NEW ENGLAND
The BEACON
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2016 PATIENT EDUCATION SEMINAR - SOMETHING FOR EVERYONE!

Attendees at the Patient Education Seminar show their star power!

There is a bit of a formula in pulling together the Biennial Patient Education Seminar. It goes a roughly like this: reserve a venue, graph out the day, get great speakers, send out a mailing, fill the room, arrange lunch, have relevant topics, and make everyone feel like a star!

As we have learned, the devil is indeed in the details! In the afterglow of our recent PES 2016, we are able to reflect on what made it so successful. As well, we analyze all details so that our next PES will be in improvement on an already highly effective day.

It cannot be overstated that SFNE staff is the key to any successful event. As those of you who attended can attest, if SFNE Office Manager Rebecca Dube were not at the other end of the phone and e-mail trails resolving the myriad issues that emerge, we could not possibly build this day! From special considerations about luncheon constraints to the discussion about what microphone works best for which speaker, Rebecca is the details person who makes it all fall into place.

Dr. Richard Burt opened the seminar with a precise presentation on a topic that is near and dear to all of us – Hematopoietic Stem Cell Transplantation (HSCT). It was technical, perhaps a bit academic for many and still, his dedication and passionate understanding of the profile of the patient requiring HSCT is undeniable. Four of Dr. Burt's post-HSCT patients were in attendance and it is clear that each of them is highly grateful to this man for bringing quality back into their day-to-day life. What is also apparent to all who listened intently to Dr. Burt is that we have a great deal of ground to cover in the unraveling of therapies that work. We are witnessing the long-awaited outcome measurements that assure us that progress is being made for the benefit of all who are living with scleroderma.

Dr. Nicole Orzechowski and Dr. Michael Whitfield made a much anticipated presentation on the research and treatment capacities of the newest New England based scleroderma center. We were thrilled earlier this year when the announcement was made that the Dartmouth Hitchcock Medical Center has been recognized as a "Scleroderma Center" for treatment and care. This assignation is the result of a carefully considered eligibility by a team of reviewers and staff from the National Scleroderma Foundation offices. Dr. Orzechowski is a scleroderma specialist who can serve in the role of primary care physician for anyone diagnosed with scleroderma. This is an unprecedented option for diagnosees living in northern New England. Dr. Whitfield, reflecting on his recent Falk Transformational Award for research, spoke eloquently and entertainingly about the complex aspects of biological systems and genome-wide analyses in order to better understand the cell biology of the systemic autoimmune disease, scleroderma.

(story continued on page 7)

NEW SCLERODERMA CENTER NAMED!

(See page 4 for details)

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Scleroderma Foundation
New England Chapter

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Marie A. Coyle   Walter A. Coyle

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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.*

SUPPORT GROUP LEADERS' SPRING LUNCHEON

SFNE support group leaders and guests (l-r): Back row - Sandra Mahoney, Tony Cappellucci, Deb Magnuson, Jack Armitage, Don Chapman, Janel Rogers, Carla King, Patty Kittredge, Don Legere; Front Row - Bunny Cappellucci, Jean Chapman, Sandy Lunner, Roberta Mauriello, Tricia Legere, Tom Legere, Cathy Legere (not pictured - Christine T. Maroney, Donna Bernier, Peg Bernier, Rebecca Dube, Patty Meaney)

Our Support Group Leader Luncheon is a very special event. Not enough is said for the role that our support group leaders play in the overall goals and accomplishments of our organization. It is fair to say that they are the heartbeat of our outreach and the soul of our mission. Without our leaders, we would have no measurable justification of service and less empirical proof of our value.

Twice annually, we host a luncheon for this special team. On April 15, we gathered – 22 strong – at The Country Tavern Restaurant in Nashua, NH, an approximate geographic mid-point in our service area. We encouraged this group to use the meeting to address their own support needs and, typically, there was an abundance of giving in the room. Generous advice was offered regarding self-care and the importance of "down" time. There was a vigorous discussion of co-leadership as a way to lighten the tasks of leadership. We had four sets of co-leaders in the room.

