

Letter from the President

Dear Friends,

I hope that you and your dear ones are well.

The COVID-19 vaccination started in Europe a few months ago and the positive effects on the epidemic curve are becoming more tangible every day. The vaccination campaign is picking up speed for several weeks now and we hope restrictions can be eased further and eventually lifted in a near future. As you already know, the ECFS-Patient Registry regularly presents data on the incidence of SARS-CoV-2 in patients with cystic fibrosis on our website. Recently, Lütz Naehrlich et al. published an incidence study in Europe during the first months of the pandemic. The article is in open access in the Journal of Cystic Fibrosis (JCF).

In this difficult period, many of you expressed the need to network, exchange ideas and experiences, and maintain discussions. We are happy we could keep contact with you all thanks to the ECFS Digital 2020 and through numerous webinars and meetings organised by various ECFS groups.

We are excited to build upon the experience of our first successful Digital conference in September and we invite you to join us at our 44th European Cystic Fibrosis Conference that will take place online on 09-12 June 2021. The Scientific Committee has put together an outstanding [programme](#) and you will have access to more than 50 sessions including symposia, workshops, ePoster sessions amongst others. I would like to thank the Scientific Committee and the Steering Committee for all their hard work over the last year in preparing the programme, selecting the abstracts and organising the various sessions.

I would also like to thank all of you who have submitted an abstract to the conference. We are very excited to learn about the new science on cystic fibrosis. As part of our commitment to support young researchers, three Young Investigators Awards were awarded to young investigators based on the merit of their abstract submissions. As we do every year, we will also present the Gerd Döring Award to honour a young European scientist in their early career. Congratulations to them for their prizes!

Let me remind you of the ECFS elections, which are taking place this month. There are three vacancies at the Board this year. Prof. Jane Davies, Prof. Pavel Drevinek and Prof. Barry Plant finish their first terms and I wish to express my deepest thanks to them for their contribution to the Board over the past three years. As you all know, last year was very special and I wish to thank them for their continued commitment to the Society.

Your involvement in the ECFS Board Elections is critical and will contribute to shape the future direction of the Society. It is essential that the Board has a strong and engaged membership to provide leadership to our Society so please cast your vote [here](#) without delay.

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

We are very much looking forward to welcoming you to the Annual Conference in a few weeks from now. It will be the perfect opportunity to meet again online before the next conference in 2022 in Rotterdam, the Netherlands, where we hope to meet you in-person.

Yours sincerely,

Isabelle Fajac, ECFS President.



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ECFS Board Elections

The European Cystic Fibrosis Society Board has three vacancies this year. Prof. Jane Davies, Prof. Pavel Drevinek and Prof. Barry Plant finish their first terms and we wish to express our deepest thanks to all three for their contribution to the Board over the past 3 years.

We have received nominations for five senior figures of the CF community.

The Board should represent the ECFS membership in all aspects of our activities and should be drawn from a number of different European countries and reflect important areas of our activity.

The Society needs you to vote in large numbers so that your support for those elected and appointed to lead the Society is clearly expressed.

The online secured voting poll can be found [here](#).

Job Descriptions are available for both the President and Board Members
[Board Member's Job Description](#).

POLLS CLOSE ON MONDAY 07 JUNE at 19:30 (CEST)



Janet Allen (UK)



Ian Balfour-Lynn (UK)



Jane Davies (UK)



Pavel Drevinek (CZ)



Barry Plant (IE)

ECFS Annual General Meeting

Save the date!

The Annual General Meeting will be held on **Wednesday 09 June 2021 - From 18:00 to 19:15 (CET)**.

The Meeting will be organised on-line. We need your active participation and look forward to a great discussion. The link to the meeting will be sent shortly by email.

