



INTERNATIONAL PHYSIOTHERAPY GROUP
FOR CYSTIC FIBROSIS

NEWSLETTER 2, 2021

Dear all,

Welcome to our second newsletter 2021.

The ECFS conference 2021 is fast approaching, so we would like to inform you about the latest information and remind you of the most important points that you should not forget.

The main topics of this newsletter:

1. ECFS digital conference and its highlights
2. Case presentations
3. Annual general meeting
4. Annual reports
5. Reflection on topics (workshops, symposia, ECFS conference 2022)

1. The ECFS 2021 Digital Conference:

- The ECFS 2021 Digital Conference, on 9 – 12 June 2021, will feature 4 parallel sessions including symposia, workshops and other interactive sessions
- What not to miss?



44th EUROPEAN
CYSTIC FIBROSIS
CONFERENCE
9-12 June 2021
#ECFS2021



Physiotherapy
Workshop
Track 4

Thursday, June 10, 09:00 - 10:00

WS04 Workshop 4 - Improvements in understanding how physical activity and exercise impact cystic fibrosis

Helge Hebestreit (Würzburg, Germany)
Maire Curran (Limerick, Ireland)

WS04.1 A comparison of subjective verses objective measures for assessing physical activity in cystic fibrosis: a systematic review

Molly Dundas (Ireland)

WS04.2 To investigate which physical factors influence the cardiorespiratory fitness in paediatric patients with cystic fibrosis who have no ventilatory limitation during exercise (ventilatory reserve $\geq 15\%$)

Marcella Burghard (Utrecht, Netherlands)

WS04.3 Lung function as a determinant of the evolution of exercise capacity over a three-year follow-up period in patients with cystic fibrosis

Natália Evangelista Campos (Porto Alegre, Brazil)

WS04.4 Exercise testing and training in German cystic fibrosis centres – temporal trends from 2001 to 2019

Alexandra Hebestreit (Würzburg, Germany)

WS04.5 Exercise testing using supramaximal verification in cystic fibrosis

Craig Anthony Williams (Exeter, United Kingdom)

WS04.6 Effects of a partially supervised conditioning program in cystic fibrosis: an international multi-centre, randomised controlled trial (ACTIVATE-CF)

Helge Hebestreit (Würzburg, Germany)



Physiotherapy
ePoster Session
Track 1

Thursday, June 10, 12:30 - 13:30

ePoster Session 1 - Developments of remote physiotherapy during COVID-19 restrictions on usual practice

Marie Mittaine (Toulouse, France)

Catherine Brown (Birmingham, United Kingdom)

EPS1.01 Physiotherapy practice of French cystic fibrosis children changed during lockdown due to COVID-19 pandemic

Marie Mittaine (Toulouse, France)

EPS1.02 The impact of COVID-19 on the prescribing practice of specialist cystic fibrosis physiotherapist non-medical prescribers in the UK

Catherine Brown (Birmingham, United Kingdom)

EPS1.03 Recommended shielding against COVID-19 impacts physical activity levels and adherence to airway clearance therapy in patients with cystic fibrosis

Elpis Hatziagorou (Thessaloniki, Greece)

EPS1.04 Audit of virtual exercise class during COVID-19 in children with cystic fibrosis

Zoe Johnstone (Edinburgh, United Kingdom)

EPS1.05 Evaluating impacts of the change from clinic to home spirometry on clinicians and adults with cystic fibrosis

Tracey Daniels (York, United Kingdom)

EPS1.06 A retrospective audit of home-based spirometry quality in a large UK adult cystic fibrosis centre

Ian Waller (Manchester, United Kingdom)

EPS1.07 Impact of COVID-19 on cystic fibrosis physiotherapy outpatient clinics

Emily Scott (Liverpool, United Kingdom)

EPS1.08 Exercising online a “Beaming” good initiative

Gemma McCrea (Glasgow, United Kingdom)

EPS1.09 Adapting services during the COVID-19 pandemic – a patient evaluation of physiotherapy telephone reviews within multidisciplinary team virtual clinics

Sarah Fitzgerald (London, United Kingdom)



INTERNATIONAL PHYSIOTHERAPY GROUP
FOR CYSTIC FIBROSIS

Physiotherapy
Symposium
Track 4

Saturday, June 12, 09:00 - 10:15

S20 Symposium 20 - Upper airways – Attention please!

Marlies Wagner (Graz, Austria)

Emma Dixon (London, United Kingdom)

What do we know about bacterial colonisation in the upper airways?

