

ECFS Exercise Working Group

Year of report:
2023/24

Date of initial approval of working group:
2011

Coordinator name Dr Thomas Radtke
Vice coordinator name Dr Don Urquhart
Assistant name Zoe Saynor

Long term aims of the working group including estimated achievement date:

- Provide forum (the working group) for sharing exercise knowledge amongst CF professionals
Meeting alongside ECFS conference in Vienna in June 2023 attended by around 50 people
Virtual WG meeting February 2024 with 32 log-ins (some with multiple attendees)
Planned meeting at ECFS Glasgow Wednesday 5th June 2024
ECFS Exercise WG Virtual Journal Club meets every 2nd months (commenced February 2022)
- Curate technical standards and position statements for clinical practice in the fields of exercise and physical activity
- ***3 x documents published 2014-2015***
- ***Recently published guideline in Eur Respir Rev August 2023***
Saynor ZL, Gruet M, McNarry MA, Button B, Morrison L, Wagner M, Sawyer A, Hebestreit H, Radtke T, Urquhart DS, on behalf of the European Cystic Fibrosis Society Exercise Working Group.
Guidance and standard operating procedures for functional exercise testing in cystic fibrosis. *Eur Respir Rev* 2023;**32**:230029. doi:10.1183/16000617.0029-2023.

- ***New document in progress:***
Update of 2014 physical activity position statement (due for completion in June 2023).
- Establishment of educational package to provide support for those undertaking exercise testing and exercise counselling in persons with CF
This is well underway, and we are working jointly with the ECFS Education WG on this.
We have an agreed syllabus of exercise modules, and recording of these has begun.

Our group has contributed to the wider ECFS online resource and have finalised a resource for the Part 3 ECFS Educational package.

Urquhart DS, Radtke T.
Exercise and Sports Activities for people with CF.
Approved – awaiting recording.
- Pre-Conference Courses
Exercise short course (Liverpool 2019)
Exercise short course (Vienna 2023)
Musculoskeletal short course (jointly with PhysSIG) – Glasgow 2024
- Develop Exercise WG Journal Club
Meetings every 2nd month began in February 2022.

This has been an excellent addition to the ECFS exercise EG portfolio with authors and early career researchers discussing and critically appraising papers together.

- Utilise Working Group as a Clinical Research Network for research theme of exercise in CF
Ongoing – 5 studies completed + projects ongoing

Outcomes already achieved:

- **Knowledge sharing**
 - Meetings have been a great resource for CF exercise professionals since 2011
 - Currently 1 x meeting at ECFS (In person, June) and 1 x virtual meeting (January/February) each year
- **Peer Support**
 - Support for early career researchers to present and attend meetings
 - Young career researcher prize awarded by group to allow attendance at ECFS
 - ECR presentations as part of journal club activities
 - Informal mentorship available within the group.
- **Technical Standards/Position Statements:**
 - Exercise Testing (*Respiration* 2015)
 - Physical Activity (*J Cyst Fibros* 2014)
 - Exercise Recommendations (*Cardiopulm Physiotherapy J* 2015)
 - Standardisation of functional exercise tests (*Eur Respir Rev August 2023*)
Saynor ZL, Gruet M, McNarry MA, Button B, Morrison L, Wagner M, Sawyer A, Hebestreit H, Radtke T, Urquhart DS, on behalf of the European Cystic Fibrosis Society Exercise Working Group.
Guidance and standard operating procedures for functional exercise testing in cystic fibrosis. *Eur Respir Rev* 2023;**32**:230029. doi:10.1183/16000617.0029-2023.
 - UPDATE: Physical activity - In progress (Aim to submit in 2024)
- **Education**
 - Previous Exercise short course (Liverpool 2019)
 - New Exercise short course (Vienna 2023)
 - Musculoskeletal short course (jointly with PhysSIG) – Glasgow 2024
 - Online education package underway – in collaboration with ECFS Education WG.
 - Recorded session for Part 3 educational package on Exercise and Sports Activities in CF (Urquhart/Radtke)
- **Research**
 - Completed studies:**
 1. Exercise capacity and CF genotype – *Ann Am Thorac Soc* 2018
 2. Exercise capacity and mortality – *Am J Respir Crit Care Med* 2019
 3. ACTIVATE-CF – *Am J Respir Crit Care Med* 2022
 4. Glycaemic control sub-study of ACTIVATE-CF – *J Cyst Fibros* 2022
 5. Exercise capacity and outcome in advanced lung disease - *Ann Am Thorac Soc*, March 2024
 - Oral presentation of work in WS01.01, 46th European Cystic Fibrosis Conference, Vienna, June 2023.