Upcoming Events

- **ECFS Board Summer Meeting**
8 June 2021
- **Annual General Meeting ECFS**
9 June 2021
- **ERS Virtual Congress**
5-8 September 2021
- **North American Cystic Fibrosis Conference**
30 September - 2 October 2021
San Antonio, TX, US
- **ECFS Winter Meetings**
26–28 January 2022
Brussels, Belgium
- **ECFS Diagnostic Network WG Meeting,**
10-12 February 2022
Montpellier, France
- **Basic Science Conference,**
30 March - 02 April 2022
Albufeira, Portugal
- **45th European CF Conference**
8-11 June 2022
Rotterdam, The Netherlands

45th EUROPEAN CYSTIC FIBROSIS CONFERENCE

8–11 JUNE 2022
ROTTERDAM, NETHERLANDS

AGENDA

1. President's Report – Isabelle Fajac
2. Secretary's Report – Isabelle Sermet
3. Treasurer's Report – Trudy Havermans
4. ECFS Board Elections – Isabelle Fajac
5. Update on Journal of Cystic Fibrosis – Patrick Flume
6. CTN Report – Damian Downey
7. ECFS Standards of Care Report – Carlo Castellani
8. ECFS Patient Registry Report – Andreas Jung
9. ECFS Education Report – Daniel Peckham
10. ECFS Working Group Reports
 - [Basic Science Working Group](#)
 - [Diagnostic Network Working Group](#)
 - [Exercise Working Group](#)
 - [Fungal Pathogens Working Group](#)
 - [Mental Health Working Group](#)
 - [Neonatal Screening Working Group](#)
 - Pulmonary Exacerbations Working Group
11. ECFS Special Interest Groups
 - [Nursing Special Interest Group](#)
 - [European CF Pharmacy Group](#)
 - [European CF Nutrition Group](#)
 - [European Psychosocial Special Interest Group](#)
12. Presentation of the 2022 European CF Conference

Highlights of the Conference



44th EUROPEAN CYSTIC FIBROSIS CONFERENCE

9–12 June 2021

#ECFS2021

At the 2021 digital conference, participants will have access to over 50 live sessions. All sessions will be recorded and will be available from 30 minutes after the end of the session and for 3 months after the conference, for participants to watch at their own discretion. All conference content will of course also be uploaded on the ECFS Education platform with unrestricted access for ECFS members.

The conference platform will host 4 parallel sessions featuring symposia from invited speakers, workshops to present selected abstracts as well as “Meet the Experts” and ePoster sessions.

Posters will be presented on a dedicated space of the conference platform.

Several ECFS Working Groups and Special Interest Groups will also organise their meetings online as well as interactive sessions (ECFS Tomorrow Lounge sessions).

Satellite symposia from partners from the industry will also be organised during the Conference.

THURSDAY 10 JUNE 2021				
08:30	OPENING PLENARY 08:30 - 09:00			
09:00	WORKSHOP 1 09:00 - 10:00	WORKSHOP 2 09:00 - 10:00	WORKSHOP 3 09:00 - 10:00	WORKSHOP 4 09:00 - 10:00
09:30	<i>Pseudomonas aeruginosa</i> : pathogenesis and treatment	Challenges in diagnosis and management of extra pulmonary complications of cystic fibrosis	Genetic heterogeneity in CFTR	Improvements in understanding how physical activity and exercise impact cystic fibrosis
10:00				
10:30	INDUSTRY Q&A 10:15 - 10:45	INDUSTRY Q&A 10:15 - 10:45	INDUSTRY Q&A 10:15 - 10:45	INDUSTRY Q&A 10:15 - 10:45
11:00				
11:30	SYMPOSIUM 1 11:00 - 12:15	SYMPOSIUM 2 11:00 - 12:15	SYMPOSIUM 3 11:00 - 12:15	SYMPOSIUM 4 11:00 - 12:15
12:00	Clinical trials in a new era	The pancreas	Diagnosis and treatment of pulmonary exacerbations	Gene and cell therapy
12:30	TOMORROW LOUNGE 12:30 - 13:30	EPOSTER SESSION 1 12:30 - 13:30	EPOSTER SESSION 2 12:30 - 13:30	MEET THE EXPERTS 12:30 - 13:30
13:00		Developments of remote physiotherapy during COVID-19 restrictions on usual practice	Extrapulmonary and nutritional issues	Lung infection beyond CFTR modulators
13:30				The psychological impact of CFTR modulators
14:00	SATELLITE SYMPOSIUM 13:45 - 14:45			
14:30				
15:00	SYMPOSIUM 5 15:00 - 16:15	SYMPOSIUM 6 15:00 - 16:15	SYMPOSIUM 7 15:00 - 16:15	SYMPOSIUM 8 15:00 - 16:15
15:30				
16:00	Post-COVID cystic fibrosis care	Omics and the resistome	Genetics meets ethics	Cystic fibrosis in a changing world
16:30	SPECIAL SYMPOSIUM 16:30 - 17:45	WORKSHOP 5 16:30 - 17:30	WORKSHOP 6 16:30 - 17:30	WORKSHOP 7 16:30 - 17:30
17:00	Best of Journal of Cystic Fibrosis / Lancet Respiratory Medicine / European Respiratory Journal	Infection and inflammation carousel	Strategies for early and late diagnoses	Novel approaches to unravel disease mechanism
17:30				
18:00	SATELLITE SYMPOSIUM 17:45 - 18:45			



