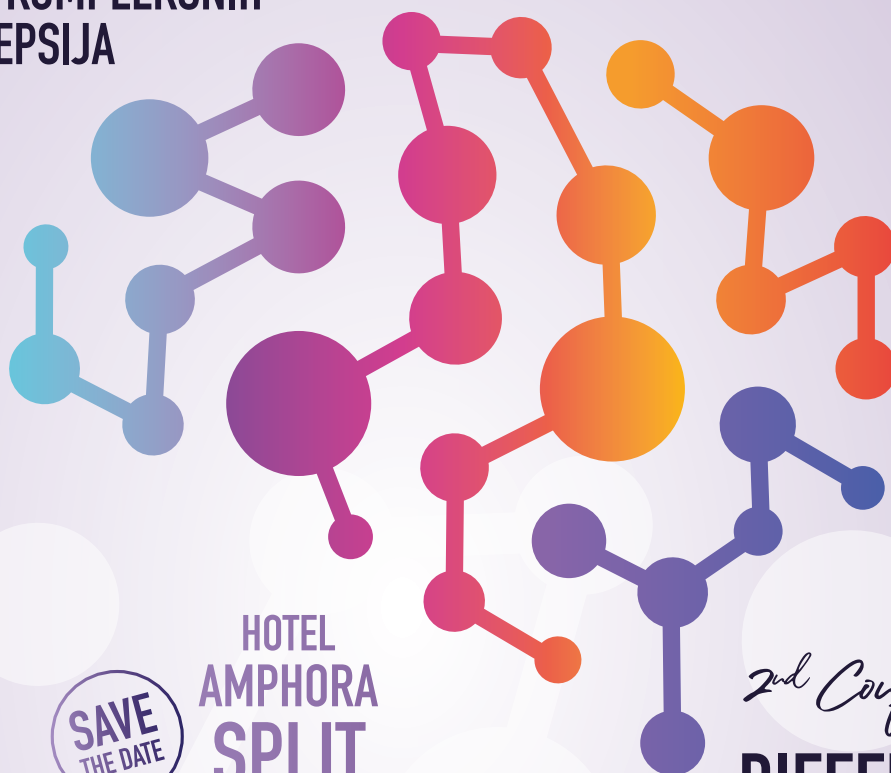


*2. konferencija*

# 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

### SPONZORSKE MOGUĆNOSTI

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# PISMO DOBRODOŠLICE

Zadovoljstvo nam je najaviti drugu konferenciju, **RAZLIČITA LICA RIJETKIH I KOMPLEKSNIH EPILEPSIJA** koja se održava u **Splitu, Hrvatska** od **četvrtka 17. listopada do subote 19. listopada 2024. godine**.

Pozivamo vas da svojim prisustvom predstavite svoju tvrtku te putem vašeg zagovornika upoznate sudionike o ulozi i mogućnostima i perspektivama vaše tvrtke u liječenju epilepsija.

**Organizatori Konferencije** su:

1. Udruga Dravet sindrom Hrvatska, član ePAG ERN EpiCARE-a
2. Referentni centar Ministarstva zdravstva Republike Hrvatske za epilepsiju i konvulzivne bolesti razvojne dobi
3. Referentni centar Ministarstva zdravstva Republike Hrvatske za epilepsiju, pridruženi član ERN EpiCARE-a
4. Referentni centar Ministarstva zdravstva Republike Hrvatske za predoperativnu obradu bolesnika s farmakorezistentnom epilepsijom
5. KBC Sestre milosrdnice, Klinika za pedijatriju, Odjel za dječju neurologiju, pridruženi član ERN EpiCARE-a

Konferencija se održava uz pokroviteljstvo Europske Referentne Mreže za rijetke i kompleksne epilepsije, ERN EpiCARE-a, sufinancirana od strane Europske Unije, Ministarstva zdravstva Republike Hrvatske i Splitsko-dalmatinske županije, te u suradnji s Hrvatskom ligom protiv epilepsije i Hrvatskom udrugom za epilepsiju.

