

ECFS EXERCISE WORKING GROUP

Year of report: 2020/21	Detailing activities from 14 th May 2020 to 30 th April 2021
Name of Working Group: ECFS Exercise Working Group	Date of initial approval of working group: 2011

Coordinator Dr Thomas Radtke
Vice coordinator Dr Don Urquhart

Long term aims of the working group (maximum 100 words) including estimated achievement date:

- Provide forum (the working group) for sharing exercise knowledge amongst CF professionals
Ongoing
- Curate technical standards and position statements for clinical practice in the fields of exercise and physical activity
3 x documents published 2014-2015
New standard document on multimodal testing and update of 2014 physical activity position statement in progress
- Establishment of educational package to provide support for those undertaking exercise testing and exercise counselling in persons with CF
Ongoing – First exercise education modules complete by June 2021
- Utilise Working Group as a Clinical Research Network for research theme of exercise in CF
Ongoing – 3 studies completed
New study in progress

Outcomes already achieved (maximum 100 words):

- **Knowledge sharing**
- Biannual meetings great resource for CF exercise professionals since 2011
- **Technical Standards/Position Statements:**
- Exercise Testing (Respiration 2015)
- Physical Activity (JCF 2014)
- Exercise Recommendations (Cardiopulm Physiotherapy J 2015)
- NEW: Multimodal exercise testing - *In progress*
- UPDATE: Physical activity - *In progress*
- **Education**
Previous Exercise short course (Liverpool 2019)
Online education package in development - First 3 modules due for completion 06/21
- **Research**
Completed studies:

Exercise capacity and CF genotype – *Ann Am Thorac Soc* 2018
 Exercise capacity and mortality – *Am J Respir Crit Care Med* 2019
 ACTIVATE-CF – *Eur Respir J* [under review]

Ongoing studies:

Exercise capacity and outcome in those with FEV₁<40%predicted

Report for this year (max 1000 words)

- **Short term goals for the year**

- **Knowledge-sharing**

Meeting (virtual) took place on 3rd June 2020

The meeting was conducted on Zoom and was attended by 30 delegates

Table 1: Delegate list from 2020 ECFS Exercise Working Group Virtual Meeting

Bert Arets	Mathieu Gruet	Kelly Macintosh	James Shelley
Brenda Button	Elpis Hatziagarou	Melitta McNarry	Julia Taylor
Adam Causer	Helge Hebestreit	Lisa Morrison	Owen Tomlinson
Ciara O' Connor	Nicola Hodgson	Thomas Radtke	Ian Waller
Frank Cerny	Raquel R Iniesta	Claire Reilly	Craig Williams
Jamie Duckers	Asterios Kampouras	Zoe Saynor	Don Urquhart
Tiffany Dwyer	Sally Kiernan	Jane Schneiderman	
Wolfgang Gruber	Larry Lands	Hiran Selvadurai	

Agenda covered at 2020 meeting

- 1) 12:00 – 12:15 Welcome and introduction (Helge Hebestreit)
- 2) 12:15 – 12:30 Update ACTIVATE-CF (Helge Hebestreit)
- 3) 12:30 – 12:45 Project: Prognostic value of exercise testing II (Thomas Radtke)
- 4) 12:45 – 13:00 Feedback on Exercise testing course in Liverpool (Don Urquhart)
- 5) 13:00 – 13:15 Election of WG coordinator and deputy coordinator (Helge Hebestreit)
- 6) 13:15 – 14:00 Discussion future work on Educational Material (meeting?) (Don Urquhart, all)
- 7) 14:00 – 14:30 Revision of Exercise Testing Statement / Activity assessment paper / Activity counselling paper (all)
- 8) 14:30 – 14:45 New ideas?
- 9) 14:45 – 15:00 Wrap-up + to do lists

Meeting (virtual) planned for 8th June 2021

Programme as below

ECFS Conference 9-12 June 2021

Exercise Working Group Meeting: 8 June 2021

Programme

10.00 – 10.15* Welcome (Tom Radtke & Don Urquhart)

10.15 – 10.45 Update on current research activities (Moderator Don Urquhart)

- Update New Exercise Testing Paper (Zoe Saynor)
- Update Physical Activity Paper (Craig Williams)
- Update Exercise Testing & Mortality II Study (Tom Radtke)

10.45 – 11.30 Update on current educational activities (Moderator Tom Radtke)

- First insights into educational activities (Craig Williams)
- Define next steps and topics on educational activities (All)

