



The Scleroderma Foundation's advocacy efforts remain a priority during the COVID-19 (coronavirus) pandemic. To maximize our grassroots efforts across the country during the current situation, a virtual **National Day of Action** is scheduled for **Monday, June 29, 2020**.

The health, safety and well-being of everyone within the scleroderma community is of paramount importance to us. Fortunately, we can effectively communicate with Members of Congress from home by email, phone and video meetings. Your active participation helps us educate Members of Congress with increased awareness of scleroderma, how it affects you, and what Congress can do to support those living with scleroderma.

We encourage our community to call and/or email your representatives to discuss the Scleroderma Foundation's policy priorities. Whether you are a seasoned advocate or completely new to this process, the National Day of Action is designed to make it easy to ask your elected officials to support issues important to the scleroderma community.

Take Action:

- **Email** your Senators and Member of the House of Representatives to share your scleroderma experience and ask them to help us (*information on the ask provided below*).
- **Call** the offices of your Senators and Member of the House to share your scleroderma experience and ask them to help us (*information on the ask provided below*).

Make Virtual Visits:

If you live within the [boundaries of a Scleroderma Foundation chapter](#), please contact chapter leadership before scheduling a meeting. A group of constituents meeting together with a Member of Congress (or their staff) can be much more effective.

To find and contact your U.S. Senator:

1. Visit the Senate website at www.senate.gov.
2. Conduct a search using the **Find Your Senators** pull-down menu in the upper right corner (select your state and click Go).
3. On the results page is a link to the Senators' websites, contact information, and links to an online contact form (forms vary by Senator).

To find and contact your U.S. Representative:

1. Visit the House of Representatives website at www.house.gov.
2. Conduct a search using the **Find Your Representative** ZIP Code search box in the upper right corner (enter your ZIP Code and click Go).
3. On the results page is a photo of your Representative(s), links to the Representative's website, an online contact form, and a local map.
4. If your ZIP Code overlaps multiple congressional districts, the results page will include boxes for you to enter your ZIP Code+4 or street address to find your Representative.



LEGISLATIVE AGENDA – 116th CONGRESS, 2nd SESSION

About Scleroderma:

Scleroderma is a chronic connective tissue disease affecting approximately 300,000 Americans. The word *scleroderma* means hardening of the skin, which is one of the most visible manifestations of the condition. The cause of this progressive and potentially fatal disease remains unknown. There is no cure, and treatment options are limited.

Symptoms vary greatly and are dependent on which organ systems are impacted. Prompt diagnosis and treatment by a qualified physician may improve health outcomes and lessen the chance for irreversible damage. Serious complications of the disease can include pain, skin ulcers, anemia and pulmonary hypertension.

About the Scleroderma Foundation:

The Scleroderma Foundation is dedicated to the concerns of people whose lives have been impacted by the autoimmune disease scleroderma, also known as systemic sclerosis, and related conditions. The foundation's mission is to **1)** support individuals affected, **2)** promote education and public awareness, and **3)** advance critical research and improve scientific understanding to improve treatment options and find the causes and a cure. The foundation has a research program that funds clinical research to find the cause and cure for scleroderma and related conditions.

FY 2021 Funding Priorities:

- **Please work with your colleagues to support the \$5 million Scleroderma Peer-Reviewed Research Program in FY 2021.** Scleroderma had been part of PRMRP research activities since FY 2005, which has resulted in over \$10 million in research funding. The onset of scleroderma is linked to environmental triggers, including occupational silica and jet fuel that place members of the military at an elevated risk. The new specific scleroderma program will continue the advances in research that benefits the scleroderma community.
- **Please provide the National Institutes of Health (NIH) with at least \$44.7 billion in FY 2021.** While NIH supports a scleroderma research portfolio, years of near level funding and sequestration have significantly reduced research resources. This funding increase will ensure that NIH can continue to expand and advance the research portfolio in this area.
- **Please preserve basic patient protections from the Affordable Care Act including:**
 - Prohibiting insurer discrimination against pre-existing conditions.
 - Allowing young adults to stay on their parents' insurance until the age of 26.
 - Establishing out-of-pocket maximums for covered services.
 - Prohibiting annual and lifetime caps on insurance coverage.

These protections have made it possible for patients living with chronic disease to obtain insurance coverage that protect them from stratospheric medical bills.

2020 Policy Priorities:

Click the link on each bill number to read the bill, see current cosponsors and follow its progress.

H.R. 3446 and **S. 2477**, the *National Commission on Scleroderma and Fibrotic Diseases* will establish a national commission within the National Institutes of Health (NIH) to evaluate, coordinate, improve and advance NIH-supported research related to fibrosis and fibrotic diseases, which may include scleroderma as a prototypical condition that can cause fibrosis in various organs.

