

## SCLERODERMA FOUNDATION GEORGIA CHAPTER'S ANNUAL DAY OF FUNDRAISING CANCELLED

### Special points of interest:

- 2013 Patient Education Conference
- 2012 Family Fun Run
- Knocking Out Scleroderma
- 2013 Calendar of Events

The Scleroderma Foundation Georgia Chapter's Annual Day of Fundraising has been cancelled this year because we will be hosting the National Patient Education Conference here in Atlanta, July 26<sup>th</sup> – July 28<sup>th</sup>. We will be working with the National Foundation to host this year's event which is taking place when we typically have our "Annual Day of Fundraising" so you can see why we have had to make some changes to our calendar of events this year. We encourage you to attend the Patient Education Conference at the Hyatt Regency Atlanta. To find out more about the conference please see the blue boxing glove on page 2 of the newsletter

Don't worry, we are still going to have ways for **you** to support our chapter in 2013. We are still planning to host the "5<sup>th</sup> Annual Kathleen Basile Memorial Golf Tournament" on Friday, August 2, 2013 at Reunion Country Club in Hoschton GA. We are also going to have a "Stepping out to Cure Scleroderma" event on June 15<sup>th</sup> because June is Scleroderma Awareness month (Teal Blue is the color of the month!)

For those of you who have supported our Annual Day of Fundraising dinner event we welcome you to join us on June 15<sup>th</sup> at Lilburn Park. We promise it will be a good time for all ages (see more information on this event on page 7). We have already begun to plan for our 2014 event a "Wild, Wild, West Theme" We are hoping to catch up with the *Jims* to see what they will be up to by then.

It is important for our organization to keep in touch with all our supporters at least annually so please consider attending or supporting these events or becoming a SFGA member or making a donation to support our efforts.

### Hiking and Hotcakes (a Stepping Out To Cure Scleroderma Event)

#### June 15<sup>th</sup> – Lilburn City Park

*(Please join us even if you're not a runner. We are planning to have raffles, prizes, and a GREAT hotcake breakfast)*

### 5<sup>th</sup> Annual Kathleen Basile Memorial Golf Tournament – August 2nd - Reunion Golf Club

**Make a donation or become an SFGA member** by going to the National Foundation donation page at [www.scleroderma.org](http://www.scleroderma.org)

The money will be directed back to the chapter level to help us help the people living with scleroderma here in Georgia, by allowing us to continue to host continuing education events, continue to support and create new support groups, and make contributions to aid the much needed research to find a better treatment and ultimately a cure!

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# SCLERODERMA FOUNDATION

2013 NATIONAL PATIENT EDUCATION CONFERENCE

## "KNOCK OUT SCLERODERMA"

FIFTEEN YEARS OF FIGHTING

JULY 26 - 28, 2013  
HYATT REGENCY ATLANTA  
ATLANTA, GEORGIA



Join us for the 2013  
National Patient Education  
Conference and celebrate the  
Scleroderma Foundation's  
15th Anniversary!



To find out more about the 2013 National Patient Education Conference,  
call us at (800) 722-HOPE (4673) or visit  
[www.scleroderma.org/conference](http://www.scleroderma.org/conference).

CLICK HERE TO REGISTER FOR THE CONFERENCE [www.scleroderma.org/conference](http://www.scleroderma.org/conference)

### NATIONAL PATIENT CONFERENCE IN ATLANTA 2013 UPDATE

Members of the SFGA board met with the National Foundation here in Atlanta on 2-19-2013 at the Hyatt Regency. We toured the facilities and feel confident that the location is very well suited for the conference. We are all very excited to help host this year's event. We hope that all of our SFGA members will be able to attend this very informative, and supportive opportunity for people living with scleroderma, as well as their care givers and family members.



## 2012 SFGA Chapter Holiday Meeting & Luncheon

The Georgia Chapter ended 2012 with a Holiday Appreciation Luncheon on Sunday December 8<sup>th</sup> at Killian Hall in Lilburn, Georgia. The invitation was extended to all chapter members, the medical advisory staff, support group members and friends of the chapter. The afternoon started with a meet and greet as we welcomed members from the Atlanta, Athens, Macon and Peachtree City area. Everyone enjoyed a wonderful lunch prepared and served by our hospitality chair Mary Wetherington and other board members.

A short meeting was conducted by Co-Presidents Doreen Towhey and Peggy Levengood, a financial report was delivered by Treasurer Jim Walsh and Ann Basile shared a report on the patient conference in Dallas, and Carla Basile reported on the October 2012 Family Fun Run and social media. Secretary Andrea Wetherington gave us an update on our Facebook activity. Vice President Evan Busman reported on the Support Group information and Support Group leader Richard Moore gave a report on our new support group in the Peachtree City. The new board for 2013 was introduced, and an overview of our 2013 work plan we shared along with the budget for 2013.

