NEWSLETTER 3, 2018 INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

Dear all, welcome to our third Newsletter 2018!

It was a really exciting meeting and so many of you were in Belgrade.

At first I want to thank Marta who spent so much time on organizing the physio pre-course – I am still stunned what great work she did!



Thank you to all country contacts who already submitted their reports.

Updated reports are now due from all country contacts to be submitted as soon as possible.

Annual reports do not need to be lengthy, they just need to provide information regarding the number of CF physiotherapists (perhaps with the number of CF patients they manage), recent activities and planned events.

If you are receiving this newsletter we are happy if you wouldsend it on to your colleagues. As always, we welcome your feedback and input – Enjoy!

Marlies Wagner, MSc (<u>marlies.wagner@medunigraz.at</u>) IPG/CF Secretary

WANTED!!!

People, in particular bilingual, who are interested in rating articles for PEDro!

The PEDro database provides lots of information about Cystic Fibrosis regardless of the language of publication. At the moment, there are about 200 randomised trials, systematic reviews and clinical practice guidelines related to Cystic Fibrosis in the database. However, we need the assistance of volunteers to keep the database up to date.

Do you speak Dansk, Norsk, Svenska, русский язык or فارسى?

PEDro needs more bilingual raters to help us evaluate trials. We are particularly looking for physiotherapists with an interest in research or evidence-based practice who speak Dansk, Norsk, Svenska, русский языкого.

What is in it for you?

- Free PEDro rating training for the first five people who contact us.
- Volunteer hours count towards continuous professional development.
- Knowing you are contributing to an evidence tool that supports the global physiotherapy community.

If you get involved, you can specify how much time you would like to contribute. It could be as simple as rating 2 articles each month!

If you are interested in finding out more, please <u>contact us</u>.

MINUTES OF THE ANNUAL GENERAL MEETING OF THE INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

Belgrade, Wednesday, 6th June 2018, from 12:30 to 14:00

33 Participants – 13 country contact representatives (valid proxies received from Australia and Ireland)

Ad 1) Introduction of the Committee and Contact Persons, apologies for absence.

Marta Kerstan, IPG/CF Vice-Chair opened the meeting by welcoming everyone.

Introduction of the board:

Marta Kerstan, Vice-Chair Marlies Wagner, Secretary Peter Suter, Treasurer Excused Cecilia Rodriguez, Chairperson (still on maternity leave)

IPG/CF country contact representatives were asked to stand and introduce themselves.

The AGM was attended by 13 Contact Persons i.e. Australia, Austria, Canada, Czech Republic, Denmark, France, Germany, Greece, Ireland, Norway, Poland, Portugal, and Switzerland.

IPG/CF Board received 2 valid proxies (Australia and Ireland)

3 Alumni members attended AGM

Thus, with 13 present Contact Persons and 2 valid proxies a quorum of current active countries was present.

- Ad 2) Change in the agenda election of a new treasurer not necessary this year is going to happen next year if you are interested to join the board in this position keep that in mind
- Ad 3) Board reports

Marta:

A big thank you to **Dr. Predrag Minić** and **Valentina Pavković** for their support during the pre-course preparation.

Peter:

The Annual Fee of 50.- Euro will stay the same for next year. All countries are invited to pay in the Annual Fee.

Description	Date	Credit EUR	Debit EUR	Balance EUR
Balance	31.07.2017			3543.65
Bank Fee	30.09.2017		15.34	
Bank Fee	31.12.2017		12.84	
Annual Fee 2018 Germany	29.03.2018	50.00		
Bank Fee	31.03.2018		15.64	
Annual Fee 2018 Italy	04.04.2018	50.00		
Annual Fee 2018 Switzerland	14.05.2018	50.00		
Annual Fee paid cash at AGM Greece, Poland, France	06.06.2018	150.00		
Annual Fee 2018 Austria		50.00		
Total	06.06.2018	350.00	43.82	3849.83

Marlies:

Member countries – currently 40 countries

Alumni Members – currently 7 persons

Two newsletters had been circulated this year prior to the AGM

Call for annual reports – Annual country reports were submitted by 4 country contacts (till June)

Duties of a country contact representative:

- o Submit an Annual Report to the secretary of IPG/CF to be listed in the NL
- Hand on the NL from IPG/CF in your country to as many physios working with CF as possible

- Ad 4) IPG/CF Board decision to exchange Chair and Vice-Chair: unanimously decision of all present country contact reps Marta is taking on the Chair position and Ceci the Vice-Chair. For both the term will end in 2020.
- Ad 5) Clarification of the election of treasurer.

