

# NEWSLETTER 1, 2006



International Physiotherapy Group for Cystic Fibrosis

**January 23, 2006**

Greetings to everyone and wishing you all a happy and prosperous 2006.

This is the first Newsletter for 2006 and the next one will follow in the next few months.

We have a few new Contact Persons to add to our list and we welcome Saeid Rahbar from Dubai (also a new member country), Lynne Gummery from the United Kingdom and Zagorcapopa Popa from Romania.



Committee and members of the IPG/CF

## **Contents:**

Minutes of 2005 AGM.....	Page 2-4
Chairpersons Report.....	Page 5-7
Treasurers report.....	Page 8-9
Membership fees information.....	Page 10
Secretary report .....	Page 11
Message from Filip Van Ginderdeuren.....	Page 12
Crete CF conference reports.....	Page 13-15
American CF conference reports.....	Page 16-17
Contact Person details January 2006.....	Page 18-20

## Minutes

Minutes of IPG/CF held in Crete, 23 June 2005

### Present:

#### Country

Argentina  
Australia  
Belgium  
Canada  
Czech Republic  
Finland  
France  
Germany  
Israel  
Italy  
Netherlands  
Norway  
Poland  
Slovak Republic  
Sweden  
Switzerland  
Turkey  
UK

#### Contact Person

Marcella Bandoni  
Brenda Button  
Filip van Ginderdeuren  
Maggie McIlwaine  
Libuse Smolikova  
Leena Jokinen  
Hugues Gauchez  
Jovita Zerlik  
Vivi Armon  
Paolo Buonpensiero  
Yette Nomden  
Sandra Guersli  
Teresa Orlik  
Marta Heroutova  
Louise Lannefors  
Christine Lully (proxy vote)  
Osman Coban  
Esta-Lee Tannenbaum

Other attendees: 30 people

### Apologies:

Austria	Beatrice Oberwaldner
New Zealand	Rebecca Udy
USA	Anne Lapin

## 2. Minutes from previous meeting held in Birmingham 2004

Accepted by: Sandra Guersli

Seconded by: Libuse Smolikova

**3.1 Chairperson Report** – see separate report

**3.2. Treasurer Report** – see separate report

**3.3 Secretary Report** – see separate report

**4. Election of New Chairperson:** Filip van Ginderdeuren – automatically elected - this is a formality and he was welcomed into his new position.

### 5. Election of Vice Chairperson:

Nomination: Maggie McIlwaine

Nominated by: Filip van Ginderdeuren

Seconded: Louise Lannefors

**6. Farewell H Weggen** – Herman was thanked for his work and support over the years. We wish him well. We are waiting for the official confirmation of his successor and will be informed of a new editor for the newsletter.

## **7. Transplant Questionnaire**

Paolo Buonpensiero (Italy) and Prue Munroe (Australia) have joined resources and have developed an international survey on Physiotherapy and Lung Transplantation. The IPG/CF adopted to continue with their project.

The questionnaire will consist of 2 parts:

Lung Transplant experience (numbers)

Pulmonary rehabilitation (18 questions on exercise, outcome measures and airway clearance techniques)

The questionnaire will be e-mailed to all contact persons by the secretary (Esta-Lee) and they will be asked to e-mail the document to all physiotherapists working in transplant centres within their country. The completed questionnaires will then be e-mailed back to the secretary (Esta-Lee) who will forward the completed questionnaires onto Paolo and Prue.

## **8. Paediatric Working party update:**

It is difficult to have guidelines because of world-wide variations in practice. A draft document has been written by Brenda Button title: Information to guide physiotherapists. This draft document will be sent all Contact Persons who will be asked to send it to interested physiotherapists within their country for their comments and feedback. This feedback should be returned to the secretary who will forward this onto Brenda. This is a very important document and feedback would be very much appreciated.

## **9. Blue Physiotherapy Booklet**

Background: The last edition was published in 2002. It is available on the CFW website and is very popular.

Items for discussion included:

The need for two versions established at last year's AGM: one for professionals and one for the lay community?

Should the new booklet include other items e.g. stress incontinence, posture, CF and pregnancy?

