Volunteer of the Year Inside!

NEW ENGLAND
The BEACON
A Publication of Scleroderma Foundation New England
Fall 2017

CROSS-REFERENCING RESEARCH RESULTS CAN LEAD TO NEW TREATMENTS FOR SCLERODERMA

By: Rebecca Dube

Research is not always about inventing a new medicine or treatment. Sometimes it is investigating a new use for an existing treatment. The human body is comprised of many overlapping, interworking systems, but often treatment studies are isolated in a way that only applies to one disease being studied.

In fact, research seeking a treatment may be an investigation into connections between diseases, and how the symptoms of one disease can be treated with the application of a therapy from another disease. The scleroderma research community is seeing that in two current studies.

A recent study published in the journal *Arthritis and Rheumatology* discussed how the antireoviral drug Viracept, currently used to treat human immunodeficiency virus (HIV), could also be used to treat collagen production in systemic sclerosis.

As an autoimmune disease causes the body to attack its own tissue, it is the messaging (or signaling) from the body to attack that needs to be addressed. Viracept can hold back the transformation of fibroblasts and stop the signaling of a transforming growth factor known as TGF-beta1 in human lung fibroblasts. TGF-beta1 promotes the development of fibroblast cells into collagen-forming cells called myofibroblasts. This promotes the development of collagen, which leads to fibrosis, a negative aspect of scleroderma.

While Viracept (along with other treatments) had been used to treat HIV, it was found that it's use could possibly treat symptoms of a broader range of diseases. Thus a study was conducted to research whether the qualities of Viracept could be used to stop fibrosis development in people with systemic sclerosis (SSc).

The study used the fibroblast cells of healthy human lungs, skin and

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THE PES IS APPROACHING!

Members of the 2016 PES Ask-the-Experts panel l-r: Dr. Michael Whitfield, Dr. Nicole Orzechowski, Dr. Andrew Plaut, Dr. Robert Simms, Dr. Vaishali Sanchorawala, and Don Legere.

Save the Date for the 2018 SFNE Patient Education Seminar, being held on Saturday, April 7 at the Peabody Marriott in Peabody, MA. Registration will begin at 8:00 am and the conference will run until about 3:30 pm. It will feature multiple speakers as well as an afternoon Ask-the-Experts panel on a variety of topics. There will be a continental breakfast and a luncheon provided. Registration will be $15 and will begin in early 2018. More details on the event will be in the wintert edition of the BEACON. Mark the date on your calendar and plan to join us on April 7!

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

CROSS-REFERENCING RESEARCH

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cardiac ventricles, along with fibroblast cells from people with systemic sclerosis. It also used a bleomycin-induced animal model of SSc. The results showed that Viracept prevented the creation of myofibroblasts in many tissues, including lungs. It also reduced collagen in these cells.

This discovery can further guide researchers to continue to study the effect of Viracept on the pathophysiology of systemic sclerosis. However, this discovery would not have occurred without a researcher having taken a closer look at the results of one therapy and applying it to another disease's progression. The continued funding of research allows these studies to happen.

The Scleroderma Foundation offers a Multi-Center Collaborative Grant that supports two or more institutions to significantly enhance scleroderma research. As the old saying goes, two heads are better than one! In 2017, the grant was awarded to Maria Trojanowska, Ph.D. of Boston Medical Center to study the use of Dimethyl Fumarate (DMF), an anti-inflammatory agent used to treat multiple sclerosis, as a potential drug to treat Pulmonary Arterial Hypertension (PAH). She will be working with investigators from the University of Pittsburgh using patient-derived cells and the in vivo novel mouse PAH models.

By looking at the treatment for another disease and the positive outcomes it creates, investigators can further study it as a potential treatment for scleroderma-related conditions. In both cases researchers are looking in new directions, considering research done in other areas, and talking to each other about that research. Collaboration continues to be the key to research discovery.

Technical trial is one of the final steps in the development of a drug therapy. It is how a person living with scleroderma can get involved. See our article on page 4 about getting involved with clinical trials in the New England area. Please continue to support the ongoing research into treatments and therapies to combat scleroderma and hopefully someday find a cure.

