



European Reference Network

for rare or low prevalence complex diseases

 **Network**
Heart Diseases
(ERN GUARD-HEART)

Agenda of the 19th ERN Board Meeting

19 March 2026



*Courtyard by Marriott Bucharest Floreasca Hotel
Boulevard Dimitrie Pompeiu 2A, Bucharest*

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)
- Publications

15:00 Work package 6: Training and education

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

15:50 Work package 4: Healthcare & CPMS

- CPMS 2.0: Update & Plan for Action

16:10 Coffee break

16:25 European Patient Advocacy Groups (EPAGs) ERN GUARD-Heart

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

16:55 ORPHANET Classifications for rare cardiac disease

- Updates A. Wilde (15 min)
- Mickael Carvalho, Orphanet (15 min)

17:25 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

18:00 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

20:00 Board Dinner at [Restaurant Nor](#) (Meeting point Marriott Hotel lobby (ground floor) at 19:45)