



## PROGRAM

*National conference on rare diseases  
with International participation*



Ministarstvo  
zdravstva

Sponsored by the City of Zagreb and the Ministry of Health of the Republic of Croatia

JUNE 10. 2023

HOTEL ACADEMIA  
ZAGREB



## PLENARY LECTURES

### HALL GLORIA

#### 9:00-9:20 am Opening and welcome speech

Sara Bajlo – Rare Diseases Croatia

Ministry of Health

Croatian Institute for Health Insurance

Ministry of Labour, Pension System, Family and Social Policy

#### 9:20 am – 10:00 am Panel discussion on "rare diseases in Croatia - analysis of the situation, cooperation"

Participants: representatives of the Ministry of Health, the Croatian Institute for Health Insurance, the Ministry of Labour, the pension system, family and social policy, Croatian Institute of Public Health, Rare Disease Committee.

#### 10:10 am – 10:50 am Panel discussion on "rare diseases - holistic approach to care"

Participants: experts from various fields of patient care ( MD, psychologist, occupational therapist, physiotherapist)

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### 10:50 am-11:10 am Coffee break

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#### 11:10 am – 11:50 am Panel discussion on the topic "analysis of the situation in the region"

Participants: patient organizations representatives from the Balkan region

#### 11:55 am - 12:10 am

Eurordis representative: EUROPEAN ACTION PLAN FOR RARE DISEASES

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### 12:10 am-1:10 am Lunch break

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## PATIENTS WORD

#### 1:10 pm – 1:25 pm

Association 'Silent Angels' Croatia- Rett syndrome

#### 1:25 pm – 1:40 pm

Fabry disease

#### 1:40 pm – 1:55 pm

Cf Croatia

#### 1:55 pm – 2:10 pm

Spinal muscular atrophy

#### 2:10 pm - 2:25 pm

Student Rare Disease Help Line

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## MEETING ROOM

1:00 pm – 4:00 pm

Active citizens fund - presentation of research results

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## END OF PROGRAM

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5:00 pm – 7:00 pm RARE DISEASES CROATIA - ELECTORAL ASSEMBLY

## CONFERENCE SPONSORS

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