

NEW ENGLAND
The BEACON

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Winter 2018

DR. JONATHAN GARLICK SHARES RESEARCH SUCCESS

By: Jack Armitage

Doctor Jonathan Garlick is a study in both understated accomplishment and academic generosity. Gentlemanly in demeanor, he is a classic teacher and instructor, excited by his research and compelled to bring good results to his constituents.



Dr. Jonathan Garlick (right) with his team (l-r): Avi Smith, Trishawna Watkins, Maya Leschinsky, and Olga Kashpur

In a recent return visit to his friends in the New England Chapter's North Shore support group, Dr. Garlick brought exciting news: significant lab results coming from skin punch samples gathered from members of the group in 2016, and an announcement regarding a new partnership between his research lab at Tufts University, Boston, and Dr. Michael Whitfield's research team at the Geisel School of Medicine at the Dartmouth Hitchcock Hospital in Lebanon, NH.

This partnership began with a simple meeting over lunch at the 2016 Patient Education Seminar between Dr. Garlick and Dr. Whitfield. Each seeing the opportunities in working together, they applied for and received a grant for \$225,000 from the National Institutes for Health. This grant is for the Phase 1 laboratory development of complex three-dimensional tissue models.

The success that Dr. Garlick had in growing scleroderma-affected

skin using the samples he gathered from the North Shore support group helped them secure this grant. Depending on the outcome of this study, the doctors and their laboratories will be eligible for a Phase 2 award to continue this important work. As Dr. Garlick closed his initial remarks, he stated, "Without the skin tissue samples from this group, none of this would have happened!"

The role of our tissue donors from the North Shore support group is of great relevance in this research. They are part of the solution as we seek a cure for scleroderma. Support group leader Roberta Mauriello remarked on the pride and commitment of her group members in the shared effort to bring success to the research effort. As one member of the group remarked, "We have learned our first lesson in *paying it forward!*"

Dr. Garlick made the presentation more interesting to those attending

by bringing actual samples of skin grown in the laboratory - tissues that mimic human skin and more notably, that mimic the properties of scleroderma skin. Distributing a non-scleroderma sample for our 20 attendees to view and actually touch, Dr. Garlick described the sample as skin that can be used by patients who have wounds that won't heal. Mimicking the way that skin grows on the body, the potential for this tissue to be developed as a healing device is perhaps an achievable goal in this research.

Dr. Garlick then described the step-by-step process from skin tissue collection (from attendees in this meeting) through the 18 month process of growing the new tissue, such as that being passed around the room. Dr. Garlick's group is

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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.

RESEARCH SUCCESS

(continued from page 1)

also working on developing smaller, multiple sizes of tissue so that many different drugs and treatments can be tested with shorter lead times. Larger tissues are used for research on scleroderma and smaller tissues used to screen drugs and their impact on tissue.

Each of Dr. Garlick's assistants (Avi, Tricia, Maya and Olga) presented on the different aspects of their roles in the research process. Avi described the laboratory growth of human foreskin samples in the cultivation of delicate 'dermis' growth. Further discussion depicted blood samples being centrifuged to isolate different cells and materials for research. Subsequent cell division in a petri dish can lead to the creation of usable skin tissue. Maya's work in 'segmenting' the samples allows for further microscopic research on developing tissue. Olga closed the presentation with a compelling description of tissue characteristics and the role of DNA in this research. In the laboratory, she is able to isolate DNA from the cells. This helps her to understand through analysis how certain genes are regulated and how that process contributes to skin behavior mechanisms.

"Scleroderma action" Avi described, "is in the deeper layers of the skin." With the artificial tissue samples, Dr. Garlick's staff is able to do research and experimentation with scleroderma-like skin involvement. Tricia observed, "It is not a trivial thing to take cells out of blood and keep them happy. The way that cells communicate with each other suggests that the activation of interactive cells can initiate the manufacture of products that can lead to fibrosis in a holistic sense."

Dr. Garlick closed the meeting with a visual on the process of discovery and the importance of collaborative



Dr. Garlick explaining sample sizes

outcome through scientific investigation. He described what he called "excellent results" coming from our long term relationship with him.