MONTAUP CHARITY DAY 2017

Members of the Fall River/ Bristol County support group were on hand on September 27 to accept a check for $1500.00 to SFNE, donated by the Montaup Country Club's annual golf charity tournament. Pictured here in the back row are (l-r): Eileen Gabriel, Montaup Charity Chairman Adam Fernandes, Rebekah Acevedo, Doreen Pinault, and Jeanne Oliveira. In the front row are (l-r): Jean Sousa, Donna Bernier, and Christine T. Maroney. Not pictured, but in attendance, is Elise Lachance. Our great thanks to the members of the support group and to the Montaup Country Club for once again including SFNE in their charitable giving.

FROM THE DIRECTOR'S DESK

By: Jack Armitage

To all in our readership, I want to weigh in with sincere festive wishes as the holiday season gets underway. My hope is that whichever holidays you celebrate are restful, personally fulfilling and bring joy and health into your life.

At this time each year, we reflect back on the cumulative bounty of your support through the year. The six Walks for a Cure, Golf Classic, various third party events and your donations all add up to determine what we are able to provide to fund research and constituent care. THANK YOU for helping us to meet and exceed our goals.

We never lose sight of the directive we have to find a cure for scleroderma in our lifetime, nor do we waver in our determination to meet and exceed our support and education goals. Our success in bringing increased services to our constituency is evidenced in the growing vibrancy of our support groups and the speakers featured at them. Five years ago, our support group leaders (SGLs) were doing their work in isolated regions in New England. Most had never met each other. Now, with our biennual Support Group Leader Luncheons (*story, p. 5*), we have a strong and cohesive group of SGLs who are interacting, sharing attendees and building policy together. Speakers such as Lilly Stairs and Rachel Basso from Clara Health (*story, p. 4*) are sharing their expertise and services with support groups that can help constituents with the daily challenge of living with scleroderma.

We continue to work towards our education goals with the planning of the New England Patient Education Seminar coming up in April of 2018. We will be expanding this year with vendor tables, new speakers, and space to accommodate more participants.

On page one, Rebecca Dube reflects on our goals in research by sharing with you the benefits that utilizing research crossover results provide in the treatments of multiple conditions. As those of us in the rare disease world know, successful research for one disease is certain to benefit others as well – we welcome this shared outcome.

Presenting with other specific disease representatives, Sandy Lunner (Maine support group leader) recently sat on a panel addressing medical students at Boston University Medical Center. They shared their journey to further the understanding of various rare diseases with medical students. What Sandy has done in this outreach effort is to show that each act of outreach results in many lives being touched.

This edition of the *BEACON* also includes a fun poem and serious sharing and suggestions from other people dealing with scleroderma in everyday life (*pages 8 and 11*). Our thanks to bloggers Kim Tocker and Lori Pierce for their contributions to this publication. If you want to see a video of our Boston Walk featuring doctors Robert Simms and Harrison Farber, along with interviews with constituents about support groups and the walk itself, go to our website at *www.scleroderma.org/newengland*. Volunteer videographer Carl Botti of BottiWebs did a fantastic job in putting this together. Let us know what you think!

All of us at Scleroderma Foundation New England work to increase our impact and move toward our goal to find a cure. This feels good. As you nestle in for winter, see to your warmth, your open heart and your shared successes. We will continue to shine a beacon into the future with a clear understanding of our shared mission.

* * *

SAVE THE DATE

National Patient Education Conference

JULY 27-29, 2018, PHILADELPHIA, PA

Loews Philadelphia Hotel

CLINICAL TRIALS DEMYSTIFIED

By: Jack Armitage

Sometimes it feels as if there is a “disconnect” between established clinical trials and the process by which a patient gets involved in them. Because of the imperatives of timing in so many research and trial efforts, bridging the gap between laboratory research and access for trial participants has become the singular motive of start-up organization Clara Health.

Rachel Basso (far right) and Lilly Stairs (second from right) discuss clinical trials with North Shore support group members (l-r): Bunny Cappellucci, Pat Weisberg, Janel Rogers, Tricia Legere, Kim Tebbetts and Roberta Mauriello. Not pictured: Joan Kingsbury.