Ongoing studies:

1. Role of sub-maximal exercise measures in advanced CF lung disease
Oral presentation of work in EPS1.03, 47th European Cystic Fibrosis Conference, Glasgow, June 2024.
2. Characterising breathing pattern disorder during exercise in people with Cystic Fibrosis (Ahmed, Hebestreit)
3. Physical literacy in Cystic Fibrosis (Burghard, Hulzebos, Gruber, Mackintosh)

Report for this year:

- short term goals for the year
- current number of members
- measures taken to encourage ECFS membership
- outcomes/achievements (e.g. meetings, activities, website development, awards, publications etc).

SHORT TERM GOALS FOR THE YEAR

Knowledge-sharing

- ECFS Virtual Exercise Working Group Educational Meetings took place in June 2023 and February 2024
- ECFS Exercise Journal Club Meetings took place every 2 months.

June 2023 Exercise Working Group Meeting

This was a half-day meeting alongside the Vienna ECFS.

The programme included updates on ECFS exercise WG projects, and invited speakers – see below for full details. The invited speaker at this meeting was an early career researcher – Dr Barlo Hillen from Mainz, Germany.



ECFS EXERCISE WORKING GROUP

Wednesday, 7 June 2023

Venue: Austria Center, Bruno-Kreisky-Platz 1, 1220 Wien, Austria

Time: 13:45 – 17:00 CEST

Setup: Theatre

The meeting is open to everyone who is interested in exercise.

Meeting Outline

13:45-13:50	Welcome	Dr Thomas Radtke, Zurich (CH) Dr Don Urquhart, Edinburgh (UK)
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13:50-14:30	Presentation from Young Investigator	Barlo Hillen (MSc), Mainz (GER)
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Title: «The impact of ETI treatment on cardiopulmonary exercise testing outcomes: results of a longitudinal, single centre study»

14:30-15:00	Break	
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15:00-15:30	Educational activities - Update video recordings - Journal club	Dr Thomas Radtke, Zurich (CH) Dr Don Urquhart, Edinburgh (UK) Dr Owen Tomlinson, Exeter (UK)
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15:30-16:55	Turning ideas into action	ALL
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We would like to encourage members to discuss research ideas, large or small. The expertise and experience within the group can hopefully lead to partnership and mentoring, enabling an idea to become a live project.

16:55-17:00	Wrap up	Dr Thomas Radtke, Zurich (CH) Dr Don Urquhart, Edinburgh (UK)
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February 2024 Virtual ECFS Exercise Working Group Meeting

This was a half-day meeting attended by around 50 delegates (32 separate log-ins) across 4 continents (Europe, Africa, North America and Australasia) via Zoom Platform.

The programme included updates on ECFS exercise WG projects, and invited speakers – see below for full details.



ECFS EXERCISE WORKING GROUP

Friday 2nd February 2024

Time of meeting

11:00-13:15 CEST

10:00-12:15 GMT (UK)

Zoom Link: <https://uzh.zoom.us/j/67152582776?pwd=aTdYMDVaYjU5VXljbWJiQWpmQU4rdz09>

Meeting-ID: 671 5258 2776 **Code:** 024345

Welcome

11:00-11:05 Introduction

Dr Thomas Radtke, Zurich (CH)
Dr Don Urquhart, Edinburgh (UK)

Session 1 Update on working group projects

11:05-11:20 Physical activity measurement in CF

Professor Craig Williams
Exeter (UK)

11:20-11:35 Dysfunctional breathing in CF

Professor Helge Hebestreit
Wuerzburg (DE)

11:35-11:50 Physical Literacy in CF

Dr Erik Hulzebos
Utrecht (NE)

Session 2 Exercise 'hot topic'

Dr Zoe Saynor
Portsmouth (UK)

11:50-12:20 Exercise in CF in a resource-poor setting
How to assess and what to advise

Professor Brenda Morrow
Cape Town (RSA)

Session 3 Developing ECFS Project Ideas

Dr Don Urquhart
Edinburgh (UK)

12:30-12:45 Exercise outcomes post-modulator therapy
Exploring a core dataset for registry inclusion

Dr Thomas Radtke
Zurich (CH)

12:45-13:00 Discussion about ECFS Memberships

ALL

13.00-13.15 Any other business

Dr Thomas Radtke, Zurich (CH)
Dr Don Urquhart, Edinburgh (UK)

Feedback from these meetings has been good.

