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”


13.40 – 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 Bușoi (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)