

1. Konferencija RAZLIČITA LICA DRAVET SINDROMA



1st Conference DIFFERENT FACES OF DRAVET SYNDROME

7. - 9. 11. 2019. / Split - CROATIA





POKROVITELJ
MINISTARSTVO ZDRAVSTVA REPUBLIKE HRVATSKE
UNDER THE AUSPICES
MINISTRY OF HEALTH OF THE REPUBLIC OF CROATIA

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1. Konferencija
**RAZLIČITA LICA
DRAVET SINDROMA**

1st Conference
**DIFFERENT FACES
OF DRAVET SYNDROME**

Prva konferencija o Dravet sindromu **RAZLIČITA LICA DRAVET SINDROMA**



Dravet sindrom ne predstavlja samo jedan od epileptičkih sindroma, već u sebi uključuje niz dodatnih, pridruženih poremećaja koji se ne odražavaju samo simptomima središnjeg živčanog sustava. Učestali su psihijatrijski i psihosocijalni poremećaji uz poremećaje ponašanja i spavanja, kao i poremećaje hodanja i abnormalnosti srčanog ritma.

Velik broj dječjih i adultnih neurologa kao i liječnici i stručnjaci drugih specijalnosti (ortopedi, psihijatri, radni terapeuti, logopedi itd.) uključeni su u skrb pacijenata s Dravet sindromom. Cilj cjelokupne skrbi za oboljele od Dravet sindroma je optimalan pristup u liječenju, poboljšavajući kvalitetu života pacijenata i njihovih obitelji. Stoga je potrebna aktivna suradnja kao i izmjena i znanja i iskustva svih stručnjaka, što je osnovna nakana ovog skupa.

Stoga, glavni je cilj konferencije razotkriti “Različita lica Dravet sindroma”. Ovaj skup obuhvaća, osim plenarnih sjednica i okruglih stolova, nekoliko glavnih tema kao što su genetički spektar Dravet sindroma, terapija i liječenje, komunikacija između stručnjaka i roditelja te najnovija izvješća kliničkih istraživanja. Nadamo se da ćemo omogućiti svim sudionicima priliku okupljanja i rasprave o novim saznanjima o Dravet sindromu, jačajući mrežu s kolegama istraživačima, kliničarima, ostalima stručnjacima te roditeljima koji su temelj u skrbi osoba s Dravet sindromom.

Split je grad bogate kulturne povijesti s toplom i opuštajućom atmosferom.

Radujemo se Vašem dolasku na ovaj skup!

U ime znanstvenog odbora,
Prof. dr. sc. Igor Prpić, dr. med.



First Conference about Dravet syndrome

DIFFERENT FACES OF DRAVET SYNDROME

Dravet syndrome is much more than an epilepsy syndrome. Patients with Dravet syndrome present a spectrum of both neurological and non-neurological symptoms. Disorders such as intellectual disability, autism spectrum disorders, behaviour and sleep problems are frequently reported, combined with non-neurological ones including gait disorders and cardiac rhythm abnormalities.

A large number of paediatric and adult neurologists, but also other specialists (orthopedists, psychiatrist, occupational and speech therapy, etc.) are involved in the care of patients with such complex diseases as the Dravet syndrome. In order to offer optimal therapeutic options, improving the patient's and family's quality of life, the necessity of interaction and collaboration in the highest level must be met accordingly. It is the highlight of this Conference.

Therefore the main goal of the Conference is to elucidate the "Different faces of Dravet syndrome". This Conference will cover, in plenary sessions and round tables, several major topics such as the genetic spectrum of Dravet syndrome, real life therapy and treatment, communication between professionals and parents associations as well as the latest evidence from clinical trials.

We hope to give all participants the chance to gather and discuss the latest developments in basic and clinical spectra of Dravet syndrome, strengthening the network with fellow researchers, clinicians and other health care practitioners and parents.

Split is a culturally rich city with a warm and relaxed atmosphere. We look forward to welcoming you at the Conference.

