

NEW ENGLAND The BEACON

A Publication of Scleroderma Foundation New England

Fall 2016

THE IMPACT OF GIVING

By: Rebecca Dube

In each issue of *The BEACON* we gratefully promote the fundraising efforts of constituents, volunteers and support groups throughout New England. The generosity of individuals through walks, direct mail contributions, local events and end-of-year giving all contribute to the ongoing work of Scleroderma Foundation New England. Every day, we engage to honor its mission of education, support and research for those living with scleroderma, their families and caregivers.

By way of this article, we'd like to give you an overview of the impact of the ongoing work that your dollars support and how it affects both the scleroderma community and the New England community at large.

We can start with *The BEACON* itself. As an affiliate of the National Scleroderma Foundation, it is our responsibility to provide information and education to the New England area. Each quarter, the staff at SFNE, along with contributing writers, puts together a twelve-page document that provides updates on events, highlights the hard work of constituents throughout the region, and offers medical and insurance articles. Additionally, it gives insight into our board of directors, spotlights personal scleroderma stories, and tries to provide a little fun with puzzle contests and inspiring quotes. *The BEACON* goes out to over 1,000 constituents,

and is shared with chapters around the country. We supplement this printed publication with ongoing Facebook posts that provide photo albums from walks, real-time updates, support group reminders and our scleroderma awareness campaign in June.

Every two years, continuing with the theme of education and awareness, we host a Patient Education



Seminar. In 2016, 138 registrants joined nationally-known doctors to discuss scleroderma topics, to learn about regional health care options, and to network with others living with scleroderma. This biennial seminar provides an alternative for New England patients, caregivers and their families who cannot make the trip to the National Conference for whatever reason. It can also be a supplement to that conference, providing additional information or time to talk one-on-one with doctors and researchers active in the scleroderma field in a more intimate setting.

SFNE also provides an annual scholarship, the Walter Coyle

Fund, to make patient attendance at the National Conference more attainable. A panel coordinated by the National Scleroderma Foundation reviews applications for scholarships submitted by constituents each year. This allows patients the opportunity to attend this major educational event.

For those living with scleroderma, we provide nine support groups throughout New England to offer a place of comfort, sharing and community with others living with the disease. These groups, run by volunteer support group leaders, are supported by raised funds and include reminder mailings each month as well as outreach to attendees as needed. Support group leaders will bring in topical speakers to educate the group on a particular issue. Often these groups are the

(continued on page 2)

IN THIS ISSUE

<i>The Impact of Giving</i>	1
<i>From the Director's Desk</i>	3
<i>Phase 2 Trials for Rituxan</i>	4
<i>Fuddruckers Event</i>	5
<i>Advocacy Day</i>	5
<i>Montaup Golf Tournament Gift</i>	5
<i>Fall Walks Review</i>	6 & 7
<i>NH Group Hosts Doctors</i>	8
<i>Newsbytes/Save the Date</i>	9
<i>Support Group Leader Luncheon</i>	10
<i>Study on Slowing Fibrosis</i>	10
<i>Chicken Salad Recipe</i>	11
<i>Support Groups</i>	11
<i>Holiday Greeting/Puzzle</i>	12

Scleroderma Foundation

New England Chapter

Founders:

Marie A. Coyle Walter A. Coyle

The New England BEACON
published quarterly by SFNE
462 Boston Street, Suite 1-1
Topsfield, MA 01983

Rebecca Dube, Editor

SFNE is a 501(c) (3) organization. All contributions are tax deductible and should be sent to the above address.

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

Board of Directors

Don Legere, President

Katherine Bedard, Vice President

Peter Hart, Treasurer

Tony Cappellucci

Jane Ladas

Elysia Cappellucci

Andrea Mahoney

Marie Coyle

Selena Valeriani

Tim Hagan

Board Advisors

Tom Curran, Walter Zagrobski

Executive Director

Jack Armitage

Office Manager

Rebecca Dube

Golf Classic Co-Chairs

Bruce Gordon David Rosenberg

Medical/Scientific Advisory Board

Vincent Falanga, M.D.

Boston, MA - (Dermatologist)

Carol Feghali-Bostwick, Ph.D.

Charleston, SC - (Researcher)

Harrison Farber, M.D.

Boston, MA - (Pulmonologist)

Humphrey Gardner, M.D.

Cambridge, MA - (Researcher)

Robert Lafyatis, M.D.

Pittsburgh, PA - (Rheumatologist)

David Leader, D.M.D.

Malden, MA - (Dentist)

Thomas Medsger, Jr., M.D.