Alexander Moeller (Zurich, Switzerland)

Do we treat upper airways colonisation in asymptomatic patients - PRO

Hugues Gauchez (Lille, France)

Do we treat upper airways colonisation in asymptomatic patients - CON

Gemma Marsh (London, United Kingdom)

Discussion

How to manage Upper Airway disease

Jochen G. Mainz (Brandenburg an der Havel, Germany)



INTERNATIONAL PHYSIOTHERAPY GROUP
FOR CYSTIC FIBROSIS

2. Case presentations

“International Physiotherapy Group-CF - Case presentations” will take place on the ECFS 2021 digital platform on Wednesday 09 June from 17:00 to 18:30. It is accessible to all physiotherapist, who are interested.

3. Annual general meeting

“International Physiotherapy Group-CF AGM” will take place on the ECFS 2021 digital platform on Wednesday 09 June from 16:00 to 17:00. It is accessible to all physiotherapist, who are interested.

4. Annual reports

Annual National Report 2020/21 from Austria

There are 16 CF centers in Austria, caring for approx. 800 CF patients in in- and outpatient settings in multidisciplinary teams. In addition, there are 2 centers for rehabilitation specialized in CF. The group of CF-physiotherapists includes approx. 50 members.

There is at least one annual meeting of the group and additionally meetings of the Austrian group of cardiorespiratory physiotherapists within the framework of the Austrian Society of Pneumology. Recently, we integrated CF-physiotherapists who are not specialized in pneumology but working with CF patients (mostly from small centers), in this group, with the aim to increase nationwide quality standards in the daily treatment routine with CF patients. The group actively contributes with lectures and symposia to the annual conference of the Austrian Society of Pneumology as well as to international CF meetings. There are also several advanced training courses to teach and train colleagues, patients and their relatives.

Annual National Report 2020/21 from Brazil

The last available edition of the CF Brazilian registry (2018) shows that 5417 patients were registered and followed at 51 different reference centers across the country. It is estimated that approximately 150 physiotherapists are directly working in CF units (CF centers and hospitals).

Recent activities:

- Publication of the Brazilian guidelines for physiotherapy management of CF patients (Brazilian Recommendations on Physiotherapy in Cystic Fibrosis: A Guide to Clinical Practice – ASSOBRFIR CIENCIA. 2019;10(1):1-188).
- Article presenting a national survey on most recommended physiotherapy techniques for patients with CF (Donadio MVF, Campos NE, Vendrusculo FM, et al. Respiratory physical therapy techniques recommended for patients with cystic fibrosis treated in specialized centers. Braz J Phys Ther. 2020;24(6):532-538).
- Upcoming events: VIII Brazilian Multidisciplinary CF Conference – 2022.

Annual National Report 2020/2021 from the Czech Republic

There are currently 5 centres for patients with cystic fibrosis, caring for 684 patients in total (339 children, 345 adults). During the last 12 months we have diagnosed 24 new patients. Around 25 respiratory physiotherapists take care of CF patients, either on a full or a part time basis. The number of patients for one physiotherapist differs from 2 to 50 (based on the size and location of the centre).



The Czech conference called RECYF, where pulmonologists, physiotherapists, psychologists, nutrition therapists, nurses and other experts participated, was hosted online this year due to the COVID pandemic. The accompanying course for physiotherapists has been rescheduled for autumn 2021. The annual CF meeting for families/friends/relatives of patients was also performed using a digital platform, with the expert physiotherapy lecture focusing on coughing, and how to manage this problematic area.

Recent activities:

With the support of the Czech CF Foundation, educational videos were made for children and adult CF patients. The videos focused on airway clearance techniques of upper and lower airways and inhalation.

Annual National Report 2020/21 from France

So as every year our French Physio group for cf has organized courses for Physio, courses for patient, courses for parents. Everywhere in the country with the French association support our group has realised videos about ACT and instrumental aids and développée teleconsulting because of Covid period. Sophie Jacques became president of our group. She was working since 20 years in a private activity in Rennes for cf rehabilitation. Our project: All the Physiotherapist who are working in cf reference center will have been trained in autogene drainage with Hugues gauchez and his team. No courses that year in east countries of Europe but where are very enjoy to be able to do it in July 2021.

Annual National Report 2020/21 from Germany

The German CF working group consists of about 170 members at this moment. Our annual meeting takes place once a year in November at the National Cystic Fibrosis Meeting.

Out of this group an executive board comprising 5 members is elected every 3 years.

