



SPRING 2016 NEWSLETTER

Hello to Everyone from your South Carolina Chapter Board. Spring has sprung in the Upstate and we are covered in dusty yellow pollen. The flowers are beautiful, though!

The Sixth Amy K. Parrish Patient Education Conference was held on Saturday, January 30, 2016 and it was a wonderful day! Tracy M. Frech, M.D. was our Keynote Speaker, speaking on Gastrointestinal Issues and the Importance of Personalized Medicine. Other speakers were Drs. Faye Hant and Michelle Ravenel speaking on Oral Health, Dr. Carol Feghali-Bostwick on New Drug Development at MUSC, Dr. Richard Silver with the latest news from MUSC and Nurse Educator Paula Erwin-Toth on Fragile Skin Care. We tried a new caterer for lunch, Dish & Design from Mount Pleasant, SC. Everything was delicious and we have already booked them for 2017. Wildflour Pastry and Starbucks provided our tasty breakfast pastries & savories and hot coffee for the sixth year in a row. Actelion Pharmaceuticals provided warm blankets, socks and wristies for our Scleroderma patients. We had fabulous gifts for all patients in our take-home bags: Basic Bites by Orteck Therapeutics; MightTeaFlow products from Camellix; Low FODMAP Oatmeal and Protein Bars from Nicer Foods; Oracoat Xylimelts; Scandinavian Formulas Saliva Sure; and Welmedix Homecare Pro full size product samples for fragile skin care.

Please mark your calendars for Saturday, January 28, 2017 for our Seventh Amy K. Parrish Patient Education Conference. We are in the planning stages now; more information will come your way this fall.

Our next SC Chapter Event is the Second Stepping Out to Cure Scleroderma Fundraiser – Thomas Mills 5K & Walk to be held at Saluda Shoals Park in Columbia, SC on Saturday, June 11, 2016. The 5K Race will be professionally timed and there will be awards to third place in each division, plus a special award for the Male and Female with the best time. An untimed 5K Walk, a One Mile Family Fun Walk, and Stepping Out in Spirit (just enjoy the day with us) are also on the agenda and drawings for door prizes will be held in all of these categories. We are planning a tasty light brunch, lots of activities and games for families and kids and a wonderful DJ playing music!

Registration may be done either online at www.scleroderma.org/steppingoutthomasmills or by mail, using the registration form from the flyer included with this mailing. Mail entries to SC Chapter – Scleroderma Foundation; 713D East Greenville Street Box 194; Anderson, SC 29621. Your online or mailed registration must be received **BY MAY 31, 2016** to guarantee your t-shirt in the correct size. \$35.00 entry fee for all 5K Race Participants regardless of age. All other categories: \$25 .00 for adults (age 14+) and \$15.00 for children (ages 4-13 years). Children 3 and under are free unless you want them to have a t-shirt, in which case they must be registered and the cost is \$5.00.

The Scleroderma Foundation National Conference will be held July 29-31, 2016 in New Orleans, LA. For more information, please go to www.scleroderma.org and click on the Conference button. This is a wonderful opportunity to learn more about scleroderma and to meet others “just like you”. Earlybird Registration (\$200 vs. \$250) ends May 31st! We hope to see many of you there!

Susan Melvin, President ~ Karen Kemper, Vice President
Francis Parrish, Secretary & Webmaster ~ Jeannie Freeman, Treasurer
Laura Baur, Julie Runyan-Brown and Lynn Whaley Simmons – Members-at-Large
Doris Frazier – Piedmont Support Group Representative

Look for us on Facebook! “Scleroderma Foundation – South Carolina Chapter”



NEWS FROM THE PIEDMONT AREA SUPPORT GROUP

Please see below for a note from Jerry and Kay Misik, Support Group Leaders for the Piedmont Area Support Group, which meets at the Piedmont Medical Center in Rock Hill, SC.

Happy Easter!

Our March 15th meeting was a smashing success. Dana Scott and Marsha Petrin, both Occupational Therapists, presented many new ideas to strengthen and help increase hand flexibility. Thank you Jen Amendo for arranging for Dana and Marsha to join us for the evening. It was a pleasant and worthwhile experience.

Next up... **Mark your calendars... Tuesday, June 14th.** We will have the luxury of meeting with two young rheumatologists who have a specific interest in scleroderma. And, to top it off, one of them has had experience working directly with Dr. Silver. Here is a quick look at both of the two speakers scheduled for June 14th:

Dr. Ashley L. Toci earned her Doctor of Medicine Degree (summa cum laude) at West Virginia University. She said the following when asked for reasons she has a special interest in scleroderma: "I initially became interested in rheumatology because my grandfather had rheumatoid arthritis and my brother was diagnosed with juvenile arthritis at age 2. When I was interviewing for residency programs, I was very impressed with the rheumatology department at MUSC and knew I wanted to train under Dr. Silver. **I worked very closely with Dr. Silver for 2 years and learned a great deal about scleroderma.** Scleroderma is a fascinating disease that affects patients in very different ways....no two scleroderma patients are the same. Although I saw and treated scleroderma patients every day at MUSC, it is still a rare condition in the field of rheumatology. I quickly became aware that many rheumatologists out in the community were not familiar with this disease and knew that I wanted to provide care for scleroderma patients the best I could outside of an academic institution."

Dr. Heather S. Gladue earned her Doctor of Osteopathic Medicine Degree at Nova Southeastern University College of Osteopathic Medicine located in Ft. Lauderdale, FL. Here's what she had to say when asked for reasons she has a special interest in scleroderma: "I developed a passion for Scleroderma in fellowship at the **University of Michigan.** I was lucky enough to work with one of the leading researchers in Scleroderma and was able to do research in scleroderma - particularly focusing on **pulmonary hypertension.** After fellowship, I went to Emory and had a scleroderma clinic for two years. I participated in a GWAS study with NIH while I was there. Now that I am in North Carolina, I still have a passion for taking care of scleroderma patients."

SAVE THE DATE! You won't want to miss our meeting on Tuesday, June 14th starting at 6 PM at the Piedmont Medical Center in Rock Hill, SC.

Should you have any questions that we should present to Doctors Toci and Gladue before the June 14th meeting, please pass them along to us. We will be happy to relay them to our speakers so that they may do a little research before the meeting.

We hope you all have a very blessed Easter!

Sincerely,

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