

European Cystic Fibrosis Nutrition Group (ECFNG)

Year of report: 2023/2024

Date of initial approval of Special Interest Group: not known

Contact details of coordinator, vice coordinator and assistant (if applicable) including ECFS membership numbers:

Coordinator name:
Monika Mielus (co-chair)
Joanna Snowball (co-chair)

Long term aims of the Special Interest Group including estimated achievement date:

- Promote communication and networking between dietitians working in cystic fibrosis across Europe and beyond.
- Information-sharing at the annual ECFNG meeting and ECFS nutrition webinars, including via the ECFS website, and ECFNG Twitter account.
- Provide dietetic expertise and support to members of less well-resourced European countries.
- Continue to raise profile of the group internationally and encourage dietitians from outside of the UK to join the committee.

Aims are ongoing.

Outcomes already achieved:

- New-established committee, with representation from different European countries – international focus.
- Successfully run annual meeting/study day at ECFC which is well-attended by dietitians.

Report for this year:

- short term aims and objectives for the year
- current number of members
- measures taken to encourage ECFS membership
- outcomes/achievements (e.g. meetings, activities, website development, awards, publications etc).

The 2023 year marked a significant period of transition for our committee, as we successfully established a new nutrition committee team. This team consists of specialists in both pediatric dietetics and adult cystic fibrosis care.

- Co-chair: Monika Mielus,
- Co-chair: Joanna Snowball

Furthermore, we appointed two individuals to positions of membership secretary:

- Marie Barret
- Clodagh Landers

Among our ordinary members, we have:

- Dee Shimmin
- Fiona Moore
- Juliana Roda

At the end of April 2024, we have 101 members in our group, of which 26 out of 101 (26%) had paid their ECFS membership at that time.

We have made extra efforts to encourage our members to join ECFS and regularly promote the benefits of membership including the ECFS education platform in each email we send out. We also ensure members are aware that of the discount available for conference registration for those that are ECFS members. We also promoted the benefits of membership at Vienna 2023 and plan to do the same at Glasgow 2024. Many of our members take advantage of the joint membership and registration rates available and join ECFS at the time of conference registration. They then let their membership lapse until the next conference they attend (which may be several years). We will promote the benefits of paying the membership fee each January to ensure they have access to the benefits of ECFS all year round.

Throughout from June 2023 our **Committee has been engaged in organizing various events and initiatives.** Notable highlights include:

- Organizing the European Cystic Fibrosis Nutrition Group Lunchtime Webinar titled "Gastrointestinal Issues - Considerations in CF Care" on 04/12/2023. This well-attended event drew participants from diverse countries.
- Organizing the Nutrition Group meeting on 05/06/2024 in Glasgow, which featured an keynote lecture, two thematic sessions based on selected abstracts from 8 different countries, and an interactive session.
- Facilitating a Tomorrow Lounge session in Glasgow, which will be providing a platform for informal networking and discussions.
- Demonstrating active participation by each committee member during the conference held in Glasgow as a moderator or speaker.

In addition to these endeavors, **co-chairs collaborated in co-organizing the pre-conference Clinical Nutrition Course** alongside Chris Smith and Dimitri Declercq.

Furthermore, **we were shaping the program for the symposium sessions in Glasgow**, covering a range of Nutrition/GI and Liver topics in cystic fibrosis care:

- S06 Symposium 06 - Gastrointestinal, metabolic, and malignant complications in adults with cystic fibrosis
- S12 Symposium 12 - Exploring novel nutritional paradigms in cystic fibrosis care: Insights from updated guidelines
- S24 Symposium 24 - Cystic Fibrosis Hepatic Biliary Involvement (CFHBI)

In collaboration with ECFS Physiotherapy Special Interest International Group, we also create during the 2024 Glasgow Conference a Meet the Expert Session "Implementing a healthy lifestyle in cystic fibrosis - diet and physical activity"

The Committee meets online regularly every two months and earlier if needed.

2023/2024 Publication of the committee members:

Snowball JE, Flight WG, Heath L, Koutoukidis DA. A paradigm shift in cystic fibrosis nutritional care: Clinicians' views on the management of patients with overweight and obesity. J Cyst Fibros. 2023 Sep;22(5):836-842. doi: 10.1016/j.jcf.2023.03.011.

Southern KW, Addy C, Bell SC, Bevan A, Borawska U, Brown C, Burgel PR, Button B, Castellani C, Chansard A, Chilvers MA, Davies G, Davies JC, De Boeck K, Declercq D, Doumit M, Drevinek P, Fajac I, Gartner S, Georgiopoulos AM, Gursli S, Gramegna A, Hansen CM, Hug MJ, Lammertyn E, Landau EEC, Langley R, Mayer-Hamblett N, Middleton A, Middleton PG, **Mielus M**, Morrison L, Munck A, Plant B, Ploeger M, Bertrand DP, Pressler T, Quon BS, Radtke T, Saynor ZL, Shufer I, Smyth AR, Smith C, van Koningsbruggen-Rietschel S. Standards for the care of people with cystic fibrosis; establishing and maintaining health. J Cyst Fibros. 2024 Jan;23(1):12-28. doi: 10.1016/j.jcf.2023.12.002

Caley LR, Jarosz-Griffiths HH, Smith L, Gale L, Barrett J, Kinsey L, Davey V, Nash M, Jones AM, Whitehouse JL, **Shimmin D**, Floto RA, White H, Peckham DG. Body mass index and nutritional intake following Elexacaftor/Tezacaftor/Ivacaftor modulator therapy in adults with cystic fibrosis. J Cyst Fibros. 2023 Nov;22(6):1002-1009. doi: 10.1016/j.jcf.2023.06.010.

Caley LR, Zagoya C, Duckstein F, White H, **Shimmin D**, Jones AM, Barrett J, Whitehouse JL, Floto RA, Mainz JG, Peckham DG. Diabetes is associated with increased burden of gastrointestinal symptoms in adults with cystic fibrosis. J Cyst Fibros. 2023 Mar;22(2):275-281. doi: 10.1016/j.jcf.2023.01.010.

Aims for the coming year:

To organize the next Lunch Time Webinar in November/December, and this activity will continue into the next year. Two webinars per year are planned to organise.

Organizing all required activities in the nutrition area for the 2025 ECFS Conference.

We will continue to promote our mentorship scheme for those new to working in CF, this has successfully paired dietitians from different countries to support each other with clinical practice.

We are planning to send out recent important nutrition publications via email to the members as a form of education and to provide up-to-date knowledge.

Summary:

The ECFNG has developed this year with a more streamlined membership process, a newly established committee with wider European representation and a successful programme of events. We continue to generate discussion and research priorities as the nutritional care of people with CF continues to evolve. We plan to consolidate these improvements over the coming year and engage with our members regularly particularly promoting the benefits of ECFS membership and access to the ECFS Educational platform.

Breakdown of expenses

- Sponsorship has been secured from DEKAsvitamins® for refreshments at the ECFNG meeting

Budget amount requested for next year (please give the amount in Euros and the year): **N/A**