

NEWSLETTER June 2020

Dear Member,

Sadly, due to Covid-19 we have been unable to provide our usual meeting and AGM. As we all get used to new ways of working and communicating, the committee hopes you find the information in this newsletter informative. The opportunities to share information and catch up with colleagues at the annual ECFS conference in Lyon, and other events, will also be missed. However, we hope that anyone who was due to present work at this will have an opportunity to share this with the group at some point in the near future. The NACFC is currently planned to go ahead in October, but in the current climate we understand that it may be unlikely that any of our members will be able to attend. For this reason we have amended our Educational Award, so please read on for more information.

Chairpersons Report (Kerry-Lee Watson and Jacqui Lowden)

Key Achievements in 2019

* Successful meetings with feedback and membership participation plus sponsorship:

15 May 2019 – London (AGM and Study day) ~40 people

14 November 2019 – Birmingham (Study day) ~ 40 people

Mylan Supported May 2019

DEKA’s supported November 2019

* Resources produced e.g. newsletters for members, resources for members, public/patient information.
* CF Trust Nutrition Fact Sheets (produced and reviewed by the group’s members)
* Review of PEN
* CTAP- Project Reviews.
* BDA Ambassadors

Planned events postponed due to COVID-19 were:

* Present at the CF Psychology group study day April 2020 (Kerry-Lee Watson)
* Present at the NIHR GI Workshop March 2020 (Kerry-Lee Watson)
* Present at the Gastroenterology Conference in Liverpool June 2020 (Kerry-Lee Watson)
* Other Member involvement:
  + CF Trust Clinical Advisory Group Representation
  + Abstract submissions for European CF Conference (Poster and E- Poster submissions)
  + Abstract for the European CF Conference accepted on behalf of paediatric staffing working group (Poster)
  + Alliance, promotion and feedback to the Scottish CF Group
  + BAME Representative for the CF Trust
  + CF Trust COVID nutrition support for Website

Treasurer Report (Alison Marshall)

Crossley Accounting now monitor and produce the accounts on behalf of the BDA. We have forecasted an income of around £3900 for this financial year, which was due to be from sponsorship and group membership. We also have some surplus from last year which we planned to use to offer the Educational Award and buy resources for the running of the group i.e. a lap top. Due to COVID 19, these figures will differ and the committee plan to make best use of the funds available.

Membership Update 2019/20

Total 147

Full membership and international (2) Full – 145 International – 2

Research officer report (Helen White)

**Review of accomplishments for 2019:**

The obesity working Group is progressing and statistical support is being finalised.

Strategic Grant funding was secured for a PhD Dietetic post (Laura Caley, Leeds adults CF unit). This has been funded by the CF Trust to characterise the microbiome in CF and then adjust fibre intakes and assess any affects on the microbiome. It will also potentially assess the advice regarding high fat diet and impact on the microbiome. This funding has been extended to Cambridge (Lucy Gale), Birmingham (Jo Barrett) and Manchester for data collection and has therefore brought in dietitians at several of the large UK centres to the project.

Input was provided to organise the content for the CF Masterclass at the European CF Conference, Liverpool 2019.

Work on use of continuous glucose monitoring, by Dee Shimmin (Leeds adult CF unit), was presented at ECFS 2019

Completion of data collection, examining nutritional status across mutation class. This data collection was undertaken by a student at Leeds Metropolitan University and is aiming to be published in the near future.

There is somearly work on branched chain amino acid (Leucine) Supplementation, which is currently being piloting this in respiratory medicine before taking forward into CF. This work is in partnership with a pharmaceutical company, it is awaiting it’s European patent currently. The plan is for this to be offered out to the CF Group over the next year for multi-centre study.

Committee Update

**Current Committee March 2020**

Kerry-Lee Watson (Co-Chairperson) (May 2019 – April 2021)

Jacqueline Lowden (Co-Chairperson) (May 2019- April 2021)

Alison Marshall (Treasurer) (May 2019- April 2021)

Katie Stead (Communication Officer- leaving June 2020-maternity leave)

Helen White (Research Lead- end of term)

Secretary: Vanessa Bara (Left post Dec 2019) \*VACANT\*

Ordinary Member: Megan Price (Left Post January 2020 – maternity leave) \*VACANT\*

**New positions** to be requested and advised on in May 2020

Removal of Communications Officer

Addition of the following:

- Social Media

- Website

- Education/Working Groups

For more information and job descriptions go to <https://www.bda.uk.com/specialist-groups-and-branches/cystic-fibrosis-specialist-group/committee.html>

**Building for the Future**

The current committee had a meeting at the BDA offices in March 2020, where we completed our annual report for the BDA. Some of the areas we want to continue to build on are:

* **Increasing our profile and awareness via social media.**
* **Maintaining membership subscriptions.**
* **Developing professional standards within CF**
* **Support and develop research within CF dietetics. (Study day dedicated to Research)**
* **(ensuring access to leading research and innovative practice)**
* **Supporting members with up to date information relevant to CF Nutrition (via study days)**
* **Invest in resources within emerging areas with CF nutrition and prioritizing areas of interest**
* **Accessing laptops to enable improved communication and embedding an IT structure to our group and enhancing our social media presence.**
* **Developing standardized competencies/skill sets for CF Dietitian’s.**
* **Reviewing and updating on CF Nutrition Consensus Guidelines in collaboration with the Australian and New Zealand CF Dietitians.**

**Other Updates and Business**

**CF Trust Clinical Advisory Group Update**

**CF Trust Resource Update**

Information resources catalogue: Published Jan 2020

This is a catalogue of all the current information resources available from the CF Trust. It's updated annually and can be ordered from our helpline or downloaded here: https://www.cysticfibrosis.org.uk/information

**CF Trust Resources Survey**

This is a generic paper survey that is going out with all information resource orders, along with a freepost return envelope. There is also the option for people to complete the survey online. This will allow us to gather qualitative feedback on our resources. The surveys should be returned to CF Trust HQ, so there may be some delay with processing them while the COVID-19 crisis continues. The link for the online survey has been put up on the BDA CF Group website.