The meeting concluded with recognition and appreciation to our support group leaders, our committee chairs and board members. The meeting ended with a "Knockout Scleroderma" Campaign for the Patient Seminar 2013 which will be hosted by the Georgia Chapter in July.

## GEORGIA IS WORKING ON "KNOCKING OUT" SCLEORDERMA!



## Do we have your e-mail address?

Most of you will be receiving this newsletter electronically so this article may seem out of place to you but we have many members who receive by mail The Georgia Gazette Newsletter. So, if you are getting this newsletter by way of the US Post Office, this article is for you.

We here at SFGA want to make sure we are using our funds wisely so to save on the cost of mailing a hardcopy newsletter to you we would prefer sending it by way of e-mail. If you would be willing to receive our newsletter by e-mail please send you e-mail address to us : [gachapter@scleroderma.org](mailto:gachapter@scleroderma.org)

No worries if you don't have an e-mail account. We are still very pleased to send you a hard copy to keep you up to date on what is happening with SFGA in 2013.

### **Want to make sure you keep receiving you The Georgia Gazette?**

Just make sure to keep you membership current with the National Scleroderma Foundation and you will automatically be added to our Georgia Chapter Membership database.

## 2013 Spring Patient Seminar

There are alarming trends in our nation related to our aging population. American culture has drifted away from respect for our elders. We are in denial that we all are aging. We mistakenly assume that social security, Medicare and other entitlement programs are enough to allow us to age in our homes. As a country, we are not cognizant of the impact our aging population will have on our communities over the next 30 years and the extreme urgency for everyone to plan for their own and their loved one's aging experience.

I will be among those presenting at the upcoming patient educational seminar on March 10<sup>th</sup> at 2:30p.m. at Shorty Howell Park Activities Building. My presentation will focus on planning and cultural issues impacted by our aging population. Also, I will present what Medicare/Medicaid does/does not cover and pay for. I will inform about the steps every individual should go through to have a successful "Aging in Place" experience and the need for "Culture Change" in this nation as our communities experience the largest aging population since the founding of our country. The data and other information easily segue to the disability community, as well. This event is open to the public.

Scott Morrison  
Certified Senior Advisor (CSA)  
President  
BrightStar Healthcare Duluth and Gainesville, GA



**Healthcare**

**Homecare**

**Family Care**

**(Advanced Directives)**

**SFGA**

**Spring Patient Seminar**

**Sunday March 10, 2013**

**2:30p.m.**

Shorty Howell Park  
Activities Building  
2750 Pleasant Hill Road  
Duluth, GA 30096

Please come and join us for:  
**Soup, Sandwiches and some  
Solutions to your healthcare needs.**  
The topics that will be discussed are good  
for **ALL** of us to learn more about.

Hope to see you there!

**Your R.S.V.P is appreciated. Please e-mail us at  
[gachapter@scleroderma.org](mailto:gachapter@scleroderma.org) or call 770-925-7037**

**Guest Speaker: Scott Morrison**

Scott has served on the Board of the Georgia Chapter of the National Scleroderma Foundation since we received our charter in 2011. Scott is the Owner/President of BrightStar Healthcare in Duluth, Georgia. BrightStar is a national franchise and Atlanta's trusted premier provider of private-duty, in-home healthcare ranging from companion care and skilled nursing to physical therapy, occupational therapy and transportation. In addition, BrightStar offers healthcare staffing services to physician offices, hospitals, nursing homes, assisted living and independent living facilities.

Scott Morrison is a ready reference resource for everything "Elder". He will share with us important educational knowledge that caregivers of both Elders and those living with disability should know.

**Guest Speaker: Mike Levensgood**

Mike Levensgood is a partner in the international law firm of McKenna Long & Aldridge LLP where he has practiced law for more than thirty years. He is a Georgia Hospital Association certified Board Trustee and is a member of the Board of Directors of the Gwinnett Health System. Mike chairs the Board Policy Review Committee and also serves on the Gwinnett Health System's Bioethics Committee. He and his wife, Peggy, live in Lilburn where they raised their three sons.

Mike and Dr. Murtaza Cassoobhoy will be leading an educational session on the role and importance of communication through the use of Advance Directives and Physicians Orders for Life-Sustaining Treatment in Georgia.

