NEW ENGLAND

The BEACON

A Publication of Scleroderma Foundation New England

Winter 2017

SFNE GOES INTERNATIONAL!

Villson Viscardi, Jack Armitage, and Juliana Viscardi

SFNE recently welcomed international visitors when Juliana Viscardi and her husband Villson visited to share their story and gather information on scleroderma and SFNE's programs to bring back to her homeland of Brazil.

Juliana had lived for many years in America and currently lives on Santa Catarina island in southern Brazil, where there is very little information or support available for those living with scleroderma. She would like to change that by becoming a source for information, filtering data from America and translating it into Portuguese.

At our meeting we provided her with brochures, newsletters, links to information and videos, and just generally listened to her story and her goals. It was such an enriching experience to be able to provide this information to someone who so strongly needed it and wanted to share it with others. To quote Juliana, "Thank you for giving me the tools to replicate everything I've learned. More importantly, thanks for making me feel understood, that I belonged. I had a voice. You let me speak, and you really listened! [I am] forever grateful for the profound impact you've had on me."

Juliana is hoping to create a live support group in her area and to translate further information on scleroderma to be available online in Portuguese. The Scleroderma Foundation national office already provides many of its brochures in Portuguese and Spanish, as well as English. Copies can be downloaded from our website, *www.scleroderma.org/newengland* under Local Resources. We are honored to be a part of her amazing journey and look forward to more positive international discussions in the future. Thank you Juliana and Villson!

THE CANNABIS DEBATE: ONE MAN'S STORY

By: Jack Armitage

In April of 1990, then 46-year old Joe Hutchins of Byfield, MA waited patiently for the results of an appeal of his conviction for possession of marijuana. Charges had been brought against him when he'd been "busted" nearly five years earlier.

Joe, diagnosed with scleroderma, suffered with esophageal constriction, loss of appetite, depression and lethargy resulting from the strong medications he had been prescribed. He attempted suicide at one point because of the side effects of these medications which, he claimed, left him "brain dead." In response to his survival, Joe "weaned himself off prescription drugs and decided to legally seek a way to use marijuana," as reported in the *Newburyport Daily News*.

Joe was acquitted of the charges in a complex proceeding, in part because of Marie Coyle's testimony on his behalf. She suggested that marijuana might someday actually prove to be a method of treatment

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

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Rebecca Dube, Editor

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

FROM THE DIRECTOR'S DESK

By: Jack Armitage

In this issue of the *BEACON*, we tackle one of the burning topics of our time, the medical use of marijuana. It is currently in hot debate for symptom and pain alleviation as well as appetite stimulation. I'd been aware of Joe Hutchins and his long journey for a few years and wish now that I had sought him out earlier for his perspective. I talked with Joe by telephone. He more than answered my questions without prompting. He is glad to tell his story and, proud to have reached age 73; he is enjoying all of the normative ravages of his emerging elder years.

As I have alluded in this column and in earlier issues of the *BEACON*, we are pressed to encourage and support research as a primary function of our mission. With increasing frequency, our imperative to find a cure for scleroderma is followed by the words, "in my lifetime" by our leadership and our constituents. Joe Hutchins' personal research, advocacy and brave representation of his beliefs show the determination of a man who is confident that his lifetime has been lengthened by his own diligence and by trusting his instincts after a rocky start. Research occurs at many levels. I emerged from our conversation with admiration and open-minded support of Joe's personal mission and accomplishments.

My personal thanks goes out to Joe for his determination and generosity. You can read his story starting on our cover page. Semper Fortis Joe!

As we prepare for our first quarter meeting of the board of directors, I'd like to express my gratitude to former board member Peter Hart for his board service for six years. Pete's term came to a close and, because we are being diligent in honoring board terms, he has committed to the mandatory year off. Pete will serve on our Advisory Board going forward and may rejoin us at the board level when the pasture gets old and his eligibility returns. Replacing Peter as Board Treasurer will be Tim Hagan and our ongoing accountantcy will be managed by Julie Couto of Bernard and Johnson.

I'd also like to offer my heartfelt thanks to all of my peer executive directors across this country for not only doing amazing work for their constituents, but for continuing to meet monthly with vibrant ideas and plans as we all move forward together. Our national presence includes chapter and affiliate organizations led by directors who roll up their sleeves and meet the demands of grass-roots provision of services. Each chapter has an astonishing identity and continues to bring the best possible options for care and support to our constituency.

