

U.S. Senate Advocacy Letter

Ask your Senators to cosponsor

S. 2477: National Commission on Scleroderma and Fibrotic Diseases Act of 2019

THE CHALLENGE

The National Institutes of Health (NIH) is part of the federal government and is the world's foremost medical research entity. Annually, NIH supports research projects that advance 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 to use their resources effectively for quality research.

THE SOLUTION

Senator Kirsten E. Gillibrand (D-NY) introduced [S. 2477](#), the *National Commission on Scleroderma and Fibrotic Diseases Act of 2019* into the United States Senate on September 12, 2019. Senator Susan Collins (R-ME) became the first cosponsor on September 26, 2019. *Click the link to follow bill progress.*

S. 2477 will establish a National Commission on Fibrotic Diseases within NIH to evaluate and to 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 of 2019* 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, prevention and treatment of fibrotic diseases.
- Develop a long-range plan that establishes NIH collaboration focused on fibrotic-related research.

IMPORTANT FACTS ABOUT THIS LEGISLATION

- **Bipartisan support** from Democrats and Republicans.
- Budget neutral—the bill will not increase federal spending.
- **Not disease specific** as all fibrotic diseases (including scleroderma) will benefit.

YOUR ROLE IN THE SOLUTION

- Your Senators will only support this effort if constituents ask for their co-sponsorship. The more Senators who support and cosponsor this bill, the greater its chance to be passed into law.
- Complete the advocacy letter on the opposite side. Name, signature, mailing address, city, state and ZIP Code are required. **Do not mail letters to Capitol Hill.** Email completed letter to advocacy@scleroderma.org or mail to the national office in Danvers, MA. Complete electronically or print, complete and scan. All letters will be hand-delivered to Capitol Hill.
- To schedule a meeting with your Senators' local offices to ask them to cosponsor, email Philip Goglas II at Goglas@hmcw.org. Phil is our representative at Health and Medicine Counsel of Washington who coordinates all advocacy efforts in collaboration with foundation staff. Your story is what policymakers need to hear, and they want to hear from constituents!
- Advocacy letters are intentionally addressed to the *Health Legislative Assistant*, the staff person who reviews letters and recommends action to the Senator. Ask your friends, family and neighbors to sign too. *More letters = a stronger, more unified voice!*

Please return only the completed U.S. Senate Advocacy Letter.

This page is for informational purposes only.

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U.S. Senate Advocacy Letter

Dear Health Legislative Assistant,

My name is _____ . I am one of your constituents
and I live in _____ .
City and State

Please cosponsor **S. 2477**, *the National Commission on Scleroderma and Fibrotic Diseases Act of 2019*. This budget-neutral legislation is important to me and many in our state who are affected by scleroderma and other fibrotic illness such as pulmonary fibrosis and liver fibrosis.

S. 2477 will establish a national commission within 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 of 2019* 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.

Please cosponsor **S. 2477** by contacting Gil Ruiz in the office of Senator Gillibrand at 4-4451 or Gilbert_Ruiz@gillibrand.senate.gov. Thank you for considering my request.

Sincerely,

Constituent Signature _____
required - typed signature is acceptable.

Constituent Printed Name _____
required

Mailing Address _____
required

City _____ **State** _____ **ZIP** _____
required *required* *required (+4, if known)*

Date _____