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# *Invitation*

to

## **9<sup>TH</sup> SOUTH EASTERN EUROPEAN CYSTIC FIBROSIS CONFERENCE**

16<sup>th</sup> and 17<sup>th</sup> November 2018  
The Krka Hall, Dunajska 65,  
Ljubljana, Slovenija

The conference covers cystic fibrosis and other rare diseases in Slovenia as well as the usual diagnostic process of cystic fibrosis patients in the Western European countries. The conference is intended for doctors and other healthcare professionals who care for cystic fibrosis patients in their line of work or who wish to expand their knowledge on the subject, and for the patients in their families.

**The event is held under the patronage of  
the President of the Republic of Slovenia, Mr Borut Pahor.**

# PROGRAMME: Friday, 16<sup>th</sup> november 2018

**8.30-9.00 Registration of participants**

**9.00-9.30 Welcome**

Slavka Grmek Ugovšek – President of the Cystic Fibrosis Association of Slovenia  
Jacqueliën Noordhoek – President of the Cystic Fibrosis Europe

## Cystic Fibrosis and Rare diseases in Slovenia

**9.30-10.00 Action plan for the field of rare diseases**

Borut Peterlin – President of the Working Group on Rare Diseases at the Ministry of Health

**10.00-10.30 Financing of rare disease treatment in Slovenia - access to medicines and special nutritional preparations**

Alenka Marič Cevzar – Department of Medicines at the Health Insurance Institute of Slovenia

**10.30-11.00 COFFEE**

**11.00-11.30 Ethical dilemmas in the treatment and research of children and their rights**

Marjeta Terčelj Zorman - Member of the Commission for Medical Ethics at the Ministry of Health

**11.30-13.00 LUNCH**

## Detection and Standards of Care

**13.00-13.45 Early detection of Cystic Fibrosis and efficient treatment**

Yasemin Gokdemir (Turkey)

**13.45-14.15 Significance of holistic treatment of Cystic Fibrosis patients – multidisciplinary team, integral medical care for a cystic fibrosis patient the whole life through**

Trudy Havermans (BE)

**14.15-15.15 Transition**

Maya Kriszenbaum (FR)

**Providing up-to-date management of Cystic Fibrosis patients through transition**

Ana Kotnik Pirš, Barbara Salobir – University Medical Centre Ljubljana,  
Matjaž Fležar – University clinic Golnik

**15.15-15.45 Multiresistant bacteria in Cystic Fibrosis patients**

Emmanuel André (BE)

**15.45-16.15 COFFEE**

## Cystic Fibrosis Registry and Cystic fibrosis Clinical Trials

**16.15-16.30 National register for rare diseases**

Eva Murko – National institute of Public Health

**16.30-17.00 The European Cystic Fibrosis Registry**

Jacqui van Rens

# PROGRAMME: Saturday, 17<sup>th</sup> november 2018

## Cystic Fibrosis and Social Security

**9.00-10.00 Implementation of social security rights in practice – examples of good practice in Europe**

**Importance of special care and protection of a Cystic Fibrosis child and assistance in school**

**Employment possibilities of Cystic Fibrosis patients – part-time work**

Sangeeta Enright (UK)

**10.00-10.30 COFFEE**

## Diet and Physical Activity

**10.30-11.00 Physical exercise of Slovene Cystic Fibrosis patients – presentation of a pilot project**

Rok Bavdek – Cystic Fibrosis Association of Slovenia

**11.00-11.30 Cystic Fibrosis and Diet**

Dimitri Declercq (BE)

## Mental Health

**11.30-12.00 Psychological support to parents and children – first to parents when their child is diagnosed with Cystic Fibrosis and then to the Cystic Fibrosis patient through his entire lifetime, also before transplantation**

Samantha Philips (UK)

**12.00-12.30 Early detection of mental vulnerability and adequate treatment – a path to a better life quality of Cystic Fibrosis patients and a longer life**

Maya Kriszenbaum (FR)

**12.30-14.00 LUNCH**

## Managing infections of CF patients

**14.00-15.00 Innovative approaches – state of affairs**

**Infections with non-tuberculosis micobacteria – origin, transmission path, prevention, measures, treatment**

Bert Arets (NL)

**15.00-15.30 COFFEE**

**15.30-17.00 MyCyFAPP – self management app for enzyme intake**

Annabel Zettl (DE)

The event is moderated by **Saša Einsiedler, Pia Renner, Tea Žagar and Hilde De Keyser.**

The South Eastern European CF Conference will be conducted in Slovenian and English. Simultaneous interpretation will be provided.

The procedures of awarding credit points at the Medical Chamber of Slovenia and licensing points at the Chamber of Health Care and Midwives of Slovenia are pending.

The event is free, pre-registration is required. **Applications are requested until November 9<sup>th</sup>, 2018** or until the places are filled

<http://www.drustvocf.si/registration-form/>

The conference is supported by the following donors:



**triglav**



and other donors listed on the website of the CF Association.

<http://www.drustvocf.si/2018/10/16/evropska-konferenca-o-cisticni-fibrozi/>