NATIONAL PATIENT EDUCATION CONFERENCE IN PHILADELPHIA JULY 27-29

NEW ENGLAND
The BEACON
A Publication of Scleroderma Foundation New England
Spring 2018

THE 2018 PATIENT EDUCATION SEMINAR

By: Rebecca Dube

Executive Director Jack Armitage discussing a point with Ask-the-Experts panel member Dr. Jonathan Garlick. Other panelists included (l-r): Dr. Andrew Plaut, Maureen Kerrigan, Esq., Andrew Botieri, Dr. Eva Guinan, Dr. Robert Simms, and Dr. Michael Whitfield.

Were you able to join us at the 2018 Patient Education Seminar? More than150 constituents braved the raw April weather on the 7th for a day rich with learning and connecting.

Dr. Andrew Plaut from Tufts University kicked off the day with a presentation on gastrointestinal issues with scleroderma. He was followed by presentations about enrolling with Medicare or Medicaid by Maureen Kerrigan, Esq. of the Consortium for Medicare Health Plan Operations (MA), and a presentation by Dr. Jonathan Garlick of Tufts University on the research advances being made at Garlick Labs in the area of skin tissue sample development.

Scleroderma Foundation National Conference keynote speaker Andrew Botieri addressed the audience about HOPE in dealing with the disease, and yoga instructor Kendra Raymond of Me-Time Yoga led the group in a relaxing session of chair yoga.

The audience then had a chance to stretch their legs and visit the exhibitor tables around the room.

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ADVOCACY: A “MAINE” EVENT

USING YOUR VOICE

The setting was Senator Susan Collins’ (R) ME regional office in Portland, ME, where seasoned advocate Sandy Lunner and first-time advocate, Ellen G., met with Kate Norfleet, the Senator’s State Office Representative. The mission: to educate the staffer about scleroderma, utilizing literature and more importantly, sharing personal experience with the disease. The goal: to ask Senator Collins to join Senator Kirsten Gillibrand (D) to introduce to the Senate the companion bill to H.R. 4638, the *National Commission on Scleroderma and Fibrotic Diseases Act of 2017.* Sen. Gillibrand wants to introduce the bill with a Republican Senator to ensure that the community is represented in a bi-partisan manner.

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IN THIS ISSUE

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

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ADVOCACY: A "MAINE" EVENT

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Sandy reported that the meeting went well, starting with the expression of thanks for the Senator's continued support in getting scleroderma re-listed in the Department of Defense research appropriations list. Sandy said that the staffer, Kate, was wholly engaged with Ellen and her story noting that "in all my meetings with congressional staff over the last four years, I have never seen anyone take such copious notes as Kate did that day!" Sandy shared that what made advocate Ellen's story so compelling was that it was relatable – both the staffer and Ellen are mothers of adolescent children – and more importantly, "her story was delivered from the heart."

First-time advocate Ellen recounted that she was very excited and privileged to have participated. "I felt very honored… I felt that I could make an impact and that my story was important. This disease is devastating, and to be able to help was fantastic." Ellen was a long-time HR generalist in the greater Boston area, but stepped away from her career after the birth of her children. When trying to work her way back into the workforce, she was taken ill. Having been out of the workforce for some time, she felt she'd lost her footing, however, she's finding that advocacy work is not only very important, but immensely gratifying. "Knowing I'm making a difference for myself and for others affected by this awful disease is fulfilling. I'm doing something purposeful." She hopes that her experience will inspire other patients to come forward and share their stories because there is a real need for more advocates, adding "This keeps me going…I want to do more!"

Sandy concluded that while the staffer did not indicate support one way or the other, she invited them to call or email her at any time and to forward any pertinent information that might help back up a decision to co-sponsor the Act.

Both Sandy and Ellen are Support Group Leaders in Maine (Portland, So. Berwick), and are prepared to engage support group members to email their delegates, and perhaps inspire others to use their voices for advocacy.

SERVE WITH LIBERTY

Serve with Liberty is Liberty Mutual Insurance Company's annual enterprise-wide day of community service held during the first two weeks of May. On Tuesday, May 1, we had the pleasure of enjoying the assistance of several Liberty Mutual staffers, who rolled up their sleeves and created raffle baskets, prepared mailings, assembled snack bags for our annual Golf Classic, and more! The energy was deeply appreciated. Our thanks to Andrea Mahoney, Malini Biswas, April Cook, Paul Perrotta, Christine Lee, and Kimberly Muse, as well as Don and Cathy Legere.

