



International Physiotherapy Group for Cystic Fibrosis

NEWSLETTER 1, 2007

Introduction

Welcome to the 1st Newsletter of the IPG/CF for 2007. We hope that you will find the newsletter informative and that you are kept up-to-date with current matters.

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. This is essential so that we can maintain and improve our communication. An updated contact list can be found on the website: www.cfww.org/IPG-CF/index.asp

Below is a picture taken from the CF conference in Copenhagen, including the IPG/CF committee and Contact Persons.



Best wishes for 2007
Esta-Lee Tannenbaum
Secretary for IPG/CF

CF Conference Belek, Turkey 2007

Information regarding the CF conference in Belek can be found at the following website:
www.europeancfconference.org

Highlights for physiotherapists include the following:

June 12-13: Physiotherapy Short Course Topic: Inhalation Therapy

June 13th (midday): AGM for the IPG/CF

June 13th (pm): Physiotherapy Case Presentations

June 14th: Workshop 8 Promoting physical exercise in CF

June 15th: Workshop 15 Physiotherapy treatment strategies in CF

Please consider participating in the conference by sending in abstracts for the workshops above and also the case presentations.

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Minutes of IPG/CF held in Copenhagen, Denmark 15 June 2006

Present:

Country	Contact Person
Australia	Brenda Button
Austria	Beatrice Oberwaldner
Belgium	Filip van Ginderdeuren
Czech Republic	Libuse Smolikova
Finland	Leena Jokinen
France	Hugues Gauchez
Germany	Jovita Zerlik
Ireland	Irene M
Italy	Paolo Buonpensiero
Norway	Sandra Guersli
Poland	Teresa Orlik
Slovak Republic	Marta Heroutova
Sweden	Louise Lannefors
Switzerland	Patrick Althuis
Russia	Alena
UK	Lynne Gummery

Other attendees: Esta-Lee Tannenbaum

Apologies:

Turkey	Osman Coban
Canada	Maggie McIlwaine

2. Minutes from previous meeting held in Crete, 2005

Brenda Button noted that in the minutes – there was an error in that she had been on the committee for 5 years and not the 4 years as mentioned. This was corrected.

Accepted by: Lynne Gummery

Seconded by: Beatrice Oberwaldner

3.1 Chairperson Report

Chairperson's Report, Annual General Meeting, Copenhagen, Thursday June 15, 2006.

Prepared by Filip Van Ginderdeuren, July, 2006

On behalf of the IPG/CF board I welcome you to the 2006 annual general meeting. This is my first AGM officiating in the role of chairperson, a real challenge. I have received great support from the other members of the board, as well as from Brenda Button, Louise Lannefors, Sandra Gursli and Jennifer Pryor in preparing this conference. So I would like to thank them all for their help.

Physiotherapy courses organised by the IPG/CF

In 2002, The Scientific Advisory committee requested that IPG/CF run pre conference training courses on relevant aspects of physiotherapy in CF. Already five courses have been organised. Last year we ran a Non-invasive Ventilation in CF course and a half a day course on Inhalation therapy. This year we presented a 1.5 day course on “Integrating the pulmonary, musculoskeletal and neuromuscular systems: A physical approach to CF”. Next year we’re planning a 1.5 day course on Inhalation therapy. Feedback from all of the courses has been excellent. The courses have been well attended and have been profitable; this resulted in a greater funding of expenses (for example for instructors and to print handouts), although there is still a long way to go.

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 fourth consecutive year. Maggie and I have been invited to serve on the ECFS Scientific Committee organising the conference in 2007 in Belek, Antalya, Turkey. 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 and translation into Spanish

The current version of the Physiotherapy Blue Booklet has been translated into Spanish by volunteer translators of Cystic Fibrosis Worldwide. Marcella Baldoni, our contact person in Argentina accepted our proposal to double-check and improve the translation, before it was posted on the IPG/CF website. The English and Spanish version of the booklet can now be downloaded. Reprints and translations of the booklet are only possible after permission of the IPG/CF board. The Blue Booklet is the most downloaded document on the CFW website!

An updated edition of the Blue Booklet will be developed. A lay version of the booklet will be written concurrently to meet popular demands.

Cystic Fibrosis Worldwide Newsletter

Jill Weinstein, the new editor of the CFW Newsletter, invited me to submit a physiotherapy article to their publication. Her aim is to gather new physiotherapy developments, techniques, and information at least once a year.

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. The physiotherapy article will appear in this month's issue.

