

Cystic Fibrosis Worldwide
210 Park Avenue #267
Worcester, MA 01609
(508) 762-4232
www.cfw.org

Company Name
Address
Number

Dear [],

We need your help! In collaboration with Cystic Fibrosis (CF) Europe and the European CF Society, Cystic Fibrosis Worldwide (CFW) is hosting two days of meetings at an upcoming conference that will benefit CF patients, CF organizations, and medical professionals. With your support, CFW can improve the lives of CF patients.

An estimated 700,000 to 100,000 people worldwide suffer from cystic fibrosis (CF), a genetic life-threatening disease that clogs the internal organs, especially the lungs and digestive track. In the US and UK, life expectancy for CF patients is 35 to 40 years old. In other countries, however, this disease is taking the lives of young children. For instance, in Macedonia, the life expectancy is only 12 to 15 years old. All CF patients, regardless of their country of residence, deserve access to appropriate care and medical equipment and improved quality of life.

Cystic Fibrosis Worldwide strives to end this injustice by educating medical and allied healthcare professionals as well as governments around the world. The key to change is knowledge, so CFW uses innovative tools such as the CFW website and educational podcasts to spread information to those who can change the lives of CF patients as well as to families and patients dealing with CF. In addition, CFW helps other CF organizations raise funds and awareness to help treat, diagnosis, and one day cure CF. CFW currently supports over 65 member countries around the world.

In Dublin, Ireland this June, CFW will continue this mission by participating in a joint conference with CF Europe and the European CF Society. During the event, which takes place June 5th through 9th, CFW will host two days of meetings that will educate medical professionals as well as member countries. For instance, Barbara Floersch, director of The Grantsmanship Center, will present a grant writing workshop that will teach member countries how to research, write, and submit paper and online grants. This skill will significantly improve organization sustainability and fundraising, which will ultimately result in better care and quality of life for CF patients. In addition, the conference will feature lectures such as “Impacting on Health Policy to Improve Access to Care in CF” by Anil Mehta and Karleen De Rijcke and “The Strength of Working Together” by Stuart Elborn and Karleen De Rijcke. As President of the European CF Society, Stuart Elborn is one of the most prominent members in the CF community. To learn more about Stuart and the other featured speakers, please review the attached material that details the conference agenda and presenters.

Every year, CFW and CF Europe hold an annual meeting of members. This meeting brings together representatives from countries and important decision makers such as CEOs and medical advisors. While the meeting discusses concerns, issues, and plans related to all countries across the globe, there is a focus on European countries. The annual meeting of members will take place at the conference in Dublin.

To make this event a success and improve the lives of all of those who suffer from CF, Cystic Fibrosis Worldwide needs your help. CFW is currently seeking sponsors to help fund the costs of the two-day event, which includes the venue, food, technical equipment, and printed materials. Attached is a budget illustrating how the funds will be used. By donating \$3,000 Euro, you will not only improve the lives of CF patients but you will receive significant exposure that will benefit your company. Sponsors can expect the following benefits:

- Opportunity to provide handouts about your products to attendees
- Your logo and company information included on all CFW handouts and postings
- Your logo and company information displayed at the CFW booth, including conference banner, flyers, and advertisement materials
- Featured in a press release that will be sent out to various sources prior to the conference to acknowledge all sponsors and presenters

Sponsoring this event will result in global exposure for your company and products. In addition, your contribution will have a positive impact on the lives of countless CF patients. To sponsor this event, please contact me at cnoke@cfww.org or (508) 762-4232. We sincerely appreciate for your support.

Sincerely,

Christine Noke

CFW Agenda for Conference in Dublin, Ireland

June 5, 2012

- 9:00 CFW Annual Meeting of the Members
- 11:00 Coffee Break
- 11:15 **Worldwide CF Day Launch**
- 12:30 Lunch, Welcome
- 13:30 CFE/CFW Member Workshop, Chair: Christine Noke
- How to Build or Fix Your Nonprofit Facebook Page - Critical Mistakes to Avoid*** - *John Haydon*
- How To Correctly Use Facebook Insights - 5 Critical Metrics You Need To Know **** - *John Haydon*
- 14:30 Coffee Break
- 15:00 CFE - AGM General Assembly
- 19:00 CF Worldwide and CF Europe Welcome Reception for Members
(Sponsors of the days event will be present.)