We are proud to have ended 2016 with robust proceeds from donations and events to support our services and, of course, our imperative *to fund research for a cure*. From 2016, SFNE will contribute over **$100,000** to the National office in support of scleroderma programs and to fund research. We thank all of you who have worked with us by participating and supporting our events, making a donation, or helping as a volunteer. We look forward to 2017!

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THE CANNABIS DEBATE: ONE MAN'S STORY

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for a condition for which little curative treatment was known. Joe won his case and thrived in subsequent years.

Considering where we are today, nearly 30 years later, we must admire Joe for his heroic effort to find a way through the maze that these possession charges imposed upon his effort to simply stay well, nourished and in control of his future. While the merits of the medical use of marijuana will continue to be debated, it is surely of value to engage in the discussion as it unfolds. While SFNE does not endorse any methods of treatment that are not currently approved, we do encourage conversation and research; we work tirelessly to represent our constituents' urgent imperative to find alleviation of pain and discomfort and to find optimum nutritional health. We listen intently to the individuals who add to our knowledge base and bravely work to find a way through the maze that scleroderma presents.

A Conversation with Joe today:
In 1964, in his early 20's, Joe was discharged from the Navy having served his country well. Shortly after, he married and had three children. During this time, Joe began to experience symptoms of what was later diagnosed as "acute scleroderma of the esophagus." Joe joined a new support group headed up by Marie Coyle and Norma Nadeau – the pioneers of what was to become Scleroderma Foundation.

It was awkward for Joe. He was unique to this group of women and unfamiliar with how to proceed. By 1974, Joe was in "rough shape," as he describes it. It was Dr. John Sullivan at St. Elizabeth's Hospital in Boston who diagnosed him correctly. The recommendation at that time was surgery to remove Joe's esophagus, from his throat to his stomach. Joe was reluctant and opted not to have the surgery. He reflected upon the decision saying frankly, "It was a good thing that I didn't sign up for the operation – I'd be dead."

Joe reflected on this time in his life, "There were different medications at the time. I was a young father with a wife and young children. Looking back, I was a redneck, straight [meaning *conservative*]. I was naïve and I had never smoked marijuana. Every time a doctor offered me new medications I thought, 'Wow – a miracle!' and each time I was disappointed. I lost 30 pounds. It was hell getting food into my stomach.

"Over the years, until about 1980, I learned that it was inflammation that caused the real problem. Not just tightening and stiffening, but also weakness in the lower esophagus, leading to esophagitis, like a skinned knee inside my throat. In those days, there was no Prilosec and treatment medicines for this condition.

"It took years for me to figure it out. It was not an overnight process. In the late 1970s, friends who had been suggesting that I should *'Try weed, it will give you the munchies,'* finally convinced me. The effect was immediate. It helped with the severe condition in my throat. It helped me with nausea and helped me to get and keep food down. One would have thought that the smoke would be an irritant, but it was not. The effect was nearly spontaneous."

In short time, Joe learned how cannabis worked for him. He assured me that he is not offering his story as a blanket solution for all people, but he feels that his perspective is valuable. He said, "Cannabis relaxes me. You call it 'high', I call it relaxation." Relaxation allowed him to crave food, to chew it, to swallow it and digest it. "It allowed me to eat again." At this point, Joe described what it was like to try to swallow and to choke, to reach fingers down into his throat to dislodge food.

Concurrent to this discovery was Joe's ongoing determination to follow the regimen recommended by his doctors at the Veterans Administration Hospital (VA) in Boston. "They liked to give out meds liberally and I became sick and dependent. From '74-'78 I suffered a lot. The VA is a pharmaceutical company's dream. Only the cannabis helped when I began to smoke it. In 1978, I met a good doctor who introduced me to esophageal dilation. It was painful as hell, but he succeeded in ballooning out my esophagus which allowed me to eat for a time."

Problems with his esophagus were not Joe's only challenge. He said, "Let me tell you about my Raynaud's Disease. The VA tested my fingers when they were cold and changing colors. The average temperature of my fingers was 75 degrees consistently. After introducing cannabis into my treatment plan, my Raynaud's reversed and today my hands are as warm as yours.

