NEW ENGLAND
The BEACON
A Publication of Scleroderma Foundation New England Summer 2016

ONCE IN A WHILE, IN A BIG BLUE MOON...

By: Jack Armitage

Scleroderma Foundation Volunteer of the Year Don Legere

A year ago in the summer 2015 issue of *The BEACON*, we introduced Donald Legere to our readership. His deeply personal story of scleroderma diagnosis, adjustment, acceptance and treatment via HSCT (hematopoietic stem cell transplantation) was inspirational, and continues to be.

We could not have known then what the outcome could be but, because of Don's endless optimism and almost uncanny ability to advocate for himself, we stood in awe as he wended his way from diagnosis through a very complex insurance system, eligibility and, ultimately, the grueling reality of harvesting and reintroducing his stem cells and sweating it out as he slowly regained strength and capacity.

Flash forward, if you will, to July 29, 2016. It is a year later and Don is being roundly applauded at the 2016 National Conference in New Orleans as "Volunteer of the Year" - a recognition at the national level for exemplary volunteerism!

In the twelve month period between last year's recovery and this year's recognition, Don's milestones have included (but are by no means limited to) the following: advocacy and representation of others who need one-on-one help to navigate the insurance system; home visits to the ill and newly diagnosed as well as frequent counsel on general topics related to scleroderma; an expressed interest in joining the Board of Directors at SFNE and subsequent election to the presidency; introductions to and joining with the national office by becoming an active member of the Chapter Relations Committee, a position shared by new national board members and chapter leaders across the nation.

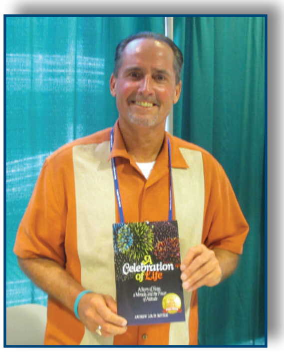
Additionally, Don has hosted a very successful fundraiser in Concord, NH, near where he lives. He speaks publicly whenever asked. He has walked with us in at least three Walks for a Cure in the past year. In his spare time, he has spearheaded a new support group which he co-leads with his best friend and wife (who are the same person), Cathy. He has forged an alliance between this group and the new scleroderma center at Dartmouth Hitchcock Hospital in Lebanon, NH.

(continued on page 4)

BE THAT VOICE...

By: Rebecca Dube

ANDREW BOTIERI CLOSING KEYNOTE SPEAKER AT NATIONAL CONFERENCE



Andrew Botieri with his book A Celebration of Life

"Don't give up," notes Andrew Botieri at his closing keynote speech in New Orleans. "Be your own advocate. We are the faces of scleroderma. We are the fighters, and we are survivors."

Andrew Botieri, author and motivational speaker, is the chair of the Plymouth Stepping Out to Cure Scleroderma Walk. Andrew was asked by the Scleroderma Foundation to be the closing keynote speaker at the 2016 National Conference in New Orleans, and he certainly delivered.

(continued on page 2)

IN THIS ISSUE

Scleroderma Foundation
New England Chapter
Founders:
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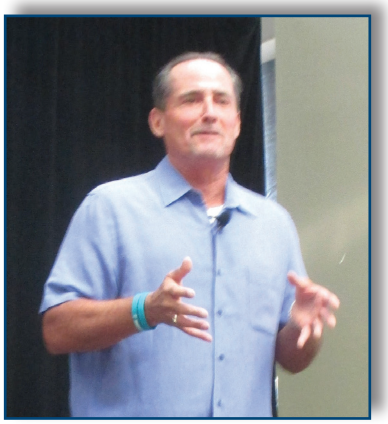
DISCLAIMER: *SF/New England Chapter in no way endorses any drugs or treatments reported in this newsletter or at SFNE sponsored meetings. Information is provided to keep readers informed. Because the manifestations and severity of scleroderma may vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) to assure proper evaluation and treatment.*

BE THAT VOICE...

(continued from page 1)



Andrew speaking to attendees at the New Orleans Conference

Andrew is always an inspiration when he speaks. His infectious energy and optimism are undeniable. "We have the ability within us to do amazing things," he tells the crowd in attendance. "We have two weapons within us: positive thinking and perseverance." Andrew himself used those two weapons in dealing with his own journey with scleroderma, from renal failure and coma in 2000 to acceptance of the disease and working to get off dialysis in 5½ months, while cheering and comforting those around him.

