

CFW began operating in January 2003 following the merger between ICF(M)A and IACFA. The merger had been agreed in June 2002 during the Annual Business meetings of ICF(M)A and IACFA in Genoa. It has therefore been decided to present a joint annual report of both organizations under the name of:

cystic fibrosis worldwide



## Annual Report 2002

### **Member countries of Cystic Fibrosis Worldwide**

Argentina, Australia, Austria, Belgium, Brazil, Bulgaria, Canada, Chile, Colombia, Costa Rica, Cuba, Czech Republic, Denmark, Ecuador, El Salvador, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Latvia, Lithuania, Mexico, Netherlands, New Zealand, Norway, Panama, Poland, Portugal, Romania, Slovak Republic, South Africa, Spain, Sweden, Switzerland, Turkey, United Kingdom, United States of America, Uruguay, Venezuela.

### **Associate members of Cystic Fibrosis Worldwide**

Azerbaijan Republic, Bahrain, Dominican Republic, Egypt, Estonia, Guatemala, India, Jordan, Luxembourg, Macedonia, Qatar, Russia, Saudi Arabia.

CFW is a Non Governmental Organization (NGO) in official relation with the World Health Organization.

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**Enclosures:**

- WHO/ CFW workplan 2003 – 2005
- WHO / ICF(M)A review 2000 – 2002

Hoeven, March 2003

Dear ladies and gentlemen, friends and members of CFW,

For our organization the year 2002 has been a special year.

The merger process between IACFA and ICF(M)A saw the establishment of Cystic Fibrosis Worldwide from January 2003, following the adoption of the by-laws and incorporation papers at the Annual Business Meeting in Genoa on June 19, 2002.

The new by-laws of Cystic Fibrosis Worldwide are in some aspects different from the ICF(M)A by-laws. A new mission statement has been formulated and agreed and our new logo was revealed during the Annual Business Meeting in Genoa in June 2002.

The conference in Genoa was a milestone for our organization as our first merger discussions started in February 1999 in Madrid. It took some years of preparation to merge but we are all convinced that we now will be able to continue our work with a worldwide mandate to fulfil our vision and mission.

I am proud and very happy that we are now one worldwide organization and I also want to thank all our national organizations and advisors and the members of the board who supported me in helping to carry out the work.

It is my pleasure to announce the new associated membership of Georgia and Paraguay.

We hope that Cystic Fibrosis Worldwide will provide better support and acknowledgement of the challenges facing all those whose lives are affected by Cystic Fibrosis.

It is with great honour and pleasure that I present to you this annual report 2002 and I welcome your comments or suggestions.

Warm regards,

Herman Weggen  
President CFW

Perth, Australia, March 2003

### **IACFA – In brief**

On the 1<sup>st</sup> of January 2003 a new organisation, Cystic Fibrosis Worldwide, was born and its two predecessor organisations, ICF(M)A and the International Association of Cystic Fibrosis Adults (IACFA) became a part of history. This is my final duty as the last Chairperson of IACFA.

The change came after many years of courting and I think it would be remiss not to take a short look back to see where we have come from, as we begin this new journey forward.

The seed that was to become IACFA was planted when a woman named Mimi Verselles saw a need for people with CF to have a voice in the CF community. She along with a small number of others (including Ies Fride) convinced the ICF(M)A that it would be a good idea to have people with CF from all parts of the world get together to discuss issues that were important to them and to report back about these ideas/issues to the wider CF community.

This gathering occurred in Brussels in 1982 when about 40 people with CF, who came from many parts of the world, met to talk about the issues that were important to them. This was a momentous occasion, as it is important to remember that this was still in the days when in many places (sadly it is still the case for some) ‘patients’ were supposed to ‘comply’ with what they were told to do without question and CF Adult Clinics were unknown in most parts of the world. Adults with CF were just emerging as a ‘new’ challenge in CF care.

I was lucky to be one of the people who attended this first gathering. We met over a couple of days in a conference room where the European CF Conference was being held. I vividly remember some of the doctors/scientists attending the Conference wanting to come in and sit in on our discussions, however they were told that it was a closed meeting, as we did not want anyone feeling uncomfortable about raising/discussing issues. I also remember how some of those who were refused entry were less than gracious about it. When the point was raised that the medical sessions were closed to us, we were told that was different.

The most important decision that was made in those days was to move to form what became IACFA. There was also a report back session to the medical conference.

From that time, IACFA began to take shape and grew into a strong and vibrant organisation that worked to provide people with CF information and hope no matter where they lived. One of the major ways we were able to do this was through the IACFA Newsletter. If nothing else IACFA was able to create an information flow in the CF community that continues today.

Everyone who has been a member of the IACFA Executive over the years has worked hard to help run the organisation and guide it. There are a few people who stand out – Mimi Verselles, Ies Fride, John Alaimo, Barbara Palys, Lisa Hoyer, Samantha Hillyard, Jan Sperry,

Anne Wren, Francesco Antognini, Birgit Dembski, Ami Kolumbus and Jose Pulido. This is not an exhaustive list and I apologise to anyone I have left off. I hope you will forgive me.

Early in its history IACFA also recognised the need to have people available to provide advice about specific issues. These advisors have come from many areas and have also given many years of service. Special recognition needs to be given to Anna Rudeberg, Evelien Alaimo-Grolle, Peter Kent, Gerd Doring, Paul Quinton and Dieter Gruenert. Once again, apologies to anyone I have missed. It has not been deliberate.

IACFA faced many challenges in its history. Early on it was to be recognised as having a legitimate place in the CF Community. More recently it has been the challenges posed by cross infection.

It has endured through all of these things. We have now come to a time when the need for a separate body has receded. People with CF now take their place at the table in all of the forums that talk about the needs of people with CF. They have a voice in National Associations, are Board members of these organisations, they are scientists, doctors and allied health workers.

While there have been people with CF in these positions for many years, it has only been over the past 10-15 years that the pace of change and acceptance of this has been recognised by all as positive. Dare I say it has been the existence of IACFA that has allowed this change to take place?

We have come a long way since one of the questions asked at that first gathering in Brussels – How do I talk to my doctor about my treatment?

One of the questions now is – How do we continue to develop this partnership between all parts of the CF community to further improve the lives of people who face the daily challenges of living with CF?

I think that one answer is to help CFW grow and prosper.

Finally, I would like to pay a special tribute to 2 people. Herman Weggen who managed to steer the merger process to a successful conclusion following a couple of previous attempts and to Barbara Palys, who retired as Chair of IACFA early in 2002. Barbara gave much of herself and made many personal sacrifices over many years to help guide IACFA. Her contribution as Chair was and remains immeasurable. Thank you Barbara for everything.

I look forward to working with you all in the future.

