

## INSIDE:

### EDUCATION

CFW hosts educational conferences globally. Join us at our next regional educational conference in Beirut, Lebanon 2010.

### THE SPREAD OF INFORMATION

The CFW Newsletter and Website offers multilingual contact to the international CF community. CFW launched a new and improved website on January 2009!

### OPENING ACCESS TO MEDICATION

CFW lobbies local governments to supply necessary medication to patients in need. CFW Has successfully lobbied to have pancreatic enzymes, a necessary medication for over 80% of all CF patients, listed on the WHO necessary drug list.

### PROGRAMS FOR 2009 - 2010

Regional conferences

- Skopje, Macedonia
- Brisbane, Australia
- Beirut, Lebanon

Web based education

Social Networking drive

5 for 5 Campaign

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# CFW

cystic fibrosis worldwide

## ANNUAL REPORT 2009



[www.cfww.org](http://www.cfww.org)



## What is Cystic Fibrosis?

Cystic fibrosis (CF), also called Mucoviscidosis, is a hereditary disease that affects the entire body, causing progressive disability and early death. Formerly known as cystic fibrosis of the pancreas, this entity has increasingly been termed simply 'cystic fibrosis.'

Difficulty breathing and insufficient enzyme production in the pancreas are the most common symptoms. Thick mucous production, as well as a low immune system, results in frequent lung infections, which are treated, though not always cured, by oral and intravenous antibiotics, inhalation of mucolytics and hypertonic saline solution, chest physiotherapy and daily exercise. It is vital for CF patients who are pancreatic deficient to use sufficient pancreatic enzymes with every meal and to consume high caloric nutritional foods. A multitude of other symptoms, including sinus infections, poor growth, diarrhea, and potential infertility (mostly in males) result from the effects of CF on other parts of the body.

1 in 2500 children is born with cystic fibrosis, and it is one of the most common fatal inherited diseases. Individuals with cystic fibrosis can be diagnosed prior to birth by genetic testing or in early childhood by a sweat test. There is no cure for CF, and most individuals with cystic fibrosis die young — many in their 20s and 30s from lung failure although with many new treatments being introduced the life expectancy for people with CF are increasing. Ultimately, lung transplantation is often necessary as CF worsens.

While the earliest clear medical descriptions date from the 1930's, CF obviously existed prior to this date but was un-recognized. Its clinical characteristics individually resemble those of other diseases such as pneumonia, bronchiectasis, failure to thrive, and celiac disease. Indeed, where these conditions are prevalent CF goes un-recognized. Moreover, if clinicians believe that CF is absent from their population they will not consider it in a differential diagnosis. A better awareness of and the increasing availability of diagnostic tests- the sweat test and/or DNA tests – frequently leads to the identification of a higher number of affected individuals. In the past it was believed CF only existed in Caucasians, through continued advancements and diagnosis we understand CF is a global disease with many different mutations and symptoms.

In the last two decades, CF has been increasingly diagnosed in Latin America, the Middle East, and populations derived from the Indian subcontinent that have emigrated to Western Europe, thus implying the presence of CF in significant numbers among the citizens of India and Pakistan who have remained in their homeland. We now see CF as an emerging disease state throughout the Middle East and Arab populations. Due to the practice of consanguinity among Arabs, in most cases over 50%, we see CF according in dramatically high numbers.

CF is a multi-organ disease and children with CF need access to all necessary

medications and multidisciplinary team care in CF centre's regularly. This multidisciplinary team should consist of a CF Nurse, Pediatric Pulmonologists, Pulmonologists, Gastroenterologist/Nutritionist, Nurse, Physiotherapist, Microbiologist and Psychologist/Social worker who have been trained in the specific needs of patient care. Daily home care that requires both parent and patient participation is also needed to ensure the patients experience a better quality of life and life expectancy.

## VISION

All persons living with cystic fibrosis will have access to knowledge and appropriate care.

## MISSION STATEMENT

Cystic Fibrosis Worldwide promotes access to knowledge and appropriate care to those people living with cystic fibrosis and among medical, health professionals and governments worldwide.