Personal membership of the European Cystic Fibrosis Society (ECFS)

During a meeting at the North American CF conference in Baltimore (October 2005), Marie Johansson, the President Elect of the European Cystic Fibrosis Society (ECFS), asked us to motivate all physiotherapists to become member of the ECFS. Apart from the advantages of this membership (please find them in our second newsletter or on the CFW website), Marie Johansson promised us that the more PT's becoming member of the ECFS, the stronger our (financial) position could be in negotiating for international speakers during the conference.

Chiron Best Care Travelling Scholarship – 2006 Winner

Alena Scherbakova from the Research Centre for Medical Genetics, Russian Academy of Medical Sciences, Department of Cystic Fibrosis in Moskvoehie, Russia is the deserving winner of the 2006 Chiron Best Care Scholarship. She plans to study and undertake practical training in October at the Birmingham Heartlands Hospital in the United Kingdom, under the supervision of Lynne Gummery.

Alena accepted the framed certificate and cheque from Mr. Clive Bertram, the Novartis Representative who attended the meeting.

I had a meeting in Brussels with Clive Bertram from Chiron, now Novartis about sponsoring. He decided to continue our sponsoring for the Best Care Scholarship in 2007 (2500 euros) for physiotherapist from countries where there is limited opportunity for education. I promised him to look for better ways to find, contact and stimulate these physiotherapists to apply for this scholarship. To reduce the costs, we will only have electronic application forms or forms to download from the IPG/CF website. So no hard copies anymore.

A part of this budget will probably be used for a second scholarship (1500 euros) for physiotherapists from all over the world, working in so called "developed" countries. The 1500 euros should support them (with, if necessary, financial support of their own center) to visit other qualified CF centers all over the world.

3.2 Treasurer Report

Prepared By Jovita Zerlik



INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

IPG/ CF treasurer Jovita Zerlik
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Germany
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Closing balance 31 December 2005: Euro 3.239,28

Received subscriptions 2006:

Germany	Euro 50
Switzerland	Euro 48,20
Finland	Euro 50
Belgium	Euro 100
The Netherlands	Euro 50
Australia	Euro 56,42
France	Euro 87,50
total:	<u>Euro 442,12</u>

Bank expenses: Euro 36,40

Closing balance 31 December 2006 : Euro 3.645,00

Jovita Zerlik, IPG/CF treasurer

Hamburg, Germany 4.1. 2007

3.3 Secretary Report

Prepared by Esta-Lee Tannenbaum

In the last year we welcomed some new members to the IPG/CF. They are: Saied Rahbar from Dubai (also a new member country), Zagorcapopa Popa from Romania and Lynne Gummery from the United Kingdom.

In total we have 52 member countries. The first newsletter was sent out in November/December last year and the second in early May 2006. I would like to thank everyone who contributed to the newsletters.

Over the past few years there are about 8 or 10 members who have not been responding to e-mail contact or postal letters. My aim for this year is to make contact with the respective CF organization in that country and re-introduce the physiotherapy ties that had previously worked well.

4. 20th Anniversary of the IPG/CF

Louise Lannefors gave a brief but comprehensive overview of the history and formation of the IPG/CF.

5. Paediatric Working Party

Reported by Brenda Button (Australia).

From the questionnaire relevant information had been obtained and prepared as a Manuscript. As the European Respiratory Journal does not accept manuscripts, guidelines have been written as to the physiotherapy management of infants and children with CF. The process of developing these guidelines included the request for feedback from member countries and their colleagues interested in CF. The IPG/CF secretary had e-mailed all members the guidelines in the early part of 2006. The guidelines are 9 pages and include 62 relevant publications which are evidence based.

Further questions raised included the following suggestions:

- The guidelines will also be condensed into a small document to be included in the Blue Booklet, and will be made available on the website. With regards to translating the guidelines – CFW will be approached for funding. All translation requests must be submitted to the IPG/CF committee.

6. Blue Booklet

Reported by Louise Lannefors (Sweden). The current blue booklet is now available in Spanish. The new booklet will include 2 versions; namely a physiotherapist and lay person version. The new booklet is still a work in progress. More broad topics to be included are: postural issues, pregnancy and stress incontinence

7. Glossary

Reported by Louise Lannefors (Sweden). The group is currently on the 4th working version who aims to finalize the first draft by the end of 2006. The aim is to define physiotherapy words and terms currently used to standardize language and its meaning. The glossary will include inhalation therapy, airway clearance techniques and physical therapy. The glossary will be mentioned in the new blue booklet and linked to the IPG/CF website. Connections will be made with the ERS, ATS and WCPT for further improvements and discussion.