FRIDAY 11 JUNE 2021				
09:00	WORKSHOP 8 09:00 - 10:00	WORKSHOP 9 09:00 - 10:00	WORKSHOP 10 09:00 - 10:00	WORKSHOP 11 09:00 - 10:00
09:30	Clinical and treatment outcomes: data from Registry studies	Future therapeutic approaches and insights into our current practice	Challenges in optimising nutrition in cystic fibrosis	Anxiety and stress in cystic fibrosis through a challenging 2020 and novel interventions
10:00				
10:30	INDUSTRY Q&A 10:15 - 10:45	INDUSTRY Q&A 10:15 - 10:45	INDUSTRY Q&A 10:15 - 10:45	INDUSTRY Q&A 10:15 - 10:45
11:00	SYMPOSIUM 9 11:00 - 12:15	SYMPOSIUM 10 11:00 - 12:15	SYMPOSIUM 11 11:00 - 12:15	SYMPOSIUM 12 11:00 - 12:15
11:30	Early lung disease monitoring	Clinical trials on CFTR modulation - What lies beyond?	Pharmacovigilance in cystic fibrosis care	Impact of COVID-19 pandemic on mental health and self-management
12:00				
12:30	TOMORROW LOUNGE 12:30 - 13:30	EPOSTER SESSION 3 12:30 - 13:30	SPECIAL SYMPOSIUM 12:30 - 13:30	MEET THE EXPERTS 12:30 - 13:30
13:00		Characterisation and treatment of CF pathogens	ECFS/CFE Post-Doctoral Research Fellowship project	Mucus and mucolytic agents
13:30				Transplantation and the coordination of care
14:00	SATELLITE SYMPOSIUM 13:45 - 14:45			
14:30				
15:00	SYMPOSIUM 13 15:00 - 16:15	SYMPOSIUM 14 15:00 - 16:15	SYMPOSIUM 15 15:00 - 16:15	SYMPOSIUM 16 15:00 - 16:15
15:30	Diagnosis: soon and right	Nutritional status	CFTR structure function and rescue	Registries used to anticipate the future of cystic fibrosis care
16:00				
16:30	WORKSHOP 12 16:30 - 17:30	WORKSHOP 13 16:30 - 17:30	WORKSHOP 14 16:30 - 17:30	WORKSHOP 15 16:30 - 17:30
17:00	Real-life experiences with CFTR modulators	The airway microbiota and problematic pathogens	Innovative nursing and psychosocial treatment delivery developed during COVID-19 restrictions	Late Breaking Science
17:30				
SATURDAY 12 JUNE 2021				
07:30				
08:00				
08:30				
09:00	SYMPOSIUM 17 09:00 - 10:15	SYMPOSIUM 18 09:00 - 10:15	SYMPOSIUM 19 09:00 - 10:15	SYMPOSIUM 20 09:00 - 10:15
09:30	Timing in newborn screening	Addressing inflammation in cystic fibrosis	What's new in cystic fibrosis microbiology?	Upper airways – Attention please!
10:00				
10:30	INDUSTRY Q&A 10:25 - 10:55	INDUSTRY Q&A 10:25 - 10:55	INDUSTRY Q&A 10:25 - 10:55	INDUSTRY Q&A 10:25 - 10:55
11:00	CLOSING PLENARY 11:00 - 12:15			
11:30				
12:00				