Further discussion followed on the topic of a recent requisitioning of patients for skin samples via the research lab of Dr. Jonathan Garlick at Tufts Medical Center. All agreed that the value of such research outweighs the inconvenience!

As a group, we discussed having topical speakers in support meetings and debated how often they should be used. Leaders shared strategies with an attendee considering starting a new group in her area. There was also much enthusiastic conversation about the recent Patient Education Seminar. Speaking generally, all those who attended were enthused and felt validated.

True to form, there was the pressing topic of Raynauds and different efforts at prevention of symptoms – all continue to agree that it is a nasty day-to-day challenge and several workable therapies were suggested. Of note: the coffee cups used at the Country Tavern were perfect for wrapping hands for warmth. It was a wonderful lunch meeting and it is gratifying to observe the emerging friendships and bonds that result from this semi-annual lunch seminar.

We hold a very special place in our daily appreciations for the Support Group Leaders in New England. Thank you one and all.

FROM THE DIRECTOR'S DESK

By: Jack Armitage

We enter fundraising season with confidence this year, appreciating the successes and growth that we achieved in 2015. What stands out most as I reflect over 12 months, is the following:

First, our maturing Board of Directors has made a notable impact on *HOW* we do what we do. Five members attended a recent Institute for Trustees Conference (hosted by Essex County Community Foundation) which succeeded in invigorating specific board skills for this already enthusiastic group. As a whole, the SFNE board is moving us in a very good direction building on the confidence of our ongoing mission and goals. We are honoring term limits in the effort to stay fresh and energetic – and we are actively seeking new candidates for next year's appointments.

Second, we recently enjoyed a remarkable Patient Education Seminar (PES), reminding me of *WHY* we do what we do. The PES, reviewed in this issue of *The BEACON*, was attended by more than 140. The sessions were of enviable high quality. Our only regret in hindsight was that we did not video-record them. We are already in discussion about our next seminar with big ideas emerging.

Third, our events planning has not only shown a notable up-tick in vibrancy, but early reports and registration for all of them is increased at this early stage in the year with no signs of slowing down. As of this writing, the funds raised at the Worcester Walk ($31,320) have exceeded the numbers of recent years. The Golf Classic, held in July, is our major annual fund raiser and mailings for it have gone out to our incredible supportive golfers.

Fourth, we are witnessing a growth in advocacy and political enthusiasm in our constituency. Commitment to organize and advance research in fibrotic illnesses shows new momentum. Please do continue to think politically in pushing legislation of The Scleroderma and Fibrosis Research Enhancement Act (H.R. 3666) and contact SFNE or the National Office to further your zeal and commitment.

Additionally, we are allied with the new "Patients as Partners" program, creating a venue for any constituent to weigh in on pharmaceuticals' research and development projects. This exciting new initiative will create a direct pipeline of advocacy from any person who is diagnosed to the pharmaceutical companies doing research and product development. It is unprecedented. Contact Karen Gottesman for more information or to participate (*KGottesman@scleroderma.org*).

Fifth, we are honoring our history and building on it. We are proud to be building *precedent* into our goals, as a reflection of our historic path. Our ongoing thanks goes to Marie Coyle and her diligent defense of our history and the people who built this organization.

Sixth, we have made confident financial decisions this year and are scrutinizing the overall efficiency of our resources to increase our research support and our constituent programs. Our Support Group Leader recognition efforts via semi-annual seminars and increased interactions has made a dramatic difference in our goals. Additionally, we have increased our staff by one! Please read about Patty Meaney in this issue and join us in welcoming her enthusiasm and skills. She has become an indispensable addition to our busy season.

Seventh, in our ongoing efforts to expand our larger geographic and shared national presence, we have actively sought counsel and perspective from other chapters. Fee Sapahi, Executive Director at the Delaware Valley Scleroderma Foundation, joined us at our recent PES, as did new National Board member Katayun Jaffari. We continue to build collaboration with other chapters and affiliates and will continue to nourish the network of communication at this year's National Conference, counting on the guidance of Liz Heath and others who have a vested interest in our shared strengths. We greatly appreciate the collaboration of all chapter leaders whose input continues to build our growth.

