

## The evolving role of COPD patient advocacy organizations for COPD

John W. Walsh

COPD Foundation, Washington, DC, USA

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Historically, individuals with COPD have not engaged in organized patient advocacy activities, but there is an increasing global realization that COPD patients need to work together to advocate for improved COPD care and prevention. In the U.S., groups of patients sometimes had an opportunity to participate in support groups or Better Breather clubs; however, it was clear that the COPD community in the U.S. did not have a unified voice and most individuals affected never had access or knowledge of any peer group activities.

### The COPD Foundation

Since its founding in 2004, the COPD Foundation has worked to improve awareness, public policy and advancing research for COPD. The Foundation has partnered with the U.S. scientific and clinical community to create a platform that engages the patients as well as the researchers. Figure 1 displays our logo.

The Foundation has strategically organized its programs with a specific focus on three programmatic areas:

- Education and Awareness
- Public Policy and Advocacy
- Research

All Foundation activities, programs, and initiatives are designed to impact at least one of these key areas (Figures 2,3,4).

The COPD Foundation has sought to establish itself as a primary resource for information and calls to action concerning COPD for the patient community, the scientific and clinical community, governmental agencies and the U.S. Congress and State Legislators. The Foundation provides the community with a unified resource designed to represent the interests of all stakeholders. The global COPD community needs to have a strong voice to inform, educate, empower, and engage the

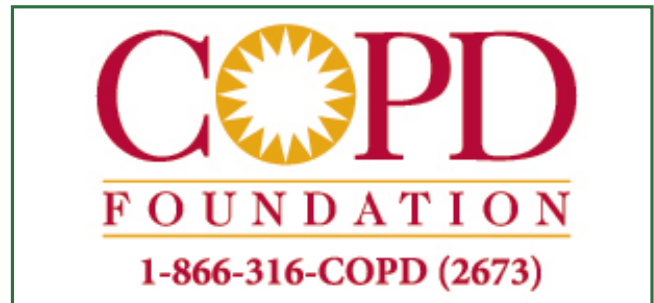


Figure 1. COPD Foundation logo.

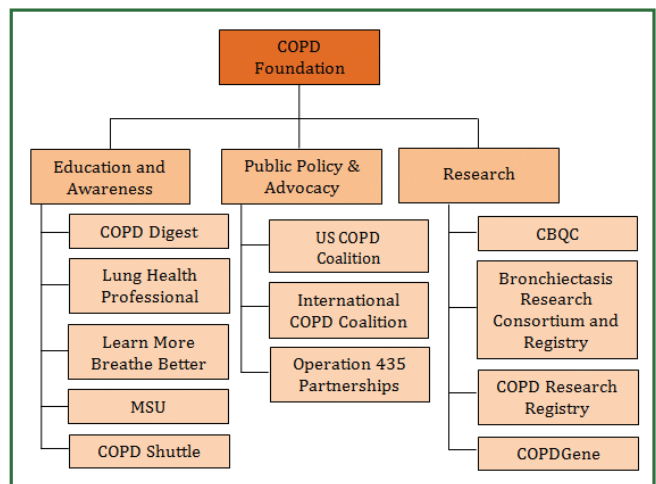


Figure 2. COPD Foundation Program chart.



