

NEW ENGLAND The BEACON

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Spring 2019



Marie A. Coyle
October 16, 1931 - April 13, 2019

SAYING GOODBYE TO MARIE COYLE, FOUNDER AND SCLERODERMA CHAMPION

By: Jack Armitage

Saying goodbye to Marie Coyle took on a universal aspect as we realized that our grief and sadness at losing her was felt across many levels of care and cure, support and survival, honor and history. From our desks and in our support groups throughout New England, Marie's influence had been remarkable. We who knew her personally have spent time recently telling stories about her laser focus and her capacity to combine visionary leadership with homespun humor. Daily, we were in awe of her energy and dedication to building a network of care for people diagnosed with scleroderma in our service region.

Until her retirement at 83, Marie would attend our board meetings, fund raisers and Walks for a Cure. More broadly, Marie traveled to the annual Scleroderma Foundation national conferences and enthused and reignited the passions of those whom she met there. Her energetic efforts to host the

singularly successful Golf Classic for a Cure for Scleroderma gave Marie a platform to remind her supporters of the importance of continuing to fund this cause and to work by her side to find a cure in her lifetime.

It was only in the days that followed her death that we were reminded of the truly astonishing impact that Marie had across this country and much of the world. Marie kept peerage in the higher levels of research, patient care and innovation and with the large picture thinkers in this rare disease field. She had the unique capability of being able to mingle in any circle without being out of place or minimized.

Her death notice described her life path from the time of her diagnosis as follows:

At the age of 12, Marie was diagnosed with the rare disease, scleroderma. At the time, little was known about the condition and Marie's doctors advised her that she would not live to see twenty. This ignited a spark in Marie that carried her energetically through the next 75 years. Her circle of friends grew to include other diagnosed individuals who, like her, were focused on living the best life possible with a rare condition. The momentum of interest in mutual patient support and emerging treatment led her to build an organization, the Scleroderma Society of New England. This group grew under Marie's leadership and evolved to include a network of others around the country, becoming the Scleroderma Federation. The Scleroderma Federation gave people with scleroderma a place to share their stories and to advocate for improved medical research and treatment.

Marie served as a full-time volunteer for the organization. Her continued leadership and influence led to the creation of the Scleroderma Foundation which is, today, the world's largest patient organization focused on the disease. She recognized the need for regional chapters to carry targeted services to geographic areas and to build a medical presence with specific specialists in the field.

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New England Chapter

Founders:

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.

THIRD ANNUAL "SERVE WITH LIBERTY" DAY



Andrea, Jack, Nicole, Nikki, Paul, Malini, Nancy, April, Lauren, Sireesha, Anne



Liberty Mutual Insurance has been a stalwart, a loyal supporter of our mission here at SFNE. For the third consecutive year, we have enjoyed the energetic volunteer skills of nine Liberty Mutual employees who gave a day of work to assist us in our preparation for our busy fund raising season.

Lauren Salines orchestrated the day bringing eight colleagues from different Liberty Mutual offices. Our enthusiastic THANKS goes out to all of them. In addition to Lauren we enjoyed the company of Malini Biswas, Paul Perrotta, April Cook, Nicole Steeves, Nikki Wonoski, Nancy Boover, Sireesha Kolli and our perennial return volunteer and SFNE board member, Andrea Mahoney.

By the end of the day, our mission was accomplished. We had sorted, rolled up and inventoried more than 450 t-shirts, prepared 147 snack packs for the Annual Golf Classic for a Cure for Scleroderma and completed a collated mailing of 200 pieces. This was such an accomplishment for all who participated and truly freed up a great deal of valuable office time for the three of us on staff.

As we are a grassroots organization serving the broad territory of New England, all assistance of this sort is essential to our success. We continue to achieve the near-impossible year after year, thanks to our volunteer corps! To Liberty Mutual, we extend both our gratitude and our admiration for an amazing community service commitment.



CALL FOR VOLUNTEERS!



SFNE is a volunteer-drive non-profit organization that owes a great deal of appreciation to the volunteers who have driven our success for many years.

