



43rd EUROPEAN CYSTIC FIBROSIS CONFERENCE 24–25 September 2020

#ECFSgoesDigital

ECFS Newsletter
September 2020
Issue 64

Letter from the President

Dear Colleagues and Friends,

I hope that you and your dear ones are all safe and well, and that you could enjoy some rest during the Summer.

Since April, the ECFS-Patient Registry presents data on the incidence of COVID-19 in patients with CF. Thanks to the national registries, anonymised data are consolidated and are regularly [reported](#). Fortunately, it seems the pandemic has had a limited impact on patients with CF. You will get the latest update further down in this newsletter.

In June, we organised our Annual General Meeting on line for the first time. This was the opportunity to warmly thank Marcus Mall and Kevin Southern who ended their mandates as Board members and welcome our newly elected Board members, Dorota Sands and Carsten Schwarz. We also welcomed on the ECFS Board Andreas Jung who is taking over the reins of the ECFS-Patient Registry following the successful leadership of Lutz Naehrlich, and Patrick Flume, who is the new Editor-in-Chief of the Journal of Cystic fibrosis, succeeding Scott Bell's wonderful leadership. There were also changes in leadership in the ECFS Exercise Working group, Helge Hebestreit handing over the leadership to Thomas Radtke and Don Urquhart. Thanks again to them all for their dedication and commitment.

After the major disruption of these past months and the cancellation of several events, the CF community is in dire need to meet again, exchange and network. In-person meetings remain difficult today to organize and the ECFS 2020 Digital Conference that will take place on 24-25 September will be the perfect opportunity to meet again online before the next in-person conference in Milan in June 2021. The Conference in September 2020 will be fully digital and it will include excerpts of the scientific programme which was originally prepared for the conference in Lyon. Financially, this year will of course be an *annus horribilis* for the ECFS as we had to cancel our Annual Conference which is our major source of income to run the Society and all its projects. However, at the Board, we felt that we needed to open up the Digital conference to the largest audience possible, to give our community the opportunity to get important updates on cystic fibrosis and to meet online.

We therefore decided to offer free registration to all participants.

I am happy that so far more than 2,300 people have already marked the event in their agendas and registered! With this event you will receive access to all live symposia and satellite symposia, virtual exhibition booths, and will be able to interact with other participants. The conference has also been accredited with 11 European CME credits (ECMEC®s). All symposia will then be available on the ECFS Education Platform accessible to all ECFS members. However, to get the CME credits, you will need to attend the online event.

We need you to make a success out of this new conference format. So please do not hesitate and [register now](#). We are counting on you!

Isabelle Fajac, ECFS President



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ECFS Annual General Meeting 2020

Due to the cancellation of the in-person conference in Lyon, the Annual General Meeting took place on line on 05 June 2020.

We were very happy to see the numbers of members attending the AGM and 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.

You will find the full minutes of the Annual General meeting 2020 here:

[Full AGM Minutes](#)

ECFS 2020 Board Elections

The ECFS is happy to announce the results of the 2020 Board Elections. We would like to warmly thank Marcus Mall and Kevin Southern who ended their mandates at the Board for their input and commitment. We also thank the five excellent candidates who applied for the elections and welcome Dorota Sands and Carsten Schwarz who have been elected and joined the ECFS Board in June.



Dorota Sands (PL)



Carsten Schwarz (DE)

Upcoming Events

- **ECFS 2020 Digital Conference**
24-25 September 2020
- **Webinar: Practical therapeutic modalities to manage anxiety, depression, sleep and pain in routine CF care**
22 September 2020
- **ECFS Diagnostic Network Working Group Meeting - On line Meeting**
23 September 2020
- **ECFS Winter Board Meeting**
Brussels, 27 January 2021
- **CTN Steering Group Meeting**
Brussels, 28-29 January 2021
- **ECFS Standards of Care Meeting**
Brussels, 28 January 2021
- **Registry Steering Group Meeting**
Brussels, 29 January 2021
- **ECFS Diagnostic Network Working Group Meeting**
Montpellier, France
11-13 February 2021
- **ECFS Basic Science Conference**
Albufeira, Portugal
17-21 March 2021
- **44th European CF Conference**
Milan, Italy
9-12 June 2021

ECFS 2020 Digital Conference



We are happy to announce our first fully digital conference that will take place on 24-25 September 2020.