**Guest Speaker: Dr. Murtaza Cassoobhoy, M.D. FACP**

Dr. Cassoobhoy sits on the Medical Advisory Board of the Georgia Chapter of the Scleroderma Foundation. He became involved with our organization through a family member who is living with scleroderma. He is Board Certified in Internal Medicine, Hospice and Palliative Care and a Hospitalist at Gwinnett Medical Center. He attended Wake Forest University and completed his residency at Emory University.





## **Hitting the Wall**

I was asked me to write an article about the MUSC Scleroderma patient conference held in Charleston in February. The sad fact is that I did not attend. The agenda looked great with topics that were relevant to people in the Georgia Chapter and me.

Cheri and I were going to stay over Saturday evening and spend time in our favorite city in the US. But for the two weeks prior to the conference and the two following weeks, I was working. That's not too different from what you and a lot of people do but work included weekends and long days during the weeks on projects and conference presentations. One Friday night not too long ago, I got a reminder. I hit the wall.

Allow me to digress. If you've ever run a marathon, you've most likely heard the term "hitting the wall". During the later points of a marathon a runner can deplete their glycogen stores in the liver and muscles, which manifests itself by sudden fatigue and loss of energy. It becomes difficult to continue but those running 26.2 miles often do. By no means did this specifically happen to me (it was the only analogy I could come up with) but one Friday night I revisited the bouts of chills, body aches, and fever that I had prior to be diagnosed. My body was telling me to slow down and to get back to taking care of me. I had not been to gym, no yoga, not eating right, travel, long days, etc., etc., and etc. As we know, this is not a kind or forgiving disease.

I had received a not so gentle reminder that there are limits that must be respected, even with the medicine I take, the great doctors I have and my amazing wife. Part of the reason marathoners hit the wall is a pace that is too fast for them. This can apply to runners, non-runners and those with autoimmune diseases like Scleroderma. My previous visits to my Rheumatologists and Internist had been sparkling. I was above it. I was in control. I was wrong.

The good news is I've started the process of getting back to caring for me and I recognize that we all have limits. I'm still traveling but have been focusing on better dietary habits and working out more.

Seems life and the things that directly impact us have a way of reminding us what is really important.

Mike English

## SUPPORT GROUP NEWS



**Evan Busman**  
**Atlanta Support Group**  
**Leaders**

Greetings everyone! The state of our support group is “thriving”. Newly diagnosed patients continue to seek out the wisdom of those who have been living with scleroderma for quite some time and all are benefiting from ongoing information sharing and patient education seminars.

We said farewell to 2012 with a special holiday party honoring Chapter and Support Group Members. And we’ve lined up a very exciting 2013 with bigger and better round table support group meetings, patient education seminars, and fund raising events. The round table support group meetings are scheduled for 7pm at The Glancy Rehabilitation Center (3215 McClure Bridge Road, Duluth, GA) on Tuesday - February 26, Thursday – April 25, and Thursday – June 27. (Support group meetings for the second half of 2013 will be scheduled in June.) Patient education seminars are scheduled for Sunday, March 10 at Shorty Howell Park (2750 Pleasant Hill Rd., Duluth, GA) and the National Patient Conference is scheduled for Saturday/ Sunday at the Hyatt Regency Atlanta on July 28 and 29.

Before signing off, I wanted to mention an article that I sent out a few months ago and received overwhelming feedback. If you have ever tried to explain to someone what scleroderma is all about and how it makes you feel only to be told that you “don’t look sick”, then this article is for you. Please check out “The Spoon Theory” written by Christine Miserandino at: <http://www.butyoudontlooksick.com/wpress/articles/written-by-christine/the-spoon-theory/>

## WHAT’S NEW IN NEWNAN!



**Richard & Barbara Moore**  
**Newnan Support Group**  
**Leaders**

The Newnan-Peachtree City Support Group meets on the third Sunday every other month. If you have been diagnosed with scleroderma and live south of Atlanta, mark you calendar and come share a couple of hours with our group of caring supportive friends. We meet from 3:00 to 5:00 pm at the beautiful community center called **The Bridge**, located at 225 Willowbend Road in Peachtree City.

We have light refreshments and discuss everything from how we feel to problems with disability and financial aid concerns. We have had an informative talk by a dentist experienced with scleroderma. She talked to us about dental care and mouth issues.

Because “We Look So Good” it is just nice to share time with others who understand how we feel and what we are going through and truly care about our health concerns.

We will meet March 17, May 19, and July 21.

