

# COPD Foundation



## Mission

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[www.copdfoundation.org](http://www.copdfoundation.org)

The COPD Foundation's mission is to prevent and cure Chronic Obstructive Pulmonary Disease (COPD) and to improve the lives of all people affected by COPD.

The foundation was established in 2004 to speed innovations that will make treatments for COPD more effective and affordable, and expand services for COPD patients.

## Strategy/Approach

COPDF is committed to improving the lives of all people affected by COPD while working on preventing and curing the disease. It achieves this through a series of research, education, and advocacy-focused initiatives.

- **Education:** The foundation offers a variety of tools and initiatives aimed at raising awareness about the disease and providing support for patients living with COPD. Programs and resources, such as the toll-free COPD Information Line, DRIVE4COPD public health campaign, educational workshops, and COPD shuttle, are all part of the organization's comprehensive educational efforts.
- **Research:** Research has held a pivotal role in the evolution of COPDF—from creating the COPD Biomarker Qualification Consortium to help fast track research for better treatment to supporting the COPD Gene® Study, which looks at genetic factors that can contribute to an individual's risk for developing COPD.
- **Advocacy:** Mobilizing COPD advocates through several programs has created outlets for the COPD community to make their voices heard. The COPD Advocate Program, State Advocacy Leaders, and Operation 435 serve as the foundation for advocacy at COPDF. In partnership with the National Institutes of Health (NIH), the foundation works with the National Heart, Lung, and Blood Institute's Learn More Breathe Better Campaign to spread awareness of under-diagnosis and under-funding of COPD.

## Research Portfolio

- **COPD Research Registry**—a confidential database of individuals diagnosed with or at risk of developing COPD.



- **COPD Gene Study**—A study aiming to find inherited genetic factors that make some people more likely to develop COPD. Currently in Phase II of the study, with more than \$30 million in NIH support, this involves second clinical visits for all subjects. The long-term goal is to achieve whole genome analysis on all cohort members.
- **COPD Biomarker Qualification Consortium**—As a result of a 2011 workshop, the COPD Biomarker Qualification Consortium pools data related to biomarkers from many clinical trials conducted by a variety of stakeholders.
- **Bronchiectasis Research Registry**—A database of non-CF Bronchiectasis and Nontuberculosis Mycobacteria patients from clinical institutions nationwide. The goal of this registry is to support collaborative research and assist in planning multi-center clinical trials for the treatment of non-CF bronchiectasis.

## Partnership Practices

The COPD Foundation collaborates with a variety of organizations to further its mission and programs. Project partners include other nonprofit disease organizations, divisions of the NIH, and academic research centers. The foundation has also worked with industry partners on grants and programs such as the DRIVE4COPD and Pulmonary Education Program.

## Financials

The COPD Foundation is a 501(c)(3) organization. The most recent financial information available is from FY2011.<sup>1</sup>

Year Ending 6/30/12:

- Revenue: \$5,889,533
- Assets: \$5,488,772
- Grants Paid: \$410,185
- Gifts Received: \$7,081,227
- Expenditures: \$3,735,212

## Key Accomplishments

The foundation celebrated its 10<sup>th</sup> Anniversary in January 2014. In the past decade, it has:

<sup>1</sup> Information obtained from GuideStar.  
<http://www.guidestar.org/organizations/20-1048322/copd-foundation.aspx> Accessed March 2014.

- Emerged as a respected voice on behalf of the COPD community through its original publications, including COPD Digest magazine (the first free magazine on COPD) and Lung Health Professional magazine (a publication geared toward providers).
- A team led by the COPD Foundation, in collaboration with the COPD Outcomes-based Network for Clinical Effectiveness and Research Translation (CONCERT) and the COPD Gene research networks, has been approved for a funding award by the Patient-Centered Outcomes Research Institute to develop and expand a health data network that will be part of PCORnet: the National Patient-Centered Clinical Research Network.
- Awarded the Aesculapius Award of Excellence for a health-related Web site in 2013 and a health-related television public service announcement for the DRIVE4COPD campaign in 2012.
- Beginning in 2014 the COPD Foundation launched an open access journal, *Chronic Obstructive Pulmonary Diseases: Journal of the COPD Foundation*.
- Created CMAP, the largest database of people with COPD and their medical information in the world.
- Accredited with the National Health Council Standards of Excellence Certification.

## Leadership

The foundation is governed by an 18-member **Board of Directors** and run by staff in Miami and Washington.

- **Co-Founder and President:** John C. Walsh
- **Executive Director:** Craig Kephart, [ckephart@copdfoundation.org](mailto:ckephart@copdfoundation.org)
- **Associate Director of Development:** Janina Kowalski, [jkowalski@copdfoundation.org](mailto:jkowalski@copdfoundation.org)
- **Senior Director of Public Policy:** Miriam O'Day, [moday@copdfoundation.org](mailto:moday@copdfoundation.org)
- **Senior Director of the COPD Biomarkers Qualification Consortium:** Debbie Merrill, [dmerrill@copdfoundation.org](mailto:dmerrill@copdfoundation.org)