WALKING WITH STRENGTH

This is the second year that Jennifer E. Loud, a Chapter Board member, has had a team at the Scleroderma Foundation Greater Washington, DC Chapter’s (SFGWDC) Stepping Out to Cure Scleroderma 5K Walk/Run.

"I think that it is hard for anyone to hear that they have scleroderma," says Jennifer. "It was for me. Initially my plan was to deal with scleroderma my way by calling on God, faith, family and close friends. In other words, I was going to deal with it in private."

Jennifer has had scleroderma for 13 years, and by nature she is a fighter. Jennifer shares her journey with us, adding humor to the story in places. She is a force to be reckoned with, and an inspiration to us all.

Jennifer says, "I wanted to have a clear appreciation for my opponent. I needed to determine how much I was going to have to fight and how much stronger I needed to become. That was before scleroderma invited itself throughout my body. Wouldn’t you know it - it is that typical rude house guest that invites others like, Sarcoidosis, Raynaud's, digital ulcers, Sjorgen’s Syndrome, GERD, arrhythmia, and esophageal dysmotility. I must add that each one of these menaces has its own set of bad behaviors. But for sure the worst one, the most obnoxious, true to its abhorrent behavior, Pulmonary Arterial Hypertension is trying to force itself into my life. I have needed herculean strength."

Jennifer’s strength and determination will be demonstrated on May 20th at our Walk. Jennifer says with a smile that last year she started late, and her team raised a small amount of money. "This year I am off to a better start! I have set a good strong goal of $1,500.00. No worries! With the help of family, friends and supporters, I have every confidence that Team JLo will reach our goal."

SFGWDC thanks Jennifer and the members of her team for their efforts to help the chapter raise funds for research and to support the chapter's activities!

Register today to join Team JLo and others at our 2017 Walk!

JENNIFER LOUD'S JOURNEY

Jennifer is an attorney, and has owned and operated her own law practice in the District of Columbia for 15 years. Prior to starting her own firm, she worked as an attorney for 10 years with the District of Columbia law firm of Eaton & McClellan. She began her legal career as judicial law clerk to a District of Columbia trial court judge. Jennifer is married and the proud mother of twin teen sons.

She was diagnosed with scleroderma in 2004. Since then, she has encountered new and more challenging aspects of the disease. "The more I learned and encountered, the more I struggled with my need to treat my challenge with scleroderma as a private matter." She says she learned that scleroderma is much more severe for African Americans. The belief is that the severity is most likely attributed to genetics with some influence of social, economic and other factors. "My good fortune is that Dr. Virginia Steen, the physician who has led the research on the impact of scleroderma on African Americans for more than 30 years, is one of my physicians."

It was in Dr. Steen’s waiting area at Georgetown University Hospital that Jennifer met a young woman who was giving everything that she had to fight against scleroderma. She was a young wife and mother of a five year old son. "We shared, laughed and prayed," Jennifer says. "A few years ago scleroderma won. Her mother later told me that her connection with me, another scleroderma patient, was very significant to her."

"A year ago when I needed a new medication that cost $13,000.00 per month (yes the comma is in the right place), I was so thankful that my health insurance would pay for all but $40.00 each month," she says. Jennifer comments on the difficulty presented to so many scleroderma patients. "I ask myself: What about the patients who do not have a Dr. Steen, or even worse, have a physician who knows nothing about this horrible disease? What about those whose insurance companies will not pay as much as mine pays each month for a $13,000.00 prescription or worse, those who do not have any insurance at all?"

Over time, Jennifer says her struggle with the need for privacy was no longer an issue, as it was replaced with a responsibility to share and advocate for others.
"I had to become more involved and more open with my experience," she says. "My hope is that with my transparency and knowing the experiences of others who have been equally transparent, scleroderma patients and their wonderful caregivers will know and take comfort in the wise words of Dr. Maya Angelou: "In the face of such uncertainty, remember these two things - you are stronger than you think and you are not alone."

SFGWDC thanks Jennifer for sharing her story with us and for all she does to serve as an advocate for the scleroderma community!