

FALL 2023 PARTICIPANT NEWSLETTER: WELCOME TO PHASE 4!



**You are invited to participate in
COPDGene Phase 4!**



A LETTER FROM THE INVESTIGATORS

Dear COPDGene Participants,

We are pleased to provide this newsletter describing recent updates in the COPDGene Study. We are extremely grateful that the National Heart, Lung, and Blood Institute of the National Institutes of Health has approved funding for Phase 4 of COPDGene, which will allow us to obtain 15-year follow-up visits from our study volunteers. This extended follow-up with lung function testing, chest CT scans, questionnaires, blood samples, and other assessments will provide unique insights into the development and progression of chronic obstructive pulmonary disease (COPD). In addition, the extensive data we have collected will enable studies of other lung diseases (such as pulmonary fibrosis), aging, and non-lung diseases (such as coronary heart disease). We know that none of this research would be possible without the dedication and commitment of our COPDGene study participants. We hope that you will enjoy learning about our plans for COPDGene Phase 4, recent scientific discoveries using COPDGene data, and our COPDGene Participant Advisory Panel. Most importantly, we hope that you will strongly consider coming in to your COPDGene Clinical Center for your Phase 4 visit. Thanks so much for your help.

Sincerely,

**Dr. James Crapo, Dr. Ed Silverman, & the
COPDGene Research Team**

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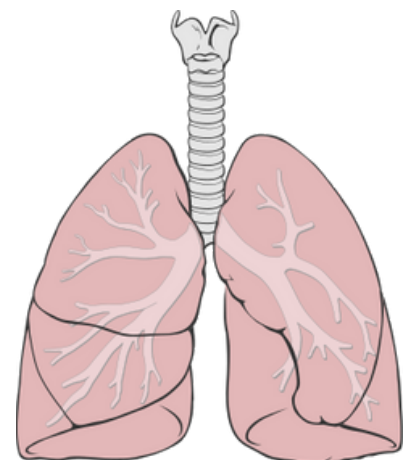
Patient Advisory Board

**Lung Cancer Screening -
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Thank you!



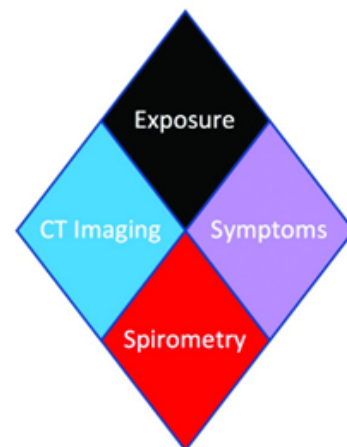
PHASE 4 VISIT: 15 YEAR FOLLOW-UP

What's involved?

The COPDGene Phase 4 visit will be similar to past research study visits. This includes:

- **Questionnaires** about your health and lung disease status
- **Blood sample collection**
- **6-minute-walk test**
- **Spirometry** - a pulmonary function test to help us compare your lung health to your other study visits
- **CT Scan** - a low dose scan to compare to previous study scans and identify potentially clinically significant nodules

Figure 1. Features Used to Define COPD in the COPDGene® Study



STUDY SNAPSHOT

COPDGene by the numbers:

- 10,000 + participants enrolled in Phase 1 nationally across 20 clinical centers
- 7,189 participants returning for a Phase 2 visit
- 4,764 participants returning for a Phase 3 visit
- 1,772 Dried Blood Spots collected for COVID-19 antibody testing
- 500+ publications in scientific journals

FREQUENTLY ASKED QUESTIONS

When can I come into the clinic for a Phase 4 visit? A clinical coordinator will be in contact with you for a visit approximately 15 years after your first visit with us (or 10 years if enrolled in Phase 2). You can also contact your local site's team if you are interested, and they can schedule you at the appropriate time.

I'm not sure if I can come into the clinic for a visit right now. How can I continue to participate? You can participate in COVID-19 research within COPDGene and continue to answer our LFU survey every 6 months.

Why do I get an automated call or email every 6-months? As a longitudinal study, we want to check in on your health status and update your contact information so we can inform you of new study activities and findings.

