European Reference Networks Conference
& ERNs 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
   - Vytenis Andriukaitis, Commissioner on Health & Food Safety
   - Françoise Grossetête, Member of the European Parliament and former rapporteur of the Directive of Cross-border Healthcare (video message)
   - Aurelijus Veryga, Minister of Health Lithuania
   - Christopher Fearne, Minister of Health Malta

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: Despina Spanou (Director, Digital Society, Trust and Cybersecurity, DG CNECT)
     Speakers:
     o Rare Diseases policies in the EU: John F Ryan (Director, Public health, country knowledge, crisis management, DG SANTE)
     o RD-ACTION (mission and state of play of RD-ACTION, future challenges): Victoria Hedley & Ana Rath (RD Joint Action coordination)
     o Rare Cancer Joint Action: Paolo Casali (JA coordinator and ERN EUROCAN 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 CEO)
   - **Speakers:**
     - Patient pathways and clinical governance: **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, Netherland’s 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

   - Chair: **Xavier Prats Monné** (Director General, DG SANTE)
   - **Speakers:**
     - Health care provider perspective: **Arimantas Tamasauskas** (member of the ERN Neuro)
     - Coordinator perspective: **Christopher Chapple** (Coordinator of the eUROGEN network proposal)
     - Patient perspective: **Rebecca Tvedt** (patient representative in ERN BOND) & **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 Commissioner with the presence of MEP and Ministers)
   - Certificates given by **Vytenis Andriukaitis** Commissioner for Health & Food Safety

10. **18:00-19:00h **Cocktail and Poster walk hosted by the Lithuanian Ministry of Health to all participants
10 March 09:00 to 14:00

Kick-off meeting of the 24 approved ERNs

Venue: Litexpo;
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 & 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 and transfer to Airport / Hotels