"Be full of wonder!" he advised. "We work very hard to get results. We are humbled, and we continue to communicate with every population that is affected, with all researchers and team members, to find ways to be sure that what we do is valid!"

Dr. Garlick concluded the meeting with a renewed request for volunteers willing to give blood samples to further research with the deeper levels of the skin and how the immune system interacts with them. Always at the ready, several members of the North Shore and Granite State support groups offered to help and be a part of this amazing research progress.

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*Research is to see what everybody else has seen, and to think what nobody else has thought.*

*~ Albert Szent-Gyorgyi*





## FROM THE DIRECTOR'S DESK

By: Jack Armitage

In the upcoming year, we anticipate that our seasons will be marked by dynamic growth in our events and emerging partnerships. We are developing a full calendar and will begin this year's events season with our Patient Education Seminar – hopeful, of course, that we will see all of you there!

As you are most likely aware, the Patient Education Seminar is an every-other-year event that sets exciting goals to bring a day of current information in areas of treatment, research and collaboration. This year's seminar will be no exception. The day will begin with a presentation from Dr. Andrew Plaut, who many of you know because of his dedication to gastrointestinal challenges discussed in a clear and often humorous way. Dr. Robert Simms will take on the topic "The Role of Cannabis and Related Substances in Scleroderma: Clinical Trial Update." This discussion amplifies with each year and we have stayed on the cutting edge of the research and relevant discourse.

Following these introductory presentations, Maureen Kerrigan from the Massachusetts SHINE (Serving the Health Insurance Needs of Everyone) Program will give a tutorial update on Medicare and disability insurance.

We will then hear an update from Dr. Jonathan Garlick who, as many of you know, is doing research on skin tissue growth in a collaborative effort with Dr. Michael Whitfield at the Dartmouth Hitchcock Medical Center Geisel School of Research. Andrew Botieri will follow with an inspirational presentation on the power of hope in his personal journey. Many of you know Andrew as our Plymouth Walk for a Cure co-host and author of the much read book, *A Celebration of Life – A Story of Hope, a Miracle and the Power of Attitude*.

Meanwhile, we will have several sponsor tables of relevant information ranging from research and development to assistive devices and innovations. At the lunch hour, The Boston Peabody Marriott staff will serve a delicious meal as always, and there will be a presentation of the raffle gifts.

Those of you who have attended our PES in the past don't need to be convinced of the dynamic end of day Speakers' Panel, featuring all of our presenters in an audience participation discussion on the topics of the day. Beyond being completely enthused by our lineup of dynamic presenters, we are absolutely pumped about greeting all of you and making this another memorable day of education. Please see the registration form in this issue (page 7) and submit it to us at your earliest opportunity. We will have space for 160 attendees and we will fill up quickly. Please contact us if you have need of scholarship assistance.

When you've got our PES well behind you, make certain that you've marked your calendar for the annual National Conference. We haven't had the conference on the east coast in several years, so this might be your year to attend. The Scleroderma Foundation National Patient conference will be held in Philadelphia this year. Visit

[www.scleroderma.org/conference](http://www.scleroderma.org/conference) to research scholarship opportunities and to register.

Rebecca and I recently welcomed Anne Sweeney to our staff with enthusiasm. Many of you who already know Anne from her years of work at the national Scleroderma Foundation are sure to enjoy a reunion with her on the day of our PES. Her shared effort with Rebecca has influenced all of our events planning in 2018 for the better.

Winter has nearly retreated. Please join us in recognizing the importance of the upcoming new year and the incredible roles that each of us holds in making a difference in our search for a cure for scleroderma, in bringing support and optimism to those of you living with scleroderma and to those who assist you in your challenges. We are seeing regular advances in research. Because of your invested faith in our mission, we have been able again in 2017 to bring **\$100,000** to the national research effort and (as you will learn at the PES) are seeing research results not only in the laboratory, but at the grassroots level, where many of our tissue and blood donors are being brought measurable results in real time. We are all dedicated to this mission together.

