

2. konferencija

RAZLIČITA LICA

RIJETKIH I KOMPLEKSNIH
EPILEPSIJA



SAVE
THE DATE

HOTEL
AMPHORA
SPLIT

17.-19.10.2024

2nd Conference

DIFFERENT FACES

OF RARE AND COMPLEX
EPILEPSIES

PRELIMINARNI
PROGRAM

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Četvrtak, 17. listopada 2024

Dolazak predavača do 19 h i zajednička večera

Petak, 18. listopada 2024

Uvod

9:00-09:15 Pozdravni govor:

Bibić Irena (Dravet sindrom Hrvatska), Prpić Igor (Znanstveni odbor udruge Dravet sindrom Hrvatska), predstavnik Splitsko-dalmatinske županije, predstavnik sabora/Ministarstva zdravstva Republike Hrvatske

9:15-10:50

Panel rasprava 1:

PARTNERSTVO S ORGANIZACIJAMA OBOLJELIH

MODERATORI:

V. de Giorgis – A. Struk (5 min)

Uvod u temu panel rasprave:

A. Arzimanoglou: EpiCARE ERN (10 min)

I. Brambilla: ePAG (10 min)

Mirjana Huić: HTA (10 min)

Panel rasprava s predavačima i:

M. Malenica, F. Borovečki, D. Skoko Poljak (45 min)

Rasprava (10 min)

Zaključak (5 min)

10:50-11:10

Coffee break

11:10-12:45

Panel rasprava 2:

KAKO PRIRODNA POVIJEST BOLESTI MOŽE POMOĆI U POSTIZANJU RANE DIJAGNOZE I IDENTIFIKACIJI KOMORBIDITETA

MODERATORI:

L. Lagae – S. Bašić (5 min)

Uvod u temu panel rasprave:

B. Dalla Bernardina: Prirodna povijest bolesti (10 min)

I. Prpić: Postizanje rane dijagnoze i dijagnostičkih standarda (10 min)

F. Darra: Komorbiditeti povezani s rijetkim i kompleksnim epilepsijama (10 min)

Panel rasprava s predavačima i:

D. Sporiš, V. Šulentić, I. Vlašić-Cicvarić (45 min)

Rasprava (10 min)

Zaključak (5 min)

12:45-14:15

Pauza za ručak

**14:15-15:50 Panel rasprava 3:
TERAPIJSKI PRISTUPI LIJEČENJA RIJETKIH I KOMPLEKSNIH EPILEPSIJA**

MODERATORI:

A. Arzimanoglou – M. Malenica (5 min)

Uvod u temu panel rasprave:

L. Lagae: Pozicioniranje novih mogućnosti liječenja (10 min)

R. Nabbout: Monoterapija vs. politerapija u liječenju rijetkih i kompleksnih epilepsija (10 min)

V. de Giorgis: Dijetoterapija rijetkih i kompleksnih epilepsija (10 min)

Panel rasprava s predavačima i:

F. Darra, Ž. Petelin Gadže, V. Bibić (45 min)

Rasprava (10 min)

Zaključak (5 min)

15:50 -16:10 Coffee break

16:10-18:00 Satelitska predavanja farmaceutskih kuća

18:00 Zatvaranje internacionalne konferencije

Subota, 19. listopada 2024

Za nacionalne udruge oboljelih i njihove članove.

10:00-12:00 Panel rasprava 4: MOGUĆNOSTI I POSTIGNUĆA ORGANIZACIJA OBOLJELIH U HRVATSKOJ

MODERATORI:

A. Franjević – I. Prpić (5 min)

Panel rasprava s predavačima:

A. Sruk (Hrvatska udruga za epilepsiju),

I. Belina (Koalicija udruga u zdravstvu),

V. Zmazek (Debra),

F. Borovečki (Povjerenstvo za rijetke bolesti Ministarstva zdravstva Republike Hrvatske),

D. Skoko Poljak (Ministarstvo zdravstva Republike Hrvatske),

I. Bibić (Dravet sindrom Hrvatska) (1 h)

Rasprava (35 min)

Zaključak (15 min)

12:00 Ručak

13:00 Zatvaranje konferencije

14:00-17:00 Radionica: HTA (engl. Health Technology Assessment)

Nakon zatvaranja konferencije održat će se radionica o HTA (Health Technology Assessment), samo uživo, koja je otvorena i besplatna za zdravstvene djelatnike i predstavnike pacijenata (udruge).

