

Dear Colleagues,

Welcome to our fourth newsletter of 2022.

This newsletter summarizes the most important moments from the **45th ECFS Conference 2022** (8-11th June) in **Rotterdam** and brings the reports of the chair, treasurer and secretary. Be sure to read to the end, because in the last part you will find interesting annual reports from member countries.

At the beginning, we would like to **thank** everyone who participated in the conference in any way. Thanks to the French team for a great **pre-conference course**. We thank the **organizers, speakers, moderators**, but no less also the **participants** of the conference. It wouldn't have been possible without any of you. And now to the point. Important things were discussed at the annual general meeting this year. The following reports summarize the most important ones.

Don't be alarmed, this newsletter is quite long as it summarizes important historical moments and the future of IPG, so be patient while reading it :)

1. Chairperson report by Marlies Wagner

It was so good to see so many of you in Rotterdam. Reconnection, networking, socializing ... I have missed those things in the last 2 years! Let me give you a short overview what is actually going on in the IPG:

This year's pre-conference course:

- Thank you to both, our speakers from France and all attendees of the pre-conference course. There has been some excellent discussion and debate over the 1.5 days and we even managed a bit of practical despite the very narrow room! The 2nd day was quite special – thanks to our 2 special guests from overseas – Brenda Morrow and Brenda Button!
- Thank you to friends of the IPG and the board members and the physiotherapy special interest group for supporting the IPG in speaking in the preconference course, in moderating of case presentation sessions and symposiums. The commitment and preparation required in your own time no doubt, is much appreciated.
- Finally thank you to Ana Filipa Rocha – she is our pre-conference course coordinator – we would not have had any chance to organize the course like this. I am sorry that she did not have the chance to be here in Rotterdam after spending so many hours of work in this project.

This report also includes information regarding the ECFS special interest group -PHYSiG: Physiotherapy special interest group: Some of you, who are members of the ECFS got an email in summer 2021 concerning the formation of a physiotherapy SIG (special interest group). The IPG board members did not know about that intuition of the ECFS – mostly because there was a confusing change of board members, and information got lost.

So, looking up earlier newsletters I found some information about that.

It was first mentioned in 2015 – the ECFS proposed for a SIG to be aligned with the ECFS.

In the following years this offer was discussed a few times at AGMs. The outcome was that *there were concerns from the membership that there may be a loss of autonomy and financial freedom and many at the AGM recognised that this was certainly a strength of the IPG. It was felt that the affiliation may assist with some of the complexities of holding an account in the treasures name, in addition to the fact that we have been unable to accept educational grants as we are not considered a 'company' or 'association' according to company law, there are a few questions that have yet to be answered including concerns around our autonomy, financial freedom, expectations etc.*

The ECFS offered:

- Financial support of 3000 €
- More visibility with space on the ECFS website

We would need to:

- Become members of ECFS
- Model the ECFS organizational structure (leadership rotation 3 yrs, good representation across Europe, formulate aims, transparency of functioning and attract new young talent)

Then there were a few changes concerning board members and this topic totally vanished.

So far so good...

Last autumn a SIG for physiotherapy was formed by the ECFS.

Emma and I joined these meetings because we wanted to build up a connection between the 2 groups.

From the very first moment it was clear that we all wanted to work together – that there will be no competition between the groups.

Brenda Button, who does not know her, also joined the SIG – this was really a start of a fruitful connection.

The strength of the IPG is based on a long history that started more than 30 years ago in 1985. Plans were made to optimize CF treatment, cooperate with other CF organizations, passing information and education to physiotherapists worldwide.

The IPG ran 8 training courses for physiotherapists worldwide before the turn of the millennium. In 2003 ten physios were accredited as IPG/CF instructors. This involved training with the developers of the techniques then 5 years' experience in hospital teaching the techniques then a further accreditation course at an ECFC pre-conference. In 2013 another 10 were accredited.

