

Newsletter

October 2024

Letter from the President

Dear Colleagues and Friends,

I hope this letter finds you well and that you had a restful summer.

In June, we held our Annual General Meeting at the annual European Cystic Fibrosis Conference in Glasgow, UK. I took over the Presidency from Isabelle Fajac, who has served in this role for six years, some of them heavily disrupted by the COVID-19 pandemic, for which we thank her enormously. Damian Downey ended his mandate as CTN director and we officially welcomed Lieven Dupont as the new ECFS CTN director. We said goodbye to Barry Plant as treasurer, and Pavel Drevinek ended his term on the Board. I am delighted to welcome the following changes to the board as Silke van Koningsbruggen-Rietschel steps into the Vice President role, Dorota Sands as Treasurer and Carlos Farinha as Secretary. We had 3 candidates standing for elections and are happy to announce the election of Jürg Barben, Pierre-Regis Burgel and Charles Haworth as Board members.

At the Opening Plenary, Isabelle Fajac presented the ECFS Award to Prof. Scott Bell, who delivered a fascinating talk that set the tone for an enriching and stimulating conference. The Gerd Döring Award, given annually to an exceptional early career young European scientist, was presented to Livia Delpiano for her <u>paper</u>, "Dynamic regulation of airway surface liquid pH by TMEM16A and SLC26A4 in cystic fibrosis nasal epithelia with rare mutations".

The ECFS continues its tradition of awarding grants to young researchers based on the merit of their submitted abstracts. This year, we granted 3 Young Investigator Awards and were delighted to present these awards to Ranmal Avinash Bandara, Johan Sergheraert and Irene Tomarelli at the Closing Ceremony. We were also happy to support 20 young researchers with a Travel Grant. More information on the ECFS Awards can be found <a href="https://example.com/here-nc-market-nc-mar

Several symposia and sessions were recorded and are accessible on the ECFS Education platform with unlimited access for ECFS members with a full or reduced subscription. I would highly encourage you to go back and look at any talks you missed.

The ECFS Conference in Glasgow was a great success and we were delighted to welcome more than 2,000 enthusiastic participants. I would like to thank the Conference President, Gordon MacGregor, as well as the Vice-Presidents, Robert Gray and Lisa Morrison for their enthusiasm and tremendous support. I would also like to thank the Scientific Committee for producing an excellent programme, the Steering Committee for their commitment in making the conference a success, and the speakers, moderators, and presenters for their superb contributions.

The Scientific Committee and the Steering Committee are already preparing an exciting program for the next ECFS conference, which will take place in Milan, Italy on 4-9 June 2025. Save the date so you don't miss it! Abstract submissions will open in December and close on 14 January 2025, so be prepared to submit your research for presentation to your peers!

In other news, many thanks, as always, to Dr. Henry Ryley for compiling the current references in cystic fibrosis in this newsletter.

As always, I encourage you to send us articles that you would like to have included in forthcoming newsletters. This is a great way to communicate with your colleagues and keep them informed about the latest developments in cystic fibrosis research.

Best wishes, Jane Davies ECFS President



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Annual General Meeting



The Annual General Meeting took place during the 47th European Cystic Fibrosis Conference, Glasgow, UK on 07 June 2024.

As usual, we had a very busy agenda with reports from the ECFS President, ECFS Secretary and ECFS Treasurer followed by reports from the Directors of the ECFS projects. The reports from the ECFS Working Groups and Special Interest Groups were provided to the membership ahead of the meeting and coordinators were present to answer any question from the audience.

Changes in the Board include a new CTN Director, a new President and 3 new elected Board members. Damian Downey ended his mandate as CTN director and Isabelle Fajac, Barry Plant and Pavel Drevinek ended their term on the Board.



A new membership category was proposed by the ECFS Secretary, a community membership, which would be for patient organisation representatives, patients and parents, and set at 100 € with full membership benefits excluding voting rights. This received a favourable vote.

