

# ECFS Newsletter

May 2025



## Letter from the president

Dear Friends,

There has been a lot of activity at the ECFS since the last edition of our newsletter and here is a brief review of the special projects, what's new with our society and a few highlights of the upcoming 48th European Cystic Fibrosis Conference taking place in a few days, this year in Milan, Italy.

The ECFS Basic Science Conference was held in Italy in March. Once again, the conference was a resounding success with brilliant speakers and lots of questions and discussions from the audience. We would like to thank the organisers, Patrick Harrison (US), Batsheva Kerem (IL) and Dean Madden (US) for putting together a high-quality programme. The abstract book is available on the [ECFS website](#). The ECFS Diagnostic Network Working Group met in Brussels in February, with Elke De Wachter as host. All agreed this was a fantastic meeting scientifically and with excellent networking opportunities. The report of the meeting can be found [here](#).

We are rapidly approaching our annual conference in Milan and the final preparations are well underway. The Scientific Committee has put together an outstanding programme and we have some exciting new basic research and results from clinical trials to discuss. You can find the final programme on the [ECFS website](#). I would like to thank the Scientific Committee and the Steering Committee for all their hard work over the last year in preparing the programme, selecting the abstracts and sorting the various sessions. Besides the conference App featuring the programme and other useful information, other initiatives to note include the Grand Rounds in Clinical CF, some 'meet the experts' sessions organised in the early morning and open to all, and the ECFS Tomorrow lounge which will feature a series of interactive sessions. As part of our commitment to support young researchers, three Young Investigators Awards and twenty travel grants have been awarded to young investigators based on the merit of their abstract submissions. Congratulations to them for their prize! Please don't miss a visit to the "CF Community" booth area in the Exhibition Hall for information on the various ECFS initiatives and programmes.

The ECFS Annual General Meeting (AGM) will be held on Friday 06 June (18:30-19:45, Sky 1) and is open to all ECFS members having a valid 2025 membership. We very much hope that many of you will attend! The AGM is the moment where members can express their wishes and expectations for the Society. We value your involvement and hope to see more members contribute and input new ideas. More information on the AGM will appear further down in the newsletter.

Please contact us if you have news items you would like to have included in future Newsletters or published on our website.

Yours sincerely,

Jane Davies  
ECFS President



**JANE DAVIES**

## Inside this newsletter

Letter from the President.....1

ECFS Board Elections.....2

Basic Science Conference 2025.....2

Annual General Meeting.....3

ECFS Milan 2025.....4 -15

Upcoming Events .....7

New ECFS Working Groups .....16

In Other News.....17

# ECFS 2025 Board Elections

Dr. Silke van Koningsbruggen-Rietschel and Prof. Carlos Farinha have reached the end of their first term on the board and have expressed their interest in applying for a second term. We have received no additional applications for board member positions.

In our constitution, and in the interest of democracy, we do require to have a vote on the two candidates' applications. Please see the candidates' nominations, CV and personal statements [here](#). There is an opportunity if anyone wishes to express a NO vote for either nominee in the [anonymous webform](#).

The form will remain open until Friday 30 May 2025 at 08:00 CEST AM and is accessible when logged into [MyECFS](#).



## Basic Science Conference 2025

The ECFS Basic Science Conference was held in Lido di Camaiore, Italy from 26 – 29 March 2025. We would like to thank the organisers Patrick Harrison (US), Batsheva Kerem (IL) and Dean Madden (US) for putting together a high quality programme for the 139 delegates.



The [abstract book](#) is available on the ECFS website.

Congratulations to this year's prize winners

### Best Oral Presentation



Raquel Ibañez, Roberto Plebani, Laudonia Lidia Dipalo & Arianna Venturini.

### Best Poster Presentation



Joana Alves, Marie Overtus, Arina Svoeglazova & Anna Borelli

### NACFC Travel Grant



Marjolein Ensinck pictured with Bob Emmelkamp

# ECFS Annual General Meeting

Friday 6<sup>th</sup> June 2025

Save the date!

**18:30 to 19:45 - Sky 1, MiCo.**

The Meeting will be organised in person. Open to all ECFS members with a valid 2025 subscription. We need your active participation and look forward to a great discussion.

## Meeting Agenda

<b>President's Report</b>	Jane Davies
<b>Secretary's Report</b>	Carlos Farinha
<b>Treasurer's Report</b>	Dorota Sands
<b>ECFS Board Elections</b>	Jane Davies
<b>Update on Journal of Cystic Fibrosis</b>	Patrick Flume
<b>ECFS CTN Report</b>	Lieven Dupont
<b>ECFS Patient Registry Report</b>	Egil Bakkeheim
<b>ECFS Standards of Care Report</b>	Kevin Southern
<b>ECFS Education Report</b>	Chris Smith
<b><u>Airway Epithelial Cell Models Working Group</u></b> <b><u>Diagnostic Network Working Group</u></b> <b><u>Exercise Working Group</u></b> <b><u>Mental Health Working Group</u></b> <b><u>Neonatal Screening Working Group</u></b> <b><u>Pulmonary Exacerbations Working Group</u></b> <b><u>Telehealth in CF Care Working Group</u></b>	ECFS Working Group Reports
<b><u>ECFS Nursing Special Interest Group</u></b> <b><u>European CF Pharmacy Special Interest Group</u></b> <b><u>European CF Nutrition Special Interest Group</u></b> <b><u>European Psychosocial Special Interest Group</u></b> <b><u>ECFS Physiotherapy Special Interest International Group</u></b>	ECFS Special Interest Group Reports
<b>Presentation of the 2026 European CF Conference</b>	

# 48th ECFS Conference - Milan, Italy

What's to come



The 48th European Cystic Fibrosis Conference is happening in Milan, Italy this year! The event will feature a comprehensive scientific programme, covering the latest advancements in cystic fibrosis research, clinical care, and patient advocacy.

