

REGIONAL CONFERENCE ON RARE DISEASES

CONFERENCE PROGRAMME

Venue: Hotel Mona Plaza

Address: Cara Uroša 62-64, Belgrade, Serbia



THURSDAY, SEPTEMBER 12

09:30 - 10:30

OPENING CEREMONY

10:30 - 11:00

PRE-SESSION PROGRAMME / COMFORT BREAK

11.00 - 12.30

THE IMPACT OF CARING FOR CHILDREN WITH RARE DISEASES

- Florian Deval, Head of International relations, Foundation IPSEN
 - Anđelka Stupar, parent
 - Vukašin Čobeljić, psychologist, University Children's Clinic Tiršova
 - Vladan Žikić, NORBS
-

12.30 - 14.00

LUNCH BREAK

14.00 - 15.30

THE IMPACT OF RARE DISEASES ON SIBLINGS

- Ida Mirković Knaus, Croatian Neurofibromatosis Association (sibling)
 - Stefan Živković, NORBS (sibling)
 - Nicola Miller, Editor, Rare Revolution Magazine
 - Danica Vučić, psychologist, NORBS
-

16.00 - 17.30

HOW PATIENTS ARE SHAPING RARE DISEASE ECOSYSTEM

- Dorica Dan, Romanian Alliance for Rare Diseases
 - Bojana Miroslavljević, Association LIFE, Serbia
 - Vesna Aleksovska, North Macedonia
 - Sara Brambilla, Rare Disease International
-

17.30 - 18.00

WRAP-UP OF THE FIRST DAY

*19.00 - 22.00 Conference Networking Dinner (invitations only)

SATURDAY, SEPTEMBER 14

WORKSHOPS FOR PATIENT ADVOCATES

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

10.00 - 11.00

EMPOWERING PATIENTS: UNDERSTANDING 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