Prof. Davies announced the publication of the ECFS Book 'Inflammation and infection in cystic fibrosis' and thanked the chief editor, Prof. Carsten Schwarz and co-editors Prof. Isabelle Sermet, Prof. Dorota Sands, Prof. Daniel Peckham as well as all the authors for their hard work. The eBook will be available on the ECFS education platform.

You will find the full minutes of the Annual General meeting 2024 <u>here</u>.

ECFS 2024 Board Elections

We held Board elections last May. There were two positions open for Board members, and we also elected a new President for the Society, as Isabelle Fajac finished her second term in June 2024. We happily announced Prof. Jane Davies was became President of the ECFS at the AGM in June 2024.

Congratulations also goes to Prof. Jürg Barben, Prof. Pierre-Régis Burgel and Dr. Charles Haworth on their election to the Board .



Prof. Jürg Barben



Prof. Pierre-Régis Burgel



Dr. Charles Haworth

GLASGOW2024

The ECFS Conference in Glasgow was a resounding success, attracting over 2,000 enthusiatic participants. We extend our sincere gratitude to Conference President Gordon McGregor and Vice-Presidents Robert Gray and Lisa Morrison. The Scientific and Steering Committees meticulously crafted an excellent programme that contributed significantly to the conference's success. We also thank the speakers, moderators, and presenters for their outstanding contributions and all participants for their involvement. We look forward to seeing you in Milan next year!

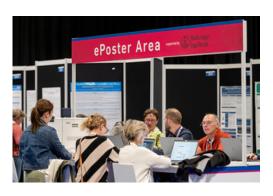




Conference in numbers

2053 participants 1870 app downloads 695 submitted abstracts





62 countries 52 volunteers 18 exhibitors





GLASGOW2024

Conference Award Winners



Scott Bell was awarded the 2024 ECFS Award for his outstanding contribution to cystic fibrosis.



Livia Delpiano was awarded the Gerd Doring Award for her research project. Read the article <u>here</u>.



Travel Grant Award winners

Survey winners

Congratulations to the winners of the post-conference survey who will receive free registration to next year's conference!

- Ngoc Hoa Truong (Paris, France)
- Claudia Mori (Vienna, Austria)
- Maggie McIlwaine (Vancouver, Canada)





ECFS Winter Board Meeting

22 January 2025 Brussels, Belgium

ECFS Winter Meetings of ECFS Projects

23-24 January 2025 Brussels, Belgium

Diagnostic Network WG Meeting

February 2025 TBC

18th European Young Investigator Meeting

26 - 28 February 2025 Paris, France

ECFS Basic Science Conference

26 - 29 March 2025 Lido di Camaiore, Italy

48th European Cystic Fibrosis Conference

04 - 07 June 2025 Milan, Italy

GLASGOW 2024



Conference Experience: Young Investigator

At this, my 7th ECFS conference, I am still in awe of how very special the event is. The opening ceremony is my favourite part of the conference (would you judge me if I said it's one of my favourite parts of the year?!) Feeling awash with excitement and emotion; so many passionate, committed people all together. How far we have come! How far we have to go! The sense of excitement and anticipation in the room is palpable. I love hearing The ECFS Award winners talk about the changing CF landscape throughout their careers, and even better, hearing anecdotes and seeing photos of the questionable hair dos and fashion choices of various CF legends in the 1970s or 80s. Scott Bell did not disappoint, and we saw an array of 'interesting' shirts on people who really should have known better. The opening ceremony's entertainment is always a source of delight, and this year, we were treated to the World's Best Bagpipers (or an accolade to that effect). I immensely enjoyed their stirring melodies as we departed the auditorium to a waiting glass of wine and a catch up with old friends and colleagues at the reception. All these people coming together in one place make it the ideal time to finally meet the disembodied Teams voices we have come to know and love over the years.