The booklet is currently available in English and has been unofficially translated into Italian without any involvement with the IP

Outcome:

A lay version and a medical version will be written

The 2 versions will include more broad topics as listed above.

The booklet will be kept short and simple for easy reference and access, and will include references

All future translations will be done officially through the IPG with standard double translations to ensure that all translations are accurate.

The group writing the booklet include: Anne Lapin, Filip van Ginderdeuren, Maggie McIlwaine, Jennifer Pryor, Louise Lannefors, Brenda Button

## **10. Glossary Terms: Louise Lannefors**

Background: Currently, the terms being used world-wide differ to a great extent which has implications in terms of understanding what the definition is.

A group consisting of Louise Lannefors, Beatrice Oberwaldner, Brenda Button, Jennifer Pryor and Sandra Guersli are defining scientific physiotherapy words and terms currently being used. This will take another year of work and the aim will be to publish the document. It was also recommended that the document be translated into other languages for scientific and medical purposes.

#### **11. Georgia: Libuse Smolikova**

This project has been discontinued for now. No new updates.

#### **12. Chiron Scholarship for Physiotherapists**

Clive Bertrum from Chiron announced the 2006 Chiron Scholarship award. The award is open to all international physiotherapists to improve their knowledge and experience in the area of CF. The value of the award is Euro's: 2500-00. The application is available at the Chiron stand and will be posted on the IPG/CF newsletter. Deadline for applications is the 1st December 2005

The 2004 winner was Osman Coban from Turkey. Osman gave a presentation of his visit to Belgium where he spent time at Zeepreventorium (with Jean Chevaillier) and the Free University of Brussels Children's Hospital (with Filip van Ginderdeuren).

The 2005 winner was Marie Rodriguez from Argentina. She spent a month in Lund with Louise Lannefors. Louise Lannefors received the prize on behalf of Maria Cecilia Rodriguez.

#### **13. WHO liason**

Liliane Heidet has written a letter to WHO. CFW have responded to Liliane re future involvement of CFW with WHO.

#### **Future conferences:**

2006 Copenhagen

2007 Turkey (not confirmed)

#### **14. Other business**

The IPG/CF wished Jean Chevaillier the very best with his retirement and thanked him for his contribution to physiotherapy and CF.

The IPG/CF thanked Brenda Button for all her hard work and dedication over the past four years on the committee as vice-chair and chairperson. Brenda remains on the IPG/CF as the contact person for Australia and she is involved with numerous IPG/CF working parties.

Prepared by Esta-Lee Tannenbaum, July 2005

## **Chairperson's Report, Annual General Meeting, Crete, Wednesday June 22, 2005**

**Prepared by Brenda Button July, 2005**

On behalf of the IPG/CF Board I welcome you to the 2005 annual general meeting. This is my final AGM officiating in the role of chairperson. I will be handing over the reigns to Mr Filip Van Ginderdeuren, who was elected four years ago as Vice-Chairperson, a preparatory role for that of Chairperson. I have received great support from Filip together with the other members of the Board, namely Esta-Lee Tannenbaum (Secretary) and Jovita Zerlik (Treasurer) as well as Sandra Gursli (past Chairperson), Carien Beurskens (past Treasurer) and Libuse Smolikova (past secretary). Thank you all for your support, advice and friendship during the time we have served on the IPG Board together. It has been a great privilege to serve on the IPG/CF Board first as Vice-Chairperson and then as Chairperson.

### **Cystic Fibrosis Worldwide and its relationship to the IPG/CF**

The current IPG/CF Board has representation on the Executive Committee of the newly formed Cystic Fibrosis Worldwide (CFW) which incorporated the original associations of ICFMA and IACFA. The IPG/CF was associated to the ICFMA via the Scientific Advisory Committee (SMAC) which was disbanded at the time of the formation of CFW. Mr Herman Weggen from the Netherlands was elected as the founding President of CFW. Due to personal reasons he has recently resigned from the position and Mr Mitch Messer from Australia has been elected as the future President of CFW. We the IPG/CF congratulate Mitch on his appointment and look forward to working with him in the future. Ms Ella Weggen current Editor of the CFW Newsletter has also for personal reasons stepped down from her role. She will be pursuing studies abroad. We wish Ella all the very best. Ms Jill Weinstein will be taking over the role of Editor from Ella. We the IPG/CF look forward to working with Christine in the future.

