European Reference Networks Conference
& ERN Kick-off meeting
Vilnius, Lithuania, 9-10 March 2017

Organised by the European Commission

Hosted by the Ministry of Health of Lithuania

Under the auspices of the Maltese Presidency of the Council of the EU
9 March 2017

3rd European Reference Networks Conference
Vilnius, Lithuania

Venue: Lithuanian Exhibition and Congress Centre LITEXPO, Laisves pr. 5, 04215, Vilnius

1. 08:00–09:00h: Registration and coffee

2. 09:00–09:40h: WELCOME AND OPENING SPEECHES

   o Jean-Claude Juncker, President of the European Commission (video message)
   o Vytenis Andriukaitis, Commissioner for Health and Food Safety
   o Aurelijus Veryga, Minister of Health Lithuania
   o Christopher Fearne, Minister of Health Malta
   o Françoise Grossetête, Member of the European Parliament and former rapporteur of the Directive of Cross-border Healthcare (video message)
   o Brian Hayes, Member of the European Parliament and leader of the European Advocates for Epilepsy group in the European Parliament (video message).

3. 09:40-12:15h: MORNING ROUNDTABLES: EUROPEAN UNION DIMENSION OF THE ERNs

   09:40-09:50h: Scene Setting and introduction to the roundtables: Xavier Prats Monné (Director General, DG SANTE)

   • 09:50–11.00h: Roundtable 1: Operating European Reference Networks: organisation and management

      Chair: Andrzej Rys (Director, Health systems, medical products and innovation, DG SANTE)

      Speakers:
      o Coordinators' view on network management and governance: Alberto Pereira (Coordinator ENDO-ERN)
      o IT platform as core element of the work; eHealth and telemedicine: Tapani Piha (Head of Unit, Cross-border healthcare and e-Health, DG SANTE)
      o Cross-linking European Reference Networks: Maurizio Scarpa (coordinator MetabERN)

   • 11:05–12:15h: Roundtable 2: EU Policies and Supporting Actions to the ERN

      Chair: Speakers: John F Ryan (Director, Public health, country knowledge, crisis management, DG SANTE)

      o Rare Diseases policies in the EU: Jaroslaw Waligora (Policy Officer, EU policy on Rare Diseases)
      o RD-ACTION (mission and state of play of RD-ACTION, future challenges): Victoria Hedley and Ana Rath (RD Joint Action coordination)
      o Rare Cancer Joint Action: Paolo Casali (JA coordinator and ERN EURACAN representative)
      o Registries platform: Simona Martin (Policy Officer, Health in Society, JRC)
      o Research policies and ERNs: Iiro Eerola (Policy Officer, Innovative and Personalised Medicine, DG RTD)
4. 12:15-13:45h: LUNCH, NETWORKING & POSTER SESSION

5. 13:50-13:55h: Scene setting for the afternoon roundtables: Justina Januseviciene (Member of the ERN Board, Ministry of Health of Lithuania)

6. 14:00-15:10h: Roundtable 3: ERNs and national healthcare systems
   
   Chair: Yann Le Cam (Eurordis Chief Executive Officer)
   
   Speakers:
   - Patient pathways and clinical governance: Patient flow knowledge generation and clinical practice: Jean-Yves Blay (coordinator ERN EURACAN)
   - Interrelationship between national systems and ERN: Member States view: Nora Gamst (ERN Board of MS, Norway’s representative) and Paul Boom (ERN Board of MS, The Netherlands’ representative)
   - Coordination hubs and ERN: an example of best practice in Malta: Miriam Dalmas (ERN Board of MS, Maltese representative)

7. 15:10-15:40h Coffee break & Poster session

8. 15:40-16:50h: Roundtable 4: ERN: The way forward
   
   Chair: Xavier Prats Monné (Director General, DG SANTE)
   
   Speakers:
   - Health care provider perspective: Arimantas Tamasauskas (member of EURACAN)
   - Coordinator perspective: Christopher Chapple (Coordinator of the eUROGEN network proposal)
   - Patient perspective: Rebecca Tvedt (patient representative in ERN BOND) and Avril Daly (patient representative in ERN-EYE)
   - Member States perspective: Till Voigtlander (Chair of the ERN Board of Member States, Austria’s representative)

9. 17:00-18:00h: Award Ceremony (approved ERNs) (short introduction by the Commissioner, with the presence of MEP and Ministers)
   
   - Certificates given by Vytenis Andriukaitis, Commissioner for Health and Food Safety

10. 18:00-19:00h Cocktail and poster walk, hosted by the Lithuanian Ministry of Health
10 March 2017, 09:00 to 14:00

Kick-off meeting of the 24 approved ERNs

Venue: LITEXPO, Laisves pr. 5, 04215, Vilnius
Participants: 400 members of the 24 approved ERNs (only for ERN members)

1. **08:00-08:30**: Transfer from the Hotels and Welcome coffee
2. **08:30-09:00**: Walking coffee with Commissioner (ERNs Coordinators)
3. **09:00-12:00**: First session: separated meetings of the 24 ERNs
4. **11:00 to 12:00**: Parallel technical meeting: 23 ERNs Coordinators (grant holders) and CHAFEA
5. **12:00-13:00**: Lunch break and networking of all ERN members
6. **13:00-14:00**: Second session: separated meetings of the 24 ERNs. Conclusions of the day
7. **14:00**: End of the meeting.