



## NEWSLETTER 4, 2015

### INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

Welcome to our fourth and final IPG/CF newsletter for 2015. Amazing how quickly Christmas and the New Year arrive. It has been a great year with many of you communicating through the IPG/CF. This Newsletter includes an update from Helen our Chairperson regarding the ECFS proposal for special interest groups which are aligned with the ECFS. Peter Suter our incoming Treasurer provides the new bank details. We welcome Myriam Vreys as the new contact person for Belgium and once again thank Fred for his contribution as treasurer. We also welcome Cecilia Rodriguez Hortal as the new contact for Sweden. Margareta Sahlberg is our second Alumni member after many years as the contact person for Sweden.

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.

Dr Ruth Dentice ([ruth.dentice@sswahs.nsw.gov.au](mailto:ruth.dentice@sswahs.nsw.gov.au))

IPG/CF Secretary.

### IPGCF CONTACT LIST FOR MEMBER COUNTRIES

Below is the current contact list as of mid December 2015. 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 36 actively responding to email currently. Countries in **green** (n=12) submitted an annual report for June 2014-June 2015, thank you. A √ indicates attendance at the 2015 AGM.

Country	Contact	Email
Argentina:	Patricia Ratto √	<a href="mailto:patriciaratto@hotmail.com">patriciaratto@hotmail.com</a>
Australia:	Brenda M. Button √	<a href="mailto:b.button@alfred.org.au">b.button@alfred.org.au</a>
Austria:	Beatrice Oberwaldner √	<a href="mailto:beatrice.oberwaldner@medunigraz.at">beatrice.oberwaldner@medunigraz.at</a>
Bangladesh:	Md.Abdullah Al-Mamun	<a href="mailto:abdullah15ca@yahoo.ca">abdullah15ca@yahoo.ca</a>
Belgium:	Myriam Vreys	<a href="mailto:myriam.vreys@uzleuven.be">myriam.vreys@uzleuven.be</a> (new)
Brazil:	Hilda Angelica Jimenez	<a href="mailto:hildajimenez38@yahoo.com.br">hildajimenez38@yahoo.com.br</a>
Bulgaria:	Anni Konfarjiveva	
Canada:	Jennifer Agnew √	<a href="mailto:jennifer.agnew@sickkids.ca">jennifer.agnew@sickkids.ca</a> ;
Cayman Islands:	Zillah Isaac	<a href="mailto:zillah.isaacs@gov.ky">zillah.isaacs@gov.ky</a>
Chile:	M. Alejandra Vila Irarrazavel	
Colombia:	Janeth Buendia Algeria	
Costa Rica:	Rodolfo . A . Bonilla Abarca	<a href="mailto:rhbonilla@yahoo.com">rhbonilla@yahoo.com</a>
Croatia:	Anja Kladar	<a href="mailto:anja.kladar@gmail.com">anja.kladar@gmail.com</a>
Cuba:	Romario Arjona Rodrigues	<a href="mailto:mirojo@infomed.sld.cu">mirojo@infomed.sld.cu</a>
Czech Republic:	Libuse Smolikova √	<a href="mailto:libuse.smolikova@lfmotol.cuni.cz">libuse.smolikova@lfmotol.cuni.cz</a> ;
Denmark:	Camilla Pedersen	<a href="mailto:camipede@rm.dk">camipede@rm.dk</a>
Ecuador:	Maite Mijares	<a href="mailto:maite@crespomijares.com">maite@crespomijares.com</a>

