



ROUND TABLE

Working Together on Rare Diseases Shared Decision-Making for Advanced Technologies

10 December 2024, 10:00-13:30 CET
Warwick Brussels Hotel, Brussels, Belgium

DRAFT PROGRAMME

9:30 – 10:00	Registration
10:00 – 10:15	Welcome and introduction <i>Dr Maria Elisa Mancuso, EHC Medical Advisory Group</i>
10:15 – 10:30	Reform of the EU Pharmaceutical Legislation: what is in it for patients? <i>MEP Tomislav Sokol, EPP, Croatia</i>
10:30 – 11:00	Towards a more patient-centered EU policy on rare diseases <i>MEP Vytenis Andriukaitis, S&D, Lithuania</i>
11:00 – 11:15	Coffee break
11:15 – 12:00	Innovative therapies for rare bleeding disorders: new challenges on sharing and deciding <i>Dr Maria Elisa Mancuso, EHC Medical Advisory Group</i>
12:00 - 12:45	Working together on rare diseases: a common design between patients and clinicians <i>Dominik Cepic, Društvo Hemofiličara Hrvatske (TBC)</i>
12:45 – 13:15	Q&A and discussions
13:15 – 13:30	Conclusions and closing <i>Dr Maria Elisa Mancuso, EHC Medical Advisory Group</i>