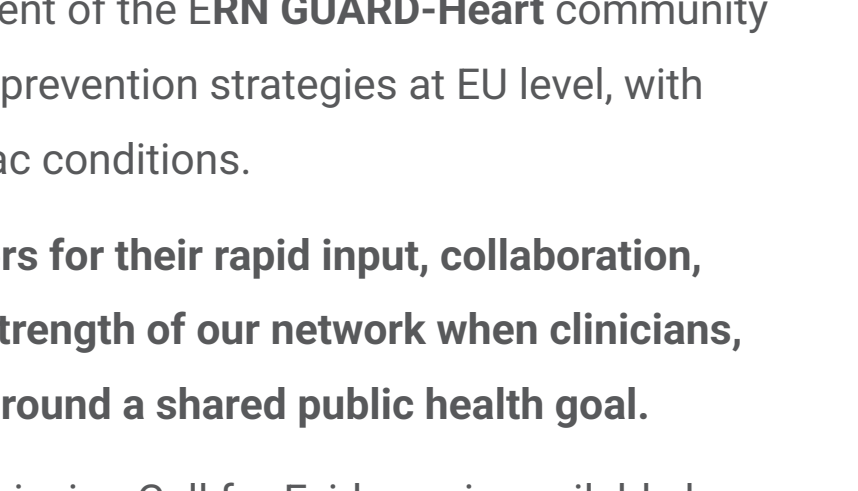
 Read the full report and view photos [here](#) ♥




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ERDERA Clinical Trial Call 2026

ERDERA will launch its **Clinical Trial Call 2026** on **1 July 2026**, supporting multinational Phase I–II clinical trials in rare diseases. The call promotes collaborative studies across countries, focusing on areas of high unmet medical need, and follows a multi-stage application process starting with a mandatory Expression of Interest.



 Join the **information webinar on 6 July 2026 (15:00–17:00 CEST)**

 Read full details on eligibility, scope, and application process: [Call Text](#)

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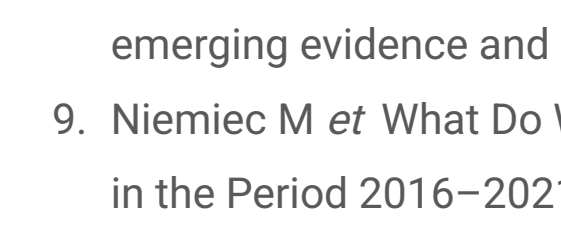
Support ERN GUARD-Heart Members in ESC Genomics Council Elections

ESC Council on Cardiovascular Genomics Nucleus Elections 2026-2028
Vote to shape the future of your Council!

The ESC Council on Cardiovascular Genomics has opened its elections, taking place from **10 to 24 June 2026**. Several members of ERN GUARD-Heart are among the candidates, highlighting the strong collaboration between the network and the European Society of Cardiology (ESC). Eligible members are encouraged to cast their vote and support colleagues from the network, helping to further strengthen ties between ERN GUARD-Heart and the ESC. **Please also share this information within your networks** ♥.

More information on the candidates and voting process is available via the ESC website: <https://www.escardio.org/communities/councils/genomics/elections/>

ERN GUARD-Heart Contributes to EU Call for Evidence on Cardiovascular Health Checks




ERN GUARD-Heart has successfully contributed to the European Commission's Call for Evidence on cardiovascular health checks with the submission of a coalition document titled:

“Strengthening EU cardiovascular health checks: Integrating inherited, congenital and sudden-death-related cardiovascular risk.”

The document was submitted on behalf of the **European Coalition for Inherited, Congenital and Sudden-Death-Related Cardiovascular Disease Prevention**, with the support of numerous organisations, patient representatives, and experts across Europe.

This joint effort reflects the strong commitment of the **ERN GUARD-Heart** community and its partners to improving cardiovascular prevention strategies at EU level, with particular attention to genetic and rare cardiac conditions.

We would like to warmly thank all contributors for their rapid input, collaboration, and trust. This achievement highlights the strength of our network when clinicians, researchers, patients, and advocates unite around a shared public health goal.

 More information on the European Commission Call for Evidence is available here: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/17812-Cardiovascular-diseases-health-checks_en

 You can read the full submitted document [here](#) ♥

[READ FULL DOCUMENT](#)

Latest ERN GUARD-Heart Publications

Here is an overview given of scientific Latest ERN GUARD-Heart publications related to ERN GUARD-HEART. 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 “ERN GUARD-HEART”** :

1. Baggio C *et al* Insights Into the Natural History of Recurrent Myocarditis, A Multicenter International Study (Re-Myo Study). *J Am Heart Assoc*. 2026.
2. Sikking MA *et al* Improved Outcome up to Ten Years after Intravenous Immunoglobulin Therapy in Patients with Dilated Cardiomyopathy. *Eur J Heart Fail*. 2026.
3. Haydarlou P *et al* Multi-trait polygenic risk scores improve genomic prediction of atrial fibrillation across diverse ancestries. *Nat Commun*. 2026.
4. Barbieri M *et al* SGK1-inhibition restores cardiac repolarization in LQT2 rabbits and LQT3 mice by reducing late sodium current. *Pharmacol Res*. 2026.
5. Bhardwaj P *et al* Regional and Socioeconomic Disparities in the Diagnosis of Primary Electrical Diseases in a Universal Healthcare System: A Nationwide Danish Study. *Eur Heart J Qual Care Clin Outcomes*. 2026.
6. Gasperetti A *et al* External validation of the DSP-risk score for prediction of clinically significant ventricular arrhythmias in primary prevention patients with desmoplakin cardiomyopathy-associated genetic variants. *Heart Rhythm*. 2026.
7. Milman A *et al* Clinical Profile and Mode of Initiation of Spontaneous Ventricular Tachyarrhythmias in Patients With Brugada Syndrome (START-BrS). *JACC Clin Electrophysiol*. 2026.
8. Kendall S *et al* Physical activity and competitive sport safety for children affected by inherited cardiac conditions and selected acquired cardiomyopathies: emerging evidence and areas for further inquiry. *Eur J Pediatr*. 2026.
9. Niemiec M *et al* What Do We Know About Hypertrophic Cardiomyopathy in Poland in the Period 2016–2021 Based on Data From the Public Health System? *Int J Public Health*. 2026.
10. Bianchi L *et al* Efficacy and safety of sodium-glucose cotransporter inhibitors in hypertrophic cardiomyopathy: a systematic review. *Int J Cardiol Heart Vasc*. 2026.
11. Fortuna I *et al* Staging of Fabry cardiomyopathy in clinical practice: an algorithm proposal. *Int J Cardiol Heart Vasc*. 2026.

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

[PUBLICATIONS](#)

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