

CF Organization

Request to  
TARGET NAME

For general operating support

Amount:

Date

## **Organization Information**

### *History*

\_\_\_\_\_ is a non-profit organization located in \_\_\_\_ and \_\_\_\_\_. \_\_\_\_\_ is dedicated to improving quality of life and life expectancy for people living with Cystic Fibrosis (CF), a genetic life-threatening disease. Since inception in 20\_\_, \_\_\_\_\_ has used a variety of programs to aid the CF community in \_\_\_\_\_, across the US, and throughout the world. With \_\_ member countries, \_\_\_\_\_ primary function is to spread information about the disease among scientists, medical professionals, caregivers, patients, and families and to act as a platform for the international exchange of information. In addition, \_\_\_\_\_ helps member countries, both developed and developing, by providing capacity-building tools in areas of governing, operating, and fundraising. For instance, \_\_\_\_\_ supports member countries by helping them develop CF Centers and lobbying for government support.

### *Mission and Goals*

\_\_\_\_\_ promotes access to knowledge and appropriate care for people living with cystic fibrosis and among medical/health professionals and governments worldwide. The primary goal is to improve the lives of people born with cystic fibrosis. To achieve this mission, \_\_\_\_\_ has three key areas of focus: capacity building for Cystic Fibrosis Associations and Cystic Fibrosis Worldwide members, a platform for education and the global exchange of information, and a global voice for people with cystic fibrosis.

### *Programs and Activities*

In accordance with \_\_\_\_\_ mission and goals, \_\_\_\_\_ participates in the following programs and activities:

#### International \_\_\_\_\_ Data Resource:

Although national and regional CF data registries publish results regularly, usually annually, few people know about the available registry information and where it can be found. Potential users range from those with a casual interest to the CF community to important external stakeholders such as national and international governments. Interests range from descriptive information to more complex analytical requirements of CF treatment teams. The establishment of a CF data resource allows for the comparison of patient data and international benchmarks as well as aids in future research.

#### \_\_\_\_\_ Education Program:

\_\_\_\_\_ website, [www.\\_\\_\\_\\_\\_.org](http://www._____.org), currently offers educational podcasts. This year, \_\_\_\_\_ is improving the site by adding online educational courses, reading materials, and learning tools. This information will be available in over 15 different languages. \_\_\_\_\_ also hosts annual conferences in areas where little information is known about the disease. In addition to making the website more

educational, \_\_\_\_\_ is revamping the website to make it more interactive, up-to-date, and user-friendly. For instance, the new website will feature RSS feeds, live forums, and updated content. Like the educational materials, these features will be available in multiple languages.

\_\_\_\_ Pocket Guide in the Management of Cystic Fibrosis:

The \_\_\_\_\_ Educational CF Treatment and Management Guide will be an educational resource that provides an overview of content from \_\_\_\_\_ educational conferences and seminars. The guide will be designed for clinicians involved in the management of patients with cystic fibrosis as well as patients and families coping with CF.

Member Capacity-Building Program:

\_\_\_\_\_ aims to raise \$\_\_\_\_\_ each year for the capacity-building program. This money will be given to member countries for the purchase of clinical equipment, patient equipment, and education. For instance, grants will be provided to \_\_\_\_\_ members to attend a CF course run by \_\_\_\_\_, Dr. \_\_\_\_\_. (More information about this course can be found at [www.\\_\\_\\_\\_\\_](http://www._____).) Grants will also be given to members to attend the annual business meeting and ECFC.

### ***Results and Qualifications***

Due to the top specialist working on \_\_\_\_\_ educational programs and the highly educated and experienced board members governing \_\_\_\_\_, \_\_\_\_\_ has been able to bring sustainable change to many CF populations via target projects aimed at increasing awareness, gaining access to necessary medication, and creating specialized CF Centers and specialized CF care teams. \_\_\_\_\_ major accomplishments include:

- Getting Pancreatic Enzymes listed on the World Health Organization (WHO) Pediatric List of Necessary Drugs
- Publishing the Molecular Genetic Epidemiology of Cystic Fibrosis Report in partnership with the World Health Organization
- Establishing the Cystic Fibrosis Worldwide Education Program
- Hosting a variety of successful conferences and workshops worldwide
- Establishing a Cystic Fibrosis Specialized Clinic in Yerevan, Armenia
- Establishing the Cystic Fibrosis South Asian Trust and CF Center at AIIMS in New Delhi, India
- Delivering emergency medication to patients with cystic fibrosis in Gaza after the recent Gaza War

### ***Relationships with Other Organizations***

\_\_\_\_\_ supports \_\_\_\_\_ member associations from both developed countries and countries that lack adequate resources to support CF patients. The World Health Organization, international CF working groups, and numerous respected CF specialists complete the network that is needed to support \_\_\_\_\_ mission. \_\_\_\_\_ offers a platform for the international exchange of information and is

the only global CF organization in existence. In the United States, \_\_\_\_\_ works in partnership with the CF Foundation, US CF Adults Organization, and Cystic Fibrosis Research Inc. to spread news and information to the international CF community.

### ***Board Members, Paid Staff, and Volunteers***

\_\_\_\_\_ is governed by a #-person volunteer board of directors. There are # full-time paid staff members, the executive director and the assistant director. \_\_\_\_\_ has over # international volunteer translators. Their work allows \_\_\_\_\_ to offer materials in a variety of languages. Volunteers also make up \_\_\_\_\_ education team, which consists of top CF specialist from around the world.