At no additional cost to the federal government, the *National Commission on Scleroderma and Fibrotic Diseases Act* establishes a national commission to include the following:

- Study of the incidence, duration and mortality rates of fibrotic diseases.
- Evaluate facilities and resources for the diagnosis, prevision and treatment of fibrotic diseases.
- Develop a long-range plan that establishes NIH collaboration within a working group focused on fibrotic-related research.

How Members of the House Can Co-Sponsor H.R. 3446:

Please cosponsor H.R. 3446, the *National Commission on Scleroderma and Fibrotic Diseases Act* by contacting Deena Tauster (Deena.Tauster@mail.house.gov) in the office of Congressman Peter King at 5-7896 or Sahil Chaudhary (S.Chaudhary@mail.house.gov) in the office of Congressman Eliot Engel at 5-2464.

How Members of the Senate Can Co-Sponsor S. 2477:

Please cosponsor S. 2477, the *National Commission on Scleroderma and Fibrotic Diseases Act* by contacting Gil Ruiz (Gilbert_Ruiz@gillibrand.senate.gov) in the office of Senator Gillibrand at 4-4451.

ISSUE BRIEF – ASK #1

Support Meaningful Funding for Medical Research

This issue is of interest to members of the Appropriations Committee.

Background:

The National Institutes of Health (NIH) forms the cornerstone of this nation's biotechnology industry. NIH supports basic, translational and clinical research into various diseases and disorders, including scleroderma. This federally funded research often serves as a catalyst with industry turning medical breakthroughs and scientific advancements into innovative therapies and cutting-edge diagnostic tools.

Congress funded NIH at \$41.6 billion, an increase of approximately \$2 billion from FY 2019. Congress is again working through the appropriations process for fiscal year (FY 2021), and it is important to let our legislators know that we support consistent and predictable funding increases for NIH in the next appropriations cycle.

Talking Points:

- The National Institutes of Health supports research into scleroderma, primarily through the National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).
- Our community thanks Congress for providing the approximate \$2 billion increase for NIH in FY 2020 that will assist research activities at a time when there are many emerging opportunities to advance our scientific of scleroderma.
- Our overarching concern is that without continued meaningful financial support, the development of treatment options will be delayed, and we may lose the next generation of talented young investigators to foreign competition and other fields.
- To fully capitalize on innovative research projects investigating scleroderma, please work with your colleagues to provide NIH with \$44.7 billion in FY 2021.

Please look to see if your Representative or Senator is on the [House Committee on Appropriations](#) or [Senate Appropriations Committee](#) as they have influence to **increase** NIH's funding.

ISSUE BRIEF – ASK #2

Support Continued Research through the Department of Defense

This issue is of interest to members of the [Appropriations Committee](#).

Background:

The Department of Defense (DoD) supports medical research into conditions that impact veterans and active duty military personnel through several programs with eligible condition including the Scleroderma Peer-Reviewed Medical Research Program. Unlike NIH, which funds any meritorious research proposal, the Scleroderma Peer-Reviewed Medical Research Program only funds research into scleroderma.

Before our own program, scleroderma had been listed regularly as an eligible condition in the broader Peer-Reviewed Medical Research Program since FY 2005. As a result, over \$10.5 million has funded important scleroderma research projects through the PRMRP. In fact, in FY 2013 alone, three new scleroderma research projects were supported. There is a strong connection between environmental exposures and the onset of autoimmune diseases, which leaves military personnel at risk for developing conditions like scleroderma. Further, scleroderma impacts military personnel because the scarring associated with the disease process has broad applications to combat injuries. These connections make scleroderma a good candidate for study through DoD research activities.

Scleroderma now has a separate dedicate program entitled the Scleroderma Peer-Reviewed Medical Research Program that Congress created in FY 2020. Currently, we need to thank legislators for their support and ask them to continue supporting the \$5 million Scleroderma Peer-Reviewed Research Program at the Department of Defense.

Talking Points:

- Since FY 2005, scleroderma has been listed as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP). This funding opportunity has resulted in more than \$10.5 million in scleroderma research.
- In FY 2020, Congress created the Scleroderma Peer-Reviewed Medical Research Program funded at \$5 million specifically for scleroderma research.
- Please work with your colleagues to support the \$5 million Scleroderma Peer-Reviewed Research Program in FY 2021.

