EuRREB
European Registries for Rare Endocrine and Bone conditions

EuRREB Symposium

12 September 2025
Academy Building, Rapenburg 73, Leiden, the Netherlands

09:30 - 10:00	Registration - Welcome coffee and tea	
10:00 - 10:05	Opening	Natasha Appelman-Dijkstra
10:05 - 10:25	Registries and ERN's	Luca Sangiorgi
10:25 - 10:45	5 years of European Registries of Rare Endocrine and Bone Conditions	Ana Priego Zurita
10:45 - 10:55	The Melorheostosis module: a collaboration between ECTS, ERN BOND and EuRREB	Martine Cohen Solal
10:55 - 11:05	The LCH module: a collaboration between ERN BOND, ERN-EuroBloodNet and Endo-ERN	Polyzois Makras
11:05 - 11:15	Outcomes of the FD/MAS module	Sophie Huisman
11:15 - 11:25	The Rare Hypophosphataemia module	Alexandra Ertl
11:25 - 11:35	Contributing to the Achondroplasia module: a student experience	Chady Omara
11:35 - 11:45	The importance of a pregnancy module	Claudia Finis
11:45 - 12:05	Discussion: How to proceed with the first modules?	Facilitated by Faisal Ahmed
12:05 - 12:25	Coffee break	
12:25 - 12:45	Remodeling an existing rare disease registry to be used in regulatory context	Marina Mordenti
12:45 - 13:00	Ethics approval and data sharing process	Tess de Rooij
13:00 - 13:20	FAIR Data Stewardship	Bruna Dos Santos Vieira
13:20 - 13:40	Rare Disease Registries – seeing the forest for the trees	Faisal Ahmed
13:40 - 13:50	Closing words and group picture	Faisal Ahmed/Tess de Rooij
13:50 - 15:00	Lunch	