# Letter from the President

Dear Friends and Colleagues,

I hope you are well and that you had a good start of the year.

2023 was a great year for the ECFS with the Basic Science Conference in Dubrovnik, the Annual Conference in Vienna, and a number of meetings of Working Groups and Special Interest Groups. There were also a broad range of activities within the special projects of ECFS among which we can highlight the e-learning programme on cystic fibrosis which is available on the ECFS Education platform for ECFS members and accredited with CME credits by the EACCME®. Moreover, an update of ECFS Standards of Care in the form of several papers was published in the Journal of Cystic Fibrosis. These are very important pieces for the multidisciplinary team and the patients in the changing world of cystic fibrosis.

Planning for the 2024 conferences is well underway and you can find all information on the 2024 Basic Science Conference in Valletta, Malta and on the Annual Conference in Glasgow, United Kingdom on the website. The registration for the conference in Glasgow is now open and I hope to see you all there. We have had a record-breaking 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.

There will be ECFS Board elections in 2024. Changes in the ECFS Board are already happening. Jane Davies will take on the role of President and will officially start her 3-year mandate at the ECFS conference this June. I will be stepping down and Pavel Drevinek and Barry Plant will also end their terms in June. I would like to encourage you all to consider your own nomination or to nominate an ECFS member you believe would benefit the ECFS community by being actively engaged in the Board. Please consider how important these elections are for the future of the Society. Further information about the elections is included in this Newsletter.

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.

The call for applications for the Twinning Expansion Project (TEP) closed at the end of January and we are delighted to see 40 applications from both mentor and mentee sites! The TEP is a three-year collaboration between CF Europe (CFE) and ECFS building on the ECFS Twinning project launched in 2020 to improve patient care, aiming at better access to high quality, multidisciplinary CF care and optimal treatment.

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 six applications which are currently being reviewed, and the winner will be announced at the conference in June.

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

Isabelle Fajac, ECFS President Newsletter February 2024 Issue 74





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# **ECFS 2024 Board Elections**

The ECFS cordially invites nominations for three Board positions. Isabelle Fajac, Pavel Drevinek and Barry Plant will end their terms in June 2024.

Job Description and person specifics are available here.

### Board Member's Job Description.

Nominations should be sent to the ECFS Executive Director Christine Dubois (christine.dubois@ecfs.eu) by **05 April 2024** together with a personal statement, confirmation that the candidate has agreed to the nomination and a curriculum vitae. All nominated candidates must be current ECFS members. Information about the nominated candidates will be sent to our members in April for an online vote prior to the Annual General Meeting in June where the results will be announced.



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 05 June 2024 of the annual conference in Glasgow, United Kingdom. You are cordially invited to nominate a candidate for this award. The deadline for proposals is **11 March 2024**. Please mail your proposal, accompanied by a detailed motivation and curriculum vitae of the candidate to the ECFS Executive Director Christine Dubois (<a href="mailto:christine.dubois@ecfs.eu">christine.dubois@ecfs.eu</a>).

# Gerd Döring Award – Call for nominations

The Gerd Döring Award is an initiative of the ECFS and is given annually to honour an exceptional young European scientist in their early career. The Award consists of a monetary donation of 5,000 euro to support research.

The award will be judged primarily on a paper published in the previous 3 calendar years (2021-2023) which has made a significant impact on the understanding or treatment of cystic fibrosis. Personal statements and CVs will make a 20% contribution to the scoring.

The award is open to PhD students and post-doctoral researchers with up to a maximum of four years' academic research experience following the completion of their PhD, or be of equivalent professional standing at the date of publication of the paper.

We encourage mentors, supervisors and co-workers of today's most exceptional early career European scientists to send in nominations for this award. The deadline for proposals is **11 March 2024**. Please email your proposal accompanied by a detailed personal statement, a PDF of the nominated paper and curriculum vitae of the candidate to the ECFS Executive Director Christine Dubois (christine.dubois@ecfs.eu).