June 2024 Exercise Working Group Meeting.

A half-day exercise WG meeting is planned for ECFS Glasgow 2024.

This will be preceded by a 1.5 day short course entitled “**Musculoskeletal issues in cystic fibrosis - muscle dysfunction & strength - posture and pain**” that the exercise working group are jointly hosting with the physiotherapy specialist interest group. The provisional programme for our working group meeting follows:



ECFS EXERCISE WORKING GROUP Wednesday 5th June 2024

Time of meeting: 12:45-17:00

Venue: Scottish Event Campus, Glasgow G3 8YW, UK

Room: Dochart 2

Welcome

12:45-12:55	Introduction & Welcome*	Dr Thomas Radtke, Zurich (CH) Dr Don Urquhart, Edinburgh (UK)
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Session 1 Update on working group projects

12:55-13:30	Finalisation of physical activity project	Prof. Craig Williams, Exeter (UK)
13:30-14:00	Dysfunctional breathing in CF	Dr Imad Ahmed, Leicester (UK) Prof. Helge Hebestreit, Wuerzburg (DE)
14:00-14:30	Mortality II - Subproject	Dr Thomas Radtke, Zurich (CH) Dr Don Urquhart, Edinburgh (UK)
14:30-14:45	Physical Literacy in CF	Dr Erik Hulzebos, Utrecht (NE)
14:45-15:00	ECFS Education: Strategy & Vision	Dr Chris Smith, Brighton (UK)
15:00-15:30	Coffee break, exchange, chatting	ALL
Session 2 Developing new project ideas		
		Dr Thomas Radtke, Zurich (CH) Dr Don Urquhart, Edinburgh (UK)
15:30-16:45	Discussion round	ALL
16.45-17.00	Any other business	Dr Thomas Radtke, Zurich (CH) Dr Don Urquhart, Edinburgh (UK)

ECFS Journal Clubs:

For 2023, we had 5 journal club sessions:

- Dr Zoe Saynor, University of Portsmouth, UK (Elexacaftor–Tezacaftor–Ivacaftor improves exercise capacity in adolescents with cystic fibrosis)
- Manon Kinaupenne, Ghent University, BEL (Physical activity and its correlates in people with cystic fibrosis: a systematic review)
- Maryam Almulhem, Newcastle University, UK (Exploring the impact of elexacaftor-tezacaftor-ivacaftor treatment on opinions regarding airway clearance techniques and nebulisers: TEMPO a qualitative study in children with cystic fibrosis, their families and healthcare professionals)
- Curtis Wadey, University of Exeter, UK (Normal reference values for aerobic fitness in cystic fibrosis: a scoping review)
- Tom Radtke, University of Zurich, SUI (Cardiopulmonary Exercise Testing Provides Prognostic Information in Advanced Cystic Fibrosis Lung Disease)

3/5 were early career researchers (pre-PhD), and we have an equal male/female split. A total of 104 attendees were present across these talks.

For 2024, thus far we had:

- Dr Sophie Gohy, UC Louvain, BEL (One-minute sit-to-stand test is practical to assess and follow the muscle weakness in cystic fibrosis)
- Dr Imad Ahmed, University Hospital Leicester, UK (Impact of CFTR modulators on exercise capacity in adolescents with cystic fibrosis)

Over these two talks, we have had a total of 60 attendees already.

We have another two lined up already (Meg Poulsen, Melbourne, AUS; Tony Fischer, Iowa City, USA).

We now have 235 people on the mailing list, the majority of whom are from the UK, but with notable proportions from Australia, Ireland, Belgium, and the USA. 62/235 are directly from the ECFS members list you've previously provided, so at least ~1/4 are identified as ECFS members. The YouTube channel with all the previous sessions has now exceeded 350 views.