In this year 5 courses to qualify physiotherapists in airway clearance techniques for patients with CF and other chronic pulmonary diseases were realized.

Due to the restrictions of the Covid 19 pandemic all activities such as airway clearance courses for physiotherapists, programs for patients and parents and all annual meetings could only be realized in a digital way.

Annual National Report 2020/21 from Ireland

There are approximately 40 Irish physiotherapists working in Cystic Fibrosis (CF), either on a full or a part time basis. (Some of these physiotherapists work in Northern Ireland, and are part of the NHS, so do not work with the patients mentioned below).

The most recent registry data reports that there are 746 adults and 508 children living with CF, and receiving care in the Republic of Ireland. The largest centre, which is situated in Dublin, provides care for almost 400 adults with CF, several other centres throughout the country provide care for the remaining adults with CF. Children's Hospital Ireland (CHI) provide paediatric care in conjunction with several regional centres. Over the last year, the Irish physiotherapy group has attended the ACPCF conference, and had a focus on developing and providing virtual care where appropriate.

Planned activities for the Irish physio group for the coming year include running a study day, attending the ACPCF conference, and continuing with current research and service development projects within the various centres.

Annual National Report 2020/21 from Israel

There are about 700 people diagnosed with cystic fibrosis (CF) in Israel.

There are seven CF centers and one center only for adults, with about 130 members of the multidisciplinary team, including 13 physiotherapists. Two transplantation centers at Rabin medical center, and Sheba Hospital.

There are about 300 physiotherapists and physiotherapy students who treat the patients in their home. There are more than 600 physiotherapists and physiotherapy students registered in the Cystic Fibrosis Foundation of Israel (CFFI).

Since 2013 all the CF patients are entitled to receive a monthly refund for the physiotherapy treatments at home from the Health care services, up to 25 € per day.

The CFFI is responsible for and manages several projects:

Manage the database therapists, physiotherapists and physiotherapy students who are willing to treat CF patients at home.

Therapists annual conference – learning about the treatment and enhance knowledge about respiratory techniques and other treatments, such as musculoskeletal exercises and pelvic floor treatments for CF patients.

Yearly recruiting of therapists from all classes of physiotherapy in the country.

Financial assistance to patients.

Free subscriptions to gyms for patients, surfing classes, and more sports activity.

Annual National Report 2020/21 from Norway

There are about 402 persons with CF in Norway (children 134, adults 268). Norway has Newborn screening since 2012 and CF Patient Registry since 2016. The National working group consist of 19 Physiotherapists working with children and/or adults with CF at CF-centre/in the specialist health care. According to the Norwegian working model, CF-centre's Physiotherapists establish/adjust treatment and mainly collaborates with Physiotherapists in the primary health services on follow-up. Adolescents and adults mainly perform established/adjusted self-treatment at home.

Main activities in the group/for participants in the group have been:

- Digital meetings with Physiotherapists in regional hospitals/primary health service regarding individual patients. Video/telephone consultations with adults
- Participation on ECFC digital 2020
- National and International Webinars
- Interdisciplinary digital course for families with newly diagnosed children after NBS
- Infection control: Routines for Physiotherapy during Covid-19
- National contact person - IPG/CF – related work: Annual general meeting 2020, IPG/CF Questionnaire review

Events coming up:

- June 15th - Subject day National Working Group:
 - o Kaftrio, with guest participants from Copenhagen
 - o Airway Clearance Physiotherapy for patients with little symptoms
- National course for Physiotherapists regarding newly diagnosed CF
- ECFC digital - National and International Webinars

Annual National Report 2020/21 from Slovak Republic

This year there have been organizational changes in ambulances and hospitals, which led to limitations on physiotherapy. We have created educational videos for use in a mobile application with CF Foundation. More media appearances have been arranged, which contributed to the result that Simeox is now covered by the mandatory public health insurance from the age of 8 years. 3-6 June, 2021 3rd International Meeting of Physiotherapists organized by the Association of Cystic Fibrosis and delivered by Lecturers Doc. PaedDr. Libuse Smolikova (CZ) and Petra Kolcunova (SR).

5. Ideas for topics (workshops, symposia) for ECFS conference 2022



INTERNATIONAL PHYSIOTHERAPY GROUP
FOR CYSTIC FIBROSIS

If you have any suggestions for topics and or speakers for next years conference, please feel free to email Jana below or put in the chat box during Annual General Meeting.

If you are receiving this newsletter, we are happy for you to forward it to your colleagues.

As always, we welcome your feedback and input. Enjoy!