Mitch Messer

Chairperson - International Association of Cystic Fibrosis Adults

## **2. What is Cystic Fibrosis ?**

Cystic Fibrosis (CF) is a genetic disease affecting 1: 2500 to 1:3500 newborn infants in white populations and, with a lesser frequency, those in the Middle East, Africa, Asia and South America.

Also called mucoviscidosis, CF is incurable and fatal but, as therapeutic options have expanded over the last decade, significant advances have been achieved in both life expectancy and quality of life.

The respiratory system and gastrointestinal tract are mainly involved leading to chronic lung disease and impaired digestive function of the gut, the pancreas and the liver. Additional organ systems involved are the reproductive tract and the sweat glands. Other organ systems may be involved to lesser degrees.

Present understanding of the underlying defect points to impaired salt transport within cells lining the lungs and the pancreas and possibly other organs. Sticky secretions resulting from this defect cannot be cleared easily and may result in cycle of infection and inflammation.

The quality of life of people living with CF depends on the severity of the disease but all need constant medical attention and regular treatment. This treatment must usually occur on a daily basis.

Despite these hardships, improved medical care has produced significant advances in life expectancy. At present, the majority of adolescent and adult living with CF who are receiving good medical care are able to live relatively normal lives not dissimilar to those of their peers. Treatments include antibacterial strategies combined with high-calorie nutrition and regular chest physiotherapy and/or physical activity. Transplantation of the lungs has become a viable option for some and ongoing research opens perspectives for improved treatment in the future.

It is one of the pre-eminent goals of CFW to improve awareness of CF and to achieve treatment of a uniformly excellent quality wherever people with CF live through specialized CF centres.

### **3. Cystic Fibrosis Worldwide**

#### **3.1. General**

The members of Cystic Fibrosis Worldwide are divided into voting members and associate members. The corporation's voting members are national Cystic Fibrosis Organizations. The associate members are not-for-profit organizations active in the field of Cystic Fibrosis, and individuals affected by Cystic Fibrosis who shall be at least eighteen years of age. Only voting members shall have voting rights at the annual business meetings which will be held each year, together with a Medical Cystic Fibrosis conference.

Cystic Fibrosis Worldwide works closely with the organising committee and medical & scientific team responsible for the Cystic Fibrosis conferences. The national organization of the host country enables the Cystic Fibrosis Worldwide organization to set up their own programme, such as the meetings of the executives of CFW with their medical advisors and the CFW annual business meeting. During these annual medical conferences Cystic Fibrosis Worldwide gets the opportunity to incorporate their own lay programme for people with CF, partners, parents and others. CFW also has established strong relationships with the WHO, the International Physiotherapy Group for CF, the International Nutrition Group for CF and the International Nurses Group for CF.

The CFW produces a quarterly publication, the CFW newsletter and also has a website: [www.cfww.org](http://www.cfww.org).

Both of these resources are great ways of spreading information, education and support to the CF community. The CFW newsletter incorporates details on the latest research, ongoing projects, along with personal experiences and support from around the world. The aim of Cystic Fibrosis Worldwide is to operate as a charitable or scientific organisation not for profit: for the benefit or in aid to scientific research, study, training and the dissemination of information with respect to Cystic Fibrosis.

CFW is dedicated to advancing understanding of Cystic Fibrosis in all parts of the world.

For a very long time it was thought that Cystic Fibrosis was unique to Caucasians. That is one of the reasons why the focus of CF care has been in North America and Western Europe and these parts of the world have a high standard of Cystic Fibrosis care.

Since the discovery of the Cystic Fibrosis-gene in 1989 we know that Cystic Fibrosis is not so confined to these areas and CFW has contacts in South-America, the Caribbean, the Middle East and the Far East

### **3.2. Vision and Mission**

The CFW annual business meeting in Genoa in 2002 has formulated and approved the following vision and mission.

#### ***Vision:***

People whose lives are affected by Cystic Fibrosis must have equal opportunities to participate in their society no matter where they live.

#### ***Mission:***

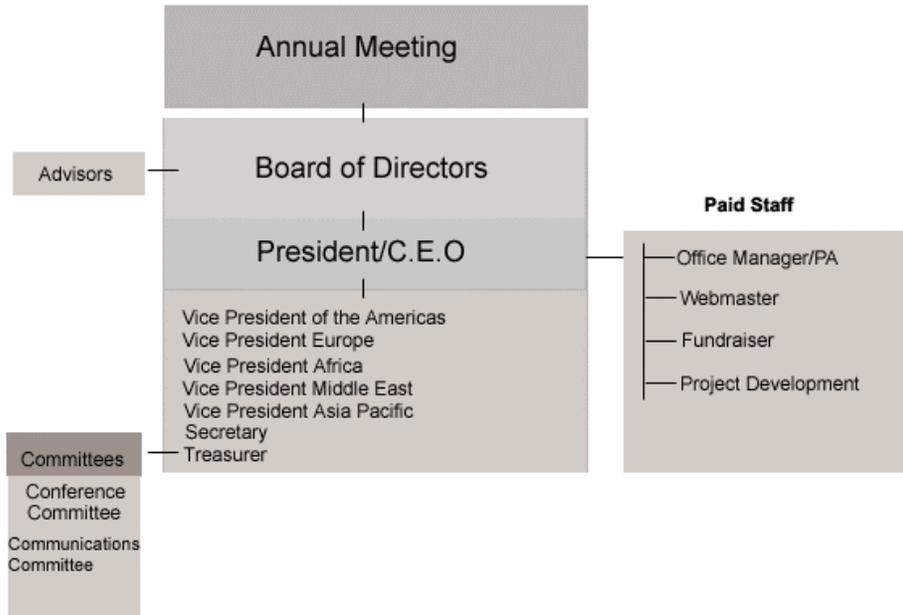
- Promote access to appropriate care for all people with Cystic Fibrosis.
- Act as an international platform for the exchange of information
- Support the search for a cure.

### **3.3. Activities of CFW**

- Improve the knowledge of CF among medical professionals, governments and lay persons;
- Encourage the formation of national CF associations, and strengthen those already in existence;
- Promote linkage between countries in order to share experiences, research and education;
- Build partnership with other governmental and non-governmental organizations that share our vision and mission;
- Form a platform for related organizations;
- Present a CFW newsletter and website with the most topical issues at an international level;
- Provide a forum via our meetings, periodicals and website for members of the CF community to share and support each other;
- Offer the Physiotherapy book, “Physiotherapy in the treatment of Cystic Fibrosis”;
- Provide administrative support and services on the web with the Physiotherapy Best Care Award;
- To stimulate CF congresses all over the world;
- To assist developing countries in diagnosis and treatment of Cystic Fibrosis;
- To assist developing countries in the establishment of a national Cystic Fibrosis organisation;
- To organise training courses for allied health professionals all over the world;
- To promote Cystic Fibrosis at the World Health Organisation;
- To finance scholarships, visiting experts and research projects.

