Boston Walk September 30
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NEW ENGLAND
The BEACON

A Publication of Scleroderma Foundation New England
Summer 2018

THE 2018 NATIONAL PATIENT EDUCATION CONFERENCE

By: Rebecca Dube

This year's National Patient Education Conference was held July 27-29 at the Loew's Hotel in Philadelphia, PA. There were over 650 attendees from around the country and the world, a record amount for this event. People from as far away as Denmark came to be a part of the gathered scleroderma community and learn new information about treatments, research, and coping with scleroderma.

Bev Olean, Sandy Lunner, Lori Chason, Deborah Young and Ilene Wax gather at the National Patient Education Conference in Philadelphia.

"I loved connecting with old friends and meeting new ones," noted Vermont attendee Ilene Wax. "I loved the positivity that exudes throughout the community."

The opening keynote speaker was Carol Feghali-Bostwick, Ph.D., a long-time champion of scleroderma research and a member of the Scleroderma Foundation's board of directors. Dr. Feghali-Bostwick conducts research out of the Medical University of South Carolina. She was first aided on her research journey by a small grant awarded by the Scleroderma Foundation, and has been a part of both the national organization and a contributor to SFNE's Patient Education Seminar. She has a presentation style that brings fun and understanding to complex research topics. For her keynote, Carol reviewed what had been accomplished in the scleroderma field in the past twenty years, and the many puzzle pieces

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PATIENT INSPIRED INVENTION AND INNOVATION

By: Jack Armitage

HARVARD CATALYST
THE HARVARD CLINICAL AND TRANSLATIONAL SCIENCE CENTER

Early in 2017, I received a request from Dr. Eva Guinan, Director of the Translational Innovator program, Harvard Catalyst/The Harvard Clinical and Translational Science Center, asking if I would consider joining her and her highly creative team of scientists and administrators at The Harvard Catalyst's Program for a working meeting on *patient-driven* innovation. Initially it seemed to be a very heady invitation and surely out of the realm of what we do here at SFNE. In hindsight, I am glad that I followed my "gut" and responded with an enthusiastic *yes*.

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IN THIS ISSUE

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

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Rebecca Dube, Editor

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www.scleroderma.org/newengland

__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.

IF YOU WILL...

By: Jack Armitage

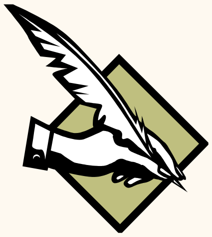
We have a long and notable history with Joe Hutchins, a man who becomes more and more heroic to me over time. In the 1970s, Joe returned as an honorably discharged soldier in the U.S. Navy and started his family. His unexpected diagnosis with scleroderma and subsequent onset of debilitating symptoms resulted in his turning reluctantly to cannabis to stay alive.

It worked, alleviating his symptoms and allowing him to withdraw from the prescriptions that had been provided him through the Veterans Administration. Still, he was arrested for growing plants and had to defend himself (with Marie Coyle's help) in a court of law. He was acquitted and the subsequent legal action resulted in what is now known as the Joe Hutchins Act – a liberalizing of the marijuana laws in MA for medicinal use (*General Laws, Part 1, Title xv, Chapter 94C, Section 34*). We can all thank Joe for his early influence in the conversation about cannabis therapies in a medicinal capacity.

Joe has surprised us with an initiating check to endow the first medicinal cannabis research fund for New England constituents living with scleroderma. We are very proud to have been selected for this honor. There was a time when Joe thought that his life would end in his 30s, when he was a young father. Now 73, he talks about the length of his life with the satisfaction of a man who has been granted a normal trajectory. Joe has committed to further this endowment with a significant gift at the end of his life. Please consider helping us to grow this promising research fund.

We know too little about medicinal cannabis application in 2018, but what is clear is that the trend towards research and use of this naturally occurring plant is showing significant promise. Let's work together towards advanced research in this emerging realm of treatment. And let's work together to bring the Joe Hutchins Medicinal Cannabis Research Fund to significance.

