



NEWSLETTER 3, 2017

INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

Welcome to our third IPG/CF newsletter for 2017. It was great to see so many of you in Sevilla.

I extend my apologies for the delay in distribution of this edition due to the slow submission of annual reports by country contacts. Thank you to the country contacts who submitted an annual report. The number of submitted reports is 11 of the 55 member countries represented thus far. We had 2 prior to the AGM and now have 9 further included in this Newsletter. We would still be delighted to include more in our next newsletter.

This years AGM showed a lot of changes. Firstly, Helens period as Chair person ran out and Cecilia took over. We would like to thank Helen for her sedulously work within the group in the last years. Her heartily nature always encouraged our motivation to enhance the work in the IPG/CF!

One left and another one is joining the board – we are glad to welcome Marta Kerstan our newly elected IPG/CF Vice-Chair!

For research reasons Maggie McIlwaine was elected as contact person. Please do not hesitate to contact her if you have any questions!

We also welcome Maggie McIlwaine and Helen Parrott as our latest alumni members!

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

As always we welcome your feedback and input. Enjoy.

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Marlies Wagner, MSc (marlies.wagner@medunigraz.at)

IPG/CF Secretary

IPGCF CONTACT LIST FOR MEMBER COUNTRIES

Below is the current contact list as of end May 2017. Countries in **red** are still lacking an active contact person. We are happy to hear of email updates or alternatives for inactive red countries if you have suggestions. In summary there are .. member countries with .. actively responding to email currently.

Country	Contact	Email
Argentina:	Patricia Ratto	patricianancyratto@gmail.com
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Austria:	Marlies Wagner	marlies.wagner@medunigraz.at
Bangladesh:	Md.Abdullah Al-Mamun	abdullah15ca@yahoo.ca
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Canada:	Nancy Alarie	nancy.alarie@muhc.mcgill.ca
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Chile:	M. Alejandra Vila Irarrazavel	
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Helen Parrott	H.Parrott@rbht.nhs.uk

A warm welcome to our new Alumnimember Maggie McIlwaine and Helen Parrott!



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

Sevilla, Wednesday, 7th June 2017, from 12:30 to 14:00

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

Helen Parrott, IPG/CF Chairperson opened the meeting by welcoming everyone.

Introduction of the board:

Cecilia Rodriguez, Vice-Chair

Marlies Wagner, Secretary

Peter Suter, Treasurer

1. IPG/CF contact persons were asked to stand and introduce themselves. AGM was attended by 13 CP from Australia, Austria, Belgium, Canada, Czech Republic, Denmark, France, Germany, Ireland, Norway, Portugal, Sweden, Switzerland, and UK.
2. IPG/CF Board received 1 proxy: Czech Republic
3. AGM was attended by one Alumni member and 32 guests.

Thus there were 13 contact members present and 1 proxy. This represented a quorum of current active countries and the meeting was officially opened by Chairperson of the IPG/CF.

- 2) Thank you to Cecilia Rodriguez and Ana Fillipa for organizing the physio short course

- 3) Reports:

1. IPG/CF Chairpersons report – 2017

My last AGM

I have now completed my term as Chair of the IPG/CF and hand over the reins to Ceci wishing her lots of luck. I have loved being a part of this international community, responding to your emails and feedback and organising the physio content of the conference. I would like to thank the past and current board members for all of their support and helping me when I needed advice, in particular Ruth, Brenda and Irene. I wish Ceci lots of luck as chair and offer you my continued support. I am supposed to present her with the 'IPG/CF gavel' which was given to the IPG/CF by the lovely Jennifer Prior however, as it looks like a weapon, I thought it would be too risky to carry this on the plane so I will have it couriered to you!

I will also be stepping down from my role as UK country contact in January when there will be a new rep elected by the ACPFCF at their AGM. I would therefore like to now join the IPG/CF alumni and will continue responsibilities with regard to editing the blue booklet and supporting the online course.

My advice to the IPG on my departure:

- Increase your project sub-groups and engage people willing to give a bit of time – there is too much work for the conference for the board to complete whilst pushing forward projects and collaborating with others
- Regularly ask country contacts what the membership want from this international group – the survey monkey from last year was helpful in guiding us this year

- Consider how to spread the expertise further than face-face training, how can we do things differently and reach a wider audience?