Representing Clara Health, Lilly Stairs and Rachel Basso recently visited the Scleroderma Foundation New England’s North Shore support group. Support group leaders Roberta Mauriello and Joan Kingsbury welcomed them and in short time a discussion was underway with the attending members.

Lilly described her own history. At 19 she had total body arthritis and was unable to move. The combination of psoriatic arthritis and Crohn’s disease had brought her daily activity to an abrupt halt and only through the intervention of treatment with a biologic was she able to treat both onset diseases successfully. Lilly was able to channel her enthusiasm for treatment and clinical trial involvement into her current work at Clara Health, the organization in Boston whose mission is to connect a diagnosed person to the right clinical trial by accompanying the patient through the process of application, eligibility and enrollment.

“At Clara Health,” said Lilly, “we are about empowerment. We understand that as patients, we must be active participants in our own health – we at Clara want to help you to reach that objective.”

Lilly and Rachel described two categories of clinical trials: observational and interventional. There are lots of opportunities for observational clinical trial participation. One can donate skin samples for laboratory research, for example. In the intervention model, patients are actively involved in treatment, taking medications and ongoing trial treatment modalities.

The presentation explored possible predictors and outcomes of the clinical trial process. Lilly continued, “In diseases for which cause and/or cure are unknowns, the possibility of failure to thrive leads logically to enrollment in clinical trial. Enrollment often gives the enrollee early access to medications, better care and monitoring, and often cost-free care.” Encouragingly, it seems that in the older clinical trial models, the placebo was most often what we used to call *sugar pills*. These days, she went on to say, “it is more likely that the current standard of care is used so that treatment is ongoing. Patient advocacy is what has made this logical giant step forward possible.”

Interesting facts about clinical trials emerged in the discussion. Clinical trials are the lifeblood of innovation and essential to bringing new treatments to the patients who need them most. Unfortunately over 80% of trials run are delayed due to difficulty finding participants. This is largely due to lack of awareness.

While trials can offer patients breakthrough treatments, many physicians don’t have time to keep up to date with all the trials being run at their hospitals, let

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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*.

FALL SUPPORT GROUP LEADER THANK YOU LUNCHEON

Back row (l-r): Rebecca Dube, Tony Cappellucci, Jane Ladas, Carol Taylor, Jack Armitage, Don Chapman; Middle Row (l-r): Doreen Pinault, Roberta Mauriello, Donna Bernier, Carla King, Jeanne Oliveira, Brenda Brown Front Row (l-r): Bunny Cappellucci, Christine T. Maroney, Marie Coyle, Sandy Lunner, Jean Chapman, Keisha Burton-Levy.

Twice annually the New England Chapter, including staff and board of directors, hosts a luncheon to honor the selfless efforts of our nine support group leaders (SGLs). Yes, it is an opportunity to thank them with a meal and a small gift, but more importantly it is the chance to create a setting in which all leaders can accept the support that they might otherwise not receive in their own groups.

Our recent meeting held at the BreakAway in Danvers, MA was a powerful reminder of the imperative we all share to bring consistent and emotional strength to those we serve. It is a classic and shared attribute of our SGLs that they are often overlooked in their selfless willingness to serve others.

The group discussed possible topics for the upcoming Patient Education Seminar, challenges for leading groups of people with very different needs, and ways to offer support both over the phone and in person. Different group leaders shared tips on keeping a support group setting positive while letting members express all of their emotions. The group discussed invention updates from the last meeting, in which researchers from Harvard were looking for input from patients on needs to be met for those living with chronic diseases. A call went out to help a leader in need and our other leaders were happy to lend their support. Steve Sookikian from the national office discussed Advocacy Day, coming up on April 16-18.

We offer our sincere appreciation for all attending guests: support group leaders and their guests, SFNE staff and members of our board of directors, and Steve Sookikian from the national office. Through this twice annual event we touch base with the essence of our mission and have the opportunity to revisit *why we do what we do.*

INCREASING SCLERODERMA AWARENESS

SFNE volunteer Sandy Lunner (left) along with fellow panelists Sonia Pina, Anne Brown and moderator Linett Matirossian.

