



Cystic
Fibrosis
Worldwide



"...if we don't care who will?"

2006 ANNUAL REPORT

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 and other medications. 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 are born with cystic fibrosis, and it is one of the most common fatal inherited diseases. It is most prevalent among Europeans and Ashkenazi Jews; one in twenty-two people of European descent carry one gene for CF, making it the most common genetic disease among them. 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 is 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 may still lie 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 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.

CF is a multi-organ disease and children with CF need multidisciplinary team care in CF centres regularly. This multidisciplinary team should consist of a CF Nurse, Paediatric Pulmonologist, Pulmonologist, 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, is dedicated to improving quality of life and life expectancy for persons living with cystic fibrosis globally. CFW has 52 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.

CURRENT OPERATIONAL ENVIRONMENT

Target Population

The current target population is people with CF, families and medical/health professionals globally. A major effort is placed on reaching those suffering in countries that are currently without any resources to treat cystic fibrosis. Cystic Fibrosis Worldwide also provides services to people living with CF, family members and medical/health professionals in countries already having adequate care.

Key Areas of Focus

Cystic Fibrosis Worldwide works in a number of areas;

1. Capacity building for Cystic Fibrosis Associations and Cystic Fibrosis Worldwide members;
Through the global network formed by the many Cystic Fibrosis Worldwide member countries and partners, newly formed Cystic Fibrosis Associations can access an international support group. Resources that develop infrastructure for long term sustainability and growth are made available.
2. A platform for education and the exchange of information globally;
Through vehicles such as the Cystic Fibrosis Worldwide Website, Newsletter and Conferences, we reach people in over 70 countries.
3. Global voice for Cystic Fibrosis people with CF;
Cystic Fibrosis Worldwide actively lobby's for improved care and access to necessary medication for people with CF globally.

KEY ACTIVITY AREAS OF ACTIVITY

Key Activity 1 – Capacity Building for Cystic Fibrosis Associations globally

**Key Activity 2 – Educate parents, people living with cystic fibrosis and
Medical/Health Professionals in the treatment and
care of cystic fibrosis**

**Key Activity 3 – Provide local and international policy and political
support to Cystic Fibrosis Associations and people
living with cystic fibrosis**

**Key Activity 4 – Act as a Key Source of international cystic fibrosis
information and resources**

**Key Activity 5 – Support cystic fibrosis clinical care development with a
focus on developing countries**

Projects

REGIONAL SUPPORT

Cystic Fibrosis Europe (CFE)

In 2005 CF Worldwide supported the development of CF Europe, an organization established to target cystic fibrosis in Europe with a focus on Eastern European countries.



CF Worldwide works to support CF Europe by hosting their website within the CF Worldwide website, supported the CF Europe board meeting in Copenhagen, Denmark and used the CF Worldwide newsletter to distribute information about this new organization.

Visit CF Europe at www.cfww.org/cfe/

The Cystic Fibrosis South Asian Trust (CF-SAT)

CF Worldwide supported the Cystic Fibrosis South Asian Trust by funding the development of the organization's infrastructure and governance.

CF was thought to be extremely rare in South Asia. However published reports, reviews and comments indicate that CF is probably far more common in people of south asian origin than previously thought but is under diagnosed or missed in the majority of cases. The precise incidence of CF among these populations is unknown. Due to the widespread belief that CF does not occur in these populations, the disease is rarely suspected and even if it is the diagnosis is not confirmed due to the poor availability diagnostic equipment. The median age of diagnosis among Indian Americans is 12 months compared with 6 months among Caucasian American children and reflects a low index of suspicion for the disease even among Indians in western countries. These reports suggest that the diagnosis of CF is delayed in Indian children resulting in severe malnutrition. Early diagnosis and appropriate management of children with CF may improve their long term outcome.

Now many centres in India suspect and diagnose CF. However there is need to create awareness as well as training of manpower for improving diagnosis and management of CF patients in India.

Cystic fibrosis services were developed at the All India Institute of Medical Sciences (AIIMS), New Delhi India in 1999 with help from the International Cystic Fibrosis (Mucoviscidosis) Association. The aim of these services was to provide care to CF patients utilizing the limited available resources. Over the last 7 years services have been developed and now provide clinical care, genetic services and training of persons from other institutions. The services are being run by doctors (Dr S K Kabra and Dr Madhulika Faculty at AIIMS) with help from a trained nurse.

