

## INSIDE:

### EDUCATION

CFW hosts educational conferences globally. Join us at our next regional educational conference in Amman Jordan 2010.

### CLINICAL CARE DEVELOPMENT

CFW supports the development of specialized CF Centers in developing countries. Next planned CFW supported CF Centre, Hebron- Palestinian Territories

### THE SPREAD OF INFORMATION

The CFW Newsletter and Website offers multilingual contact to the international CF community. CFW launched a new and improved website Jan 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

Amman, Jordan

Spit, Croatia

Building Capacity among members

Supporting the CF South Asian Trust (CF-SAT)

Developing clinical care

Palestine and Gaza

Macedonia

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## ANNUAL REPORT 2008

If we don't care, who will?

## 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.

## 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 continuity 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.

## Education

*"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.

### 2008 Conferences/Workshops

#### Annual CFW Lay Seminar Day Prague 2008

Every year, CF Worldwide and CF Europe organize a lay seminar where people with CF, their families and caregivers from all over the world along with CFW Representatives and others interested in CF, spend the day attending educational lectures and workshops.

The CFW Lay Seminar provides updates on CF Care and Research to enhance the exchange of information throughout the CF community. In 2008, CFW welcomed over 100 registrants in Prague. We enjoyed a successful day and had positive feedback from attendees.

#### 2008 Lay Seminar Guest Speakers and topics;

"Update on CF Research," Stuart Elborn - UK,  
"Update on Basic CF Care; what can you do with little?," "Update on CF Care,"  
"The golden standards of care" Birgitta Strandvik – Sweden,  
"Managing my life with CF," *Ulrike Pypops and Reto Weibel*  
"Adult Care," Dr Harry Heijerman – The Netherlands  
"Physiotherapy Short Course: Autogenic drainage/practical training," Jean Chevaillier - Belgium

### 2009 Conferences/Workshops

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

**CFW Middle East**  
**Regional**  
CF Conference  
Amman Jordan  
March 2010

**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.....

# CFW Pocket Guide

*"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 2008!

Solvay Pharmaceuticals, Germany  
 Roche Pharmaceuticals, Switzerland  
 EuroCare CF, Italy

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**Capacity Building for Parent/Patient Organization**

Development Guidelines for Associations  
*By-Laws*  
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 Lobbying local and national government for support  
 Development of Strategic plan (What do patients need now?)  
 Fundraising for programs  
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*International and Local Resources*  
*Hosting Events*  
*Corporate Sponsors*

## Capacity Building

“Cystic Fibrosis Worldwide promotes Capacity Building for CF member associations internationally”



An essential part of CFW programs is to build capacity among our developing member associations. We do this by aiding members to develop strategic plans that include creating effective programs that benefit patients and by offering a network of CF association and advisors globally. We also work to encourage organizations to run fundraising events, apply for grants and develop corporate sponsors. Our educational program includes defined capacity building education from development of associations to the long term goals and support needed to carry out the mission.

Many new CFW organizations are in developing stages and rely on the international CFW network for guidance and support. CFW helps garner financial resources to aid targeted countries in development stages. Through the CFW Annual Meeting of the Members many ideas, concepts and advice is shared. An open forum fosters continued communications and relationships among CF Associations globally. Through lobbying, clinical development and education along with organizational development support, we reach as many patients as possible with long term solutions.

*In India....*

2006 – 2011

Cystic Fibrosis Worldwide has put considerable resources to work in India to develop a CF patient association. The Cystic Fibrosis South Asian Trust (CF-SAT) is now a legally established organization. The final step in capacity building for the CF-SAT is to provide financial support for the employment of a Health and Social Welfare specialist to act as the Director of CF-SAT and establish a permanent office in Delhi. The objective of the Director of CF-SAT will be to implement the CF-SAT strategic plan that was developed in cooperation with CFW in 2007. CFW will fund only 2 years of operational costs allowing CF-SAT to develop and resource funding to support actual projects detailed in the strategic plan. CFW will have the option to assist in individual projects as requested by CF-SAT utilizing our international network and resources.

*In Turkey....*

2007 – 2008

During the 2007 CFW Seminar Day held in Belek, Turkey with over 100 Turkish families in attendance, CFW carried out a general needs assessment. It was determined that Turkey as a CFW member would become a target country for capacity building to improve quality of life and life expectancy of patients born with CF. Therefore, an analysis of the current needs of patients and the medical professionals who care for them will be carried out and a 5 year strategic plan developed. CFW was awarded a \$15,000 Grant from Gilead Pharmaceuticals to carry out this 6 month program in 2008. The program has carried over to 2009 with continued analysis of current needs.

