



International Physiotherapy Group for Cystic Fibrosis

NEWSLETTER 2, 2007

Introduction

This is a bumper edition for the final newsletter for this year. Thank you to everyone for their contribution. The newsletter includes the minutes from the CF conference in Belek, Turkey and the Country Contact person's reports for the year 2006. Welcome to Kostas Katsoulakis—new contact person from Greece.

Esta-Lee Tannenbaum
IPG/CF Secretary



Pictured above: Physiotherapists at the conference

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ANNUAL GENERAL MEETING JUNE 13TH 2007, HELD AT THE 30TH EUROPEAN CF CONFERENCE, BELEK, TURKEY

Welcoming remarks:

The Chair, Filip van Ginderdeuren welcomed everyone to the IPG/CF AGM.

Regrets:

Regrets from the secretary, Esta Tannenbaum who is pregnant and cannot travel. Anne Lapin from USA announced her resignation and indicated that Jan Tecklin will be replacing her. Jan Tecklin was not present. Apologies received from:

Irene Maguire – Ireland

Beatrice Oberwaldner - Austria

Present:

17 contact persons were present from UK, Romania, France, Slovakia, Czech Republic, Sweden, Italy, Denmark, Holland, Norway, Switzerland, Litvia, Turkey, Greece, Belgium, Canada, Austria, Germany and Hungary. Hence a quorum was met.

Minutes of last AGM:

Were accepted by Lynn Gummery and seconded by Sandra Gursli.

Reports:

Chairman – see Filip's report

Treasurer report – See report, only 3 countries have paid this year.

Secretary Report – See Esta-Lee's report.

New Business:

Eurocare.

Libuse and Louise are members of this group. They gave an update of this group and directed everyone to the Eurocare website at www.eurocarecf.eu. They are involved in WP1 optimising CF care through teamwork. They are also involved in providing training courses and developing consensus guidelines. It is sponsored by the EU, so although Louise and Libuse would like to get input from all countries, International contact persons may not be members.

Paediatric Physiotherapy Guidelines.

Brenda reported that the paediatric guidelines was in manuscript form but was not accepted by a peer review journal. Instead it will be put on the IPG/CF website. It is difficult to get consensus on the guidelines as there are many differences in practice between countries.

Blue Booklet report:

The blue booklet has now been translated from English to Spanish, Italian and Greek. It was last published in 2002 and now needs to be updated. The blue booklet includes evidence based physiotherapy techniques. We need to redefine which techniques are included in the Booklet and include a glossary of terms. There needs to be a lay booklet for families.

Physiotherapy Glossary of Terms:

The 1st Edition is anticipated to be completed by the end of June 2007. It will be posted on the website and sent out in the Newsletter. It is anticipated that a 2nd Edition will soon follow.

Transplant Questionnaire:

There have only been 22 responses to this questionnaire which is not enough to conclude anything. It is hope that more people will respond.

Novartis Best Care Scholarship:

Jenna Al-Had from Novartis spoke about the work of Novartis and their involvement with the Cystic Fibrosis population and in particular the use of Tobramycin. Lynn Gummery presented a slide show of last year's winner who spent some time at Birmingham's CF centre with Lynn. This year's winner is Patrick Williams from Finland.

Any other business:

There were no elections this year but next year, the positions of Secretary, Treasurer and Vice-Chairperson will be up for election. The committee is asking for nominations. A formal nomination announcement will be sent out later in the year.

Meeting adjourned.

Notes taken by Maggie McIlwaine, 13th June 2007

Chairperson's Report, Annual General Meeting, Belek, Wednesday June 13, 2007.

Prepared by Filip Van Ginderdeuren, July, 2007.

On behalf of the IPG/CF board I welcome you to the 2007 annual general meeting. This is my second AGM officiating in the role of chairperson. I have received great support from the other members of the board, as well as from Brenda Button and Louise Lannefors 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 six courses have been organised . Last year we ran a 1.5 day course entitled “ Integrating the pulmonary, musculoskeletal and neuromuscular systems: a physical approach to CF.” with Dr. Mary Massery as the instructor . This year we presented a 1.5 day course on Inhalation therapy (instructor: Louise Lannefors). Next year we're planning a 1.5 day “Basic airway Clearance Course’ . Feedback from all of the courses has been excellent. The courses have been well attended and have been profitable. This resulted in a better funding of expenses, although there is still a long way to go. I would also like to discuss the possibility of making a DVD during the Basic Airway Clearance Course, next year.