It will include excerpts of the scientific programme which was originally prepared for the conference in Lyon. It will not replace the Annual Conference, rather be a special edition this year. We see this event as a great opportunity to give important updates on cystic fibrosis and for us all to meet online before the next in-person conference in Milan in June 2021.

We are excited to bring you eight live symposia over this two-day conference. Have a look at the [scientific programme](#). It has been prepared by our Scientific Committee and Conference Steering Committee and will present the hottest topics in cystic fibrosis basic research, diagnosis, care, clinical trials and new therapies.

We are also pleased to announce that industry partners will support the event and organise [satellite symposia](#).

Our commitment to our ECFS Members and the cystic fibrosis community is unwavering, which is why, for this first edition, registration to the ECFS 2020 Digital Conference will be free.

We are happy to confirm that the Conference has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) with 11 European CME credits (ECMEC®s).

The symposia will be available on the ECFS Education Platform afterwards and accessible to ECFS members only.

We hope that you will be able to join us on 24-25 September!

THURSDAY 24 SEPTEMBER 2020	FRIDAY 25 SEPTEMBER 2020
All times are indicated in CET.	07:45 - 08:45 Satellite Symposium
S01 09:00 - 10:00 OPENING SYMPOSIUM	S05 09:00 - 10:30 New challenges for diagnosis in cystic fibrosis, from pregnancy to adulthood
S02 10:15 - 11:45 Following treatment outcomes in patients on CFTR modulators	S06 11:00 - 12:30 Body and Soul Psychological influences on physical outcomes
12:45 - 13:45 Satellite Symposium	12:45 - 13:45 Satellite Symposium
S03 14:15 - 15:45 The future of clinical research	S07 14:00 - 15:30 From disease mechanisms to novel therapies
S04 16:00 - 17:30 Non-Pseudomonas aeruginosa pathogens in cystic fibrosis	S08 16:00 - 17:30 Updates for the gut and the pancreas
17:45 - 18:45 Satellite Symposium	17:45 - 18:45 Satellite Symposium

[Schedule at a glance](#)

Save the date!

44th European Cystic Fibrosis Conference, Milan, 9-12 June 2021

The ECFS looks forward to seeing you at the 44th European Cystic Fibrosis Conference in Milan, Italy on 9-12 June 2021.

For the first time we will organise a hybrid conference.

This new format will allow you to attend the sessions in-person or online.

9 – 12 JUNE 2021
MILAN, ITALY



44th EUROPEAN
CYSTIC FIBROSIS
CONFERENCE



SAVE THE DATE

WWW.ECFS.EU/MILAN2021



[First Announcement](#)

We are happy to announce that Carlo Castellani will be the President of the Conference. Carla Colombo and Francesco Blasi kindly accepted to be the Vice Presidents of the Conference.



Carlo Castellani



Carla Colombo



Francesco Blasi

[Annual Conference Milan 2021](#)

Online course:

PRACTICAL THERAPEUTIC MODALITIES TO MANAGE ANXIETY, DEPRESSION, SLEEP AND PAIN IN ROUTINE CF CARE

Webinar:

Tuesday 22nd September 2020
13:30 CET – 17:00 CET

Free Registration

Chair: [Eddie Landau \(IL\)](#)

Facilitators: [Lore Willem \(BE\)](#) and [Johanna Gardecki \(DE\)](#)



Johanna Gardecki (DE)



Lore Willem (BE)

Prior to the ECFS 2020 Digital Conference, the ECFS Psychosocial Special Interest Group and the ECFS Mental Health Working Group will organise a special webinar on Tuesday 22 September from 13:30 to 17:00 (CET). The course is an introduction in the use of Cognitive Behavioural Therapy and Systemic and Family focused Therapy in supporting people with CF to manage anxiety, depression, sleep and pain.

