

SPRING 2025 PARTICIPANT NEWSLETTER: PHASE 4 CONTINUES!



**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 more than one year into phase 4 of the study, which centers around our 15-year follow-up visit with you, our wonderful participants. We'd like to take this opportunity to celebrate our success so far in this phase, and to thank you again for your continued participation. We could not do this amazing work without you and your contribution of time and information collected during your study visits. Along with over 10,000 of your peers, this study hit the ground running from the start. You have all provided incredible follow-up with nearly 5,000 participants returning for 10-year visits. Results from your visits have contributed to over 600 scientific publications that have shaped the diagnosis and treatment of COPD. A few highlights include: 1) The recent identification of mucus plugs within airways (visible on chest CT) which are associated with flare ups of chest trouble and progression of COPD; 2) Finding more than 80 genetic determinants of COPD risk, and the creation of a genetic risk score which predicts the chance of developing COPD; 3) Demonstrating that many COPD patients first develop damage to their airways, rather than emphysema; and 4) Showing that small abnormalities on chest CT (interstitial lung abnormalities) are likely early indicators of lung fibrosis, another chronic lung disease. Your engagement has been the cornerstone of our shared success, and we would like to extend our deepest gratitude. Without you, none of this progress would be possible. Thank you so much, and we look forward to seeing you again soon.

Sincerely,

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

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FAQs

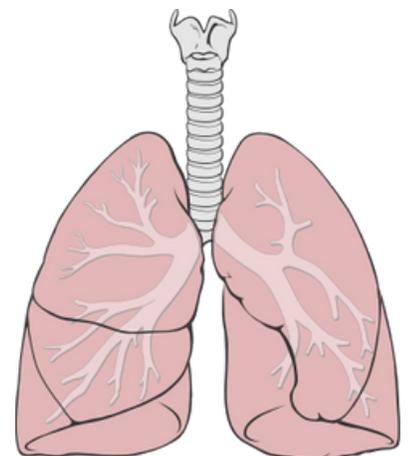
Follow-up Contact

**Participant Advisory
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Future Impacts

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Thank you!

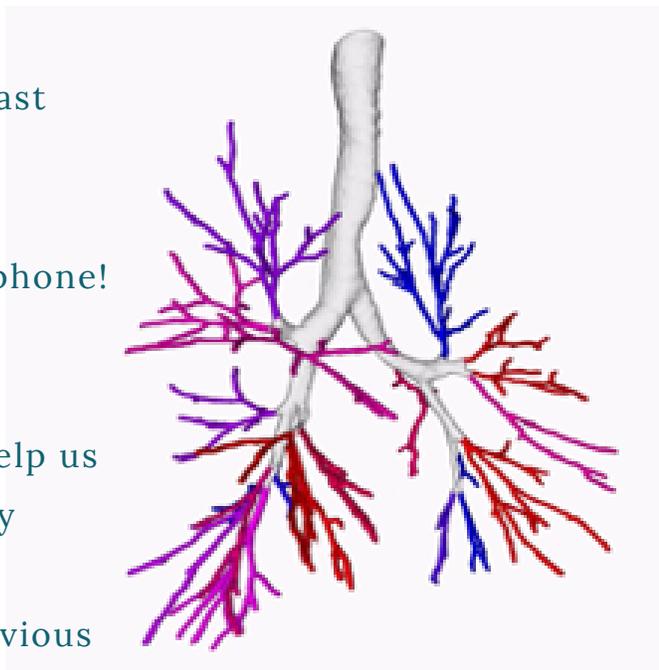


PHASE 4 VISIT: 15 YEAR FOLLOW-UP

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 - these may be completed by phone!
- **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 potential clinically significant nodules



All clinically important results of study testing will be available to share with you and your primary care physician. Data from this full study visit is the most valuable thing you can share with the COPDGene study - Thank you!

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
- **Over 400 participants** have returned for the phase 4 visit so far! **If this includes you - thank you for coming in!!**
- 1,772 Dried Blood Spots collected for COVID-19 antibody testing
- 600+ publications in scientific journals has focused the research community onto COPD and spurred interest in future research opportunities to better understand and more effectively treat lung disease

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. Any level of participation is helpful for our research!

I may need assistance to participate in the study visit, what accommodations are available? Your center may be able to provide transportation assistance to get you to and from the study visit, ask your coordinator when scheduling your visit. Wheelchairs and supplemental oxygen can be provided during the study visit.

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 completed 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 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.

FUTURE IMPACTS OF COPDGENE RESEARCH

COPDGene Investigators are interested in focusing future research on a broad range of topics

- Social Determinates of Health - how your environment can shape your health
- The use of Artificial Intelligence (AI) in research, especially for CT scan analysis
- Study of Aging Overall, including frailty and comorbidities

**DATA FROM YOUR
STUDY VISITS WILL
DIRECTLY
IMPACT THE FUTURE
OF COPD
DIAGNOSIS,
TREATMENT, AND
RESEARCH!**

PUBLICATION HIGHLIGHTS

All publications are available on our public website at copdgene.org/publications and also [PubMed.gov](https://pubmed.gov). This digital version contains live links to click for the full article. To view previous newsletters, visit copdgene.org/newsletters

1: Yang HM, Ryu MH, Carey VJ, Kinney GL, Hokanson JE, Dransfield MT, Hersh CP, Silverman EK; COPDGene Investigators †. Chronic Obstructive Pulmonary Disease Exacerbations Increase the Risk of Subsequent Cardiovascular Events: A Longitudinal Analysis of the COPDGene Study. J Am Heart Assoc. 2024 Jun 4 - <https://pmc.ncbi.nlm.nih.gov/articles/PMC11255614/>

This study used COPDGene Longitudinal Follow-Up data to show that people with increased rates of COPD flare-ups (exacerbations) may have increased risk of developing heart disease.

2: Rose JA, Tukpah AC, Cutting C, Wada N, Nishino M, Moll M, Kalra S, Choi B, Lynch DA, Raby BA, Rosas IO, San José Estépar R, Washko GR, Silverman EK, Cho MH, Hatabu H, Putman RK, Hunninghake GM. Development, Progression, and Mortality of Suspected Interstitial Lung Disease in COPDGene. Am J Respir Crit Care Med. 2024 Dec 15 -

<https://pubmed.ncbi.nlm.nih.gov/39133466/>

This study indicated that people with early chest CT changes reflecting scars in their lungs are at increased risk for progressive lung disease.

3: Wan E, Yen A, Elalami R, Grumley S, Nath HP, Wang W, Brouha S, Manapragada PP, Abozeed M, Aziz MU, Zahid M, Ahmed AN, Terry NL, Nardelli P, Ross JC, Kim V, Sonavane S, Kligerman SJ, Vestbo J, Agusti A, Kim K, San José Estépar R, Silverman EK, Cho MH, Diaz AA. Airway Mucus Plugs on Chest Computed Tomography Are Associated with Exacerbations in COPD. Am J Respir Crit Care Med. 2024 Oct 29 - <https://pubmed.ncbi.nlm.nih.gov/39470402/>

This study showed that people with mucus within their bronchial tubes, visible on chest CT scans, have increased risk for flare-ups of chest trouble.