

## Letter from the President

Dear Colleagues and Friends,

I hope that you and your dear ones are well and that you were able to have some rest at the end of December.

It has been a year since the first cases of COVID-19 were reported in Europe. This unprecedented health crisis affected us all in our everyday life and significantly impacted the organisation of health care worldwide. While I am writing these lines the vaccination campaign has started in a lot of countries and though this brings us a lot of hope, it remains a huge challenge to complete the process on such a large scale. As you already know, the ECFS-Patient Registry regularly presents data on the prevalence of COVID-19 in patients with cystic fibrosis, based on anonymised data provided by national registries and individual centres. Fortunately, the incidence of COVID-19 during the first two waves seems to be lower amongst the patients with cystic fibrosis than in the general population and SARS-CoV2 infection in patients with cystic fibrosis was usually of mild severity. A last update published on 20 January can be found on our [website](#).

In this difficult situation, the format of all events that were planned for the first half of this year has to be adapted. Several working groups decided to meet online in the coming months. The organisers of the Basic Science conference have decided to postpone the event to March 2022. Nevertheless, to keep up with science and allow discussion and communication, they are preparing a series of webinars on hot topics for later this year.

As you already know, the ECFS Board opted for a second digital conference on June 9-12 2021 to replace the ECFS Conference initially planned in person in Milan. The scientific programme has been adapted for an online event. At our Digital conference you will be able to access 20 live symposia with invited speakers, workshops with oral presentations of abstracts, satellite symposia and other interactive sessions. All sessions will be recorded and made available to all registrants until early September 2021 so that everyone can follow the sessions on-demand after the event. The digital conference sessions will also be posted on the ECFS Education platform accessible to the ECFS members. The annual conference will be the perfect opportunity to meet again online before the next conference in Rotterdam, the Netherlands, where we are very much looking forward to welcoming you in person next year.

There will be ECFS Board elections in 2021 as Jane Davies, Pavel Drevinek and Barry Plant 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.

I want to express my deepest thanks to Dr. Silke van Koningsbruggen-Rietschel who ended her mandate as the ECFS-CTN Director. The network expanded and grew stronger under her gentle and inclusive leadership. I welcome Dr. Damian Downey (Belfast) who took over her role and is now the ECFS-CTN Director for the coming 3 years.

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



### Inside this issue

Letter from the President.....	1
Gerd Döring Award – Call for nominations.....	2
ECFS Board Elections 2021.....	2
Deadlines to remember.....	2
ECFS 2021 Digital Conference.....	3
Upcoming Events.....	3
Scientific Programme ECFS Digital Conference 2021.....	4
Young Researchers Session.....	4
ECFS Basic Science Conference.....	5
ECFS Winter Meetings.....	6
Mental Health Working Group – Special CF Lunchtime Series.....	6
COVID-CF project in Europe.....	7
Standards of Care – Twinning Project.....	7
Diagnostic Network Working Group - Save the Dates.....	8
A day in the life of Monika Mielus.....	8-9
Current References in cystic fibrosis.....	9

## 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 (2018-2020) 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 1<sup>st</sup> March 2021. 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 .

## ECFS 2021 Board Elections

The ECFS cordially invites nominations for 3 Board positions.

Jane Davies, Pavel Drevinek and Barry Plant will end their terms in June 2021.

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

Nominations should be sent to the ECFS Executive Director Christine Dubois ([christine.dubois@ecfs.eu](mailto:christine.dubois@ecfs.eu)) by 22<sup>nd</sup> March 2021 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.



### Deadlines to remember

01 March 2021  
Nominations Gerd Döring Award

22 March 2021  
Nominations ECFS Board Elections

29 April 2021  
Standard Registration Fees to the ECFS 2021 Digital Conference



# 44th EUROPEAN CYSTIC FIBROSIS CONFERENCE

9–12 June 2021

#ECFS2021

## ECFS 2021 Digital Conference

Due to the current health situation, the ECFS Board took the hard decision to use a digital format for our annual conference instead of the in-person meeting which was planned in Milan. We are confident that this format will be a success as shown by the high attendance (more than 3700 professionals in cystic fibrosis) who participated in our first digital edition in September 2020.

