The Marketing Opportunity

[Organization name] will host the first[event name] on[date]. To manage and promote the event, ____ will create a website dedicated to the event and employ a large marketing campaign. ____ is currently looking for sponsors to support the website, administrative costs, and marketing campaign. In return, sponsors will be part of an international media campaign that will result in global exposure for their products and research. For instance, sponsors will be highlighted on the website, marketing materials, and subscriber communications. This event will reach a wide audience, including people with CF and government officials, and the website will have significant traffic each day.

What is [event name]?

With the support of the _____ and global contacts, ____ will host the first _____ on [date]. The main goal is to harness the power of the ____ network to internationally spread information about cystic fibrosis, which will improve the lives of people born with CF.
[Event date] will become a globally acknowledged [event name], bringing people together from around the world to host events in their countries, raise funds to support their local CF organization, and spread awareness and share information about cystic fibrosis.

This event will bring the international CF community together to help fight for better standards of care, equal access to care and necessary medication and equipment, and support for research for a cure. Cystic fibrosis, a genetic disease, is the most common life-threatening disease in the Caucasian population. It is estimated that there are between 700,000 and 100,000 people with CF worldwide, but it is difficult to state an accurate figure as people with CF in countries without developed healthcare may die before diagnosis. CF clogs the internal organs (especially the lungs and digestive tract) with thick sticky mucus, which makes it very difficult to breathe and digest food. Rigorous daily treatment is required to keep people healthy. This includes hours of physiotherapy and taking inhaled and intravenous drugs as well as enzyme pills to digest food.

In the US and UK, average life expectancy is 35 to 40 years old. In Macedonia, however, life expectancy is only 12 to 15. The [event name] will bring awareness to the differences in standards of care, diagnosis, and access to medical care and equipment. While the event will educate people on the disease, its main goal is bring light to the global care situation. This includes life expectancy and available medication, equipment, and trained CF professionals. During the event, CFW will publish a report on how different countries' health budgets cover people with CF such as what medications are reimbursed or provided free, what clinical care is free, and what the plans are for future development of care. This report will act as a lobby tool to push the governments to respond, resulting in increased life expectancy and improved access to medical care, medicine, and equipment.

What is the [event name] Declaration?

The _____ Declaration will be signed by thousands of people all over the world who specialize in CF care as well as all CFW member country organizations. The declaration will also be added to the ____ website as a petition, and CFW will ask people who visit the website to sign the declaration, adding public support to the document. All member countries will have access to the declaration, which will be translated into the local language of every participating member country. The declaration will become a lobbying tool and established standard to help bring equality of care and access to necessary medication and equipment to all persons born with CF. It will include the following information:

- Facts about CF
- Facts about global life expectancy and quality of care comparisons
- Facts about necessary medication availability comparisons
- Facts about necessary equipment availability comparisons
- Facts about necessary treatment facilities/standards of care comparisons
- Facts about necessary CF specialized care teams
- Facts about the need to find a cure and continue to develop research

Why is This Declaration Important?

This document is critical to creating change for the CF community because it will…

- Explain the need for governments and health officials to acknowledge CF, follow recommended standards of care, and support research.
- Help to develop laws to protect patients, provide adequate funding to care for patients in all countries, and support research.

Who will Participate in [event name]?

All 67 CFW members will be asked to participate. CFW will also accept individuals who are supporting CFW or CFW member countries that do not have an organized CF association.

Why is [event name] Important?

__________ benefits CF patients, CFW, CFW member countries, and sponsors.

Benefits for People with CF

- Increased awareness and public understanding of CF globally
- Informed public health officials locally and internationally
- Education and sharing of information
- Fundraising campaigns aiding local and international patient organizations

Benefits for CFW

- Increased international exposure for CFW and its programs
- Opportunity to create an international awareness campaign
- Ability to education and share information globally
- Opportunity to develop an international pubic fundraising campaign (CFW will receive a percentage of funds raised by each country to cover expenses related to website, media, event tools, merchandise, etc.)
- Opportunity to host a CFW event with the CFW sister office in Izmir, Turkey
- Merchandise sales

Benefits for CFW Member Countries

- Global exposure for the programs and organization
- Aid in developing an international awareness campaign
- Education and sharing of information
- Opportunity to develop a local pubic fundraising campaign
- Merchandise to sell for fundraising
- Opportunity to raise funds and awareness locally and internationally
- A global standards of care declaration
- Local awareness and education campaign
- Global recognition for the local member organization

Benefits for Sponsors/Donors

- Global exposure for sponsor product and research
- Opportunity to aid in developing an international awareness campaign
- Opportunity to support CF education and sharing of information
- Ability to aid in increasing diagnosis through awareness
- Participation and recognition in international media
- Opportunity to support local organizations and CFW
- Opportunity to support patients and medical professionals

How Will This Event Be Promoted and Marketed?

CFW has created a marketing concept that consists of two major components. First, CFW will host a website dedicated to the __________. Second, CFW will create a declaration that joins people together globally to fight for people with CF. CFW members will have the opportunity to use the ___________ website and date to host local events to raise funds, spread awareness, and offer education. The _____ website will provide tools that will aid in developing events and encouraging local participants. It will also offer a platform for CF member countries to bring international public awareness to their programs supported by the local member organization.

The website will be used for the following activities:

- Collect email addresses, names and basic information from visitors. This will create a database that CFW will use to market the events and ask for donations.

