

15 March 2005



International Physiotherapy Group for Cystic Fibrosis

NEWSLETTER 2, 2005

Introduction

The second Newsletter of the year is made up of a contribution of Annual Reports from the Member Countries (listed in alphabetical order), announcement of the winner of the 2005 Chiron Best Care Scholarship, a reminder about the CF conference in Crete and a list of the IPG/CF Officers and updated e-mail addresses. An updated list of Contact Persons e-mail addresses details can also be found on the website: www.cfww.org/IPG-CF/index.asp

Our treasurer, Jovita Zerlik, has included the treasurers reports for 2003 and 2004, and also the membership fees format for member countries that are able to pay the annual subscription of 50 Euros, or any donation would be appreciated.

Crete Conference

The CF conference is taking place in Crete, Greece from the 22-25 June 2005. The last date for early (and cheaper) registration is the 31st March 2005.

For further details and updates, please visit the conference web page:

www.europeanCFconference.org

The Agenda for the AGM and Proxy for Contact Persons (appointing a delegate to vote in your abstention) will be e-mailed to the Contact person the beginning of May.

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.

Esta-Lee Tannenbaum
Secretary for IPG/CF

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WINNER OF THE CHIRON BEST CARE SCHOLARSHIP 2005

Prepared by Dr Brenda Button, 14 March, 2005

Maria Cecilia Rodriguez from the Santosanni Hospital in Buenos Aires, Argentina is the winner of the 2005 Chiron Best Care Scholarship. She plans to study and undertake practical training at the Lund CF Centre in Sweden. Maria Cecilia has an interest in exercise training in CF and airway clearance techniques and wishes to further her knowledge in these areas as well as aerosol therapies. She also wishes to learn about improving quality of life in CF. She expects that dissemination of this knowledge in Argentina to patients and health professionals will assist in improving patients' clinical status and lung function and consequently adherence to treatments. She plans to disseminate this new knowledge and the practical skills acquired through lectures and seminars and conferences in her region in South America. She also plans to conduct practical workshops for CF colleagues about the physiotherapy and multi-disciplinary management and up to date treatments for patients with CF. Louise Lannefors at the Lund CF Centre in Sweden will be the host physiotherapist who will organise the theoretical and practical instruction that Maria Cecilia wishes to gain during her scholarship.

The members of the IPG/CF Board wish to congratulate Maria Cecilia Rodriguez and wish her all the very best as she undertakes this Chiron Best Care Scholarship.

IPG/CF Board:

Dr Brenda Button, Chairperson

Mr Filip Van Ginderdeuren, Vice Chairperson

Ms Jovita Zerlik, Treasurer

Ms Esta-Lee Tannenbaum, Secretary

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

Chiron Best Care Scholarship

The Chiron Best Care Scholarship (CBCS) is an International award sponsored by Chiron. It is an educational grant with the aim of providing greater support to the CF community. The CBCS 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.

Report from the Winner of the 2004 Chiron Best Care Travel Scholarship

Osman Coban, the winner of Chiron Best care Award 2004, visited the Free University Hospital of Brussels and got one week course by Filip Ginderdeuren about Modern Airways Clearance Techniques including PEP, Autogenic Drainage, Assisted Autogenic drainage Combined with Bouncing, Flutter and Intrapulmonary Percussive Ventilation (IPPV). After that visit we have planned a course, which includes Modern airways clearance techniques such as PEP, Intrapulmonary Percussive Ventilation (IPPV), Autogenic Drainage, for patients with CF and caregivers. This course took one month and has been given for 3 times in a week, 32 patients and their caregivers participated in it. This course is still going on. Also a booklet, which includes introduction, treatment and physiotherapy techniques for the caregivers, has been prepared by our team and given to them.

Annual Report from Australia

Prepared by Dr Brenda Button, Australian country contact person, January, 2005.

Louise Lannefors inspires CF care teams in Australia in 2004

We were most fortunate to have Louise and her family living in Melbourne on sabbatical leave in 2004. Louise and Leif Eriksson (her husband) shared much of their enthusiasm and knowledge about CF care and the Swedish approach to treatment with multi-disciplinary teams during their stay. Louise with the support of Elizabeth Cook and Roche Products developed a two-day "Optimising Inhalation Therapy" course, which was held in all the states of Australia (and allowed some sight seeing for the family too). Louise also presented workshops on basic and advanced airway clearance therapy at conferences in Australia and New Zealand during her year 'down under'.

