



NEW ENGLAND The BEACON

A Publication of Scleroderma Foundation New England

Fall 2019

ROBERTA MAURIELLO: NATIONAL SUPPORT GROUP LEADER OF THE YEAR



Roberta accepts her leadership award

It is understatement to say that Roberta Mauriello is very special to us at Scleroderma Foundation New England. It was confirmed in a big way by the recent award that she was given at the 2019 Scleroderma Foundation National Conference in Chicago. In front of an audience of just under 1,000 attendees, Roberta's name was called as she

was awarded the *Support Group Leader of the Year* award.

Roberta has been an unsung hero of scleroderma for many years – mostly because she very quickly brushes aside any suggestion that she is incredible, valued and respected. There was no brushing it aside this time and in front of a national conference of patients, caregivers, staff and peers, Roberta received a long-deserved recognition by the scleroderma leadership.

We were able to surprise her with the award with family and friends present at the annual Fuddruckers fundraiser that she and Fran host each year. With a crowd of about forty onlookers, we gave Roberta her much deserved acknowledgment.

Moved by this deserved recognition, Roberta responded saying, *"I am deeply honored, humbled and grateful*

to receive the award of National Scleroderma Foundation Support Group Volunteer of the Year!"

Thank you to the Scleroderma Foundation for selecting me, and to all who have helped me achieve this award, especially my husband, Fran, who has always assisted me. I hope to continue to be available for whomever needs me in the future.

I will always cherish This Award!"

Congratulations Roberta! We are lucky to have you as our own here in New England. What you accomplish for people living with scleroderma is nothing short of remarkable. You are a true crusader for a cure and a remarkable caregiver for those who land in your path, call you on the phone, attend your meetings and count on you for solid, honest and sincere advice.

A DAY WITH THE SCIENTISTS AT CORBUS PHARMACEUTICALS



Joan Meissner speaks passionately about the need to have access to affordable drugs and therapies.

June was a very busy month for us at SFNE, as we prepared for the Golf Classic and the Marshfield Comedy Night. We had just mailed out the Spring issue of The BEACON and knew that we had to accomplish the challenges of training new staff and meeting our budget development for the upcoming board meeting. In short, we were as busy as we could be. And still, in an enthusiastic ongoing plan with our friend Lindsey Smith, Associate Director, Patient Engagement at Corbus Pharmaceuticals, we managed to

(continued on page 2)



IN THIS ISSUE

<i>Support Group Leader of the Year</i>	1
<i>Corbus Pharmaceuticals</i>	1
<i>From the Director's Desk</i>	3
<i>New Research Studies</i>	4
<i>2019 Golf Classic</i>	5
<i>Newsbytes</i>	6
<i>Stroll for Scleroderma, Events</i>	7
<i>SFNE Support Groups</i>	8

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

Jack Armitage, *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

Board of Directors

Don Legere, President
Katherine Bedard, Vice President
Tim Hagan, Treasurer
Steve Lang, Clerk
Jane Ladas
Brenda Brown Andrea Mahoney
Tony Cappellucci Joan Meissner
Jeff Daddio Christopher Simms

Board Advisors

Tom Curran, Walter Zagrobski

Executive Director Jack Armitage

Golf Classic Co-Chairs

Bruce Gordon David Rosenberg

Medical/Scientific Advisory Board

Vincent Falanga, M.D.
Boston, MA - (Dermatologist)
Carol Feghali-Bostwick, Ph.D.
Charleston, SC - (Researcher)
Harrison Farber, M.D.
Boston, MA - (Pulmonologist)
Humphrey Gardner, M.D.
Cambridge, MA - (Researcher)
Robert Lafyatis, M.D.
Pittsburgh, PA - (Rheumatologist)
David Leader, D.M.D.
Malden, MA - (Dentist)
Thomas Medsger, Jr., M.D.
Pittsburgh, PA - (Rheumatologist)
Nicole Orzechowski, D.O.
Lebanon, NH - (Rheumatologist)
Andrew Plaut, M.D.
Boston, MA - (Gastroenterologist)
Robert Simms, M.D.
Boston, MA - (Rheumatologist)
Michael Whitfield, Ph.D.
Lebanon, NH - (Ph.D. Scientist)
Michael York, M.D.
Boston, MA - (Rheumatologist)

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.

bring a remarkable group of our constituents living with scleroderma to speak as a panel to the full staff of more than 100 at Corbus headquarters. It was a day we will not soon forget and the acknowledgment and enthusiasm on both sides of the microphones was genuine.

