Dear Alpha-1 Research Registry Members,

As you know, the Alpha-1 Foundation has been a model for how to engage people in clinical research - the COPD Foundation is utilizing that model to engage patients in a new research effort. As an individual with Alpha-1 genetic related COPD we would like to inform you of a research study led by the COPD Foundation - the COPD Patient-Powered Research Network (COPD PPRN). The purpose of the COPD PPRN is to create a research registry of over 75,000 people affected by chronic obstructive pulmonary disease (COPD) who have agreed to share their health information and the impact the disease has on their lives. The COPD PPRN is part of a larger project funded by the Patient-Centered Outcomes Research Institute (PCORI) with the purpose to support patient-driven research.

Eligible participants must:

1.) Be at least 18 years old.

2.) Have been told by a doctor that you have chronic obstructive pulmonary disease, also called COPD (a progressive lung disease including emphysema, chronic bronchitis, refractory (non-reversible) asthma, and some forms of bronchiectasis).

3.) Be able to be contacted in the future. This can be a personal email address OR a mailing address and telephone number where you can be contacted.

To get started, type the following web address into a web browser: www.copdpprn.org

When you get to the website it will ask you if you have an access code.

Your Access Code is: XXXXXX
Please enter your access code to proceed and join the COPD PPRN by signing an informed consent and completing a short survey.

If you would prefer to enroll through a paper form or have questions about the process, you can request an enrollment package and find out more information by calling the C.O.P.D. Information Line at 1-866-316-COPD (2673).

If you have any questions, you may also contact the Alpha-1 Foundation Research Registry at 1-877-886-2383.

Sincerely,

Charlie Strange, MD
Director, Alpha-1 Foundation Research Registry

John Walsh, COPD Foundation
Co-Principal Investigator for the COPD PPRN

Richard Mularski, MD, MSHS, MCR
Co-Principal Investigator for the COPD PPRN