You can explore the full programme [here](#).



To help plan your visit to Milan, visit the [official website of Milan Tourism](#)



## ECFS Patient Registry - Data For Presenters



We are pleased to share with you a [slide deck](#) containing the most recent data and graphics from the [European Cystic Fibrosis Society Patient Registry \(ECFSPR\) Annual Report 2023](#). These have been prepared specifically to support your presentations and ensure consistency and accuracy when referring to ECFSPR data during your talk.

Please note that the slides have been created in a non-editable format to preserve the integrity of the data presented. However, you are very welcome to copy and paste any of the figures or graphics into your own presentation, should you wish to include them when referring to ECFSPR data.

## Programme Timetable

WEDNESDAY, JUNE 4		
Coral 2+3	Exhibition & Poster Area (Coral 4+5+6)	Other
		08:30
		17:00
	POSTER HANGING 17:00 - 18:00	17:30
		18:00
OPENING PLENARY 18:30 - 20:00		18:30
		19:00
		19:30
	EXHIBITION & POSTER AREA OPEN 19:30-21:30	20:00
		20:30
	WELCOME RECEPTION 20:00-21:30	21:00
		21:30

The online session planner can be used to access all sessions and participations.

Download it [here](#).

#ECFS2025

# 48th ECFS Conference - Milan, Italy

## What's to come

### THURSDAY, JUNE 5

	Coral 2+3	Ocean 1+2	Ocean 3+4	Sky 1	Coral 1	Aqua 1	Aqua 2	Exhibition & Poster Area (Coral 4+5+6)	
07:30									07:30
08:00				MEET THE EXPERTS 1 07:45 - 08:45		MEET THE EXPERTS 2 07:45 - 08:45	MEET THE EXPERTS 3 07:45 - 08:45		08:00
08:30									08:30
09:00	SYMPORIUM 1 09:00 - 10:30	SYMPORIUM 2 09:00 - 10:30	SYMPORIUM 3 09:00 - 10:30	SYMPORIUM 4 09:00 - 10:30	SYMPORIUM 5 09:00 - 10:30			TOMORROW LOUNGE SESSION 09:00 - 10:00	09:00
09:30	The European initiative for (ultra-)rare variants	Unveiling novel therapeutic targets for microbial pathogen control	Is inflammation still relevant in cystic fibrosis?	When care causes trauma - how to support patients with cystic fibrosis and their families	Getting to grips with CFTR genetics to optimise patient care				09:30
10:00									10:00
10:30			COFFEE BREAK IN EXHIBITION		COFFEE BREAK IN EXHIBITION				10:30
11:00	SYMPORIUM 6 11:00 - 12:30	SYMPORIUM 7 11:00 - 12:30	SYMPORIUM 8 11:00 - 12:30	SYMPORIUM 9 11:00 - 12:30	SYMPORIUM 10 11:00 - 12:30			EXHIBITION & POSTERS 09:00 - 18:00	11:00
11:30	Considerations in advanced lung disease	Infestation management in cystic fibrosis - beyond <i>Pseudomonas aeruginosa</i> and <i>Staphylococcus aureus</i>	Organ-specific interplay between CFTR and channels/transporters in transepithelial anion transport	The new faces of pancreas	Exercise and physiotherapy throughout the lifespan				11:30
12:00									12:00
12:30									12:30
13:00	SATELLITE SYMPOSIUM 13:00 - 14:00		LUNCH BREAK		LUNCH BREAK			TOMORROW LOUNGE SESSION 12:45 - 13:45	13:00
13:30									13:30
14:00				ePOSTER SESSION 1 14:00 - 15:00	ePOSTER SESSION 2 14:00 - 15:00	ePOSTER SESSION 3 14:00 - 15:00	ePOSTER SESSION 4 14:00 - 15:00	POSTER VIEWING 14:00 - 15:00	14:00
14:30									14:30
15:00	WORKSHOP 1 15:00 - 16:30	WORKSHOP 2 15:00 - 16:30	WORKSHOP 3 15:00 - 16:30	WORKSHOP 4 15:00 - 16:30	WORKSHOP 5 15:00 - 16:30				15:00
15:30	The power of real-world data to solve long term problems	Mental health and care in the post CFTR modulator era - broaden the view	Airway clearance and exercise: practical physiotherapy approaches	From dysbiosis to dysfunction: gastrointestinal and metabolic complications to cystic fibrosis	Nucleic acid based therapies: progress and potential			EXHIBITION & POSTERS 09:00 - 18:00	15:30
16:00									16:00
16:30			COFFEE BREAK IN EXHIBITION		COFFEE BREAK IN EXHIBITION				16:30
17:00	WORKSHOP 6 17:00 - 18:30	WORKSHOP 7 17:00 - 18:30	WORKSHOP 8 17:00 - 18:30	WORKSHOP 9 17:00 - 18:30	SPECIAL SYMPOSIUM 17:00 - 18:30			TOMORROW LOUNGE SESSION 17:00 - 18:00	17:00
17:30	The new frontier: pregnancy in the CFTR modulator era	Novel monitoring of cystic fibrosis lung disease: imaging, lung function and other biomarkers	Microbial shifts: the impact of ETI on infection, and the lung microbiome	CFTR-expressing epithelia in health and disease	Best of Journal of Cystic Fibrosis, Lancet Respiratory Medicine and European Respiratory Journal				17:30
18:00									18:00
18:30									18:30

