

MEET THE BOARD OF DIRECTORS

In our last newsletter, we introduced you to two of our board members, Solomon Reed and Jennifer Loud. We feature our other two board members in this issue, Mary Beth Tourbin and Michael Senisi!



Mary Beth Tourbin has been involved with the SFGWDC Chapter since July 2013 and became a board member later that year in November. She currently serves as the Chapter's Board President.

"Allen never gave up and fought the good fight every step of the way," Says Mary Beth when speaking about her brother. Allen battled scleroderma for more than 18 years. His diagnosis of systemic scleroderma came in his early 30s, and he was treated over the years at two major scleroderma centers, Johns Hopkins University and University of Pittsburgh

Medical Center (UPMC). Mary Beth's paternal grandmother had limited scleroderma and was also treated at UPMC. Her story was a different one in which she lived a long life into her early 90s.

Having spent many years in the corporate world of sales and marketing, Mary Beth always wanted to use her experience to do something more to help others. The SFGWDC Chapter became the perfect place for her to get involved. She knew the needs of the Chapter and was passionate about helping those living with scleroderma and their families.

As the Board President, Mary Beth sees fulfilling the Chapter's mission and building a stronger Chapter Board of Directors as key goals. "I would like to see the board of directors grow in numbers which will not only provide a stronger foundation to manage the chapter, but also improve the strength of our chapter." She also says she would like to see a few more educational or supporting activities which will strengthen our community and enhance our capabilities to service our patient membership.

Mary Beth is the Director of Marketing at a boutique systems integrator. She has served for many years in leadership roles at several large corporations, including Cisco Systems, Nortel, and BellSouth. She enjoys working in a small organization, where she can stay in touch with technology, while using her skills and experience in a multitude of ways.

"To net it into two words, Engagement and Growth," says Mary Beth. "If my service can accomplish both, then I will be pleased and hopefully so will all of you."

Mary Beth is married with two sons and lives in Virginia.

Michael Senisi became interested in addressing scleroderma because his mother-in-law is a scleroderma patient and a board member for the SF Tri-State Chapter in New York. Over the years, Michael attended several activities sponsored by the Tri-State Chapter, prompting him to get involved with the local Chapter serving the Baltimore/Washington, DC area. Michael joined the SFGWDC Board of Directors in January 2014 and currently serves as the Vice President.



Participating in several Awareness Walks hosted in New York, Michael believed that a walk in the Baltimore/Washington, DC area could raise awareness and funds for the Foundation. Prior to joining the board, Michael started the Stepping Out to Cure Scleroderma 5K Walk/Run at Atholton High School, in Columbia, MD, where he worked as the Athletic Director. "I thought this would be a great way to create awareness for students, raise some funds for scleroderma research, and bring together the community," says Michael. Now moving into its 6th year, the Stepping Out to Cure Scleroderma 5K Walk/Run has doubled in participants and raised over \$100,000. Michael has successfully led this effort for the past 5 years, and we can all look forward to this wonderful event on May 14, 2016.

Michael has worked for the Howard County Public School System for the past 22 years in different positions, including the Athletic Director for Atholton High School and an Adaptive PE Teacher, where he assisted students with disabilities. He currently works in the Central Office as an Instructional Facilitator for Physical Education.

"My personal goals while serving on the board are to continue raising funds for scleroderma research and increasing awareness for all individuals about the disease," says Michael. "Hopefully, we can help to find a cure."

Michael lives in Columbia, MD with his wife and three children.

INTERESTED IN BEING A BOARD MEMBER?

We are seeking committed individuals with a passion for helping scleroderma patients and their families!

Boards members and Chapter volunteers are asked to:

- Serve as an ambassador for the Chapter and the Foundation by informing individuals about scleroderma and the Chapter's mission, services, policies, and programs.
- Prepare for board meetings.
- Participate in year-round Chapter activities and programs.
- And have fun while doing all of the above!



If you are interested, please call our executive director Carole Bernard at 571-291-1480 or email her at cbernard@scleroderma.org. We welcome you to join us in our efforts!

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Scleroderma Foundation Greater Washington, DC Chapter

carole.bernard@comcast.net

