Chronic Obstructive Pulmonary Diseases:
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Letter to the Editor

Letter to the Editor: A Patient Perspective

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Abbreviations: chronic obstructive pulmonary disease, **COPD**; pulmonary rehabilitation, **PR**; COPD Genetic Epidemiology study, **COPDGene®**; National Institutes of Health, **NIH**

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Dear Editor:

We are 250 million souls with chronic obstructive pulmonary disease (COPD) worldwide. It's the third leading cause of death globally. In the United States alone, we are 30 million and the third leading cause of death among chronic diseases. I have been diagnosed for 18 years with severe and very severe COPD, but COPD took decades to reveal itself in my lungs. Too many COPD patients feel abandoned, alone, fearful, anxious, and depressed, as we descend deeper and deeper in the downward spiral that has only one ending— death. Only 3 major therapies for COPD exist— inhaled medications that control symptoms for most, supplemental oxygen (only if our resting oxygen level is very low) and pulmonary rehabilitation (PR). PR is evidence-based and is a program that can and does improve our function and quality of life. It is not widely available and is dismally reimbursed. Only 1.8%–3.7% of patients have access to PR. There is presently no cure for COPD, nothing to stop the progress of the disease or to reverse it. Ironically, we have a therapy (PR) and we are not supporting its use as we should.

Tragically COPD is diagnosed much too late and typically we have already lost 50% or more of our lung function when we are diagnosed. This is where the COPD Genetic Epidemiology (COPDGene®) study makes a profound difference. We have new hope, new stunning data, new provocative results[1] from a landmark clinical trial of over 10,000 COPD patients with a smoking history, funded by the National Institutes of Health (NIH) since 2008. The principal investigators looked deep in our genes and now propose new ways to define and diagnose COPD. We are facing hope that current and future interventions can slow and ultimately stop COPD progression before disability or irreversible lung structural changes develop. The framework— exposures (here cigarette smoking), spirometry (forced expiratory volume in 1 second), symptoms (dyspnea, exacerbations), computed tomography imaging (structural lung abnormalities) — support a new formula allowing a re-examination of how COPD patients might be identified earlier, treated earlier and classified ultimately by phenotype. We are not all the same.

For patients, this represents a much-needed infusion of hope and progress. Of course, the 25% of COPD patients who never smoked are not part of this database, an important limitation. But....we are moving forward with clinical trial discipline and science in re-thinking how to diagnose and treat COPD patients earlier, thanks to the COPDGene® lead investigators Drs. James Crapo, Ed Silverman and Barry Make and to the ongoing support of the National Heart, Lung, and Blood Institute of the NIH. It is also not incidental that over 90 pulmonologists, the cream of

pulmonology research and clinical care, have joined as co-authors of the COPDGene® article published in this issue of *Chronic Obstructive Pulmonary Diseases: Journal of the COPD Foundation*.[1]

This is not the end of the journey to earlier diagnosis and phenotyping of COPD patients, but it is a giant leap for COPD personalized medicine and COPD patients worldwide. As the experts parse and contribute new insights, COPD patients applaud.

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