Target audience: All members of the multi-disciplinary team including doctors, nurses, dietitians, physiotherapists, psychologists, social workers etc.

Part of the webinar will be recorded and available on the ECFS Education Platform afterwards for ECFS members.

Free Registration

[Programme and Registration](#)

ECFS Diagnostic Network Working Group - Virtual session

The ECFS Diagnostic Network Working Group will organise an on-line meeting on Wednesday 23 September 2020 - 11:00 - 13:00 (CET).

During this online meeting active DNWG members and external speakers will present their work within the diagnostic field. Ongoing and future DNWG projects will be discussed.

[Programme and registration](#)

Standards of Care – Twinning Project

The European Cystic Fibrosis Society (ECFS) is opening a call for a new project which aims to create a partnership between two CF sites: one of them being an expert CF centre with a long-term, outstanding history in CF care (known as the "mentor site"), and the other one (known as the "mentee site") being a site which has an ambition to improve clinical outcomes and is ready to welcome the guidance, advice and collaboration of a well-established CF centre.

If you and your CF team think there is an area in CF care that could be optimised at your site and you would like support and advice from another site, please consider applying for this project as a mentee site. If your site is an ECFS-CTN site and you and your CF team would like to become linked to a mentee site, please consider applying for this project as a mentor site.

Deadline for application: 30 September 2020

[More information](#)

Twinning project



ECFS Clinical Trials Network – Annual Report

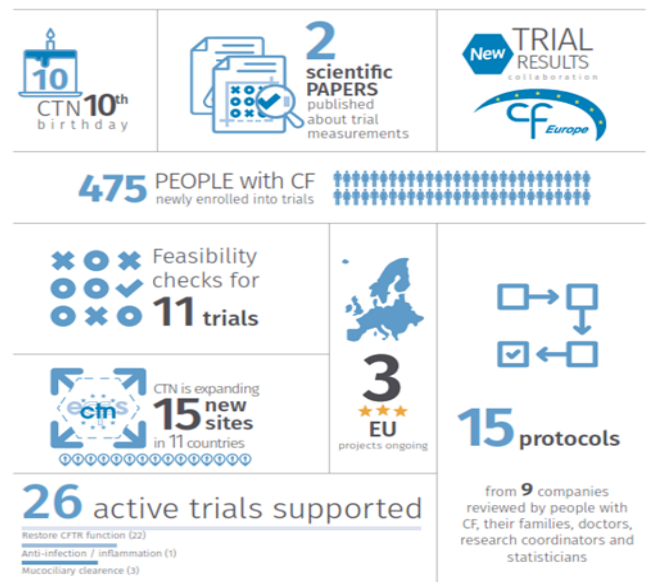
A few weeks ago the ECFS-Clinical Trials Network (CTN) Team shared its annual report 2019. The ECFS-CTN Annual Report outlines the ECFS-CTN activities of 2019 to patients, their families and other interested parties. The report is based on the detailed and critical input of individual patients, families, patient reviewers and patient organisations

[Annual Report](#)

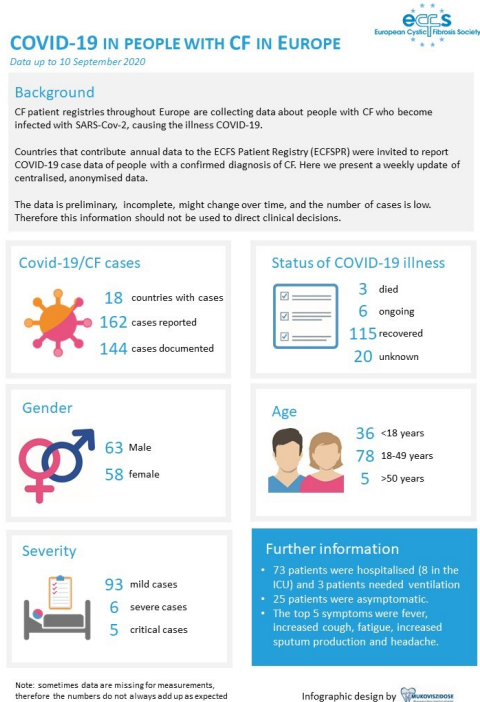
CTN Training Session

The CTN will organise its CTN Training session on-line on 23 September 2020.
(meeting by invitation only)