## PRESIDENT'S POINT

**BELOW ARE TWO WAYS YOU CAN SUPPORT OUR ONGOING EFFORTS HERE IN GEORGIA THIS YEAR:**

### ***Hiking and Hotcakes (a stepping out to cure scleroderma event)***

This year the Georgia Chapter will be “Stepping Out” in June with a Hiking and Hotcakes 5K race and 1 mile fun run. The race is scheduled for Saturday June 15th beginning at 8:00 AM at Lilburn City Park. This year is the first year for the chapter to participate in a “Stepping out for a cure” event in recognition of national Scleroderma month.

The event will begin at 8:00AM with a Zumba warm-up and the race will begin at 8:30 and will conclude with a hotcakes breakfast and awards ceremony. The race will be timed by the RoadRunners and the race includes a soft surface trail and a greenway path.

Lilburn Park is a beautiful city park, playgrounds, tennis courts, large pavilion and a great family park

Race information will be listed on Active.com, Run and See Georgia, and on our website.

We encourage all of you to come out and run, walk, eat hotcakes and enjoy the morning as we celebrate National Scleroderma month and “Stepping out for a Cure”.

For more information and sponsor opportunities please visit our giving website @ [www.scleroderma.org/steppingoutgeorgia](http://www.scleroderma.org/steppingoutgeorgia) or contact us at [gachapter@scleroderma.org](mailto:gachapter@scleroderma.org) or call 770-925-7037

### ***5th Annual Kathleen Basile Memorial Golf Tournament***

August 2, 2013, Reunion Gold Club, Hoschton, GA

To find out more information and to register please visit [www.scleroderma.org/golfgeorgia](http://www.scleroderma.org/golfgeorgia)







Stepping Out  
To Cure Scleroderma  
Hiking & Hotcakes

**Saturday**  
**June 15, 2013**



## **10K - 5K - 1 Mile Fun Run**

**A Stepping Out To Cure Scleroderma Event**

**Sponsored by:**

**The Georgia Chapter of  
the Scleroderma Foundation**

**Lilburn City Park - Greenway Trail**

- Registration & Zumba Warm Up - 8:00am
- 10K Start - 8:30am - \$25 "Are You Ready For The Peachtree?"
- 5K Start - 8:45am - \$25
- 1 Mile Family Fun Walk/Run Start - 9:00am - \$25 or a family of 4- \$40
- Breakfast and Awards - 10:00am

**REGISTER TODAY!**

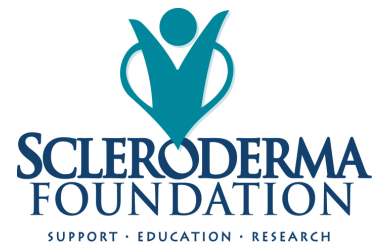
Registration can be made through our website @

[www.scleroderma.org/steppingoutgeorgia](http://www.scleroderma.org/steppingoutgeorgia)

or call 770-925-7037

To find out more about scleroderma and ways you can support our efforts please visit the Georgia page on the National website @ [www.scleroderma.org](http://www.scleroderma.org)

Lilburn Park, 76 Main St NW, Lilburn, GA 30047



Hi everybody! Hope all of you had blessed holidays and a great start to a wonderful 2013. Many opportunities await us this year so be sure and stay in touch with our scleroderma website for the things on the agenda prior to and including the upcoming Scleroderma Foundation National Patient Conference in July right here in Atlanta!

Reflecting back on opportunities, a young couple so very dear to us had a beautiful Christmas wedding and reception in a barn. During the reception when the DJ really got some good music going, somehow I knew it was time to test my recent graduation of 18 sessions of pulmonary rehab! Grabbing my better half Steve who dances with his “hands” only ... we hit the floor so we could “shake, shake, shake my booty”. During the process, next thing we knew , there stood our Pastor filming us!

Also a little over a week later on Christmas day as we arrived at our family gathering, we were greeted at the door by our grandchildren with their new karaoke machine in full swing. They were so excited to see that they caused Nana to immediately “get down” and so was dear Papa Steve!

A more recent opportunity was experiencing actually pulling off Steve’s big surprise “60” birthday celebration to the point of actually seeing his jaw drop! It got pretty stressful when he got called into work the very day of the reservations and all his siblings arriving from out of town. Keeping the faith and with a lot of help from my daughter, Rebecca, and the rest of our family, everything fell neatly into place. Sometimes when we least expect it, we can accomplish more than we can dream of! Next Rebecca and I splurged at I-Hop for my “B” day!

Now we should all be looking forward to “Going Green, Kissing the ole Blarney Stone for St. Patty’s, with Easter just around the corner and all the days in between and there after. We do all know we have to watch not to over exert physically and emotionally but joining in on the fun is such good practice for pacing ourselves too. So don’t be shy...”hit um with your best shot”! By the way my 91 year old dad and step mother put their ailments aside for a daily chair aerobic class and even do Zumba on Mondays!

