

Agenda

3 April 2025

Day 1

Date: **03.04.2025**
 Time: **13:00 pm to 18.00 pm**
 Location: **Emerald Hotel**
 10000 Prishtina
 Str. Prishtina-Skopje highway, 5th km
 Kosovo

13:00-13:20 CONFERENCE OPENING - Welcome and introductions

Hilde De KEYSER, CFE
 Pavel DREVINEK, ECFS
 Vlora NIMANI, Republic of KOSOVO
 Atdhe RAMA, Republic of KOSOVO
 Irena KASMI, ALBANIA

Twinning Project - Part I

Chairs: Hilde De KEYSER, Pavel DREVINEK, Chris SMITH

Time 13:20- 14:15	Description	Speakers
13:20-13:40	Twinning project introduction	Pavel Drevinek , ECFS Standards of Care, Czech Republic Hilde De Keyser , Cystic Fibrosis Europe
13:40-14:00	Being a parent of a child with CF. How to be an impactful patient organization	Jacqueliën Noordhoek , Netherland
14:00-14:10	Learning package: Education learning platform of ECFS	Chris Smith , UK
14:10-14:20	Discussion / Q&A	
14:20-14:30	Coffee Break	

Twinning Project – Part II**Twinning project: Insights and testimonials***Chairs: Hilde De KEYSER, Pavel DREVINEK, Katarina STEPANKOVA*

Time 14:30- 16:10	Description	Speakers
14:30-14:40	Twinning project: Prishtina, Republic of KOSOVO and Utrecht, NETHERLAND	Vlora Nimani , Republic of Kosovo Marit van Oirschot, Marian Kruijswijk , Netherlands
14:40-14:50	Twinning project: Patient Org Republic of KOSOVO and Patient Org NETHERLAND	Atdhe Rama , Republic of Kosovo Jacqueline Noordhoek , Netherlands
14:50-15:00	Twinning project: Tirana, ALBANIA and Rome, ITALY	Fabio Majo , Italy Irma Tashi , Albania
15:00-15:10	Twinning project: Patient Org, ALBANIA and Patient Org, ITALY	Fjorza Mullaji , Albania
15:10-15:20	Twinning project: Skopje, NORTH MACEDONIA and Berlin, GERMANY	Valentina Cvejsna Cholakovska , North Macedonia
15:20-15:30	Twinning project: Kozle, NORTH MACEDONIA and Cambridge, UK	Tatyana Maretti , North Macedonia
15:30-15:40	Twinning project: Patient Org NORTH MACEDONIA and Patient Org GERMANY	TBD
15:40-15:50	Twinning project: Zagreb, CROATIA and Copenhagen, DENMARK	Duska Tjesic-Drinkovic , Croatia Andrea Vukic Dugac , Croatia
15:50-16:00	Twinning project: Patient Org, CROATIA and Patient Org, DENMARK	TBD
16:00-16:10	Discussion / Q&A	
16:10-16:30	Coffee Break	

Enhancing CF Care:
The Role of Standards of Care and CF Patient Registries

Chairs: Lutz NAEHRLICH, Marian KRUIJSWIJK, Katarina STEPANKOVA

Time 16:30- 18:00	Description	Speakers
16:30-16:45	European Standards of CF care: The importance of centralised care models	Marit van Oirschot, Marian Kruijswijk, Netherlands
16:45-17:00	ECFSR's role in advancing CF Care: Insights from the Balcan countries	Lutz Naehrlich, ECFSR
17:00-17:10	A Global Perspective: The State of CF Care in: Republic of KOSOVO	Vlora Nimani, Republic of Kosovo
17:10-17:20	A Global Perspective: The State of CF Care in: ALBANIA	Irena Kasmi, Tirana- ped. Irma Tashi, Tirana - adult
17:20-17:30	A Global Perspective: The State of CF Care in: NORTH MACEDONIA	Valentina Cvejosa Cholakovska, Skopje - ped. Tatyana Maretti, Kozle - adult
17:30-17:40	A Global Perspective: The State of CF Care in: CROATIA	Duska Tjesic-Drinkovic, Zagreb - ped. Andrea Vukic Dugac, Zagreb - adult
17:40-17:50	A Global Perspective: The State of CF Care in: MONTE NEGRO	Tomo Plamenac, Sladjana Radulovic, Podgorica, mix
17:50-18:00	Discussion / Q&A	

