NEW ENGLAND
The BEACON
A Publication of Scleroderma Foundation New England
Summer 2017

REVIEW OF THE 2017 NATIONAL PATIENT EDUCATION CONFERENCE

By: Jack Armitage

With kudos to the staff at the national office, the National Patient Eucation Conference was not only a success, but it brought conference dynamism to a new high. Held in Chandler, Arizona, at the Sheraton Wild Horse Pass, the setting could not have been more appropriate for all of the 600+ attendees. The hotel and conference center are situated on Native American land and the obvious efforts to blend cultures has resulted in a healing and "wellness" vibe that was evidenced in all aspects of their accommodation from the meditative flute music piped through a speaker system to the serene environment throughout.

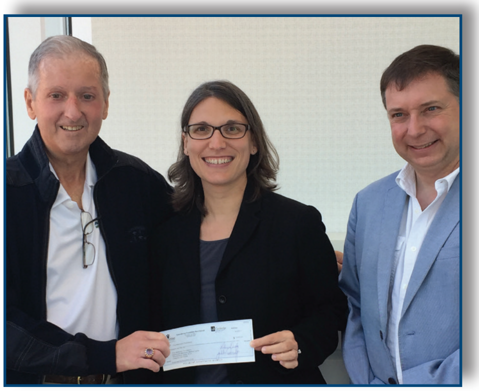
From my perspective, the Leadership Day kick-off was an intensive and successful opportunity for all of us in leadership roles to get familiar with one another and vigorously share ideas and successes. National Board Chair Cos Mallozzi spoke passionately about our challenges and advised, "Don't leave here this weekend with unanswered questions!"

Each breakout discussion was led by a chapter director, confirming the incredible potential *from within* the organization. Members of the National Board were in attendance as well, and a dynamic by-laws and board governance presentation was led by board member Katayun Jaffari. Presenters from leadership roles were Laura Dyas, Cindy Besselievre and Debbie Metz, Doreen Towhey and Peggy Leavengood, Bill Martin and Bruce Cowan. I co-presented on the topic of Support Group Leadership with Mary Beth Bobik Kadylak from the Tri-State chapter.

A meeting of chapter executive directors, led by Fee Sepahi (Delaware Valley) and Cyndy Besselievre (Rocky Mountain), resulted in strong affirmation of our individual roles and collective potential. Tina Fellows (Ohio) offered a convincing perspective on grant writing. Dan Burke (Heartland) spoke persuasively on the challenges of broad geographic outreach. Stephanie Somers Gresh (Greater Chicago) described her fundraising efforts and inventive ideas. Laura Dyas (Michigan) offered constructive perspective on agency health

(continued on page 4)

DARTMOUTH-HITCHCOCK RECEIVES GRANT


SFNE board president Don Legere, Dr. Nicole Orzechowski and Dr. Michael Whitfield

When the Dartmouth-Hitchcock Medical Center was designated as a Scleroderma Center for care of patients in our service area, we took the opportunity to meet the practitioners there and very quickly got to know Drs. Nicole Orzechowski and Michael Whitfield.

Dr. Orzechowski is a primary care physician whose specialty is scleroderma and Dr. Whitfield is a researcher in the field, connected

(continued on page 2)

IN THIS ISSUE

Scleroderma Foundation
New England Chapter
Founders:
Marie A. Coyle Walter A. Coyle

The New England BEACON
published quarterly by SFNE
462 Boston Street, Suite 1-1
Topsfield, MA 01983
Rebecca Dube, Editor
SFNE is a 501(c)(3) organization. All contributions are tax deductible and should be sent to the above address.

Tel: 978-887-0658 Fax: 978-887-0659
E-mail: sclerodermainfo@sfnewengland.org
www.scleroderma.org/newengland

DARTMOUTH-HITCHCOCK

(continued from page 1)

through shared interests with the doctors at Boston University Medical Center.

Because of a fast growing relationship with them and a shared patient base out of Don Legere's Bow, New Hampshire support group, we found ourselves at the board level discussing what we could do to enthuse their growth and presence.

