

FROM POSSIBLE TO ACCESSIBLE?

Launch event of RARE IMPACT report: 'Challenges and solutions for improving patient access to advanced therapies medicinal products at the European level'

FINAL AGENDA

23 November 2020, 14h00 - 16h00 (CET)

(The link to the **zoom link** is sent in a separate message)

Moderation: **Simone Boselli**, EURORDIS-Rare Diseases Europe

14h00 - 14h05

Welcome: **Yann Le Cam**, EURORDIS-Rare Diseases Europe

Short poll about the audience

14h10 - 14h20

Patient perspective: **Avril Daly**, Retina International

14h20 - 14h30

RARE IMPACT: overview of initiative, results and recommendations:
Karolina Hanslik, EURORDIS and **Adam Hutchings**, Dolon

14h30 - 15h20

Stakeholders' views on the RARE IMPACT recommendations:

(3- 5 min. per speaker)

- Patients: **Dr Mariette Driessens**, Dutch Genetic Alliance-VSOP
- Researchers: **Prof. Hans-Dieter Volk**, Charité-Universitätsmedizin Berlin
- Patients: **Dr Hervé Nabarette**, AFM-Téléthon
- Industry: **Tresja Bolt**, Bluebird bio

Short poll about the RARE IMPACT solutions

- HTA: **Marcus Guardian**, EUnetHTA Joint Action
- European Commission: **Rocio Salvador Roldan**, DG SANTE
- European Medicines Agency: **Dr Xavier Kurz**, Task force on registries
- European Parliament: **MEP Katerina Konecna**, GUE/NGL

15h20 - 15h50

Panel discussion and questions

15h50 - 16h00

Conclusions: Yann Le Cam, EURORDIS-Rare Diseases Europe