On behalf of Scientific Committee
Prof. Igor Prpić, MD, PhD



ČETVRTAK / THURSDAY, 7.11.2019. - PRVI DAN / DAY 1

9:00-9:15 OTVORENJE KONFERENCIJE - POZDRAVNI GOVOR /
OPENING OF THE CONFERENCE - WELCOME SPEECH

Dravet sindrom – od rane encefalopatije do sindroma / Dravet Syndrome – from early encephalopathy to syndrome

Moderatori / Moderators:

M.Malenica, B.Dalla Bernardina, I.Prpić

- 9:15-9:45 (30') CHARLOTTE DRAVET
POVIJEST DRAVET SINDROMA /
THE HISTORY OF DRAVET SYNDROME
- 9:45-10:15 (30') BERNARDO DALLA BERNARDINA
KLINIČKA SLIKA DRAVET SINDROMA /
CLINICAL PRESENTATION OF TYPICAL DRAVET
- 10:15-10:45(30') FRANCESCA DARRA
EEG OD DJEČJE DO ODRASLE DOBI /
EEG FROM INFANT TO ADULTHOOD
- 10:45-11:00 (15') RASPRAVA / DISCUSSION
- 11:00-11:15 (15') STANKA UZ OSVJEŽENJE / COFFEE BREAK

Genske mutacije u Dravet sindromu / Genetic mutations in Dravet syndrome

Moderatori / Moderators: F.Borovečki, T.Granata, R.Guerrini

- 11:15-11:45 (30') MASSIMO MANTEGAZZA
MUTACIJE SCN1A / NAV1.1: MEHANIZMI
IDENTIFICIRANI U EKSPERIMENTALNIM MODELIMA /
SCN1A/NAV1.1 MUTATIONS: MECHANISMS
IDENTIFIED IN EXPERIMENTAL MODELS
- 11:45-12:15 (30') DAVIDE MEI
PREDIKVITNA VRIJEDNOST SCN1A /
PREDICT VALUE OF SCN1A
- 12:15-12:45 (30') FRAN BOROVEČKI
GENETIČKA ANALIZA U HRVATSKOJ /
GENETIC ANALYSIS IN CROATIA
- 12:45-13:00 (15') RASPRAVA / DISCUSSION
- 13:00-14:30 LUNCH / RUČAK



**Klinička, kognitivna i bihevioralna ekspresija Dravet sindroma/
Clinical, cognitive and behavioral expression of Dravet syndrome**

Moderatori / Moderators: S. Bašić, L. Lagae, N. Specchio

- 14:30-15:00 (30')** CATHERINE CHIRON
PREGLED KOGNITIVNIH I BIHEVIORALNIH STUDIJA I
REZULTATI U DRAVET SINDROMU TIJEKOM GODINA /
REVIEW OF THE COGNITIVE AND BEHAVIORAL
STUDIES AND RESULTS IN DRAVET SYNDROME
ACROSS AGES
- 15:00-15:30 (30')** DOMENICA BATTAGLIA
NEUROPSIHIJATRIJSKI PROFIL U DRAVET SINDROMU:
OD DJEČJE DOBI DO ODRASLE DOBI /
NEUROPSYCHOLOGICAL PROFILE IN DRAVET
SYNDROME: FROM CHILDHOOD TO ADOLESCENCE
- 15:30-16:00 (30')** ALESSANDRA DEL FELICE
ANALIZA MOTORNIH VJEŠTINA I HODA /
MOTOR SKILLS AND GAIT ANALYSIS
- 16:00-16:30 (30')** IGOR PRPIĆ
KOMORBIDITET: POTREBE RODITELJA - HRVATSKA
PERSPEKTIVA / COMORBIDITY: PARENTS NEEDS -
CROATIAN PERSPECTIVE
- 16:30-16:45 (15')** RASPRAVA / DISCUSSION

**Prepoznavanje potreba i podrška obitelji /
Recognition of needs and family centered approach**

Moderatori / Moderators: I. Belina, I. Brambilla

- 16:45-17:45 (60')** FRANCESCA RAGONA; SLAVEN PIKIJA;
INGE VLAŠIĆ – CICVARIĆ
- 17:45-18:00 (15')** RASPRAVA / DISCUSSION
ZAVRŠETAK PRVOG DANA /
CONCLUSION OF THE FIRST DAY
- 20:00-23:00** SVEČANI PRIJEM / OPENING CEREMONY
KAVANA LUXOR, Kraj Sv. Ivana 14



PETAK / FRIDAY, 8.11.2019. - DRUGI DAN, DAY 2

8:30 UVODNA RIJEČ / WELCOME SPEECH

Tijek Dravet sindroma i mogućnosti liječenja i tretmana / Course of Dravet syndrome and treatment options

Moderatori / Moderators: D.Battaglia, V.Đuranović, A.Sruk

8:30-9:00 (30') BERNARDO DALLA BERNARDINA; TIZIANA GRANATA
DUGOTRAJNI ISHOD DRAVET SINDROMA /
LONG TERM OUTCOME

9:00-9:45 (45') LEY SANDER
OTHER EPILEPTIC SYNDROMES WITH SCN1A MUTATIONS /
SRODNI EPILEPTIČKI SINDROMI SA SCN1A MUTACIJOM
DRAVET IN ADULT NEUROLOGY PRACTICE /
DRAVET U ADULTNOJ NEUROLOGIJI