He calls scleroderma the "uninvited guest", but asks those with that guest to "embrace it, accept it, then you can fight it." That is what Andrew does every day. Although he has his ups and downs with scleroderma ("you've got to bring your A-game, but there are days when you don't have an A-game"), he continues to beam with his positive attitude and makes it his goal to continually help others however he can.

In a breakout session earlier in the conference, *Balancing Work, Life and Your Diagnosis*, he sat on a panel with Karen Gottesman, Director of Pharmatech Engagement, and Joy Mitchell, support group leader in New Orleans, and discussed the benefits of support and community while dealing with this disease.

It was a very interactive session with conversation throughout, as attendees spoke of their own support systems and how they have helped them on their journeys. "You find friends," noted Joy Mitchell, "when you reach out to support groups either in person, by phone, or online." Andrew called his support network of friends, support groups, and SFNE "my scleroderma family."

It is a pleasure and a privilege for SFNE to be part of Andrew's scleroderma family and of so many others as well. Andrew himself continues to be a leader, a voice of awareness and support for the scleroderma community.

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You can purchase Andrew's book, *A Celebration of Life: A Story of Hope, a Miracle, and the Power of Attitude* at *www.totalpeakperformance.com* or at *www.amazon.com.*

Andrew hopes to start a men's scleroderma Facebook page - a type of support group geared to men's experiences with scleroderma. We will keep you updated on the progress of that project. In the meantime, Andrew recommends the following Facebook pages for online community:

- Angels Sharing Scleroderma Awareness
- Project Scleroderma/ Dear Scleroderma
- Scleroderma Strong
- And, of course, Scleroderma Foundation New England!
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FROM THE DIRECTOR'S DESK

By: Jack Armitage

This 2016 summer issue of *The BEACON* is chock-full of reflection on this year's accomplishments to date. The intersection of our events, our education outreach, our patient support and our research efforts always seems to reach a zenith by summer's end and we are pleased to bring you a vibrant newsletter as the third quarter draws to a close.

As most of you know, we launched the 2016 events season with our Patient Education Seminar (PES) which was reviewed in our last issue of *The BEACON*. Living with scleroderma is tough in any capacity and we came away from this event feeling that we brought comfort, hope and new care options to many. Please give us your feedback and help us to develop an EXEMPLARY PES for 2018!!

In this issue, we will revisit the fun and successful events that only increased the momentum of that auspicious start. They include the Worcester Walk, the Maine Walk, the Plymouth Walk and the Golf Classic (our fourteenth). Looking ahead to the fall, we will host our twelfth North Shore Walk, our fifth Westfield Walk and our second Boston Walk for a Cure – being held this year to celebrate Kiesha Burton-Levy and Heather Olsen, two of our spectacular Boston support group members.

Special mention must be made regarding the 2016 SFNE Golf Classic for a Cure for Scleroderma held at the Salem Country Club. Remarkably promoted and efficiently executed, it surpassed all expectations this year, bringing more than $167,000 in gross income. What this means is that after the costs associated with it are settled, we will have had the first event in our history to *net* more than $100,000. Great thanks to Rebecca Dube for her daily attentions to all details and to David Rosenberg and Bruce Gordon for being our platinum sponsors and overseers of the event. To all of our sponsors and attendees, thank you.

Additionally, we have enjoyed increasing vibrancy in our collaborations with the National Scleroderma Foundation office and with other national chapters and affiliates. Under the guidance of David Murad, Director of Chapter Relations, we busily engage in the "monthly chapter call", allowing all of us in the different chapters to share ideas and to learn from one another. We recently discussed the success of the annual *Hard Word, Harder Disease* campaign which drew an astonishing 80,000 "hits" on the internet, and we ironed out the itinerary for the Leadership Day held at the National Conference in New Orleans.

At the Board level, we have lots going on. Recently, members Peter Hart and Kate Bedard initiated an Annual Strategies Initiative which will creatively determine a strategic approach to our annual goals and directives. As well, we are working on a draft update of our organizational by-laws, thanks to diligent editing by our friend and advisor, David Tory. Our tax season showed health in our financial profile as presented by board member Tim Hagan. Don Legere, board president, reported on his emerging role as a member of the new national office Chapter Relations Committee. The SFNE Board of Directors continues to grow and diversify – we have added two new board members (*see page 11)*. We are very fortunate to have such an experienced group of leaders and such a dedicated mission in governance.

Deborah Dillon Pearce, whom we had all gotten very used to on our Board of Directors, has been hired by the National office in the role of Chief Operating Officer and we wish her great excitement in this new role and we look forward to our enhanced interactions in our continued momentum with National!

