



NEWSLETTER 3,2016

INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

Welcome to our third IPG/CF newsletter for 2016.

Thank you to the country contacts who submitted an annual report. We had 7 prior to the AGM and now have 14 included in this Newsletter. Would still be delighted to include more in our next newsletter. This newsletter includes the minutes of the AGM 2016 in Basel. It includes the reports of the chairperson, the treasurer, and the secretary as well as a brief research update.

Further, there have been a few changes on the board: Jennifer Agnew (Vice Chair) submitted her resignation and Ruth Dentice (Secretary) left the board after 3 years of amazing work for the IPG/CF. Thank you very much for your fantastic input and never ending patience, and for bringing in new spirit.

Two new members were elected: Cecilia Rodriguez Hortal as the new Vice Chair, and myself as new Secretary.

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.

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 2016. 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 55 member countries with 33 actively responding to email currently.

Country	Contact	Email
Argentina:	Patricia Ratto	patriciaratto@hotmail.com
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Belgium:	Myriam Vreys	myriam.vreys@uzleuven.be
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Canada:	Maggie McIlwaine	mmcilwaine@cw.bc.ca (new update contact)
Cayman Islands:	Zillah Isaac	zillah.isaacs@gov.ky
Chile:	M. Alejandra Vila Irarrazavel	
Colombia:	Janeth Buendia Algeria	
Costa Rica:	Rodolfo . A . Bonilla Abarca	rhbonilla@yahoo.com
Croatia:	Anja Kladar	anja.kladar@gmail.com
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Czech Republic:	Libuse Smolikova	libuse.smolikova@email.cz (updated email)
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Greece:	Kostas Katsoulakis	katsoul@freemail.gr
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India:	Sumita Gupta	bisoia@rediffmail.com
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Italy:	Giulia Mamprin	gmamprin@ulss.tv.it
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Macedonia:	Minola Paunovska	oliverdod@gmail.com (new)
Mexico:	Zoila Popper	amfmx@mexis.com
New Zealand:	Rebecca Scoones	RScoones@adhb.govt.nz
Norway:	Sandra Gursli	sangur@ous-hf.no
Oman:	Kamla Al-Qasbi	kaq83@yahoo.com
Palestine:	Amal Nassar	amal.nassar@crb-mail.org
Panama:	Gherson Cukier	gcukier@chiriqui.com
Poland:	Teresa Orlik	zaklad.usprawnień@imid.med.pl
Portugal:	Filipe Prospero	filipe_prospero@yahoo.com
Romania:	Bogdan Almaja-Guta	bogdisport@yahoo.com
Russia:	Dr. Anna Tomilova	tomilova@nczd.ru
Saudi Arabia:	Tareq M Aref Hussein	web_rcs@shrc.edu.sa
Slovakia:	Marta Heroutová	fyzio.pp@falck.sk ; heroutovi@sudtarch.sk .
South Africa:	Brenda Morrow	bmorrowstaffchrxhuct@mail.uct.ac.za
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UAE:	Saeid Rahbar Soureh	saeed849@yahoo.com
UK:	Helen Parrott	H.Parrott@rbht.nhs.uk
Uruguay:	Kitty Löwensberg	kittylowensberg@movinet.com.uy
USA:	Eilbacher, Jaime	EILBACHER@email.chop.edu

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Name	Email
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Esta Tannenbaum	esta.tannenbaum@rch.org.au (new)
Ruth Dentice	Ruth.dentice@sswahs.nsw.gov.au (new)



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

Basel, Wednesday, 8th June 2015, 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 and introducing the IPG/CF Board: Peter Suter (Treasurer) and Ruth Dentice (Secretary). Jennifer Agnew (Vice-chairperson) was an apology for the meeting.

1. IPG/CF contact persons were asked to stand and introduce themselves. AGM was attended by 12 CP from Australia, Canada, Czech Republic, Germany, Ireland, Isreal, Italy, Norway, Poland, Sweden, Switerland, and UK.
2. IPG/CF Board recieved 2 proxies:Austria, Greece.
3. AGM was attended by one Alumni member and 37 guests. One previously inactive country had representation present and agreed to be a new country contact for Macedonia

Thus there were 13 contact members present and 2 proxies. This represented a quorum of current active countries and the meeting was officially opened by Chairperson of the IPG/CF.

2) Minutes of the AGM in Brussels, June 2015 were passed (Maggie M, Irene M .)

3) Reports:

1. IPG/CF Chairpersons report - 2016 Helen Parrott

I would firstly like to formally welcome our new members of the board, Cecilia Rodriguez Hortal as vice chair and Marlies Wagner as our new secretary elected at the AGM in Basel. Thank you to those of you who attended the AGM and voted for these appointments - this is an essential part of keeping this group going. Cecilia and Marlies - I am thoroughly looking forward to working with you in my last year as chair and in preparing for the ECFC in Seville.

Goodbye.....or is it?!

Sadly, after a period away from work, our vice chair Jennifer informed us she is retiring from her role. We wish her well and thank her for her joining us for a short while.

After 3 years on the board, It was also time for us to say goodbye to our secretary, Ruth Dentice. Ruth has been a driving force in keeping us all connected by writing our regular newsletter, trying to identify areas which are missing country contacts and promoting research and good practice - we will miss you! I know Ruth is very supportive of the work of the IPG/CF and is a fantastic airway clearance instructor so I don't think this is the last we will see of her!

This year in Basel.....

Thank you to both our speakers and all attendees of the pre-conference course - 'Airway clearance - the foundations and the evidence'. There was some excellent discussion and debate over the 1.5 days and I would like to thank everyone involved in making this a really interesting airway clearance course based on presentations from the past, present and future. What a great opportunity to share international practice. Thank you to Marta Kerstan, Peter Suter and the Swiss physio group for devising such a stimulating programme. If you haven't yet done so, please give us your feedback via the following online survey

<https://www.surveymonkey.co.uk/r/IPGCFsurvey>

Thank you also to friends of the IPG and past and present board members in moderating and facilitating workshops, case presentation sessions and symposiums in Basel. The commitment and preparation required in your own time no doubt, is much appreciated. We have been commended for the strength of the physiotherapy content and I am incredibly proud of what has been achieved.

Next years ECFC.....

Thank you to those of you who filled in the online survey via survey monkey in the lead up to the conference asking for suggestions for the preconference course. We have collated this information and have already started discussing next years ECFC physiotherapy content.

Please look out in future newsletters as we may ask for comments, suggestions or speakers.