9:45-10:15 (30') NINA BARIŠIĆ
SUDEP - POTENCIJALNI MEHANIZMI I ŽIVOTNO
UGROŽAVAJUĆA STANJA U DRAVET SINDROMU KOJE
JE MOGUĆE PREVENIRATI / SUDEP – POTENTIAL
MECHANISMS AND LIFE THREATENING CLINICAL
CONDITIONS IN DRAVET SYNDROME IS PREVENTION POSSIBLE

10:15-10:30 (15') RASPRAVA / DISCUSSION

10:30-10:45 (15') STANKA UZ OSVJEŽENJE / COFFEE BREAK

Ishodi Dravet sindroma u stvarnom životu / Real life outcomes of Dravet syndrome

Okrugli stol - Adekvatna terapija Dravet sindroma /
Round table - Real life therapy

Moderatori / Moderators: C. Chiron, F.Darra, R.Kuzmanić Šamija


10:45-11:15 (30') NICOLA SPECCHIO

11:15-11:45 (30') LIEVEN LAGAE

11:45-12:15 (30') CATHERINE CHIRON
TRETMAN: DOKAZI IZ ISTRAŽIVANJA /
TREATMENT: EVIDENCE FROM TRIAL

12:15-12:30 (15') RASPRAVA / DISCUSSION

12:30-14:00 RUČAK / LUNCH



**Suradnja stručnih društava i udruga pacijenata /
Round table theme: cooperation of professional association
and association of patients**

Moderatori: T.Granata, S.Pikija, F.Darra

14:00-15:00 (60') ISABELLA BRAMBILLA; CHARLOTTE DRAVET;
ANA SRUK

15:00 -15:30 (30') ZAKLJUČAK KONFERENCIJE / CONCLUSION
ZATVARANJE KONFERENCIJE I DODJELA
CERTIFIKATA/ CLOSING OF THE CONFERENCE
AND DISTRIBUTION OF THE CERTIFICATES OF
ATTENDANCE

16:00-19:00 WORKSHOP BRANDING DRAVET PRESENTATION AND
OBJECTIVES
For Federation members only

20:00 Večera za predavače i goste (DSEF) /
Dinner for speakers and guests



Workshop Agenda - Split - November 8th and 9th 2019

Day 1

- 16:30** Introduction to the Workshop and Research Highlights
Presentation by José Filipe Torres, Bloom Consulting.
- 17:00** Session 1: Central Idea
Introduction to the task - Dravet Syndrome Brand Wheel©;
Objectives for the global Brand;
Definition of audiences and needs;
Teamwork and proposals;
> Evaluation and selection of Central Idea.
- 18:30** Wrap Up
Summary of the Session;
Main Conclusions;
Preparation for next session.

Day 2

- 08:30** Introduction to day 2 and validation of Central Idea
Presentation by José Filipe Torres, Bloom Consulting.
- 09:00** Session 2: Projects to Implement
Introduction to the task - Dravet Syndrome Spider Brand©;
Definition of projects to be developed globally and locally;
Teamwork and proposals.
- 10:30** Coffee Break
Informal Discussions
- 10:45** Session 3: Projects to Implement
Teamwork and proposals (conclusion)
Evaluation and Selection of final Projects for Brand
activation purposes on a 3 year plan
- 11:45** Wrap Up
Summary of the Session
Main Conclusions
Next Steps
- 13:00** End of Workshop



Our mission is to leverage cannabinoid science. We recognize the needs of patients and their caregivers and use these insights to guide our research programs.

GW Pharmaceuticals is committed to evaluating new treatment options in neurology, oncology and psychiatric illness.

**Committed to
making a difference**

GW Pharmaceuticals is a biopharmaceutical company developing novel medicines in a broad range of disease states.



Healthcare with
passion and **conviction**



NOVARTIS



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UDRUGA DRAVET SINDROM HRVATSKA / DRAVET ASSOCIATION CROATIA

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Dravet sindrom Europa Federacija / Dravet Syndrome European Federation

Hrvatsko društvo za dječju neurologiju / Croatian Society for Pediatric Neurology

Hrvatsko društvo za kliničku genetiku / Croatian Society for Clinical Genetics

Hrvatska liga protiv epilepsije / Croatian League Against Epilepsy

Referentni centar Ministarstva zdravlja za epilepsiju i konvulzivne bolesti razvojne dobi / Reference center of the Ministry of Health for epilepsy and convulsive developmental diseases

Hrvatska udruga za epilepsiju / Croatian Association for Epilepsy

Koalicija udruga u zdravstvu / Coalition of Associations in Healthcare

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