With diagnosis of more patients with CF from other parts of India and South Asia, there is need to establish a CF Association with a focus on developing care, spreading awareness and education and establishing access to necessary medications. CF Worldwide, through a grant from the Chiron Foundation, supported the development of By-Laws, Strategic Plan, and legally registered the

new Trust in Delhi, India. An office was established in Delhi and parents and persons with CF are now working to find permanent staff to manage and develop the new Trust.



EDUCATION

CFW/CFE Lay Seminar

Each year the European Cystic Fibrosis Society organizes the European CF Conference for health professionals and researchers. In the days prior to the conference special interest groups meet to discuss matters specific to their field of interest. CF Worldwide and CF Europe hold their Annual Meetings and organize a Lay Seminar Day for persons with CF, families, member country representatives and others. The aim of this Lay Seminar is to present an update on CF care and research, comprehensible for lay people, and to enhance the exchange of information and experiences between persons with CF and associations from around the world.

In 2006 CF Worldwide and CF Europe hosted over 80 parents, patients and caregivers in Copenhagen, Denmark. The agenda for the Lay Seminar consisted of; Update on CF Care and Research, Diana Bilton, UK, The neonatal screening model in France, Anne Munck; Newborn screening and the new Carrier Screening Program in Australia, Mitch Messer, A patient's point of view on screening, Erik Wendel, Denmark; CF and Nutrition, "Zoom on small", Eddy Robberecht, Belgium; Enhancing family strengths, Charlotte Dawson, UK and Physiotherapy, Louise Lannefors, Sweden. The seminar was received well by all who attended and feedback from attendees will be used to create future Lay Seminars.

CF parent/patient workshop in the Republic of Georgia

Cystic Fibrosis Worldwide (CFW) held a workshop at the new Georgian CF Centre in Tbilisi from November 13th - 15th to train parents and patients in CF nutrition and physiotherapy. This was the first CF workshop held in the former Soviet Republic and it offered a support system and health information to parents and patients.

Dr. Gabriela Sabolova, Nutritionist from Slovakia and Hughes Gauchez, a Physiotherapist from France, led the workshop attended by 32 patients and their parents. The workshop was planned and arranged by Katarina Stepankova, CFW board member. Gabriela also handed out nutritional handbooks for participants translated into Russian.

CFW arranged with the CF Pharmacy, a subsidiary of the CF Foundation, to purchase flutters for the workshop at wholesale cost, enabling CFW to provide a free flutter to every patient who attended the workshop in Georgia. In addition all patients will also receive a free nebuliser and thanks to the support of families from Slovakia all patients who attended the workshop received Enzymes. The enzyme donation was coordinated by Katarina Stepankova.



CF parent/patient workshop in Armenia

CF Worldwide was invited to Yerevan, Armenia to educate parents and patients as well as medical professionals about CF and nutritional care. Dr. Gabriela Sabolova, Nutritionist from Slovakia met with 10 CF patients and their parents. She offered advice on nutritional needs, proper diet and use of enzymes for CF patients and gave out nutritional handbooks translated into Russian. The Armenian Ministry of Health has already established a program for CF patients and they all receive free enzymes, antibiotics and clinical care. But there is little

knowledge of CF among medical professionals and no specialized CF clinics in the country.

In addition, we spoke to a group of medical professionals about CF and planned for future educational programs. CFW has recently received a project proposal from the Armenian CF Association and we look forward to working to improve CF care in Armenia.



Supporting the 1st Brazilian CF Conference

CFW was also able to support the CF community in Brazil by sponsoring the attendance of 2 allied health professionals to run short courses for nurses and physiotherapists at the 1st Brazilian CF Conference in Sao Paulo. The CFW President also attended to meet with representatives of the local CF community and to participate in the Conference.

Evaluating our Outcomes

Cystic Fibrosis Worldwide (CFW) and the All India Institute of Medical Sciences (AIIMS) will work in collaboration to evaluate project development for improved management of cystic fibrosis in South Asia. The full program will evaluate the capacity building project to improve quality of life and life expectancy in CF patients living in South Asia.

Program evaluations with a focus on outcomes have become increasingly important for nonprofits, and funders are demanding it more and more. The outcomes evaluation will help CFW, All India Institute of Medical Sciences (AIIMS) and the CF South Asian Trust (CF-SAT) decide if we are really conducting the right program activities to bring about the results we have verified to be

needed. Outcomes are benefits to clients who utilize the CF clinics, participate in the Epidemiology study and access the information and resources created by the CF-SAT. The evaluation will also include effects on families, the medical professionals treating the patients and the communities where people with CF live. Outcomes should not be confused with program outputs or services e.g. the number of clients who visit the clinic each month but instead focus on how the lives of those who do visit have changed. The staff operating the AIIMS CF Centre and the CF SAT will also benefit from the outcomes evaluation that will tease out and define program strengths and weaknesses.