### **Physiotherapy courses organised by the IPG/CF**

In Genoa, 2002, the Scientific Advisory Committee requested that the IPG/CF run pre-conference training courses on relevant aspects of physiotherapy in CF. In 2003, we held a Basic Airway Clearance Training Course in Belfast, Ireland. This was followed by an Advanced Airway Clearance Course and an Exercise Testing in CF Course in Birmingham, UK in 2004. This year we presented a Non-Invasive Ventilation in CF Course and a course on Inhalational Therapy. Feedback from all of the courses has been excellent. Attendees have been pleased to receive certificates of attendance signed by the instructors and endorsed by the IPG/CF and the European CF Society (ECFS). To date the courses have been well attended and have been profitable. One of our goals is to lobby for greater funding of expenses for instructors and course organisers than is currently available.

### **ECFS Scientific Committee Representation**

The Chairperson and Vice-Chairperson (Brenda Button and Filip Van Ginderdeuren) have been invited to be members of the ECFS Scientific Committee organising the physiotherapy program together with local physiotherapists in different countries. Particularly difficult challenges arise when there are no local physiotherapists to assist the Scientific Committee such as in Crete this year. Filip Van Ginderdeuren and

Maggie McIlwaine have been invited to serve on the ECFS Scientific Committee organising the conference in 2006 in Copenhagen, Denmark.

### **Blue Booklet and translation into various languages**

The IPG/CF was informed that the Blue Booklet is the most downloaded document on the CFW website. There have been numerous requests for translations into multiple languages. Following discussion with the membership it was decided that following the development of the next edition, verified reverse translations will be carried out in all the languages requested by CFW and funded by the organisation to ensure accuracy of translation. Once this process is completed then the new edition together with the lay version in all languages will be made available on the CFW website. This was discussed at the meeting with the CFW Board and its new president, Mr Mitch Messer and adopted as the future plan of action.

### **Farewell Herman Weggen (President, CFW) and Ella Weggen (Editor of CFW Newsletter)**

The IPG/CF acknowledged the contribution made by Herman and Ella Weggen in their respective roles in CFW. For personal reasons both have resigned from their positions. We the IPG/CF Board wish Herman all the very best in his future life. We also wish Ella all the very best in her studies and future.

### **Paediatric Working Party: future directions**

The manuscript reporting the results of the International Infant Questionnaire is completed and is currently being submitted to a peer review journal for publication. A first draft of an information document has been developed by Brenda Button (Co-ordinator of the Paediatric Working Party) for review and comments in an attempt to develop broad guidelines for the physiotherapy treatment of infants with CF. A draft copy "Information to guide physiotherapists in the treatment of infants" was made available at the end of the AGM. Each country contact person of the IPG/CF will be forwarded an electronic copy with this Newsletter so that all countries can provide critical review and comments. The next draft will be made available at the ECFS Conference in Copenhagen next year.

### **Updating the IPG/CF Blue Booklet**

A working party has been formed to develop the next edition of the IPG/CF Blue Booklet. A lay version of the booklet will be written concurrently to meet popular demand. The members of this working party are: Anne Lapin (USA), Louise Lannefors (Sweden), Filip Van Ginderdeuren (Belgium), Brenda Button (Australia), Maggie McIlwaine (Canada) and Jennifer Pryor (UK).

The IPG/CF membership was asked to comment on what form the next edition should take. Discussion ensued and broadly speaking the membership felt the booklet should be remain concise but should include pathophysiology of CF together with the physiotherapy management of pregnancy and urinary incontinence in CF. An evidence based approach was recommended.

See Chairperson's report regarding translation of the Blue Booklet in various languages.