8. Transplant Questionnaire

Reported by Paolo Buonpensiero (Italy). 22 responses were received from 50 member countries. This is a disappointing response. Preliminary data did not reach any significant conclusion.

Action Plan: Paolo and Prue Munro (Australia) will contact Transplant centres directly and send them the questionnaire. The questionnaire will be re-defined and then the IPG/CF secretary will re-send it to all Contact Members via e-mail.

9. Chiron Best Care Scholarship

Chiron is now called Novartis. This year's winner is Alena Scherbakova from Russia. The award was presented to Alena by Clive Bertram from Novartis, with Filip (on right – our chairperson) - Picture below:



10. Future Conferences:

2007: June 13-16th Belek, Turkey

2008: June 15-18th Prague, Czech Republic

2009 :



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Treasurer report July 2003 – December 2006

Closing balance 17 July 2003: Euro 1.958,91

Received subscriptions 2003:

Italy	Euro	55,50
Austria	Euro	100
The Netherlands	Euro	43
Switzerland	Euro	48,47
Finland	Euro	50
Poland	Euro	50
Norway	Euro	50
Slovakia	Euro	50

Received subscriptions 2004:

Germany	Euro	50
Australia	Euro	51,62
Czech Republic	Euro	80,58
Norway	Euro	100
Turkey	Euro	50
United Kingdom	Euro	230
The Netherlands	Euro	50

Received subscriptions 2005:

Belgium	Euro	100
Sweden	Euro	50
Germany	Euro	50
Austria	Euro	150
Finland	Euro	50

Received subscriptions 2006:

Germany	Euro	50
Switzerland	Euro	48,20
Finland	Euro	50
Belgium	Euro	100
The Netherlands	Euro	50
Australia	Euro	56,42
France	Euro	87,50

Closing balance 31 December 2006: Euro 3.645,00



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Information about Membership fees for IPG/CF Contact Persons

1. When sending your membership fee to the IPG/CF treasurer please subscribe it to:

Jovita Zerlik, IPG/CF treasurer
Hamburger Sparkasse
Account No.: 1042 880 250
BLZ 200 505 50
IBAN DE73 2005 0550 1042 8802 50
BIC HASPDEHHXXX

Description: IPG/CF membership fee from..... (country)

2. Please make clear which country is sending the membership fee.
3. The membership fee rate is **50 Euro** for one year or the equivalent in other currency. Of course you are free to pay a higher amount. If your country can only pay less than 50 Euro any other sum is also welcome.
4. If you have any problems paying the membership fee please contact any of the IPG/CF committee members for advice.
5. You will receive a receipt after payment.

Thank you very much for your support!

Hamburg, Germany 4.1. 2006

Report from the 29th European Cystic Fibrosis Conference, Copenhagen, Denmark, 2006
Prepared by Filip Van Ginderdeuren

More than 2500 delegates registered for the 29th European Cystic Fibrosis Conference in Copenhagen, well known for her little mermaid, musea and the Carlsberg brewery. The conference was held from 15-18 June 2006.

Pre conference course

1) Integrating the pulmonary, musculoskeletal and neuromuscular systems : a physical approach to CF

The one and a half day course was held at the Industriens Hus Creta Maris hotel on June 14 and June 15, before the official opening of the conference. More than 70 physiotherapists registered for the course.

Dr. Mary Massery from Chicago, USA was the course instructor. She was assisted during the practical sessions by Dr. Brenda Button from Australia and Ms. Irene Maguire from Ireland.

Dr. Mary Massery has a private practice, teaches in the physical therapy curriculum at several universities, conducts clinical research, consults at numerous Chicago area hospitals, schools and clinics and conducts year-long multi-disciplined pulmonary mentorship programs. In 2002 she received the American Physical Therapy Association's highest clinical award (*The Florence Kendall Practice Award*), for her outstanding and enduring contributions to the practice of physical therapy.

The course demonstrated the simultaneous role of the trunk muscles for regulation of postural control and ventilatory support and the consequences of this duality for children and young adults with CF on their maturing musculoskeletal frames.