To stimulate all the activities above CFW tries to reach as many people as possible all over the world, from an individual level to a governmental level.

### 3.4. Organization chart of Cystic Fibrosis Worldwide



Directors must be elected by the members  
 The numbers of Directors = 5-9  
 Directors are not paid  
 Board of Directors can delegate authority to any other officers or agents

Advisors are designated by the board  
 Advisors are not Directors/officers

Chairperson of the committee is a member of the board of Directors

## **4. Report 2002**

### **4.1. Mergerprocess between IACFA and ICF(M)A**

As agreed during the Annual Business Meeting in Genoa on June 19, 2002 via the draft by-laws and incorporation papers of the new organization 'Cystic Fibrosis Worldwide', the merger process between IACFA and ICF(M)A was finalised on January 1, 2003.

The meeting in Genoa was a milestone for our organization as our first merger discussions began back in February 1999 in Madrid. It took some years of preparation to merge but we are all convinced that we will now be able to continue our work with a worldwide mandate to improve and fulfil our vision and mission.

### **4.2. Genoa 2002**

#### ***4.2.1 Annual Business meeting (short summary of the minutes)***

On June 19, 2002 the 37<sup>th</sup> Annual Business meeting was held in Genoa . It was linked to the 25<sup>th</sup> European Conference, organised by the ECFS. There were 22 countries attending and represented at the Annual Business Meeting.

The merger documents (letter of agreement signed in Genoa on June 18, 2002 between ICF(M)A and IACFA, certificate of incorporation of CFW and the bylaws of the new CFW organization) have been discussed centrally.

The suggested changes to these documents have been inserted and the national associations approved the adjusted incorporation and by-law documents.

In 2003 there will be elections for the board of directors of CFW.

The associated membership of Georgia and Paraguay has been accepted.

The new logo of the new CFW organization has been revealed officially.

The first edition of the CFW newsletter, the CFW physiotherapy booklet and the CFW website have been presented.

The outcome of the *evaluation form* filled out by the national associations has been discussed generally, most of the conclusions are:

- There is a need for a strong secretarial / administration office.
- The reaction to the merger between and IACFA were very positive.
- The relationship with WHO and other organizations is considered to be important.
- Working in regions is important so that various institutions/organisations can support each other.
- CFW must not lose the attention for the differences between the needs of children and adults with CF.
- What does CFW want to achieve with the lay conference?
- Improve educational program for People with CF

- Continue the Grant program
- Encourage drug companies to supply pancreatic enzymes free or for a low price in developing countries
- Create financial support for national conferences.
- Stimulate communication between the national organizations.

#### ***Advisory structure of CFW***

For the future of CFW it is important to have access to specialized fields of knowledge and therefore the annual meeting in Genoa in 2002 made a decision to stop working with a scientific medical advisory board for an unlimited period. It is therefore suggested and decided that CFW should approach well-known advisors (being scientists, physicians, nurses) for various tasks or a single job for a limited period.

CFW has to take this opportunity and this might even be a better tool to obtain more influence world-wide (e.g. WHO or on national/ governmental level).

#### ***4.2.2.Lay conference day in Genoa, on June 20, 2002***

##### *1 Cystic Fibrosis Literature Review 2001*

In the morning Prof. M.H. Goetz, MD started with the Cystic Fibrosis Literature Review 2001. This presentation can be found on our website [www.cfww.org](http://www.cfww.org).

*2 Antibiotics and new treatments* Presented by Dr. Ivo Knottnerus, Chiron

*3 Nutritional challenges in the 21<sup>st</sup> century* Presented by Mrs. Sue Wolfe (chairperson Nutrition group CF)

*4. Nutrition workshop* Presented by Mrs. Wianda Visser (Nutricia)

*5. Physiotherapy problem solving* Presented by Mrs. Sandra Gursli (Chairperson Physiotherapy group/CF 2000/2001)

*6. Communicating with your health care team* Presented by Bill Taub.

### **4.3. Regions (reports from our regional managers)**

It appears that the world is too big for one policy of CFW. Problems and solutions are different in several parts of the world. For that reason CFW began to implement a regional approach. Some officers from the Executive Committee have responsibility for a region. Inge-Britt Lundin for Europe, Enrique Silver for Latin-America, Mitch Messer for the Far East, Australia and New Zealand. Herman Weggen will take care of the other regions. CFW has allocated a budget for each region. Each region manager will give account of his own budget at the executive committee.

For Latin America this has already resulted in the FLAFQ (Federation Latin America Fibrosis Quística). There is currently an initiative to establish a European Branch.

#### ***4.3.1. Europe***

##### ***Meeting with ECFS, November 6, 2002 in Netherlands***

November 5-6 2002, meeting in Zoetermeer, Netherlands, with parts of the board of the ECFS, Prof Gerd Döring, Dr Marie Johannesson and Christine Dubois. The meeting took up important issues such as future cooperation between our associations, and also how to support single research etc.

#### ***4.3.2. Latin America***

During the 12 months period, as Vice president of CFW, Enrique Silver was involved in several activities in the Latin American Region.

The main activities were:

- Visiting countries where there are groups than need help to develop and become a national CF association, and help them to rise awareness about the situation of the CF patients among the government and health authorities.
- To keep in contact with the national associations, health care professionals and families who deal with different problems and situations who are in need of advise or help.
- To coordinate the efforts of lay and scientific groups in order to make arrangements for the next Latin American Cystic Fibrosis Conference in 2004.

In September Enrique Silver visited Colombia and Venezuela together with Mr. Héctor Picasso, president of FLAFQ (Latin American CF Federation). It was a very intensive and hard work during one and a half week.

In Colombia, they visited the Ministry of Health and had a meeting with Dr. Luz Elena Monsalve, Chief and Coordinator of Health Promotion. They also visited the City Hall and met Dr. María Luisa Latorre, District Secretary of Health of the Social Security Services. They participated in an International Symposium at the public university (Universidad Nacional de Colombia) related to “Models of Health Care Services with emphasis on Home Care”, and were able to talk about the impact of the diagnosis of CF in the families and the difficulties to get proper health care services in countries like Colombia. Prof. John Dodge was also at the Symposium, and took the opportunity to arrange a meeting with families and

patients during the event. The interests of all the patients and families around the country has been discussed.

With the help of a very devoted nurse, Tibisay Páez they were able to visit three hospitals in Venezuela and meet with several doctors, health care professionals and families not only in Caracas, the capital city, but also in Valencia, another city 120 kilometers from Caracas, with a very small but strong group of families and doctors trying to give a better quality of life to their CF patients.

In both countries it has been stressed the importance of founding a national CF association to work for the interests of all patients and families in the country.

Since the last meeting in November 2001 in Florianópolis, Santa Catarina, it has been considered to have the next conference in Chile in 2005. However, due to different circumstances, the conference in Chile will be postponed and now it has been decided to organize the conference together with the next Brazilian Pediatric Conference in Rio de Janeiro, in May 2004.