## HISTORY of CYSTIC FIBROSIS WORLDWIDE

**Cystic Fibrosis Worldwide** (CFW), formed after the merge of the International Association of Cystic Fibrosis Adults and the International Cystic Fibrosis (Mucoviscidosis) Association in 2003, is dedicated to improving quality of life and life expectancy for persons living with cystic fibrosis globally. CFW has 56 member countries with a number of members coming from developing parts of the world. With these new memberships comes an awareness of the desperate situation facing those who have cystic fibrosis, caregivers or medical professionals in developing countries.

Cystic Fibrosis Worldwide reaches out to these countries by working to help develop effective cystic fibrosis treatment and care. This includes helping to organize much needed medications, development, training and education of health care providers, parents and people with CF and spreading awareness of cystic fibrosis at the government and community levels. We seek to find people with CF who are living in countries where cystic fibrosis is thought to not exist and offer them hope for better tomorrows. It is our objective to find a solution that will bring long-term benefits to the existing persons with cystic fibrosis and to those people with CF who will be born in the future, leaving no people with CF behind. Until a cure is found, we will strive to provide humane situations for those who are currently suffering from cystic fibrosis globally.

*“CFW works to educate parents, people living with cystic fibrosis and Medical, Health Professionals in the treatment of cystic fibrosis”*

CFW Education Program Team:

**Dr. Harry Heijerman**, Pulmonologist, CFW Medical Advisor

**Dr. Anne Munck**, Gastroenterologist, ECFS Board of Directors

**Dr. Steven Conway**, Leeds Regional Adult CF Unit

**Dr. Ian Balfour-Lynn**, Royal Brompton Hospital, London

International Nutrition Group/CF

**Sue Wolf, ING/CF**, Dietician at Leeds Regional Adult CF Unit, UK, member of ECFNG and UK Dieticians

**Alison Morton**, Dietician at Leeds Regional Adult CF Unit, UK, member of ECFNG and UK Dieticians

International Physiotherapy Group for CF

**Louise Lannefors**, Physiotherapist, IPG-CF and other IPG/CF therapists

**Sue Madge**, CF Nurse, International Nurses Group/CF

Cystic Fibrosis Worldwide is a provider of Cystic Fibrosis (CF) educational programs for practicing clinicians, CFW member associations, patients and families globally with a focus on developing countries. Our Education team of specialists clinical experience is both broad and deep with expertise in inpatient and outpatient treatment of CF to include both well-established and emerging topics in addition to education tailored to primary care practitioners, specialists and allied health professionals.

Cystic Fibrosis Worldwide Educational Program, an integral part of the Cystic Fibrosis Worldwide programs, sponsors conferences, online, and print activities. As a result of these educational activities, Cystic Fibrosis Worldwide fosters the continuing professional development of CF health care providers, CFW member associations, families and patients. The offerings are designed to promote the professional development of physicians and health care practitioners and influence their clinical practice behavior for the purpose of improving health outcomes for Cystic Fibrosis patients. Families and patients who attend CFW workshops learn how to better cope with CF at home, what questions to ask their caregivers. Physiotherapy, Nutrition and updates on current research and developments help patients and families understand what is needed to give patients a better quality and quantity of life. The CFW Educational program also works to build capacity among our member association via governing, fundraising and program development.

In 2008 CFW worked to restructure and define our educational offerings bringing together top experts in the field of CF care and management. A round table discussion with our experts was arranged in Orlando, Florida US with the help of the CF North American Cystic Fibrosis Conference and the CF Foundation. At this meeting CFW defined upcoming conference content, scheduling and developing further education tools.