- Offer a form that members can fill in providing details about CF in their country. This information will be collected and displayed on the website. Charts will be offered for quick reference include figures such as how many people have been diagnosed with CF, what medicines they take now, what medicines and equipment are available, and what is covered by government or insurance. The information will help determine future needs and showcase disparities.
- Send out biweekly updates and information to all subscribers. These updated will include information about the event sponsors.
- Display sponsors information such as logos, product information, and website links.
- Allow persons around the world to create individual event pages on the site so they can raise money for their organization of choice.
- List member countries so donators can choice with organization they wish to support.
- Allow members to create an event page to showcase their organization and events.
- Showcase information about CF and the differences between standards of care, and access to care. For instance, in the US life expectancy for a person with CF is 35 to 40; in Macedonia, the life expectancy is 12 to 15.
- Display news and daily updates regarding upcoming events and funds raised.
- Allow each country to post their fundraising goals, current progress, and fundraising plans.
- Allow each country to post details about their programs and organizations.
- Distribute press releases using the emailing system and database.
- Include Facebook app to help spread awareness about the event and to encourage volunteers to host events.
- Share the fundraising tool kit which will include posters, event ideas, instructions for getting the media involved, etc.
- Highlight the top donors for each country and the top three sponsors.
- Share a press tool kit to help people get their event and programs in the news.

CFW will also be responsible for global public awareness by creating a media campaign to spread information about member country events and programs being funded in countries around the world. The campaign will work as follows:

- Each time a sponsor supports CFW, a press release will be sent out through PRWEB and other CFW press resources, announcing support, sponsor product, and the Worldwide CF Day.
- CFW will use the CFW E-News to again announce support, events, member information, etc. Existing subscribers will be asked to sign the pledge/declaration and to donate to a member country or CFW. They will also be asked to volunteer and host events to spread awareness and raise funds.
- A biweekly email will be sent to all people who register on the Worldwide CF Day website. The email will provide details about events, sponsor information, etc., and they will be asked to support a country of their choice or CFW.
- Banners, posters and other marketing materials will be designed and made available free to all participants. Sponsor information will be included on these marketing tools.

- CFW will host a booth at the Euro CF Conference (ECFC) and North American CF Conference (NACFC) in 2012, 2013, and every year thereafter as this will be an annual event. This booth will advertise the Worldwide CF Day, website and sponsor support. CFW will ask people to give their contact details and add them to the database
- •The website will generate individual thank you letters automatically. One letter will go out at the time of the donation to thank the donor and ask them to volunteer or donate again. Thereafter, each donor will be sent periodic thank you letters with updates on how their money was spent and asking them to get friends and family to donate or volunteer.
- The declaration will collect names and emails through the pledge option. Once they pledge, a series of emails will be sent showing number of signatures. These emails will include country news or information, new sponsor details, and requests to donate or run an event.
- Pins, T-shirts and wrist bands will be made to spread awareness and help countries raise funds. This will be managed by CFW.
- A logo will be designed specific for the day.
- Flyers and post cards will be created to include updated news and information and will be downloadable from the website. CFW will also have printed copies.
- A press kit and event tool kit will be made available through links on emailed marketing materials and printed materials to make it easy for people to find useful tools to run events or encourage people to donate. Press kits will include sponsor information.
- CFW will create a Facebook, LinkedIn and Twitter account for the day. Sponsor information will be posted along with information about the Day events, members, etc. Notices and updates will be sent to all people who join these social media network resources.

What Does CFW Need to Make This Event Happen?

To ensure a successful Worldwide CF Day, CFW needs help from sponsors and donors as well member countries. Here is a list of the event needs.

- Support for the website
- Support for the campaign
- Support for the Worldwide CF Day Event in Karsiyaka, Turkey
- Development of tools and tool kit for web and members
- Development of merchandise such as T-shirts, pins, etc.
- Development of web content
- Development of website
- Development of video for CFW Campaign*
- Development of an international media campaign
- Support and cooperation of all CFW members
- Planning and development of local CFW Event in Turkey
- A key spokesperson to represent CF patients and help spread awareness

* A short video will be created with the CFW president explaining the importance of government and asking people to sign the declaration and join in events around the globe. The video will close with people with CF being introducing themselves and briefly sharing their story.

Who is CF Worldwide?

Cystic Fibrosis Worldwide (CFW) is a non-profit organization located in Massachusetts and Turkey. CFW 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 2002, CFW has used a variety of programs to aid the CF community in the US and throughout the world. With 67 member countries, CFW's 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, CFW helps member countries, both developed and developing, by providing capacity-building tools in areas of governing, operating, and fundraising. For instance, CFW supports member countries by helping them develop CF Centers and lobbying for government support.

CFW Mission and Goals

Cystic Fibrosis Worldwide promotes access to knowledge and appropriate care for people living with cystic fibrosis and among medical and allied health professionals and governments worldwide. The primary goal is to improve the lives of people born with cystic fibrosis. To achieve this mission, CFW 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.

Additional Information

Project Coordinators:
Cystic Fibrosis Worldwide
Christine Noke, Executive Director
CFW Staff

CFW Contac Information:
Email: cnoke@cfww.org
Phone: 1-508-762-4232

Medical Advisors:
Dr. Harry Heijerman
Ian Belfour Lynn
Dr Steven Conway
Dr Anne Munck
Sue Wolfe
Sue Madge
Louise Lannefors

Technical Advisor
Cem Sences

Marketing Committee
Christine Noke
Mitch Messer
Mike Beckers
Terry Stewart
Harry Heijerman
CFW Staff

Organizing committee:
CFW Staff, Board of Directors, and Education Team

Coordinating center: CFW office in Izmir, Turkey