In March the SFNE board voted to award Dartmouth Hitchcock Medical Center and the Geisel School Genetics Program a $10,000 grant to encourage successful research, outreach and improved creative patient care. We are currently in discussion with the doctors about a smaller Patient Education Seminar there in November.

Don Legere, patient, support group leader and SFNE Board President, joined his wife Cathy in presenting the check to the doctors. We hold the highest hopes for the goals of the Dartmouth Hitchcock Medical Center Scleroderma Program and the Geisel School Genetics Program. We look forward enthusiastically to their successes and, when possible, for collaborative efforts to improve the lives of those living with scleroderma.

MASSACHUSETTS GENERAL HOSPITAL OPENS NEW SCLERODERMA CLINIC IN WALTHAM, MA

Our readers may recall that two years ago, we announced a new Scleroderma Center in Boston at Massachusetts General Hospital (MGH). Dr. Flavia Castelino, the principal scleroderma specialist there has been attentive to SFNE in the time since and, has supported a team in our annual Boston Walk in October.

Dr. Castelino has contacted us with the exciting announcement that MGH has opened a new clinic in Waltham and will provide scleroderma patient care there as well. Dr. Castelino will be there on Tuesdays and two of the other scleroderma program doctors (Dr. Schoenfeld and Dr. Bolster) will be there on Thursdays. This means that anyone seeking care outside of the city will be able to find it at this location just west of Boston.

Contact information for the Waltham location is:

Mass General Waltham
52 Second Ave
Suite 2600
Waltham, MA 02451
(781) 487-6006

Dr. Castelino adds, "We would be happy to see any patients there in addition to our location in Boston. Additionally, we would be happy to meet with the different support groups."

FROM THE DIRECTOR'S DESK

By: Jack Armitage

To the degree that we are a self-directed and highly efficient small organization, I am reminded this year especially that we are dynamically connected to many other peer organizations, each jostling to hold steady in competitive times. This was evidenced at the National Scleroderma Conference in July when most of the chapters of this nation-wide effort were gathered in Phoenix to compare notes, to enthuse skills and to improve our shared collective efforts *(story page1).*

Here in New England, we should count our blessings. Most memorable to me was some of the information that came from the conference Executive Directors' Forum, in which those of us in similar roles were given some basic topics to explore. Dan Burke from the Heartland Chapter (Nebraska, Iowa and eastern South Dakota) described what it is like to serve their constituency of as many as 3,000 in a territory that is 1,000 miles wide. Creating support groups is a significant challenge requiring a level of technology and cleverness that they are working to get in place. Building a representative board of directors in such a service area is difficult.

Ferne Robin, representing the South-east Florida chapter, described the challenges of determining how to sustain support in a region defined by seasonal residents. Ferne is additionally challenged by dollar support that is sourced from many different states and the opportunity to hold only one significant fund-raising walk annually.

By comparison, I feel as if we have significant advantages here in New England. Beyond enjoying the attributes of close geography, we are very lucky to have consistent dedicated volunteers, excellent support group leadership and a dedicated board. All of this in a service area loaded with world-renowned hospitals and treatment centers, an enthusiastic research sector and exemplary peerage. Need I mention that we are a short eight miles from the National Office where an awesome staff of skilled professionals is cheerfully poised to brighten our every day?!

Support for our constituency is a trickle down dynamic. Medical practitioners are at the top of the list. Without our doctors, nurses, therapists and dietitians our constituency would flounder. Peer support is of incomparable value in the chain of strengths we enjoy. We spend a great deal of time simply getting our constituents together in support groups, meetings, events and conferences to build that essential core of shared goals. Our Walks for a Cure are our mainstay for social outreach, financial underpinning and, frankly, good times! The newsletter that you are holding is glue for all of us, keeping us updated, sharing current information, verifying our impact. Published quarterly, it reaches out to our total constituency with reports and updates, hope and accomplishment. We are often told by our readers that they read it cover to cover.

For fifteen years, we have been given survival support by our long time sponsored event, The SFNE Golf Classic. *(story, page 7)* Our event underwriters and participants are people who understand the importance of agency support. Though their generosity, we raised more than $180,000 this year which, after the bills are paid, will be directed to the essential research and patient care to which we are committed.