Eighth, we are very proud to continue to strengthen ties with the National Scleroderma Foundation leadership. It is refreshing to have enjoyed vigorous interactions this year with Robert Riggs and Tracey Sperry, as well as their incredible staff. We continue to discuss future growth with the National Board of Directors, most notably in interactions with affiliate and chapter representatives Bill Martin, Bruce Cowan and Mary Blades.

My overall 'take home' message is that due to the many efforts of the larger scleroderma community, we are all able to flex our organizational potential and build measurable successes in real time. This is our goal and our promise – we will continue to work together with the mission to find a cause and a cure for scleroderma in our lifetime.

NEWLY NAMED SCLERODERMA CENTER IN BOSTON

To add to our thrill at a new scleroderma center being certified at Dartmouth-Hitchcock Medical center in Lebanon, NH, we recently learned that there is another certified scleroderma center in Boston. The Massachusetts General Hospital (MGH) Scleroderma Program has been named a "Scleroderma Center" by the national Scleroderma Foundation.

Dr. Flavia Castelino

The Center, located at 55 Fruit Street, Yawkey 2C-2100, Boston, MA, noted as the Massachusetts General Hospital Scleroderma Program, specializes in the care of patients with scleroderma and related fibrotic conditions. Led by Program Director Flavia Castelino, MD, the Scleroderma Program delivers state-of-the-art multidisciplinary care in the evaluation and treatment of patients with scleroderma. They are committed to improving scleroderma patient care by developing better diagnostic and treatment options, and performing innovative research to advance our understanding of what causes scleroderma.

Other program physicians include Mary Bolster, MD and Sara Schoenfeld, MD. They see adult patients with morphea (a form of localized scleroderma) and systemic sclerosis. Depending on symptoms, they will coordinate treatment with other specialists at MGH, including cardiologists, dermatologists, gastroenterologists, nephrologists and pulmonologists.

Research is underway at MGH to find therapies that will improve the quality of care for patients. Members of the Rheumatology Unit work with scientists in the Center for Immunology and Inflammatory Diseases (CIID) to better understand scleroderma and develop new treatments. Dr. Castelino is leading efforts to host clinical trials that give patients access to promising novel therapies for scleroderma. Current studies include PRISM, LPA, ASSET, PRESS, SCTC and Nentedanib in Scleroderma Lung Disease. To find out more about these trials, go to *www.scleroderma.org* and look up the Massachusetts General Hospital Scleroderma Program Center. There is a list of open clinical trials. For direct research inquiries, contact coordinator Ana Fernandes at 617-726-2792 or *afernandes@mgh.harvard.edu*.

> ***"The MGH Scleroderma Program specializes in the care of patients with scleroderma and related fibrotic conditions."***

As part of a teaching hospital, MGH's Rheumatology Unit is committed to preparing the next generation of leading academic physicians, scientists, and clinician-educators. Their fellowship program, which is affiliated with Harvard Medical School, offers physicians experience in the clinical aspects of scleroderma. Internal medicine residents also gain exposure to scleroderma patients as part of their general training.

We are excited to add another respected Scleroderma Center to our New England service area. For more information on the Massachusetts General Hospital Scleroderma Program, go to *www.massgeneral.org/rheumatology/services/*.

* * *

MASSACHUSETTS REHAB COMMISSION SPEAKERS

Two members of the Massachusetts Rehabilitation Commission meet with the North Shore Group

At the March North Shore Support Group meeting, Stephanie Jackson and Myra Caleira of the Massachusetts Rehabilitation Commission (MRC) came to speak about their vocational rehab program, which works to help people with a disability get to employment.

The program offers individualized services with qualified vocational rehabilitation counselors. It helps fund training programs that retrain someone limited in his or her ability to do one job to train to be able to perform another. This training can include a bookkeeping class, classes on using computers, or vocational training. It can even include attending North Shore Community College or achieving up to a bachelor's degree at a Massachusetts state school. The program's goal is to help a candidate gain the skills needed to go back to work.