**Development of an international questionnaire on the physiotherapy treatment of CF patients while on the transplant waiting list and after transplantation**

Mr Paolo Buonpensiero (Italy) has approached the IPG/CF with a draft fact finding questionnaire for consideration. Ms Prue Munro (Australia) has also been developing a questionnaire on the same topic. These two have now in collaboration established an international questionnaire. Paolo presented aspects of the questionnaire to the membership at the AGM. Hard copies of the questionnaire were circulated after the AGM. A copy of the questionnaire will be sent to each country contact person with this Newsletter to disseminate within their regions. Completed questionnaires should be sent to Esta-Lee Tannenbaum, Secretary of the IPG/CF who will forward them on to Paolo and Prue.

**Chiron Best Care Travelling Scholarship – 2005 Winner**

Maria Cecilia Rodrigues from Buenos Aires, Argentina, is the 2005 winner. She is undertaking an education and training course at the CF Centre in Lund, Sweden under the instruction of Ms Louise Lannefors. Louise accepted the framed certificate and cheque from Mr Clive Bertrand, the Chiron representative who attended the meeting and who promised further support from Chiron in 2006. Copies of the Chiron Best Care Scholarship application form were made available at the conference and the IPG/CF secretary will mail out a reminder of the application closing date one month before closing.

Thanks and good wishes to the new Board and all the members of the IPG/CF community. It has been a great pleasure serving on the Board. I have made many great friends, have learnt many new skills and gained much new knowledge being involved with the physiotherapy community internationally. I wish the IPG/CF Board and all its members all the very best in the future and look forward to seeing you at future conferences. Kind regards, Brenda Button



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## Treasurer report 2005

**Closing balance 31 December 2004:** Euro 2.962,73

### Received subscriptions 2005:

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

Expenses for the board: Euro 85,95

Bank expenses 2005 : Euro 37,50

**Closing balance 31 December 2005:** Euro 3.239,28

Jovita Zerlik, IPG/CF treasurer

Hamburg, Germany 9.1. 2006



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## Treasurer report 2004

**Closing balance 31 December 2003:** Euro 2.386,93

### 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

Bank expenses 2004 : Euro 36,40

**Closing balance 31 December 2004:** Euro 2.962,73

Jovita Zerlik, IPG/CF treasurer

Hamburg, Germany 6.1.2005



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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 HASPDEHH

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.

Hamburg, Germany 6.1.2005

## **Secretary report**

**By Esta-Lee Tannenbaum**

To date we have 51 member countries. I would like to thank the committee for their prompt responses to my e-mails and queries. I have updated the Yearbook of International Organizations regarding the IPG/CF in terms on member countries and our goals and aims as an organisation. Information regarding the IPG/CF can be found on the following website: [www.cfww.org](http://www.cfww.org) and follow the link through the 'partners' section. An updated list of member contact persons can be found there too.

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.

## **Copenhagen CF Conference**

The next European CF conference is taking place in Copenhagen, Denmark from the 15-18 June 2006. The programme looks very exciting and with the soccer world cup on at the same time (albeit in Germany) – I am confident that many of you will be at the conference!

The outline of topics for physiotherapists (and any other professionals!) include:

➤ **Pre-conference course:**

**Title:** 'Musculoskeletal and Neuromuscular problems and therapeutic interventions: A Physical approach to CF'

**Lecturer:** Dr Mary Massery (Physiotherapist, Chicago, USA)

**June 14<sup>th</sup> :** 9:00-17:00

**June 15<sup>th</sup> :** 9-12:30

➤ **IPG/CF AGM**

June 15<sup>th</sup> : 12:30-14:00

➤ **Physiotherapy Case Presentations**

June 15<sup>th</sup> : 14:00-17:00

➤ **Workshop: Physiotherapy**

Title: What's new in exercise and airway clearance techniques  
(Abstracts required)

June 16<sup>th</sup>

➤ **Symposium: Physiotherapy**

Title: Challenges in the physiotherapy care of patients with CF

June 17<sup>th</sup>

For further details and updates, please visit their web page:

[www.europeanCFconference.org](http://www.europeanCFconference.org)

## Message from Filip Van Ginderdeuren

Dear Colleagues

On behalf of the IPG/CF Board and all its members I would like to thank Brenda Button from Australia very much for her contribution to the IPG/CF during her three year term as chairperson on the IPG/CF Board. Thanks to her efforts, IPG/CF is well on the map again, being a member of the Scientific Committee of the European Cystic Fibrosis Society and part of the official programme by means of well-attended pre-conference courses, symposia, workshops and round tables. Brenda gave much of her time and energy to the IPG/CF and we would like to acknowledge her service to the organization. She will be past chairperson for consultation as required during the next three years.