With the business of the opening ceremony done, the conference is a wonderful time to hear from leading experts and emerging talent alike. ECFS is a great place for early career researchers and healthcare professionals to present work; it's a friendly and supportive environment with a hugely engaged audience. Glasgow 2024 had an amazing variety of sessions from novel therapeutics in multinational trials, case studies, microbiology (no comment!), sessions on lived experiences in CF and everything in between; there's something for everyone. One of the biggest challenges of the conference was picking which sessions to go to in any given time slot. The Friday morning had three symposia all at once that I wanted to attend. I compromised by hopping between three rooms, catching the parts of the talks I most wanted to hear. It was probably my most athletic endeavour of the year.

My wonderful friend from university asked me to be her bridesmaid on the second weekend of June 2024. I was, of course, thrilled. It was a beautiful day, the couple were ecstatically happy, etc etc. But alas, it did mean I could not make the infamous party this year. I've seen photos of course, and for a small fee I will tell you who left with a traffic cone on their head... But I hear it was a magnificent occasion; a fabulous Cèilidh in a stunning venue. It sounds like the organisers should be incredibly proud.

The conference president promised us that we would work hard and play hard in Glasgow, and I am delighted to report, he was right. Hearing passionate people talk about their work and networking with people with diverse sets of interests always mean I leave the ECFS conference feeling inspired and plotting the next tangent for my research (apologies to my poor colleagues and supervisors). Thank you, Glasgow 2024! What a welcoming, fun city for this great event. See you in Milan in 2025- where I fully intend to stay for the party!

Dr. Rebecca Dobra Clinical Lecturer Imperial College London

MILAN 2025

48th EUROPEAN CYSTIC FIBROSIS CONFERENCE

4-7 JUNE 2025 | MILAN, ITALY





SAVE THE DATE

Abstract Submission open
Abstract Submission Deadline
Registration open
Notification of Abstract Acceptar

WWW.ECFS.EU/MILAN2025

December 2024 14 January 2025 15 January 2025 arly March 2025

#ECFS2025

The ECFS looks forward to welcoming you to the 48th European Cystic Fibrosis Conference in Milan, Italy, on 4-7 June 2025.

Carlo Castellani and Franceso Blasi will be the Conference Presidents and Nicoletta Pedemonte be the Vice-President of the conference.

Milan is a city steeped in history and brimming with contemporary energy. We hope you will enjoy the city's unique atmosphere and discover the many treasures it has to offer.

From the grandeur of the Duomo, a 600-year-old cathedral, to the bustling fashion districts and world-class museums such as the Brera Art Gallery and Sforza Castle, Milan has something to offer to everyone. Whether you are a history enthusiast, a culture seeker, or a fashion aficionado, Milan promises unforgettable experiences and we hope you will discover the unique blend of ancient and modern that makes Milan a truly special city.

Our conference will be hosted in a brand-new building at the MiCo – Milan Convention Center. The venue boasts excellent high-end services and state-of-the-art technology, ensuring a top-notch conference experience.

It is time to mark your calendar:

The abstract submission for the conference will open in December and will close on 14 January 2025. The notifications for abstract acceptance will be sent mid-March 2025 and the deadline for early registration to the conference will be on 20 March 2025.

Looking forward to meeting you in Italy!



Francesco Blasi



Carlo Castellani



Nicoletta Pedemonte



SIFC National Congress - Italian Society For The **Study Of Cystic Fibrosis**

8 - 10 November 2024, Naples, Italy



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 organizers would also like to encourage researchers within psychosocial sciences to apply.

More Information here.

20th Basic Science Conference





This ECFS conference is a key annual event for all scientists working on cystic fibrosis allowing them to showcase the latest advances in the field. The format of the conference will be as usual a series of symposia with invited European and international guest speakers, and presentations selected from the submitted abstracts.

Patrick Harrison (US) has accepted to be the conference chairperson, supported by Betsheva Kerem (IL) and Dean Madden (US).