In cooperation with the Latin American CF Federation a document will be produced about how to deal with the different health care services in each country, when a child or an adult is diagnosed with Cystic Fibrosis. The idea is to make it easier for the families to go “through the forest” of health care services in order to have access to proper treatments and medicines. At this moment the project is at a very preliminary stage.

#### ***4.3.3. Australia and Far-East***

There have not been any activities that cover the whole of the Asia/Pacific Region over the past year, although Cystic Fibrosis Australia and the New Zealand Cystic Fibrosis Association have continued to work more closely.

As reported last year, in 2001 the first Australian and New Zealand CF Conference were held. To add to this collaboration, Cystic Fibrosis Australia also includes New Zealand data in the Australasian Cystic Fibrosis Data Registry. Both Australia and New Zealand have the same major sponsor, real estate company – LJ Hooker.

Mitch Messer has also been in contact with a small number of people seeking information about CF care in South East Asia. Unfortunately he has not been able to provide them with information about CF services in this area as there are no know services; however he has been able to provide information about how to make contact with CF Clinic services in Australia. At present this is the only option for people living in this region.

In the coming period it is hoped to begin making contact with the WHO Regional office as part of the CFW work plan in its collaboration with the WHO.

#### ***4.3.4. North American Cystic Fibrosis Conference in New Orleans, October 2002***

The CFW executive board had their first discussion with their advisors in New Orleans, Bob Beall USA, Birgitta Strandvik Sweden, Peter Durie Canada, Francisco Reis Brazil, and Anna Ruedeberg Switzerland. The Physiotherapy, Nurses and Nutritionist have been represented by: Brenda Button chairperson IPG/CF, Susan Madge chairperson Nurses Group CF, Sue Wolfe chairperson Nutrition group CF.

Some of the conclusions of this meeting were:

- Focus on vision and mission of CFW.
- Focus on three or four developing countries for a start.
- Investigate what medicines are available in which countries.
- Diagnosis is now a big issue.
- “Summer school” ideas for doctors. Focus on two way education. Also go to the developing countries for a tailor made education programme. Try to understand the developing country.

#### ***4.3.5 CFW Research, Education and Clinical Partnership Program***

During our New Orleans meetings it is proposed that the CFW Research, Education, and Clinical Partnership Program (RECP) as presented by Barbara L. Palys & Dieter C. Gruenert, Ph.D. will focus on three areas (clinical, research and education) to further CF clinical and research efforts in the developing world. The global areas of focus will be South America, Eastern Europe, India, and Africa. The purpose of the program will be to provide, clinical and research opportunities in US and Western European CF clinics and laboratories for CF clinicians and scientists as well as educational forums for small groups of CF professionals and patients/families. The RECP is initially proposed for 5 years and will support 6-8 clinical fellows, 2 research fellows, and 1-2 educational workshops per year. Clinical fellows will have the opportunity to observe and, when appropriate, participate in the latest advances in clinical care for CF children and adults over the course of 6 weeks with a 2 week recapitulation of the clinical experience. The research fellows will be immersed in a CF research laboratory under the supervision of an established CF research scientist to explore different aspects of CF cell biology, gene tics and/or therapeutics. Generally, the research fellows will be engaged in the program for 1-2 years. The CF workshops will be thematically organized to meet the needs of specific audiences comprised of clinicians, researchers, and/or lay people with a direct connection to CF. In certain cases the workshops will be geared to diverse audiences and all three groups will be able to effectively participate, in others, the subject matter will be more focused and appeal to specific backgrounds, i.e., medical, scientific or lay. The goal of the workshops will be to provide information and clarification about CF therapies and advances in our understanding of the underlying causes of CF pathology that participants in the workshops can disseminate in their countries of origin. The educational component will also generate CD's and DVD's that the participants can use to in their countries of origin as an educational tool to provide information for the medical/scientific and/or the lay communities.

The RECP will not only provide information and opportunities to learn something new, it will also be a mechanism to exchange ideas and provide insight into cultural and social elements that influence CF therapy and the care of individuals with CF. The ultimate goal will be to provide a uniform and progressive approach to enhance the quality of life of CF patients throughout the world. Changes are, at first, expected to be incremental, but will likely accelerate as the RECP matures.

#### 4.4. Sponsorship / fundraising

If CFW wants to achieve better results we have to increase our activities. But for this we need money. CFW depends on the financial contributions of its member organizations. At this time we have reached a limit with regard to the income of the financial contributions of the member organizations. There are limited funds and sponsors and there is an increasing number of developing countries who are not able to provide financial support. Because most of our new member countries come from economically disadvantaged parts of the world, we know that our revenues will not sustain all of our planned programs beyond the next several years.

As it is our vision that persons with Cystic Fibrosis have equal opportunities of participation in the activities of their societies, independently of their social or economic situation we are seeking new sources of income.

For 2002 we had the following sponsors:

We are pleased continue our sponsorship arrangement with **KPMG Health Sector Construction Management Services** who sponsor our office facilities. **KPMG Health Sector Construction Management Services** pays all the office facilities such as, telephone costs, computer costs, e-mail, paperwork, printing costs, mailing costs, inclusive of the payment of 8 hours salary per week of our office manager. This generous donation allows us to function on a more professional basis.

We are also very pleased to announce that **KPMG Health Sector Construction Management Services** paid the printing costs of the Levy Lecture, presented by Prof. John Dodge at the Genoa opening ceremony in June 2002.

**Chiron** - We are pleased to welcome Chiron as a CFW sponsor. Chiron sponsor some of the activities listed previously. Chiron sponsored the CFW exhibition stand and the simultaneous translation costs of the lay program in Genoa, Italy in June 2002.

**Solvay**, producers of Creon, a pancreatic enzyme which is used by many persons with CF. Solvay have also supported some of our projects including supporting new CF organizations, WHO matters, the CFW website and newsletter.

**Nutricia** sponsored the lunch costs at the CFW lay conference programme in Genoa 2002.

## 4.5 Newsletter

This year has seen many changes in the production of the Newsletter (NL). After Barbara Palys' retired from the Newsletter, Sam Hillyard officially took on the role of Editor. She has worked hard to maintain the the Newsletter to a standard our readers are accustomed to.

With the merger of IACFA and the ICFMA, CFW was born, as was the CFW Newsletter. With this new alliance, the editor has worked closely with our new publisher and Webmaster (Christine Noke) to partner with our website to keep our Newsletter modern and up to date with all the latest news and research. They continue to make our NL as accessible to as many members of the CF community as we can, worldwide. This has involved making the Newsletter more user friendly, including both articles that are more understandable for our expanding audience (including many lay readers) and developing our translation capabilities. Not only are we receiving articles and mail in different languages, but the Newsletter is now also on-line in Spanish and Bulgarian as well as English, with all texts in downloadable formats. We are very grateful to our translators who generously volunteer their services either free of charge or at reduced rates.

