Volunteer of the Year Inside!

NEW ENGLAND

The BEACON

A Publication of Scleroderma Foundation New England

Fall 2018

PHYSICIAN-PATIENT COMMUNICATION

By: Rebecca Dube

Have you ever left the doctor's office confused, or frustrated that your questions weren't answered, or that you didn't ask them in the first place? You are not alone. A recent study titled *Divided by a Common Language*, sponsored in part by Boehringer Ingleheim, looked at the challenges that often occur in physician-patient communications when discussing systemic scleroderma with interstitial lung disease (SSc-ILD).

The study assessed 23 consultations in five countries between rheumatologists or pulmonologists and SSc-ILD patients between 34 and 79 years old. The authors studied how physicians and patients communicated in those consultations, and sought to identify any information gaps in their mutual understanding afterward.

Many of the consultations were very effective, with the physician asking the patient to share his or her story, then guiding the patient to provide the necessary clinical information. The physicians often expressed empathy, built a rapport with the patient, and checked the patient's understanding of the information the physician was providing.

However, as in life, this was not always the case, as sometimes physicians directed the conversation so that the patient had little opportunity to explain their concerns or ask questions. Sometimes they did not give the patient a chance to answer a question, or asked two questions at once, confusing the patient or giving the impression that the physician was in a hurry. Have you ever had that kind of exchange? Has it made you ask less than you were meaning to? One patient in a consultation noted, "[The doctor] was talking nonstop." Another one stated, "He had his things to say. He did not stop to listen to what I was saying." A third patient added, "Sometimes I see him writing in the computer and he asks me 'And how have you been?' And he keeps writing." Sound familiar?

It is important to stress that this is not all physicians all of the time. Many build a wonderful rapport with their patients and check for full understanding. However, patients' understanding of SSc-ILD often differed from the medical model and was only partially correct. Physicians often use medical

(continued on page 4)

PATIENT INVENTION INITIATIVE

By: Gary Gray and Eva Guinan, Harvard Catalyst team

The collaboration between SFNE, Harvard Catalyst, and the Little Devices Lab at MIT continues, as described in the Summer 2018 issue of the *Beacon*. Our goal remains the same; to support patients and their community of care providers in the design and development of inventions and innovations to improve scleroderma patients' lives. In mid-August, we met at the Little Devices Lab at MIT to design the first prototype devices. A group of SFNE constituents traveled with us to work directly with José Gomez-Marquez's design team, led by Nik Albaran and Harvard Catalyst colleagues, Eva Guinan and Gary Gray. José and his team took ideas generated in a brainstorming session with SFNE members and worked with scleroderma patients to demonstrate how they could fashion and begin to improve upon prototype devices.

(continued on page 4)

IN THIS ISSUE

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

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

Rebecca Dube, Editor

SFNE is a 501(c)(3) organization. All contributions are tax deductible and should be sent to the above address.
Tel: 978-887-0658 Fax: 978-887-0659
E-mail: sclerodermainfo@sfnewengland.org
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.

VOLUNTEER OF THE YEAR - JANE LADAS

Jane Ladas (left) with Support Group Leader Carol Taylor at the Boston Walk

In this issue we proudly announce the volunteer of the year - Jane Ladas. Jane is a board member and volunteer who gets directly involved with our constituents and supporters at various events. She attends the Fall Support Group Leader Luncheon, serves meals and takes photos for the annual SFNE Golf Classic, and helps with the many chores of both the Boston Walk and the Patient Education Seminar, always with a helping hand and a winning smile.

Jane came to the board of directors after connecting with Jack Armitage at a cultural event. She already had a long-time friendship with founder Marie Coyle, and had been active in the medical field as a National Clinical Accounts Manager for Medical Affairs at Astrazeneca. After retirement, she saw an opportunity to continue to give back to the community as a board member for SFNE.

Jane has a warm demeanor, a vibrant presence, and is always willing to participate and be a part of an event. She solicits raffle/silent auction gifts for the Golf Classic, and doubles her contributions by also being a member of the Scleroderma Foundation national organization's board!

We honor and thank Jane for all of her time and effort on so many fronts. She is truly a great asset to this organization.