As we interact with the chapters and affiliates serving the many regions of this country, we are kept in constant awareness of the diversity and breadth of our mission. There is no singular formula to bringing comprehensive care and access to our constituents. And still, we are all highly optimistic about the immediate future. Research is showing measurable and highly productive outcome; collaboration and shared intelligence is enjoying an all-time high in enthusiasm. Staff and boards at our chapters and affiliates are enjoying team-cultivated ideas and oversight and carefully articulated improvements in our shared effort to *be the best by doing the best!* We at SFNE are proud of this momentum and will continue to work vigorously with chapter and affiliate leaders, national staff and, of course, with our remarkable constituency.

Enjoy this issue of *The BEACON*. It is our pleasure to continue to bring our readership that proven mix of news, updates and entertainment!

> ***No one who achieves success does so without acknowledging the help of others.***
>
> ***~Author unknown***

ONCE IN A WHILE...

(continued from page 1)

He has raised thousands of dollars single-handedly, then applied for match funds to double the impact. Don has spoken at the Golf Classic for a Cure, our biggest annual fund raiser, and has conscripted his family to volunteer at many of the abovementioned events. Don's frequent calls to the office in the four capacities he holds (Board President, dedicated volunteer, support group leader and client of the foundation) are always colored by humor, creative thought and carefully detailed approach.

Once in a while, in a big blue moon, there comes a guy like this. Don has surpassed any expectation that might have been levied on him by an organization seeking an exemplary volunteer. His innate sense of community service is so ingrained in him that, not unlike the Pied Piper, he draws people around him into the sphere of his creative philanthropy. He is both a humble participant and a strong leader. His intuitive "gut" regarding governance is unruffled and laser-like. Whether packing up a canopy in the rainy aftermath of a long Walk for a Cure or leading the SFNE Board of Directors in a topically challenging discussion, Don is open minded, capable, fair and deliberate.

Of course, the last thing on his mind would be that he'd be recognized for his generous volunteerism. It is so much a part of his nature that his wide-eyed surprise at being thanked and recognized results in that impish grin that we've all become so accustomed to. Thank you Don, you have surpassed any logical expectation in your recovery, your generosity and your community-spirited volunteerism. We are lucky indeed to have you in our corner.

Cathy and Don Legere with Robert Riggs

20 FACTS ABOUT PEDIATRIC SCLERODERMA

According to the Cleveland Clinic, although scleroderma may be similar in adults and children, there are some specific characteristics that are more pronounced in children.

Pediatric scleroderma is divided into systemic and localized diseases, which are further differentiated into subtypes based on clinical findings of skin involvement.

1. There are two types of pediatric scleroderma: localized and systemic.

2. Localized scleroderma is more common in children, usually only affecting the skin. In some cases, it might spread to the underlying muscles.

3. Children with systemic sclerosis may have more wide-spread skin changes which may result in limited joint movement.

4. Raynaud's phenomenon may be present early in a child with systemic sclerosis

5. Fatigue, difficulty swallowing, joint pain may also be present early in a child with systemic sclerosis.

6. Children with systemic sclerosis should be checked often in order to detect and possibly treat potential internal organ involvement.

7. Scleroderma, both in children and adults, is NOT contagious, so people cannot "catch it" or pass it on to someone else.

8. There are between 5,000 and 7,000 children diagnosed with scleroderma in the United States annually.

9. 1.5% of all scleroderma patients will develop it before the age of 10.

10. 7% of all scleroderma patients will develop it between the ages of 10 and 19.

11. The mean age of onset for both forms of pediatric scleroderma is between 7.3 and 8.8 years of age.

12. Approximately two-thirds of children with scleroderma are female.

13. There is no clear evidence for any racial predilection for either form of pediatric scleroderma.

14. There is still no cure for scleroderma but with an early diagnosis, it can be managed and treated.

15. Treatment is specialized and focused on each child. It will vary depending on his or her overall health, type of scleroderma, medical history, the presence of other symptoms and its severity.

16. Scleroderma management often includes family counseling regarding emotional, financial, cosmetic, disability, and social issues.

17. The outlook will depend on the type of scleroderma, whether or not there is internal organ involvement, and where and how much skin is affected.

