

# ***NEWSLETTER***

***1/2004***



***International Physiotherapy Group  
for Cystic Fibrosis***



***Wonderful spring***



**A short introduction from the secretary**

***Dear Colleagues,***

***I am happy to be sending you the NL 1/2004.***

***The board took note of your comments and shortened NL 2003. The reports which were not published then are to be found in NL 1/2004, together with the updated list of Contact Persons, please see: <http://www.cfww.org/IPG-CF/contact.asp>:***

***It is my big pleasure to welcome new Contact Persons: Rebecca Udy from New Zealand and Osman Coban from Turkey.***

***The most important point is the fact that my term of office as secretary is coming to an end. According to our Constitution, nominations for a new secretary must be received before the AGM at which the election takes place. This means all nominations should be with me by***

***April 30, 2004.***

***The same applies to nominations for a new treasurer. You may remember that Jovita took over when Carien could no longer do this job. Since Jovita has been Acting Treasurer for a year, I suggest that she would be the best person for election according to the Constitution. Both these appointments will be decided at the AGM in Birmingham.***

***I am looking forward to meeting you all in Birmingham. Those who can not come, please send me your excuses with the name of your proxy, who will cast her vote.***

***I am preparing the agenda for Birmingham and would be happy to receive your suggestions. What do you think we should discuss?***

***Please contact me whenever you need: [libuse.smolikova@lfmotol.cuni.cz](mailto:libuse.smolikova@lfmotol.cuni.cz)***

***On behalf of the IPG/CF Committee  
I would like to wish you  
wonderful spring***

***Hoping to hear from you soon.***

***Yours,  
Libuse Smolikova, Dr***



*Obituary*  
*Sam Hillyard*  
*Editor of the Cystic Fibrosis Worldwide (CFW) Newsletter.*  
*11 August, 1973 - 15 January, 2004*

Sam Hillyard has for many years been Editor of the Cystic Fibrosis Worldwide (CFW) Newsletter. She has long been devoted to the organisation of CFW and prior to the merger of ICF(M)A and IACFA to the IACFA organization. She will be missed by many and will leave a great void in the organisation. The Board of the IPG/CF has worked with Sam over many years, sharing and spreading information about physiotherapy in CF and answering questions asked by people with CF and their families.

I am writing on behalf of the International Physiotherapy Group for Cystic Fibrosis (IPG/CF) to express our great sadness at hearing about Sam's death. I have known Sam for four years – the time I have served on the Board of the IPG/CF where Sam and I shared information and enjoyed friendship in our different roles in CFW. Sam was an absolutely delightful and lovely young woman. She exuded such enthusiasm and had a lovely manner when dealing with people. She was a tireless and meticulous editor and served the International CF Community with great dedication and commitment. Her untimely death reminds us of why we are all involved in the fight against CF. She certainly influenced me as a physiotherapist. Sam's encouraging, caring and friendly mother, Sue, was never far off during conferences. It was obvious that she was devoted and provided Sam with whatever support required.

As Editor of the CFW Newsletter Sam was imaginative, innovative and insightful. Sam was happy to accept articles in any language as she had access to translators, and if they did not feel confident to write articles she was prepared to do interviews via telephone, face to face or via the Internet depending on confidentiality issues. Sam assisted with the organisation of lay conferences for PWCF and their families, partners, etc during the European CF Conferences. She sought topics that would be of interest and relevant.

The life of Sam, beloved daughter to Dave and Sue, much loved sister to Jason, cherished granddaughter, wonderful niece, great cousin, loyal friend and inspiration to us all was celebrated at All Saints Church, Cople, United Kingdom on the 29 January, 2004. She was 30. The funeral was, of course, very sad but beautifully organised as Sam had left detailed instructions. In excess of 300 people came to the church - they even ran out of order of service sheets. What a tribute to Sam as a person and a campaigner for CF. Mitch Messer paid tribute on behalf of CFW. Everyone who attended Sam's service was given a daffodil as they left the church - which was beautifully decorated with real old English wild spring flowers greenery and tree barks - it was just right for Sam as a real country girl. Following a private family burial a 'wake' was held in a pub in the nearby village of Northill. Sam has made a great contribution during her life and many cherished memories will be held by many.

*Prepared by Brenda Button Dr, IPG/CF Chairperson, March 2004*

**Obituary**  
***Dr Christian Koch***  
***Head of the Copenhagen CF Centre***

Consultant doctor Christian Koch, head of the Copenhagen CF centre since 1982, died suddenly, unexpected but quietly at home in bed on a Sunday morning in February. He had been working with CF for many years and under his direction the Copenhagen centre developed to present standards. Christian was everybody's friend, a skilled paediatrician able to combine clinical work with world leading science without losing the confidence of patients and their families. He always had time to listen and was loved by patients of all ages. The CF centre under his leadership has contributed a great deal to the development of CF care, not the least when it comes to physiotherapy which always has been an important part of the treatment package at the Copenhagen centre. Many patients, caregivers and scientists have lost a co-worker and a friend. The IPG/CF sympathizes with the CF centre in Copenhagen and of course with Christian's family in the sorrow resulting from his sudden and unexpected death

*Prepared by Louise Lannefors, Lund CF Centre, Sweden for the IPG/CF, March 2004*



**Letter from Jovita Zerlik, new Treasurer IPG/CF**

July 2003

***Dear IPG/ CF Contact Persons,***

my name is Jovita Zerlik and I would like to introduce myself as the new IPG/CF treasurer. For reasons of changing to another field of work my predecessor Carien Beurskens had to leave the job prematurely.