Pittsburgh, PA - (Rheumatologist)

Nicole Orzechowski, D.O.

Lebanon, NH - (Rheumatologist)

Andrew Plaut, M.D.

Boston, MA - (Gastroenterologist)

Robert Simms, M.D.

Boston, MA - (Rheumatologist)

Michael Whitfield, Ph.D.

Lebanon, NH - (Ph.D. Scientist)

Michael York, MD

Boston, MA - (Rheumatologist)

Marie A. Coyle - (Consumer Advocate)

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.

THE IMPACT OF GIVING

(continued from page 1)

drivers of a fundraising event or the creation of a new Walk for a Cure.

Twice a year we bring our support group leaders (SGLs) together to have their own seminar and support group – sharing information, questions and advice with each other. These Support Group Leader Luncheons not only thank our SGLs for their hard work throughout the year, but also provide them a peer group of their own to learn how to be better leaders.

Of course, there are the Walks themselves. Planning for these Walks for a Cure starts right after our current Walk season ends and continues well through the winter so they can be executed as smoothly as possible the following spring, summer and fall. Websites are set up, mailings created and sent out, volunteers recruited, sponsors sought, and raffle items solicited. In 2016, six Walks were held from Maine to western Massachusetts, hosting over 1,019 walkers. These Walks provide awareness, education, access to information, camaraderie, support and a feeling of participation and action against this disease. They are wonderful opportunities for families and friends to come together and show their support for a loved one.

The funds generated by the Walks, as well as the many other donations that come in throughout the year,

also comprise the contribution that we are most often asked about - *research*. Scleroderma Foundation New England has always had a high priority commitment to funding research, and over the past 15 years has given over 1.4 million dollars through the National Scleroderma Foundation's Peer Review program. This program has provided over 20 million dollars in research funding over the past 43 years. Recipients of these funding grants have included research teams and individual researchers at Boston University School of Medicine, Dartmouth-Hitchcock Medical Center, and Massachusetts General Hospital among others. Many of the doctors who treat our constituents have received research grants from this program.

All of these services require money, time, hard work, materials and volunteers. Your donations help make all of these programs happen. We receive no funding from the government, so we depend on your contributions to help us meet our mission each and every day. We share enviable peerage with the other national chapters and affiliates in the country, and are grateful to the many amazing constituents who help us meet our goal of excellence in serving the scleroderma community. You generate the impact that affects their lives every day. Thank you.



**WE WOULD LIKE TO TAKE THIS SPACE TO THANK
OUR SUPPORT GROUP LEADERS FOR THE INCREDI-
BLE WORK THEY HAVE DONE THROUGH THE YEAR.**

Blythe	Ilene
Carla	Jean
Carol	Joan
Cathy	Lori
Christine	Nancy
Don	Roberta
Donna	Sandy



FROM THE DIRECTOR'S DESK

By: Jack Armitage

A Challenge for Creative Compassion - Fourth quarter reports are always the “telling” documents on how any non-profit organization has fared and met its mission for the year. In the grass-roots sector, outcomes can be wildly variable reflecting trends and influences that can impact the already precarious predictability of sometimes fragile organizations.

A recent read of end-of-year trends in our service region has reminded me of how important it is to look *outside* of our mission and to peek in on other organizations’ efforts to bring services and optimism to their constituencies.

Two recent statistics from the county in which SFNE has its office (Essex County, MA) have compelled me to think more diligently about our overall mission in the context of our broader geographic trends. These statistics, released by the Essex County Community Foundation (www.eccf.org), our local non-profit overseer, are startling:

- Essex County homelessness has more than doubled from 12 to 26 per 10,000 residents since 2007.
- More than 400 Essex County residents die annually of drug overdose.

If we are to broadly apply these statistics to our SFNE service

region, it suggests that there is a great deal of urgency throughout New England to pay attention to *other* factors that challenge our readership. Poverty and access to quality health care continue to be significant in our mission work. It is fair to deduce that beyond a diagnosis with scleroderma, daily challenges of other sorts are likely additionally burdensome.

In my many years in the service of social betterment, I have learned that a person’s challenges don’t stop with the diagnosis primarily presented in our intake, our support groups and our interactions with them. Often, it is more the case that there are multiple factors that heap onto the already difficult challenges they face. In this issue of the *BEACON*, I ask that our readership make an effort to heighten personal awareness of the daily challenges many of our constituents face and further, to commit to factoring that sensitivity into their response. Remember that we are singularly charged with creating avenues for health and success for our members. We are all made better when one person is helped more.