(continued on page 11)

SCLERODERMA FOUNDATION "PATIENTS AS PARTNERS" PROGRAM REVIEW

DONNA AHERN

On May 13, I was fortunate enough to participate in the *Patients as Partners* program offered by the Scleroderma Foundation. There were eight scleroderma patients from all over the country that were invited to come. Our task was to listen to a presentation about a drug trial and tell them what we thought about it and what improvements we thought would make it more appealing to patients so that they might be more willing to participate. Also, they wondered how they could make the trial information easier for us to understand.

I had no idea what to expect but was pleasantly surprised by how comfortable they made us feel, and how they really listened to what we had to say. It was really wonderful to meet other patients and listen to their stories. I hope it was just as enlightening for the people sponsoring the program. I would encourage patients if the opportunity arises to participate in this great program. We as patients need to be heard so more drug companies will learn about our disease and help find medicines that will help us.

> ***How wonderful it is that nobody need wait a single moment before starting to improve the world.***
>
> ***~Anne Frank***

ROBERTA MAURIELLO

I was fortunate to have been chosen, along with other scleroderma patients to participate on the *Patients As Partners* Advisory Board, which was recently held in Boston, Massachusetts. The Advisory Board was to help provide feedback to a pharmaceutical company for their clinical trials. Due to confidentiality reasons, I cannot divulge what went on during the meeting. However, I can say, it was wonderful, exciting, and very informative.

Congratulations to Karen Gottesman, Director of Pharma and Biotec Engagement and to Robert Riggs, CEO of the National Scleroderma Office, for their creativity in bringing this program forward. I'm certain that the results of this Program will assist people living with scleroderma in the future.

I look forward to hearing that more *Patients As Partners* Advisory Board Meetings are planned in the future. I was honored to participate in this "first" meeting.

* * *

CAROL TAYLOR

I know that all of us that were on the panel were glad to have been chosen. I must congratulate Patient Advocate Karen Gottesman for launching *Patients as Partners* and also CEO Robert Riggs for giving his full support. I personally feel it imperative that pharmaceuticals take to heart the benefits coming out of this partnership program. Understanding patients' views and their experiences could add value and also improve trials. I also would like to see the patient's voice be involved in the development phase and followed right through to the end. I believe that these pharmaceutical companies have received information from only doctors. I hope that with this program that will change.

It was a wonderful experience for me to have my voice heard. I felt very positive that the pharmaceutical company learned a lot from all of us that were on this panel.

I just remember the day as very positive. It was wonderful meeting those members from other states. I know we all hope that more pharmaceutical companies think of us as truly partners. We all want the best and safest clinical trials. The more patients know about the drug from face-to-face meetings will ensure that patients remain in these trials. You're building a "trust" here.

IF YOU WILL...

Planned Giving simplified!

The Scleroderma Foundation New England can offer you assistance in developing a legacy plan that will benefit your charitable plan and which may also provide immediate and deferred tax advantages to you and your heirs.

In doing so, you can have a meaningful impact on the mission of SFNE beyond your lifetime and far in to the future. Learn more about estate planning today.

Contact us at *jarmitage@sfnewengland.org.*

2016 SPRING STEPPING OUT FOR SCLERODERMA WALKS REVIEW

Shortly after our very successful Patient Education Seminar, Walk season launched into full stride. Here is a review of our spring walks:

THE WORCESTER WALK

By May 1, the Bancroft School in Worcester was readied to throw open its doors for the fourteenth time to sponsor the Worcester Stepping Out to Cure Scleroderma Walk. Predicted rain tossed volleys of mist leading up to the walk but, for the most part, held back.


Deb Magnuson poses with raffle builder Martha Pierson and her daughter.


The Worcester walkers gather in the Bancroft School gymnasium.

The Walk was particularly vibrant this year because of the great volunteer efforts of the family of Phyllis Stoddard, the ongoing anchor support of Debbie Magnuson and her family, and the commitment of the Worcester Support Group under the leadership of Nancy Velleco. This walk continues to be successful due to the tight collaboration among the Bancroft School, the promoters, and the teams of walkers who, with scleroderma in their lives, commit to the rigorous walk and to ongoing education about the disease.

Worcester's Mayor Joseph Petty presented a proclamation, recognizing May 3 as Worcester's Scleroderma Day. The Bancroft sophomore class led by example again this year, with volunteer strength and walk participation.This year's Stepping Out to Cure Scleroderma Walk raised $33,429 to bring our mission forward – research, education and patient support being our goals. We offer thanks to an incredible team of 270 walkers, raffle builders, and to all volunteers, donors and participants.

