



# **EURORDIS WEBINARS**

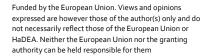
# Involvement of patient organisations, patients and family members in RD National Networks and ERN National Coordination Hubs

04 May 2023 at 14.00-15.30 CET

# **Agenda**

### Please use this link to register:

https://usozweb.zoom.us/meeting/register/tZAlcuygrTopHdNhXppfKtG-x\_J8XOKrx\_ol







## Thursday, May 4<sup>th</sup>, 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
		<b>Dan Theisen,</b> Director of ALAN - Maladies Rares Luxembourg
14:50-15.00	How are patient organisations involved in the rare disease French Filières	<b>Marie-Claude Boiteux,</b> Présidente - Cutis Laxa Internationale
15.00-15.10	Support by Alliance Maladies Rares to the French patient representatives that are involved in the filières	<b>Hélène Thiollet,</b> Responsable des affaires médicales, Alliance Maladies Rares
15:10-15.25	Q&A	
15:25-15:30	Wrap-up	Inés Hernando, EURORDIS