It was Marie Coyle's special skill to draw volunteers to our events. We will continue that tradition going forward and hope that you will join us.

In events season, March through October, we host 6 Walks for a Cure, a major Golf Classic, Patient Education events and in-office work days such as **Serve with Liberty**, described above.

Let us know if you are able to help out at an event near you! Upcoming, we will be making plans for volunteers at The North Shore Walk, The Boston Walk and the Westfield Walk. Consider the value of your help and the long term benefit to our mission.

And, as always, **THANK YOU!**



FROM THE DIRECTOR'S DESK

We enter the summer season with significant change. Our recent loss of Marie Coyle has given us pause to reflect on our mission, our goals and our reasons for serving the scleroderma community. No one more than Marie exemplified the objectives of this organization – she was the founder, the primary driving force and the charismatic leader who made scleroderma discussable, fixable and broadly recognizable.

While Marie was so well known at the national and even at the global level, we had the great fun luck of knowing her day to day here in the office and at our events. Marie's sense of humor was a bit of legend here in this setting. I had once sat with her at her desk reviewing the day's chores and had given her a pretty hefty assignment hoping to have it finished by day's end. Shortly after the meeting she called me into her office and sat with a sheet of paper in front of her with scribbled figures in multiple columns. "Jack", she said, "I am 83 years old and have been doing this work as a volunteer for most of my life. I have just, on a whim, added up the hours I have worked at this desk and, had I been a compensated employee, I figure that this office would have paid me well over a million dollars for my value. The next time you hand me a 'to do' list, keep that in mind!" It was a good lesson for me and I left that conversation aware of who wore the boss pants in the office!

Marie's sense of balance was something to appreciate. She understood the importance of meeting the directives of a busy office and understood equally as well the importance of personal interaction with our constituents. One day, we had word of a young mother who had arrived at Boston Childrens Hospital with her daughter who was suffering severe symptoms in early scleroderma diagnosis. They were from out of the country and had no experience with an American city, tall buildings, or hospitals in general. They were frightened and completely overwhelmed. Marie and I drove in to meet them, but not without stopping at several stores on the way in to buy comfort items, personal hygiene products, toys and warm clothes. Marie's maternal intuition guided her and I observed her spontaneous success when, on arrival in their room, she "became" their Boston family and they essentially collapsed into her care. They stayed in Boston Childrens for 3 months while the little girl was brought to health and stability. Marie visited them regularly and assured them that their comfort and their understanding of "belonging" was secured. I was very fortunate to have been Marie's companion at such times. As a mentor and as someone who intuitively knew what to do, she set a great example to me, among many others.

More change has taken place, this time in our staffing. After nearly seven years in her position, Rebecca has moved on to a job closer to home. We will miss Rebecca's constancy and her proven skills at anchoring this office. We all wish her the very best as she transitions her amazing skills to her new job. Anne, too, has made the decision to accept a dynamic new position and will take her overflowing bucket of skills to her next job in the health care field. We have been lucky to have had both Rebecca and Anne in our corner and wish them the best possible futures!

Another loss that we have endured is

that of longtime supporter and friend Ira Rosenberg. Ira and Judy and David and their incredible extended clan have been co-sponsors of the annual Golf Classic for a Cure for Scleroderma for all of the 17 years we have held it. Ira told it like it was and when given the chance to speak at the event, he would articulate in clear and potent terms about the need for us to find a cure. He and Marie shared a passionate goal for our successes. Our enduring sympathies go out to Judy, David and the family.

We are enjoying new change at the board level too. We are so pleased to welcome two new board members, Steve Lang and Jeff Daddio. Steve is a Risk Strategies Specialist focused on employee benefit trends minimizing employee risk, with interest in human resources and personal insurance products. Jeff is a Controller at State Garden Inc., in Chelsea, overseeing Accounting and Finance Management and has non-profit skills, bringing new perspective to us at SFNE.

We are well into fund raising season now. With thanks to our event Walkers and Team Leaders, we are off to a great start and have set lofty goals for our annual gift to research. Deb Magnuson led the Worcester Walk to significant success in April – her 17th since she and her son Eric first approached Marie Coyle with the idea in 2002.