Ova konferencija ima za cilj potaknuti razmjenu znanja i produktivne rasprave o rijetkim i kompleksnim epilepsijama. Usredotočeni smo na najnovija istraživanja kao i napredak u metodama dugotrajnog liječenja. Cilj nam je pridonijeti većoj vidljivosti ovih bolesti, te pomoći oboljelima i njihovim obiteljima da izađu iz sjene.

Udruga Dravet sindrom Hrvatska ovom Konferencijom obilježava svoju desetu obljetnicu postojanja. Svojim aktivnostima, već deset godina, odražavamo glasove roditelja/skrbnika djece i odraslih osoba s rijetkim i kompleksnim epilepsijama, zagovarajući njihove interese i podižući svijest o problemima koje donosi ovakva dijagnoza. Kao roditelji/skrbnici oboljelih od rijetkih i kompleksnih epilepsija inzistiramo na otvorenom dijalogu između struke, državnih institucija i udruga oboljelih na korist oboljelih i njihovih obitelji.

Ugledni međunarodni stručnjaci, uz nacionalne stručnjake za epilepsiju, vodit će četiri panel rasprave, pružajući sudionicima sveobuhvatan uvid u suradnju s udrugama oboljelih, prirodnu povijest bolesti, komorbiditete i najsuvremenije pristupe liječenju. Ovaj forum potiče otvoreni dijalog i razmjenu iskustava, potičući rast u području neurologije.

Osim znanstvenog doprinosa, drugi dan skupa naglašava ključnu ulogu nacionalne suradnje liječnika i udruga oboljelih. Ovaj duh suradnje služi kao vitalni temelj za postizanje naših zajedničkih ciljeva.

Vaša velikodušna podrška doprinosi našoj zajedničkoj misiji, uspješnom liječenju oboljelih od epilepsija uz sve ostale dodatne pogodnosti. Od sveg srca cijenimo doprinose naših sponzora i govornika te potičemo sve da aktivno sudjeluju u ovoj konferenciji. Zajedno možemo značajno promijeniti živote oboljelih od rijetkih i kompleksnih epilepsija i njihovih obitelji.

**Irena Bibić**

Predsjednica Udruge  
Dravet sindrom Hrvatska

# WELCOMING LETTER

It is our pleasure to announce the second conference titled **DIFFERENT FACES OF RARE AND COMPLEX EPILEPSIES**, that will be held in **Split, Croatia** from **Thursday 17<sup>th</sup> to Saturday 19<sup>th</sup> of October 2024**.

We invite you to present your company and, through your representatives, inform the participants about the roles, possibilities and perspectives of your company in the epilepsy treatment field.

**The organizers of the conference are:**

1. Association Dravet Syndrome Croatia, Member of the ePAG ERN EpiCARE
2. Reference centre of the Ministry of Health of the Republic of Croatia for epilepsy and convulsive diseases of developmental age
3. Reference centre of the Ministry of Health of the Republic of Croatia for epilepsy, Affiliated Member of the ERN EpiCARE
4. Reference centre of the Ministry of Health of the Republic of Croatia for preoperative treatment of patients with pharmacoresistant epilepsy
5. KBC Sestre milosrdnice, Clinic for Paediatrics, Department of Paediatric Neurology, Affiliated Member of the ERN EpiCARE

The conference is held under the endorsement of European Reference Network for Rare and Complex Epilepsies, ERN EpiCARE, co-funded by the European Union, the Ministry of Health of the Republic of Croatia and the Split-Dalmatia County, and in cooperation with the Croatian League against Epilepsy and the Croatian Association for Epilepsy.

This conference aims to encourage knowledge sharing and productive discussions on rare and complex epilepsies. We are focused on the latest research and advances in long-term treatment methods. Our goal is to contribute to greater visibility of these diseases, and to help patients and their families to come out of the shadows.

The association Dravet Syndrome Croatia celebrates its tenth anniversary with this conference. With our activities, for ten years now, we have been reflecting the voices of parents/caregivers about the children and adults with rare and complex epilepsies, advocating for their interests and raising awareness of the issues brought by these diagnoses. As parents/caregivers of patients with rare and complex epilepsies, we insist on an open dialogue between the profession, state institutions and patient associations for the benefit of patients and their families.

