

Conference

"Rare disease perspectives in Central - Eastern Europe"

September 16, 2019

Venue: Centre Noninvasive Medicine, Medical University Gdansk
Gdansk, ul. Dębinki 7 (Lecture room 1/D/01.1)

10:00 – 10:30	Registration, welcome coffee
10:30 – 10:45	<p>Welcome words:</p> <ul style="list-style-type: none"> • Ministry of Health of the Republic of Poland • Dean of University of Gdansk • EJP RD Coordinator dr. Daria Julkowska (<i>French National Institute of Health and Medical Research (INSERM), FR</i>)
<p><i>Chairs: prof. Aleksandra Zurowska (Centre Rare Diseases, Medical University Gdansk, PL), dr. Daria Julkowska (INSERM, FR)</i></p>	
10:45 – 11:45	<p>European Joint Programme on Rare Diseases: what it is and for whom it is?</p> <p>Training, educational and grant opportunities of EJP RD in the next 5 years</p> <p><i>Dr. Daria Julkowska (INSERM, FR)</i></p>
11:45 – 12:20	<p>Rare disease research policies in Europe</p> <p><i>Dr. Birute Tumiene (Vilnius University Hospital Santaros Klinikos, LT)</i></p> <p>Polish National Plan for Rare Diseases (<i>Ministry of Health, Poland</i>)</p>
12:20 – 12:50	<p>European Reference Networks (ERN's)</p> <p><i>Prof. Holm Graessner (University and University Hospital Tübingen, DE), Prof. Katrzyna Kotulska Józwiak (Children's Memorial Health Institute, Warsaw, PL; ERN Board of Member States)</i></p>
12:50 – 13:25	<p>Rare disease clinical research and innovation</p> <p><i>Prof. Rima Nabbout (Hôpital Necker Enfants Malades, Institute Imagine, FR), dr. Karolina Nowak, prof. Rafał Płoski (Medical University of Warsaw, PL)</i></p>
13:30 – 14:30	Lunch time

<i>Chairs: Prof. Katrzyna Kotulska Józwiak (Children's Memorial Health Institute, Warsaw, PL), dr. Birute Tumiene (Vilnius University Hospital Santaros Klinikos, LT)</i>	
14:30 – 15:00	Rare disease data ecosystem in EJP RD <i>Ana Rath (French National Institute of Health and Medical Research (INSERM) - Orphanet, FR)</i>
15:00 – 15:15	Orpha coding <i>Prof. Krystyna Chrzanowska (Children's Memorial Health Institute, Warsaw, Orphanet - Poland, PL)</i>
15:15 – 15:45	Registries <i>Dr. Eduardo López Granados (University Hospital La Paz, Madrid, ES), Anna Latos Bielenska (Medical University Poznan, Polish Registry Congenital Anomalies – EUROCAT); Aleksandra Zurowska (Polish RRT Registry, ERKNetReg, PL)</i>
15:45 – 16:10	Biobanks <i>Prof. Luca Sangiorgi (Istituto Ortopedico Rizzoli di Bologna, IT); dr. Jarosław Skokowski (Medical University Gdansk, BBMRI.pl)</i>
16:10 – 16:30	Education needs in RD research <i>Roseline Favresse, Emilie Bonnaud (French Foundation for rare diseases, FR)</i>
16:30 – 16:45	RD Patient organizations in CEE countries <i>Dr. Gábor Pogány (Hungarian Patient Forum, HU), Prof. Maria Libura (Warmia and Mazury University, Patient organization representative, PL)</i>
16:45 – 17:00	Discussions and next steps
17:00	Closing of the conference