

Letter from the President

Dear Colleagues and Friends,

I hope that you are well, and that you could enjoy some rest during the Summer.

In June, we organised our Annual General Meeting online. This was the opportunity to warmly thank Jane Davies, Pavel Drevinek and Barry Plant who ended their mandates at the ECFS Board but also to welcome them for a second mandate as the voters to the Board elections renewed their trust in the three of them. We also welcomed on the ECFS Board Damian Downey who is taking over the reins of the ECFS-Clinical Trials Network following the successful leadership of Silke van Koningsbruggen-Rietschel, and Kevin Southern, who is the director of the ECFS Standards of Care, succeeding Carlo Castellani's wonderful leadership. There are also changes in ECFS Education as Chris Smith joined Daniel Peckham as deputy director for one year. Chris will become the director of the ECFS Education in 2022. Thanks again to them all for their dedication and commitment to the ECFS.

For those of you who participated in the digital ECFS Conference in June, I am sure you will agree that it was a great success, and I would again like to thank the conference President Carlo Castellani, as well as the Vice-Presidents Carla Colombo and Francesco Blasi for their contribution to the event. With more than 2,000 participants, the attendance to the conference was beyond our expectations and we received a lot of positive feedbacks for the quality of the programme and the adaptation to the online format. My sincere thanks go to the Scientific Committee who produced an excellent programme, to the Steering Committee for their commitment to make the conference a success and to the speakers, moderators and presenters for their superb contribution.

All sessions were recorded and accessible on the conference platform for three months and are now available on the Education platform with unlimited access for the ECFS members.

For more than a year now, our online educational opportunities, with the two digital conferences as well as the numerous webinars and sessions organised online, contributed to maintaining links within the CF community. In October, there will be a third [Basic Science webinar](#) and the CTN will also launch a [webinar series on Real World Evidence](#) (RWE) in cystic fibrosis. Also, the Mental Health working group and the Psychosocial Special Interest Group will continue the [Special CF lunchtime webinars series](#) they launched last year. The digital formats allow to create a forum for discussions, exchange of ideas and network, though we are all impatient to meet in-person! We are looking forward to welcoming you in Albufeira, Portugal for the ECFS Basic Science conference at the end of March 2022 and in Rotterdam in June together with Harm Tiddens and Jeffrey Beekman who will respectively be the President and Vice-President of the Annual Conference in 2022. Learn more about the timelines to submit abstracts and register to both conferences in this newsletter.

To foster basic and translational research in CF, the ECFS and CFE have joined forces and currently support three European Post-Doctorates with a 2-year duration Research Fellowship. A new call will be launched on October 1st and we hope we will receive many applications! Learn more about it in this newsletter.

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 would like to remind you to please feel free to send us articles that you would like to have included in forthcoming newsletters as this provides a great vehicle for communication.

Best wishes,

Isabelle Fajac, ECFS President



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Annual General Meeting

The Annual General Meeting took place online on 9th June 2021.

We were very happy to see that 162 members attended the AGM and we thank you all for your commitment. 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.

Several ECFS Projects leaders ended their mandates and the AGM was the perfect opportunity to thank them and acknowledge their excellent work over the last years:

- Silke van Koningsbruggen-Rietschel for the Clinical Trials Network
New Director: Damian Downey (UK)
- Carlo Castellani for Standards of Care
New Director: Kevin Southern (UK)

You will find the full minutes of the Annual General meeting 2021 [here](#)

ECFS 2021 Board Elections

The ECFS is happy to announce the results of the 2021 Board elections. We had 3 positions open.

Jane Davies, Pavel Drevinek and Barry Plant were re-elected and already started a second mandate at the Board for three years.



Rotterdam 2022

The ECFS looks forward to seeing you at the 45th European Cystic Fibrosis Conference in Rotterdam, the Netherlands on 8-11 June 2022.

