



INTERNATIONAL PHYSIOTHERAPY GROUP  
FOR CYSTIC FIBROSIS

## **NEWSLETTER 3, 2021**

Dear all,

Welcome to our third newsletter 2021.

I hope you all enjoy beautiful summer and holiday, whether by the sea or in the wonderful relaxing countryside. I believe that you will pump up a lot of energy to the upcoming working days.

The ECFS digital conference 2021 is over, and I would like to thank all who attended the conference either actively or “just” from the listener's chair. Both roles are important for our patients. Great work was done. Great speakers, great symposia, great atmosphere. Of course, we must admit that the live conference has an even better dimension. That is why we are already diligently preparing a program for the next conference in Rotterdam. Let's hope that the situation around the pandemic will allow a personal meeting and together we will be able to meet not only at the ZOOM but also in a pub for a good beer or a delicious meal.

This newsletter brings you minutes from ECFS conference 2021 and latest news and comments from our board. And, because I think that country reports can be a strong inspiration for other countries, I decided to include reports from countries that arrived after the second newsletter of this year was send.

So please read on, enjoy, get new information and inspiration for the next days.

The main topics of this newsletter:

### **1. Minutes from AGM**

- a. Chairperson report
- b. Vicechairperson report
- c. Secretary report
- d. Tresurer report
- e. Brenda Button report - IPG/CF AIRWAY CLEARANCE TECHNIQUES INTERNATIONAL SURVEY 2021

### **2. Chairperson report August 2021 – comments on the news in the world of IPG/CF**

### **3. Further annual reports**

## 1. Minutes from Annual General Meeting

### a. Chairperson report

Marlies Wagner launched AGM, introducing board members. At least 13 representatives of countries took part in the AGM, the numbers are probably not accurate, as not all participants communicated via chat. Marlies thanked Vicechairperson Cecilia Rodriguez Horal and welcomed Mathilde Legueult as the new Vicechair. Thanks also went to Marta Kerstan, a latest Chairperson, for completing many goals and collaborating on the latest version of the Blue Booklet.

### b. Vicechairperson report

Cecilia Rodriguez Hortal said goodbye, ended her position and handed over her position to Mathilde.

**Thank you very much, Ceci, for your dedicated work for IPG / CF!**

### c. Secretary report

I, Jana Plešková, informed about the current state of the IPG / CF member countries. IPG / CF includes 41 countries from all over the world, each country is represented by one contact person, however, the number of members participating in IPG/CF and in AGM is not limited.

I also informed about vicechairperson votes process. There was one nomination for **vice chair position – Mathilde Legueult** from France. The voting process itself was managed by email voting slips. We had got 11 votes for Mathilde. So we can sincerely welcome Mathilde on the vice chair position. We hope that Mathilde will enjoy her new position.

Mathilde worked for 3 years in Paris in a pediatric hospital, and afterword she created a liberal center dedicated to the management of cystic fibrosis in the south of France, where she defends a holistic care (yoga, cardio, drainage with multiple devices, muscle strengthening, manual therapy for example) of the patient, and she also teaches it in physiotherapy schools. With Hughes Gauchez she gives trainings dedicated to cystic fibrosis in Eastern Europe and North Africa. She also actively participate in the development of research in physiotherapy by accompanying numerous theses leading to future publications.

### d. Tresurer report

#### **IPG-CF: International Physiotherapy Group for Cystic Fibrosis Treasurer Report 2020-2021**

Dear Country Representatives and members of the IPG/CF

Welcome to our 2021 AGM and the strange times that we continue to find ourselves in.

Here is the amended summary of the last 5 years' voluntary Annual Membership Fees. This is the corrected version (highlighted) since the AGM with all issues resolved regarding monies from Norway, Germany and the Czech Republic. This closes the accounts from 2020-2021. 2021 monies are due by June 2022.

