Congressional Recess Toolkit:
Telling Your CF Story to Your
Members of Congress

Why is sharing your CF experience during congressional recesses important?
Congressional recesses, also known as district work periods, occur regularly throughout the year and provide an important opportunity to meet with your members of Congress in your home state or district. While away from the distractions of Capitol Hill, members of Congress typically have more time to devote to constituent meetings. And these in-district meetings can go a long way toward building a strong relationship with your lawmakers!

With a little planning and preparation, you can use an upcoming congressional recess to hold impactful meetings with your members of Congress to introduce yourself and your/your loved one’s experience with cystic fibrosis. After all, our personal stories are the most powerful tool we have to ensure that lawmakers create health care policies that address the needs of people living with CF and other pre-existing conditions.

This toolkit provides the information you need to schedule, conduct, and follow up on a successful in-district meeting with your members of Congress. It addresses:

- **In-District Meetings**: How to schedule a meeting with members of Congress in-person while they are home during a congressional recess.

- **Personal Story Planning**: How to tell your personal story to your members of Congress.

- **Background Material**: How to answer questions about the Foundation’s current advocacy efforts.

- **Meeting Follow-Up**: How to follow up with your member of Congress after your meeting to continue building your relationship.

- **In-District Meeting Feedback Form**: Don’t forget to let our team know about your meetings!

- **Social Media**: How to engage with your lawmakers and the Cystic Fibrosis Foundation before and after your scheduled meetings.

*The Congressional Recess Toolkit is made publicly available by the Cystic Fibrosis Foundation on cff.org to volunteer advocates.*
In-District Meetings

Congressional recesses offer a great opportunity to meet with your members of Congress while they are at home and away from the distractions of Capitol Hill. These meetings will help foster positive and productive relationships with your members of Congress and help to ensure that they better understand the special health care needs of people with cystic fibrosis.

Visit www.senate.gov or www.house.gov and enter your zip code to identify your members of Congress and their contact information. Then, follow the steps below for a successful in-district meeting.

How to Request a Meeting

Call the district office closest to your home. The appropriate contact information can be found on your member’s website.

Be sure to identify that you are a constituent and that you are requesting a meeting with your member of Congress while they are on recess. If the lawmaker is unavailable, ask to meet with the member of their staff who works on health care issues. While meeting with the lawmaker is preferable, meetings with staffers are also beneficial.

You may be asked to send your request in writing to the office scheduler via email. In that event, use the sample language below.

Sample Meeting Request Email:

Subject Line: Meeting Request with [Lawmaker’s Title and Name] During Congressional Recess

Dear [Name of Scheduler]/Office of [Legislator Title] [Legislator Last Name],

I respectfully request a meeting with [Legislator Title] [Legislator’s Last Name] for [Volunteer First Name] from [Volunteer’s City/Town] during the upcoming congressional recess. [Volunteer First Name/I] would like to discuss their/my personal experiences with cystic fibrosis and the importance of preserving adequate and affordable access to quality, specialized CF care.

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 children and adults in the United States. While great progress has been made since the 1950s, CF still has no cure. The degenerative disease is challenging to navigate and expensive to treat, and people with cystic fibrosis need investments in research and drug development, as well as access to adequate, and affordable health care in order to live full lives.

Thank you in advance for your consideration. I look forward to our discussion.

Best,

[Your Name]
Preparing for an In-District Meeting
1. After you have scheduled the meeting, contact your local Foundation chapter or the Cystic Fibrosis Foundation to let us know! We can help you prepare for your meeting by providing talking points and materials.
2. Visit the lawmaker’s website, Facebook page, or Twitter feed to see the member’s most recent statements and positions on health care. If your member is new to Congress, do some research about their health care positions.
3. Print or prepare your visual aids. Send what you can ahead of time via email as well.
4. Practice your personal story and review the in-district meeting checklist below.

What to Wear and Bring to the Meeting
1. Dress professionally.
2. Bring photos of your loved one(s) with CF, or any other visual aids that help convey your personal story (e.g. pill bottles, a vest).
3. Bring the leave-behind materials provided by the Foundation.
4. Bring a business card or a leave-behind material that includes your contact information.

In-District Meeting Checklist
The goal of your meetings is to show lawmakers how cystic fibrosis impacts people in their local community, while also building a positive relationship with him or her. Use this checklist to guide your conversation during the meeting, connecting your personal story to the need for access to adequate and affordable, specialized CF care.

1. Explain CF: Even if you’ve met with your lawmaker before, it’s always helpful to remind them of the basics of cystic fibrosis. For example, “I’d like to tell you about cystic fibrosis...”
2. Tell your personal story: Explain your connection to CF and talk about your/your loved one’s coverage. Use the personal story planning sheet provided below to prepare.
3. Make the policy ask: Connect your personal story to the specific position or action the member of Congress can take.
   a. When you consider health care policies, please remember the needs of people with CF. Specifically:
      i. People with CF and other serious, chronic conditions must have comprehensive health insurance that covers the full range of care and services they need to stay healthy.
      ii. Support robust, reliable funding for the National Institutes of Health (NIH) and the U.S. Food and Drug Administration (FDA). In fiscal year 2020, please provide:
         • $41.6 billion for the NIH—a $2.5 billion increase over fiscal year 2019; and
         • $3.4 billion in funding for the FDA—including a $316 million increase in medical product program funding.
4. Thank your member of Congress!
5. Ask to take a photo: Ask to take a photo with the lawmaker or staff at the end of your meeting to share on social media using #CFadvocacy. Reference the “Social Media” section at the end of this toolkit for additional tips.
Personal Story Planning

Use the questions below to develop your personal story. After you explain the basics of cystic fibrosis in your meeting, include the answers to 2-3 questions below in your story.