Joined by the staff and board of directors at SFNE, I look forward to our shared successes over the next year, our gathering at events, and our continued work together for a cure. See you there, wherever we meet!



## SPOTLIGHT ON THE BOARD - AN OVERVIEW

The governance of the New England Chapter of the Scleroderma Foundation is overseen by a spectacular group of twelve board members.

Our Executive Board continues to be a leading point of pride and skill in governance. Don Legere is our board president, Kate Bedard, vice-president and Tim Hagan, treasurer. Each of the three has special leadership qualities that bring ongoing excellence. Our board general membership is proudly served by Tony Cappellucci, Marie Coyle, Andrea Mahoney, Jane Ladas, Peter Hart and Elysia Cappellucci. Newly elected members are Chris Simms, Joan Meissner and Brenda Brown.

Interviews and vetting are ongoing for interested candidates. We are currently in search of the person who will bring the right skills to the important executive board clerk position (records preservation and minutes-taking).

We are represented on the board by constituents (members who are diagnosed with scleroderma and who bring first-hand relevance to our work). Additionally, many skills are represented, ranging from a certified public accountant, an attorney, a retired pharmaceuticals representative, two higher education administrators, a health care professional (nurse), two insurance professionals, a financial



*Scleroderma Foundation board members (l-r): (back row) Don Legere, Peter Hart, SFNE Executive Director Jack Armitage, Kate Bedard; (front row) Andrea Mahoney, Tim Hagan, Tony Cappellucci, Jane Ladas. Not pictured are Marie Coyle, Elysia Cappellucci, Chris Simms, Joan Meissner, and Brenda Brown.*

investments manager and several other skillsets. We are strict about term limits, following a system of two elective three-year terms followed by a mandatory separation from the organization for a year minimally. This regulated turnover keeps the board fresh and accountable.

In the structure of our chapter, we are a high functioning member of a larger national presence. We are one of about 25 chapters or affiliates gathered under the very broad umbrella of the national Scleroderma Foundation. In our long term relationship with the national office, we share one SFNE board member who also serves on the national board of directors. Our board president sits on the national Chapter Relations Committee and we are in vigorous communication

not only with the national office in Danvers, but with many of the chapters as well. We well respect this breadth of high function as well as the vibrant ongoing organization-building of which we are part.

As the representative group serving the New England scleroderma constituency via care and solid governance, we have every reason to be very proud of our board of directors.



***Growth is never by mere chance; it is the result of forces working together.***

***~James Cash Penney***



**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](mailto:jarmitage@sfnewengland.org).



# SFNE POLAR PLUNGE ENJOYS A LAST HURRAH!



*Thank you Kevin Conroy!*

For many years (umpteens to be exact), the annual Polar Plunge for a Cure for Scleroderma has been the launching event of our new year. We have enjoyed the “against all odds” feel of the event and have been unflinchingly grateful to Kevin Conroy for his steadfast energies in bringing it forward to honor his sister, Liz. Each year, we have emerged from the day wide-eyed with wonder at how these thrill-crazed “plungers” find the bravery to actually dive into the ocean in such cold temperatures. The 2018 Polar Plunge was the MOST extreme of these events with participants stripping down to nearly nothing and plunging into the ocean just as the thermometers rose to absolute zero!

Sadly, Kevin has had to make the decision that 2018 is his last year organizing the event. An historic reflection shows that Kevin first contacted the New England Chapter of the Scleroderma Foundation when his sister was diagnosed with scleroderma. Beyond championing her early diagnosis, he joined our board of directors and served on the governing team as we grew. From there, Kevin allied himself with friends Jack and Susan Woods, owners of the L Street Tavern and with their help launched the annual event to benefit SFNE. Kevin has raised more than \$20,000 for research in his years of service.

In the many years of our joining the parade from the L Street Tavern to

the L Street Bath House, none was more entertaining than 2018! An understandably diminished crowd of uniquely crazed people marched in scant outfits at a temperature neither above nor below zero degrees. The dive into the frigid waters was accomplished in short time. As quickly as each one dove into the ocean, each emerged and made a beeline into the warm bath house to shake off the shards of water that had frozen to the skin.