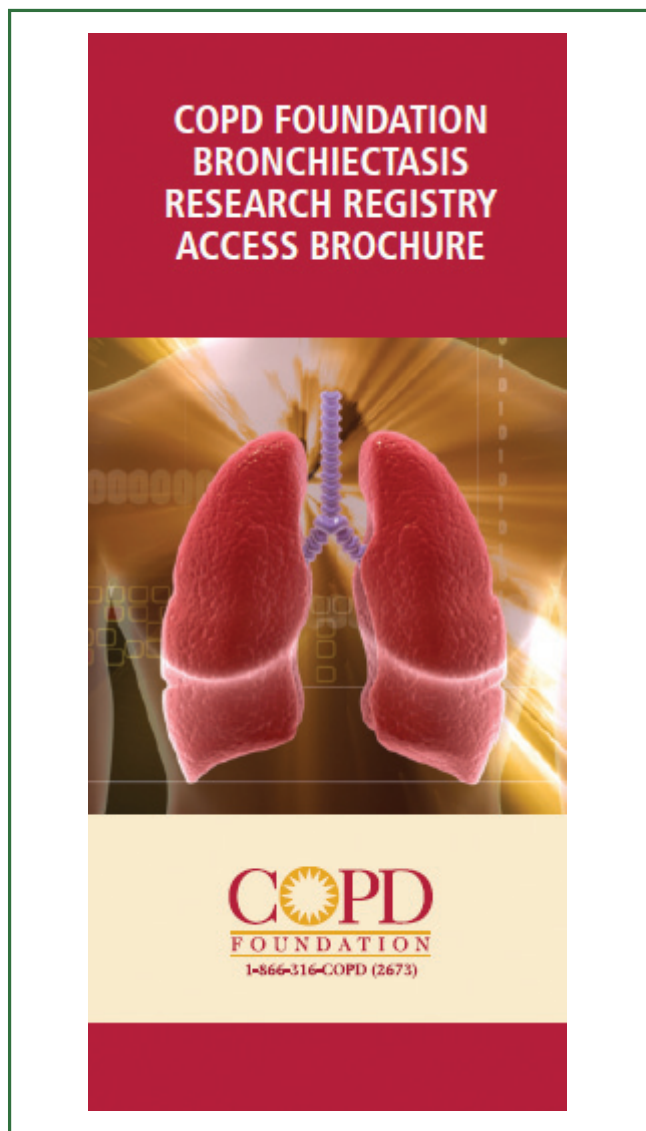
Figure 3. COPD Shuttle.

Corresponding to: John W. Walsh. President and Co-Founder, COPD Foundation, 20 F Street, NW, suite 200-A, Washington, DC 20001, USA. Email: jwwalsh@copdfoundation.org.

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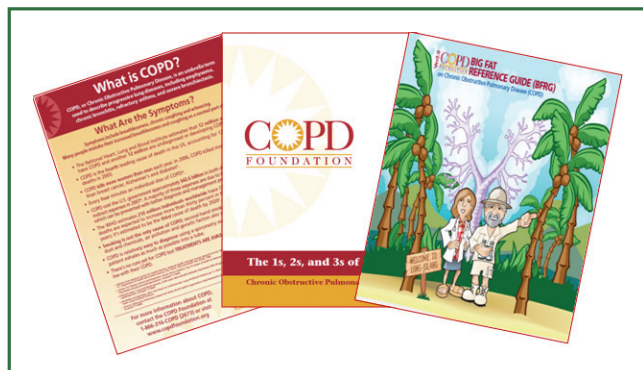
**Figure 4.** Bronchiectasis Research Registry Access.

“missing millions” of people living with COPD.

### Education and awareness

The COPD Foundation has created a significant portfolio of validated educational materials that are currently utilized as the main source of education for patients and caregivers. The Big Fat Reference Guide (BFRG) offers a vast amount of information on everything one may want to know about COPD. The BFRG is a blueprint on how patients can become involved with their care, take more responsibility to improve their quality of life, and work with their health care team (Figure 5).

All of the COPD Foundation educational and collateral materials are available on the Foundation's website ([www.copdfoundation.org](http://www.copdfoundation.org)). We are working with the ICC to assist other global COPD patient organizations to adapt, translate, and use these materials. In an



**Figure 5.** Big Fat Reference Guide (BFRG) and related Foundation publications.



**Figure 6.** Two free quarterly magazines published by the Foundation: *COPD Digest* and *Lung Health Professional*.

effort to reach a broader audience, many of these materials are already translated into other languages, such as Spanish and Chinese. The Foundation has developed additional resources to meet the needs of its diverse audiences. The Foundation publishes two free quarterly magazines: “COPD Digest”, designed for individuals with COPD, families and caregivers with a circulation of close to 500,000, and “Lung Health Professional” aimed at primary care clinicians and allied health professionals (Figure 6). In addition, the COPD Foundation has designated “The Journal of COPD” as The Scientific Journal of the COPD Foundation, just as the ICC has endorsed and partnered with the Journal of Thoracic Disease in communications.

An educational collaboration with WebMD has made much of the Foundation's educational content available to the millions of visitors seeking information lung health. More than 450,000 individuals have completed the Lung Health Check, designed for an individual to determine their risk for developing COPD and, as appropriate, encourage them to contact their health care provider. We recommend such educational partnerships with medical websites for ICC member organizations and other respiratory groups.