* * *

Jane Ladas (left) with fellow board member Tony Cappellucci at the 2017 Fall Support Group Leader Luncheon

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

Scleroderma Foundation New England is a dynamic and ever-changing organization. The outcome of this dynamism is consistent, providing improved service to our constituents, ensuring a steady building of the energy to fulfill our mission to *support*, to *educate* and to enthuse *research*.

We were so fortunate this year in increasing our staff by one. Working with Rebecca, Anne Sweeney has added to our confident presentation of events and increased support of constituency with talent and dedication. Many of you in our readership have, by now, enjoyed conversations with this newly empowered duo. The immediate and measurable impact in our support group leadership, our team captaincy for Walks and our bottom line in research funds raised is notable. We foresee creative new successes ahead with Rebecca and Anne working as a team.

Reflecting on our history, we continue to elevate Marie Coyle and her vision with gratitude. Decisions are often tough to make in small rare disease organizations and routinely, as we make tough choices, the litmus for the outcome of discussion is the question, "What would Marie do?" As the historian and visionary behind Scleroderma Foundation New England, Marie's influence continues to be constant.

We continue to build our board of directors and have admirable and diverse leadership. Because we are diligent in honoring our term limits for board members, we regularly change up the mix and welcome new voices to the leadership of SFNE. Key to our success is this active and invested ongoing nurturing of our governance.

Our volunteer base shows a measurable increase in vibrancy and has become an extension of our staff in many ways. First, our support group leaders (SGLs) are highly invested in the outcome and success of our mission, and meet as a group twice annually to compare success and to increase the breadth of their outreach (page 8). Our events volunteers and regional Walk leadership continue to astonish us. Most notable is the increasing base of regional contributors to the Maine Walk, the Boston Walk, the North Shore Walk and the Westfield Walk (pages 6 & 7).

Our successes in Plymouth have led us to discuss a new model for next year's event, about which we are very excited. Andrew Botieri and Johnny Medlin are in discussion with us currently about this. In Worcester, we are grateful to Deb Magnuson and her nearly 17-year partnership with the Bancroft School. In all, we are inspired by so many people who have willingly added themselves to our goal to find a cause and a cure for scleroderma in our lifetime.

This issue of The *BEACON* addresses the often delicate topic of self-advocacy and representation (page 1) in the often unfulfilling conversations between patients and practitioners. Be encouraged to know that you are not alone in your challenges and that we will continue to be sensitive to what can often be lost in these essential and frank discussions. We would love to have your feedback in this ongoing discussion.

To our third party events hosts, we are so grateful to you for your annual efforts to support our cause. Jeanne Oliviera – your quiet dedication to us via the Montauk Club Charity Day Golf Tournament is an annual high point for us. Ray Fernandez, thank you as always, for making us measurably more influential in our efforts to find a cure by including us in the Lynda Fernandes Golf Tournament proceeds.

We are opening the winter storage closet for the supplies that make our events doable. The canopies are packed away, contracts renewed for next year, plans in place for another vibrant fund raising season in the building of our war chest against scleroderma's advance. We ask for your continued diligence and partnership as we keep our support of research and patient care in the forefront of our daily goals. Stay in touch with us, reach out to the office, continue to educate at the peer level. We are a growing dynamic force against this tough and often unrelenting disease. As researchers and patients will attest, there is progress. There is hope. There is a future in our shared effort.

Enjoy this issue of The *BEACON*. Your efforts and commitment continue to inspire us.

* * *

> ***"The price of success is hard work, dedication to the job at hand, and the determination that whether we win or lose we have applied the best of ourselves to the task at hand."***
>
> ***~ Vince Lombardi***

PHYSICIAN-PATIENT COMMUNICATION

(continued from page 1)

terms when talking to patients, and patients often reiterate these terms without fully understanding them. When physicians used metaphors to explain concepts the patients had a better understanding.

This study showed that physicians in general need to develop better strategies for communicating with patients. Giving patients an opportunity to tell their story, building rapport and checking understanding, and using metaphors to explain complex concepts all improve communication and understanding of the disease.

Communication is a two-way street.

Patients sometimes feel like they did not get all of the information that they wanted from a consultation. Often it is because they were too embarrassed or intimidated to ask the questions of their concerns. These concerns run the spectrum, but include work, eating and drinking, sexuality, altered appearance, exercise, pregnancy and children, or holidays. When patients want the answers, they are afraid or unsure on how to ask the questions. These questions include:

- Where did I get it from?
- Can I pass it to my children?
- Can I have children?
- Will I be on these drugs for life?
- Can I still work?
- How do I cope with reflux?
- How do I keep warm?
- Am I going to die?