Presenters for the day were SFNE board president Don Legere, SFNE board member Joan Meissner, support group co-leaders Roberta Mauriello and Joan Kingsbury, and Tricia Legere. We were further bolstered that Scleroderma Foundation CEO Robert Riggs attended, and our 2017 Volunteer of the Year and SFNE/SF board member Jane Ladas was added to our ranks! We were additionally gratified that partners and caregivers of most of those attending sat on the panel as well.

The day began with a session of interviews and storytelling with the goal that an internal film would emerge for use by Corbus in their very optimistic ongoing Phase 3 trials with lenabasum. Lenabasum is a synthetic cannabinoid receptor whose properties will hopefully continue to mitigate inflammation and the advance of fibrosis in patients with scleroderma. As Lindsey pointed out, it is one thing for all these diligent scientists to seek answers for fibrosis in a lab, and quite another for them to sit, meet, talk and bond with the very people they are hoping to assist.

As lay attendees in this very heady scientific setting, we all scrambled to

better understand the possibilities of this intensive research. Don Legere described it best, explaining to all of us that "lenabasum, as I understand it, is a drug which will induce your body to produce more cannabinoid receptors to boost the immune system to fight off diseases including lupus and scleroderma." Hope is the shared component of all who attended – as we often state with confidence in our meetings, we are seeking a cure for scleroderma in our lifetime. When nothing less is acceptable, we will do what it takes to hold the attention of this notable group of incredible researchers.

Imagine the wave of acknowledgment that I experienced as I read this follow-up message form Corbus founder and CEO, Yuval Cohen: *"Dear Jack, It was an honor and a pleasure having you all over. I can't begin to explain how much this means to us. Please extend my heartfelt thanks to each member of your extraordinary group. We are here to help any way we can."*

All of us at SFNE extend our thanks primarily to our constituents who are willing to venture into front line research despite the discomfort and personal stress. To Yuval Cohen and all of the researchers and support teams at Corbus, we are proud of this alliance and wait for forthcoming news of your successes. To Lindsey Smith, whose diligence and early vision resulted in this unforgettable meeting, we offer our deep thanks. And to all of our panelists and caregivers, you are the muscle behind our mission!



Corbus Pharmaceuticals Holdings, Inc. is a Phase 3 clinical-stage pharmaceutical company focused on the development and commercialization of novel therapeutics to treat inflammatory and fibrotic diseases by leveraging its pipeline of endocannabinoid system-targeting synthetic drug candidates.

The Company's lead product candidate, lenabasum, is a novel, synthetic, oral, selective cannabinoid receptor type 2 (CB2) agonist designed to resolve chronic inflammation and fibrotic processes. Lenabasum is currently being evaluated in systemic sclerosis (scleroderma), cystic fibrosis, dermatomyositis, and systemic lupus erythematosus.

Corbus is also developing a pipeline of drug candidates from more than 600 novel compounds targeting the endocannabinoid system. The pipeline includes CRB-4001, a 2nd generation, peripherally-restricted, selective cannabinoid receptor type 1 (CB1) inverse agonist. Potential indications for CRB-4001 include NASH, among others. Corbus plans to start a Phase 1 study of CRB-4001 in National Institutes of Health (NIH)-funded proof-of-concept Phase 2 study.



FROM THE DIRECTOR'S DESK

This issue of The BEACON is chock full of information about research, support group leadership, fund raising events and appeals for your ongoing support of our mission. Our lead story is long overdue. Roberta Mauriello is our unsung hero. Her award as National Support Group Leader of the Year is a recognition that sets her apart and acknowledges her dedication, skills and perseverance. We are so proud of Roberta and her deservedness of this award!