### **Deadlines to remember**

11 March 2024
Nominations ECFS Award

11 March 2024 Nominations Gerd Döring Award

21 March 2024
Deadline Early Registration Fees for the 47th European Cystic
Fibrosis Conference in Glasgow

05 April 2024
Nominations ECFS Board Elections

# 19th ECFS Basic Science Conference

# 20-23 March 2024, Valletta, Malta



For the 19th ECFS Basic Science Conference we will be back in Valletta, Malta, from 20 March to 23 March 2024 and we are delighted that Alexandre Hinzpeter (FR) has accepted to be the conference chairperson, supported by Patrick Harrison (IE) and Marie Egan (US).

We have another exciting programme this year and we look forward to engaging discussions of data and ideas in an informal and interactive environment.

More information



Alexandre Hinzpeter (FR)





# **Upcoming Events**

- Diagnostic Network WG Meeting: **08**-10 February 2024 Hanover, Germany
- ECFS Basic Science Conference 20-23 March 2024 Valletta, Malta
- ECFS Board Summer Meeting 04 June 2024 Glasgow, United Kingdom
- European CF Conference 5-8 June 2024 Glasgow, United Kingdom
- Annual General Meeting ECFS 07 June 2024 Glasgow, United Kingdom
- ERS Conference 07-11 September 2024 Vienna, Austria
- NACEC 26-28 September 2024 Boston, MA, USA

### 47th EUROPEAN CYSTIC FIBROSIS CONFERENCE 5-8 JUNE 2024 | GLASGOW, UNITED KINGDOM





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WWW.ECFS.EU/GLASG0W2024

#ECFS2024



# 47th European Cystic Fibrosis Conference, Glasgow, United Kingdom

We are actively preparing the 47th European Cystic Fibrosis Conference that will take place from 05 to 08 June 2024 in Glasgow, United Kingdom. With a record of 695 abstracts and 28 case submissions submitted, we are sure to expect an excellent edition and are looking forward to welcoming you in Glasgow. 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.

Registrations are now open! Please see here for more information. The Second Announcement has also just been published. It contains valuable information to help you plan your participation. Download it here.

#ECFS2024

# 47th EUROPEAN CYSTIC FIBROSIS CONFERENCE

5 – 8 JUNE 2024 | GLASGOW, UNITED KINGDOM



### **List of Symposia:**

### Thursday 06 June

- Genetic therapies: getting them into the clinic
- Exploring the resilient terrain: insights into bacterial persistence in cystic fibrosis
- Hot topics in lung transplantation
- Psychosocial care in the CFTR modulator era: Did expectations align with reality?
- Incorporating extensive gene analysis into newborn screening for cystic fibrosis (successfully)
- Gastrointestinal, metabolic and malignant complications in adults with cystic fibrosis
- Airway inflammation take home messages for clinical care
- Innovations in action: advancing microbiology methodologies in cystic fibrosis clinical care
- Physiotherapy... Under Pressure

### Friday 07 June 2024

- Pulmonary exacerbations
- Exploring novel nutritional paradigms in cystic fibrosis care: Insights from updated guidelines
- Supporting information for patients and families throughout the lifespan
- Mechanisms of CFTR modulation: what do we know and what is still missing?
- Capturing data from people living with CFTR related disorders: when, why and how?
- How to adapt to changes in life expectancy?
- Clinical trial endpoints in children aged under two years
- Innovative solutions: Exploring new therapies for cystic fibrosis pathogens
- Emerging alternative targets for cystic fibrosis therapeutics
- Providing clear advice to families and children with CFSPID

### Saturday 08 June

- Masterclass in clinical CF great cases
- Stopping treatments in the era of CFTR-modulators
- Recent advances in pulmonary function testing techniques and equipment
- Cystic Fibrosis Hepatic Biliary Involvement (CFHBI)
- Widening the lens Enriching registry data to focus on the determinants of health

# More information here

As in previous years, we will apply for accreditation with CME credits by the EACCME®.





