

# European Reference Networks Conference

& ERN Kick-off meeting

Vilnius, Lithuania, 9-10 March 2017



# European Reference Networks



**Organised by the European Commission**



MINISTRY OF HEALTH  
OF THE REPUBLIC OF LITHUANIA



Hosted by the  
Ministry of Health of Lithuania

Under the auspices of the Maltese  
Presidency of the Council of the EU

**9 March 2017**

**3<sup>rd</sup> 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**

- **Jean-Claude Juncker**, President of the European Commission (video message)
- **Vytenis Andriukaitis**, Commissioner for Health and Food Safety
- **Aurelijus Veryga**, Minister of Health Lithuania
- **Christopher Fearne**, Minister of Health Malta
- **Françoise Grossetête**, Member of the European Parliament and former rapporteur of the Directive of Cross-border Healthcare (video message)
- **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:

- Coordinators' view on network management and governance: **Alberto Pereira** (Coordinator ENDO-ERN)
- IT platform as core element of the work; eHealth and telemedicine: **Tapani Piha** (Head of Unit, Cross-border healthcare and e-Health, DG SANTE)
- 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 )

- Rare Diseases policies in the EU: **Jaroslav Waligora** (Policy Officer, EU policy on Rare Diseases)
- RD-ACTION (mission and state of play of RD-ACTION, future challenges): **Victoria Hedley and Ana Rath** (RD Joint Action coordination)
- Rare Cancer Joint Action: **Paolo Casali** (JA coordinator and ERN EURACAN representative)
- Registries platform: **Simona Martin** (Policy Officer, Health in Society, JRC)
- 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 .