Members of the Senate Department of Defense Subcommittee:

[Sen. Richard Shelby](#) (R-AL), Chair
[Sen. Mitch McConnell](#) (R-KY)
[Sen. Lamar Alexander](#) (R-TN)
[Sen. Susan Collins](#) (R-ME)
[Sen. Lisa Murkowski](#) (R-AK)
[Sen. Roy Blunt](#) (R-MO)
[Sen. Jerry Moran](#) (R-KS)
[Sen. John Hoeven](#) (R-ND)
[Sen. John Boozman](#) (R-AR)
[Sen. Lindsey Graham](#) (R-SC)

[Sen. Richard Durbin](#) (D-IL), Vice Chair
[Sen. Patrick Leahy](#) (D-VT)
[Sen. Dianne Feinstein](#) (D-CA)
[Sen. Patty Murray](#) (D-WA)
[Sen. Jack Reed](#) (D-RI)
[Sen. Jon Tester](#) (D-MT)
[Sen. Tom Udall](#) (D-NM)
[Sen. Brian Schatz](#) (D-HI)
[Sen. Tammy Baldwin](#) (D-WI)

ISSUE BRIEF – ASK #3

Cosponsor the *National Commission on Scleroderma and Fibrotic Diseases Act of 2019* H.R. 3446 and S. 2477

This issue is of interest to members of the [HOUSE Energy & Commerce Committee](#) and the [SENATE Health, Education, Labor and Pensions \(HELP\) Committee](#).

Background:

Scleroderma is a prototypical condition for studying all fibrotic disease because scleroderma can cause fibrosis in different parts of the body. On an annual basis, fibrotic illness is incredibly costly in terms of healthcare dollars and human life. NIH conducts research into various organs and diseases, but this research is not coordinated or organized. Research in this area could advance much more quickly if a cross-cutting plan were laid out that ensures information is shared and breakthroughs in the underlying mechanisms of disease apply to all fibrotic illness.

The Challenge:

The National Institutes of Health (NIH) is part of the federal government and the world's foremost medical research entity. On an annual basis, NIH supports research projects that advance our scientific understanding of the mechanisms of various diseases, including scleroderma. Medical breakthroughs facilitated by NIH research are often what industry uses to develop new therapies, cures and diagnostic tools.

Currently, research is limited to respective institutes such as the National Heart, Lung and Blood Institute for pulmonary and cardio fibrosis and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for cystic fibrosis and liver cirrhosis. All institutes should be working together in conjunction to use their resources effectively for quality research.

The Solution:

Congressman Peter King of New York and Congressman Eliot Engel of New York are leading *National Commission on Scleroderma and Fibrotic Diseases Act of 2019 (H.R. 3446)*. Senator Gillibrand introduced the Senate version S. 2477.

This bill will establish within the National Institutes of Health (NIH), a National Commission on Fibrotic Diseases to evaluate and make recommendations regarding improvements to the coordination and advancement of NIH-supported research activities related to fibrosis and fibrotic diseases, which may include scleroderma as a prototypical condition that can cause fibrosis in various organs. At no additional cost to the federal government, the *National Commission on Scleroderma and Fibrotic Diseases Act* establishes a national commission to:

- Study of the incidence, duration and mortality rates of fibrotic diseases.
- Evaluate facilities and resources for the diagnosis, prevention and treatment of fibrotic diseases.
- Develop a long-range plan that establishes NIH collaboration within a working group focused on fibrotic-related research.

Important political facts about this legislation:

- It is bipartisan with support from both Democrats and Republicans.
- It is budget neutral. The bill will not increase federal spending.
- It is not disease specific. The bill would help scleroderma and all fibrotic illness.

For this important bill to move through the legislative process and become law, additional Representatives need to support the measure by cosponsoring H.R. 3446.

Talking Points (or Reading Points – *perfectly fine to read from prepared notes to stay on track*):

- Currently, NIH conducts research into multiple fibrotic diseases impacting multiple organ systems, but this research is silo-ed and conducted at multiple NIH Institutes and Centers.
- The bipartisan National Commission on Scleroderma and Fibrotic Diseases Act (H.R. 3446) calls on medical experts to work with the NIH to prepare a comprehensive, long-range research plan that coordinates efforts to advance fibrotic disease research.
 - **[Senator]**, Please cosponsor S. 2477, the *National Commission on Scleroderma and Fibrotic Diseases Act* by contacting Gil Ruiz (Gilbert_Ruiz@gillibrand.senate.gov) in the office of Senator Gillibrand at 4-4451.
 - **[House Member]**, Please cosponsor H.R. 3446, the *National Commission on Scleroderma and Fibrotic Diseases Act* by contacting Deena Tauster (Deena.Tauster@mail.house.gov) in the office of Congressman Peter King at 5-7896 or Sahil Chaudhary (S.Chaudhary@mail.house.gov) in the office of Congressman Eliot Engel at 5-2464.
 - **[House Member – if already a cosponsor]**, Thank you for supporting the scleroderma community...

Before communicating with your elected officials, check to see if your Representative is a member of the House [Energy & Commerce Committee](#) or the Senate [Health, Education, Labor & Pensions \(HELP\) Committee](#).