Journal club feedback has been generally good.

Detailed feedback has been collated and can be shared if required.

- Technical Standards/Position Statements:

The group have been actively working on two standardisation documents in 2023/24:

i. ONGOING WORK ON A NEW TECHNICAL STANDARD:

Guidance and standard operating procedures for functional exercise testing in cystic fibrosis

Leads – Zoe Saynor, Don Urquhart and Thomas Radtke

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

This document was published in European Respiratory Review in August 2023.

Saynor ZL, Gruet M, McNarry MA, Button B, Morrison L, Wagner M, Sawyer A, Hebestreit H, Radtke T, Urquhart DS, on behalf of the European Cystic Fibrosis Society Exercise Working Group.

Guidance and standard operating procedures for functional exercise testing in cystic fibrosis.

Eur Respir Rev 2023;**32**:230029. doi:10.1183/16000617.0029-2023.

ii. UPDATE OF PREVIOUS POSITION STATEMENT:

Physical activity in Cystic Fibrosis: A Systematic Review

Leads – Craig Williams and Mayara Silveira Bianchim

Co-authors – Kelly McIntosh, Melitta McNarry, Helge Hebestreit, Brenda Button, Tiffany Dwyer, James Shelley, Judy Bradley, Elpis Hatziagorou.

This will be a combination of an up-to-date review of the evidence along with expert recommendations.

The systematic review has been registered "Physical Activity Assessment in Cystic Fibrosis: A Systematic Review" to the PROSPERO register (CRD42022292165).

It is hoped that this work will be completed in June 2024.

- Education

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

A comprehensive syllabus has been developed by members of the Exercise WG (Professor CA Williams + Drs Urquhart and Radtke) in association with the Education Working Group.

This syllabus has been approved by the WG membership and includes learning resources on:

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

The first talks have been prepared.

The finalised curriculum is attached.

In addition, our group has contributed to the wider ECFS online education resource and have finalised a presentation for the Part 3 ECFS Educational package.

Urquhart DS, Radtke T.

Exercise and Sports Activities for people with CF.

Approved – awaiting recording.

- Research

Recently completed 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 FEV₁<40% predicted.

Data entry is now complete. A total of 177 separate data records were analysed including 44 cases where an adverse event has occurred including 11 deaths and 33 who have undergone lung transplantation.

Published *Annals ATS* March 2024.

Radtke T, Urquhart DS, Braun J, Barry P, Waller I, Petch N, Mei-Zahav M, Kramer MR, Hua-Huy T, Dinh-Xuan AT, Innes JA, McArthur S, Sovtic A, Gojsina B, Verges S, de Maat T, Morrison L, Wood J, Crute S, Williams CA, Tomlinson

OW, Bar-Joseph R, Hebestreit A, Quon BS, Kwong E, Saynor, ZL, Causer AJ, Stephenson AL, Schneiderman JE, Shaw M, Dwyer T, Stevens D, Remus N, Douvry B, Foster K, Benden C, Ratjen F, Hebestreit H, for the Prognostic value of CPET in CF study group. Cardiopulmonary exercise testing provides prognostic information in advanced cystic fibrosis lung disease. *Ann Am Thorac Soc* 2024;**21**:411-420.

Studies in progress:

1. Understanding submaximal data in advanced CF lung disease

This is a sub-analysis of the completed study above looking at the ability to quantify the timing of onset of anaerobic threshold (AT), and the utility of measures at AT (VO₂, breathing reserve, etc.) in predicting mortality and morbidity in people with CF.

Data collection is complete.

Abstract accepted for ECFS Glasgow 2024:

Urquhart DS, Burns P, Jamieson P, Barry PJ, Waller I, Petch N, Sovtic A, Gojsina A, Verges S, de Maat T, Morrison L, Wood J, Crute S, Williams CA, Tomlinson OW, Quon BS, Kwong E, Saynor ZL, Causer AJ, Dwyer T, Stevens D, Remus N, Douvry B, Foster K, Hebestreit H, Radtke T for the prognostic value of CPET in CF study group.