* * *



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.*

FROM THE DIRECTOR'S DESK

By: Jack Armitage

Vision is what determines the success of nearly any undertaking. Twenty years ago, when the founders of the national Scleroderma Foundation planted the seeds of an idea for an organization that would serve the support, education and research needs of an emerging population, it did so with a sense of outcome. Today, we are a confident and effective collaborative of chapters and affiliates being led by the national office which is justifiably proud to celebrate a significant 20-year anniversary. Congratulations to the founders and staff of this wonderful organization. Your arrival at this juncture is a notable accomplishment. We are very proud at the New England office to have trained up under the watchful eye and diligent guidance of Marie Coyle, who seems, from our vantage, to be the common thread in this organizational success.

We are all recently returned from the National Patient Education Conference held this year in Philadelphia. Record numbers of attendees and breakout sessions reflected the successes of 20 years of such conferences. The New England office was well represented with more than 15 attendees from our board of directors, staff and constituency and caregivers.

In the vein of vision planning and long-term goal setting, we are so proud and excited about our collaboration with Harvard Catalyst / The Harvard Clinical and Translational Science Center. Four productive meetings of SFNE staff and patients with this visionary group have brought forth measurable ongoing assistance for our constituents and promise continued collaboration. Please take time to read about this shared effort in this issue of *The BEACON*.

The Sixteenth Annual Golf Classic for a Cure is behind us with significant success again this year, raising gross revenues of $166,000! The Golf Classic is *the* major event of our financial year and is supported by a very generous sponsoring triad in Bruce Gordon, David Rosenberg and the Scleroderma Foundation Central Fund. This event generates almost half of our annual revenues and allows us to continue to be generous with our annual commitment to research for a cure for scleroderma.

We are uniquely privileged this year by our friendship with Joe Hutchins whose compelling story appeared in our Winter 2017 edition. The article can be read by visiting the SFNE website and a quick search in *The BEACON* archives. Joe has recently seeded a new research fund specifically for medicinal cannabis research in New England to benefit the constituency served out of this office. We energetically seek future funding and endowment of this fund, encouraging research in all areas of potential treatment for this disease for which there is neither known cause nor cure. Great thanks to Joe for his vision and generosity.

Scleroderma Foundation New England stays energetic, active, invested in our community and vibrant with plans going forward. We are indebted to our Support Group Leaders for their belief in our mission and their constancy. With monthly meetings and peer counsel, we feel very secure that we are reaching successfully into the community of scleroderma diagnosed individuals in our service region.

We are in the home stretch of our 2018 fund raising season with three major events remaining and two third party fundraisers yet to go. We are very grateful to our third-party hosts for their singular efforts to raise funds to support our mission. They continue to fly under the radar and get little publicity for their efforts. We wish Ray Fernandez, the Mauriellos and Jeanne Oliveira our best for their sustained energies for bringing us furthered mission success through third party event planning.

Overall, we continue to bring this organization forward with increased energy and professionalism. Rebecca and Anne are creating magic daily here in the office. Our board of directors is invested vibrantly as a team of skilled and dedicated leaders. Our constituency is as invested as any of us on staff and board and we would not see the resulting successes without their belief in us and their commitment to our successes. In 2018, we are witnessing research and collaborative partnering as never before. All of this keeps us on a very steady course. Thanks everyone!

* * *

> ***"My motto was always to keep swinging. Whether I was in a slump or feeling badly or having trouble off the field, the only thing to do was keep swinging."***
>
> ***~ Hank Aaron***

NATIONAL PATIENT EDUCATION CONFERENCE

(continued from page 1)

Dr. Carol Feghali-Bostwick was the opening keynote speaker.

that needed to be put together in order to work towards a cure. She moved on to current efforts in the research field and the vision and hopes for the future.

