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SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #561 | June 27, 2014

World Scleroderma Day - Sunday, June 29, 2014

Scleroderma Awareness Month wraps up next week but not before World Scleroderma Day on Sunday, June 29. And, there are still ways that you can get involved:

- Visit www.hardword.org to show your support of people living with scleroderma.
- Write a letter to the editor. If you live in the United States, we've made it simple for you to send an email to your local media. Visit www.sclerodermaawareness.org and click the link "Write your letter now" to get started.
- Tell people to tune-in to NBC's "Today Show" on Sunday, June 29, to see our scleroderma community on the Plaza at Rockefeller Center. (Special thanks to volunteers from our [Tri-State Chapter](#) for organizing this special opportunity!)



Finally, we want to thank all of you for your incredible support this year. You have worked tirelessly to spread awareness and educate others about this disease. But, our fight doesn't end in June. People living with scleroderma are affected every day of the year, and we are committed to finding a cure and sharing your stories in an effort to increase awareness.

We have received a tremendous response in our "Scleroderma Selfies" campaign with more than 300 submissions from patients all over the world. Please continue to send us your pictures for an upcoming awareness and education campaign! Submit your pic using the hashtag #sclerodermaselfie on Twitter, Facebook or Instagram. You also can email your snapshot to mystory@scleroderma.org. We may even share your photo on one of the social networking sites!

For more information about how you can join the fight to end Sclero-What?, please visit www.sclerodermaawareness.org or www.hardword.org to learn

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more.

Journal of the American Medical Association: Stem Cell Transplantation in Scleroderma



In this week's edition of the Journal of the American Medical Association (JAMA), the European Group for Blood and Marrow Transplantation presented the first international, multi-center randomized controlled trial of autologous hematopoietic stem cell transplant (HSCT) versus pulse monthly cyclophosphamide in 156 people with

early diffuse scleroderma (Autologous Stem Cell Transplantation International Scleroderma, or ASTIS.) Patients in this trial, selected at 29 centers in Europe, had diffuse scleroderma and a high risk of disease progression or already had internal organ involvement. The study showed significantly better long-term event-free survival and overall survival at a median follow-up of approximately 6 years, and clinically meaningful improvements in objective (skin softening, stabilization of lung physiology) and patient-reported outcome measures at 2 years. However, the trade-off was greater upfront treatment-related mortality (10.1 percent) and severe adverse events.

Dr. Dinesh Khanna, M.D., M.S., director of the University of Michigan Scleroderma Program and a member of the Scleroderma Foundation's National Medical Advisory Board wrote an accompanying editorial in JAMA. He stated that patient selection is key to determine successful outcomes for HSCT. Cardio-pulmonary involvement is associated with high mortality in HSCT and careful evaluation is necessary of heart involvement including pulmonary hypertension and arrhythmia (irregular heartbeats). Dr. Khanna also stated that stem cell transplant should be performed as part of a protocol in the United States and done in experienced centers. Currently, consideration should be limited to patients with:

- A. Early diffuse scleroderma with mild-to-moderate internal organ involvement (severe internal organ involvement will make patients ineligible due to risks associated with stem cell transplant)
- B. Limited scleroderma with progressive internal organ involvement, and should be generally restricted to patients who have failed to improve or have worsened on conventional immunosuppressive agents.

Up to 37 percent of patients have disease flare in their scleroderma after transplant and there is an ongoing multi-center trial in the U.S. called the Scleroderma Treatment with Autologous Transplant (STAT) trial, which is assessing if Cellcept® (mycophenolate mofetil) therapy can decrease the proportion of patients with disease flare.

Free Webinar on July 10 - "Muscle and Joint Involvement in Scleroderma"

The Scleroderma Foundation of Southern California invites you to join them for their next free webinar on "Muscle and Joint Involvement in Scleroderma" on



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Thursday, July 10, 2014 at 11:30 am PST. The presenter will be Dr. Daniel Furst, the Carl M. Pearson Professor of Rheumatology, UCLA.

[To join the webinar, please click here on July 10, 2014 at 11:30 am PST and you will be taken directly to the presentation.](#)

This is a web based presentation and you will not need to download any software to your computer. If you are accessing the presentation through a mobile device you will need to install the MegaMeeting Mobile App. It is free.

For those who will not have computer access or do not have computer speakers, toll free audio will be available by calling **1-877-216-1555**. Enter the passcode **981555**. For all others, follow the instructions on the screen when you click the link.

Technical questions? Please call Jerold Kappel at Scleroderma/SoCal office 310-287-0793 or email socachapter@scleroderma.org.

For other questions, contact Karen Gottesman at karengottesman@scleroderma.org.

Foods and Medications That Don't Mix



According to a study done by researchers at Kansas State University, failing to read the warning labels on prescriptions is a mistake many people over 50 make. Not knowing what foods and drinks to skip while on prescription drugs can cause serious side effects or lower the effectiveness of your medications.

To stay safe, make sure ask your doctor about side effects of your prescription. You can also talk to your pharmacist to learn the ins and outs of your prescription and what foods and beverages to avoid while you're on it. In the meantime, you can check out this list of foods and how they react with different medications.

[Read more at Grandparents.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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