Meetings and Courses during the 2021 ECFS Conference

Tuesday 08 June	
10:00 - 12:00 and 15:00 - 17:00	ECFS Board Meeting*
13:00 - 16:00	Course: Power Threat Meaning Framework
10:00 - 15:00	ECFS Exercise Working Group Meeting
17:00 – 18:30	ECFSPR Definitions Group Meeting*

Wednesday 09 June	
09:00 - 11:00	ECFS CTN Training session*
11:00 - 13:00	MH/EPSIG Meeting - Different Perspectives on Resilience
11:15 - 12:30	ECFS CTN Training session RCs only*
13:30 - 16:00	ECFS Nursing Special Interest Group Meeting
13:30 - 16:30	ECFS CTN Steering Committee*
14:00 - 17:00	ECFS Neonatal Screening Working Group Annual Meeting*
14:00 - 16:45	European Cystic Fibrosis Nutrition Group Meeting
15:00—18:15	European Cystic Fibrosis Pharmacy Group Meeting
16:00 - 17:00	International Physiotherapy Group-CF AGM
17:00 - 18:30	International Physiotherapy Group-CF - Case presentations
18:00 - 19:15	ECFS Annual General Meeting**
Thursday 10 June	
14:00 - 15:00	ECFSPR Scientific Committee Meeting*
17:30 - 18:30	ECFSPR Pharmacovigilance Working Group Meeting*
18:00 - 20:00	ECFS Standards of Care Meeting*
Friday 11 June	
11:00 - 12:00	ECFSPR Patient Project Meeting*
12:30 - 14:30	ECFS Diagnostic Network Working Group Meeting
16:30 - 18:00	ECFSPR Steering Group Meeting*
Saturday 12 June	
08:30 - 09:00	ECFSPR – CTN Executive Committees joint meeting*
14:00 - 15:30	ECFS Fungal Pathogens Working Group Meeting*

* By invitation only

** For ECFS members only

Gerd Döring Award 2021

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 includes a monetary donation of 5,000 euro to support research. This year, the Award is given to Peder Berg (DK) in acknowledgement of his work.

PEDER BERG



Biography

Peder Berg is a MD from Aarhus University, Denmark (2019). While studying medicine, Peder was a student researcher from 2017-2019. He is now in the course of his Ph.D. education at the Department of Biomedicine, Aarhus University, studying the role of the CFTR anion channel in the kidney. In close collaboration with the CF center of Aarhus University Hospital, he strives to translate his findings to further the understanding of this complex disease.

Presentation of research

CFTR is present in our kidneys, but its function has remained elusive. The kidneys are vital to maintain acid-base and electrolyte homeostasis. Patients with CF have an increased risk of developing electrolyte disturbances, including metabolic alkalosis. We hypothesised this to be a direct consequence of dysfunctional CFTR in the kidney.

With the use of cell cultures, animal models, and the participation of CF patients, we investigated the role of CFTR in renal acid-base handling.

We found that in the collecting ducts, CFTR co-localises apically with the base secreting Cl-/HCO₃--exchanger, pendrin. Loss of CFTR (in mice) or dysfunction of CFTR (in patients) causes a markedly reduced capacity of renal base excretion. In patients, treatment with lumacaftor-ivacaftor partially normalised this phenotype. These findings motivated us to develop an in vivo CF urine test to quantify CFTR function for validation of treatment efficacy. We now pursue this question in a larger clinical study.

ECFS 2021 – Young Investigators Award

Following the recommendations of the Steering Committee during the abstract review process, the ECFS wishes to commend the quality of the work presented in the abstracts of some young investigators under the age of 35 having applied for the award.

The Young Investigator Award includes a monetary grant of € 750, a free registration to the Conference, and a 2021 ECFS membership subscription. We wish to extend our congratulations to the following Young Investigators:

MELISSA IAZZI

Biography

Melissa Iazzi is a PhD candidate in the Molecular Science Program at Ryerson, University Toronto, Canada. She studies CFTR's interaction network under the supervision of Dr. Gagan Gupta. From a young age, she knew she wanted to pursue a career in medical research. It became apparent to her that she wanted to study rare terminal illnesses when her younger sister passed away. It was through the realisation of the limited treatment options for her sister that she became determined to be a part in finding solutions.