So, how do we share this good fortune with our peers across the nation? We reach out and make overtures whenever we can, being broad-minded about need and service delivery and willing to make good on our efforts to follow advice with action. It is a commitment of this office to always maintain openness in sharing our successes and accepting shared ideas from new sources.

This policy to "think globally and act locally" was enthused in my recent attendance at the National Conference. The large national family of scleroderma chapters sharing the threefold mission to offer support, to provide education and to enthuse research is brought home to us daily through our local accomplishments. Our commitment going forward is to continue to encourage the vibrant growth of our sibling chapters and to steadily increase services, success and research accomplishment for our constituents.

~~~~~~~~~

> ***There is immense power when a group of people with similar interests gets together to work toward the same goals.***
>
> ***~ Idowu Koyenikan***
~~~~~~~~~

NATIONAL CONFERENCE

(continued from page 1)

and growth. Jeremy Harrison-Smith (Washington) relayed the story of his recent gala fundraiser success. Bruce Cowan (Tri-State) offered thoughts about future development. All attending this meeting added greatly to our shared effort to add to the excellence of our national outreach to the scleroderma community.

And then, of course, the conference itself: two days of dynamic patient-focused resources and expertise aimed at bringing us all further along in our shared goal to find a cure for scleroderma in our lifetime. Patients and caregivers were in attendance from all over the country. Each found informed experts readied to discuss one-on-one, in lecture halls and in impromptu conversations in the highly socialized environment created in this setting.

Andrew Botieri, from New England, spoke passionately as our keynote presenter. His topic: Behind Every Dark Cloud is HOPE! For him, the return to Phoenix was a homecoming of sorts. It was here in Andrew's early career that diagnosis derailed his life plan and subsequently brought him to clarity, survival and success in the context of his disease. Andrew's message of hope and celebration was not lost on the audience. Andrew works tirelessly to find a cure and to bring support to those who are waiting for that good news. His most recent effort is the shared leadership of the ScleroMen support group just for men (*ScleroMen@Scleroderma.org*).

In addition to a very busy exhibitor's hall, there was an ongoing youth program for children and young adults, carefully crafted to bring accessible information to our younger peers and their parents. It was gratifying to me to have shared several conversations with parents who left the conference with exciting new information and options for their diagnosed children. As well, the opportunities for adolescents to find peerage was a goal well met. All of these outcomes are progress toward our shared goals.

For those in our readership who could not attend the annual conference, I would like to assure you that there is a great deal of passion and diligence being invested by our leadership, our researchers and our doctors in the shared effort to find a cure for scleroderma. In conversations with experts, I found that little successes in the laboratories assure giant leaps in collective progress. The "tour" of Dr. Carol Feghali Bostwick's new lab made information easily understood for the untrained attendee. Drs. Mays, Varga and Steen co-presented with highly affirming information on research and new methods just as Bill and Cindy Martin brought optimism to an audience of people considering the risks and benefits of stem cell transplantation. Dr. David Leader brought new and positive information in the oral health discussion. And an exciting new voice in the mix was that of Chanel White, whose mind-blowing enthusiasm on the value of social media in the spreading of information and hope left her audience hungry for more!

SFNE Executive Director Jack Armitage speaking to chapter leaders and board members on Support Group Leadership

All accounted for, the 2017 Patient Education Conference was unstoppable in its success in bringing hope to all attendees. The shared empowerment of so many attendees and the collaborative effort of so many skilled professionals cannot help but bring measurable and timely triumph to our readership and to the general scleroderma community.

Breaking News:
Next year's conference will be held in Philadelphia, PA.

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 intentions 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.*

FIRST ANNUAL STROLLING FOR SCLERODERMA EVENT

Board president Don Legere holds a Modern Woodmen check of funds raised with the Strolling for Scleroderma group.

When Maria and Jacek Bartoszewicki first proposed the idea of a new Walk for a Cure for Scleroderma, we jumped at the chance. Shortly after jumping at the chance we wondered how we could possibly fit another event onto our calendar. Not to worry, as a third party event coordinator, Maria stepped up to the plate and pulled off an incredible day despite rain and weather challenges. In fact, Rebecca and Jack attended as civilians with *no official duties*. It was such a pleasure to do the whole walk and chat it up with all of the participants.

