

Letter from the President

Dear Colleagues and Friends,

I hope this letter finds you well and that you had a restful summer.

In June, we held our Annual General Meeting at the annual European Cystic Fibrosis Conference in Vienna, Austria. I would like to warmly congratulate Jane Davies on her new position as President Elect. She will take over as ECFS President officially from the next Annual General Meeting in Glasgow and I look forward to working closely with her over the coming months as I hand over the reins. We had the opportunity to warmly thank Dorota Sands and Carsten Schwarz who ended their first mandates at the ECFS Board, for their continuing support of the ECFS. Both of them were re-elected and have just started a second mandate. We also welcomed Egil Bakkeheim to the Board, who is taking over as director of the ECFS Patient Registry from Andreas Jung. For three years Andreas dedicated his time and expertise to the project, and we are grateful for his commitment to the success of this important project of the ECFS.

Working Groups focus on critical CF topics and they gather large numbers of members to share their interests and work on common projects. However, the ECFS Board has noted that there are low numbers of members from Southern European countries within the Working Groups, and more generally, low numbers of ECFS members. Working Groups need a geographically diverse group to ensure projects worked on are relevant for all and all members of ECFS Working Groups should be ECFS members.

You can all play an important role in encouraging your colleagues to become ECFS members! For example, highlight the importance of having a diverse membership in the ECFS. This will help to ensure that the ECFS is representative of the CF community.

The ECFS Conference in Vienna was a great success and we were delighted to welcome more than 2,000 enthusiastic participants. I would like to thank the Conference President, Helmut Ellemunter, as well as the Vice-Presidents, Andrea Lakatos-Krepcik and Andreas Pflieger, for their enthusiasm and tremendous support. I would also like to thank the Scientific Committee for producing an excellent programme, the Steering Committee for their commitment in making the conference a success, and the speakers, moderators, and presenters for their superb contributions.

At the Opening Plenary, I had the pleasure of presenting the ECFS Award to Professor Harm Tiddens, who delivered a riveting talk that set the tone for an uplifting and invigorating conference.

In honor of the enormous contribution of Professor Gerd Döring, the ECFS initiated the Gerd Döring Award in 2015. This award is given annually to an exceptional early career young European scientist. This year, the award was presented to Dr. Lúcia Santos for her paper, Mutation-class dependent signatures outweigh disease-associated processes in cystic fibrosis cells (doi: 10.1186/s13578-023-00975-y).

The ECFS continues its tradition of awarding grants to young researchers based on the merit of their submitted abstracts. This year, we granted 3 Young Investigator Awards and were delighted to present these awards to Samantha Durfey (US), Floriana Guida (IT) and Christie Mitri (FR) at the Closing Ceremony. We were also happy to support 20 young researchers with a Travel Grant. More information on the ECFS Awards can be found [here](#).

Several symposia and sessions were recorded and are accessible on the ECFS Education platform with unlimited access for ECFS members.



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The Scientific Committee and the Steering Committee are already preparing an exciting program for the next ECFS conference, which will take place in Glasgow, UK on 5-8 June 2024. Mark your calendars so you don't miss it! Abstract submissions will open in December, so be prepared to submit your research for presentation to your peers!

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 encourage you to send us articles that you would like to have included in forthcoming newsletters. This is a great way to communicate with your colleagues and keep them informed about the latest developments in cystic fibrosis research.

Best wishes,

Isabelle Fajac
ECFS President

Annual General Meeting

The Annual General Meeting took place during the 46th European Cystic Fibrosis Conference, Vienna, Austria on 09 June 2023.

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. The reports from the ECFS Working Groups and Special Interest Groups were provided to the membership ahead of the meeting and coordinators were present to answer any question from the audience.

Andreas Jung ended his mandate as the director of the ECFS Patient Registry. Isabelle Fajac warmly thanked him for his dedication and enthusiasm over the last years, and welcomed Egil Bakkeheim, who started his mandate as director of the project.