Training of under- and post-graduate physiotherapists

The teaching of the use of all the different airway clearance therapies and state of the art CF care continues to be a priority and challenge for physiotherapists with university affiliations. In 2004 we continued to provide lectures and practical workshops on the rationale for the use of PEP, oscillating PEP, Autogenic Drainage, positioning to increase ventilation and effective huffing in patients with chronic suppurative lung disease and CF in particular.

Chiron Best Care Travelling Scholarship

Sumita Gupta from New Delhi, India who was awarded the travelling scholarship in 2002 has postponed the undertaking of her scholarship for personal reasons. She will spend approximately one month at the Alfred Hospital with Brenda Button in May 2005 learning more about up to date physiotherapy and the organisation of a CF centre. More cases of CF are being diagnosed in India, and Sumita will play a leading role in educating members of the CF care team in order to provide a quality CF service in her country.

Research and presentations at national and international conferences

Many physiotherapists in Australia with a special interest in CF continue to undertake diverse research projects. A study is underway to compare the effects of oscillating PEP using the "Acapella" with other techniques, the management of urinary incontinence in CF and COPD, interventions pre- and post lung transplantation, exercise testing, exercise therapy and adherence. Many of these studies are ongoing and some results were presented at the Thoracic Society for Australia and New Zealand Annual Conference in Sydney, The European CF Society Conference in Birmingham, UK and The North American CF Conference in St Louis, USA in 2004.

Conferences in Australia in 2005

Planning is underway for the Thoracic Society of Australia and New Zealand conference in Perth in March, the 6th Australian Cystic Fibrosis Conference in Adelaide in August, and the Australian Physiotherapy Association Cardiothoracic Special Group Conference in Melbourne in October, 2005, where physiotherapists will present research results. For further information about these conferences please email Brenda Button at:

brendab@unimelb.edu.au or b.button@alfred.org.au

Annual report from Austria 2004

Prepared by Dr. Béatrice Oberwaldner, Austrian country contact person

E-mail: beatrice.oberwaldner@meduni-graz.at, beatrice.oberwaldner@klinikum-graz.at

1. The previous year of the Austrian respiratory physiotherapy group again had to be dedicated to the postgraduate course in respiratory physiotherapy. The course is now nearly finished, 15 physiotherapists will write their final exams later this month. The physiotherapy tutors were largely recruited from the national specialist group; international experts covered several topics.
2. Besides of this time consuming activity the working group of respiratory physiotherapists has traditionally been involved in the programme of the Annual Conference of the Austrian Society of Pneumologists; physiotherapists organised a workshop on home ventilation and contributed to several other workshops with relevant lectures.
3. A group meeting was organised during the Conference with the intention to exchange information and knowledge, discuss topics of special interest and to develop a high standard of physiotherapy practice. A review of recent literature and reports on relevant conferences and meetings is always included in these meetings.
4. The educational programme on aerosol therapy was again organised for physiotherapists and nurses; special emphasis was made to teach the various techniques of inhalation and highlight the special needs of CF-patients when using the different aerosolised medications.
5. An educational programme for physiotherapists on basic respiratory physiotherapy measures was organised.
6. Several physiotherapy students and international exchange physiotherapists had an in depth training in different CF-centres.
7. 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 interest of physiotherapists in respiratory care is high; the more than 50 trained respiratory physiotherapists show a remarkable profile of knowledge and skills. In this context the specialised postgraduate training, which is offered to interested physiotherapists in Austria, distributes expertise throughout the country; thereby cystic fibrosis patients have the advantage to be treated by physiotherapists with a sound knowledge of respiratory physiology and practical skills.

Annual report from Belgium

Prepared by Filip Van Ginderdeuren, Belgium country contact person
E-Mail: filip.vanginderdeuren@az.vub.ac.be
From June 2003 to May 2004.