FROM THE DIRECTOR'S DESK

By: Jack Armitage

From my position at the podium preparing to get the 2018 Patient Education Seminar underway, I wished that everyone in the audience could have enjoyed the view that I had of them. Looking back at me were 155 eager faces reflecting unstoppable optimism as we launched another compelling education program. The day included diverse presentations and progress reports on current treatment and research results, and enjoyed a strong representation of speakers.

For the first time, we had the welcome presence of chapter event sponsors from Accredo Specialty Pharmacy, Corbus Pharmaceuticals, and People's United Bank. Ongoing sponsors included The Lee Kennedy Company and The Evelyn C. Schwager Fund. We thank our sponsors with enthusiasm for their confidence in our mission. Additionally, we thank all of you who attended and we look forward to building future Patient Education Seminars with continued excellence.

It is essential that we maintain the imperative to invigorate all three aspects of our mission. Our **education** efforts range from the comprehensive (The biennial Patient Education Seminar) to the more targeted, typically initiated via alliances with practitioners and scleroderma centers and by support group leaders. Constant **support** of our constituents is evidenced in the remarkable dedication of our support group leaders and attendees. We have 11 ongoing support groups around the region. Of course, **research** for a cure in our lifetime continues to be in the forefront of our daily energies here at the office.

This issue of *The BEACON* presents an overall theme of optimism and progress. Midway into our second quarter, we are preparing for our fifth fundraising event – there will be fifteen in all. We are growing our sponsorships and relationships with diverse pharmaceuticals companies and treatment centers. We continue to keep a sharp eye on emerging alternative therapies, including medicinal cannabis, improved dental care, centering self-help alternatives, yoga and peer support.

At SFNE we are witnessing a surge in patient driven innovations and inventions in a new partnering venture with the Harvard Catalyst Reactor program *(see p.11)*. We have enthused ongoing volunteer efforts on a larger scale, such as the annual Serve With Liberty program through Liberty Mutual Insurance Company and expanding third party events. Special thanks this year to Maria Bartoszewicki, Michael Harrison and Cassidy Poe for their independent efforts to raise funds for SFNE. Read about the fifth annual Spaghetti for Scleroderma in this issue!

It would be impossible for us to accomplish our annual goals without your ongoing enthusiastic feedback, volunteerism and investment in us. Our membership has grown notably in five years and with it, more diligent efforts to bring you timely research results, updates and relevant stories to enthuse your trust in our vision.

Consider the following ways to continue to grow with us in 2018:

- Commit to attending one of our regional walks. It is easy to register by visiting our website *scleroderma.org/newengland* to locate a walk near you.
- Consider attending the National Patient Education Conference, held this year in Philadelphia. *scleroderma.org/conference*
- Contact us to volunteer at one of our events.
- Educate those around you and promote our shared mission.

With gratitude for your partnership as we expand our reach and our shared goals, all of us at SFNE - board, staff and volunteers - invite you to continue to work with us in our shared effort to find a cure in our lifetime. Thank you.

* * *

> ***"Knowing I'm making a difference for myself and for others affected by this awful disease is fulfilling. I'm doing something purposeful. This keeps me going. I want to do more!"***
>
> ***~ Ellen G.***

STEPPING OUT TO CURE SCLERODERMA

THE 16TH ANNUAL WORCESTER WALK

TAKE A STAND, STEP OUT!
STEPPING OUT TO CURE SCLERODERMA
NEW ENGLAND CHAPTER

While we didn't have sunshine for the Worcester Walk, the rain did not diminish our spirits! There was a great turnout and lots of new faces. The Walk raised $24,009! We had 175 walkers who braved the dank weather and came out to show their support.

The top three fundraising teams were Team Magnuson, Team Phyllis, and Team Courtney Baldino. Team Bishop was close behind along with Go Team Skippy. The walk was held in memory of Courtney Baldino, whose family was in attendance. Mayor Joe Petty came by to make a proclamation declaring the week of May 6, 2018 as Scleroderma Awareness week in the city of Worcester, and we were also joined by Miss Greater Worcester, Olivia Marques.