Following the keynote speaker, sessions were broken up into many topics, sometimes too many to see at one time! Topics ranged from Musculoskeletal Manifestations of Systemic Sclerosis to Applying for Social Security Disability, and more. There was a strong yoga component of both movement and breathing that was offered throughout the conference.

Several of the information workshops on various topics were filmed on-site, and will be available for viewing on the Scleroderma Foundation's YouTube page later in the fall (*see page 5 for full list*). Scleroderma Foundation New England (SFNE) has Powerpoint handouts for some of the sessions offered, and can obtain others from the national office if you would like to receive them. Just contact us at *sclerodermainfo@sfnewengland.org* or call 978-887-0658 to let us know which you would like sent to you.

A strong and growing aspect to the National Conference is the Kids and Teens Program. While adults attended the main workshop schedule Saturday and Sunday, Kids and teens (and their parents) could attend their own programming in a separate area. This program included workshops in yoga for kids, Intersections of Health Care and Education for Children and Young People with Scleroderma, an overview of what to do after your child has been diagnosed, and more. The kids themselves could take part in a workshop in cupcake decorating or a field trip to the Philadelphia Zoo. In this gathering they could be in a community that understood their challenges, share experiences, and just be a part of the group.

Members of the Kids and Teens Program also put together the "Big Reveal," which showcased where next year's conference would be held – Chicago! Start your planning now to attend this amazing conference if you can.

The closing keynote was titled "Voices of Patient Advocates," and included a panel of members from the Advocacy Committee. These members shared what motivated them to raise awareness about living with scleroderma. One scleroderma advocate noted that "the voices of patients and family members are crucial elements in our advocacy work to advance important legislation to benefit those affected by scleroderma."

Some attendees also wore large pins that said "Ask Me About Bill." This is in reference to the H.R. 4638 bill *National Commission on Scleroderma and Fibrotic Diseases Act of 2017*. If you would like to be a scleroderma advocate and send a letter to your local congress person, contact us at *sclerodermainfo@sfnewengland* and we will send you a letter you can fill out and send to ask for support for scleroderma funding.

Overall, the National Patient Education Conference was an amazing gathering of caregivers, medical professionals, speakers, researchers, pharmaceutical companies (in the fantastic Exhibit Hall!) and people living with scleroderma in an event to share information, innovations, and most of all, hope.

* * *

National Conference volunteer and SFNE staffer Anne Sweeney (right) smiles with Tennessee board president April Simkins.

WANT TO SEE MORE?

The following National Patient Conference workshops were filmed on-site and will be available on the Scleroderma Foundation YouTube channel in the fall:

- **Pulmonary Arterial Hypertension in Systemic Sclerosis in the Current Era -** Lori Chung, M.D., M.S.
- **Localized Scleroderma** - Lisa Pappas-Taffer, M.D.
- **Esclerodermia: Conceptos Fundamentales Para Entender la Enfermedad (Espanol)** - Fabian Mendoza, M.D.
- **Health Care Maintenance and Systemic Sclerosis** - Tracy Frech, M.D., M.S.
- **Taking Care of Your Hands and Face: The Importance of Stretches, Assistive Devices and Protection** - Janet Poole, Ph.D., O.T.R./L., S.W.C.
- **How Are New Treatments Discovered? -** Lee Shapiro, M.D.
- **Your Child Has Been Diagnosed with Scleroderma. Now What?** - Kate Silver, M.D., M.S.C.R.
- **Medical Information Toolkit: How to Find Reliable Medical Information on the Internet** - Jessica Farrell, Pharm.D.
- **Pain Management: How to Empower Yourself Without Reliance on Opioids, Part 1** - JoAnna Harper, Pharm.D., R.Ph.
- **Scleroderma FAQ** - Maureen Mayes, M.D., M.P.H.
- **Pain Management: How to Empower Yourself Without Reliance on Opioids, Part 2** - Ginny Maril, Ph.D.
- **Sleep and Chronic Disease -** Sabra Abbott, M.D., Ph.D.
- **Understanding the Link Between Scleroderma and Cancer** - Laura Hummers, M.D.