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 commitment and flexibility.

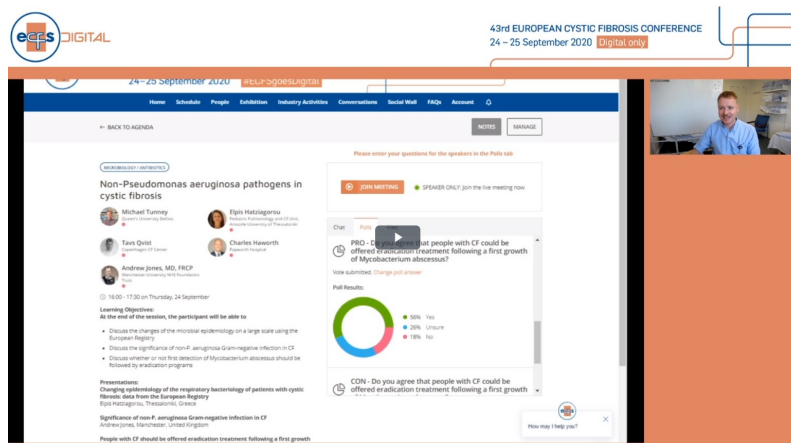
The digital platform will host 4 parallel sessions featuring symposia with invited speakers, Workshops to present selected abstracts as well as “Meet the Experts” sessions and ePoster sessions. Posters will be presented on a dedicated space. Attendees will be able to watch the sessions live and view or review these on demand at any time until early September 2021. Nearly 400 abstracts have been submitted for this edition.

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

Registration will open in a few weeks. Besides the standard registration, we will also offer reduced registration fees for ECFS members, delegates from Low- and Middle-Income Countries, Allied Health Professionals, patient organisation representatives and students. [More information](#)

### Upcoming Events

- **Diagnostic Network WG Meeting:**  
Online: 29-30 April 2021  
In person: Montpellier, France, 10-12 February 2022
- **European CF Conference Digital 2021**  
9-12 June 2021
- **ECFS Board Summer Meeting**  
Digital - 8 June 2021
- **Annual General Meeting ECFS**  
Digital - 9 June 2021
- **Conference North American Cystic Fibrosis (Hybrid)**  
30 Sept. - 2 Oct. 2021  
San Antonio, TX (US)
- **ECFS Basic Science Conference**  
30 March—02 April 2022  
Albufeira, Portugal



## Scientific Programme of the 2021 ECFS Digital Conference

Here is the list of the symposia:



- 01 - Clinical trials in a new era
  - 02 - The pancreas
  - 03 - Diagnosis and treatment of pulmonary exacerbations
  - 04 - Gene and cell therapy
  - 05 - Post-COVID cystic fibrosis care
  - 06 - Omics and the resistome
  - 07 - Genetics meets ethics
  - 08 - Cystic fibrosis in a changing world
  - 09 - Early lung disease monitoring
  - 10 - Clinical trials on CFTR modulation - What lies beyond?
  - 11 - Pharmacovigilance in cystic fibrosis care
  - 12 - Impact of COVID-19 pandemic on mental health and self-management
  - 13 - Diagnosis: soon and right
  - 14 - Nutritional status
  - 15 - CFTR structure function and rescue
  - 16 - Registries used to anticipate the future of cystic fibrosis care
  - 17 - Timing in newborn screening
  - 18 - Addressing inflammation in cystic fibrosis
  - 19 - What's new in cystic fibrosis microbiology?
  - 20 - Upper airways – Attention please!
- Special Symposium – Best of Journal of Cystic Fibrosis /Lancet Respiratory Medicine /European Respiratory Journal
- More information [here](#)

### Deadlines to remember

01 March 2021  
Nominations Gerd Döring  
Award

22 March 2021  
Nominations ECFS Board Elec-  
tions

29 April 2021  
Standard Registration Fees to  
the ECFS 2021 Digital Confer-  
ence

## Young Researchers Session

Further to the ECFS/CFE Post-Doctoral Research Fellowship, the successful young researchers of the award will have a dedicated session during the 2021 Digital Conference, to present their project and preliminary data.

