



# European Reference Network

for rare or low prevalence complex diseases

## Network

Heart Diseases  
(ERN GUARD-HEART)



## Agenda of the 19<sup>th</sup> ERN Board Meeting

19 March 2026

**13:00-14:00 Registration**, First-floor foyer  
& Networking lunch at Hotel Restaurant Solt Dining

**14:00 Opening remarks and aims of the meeting**

**14:05 Update on activities**

- Work package 1: Coordination
- Centre Activity Monitoring System, how do we perform
- Orphan devices' (E. Arbelo)
- High level meeting on rare diseases december 2025 (Bruxelles)

**14:50 Work package 6: Training and education**

- Regular webinars for professionals - Schedule and Evaluation
- Patient education meetings
- Summer schools – update and planning
- Exchange Programme - Update

**15:35 Work package 4: Healthcare & CPMS**

- CPMS 2.0: Update & Plan for Action

**15:55 Coffee break**

**16:15 European Patient Advocacy Groups (EPAGs) ERN GUARD-Heart**

- Update on EPAGs (overview of EPAGs & supporting partners)
- Update on EPAG activities

**16:45 ORPHANET Classifications for rare cardiac disease (A. Wilde)**

**17:15 Work package 5: Registries and Research**

- Update on registries: legal and ethical aspects
- ERDERA/RealiseD: Opportunities for support/funding
- ERDERA-Project to prioritize a list of diseases for Advanced Therapy Medicinal Products (ATMPs) development

**18:05 Work package 7: Clinical practice guidelines and Clinical decision support tools**

- Planning Focus Meetings - Update
- Layperson translations of abstracts of 'ERN Publications' - Update

**18:20 Work package 8: Capacity building and best practice sharing with Ukraine**

**18:30 Questions & Closing**