



**9. JUGOVZHODNA EVROPSKA KONFERENCA O CISTIČNI FIBROZI**  
**9<sup>TH</sup> SOUTH EASTERN EUROPEAN CYSTIC FIBROSIS CONFERENCE**  
**Dvorana Krke / The Krka Hall, Dunajska 65, Ljubljana, Slovenija**

**PROGRAM / PROGRAMME**

**Petek, 16. november 2018 / Friday, 16<sup>th</sup> 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

*Jacqueline 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 Lovrečić* (SI: 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* (SI: 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* (SI: 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* (SI: 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)



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**PROGRAM / PROGRAMME**

**Sobota, 17. november 2018 / Saturday, 17<sup>th</sup> 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)