

## SPRING 2015 NEWSLETTER

Hello to everyone from the South Carolina Chapter!

Mark your calendars and plan on attending the First Stepping Out to Cure Scleroderma Fundraiser – Thomas Mills Memorial Walk will take place on Saturday, June 13, 2015 from 9:00 AM until 11:30 AM at the Stage Area, 312 Laurel Street, Columbia, SC. We have tried for years to have something in Columbia and finally we have achieved that goal. Many thanks to the family and friends of Thomas James Mills for making this possible. See brochure included with this mailing for more information. We hope to see many of you there – especially our Columbia area Scleroderma Patients and their families.

The Scleroderma Foundation National Meeting will take place July 18 and 19 in Nashville, TN. This is driving distance for most South Carolina Chapter members. Consider going to the Conference – you will not be disappointed! See [www.scleroderma.org](http://www.scleroderma.org) and click on the button for Conference for more information.

Also mark your calendars for our Tenth Stepping Out to Cure Scleroderma Fundraiser in Greenville, SC. The date is Saturday, September 19<sup>th</sup>. Events will include a 5K Run/Walk, a One Mile Family Fun Walk, Breakfast, Brown Bag Auction, Fun and Games, Music by SC Wedding DJ, and a presentation on Scleroderma.

We had a wonderful Patient Education Conference on Saturday, January 31, 2015 at MUSC in Charleston featuring Cindy Coney as our Keynote Speaker. Cindy was motivating and upbeat but also extremely credible and empathetic to the struggles of scleroderma patients. I think everyone enjoyed hearing her strategies for coping with chronic illness. Our Sixth Amy K. Parrish Patient Education Conference is scheduled for Saturday, January 30, 2016. We hope to see you in Charleston!

The Piedmont Area Support Group which meets in Rock Hill, South Carolina continues to thrive under the leadership of Jerry and Kay Misik. Bi-monthly meetings take place at the Piedmont Medical Center in Rock Hill and feature excellent speakers and tasty refreshments. If you live in the Rock Hill, SC area, please contact Jerry and Kay at 803-802-9332 or send them an e-mail at [mjmisik32@comporium.net](mailto:mjmisik32@comporium.net) and they will let you know the date of the next meeting.

We have had two ladies contact us with interest in leading the Greenville Area Support Group. We have had some logistical problems getting together with them but we hope to have news of an active Greenville Support Group when we send out our next newsletter.

We are still looking for help with leadership of our Charleston/Low Country Support Group. If you have interest in volunteering for this, please let us know. You may call 864-617-0237 or e-mail the Chapter at [scchapter@gmail.com](mailto:scchapter@gmail.com).

Susan Melvin, President ~ Karen Kemper, Vice President

Julie Runyan-Brown, Secretary ~ Jeannie Freeman, Treasurer

Laura Baur and Lynn Whaley Simmons – Members-at-Large

Doris Frazier – Piedmont Support Group Representative

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

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**SC Chapter – Scleroderma Foundation ~ 713D East Greenville Street Box 194 ~ Anderson, SC  
29621**

**FALL 2014 NEWSLETTER**

Hello to Everyone from the South Carolina Chapter of the Scleroderma Foundation!

We are excited to report that our recent *Stepping Out to Cure Scleroderma Event – Amy’s Walk and Betty’s Run* was a huge success!!!! After expenses, we raised over \$15,000! This is huge and it should be noted that our overall goal was to raise \$10,000 before expenses. Thank you to everyone who participated in any way at all because this wonderful success would not have been possible without each one of you.

This was our first time incorporating a 5K Race into our Stepping Out Event and we didn’t know how it might work out. It quite obviously was successful and we are pleased to say that the 5K will be back for 2015.

It was also our first time to have our event in September rather than June. Despite the unseasonably cool weather, it was a wonderful day. We are going to try September again next year – a Saturday this time! Please mark your calendars for Saturday, September 19, 2015. More information will be forthcoming as the date gets closer.