Andreas Jung (CH)



Egil Bakkeheim (NO)



At the end of the Annual General Meeting, Lyudmila Bober, Head of the CF centre in Lviv, Ukraine and Halyna Makukh, Head of the regional center of newborn screening thanked the ECFS community for the support of Ukrainian CF patients in these difficult times. They presented Prof. Fajac with a framed engraving as a token of gratitude to the CF community.

You will find the full minutes of the Annual General meeting 2023 [here](#)

ECFS 2023 Board Elections

We held Board elections last May. There were two positions open for Board members, and we also elected a new President for the Society, as Isabelle Fajac will finish her second term in June 2024. We are happy to announce that Prof. Jane Davies has been elected as ECFS President Elect and will become President of the ECFS at the AGM in June 2024.

Congratulations to Prof. Dorota Sands and Prof. Carsten Schwarz on their election to the Board for a second term.



Jane Davies

Dorota Sands

Carsten Schwarz

Glasgow 2024

The ECFS looks forward to welcoming you to the 47th European Cystic Fibrosis Conference in Glasgow, UK, on 5-8 June 2024. Gordon MacGregor will be the Conference President and Robert Gray will be the Vice-President.

Known as a hub for academic excellence, Glasgow boasts world-renowned universities and cutting-edge research facilities. The SEC Centre where our conference will be held is a stunning piece of architecture designed by Sir Norman Foster and is often referred to by Glaswegians as 'the armadillo'. This modern and bright venue is located on the outskirts of Glasgow and is within walking distance of the city centre.

Upcoming Events

- **North American Cystic Fibrosis Conference**
02–04 November 2023
Phoenix, US
- **Adult Cystic Fibrosis Conference**
01–02 December 2023
Milan, Italy
- **ECFS Board Winter Meeting**
24 January 2024
Brussels, Belgium
- **ECFS Winter Meetings of ECFS projects**
25–26 January 2024
Brussels, Belgium
- **Diagnostic Network WG Meeting:**
08-10 February 2024
Hanover, Germany
- **17th European CF Young Investigator Meeting**
06-08 March 2024
Paris, France
- **ECFS Basic Science Conference**
20–23 March 2024
Valletta, Malta
- **47th European Cystic Fibrosis Conference**
05-08 June 2024
Glasgow, UK

47th EUROPEAN CYSTIC FIBROSIS CONFERENCE 5 – 8 JUNE 2024 | GLASGOW, UNITED KINGDOM



SAVE THE DATE

Registration and Abstract Submission	December 2023
Abstract Submission Deadline	15 January 2024
Notification of Abstract Acceptance	Mid-March 2024
Deadline for Early Registration	21 March 2024

WWW.ECFS.EU/GLASGOW2024

#ECFS2024

Glasgow offers a wide range of accommodation options to suit all tastes and budgets, so you'll easily find the perfect place to rest and recharge after a day of stimulating discussions and presentations.

In your free time, you will be able to immerse yourself in Glasgow's vibrant culture and history, take a stroll through the charming West End, renowned for its Victorian architecture and lively atmosphere, and explore the city's thriving arts scene at the Kelvingrove Art Gallery and Museum, which houses an impressive collection of artworks.

With its warm and welcoming atmosphere, Glasgow is sure to leave you with a lasting impression. Prepare to be inspired by the city's energy!

The abstract submission for the conference will open in December and will close on 15 January 2024.

The notifications for abstract acceptance will be sent mid-March 2024 and the deadline for early registration to the conference will be on 21 March 2024.

Join us in Glasgow!



Gordon MacGregor



Robert Gray

Basic Science Conference 2024

The 19th ECFS Basic Science Conference will be held in Malta from 20 to 23 March 2024.