## 2009 Conferences/Meetings

**CFW Balkans Regional Cystic Fibrosis Conference**  
Skopje, Macedonia  
April 17th and 18th 2009

**Cystic Fibrosis Worldwide Annual Meeting of the Members**  
Brisbane Australia  
September 2009

**Some Topics on the Agenda;**  
Cystic Fibrosis, From Gene to Disease  
Early lung disease, Diagnostics/ Monitoring  
Prevention of Chronic Infection with PA  
Treatment of Pseudomonas Infections  
Diagnosis and Treatment of Malabsorption  
Nutrition in CF  
Treatment of Pulmonary Exacerbations  
Home IV  
CF Liver Disease  
Cystic Fibrosis Related Diabetes  
Inhaled Therapies  
**Allied Health Professional Workshop**  
CF Nursing  
Nutrition “Nutrition and Enzymes:  
Physiotherapy  
**CFW Lay Seminar**  
Physiotherapy why is it important?  
Physiotherapy Workshop, Technique  
Equipment used in Physiotherapy  
Living with CF  
Standards of Care European Consensus  
Developing CF Centre's  
Developing a Board of Directors... and more...

## 2010 Conferences/Workshops

**CFW Middle East Regional CF Conference**  
In collaboration with the Arab Pediatric Pulmonology Association  
Beirut, Lebanon  
November 2010

**Cystic Fibrosis Worldwide Annual Meeting of the Members**  
Valencia, Spain  
2010

**Some Topics on the Agenda;**  
Cystic Fibrosis, From Gene to Disease  
Early lung disease, Diagnostics/ Monitoring  
Prevention of Chronic Infection with PA  
Treatment of Pseudomonas Infections  
Diagnosis and Treatment of Malabsorption  
Nutrition in CF  
Treatment of Pulmonary Exacerbations  
Home IV  
CF Liver Disease  
Cystic Fibrosis Related Diabetes  
Inhaled Therapies  
Developing Registries  
Developing a Board of Directors... and more...

**CFW welcomes members to the Annual Business Meeting in Valencia, Spain**  
Topics of discussion  
Registries  
Future Programs  
Member programs... and more!

*“An Educational Guide to the Treatment and Management of Cystic Fibrosis”*

In 2008 CFW developed a project to create the CF Pocket Guide for medical professionals, patients and families. The CFW Pocket Guide is an educational resource that is an overview of content of CFW Educational Conferences and Seminars. It is specially designed to meet the needs of developing countries and countries where there is little known about cystic fibrosis. Our main objective is to create a resource to encompass all the needs that surround supporting and managing cystic fibrosis effectively.

- Each educational program is comprised of 6 to 8 educational tracks. The Resource Guide will contain the complete content of each educational track
- 1 or 2 thought leaders in the topic area will present evidence-based educational content through clinical presentations, workshop, case analysis, and question and answers sessions. Thought leaders will be members of the CFW Educational Team.
- Patient content will also be present offering instructions on home therapy, daily care and capacity building for CF organizations.
- The completed Resource Guide will be translated to Russian, Hindi, Arabic and Spanish to increase the spread of information.

Cystic Fibrosis Worldwide Educational Program and Pocket Guide are designed as a single-topic, deep dive format that allows for complex case presentations, an opportunity to develop knowledge of an emerging disease state, special populations and co-morbidities surrounding a therapeutic area. The program also addresses the need to reach the patients and families directly improving home therapy and the capacity within patient organizations.

**Target Audience**

Clinicians involved in the management of patients with cystic fibrosis and patients, patients and family members who are coping with CF daily and leaders of CF Associations supporting increased life expectancy and quality of life for CF patients.

**CFW thanks our sponsors in 2009!**

**Solvay Pharmaceuticals,  
Inspire Pharmaceuticals, USA  
EuroCare CF, Italy**

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## *“Act as a Key Source of international cystic fibrosis information and resources”*

CF Worldwide offers an effective platform for the exchange of current information via the Internet in multiple languages for the international CF community. CFW also produces the CFW Newsletter with an active strategy to expand the readership that includes new parents, younger patients and caregivers. We are proud of how we also reach out to the “non-medical” needs of patients and their families with thought provoking articles and personal interest stories.

The Internet is a reliable and convenient information medium for all CFW members/users and medical advisors. The CFW website currently utilizes the very highest standards of web technology, while maintaining a friendly and easy-to-navigate graphic user interface. CFW utilizes feedback from our subscribers and web users to make continued improvements.

