

## Best Wishes to our Retired Support Group Leaders

Support groups are important when someone is facing a chronic illness. For those scleroderma patients who have been newly diagnosed, support groups put them in contact with other patients who may be experiencing similar symptoms and can offer support to them. Support Group Leaders are vital to these support groups and our chapter is grateful to these leaders who have volunteered their time to help others. We thank these Support Group Leaders who have retired in 2011.

**Joanne Cipollini** was inspired to become a Support Group Leader since her husband's grandmother lost her battle with scleroderma. Joanne works in nursing and had been a support group leader for more than ten years for the Norristown Support Group.



**Andrea Balkiewicz** was the co-leader for the Norristown Support Group. Her mother had been diagnosed with scleroderma in 1997 at age 50. Andrea became a support group co-leader because she wanted to be there for her mother and she and her mother have both been active in the support group for many years. They both wanted more information about scleroderma, and it really helped a lot to talk to others who understood, even though each one of them was different and had different things going on. The Norristown Support Group was a small close knit group, and they enjoyed seeing each other once a month. They shared many stories, laughed and cried sometimes.

Andrea met so many wonderful people through the support group. Andrea is also active at the Philadelphia walk and enjoys fundraising and attending the walk each year. Currently she is a freelance court reporter and a realtor at Keller Williams Realty Group in Limerick.



**Marsha Niederman** has been a scleroderma patient for the past 28 years after being diagnosed at age 32. Her scleroderma affects her skin and some of her internal organs such as her lungs and esophagus and she also suffers from rheumatoid arthritis. Marsha became a Support Group Leader when the previous Leader retired from the group. She had been leading the Monmouth Support Group for the past eight years and had attended the support group for longer than that. As a Support Group Leader, Marsha enjoyed being able to help others cope with the disease. She felt that sometimes it was nothing more than an ear to listen to a newly diagnosed patient, but it was someone who understood and offered encouragement. She always gave her group a positive attitude as negativity was not allowed. A bad day happens sometimes, but her thought was to deal with it and move on. Marsha has made many lasting friendships with the others that attended her support group. Since then, Marsha retired last November under her doctor's orders after working for ten years at Barnes & Noble. It was a wise decision, but not easy for her to accept at first. Marsha plans to spend more time at her second home in Cape Cod, enjoying her 17-month old grandson, taking care of her parents and keeping herself healthy.



**Ilene Nusblatt** has suffered from systemic scleroderma for the past four years. Previous to her scleroderma diagnosis, she was being treated for Lupus for two years and those symptoms have since subsided. Ilene started the Bucks County Scleroderma Support Group in mid-2008 because there was a need for a local support group. When Ilene started the support group her hopes were to offer a friendly and welcoming support group meeting where participants got to know one another and their issues and needs. Meetings are a great opportunity to talk about their commonalities and connect with others. She wished that people would leave with a sense of hope and connection which will prompt them to want to return for more support. She had been an active support group leader for the past three years. Currently Ilene is raising her 14-year old daughter, Ava, who is an active fundraiser for Team Come on Ilene at the Philadelphia walk each year.

**Debra Wagner** was diagnosed with systemic sclerosis in mid-2007 after about three years of searching for a diagnosis. Debra was the Support Group Leader for the North Delaware Support Group that met in Wilmington and she and her daughter, Athena, had been active in the support group for the past year. She became a group leader after attending past conferences and walks and realizing how many sufferers feel alone and have nobody to share their feelings with and nobody that has the same pain, questions, fears or frustrations.

As a scleroderma patient herself, Debra hoped to bring fellow sufferers and their caregivers or friends together to inform them and support them. Many sufferers that she spoke to knew nothing of the support from the foundation, the current trials, and ongoing lobbying on Capitol Hill for funding for research. Debra recalls that it was amazing to see, that in just her small area, there were so many that suffered from scleroderma. She found it very gratifying to get these wonderful people together to bond and form friendships. Their support group lost a member battling scleroderma in November and to hear from the patient's family that the group and friendship she formed from the group was a great part of the end of her life was awesome.



We welcome Kathy Sammons and Angie Crowl who have accepted the roles of Support Group Leader for the North Delaware Support Group. **Kathy Sammons** was diagnosed 16 years ago with systemic scleroderma and she has been fundraising for our chapter with



an annual Grotto's Pizza night in Wilmington, DE. This year's event took place on March 1<sup>st</sup>. **Angie Crowl** has been supporting the Delaware Valley Chapter since her husband, Al, was diagnosed with scleroderma in 1999. Angie and Al Crowl along with some others affected by scleroderma have started a Cruise for a Cure event. The car



show took place on April 15<sup>th</sup> in Wilmington, DE following a Stepping Out to Cure Scleroderma 5K Run and Fun Walk.

Thank you also to **Sharon Durham** who helped with the Bucks County Support Group meetings last year. We are truly grateful for all of these Support Group Leaders and their dedication to the Scleroderma Foundation.