 Change of Agenda because of a communication error the term of the treasurer is for 4 years, so Peter is finishing being treasurer next year (2019.
- Ad 6) Report and election of research representative and lead of education sub-committee (1-year term): Report of the actual research representative Maggie McIlwaine. She was not contacted in the last year.

 She offered her support (in writing abstracts, applying for research funding or just getting an opinion on a physio research idea) in this position for another year! She also drew attention to the importance of scientific work so don't hesitate and get in touch with Maggie!!! mmcilwaine@cw.bc.ca
 Thank you, Maggie!!
- Ad 7) Date of next Meeting: ECFS conference 5-8 June 2019, Liverpool/UK
 At the end of this AGM Marta expressed her sincerest thanks to all participants for active cooperation and invited them all to ECFS conference 2019 in United Kingdom.

IPGCF CONTACT LIST FOR MEMBER COUNTRIES

Below is the contact list as of August 2018. 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:	Hilda Angelica Jimenez	hildajimenez38@yahoo.com.br
Canada:	Nancy Alarie	nancy.alarie@muhc.mcgill.ca
Costa Rica:	Rodolfo A. Bonilla Abarca	rhbonilla@yahoo.com
Croatia:	Anja Kladar	anja.kladar@gmail.com
Czech Republic:	Jana Zelenkova	jana.zelenkova2@fnmotol.cz
Denmark:	Lue Philipsen	<u>luephilipsençhotmail.com</u>
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	pmylau@ha.org.hk
India:	Sumita Gupta	bisoiak@rediffmail.com
Ireland:	Louise Collins (new)	louisee.collins@hse.ie
Israel:	Eynav Manor	e_manor@rambam.health.gov.il
Italy:	Simone Gambazza (new)	simone.gambazza@policlinico.mi.it
Macedonia:	Blazhe Arsov	president@mfz.mk
New Zealand:	Rebecca Scoones	RScoones@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	lauramgfisio@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

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

IPGCF June 2017 - June 2018 ANNUAL REPORTS FOR MEMBER COUNTRIES

Annual report from Austria 2017-2018

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 an 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.

Marlies Wagner, Graz/Austria

E-mail: marlies.wagner@medunigraz.at

Annual report from Switzerland 2017-2018

The Swiss CF Working Group (cf-physio.ch) consists of 16 members from all parts of Switzerland, representing physiotherapists from adult and paediatric CF centres as well as representatives from outpatient physiotherapy practices. The group meets 3 to 4 times a year and the Annual Meeting generally takes place in December. During the Annual Meeting in December, new members are elected and after the administrative part a specialist lecture, open to all interested physiotherapist from the CF centres as well as quality circles, follows. This year's topic will be "Coaching Skills ". The working group is in close exchange with the Swiss Working Group for Cystic Fibrosis (association of physicians, nurses, therapists and scientists) as well as the Swiss Association for Cystic Fibrosis (CFCH) funded in 1966. The objectives of cf-physio.ch is to continuously educate physiotherapists as well as inform CF patients and their environment.

In 2017, two seven-day Basic Courses for airway clearance techniques in patients with CF and other chronic pulmonary diseases took place with altogether 30 participants. One course was held at the Children's Hospital in Geneva in French and the second course in Bellinzona, Ticino. This was a milestone as it was the first time a course was held in the Italian speaking part of Switzerland. In 2018, we held a one-day Baby Course, a two-day Refresher Course in Bern and a Basic Course in Basel with a total of 45 participants.

Marta Kerstan, Aarau/Switzerland E-mail: internationales@cf-physio

Annual report from Portugal 2017-2018

The Portuguese Cystic Fibrosis Association has 3 physiotherapists, one is managing 3 patients north from Oporto, the other is managing 4 on the outskirts of porto, the other is managing 18 patients and is solely devoted to the association project, the "Home-care physical therapy and exercise on CF patients".

The association project is still up and running and we had a new physiotherapist join us, since one of our other colleagues had to quit.

Apart from the weekly sessions, we have been mainly focused on teaching our patients, the parents and care takers on how to maintain a good airway clearence and exercise routine when we are not there.

In November of last year The association presidente gave an interview to a portuguese newspaper, to provide awarness on what CF is and what is beeing done in Portugal to adress it.

