

1 February 2005



International Physiotherapy Group for Cystic Fibrosis

NEWSLETTER 1, 2005

Introduction

Welcome to the 1st Newsletter of the IPG/CF for 2005. We hope that you will find the newsletter informative and that you are kept up-to-date with current matters.

It is an honour to have been elected into the post of secretary for the IPG-CF. I would like to thank Libuse for her hard work and for making our communication so much easier with e-mails.

I would like to welcome three new Contact Persons to our group:

Bente Kristensen from Denmark (Mette Kelstrup has retired. See message to Mette from IPG/CF on page ..)

Mr Paulo Buonpensiero from Italy and
Alena Sherbakova from Russia

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.

Best wishes for 2005
Esta-Lee Tannenbaum
Secretary for IPG/CF

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**Minutes of the Annual general meeting of the IPG/CF, Birmingham, UK
Sunday 13 June 2004**

List of Contact persons attending the AGM/IPG/CF/2004

Present: (alphabetically by country)

Country:	Name:
Australia	Brenda M. Button
Austria	Libuse Smolikova deputising for Béatrice Oberwaldner
Belgium	Filip van Ginderdeuren,
Canada	Maggie McIlwaine
Czech Republic	Libuse Smolikova
Germany	Jovita Zerlik
Norway	Sandra Gursli
Oman	Nasser Saeed Al Hajry
Poland	Teresa Orlik
Slovakia	Marta Heroutová
Sweden	Louise Lannefors
The Netherlands	Lourens Albeda
Turkey	Osman Coban,
United Kingdom	Esta-Lee Tannenbaum

Apologies received from Contact Persons:

Austria	Béatrice Oberwaldner
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The Chiron Best Care Award 2004 was presented to Osman Coban from Turkey. See Chairperson's report

Reports:

Chairperson
Treasurer
Secretary
See below.

Election of a new Secretary: Esta-Lee Tannenbaum was unanimously elected secretary for the next four years.

Jovita Zerlik was confirmed as Treasurer for the next four years.

Christine Noke the business manager for CFW asked Libuse Smolikova to participate in the preparations for a workshop for therapists and parents of CF children in Georgia. The IPG/CF board agreed to cooperate in this way. For more information please see www.cfww.org

Paediatric Working Party – see Chairperson’s report

The International Committee to develop the draft document consists of Brenda Button (Australia), Beatrice Oberwaldner (Austria), Maggie McIlwaine (North America), Louise Lannefors (Sweden), Elaine Dhouieb (UK) and Jan Custers (Netherlands)

Scientific Research Peer Review Committee – Discussion of the need to unify the terminology used in CF physiotherapy publications see Chairperson’s report

Future physiotherapy conference topics – a subcommittee has been established of past Chairpersons to co-ordinate requests/ideas for future physiotherapy topics at the CF conferences. The sub-committee includes: Sandra Gursli, Jennifer Pryor and Maggie McIlwaine. The contact persons will liaise with their respective countries as to requests for future topics; e-mail them to the secretary who will co-ordinate the list and send it to the sub-committee.

Artimino – see Vice Chair report.

Development of International Questionnaire of physiotherapy treatment before and after transplantation – See Chairperson’s report.

Filip van Ginderdeuren called for more case presentations for the Conference in Crete and for more active participation by physiotherapists in the preparation of future conferences.

Chiron Best Care Award 2005 – deadline for application has been extended to 20 February, 2005.

IPG/CF is happy to cooperate in future courses for CF physiotherapists and the board welcomes any proposals. We will cooperate in setting standards, because attendants will receive a certificate.

Future conferences:

2005 Crete, Greece

2006 Copenhagen, Denmark

2007 Probable venue Turkey

Prepared by Libuse Smolikova and Esta-Lee Tannenbaum
September 2004

IPG/CF Chairperson's Report

Prepared and respectfully submitted by Dr Brenda Button, January, 2005.

Changes to the IPG/CF Board

On behalf of the IPG/CF Board and all its members I would like to officially thank Libuse Smolikova and Carien Beurskens for their long and excellent service as Secretary and Treasurer, respectively, to the IPG/CF Board. Both have been involved in CF care for many years and have brought a wealth of knowledge, experience and dedication to their positions. Serving together on the IPG/CF Board results in strong international links and we look forward to continuing our friendship with you as you go forward and tackle new tasks. Esta-Lee Tannenbaum and Jovita Zerlik were unanimously elected and confirmed respectively as secretary and treasurer for the following four years. We all welcome you both and look forward to working with you in the 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. Discussion at the ECFS Conference in Birmingham led to the conclusion that a set of broad guidelines should be prepared from the results of the survey for circulation amongst all interested physiotherapists with the objective of establishing broad guidelines for physiotherapists treating infants with CF. This task will commence in 2005. Brenda Button, Beatrice Oberwaldner, Maggie McIlwaine, Louise Lannefors, Elaine Dhouieb and Jan Custers will develop the draft proposal to present to the IPG/CF membership in Crete, June 2005 for review and comment.