### FRIDAY, JUNE 6

	Coral 2+3	Ocean 1+2	Ocean 3+4	Sky 1	Coral 1	Aqua 1	Aqua 2	Exhibition & Poster Area (Coral 4+5+6)	
07:30									07:30
08:00				MEET THE EXPERTS 4 07:45 - 08:45	SATELLITE SYMPOSIUM 08:00 - 08:45	MEET THE EXPERTS 5 07:45 - 08:45	MEET THE EXPERTS 6 07:45 - 08:45		08:00
08:30									08:30
09:00	SYMPORIUM 11 09:00 - 10:30	SYMPORIUM 12 09:00 - 10:30	SYMPORIUM 13 09:00 - 10:30	SYMPORIUM 14 09:00 - 10:30	SYMPORIUM 15 09:00 - 10:30			TOMORROW LOUNGE SESSION 09:00 - 10:00	09:00
09:30	Imaging in cystic fibrosis, my view!	Every breath you take	Nutrition throughout life	Navigating challenges in gene therapy	Closing the gap: the intersection of epidemiology, data harmonisation and access to treatments in cystic fibrosis				09:30
10:00									10:00
10:30			COFFEE BREAK IN EXHIBITION		COFFEE BREAK IN EXHIBITION				10:30
11:00	SYMPORIUM 16 11:00 - 12:30	SYMPORIUM 17 11:00 - 12:30	SYMPORIUM 18 11:00 - 12:30	SYMPORIUM 19 11:00 - 12:30	SYMPORIUM 20 11:00 - 12:30			EXHIBITION & POSTERS 09:00 - 18:00	11:00
11:30	Smart monitoring for trials and clinical care	Looking to the future	Facing challenges in the post CFTRm era	Evolving tactics in <i>Pseudomonas aeruginosa</i> resistance development	Pushing the boundaries of newborn screening for cystic fibrosis				11:30
12:00									12:00
12:30									12:30
13:00	SATELLITE SYMPOSIUM 13:00 - 14:00		LUNCH BREAK		LUNCH BREAK			TOMORROW LOUNGE SESSION 12:45 - 13:45	13:00
13:30									13:30
14:00				ePOSTER SESSION 5 14:00 - 15:00	ePOSTER SESSION 6 14:00 - 15:00	ePOSTER SESSION 7 14:00 - 15:00	ePOSTER SESSION 8 14:00 - 15:00	POSTER VIEWING 14:00 - 15:00	14:00
14:30									14:30
15:00	WORKSHOP 10 15:00 - 16:30	WORKSHOP 11 15:00 - 16:30	WORKSHOP 12 15:00 - 16:30	WORKSHOP 13 15:00 - 16:30	WORKSHOP 14 15:00 - 16:30				15:00
15:30	Targeting inflammation and immunity in cystic fibrosis	Infectious dynamics of cystic fibrosis pathogens	The changing nutrition markers in the age of modulators	Updates in genetics screening and diagnosis	Therapeutic approaches for CFTR mutations			TOMORROW LOUNGE SESSION 15:00 - 16:30	15:30
16:00									16:00
16:30			COFFEE BREAK IN EXHIBITION		COFFEE BREAK IN EXHIBITION			EXHIBITION & POSTERS 09:00 - 18:00	16:30
17:00	WORKSHOP 15 17:00 - 18:30	WORKSHOP 16 17:00 - 18:30	WORKSHOP 17 17:00 - 18:30	WORKSHOP 18 17:00 - 18:30	WORKSHOP 19 17:00 - 18:30				17:00
17:30	ETI era: transforming outcomes from lung function to longevity	Cystic fibrosis related diabetes	Late Breaking Science	Complex Psychosocial Issues/Nursing Case studies	Upstream/downstream: new therapies for people with cystic fibrosis			POSTER DISMANTLING UNTIL 18:00	17:30
18:00									18:00
18:30									18:30

# 48th ECFS Conference - Milan, Italy

What's to come

SATURDAY, JUNE 7					
	Coral 2+3	Ocean 1+2	Ocean 3+4	Sky 1	Coral 1
09:00	SYMPOSIUM 21 09:00 - 10:30	SYMPOSIUM 22 09:00 - 10:30	SYMPOSIUM 23 09:00 - 10:30	SYMPOSIUM 24 09:00 - 10:30	SYMPOSIUM 25 09:00 - 10:30
09:30	Grand Rounds in Clinical CF	Above the glottis	Managing metabolic health in cystic fibrosis	Unlocking the power of registries: enhancing our understanding of cystic fibrosis and futureproofing data collection	Lung disease modelling - learning from other lung diseases
10:00					
10:30	COFFEE BREAK IN EXHIBITION				COFFEE BREAK IN EXHIBITION
11:00					
11:30	CLOSING PLENARY 11:00 - 12:30				
12:00					
12:30	CLOSING CEREMONY 12:30 - 13:00				
13:00					

## Pre Conference Courses



Limited Seating

### AIRWAY CLEARANCE TECHNIQUES TRAINING COURSE

Tuesday 3 June 08:00 - 17:00

Wednesday 4 June 08:00 - 12:30

This course will teach and consolidate knowledge of physiological and theoretical principles of airway clearance techniques with practical teaching and demonstrations. Suitable for any physiotherapists wishing to optimise airway clearance skills for patients with suppurative lung disease. This course is a pre-requisite to the PhySIIG ACT instructors course.