El Salvador:	María Azucena Flores Alemán ✓	<a href="mailto:mafa.azucena@gmail.com">mafa.azucena@gmail.com</a> (new email)
Estonia:	Karin Tammik	<a href="mailto:karin.tammik@ut.ee">karin.tammik@ut.ee</a>
Finland:	Katrr Partanen	<a href="mailto:katri.partanen@suomenfysioterapeutit.fi">katri.partanen@suomenfysioterapeutit.fi</a>
France:	Hugues Gauchez ✓	<a href="mailto:hgauchez@hotmail.fr">hgauchez@hotmail.fr</a>
Germany:	Jovita Zerlik ✓	<a href="mailto:jovita.zerlik@kinderkrankenhaus.net">jovita.zerlik@kinderkrankenhaus.net</a>
Greece:	Kostas Katsoulakis ✓	<a href="mailto:katsoul@freemail.gr">katsoul@freemail.gr</a>
Hong Kong:	LAU Mo Yee, Polly	<a href="mailto:pmylau@ha.org.hk">pmylau@ha.org.hk</a>
Hungary:	Peter Borka	<a href="mailto:borka@chello.hu">borka@chello.hu</a>
Iceland:	Dr. Hordur Bergsteinsson	<a href="mailto:hordurb@landspital.is">hordurb@landspital.is</a>
India:	Sumita Gupta	<a href="mailto:bisoiak@rediffmail.com">bisoiak@rediffmail.com</a>
Ireland:	Irene Maguire ✓	<a href="mailto:maguire.irene@gmail.com">maguire.irene@gmail.com</a>
Israel:	Eynav Manor ✓	<a href="mailto:e_manor@rambam.health.gov.il">e_manor@rambam.health.gov.il</a> (new email)
Italy:	Giulia Mamprin ✓	<a href="mailto:gmamprin@ulss.tv.it">gmamprin@ulss.tv.it</a>
Lithuania:	Rima Budrekiene	<a href="mailto:rbudrekiene@hotmail.com">rbudrekiene@hotmail.com</a>
Latvia:	Inese Znotina	<a href="mailto:Inese.Znotin@vsu.lv">Inese.Znotin@vsu.lv</a>
Macedonia:	Biljana Pacevska	<a href="mailto:snezanabojcin@gmail.com">snezanabojcin@gmail.com</a>
Mexico:	Zoila Popper	<a href="mailto:amfqmx@mexis.com">amfqmx@mexis.com</a>
New Zealand:	Rebecca Scoones	<a href="mailto:RScoones@adhb.govt.nz">RScoones@adhb.govt.nz</a>
Norway:	Sandra Gursli ✓	<a href="mailto:sangur@ous-hf.no">sangur@ous-hf.no</a>
Oman:	Kamla Al-Qasmi	<a href="mailto:kaq83@yahoo.com">kaq83@yahoo.com</a>
Palestine:	Amal Nassar	<a href="mailto:amal.nassar@crb-mail.org">amal.nassar@crb-mail.org</a>
Panama:	Gherson Cukier	<a href="mailto:gcukier@chiriqui.com">gcukier@chiriqui.com</a>
Poland:	Teresa Orlik ✓	<a href="mailto:zaklad.usprawnienia@imid.med.pl">zaklad.usprawnienia@imid.med.pl</a>
Portugal:	Filipe Prospero	<a href="mailto:filipe_prospiero@yahoo.com">filipe_prospiero@yahoo.com</a>
Romania:	Bogdan Almaja-Guta	<a href="mailto:bogdisport@yahoo.com">bogdisport@yahoo.com</a>
Russia:	Dr. Anna Tomilova	<a href="mailto:tomilova@nczd.ru">tomilova@nczd.ru</a>
Saudi Arabia:	Tareq M Aref Hussein	<a href="mailto:web_rcs@shrc.edu.sa">web_rcs@shrc.edu.sa</a>
Slovakia:	Marta Heroutová	<a href="mailto:fyzio.pp@falck.sk">fyzio.pp@falck.sk</a> ; <a href="mailto:heroutovi@sudtarch.sk">heroutovi@sudtarch.sk</a> .
South Africa:	Brenda Morrow	<a href="mailto:bmorrowstaffichrxhuct@mail.uct.ac.za">bmorrowstaffichrxhuct@mail.uct.ac.za</a>
Spain:	Laura Muelos Gomez	<a href="mailto:lauramgfisio@hotmail.com">lauramgfisio@hotmail.com</a>
Sweden:	Cecilia Rodriguez Hortal	<a href="mailto:cecilia.rodriguez-hortal@karolinska.se">cecilia.rodriguez-hortal@karolinska.se</a> (new)
Switzerland:	Marta Kerstan ✓	<a href="mailto:mkerstan@hispeed.ch">mkerstan@hispeed.ch</a>
The Netherlands:	Lianne van der Giessen	<a href="mailto:l.vandergiesen@erasmusmc.nl">l.vandergiesen@erasmusmc.nl</a>
Turkey:	Osman Coban	<a href="mailto:osmancbn@yahoo.com">osmancbn@yahoo.com</a>
UAE:	Saeid Rahbar Soureh	<a href="mailto:saeed849@yahoo.com">saeed849@yahoo.com</a>
UK:	Helen Parrott ✓	<a href="mailto:H.Parrott@rbht.nhs.uk">H.Parrott@rbht.nhs.uk</a>
Uruguay:	Kitty Löwensberg	<a href="mailto:kittylowensberg@movinet.com.uy">kittylowensberg@movinet.com.uy</a>
USA:	Eilbacher, Jaime	<a href="mailto:EILBACHER@email.chop.edu">EILBACHER@email.chop.edu</a>