Za prijave na radionicu, molimo Vas kontaktirajte:

info@dravet-sindrom-hrvatska.hr

LOKACIJA - Hotel Amphora 4*
Šetalište Pape Ivana Pavla II 51,
21000 Split

**SPONZORSKE
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PRELIMINARY PROGRAM

Thursday, October 17th, 2024

Arrival of the speakers by 7 pm and networking dinner

Friday, October 18th 2024

Introduction

9:00-09:15 **Welcome speech:**

Bibić Irena (Dravet syndrome Croatia), Prpić Igor (Scientific board of Dravet syndrome Croatia), representative of Split-dalmatian County, representative of the government/ Ministry of Health of Republic of Croatia

9:15-10:50 **Panel discussion 1: PATIENT PARTNERSHIP**

MODERATORS:

V. de Giorgis – A. Struk (5 min)

Short presentation of topics:

A. Arzimanoglou: EpiCARE ERN (10 min)

I. Brambilla: ePAG (10 min)

Mirjana Huić: HTA (10 min)

Panel discussion with speakers and:

M. Malenica, F. Borovečki, D. Skoko Poljak (45 min)

Discussion (10 min)

Conclusion (5 min)

10:50-11:10 **Coffee break**

11:10-12:45 **Panel discussion 2: HOW CAN NATURAL HISTORY HELP IN ACHIEVING EARLY DIAGNOSIS AND IDENTIFYING COMORBIDITIES**

MODERATORS:

L. Lagae – S. Bašić (5 min)

Short presentation of topics:

B. Dalla Bernardina: Natural history (10 min)

I. Prpić: How to achieve early diagnosis and diagnostic standards (10 min)

F. Darra: Comorbidities associated with rare and complex epilepsies (10 min)

Panel discussion with speakers and:

D. Sporiš, V. Šulentić, I. Vlašić-Cicvarić (45 min)

Discussion (10 min)

Conclusion (5 min)

12:45-14:15 **Lunch break**

**14:15-15:50 Panel discussion 3:
THERAPEUTIC APPROACHES FOR RARE AND COMPLEX EPILEPSIES**

MODERATORS:

A. Arzimanoglou – M. Malenica (5 min)

Short presentation of topics:

L. Lagae: Positioning of novel treatment options (10 min)

R. Nabbout: Monotherapy vs. polytherapy for treating drug-resistant epilepsies (10 min)

V. de Giorgis: Dietary therapy for rare and complex epilepsies (10 min)

Panel discussion with speakers and:

F. Darra, Ž. Petelin Gadže, V. Bibić (45 min)

Discussion (10 min)

Conclusion (5 min)

15:50 -16:10 Coffee break

16:10-18:00 Satellite lectures by pharmaceutical companies

18:00 Closing of the international conference

Saturday, October 19th, 2024

For national patient associations and their members.

**10:00-12:00 Panel discussion 4:
POSSIBILITIES AND ACHIEVEMENTS
OF PATIENT ORGANISATION IN CROATIA**

MODERATORS:

A. Franjević – I. Prpić (5 min)

Panel discussion with speakers:

A. Sruc (Croatian Association for Epilepsy),

I. Belina (Coalition of Association in Healthcare),

V. Zmazek (Debra),

F. Borovečki (Committee for rare diseases of the Ministry of Health),

D. Skoko Poljak (Ministry of Health of Republic of Croatia),

I. Bibić (Dravet syndrome Croatia) (1 h)

Discussion (35 min)

Conclusion (15 min)

12:00 Lunch

13:00 Closing of the conference

14:00-17:00 Workshop: HTA (Health Technology Assessment)

A workshop in Croatian about HTA (Health Technology Assessment) will be held only in person after the closing of the Conference. Workshop is open and free of charge for healthcare professionals and patient representatives.

To register for the workshop, please contact:

info@dravet-sindrom-hrvatska.hr

LOCATION - Hotel Amphora 4*

Address: Šetalište Pape Ivana Pavla II 51,
21000 Split, Croatia



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