

## PFF Hill Day 2025 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 community. [Register today to join us virtually to advocate for these important issues!](#)

“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*

### Why is PFF Hill Day 2025 so important?

2024 was an incredible year: the PFF joined over 25 other patient, professional, and industry advocacy organizations in successfully advocating for the introduction of the [Supplemental Oxygen Access Reform \(SOAR\) Act](#) in Congress! We ended the year with 40 sponsors and cosponsors for the SOAR Act and excellent momentum to get the bill passed in the new Congress. 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 2025! We will also continue our successful advocacy for federal funding for PF research.

### Frequently Asked Questions

#### When is PFF Hill Day?

Wednesday, March 5, 2025! Mark your calendars from 9:00am – 5:00 p.m. in your time zone.

#### Where do I register for PFF Hill Day?

[Register here](#) by Friday, February 21 to participate in PFF Hill Day 2025.

#### 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 26 by notifying the PFF at [advocacy@pulmonaryfibrosis.org](mailto:advocacy@pulmonaryfibrosis.org) or 312.224.9802.** After you register, the PFF will set up meetings with your members of Congress. The PFF must provide congressional offices **with at least 1 week’s notice** if a meeting is going to be cancelled. Please only register for PFF Hill Day if you are available **ALL DAY** on March 5.

“In 2016 I worked at the U.S. House of Representatives on Medicare issues. I met many people like us who are simply advocating to make Medicare better. The personal stories we tell about our journeys with pulmonary fibrosis MAKE a huge difference! Please join me and others touched by pulmonary fibrosis on PFF Hill Day.”

- Tom Mayes  
*PFF Hill Day participant, Lung transplant recipient*

### **Is PFF Hill Day held in-person or virtually?**

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

### **Who should participate in the virtual PFF Hill Day?**

PFF Hill Day welcomes patients, caregivers, family members, people who have lost a loved one to pulmonary fibrosis, lung transplant recipients, and healthcare providers to participate. Please note that PFF Hill Day is not open to industry partners or individuals who live outside of the United States. No previous experience with meeting with your members of Congress or with advocacy is necessary!

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

### **What should a participant expect on the virtual PFF Hill Day?**

The PFF will schedule meetings for you to meet with your Senators, Representative, and their staff on March 5. You will be scheduled for between 4 and 7 meetings and will receive your timed schedule the week before Hill Day. 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.** All meetings will be held on Zoom. The meetings are scheduled by our partner, Advocacy Associates. You will have access to their platform to find information on your meetings, access the Zoom links for your meetings, and provide feedback on the experience.

### **Will I have to meet with the congressional offices by myself?**

You will be in a group of PFF Advocates and possibly PFF staff for each meeting to work together to deliver your message. The PFF Advocates in your group may be from a different state and/or district from you so you will also meet with their congressional offices. During the PFF Hill Day training, you will be connected to your fellow group members and have the chance to prepare for your meetings together beforehand.

“Participating in Hill Day is one of my favorite Pulmonary Fibrosis Foundation events. It is an opportunity to speak with congressional offices about the things that matter for my patients. In the office patients often ask about the regulations around oxygen or the research that is happening in the field. Hill Day gives me the chance to take those topics out of the office and use my voice to share the voices of the patients I care for every day. It is a unique opportunity to be able to meet with government officials to share the stories of those with pulmonary fibrosis and to encourage our congressional leaders to support research and legislative changes that can impact the lives of the patients I care for today and the patients I will care for in the future.”

**- Jamie Lederer,**  
*PFF Hill Day participant, Nurse practitioner*

## What will I talk about during the virtual PFF Hill Day?

You will have the opportunity to educate the congressional staff on pulmonary fibrosis, briefly share your experience as a member of the PF community, and provide an understanding on why we need their support to improve patients' access to supplemental oxygen and to fund PF research.

## What will we ask congressional offices to do?

- Improve patients' access to supplemental oxygen
  - In 2025, the PFF is focused on asking members of Congress to 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 the Supplemental Oxygen Access Reform (SOAR) Act, legislation that would fix these issues.
  - [Learn more about the Four Pillars for Oxygen Reform that provide the basis of the SOAR Act legislation.](#)
- 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.

"You more than likely won't be addressing the Representative or Senator directly, but rather members of their staff. These are smart and engaged people who will be interested in your presentation. Take these opportunities to impress upon them the need so they can in turn impress it upon their bosses.

Prepare and practice what you want to say. Keep your presentation direct and concise and invite their questions. Remember you are representing the foundation and are charged with a great responsibility in conveying its message."

**- Pete Carran**  
*PFF Hill Day participant, Patient with pulmonary fibrosis*

## Will I receive any training before the virtual PFF Hill Day?

The PFF will provide training for PFF Hill Day on Wednesday, February 26 from 1:00 p.m. – 2:30 p.m. Eastern Time. The training will cover the policy requests of the PFF, how to prepare for your meetings, and the best ways to engage with members of Congress and their staff. You will also have the opportunity to meet with your PFF Hill Day group that you will be working with.

## Will the training be recorded?

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?

The deadline to register is Friday, February 21.

“Each of us has a voice and each one is important. We come from different backgrounds, with varied experiences, and varied paths along the journey of pulmonary fibrosis. Hill Day is an opportunity for those voices to be heard, for language to then be crafted, and for funding to be appropriated for research and eventual treatments and a cure.

17 years ago, when my husband passed away from IPF, there were few support groups, the lone medication was steroids, and supplemental oxygen was a coordinating nightmare. Today there is a registry, support groups, research, and treatments, and all because people used their voices, united voices. Hill Day is one of those opportunities for voices to unite and make a difference.”

**- Marla Brady,**  
*PFF Hill Day participant, Lost a loved one to pulmonary fibrosis*

“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*

### **Is there a cost to participate in Virtual Hill Day?**

The fee to participate in PFF Hill Day is \$25.

Scholarships are available to cover the participation fee. Email

[advocacy@pulmonaryfibrosis.org](mailto: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 26. After February 26, a refund can no longer be offered.

### **Who do I reach out to if I have any questions?**

Please email [advocacy@pulmonaryfibrosis.org](mailto:advocacy@pulmonaryfibrosis.org) or call 312.224.9802 with any questions.

### **What do I do next?**

**[Sign up to participate in helping your members of Congress understand why access to supplemental oxygen and pulmonary fibrosis research are so critical to the PF community!](#)**

“I have participated in Hill Day the past few years and find it a privilege and honor to do so. The Congressman want/need 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 new congressman. 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*