European Cystic Fibrosis Society

Newsletter September 2019
Issue 61

Letter of the president

Dear Friends,

I hope this letter finds you well and that you all have had a chance to enjoy some relaxing summer vacation.

For those of you who participated in the June ECFS Conference in Liverpool, I am sure you will agree that it was a great success, and I would again like to thank the conference President Jane Davies as well as the Vice Presidents Kevin Southern and Craig Winstanley for their contribution to the event. I would also like to thank the UK CF Trust and all the volunteers for their considerable and enthusiastic support. My sincere thanks go to the Scientific Committee who produced an excellent programme, and to the speakers, moderators and presenters for their superb contribution.

At the Opening Plenary, Prof. Stuart Elborn, recipient of the ECFS Award 2019, delivered a thought-provoking address and many asked for a transcript of the talk. This is now published in the last Journal of Cystic Fibrosis issue.

The ECFS continued its tradition of awarding grants to young researchers based on the merit of their submitted abstracts.

We also granted 3 Young Investigator Awards and were delighted to welcome the Young Investigator Awardees to the Closing Ceremony. All the award winners also received a one year free membership subscription to the ECFS. We were also happy to support 20 young researchers with a Travel Grant.

From left to right:Francesco Renato Luly (IT), Martial Delion (BE), Christian Voldby (DK)

To honour the enormous contribution of Prof. Gerd Döring, the ECFS has initiated a Gerd Döring Award in 2015 that is given annually to honour an exceptional early career young European scientist. This award includes a monetary grant of € 5,000 to support research. This year, the Award was presented to Dr. Elvira Sondo (IT), in acknowledgement of her work.

More information on the ECFS Awards can be found here .

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Once again, speakers at this year's conference were asked to make their presentations (slides) available on the ECFS website (for members only) and these can be viewed by signing in under the "MY ECFS" tab on the homepage of our website.In addition, we filmed a number of sessions at the conference and these are available on the [ECFS Education platform]


3 – 6 JUNE 2020
LYON, FRANCE

43rd EUROPEAN CYSTIC FIBROSIS CONFERENCE

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WWW.ECFS.EU/LYON2020

Thanks go to all of you who participated to the Board elections. We are happy to announce that Trudy Havermans and Isabelle Sermet have been elected as ECFS Board members. I take this opportunity to thank Margarida Amaral, who served two terms as Board member, for her contribution and commitment over the years

We are well into the planning for the Basic Science Conference which will be held in Albufeira, Portugal 25-28 March 2020 and the Annual conference which will be held 03-06 June 2020 in Lyon, France. Programmes for both conferences will be available in the coming months and we hope that you will take an active part in these events and consider submitting your best work for presentation and discussion. The abstract submission deadline for the conference in Lyon will be 17 January 2020. More information about the conferences can be found on our website and you will also have the possibility to have a look at the Lyon 2020 promotion video. Do not hesitate to share it!

I would like to thank those members who participated in this year's Annual General Meeting in Liverpool, and you will find the minutes from the meeting included in this Newsletter.

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

Best wishes,

Isabelle Fajac, ECFS President

Inside this issue

Annual General Meeting

The Annual General Meeting took place during the 42nd European Cystic Fibrosis Conference, Liverpool, United Kingdom, on 7th June 2019.

Several Working Groups' coordinators ended their mandates. Isabelle Fajac thanked them for their excellent work over the last years. and welcomed the new coordinators. Hereunder:

- Nico Derichs for the Diagnostics Network Working Group
  New coordinators: Elke De Wachter (BE) and Nick Simmonds (UK)
- Trudy Havermans and Janice Abbott for the Mental Health Working Group
  New coordinators: Marieke Verkleij (NL) - Eddie Landau (IL)
- Kevin Southern for the Neonatal Screening Working Group
  New coordinator: Jürg Barben (CH)

The minutes of the AGM2019 are available here

Upcoming Events

- **ECFS Board Autumn Meeting**, Nashville (US) - 30 October 2019
- **Strategic Plan Project Meeting:** Brussels (BE) - 27 November 2019
- **ECFS Winter Board Meeting**: Brussels (BE) - 22 January 2020
- **CTN Steering Group Meeting** Brussels (BE) - 23-24 January 2020
- **Registry Steering Group Meeting:** Brussels (BE) - 24 January 2020
- **Standards of Care Steering Group Meeting**: Brussels (BE) - 23 January 2020
- **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

2019 ECFS Board Elections

The ECFS is happy to announce the results of the 2019 board elections. We had 2 positions open. We thank our departing Board member, Margarida Amaral for her insightful contribution to the ECFS. Trudy Havermans will join the ECFS Board and Isabelle Sermet has been elected for a second 3-year mandate.

