

Time	Programme	Speaker
13:15 – 13:30	WELCOME	
	<p><b>Prof. Vlastimil Válek, MD, PhD., MBA, EBIR (TBC)</b> Minister of Health of the Czech Republic</p> <p><b>Jakub Dvořáček MSc., LL.M</b> Deputy Minister of Health of the Czech Republic</p> <p><b>Lumír Kantor, M.D</b> (video presentation) Senate of the Parliament of the Czech Republic</p> <p><b>Prof. Milan Macek Jr., MD., DSc.</b> National Coordination Center for Rare Disease</p> <p><b>Prof. Viktor Kožich, M.D, CSc.</b> Coordination Center for Neonatal Screening</p> <p><b>Ondřej Májek, RNDr. PhD</b> National Screening Centre, Institute of Health Information and Statistics of the Czech Republic</p>	
<b>13:30 – 15:30</b>	<b>SESSION I. – NEWBORN SCREENING (NBS): A GATEWAY TO EARLY DIAGNOSIS</b> (CHAIRS: Dr. Gulcin Gumus and Prof. Viktor Kožich)	
13:30-13:50	Overview of European NBS activities-synergies and overlaps	<b>Prof. Jim Bonham,</b> United Kingdom
13:50-14:05	Role of European Reference Networks for rare diseases in NBS	<b>Prof. Maurizio Scarpa,</b> Italy
14:05-14:20	Developing a blueprint of NBS in Europe: overview of workstreams	<b>Dr. Peter Schielen,</b> The Netherlands
14:20-14:35	Key indicators for planning, monitoring and evaluation of newborn screening: international context and future perspectives for cooperation	<b>Dr. Ondřej Májek,</b> Czech Republic

14:35-14:50	The tower of Babel: why do we need case definitions?	<b>Dr. Rolf Zetterstroem</b> , Sweden
14:50-15:05	The key role of registries in assessing clinical outcome	<b>Prof. Stefan Koelker</b> , Germany
15:05-15:20	Experience with expanding NBS in Czechia	<b>Ms. Anna Arellanesová</b> , Czech Association for Rare Diseases, Czech Republic
<b>15:20 - 15:45</b>	<b>Coffee break</b>	
<b>15:45 - 16:30</b>	<b>SESSION II. - CURRENT EXPERIENCE AND FUTURE DEVELOPMENTS IN NBS</b> (CHAIRS: Ms. Anna Arellanesová and Prof. Maurizio Scarpa)	
15:45-16:05	Newborn screening: the perspective of people with RD and future potential	<b>Dr. Antoni Montserrat</b> , EURORDIS
16:05-16:20	The use of a patient management system to improve long-term outcome	<b>Dr. Rolf Zetterstroem</b> , Sweden
16:20-16:35	Screen4care EU IMI project	<b>Prof. Alessandra Ferlini</b> , Italy
16:35-17:10	<u>Panel discussion</u> (CHAIRS: Dr. Antoni Montserrat and Dr. Peter Schielen)	
	<b>Ms. Martine Pergent</b> IPOPI President/Screen4rare, France  <b>Mr. Stelios Kypouropoulos</b> MEP (TBC)  <b>Dr. Jose Valverde</b> European Commission, DG SANTE Unit B3 (TBC)	

	<p><b>Ms. Dorica Dan</b> Specifics of care in the Romanian and minority populations living in Romania, NoRo Romania</p> <p><b>Prof. Gunnar Douzgos Houge</b> IVD-R: beneficial or just an expensive strait jacket? Norway</p> <p><b>Dr. Sofia Douzgos Houge</b> IVD-R: Case example of a rare recessive disorder, Norway</p> <p><b>Dr. Gulcin Gumus</b> EURORDIS</p>
<b>17:10-17:40</b>	<p><b>GENERAL DISCUSSION</b> (Speakers, panelists and on-line guests (on-line attendance by invitation only))</p>
<b>17:40-18:00</b>	<p><b>SUMMARY AND CLOSE OF MEETING</b></p>
	<p><b>Prof. Jim Bonham,</b> United Kingdom</p> <p><b>Dr. Rolf Zetterstroem,</b> Sweden</p> <p><b>Dr. Antoni Montserrat,</b> EURORDIS and ALAN Maladies Rares, Luxembourg</p>