



International Physiotherapy Group for Cystic Fibrosis

## ***NEWSLETTER 1, 2008***

### **Introduction**

Greetings to everyone with the first newsletter of 2008. We would like to welcome to Manar Jaber – the new contact person from Palestine. This newsletter includes the annual reports from member countries for the year 2007. Also included is the document regarding the annual fees. If possible – please bring the payment along to the CF conference in Prague – or contact Jovita Zerlik (the Treasurer) if you have any queries.

Esta-Lee Tannenbaum  
IPG/CF Secretary

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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



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 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

## **Annual report from Australia**

Prepared by Dr Brenda Button, Australian country contact person  
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Thirty physiotherapists treating patients in CF Units around Australia continued to work together throughout 2007 advancing the initiative "Physiotherapy for Cystic Fibrosis in Australia: a Consensus Statement". They started working together on the project in 2005 with the aim of completion early in 2008. In March, 2008 the project was completed and has been endorsed by the "Thoracic Society of Australia and New Zealand". The Consensus Statement has been posted on the TSANZ website. The project included a thorough search of the literature, identification of the variations in national clinical practice followed by implications for physiotherapy and clinical recommendations which were scored using the National Heart, Lung and Blood Institute grading system with four categories.

The document consists of 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 and urinary incontinence, CF related diabetes and aspergillus infections; lung transplantation and palliative care. The members of the writing group met for the second time face to face at the bi-ennial Australia and New Zealand Cystic Fibrosis Conference in Sydney 2007 to discuss and resolve a few differences of opinion and fine tune the document. Dr Anne Holland was employed as a professional writer to edit the different sections into a coherent, readable and succinct document. She has been highly successful in achieving this goal with funding from a scholarship from the Australian Cystic Fibrosis Association.

The IPG /CF country contact person and chairperson of the consensus initiative approached the IPG/CF on behalf of the group to seek permission for the group to be named "The Australian Chapter of the International Physiotherapy Group for Cystic Fibrosis". Permission was granted by the Board of the IPG/CF. This initiative has been undertaken with much good will, co-operation and hard work by each of the members of the writing group. We are all truly proud of what we have achieved together in reaching consensus in the broad application of physiotherapy in CF. Questionnaires were completed relating to all aspects of clinical practice prior to commencement of the project. We plan to evaluate changes in clinical practice in the future to establish whether the consensus statement actually lead to a change in practice. The document will be reviewed in five years. To view the document go to:  
<http://www.thoracic.org.au/physiotherapyforcf.pdf>

## **Annual report from Austria**

Prepared by Dr. Béatrice Oberwaldner, Austrian country contact person

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The Austrian respiratory physiotherapy group was mainly busy with the development of syllabus and curriculum for the International University Degree Course in Cardio-respiratory Physiotherapy at the Medical University of Graz. Chair and co-chair of this group are appointed as director and co-director of the three year course, which commenced recently. Participants come from a variety of cardio-respiratory institutions; several of them work in CF-centers.

Several meetings took place; the main aim of these was to discuss relevant literature and spread news on best practice in respiratory physiotherapy.

The working group of respiratory physiotherapists has traditionally been involved in the programme of the Annual Conference of the Austrian Society of Pneumologists and has organised a scientific session on “physiotherapy management of the patient with neuromuscular disease”.

An educational programme on tracheostomy care and long-term home ventilation was organised for physiotherapists and nurses.

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

Several physiotherapy students and CF-physiotherapists had an in depth training in physiotherapy management of patients with CF over a life span.

For the Annual Meeting of the Austrian CF lay organisation physiotherapists have arranged sessions on training as well as inhalation therapy.

In summary, the profile of the specialised respiratory physiotherapists of Austria is high, since the introduction of the postgraduate specialisation, numbers are constantly increasing. This provides a high level of theoretical knowledge and practical skills also for the physiotherapy management of CF-patients.

## **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 3 activities in the past year. The number of participants varied between 50 and 100 PT's. The topics were: Flow modulation concept, Asthma, Anatomy and physiology of the respiratory tract.

### **II. Organisations and participation by members of the group.**

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

- International: in France (112 hours, 82 participants), Germany (48 hours, 70 participants), Switzerland (38 hours, 40 participants), Spain (48 hours, 37 participants), Italy (24 hours, 40 participants), Luxemburg (32 hours, 13 participants), Israel (48 hours, 14 participants)
- National: 3 courses (72 Hours each for 58 PT's).

#### **2)-Refresher courses for trained PT's: 1 refresher course in Spain**

#### **3)-Lectures and/or practical training.**

9 lectures for different medical and paramedical audiences.  
Lectures at the CF Conference in Belek, Turkey (Lay people)

#### **4)-4 weeks training courses for PT students.**

A total of 80 PT students from different Belgian PT schools.

#### **5)-Participation: CF conference in Belek (3 members)**

CF symposium (Brussels, Belgium)

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

6 in total

#### **7)-Belgian IPG/CF board meetings: 6.**

#### **8)-Articles/Abstracts:**

Chest physiotherapy in Cystic Fibrosis: Short-Term effects of Autogenic Drainage preceded by wet inhalation of saline versus Autogenic Drainage preceded by Intrapulmonary Percussive Ventilation. (2007) Respiration, Nov 28, Epub ahead of print. (SCI: 1.649).