2019 OUR YEAR IN NUMBERS



COVID-CF project in Europe



CF patient registries throughout Europe have collected data about people with CF who became infected with SARS-Cov-2, causing the illness COVID-19. Countries that contribute annual data to the ECFS-Patient Registry (ECFSPR) were invited to report COVID-19 case data of people with a confirmed diagnosis of CF. Centres reported data directly to the ECFSPR, and aggregated data were provided by national registries that use their own data-collection system. Centralised anonymised data are reported regularly and a summary is available on the ECFS website at this [address](#).

ECFS / CF Europe Post-Doctoral Research Fellowship

With aim to foster basic and translational research on CF, the ECFS and Cystic Fibrosis Europe (CFE), the federation of national CF associations in Europe, have joined forces to support a number of European Post-Doctoral 2-year duration Research Fellowships. We are happy to announce that three Post-doctoral Research fellowships have been awarded and we would like to extend our congratulations to Dr Katherine Sutcliffe (UK), Dr Emmanuelle Bardin (FR) and Dr Matthew Coates (UK).

Katherine Sutcliffe (UK) will work on:

Molecular dynamics simulations to identify the molecular mechanism of CFTR copotentiation by ivacaftor and CP-628006

Emmanuelle Bardin (FR) will work on:

Novel insights into the impact of CFTR modulators on the response of the cystic fibrosis respiratory epithelium to *S. aureus* infection

Matthew Coates (UK) will work on:

The role of CFTR in the infection and early inflammatory response of respiratory epithelia to *Aspergillus fumigatus*

[More information](#)



ECFS Strategic Plan to speed up Access to new Drugs Taskforce Publication

CFTR modulators associated with substantial clinical benefit are expected to rapidly improve the baseline condition of people with cystic fibrosis as well as decrease the rate of lung function decline, the occurrence of pulmonary exacerbations and likely even other disease complications. These changes in clinical status of people with CF introduced by clinically effective modulator therapy will have major repercussions on modalities of future CF drug development.

As part of its 'Strategic Plan to speed up Access to new Drugs', the ECFS convened a meeting in Brussels on 27 November 2019 with relevant stakeholders (CF researchers and clinicians, patient organisations and pharmaceutical company representatives, regulators, and health technology assessors) to discuss the future of clinical trials in CF in the context of highly effective modulator therapies entering the clinical arena.

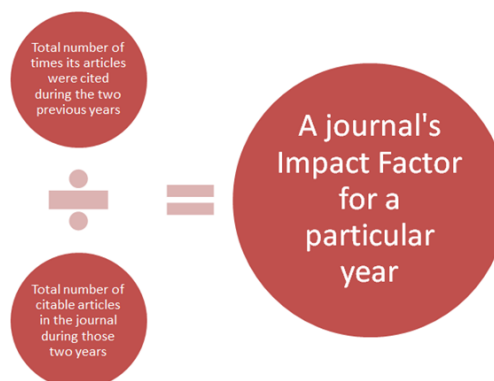
An article has been published in the Journal of Cystic Fibrosis presenting the conclusion of the presentations and discussions (*"Cystic fibrosis drug trial design in the era of CFTR modulators associated with substantial clinical benefit: stakeholders' consensus view »*). It is hoped that these concepts will be considered in future regulatory guidelines and may provide rationale and support for alternative trial designs.

[Article - Journal of Cystic Fibrosis](#)

Journal of Cystic Fibrosis - Impact Factor

The ECFS is pleased to announce that the official 2019 Impact Factors (IF) were recently released, and the Journal of Cystic Fibrosis (JCF) has increased its IF from the 2018 IF of 4.29 to 4.759. JCF ranks 14th in the Respiratory System category.

Congratulations to the JCF editorial team and particularly to Scott Bell, whose leadership hugely contributed to these great results.



