

PFF Hill Day 2024 FAQ

We need YOU to help your members of Congress understand why access to oxygen and pulmonary fibrosis research are so critical to the PF community. If you've ever considered participating in advocacy before, this is the year to join! [Register today to join us virtually on Wednesday, March 6 to advocate for these important issues.](#)

"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 this March 6th."

- Tom Mayes
PFF Hill Day Participant, Lung transplant recipient

Why is PFF Hill Day 2024 more important than ever?

This is a HUGE year for advocacy. We expect that legislation to improve patients' oxygen access will be introduced in Congress soon. This legislation will include changes to help patients get liquid oxygen, add respiratory therapists to make sure patients are getting the correct oxygen, and add a patients' bill of rights for their oxygen services. We need you to ask your members of Congress to pass this legislation, which will be known as the **SOAR Act (Supplemental Oxygen Access Reform Act)**.

Frequently Asked Questions

Where do I register for the Virtual Hill Day?

[Register here](#) by Wednesday, February 21 to participate in PFF Hill Day 2024.

Who should participate in Virtual 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.

"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

Who should participate in Virtual Hill Day? (continued)

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 for Virtual Hill Day?

The PFF will schedule meetings for you to meet with your Senators, Representatives, and their staff on March 6. 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.

“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*

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

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.

What will I talk about during Virtual Hill Day?

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

What will we ask congressional offices to do?

- Improve patients' access to supplemental oxygen
 - In 2024, 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 legislation that would fix these issues.
 - [Learn more about the Four Pillars for Oxygen Reform that will provide the basis of 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.

Will I receive any training before Virtual Hill Day?

The PFF will provide training for PFF Hill Day on Thursday, February 29 from 11:00 a.m. – 12:30 p.m. Central Time. The training will cover the policy requests of the PFF, how to prepare for your meetings, and best ways to engage with members of Congress and their staff. You will also have the opportunity to meet with your PFF Hill Day team that you will be working with. The training will be recorded and shared afterwards with the meeting materials. Participants will be able to review them before their meetings on PFF Hill Day.

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. Please email advocacy@pulmonaryfibrosis.org to inquire about receiving a scholarship.

“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

“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. These are busy people, so you don’t want to waste their time fumbling around. Again, 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

What is the cancellation policy?

A full refund is available up to one week before the event, through Wednesday, February 28, 2024. After February 28, a refund can no longer be offered.

Is there a deadline to register?

The deadline to register is Wednesday, February 21, 2024.

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

Please email 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 oxygen and pulmonary fibrosis research are so critical to the PF community. [Register today to join us virtually on Wednesday, March 6 to advocate for these important issues!](#)