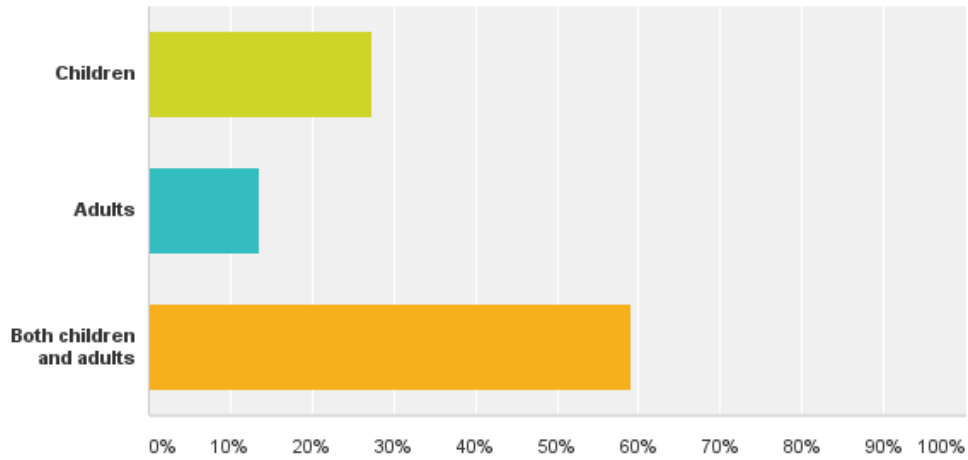
Preparing the content for the ECFC takes a lot of the boards time and I suggested at the AGM that the IPG/CF consider taking on a little extra help with the theme and finding suitable speakers, arranging catering with ECFC etc. So for the next conference in Seville, we now have a small working group for the pre conference course which will be led by Cecilia as vice chair and a second group led by me which will arrange the rest of the conference content. We will be in touch when we have more information to share.

IPG/CF members survey

As presented at the AGM - here are the results of the online survey which was sent prior to the conference in Brussels to get your views, 22 of the membership responded:

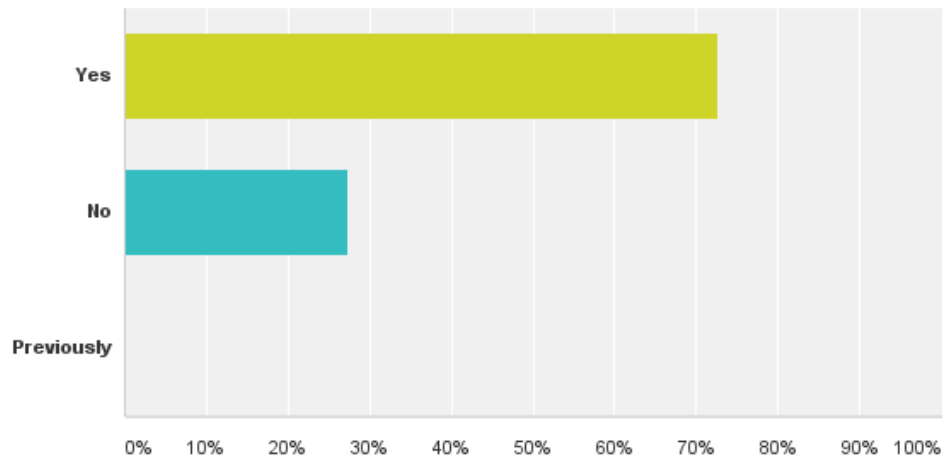
Q1 Which patient group do you currently work with?

Answered: 22 Skipped: 0



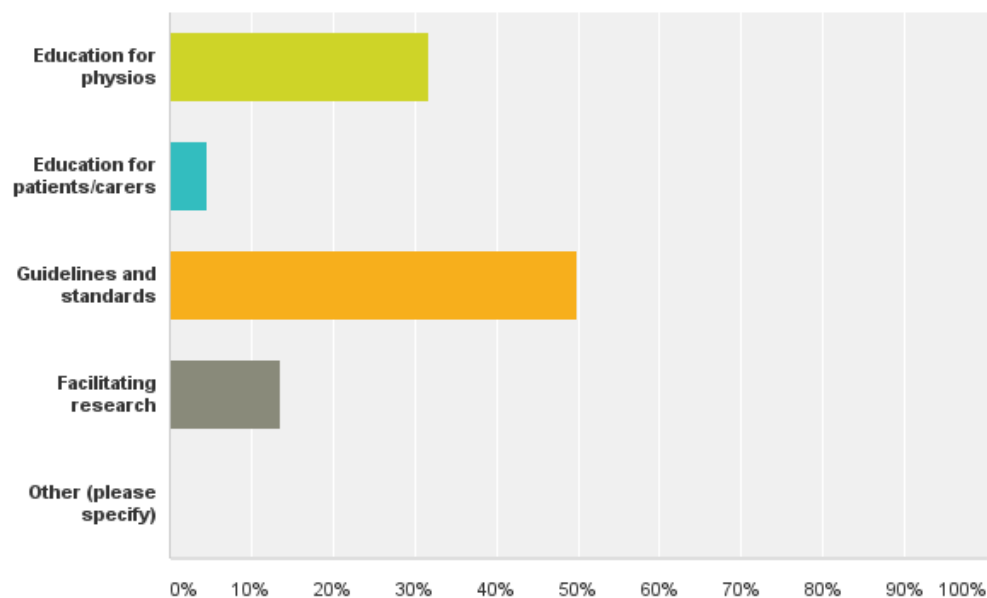
Q2 Are you a country contact person?

