

European Cystic Fibrosis Pharmacy Group (ECFPG)



Year of report: 2024

Date of initial approval of Special Interest Group:
2015

Coordinator name: Maarten Ploeger

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

Incorporating the evolving disease burden due to use of CFTR modulators, long-term goals of the ECFPG include providing more remote patient support, organizing patient follow-up using the Personalized Care Mode; to tailor care, integrating physician input for an effective, patient-centered model. Maintaining vigilance on medication interactions and side-effects. This approach aims to optimized care and outcomes for individuals with Cystic Fibrosis.

Outcomes already achieved:

- Larger and well attended annual meetings ensuring sharing of knowledge between Pharmacy teams across Europe (and beyond). 2023: over 35 participants!
- Developing a more multidisciplinary setting during the annual ECFPG meeting. The changes and challenges in healthcare advocate for increased collaboration. Over 6 physicians will participated in the next meeting.
- An multidisciplinary program has been assembled with the following topics:
- The Pharmacy syllabus is completed and approved by the ECFS board
- The App is completed in a basic form.
 - a. Establishing effective policies for prevention and managing of liver-related side effects of CFTR modulators:
 1. Start dosing in case of liver disease: development of guideline (Child-Pugh or other criteria)
 2. Isolated elevation of Bilirubin: Gilbert Syndrome; need for testing?
 3. Elevation of transaminases: dose adjustments: development of guideline.
 - b. Investigating drug-drug interactions associated with CFTR modulators.
 1. Guideline development of interactions with CF related drugs
 2. Guideline development for the use CFTR modulators in patients with CF after solid organ transplantation.
 - c. Developing policies to address and manage psychological side effects of CFTR modulators.
 1. Definition of CFTR related mental disorders.
 2. Dose adjustment of CFTR in patients with mental disorders due to CFTR modulators
 - d. Early and late skin disorders after the use of CFTR modulators
 1. Definition and diagnosis

Aims and Objectives for the year 2024-2025

Aims:

- To provide an educational meeting and networking opportunities for its membership at the ECFS 47th annual conference in June 2024.
- To promote the role and expertise of the CF pharmacist in the care of the PwCF and as a valuable member of the CF MDT.
- 2 Follow-up meetings for feedback from the Working Groups (composed during the annual meeting)
- To finalize the Pharmacy Syllabus and education program
- Introducing the drug dosing app in the basic form in Glasgow and gain feedback
- 2 meetings 1 year to agree on additions and modifications to the app in a multidisciplinary team.

Objectives:

- To encourage its membership to participate in research activities.
- To encourage collaborative working within the group and wider CF community.
- To support members who are new to the role or those that wish to develop their skills further.

Membership

As of April 2024, the European CF Pharmacy Group had 49 members. Unfortunately it is known that not all ECFPG members have an active ECFS membership. I would like to receive an update on the members for whom this is the case. The remainder of applicants were emailed on receipt of their membership application form to recommend registration with ECFS but were permitted to join the mailing list for the group. We will develop a mechanism this year to cross reference those on the mailing list with those that have maintained or joined ECFS so that we can proactively encourage individuals to join the ECFS or renew their membership. Moving forward we will consider whether to remove those from our membership / mailing lists if they are not members of the ECFS. We will use the forthcoming conference meeting to again encourage membership and the benefits of being a member of the ECFS.

Aims for the coming year:

The chairmanship has been transferred as of 01-01-2023. I want to use this year to take inventory of the current members and determine if they still want to remain active within the group. There are several challenges that we want to complete this year. These include finalizing the syllabus, the dosing app, and updating various sections in the standards for the care of people with CF.

Summary

The chairmanship has been transferred as of January 1st, 2023, and this year will be used to assess current members' interest in remaining active within the group. The group faces several challenges this year, such as updating the syllabus, dosing app, and various sections in the standards for the care of people with CF. In addition to completing these challenges, the group aims to inspire and attract new members.

Breakdown of expenses

There are no expenses known for now

Budget amount requested for next year:

nil