Change being the theme this year, we will hold steady nonetheless with our shared mission to bring **Support** and care to those living with scleroderma, to **Educate** the general public and to fund **Research** for a cure for scleroderma. Please join us in 2019 to make this our most successful year ever!

Thank you.



Today, as a legacy to Marie and others, there are 20 national chapters and a remarkably efficient national presence for scleroderma diagnosed individuals and caregivers. The New England Chapter of the Scleroderma Foundation is the organization at which Marie volunteered full time until she was 83. In 2014, Marie was awarded the Boston Patriots Myra Kraft MVP award for volunteerism and excellence by the Boston Patriots Foundation.

Among the many people who sent their condolences and remembrances, several stand out. Robert Riggs, National Scleroderma Foundation CEO wrote, "Much can and will be said about Marie's contributions to the scleroderma community and what she accomplished over her amazing life of service. There are many stories that could be told about what she did, how she did it, and the legacy that her determination, influence and kindness towards others has left behind. To say that I've lost a mentor is a gross understatement. What strikes me most about Marie was her insatiable curiosity.

A curiosity about everything. Marie is an example - to me and to others - that a well-lived life requires one to be open to new things; to never cease to be curious; and to always remember that everyone you meet can teach you something, if you are open and curious enough to listen."

Cathy Legere appealed to our better selves, "Marie Coyle is carrying her mission to heaven. Let's all carry her mission on Earth. She will be missed."

Juliana Viscardi in Brazil who, not unlike Marie, having established the first scleroderma-based organization in her country while struggling with her own diagnosis wrote, "Thank you Marie Coyle! Your efforts have no boundaries. I can say that because of you, today in Brazil we are launching much needed regional 'chapters' in nine states. You have influenced me to follow your legacy with determination and tenacity!"

Looking back over many years of advocacy and agency building, we gladly celebrate the successes that

Marie brought to bear. Marie's singlemost significant legacy was the establishment of the National Scleroderma Foundation's peer review research program. Because this program is streamlined and diligently monitored, it has determined an incomparable method for focusing directed research that is both quantifiable and ground breaking. For the estimated 300,000 people living with scleroderma in the United States, Marie Coyle's influence stands alone.



Walter and Marie Coyle

Remembering Marie's earliest years in this work, the unflinching support of her husband Walter cannot be overlooked. As a team, they were unstoppable in supporting one another's dreams and they created magic. Although her fervent hope for a cure for scleroderma in her lifetime was perhaps not realized, she was gratified to enjoy the remarkable successes in the laboratories of her friends in the research arena.

In the book that Marie edited, *The Best of the BEACON*, she thanks that she expresses to Walter for his role in supporting her authorship might well be applied to the role that he held in her life. She wrote, "Last, but certainly not least, my deepest affection and appreciation to my husband Walter, without whose forbearance I might never have undertaken or completed this task."

For those living with scleroderma, be assured that Marie never wavered in her dedication to get you to your best possible outcome. Goodbye to Marie Coyle, longtime friend, scleroderma champion and shining beacon for all.



PAINT FOR A CAUSE . . .

Just how many perfect sunsets are there?



Michael Harrison has brought us a successful third party event with a simple idea and a group of enthusiastic participants. His May 19 "Paint For A Cause" party paired willing budding artists with easels, canvas and paint brushes. The outcome is fresh original art, lots of fun and proceeds from the event (and a raffle!) to benefit Scleroderma Foundation New England.

Mike is one of our most enthusiastic supporters and his personal dedication to our cause coupled with his ability to bring people together is a win/win for all of us in this mission driven work. Proceeds from the event (\$550!) will bring support to our mission and continue the momentum in our goal to find a cure for scleroderma. Thank you Mike and all of your friends who joined in this effort!



FROM THE NATIONAL OFFICE . . .



**Attend Capitol Hill Day
September 16-18, 2019
Washington, D.C.**

The Scleroderma Foundation's **Advocacy** program provides you with the opportunity to meet policy makers on Capitol Hill to educate them and to generate awareness about scleroderma-related issues that are important for continued scientific research.

