Chronic Obstructive Pulmonary Diseases:
Journal of the COPD Foundation

Statement of the COPD Foundation

Time to Redefine? A Statement of the COPD Foundation

COPD Foundation Board of Directors[1]

Abbreviations: chronic obstructive pulmonary disease, **COPD**; COPD Genetic Epidemiology study, **COPDGene®**; computed tomography, **CT**

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From the COPD Foundation Board of Directors

The COPD Foundation was launched some 15 years ago. The COPD Foundation Board and staff includes a mix of patients, care givers, primary care physicians, pulmonologists, respiratory therapists, clinicians, researchers, lawyers and businesspeople. Our online social network, COPD360social, with its 43,000 plus members, our research registries with over 10,000 members, and our PRAXIS network with its 15,000 members, hope to provide a voice for patients, care givers and health care professionals. We share the mission to prevent and cure chronic obstructive pulmonary disease (COPD) and to improve the lives of all people affected by COPD.

We also share frustrations. While our therapeutic options have improved over the 15 years, it is unacceptable that over those years only 1 drug of a new class has been approved for COPD. It is likewise unacceptable that pulmonary rehabilitation, a remarkably effective therapy, is rarely available, under reimbursed and tragically underutilized. We share concerns with those patients who continue to struggle to get the oxygen equipment they require. Also, we remain frustrated that despite COPD's impact, COPD continues to receive only a fraction of the research funding provided to other major chronic diseases. We understand that research is the engine that powers medical progress. The COPD Genetic Epidemiology (COPDGene®) study is an example of what a research program can provide. The National Heart, Lung, and Blood Institute deserves a tremendous amount of credit for providing COPDGene® funding from its inception in 2007. The leadership of COPDGene®, Drs. James Crapo, Ed Silverman and Barry Make, deserve tremendous credit for guiding this project for 12 years. We also all owe a debt of gratitude to the hundreds of researchers who have dedicated their lives to this program, and to the thousands of patients who have made this study possible. COPDGene® provides us with hope that we can move beyond some of the barriers that have impeded progress with this disease.

COPDGene® is a landmark study. In this volume of *Chronic Obstructive Pulmonary Diseases: Journal of the COPD Foundation* is a remarkable summary[1] of the clinical epidemiology of smoking-related lung disease that extends the domains of COPD beyond airflow limitation to include structural abnormalities revealed by quantitative computed tomography (CT) and patient-reported symptoms. Primary care physicians and specialists alike are often confronted by such individuals and are unable to make evidence-based therapeutic and diagnostic recommendations. Patients are left without a clear diagnosis or prognosis.

Understanding the natural history of these smoking-related disease categories that do not meet the current diagnostic criteria for COPD is an important advance. By adding findings from CT imaging to information regarding exposures, symptoms, and spirometry, COPDGene® investigators suggest that we can include groups with possible and probable COPD to those with more definite disease. Longitudinal data suggests that over time many with imaging abnormalities but no measurable spirometric obstruction ultimately progress to abnormal spirometry. As noted in the article, "current COPD diagnostic criteria fail to capture individuals with smoking-related disease who are at increased risk of progressive lung function loss and mortality."[1] In addition, other data from the COPDGene® study suggests that all COPD does not progress along the same route. As many of us have believed for years, not all COPD is the same. The framework for categorizing smoking-related pulmonary conditions that is outlined by the COPDGene® study will lay the foundation for future research and treatment recommendations.

We understand that there are limitations to this study. We understand that as many as 25% of COPD patients in the United States never smoked and that worldwide exposure to biomass fuels is increasingly recognized as a cause of COPD. We do not know whether the information generated by COPDGene® can be applied to these groups as well. For this new approach to defining COPD to work, we need to be able to use low dose CT scanning to minimize x-ray exposure, and there needs to be software that can simplify the interpretation of the critical CT scan component. Moreover, medications aimed for more specific types of COPD need to be developed. Much more work needs to be done. But we believe the data generated by COPDGene® provides hope, something that has been sadly missing in the COPD community. The work suggests that we have the potential to make the diagnosis earlier, increasing the possibility that treating earlier could slow or halt progression, reverse damage before it is irreversible, and impact the ultimate course of the disease. The data from COPDGene® suggests that it may be time to broaden the definition of COPD beyond the limitations of spirometric obstruction. The COPD Foundation Board of Directors enthusiastically supports this proposal.

John W. Walsh, the founder of both the COPD Foundation and the Alpha-1 Foundation, was one of the leading forces behind the launching of COPDGene®. John passed away several years ago, but his vision and legacy live on. He would be thrilled with the progress being made. He would understand that this is just the first step towards better therapies and amelioration of the suffering COPD patients endure. But John, with a gleam in his eyes, would urge all of us to "keep the faith."

References

1. Lowe KE, Regan EA, Anzueto A, et al. COPDGene 2019: redefining the diagnosis of chronic obstructive pulmonary disease. *Chronic Obstr Pulm Dis*. 2019;6(5):384-399. doi: https://doi.org/10.15326/jcopdf.6.5.2019.0149