45th EUROPEAN CYSTIC FIBROSIS CONFERENCE

8 – 11 JUNE 2022 | ROTTERDAM, THE NETHERLANDS



SAVE THE DATE

Registration and Abstract Submission	December 2021
Abstract Submission Deadline	14 January 2022
Notification of Abstract Acceptance	10 March 2022
Deadline for Early Registration	24 March 2022

WWW.ECFS.EU/ROTTERDAM2022 #ECFS2022

Upcoming Events

- **CF course in Italian:**
Online: 27-30 Sept. 2021
- **Diagnostic Network WG Meeting:**
Online: 01 Oct. 2021
In person: 10-12 Feb. 2022
Montpellier, France
- **Webinar “Other channels that modify CFTR containing epithelia”**
13 October 2021
- **Webinar “The basic approach towards CFTR modulators in this new era”**
27 October 2021
- **North American Cystic Fibrosis Conference**
02–05 Nov. 2021
Fully digital
- **ECFS Board Winter Meeting**
25 Jan. 2022
Brussels, Belgium
- **ECFS Winter Meetings**
26–28 Jan. 2022
Brussels, Belgium
- **ECFS Basic Science Conference**
30 March–02 April 2022
Albufeira, Portugal
- **45th European CF Conference**
8-11 June 2022
Rotterdam, The Netherlands

We received a lot of positive feedbacks for the digital conference in June. However, all participants expressed a strong wish to meet again in person and this definitely indicates that the conference in 2022 will be a great success!

A few days ago, we visited the brand-new venue that will host our conference. The Rotterdam Ahoy Convention Centre (RACC) opened its doors in 2020 and we are convinced that this state-of-the-art facility will be the perfect location to meet again your colleagues and friends after such a long time.

The abstract submission for the conference will open in December and will close on 14 January 2022. The notifications for abstract acceptance will be sent by 10 March 2022 and the deadline for early registration to the conference will be on 24 March 2022.



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 cystic fibrosis, the ECFS and CFE have joined forces to support a number of European Post-Doctoral 2-year duration Research Fellowships.

Applications are due by 16 January 2022 (23:59 CET)

More details on the project and application form can be found [here](#)

- Call: 01 October 2021 until 16 January 2022 23:59 CET



TIMELINE FOR 2022 CALL

- Evaluation and selection: January to mid-May 2022
- Results: June 2022 presented at the ECFS annual conference
- Contracts with institutions over the Summer/Autumn
- Launch: As from September 2022 and as soon as contract in place with institution

Two new positions open at the ECFS Patient Registry

For pharmacovigilance studies, the ECFS Patient Registry and the Justus Liebig University Gießen, Germany are recruiting:

- a data quality manager who will be the in-house data expert and will foster and ensure data quality across the Registry and the participating countries under the supervision of PD. Dr Lutz Naehrlich and the international Registry team.
[More information](#)
- a project coordinator to coordinate and administer the pharmacovigilance studies associated activities under the supervision of PD. Dr Lutz Naehrlich. The project coordinator will assist the Study Manager and will be part of the Registry team led by the Registry Coordinator.
[More information](#)



Application deadline: 19 October 2021.

Education

- CF Toolkit 2021 in three languages!

On 23 September, the ECFS Education organised A Tour of Cystic Fibrosis- “The Essential Toolkit”, a CF Course intended for early career medical and paramedical health care workers involved in CF care and / or CF research.

The course was organised online and we were very happy to see so many joining us for this event which was awarded 3 continuing medical education credits. The course will soon be available on the ECFS education platform.

Together with the Italian CF Society, the CF course was developed in Italian. The course, “Gli strumenti essenziali per avvicinarsi alla fibrosi Cistica”, is being held online over 4 days (27-30 September) and will also be available as an accredited distance learning educational opportunity for a few months from October. The recordings of the Italian edition of the CF course will be available to the ECFS members on the ECFS Education platform.



We take the opportunity to remind you that the Spanish edition of the course, “Un Recorrido por La Fibrosis Quística: 'Herramientas esenciales’”, is also available on the Education platform.

Once again, we thank all the speakers and moderators for their kind cooperation

- Basic Science Webinar

Close to 250 people registered to the second Basic Science Webinar held in July. The sessions were recorded and are available on the ECFS Education Platform.

Mark your calendar for the third webinar, “Other channels that modify CFTR containing epithelia”, on 13 October 2021. [More information](#).