Thank you to the Scleroderma Foundation for putting the videos together!

LAB TOURS

Sporting matching hats, Don Legere (right) tours Garlick Labs with Dr. Jonathan Garlick to learn more about his research with skin sampling.

Joan Kingsbury (right) and her husband R.C. (left) tour Garlick Labs with Dr. Jonathan Garlick.

SCLERO-MEN COORDINATORS WIN AWARD AT NATIONAL CONFERENCE

Cos Mallozzi, Andrew Botieri, Mary Beth Bobik Kadylak and Lee Korotzer

Andrew Botieri of Plymouth, MA and Lee Korotzer, of FL were awarded a plaque at the National Conference in Philadelphia for their efforts to resurrect and drive the new Sclero-Men Facebook page for men only. This page allows men to chat/discuss about their unique issues. The group now has over 120 members from all over the world. If you are a male are living with scleroderma and would like to join the Sclero-Men group, please go to: www.facebook.com/groups/1238203139547638/.

* * *

STEPPING OUT TO CURE SCLERODERMA

THE TENTH ANNUAL “WALK, TALK AND ROCK” PLYMOUTH WALK

What better way to enjoy a beautiful summer day at the beach than to participate in the Tenth Annual Plymouth Stepping Out to Cure Scleroderma Walk? Over 132 walkers joined SFNE at Nelson Park in Plymouth, MA for a fun morning that included clowns, face painting, balloons, bag toss games, fresh fruit and an amazing raffle. They were really there, however, to show their support for family and loved ones living with scleroderma by raising funds for the many programs and research supported by Scleroderma Foundation New England (SFNE).

Andrew Botieri and Johnny Medlin led the way by coordinating many volunteers into a smooth event. Members of the Medlin family volunteered in multiple areas, including promoting raffle ticket sales, setting out walk signs, and leading a stretch session before the walk. Courtney Medlin was a star at the food tent just a few short weeks after becoming a new mom! Sue Norton, Matt Dube and Jean Berg helped with registration and t-shirt tasks while Tracy Cavallo and more members of the Medlin family helped put together the exciting raffle. Maureen, Twinkles and the clown crew provided face painting and balloons in the Kids’ Zone.

This year’s walk was held in memory of long-time walk attendees Christine T. Maroney and Norie Leonard, and raised $18,729. Top fundraising teams included Team Medlin, Tina’s Warriors, Team Alyssa, Botieri’s Brigade, Team Rich Gilson, Kimme’s Crew, Fans of Jan, Meme’s Walkers, Team Paul Trites and more.

Johnny’s uncle selected SFNE as the recipient charity at the 12th Annual Summer Classic Baggo Tournament on June 16 in Pembroke, MA and donated the funds from that event to the Plymouth Walk. We thank him for his creativity and contribution!

We’d like to thank everyone who walked, donated, raised funds, or volunteered for you amazing contributions to this event. Ready for a run next year?

* * *

See an expanded photo album of the Plymouth Walk on our Facebook page *sfnewengland*!

Team Meme’s Walkers

Team Medlin

Johnny and Courtney Medlin at the food tent

STROLL FOR SCLERODERMA

It's been a hot summer, so walkers were more than happy to catch a few sea breezes coming in off the Boston Harbor at Deer Island. Sporting the new sneaker-graphic, yellow New England t-shirts, participants gathered in the History Center of the Deer Island Waste Water Treatment Plant to lend their support to SFNE programs and research funding.

An odd place to have a walk? It may seem so until you see the beautiful paved walkways that circle the island and look out on the harbor. The History Center served as home base where walk coordinator Maria Bartoszewicki, along with her husband Jacek (and their brand new baby boy), family members and volunteers registered attending walkers, provided refreshments and offered raffle opportunities.