These are a sampling of the questions gathered from 21 patients in five countries in a second study by the same group (see credits at end of article) titled *Things Left Unsaid*. This study also included 42 physicians, 16 specialist nurses and five caregivers. Questions from caregivers echoed those of the patients, but also included "What help can I get with housekeeping/child care?"

A healthcare team can help to break down barriers and get a patient's questions answered, but the physician or team may not have all the answers yet on how the disease will progress with each particular person. With scleroderma, the path of the disease is unpredictable and is difficult to ascertain in the early stages of the disease.

While patients want a degree of certainty and predictability in developing a plan to manage their condition, physicians find this difficult to assess until they see more of its progress. They at times try to avoid answering questions on the future course of the disease, for fear of causing unnecessary distress. This can leave a patient feeling frustrated when they need to feel that the physician is in control. Patients are uncertain about the future and feel less equipped to manage the disease.

This study found that death and disease course are topics not often discussed between a physician and a patient, but are the most relevant for those dealing with SSc-ILD and their care team. If healthcare professionals use a team-based approach and proactively raise the difficult issues of disease course, communications may improve for patients, caregivers and health teams alike.

Both studies were authored by C.P. Denton, B. Laird, L. Moros, J.L. Luna Flores, Royal Free Hospital, London, UK; The Research Unit, UK, Boehringer Ingleheim, Ingleheim, Germany and were presented in poster form at the Scleroderma Foundation 2018 Patient Education Conference. A .pdf version of the posters can be found on our website at www.scleroderma.org/newengland.

INVENTION INITIATIVE

(continued from page 1)

These included the following: a conductive stylus for technology otherwise impossible for scleroderma-affected fingers; a shower wand for hard-to-reach places; a "grabber" to assist people with compromised dexterity and strength; and a device to assist in closing car liftgates.

The scleroderma group left the meeting with the prototype devices described above. They were instructed to use them in their daily lives and "try to break them". The goal was to see how the prototypes performed in a real-world setting, how well they addressed the stated needs, and how the devices could be improved. They are not final products, but will form the basis for continued rounds of collaborative development between Little Device lab and SFNE members. A collaborative web site (*MakerHealth*) has been established where both SFNE members and researchers can contribute their experiences with the prototype devices, suggest improvements and modifications, and identify new opportunities for related or new devices.

In addition to the MakerHealth site, in December we will reconvene the original SFNE and Little Devices working group at the SFNE offices in Topsfield for a face-to-face meeting to review progress with the prototype devices and begin the second round of device design and development based on user experiences. To join us in this meeting, contact Anne Sweeney (asweeney@sfnewengland.org) at the New England office.

* * *

BRINGING DR. SIMMS TO THE BOSTON SUPPORT GROUP

By: Carol Taylor, Boston Support Group leader

A special thanks to Robert W. Simms, MD, Chief of the Section of Rheumatology and Professor of Medicine at the Boston University School of Medicine for his appearance as guest speaker at the Boston Scleroderma Support Group meeting on September 16.

Dr. Simms graciously accepted our invitation to be the guest speaker at a special meeting when four new members expressed a desire to experience a support group. We have not had four new patients attend our support group at one time before!

Each of the new members had contacted me earlier for information about the group and expressed a desire to experience our group in person. At the August meeting each new member shared his or her story and we listened with our hearts open. All of us spoke of our own experiences with this disease and the treatment plans started for combating the diseases progression.

We also gave them encouragement in facing the many challenges of this disease. It was one of our finest hours as a support group. There are no words to express the feelings of connectedness that all of us felt at the end of that meeting. I can honestly say that the the caring and trusting of one another in a support group setting can be the beginning of healing the heart and spirit when faced with this disease or any other. It was definitely a humbling experience for all of us.

Dr. Simms speaking at the Boston Walk

I knew after that meeting it would be helpful to our newest members if they could hear more about this disease from a leading scleroderma expert. I was hoping to get Dr. Simms as speaker as he has been a staunch supporter of the foundation and of our Boston support group. I remained hopeful that even with a short notice he still would be able to attend the September meeting.