Our fourth quarter is coming to a close and we are pleased to be able to report another successful fund raising season, the direct end result of which is increased support of research efforts. In addition to enthused research, at the board level we have spent time developing an annual strategies plan which includes an increased sensitivity in our interactions with those who are diagnosed with scleroderma. The plan will determine ways that we can increase our direct impact as a high-functioning organization and on the day-to-day care and access to improved specific services for our constituents.

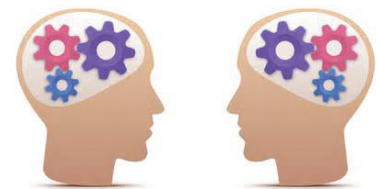
Many of you participated in any of our 14 events this year. THANK YOU! As you will attest, weather was a big factor – for the first time in many years (and despite the drought) we had significant rain

and thunderstorms at most of our fund raisers. You all rose to the occasion and everything BUT your enthusiasm was dampened! They were all successful, thanks to you.

We are growing as a regional chapter and are enjoying similar growth nationally with the many other chapters and affiliates. At the National office, staff and board continue to perfect the delivery of professional services to all of us. The positive outcome of the annual National Conference in New Orleans has been measurable in many ways.

Please take time to visit Youtube (<https://www.youtube.com/user/SclerodermaUS>) to view videos from the conference. It will convince you of the very high quality of research, delivery of services and integrity of the scientists and doctors serving our scleroderma patients.

As a unified group - chapters, affiliates, National office - we all prepare to close our books on another shared annual effort to find a cure for scleroderma. I urge your compassion and your attention to the details of the lives and daily challenges of our constituents. We have much to gain and much to learn in our shared goals and successes.



Big ideas come from forward thinking people who challenge the norm, think outside the box, and invent the world they see inside rather than submitting to the limitations of current dilemmas.

~T.D. Jakes

PHASE 2 TRIAL: RECRUITING SCLERODERMA PATIENTS WITH PAH IN TEST OF *RITUXAN*

A clinical trial exploring if Rituxan (rituximab) is effective in managing pulmonary arterial hypertension (PAH) in patients with scleroderma is now recruiting participants in numerous locations across the U.S.

Rituxan is an immunotherapy drug in the form of an antibody against the CD20 molecule, found on the surface of certain immune cells. The drug can prevent the actions of these immune cells. Rituxan, produced by Genentech, is an approved treatment for several types of non-Hodgkin's lymphoma, chronic lymphocytic leukemia, and certain rheumatoid arthritis patients. It is an investigative therapy for any type of PAH.

The trial (NCT01086540) is a Phase 2 study with the main goal of changing the resistance in lung blood vessels. This will be measured by right heart catheterization after 24 weeks of treatment.

While the efficacy of the treatment is a primary objective, study researchers will also evaluate the safety of Rituxan in scleroderma patients and assess a number of other disease-related parameters, such as the time it takes for patients to get worse, number of new digital ulcers, severity of Raynaud phenomenon, exercise capacity, and quality of life. In addition, researchers will test lung function and evaluate biomarkers indicating disease progression.

Participants will be randomized to receive either Rituxan or placebo in a double-blind manner, meaning that neither patients nor study staff will be aware of which group a patient belongs to. All patients will continue taking their standard treatment — prostanoids, endothelin receptor antagonists, and phosphodiesterase 5 (PDE-5) inhibitors — during the trial.



The trial will also include a sub-study, called the RESTORE Sub-study, where researchers will measure changes in heart parameters using magnetic resonance imaging (MRI). These measurements will act as surrogates of right ventricle function and prognosis. Enrollment in the sub-study will be in parallel to that of the main trial.

Adult patients, ages 18-75, are eligible to enroll in the study. Participants need to have a New York Heart Association (NYHA) Functional Class II, III, or IV PAH, be able to do at least 100 meters on the 6-minute Walking Distance test, and must maintain oxygen saturation of at least 90% at rest, with or without oxygen.

Researchers also set up a list of factors excluding patients from eligibility. PAH patients not eligible for the study include those with PAH for more than five years, those with chronic infections or a history of certain serious infections, kidney disease, cancer within five years of the trial, low blood pressure, lung transplant, history of heart disease, and moderate or severe lung fibrosis.

Also, patients who have recently been treated with cyclophosphamide, immunocompromising biologic drugs or Remicade (infliximab), high-dose corticosteroids, and certain other immunosuppressants or immunomodulating drugs are also not allowed to participate. Patients

who have ever been exposed to any treatment depleting lymphocytes or B-cells are not eligible either.