It is perhaps appropriate to describe the importance that our Support Groups Leaders hold for SFNE. Simply put, without them, we would have little justification of our efforts. They seek and find people who are living with scleroderma and direct their worries and fears into a monthly peer group discussion. They ease the burdens of diagnosis and complex medical follow-up. They teach and encourage caregivers. They communicate with each other to determine best methods and outcome and they bring their concerns to this office for representation and resolution. They often go without support themselves. They are the silent outreach team that finds, nourishes and strengthens our constituency. What free time they might have is often consumed in

outreach and referral. They ask for little in return. If we on the staff at SFNE are credited with doing our jobs well, it is largely because of the field work of our support group leadership. Roberta Mauriello is the most dedicated of this group. She is a Leader among leaders. Congratulations Roberta, thank you for your strengths and sophisticated skills. We are so proud to have you in our leadership and thank you and all our other support group leaders for your magnificence.

Research continues to be the #1 directive in our efforts. Every day, we affirm that we seek a cure for scleroderma, always adding "in our lifetime" to this goal. In the research realm, we have more leads than resources to resolve them, hence the imperative to continue to raise research dollars. We have been recognized and hosted by Corbus Pharmaceuticals and their research team in this quarter (story, p1). Their support of our mission is of critical importance to our dedication to find a cure. Meanwhile, at the Medical University of South Carolina, Dr. Carol Feghali-Bostwick continues to bring creative and groundbreaking research to the front lines (story, p4). You will read about her current efforts in determining the possible role that estrogen plays in the advancement of scleroderma in both men and women.

Our fundraising effort is ongoing and seemingly relentless. Because of the continued generosity of so many supporters, we have done well again this year. The Golf Classic continues to be the cornerstone of our organizational financial health, and our Walks for a Cure invest the energies and the dedication of our constituents, their families and supporters and their community businesses. By end of September, we will have hosted fourteen events and partnered with as many as five

third party find raisers.

Patient and caregiver education continues to be a priority here at SFNE. As well, awareness in the broader community. We are underway with plans for our 2020 Patient Education Seminar – mark your calendars for April 4, 2020.

I would like to thank our board of directors for their leadership and excellent governance in a year that has been challenged by staff turnover, competitive fundraising, the loss of Marie Coyle and the ongoing dynamic imperative of keeping this organization on track and focused and serving those diagnosed with scleroderma. We have successfully rewritten our most important governing documents with pro-bono assistance from the prestigious law firm Ropes and Gray. We are leading with both Succession and Strategic Plans that are preparing us for the future and we continue to be creative and open-minded at the board level with regard to embracing a leadership that reflects our constituency and a skillset that includes a breadth of professions. Our directors honor term limits and volunteer regularly at our events. Their collective generosity shows leadership and sets example for others to give generously as well.

As we round the corner toward our fourth quarter 2019, we are able to reflect on another year of successes despite this having been a stretch of unexpected surprises, recovery and positive change. This is to be expected in this rare disease world. We will all keep working together to achieve the success we seek!



"The pessimist complains about the wind. The optimist expects it to change. The leader adjusts the sails."

- John Maxwell

NEW RESEARCH STUDIES ELEVATED ESTROGEN LEVELS IN BOTH MEN AND WOMEN



Dr. Carol Feghali-Bostwick, Ph.D.

Online magazine Science Daily has published a compelling article on the relationship between estrogen and scleroderma. The Medical University of South Carolina team, funded by National Institutes of Health, studied estrogen levels in both older men and postmenopausal women with scleroderma. Following are a few of their observations:

- Scleroderma develops in women during their child-bearing years, when estrogen levels are at their highest.
- A type of estrogen, estradiol, was more abundant in older men with scleroderma than in postmenopausal women with the disease.
- Men with scleroderma and higher levels of estradiol had more severe disease and heart involvement.
- Women who were treated with hormone replacement in therapy trials showed thickening of the skin which returned to normal after completion of treatment.

All of this is an unexpected outcome as estrogen is considered to be a primarily “female” hormone and this crossover tendency between the sexes merits further research. In a disease model that is broadly typified

by the overproduction of connective tissue and a disproportionate ratio of men and women with the disease, the estrogen connection is, at the least, curious.