### THE CHALLENGES OF MANAGING THE NEUROPSYCHIATRIC AND PSYCHOLOGICAL EFFECTS OF MODULATORS: PRACTICAL AND CLINICAL IMPLICATIONS.

Tuesday 3 June 14:00 - 18:00

Organised by the European Psychosocial Special Interest Group (EPSIG) and the ECFS Mental Health Working Group. We will explore how CF teams are managing the neuropsychiatric and psychological effects of modulators. This course will include a review of the evidence on side-effects related to new genetic modulators as well as strategies CF Teams are using to manage them. The course will include case presentations on the assessment of side effects and clinical interventions that have been used to address them. We will emphasize practical approaches to screening and intervention in this new era of modulator therapy. Cases will cover the life span from childhood through adulthood.

### CLINICAL NUTRITION COURSE: FROM KNOWLEDGE TO PRACTICE: SHAPING EFFECTIVE NUTRITION HABITS.

Tuesday 3 June 12:30 - 17:15

This course provides healthcare professionals with a unique opportunity to engage with leading experts in the field of nutrition. The course will focus on both proactive nutritional strategies for long-term health and reactive nutritional approaches in the management of emerging illness. Renowned international speakers will present the most recent clinical data, offering insights and interpretations relevant to clinical practice.

Interactive discussions will be facilitated, allowing attendees to share their experiences and perspectives.

# 48th ECFS Conference

Milan, Italy - 4-7 June 2025

## Sweat Test Hands-On Session 2025

Wednesday 4th June 2025, 15:00 - 17:00

The aim is to support centres and help in problem solving to achieve acceptable standards for good sweat testing practice in their CF centre. This year's session will only focus on the Macroduct® Advanced sweat induction and collection system, and the ChloroChek® Chloridometer® for analysis.

What to expect?

- A short theoretical introduction on sweat testing: technique, practical information and interpretation
- Printed handouts, demonstrating each step, will be provided
- Participants will be able to perform a sweat test (iontophoresis, collection, analysis) in real life under the supervision of an expert in the field. Participants will be requested to act as 'subject' and 'performer'
- Sessions will be led in English, German, Spanish, French and Dutch (separate tables according to language)
- A certificate of attendance will be provided at the end of the session.

Who can register?

- Lab technicians, biologists or nurses who perform sweat testing in the clinic or who are planning to start doing sweat testing in the near future.
- Physicians who support the sweat test services in their centre
- Deadline for registration: 29 May 2025, 23:59 CEST
- Please note that the session is open to a maximum of 20 participants. We will follow a "first come, first serve" policy. As soon as 20 participants have registered, the link will no longer allow you to register

More information and registration [here](#).



## Meet the Experts

Meet the Experts sessions are small interactive sessions led by experts to stimulate discussion, answer questions and offer advice. The format encourages a more personal approach to learning. Each session is limited to 50 participants. Attendance is free for registered participants.

Thursday 05 June 07:45 – 08:45

- Menopause – understanding and supporting women
- Lung transplant – indications and management
- Lessons learned from real-world studies – why, how and what?

Friday 06 June 07:45 – 08:45

- To test or not to test - the impact of antibiotic susceptibility testing on clinical outcomes
- Pharmacology and psychological side effects of modulator therapy
- How to better diagnose a CFTR-RD with the wide range of tools available (from genetics to functional and clinical explorations)

Upcoming  
Events

### 48th European Cystic Fibrosis Conference

04 - 07 June 2025

Milan, Italy

### North American Cystic Fibrosis Conference

23 - 25 October 2025

Seattle, Washington

### ERS

27 Sept - 01 Oct 2025

Amsterdam,  
Netherlands

# 48th ECFS Conference

Milan, Italy - 4-7 June 2025

## Speaker Corner

The Speaker Corner allows speakers to engage with participants in interactive discussions during the coffee breaks, fostering connections and exchanging ideas. Join us at the Tomorrow Lounge with the following speakers:

Thursday 05 June 10:30 - 11:00

- Stéphanie Bui
- Anna-Maria Dittrich
- Kris De Boeck
- Sonia Graziano
- Karen Raraigh
- Cliff Taggart

Thursday 05 June 16:30 - 17:00

- Peder Berg
- Steven Freedman
- Tanja Gonska
- Andrew Jones
- Carsten Schwarz
- Donald Urquhart

Friday 06 June 10:30 - 11:00

- Scott Bell
- Anna Cereseto
- Daina Kalnins
- Sarath Rangnatha
- Anne Stephenson

Friday 06 June 16:30 - 17:00

- Catherine Armbruster
- Trudy Havermans
- Eitan Kerem
- Alexandra Quittner
- Marco Zampoli

### Physiotherapy Special Interest International Group

Thursday 09:00-10:00

#### **CF Life: more than just popping a pill - challenges for physiotherapy**

Brenda Button, Australia  
Lisa Morrison, UK  
Gemma Stanford, UK

## Tomorrow Lounge



### Mental Health Working Group

Thursday 12:45-13:45

#### **How are we measuring mental health and quality of life impacts of CFTR modulators?**

Eddie Landau, Israel  
Anna M. Georgopoulos, USA  
Helen Love, UK  
Marieke Verkleij, Netherlands

