

Letter from the President

Dear Friends and Colleagues,

I hope you and your dear ones are well and that you had a good start to the new year. We very much hope that 2022 will be the year when we see the end of the pandemic and the restrictions it imposes. Over the last months, many of you expressed the need to network, exchange ideas and experiences, to have live discussions and meet again. We are happy to be organising two in-person events in the coming months with the Basic Science Conference in Portugal end of March, and the Annual European Cystic Fibrosis Conference in Rotterdam in June. The ECFS Basic Science Conference 2020 was the first ECFS event to be cancelled because of the COVID-19 pandemic and we are very happy to see the 2022 ECFS Basic Science conference happening in person in Albufeira, Portugal from 30 March to 2 April.

Planning for the 2022 conferences is thus well underway with all necessary information available on the website. I would like to thank all those who have submitted abstracts and all the speakers who have accepted to contribute to conferences. We have excellent programmes and courses planned and we look forward to your participation.

There will be ECFS Board elections in 2022 as Trudy Havermans and Isabelle Sermet-Gaudelus will finish their terms in June. I wish to thank them for their commitment at the Board: Trudy spoke for allied-health professionals and it is extremely important that as pivotal members of the multidisciplinary team, their views are expressed at the Board. Isabelle undertook to organise an e-learning programme on CF that will soon be available on the ECFS Education platform. She will continue to develop this programme. 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 later in the Newsletter.

The ECFS will, this year again, be granting a Gerd Döring Award to honour an exceptional young European scientist in early career. The award is open to PhD students and post-doctoral researchers with up to a maximum of four years' academic research experience and will be based on a paper published in the last 3 years (2019-2021). Please send in your nominations for this important award.

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



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ECFS 2022 Board Elections

The ECFS cordially invites nominations for two Board positions.

Trudy Havermans and Isabelle Sermet-Gaudelus will end their terms in June 2022.

Job Descriptions and person specifics are available [here](#).

Nominations should be sent to the ECFS Executive Director Christine Dubois (christine.dubois@ecfs.eu) by 28th March 2022 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.



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 (2019-2021) 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 1st March 2022. 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

01 March 2022
Nominations Gerd Döring Award

28 March 2022
Nominations ECFS Board Elections

24 March 2022
Early Registration Fees for the
45th European Cystic Fibrosis
Conference in Rotterdam

The 17th ECFS Basic Science Conference will be the first in person event that the ECFS will organise this year. We will be back in Albufeira, Portugal, from 30 March to 02 April 2022 and we are delighted that Carlos Farinha (PT) has accepted to be the conference chairperson, supported by Nicoletta Pedemonte (IT) and Jeff Brodsky (US). We have an exciting programme this year again and we look forward to fruitful discussions of data and ideas in an informal and interactive environment.

[More information](#)



Carlos Farinha (PT) Nicoletta Pedemonte(IT) Jeff Brodsky (US)



45th EUROPEAN CYSTIC FIBROSIS CONFERENCE

8 – 11 JUNE 2022 | ROTTERDAM, THE NETHERLANDS



Upcoming Events

- **Diagnostic Network WG Meeting:**
Online: 9-11 February 2022
- **ECFS Basic Science Conference**
30 March—02 April 2022
Albufeira, Portugal
- **ECFS Board Summer Meeting—Rotterdam**
7 June 2022
- **European CF Conference**
Rotterdam, Netherlands
8-11 June 2022
- **Annual General Meeting ECFS**
Rotterdam -10 June 2022
- **ERS Conference**
Barcelona,
4-6 September 2022
- **NACFC**
November 3-5, 2022
Philadelphia, USA

REGISTRATION IS OPEN



We are actively preparing the 45th European Cystic Fibrosis Conference that will take place from 08 to 11 June 2022 in Rotterdam, the Netherlands. We will all be happy to meet again in person. The success of two digital conferences organised in September 2020 and in June 2021 was beyond our expectations. We received a lot of positive feedbacks for the quality of the programme and the adaptation to the online format. However, all expressed a strong wish to have a live conference to exchange ideas and network and this definitely indicates that we are set to break a record of attendance in 2022, as the CF community is so much looking forward to meeting in person in Rotterdam. 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.

