



ERICA & EJP RD Joint Conference



Tuesday 21 November 2023 (Amsterdam, The Netherlands)

	MORNING SESSION
09:00 - 09:30	Coffee & Registration
09:30 - 09:40	Welcome and introduction Alberto Pereira and Daria Julkowska
	Examples of Synergies between both projects (ERICA & EJP RD)
09:40 - 10:00	Input to Virtual Platform and its functionalities Franz Schäfer, Ana Rath and ERN example
10:00 - 10:15	Biobanking and Clinical Trials Eduardo L. Granados and Luca Sangiorgi
10:15 - 10:30	ERN Clinical Trials Survey(s) Rima Nabbout, Luca Sangiorgi and Dieter Hilgers
10:30 - 10:45	Developed tools for RD researchers (IMT, webinars) Adriana Planinic
10:45 - 11:00	Communication & Dissemination Mari Murel and Yanis Mimouni
11:00 - 11:20	Coffee Break
	Collaboration of ERNs and non-ERNs researchers
11:20 - 11:40	JARDIN-Data Sharing & Integration Holm Graessner (TBC)
11:40 – 12:00	IHI Call for Clinical Research Magda Chlebus (TBC) and Dieter Hilgers
12:00 - 12:20	Together4RD: position statement on collaboration between ERNs and industry Mathieu Boudes
12:20 - 12:50	International Collaboration – NIH and IRDIRC and Canadian RD network Tiina Urv (NIH), David Pierce (IRDiRC) and Breanne Stewart (MICYRN)
12:50 - 13:00	Discussion Moderated by <i>Maurizio Scarpa</i>
13:00 – 14:00	Lunch

Location:

Amsterdam UMC, Conference Room 4, Meibergdreef 9, Amsterdam Pre-conference dinner at **19:00**. The restaurant (**de Waag**) is in historical centre!







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	AFTERNOON SESSION
	Preparing the path to the European Rare Diseases Research Alliance (ERDERA)
14:00 - 14:20	General introduction Daria Julkowska and Yanis Mimouni
14:20 – 14:40	Updates & Special WP25 Task for ERNs Maurizio Scarpa, Luca Sangiorgi and Alexis Arzimanoglou
	Q&A
14:40 – 14:50	Accomplished tasks to be transferred to ERDERA Moderated by Franz Schäfer
14:50 – 15:00	Data Hub Ronald Cornet
15:00 – 15:10	PROMs/PREMs Ana Rath
15:10 – 15:20	Overview of use cases Franz Schäfer and Mar Mañu Pereira
15:20 – 15:40	Discussions Q&A
15:40 - 16:00	Coffee Break
16:00 – 16:30	Discussion and next steps Alberto Pereira and Daria Julkowska
16:30 - 17:30	Borrel & Drinks



Recommended conference hotel

Leonardo Royal Hotel Amsterdam

Booking code: 2011UMC