For a full list of inclusion and exclusion criteria, please visit the trial web page at <https://clinicaltrials.gov/ct2/show/study/NCT01086540#locn>.

The trial will run at about two dozen locations across the U.S. For a full list of locations and contact details, please see the locations section of the trial web page. Patients or their physicians can contact the study staff to discuss details and the possibility of signing up for the study.

Boston University Medical Center

Contact:

Eric Stratton [eas@bu.edu](mailto: eas@bu.edu)
617-414-2507

Principal Investigators:

Harrison Farber, MD
Robert Simms, MD

Researchers point out that the choice to participate in a clinical trial is an important personal decision, recommending that patients discuss the decisions with their doctor and family members before joining.

This article originally appeared in Pulmonary Hypertension News. Open trials are also listed on the Scleroderma Foundation website www.scleroderma.org.



As soon as you open your mind to doing things differently, the doors of opportunity practically fly off their hinges.

~Jay Abraham

NORTH SHORE SUPPORT GROUP HOSTS FUDDRUCKERS EVENT

On Friday, August 19, Roberta Mauriello and members of the North Shore Support Group, with help from Marie Coyle, hosted a night of fun, food and raffles at the Fuddruckers restaurant in Saugus, MA. Friends and family attended with coupons in hand to buy a delicious meal and support Scleroderma Foundation New England. After dinner a raffle was held with prizes solicited or created by group members. The event raised a total of \$875, and lots of good spirits!



Fran and Roberta Mauriello



Tricia and Tom Legere

MONTAUP GOLF CLASSIC DONATION



Jeanne Oliviera (left) and Christine T. Maroney pose with a member of Montaup Country Club.

Each year Montaup Country Club in Portsmouth, RI hosts a charity tournament and for the past two years Jeanne Oliviera has put in a request for SFNE to receive some of its charity funds. This year the amount increased by \$300 for a total of \$800! Thank you Jeanne!



ADVOCACY DAY 2016

By: Ilene Wax

Attending this Advocacy Day was a very powerful experience for me. It was a grass roots event that helped me feel that we were supporting the scleroderma community and that our voice was important. The staffers sincerely listened to us and took notes. I was confident they would present them to their respective Congressmen and Senators.

The group of about 50 patients and caregivers was from all over the United States. The Foundation's leaders made us all feel very comfortable: meals, room temperatures, transportation, etc. They even carried a wheelchair-bound person into the bus when the handicap entrance did not work. At a dinner the evening before Advocacy Day, instructions on what we were expected to do were clearly explained.

My group included two women from Maine, and myself from Vermont. We met with our senators' staffers in the morning and congressman's staffers in the afternoon. We told our scleroderma story, as well as strongly requesting support of monies for scleroderma and other fibrotic disease research. We were treated with the utmost respect. We had a voice in our government.

I enjoyed attending these advocacy events on 'The Hill.' My scleroderma community keeps growing from all of these events. I am enriched by the people that I meet and that I can now call my friends. Everyone is so quick to exchange Facebook and email information so that we can all network and support each other.



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.

2016 FALL STEPPING OUT FOR SCLERODERMA WALKS REVIEW

NORTH SHORE WALK

The Twelfth Annual North Shore Stepping Out to Cure Scleroderma Walk started with stormy skies, but by the time the walk began all 236 walkers were able to move forward without fear of getting wet. With everyone working together, the walk raised \$30,368! This is an amazing accomplishment that eclipses last year's number. Top fundraising teams included Team Krissy, AZTHTX, and Team McGrane. Every team and individual was essential in achieving our final number. We thank you all for everything you do for this event.

Also working the event were our many volunteers who take on the multiple tasks needed to make the walk go smoothly. Thank you to the Great Hill volunteers, Gerry Colantuoni, Joan Kingsbury and her daughter, Tricia Legere, Don and Jean Chapman, Marie Coyle, Joyce Steyer, Deb Pearce, Ann LeBlanc, Tom Curran and Toni-Anne Micalizzi. We couldn't have done it without you!



North Shore Walkers head down Main Street in Topsfield, MA



Emily Winnerman and Krissy Scollin speak to the crowd before the Walk.

WESTFIELD WALK

Our thanks to all the participants of the Seventh Annual Westfield Stepping Out to Cure Scleroderma Walk who braved the forecasts of thunderstorms and came out to support Nina, Sami, and all the participants.

The thunderstorms did not materialize, and the walk raised a total of \$12,552. Team Nina and Shannon was the top fundraising group, with Team Sami a close second. A new team was added this year, Leaps for Peeps - thank you! We greatly appreciate the efforts of all our volunteers from the Broderick and Stackpole families, as well as all their friends. We couldn't do this without you!

