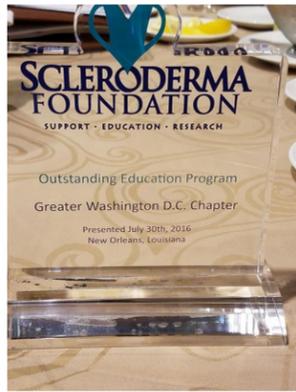


## 2016 National Patient Education Conference

The **18th Annual National Patient Education Conference**, held July 29-31 in New Orleans was an informative and inspiring time. This year's theme, "Unmask the Cure," brought together more than 600 people from around the country for an educational, uplifting, and fun experience. With 74 sessions, the conference covered topics that touched on every aspect of living with scleroderma. Congratulations to the National staff for hosting another successful conference. We are looking forward to next year's conference in Phoenix, Arizona!



During the Awards Luncheon, **Scleroderma Foundation CEO Robert Riggs** presented the Greater Washington, DC Chapter with the **Outstanding Patient Education Program Award** for its 2015 African American Patient Education Conference. Accepting the award on behalf of the Chapter was its **Executive Director Carole Bernard** and **Board Member Jennifer Loud**!



We are thrilled to be recognized for our work on behalf of scleroderma patients and their families, and we dedicate this award to all of you!

**Congratulations to the Chapter's board members, executive director, support group leaders, members, and volunteers!**

**Together, we are making a difference!**

### Enjoy a few photos from the conference!



## Need Your Feedback - Launching New Support Groups



The Chapter serves a large geographic area that includes Maryland, Virginia, and Washington, DC. To better meet the needs of our members and their families, the Chapter is exploring launching three new Support Groups in:

1. **Howard County/Baltimore County/ Baltimore City**
2. **Prince George's County/ Calvert County, and**
3. **Northern Virginia.**

Currently, we have the Maryland Support Group that meets in Bethesda and Chevy Chase, Maryland offering wonderful presentations and the opportunity for individuals to gather together on a monthly basis. These three additional Support Groups would create new opportunities for our growing membership to connect with one another closer to their homes. We also would like to offer Virtual Support Group Meetings during the winter months, when it can be difficult for some folks to leave their homes. All one would need is a computer, and we would do the rest to schedule informative presentations and a virtual meeting space via the Internet. We are very excited about these new endeavors, and we want to get your input!

Below is a link to a survey that we very much would like for you to fill out. Your responses will assist us in knowing your interest in the three additional Support Groups, as well as the Virtual Support Groups! **We ask that you complete the survey by August 19, 2016.**

Thank you in advance for your assistance!

Click [HERE](#) to take the survey!

## Vascana Study Looking at Treating and Preventing Raynaud's Phenomenon



Do you have painful hands from Raynaud's Phenomenon?

If so, this **Vascana Study** may be what you are looking for. This clinical research study is trying to determine whether a topical formulation of nitroglycerin can be used to treat and prevent symptoms of Raynaud's Phenomenon (RP).

We are looking for individuals who have Raynaud's Phenomenon associated with scleroderma, lupus or rheumatoid arthritis who can help us determine whether this treatment is effective.

Would you like to take part in a study like this? You may be a good fit for this study if:

- You are 18-75 years of age
- You have been diagnosed with Raynaud's Phenomenon and scleroderma, RA or lupus
- You are able to comply with all study requirements

If you agree to take part in this study, you will:

- Agree to attend 6 study visits over 6 weeks, where you will be exposed to cold temperatures.
- Agree to use the topical formulation during the course of the study.
- Complete a physical examination and health assessments to monitor your health and well-being.
- You will be reimbursed for travel and time.

**If you are interested in taking part in this study or would like to know more about it, please contact Dr. Virginia Steen's Office:**

**Jonathan Smith @ 202-444-6211 or [jds293@georgetown.edu](mailto:jds293@georgetown.edu) or  
Maia Cecire @ 202-444-6212 or [mz381@georgetown.edu](mailto:mz381@georgetown.edu)**

## Research Study for People with Systemic Sclerosis

Persons with systemic sclerosis needed for research study to evaluate an internet self-management program for people with scleroderma.

**Dr. Janet L. Poole**, a member of the National Foundation's Medical and Scientific Advisory Board and a Professor of Occupational Therapy Graduate Program, School of Medicine at the University of New Mexico, asked if we could share this information with our members.



This research study evaluates an Internet self-management program for people with scleroderma.

You will complete a packet of questionnaires at 3 points in time: before the intervention, after the intervention is completed and 6 months later. You will be randomly assigned to an internet intervention group or a control group. If you are assigned to the internet group, you will access and complete the internet self-management program at home over a 16 week time period and participate in the Discussion board. If you are assigned to the control group, you will receive an educational book written by an expert on systemic sclerosis; at the end of the study, you will also have the chance to access the internet self-management

program.

You will receive a separate email within 2-4 weeks after completing the surveys with details about the group that you are assigned to.

If you are interested, please log into <http://bit.ly/selfmanagementssc> where you will be provided with an electronic consent, please take the time to review this and contact Jennifer Serrano with any questions prior to agreeing to the study. If you agree to participate in the study you will be routed directly to your first set of questionnaires for completion.

**For more information about the study and the eligibility requirements please contact Jennifer Serrano at 734-232-2119 or [scleroderma-selfmanagement@umich.edu](mailto:scleroderma-selfmanagement@umich.edu).**

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**Scleroderma Foundation Greater Washington, DC Chapter**

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