We want to thank our AMAZING team of volunteers, beginning with Debbie Magnuson, Sara Graves and Martha Pierson. We also had help from Gail LeBlanc, Mike Graves, Olivia Marques, our DJ Glenn Petrucci, and the Bancroft School sophomores. Also Nancy Valleco, Betty Bellevick, the Worcester Support Group, and Kathy Moriconi. Thank you all! We couldn't have done it without you. A special thank you to all our team captains, participants and donors. You are the backbone of this event. Go Worcester!

Team Amy sporting the new Stepping Out Walk shirt designs.

Team Cris gathers for a photo op in Worcester.

Sara Graves and Rebecca Dube

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.*

See an expanded photo album of both walks on our Facebook page *sfnewengland*!

THE NINTH ANNUAL “HARDY MAINERS” WALK

Hardy Mainers proved their stock and came out to show their support despite foreboding forecasts of rain. The weather actually held off and over 70 walkers joined together to raise $10,470 for scleroderma education, research and support.

Team Heather B. was the fundraising leader with over $3,000, followed by Lunner’s Runners and Team Ambrose in the top three. There was plenty of pizza and raffle prizes for all the friends and family gathered to make the day a success. Our thanks go out to Matt Dube, Sandy Lunner, Sandy Kneeland, Lori Chason and Angela Champagne, as well as Dunkin Donuts Westbrook and Westbrook House of Pizza. It was a great day! Will you join us next year?

Sandy Kneeland keeps the raffle moving!

A gathering of Hardy Mainers

STRIKE OUT SCLERODERMA BOWL-A-THON

By: Cassidy Poe, Strike Out Bowl-a-thon coordinator

Each year, high school seniors are put to the difficult task of completing a senior project in order to graduate. As a senior at North Kingstown High School in Rhode Island, I had the option of conducting a study, improving a system, providing a service, creating a product, or planning and hosting an event.

Surprisingly, I knew exactly what I wanted to do for my project when I entered this year. Last March, my grandmother passed away from scleroderma. Ever since her death, I wanted to do something to honor her and to spread awareness about this terrible disease.

High school student Cassidy Poe hosts the registration table at the bowl-a-thon event.

After a long planning process, on February 24th, 2018 I hosted a Bowl-a-thon Fundraiser for my senior project in loving memory of my grandmother. She loved to bowl so I thought this was the perfect way to honor her. The

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THE 2018 SFNE PATIENT EDUCATION SEMINAR

(continued from page 1)

These included tables from Corbus Pharmaceuticals, Accredo Specialty Pharmacy, People's United Bank, Clara Health, Garlick Labs, and speaker tables with Andrew Botieri, Kendra Raymond, Harvard Catalyst and Maureen Kerrigan. There were also tables from SFNE with area walks information, Scleroderma Foundation items for sale, and take-away information on scleroderma.

The Products That Benefit table, hosted by support group co-leaders Joan Kingsbury and Jean Chapman, showed a variety of aids to help people with scleroderma do everyday tasks such as securing a button or opening a bottle with greater ease. There was gift tubing that participants could put on silverware for better grip. Jean showed off a lamp that could be turned on and off with a touch instead of turning a small knob, and a grip for inserting credit cards into small slots (such as at gas stations).

After the break Dr. Robert Simms from The Boston University Scleroderma Center spoke on the much anticipated topic of the role of cannabinoids in clinical trials. The group then adjourned to the Centennial Ballroom to have a delicious lunch and listen to a presentation by members of Harvard Catalyst Reactor Program, Dr. Eva Guinan and Gary Gray. They discussed the program, bringing patient input into product development and improvement for those dealing with disease or impaired mobility. A chocolate raffle yielded five winners of tasty prizes, as well as one winner of an overnight stay and breakfast at the Boston Marriott Peabody.

Following lunch, the speakers sat down to an Ask-the-Experts panel moderated by SFNE Programs and Events Specialist Anne Sweeney. Anne asked the speakers questions submitted by audience members throughout the day and prior to the event. The crowd loved the down-to-earth style of Dr. Plaut, the inspiration of Andrew Botieri, and the technical information of Dr. Simms, Dr. Garlick, Dr. Michael Whitfield and Maureen Kerrigan. Jack Armitage was the master of ceremonies who pulled it all together.

Respondents who filled out surveys and made comments agreed that the event was a wonderful success! Participants enjoyed receiving the information and having the chance to come together with the larger scleroderma community. Each participant received a beautiful pale blue pashmina scarf to keep warm and a thermal mug with treats inside.