Dr. Massery looked at the "external" musculoskeletal support system and how this compromised system can effect the function of "internal" structures such as lungs, internal organs, and vice versa. Recent studies now consistently show bone mass density (BMD) deficiencies and other related musculoskeletal abnormalities in all age groups. Medical treatment is primarily focused on microscopic interventions with biphosphonate. Physical Therapy (PT) or other physical rehabilitation strategies are not suggested nor reported in current MD studies. Current physical studies are primarily focused on macroscopic interventions (PT). Optimal time for postural intervention is between 8-12 years to prevent or minimize secondary musculoskeletal impairments.

Dr. Massery explained the relation between the demands of breathing and the musculoskeletal development by using the "Soda-Pop Can" model and looked at the dual nature of postural control and breathing. Every muscle of the trunk is both a respiratory *and* a postural muscle.

In the next part the screening for musculoskeletal and/or neuromuscular recruitment impairments in CF were highlighted by case reports and practical sessions. All participants practiced postural screening, shoulder and rib cage screening and specific testing of the "thoracic spine, shoulder, scapulae, rib cage and breathing patterns in small groups.

The final part of the course was focused on designing targeted interventions for the thoracic spine (trunk extension and rotation), shoulder/scapulae and rib cage by mobilization and neuromuscular retraining and strengthening. All joint mobilizations and stretching exercises were practiced by the participants.

Dr. Massery discussed also the potential long term benefits of incorporating targeted postural and muscle retraining interventions in CF programs such as improved mechanical support and breathing mechanics, preventions of painful joint conditions due to malalignment or misuse.

Physiotherapy case presentations

Eight physiotherapy case presentations were moderated by J. Zerlik (D) and R. Dentice (Aus). To remember:

- The need for a flexible approach to choosing a suitable physiotherapy regime in CF children, especially in those patients showing a wide range of other complex problems which make “conventional physiotherapy” difficult. Multidisciplinary team involvement in actioning a plan was paramount.
- Is there a danger to slim treatment to enhance adherence? Who carries the responsibility?
- With improved survival, young women with cystic fibrosis (CF) are increasingly requiring counselling with regard to the likely effect of pregnancy on their clinical course. Recent reviews regarding CF pregnancies have reported good outcomes even for those with relatively severe lung disease if antenatal care is optimised
- Peripheral mucus plugging, uncontrolled pulmonary infections and sepsis during invasive ventilation was possible to avoid despite CRP >400, by aggressive ACT (instillation of saline, manual bagging and thoracic compressions) as a main component of the intensive care.

Symposium

The physiotherapy symposium on “ Challenges in the physiotherapy care of CF patients“ was chaired by Dr. B. Button (Aus) and S. Gursli (NO) .Dr. J. De Schepper(Bel) gave an overview of pain caused by musculo-skeletal problems in CF. Musculo-skeletal pain originates from several bone disorders involving mainly spine and leg bones and from inflammation of the major joints. Musculo-skeletal pain increases with age and deteriorating lung disease and needs a rapid and aggressive pain management.

Dr. M. Massery (USA) discussed the physiotherapy treatment for musculo-skeletal problems in CF.

Dr. B. Button (Aus) talked about the prevention, control and treatment of urinary incontinence (UI). Urinary incontinence is common in women with chronic lung disease, across all age groups. The pelvic floor muscle function appears to be normal, but muscle

fatigue with prolonged force applied to the pelvic floor with huff and cough, during acute exacerbations, worsens the urinary incontinence. An effective physiotherapy treatment to prevent, control and treat UI consist of:

- Teaching the knack: a pre-contraction of the pelvic floor, prior to a precipitating activity: coughing, huffing, sneezing and all activities that apply pressure to the pelvic floor.
- Neutral or extended pelvic spine during ACT, huffing and coughing, to facilitate recruitment of the pelvic floor muscles and transversus abdominus.
- pelvic floor muscle training.

Dr. G. Davidson (CDN) discussed the factors to consider when using mucolytic agents with airway clearance. Factors to consider are: when to commence their use, timing with the airway clearance, effectiveness, cost effectiveness.

Most promising results are found with hypertonic saline and rhDNase (Pulmozyme).

Workshops

“What’s new in exercise and airway clearance techniques” was moderated by EL Tannenbaum (Aus) and Dr. O-T StorrØsten (NO). Presentations on aerobic and strength training in patients with CF and severe airway obstruction; Chest strength and mobility training: a new approach to airway clearance ; short-term effects of Autogenic Drainage combined with wet inhalation of saline versus Autogenic Drainage combined with Intrapulmonary Percussive Ventilation with saline; A comparison of five airway clearance techniques in the treatment of CF patients; and pulmonary deposition of inhaled tobramycin, before and after physiotherapy and inhaled salbutamol and correlation with Shwachmann Score in CF patients. For more details on these studies, please find abstracts 375, 371, 349,347 and 180 in “Journal of Cystic Fibrosis”, vol 5, suppl 1, June 2006.

