

Letter from the President

Dear Friends,

I hope you had a good start to the year. I wish you and your family all the best for 2020!

2019 was another busy year for the European Cystic Fibrosis Society, with not only the Basic Science Conference in Dubrovnik and the Annual Conference in Liverpool, but a number of special projects and Working Group meetings were held and some selected updates are given below.

There will be ECFS Board elections in 2020 as Marcus Mall

and Kevin Southern will finish 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 later in the Newsletter.

Planning for the 2020 Conference is 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 the conference.

There is a special discounted rate for attendees from lower income countries in an effort to encourage participation of healthcare professionals from all countries. We have excellent programmes and courses planned and we look forward to your participation.

To foster basic and translational research in CF, the ECFS and CFE have joined forces to support a number of European Post-Doctoral 2-year duration Research Fellowships. This is a very important project that we think will help research in CF and bring new young talented researchers in the field of CF. The deadline is fast approaching and we hope this new project will be successful!

We have a lot to do over the coming months and I hope you will join us for some of these activities.

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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3 – 6 JUNE 2020 LYON, FRANCE

43rd EUROPEAN CYSTIC FIBROSIS CONFERENCE



SECOND ANNOUNCEMENT

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ECFS Award – Call for nominations

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 of the annual conference in Lyon on 3 June 2020.

You are cordially invited to nominate a candidate for this award. The deadline for proposals is 28 February, 2020. Please mail 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 – Call for nominations

The Gerd Döring Award is an initiative of the European Cystic Fibrosis Society and is given annually to honour an exceptional young European scientist in their early career. The Award, a monetary donation of 5,000 euro to support research, will be presented at the Opening Plenary of the annual ECFS conference in Lyon.

The award will be judged primarily on a paper published in the previous 3 calendar years (2017-2019) 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 competition. The deadline for proposals is 28 February, 2020. Please mail 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).

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ECFS-CFE Post-Doctoral Research Fellowship

The ECFS and CF Europe are pleased to announce a call for applications for their Post-Doctoral Research Fellowship programme. With the aim to foster basic and translational research on CF, the ECFS and CFE have joined forces to support a number of European Post-Doctoral 2-year duration Research Fellowships. Applications are due by 23.59 on 14 February 2020

More details on the project and application form can be found here

2020 ECFS Board Elections

Upcoming Events

- Diagnostic Network WG Meeting: Utrecht (NL) 6-8 February 2020
- ECFS Basic Science Conference, Albufeira (PT) 25-28 March 2020
- European CF Conference Lyon (FR) - 3-6 June 2020
- ECFS Board Summer Meeting Lyon (FR) - 2 June 2020
- Annual General Meeting ECFS Lyon (FR) - 5 June 2020
- North American Cystic Fibrosis Conference October 22-24, 2020 Phoenix, AZ (US)

The ECFS cordially invites nominations for 3 Board positions.

Marcus Mall and Kevin Southern will end their terms in June 2020.

President Elect: Isabelle Fajac will finish her term as President in 2021.

Job Descriptions and person specifics are available for both the President and Board members.

President's Job Description | Board Member's Job Description.

Nominations should be sent to the ECFS Executive Director Christine Dubois (christine.dubois@ecfs.eu) by 23 March 2020 together with a personal statement, confirmation that the candidate has agreed to the nomination and a curriculum vitae. All nominated candidates must be current members of the ECFS. Information about the nominated candidates will be sent to the membership in April for an online vote prior to the Annual General Meeting in June where the results will be announced.



ECFS Board Meeting - Brussels, 22 January 2020

ECFS Meetings - CTN, Patient Registry, Standards of Care



ECFS CTN Steering Committee

The ECFS Clinical Trials Network and the ECFS Patient Registry Steering Committees met on 23-24 January in Brussels for their annual winter meetings. The Standards of Care Group also met in Brussels. This was an excellent opportunity to meet across ECFS projects, discuss common subjects and find new and even better opportunities for cooperation

Deadlines

• 14 February 2020

Applications for the ECFS-CFE Post-Doctoral Research Fellowship

- 28 February 2020 Nominations ECFS Award
- 28 February 2020 Nominations Gerd Döring Award
- 25 February 2020 Early Registration Fees Basic Science Conference
- 19 March 2020
 Early Registration Fees
 ECFS Conference Lyon
- 23 March 2020 Nominations ECFS Board Elections



ECFS Patient Registry Steering Committee

17th ECFS Basic Science Conference



The 2020 ECFS Basic Science Conference will be back in Albufeira, Portugal, from 25 to 28 March 2020. 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