Music filled the air throughout the day as a portable amp was rolled through the entire walk! Those sea breezes kept participants energized to the final raffle call back at home base. Dr. Jonathan Garlick and members of his lab team joined the walkers, along with board members Chris Simms, Jane Ladas, Andrea Mahoney and Don Legere.

Over $5,300 dollars were raised, including a matching grant from Modern Woodmen Fraternal Financial and a $300 donation from software innovator AVAAP. Sincere thanks go out to Maria and Jacek, Don and Cathy, their extended family, Modern Woodmen and AVAAP, along with all of the donors and participants who made this beautiful event possible.

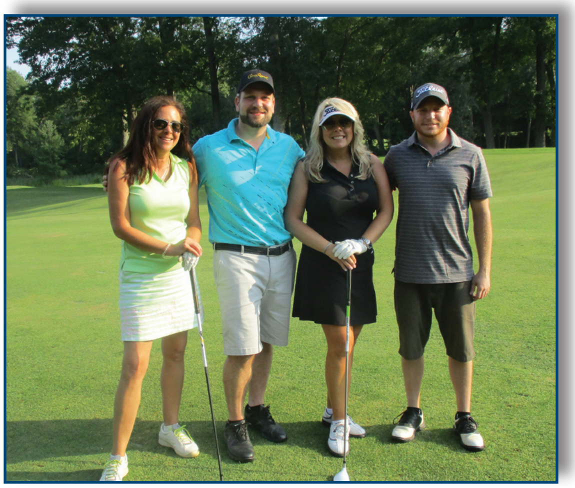
* * *

SFNE ANNUAL GOLF CLASSIC - 16 YEARS AND GOING STRONG!

For sixteen years, we have had the great fortune of being supported financially by committed sponsors at our major annual event, the SFNE Golf Classic. What this annual sponsorship brings, in addition to significant seed money, is the participation of players from diverse companies and families. As such, it is a big field day for some very skilled golfers and an opportunity for them to support us at about 40% of our total annual budget. Their generosity and goodwill allow us to bring significant funding to the national research effort. We offer our heartfelt gratitude to them for this loyalty.

Most notably, our measurable success is accountable to Columbia Construction Company and Prime Motor Group, as well as from the Scleroderma Foundation Central Fund. These major sponsors have supported us for all of the sixteen years of our hosting the Golf Classic. As of this year, the resulting sixteen year gross revenues *exceeded $2 million dollars*!

Our annual Golf Classic for a Cure for Scleroderma is no small feat. It is the single most important event of our year and its success is unparalleled. Because of that, our constituency is well cared for and research efforts for a cure in our lifetime are given every chance to be realized.



Prime Motor Group golfers Lori Talanian, Joe Sacchetti, Desiree Lev and Noah Stern

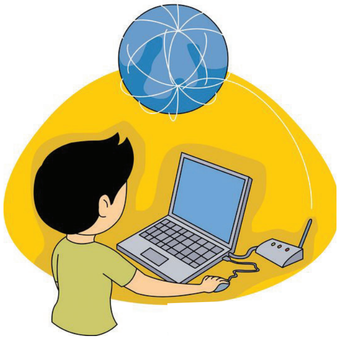
Thank you to all participants in this major annual event.

* * *

EVALUATING HEALTH INFORMATION ON THE INTERNET

By: Rebecca Dube

Many people, upon receiving a scleroderma diagnosis, are told by their doctors to stay away from the internet for information. But in this interconnected world of the Information Age, the internet fast becomes the go-to place for research about a condition. So how can you distill the valuable information from false, misleading and sometimes scary claims? The National Institute of Health* offers some key points in evaluating health information on the internet:



- Any website should make it easy for you to learn who is responsible for the site and its information (and you should look).
- If the person or organization in charge of the website did not write the material, the website should clearly identify the original source of the information.
- Health-related websites should give information about the medical credentials of the people who have prepared or reviewed the material on the site.
- Any website that asks you for personal information should explain exactly what the site will and will not do with that information.