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 fifth consecutive year. Maggie McIllwaine, Libuse Smolikova and I have been invited to serve on the ECFS Scientific Committee organising the conference in 2008 in Prague, Czech Republic. 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 Greek

The current version of the Physiotherapy Blue Booklet has been translated into Greek by Mr. Costas Katsoulakis, a Greek physiotherapist. Volunteer translators of Cystic Fibrosis Worldwide accepted our proposal to double-check and improve the translation, before it was posted on the IPG/CF website. The English, Spanish and Greek 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, invites us for the second year to submit any interesting news or articles about physiotherapy. She has also accepted 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 Traveling Scholarship – 2007 Winner

Patrick WILLAMO from the Helsinki University Hospital for Children and Adolescence in Hus, Finland is the winner of the 2007 Novartis Best Care Scholarship. Since 1999 he is responsible for the physiotherapy treatment of his CF patients. Louise Lannefors at the Lund CF Centre and Henrik Johansson at the Uppsala CF centre in Sweden will be the host physiotherapists who will organise the theoretical and practical instruction that Patrick Willamo wishes to gain during his scholarship. Patrick will not be in Belek to collect his certificate and cheque, but promised to attend next year's conference in Prague, where he will do a small presentation on his experience at both CF centers.

The winner will be announced at the end of our AGM.

Fortunately **Jenan Al-Hafidh ,Global Brand Manager for TOBI, from Novartis** confirmed its continued support to our scholarship into 2008; and I quote “ physiotherapists are important members of the CF teams and we are pleased to offer this. I have already scheduled a meeting with the other members of the IPG/CF board and Jenan Al Hafidh, from Novartis, to discuss the practical details of the scholarship. As you all probably remember, I had a meeting with Clive Bertram before he left the company. We decided to reduce the printing costs of the scholarship, by using only electronic application forms or forms downloadable from the IPG/CF website. So no hard copies anymore. The idea was to use a part of this money for a second scholarship for physiotherapists from all over the world, working in so called "developed" countries. The money should support them (with, if necessary, financial support of their own center) to visit other qualified CF centers all over the world.

CFW Georgia Project

Cystic Fibrosis Worldwide held a workshop at the new Georgian CF Center in Tbilisi from November 13-15 to train parents and patients on proper nutrition and physiotherapy. This was the first CF workshop held in the former Soviet Republic, and it offered a support system and health information to over thirty patients and their parents. Dr. Gabriela Sabolova from Slovakia and Hugh Gauchez, our IPG/CF contact person from France, led the workshop. Although I'm very pleased with this initiative, the IPG/CF board was to my surprise not involved in this project, for example to decide the content of the workshop and the practical session with patients. For that reason I wrote a letter to Mitch Messer, the CFW president for some explanation, but never got an answer. I will bring up this issue again during the meeting with the CFW board members on June 14th.

Secretary Report: Prepared by Esta-Lee Tannenbaum

At present we have 54 members, although there are some members whose e-mail addresses do not work anymore as their e-mails are returned to me. Unfortunately I have been unable to make contact with them via their postal address either. If any contact person changes their e-mail address or is no longer the contact person – please let the secretary know.

We have the following information on future conferences:

2008: June 11-14th Prague, Czech Republic

2009: Brest, France

More details to follow at [http:// www.europeancfconference.org](http://www.europeancfconference.org)

North American CF Conferences:

2007: October 3-6, Anaheim, California

2008 October 23-26, Orlando, Florida

2009 October 15-18, Minneapolis, Minnesota

More details available at <http://www.nacfconference.org>

I shall be on maternity leave for my final term as secretary – but will fulfil my duties from home.

Best wishes to you all.



INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

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Treasurer report 2007

Closing balance 31 December 2006: Euro 3.645,00 +

Received subscriptions 2007:

Germany	Euro	50
Finland	Euro	100
Romania	Euro	40

total: Euro 190

Bank expenses: Euro 18,70

Closing balance 31 July 2007: Euro 3.816,30 +

Jovita Zerlik, IPG/CF treasurer

Hamburg, Germany 31.7. 2007



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Treasurer report 2006

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



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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 30th European Cystic Fibrosis Conference, Belek, Turkey, 2007

Prepared by Filip Van Ginderdeuren

More than 1200 delegates registered for the 30th European Cystic Fibrosis Conference in Belek, at the sunny Turkish Riviera, South-Turkey. The conference was held from 13-16 June 2007.

Pre conference course

1) What do we know about Inhalation Therapy

The one and a half day course was held at the Maritim Pine Beach Resort on June 12 and June 13, before the official opening of the conference. More than 40 physiotherapists registered for the course.

Louise Lannefors from the CF center in Lund was the course instructor. Filip Van Ginderdeuren from the CF center in Brussels moderated the course.

The aims of this course were to give a brief review of what we know about inhalation therapy, to discuss the factors that influence the outcomes of the therapy, to take a look at techniques and systems available, to stimulate to critical thinking and to pay more attention to inhalation therapy



Picture above: Louise Lannefors

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.

Louise looked at:

- The different agents for inhalation therapy, the target for the drugs (airway muscle, airway mucous membrane, mucus or micro-organisms in mucus) and how to evaluate the dose.

- Factors influencing the choice of the nebuliser system (prescribed drug, target area, lung function, physical/mental capacity, adherence and using situation) and the different inhalation devices (driving source, working pressure, compressor size...). Aerosol quality is described in Mass Median Diameter.
- Effective inhalation technique (depending on free airways, slow drug delivery speed, low inspiratory flow velocity and good ventilation distribution) and optimised deposition pattern (impaction, sedimentation, diffusion).
- The follow-up and evaluation of the treatment; what is the purpose of the treatment (rehabilitative or preventive): immediate positive effect or reduced decline over a long period of time.
- Cleaning and disinfecting the material the different devices.