*“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 WHO guidelines for the management of CF. We have over 164 translators that help to eliminate language barriers and open lines of communication globally, publications and the latest news and developments in the CF community. The CFW website receives over 100,000 visitors monthly and we look forward to continuing to provide an international platform for the exchange of information.

In 2008, CFW embarked on a project to upgrade our current website to make it more user friendly and easier to manage. The new site will be launched in March 2009.

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

### Newsletter

The CFW newsletter is offered in print and on our website in several languages. The aim of the CFW newsletter is to circulate information pertaining to CF and to create a platform for the exchange of information globally. The CFW newsletter is distributed to 62 countries and over 4,000 readers worldwide. CFW is expanding the reach of the newsletter and making it more accessible via the Internet. CFW produces the publication online in 11 languages including Spanish, French, Arabic, Hindi, Bulgarian, Georgian and Portuguese with positive results.

### Upcoming articles in 2009.....

- 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 Bojicic, 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 Macedonia there are still some necessary medications unavailable to patients such as CF vitamins and high quality enzymes. CFW used our network of pharmaceutical friends to start the process to get these medications to the patients in Macedonia. We are looking to see positive results in 2009 and hope to continue to support Macedonia in all their efforts for CF patients in the region.

### CF Palestine-Gaza Program

In 2007 and 2008 CFW accepted two new member countries from the Palestinian Territories.

CFW is working to develop CF care in Palestine Territories. We have formed new partnerships with local NGO's in Palestine to implement this program. The proposed program will provide the following; a specialized CF Care Center inside the Palestinian Red Crescent New Hospital in Hebron; a CF specialized team of trained caregivers to work in the new clinic; and an agreement with the Ministry of Health to cover the costs of care and medication for all patients. The proposed program will also help to spread awareness of CF in the Arab communities and act as a platform for a duplicate program in Gaza. By creating a long term solution to treating CF in Palestine we can help alleviate the continued reliance on Israel specialized CF medical services and international aid organizations to provide necessary treatment.

**Aim of the Program:** Optimal treatment provided for children born with CF in Palestine and Gaza.

**Objective:** To develop a CF Center and specialized team of care givers in Hebron with treatment and necessary medication supported by the Ministry of Health and Palestinian Red Crescent Hospital in Hebron.

**Secondary objectives:** To spread awareness and clinical care for the management of cystic fibrosis in Gaza and the Middle East.

# Collaboration

## Member Partnerships

CFW has 67 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**

	<i>Associate members</i>
Argentina	Armenia
Australia	Austria
Belgium	Azerbaijan Republic
Canada	Bahrain
Chile	Brazil
Czech Rep	Bulgaria
Denmark	Costa Rica
Ecuador	Colombia
France	Dominican Republic
Germany	Egypt
Greece	El Salvador
Hungary	Estonia
Iceland	Finland
Ireland	Palestine (WB)
Israel	Gaza
Latvia	Italy
Luxembourg	India
Macedonia	Jordan
Netherlands	Mexico
New Zealand	Moldova
Norway	Lebanon
Poland	Lithuania
Portugal	MATIO
Romania	Panama
Slovak Republic	Paraguay
Spain	Qatar
Sweden	Russia
Switzerland	Saudi Arabia
Turkey	South Africa
United Kingdom	Uruguay
United States	Venezuela

### **CF Worldwide welcomes new members in 2008.**



**Cystic Fibrosis Lebanon Association** Today, CFLB is aiding 50 different families of children with CF with proper medical care, counseling and hospitalization and approximates this number to substantially keep on increasing. As a member of "Cystic Fibrosis Worldwide", CFLB stands stronger everyday because it is united with similar associations all over the world and with that, a world of difference shall be made.



**Association of Cystic Fibrosis patients and parents of Moldova** This new member to CF Worldwide is working to improve quality of life and life expectancy for CF patients in Moldova. They recently held the first CF conference in Moldova and plan future similar activities with the aid and support of the CF Worldwide member network.



**Cystic Fibrosis Palestine – Gaza program** Seeks to provide comprehensive consultation, diagnosis, treatment and psychological and social rehabilitation to CF patients . They also seek to fund drugs not included in the basket of health services provided by the MOH. They also seek to provide nutritional food, necessary equipment and psychosocial support for families.