Feasibility of obtaining submaximal outcomes in people with advanced (FEV₁ ≤40% predicted) CF lung disease undergoing cardiopulmonary exercise testing.

Oral presentation in ePoster Session 1 - Advances in exercise interventions in the management of cystic fibrosis. (EPS1.03) at European Cystic Fibrosis Conference, Glasgow, June 2024.

Manuscript in preparation – target journal ERJ Open Research.

2. Characterising breathing pattern disorder during exercise in people with Cystic Fibrosis

(Ahmed, Hebestreit)

Study in development.

3. Physical literacy in Cystic Fibrosis

(Burghard, Hulzebos, Gruber, Mackintosh)

Study actively recruiting.

- Peer support

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.

a) Encouraging presentations:

Early career researcher slots are available at all of our meetings, and the journal club is also another forum for ECR presentations.

b) Establishment of junior researcher award:

The first 'Junior researcher Award' was won by Dr Myara Bianchim for a presentation entitled:

"Compositional Analysis of Physical Activity, Sedentary Time and Sleep and Associated Health Outcomes in Children and Adults with Cystic Fibrosis" - The prize was registration for the ECFS 2022 conference.

The 2023 award was won by Dr Barlo Hillen for a presentation entitled:

"The impact of ETI treatment on cardiopulmonary exercise testing outcomes: results of a longitudinal, single centre study" - The prize was registration for the ECFS 2023 conference.

- Development

Executive group meeting of ECFS exercise working group held in London in February 2024

Present:

Dr Thomas Radtke (Co-ordinator) in person

Dr Don Urquhart (Deputy Co-ordinator) in person

Dr Zoe Saynor (Guidelines Lead) in person

Professor Helge Hebestreit (Previous Co-ordinator) via Zoom

We discussed the future of the group and how we might identify future leaders and office-bearers.

We discussed how we attract younger members and how we attract members from low-middle income countries.

We discussed current and future education projects.

We discussed developing a research project aimed at measuring physical activity across Europe in people with CF and how we might approach this.

We all felt that this was an invaluable 1.5 days being able to spend time away from busy work roles to consider these key strategic questions for our working group.

CURRENT NUMBER OF MEMBERS

The exercise working group has 71 current members

These have been provided as an Excel spreadsheet of:

- Member
- Institution
- ECFS membership status*

**Up to date as far as last ECFS-provided membership data*

MEASURES TAKEN TO ENCOURAGE ECFS MEMBERSHIP

The working group highlights the benefits of ECFS membership when communicating with members.

The holding of a meeting (face to face) at ECFS conference is encouraging attendees to join ECFS.

We had an open discussion on the value of ECFS membership at our February 2024 virtual working group meeting (see above programme).

Our logo (see below) makes it very clear that the Exercise Working Group is a sub-group of the ECFS.



OUTCOMES/ACHIEVEMENTS

- **Meetings (Agendas as listed above)**

- i. ECFS Exercise Working Group Meeting [Vienna] 7th June 2023
- ii. ECFS Exercise Working Group Meeting [Virtual] 2nd February 2024
- iii. ECFS Exercise Working Group Meeting [Vienna] 5th June 2024

- Developments

The instigation of the ECFS CF and Exercise Journal Club in early 2022 has been a good new development. This initiative is being led by one of the Early Career Researchers (Dr Owen Tomlinson, Exeter, UK), which is great for the sustainability of our group.

New projects on dysfunctional breathing and physical literacy are underway.

Each of the projects has new, younger researchers at the heart

- Imad Ahmed (Leicester, UK) jointly leading dysfunctional breathing project

- Marcella Burghard (Utrecht, NETH) jointly leading physical literacy project

- Presentations 2023/24

Oral presentations:

Radtke T, Urquhart DS, Braun J, *et al.*

Cardiopulmonary exercise testing provides prognostic information in advanced cystic fibrosis lung disease.

WS01.01, 46th European Cystic Fibrosis Conference, Vienna, Austria, June 2023.

Saynor ZL, Gruet M, McNarry M, Button B, Morrison L, Wagner M, Sawyer A, Hebestreit H, Stanford GE, Radtke T, Urquhart DS.

The current state of play regarding exercise testing in cystic fibrosis: co-development with the community.