The setting at Deer Island could not have been more interesting. Deer Island, which is the water treatment plant for the city of Boston, features five miles of public walkways and trails for walking, jogging, sightseeing, picnicking, fishing and bicycling. There are 60 acres of open public space, including 2.6 miles of paved handicapped accessible perimeter path, dramatic views of the Boston skyline and incomparable vistas of the Boston Harbor Islands. What a setting!

A major sponsor for the event was Modern Woodmen Fraternal Financial. They have become a mainstay in our annual successes, thanks to Don and Cathy Legere, Maria's parents. Maria's extended family, friends, and business associates supported the Walk for a Cure generously. In all, a total of $4,988 was raised at the walk and it was a remarkably heartfelt day.

As we look to the future of this event, we realize that it is amazingly accessible to our constituency and supporters in the greater Boston area. Please do consider a day trip to Deer Island next year – the combination of a gorgeous destination and a worthy cause should make the decision compelling!

~~~~~

THE MO' THE MERRIER!

On June 11, Kathleen Napoli and eight of her friends and family participated in the *Beach and Back Half Marathon* in Mashpee, MA to raise funds for scleroderma research and education. Their run was in memory of Kathleen's Aunt Moe Donahue Fallon. Aunt Moe was described as an amazing woman who suffered with scleroderma and succumbed to the disease ten years ago. In honor of her, their team was called Mo' the Merrier and included members travelling from as far away as Aberdeen, Maryland to participate.

Aunt Moe Donahue Fallon

Months earlier, Kathleen had contacted SFNE and asked to set up a ticketing and donation site for her team. This third-party fundraiser brought in $1,750 towards scleroderma research and education.

Kathleen, we cannot thank you enough! If you would like to know more about third-party fundraisers or sign up one of your own, go to www.scleroderma.org/newengland and click on Start a Fundraiser.

The Mo' the Merrier Team is ready to run!

> ***To achieve greatness: Start where you are. Use what you have. Do what you can.***
>
> ***~Arthur Ashe***
~~~~~

THE “WALK, TALK AND ROCK!” PLYMOUTH WALK

The Ninth Annual Plymouth “Walk, Talk and Rock!” for a Cure went off without a hitch in early June. It was a blistering hot day and participants arrived eager to bring continued success to an event that now enjoys a long history. It was fortunate that we got underway with the Walk by 10 am as temperatures soared by mid-day.

Team Christine

The big tent has proven to be a great asset to our day and, under it, registration and raffle gifts were overseen by capable volunteers and staff. Andrew Botieri, Plymouth Walk co-chair, set up a new table advertising the ScleroMen scleroderma support group, a private Facebook support group for men (*ScleroMen@Scleroderma.org*).

Team Fans of Jan

Courtney Medlin took on the food table and did amazing work with all of her helpers cutting the fruits, presenting snacks and beverages and preparing the table for pizzas after the Walk.

This year, the Walk was held in memory of Jane Berg. Jane’s sister Jeanne has been on the Walk drive team for four years and we were pleased to honor her sister’s memory. Lots of Jeanne and Jane’s friends attended in Jane’s honor. Other past honorees were remembered, particularly Mary Van Neste, Marie Reid, Peggy Karp and Paul Trites.

Teams arrived to show their support, including Team Alyssa, Team Medlin, Fans of Jan, Meme’s Walkers, Team Christine, Team Landers, Team Berg, Kiki’s and Kimme’s Crews, Botieri’s Brigade and more! Alyssa’s grandparents ran a smooth pre-registration table while Alyssa’s mom held court over the raffle items. Graciously handling the saleables, t-shirts and information table were Sue Norton and her oldest friend Deb.

Rockland Athletics, Johnny Medlin’s company, surprised us with new aprons featuring our logo, so the food service table looked as professional as it possibly could! Johnny and Linda’s never-ending extended family, including our favorite Aunt Rita, scurried around the beachfront, seeing to all of the details and making certain that things ran smoothly.