Answered: 22 Skipped: 0



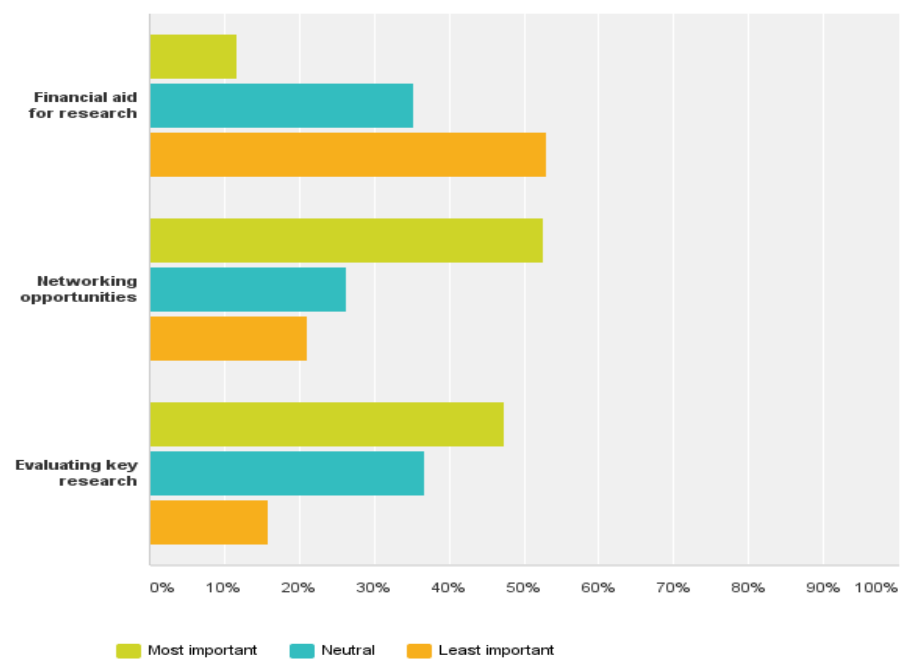
Q3 If you could pick one area for the IPG/CF to focus on in 2016, what would it be?

Answered: 22 Skipped: 0



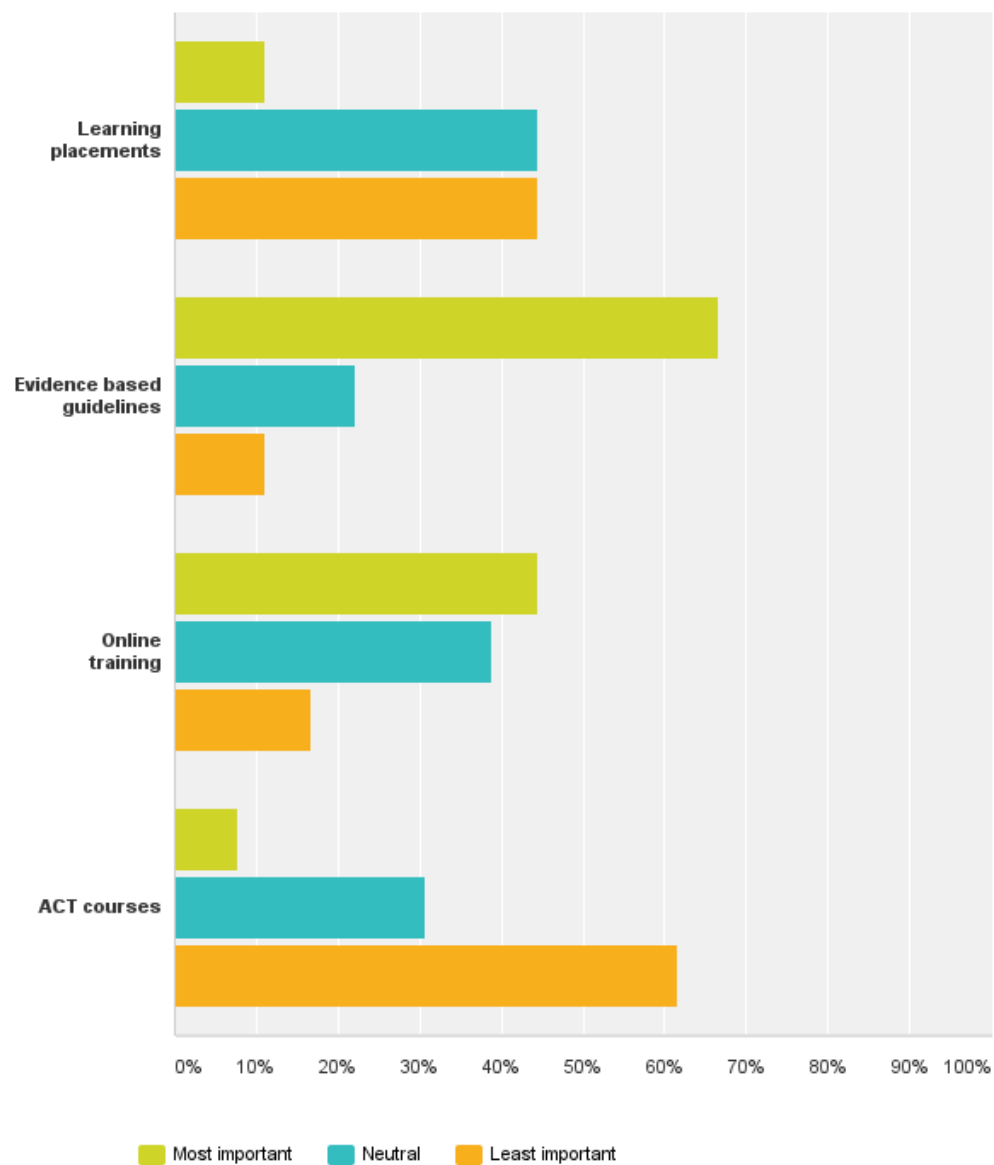
Q4 How would you rate the importance of the following IPG/CF research activities?

Answered: 21 Skipped: 1



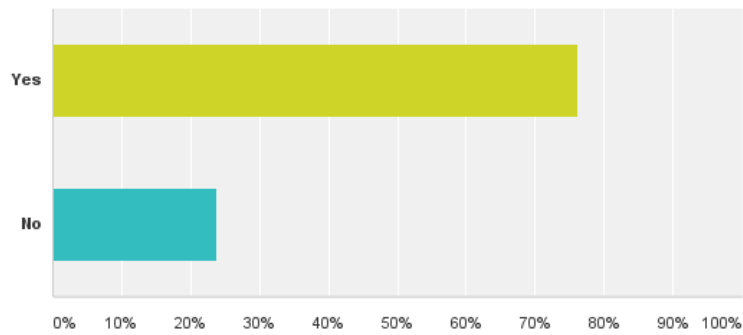
Q5 How would you rate the importance of the following IPG/CF education activities?