WS01.02, 46th European Cystic Fibrosis Conference, Vienna, Austria, June 2023.

Urquhart DS, Burns P, Jamieson P, Barry PJ, Waller I, Petch N, Sovtic A, Gojsina A, Verges S, de Maat T, Morrison L, Wood J, Crute S, Williams CA, Tomlinson OW, Quon BS, Kwong E, Saynor ZL, Causer AJ, Dwyer T, Stevens D, Remus N, Douvry B, Foster K, Hebestreit H, Radtke T for the prognostic value of CPET in CF study group.

Feasibility of obtaining submaximal outcomes in people with advanced ($FEV_1 \leq 40\%$ predicted) CF lung disease undergoing cardiopulmonary exercise testing.

Oral presentation in ePoster Session 1 - Advances in exercise interventions in the management of cystic fibrosis.

(EPS1.03) at European Cystic Fibrosis Conference, Glasgow, June 2024.

Poster presentations:

Smith C, Chadwick HK, Farinha C, Southern K, Havermans T, Borawska-Kowalczyk U, MacDuff N, Shaw N, Declercq D, Wagner M, Dunlevy F, Hayes/Hill K, Stanford G, Bentley S, Urquhart DS, Radtke T, Williams C, De Wachter E, Peckham DG. ECFS syllabuses for the multidisciplinary team: a guide for comprehensive education.

Poster presentation at 46th European Cystic Fibrosis Conference, Vienna, Austria, June 2023.

Smith C, Chadwick HK, Farinha C, Southern KW, Havermans T, Landau E, Borawska - Kowalczyk U, MacDuff N, Shaw N, Bentley S, Declercq D, Mantin H, Stanford G, Urquhart DS, Radtke T, De Wachter E, Hill K, Dunlevy F, Reilly C, Meir-Zahav M, Schwarz C, Wagner M, Peckham DG.

E-learning within the European Cystic Fibrosis Society - A multidisciplinary cross sectional survey.

Poster presentation (P097) at European Cystic Fibrosis Conference, Glasgow, June 2024.

Tomlinson OW, Williams CA, **Urquhart DS**, Radtke T.

Exercise education for professionals in cystic fibrosis: an international journal club.

Poster presentation (P472) at European Cystic Fibrosis Conference, Glasgow, June 2024.

- Publications 2023/24:

International Guidelines:

Saynor ZL, Gruet M, McNarry MA, Button B, Morrison L, Wagner M, Sawyer A, Hebestreit H, Radtke T, Urquhart DS,

on behalf of the European Cystic Fibrosis Society Exercise Working Group.

Guidance and standard operating procedures for functional exercise testing in cystic fibrosis. *Eur Respir Rev* 2023;**32**:230029. doi:10.1183/16000617.0029-2023.

Original articles:

Radtke T, Kriemler S, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands LC, Schindler C, Eber E, Haile SR, Hebestreit H, on behalf of the ACTIVATE-CF Study Working Group*. Cystic fibrosis related diabetes is not associated with maximal aerobic exercise capacity in cystic fibrosis: a cross-sectional analysis of an international multicentre trial [ACTIVATE-CF]. *J Cyst Fibros* 2023;**22**:31-38.

Radtke T, Urquhart DS, Braun J, Barry P, Waller I, Petch N, Mei-Zahav M, Kramer MR, Hua-Huy T, Dinh-Xuan AT, Innes JA, McArthur S, Sovtic A, Gojsina B, Verges S, de Maat T, Morrison L, Wood J, Crute S, Williams CA, Tomlinson OW, Bar-Joseph R, Hebestreit A, Quon BS, Kwong E, Saynor, ZL, Causer AJ, Stephenson AL, Schneiderman JE, Shaw M, Dwyer T, Stevens D, Remus N, Douvry B, Foster K, Benden C, Ratjen F, Hebestreit H, for the Prognostic value of CPET in CF study group. Cardiopulmonary exercise testing provides prognostic information in advanced cystic fibrosis lung disease. *Ann Am Thorac Soc* 2024;**21**:411-420.

Letters to Editor:

Urquhart DS, Hebestreit H, Saynor Z, Radtke T. 'Gold standard field test is a non-sequitur. *Pulmonology* 2023;**29**:173.