Responding to the great need to generate awareness to identify the 12 million Americans who are symptomatic of

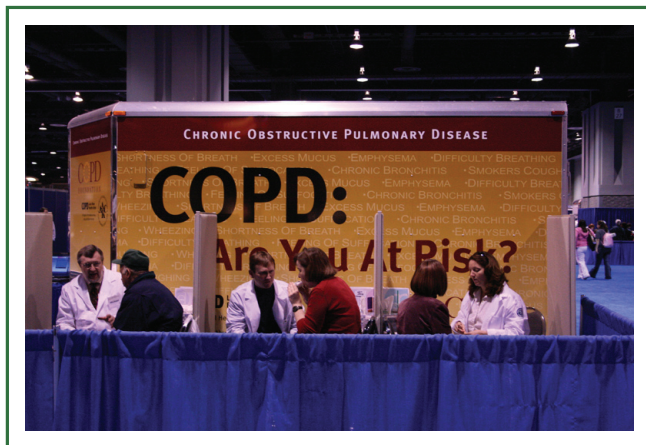


Figure 7. Mobile Spirometry Unit.



Figure 8. Logo of the Drive4COPD Campaign.

COPD but not diagnosed yet with COPD, the Foundation has taken a leadership role in increasing public awareness in the U.S. The Foundation collaborated with the National Heart Lung and Blood Institute (NHLBI) of the U.S. National Institutes of Health on the “Learn More Breathe Better” National Public Awareness Campaign from its inception.

To support the launch of the Learn More, Breathe Better campaign, the C.O.P.D. Information Line 866-316-COPD was established as a toll free service for the campaign, and launched the Mobile Spirometry Unit (MSU), a program to conduct free risk screenings and spirometry at public venues (Figure 7). The C.O.P.D. Information Line currently conducts 5,000 calls on a monthly basis. The MSU continues to build on its initial success and to date, 40,000 individuals have been tested with spirometry across the country at MSU events, and hundreds of thousands of education and awareness collateral materials have been distributed to support the awareness effort. Such efforts could also prove valuable for international COPD patient organizations. The Foundation was fortunate to have contributions from individuals in the COPD community and educational grants from industry to provide these services to COPD patients.

The Foundation was a founding partner of the DRIVE4COPD Campaign, the largest public COPD awareness initiative ever implemented in the U.S., and now leads the Campaign. Through the newly developed Employer Toolkit, we have expanded the



Figure 9. Logo of the US COPD Coalition.

DRIVE4COPD campaign into U.S. corporate wellness programs and coordinated promotion for risk screening, proper diagnosis and providing education and guidance to those diagnosed with COPD (Figure 8).

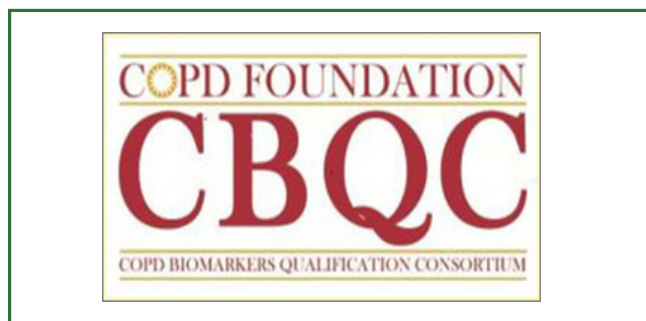
### Public policy and advocacy

COPD Foundation leadership has been involved in the U.S. COPD Coalition, and International COPD Coalition, since inception and led the effort to expand the number of State COPD Coalitions across America (Figure 9). As the management agent for the U.S. COPD Coalition, the Foundation coordinates the activities of over 25 patient organizations, professional societies, industry representatives and federal government liaison representatives working with the Coalition and serves as the principal liaison with the Congressional COPD Caucus, a group of US members of Congress involved in improving COPD care and awareness. The Foundation has organized all of its affiliates by Congressional district to mobilize individuals in key districts to influence public policy. Our successful grass roots efforts to advocate for COPD questions to be included in the Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System (BRFSS) (the first collection of COPD impact data ever) and advocacy on the airline oxygen issue are two successful examples of the power of a united advocacy effort for COPD.