Of critical importance in 2019 is our drive to have scleroderma re-listed as an approved condition eligible for research funding through the **Department of Defense's Peer-Reviewed Medical Research Program.**

Visit: https://www.scleroderma.org/site/SPageServer?pagename=Action_CapitolHillDay&AddIntere st=1181#.XORRa9h7mos

2019 EVENTS

- ✓ **Spaghetti for Scleroderma**
Bello Center, Bryant University
Smithfield, RI
Saturday, February 24, 2019
- ✓ **Team Skippy's Lobster Shoot**
VFW Hall, Hudson, MA
Friday, March 22, 2019
- ✓ **Seventeenth Annual Worcester Stepping Out for a Cure Walk**
Bancroft School, Worcester, MA
Sunday, April 28, 2019
- ✓ **Tenth Annual Maine Stepping Out for a Cure Walk**
Riverbank Park, Westbrook, ME
Saturday, May 18, 2019
- ✓ **Plymouth "Virtual" Walk**
June 1-30, 2019
- ✓ **NCRS/NE Corvette Day**
Larz Anderson Auto Museum
Brookline, MA
Sunday, June 9, 2019
- Strolling for Scleroderma**
Deer Island, Boston, MA
Saturday, June 15, 2019
- Comedy Night**
Venus II, Marshfield, MA
Friday, June 28, 2019
- Golf Classic for a Cure**
Salem Country Club, Peabody, MA
Monday, July 15, 2019
- Fuddruckers Fundraiser**
Fuddruckers, Saugus, MA
Friday, August 16, 2019
- Fernandes Golf Tournament**
Midville Country Club
West Warwick, RI
TBD, 2019
- Fifteenth Annual North Shore Stepping Out for a Cure Walk**
Proctor School, Topsfield, MA
Sunday, September 8, 2019
- Tenth Annual Westfield Stepping Out for a Cure Walk**
Stanley Park, Westfield, MA
Sunday, September 15, 2019
- Fifth Annual Boston Stepping Out for a Cure Walk**
Artesani Park, Boston, MA
Sunday, September 29, 2019

ON THE EDGE OF SEVENTEEN...

The 17th Annual Worcester Walk for a Cure for Scleroderma went off without a hitch. The weather was less than ideal for the 101 walkers but the walk was invigorating - all were rewarded at its conclusion by a banquet spread of hot dogs, burgers and pizza!

We had the usual cast of amazing characters. Rebecca and Anne orchestrated the day. Although absent as she was recovering from surgery, Debbie Magnuson's fingerprint was everywhere! She saw to the details before her hospitalization and then, as usual, assigned her family with all sorts of Walk related chores. To think that it was 17 years ago that Debbie and her son Eric first presented the idea of a Walk for a Cure to a reluctant audience who couldn't visualize success coming from it. Lesson learned!



Volunteer Girl Scouts



painting, games, food prep, water table and general public relations went above expectation. Nancy Velleco, Betty Belevick, Sara and Mike Graves, Martha Pierson, Dave and Eric Magnuson and many others comprised the exemplary volunteer leaders. There was a record number of teams represented: Team Skippy, Patty G's Penguins, Team Susan Porcaro, Team Amy, Team Barbara, Team Bishop, Team Deedy, Team Magnuson, Team Phyllis, Team Robinson.

All counted, we raised \$20,665 and we thank everyone involved in this concerted group effort! For 17 years we have proven that there is an incredible supportive force in the Worcester area – THANK YOU to all who contributed, worked and walked for a cure!



Michelle Monteiro and Anne Sweeney with photograph of founder Marie Coyle.



Happy members of Team Bishop



Eric Magnuson and Mike LaMusta

Tribute was made to Marie Coyle and her long standing loyalty to this walk. She was featured prominently at the registration table. Her death five days before the Walk was sadly ironic given her longtime history with Debbie and Eric, the Walk creators.

Volunteers were everywhere on site this year! Debbie's sister Randi Jacob brought a force of Girl Scouts whose skills at handling t-shirt sales, face

A Special Thank You!



Martha Pierson and her two children, all star volunteers!