I would also like to congratulate Mr. Jean Chevaillier for his long and outstanding career as physiotherapist at the Zeepreventorium, a long-staying centre for patients, needing special respiratory care. Starting his career back in the sixties, Mr. Chevaillier worked with asthmatic and CF patients and developed his own airway clearance technique: Autogenic Drainage. According to Jean, effective clearance of airway secretions depends on a number of factors:

- An effective “pump”
- Effective mucociliary transport
- Optimal air velocity and -flow

He refined Autogenic Drainage over the years to what it is at this moment: a modern and efficient airway clearance technique

Autogenic Drainage can be combined with or incorporated in other ACT's, mobilisation exercises and physical training.

Jean is also well-known as an instructor and is teaching many courses all over the world. Being a clinician for over thirty years with an enormous practical experience, his purpose has always been to put the theoretical evidence into practice. We would like to congratulate him on his retirement and are convinced that we can count on his knowledge and experience for many years.

I look forward to serving you as Chairperson for the next three years and welcome your comments, concerns or suggestions regarding IPG/CF. Please contact me by email at: [Filip.vanginderdeuren@az.vub.ac.be](mailto:Filip.vanginderdeuren@az.vub.ac.be)

Yours sincerely,

Filip Van Ginderdeuren  
New Chairperson IPG/CF

## **Report from the 28th European Cystic Fibrosis Conference, Hersonissos, Crete, 2005**

**Prepared by Filip Van Ginderdeuren**

Crete, well known as an excellent holiday destination, was the place to be for over 2000 members of CF care teams from Europe and all over the world. The ECF conference was held from 22-25 June 2005 in Hersonissos, Crete, Greece.

### **Pre conference courses**

#### **1) Non-invasive ventilation in Cystic Fibrosis : theory and practice**

This one day course was held at the Creta Maris hotel on the Tuesday before the main conference. Dr. Alan Young and Dr. Anne Holland from Australia started with an overview of the pathophysiology of acute (ARF) and chronic respiratory failure (CRF), evidence for O<sub>2</sub> therapy in CRF, evidence and guidelines for use of NIV in ARF and CRF, implementing and titrating NIV in chronic respiratory failure in CF and complications in NIV, such as pneumothorax and nasal obstruction.

Factors associated with NIV success are:

- high PaCO<sub>2</sub> with low A-a oxygen gradient;
- improvement in pH, PaCO<sub>2</sub> and Respiratory Rate after one hour of NIV
- good level of consciousness.

Because NIV delivers air at high flow rates and low relative humidity, the capacity of the mucosa to heat and humidify inspired air may be overwhelmed. This means that efficient humidification is very important to avoid sputum retention in patients at risk. Treatment effectiveness can be achieved with commercially available heated humidifiers with an absolute humidity between 19 and 34 g/m<sup>3</sup>.

Marianne Borremans, from Belgium, completed this session with the use of NIV in the Intensive Care Unit, looking at the indications for NIV in ICU, success and failure in NIV use and pitfalls, complications and contra-indications.

During the practical session, participants were divided into small groups and practiced in different steps the use of BIPAP on each other, focusing on humidification and IPAP and EPAP.

Frederic Van Hille (Bel) explained the Intrapulmonary Percussive Ventilation (IPV) technique. IPV is a method of treatment and short term ventilation of obstructive or/and restrictive, acute or chronic respiratory diseases. IPV delivers a continuous pulsatile flow rate, superimposed on the patient's breathing pattern, improving the bronchial and pulmonary mucus clearance.

Contra-indications are severe haemoptysis and a non-drained pneumothorax. IPV should always be combined with other airway clearance techniques.

Jean Chevaillier (Bel) and Dr. Anne Holland (Aus) discussed the physiotherapy applications of NIV.