It takes a certain sort of reckless bravery to make such a commitment – one that has served our constituents well given the dedication and faith that each shows in this annual ritual. To Kevin, whose loyalty to our mission is unequalled, we offer our gratitude and our appreciation for longtime support. The Polar Plunge is one of the most unique annual events that can be imagined – a measure of the indomitable human spirit and a classic lesson in dedication to a worthy cause.

We send out our enthusiastic thanks to the many people who have sustained us in the annual effort for so many years. Most especially, we thank Liz Lombard and her brother Kevin Conroy, Jack and Susan Woods, Cookie Tallent, The 103<sup>rd</sup> Postal Fire Column Pipes and Drums and the many people who have braved the frigid Atlantic waters annually to join us in the effort to find a cure. To the L Street Brownies who have welcomed us into their fold, THANK YOU and please carry the memory of our longtime partnership with you into the future.



*Leading the 103<sup>rd</sup> Postal Fire Column Pipes and Drums*



*A bold dash in*



*A mad retreat out!*



*Brave brothers relaxing at the L Street Tavern*

# THE 2018 SFNE PATIENT EDUCATION SEMINAR

The 2018 SFNE Patient Education Seminar is looking to be a significant event this year. Our first key speaker will be gastroenterologist and SFNE medical advisory board member Dr. Andrew Plaut. Dr. Plaut is a highly respected staff physician at the New England Medical Center in Boston and Professor of Medicine at Tufts University School of Medicine. He will be speaking on the latest updates on dealing with gastrointestinal issues related to scleroderma.

Our second key speaker will be Dr. Robert Simms, rheumatologist from the Scleroderma Center at Boston University Medical Center. He will outline the exciting role of cannabis and related substances in scleroderma, giving a clinical trial update.

This year we have a round of three speakers who will be addressing some of the other issues that are a part of life with scleroderma. Maureen Kerrigan will first explain about programs that assist individuals with health insurance,



*Dr. Andrew Plaut speaking on gastrointestinal issues.*

Medicare, and Medicaid enrollment and coverage.

Dr. Jonathan Garlick of the Tufts Medical Center will report on his research in developing scleroderma skin samples that can be used to test various therapies and medications. He will also discuss his new grant to work with previous PES speaker Dr. Michael Whitfield of Dartmouth-Hitchcock's Geisel School of Medicine.

Former national conference keynote speaker Andrew Botieri will offer a personal perspective on everyday living with scleroderma and the attitude needed to face its challenges.

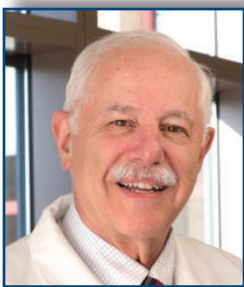
In the afternoon there will be a delicious luncheon of chicken Madeira or seared atlantic salmon, with time built in for networking.

The afternoon session will feature an Ask-the-Experts panel that will include our various speakers. Participants will be able to write down questions throughout the day to be answered by our speakers during the panel.

Mark your calendar for Saturday, April 7. The seminar will be held from 8 am to 3:30 pm at the Boston Marriott Hotel Peabody in Peabody, MA. Registration begins at 8:00 am. Directions to the hotel can be found through the main website [www.marriott.com](http://www.marriott.com). We must limit the number of registrants to 160, so register early. You can register by filling out the form on the facing page and sending it in, or by registering on the site [www.scleroderma.org/2018PES](http://www.scleroderma.org/2018PES). See page 7 for directions. Deadline for reservations is March 30. We look forward to seeing you there!

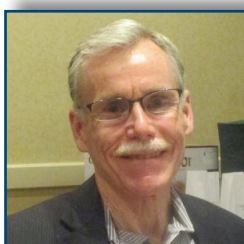


## MEET THE SPEAKERS



*Dr. Andrew Plaut*

**Dr. Andrew Plaut** is board certified in Internal Medicine. He has special expertise in gastrointestinal issues such as diarrhea, Inflammatory Bowel Disease (IBD), and malabsorption syndromes, such as those seen with scleroderma. He graduated from Tufts University in Boston, and is now affiliated with Tufts Medical Center and Christiana Care Health Services. He has 51 years of experience, and has contributed to over 86 publications. He will be speaking on gastrointestinal involvement with scleroderma.



