

# 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	Description	Speakers
13:20-14:25		
13:20-13:40	<b>Twinning project introduction</b>	<b>Pavel Drevinek</b> , ECFS Standards of Care, Czech Republic <b>Hilde De Keyser</b> , CEO of CF Europe
13:40-13:50	<b>Learning package: Education learning platform of ECFS</b>	<b>Chris Smith</b> , UK
13:50-14:20	<b>How to be an impactful patient organization</b>	<b>Jacqueliën Noordhoek</b> , CEO Dutch CF Foundation - Former President of CFE
14:20-14:30	<b>Discussion / Q&amp;A</b>	
14:30-14:40	<b>Coffee Break</b>	

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

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

**Enhancing CF Care:****The Role of Standards of Care and CF Patient Registries***Chairs: Lutz NAEHRLICH, Jacquelin NOORDHOEK, 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	ECFSPR's role in advancing CF Care: Insights from the Balcan countries	Lutz Naehrlich, ECFSPR
17:00-17:10	A Global Perspective: The State of CF Care in: Republic of KOSOVO	Vlora Nimani, Pristina, mix
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-Cymerberknoh, Andrea VUKIC DUGAC, Irma TASHI, Tanya MARETTI*

Time	Description	Speakers
09:30-11:00		
09:30-09:40	<b>Evolving Perspectives in Adult CF Management: A Multidisciplinary Approach</b>	Malena Cohen-Cymerberknoh, Israel
09:40:09:55	<b>Building an Adult CF Center: Key Steps for Success</b>	Andrea Vukic Dugac, Croatia
09:55-10:10	<b>Treating adults with CF in Albania</b>	Irma Tashi, Albania
10:10-10:25	<b>Transition from children to adult CF Center</b>	Duska Tjesic-Drinkovic, Croatia
10:25-10:45	<b>Fertility, pregnancy and breastfeeding in women with CF</b>	Malena Cohen-Cymerberknoh, Israel
10:45-11:00	<b>Discussion / Q&amp;A</b>	
11:00-11:15	<b>Coffee Break</b>	

### Extrapulmonary involvement in CF

*Chairs: Irena KASMI, Vlora NIMANI, Chris SMITH*

Time	Description	Speakers
11:15-13:00		
11:15-11:35	<b>Comprehensive management of gastrointestinal and other manifestations in CF, pre and post modulator therapy</b>	Federico Alghisi, Italy
11:35-11:45	<b>CF liver disease</b>	Urata Efendija Beqa, Republic of Kosovo
11:45-11:55	<b>Challenges in Treating CF Patients in Kosovo</b>	Vlora Ismaili-Jaha, Republic of Kosovo
11:55-12:10	<b>Nutrition of children and adult with CF - "Guidelines"</b>	Chris Smith, UK

Time 11:20- 13:00	Description	Speakers
12:10-12:25	<b>Key nutrition priorities</b>	Chris Smith, UK
12:25-12:45	<b>No Health Without Mental Health</b>	Sonia Graziano, Italy
12:45-13:00	<b>Discussion / Q&amp;A</b>	
13:00-13:40	<b>Lunch</b>	

### 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	<b>Innovative molecules in CF therapy</b>	Pavel Drevinek, Czech Republic
14:00-14:15	<b>HIT-CF project</b>	Marlies Destoop, Netherland
14:15-14:35	<b>Standard therapy of CF lung disease – pre and post modulators</b>	Fabio Majo, Italy
14:35-14:45	<b>Standard therapy of CF in Albania</b>	Irena Kasmi, Albania
14:45-14:55	<b>Standard therapy of CF in Kosovo</b>	Vlora Nimani, Republic of Kosovo
14:55-15:05	<b>Microbiology in CF</b>	Yllka Begolli, Republic of Kosovo
15:05-15:20	<b>Chest physiotherapy as an important part of CF lung disease treatment</b>	Erik Hulzebos, Netherland
15:20-15:30	<b>The role of Autogenetic Drainage on spirometry parameters in different ages of patients with CF</b>	Arian Selmani, North Macedonia
15:30-15:45	<b>Discussion / Q&amp;A</b>	
15:45-16:00	<b>Coffee Break</b>	

# WORKSHOPS

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

## 19:00 GALA DINNER



### TWINNING EXPANSION PROJECT




**MENTORS**

- Zurich, Switzerland
- Rotterdam, The Netherlands
- Southampton Paed, UK
- Copenhagen, Denmark
- Milano, Italy
- Cardiff, UK
- Hannover, Germany
- Southampton Adult, UK
- Utrecht, The Netherlands
- Bordeaux, France
- Cambridge, UK
- Berlin, Germany
- Leuven, Belgium
- Brussels, Belgium
- Manchester, UK
- Barcelona, Spain
- Leeds Adult, UK
- 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-Kozle
- 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	Description	Speakers
09:30-11:10		
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 genotypisation 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	Stojka Fushtikj, Skopje, 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-Cymerberknoh, Irena KASMI, Vlora NIMANI*

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

**13:30 CONFERENCE CLOSING** - Thank You!

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