PFF Hill Day 2026 FAQ

We need YOU to help your members of Congress understand why access to supplemental oxygen and pulmonary fibrosis (PF) research are so critical to the pulmonary fibrosis and interstitial lung disease (ILD) community. Register today to join us virtually and advocate for these important issues!

Why is PFF Hill Day 2026 so important?

Congress has made significant progress towards passing the **Supplemental Oxygen Access Reform (SOAR) Act** over the past year. We need as many patients, family members, caregivers, and healthcare providers as possible to join us to ask Congress to pass the SOAR Act in 2026! Additionally, advocating for **pulmonary fibrosis research funding** is more critical than ever, given recent cuts to federal medical research budgets. Please join us!

> "I have participated in Hill Day the past few years and find it a privilege and honor to do so. Congress wants/needs to hear the goals of the PFF, and they especially want to hear our stories. Many don't really know the needs of their constituents in the field, especially if they are new. I have been impressed to learn and ask for support in various areas such as the Peer Reviewed Medical Research Program which funds grants for research for many diseases, including pulmonary fibrosis. Each person can make a difference. Join us for Hill Day and let your voice be heard!"
>
> **- Charolette Saunders**
> *PFF Hill Day participant, Lung transplant recipient*

Frequently Asked Questions

When is PFF Hill Day?

Wednesday, March 4, 2026! To participate, you must be available between 9:00 a.m. and 5:00 p.m. in your time zone. Please mark your calendars for the full day.

Where do I register for PFF Hill Day?

Register here by Wednesday, February 18 to participate in PFF Hill Day 2026.

Can I cancel my registration for PFF Hill Day?

The Foundation understands that situations may arise that make it not possible to participate in the full PFF Hill Day. If you are no longer able to participate, **you MUST cancel your registration on or before Wednesday, February 25 by notifying the PFF at advocacy@pulmonaryfibrosis.org or 312.224.9802**. As soon as an individual registers for Hill Day, the PFF begins scheduling meetings with their members of Congress. Congressional offices require at least one week's notice for cancellations. Please only register for PFF Hill Day if you are available **ALL DAY** on March 4.

Is PFF Hill Day held in-person or virtually?

PFF Hill Day is held virtually via Zoom. No need to travel to Washington, D.C.; meet with the offices of your members of Congress from the comfort of your home.

Who should participate in PFF Hill Day?
PFF Hill Day welcomes patients, caregivers, lung transplant recipients, family members, people who have lost a loved one to PF, and healthcare providers to participate. Please note that PFF Hill Day is not open to industry partners or individuals who are not residents of the United States. No previous experience with advocacy is necessary.

If you have ever used supplemental oxygen or cared for someone who has, we <u>ESPECIALLY</u> need your voice to speak on the issues with accessing supplemental oxygen. If you do not have experience with supplemental oxygen, we still strongly encourage you to participate and advocate for all the policy priorities of the PFF.

What should participants expect on PFF Hill Day?
The PFF will schedule meetings with your Senators, Representative, and their staff. To participate, **you must be available between 9:00 a.m. and 5:00 p.m. in your time zone as meetings are scheduled throughout the day**. Most participants will be scheduled for 4-7 meetings of 30 minutes each. All meetings will be held on Zoom.

> "I find it encouraging to speak to the staff of our elected government officials, including my state's Congressmen and Congresswomen and my Senators. This is a unique opportunity to share a personal account of someone who is living with a progressive, incurable disease. It is important for these elected officials, as they prepare the funding recommendations for the federal government, to understand the importance of medical research at the National Institutes of Health and the Department of Defense, especially for rare diseases such as pulmonary fibrosis. We have an additional opportunity to advocate for the SOAR Act. For those of us relying on supplemental oxygen to live an active life, we can relay firsthand experiences with the limitations of Medicare regarding supplemental oxygen access."
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> **- Ken Vella**
> *PFF Hill Day participant, Patient with pulmonary fibrosis*

You will receive your personalized meeting schedule the week prior to Hill Day. The meetings are scheduled by our partner, Advocacy Associates. You will have access to their website to view your schedule, join meetings, and provide feedback on the experience.

Will I meet with congressional offices by myself?
No. You will be in a group of PFF Advocates, and possibly PFF staff, for each meeting to work together to deliver your messages to the office. Group members may be from different states or districts, allowing you to participate in meetings with multiple congressional offices. During the PFF Hill Day training, you will be introduced to your group and have time to prepare for meetings together beforehand.