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.

Airway clearance instructors course

I put a call out in the last newsletter for any interest in an airway clearance instructors course and have had quite some interest. We will be considering whether we need to run this again or if indeed we could do this differently and recruit people to assist with an online training module. We will provide more information on this soon.

IPG research representative

This was a suggestion from last years' survey monkey and Maggie McIlwaine was elected by country contacts at the AGM in Seville. This idea of this role is for members to be able to access research expertise to help with writing abstracts, applying for research funding or just getting an opinion on a physio research idea. There will be more information coming up in the newsletter about how to get in touch with Maggie! Wishing you all the best for the rest of this year!

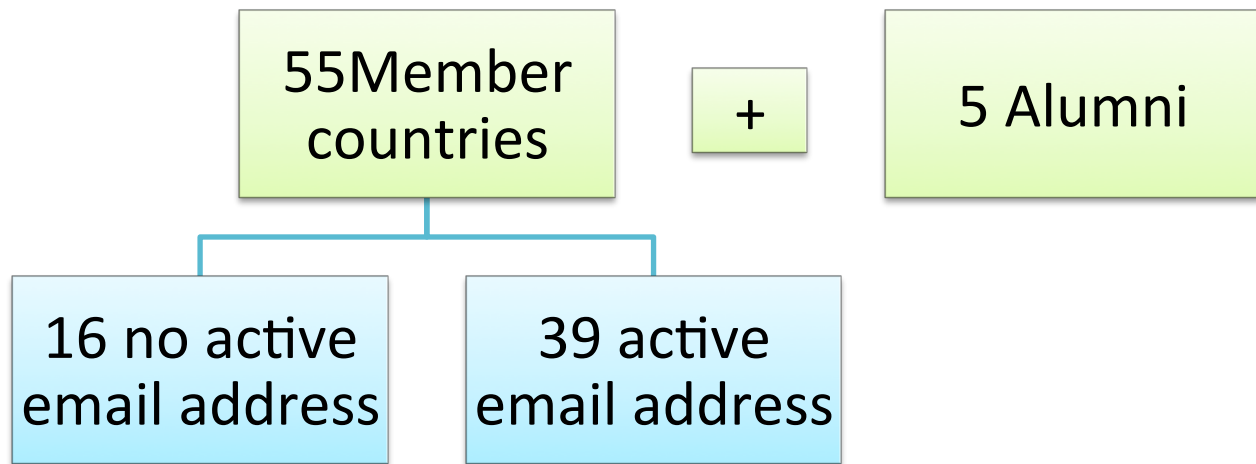
Helen Parrott
Outgoing Chairperson

2. IPG/CF Treasurer Report – 2017

Balance IPG/CF 30.06.2016 – 05.06.2017				
Description	Date	Credit EUR	Debit EUR	Balance EUR
Balance	30.06.2016			4509.56
Bank fees	30.09.2016		15.33	
Bank fees	31.12.2016		13.96	4480.27
Annual Fee Germany	08.03.2017	50.00		
Bank fees	31.03.2017		17.19	
Annual Fee Switzerland	22.05.2017	50.00		4563.08
Total	05.06.2017	4609.56	46.48	4563.08
Annual Fee paid cash at AGM NO/AUSTR/IR/ISR	07.06.2017	200.00		4763.08

3. IPG/CF Secretary Report June 2017

Marlies Wagner, the IPG/CF Secretary informed in her report that IPG/CF had 39 active member countries of the 55 members.



Two newsletters had been circulated this year prior to the AGM.

Annual country reports were submitted by 4 country contacts (till now): Austria, Belgium, Germany and Sweden

4) Elect of new Vice-Chair

Cecilia Rodriguez Hortal was welcomed as incoming Chairperson.

Within the Chair report the call for a new vice chairperson was announced. One nomination (from Brenda Button and Irene Marguire) was received for the role of Vice Chair: Following a blind ballot by country contacts present, **Marta Kerstan** was unanimously elected and welcomed as IPG/CF Vice Chairperson.