### ECFS Basic Science Conference

Sadly, it will not be possible to organise the ECFS Basic Science conference this March in Portugal and we will have to wait for Spring 2022 for an in-person conference.

Save the date: the conference will be postponed to 30 March —02 April 2022



In the meantime, we are happy to inform you that we will be holding 3 webinars, over the next months.

We would like to thank the organisers, Carlos Farinha, Nicoletta Pedemonte and Jeff Brodsky for their work and dedication in finding suitable alternatives and proposing this exciting webinar series:

28 April 2021: Webinar 1 – From genotype to phenotype

14 July 2021: Webinar 2 – CFTR Trafficking and Interactions

20 October 2021: Webinar 3 – Other channels that modify CFTR containing epithelia

More information on the webinars detailed programme and registration will be published in due time on the [conference page](#).



## ECFS Winter Meetings

The ECFS Clinical Trials Network and the ECFS Patient Registry Steering Committees met online on 28 and 29 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. All are looking forward to meeting in person again as soon as the situation allows it!

### Thank you Silke and Welcome Damian!

Dr. Silke van Koningsbruggen-Rietschel has ended her mandate as the ECFS-CTN Director. She was warmly applauded by the CTN Steering Committee for her excellent leadership and for having moved the network forward during her term. Dr. Damian Downey (Belfast) took over her role and is now the ECFS-CTN Director for the coming 3 years.



## Mental Health—Special CF Lunchtime Series

The ECFS Psychosocial Special Interest Group and the ECFS Mental Health Working Group launched a “A Special CF Lunchtime Series” that features multi-disciplinary webinars.

More than 150 participants attended the first webinar: *Challenges and complexities of care in transition* in December 2020. The webinar is available on the [ECFS Education platform](#).

Next webinar: 18 February 2021 - 13:00-14:00 CET

### ***Food and CF: Friend of foe?***

The registration is free.

[More information](#)

## FOOD AND CF: FRIEND OR FOE?

Webinar 18 February 2021



Trudy  
Havermans (BE)



Mandy  
Bryon (UK)



Elizabeth  
Owen (UK)



Eddie  
Landau (IL)



Dana  
Serfaty (IL)

### Upcoming webinars Special CF Lunchtime Series

- "How Covid-19 changed the clinic: learning as we move along in uncertain times"  
18 March 2021, 13.00-14.00 CET
- "New challenges in CF care: Physiotherapist and pharmacologist joining forces"  
22 April 2021, 13.00- 14.00 CET
- "Women's Health and Cystic Fibrosis"  
20 May 2021, 13.00-14.00 CET

## COVID-19 IN PEOPLE WITH CF IN EUROPE

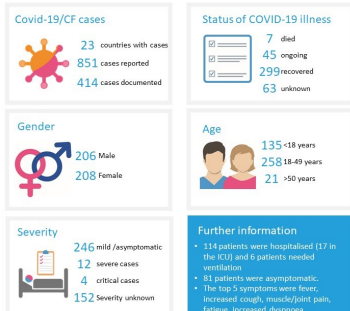
Date: up to 20 January 21

### Background

CF patient registries throughout Europe are collecting data about people with CF who become 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. Here we present a weekly update of centralised, anonymised data.

The data is preliminary, incomplete, might change over time, and the number of cases is low. Therefore this information should not be used to direct clinical decisions.



Note: sometimes data are missing for measurements, therefore the numbers do not always add up as expected

Infographic design by ECFS

## 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](#)—Last update 20<sup>th</sup> January 2021.



## Standards of Care – Twinning Project

The call for the Twinning Project, aiming to create a partnership between CF sites has been very successful. A total of 10 applications were received from mentee sites and 27 applications from mentor sites. The Twinning Evaluation Board assigned pairs amongst new sites and also confirmed several existing partnerships that were already set up before the call. The selection criteria consisted of: linking paediatric, adults or mixed sites together and linking the expertise of mentor sites with needs from mentee sites.