Alexandre Hinzpeter (FR) will be the conference chairperson, supported by Patrick Harrison (IE) and Marie Egan (US)

A key characteristic of the conference is the attendance of PhD students and post-docs, who contribute enormously to the success of this annual event with their enthusiastic discussions. So, if you are a young researcher, we strongly encourage you to join us and to submit your current research. There will be excellent opportunities to discuss your data, interact and discuss science in a great atmosphere, with the best of European and international experts in the field of cystic fibrosis.

Abstract submission will open in early December 2023.

Abstract submission deadline: Friday 05 January 2024.

More information on the registration conditions and abstract submission will be published soon on the [conference page](#).



Alexandre Hinzpeter



Patrick Harrison



Marie Egan

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 aim to foster basic and translational research on CF, the ECFS and CFE have joined forces to support a number of European Post-Doctoral 3-year duration Research Fellowships. It is foreseen that a call for this 3-year support will be launched each year.

Applications are due by 24 November 2023 (23:59 CET)

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

- Call: 15 September—24 November 2023 (23:59 CET)

TIMELINE FOR 2024 CALL

- Evaluation and selection: December 2023 to end of April 2024
- Results: June 2024 presented at the ECFS annual conference
- Contracts with institutions over the Summer/Autumn
- Launch: As from September 2024 and as soon as contract in place with institution

ECFS Working Groups

The ECFS is proud to count on active Working Groups and Special interest Groups with enthusiastic members who organise a variety of activities throughout the year.

We believe that this newsletter is a great opportunity to highlight our groups, and we will be featuring one of them in each issue.

In this issue, the Exercise Working Group is happy to give you more information on its objectives and meetings.

ECFS EXERCISE WORKING GROUP

Who are we?

We are a multi-disciplinary group of professionals who are interested in the role of exercise and exercise testing for people with cystic fibrosis.

Our aims are to provide a forum for sharing exercise knowledge amongst CF professionals.

The group have published several technical standards documents and position statements on exercise testing over the last decade; and have also co-developed research studies including randomised trials (the ACTIVATE-CF trial) and investigator-led studies on a) the effects of genotype on exercise capacity, and b) the effects of exercise capacity on mortality risk. Several existing projects are nearing completion, whilst new research studies are being planned.

We have a keen interest in education and are developing a curriculum of modules that can be accessed by all ECFS members. We are keen to provide peer support to junior members. We have organised pre-conference courses alongside ECFS meetings in Liverpool (2109) and Vienna (2023) that have been well-received.

When do we meet?

The exercise working group meets twice a year – i) alongside the annual CF conference (in person); and ii) in January/February each year (by videoconference). In addition there are ECFS exercise journal clubs that run every 2 months throughout the year.

We encourage early career researchers to present at our meetings and have an annual prize for junior researchers.

Who can join?

The exercise working group is an open group, and we welcome members from all disciplines who may have an interest in exercise.

Being an ECFS member is desirable for those who wish to join our working group.

Anyone interested in joining or those requiring further information are encouraged to contact:

Dr Tom Radtke (Zurich, CH) – Exercise Working Group Co-ordinator

thomas.radtke@uzh.ch

Dr Don Urquhart (Edinburgh, UK) – Exercise Working Group Deputy Co-ordinator

don.urquhart@nhslothian.scot.nhs.uk



Exercise Working Group

Outputs.

A list of publications follows:

Research Publications:

Radtke T, Kriemler S, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands LC, Schindler C, Eber E, Haile SR, Hebestreit H, on behalf of the ACTIVATE-CF Study Working Group. Cystic fibrosis related diabetes is not associated with maximal aerobic exercise capacity in cystic fibrosis: a cross-sectional analysis of an international multicentre trial [ACTIVATE-CF]. *J Cyst Fibros* 2023;22:31-38.

Hebestreit H, Kriemler S, Schindler C, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands L, Schaeff J, Radtke T, ACTIVATE-CF Study Working Group. Effects of a partially supervised conditioning program in cystic fibrosis: an international multicenter randomized controlled trial (ACTIVATE-CF). *Am J Respir Crit Care Med* 2022;205:330-339.