The biggest treat for us was to be able to present this day of information and networking to all of you. We couldn't have done it without the support of our generous sponsors: The Evelyn C. Schwager Fund, The Lee Kennedy Company, Corbus Pharmaceuticals, Accredo Specialty Pharmacy, and People's United Bank, along with individual donations from Digital Credit

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Dr. Plaut speaking to the group on gastrointestinal issues with scleroderma.

Kendra Raymond leads the audience in a relaxing stretch with chair yoga.

Joan Kingsbury and Jean Chapman discuss products that benefit with Michael Harrison.

The entire group gives a big toast to SFNE 's Patient Education Seminar!

SPEAKERS AND SPONSORS

Dr. Jonathan Garlick drew a crowd when discussing his skin sample lab work.

Andrew Botieri signing a copy of his book for a PES participant.

Attendees at the Patient Education Seminar spoke with John Papamechail of Accredo Specialty Pharmacy

Lindsey Smith (r) and members of Corbus Pharmaceuticals greeted guests at their sponsor table.

WANT TO SEE MORE?

If you weren't able to attend the 2018 Patient Education Seminar, or just want to see it again, you can view the speakers at our YouTube page. Just go to *www.youtube.com* and search for Scleroderma Foundation New England. Click on videos and you will be able to view the following speakers:

- Dr. Andrew Plaut
- Maureen Kerrigan, Esq.
- Dr. Jonathan Garlick
- Andrew Botieri
- Kendra Raymond
- Dr. Robert Simms
- Ask-the-Experts panel

Thank you Carl Botti of Botti Webs for all your hard work in putting the videos together!

Carl Botti hard at work capturing video of Kendra Raymond's presentation.

(continued from previous page)

Union and Dr. Nicole Orzechowski. Also key was the support of our volunteers: Patty Meaney, Tom Curran, Jean Chapman, Joan Kingsbury, Tricia, Tom and Matt Legere, Jane Ladas, Don and Cathy Legere. Thank you!

And finally we thank our speakers for their time, effort and expertise in providing a broader range of understanding for our New England scleroderma family. If you would like to see videos of any of the presentations of the 2018 Patient Education Seminar, go to our page on YouTube at *youtube.com*, then search for Scleroderma Foundation New England. We are honored to work with this amazing community and thank you for everything that you do to help us be a part of your lives. The next Patient Education Seminar with be in 2020!

* * *

PES volunteer Patty Meaney helps a participant register for the event.

SPAGHETTI FOR SCLERODERMA

Danielle Sturgeon

On February 24, the sisters of Alpha Omicron Pi at Bryant University in Rhode Island hosted the fifth annual Spaghetti for Scleroderma dinner in memory of Wendy Coleman Frazier, the mother of Alpha Omicron Pi member Victoria Frazier.

This year's event was coordinated by Danielle Sturgeon. The event was held at the Bello Center and was full of participants enjoying a delicious italian dinner (with Italian cookies at each place setting), a photo booth, and good company. The speakers for the evening were Victoria Frazier, talking about her experience as a daughter and caregiver of someone who struggled with scleroderma, and Boston support group member Keisha Burton-Levy, who spoke of her post-pregnancy journey with scleroderma and stem cell transplantation.

There was a photo booth for well-dressed attendees to pose with friends and family, and music playing throughout the evening. Members of the Boston support group and SFNE staff attended, along with board member Brenda Brown.

The raffle featured many beautiful prizes, three of which were won by SFNE attendees! The Alpha Omicron Pi sorority did another wonderful job of bringing people together to learn about scleroderma and offer their support. Overall, the evening raised $5,015 to support Scleroderma Foundation New England programs.

THANK YOU FOR ATTENDING ALPHA OMICRON PI'S 5TH ANNUAL

SPAGHETTI *for* SCLERODERMA

On behalf of the sisters of Alpha Omicron Pi, we want to express our sincere gratitude for your effort in making this event so successful for the past five years. We have raised thousands of dollars and strong awareness for this tragic and incurable disease.

In loving memory of Wendy Coleman Frazier

Spaghetti for Scleroderma is a time for us to open our hearts and make memories with our friends and family. We hope you enjoy this event and that your night is filled with lots of spaghetti, Alpha love, and laughter.