Workshop Overview

**How to Build or Fix Your Nonprofit Facebook Page - Critical Mistakes to Avoid*

Author: John Haydon

For nonprofits, the power of Facebook offers an opportunity to reach people interested in their cause. With 800 million users worldwide, it is a priceless tool for nonprofit organizations. Unfortunately, many nonprofits have unknowingly set up their Facebook Page incorrectly, which impedes their ability to get the results they want. For instance, you'd be amazed at how many nonprofits have the wrong page type and category!

For many people, Facebook is sometimes very difficult to understand. This video will show viewers how to avoid critical mistakes when setting up a Facebook Page as well as fix the mistakes they may already have. Viewers will learn how to select the right page type and category, the best size for their main image, how to configure their wall, and how to

automatically block offensive comments. They'll also learn which parts of the page are editable and which parts are set in stone. Getting these things right will save time and improve results from nonprofit Facebook marketing efforts.

***How To Correctly Use Facebook Insights - 5 Critical Metrics You Need To Know*
Author: John Haydon

On Facebook, getting results is all about the content. In order to create reach, engagement, and ultimately action, users need to post stories on their Facebook Page that get attention and inspire Facebook users to share that content. But how do you know what's working and what's not? How do you know which stories create the most reach? How do you know when your Page is no longer interesting to people?

This step-by-step video covers the basics of Facebook Insights, the analytics tool that every Facebook Page has. Users will learn how to adjust their content strategy based on the Dashboard reports, the Like reports, the Reach reports, and the Talking About This report. Plus, they'll learn the 5 critical metrics for Facebook success: Reach, Talking About This, Virality, Viral Reach, and Like Sources.

June 6, 2012

- 9:30 Registration, Tea and Coffee
- 9:45 Welcome: John Coleman Chair of CFAI
- 10:00 **Summary of Important Recent Developments in CF Care and Research (ECFS)**
- 10:45 **The Strength of Working Together:** Stuart Elborn (ECFS) and Karleen De Rijcke (CFE)
- 11:00 **Quality Improvement in CF Care, Successful Experiences in Europe**
Chair: Vincent Gulmans, NCFS
- Jo Osmond on the peer review project in clinical care by the CF Trust
 - The quality improvement programme by Muco Germany
 - Q&A session
- 11:50 Coffee and Tea
- 12:15 **Impacting on Health Policy to Improve Access to Care in CF**
Chair: Anil Mehta (ECFS) and Karleen De Rijcke (CFE)

- How patient associations and government can join forces to improve access to care,
a successful story from Macedonia
- Ireland

13:00 Lunch

14:30 **Grant Writing**, Chair: Christine Noke, CFW Executive Director

Trainer: Barbara Floersch, Director of The Grantsmanship Centre since 2011

- What is a grant?
 - Who makes grants?
 - Components of a grant proposal
 - The most critical parts of your case for funding
 - Searching for appropriate funders
- *(Coffee and tea will be available during this session but there will be no official break due to time constraints)

Christine Noke

17:30 - How to fill out online applications for grant funds with pharmaceutical companies (Example: Gilead online grant applications)

18:00 Final plenary
Key issues for moving forward: Chair Philip Watt CFAI

CF Worldwide Presidents Dinner
‘Craic agus Ceol’ - Evening Dinner and Concert
(Free to those attending the symposium and invited guests.)

21: 00 Buffet meal: Gibson Hotel, Dublin

21:45 De Dannan concert: Gibson Hotel, Dublin

Key Presenters

Barbara Floersch, director of The Grantsmanship Center since 2011, has over 30 years of experience in nonprofit management, proposal writing, grants administration, and nonprofit consulting. She has secured tens of millions of dollars in federal, state, and foundation grants; taught hundreds of seminars and classes at conferences, colleges, and nonprofits; testified before Congress; published numerous articles; and served as an expert reviewer for much government grant competitions. Barbara has been a trainer for The Grantsmanship Center for 12 years.

Stuart Elborn is one of the most prominent members of the CF community. He is a professor of respiratory medicine at Queens' University in Belfast, the director of the adult CF center at Belfast City Hospital, the chairman of the Research and Medical Advisory Committees of the Cystic Fibrosis Trust in UK, and the president of the European Cystic Fibrosis Society. Elborn trained in Belfast and has helped develop Cystic Fibrosis centers for adult in Nottingham and Cardiff. In 1995, he started a new adult CF center providing care for all adults with cystic fibrosis in Northern Ireland.