Answered: 22 Skipped: 0



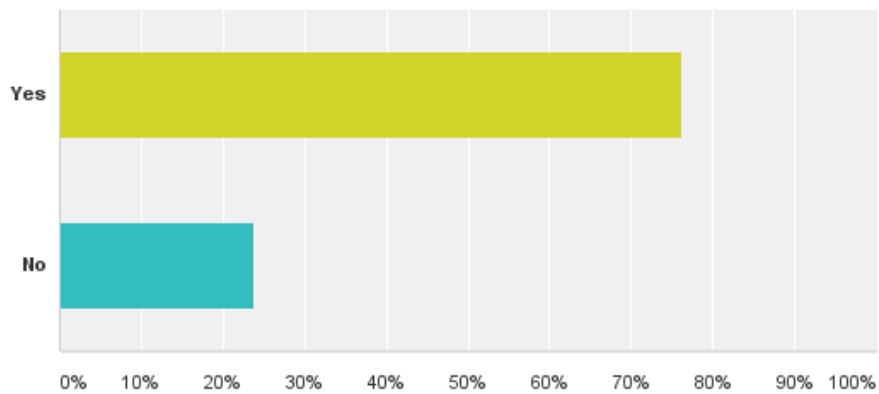
Q9 If there was help available in writing an abstract or case presentation from the IPG would you use this service?

Answered: 21 Skipped: 1



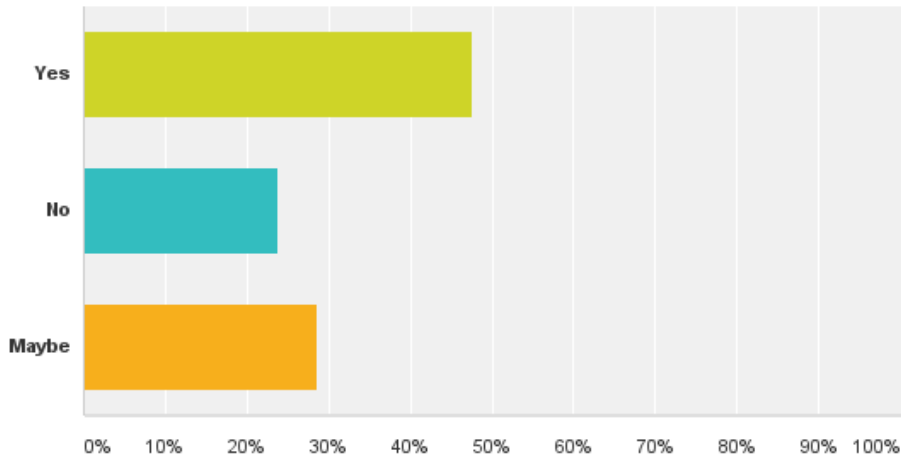
Q9 If there was help available in writing an abstract or case presentation from the IPG would you use this service?

Answered: 21 Skipped: 1



Q11 Would you be interested in joining the IPG/CF board in the future?

Answered: 21 Skipped: 1



The action points from this survey that I will take forward this year are:

- Appointing a research representative of the IPG/CF who can provide assistance to members in abstract writing and developing research streams
- Raise awareness among the membership of new physiotherapy related published guidance and key research studies via the newsletter
- We also discussed financial assistance for board members from the IPG/CF who are unable to attend the European conference or are using personal funds to do so. The board felt that without this option, people may be discouraged from volunteering for vacant board positions and that there was sufficient funds to support board attendance and meeting if needed

I look forward to working with you all this year!
Happy summer holidays
Helen

2. IPG/CF Treasurer Report June 2016

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

The following countries have paid the annual Fee:
Germany, England, Switzerland, Czech Republik, Australia, Italia, Norway, France, Ireland, Greece

For those who still want to pay, here are the IPG/CF bank account details:

Bank Name: Credit Suisse 8070 Zürich

Address: cf-physio.ch, Scheuermattweg 21, 3007 Bern, Switzerland

IBAN: CH51 0492 5162 5621 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. *Switzerland 2016*

You will receive a receipt.

The balance of the IPG/CF on June 30 2016 is 4509.56 Euro.

Thank you very much for your cooperation. If you need information or have a question don't hesitate to contact me.

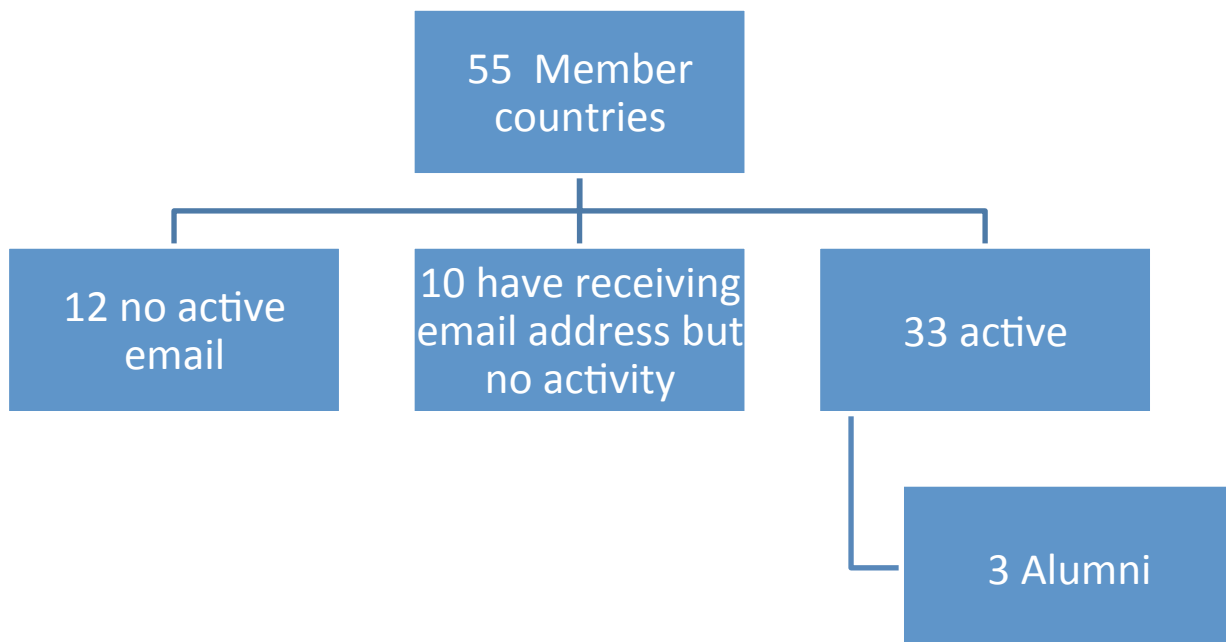
Kind regards,

Peter Suter

IPG/CF Treasurer Peter.Suter@usb.ch

3. IPG/CF Secretary Report June 2016

Ruth Dentice, the IPG/CF Secretary informed in her report that IPG/CF had 33 active member countries of the 55 members.



Two Newsletters had been circulated this year prior to the AGM with a further two planned. Annual country reports were submitted by 7 country contacts prior to the AGM: Austria, Belgium, Brazil Greece, Italy, Poland and Sweden. It is planned they will be circulated in the third newsletter due for circulation in August. (12 were recieved last AGM).