Future physiotherapy research in CF

Discussion relating to physiotherapy research in CF resulted in a decision to establish an IPG/CF Scientific Research Peer Review Committee to assist researchers establish high quality research proposals and sound methodology for future individual centre and multi-centre research. Past Chairpersons of the IPG/CF will make up this committee.

IPG/CF Course Certificates for Course Attendants at IPG/CF sponsored courses

The IPG/CF Board was asked whether certificates of attendance endorsed by the IPG/CF could be provided to attendees of IPG/CF approved courses in the future. This request was proposed to the members at the AGM in Birmingham and unanimously adopted following discussion. Certificates were provided to attendees of the 'Advanced Airway Clearance Therapy' course and the course titled 'Exercise Physiology & Practical Aspects of Exercise Testing and Programmes' at the ECFS Conference in Birmingham, UK in June 2004. Certificates will be presented to all attendees of future courses approved by the IPG/CF Board.

Election of Board members who subsequently move to other countries while in office

A question arose as to what would happen if one was elected to the IPG/CF Board and then, being a member of the global village, moved to another country. Following discussion the decision was that the person moving would resign as country contact person and would serve out the full term of office of the IPG/CF Board position in the new country.

Winner of the Chiron Best Care Scholarship – 2004

Congratulations to Osman Coban, winner of the scholarship to study airway clearance therapy and in particular Autogenic Drainage in Belgium with Filip Van Ginderdeuren and with Lyn Gumery in Birmingham in the UK.

Physiotherapy course for Georgia

Libuse Smolikova will run a training workshop for therapists and parents of CF children in Georgia, Eastern Europe. The IPG/CF Board supports Libuse in this project and offers appropriate support. For more information about CFW's plans to set up a CF centre in Georgia please see www.cfww.org

Terminology used in CF physiotherapy publications – developing an international bibliography

Many discussions have been held over the years about the discrepancies and differences in the use of terms and definitions that relate to physiotherapy. Louise Lannefors proposed the establishment of an international working party that would develop a bibliography of commonly used terms and definitions for use in research proposals and publications to avoid the confusion that currently exists. The following will make up this working party: Louise Lannefors (Sweden), Jean Chevaillier (Belgium), Sandra Gursli (Norway) Jennifer Pryor (UK), Maggie McIlwaine (North America), Beatrice Oberwaldner, (Austria), Brenda Button (Australia). The first draft of the bibliography will be presented at the Annual General Meeting of the IPG/CF in Crete, June 2005.

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), Maggie McIlwaine (Canada) and Jennifer Pryor (UK).

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

It has been recognised that not much is known about how physiotherapists around the world treat patients before and after lung transplantation. A growing number of patients with CF are being transplanted. Paolo Buonpensiero (Italy) has approached the IPG/CF with a draft fact-finding questionnaire for consideration. Prue Munro (Australia) has also been developing a questionnaire on the same topic. These two are now collaborating to establish an international questionnaire to be considered by the IPG/CF Board for dissemination to all country contact persons. The draft questionnaire will be presented to members at the Annual General Meeting of the IPG/CF in Crete for consideration and comments.

Farewell, Mette Kelstrup and all the very best in your retirement

Prepared by Brenda Button on behalf of the IPG/CF membership

Mette Kelstrup and Merete Falk were the physiotherapists who with their team developed PEP therapy in the early 1980s. Their early publications describing the technique and comparing it to other techniques of the day remain landmark papers related to this important technique. PEP therapy is used by physiotherapists and patients with problems with excess airway secretions and decreased lung volumes in many parts of the world and many believe it is one of the most effective, efficient and user friendly techniques available in the current physiotherapy 'toolbox'. Mette and Merete were responsible for disseminating this technique via peer review journals, at international conferences, and over the years have very graciously hosted physiotherapists during educational visits to the Rigshospitalet in Copenhagen.

(I was one of those lucky people who had a memorable visit in 1994). In the last decade, Mette has graciously presented PEP therapy for infants and older patients at airway clearance therapy training courses during CF conferences in North America and Europe.