5) Any other business and date of next meeting

Election of **IPG research representative**

One nomination was received for this role. Following a blind ballot by country contacts present, Maggie McIlwaine from Canada was unanimously elected and welcomed. She should be contacted for any research question - mmcilwaine@cw.bc.ca

Date of next Meeting: ECFS conference 2018, Belgrade/Serbia (day to be confirmed)

At the end of this AGM Helen expressed her sincerest thanks to all participants for active cooperation and invited them all to ECFS conference 2018 in Serbia.

IPGCF June 2016 - June 2017 ANNUAL REPORTS FOR MEMBER COUNTRIES

Annual Report from Argentina 2016 – 2017

There are 25 CF centers in Argentina with a total of 1611 patients. The main 5 centers located in Buenos Aires have 744 patients, 3 of them with 209 adults (130, 70 and 9 patients each) Most of these centers have only one physiotherapist involved in outpatient controls. All are multidisciplinary centers that work in connection with the ones dealing with adult patients in order to transfer adolescents. Last year two patients were successfully transplanted.

Pulmonary Rehabilitation Programmes are performed in three hospitals with specific assessment protocols. There is another hospital which works with inpatients doing Reconditioning Exercises during exacerbation periods and where non invasive ventilation is one of the most important tools in the treatment.

Education is carried out by each physiotherapist in their center, not only with patients and their relatives but also with their local colleagues. Most of these major centers have teaching programmes supported by the University or scientific societies and two of them have post graduate courses in Paediatrics Physiotherapy with specific training in CF. Other short courses are given in some Argentine provinces and in neighboring countries like Perú.

As regards Conferences, we have two principal societies which have assemblies of CF. Besides, there is a national Cystic Fibrosis Society which accomplished a successful conference this year where 180 physiotherapists attended lectures and workshops and where we had the highly appreciated and most welcome attendance of Cecilia Rodriguez.

Patricia Ratto, Argentina

Annual Report from Australia 2016 – 2017

The 12th Australia and New Zealand Cystic Fibrosis Conference was held in Melbourne two weeks ago. Sixty physiotherapists who work in CF in Australia and NZ attended the pre-conference course and the three day conference. The pre-conference course was titled “The Musculoskeletal management of patients with chronic lung disease”. Jane Ashbrook and Julia Taylor from the Manchester CF Unit in the UK travelled to Australia to lead the course and present at the conference and were very well received. The Metaneb and Aerobika devices are being trialed with patients in Australia and a number of case series were presented at the conference which suggest that they are useful adjuncts to our ACT tool box.

Many physiotherapists were delighted to learn firsthand from Dr Filip Van Ginderdeuren from Brussels about Autogenic Drainage (AD), Assisted AD and IPV at the two “Advanced Airway Clearance Across the Lifespan” courses run in the Perth and Melbourne in November 2016 and organised by Jamie Wood and Brenda Button who were co-presenters. This was followed by the annual “Modern Airway Clearance Course” held at the Alfred Hospital, Melbourne in April to provide in depth theoretical and practical education to post-graduate physiotherapists.

A number of Masters and Phd research degrees in CF are currently underway in Australia. Anna Middleton is investigating exercise and bone health in the CF paediatric population; Jamie Wood is researching the use of Telehealth as a way to improve outcomes in people with CF who live in remote parts of the Australian outback; Nathan Ward is studying the role of exercise in those with mild, moderate and severe lung disease; and Lisa Wilson is developing a maximal incremental step test for use in adults with CF to name a few who show cased some of their work at the recent CF conference where many also attended the update of the IPG/CF . We continue to find ways to disseminate our most recent “Physiotherapy for Cystic Fibrosis in Australia and New Zealand: A Clinical Practice Guideline” available on the TSANZ website.