"All of my doctors condoned my

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CYTORI MAKING ADVANCES IN HAND DYSFUNCTION THERAPY

Where is research on scleroderma making advances? Well, for one, the San Diego-based, global company Cytori Therapeutics, Inc. announced in November 2016 that it had recently published a two-year clinical follow-up on patients with hand dysfunction associated with scleroderma who had participated in the SCLERADEC-I pilot trial of Cytori cell therapy. These patients received a single dose of ECCS-50 in a single [level], open label study of 12 individuals.

In the report, which was published in the journal *Current Research in Translational Medicine,* it was noted that patients reported on key clinical benefits that had occurred by the six-month time period were sustained at two years. These benefits, or “endpoints”, included a Cochin Hand Function Score that improved 62.5% over the baseline score. Pain was also reduced in the hands, with scleroderma-associated disability reduced by 51.1% and a Raynaud’s Condition Score improved by 88.3%. Patients reported improvement in hand mobility, and eight participants who had been previously treated with prostanoids had not needed follow-up treatment with the prostanoids after this period.

With these positive results, Cytori is going to expand its development of ECCS-50 treatment to include secondary Raynaud’s phenomenon, often a part of scleroderma but also occurring independent of it, under the brand Habeo Cell Therapy. Habeo means “to hold” in Latin. Cytori hopes that this therapy will someday become available to treat hand dysfunction associated with scleroderma.

What is ECCS-50? ECCS-50 is a cell therapy that involves adipose-derived regenerative cells (ADRCs). According to the National Cancer Institute Drug Dictionary, ADRCs are “a population of cells derived from adipose [fatty] tissue with stem cell and wound repair activities…These cells contributed to wound repair through a variety of mechanisms by promoting blood vessel growth and blocking apoptosis [programmed cell death].”

In a recent news release, Cytori president and CEO Marc Hedrick noted, “Pilot trial data suggest that ECCS-50 cellular therapeutic may help to address secondary Raynaud’s Phenomenon [RP] symptoms and other autoimmune and inflammatory conditions of the hand. Our plan is to leverage published and ongoing pre-clinical and clinical data to expand our investigation of ECCS-50 to a much larger patient population with secondary RP under the new Habeo brand name.”

Other Cytori clinical trials that are studying Raynaud’s symptoms are the SCLERADEC II trial and the STAR trial. The SCLERADEC II trial is studying 40 individuals in France with hand dysfunction due to scleroderma. The STAR trial is studying 88 individuals in America with scleroderma-associated hand dysfunction. The results of both these trials are expected to be released by mid 2017.

For more information, you can go to : http://www.nasdaq.com/article/cytori-announces-two-year-followup-published-on-eu-scleroderma-trial-20161129-00203#ixzz4VaD990Nv or http://raynaudsnews.com/2017/01/11.

The NCI Drug Dictionary is at https:\\www.cancer.gov/publications/dictionaries/cancer-dru?cdrid=589135.

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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.*

MAINE SUPPORT GROUP HOSTS MEETING WITH DR. ROBERT SIMMS

On December 8, the Maine Support Group held a special meeting featuring Dr. Robert Simms from Boston University Scleroderma Research Center. The meeting was held at The Dana Center at Maine Medical Center in Portland, ME and had 21 people in attendance.

Dr. Simms provided the group with an update on research being done on scleroderma and related symptoms. There was a question and answer period as well, during which attendees asked questions about medications, and about treating various symptoms. Dr. Simms talked about how to get an appointment with his office, reminding them that they do not need a referral if they have a confirmed scleroderma diagnosis.

Dr. Robert Simms speaks with a group of 21 people at The Dana Center at Maine Medical Center in Portland, ME.

The meeting was very well received and we thank Lori Chason, Sandy Lunner, the Maine support group and Dr. Simms for all they did to make this educational meeting possible.

MARIE COYLE HOSTS NORTH SHORE SUPPORT GROUP EVENT

Marie Coyle speaks to the North Shore group

Marie Coyle, SFNE Founder and Peabody, MA resident, recently hosted a luncheon event for the North Shore scleroderma support group. Marie had won an ice cream social to be hosted at Brooksby Village in Peabody, and chose to use her winnings toward bringing a full Christmas luncheon for the North Shore support group and guests. Eighteen people attended and were treated to a full meal followed by ice cream sundaes for everyone. During the event, Marie was asked to give a history on the founding of both the Scleroderma Foundation and Scleroderma Foundation New England.