Dr. Carol Feghali Bostwick, PH.D., chair for Scleroderma Research at Medical University of South Carolina is furthering this research in her study of similar thickening in skin cultures exposed to estradiol. As reported in the Science Daily article, “The MUSC team’s recent findings provide some of the first evidence to confirm a link between high estrogen levels and the development of scleroderma. They may also begin to explain why men, in whom the disease is less frequent, often have more severe symptoms.”

Dr. Feghali-Bostwick and her research team speculated on the the potential overlap of post-menopausal women and men of the same age using materials from banked serum samples from men 50 and older who suffered with diffuse cutaneous systemic sclerosis, and compared them to samples of healthy men of the same age. The men with systemic sclerosis had “significantly higher levels of estradiol than both healthy men and post-menopausal women with scleroderma.”

The technical description of how men have these elevated levels of estrogen is interesting. Via an enzyme called aromatase, a man’s testosterone can be converted to estrogen. The obvious suggestion is that the possible therapeutic approach to scleroderma is to prevent that conversion. A current consideration of a trial for these patients may prove to be unaffordable, but Dr. Feghali-Bostwick can lean on data from existing breast cancer trials of aromatase inhibitors - any patient with breast cancer and scleroderma

who was treated with the aromatase inhibitor for the breast cancer might have measurable secondary influence on their scleroderma. If this information can be determined from existing data, surely there would be much learned about aromatase inhibition relative to scleroderma.

Feghali-Bostwick research associate DeAnna Baker Frost observes, “... we also have to show concretely that having high estrogen levels is the causative factor for clinical characteristics of scleroderma.”

Consistent with Dr. Feghali Bostwick’s prior interests in scleroderma study, there is an effort in this current research to point to estrogen as a potential environmental trigger for scleroderma. The article reports that ‘most people who develop the disease are likely genetically susceptible. However research suggests that the environment also plays a role.’ Dr. Feghali Bostwick furthers this saying, “Estrogen is around us. It’s not just what your body produces.”

The constituency of SFNE is always very interested in any research developments in the pathway to finding a cure for the disease. Our appreciation of Dr. Feghali-Bostwick’s diligent and relentless search for answers through research is constant. She has been a true supporter of all aspects of our mission and we appreciate her dedication, wishing her the best outcome and results in her work.

For further reading on this topic visit the captioned article online: <https://www.sciencedaily.com/releases/2019/06/190606101820.htm>



GOLF CLASSIC, 2019

MARIE and IRA - Thanks for the Memories!

The backdrop for the 2019 Golf Classic for a Cure was a photomontage reflecting fifteen years of images of the event honoring Marie Coyle and Ira Rosenberg and all the people they'd influenced to attend the event for many years. The inevitability of loss is part of life, of course, and the indelible influence that both Ira and Marie had on this event will be long honored and remembered. We are proud of our association with them as we move into the future and our gratitude for their influence inspires us.

There was an infectious enthusiasm going into the 2019 Golf Classic for a Cure for Scleroderma.

We started the day early at our offices in Topsfield, loading six cars with supplies to transport to the Salem Country Club, assuring the careful handling of our 33 raffle items, registration materials and all accessories. Loading cars were Jack and Michele, Carol and Patty, Tony Cappellucci and Tom Curran. Tom is still volunteering ten years after retirement from doing it for pay!

By the time the registration table was set up and volunteers prepped and ready to get day started, it was clear to all of us that we had a good day ahead. Volunteers Mike Hyde and Jenn Dobson from the national office joined us at the registration table and ushered all registrants through the line, encouraging mulligan sales, distribution of golf gifts and sales of raffle tickets. Other volunteers kept the process moving smoothly overseeing much of the arrival and diplomatic handling of our guests. Perennial volunteer Patty Meaney kept humor and conversation lively.



Bobby Jones, vintage photo c. 1930



In short time, Tom and Matty Legere arrived and joined long timers Tom and Tony in distributing the sponsorship signs to the 18 holes being played. Meanwhile, board members Jane Ladas and Kate Bedard joined Bunny Cappellucci in distributing golf gifts, lunches and filling the golf carts with snacks and signage! We hurried all the first shift Hole Sitters to their respective locations and before long, the shotgun blast signaled the start of the day. 128 golfers rolled out onto the lush green course.

