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
13.45 – 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 Bușoi (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)*
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)