

ECFS Psychosocial Special Interest Group

Year of the report: 2023/2024

Coordinator name **Urszula Borawska – Kowalczyk**
 Vice coordinator name **Dagmar Brocke**
 Assistant name **Annet Bongen**

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

The aim of EPSIG is to provide education and support for CF psychosocial professionals and teams by sharing good practice, research, and information in a friendly and supportive environment. Understanding and addressing psychosocial factors is important in helping people with CF and their relatives achieve the best possible health outcomes. In part, the psychosocial role is to deliver a psychological and social work service to the MDT.

It is also essential to cooperate with other ECFS special interest groups and the Mental Health Working Group to collaborate in activities aimed at improving the care of patients with CF and their families. In addition, EPSIG participates in tasks conducted by the ECFS Education Group.

Outcomes already achieved:

The described goals are systematically achieved by sharing the experience of group members and organizing meetings, workshops, and courses.

The main activity of the group takes place during the annual ECFS conferences, during which members organize and actively participate in such activities as Pre-conference ECFS Psychosocial Special Interest Group Meetings, Pre-conference Short Courses, and Interactive sessions "Tomorrow lounge".

In addition to the activities during the annual conference, EPSIG co-organized the ECFS Lunchtime webinar series.

The EPSIG Committee meets regularly online monthly to organize the EPSIG pre-conference meeting and course, discuss the group's goals, and plan future activities.

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 EPSIG Committee update. Urszula Borawska-Kowalczyk, Clinical Psychologist from Poland, has been appointed as the Coordinator for the second term. Sejal Patel, Clinical Psychologist, UK stepped down from the EPSIG Committee. The current EPSIG committee consists of three psychologists and four social workers:: Urszula Borawska-Kowalczyk, Clinical Psychologist, PL, Annet Bongen, Medical Social Worker, Dagmar Brocke, Clinical Social Worker, NL; Stina Järholm, Clinical Psychologist, SE; Katie Smith, Social Worker, UK; Sue Braun, Clinical Psychologist, BE; Jacqueline Boekhoff, Social Worker, NL. The EPSIG comprises approximately 70 psychosocial professional members.

The EPSIG committee has organized the following activities during the 46th European Cystic Fibrosis Conference in Vienna:

- EPSIG pre-conference meeting "Coping with Change" on the 7th of June 2023
- Pre-Conference Short Course - Psychodynamic Aspects in Chronic, Medical Illness by Dr. Maya Kirszenbaum, Paris, FR on 6th of June 2023, in collaboration with the MHWG
- Interactive session "Tomorrow lounge" titled Psychosocial aspects of getting older with CF

All activities provided participants with opportunities to acquire new skills, share experiences, and establish professional connections. All of them were well attended and received favorable feedback in the evaluation surveys completed by participants, who found them to be valuable educationally and efficiently organized.

The EPSIG and MH WG have organized a series of three lunchtime webinars for the CF MDT. The topics concerned broadly understood areas of care in the context of mental health aspects and psychosocial care. The aim was to present various specialists' cooperation in creating the best practices in MDT. Additionally, the online format allowed for the participation of clinicians from many regions (participants from many countries registered). The topics of organized webinars:

- CFSPID: Don't we all want to know more about it – 29th of November 2023 (187 registrations from 36 countries)
- Challenges in the clinic in the era of CFTR modulator therapy: educational and informational insights - 21st of February 2024 (203 registrations)
- Ethical Issues in CF Care: CFTR modulators – 17th of April 2024 (184 registrations)

In addition, EPSIG co-authored the syllabus on psychosocial care for the ECFS Education Group and took an active part in creating the psychosocial educational content available at the ECFS Education Platform.

The EPSIG Committee actively encourages members to renew their ECFS membership by sending emails to the entire contact list at the beginning of the year, during the ECFS conference registration period, and in every email correspondence regarding EPSIG membership. Additionally, during EPSIG meetings and activities, we remind participants and strongly recommend ECFS membership. However, despite offering an attractive reduced rate for Health Allied Professionals, we have received feedback that some members, especially from less prosperous countries, face challenges in obtaining funds or renewing their ECFS membership from their resources every year. An additional challenge is that psychosocial professionals in many hospitals often do not hold full-time positions within the CF MDT, but engage with CF patients on a part-time basis.

Aims for the coming year:

The EPSIG committee is organizing the following activities during the 47th European Cystic Fibrosis Conference in Glasgow:

- **EPSIG pre-conference meeting** “Well-being, an important topic for patients and professionals” on the 5th of June 2024.
- **Pre-Conference Short Course** – Co-creating personalized treatment plans - how to live your best life. Facilitator: dr Steve Jones on the 4th of June 2024, in collaboration with the MHWG
- **Interactive session “Tomorrow lounge”** titled CFSPID – what is the role of psychosocial professionals and how to organize support and care.

The CF lunchtime webinar series organized jointly with MH WG is planned to be continued next year.

Summary:

Most of the goals and plans set for 2023 have been successfully achieved. The EPSIG activities held during the ECFS conference in Vienna were well-attended and well-received by participants. The Committee meets online monthly, facilitating the organization of EPSIG tasks and the attainment of group objectives.

EPSIG's primary regular activities, including pre-conference meeting, course, and interactive session, will continue during the 47th ECFS Conference in Glasgow. EPSIG will also maintain its collaboration with other ECFS

Groups, resulting in joint initiatives such as courses and webinars, as well as participation in ECFS projects like the syllabus and Education Platform. The EPSIG Committee will actively encourage members to renew their ECFS membership.

Breakdown of expenses

EPSIG received 3000€ of ECFS Support in 2023.

Pre-conference short course Instructor's fee 700€, travel (estimated 300€) and accommodation 1 night (estimated 100€); catering 650€: to be split equally between the EPSIG and MH WG

Pre-conference EPSIG meeting: catering 1350€

Budget amount requested for next year:

2024 – According to the Special Interest Group Terms of Reference, we are applying for 3000 euros. However, if possible, we would like to request a slightly higher amount as catering costs have significantly increased, and our budget is estimated at 3200 euros (catering costs will be adjusted directly to the number of registrations).

Pre-conference short course (EPSIG covers half of the course costs, while the MGWG covers the other half)
EPSIG costs: Instructor's fee 350€, travel (estimated 100€) and accommodation 1 night (estimated 75€); and moderators' registration 150€, catering 450€

Pre-conference EPSIG meeting: catering 2000€, speakers' registration 75€

Catering costs are estimated and will be adjusted directly to the number of registrations