

EURORDIS WEBINARS

Involvement of patient organisations, patients and family members in RD National Networks and ERN National Coordination Hubs

04 May 2023 at 14.00-15.30 CET

Agenda

Please use this link to register:

<https://us02web.zoom.us/j/81234567890>

Thursday, May 4th, 2023 at 14.00-15.30 CET

An exchange of views on existing approaches to organise and structure patient involvement in Rare Disease National Networks and ERN National Coordination Hubs.

Time	Topics	Speaker
14.00-14.05	Welcome & Introductions	Inés Hernando , EURORDIS
14:05-14:15	ERN National Coordination Hub for Luxembourg, Centre Hospitalier de Luxembourg	Aline Bernassola , Administrative Coordinator of the National ERN Hub in Luxembourg
14:15-14:25	Slovenian ERN National Coordination Hub, University Medical Center Ljubljana	Prof. Luca Lovrecic , Clinical Geneticist, Laboratory Medical Geneticist, Assist Prof Human Genetics. Clinical Institute for Genomic Medicine, University Medical Center Ljubljana
14:25-14:50	Q&A	Aline Bernassola , Administrative Coordinator of the National ERN Hub in Luxembourg Prof. Luca Lovrecic , Clinical Geneticist, Laboratory Medical Geneticist, Assist Prof Human Genetics. Clinical Institute for Genomic Medicine, University Medical Center Ljubljana Dan Theisen , Director of ALAN - Maladies Rares Luxembourg
14:50-15.00	How are patient organisations involved in the rare disease French Filières	Marie-Claude Boiteux , Présidente - Cutis Laxa Internationale
15.00-15.10	Support by Alliance Maladies Rares to the French patient representatives that are involved in the filières	Hélène Thiollet , Responsable des affaires médicales, Alliance Maladies Rares
15:10-15.25	Q&A	
15:25-15:30	Wrap-up	Inés Hernando , EURORDIS