Physiotherapy case presentations

Five physiotherapy case presentations were moderated by D. Inal-Ince (Tur) and R. Dentice (Aus). Points to remember:

- Psychological and social support is essential for patients in a depressive state to enable them to perform their daily treatment at home.
- The use of devices generating Positive Expiratory Pressure and the inhalation of mucolytics should be well considered and if necessary avoided in CF patients with severe and ongoing haemoptysis. Rest, controlled sputum clearance, IV antibiotics and vitamin K may be necessary as well as a bronchial angiogram and bronchial artery embolisation.
- Patients segregating themselves from the hospital, their friends and even their family to minimise the risk of infection are becoming increasingly difficult to manage for the CF team. Having almost all their courses of antibiotics as an outpatient, the different aspects of their care become difficult to monitor. To consider : Has the focus on cross infection and segregation by health care professionals promoted the isolation and poor quality of life in some patients with CF ?
- The difficulties encountered when essential treatment options (NIV initiation, PEG insertion and transplant assessment) are highlighted by the physiotherapy team at the earliest appropriate time and the postponing of these important decisions by the patient, due to his perception of his quality of life, despite continuing deterioration in health.
- More training is needed for the psychosocial support given by the physiotherapist in young adult CF patients towards the end of life.

Symposium

The physiotherapy symposium on “Managing advanced lung disease – from transplantation to palliative care “was chaired by Dr. C. Knoop (Bel) and H. Arian (Tur).

Dr. Knoop (Bel) talked about the impact of lung transplantation on the site of death and treatment given in palliative care (opiates, IV antibiotics, oral vitamins, chest physiotherapy, phlebotomy); she also discussed the pro and cons of lung transplantation and gave her personal opinion on lung transplantation versus palliative care, intertwining with each other. She talked about the general selection criteria and relative and absolute contraindications for lung transplantation. Conditions that need optimal treatment before transplantation are diabetes mellitus, gastro-oesophageal

reflux, cachexia, psycho-social instability and osteoporosis. Lung transplantation in 2007 is a high-risk surgery. It is not a cure, but offers reasonable hopes for a significant survival benefit.

Prue Munro (Aus) talked about the physiotherapy and rehabilitation before and after transplantation to optimize the physical and social function of the patient. During transplant assessment and waiting period, the patient is kept as fit as possible, addressing deconditioning and maintaining independence. Exercise training to minimize peripheral muscle and skeletal changes are very important, because of the impact on rehabilitation post transplant.

Rehabilitation immediately after surgery is important to improve ventilation and mobility and in preparing the patient for discharge from hospital.

Rehabilitation for the outpatient remains important to improve fitness, participation and self management. Supervised exercise training (min 3X/week), education and support are necessary.

Long term rehabilitation is needed to manage changes in functional state.

Mr. Vrijsen (Bel) discussed the role of exercise in end-stage lung disease, slowing the decline of FVC and FEV₁. Stimulation of patients before lung transplant to achieve a high as possible exercise capacity and muscle strength is indispensable because VO₂ peak and muscle strength improve after transplantation, but are still reduced versus normal. Aerobic exercise can improve the time of exercise, VO₂ peak, lactate concentration, saturation and muscle strength. Anaerobic exercise can improve muscle strength, lactate levels, saturation and VO₂ peak, but we must be attention to the reversibility. An active lifestyle is necessary! Exercise plays also an important role in the quality of life of our patients.

Penny Agent (UK) highlighted the role of non invasive ventilation (NIV) in end-stage lung disease. NIV is one of the most valuable therapeutic treatment options of the last 15 years in CF. Symptomatic relief of breathlessness in acute and chronic episodes, stabilisation of hypercapnia and a decrease of the work of breathing are some benefits of NIV. It can also be a bridge to transplant.

Workshops

“Promoting physical exercise in CF” was moderated by M. McIlwaine (Can) and S. Savci (Tur). Presentations on “Exercise capacity, muscle strength and quality of life in adult CF patients”; “ The effect of maximal exercise on FEV₁ in adult CF”; “Pulmonary rehabilitation following lung transplantation” ; “ Effect of global posture reeducation (G.P.R.) program on respiratory muscle strength” and “ BODE index and functional health status in CF patients”. For more details on these studies, please find abstracts 256,259,255,258 and 278 in “Journal of Cystic Fibrosis”, vol 6, suppl 1, June 2007.



Picture above: Maggie McIlwaine



Picture above: Brenda Button

“Physiotherapy treatment strategies in CF” was moderated by B. Button (Aus) and U. Tugay (Tur)

This workshop included presentations on:

- A prospective randomized trial comparing airway clearance strategies following lung transplant
- Can physiological parameters determine the optimal method of airway clearance for the individual with CF?
- A retrospective analysis of physiotherapy input during a standard admission compared to a terminal admission in adults with CF
- Achieving sustained compliance with nebulised therapies in a paediatric population RhDnase before or after going to sleep in children with CF

To read more, please find abstracts 253,250,254,271 and 274 in “Journal of Cystic Fibrosis”, vol 6, suppl 1, June 2007.