If you need accommodations in your workplace to help you work at the job you have, they can help with that as well. The Massachusetts Rehabilitation Commission can help with assistive technology devices. For example, if you are unable to type because of physical limitations, they can pay for a "speaking software" that turns your spoken words into typed text on a page. They will also train you on the software. They can help with hearing aids, glasses, and other assistive devices, including vehicle and home modifications.

One topic of interest to the attendees at the meeting was the Commission's availability of a Benefits Specialist. This person can work with participants to figure out what hours they can work if they are or will be receiving a disability income, or if they are first eligible for disability income from Social Security.

The MRC office is located at 45 Congress Street, Suite 4120 in Salem, MA. If you were to apply for services, there is a 30-day wait period, then you meet with a counselor to get a functional capacity assessment. From there you go over your career assessments and develop a plan for employment. To qualify you do need to have a disability that causes a barrier to employment. The Commission is then there to help you overcome that barrier and get back to work!

If you would like to find out more about the Commission and other offices they have throughout the state, call 800-245-6543 or go to *www.mass.gov/mrc*. For the Salem office, contact Stephanie or Myra at 978-745-8085. Our sincere thanks to both of them for attending the meeting and letting us know of all the great services they offer!

* * *

IF YOU WILL...

Planned Giving at SFNE simplified!

Arranging a bequest to SFNE will assure legacy planning in regard to research and patient care. *Contact Jack Armitage at SFNE by calling 978-887-0658 or clip and return this form to SFNE in the attached envelope for more information.*

☐ I'd like to know how to put SFNE in my will.

☐ SFNE is already included in my will.

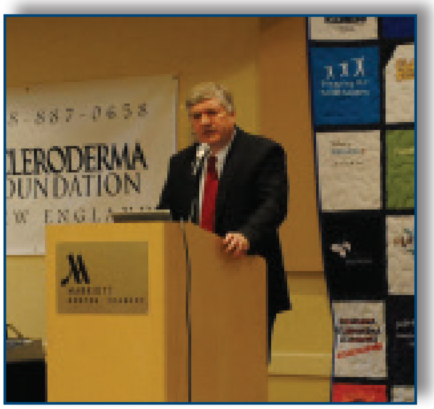
Name (please print): ______________________________

Address: ______________________________

Phone: ____________________ Email: ____________________

2016 PATIENT EDUCATION SEMINAR IN PICTURES

Rebekah Acevedo poses a question to the doctors



Dr. Richard Burt spoke on hematopoietic stem cell transplantation for scleroderma

Dr. Andrew Plaut spoke about the gastric challenges of scleroderma

The afternoon Ask-the-Experts panel consisted of (l-r): Dr. Michael Whitfield, Dr. Nicole Orzechowski, Dr. Andrew Plaut, Dr. Robert Simms, Dr. Vaishali Sanchorawala and Don Legere

Attendee Kristine Scollin asks a question of Dr. Plaut

A full house of Patient Education Seminar attendees listen to the doctors' presentations

Robert Riggs and Laura Koumarianos of the Scleroderma Foundation watch with SF/SFNE founder Marie Coyle

Dr. Robert Simms

Dr. Nicole Orzechowski and Dr. Richard Burt

P.E.S. REVIEW, CONT.

(continued from page 1)

Dr. Andrew Plaut, our longtime SFNE friend and gastroenterologist was, as indicated by post-event surveys, the favorite speaker of the day. It has to be said about Dr. Plaut that he seems to effortlessly cross the chasm between making information exacting and accessible in an entertaining way. His presentation was compelling and he tirelessly addressed a broad range of questions from a very enthusiastic audience.

The afternoon "Ask The Experts" panel was a high point of the conference. Because of the diverse members of the panel, it achieved excellence. Panel Moderator Kerri Connolly (Director of Programs and Services, Scleroderma Foundation National Office), brought a new dimension of professionalism to the day. Great thanks as always to Dr. Robert Simms for leading the panel and to participants Dr. Vaishali Sanchorawala, Drs. Orzechowski and Whitfield, SFNE Board President Don Legere and Dr. Andrew Plaut for their diligent responses, their humor and their loyalty to our constituents.