All of these “shoulds” are the responsibility of the website owner, but it is the consumer’s responsibility to look for these credentials and supports when reviewing health information. Frustrated by unsubstantiated claims in the cancer community, and inspired by the general library guidelines on evaluating web-based resources, Dr. Skyler Johnson of the Yale School of Medicine created his version of the CRAAP test (*see below for link*) for evaluating cancer claims. However this test could be used for evaluating online data on most health conditions.

The CRAP test (vs. the library’s CRAAP test**) consists of asking yourself a series of questions when researching online:

☐ C – Conspiracies or Claims too good to be true

- Does the person or website elicit conspiracies of ineffective treatments, cure suppression or natural cures?
- Are the claims made too good to be true, like “no side effects” or “Miracle Cure?”

☐ R – Requests for Money

- Are products for sale like herbal/botanical supplements, vitamins, consultations, books or DVDs?

☐ A – Anecdotes

- Are the stories unverifiable in another reputable source?
- Is the information supported by medical literature?

☐ P – Publisher

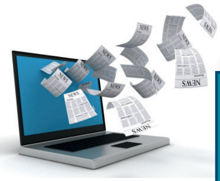
- Are the author’s medical credentials hidden or difficult to verify? If so, is the site anything other than an .edu, .gov, or Scleroderma Center/Hospital website?

Put a 1 next to each letter as you evaluate a website. If your total score is zero, the site would be acceptable, although it is always best to remain vigilant. A score of 1 would make you even more careful, and a score of 2 or above might be qualified as misinformation.

Of course it is up to each individual to decide whether he or she wants to believe a claim or not, but knowledge of the true source and viability of a claim can help inform those decisions. Always discuss any health decisions with your health care practitioner and carefully consider the source of any information you find on the internet. (They sell Golden Gate bridges there as well!)

*https://ods.od.nih.gov/Health_Information?How_To_Evaluate_Health_Information_on_the_Internet_Questions_and_Answers.aspx.;**www.libguides.library.neat.edu. Dr. Skyler Johnson’s site is www.canceranswers.com/blank-1/2017/10/27/The-Cancer-Claims-CRAPTest.

NEWS BYTES



MONTAUP CLUB CHARITY DAY GOLF TOURNAMENT

Brenda Pomprowicz, Donna Bernier and Jeanne Oliveira of the Fall River/ Bristol County support group volunteer at the Montaup Country Club Charity Day Golf Tournament. Volunteers not pictured are: Jean Souza, Joan Smith, and Elise LaChance. See full story on page 10.

FUDDRUCKERS FUNDRAISER

Joan Kingsbury and Roberta Mauriello joined other members of the North Shore Support Group, the Mariello extended family, friends and more for a delicious meal and raffle at Fuddruckers in Saugus to raise funds for SFNE. With the percentage from Fuddruckers included, the event raised $998.60. Thank you to everyone who helped and participated!

OVER 2 MILLION!

In its sixteen-year history, the Annual SFNE Golf Classic has brought in gross revenues of over 2 million dollars to underwrite SFNE programs of support, education and ongoing research funding!

* * *

JOIN US AT THE BOSTON WALK

Join SFNE on Sunday, September 30 for the fourth annual Boston Stepping Out to Cure Scleroderma Walk at Artesani Park in Brighton, MA. The walk curves right along the Charles River, and is accented by the changing leaves of early autumn.

The annual walk, coordinated by Carol Taylor and the Boston support group along with members of Marching for Maggie, will include refreshments, face painting, balloon animals, a large raffle, and more.

Two of our on-site sponsors will be Corbus Pharmaceuticals and Reata Pharmaceuticals. Each will be hosting a table in our medical tent, so stop by and see what they have to offer.

The street team from WROR radio (105.7 FM), along with radio personality LBF (Lauren Beckham Falcone) will be on site providing music, giveaways and commentary.

