

Agenda of the 20th ERN Board Meeting

Thursday 27th August

AGENDA

13:00-14:00 Registration, & Networking lunch

14:00 Opening remarks and aims of the meeting

14:05 Update on activities

- **Work package 1: Coordination**
 - Update new GRANT and governance
 - Centre Activity Monitoring System, how do we perform
 - Affiliated Partners call
 - Collaborative partners (as informal form to participate in ERN)?
- **Work package 2: Dissemination**
 - Website & Logo
 - Publications
 - ESC CCVG Proposal Consensus Document- Philippe Charron
 - Layperson translations of abstracts of 'ERN Publications' - Update

14:45 European Patient Advocacy Groups (EPAGs) ERN GUARD-Heart (ePAGs)

- Update on EPAGs & activities (overview of EPAGs & supporting partners)
- Rare Barometer survey on the mental health of people with rare diseases.

15:15 Work package 4: Healthcare & CPMS

- CPMS 2.0: Updates of Bi-weekly meetings & panels
- Example of use of CPMS-Intentional non-treatment LQTS.

15:25 Work package 6: Training and education

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

15:45 Coffee break

16:00 Work package 5: Registries and Research

- Research opportunities for ERNs ERDERA/Realised: Opportunities for support/funding
- **ERN Opportunities for Engagement with Public-Private Partners** Sheela Upadhyaya, Together4RD (online)
- **Update on registries:**
 - Idiopathic VF Registry Utrecht Rutger Hassink

17:00 ORPHANET Classifications for rare cardiac disease Updates A. Wilde

17:10 JA -Jardin deliverables impact to ERNs Marco Roos

17:25 Work package 7: Clinical practice guidelines and Clinical decision support tools

- Planning Focus Meetings - Update
- Focus meeting: "Brugada Syndrome in Children: Management of Challenging Cases".G. Sarquella Brugada
- Orphan devices' update E. Arbelo

17:40 Work package 8: Capacity building and best practice sharing with Ukraine

17:50 Questions & Closing

18:15 Walking & City tour by local host to Restaurant

19:00 Board Dinner at Munich city centre: [Spatenhaus an der Oper - Kuffler Gruppe](#)



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