The Patient Education Seminar is a cornerstone of our mission. We will continue to bring it to our scleroderma family with consistent dedication to excellence and high quality. Our greatest thanks to all who participated!

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Speakers' Panel Moderator Kerri Connolly

WHAT THE DOCTORS SAID...

Systemic sclerosis is a matter of the heart. This is unique relative to other autoimmune diseases. Tight skin can equal a stiff heart (tight ventricle). Extensive testing of the heart is needed prior to HSCT.

- Richard Burt, MD

Gastric problems occur among those with diffuse or localized scleroderma. Loss of gut muscle cells and strength make the stomach too weak to empty. Bacteria can build up in the small intestine. There can also be scarring (fibrosis). Ninety percent of scleroderma patients have problems with GERD, 40% without symptoms!

- Andrew Plaut, MD

A genome is a haploid set of chromosomes; the sum total of the genes in such a set. The human genome consists of perhaps as many as 10 million genes. There are molecular fingerprints in multiple tissues and we are mapping it out like a social network - which genes talk to which genes.

- Michael Whitfield, PhD

It is a pleasure to work with such a great organization. Keep up the good work!

- Nicole Orzechowski, MD

I was so impressed with the spirit and the value of this day to so many. I feel fortunate to have been a part of this great event. It was also great to have time to talk to the wonderful members of our local [North Shore] group!! Always great to see them. I can only imagine what goes into creating such a dynamic day. All the best, thank you!!!

- Jonathan Garlick, MD

AN ATTENDEE REVIEW

After returning home, I couldn't wait until the next business day to call the New England chapter to thank the staff for putting on the Patient Education Seminar at the Peabody Marriott on April 2, 2016. My name is Tina Johnson and I have scleroderma.

It's gotten real bad, especially in my hands. They're disfigured, have no dexterity and are always hurting me. I always look forward to these events to see if there are any new developments with this disease. I'm eager to learn about any new information regarding trials and possibly, a cure.

A lot of my questions were answered, and I had many. From real-time data slides on swallowing to expulsion, I now have a much better understanding of what my body is going through. The explanation of stem cell transplantation and hyperbaric oxygen therapy, along with being able to ask our own questions was fantastic. Even the dentist, Dr. David Leader, although he wasn't on the speaking panel, was there to support and answer any questions, which he did very well.

To the much needed sponsors, thank you for your support and to all the doctors for their research. This is such an important and appreciated educational event that Scleroderma Foundation New England puts on. To all of the scleroderma patients and their families, be brave, you are all loved.

Love,
Tina Johnson

P.S. Patients who need to use special utensils and cups with handles, please remember to bring them next time, so we can all share ideas and see what works for others.
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SPAGHETTI FOR SCLERODERMA STRIKES AGAIN!

2016 brought another successful evening for sorority Alpha Omicron Pi at Bryant University in Rhode Island with their third annual Spaghetti for Scleroderma event. Paige Lemieux held the reins for the event this year, taking over from last year's coordinators Lauren Conrad and Catherine Glavin.

This third-party event is held in honor and memory of Alpha Omicron Pi sister Victoria Frazier's mother Wendy Coleman Frazier. Victoria, who launched the event in 2014, was on hand to make a presentation to attendees about scleroderma and how it affected her and her mother's lives.

Members of Alpha Omicron Pi and coordinators of the past three Spaghetti for Scleroderma events (l-r): Paige Lemieux, Victoria Frazier and Lauren Conrad

The color teal abounded as guests arrived to balloon displays, bead necklaces, outfits and signs, all in Scleroderma Foundation New England's signature color. Paige had beautiful baseball jerseys created to promote the event (see photo, right). There was a delicious meal of (of course) spaghetti and chicken parmesan, along with a musical performance by Bryant senior Matt Beckius, a photo booth and a raffle. The young men from Sigma Chi fraternity got involved as well, as they sported coats and ties for the photo booth.