A total of $16,303.77 was raised at the Walk, thanks to all involved. We have a team dedicated to raising funds for a cure. To Walk team members Andrew, Johnny, Tracy, Linda, Louise, Phil, Jeanne and Sue, THANK YOU! We also thank all of the Plymouth town business sponsors and other companies, such as the Cranberry Growers Service, without whose help we could not possibly accomplish this success. And of course all of the participants and donors! We are already looking forward to next year’s event, so mark your calendars for Sunday, June 10, 2018.

Plymouth Walk Co-coordinators Johnny Medlin and Andrew Botieri

T-shirt mavens Sue and Deb

This year’s walk was held in memory of Jane Berg

15TH ANNUAL SFNE GOLF CLASSIC

It would be understatement to say that this year's Golf Classic for a Cure for Scleroderma was a success. Perhaps better said, it was a Hole in One!

From the beginnings of the planning process to the closing of the books, we are able to say that it was not only our most successful to date, but that it was reviewed in superlative terms by all who attended. Our 2017 gross total was over $181,000!

The most enjoyed highlight of the day was the surprise presence of the Golf Cannon, sponsored by co-chair Marie Coyle. Marie was not only excited that the cannon was on-site, but insisted on shooting it herself. At $20 per shot, we were able to generate $2,400 towards our goal to exceed our previous year totals.


Stephen Fournier from Nationwide Hole in One helps Marie Coyle line up the golf cannon for a shot.

Our volunteers were spectacular. It takes a very special group of people to work nearly invisibly behind the scenes to register all of the players, to lay out the sponsor signs, to deliver the lunches and snacks, to set up the raffle and silent auctions, to answer questions and to generally make the Golf Classic run smoothly. Our great thanks goes out to them, though mostly to our fifteen year loyal volunteers from the Great Hill residences in Topsfield.

To celebrate our special anniversary, we surprised co-chairs Bruce Gordon, David Rosenberg and Marie Coyle with a large cake thanking them for their years of dedication and loyalty to us. As a grass roots, non-profit, rare disease organization, we know how fortunate we are to have such benefactors.

Here's something to consider as we all prepare for next year: in fifteen years of Golf Classic events, we have raised a total of $1,926,102.53. It is reasonable for us to project that in 2018, we will cross the $2 million dollar mark!

Perhaps that will call for fireworks!

* * *


The Superior Contracting team lines up their best shot!

PAYING IT FORWARD

Deborah Pearce, National Foundation Chief Operating Officer and a regular volunteer for the SFNE Tournament, relayed to us the following story about the winner of the golf cannon grand prize...

"A gentleman arrived and asked what the golf cannon was all about. I explained the setup to him. He looked at me and said 'I haven't handled a firearm since Vietnam. It was a terrible experience, and made even more terrible when I arrived home.' He struck me as pensive.

"He quietly handed me a $20 bill and fired the cannon. His ball landed four feet from the hole! And his record stood all day. No one else came close to beating him.

"Later, the gentleman arrived in his golf cart to inquire if he was still the winner of the vacation. We assured him that he was.

"He presented me with the winning token and said, 'please give this trip to a family touched by this awful disease so that they can make some memories. I know what it is like to suffer and perhaps, this trip will give one of your patients some pleasure. I just lost my grandson to cancer.'

"I gave him a big hug and said, 'Thank you so much for your generosity and I am so sorry for your loss'. His eyes welled and a tear rolled down his face and he returned to his cart.

I was deeply touched. What a kind and generous person."

CORVETTE DAY WITH NCRS

By: Jack Armitage

On Sunday, June 11, the National Corvette Restorers Society (NCRS) hosted their annual showcase event at the Lars Andersen Auto Museum in Brookline, MA. We at SFNE have been very fortunate for many years to be the recipient of their charitable contribution coming from the event. This year was no exception.

I do feel fortunate to have gotten to know Glenda Fisher better via our phone conversations and we are especially pleased that longtime Support Group Leaders and all-around delightful friends Jean and Don Chapman attended the event representing us.

Perhaps it was helpful that both Don and Jean LOVE Corvettes! Jean noted, “We were received very warmly by Glenda Fisher, the Corvette organizer. She had graciously set up a table with chairs and a tablecloth. We laid out the information, and enjoyed the rest of the day.”

