Greetings to everyone reading our IPG/CF newsletter. This release summarizes main events of our society during the past year 2008 in Europe, the 31st European Cystic Fibrosis Conference, held in Prague, Czech Republic.

I would also like to welcome Camilla Pedersen, our new contact in Denmark to IPG/CF. Please find the complete list of contacts at the end of this newsletter.

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*Prepared by Libuse Smolikova*

*IPG/CF Secretary, May 2009*
1. Filip Van Ginderdeuren opened the meeting by welcoming everyone and introducing the IPG/CF Board. He then thanked Maggie McIlwaine (Vice Chair of the IPG/CF and Jovita (Treasurer for all their hard work and support to him as Chair of the IPG/CF. IPG/CF contact persons were asked to stand and introduce themselves. There were 20 contact members present and Dr George Davidson our Medical Advisor. This represented a quorum and the meeting was officially opened.

2. Minutes of the Annual General Meeting from Belek, June 13th 2007 were passed.

3. Reports: Full reports will be published in the next Newsletter of the IPG/CF.
   3a) Chairpersons report: Filip reported on the activities of the chairperson – see full report
   3b) Treasurer: Jovita gave a treasurer’s report, concern was expressed that not all countries paid their subscriptions. However, the finances are in good shape, partly due to low expenses and also due to the scholarship provided by Novartis. This scholarship money is only transient and will be distributed to the Novartis scholarship winners. The treasurers report is available in the next Newsletter.
   3c) Secretary report: Estee Tannebaum sent her regrets, but sent a report which Maggie read. We now have a new contact country, Palestine. This makes our total number of member countries to 55, although it has been difficult to contact some of these countries. The secretary’s report will also be in the next Newsletter.
   3d) Business arising from reports: There was no business arising from any of the above mentioned reports.

4. Election of new Chair-person
Maggie McIlwaine who has been the Vice chair for the past 3 years moved to the position of chair as per the constitution.

5. Election of Vice-Chair.
Lynn Gummery was the only nomination. Nominated by Filip and seconded by Brenda Button. All contact persons supported the nomination and Lynn was elected as Vice Chairperson.

6. Election of Treasurer
Irene McGuire was nominated as Treasurer by Maggie McIlwaine and Filip Van Ginderdeuren. All contact persons supported the nomination and Irene was elected as the Treasurer.

7. Election of Secretary
Libuse Smolikova was nominated as Secretary by Louise Lannefors and seconded by Lynn Gummery. All contact persons supported the nomination and Libuse was elected the Secretary.

8. Eurocare report
Libuse and Louise are the Physiotherapy representatives on this committee. They both reported on the activities of Eurocare this year.
9. **Paediatric Working Party**
There was nothing to report, except that their report from the International Paediatric Survey is on the IPG/CF website.

10. **Physiotherapy Glossary is also on the IPG/CF website.**

11. **Physiotherapy Blue Booklet.** A new edition of the Blue Booklet is hoped to be ready in draft form by August and for the web by October 2008. Filip is chairing the committee for this. There will be no hardcopies made, it will only be available on the IPG/CF website.

12. **Novartis Best Care Scholarship 2007.** Patrick Willamo from Finland was the winner. Patrick gave a presentation on Physiotherapy care in Finland.

13. **Novartis Best Care Scholarship 2008** winners were announced.

*Prepared by Maggie McIlwaine,*
*IPG/CF Chairperson, April 2009*
On behalf of the IPG/CF board I welcome you to the 2008 annual general meeting. These are my last moments as IPG/CF chairperson. Time is really flying by! It was a great pleasure and also a magnificent chance to work together with so many dedicated people. When Brenda invited me 6 years ago to become her new vice chairperson, I was not sure of the consequences of my decision, being rather “new” and without any experience in this field, but she was my perfect guide and teacher during these years. What interested me in IPG/CF and I believe that it has always been its strength also, is the perfect mixture of and balance between the theoretical part / evidence based knowledge and the practical part, the “hands on” sessions, being reflected during our pre-conference courses, workshops and symposia. Every year the board receives a lot of compliments about the physiotherapy programme. Colleagues often say “We’ve learned a lot during this conference that will be very useful during our daily work with our CF patients. I hope we can continue and I would like to wish the new board all the best for the future.