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 90 PT's. The topics were:

GOR

LFT, theoretical and practical aspects

Medication in respiratory diseases: an updating

The cough: theory and practice

BPD medical and physio aspects

Hygiene: in the hospital, at home and in private practice

Physio "clinics": meeting patients, their parents and PT (3).

II. Organisations and participation by members of the group.

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

International: in France (4 WE's), Germany (5 WE's), Austria (1 WE),
Switzerland (3 WE's), Spain (1 week), Belfast.

National: 4 courses (40 Hours each for 120 PT's) and 5 instructor's courses.

Part time lecturer at the Brussels University in respiratory care. (Filip)

2)-Refresher courses for trained PT's.

17 weeks for 17 PT's from Germany, France, Spain, Australia.

Training of 3 Belgian PT's (3 weeks)

3)-Lectures and/or practical training for PT students.

11 lectures for different medical and paramedical audiences.

Several lectures at the Belfast CF Conference (Filip, Jean)

4)-4 weeks training courses for PT students.

A total of 45 PT students from different Belgian PT schools.

5)-Participation

CF conference in Belfast (3 members)

6)-Lectures for Parents, MD's, PT's, Nurses and other caregivers

4 in total

7)-Belgian IPG/CF board meetings: 4.

8)-Abstracts: none// Thesis supervision: at least 5 (Dirk, Jean)

From June 2003 to May 2004.

Annual Report from Czech Republic

Prepared by Dr Libuse Smolikova, Czech Republic country contact person
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- There were 6 conferences during the year, presenting the most modern physiotherapy techniques for treatment of CF and other chronic respiratory diseases; they were attended by paediatric physicians as part of a program updating methods used in children pneumology
- Regular courses were held for 40 physiotherapists
- Respiratory physiotherapy is included in the study program for bachelor's and master's degree and is taught to medical students on the 2nd Medical School of Charles University, Prague
- Grant-aided research continues

Annual Report from Costa Rica

Prepared by Rodolfo Bonilla, Costa Rican country contact person
rhbonilla@hotmail.com or rhbonilla@yahoo.com

Dear Friends!

Today, the Clinic in Costa Rica is attending a total of 74 of 84 patients, 10 of them are adults and have been already transferred to the Adults Clinic at the Hospital Calderon Guardia.

Normally, all services are provided by the National Children's Hospital (HNN). However, some of them are able to meet their needs at the health centers of their communities. For this reason, we will be conducting a training session with local staff, in order to update their knowledge.

In spite, local staff are able to provide some services, all chest physical therapy is mostly perform by family members. We are still working on education, with the goal to promote among our patients a more effective self care course of treatment, and to promote a more independent way of life.

In respect of physical therapy, this year we attempt to improve services at the HNN, introducing new equipments and renovations in an area for individual attention. Besides, some more lectures, workshops and training sessions with respiratory therapists, nurses, and family members of patients with CF.

My best regards,
Rodolfo Bonilla A. BS RRT, MA
Hospital Nacional de Niños
San Jose, Costa Rica

Annual Report from The Netherlands 2004

Prepared by Jettie Nomden, The Netherlands contact country person

E-mail: j.g.nomden@rev.umcg.nl

In the Dutch working group CF physical therapist from almost every CF centre in the Netherlands are represented.

The aim of the group is to deepen the knowledge about the physical therapy for CF patients and to spread these knowledge and skills to physiotherapists in the Netherlands. We did so by giving information to colleagues who are treating CF patients by special organised events or by phone.

Recently we made an inventarisation about the care given to the CF patient in hospital and outpatient clinic.

This inventarisation is published in the magazine of the Dutch CF foundation.

This inventarisation showed that many resemblances exist in the CF centres. Differences are mostly due to the organisation structure of the CF-team's.

In 2004 the working group has started to make a new extensive brochure on all aspects of physical therapy for CF patients such as physiotherapy at home and in hospital, breathing techniques, sports, lung transplantation, etc. The Dutch CF Foundation and some experts have commented a first version. These days the second version has been sent to them.

Annual National Report from Norway 2004

Prepared by Sandra Gursli, Norwegian country contact person

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The Norwegian National Working Group for CF (FF-Fysio/CF) met for four days in September 2004 in connection with a multidisciplinary Course arranged by the Norwegian National Center for CF in Oslo.

