# **ECFS** Newsletter

February 2025



## Letter from the president

Dear Colleagues and Friends,

I hope you are well and that you had a good start of the year. 2024 was a great year for the ECFS with the Basic Science Conference in Malta, the Annual Conference in Glasgow, and a number of meetings of Working Groups and Special Interest Groups.

We have recently opened our memberships for 2025 and I encourage you all to become an ECFS member once more.

Planning for the 2025 conferences is well underway and you can find all information on the 2025 Basic Science Conference in Lido di Camaiore and on the Annual Conference in Milan, Italy on the website. The registration for the conference in Milan is now open and I hope to see you all there. We have had a fantastic number of abstracts submitted this year so I would like to thank all those who have submitted and all the speakers who have accepted to contribute to these conferences. We have excellent programmes and courses planned and we look forward to your participation.

This year again, the ECFS award and the Gerd Döring Award will be presented at the European conference. The ECFS award honours 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. The Gerd Döring award honours an exceptional young European scientist in early career. More information is enclosed in this newsletter. Please send in your nominations for these important awards.

I am delighted to announce a new award for 2025; the Outstanding Contribution Award for Allied Health Professionals. This award will honour a current Society member who has made either a sustained commitment, achieving excellence in the CF field over the course of their career, or who has had a more recent, specific achievement with major impact.

The European Post-Doctoral 3-year Research Fellowship is another project with CFE that continues this year. This important project will help to foster basic and translational research on CF and bring new young talented researchers into the field. We have received five applications which are currently being reviewed, and the successful awardee will be announced at the conference in June.

Many thanks, as always, to Dr Henry Ryley for compiling the current references in cystic fibrosis in this Newsletter. This will be the last compilation from Henry so we thank him for the 77 compilations over the years!

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

Best wishes,
Jane Davies
ECES President



#### **JANE DAVIES**

#### Inside this newsletter

Letter from the President......1

ECFS Board Elections.....2

ECFS Winter Meetings.....2

Basic Science Conference 2025.....3

ECFS Milan 2025.....4 -7

ECFS Education
Webinars.....8

Upcoming Events .....9

Current References in

## Call for Editor-in-Chief of the Journal of Cystic Fibrosis

The current Editor-in-Chief, Patrick Flume, will complete his mandate as Editor-in-chief on June 30, 2026. It is anticipated that the next Editor-in-Chief will shadow the incumbent from July 2025, assuming full responsibility in July 2026. The ECFS is seeking candidates with the following qualities for this challenging position: previous international editorial experience, organisational ability, leadership skills, prestige in the field, willingness to devote time to the JCF and ECFS, and the ability to communicate clearly.

A detailed job description for the role can be found here.

To apply, please send a CV and a covering statement of suitability for the post to info@ecfs.eu by 18 April 2025. Interviews of selected candidates will be held in June during the 48th European Cystic Fibrosis conference.





#### Diagnostic Network WG Meeting

06-08 February 2025 Brussels, Belgium

# 18th European Young Investigator Meeting

26 - 28 February 2025 Paris, France

# ECFS 20th Basic Science Conference

26 - 29 March 2025 Lido di Camaiore, Italy

# South Eastern European CF Conference

03 - 05 April 2025 Prishtina, Kosovo

# **48th European Cystic Fibrosis Conference**

04 - 07 June 2025 Milan, Italy



### ECFS 2025 Board Elections

The ECFS cordially invites nominations for two Board positions. Carlos Farinha and Silke van Koningsbruggen-Rietschel will complete their first term on the ECFS Board in June 2025. Information about the nominated candidates will be shared with members for an online vote ahead of the Annual General Meeting in June, where the election results will be announced.

The Board Member's Job Description is available here.

Nominations should be submitted to ECFS Executive Director Christine Dubois (christine.dubois@ecfs.eu) by 5 April 2025. Each nomination must include a personal statement, confirmation of the candidate's agreement, and a CV. All nominees must be current ECFS members.