In June this year, to celebrate the 30th anniversary of the Portuguese Cystic Fibrosis Association, we had an awarness event, which included a smal running/walking trail and a gathering afterwards.

We also had the launch of a recipe book for CF patients. It has recipes and all the nutritinal information in each of them, and we put it on the Association web site for free download. We had last year the celebration of the European CF day in November, where we had lectures and a physiotherapy workshop on airway clearence and exercise in CF.

This year will also have the celebrations of the European CF day on the 25th November, due to the actual day, the 21st, beeing a week day. This way we can have more people attending. We will have lectures and discussion pannels on physiotherapy, nutrition, transplant, the home-care program and other topics of interest.

We also have planned for next year a series of meetings, workshops and lectures for parents and patients to attend as well as any other physiotherapists that has patients with CF on their clinics.

Ana Filipa Rocha Portugal

E-mail: anafilipa777@hotmail.com

Annual report from United Kingdom 2017-2018

Association of Chartered Physiotherapists in CF (ACPCF) continues to be a well-supported and active group. There are currently 201members representing 29 adult CF centres and 41 paediatric centres (specialist and associated shared care). There are 8 regional groups in England and 1 each for Scotland, Wales and Northern Ireland. These groups meet throughout the year and information is communicated to and from the committee via regional representatives.

The ACPCF continues to hold an annual study event which takes place over 2 days each January. In 2018 the programme included presentations delivered via MDT speakers on topics including Advanced Care Planning, Psychological Implications of transplantation, non-invasive ventilation, end of life issues and feedback from various 2017 CF conferences.

Hannah Langman, Manchester/UK E-mail: hannah.langman@mft.nhs.uk

Annual report from Canada 2017-2018

We currently have approximately 50 therapists involved in CF care across Canada. Several therapists manage over 200 patients either adult or pediatric. Certain smaller centers have both pediatric and adult patients in the same clinic. Currently in Canada there are over 4200 CF patients followed in 42 CF multidisciplinary clinics across the Country. In 2016 the current median age is 22.7 years and the estimated age of survival is 53.3 years. In 2016, 60.8% of the CF population in Canada are adults. In the clinics our therapists are involved in the teaching and monitoring of airway clearance techniques to the families and to the patients. Ongoing education is an integral part of the physiotherapist's role in the clinic. They are also involved in the airway clearance management of these patients during hospital admissions. Exercise is also an integral component of CF care and many of our therapists are involved in assessing exercise and exercise prescription. We meet as a group once a year at the North American Cystic Fibrosis Conference. Our goal this year is to work toward establishing a mentoring program.

Here is the distribution of patients by province

Province	Total patients	Adult/Pediatric
Alberta	587	335/252
British Columbia	424	258/166
Manitoba	113	57/56
New-Brunswick	45	32/13
Newfoundland	74	54/20
Nova-Scotia	236	145/91
Ontario	1473	885/588
Quebec	1198	761/437
Saskatchewan	129	69/60

Nancy Alarie, Montreal/Canada E-mail: nancy.alarie@muhc.mcgill.ca

Annual report from Germany 2017-2018

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. The latest elections for the Board took place during last year's meeting.

In this year 6 courses to qualify physiotherapists in airway clearance techniques for patients with CF and other chronic pulmonary diseases are being planned in different cities in Germany.

In December 2017 a working group that consists of 4 CF Physiotherapists was founded. The aim of this group is to establish a new training concept to replace the former "CF physiotherapy advanced courses". Instead of a one-week course at a rehabilitation centre, "intensive seminars" that take 1 $\frac{1}{2}$ to 2 days will accentuate various subjects concerning CF medical and physiotherapy treatment. These seminars will start in 2019.

On May 5th a one-day symposium on "New Developments in Inhalation Therapy" was realized in Munich. About 60 Physiotherapists and other CF professionals attended the event. This symposium was already realised in September 2014 in Berlin and in April 2016 in Köln.

Jovita Zerlik, Hamburg/Germany

E-mail: jovita.zerlik@kinderkrankenhaus.net

Annual report from Italy 2017-2018

The Italian Physiotherapy Group for CF (GIFT/FC) is represented by Simone Gambazza, (coordinator) and Anna Brivio (secretary). Past Contact Person Clizia Cazzarolli left the group due to personal issues and the coordinator covers this position now. The group includes almost a hundred physiotherapists working in 31 CF Centers, spread all over the Country, taking care of more than 5200 patients. GIFT/FC belongs to the Italian Society of Cystic Fibrosis (Società Italiana per lo Studio della Fibrosi Cistica, SIFC), which organizes an annual conference and a spring annual meeting as well, with the purpose of sharing best practices and evidences, other than fostering networking among CF professionals. Participation in society activities requires an annual fee membership. Some physiotherapists involved in the GIFT/FC are also members of ARIR (Associazione Italiana Riabilitatori Insufficienza Respiratoria), the Italian respiratory care association made by respiratory physiotherapists.