Jana Plešková, MSc (jana.pleskova@fnmotol.cz)
IPG/CF Secretary

CFIRG/IFPG/CF CONTACT LIST FOR MEMBER COUNTRIES

Below is the contact list as of February 2021. In summary, there are currently 41 member countries receiving our correspondence.

Country	Contact	Email
Argentina:	Patricia Ratto	patricianancyratto@gmail.com
Australia:	Brenda M. Button	b.button@alfred.org.au
Austria:	Marlies Wagner	marlies.wagner@medunigraz.at
Bangladesh:	Md.Abdullah Al-Mamun	abdullah15ca@yahoo.ca
Belgium:	Myriam Vreys	myriam.vreys@uzleuven.be
Brazil:	Marcio Donadio	mdonadio@puhrs.br
Canada:	Nancy Alarie	nancy.alarie@muhc.mcgill.ca
Costa Rica:	Rodolfo A. Bonilla Abarca	rbonilla@yahoo.com
Croatia:	Anja Kladar	anja.kladar@gmail.com
Czech Republic:	Jana Pleskova	jana.pleskova@fnmotol.cz
Denmark:	Lue Philipsen	luephilipsen@hotmail.com
Ecuador:	Maite Mijares	maite@crespomijares.com
El Salvador:	María Azucena Flores Alemán	mafa.azucena@gmail.com
Finland:	Katrr Partanen	katri.partanen@suomenfysioterapeutit.fi
France:	Hugues Gauchez	hgauchez@hotmail.fr
Germany:	Jovita Zerlik	jovita.zerlik@kinderkrankenhaus.net
Greece:	Kostas Katsoulakis	katsoul@freemail.gr
Hong Kong:	LAU Mo Yee, Polly	alumni@polyu.edu.hk
India:	Sumita Gupta	bisoiak@rediffmail.com
Ireland:	Louise Collins	louisee.collins@hse.ie
Israel:	Eynav Manor	e_manor@rambam.health.gov.il
Italy:	Luigi Graziano	luigi.graziano@uniroma1.it
Macedonia:	Blazhe Arsov	president@mz.mk
New Zealand:	Roisin Varley (new)	RoisinV@adhb.govt.nz
Norway:	Sandra Gursli	sangur@ous-hf.no
Oman:	Kamla Al-Qasmi	kaq83@yahoo.com
Palestine:	Amal Nassar	amal.nassar@crb-mail.org



Poland:	Natalia Jeneralska	natalia.jeneralska@gmail.com
Portugal:	Ana Filipa Rocha	anafilipa777@hotmail.com
Romania:	Bogdan Almaja-Guta	bogdisport@yahoo.com
Serbia:	Valentina Pavković	malavanja78@gmail.com
Slovakia:	Marta Heroutová	fyzio.pp@falck.sk
Spain:	Laura Muelos Gomez	lauramgfsio@hotmail.com
Sweden:	Cecilia Rodriguez Hortal	Cecilia.rodriguez-hortal@sll.se
Switzerland:	Marta Kerstan	mkerstan@hispeed.ch
The Netherlands:	Lianne van der Giessen	l.vandergiessen@erasmusmc.nl
Turkey:	Osman Coban	oscoban28@gmail.com
UAE:	Saeid Rahbar Soureh	saeid849@yahoo.com
UK:	Hannah Langman	hannah.langman@mft.nhs.uk
Uruguay:	Kitty Löwensberg	kittylowensberg@movinet.com.uy
USA:	Jaime Eilbacher	EILBACHER@email.chop.edu



IPG/CF CONTACT LIST FOR ALUMNI MEMBERS

Name	Email
Esta Tannenbaum	esta.tannenbaum@rch.org.au
Helen Parrott	H.Parrott@rbht.nhs.uk
Irene Maguire	babasmurf@hotmail.com
Louise Lannefors	louise.lannefors@gmail.com
Maggie Mcllwaine	mmcilwaine@cw.bc.ca
Margareta Sahlberg	margareta.sahlberg@telia.com
Ruth Dentice	Ruth.dentice@sswahs.nsw.gov.au

Alumni member

Past country contacts or board members who wish to join our Alumni members should contact our Secretary Jana with details of their terms with the IPG/CF and their areas of expertise/interest. We are compiling a list of experienced alumni members who might



INTERNATIONAL PHYSIOTHERAPY GROUP
FOR CYSTIC FIBROSIS

help us with conference preparations, and they will receive all IPG/CF communications directly as supporters of the IPG/CF.