**CF Trust Nutrition Leaflets**

The nutrition leaflets are now almost all complete. Since November 2019, the following leaflets have been published, and can be found on the CF Trust website:

* Healthy eating in CF
* Food refusal
* Pancreatic enzyme supplement and CF
* Teaching your child to swallow their enzymes/pills

The CF Trust also worked with a young person with CF to promote a resource for children called ‘Benji’s Cystic Fibrosis Food Friend’.

**CF Trust Leaflets Supporting Clinical trials for Young People**

These resources are almost completed and should be sent off to print soon:

* A ‘Little Agents’ comic for children. This comic explains what clinical trials are and is intended for use by younger children. It encourages children to think of clinical trials as something interesting that they can become involved in because of the ‘special skills’ they have as children with CF.
* A parent’s flyer to help parents to get the most out of reading the comic with their child. This flyer includes tips from other parents whose children have been involved in clinical trials, explaining how to talk to children about trials. It also includes tips from a CF psychologist for how best to start these conversations.
* A young person’s flyer to encourage young people to get involved in clinical trials – this is aimed at a slightly older teenage audience, and uses imagery from our clinical trials video ‘Can you change the future of CF?’, which was developed with help from a young person called Jade who is in our Youth Advisory Group.

**Upcoming resources in the pipeline from the CF Trust:**

Transition pack – The CF Trust are working on a resource to support young people and their parents through what can be a challenging time. They are currently scoping what format these will be in, what content will be included and are working with service users to develop them. There has been some delay to this project due to COVID-19, but it is now back underway.

* An individual healthcare plan for secondary students – like the version for parents to fill in for their primary-age children but for young people at secondary school to fill in for themselves for school.
* Accessibility of information – The CF Trust will be working over the coming months to improve the accessibility of their information resources. This will include creating an accessibility guide for professionals and staff to refer to when they are writing information for our resources, working out ways to create accessible versions of our current resources (i.e. easy reading versions), and scoping work for ensuring our resources in the future are designed to be accessible.
* COVID-19 content, including nutrition for people shielding
* New physiotherapy leaflets
* Information on Ramadan and nutrition

**Upcoming CF Trust leaflets:**

|  |  |
| --- | --- |
| GI issues and CF | Stress incontinence for children – a leaflet for parents |
| Enzyme refusal | Pelvic floor exercises for children and young adults |
| Good posture for children | Airway clearance in babies and young children |

**Key stats**

The top information resource downloads between 1 November 2019 and 1 May 2020 have been:

1. Pre-school and primary school pack for parents
2. Employment factsheet
3. Consensus document on physiotherapy management
4. Family planning pack
5. Antibiotic treatment consensus document

**BDA CF Group Educational Award 2020**

We have revised the terms of application for the Educational Award in light of the current global position with Covid-19. Any opportunity for education or development will be considered by the committee for an award of up to £350. Please see our web pages for more information and applications by the **end of December 2020.**

**CF Nutrition Guidelines**

The committee have reached out to the authors of the 2017 Nutrition Guidelines for Cystic Fibrosis in Australia and New Zealand, to discuss the co-production of updated guidelines. Initially, this has been really positive with talks of producing a “commonwealth set of guidelines for cystic fibrosis nutrition” – with BDA and CF Trust leading the way and building on the previous work of the AUS/NZ group (the previous guidelines already had Australian, New Zealand, Canadian input and if the UK comes onboard then essentially it would be a “commonwealth” nutrition guideline).

*Anyone interested in dedicating time to some small sections of this should be in touch with us via the group email or Kerry or Jacqui.*

**How to manage the BDA Website**

We realise that it is not always obvious how to access information on the BDA site for the CF group and that communication can be hard to find.

We have now set up the newsletters which come via the BDA to appear in your email in box twice per month and this should prompt you to click on the links which take you our group via the BDA web pages. Alternatively, log in to the BDA main site and click on My BDA, My groups and branch, choosing Cystic Fibrosis Group.

On our main page is some information about the group. Announcements are below this and you can click at the bottom to see all the archived ones. This will be any information that has come into the group and we feel we need to share with our members. It generally is for information and not requiring a response. Below this is the discussion forum. You can view discussions already taking place or start your own *– Note that they are defaulted to last reply rather than date created, so you might want to change this to see the most recent discussions*. You will not automatically receive updates about the discussion forum unless you have started a discussion and click on the ‘subscribe to notifications’ tab. The tool bar on the left has info on the committee including roles and vacant positions and info about the Educational Award.

We hope this helps you navigate the BDA web pages and please spend some time familiarising yourself if you have not already done so.

**Finally**

**Thank you**

We would like to thank the outgoing committee members for their extensive hard work for the group and the education days provided.

We would also like to thank our group members without whom we could not exist, for your ongoing support to the group.

Thank you and good luck to Katie who is leaving us to go on maternity leave in the very near future!

***The Committee***