As an opportunity to spread awareness, educate others about scleroderma, and raise funds ($4,081!) for research and programs, the Spaghetti for Scleroderma legacy has continued to grow and thrive throughout the years. Thank you Alpha Omicron Pi!

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Helping members of Alpha Omicron Pi

Sigma Chi fraternity got involved as well

Ally Favuzza and Paige Lemieux sport Spaghetti for Scleroderma shirts

SCLERODERMA FOUNDATION LAUNCHES "PATIENTS AS PARTNERS" PROGRAM

The Scleroderma Foundation is seeking people who have been diagnosed with systemic scleroderma (or systemic sclerosis) to partner with them and key pharmaceutical companies that are developing clinical trials for therapies to combat scleroderma. The Scleroderma Foundation has launched a new program called "Patients as Partners." It is designed to partner the scleroderma community with pharmaceutical and biotech companies.

THIS IS NOT ENROLLMENT/RECRUITMENT INTO A SPECIFIC TRIAL. This is an opportunity for people living with scleroderma to educate scientists about specific challenges associated with scleroderma and how clinical trials can be designed to accommodate the unique needs of people living with scleroderma to better ensure successful outcomes. Constituents of SFNE can present their experiences and ideas to pharmaceutical companies by committing to roundtable discussions with actual pharmaceutical representatives and through conference meetings by telephone. For further information, check the current issue of the *Scleroderma Voice* or contact coordinator Karen Gottesman at *kgottesman@scleroderma.org*.

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NEWS BYTES

NEW WALK TIME FOR PLYMOUTH WALK!

Please note that the start times for the Plymouth Walk on June 5, 2016 have been changed. They are now as follows: registration begins at 8 a.m., and the walk kicks off at 10 a.m. So all you early birds, get out there and walk!

* * *

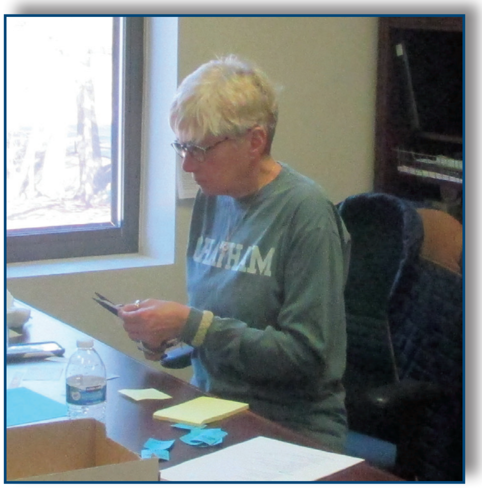
EVERETT SENIOR HEALTH FAIR

On March 10 Roberta and Fran Mauriello participated in the annual Senior Health Fair at The Connolly Center in Everett, MA.

They provided a table with scleroderma information and were available to answer any questions regarding the disease: a great way of spreading awareness. Thank you Roberta and Fran!

* * *

WELCOME PATTY!



Patty Meaney cutting tags for the Support Group Leader Luncheon

Patty Meaney has joined the SFNE group to help a few hours a week with the many tasks that go into putting together a walk.

It quickly became clear that Patty's motivation, energy and creativity were just what we needed this season, and we soon had an overabundance of raffle baskets completed.

Patty's often sardonic humor and generous nature speak volumes about her and make her a great addition to the office. She has bonded with clients and visitors and seems to have settled in nicely. Welcome Patty!

* * *

HOOPS FOR HOPE

In March the student council of Bridgewater Raynham Regional High School, led by English teacher and Student Council Advisor Nicole Turcotte, held their second annual Hoops for Hope fundraiser basketball game between students and teachers. Seven teams competed and raised a total of $200! We love to see people coming together for a great cause, and having a fun time doing it! Thank you so much Nicole and all the participants and donors of this great event.