Round tables

There were also numerous round table discussions to attend. ‘Physiotherapy in infants’ was moderated by M. McIlwaine (Can), ‘Exercise in CF’ was moderated by H. Arikan (Tur), ‘Autogenic Drainage ’ by J. Chevaillier (Bel), ‘Physiotherapy for the pregnant woman in CF’ by B. Button (Aus) and ‘ Nebuliser therapy ‘ by L. Lannefors (Swe).

WINNER OF THE NOVARTIS BEST CARE SCHOLARSHIP 2007

Prepared by Filip Van Ginderdeuren, 6 March , 2007.

Patrick WILLAMO from the Helsinki University Hospital for Children and Adolescence in Hus, Finland is the winner of the 2007 Novartis Best Care Scholarship. Since 1999 he is responsible for the physiotherapy treatment of his CF patients.

Cystic Fibrosis is very rare in Finland. They have about 60 patients and the number of physiotherapists involved in the CF care is rather small and spread all over the country. CF centers or an active professional network are non-existing. CF patients visit the nearest university hospital for follow-up.

Mr. Willamo gathered most of his knowledge about physiotherapy and CF by reading literature. He wishes to further his knowledge in airway clearance techniques, exercise training and mobilization exercises in CF. He plans to disseminate the new knowledge by organizing a CF up-to-date care system in his hospital district and all over the country, improving CF patients' clinical status and lung function and consequently adherence to treatment. He would also integrate his new knowledge in the lectures for his physiotherapy students and activate the "CF - physiotherapist" network. Workshops and lectures during the CF summer camp would be another way of sharing his knowledge, skills and experience with the Finnish CF community. Louise Lannefors at the Lund CF Centre in Sweden and Henrik Johansson at the CF centre in Uppsala, Sweden will be the host physiotherapists who will organise the theoretical and practical instruction that Patrick Willamo wishes to gain during his scholarship.

The members of the IPG/CF Board wish to congratulate Patrick Willamo and wish him all the very best as he undertakes this Novartis Best Care Scholarship.

IPG/CF Board:

Mr Filip Van Ginderdeuren, Chairperson

Ms Maggie McIlwaine, Vice-Chairperson

Ms Jovita Zerlik, Treasurer

Ms Esta-Lee Tannenbaum, Secretary

We would like to acknowledge and thank **NOVARTIS** for making this award possible again this year. Many thanks also to Christine Noke of Cystic Fibrosis Worldwide for assistance with the advertising and processing of applications.

Novartis Best Care Scholarship

The Novartis Best Care Scholarship (NBCS) is an International award sponsored by Novartis. It is an educational grant with the aim of providing greater support to the CF community. The NBCS was launched in 2000 with the CF specialist nurses. It was promoted for physiotherapists for the first time in the IPG/CF Newsletter 2/2001 under the direction of Sandra Gursli, IPG/CF Chairperson 2001. It is intended that this will be an annual award.

The winner receives 2500 Euro to spend time at an international CF-centre approved by the IPG/CF Board. The new knowledge and experience gained will be presented at the following IPG/CF Annual General Meeting.

Any physiotherapist who wishes to apply has to provide some written details through an application form including:

- Centre of choice
- What they hope to achieve by the visit
- How the experience will benefit patients and colleagues
- How they plan to communicate the knowledge back home

A scoring system has been developed to objectively assess the most appropriate candidate.

Annual report from Australia

Prepared by Dr Brenda Button, Australian country contact person

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Many Australian physiotherapists continue to be involved in CF research. Some of the studies that have been completed recently include the investigation of the effects of hypertonic saline on longer term outcomes in CF and the benefits of this treatment; the effects of massage and musculo-skeletal physiotherapy on pain and function; the prevention and treatment of urinary incontinence across the life spectrum; timing of RhDNASE; physiotherapy before and after lung transplantation; and the physical and psycho-social impact of the diagnosis of CF in an infant on families. These studies were all presented at international and national conferences.

During the past two years, thirty physiotherapists with a special interest in CF have been involved in an initiative to develop consensus guidelines in the physiotherapy treatment of CF across the lifespan. Seven groups have been formed to research the literature, identify current clinical practice and develop recommendations. The groups have been investigating: the physiotherapy management of the newly diagnosed infant and adult; airway clearance therapy, inhalation therapy, exercise and musculo-skeletal problems and management; the complex patient including haemoptysis, pneumothorax, pregnancy, urinary incontinence, CF related diabetes and aspergillus infections; infection control; lung transplantation and palliative care. A highly effective two day consensus conference was held in September, 2006 for discussion to advance the project. The next stage is the development of Draft 2 of the document and the employment of a professional writer (Dr Anne Holland) to edit the works into a coherent, readable and succinct document. The aim is for the consensus guidelines to be completed and available to physiotherapists in clinical practice in early 2008.

