

ACTION ALERT

Ask your Congressperson in the House of Representatives to cosponsor
H.R. 3446, *the National Commission on Scleroderma and Fibrotic Diseases Act*.

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

Congressman Peter King (R-NY-2) and Congressman Eliot Engel (D-NY-16) introduced H.R. 3446, the *National Commission on Scleroderma and Fibrotic Diseases Act*. The bill has been referred to the House Committee on Energy and Commerce.

This bill will establish a National Commission on Fibrotic Diseases within the National Institutes of Health (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* 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 within a working group 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

- Congressmen King and Engel need colleagues in the House to cosponsor this important legislation. The only way your member of Congress will consider supporting this effort is if constituents officially asks them to do so. The more legislators 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, city, state and ZIP Code are required. Mailing address is optional. ***Do not mail*** advocacy letters to your member of Congress. Scan and email your advocacy letter to Goglas@hmcw.org, and it will be hand-delivered to Capitol Hill. Please do not include this side of the document with your completed advocacy letter.
- To schedule a meeting with your member's local office to ask them to cosponsor the bill, email Philip Goglas II at Goglas@hmcw.org. Phil is our representative with Health and Medicine Counsel of Washington (HMCW), and he coordinates all advocacy efforts in collaboration with the Scleroderma Foundation. Your scleroderma story is what policymakers need to hear, and they want to hear from constituents! Contact advocacy@scleroderma.org for talking points and tips.

Dear Health Legislative Assistant,

My name is _____ . I am one of your constituents,

and I live in _____ .

Please cosponsor **H.R. 3446**, *the National Commission on Scleroderma and Fibrotic Diseases*. This budget-neutral legislation is important to me and many people in your district and across the country who are affected by scleroderma and fibrotic illness (such as pulmonary fibrosis and liver fibrosis).

H.R. 3446, *the National Commission on Scleroderma and Fibrotic Diseases* 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* 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 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 Elliot Engel at 5-2464. Thank you for considering my request.

Sincerely,

Constituent Name (signature) _____
required

Constituent Name (printed) _____
required

Street Address/P.O. Box _____

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

Date _____