2018 EVENTS

☑ **The Polar Plunge**
L Street Tavern, Boston, MA
Monday, January 1, 2018

☑ **Spaghetti for Scleroderma**
Bello Center, Bryant University
Smithfield, RI
Saturday, February 24, 2018

☑ **Sixteenth Annual Worcester Stepping Out for a Cure Walk**
Bancroft School, Worcester, MA
Sunday, May 6, 2018

☑ **Ninth Annual Maine Stepping Out for a Cure Walk**
Riverbank Park, Westbrook, ME
Saturday, May 19, 2018

☑ **Tenth Annual Plymouth Stepping Out for a Cure Walk**
Nelson Beach, Plymouth, MA
Sunday, June 10, 2018

☑ **NCRS/NE Corvette Day**
Larz Anderson Auto Museum
Brookline, MA
Sunday, June 10, 2018

Strolling for Scleroderma
Deer Island, Boston, MA
Saturday, June 30, 2018

Golf Classic for a Cure
Salem Country Club, Peabody, MA
Monday, July 16, 2018

Fuddruckers Fundraiser
Fuddruckers, Saugus, MA
Friday, August TBD, 2018

Lynda Fernandes Golf Tournament
Midville Country Club
West Warwick, RI
Saturday, September TBD, 2018

Fourteenth Annual North Shore Stepping Out for a Cure Walk
Proctor School, Topsfield, MA
Sunday, September 9, 2018

Ninth Annual Westfield Stepping Out for a Cure Walk
Stanley Park, Westfield, MA
Sunday, September 16, 2018

Fourth Annual Boston Stepping Out for a Cure Walk
Artesani Park, Boston, MA
Sunday, September 30, 2018

NEWS BYTES

“FUN”DRAISING!

Our thanks and congratulations to Michael Harrison and his “crew” for running their first successful fundraiser on behalf of SFNE! A Paint-Your-Own-Pottery event was held on Sunday, April 22 at the Once Upon a Kiln in Bellingham, MA . It was a night full of fun, food, and libations. Michael and company raised awareness of scleroderma, AND more than $550 to further our mission. Call us at 978-887-0658 to find out how easy it is to fundraise for SFNE!

NATIONAL PATIENT EDUCATION CONFERENCE

There’s still time to register for the National Patient Education Conference, which is being held in Philadelphia, PA July 27-29. Go to *www.scleroderma.org/conference* to learn more or to register. Act fast as hotel rooms are filling up!

* * *

EVERETT HEALTH FAIR

North Shore Support Group Leader Roberta Mauriello and her husband Fran recently participated at the Everett, MA Health Fair with a scleroderma awareness table. Roberta was also interviewed by a local TV station where she was able to speak all about scleroderma and note that there is help and support available. She provided SFNE contacts for additional information.

Roberta and Fran have attended many health fairs in surrounding towns in recent years representing the New England constituency.

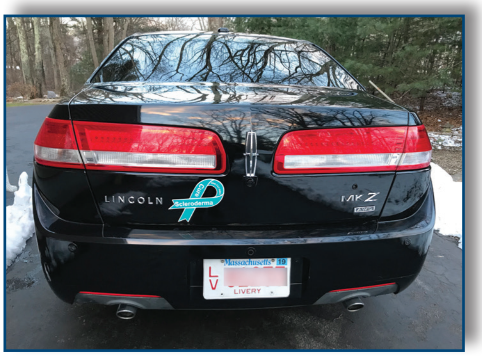
* * *

BOSTON UNIVERSITY SCLERODERMA RESEARCH CENTER

DR. BUJOR JOINS BU FACULTY

Dr. Andrea Bujor recently joined the clinical and research faculty at the Boston University Scleroderma Program as an Assistant Professor of Medicine. She is actively involved with scleroderma research and clinical care with the program and is very interested in seeing patients. You can contact her office at 617-638-7460.

JUNE IS SCLERODERMA AWARENESS MONTH



Bristol Coach and Limo service sports a scleroderma awareness magnet on one of their cars.

Watch our Facebook page *(sfnewengland)* for posts about scleroderma facts and how you can get involved with scleroderma awareness.

To get your own scleroderma awareness car magnet to show around town, contact SFNE at 978-887-0658 or *sclerodermainfo@sfnewengland.org*.

* * *

BOWL-A-THON

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event was at Old Mountain Lanes in South Kingstown, RI and each participant bowled for 2 hours and then I gave a short speech about why I hosted the event and provided information about scleroderma.

We had 25 bowlers participate and with donations included, I reached my goal and raised a total of $1,000! Thanks to family, friends, the bowling alley, and the Scleroderma Foundation New England Chapter I was able to achieve this feat while raising awareness for this awful disease.