On this year's Annual General Meeting on June 5<sup>th</sup> in Belfast I was elected treasurer for one year for the time being.

Since 1983 I am working as a Senior Physiotherapist at the „Altonaer Kinderkrankenhaus“, a children's hospital in Hamburg, northern Germany. The CF patients we are working with are mostly children and adolescents but also some adults.

I am a member of the German CF physiotherapy working group and since last year also a member of our executive board.

During all this time I also have been teaching the chest physiotherapy techniques used in Germany as an instructor for basic and advanced courses for CF physiotherapists .

I am attending the ECFC since 1997 and since 2001 I represent the German national contact person to IPG/CF.

I would like to thank Carien for the great work she has done as IPG/CF treasurer.

I am very much looking forward to working together with all of you and with Brenda, Filip and Liba on the executive board.

Most of you already received an email from me with further information on the new bank account. In this newsletter and in periodical distances I will inform you on how to pay the fees and about the actual received subscriptions and the closing balance.

*prepared by Jovita Zerlik, March 10, 2003*

**Received subscriptions for 2003 before June 2003:**

Germany	Euro	50
Belgium	Euro	240
Uruguay	US \$	125

**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

**Received subscriptions 2004:**

Germany	Euro	50
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Bank expenses 2004: Euro 6,15

**Closing balance 10 March 2004:**

Euro 2.430,78



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**Membership fees for IPG/CF Contact Persons**

1. When sending your membership fee to the IPG/CF Treasurer please send it to:

**Jovita Zerlik, IPG/CF treasurer**  
**Hamburger Sparkasse**  
**Account No.: 1042 880 250**  
**BLZ 200 505 50**

2. Description: membership fee .... (year), from..... (country)
3. Please make clear which country is sending the membership fee and for which year; if possible please use also the tear off form at the end of this page to send to the Treasurer.
4. The membership fee rate is **50 Euro** for one year, or 100 Euro for two years or the equivalent in other currency.
5. If you have any problems paying the membership fee then please contact any of the IPG/CF committee members for advice.
6. You will receive a receipt after payment.

Dear Treasurer IPG/CF

Please find enclosed the IPG/CF subscription for ..... (year)

From ..... (country).

Amount .....

signed ..... (Contact Person)

**CHIRON BEST CARE SCHOLARSHIP**

***Winner 2004***

We are very pleased to announce that the following applicant for the Chiron Best Care Scholarship is the winner for 2004:

**Osman Coban**



research associate at the Istanbul University, School of Physical Therapy and Rehabilitation and physiotherapist at the CF Centre, Istanbul, Turkey. Osman has worked as a full time physiotherapist treating patients with cystic fibrosis for two years. In the Asthma-Allergy Department there are more than 100 patients with CF and in the Nutrition Department there are over 80 patients with CF. Osman writes "So I have to learn so many things for these patients. All my knowledge, skills and experience about CF will improve the morale of patients, motivation of physiotherapists and other health care persons. I'm hoping to progress my knowledge about CF. I also want to learn the role of the physiotherapist in the treatment of CF, physiotherapy methods used in Belgium for patients with CF, skills of the center in the treatment of patients with CF and enlarge my experience abroad with treatment methods of this center".

Osman wishes to spend three to four weeks at the Physiotherapeutic Institute, Zeepreventorium, De Haan, Belgium with Mr Jean Chevaillier. When asked 'How do you expect this experience will benefit your CF patient group?' Osman replied: although there are many people with CF in Turkey, there are not enough physiotherapy centers for patients with CF. All patients with CF go to University Hospitals which are in the different parts of Turkey. Osman wants to present lectures and courses to all the different centers and give more information about physiotherapy for patients with CF. Osman plans to teach patients with CF, physiotherapy colleagues and other health care professionals following the training period in

Belgium.

Furthermore, Osman wants to disseminate the knowledge via a newly developed webpage, via a booklet and by seminars. Osman also wishes to present information to the international CF community about the experience of CF in Turkey.

E-mail address:

osman28@istanbul.edu.tr

*We would all like to congratulate Osman Coban for being the winner for 2004.*

**IPG/CF Board:**

***Dr Brenda Button, Chairperson***

***Mr Filip Van Ginderdeuren, Vice Chairperson***

***Ms Jovita Zerlik, Treasurer***

***Dr Liba Smolikova, Secretary***

**We would like to acknowledge and thank Melanie Rochford of 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***

*Prepared by Dr Brenda Button, 7 March, 2004*

**The Best Care Award (BCA) is an International award sponsored by Chiron. It is an educational grant with the aim of providing greater support to the CF community. The BCA 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 and can spend time in a qualified CF-centre anywhere in the world. 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.