Experienced IPG nominated physios went in pairs to different countries to teach courses some as long as a week or more depending on the level of physio education. Sometimes the physios went with a physician. These were sponsored by the physios themselves and the IPG registration fees helped pay the costs of airlines, low-cost B&Bs and other necessary expenses. Physios were needed to be supported by their institutions in terms of leave away from their hospital.

We also had applications and a competitive process and one physio per year could apply to study for a period with an experienced CF physio at their institution as an additional opportunity.

The trainings and the pre-conference courses were the main educational opportunities via the IPG. Of course, the internet and on-line webinars has changed the focus of education radically, but as we experienced in the pandemic years, there is no way better to learn ACT but in hands-on-courses.

In 1993 the IPG published a guideline for physiotherapist about chest-physiotherapy in CF

the previous model of the blue booklet – that is now available for everyone on the ECFS website.

This was just a short overview – there are great people who take big efforts and I think we can proudly notice that the outcomes are awesome.

Summary:

- The IPG has a long history
- Our community includes more than 40 countries – so that we are able to share information internationally
- International board members from different countries with a breadth of languages
- A list of experienced alumni – to be contacted when necessary – to ensure benefit of experience and opportunity to access these past board members for their expertise as necessary
- The IPG delivers 4 newsletter per year including country reports which increases the inclusiveness of the group

But now it's time to move on!!

Where are we now?

We already had a few meetings with the SiG.

Soon it was very clear that there is no way/necessity of 2 different groups of physiotherapists – thinking about the last few years there the IPG already had difficulties in gaining board-members – we cannot afford wasting human resources. Having 2 groups would certainly dilute the membership and quality of any work either group achieved.

Facts:

- **Scientific Committee:**

The ECFS already approached to PhySiG to take the physio lead in the Scientific Committee which is responsible for the generation of the proposed programme of events for the subsequent year conference. This year there will be 1 representative from the IPG and 2 from the PhySiG at the planning meeting.

- **Communication with ECFS:**

Since there is the SiG we definitely experienced communication issues.

- **ECFS membership** is only necessary if you want to become a PhySiG board member

This ECFS membership fee was a big issue to the IPG, because it was considered to limit membership to those countries and members who were in the middle to high income countries.

Process of fusion:

It was generally felt that there would not be a fixed concept but a flexible approach to joining the 2 groups.

- Fusion of IPG and PhySiG constitution
- It was generally felt, that the 2 boards would merge fairly easy and where there were more than one person in a role (for example 2 secretaries and 2 treasurers..) that additional roles and responsibilities could be generated to allow the experience of the individuals to be maintained within the larger group. Where it was difficult to do this there would be a vote.
- Gradually phase out with the current IPG board members working their term of office but no further election
- Establish an IPG representative on the board of PhySiG – business has to be defined
- Where achievable combine the logos of the respective groups
- By next year the groups could be fused and there will be only 1 AGM
- At the AGM next year in Vienna, there will be a voting to comply with IPG constitution for the groups to formally fuse

What matters to all of us:

- One of the key factors was to ensure we continued to have **country contacts** to maintain the opportunity for networking and communication
- Ensure to have an international “reach”, this includes using the educational webinars to enable less financially viable countries to participate as these were free and would be on the ECFS website and possibly a YouTube site for PhySiG members after the event

Finally, I think that there is no alternative but to embrace this change and I think the time is right to do this. I am sure that both groups will profit from the collective capabilities the groups can offer. I am already encouraged by their positive spirit and also not to forget the delivery of their first webinar!

As there is no financial barrier to being a member of the PhySiG this is an opportunity to move together for CF management around the world.

We only will be better and stronger together!

Best wishes,

Marlies Wagner

2. Treasurer Report by Emma Dixon

Dear Country Representatives and members of the IPG/CF

Welcome to our 2022 AGM as my colleagues have already said, it so lovely to see you all in person.

I will try and keep the treasurer report short and sweet as it is a necessary part of any AGM, so please bear with us.

Here is a summary of the voluntary Annual Membership Fees until 6th June 2022. (no changes to new bank statement received post conference).