Sara and Mike Graves and Martha Pierson and their extended families were our MOST amazing volunteers of the day. They procured food, baked, raised funds, served all attendees and generally oversaw all aspects of our success. We owe them great gratitude for their annual energy and vision.

HARDY MAINERS CREATE A *BIG* SUCCESS!



It started out as a windy day in Westbrook at Riverbank Park, the site of our Tenth Annual Hardy Mainers Walk for a Cure for Scleroderma. Volunteers for the day got the canopies up, registration readied and the raffle table in great shape. Off to a good start!

The day was made STUPENDOUS by the remarkable donations brought to us by Team Heather B. As a group they raised just over \$4,000 in memory of Heather, a record for a single team in Maine. Heidi, Heather's sister, who worked so diligently to bring this team to success noted that as a group they would do "anything to help. My sister would be very proud!", and promising to see us all next year.

We are always so incredibly affected by the generosity and the vibrancy of families, friends and caregivers of those whose lives are changed by diagnosis. Carol Russell, sister of Debbie LeHouillier joined us at the registration table and volunteered through the whole day – her assistance was invaluable. Other family members attended as well and honored Debbie's memory with stories about her. On the raffle table was a beautifully crafted Walnut storage box, donated in Debbie's name by the Thomas Moser Company where she worked for many years.

Sandy Kneeland, whose help we count on every year, showed up early to get ahead on the raffle table and she and her man Kris made

purchasing tickets a breeze for all attending. The raffle raised more than \$400 thanks to Sandy's hard-sell technique!

Sam and Laura Drummond arrived with their beautiful and rambunctious new field dog. Sue Zemla made our day arriving on foot and beaming with that gorgeous smile – her family all with her! We really missed Lori Chason and family – and we never lose sight of the many years of effort that Lori put into building this event. Staff Anne Sweeney and Patty Meany were joined by board member Jeff Daddio and left no detail out. They are the organizers who put extra time and effort into the day – THANK YOU!

It is imperative that we remember all of our generous attending teams: Team Heather B, Team Ambrose, Team Down East, Team Ellsworth Coast Busters, Team Shining Stars and, of course, Team Debbie LeHouillier. We extend our sincere thanks to all of you. And to our single walkers, you are a brave bunch to go it alone – maybe next year we will persuade you to create teams too!

Thanks everyone for an amazing day in beautiful Maine. You are a Hardy Bunch as our walk name suggests, and we look forward to seeing you ever year.



Sandy and Kris, rafflers



Honoring Debbie LeHouillier



Team Heather B

DR. GARLICK SEEKS PARTICIPANTS IN PHASE II RESEARCH EFFORT



Dr. Jonathan Garlick, Professor of Oral Pathology at Tufts Dental School, has become a regular visitor to the offices at SFNE, specifically as a guest speaker for our North Shore Support Group. In an emerging partnership of ideas and hope, Dr. Garlick has enthused eight of our members regarding a Phase II study being conducted from his laboratory at Tufts University School of Dental Medicine. A specific scleroderma research study, this effort will, under the guidance of Dr. Garlick and his lab associates, continue to understand how scleroderma develops. The process involves the diligent collection of blood and skin biopsy samples from individuals whose skin meets specific criteria. Participants must be diagnosed with scleroderma and be over 18 years of age.

Commitment of participants involves two visits to Dr. Garlick's lab. The first visit (which includes blood sampling and skin biopsy) will last approximately 1 ½ - 2 ½ hours. The second visit is a standard of care follow-up appointment that will last approximately 30 minutes.

Phase II Scleroderma Skin Study

Because of recent Phase II funding from the National Institutes of Health, Dr. Garlick will partner with Dr. Michael Whitfield of the Geisel School of Medicine at Dartmouth University and the biotechnology company Celdara to discover how to mass produce scleroderma skin tissue in the lab and make it widely available to the scleroderma research community.