We have all enjoyed your down to earth approach and delightful sense of humour, Mette, and we hope you will come and visit your friends at the conference in Copenhagen in 2006. We all wish you a very healthy and happy retirement and when you travel internationally we hope you will contact us for a visit. We welcome Bente Kristensen as the new contact person from Denmark and look forward to your involvement with the IPG/CF.

Vice Chairpersons Report

Prepared by Filip van Ginderdeuren

Artimino, Italy, March 26-27, 2004

European Consensus on Standards of Care in Cystic Fibrosis

The European Cystic Fibrosis Society invited 35 specialists of all disciplines in the multi disciplinary treatment of Cystic Fibrosis (pulmonologists, dieticians, physiotherapists, psychologists, basic scientists etc...) to prepare a consensus document on Standards of Care in CF. This document will be published in The Journal Of Cystic Fibrosis in 2005.

In order to have the most efficient meeting, a list of questions was sent to each participant. They were required to prepare their answers to the questions, including references. These answers were discussed in five round tables to come to a first draft of the document.

In a first part this document defines in a very precise way what standards a CF center has to meet. The following topics will be discussed:

- a) definition of a CF center
- b) members of the multidisciplinary team : their knowledge, responsibilities, involvement and role in the team and towards the CF patient

In a second part the routines of CF care are discussed: outpatient care; inpatient care; shared care and transitional care; the annual assessment, reviewing all the topics that must be included; pulmonary function tests

In a third part the initial assessment of the newly diagnosed patient is described, followed by the education and treatment program.

Finally the role of other specialist input (gastro- enterology, obstetrics and gynecology, fertility, genetic counseling, imaging requirements) into CF care and the cost and staffing of care at the cystic fibrosis center have been looked at.

For your information I would like to include the final draft of the physiotherapy document Louise Lannefors and I prepared for this consensus (see next page).

The CF Center Physiotherapist

Report by Filip van Ginderdeuren and Louise Lannefors

The physiotherapy aims at

- a) ventilating all parts of the lungs daily and to compensate for impaired mucociliary clearance in order to minimize lung disease and preserve lung function,
- b) encouraging good posture and avoid musculoskeletal complications
- c) maintaining endurance and allow a good quality of life.

The CF physiotherapist should be involved in recording the evaluation of patients, the instructions given to them, quality control, and professional development (11). The role of the CF center physiotherapist is, in co-operation with the patient and family, to tailor an individualized, reasonable, optimal, effective and efficient physiotherapy regimen. This should take into account all relevant physical and psychosocial factors. Modern physiotherapy in CF is primarily preventative and has to be incorporated into each patient's daily routine in a lifetime perspective (12). Therefore physiotherapy must always be carried out in a way that makes future co-operation possible.

The CF center physiotherapist should assess patients every 1-3 months or at every outpatient clinic visit by:

- 1) carrying out and/or analyzing results of pulmonary function tests including volumes, flows, breath sounds, cough sounds and quality, and exercise capacity;
- 2) monitoring sputum volume and characteristics, and the degree of dyspnoea;
- 3) assessment of posture and, intermittently, chest mobility and muscle strength. A full treatment session and an assessment of physical capacity by standard protocols should be carried out annually. If needed, full treatments may also be given at the clinic or during home visits, where adherence to and quality of the treatment is assessed. Each individual's physiotherapy program needs to be continuously modified as needs and opportunities change.

The CF center physiotherapist has an important role in:

- a) inhalation therapy: choice of appropriate inhalation device(s), training of the patient/family in its optimal use, handling, cleaning and replacement of the device.
- b) airway clearance therapy: choice of technique(s) and training of the patient in optimal use.
- c) physical education and exercise: providing the patient and family with appropriate and stimulating physical education and exercise programs.
- d) education: improving and up-dating patients', families' and locally involved physiotherapists' knowledge of CF and its treatment.

Treasurer report 2004

Jovita Zerlik

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

Received subscriptions 2005:

Belgium	Euro	100
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Closing balance 06 January 2005: Euro 3.062,73

Jovita Zerlik, IPG/CF 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

Libuse Smolikova, Dr

Dear Colleagues,

In my tradition my report will be very short.

We now have 51 (see current list) contact persons, the latest are Nasser Saeed Al Hajry from Oman and Osman Coban from Turkey.

Thanks to technical progress, the secretary no longer has to write and post papers. E-mail is much quicker. Instead of my printing and distributing the Newsletter, which was not only time consuming and expensive, you now have it on the CFW website. I am sure my successor will experience even greater progress. She has all my good wishes.