We have a great variety of teams at the event, which is being held in memory of Christine T. Maroney. Please join us and show your support for the many programs and research funding support of Scleroderma Foundation New England. Meet you in Boston!

* * *

2018 EVENTS

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

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

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

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

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

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

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

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

☑ **Fuddruckers Fundraiser**
Fuddruckers, Saugus, MA
Friday, August 17, 2018

Lynda Fernandes Golf Tournament
Midville Country Club
West Warwick, RI
Saturday, September 1, 2018

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

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

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

SHOWING THEIR SUPPORT

We are always amazed by the incredible support offered by our support group leaders all year throughout New England and beyond. These leaders not only offer their time and effort to the group, they often volunteer for local events to spread awareness of scleroderma and raise funds. This summer, support group leaders Don and Jean Chapman took part in Corvette Day in Brookline, MA while Fall River/Bristol County support group leader Donna Bernier and group members volunteered at the Montaup Charity Tournament in Portsmouth, RI.

CORVETTE DAY

Jean Chapman at Corvette Day

Once again support group leaders Don and Jean Chapman provided a table of information on scleroderma to attendees of Corvette Day at the Larz Anderson Auto Museum in Brookline, MA. For $20 attendees received access to the museum as well as the opportunity to view a collection of Corvettes presented by the New England Chapter of National Corvette Restorers Society (NCRS).

NCRS/NE has been an ongoing supporter of SFNE, with donations of the day's event supplemented annually with a $500 donation from the New England Chapter itself. This year's event with match is expected to be $862.00. Thank you to NCRS/NE, Corvette Event coordinator Glenda Fischer (who is, sadly for us, retiring) and especially our table hosts Don and Jean!

MONTAUP CHARITY DAY

The 7th Annual Montaup Charity Day was held on Sunday, July 29 at Montaup Country Club. The club's mission is to give back to its local community and increase awareness of the real challenges some people face. Several years ago Fall River/Bristol County support group member Jeanne Oliveira asked the club to include Scleroderma Foundation New England as one of the over 25 charities that receive proceeds from this event. They agreed and we have been a part of Charity Day since.

Members of the Fall River/Bristol County group spend the day helping out with the very busy logistics of a double shotgun golf day and later in the year we receive a donation from the club. Last year we received $1,500! There will be an awards ceremony on September 26 at the Montaup clubhouse where the Fall River/Bristol County group will accept this year's donation.

SFNE SUPPORT GROUPS

Massachusetts

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

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

North Shore Support Group (Topsfield)
Meets the 2nd Wednesday of each month
SFNE Office, Topsfield
Co-Leaders: Roberta Mauriello
781-324-7426
Joan Kingsbury
joan.kingsbury@comcast.net

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

New Hampshire

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

Central NH Support Group (Bow)
Meets the 1st Wednesday of each month
Baker Free Library, 10 am - 12 pm
Co-Leaders: Don & Cathy Legere
603-566-3145, donlegere@comcast.net

Vermont

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

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

Maine

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

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

Online

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

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

PATIENT INSPIRED INVENTION AND INNOVATION

continued from page 1

HARVARD CATALYST
THE HARVARD CLINICAL
AND TRANSLATIONAL
SCIENCE CENTER

If we cannot expand our reach, our horizons and our risk-taking for our constituency, we risk falling short in our mission. After all, we are committed to the support of our patients, to educate the community at large, and to enthuse research for a cure in our lifetime. This, it seemed, was an invitation to accomplish all three.

SFNE Board President Don Legere and I travelled to the event, completely unsure of our place in a Harvard Catalyst-driven initiative. And still, when it came time to speak, it was clear that we had a message and an imperative to deliver it with passion and commitment. Resulting, we were selected from among the other presenters to become the lead patient-based organization in a drive to foster co-invention between patients and their communities, and groups of researchers to build actual devices and innovations to make life better, easier and exciting for our constituents.