> ***Education is the most powerful weapon which you can use to change the world.***
>
> ***~Nelson Mandela***

On October 5, Maine support group leader Sandy Lunner took part in a seminar for medical students at the Boston University Shapiro Clinic in Boston, MA. Over 100 students attended and listened to lectures on various diseases, such as lupus and scleroderma. The students were then able to ask questions of someone living with the disease. These questions elicited what symptoms they presented, how they were finally diagnosed, and which treatments worked and did not work along the way. This seminar was coordinated by Linett Matirossian, a rheumatology fellow at Boston University School of Medicine.

“I was pleased to be able to help with this exercise,” said Sandy. “The medical students were engaged and responsive. They asked excellent questions and, more importantly, listened to our stories. They seemed to really hear how frustrating it can be navigating the medical system when a patient has a little known or understood disease.”

Thank you Sandy for bringing a patient’s perspective to the medical professionals of tomorrow and spreading awareness about this rare disease!

THE THIRTEENTH ANNUAL NORTH SHORE WALK

On a beautiful September day, 172 walkers gathered at the Proctor School in Topsfield, MA to join in on a great day of fun, music, food, and of course, raffles! Together we raised $24,000 towards SFNE's mission of education, support and research for those living with scleroderma.

Our efforts were supported by the excellent staff at the Proctor school, Ann and Billy. Paul Beaulieu sponsored the purchase of the pizza. Volunteer Sharon Glasser helped with registration and Joyce Steyer was once again at the silent auction table. We thank Jean and Don Chapman along with our Great Hill volunteers for their continued support of this event.

This year's walk was a success and we are grateful to everyone for their great work. We couldn't have done it without you! Emily Winnerman kicked off the walk with a few words thanking everyone for their participations and donations. The teams gathered showed their colors in t-shirts of blue, green, and of course SFNE yellow. Kudos go to all of our teams, walkers and donors.

Counting donations brought in on the day of the event, the top fundraising team was Team Krissy, followed by Team Marcie and Donna's Team. A great thank you to all our other teams and single walkers as well! We hope to see you again next year!


Team Krissy expresses their enthusiasm for the North Shore Walk.

Donna's Team


Team Insanemom shows their crazy side!

THE EIGHTH ANNUAL WESTFIELD WALK


Shannon Broderick (center) helps the other volunteers set out food for hungry walkers.

A new, earlier time frame was a hit this year at Stanley Park in Westfield and allowed all to see the afternoon Patriots game.

The two major teams, Nina and Shannon's Team and Team Sami came together to set up, participate, and enjoy the walk together with friends, family, and other individual walkers, The event raised over $9,000 and even brought awareness of scleroderma to some other park patrons!

A big hit of the day was a complete bean bag toss game that was hand made by Jeff Collingwood and donated as a raffle gift at the walk. The front of each bean bag toss board was painted with a large scleroderma ribbon, and the inside was signed by everyone attending the walk. The lucky winner was 13 year old Sami Stackpole, who said she will be sure to bring it to be used at future walks!


Sami Stackpole

Our sincere thanks go to Gina, Kara, Shannon, Bruce, Scott, Sami, Matt, Mike, and all our other volunteers for everything they did to make this day a success. Thank you also to all our teams, walkers and donors. We appreciate your support!


This hand-made, scleroderma-themed bean bag toss game was made by Westfield resident Jeff Collingwood.

THE THIRD ANNUAL BOSTON WALK

By: Carol Taylor

See the Boston Walk video on our web page!
www.scleroderma.org/newengland

It has been a pleasure and honor to host the Annual Boston Stepping Out To Cure Scleroderma Walk. This was our third year in the fun-loving city of Brighton.

The total raised was $24,407. We are humbled and grateful for the kindness and generosity of everyone, especially the Boston support group members and all our team captains, volunteers, participants, donors and sponsors. We all share a sense of responsibility in this world and when we respond with open hearts to "giving," it empowers and strengthens our sense of belonging and doing good things within our communities. We've seen this goodness expressed at the Scleroderma Foundation New England walks.

Carol Taylor gets her face painted by Lisa Ferreira.

Our top fundraisers at this year's walk were from Team Heather with $4,805 and Mamma's K.I.D.S., $2,859. We also had an incredible amount of raffle gifts that brought in $3,027 towards our final goal of scleroderma research and education. Phenomenal!