Annual Membership Fees Summary

Country	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/2023
Australia	✓	✓		✓			
Austria			✓	✓	✓	✓	✓
France	✓		✓				
Germany	✓	✓	✓	✓	✓	✓	✓
Greece	✓		✓	✓			
Ireland	✓	✓					
Israel		✓				✓	
Italy	✓		✓	✓			
Norway	✓	✓	✓	✓	✓	✓	
Poland			✓				
Sweden		✓					
Switzerland	✓	✓	✓	✓	✓	✓	✓
Czech Re- public	✓				✓	✓	
UK	✓	✓	✓		✓	✓	
Total Pay- ees	10	8	9	7	6	7	

I am aware I say this every year, but for the new members among us, welcome and a little background. The annual membership fee for the IPG/CF is remains set at 50 Euros and is non-compulsory. The money is mainly used to support the Physiotherapy Short Course at the ECFC, speakers at the ECFC conference who are not funded by the ECFS Organising Committee, special occasions and bank fees. The IPG-CF Board work voluntarily and no salaries are paid to them. We are mindful that not all membership countries are financially equal, but we would ask if your organisation is able to contribute, we would be grateful.

As many of you are aware we have had difficulties changing bank accounts from Credit Suisse in Switzerland to a UK bank due to; dual signatures being required, Brexit and a pandemic. The board have agreed not to change the bank, now, as I am in my final year of post. Peter Suter remains signatory.

You may also remember to overcome the issues above and prevent these issues for treasurers in the future: the IPG-CF approached the ECFS to apply for special interest group status. This would mean ECFS would manage the admin for the finances, but we would remain in control of the expenditure. More importantly each time the treasurer changes we do not need to change banks.

However, this did not occur and a separate ECFS Physiotherapy special interest group was born, whom we work closely with.



INTERNATIONAL PHYSIOTHERAPY GROUP
FOR CYSTIC FIBROSIS

- Current balance, as of 8th May 2022 - 4,633.95 Euros. Please be aware that no short course funding has been used for the last 2 years so next years balance will be a lot less.
 - No expenses, other than bank charges, were incurred this year (88.02 Euros) and we have had an increase in Income (550 Euros) from 7 countries, highlighted in the table above, with 3 countries paying for the 2022-2023 year, thank you very much.
 - The annual membership fee for the IPG/CF is set at 50 Euros and is non-compulsory
1. Payments are made by Bank Transfer: Please note new address which is different from the one presented at conference.

Bank Name: Credit Suisse 8070 Zürich
Address: cf-physio.ch, Münchwilerstrasse 25, 4332 Stein, Switzerland
IBAN: CH51 0483 5163 5631 6200 0
BIC: CRESCHZZ80A
Account Nr: 0094-1635631-62
Account Name: CFinternational
Currency: EURO! Not Swiss Francs
Please declare clearly for which **country and year** you are paying e.g. *UK 2022/23*
New Address!

As I am not signatory for the back, we are unable to take cash payments at Conference, as we have done in the past. Many apologies for this inconvenience. I am able to create invoices for those who require them to make payments if that is helpful.

No queries were raised at the AGM, so this closes the accounts for 2021/2022

Hoping you all had an enjoyable conference.

If anyone has any questions, please do not hesitate to contact me, otherwise this closes the accounts for 2021/2022. Next fees are due by June 2023.

Kind regards

Emma Dixon, Treasurer IPG/CF (e.dixon@rbht.nhs.uk)

3. Secretary report by Jana Plešková

First I would like to inform you that we have 41 member countries in IPG. Some changes have taken place in the country representatives of member countries, current contact persons can be found at the end of the newsletter, on the ECFS website in the IPG section.

A big thank you to everyone who sent an annual report after the call.

Annual report from Argentina

There are 26 CF centres in Argentina. Of them, 19 are paediatrics and 7 are adults'. Nearly all are multidisciplinary groups with only one physiotherapist each but in others, there are 2 or 3. The three paediatrics centres in Buenos Aires had between 150 and 160 patients each.