I emailed him with an invitation out of concern for our newest members who bravely shared their difficulties and their feelings at the August support group meeting.

Not surprisingly, I received a response from Dr. Simms stating his delight in the invitation and that he would be available to speak at the September meeting. He asked me if I had something specific for him to get across. I requested the talk and screen demonstration he gave to our group awhile back about the “rogue cells” and how they took over the good cells.

All eyes and ears were upon him as each member listened attentively to his presentation. When he finished, he gladly stayed behind to answer any questions. Afterwards, our group expressed their appreciation and said they learned a lot. He spoke with perfect clarity and the information he gave was reassuring, especially to our newest members.

Thank you Dr. Simms!

DR. FLAVIA CASTELINO VISITS WORCESTER SUPPORT GROUP

At the end of summer, Worcester support group leader Nancy Velleco contacted SFNE to request a visit from Dr. Flavia Castelino, Director of the Massachusetts General Hospital Scleroderma Program.

Program and Events Specialist Anne Sweeney connected Dr. Castelino with Nancy who agreed on a presentation at the October support group meeting.

In October, Dr. Castelino journeyed to Worcester and spoke with the group about clinical trials - the benefits, the procedures, and the need for participants. The meeting was well received by all.

Dr. Flavia Castelino

We would like to thank Dr. Castelio for taking the time to speak with the group, as well as Nancy Valleco for requesting this educational meeting for her group. And of course thank you to Anne for bringing the two together!

If you would like to become a member of the Worcester group, or any one of the New England support groups, check out the individual leader contact information on page 10.

STEPPING OUT TO CURE SCLERODERMA

THE 16TH ANNUAL NORTH SHORE WALK

Change can be good! Mere weeks before the North Shore Walk was meant to launch, we received notice from the Proctor School that their gym was under delayed construction and that we would not be able to hold the event from the gym, as we had for fourteen years. Of course, we rallied and went into warp speed to resolve the challenge.

Working with the incredible Proctor School Principal, Sarah O'Leary, Plan B emerged – we would use the main hallways of the school and launch the Walk from the South entrance. Our expectations were exceeded and we learned to love the new arrangement. Rebecca and Anne will surely follow this new format going into future years.

Team Jennifer walks in memory of Jennifer Valianti.

The event was vibrant and successful – we raised nearly $26,000 thanks to the amazing efforts of our walkers. A shout-out of thanks to Krissy Scollin and her expansive team for bringing $5,620 to the Walk. Krissy, your team, your family and your friends continue to raise the bar and bring us closer to a cure. Tricia Legere's team brought an amazing $4,915 to the Walk, Followed by Team Marcie at $1,910 and Team Jennifer, our newest team, bringing $1,810 in memory of Jennifer Valianti.

New participant volunteers came from several teams and our special

(continued on page 7)

WALKING IN WESTFIELD

Family and community are herald concepts at the annual Westfield Walk in Westfield, MA. The Broderick, Pozgar and Stackpole families come together to coordinate a community of supporters and volunteers who bring hope and comfort to all attending this event. "It's like a big hug to see everyone's support," says walker and honoree Nina Pozgar. "As a person living with scleroderma, sometimes it's just what you need."

Volunteers from Sami Stackpole's high school, the Southampton Road school, friends and family showed their support by coming out to help and participate in the day at Stanley Park. The bean bag toss game that Sami won last year was a hit, with many games being played. The raffle was vibrant as ever. A frequent winner was George Pozgar, who invested well in raffle tickets, but often gave away his prizes once he received them! We thank George for his generous support.

Members of Team Sami

The event hosted 104 walkers and raised $9,807. This year's walk introduced some new teams to the group: #Aramis Strong, Estelle Streeter, Team Sullipenn, and Wendy's Walkers. The latter team included Victoria Frazier, from our Spaghetti for Scleroderma event in February, and her sister walking in honor of their mother Wendy. Two members of Karin's Krew, from the North Shore Walk, participated in Westfield as well.

Victoria Frazier (right) and her sister Jackie walk in their mother Wendy's honor.