SAVE THE DATE

2016 EVENTS

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

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

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

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

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

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

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

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

Lynda Fernandes Golf Tournament
Midville country Club
West Warwick, RI
Saturday, TBD, 2016

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

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

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

SWALLOWING MEETING REVIEW

By: Joan Kingsbury

As many scleroderma patients will agree, swallowing is a necessary evil. When swallowing is difficult, It can cause anxiety, embarrassment, and concern about nutrition - am I getting enough of the right foods? Is cream of wheat, scrambled eggs and ice cream a well-balanced meal? Does going out to dinner with friends bring a feeling of dread? What if something gets stuck? However, there may be hope on the horizon.

Speech therapist Allie Madden, Bunny Cappellucci, Joan Kingsbury and Jack Armitage

Dysphagia means difficulty swallowing. For someone with dysphagia, it may take more effort to move food or liquid from the mouth to the stomach, and swallowing may be painful. Not many people have heard of Synchrony™, a new program which is helping to improve dysphagia. Allie Madden, speech therapist at Peabody Glen Health Care Center, explained the process at a recent Greater North Shore Links Partners meeting. "Synchrony™ Dysphagia Solutions by ACP is a comprehensive system combining evidence-based protocols, advanced therapist training and a revolutionary new sEMG Biofeedback." It allows the swallowing muscles to be stimulated and gain some strength, which in turn has improved her patients' ability to swallow.

Madden explained that using one technology of the program, the OmnisEMG®, she and the patient can actually "see the swallow", which allows her to measure the effort expended in trying to swallow. She can use gentle electrical stimulation and biofeedback to help the patient strengthen muscles that have weakened from stroke or disease. As part of the initial evaluation, a patient is given one teaspoon of a liquid and is then monitored as it is swallowed. Colored bars appear on the screen, allowing easy access to the swallowing effort. As they learned to do exercises with the help of Synchrony, many of her patients have seen remarkable improvement.

Dysphagia patients are often given feeding tubes or soft foods because the muscles have weakened, not allowing normal food to be swallowed. Aspiration pneumonia and higher-than-average rates of infection are common in these patients. These are only two of the reasons that 60,000 deaths occur from dysphagia yearly in the U.S.

Because dysphagia can be one of the first signs of disease, it is important to tell your doctor immediately. Some physicians are not trained to pick up on a seemingly harmless symptom, in which case a speech therapist may be the medical professional you need to consult.

The size and cost of Synchrony™ currently makes it only available in certain settings. Rehabilitation centers and long-care facilities are currently the usual sites to find Synchrony. Allie Madden works with the Peabody Glen Health Care Center located in Peabody, MA. For more information on the Sychrony program at the Center, contact Director of Rehabilitation Paul Sampson at 978-531-0772. To find an Accelerated Care Plus (ACP) facility near you, call 800-350-1100.

FUDDRUCKER'S FUNDRAISER

On Friday, August 19, 2016, the North Shore support group will hold its annual fundraiser at Fuddruckers in Saugus, MA (Route 1 North) from 5 p.m. to 8 p.m.

Fuddruckers will donate 20% of your total meal price to the SFNE chapter. The bottom portion of the "Burgers for Benefits" flyer must be presented to the cashier when placing your order on the fundraiser date.

A mailing will go out to local participants in early August or contact SFNE to get a flyer. Flyers may not be given out at the restaurant, but can be copied to give to friends and family beforehand.

There will be good food, raffles, and lots of fun getting together, as we have in the past. Hope to see you there!

- Roberta Mauriello
  North Shore Support Group Leader

MAINE SUPPORT GROUP REVIVAL

Former Maine support group leader Lori Chason, along with new co-leader Sandy Lunner, will be reviving a Maine support group in Windham, ME.

The group will meet the first Friday of each month from 11 a.m. to 1 p.m. at the Windham Public Library, 217 Windham Center Road, Windham, ME. Refreshments will be served.

Lori will also continue to provide one-on-one support over the phone or e-mail to those unable to attend meetings (*see page 11*).

