



NEWSLETTER 1, 2016

INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

Welcome to our first IPG/CF newsletter for 2016. 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 and guidance regarding payment.

Thank you to the country contacts that submitted an annual report for 2015. You all now have a fresh start! Please aim to submit a report for our next newsletter that will circulate when we provide notification of our June AGM at the ECFC. This report does not have to be lengthy, it just needs to provide information regarding the number of physiotherapists in your CF group locally (perhaps a number of patients with CF they manage), recent activities and planned events.

I am already very excited about the opportunity to see you all in person at our June Conference. We have included some highlights to inspire you.

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)

IPG/CF Secretary.

IPGCF CONTACT LIST FOR MEMBER COUNTRIES

Below is the current contact list as of mid February 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 36 actively responding to email currently.

Country	Contact	Email
Argentina:	Patricia Ratto	patriciaratto@hotmail.com
Australia:	Brenda M. Button	b.button@alfred.org.au
Austria:	Beatrice Oberwaldner	beatrice.oberwaldner@medunigraz.at
Bangladesh:	Md.Abdullah Al-Mamun	abdullah15ca@yahoo.ca
Belgium:	Myriam Vreys	myriam.vreys@uzleuven.be (new)
Brazil:	Hilda Angelica Jimenez	hildajimenez38@yahoo.com.br
Bulgaria:	Anni Konfarjivea	
Canada:	Jennifer Agnew	jennifer.agnew@sickkids.ca ;
Cayman Islands:	Zillah Isaac	zillah.isaacs@gov.ky
Chile:	M. Alejandra Vila Irrazavel	
Colombia:	Janeth Buendia Algeria	
Costa Rica:	Rodolfo . A . Bonilla Abarca	rhbonilla@yahoo.com
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Iceland:	Dr. Hordur Bergsteinsson	hordurb@landspital.is
India:	Sumita Gupta	bisoiak@rediffmail.com
Ireland:	Irene Maguire	maguire.irene@gmail.com
Israel:	Eynav Manor	e_manor@rambam.health.gov.il (new email)
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IPGCF CONTACT LIST FOR ALUMNI MEMBERS

Name	Email
Louise Lannefors	louise.lannefors.4457@med.lu.se (updated email)
Margareta Sahlberg	margareta.sahlberg@telia.com (new)

IPGCF CHAIRPERSONS REPORT FEBUARY 2016

Hello all and welcome to your newsletter!

In this report I will give information regarding the ECFS special interest groups and a conference update. I hope to see you many of you in Basel either at the pre conference course, the AGM, the case presentation session, on the poster tour or indeed in the audience of one of the excellent symposia or workshops. If you have submitted abstracts or cases this year - best of luck! I really hope you get accepted. I am really looking forward to seeing all of the work submitted to this conference. Thank you to the IPG/CF board and friends of the board for helping me with the preparations so far.

As mentioned in the last newsletter - the IPG board would like to apply to the ECFS this year for funding to create a special interest group with a focus on improving access to physiotherapy education. We have been assured that our our organisational and financial autonomy would not change and that this group and the funding associated would be a 'sub group' of the IPG.

I would like our first meeting to be at the ECFC in Basel and I am looking for volunteers who would be interested in being involved in a funded project. This is a chance to be innovative...could we develop an online training educational programme? Could we create online IPG approved airway clearance material? How could we best improve and standardise CF physio education? If you have ideas and could give time to this sub group of the IPG, please email me at h.parrott@rbht.nhs.uk, I would love to hear from you.

Please see below the terms of reference for ECFS special interest group. Regarding the ECFS membership requirement, we would consider using IPG funds to obtain the membership for sub group members and we have been offered a discounted rate.

Please get in touch!

Special Interest Group

Terms of reference

Establishment

ECFS Constitution extract:

2-01-03: The ECFS may form special project or working groups for any purpose related to the objective of the society. Such sub-groups will be appointed and approved by the ECFS Board and their members are expected to be ECFS members. While special projects are not subject to a pre-defined term of existence, working groups will be supported for 1 year and up to a maximum of 3 years. Annual reports from these sub-groups will be presented at the summer Board meeting and at the Annual General Meeting (AGM).

Any active member of the Society may consider the establishment of a Special Interest Group supporting a specialist area related to CF.

An application for the establishment of a Special Interest Group is to be made in writing, using the Application Form template. This form is to include details about the aims, objectives and structure of the proposed Special Interest Group. Applications are to reach the ECFS Office by the end of August for evaluation/selection by the ECFS Board at their Autumn Board Meeting.

Terms of Reference

Definition: A Special Interest Group is a community within a larger organization with a shared interest in advancing a specific area of knowledge or care.

- a. The existence of each Special Interest Group is not limited in time but will be reviewed by ECFS Board every 3 years.
- b. Structure: A Special Interest Group is to have at least one Coordinator who is responsible for the overall activities of the group. The mandate of the Coordinator will be of 3 years duration.
- c. There should be a statement of aims and objectives for the Special Interest Group to include specific goals.
- d. Members of a Special Interest Group are to be ECFS members.
- e. The Coordinator, or their representative, will provide the ECFS Board with a report at the summer Board Meeting and to the Annual General Assembly. The annual report should also be prepared in a written format for publication on the ECFS website.
- f. Special Interest Groups are encouraged to use the annual conference as an opportunity to conduct a meeting of its members. Attendance to this meeting will be free of charge for ECFS members.