What will I talk about during my meetings?
You will have the opportunity to educate the congressional staff on PF and ILD, briefly share your experience as a part of this community, and explain why research and access to supplemental oxygen are so important to us. Make your voice heard on Capitol Hill and participate in PFF Hill Day!

What will we ask congressional offices to do?
We need elected officials to understand why it is so important for **PF research to receive robust funding** and why there needs to be **improved access to supplemental oxygen**.

- Fund PF research through the **National Institutes of Health** and the **Congressionally Directed Medical Research Programs**
    - We need elected officials to understand why it is so important for PF research to receive robust federal funding. PF research receives tens of millions of dollars of federal funding each year. Meet with your elected officials and their staff to ensure funding for research continues.

- Improve patients' access to supplemental oxygen
    - In 2026, the PFF is focusing on the Supplemental Oxygen Access Reform (SOAR) Act by asking members of Congress to cosponsor this legislation which will change the way that oxygen is covered for patients who have Medicare. Many patients are currently unable to access the type of oxygen and the appropriate services that they need. We are asking Congress to pass legislation that would fix these issues. In partnership with over 30 other patient advocacy, professional, and industry groups, the PFF is advocating for this change and needs your voice to emphasize this issue.
    - Learn more about supplemental oxygen, the challenges patients on Medicare face in accessing supplemental oxygen, and what the SOAR Act will do to address these challenges in the **SOAR Act One Pager**.

> "I participate in PFF Hill Day because I want to bring attention to this disease and stress the importance of funding for continued research. It is also a great opportunity to discuss the importance of oxygen reform with those that will be casting their vote to get this measure passed. As someone who has lost a loved one to PF, I feel that we are the voices for this disease and we need to ensure we are continually heard until a cure is found."
>
> **- Julie Rossignol**
> *PFF Hill Day participant, Lost a loved one to pulmonary fibrosis*

Will I receive training before PFF Hill Day?
Yes. Training will be held virtually on Zoom on **Wednesday, February 25 from 1:00 p.m. – 2:30 p.m. Eastern Time** (12:00 p.m. – 1:30 p.m. Central Time / 11:00 a.m. – 12:30 p.m. Mountain Time / 10:00 a.m. – 11:30 a.m. Pacific Time / 9:00 a.m. - 10:30 a.m. Alaska Time). The training will cover PFF policy requests, how to prepare for your meetings, and the best practices for engaging with members of Congress and their staff. You will also have the opportunity to meet with your group that you will be working with for meetings on PFF Hill Day.

Will the training be recorded?
Yes. The training will be recorded and shared afterwards with the Hill Day meeting materials. Participants will be able to review them before their meetings on PFF Hill Day.

Is there a deadline to register?
Yes. The deadline to register is Wednesday, February 18.

Is there a cost to participate in PFF Hill Day?
The fee to participate in PFF Hill Day is $25. Scholarships are available to cover the participation fee. Email advocacy@pulmonaryfibrosis.org to inquire about receiving a scholarship.

Do you have a refund policy?
A full refund is available up to one week before the event, through Wednesday, February 25. After February 25, a refund can no longer be offered.

Who do I reach out to if I have any questions?
Please email advocacy@pulmonaryfibrosis.org or call 312.224.9802.

What do I do next?
Sign up to participate in helping your members of Congress understand why pulmonary fibrosis research and access to supplemental oxygen are so critical!

"My participation in Hill Day as a person with a rare incurable disease was empowering. By sharing my story of living with pulmonary fibrosis, I was able to emotionally connect with each congressional representative. I felt they understood our desire for more research opportunities by my words."

- Cheri Riley
PFF Hill Day participant, Patient with pulmonary fibrosis

My first PFF Hill Day was a bit nerve racking, making sure we asked the requests in the time allotted, but with each session I felt not only more comfortable, but empowered that as the stories of those with me were being told we could, and we were making a difference. The congressional staff were seeing faces and hearing what life is like with pulmonary fibrosis and most recently the issues that folks face with oxygen. My hope is as long as I am able, I will plan to be a part of this incredible day, as with all that is going on, continuing to share our faces and stories even if the effects are not felt or seen right away is making an impact and we need to keep pulmonary fibrosis and interstitial lung disease on everyone's radar!

- Lori Flint
PFF Hill Day participant, Registered Nurse