Thesis supervision: at least 4

#### **9) Organisation of the "Belgian Association for Respiratory Physiotherapy" Conference**

Organisation of the physiotherapy sessions at the European CF Conference in Belek, Turkey.

## **Annual Report from Italy**

Prepared by Paolo Buonpensiero, Italian country contact person  
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As member of the Italian Scientific Society of Cystic Fibrosis (S.I.F.C.) the Italian Group of Physiotherapist for Cystic Fibrosis continues to actively participate to the following interdisciplinary Working Groups:

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

From the 30th of November to the 2nd of December 2007 “Course on “Non Invasive Mechanical Ventilation “ 2nd Edition. Milan.

From 18th to 19th of April 2008 “4th Meeting of Italian Society of cystic fibrosis: “Home Care Issues in cystic fibrosis patients.” Scientific and policy issues in programming home care assistance.

One member of the Physiotherapist Group has been voted onto the Executive Committee of the Italian Scientific Society for Cystic Fibrosis.

As educators in the Italian Universities (Medical Faculties) many Cystic Fibrosis physiotherapist organize every year specific training courses on:

Airway Clearance Techniques  
Physical Exercise  
Posture Problems and treatment

Lectures, seminars, and Doctor Physiotherapy Thesis are also produced.

## **Annual National Report from Norway**

Prepared by Sandra Gursli, Norwegian country contact person  
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In Norway we have 271 persons with CF, 118 children and 153 adults. We have shared care between The National Centre in Oslo and regional Centres in the different parts of Norway. The National Centre has two multidisciplinary teams that meet persons with CF in planned controls from all over Norway. In addition the regional Centres meet them on regular basis in between.

### The Norwegian National Working Group for CF

The Norwegian National Working Group for CF consists of 14 physiotherapists from the National Centre and regional Centres. One physiotherapist is a member of the advisory council organized by the Lay organization. The Group is looking for solutions for how to extend the Group with more Physiotherapists working with adults, and to cover more regions.

Members from the working group met for two days in Oslo, in January 2008. The group shared information about work that has been done, as well as knowledge and experience on the following items:

Transition child - adult

Guidelines in Respiratory Physiotherapy

Information from the IPG/CF: Glossary, etcetera

Theoretical and Practical day: Work done by the Physiotherapists at the National Centre on Nebulizer systems (2005 – 2007): Overview of the most common devices with defined criteria for assessment and evaluation in clinical practice. The aim is to make it easier to choose which one to use and to be able to assess new equipment.

The National Contact Person, was invited as a speaker at the Annual National Conference, in Galway, Ireland in March 2007. The title was: "Motivation to maintain adherence". She also attended the European Cystic Fibrosis Conference in Belek, June 2007, including the pre – conference course on Inhalation Therapy.

### The Norwegian National Centre for CF

The National Centre has three Physiotherapists employed. Main activities, in addition to patient – related work, have been as outlined below:

Cooperation with physiotherapists from different Regional/University Hospitals as well as local physiotherapists about follow up/outreach activities.

Transition child - adult: Content and routines.

Cooperation with an author who is writing a book for children about CF.

Multidisciplinary meetings with other regional Centres, as well as the National organ transplant team.

Revision of a chapter for the Lay Organization in Norway on Physiotherapy in CF.

Education and Courses for Physiotherapists in Respiratory Physiotherapy in CF.

The National Contact Person participated in writing a chapter about the use of Physical Activity/training in CF, together with Johan Stanghelle from Norway and Louise Lannefors and Ulrika Dennersten from Sweden.

## **Annual National Report from Palestine**

Prepared by Manar Jaber, Palestinian country contact person

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Cystic Fibrosis in Palestine is assumed to be a rare chronic disease, with a poor prognosis. Children with CF are having a hard life because of three difficult situations: the poor economic and social condition in Palestine, the poor awareness of the society about CF, and third the military occupation that aggravates the two previous conditions.

The political situation in Palestine has a direct effect on both health and economy; this bad political situation brings more poverty to the poor CF families, which prevent them to secure medication and food for their sick children. Also the limitation on moving from one place to another imposed by the occupation makes it difficult for these families to seek medical help in clinics, hospitals, and physiotherapy centers. It is well known that CF patients need continuous medications and continuous follow up in physiotherapy centers, and both of these are expensive and not offered free anywhere.

Our public health sector is trying to be active in taking care of chronic disease in general but there are many limitations. Our health services miss a pediatric even an adult pulmonologist to follow up these patients hand in hand with the physiotherapist. Moreover the physiotherapy services in Palestine don't deal with these patients as priority because they have to deal with the injured and the geriatric population. To diagnose CF patients we relay mainly on the sweat chloride test, and this test is offered only in few places in the West Bank. As these places are in private sector, this gives a partial explanation about the absence of statistics of CF patients, but our society is eager to know more about CF disease and its prevalence in our society so that support will be provided to CF patients.