### Website

Cystic Fibrosis Worldwide operates a multi-lingual website and online newsletter distributing information about CF globally. The website also hosts forums on our website that allow for the exchange of information internationally and contact with trained CF specialists, something not available in many countries, for parents of children with CF and adult CF patients. The CFW website also offers publications such as the Joseph Levy Lecture, the IPG/CF physiotherapy manual and many others produced in conjunction with the World Health Organization, such as the guidelines for the management of CF.

In 2009 the website incorporated new features to display its over 1200 articles dynamically in the corresponding sections throughout the site as soon as they are posted. Articles are now classified according to topics, languages, keywords, and other details, which allows for flexibility to display and search for contents, as well as the creation of archives to find articles of specific dates in certain sections of the site.

More than 210 professional translators have collaborated over the last 7 years to eliminate language barriers and open lines of communication globally, providing publications and the latest news and developments in the CF community. We look forward to continue growing our reach to provide an international platform for the exchange of essential information for families and healthcare professionals.

[www.cfww.org](http://www.cfww.org)

### Newsletter (online at [www.cfww.org](http://www.cfww.org))

#### Upcoming articles in 2010...

- **Dietary treatment of adult patients with Cystic Fibrosis Related Diabetes, Francis Hollander, RD**
- **Prevention of Essential Fatty Acids Deficiency as a Part of Nutrition Therapy in Patients with CF, Gabriela Sabolová, PhD**
- **Motivational interviewing and adherence in CF, Gary Latchford, PhD; Alistair Duff, PhD; Kristin Riekert, PhD; and Mary Wells Moore, LCSW**
- **CFW Update: Lay Day in Prague, Czech Republic**
- **Organ transplantation as a “gift of life”? Interviews with young adult lung transplant recipients, Gerald Ullrich, PhD**
- **Airways Clearance Techniques, Rebekah Mills, Senior Physiotherapist**
- **Guide to Travelling with CF, Walter van Praag**
- **Book Review: The Power of Two: A Twin Triumph Over Cystic Fibrosis, By Isabel (Isa) Stenzel Byrnes and Anabel (Ana) Stenzel**

*“Provide local and international policy and political support to Cystic Fibrosis Associations and people living with cystic fibrosis”*

CF Worldwide has a network with partners in the cystic fibrosis global community such as Cystic Fibrosis Worldwide members, international Cystic Fibrosis working groups and the World Health Organization to bring awareness of cystic fibrosis and the needs of persons with cystic fibrosis at the local and international levels in government, health and public sectors. CFW recently submitted an application to have Pancreatic Replacement Therapy for CF placed on the WHO List of Necessary medication. We will continue to work towards including a full list of necessary medication used in the treatment of cystic fibrosis.

CFW also lobby's governments and private sectors of individual countries to ensure support for persons living with cystic fibrosis.

## **Macedonia**

**“Thanks to CFW, we are achieving our goals and reaching our patients.” Snezana Bojoicin, Macedonia CF Association President and mother of a CF child.**

In 2007 CFW supported the CF Association in Macedonia to lobby their government to make available to all CF patients – Pulmozyme, Colistin, Tobramycin and Creon. The lobby was very successful and the above medications are included in government plans and budgets.

In 2008 we have continued to support Macedonia by holding meetings in Skopje with persons in charge of organizing budgets for the existing CF Center and officials responsible for processing admissions of new medications for sale in Macedonia. Though in 2007 the government agreed to support patients they did not increase the budgets of hospitals treating patients. Instead it is up to the hospitals to afford medication and treatment with existing income. This has meant there is still not enough funding for patients limiting their access to inhalation/IV therapies and access to some necessary medications. During our discussions with hospital representatives we worked to increase yearly budgets for CF patients.

In 2009 we offered a regional conference in Partnership with CF Macedonia, our member country. The conference was very successful in bringing attendees from all over the region even as far as the US and Iceland. We are very pleased our efforts have led to a CFE supported 2010 CF regional conference in collaboration with CF Croatia. We wish them much success in 2010.

