Back in 1971, what dazzled me were her knock-out brown eyes that made my heart melt the day I met her in Philadelphia, PA at a friend's college event," wrote Sheldon Lehner in *Always Courageous*, a moving manuscript dedicated to his late wife Arlene who passed away December 28, 2011 after a long battle with systemic scleroderma. "We feel a sense of pride in writing about Arlene's skills and courage to live life to its fullest despite a severe disease," he wrote.

In 2012, Sheldon and his daughter, Laurin, joined the Chapter's efforts to raise funds through our annual *Stepping Out to Cure Scleroderma Walk/Run* in Columbia, Maryland. That year, Team Arlene raised the most money of all the participants. "Laurin and I wanted to help raise awareness about scleroderma and honor Arlene's memory by getting friends and family members together to support an important cause. We are looking forward to this year's event in May," says Sheldon. Join Team Arlene and others at our 2016 Walk on May 21st.

In his Silver Spring, Maryland home, Sheldon, a retired federal employee, tells the Chapter's Executive Director Carole Bernard that he and Arlene were married for 37 ½ years. He points to various photos of Arlene in the manuscript and tells her about a woman whose strength was only matched by her humor that was shown in her writings and everyday life. "Arlene was a journalist and had worked as an editorial writer in Washington, DC and Pennsylvania," says Sheldon. "She thought she would be the next Erma Bombeck. She loved to watch people at the mall. She would say, 'Wouldn't that be a great story' about something she just saw.'" Even though Arlene did not get the chance to publish any of her personal writings, she was working on an essay, *Giving in Is Not Giving Up. Finding a Way to Personal Medical Comfort.* "We'll never know whether it would have been a best seller. However, I'm pretty sure Arlene would have been satisfied just to know that it helped a family, especially the person suffering from scleroderma, to have new hope for dealing with its symptoms and ramifications," wrote Sheldon.

Arlene was diagnosed with Lupus when she was 16 years-old in 1969 at Temple University.
Four years after they married in 1974, Sheldon and Arlene moved from Harrisburg, PA to Silver Spring, where Arlene's diagnosis was later changed to scleroderma. With numerous symptoms, some more severe, than others, Arlene dealt with the challenges of acid reflux, tight esophagus, swollen feet, kidney pain, ulcerations, just to name a few. In the manuscript, Sheldon writes, "Towards the end, Arlene had twenty different medications/vitamins to take regularly. Arlene once wrote, 'Why does my body always have to be my enemy instead of my friend?'"

Arlene had a joy for life. She had strong family support, and she enjoyed watching her daughter grow up through the different stages, playing with her grandson, needle point, her cats, cooking, and going to the movies. "We really enjoyed watching Seinfeld together and laughing," says Sheldon.

Sheldon shares that he wrote the manuscript because Arlene was a gifted writer in addition to being a wonderful wife, mother, daughter and sister. Despite not having the energy during the years she was coping with scleroderma, Sheldon has compiled some her writings for others to enjoy. "I used to leave her notes around the house, mostly of encouragement, to help her get through the days. She returned that practice, and here's one she left for me," he says with a smile.

Sheldon says that it is important to have a strong support system when going through any type of medical issue, and Arlene's family was always close despite the new distance of being in a different state when they moved from Pennsylvania. It is also critical to be your own patient advocate. "I remember when one of her doctors was being very difficult, and Arlene said, 'I don't want to go to someone else, but I don't want to deal with you either," Sheldon says while smiling. In the manuscript, he describes it this way: It was never easy to coordinate all of the doctors’ review of a new episode or problem, but Arlene learned to become an advocate for herself...She would analyze results and become extremely knowledgeable about her medical tests and consequently demand answers from her doctors.

Sheldon's manuscript is a poignant and compelling story of one woman's strength and a family's love in the face of adversity. The Scleroderma Foundation Greater Washington, DC Chapter is very grateful to Sheldon Lehner for sharing this manuscript with us and for inspiring all of us. We also are grateful to him and his family for their efforts to help the Chapter raise funds through our walk for scleroderma research and to provide support services and educational forums to our members and their families.
6th Stepping Out to Cure Scleroderma
Greater Baltimore Walk/Run
May 21, 2016
Atholton High School Track
6520 Freetwon Road
Columbia, MD 21044

Hosted by the Scleroderma Foundation
Greater Washington, DC Chapter and Sponsored by the Atholton Athletic Boosters and SGA.

April Support Group Meeting

Save the Date!

Maryland Support Group Meeting
Saturday, April 23
11:00am - 1:00pm
Chevy Chase Library, 8005 Connecticut Avenue,
Chevy Chase, MD (easily accessible from East West Highway or the Beltway)

Film to be presented with discussion from the July 2015 National Patient Education Conference.

Hope to see you there!

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