*"Our ambitions and our great but we can have success with the support of CF Worldwide and the international CF community. **(Let Us Live With Careful Attention Like Everybody Else)**" Ashraf Alshanti, President CF-PG*



**Lopen voor Lucht** is a Dutch organization setting a precedence of being our first non-country member as we recognize their efforts to raise funds exclusively for CFW and our mission. Marc Bastiaensen, his brother Patrick and some friends founded Lopen voor Lucht in 2007. Marc is a CF-patient himself. The organization wants to help CF-patients, especially in countries where treatment of the disease is at a poor level. They raise funds to support projects of CFW in these countries, and they also try to interest other CF-patients in Europe to start up fundraising for CFW. The first fundraising project was a walk made by Marc himself from his place of birth in The Netherlands to Rome in Italy. With this walk they raised more than 20.000 euros which were donated to CFW for a project in India. Website: [www.lopenvoorulucht.nl](http://www.lopenvoorulucht.nl)

## Support

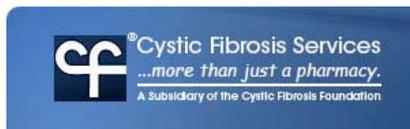
 Romedic of the Netherlands donated 55 refurbished PortaNeb-Sidestream nebulisers. This donation is valued at over €2500. Romedic has agreed to continue to supply nebulisers for CFW programs globally.



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 2008. Inspire will continue to look for ways to expand their support in 2009.



Roche Supported the CFW education program and Pocket Guide in 2008 and will look to further support programs in 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 19<sup>th</sup> 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.cfww.org](http://www.cfww.org) or contact [burke@cfww.org](mailto:burke@cfww.org).



### **The Building Bridges Campaign**

**BUILDING  
BRIDGES**



if we don't care, who will?

**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.



**The Building Bridges Charitable Art Gallery** is part of the CFW [“Building Bridges Campaign”](#) to bridge the gap between life expectancy and quality of life for CF patients globally. The artists featured in this on line gallery have donated their artwork in the hopes of contributing to the plight of thousands of CF patients who go untreated everyday. This gallery would not be possible without their generosity and we hope you enjoy their contributions. We invite you to browse our gallery and hope you will find something

of interest to purchase today. All proceeds of this art sale go directly to funding CFW projects in developing countries. Visit [www.cfww.org](http://www.cfww.org) to view our online art gallery.

### **Breath...A Precious Gift Campaign**

Cystic Fibrosis Worldwide started a new fundraising campaign in 2006. The “Breath...A Precious Gift” Campaign allows CFW supporters to purchase a donation cards in honor of a family member, friend, neighbor or co-worker. The elegantly designed card reads, “**A donation has been made in your honor to Cystic Fibrosis Worldwide. Your gift helps Cystic Fibrosis Patients around the world breathe easier.**” The honoree receives this verse on 4x4 card of white cardstock with a linen finish along with a white envelope.



Send this gift with your holiday cards. Stuff them in stockings. Include them with “Thank You” notes. Donation cards make great gifts for holidays, birthdays, anniversaries and other special occasions.

CFW donation cards cost 5 USD or 5 Euros each. Save by purchasing a bundle of 5 cards for 20 USD or 20 Euros. CFW accepts credit cards, check or money orders and wire transfers as payment. Orders mailed upon receipt of funds. Proceeds from this campaign fund CFW projects in developing countries and provide continued support of CFW. To learn more about CFW projects visit [www.cfww.org/projects/](http://www.cfww.org/projects/).

### **Flower Power Fundraising Event**



Cystic Fibrosis Worldwide is proud to participate in the Flower Power Fundraising Event for the second time. Flower Power Fundraising Inc, in Burlington, VT, USA, provides a unique way for people to beautify their gardens while contributing to our mission. They offer gorgeous, quality flower and plant bulbs, at a reasonable price and CFW receives 50% of the sales! People sign up, place their order, and then send the link on to friends and family, as we watch the event grow and the happiness bloom.

For more details, sign on to: [http://www.flowerpowerfundraising.com/campaign?campaign\\_id=184](http://www.flowerpowerfundraising.com/campaign?campaign_id=184)



**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)

**You can now follow CF Worldwide on:**



Twitter

<http://twitter.com/CFWorldwide>



Facebook

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



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

*"If we don't care, Who*  
*..."*