Review Articles:

Gruet M, Saynor ZL, Urquhart DS, Radtke T. Rethinking physical exercise training in the modern era of cystic fibrosis: a step towards optimising short-term efficacy and long-term engagement. *J Cyst Fibros* 2022;**21**:e83-e98.

Abstracts:

Radtke T, Urquhart DS, Braun J, Barry P, Waller I, Petch N, Mei-Zahav M, Kramer MR, Hua-Hut T, Dinh-Xuan AT, Innes A, McArthur S, Sovtic A, Gojsina B, Verges S, de Maat T, Morrison L, Wood J, Crute S, Williams CA, Tomlinson OW, Bar-Joseph R, Hebestreit A, Quon BS, Kwong E, Saynor, ZL, Causer AJ, Stephenson A, Schneiderman JE, Shaw M, Dwyer T, Stevens D, Remus N, Douvry B, Foster K, Benden C, Ratjen F, Hebestreit H, for the Prognostic value of CPET in CF study group. Cardiopulmonary exercise testing provides prognostic information in advanced cystic fibrosis lung disease. *J Cyst Fibros* 2023; *In press*.

Saynor ZL, Gruet M, McNarry M, Button B, Morrison L, Wagner M, Sawyer A, Hebestreit H, Stanford GE, Radtke T, Urquhart DS. The current state of play regarding exercise testing in cystic fibrosis: co-development with the community. *J Cyst Fibros* 2023; *In press*.

Smith C, Chadwick HK, Farinha C, Southern K, Havermans T, Borawska-Kowalczyk U, MacDuff N, Shaw N, Declercq D, Wagner M, Dunlevy F, Hayes/Hill K, Stanford G, Bentley S, Urquhart DS, Radtke T, Williams C, De Wachter E, Peckham DG. ECFS syllabuses for the multidisciplinary team: a guide for comprehensive education. *J Cyst Fibros* 2023; *In press*.

Tomlinson OW, Williams CA, **Urquhart DS**, Radtke T.

Exercise education for professionals in cystic fibrosis: an international journal club. *J Cyst Fibros* 2024;*In press*.

Smith C, Chadwick HK, Farinha C, Southern KW, Havermans T, Landau E, Borawska - Kowalczyk U, MacDuff N, Shaw N, Bentley S, Declercq D, Mantin H, Stanford G, **Urquhart DS**, Radtke T, De Wachter E, Hill K, Dunlevy F,

Reilly C, Meir-Zahav M, Schwarz C, Wagner M, Peckham DG.

E-learning within the European Cystic Fibrosis Society - A multidisciplinary cross sectional survey.

J Cyst Fibros 2024;**In press**.

Urquhart DS, Burns P, Jamieson P, Barry PJ, Waller I, Petch N, Sovtic A, Gojsina A, Verges S, de Maat T, Morrison L, Wood J, Crute S, Williams CA, Tomlinson OW, Quon BS, Kwong E, Saynor ZL, Causer AJ, Dwyer T, Stevens D, Remus N, Douvry B, Foster K, Hebestreit H, Radtke T for the prognostic value of CPET in CF study group.

Feasibility of obtaining submaximal outcomes in people with advanced ($FEV_1 \leq 40\%$ predicted) CF lung disease undergoing cardiopulmonary exercise testing. *J Cyst Fibros* 2024;**In press**.

Aims for the coming year:

The aims for the coming year are as follows:

- **Knowledge-sharing**
 1. Short course prior to ECFS Glasgow June 2024 (jointly with PhysioSIG).
 2. Undertake face-to-face meeting at ECFS Glasgow in June 2024
 3. Continue 2 working group meetings per year
 - a) Virtual - January 2025
 - b) Face-to-face at ECFS June 2025
 4. ECFS CF and Exercise Journal Clubs (Virtual) every 2 months
- **Technical Standards/Position Statements:**

Complete Physical Activity position statement update
Ratify within ECFS WG at June 2024 meeting.
- **Education**

Continue to build online knowledge network for exercise in CF.
This is a 3-5 year workstream.
ECFS CF and Exercise Journal Clubs (Virtual) every 2 months
ECFS online education resource - Part 3 ECFS Educational package.
Exercise and Sports Activities for people with CF (DSU/TR) - **Approved – awaiting recording.**
- **Research**

Publication of sub-study looking at submaximal exercise data in advanced CF lung disease
- being presented at ECFS 2024 with aim to publish thereafter.