She did not disappoint, covering how far services for those with scleroderma have come and hopes she has for the future. She expressed a renewed optimism regarding current research and confirmed her belief that there is good reason to be confident that diligent research is about to bring big results. She reflected on the growing team of practitioners and support that is bringing increasing hope to those who are diagnosed. She remarked that she is very proud of where research services and community understanding are relative to her early days in founding the organization.

The event was topped off by a visit from her newest companion, a Chihuahua/ Jack Russell mix named Buzzy. Thank you Marie!

Marie and Buzzy

2017 POLAR PLUNGE

By: Jack Armitage

It is always a unique pleasure to arrive at the L Street Tavern early on New Year's Day to join the revelers for the Annual Polar Plunge for a Cure for Scleroderma. And still, I spent my time there thinking that these are perhaps the most foolhardy people on the planet. Really, who "plunges" into the ocean on a mid-winter day? The *brave*, that's who! It is a dedicated and loyal group that endures the inconvenience of this day to raise funds for research and patient care. This year we raised $3,353.88!

Briana Garcia (L) poses with fellow Polar Plunge supporters Ronnie and his two sisters.

A Plunger shows his support with style.

Because we have lost count of the number of years that we've done the Polar Plunge (probably 14) we now refer to it as the "Umpteenth Annual". I see many of the same people returning for the event and many more new ones making new commitment to support our cause. As crazy as you all are, THANK YOU!

What set this year's event aside from other years are the connections that came as a result of the day. At one point early in the morning, I looked up to see our good friend Briana with her husband and daughter ready to brave the weather. Briana has been a force in raising awareness about scleroderma and has been very open about her own battle and her advocacy for others. Shortly, she was talking with Liz Lombard, Kevin Conroy's sister. Kevin is the organizer of the Plunge and does so in Liz' name.

Then I observed as Briana became engrossed in a conversation with a local man who had lost his wife to scleroderma recently and who was at the Plunge with two of his many sisters honoring her memory. A man in red pajamas grinned as he prepared for the dive and noted that he has Raynaud's disease – wow, that's a brave challenge as Raynaud's renders the hands (and often the feet) painfully and chronically cold. BRRRRrrrrrr….. Kevin Conroy is a loyal supporter of our cause – whenever you hear bagpipes, think of Kevin and thank the powers that be that he is on our side! Briana, Liz, Ronnie, Kevin, Ace, two people named Cookie and all of our other supporters at the Umpteenth Annual Polar Plunge for a Cure – THANK YOU!

Union suits for a cold plunge!

Kevin Conroy leads the parade with his pipes and robe.

A beautiful day at the beach!

Briana Garcia (l) and Liz Lombard (r)

Stepping Out
To Cure Scleroderma

CONGRATULATIONS TO THE TOP 15 WALK TEAMS OF 2016!

We are proud of and grateful to all of the teams and individuals who participated in our Stepping Out to Cure Scleroderma Walks in 2016. Your support and dedication make it all happen for SFNE and our constituents throughout the year. We use this space to recognize our top 15 teams. We look forward to another exciting season of working with fun teams, participants and volunteers, and having a great time!

1	**Team Krissy**	North Shore Walk	$7,097.00
2	**Team Medlin**	Plymouth Walk	$5,810.00
3	**Team Heather**	Boston Walk	$5,761.16
4	**Team Sami**	Westfield Walk	$4,214.00
5	**Team Deb**	Worcester Walk	$4,198.00
6	**AZTHTX**	North Shore Walk	$3,770.00
7	**Team Barbara**	Worcester Walk	$3,730.00
8	**Nina & Shannon**	Westfield Walk	$3,135.00
9	**Mamma's K.I.D.S.**	Boston Walk	$3,057.40
10	**Team Landers**	Plymouth Walk	$2,939.00
11	**Team Magnuson**	Worcester Walk	$2,835.00
12	**Team Gilda**	Worcester Walk	$2,790.00
13	**Team Phyllis**	Worcester Walk	$2,610.00
14	**Fans of Jan**	Plymouth Walk	$2,590.00
15	**Kimme's Crew**	Plymouth Walk	$2,465.00

Honorable Mention: Team McGrane (North Shore), Leaps for Peeps (Westfield), Team Sheryl (Boston), Team Ambrose (Maine)

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 25, 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 20, 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 1, 2017