The winner of the BCA 2002 was Angela Potter from Adelaide, South Australia. She planned to study with Jean Chevallier at the Zeepreventorium in De Haan, Belgium Angela reported on her experience in the most recent IPG/CF Newsletter. Sumita Gupta from India was the winner in 2003 and plans to spend three to four weeks with Brenda Button at the Alfred Hospital, Melbourne, Australia in 2004 learning the different modern airway clearance techniques used with CF patients.



***The 27<sup>th</sup> European Cystic Fibrosis Conference, Birmingham, UK 2004***

*Prepared by Filip van Ginderdeuren*

The next conference will be held at the International Convention Centre, Birmingham, England, from Sunday 13<sup>th</sup> until Thursday 17<sup>th</sup> June 2004.

Please note that the physiotherapy programme starts earlier on with **two** pre conference courses :

- 1) Saturday : June 12<sup>th</sup> : Advanced Airway Clearance Course. This course will be organised in the Birmingham Heartlands Hospital. Transport will be available to and from the International Convention Centre. Participants must have attended a basic airway clearance course at the European or North -American Conferences in the past , otherwise they will be refused.
- 2) Sunday : June 13<sup>th</sup> : a short course ( half a day in the morning ) on Exercise Physiology and Practical Aspects of Testing and Programmes . This course will be organised at the International Convention Centre and will be followed by our Annual General Meeting. Because of last year's success a new session on Physiotherapy Case Presentations will be organised on Sunday afternoon.

Full instructions for submitting case summaries and fee to attend the Physiotherapy Courses will be available on conference website [www.cftrust.org.uk](http://www.cftrust.org.uk)

Furthermore we have a seminar on "Women's Health; issues and treatment ( June 14<sup>th</sup> ) and a workshop on Evaluating the effectiveness of Airway Clearance. Mary Dodd ( UK ) will be presenting a lecture on " Physiotherapy for CF, more than airway clearance " during a plenary session on patient care. ( June 15<sup>th</sup> )



***Everybody is welcome at the Annual General Meeting of the IPG/CF, Birmingham, UK, Sunday, June 13, 2004. The place, time and agenda of the AGM will be given in a letter from the secretary in due course.***

***Please see:***

***[www.cftrust.org.uk/cf2004](http://www.cftrust.org.uk/cf2004)***



***IPG/CF Board:***

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*In this electronic age I thought it unnecessary to give telephone, fax etc. But all this information is available if you need it. Just apply to me:*  
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Updated March 2004

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INTERNATIONAL PHYSIOTHERAPY GROUP FOR CYSTIC FIBROSIS

## **ANNUAL NATIONAL REPORTS 2003**

*March 2004*

Dear friends,

**We would like to know more about physiotherapy in your country:  
which techniques you use most often,  
how many physiotherapists in how many centers are working with  
how many patients and with what success.**

**It is an old tradition of ours to share such information.**

**Unfortunately there are some countries where the CPs shown no sign of life  
for the four years I have been Secretary.**

**We are looking forward to your National Report in e-mail form at any time.**

*Yours*

*Dr Libuse Smolikova, IPG/CF Secretary*

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## ANNUAL NATIONAL REPORTS 2002 - 2003

*(alphabetically by country)*

### Report from Australia

*Prepared by Dr Brenda Button, Australian country contact person, March, 2004*

#### **Australian Chapter of the IPG/CF**

A meeting of the Australian Chapter of the IPG/CF was held during the 5<sup>th</sup> Australian Cystic Fibrosis Conference in Melbourne in August 2003. The aim of this meeting was to inform physiotherapists with a special interest in CF, about international events, conferences and general information relating to the organisation including the Chiron Best Care Scholarship.

#### **The 5<sup>th</sup> Australian Cystic Fibrosis Conference, Melbourne, August 2003.**

This conference, held every two years in Australia, was attended by a record number of 450 multi-disciplinary delegates from Australia and New Zealand. Invited international speakers for the physiotherapy program included Louise Lannefors, Sweden, and Craig Lapin and Anne Lapin, USA. The physiotherapy program included presentations on airway clearance, inhalation therapy and exercise across the lifespan in CF, urinary incontinence, NIV, The ThAIRapy Vest and care of the critically ill patient. Exercise interventions for bone health in CF, management of musculo-skeletal problems including massage therapy and the physiotherapy management of the infant with CF were discussed together with a physiotherapy educational intervention in children with CF. A number of interesting research studies were presented during the conference and stimulated discussion.

#### **Post 5<sup>th</sup> Australian CF Conference Physiotherapy Course**

A post conference course relating to adapting modern airway clearance techniques across the lifespan in patients with suppurative lung disease was enthusiastically attended by 85 physiotherapists from Australia and NZ. The course was presented by Louise Lannefors, Anne and Craig Lapin, Anne Holland, Prue Munro and Brenda Button.

#### **Australian Physiotherapy Association, Cardio-thoracic Special Group Conference, Brisbane, September, 2003**

This conference attended by physiotherapists with a special interest in cardio-respiratory physiotherapy is held every two years in Australia. Numerous interesting and innovative CF research studies were presented by physiotherapists from Australia and New Zealand. An airway clearance therapy workshop was presented by Brenda Button. Many physiotherapists in Australia and New Zealand are becoming increasingly interested in modern airway clearance techniques and integrating them into their clinical practice.

