

9. JUGOVZHODNA EVROPSKA KONFERENCA O CISTIČNI FIBROZI

16. in 17. november 2018

Ljubljana, Slovenija



9TH SOUTH EAST EUROPE CYSTIC FIBROSIS CONFERENCE

16th and 17th november 2018

Ljubljana, Slovenia





Dogodek poteka pod častnim pokroviteljstvom
predsednika Republike Slovenije Boruta Pahorja.

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PROGRAM / PROGRAMME

Petek, 16. november 2018 / Friday, 16th november 2018

8.30-9.00 **REGISTRACIJA UDELEŽENCEV / REGISTRATION OF PARTICIPANTS**

9.00-9.30 **UVODNI POZDRAV / WELCOME**

Slavka Grmek Ugovšek – predsednica Društva za cistično fibrozo Slovenije
/ President of the Cystic Fibrosis Association of Slovenia

Jacquelien Noordhoek – predsednica Evropskega združenja za cistično
fibrozo / President of the Cystic Fibrosis Europe

CISTIČNA FIBROZA IN REDKE BOLEZNI V SLOVENIJI /
CYSTIC FIBROSIS AND RARE DISEASES IN SLOVENIA

9.30-10.00 **AKCIJSKI NAČRT DELA NA PODROČJU REDKIH BOLEZNI / ACTION PLAN IN THE FIELD OF RARE DISEASES, *Luca Lovrečič* (Sl: Slovenia)**

10.00-10.30 **FINANCIRANJE OBRAVNAVE REDKIH BOLEZNI V SLOVENIJI – DOSTOPNOST ZDRAVIL IN ŽIVIL ZA POSEBNE ZDRAVSTVENE NAMENE / FINANCING TREATMENT OF RARE DISEASES IN SLOVENIA – ACCESS TO MEDICINES AND DIETARY FOODS FOR SPECIAL MEDICAL PURPOSES, *Alenka Marič Cevzar* (Sl: Slovenia)**

10.30-11.00 **ODMOR / COFFEE**

11.00-11.30 **ETIČNE DILEME PRI ZDRAVLJENJU IN RAZISKAVAH OTROK IN OTROKOVE PRAVICE / ETHICAL DILEMMAS IN THE TREATMENT AND RESEARCH OF CHILDREN AND CHILD'S RIGHT, *Marjeta Terčelj* (Sl: Slovenia)**

11.30-13.00 **KOSILO / LUNCH**

ZGODNJA DIAGNOSTIKA IN STANDARDI OSKRBE / DETECTION AND STANDARDS OF CARE

13.00-13.45 EARLY DETECTION OF CYSTIC FIBROSIS AND EFFICIENT TREATMENT / ZGODNJE ODKRIVANJE CISTIČNE FIBROZE IN UČINKOVITO ZDRAVLJENJE, *Yasemin Gokdemir* (TR: Turkey)

13.45-14.15 SIGNIFICANCE OF A HOLISTIC TREATMENT OF PATIENTS WITH CYSTIC FIBROSIS / POMEN CELOSTNEGA ZDRAVLJENJE BOLNIKOV S CISTIČNO FIBROZO, *Trudy Havermans* (BE: Belgium)

14.15-14.45 TRANSITION FROM PEDIATRICS TO ADULT CARE FOR PEOPLE WITH CYSTIC FIBROSIS / PREHOD IZ PEDIATRIČNE NEGE V ODRASLO NEGO PRI LJUDEH S CISTIČNO FIBROZO, *Maya Kirszenbaum* (FR: France)

14.45-14.55 ZAGOTAVLJANJE CELOSTNE OBRAVNAVE BOLNIKOV S CISTIČNO FIBROZO S TRANZICIJO / HOLISTIC TREATMENT OF CYSTIC FIBROSIS PATIENTS INCLUDING TRANSITION, *Ana Kotnik Pirš* (Sl: Slovenia)

14.55-15.05 **ZAGOTAVLJANJE CELOSTNE OBRAVNAVE BOLNIKOV S CISTIČNO FIBROZO MED TRANZICIJO V ODRASLO DOBO** / HOLISTIC TREATMENT OF PATIENTS WITH CYSTIC FIBROSIS IN ADOLESCENCE DURING TRANSITION TO ADULT CARE, *Barbara Salobir* (SI: Slovenia)

15.05-15.15 **OSKRBA ODRASLIH BOLNIKOV S CISTIČNO FIBROZO – KLINIKA GOLNIK** / ADULT CYSTIC FIBROSIS PATIENT CARE – UNIVERSITY CLINIC GOLNIK, *Matjaž Fležar* (SI: Slovenia)

15.15-15.45 **BACTERIAL RESISTANCE TO ANTIBIOTICS IN THE LUNGS OF PATIENTS LIVING WITH CYSTIC FIBROSIS** / BAKTERIJSKA ODPORNOST NA ANTIBIOTIKE V PLJUČIH BOLNIKOV S CISTIČNO FIBROZO, *Emmanuel André* (BE: Belgium)

15.45-16.15 **ODMOR** / COFFEE

REGISTER ZA CISTIČNO FIBROZO IN KLINIČNE RAZISKAVE ZA CISTIČNO FIBROZO /
CYSTIC FIBROSIS REGISTRY AND CYSTIC FIBROSIS CLINICAL TRIALS