FOLLOW-UP CONTACT

- Your participation in our 6-month follow-up surveys (longitudinal follow-up abbreviated LFU) is an important part of our ongoing research efforts.
- These surveys sent by **phone or email every 6 months** help our researchers track disease progression over time and monitor the status of your health. They are also important to obtain current contact information and learn about any flare-ups you may have had recently.
- **Thank you** for your continued participation in these important surveys!

COPDGene Participant Advisory Panel: Interested in participating?

- The **COPDGene Participant Advisory Panel** is a group of nine COPDGene study participants who have provided valuable guidance regarding the COPDGene study protocol and return of results.
- If you are interested in joining the Participant Advisory Panel, please contact **Sara Cummings at (303) 398-1485 or cummings@njhealth.org**.

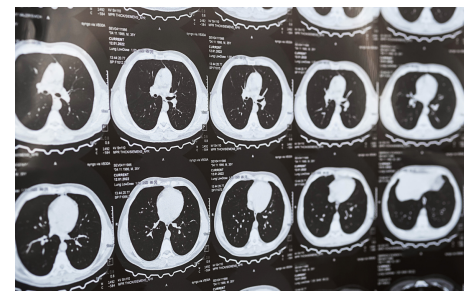
LUNG CANCER SCREENING RECOMMENDATIONS

- The U.S. Preventative Services Task Force recommends screening for lung cancer annually with a low dose chest CT scan in people:

AGES 50-80

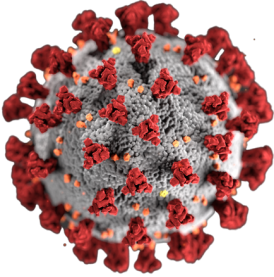
20 PACK-YEAR SMOKING HISTORY OR MORE

CURRENTLY SMOKING OR HAVE QUIT WITHIN THE PAST 15 YEARS



- If you meet these criteria, consider asking your health care professional about the benefits of yearly chest CT scans or finding a lung cancer screening program at a medical center near you. Medicare and most medical insurance plans pay for annual lung cancer screening.
- **Your Phase 4 COPDGene CT scan meets the requirements for lung cancer screening. We inform each person about other potentially significant findings and suggest they be shared with your health care professional.**

HOW DOES COVID-19 RESEARCH FIT INTO COPDGENE?



- COPDGene continues to be a part of The Collaborative Cohort of Cohorts (C4R) for COVID-19 Research, a nationwide study of more than 50,000 individuals to determine factors that predict disease severity and long-term health impacts of COVID-19
- COPDGene patients can participate in a 10 minute questionnaire about their experience with COVID-19 illness and their general health throughout the pandemic.

PUBLICATION HIGHLIGHTS

Over 200 investigators at more than 20 medical centers across the United States have been involved with the COPDGene study and have produced **over 500 publications** in scientific journals providing new information on how COPD develops and progresses. Recent published findings include:

- **Assessments of emphysema on chest CT scans from COPDGene Phases 1, 2, and 3 demonstrated that individuals with emphysema who continued to smoke cigarettes had the greatest progression of emphysema over time.** (David Baraghoshi and colleagues, Radiology 2023)
- **Widely used race-specific prediction equations for lung function may underestimate COPD in African Americans.** (Elizabeth Regan and colleagues, American Journal of Respiratory and Critical Care Medicine 2023)
- **Blood expression levels of multiple genes were associated with COPD exacerbations, and lower levels of a certain type of blood immune cell (CD4 lymphocytes) were also associated with higher COPD exacerbation risk.** (Min Hyung Ryu and colleagues, American Journal of Respiratory and Critical Care Medicine 2023)

THANK YOU!

On behalf of all the COPDGene research centers, Principal Investigators, clinical coordinators, and research staff, ***thank you for your ongoing contribution to COPDGene and this important medical research.*** None of this would be possible without your participation! **If you have questions or would like to get in touch with your local clinical center, please contact Sara Cummings at cummings@njhealth.org or (303) 398-1485.**