THE MAINE WALK


l-r: Don Legere, Cathy Legere, Sandy Lunner and Jack Armitage

We found ourselves in Westbrook, Maine on the weekend of May 21, happy to join forces with Sandy and Chet Lunner, Lori Chason and her incredible family for our seventh Walk for a Cure there. We have such a ready group of volunteers in Maine and it is made additionally easy for us as most of them seem to be named "Sandy"! What a great turnout, what a fun crowd and what a perfect time of year for the walk in Maine.


Sandy Kneeland (l) and the raffle support team kept things moving!

Because of the presence of a very diverse cross section of people from a vast geographic area, we take full advantage of the walk in Maine to touch base there, to connect people with services, and to generally check in on our friends. One aspect that makes the Maine constituency unique is their connection to the political efforts to bring scleroderma into the forefront of discussion of research funding and constituent representation. Kudos to Lori Chason and Sandy Lunner for their tireless work in advocacy.

Terri Ireland donated pizzas from her pizza parlor, *Pizza, Wings & Things* in Gray, Maine. Every year, she honors her mother-in-law with this generous donation in her memory. Sue Zemla's family was well represented and we welcome Sue back from her recent treatments out of state. Amanda Phillips from Amica volunteered and brought her experience from participating in the Worcester Walk, where her mother lives. Overall, the Maine Walk is a fun ongoing annual tradition and we love being a part of it. Total funds raised at this important annual Stepping Out Walk was $7,389.

WALKS REVIEW

(continued from page 6)

THE PLYMOUTH WALK

Andrew Botieri at the megaphone

The annual Plymouth Stepping Out to Cure Scleroderma Walk seems to pick up momentum in each passing year. Andrew Botieri (*see page 1*) and Johnny Medlin whip together an unstoppable volunteer corps and a very committed group of annual team leaders. With a bit of wet weather predicted, we made a decision to bring in a large tent, and what a difference it made!! Somehow, the festive aspect of the day bumped forward a few notches and it ran like a well-oiled machine. Johnny's sister and his wife Courtney set up the food table and made a feast for all walkers. The extended Medlin clan joined in with all of the other attendees, bringing the total number of walkers to 195.

Medlins and Cavallos prep for the event

The Walk did indeed kick off to a drizzly start and ended in an outright rainy downpour. There were 14 teams in all and, of course, Team Alyssa was somehow the most boisterous and "ready" for the Walk. Spirits were still not dampened as the raffle got underway. The rain then let up and everyone got re-enthused. Andrew Botieri stepped in as Master of Raffles and delivered the goods, literally! There were wonderful and creative raffle prizes throughout. We send special thanks to all of the local Plymouth merchants who donated generously. Total funds raised at the Plymouth Walk for a Cure was $22,073, due to the unstoppable dedication of all those involved.

Team Alyssa

As we look ahead to our fall fundraisers, we are excited and grateful for all the amazing people who put forth their time and effort to make these amazing walks happen. Thank you all! For dates and locations of our upcoming walks, see our listing on page 8.

Plymouth Tent

Worcester Thumbs Up

"Hardy Mainer" Sandy Lunner

FOURTEENTH ANNUAL GOLF CLASSIC TO CURE SCLERODERMA

On a very hot (and stormy) day toward the end of July, SFNE held its 2016 Annual Golf Classic to Cure Scleroderma - an annual fundraiser that brings golfers from all walks of life to the Salem Country Club in Peabody, MA to play an amazing round of golf and support SFNE's mission of education, support, and research funding. What a turnout, what a success and what a proud anchoring event!


David Rosenberg (second from left) and other golfers relax at the Salem Country Club clubhouse.

First and foremost, we offer our sincere gratitude to our major sponsors, David Rosenberg and Bruce Gordon. Their annual dedication and generous inclusion of their friends and colleagues bring us continued success and make our goals possible. This year, through the Scleroderma Foundation, we also received the Major Event Central Fund Grant Award from Actelion/Bayer and Reata Pharmaceuticals.


The Great Hillers volunteer team await the golfers.

As always, our Great Hill volunteers are our volunteer "glue." Marie Coyle's returning group dazzles us each year with their enthusiastic and cheerful energy, despite the blistering temperatures. Starting with the loading of the vehicles at the SFNE office through the final cleanup, we would not be able to have this event without them. THANK YOU Great Hillers!