Hebestreit H, Hulzebos EHJ, Schneiderman JE, Karila C, Boas SR, Kriemler S, Dwyer T, Sahlberg M, Urquhart DS, Lands LC, Ratjen F, Takken T, Varanistkaya L, Rücker V, Hebestreit A, Usemann J, Radtke T; Prognostic Value of CPET in CF Study Group. Cardiopulmonary Exercise Testing Provides Additional Prognostic Information in Cystic Fibrosis. *Am J Respir Crit Care Med* 2019;199:987-995.

Radtke T, Hebestreit H, Gallati S, Schneiderman JE, Braun J, Stevens D, Hulzebos EH, Takken T, Boas SR, Urquhart DS, Lands LC, Tejero S, Sovtic A, Dwyer T, Petrovic M, Harris RA, Karila C, Savi D, Usemann J, Mei-Zahav M, Hatziagorou E, Ratjen F, Kriemler S; CFTR-Exercise study group. CFTR Genotype and Maximal Exercise Capacity in Cystic Fibrosis: A Cross-sectional Study. *Ann Am Thorac Soc* 2018;15:209-216.

Hebestreit H, Lands LC, Alarie N, Schaeff J, Karila C, Orenstein DM, Urquhart DS, Hulzebos EHJ, Stein L, Schindler C, Kriemler S, Radtke T; ACTIVATE-CF Study Working Group Effects of a partially supervised conditioning programme in cystic fibrosis: an international multi-centre randomised controlled trial (ACTIVATE-CF): study protocol. *BMC Pulm Med*. 2018;18:31.

Guidelines/Technical Standards/Position Statements:

Saynor ZL, Gruet M, McNarry MA, Button B, Morrison L, Wagner M, Sawyer A, Hebestreit H, Radtke T, Urquhart DS, on behalf of the European Cystic Fibrosis Society Exercise Working Group. Guidance and standard operating procedures for functional exercise testing in cystic fibrosis. *Eur Respir Rev* 2023;32:230029. doi:10.1183/16000617.0029-2023.

Hebestreit H, Arets HG, Aurora P, Boas S, Cerny F, Hulzebos EH, Karila C, Lands LC, Lowman JD, Swisher A, Urquhart DS; European Cystic Fibrosis Exercise Working Group. Statement on Exercise Testing in Cystic Fibrosis. *Respiration* 2015;90:332-351.

Bradley J, O'Neill B, Kent L, Hulzebos EH, Arets B, Hebestreit H; Exercise Working Group European CF Society, for publication in *Journal of CF*; Exercise Working Group European CF Society. Physical activity assessment in cystic fibrosis: A position statement. *J Cyst Fibros* 2015;14:e25-32.

Swisher A, Hebestreit H, Mejia-Dawns A, Lowman JD, Gruber W, Nippins M, Alison J, Schneiderman J. Exercise and habitual physical activity for people with cystic fibrosis: Expert consensus, evidence-based guide for advising people. *Cardiopulm Phys Therap J* 2015;26:85-98.

ECFS "A Special CF Lunchtime Series" Webinars. Save the dates

The ECFS Psychosocial Special Interest Group and the Mental Health Working Group are happy to announce the following webinar as part of the "Special CF Lunchtime Series":

"CFSPID: Don't we all want to know more about it"

on Wednesday 29th November 2023, 12:00- 13:00CET/ 11:00-12:00 UK

Their next webinars are planned on Wednesday 21st February and 17th April 2024 and the topics will be communicated soon.

Free registration.

[More information](#)

ECFS Education section: e-Learning programme on CF

The ECFS has been developing an e-learning programme on cystic fibrosis (CF). Part 1 “CF for Beginners” (7 modules covering the fundamental basics) and Part 2 “More about CF” (17 modules which built upon the first part) have received UEMS EACCME accreditation and are available on the ECFS Education Platform for free for ECFS members.

