



# OPENING ADDRESS

DEAR GUESTS,

Welcome to the **12th Southeastern European Cystic Fibrosis Conference**, organized with the support of CF Europe (CFE) and the European Cystic Fibrosis Society (ECFS), as part of the Twinning Expansion Project, and in partnership with the Association for persons with cystic fibrosis in Kosovo.

The Twinning Expansion Project fosters collaboration between well-established patient organizations and those in need of support or specialized training. Through both in-person and online knowledge exchange, this initiative helps address specific needs within the cystic fibrosis (CF) community.

Now this project aims to build strong partnerships between leading CF centers and those striving to develop their expertise, with the ultimate goal of improving CF patient care across Southeastern Europe.

During these three days, we are excited to welcome renowned speakers, explore the latest advances in cystic fibrosis treatment, and share valuable practical and methodological experiences among healthcare professionals working in the field.

We are honored to bring together physicians and specialists from across Europe, creating a unique platform for exchanging knowledge, expertise, and best practices in CF management.

This conference is not only an opportunity for medical professionals but also for parents and families of people living with cystic fibrosis to engage in meaningful discussions with experts, share experiences, reflect on past successes, and gain new insights.

Throughout the event, we will address key topics such as cystic fibrosis treatment protocols, the critical role of physiotherapy, nutritional management in respiratory diseases, and also explore cutting-edge therapies, including the latest CFTR modulators like Orkambi, Kalydeco, and Trikafta.

We are grateful for this opportunity to exchange knowledge, discuss new developments, and continue working together to improve the quality of care for people with cystic fibrosis across the region.

We invite you to stay with us until the end of the conference and hope that this experience will meet — and hopefully exceed — your expectations.

Thank you for your participation!

# 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

Vlora NIMANI, Republic of Kosovo  
 Arben VITIA, Minister of Health, Republic of Kosovo  
 Naim BARDIQI, Secretary General of the Ministry of Health  
 Hilde De KEYSER, CF Europe  
 Pavel DREVINEK, ECFS  
 Irena KASMI, Albania  
 Atdhe RAMA, Republic of Kosovo

### Twinning Project – Part I

*Chairs: Hilde De KEYSER, Pavel DREVINEK, Chris SMITH*

Time	Description	Speakers
13:20-14:30		
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- 16:10	Description	Speakers
14:40-14:50	<b>Twinning project: Prishtina, Republic of KOSOVO and Utrecht, NETHERLANDS</b>	<b>Vlora Nimani</b> , Republic of Kosovo <b>Marit van Oirschot, Marian Kruijswijk</b> , Netherlands
14:50-15:00	<b>Twinning project: Patient Org Republic of KOSOVO and Patient Org. NETHERLANDS</b>	<b>Atdhe Rama</b> , Republic of Kosovo <b>Jacquelin Noordhoek</b> , Netherlands
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 Mullahaj</b> , Albania <b>Silvia Ranocchiarì</b> , Italy
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>Elmir Sejfulaj</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>Discussion / Q&amp;A</b>	
16:10-16:30	<b>Coffee Break</b>	



**SUBSCRIBE**



## Don't miss the latest updates

Visit our website and sign up for the **13th edition** of the **South Eastern European Cystic Fibrosis Conference**

**See you there!**

## 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, Prishtina, mix
17:10-17:20	A Global Perspective: The State of CF Care in: ALBANIA	Irena Kasmí, Tirana - ped. Irma Tashi, Tirana - adult
17:20-17:30	A Global Perspective: The State of CF Care in: NORTH MACEDONIA	Valentina Cvejaska Cholakovska, Skopje - ped. Tatjana 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	

## SPONSORS



# Agenda

## 04 April 2025

### Day 2

Date: **04 April 2025**  
 Time: **9.30 am to 18.00 pm**  
 Location: **Emerald Hotel**

#### Managing Adults with CF: Strategies for Comprehensive care

*Chairs: Malena COHEN-CYMBERKNOH, Andrea VUKIC DUGAC, Irma TASHI, Tatjana 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-Cymerbknoh, 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-Cymerbknoh, 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>Newborn screening in Kosovo</b>	Shqipe Spahiu, Republic of Kosovo
11:55-12:10	<b>Nutrition of children and adult with CF - "Guidelines"</b>	Chris Smith, UK

Time 11:15- 13:00	Description	Speakers
12:10-12:25	Key nutrition priorities	Chris Smith, UK
12:25-12:45	No Health Without Mental Health	Sonia Graziano, Italy
12:45-13:00	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, Netherlands
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, Netherlands
15:20-15:30	The role of Autogenetic Drainage on spirometry parameters in different ages of patients with CF	Arian Selmani, North Macedonia
15:30-15:45	Discussion / Q&A	
15:45-16:00	Coffee Break	

# 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>Jacqueline 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> , Netherlands <b>Marcella Burghard</b> , Netherlands

## 20:00 GALA DINNER

# TWINNING EXPANSION PROJECT



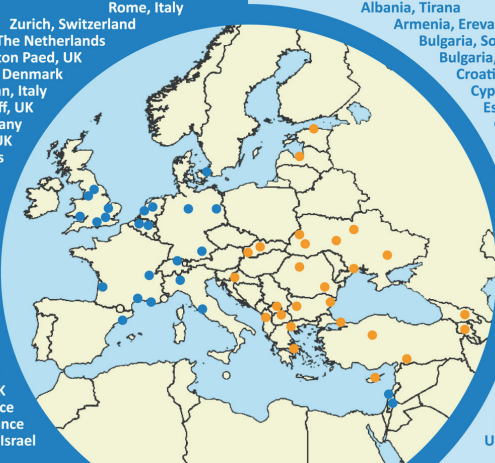
MENTORS



MENTEES



- Rome, Italy
- 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
- 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



- 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
- 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**

#### Diagnosis of CF

*Chairs: Lutz NAEHRLICH, Milan MACEK, Anila BABAMETO*

Time	Description	Speakers
09:30-11:20		
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	Challenges in Treating CF Patients in Kosovo	Vlora Ismaili-Jaha, Republic of Kosovo
10:50-11:10	CFSPID	Marlies Destoop, Netherlands
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	Comprehensive care in CF – The role of the multidisciplinary team management	Malena Cohen-Cymerberknoh, 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 the parent of the child with CF	Jacqueliën 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





# EXPLORE

## The Twinning Expansion Project

*Scan me*



The Twinning  
Expansion Project  
is kindly supported by the  
CF Foundation



[www.southeastcf.eu](http://www.southeastcf.eu)  
[hello@southeastcf.eu](mailto:hello@southeastcf.eu)