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Mission Statement

The European Cystic Fibrosis Pharmacy Group is committed to promoting good practice in the supply of, and equitable access to, medicines and information about medicines to patients; setting high standards of pharmacy practice; supporting patients to achieve greatest benefit from their medicines; promoting the role of pharmacists and affiliated professions in the pharmaceutical care of patients with CF; delivering continuing professional education and development, and pharmacy practice research.

Introduction

The European CF Pharmacy Group was formed in 2015, following an invitation from the then ECFS President, recognising the role that pharmacists have to play in the modern management of cystic fibrosis, and the notable absence of a pharmacist group within ECFS. Since then the group has gone from strength to strength and this year (2018-19) has seen the largest ever attendance at a conference meeting (Belgrade) since the inception of the group.

Membership

As of 31st March 2019, the European CF Pharmacy Group had 32 members. Whilst members are encouraged to join the ECFS, only 8 members included their ECFS membership number on registration forms. 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 use the forthcoming conference meeting to again encourage membership and the benefits of being a member of the ECFS.

Geographical origin of the group membership is shown in Table 1.

Country	Number of members
United Kingdom	18
Ireland	3
Northern Ireland	1
Belgium	2
Cyprus	1
France	1
Germany	1
Switzerland	1
Uruguay	1
The Netherlands	1
Canada	1
Slovenia	1

The fledgling group has attracted members from a range of countries described above. There has been a slight increase in numbers and further expansion with representation from 2 further

countries, following the successful meeting at the ECFC in Belgrade 2018, and through continued engagement with the UK CF Pharmacy Group which 'hosts' the ECFPG in the UK.

Group activities

1. ECFPG Annual Meeting

The 3rd ECFPG Annual Meeting was held within the European CF Conference in Belgrade, Serbia, in June 2018 and was well attended with 20 attendees, our highest attendance at a meeting so far, and testament to the growth of the group on the CF platform. The agenda and feedback from the meeting can be found in the next section.

2. ECFS Standards of Care Committee

This is a priority group within the ECFS for the coming years and a member of the ECFPG was invited to be part of this group by the existing committee. Edwin Brokaar, CF pharmacist from HagaZiekenhuis, The Hague, Netherlands, kindly agreed to represent our group and be part of the work streams. We look forward to contributing to the work that this group undertakes.

3. ECFS Standards of Care book: Optimising Pharmaceutical Care in CF

As part of the above Standards of Care Committee initiatives, the chair of the committee, Carlo Castellani, identified the need for a book encompassing pharmaceutical care in CF, and has invited the ECFPG to contribute to its production. With our ever-growing armoury of medicines for CF, there are increasing complexities surrounding choice of medicine, drug interactions, dose and formulation, amongst others, and this is an opportune time to use the expertise of our members to improve patient care. It will also serve to highlight the important role that the CF clinical pharmacist has to play in managing the challenges of medicines optimisation in adults and children with CF.

4. Communication

Communication with group members continues to be via email using a dedicated email address: ecfpg@outlook.com, and also through the UK CF Pharmacists Group forum hosted on NHS networks. Twitter [[@ecfpg](https://twitter.com/ecfpg)] is also used to inform the group of the annual meeting and other relevant material. The annual meeting provides the best opportunity for members to discuss relevant issues and meet others working within CF centres within Europe.

ECFPG Annual Meeting 2018

The 2018 Annual European CF Pharmacy group meeting was held on Wednesday 6th June in Belgrade, Serbia, prior to the 41st European Cystic Fibrosis Conference. The meeting was attended by 16 pharmacists, 1 clinician and 3 members of CF Ireland team. The delegates represented 10 countries - table 2

Table 2 : Origin of Delegates for 2018 ECFPG pharmacy meeting.	
Country	Number of delegates
United Kingdom	5
Canada	2
Ireland	4
Northern Ireland	1
Netherlands	3
France	1
New Zealand	1
Luxemburg	1
Australia	2

The meeting commenced with a welcome and introduction to the meeting led by the co-chairs of the ECFPG Siân Bentley (Lead Pharmacist, Paediatrics, Royal Brompton Hospital, London, UK) and Nicola Shaw (Advanced Clinical Pharmacist, Adult Cystic Fibrosis, Leeds, UK).

This introduction was followed by presentations from a number of guest speakers (Table 3).

Table 3: Presentations delivered at ECFPG Annual Meeting 2018		
Title	Presenter	Representing
Initiatives to prevent aminoglycoside ototoxicity in CF children	Sukeshi Makhecha	Royal Brompton and Harefield NHS Foundation Trust
Orkambi® – experience from the Netherlands	Edwin Brokaar	HagaZiekenhuis, The Hague, Netherlands
Pharmacist consultation at Annual review	Michaela Smith	Christchurch Hospital, New Zealand
Isavuconazole: our experience to date	Elaine Bowman	Royal Brompton and Harefield NHS Foundation Trust
Aseptic centralized versus home extemporaneous preparation for cystic fibrosis outpatients' parenteral antibiotic therapy: a survey	Stephen Garcia	Hospices Civils de Lyon, Lyon, France

Feedback was provided on individual presentations (Table 4)

Table 4: Feedback from delegates regarding presentations			
Title	How relevant was the focus of the session to your work? (Max 5)	The session advanced my knowledge (Max 5)	Overall the session was (Max5)
Initiatives to prevent aminoglycoside ototoxicity in CF children	4.6	4.2	4.6
Orkambi®- experience from the Netherlands	4.6	4.3	4.3
Pharmacist consultation at annual review	4.5	3.9	4.3
Isavuconazole: our experience to date	4	4.6	4.4
Aseptic centralised versus home extemporaneously preparation for CF outpatients' parenteral antibiotic therapy: a survey	3.9	3.9	4

The overall rating for the study day was 4.3 on a scale of 1-5 with 1=not very useful to 5 = extremely useful.

Conclusion

The ECFPG has continued to establish its place in the European CF community. Although membership is small, the group continues to have a presence within the European CF Conference, and in the coming months, there should be a focus on increasing membership and contributing to the exciting Standards of Care projects identified above. ECFPG members will be reminded that they need to retain membership of ECFS.