Ruth thanked the board and country contacts for a fantastic time serving as their Secretary (and enduring all the nagging). Ruth will support the incomming secretary and join the Alumni as a past board member.

- 4) New alumni members
Esta Tannenbaum was welcomed as our third alumni member
- 5) ECFS special interest group application
Within this discussion Maggie McIlwaine presented the results of her survey regarding physiotherapy practice in infants (19 responses from 16 hospitals). It was agreed the interested parties would meet the following day at 12.30 to discuss future plans.
- 6) Future capacity of the IPG - discussion and ideas. See Chairperson report.
- 7) Glossary and blue booklet updates
Sandra Gursli updated the group regarding the latest Glossary update. Irene Maguire updated the attendees regarding the blue booklet
- 8) Elect of new secretary
One nomination was received for the role of Secretary: Following a blind ballot by country contacts present, Marlies Wagner was unanimously elected and welcomed as IPG/CF Secretary
- 9) Any other business and date of next meeting
Within the Chair report the call for a new vice chairperson was announced. One nomination was received for the role of Vice Chair: Following a blind ballot by country contacts present, Cecilia Rodriguez Hortal was unanimously elected and welcomed as IPG/CF Vice Chairperson
- 10) Anniversary speech and toast.
The 30th Anniversary of the formation of the IPG/CF was celebrated with a presentation by Liliane Heidet (one of our founders in 1986)



Date of next Meeting: ECFS conference 2017, Spain (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 2017 in Spain.

*Prepared by HELEN PARROTT and Ruth Dentice,
IPG/CF Chairperson and Secretary June 2016*

IPGCF NEW BOARD MEMBERS

Our new Vice Chair: Cecilia Rodriguez

I specialised in respiratory care early in my career as a physiotherapist and have been working at Karolinska University Hospital in Stockholm since 2005 as a CF physiotherapist. I have been working in paediatric care and with adults with cystic fibrosis. My special interest is in advanced disease, Non-invasive ventilation and physical training.

Other than CF, I love sports!

I want to share knowledge, discuss and improve our clinical practices.

I look forward working together with you.



Our new Secretary: Marlies Wagner

Marlies has been working as a chest physiotherapist in the Division of Paediatric Pulmonology and Allergology, Department of Paediatrics and Adolescent Medicine, Medical University of Graz/Austria for more than 20 years. Her clinical expertise is in respiratory disorders with a special interest in cystic fibrosis (children & adults).

For the last two years she has been chairing the Working Group for Cardiorespiratory Physiotherapy of the Austrian Society of Pneumology.

She co-authored a couple of papers and is an active collaborator of ongoing studies, including ACTIVATE-CF. In addition, she is a lecturer in basic respiratory education for students in physiotherapy.



IPGCF June 2015-June 2016 ANNUAL REPORTS FOR MEMBER COUNTRIES

Annual report from Argentina 2015-2016

In Buenos Aires there are four main centres with 631 patients. Three of these, are paediatric centres with 11% of patients younger than two years. There is one adult centre with 91 patients. Most centres have one or two physiotherapists involved with care of both in and outpatients. There are 30 patients who have been transferred to adult centres, there are also 10 patients who have been successfully transplanted. Pulmonary Rehabilitation is performed in two paediatric hospitals and in the third one a Reconditioning Exercise Programme.

Related to *education*, during 2015 there were 4 multicentre meetings. Since 2011 there is an Argentine Association of CF, which organize a Meeting every two years, where Physiotherapist lectures usually take place. In the last 2015 Congress more than 70 physiotherapists had participated and there were different workshops for physiotherapists and parents. The next national conference will be held in April 2017.

Different types of courses are given, for parents with small babies, for colleagues in all the country's province's, and similarly in neighbouring countries like Peru. In the same manner there are conferences and training for university students in our hospital.

Our *plan* is to try improve the contact with the rest of the physiotherapists who work with cystic fibrosis patients in the rest of our country and to continue teaching parents.

Marcela Baldoni and Patricia Ratto

Annual report from Austria 2015-2016

In Austria there are presently 15 CF-centres, which care for around 850 CF-patients. More than 50% of the patients are already adults, however, there are still only 5 designated adult centres, 3 of the 10 paediatric centres also care for adult patients so far. An increasing number of people with CF had an organ transplantation, most of them received lungs, a few received liver, kidney or a combination of two organs. The majority of transplantations are performed in one of two transplantation centres and most of the patients receive their further CF-care within the multidisciplinary setting of these centres.

In Austria the CF-centres are incorporated in pulmonary departments, therefore the 30 – 35 physiotherapists treating CF-patients also care for patients with other respiratory diseases. Hence the PT-working group of the Austrian Society of Pneumology is home for all physiotherapists dealing with cardiorespiratory patients in the paediatric, adult, surgical, intensive care, as well as rehabilitative setting. The group is usually very active in raising the general standard of cardiorespiratory physiotherapy in Austria.

During the recent year the activities have been somewhat more modest, members of the group:

- Participated in a CF-experts meeting
- Contributed actively with lectures to the programme of the experts meeting, the Annual Conference of the Austrian Society of Pneumology and the Annual Meeting of the CF-lay group
- Promoted specific hygiene guidelines for CF-physiotherapy treatment situations
- Beyond the scientific contributions, the specialised physiotherapists were again very active in teaching and training less experienced physiotherapists in all aspects of CF

Best wishes

Beatrice Oberwaldner, April 2016 E-mail: beatrice.oberwaldner@medunigraz.at; oberbeat@gmail.com;

Annual report from Belgium 2015-2016

IPG-CF/Belgium: half day course on Saturday for colleagues who are working in the field:

- 24/10/15: Devices For bronchial drainage: theory and practice: Attendance: 60 colleagues
- 30/1/2016: Respiratory physiotherapy in Cerebral Palsy: Attendance: 55 colleagues
- 5/3/2016: Bronchial drainage in babies: Attendance: 150 colleagues
- 27/4/2016: Praktical update on Cystic Fibrosis anno 2016: Attendance: 50 colleagues

- Several local committee meetings with general practitioners, pneumologists, physiotherapists about "Respiratory physiotherapy in CF, asthma, COPD and respiratory disorders: Attendance: 100 persons
- 3 lectures for parents and caregivers: Respiratory physiotherapy in CF: Attendance: 35 persons
- Physio-clinics local: 20 attendees
- University of Antwerp: 350 students 3e Bach – 1st Master: Bronchial drainage en respiratory rehabilitation: theory and practice
- Studentcounseling 3e Bach – 1st en 2 Master, observational internships coaching: 2e Bach Attendees: 55 students
- 2 courses given by Jean Chevaillier: 1 week at the university of Barcelona and 4 days at ARIR (IPG group of Italy).