Note: The amount of information you share about your family’s experience with CF is entirely up to you – please do not feel you need to share more than you are comfortable sharing.

1. What kind of insurance do you or your loved one with CF have?
   - Employer insurance
   - Individual marketplace
   - Public plan (e.g. Medicaid, Children’s Health Insurance Program, Medicare, state plan, Tricare/military, etc.)
   - Other (explain what type in your meeting)

2. How do you explain CF to people who don’t know about it? How can you describe the daily treatment regimen? (Try to stay away from complicated terms like “nebulizer” or “PICC line” that people might not understand. Instead, describe the treatment in simple terms.)

3. What pictures or visual aids (e.g. pill bottles, a vest) could you bring to your meeting to help illustrate life with CF?

4. What is your biggest wish for yourself/your loved one with CF?

5. In the past year, what was the largest CF-related challenge you/your loved one faced?

6. Describe a moment that made you feel hopeful for the future of CF.

7. Describe a moment when you/your loved one felt isolated due to CF.

8. Identify something you/your loved one living with CF missed out on because of CF.

9. What are your biggest worries for the future for you/your loved one with CF?

10. Which CF-related news made you the most frustrated or was the hardest to hear?
Background Material

The Foundation has a variety of materials on our website to help you prepare for your meeting. In the days before your scheduled visit, use our website and social media accounts to familiarize yourself with the Foundation’s current initiatives and programs that support individuals living with CF and their loved ones. These materials include:

1. **4 Tips for Telling Your CF Story to Legislators**: Learn four tips for telling your story effectively and efficiently to engage lawmakers and inspire them to act.

2. **Why We Must Advocate**: Read a blog post by CF advocate Austin Faught, who started advocating for those living with CF in 2016 when his health insurer dropped his son’s CF care team from its plan. In his blog post, he describes that advocating gets easier with practice.

3. **Current Advocacy Actions**: Visit act.cff.org to learn about the Foundation’s current campaigns and issues of focus. You can also sign up for advocacy action alerts if you haven’t done so already.

4. **Our Advocacy Work**: Dive deeper into the programs, agencies, and policies that help advance research and drug development, improve access to specialized, high-quality CF care, and raise awareness about the disease.

5. **Our Policy Priorities**: Learn about the Foundation’s policy priorities principles that guide our work to ensure people with CF have access to high-quality, specialized care.

6. **Foundation Press Releases**: Read our latest press releases and statements about administrative and congressional actions.

7. **Watch Teens Make Their Voices Heard on Capitol Hill**: Watch our latest advocacy video featuring footage captured by teens at the 10th annual Teen Advocacy Day.
Meeting Follow-Up

After meeting with your member of Congress, follow up with both the congressional office and the Foundation. If you are asked a question that you don’t know how to answer, tell the lawmaker that you will follow up. The Foundation is always available to assist in responding.

Follow Up with the Congressional Office
Sample language for a follow-up email is below, but please make it personal by mentioning your/your loved one’s experience with CF and any topics that were addressed during your meeting.

Sample Follow-Up Email
Subject: Following up on Today’s Meeting about Cystic Fibrosis

Dear [Legislator/ Staffer Title] [Legislator/ Staffer Last Name],

Thank you for taking the time to meet with me on [date of your meeting] to discuss cystic fibrosis and how it impacts me/my family/loved one. It was a pleasure to meet you and discuss issues that impact individuals with CF.

Preserving access to high-quality, specialized care is crucial to those with CF and other rare diseases. We urge the [Senator/Representative/you] to work toward a system that preserves health care for people living with cystic fibrosis.

Again, thank you for meeting with me. I look forward to working together in the future to ensure adequate and affordable health care is accessible for people living with CF.

If you have any questions, please contact me or Jonathan Daniels, the Cystic Fibrosis Foundation’s policy & advocacy manager, at jdaniels@cff.org.

Best,
[Your name]
[Your contact information]

Follow Up with the Cystic Fibrosis Foundation
Let us know how your meeting went by submitting an In-District Meeting Feedback form. This form is a great place to include questions that required follow-up with the member’s office so that our staff can help. If necessary, a representative from the Foundation will follow up with you.
Social Media

Active on social media? Talk about your time with your member of Congress. Use the hashtag #CFadvocacy and tag the Foundation (and your lawmakers’ official accounts) before and after your meetings. You can use social media to say “thank you” for the meetings, or to share any photos taken with your lawmaker or their staff. See below for our accounts on Twitter, Instagram, and Facebook:

- Twitter: @CF_Foundation
- Instagram: @CF_Foundation
- Facebook: @CysticFibrosisFoundation