ECFS Funding Support

- a. The Society will provide funding support of up to Euro 3,000 per annum for three years.
- b. ECFS funds will not be granted for research, consumables or personnel.
- c. ECFS funds are not to be used for travel of Special Interest Group Members
- d. Individual budgets, per Special Interest Group, will be held and maintained at the ECFS Office

ECFS Website Support

- a. Each Special Interest Group will have one dedicated page on the ECFS website. The page will contain the aims of the project, the group's structure, notification of forthcoming meetings, etc.
- b. Additionally, there will be a generic page with the annual reports from each Special Interest Group.
- c. If required, Special Interest Groups may use the ECFS collaborative tool to upload and share documents of general interest, or restricted viewing of documents to special interest sub-groups. This area is subject to a login and can be entirely restricted to members of the group.
- d. If warranted, a discussion forum for the Special Interest Group can be established. It is, however, imperative that the group nominates a member to monitor and maintain the content. The ECFS office will not be responsible for the content included in such a forum. Access is subject to a login and may only be provided to ECFS members and can be entirely restricted to members of the group.

Conference Update:

ECFC Basel 8th- 11th June

Here's your sneak preview of the physiotherapy content of this years european CF conference!

Physiotherapy Symposium 09.06.2016 10:30-12:00 Shanghai		Physiotherapy Symposium 10.06.2016 10:30-12:00 Shanghai	
S11 Airway clearance – questions and conflicts Brenda Button (Melbourne, AU)  Marta Karstan (Zurich, CH) 		S23 Exercise for everybody Donald Urquhart (Edinburgh, UK)  Thomas Radtke (Zurich, CH) 	
Are you doing a good job as a physiotherapist? Eleanor Main (London, UK) 	10:30-10:52 22min	Exercise testing - the why and how Helge Hebestreit (Würzburg, DE) 	10:30-10:52 22min
Physio for all babies diagnosed via newborn screening – PRO Maria Cecilia Rodriguez Hortal (Stockholm, SE) 	10:52-11:10 18min	Exercise testing as an outcome measure Larry Lands (Montreal, CA) 	10:52-11:14 22min
Physio for all babies diagnosed via newborn screening – CON Sarah Rand (London, UK) 	11:10-11:28 18min	Physical activity assessment and habits in cystic fibrosis: the ACTIVATE-CF experience and beyond Thomas Radtke (Zurich, CH) 	11:14-11:36 22min
Discussion	11:28-11:38 10min	Useful tools for activity counselling Marlies Wagner (Graz, AT) 	11:36-12:00 24min
Airway clearance research – where do we go from here? Maggie McIver (Vancouver, CA) 	11:38-12:00 22min		

Please also join us for the IPG/CF AGM and case presentation sessions
On Wednesday 7th June from 1230 (lunch provided)



ECFC Basel – Dates for your diary

- **Physiotherapy pre conference course:**
 - Tuesday 7th June (1 day) Wednesday 8th (0.5 day)
 - ‘Airway Clearance: the foundations and the evidence’ (excellent speakers TBC)
 - Multi-national perspectives to be discussed!
- **‘Meet the Expert’ sessions (Euro 45 extra):**
 - Thursday 9th at 0715-0815
 - Tips on publishing → the JCF perspective!
 - Would be great to see some physio’s here!

[IPGCF TREASURERS REPORT FEBRUARY 2016](#)

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

The first two months of the year has nearly passed and the Annual General Meeting is approaching soon. For me as the treasurer it's time to ask you to pay the annual fee. Although the annual fee is not compulsory I invite all countries, who are able to, to participate.

The annual fee of 50.- Euro is due by June 30, 2016.

There are two methods for payment:

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

Bank Name: Credit Suisse 8070 Zürich

Address: cf-physio.ch, Scheuermattweg 21, 3007 Bern, 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. *Switzerland 2016*

2. Cash payment to me at the Annual General Meeting on June 8, 2016 at the ECFS Conference in Basel

In both cases, the currency must be in EURO and you will receive a receipt.

Should another person be in charge of making the payment please pass this information on to them.

The balance of the IPG/CF on December 31 2015 was 4577.06 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

IPD/CF Treasurer Peter.Suter@usb.ch

[IPGCF ANNUAL REPORTS FOR MEMBER COUNTRIES](#)

No additional submissions since last Newsletter for 2015. This section should be full next Newsletter in preparation for our AGM in June.

[RESEARCH UPDATE](#)

Learn how to search PEDro to find the evidence you want by watching these free videos available in multiple languages

Go to YouTube and type in PhysiotherapyEvidenceDatabase.PEDro

Alternatively, go to the PEDro website (www.pedro.org.au) and click on 'Search Help'.

If you speak a language other than English, make sure you remember to see if the videos are available in your preferred language.

Once you find one PEDro video in YouTube, you will see other related videos in the right-hand margin. Have fun!



["What are systematic reviews?"](#)

Watch a new video which answers this question clearly and simply for people who may not be familiar with the concept of systematic reviews.

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