## [IPGCF CONTACT LIST FOR ALUMNI MEMBERS](#)

Name	Email
Louise Lannefors ✓	<a href="mailto:louise.lannefors.4457@med.lu.se">louise.lannefors.4457@med.lu.se</a> (updated email)
Margareta Sahlberg	<a href="mailto:margareta.sahlberg@telia.com">margareta.sahlberg@telia.com</a> (new)

## [IPGCF CHAIRPERSONS REPORT DECEMBER 2015](#)

Hello all,

Welcome to the end of 2015 newsletter. We have been busy preparing for next years conference in Basel, Switzerland. We look forward to seeing many of you there. I am working closely with our Swiss representation on the pre conference course which is entitled 'Airway Clearance - the Foundations and the Evidence', Tuesday the 7th and Wednesday 8th June - 1.5 days. If you have any ideas on what you wish to see as part of this course please email me at [h.parrott@rbht.nhs.uk](mailto:h.parrott@rbht.nhs.uk). We are liaising closely with the organising committee to ensure the room we are allocated is suitable for the group as there may be some practical elements to the course.

Since the AGM I have been in discussion with the ECFS regarding their proposal for special interest groups which are aligned with the ECFS. We were invited to join but advised that the conditions are as follows. At the AGM, representatives expressed concerns regarding losing our autonomy as a group and in particular our financial freedom.

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

Would you be interested in leading a small working party on an educational project?

Do you have any ideas on on the educational priorities for the IPG?

Please look out for the application process in the next newsletter.

**Helen Parrott, Chairperson IPG/CF**

## [IPGCF TREASURERS REPORT DECEMBER 2015](#)

Dear all, countries that paid their inscription:

Greece, Australia, Norway, France, Belgium, Switzerland, Ireland, Argentina

Best regards and merry christmas to you and your family! **Fred**

The new bank account is open. The details are:

Banc Name: Credit Suisse 8070 Zürich

Adress: cf-physio.ch  
Scheuermattweg 21  
3007 Bern

**IBAN: CH51 0483 5163 5631 6200 0**

**BIC: CRESCHZZ80A**

Account Nr: 0094-1635631-62

Account Name: CFinternational

**Currency: EUR !!!! So please don't send it in Swiss Francs**

Yours sincerely,

Peter Suter

IPD/CF Treasurer [Peter.Suter@usb.ch](mailto:Peter.Suter@usb.ch)

## **IPGCF 2014 ANNUAL REPORTS FOR MEMBER COUNTRIES**

### **Annual report from Argentina 2014-2015**

In Argentina there are only few news:

Recently, the Argentinian Paediatric Pulmonology meeting was held in Mar del Plata.

There, the physiotherapist of CF Group from Sor Ludovica Children Hospital (Graciana D'Agostino), presented two Oral Presentations:

- *Progressive load walking test in Cystic Fibrosis.* Rentería, F. D'Agostino, G. Dela Fuente, G., Diez, G
- *Effects on exercise tolerance in hospitalized patients with Cystic Fibrosis.* Rentería, F. D'Agostino, G. Dela Fuente, G., Diez, G.

Our CF center presented an oral presentation (Dr. Lubovich):

- *Risk factors for Pulmonary Exacerbations in pediatric patients with Cystic Fibrosis.* S. Lubovich, J. Buendía, S. Zaragoza, V. Rodríguez, B. Camargo, J. Alchundia, L. Galanternik, P. Ratto, A. Teper.

These were the most relevant news

Kind regards,

**Pt. Patricia Ratto**

### **Annual report from Australia 2014-2015**

The Australian Chapter of the IPG/CF continues to be active in research, conference presentations, higher degrees and professional growth. A number of our group attended the European CF Conference in Brussels. Anna Middleton and Brenda Button presented in the pre-conference course on musculoskeletal problems in CF and musculoskeletal screening as part of annual reviews. Ruth Dentice and Mark Elkins debated whether or not patients with mild lung disease should be prescribed airway clearance therapy from the time of diagnosis. This session was interesting, innovatively presented and highly entertaining.