#### **Research**

Many physiotherapists with a special interest in CF are undertaking diverse and imaginative research projects. These include airway clearance therapy, positioning, urinary incontinence, non-invasive ventilation, physiotherapy interventions pre- and post lung transplantation, exercise testing, exercise therapy and adherence. These will be submitted to national and international conferences as they are completed.

## **Report from Austria**

*Prepared by Dr Beatrice Oberwaldner, March 2004*

1. The previous year of the Austrian respiratory physiotherapy group again had to be dedicated to the planning and organisation of another postgraduate course in respiratory physiotherapy. The course is now well on its way; more than 20 Austrian and German physiotherapists participate, the physiotherapy tutors come to a large extent from the national specialist group, several topics are covered by international experts.
2. Besides of this time consuming activity the working group of respiratory physiotherapists has been involved in the programme of the Annual Conference of the Austrian Society of Pneumologists; physiotherapists contributed to several 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. An educational programme on aerosoltherapy was 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. A similar programme was also offered to CF-patients and parents.
5. Several physiotherapy students and exchange physiotherapists had an in depth training in different CF-centres; several physiotherapy students wrote their thesis on various aspects of physiotherapy in CF.
6. A member of the national group of respiratory physiotherapists has created our homepage [www.atempphysiotherapie.at](http://www.atempphysiotherapie.at), with which we hope to initiate a permanently open forum for discussion and exchange of information between interested physiotherapists.

In summary, the interest of physiotherapists in respiratory care is constantly growing. 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 .

## **Report from the Belgian IPG/CF-June 2003**

*From June 2002 to June 2003.*

*Prepared by Jean Chevaillier and Filip van Ginderdeuren, March 2004*

### **I. Specific Belgian IPG/CF activities.**

The Belgian Working Group organised 4 activities in the past year. The number of participants varied between 48 and 80 physio's. The topics were:

Basic principles of the actual ACT's

Palliative care

Physio clinics; meeting patients, their parents and physio's.

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

1)-ACT courses for PT's.

International: in France (5 WE's), Germany (3.WE's), Austria (2 WE's), Switzerland (3 WE's), Italy (1 WE).

National: 4 courses (40 Hours each for 90 physio's) and 6 instructor's courses.

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

2)-Refresher courses for trained PT's.

4 weeks for 5 physio's from Belgium, Germany, France and Switzerland.

Training of 5 home therapists.

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

4 students from 3 Belgian Physio Schools.

24 students from Brussels Free University

1 lecture at the Genua CF Conference.

1 lecture at the New-Orleans CF Conference

4)-4 weeks training courses for PT students.

A total of 4 PT students from different Physio schools.

5)-Participation

CF conference in Genua (3 members)

CF conference In New-Orleans ( 1 member )

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

4 in total for +/- 120 participants

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

8)- abstract: Influence of AAD, and bouncing combined with AAD on GOR in babies under the age of 5 months."

### **Cayman Islands**

*Prepared by Zillah Isaac, March 2004*

In the Cayman Islands, we only have one (1) patient with cystic fibrosis.

The 22 year old male is employed full time as a car salesman.

He has been taught autodrainage and does his programme daily.

During periods of infection he is referred for Physiotherapy.

He was seen for 2 short periods in 2003.

### **Report from the Czech Republic**

*Prepared by Dr Libuse Smolikova, March 2004*

- As in previous years, a course for 20 physiotherapists was organised in 2002 and 2003, according to the Guidelines for teaching basic ACT's. In 2003 an advanced course in ACT's for patients in IUC was arranged in UH Motol, for which I was responsible. There is enormous interest in modern ACT's here.
- Since 2000 the preventive hygiene rules for CF patients, colonised *Pseudomonas aeruginosa* and *Burkholderia Cepacia* have been made very stringent for both in- and out- patients.
- Our project in cooperation with the Faculty of Physical Education and Sports, Charles University, Prague to test the physical condition of CF adults is continuing. The results will be published in the future.
- CF Physiotherapy is taught to all students of Physiotherapy at 3 medical faculties of Charles University and to students of medicine at the 2<sup>nd</sup> Medical Faculty of Charles University, Prague.
- Respiratory physiotherapists are automatically included in grants, research projects concerning CF, COPD etc. in the Czech Republic.

- At the 7th European CF Network International Symposium for Eastern Europe, Bratislava, Slovakia, I was chosen to speak for the Czech Republic. I presented ACT, Inhalation therapy etc., and Respiratory Handling for CF infants, which aroused great interest among doctors and physiotherapists from Eastern Europe, for whom it was a novelty.