The raffle filled the tables and brought many prizes to ticket takers. Walkers enjoyed pizza and subs after the walk, and music was provided by Mike Broderick via iPod. Thank you again to all participants and donors for supporting the mission of SFNE and giving us a great event in western Massachusetts.



Team Nina and Shannon, Team Sami, and Leaps for Peeps come together for the Westfield Walk

WALKS REVIEW *(continued from page 6)*

BOSTON WALK

By: Carol Taylor

The Second Annual Stepping Out to Cure Scleroderma Walk hosted a group of extraordinary people with unwavering dedication. The Walk was held at Artesani Park, Brighton, MA on October 2, raising more than \$23,770. Combined with earnings from last year's walk, we have raised over \$50,000 for the Scleroderma Foundation New England. Remarkable!

I want to thank all our participants, volunteers, sponsors, and our phenomenal Team Captains. Thank you to Boston Support Group members Mary McClay, Irene Kopp and her husband Rob, Keisha Burton-Levy, Deanna White-Hebert and Mary Walsh for your commitment, support and hard work. Thank you also to Irene Kopp's brother-in-law, Carl Botti, for his dedication

in creating a video which will be available on the SFNE website soon. We could not have had the success of this event without your dedication and support. Ongoing thanks to the Boston University Scleroderma Center doctors, Dr. Robert Simms and Dr. Harrison Farber and their staff for their participation and loyal support of the foundation. It was exciting to enjoy such a great turnout despite the chilly day.

A very special thanks goes to the Coughlin, Ulrich, and Olson families for their tremendous work from day one until the day of the walk. These three families have lost a loved one to this devastating disease. Heather's and Maggie's bright lights will remain in all who knew and loved them.

Volunteers from the North Shore and Fall River support groups added to the success of the day. Tricia, Tom and Matt Legere, Christine Maroney and Donna Bernier, and the indefatigable Patty Meaney from the New England office kept the display tables, and details in place. Matt Dube and Dave Meaney were also a great help with banners and signs.

Although the past two years have been tough on our support group members, we know that those who walked celebrated their loved ones struggling with this disease and others walked silently in remembrance of their loved ones. Walks are for all and it is wonderful to be a part of this growing group of loyal friends.

We are most grateful for everyone's generosity and participation in our walk and hope you will join us for our third annual walk in 2017. Until then, see you next year!!



Carol Taylor (center) with her daughter and granddaughter



Heather Olsen's brother, and many other members of her family, walk in her memory.



The Fall River/Bristol County Support Group members (in blue shirts) join other walkers along the route.



The Coughlin family volunteered at the Walk and brought their memorial banner from last year's inaugural Walk.



WESTFIELD QUOTES

Such an amazing turnout. I am so happy we went above and beyond our goal amount. It truly warmed my heart to see the support displayed on Sunday. I am so proud to be a part of such a wonderful cause. Thank you to everyone for their help and hard work. It has been an amazing seven years! I can't wait for Walk #8!

- Shannon Broderick

It is incredible when I think that this amazing young woman with the big heart started this Walk when she was a senior in high school, not at anyone's urging, but merely because she thought she could help do something. I was so touched and proud of her then and every year thereafter!

- Nina Pozgar
(Shannon's aunt)

CENTRAL NH SUPPORT GROUP HOSTS DRS. ORZECZOWSKI AND WHITFIELD

By: Don and Cathy Legere

On Wednesday, October 5, the Central NH Support Group had a very successful combination support group/educational meeting at Dartmouth Hitchcock Medical Center with Dr. Michael Whitfield and Dr. Nicole Orzechowski. There were 22 people in attendance, 17 of whom were patients and caregivers. Attendees were from Massachusetts, Vermont and New Hampshire. Five attendees were colleagues of Drs. Whitfield and Orzechowski.

Support Group Leader Don Legere opened the meeting with a short summary of his own scleroderma story and then continued around the room, with each participant introducing him/herself and his or her involvement as a scleroderma patient or caregiver.

Several people shared their personal stories and concerns prompting many questions and producing helpful hints on coping with some frustrating scleroderma symptoms and medications.

After about 40 minutes of energized discussion with patients and caregivers, we introduced Dr. Michael Whitfield Ph.D., professor of genetics at Dartmouth Medical School.

Dr. Whitfield has been doing research strictly on scleroderma since 2001. He spoke about the work that he and his staff are doing to find differences in the genes of scleroderma patients. They want to find drugs that will work in the different stages and symptoms of scleroderma. They work to find what triggers the onset of scleroderma and they work to find a cure.