THE CANNABIS DEBATE: ONE MAN'S STORY

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use of marijuana. This is what I feel is most important. I have learned over the years about the impact marijuana has on all of the symptoms of scleroderma in my circumstance. When Marie Coyle defended the appeal of my conviction in 1990, the most important thing that she said was, 'Modern medicine is not doing it!' "

Joe continued, "Most people don't know a thing about cannabis. A person like me has multiple symptoms with scleroderma – we just want some help! Prescribed medications made me sicker. Marijuana works. It is subtle; it works with multiple symptoms, all of which can be treated well. Before marijuana, I was getting signs of microstoma [the condition that leads to shrinking of the mouth and tightening jaw]. A dentist who was doing research at the Veteran's Administration made a rig and a wedge to forcibly open my jaw. It was painful and did not work at all. As soon as I started using cannabis, my condition got better and these advancing symptoms reversed.

"Scleroderma affects the blood and capillaries – the scientific proof is there. Smooth muscle encircles the veins. It is my experience and opinion that the cannabis response creates inner warmth, probably a result of improved circulation because of relaxation. The inner warmth that results relaxes smooth muscle better than any medicine in my experience. It reverses the first symptoms of scleroderma – *constriction*.

"In 1981 after a suicide attempt because of depression and essential addiction to prescribed medications, I took control of my disease. Lucky to have survived the suicide attempt, I told my doctors, 'No more prescriptions!' I went pill-free for ten years. In 1990, my doctor prescribed Prylosec for acid in my gut. It is the ONLY concession I have made.

"I am not an angry person. I am happy by nature. My life was junk. I am not at battle anymore after 40 years. I know darn right well that it helps my blood flow better. My battle was multiple. Cannabis saved my life. Regarding my arrest, I was determined, even with the law against me. Thinking back to that time, I was lucky to have some very good law firms that got behind me. The battle for my rights resulted in what is commonly known now as The Joe Hutchins Act *[see inset]* – reflecting my defense of medical necessity.

"At 73, contrary to what I have just told you, I now find current modern medicine to be pretty incredible. I am enjoying the normal things that a guy my age goes through. I had a heart attack, and modern treatments for it have been great. I have started blood pressure medication and am under good care. It is nice to have medical challenges that are typical versus the nightmare of my experience with scleroderma."

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THE CANNABIS DEBATE: A RESEARCH UPDATE

Maine support group leader Lori Chason directed my resource search to results of a European Union step forward in the use of a non-cannabinoid synthetic orphan drug called Resunab. Resunab imitates the properties of cannabis without the mind-altering side effects.

Corbus Pharmaceuticals CEO Yuval Cohen says, "We look forward to the continued advancement of our global clinical and regulatory strategy for Resunab for the treatment of rare inflammatory and fibrotic diseases." Research on this might further our understanding of the properties of both cannabinoid and non-cannabinoid products which have potent analgesic and anti-inflammatory properties."

Resunab (JBT-101) continues to be in clinical development by Corbus Pharmaceuticals.

THE JOE HUTCHINS ACT

The legal Act resulting from Joe's case, while a lengthy description of the legal consequences of marijuana, for the first time includes language referencing medical advice or prescription. It has been colloquially referred to by Joe's name. A relevant extraction from the act is below:

(General Laws, Part 1, Title xv, Chapter 94C, section 34)
Section 34: *Unlawful possession of particular controlled substances, including heroin and marihuana*
No person knowingly or intentionally shall possess a controlled substance unless such substance was obtained directly, or pursuant to a valid prescription or order, from a practitioner while acting in the course of his professional practice, or except as otherwise authorized by the provisions of this chapter.
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NEWS BYTES

SCLEROMEN HAS BEEN RELAUNCHED!

SCLEROMEN
TOGETHER WE ARE STRONG

ScleroMen has been relaunched and the leaders encourage men with scleroderma to join the group as soon as possible!

A closed group has been created on Facebook and will be hosted by the Scleroderma Foundation's Tri-State Chapter. In order to become part of this group, you will need to send a message to **ScleroMen@scleroderma.org** asking to join.

The new group leaders are Andrew Botieri from Massachusetts and Lee Korotzer from Florida. These two men are anxious to jump start the group and determine what types of support might be needed for men with scleroderma - and we thank them for this commitment.

Feel free to send a request to Andrew or Lee to join - your request should include your name and contact information which will help them to vet the inquiries so that *only men with scleroderma will be able to participate.*

If you should have any questions or suggestions, contact Mary Beth Bobik-Kadylak, Tri-State Director of Patient Education and Support at: mbbkadylak@sclerodermatristate.org.