As coordinator, it has been a true blessing having the support of the Coughlin, Ulrich, and Olsen families and for their enthusiasm and perseverance in the planning and execution of the Boston walks. Joyful thanks Bob, Mary, Genevieve, Michelle, Kim, and Joseph.

Members of The Beth Foundation Team pose before the walk.

This year we had 188 incredible walkers, including those young-uns in strollers enjoying the warm sunny day while hearing the sounds of happiness all around them. This year we added two crowd pleasers: Lisa Ferreira at face painting, and Logan Coughlin as Animal Balloon Twister. Thank you both so much for delighting the kids with your talent. Many thanks also to Carl Botti and Owen Tansey for creating an amazing video of the day. A deep appreciation goes to volunteers Mary McClay, Mary Walsh-Seabury, Irene and Rob Kopp, Mary and John Ulrich, Chloe and Maeve Coughlin,

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CONGRATULATIONS TO THE TOP 15 WALK TEAMS OF 2017!

We are proud of and grateful to all of the teams and individuals who participated in our Stepping Out to Cure Scleroderma Walks in 2017.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 in 2018 of working with fun teams, participants and volunteers while having a great time!

1	**Team Krissy**	North Shore Walk	$6,130.00
2	**Team Heather**	Boston Walk	$4,805.00
3	**Team Magnuson**	Worcester Walk	$4,186.00
4	**Team Heather B**	Maine Walk	$3,942.00
5	**Team Medlin**	Plymouth Walk	$2,960.00
6	**Mamma's K.I.D.S.**	Boston Walk	$2,859.00
7	**Nina & Shannon**	Westfield Walk	$2,852.00
8	**Team Marcie**	North Shore Walk	$2,750.00
9	**Team Sami**	Westfield Walk	$2,595.00
10	**Donna's Team**	North Shore Walk	$2,445.00
11	**Team Phyllis**	Worcester Walk	$2,147.00
12	**Team Landers**	Plymouth Walk	$2,021.77
13	**Team Ambrose**	Maine Walk	$1,975.00
14	**Team Emily**	North Shore Walk	$1,880.00
15	**Go Team Skippy**	Worcester Walk	$1,845.00

GADGETS AND GIZMOS: A LITTLE DITTY ABOUT THINGS THAT MAKE LIFE BETTER

For many living with scleroderma, even simple tasks can become extremely difficult, and little gadgets are often necessary to help you get through the day. New Zealand scleroderma blogger Kim Tocker wrote a poem to acknowledge just a few of these gadgets, and to celebrate their presence in her life:

Scleroderma snuck right in
It stole away my life
It gave me heaps of collagen
As well as heaps of strife

It hardened up my fingers
My skin's under attack
My GI tract, my heart and lungs
I want my old life back!

But now I know it's here for good
Unless they find a cure
So my special little helpers
Are what help me to endure

My special little helpers
I hold close, and, oh, so dear
But they're not the small, round pill types
That I refer to here

These special little helpers
Are so many and so handy
They are, of course, devices
That keep life running dandy

There's my awesome stretchy laces
No tying, no more ache
My shoes slip on, my shoes slip off
My fingers get a break

My shower stool, now that's a must
It gives me back my power
No more being out of breath
While soaping in the shower

Specially angled garden trowels
Make gardening a song
My wrist pain is much better now
And doesn't last as long

And who invented Velcro?
Because they really are a star!
I've replaced the hooks with that stuff
And can now do up my bra

Although I must take heaps of pills
Because of this disease
My weekly plastic sorting box
Makes taking meds a breeze

My lungs don't work, my heart conks out
It really gets me down
But a speedy motorized bike
Now lets me zoom around the town

And if I'm feeling tired
There's my trusty old recliner
I can snooze at any time
There's really nothing finer

Now hear this, scleroderma,
Despite the slow decline
With gadgets, tools, and gizmos
I can get along just fine

So those who have become unwell
And things are getting grimmer
Try not to fight against it
If you have to, use a Zimmer

Take all the help that's out there
Every gadget that's on hand
Despite the aches and pain and stuff
Your life can still be grand!