Kind regards,
Myriam Vreys
On behalf of IPG Belgium

Annual report from Brazil 2015-2016

Here in Brazil we have just two associations for exclusive attention for physiotherapy treatments for CF. The last report of Groups of Studies for CF (2012) showed we have a population of 2649 subjects with CF. So the physiotherapist treatments are done in general hospital; adults or pediatrics. Brazil has a Respiratory Physiotherapy Association for 30 years. This June will be held an International Symposium, where will have a round table about CF.

The best wishes for all
Hilda Angelica Iturriaga Jimenez

Annual report from France 2015-2016

Our physio association for CF continues to organize courses and practical workshop for parents, physio and patients to be expert of their disease
20 meetings per year in all the country
One national journey for the référent physio from the 42 CF centers in France, adult and pediatric
One National congress for CF
Three week end of courses for instructors junior and senior
Our association collaborates with pharmaceutical industry in the management of the disease and therapeutic education
We start in 2012 a plan for the accessibility of sport and rehabilitation for all all around the country
We work on studies about physio and ORL, nose, quality of Life and project of Life, so new instrumental aid for ACT

For the future I think that our priority is to help the family and patients in the country without physio and to collaborate on multicentric studies to improve the ACT for young children as soon as the diagnosis
I dream of a consensual conference on the mucus to help physiotherapy and patient in a good way of efficiency and efficacy in the respect of daily quality of Life

Best regards
Hugues gauchez.
French contact person

Annual report from Germany 2015-2016

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 at this year's annual meeting.

In this year 5 courses to qualify physiotherapists in airway clearance techniques for patients with CF and other chronic pulmonary diseases were again held in different cities in Germany.

Additionally, one advanced course (one week at a rehabilitation centre for CF patients) took place in 2015 in Tannheim/ Schwarzwald and will be repeated in October 2016 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 repeated this year.

Jovita Zerli

Annual report from Greece 2015-2016

In cooperation with the Association for Cystic Fibrosis we organised a two day course titled "Physiotherapy in Cystic Fibrosis" in Thessaloniki, 8-9th February 2016. The course instructors were Dr. Louise Lannefors and Dr. Sarah Payne, both official instructors of the IPG/CF. Thessaloniki is in northern Greece, so we took the opportunity to invite physiotherapists from FYROM and Serbia to attend the course. In total 16 Greek and 7 physiotherapists from abroad attended the course. The instructors had the opportunity to present the work and the scope of the IPG/CF.

Through the Association for Cystic Fibrosis we have managed to secure a sponsor for printing the new, upcoming edition of the IPG/CF blue booklet.

Kostas Katsoulakis

Annual report from Israel 2015-2016

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

There are seven 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 800 physiotherapists and physiotherapy students registered in the Cystic Fibrosis Foundation of Israel (CFFI).

Since 2013 all the CF patients are entitled to receive a monthly refund for the physiotherapy treatments at home from the Health care services, up to 20 € per day.

The CFFI is responsible for and manages several projects:

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 and pelvic floor treatments for CF patients.

Yearly recruiting of therapists from all classes of physiotherapy in the country.

Financial assistance to patients.

Free subscriptions to gyms for patients, surfing classes, and more sports activity.

Eynav Manor, BPT

Pediatric Pulmonary Institute and CF Center,

Rappaport Children's Hospital Rambam Health Care Campus Haifa Israel

Annual report from Italy 2015-2016

MEMBERSHIP: Italian Physiotherapy Group for CF is formed by Sara Tomezzoli (president), Anna Brivio (secretary) and me (contact person in IPG/CF); in November 2016 new members election will take place and one of our group's physiotherapists will be involved in the membership of Italian Cystic Fibrosis Society's (SIFC) board.

Our group is composed by junior and senior physiotherapists from many Italian CF Centres; our mailing list counts over an hundred contacts for communications.

Our group is part of SIFC and the society organizes an annual meeting course and a conference; participation our group's activities requires an annual fee for membership.

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

ACTIVITIES IN THE LAST YEAR (2015):

- Some members of the group created multicenter studies in the field of exercise (one about habitual physical activity and exercise performance in CF adolescents and another about 6 minutes walking test in CF children);
- a multidisciplinary group of expert CF physiotherapists has been built to create internal guidelines on exercise and training in CF children, adolescents, adults and patients after lung transplantation, in order to uniform activities in the different Centres;
- a physiotherapist from each Italian CF Centre attended to a course about autogenic drainage with Jean Chevaillier.

ACTIVITIES FOR THIS YEAR (2016):

- to participate in the European CF Conference in Basel with poster presentations;
- to translate and publish in a scientific journal the "Core Competence of CF Italian Physiotherapist" written by a group of senior CF physiotherapists;
- to build a group of expert CF and lung transplantation physiotherapists aiming to standardize the treatment of patients with CF before and after lung transplantation and drawing up some guidelines for pulmonary rehabilitation in these patients;
- to analyze data and publish the results of the multicenter study about habitual physical activity and exercise performance in CF adolescents;
- to start the new multicenter study about 6MWT in CF children.

Giulia Mamprin

Italian member in IPG/CF

Annual report from Norway 2015-2016

In Norway we have about 300 persons with CF, of which 60 % are adults. We have NBS since March 1, 2012.

The National group consists of up to 15 Physiotherapists working with children and/or adults with CF. Main activities in the group have been:

- National meeting 2016. 11 members of the group met in Oslo for two days from 14-15 March. Main topics were:
 - NBS
 - CF Patient Registry
 - New treatments
 - Inhalation therapy and equipment
 - Follow up and effective course of treatment
- Nordic meeting in Aarhus (DK) - September 2015: Seven physiotherapists from Norway (Oslo and Bergen) participated in the meeting in Denmark.

- ECFC Basel 2016: Four Physiotherapists from Norway participated in the pre-conference course and the conference.
- IPG/CF – related work: The National Contact Person has contributed with work on the update of IPG/CF Glossary as well as work regarding the Blue Booklet.