As I say goodbye to the post of secretary, I would like to thank all of you for the help you have given me over the last four years – both Chairpersons, Dr. Brenda Button and Sandra Gursli, Vice-chairperson Filip van Ginderdeuren and both Treasurers, Jovita Zerlik and Carien Beurskens and all the national representatives. Your prompt replies to my sometimes, annoying demands - have been a great help.

Thank you for your cooperation, which I hope my successor will also enjoy.

Birmingham CF conference reports June 12-17, 2004

By Esta-Lee Tannenbaum

Advanced airway clearance course

This course was held at the Heartlands Hospital, Birmingham on the Saturday before the main conference. The morning consisted of lecturers and the afternoon of a practical session. The day started with an overview by Louise Lannefors of 'modern physiotherapy' in CF. She outlined the rationale for chest physiotherapy and the aims of treatment. Maggie McIlwaine, from Canada, discussed the Active Cycle of Breathing Techniques and emphasized the importance of all the individual components of the technique. Jean Chevaillier, of Belgium, presented Autogenic Drainage. He spoke about adapting the technique to the presenting pulmonary state of the individual patient e.g. whether they are wheezy or breathless. Jean gave a trouble-shooting guide for when Autogenic Drainage is not effective. He also spoke about oscillating PEP – including the Acapella and Flutter stressing those patients should not exhale to low lung volume levels.

Louise Lannefors then spoke about PEP and high-pressure PEP with the emphasis on trouble shooting. She also mentioned the topic of exercise including cardiovascular, strength and chest wall mobility. Louise also discussed postural drainage and questioned

the theory that gravity aids the mobilization of thick secretions but suggested that altered clearance in different positions owed more to the redistribution of ventilation. Other topics such as gastro-oesophageal reflux and the management of stress incontinence, pneumothorax, haemoptysis and pregnancy were discussed.

The afternoon consisted of three practical workshops with different patients moderated by each of the speakers, namely Louise Lannefors, Jean Chevaillier and Maggie McIlwaine. The participants were divided into three groups and rotated through the different workshops whereby the different airway clearance techniques were used. This was the highlight of the course.

Exercise Physiology and practical aspects of Exercise Testing and Programmes

This was a half-day course run by Charles Gallagher and Ammani Prasad and Mary Dodd

The presentation gave an overview of the differences between the normal responses to exercise and those seen in patients with CF, namely:

- In patients with CF there is less effective ventilation with a greater waste of ventilation (i.e. dead space ventilation)
- In patients with CF there is a higher total ventilation than normal for the same rate of work
- Patients with CF reach a maximum ventilation, normal subjects do not
- PO₂ (blood gas) may fall in CF patients but not in normal subjects
- Patients with CF will have a greater increase in lactic acid for a given work rate than normal subjects

The practical aspects of Exercise testing and what information exercise tests give was addressed. Exercise tests may be used to:

- Recommend safe and effective exercise programmes for individuals
- Monitor the disease progression
- Evaluate therapeutic intervention (outcome measure)

Physiotherapists often ask ‘Which test/s should we use?’

The test chosen will depend on the information required e.g. maximal or functional level of exercise, the facilities available and the age and clinical state of the patient

What tests can we use?

- The main field tests used are:
- Modified shuttle walk test
- 3 minutes step test
- Cycle ergometer progressive test

General recommendations to consider:

- Equipment maintenance
- Oxygen/resuscitation equipment
- CPR trained personnel

- Determine variables to be monitored during the test
- Criteria to terminate a test

Outcome measures of the exercise tests include:

- Heart rate
- Saturation
- Subjective scores (modified borg scale, visual analogue scale)
- Objective score (15 count score)

STRESS INCONTINENCE

A session was dedicated to the topic of stress incontinence. M van Nysten from Belgium explained factors that increase the risk of Urinary Incontinence (UI). She stressed that although UI has a negative impact on airway clearance techniques, patients do not seek help, as they perceive the problem to be relatively minor compared to other CF problems. During puberty as the pelvis widens there is an increased risk of UI and trampoline activities should not be recommended for this group especially if they report symptoms of UI.

Ammani Prasad of the UK presented data on UI in a paediatric CF population compared to a similar age group of patients with asthma and controls. There is an increased prevalence of UI in the CF population.