Our CF patients have miserable life because of lack of enough medications, because of lack of money to buy food, and because of inability to seek even general physiotherapy.

Most of our hospitals do not have physiotherapy departments, so when a child with CF is admitted to the hospital, he just receives pure medical treatment without any physiotherapy intervention. I am working in Caritas Baby Hospital in a small physiotherapy department, which consists of three physiotherapists. Caritas Baby Hospital is the main pediatric hospital serving the south and middle of Palestine. Since 2002, twenty one children with CF were admitted to the hospital, but they are not able to be followed up for continues physiotherapy because of the above limitations, even if the hospital offers free services to them. Our plan is to get close to these families by setting up a home visit program (a joined physiotherapy and social worker): our main goal is to meet these families in their home situation, by passing the financial and the political obstacles in order to direct them for the best of their child by assessment, advice, recommendation, and physiotherapy home program, in the hope that they will be encouraged to continue follow up with us!!

During 2007, our hospital mainly the physiotherapy section was invited to share the experience of managing CF patients in a Dead Sea Resort (Christiane Herzog Stiftung Center). As a result of this invitation, I accompanied one 11-year-old child to this center. In that center extensive rehabilitation, practical education, and Clima therapy (Dead Sea climate and below sea level advantage) is offered. Also during my stay there I attended "Basic Airway Clearness Course" conducted by Mr. Jean Chevaillier. This short stay in that resort gave me a new experience how to deal with these chronic patients.

Most of our children with CF come from villages, whereby health education and awareness are minimal. Usually in families of CF patients consanguinity runs very high and in the same family there is more than one child with CF. This puts a large burden on the family did give birth to other children and are not aware of the consequences. Therefore we find families in our vicinity with two or more children afflicted with CF.

Children can receive freely pancreatic enzyme capsules (Creon or Pancrease) from the public health insurance, but other medications such as inhalation medications are not available, and they to be purchased by the family. Now our hospital tries to help these patients in things that are not offered by the public health insurance and usually does not charge these patients the outpatient clinic fees or their hospitalization fees. There are no organizations that are concerned with helping CF patients and I hope that in future such organizations will be established (e.g. similar to diabetic organizations that exist in our community).

During my work with children with CF, I can realize that there is serious problem in the awareness of families about CF. This poor awareness resulted in more complications for their children in early life, and shortened their life expectancy. So it is unusual to see CF patients growing into adolescence.

Families and their children are suffering, just because they choose the wrong way to deal with this illness in the absence of right direction from any professional. Families did not know about "how bad their child was", until they needed oxygen.

I saw a number of children in very bad chest condition, when they were admitted to the hospital, most of them did not accept my touch on their body, because simply they are not used to physiotherapy in their life!!! This brought more difficulty to our job, because we have to spend more time in communication and less time in treatment. Even so, after a time, we could apply our therapy in a better manner. In a short sentence, families did not realize that physiotherapy and inhalation are best way to help their children.

In conclusion I can say that we need a lot to do for our CF patients, being this in health education or in financial and moral support. I hope that hospitals will pay more attention and give more specialized care to these chronic CF patients.

## **Annual National Report from Sweden**

Prepared by Louise Lannefors, Swedish 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 had telephone and e-mail contacts  
had continuous contacts with the different regional patient associations in Sweden  
collected data for a summary of the last 25 years of working in Sweden, the ambition is to publish these results  
hosted several visitors from different countries

## **Annual National Report from Switzerland**

Prepared by Patrick Althaus, Swiss country contact person  
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The Swiss Physiotherapy and Cystic Fibrosis Working Group has 21 members, representing the every CF centres in Switzerland.  
The Working Group has met 4 times during the last years.  
The main activities were:

### Autogenic Drainage and Modern Airway Clearance Techniques Courses

Jean Chevaillier is the international invited speaker for physiotherapy courses, assisted by 3-4 physiotherapists specially prepared to be the instructors assistants for the Basic course held in Basel (German speaking) and in Lausanne (French speaking).

### Continuing Professional Development.

The group has a very close co-operation with:

The National CF association.

The collaboration between CF physio and National CF association has been fixed in a partnership contract.

The new concept Sports / Social events during the week-end are organized for adults. (<http://www.cfch.ch>)

### The Marchethon

Many physiotherapists have participated to the running events named Marchethon in Lausanne, Fribourg, St. Léonard, Bern, Zurich, Bellinzona, Davos, la Chaux-de-fonds and had the opportunity to sustain the CF by buying the mascotte O2 (<http://www.marchethon.ch/>)



The National Physiotherapy association.

Physiotherapists from the group animate the Quality circle sessions held in Bern, Zürich and St- Gallen. (<http://www.fisio.org>)

The Pediatric Physiotherapy association,

The group is involved in Best practice for babies and infants treatment guidelines (Babyproject). (<http://www.paediatrica.ch/>)

Communication strategy and spreading of information

Just have a look on our Website <http://www.cf-physio.ch>