NIV can assist Airway Clearance. NIV is well tolerated during AC and patients have less dyspnoea. NIV during AC is more beneficial for those patients with poor respiratory muscle strength and more severe bronchial obstruction.

NIV may enable more effective exercise training in patients severely limited by dyspnoea, because NIV unloads respiratory muscles during periods of high ventilatory demand. NIV can also prevent exercise-induced desaturation.

The course day ended with small group in-depth discussions of one case, followed by whole group discussion of all cases.

## **2) Optimising inhalation therapy in CF**

Dr. Leif Eriksson and Louise Lannefors from Sweden planned to discuss the drugs, treatment of strategy and choice of device; current and future nebuliser systems and the inhalation technique and optimized deposition pattern in this half-day course, but never got to the end because of the enormous amount of interesting questions. So we already decided with the approval of Louise (thank you !!) to organise a one and a half day pre-conference course on nebulisation and inhalation therapy in 2007.

Intrapulmonary deposited dose and deposition pattern depend on many factors, f.e. aerosolised nominal dose, respirable aerosol, drug output, ventilation distribution, breathing pattern and inhalation technique...

Using one aerosol device for all inhaled medication by a given patient should be avoided. Selecting the appropriate nebulisation devices optimizes aerosol delivery and lung deposition, avoiding side effects. The choice of a nebuliser system should be influenced by:

- 1) the prescribed drugs
- 2) the physical/mental capacity
- 3) lung function
- 4) personality and back up
- 5) using situation

The alternative inhalation modes are powder inhalers, pMDI's and nebulizer systems. A MMAD of 3µm is necessary for a good peripheral airway deposition of aerosolized particles.

Maintenance and cleaning of the different devices are necessary for an optimal performance and delivery of the medication and to avoid microbacterial growth on the different parts.

### **Physiotherapy case presentations**

Six physiotherapy case presentations were moderated by J. Zerlik (D) and J. Howard (UK). To remember:

- High intensive exercise training (top athlete) is possible despite Cepacia infection.
- Treatment of Aspergillous infection should be started early, even without APBA diagnosis.
- Preventive chest mobilisation should be included in daily treatment as soon as possible.

- Use of a negative pressure RTX Biphasic Cuirass Ventilation as a bridge for lung transplantation in patients with end-stage lung disease showed no side effects in a preliminary study on two patients.

### **Symposium**

The interesting symposium on “Management of the upper airways “ was chaired by S. Halewijck (Bel) and A. Holland ( Aus ) and included presentations on ‘Anatomy and physiology of the upper airways’ ( S. Halewijck), Medical and surgical treatments’ ( A. Coste ), ‘Oxygen therapy, NIV and the upper airways’ ( A. Young , A. Holland )and ‘Physiotherapy treatment options’ ( J. Chevaillier). All speakers stressed the importance of physiotherapy for the upper airways as a preventative measure to avoid upper and lower respiratory tract infections. Jean Chevaillier gave a practical demonstration of correct nose rinsing with the Jala-Neti at the end of the session.

### **Workshops**

“Optimizing physiotherapy in CF” was moderated by L.Smolikova(CZ). Presentations on evaluation of a CF physiotherapy homecare service for adults; the relationship between pulmonary function and adherence in performing physiotherapy- a follow-up study; timing of nebulisation of rhDNase and airway clearance techniques in children with CF and long term effects of PEP or RC Cornet on FEV1 and perceived health in children with CF. For more details on these studies, please find abstracts 371, 362, 363 and 374 in “Journal of Cystic Fibrosis, vol 4, suppl 1, June 2005.

“ Motivating exercise in CF” was moderated by L. Lannefors ( SW) and S. Gursli (NO). This workshop included presentations on walking distance , perceived physical functioning and respiratory problems in children with CF; Modified Shuttle Test and 20 m Shuttle Test in children with CF; relationship between Six-Minute Walk Test Distance and coordination and leg muscle dysfunction in CF patients and severe airway obstruction. To read more, please find abstracts 367,360,378,373.