# 47th EUROPEAN CYSTIC FIBROSIS CONFERENCE

5 - 8 JUNE 2024 | GLASGOW, UNITED KINGDOM



# Master Class in Clinical CF – Call for case presentations

For the Master Class in Clinical CF session, a call for the submission of clinical cases has been launched a few days ago. Please consider submitting by **01 March 2024**!

More information

# Master Class in Clinical CF Case Studies Call for Case Presentations Submission Deadline: Friday 01 March 2024 ECFS

# Meet the Experts

The 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 of the expert sessions is limited to 50 participants. Attendance is free for registered participants.

Thursday 06 June: 07:45 - 08:45

- MTE 01: Implementing a healthy lifestyle in cystic fibrosis diet and physical activity
- MTE 02: Maximising the value of registries: novel approaches to study design
- MTE 03: Sampling and diagnostics of airway infections in the future

Friday 07 June: 07:45 - 08:45

- MTE 04: Navigating inflammation and its resolution through the lens of CFTRm
- MTE 05: Physiotherapy data harmonisation
- MTE 06: Pharmacology and psychological side effects of modulator therapy



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 Glasgow!

# **Pre-Conference Courses**

We will be offering a selection of courses prior to the conference. Please note these courses all have limited seating so please book early.

### **Nutrition Short Course**

# Optimising Nutritional Health for the 21<sup>st</sup> Century – Evidence and Clinical Practice

Tuesday 4 June 13:30 - 17:00

This course will provide health care providers with an opportunity to learn and interact with key experts in the field of nutrition. Focus will be placed on addressing some of the emerging situations faced by nutritional experts and provide practical solutions whilst highlighting key publications from the last year.



# 47th EUROPEAN CYSTIC FIBROSIS CONFERENCE

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### **PhySIIG Airway Clearance Instructors Course**

Tuesday 4 June 08:30 - 17:00 Wednesday 5 June 08:30 - 12:30

This course is organised by the ECFS Physiotherapy Special Interest International Group (PhySIIG) and should be attended by highly experienced physiotherapists to train to become certified airway clearance instructors. This course requires completion of an application of interest, which will not guarantee places, to be submitted by **14 February**. Successful applicants will be notified by the PhySIIG committee.



More information.



# Musculoskeletal Issues in Cystic Fibrosis – Muscle Dysfunction & Strength – Posture and Pain

Tuesday 4 June 08:30 - 16:30 & Wednesday 5 June 08:30 - 12:30

This course is organised by PhySIIG and the ECFS Exercise Working Group and will provide the theoretical and practical basis for muscle strengthening incorporation into clinical practice. The second day will include the assessment of posture and pain in people with cystic fibrosis (pWCF) and early pathways for prevention and treatment of MSK issues.

# **Psychology Short Course**

# Co-Creating Personalised Treatment Plans, How to Live Your Best Life Tuesday 4 June 13:00 - 17:00

This course is organised by the European Psychosocial Special Interest Group (EPSIG) and the ECFS Mental Health Working Group and will explore how we as a team can support people with cystic fibrosis to live their best lives, particularly in the new era of modulators. The course will involve developing a deeper understanding of the theory and application of evidence-based treatments; this will include different kinds of approaches for decision-making, including Motivational Interviewing, Strengths Based Approach, Acceptance and Commitment Therapy and



# **Education Group Short Course**



# **ECFS Essential Toolkit 2024**

Wednesday 5 June 12:00 - 17:00

The 2024 version of The Essential Toolkit provides a dynamic and unique comprehensive overview of the changing face of cystic fibrosis (CF). This course is intended for medical and health care professionals involved in either adult and paediatric CF care and/or CF research, and provides a great opportunity to meet, learn and discuss the new era of CF with experts in the field. It is also great fun! Participants will leave with principles and new skills to apply in practice. Pre-course requirements: Basic knowledge on CF pathogenesis and clinical care is preferable, but not essential.