### **Report from the Finland**

*Prepared by Leena Jokine, March 2004*

#### ***Cystic Fibrosis is very rare***

**CF is a very rare disease in Finland. The incidence of CF is only 0.001 %. With a population of 5.206.000, only 59 Finns, have CF diagnosis. Of the 56.600 babies born in a year, one or two are diagnosed with CF.**

#### ***CF persons in Finland (31.12.2003)***

<u>Age/years</u>	<u>Male</u>	<u>Female</u>	<u>Persons</u>
0 – 2	4	1	5
3 – 6	2	8	10
7 – 12	4	9	13
13 – 16	5	4	9
17 – 20	2	2	4
21 – 25	7	1	8
26 – 38	5	5	10
<u><i>In all</i></u>	<b>29</b>	<b>30</b>	<b>59</b>

#### ***Resource Centres***

Nine separate associations for the disabled have founded Resource Centres for rare and difficult illnesses and disabilities. The Finnish Slot Machine Association provides them with an allowance for their activities. More of this network of Resource Centres is:

<http://www.harvinaiset.org/>

The Resource Centres work to improve the status of these patient groups by providing services that improve the quality of life and give meaning to life. Hoikka Centre of Pulmonary Association Heli is one of these centres and serves as the National and International Resource and Expert Centre for Rare Pulmonary Diseases. It produces materials for educational and informative purposes, arranges rehabilitation and adaptation training courses and provides support to those suffering from rare pulmonary diseases, their families and experts.

The most active group by diagnosis is the CF-group. Pulmonary Association Heli has been arranging activities for CF families since 1983. The Coordinator in Hoikka Resource Centre is a physiotherapist who has been interested in cystic fibrosis for years. She is the Finnish member in the International Physiotherapy Group for Cystic Fibrosis. The coordinator knows all the CF-families in Finland, and has contacts with experts in hospitals, municipal authorities and the physiotherapists who treat CF-patients. Hoikka Resource Centre can provide appropriate services to all rare pulmonary disabled individuals and their families. These activities can help all families to live a normal happy life with their children, even if they have CF or some other serious pulmonary disease.

#### ***Health Care in Finland***

Finnish health care has always stressed the equal availability of services. The intent has been to provide services to all, regardless of social group, income or place of residence. Municipalities bear the main responsibility for providing health services. Most municipalities provide primary health services through their own health centres, whereas the smallest municipalities form joint municipal authorities for this purpose.

There are no CF Specialist Clinics in Finland. For specialized care, the country is divided into 21 hospital districts. The Act on Specialized Medical Care specifies the hospital district to which a municipality must belong. The University Central Hospitals take care of all patients. For this reason, CF patients use services in their nearest University Central Hospital. The Helsinki University Hospital is the only place for transplantations. In the year 2003 one CF young man got new lungs and he is doing well after that.

### ***Rehabilitation***

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

The rehabilitation course staff at Hoikka Centre include a doctor (chest physician), trained nurse, physiotherapists, social worker, psychologist, nursemaid as well as other CF experts such as paediatrician, dietician. Courses for families include discussions of the disease and treatment, nutrition, physiotherapy, as well as about treatment at home, support for families and social security. Additionally, the courses for the young aim to help participants to become independent and to clarify the job possibilities.



Five days courses for families with CF children and for young CF persons take place every summer in Hoikka Centre. The 8<sup>th</sup> of June 2003 was a national CF-day and 33 persons took part in it. The CF-courses were also in June and nine families with CF children and nine CF young persons took part in the courses. During these courses there was a guest physiotherapist from Turkey Istanbul at Hoikka Centre and he got to know the Finnish systems in CF rehabilitation and also the CF-persons.

### ***CF physiotherapy***

In Finland, physiotherapists in hospitals meet CF patients mostly in outpatient departments when they have control meetings with the doctor, physiotherapist and dietician. For that reason, the physiotherapists in hospitals have very little experience with CF physiotherapy and treatment. CF patients are very seldom in inpatient departments in hospitals. In addition, intravenous antibiotics can be given daily in the outpatient departments of the hospital, or in the nearest health centres.

Each CF person is provided with an individual rehabilitation plan and is treated by a private physiotherapist either at the private institution, or at home. It is beneficial that CF persons are usually treated by the same, "their own private," physiotherapist for years.

For more info please see: [www.hoikka.fi](http://www.hoikka.fi) , [www.hengitysliitto.fi](http://www.hengitysliitto.fi) , [www.harvinaiset.org](http://www.harvinaiset.org)

## **Report from Georgia**

*For information about the situation in Georgia see website [www.cfww.org](http://www.cfww.org)*

## **Report from Germany**

*Prepared by Jovita Zerlik in March 2004*

Development of knowledge is one main subject of the German physiotherapy working group. Apart from basic- and advanced courses for physiotherapists, there are also training courses for the referees on a regular basis. In the year 2002, there was an event on the theme „how to enforce a study/ studies design“, a seminar on „inhalation“ and a workshop on „sports“ in consolidation with sports scientists. The theme of the annual meeting of referees was „physiology of breath“.

In 2003 a meeting of members of the working group „the adult patient“ took place in Berlin. Since spring 2002 three members of the executive board met with Jean Chevaillier from Belgium to talk about closer cooperation between the Belgian and the German physiotherapy working group on the one hand and assimilation of the curriculum for basic courses on the other.

Since 2003, our curriculum for basic courses contains 56 learning units taught on six days.

By use of a questionnaire the present state of handling of CF- patients was determined.

Finally, the physiotherapy working group was also present with a range of events during the annual CF meeting. On this occasion, also a new executive board for the CF physiotherapy working group was elected in November 2002.