Brenda Button, Melbourne/Australia

Annual report from Austria 2016-2017

There are 15 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. Presently, there are efforts to integrate 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

Annual report from Belgium 2016 – 2017

Several half day courses were organized for colleagues who are working in the field:

- De specifieke werking van medicatie bij respiratoire aandoeningen, bij kinderen en volwassenen met een link naar de respiratoire kinesitherapie.
- Het respiratoir kinesitherapeutisch bilan bij baby's en jonge kinderen.
- Het respiratoir kinesitherapeutisch bilan bij kinderen en volwassenen "Medische- en kinesitherapeutische aspecten van bronchiëctasieën".
- Interactief overleg over "Bronchiëctasieën".
- "Ademspiertraining bij Topsporters en de link naar respiratoire patiënten. De interactie tussen het diafragma en de intrinsieke heupcontrole" – Online software: "Skill-up.com" voor revalidatie en retraining programma's".
- COPD in de 1^{ste} Lijn", Welke mogelijkheden zijn er? Wat wordt er verwacht van de resp. kine en aan wat moet hij voldoen? Welke criteria?
- Different subjects on the annual conference of Bvrk/ABKR in Mechelen : march 2017
- Several local comittee meetings with general practioners, pneumologists, physiotherapists about "Respiratory physiotherapy in CF, astma, COPD and respiratory disorders. Attendance: 150 persons
- 3 lectures for parents and caregivers: Respiratory physiotherapy in CF: Attendance: 50 persons
- University of Antwerp: 240 students 3e Bach – 1^{ste} Master: Bronchial drainage en respiratory rehabilitation: theory and practice
- Studentcounseling 3e Bach – 1^{ste} en 2 Master , observational internships coaching: 2e Bach: Attendees: 10 students
- Promotor of 10 masterthesis University of Antwerp
- Member of VECQ : commission of expertise in specific training of physiotherapists: respiratoire kinesitherapie

Myriam Vreys, on behalf of IPG Belgium

Annual report from Germany 2016 – 2017

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 5 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.

Additionally, one advanced course (one week at a rehabilitation centre for CF patients) is planned for September 2017 at the clinic "Satteldüne" on the island of Amrum.

On 16th of April 2016 a one-day symposium on "New Developments in Inhalation Therapy" was realized in Köln. About 60 Physiotherapists and other CF professionals attended the event. This symposium was already realised in September 2014 in Berlin and due to the great response this symposium will be repeated again on May 5th 2018 in München.

Jovita Zerlik, Hamburg/Germany

Annual report from Israel 2016 – 2017

There are 680 people diagnosed with cystic fibrosis (CF) in Israel.

There are six CF centers with about 120 members of the multidisciplinary team, including 11 physiotherapists. One transplantation center at Rabin medical center – Belinson.

There are about 200 physiotherapists and physiotherapy students who treat the patients in their home. There are more than 1.000 physiotherapists and physiotherapy students registered in the Cystic Fibrosis Foundation of Israel (CFFI).

Since 2013 all 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 manages several projects and is responsible for and:

- 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.
- Families gathering about physiotherapy. The CFFI believes in the importance of the family's knowledge for their children.
- Yearly recruiting of therapists from all classes of physiotherapy in the country.
- Financial assistance to patients.
- Free subscriptions to gyms for patients, surfing classes, providing treadmill to the patients homes, and more sports activity.

Eynav Manor, Haifa/Israel

Annual report from Italy 2016 – 2017

The Italian physiotherapy group for CF (Gruppo Italiano Fisioterapisti Fibrosi Cistica (GIFT/FC)) is composed by Simone Gambazza (coordinator), Anna Brivio (secretary) and me (contact person in IPG/CF), as elected in November 2016. The group includes about a hundred of physiotherapists from Italian CF Centres and it is part of SIFC (Società Italiana per lo Studio della Fibrosi Cistica). SIFC organizes an annual meeting course and one conference; the participation in society activities requires an annual fee for membership.

Some physiotherapists are also members of ARIR (Associazione Riabilitatori dell'Insufficienza Respiratoria) and AIFI (Associazione Italiana Fisioterapisti).