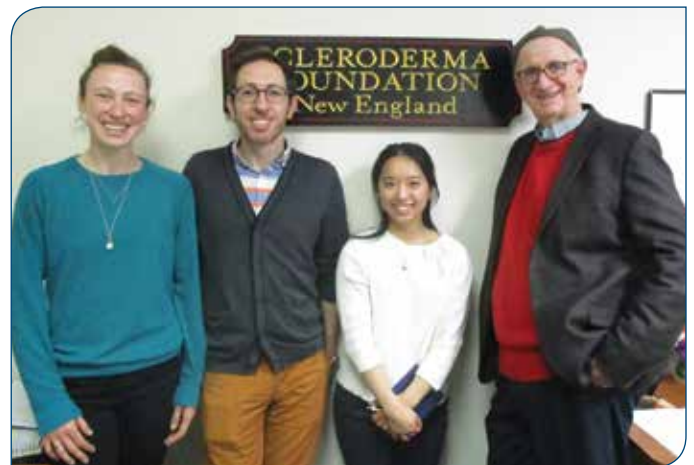
Dr. Garlick demonstrated samples of the skin research results in a discussion with our support group attendees. He was thrilled to be able to point to the samples and say, "Each of these samples is the direct result of your recent biopsy donation to the research. You are responsible for successful research in this early phase!" He demonstrated tissue samples in 24-paks resulting from the successful growth outcomes. They can be sent to pharmaceuticals companies and labs for the testing of new treatments.

Seeking more patients willing to participate and donate skin samples

"We are bringing scleroderma drug screening research into the 21st century" noted Dr. Garlick. For Phase II of the study, he is hoping to recruit 16 scleroderma patients to give blood and skin samples that can be used together. It would require two visits to Boston within a 14 day window of time. Dr. Garlick and his team (Avi Smith, Elena Knight and Irene Lang) gathered several sign-ups at the meeting from SFNE members eager to make their contribution to scleroderma research. As Dr. Garlick has noted before, "Without skin samples from this group, none of this would have ever happened!"

As of this printing, eight members of the North Shore support group have visited the labs and made sample donations. If you are interested in being a part of this research effort, please call **Dr. Garlick at (617) 636-2444**.

[See insert, page 11]



Elena Knight, Avi Smith, Irene Lang, Dr. Garlick



North Shore Support Group members with Dr. Garlick and researchers



MICHAEL WHITFIELD, PHD, NAMED CHAIR OF THE DEPARTMENT OF BIOMEDICAL DATA SCIENCE AT DARTMOUTH'S GEISEL SCHOOL OF MEDICINE

It is an honor to count Dr. Michael Whitfield among the very strong supporters of our mission at Scleroderma Foundation New England. Dr. Whitfield has been named the chair of the Department of Biomedical Data Science at Dartmouth's Geisel School of Medicine. Whitfield, a professor

of biomedical data science (BMDS) and molecular and systems biology, has served as the department's interim chair since November 2017. Congratulations Mike, and our enthusiastic encouragement of your ongoing research to benefit those living with scleroderma!

RESEARCH FUND FOR MARIE COYLE

We are pleased to announce that more than \$10,000 has been raised in memoriam for the Marie Coyle Research Fund. For Marie, research is key to finding a cure for scleroderma. We are grateful to all who generously donated in Marie's memory.

CORBUS PHARMACEUTICALS PARTNERS WITH SFNE

Our friend Lindsey Smith at Corbus Pharmaceuticals has asked us to join the full staff at Corbus to do a panel discussion offering the very real perspective of people living with scleroderma with their researchers and staff, and to reflect Corbus' commitment to Scleroderma Awareness month. This is an honor and an opportunity. Headed up by board president Don Legere we will arrive en force with Roberta Mauriello, Joan Kingsbury, Tricia Legere and Carol Taylor to further research that is considerate of the individual. Hats off to Corbus!



The Mauriellos at the 2018 Everett Health Fair

EVERETT HEALTH FAIR

Our North Shore Support Group leader, Roberta Mauriello, attended the Everett Health Fair on March 26, heightening awareness of scleroderma and providing information to attendees. As always, Fran was with her. Roberta represents the needs of people living with scleroderma at this annual meeting and makes all contact information and brochures available. Roberta continues to be our most active ambassador to the public in the regard of creating pathways to wellness for those afflicted.