We have been thrilled at the response to our new approach to the NL, both on paper and on-line, and our readership and feedback rate has increased dramatically. The downside to this of course is that our editorial expenses have increased substantially, and whilst we still have support from selective sponsors, this is not enough to cover the costs of the NL production much longer.

It is therefore important to take this opportunity to emphasise **that CFW is a non-profit making organisation that relies upon donations from CF charitable associations and subscriptions to the Newsletter**. Each copy of the Newsletter costs the equivalent of approximately US\$5 (GB£3) to produce.

Donation and subscription information can be found at the back of each issue of the NL or online at <http://iacfa.crocker.com/newsletter/cfsubs.htm>

## 4.6 Website/marketing

2002 has seen the birth of the CFW website: [www.cfww.org](http://www.cfww.org) Christine Noke, CFW webmaster and marketing advisor has been working very hard and through her input, the CFW website has reached a very professional level. She succeeded in making connections between CFW and Pharmaceutical companies for funding the website forum for the exchange of information.

Some of the issues she has been working on are:

- Creating a forum for the exchange of information in Gastroenterology/Nutrition
- Created an International Physiotherapy Group/CF section on the web

- Created the on line application and information about Best Care Award
- Building a section on Pulmonology and Physiotherapy to include a forum
- Building an online video of the physiotherapy techniques used in the treatment of CF
- Building a member country section to include all member country links and clinics found in that country and contact information. This information will be searchable through a SQL database
- All grants and application information are now on line
- Building an on line database of the newsletter subscribers so that subscription information such as change of address or additions and deletions can be done by the member. Payment forms are also available on line for the newsletter.
- Producing the newsletter in a timely manner on line in Spanish, English and Cyrillic.

#### **4.7. Administration office**

Compared to a few years ago the work of the administration office has increased tremendously. This is of course very promising. 2002 was a year in which merger issues played an important role. The CFW office is now a central point where all sort of questions are being asked. Some of the tasks of the office manager are as follows:

- Central correspondence point of CFW
- Making the minutes of CFW meetings
- Preparation of all the news mailing
- Supporting the marketing activities of CFW
- Support the total administration of the grant applications
- Financial administration of CFW
- Preparing the yearly auditor's report
- Maintains a survey of the activities of the executives and committees
- Organizing the CFW lay conference programme

The office manager (domicile: Netherlands) works very closely with the webmaster (domicile: USA) and the newsletter editor (domicile: United Kingdom). Working on this close level leads to efficient handling of all kinds of issues.

## **5. World Health Organization**

### ***WHO Executive Board***

On 14-21 January 2002, the 109<sup>th</sup> session of the executive board took place in Geneva. Mrs. Liliane Heidet represented our organization.

Agenda items with regard to Health Matters were: Intensifying the response to the conditions associated with poverty, including the Global Fund to fight against Aids, Tuberculosis and Malaria, Quality of care: patient safety. WHO medicines strategy: revised procedure for updating the WHO model List of Essential Drugs (EB 109/7 and EB 109/8).

Food safety and health, diet, physical activity and health.

### ***Fourth Intergovernmental Negotiation Body on the WHO framework convention on tobacco control, Geneva, 18-23 March 2002***

The first and second and fourth session of the Intergovernmental Negotiating Body on the WHO framework convention on tobacco control have been attended by Mrs. Liliane Heidet as our representative. ICF(M)A wrote a response on the WHO Tobacco-free initiative and encouraged its national members to create some kind of action to draw attention to this day on May 31, 2001.

The conclusion is that progress has been made since the first meeting. Awareness by education, publications, and statistics of health damage and the effects of passive smoking were analyzed. The most impressive statistic was that there have been more than 9 million deaths due to tobacco since the first meeting in 1999. It is regrettable that there are still countries not taking all measures to restrict tobacco advertising and commerce.

### ***The 55<sup>th</sup> world health assembly, May 13 – 18, 2002***

The red line during this 55<sup>th</sup> world health assembly was that the world is living dangerously. On the one side are the millions who are dangerously short of food, water and security on the other side are the millions who suffer because they use too much.

Mrs. Liliane Heidet, representing our organization had the opportunity to discuss important CF issues with representatives of national health authorities.

The health minister of Georgia promised to support the new CF Association of Georgia.

The health authorities of India and Argentina promised to include the necessary medicines for the CF patients in their national list.

### ***12<sup>th</sup> Joint WHO/ICFMA and ECFS European Network on June 19, 2002***

A joint WHO/ECFTN/ICFMA/ECFS meeting (organising committee: Dr. V. Boulyjenkov (WHO), Prof. J.J. Cassiman (ECFTN), Prof. J. Dodge (ICFMA)) on the molecular genetic epidemiology of cystic fibrosis was organised. The meeting took place on June 19, 2002 at the Gaslini Foundation in Genoa (Italy).

The meeting brought together a series of experts from different global regions to try to get a better view of the frequency of CF and CFTR mutations in the world.

More specifically, the following working documents were prepared and discussed:

- Classification of CF and related disorders (J. Dodge)

- Spectrum of mutations in the CFTR gene (J. Zielenski)
- Genotypes in late diagnosis (D. Gruenert)
- Variants of CF disease: Diffuse panbronchiolitis, diffuse bronchiectasis, COPD, idiopathic pancreatitis, CBAVD (K Yoshimura, PF. Pignatti, P. Durie)
- Human genetic diversity of CFTR (A. Piazza)
- Frequency of CFTR mutations in the CF population versus non-CF population (P. Lewis, G. Modiano, M. des Georges)
- High carrier frequency of CFTR mutations (fertility advantage/meiotic drift) (M. Super)
- Origin of frequent CFTR mutations (F. Calafell)
- Distribution of CFTR mutations in Europe (West- and East-Europe) (M. Macek)
- Distribution of CFTR mutations in the USA (G. Cutting, M. Macek)
- Distribution of CFTR mutations in Canada (J. Zielenski)
- Distribution of CFTR mutations in Africa (M. Ramsay)
- Distribution of CFTR mutations in South-America (O. Pivetta, G. Keyeux)
- Distribution of CFTR mutations in Asia (M. Kabra, K. Yoshimura)
- Distribution of CFTR mutations in the Middle-East (H. Eskandarani, T. Dörk)

A document regarding the findings, statements, and conclusions of this meeting has been made public by the end of the year 2002.

#### ***Co-operation with Dr. V. Boulyjenkov WHO***

Dr. V. Boulyjenkov was invited to attend our Annual Business Meeting in Genoa 2002. Unfortunately he was not able to be present. Nevertheless, we want to thank him very much for his support and co-operation.