Dr. Whitfield then introduced two of his associates, Diana Toledo and Michael Johnson.

Diana spoke about microphages

and how samples of the skin, lungs, gut, blood and other organs that are donated by scleroderma patients are helping research tremendously.

Michael Johnson spoke about his study of the microbiome, which represents all fungus, bacteria and virus in or on the human body and how it differs in a person with scleroderma vs. a healthy person.

Next we introduced Dr Nicole Orzechowski, section chief of rheumatology at Dartmouth Hitchcock Medical Center. She specializes in scleroderma and began her discussion with how to cope with keeping your body warm during cold weather and which medications can help.

She said that calcium channel blockers can help to dilate veins but also can cause side effects. Sildenafil, Botox injections, nitro paste, and nerve stripping if the Raynauds is extremely severe were other suggestions. Otherwise, she suggested turning up the heat and wrapping up in blankets.

We asked Dr. Orzechowski to explain the difference between limited



Dr. Nicole Orzechowski

and diffuse scleroderma, and systemic sclerosis. Limited used to be referred to as CREST. There is less internal involvement (with the one exception of pulmonary hypertension) and less skin involvement. It affects mostly limbs, such as feet to knees and hands to elbows.

In diffuse scleroderma, there is interstitial lung disease which can



Dr. Michael Whitfield

lead to pulmonary hypertension, more skin involvement (including the trunk) and there can be kidney involvement.

The type of scleroderma can usually be diagnosed by the type of antibody present in your blood.

There was some discussion on comorbidity, which is the presence of two or more chronic diseases or conditions. Dr. Orzechowski suggested keeping in touch with your rheumatologist to decide what IS scleroderma and what ISN'T.

Another concern of many people was how to get insurance companies to approve medications. Dr. Orzechowski said she understood the frustration all too well as she deals with it on a weekly basis. She recommended having your doctors write letters and send in clinical study reports.

We closed our meeting with both Dr. Orzechowski and Dr. Whitfield encouraging scleroderma patients to participate in clinical trial studies by donating blood or tissue samples, if they are comfortable doing so. Many came forward offering to participate.

Clinicaltrials.org is a website where you can search for current trials by city and state or by disease.





NEWS BYTES

POLAR PLUNGE

Join us for a frigid plunge and warm giving on Sunday, January 1, 2017 at L Street Beach in South Boston. This annual event, led by Kevin Conroy, begins at the L Street Tavern in south Boston with participants dressed in wild costumes and bathing suits, followed by a grand march featuring bagpipes and drums down L Street to the bath house. The group then plunges into the Boston Harbor for a quick dip to kick off the year.

This event is a lot of fun and raises funds for SFNE. That's why it's called "Freezin' for a Reason"! Contact Kevin Conroy at kconroy3012@yahoo.com or go to www.scleroderma.org/taketheplunge for further details or to register or donate.



LOW INCOME HOME ENERGY ASSISTANCE PROGRAM

The U.S. Department of Health and Human Services (HHS) offers an energy assistance program to families who qualify. The Low Income Home Energy Assistance Program, or LIHEAP, helps keep families safe during the brutal winter months by offering federally-funded assistance to help with:

- Home energy bills
- Energy crises
- Weatherization and energy related home repairs

To learn more about this opportunity, go to www.acf.hhs.gov/ocs/programs/liheap.



GIVING TUESDAY

SAVE
THE
DATE



November 29, 2016

#GIVINGTUESDAY

Remember Giving Tuesday this year by making a donation online at scleroderma.org/newengland, sharing an "unselfie" on Facebook, Instagram or Twitter with our website address and #unselfie and #givingtuesday on a sign along with your reason for giving, asking others to give over Twitter and other platforms, or mailing a donation in the envelope included in this newsletter. Join the over 30,000 partners in 68 countries taking part in this annual day of giving.



North Shore Support Group Co-leader
Joan Kingsbury's "unselfie"



SUPPORT GROUP WINTER UPDATES

As cold New England winters often make people living with scleroderma reluctant to venture in to the freezing temperatures, the Worcester and Maine support groups will suspend their in-person meetings over the winter season and will resume again in spring. Please contact Nancy Velleco at 508-869-2997 for Worcester and Lori Chason at 207-892-7323 or Sandy Lunner at 207-420-3337 in Maine for more information on the date of the next meeting.