You can find many of Kim Tocker's posts from her blog Scleroderma and the Ordinary Girl at Scleroderma News. www.sclerodermanews.com

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 TBD, 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 TBD, 2018

Strolling for Scleroderma
Deer Island, Boston, MA
June TBD, 2018

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

Fuddruckers Fundraiser
Fuddruckers, Saugus, MA
Friday, August TBD, 2018

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

Third Annual Boston Stepping Out for a Cure Walk
Artesani Park, Boston, MA
Saturday, September 29, 2018

BOSTON WALK

(continued from page 7)

Tom and Tricia Legere, Kathy Moriconi, Sharon Glasser, Matty Legere, Unai and Esai Barrera, and Matt Dube.

Another big thanks to Big Y, Milford, and Tougas Farms, Northborough, for providing us with snacks. Also to Domino's, Brighton, for donating the pizzas. Delizioso!

Lilly Stairs and Rachel Basso were also present from Clara Health, an organization that helps patients through the clinical trial process. We are grateful to the teams from Boston University Medical Center, Massachusetts General Hospital and Corbus Pharmaceuticals for taking part in this event. Most of all we again thank all of our donors who contribute to make this event so special and to support the programs of Scleroderma Foundation New England.

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The MGH Scleroderma team

LOCAL CLINICAL TRIALS

Dr. Flavia Castelino of Massachusetts General Hospital is the principal investigator in two current clinical trials. One is for "Oral Ifetroban to Treat Diffuse Cutaneous Systemic Sclerosis (SSc) or SSc-associated Pulmonary Arterial Hypertension". The second trial is "Abituzumab in Systemic Sclerosis-associated Interstitial Lung Disease". For more info on either of these trials, contact Kaitlin Schalago or Ana Fernandez at 617-724-2792. Find a listing of the trial with information at www.clarahealth.com or www.clinicaltrials.gov.

* * *

Dr. Richard Chaddick of Massachusetts General Hospital, and Dr. Harrison Farber at Boston University School of Medicine, are investigators on a current clinical trial for "Bardoxolone Methyl in Patients With Connective Tissue Disease-associated Pulmonary Arterial Hypertension". Contact the Research Coordinator for Dr. Chaddick at 617-724-5548, or the Research Coordinator for Dr. Farber at 617-638-4475. Find a listing of the trial with information at www.clarahealth.com or www.clinicaltrials.gov.

* * *

IN MEMORY OF

This year we lost two long-term SFNE volunteers from the local Great Hill community, George O'Connor and Merelyn Adams. George was always helpful getting everything set up at the North Shore walk, as well as manning the Hole in One at our annual Golf Classic. Merelyn was a steady presence at both the North Shore Walk and the Golf Classic, soliciting baskets, selling raffle tickets, and setting supplies in golf carts at our golf event. We will miss them both dearly and are thankful for the remembrances of friends and family.

MATTY LEGERE AWARDED SFNE VOLUNTEER OF THE YEAR

Matty Legere at the Boston Walk

Matty Legere arrives with energy and good cheer at any event he attends. He walks with purpose and resolve and always seems to be planning for the next chore.

His mom, Tricia, is often in a wheelchair, especially where the terrain is uncertain, so he keeps a watchful eye on her to be sure that she is comfortable and well cared for. It is a pleasure to observe him doing heavy lifting as he seems to have a careful approach to safety and efficiency. He maneuvers a two-wheeler like an experienced trucker.

His orderly approach to setting up the T-shirt table at our Boston Walk makes our work much easier. Matty is comfortable with public speaking. He is never at a loss for words to promote our cause and to honor his parents. He also offers his help to monitor walkers along the Boston Walk route and lead them safely to the finish.

For these reasons and more, we have voted Matty Legere **2017 Volunteer of the Year** at SFNE. Congratulations Matty, you helped us to make 2017 an excellent year!

CLINICAL TRIALS DEMYSTIFIED

(continued from page 4)

alone everywhere else. This leaves patients to research for themselves if they want to participate. They often don't because the trials are difficult to find and challenging to enroll in.