Planned events:

- Nordic meeting in Stockholm - September 2016
- Video conference – Winter 2016
- National meeting – Spring 2017
- ECFC Sevilla - June 2017

Sandra Gursli, 1st July 2016 sangur@ous-hf.no

Annual report from Poland 2015-2016

In Poland there are 4 main pediatric CF-centers and 11 district centers. There are also 3 adult CF-centers, it is not enough taking into account the growing number of adult patients. All the centers take care of a total of 1725 CF patients, of which 715 are adults patients. In Poland there are presently 2 lung transplantation centers for CF patients. The new center was established three years ago in Szczecin, and a year ago in the Polish famous cardio-pulmonary transplantation center in Zabrze created a separate branch only for patients with CF.

At present the group of twenty physiotherapists from main cystic fibrosis centers is active within Polish Cystic Fibrosis Society which unite together representatives of all professions involved in the cystic fibrosis. As usually they participated actively in Society Conference held in May in Ossa near Warsaw. 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. The practice physiotherapy workshops for patients and parents was organized during this conferences.

In Poland, unfortunately, there is no home physiotherapy for CF patients and so far there is no possibility solution to this problem of a systemic. However, this year there is the possibility of financing a home physiotherapy from other sources. 20 physiotherapists have already been trained in this realm.

Best wishes

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Contact Person for Poland
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Annual report from Sweden 2015-2016

There are 4 centers with totally 660 patients with CF in Sweden, of whom around 245 are children.

1) Projects:

- “Our future”: To get involved the young patients (8-16 yrs) more in the treatment of their disease. Staff members and the patients have met through video conferences (via Skype), where have listened and discussed the disease, treatment, and future.

“Genia”: The next 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 Stockholm and Jönköping 2015.
- National meeting or video conference (once a month) where physiotherapist working with children discuss about different topics.
- One recreational week in Mallorca for teenagers was arranged with two physiotherapists.
- Master about non invasive ventilation in CF (Charlotte Wallman Jansson).
- New publication: "Non-invasive Ventilation as Airway Clearance Technique in Cystic Fibrosis" Physiotherapy research international 2016. (Rodriguez Hortal et al).

3) Conference:

- Some of the physiotherapists attended the ECFS Basel 2015 and the NACFS Phoenix 2015 conferences, both with and without own presentations.
- Some of the physiotherapist attended the ERS-course in Prague 2015, Czech Republic "Basics in CF".
- Nordic meeting in Aarhus Denmark for physiotherapist working with CF. CPET testing on ergometer with a patient followed by discussions, treatment of urinary incontinence in children, nasal rinse, treatment differences and similarities in our countries.

Annual report from Switzerland 2015-2016

In Switzerland we have currently 12 CF centers, which look after approx. 1000 CF patients. The majority of the patients receive CF care within the multidisciplinary setting of these centers.

The Swiss Working Group for cystic fibrosis (SWGCF) is an association of physicians, therapists and scientists taking care of CF patients while being involved with scientific projects or while otherwise professionally engaged with the CF disease.

The Physiotherapy Working Group (cf-physio.ch) on the other hand provides professional information and education about physiotherapy treatment methods to both CF patients as well as health care professionals with the aim to ensure excellence in CF care to improve quality of life.

This year's activities of the cf-physio.ch have been:

- Participation in CF-expert meetings
- Educational activities:
 - Lectures at the university of applied science
 - Courses in Airway Clearance Techniques (ACT) according Jean Chevaillier in Basel, Geneva
 - ACT course with focus on babies and toddlers
- Update of the homepage (www.cf-physio.ch)
- IPG/CF:
 - Support in planning and preparation of the physiotherapy short course at the occasion of the ecfs congress in Basel
 - Blue Booklet: Revision of the oscillating PEP article

Greetings,

Marta Kerstan, July 2016 E-mail: marta.kerstan@hispeed.ch

Annual report from UK 2015-2016

The UK CF physiotherapy group (known as the ACPCF) currently has approximately 150 active members. There is a core committee which includes a chair, vice chair, secretary and treasurer and a wider committee which includes representatives from each UK region and additional posts that are invited to work on specific projects for the membership such as research and public relations.

Activities:

- Committee meets 3-4 times per year
- Regular newsletters to membership biannually
- Sponsorship provided for CF related courses and the European and North American CF conferences
- Annual 2 day study event and AGM
- Sub group of CF physiotherapy prescribers meet biannually
- Representation on significant CF related steering groups/committees such as the UK CF Trust IPG/CF country contact on the committee (currently to IPG/CF chair) to provide communication through this group

This year has been an active and happy year for the ACPCF as we have been writing the update of our UK physiotherapy guidelines which was last published in 2011. The editors have been very busy, with many members contributing to this edition which has extra sections including prescribing, critical care and end of life. It is due for publication very soon!

The annual study event in January 2016 was based around exercise and was well received with 88 members attending and presentations from Don Urquart, Judy Bradley and Penny Agent to name a few! The upcoming event in January 2017 is currently in planning stages and hopes to cover the ever changing role of the CF physiotherapist.

RESEARCH UPDATE

Selected publications from the last 12 months:

[Telehealth clinics increase access to care for adults with cystic fibrosis living in rural and remote Western Australia.](#)

Wood J, Mulrennan S, Hill K, Cecins N, Morey S, Jenkins S.
J Telemed Telecare. 2016 Jul 20. pii: 1357633X16660646. [Epub ahead of print]

[Active cycle of breathing technique for cystic fibrosis.](#)

Mckoy NA, Wilson LM, Saldanha IJ, Odelola OA, Robinson KA.
Cochrane Database Syst Rev. 2016 Jul 5;7:CD007862. [Epub ahead of print] Review.

[Listening to motivational music while walking elicits more positive affective response in patients with cystic fibrosis.](#)

Calik-Kutukcu E, Saglam M, Vardar-Yagli N, Cakmak A, Inal-Ince D, Bozdemir-Ozel C, Sonbahar-Ulu H, Arikan H, Yalcin E, Karakaya J.
Complement Ther Clin Pract. 2016 May;23:52-8. doi: 10.1016/j.ctcp.2016.03.002. Epub 2016 Mar 16.

[Short-Term Effect of Different Physical Exercises and Physiotherapy Combinations on Sputum Expectoration, Oxygen Saturation, and Lung Function in Young Patients with Cystic Fibrosis.](#)

Kriemler S, Radtke T, Christen G, Kerstan-Huber M, Hebestreit H.
Lung. 2016 Aug;194(4):659-64. doi: 10.1007/s00408-016-9888-x. Epub 2016 May 4.

[Relationship between lung function and Modified Shuttle Test performance in adult patients with cystic fibrosis: a cross-sectional, retrospective study.](#)

Doeleman WR, Takken T, Bronsveld I, Hulzebos EH.
Physiotherapy. 2016 Jun;102(2):184-8. doi: 10.1016/j.physio.2015.10.015. Epub 2015 Dec 12.