Summary (maximum 100 words):

The ECFS Exercise Working Group is now 13 years old.

The group has been a fertile ground for knowledge-sharing and developing collaborations.

Group output:

Published international technical standards and position statements on:

- 1) Exercise Testing (Respiration 2015, Eur Respir Rev 2019)
- 2) Physical activity (J Cyst Fibros 2015)
- 3) Exercise recommendations (Cardiopulm Physiotherapy J 2015)

4) Functional exercise testing – guidelines (Eur Respir Rev 2023)

Letters to Editor published on behalf of ECFS exercise WG regarding exercise testing practice:

- Hebestreit *et al.* Respiration 2016
- Urquhart *et al.* Pulmonology 2023

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)
- Randomised, controlled trial of exercise intervention - ACTIVATE-CF (published Am J Resp Crit Care Med 2022)
- Glycaemic substudy from ACTIVATE-CF (published J Cyst Fibros 2023)
- Exercise testing in advanced cystic fibrosis lung disease (published Ann Am Thorac Soc 2024)

Education:

- Pre-course workshop on exercise testing at ECFS Liverpool (2019).
- Pre-course workshop on exercise testing and training in the post-ETI era at ECFS Vienna (2023).
- Pre-course workshop on musculoskeletal function at ECFS Glasgow (2024).
- Online modular education resource
- Curriculum agreed and process of laying down information now underway
- Regular Exercise Journal Club held virtually every 2 months.
- Contribution to Part 3 of ECFS online resource.

Ongoing:

Current projects include ongoing education resource development and research in advanced CF lung disease.

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

Breakdown of expenses

Total amount received: 10'000 Euro

Expenses (expected)

- ECFS Exercise Working Group Core Group Meeting **€1300 approx.**
1.5 day face-to-face meeting held February 2024 in London with Thomas Radtke (Co-ordinator), Don Urquhart (Deputy Co-ordinator), Zoe Saynor (Lead for ECFS exercise guideline updates), and Helge Hebestreit (Chair of group from 2011-2019) – virtual attendee.
- Publication fees (open access) for European Respiratory Review: **~€1300**
- Fees for Mind the Graph: **€240**

Budget amount requested for next year : **€8140**

Junior Researcher Award - €1000

Flights from within Europe and registration for ECFS 2025 for winner of best early career researcher presentation at ECFS Exercise Working Group virtual meeting in January 2025.

ECFS Exercise Working Group Core Group Meeting €3000 approx.

Plan for 1 day face-to-face meeting at airport hotel (e.g. Amsterdam, Frankfurt, London)
Proposed attendees would be: Thomas Radtke (Co-ordinator), Don Urquhart (Deputy Co-ordinator), Helge Hebestreit (Chair of group from 2011-2019), Zoe Saynor (Lead for ECFS exercise guideline updates)

Proposed agenda for meeting would include:

- Group peer review of received education videos
 - Prioritisation exercise to guide direction of future projects
 - Succession planning for DU/TR reaching end of 3-year term as group co-ordinators in January 2025
- Airport hotel would allow all to attend for 1-day meeting with 1 night of overnight accommodation
Cost - €750 per person approximately.

Video-recording €2000 approx

We approached the ECFSPR board and requested the integration of exercise-related outcomes in the registry (eg, peak power, peak heart rate). Decision pending for June 2024.

In case of positive feedback, we would record a video to provide instructions on how to run a peak workrate test on a cycle ergometer to ensure standardised testing procedures across site who wish to provide exercise testing outcomes for the registry.

Planning pre-course alongside ECFS 2025 : €2000 approx

Standardising exercise testing across registries and across wealthy and low-middle income countries.

A 0.5 day course to be based around the peak power (W_{peak}) test.

We would wish to keep the cost of this course to a maximum of €50 per delegate in order to maximise attendance from low-middle income countries.

Fees for Mind the Graph Software: €140

The deadline for submission to the ECFS Office is 1st May. The report will then be presented to the board prior to the summer ECFS board meeting and then a decision will be made at the next board meeting for approval before being distributed.