COPDGene®
COPD Genetic Epidemiology

SPRING 2026 PARTICIPANT NEWSLETTER: PHASE 4 CONTINUES!

Thank you for your continued participation and support for COPDGene!

PHASE 4 VISIT: YOU ARE INVITED TO THE 15 YEAR FOLLOW-UP

The COPDGene Phase 4 visit will be similar to past research study visits. They include:

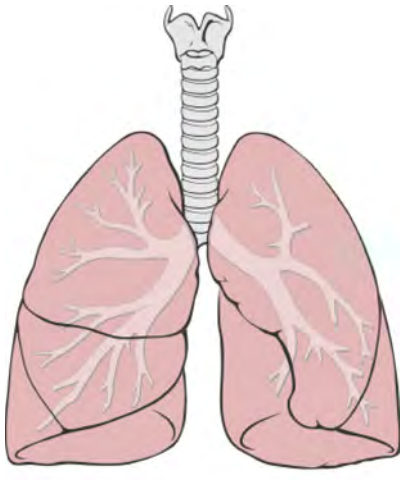
- **Questionnaires** about your health and lung disease - these may be completed by phone!
- **Blood sample collection**
- **6-minute-walk test**
- **Spirometry** - a breathing test to help us compare your lung health to your other study visits
- **CT Scan** - a low dose scan to compare to previous study 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 doctor. **Data from this full study visit is the most valuable thing you can share with the COPDGene study - Thank you!**

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SUCCESS SO FAR: COPDGENE STUDY SNAPSHOT



- 10,000 + participants enrolled in Phase 1 nationally across 20 clinical centers
- 6,132 participants returned for a Phase 2 visit
- 4,733 participants returned for a Phase 3 visit
- **Over 1300 participants** have returned for the phase 4 visit so far! **If this includes you, thank you for coming in!!**
- Data from COPDGene has resulted in over **600 publications** in scientific journals!

COPDGENE DATA WILL CHANGE HOW DOCTORS DIAGNOSE COPD

For many years, COPD has been diagnosed using a single test called spirometry. This is the breathing test where you blow as hard and as fast as you can into a tube - which we do in our study visits. If the test showed that it is hard for you to blow air out of your lungs (this is called Obstruction), your doctor would diagnose COPD. However, data from COPDGene showed that spirometry alone is not enough to know if you have lung disease. Even in people whose breathing tests look normal, pictures of your lungs called CT scans can show damage.

In 2025, researchers from COPDGene published a study using data from over 9,400 participants like you. They developed a new way to diagnose COPD, one that looks at the whole picture of someone's health. This study showed that relying only on the breathing test misses some people who truly have COPD.
The new approach still uses the results of the breathing tests, but also looks at other signs of lung disease:

- **2 types of lung damage seen on CT scans**
- **Shortness of breath**
- **Poor quality of life**
- **Chronic bronchitis (a long-term cough with mucus)**

THIS SUMMARY IS FROM DR. SURYA BHATT'S 2025 PUBLICATION IN JAMA:

Using this new method, a person can be diagnosed with COPD if:

- **They have a breathing test that shows blocked airflow AND one of the signs above – OR**
- **They have three of the five signs, even when their breathing test looks normal.**

Looking at COPDGene participants in this study who had a normal breathing test, 15% would have been diagnosed with COPD using the new system. These people experienced more COPD flare ups (infections with more shortness of breath, cough, and mucus needing treatment) and faster loss of lung function than people with healthy lungs. They were also at a greater risk of death over-all, showing that the old way of diagnosing COPD was truly missing people who had lung disease.

Finding COPD earlier means people can start treatment sooner. This may slow down the disease and help them feel better for longer. These discoveries were only possible because of the long-term dedication of COPDGene participants. Your willingness to fill out questionnaires, and complete breathing tests and CT scans over the last 15 years has made a real difference in the understanding of this disease. Thank you!

These guidelines are not yet standard practice. If you have questions about your lung health please talk to your doctor.

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 continue to answer our LFU (longitudinal follow-up) survey every 6 months and/or join our COPDGene Participant Advisory Panel. 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. Please ask your coordinator for assistance when scheduling your visit. Wheelchairs and supplemental oxygen can be provided if needed during the study visit.

FOLLOW-UP CONTACT

- Your participation in our 6-month follow-up surveys (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 confirm your current contact information.
- You can complete these surveys whether or not you come in for a phase 4 visit
- **Thank you** for your continued participation in these important surveys!

Find our digital newsletters, and a full list of publications on the COPDGene Website:

Learn more about lung health with the COPD Foundation Podcasts!

COPDGene Participant Advisory Panel: Interested in participating?

COPDGene® COPD Genetic Epidemiology

The **COPDGene Participant Advisory Panel** is a group of COPDGene study participants who have provided valuable guidance regarding the COPDGene study protocol, return of results, and subject contact.

If you are interested in joining the Participant Advisory Panel, please contact **Sara Cummings at (303) 398-1485 or cummingss@njhealth.org .**

From everyone on the COPDGene investigator's team, Thank You for your continued support and participation. This study could not succeed without you!

FIND ALL 19 CLINICAL CENTER'S CONTACT INFO HERE

COPDGENE CLINICAL CENTER LOCATIONS