Projects 2016:

- Creation of multicenter study on 6MWT in CF children
- Creation of a document on exercise and training in CF children, adolescents, adults and patients after lung transplantation, in order to even activities in the different Centers
- Join in multidisciplinary group for lung transplant management
- Join in multidisciplinary group for the study of adherence
- Sustaining adherence to antibiotic treatment through a multicenter physiotherapist supervised program at home
- Critical review of CF guidelines

Education 2016:

- Organization of national annual meetings promoted by SIFC
- ECFS Conference attendance in Seville
- Literature review on pulmonary rehabilitation after lung transplantation

Projects 2017:

- Multicenter study on 6MWT in CF children
- Standardization of treatment of patients with CF before and after lung transplantation: development of a document for their rehabilitation by a group of experts in CF and lung transplantation
- Publication of the Core Competence of CF Italian Physiotherapist written by a group of senior CF physiotherapists
- Development of a multicenter study on new therapies (Orkambi, Kalydeco,...)
- Creation of a group for the study of urinary incontinence

Education 2017:

- Symposia on urinary incontinence at national annual meeting
- ECFS and NAFC Conferences attendance

Clizia Cazzarolli, Verona/Italy

Annual report from Norway 2016 – 2017

In Norway there are about 350 persons with CF, of which more than 60 % are adults. Norway has had Newborn screening since 2012.

The National working group consists of 15 Physiotherapists working with children and/or adults with CF in the specialist health care, and in cooperation with Physiotherapists in the primary health services. One Physiotherapist is the head of the professional council in the patient association (M.L.Veie). Main activities in the group have been:

- National video meeting December 6th 2016. 14 members of the group participated. Main topics were: Expectations regarding cooperation and patient follow-up, Specific Cough Technique, and reports from Basel and Stockholm.
- Written contribution to the Swiss Working group. Visions and thoughts on CF-treatment: "Physiotherapy in CF– the Future".
- Scandinavian meeting in Stockholm in September 2016: Five physiotherapists from Norway participated in the meeting.
- ECFC Seville June 2017: Five Physiotherapists from Norway participated in the pre-conference course and the conference. Two Physiotherapists presented their posters (M. Larsen and M.v.Weelie).

Other activities (S. Gursli):

- Two days National course for physiotherapists on Newborn screening (NBS) and newly diagnosed CF. Five day's interdisciplinary course for families with newly diagnosed children with CF after NBS.

- The Norwegian working model in Physiotherapy for the follow up of newly diagnosed children. Seminar and clinical practice. Pilot project on training, practical review and guidance. Cooperation between the Norwegian Resource Centre for Cystic Fibrosis/Oslo University Hospital and Haukeland University Hospital in Bergen.
- IPG/CF – related work: The National Contact Person has continued with leading the work updating the IPG/CF Glossary and contributed with work regarding the Blue Booklet, i.e. revised text concerning the Specific Cough Technique and comments concerning other topics.
- Publication of article March 2017: Gursli S, Sandvik L, Bakkeheim E, Skrede B, Stuge B. Evaluation of a novel technique in airway clearance therapy – Specific Cough Technique (SCT) in cystic fibrosis: A pilot study of a series of N-of-1 randomized controlled trials. *SAGE Open Medicine* 2017; 5:1-8.
- Participation on the annual Nordic CF Masterclass in Stockholm May 2017.

Events coming up:

- Patient association: Contribution on their annual weekend; Respiratory Physiotherapy in CF – age and milestones, inhalation therapy and equipment – choice and order (S. Gursli). Presenting the project: Cardiorespiratory fitness and physical activity among Norwegian adolescents with cystic fibrosis (M. Larsen).
- Meeting with the National group and the Scandinavian meeting for Physiotherapists in Oslo in September.
- Participation in ECFC Belgrade in June 2018.

Sandra Gursli, Oslo/Norway

Annual report from Poland 2016 – 2017

In Poland organizational structure providing care to CF patients consist of 4 main pediatric CF-centers and 11 district centers. There are also 3 adult CF-centers. All the centers take care of a total about 1700 CF patients of which about 700 are adults patients.

At present the group of twenty physiotherapists from main cystic fibrosis centers is active within Polish Cystic Fibrosis Society. The others 20 physiotherapists take carry home physiotherapy for CF patients and they do not belong to the Society.