* * *

SPRING SUPPORT GROUP LEADER LUNCHEON

Support Group Leader Luncheon attendees. (l-r): Carol Taylor, Rebecca Dube, Patty Kitteridge, Don Chapman, Jean Chapman, Richard Kitteridge, Roberta Mauriello, Don Legere, Cathy Legere, Janel Rogers, Donna Ahern, Joan Kingsbury.

On a crisp spring morning in April, thirteen support group leaders, SFNE staff and guests gathered at Country Tavern in Nashua, NH to meet, discuss relevant topics, and enjoy a hearty thank-you luncheon.

Support group leader and SFNE board president Don Legere started the discussion with information he had gathered from a successful visit with dentist Dr. Leader, who specializes in scleroderma. He also discussed his experience with the Granite State support group, which recently hosted a speaker on the topic of non-THC cannabidiol (CBD) oils. Jean Chapman and Don Legere discussed their visits and tours at Dr. Jonathan Garlick's research lab, where they provided blood samples for his skin development research.

Attendees also discussed the recent Patient Education Seminar (PES), providing valuable feedback and ideas for the next one in 2020. A smaller version of the Products that Benefit table was presented, which was a hit with all attending.

Fall River support group co-leader Christine T. Maroney was fondly remembered with a presentation that played as people arrived and mingled. The group received hard copies of the presentations shown at the PES to hand out to their support groups, and had the opportunity to sign up for the upcoming Harvard Catalyst Reactor program, a program that creates opportunities for patients to collaborate with the scientific community in the development of health care advancements to improve lives *(see page 11)*.

The Country Tavern provided a delicious, healthy meal as always, and participants left renewed and ready to continue their amazing work in the scleroderma community. Thank you all!

SFNE SUPPORT GROUPS

Massachusetts

Boston Support Group
Boston University Medical Center
Shapiro Building, 1st Floor conf. room
Meets the 3rd Sunday of each month, 2pm
Group Leader: Carol Taylor
774-233-2174, carolvtaylor22@comcast.net

Fall River/Bristol County Support Group
Meets the 3rd Tuesday of each month
6:30 - 8:30pm
Stop & Shop conf. room
Group Leader: Donna Bernier
donnabdab2@hotmail.com, 774-488-6775

North Shore Support Group (Topsfield)
Meets the 2nd Wednesday of each month
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 - call for date
Group Leader: Nancy Velleco
508-869-2997

New Hampshire

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

Central NH Support Group (Bow)
Meets the 1st Wednesday of each 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 each month
Brattleboro Memorial Hospital, 6:00 - 7:30pm
Group Leader: Ilene Wax
802-464-5847, ilenewax@gmail.com

Maine

Maine Support Group
Meets the 3rd Wednesday of each month, 1pm
Scarborough Campus of Maine Health
Group Leader: Sandy Lunner
207-420-3337
slunner@aol.com

South Berwick Support Group
Madison's Cafe
Meets the 1st Tuesday of each month
Contact the SFNE office at 978-887-0658 or sclerodermainfo@sfnewengland.org for more information.

Online

ScleroMen Support Group
Facebook Group
Co-Leaders: Andrew Botieri
Lee Korotzer
ScleroMen@scleroderma.org

Also check out the Scleroderma Foundation page on **Inspire.com** for online support.

CREATING FROM NECESSITY: AN INVITATION TO BE PART OF THE SOLUTION

By: Dr. Eva Guinan

HARVARD CATALYST
THE HARVARD CLINICAL AND TRANSLATIONAL SCIENCE CENTER

Dr. Eva Guinan

At the Scleroderma Foundation New England (SFNE) Patient Education Seminar, Eva Guinan, MD, from the Dana-Farber Cancer Institute at Harvard Medical School, presented a new initiative directed at creating opportunities for patients, family members, and advocates. The initiative encourages participants to be proactive in identifying problems and inventing solutions in collaboration with the scientific and medical communities. This “Patient Inspired Invention” initiative will engage the community of academic researchers to address the problems and solutions identified by people living with scleroderma. The goal is to foster a co-creation endeavor that brings patients, caregivers, family members and researchers together to develop and fine-tune novel health care innovations to improve the lives of scleroderma patients.

Last year, Jack Armitage presented at the launch of the Patient Inspired Invention program at Harvard Medical School. Resulting, the Harvard Catalyst Reactor leadership attended and presented on the topic at the recent 2018 SFNE Patient Education Seminar (PES).