Mental Health Working Group Survey

Last year, the ECFS Mental Health Working Group initiated a survey to evaluate the impact of the Mental Health guidelines from a patient or caregiver perspective. A total of 474 patients and caregivers participated to the survey which covered both Europe and the US. The final results of the survey have been published and can be found [here](#)

Job Postings

The ECFS is recruiting a **data quality manager** (0.8 – 1 FTE) for the **Patient Registry**, who will be the in-house data expert and will foster and ensure data quality across the Registry and the participating countries.

Application deadline: 01 October 2020

[More information](#)

A postdoctoral position on CFTR pharmacology is available in the laboratory Signalisation et Transports Ioniques membranaires (Laboratoire STIM, University of Poitiers, Poitiers, France).

Starting date: September/December 2020/January 2021 Duration : 2x12 months.

Closing date for applications: 30 September 2020

[More information](#)



A day in the life of...Trudy Havermans

In the last issue of the Newsletter, we made a call out to our readership to ask for any ECFS members who wanted to be featured in the September edition of Newsletter. Trudy Havermans, Clinical Health Psychologist and ECFS Board Treasurer, kindly volunteered to share a typical day with us:

A bit of background information from me first. I have worked as a Clinical Health Psychologist for almost 20 years, after training as a Clinical Child Health Psychologist in the Netherlands. I currently work in a university hospital setting, dedicating my professional life to cystic fibrosis patients. Our CF centre cares for about 90 paediatric patients and their families, 160 adult patients and 110 CF transplanted patients.

As I'm sure is the case with many of you, a 'typical' day doesn't really exist for me as it really depends on which patients have been admitted into the hospital on that day. This makes my role varied and keeps me on my toes!

On a typical morning, I arrive at the clinic by bicycle by about 08h30 and grab a coffee to help me to start my day. After catching up with colleagues I check my emails and look to see who is in hospital.

I walk to the ward (I walk up to 5 km per day) and spend most of my day with patients or parents; for short conversations, catch-ups or for more in-depth psychotherapy. My work takes me to a variety of settings including the paediatric and adult wards, outpatient settings and the outpatient transplantation setting. Occasionally I see patients at the intensive care unit or the dialyses unit. The fact that I work exclusively with patients with CF means that many patients have known me all of their lives. For example, the group who are now transferring to the adult clinic have known me since their diagnosis. This allows me to really observe and experience the ups and downs patients face in their lives. I can work preventatively and, as I work full time in the clinic, I have the flexibility to see patients within a day if necessary.

I use different psychological approaches, but predominantly existential psychotherapy, cognitive behavioural and interpersonal psychotherapeutic techniques. Therapy topics range from coping with the CF diagnosis or subsequent diagnosis, monitoring child development, addressing existential themes, anxiety and depression, coping with deterioration, preparing for transplantation, trauma psychology, bereavement, end of life, but also child rearing topics, behavioural problems, loneliness and isolation, adherence to therapy and so forth. The list is endless!

On Mondays, Tuesdays and Wednesdays we have patient care meetings, where we discuss hospitalized patients and outpatients. These are multidisciplinary team meetings in the truest sense of the word as everyone has a specialist say on patient treatment and care.



At the end of the day I reserve time to think and reflect on the many stories I witnessed that day and I write my notes.

My day typically ends around 18h30, with a relaxed cycle ride home. Home is where my books are, as I am fond of literature. I have two grown-up daughters and I love spending time with them and with friends, be it virtually or face-to-face.

A real challenge is to keep up with the CF literature and do some research. This is often done outside of working hours. I am also kept busy by providing lectures on psychological aspects of CF or transplantation in nursing courses as well as supervising master students. And then there is the work for conferences and the ECFS, of course!

I gladly dedicate my career to patients who have cystic fibrosis. I admire their resilience and capacity to cope with, at times, very difficult and traumatic experiences. I find it a great honour to be part of their lives within a multidisciplinary, highly complex care setting.

Many thanks to Trudy Havermans for sharing with us her fascinating role with CF patients.

If you would like us to feature you in the next Newsletter, please don't hesitate to contact us at: membership@ecfs.eu We very much look forward to hearing from you!

Current References in Cystic Fibrosis

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



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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