Clara Health, with its innovative and capable team, wants to help patients - bottom line. Their trajectory to that end is to help candidates for a clinical trial to learn about the process in an accessible and attainable way; then, to help them through the process of application, enrollment and participation. Knowledge is empowering. Partnering with patients through the process can bring far more measurable success.

As the group meeting continued, Rachel walked those attending through the platform for Clara Health. For many of the attendees, this was highly effective in removing the computer intimidation factor: from following a URL (*www.clarahealth.com*) to entering the site, searching for specific trials and developing comfort with the steps that would lead to enrollment. *In live time*, any potential participant can send a request from the platform to either Lilly or Rachel for immediate partnering and guidance.

Energetic discussion followed the presentation and there was a measurable increase in enthusiasm and confidence in the clinical trial process, especially with the added "bump" of partnership with our constituents. We welcome Clara Health and our new friends Lilly and Rachel into our expanding services.

> ***I didn't know it a few years ago, but patients saved my life. Because of the brave patients who took part in clinical trials, the biologic I take was approved by the FDA. I now have the remarkable opportunity to pay it forward and support the patients who allow me to live fearlessly.***
>
> ***~ Lilly Stairs***

* * *

SFNE SUPPORT GROUPS

Massachusetts

Boston Support Group
Boston University Medical Center
Shapiro Building, 1st Floor Conf. Room
Meets the 3rd Sunday of every month, 2pm
Group Leader: Carol Taylor
774-233-0558, cvsing@comcast.net

Fall River/Bristol County Support Group
Meets the 3rd Tuesday of every month
6:30 - 8:30pm
Stop & Shop Conf. Room
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 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 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
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 every month
Brattleboro Memorial Hospital, 6:00 - 7:30pm
Group Leader: Ilene Wax
802-464-5847, ilenewax@gmail.com

Maine

Maine Support Group
Windham Public Library 11 am - 1 pm
Next meeting in the Spring of 2018
Group Leader: Sandy Lunner
207-420-3337
slunner@aol.com

South Berwick Support Group
Madison's Cafe
Monthly meeting - Tuesday
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

HOW YOGA HAS HELPED ME MANAGE MY SCLERODERMA

By: Lori Pierce

Editor's note: The following is based on an individual's experience and shouldn't be taken as medical advice. Please consult your doctor before starting new treatment or activity programs.

I started yoga back in 2010. I had just been sidelined from work and knew I needed to start focusing on some other things in life. Like taking care of my body – as a job. At the time of my first class, I was unable to put socks on by myself without an assistive device or my husband's help. My flexibility was all but non-existent. It's not superb now, but it's improved. Thanks to yoga.

Yoga helped me so much more than physically. The increased movement was what opened the door for me. Then, the community of people I started finding myself around was so welcoming and people wanted to understand my condition and wanted to be able to help me lead an easier life.

Through the yoga studio, I was turned onto massage therapy. I had been for massages before, and yet, when I met Annette, my massage life changed. I now get a weekly massage – hands on my muscles, as well as another set of eyes, so to speak, that is in tune with me and aware of when things are different and might need some extra attention.

Annette is also a yoga instructor. At the beginning of our relationship, we also began one-on-one yoga sessions. She was able to help me learn how to modify postures even more so I was reaping the benefits, even if I didn't look like a yoga journal model. The additional ideas were confidence builders and helped me realize even more that yoga was going to be a part of my life forever.

For me, this all become a transformative period in life. I found my attitude towards life and people changing. As my body was feeling better I was just better. I decided to dive deeper and took yoga teacher training. I wasn't sure I could do it. I mean, *my* yoga looked absolutely nothing like anyone else's yoga. I didn't do it with the intent of actually teaching yoga, either. It was more for myself. So I could learn to help my body more. Here's the thing though: yoga is personal. Yoga is different for everyone. (Sounds a little like having scleroderma, right?)

Everyone can do yoga. Even if you can barely move. Some of "doing yoga" is really in your mind's eye. Just thinking of your body part moving in a specific way activates those areas of the body, whether they move a millimeter or not at all. Remember, just because we can't see something doesn't mean it's not happening. As scleroderma warriors, we're experts at that idea!

During the yoga teacher training, my life transformed in ways I never imagined.