## **Report from New Zealand**

*Prepared by Rebecca Udy*

I am the physiotherapist involve in the paediatric center, so all of the information I will give you is from the paediatric perspective.

The Starship Cystic Fibrosis Clinic looks after approx. 100 patients with 60 of these within the Auckland region. The rest come from around New Zealand to attend clinic. We are the only specialist clinic within New Zealand. We have 7 full time paediatric physiotherapists at Starship Childrens Hospital, and have two physiotherapists looking after the CF inpatients and outpatient clinics. We split these into two groups with one therapist looking after the over 10 year olds and the other looking after the under 10 year olds. We find this works very well. The main treatment modalities used include PEP-Astra and Pari, oscillating PEP (Acapella/Flutter), modified postural drainage and percussion, ACBT with FET, bubble PEP, and of course alot of exercise.

We are lucky enough to attend a few courses and keep very much up to date with current international practice, but find we are very busy and do not have as much time as we would like to do research.

## **Report from Norway**

*Prepared by Sandra Gursli, Oslo, March 10th, 2004*

The Norwegian National Working Group for CF (FF-Fysio/CF) consist of 12 Physiotherapists working at hospitals in different regions in Norway. The Group was founded in 1992 and has

received financial support from the Norwegian Association for Cystic Fibrosis, NCF. The Norwegian National Center for Cystic Fibrosis, NSCF, which was established in 1998, has three Physiotherapists permanently employed since 1 th December 2003.

**Main activities in 2003 have been related to items as outlined below:**

1. Members of the Norwegian National Working Group for CF met for three days in Oslo in June 2003. The Group had a fruitful exchange of information and knowledge, discussions related to topics given special priority and interesting reports from relevant conferences
  2. Organising of treatment and follow up of patients with CF in Norway
  3. Lectures and/or practical training of physiotherapists, physiotherapist students, other health care professionals as well as patients and parents. Regional seminars, courses and education days have been arranged.
  4. Some of the members attended the ECFC in Belfast, June 2003
- The Group will meet again for four days in September 2004 in connection with a multidisciplinary Course arranged by the Norwegian National Center for CF in Oslo

### **Report from Poland**

*Prepared by Dr Teresa Orlik*

**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: 12-14.05 and 17-19.11.2003). This courses was aimed at physicians which specialize in rehabilitation.
2. Two-days courses organized by Physiotherapy Department of the Institute of Mother and Child (2 courses a year: 28-29.04 and 13-14.10.2003). The course was including theoretical and practical aspects of physiotherapy used in cystic fibrosis - taught by Teresa Orlik . This course was aimed at physiotherapists involved in treatment CF patients who would like to have more knowledge of CF management and airways clearance techniques.

**Organizations and participation in Conferences by members of the Group.**

1. The Polish Pediatric Society Conference including cystic fibrosis session organized by Polish Working Group for CF was held in Bydgoszcz in June. On this session Teresa Orlik presented lecture “The influence of bronchodilators on chest physiotherapy effect in children with CF”
2. The Annual Conference for patients with CF and their parents was held in Krakow in November 2003. On this Conference Teresa Orlik presented physiotherapy in cystic fibrosis.

**The other activities**

Experts from Polish Working Group for Cystic Fibrosis worked up and published “Long-term physiotherapy model in CF”. Teresa Orlik was supervisor and coordinator of that work.

## Report from Romania

Romanian Cystic Fibrosis Association  
Paltinis st, 1-3, Timisoara, Romania  
Tel/Fax: 0040 256 494529



### ROMANIAN CF ASSOCIATION ANNUAL REPORT 2003

Timisoara, 11 03 2004

#### **Overview**

Within the context of special economic problems that our country has encountered, Romanian CF Association activity has been limited because of the following reasons:

-lack of a sponsorship law which should stimulate the potential sponsors and as a consequence very low funds;

-no personnel employed to deal as a priority with the management of the Romanian CF Association activity; actually, the association problems remain to be solved and managed only by the President and a few fellow-workers; but they are busy most part of their time with their work activities (medical and teaching programs);

-CF children's parents do not involve in the Romanian CF association; generally, there are families which have financial problems to ensure their daily living expending.

#### **Results**

By several steps, we have succeeded to maintain CF within the National Health Programs which allows supplementary funds for the treatment of CF patients.

Although with great efforts, it has been possible to found Adult CF Association, which demonstrates on one hand that CF management has been considerably improved, and on the other hand that the necessity of a nongovernmental association to support CF patients has been clearly understood.

One of the most significant events of the year 2003 has been represented by The First National Congress of Mucoviscidosis with International Participation. The congress was held in May 7<sup>th</sup>-9<sup>th</sup>, 2003, under the care of CFW and had a great number of participants, some of them being personalities of the international CF world: Inge Britt-Lundin, vice-president ICF(M)A, Prof. Birgitta Strandvik, Institute of the Health of Women and Children, University Göteborg, dr. Garry Hambleton, Royal Manchester Children's Hospital (RMCH), UK, dr. Harm Tiddens, Erasmus Medical Centre, Rotterdam.