*Dr. Robert Simms*

**Dr. Robert Simms** is board certified in Internal Medicine and Rheumatology, and is the Rheumatology Section Chief at the Boston University school of Medicine. His major research interest is in scleroderma clinical outcome measures and clinical trials. He has over 38 years of experience and is part of the Boston University Scleroderma Program, which has treated over 1200 patients with scleroderma from around the world and participates in clinical research and trials. He will be speaking on the use of cannabis in treating scleroderma.

*(continued on page 8)*





## PATIENT EDUCATION SEMINAR REGISTRATION

SFNE's Patient Education Seminar is just around the corner, on April 7, 2018. We are excited to present this informative day of speakers, exhibitors, a panel, good food and camaraderie. It will take place at the Boston Marriott Peabody Hotel in Peabody, MA.

If you are interested in attending, there are multiple ways to register. You can fill out the registration form below and mail it in, with a check for \$15.00 per person listed, in the envelope attached to this newsletter. You can call the SFNE office at 978-887-0658. You can register and pay online at our website. Instructions on how to register online are listed to the right.



To register for the PES online, just follow these steps:

- On your web browser, go to [www.scleroderma.org/2018PES](http://www.scleroderma.org/2018PES).
- Click on the Register Now arrow or Buy Tickets button.
- Enter your name and email address. Enter the number of registrations.
- Answer the chicken or fish question regarding the luncheon. There are also vegetarian and gluten-free options. If you have special dietary needs, please send a separate e-mail to [rdube@sfnewengland.org](mailto:rdube@sfnewengland.org) to let us know.
- Click on *Next Step*.
- A review of your ticket choice will display. Scroll down and enter in your billing address.
- Select the type of credit card you would like to use (we accept VISA, MasterCard, and American Express). Then type in the card number, verification code and expiration month and year.
- Leave the check mark in the box if you would like to receive periodic updates from us, and if you want your computer to remember your input (*Remember Me*).
- Click on *Next Step*. A review of your registration will display. Click the Process button at the bottom of the screen. This will process your registration and payment, and you will receive a confirmation by email.



To register by mail, please fill out, clip and return this form to SFNE in the attached envelope with payment.

## PATIENT EDUCATION SEMINAR RESERVATION FORM

YES, I/We plan to attend the Patient Education Seminar on Saturday, April 7, 2018.

Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_ City, State, Zip: \_\_\_\_\_

Please reserve \_\_\_\_\_ seats @ \$15.00 each. Total of check enclosed \$ \_\_\_\_\_

Menu selection: How many of each? Chicken \_\_\_\_\_ Fish \_\_\_\_\_ Vegetarian \_\_\_\_\_ Gluten-Free \_\_\_\_\_

Names of people attending: \_\_\_\_\_

## MEET THE SPEAKERS *(continued from page 6)*



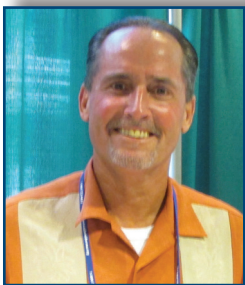
*Maureen Kerrigan*

**Maureen Kerrigan, Esq.** is the Technical Advisor for the Consortium for Medicare Health Plan Operations at the centers for Medicare and Medicaid Services. She will be explaining about programs that assist individuals with health insurance, Medicare and Medicaid enrollment and coverage.



*Dr. Jonathan Garlick*

**Jonathan Garlick, DDS, PhD,** is a stem cell scientist and a professor of Oral Pathology at Tufts Dental School. He has a PhD in molecular biology and started his own research lab. This lab uses 3D, skin-like tissues constructed from cells to study their behavior in a realistic, biologically-relevant tissue context, or how tissue behaves when interacting with a larger body system vs. a sterile petri dish. He is the director of the Division of Cancer Biology and Tissue Engineering at Tufts University, and loves to create rap songs to explain scientific concepts.