Physiotherapy courses organised by the IPG/CF
Last year we ran a 1.5 day course “on Inhalation therapy (instructor: Louise Lannefors)” Feedback from this course has been “very good to excellent”. This year we presented a 1.5 day “Basic Airway Clearance Course with Maggie McIlwaine, Louise Lannefors, Jean Chevaillier, Brenda Button, Beatrice Oberwaldner and Jennifer Pryor as instructors. The courses have been well attended and have been profitable. IPG/CF received also the request to run courses in Armenia (Yerevan) October 2007 and India (Dehli) in December 2007. Course instructor for both courses was Louise Lannefors

ECFS Scientific Committee Representation
Our request to invite The Chairperson and vice-chairperson to be members of the ECFS Scientific Committee organising the physiotherapy programme has been conceded for the sixth consecutive year. Maggie McIlwaine, Lynne Gummery and Hugues Gauchez have been invited to serve on the ECFS Scientific Committee organising the conference in 2009 in Brest, France. A subcommittee of Past chairpersons plays a key role in co-ordinating requests and ideas for future physiotherapy topics at the CF conferences.

Blue Booklet: new version
Two weeks ago I received the last draft for the new version of the Blue Booklet. I would like to thank Louise Lannefors, Jennifer Pryor, Brenda Button, Maggie McIlwaine, Jean Chevaillier, Patrick Althaus and Beatrice Oberwaldner for their time and efforts in preparing this new version. The New version of the Blue Booklet will not only be an update of the current version. Adaptation of the different AC techniques to non-cooperating patients, if possible, will be included. A chapter on physiotherapy management of the pneumothorax, haemoptysis, Physiotherapy for the prevention and treatment of urinary incontinence in cystic fibrosis, Non-invasive ventilation in CF and Physiotherapy during pregnancy, labour & the post-natal period will also be included. Immediately after this conference I will prepare a first draft of the new booklet in a new format and referencing and circulate this version to all the
authors for their comments and remarks. As soon as we all agree about the final document, the new version of the Blue Booklet will be available on and downloadable from our IPG/CF website.

Cystic Fibrosis Worldwide Newsletter
Jill Weinstein, the new editor of the CFW Newsletter, invites us for the second year to submit any interesting news or articles about physiotherapy. She accepted also to announce our Novartis Best Care Scholarship winner in the newsletter. Her aim is to gather new physiotherapy developments, techniques, and information at least once a year. So if you wish to see an article published in the CFW newsletters, please contact the IPG/CF board.

CFW's newsletter has an international readership of approximately 5,000 people. It is published in print several times a year in English, and is downloadable online in seven languages. It features 50-60 pages of new research, health & fitness, physiotherapy, conference and workshop summaries, book reviews, and other information of interest to the scientific and lay community.

Novartis Best Care Travelling Scholarship – 2008 Winner
During a meeting at the ECFS Conference in Belek, last year, Jenan Al-Hafidh, Global Brand Manager for TOBI, from Novartis at that time confirmed its continued support to our scholarship into 2008 and doubled the prize money to 4000 euro’s. This gives us the opportunity of having two Novartis Best Care Scholarship winners every year. This years winners of the scholarship will be announced at the end of this meeting.
Manar Adner JABAR is our first winner of the 2008 Novartis Best Care Scholarship. She apologises for her absence during this conference.
Sylvie VANLAETHEM from the Hospital of the Free University of Brussels is our second winner of the 2008 Novartis Best Care Scholarship. She will be present during the AGM to collect her certificate and cheque.
For more information concerning our Novartis Best Care Scholarship winners and their plans please check our website www.cfww.org/ipg-cf/

IPG/CF Secretary report 2007/2008
Prepared by Esta-Lee Tannenbaum
We have a new contact member country – who will be represented by Manar Jabar from Palestine. Also, Marika Kiikala is the new contact person from Finland – welcome to the IPG/CF. This takes the number to 55 IPG/CF country members. However, there are many countries whereby the contact person is no longer ‘in contact’. This information will be passed onto the new secretary. Two newsletters have been collated in the last year – November 2007 and the recent May 2008.
This is my last report as secretary – it has been an honour to work with the committee. I would especially like to thank Filip – for his support and excellent communication with me from various parts of the world. My congratulations and gratitude to you for your excellent leadership.
Wishing you all a learned conference – it is a privilege to attend these conferences.
Best wishes,
Esta-Lee Tannenbaum
IPG/CF Secretary 2005-2008
More than 1700 delegates registered for the 31st European Cystic Fibrosis Conference taking place at the Prague Congress Centre in Prague, Czech Republic. The conference was held from 11-14 June 2008.

**Pre conference course**

**Basic Airway Clearance Course**

The one and a half day course was held at the Prague Congress Centre on June 11 and June 12, before the official opening of the conference. 55 physiotherapists registered for the course.