GLOBAL VOICE FOR PEOPLE WITH CF

World Health Organization

Cystic Fibrosis Worldwide (CFW) and the World Health Organization Human Genetics Department (WHO HGD) have been working in official relations since CFW's inception in 2003. The main priorities of this partnership are having Pancreatic Enzymes listed on the WHO Model List of Essential Medicines, to develop a Global CF Registry and through evaluations of CFW projects, publish a manual on developing CF associations and implementing CF care in developing countries. An additional priority is to build a partnership with the European CF Society, CFW and WHO to conduct an Epidemiology study in South Asia determining carriers, number of patients and mutations. Cystic Fibrosis Worldwide has formed a committee to work in collaboration with WHO leaders and decisions makers. A three day work session at the WHO headquarters included reviewing and submitting our WHO Model List of Essential Medicines application and proposal, establishing the framework to begin the global CF registry and investigating resources to support continued evaluations and research.



The International Physiotherapy Group for CF (IPG/CF)

CF Worldwide supports this important international group by hosting the IPG/CF website within the CF Worldwide website and offers information about the IPG/CF in the CFW Newsletter. CFW also supported the Best Care Scholarship by managing applications and developing an online form that could be accessed readily by all interested applicants. CF Worldwide had the manual produced by IPG/CF and CFW, *Physiotherapy in the Treatment of CF*, translated into Spanish and Greek and now offers it on line in easy to download format. Visit the IPG/CF at www.cfww.org/IPG-CF/index.asp

Lobby the Government of Georgia to support patients

Though the Tbilisi CF clinic was completed in early 2006 we had not reached an agreement with the Georgian government to support CF patient's needs such as enzymes and salaries for medical professionals who treat the patients. Because of this, patients were not benefiting from the new clinic as much as we had hoped. During the a workshop held in November 2006, the Georgian Government sent a representative from the Health Ministry to announce to all families that CF would

now be covered under the Child Health and Welfare program, ensuring free necessary medications and treatment. We now look forward to a more favourable outcome for the patients and will be monitoring the progress closely.

Developing our Member Network

Cystic Fibrosis Worldwide and our 56 member countries work in collaboration to increase awareness, clinical care and to address the needs of families globally. In 2006 CF Worldwide and our members were able to directly assist individual needs of patients via donations of medication and necessary equipment as well as exchanging information among parents, patients and care providers. In the future we will work to continue to grow this network and assist our members in addressing specific needs of patients globally.

Supporting Medical Staff at All India Institute of Medical Sciences

Cystic Fibrosis Worldwide supported the development of a specialized CF care team to work at the CF Centre at the All India Institute of Medical Sciences (AIIMS). The team consists of Pulmonologists, Physiotherapist, Nurse and Nutritionist. Because AIIMS is a teaching hospital, this team is now offering training courses for medical professionals from India as well as Pakistan, Sri Lanka and Bangladesh. AIIMS is a government funded hospital and through this connection we are able to begin to lobby the Indian government to support people with CF by providing specialized Centres and to continue to train medical professionals in the treatment of cystic fibrosis.

Developing optimum treatment plans for persons with CF in Georgia

An important factor in creating long term positive outcomes for patients is to develop low budget optimal treatment plans that will address the needs of people with CF. During a recent pilot project to build a CF Centre in the Children's Central Hospital in Tbilisi, Georgia, CFW was able to develop an understanding of how to build CF care in an underprivileged country. Following the initial phase of the plan in Georgia we ran an Outcomes Evaluation which showed that while there were some benefits to having the local medical professionals travel to visit CF Centres in developed countries there was a need for local people to be trained in a way that would allow them to provide a service using the facilities that were available in their country of origin. There was more benefit gained by bringing in expert care givers to train people in the local area. This allowed us to provide a more comprehensive approach that is sustainable. We are able to reach and train local health professionals, provide basic courses for parents/patients in the local area and to meet and obtain support for CF care from health policy makers and officials. This approach has been successful as it shows a high level of commitment from CFW and all who are working in the project.

COMMUNICATION

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.

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 70,000 visitors monthly and we look forward to continuing to provide an international platform for the exchange of information.