Now lets see how happy and healthy we can make all of 2013. There’s a lot of blessing to look forward too. Please feel free to share your blessings in our Peach Pit Stop article anytime.

*Please send Peach Pit Stop article submissions to: [gachapter@scleroderma.org](mailto:gachapter@scleroderma.org)*

# 2nd Annual Family Fun Run - October 28, 2013

## Shorty Howell Park, Duluth, GA

The day was chilly and the threat of rain was in the air, but the weather could not dampen the spirits of all those who participated in the 2<sup>nd</sup> Annual Family Fun Run. Children, parents, grandparents and friends took to the track for a 1 mile walk/run or a 5K run.

Games like pin the nose on the pumpkin, fishing for ghosts, and pumpkin toss were played. The smell of popcorn filled the air and hotdogs were roasted. Hot chocolate was the favorite beverage for keeping hands warm! First, second, and third place medals were awarded to the walk and race winners. Raffle tickets were given to everyone who signed up for the event. As the raffle ticket numbers were called, the raffle items were given out. Some people were very lucky!

Thank you to all who came out to our SFGA day of family fun.



## 2013 CALENDAR OF EVENTS

<b>MARCH 10TH</b>	CHAPTER BOARD MEETING - 1PM SHORTY HOWELL RECREATION BUILDING
<b>MARCH 10TH</b>	CHAPTER MEMBER MEETING & SPRING PATIENT SEMINAR - 2:30PM SHORTY HOWELL RECREATION BUILDING
<b>MARCH 17TH</b>	NEWNAN SUPPORT GROUP MEETING – THE BRIDGE, PEACHTREE CITY 3PM
<b>APRIL 25TH</b>	ATLANTA SUPPORT GROUP MEETING - GLANCY, DULUTH 7PM
<b>MAY 19TH</b>	NEWNAN SUPPORT GROUP MEETING – THE BRIDGE, PEACHTREE CITY 3PM
<b>JUNE 15TH</b>	HIKING AND HOTCAKES STEPPING OUT TO CURE SCLERODERMA- LILBURN PARK
<b>JUNE 27TH</b>	ATLANTA SUPPORT GROUP MEETING - GLANCY, DULUTH 7PM
<b>JULY 21ST</b>	NEWNAN SUPPORT GROUP MEETING - THE BRIDGE, PEACHTREE CITY 3PM
<b>JULY 26-28</b>	NATIONAL PATIENT CONFERENCE - HYATT REGENCY - ATLANTA
<b>AUGUST 2ND</b>	5TH ANNUAL KATHLEEN BASILE MEMORIAL GOLF TOURNAMENT
<b>AUGUST 11TH</b>	CHAPTER BOARD MEETING - LOCATION TBD
<b>AUGUST 18TH</b>	CHAPTER MEMBER MEETING – LOCATION TBD
<b>SEPTEMBER 2013</b>	FALL PATIENT SEMINAR - TBD

*\*Dates are subject to change. All this information and more can be found at our chapter page on the National Foundation's website @ [www.scleroderma.org](http://www.scleroderma.org) then click on find a chapter and then click Georgia!*

## GEORGIA CHAPTER MEMBERSHIP

Becoming a member of the Georgia Chapter of the Scleroderma Foundation is easy. If you have made a donation to the National Foundation or have paid their membership dues, you are already a Georgia member. Your tax-deductible gift of \$25 or more makes you a member of both the National Foundation and the Georgia Chapter and supports our mission of Support, Education and Research.

### **Membership includes:**

Receiving National's quarterly magazine, *Scleroderma Voice*, that includes:

- Updates on the latest scleroderma research and treatments
- Articles by leading doctors and other health professionals
- Answers to your medical questions by health professionals
- Practical tips on coping with scleroderma
- Heartwarming stories by and about people with scleroderma, describing how they have met and overcome their challenges
- Articles about what the Scleroderma Foundation is doing for you - such as funding new research, advocating for more federal research funding on Capitol Hill, and working nationwide, year-round to raise public awareness of scleroderma and its impact on individuals and their families.

You will also receive SFGA's newsletter "*The Georgia Gazette*" that will keep you informed about local issues and our upcoming events; and gain access to opportunities to serve on the SFGA board and support SFGA fundraising efforts. *For additional information on membership and leadership opportunities please contact Doreen Towhey @ [gachapter@scleroderma.org](mailto:gachapter@scleroderma.org) or call 770-925-7037.*