#### ***Collaboration program with WHO***

ICF(M)A had an official relationship with the WHO. As stated before Cystic Fibrosis Worldwide began operating in January 2003. With this new organization, new by-laws have been approved by the annual business meeting in Genoa 2002. One of the main changes is the structure of the advisory system.

This new advisory structure has been discussed with Dr. V. Boulyjenkov. Dr. V. Boulyjenkov informed the executive board of CFW that these new bylaws and incorporation documents needed to be reviewed by the Executive Board of the WHO. The President of CFW with the advisory help of Prof. J. Dodge & Mrs. Liliane Heidet prepared a draft collaboration plan for the period 2003 – 2005 as well as a review over the period 2000 – 2002. (see enclosure). CFW is delighted that in January 2003 the 111<sup>th</sup> session of the Executive Board of the WHO has approved that CFW and its new structure has an official relation with the WHO.

#### ***Promote several documents on Cystic Fibrosis***

During the past years ICF(M)A has developed several documents in collaboration with the WHO. We think that these documents could be used as a practical guide to increase a better understanding of CF in these parts of the world and therefore we have requested the WHO to support us in the form of a letter to promote these documents to governments and health authorities of developing countries.

The documents developed in collaboration with the WHO are: (these documents can be downloaded from our CFW website: [www.cfw.org](http://www.cfw.org))

- Report of a joint WHO/CF organizations meetings on Classification of CFTR disorders / Stockholm, Sweden June 3, 2000 / WHO/ ICF(M)A/H/HGN/00.2
- Report on a joint WHO/ICF(M)A/IACFA meeting on Services for Adults with Cystic Fibrosis/ The Hague, The Netherlands, 7-8 June 1999/ WHO/ICF(M)A/IACFA/99.6
- Manual for Cystic Fibrosis Patients and their Parents / WHO/HGN/ICF(M)A/GL/96.6
- Guidelines for the Diagnosis and Management of Cystic Fibrosis/ WHO/HGN/GL/CF/96.2
- Report on a joint WHO/ICF(M)A meeting on the implementation of Cystic Fibrosis Services in Developing countries / Manama, Bahrain, 18-19 November 1995 / WHO/HGN/ICF(M)A/WG/95.6
- Work plan WHO/ICF(M)A 1/1/2003 - 31/12/2005

## 6. Human Genetics

### ***Paper on stem cells and therapeutic cloning.***

The position paper on stem cell research, therapeutic cloning and embryo status has been signed by some of the European associations. As to the fact that there was no common consent, the President did not sign this position paper on behalf of the worldwide organization.

On initiative of the Danish association it will be considered in the best possible way to promote the CF views towards the EU institutions, whilst, importantly, being sensitive to the CF groups not supporting the views on therapeutic cloning and embryo status regarding the use of unfertilized egg cell in research.

### ***European Institute for the Management of Cystic Fibrosis and Related disease, network of excellence, prepared by J.J. Cassiman, Leuven Belgium***

The president of CFW has expressed his interest on this initiative, which aims are to create a model virtual institute for the comprehensive management of rare diseases by using cystic fibrosis and its related diseases as a model.

### ***Meeting in Leuven November 22 – 22 Guidelines for Genetic Testing and Screening***

Herman Weggen and Inge-Britt Lundin visited Leuven on 22 and 23 November, 2002.

The ECFTN organized a consensus meeting about guidelines for Genetic Testing and Screening. The participants of this meeting were all working in the field of Cystic Fibrosis, among them clinicians, ethicists, geneticists, insurers and representatives of lay CF organisations.

The guidelines presented deal with the subject of informed consent and information that should be given by all types of genetic tests. Further they focus on prenatal carrier testing, prenatal foetal testing, pre-implantation genetic testing, neonatal screening and diagnostic genetic testing. They also refer to communication and information of the test results and about storage of DNA. They state that the decision making authority of the stored DNA remains with the person from whom the sample was taken.

A very important paragraph is about insurers. It says that insurers should not have the right to require genetic testing, to enquire about the results of previously performed carrier tests as a precondition for the conclusion or modification of an insurance contract.

Every participant was asked to give his comments on the draft text after which a discussion followed.

The ECFTN will modify the text based on the comments and try to finalize them in 2003.

Information about ECFTN can be found on [www.med.kuleuven.ac.be/cme/cf/cfnetwork.htm](http://www.med.kuleuven.ac.be/cme/cf/cfnetwork.htm)

### ***STRATA-group (EU Commissions high level expert group on Genetics tests)***

The EU Commission has appointed Eric Wendel from Denmark (EU involvement via the network European Patients' Voice) as a member of the STRATA-group (EU Commission high level expert group on Genetics tests).

The purpose of the ETAN-STRATA group is to establish a dialogue platform where key industrial stakeholders, representatives of the civil society and experts of the fields sit together and discuss ethical implication of genetic tests.

Given the fact that the past decade has shown huge differences in organizational structure, activities, political scope etc. among the national CF associations in Europe due to national and cultural differences, position papers on genetic tests, will be signed per national association to promote a fair European viewpoint on this important subject. CFW is very happy to have this representation of Cystic Fibrosis in this Strata-group.

### ***Consumer Perspectives on the Promise of CF Gene Therapy***

CFW is collaborating with partners at Education Development Center, Temple University, St. Vincent's Hospital and Medical Center of New York, and Brigham and Women's Hospital in Boston on a project to assess the impact of publicity associated with gene therapy research on patients, families, and their physicians. The project is funded by the U.S. National Human Genome Research Institute. The study team is conducting a content analysis of mass media coverage of CF gene therapy research, as well as interviews with adults with CF, parents of children with CF, and CF center physicians. The content analysis and interview results will be used to develop a consumer-focused survey tool which will be administered to adults who have CF and parents of children who have CF at a cluster of U.S. CF centers and to U.S. members of Cystic Fibrosis Worldwide. The findings from the content analysis, interviews, and survey will be presented to an expert advisory group composed of people living with CF, researchers, clinicians, ethicists, journalists, and representatives from the biotechnology industry. The advisory group will assist the study team in drafting recommendations for how best to reconcile the promise of a cure with the reality of CF gene therapy research. The recommendations will focus on improving education to help protect vulnerable consumer groups from potential harms and enhancing trust in biomedical research, needs identified by two reports on gene therapy research issued by the U.S. National Institutes of Health. The recommendations are also expected to have relevance for a broader array of issues, such as recruitment into gene therapy trials.

## **7. Initiatives & Educational Programs**

Cystic Fibrosis Worldwide offers grants to initiatives and educational programs for work related to Cystic Fibrosis. The deadline for request is March 1 and September 1 annually.

Four types of grants are available:

- 1 *Scholarships*  
These will be for individuals working in the field of clinical CF care wishing to improve their knowledge in a recognized CF centre worldwide.
- 2 *Visiting Experts*  
These will be for highly qualified CF experts in order to facilitate their travel and sojourn in CF centres wishing to improve their clinical or scientific expertise.
- 3 *Research projects*  
These will be for internationally relevant projects of a globally applicable nature.
- 4 *Training courses for allied health professional*  
These grants will cover costs for courses both in the applicant's country and abroad.