Other channels that modify CFTR containing epithelia

13 October 2021

04:00 – 05:20 p.m. (CEST)
03:00 – 04:20 p.m. (UK time)

BASIC SCIENCE WEBINAR

Please also mark your calendar for the Basic Science Conference that will take place in Albufeira, Portugal from 30 March to 02 April 2022.

Abstract submission will open in December.

- Special CF lunchtime webinars series

The Mental Health Working Group and the Psychosocial Special Interest Group will organise 4 [webinars](#) in the coming months.

Save the date:

- 27 October 2021: “The basic approach towards CFTR modulators in this new era”
- 15 December 2021
- 23 February 2022
- 27 April 2022

Timing: 12:00-13:00 CET / 11:00-12:00 UK time

- CTN – Real World Evidence in Cystic Fibrosis

With the arrival of new therapies in clinic, real world evidence (RWE) is becoming important in CF. Meanwhile regulatory and HTA requirements are evolving, and often reference CF therapies in their case studies.

ECFS-CTN invites you to join a webinar series to learn all about RWE in cystic fibrosis. We bring together speakers from across the spectrum of stakeholders, from patients, to academic experts in CF and other rare diseases, industry, EMA and reimbursement agencies.

The webinars are open to anybody with an interest in RWE including clinicians, research coordinators, academics, patient organisation representatives and industry.

We thank Fiona Dunlevy for having setup the programme and all the speakers and contributors.

[More information](#)

Sign up! An ECFS-CTN webinar series

Real world evidence & cystic fibrosis :

Clinical research in the real world

ecfs-ctn
webinar series

Schedule

- **Real world evidence: an introduction, the ECFS Patient Registry, and the patient perspective**
Wednesday 6th October 2021, 12:30-14:00 CET
- **Real "real world" studies in cystic fibrosis and beyond**
Wednesday 13th October 2021, 12:30-14:00 CET
- **Real world evidence in regulatory approval and reimbursement**
Wednesday 20th October 2021, 12:30-14:00 CET

See the full programme and register here www.ecfs.eu/ctn/webinars

Open to anyone with an interest in evidence generation and synthesis for bringing new medicines to people with CF in Europe as quickly as possible.

Upcoming webinars

- 06 Oct. 2021, 12:30-14:00 CET
Introduction to RWE, the ECFSPR and the patient perspective (CTN)
- 13 Oct. 2021, 12:30-14:00 CET
Real "real world" studies in CF and beyond (CTN)
- 13 Oct. 2021, 16:00-17:20 CET
Basic Science Webinar - Other channels that modify CFTR containing epithelia
- 20 Oct. 2021, 12:30-14:00 CET
The regulatory and reimbursement perspective (CTN)
- 27 Oct. 2021, 12:00-13:00 CET
The basic approach towards CFTR modulators in this new era (Mental Health WG & Psychosocial SIG)
- 15 Dec. 2021, 12:00-13:00 CET
special CF lunchtime webinars series (Mental Health WG & Psychosocial SIG)
- 23 Feb. 2022, 12:00-13:00 CET
special CF lunchtime webinars series (Mental Health WG & Psychosocial SIG)

Protecting clinical trials in cystic fibrosis during the SARS-CoV-2 pandemic: risks and mitigation measures

During the SARS-Cov-2 pandemic, the European Cystic Fibrosis Society-Clinical Trials Network (ECFS-CTN) has tracked clinical trial disruption by surveying member sites across 17 European countries and collated information on measures to mitigate the impact of the pandemic and ensure trial continuity.

Please check the publication resulting from this work: van Koningsbruggen-Rietschel et al., Protecting clinical trials in cystic fibrosis during the SARS-CoV-2 pandemic: risks and mitigation measures. Trials (2021) 22:578, following this [link](#).

Incidence of SARS-CoV-2 in people with cystic fibrosis in Europe between February and June 2020

The Registry published a study, looking at 130 cases of SARS-CoV-2 (COVID-19) in people with CF in Europe, reported up to 30 June 2020 by 16 countries participating in the European CF Registry.

It shows that people with CF were at a slightly higher risk of catching COVID-19 than the age-matched general population (2.70/1000). It also found that 58% of patients were admitted to hospital with 9% requiring intensive care. Patients who had a lung transplant were at higher risk of needing hospitalisation or intensive care treatment. In conclusion, due to the potential for severe disease the vaccination of CF patients should be prioritised.