Annual report from Austria

Prepared by Dr. Béatrice Oberwaldner, Austrian country contact person

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The previous year of the Austrian respiratory physiotherapy group was dedicated to the development of a syllabus for the postgraduate university degree in cardiorespiratory physiotherapy. The course will be commenced in the winter semester at the Medical University of Graz; several group members will be involved in teaching.

The Austrian respiratory physiotherapy group had 2 meetings to discuss the organisation of further CF-adult physiotherapy services in the country. Information on the necessary additional aspects of physiotherapy in an adult service was spread. The homogenisation and quality of physiotherapy practice for children and adults with CF is further improved.

The working group of respiratory physiotherapists has traditionally been involved in the programme of the Annual Conference of the Austrian Society of Pneumologists.

An educational programme on aerosol treatment was organised for physiotherapists and nurses; special emphasis was made to highlight the special needs of CF-patients.

An educational programme for parents and patients on training methods for CF-patients was organised.

Several physiotherapy students and international exchange physiotherapists had an in depth training in different CF-centres.

The PT input into the programme of the annual conference of the national CF lay organisation has traditionally been large.

A member of the national group of respiratory physiotherapists is regularly updating our homepage www.atemphysiotherapy.at. This homepage has provided a permanently open forum for discussion and exchange of information between interested physiotherapists.

In summary, the number of specialised respiratory physiotherapists is constantly increasing in Austria; the high level of theoretical knowledge and practical skills is a prerequisite for an excellent physiotherapy management of CF-patients throughout the country.

Annual report from Belgium

Prepared by Filip Van Ginderdeuren, Belgian country contact person,
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I. Specific Belgian IPG/CF activities.

The Belgian Working Group organised 4 activities in the past year. The number of participants varied between 50 and 100 PT's. The topics were:

- Inhalation therapy
- Airway Clearance techniques
- COPD
- Cystic Fibrosis anno 2006 : an update

II. Organisations and participation by members of the group.

1)-ACT courses for PT's. (basic) :

International: in France (19 days, 104 participants), Germany (11 days, 100 participants), Switzerland (4 days, 30 participants), Spain (6 days, 24 participants), Italy (3 days, 24 participants)

National: 3 courses (48 Hours each for 180 PT's) .

Part time lecturer at the Free University of Brussels in respiratory physiotherapy.

2)-Refresher courses for trained PT's.

- 1 refresher course in Switzerland.
- 1 refresher course in Germany

- 3)-Lectures and/or practical training .
9 lectures for different medical and paramedical audiences.
Lectures at the CF Conference in Copenhagen, Denmark.
- 4)-4 weeks training courses for PT students.
A total of 60 PT students from different Belgian PT schools.
- 5)-Participation
CF conference in Copenhagen (1 member)
Astma conference (De Haan, Belgium)
CF symposium (Brussels, Belgium)
- 6)-Lectures for Parents, MD's, PT's, Nurses and other caregivers
7 in total
- 7)-Belgian IPG/CF board meetings: 6.
- 8)-Abstracts: none// Thesis supervision: at least 5
- 9) Organisation of the "Belgian Association for Respiratory Physiotherapy"
Conference

Annual Report from Finland 2006

Prepared by Leena Jokinen, Finland country contact person
E-Mail: leena.jokinen@heli.fi

CF in Finland

CF is a very rare disease in Finland. With a population of 5 277 300 only 64 Finns have CF diagnosis. Annual 1 – 2 persons, mainly babies, are diagnosed with CF. CF patients age groups are from babies to adults, almost 40 years of age.

Medical Care, Rehabilitation and Physiotherapy

There are no CF specialist clinics or hospitals in Finland. Five University Hospitals and twenty Central Hospitals give medical treatment for CF patients as well as other patients and therefore 64 CF patients are treated in more than twenty several clinics.

Physiotherapists in hospitals meet CF patients usually in outpatient departments when patients meet also the doctor, dietician or other specialists. CF patients are seldom in inpatient departments in hospitals.

The Social Insurance Institution of Finland oversees the Rehabilitation Programme for Seriously Disabled. CF patients receive an individual rehabilitation plan including individual physiotherapy, facilities and training equipment needed for self-care, an opportunity to attend rehabilitation or adaptation training courses as well as facts concerning social security.

Resource Centre for CF: Courses, Meetings and Seminars 2006

Pulmonary Association Heli has five regional centres and Hoikka Centre is one of those. Hoikka has specialized for rare pulmonary diseases such as CF. The coordinator at Hoikka organizes rehabilitation courses, meetings and weekends for persons with rare pulmonary diseases and their families as well as health care professionals.

A weekend meeting for mothers of CF children was in February at Hoikka Centre. 18 mothers took part in this weekend meeting.

One day course for health care professionals was held in April in the north part of Finland in Kajaani. The main topics were medical treatment and physiotherapy of CF and bronchiectasis.

Five days courses for families with CF-children, -young and -adults was in June at Hoikka Centre. Ten families and five CF-young/-adults took part in the courses. The rehabilitation course staff included a doctor (chest physician), nurse, physiotherapists, social worker, psychologist, nursemaids as well as other CF experts such as paediatrician and dental hygienist. Courses for families with CF-children include discussions of CF treatment, nutrition, physiotherapy, as well as treatment at home, support for families and social security. Additionally, the courses for young CF-persons and CF-adults, aim to help participants to become independent and to clarify the job possibilities.