11.30 – 11.45 Break

11.45 – 13.05 Invited Presentations (Moderator Helge Hebestreit/Erik Hulzebos)

- Topic I: Engaging people with CF in exercise during the pandemic (Lisa Morrison: 15 min plus 5)
- Topic II: Pro/Con Debate: Exercise versus Chest Physiotherapy for Airway Clearance in CF (Nathan Ward/Maggie McIlwaine: 2x15min plus 10)
- Topic III: Exercise in the world of CFTR Modulators (Casey Derella: 15 min plus 5)

13.05 – 13.45 Break

13.45 – 14.30 Selected presentations* (Jury: Brenda Button/Mathieu Gruet/Larry Lands)

- Topic I: XXX (10min + 5min discussion)
- Topic II: XXX (10min + 5min discussion)
- Topic III: XXX (10min + 5min discussion)

14.30 – 15.00 Plans for the future/Varia (Tom Radtke & Don Urquhart)

Central European Time

- **Technical Standards/Position Statements:**

The group are actively working on two standardisation documents:

- i. **NEW TECHNICAL STANDARD:**
Multimodal exercise testing in cystic fibrosis: translating research into clinical practice

Leads – Zoe Saynor, Don Urquhart and Thomas Radtke

Co-authors – Helge Hebestreit, Mathieu Gruet, Melitta McNarry, Lisa Morrison, Marlies Wagner, Abbey Sawyer

This document is close to completion with an anticipated submission date of July 2021. The plan is to submit for consideration with Journal of Cystic Fibrosis.

ii. UPDATE OF PREVIOUS POSITION STATEMENT:

Physical activity in Cystic Fibrosis

Leads – Craig Williams and Kelly McIntosh

The 2014 Physical activity position statement is to be updated.

A group are being identified to co-ordinate this update.

- **Education**

The group are planning a comprehensive online exercise teaching and training resource comprising of a series of themed presentations with embedded questions and answers.

In brief, this would cover the following modules:

- Exercise Physiology
- Exercise Testing
- Physical Activity
- Exercise Counselling and Advice
- Preparation for Exercise
- Exercise and specific situations

A series of talks would be available for each of the above headings, providing an online knowledge network that links CF health professionals and provides a comprehensive modular curriculum devoted to the field of exercise in CF.

The education workstream is being co-ordinated by Professor Craig Williams, Exeter, UK.

The first 3 talks are to be prepared in advance of the June 2021 virtual meeting.

These form part of the Exercise Physiology module:

- a) Exercise responses in health
- b) Exercise responses in disease
- c) Exercise responses in CF

A more complete draft curriculum is available should further details be required (attached).

- **Research**

Active studies:

1. Does cardiopulmonary exercise testing provide short-term prognostic information in advanced cystic fibrosis lung disease?

Leads – Thomas Radtke, Helge Hebestreit

Study sites in Australia, Austria, Canada, France, Germany, Greece, Israel, Serbia, Spain,

Switzerland, UK, USA

This is a study assessing the prognostic value of exercise parameters in subjects with CF with $FEV_1 < 40\%$ predicted. A total of 127 separate data records so far including 25 cases where an adverse event has occurred including 10 deaths and 15 who have undergone lung transplantation. It is anticipated that around 200 records in total will be available with a completion date for the study estimated as late 2021 and submission of these data for publication in early 2022.

2. Exploration of physical activity and airway clearance therapy behaviours following initiation of elxacaftor/tezacaftor/ivacaftor in people with CF in Europe

This is a proposed study to be conducted by patient survey. There is provisional support for this being co-ordinated by the ECFS (Christine Dubois – *Personal communication*). The aim of the study will be to explore whether highly-effective modulator therapy has been an enabler of exercise ability in people with CF, and also whether starting Kaftrio has enabled a reduction in airway clearance physiotherapy (and thus treatment burden) and whether exercise has replaced chest physiotherapy for airway clearance post-Kaftrio. A draft survey has been prepared and is out for peer review prior to this work commencing.

Establishment of junior researcher award:

The group are mindful of the need for succession planning within the field of exercise and CF. It is necessary to nurture the younger members of the group, to involve them in research and presentation, to enthuse them and to offer mentorship from senior group members.

The junior researcher award will be awarded to the best presentation given by an author aged <35 years on an exercise and CF-related topic at the 2021 ECFS virtual exercise group meeting.

The prize will be registration for the ECFS 2022 conference.