#### **Annual Membership Fees Summary**

Country	2016	2017	2018	2019	2020	2021
Australia	√	√		√		
Austria			√	√	√	√

France	✓		✓			
Germany	✓	✓	✓	✓		
Greece	✓		✓	✓		
Ireland	✓	✓				
Israel		✓				
Italy	✓		✓	✓		
Norway	✓	✓	✓	✓		
Poland			✓			
Sweden		✓				
Switzerland	✓	✓	✓	✓	✓	
Czech Republic	✓				✓	
UK	✓	✓	✓		✓	

The annual membership fee for the IPG/CF is 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.

We continue to have difficulty transferring the current bank account, which is held with Credit Suisse in Switzerland, due to requiring two bank signatories and COVID 19. Peter Suter remains signatory.

To overcome these issues and prevent these issues for treasurers in the future it has been agreed by the IPG-CF board to apply for special interest group status within the ECFS as many of our multi-disciplinary colleagues do (Pharmacy, Nursing etc). 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.

Current balance, as of June 2021 - 4,151.94 Euros. No expenses, other than bank charges, were incurred this year. Payments are made in 2 ways: **The Annual Fee of 50 Euro**

1) Bank transfer, details currently:

Bank Name: Credit Suisse 8070 Zürich

Address: cf-physio.ch, Artishus 1, 3527 Grossaffoltern, 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 2019*



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- 2) Cash with receipt at the annual ECFC.

If anyone has any questions, please do not hesitate to contact me.

Kind regards

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

#### **e. Brenda Button report - IPG/CF AIRWAY CLEARANCE TECHNIQUES INTERNATIONAL SURVEY 2021**

##### **Background**

In the late 1990s an international questionnaire regarding the use of Airway Clearance Techniques (ACT) was developed by the IPG/CF working party co-ordinated by Brenda Button. This was disseminated in paper form at conferences and mail outs via IPG/CF country contact persons. From the year 2000 results were presented at the European CF Conference (ECFC) and North American CF Conference (NACFC) and published on the ECFS website. The IPG/CF accredited instructors who in turn taught ACT courses in different countries and at pre-conference courses at the ECFC and NACFC on a regular basis during the past two decades.

##### **Actions**

At the IPG/CF Annual General Meeting in Liverpool in June, 2019, Brenda Button proposed repeating the survey 20 years on to determine current practices relating to ACT in CF internationally. The IPG/CF Board accepted this proposal and called for volunteers to form the IPG/CF ACT Working Group. The following comprise the Working Group: Emma Dixon (UK), Simone Gambazza (Italy), Sandra Gursli (Norway), Marta Kerstan (Switzerland), Louise Lannefors (Sweden), Hannah Langman (UK), Irene Maguire (Ireland), Maggie McIlwaine (Canada), Cornelia Mesman, Ana Filipa Rocha (Portugal), Marlies Wagner (Austria), Jovita Zerlik (Germany) with Brenda Button (Australia) as co-ordinator of the project.

A draft survey based on the questions asked in the original survey (1998-1999) was developed and circulated to the Working Group (2019 – 2020). Feedback was incorporated together with opinions about which online survey platform to use. Survey Monkey was selected. Professor John Wilson, CF Centre Director at the Alfred Hospital, Melbourne, Australia paid for the Survey Monkey licence needed for a large study. Mr Anthony Talbot, Psychologist, Alfred Hospital, Melbourne with experience using Survey Monkey assisted Brenda in developing the survey. The first draft of Survey Monkey was circulated to the Working Group via email in April 2021. Feedback was incorporated and presented at the IPG/CF Annual General Meeting (AGM) in June, 2021.

At the AGM the following were discussed: whether there was a need for registration of the project; ethics approval, circulation of the electronic version to all countries and CF centres; size of centres eligible; the need for tracking the number of surveys disseminated and the number of responses received for peer reviewed publication.

