



DRAFT AGENDA
Rare2030 Final Conference (online)
23rd February 2021
13.30-18.30 CET

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.

***“The Future of Rare Diseases Starts Today:
Recommendations from the Rare 2030 Foresight Study”***

- 13.30 – 13.40 **Welcome**
- 13.30 – 13.40 **Greetings:** Frédérique Ries & Cristian 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 – 14.10 **Opening remarks:** Olivier Véran (Ministry of Health, France); Terkel Andersen (EURORDIS – Rare Diseases Europe)
- 14.10 – 14.20 **Keynote speakers:** Nikolaos Milionis (European Court of Auditors); Rebecca Skarberg (ePAG advocate)
- 14.20 – 14.25 **Presentation of the final recommendations** (Prof. Kate Bushby)
- 14.25 – 14.55 **Discussion panel:** Yann Le Cam (EURORDIS); Victoria Hedley (Newcastle University); Prof. Maurizio Scarpa (MetabERN); Lucia Monaco (Telethon Italia); Ana Rath (Orphanet); Christian Buşoi (European Parliament); ISINNOVA; Fanni-Laura Mäntylä (Rare2030 Young Citizens)
- Moderator: Prof. Kate Bushby (Newcastle University)
- 15.05 - 15.10 **Keynote Speaker:** Andrzej Ryś (European Commission, DG Health and Food Safety);
- 15.10 – 15.15 **Video by Young Citizens (“In ten years’ time...”)**
- 15.30 – 16.00 *Comfort break*
- 16.00 – 17.30 **Parallel breakout sessions** - (Diagnosis, Research, Data, Holistic Care, Access to OMPs, Access to Healthcare, Patient Partnership)
- Deep-dive and discussion on the final policy recommendations per topic
 - Information about how to use Rare 2030 recommendations in practice
 - Case studies from stakeholder perspectives
- 17.30 – 17.45 *Comfort break*



- 17.45 - 18.30 **Closing remarks:** Kateřina Konečná (European Parliament); Milan Macek (Czech National Coordination Centre for Rare Diseases - UH Motol Prague, Czech Republic); Jan Blatný (Ministry of Health, Czech Republic); Yann Le Cam (EURORDIS – Rare Diseases Europe)
- 18.30 – 19:30 **Open Networking Session**

Rare2030 Breakout sessions (online)

Agenda

23rd February 2021

16:00-17:30 CET

The breakout sessions (16:00-17:30 CET) 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 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 (DG Employment)

Case study: Dorica Dan (Romanian National Alliance for Rare Diseases)

Virtual Host: Raquel Castro (EURORDIS)



3. Access to High Quality Healthcare

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)

5. Earlier, Faster, More Accurate Diagnosis

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 Benefit

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)

