# REGIONAL CONFERENCE ON RARE DISEASES



## CONFERENCE PROGRAMME

Venue: Hotel Mona Plaza Address: Cara Uroša 62-64, Belgrade, Serbia

THURSDAY, SEPTEMBER 12
OPENING CEREMONY
PRE-SESSION PROGRAMME / COMFORT BREAK
THE IMPACT OF CARING FOR CHILDREN WITH RARE DISEASES
<ul> <li>Florian Deval, Head of International relations, Foundation IPSEN</li> <li>Anđelka Stupar, parent</li> <li>Vukašin Čobeljić, psychologist, University Children's Clinic Tiršova</li> <li>Vladan Žikić, NORBS</li> </ul>
LUNCH BREAK
THE IMPACT OF RARE DISEASES ON SIBLINGS
<ul> <li>Ida Mirković Knaus, Croatian Neurofibromatosis Association (sibling)</li> <li>Stefan Živković. NORBS (sibling)</li> <li>Nicola Miller, Editor, Rare Revolution Magazine</li> <li>Danica Vučić, psychologist, NORBS</li> </ul>
HOW PATIENTS ARE SHAPING RARE DISEASE ECOSYSTEM
<ul> <li>Dorica Dan, Romanian Alliance for Rare Diseases</li> <li>Bojana Mirosavljević, Association LIFE, Serbia</li> <li>Vesna Aleksovska, North Macedonia</li> <li>Sara Brambilla, Rare Disease International</li> </ul>

17.30 - 18.00

WRAP-UP OF THE FIRST DAY

# FRIDAY. SEPTEMBER 13

10.00 - 11.30	EMPOWERING RARE DISEASE RESEARCH THROUGH DATA
	<ul> <li>Jelena Malinina, Data Director, EURORDIS</li> <li>Branislava Gemović, Data and Bioconvergence project Manager, C4IR</li> <li>Matteo Bregonzio, Project Coordinator, BETTER project</li> <li>Maja Stojiljković, Senior Research Associate, IMGGE</li> </ul>
11:30 - 12:00	COMFORT BREAK
12.00 - 13.30	<ul> <li>AGING WITH RARE DISEASES: OVERCOMING UNIQUE CHALLANGES</li> <li>HCP (TBA)</li> <li>Dejan Bojadžievski, patient, Norht Macedonia</li> <li>Alain Geille, president, Euro-DyMA</li> <li>Nadežda Pejović, NORBS</li> </ul>
13.30 - 15.00	LUNCH BREAK
15.00 - 16.30	<ul> <li>NEWBORN SCREENING</li> <li>Prof. dr Maja Đorđević Milošević, Institute for Mother and Child, Department of Metabolic Disease Examination and Treatment, Clinical Genetics, and Nutrition, Serbia</li> <li>TBA</li> <li>Prof. dr Mojca Žerjav Tanšek, University Children's Hospital, Department of Endocrinology, Diabetes and Metabolic Diseases, Ljubljana, Slovenia</li> <li>Olivera Jovović, NORBS</li> </ul>
16.30 - 17.00	CLOSING CEREMONY

### SATURDAY, SEPTEMBER 14

#### **WORKSHOPS FOR PATIENT ADVOCATES**

Venue: Prostor Miljenko Dereta Adress: Dobračina 55, Belgrade Time: 10:00 - 15:00

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10.00 - 11.00	EMPOWERING PATIENTS: UNDERSTADING AND EXERCISING YOUR RIGHTS IN HEALTHCARE
11.00 - 12.00	PSYCHOLOGICAL WORKSHOP: BUILDING MENTAL RESILIANCE
12.00 - 14.00	NETWORKING LUNCH
10.00 - 14.00	WORKSHOPS FOR CHILDREN