- **Current number of members**

The exercise working group has 43 current members
These have been provided as an Excel spreadsheet of:

- Member
- Institution
- ECFS membership status

- **Measures taken to encourage ECFS membership**

The working group highlights the benefits of ECFS membership when communicating with members. Our newly-developed logo (see below) makes it very clear that the Exercise Working Group is a sub-group of the ECFS.

- **Outcomes/achievements (e.g. meetings, activities, website development, awards, publications etc).**

- **Meetings**

- i. ECFS Exercise Working Group Meeting 3rd June 2020
- ii. ECFS Exercise Working Group Meeting 8th June 2021

Agendas as listed above

- **Developments**

The group held a competition to design a logo for our working group.
The design has been approved by the ECFS.
The winning design is highlighted below.



- **Presentations**

Hebestreit H, Kriemler S, Schindler C, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands L, Schaeff J, Radtke T, ACTIVATE-CF Study Working Group.

Effects of a partially supervised conditioning program in cystic fibrosis: an international multi-center, randomized controlled trial (ACTIVATE-CF).

Workshop 04 – Improvements in understanding how physical activity and exercise impact cystic fibrosis at European Cystic Fibrosis Conference (Virtual) 2021.

- **Publications**

Original articles:

The following has been submitted to Eur Respir J and is presently under review:

Hebestreit H, Kriemler S, Schindler C, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands L, Schaeff J, Eber E, Radtke T, ACTIVATE-CF Study Working Group.

Effects of a partially supervised conditioning programme in cystic fibrosis: an international multi-centre, randomized controlled trial (ACTIVATE-CF).

Under Review

Abstracts:

Hebestreit H, Kriemler S, Schindler C, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands L, Schaeff J, Radtke T, ACTIVATE-CF Study Working Group.

Effects of a partially supervised conditioning program in cystic fibrosis: an international multi-center, randomized controlled trial (ACTIVATE-CF).

J Cyst Fibros 2021; ***In press.***

Aims for the coming year (please state year) (max 50 words):

The aims for the coming year are as follows:

- **Knowledge-sharing**
Undertake virtual meeting in June 2021
Plan for 2 meetings per year thereafter
a) Virtual -January 2022
b) Face-to-face at ECFS June 2022
- **Technical Standards/Position Statements:**
Complete multimodal testing in CF document and submit for publication
Commence Physical Activity position statement update
- **Education**
Begin to build online knowledge network for exercise in CF
- **Research**
Completion of existing research project on exercise testing in advanced lung disease
Estimated date of completion October 2021

Commence International survey on 'physical activity and airway clearance therapy behaviours following initiation of elexacaftor/tezacaftor/ivacaftor' - *Projected start date August 2021*

Summary (maximum 100 words):

The ECFS Exercise Working Group celebrates its' 10 year anniversary in 2021.
The group is a fertile ground for knowledge-sharing and developing collaborations.

Group output:

Published international technical standards and position statements on:

- 1) Exercise Testing
- 2) Physical activity
- 3) Exercise recommendations

Investigator-initiated research:

Exercise Capacity and CFTR genotype (published Ann Am Thorac Soc 2018)
Exercise Capacity and Mortality (published Am J Respir Crit Care Med 2019)
Exercise testing in advanced cystic fibrosis lung disease (study ongoing)
Randomised, controlled trial of exercise as an intervention - ACTIVATE-CF (Under Review - *Eur Respir J*)

Education:

Pre-course workshop on exercise testing at ECFS Liverpool (2019).
Online modular education resource – *In development*.

Ongoing:

Current projects include guideline development, education and research.

We would value your ongoing support to complete these projects and to develop new ideas.

Breakdown of expenses (please include total amount received as well as expenditure and, if applicable, the outstanding balance (Euros)):

- Total amount received: €10'000
- Expenses: €274 for Exercise Working Group Logo

Budget amount requested for next year (please give the amount in Euros and the year):

Junior Researcher Award - €1000

Flights from within Europe and registration for ECFS 2022 for winner of best presentation at ECFS Exercise Working Group meeting in June 2021.

Support for survey:

'Exploration of physical activity and airway clearance therapy behaviours following initiation of elexacaftor/tezacaftor/ivacaftor in people with CF in Europe'

Support costs will include

- Database management
- Translation into other languages

€3000 approx.

Development of patient-facing pages for working group

- Factsheets on working group projects
- Factsheets on physical activity and exercise by people with CF for people with CF

€2000 approx.