16.15-16.30 **REGISTER REDKIH NEMALIGNIH BOLEZNI** / REGISTRY FOR RARE NON-MALIGNANT DISEASES, *Eva Murko* (SI: Slovenia)

16.30-17.00 **THE EUROPEAN CYSTIC FIBROSIS SOCIETY PATIENT REGISTRY (ECFSPR)** / EVROPSKI REGISTER BOLNIKOV S CISTIČNO FIBROZO, *Jacqui van Rens* (BE: Belgium)

Sobota, 17. november 2018 / Saturday, 17th november 2018

CISTIČNA FIBROZA IN SOCIALNA VARNOST / CYSTIC FIBROSIS AND SOCIAL SECURITY

9.00-10.00 **WORKING TOWARDS LIVING A LIFE UNLIMITED BY CF / ZA ŽIVLJENJE, KI GA CF NE OMEJUJE**, *Sangeeta Enright* (UK: United Kingdom)

10.00-10.30 **ODMOR / COFFEE**

PREHRANA IN TELESNA VADBA / DIET AND PHYSICAL ACTIVITY

10.30-11.00 **TELESNA VADBA SLOVENSКИH BOLNIKOV S CISTIČNO FIBROZO – PREDSTAVITEV PILOTNEGA PROJEKTA DRUŠTVA / PHYSICAL EXERCISE OF SLOVENE CYSTIC FIBROSIS PATIENTS, PRESENTATION OF THE ASSOCIATION'S PILOT STUDY**, *Rok Bavdek* (SI: Slovenia)

11.00-11.30 **NUTRITION IN CYSTIC FIBROSIS / PREHRANA PRI CISTIČNI FIBROZI**, *Dimitri Declercq* (BE: Belgium)

DUŠEVNO ZDRAVJE / MENTAL HEALTH

11.30-12.00 PSYCHOLOGICAL SUPPORT TO PARENTS AND CHILDREN, FIRST TO PARENTS WHEN THEIR CHILD IS DIAGNOSED WITH CF AND THEN TO THE CF PATIENT THROUGH HIS ENTIRE LIFETIME, ALSO BEFORE TRANSPLANTATION / PSIHOLOŠKA PODPORA STARŠEM IN OTROKOM, NAJPREJ STARŠEM, KO JE NJIHOVEMU OTROKU POSTAVLJENA DIAGNOZA CF, IN POTEM BOLNIKU S CF V CELOTNEM ŽIVLJENJSKEM OBDOBJU, TUDI PRED PRESADITVIJO, *Samantha Phillips* (UK: United Kingdom)

12.00-12.30 EARLY DETECTION OF MENTAL VULNERABILITY AND ADEQUATE TREATMENT – A PATH TO A BETTER LIFE QUALITY OF CF PATIENTS AND A LONGER LIFE / ZGODNJE ODKRIVANJE DUŠEVNE RANLJIVOSTI IN USTREZNO ZDRAVLJENJE – POT K BOLJŠI KAKOVOSTI ŽIVLJENJA BOLNIKOV S CF IN DALJŠEMU ŽIVLJENJU, *Maya Kirszenbaum* (FR: France)

12.30-14.00 KOSILO / LUNCH


**OBVLADOVANJE OKUŽB PRI BOLNIKI S CISTIČNO FIBROZO /
MANAGING INFECTIONS OF CYSTIC FIBROSIS PATIENTS**

14.00-14.30 NEW OR OLD KIDS ON THE BLOCK: THE ROLE AND MANAGEMENT OF NON-TUBERCULOUS MYCOBACTERIA IN CYSTIC FIBROSIS / NOVI ALI STARI MULCI NA ULICI: VLOGA IN OBVLADOVANJE NETUBERKULOZNIH MIKOBAKTERIJ PRI CF, Bert Arets (NL: The Netherlands)

14.30-15.00 THE FUTURE STARTS TODAY: AN UPDATE ON THE ROLE OF INNOVATIVE DIAGNOSTIC AND THERAPEUTIC APPROACHES / PRIHODNOST SE ZAČNE DANES: ZADNJI IZSLEDKI O VLOGI INOVATIVNIH DIAGNOSTIČNIH IN TERAPEVTSKIH PRISTOPIH, Bert Arets (NL: The Netherlands)

15.00-15.30 ODMOR / COFFEE

15.30-17.00 MyCyFAPP – SELF MANAGEMENT APP FOR ENZYME INTAKE / MyCyFAPP – APLIKACIJA ZA POMOČ PRI JEMANJU ENCIMOV, Annabel Zettl (DE: Germany)



Pri organizaciji jugovzhodne evropske konference o cistični fibrozi so pomagali:
The following persons participated in the organization of the conference:

Hilde De Keyser

Slavka Grmek Ugovšek

Nataša Henigman

Mojca Hrvatin

Dragica Sajko

Uroš Sajko

Alja Klara Ugovšek

Sabina Ugovšek

Aljaž Ugovšek

Dragica Iskrenovič

Boštjan Čepelnik

Aljaž Hrvatin

Mauro Hrvatin

Marjeta Terčelj

Marija Špelič

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Pia Rener

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Nika Švigelj

Polona Drobnič

Maksima Oblak Trkov

Tanja Jambrovič

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Aleš Šubelj



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ki so pomagali pri izvedbi tega dogodka.

THANKS

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