**In March 2002** we received 4 requests for applications and approved them.

**Mrs. Oller de Ramire from Argentina,**  
visited Cemeco in Spain as a visiting expert. Her aim was:  
investigation of CFTR gene mutations in Argentinean CF patients  
with incomplete or unknown genotype.

**Drs. S. Kabra from India,**  
Received a donation to study the effect of climatic changes on growth of Indian children with Cystic Fibrosis. This study will be done in co-operation with  
Dr Gary Connet of the General Hospital Cystic Fibrosis Unit Southampton, UK

**Mrs. Madhu Sharma from India,**  
visited the Cystic Fibrosis Centre in Southampton University for training in  
Nutritional management of children with CF.

**Dorian Tjesic-Drinkovic &  
Duska Tjesic Drinkovic from Croatia,**  
Both pediatricians, one is specialized in Gastroenterology and nutrition, the other in respiratory medicine, wanted to upgrade knowledge and skills regarding diagnosis and treatment of patients with CF. They both visited the CF centre in Copenhagen, Denmark.

**In September 2002** we received 3 requests for applications. Only one of them has officially been approved.

**Stojka Naceva Fustik from Macedonia**

Received a scholarship in order to gain more knowledge and experience in clinical following and treatment of CF patients. Visited the Danish CF Centre in Copenhagen.

## 8. Members of the Executive Committee CFW & Staff CFW

<b>Function</b>	<b>Name</b>	<b>Domicile</b>
President	Herman Weggen	Netherlands
Vice – President	Inge-Britt Lundin	Sweden
Vice – President	Enrique Silver	Uruguay
Secretary	Mitch Messer	Australia
Treasurer	Ami Kolombus	Israel
Newsletter Editor	Sam Hillyard	United Kingdom

### *Advisors CFW*

	Robert J. Beall Ph.D.	USA
	Peter R. Durie M.D. F.R.C.P.(C)	Canada
	Francisco Reis M.D.	Brazil
	Anna Rådeberg, M.D.	Switzerland
	Birgitta Strandvik MD, PhD	Sweden
Chairperson of the Physiotherapy Group	Mrs. Brenda Button	Norway
Chairperson of the Nutrition Group	Mrs. Sue Wolfe	United Kingdom
Chairperson of the Nurses Group	Mrs. Sue Madge	United Kingdom

### *Office*

Webmaster/marketing	Mrs. Christine Noke	USA
Office Manager	Mrs. Gina Steenkamer	Netherlands

## **Work plan WHO/ICF(M)A 1/1/2003 - 31/12/2005**

This work plan is a continuation of the work plan 2000 – 2002. Many of the items in the existing work plan are still relevant. Collaboration between WHO and ICF(M)A is beneficial for both organisations because as the emphasis on advocacy and health promotion in general is a target for WHO, it is the same for ICF(M)A but with special attention to those with Cystic Fibrosis.

Knowledge of CF is growing in Western Europe, North America and other industrialized countries, but application of that knowledge to health care provision is very patchy. The advocacy and authority provided by WHO is a very important factor in bringing the needs of CF patients and families to the attention of governments around the world.

How can ICF(M)A contribute to the goals and responsibilities of WHO?

- ICF(M)A has a network of lay, medical and scientific people all over the world, who have expertise in the field of Cystic Fibrosis.
- ICF(M)A representatives will visit WHO meetings where they can make WHO officers and representatives of Governments aware of the needs of persons with Cystic Fibrosis.
- WHO and ICF(M)A could organize joint conferences and training courses bringing information to countries around the world.
- Through excellent cooperation and mutual goals, a collaboration has formed between ICF(M)A and the global association for adults with Cystic Fibrosis( IACFA), evolving into one association called Cystic Fibrosis Worldwide. ICF(M)A will continue with its work in the same way as it has done in past years. With representatives of adults with Cystic Fibrosis in the Executive Board and among the medical and scientific advisors, CFW will be able to advocate in a better way for adults with Cystic Fibrosis as well as continue the work of ICF(M)A.

This leads to the following actions in the period 2002 – 2005

1. The president of ICF(M)A will visit the WHO Headquarters once a year with a clear agenda to meet WHO officers from several sections to discuss the opportunities for collaboration and to evaluate the progress. This visit could be connected to the Executive Board meeting or the World Health Assembly if there is a reason to make a statement during these meetings.
2. ICF(M)A is developing a regional structure. Each region has a responsible officer in the Executive Board of ICF(M)A and a medical/scientific advisor. Regions are more or less the same regions from WHO. The responsible officer for each region should develop a regional work plan where possible and desired together with the regional WHO office. For the planning period we start with:
  - o EURO - Execute the work plan for Georgia

- EMRO – Jordan, training course for physiotherapists
  - AMRO – make a work plan for Paraguay
  - SEARO - India
3. Collaboration with the WHO Headquarters, the WHO department of Human Genetics. Continuation of participation in updating and disseminating the WHO Model List of Essential Drugs. The goal for ICF(M)A is that the essential drugs as pancreatic enzymes and antibiotics are part of this list for persons with Cystic Fibrosis.
  4. A joint WHO/ICF(M)A/CF-Nurse specialist Group project creating guidelines,, as a part of the general guidelines, for the nursing management of Cystic Fibrosis. This could be done together with other NGO's in official relation of WHO, as the International Council of Nurses.
  5. Producing an information package with WHO/ICF(M)A documentation and guidelines for (starting) national Cystic Fibrosis associations in developing countries and how to improve Cystic Fibrosis care in their own countries and the support they can expect from WHO and ICF(M)A
  6. Work on the recommendations in the report 'Collaboration in Medical Genetics'. The medical liaison from ICF(M)A, Prof. J.A. Dodge, participated in the meeting in Toronto, Canada on 9-10 April 2002. A joint WHO/ICF(M)A meeting in 2004 about how CF professionals within several parts of the world can contribute to the implementation of these recommendations.
  7. Execute the work plan for Georgia together with the Georgina Government for Health and Labour, the WHO Regional office in Denmark and the WHO liaison officer in Tbilisi. This in close cooperation with ECFS.
  8. Organizing physiotherapy-training courses in Jordan and Georgia in conjunction with the WHO regional offices.
  9. Updating the joint WHO/ICF(M)A documents, produced in 1996, 'Guidelines for the diagnosis and management of Cystic Fibrosis' and 'Manual for Cystic Fibrosis Patients and their Parents'.
  10. Evaluate the WHO International Classification of Functioning, Disability and Health (ICF) on the consequences for persons with Cystic Fibrosis. The CCFF will carry this out for ICF(M)A as soon as the CD-Rom is available.
  11. Disseminating the WHO publication 'Innovative Care for Chronic Conditions: Building Blocks for Action' among the members of ICF(M)A. The English version for the English speaking countries as soon as possible, the Spanish and Arabic version to the countries with these languages as soon as these versions are available.