Reputable international experts, along with national experts in epilepsy, will lead four panel discussions, providing participants with a comprehensive insight into cooperation with patient associations, the natural history of the disease, comorbidities and the most up-to-date approaches to treatment. This forum encourages open dialogue and exchange of experiences, encouraging growth in the field of neurology.

In addition to scientific contribution, the second day of the conference emphasizes the key role of national cooperation between physicians and patient associations. This spirit of cooperation serves as a vital foundation for achieving our common goals.

Your generous support contributes to our common mission, the successful treatment of epilepsy patients with all other additional benefits. We wholeheartedly appreciate the contributions of our sponsors and speakers and encourage everyone to actively participate in this conference. Together, we can significantly change the lives of patients with rare and complex epilepsies and their families.

**Irena Bibić**

President of the Association  
Dravet syndrome Croatia

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# PRELIMINARNI PROGRAM

## Četvrtak, 17. listopada 2024

Dolazak predavača do 19 h i zajednička večera

## Petak, 18. listopada 2024

Uvod

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### 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

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### 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)

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

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### 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)

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### 12:45-14:15 Pauza za ručak

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**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)

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**15:50 -16:10 Coffee break**

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**16:10-18:00 Satelitska predavanja farmaceutskih kuća**

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**18:00 Zatvaranje internacionalne konferencije**

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## Subota, 19. listopada 2024

Za nacionalne udruge oboljelih i njihove članove.

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**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)

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**12:00 Ručak**

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**13:00 Zatvaranje konferencije**

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**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](mailto:info@dravet-sindrom-hrvatska.hr)

**LOKACIJA** - Hotel Amphora 4\*

Šetalište Pape Ivana Pavla II 51,

21000 Split

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# PRELIMINARY PROGRAM

## Thursday, October 17<sup>th</sup>, 2024

Arrival of the speakers by 7 pm and networking dinner

## Friday, October 18<sup>th</sup> 2024

Introduction

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### 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

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### 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)

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

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### 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)

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

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**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)

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**15:50 -16:10 Coffee break**

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

**18:00 Closing of the international conference**

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## Saturday, October 19<sup>th</sup>, 2024

For national patient associations and their members.

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**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. Srak** (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)

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**12:00 Lunch**

**13:00 Closing of the conference**

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**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](mailto:info@dravet-sindrom-hrvatska.hr)

**LOCATION** - Hotel Amphora 4\*

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



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# KATEGORIJE SPONZORSTAVA

Dobit ćete status kategorije podrške ovisno o ukupnom iznosu vaše potpore. Imat ćete koristi od izvanrednih prednosti povezanih s vašom kategorijom. Status će biti dodijeljen na sljedeći način:

## SPONZORSKI PAKETI

### DIJAMANTNI SPONZOR, EUR 15.000,00 + PDV

- sponzorirano predavanje 30 minuta
- izložbeni prostor 6 m<sup>2</sup>
- 8 kotizacije za predstavnike tvrtke ili goste
- 2 oglasne stranice u finalnom programu
- objava logotipa na službenoj web stranici
- objava logotipa u finalnom programu
- umetak u kongresne torbe (do 6 umetaka)
- objava logotipa na roll up banneru koji će biti izložen za vrijeme trajanja konferencije
- puštanje reklame u dvorani na platnu u pauzama od predavanja (5 puštanja)
- mogućnost izrade online izlagačkog prostora na online platformi koji može uključivati do 4 PDF brošure + video reklamu
- logotip prikazan na pozadini ekrana tijekom konferencije
- najava sponzoriranog predavanja prije početka konferencije putem newslettera na bazu registriranih sudionika

### PLATINASTRI SPONZOR, EUR 12.500,00 + PDV

- sponzorirano predavanje 20 minuta
- izložbeni prostor 4 m<sup>2</sup>
- 6 kotizacija za predstavnike tvrtke ili goste
- 2 oglasne stranice u finalnom programu
- objava logotipa na službenoj web stranici
- objava logotipa u finalnom programu
- umetak u kongresne torbe (do 4 umetka)
- objava logotipa na roll up banneru koji će biti izložen za vrijeme trajanja konferencije
- puštanje reklame u dvorani na platnu u pauzama od predavanja (4 puštanja)
- mogućnost izrade online izlagačkog prostora na online platformi koji može uključivati do 4 PDF brošure + video reklamu
- najava sponzoriranog predavanja prije početka konferencije putem newslettera na bazu registriranih sudionika

