

CONFERENCE ON RARE DISEASES
SEPTEMBER 14-16, 2023
BELGRADE, SERBIA



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CONFERENCE AGENDA

THURSDAY, 14. SEPTEMBER 2023

09:30 - 10:30

Moderator:
Ana Stamenković

OPENING CEREMONY

Ms Tamara Vučić, Spouse of the President of the Republic of Serbia

Stana Božović, State Secretary, Ministry of Family Welfare and Demography

Prof. dr Sanja Radojević Škodrić, Director, National Health Insurance Fund of the Republic of Serbia

Biljana Barošević, Assistant Minister, Ministry of Labour, Employment, Veteran and Social Policy

Representative, Ministry of Health

Ms Olivera Jovović, President, NORBS

10:30 - 11:30

SETTING THE SCENE: RARE DISEASE POLICY LANDSCAPE IN EUROPE

Moderator:
Ana Đukić

Olivera Jovović, President, National Organisation for Rare Diseases of Serbia

Ivana Hrastar, Social worker, Rare Diseases Croatia

Marzena Nelken, Director, National Forum Orphan (Krajowe Forum Orphan)

Eva Pesaro, Vice-President, UNIAMO - Federazione Italiana Malattie Rare

11:30 - 12:00

COFFEE / NETWORKING BREAK

12:00 - 13:30

INTEGRATION OF RARE DISEASES INTO SOCIAL POLICIES AND SERVICES

Moderator:
Ana Đukić

Milica Perić, President, Cystic Fibrosis Association Serbia

Sandra Pavlović, Vice-president, NORBS

Raquel Castro, Social Policy and Initiatives Director, EURORDIS

Dorica Dan, President, Romanian National Alliance for Rare Diseases / Vice-President, EURORDIS

13:30 - 14:30

LUNCH BREAK

14:30 - 15:30

PALIAIVE CARE FOR PERSONS LIVING WITH RARE DISEASES

Moderator:
Iva Omrčen

Vera Madžgalj, CEO, BELhospice

Isodora Jarić, Full Professor, Faculty of Philosophy, University of Belgrade

Jordi Cruz, Director, MPS Spain

15:30 - 17:00

Moderator:
Stefan Živković

SHAPING THE FUTURE OF PATIENT ADVOCACY: THE ROLE OF YOUNG PATIENT ADVOCATES

Nadežda Pejović, President, National Association of Phorphyrias Serbia

Adéla Odrihocká, Co-Chair, Ehler-Danlos syndrome and hypermobility syndrome Czech Republic / Patient Advocate, Rare Diseases Czech Republic (ČAVO)

Julian Delaye, Patient Engagement Manager - HTA, EURORDIS / Rare2030 Young Citizen

Emina Hadžihasanović, President, Association of Rare Disease Patient

FRIDAY, 15. SEPTEMBER 2023

10:00 - 11:30

Moderator:
Ana Đukić

HOW NEW TECHNOLOGIES ARE TRANSFORMING RARE DISEASES

Branka Rakić, Team lead for the AI for Healthcare & Life Science group, The Institute for Artificial Intelligence Research and Development of Serbia

Arsen Ristić, Head of Heart Failure Ward and Ass. Director, Department of Cardiology of the University Clinical Center of Serbia, Vice-Dean for Postgraduate Studies, Faculty of Medicine, University of Belgrade, Board Member, Heart Failure Association of the European Society of Cardiology President, Pulmonary Hypertension Society of Serbia,

Elin Haf Davies, CEO / Founder, Aparito

Tanja Zdolšek Draksler, Researcher and project manager, Jožef Stefan Institute / Founder of NGO IDefine Europe,

11:30 - 12:30

Moderator:
Iva Omrčen

ACCESS TO TREATMENT

Simone Boselli, Public Affairs Director, EURORDIS

Dragana Atanasijević, Public Health Consultant

Bojan Trkulja, Director, INOVIA

12:30 - 14:00

LUNCH / NETWORKING BREAK

14:00 - 15:30

Moderator:
Ana Stamenković

CHALLENGES IN TRANSITION FROM CHILDHOOD TO ADULTHOOD CARE IN RARE DISEASES

Gordana Vilotijević Dautović, Associate Professor, Faculty of Medicine, University of Novi Sad / Director, Paediatric Clinic, Institute for Child and Youth Health Care

Mirna Đurić, Full Professor, Faculty of Medicine, University of Novi Sad / Head of the Department of Acute pneumopathy, Clinic for Obstructive Lung Diseases and Acute Pneumopathy, Institute for Pulmonary diseases of Vojvodina

Natalija Ilić, Patient Advocate, MPS Serbia

Jana Sotirović, Patient Advocate, CF Serbia

15:30 - 16:00

COFFEE / NETWORKING BREAK

16:00 - 17:30

ADVANCES IN RARE DISEASE THERAPIES

Moderator:
Maja Stojiljković

Cynthia J. Tifft, MD, PhD, Deputy Clinical Director, National Human Genome Research Institute Director, Pediatric Undiagnosed Diseases Program, National Institutes of Health

Prof. dr Mojca Benčina, Department of Synthetic Biology and Immunology, National Institute of Chemistry / Centre for the Technologies of Gene and Cell Therapy (CTGCT)

Djordje Djordjevic, Founder in Residence, Deep Science Ventures

SATURDAY, 16. SEPTEMBER 2023

10:00 - 14:00

PARALEL WORKSHOPS:

- BETTER CARE FOR RARE DISEASES IN THE REGION STARTS WITH YOU
- THE ROLE OF YOUNG PATIENT ADVOCATES

14:00 - 15:00

LUNCH / FAREWELL

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