



NEWSLETTER 3, 2019

INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

Dear all,
Welcome to our post conference Newsletter!

What an exciting meeting – it was so good to see so many of you in Liverpool!
Marta really did a great job in organizing the pre-conference course in cooperation with the Exercise Working group. There had been about 50 participants and we have had many interesting and really fruitful discussions!

A great thank you to Peter who finished his period of four years as treasurer – thank you for your swiss reliability in money control and also in helping in decision making and in congress preparations! **We will miss you!**

Saying good-bye to Peter also means to say hello to Emma. **A warm welcome to Emma Dixon the new treasurer for the IPG/CF!**

This newsletter also encloses 4 annual reports –thank you to the providers! Please help us to give information from your country to the others and feel welcome sending us the annual report of your country!

If you are receiving this newsletter please forward it to your colleagues and your feedback and input is always welcome. Enjoy!

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



Minutes of the AGM of the IPG/CF

Liverpool, Wednesday, 5th June 2019, from 12.30 to 14.00

22 Participants – 13 country contact representatives (valid proxies received from Italy, France, Sweden)

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

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

Introduction of the board:

Marta Kerstan, **Chair**

Peter Suter, **Treasurer**

Marlies Wagner, **Secretary** (absent because of accident)

Cecilia Rodriguez, **Vice-Chair** (excused)

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

13 Contact Persons attended the AGM (Australia, Canada, Czech Republic, Denmark, France, Germany, Italy, Norway, Poland, Portugal, Sweden, Switzerland, UK)

IPG/CF Board received 2 valid proxies (France and Italy)

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

Ad 2) Board reports

Chair Marta:

- Thanks to Ana and Don for the prep of the pre-con course
- In January the 5th edition of Blue booklet was published – the last chapter including HFCWO was added and published on the website – in the future there will be only literature updates – the conduct literature search related to blue booklet topics will be a future task of the IPG/CF board. This work is a voluntary work – we always need people to contribute the knowledge and competences.
- Website needs to be updated – we have planned to use it as a platform for sharing information e.g. newsletter, description of the board member-functions, statutes, contact details of board members and research representative.
- Elections 2020:
Chair, Vice Chair and Secretary positions come to the end of their term.
These positions need to be replaced with new members – if you are interested or have an idea who is qualified for the position please get in contact with Marta.

Treasurer Peter:

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

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

Secretary Marlies:

- Member countries – currently 41 countries
 - Two newsletters had been circulated this year prior to the AGM
 - Call for annual reports
- Duties of a country contact representative:
- Submit an Annual Report to the secretary of IPG/CF to be listed in the NL (short information about the activities of the national CF-physios e.g. courses, information events, number of CF-centers...)
 - Spread the NL from IPG/CF in your country to as many physios working with CF as possible

Reminder about the physio-case presentations following the AGM – the deadline for abstracts is the **17 of January 2020** – this is the same deadline as for any other abstract for the ECFS

Ad 3) Election of a new Treasurer

Emma Dickson, Specialist Physiotherapist in Paediatric CF homecare at RBH from Birmingham /UK was elected with a big applause!

Ad 4) Research Representative

Maggie 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 – **Don't hesitate and get in touch with Maggie!**

Thank you, Maggie!

Ad 5) Brenda Button: Survey about physiotherapy in CF-infants in 1999
20 years after the initial survey Brenda suggests repeating the survey – the audience supported the idea – Brenda is going to write an outline. Some interested people already agreed to form a working group with Brenda Button (C&A); Maggie MacIlwaine (C), Jovita Zerlik (C), Irene Maguire (A) Sandra Gursli (A), Louise Lannefors (C&A), Emma Dickson (C), Cornelia Mesman (C), Hannah Langman (A), Ana Filipa Rocha (A), Marta Kerstan (A&C), und Simone Gambazza (A). (Children & Adults = C&A)

Maggie McIlwaine: She reported about the “CF Circle of Care” sponsored by Vertex. As this is an opportunity for physiotherapists as well, she proposed to apply for it!

Date of next Meeting: ECFS conference 5-8 June 2019, Lyon/France

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 May 2019. In summary, there are currently 41 member countries receiving our correspondence.

Country	Contact	Email
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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.

Annual report from Austria 2018-2019

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.

Marlies Wagner, 2019-05-01

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Annual report from Brasil 2018-2019

This year in May 02-4-2019 we are going to have the VII Congresso Brasileiro de Fibroses Cystica in Campinas Brasil. There will be several international guests. The group of Physiotherapist will approach physio-treatment about history to up day, and will promote a discussion with the parents or helper about physiotherapist techniques. It is necessary to point out that we already don't have special centers who look after CF patients. The patients attend in general hospital or associations.

Hilda Jimenez, 2019-02-21

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Annual report from Czech Republic 2018-2019

There are currently 6 centres for patients with cystic fibrosis (Prague, Brno, Plzeň, Hradec Králové, Olomouc, Ostrava) with 645 patients in total (330 children, 315 adults). Around 25 respiratory physiotherapists take care of them. The number of patients for one physiotherapist differs from 2 to 50 (based on the size and area of the centre).

Education of the therapist

- A possibility of visiting special training courses focused on respiratory physiotherapy
- A conference called RECYF held once a year in Prague
 - o Meeting of pneumologists, physiotherapists, psychologists, nutrition therapists, nurses and other experts dealing with patients with CF
 - o Experts from the Czech Republic, who visited ECFS conference during that year, speak about the latest topics
- Discussion about patients between physiotherapists is possible via email contact, supervision and during internships

Education of the patients, parents

- Educational week - after setting the diagnoses from the newborn screening - parents and their baby are admitted to the hospital for three days (inhalation, airway clearance physiotherapy training)
- Outpatient controls - 2-10 times/year according to needs and skills of the patient/parent
- Inpatient controls – if it's needed
- Once a year – CF meeting for families/friends/relations of patients – expert lectures about physiotherapy (various topics) and other fields

Projects

- We have already finished a project (pilot study) dealing with the effect of the reflex zone stimulation technique on lung functions in patients with cystic fibrosis
- Some of our centres have started to use Simeox device as a supportive device for airway clearance
- During April 2019 the first version of CF HERO App was activated
 - o CF HERO APP helps teenagers with CF have better control over the inhalation process and respiratory physiotherapy in entertaining form

Jana Pleskova, 2019 -May

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Annual report from United Kingdom 2018-2019

Association of Chartered Physiotherapists in CF (ACPCF) continues to be a well-supported and active group. There are currently 240 members representing 29 adult CF centers and 41 paediatric centers (specialist and associated shared care). There are 8 regional groups in England and 1 each for Scotland, Wales and Ireland (the Northern Ireland and Ireland groups have merged this year). 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 2019 there was a record attendance of 120 members and the programme included presentations on topics including anatomy and physiology of upper airways, a problem solving approach to airway clearance, interpretation of CPET and putting results

into practice, exercise and nutritional considerations in CF, an update on new therapies and feedback from various 2018 CF conferences.

Hannah Langman, 2019-May

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Please feel free to provide feedback and forward your suggestions or content to the IPG/CF secretary – marlies.wagner@medunigraz.at

Distribute the Newsletter widely, and enjoy!