

MEET with your members of Congress this August

U.S. Senators and Representatives are in their home districts during August. Schedule a visit to meet with your official while they are working locally!

1. Find Your Members of Congress. Visit pulmonaryfibrosis.org/advocacy to identify your U.S. Senators and U.S. Representative.
2. Identify the closest local office. Check each official's website by clicking on the  link. Then, look at the locations of their local offices. Determine which local office is most convenient for you to visit.
3. Make an appointment. After identifying the most convenient local offices of your officials, call each office to make an appointment to meet with the official or a member of their staff. Remember – it is still very helpful to meet with a staff person, even if you are unable to make an appointment with the official!
4. Print out the “asks.” The PFF’s current policy priorities (or “asks”) are on the second page of this handout. Fill in your contact information at the top of the page. Then print out a few copies for each meeting. Next, pick one or more of the “asks” to discuss during your meeting.
5. Meet! During the meeting, remember to identify yourself as someone who lives in the official's district or state and to share your story. Your personal connection is the most important reason for your advocacy! Keep your story brief – less than 5 minutes. Discuss one or more of the PFF's “asks” and leave a copy of the PFF's Policy Priorities (attached).
6. Report on your visit. After the visit, complete the PFF Legislative Advocacy Visit report. The link for the PFF Legislative Advocacy Visit Report is available at pulmonaryfibrosis.org/advocacy.
7. Follow up. Within 48 hours of your meeting, write/email and thank them for their time. This is a must to build relationships. Remember to include your contact information. (And plan your next visit!)



TIPS TO REQUEST AN APPOINTMENT

- Briefly explain that you would like an appointment to talk about the importance of supporting research for pulmonary fibrosis.
- Let them know that you live in the official's state or district.
- Be courteous and persistent. You may need to call a couple of times and be flexible with the date of your visit, but persistence will pay off.



QUESTIONS ABOUT THE ASKS?

Just ask! Contact Kate Gates at kgates@pulmonaryfibrosis.org or 312.224.9820 for more information about the PFF's policy priorities or any other aspect of meeting with your officials.

Contact name: _____

Contact phone number: _____

Contact email: _____

Pulmonary Fibrosis Foundation 2019 Policy Priorities

Pulmonary fibrosis (PF) is becoming less and less rare. This group of deadly lung diseases affects 200,000 Americans and results in 40,000 deaths annually – one every 13 minutes. 50,000 new cases are diagnosed each year and there is no known cure. The annual per capita cost of healthcare for patients with idiopathic pulmonary fibrosis (IPF), one form of PF, is estimated to be twice as high as healthcare costs for age-matched patients without IPF.

The Pulmonary Fibrosis Foundation (PFF) mobilizes people and resources to provide access to high-quality care and leads research for a cure so people with pulmonary fibrosis (PF) will live longer, healthier lives.

It will take everyone working together to create a different outcome for those with PF. We ask members of the 116th Congress to join us in this nonpartisan, life-saving fight.

1. Support a \$2.5 billion increase for the National Institutes of Health and a proportionate increase in NIH funding for pulmonary fibrosis research at the National Heart, Lung, and Blood Institute

We ask that officials support a \$2.5 billion, or 6.4%, increase for the National Institutes of Health (NIH) in fiscal year 2020. The NIH is the world's biggest public funder of medical research. The NIH has funded research into areas such as familial PF and the benefits of pulmonary rehabilitation for PF patients. We urge Congress to support a corresponding 6.4% minimum increase in funding for pulmonary fibrosis research through the National Heart, Lung, and Blood Institute (NHLBI) at the NIH.

2. Support pulmonary fibrosis research through the Congressionally Directed Medical Research Programs

We ask that officials support full funding for the Congressionally Directed Medical Research Programs (CDMRP) in the National Defense Authorization Act for Fiscal Year 2020. Through the CDMRP's Peer Reviewed Medical Research Program, Service Members, Veterans, and the PF community have benefited from over \$38 million in PF research funding.

3. Raise awareness of barriers to oxygen

We ask that officials work with us to identify solutions to the barriers that patients in your community face to receiving the necessary supplemental oxygen. 51% of oxygen users report problems with supplemental oxygen. Barriers to adequate supplemental oxygen provision include inadequate access to high flow oxygen and a lack of portable options.¹ The PFF is collaborating with other patient organizations to develop a plan to address supplemental oxygen access and reimbursement issues.

¹ S. S. Jacobs, K. O. Lindell, E. G. Collins, C. M. Garvey, C. Hernandez, S. McLaughlin, A. M. Schneidman, P. M. Meek, "Patient Supplemental Oxygen Survey: Results of the American Thoracic Society (ATS) Nursing Assembly Oxygen Working Group," abstract, *American Journal of Respiratory and Critical Care Medicine* 2017, 195(May 2017), http://www.atsjournals.org/doi/abs/10.1164/ajrccm-conference.2017.195.1_MeetingAbstracts.A7645

Pulmonary Fibrosis

FOUNDATION

230 EAST OHIO STREET, SUITE 500
CHICAGO, ILLINOIS 60611
844.TALKPFF