Additional Gold Sponsor Reata Pharmaceuticals provided materials on their current clinical trial. Also attending was Dr. Deborah Rothman, who works with pediatric scleroderma at the Massachusetts General Hospital for Children in Springfield, MA. (Look for her contact information on page 9.*)*

We'd like to thank the Broderick, Pozgar, and Stackpole families, all the volunteers, donors and walkers for taking such crucial roles in working to raise funds for support and education programs, and to research a cure. An amazing community indeed.

* * *

THE 16TH ANNUAL NORTH SHORE WALK

(continued from page 6)

thanks to Jenn and Jeffrey Krisko for their energetic and committed volunteering! Return volunteers included Pat O'Connor, Ed Blum, Paul Beaulieu, Tom and Cathy Curran, Tony Cappellucci, Joyce Steyer, Patty Meaney, Toni Micalizzi, Jean and Don Chapman, North Shore Support Group members Roberta, Joan, Bunny, Pat, Tricia, and Shelly Marinucci, our cheerful return volunteer (and Joan's daughter). As she always does, Donna Ahern brought a strong team of walkers and a beautiful raffle centerpiece! Karin's Krew made a strong impact with beautiful new red t-shirts this year.

As we revisit these Walks and events that sustain us, we need to remember with gratitude that the Scleroderma Foundation seed funds these events via grants from the pharmaceuticals companies that support us in our zeal to find a cure – great thanks to the national office, Actelion, Boehringer Ingleheim, Bayer and Reata pharmaceuticals companies.

Finally, we send out our special encouragement and thoughts to the family of Jennifer Valianti, our ongoing thanks to the Topsfield Police, local sponsors, all departments in the Town Hall and to all who have supported us in this successful regional walk. We look forward to the 2019 North Shore Walk, embracing change!

Team Donna

* * *

See an expanded photo album of these Walks on our Facebook page, *sfnewengland*.

GROWING IN BOSTON

The Corbus Pharmaceuticals Team

The Boston Walk continues to grow as we add sponsors, medical teams, DJs, and a crack volunteer base. Boston support group leader Carol Taylor helped pull together a team of solicitors and volunteers to help with the many elements required for a successful walk. Members of the Coughlin, Ulrich, Olsen and McGinn families joined in and brought amazing raffle gifts, teams of walkers, and helping hands to the event.

This year we added a diamond sponsor, Corbus Pharmaceuticals, who provided their own booth with information on their Phase 3 clinical trials for people with systemic sclerosis. Lindsey Smith was at the forefront of this effort – thank you! Corbus Director of Clinical Research Scott Constantine spoke at the launch of the walk.

The 2018 walk was held in memory of Christine T. Maroney, Fall River/Bristol County support group co-leader who loved to volunteer at the walk. It included teams from Corbus Pharmaceuticals, Massachusetts General Hospital, Boston University Medical Center, and the Garlick Lab at Tufts University. These teams were joined by Brenda's Buddies, Marching for Maggie, Mama's K.I.D.S., Team Heather, Irene Lowney, Teams Sonia and Sunshine, and the Fall River/Bristol County team, along with plenty of single walkers.

WROR radio's street team joined the day with music and lawn games, accompanied by on-air personality Lauren Beckham Falcone (LBF) from the Loren and Wally Show (different Loren!). Lauren was familiar with scleroderma, as the mother of her high school friend lived with the disease. Genevieve Coughlin, Michelle Zayas and Mary Ulrich put together an amazing raffle while Logan Coughlin offered balloon animals and Lisa Ferreira painted faces with bright designs.

Raffle stars Michelle Zayas and Genevieve Coughlin

Kevin Conroy led the walk with bagpipes playing, and Carl Botti offered his videography skills to put together a wonderful video of the walk. Check out his work on the Scleroderma Foundation New England YouTube page under videos. You can also go to our web page *www.scleroderma.org/newengland*.

The walk hosted 200 walkers and raised an amazing $24,716! Our sincere thanks go out to DCR Artesani Park, Carol Taylor, all of our volunteers and solicitors, the walkers, donors, and sponsors, which include Central Fund Sponsors Actelion Pharmaceuticals, Bayer, Reata, and Boehringer-Ingleheim. We look forward to an even larger event with more fun next year!

