



# Scleroderma Foundation Greater Washington, DC Chapter

Serving the District of Columbia and the surrounding metropolitan areas in Maryland and Virginia.



## Mission

**Our Three-Fold Mission of Support, Education and Research:**

**Support:** To help patients and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals and educational information.

**Education:** To promote public awareness and education through patient and health professional seminars, literature and publicity campaigns.

**Research:** To stimulate and support research to improve treatment and ultimately find the cause of and cure for scleroderma and related diseases.



**Building a Community of Support & Connecting Individuals and Families**



## A Message from the Board President

On behalf of the Scleroderma Foundation Greater Washington, DC (SFGWDC) Chapter, I want to thank you for your ongoing support of our efforts.

This year has been very exciting, and I am proud of the chapter's commitment to fulfilling our three-fold mission of "Support, Education and Research." Our executive director, Carole Bernard, and our board members have worked hard this year to ensure the chapter is providing individuals and their family members with important

information about scleroderma through our conferences and communications vehicles. Our Support Groups are providing forums for individuals to come together to share stories, ideas, and to learn from speakers covering various topics. And our participation at local health fairs and community events, as well as our annual Stepping Out to Cure Scleroderma Walk/Run continue to raise awareness about scleroderma.

We are looking forward to building upon our 2016 accomplishments,

and to your continued support of our work. We are in need of volunteers, from helping with our daily social media communications to stuffing envelopes. No activity is too small, and all are worthy.

Together, we will help to improve the lives of individuals living with scleroderma, provide support and educational services, and raise funds for research. Enjoy reading our *2016 Year in Review!*

*Mary Beth Tourbin*  
Board President

## Mission

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# Programs

## Education

SFGWDC provides educational and networking opportunities at its Patient Education Conference for people living with scleroderma, their caregivers, family members and friends. Presentations are conducted by leading scleroderma medical professionals and researchers.



### Receiving an Award in 2016

At the 18th Annual National Patient Education Conference, held July 29-31 in New Orleans, Scleroderma Foundation CEO Robert Riggs presented SFGWDC with the *Outstanding Patient Education Program Award* for its 2015 African American Patient Education Conference. Accepting the award on behalf of the Chapter was its Executive Director Carole Bernard and Board Member Jennifer Loud (see top photo).

We are thrilled to be recognized for our work on behalf of scleroderma patients and their families, and SFGWDC dedicates the award to all of you!

### 2016 Patient Education Conference

More than 60 patients and caregivers had the opportunity to hear informative presentations on October 8<sup>th</sup> from leading medical professionals and researchers at our Patient Education Conference held at George Washington

University. With seven presenters, the conference covered diverse topics important to scleroderma patients.

"This is a very exciting time for patients with scleroderma, as there is so much interest in studying different medications for this disease," said Dr. Virginia Steen from Georgetown University Hospital. "During this conference, we look forward to sharing with you both the possibilities for participating in clinical trials as well as the results of some of the recent trials." Dr. Steen presented on *Lung Disease in Scleroderma*.

Other presenters included Dr. Ronald Brown, from Howard University, who discussed *Dental Issues in Scleroderma*.

Dr. Kathleen Holton, from American University, discussed



*Optimizing Nutrition in Scleroderma Patients*.

Dr. Zsuzsanna McMahan, from Johns Hopkins University, presented the *Complexities of Scleroderma GI disease: Clinical Manifestations, Risk Factors, Diagnosis, and Management*.

Dr. Victoria Shanmugam, from George Washington University



Hospital, discussed *Wound Care and Digital Ulcers*.

Dr. Laura Hummers, from Johns Hopkins University Hospital, discussed *Updates in Research*.

Dr. Joshua Woolstenhulme, from The George Washington

# 2016 Patient Education Conference

University, presented on the *National Institutes of Health Interstitial Lung Disease and Exercise Study*.

Many thanks to our presenters for sharing information with our attendees; to Dr. Shanmugam and her staff for helping us to secure the space at George Washington University and for helping with set-up; and to Debbie Drell from the Pulmonary Hypertension Association for attending, helping with registration, and for providing giveaways at the event. Thanks to Board Members Mary Beth Tourbin, Sharon Fine Parker, and Jennifer Loud for their assistance and to Executive Director Carole Bernard for coordinating the event.

Funding provided in part from the National Gold Sponsors: Actelion Pharmaceuticals US and Bayer HealthCare.



## Medical and Scientific Advisory Board

As part of our education mission, we also work with our Medical and Scientific Advisory Board (MSAB) of leading scleroderma experts.

MSAB members are distinguished individuals in related research, clinical and pharmaceutical fields with concentrations in scleroderma clinicians in scleroderma and related fields.

The MSAB is a tremendous asset to the chapter, and we look to these medical professionals for advice and guidance on all medical and scientific issues.

### Expanding the MSAB

This year, SFGWDC revamped the MSAB to broaden the expertise to better address the needs of our members.

Our MSAB currently includes: Dr. Virginia Steen from Georgetown University Hospital; Dr. Laura Hummers from Johns Hopkins University Hospital; Dr. Kathleen Holton from American University; Dr. Janet Poole, PhD, OTR/L, from the University of New Mexico; and Dr. Victoria Shanmugam from George Washington University Hospital.

