ERN ITHACA Board Meeting

Budapest, December 8-10

Thursday, December 8 - Patient Council Workshop, draft program

9h00	Welcome in Budapest, Added value of ERN to engage Patient organisation at National level | Gabor Pogany
9h20	A case study within ITHACA from a national to a EU scale: history of our journey in Rasopathies | Ioel Detton
9h30	Round Table presentation & my plans with Ithaca | All participants
10h30	Coffee break
10h00	ITHACA 5 years of involvement and evaluation, achievements and challenges | Dorica Dan
11h15	ITHACA Activity report & Work Group | Anne Hugon
11h30	Role of EURORDIS in supporting Patient Partnership : A spotlight on ERN ITHACA | Rita Francisco
12h00	Team building training: ITHACA's experience and discussion | Ammi Andersson, Rita Francisco
12h30	Election of the new Patient Board 2022 | Dorica Dan, Gabor Pogany
13h00	Lunch
14h30	When and how should be Patients be involved in guidelines, asking your opinion | Moderators from Guidelines WG: Agnies van Eeghen, Charlotte Gaasterland, Mirthe Klein Haneveld, Anne Hugon
16h00	What resources can I rely on, what can we develop as educational support needed, asking your opinion | Moderator from Teaching & Education WG: Laurence Faivre, Anne Hugon
16h30	Coffee Break
17h00	Over view on Neuro-developmental Disorders work Group | Moderator from WG NDD: Tjitske Kleefstra, Anne Hugon
17h20	Go deeper into a European cross talk between clinical geneticist and neuropathologist | Moderator from WG NDD: Tjitske Kleefstra, Jolanda Van Golde, Claudine Laurent Levisson
18h00	Final discussion and conclusion | Dorica Dan, Gabor Pogany

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Friday, December 9 - Plenary Board day 1, draft program

9h00	Board Meeting opening
9h15	Rare diseases reality and Patient Organisation in Hungary
9h30	ERN-ITHACA Activity report, Budget overview, upcoming evaluation process
9h45	ERN-ITHACA Assessment of past year, Workplan, Activities to come
10h00	WG Guidelines activity review
10h15	WG CPMS activity review
10h30	Coffee break
11h00	WG Research & Innovation activity review
11h15	WG Fetal Medicine activity review
11h30	WG NDD activity review
11h45	WG ILIAD activity review
12h00	Clinical Trials for Rare Diseases
12h30	Lunch break
14h00	Talk by the European Commission
14h20	Talk: Non invasive prenatal diagnosis of single gene disorders, By Dr Juliette Nectoux
14h50	WG Digital activities
15h05	Patient Advisory Board activity review
15h20	WG Education and Training activity review
15h35	APOGeE: a progress report
15h45	Young Geneticists Committee (ESHG-Y) talk
15h55	Coffee break
16h10	The Future of Solve RD
16h40	EpiEuroNet
17h10	Research, innovative subject
17h40	Talk: 3D facial morphometrics for dysmorphologists, by Dr Hilde Peeters
18h10	JA on the integration of the ERNs
18h30	Closing remarks
21h00	Joint dinner

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Saturday, December 10 - Plenary Board day 2, draft program

9h00	Talk: ERICA and ERNs Research support (The new RD Partnership SRIA agenda) by Mari Murel
9h30	WG SBoD activity review
9h45	Talk: Presentation of TEHDAS / EU Health data space, by Markus Kalliola
10h15	Coffee break
11h00	Talk by Eurordis
11h30	Talk: The Rare Disease Partnership by Alexandra Tataru (EJPRD)
12h00	Closure of the meeting