* * *

SUPPORT GROUP LEADER FALL LUNCHEON

Back row left to right: Anne Sweeney, Rebecca Dube, Debbie Magnuson, David Magnuson, Donna Chouramanis, Beth Gagnon, Don Chapman, Ilene Wax, Carla King, Tim Gray, Tony Cappellucci, Jane Ladas. Front row left to right: Sandy Lunner, Donna Ahern, Jean Chapman, Roberta Mauriello, Joan Kingsbury, Bunny Cappellucci .

Each year we at Scleroderma Foundation New England (SFNE) like to thank one of our most important assets – our support group leaders – with a luncheon and support meeting of their own. For the past two years we have held this event at the Breakaway Restaurant in Danvers, MA, in part due to its facilitation of a roundtable discussion area (without the table!)

Prior to the luncheon, support group leaders and guests along with the SFNE staff meet in a large circle to discuss the benefits and challenges of managing a support group. Both leaders and guests share ideas and insights for running an effective group, and offer support and encouragement to each other.

“The purpose of this luncheon is to thank our support group leaders and provide support for them,” noted Executive Director Jack Armitage. “Without these leaders we would not be able to justify our mission and claims for success.”

Topics discussed included ways to bring your group together socially as well as a support setting, positively dealing with challenging member dynamics, creating a speaker’s list for groups to use for education, and sharing ground rules with a group. Beth Gagnon showed the participants a product that worked for her, a ring guard that enabled larger rings to fit when fingers weren’t swollen. Roberta Mauriello invited other groups to join her group’s upcoming meeting with Attorney Mark Bronstein. The relationships that form in a support group are “the bonding that keeps a group together” said Roberta. “It’s a family,” added Don Chapman.

Twenty-one people attended, including board members Tony Cappellucci and Jane Ladas. The meeting ended with a delicious meal and group photo. Thank you so much to our hard-working support group leaders that offer such a valuable service to this organization and to all the people they serve.

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

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

NEWS BYTES

MONTAUP CLUB CHARITY DAY GOLF TOURNAMENT

The Montaup Country Club distributed the proceeds from their annual Montaup Charity Day Golf tournament to 24 charities this year. SFNE is proud to say it received one of the largest disbursments at $2,000! Thank you to the Fall River/Bristol County Support Group for being a part of this amazing event, and thank you to Montaup Country Club! Thanks, too, to Jeanne Oliveira for her efforts to secure this donation.

Back row left to right: Mark Oliveira, Jeanne Oliveira, Brenda Pomprowicz. Front row: left to right: Jean Souza and Donna Bernier.

PEDIATRIC RHEUMATOLOGIST IN SPRINGFIELD, MA

Dr. Deborah Rothman is a practicing pediatric rheumatologist at the Massachusetts General Hospital for Children at 3640 Main Street in Springfield, MA. You can reach her at 413-304-2650 or *drothman@mgh.harvard.edu.*

> ***Check out a video of the 2018 Boston Walk on our YouTube page, or visit our website!***

LYNDA FERNANDES GOLF TOURNAMENT

The Lynda Fernandes Golf Tournament, which is held every year at the Midville Country Club in West Warwick, RI in early September, raised $1,435 for SFNE's mission. This year marked its 15th year. Thank you to Ray Fernandes and all the participants for their support!

#GIVINGTUESDAY™
November 27, 2018

Did you remember Giving Tuesday this year? There is still time to give in 2018! You can make a donation online at *scleroderma.org/newengland.* Share an "unselfie" on Facebook (see below), Instagram or Twitter with our website address and #unselfie or #givingtuesday on a sign along with your reason for giving, now or any other time, asking others to give over Twitter and other platforms. You can also mail a donation in the envelope included in this newsletter. Join the over 30,000 partners in 68 countries taking part in this annual day of giving.

I'm supporting SFNE because SFNE supports me.

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

CORBUS PHARMACEUTICALS RECEIVES PATENT

By: Rebecca Dube

Corbus Pharmaceuticals, a diamond sponsor at the Fourth Annual Boston Stepping out to Cure Scleroderma Walk, has recently received a new patent from the U.S. Patent and Trademark Office that covers the use of investigational lenabasum-based therapies for the treatment of fibrotic diseases, including scleroderma.

This patent allows Corbus to have exclusive rights to use lenabasum-based pharmaceutical compositions in the U.S. until the year 2034. Corbus already has other patents and applications to cover the composition, synthesis, manufacturing, formulation and applications of lenabasum. They are targeting a 2021 launch for systemic sclerosis.