Information about the nominated candidates will be shared with members for an online vote ahead of the Annual General Meeting in June, where the election results will be announced.

## **ECFS Winter Meetings**

Brussels, January 2025

The ECFS Board, the ECFS Clinical Trials Network and the ECFS Patient Registry Steering Committees met in Brussels for their annual winter meetings at the end of January. This was an excellent opportunity to meet across ECFS projects, discuss common subjects, find new opportunities for co operation, and catch up with colleagues.



**ECFS CTN Steering Committee** 



## 20th ECFS Basic Science Conference

Lido di Camaiore, Italy - 26 - 29 March 2025





The ECFS Conference is a premier annual event for scientists dedicated to cystic fibrosis research, providing a platform to showcase the latest advancements in the field. The programme will feature a series of symposia with distinguished European and international guest speakers, alongside presentations selected from submitted abstracts. Patrick Harrison (US) will serve as the conference chairperson, supported by Batsheva Kerem (IL) and Dean Madden (US).

For further details, click here.



PATRICK HARRISON



BATSHEVA KEREM



DEAN MADDEN

#### **Symposia**

| Therapeutic approaches for Nonsense and splicing mutations                   |  |  |
|--|--|--|
| Mucus and mucins in CF   |  |  |
| CFTR and cancer / ageing   |  |  |
| CFTR structure and function and therapeutic relevance                        |  |  |
| Patient Organisations-initiated symposium: CFRD from different perspectives: |  |  |
| How do pwCF, clinicians, researchers deal with diabetes in CF?               |  |  |
| Lung regeneration  |  |  |
| Gut microbiome, gut-lung -axis   |  |  |
| Gene editing and delivery  |  |  |

## 48th ECFS Conference

Milan, Italy - 4-7 June 2025



We are actively preparing the 48th European Cystic Fibrosis Conference that will take place from 04 to 07 June 2025 in Milan, Italy. We are delighted to share that 684 abstracts and 17 cases were submitted. This in-person conference will be the perfect opportunity to exchange ideas and network. The Scientific Committee and the Steering Committee have prepared an exciting programme covering all fields of cystic fibrosis and we would like to thank them for their dedication and commitment.

The programme of the conference will also include two plenary sessions, workshops and ePoster sessions for oral presentations of selected abstracts, satellite symposia from the industry and much more. Looking forward to meeting you in Milan!



The Second
Announcement
contains valuable
information to help you
plan your participation.
Download it <u>here</u>.
#ECFS2025

## 48th ECFS Conference

Milan, Italy - 4-7 June 2025

## Symposia

#### <u>Thursday</u>

- The European initiative for (ultra-) rare variants
- Unveiling novel therapeutic targets for microbial pathogen control
- <u>Is inflammation still relevant in cystic fibrosis?</u>
- When care causes trauma how to support patients with cystic fibrosis and their families
- Getting to grips with CFTR genetics to optimise patient care
- Considerations in advanced lung disease
- <u>Infection management in cystic fibrosis beyond Pseudomonas aeruginosa and Staphylococcus</u> aureus
- Organ-specific interplay between CFTR and channels/transporters in transepithelial anion transport
- The new faces of pancreas
- Exercise and physiotherapy throughout the lifespan
- Best of Journal of Cystic Fibrosis, Lancet Respiratory Medicine and European Respiratory Journal

#### <u>Friday</u>

- <u>Imaging in cystic fibrosis, my view!</u>
- Every breath you take
- Nutrition throughout life
- Navigating challenges in gene therapy
- <u>Closing the gap: the intersection of epidemiology, data harmonization, and access to treatments in cystic fibrosis</u>
- Smart monitoring for trials and clinical care
- Looking to the future
- Facing challenges in the post CFTRm era
- Evolving tactics in Pseudomonas aeruginosa resistance development
- Pushing the boundaries of newborn screening for cystic fibrosis