Other volunteers include our return champion volunteer, Kathy Moriconi, as well as Patty and Dave Meany, Deb Pearce, Tony and Bunny Cappellucci, Cathy Legere and her friend Helen Simonelli. This year's event seemed flawless and smooth throughout. A silent auction, a live auction and a raffle dominated the dinner event after the day on the course. We did experience a new wrinkle this year – lightning and thunder! Golfers were called off the course twice and, in the end, it made for an exciting end to the day and a fun evening.

This event brings out many generous players, donors and supporters. Your importance to us and to our mission cannot be overstated in this reflection of the event. THANK YOU to one and all.


SFNE board member and volunteer Tony Cappellucci helps a registering golfer.

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Stephen Sherman/Neal Goldman

NEWS BYTES

DID YOU KNOW?

- **Your donation of $50 will fund one hour of research?**
- **A gift of $500 will fund one day of research?**
- **A gift of $2,500 will fund a week of research?**

While all efforts to advance our understanding of scleroderma are proceeding at a record pace, we have more leads than we have resources to pursue them.

Tomorrow's cures start today.

CAPITOL HILL DAY

On Tuesday, September 13, members of the Scleroderma Foundation and participants from around the country will participate in the 2016 Capitol Hill Day in Washington, DC.

They will be meeting with as many as 15 Congressional offices throughout the day. Participants will share their story of the impact of scleroderma on their lives.

Pairing people living with scleroderma with members of the Senate and House who sit on key committees is extremely valuable for advancing awareness of scleroderma and advancing our goals for more scleroderma research funding at federal levels. We look forward to hearing more about the outcome!

* * *

> ***Those who can, do. Those who can do more, volunteer.***
>
> ***~Author unkown***

NATIONAL CONFERENCE

Great thanks to the Scleroderma Foundation National Office for a fantastic conference in New Orleans. Despite the heat, there was a grand collection of informative workshops, classes, speakers, entertainment and comraderie. Some of these workshops will be available on the Scleroderma Foundation YouTube page in the coming months.

Next year's conference will take place July 21 - 23 in Chandler, AZ. So cinch up your saddle and get ready to ride!

BOSTON WALK

The Second Annual Boston Stepping Out to Cure Scleroderma Walk is coming up on October 2nd. As you know, we'd like to make this annual major city walk our "flagship" Walk for a Cure! Come and walk with us, build a team and travel into Boston for a beautiful autumn walk along the Charles River at Artesani Park.

The Walk is hosted by Carol Taylor's Boston Support Group members and is sponsored by the doctors and Scleroderma Centers at Boston University Medical Center and Massachusetts General Hospital. Last year we raised over $30,000 with this walk, and we would love to see everyone be a part of it this year. Thank you to all of our walkers throughout New England. Keep on walking!

The BU Medical Center team at the first Boston Walk for a Cure

* * *

SAVE THE DATE

2016 EVENTS

☑ **The Polar Plunge**
L Street Tavern, Boston, MA
Friday, January 1, 2016

☑ **Spaghetti for Scleroderma**
Bello Center, Bryant University
Smithfield, RI
Saturday, February 27, 2016

☑ **Patient Education Seminar**
Boston Marriott Peabody Hotel
Peabody, MA
Saturday, April 2, 2016

☑ **Fourteenth Annual Worcester Stepping Out for a Cure Walk**
Bancroft School, Worcester, MA
Sunday, May 1, 2016

☑ **Seventh Annual Portland Stepping Out for a Cure Walk**
Riverbank Park, Westbrook, ME
Saturday, May 21, 2016

☑ **Eighth Annual Plymouth Stepping Out for a Cure Walk**
Nelson Beach, Plymouth, MA
Sunday, June 5, 2016

☑ **SFNE Golf Classic for a Cure**
Salem Country Club, Peabody, MA
Monday, July 18, 2016

☑ **NCRS/NE Corvette Day**
Larz Anderson Auto Museum
Brookline, MA
Sunday, June 12, 2016

Lynda Fernandes Golf Tournament
Midville Country Club
West Warwick, RI
Saturday, September 3, 2016

Twelfth Annual North Shore Stepping Out for a Cure Walk
Proctor School, Topsfield, MA
Sunday, September 11, 2016

Sixth Annual Westfield Stepping Out for a Cure Walk
Stanley Park, Westfield, MA
Sunday, September 18, 2016

Second Annual Boston Stepping Out for a Cure Walk
Artesani Park, Boston, MA
Sunday, October 2, 2016

CONCORD MARKET DAYS FESTIVAL

Don and Cathy Legere at their booth at Concord Market Days Festival

On a warm, sunny day in June, Don and Cathy Legere set up a canopy next to Don's 1959 classic Cadillac, and filled it with scleroderma information and raffle items. The car (which is teal) caught the attention of passersby, but the booth provided the info.