The Sky is the Limit in Chicago

July 19-20-21, Chicago, Illinois

The National Patient Education Conference is in Chicago, Illinois this year, where the sky is the limit. Get access to world renowned scleroderma experts, reunite with old friends, and connect with others who have scleroderma.

Visit www.scleroderma.org to register today.

Follow this link to see a video of the 2018 conference: <https://www.youtube.com/watch?v=nCgStqSxRWc&feature=youtu.be>

JUNE IS SCLERODERMA AWARENESS MONTH

June is Scleroderma Awareness month, everywhere, for everyone! This issue of the BEACON will be coming to your doorstep late in the month, but we will have celebrated scleroderma awareness in several ways.

JUNE						
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First, Andrew Boteiri and Johnny Medlin will be hosting a comedy night, "Laugh in the Face of Scleroderma" at Venus II Restaurant in Marshfield on **June 28th**. It may not be too late to get your tickets! Check out the web site for ticket sales at www.scleroderma.org/comedymarshfield.

Plymouth's Walk this year is a month long event celebrating our mission. The "Stepping out Plymouth VIRTUAL Walk for a Cure asks you to choose your own date in June to walk and raise funds for a Cure. Even if you receive this notice late

in June, you can STILL WALK FOR US! Go to www.Scleroderma.org/steppingoutplymouth to register. Take pictures, post on Facebook and support our mission in the process.

We will have already had our walk for a cure, Strolling for Scleroderma, on Deer Island on June 15th. Hosted by Maria Bartoszewicki and her extended family, this was the third annual. The three mile walk around Deer Island is a rare treat with magnificent views out to the harbor Islands. Please join us there next year! To donate to this walk, go to www.scleroderma.org/strollingforscleroderma.

As they do every year, The National Corvette Restorers Society New England hosts its annual event at the Lars Andersen Auto Museum, sending proceeds to us at SFNE. We are so grateful to them for this annual support. Their loyalty to our mission goes back nearly 15 years! Thank you to Jean and Don Chapman for representing SFNE on that day!

Celebrate Scleroderma Awareness Month in your own way – we all share the goal to find a cause and a cure for scleroderma in our lifetime.



SFNE SUPPORT GROUPS

<p style="text-align: center; color: #c00000;">Massachusetts</p> <p style="text-align: center;">Boston Support Group</p> <p>Boston University Medical Center Shapiro Building, 1st Floor conf. room Meets the 3rd Sunday of each month, 2pm Group Leader: Carol Taylor 774-233-2174, carolvtaylor22@comcast.net</p> <p>Fall River/Bristol County Support Group</p> <p>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</p> <p>North Shore Support Group (Topsfield)</p> <p>Meets the 2nd Wednesday of each month SFNE Office, Topsfield Co-Leaders: Roberta Mauriello 781-324-7426 Joan Kingsbury joan.kingsbury@comcast.net</p> <p>Worcester Area Support Group</p> <p>Meets once a month on Sunday - call for date Group Leader: Nancy Velleco 508-869-2997</p>	<p style="text-align: center; color: #c00000;">New Hampshire</p> <p style="text-align: center;">Granite State Support Group (Hampstead)</p> <p>Meets the last Saturday of each month Co-Leaders: Carla King, 978-884-4866 carla.king@comcast.net Jean Chapman, 603-465-7647 chappybear@charter.net</p> <p style="text-align: center;">Central NH Support Group (Bow)</p> <p>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</p> <p style="text-align: center; color: #c00000;">Vermont</p> <p style="text-align: center;">Burlington Vermont Support Group (Williston/South Burlington)</p> <p>Meets each month on Wednesday or Saturday Group Leader: Blythe Leonard 802-324-4826, blythe.leonard62@gmail.com</p> <p style="text-align: center;">Brattleboro Area Support Group</p> <p>Meets the 2nd Wednesday of each month Brattleboro Memorial Hospital, 6:00 - 7:30pm Group Leader: Ilene Wax 802-464-5847, ilenewax@gmail.com</p>	<p style="text-align: center; color: #c00000;">Maine</p> <p style="text-align: center;">Maine Support Group</p> <p>Meets the 3rd Wednesday of each month, 1pm Scarborough Campus of Maine Health Group Leader: Sandy Lunner 207-420-3337 slunner@aol.com</p> <p style="text-align: center;">South Berwick Support Group</p> <p>Meets the 1st Tuesday of each month Contact the SFNE office at 978-887-0658 or sclerodermainfo@sfnewengland.org for more information.</p> <p style="text-align: center; color: #c00000;">Online</p> <p style="text-align: center;">ScleroMen Support Group</p> <p>Facebook Group Co-Leaders: Andrew Botieri Lee Korotzer ScleroMen@scleroderma.org</p> <p>Also check out the Scleroderma Foundation page on Inspire.com for online support.</p>
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TUFTS UNIVERSITY SCHOOL OF DENTAL MEDICINE RESEARCH STUDY SEEKING VOLUNTEERS