#### Saturday

- Grand Rounds in Clinical CF New!
- Above the glottis
- Managing metabolic health in cystic fibrosis
- <u>Unlocking the power of registries: enhancing our understanding of cystic fibrosis and future proofing data collection</u>
- <u>Lung disease modelling learning from other lung diseases</u>

### Grand Rounds in CF

We are changing the format of the Grand Rounds in Clinical CF session this year (previously Master Class in CF) so cases are open to **all disciplines.** The presenting author of the case study has to be a medical trainee or fellow. The submission must have been supervised by the presenting author's mentor. Besides a free registration to the conference, each presenter of a case study will receive an award of €500.



The session will be held 09:00 - 10:30, Saturday, 07 June2025.

Details on submission will follow soon.

## 48th ECFS Conference

Milan, Italy - 4-7 June 2025

# 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)

## Pre Conference Courses



#### 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 supperative 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 - 17:00

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.

### Call for Nominations

### **ECFS Award**

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. The winner of the award will be invited to present a lecture at the Opening Plenary on 04 June 2025 of the annual conference in Milan, Italy. The deadline for proposals is 14 March 2025. Please email your proposal, accompanied by a detailed motivation and curriculum vitae of the candidate to the ECFS Executive Director, Christine Dubois (christine.dubois@ecfs.eu).

## Gerd Döring Award

The Gerd Döring Award honors an outstanding early-career European scientist annually with a €5,000 research grant. It is awarded based on a significant paper published between 2022-2024, with CVs and personal statements contributing 20% to the evaluation. Eligible candidates are PhD students or postdocs with up to four years of research experience. Nominations from mentors, supervisors, and colleagues are encouraged. The submission deadline is 14 March 2025. Send proposals, including a personal statement, nominated paper (PDF), and CV, to ECFS **Executive Director Christine Dubois** (christine.dubois@ecfs.eu).

## **Outstanding Contribution Award**

The ECFS will establish a new 'Outstanding Contribution Award' to be presented to an AHP each year at the annual conference. Similar to the ECFS award (which remains open to AHP nominations), we ask for nominations from across the ECFS membership and will be seeking to honour a current Society member who has made either a sustained commitment, achieving excellence in the CF field over the course of their career, or who has had a more recent, specific achievement with major impact. The prize winner will be selected by the ECFS Board and invited to the conference, with free registration and have a presentation in the closing plenary. Please email your proposal accompanied by a detailed personal statement of the candidate to jess.matthews@ecfs.eu.

## **ECFS Nursing Special Interest Group**

The NSiG are funding two awards for the conference this year. Please click on the links below for further details.

Nursing Innovation and Research Award

**ECFS Nursing Special Interest Group Travel Grants** 

# ECFS Education Webinars 2025 Save the Dates



#### **Basic Science**

#### Organised by Carlos Farinha and Nicoletta Pedemonte

| Date   | Webinar topic      | Speakers               |
|--|--------------------|------------------------|
| 28th Feb 2025<br>17:00- 18:00 CET /<br>16:00- 17:00 UK | Inflammation in CF | Emanuela Bruscia (USA) |
| 11th Apr 2025<br>17:00- 18:00 CET /<br>16:00- 17:00 UK | The CF Microbiome  | Aurélie Crabbé (BE)    |
| 16th May 2025<br>17:00- 18:00 CET /<br>16:00- 17:00 UK | Models to study CF | Martina Gentzsch (USA) |

#### **Psychosocial and Mental Health**

### Organised by Psychosocial and Mental Health Working Group

| Date  | Webinar Topic   | Speaker(s)   |
|---|---|--|
| 12th Feb 2025<br>12:00 - 13:00 CET /<br>11:00 - 12:00 UK  | Perspectives from different ages: From generation to generation | Els van der Heijden (NL)<br>Urszula Borawska – Kowalczyk (PL)<br>Grażyna Dykowska (PL) |
| 9th April 2025<br>12:00 - 13:00 CET /<br>11:00 - 12:00 UK | Substance abuse and risk-taking behaviour                       | TBC  |