45th EUROPEAN CYSTIC FIBROSIS CONFERENCE

8 – 11 JUNE 2022 | ROTTERDAM, THE NETHERLANDS

List of symposia:

Thursday 09 June

- 1 - CF Research in the roaring twenties
- 2 - New antimicrobial therapy
- 3 - Clinical Responses to CFTR modulator therapy from cell to patient
- 4 - Out in the wilderness: Transplantation and the co-ordination of care
- 5 - A whole new world - Physiotherapy management in good responders to modulator therapy: ideas please!
- 6 - Understanding the mechanisms of CFTR modulation
- 7 - Infection beyond CFTR modulators
- 8 - Monitoring cystic fibrosis in 2022 – Research tools or ready for clinic?
- 9 - Inflammation in early CF lung disease
- 10 - Ethics in genetics
- 11 - Individual cell cultures as biomarkers of CFTR function
- 12 - Thinking differently about the GI tract



Friday 10 June

- 13 - What's next for CFTR modulators?
- 14 - Lung transplantation – 2022 update
- 15 - "It's life, Jim, but not as we know it"
- 16 - Nutrition in cystic fibrosis
- 17 - Best of Journal of Cystic Fibrosis / Lancet Respiratory Medicine / European Respiratory Journal
- 18 - Enhancing CF registry studies through linkage with other data sources
- 19 - Ageing with cystic fibrosis
- 20 - Real world data with CFTR modulators
- 21 - The "haves" and the "have nots" – Psychological sequelae of CFTR modulator therapies
- 22 - Impact of biofilm in cystic fibrosis
- 23 - The changing face of newborn screening for cystic fibrosis
- 24 - Advances in gene and cell therapies for cystic fibrosis



Saturday 11 June

- 25 - What's new with fungi in cystic fibrosis
- 26 - Women's health
- 27 - Master Class in Clinical CF - Case Studies
- 28 - Liver disease in cystic fibrosis
- 29 - Epidemiology of screening and CF genotype
- 30 - Targets for CFTR bypass therapy

More information [here](#)

For the Master Class in Clinical CF session, a call for the submission of clinical cases will be sent in the coming weeks. Please consider submitting!

The programme will also include workshops and ePoster sessions for the oral presentations of selected abstracts, Meet the Experts sessions, Satellite symposia from the industry and much more.



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

We will be offering a selection of courses prior to the Conference.

Clinical Nutrition Course

**Practical interventions to optimise nutrition.
A basic/revision course**

Tuesday 7 June – Half Day

The aim of this course is to provide practical information for clinical application to maximise nutrition outcomes. It will signpost towards the most recent data / guidelines that underpin the above. This course is meant for those new to CF or those who work directly with CF patients wishing to revisit the fundamental principles.



Physiotherapy Short Course

Assessment and interpretation of literature – how to translate research results into working practice recommendation – the upper airways

Tuesday 7 & Wednesday 8 June – 1.5 Day

This course is intended for physiotherapists, physical or respiratory therapists who require training in the assessment and interpretation of literature and the upper airways. The course will help build on existing knowledge as well as how research results can be translated into daily working practice recommendations.

The course will include both theory and practical sessions, while small group sessions allow lots of opportunity for discussion.



Managing Challenging Conversations

A simulation-based masterclass for trainees and healthcare professionals working with persons who live with cystic fibrosis

Tuesday 7 June - All day

The aim of this course is to enhance effective communication skills for medical trainees and health professions who work with people living with CF. Due to the nature of CF, healthcare professionals (HCPs) are faced with a unique and often diverse range of challenging situations to manage. Training in this area is often not easily facilitated in the clinical arena. Simulation offers training and development in a safe learning environment.

The course is intended for medical trainees specialising in working with people with CF, with the intended impact of this masterclass to enhance the skills of trainee or early career HCPs in managing challenging encounters with people living with cystic fibrosis.