As for the developing of Romanian CF network, the activity of new regional centers has been improved, such as: Bucuresti, Brasov, Iasi, Cluj, Oradea, Craiova.

Regarding medical and scientific cooperation, we are carrying on the collaboration with Royal Manchester Children's Hospital (RMCH) concerning identification of special mutations of CF patients in Romania. We would like to thank to RMCH's personnel and especially to Dr. Garry Hambleton and Dr. Martin Schwarz.

#### **Unfulfilled tasks and future plans**

One of the most important issues to be solved is Romanian National Health Program for CF which is still slowly carried on.

We have not yet succeeded in finding a national CF association from the developed countries in order to collaborate on different problems related to CF.

Developing of an efficient cooperation with colleagues from other medical centers and continuing the collaboration with Royal Manchester Children's Hospital would be of great benefit for CF patients.

Prof. Dr. Ioan Popa  
President of Romanian CF Association

## **Report from Slovakia**

*Prepared by Marta Heroutova, March 2004*

1. February 2003: Annual meeting of CF Club  
Theme: ACT - Clearance Upper Airways Techniques - Neti, nose hygiene  
Participants: parents of CF children, adult CF patients
2. April 2003 Seminary  
Theme: Respiratory Physiotherapy for newborn babies up to 3 year old children  
Participants: physiotherapists and pediatricians
3. June 2003 International CF conference in Belfast
4. September 2003 Pneumology Day in the Tatras  
Theme: RPT – What does it mean?  
Participants: nurses, teachers and physiotherapists
5. September 2003  
Bratislava: Slovak CF Physiotherapist experts meeting.  
ACT course led by Dr Libuse Smolikova  
**7th European CF Network International Symposium for Eastern Europe, Bratislava, Slovakia**, participants CF experts, physiotherapists, doctors, nurses, psychologists
6. November 2003: meeting of teachers and doctors to discuss the quality of education in respiratory techniques at the faculty.
7. December 2003: CF Annual Slovak CF Conference  
Theme: Daily Program for CF Patients – theory and practice  
Participants: parents of CF children, adult CF patients, doctors, nurses, schoolteachers, physiotherapists and social workers.

## **Report from Sweden**

*Prepared by Louise Lannefors in March, 2004*

Sweden sees about 560 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 the year passed the national physiotherapy council has met twice.
2. The council has organised one national education and exhibition day for physiotherapists involved in CF all over the country. The education day is sponsored by the patients association.
3. Colleagues both from within the country and from all over the world have visited the CF-centres during the year.
4. The IPG Newsletters have been forwarded to colleagues at all CF-centres, who have been stimulated to forward it to colleagues at referral hospitals.
5. The Chiron's Best Care Award information and form have been forwarded to colleagues at all CF-centres, who have been stimulated to forward it to colleagues at referral hospitals.
6. The follow-up summary of our patients' functional parameters, summarised by the council was presented at the last NACF-conference in October. We are very proud over the fantastic current results of our modern care, but are sorry for that we have to struggle to make care-givers at conferences believe that this is a level possible to achieve. We are now working on an article to get published.

## **Report from Switzerland**

*Prepared by Patrick Althaus, physiotherapist.*

The Swiss Physiotherapy and Cystic Fibrosis Working Group has 20 members, representing the every CF centres in Switzerland.

The Working Group has met 4 times/year during the two last years.

The main activities from June 2002 – June 2004 were:

### **Autogenic Drainage and Modern Airway Clearance Techniques Courses**

Jean Chevaillier was and always is the international invited speaker and practiser for physiotherapy courses, assisted by 5 physiotherapists specially prepared to be the instructors assistants for the course held in Lausanne and Berne. For both courses were around sixty physiotherapists with a special interest in CF who participated.

During the last years, this concept of course, which content is IPG/CF guidelines oriented, has been given for the whole country during 3 week-ends separated with the needed time to practice. The medical part is given in the different areas by the medical staff of the CF center in the region during a special day, opened to other physiotherapist interested in continuous education but not for the whole course. The physiotherapy part is given by J. Chevaillier and his assistants, according to the region where the course is given.

*The aims to involve different instructors-assistant in the course are*

- Discuss consensus on airway clearance techniques, inhalation, etc.
- Impart knowledge to others in the CH AG PT CF
- Develop a process of training other Physiotherapists to be competent in teaching Airway Clearance Techniques (ACT' s)
- Extend the number of CH AG PT CF Instructors, to find the next “generation” of instructors
- Offer the possibility to practice the ACT' s in little groups (6 persons) under the control of trained Physiotherapists

### **Continuing Professional Development.**

The group has a very close co-operation with :

- The National CF association. Physiotherapists from the group have educated participants and have been responsible for every day treatment at the summertime camps for CF-children and/or adults.
- The National Physiotherapy association. The group has been accepted as a specialized group, involved in Quality Insurance projects, Outcome project, ...
- Private Respiratory Producer: The group has been involved in the translation from German to French of the main Booklet of inhalation therapy
- The swiss working group of Physiotherapists in Pediatrics: the CF-group is involved in the discussions about politics on how to procede in development courses (weather university or highschool-level)

### **Communication strategy and spreading of information**

***The Beta version of the web-site CH AG PT CF is nearly prepared, the financial support for the entertainment of the site has to be found by sponsorings. The translation (into others but first) into the french language will be mainly supported by the Swiss Cystic Fibrosis Association.***

A list of physiotherapist (qualified in respiratory therapy) has been up dated to answer the demand of information from medical staff and patients searching this kind of specialised professional in the different regions of the country.