This led to the following decisions: physiotherapy practice was being surveyed with no patient related information included; physiotherapists who elected to complete the survey were providing consent; surveys were to be distributed to all country contact persons of the IPG/CF. They would disseminate the Survey Monkey link to all CF centres in their countries (regardless of size) and would keep track of the number of centres sent the survey to be matched with the number of responses received. Results would be analysed

and presented at the ECFC and NACFC in 2022-2023 with a manuscript to be completed and submitted to an appropriate peer reviewed journal.

Currently, the final electronic version is being prepared, incorporating all the feedback received. This will be disseminated to the IPG/CF Working Party for approval prior to the final version of Survey Monkey being sent to each Country Contact Person for dissemination and completion.

Prepared by Brenda Button 27 July, 2021

## 2. Chairperson report August 2021 – comments on the news in the world of IPG/CF

**Hello and thank you for reading newsletter 3, our post-conference edition!**

The pandemic situation last year led to a digital mini-43<sup>rd</sup> European CF conference in September 2020 – big efforts had been taken to set up this mini conference – but we all learned a lot in this year and although it is not possible to meet in person – the ECFS took the chance to make a bigger version of the 44<sup>th</sup> congress possible this year!

The covid pandemic taught us many things – amongst them how to treat patients in a crisis – to use virtual reality to find connection to our patients – to treat them on distance – to keep them motivated – to go to our limits. It's not over by now – but it's getting better/easier for the most of us.

It was also a year of progress in CF-care - Tricafort conquered the market – I think we all saw many Patients treated with this new modulator therapy and I assume most of us witnessed awesome results. These new developments will for sure influence the physiotherapy treatment in CF patients and I am already very curious where this leads us to!

On the other hand, we must not forget the ones who are even not able or cannot afford to have standard CF treatment at all. To understand the needs of these people to help with educational issues has always been in the mind of the IPG/CF.

### **Special Interest Group (SiG)**

In 2015 the ECFS made an approach to the IPG about becoming a Special Interest Group (SiG) within the ECFS. The IPG was discussing the advantages and disadvantages at the AGM in Brussels - thus it was decided at this meeting not to become a SiG because of a loss of autonomy and financial independency.

On further conversations in 2015/16, the ECFS would allow us to form a sub-group of the IPG that could be a physiotherapy SiG. The funding from the ECFS cannot be spent on research however, it would be suitable for an education programme/project.

We have been assured that our organisational and financial autonomy would not change and that this group and the funding associated would be a 'sub-group' of the IPG.

### Today:

A few weeks ago, the ECFS sent out a mail for application to form a Physiotherapy SiG.

The ECFS Board appreciates the work of the IPG/CF, but felt it is important to support an ECFS physiotherapy Special Interest Group, similarly to other Special Interest Groups currently part of the ECFS.

The ECFS Board communicated this to the ECFS membership with a request for expression of interest. By now they report that close to 30 individuals showed an interest in joining an ECFS Physiotherapy Special Interest Group.



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An invitation to a virtual meeting in September will be sent from the ECFS to those who expressed interest in this ECFS Physiotherapy Special Interest Group to discuss the aims, objectives and activities of this future group and to call for possible coordinators. Should members of the IPG/CF wish to attend this meeting, they should make themselves known by sending an email to [membership@ecfs.eu](mailto:membership@ecfs.eu). It would certainly be an asset to have members working with both groups.

Both the IPG/CF and the ECFS physiotherapy Special Interest Group have their value, and the ECFS Board sees no barriers to co-exist. The ECFS Physiotherapy Special Interest Group will follow the rules as set in the ECFS Terms of reference and therefore receive a small annual allowance. The IPG/CF, wishing to remain independent from the ECFS, can meet up and work on their own specific projects, also during the conference, as it has done so far.

Finally...

### **Alumni**

Can I urge country contacts that have been in their position for a while and are not interested in taking a board position in the near future to consider relinquishing the role to allow people with time to spare to come on board and move the IPG forward.