19:00 DINNER

Agenda

04 April 2025

Day 2

Date: **04 April 2025**
 Time: **9.30 am to 18.00 pm**
 Location: **Emerald Hotel**
 10000 Prishtina
 Str. Prishtina-Skopje highway, 5th km
 Kosovo

Managing Adults with CF: Strategies for Comprehensive care

Chairs: Malena COHEN-CYMBERKNOH, Andrea VUKIC DUGAC, Irma TASHI, Tanya MARETTI

Time 09:30- 11:20	Description	Speakers
09:30-09:50	Evolving Perspectives in Adult CF Management: A Multidisciplinary Approach	Malena Cohen-Cymerbknoh, Israel
09:50:10:05	Building an Adult CF Center: Key Steps for Success	Andrea Vukic Dugac, Croatia
10:05:10:20	Treating adults with CF in Albania	Irma Tashi, Albania
10:20-10:35	Transition from children to adult CF Center	Duska Tjesic-Drinkovic, Croatia
10:35-10:50	Fertility, pregnancy and breastfeeding in women with CF	Malena Cohen-Cymerbknoh, Israel
10:50-11:05	Discussion / Q&A	
11:05-11:20	Coffee Break	

Extrapulmonary involvement in CF

Chairs: Irena KASMI, Vlora NIMANI, Chris SMITH

Time 11:20- 13:00	Description	Speakers
11:20-11:40	Comprehensive management of gastrointestinal and other manifestations in CF, pre and post modulator therapy	Federico Alghisi, Italy
11:40-11:50	CF liver disease	Urata Efendija Beqa, Republic of KOSOVO
11:50-12:05	Nutrition of children and adult with CF - „Guidelines“	Chris Smith, UK
12:05-12:20	Key nutrition priorities	Chris Smith, UK

Time 11:20- 13:00	Description	Speakers
12:20-12:40	No Health Without Mental Health	Sonia Graziano, Italy
12:40-13:00	Discussion / Q&A	
13:00-13:40	Lunch	

Standard and advanced therapy in CF in the era of the CFTR modulators

Chairs: Pavel DREVINEK, Fabio MAJO, Vlora NIMANI

Time 13:40- 15:45	Description	Speakers
13:40-14:00	Innovative molecules in CF therapy	Pavel Drevinek, Czech Republic
14:00-14:15	HIT-CF project	Marlies Destoop, Netherland
14:15-14:35	Standard therapy of CF lung disease – pre and post modulators	Fabio Majo, Italy
14:35-14:45	Standard therapy of CF in Albania	Irena Kasmi, Albania
14:45-14:55	Standard therapy of CF in Kosovo	Vlora Nimani, Republic of Kosovo
14:55-15:05	Microbiology in CF	Yllka Begolli, Republic of Kosovo
15:05-15:20	Chest physiotherapy as an important part of CF lung disease treatment	Erik Hulzebos, Netherland
15:20-15:30	Prevalence of postural deviations in CF patients	Arian Selmani, North Macedonia
15:30-15:45	Discussion / Q&A	
15:45-16:00	Coffee Break	

WORKSHOPS

Time 16:00- 18:00	Description	Speakers
16:00-18:00	WORKSHOP 1: Twinning project POs representatives meeting	Chairs: Pavel Drevinek , Hilde de Keyser , Claire Francis , Jacqueline Noordhoek
16:00-18:00	WORKSHOP 2: Sweat test	Moderator: Lutz Naehrlich , ECFSPR
16:00-18:00	WORKSHOP 3: Airway Clearance techniques	Moderator: Erik Hulzebos , Netherland Marcella Burghard , Netherland

