

FINAL POLICY CONFERENCE

23rd February 2021
13.30-18.30 CET

The future of rare diseases starts today
Recommendations from the Rare 2030 Foresight Study

OPENING PLENARY

13.30 - 13.40 Welcome

Moderator **Tamsin Rose** (Friends of Europe)

13.40 – 13.45 Greetings:

Frédérique Ries & **Cristian-Silviu Buşoi**
(European Parliament)

13.45 – 13.50 Opening remarks:

Stella Kyriakides (Commissioner for Health)

13.50 – 13.55 "Getting to know the Rare2030 project" (video)

14.00 – 14.20 Keynote Speakers:

Olivier Véran (Ministry of Health, France)
Terkel Andersen (EURORDIS –Rare Diseases Europe)
Nikolaos Milionis (European Court of Auditors)
Rebecca Skarberg (Osteogenesis Imperfecta Federation Europe (OIFE), Norway)

14.20 – 14.30 Presentation of the Rare 2030 recommendations: (Prof. **Kate Bushby**)

14.30 – 15.05 Discussion panel:

(moderated by Kate Bushby)
Yann Le Cam (EURORDIS - Rare Diseases Europe)
Victoria Hedley (UNEW)
Prof. Maurizio Scarpa (MetabERN)
Lucia Monaco (Fondazione Telethon)
Ana Rath (Orphanet)
Giovanna Giuffrè (ISINNOVA)
Fanni-Laura Mäntylä (Rare2030 Young Citizens)

15.15 - 15.20 Keynote Speaker:

Andrzej Ryś (European Commission, DG Health and Food Safety)

15.20 – 15.25 Video by Young Citizens ("In ten years' time...")

15.30 – 16.00 Comfort break

BREAKOUT SESSIONS

16.00 – 17.30 Parallel breakout sessions

Topics: Diagnosis, Research, Data, Integrated Care, Treatments, Access to Healthcare, Patient Partnership

17.30 – 17.45 Comfort break

CLOSING PLENARY

17.45 - 18.30 Closing remarks:

Kateřina Konečná (European Parliament)
Milan Macek (Rare2030 Research Advisory Board)
Jan Blatný (Ministry of Health, Czech Republic)
David Maria Sassoli (President, European Parliament)
Yann Le Cam (EURORDIS –Rare Diseases Europe)

BREAKOUT SESSIONS

16:00-17:00 CET

The breakout sessions will help the audience to **(1)** gain a deeper understanding of the recommendations, **(2)** provide concrete examples of how the recommendations can be used (case study), **(3)** allow participants to discuss/brainstorm in small groups, give feedback, take ownership of the content and be inspired to take action in helping the community get to where we want to be by 2030. **7 parallel breakouts** will be proposed and split by the recommendation topics and presented by:

- Moderator (topic expert): introduce the recommendations by topic.
- Policy maker: present how these recommendations could be used from the policy maker perspective.
- Case study: provide comments on recommendations and how they will be used in their work.

1. Innovative and Needs-Led research and development

- Moderator (topic expert): **Stefano Benvenuti** (Fondazione Telethon)
- Policy maker: **Catherine Berens** (European Commission, DG Research & Innovation)
- Case study: **Ines Alves** (Patient Expert in Rare diseases)
- Virtual Host: **Davor Duboka** (EURORDIS)

2. Integrated and Person-Centred Care

- Moderator (topic expert): **Clara Hervas** (EURORDIS)
- Policy maker: **Inmaculada Placencia Porrero** (European Commission, DG Employment)
- Case study: **Dorica Dan** (Romanian National Alliance for Rare Diseases)
- Virtual Host: **Raquel Castro** (EURORDIS)

3. Access to High Quality Care

- Moderator (topic expert): **Victoria Hedley** (UNEW)
- Policy maker: **Martin Dorazil** (European Commission, DG Health and Food Safety)
- Case study: **Ilaria Galetti** (ePAG ERN ReCONNET)
- Virtual Host: **Lenja Wiehe** (EURORDIS)

4. Available, Accessible and Affordable Treatments

- Moderator (topic expert): **Simone Boselli** (EURORDIS)
- Policy maker: **Kaja Kantorska** (European Commission, DG Health and Food Safety)
- Case study: **Diego Ardigo** (Chiesi)
- Virtual Host: **Maria Cavaller** (EURORDIS)

BREAKOUT SESSIONS

16:00-17:00 CET

5. Earlier, Faster and More Accurate Diagnostics

- Moderator (topic expert): **Dr Luca Sangiorgi** (ERN BOND, Istituto Ortopedico Rizzoli)
- Policy maker: **Dr Holm Graessner** (Coordinator ERN-RND)
- Case study: **Dr Christine Mundlos** (ACHSE)
- Virtual Host: **Gulcin Gumus** (EURORDIS)

6. Partnership with Patients

- Moderator (topic expert): **Virginie Bros-Facer** (EURORDIS)
- Policy maker: **Antoni Montserrat Moliner** (ALAN)
- Case study: **Fani Petridis** (Roche)
- Virtual Host: **Jo Marshall** (EURORDIS)

7. Optimising Data for Patient and Societal Benefits

- Moderator (topic expert): **Ana Rath** (Orphanet)
- Policy maker: **Ceri Thompson** (European Commission, DG Communications Networks, Content and Technology)
- Case study: **Anne Charlet** (Lupus Europe)
- Virtual Host: **Veronica Popa** (EURORDIS)

This event marks the end of the Rare2030 foresight project with the presentation of the final recommendations that will lead us to improved policy and a better future for people living with a rare disease in Europe.