### Research

The Foundation has worked hard to support research initiatives and foster public-private research partnerships. In an effort to get new biomarkers qualified for COPD, the U.S. Food and Drug Administration (FDA) approached the Foundation to organize a workshop and invite all stakeholders to identify biomarker candidates and build a collaborative framework to accelerate therapeutic development and approval. As the result of a consensus recommendation by the attendees, representing the



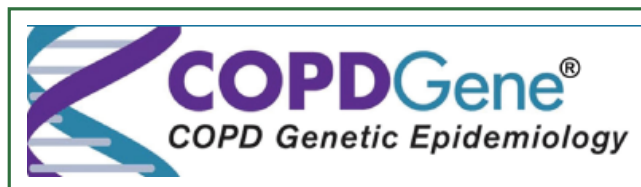


**Figure 10.** Logo of the COPD Biomarkers Qualification Consortium (CBQC).

FDA, NIH, academic researchers and scientific leadership from industry, the Foundation established the COPD Biomarkers Qualification Consortium (CBQC). The consortium has integrated the data from 90 clinical studies with as many as 120,000 study subjects per biomarker. Qualification for Fibrinogen, Saint George Respiratory Questionnaire (SGRQ) and 6-minute walk are well under way with scientific leadership from academia and industry working collaboratively (Figure 10). This is a first for industry and for the FDA. The CBQC is currently organizing a follow-up workshop to determine the next set of biomarker targets. The Foundation will work with ICC in disseminating this useful information to all ICC COPD patient organization members where it can benefit COPD diagnosis, management, and care.

The Foundation co-sponsored a workshop with the National Heart Lung and Blood Institute (NHLBI) on COPD Case Finding that resulted in the execution of a COPD Case Finding Validation Study by the Foundation. This study used the MSU as a mobile platform to validate a three-step process (risk screener, peak-flow, and spirometry) for case finding with over 16,000 study subjects at public events. The ability to execute this study within months after consensus development of a protocol was made possible with Foundation's support. Findings from this study were published in the December 2011 electronic issue of CHEST and in the August 2012 hard copy issue of CHEST (<http://journal.publications.chestnet.org/article.aspx?articleid=1262327>).

There are numerous examples of other activities in which the COPD Foundation has become involved with in efforts of advancing research and therapeutic development concerning COPD. Supporting the accelerated enrollment in the COPDGene Study and organizing an Industry Advisory Committee to participate in the Study has proved to be invaluable to completing enrollment almost a year ahead of schedule and securing \$4.2 million in funding for ancillary studies, including adding the longitudinal follow-up study, and enabling CT imaging and genome-wide association study (GWAS) to be collected on the entire COPDGene Study



**Figure 11.** Logo of the COPDGene Study.



**Figure 12.** Logo of the Bronchiectasis Research Consortium and Registry.

cohort. The Foundation provided the platform for this critical collaboration and additional support that enhanced this historic study and enriched the characterization of the cohort (Figure 11). The COPDGene Study has now been re-funded for another 5 years and the Foundation co-sponsored the 2<sup>nd</sup> International COPD Genetics Conference in September, which was convened in Amsterdam with over 50 cohorts from around the world discussing next steps. The Foundation will work with ICC in disseminating the results of these studies as they become available to ICC member organizations.

Responding to a plea from an affected family, the Foundation organized the Bronchiectasis Research Consortium and Registry (Figure 12). This Registry has become the largest cohort of individuals with non-CF related Bronchiectasis from 15 participating centers across the U.S. The Registry was recently expanded to include individuals with Nontuberculous Mycobacteria (NTM) and the Consortium has recently announced its intention to expand internationally. This Consortium and Registry have proven to be a valuable resource for the investigator community supporting research for this neglected disease. For international investigators and for international COPD patient organizations interested in participating in this registry, please contact Randel Plant at [rplant@copdfoundation.org](mailto:rplant@copdfoundation.org).

### COPD Foundation call to action

The role of COPD patient advocacy in countries around the world can be expanded by organizations that develop comprehensive education platforms, a publication portfolio, national public awareness campaigns, strategic advocacy, and

support for COPD research. The COPD Foundation's Call to Action now provides a diverse set of opportunities for any individual to become involved and engaged in our war against COPD—soon to be the third leading cause of death in the world. We recommend such a Call to Action be developed by each national COPD patient organization. The Foundation wishes to share its materials and experience with many organizations around the world, and looks forward to united global action on



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COPD. Together, we can make a difference.

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