2019 ECFS Award - Prof. Stuart Elborn

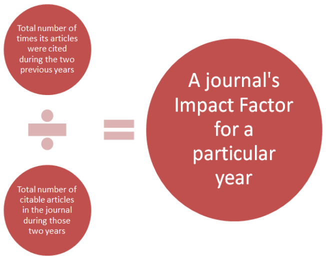
In Liverpool, we were happy to hand over the ECFS Award to Prof.Stuart Elborn. This award honours a person who has made a significant contribution to our understanding of CF or to the treatment or care of patients with CF. Stuart Elborn is a strong role model as a clinical academic combining clinical care and research aimed at improving outcomes in people with CF. He passionately champions interdisciplinary person-centered care delivery, driven by data and implemented with respect and compassion.

Stuart Elborn was the ECFS President for 7 years. Under his leadership and vision the Society flourished with among other achievements, the launching of the clinical trials network, the publication of updated guidelines as well as the growth of the European registry and of the Journal of Cysti Fibrosis.

JCF - Increase of the 2018 Impact Factor

The European Cystic Fibrosis Society is pleased to announce that the official 2018 Impact Factors (IF) were recently released, and the Journal of Cystic Fibrosis (JCF) has increased its IF from the 2017 IF of 3.858 to 4.29. JCF ranks 14th in the Respiratory System category.

JCF has continued to work hard for this achievement, through thoughtful structuring of its editorial pages and continuing growth in our international presence. The ECFS would like to thank the Editor in



We are looking for volunteers to tweet about the CF Research News articles!

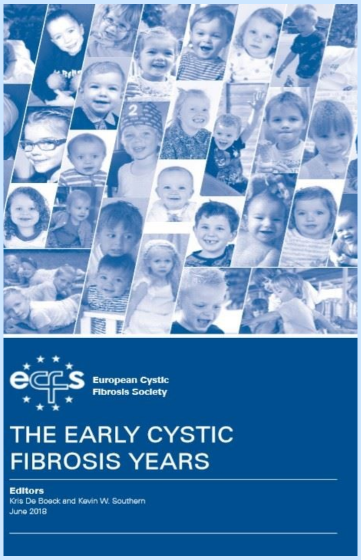
CF Research News

This initiative aims to provide access to scientific work mainly published in the Journal of Cystic Fibrosis to patients, parents, relatives, friends and caregivers. More than 400 CF Research News articles have been published over the last 5 years on our website

Luke Garratt has been promoting the articles through Twitter for the last 3 years. Thanks to his excellent work we passed the 600 followers. Luke would like to step down from this role. So, if you feel like taking over the reins for the Twitter communication do not hesitate to contact us!

The Early CF Years
Free Access

The ECFS Book - The early cystic fibrosis years (Editors Kris De Boeck and Kevin W. Southern) which has been published last year is available now in Free Access


ecfs European Cystic Fibrosis Society

THE EARLY CYSTIC FIBROSIS YEARS

Editors
Kris De Boeck and Kevin W. Southern
June 2018

2017 ECFS Registry Annual Report

Each calendar year the ECFS Patient Registry publishes a detailed Annual Report with demographic and clinical data from people with CF throughout Europe and neighbouring countries who agree to participate in the Registry.