The bi-ennial Australia and New Zealand Conference was held in Sydney in August, 2015. The Sydney based organizing committee put together an excellent physiotherapy program. The pre-conference day on exercise was well attended and covered a wide range of topics. Professor Anne Holland launched the updated "Physiotherapy for CF in Australia Guidelines" which was endorsed by the TSANZ in August, 2015. Thirty-seven physiotherapists with a special interest in CF made up the writing group. They undertook the literature search and updated the consensus guidelines. Professor Eleanor Main was the invited speaker and gave a number of interesting presentations on modern physiotherapy and changes that have occurred in recent years. She challenged physiotherapists about useful study designs and appropriate outcome measures for future clinical trials in physiotherapy where randomized double blind placebo controlled trials are not possible. Many physiotherapists from around Australia presented their clinical research. Brenda Button presented the results of her Winston Churchill Fellowship where she visited hospitals in Belgium, Germany, France, the USA and Canada investigating state of the art physiotherapy for patients with lung disease treated with awake and ambulatory ECMO while being bridged to lung transplant.

Professor Anne Holland was awarded a full professorship at La Trobe University. She was also elected to the Board of the TSANZ and served this year on the NHMRC Grants Selection Panel. She was successful in obtaining an NHMRC grant to study the use of telehealth in pulmonary rehabilitation, the subject of her Winston Churchill Fellowship undertaken in 2009.

An advanced airway clearance course is being planned by Jamie Wood and Brenda Button during the last two week-ends in November, 2016, one in Perth and the other in Melbourne. We are so pleased Filip van Ginderdeuren from Brussels has agreed to travel to Australia and to present at the two day course. The annual basic airway clearance course will be held at the Alfred in Melbourne in April, 2016.

2015 was a busy year with many physiotherapy achievements in Australia and we look forward to an equally productive 2016.

**Brenda Button, country contact person**

### [Annual report from Czech Republic 2014-2015](#)

There were 4 conferences during **2014**, presenting the most modern physiotherapy techniques for treatment of CF and other chronic respiratory diseases; they were attended by paediatric physicians as part of a program updating methods used in children pneumology

Regular courses were held for 60 physiotherapists, interested in respiratory physiotherapy

Respiratory physiotherapy is included in the study program for bachelor's and master's degree and is taught to physiotherapy and medical students on the 2<sup>nd</sup> Faculty of Medicine, Charles University, Prague

Grant-aided research continues

November 2014 – Study Stay Week for CF team - physician from Ukraine

RECYF III/2014, Prague, November: National Meeting for CF teams in Czech Republic, ACT – what's new?

LEAD – Lectures Education Awareness and Discussions, Prague meeting – Lead Training Programme,

Clinical session – panel discussion, December 2014, about 20 -25 participants

There were 5 conferences during **2015**, presenting the most modern physiotherapy techniques for treatment of CF and other chronic respiratory diseases; they were attended by physicians as part of a program updating methods used in pneumology

Regular courses were held for 40 -50 physiotherapists, interested in respiratory physiotherapy

Regular workshops were held for 40-50 physicians – pneumologists and allergologists *Physiocafe* – new activity of physiotherapy students on the 2<sup>nd</sup> Faculty of Medicine, Charles University, Prague - workshop for physiotherapy students in Czech Rep. practical and theoretical meetings about ACT and respiratory physiotherapy

Respiratory physiotherapy is included in the study program for bachelor's and master's degree and is taught to physiotherapy and medical students on the 2<sup>nd</sup> Faculty of Medicine, Charles University, Prague

Grant-aided research continues

RECYF IV/2015, Prague, November – National Meeting for CF teams in Czech Republic, Physiotherapy for CF patients in ICU

European Respiratory Society, ERS – Cystic Fibrosis School 2015, invited speaker at the ERS Course,

Workshop – Physiotherapy: inhalation, exercise, urinary incontinence, spinal evaluation – L.van der Giessen, L. Smolikova

**Libuse Smolikova IPG/CF - Czech Republic national contact person**

### [Annual report from Sweden 2014-2015](#)

There are 4 centers with totally 650 patients with CF in Sweden, of whom around 225 are children. We almost cover the recommendations according to the Consensus, with one physiotherapist/50 patients

The last two years there have been works done at all centers with two big projects:

The first is “Our future”

1. The goal has been to involve the young patients (8-16 yrs) more in the treatment of their disease. Staff members and the patients have met through video conferences, where we e.g. have listened to each other, discussed the disease, treatment, future

The second is “Genia”

2. The next project has been to introduce and evaluate the App “Genia”, which is created by a father to a patient. The goal with this App is to give the patients a better control over the disease, day by day and to have an easy way to submit data to a register ahead of a visit to the clinic.