#### **Nutrition**

### Organised by European CF Nutrition Group

| Date   | Webinar Topic  | Speaker(s)                                 |
|--|--|--|
| 26th Feb 2025<br>13:00 - 14:00 CET /<br>12:00 - 13:00 UK | Round up of the new clinical trials and the latest CF nutrition research | Monika Mielus (PL)<br>Joanna Snowball (UK) |

#### **Physiotherapy**

## ECFS Physiotherapy Specialist International Interest Group

| Date  | Webinar Topic             | Speaker(s)           |
|---|---------------------------|----------------------|
| 27th March 2025<br>13:00 - 14:00 CET /<br>12:00 - 13:00 UK  | Inhalation theory         | Catherine Brown (UK) |
| April / May 2025<br>13:00 - 14:00 CET /<br>12:00 - 13:00 UK | Inhalation practical tips | TBC                  |

# Don't Miss



# ECFS Diagnostic Network Working Group Meetings

22nd Annual ECFS DNWG meeting 6-8 February 2025, Laarbeeklaan 103, 1090 Brussels, Belgium (Faculty of Medicine VUB)

ECFS DNWG sweat test workshop 04 June 2025, 15:00 – 18:00

During the conference in Milan, the ECFS DNWG will organize a sweat test workshop (Macroduct® Advanced) for nurses, doctors and lab lab-technicians, supported by Elitech. Registration is required. Further details on how to register will be provided on the ECFS conference website soon.

ECFS DNWG Meeting 06 June 2025, 12:30 – 14:30

During the ECFS conference, the ECFS DNWG will host an open meeting. More information on the program will be available on the ECFS conference website soon



# 18th European Cystic Fibrosis Young Investigator Meeting

26 - 28 February 2025, Paris, France

The European Cystic Fibrosis Young Investigator Meeting (EYIM) is a scientific meeting organised by seven national CF patient organisations, under the umbrella of CF Europe and endorsed by the ECFS. It aims to foster interactions between young scientists in order to create a long-term collaborative European network of CF investigators. The meeting is open both to fundamental and clinical researchers, and the organisers would also like to encourage researchers within psychosocial sciences to apply.



More Information here.

# South Eastern European CF Conference



We are excited to announce the next Southeastern European Conference (SEEC 2025) which will take place in Prishtina, Republic of Kosovo from Thursday 03 to Saturday 05 April, 2025.

The conference is being organised by CF Europe, ECFS and the Association for people with CF in Kosovo with the support of the CF Foundation.

Check out the conference website for full information and to register!

www.southeastcf.eu

# In Other News

#### The Cystic Fibrosis Qualitative Research Network

Are you interested in connecting with other qualitative researchers in CF?

The Cystic Fibrosis Qualitative Research Network (CFQRN) is an international group of researchers with an interest in using qualitative methods in cystic fibrosis research. The network provides a space for peer support, shared learning and collaboration. Hosted from the University of Nottingham, we meet on a quarterly basis via Microsoft Teams and have a Teams channel for the sharing of information. The network is open to all and we are particularly keen to connect with more researchers from outside the UK. If you are interested in joining or would like further information then please visit our Research <u>website</u>, or email Dan Beever. Fellow daniel.beever@nottingham.ac.uk.



#### **Italian Cystic Fibrosis Research Foundation**

The 2024's Italian CF Foundation (Fondazione Ricerca Fibrosi Cistica) annual investigator convention was, for the first time, completely in English. Highlights from the presentations can be watched on <u>YouTube</u>.

A bilingual abstract book can also be found here.





### **Current References in Cystic Fibrosis**

Many thanks to Dr. Henry Ryley for compiling the current references in Cystic Fibrosis that you can download through this <u>link</u>.

## Contact Us

Please contact us if you have news items you would like to have included in future Newsletter or published on the <u>website!</u>









info@ecfs.eu