Sex, intimacy and reproductive health in cystic fibrosis

Tuesday 7 June - All day

The ECFS Mental Health Working Group and European Psychosocial Special Interest Group (EPSIG) will hold a joint one-day course about sexuality, fertility, and family planning in cystic fibrosis, and the practical skills how to talk about it with patients. This course will discuss the opportunities and challenges for health services in applying a life-course perspective to address sexual and reproductive health with people with CF. It will give the opportunity to learn about the importance of sexuality and how it affects quality of life for both patients with CF and their partners. The course will have a theoretical framework with opportunities to practice applying it to CF case examples. The course is intended for all members of the multi-disciplinary team (MDT).

ECFS Winter Meetings

The ECFS Clinical Trials Network and the ECFS Patient Registry Steering Committees met online on 27 and 28 January for their annual winter meetings. This was an excellent opportunity to meet across ECFS projects, discuss common subjects and find new and even better opportunities for cooperation.

The CTN organised a Steering Committee meeting on January 27th. This meeting was very well attended by CTN investigators and patient organisation representatives: 90 attendees joined in real time. The ECFSPR held its Steering Committee meeting on January 28th. This meeting was very well attended by all those participating to the ECFS Patient Registry.

All are looking forward to meeting in person again for the next meetings in Rotterdam in June!

ECFS Diagnostic Network Working Group Meetings

The ECFS Diagnostic Network Working Group had to take the difficult decision to hold its annual winter meeting online. The in-person meeting will be postponed to 2023.

The online meetings will be held over three days, from Wednesday 9 February to Friday 11 February, 09:00 to 12:30 CET each day.

[Meeting programme](#)



“Special CF Lunchtime Series » Webinar

PAST, PRESENT AND FUTURE PSYCHOSOCIAL CARE IN CF

Webinar:

Wednesday 23rd February 2022

12:00 – 13:00 CET / 11.00 - 12.00 UK*

FREE REGISTRATION

****Please check the time of the webinar in your country / time zone!***



Urszula
Borawska
- Kowalczyk (PL)



Mandy
Bryon (UK)



Johanna
Gardecki (DE)



Trudy
Havermans (BE)

The ECFS Psychosocial Special Interest Group and the ECFS Mental Health Working Group will organise a webinar as part of the “Special CF Lunchtime Series” on Wednesday 23rd February 2022 at 12:00-13:00 CET / 11:00-12:00 UK time.

PAST, PRESENT AND FUTURE PSYCHOSOCIAL CARE IN CF will be a special webinar, in light of Mandy Bryon's retirement in 2022.

More information and registration [here](#)

Job Posting

The University of Milan is recruiting a statistician for the joint research activity with the European Cystic Fibrosis Society Patient Registry (ECFSPR).

[Job Posting](#)



Obituary

We are saddened to inform you that Professor Gabriel Bellon passed away on November 24, 2021 at the age of 74.

He will be remembered as a paediatrician of great kindness towards the members of his team, the parents and the many children he took care of throughout his career as a paediatrician at the Lyon Sud hospital, at the Debrousse hospital and at the Woman Mother Child Hospital.

He developed paediatric pneumology in Lyon, at a time when paediatric subspecialties did not exist and everything had to be invented. Gabriel Bellon was devoted to the local, regional (EMERAA network) and then national organization of the care of patients with cystic fibrosis. He was a pioneer in many areas of what makes the model of rare disease pathways so successful today.

He also participated in the creation of learned societies such as the society of paediatric pneumology and allergology (SP2A), the French society of cystic fibrosis (SFM), was president of the French society of paediatrics and organized during his mandate the first congress which brought together for the first time in one place all the medical and surgical specialists of paediatrics.

A tribute written by Prof Isabelle Durieu and Prof Philippe Reix:

[Décès du Pr Gabriel Bellon - Filière Muco CFTR - mucoviscidose \(muco-cftr.fr\)](#)

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](#).



European Cystic Fibrosis Society
Kastanieparken 7
7470 Karup
Denmark