The Group had a fruitful exchange of information and knowledge, and discussions related to items given special priority. Main items were presented and discussed as outlined below:

- Technical aids centre and equipment approved for use in Physiotherapy at home
- Case presentations and discussions in regard to treatment and follow-up of shared patients, i.e. different Health regions and the National Center

- Hygiene Guidelines in regard to treatment in the Hospital as well as in daily life
- Three of the members attended the ECFC in Birmingham, June 2004 and reported on interesting topics like: Women's health issues, ACT, Inhalation – therapy and IPV

Main activities throughout the year have further been as outlined below:

- National Course for families with newly diagnosed children
- Education and practical training of physiotherapists and assistants, physiotherapist students, as well as patients and parents
- Regional education days and courses

Annual Report from Poland

Prepared by Teresa Orlik, Polish country contact person

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Main Activities in 2004

Organizations and participation in courses by members of the Group.

1. Three-days post-graduate courses including aspects of physiotherapy in pulmonary diseases organized by Physiotherapy Department of the Institute of Mother and Child in Warsaw (2 courses a year: 10-12.05 and 17-19.11.2004). The courses were aimed at physicians who specialize in rehabilitation.
2. Two-days course organized by Physiotherapy Department of the Institute of Mother and Child (28-29.10.2004). The course included theoretical and practical aspects of physiotherapy used in cystic fibrosis - taught by Teresa Orlik. This course was aimed at physiotherapists involved in treatment of CF patients who would like to have more knowledge about CF management and airways clearance techniques.

Organizations and participation in conferences by members of the Group.

1. Polish Working Group Conference was held in Białowieża in October. On this conference Teresa Orlik presented lecture "Physiotherapy situation of cystic fibrosis patients in Poland"
2. The Annual Meeting of Polish Society Against Cystic Fibrosis was held at the Institute of Tuberculosis and Lung Diseases in Rabka in May. Teresa Orlik presented lecture "Physiotherapy in cystic fibrosis – practical aspects.

3. The Annual Conference for patients with CF and their parents was held in Krakow in November 2004. On this Conference Teresa Orlik again presented lecture “Physiotherapy situation of cystic fibrosis patients in Poland”
- 4.

The other activities

The Life Club programme has been started since November 2004. This is a treatment motivation program for CF patients who score for treatment and physiotherapist's, dietitian's and psychologist's visits. The Life Club program was worked out **by Matio Foundation in co-operation with Polish Working Group for Cystic Fibrosis. Physiotherapists are actively involved in this programme.**

Annual Report from Romanian

Prepared by, Romanian country contact person
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Achievements

1. During The First Congress of Cystic Fibrosis with International participation which took place in Timisoara in 2003, a special section for physiotherapy was designed. Following up the discussions, a project for training in CF physiotherapy was started. This project is designed for specialists in physiotherapy that have no experience in CF and for the nursing staff. The period for such a special training is 14 days. The aim of the project is to create in each important Romanian CF Centre a medical team: one physiotherapeutic specialist and one specialized nurse in CF Physiotherapy. Up to the moment there were trained two persons. The project is carried on difficulty because of financial problems.
2. During the year 2004, a PhD thesis was started within the Timisoara CF Centre about physiotherapy in CF and it represents the first paper on this topic in Romania. In order to finish his thesis, our PhD student has asked for support some European CF Centers that have experience in CF physiotherapy to be accepted for a period of study probation. We do not have yet an answer in this respect.
3. We translated into Romanian the booklet “A manual for Cystic Fibrosis Patients and their Parents” which was sent by CFW and we added some information about domiciliary physiotherapeutic treatment. Our colleague from Brasov, Dr. Laura Dracea has done the same thing for her patients.
4. The coordinator of Romanian CF Centre and of the Group for Physiotherapy in Romania, Dr. Zagorca Popa, has become since 2004 a graduate of Faculty of Physiotherapy of the University of Medicine and Pharmacy Timisoara. We hope

that will contribute to extend the knowledge of CF physiotherapy on a national level in our country.

