

How is my confidentiality protected?

Every effort will be made to maintain participant confidentiality. All identifying information, such as names and contact information, will be kept in a secure location at the clinical center. This information will also be stored separately from the genetic research data.

Compensation for your time and effort will be provided.

HOW DO I GET INTO THE BOSTON EARLY-ONSET COPD STUDY?

If you feel that you may meet the eligibility criteria and would like to participate in this research study, please call our toll free contact number:

1-866-328-9494 extension 2

Or by e-mail:
EOCOPD.study@channing.harvard.edu

Principal Investigator:

Edwin Silverman, M.D., Ph.D.

The Boston Early-Onset COPD Study

A Research Study That
May Interest You

Brigham & Women's Hospital
181 Longwood Ave
Boston, MA 02115
1-866-328-9494



WHAT IS COPD?

Chronic obstructive pulmonary disease (COPD) includes emphysema and chronic bronchitis. Many studies have shown that for most people with COPD, cigarette smoking has been a major contributor to their disease. However, many smokers do not develop COPD, and some people with COPD have not smoked at all. A small group of people develop severe COPD at an early age. Some of these individuals have inherited a deficiency of a protein in their blood, called alpha 1-antitrypsin. Alpha 1- antitrypsin deficiency is a proven inherited risk factor for COPD, but only a small percentage of all COPD patients have this protein deficiency. There are likely other important inherited risk factors for COPD, but they have not been identified. Our research program is focused on identifying new inherited risk factors for COPD.

THE BOSTON EARLY-ONSET COPD STUDY...

We are trying to learn if the development of severe early-onset COPD, unrelated to alpha 1-antitrypsin deficiency, runs in families. In order to determine this, we are:

- performing measurements of pulmonary function with routine testing
- assessing respiratory symptoms and environmental exposures with an in-depth questionnaire
- obtaining a blood sample, urine samples, and cheek swabs for laboratory studies

In order to determine if COPD runs in families, we are contacting relatives of the COPD patients that participate in this research study, including any siblings, parents, children, grandparents, aunts, and uncles who are available and interested in participating.

Our ultimate goal is to provide better treatment for people who are at risk for developing COPD.

WHO IS ELIGIBLE FOR THE RESEARCH STUDY?

To be included in the research study, individuals must...

- have COPD
- have significantly reduced pulmonary function
- be younger than 53 years of age
- not have alpha 1-antitrypsin deficiency

Who is funding this study?

This study is funded by a grant from the National Institutes of Health.

How long does it take to participate?

The single study visit lasts one to two hours, and includes a breathing test, a questionnaire, a blood sample, cheek swabs, and a urine sample. Study visits can be performed at the participant's home or at Brigham and Women's Hospital.