Work has started on the final part, Part 3 “Becoming a CF clinical expert: How to manage...” and will allow in-depth discussion about care and treatment of very specific situations occurring in people with CF. We will keep you updated with the progress of this project as it advances.

To access the e-learning programme on the ECFS Education Platform:

Log into your ECFS account (<https://www.ecfs.eu/user/login>), and then access the ECFS Education homepage (www.ecfs.eu/education) and click on the button for the Platform.

Once on the ECFS Education Platform home page, click on ‘ECFS courses, conferences and meetings’. To access the e-learning programme, select the ‘ECFS e-learning programme on CF’ and click on ‘Start’ to commence the course!

It is possible to stop and start the course and come back to it later; If the e-learning was the last resource you have viewed, simply click on the resume icon on your Education Platform home page and you will be taken back to the course.

Adult Cystic Fibrosis Conference



This conference, organised by the European Respiratory Society in partnership with the European Cystic Fibrosis Society, will provide an integrated approach to diagnosis, treatment, and continuous management of cystic fibrosis in adults.

This will be a hybrid event, with participants able to attend both online, and on-site in Milan, Italy.

The deadline for abstract submission is **September 28, 2023**.

The registration and abstract/clinical case submission are now open

[More information](#)

Job Posting

An Adult Cystic Fibrosis and Obstetric Medicine Fellow position has become available at the Royal Brompton Harefield Hospitals, London, UK

[More information](#)

Obituary

Margaret Hodson

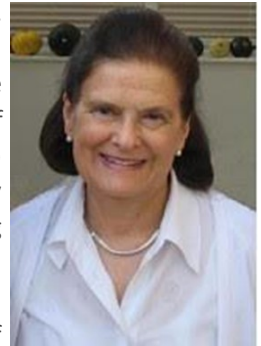
Prof. Margaret Hodson has died aged 79 having dedicated her life's work to people with CF. Margaret became involved in CF early in her working life. After house jobs in Leeds, she was appointed registrar at Sir John Batten's newly established department for adults with CF at the Royal Brompton hospital. Margaret's innovative contributions to CF included novel methods of physiotherapy and airway clearance, nebulised antibiotics, and together with Sir Magdi Yacoub lung transplantation for people with CF. Margaret was a strong advocate of multidisciplinary teams and pioneered the development of some of the first CF clinical nurse specialists working across both hospital and home.

Margaret was appointed consultant at the Royal Brompton Hospital in 1978 and professor in 1996. As well as clinical care and research, Margaret was a great educator and was director of medical education at the Royal Brompton and a tutor for the Royal College of Physicians. Informally Margaret shared her expertise with the CF multidisciplinary team throughout every working day.

In recognition of her contribution to CF care, in 2012 Margaret was awarded an OBE by the Queen for services to respiratory medicine and in 2002 she was the first recipient of the European Cystic Fibrosis Society's Rossi medal (now the ECFS Award).

For over 40 years Margaret led the CF multidisciplinary team with enthusiasm, dedication, and the belief that we were making lives better for adults with CF, she will be missed by many – colleagues and people with CF.

Margaret Ellen Hodson (born 1943, died 2023)



Laura Minicucci

The CF Center of the Gaslini Institute sadly announces that Dr. Laura Minicucci has passed away. Laura has been a committed researcher, vice-president of the Italian Cystic Fibrosis Society and head of the Genoa CF clinic, one of the few centers participating in the ECFS CTN since its beginning. She dedicated most of her professional career to the care of people with CF with competence, participation and passion.

Laura was an important point of reference for people with CF, families and colleagues, and even after her retirement kept working in the CF field for the Italian CF Research Foundation. She will be missed by all her colleagues and friends who shared many years of professional life with her, always appreciating her pragmatic vision and ability to listen and participate.



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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