June is scleroderma awareness month, and did you know that World Scleroderma Day on June 29 coincides with the death of famous artist Paul Klee, who suffered from scleroderma? His disease (diffuse scleroderma) was not identified until almost ten years after his death, but its effect on his work can be seen in his later paintings, which became fewer and farther between as the disease progressed.

As many living with scleroderma know, public awareness of scleroderma and familiarity with its symptoms greatly helps the potentially long journey to diagnosis. Increasing awareness and education of this disease among doctors, nurses, and other medical practitioners, as well as the general public, is an essential part of a establishing a quicker path to quality care.

Each year SFNE works with the Scleroderma Foundation and affiliates, the Scleroderma Society of Canada and the Scleroderma Research Foundation to spread the "hard word" of scleroderma to increase awareness and education. There are many different ways that you can get involved as well. Here are a few ideas:

- **Teal is seen as the scleroderma awareness color:**
- Change your social media (Twitter/Facebook, etc.) cover photo and profile photo to an awareness photo or teal theme
- Flood twitter using #scleroderma in your tweets
- Contact your local media/radio/paper to give an interview or an awareness feature
- Wear teal and post your photos on social media event pages
- Organize an awareness event where the dress code is teal only
- Take awareness leaflets (available from SFNE) to all community healthcare professionals *e.g.*, GP surgeries, pharmacies, practice nurses
- Organize an awareness raising stand in your local hospital/ healthcare provider's building
- Participate in Scleroderma Foundation's virtual walk on June 29

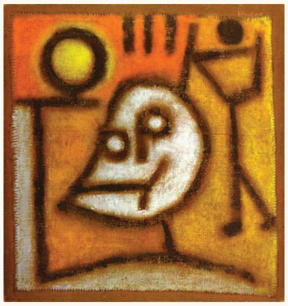
Learn more about Scleroderma Awareness at sclerodermaaware.org, hardword.org or #hardword.

http://sclerodermanews.com/2016/04/11/world-scleroderma-day-june-29th-2016/

"You adapt yourself to the contents of the paintbox."

- Paul Klee

For more information about the artist Paul Klee and his paintings, go to http://www.theartstory.org/artist-klee-paul.htm



Death and Fire (1940) - Paul Klee

SFNE SUPPORT GROUPS

Maine

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

One-on-One Support
Contact Lori Chason, 207-892-7323
chason.lori@yahoo.com

Massachusetts

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

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

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

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

New Hampshire

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

Central NH Support Group (Bow)
Meets the first Wednesday of the month
Group Leader: Don Legere
603-566-3145, donlegere@comcast.net

Vermont

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

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

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

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A FEW QUESTIONS...

Q: A boy and a doctor are fishing. The boy is the doctor's son, but the doctor is not the boy's father. Who is the doctor?

Q: A farmer has 17 sheep and all but nine run away. How many are left?

Q: Which word, if pronouced right, is wrong, but if pronounced wrong is right?

Q: You are in a pitch black cabin with one match on you. Around you there is a newspaper, a lamp, a candle and firewood. Which do you light first?

Answers: His mother, Nine, Wrong, The match!

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

We really stumped you this time, with an incorrect letter in the fourth clue! While unintentional, it did not affect the letters for the final theme word. Congratulations to Marie Spinney, who sent in the most correct answers. Here they are:

1. ESc iteKa	ICE SKATE
2. hOo ctohceatL	HOT CHOCOLATE
3. clArpeiFe	FIREPLACE
4. teeNow rindeW	WINTER WONDER
Theme word:	SNOWFLAKE

NEW PUZZLE

The phrases below are palindromes - phrases that spell the same thing forward and backward, like TOP SPOT or TUNA NUT. From the clues, try to decode the following palindromes:

1. Hermit from Nevada: R __ N __ __ __ N __ R

2. Kingly Beer: R __ __ __ L L __ __ __ R

3. Fruit Given as a Gift: G __ __ __ __ __ G

4. Wood touched by Midas: __ O __ D __ O __

5. Socially challenged physician:
__ R. __ __ K __ __ __ D

Puzzle by Emily Cox and Henry Rathvon

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