Maggie McIlwaine from Canada was the course organiser.

The aims of this course were to give a theoretical and practical overview of all the different modern airway clearance techniques. The airway clearance course is an excellent opportunity for physiotherapists who are new to working with cystic fibrosis patients or for physiotherapists who want to update their skills on airway clearance techniques. Different course instructors were involved.

On the first day (theoretical part) Jean Chevaillier (Belgium) looked at the respiratory physiology and explained Autogenic Drainage (AD).

Jennifer Pryor (UK) discussed the Active Cycle of Breathing Techniques (ACBT), Brenda Button (Australia) talked about Oscillating PEP devices (Flutter, Acapella). Maggie McIlwaine (Canada) covered the Positive Expiratory Pressure Mask and other considerations such as HCFWO, application to infants, etc.). Beatrice Oberwaldner (Austria) explained High Pressure PEP and Louise Lannefors (Sweden) talked about Exercise and Inhalations.

Mrs. Lannefors introduced her course with an overview of the corner stones in modern CF care (nutrition, drugs, education, physiotherapy, psycho-social support) and the pre-requisites for successful nebulisation therapy: adequate indication, optimal intrapulmonary deposited dose, optimal deposition pattern and good treatment adherence.

On the second day all participants were divided into smaller groups for the hands on session. The instructors guided all the participants through the airway clearance techniques. Czech CF patients were invited and demonstrated the different techniques. A special thank goes to all the patients and to Libuse Smolikova (Czech rep.) for helping us with the organisation of this course.

**Physiotherapy case presentations**

Six physiotherapy case presentations were moderated by L. Fila (CZ) and B. Button (Aus). Topics were:

- *Clinical Instability, but too well for transplant?*
• Intensive airway clearance and serial bronchoscopies for the management of lobar pneumonia in cystic fibrosis
• Physiotherapy: what to do when no therapy seems to work?
• Symptomatic Screened CF Infant
• Managing End of Life: Issues for the physiotherapist
• Never Give up! A good outcome in CF post liver transplantation following extensive complications and prolonged intensive care.

For the first time, the best case presentation was rewarded with a cheque of 250 euro. H. Parrot (UK) was the winner with her presentation on “Managing End of Life: Issues for the Physiotherapist.” She discussed the importance of the input of a palliative care professional in managing end of life issues; the risk of under medicating for fear for over medicating and how the physiotherapist could have been more effectively involved in the end of life decisions.

Symposium

The physiotherapy symposium on “Physiology of Airway Clearance” was chaired by M. McIlwaine (Can) and L. Smolikova (Cz).

M. Elkins (Aus) talked about enhancing mucociliary clearance (MCC) in CF. He discussed the mechanism of mucociliary clearance in healthy individuals and CF and how medication (NaCl 6%) and physiotherapy improves the MCC. Hypertonic Saline reduces the viscosity of the sputum, restores the airway surface liquid, stimulates cough and reduces Pseudomonas Aeruginosa motility. Hypertonic Saline improves lung function, reduces the number and the duration of exacerbations, improves quality of life in adults and children > 10 years and improves the efficacy of airway clearance techniques. He discussed also the importance of ordering the different therapies to optimise the mucociliary clearance.

B. Button (Aus) talked about changes in position to alter ventilation and optimise airway clearance therapy. She looked at the importance of physical exercise and the effect of positioning on ventilation and airway clearance. She looked also at the effect of body position on distribution of mucus within the bronchi; on the bronchial diameter and on the level and movements of the diaphragm.

L. Lannefors (Swe) presented expiratory resistance breathing. She talked about the changes in lung volumes as airway obstruction increases. She discussed the Pursed Lips Breathing, the expiration towards a resistance, needing a good instructor to use the tools properly. The common ways of using expiratory resistor breathing for airway clearance are PEP, High Pressure PEP and oscillating PEP.

J. Chevaillier (Bel) talked about optimising airflow velocity in airway clearance therapy. He discussed the “funnel” shape and function of the bronchial tree. All efficient airway clearance techniques are based on “erosive” phenomena and fluid dynamics. It is important to modulate the expiratory flow versus airway compression. He showed the effect of a forced expiration, with the cough as an example. He discussed the “musts” in bronchial drainage and how to optimise the expiratory airflow velocity.

