



# European Reference Network

for rare or low prevalence  
complex diseases

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



**15 March 2023**

**Trippenhuis**

**Room: Tinbergen Zaal**

**Kloveniersburgwal 29**

**1011 JV Amsterdam.**

## Agenda for the 13<sup>th</sup> Board Meeting

- 12.45**      **Welcome with coffee and lunch (foyer)**
- 13.30**      **Opening remarks and aims of the meeting**
- 13.35**      **Updates from the Network**
- Network agreement
  - Next grant (period)
  - Podcasts
  - Webinar Series for professionals
  - Evaluation Exchange Visits Programme
  - Update and plans for national topic meetings for patients
- 14.00**      **Update on guidelines, research and registries**
- Overview of ERN-adopted guidelines
  - Overview of current registries
  - Registry grant – Heart CORE registry
  - Data sharing agreement and data access policy
  - Plans for disease specific registries
- 15.15**      ***Coffee-break and group-picture***
- 15.45**      **CPMS updates and plans**
- number of accounts and activity
  - helpdesk
  - uploading cases
  - update LQTS Sports Project
- 16:05**      **European Patient Advocacy Groups (EPAGs)**
- update on EPAGs
- 16.35**      **Official monitoring**
- collecting the indicators
  - deadlines
  - discussion, questions and experiences
- 16.55**      **Questions and closing**