[Open Access Article](#)

JCF - Increased Impact Factor

The European Cystic Fibrosis Society is pleased to announce that the official 2020 Impact Factors (IF) were recently released, and the Journal of Cystic Fibrosis (JCF) has increased its IF from the 2019 IF of 4.759 to 5.482. JCF ranks 15th in the Respiratory System category.

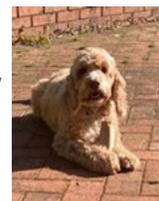
The Journal Impact Factor is published each year by Thomson Reuters. It is a measure of the number of times an average paper in a particular journal is cited during the preceding two years.

The ECFS would like to thank the Editor-in-Chief, Dr Patrick Flume, Prof. Scott Bell, past Editor-in-Chief and the Editorial Board. Their excellent work has helped JCF gain its current standings and continues to aid its growth.

A day in the life of... Nicky

In this edition, we will hear from advanced nurse practitioner Nichola MacDuff who kindly volunteered to share a typical day of her life with us. We hope you enjoy reading about her interesting role!

I am South African by birth (to British parents) and after attaining my Masters Degree I decided to travel, eventually settling in London where I worked at the Royal Brompton Hospital for 6 years. I moved to Scotland in 2001 (for love!) and worked in a variety of roles including Cardiothoracic Surgery and finally found my home in Cystic Fibrosis. I then moved to Wolverhampton in 2012 where I set up the CF service I am still with today.



I have a 12-year-old son, a cockapoo called Rusty and a husband who is an Intensive Care Consultant, so my mornings are often a mad rush of breakfasts, dog walks and finding "lost" gym shorts! I usually arrive at work at 8:15 which gives me time to have a coffee, sort through my urgent emails and plan my day. Aside from fixed items (like clinics and meetings) my diary usually fills up the week before with ad hoc reviews; vascular access device management; home IV antibiotic treatments, home visits and more.

I have a dedicated CF mobile which patients can ring if they need to talk to me. This phone starts ringing at 8:30 and keeps going until I turn it off at 5pm.

A typical day for me starts at around 9am with my first patient appointment. I try to keep the time around midday free to allow me to regroup, write my notes, dictate any letters and, hopefully, have some lunch. When I can, I try to have my lunch outside (weather permitting) and go for a walk to get some fresh air. I often have to attend meetings in the afternoon – either hospital governance meetings or CF MDT meetings to discuss complex patients, consider those transitioning to our service or have annual review discussions. If I have no patients or home visits planned in the afternoon, I always have a pile of tasks to get through – including ordering tests, managing the monitoring of patients on Kaftrio and other treatments, co-ordinating the care of complex patients who are under the care of multiple physicians; keeping in touch with the regional

CF Service and following up on any test results. I am also asked to support patients who are seeking to apply for benefits and housing - this usually involves writing letters to articulate how CF affects them. I also provide letters for airlines for patients travelling with medical equipment and supplies and support their appeals for charitable grants.

In addition to my clinical workload, I am also involved with NICE (National Institute for Clinical Excellence) as an expert advisor and am heavily involved in various committees for the ECFS (Education, Standards of Care, Nursing special Interest Group). I work for an NHS affiliated organisation called The West Midlands Clinical Senate which advises hospitals on organisational, quality and safety issues, and am the Nurse Representative of the West Midlands Thoracic Society Committee. I am also a peer reviewer for the NIHR (National Institute for Healthcare Research). I lecture on the Intensive Care Foundation Course and mentor nurses doing their non-medical prescribing modules at the local university. All this keeps me very busy, but I have always worked best under pressure.

During the recent Covid surges I was redeployed to intensive care so I only returned to my current post in April of this year. It has taken me several months to get back into the swing of things, and I confess I had missed my patients more than I thought I would. Working in Cystic Fibrosis is always interesting and every day brings new challenges.

If you would like to be featured in the next issue of our newsletter, please contact a member of the ECFS Office at membership@ecfs.eu

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 [link](#).

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7470 Karup
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