### ZLATNI SPONZOR, EUR 10.000,00 + PDV

- sponzorirano predavanje 15 minuta
- izložbeni prostor 4m<sup>2</sup>
- 4 kotizacija za predstavnike tvrtke ili goste
- 1 oglasna stranice u finalnom programu
- objava logotipa na službenoj web stranici
- objava logotipa u finalnom programu
- umetak u kongresne torbe (do 3 umetka)
- objava logotipa na roll up banneru koji će biti izložen za vrijeme trajanja konferencije
- puštanje reklame u dvorani na platnu u pauzama od predavanja (3 puštanja)
- mogućnost izrade online izlagačkog prostora na online platformi koji može uključivati do 3 PDF brošure + video reklamu
- najava sponzoriranog predavanja prije početka konferencije putem newslettera na bazu registriranih sudionika



# SPONSORSHIP CATEGORIES

You will receive support category status depending on the total amount of your support. You will benefit from the outstanding benefits associated with your category. Status will be assigned as follows:

## SPONSORSHIP PACKAGES

### DIAMOND SPONSOR, EUR 15,000.00 + VAT

- sponsored lecture 30 minutes
- exhibition space 6 m<sup>2</sup>
- 8 registration fees for company representatives or guests
- 2 advertisement pages in the final program
- publication of the logo on the official website
- publication of the logo in the final program
- insert in congress bags (up to 6 inserts)
- publication of the logo on the roll up banner that will be displayed during the conference
- playing commercials in the hall on the screen during breaks from lectures (5 plays)
- the possibility of creating an online exhibition space on an online platform that can include up to 4 PDF brochures + a video advertisement
- logo displayed on the background of the screen during the conference
- announcement of a sponsored lecture before the start of the conference through a newsletter based on registered participants

### PLATINUM SPONSOR, EUR 12,500.00 + VAT

- sponsored lecture 20 minutes
- exhibition space 4 m<sup>2</sup>
- 6 registration fees for company representatives or guests
- 2 advertisement pages in the final program
- publication of the logo on the official website
- publication of the logo in the final program
- insert in congress bags (up to 4 inserts)
- publication of the logo on the roll up banner that will be displayed during the conference
- playing commercials in the hall on the screen during breaks from lectures (4 plays)
- the possibility of creating an online exhibition space on an online platform that can include up to 4 PDF brochures + a video advertisement
- announcement of a sponsored lecture before the start of the conference through a newsletter based on registered participants

### GOLD SPONSOR, EUR 10,000.00 + VAT

- sponsored lecture 15 minutes
- exhibition space 4m<sup>2</sup>
- 4 registration fees for company representatives or guests
- 1 advertisement page in the final program
- publication of the logo on the official website
- publication of the logo in the final program
- insert in congress bags (up to 3 inserts)
- publication of the logo on the roll up banner that will be displayed during the conference
- playing commercials in the hall on the screen during breaks from lectures (3 plays)
- the possibility of creating an online exhibition space on an online platform that can include up to 3 PDF brochures + a video advertisement
- announcement of a sponsored lecture before the start of the conference through a newsletter based on registered participants

## SREBRNI SPONZOR, EUR 7.500,00 + PDV

- sponzorirano predavanje 10 minuta
- izložbeni prostor 4m<sup>2</sup>
- 2 kotizacija za predstavnike tvrtke ili goste
- 1 oglasna stranice u finalnom programu
- objava logotipa na službenoj web stranici
- objava logotipa u finalnom programu
- umetak u kongresne torbe (do 2 umetka)
- objava logotipa na roll up banneru koji će biti izložen za vrijeme trajanja konferencije
- puštanje reklame u dvorani na platnu u pauzama od predavanja (2 puštanja)
- mogućnost izrade online izlagačkog prostora na online platformi koji može uključivati do 2 PDF brošure + video reklamu
- najava sponzoriranog predavanja prije početka konferencije putem newslettera na bazu registriranih sudionika

