



Agenda

Rare2030 Panel of Experts Conference

7 November 2019

Hotel Pullman

Place Victor Horta 1, Brussels

“Validation of Trends to Build Future Scenarios in Rare Disease Policy”

- | | |
|---------------|---|
| 08.30 – 09.00 | Registration |
| 09.00 - 09.10 | Welcome
- <i>Frédérique Ries, Member of European Parliament</i> |
| 09.10 - 09.30 | Review of the Rare2030: Preparing the Future of Rare Disease Policy
- <i>Yann Le Cam, EURORDIS-Rare Diseases Europe</i> |
| 09.30 – 10.30 | Rare 2030 Research Advisory Board Panel Discussion: Global insights
Moderated by Andrea Ricci , ISINNOVA
- <i>Robert Madelin, FIPRA, former Director DG CNECT and DG SANTE</i>
- <i>Didier Schmidt, ESA, former advisor on Foresight to the EC President</i>
- <i>Rüdiger Krech, WHO Health Systems and Innovation (video)</i>
- <i>Terkel Andersen, EURORDIS-Rare Diseases Europe Board of Directors</i> |
| 10.30 -10.50 | Coffee break |
| 10.50 – 12.00 | Presentation of Methods and Trends
- <i>Victoria Hedley, University of Newcastle Institute of Genomic Medicine</i>
- <i>Giovanna Giuffrè, ISINNOVA</i> |
| 12.00 - 13.00 | Interactive Session Validating the Trends
- <i>Rare 2030 Project Partners</i> |
| 13.00 – 13.45 | Lunch (walking buffet) |
| 13.45 - 14.00 | Intro to the afternoon: What does it mean to build a scenario space? |
| 14.00 - 16.00 | Looking forward to our Future: Creating the Scenario Space (small working groups) |
| 16.00 – 16.30 | Coffee break |
| 16.30 – 17.00 | Feedback and Next Steps
- <i>Milan Macek, Dept of Biology and Medical Genetics, Charles University Orphanet Czech Republic</i> |