As usually physiotherapists participated actively in annual Polish Society Conference held in newly created center of Cystic Fibrosis in Dziekanów near Warsaw in September. As well the physiotherapists were actively involved in the Annual Conference for patients with CF and their parents organized by MATIO Foundation and in the Annual Meeting of Polish Society Against Cystic Fibrosis. The practice physiotherapy workshops for patients and parents were organized during this conference.

Recently updated CF standards of Care by ECFS were translated on polish with experts comments adequate to local situation. The comments also addressed the organizational structure of physiotherapy in Poland.

Teresa Orlik, Warsaw/Poland

Annual report from Sweden 2016 – 2017

There are currently 4 centers with totally 670 patients with CF in Sweden; the majority (60-65%) are adults (>18years).

1) Projects:

- “Our future”: This project continues. To get involved the young patients (8-16 years) more in the treatment of their disease. Staff members and the patients have met through videoconferences (via Skype), where have listened and discussed the disease, treatment, and future.
- “Genia”: The other project has been the App “Genia”. The goal with this App is to give the patients a better control over the disease, and to have an easy way to submit data to a register ahead of a visit to the clinic.

The last update is a new function called: "Under the meeting " where we, together with the patient summarized what we have discussed during the meeting.

2) Education:

- Within the country there have been education opportunities for patients and parents at the centers.
- National educational days for the staff members at Uppsala.
- National meeting or videoconference (once a month) where physiotherapist working with children and patients discuss about different topics.
- Two physiotherapists arranged a recreational week in Mallorca for teenagers.

3) Conference:

- Some of the physiotherapists will attend the ECFS Sevilla 2017 with oral and poster presentation. Some attended the NACFS Orlando 2016 conferences, with and without own presentations.
 - Nordic meeting in Stockholm, Sweden in September 2016 for physiotherapist working with CF.
- Bacteriology, physiotherapy from the diagnosis, inhalation therapy followed by discussions, treatment differences and similarities in our countries.

Cecilia Rodriguez-Hortal, Stockholm/Sweden

Annual report from UK 2016 – 2017

The UK CF Physiotherapists group (ACPCF) currently has 227 members. They run an annual 2 day study event which is attended by approximately half of the membership and showcases a mix of new research, feedback from conference and speaker presentations. The ACPCF has been focusing this year on a number of different projects. A huge achievement this year is the publication of the updated 'standards of care and good clinical practice for the physiotherapy management of cystic fibrosis' on 25th April. This document replaces the 2011 predecessor with some additional chapters. Other projects include airway clearance leaflets and videos for people with CF and their carers, a new database of the UK centres and their contacts and a CF physio training fellowship with the CF trust. The UK group will be electing a new UK country contact in January as Helen Parrott steps down from this role.

Helen Parrott, London/UK

IPGCF TREASURERS REPORT SEPTEMBER 2017

Attention:

Where are the countries who can also pay the Annual Fee?



Dear Members of the IPG/CF,
Dear Country Contact Persons,

The IPG/CF has 55 member countries with 39 actively responding. From these 39 countries eight (!) have paid the Annual Fee in 2017: UK, Ireland, Germany, Australia, Norway, Switzerland, Israel and Sweden. Indeed not a very high quota!

Although, we are aware that not all member countries are financially equally strong, I would like to ask you to ask in your organization whether it would be possible for your country to pay the 50 Euro Annual Fee.

What is the money needed for?

Mainly for speakers at the CF-Conference, who are not funded by the Organizing Committee, special occasions, such as last year's 20th Anniversary of the IPG/CF and bank fees.

The IPG/CF Board works voluntarily. No Salary or expenses are paid to them.

Thanks for talking to your responsible persons about this issue.

The balance of the IPG/CF on August 31, 2017 was 3543.65 Euro.

Kind regards,

Peter Suter

IPG/CF Treasurer Peter.Suter@usb.ch

Payment to the IPG/CF bank account. Bank details are as follows:

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** (several years at once is possible) you are paying e.g.

Switzerland 2017

Please feel free to provide feedback and forward your suggestions or content to the IPG/CF secretary - Marlies.Wagner@medunigraz.at Distribute this widely, and enjoy!