## SPONZOR, EUR 5.000,00 + PDV

- 1 kotizacija za predstavnike tvrtke ili goste
- objava logotipa na službenoj web stranici
- objava logotipa u finalnom programu
- umetak u kongresne torbe
- objava logotipa na roll up banneru koji će biti izložen za vrijeme trajanja konferencije
- puštanje reklame u dvorani na platnu u pauzama od predavanja (1 puštanje)

## POSEBNI ZAHTIJEVI

Paketi po mjeri mogu se organizirati prema vašim ciljevima. slobodno se obratite agenciji za tehničku organizaciju konferencije: [ivana@conventuscredo.hr](mailto:ivana@conventuscredo.hr)

### **MOLIMO VAS DA REZERVACIJU SPONZORSTVA POŠALJETE NA:**

Ivana Marković

[ivana@conventuscredo.hr](mailto:ivana@conventuscredo.hr)

Conventus Credo d.o.o.

T +385 1 4854697

### **NAČIN PLAĆANJA**

Molimo Vas da uplatu sponzorstva izvršite na:

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IBAN: HR5324840081103726602

Raiffeisen bank Austria d.d. Zagreb, Petrinjska 59, 10 000 Zagreb, Croatia

SWIFT: RZBHHR2X

### **UVJETI OTKAZIVANJA SPONZORSTVA**

Organizator će zadržati:

50 % ugovorenog iznosa ako se otkazivanje dogodi 30 dana prije održavanja konferencije. 100 % ugovorenog **iznosa** ako se otkazivanje dogodi u vremenskom periodu manjem od 30 dana prije održavanja konferencije.

## SILVER SPONSOR, EUR 7,500.00 + VAT

- sponsored lecture 10 minutes
- exhibition space 4m<sup>2</sup>
- 2 registration fees for company representatives or guests
- 1 advertisement page in the final program
- publication of the logo on the official website
- publication of the logo in the final program
- insert in congress bags (up to 2 inserts)
- publication of the logo on the roll up banner that will be displayed during the conference
- playing commercials in the hall on the screen during breaks from lectures (2 plays)
- the possibility of creating an online exhibition space on an online platform that can include up to 2 PDF brochures + a video advertisement
- announcement of a sponsored lecture before the start of the conference through a newsletter based on registered participants

## SPONSOR, EUR 5,000.00 + VAT

- 1 registration fee for company representatives or guests
- publication of the logo on the official website
- publication of the logo in the final program
- insert in congress bags
- publication of the logo on the roll up banner that will be displayed during the conference
- playing commercials in the hall on the screen during breaks from lectures (1 play)

## SPECIAL REQUIREMENTS

Tailor-made packages can be arranged according to your goals. Feel free to contact the agency for the technical organization of the conference: [ivana@conventuscredo.hr](mailto:ivana@conventuscredo.hr)

### PLEASE SEND THE SPONSORSHIP RESERVATION TO:

Ivana Marković

[ivana@conventuscredo.hr](mailto:ivana@conventuscredo.hr)

Conventus Credo d.o.o.

T +385 1 4854697

### METHOD OF PAYMENT

Please make the sponsorship payment to:

Conventus Credo d.o.o.

IBAN: HR5324840081103726602

Raiffeisen bank Austria d.d. Zagreb, Petrinjska 59, 10 000 Zagreb, Croatia

SWIFT: RZBHHR2X

### SPONSORSHIP CANCELLATION CONDITIONS

The organizer will keep:

50% of the agreed amount if the cancellation occurs 30 days before the conference.

100% of the agreed amount if the cancellation occurs less than 30 days before the conference.



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EPILEPSIJA



SAVE  
THE DATE

HOTEL  
AMPHORA  
SPLIT  
17.-19.10.2024

*2nd Conference*  
**DIFFERENT  
FACES**  
OF RARE AND COMPLEX  
EPILEPSIES