12. Making a joint WHO/ICF(M)A work plan for Paraguay. In 2002 the vice-president for Latin America visited Paraguay together with the president of FLAFQ. The next step is to make a work plan to improve the health care for persons with Cystic Fibrosis.
13. Participation in the Intergovernmental Negotiating Body on the WHO framework convention on tobacco control.
14. Working further on the documenting of the worldwide distribution of CF. The first meeting has been in Genoa in June 2002. This was the first step which should be continued as joint project from WHO/ICF(M)A/ECFTN.

Further collaborative opportunities will be constantly under review.

Herman Weggen  
President ICF(M)A

## World Health Organization

Collaboration with International Cystic Fibrosis (Mucoviscidosis) Association

Review 1/1/2000 – 31/12/2002

Date of completion of the report: July 2002-08-12

<b>Geographical Area</b>	<b>Title project or activity</b>	<b>Brief description Specific contribution year</b>	<b>Cooperating partners (1) WHO (2) National Government (3) other NGO's</b>	<b>Indicate:</b>
Global	105 <sup>th</sup> Session Executive Board January 2000	Representative Mrs. Liliane Heidet statement with NCD	(1)	
Global	Framework Convention on Tobacco Control 2 <sup>nd</sup> meeting March 2000	Representative Mrs. Liliane Heidet	(1)	
Global	53 <sup>rd</sup> World Health Assembly May 2000	Representative Mrs. Liliane Heidet	(1)	
Global	WHO/ICF(M)A/ECFTN meeting June 2000 Stockholm	Classification of Cystic Fibrosis and Related Disorders	(1) (3)	

### **Member countries of Cystic Fibrosis Worldwide**

Argentina, Australia, Austria, Belgium, Brazil, Bulgaria, Canada, Chile, Colombia, Costa Rica, Cuba, Czech Republic, Denmark, Ecuador, El Salvador, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Latvia, Lithuania, Mexico, Netherlands, New Zealand, Norway, Panama, Poland, Portugal, Romania, Slovak Republic, South Africa, Spain, Sweden, Switzerland, Turkey, United Kingdom, United States of America, Uruguay, Venezuela.

### **Associate members of Cystic Fibrosis Worldwide**

Azerbaijan Republic, Bahrain, Dominican Republic, Egypt, Estonia, Guatemala, India, Jordan, Luxembourg, Macedonia, Qatar, Russia, Saudi Arabia.

**CFW** is a Non Governmental Organization (NGO) in official relation with the World Health Organization.

<b>Geographical Area</b>	<b>Title project or activity</b>	<b>Brief description Specific contribution year</b>	<b>Cooperating partners (1) WHO (2) National Government (3) other NGO's</b>	<b>Indicate:</b>
Global	NGO Forum meeting January 2001	Representative Mrs. Liliane Heidet, liaison officer	(1) (3)	Subjects covered for the 107th EB
Global	WHO meeting on Chronic Lung diseases January 2001	Representatives Prof. John Dodge, medical liaison officer and Mrs. Liliane Heidet, liaison officer	(1) (3)	
Global	107th session Executive Board January 2001	Representatives Mr. Herman Weggen, the new elected president of ICF(M)A, Prof. John Dodge, medical liaison officer Mrs. Liliane Heidet, liaison officer	(1) (2) (3)	Also informal meetings with governmental representatives and other NGO's
Global	Framework Convention on Tobacco Control	Representative Mrs. Liliane Heidet	(1)	ICF(M)A encouraged member countries for actions on the non tobacco day
Global	54th World Health Assembly May 2001	Representative Mrs. Liliane Heidet, liaison officer	(1)	Statement on Tobacco control, passive smoking and CF.
Europe	WHO meeting on Human Genetics Vienna, June 2001	Statement ICF(M)A president Mr. Herman Weggen	(1)	Statement CF-patients

<b>Geographical Area</b>	<b>Title project or activity</b>	<b>Brief description Specific contribution year</b>	<b>Cooperating partners (1) WHO (2) National Government (3) other NGO's</b>	<b>Indicate:</b>
Global	Distribution WHO/CF/HGN//00.2 Vienna, June 2001	Document distribution to visitors of the European CF conference, Vienna 2001	(1) (3)	Classification of Cystic Fibrosis and Related Disorders
Europe	WHO regional meeting Madrid 2001	Representative mr. Jose Polido, Spain	(1)	
Global	Updating and Disseminating the WHO Model List of Essential Drugs	Contacts and attending meetings by Prof. George Davidson, Vancouver	(1)	Request for adding essential drugs for CF
Global	109th session Executive Board, Geneva January 2002	Representative mrs. Liliane Heidet, liaison officer	(1)	
Global	Fourth Intergovernmental Negotiation body on the Framework Convention on Tobacco control, March 2002	Representative mrs. Liliane Heidet, liaison officer	(1)	
Global	WHO meeting Collaboration in medical Genetics, Toronto April 2002	Representative Prof. John Dodge, medical liaison officer	(1) (3)	april 2002
National	Cystic Fibrosis Care in Georgia, April 2002	The President of ICF(M)A met with mrs. Klimiashvili, WHO liaison officer in Georgia and	(1) (2) (3)	Developing a workplan made by H. Weggen and CF Charity Foundation

<b>Geographical Area</b>	<b>Title project or activity</b>	<b>Brief description Specific contribution year</b>	<b>Cooperating partners (1) WHO (2) National Government (3) other NGO's</b>	<b>Indicate:</b>
		mr. Cheishvili, deputy minister of health		in Georgia
Global	55th World Health Assembly May 2002	Representative Mrs. Liliane Heidet, liaison officer	(1)	Contacts with dr. Gamkrelidze, Minister of Health, Georgia dr. Torres, Argentina prof. Roy, India
Global	WHO/ICF(M)/A/ECFTN meeting June 2002, Genoa	Worldwide distribution of Cystic Fibrosis	(1) (3)	
Global	Guidelines for the Diagnosis and Management of Cystic Fibrosis	Updating of this joint WHO/ICF(M)/A document	(1)	Future activities Ongoing in 2002-2005
Global	Manual for Cystic Fibrosis Patients and their Parents	Updating of this WHO/ICF(M)/A document	(1)	Future activities Ongoing 2002-2005
Global	The International Classification of Diseases Family	Scrutinize this document on the consequences for persons with Cystic Fibrosis	(1)	CD-Rom not yet available, moves on to the workplan 2002-2004
Regional	Trainingcourse Physiotherapy In Jordan/Amman	Discussing co-sponsorship of EMRO	(1)	ongoing