These multiple activities indicate that there is much enthusiasm and energy being focused on CF treatment and research amongst physiotherapists in Switzerland.

## **Report from Turkey**



*Prepared by Osman Coban in March 2004*

Our Physiotherapy working group for CF consists of 3 physiotherapists work at the Istanbul University, School of Physical therapy and Rehabilitation. We have been contacting with Paediatric Unit which has more than 100 patients with CF and other patients with other pulmonary disease. Our group for CF spent very busy year, during last year:

We

- invited PTs who work in the different departments of Istanbul University hospital to give information about physiotherapy applications for CF,
- made a course called 'physiotherapy treatment of patients with CF' for last year students of our Physiotherapy school,
- added a chapter called physiotherapy in CF to the Therapeutic exercises and its principles (4th semester students)
- prepared a booklet about chest physiotherapy and its importance in CF,

and

- Osman Coban who is coordinator of our physiotherapy working group, has been working patients with CF, he has been informing all patient with CF and their caregivers for Chest Physiotherapy for two years,
- Osman Coban visited Hoikka Resource Center - Leena Jokinen in June, 2003 and he made a presentation about his experience in Finland to all his colleagues,
- We also have been planning to build a webpage including information about CF, Although there are not many specific Physiotherapy Center dealing with CF in Turkey, there are PT groups who have been working on CF at University Hospitals. There is also physiotherapy group in Hacettepe University Child Chest Disorder Unit, with 6 physiotherapists working on CF specifically. Therefore, our aims to unite all PT groups working in all University Hospitals in Turkey and cooperate with them.

## **Report from U.K.**

*Prepared by Esta-Lee Tannenbaum in March 2004*

The ACPCF (Association of Chartered Physiotherapists in Cystic Fibrosis) committee continues to meet twice a year. The group has 12 committee members and 11 regional representatives who organise meetings in their local region on various topics.

In November 2003 the ACPCF held a successful two-day meeting in Birmingham, which was attended by over 60 members. The topics included

Annual reviews – examples used from paediatric, adult and community centres

Outcome measures in CF

Non-Invasive ventilation (theory and practical)

Urinary incontinence (theory and practical)

Some of the tasks from the previous report are continuing. Following last years meeting on the topic of Outcome measures – the ACPCF aims to identify CF specific measures and to make these available to members using study days.

*We are delighted to be hosting the 27<sup>th</sup> European Cystic Fibrosis Conference in Birmingham and look forward to seeing everyone there.*

***Please see:***

**[www.cftrust.org.uk/cf2004](http://www.cftrust.org.uk/cf2004)**

**Report from U. S.A.**

*Prepared by Anne Lapin, M.C.S.P., March 2004*

Once again it has been a busy year in the U.S.A.

The 17<sup>th</sup> Annual North American Conference was held in beautiful, downtown Anaheim, California. It was very well attended by therapists from around the world. This year the subject of airway clearance was expanded in the pre-course conferences and included:

1. Advanced Airway Clearance Techniques taught by Brenda Button and Maggie McIlwaine. This was a two day course targeted at care-providers already experienced and knowledgeable on many of these modalities.
2. Mary Massery and Dr. Chung presented a superb course on musculoskeletal and neuromuscular treatments. The feedback was so extremely positive that this course is already scheduled again for next year!
3. Airway Clearance Techniques for the CF Team was taught by myself and Craig Lapin. This has been a popular course for physicians, nurses, and other team members, helping to spread the understanding and use of multiple therapies.

There were numerous other presentations and abstracts by therapists. Brief high points included the sessions on Complementary Medicine, the controversial topics raised in the session on Issues in Airway Clearance, the important of Sleep-related Disorders, and of course, it was always good to meet and speak with people during the networking sessions.

This is the 3<sup>rd</sup> year that I have been part of the North American Cystic Fibrosis Foundation Education Committee, charged with reviewing all frequently used teaching materials, books and videos, on all CF-related subjects (e.g. physiotherapy, diabetes, new diagnoses, adult issues, etc) across the United States. As you can imagine, this is an enormous task, but we have a strong, multidisciplinary committee, primarily made up of physicians. This year *An Introduction to Cystic Fibrosis* and *Managing Cystic Fibrosis-Related Diabetes (CFRD)* was published. Guidelines on *Cleaning and Maintenance of Respiratory Equipment* and handout on infection control have been developed and distributed.

Many therapists around the United States continue to be involved with lectures and teaching of short courses. 2005's North American CF meeting will be held in Saint Louis, Missouri, October 13<sup>th</sup> – 17<sup>th</sup>. Once again there are several excellent topics of interest to respiratory and physiotherapists being offered. Annie Downes is the therapy representative to the Planning Committee.

I also wish to take this opportunity to wish everyone well for 2004 and look forward to seeing you at the many meetings around the world.

Respectfully submitted,

Anne Lapin

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