



European Reference Network

for rare or low prevalence
complex diseases



Network
Heart Diseases
(ERN GUARD-HEART)



22 March 2024

Sorbonne, University Building

Meeting room: Bordeaux

105 Boulevard de l'Hopital 75013 Paris

Agenda for the 15th Board Meeting

08:30 Welcome with coffee and introduction

08:45 Opening remarks and aims of the meeting

08:55 Work plan and work packages for grant (2023 – 2027)- updates on activities

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

09:15 Updates per thematic area by thematic area leaders (à 10 minutes), followed by short discussion

- Thematic area 1: Elena Arbelo
- Thematic area 2: Philippe Charron
- Thematic area 3: Georgia Sarquella-Brugada
- Thematic area 4: Nico Blom/Annemien v.d. Bosch
- Thematic area 5: Alida Caforio

10:30 Coffee break

11:00 European Patient Advocacy Groups (EPAGs) ERN GUARD-Heart

- Update on EPAGs (overview e-PAGs & supporting partners)
- Update on ePAGs activities
- Summary of meeting on genetic testing (7 February 2024)
- Update PROMS – presentation by Saar van Pottelberghe (online)

12:15 Lunch

13:15 Work package 4: Healthcare & CPMS

- New CPMS version
- Helpdesk
- Uploading cases in CPMS & LQTS sports project

13:35 Work package 5: Registries, data management and analysis

- Planning individual appointments with HCP representatives
- Update current registries and already accepted new registries

14:20 Work package 6: Training and education

- Regular webinars for professionals
- Patient education meetings
- Scientific conferences for thematic areas
- Exchange Programme
- Summer School

14:50 Work package 7: Clinical practice guidelines and Clinical decision support tools

- Collaboration with ESC
- Organization of focussed meetings
- Layperson translations of abstracts of 'ERN Publications'
- Patient pathways

15:10 Workpackage 8: capacity building and best practice sharing with Ukrainian competent authorities and healthcare units.

15:20 Questions & closing