



European Reference Network

for rare or low prevalence complex diseases

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



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Agenda of the 18th ERN Board Meeting

1 September 2025

12:00 Welcome with lunch

12:30 Opening remarks and aims of the meeting

12:35 Work plan and work packages for grant (2023 – 2027) - updates on activities

- Work package 1: Coordination
- Centre Activity Monitoring System: performance indicators ERN GUARD-Heart
- General Monitoring of all ERNs

13:05 Work package 6: Training and education

- Regular webinars for professionals - Schedule and Evaluation
- Patient education meetings
- Focus Meetings for thematic areas
- Exchange Programme - Update
- Summer School - Update on plans (Caforio/Janousek)

13:50 European Patient Advocacy Groups (EPAGs) ERN GUARD-Heart

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

14:15 Coffee break

14:35 ORPHANET Classifications for rare cardiac disease (Arthur Wilde)

15:05 Work package 5: Registries and Research

- Update on registries: legal and ethical aspects
- ERDERA: Opportunities for support/funding

15:40 Work package 7: Clinical practice guidelines and Clinical decision support tools

- Organization of dedicated focus meeting - Update (Rotterdam - report)
- Layperson translations of abstracts of 'ERN Publications' - Update

15:55 Work package 4: Healthcare & CPMS

- CPMS 2.0: Update & Plan for Action

16:15 Work package 8: Capacity building and best practice sharing with Ukraine

16:30 Questions & Closing