[Physiotherapy for cystic fibrosis in Australia and New Zealand: A clinical practice guideline.](#)

Button BM, Wilson C, Dentice R, Cox NS, Middleton A, Tannenbaum E, Bishop J, Cobb R, Burton K, Wood M, Moran F, Black R, Bowen S, Day R, Depiazzi J, Doiron K, Doumit M, Dwyer T, Elliot A, Fuller L, Hall K, Hutchins M, Kerr M, Lee AL, Mans C, O'Connor L, Steward R, Potter A, Rasekaba T, Scoones R, Tarrant B, Ward N, West S, White D, Wilson L, Wood J, Holland AE.
Respirology. 2016 May;21(4):656-67. doi: 10.1111/resp.12764. Epub 2016 Apr 18.

[Death after cessation of treatment by cystic fibrosis patients: An international survey of clinicians.](#)

Pisaturo M, Deppen A, Rochat I, Robinson WM, Hafen GM.
Palliat Med. 2016 Mar 15. pii: 0269216316637773. [Epub ahead of print]

[Non-invasive Ventilation as Airway Clearance Technique in Cystic Fibrosis.](#)

Rodriguez Hortal MC, Nygren-Bonnier M, Hjelte L.
Physiother Res Int. 2016 Feb 29. doi: 10.1002/pri.1667. [Epub ahead of print]

[A comparison of the six-minute walk and incremental shuttle walk tests in CF.](#)

Saglam M, Vardar-Yagli N, Savci S, Inal-Ince D, Aribas Z, Bosnak-Guclu M, Arikan H, Calik-Kutukcu E, Gunes-Yalcin E.
Pediatr Int. 2016 Jan 12. doi: 10.1111/ped.12919. [Epub ahead of print]

[Physical activity participation by adults with cystic fibrosis: An observational study.](#)

Cox NS, Alison JA, Button BM, Wilson JW, Morton JM, Holland AE.
Respirology. 2016 Apr;21(3):511-8. doi: 10.1111/resp.12719. Epub 2015 Dec 30.

[Chest physiotherapy compared to no chest physiotherapy for cystic fibrosis.](#)

Warnock L, Gates A.
Cochrane Database Syst Rev. 2015 Dec 21;(12):CD001401. doi: 10.1002/14651858.CD001401.pub3. Review.

[Inspiratory Muscle Strength and Endurance in Children and Adolescents with Cystic Fibrosis.](#)

Vendrusculo FM, Heinzmann-Filho JP, Piva TC, Marostica PJ, Donadio MV.
Respir Care. 2016 Feb;61(2):184-91. doi: 10.4187/respcare.04231. Epub 2015 Nov 24.

[Urinary incontinence in patients with cystic fibrosis.](#)

Reichman G, De Boe V, Braeckman J, Michielsen D.
Scand J Urol. 2016;50(2):128-31. doi: 10.3109/21681805.2015.1096826. Epub 2015 Oct 19.

[The Short-Term Effect of Breathing Tasks Via an Incentive Spirometer on Lung Function Compared With Autogenic Drainage in Subjects With Cystic Fibrosis.](#)

Sokol G, Vilozni D, Hakimi R, Lavie M, Sarouk I, Bat-El Bar, Dagan A, Ofek M, Efrati O.
Respir Care. 2015 Dec;60(12):1819-25. doi: 10.4187/respcare.04008. Epub 2015 Sep 15.

[A comparison of respiratory and peripheral muscle strength, functional exercise capacity, activities of daily living and physical fitness in patients with cystic fibrosis and healthy subjects.](#)

Arikan H, Yatar İ, Calik-Kutukcu E, Aribas Z, Saglam M, Vardar-Yagli N, Savci S, Inal-Ince D, Ozcelik U, Kiper N.
Res Dev Disabil. 2015 Oct-Nov;45-46:147-56. doi: 10.1016/j.ridd.2015.07.020. Epub 2015 Aug 1.

[Influence of respiratory physiotherapy on gastro-oesophageal reflux in infants: A systematic review.](#)

Van Ginderdeuren F, Kerckhofs E, Deneyer M, Vanlaethem S, Vandenplas Y.
Pediatr Pulmonol. 2015 Sep;50(9):936-44. doi: 10.1002/ppul.23218. Epub 2015 Jun 10. Review.

[Positive expiratory pressure physiotherapy for airway clearance in people with cystic fibrosis.](#)

McIlwaine M, Button B, Dwan K.
Cochrane Database Syst Rev. 2015 Jun 17;(6):CD003147. doi: 10.1002/14651858.CD003147.pub4. Review.

[Mucociliary clearance techniques for treating non-cystic fibrosis bronchiectasis: Is there evidence?](#)

Snijders D, Fernandez Dominguez B, Calgaro S, Bertozzi I, Escribano Montaner A, Perilongo G, Barbato A.
Int J Immunopathol Pharmacol. 2015 Jun;28(2):150-9. doi: 10.1177/0394632015584724. Epub 2015 Jun 15.

[Patients' experience of portacaths in cystic fibrosis: questionnaire-based study.](#)

McIntosh LA, Walker GM.
Arch Dis Child. 2015 Jul;100(7):659-61. doi: 10.1136/archdischild-2014-308045. Epub 2015 Jun 1.

[Airway clearance techniques used by people with cystic fibrosis in the UK.](#)

Hoo ZH, Daniels T, Wildman MJ, Teare MD, Bradley JM.
Physiotherapy. 2015 Dec;101(4):340-8. doi: 10.1016/j.physio.2015.01.008. Epub 2015 Mar 14.

[Prevalence and impact of urinary incontinence in men with cystic fibrosis.](#)

Burge AT, Holland AE, Sherburn M, Wilson J, Cox NS, Rasekaba TM, McAleer R, Morton JM, Button BM.
Physiotherapy. 2015 Jun;101(2):166-70. doi: 10.1016/j.physio.2014.11.001. Epub 2014 Nov 11.

[Short-term effects of physiotherapy on ventilation inhomogeneity in cystic fibrosis patients with a wide range of lung disease severity.](#)

Pfleger A, Steinbacher M, Schwantzer G, Weinhandl E, Wagner M, Eber E.
J Cyst Fibros. 2015 Sep;14(5):627-31. doi: 10.1016/j.jcf.2014.12.017. Epub 2015 Jan 19.

Please feel free to provide feedback and forward your suggestions or content to the IPG/CF secretary -