“There were well over 100 Corvettes. They just kept coming and going all day, and we were able to see quite a few of them, as we were set up by the main entrance!”

“There was one special Corvette, a white 1954, which was the year of the first Corvettes. That car was being judged and it received a 98 score out of 100. The judges said that it was in better shape than when it was new!”

Don and Jean Chapman

“Don and I were happy and pleased to be there representing the Scleroderma Foundation New England community.”

In previous years, NCRS has honored us with as much as $1,000 coming from both the event and a matching gift. While we are not sure yet what this year’s event brought to us, we are most grateful to NCRS, to Glenda and to Don and Jean for representing us so well!

* * *

Corvette Day at Larz Anderson Car Museum

SAVE THE DATE

2017 EVENTS

☑ **The Polar Plunge**
L Street Tavern, Boston, MA
Sunday, January 1, 2017

☑ **Spaghetti for Scleroderma**
Bello Center, Bryant University
Smithfield, RI
Saturday, February 25, 2017

☑ **Fifteenth Annual Worcester Stepping Out for a Cure Walk**
Bancroft School, Worcester, MA
Sunday, May 7, 2017

☑ **Eighth Annual Maine Stepping Out for a Cure Walk**
Riverbank Park, Westbrook, ME
Saturday, May 20, 2017

☑ **Ninth Annual Plymouth Stepping Out for a Cure Walk**
Nelson Beach, Plymouth, MA
Sunday, June 11, 2017

☑ **NCRS/NE Corvette Day**
Larz Anderson Auto Museum
Brookline, MA
Sunday, June 11, 2017

☑ **Strolling for Scleroderma**
Deer Island, Boston, MA
Sunday, June 24, 2017

☑ **Golf Classic for a Cure**
Salem Country Club, Peabody, MA
Monday, July 17, 2017

☑ **Fuddruckers Fundraiser**
Fuddruckers, Saugus, MA
Friday, August 18, 2017

☑ **Lynda Fernandes Golf Tournament**
Midville Country Club
West Warwick, RI
Saturday, September 2, 2017

Thirteenth Annual North Shore Stepping Out for a Cure Walk
Proctor School, Topsfield, MA
Sunday, September 10, 2017

Eighth Annual Westfield Stepping Out for a Cure Walk
Stanley Park, Westfield, MA
Sunday, September 17, 2017

Third Annual Boston Stepping Out for a Cure Walk
Artesani Park, Boston, MA
Sunday, October 1, 2017

NEWS BYTES

DID YOU KNOW?

The following three grant awards were recently funded by the Rheumatology Research Foundation.

- Interleukin-13 and Scleroderma in African-Americans - **Johns Hopkins University**
- Lysophospatidic Acid as a Biomarker in Systemic Sclerosis - **Massachusetts General Hospital**
- Discovering Predictors of Treatment Response in Scleroderma Lung Disease - **University of California.**

Thank you to the Scleroderma Foundation eLetter #722 for this information!

SFNE BOARD MEMBER JANE LADAS APPOINTED TO NATIONAL BOARD

SFNE board member Jane Ladas has a long and loyal history in the effort to find a cure for scleroderma. She served on the SFNE board of directors in the early years and built her career in the pharmaceutical industry until her retirement two years ago. Circling back, Jane serves again on the SFNE board and has been asked to serve on the National Scleroderma Foundation Board as well. We are so proud of Jane's dedication and her continued loyalty to our effort to build a strong national presence in the collective effort to find a cure for scleroderma in our lifetime.

* * *

My life is my message.

~ Ghandi

ADVOCACY DAY RESCHEDULED TO SPRING 2018

Capitol Hill Day, which was originally scheduled for October 25, has been rescheduled for Spring 2018. Advocacy work will continue this fall and winter through grassroots efforts in congressional districts.

Training opportunities will be announced by the Scleroderma Foundation national office in future e-newsletters, and the date for Capitol Hill Day 2018 will be announced once it is confirmed.