In 2016, June 23 to 25 were the dates of the Concord Market Days Festival in Concord, NH. On these days local vendors set up booths along Main Street to share information and sell their wares. Main Street is open to pedestrian traffic only and offers a great stroll to see the best of Concord.

The insurance company that Don represents, Modern Woodmen of America, usually sponsors a booth at this event. This year, Don used one of his days to instead showcase information about scleroderma and to hold a raffle to benefit Scleroderma Foundation New England (SFNE). After soliciting many area restaurants and businesses, he filled the booth with exciting raffle prizes that eventually (over all three days) brought in $649.00. Don then used the Matching Gift Program offered through Modern Woodmen for another $500.00 donation to SFNE!

We'd like to thank Don and Cathy for their tireless efforts to both promote awareness of scleroderma and raise funds for SFNE's mission. Volunteers like Don and Cathy, and so many others who create and coordinate events and awareness, make it all happen. Thank you!

* * *

BOSTON GROUP'S KICK-OFF FUNDRAISER

As a prelude to the second annual Boston Stepping Out to Cure Scleroderma Walk, the Boston support group held a kick-off event at Home Plate Bay Street Grill in Taunton, MA. Participants were invited to enjoy a terrific meal at a great restaurant with friends and family and try to win some local raffle prizes.

Led by Mary McClay, the raffle table was quite a spread, as raffle proceeds alone brought in $979.00! Home Plate Bay Street Grill will also donate 20% of the night's proceeds (from those showing an event slip that night) to Scleroderma Foundation New England. What a wonderful start to a vibrant walk in a beautiful Boston autumn.

The Boston Walk will take place on Sunday, October 2 at Artesani Park in Brighton, MA. You can get more information or register online at *www.scleroderma.org/steppingoutboston*. Thank you to Mary, Carol Taylor, and the rest of the Boston support group for all that you do! You're amazing!

* * *

> ***We celebrate the selfless individuals around our country who channel their civic virtues through volunteerism...devoted to a cause bigger than themselves...Volunteers help drive our country's progress, and day in and and day out, they make extraordinary sacrifices to expand promise and possibility.***
>
> ***~ Barack Obama***

SPREADING THE WORD

Also in June, Sandy Lunner, co-leader of the Maine support group, did an interview for Total Health with Tracy Sabol of WMTW. Sandy discussed World Scleroderma Awareness Day on June 29 and the *Hard Word, Harder Disease* campaign. Sally Connolly joined her and talked about her neice Andrea, who lives with scleroderma.

The story aired on June 27. Go to *www.WMTW.com*, click on News/Health, then search for scleroderma.

Sandy getting prepped for her interview.

* * *

SFNE HAS TWO NEW BOARD MEMBERS!

By: Jack Armitage

As we continue to cultivate growth and proper governance here at SFNE, we are so happy to have added two new members to our Board of Directors in this quarter. Andrea Mahoney and Jane Ladas will join us for our third quarter meeting of the board in September and continue with us into the future.

Andrea brings a breadth of experience in the world of insurance and insurability, working in the specific area of commercial insurance and having experience in claims case management and worker's compensation. Her presence on the board is additionally exciting as she is Don Legere's daughter and will bring personal passion and familiarity with scleroderma to our mission. We hope to expand our outreach and continued education for constituents of SFNE via the experiences that Andrea brings as well as expanded governance and mission specificity.

Jane has joined us *again* after having been a board member with SFNE many years ago. Jane and I joined Marie Coyle recently for lunch to reminisce about the many years of service and support that have led us to where we are today! Jane comes to us with a wealth of experience in the pharmaceuticals world, working until recently with Astrazeneca as a National Clinical Account Manager with specific expertise in clinical accounts management, medical science and affairs in the area of oncology. Jane's current volunteer role in hospice and visitation to elders is an extension of her compassionate interest in the hands-on care of the ill and health-challenged.

Our Board of Directors is a reflection of our steadily growing mission dedication and we welcome Andrea and Jane enthusiastically, knowing that our best interests are being served with their skills and personal dedication.

I should point out that we have "graduated" Deborah Pearce from our board! She has been brought onto the National Scleroderma Foundation staff as their new Chief Operating Officer. We are so delighted to have access to Deb in this new and exciting role and her advisory on governance and future planning will continue to influence our direction at SFNE. Congratulations Deb!