There have been some other activities as well going on

- Some of the physiotherapists visited the ECFS and the NACFS conferences, both with and without own presentations. At the NACFS conference the App Genia was presented as a poster.
- Within the country there have been education opportunities for patients and parents at the centers
- One recreational week in Mallorca for teenagers was arranged with two physiotherapists supporting during inhalation, ACT, physical exercise and education
- Through IPG one physiotherapist has been in Bosnia educating patients and relatives in CF treatment.
- Physiotherapist Cecilia Rodrigues Hortal is a Phd student with studies in Noninvasive ventilation. The last study has just started.
- In September colleges in Aarhus Denmark hosted a Nordic conference during two days for physiotherapist working with CF, 26 attended. The program covered different areas such as – 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.

### **A note to all from Margareta:**

I have just retired from my work at Gothenburg CF center where I have been 21 yrs, celebrated 67 yrs last September. I'm continuing with some research.

For the coming years Cecilia Rodriguez Hortal at Stockholm CF center will continue as our Contact person in IPGCF. You can mail to her for further information : [cecilia.rodriguez-hortal@karolinska.se](mailto:cecilia.rodriguez-hortal@karolinska.se)

I will thank you all for interesting years and will continue to take part in future work for patients with CF.

With best regards, Margareta [margareta.sahlberg@telia.com](mailto:margareta.sahlberg@telia.com)

**We welcome Margareta as a new Alumni Member**

## ***Annual report from The Netherlands 2014-2015***

### **General**

The Dutch group of physiotherapist working in CF Centres consists of 14 members. Six are pediatric physiotherapist; eight are working with CF adult patients.

### **Education**

- February 2015 Workshop during CF symposium for CF specialists ; 'Bewegen is beter dan genezen': about Physical Activity, exercise and training in CF patients.
- October 2015 CF on the move – Symposium for physiotherapist who treat CF patients. Organisation CF Centre Groningen. Number of participants 50.
- CF on the move will be every year organized by another CF centre.

### **Meetings**

We had two meetings for all physiotherapist working in CF centres. Main Subjects:

- Inventarisation of time spend in each CF centre for CF patients
- Standards of care of the ECFS

### **Special Interest and activities**

Erik Hulzebos: member of the European Cystic Fibrosis Exercise Working Group of the ECFS. Three published articles from the European Cystic Fibrosis Exercise Working Group of the ECFS.

- Statement on Exercise Testing in Cystic Fibrosis. *Respiration* 2015;90:332–351. Helge Hebestreit, Hubertus G.M. Arets, Paul Aurora, Steve Boas, Frank Cerny, Erik H.J. Hulzebos, Chantal Karila, Larry C. Lands, John D. Lowman, Anne Swisher, Don S. Urquhart.
- Physical activity assessment in cystic fibrosis: A position statement. *Journal of Cystic Fibrosis* xx (2015) xxx–xxx. Judy Bradley, Brenda O'Neill a, Lisa Kent, Erik H.J. Hulzebos, Bert Arets, Helge Hebestreit. On behalf of the Exercise Working Group European CF Society
- Exercise and Habitual Physical Activity for People With Cystic Fibrosis: Expert Consensus, Evidence-Based Guide for Advising Patients. *Cardiopulm Phys Ther J.* 2015;00:1–14. Anne K. Swisher, Helge Hebestreit, Anne Mejia-Downs, John D. Lowman, Wolfgang Gruber, Matt Nippins, Jennifer Alison, Jane Schneiderman.

**LJ van der Giessen:** ERS CF basic course Faculty member

## [RESEARCH UPDATE](#)

### **Subscribe to Evidence in your inbox**

The latest clinical practice guidelines, systematic reviews and clinical trials for each area of physiotherapy and for selected topics in physiotherapy (such as chronic lung disease) can be delivered to you by email for free.

You can subscribe to Evidence in your inbox using the form at this link:

<http://www.pedro.org.au/english/evidence-in-your-inbox/>

Select from 14 areas of physiotherapy practice. The latest research will arrive in your inbox each time PEDro is updated.

**Please feel free to provide feedback and forward your suggestions or content to the IPG/CF secretary - [ruth.dentice@sswahs.nsw.gov.au](mailto:ruth.dentice@sswahs.nsw.gov.au). Distribute this widely, and enjoy!**



*Merry Christmas and Happy Year Year*

**Dr Ruth Dentice** (photo in Greenland at The Polar Circle Marathon 2015)