These committees are key committees to advancing our bill, and it is an important point to make in your communications.

SAMPLE PHONE CALL SCRIPT:

Good Morning/Afternoon,

My name is _____, and I live in _____ (city/state – *establishes that you are a constituent in their congressional district*).

I am an advocate with the Scleroderma Foundation, a nonprofit organization dedicated to the concerns of people whose lives have been impacted by the autoimmune disease scleroderma, also known as systemic sclerosis, and related conditions.

The Scleroderma Foundation’s mission is to **1)** support individuals affected by scleroderma, **2)** promote education and public awareness, and **3)** advance critical research and improve scientific understanding to improve treatment options and find the causes and a cure. The foundation funds clinical research to find the cause and cure for scleroderma and related conditions.

Scleroderma is a chronic connective tissue disease affecting approximately 300,000 Americans. The word *scleroderma* means hardening of the skin, which is one of the most visible manifestations of the condition. The cause of this progressive and potentially fatal disease remains unknown. There is no cure, and treatment options are limited.

Symptoms vary greatly and are dependent on which organ systems are impacted. Prompt diagnosis and treatment by a qualified physician may improve health outcomes and lessen the chance for irreversible damage. Serious complications of the disease can include pain, skin ulcers, anemia and pulmonary hypertension.

Share a glimpse into your scleroderma story. Be concise and let them know how scleroderma has affected your life. Consider developing 2 or 3 impactful statements or examples to share. You will not have time to share a timeline or full story.

I am calling today to ask for _____ (Name of Senator or Representative)’s help.

I realize the country is dealing with the coronavirus outbreak, and we appreciate your efforts with this critical issue. However, we know that your work on other important issues continues, and we need your help.

We ask for support in increasing funding at the National Institutes of Health, cosponsoring legislation to establish a National Commission on Scleroderma and Fibrotic Diseases, supporting scleroderma research at the Department of Defense and maintaining critical patient protections of the Affordable Care Act.

Research remains critical to ultimately improving the health of individuals suffering from scleroderma. We urge you to support a funding level of \$44.7 billion for NIH in the FY 2021 Labor-HHS-Education Appropriations bill. This level of funding will support the progress NIH has made on medical research.

The *National Commission on Scleroderma and Fibrotic Diseases Act* will establish within the National Institutes of Health (NIH), a National Commission on Fibrotic Diseases to evaluate and make recommendations regarding improvements to the coordination and advancement of NIH-supported research activities related to fibrosis and fibrotic diseases, which may include scleroderma

as a prototypical condition that can cause fibrosis in various organs. At no additional cost to the federal government, the *National Commission on Scleroderma and Fibrotic Diseases Act* establishes a national commission to:

- Study of the incidence, duration, and mortality rates of fibrotic diseases.
- Evaluate facilities and resources for the diagnosis, prevision and treatment of fibrotic diseases.
- Develop a long-range plan for the use and organization of national resources to effectively advance research and effectively deal with fibrotic diseases.

Currently there is a \$5 million Scleroderma Peer-Reviewed Medical Research Program at the Department of Defense for continued research into scleroderma. There is a strong connection between environmental exposures and the onset of autoimmune diseases, which leaves military personnel at risk for developing conditions like scleroderma. Further, scleroderma impacts military personnel because the scarring associated with the disease process has broad applications to combat injuries.

Health coverage and access are critically important to scleroderma patients and the entire community. We ask that Congress maintains and support crucial patient protections that promote access and prevent financial hardships.

Specifically, please continue to:

- prohibit pre-existing condition discrimination.
- allow young adults to stay on family coverage until they are 26.
- limit out-of-pocket costs for patients.
- prohibit lifetime and annual caps on benefits.

Please consider me a resource if you have any questions about scleroderma or the Scleroderma Foundation that I can answer or pass along to the national office staff. Thank you for your time and consideration.

Sincerely,

YOUR NAME
CITY, STATE

SAMPLE EMAIL COPY:

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Please consider me a resource if you have any questions about scleroderma or the Scleroderma Foundation that I can answer or pass along to the national office staff. Thank you for your time and consideration.

Sincerely,

YOUR NAME
CITY, STATE

Important Reminders:

- You do not have to memorize anything about the bills or the legislative process.
- It is entirely appropriate to speak directly from written notes.
- You represent the Scleroderma Foundation. Focus on the specific “asks” outlined.
- Be prepared to briefly share a few examples of how scleroderma has affected *your life* to support your request for their co-sponsorship and support of the scleroderma community.

Even the smallest investment of time makes a difference in advocating for research funding. Thank you for being part of this process today and (hopefully) in our ongoing grassroots efforts.