About the research presented at the 44th European CF Conference, abstract number WS07.1:

The limited efficacy of therapies for CF could be partly explained by uncharacterised molecular defects caused by mutations in CFTR. This highlights the importance of understanding the dynamic network of interacting proteins that impact CFTR synthesis, folding, stability, localisation and function. Proximity-dependent biotin identification (BioID) is a powerful approach for comprehensive interactome mapping as it can reveal novel interactions and monitor alterations under different conditions. For the first-time, we will be performing this technique on BirA*-CFTR lines grown at the air-liquid-interface (ALI). The ALI induces further differentiation which reconstitutes many aspects of the in vivo airway. It is likely that this model has specialised interactions vital for CFTR biology.

MARIE-MADLEN PUST

Biography

Marie-Madlen Pust grew up in Berlin the capital city of Germany and obtained the degree of Bachelor of Science in Natural Sciences (Chemistry) from the Open University (UK, Milton Keynes) in 2017 as well as a Master of Science in Biomolecular and Biomedical Science (Microbiology and Infection Biology) from the University College Dublin (IRL, Dublin) in 2018. That same year, she received a scholarship from the German Center for Lung Research and later from the German Academic Scholarship Foundation to pursue her PhD studies at the Hannover Biomedical Research School in Germany.



About the research presented at the 44th European CF Conference, abstract number WS13.1:

Under the supervision of Prof. Dr. Burkhard Tümmler, Marie-Madlen is investigating the development of the human airway microbiome in the early years of life and is searching for diseased microbial community signatures in children with cystic fibrosis. In general, the human airway microbiome consists of a few high-abundant and many low-abundant bacterial taxa. The latter remain largely unexplored due to the high DNA background pattern and hence low signal-to-noise ratio in next-generation sequencing applications. They developed a software tool and utilised machine learning algorithms to distinguish rare species from DNA background noise and to study their role in the early years of life. While doing this, they discovered that the presence or absence of rare species is the key variable in differentiating between the healthy and CF airway metagenome. Transferring healthy rare commensals into the early CF bacterial network was found to be the most essential part to rescue the vulnerable CF background structure of bacterial commensals.



IRIS SILVA

Iris Silva started her career in science in 2010 after joining a molecular biology lab in the University of Algarve, Portugal to do her master's. In 2012, she started her PhD in the analysis of mutations in Paget's disease of bone patients, in a collaboration between the University of Algarve and the Centre Hospitalier Universitaire du Québec, Canada. In 2016, she joined professor Amaral's group as a Postdoc fellow and she has been participating in several CF-related projects, such as the innovative "HIT-CF".

About the research presented at the 44th European CF Conference, abstract number WS09.1:

In Europe there are still ~15% of people with CF (PwCF) not eligible for highly effective modulator therapies, and there is thus the unmet need to find alternative therapies. As part of the HIT-CF project, that aims at implementing personalised CFTR modulator treatments for PwCF with rare mutations by pioneering the use of intestinal organoids, we analysed the efficacy of novel therapies, such as from Proteostasis Therapeutics and Elox Pharmaceuticals. Organoids from 489 individuals from 47 CF-centers in 16 European countries were analysed and our data show clear responsiveness to the triple combination of the potentiator Dirocaftor, the corrector Posenacaftor, and the amplifier Nesolicaftor in 75% of the samples. Based on this, 26 individuals will be invited to participate in a clinical trial, which constitutes a unique opportunity for these individuals with ultra-rare mutations to benefit from novel drugs. The clinical trial could also validate the organoid-based personalised medicine approach.

ECFS / CF Europe Post-Doctoral Research Fellowship



With the aim to foster basic and translational research on CF, the ECFS and CF Europe launched a joint Post-Doctoral Research Fellowship programme.

Three candidates were selected last year for a two-year post-doctoral research fellowship.

They will give a presentation of their research in a special session organised during the Conference on Friday 11 June - 12:30 – 13:30 (CET). We hope you will be attending this session!

We are happy to announce that, together with CFE, ECFS will support a second Post-Doctoral Research Fellowship programme next year. All information on the application process will be published in the autumn.

ECFS Webinars

The success of the Digital Conference organised in September last year showed the appetite of the CF Community to stay connected, interact, discuss and exchange.

