

Rare Diseases Europe Roundtable

Brussels, Wednesday 17th October 2018

Programme

Chair: Dr. Till Voigtländer, Associate professor, Medical University of Vienna

- 09:30 – 10:00** Registration and Morning Coffee
- 10:00 – 11:30** **Session I: analysing the current policy framework of rare diseases in the EU and Member States**
- Introduction & opening of roundtable: Dr. Till Voigtländer
 - Viewpoint: **European Parliament**
 - Analysing current EU policy – looking at recent and upcoming changes
 - National Plans and National Strategies on Rare Diseases: How far are we?
 - Advances of the European Platform on Rare Diseases Registration (EU RD Platform)
 - Opportunities and challenges of the **Rare Disease European Joint Programme Cofund**
 - New EU budget: What are the implications for Rare Diseases research?
 - EU enhancing international cooperation: lessons learnt from the ICD-11 update
- 11:30 – 11:45** Coffee Break
- 11:45 – 13:00** **Session II: Improving diagnosis, patient treatment and access to care**
- Evaluating current screening population practices
 - How can we improve recognition and visibility of rare diseases for a targeted patient treatment?
 - How to better gather national expertise on rare diseases and support its pooling?
 - Holistic care: How can we address its challenges for improving patient's lives
 - Innovative care practices in health and social services
 - Optimising treatment options and diagnostic tools
 - How does the EU support patients organisations?
- 13:00 – 14:00** Networking Lunch
- 14:00 – 15:15** **Session III: fostering research, innovation and drugs development**
- Encouraging further research into rare diseases and ensuring rapid translation of research results into clinical applications
 - Innovative medicine, regulation and accessibility: ensuring access to Orphan Medical Products
 - E-Health and telemedicine: what is the best way of adopting these new technological developments?
 - How can we maximise the impact of the European Reference Networks (ERNs) for fostering research?
 - Academic registries: challenges for its establishment, governance and financing.
 - Enabling data analysis within and across many RD and facilitating clinical trials and other studies
 - Data protection and privacy: discussing the new EU General Data Protection Regulation (GDPR) and its potential effects on clinical trials
- 15:15 – 15:45** **Recommendations and Close of Roundtable**
- Recommendations for policy makers, governments and key stakeholders to support an EU-wide strategy : *tour de table* of each participant's final recommendation for the Rare Disease Report
 - Chair's closing remarks