### Psychosocial Special Interest Group

Thursday 17:00-18:00

#### **I've got a gut feeling this is going to be important: the brain-gut axis in CF care**

Kerry-Lee Watson, UK  
Rachel Massey-Chase, UK

### Pharmacy Special Interest Group

Friday 09:00 - 10:00

#### **Supporting adherence – the pharmacists' perspective**

Kerry-Carina Hansen, Netherlands  
Elena Schneider-Futschik, Australia

### Education, Twinning Project & CF Europe

Friday 15:00 - 16:30

#### **Shared experiences in cross border collaboration**

Helen Chadwick, UK  
Hilde de Keyser, Belgium

# 48th ECFS Conference - Milan, Italy

4-7 June 2025

## Meetings and Courses

**Tuesday 03 June 2025**

08:00	17:00	PhySIIG Airway Clearance Techniques Training Course **	Aqua 1
08:30	18:00	ECFS Board Meeting	Meeting N3
12:30	17:15	Clinical Nutrition Course: From knowledge to practice: shaping effective nutrition habits**	Meeting N7+N8
14:00	18:00	The challenges of managing the neuropsychiatric and psychological effects of modulators: Practical and clinical implications.**	Meeting room N4+N5

**Wednesday 04 June 2025**

08:00	12:30	PhySIIG Airway Clearance Techniques Training Course**	Aqua 1
08:30	12:45	ECFS CTN Training and Development*	Sky 1
09:00	16:00	ECFS Nursing Special Interest Group Meeting**	Aqua 2
09:00	16:00	ECFS Psychosocial Special Interest Group (EPSIG) Meeting**	Coral 1
09:30	15:00	ECFS Neonatal Screening Working Group Annual Meeting**	Aqua 3
10:30	15:45	European Cystic Fibrosis Nutrition Group Meeting**	Ocean 3+4
12:00	14:00	ECFS Patient Registry Executive Committee Meeting*	Meeting N7+N8
13:00	17:00	ECFS Exercise Working Group Meeting	Aqua 4
13:30	16:30	ECFS CTN Training Research Coordinators*	Sky 2
13:30	17:30	ECFS CTN Steering Committee Meeting*	Sky 1
13:30	17:30	ECFS Cystic Fibrosis Pharmacy Group Meeting	Meeting N4+N5
14:00	16:00	Physiotherapy Case Presentations	Aqua 1
14:30	16:00	ECFS Patient Registry Scientific Committee Meeting*	Meeting N7+N8
15:00	18:00	ECFS-DNWG Sweat Test Workshop**	Meeting Room N3
16:00	18:00	PhySIIG Annual General Meeting and Networking Event	Aqua 1
17:00	18:30	ECFS Patient Registry: International CF Registry (Global Reg. Group)*	Ocean 3+4
17:30	18:15	ECFS CTN Executive Committee Meeting*	Sky 2

\* By invitation only

\*\* Extra registration needed

# 48th ECFS Conference - Milan, Italy

4-7 June 2025

## Meetings and Courses

### Thursday 05 June 2025

07:00	09:30	Journal of Cystic Fibrosis (JCF) Editorial Board Meeting*	Meeting N4+N5
07:30	08:30	ECFS CTN Standardisation Committee Meeting*	Meeting N3
10:30	11:30	ENHANCE Study Team Meeting*	Meeting N3
10:30	12:00	ECFS Patient Registry CFSPID Meeting*	Aqua 1
12:30	13:45	ECFS Education Committee Meeting*	Aqua 4
12:30	15:00	CTN – CFF – TDN – CanAct Meeting*	Meeting N4+N5
13:45	15:00	ECFS Patient Registry Definitions Group Meeting*	Meeting N7+N8
15:30	17:30	Telehealth for CF (THCF) Working Group Meeting *	Meeting N4+N5
16:00	18:00	ECFS Standards of Care Group Meeting*	Meeting N3
17:00	18:00	ECFS Patient Registry Software Training – Walk in Session 1	Meeting N7+N8
18:00	19:00	ECFS Patient Registry Annual Report Working Group Meeting*	Meeting N7+N8
18:30	19:30	ECFS CTN Standardisation Sub-Group Meeting*	Aqua 1
18:30	20:30	Pulmonary Exacerbation Working Group Meeting*	Meeting N3

### Friday 06 June 2025

07:30	08:30	PhySIIG Committee Meeting*	Meeting N7+N8
12:00	14:00	ECFS CTN Lung Clearance Index Workshop	Aqua 1
12:30	13:30	Cough Monitoring in pwCF	Aqua 2
12:30	14:00	ECFS Mental Health Working Group Meeting*	Meeting N7+N8
12:30	14:30	ECFS Patient Registry Steering Group Meeting*	Ocean 1+2
12:30	14:30	ECFS Diagnostic Network Working Group Meeting	Ocean 3+4
16:00	17:00	ECFS Patient Registry Software Training - Walk In Session 2	Meeting N7+N8
16:00	18:00	UKCFMA Meeting	Aqua 1
18:30	19:45	ECFS Annual General Meeting	Sky 1

### Saturday 07 June 2025

13:30	16:30	Italian Patient Association Meeting* <i>in Italian</i>	Meeting N7+N8
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\* By invitation only

\*\* Extra registration needed

# 48th ECFS Conference

Milan, Italy - 4-7 June 2025

## ECFS Award 2025

The ECFS Award is given annually to honour a person who has made an outstanding contribution to our basic understanding of cystic fibrosis or to the treatment or care of patients with cystic fibrosis. This year, the ECFS wishes to acknowledge **Pierre-Régis Burgel**.



Pierre-Régis Burgel is a pulmonologist who is a leading international clinician and scientist in respiratory medicine and in cystic fibrosis. He was trained in Paris in France and also spent 2.5 years in California in the USA, at the University of California in San Francisco. He has performed work on the role of mucus hypersecretion in chronic airways disease and lung immunology during chronic bacterial infection. He was involved early in his career in the care of people with cystic fibrosis. He has been appointed as Medical Director of the CF centre at Cochin Hospital in 2016, and is the current coordinator of the French CF center reference network, which comprises all 47 pediatric and adult CF centers in France.