Problems

The knowledge for CF Physiotherapy is still limited on a national level, even though it is accepted its necessity. In many centers physiotherapy is extremely limited both regarding the techniques and the accurateness of their use.

Objectives for 2005

1. To continue the project of training of specialists in CF Physiotherapy
2. To publish the second edition of the monography "Physiotherapy in Cystic Fibrosis". The first edition published in 2003 (in a limited number of copies because of lack of funds) is out of print and there are many requests for it.

Annual report from Sweden

Lund, Jan 27th, 2005

Prepared by Louise Lannefors, Swedish country contact person

E-Mail: Louise.Lannefors@lung.lu.se

Sweden sees about 580 CF-patients and the care is organised in four CF-centres (Stockholm, Uppsala, Gothenburg and Lund). Each centre has at least one representative within the Swedish national CF physiotherapy council.

1. During last year the council has met twice.
2. The council has organised one education and exhibition day for physiotherapists involved in CF from all over the country.
3. Colleagues both from within the country and from abroad have visited the CF-centres.
4. The IPG Newsletters and other information have been forwarded to colleagues at all CF-centres, who have been stimulated to forward them to colleagues at referral hospitals.
5. The follow-up summary of our patients' functional parameters, produced by the council and presented at international CF-conferences, is being worked upon and the ambition is to have it published.

National Report from Turkey

Prepared by Osman Coban. Turkish country contact person

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All of the physiotherapists have just basic knowledge about Respiratory Therapy except for physiotherapists who have improved their knowledge and skills with master or doctoral education in Cardiopulmonary Rehabilitation, in Turkey. Generally physiotherapists have possibility to meet patients with CF and other respiratory disorders in hospitals. That is why we focused on improving knowledge of Physiotherapists on Cystic Fibrosis and Chest Physiotherapy. So we informed around 571 physiotherapists who work in different parts of Turkey via mail and web page. We also gave seminars to the 4th year students of Physical Therapy and Rehabilitation School at Istanbul University.

Our working group developed the first Turkish Cystic Fibrosis Web Page (www.osmancoban.com.tr.tc). The web page includes basic knowledge about CF, treatment, diagnosis, Nutrition, Physiotherapy and physiotherapy modalities for CF. Osman Coban was awarded the 2004 Chiron Best Care Travel Scholarship and plans to disseminate new information and knowledge to patients, carers and health professionals in Turkey. For details of this undertaking please read Osman Coban's report in this Newsletter on page 3.

Annual report from United Kingdom

Prepared by Esta-Lee Tannenbaum, UK country contact person

E-mail: etannenbaum@hotmail.com

The ACPCF (Association of chartered physiotherapists in cystic fibrosis) at the end of 2004 has a membership of 112 members. The UK was proud to host the 27th European CF conference in Birmingham 12-17th June. The ACPCF encouraged all physiotherapists in the UK to attend the conference, sessions or one of the courses.

Our AGM held in November included smaller working parties on the following topics:

- Review/re-write the CF trust physiotherapy booklet for patients and families
- Review current ACPCF protocols
- Outcome measures – standardize and disseminate information to members
- Organising the 2005 study days

The nine regional groups in the UK organize their own meetings and courses throughout the year. The regional group membership has grown over the years and they enjoy the opportunity to share information and experiences.



INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC

FIBROSIS

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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



INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC
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Treasurer report 2004/ 05

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
Sweden	Euro 50

Bank expenses : Euro 6,65

Closing balance 14 March 2005 : Euro 3.106,08

Jovita Zerlik, IPG/CF treasurer

Hamburg, Germany 14.3.2005



INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC
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Treasurer report 2003

Closing balance 17 July 2003: Euro 1.958,91

Received subscriptions since July 2003:

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

Bank expenses since 17 July 2003: Euro 18,95

Closing balance 31 December 2003: Euro 2.386,93

Jovita Zerlik, IPG/CF treasurer

Hamburg, Germany 6.1.2005

IPG/CF Officers:

Chairperson: Brenda Button (Australia)
Vice Chair: Filip van Ginderdeuren (Belgium)
Secretary: Esta-Lee Tannenbaum (UK)
Treasurer: Jovita Zerlik (Germany)

Updated: March 2005

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