### **Round tables**

There were also numerous round table discussions to attend. ‘Optimising airway clearance and inhalation therapy’ was moderated by F. Van Ginderdeuren(Bel) and ‘Setting up a physical training programme’ by L. Lannefors (SW).

## **19th North American Cystic Fibrosis Conference. Baltimore, Maryland, October 19-23, 2005: Respiratory and Physical Therapy (Physiotherapy) Report – prepared by Dr Brenda Button**

This year, over 3,000 people attended and according to the enthusiastic and positive comments received by the Foundation; this was their “best conference yet!”

### **Airway Clearance Techniques Training Course**

This popular pre-conference day and a half course was instructed by Maggie McIlwaine, Filip Van Ginderdeuren and Brenda Button. The course is primarily directed towards Respiratory and Physical Therapists (Physiotherapists) who are responsible for teaching airway clearance techniques to patients with CF. Day one consisted of lectures on the physiological principles of the different techniques as they affect CF airway patho-physiology together with practical demonstrations. On Thursday morning, participants divided into smaller groups for practical hands-on experience of the techniques including the participation of patients. Kevin Blake, Tom Newton and Jim Bolek assisted with the groups.

### **Workshops**

There were three physiotherapy and exercise specific workshops that stimulated interest and discussion. (1) “Forgotten Muscles: Pelvic Floor Weakness & Urinary Incontinence in CF” was moderated by Mary Dodd and Brenda Button. Mary Dodd presented a comprehensive review of “Incontinence in CF: what we know” which was followed by Abstracts 368 & 369, research on pelvic floor muscle function in CF and COPD and physiotherapy treatment. Marg Sherburn, a specialist continence physiotherapist from Melbourne, Australia spoke about state of the art investigation of pelvic floor muscle function and treatment. Brenda Button completed the session with evidence based clinical recommendations.

(2) “Challenges in Pulmonary Rehabilitation” was moderated by Ellen Newbold and Roberts Dekerlegand. This Abstract led workshop (Abstracts 370 – 375) included exercise testing; the relationship of lung function, nutrition and exercise; bone mineral density; inspiratory muscle training; habitual, aerobic and anaerobic exercise on lung health in CF. (3) “ACTs – What’s New in 2005” was moderated by Jennifer Agnew and Catherine O’Malley. This session included Abstracts 377 – 382 which incorporated HFCWO and PEP therapy; a comparison of manual chest physiotherapy, PEP and OscPEP on mucociliary clearance in CF; use of a “Frequencer” in CF; use of a well-being scale in children with CF; and the provision of consistent effective airway clearance to patients with CF.

### **Symposium presentations**

“But I thought it was my lungs: muscle function in CF” – this interesting symposium chaired by Anne Swisher and Larry Lands included exercise limitation in CF, the effects of gender; muscle metabolism and its relation to CFTR; the effect of pseudomonas lung infection on muscle function- lessons from animal models.

### **Care giver discussion groups**

The two ever popular interactive, discipline specific, Caregivers Discussion Groups for therapists this year included one session on “Patient Care: Interesting or Unusual Cases” led by Tom Newton. The second session was “Nebulized Medications” led by

Robert Kuhn (pharmacist) and David Blackney for respiratory therapists, while, “Practical Aspects of Exercise Training”, a practical session was instructed by Ammani Prasad and Kevin Blake for physiotherapists.

### **Roundtable Discussion Groups**

These breakfast and lunchtime sessions included many different topics related to airway clearance therapy, exercise and inhalation therapy.

### **Posters**

There were many interesting posters presented on Physical and Respiratory Therapy - see Abstracts 368 – 385.

### **Conference Symposia Session Summaries and Abstracts**

These can all be read in Pediatric Pulmonology 2005; Supplement 28.

### **Acknowledgement**

A big thank you to Annie Downs, the representative for Respiratory and Physical Therapists on the Program Committee who has once again put together a conference program of high quality and interest for therapists worldwide.



**LIST OF THE NATIONAL CONTACT PERSONS OF THE IPG/CF**  
**e-mail addresses**

Updated January 2006

Chairperson: Filip van Ginderdeuren  
Vice Chairperson: Maggie McIlwaine  
Treasurer: Jovita Zerlik  
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