He became a Professor of Respiratory Medicine at the University Paris Cité in 2011 and also holds senior executive leadership position at the Institut Cochin, Inserm U1016. He is current president of the French CF Society.

Prof Burgel has contributed to consensus statements nationally and internationally in the fields of CF and bronchiectasis, including the 2024 ECFS Standards of Care. He has participated in several European and international groups that framed policy of adult CF Care. This included the ERS/ECFS task force on the Provision of Care for Adults with CF in Europe; within this task force, Prof Burgel developed the first demographic forecasts for a large number of European countries, helping to raise awareness on the ongoing demographic changes in people with CF. He made significant contributions in the field of CFTR modulators through real-world studies in France, organizing large cohorts of CF patients.

He is the principal investigator of the French Compassionate Program, a unique program that has allowed multiple people with CF but no F508del variant to benefit from an open label trial of elexacaftor-tezacaftor-ivacaftor. The program not only allowed access to elexacaftor-tezacaftor-ivacaftor to hundreds of patients in France, but also provided new knowledge on the responsiveness to modulators of (often rare) non-F508del variants. These data contributed to recent label expansion by the European Medicines Agency.

Over the years, Prof Burgel has trained many students for clinical care of people with CF, as well as researchers who are now independent investigators in the field of CF research.

Besides his contribution to many groups of the ECFS, he serves as an associate editor of the Journal of Cystic Fibrosis since 2018 and the European Respiratory Journal since 2022. He has been elected as a board member of the ECFS in 2024. He has received the Gold Medal Mid-Career Award for research in cystic fibrosis from the European Respiratory Society in 2022.

We are delighted that Pierre-Régis Burgel was granted the ECFS Award 2025 and look forward to hearing his talk at the European CF Conference Opening Plenary on 4 June, 2025 in Milan.

# 48th ECFS Conference

Milan, Italy - 4-7 June 2025

## ECFS Allied Health Professional Outstanding Contribution Award 2025

The ECFS Allied Health Professional Outstanding Contribution Award 2025 is being introduced for the first time this year, recognizing allied health professionals who have made a sustained commitment to excellence in the cystic fibrosis field or has had a more recent, specific achievement with major impact. The inaugural award goes to **Chris Smith**.



Chris Smith is a dedicated paediatric dietitian specialising in cystic fibrosis. He began his clinical training in London and subsequently moved to the Royal Alexandra Children's Hospital in Brighton, where he developed his specialist practice in CF care. In recognition of his academic and clinical contributions, he was appointed as an Honorary Senior Clinical Lecturer at Brighton and Sussex Medical School in 2023.

Over the past 16 years, Chris has been an active and valued contributor to the European Cystic Fibrosis Society (ECFS). His engagement with the ECFS Nutrition Group Committee began as a regular member.

Then in 2014, he was invited to co-chair this group alongside Dr. Declercq, a role they jointly held for five years. During their tenure, they collaboratively conceived, developed, and launched the ECFS Nutrition Pre-Conference Course in 2016—an initiative that continues to run successfully. This course has brought together a wide range of international experts and has supported the professional development of clinicians across Europe and beyond. Also during this period, he served for several years on the Conference Steering Committee, including leading the Gastrointestinal/Nutrition/Endocrine/Liver session in a designated year.

In 2019, Chris joined the ECFS Education Committee under the leadership of Professor Peckham, representing the field of nutrition. He was invited to lead the committee in 2022 and formally took on the role of ECFS Director of Education. Under his guidance, the committee undertook one of the most comprehensive surveys of the ECFS community to date, aiming to identify key educational needs and priorities. The findings of this survey, published in the same year, have directly influenced the committee's strategic direction, leading to a marked expansion in the society's educational offerings—including significant development of the webinar program with increases in both the quantity and diversity of content. The survey also underscored the need for greater accessibility through translated educational materials. In response, Chris has overseen the development of multilingual education modules, in collaboration with Dr Helen Chadwick, with completed content now available in languages including Turkish, Romanian, Ukrainian, and Albanian. These efforts have improved access to high-quality educational resources and supported clinical practice across a broader international audience. They have also strengthened and enhanced the international collaborative efforts of the ECFS.

As Director of Education, Chris is also an active and keen supporter of the Twinning Project, serving on the steering committee. He also works closely with the exceptionally dedicated ECFS e-Learning team to coordinate and develop new modules.

Since 2022, he has served on the ECFS Board, contributing to several strategic initiatives.

Chris is also a committed advocate of CFEurope's work. Since 2010 he has regularly contributed to educational initiatives at outreach conferences in many countries, including Ukraine, Romania, Latvia, Estonia, and Kosovo.

Chris's contributions extend to authorship of international consensus statements and several chapters of textbooks in the fields of CF and nutrition. His commitment to education and collaboration continues to have a meaningful impact across the CF community.

In his spare time he happily runs a taxi service for his teenage children.

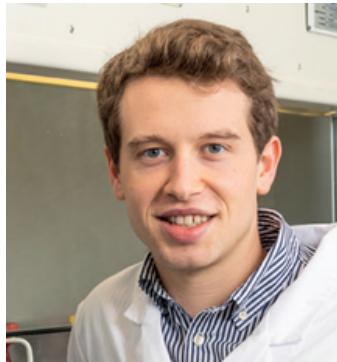
# 48th ECFS Conference

Milan, Italy - 4-7 June 2025

## Gerd Döring Award 2025

The ECFS annually awards the Gerd Döring Award to an outstanding early-career European scientist for impactful research into the understanding or treatment of cystic fibrosis. Judged on a paper published within the last three years, this year's award goes to Mattijs Bulcaen for his remarkable contribution. The honor includes a €5,000 grant to support research and will be presented during the Opening Plenary of the conference.