We all became more familiar with the virtual meetings and webinars and over the last months several ECFS groups took the initiative to organise webinars open to all.

As an ECFS member, you can access all the recorded sessions on the [ECFS Education platform](#) where new material is uploaded regularly.

We thank the ECFS Psychosocial Special Interest Group and the ECFS Mental Health Working Group who have put together the following sessions:

- Practical therapeutic modalities to manage anxiety, depression, sleep and pain in routine CF care
- Challenges and complexities of care in transition
- Food and CF: friend or foe?
- How Covid-19 changed the clinic: learning as we move along in uncertain times
- New challenges in CF care: physiotherapist and pharmacist joining forces

Do not miss the next webinar:

[Women's Health and Cystic Fibrosis](#) on Thursday 20 May 2021 - 13:00 - 14:00 (CET)

Free Registration

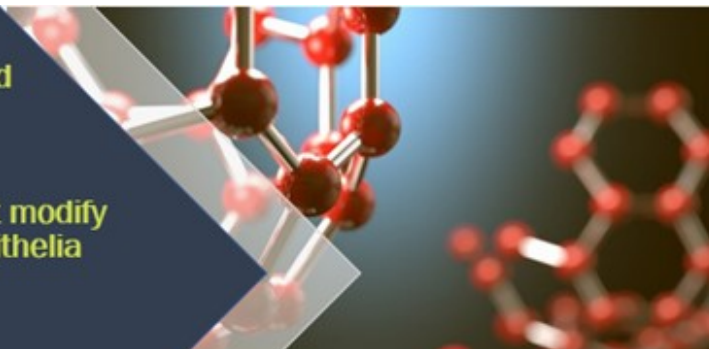
We also thank the Basic Science Conference organisers, Carlos M Farinha, Nicoletta Pedemonte and Jeff Brodsky, who prepared a specific programme before the in-person ECFS [Basic Science Conference](#) in Portugal on 30 March – 02 April 2022

The first webinar, *From genotype to phenotype*, took place at the end of April and was a tremendous success with more than 250 participants from 28 countries.

Save the date for the next sessions:

CFTR Trafficking and Interactions - 14 July 2021, 16:00 CET

Other channels that modify CFTR containing epithelia - 20 October 2021, 16:00 CET



CFTR Trafficking and Interactions
14 July 2021

Other channels that modify CFTR containing epithelia
20 October 2021

16:00 – 17:20 (CET)

Free Registration

BASIC SCIENCE WEBINARS

In Memoriam



Professor Gianni Mastella graduated as a medical doctor in 1955 and as a paediatrician in 1958. In 1967 he was appointed director of the newly established Verona CF Center. He was a visionary and a key figure in the Italian CF community, pioneering the set-up of a multi-disciplinary team and mentoring a whole generation of health professionals to build a greater CF clinical network.

He strongly believed in early diagnosis and initiated a laboratory that anticipated newborn screening, first by measuring meconium proteins and later being one of the first CF centers to adopt immunoreactive trypsinogen in dried blood spots. In the years before 1989, the laboratory was already offering prenatal diagnosis by microvillar enzyme testing, and shortly after the CFTR gene discovery a pilot project of cascade carrier screening was started.

Prof. Mastella received the Rossi Medal in 2003, now known as the ECFS award, given annually to honor a person who has made an outstanding contribution to the treatment or care of patients with CF.

After his retirement, he was the catalyst for the establishment of the Italian CF Research Foundation, of which he was Scientific Director until his demise. The Foundation has been a major channel for CF research in Italy and also a true supporter of the ECFS Basic Science conference, generously funding the participation of young researchers to the conference for many years.

The CF community will sorely miss this pioneer in care and research.

Meetings

20th Scientific Meeting hosted by the scientific board of the Mukoviszidose e.V.
9-10 September 2021

CF Registry: Ready for science!? - Value of registry data to improve CF care

[More information](#)

The ECFS app is available for download for free on iOS and Android! The app includes automatic messaging about ECFS Events including the ECFS 2021 conference, links to the education Platform for access to SOPs and materials, newsletters and much more. Search for ECFS Society on App Store and Play Store



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

Email:
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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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