**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

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**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

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**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

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**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)
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)
### 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)

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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.