**CF Worldwide also arranged for 3 diagnostic machines to be donated by Wescor and supported by the Ministry of Health.**

## **CF Gaza**

CFW arranged for an emergency supply of pancreatic enzymes to be shipped to Gaza after the war in the early part of 2009. These enzymes were desperately needed and supported the patients until May of 2009. Currently CFW is arranging to send in another needed donation of enzymes, two pulse oximeters and one spirometer.

## **CF Lebanon**

In 2010 CFW will host in collaboration with CF Lebanon, Arab Pediatric Pulmonology Association a CF regional conference in Beirut Lebanon. CFW is also supporting CF Lebanon by lobbying the Ministry of Health to add CF to its list of supported medication and treatment.

## **CF Palestine**

CFW is working to resource donated patient and clinical equipment and actively seeking funding to send a CF team of caregivers to a month long course in London via our Facebook, Twitter and social networking. We hope to raise the funds needed in 2010 and have the team attend the course in April 2011.

## Member Partnerships

CFW has 62 member countries with a number of members coming from developing parts of the world. With these new memberships comes an awareness of the desperate situation facing those who have cystic fibrosis, caregivers or medical professionals in developing countries.

Cystic Fibrosis worldwide members are a continuous support for the many activities carried out by CFW globally. In 2007 members assisted beyond their annual member dues in order to better facilitate the needs of patients in crises. CFW looks forward to continuing to collaborate with our global network of members.

### **Our Members**

- Argentina
- Australia
- Belgium
- Canada
- Chile
- Czech Republic
- Denmark
- Ecuador
- France
- Greece
- Hungary
- Iceland
- Ireland
- Israel
- Latvia
- Luxembourg
- Macedonia
- Netherlands
- New Zealand
- Norway
- Poland
- Portugal
- Romania
- Slovak Republic
- Spain
- Sweden
- Switzerland
- Turkey
- United Kingdom
- United States

### *Associate members*

- Armenia
- Austria
- Azerbaijan Republic
- Bahrain
- Brazil
- Bulgaria
- Costa Rica
- Colombia
- Cuba
- Dominican Republic
- Egypt
- El Salvador
- Estonia
- Finland
- Palestine (WB)
- Gaza
- Georgia
- Guatemala
- India
- Jordan
- Mexico
- Moldova
- Lebanon
- Lithuania
- MATIO
- Panama
- Paraguay
- Qatar
- Russia
- Saudi Arabia
- South Africa
- Uruguay

### **Online Member resources**

Online accounts have been added for CFW Member Associations to manage their profile information, and keep their contact details up-to-date for the ease of communication with patients in their respective countries.

The accounts are also being used to streamline the registration process for upcoming conferences, seminars, and Annual Board Meetings.

The CFW website is now dynamic and database driven, which allows members to have their information published online faster and optimized for search engines, to promote their local conferences and events throughout the site, or submit articles about other activities of interest to the global CF Community.

New features are being added, including the collection of statistical information about national CF care and patients, as part of an ongoing process to share and update data promptly through simple questionnaires, which will help to recognize the needs in member countries and objectify comparisons. The list of CF Centers will now be constantly updated as well, as a resource for patients to find the most convenient institutions near their homes and as a statistical measure of center/patient density at national or regional level.

**ROMEDIC B.V.** *Romedic* of the Netherlands donated 55 refurbished PortaNeb-Sidestream nebulisers. This donation is valued at over €2500. Romedic has agreed to continue to supply nebulisers for CFW programs globally.

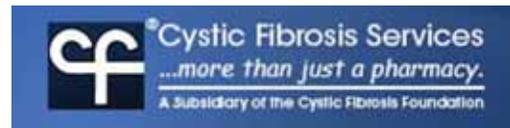


*Solvay* - makers of Creon - a pancreatic enzyme used by many persons with CF worldwide. Solvay Pharmaceuticals has provided CFW with an unrestricted educational grant for the CFW website. Solvay has also contributed to the CFW newsletter and offered support to CFW in our efforts to have pancreatic enzymes included on the WHO Model List of

Essential Medicines. Solvay recently supported the CFW Education Program and the development of the CFW Pocket Guide.