# **ECFS Winter Meetings**

The ECFS Board, the ECFS Clinical Trials Network, the ECFS Patient Registry Steering Committees and the Standards of Care Group 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 cooperation, and catch up with colleagues.



**ECFS Clinical Trials Network Steering Committee Meeting** 



**ECFS Patient Registry Steering Committee Meeting** 

# **ECFS Diagnostic Network Working Group Meetings**

### 21st Annual ECFS DNWG meeting

08-10 February 2024, Hanover, Germany.



04 June 2024, 16:00 - 18:00

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



# **ECFS Diagnostic Network Working Group Meeting**

07 June 2024, 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.

# **ECFS Education**



# Webinars

ECFS Education would like to announce the next two "Special CF Lunchtime Series" webinars by the ECFS Psychosocial Special Interest Group and the ECFS Mental Health Working Group:

"Challenges in the clinic in the era of CFTR modulator therapy: educational and informational insights" Wednesday 21 February 2024, 12:00 - 13:00 CET/ 11.00 - 12.00 UK

For more information and how to register for this webinar, please visit <a href="https://www.ecfs.eu/mental\_health-tools/news">https://www.ecfs.eu/mental\_health-tools/news</a>

'Should all children with cystic fibrosis who have responsive CFTR mutations be prescribed CFTR modulators?' Wednesday 17 April 2024, 12:00 – 13:00 CET/ 11.00 - 12.00 UK

More information about this webinar will be released soon!

# **eLearning Programme**

The ECFS has also been developing an e-learning programme on cystic fibrosis (CF). Part 1 "CF for Beginners" (7 modules covering the fundamental basics) and Part 2 "More about CF" (17 modules which built upon the first part) have received UEMS EACCME accreditation and are available on the ECFS Education Platform for free for all eligible ECFS members.



Work has started on the final part, Part 3 "Becoming a CF clinical expert: How to manage...". It will contain 31 modules and will allow in-depth discussion about care and treatment of very specific situations occurring in people with CF. We will keep you updated with the progress of this project as it advances.

To access the e-learning programme on the ECFS Education Platform:

- ⇒ Log into your ECFS account (https://www.ecfs.eu/user/login), and then access the ECFS Education homepage (www.ecfs.eu/education) and click on the button for the Platform.
- ⇒ Once on the ECFS Education Platform home page, click on 'ECFS courses, conferences and meetings'. To access the e-learning programme, select the 'ECFS e-learning programme on CF' and click on 'Start' to commence the course!
- ⇒ It is possible to stop and start the course and come back to it later; If the e-learning was the last resource you have viewed, simply click on the resume icon on your Education Platform home page and you will be taken back to the course.

# **Twinning Expansion Project**

The expansion of the successful Twinning Project began last year. The Twinning Project was set up to build partnerships between a pair of CF sites: one of the pair being an expert CF centre with a long-term outstanding history in CF care ("mentor site"), and the other ("mentee site") being a site which has an ambition to improve clinical outcomes and welcome the guidance, advice and collaboration of a well-established CF centre. Funding is given to both mentor and mentee sites for site visits to strengthen these collaborations.

Final numbers from the Twinning Expansion Call were received at the end of January and we are delighted to see a total of 40 applications from 19 mentor and 21 mentee sites. The Twinning Executive Board has been appointed by the ECFS Standards of Care Group and will shortly begin to review the applications. Pairs will be matched according to expertise needed and offered. The twinning pair proposals will be presented to the ECFS Board for final approval later this month. Following this, the newly twinned pairs will be announced. As well as the twinned pairs building their partnership, the project also aims to support and facilitate networking between patient organisations and CF centres participating in the project.







### ECFS on Social Media

Follow us on social media Follow us on social media to stay connected and receive updates on the ECFS activities!











# **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>.

European Cystic Fibrosis Society Kastanieparken 7 7470 Karup Denmark