NATIONAL CONFERENCE SCHOLARSHIP APPLICATIONS NOW BEING ACCEPTED

Save the Date!

19th Annual Patient Education Conference
July 21-23, 2017
Sheraton Grand at Wild Horse Pass
Chandler, Arizona

Each year, the Scleroderma Foundation, with donations from individual chapters, builds the Scleroderma Foundation Scholarship Fund, allowing constituents to apply for scholarships to attend the National Conference. For first time attendees, the National Conference brings hope. For others, it is a chance to continue their education about scleroderma, meet with doctors and other people living with scleroderma, even catch up with old friends! Thanks to the generous support of many donors and chapters, such as SFNE's annual Walter Coyle funds, scholarships will be available to the 2017 National Patient Education Conference in Chandler, Arizona from July 21-23, 2017.

SOLETICS GLOVES UPDATE

In January, SFNE received a pair of the Soletics' Raynaud's Smart Glove prototype for testing (see photo, right). Our peliminary tests showed that when exposed to colder temperatures, the glove would heat up along the base knuckle line. The gloves were then sent on to a member of the North Shore support group for further testing. Soletics will gather information from several prototypes being tested around the country and incorporate those results into their final design discussion.

These gloves use a special heated fabric to increase their dexterity, and has sensors placed throughout the gloves to detect temperature changes and heat accordingly. We look forward to more news updates!

The testing prototype of Soletics heated gloves for people with Raynaud's Phenomenon.

NEW FEATURE ON INSPIRE.COM - REACTIONS

Often in the BEACON we have referred our readers to the Scleroderma Foundation page on the website Inspire.com, where participants from anywhere the country can post questions, have discussions, or just generally support each other online with regard to living with scleroderma. This site offers forums on all tyes of topics, and is always looking to improve its services. Recently, a coordinator on the site, Erik, created a post to explain the new Reactions feature that allows participants to react to other posts, as one does on Facebook. Below is his post.

ErikInspire's Journal 12/1/2016

Earlier this year, we had a wonderful discussion with all of you about Facebook-style "Like" buttons on Inspire, and all of the positives and negatives that are associated with them. Through more than 200 replies we heard from many of you with widely differing opinions. The overwhelming consensus was that, while the idea of being able to give reactions to posts and comments could be a positive one, the idea of using Facebook-style reactions (Like, Love, Ha-ha, Wow, Sad, Angry) were inappropriate for a site like Inspire.

So we spent a lot of time thinking about what kind of reactions we could use that would make sense for Inspire. How could we give our members another chance to interact with posts and comments, especially on mobile phones? So today we present to you Inspire reactions.

On every post and comment you will be able to select one or more of three reactions. We hope that these are self-explanatory, but I did want to show you what we were thinking in our selections.

First, we wanted you to be able to show your **Support** for something that another member wrote, whether they were posting something positive or struggling with something heart-wrenching. That's why we chose the first reaction to be **Support**, with the Inspire icon, so you can reach out and let the other member know that you are thinking about them.

Second, we wanted you to be able to give your **Thanks** to someone for what they wrote. This is your way of showing another member that you appreciate what they said, and that they added to the ongoing discussion.

Finally, we wanted you to be able to indicate something as **Useful**, meaning that the post or comment contains valuable information that you think other Inspire members should read. This is a very important reaction for us, because soon it will help to inform the **Read More** posts and search results. The more a post is marked as Useful, the more likely it will be to show up for other members who need your help.

Along with these new reactions, we have also made the **Reply** button much more prominent. Since replies are now written right where you hit the button, rather than jumping to the bottom of the page, we hope to emphasize that there is nothing better than a personal reply.

We hope you enjoy the new reaction buttons, and I personally am thankful to all of you who took the time to participate in our discussion thread earlier this year.

Journal entry origially posted on Inspire.com.

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HAVE YOU TRIED GUMCHUCKS?

At the most recent Support Group Leader Luncheon, guest Beth Gagnon, a former dental hygienist, showed the group the benefits of using GumChucks Adult Pro Floss for people with limited dexterity of their hands or mouth.