FUNDRAISING

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.cfww.org or contact burke@cfww.org.



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.



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 to view our online art gallery.

Breathe...A Precious Gift Holiday Campaign

Cystic Fibrosis Worldwide started a new fundraising campaign in 2006. The "Breath...A Precious Gift" Holiday 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 gifts 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/.

**Lopen Voor Lucht (Walking for Air):
From Nispen to Rome**

Planning took place in 2006 for a project being run by Marc Bastiaensen who aims to walk from birthplace of Nispen, a small village in the south of The Netherlands,



to Rome. His journey will take him through Belgium, Luxemburg, Germany, and Switzerland before arriving in Italy. He aims to raise 100,000 Euro for Cystic Fibrosis Worldwide (CFW) and estimates that the walk will take four months. Many people have accomplished this walk - but this one is different. Marc is a 42 year old with cystic fibrosis.



Marc says - "I want to be a positive example and I hope that my walk can stimulate these patients to try a little bit harder and to show that you can reach a higher

quality level of life"

CFW Invited to Join Million Artists Project



In 2006 Cystic Fibrosis Worldwide was invited to join Million Artists, an international fund-raising project for medical charities. The website aims to break the Guinness Book of World Records' largest piece of collaborative abstract art record while collecting donations for non-profits. Each donor selects a pixel of color to become part of a huge abstract "painting."



Computer programmers Eugene Pik and Anthony Barker created the technology that allows an image to be created from the random pixels. Users go to the website, make a

donation through Paypal, and choose the color of their pixel. The computer randomly assigns the pixel a location, and an image is slowly created.

The current world record, set by Jim Campbell in 1998, used 25,297 people to paint a picture. "I wanted to use Internet and computer technology to invite a million artists to break that record," Pik said.

The site is translated in 25+ languages, making it easy for anyone to become a part of the project. Many of the donors are artists themselves who wanted to support the project. A randomly selected list displays donors and links to their homepages. Money collected is sent to a charity of the donor's choice.

Tim Seaward, an artist-donor from Great Britain, commented that: "I will place a link on my index page, and because I am a member of a local Arts Group, I shall share the news with them... and tell anyone else I can! This is going to be amazing!!"

To find out more about this exciting project, please visit <http://www.millionartists.com> and donate today.



Reflections on Children Exhibition in Genoa, Italy

September 2nd – September 16th, 2006
by Natalie Saiph Massone (Artist)

Natalie Saiph Massone, an artist from Italy worked to support CF Worldwide and our many projects by holding an Art Exhibition in September 2006.

The *Children* Charitable Art Exhibition at the Berio's Events Showroom in Genoa, Italy was held for two weeks.

The event was carefully planned a year in advance and the results are a mixture of the good and the unexpected with the typical dissatisfaction of the "artist" herself. In Genoa, charitable art shows are rare. However, this event caught the attention of the media, which was a pleasant surprise. The local newspapers, the *Il Secolo XIX* and the *Il Mercantile* gave us constant visibility with some articles that included news on the "exhibitions list" almost every day. The local television stations, "PrimoCanale" and "Telecittà", also covered the event.

About 200 visitors attended the show over the course of two weeks. Some works sold and we are confident that more will sell in CFW's On-line Charitable Art Gallery, where the exhibition will be permanent (See <http://www.cfw.org/store/gallerychildren>).

Corporate Sponsors



CFW received a 65,000USD grant from the Chiron Foundation to support a program that will attempt to raise the life expectancy of CF patients in India. "The Chiron Foundation is an independent, non-profit organization committed to improving lives through better health care, empowering lives through better education and enriching lives through better communities."

Romedic of the Netherlands donated 50 refurbished PortaNeb-Sidestream nebulisers, which will be used in the CF Clinic in Tbilisi, Georgia. **ROMEDIC B.V.** This donation is valued at over €3000. Romedic has agreed to continue to supply nebulisers for CFW programs globally.

ICCO and Wilde Ganzen awarded 93,000USD to begin construction on the Georgian National CF Center. Both are Netherlands inter-church organizations for development co-funding.



Van Aarle De Laat Health Sector Construction Management Services donated office facilities and secretarial support to CFW. Van Aarle De Laat will

continue to support our distractive costs for the Netherlands CFW office through 2007.



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's contributions have made it possible for the CFW to carry out our mission of creating a platform for the exchange of information worldwide.

