

Subject: Scleroderma Awareness Month: Have You Taken the Pledge Yet?

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SCLERODERMA FOUNDATION

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Scleroderma Awareness Month: Have You Taken the Pledge Yet?



It takes less than a minute to sign the online pledge to tell at least one other person about scleroderma. Join the more than 1,000 people who have already pledged to do their part. Visit www.hardword.org today and take action as part of Scleroderma Awareness month.

Be sure you're following the Scleroderma Foundation, Scleroderma Society of Canada and Scleroderma Research Foundation this month on Facebook and

Twitter as we have teamed up to share information online to help you let others know about scleroderma.

You also can [share your own scleroderma story](#) and [write a letter to your local media](#) from our website.

FDA Grants Breakthrough Therapy Designation for Actemra in Systemic Sclerosis



Trial investigator and Scleroderma Foundation Medical Advisory Board Member Dinesh Khanna, MD, MS, Professor of Internal Medicine in the Division of Rheumatology, and director of the University of Michigan Scleroderma Program, offers his comments on recent Actemra study results -

"Research has shown that scleroderma patients with high levels of a protein

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called IL-6 in their bodies have more severe disease, higher risk of lung tissue scarring (lung fibrosis), and greater mortality. This insight coupled with clinical experience in patients, led to the faSScinate study to assess the efficacy and safety of Actemra in patients with early scleroderma. The medicine was well-tolerated and there is great enthusiasm regarding the effect of Actemra on skin hardening.

One surprising result seen in the Phase II trial was the potential stabilization of lung function in the Actemra group vs. continuing decline of approximately 25 percent of patients in the placebo group over a 48 week period. As lung fibrosis is the leading cause of death in scleroderma, this finding is very exciting but needs to be confirmed in a larger trial. We hope that Phase III of the faSScinate trial, which is currently enrolling patients, will provide us with the evidence we are looking for.

This Breakthrough Therapy Designation for Actemra underscores the high unmet need in scleroderma and the potential of the medicine to improve the symptoms of the disease for which there are no FDA-approved treatment options.

I'm thrilled to be a part of a study that has the potential to bring an important and much-needed therapy to my patients."

[Read the full press release about the Breakthrough Therapy Designation for Actemra at Gene.com >>](#)

[Download an infographic with information and statistics on systemic sclerosis >>](#)

What You Need to Know: Reviewing Your Disability



If you receive Social Security or Supplemental Security Income (SSI) disability benefits your medical condition is reviewed from time to time to make sure you continue to be disabled. The review process is designed to give you every opportunity to show that you are still disabled and to assure that your benefits are not stopped incorrectly. This publication from the Social Security

Administration will help you understand how you can best prepare yourself for a review.

[Download the publication from SSA.gov >>](#)

Eating Right on the Road

Paying attention to what and when you eat can give you some important information related to how you feel. If you're not feeling well now, think about what you ate in the last 12 to 24 hours. Headache? Heart burn? High acid foods may cause indigestion, a rich dessert may cause fatigue, and going too long between meals may leave you feeling



anxious or cranky. Who wants any of that while on vacation or even doing errands?

[Read the full article on caregiver.com >>](#)

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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