A weekend seminar for CF-physiotherapists was in August at Hoikka Centre. 20 physiotherapists all over Finland took part the seminar. The main topic was regards from Copenhagen 29th both Physiotherapy Short Course and CF Conference. Discussions with each other were important.

An annual CF-meeting for CF-persons and their families was held also in August and 40 participants, families with CF-children, CF-young and -adults with their friends took part in the meeting.

ANNUAL REPORT FROM FRANCE

Prepared by Hughes Gauchez , France's country contact physiotherapist,
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France see about 5000 CF patients and the care is organized into 48 CF referral centre. 2/3 of CF patients are adults.

The French working group (AMK) organized 5 activities in the year around the countries: 3 days of courses with theory on CF and practice of airways clearance techniques. To teach, one senior PT and 2 juniors. The number of participants was limited at 25 pts;

The French association for CF has organized its annual CF meeting for CF persons, families and professionals.

2 days in September for PT in Paris. We were very enjoyed to welcome Louise Lannefors from Sweden.

Participation of the French working group of PT:

- Congress of pulmonology society of French language in Nice in January
European CF conference in Copenhagen (Hughes Gauchez IPGCF French contact person)

ERCA (European Respiratory care association)) congress in Athens in October
Hughes Gauchez was invited for

3 days of courses in Kosice (Slovenia)

4 days in Tbilisi in Georgia in November

The topics were:

Airway clearance in babies and young children

Inhalation therapy

Pathophysiology of the respiratory tract

Using instrumental devices; (flutter...)

Lectures and practical training for PT students

Lectures for parents

Organization and participation by members of the group: ACT courses for PT's in Cabo Verde, Island, and a project for Morocco

In the French association of CF PT'S (AMK) every CF center in France are represented, all the PT's who take in charge a CF patient are members.

The aim of the group is to deepen the knowledge about therapies and physical therapy for CF

The group has made a guideline on treatment of CF patients (CDrom) and a contact between patient and PT.

AMK is represented in the French association for CF ("vaincre la mucoviscidose") and develop the relations with all the partners (Caregivers, nurses, pharmaceutical firm...)

Some members of the group work on the development of rehabilitation center for Impatient out patient or at home(accessibility, financial proximity etc...)

In France physiotherapy start until the diagnosis, with education and practical training
On / two sessions per days depend of the level of severity.

Its work to prevent complications.

He has to follow the patient in evaluation, ACBT, education, inhalotherapy, physical activities, and compliance.

The place of PT is very important and recognize . Since the tenth last year, the results are very uncourageous for patient, family and the medical team.

Annual Report from Germany

Prepared by Jovita Zerlik, German country contact person

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The German CF Physiotherapy working group has been going on working as described in the reports from the last years.

At present, we are engaged in exploring the possibilities to merge the techniques of physiotherapy and the capabilities of sports.

Therefore, 20 physios participated in a 5 weekend course on medical training concepts, including strength and endurance training. We are striving to work closer to sports therapists in Germany to establish training concepts for people with chronic lung diseases, esp. CF.

Annual Report from Hungary

Prepared by Dr Peter Borka (PT), Hungarian country contact person

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Fourteen physiotherapists work in our Hungarian group. These colleagues are employed in 10 hospitals and 8 of them are in CF Centres.

Four to six times in a year I send circular letters with scientific and social program information, and I forward the information coming from IPG/CF.

In 2006 three members of our group took part in a study tour with Acapella. In one adult and two paediatrics CF centres we controlled the efficacy of the Acapella and Flutter in helping the mucus clearance.

Unfortunately, the inactivity in our group written about it in the last year has been continued. Except from the study tour mentioned above, any of other extra activities has not been occurred in last the year. Thus, I have to repeat this year: I ought to be more active or 'aggressive' but the inactivity cooled my enthusiasm.

In summer of 2006, the habitual ten-day Rehabilitation Camp organised by National CF Association was held in our country. One physiotherapist of our group took part to help the patients and their parents in learning the physiotherapy techniques.

Later on this summer, there was another ordinary training camp in our CF centre. The newness was that we organised it together with asthmatic patients. We were afraid of conflict between the two groups that really appeared in the very beginning of the camp, but we have succeeded to solve it with the help of our psychologist.

Annual Report from Italy

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The Italian Group of Physiotherapist for Cystic Fibrosis was born in 1989 and now is actually active member of the **Italian Scientific Society for Cystic Fibrosis (S.I.F.C.)** a Multidisciplinary Scientific non profit Society. Most of the Physiotherapist works in Cystic Fibrosis Centers, other in Cystic Fibrosis Support Clinics (actually 31).

All the members of the group works in accordance with the Standard of Care for Cystic Fibrosis and in accordance with the latest suggestions and Guidelines of the International Group. In the same time pursuing the same tasks and aims of the International Group. Actually in Italy there are about 4100 living Cystic Fibrosis Patients and more than 30 % of them are over 18 years of age.