Workshops

“Exercise in CF” was moderated by J. Bradley (UK) and L. Smolikova (Cz). Presentations on “Attitudes to Recreational Androgenic Anabolic Steroids among Adult CF patients”; “Pelvic floor muscle training in adolescent females with cystic fibrosis”; “Developing a
musculoskeletal service for adults with cystic fibrosis”; “Only a few osteoporotic adult CF patients and no vertebral fractures”; “Working capacity and oxygen uptake in CF” and “First results of five-year follow-up of exercise capacity in Belgian CF-children: what do they tell us for the future?”. For more details on these studies, please find abstracts 288, 289, 290, 291, 238 and 292 in “Journal of Cystic Fibrosis”, vol 7, suppl 2, June 2008.

“New trends in physiotherapy” was moderated by L. Van der Giessen (NL) and F. Van Ginderdeuren (Bel)
This workshop included presentations on “High frequency chest wall oscillation in cystic fibrosis”; “A proactive approach pays off in screened infants with CF”; “Influence of inhaled hypertonic saline, combined with airway clearance on SpO2, heart rate, dyspnoea and wet sputum weight in hospitalised CF patients.” And “Use and perceived benefits of nebulised hypertonic saline (HS) treatment in adult patients with cystic fibrosis.”
To read more, please find abstracts 295, 310, 285 and 286 in “Journal of Cystic Fibrosis”, vol 7, suppl 2, June 2008.

Round tables

There were also two round table discussions to attend. ‘Managing urinary incontinence’ was moderated by M. Dodd (UK), ‘Aging in CF – from the physiotherapy perspective’ was moderated by B. Button (Aus).

Prepared by Filip Van Ginderdeuren
IPG/CF Chairperson 2004-2008
Hi Everyone
I would like to introduce myself as the new Chairperson of the International Physiotherapy Group for Cystic Fibrosis. Presently, I live in Vancouver, Canada and work at the BC Children’s Hospital Cystic Fibrosis Clinic. First, I would like to thank my predecessor Filip Van Ginderdeuren for all the hard work he has done on behalf of the IPG/CF. Filip has done a tremendous job in promoting the IPG/CF throughout the CF community and with CF Worldwide. I wish him all the best in his future endeavours.
I am really excited about taking on the role as Chairperson of the IPG/CF, it is a great privilege to be elected to this position and I hope I can live up to expectations. It has already been a busy 6 months since being elected. Unfortunately, our Vice Chair, Lynn Gummery resigned for personal reasons soon after being elected. Thankfully, Irene MaGuire who was elected Treasurer has agreed to stand in as Vice Chair until next year’s AGM, when a Vice-Chairperson will be elected.
We have also been working quite closely with CFW regarding coordinating CFW courses to underdeveloped countries. CFW hope to hold 2 CF courses per year with an educational team composing of Physicians, Nurses, Physiotherapists and Dieticians. I wish to thank Louise Lannefors for all her hard work in developing these courses with CFW and the IPG/CF Board. Louise has been our main Physiotherapist Instructor for these courses and has agreed to teach the next course in Macedonia in April. However, we need a group of 2 or 3 more Physiotherapists who would agree to assist in teaching these courses. If you are interested, please contact me at mcilmorris@shaw.ca.
We are also in the planning stages of June’s CF Conference in Brest France, we are hoping to arrange a pre-conference course and are working very closely with our French Colleagues in planning this. Information is already on the ECFS website.
As we move forward in 2009, I am hopefully that we will be able to make great stride in the treatment of CF.
Yours

Maggie McIlwaine.
Message from Libuse Smolikova, IPG/CF Secretary

Dear Colleagues,

I would like to thank the members of IPG/CF for selecting me to take the secretary office position. It is a great honor to work with the society once again, as I have had the pleasure of carrying out secretarial responsibilities from 2000 to 2004. For the past 30 years I have been working at the Motol University Hospital in Prague, Czech Republic with the National CF Center. My work here was devoted to children, adolescents and adults suffering from chronic lung disorders, especially Cystic Fibrosis.

I would like to give my warmest thanks for all the help and support that I have received from friends and colleagues for the past 15-20 years, to name a few, Louise Lannefors, Rita Kiesselmann, Liliane Heidet, Hugues Gauchez, Jean Chevalier, and Brenda Button.

I would also like to give special thanks to everyone who helped me to organize the pre-conference IPG/CF course for physiotherapists in Prague 2008. The feedback from the participants was very positive, as they rated the course highly useful for their profession. For more information, please see Filip’s report.

Please do not hesitate to contact me with comments or questions via any contacts below.

Yours

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Can I please ask all Contact Persons to keep the IPG/CF Secretary informed of any changes in either: a new Contact Person, e-mail or postal address or fax number. This is essential so that we can maintain and improve our communication.

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