FUDDRUCKERS FUNDRAISER

A good hamburger is never tastier than when coupled with a fundraising event to benefit SFNE! On Friday, August 18, Roberta and Fran Mauriello, along with members of the North Shore support group, hosted another successful evening at Fuddruckers in Saugus, MA. Attending were family members, friends, constituents of SFNE, repeat supporters and generally speaking, some very hungry guests.

The event had a raffle of four prizes for which ticketholders waited patiently as the winning tickets were pulled from each bag.

The Mauriello family and the North Shore group give graciously of their time and energies annually for this event. Many thanks to all who attended and helped us raise $1,093. There has been a steady increase in the success of this event over the five years that the Mauriellos and the North Shore support group have been hosting it!

MEDICAL AND PHARMACEUTICAL TEAMS JOIN THE BOSTON WALK

The Boston Stepping Out for a Cure for Scleroderma Walk, taking place on Sunday, October 1, will include teams from several medical and pharmaceutical organizations. Teams so far include the following:

Corbus Pharmaceuticals is a Phase 3 clinical stage pharmaceutical company focused on the development and commercialization of novel therapeutics to treat rare, chronic, and serious inflammatory and fibrotic diseases. They are located in Norwood, MA.

Massachusetts General Hospital is an approved Scleroderma Center and recently opened a scleroderma clinic in Waltham, MA *(see page 2)*.

Several members of **Boston University Medical Center** are regular participants in the Boston Walk. These include Dr. Robert Simms and Dr. Harrison Farber.

Clara Health will be there as well. Clara Health walks people with automimmune diseases through the process or eligibility and participation in clinical trials.

Would you like to join or create a team at the Boston Walk? Go to *www.scleroderma.org/steppingoutboston* for more information or to register.

SAVE THE DATE!

for the 2018 SFNE

Patient Education Seminar

Saturday, April 7, 2018

SFNE SUPPORT GROUP ACTIVITIES

BRATTLEBORO BAG-A-BEAN

The Brattleboro, VT, support group, led by Ilene Wax, worked with the Brattleboro Food Co-op in June to be a part of their "Bag-a-Bean" program. Jon Megas-Russell, Community Relations Coordinator for the Co-op, explains:

"Whenever a customer brings in their own grocery bag, or their own receptacle for bulk foods or hot beverage, the Co-op thanks them with a five cent credit - or offers them a fava bean instead, which they can drop into a big container with a local non-profit's name on it."

After a month's time, the Co-op's customers collectively chose to donate $237.50 to SFNE through the Brattleboro support group! We are grateful to the Brattleboro Food Co-op, the kind people of this and surrounding towns for their patronage, and the members of the Brattleboro support group for coordinating this fundraiser!

* * *

BRISTOL COUNTY MONTAUP GOLF

On July 31, Bristol County/ Fall River support group member Jeanne Oliviera played in the Montaup Country Club charity golf tournament in Portsmouth, RI. Support group members Christine T. Maroney and Elise Lachance, along with three members of Elise's family, volunteered at the event for the day. For the past three years, thanks to Jeanne's diligence in securing approval with Montaup, SFNE has been a regular recipient of funds from this event. Our special thanks to Jeanne Oliviera, Christine, Elise and her family for their support!

* * *

A recent speaker at the Bristol County/Fall River support group was Kristen Couture, CAN, ETP, CTN, CD, PhD from Transitions to Health. This support group continues to bring in dynamic speakers and has participants at both the Plymouth and the Boston walks.

* * *

BOSTON GROUP FUNDRAISER

As part of the upcoming Boston Stepping Out to Cure Scleroderma Walk, the Boston support group will be holding its annual kick-off event at Home Plate Bay Street Grill in Taunton, MA on September 19. Home Plate Grill will donate 20% of the dinner tab to SFNE from anyone showing an event slip that night.

The Boston Walk for a Cure will be held on Sunday, October 1 at Artesani Park in Brighton, MA. Thank you to support group leader and Boston Walk coordinator Carol Taylor, members of the support group, and all attendees at Home Plate Bay Street Grill for your ongoing support!