Batsheva Kerem



Dean Madden

ECFS Education Webinars 2024 and 2025 - Save the Dates



Basic Science Webinars

Organised by Carlos Farinha and Nicoletta Pedemonte

Date	Webinar topic	Speakers
18th Oct 2024 17:00- 18:00 CET / 16:00- 17:00 UK time	Alternative targets in CF	Luis Galietta (IT)
29th Nov 2024 17:00-18:00 CET / 16:00-17:00 UK time	CFTR in the kidney	Jens Leipziger (DK)
30th Jan 2025 17:00- 18:00 CET / 16:00- 17:00 UK time	Modifier genes in CF	Harriet Corvol (FR) & Loic Guillot (FR)
28th Feb 2025 17:00- 18:00 CET / 16:00- 17:00 UK	Inflammation in CF	Emanuela Bruscia (USA)
11th Apr 2025 17:00- 18:00 CET / 16:00- 17:00 UK	The CF Microbiome	Aurélie Crabbé (BE)
16th May 2025 17:00- 18:00 CET / 16:00- 17:00 UK	Models to study CF	Martina Gentzsch (USA)

Standards of Care

Organised by Standards of Care Committee

Date	Webinar Topic	Speakers
22nd Oct 2024 12:30 - 13:30 CET / 11:30 - 12:30 UK time	Timely and accurate diagnosis	Carlo Castellani (IT) & Kevin Southern (UK)
29th Oct 2024 12:30 - 13:30 CET / 11:30 - 12:30 UK time	Establishing and maintaining health	Silke van Koningsbruggen Rietschel (DE) Chris Smith (UK) & Kevin Southern (UK)
5th Nov 2024 12:30 - 13:30 CET / 11:30 - 12:30 UK time	Identifying and addressing CF health issues	Pierre-Regis Burgel (FR), Peter Middleton (AU), Eddie Landau (IL) & Kevin Southern (UK)
12th Nov 2024 12:30 - 13:30 CET / 11:30 - 12:30 UK time	Planning for a longer life	Andrea Gramegna (IT) & Kevin Southern (UK)

Psychosocial and Mental Health

Organised by Psychosocial and Mental Health Working Group



Date	Webinar Topic	Speaker(s)
27th Nov 2024 12:00 - 13:00 CET / 11:00 - 12:00 UK time	Telehealth in psychosocial care	Trudy Havermans (BE), Tamara Vagg (IE), Marieke Verkleij (NL)
5th Feb 2025 12:00 - 13:00 CET / 11:00 - 12:00 UK	The extended CF family and psychosocial issues	TBC
2nd April 2025 12:00 - 13:00 CET / 11:00 - 12:00 UK	Substance abuse and risk-taking behaviour	TBC

Nutrition

Organised by European CF Nutrition Group

Date	Webinar Topic	Speaker(s)
20th Nov 2024 13:00 - 14:00 CET / 12:00 - 13:00 UK time	Liver complications in people with CF: New definitions and implications for nutritional management	Joanna Snowball (UK), Fiona Moore (UK), Monika Mielus (PL)
26th Feb 2025 13:00 - 14:00 CET / 12:00 - 13:00 UK time	Round up of latest CF nutrition research and new clinical trials'	TBC

Conference preparation - applicable to all

Organised by ECFS Physiotherapy Specialist International Interest Group

Date	Webinar Topic	Speaker(s)
Dec 2024 Date & time TBC	Road to Conference (Part 2)	Gemma Stanford (UK), Helen Douglas (UK), and other panel guests

Call for Application: ECFS / CFFE Post Doctoral Research Fellowship

With the aim to foster basic and translational research on cystic fibrosis, the ECFS and CFE have joined forces to support a European Post-Doctoral 3-year duration Research Fellowship starting in September 2025.

All details on the project and application form can 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 link.

Contact Us

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

info@ecfs.eu