# Support Groups



SFGWDC connects people living with scleroderma through its Support Groups, which are hosted by our volunteer Support Group Leaders.

Our groups host patient education seminars to inform those affected by the disease, including patients, caregivers, family members and friends. Individuals living with scleroderma are welcomed into a safe, positive and inspiring environment to learn more about the disease and to share their stories.

Our Maryland Support Group continues to meet in Bethesda and Chevy Chase, Maryland, offering wonderful presentations and the opportunity for individuals to gather together on a monthly basis.

## Launching New Support Group

This year, we launched a new Support Group in Northern Virginia, on October 29, to better meet the needs of our members. Deborah Aloof and Sharon Parker Fine are the new Co-Leaders for the group.

Our goal is to launch two more Support Groups in Baltimore/Howard Counties and Calvert/Prince George's Counties. These additional Support Groups will create new opportunities for our growing membership to connect with one another closer to their homes.

We also plan to offer Virtual Support Group Meetings during the winter months, when it can be difficult for some folks to leave their homes. We are very excited about these new initiatives.



SFWGDC thanks our Support Group Leaders for their volunteerism and for their dedication!



# 2016 Stepping Out to Cure Scleroderma Walk/Run

## Raising Awareness and Funds for Research

The 6th Annual Stepping Out to Cure Greater Baltimore 5K Walk/Run brought together more than 150 people at Atholton High School in Columbia, MD on May 21. The morning started out rainy with clouds in the sky, but that did not dampen our spirits. People poured into the school's gymnasium with enthusiasm to sign-in, get their t-shirts and team signs, and meet their team members. By 10am, the rain had subsided and people moved out to the school's track and walked with pride! It was wonderful sense of community! Check out our photo gallery!

We had more than 190 participants and 24 teams who helped us to exceed our goal by raising \$31,448 for research and to support the Chapter's activities! The Chapter is very grateful for the support from all of our participants and donors.

During the event, Board President Mary Beth Tourbin presented Board Member Michael Senisi with an Outstanding Achievement Award for his commitment and dedication to starting and coordinating the Walks. Prior to joining the board in 2014, Michael started the Stepping Out to Cure 5K Walk/Run in 2011 at Atholton High School in Columbia, MD, where he worked as the Athletic Director.



SFGWDC thanks our sponsors: Actelion, Envirotest, Wegman's, Dominos, Chic Filet, and Ed Hubert Photography. We could not do this without all of you!

We also want to thank the people who helped to make this year's Walk so successful: Executive Director Carole Bernard, Board Member Mike Senisi and his wife, Alycia Markoff Senisi; Rosemary Markoff;

Board President Mary Beth Tourbin; and Board Member TJ Keilty.

Many thanks to the Atholton High School Athletic Boosters and SGA for sponsoring our Walk, and to Atholton High School for accommodating us in the gymnasium and for their ongoing support for the past 6 years.

We look forward to our 2017 Walk/Run!



# 2016 Stepping Out to Cure Scleroderma Walk/Run

## 2016 TEAM AWARDEES

Each year, we recognize the Team that raised the most money. This year, The Dorsey Family Team was presented with a plaque for raising \$4,360. In 2nd place was Team Gary, and in 3rd Place was Team Mama Liz. Congratulations to all of our Teams for their hard work!



## 2016 INDIVIDUAL AWARDEES

We also recognize the individual who raised the most money. Debra Berman received a plaque for her efforts. She raised \$2,110. Charles Theisen was in 2nd place, raising \$2,010. Susan Kushner was in 3rd place bringing in \$1,325. Thanks you to all of our participants!



SFWGDC thanks all of our participants for supporting our efforts to raise funds for research and for our programs!



# Outreach Program

## Board Members

Mary Beth Tourbin  
President

Solomon Reed  
Treasurer

Thomas Keilty

Jennifer Loud

Sharon Parker Fine

## Staff

Carole Bernard  
Executive Director

## Support Group Co-Leaders

Deborah Aloof  
Northern Virginia

Ingrid Denis  
Maryland

Sharon Parker Fine  
Northern Virginia

Katherine Kirlin  
Maryland

Susan Rae  
Maryland

Sarena Welch  
Maryland



SFGWDC participates in different community events to educate and inform individuals about scleroderma and to share the chapter's activities. Staff, volunteers, and board members have the chance to talk to many people about scleroderma, hand out brochures, and sign up new volunteers.

SFGWDC participates in the NBC 4 Health and Fitness Expo at the Washington, DC Convention Center, which offers a wide range of fitness, health and informational programming.

We also participate in the Sjögren's Walkabout & Autoimmune Disease Health Fair in Washington, DC. The event provides valuable information about the different autoimmune diseases affecting so many people.

The KLM Community Day Health Fair in Largo, Maryland offers the chapter the opportunity to join over 40 health care organizations in sharing information with a broad audience.

The event is sponsored by the Kettering Recreation Council, KLM Boys Girls Club, The Maryland Park Planning Commission, B&K Productions, and P.I.T.S Sports.



We are always looking for volunteers to help us in manning a table and sharing information at these and other local community events.