**Marlies Wagner, Chairperson IPG/CF**

## **3. Annual report**

### **Annual report 2020/2021 from Australia**

A group of twenty-five experienced physiotherapists (from all the CF Centres in Australia and New Zealand) with a special interest in Airway Clearance Techniques and the management of people with cystic fibrosis have developed two online education packages. One is for physiotherapists and the other for people with CF and their carers. Jen Hauser from Hobart, Tasmania has led these initiatives which continue to evolve and are available at [CFPhysio.com](http://CFPhysio.com)

The descriptions of the techniques and the evidence underpinning them are based on the IPG/CF Blue Booklet available on the ECFS website. Brenda Button, Ruth Dentice and Jamie Wood, all IPG/CF accredited instructors, have been involved in the development of the programs and continue as members of the Education Committee associated with the not for profit organisation of CFPhysio Inc., the organisation supporting these programs.

Experienced physiotherapists from around Australia and New Zealand have been involved in making demonstration videos together with children and adults with CF and their carers. [CFPhysio.com](http://CFPhysio.com) has been endorsed by the Thoracic Society of Australia and New Zealand as well as the Australian Physiotherapy Association. The educational platform is free of charge and a useful educational tool for physiotherapy students and respiratory physiotherapists working with people with CF as well as people with CF and their carers. To access these educational packages on Airway Clearance Techniques go to [CFPhysio.com](http://CFPhysio.com).

### **Annual report 2020/2021 from Netherlands**

The NWFCF ( Dutch Workinggroup of Physiotherapists, working in Cystic Fibrosis-Centres) is a group of 23 physiotherapists and one researcher and a representative of the Dutch patient association.

The chairman of the group is W. Doeleman. Our members are working in the following CF Centre:



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### **CF Centre Utrecht**

W. Doeleman and M. Burghard: adults 303 patients  
E. Hulzebos, M. Sprong: children 143 patients

### **CF Centre Amsterdam**

M Bergsma : adults 125 patients  
R. de Vries, D. Cornelissen, V. Schaaf: children 101 patients

### **CF Centre Groningen**

CY Timmer: adults 86 patients  
Y. van der Velde: children 64 patients

### **CF Centre den Haag**

L. Albeda, F. Kastelein, B. van der Heijden: adults 197 patients  
K. Burggraaf: children 53 patients

### **CF Centre Rotterdam**

S. Jongenotter : adults 153 patiënts  
L.J. vanderGiessen: children 137 patients

### **CF Centre Maastricht**

R Marcellis: adults 52  
J. Schellings, Y Crijns: children 28

### **CF Centre Nijmegen**

M. Salemans, S Lasche: adults 61 patients  
M. Brienne, L. van Vlimmeren: children 82 patients

Last year the group reached consensus on the practical implications of the New Quality standards. We presented our opinions during a lifestream symposium hosted by the Dutch patient association (NCFS). In the following years we will monitor the patients who started treatment with the new CF modulators and adjust our care where needed.

Planned events for the near future are: To organize a national symposium for primary care physiotherapists. Also creating educational sessions inside our own group and network. As a group we want to further optimize and standardize our clinical measuring strategies.

### **Annual report 2020/2021 from United Kingdom**

The 2019 annual UK CF Registry reports 3966 patients <16 years of age and 6104 patients ≥ 16 years received care within 26 specialist adult centres, 31 specialist paediatric centres and 65 smaller paediatric network centres (overseen by the paediatric specialist centres).



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The Association of Chartered Physiotherapists in CF (ACPCF) currently has 265 individual members and 11 departmental memberships.

Communication within the group has continued online during the Covid 19 pandemic which included a successful virtual study event held over 2 days in March 2021. This hosted international speakers covering a wide variety of topics including CFTR modulation, long term outcome measures, exercise capacity, management of pregnancy, cough as an aerosol generating procedure, adherence and feedback from meeting and training programmes.

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!  
Have a beautiful rest of the summer!

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



## CFIRG IPG/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
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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



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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.