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# SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #616 | July 24, 2015

## The Scleroderma and Fibrosis Research Enhancement Act of 2015: *Help and Support is Needed in Key States*



*Attention scleroderma supporters who live in: Alabama, Alaska, Arkansas, Arizona, Colorado, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Michigan, Missouri, Mississippi, Nebraska, Nevada, New Hampshire, North Carolina, North Dakota, Ohio, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Utah, West Virginia, Wisconsin, and Wyoming.*

Sen. Kirsten Gillibrand (D-NY) is prepared to introduce the Scleroderma and Fibrosis Research Enhancement Act into the Senate. But before she can introduce the legislation, she needs a Republican Senator to join her to lead this important bipartisan effort. Any Republican Senator can become a scleroderma champion, but first they need to be educated by the people they represent...YOU!

Some senators are particularly well-positioned to lead this legislation based on their positions on key committees or their leadership on rare disease issues.

If a Republican Senator represents your state, the community needs you to make the commitment to reach out to their office on Capitol Hill and ask them to lead this important legislation.

[Please take action now and write your Republican Senator today >>](#)

## Thank You for an Amazing 2015 National Patient Education Conference!

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“Stomping Out Scleroderma”

The 17th Annual  
Scleroderma Foundation  
National Patient Education  
Conference

July 17-19, 2015  
Nashville, Tennessee

Registration is now open!  
[www.scleroderma.org/conference](http://www.scleroderma.org/conference)




From the Foundation's National Office, we'd like to thank everyone who attended this year's National Patient Education Conference in Nashville, TN for such an amazing weekend. The Conference provided an incredible opportunity for the more than 500 attendees to learn more about scleroderma, and connect with others who are affected by the disease.

If you haven't done so already, [please take a moment to complete this post-conference survey](#). Your feedback helps us improve the conference experience each year. We appreciate you taking time

to offer us your thoughts!

## Association for Patient Experience - Choosing a Provider



Choosing a doctor or hospital is an important decision, but it is ultimately your choice. Community reputation and recommendation from family or friends are traditional methods used when making a decision, but when you have time to plan ahead there are resources to help you judge the quality of hospital care.

[Learn more at Patient-Experience.org >>](http://Patient-Experience.org)

## Sunburn Prevention



Sunburn prevention is very important during the summer, but it's also crucial to practice good skincare even on cool, cloudy or hazy days. This list from the Mayo Clinic offers a number of effective methods for preventing sun damage to your skin, from sunscreen tips to times when you should avoid sun exposure.

[Read the entire article at the Mayo Clinic >>](#)

**Disclaimer:** The Scleroderma Foundation in no way endorses any drugs, treatments, clinical trials, or studies reported in the eLetter. Information is provided to keep the readers informed. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) for proper evaluation and treatment.

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