The Italian Group of the Physiotherapist for Cystic Fibrosis calls in meeting twice in a year: once for independent scientific updating and once during the Italian National Congress of the Cystic Fibrosis Scientific Society. (SIFC)

During the last years The Italian Group has organized specific training courses on Airways Clearance Techniques, Physical Exercise, NIMV and Evidence Based Medicine Stages.

As member of the Scientific Society for Cystic Fibrosis the Italian Physiotherapist actively take part in official **“Scientific Boards “ of the Society :**

- **Terminal Care and Palliative Issues.**
- **Long Distance Monitoring.**
- **Infection Control Strategies.**
- **Adult Care.**
- **Compliance and Adherence Issues.**

From 29th to 31st of May 2006: 2nd Meeting of the SIFC – Two day about “Inhalation Therapy in Cystic Fibrosis.

From 23rd to 25th November 2006 “Methodological and Practical Approach to Non Invasive Mechanical Ventilation in Cystic Fibrosis “Clinical Practice and Procedures.

Actually one member of the Physiotherapist Group has been voted in the Executive Committee of the Italian Scientific Society for Cystic Fibrosis.

Since some members of the Group are Educators – Professors in the Faculties of Medicine and since some Cystic Fibrosis Centers are located inside the Medicine Faculties of the Italian Universities , in the last year they produced seminars, lectures , and Doctor Physiotherapy Thesis concerning Physiotherapy , Respiratory Care , and Pulmonary Rehabilitation Programmes in Cystic Fibrosis Patients.

Annual Report from Norway

Prepared by Sandra Gursli, Norway country contact person
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The Norwegian National Working Group for CF

The Norwegian National Working Group for CF consists of 14 Physiotherapists from all over the country. Members from the working group met for five days in connection with a course in Airway Clearance Techniques in Oslo in May, 2006. In this connection a meeting was arranged where members of the group discussed different tasks and activities. The members also keep in contact through e-mail and telephone in between the annual meeting.

The members of the Group form a part of the national network in Physiotherapy working with CF. They participate in spreading knowledge and practical skill training for patients and assistants as well as other Physiotherapists and Physiotherapist students.

Five Physiotherapists from the Group attended the European Cystic Fibrosis Conference in Copenhagen in June 2006, and participated in the pre – conference course as well.

The Norwegian National Centre for CF

Main activities organized by the National Centre in 2006 have been as outlined below:

- Cooperation with physiotherapists from different Regional/University Hospitals as well as local physiotherapists in regard to clinical follow up and outreach activities with patients.
- Regional Courses for Physiotherapists in the different parts of Norway.

Annual Report from Poland

Prepared by Teresa Orlik, Poland country contact person

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The first General Meeting of The Polish Cystic Fibrosis Society was held in 29.06.2006 at Institute of Mother and Child in Warsaw. The group of ten physiotherapists from main cystic fibrosis centers in Poland is active within The Society.

Organizations and participation at courses by members of the Polish Cystic Fibrosis Society

1. As usually, Physiotherapy Department of the Institute of Mother and Child in Warsaw organized three-days post-graduate courses including aspects of physiotherapy in pulmonary diseases (2 courses a year: 27-29.03 and 20-22.11.2006). The courses were aimed at physicians who specialize in rehabilitation.
2. Unfortunately we could not organized annual two-day course which is aimed at physiotherapists involved in treatment of CF patients who would like to have more knowledge about CF management and airways clearance techniques. I hope we will organize this course this year.

Organizations and participation in conferences by members of the Group.

1. The Annual Meeting of Polish Society against Cystic Fibrosis traditionally was held at the Institute of Tuberculosis and Lung Diseases in Rabka in May. Teresa Orlik presented lecture "The PEP system in physiotherapy of patients with cystic fibrosis". The practice physiotherapy workshop for patients and parents was organized during conference.
2. The Annual Conference for patients with CF and their parents was held in Warsaw in November 2006. On this Conference Teresa Orlik presented lecture "Physiotherapy problems of adolescents and adult cystic fibrosis patients in Poland".

The other activities

One day practice physiotherapy workshops for patients and parents were organized by Teresa Orlik in many cystic fibrosis centers in Poland (Łódź, Kielce, Poznań). The Life Club programme is continued. This is a treatment motivation programme for CF patients who score for their good compliance with treatment and regular physiotherapist's, dietitian's and psychologist's visits. Physiotherapists are actively involved in this programme.

Annual Report from Romania

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During the year 2006 we continued the training of newly diagnosed patients and their families while regular reviews were performed in the followed up cases. At the same time, our senior physiotherapist carried on the training of physiotherapists from the regional centers. A study regarding the effectiveness of physiotherapy in 79 CF children has been performed by Almajan Guta Bogdan and presented as his PhD thesis in April 2006. In December 2006 we had the annual meeting with doctors and nurses involved in CF care in Romania and discussed the progress of the CF regional centers. Helped by La Roche Company we finally managed to offer nebulizers to all our patients who receive treatment with Pulmozyme.