Concerning education, two centres have postgraduate courses in Paediatrics Physiotherapy supported by universities with specific training in CF. One paediatric centre gave education in some provinces and other countries of South America.

In December 2021, the 6th Congress was held in Buenos Aires and organized by the National Cystic Fibrosis Society with a track for Physiotherapy. In this case, was only virtual.

Among our special guests, we received Ms Brenda Button and Ms Cecilia Rodriguez, we thank them for their compromise, good willingness, and high quality of their dissertations.

Three centres had completed Ms Brenda Button's survey and are interested in performing the A-Step Test which is a good alternative for evaluating exercise when CPET are not available. We thank Brenda Button again and Viviana Llugdar, who kindly teach us how to use it.



INTERNATIONAL PHYSIOTHERAPY GROUP
FOR CYSTIC FIBROSIS

Annual report from Australia

While Covid19 has continued to challenge our health system in Australia physiotherapists have continued to carry out research and educational activities. A national multicentre research project **BEAT CF** has been led by Dr Jamie Wood from Perth, Western Australia, now undertaking a post-doctoral appointment at Mount Sinai Hospital, New York. This project involves physiotherapists from CF Centres around Australia documenting details of physiotherapy treatments carried out with patients during their hospital admissions. The main aim is to inform physiotherapists about types of treatments and time taken to provide them during acute exacerbations of CF. This will provide information to guide physiotherapists in how to manage acutely ill CF patients and the resources required for optimal outcomes.

The recently formed online physiotherapy education initiative (described in our 2021 report), [CFPhysio.com](https://cfphysio.com), has continued to evolve. A number of experienced physiotherapists under the leadership of Jen Hauser have developed a number of podcasts including 'Pregnancy in CF'; 'Early Parenting in CF'; 'Fatherhood & CF'; 'Effective huffing in CF' and an educational video for children with CF and their carers. [CFPhysio.com](https://cfphysio.com) has partnered with Beam Feel Good, UK ACPCF, and clinicians globally to develop the Research Education And Collaboration Hub for CF (REACH for CF), to provide education virtually and create collaboration opportunities in different aspects of physiotherapy and research. Recordings of these webinars can be accessed online through www.beamfeelgood.com.

A project is underway across Australia to develop relevant physiotherapy outcomes to contribute to the [Australian Data Registry](https://australian-data-registry.org.au). The newly developed incremental maximal effort step test, the **A-STEP**, protocol and feasibility study in children and adults are now published in Pediatric Pulmonology. For further information contact me: b.button@alfred.org.au

Annual report 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. In 2019, 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. This year we already had a meeting in February concerning CF Physiotherapy in the area of CFTR Modulators. 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 report from Brazil

The last available edition of the CF Brazilian registry (2019) shows that 5773 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:

- Webinar "Physiotherapy in cystic fibrosis: from pandemic to the future", sponsored by the Brazilian Association of Cardiorespiratory Physiotherapy (ASSOBRAFIR) and the Brazilian Cystic Fibrosis Study Group (GBEFC).
- Webinar "Physiotherapy and the New Era in Cystic Fibrosis", sponsored by Vertex, March 2022.
- Theoretical and practical training of physiotherapists in new CF centers across Brazil, May 2022.
- Organization of upcoming events: VIII Brazilian Multidisciplinary CF Conference – May 2023.

Annual report from the Czech Republic

Basic information:

- There are currently 5 centers for patients with cystic fibrosis with 699 patients in total (339 children, 360 adults).
- During the last 12 months we have diagnosed 18 new patients.
- Around 30 respiratory physiotherapists take care of CF patients, predominantly on a part time basis.

- The number of patients for one physiotherapist differs from 2 to 50 (based on the size and area of the center).

Education:

After a two-year online version, the RECYF conference was organized this year in person. The conference is intended for pneumologists, physiotherapists, psychologists, nutrition therapists, nurses and other experts participating in the CF care.

