



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

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:** Frédérique Ries & Cristian Buşoi (European Parliament)
- 13.40 – 13.45 **Opening:** Stella Kyriakides (Commissioner for Health)
- 13.45 – 13.50 **“Getting to know the Rare2030 project” (video)**
- 13.50 – 14.00 **Opening remarks:** Olivier Véran (Ministry of Health, France); Terkel Andersen (EURORDIS – Rare Diseases Europe)
- 14.00 – 14.20 **Keynote speakers:** Maroš Šefčovič (Vice-President, European Commission); Pierre Delsaux (European Commission, DG Health and Consumers); Nikolaos Milionis (European Court of Auditors); Rebecca Skarberg (ePAG advocate)
- 14.25 – 14.35 **Presentation of the final recommendations**
- 14.45 – 15.15 **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)
- 15.20 – 15.25 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 (Rare2030 Research Advisory Board); Jan Blatný (Ministry of Health, Czech Republic); Yann Le Cam (EURORDIS – Rare Diseases Europe)