### **Purpose of Grant**

#### ***Situation***

Prior to the establishment of \_\_\_\_\_, there was no main source of international news and information that met the needs of the entire CF community. Many people did not understand that CF exists all over the world with varying levels of care in different regions. Due to language barriers, the minority CF populations in the US often went without necessary information. European CF news was delivered in multiple languages, but it fell short of informing beyond certain countries' borders. CF Organizations existed globally, but there was little to no communication between them and they were not learning from each other. There is still a large gap between CF specialists and caregivers in the west and the rest of the world. More needs to be done to address this problem; otherwise, patients suffer the consequences. International awareness of CF is poor outside of western countries, and many governments do not support CF patients. By continuing to develop programs that spread information and awareness about CF, \_\_\_\_\_ can end the ignorance that has decreased the life expectancy of CF patients globally and offer an equal opportunity for all born with this life-threatening disease here in Massachusetts and around the world.

\_\_\_\_\_ is a member-supported organization. Traditionally, \_\_\_\_\_ annual member dues covered operational expenses while corporate and private sector donations directly supported programs. However, the recent global economic situation has caused many members to dramatically reduce support. In the past two years, \_\_\_\_\_ has lost % of operational support from members, but at the same time, has increased membership by %. Because member dues are no longer reliable, \_\_\_\_\_ has made two specific changes to ensure the fiscal health of the organization. First, \_\_\_\_\_ has developed new and innovative education projects aimed at increasing members' fundraising and structural viability. Second, \_\_\_\_\_ has brought new fundraising staff onboard. With new staff support, \_\_\_\_\_ will be able to explore new funding opportunities in the US and internationally. Along with \_\_\_\_\_ many programs, new fundraising initiatives will be a major focus for \_\_\_\_\_ in 2011 and forward.

#### ***Funding Request***

\_\_\_ respectfully requests \$\_\_\_\_\_ from \_\_\_\_\_ to support general operating expenses that will aid in the treatment and education of cystic fibrosis. This funding will allow \_\_\_ to improve the lives of people who live with CF worldwide and to provide information to caregivers, health and medical professionals, patients, and families.

### ***Anticipated Outcomes***

\_\_\_ aims to improve the lives of those who survive from cystic fibrosis and to educate caregivers, health and medical professionals, patients, and families. The programs at \_\_\_ will have the following important impacts:

- Improve quality of life for people who suffer from CF worldwide
- Improve life expectancy for people who suffer from CF worldwide
- Provide access to information to people who suffer from CF worldwide
- Provide access to appropriate treatment for people who suffer from CF worldwide
- Educate caregivers, health and medical professionals, patients, and families
- Provide a platform for the international exchange of information
- Support regional partners who fall within the parameters of the CFW mission
- Publish International Standards of Care for CF
- Educate regions who lack information on CF by hosting annual conferences
- Develop an international CF data network that allows for comparison of patient data and benchmarks and aids in future research
- Increase the capacity of member countries
- Develop an international news source that uses RSS feeds, live forums, and social media

### **Evaluation**

\_\_\_ runs extensive outcome evaluations for all programs and continues to closely monitor past programs to determine if objectives have been met long-term. By evaluating program strengths and weaknesses, \_\_\_ is able to shift the program logic model. For instance, by analyzing web user data, \_\_\_ understands that the Spanish and Portuguese speaking CF community in Massachusetts frequently visits the \_\_\_ website. This occurs because there are limited resources available in their native languages. Therefore, \_\_\_ has been steadily adding more information in Spanish and Portuguese to the website. \_\_\_ employs the United Way Outcome Evaluation Model for all projects including the organization's internal operations. To assess outcomes, \_\_\_ utilizes online forms, email questionnaires, and live interviews. Member organizations, \_\_\_ Board of Directors, Medical and Allied Health Advisors, and core staff review outcomes. Programs are frequently adjusted in accordance to evaluation data.

### **Sustainability**

In response to unreliable member dues, \_\_\_ has developed a strategic business and fundraising plan for 2011-2012. With a new emphasis on fundraising, CFW has hired new fundraising staff. CFW currently has the following sources of funding:

## Member Dues

Income 2009: \$

Proposed income 2010: \$

## Grants (restricted and unrestricted)

Income 2009: \$

Proposed Income 2010: \$

## Public Donations

Income 2009: \$

Proposed income 2010: \$

For 2011-2012, CFW has set the following funding goals:

- Raise \$in 2011
- Use the 5 for 5 campaign, email subscribers, public forums, and major donors to raise the funds needed for the Member Capacity-Building Program. This strategy should raise \$ per year. Other donations not needed for operational or funding expenses will be added to this fund.
- Implement a social media campaign using Facebook and Causes, online giving sites, and partner causes. This campaign should inspire general public donation that can be used for operational expenses and project costs. \_\_\_ should raise a minimum of \$ in 2011 from a social media campaign.
- Submit 5 online grant applications monthly (maximum request \$ )
- Submit 1 program grant to corporation or private foundation or government funding source monthly (minimum request \$)
- Raise a minimum of \$from grants
- Increase corporate and large donor income.
- Raise \$ from corporation
- Ensure \$ in member dues for 2011

## **Budget**

## **Appendix**

### **501(c)(3) Letter**

### **Board Member List**

### **Medical Advisor List**

### **20-- Annual Report**