The Research Administration Department of Tufts University School of Dental Medicine is conducting research regarding scleroderma. This study will collect blood samples and a skin biopsy sample that will be used for laboratory studies in the hopes of providing an improved understanding of how scleroderma develops.

We are seeking volunteers who:

- Have been diagnosed with scleroderma
- Are 18 years of age or older

We are also seeking volunteers without scleroderma who:

- Do not have a previous diagnosis of connective tissue disease
- Are 18 years of age or older

There are two visits.

The first visit (which includes the blood sampling and skin biopsy) will last approximately 1 ½ - 2 ½ hours.

The second visit is a standard of care follow-up appointment that will last approximately 30 minutes.

- You will receive a \$75 Target gift card for participating in this study.

Please contact Principal Investigator Dr. Jonathan Garlick at (617) 636-2444 if you have any questions, or think you may qualify to participate.



LAUGH IN THE FACE OF SCLERODERMA COMEDY NIGHT

June 28

At the Venus II Restaurant, Marshfield

Featuring:

Christine Hurley and friends

There is still time to register!

\$40 ticket

Raffle and Event Proceeds to benefit SFNE

Go to: Scleroderma.org/comedymarshfield

See you there!!



SCLERODERMA FOUNDATION
NEW ENGLAND

If You Will ♦ ♦ ♦

Scleroderma Foundation New England's office directives now include a Planned Giving Initiative.

By simply naming SFNE as a beneficiary in a will, designating SFNE on a life insurance policy or setting up a gift annuity or trust, you can continue to make the difference for people living with scleroderma and/or the research effort to find a cure for years to come. Contact Jack Armitage: 978-887-0658



Yes, I'd like more information on how to include Scleroderma Foundation New England in my will.

Name (please print): _____

Address: _____

City, State, Zip: _____

Phone: _____

Email: _____

- Please contact me
- SFNE is already included in my will, I will send the language
- Enclosed is a gift of \$ _____



SUPPORT ★ EDUCATION ★ RESEARCH

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

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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).

We need your feedback . . .



The BEACON

We are determining a new direction in the delivery of The BEACON and would love to have your input. Currently, our distribution is about 1,200 physical copies and we have come to realize that there are those of you who would prefer to receive your quarterly edition in digital format. In the first effort to determine relative numbers, I ask that you send me a quick email so that I can build a discussion about how to proceed. We intend to always have printed and mailed editions – that will not change. But we want to accommodate those who prefer to read an on-line version and we might even save a tree in the process! Drop me a quick line at: jarmitage@sfnewengland.org

PRODUCTS THAT BENEFIT



OXO Good Grips Utensils Kitchen Fork, Spoons & Knife



Good Grips Utensils have a soft cushion grip that keeps the utensil in the hand - even when wet! The built-up handles are made of a soft rubber-like material, with flexible ribbing that's comfortable to hold and adapts to any grip.

Choices for these utensils include a Good Grips serrated rocker knife, fork, teaspoon, tablespoon and youth spoon. Also a flexible spoon for adaptation to your needs!

Here's a link to a site that will show you all sorts of time saving and easy assist devices:
<https://www.activeforever.com/>