There's an anatomy portion to learning to teach yoga. I learned so much about the physical body and could apply what I was learning to get a better picture of how my body was being affected by scleroderma. I learned more postures that could benefit me in the future.

There are portions that teach us about our breathing and how it affects our health. There are teachings on how to feed and nourish our bodies properly. Teachings on feeding and nourishing our minds and how we talk to ourselves and others. All of which has an impact on our health.

I have recently partnered with a yoga teacher (who doesn't have scleroderma) who offers Yoga for Scleroderma and we've begun to lecture and teach scleroderma (and chronically ill) warriors across the country how to improve their health with yoga. One of her clients at her home studio began practicing yoga with her just over a year ago after recently being diagnosed with scleroderma. This individual had begun doing yoga in a chair. In the year since, she has:

- *Reversed* effects that scleroderma had in curling her fingers

- Improved her lung function tests (due to a yogic breathing practice)

- Been able to complete her yoga practice on the floor instead of a chair

It can really improve our overall health and wellness!

Yoga is more than just the moving practice, known as asana, that we often think of where folks have their foot behind their head. Yes, there are some *very* bendy yogis out there. Good for them.

If you really study yoga as a lifestyle, it has a "spiritual" component to it as well which spoke to me. In yogic texts there is little instruction or guidance on the movement portion we know today. The benefits of the moving practice can spill into so many other aspects of our health and our lives.

It can be life-changing, if we're open to it.

It can also simply help us move better, and that's OK, too! I believe moving our bodies is essential.

Diagnosed with scleroderma at 25, Lori Pierce is an active scleroderma awareness blogger, helps to run a yoga studio in Tampa, FL, and has started to lecture and teach other scleroderma (and chronically ill) warriors across the country how to improve their health with yoga (www.yogaforscleroderma.com).

Lori is a contributor on TheMighty.com You can follow her at www.scleroscoop.com, and she can be contacted via email at scleroscoop@gmail.com.

SCLERODERMA FOUNDATION
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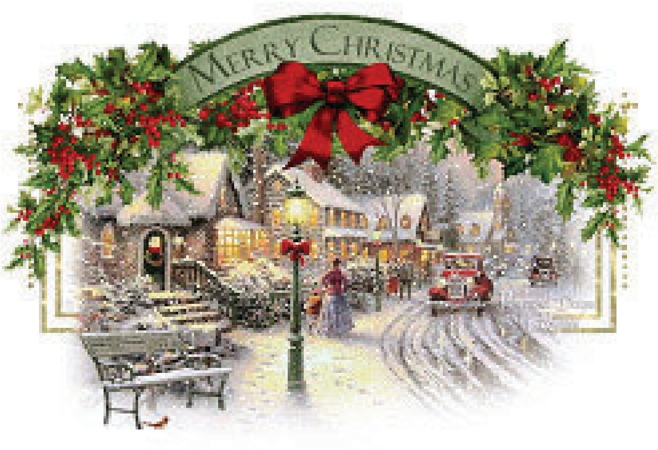


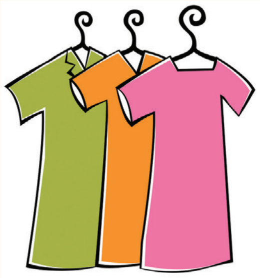
The Scleroderma Foundation New England wishes you and your loved ones a wonderful holiday season and a very happy and healthy new year.

Jack Rebecca

PUZZLE ANSWERS

Congratulations to Mary Jane Solimine of Lynn, MA, the winner of our Summer BEACON puzzle! See the correct answers below.

1. Scarf
2. Cloak
3. Glove
4. Bikini
5. Sarong
6. Bonnet
7. Dress
8. Shawl
9. Stocking



FOR YOUR ENJOYMENT

Match the numerical measurement on the left with the product on the right to which it relates.

Example: 8”x10” - photograph

1. 10cc ______	a. air conditioner
2. 35mm_____	b. stock price
3. 32W 35L________	c. telescope
4. $17^{3/8} + {}^{1/4}$ ______	d. film
5. 200X _______	e. noise
6. 250BTU _______	f. pants
7. 95wpm _______	g. typing
8. 95 dB_____	h. medicine