



European Reference Network

for rare or low prevalence
complex diseases

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



**28 August 2023, Rosarium
Amstelpark 1, Europaboulevard
1083 HZ Amsterdam**

Agenda for the 14th Board Meeting

12.15 Welcome with coffee and lunch

13.00 Opening remarks and aims of the meeting

13.10 Work plan and work packages in the new grant (2023 – 2027)

- Work package 1: Coordination
 - Overview of Network coordination Team
 - HCP Activity Monitoring System: Performance Indicators ERN GUARD-Heart
- Work package 2: Dissemination activities
- Work package 3: Evaluation
- Work package 4: Healthcare and CPMS
 - New CPMS version
 - Helpdesk
 - Development of PROMS/PREMS
- Work package 5: Registries
 - Survey among HCPs
 - Individual appointments with HCP representatives & ePAGs
 - Update current registries and already accepted new registries
 - Development of standard forms for joint data registry agreement, data access policy, data sharing agreement and data consent form

14:30 Coffee-break

15:00 European Patient Advocacy Groups (EPAGs)

- update on EPAGs

15:30 Work plan and work packages in the new grant (2023 – 2027)

- Work package 6: Training and education
 - Regular webinars for professionals
 - Patient education meetings
 - Scientific conferences for the thematic areas
 - Continuation of the ERN Exchange Programme
 - Summer Schools
 - Patient empowerment activities
- Work package 7: Clinical practice guidelines and Clinical decision support tools
 - Collaboration with ESC
 - Organization of focus meetings
 - Layperson translations of abstracts 'ERN Publications'
 - Survey cross-border patient pathways

16.55 Questions and closing