Annual Report from Russia

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Alena Scherbakova's report about learning physiotherapy course as a winner of the best care scholarship 2006:

As a winner of the best care scholarship 2006 in November 2006 I had learning physiotherapy course with Lynne Gumery in Birmingham Heartland Hospital.

I am very grateful for IPG/ CF and Chiron-Novartis Company and also Lynne Gumery, Paoula Agostini, Lisa Kanyon and CF-team of Birmingham Heartland Hospital. I got new knowledge and experience in different techniques of physiotherapy in CF for children and adults patients. Now I am working not only with children, but with adult patients too and I am using my knowledge and practical skills with benefit. In December 2006 I explained report about my trip and seminar about techniques of airway clearance and NIV for my colleagues.

In January 2007 I organized a workshop for adult patients and caregivers about autogenic drainage and PEP-therapy. I plan to write a booklet about techniques of airway clearance for patients this year. I plan several reports in national conferences and workshops for colleagues and patients.

Annual report continued:

*National Conference was organized in Voronegz in April 2006.

*Jean Chevaillier with assistant visited in June two Russian CF-centers (Novosibirsk and Moscow) for 2 days physiotherapy courses for CF-children and their parents.

*An annual CF-meeting for CF-persons and their families was held in September at Moscow CF-center. 38 participants, CF-children's parents and adult CF-patients took part in the meeting.

*An educational program on Autogenic Drainage was organized for pulmonary specialists.

*An educational program and workshop was organized for adult patients and caregivers on Autogenic Drainage and its combine with physical exercise.

*Several reports about different physiotherapy techniques was presented by Dr. Kashirskaya on national CF and pulmonary conferences (in Chelyabinsk, Saransk and other towns)

*In Moscow adult CF-center was conduct the research efficiency of Treshold PEP and Treshold IMT devices.

*Physiotherapist Alena Scherbakova presented clinical case about hippotherapy for CF-patients and continues to study positive and negative effects of hippotherapy.

*She had learning course "Integrating the pulmonary, musculoskeletal and neuromuscular systems: a physical approach to CF" in Copenhagen

Annual Report from Sweden

Prepared by Louise Lannefors, Sweden country contact person

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Sweden has 4 CF-centres

- 1-2 physiotherapists from each centre is a member of a national physiotherapy working group

This national physiotherapist working group for CF has

- met twice during the past year, to exchange experiences, discuss patient cases, “self education”
- been responsible for the content in a physiotherapy education day for lay people, organized by the national patient association organized
- organized a national education day for physiotherapist involved in CF care
- had continuous contacts with the different regional patient associations in Sweden

Annual Report from the United Kingdom

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I have had the pleasure of attending the European CF Conference in Copenhagen and strengthening communications mainly via e-mail with physiotherapists from many of the 52 member countries of the IPG/CF since November 2005. UK membership fee is paid up to 2009. Due to work commitments I was unable to attend the North American CF Conference however, feedback was very positive from the delegates I have spoken too. I would like to thank all of you who responded so positively to my requests from colleagues world-wide for help and advice, which I have forwarded those interested.

I have also had the opportunity to host Alena Scherbakova, the winner of the Chiron/Novartis Best Care Scholarship for Physiotherapy 2006. She traveled from Moscow, to Birmingham in November and spent 12 days undergoing tuition in the care of both CF adults and children at The West Midlands Regional CF Centre, Birmingham Heartlands Hospital. Subjects which we covered included an excellent practical anatomy and dissection session, with Mr Richard Steyn Consultant Thoracic Surgeon. Non invasive ventilation, theory and practice with senior physiotherapists Emma Gallagher and Shabnam Moledena. Paediatric care with senior physiotherapists

Bethan Haeney and Georgina Ashdown. Airway clearance techniques and Autogenic drainage courses with myself and fellow clinical specialist Paula Agostini.

Alena also undertook observational training with myself and the CF physiotherapy team Lisa Kenyon, Aruna Kailey, Gail Murdoch and Jocelyn Barrett. We covered assessment, evaluation, annual review, adherence to inhalation therapy and associated equipment, ACT, exercise prescription and education within the CF Wards, gymnasium and clinic.

Alena attended the multidisciplinary team meetings and ward round spending time individually with our CF consultants Dr David Honeybourne and Dr Jo Whitehouse, clinical nurse specialists, dietitian and social worker. I would like to thank all of my colleagues in the CF team for their kindness in supporting the production of an interesting and informative worthwhile programme for Alena. We were able to supply Alena with many varied educational materials, including PowerPoint presentations and patient information leaflets.

I thank everyone involved for their input and hope that the good relationship forged with Alena will be helpful as she begins to disseminate her knowledge to physiotherapists throughout Russia, thereby improving patient care.

If I can be of assistance, I am willing to pass on advice to the host of next years Chiron/Novartis Best Care Scholarship award winner regarding organising this type of visit.

Our main UK study days this year will be in November in Birmingham, where we will be exploring a wide range of issues in both adult and paediatric CF care, with internationally respected speakers attending including Louise Lannefors and Ammani Prasad. In the meantime I will keep you informed of any new developments, as they arise.