Counterpart International continues to provide CFW with shipments of equipment for projects in the Caucasus and Eastern Europe. Shipments contain things such as basic furnishings and supplies, laboratory and physiotherapy equipment. This service is provided as an in-kind donation and is valued at \$7,000 per shipment. Visit www.counterpart.org for more information on this project partner.

Project C.U.R.E. has delivered donated medical supplies and equipment to the most desperately ill and needy people in more than 100 countries around the world. By collaborating with Project C.U.R.E, CFW will decrease our volunteer and staff requirements for acquiring and centralizing donated medical equipment and supplies from all over the US.

Private Sponsors



Alternative Gifts International raised 18,000 USD for patients in Georgia. **The global mission of AGI is to send** authentic, life-giving gifts to a needy world - gifts that build a partnership with people in crisis and that protect and preserve the earth's endangered environment - to nourish and sustain a more equitable and peaceful global community.

AGI is a non-profit, interfaith agency. AGI provides education for people of all ages about global needs and raises funds each year in its Alternative Gift Markets and from individual donors to respond to those needs. Designated grants then are sent to the established international projects of several reputable non-profit agencies for relief and development.

Member Partnerships

Cystic Fibrosis worldwide members are a continuous support for the many activities carried out by CFW globally. In 2006 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.

CYSTIC FIBROSIS WORLDWIDE, INC.

Statements of Financial Position

December 31, 2006 and 2005

<u>Assets</u>	<u>2006</u>	<u>2005</u>
Current assets:		
Cash and cash equivalents	\$ 60,819	\$100,005
Accounts receivable - membership dues	-	530
Accounts receivable - other	9,307	-
Inventory	10,598	9,830
Prepaid expenses	<u>-</u>	<u>11,687</u>
Total current assets	<u>80,724</u>	<u>122,052</u>
Property and equipment		
Computer equipment	2,544	1,189
Less: accumulated depreciation	<u>730</u>	<u>357</u>
Net property and equipment	<u>1,814</u>	<u>832</u>
Other assets:		
Organization costs, net of accumulated amortization of \$4,361 and \$3,199 in 2006 and 2005, respectively	<u>1,447</u>	<u>2,609</u>
	<u>\$ 83,985</u>	<u>\$125,493</u>
 <u>Liabilities and Net Assets</u>		
Current liabilities:		
Accrued expenses	\$ 11,957	\$ 800
Accrued payroll and related expenses	<u>15,716</u>	<u>-</u>
Total current liabilities	<u>27,673</u>	<u>800</u>
Net assets:		
Unrestricted net assets	12,361	54,693
Temporarily restricted net assets	<u>43,951</u>	<u>70,000</u>
	<u>56,312</u>	<u>124,693</u>
Total net assets	<u>\$ 83,985</u>	<u>\$125,493</u>

CYSTIC FIBROSIS WORLDWIDE, INC.

Statement of Activities

For the year ended December 31, 2006

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Support and revenues:			
Program Service Revenue:			
Membership dues	\$ 64,447	\$ -	\$ 64,447
Subscriptions income	<u>30</u>	<u>-</u>	<u>30</u>
Total program service revenue	<u>\$ 64,447</u>	<u>-</u>	<u>64,477</u>
Public support:			
Gifts, grants and contributions	27,144	64,290	91,434
Fund raising activities, net of direct costs	1,923	-	1,923
In-kind goods and services	<u>2,450</u>	<u>17,510</u>	<u>19,960</u>
Total public support	<u>31,517</u>	<u>81,800</u>	<u>113,317</u>
Other revenues:			
Other income	<u>531</u>	<u>-</u>	<u>531</u>
Total other revenues	<u>531</u>	<u>-</u>	<u>531</u>
Net assets released from restriction:			
Satisfaction of donor restrictions	<u>107,849</u>	<u>(107,849)</u>	<u>-</u>
Total support and revenues	<u>204,374</u>	<u>(26,049)</u>	<u>178,325</u>
Functional expenses:			
Program services	185,639	-	185,639
Administrative	45,327	-	45,327
Fund raising	<u>15,740</u>	<u>-</u>	<u>15,740</u>
Total functional expenses	<u>246,706</u>	<u>-</u>	<u>246,706</u>
Change in net assets before other changes	(42,332)	(26,049)	(68,381)
Net assets, beginning of year	<u>54,693</u>	<u>70,000</u>	<u>124,693</u>
Net assets, end of year	<u>\$ (12,361)</u>	<u>\$ 43,951</u>	<u>\$ 56,312</u>