The programme is based on exchange of knowledge and experience where shared visits to both CF sites is fundamental. Due to the current travel restrictions the deadlines for first reports will be of course adapted. We are pleased to list hereunder the sites that will participate to the project:

Mentee	Mentor
Bucharest, Romania	Leuven, Belgium
Cluj-Napoca, Romania	Brussels, Belgium
Lviv, Ukraine	London Brompton, UK
Odessa, Ukraine	Lyon, France
Zaporizhzhia, Ukraine	Jerusalem, Israel

Pre-existing pairs having applied together:

Varna, Bulgaria	Southampton Paediatric, UK
Athens, Greece	Southampton Adult, UK
Thessaloniki, Greece	Southampton Adult, UK
Kozle, North Macedonia	Cambridge, Adult, UK

## Diagnostic Network Working Group - Save the Dates

The ECFS Diagnostic Network Working Group will hold its [annual meeting](#) online on 29-30 April 2021.

The [in-person meeting](#) will be postponed to 10-12 February 2022 and will be held in Montpellier, France

### A day in the life of...Monika Mielus

In this edition, we will hear from Senior Assistant Dietitian Dr Monika Mielus who kindly volunteered to share a typical day of her life with us. We hope you enjoy reading about her fascinating role!

I have been working as a cystic fibrosis Dietitian for 16 years after initially studying for my master's degree at Warsaw University of Life Sciences and then, later, getting my PhD in 2014 at the Medical University of Warsaw. I began my career working in the Institute of Mother and Child in Warsaw where I currently remain but only in a scientific capacity. The clinical part of my job takes place in the cystic fibrosis centre in Dziekanow Lesny. Within the paediatric cystic fibrosis centre, led by Prof. Dorota Sands, we see around 300 patients with CF. I share my clinical work with two other dietitian colleagues.



A typical day for me begins with a 40-minute drive from home, in Warsaw, to the CF centre, arriving by 8am each day. First on my duties is to make a daily list of patients for dietary consultations. Next off I participate in an MTD meeting (currently online due to the global pandemic). During this time, we discuss both in and out patient care as I see patients in both capacities. After this meeting I start to prepare the data for my consultations including anthropometric assessments (centiles, z-scores) and its trends also with body composition (by BIA). Once I am ready, I set off to see my patients. As I work in the paediatric setting, I am lucky enough to be able to follow my patients from when they start out life, as newborns, until they become adults. My role therefore changes as my patients grow; I begin by educating parents then my patients themselves. A lot of my consultation time is spent providing individual recommendations and educating my patients on quality of diet, pancreatic enzymes and salt and vitamin supplements as well as supervising all aspects that are required to maintain optimal nutritional status (for example glucose abnormalities). I feel that these consultations are the most important aspect of my work and where most of my time is spent.



Each patient is unique and needs an individual approach so I would say that on many occasions my patients have been my inspiration. I love these kinds of challenges!!! Work finishes around 3.30 pm and I drive home. My free time is often spent planning my next local or international trip. Traveling, and the experiences I gain when I discover new places, gives me a lot of energy and allows me to be better prepared for new challenges.

While working outside the CF centre, I prepare lectures for doctors, specialists, parents and patients. I also have had the opportunity to present my research work during annual ECFS conferences and, in 2019, I am proud to say I was awarded the best poster award in the “nutrition/growth” category. I’m also a co-author of scientific articles, chapters in books, and the Polish Cystic Fibrosis standards of care (in the nutrition section). I feel a sense of pride being part of the unique ECFS community. Being a member of the nutrition working group gives me the opportunity to discuss and share experiences with other specialists. I’m also delighted to look through presentations after ECFS conferences via the Education Platform. All of these opportunities provide me with up-to-date knowledge that I use in my clinical practice.

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](mailto: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](mailto: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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