



9. JUGOVZHODNA EVROPSKA KONFERENCA O CISTIČNI FIBROZI
9TH SOUTH EASTERN EUROPEAN CYSTIC FIBROSIS CONFERENCE

Dvorana Krke / The Krka Hall, Dunajska 65, Ljubljana, Slovenija

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* (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 (ECFSR) / EVROPSKI REGISTER BOLNIKOV S CISTIČNO FIBROZO**, *Jacqui van Rens* (BE: Belgium)