ACTIVITIES IN 2017: Some GIFT/FC members joined the study on 6MWT in children, concluded in 2017 - Results of the project on adherence to antibiotic treatment through a multicenter physiotherapist supervised programme at home were presented during last year conference in Sevilla - Attendance of ECFS and NAFC conferences ACTIVITIES IN 2018 - The Good Clinical Practice Document on exercise assessment in CF is now available on SIFC and ARIR website - Multidisciplinary group for lung transplant management is working on a shared checklist for physiotherapists to be used when assessing candidates to LTX - There is an ongoing multidisciplinary group for the study of adherence mechanisms to aerosoltherapy - Development of a working group focused on urinary incontinence Education: - Urinary incontinence short course addressed to physiotherapists and physicians from CF centers (scheduled for September 2018) - Development of a CF thematic session for the upcoming International conference on Respiratory Physiotherapy (2019) promoted by ARIR. - Attendance of ECFS and NAFC conferences.

Simone Gambazza, Milano/Italy E-mail: simone.gambazza@policlinico.mi.it

Annual report from Norway 2017-2018

In Norway we have 350 persons with CF, of which $65\,\%$ are adults. Newborn screening started in March 2012. CF Patient Registry was established in 2016 and is now being a part of the European Registry.

Main activities in the National working group have been:

- Meeting in Oslo with the National group 27 September 2017
- Meeting in Oslo with the Scandinavian group 28-29 September 2017 Main topics were:
 - NBS in Norway. Follow up of newly diagnosed children in Norway and Denmark. Being diagnosed in adulthood: experience from an adult
 - Presentation of the project: Cardiorespiratory fitness and physical activity among Norwegian adolescents with cystic fibrosis
 - Use of inhalation therapy and physical exercise in the treatment in Norway.
 Differences and similarities in Scandinavia
 - o CF- registry in Norway
 - o Status and experience: CF modulation therapy in Denmark, Norway, Sweden
 - o Reports from ECFC in Seville. Status IPG/CF Glossary
 - o Presentation of e-poster accepted at the NACFC 2017, ref. below.
- ECFC Belgrade June 2018: Four Physiotherapists from Norway participated in the pre-conference course and at the conference. The National Contact Person assisted in one of the workshops.

Other activities: National Contact Person

- IPG/CF related work: The work on updating the IPG/CF Glossary was finished June 2017. However, the preliminary revised Glossary was not launched at the ECFC in Seville since the core group in 2015/2016 agreed upon finishing the Blue Booklet first
- Participation at the NACFC in Indianapolis 2017. Poster presentation: Airway Clearance Therapy and Health Related Quality of Life in Cystic Fibrosis: A pilot study of a series of N-of-1 Randomized Controlled Trials
- Participation on the annual Nordic CF Masterclass in Arlanda, Stockholm May 2018.

Sandra Gursli, Oslo/Norway E-mail: sangur@ous-hf.no

CASE PRESENTATIONS 2018, BELGRADE



Presentations

- Personalised airway clearance in the newborn: is it possible?
 Nicole Lee, Vancouver, Canada
- Case study of physiotherapy management of a premature baby with cystic fibrosis and Tracheal Bronchus
 Niamh Kiernan, Glasgow, United Kingdom
- Intelligent volume assured pressure support modes of ventilation in severe end-stage cystic fibrosis
 Zelda Beverley, London, United Kingdom
- Case report of severe pulmonal deterioration in child with cystic fibrosis and chronic MRSA infection
 Irena Cakalaroska, Skopje, Macedonia
- Lung transplantation: exercise matters! Federica Carta, Milano, Italy

Moderation: Ruth and Marta

Rating: Ruth, Marta, Peter and audience

The winner is **Niamh Kiernan**





5 – 8 JUNE 2019 LIVERPOOL, UNITED KINGDOM

42nd EUROPEAN CYSTIC FIBROSIS CONFERENCE



SAVE THE DATE