

## Annual Report of the European Cystic Fibrosis Pharmacy Group 2019-20

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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 (2019-20) has seen the largest ever attendance at a conference meeting (Liverpool) since the inception of the group.

### Membership

As of 31<sup>st</sup> March 2020, the European CF Pharmacy Group had 35 members. Whilst members are encouraged to join the ECFS, only 12 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 delegates
United Kingdom	19
Ireland	5
Northern Ireland	1
Belgium	2
Cyprus	1
Slovenia	1
France	1
Switzerland	1
Uruguay	1
Netherlands	1
Canada	1
Germany	1

The group has attracted members from a range of countries described above. There has been a slight increase in numbers, following the successful meeting at the ECFC in Liverpool 2019, and through continued engagement with the UK CF Pharmacy Group which 'hosts' the ECFPG in the UK.

### **Group activities**

#### **1. ECFPG Annual Meeting**

The 4th ECFPG Annual Meeting was held within the European CF Conference in Liverpool, U.K., in June 2019 and was well attended with 30 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](mailto: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 2019 Annual European CF Pharmacy group meeting was held on Wednesday 5<sup>th</sup> June in Liverpool, UK, prior to the 42<sup>nd</sup> European Cystic Fibrosis Conference. The meeting was attended by 30 delegates representing 5 countries - table 2

Table 2: Origin of Delegates for 2019 ECFPG pharmacy meeting	
Country	Number of delegates
United Kingdom	23
Ireland	3
Netherlands	2
Germany	1
Canada	1

The meeting commenced with a welcome and introduction to the meeting led by the co-chair of the ECFPG Siân Bentley (Lead Pharmacist, Paediatrics, Royal Brompton Hospital, London, UK) and Patrick Wilson Chair of the UK CF Pharmacist Group (Assistant Head of Pharmacy: Clinical & Operational Services, Nottingham University Hospitals, UK).

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

Table 3: Presentations delivered at ECFPG Annual Meeting 2019.		
Title	Presenter	Representing
Access to patient electronic records & Education within the ECFS	Helen Chadwick,	Education Co-ordinator (ECFS) & CF Clinical Trials Co-ordinator Leeds Teaching Hospitals NHS Trust, UK
CFTR and disease modifiers: an update	Nick Simmonds	Consultant Respiratory Medicine, Royal Brompton & Harefield NHS Foundation Trust, London, UK
The discovery and development of CFTR modulators for CF	Fred Van Goor	Principal Research Fellow, Vertex Pharmaceuticals
How to utilise CF registries for post marketing authorisation studies	Siobhan Carr	Consultant Paediatric Respiratory Medicine, Royal Brompton & Harefield NHS Foundation Trust, London, UK
Intravenous antibiotic dosage survey of UK and Ireland adult CF centres	Michael Dooney	Adult Cystic Fibrosis Pharmacist, Blackpool Adult Cystic Fibrosis Service, UK
Anti-emetic use and guidance for patients with NTM	Lucy Wheeler	Clinical Pharmacist – Paediatric Respiratory University Hospital of Wales, Cardiff, UK
Practical approaches to adherence problems in CF	Alistair Duff	Honorary Clinical Associate Professor   Consultant Clinical Psychologist, Leeds Teaching Hospitals NHS Trust, UK

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)
Access to patient electronic records & Education within the ECFS	4.3	4.1	4.3
CFTR and disease modifiers: an update	4.8	4.7	4.8
The discovery and development of CFTR modulators for CF	4.5	4.4	4.6
How to utilise CF registries for post marketing authorisation studies	3.9	4.3	4.2
Intravenous antibiotic dosage survey of UK and Ireland adult CF centres	4.7	4.4	4.5
Anti-emetic use and guidance for patients with NTM	4.6	4.3	4.5
Practical approaches to adherence problems in CF	4.9	4.9	4.9

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.