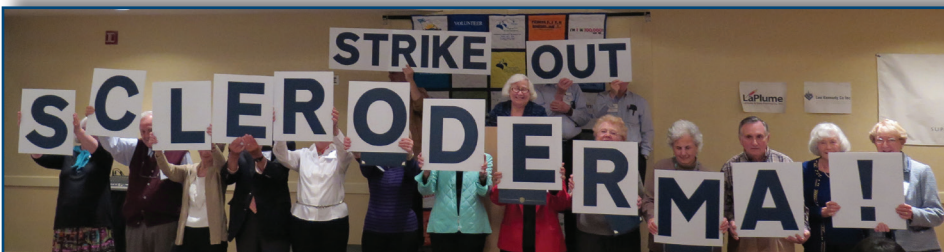
*Andrew Botieri*

**Andrew Botieri,** author and motivational speaker, is the founder of Total Peak Performance, a motivational sales and leadership training company for small and large organizations. He published the book *A Celebration of Life - A Story of Hope, A Miracle & The Power of Attitude* about his own journey with scleroderma. He is also the co-chair of the Plymouth Stepping Out to Cure Scleroderma Walk.



*Kendra Raymond*

**Kendra Raymond, MBA, ERYT, CPT,** is a private wellness coach and owner of Me Time Yoga. She works in yoga therapeutics and is a yoga, Barre fitness and stand up paddle board instructor. She is also a certified Fitness Nutrition Specialist and personal trainer. Kendra believes that yoga and balanced wellness can be enjoyed by any body.



## 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 TBD, 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



## NATIONAL CONFERENCE SCHOLARSHIP APPLICATIONS NOW OPEN!

The scholarship application for the National Patient Education Conference in July is now available for download. The application deadline is **March 21**. Scholarships are available for adult patients, children with scleroderma, and parent caregivers of minor children with scleroderma. Priority is given to applicants attending for the first time. To download an application, go to [scleroderma.org](http://scleroderma.org), click on National Patient Education Conference, and click on the Scholarship tab.

## 2018 CAPITOL HILL DAY

This year's Capitol Hill Day will be held on April 16-18 in Washington, D.C. To read about the bill the Scleroderma Foundation currently has before Congress, titled *National Commission on Scleroderma and Fibrotic Diseases Act of 2017*, go to [congress.gov](http://congress.gov) and type HR 4638 115th Congress (2017-2018) into the search bar. After clicking on the search result (H.R. 4638), you can then click on the Text (1) tab to read the bill.

To learn more about Capitol Hill Day and how to be more prepared, go to the Scleroderma Foundation's YouTube channel. There are webinars available on Grassroots Advocacy Training as well as on what to expect on Capitol Hill and strategies for impactful meetings with elected officials.

For more information on scleroderma advocacy and Capitol Hill Day, go to [scleroderma.org/advocacy](http://scleroderma.org/advocacy).

## RAYNAUD PHENOMENON

Raynaud Phenomenon is the most common early symptom of systemic scleroderma. It is present at one time or another in about 90 percent of patients. It is most obvious in the fingers and toes but can also involve the ears, nose and tip of the tongue. In Raynaud Phenomenon, the blood vessels constrict or narrow in response to cold or emotional upset and stress. The resulting disturbance in blood circulation causes a series of color changes in the skin: white, blanched or pale, when circulation is reduced; blue as the affected part loses oxygen from decreased blood flow; and then red or flushed as blood flow returns and the part rewarms. Finally, as the attack subsides and the circulation returns to normal, usual skin color is restored. In the white or blue stages, sensations such as tingling, numbness and coldness may be felt. In the red stage, a feeling of warmth, burning or throbbing may be noted. Some people find Raynaud attacks painful.