For many patients there is a gap between identifying a problem and creating a solution. Harvard Catalyst Reactor will help bridge this gap by bringing patients together with researchers at this special seminar on June 29 – to which you are enthusiastically invited. Marketing high-quality inventions is the goal.

Many of you who attended the SFNE 2018 PES added your names to a list of attendees who will participate in the seminar. The five hour meeting will be held on Friday, June 29 in Boston at the Harvard Business School iLAB, 125 Western Ave., Allston, MA 02163, 10am – 3pm. Lunch will be provided as will cost for parking. We hope to have 20 active participants representing the scleroderma community. We have developed a preliminary questionnaire to bring your specific personal observations to the seminar. To view the attendee questionnaire and to register online type this URL into your browser: *https://hsph.me/registration*. The invitation includes caregivers and we encourage that you register as soon as possible! *RSVP deadline is June 18!!*

This brainstorming meeting will be focused on scleroderma singularly and will tackle solutions to daily challenges. We encourage you to *bring your ideas, your inventions and your creative input* to this collaborative conversation among Harvard faculty and investigators. We will include a “show and tell” session! Together, we can develop innovative solutions that improve the quality of your lives in ways big and small – bring your creative excitement to this seminar. For additional information or for assistance in registering, call Jack (*jarmitage@sfnewengland.org*) or Anne (*asweeney@sfnewengland.org*), 978-887-0658.

PROGRAMS FOR FINANCIAL ASSISTANCE - A PRIMER

By: Jack Armitage

Depending on your treatment regimen and your type of health insurance, options for financial assistance for medications vary. Medications generally fall into one of two categories: Branded or Generic.

BRANDED

A branded medication is one that is owned and distributed by a pharmaceutical company. Most often the company will have an internal program that will assist the patient with the amount that their health insurance does not cover.

This will occur in either an assistance program run directly though the company or a program of a non-profit group that can assist any patient regardless of insurer or income restrictions. It is best to contact the manufacturing company, which will most often have a patient service center ready to inform you of your financial options.

GENERIC

A generic medication is one that is not patented (therefore un-branded) and so can be manufactured by any company. The price will logically be lower unless there are no competing manufacturers, in which case the single manufacturer can dictate the cost. There may be funding available from non-profit groups, for which any patient can still apply.

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

ADDRESS SERVICE REQUESTED

PROGRAMS FOR FINANCIAL ASSISTANCE - A PRIMER

(continued from page 11)

In regard to scleroderma, as there are no FDA approved treatments, the typical co-pay and financial nonprofit organizations WILL have programs for the scleroderma diagnosed patient.

We invite you to visit our web site for specific referral information on the growing list of companies and options that will provide financial relief in several categories. Examples:

- **The Relief Foundation**, for financial relief if you are diagnosed with scleroderma.
- **Associated Diseases** In the context of your diagnosis. For example:
  - *Pulmonary fibrosis* - specific branded medication relief and non-profit groups
  - *Pulmonary arterial hypertension* - five pharmaceutical companies that provide financial assistance.
- **Government Assistance** via Medicare and prescription assistance in two New England states, MA and VT.

Visit our web site (*www.scleroderma.org/newengland*) for more detailed information and links to the financial assistance providers we have identified. Thank you!

TO BRIGHTEN YOUR DAY

Find yourself, and be that.

PUZZLE ANSWERS

Congratulations to Carol Sweeney of Lawrence, MA, the winner of our Winter BEACON puzzle! See the correct answers below.

1. goat
2. cat
3. rat
4. skunk
5. gnu
6. mole
7. hog
8. hare
9. camel
10. dog
11. mink
12. ram
13. ermine
14. donkey
15. monkey
16. hedgehog

FOR YOUR ENJOYMENT

SOLITAIRE JOTTO - For this puzzle, you need to identify the five-letter secret word. You are given seven “guess” words and seven numbers. The number reveals the number of letters in that guess that also appear in the answer word. (For example, a zero means that no letters in the guess appear in the answer, a one means that one of the letters will appear in it.) Discover the five letters of each answer by deduction and process of elimination. Then rearrange the letters to form the secret word.

QUAKE - 2
THEIR - 1
ASKEW - 2
FINAL - 0
OPIUM - 3
WOMAN - 2
TWERP - 1

Secret Word: __ __ __ __ __