“Adherence in CF” was moderated by L. Lannefors (Swe) and Dr. A. Duff (UK). This workshop included presentations on: three methods of monitoring adherence in a long-term trial in CF; adherence to airway clearance therapies in patients with CF; patient satisfaction with physiotherapy techniques for airway clearance in CF; “Breath easily “: an educational program to improve patients’ adherence to daily inhalations; and positive expiratory pressure therapy: to adhere or not to adhere? To read more, please find abstracts 504, 436, 365, 440, 363.

Round tables

There were also numerous round table discussions to attend. ‘Hypertonic saline ‘was moderated by M. Elkins (Aus), ‘Role of devices during airway clearance’ was moderated by Dr. B. Button (Aus) and ‘Strategies for optimizing adherence in CF’ by L. Lannefors (Swe).

**20th North American CF Conference, Denver, Colorado, November 2006 -
Prepared by Dr Brenda Button - December 2006**

The following were items of interest summarized from plenary sessions, symposia and workshops attended at the recent conference. Life expectancy continues to increase all the time. There are currently two dozen new therapies in the pipeline being evaluated for use in CF. The ultimate objective is that CF will stand for "Cure Found" not "Cystic Fibrosis". Twenty years ago there were 150 conference attendees, while in 2006 there were around 3,200 dedicated health professionals who participated in the conference. US\$104 million is being invested in new therapies for CF in 2006 which equates to around \$4,000 per patient in the USA.

Gene therapy research is alive and well and regarded as the Holy Grail for CF. There are a number of promising vectors to get the gene to the target areas. New approaches using stealth drugs to get in under the immune radar have been effective in mice studies

The symposium on the gender gap in CF was thought provoking. Potential mechanisms include gender differences in ion transport regulation based on hormonal differences. Oestrogen and testosterone have different positive and negative effects in CF. There is sometimes delayed diagnosis in females. Male infants have narrower airways and therefore may wheeze and display symptoms sooner than female infants. Earlier *Pseudomonas Aeruginosa* colonization has been found in females. Less frequent use of oral supplements, pancreatic enzymes and enteral nutrition has been found in females in a recent study. Women with CF are more likely to develop CFRD (17% of women compared to 12% of men) CFF Patient Registry. Females with CF often eat less than males – the perfect slim woman in our society may need to take some of the blame. Women tend to overestimate their weight whereas men tend to underestimate theirs. Women with CF have higher resting energy expenditure than men. Greater non-adherence to treatment found in studies of women compared to men with CF. Women with CF tend to be involved in less physical activity than men. Skeletal muscle function in CF is different between males and females. Limb muscle strength is reduced in females while inspiratory and expiratory muscle strengths are normal or near normal. Possible mechanisms for decreased muscle strength include malnutrition, systemic inflammation, corticosteroid use, inactivity & abnormal ion transport across the cell membrane. Limb muscle dysfunction may contribute to impairment of exercise capacity in CF. A greater decline in FEV₁ in inactive girls than in active boys was measured in a recent study.

The Basic Airway Clearance Therapy Training Class was enthusiastically attended with Maggie McIlwaine and Brenda Button as principal instructors with contributions from Dr Warren Warwick, Terry Ho, Tom Newton and Jim Bolek. Kristin McFall and a number of people with CF from the Denver region generously participated in the practical teaching of the techniques.

Workshops on airway clearance and activity in patients with end-stage lung disease and airway clearance techniques and an update on evidence were of particular interest to

those practicing physiotherapy. The symposium on airway clearance therapy and the challenging patients attempted to shed light on the management of patients with gastroesophageal reflux, urinary incontinence, haemoptysis and pneumothorax as well as those patients who are non-participants when it comes to physiotherapy.

There were a number of interesting Caregivers' Networking Sessions providing focused information and the opportunity for discussion and networking. We congratulate Catherine O'Malley and Annie Downs, members of the conference program committee responsible for a great program for PTs and RTs in 2006. They would love to hear from any of you with ideas and suggestions for the program in 2007 in Anaheim. Please email them at the following addresses:

COMalley@childrensmemorial.org

andowns@iupui.edu