The one-day workshop for physiotherapists focused on a comprehensive physiotherapeutic approach in both outpatient and inpatient care for patients with CF. The most common mistakes and questions that appear in the therapy were consulted. The workshop had 4 sections: Physiotherapeutic examination of a patient with CF, Pulmonary function, imaging methods and their correlation with clinical examination, Targeted respiratory physiotherapy and Case reports.

Expert physiotherapy lecture on CF meeting for families/friends/relations of patients was focused on Physical activities in CF patients.

Recent activities:

CF physiotherapists from the Czech Republic have had to deal with the significant influx of new patients from Ukraine in recent months. Special training therapies were organized for those patients who had not yet encountered physiotherapy in their treatment. With the support of the Czech CF Foundation, educational videos for children and adults CF patients were finished. The videos basically focused on airway clearance techniques of upper and lower airways and inhalation.

Annual report 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, the next elections will take place in 2023.

In 2021 and 2022 five courses to qualify physiotherapists in airway clearance techniques for patients with CF and other chronic pulmonary diseases were realized and are planned. At least one advanced course will take place in 2022.

Due to the restrictions of the Covid 19 pandemic many 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. In March more than 60 members of the German CF Physiotherapy group attended a virtual session about the impact of Modulators on the CF patients and the resulting changes in physiotherapy approaches. For 2022 more meetings are planned to be held physically.

In January 2022 a new edition of the German "Leitfaden Physiotherapie" which is describing the CF Physiotherapy techniques used in Germany was released. The last revision had taken place in 2009.

Annual report from Norway

In Norway, we have 402 persons with CF, i.e., children 134, adults 268. We have Newborn screening since 2012 and CF Patient Registry since 2016.

The National working group consist of 19 Physiotherapists working with children and/or adults at the CF-centre in Oslo and Bergen and in other regional specialist health services.

Main activities have been:

- Physical controls and follow-up patients – partly somewhat reduced due to pandemic
- Digital meetings with Physiotherapists in the primary health service on individual patients and in local hospitals. Consultations (video/telephone) with adults
- Participation in ECFC digital 2021
- National and international webinars
- National contact person - IPG/CF – related work:
 - Annual general meeting 2021
 - IPG/CFs Questionnaire: Answered the questionnaires in collaboration with colleagues working with children and adults at the CF-centre in Oslo
- IPG/CFs Questionnaires answered by colleagues at the CF-centre in Bergen

- National Working Group: Digital meeting June 15th 2021 with main topics:
 - Experience with Kaftrio: Lue Katrine Drasbæk Philipsen from Copenhagen
 - Airway Clearance Physiotherapy for patients with little symptoms

Events coming up:

- Kaftrio to be launched in Norway 1.6.2022
- ECFC physical – Rotterdam :)
- National and international Webinars
- Scandinavian Physiotherapy meeting, 22-23 September 2022, Lund, Sweden
- National course for Physiotherapists: Newly diagnosed CF

Annual report from Switzerland

CF-Physios: 146

- CF-Patients: 1013 - 57.6% adults (Stats from 31.12.202)

There were organised:

- 1 Basic Course
- 1 Baby Course
- 2 Webinars
- 1 Group Expert Meeting

The swiss CF-physio group collaborated with the Bern University to integrate the basic course in a Masters Study.

4. PhySIG Webinar "Non-Invasive Ventilation in Cystic Fibrosis"



The ECFS Physiotherapy Special Interest Group (PhySIG) is happy to announce the third "Bitesize Physiotherapy webinar":

"Non-Invasive Ventilation in Cystic Fibrosis"

on Thursday 08 September 2022
at 13:00-14:00 CEST / 12:00-13:00 UK time

The last information we would like to mention in the newsletter is the webinar organized by PhySIG on the topic "Non-Invasive Ventilation in Cystic Fibrosis".

Webinar takes place on Thursday 08 September 2022 at 13:00-14:00 CEST / 12:00-13:00 UK time.

For more information see second attachment of this email. You are all very welcome to attend the webinar.

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

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

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



IPG/CF CONTACT LIST FOR MEMBER COUNTRIES

Below is the contact list as of July 2022. In summary, there are currently 41 member countries receiving our correspondence.

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