19:00 GALA DINNER



TWINNING EXPANSION PROJECT



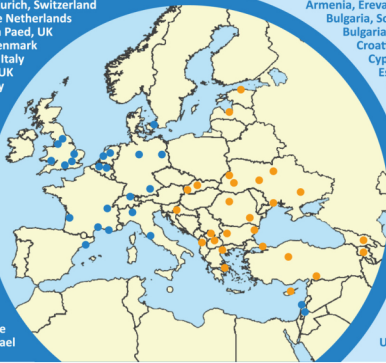
MENTORS

- Zurich, Switzerland
- Rotterdam, The Netherlands
- Southampton Paed, UK
- Copenhagen, Denmark
- Milan, Italy
- Cardiff, UK
- Hannover, Germany
- Southampton Adult, UK
- Utrecht, The Netherlands
- Bordeaux, France
- Cambridge, UK
- Berlin, Germany
- Leuven, Belgium
- Brussels, Belgium
- Leeds Adult, UK
- Barcelona, Spain
- Leeds Paed, UK
- Munich, Germany
- London, King's College, UK
- Marseille, France
- Petah Tikva, Israel
- London, Royal Brompton, UK
- Lyon, France
- Montpellier, France
- Jerusalem, Israel



MENTEES

- Albania, Tirana
- Armenia, Erevan Arabkir & Erevan Muratsan
- Bulgaria, Sofia
- Bulgaria, Varna
- Croatia, Zagreb
- Cyprus, Nicosia
- Estonia, Tallin & Tartu
- Georgia, Tbilisi
- Greece, Athens & Thessaloniki
- Kosovo, Pristina
- Latvia, Riga
- North Macedonia, Skopje
- Romania, Bucharest
- Romania, Cluj-Napoca
- Slovakia, Banska Bystrica
- Slovakia, Bratislava
- Turkey, Ankara Adult
- Turkey, Ankara Paed
- Turkey, Gaziantep
- Turkey, Istanbul
- Ukraine, Ivano-Frankivsk
- Ukraine, Kyiv
- Ukraine, Lviv
- Ukraine, Odessa
- Ukraine, Vinnitsia
- Ukraine, Zaporizhzhia



Agenda

05 April 2025

Day 3

Date: **05 April 2025**
Time: **09:30 pm to 13:30 pm**
Location: **Emerald Hotel**
10000 Prishtina
Str. Prishtina-Skopje highway, 5th km
Kosovo

Diagnosis of CF

Chairs: Lutz NAEHRLICH, Milan MACEK, Anila BABAMETO

Time 09:30- 11:10	Description	Speakers
09:30-09:50	The sweat test as an essential part of newborn screening and CF diagnosis	Lutz Naehrlich, ECFSPR
09:50-10:00	Early CF diagnosis a way for prognosis improvement - Indications for sweat test	Irena Kasmi, Albania
10:00-10:20	Genetics and CF – The importance of genotyping for modern therapies	Milan Macek, Czech Republic
10:20-10:30	Cystic fibrosis mutation testing in Albania and future challenges	Anila Babameto, Albania
10:30-10:40	Newborn screening – our experiences	Valentina Cvejosna Cholakovska, North Macedonia
10:40-10:50	Newborn screening in Kosovo	Shqipe Spahiu, Republic of Kosovo
10:50-11:10	CFSPID	Marlies Destoop, Netherland
11:10-11:20	Discussion / Q&A	
11:20-11:40	Coffee Break	

Multidisciplinary CF team

Chairs: Malena COHEN-CYMBERKNOH, Irena KASMI, Vlora NIMANI

Time 11:40- 13:30	Description	Speakers
11:40-11:50	Comprehensive care in CF – The role of the multidisciplinary team management	Malena Cohen-Cymerknoh, Israel
11:50-12:00	Role of the physician in CF team	Fabio Majo, Italy
12:00-12:10	Role of the CF nurse in CF team	Marit van Oirschot, Marian Kruijswijk, Netherlands
12:10-12:20	Role of the physiotherapist in CF team	Erik Hulzebos, Netherlands
12:20-12:30	Role of nutritionist in CF team	Chris Smith, UK
12:30-12:40	Role of psychologist in CF team	Sonia Graziano, Italy
12:40-12:50	Role of patients organisation in CF team - Being a parent of a child with CF	Jacqueline Noordhoek, Netherlands
12:50-13:10	Discussion / Q&A	

13:30 CONFERENCE CLOSING - Thank You!

Hilde De KEYSER, CF Europe
 Vlora NIMANI, Republic of Kosovo
 Atdhe RAMA, Republic of Kosovo