M Sherburn of Australia presented interesting findings from a study using ultrasound to identify the action/s of the pelvic floor muscles during huffing and coughing in patients with CF and normal controls. The topic of stress incontinence, although relatively new is an exciting area of development and research. However the physiotherapist has an important role in

- teaching all patients ‘the knack’ whilst performing huffing/coughing maneuvers so as to help prevent UI
- ensuring open communication with patients (i.e. ask male and female patients - over the age of 8 years) if they report any symptoms at their annual review

Report from the 18th Annual North American CF Conference, St Louis, Missouri, 2004.

Prepared by Dr Brenda Button, January, 2005.

The NACF conference was held from the 13-17, October 2004 in St Louis, Missouri, USA and attended by approximately 3,000 members of CF Care teams from all over the world. A broad program was offered with something for every discipline involved in CF care. The full program symposia summaries and abstracts can be read in Pediatric Pulmonology, 2004, Supplement 27. Annie Downs was responsible for the Respiratory and Physical Therapy program and some of the highlights are presented.

Pre-Conference Courses

One of the highlights of the conference was the day and a half course titled 'Musculoskeletal and Neuromuscular Interventions (MNI): a Physical Approach in CF' by Mary Massery physical therapist from Chicago, Illinois. The course was enthusiastically attended by physiotherapists involved in CF care from all around the world and included pathophysiology of musculoskeletal and neuromuscular problems associated with chronic lung disease, assessment of problems in volunteer patients with CF and participating therapists and attendees, and treatment modalities and strategies. We were all inspired to return to our centres and apply this new knowledge and approach to musculoskeletal and neuromuscular problems in patients with CF and other chronic lung diseases in order to improve physical and pulmonary function and long-term outcomes. Anne and Craig Lapin presented the popular half-day course "Airway Clearance for the CF Team".

Caregivers' Networking Groups

There were numerous Caregivers' Networking Groups which allowed discussion, brainstorming and idea sharing on a number of different topics including: Education, Transition, Exercise prescription, Transplantation, Intrapulmonary Percussion Ventilation, and Research.

Symposia

- The interesting and topical symposium "Mechanism and Treatment of Musculoskeletal Conditions in CF" was chaired by Maggie Mellwaine and Dr Larry Lands and included presentations on 'Urinary Incontinence in CF- Why does it happen?' (Hannah Langman), 'Influences on Posture' (Louise Lannefors), 'Non-nutritional factors that can limit Muscle Function in CF' (Hiran Selvadurai) and 'Exercise and Muscle Function and their effects on Bone Accretion and Maintenance in CF' (Larry Lands).
- An updating symposium with a wide audience titled "Inpatient CF Care" included an invitation to Brenda Button to present on 'Physiotherapy for the Inpatient'. Other presentations included 'Choice of Anti-Biotics for Inpatients', 'Critical Care for Patients with CF' and 'CF End of Life Care in the Transplantation Era'

Workshops

- ◆ “Exercise in CF: Looking at Non-traditional Issues” was moderated by Kathy Lee Bishop-Lindsay and Jan Tecklin. Presentations on submaximal exercise tests, exercise training programs, prediction of survival in end-stage CF using the shuttle test, scales of perceived exertion for children with CF, and urinary incontinence in women with CF compared to COPD. To read more about these interesting studies find Abstracts 353-357 and 359 in Pediatric Pulmonology 2004, Supplement 27.
- ◆ “Airway clearance Therapy: Choices and Challenges for Patients and Therapies” was moderated by Brenda Button and Tom Newton. This workshop included presentations on adherence and its relationship to pulmonary function, breathing patterns of inhalation therapy, physical training and the multi-center airway clearance study comparing oscillating PEP using the Flutter®, The Vest and postural drainage and percussion. Furthermore there were presentations on ACT, treatment satisfaction and QOL, and the effects of NIV on muco-ciliary clearance in CF. For details of these interesting and relevant studies see Abstracts 360-365.

There were also numerous Rise ‘n Shine Roundtable discussions to attend. The next NACF conference is in Baltimore, Maryland from October 19-23, 2005.

Crete CF Conference

By Esta-Lee Tannenbaum

The next CF conference is taking place in Crete, Greece from the 22-25 June 2005. For further details and updates, please visit their web page:
www.europeanCFconference.org

The outline of topics for physiotherapists (and other members of the CF team involved in NIV) include:

- 21st June: One day course on Non-Invasive Ventilation
- 22 June: Half day course on Optimising Inhalation therapy (morning)
- 22 June IPG-CF Annual General Meeting and Case presentations (afternoon)
- 23 June: Optimizing physiotherapy in CF (Abstracts)
- 24 June: Motivating exercise in CF (abstracts)

We look forward to seeing you in Crete!

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Updated January 2005

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