

NATIONAL DAY OF ACTION

Monday, June 29, 2020

Tips for Being an Effective Advocate (DOs and DON'Ts)

How can I effectively ask my member of Congress to support these issues if I can't explain them?

There is no expectation that you will be an expert on the issues. We will provide brief, straightforward information for you to prepare for virtual meetings and to draft your emails. In meetings, it is entirely appropriate to speak from prepared notes.

If I were to do one thing to prepare, what would that be?

You are the expert of *your* story. Your main task will be to share *briefly*—in less than 5 minutes—how scleroderma affects you, and why support of these issues from your member of Congress is important to you.

How can I possibly explain how scleroderma affects me and my family in just a few minutes?

That is a challenge. Think of it like this—in those 5 minutes, you want to ask them to support the bill *and* share how it affects you. Best to assume they have never heard of scleroderma. That is a lot to pack into 5 minutes, but it can be done effectively.

How do I touch each of those points in just a few minutes?

Break it down into individual parts and be as succinct as possible:

1. Introduce yourself as a representative of the Scleroderma Foundation.
2. *What is the purpose of the meeting?* **To ask the member for their support.**
3. *What is scleroderma?* **Assume the person you are meeting with has never heard of scleroderma.**
4. *How does scleroderma affect you?* **This is your time to make an impactful impression.**
5. *Wrap up by restating why you are meeting with the member of Congress.* **Ask the member to support the three issues important to the scleroderma community.**
6. Let them know you will follow up next week.

Example that follows the formula:

1. *"Thank you for meeting with us today. My name is Jane, and I am representing the Scleroderma Foundation."*
2. *"We need the Congresswoman to support issues important to the scleroderma community. Our bill is H.R. 3446, which would establish a National Commission on Fibrotic Diseases within the National Institutes of Health to recommend improvements regarding fibrosis and fibrotic disease research. The bill is bipartisan and budget neutral."* **WHY you are meeting is an essential part of what you say.**
3. *"Scleroderma is a rare autoimmune disease that affects about 300,000 people..."*

4. *“Before I was diagnosed in 2013, I was an avid runner. Today... [then and now photos can be very impactful]. These are a few examples of what scleroderma has taken from me and my family.”* **Share enough information to make a strong point. Using your entire time to tell your story in detail could result in no time to ask for their support (the goal).**
5. *“Scleroderma affects thousands of the Congresswoman’s constituents in our state, and we are asking her to consider supporting this bipartisan bill that will not cost the federal government a dime. We have almost 2,500 signed letters from her constituents asking her to support these issues.”* **Wrap up by restating why you wanted to meet with them (to ask for their support).**
6. *“I may not be able to answer questions you may have, but I will find out and get back to you next week. Thank you for taking the time to meet with us today.”* **Take notes of your conversation, questions asked, requests for more information, etc. Email that to advocacy@scleroderma.org.**

Is there a resource to help me focus my scleroderma story into concise, impactful points?

Yes. Look for My Scleroderma Story under TOOLS TO HELP YOU PREPARE. This document is a resource designed for anyone affected by scleroderma—whether you are someone who has scleroderma, a caregiver, a spouse or partner, a parent or child, a family member or friend.

If I call my Representative’s or Senators’ offices, should I expect to meet to them?

Most likely, you will meet with a staff person who focuses on healthcare related issues for the member of Congress. Meeting with staff members is an effective way to gain the member’s support. Staff are much more accessible. Following up regularly helps to build a relationship with the member’s office.

It seems like we restart this process with every new session of Congress. Why do we bother?

Once our bill is introduced, we activate our grassroots advocacy and outreach efforts. Advocates around the country raise awareness by educating elected officials about the needs of the scleroderma community. It is an ongoing process. Making your voice heard does affect change.

Our legislative work starts again with every new session of Congress, and we have had great successes in the past. Scleroderma awareness among elected officials is the highest it has ever been. Progress occurs when each person shares what is happening within the scleroderma community in their congressional districts. Awareness raised in the Senate helps us to keep scleroderma listed as an approved condition for certain research funds through the Department of Defense—a process that we must do annually.