### Mattijs Bulcaen



Dr. Mattijs Bulcaen is a 27 year-old Biochemist with a PhD in Biomedical Sciences from KU Leuven, Belgium. He conducted his PhD with prof. Marianne Carlon on innovative gene editing strategies for drug-refractory CFTR mutations. Excited about the implications for people with CF and intrigued by the biochemical beauty of precision chemistry on the genome, he is still very eager to continue this research. In 2025, he will start as post-doc in the lab of prof. David Liu at the Broad Institute of MIT and Harvard

### Precise prime editing and virus-like particle delivery for drug-refractory CFTR mutations

In 2024, dr. Bulcaen and colleagues published on the development of innovative prime editing approaches for two drug-refractory CFTR-mutations. Prime editing is one of the most advanced, elegant and potent CRISPR-derived gene editing technologies and could allow to tackle CF at its genetic roots. In cell lines, Bulcaen et al. found that prime editing lead to reappearance of the ion channel and its associated function. The team also delivered their strategies to intestinal organoids donated by pwCF. DNA correction in these 3D models led to restoration of 'forskolin-induced swelling', a phenotype directly indicative of CFTR function. Finally, the team showed that prime editing can also correct mutations in airway stem cells and that CFTR-specific chloride currents could be measured in differentiated airway epithelia. One of the most exciting findings were the relatively high chloride currents (~30% compared to healthy) following correction of only few stem cells (~1.5%). This indicates that prime editing in a small number of cells may suffice to deliver a clinically relevant benefit.

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# 48th ECFS Conference

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## Young Investigator Awards

Based on the Steering Committee's recommendations, the ECFS recognizes the outstanding research of select young investigators under 35 who applied for the award. Recipients receive €750, free Conference registration, and a 2025 ECFS membership. Congratulations to the awardees!

### Cristian Crisan



I obtained my PhD from Georgia Institute of Technology (Atlanta, USA), and I am now a Cystic Fibrosis Postdoctoral Fellow at Emory University School of Medicine (Atlanta, USA). My current projects are focused on *Stenotrophomonas maltophilia*, an emerging, multidrug-resistant cystic fibrosis pathogen that causes life-threatening infections. As a researcher, I have been investigating the molecular mechanisms of microbial antagonistic interactions. My career goal is to develop novel therapies against infections with multidrug-resistant bacteria.

#### WS11.03

#### Infectious dynamics of bacteriophages that lyse diverse cystic fibrosis *Stenotrophomonas maltophilia* isolates

Elexacaftor/tezacaftor/ivacaftor (ETI) has improved the lives of people with cystic fibrosis (pwCF), but infections remain a health concern. *Stenotrophomonas maltophilia* complex (Smc) is a bacterial pathogen that infects the lungs of pwCF. Infections are associated with increased mortality, worse symptoms, and increased hospitalization rates. Smc can persist after ETI treatment. Isolates are multidrug-resistant and alternative treatments are urgently needed. Bacteriophages (or phages) are viruses that kill bacteria. Phage therapy uses these viruses to treat bacterial infections. Little is known about phages that infect Smc CF isolates. I tested the ability of genetically diverse phages to lyse Smc CF isolates and observed that some are specialists and infect a limited number of Smc isolates while others are generalists and infect multiple strains. I am currently identifying the bacterial receptors used by phages to infect Smc isolates. Results from this work could lead to the development of novel therapeutics against resistant bacteria.

### Christopher Short



Christopher joined the ECFS Lung Clearance Index (LCI) Core Facility in 2015 where he works alongside Professor Jane Davies and Clare Saunders. He completed his MRes in 2021 where he developed a novel extension to multiple breath washout (MBWShX) to assess under-ventilated lung units which are commonly overlooked by LCI. Recently he completed his PhD at Imperial College London, investigating the clinical potential of both Oxygen enhanced (OE-)MRI and MBWShX for monitoring of people with cystic fibrosis.

#### WS07.01

#### 'Silent' lung disease progression in people receiving elexacaftor/tezacaftor/ivacaftor (ETI) therapy revealed by Oxygen Enhanced-MRI (OE-MRI) and Multiple breath washout with Short extension (MBW<sub>shx</sub>)

The research presented at this year's conference represents the final aim of my PhD project, which assessed the clinical utility of Oxygen-Enhanced MRI (OE-MRI) and MBWShX for monitoring people with cystic fibrosis (CF) (Funded by the Cystic Fibrosis Foundation). Previous findings demonstrated that these methods are sensitive to changes in pulmonary health. This final aim was to determine whether lung disease progression persists in people with CF established on triple modulator therapy (≥6 months). Thirty-six participants completed a baseline visit, followed by serial visits at 6-month intervals over an 18-month period. FEV1 and LCI appeared stable throughout; however, OE-MRI parameters showed lung disease progression at 12 and 18 months, while MBWShX revealed progression at 18 months. These findings suggest that reliance on conventional outcome measures may provide false reassurance and are suboptimal for assessing the safe withdrawal of standard treatments.