GumChucks, so named because they look like miniature nunchuks, provide two wands that hold the floss and allow the user to insert it in all areas of the mouth easily. Having two separate wands lets the user make a C shape with the floss around the tooth and under the gum line to break up bacteria and remove plaque. Small plastic flossers stay straight and cannot form the necessary C shape.

A starter pack comes with 12 tips with floss attached. Simply press the button at the end of the wand to eject the tips and insert new ones. Refill cartridges can be purchased in various quantities. Go to *www.gumchucks.com* to watch videos on how to use GumChucks or to order some for yourself!

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IN APPRECIATION

In February, we lost one of our quiet pioneers and constant messengers of hope, Mary Ann Persson. Mary Ann was a gentle leader, a "wind beneath your wings" sort of friend, a capable caregiver and nurse. We send our best to Nancy and Deb and all of the members of the group in Worcester who flourished for 30 years under Mary Ann's light.

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THE IMPORTANCE OF MENTORING

Marie Coyle (center) accepts a $1,000 check for SFNE from Clare Costello (left) of Lee Kennedy Company.

Lee Kennedy Company of Quincy, MA, has been donating very generously to SFNE for many years. In 1994 Donald Ventula, Marie Coyle's younger brother, died unexpectedly in an automobile accident. At the time, he was employed by the Lee Kennedy Company and his co-workers were shocked by the sudden tragic loss. No employee was more saddened than Lee Kennedy Jr., then a young kid, cutting his teeth in the business.

Don and Lee had bonded in their shared time at the company. Lee was a reluctant "boss's son" and Donald had taken a liking to him, having recognized the difficulty of his role in the company. They bonded over fishing and the advice that Don would offer to Lee, suggesting that he be patient, focus on the goal and stay with the work.

To honor Don's memory and as an ongoing appreciation of the role he held in Lee's life, Lee Kennedy Company has made a donation to us annually. This donation underwrites our biennial Patient Education Seminar. The mentoring role that Don Ventula had in Lee Kennedy's young life has become a symbol of the important mission-driven education program that SFNE now presents to our ever-growing constituency.

Additionally, Lee Kennedy Company honors an exemplary employee every year with the Donald Ventula Award. This person exemplifies the attributes that Don showed during his time with the company. The 2016 award recipient is Catherine Pasquantonio (shown above), an all around "go to" person who stands out as *going the extra mile*!

Don't ever shy away from the opportunity to do something important for someone else. The ripple effect might be as incredible as that of the special roles that Don and Lee had in each other's lives and the resulting educational conference that we are able to bring to our readership.

Marie Coyle is always proud to stand with Lee Kennedy Jr. to receive the award each year. On receiving the award, Marie confidently stated, "I am here for two reasons: to gratefully receive this check and to give Lee a big kiss!" Which she did. . .

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> ***A mentor empowers a person to see a possible future, and believe it can be obtained.***
>
> ***~ Shawn Hitchcock***

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
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New England Chapter
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SUCCESS WILL NEVER BE A BIG STEP IN THE FUTURE; SUCCESS IS A SMALL STEP TAKEN JUST NOW.

IF OPPORTUNITY DOESN'T KNOCK, BUILD A DOOR.

BE YOURSELF. EVERYONE ELSE IS ALREADY TAKEN.

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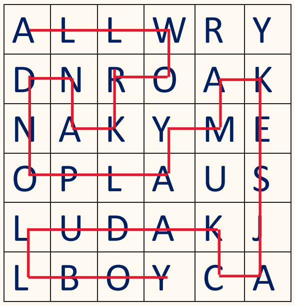
Your $25 membership fee also helps support Scleroderma Foundation New England, its programs and publications, and increases available research funds. Your subscription end date is on the bottom of your mailing label (above).

PUZZLE ANSWERS

Congratulations to Carol Sweeney, the winner of our Fall BEACON puzzle. She will receive a box of Harbor Sweets chocolates in the mail. The hidden proverb was "All work and no play makes Jack a dull boy."



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

NEW PUZZLE

Each equation below contains the initials of words that will make it correct. Find the missing words. For example: 26 = L. of the A. would be 26 = Letters of the Alphabet. Good luck!

a. 12 = S. of the Z. ______________________________

b. 88 = P.K. ______________________________

c. 4 = Q. in a G. ______________________________

d. 24 = H. in a D. ______________________________

e. 29 = D. in F. in a L.Y. ______________________________

f. 64 = S. on a C. ______________________________

g. 52 = C. in a D. ______________________________

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