



## 10 Steps to Planning a Legislative Advocacy Visit

1. Determine who your U.S. Representative and U.S. Senators are at [PulmonaryFibrosis.org/Advocacy](https://www.pulmonaryfibrosis.org/advocacy). Note their phone numbers and contact information.
2. Research your Representatives and Senators to find connections, shared interests, alma mater, residency, and anything that can provide a common talking point. You want to begin to build a relationship with this person.
3. Determine which actions you want to pursue:
  - In-district visit with legislator and/or legislative staff. **Highly recommended.**
  - Attend a town hall in your area.
  - Plan a Washington, D.C. visit to meet with the legislator/legislative staff.
  - Attend an event where the legislator will be present.
  - Invite your legislator to your special event or fundraiser.
4. Visit [PulmonaryFibrosis.org/Advocacy](https://www.pulmonaryfibrosis.org/advocacy) to identify your “ask(s)” and personalize them as appropriate. *Limit your “asks” to three.*
5. Contact your Representative’s or Senator’s office to request a time for a meeting. Be prepared to follow up – you may need to call a couple of times and be flexible with the date of your visit, but persistence will pay off.
6. Identify statistics to share with your legislator. (See page 2 for quick facts.)
7. Before the meeting, check in with the PFF for current one page “leave behinds” that you can print and leave with your legislator’s office. Print copies of the “PF Fact Sheet” from [PulmonaryFibrosis.org/Advocacy](https://www.pulmonaryfibrosis.org/advocacy) or order free copies from the Patient Communication Center at 1.844.825.5733 / [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).
8. 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! Leave your personal business card or contact information.
9. 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](https://www.pulmonaryfibrosis.org/advocacy).
10. Follow up, follow up, follow up!
  - Within **24 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!)
  - Within **48 hours** of your meeting, write letters of support or concern to your local newspaper, post on social media, etc.
  - Within **72 hours** of your meeting, recruit other PF patients, family members, or caregivers, and THEIR members of Congress
  - On **Election Day**, vote!

# Effective Advocacy for the Pulmonary Fibrosis Community



Combine your personal story with motivating universal facts. Examples of compelling PF facts:

- There are **200,000 Americans** living with pulmonary fibrosis.
- IPF alone takes the lives of about **40,000 people** in the U.S. each year – that’s approximately **110 deaths each day or 1 death every 13 minutes!**
- Annual healthcare costs for treating IPF patients in the U.S. are **over \$2 billion per year.**
- Despite the prevalence of pulmonary fibrosis, over the last four fiscal years (FY2015 – FY2018), a mere **0.18% of the National Institutes of Health (NIH) budget** was dedicated to PF research.

## Know and use facts in your meetings

For example, “If a natural disaster were claiming so many American lives each year, we all know that the nation would commit itself to a massive response to turn the tide. Not so with PF. The total spending on PF research by the NIH in the most recent year for which data are available was less than one fifth of one percent of the total NIH budget.”

## Discover the research dollars allocated to your community

Consult with the Federation of American Societies For Experimental Biology (FASEB) at **FASEB.org**.

1. Find information on funding under the “Science, Policy, Advocacy, & Communications”
2. Choose “Federal Funding Data” from the dropdown menu
3. Click on the “Federal Funding by State and District” tab from the menu on the right
4. Finally, search for your district and state to find the funding information to share with your legislators. Print copies to leave behind with your legislators.

## Articulate your “ask”

Know precisely what you want your Representative or Senators to do. Contact the PFF to ask for updates on current policies and legislation. Examples of clear “asks”:

- Proportionate research investments: “Pulmonary fibrosis research investments should be established by the National Institutes of Health at levels comparable to those of similarly prevalent diseases.”
- Oxygen: “Nothing is more important than oxygen yet PF patients often have difficulty accessing reliable, affordable, and sufficient flow volumes for daily living. Please support improved oxygen supply and funding through Medicare and Medicaid.”
- For specific legislation: “Please sign on as a co-sponsor to **[insert bill number and name]**.” OR “Please sign on as an enthusiastic supporter of **[insert bill number and name]**.”

**Face-to-face meetings are the most effective way to build relationships, but there are other important ways to follow up with your legislators.**

- Email your legislator with an update regarding the “ask” for the pulmonary fibrosis community.
- Email your official with pulmonary fibrosis statistics, other pertinent information from your district/State, and a brief summary of your connection with pulmonary fibrosis.
- Request a Proclamation for Pulmonary Fibrosis Awareness Month (September). This should be done in July to allow time for preparation.