Lenabasum is a synthetic oral cannabinoid designed to treat rare, serious autoimmune disease. It binds and activates the body's cannabinoid receptor type 2 (CB2). This protein is present in activated immune cells, fibroblasts, muscle cells and cells lining the inner part of blood vessels. Lenabasum activates CB2, promoting the production of molecules that help reduce inflammation as well as speeding up the killing of bacteria without compromising the immune system. The drug also limits the production of fibrosis-inducing proteins in fibroblasts.

In studies, the molecule has shown promising results in animal models of skin and lung fibrosis, as well as inflammation. Phase 2 and other clinical trials have yielded positive data. Additional studies are being planned and/or conducted to confirm results so Corbus can apply for regulatory approval of lenabasum.

The company is currently recruiting patients with diffuse cutaneous scleroderma for the Phase 3 RESOLVE-1 trial assessing the efficacy and safety of lenabasum. An estimated 354 patients are expected to be enrolled in the study at some 60 sites in North America, Europe, Australia and Asia. For more information on the trial and how you can participate, contact *SScpatients@corbuspharma.com*. You can find the full study at *ClinicalTrials.gov* with reference number NCT03398837 (Phase 3 SSc).

The information in this article was sourced from the October 22 press release at corbuspharma.com and the October 9 article by Diogo Pinto at SclerodermaNews.com.

Corbus Pharmaceuticals is a clinical stage drug development company with a pipeline focused on treating inflammatory and fibrotic diseases by targeting the endocannabinoid system.

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, 603-465-7647
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/South Burlington)
Meets each month on Wednesday or Saturday
Group Leader: Blythe Leonard
802-324-4826, blythe.leonard62@gmail.com

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
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.

CONGRATULATIONS TO THE TOP 15 WALK TEAMS OF 2018!

We are proud of and grateful to all of the teams and individuals who participated in our Stepping Out to Cure Scleroderma Walks in 2018. Your support and dedication make it all happen for SFNE and our constituents throughout the year. In this space, we recognize our top 15 teams. We look forward to another exciting season in 2019 working with dedicated teams, participants and volunteers while having a great time! Our contribution to the research effort comes from you!

1	**Team Krissy**	North Shore Walk	$5,620.00
2	**Tricia's Team**	North Shore Walk	$4,915.00
3	**Team Medlin**	Plymouth Walk	$4,863.00
4	**Tina's Warriors**	Plymouth Walk	$3,939.00
5	**Team Magnuson**	Worcester Walk	$3,665.00
6	**Team Heather B**	Maine Walk	$3,405.00
7	**Brenda's Buddies**	Boston Walk	$3,115.00
8	**ShanGinaNinaTeam**	Westfield Walk	$2,966.00
9	**Team Estelle**	Worcester Walk	$2,875.00
10	**Team Heather**	Boston Walk	$2,850.00
11	**Corbus Pharma**	Boston Walk	$2,135.00
12	**Team Sami**	Westfield Walk	$2,064.00
13	**Team Marcie**	North Shore Walk	$1,910.00
14	**Team Jennifer**	North Shore Walk	$1,810.00
15	**Team Phyllis**	Worcester Walk	$1,722.00

Team Krissy

Brenda's Buddies

Team Medlin

SCLERODERMA
FOUNDATION
NEW ENGLAND
SUPPORT ★ EDUCATION ★ RESEARCH
New England Chapter
462 Boston Street, Suite 1-1
Topsfield, MA 01983

ADDRESS SERVICE REQUESTED

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

MAY YOUR DAYS BE MERRY AND BRIGHT!

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

Jack Rebecca Anne

PRODUCTS THAT BENEFIT

The Trolley Dolly shopping cart is an excellent tool for carrying groceries, laundry, or any items up and down stairs, over curbs, or any rough terrain. It has been tested and continues to be used by North Shore support group leader Roberta Mauriello, who finds it very effective for bringing items to meetings in buildings accessed by stairs.

It has oversized wheels on a round of three that easily move over stairs without big thumps. It is collapsable, portable, and lightweight. Prices range from $40-$60 and the Trolley Dolly can be found on Amazon. You can even view videos of its use on YouTube!

The Trolley Dolly