SAVE THE DATE

2017 EVENTS

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

Spaghetti for Scleroderma
Bello Center, Bryant University
Smithfield, RI
Saturday, February TBD, 2017

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

Eighth Annual Portland Stepping Out for a Cure Walk
Riverbank Park, Westbrook, ME
Saturday, May TBD, 2017

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

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

NCRS/NE Corvette Day
Larz Anderson Auto Museum
Brookline, MA
Sunday, June TBD, 2017

Lynda Fernandes Golf Tournament
Midville Country Club
West Warwick, RI
Saturday, TBD, 2017

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

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

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



SUPPORT GROUP LEADERS FALL LUNCHEON

By: Jack Armitage



SFNE support group leaders and guests (l-r): Back row - Carol Taylor, Fran Mauriello, Donna Bernier, Tricia Legere, Janel Rogers, Donna Ahern, Beth Gagnon, Carla King, Don Legere, Cathy Legere, Kathleen McAndrews, Ilene Wax, Roberta Mauriello, David Murad, Brenda Brown, Tony Cappelucci, Don Chapman, Mary McClay; Front Row - Peg Bernier, Joan Kingsbury, Jean Chapman, Marie Coyle, Christine T. Maroney, Keisha Burton-Levy, Bunny Cappelucci, Kerri Connolly.

The New England Chapter of the Scleroderma Foundation is made excellent because of the often invisible work of our fourteen Support Group Leaders. Without the caring and confidence that each of them instills in our constituents we would have no way of measuring either the value or the impact of our regional efforts.

Twice annually, we try to thank them with an organized luncheon meeting complete with a support group environment so that we can address some of the needs that they have themselves. We've learned that often it is the support group leaders who go unsupported! On November 4, 29 of our cherished friends attended the luncheon at BreakAway Restaurant in Danvers. Leaders were encouraged to bring a guest, whether a spouse or a support group member. Additional guests were Kerri Connolly and David Murad from the National Office. It was a really special event made notable by vigorous and enthusiastic conversation, reunions of old friends, gifts and recognition for the leaders and an infectious enthusiasm for work that each does.

Roberta Mauriello was the hostess for the Fall SGL Luncheon. With her usual warmth and welcoming style, she made all of the attendees feel embraced and led the discussion that was inclusive on topics including holiday shortcuts, insurability and disease specific modalities.

We at SFNE are incredibly proud of our leaders in the support of all of our constituents. We actively encourage all of them to embrace new ideas and creative support styles. We are struck by the enthusiasm and shared goals that they now enjoy as a cohesive force of leaders.

Mostly, we thank them graciously for the time and energy that they invest in others for our shared mission to bring support and education to all in our region. Thank you New England Support Group Leaders –you are our heroes!

I am just overwhelmed in how we all support one another.

~Ilene Wax

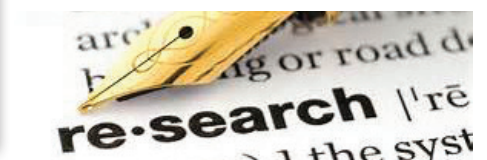
STUDY DISCOVERS POSSIBLE METHOD FOR SLOWING SKIN FIBROSIS

A recent study published in the *Journal of Clinical Investigation* has identified a potential approach for reversing some of the damage caused by scleroderma. Researchers at the Hospital for Special Surgery in New York City observed that mesenchymal stem cells (also known as adipose-derived stromal cells, or ADSC's) that are in the fat under the skin are lost in mouse models of scleroderma skin fibrosis.

According to Theresa Lu, MD, PhD of the Hospital for Special Surgery, "the few remaining stem cells depend on immune cells called dendritic cells and a molecule they express called lymphotoxin in order to survive." The researchers found that if they treated the remaining stem cells with lymphotoxin, it improves their survival and reduces fibrosis in the mouse model.

"The possibility of stimulating the lymphotoxin B pathway to increase survival of these stem cells is very exciting," lead researcher Theresa Lu adds in a press release. "By uncovering these mechanisms and targeting them with treatments, perhaps one day we can better treat the disease." While this finding is still in the early research stages, it provides a promising lead on potential future treatments for fibrosis.

If you would like to read the full UPI article by Ryan Maass, go to <http://upi.com/6447863>. Our special thanks to Kerri Connolly of the National office for providing us with additional information from Dr. Theresa Lu on this topic.



CHICKEN SALAD FOR ANTI-INFLAMMATION

When you have scleroderma, it is important to eat a diet rich in anti-inflammatory properties and antioxidants. This **scleroderma chicken salad recipe** is full of **fruits and vegetables and rich in antioxidants**. Antioxidants, like Vitamin C, can stop free radicals from damaging cells. Vitamin C also supports the immune system.