43rd European CF Conference – Lyon, France

The Annual Conference is fast approaching. With nearly 600 abstracts submitted, we can expect another excellent edition and we are looking forward to welcoming you in Lyon. To promote the access to all, we have a limited number of single day registration available and hope it will more flexibly answer the needs of the delegates. For the second year we will offer a Team ticket, allowing 3 allied health professionals from the same team to share a registration. More information on the Team ticket can be found <u>here</u>. The reduced registration rate for participants working in countries classified as low-income economies, lower-middle-income economies and upper-middle-income economies by the World Bank, will be also available. We hope this opportunity will encourage many more healthcare professionals to attend the conference. All information related to the registration can be found <u>here</u>. And do not forget to have a look at the scientific programme <u>here</u>.

New course - Managing challenging conversations: A simulation-based masterclass

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 CF.

Clinical nutrition course

The aim of this course is to focus on and explore some of the key practical nutritional decisions facing Multidisciplinary CF teams today.

There will be lectures presenting our most difficult nutritional decisions such as how and when to alter nutritional advice when body mass index accelerates, how to tailor nutritional advice in the context of modulator therapy and when and how to focus on diet quality. These current challenging issues will be examined from a practical perspective and the data that surround them critically reviewed. There will also be the opportunity for participants to submit their own challenging clinical nutritional situations. Several of these will be selected for presentation which will then be open for facilitated discussion. This is an ideal environment for participants to engage with colleagues and experts to discuss and share real-life clinical nutrition dilemmas and come away with a range of practical solutions from participants and experts from across Europe.

This course is meant for all levels of health care nutrition providers including dietitians, gastrointestinal leads and all CF multidisciplinary members.



Physiotherapy Short Course: From research to daily work practice – 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 between participants and course tutors.

This course is intended for physiotherapists, physical or respiratory therapists who require training in the assessment and interpretation of literature and the upper airways.

Practical therapeutic modalities to manage anxiety, depression, sleep and pain in routine CF care

The ECFS Mental Health Working Group and ECFS Psychosocial Special Interest Group (EPSIG) are holding a joint one-day course about the use of different therapy modalities in supporting people with CF to manage anxiety, depression, sleep and pain. The morning session will focus on introducing individuals to the concepts of each of the accessible practical therapies, the evidence for their effectiveness, the practical implications of using them in clinical settings, and a discussion about the next steps regarding further training and support. In the afternoon, individuals will break out into small groups, and have the chance to gain hands-on experience in using some of these different therapeutic skills for use in routine CF care.

This course is intended for all members of the multi-disciplinary team including doctors, nurses, physiotherapists, dietitians, psychologists, social workers etc.

CF Course - A tour of Cystic Fibrosis -"The essential Toolkit" 2020

The aim of this course is to provide participants with the essential knowledge about cystic fibrosis, its main clinical features, its pathophysiology and current and future treatments.

This course is intended for early career medical and paramedical health care workers involved in CF care and /or CF research: adult and paediatric physicians including doctors in training, nurses and nurse specialists, physiotherapists, dietitians, biomedical scientists, psychologists and social workers with background medical understanding

The course will also be organised in French in a parallel session:

Cours sur la mucoviscidose – Principes de base



All information on the pre-conference courses can be found here

ECFS Short Term Clinical Fellowship

Here are short reports sent by two recipients of the CF Preceptorship Programme: Aziz Turdiev, International University of Kyrgyzstan - <u>Report</u> Andrea Vukić, Univeristy Hospital Centre Zagreb, Croatia - <u>Report</u>



Research Fellowship Royal Brompton Hospital, London

The Royal Brompton & Harefield NHS Foundation Trust is seeking to appoint two Clinical Research Fellows in Paediatric Respiratory Medicine, based at the Royal Brompton Hospital which provides a comprehensive cardiothoracic service not only for North West London but nationwide. The posts are available from 7th September 2020 for 1-2 years in the first instance, extendable to up to 3 years by mutual consent.

More information here

Respiratory Physiologist - Royal Brompton Hospital, London

A Respiratory Physiologist post has become available within the busy lung clearance index (LCI) core facility; the main purpose will be to perform tasks within the LCI core facility, including qualification of LCI operators and over reading of LCI traces sent in from a number of European and worldwide cystic fibrosis centres participating in innovative clinical trials. This candidate will also provide training for colleagues as well as operators at global cystic fibrosis centres.

More information here

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

Email: david.debisschop@ecfs.eu



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>.

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