* * *

A COOKOUT FOR CENTRAL NH GROUP

Central NH Support Group Members (l-r): Anne Sommer, Sandy Perry, Glenda Davis, Lynne Michaud, Beth Gagnon, Donna Chouramanis, Pam Jezukawicz, Don Legere, Cathy Legere

Don and Cathy Legere, co-leaders of the Central NH Support Group, held a cookout for the group at their home in Bow, NH on August 16. The day featured Don at the grill, cooking up chicken delights for all.

Group member Anne Sommer brought two remedies she uses to share with the group. One was a zinc paste that she puts on her calcifications to help break them down, and the other was aloe finger and toe protectors. Support groups are a great place to share ideas and helpful aids, and get input on a problem you may be facing. Or, as in the case with this cookout, a great place to build friendships and have fun. Check out all our support group meeting times on page 11 and find one near you!

NORTH SHORE FASCINATING FASTENERS

North Shore Group member Tina Johnson with her modified figure skates.

Tina Johnson recently spoke at the North Shore support group to share her experiences of working with shoe companies to get the modified products she needed to continue to do the activities she loves. Tina teaches skating at the Peabody, MA arena on Sundays, and has a long history of figure skating. However, as her scleroderma advanced, her hands became stiff and curled, making a simple task, like tying up skates, much more difficult, and eventually impossible.

Tina did not want to give up an activity she loved, so she began searching for a skate she could fasten without having to deal with laces. She eventually worked with the Riedell corporation to develop a skate that would work for her. This skate has a cork base and opens up completely so it is easy to slide in your foot. It also has a series of strong Velcro fasteners that are able to hold the skate on tight enough for figure skaters to do their stuff! Riedell works with customers to individualize their skates to their own unique needs.

Tina also had success finding a sneaker that she could easily put on and off herself. This one came from Nike, which had developed the zip-back sneaker to help a boy with cerebral palsy who was going off to college and needed a sneaker he could put on himself. Nike developed a sneaker that has a zipper with a long strap around the heel of the shoe. This can be opened for easy access of the foot into the shoe, then easily zipped up again by pulling the strap.

Tina showed examples of both shoes to "oohs" and "aahhs" around the room. For her skates, she worked with Michael Bedell at Cooke's Skate Supply, Inc. in Wilmington or Boxborough, MA. The Nike sneakers are called FlyEase and can be found at www.nike.com. Tina is an endless crusader for spreading awareness on scleroderma and the needs of those living with it and we thank her for sharing her amazing discoveries!

* * *

The Nike Revolution 3 FlyEase sneaker with zipper fastener

North Shore Support Group members (l-r): Bunny Cappellucci, Joan Powers, Pat Weisberg, Janel Rogers, Tina Johnson, Tricia Legere, Roberta Mauriello and Joan Kingsbury along wtih Tricia's son Matthew and husband Tom.

SFNE SUPPORT GROUPS

Maine

Maine Support Group
Windham Public Library 11 am - 1 pm
Meets the second 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/Bristol County 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
Co-Leaders: Roberta Mauriello
781-324-7426
Joan Kingsbury
joan.kingsbury@comcast.net

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
Co-Leaders: Don & Cathy 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

ADDRESS SERVICE REQUESTED

NON-PROFIT ORG.
US POSTAGE PAID
TOPSFIELD, MA
PERMIT NO. 363

TO BRIGHTEN YOUR DAY

Quotable Quotes

We cannot change the cards we are dealt, just how we play the hand.

Do not let what you cannot do interfere with what you can do.

We make a living by what we get. We make a life by what we give.

Be not afraid of life. Believe that life is worth living, and your belief will help create the fact.

Dance like nobody's watching.

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 Judy Stevens of Mapleton, ME, the winner of our Spring BEACON puzzle! See the correct answers below.

1. Orchestra
2. Prognosis
3. Womenfolk
4. Amplitude
5. Housewife
6. Matriarch
7. Theocracy
8. Daredevil

The bonus words were:
Computer Software

FOR YOUR ENJOYMENT

Change one letter in each word below to a new letter to get an item of apparel.

Example: COST <u>COAT</u>

1. SCARE ____________________

2. CLOCK ____________________

3. GROVE ____________________

4. BIKING ____________________

5. STRONG ____________________

6. SONNET ____________________

7. PRESS ____________________

8. SHALL ____________________

9. SHOCKING ____________________