Many common-sense preventive measures can be taken by those susceptible to Raynaud Phenomenon. Most obvious is minimizing exposure to cold, such as outdoor weather, air conditioning, or reaching into a refrigerator or freezer. Keeping your extremities and body warm are very important. Gloves or mittens should be worn, and a number of warming devices are available to protect the hands. Hats, earmuffs, heavy socks and warm, layered clothing made of silk, cotton, wool and down feathers can help maintain body temperature. It is important to protect your hands with gloves when touching refrigerated or frozen items. Electric heaters, electric blankets and comforters can supplement the heat in the home or apartment. Keeping the entire body warm helps

prevent Raynaud episodes. A warm bath or shower, or heating pad or hot water bottle on the back, may relieve an attack better than just warming the hands. Avoidance of emotional upset and stress can help but isn't always possible.

Raynaud Phenomenon is not restricted to people with scleroderma. It is also seen in people with lupus, rheumatoid arthritis and other connective tissue diseases. In addition, many healthy people have Raynaud Phenomenon without any other illnesses. In this situation, it is called Primary Raynaud Disease.

## SJÖGREN SYNDROME

Sjögren Syndrome (dry eyes or mouth) is characterized by a decrease in secretions of the tear glands and the salivary glands, which provide lubrication for the eyes and mouth. The unusual dryness of the eyes resulting from this condition can lead to serious irritation and inflammation. Excessive dryness of the mouth may lead to difficulties in swallowing and speaking, a pronounced increase in tooth decay and cavities, and a reduced sense of taste. The lack of secretions in Sjögren Syndrome also may involve the vagina and other areas of the body.

## LUNG INVOLVEMENT

Multiple factors can cause lung involvement in systemic scleroderma. Build-up of collagen thickens lung tissue and causes fibrosis or scarring, making the transport of oxygen into the bloodstream more difficult. Pulmonary arterial hypertension (PAH), a state of increased resistance to blood flow through the lungs, can result from damage to blood vessels, and may lead to additional strain on the heart

*(continued on page 11)*

## INTRODUCING ANNE SWEENEY

Please join us in welcoming Anne Sweeney to the position of Events Assistant at SFNE! Anne will be working with Rebecca in all aspects of events planning and you will have the chance to meet her at your local Walk and third party events.

What makes this addition to our team even more exciting is that we have a long history with Anne, going back to the days when she served as Chapter Relations Director at our National Office.

Not enough can be said about Anne's skills, energy and long term experience with our mission. Coupled with Rebecca's dedication, attention to detail and creative sustenance of our events, we predict a very successful future.

Anne will hit the ground running with our upcoming Patient Education Seminar taking place on April 7. Your attendance at this



event is highly anticipated and we are thrilled to have all speakers and panelists in place.

This office growth spurt is a very welcome aspect of our increase in services to the scleroderma community. With Anne, you can count on the same diligence and passion that we hold in all aspects of our work.

All of us at SFNE look forward to introducing you to Anne in person at our upcoming events.

## SPAGHETTI FOR SCLERODERMA

On February 24, the ever-ambitious sorority sisters of Alpha Omicron Pi at Bryant University in Rhode Island are hosting their fifth annual Spaghetti for Scleroderma dinner in memory of Wendy Coleman Frazier, the mother of former Alpha Omicron Pi member Victoria Frazier.

In honor of the fifth anniversary of this event, their goal is to raise \$5,000 for Scleroderma Foundation New England. The event includes a three-course Italian dinner, a photo booth, a raffle, and speakers including Boston support group member Keisha Burton-Levy. We love the ongoing support of this hardworking group of amazing students!



## 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, carolytaylor22@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.



resulting in heart failure. Respiratory muscle weakness may decrease lung function.

Symptoms of lung involvement include shortness of breath, a decreased tolerance for exercise and a persistent cough. The physician may order a chest X-ray, an echocardiogram (ultrasound of the heart), special breathing tests (pulmonary function tests) or a CAT scan of the lungs to detect or confirm lung involvement.



In the early stages of lung fibrosis, medications may be given to decrease the inflammation, which is thought to lead to lung scarring.

Although many investigations are under way, there currently are no proved medications to reverse lung changes once they have occurred. It is important, therefore, for the person with scleroderma to take whatever measures are within his or her control to avoid further damage to the lungs. It is essential to avoid smoking, a major cause of lung disease. Exposure to air pollutants may worsen breathing problems and should be avoided to the extent possible. Your doctor may recommend medications to make breathing easier and may suggest deep breathing exercises and a graduated aerobic exercise program.