In April 2018, Dr. Guinan and Gary Gray, Director of Technology & Innovation at Harvard Catalyst, kindly agreed to attend our biennial 2018 Patient Education Seminar to ask our attendees to join them and us in this exploratory process. Their passion was palpable. More important, their commitment to those living with scleroderma is genuine and loaded with stated goals to follow through. As a result, they convened a daylong conference which was billed as “Maximizing the Value of Patient Driven Innovations and Inventions.”

For the first time in my memory, *patients were being invited to be the primary driving force.* It felt as if this had been a long time coming. So, the launch of the Harvard Catalyst Patient Invention Initiative at the iLab at the Harvard Business School became a reality on Friday, June 29.

Attending were nearly fifty enthusiastic participants including SFNE constituents and area scientists and doctors from Spaulding Rehabilitation hospital, The University of Massachusetts, Massachusetts General Hospital, Massachusetts Institute of Technology, Tufts Medical Center, and Harvard Medical School. In particular, José Gomez-Marquez, Director of the Little Devices Lab at MIT, compelled many of the participating patients to confidently step up to the conversation and describe their specific needs in detail. The resulting discussions were compelling. Notes were taken energetically and inquisitiveness followed. It was a meeting of passionate people in an atmosphere of resolution.

Carol Taylor, Support Group Leader for the Boston area observed, “I love the whole idea of patients, researchers and doctors working together. This first meeting produced a lot of shared enthusiasm about scleroderma. Hearing from patients about limiting aspects that have hampered their daily functioning and then to witness those challenges being resolved through invention was pretty remarkable.”

On August 16, with very specific goals in mind, ten of us travelled to MIT’s Little Devices Lab to work directly with inventors and scientists in José’s program. Eva and Gary guided us into this somewhat intimidating environment as we hesitantly presented our ideas for consideration – from well developed ideas or even existing tools and inventions that needed modification and further innovation, to concepts that required actual invention. José and his team quickly took the ideas and began to literally MAKE the devices that we were requesting. They were inclusive of (but not limited to): finger sensors for technology otherwise impossible for scleroderma-affected fingers; a shower wand that would reach hard-to-reach places including a flexible handle and a rotating sponge; a “grabber” to assist people with compromised dexterity retrieve their credit cards quickly from ATM slots; and an effort to address a complex design to build a stair-climbing crate to transport documents otherwise too heavy for the carrier.

Doreen Pinault and Dawn Costa each hold up a user-friendly conductive stylus.

We left with prototypes to use and to experiment with. Our next meeting will be to take these prototypes, incorporate the suggested improvements and see them morph into real, usable products that

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PATIENT INSPIRED INVENTION AND INNOVATION

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benefit. Thanks to José, Nik and the team of inventors at the Little Devices Lab, we left feeling empowered, included, and full of hope.

We are very proud of this emerging alliance with so many creative and invested people in our service region. We will continue to report on the progress of this patient-driven inventions track. It is our goal to share the outcome with the SFNE scleroderma constituency, the national office of the Scleroderma Foundation and any potential contributors to the invention process. We invite you to join us no matter what the level of your diagnosis, your geographic location or your ideas regarding increasing the ease of your challenges. Results are measurable and your input is what will make this effort unfold optimally. If you submit innovative and inventive ideas, be assured that your voice will add to the outcome. To join us in this collaboration, contact Anne Sweeney (*asweeney@sfnewengland.org*) or me (*jarmitage@sfnewengland.org*) at the New England office.

Lukas Kompatscher and Jean Chapman show off a credit card grabber

PUZZLE ANSWER

This was a tough one! We did not receive a winning entry for this puzzle. Were you close? See below for the final answer:

SOLITAIRE JOTTO

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

Secret Word: **MOUSE**

We would like to thank you for all your entries and participation in BEACON puzzles over the years. We will be retiring the puzzle to make room for more informative articles and Products That Benefit on this page in the future.

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).