*Altus Pharmaceuticals* has supported the CFW Newsletter through an educational grant.



*CF Services Inc.* has supported the CFW Newsletter and website through an educational grant.

*Gilead Pharmaceuticals* supported CFW's capacity building project in Turkey.



*Wescor* supported the project in Macedonia by supplying diagnostic equipment for 3 pediatric centers



*Plenus DMC* provided free services to support CFW conferences and workshops.



Plenus will continue to support CFW and our member countries by offering conference organizing globally at discount pricing and offering support with no fees.

*INSPIRE* Supported CFW Newsletter and Website in 2009. Inspire will continue to look for ways to expand their support in 2010.



*Roche* Supported the CFW education program and Pocket Guide in 2008 and 2009.



## Burke Bear

*"Burke P Bear, the Ambassador of love, peace and helping those with CF."*



In order to support our work we are reaching out to individuals, corporations and friends of the CF community asking that they join us in bringing Burke to the world to create an international campaign that positively affects those who suffer with CF globally.

Burke P. Bear was named after an incredibly spirited young man, Burke Derr, who died of Cystic Fibrosis (CF) just two days before his 19th birthday. Although his family in the USA miss Burke terribly, they believe his spirit and legacy live on in this Boyd's Limited Edition©Teddy Bear.

Burke has now joined forces with CFW in order to continue to fulfil the dream of a

young man who wished to help all who suffer with CF world wide. For more information about the Burke Bear campaign, please visit [www.cfw.org](http://www.cfw.org) or contact [burke@cfww.org](mailto:burke@cfww.org).

# BUILDING BRIDGES



**if we don't care, who will?**

## The Building Bridges Campaign

The Building Bridges Campaign is a multi-national campaign to raise funds to support projects that directly improve the lives of people who have CF and those who will be born in the future in under developed nations.

As part of the Building Bridges Campaign, CFW has begun working with volunteers to host events that raise funds to build CF care in developing countries and bridge the gap between those who suffer. CFW worked with individuals who ran events such as Bicycling along the Australian east coast, wine appreciation dinners and Art

Auctions featuring donated art works from artists in India, Italy and New Zealand.

Events are a great way to raise funds to help support CFW and give us the ability to provide educational grants, needed diagnostic and laboratory equipment, supply patients with necessary treatment facilities, equipment and medication to improve and extend their lives.

## 5 for 5 Campaign

*5 for 5 is your commitment of just \$5 annually for 5 years and to get 5 other people to join this campaign.*

What do we do with the \$5?

CF Worldwide runs programs to help children born with CF in developing countries and globally. More than half the world's population of CF patients are still dying in early childhood. We can reach them but we need your help.



**Find out more about CF Worldwide projects and see where your \$5 will go and why it's so important to join this campaign today!**

Visit

<http://www.cfw.org/5for5/>

**and share a laugh with Earl and join 5 for 5 saves lives!**



Cystic Fibrosis Worldwide joins FirstGiving. Firstgiving lets people donate to nonprofits online. It's quick, easy and safe. Their goal is to help people raise as much as they can for causes they care about, by providing an excellent service to as many people as possible. Visit [www.firstgiving.com/cfw](http://www.firstgiving.com/cfw)

# firstgiving

**5 for 5 keeps them alive!**

**Want to change lives  
of thousands of people  
who suffer from CF?**

**Just 5 for 5  
save their lives!**



[www.cfww.org](http://www.cfww.org)

***“If we don't care, Who will?”***

[www.cfww.org](http://www.cfww.org)

You can now follow CF Worldwide on

**twitter**<sup>™</sup>

<http://twitter.com/CFWorldwide>

**facebook**

<http://www.facebook.com/home.php#/pages/Bornova-Turkey/Cystic-Fibrosis-Worldwide/20003316164?ref=ts>

**ryze**  
Business Networking

<http://www.ryze.com/go/CFWW>