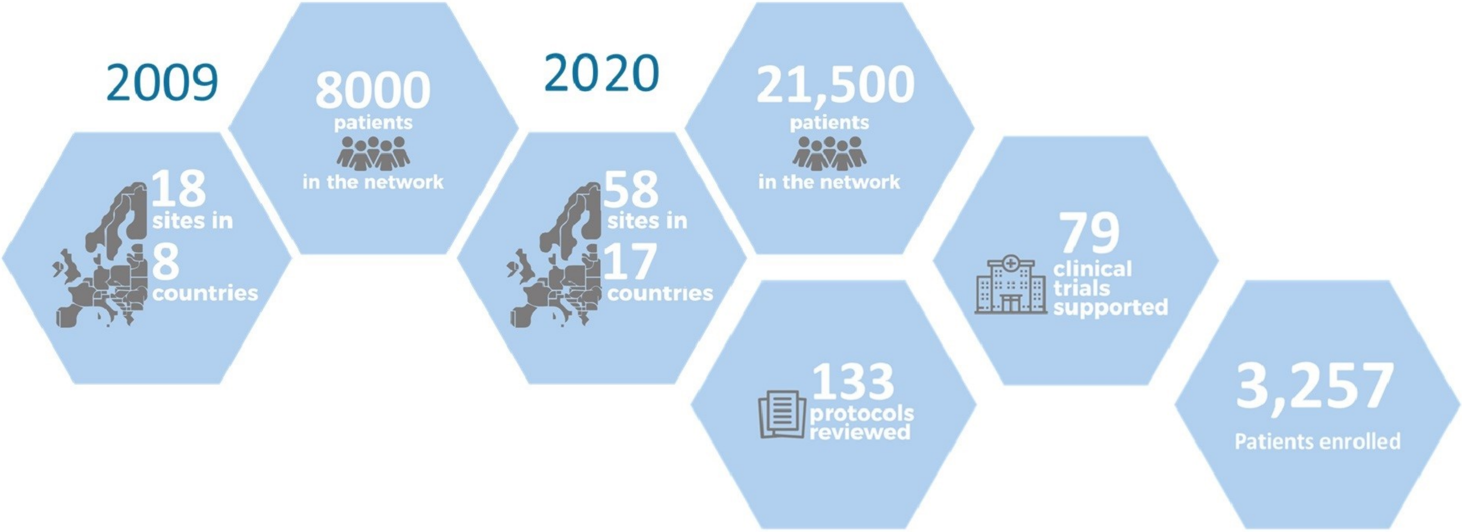
The [ECFS Patient Registry Annual Data Report 2017](#) has recently been published.

The Patient Registry also publishes a At-a-Glance-Report summarizing the data for a larger public. The 2017 edition is available [here](#).

The CTN is 10 years old. Happy Birthday!

The Clinical Trials Network started 10 years ago. We take this opportunity to thank all the CTN directors who made this initiative a success: Kris De Boeck, Isabelle Fajac, Tim Lee and Silke van Koningsbruggen Rietschel. Of course, a warm thanks goes to the CTN Team for the excellent work provided all through the decade: Veerle Bulteel - the CTN would not be what it is without her dedication –, Katia Reeber, Anne Verbruggen, Kate Hayes and Fiona Dunlevey. Also thanks to our past team members for their support!

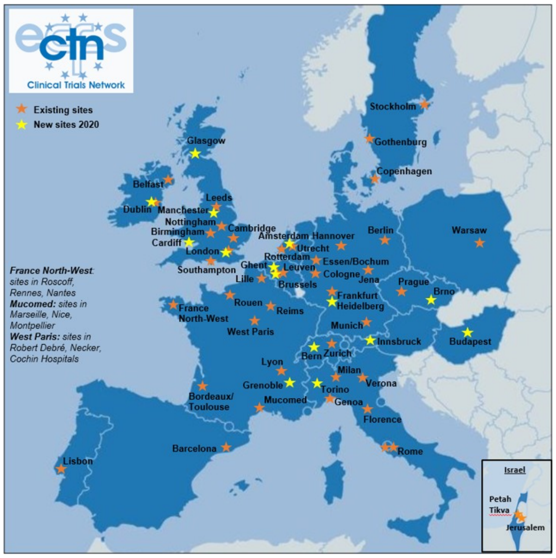
Key figures of the ECFS-CTN activities over the last 10 years



ECFS Clinical Trials Network expansion in 2020

A new expansion of the network was announced in June 2018 to increase the current capacity. CF centres specialised in clinical trials were invited to send their application by October 2018.

At the end of the evaluation process, 15 sites with the highest ranking were selected to join the ECFS-CTN from 2020. Two new countries will be involved (Austria and Hungary) and the network now will cover around 21 500 adult and paediatric CF patients in 17 countries and 58 sites. The new sites are now being prepared to actively participate in the network as from January 1st, 2020.



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.

European Cystic Fibrosis Society
Kastanieparken 7
7470 Karup
Denmark

Executive Director: Christine Dubois
Email; christine.dubois@ecfs.eu