

**Annual Report of the European Cystic Fibrosis Pharmacy Group
2017-18**

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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

On 30th October 2015, the European CF Pharmacy Group was approved by the ECFS Board, following application to form a special interest group. This was invited by the 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. This year (2017-18) has been about building on and sustaining the momentum achieved during the first year of the group.

Membership

As of 31st March 2018, the European CF Pharmacy Group had 29 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 encourage membership and the benefits of being a member of the ECFS.

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

Table 1: Origin of ECFPG pharmacy group members	
Country	Number of members
United Kingdom	18
Ireland	3
Belgium	2
Cyprus	1
France	1
Germany	1
Switzerland	1
Uruguay	1
The Netherlands	1

The fledgling group has attracted members from a range of countries described above. There has been a slow but steady growth in numbers, following the successful meeting at the ECFC in Seville 2017, sessions in the Tomorrow Lounge at the ECFC and through continued engagement with the UK CF Pharmacy Group which 'hosts' the ECFPG in the UK. We have not yet engaged Centre Directors across a wider geography, and this should be a priority for 2018-19.

Group activities

1. Communication

Presently, a dedicated discussion forum has not been adopted – communication with group members is via email using a dedicated email address: ecfpg@outlook.com and also through the UK CF Pharmacists Group forum hosted on NHS networks.

Twitter is also used to inform the group of the annual meeting and other relevant material.

2. ECFPG Annual Meeting

The inaugural ECFPG Annual Meeting occurred within the European CF Conference in Seville, Spain, in June 2017 and was well attended. The agenda and feedback from the meeting can be found in the next section.

3. Contribution to the programme of the ECFS Conference

Participation by the group in the Tomorrow Lounge Programme is important to share knowledge, promote the role of the CF clinical pharmacist, and connect with the wider CF community. Members of the ECFPG delivered two sessions within the ECFS Tomorrow Lounge programme at ECFC 2017. One session was entitled PRO/CON debate debating the merits of the specialist pharmacist as an essential member of the clinical team in the care of people with CF. This was delivered by a pharmacist from Canada and another from Australia. The session was well attended and attracted lots of questions from the audience. The second session was entitled Drug administration and was delivered in conjunction with the CF nursing group. Two pharmacists (one from Ireland and one from the UK) presented at this session. The session was well received and it was productive to work in collaboration with another AHP special interest group.

4. Collaborative research

The group is keen to move this forward in the coming year and this will form a focus for annual meeting in Belgrade this year.

ECFPG Annual Meeting 2017

The 2017 Annual European CF Pharmacy group meeting was held on Wednesday 7th June in Seville, Spain, prior to the 40th European Cystic Fibrosis Conference. The meeting was attended by 15 pharmacists, representing 6 countries- table 2

Table 2: Origin of Delegates for 2017 ECFPG pharmacy meeting	
Country	Number of delegates
United Kingdom	6
Australia	2
Ireland	3
Belgium	1
Canada	1
Netherlands	2

The meeting commenced with a welcome and introduction to the meeting led by one of the co-chairs of the ECFPG 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 2017		
Title	Presenter	Representing
Preliminary experience of the use of oral posaconazole and terbinafine to treat <i>Lomentospora prolificans</i> and <i>Scedosporium apiospermum</i> in children with CF	Siân Bentley	Royal Brompton and Harefield NHS Foundation Trust
BTS NTM guidelines consultation update	Anna Connolly	St Vincent's University Hospital, Dublin
Baseline knowledge - what do CF patients really know?	Nicola Shaw	Leeds Teaching Hospitals NHS Trust
Multifaceted aspects of adherence	Mandy Byron	Great Ormond Street Hospital for Children, London, UK
Educational film about the use of antibiotics and mucolytics in CF	Guy Van Schandevuyl	Hospital University Children Reine Fabiola, Brussels
An evaluation of home medicines review for adult patients with CF	Kingsley Coulthard	Royal Adelaide Hospital, Australia

The meeting included a guest speaker Dr Mandy Byron, Senior psychologist (Great Ormond Street Hospital for Children, London, UK). This session was rated as extremely relevant and advanced knowledge by all 15 delegates.

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 (Max 5)
Preliminary experience of the use of oral posaconazole and terbinafine to treat <i>Lomentospora prolificans</i> and <i>Scedosporium apiospermum</i> in children with CF	4.4	4.6	4.4
BTS NTM guidelines consultation update	4.5	4.3	4
Baseline knowledge - what do CF patients really know?	4.3	4.2	4.3
Multifaceted aspects of adherence	4.7	4.5	4.8
Educational film about the use of antibiotics and mucolytics in CF	3.9	3.5	4
An evaluation of home medicines review for adult patients with CF	4.1	3.7	3.9

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 identifying collaborative projects, including input to guidelines, and patient and professional information resources on the use of medicines in CF. ECFPG members will be reminded that they need to retain membership of ECFS.