### Arianna Venturini



I obtained my PhD in Experimental Medicine at the University of Genoa in 2018, and then I moved to Naples where I joined Luis Galietta's group at TIGEM as post doc. In 2022, I was awarded the ECFS/CF Europe Post-Doctoral Research Fellowship (extended for 1 year) for the project entitled "Identification of novel NMD modulators to rescue nonsense mutations in cystic fibrosis". My research is mainly focused on finding new pharmacological approach to treat CF people carrying nonsense mutations.

#### WS14.03

#### Novel pharmacological inhibitors of the NMD mechanism to rescue CFTR function in cystic fibrosis patients with nonsense mutations

Patients with a premature termination codon (PTC) in the CFTR gene are still completely excluded from the presently available drugs. The rescue of PTCs requires a combinatorial approach, with the use of inhibitors of the nonsense-mediated RNA decay (NMD) mechanism, together with readthrough agents and CFTR modulators. My project was focused on identifying new molecules able to modulate the NMD, by screening a chemical library of more than 9,000 compounds with a cell line expressing the W1282X mutation. We identified several hits that were further validated by secondary biochemical and functional assays, to assess their efficacy and specificity on CFTR function. Therefore, we have selected three potential candidates as NMD inhibitors/modulators, able to significantly increase CFTR transcript levels and promote protein expression, in parallel with CFTR channel activity. These molecules could promote the rescue of CFTR in patients with different PTCs, alone or in combination with already approved drugs.

# In Other News

## Bike 2 Congress

Thomas Vidal, a physiotherapist at the Adult CF Center in Lyon, France, actively promotes soft mobility as a means of travel to professional events while raising awareness about cystic fibrosis and advancements in care. Committed to sustainable transportation, he strives to cycle all or part of the journey to the ECFS conference each year, supplementing the rest with other forms of soft mobility. In 2024, he completed a cycling journey from London to Glasgow. This year, he aims to cycle the entire route from Lyon to Milan, further reinforcing his dedication to both environmental sustainability and CF awareness.



"As a physiotherapist at the adult cystic fibrosis center in Lyon (CRCM) and a cycling enthusiast, I try to attend some cycling conferences to promote sustainable mobility and raise awareness about this condition to the people I meet".



Follow Thomas' journey on social media



## New ECFS Working Groups

### Intestinal Organoids

Chair: Prof Jeffrey Beekman, Co-Ordinators: Dr. Sacha Spelier & Dr. Karin de Winter-de Groot

#### Objectives

1. To align current activities around organoid research and set up an international network of researchers within the ECFS
2. To standardize and implement organoid-based assays for research in a diagnostic and aca
3. To optimize implementation of ISC-based assays as predictive biomarkers, by interacting parties such as the EMA
4. Organize annual meetings & develop a training program for ISC-based methodologies t expertise in PDIO culture and CFTR function assessment for researchers across Europe

### Access to new therapy for all responsive people with cystic fibrosis

Chair: Prof. Pierre-Régis Burgel, Co-Chairs: Prof Bulent Karadag and Prof Jane Davies

#### Objectives

1. To draft guidance documents:
  - for the CF clinical community on assessment of responsiveness where individual 'trials' of modulators is possible
  - for both the community and to regulatory agencies on ex-vivo and in vitro testing methods to assess responsiveness
2. To undertake a scoping exercise:
  - To describe the labels for CFTR modulators in various age groups in the largest number of countries
  - To describe the number of CFTR patients with responsive CFTR genotypes in the largest number of countries
  - To describe the number (%) of pwCF with responsive variant treated with CFTR modulators in these countries
  - To describe the reasons for lack of access (lack of reimbursement, presence or not of specific programs for reimbursement -including Vertex's programs...) in these countries
3. To support wider access to clinical trials in countries that are not usually participating in these studies:
  - interaction with industrial sponsors to promote this endeavour prioritisation of trial sites in areas of most 'unmet need' alongside CTN

More information will be available on the [ECFS Working Groups webpage](#) shortly.

# In Other News

## Win free registration!



### 8<sup>th</sup> WORLD BRONCHIECTASIS CONFERENCE

BRISBANE, AUSTRALIA  
14-17 JULY 2025



The ECFS has **two free registrations** for the 8<sup>th</sup> World Bronchiectasis Conference. If you are a current ECFS member and would like to be in with the chance of winning one of these registrations, please email your interest to [jess.matthews@ecfs.eu](mailto:jess.matthews@ecfs.eu). Names will be selected at random and the winners contacted in June.

## Have you completed these surveys?



On behalf of the ECFS Telehealth for CF (THCF) Working Group, we kindly invite all CF Units, CF Registries, and CF Patient Associations to participate in our survey titled: "Understanding telehealth implementation for cystic fibrosis care: A survey modelled on iCHECK".

The main aim of the THCF is to develop best practice guidelines for using telehealth as part of CF care. This survey seeks to learn more about the CF communities experiences of telehealth, including those who are not currently using telehealth. Further information, consent forms, and surveys are available at the following links.

On behalf of the THCF we would like to thank you for your time and input.

Renew your  
Society  
membership  
here!

## Have News to Share?

### Help Us Spotlight Our Community!

We welcome submissions for future newsletters and website updates. If you have news, achievements, or initiatives to highlight, contact us at [info@ecfs.eu](mailto:info@ecfs.eu).

### A Day in the Life

We're looking for CF researchers, clinicians, or professionals willing to share insights into their daily work. If you'd like to contribute a short feature, we'd love to hear from you!

### Member Achievements

Have you or a colleague published new research, launched a project, or reached a milestone in CF care? Let us know so we can celebrate these achievements with the community!

### Behind the Scenes at ECFS

ECFS working groups continue to drive important initiatives. If you're involved in a working group and would like to share updates, we encourage you to send them in!