Learn more about free radicals and antioxidants from the National Cancer Institute (www.cancer.gov). Here's a sneak peek: Free radicals are highly toxic chemicals that can damage cells. They are formed naturally in the body. At high concentrations they can harm the body. This damage may play a role in cancer and other illnesses. Antioxidants can neutralize free radicals preventing them from causing damage while **anti-inflammatory foods** can help reduce inflammation.

Curry, onions, citrus fruit, apples, and raisins are all **foods rich in anti-inflammatory properties and antioxidants**. Curry, onion, and coconut are also considered superfoods. Research shows that eating curry may reduce dementia, Alzheimer's, and cancer risks. Many foods, like mint and curry, have both antioxidants and anti-inflammatory properties. Sticking to a diet low in grains, like a Paleo Diet, may be beneficial to control inflammation. Add curry to chicken salad for anti-inflammatory benefits.

How to Make Scleroderma Chicken Salad Recipe

Ingredients

1 small white onion, sliced
4 boneless, skinless chicken breasts
2 tsp. curry powder, divided
1/2 clove garlic, finely diced
1/4 cup orange juice (freshly squeeze one orange)
1 15-ounce can mandarin oranges, drained
4 green onions, chopped
1/2 cup diced apple (Granny Smith)
1/2 cup golden raisins
2 tbs. sweetened, flaked coconut, divided (fresh)
1/2 bunch mint leaves, finely chopped
1/4 cup light mayonnaise



Directions

Preheat oven to 400°F.
Arrange onion slices on the bottom of a medium, glass baking dish.
Place chicken in baking dish and sprinkle with curry and diced garlic.
Drizzle orange juice on chicken.
Bake for 20 minutes or until cooked through.
When cool, cut into bite-sized pieces.
In a medium bowl, mix chicken, mandarin oranges, green onions, apples, and 1 tablespoon of coconut.
Stir in mayonnaise.
Pour into serving bowl and top with remaining coconut and chopped mint.

For more healthy recipes, join the [Scleroderma Community](#) on Pinterest.

Article by Lora Langston, freelance writer and blogger. Posted in Sclerodermanews.com on September 22, 2016.



SFNE SUPPORT GROUPS

Maine

Maine Support Group

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

Massachusetts

Boston Support Group

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

Fall River Support Group

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

North Shore Support Group (Topsfield)

Meets the 2nd Wednesday of most months
SFNE Office, Topsfield
Co-Leaders: Roberta Mauriello
781-324-7426
Joan Kingsbury
joan.kingsbury@comcast.net

Worcester Area Support Group

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

New Hampshire

Granite State Support Group (Hampstead)

Meets the last Saturday of every month
Co-Leaders: Carla King, 978-884-4866
granitestate@scleroderma.org
Jean Chapman, chappybear@charter.net

Central NH Support Group (Bow)

Meets the first Wednesday of the month
Baker Free Library, 10 am - 12 pm
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



SUPPORT ★ EDUCATION ★ RESEARCH

New England Chapter
462 Boston Street, Suite 1-1
Topsfield, MA 01983

ADDRESS SERVICE REQUESTED

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

MAY YOUR DAYS BE MERRY AND BRIGHT



THE SCLERODERMA FOUNDATION NEW
ENGLAND WISHES YOU AND YOUR
LOVED ONES A WONDERFUL HOLIDAY
SEASON AND A VERY HAPPY AND
HEALTHY NEW YEAR

JACK

REBECCA

PUZZLE ANSWERS

Congratulations to Norma Hyde, the winner of our Summer BEACON puzzle. She will receive a box of Harbor Sweets chocolates in the mail. The answers are below:

- | | |
|-----------------------------|------------------|
| 1. Most rambunctious: | ROWDIEST |
| 2. Prying tools: | CROWBARS |
| 3. Small floor covering: | THROW RUG |
| 4. By a thin margin: | NARROWLY |
| 5. Facial features: | EYEBROWS |
| 6. Song from <i>Annie</i> : | TOMORROW |

NEW PUZZLE

The saying above the grid is a familiar proverb contradictory in meaning to the one hidden in the grid below it. Start in the upper left square and proceed square by square (horizontally and vertically, but not diagonally) to spell the answer. Do not cross your path or enter a single square twice. Not all the letters in the grid will be used. What is the proverb?

“Keep your nose to the grindstone.”

A	L	L	W	R	Y
D	N	R	O	A	K
N	A	K	Y	M	E
O	P	L	A	U	S
L	U	D	A	K	J
L	B	O	Y	C	A

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