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Our next Chapter event is the Fifth Annual Amy K. Parrish Patient Education Conference on Saturday, January 31, 2015 at MUSC in Charleston. We hope that you will make plans to attend. Registration deadlines are January 16, 2015 (postmark date) or online registration by January 22, 2015. Our host hotel is once again the Marriott Courtyard, 35 Lockwood Drive, Charleston. Special rate for our group is \$108 + tax per night. Please refer to Group Code SCH when making your reservations. Phone number is 888-724-9647 between 8 AM and 11 PM. Hotel reservation deadline is January 16, 2015.

We have an amazing keynote speaker in Cindy Coney, Lupus THRIVER, Ambassador of Hope and author of *The Wild Woman’s Guide to Living with Chronic Illness*. Our 2014 Conference Participant Survey indicated a desire for an upbeat keynote speaker and we know that Cindy will be that and more!

Other speakers will include: Dr. Carol Feghali-Bostwick (2014 Keynote Speaker) who will give us an update on her important Scleroderma research; Drs. Faye Hant and Michelle Ravenel who will speak on Dental Issues in Scleroderma Patients; Dr. Edwin Smith who will speak on Raynaud’s Phenomenon and Digital Ulcers; and of course Dr. Richard Silver who will give an update on Scleroderma and MUSC.

This will be a wonderful day of education and good company and good food (vegetarian/gluten free choice will be available). We hope you will join us! To

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register, fill out the registration form on the brochure which accompanies this newsletter and mail to the SC Chapter. You may also register online at [www.scleroderma.org/amykparrishday](http://www.scleroderma.org/amykparrishday) . If you have any questions, you may e-mail the Chapter at [scchapter@gmail.com](mailto:scchapter@gmail.com) or telephone 864-617-0237.

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Currently, the only active SC Chapter Support Group is the Piedmont Support Group led by Kay and Jerry Misik in Rock Hill, South Carolina. This active group meets every other month at the Piedmont Medical Center in Rock Hill. For information on upcoming meetings, please contact Kay and Jerry at (803) 802-9332 or e-mail them at [mjmisik32@comporium.net](mailto:mjmisik32@comporium.net) .

The Charleston (Low Country) Support Group has been without a leader since early 2014. We have had many inquiries about the Group, but no one has stepped up to take the leadership role. If any of you are interested in leading this Group, please contact the Chapter at [scchapter@gmail.com](mailto:scchapter@gmail.com) or telephone us at 864-617-0237, or speak to a Chapter Board Member at the 2015 Education Conference. MUSC is often able to provide meeting space and the SC Chapter will reimburse reasonable meeting expenses for refreshments and speakers.

The Greenville Support Group is also in need of leadership. This Group has been inactive for nearly two years now. Meeting space is available at St. Francis Hospital close to Haywood Mall in Greenville. If anyone is willing to lead this group, please e-mail the Chapter at [scchapter@gmail.com](mailto:scchapter@gmail.com) or telephone us at 864-617-0237.

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The South Carolina Chapter is pleased to welcome two new Board Members: Doris Frazier of Kershaw, SC, who will be the Piedmont Support Group Representative to the Board, and Lynn Whaley Simmons of Simpsonville, SC, who will be a Member-at-Large. Doris has been a member of the SC Chapter for many years and shares a hometown of Danvers, MA with Susan Melvin, Chapter President. Doris is married to Glenn Frazier and they have two adult children, seven grandchildren and two great-grandchildren. Lynn Whaley Simmons is the daughter of Betty Whaley, whose memory was honored with our first 5K "Betty's Run" at the recent Stepping Out to Cure Scleroderma Event. Lynn is an avid runner who competes in races all over the Upstate and throughout South Carolina. Lynn is married to Tim Simmons and they have a beautiful mini Dachshund "Coco Chanel".

Chapter Secretary Susan Worthen has retired and is enjoying lots of travel with her husband, John. Best wishes to Susan! Board Member Julie Runyan-Brown has taken over the position of Chapter Secretary.

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The South Carolina Chapter wishes everyone a happy and healthy Holiday Season. We hope to see many of you in Charleston on January 31<sup>st</sup>!

Susan Melvin, President ~ Karen Kemper, Vice President

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