People with pulmonary arterial hypertension may be treated with special medications targeted at dilating or opening up the blood vessels of the lungs, and possibly changing the underlying nature of the disease. This is one complication of scleroderma for which new medications have proven successful; there are now three different classes of medications which can be used.

### GASTROINTESTINAL ISSUES

People with systemic scleroderma may develop abnormalities of the digestive system and gastrointestinal tract from the mouth to the anal canal. The overproduction of collagen (typical in scleroderma) can cause thickening and fibrosis (or scarring) of the tissues. This can result in weakened muscles, and lead to the abnormally slow movement of food (dysmotility) in the digestive process.

#### Esophageal Dysfunction

Food travels from the mouth and throat into the stomach through a tube called the esophagus. Normally, the lower esophageal sphincter, or valve, acts as a gate, which opens to allow food to enter the stomach and then closes promptly to prevent food from coming back up. In systemic scleroderma, the gate does not close properly and the result is a backwash of acid and a burning sensation (heartburn) as food and acid return into the esophagus. The acid may also injure the lining of the lower portion of the esophagus, causing scarring and a narrowing (stricture) of the tube.

Acid production can be reduced, and the problems of acid reflux and

heartburn helped, by avoiding alcohol, greasy or fatty foods, spicy foods, chocolate, tobacco and caffeine. Antacids (particularly in liquid form) can help neutralize acids and reduce heartburn. Some antacids cause constipation while others cause diarrhea. Consult your physician or pharmacist when choosing over-the-counter products. Your doctor may prescribe antacid medications such as proton pump inhibitors or H-2 blockers to decrease acid production in the stomach. They physician also may prescribe a drug such as metoclopramide, which promotes muscular activity and causes the esophagus to work better.

The force of gravity helps to keep food and acid in the stomach; therefore, an upright position after meals is helpful. Other common-sense measures to prevent acid from coming up into the esophagus include eating smaller and more frequent meals, not eating for several hours before bedtime, and elevating the head of the bed six to eight inches with wooden blocks. Being overweight is harmful; avoid wearing girdles or other tight-fitting garments.

#### Swallowing Difficulties

Abnormally slow movement of food and narrowing of the esophagus may cause swallowing difficulties. Eating slowly and chewing thoroughly are important. Swallowing and digesting are made easier by eating softer foods (many foods can be prepared in a blender) and avoiding foods which tend to stick in the throat. If the esophagus has narrowed significantly, the physician may need to dilate the esophagus periodically to permit easier swallowing.





SUPPORT ★ EDUCATION ★ RESEARCH

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**Christine T. Maroney  
 support group co-leader**



**“Keep on Truckin”**

**We’ll miss you Christine.**

**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 Jan Ebner of Wilton, NH, the winner of our Fall BEACON puzzle! See the correct answers below.

1. 10cc - medicine
2. 35mm - film
3. 32W 35L - pants
4. 17 3/8 + 1/4 - stock price
5. 200X - telescope
6. 250BTU - air conditioner
7. 95wpm - typing
8. 95 dB - noise

**FOR YOUR ENJOYMENT**

Can you find the fifteen animals named in this grid? Each name will be connected horizontally, vertically or diagonally, but can change direction. For example: GOAT - G down to O, right to A, diagonal to T. You may re-use a letter later in a word. How many can you find? Good luck!

|   |   |   |   |   |
|---|---|---|---|---|
| Y | D | G | C | T |
| S | E | O | A | R |
| K | N | H | M | E |
| G | U | I | O | L |

- |                |           |
|----------------|-----------|
| 1. <u>Goat</u> | 9. _____  |
| 2. _____       | 10. _____ |
| 3. _____       | 11. _____ |
| 4. _____       | 12. _____ |
| 5. _____       | 13. _____ |
| 6. _____       | 14. _____ |
| 7. _____       | 15. _____ |
| 8. _____       |           |