These wonderful new changes and growth spurts will continue to expand our reach, our ability to serve and our expert governance.

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20 FACTS

(continued from page 4)

18. In systemic sclerosis, children who have lung, kidney or heart problems usually have the greatest risk of complications.

19. While localized scleroderma usually progresses in the early stages, it will often stop spreading and changing further after the first 3 to 4 years. In some cases, it might even be resolved by adulthood.

20. Scleroderma does not usually go away, but it is possible for it to remain at the same level and not getting any worse for several years.

This article was originally posted on SclerodermaNews.com on August 9, 2016.

There is always one moment in childhood when the door opens and lets the future in.

~Graham Greene

SFNE SUPPORT GROUPS

Maine

Maine Support Group
Windham Public Library 11 am - 1 pm
Meets the first Friday of most months
Co-Leaders: Lori Chason, 207-892-7323
chason.lori@yahoo.com
Sandy Lunner, 207-420-3337
slunner@aol.com

Massachusetts

Boston Support Group
Boston University Medical Center
Shapiro Building
First Floor Conference Room
Meets the 3rd Sunday of every month
Group Leader: Carol Taylor
774-233-0558, cvsing@comcast.net

Fall River Support Group
Meets the 3rd Tuesday of every month
6:30 - 8:30pm
Co-Leaders: Donna Bernier
Donnabdab2@hotmail.com, 774-488-6775
Christine T. Maroney, 508-675-4152

North Shore Support Group (Topsfield)
Meets the 2nd Wednesday of most months
SFNE Office, Topsfield
Group Leader: Roberta Mauriello
781-324-7426

Worcester Area Support Group
Meets once a month on Sunday
Group Leader: Nancy Velleco
508-869-2997

New Hampshire

Granite State Support Group (Hampstead)
Meets the last Saturday of every month
Co-Leaders: Carla King, 978-884-4866
granitestate@scleroderma.org
Jean Chapman, chappybear@charter.net

Central NH Support Group (Bow)
Meets the first Wednesday of the month
Baker Free Library, 10 am - 12 pm
Group Leader: Don Legere
603-566-3145, donlegere@comcast.net

Vermont

Burlington Vermont Support Group (Williston)
Meets the 3rd Tuesday of most months
Group Leader: Blythe Leonard
802-878-0732, b.leonard@myfairpoint.net

Brattleboro Area Support Group
Meets the 2nd Wednesday of every month
Brattleboro Memorial Hospital, 6:00 - 7:30pm
Group Leader: Ilene Wax
802-464-5847, ilenewax@gmail.com

SCLERODERMA FOUNDATION
NEW ENGLAND
SUPPORT ★ EDUCATION ★ RESEARCH
New England Chapter
462 Boston Street, Suite 1-1
Topsfield, MA 01983

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A FEW ANSWERS...

Q: Who worries that his uniform makes him look fat?
A: An insecurity guard

Q: What do you call an elephant that doesn't matter?
A: Irrelephant

Q: What do you call a fake noodle?
A: An impasta

Q: What do you call a lazy baby kangaroo?
A: A pouch potato

Q: What's red and smells like blue paint?
A: Red paint

Renew your Scleroderma Foundation New England membership today!

Renew your SFNE membership and you will not miss out on the New England *BEACON* or the National *Scleroderma Voice*, both of which feature updates on the latest research and treatment, stories of hope from fellow constituents, and reviews of fundraising events large and small.

Your $25 membership fee also helps support Scleroderma Foundation New England, its programs and publications, and increases available research funds. Your subscription end date is on the bottom of your mailing label (above).

PUZZLE ANSWERS

Congratulations to Judith Pecci, the winner of our Spring BEACON puzzle. She will receive a box of Harbor Sweets chocolates in the mail. The answer to the palindromes are below:

1. Hermit from Nevada: RENO LONER

2. Kingly Beer: REGAL LAGER

3. Fruit Given as a Present: GIFT FIG

4. Wood Touched by Midas: GOLD LOG

5. Socially Challenged Physician: DR. AWKWARD

NEW PUZZLE

Here are six eight-letter words (or two-word combos) that include the word "row." Use the clues to fill in the blanks.

1. Most rambunctious: R O W __ __ __ __ __

2. Prying tools: __R O W__ __ __ __

3. Small floor covering: __ __ R O W __ __ __

4. By a thin margin: __ __ __ R O W __ __

5. Facial features: __ __ __ __ R O W __

6. Song from *Annie*: __ __ __ __ __ R O W

Send us your answers, and you could win a prize!