Robert Sprague arrived to set up the "Bobby Jones Club Challenge" on hole 5. This gave players the opportunity to hit some balls with clubs from early in the last century to honor the stylized wood clubs of the time. Robert brings a classy piece of the past to our day and we appreciate his generosity.

He donated a period club to the raffle – it was a big and welcome surprise!

In the meantime, Jack, assisted by Donna Ahern, arranged for the dining room to be outfitted with the raffle table and the eye-popping display of live raffle items including multiple sports events tickets, an outdoor Weber grill donated by Board President Don Legere and family. Tim Kenney of W.T. Kenney Company brought us a hand crafted laminated American flag – not to mention a dynamic oversized signed Super Bowl image of a victorious Rob Gronkowski. His spontaneous support of our day was greatly appreciated by all!



(continued on page 7)



APRIL 2020

Sun	Mon	Tue	Wed	Thu	Fri	Sat
						1
						2
						3
						4
						5
						6
						7
						8
						9
						10
						11
						12
						13
						14
						15
						16
						17
						18
						19
						20
						21
						22
						23
						24
						25
						26
						27
						28
						29
						30
						31

MARK YOUR CALENDARS!!

On April 4, 2020, for the SFNE Patient Education Conference at the Peabody Marriott Hotel. Based on questionnaires and ideas coming from PES 2018, we are in for another great conference. We intend to make the 2020 event carry the tradition to be very patient-focused with speakers, on-site sponsors and research reports. Watch for specific conference information in upcoming BEACON issues, on our web site and Facebook page.

NATIONAL CONFERENCE 2019



Robert Riggs made a heartfelt tribute to SF/SFNE founder Marie Coyle at the National Conference in Chicago. He reflected on the influence Marie had on his emerging role with the Scleroderma Foundation 20 years ago and told a few fun tales of their friendship. We are very grateful to Robert and all who remember Marie's influence through story and testimony.

RESEARCH IMPERATIVE

Remember, your donation of \$50 will fund one hour of research. A gift of \$500 will fund a day of research. A gift of \$2,500 will fund a week of research! While all efforts to advance our understanding of scleroderma are proceeding at a record pace, we have more leads than we have resources to pursue them. If research is important to you, be sure to earmark your donation for research!

COMRADES IN ARMS



Members of the North Shore Support Group are showing their healing scars from having skin biopsies taken for Dr. Jonathan Garlick's Research Program at Tufts University School of Medicine. This is a tiny representation of all the scleroderma patients who have participated in research programs and trials so that new medication and (hopefully) a cure can be found ensuring that nobody in the future will have to live with scleroderma. Thanks to Roberta Mauriello for

organizing this research partnership. Thanks to all scleroderma patients everywhere for partaking in these research projects.

Remember that the Boston Walk is coming up on **September 29th!**

Register your team for the walk by going to: www.scleroderma.org/steppingoutboston
We welcome volunteers, walkers and anyone who supports our mission!

LAUGHING IN THE FACE OF SCLERODERMA

Andrew Botieri and Johnny Medlin pulled off another success with the Marshfield Comedy Night for a Cure aptly titled, "Laugh in the Face of Scleroderma." It was months in the planning with a proven history of successful comedy nights in the Plymouth/Marshfield area. There is no shortage of humor at the beach front and, as we have learned, no shortage of compassion for the challenges we face with this disease.

Johnny said of the evening, "It was

truly amazing to see how many people came out and supported our cause. The event sold out and many people came up to me after saying how much fun they had and that they haven't laughed that hard in a while! What better way to raise awareness and money than to laugh the night away?"

Christine Hurley has a knack for walking that fine comedic line and keeping her audiences in fits of laughter while wide-eyed at how far she will go to win a laugh. She didn't

disappoint and we love her brand of humor.

The event included appetizing food and a cash bar and our great thanks goes out to Venus II Restaurant for accommodating our excited crowd. There was a healthy raffle and a 50/50 drawing netting us a grand total of \$10,519. Thank you to Andrew and Johnny and all who attended for your loyal and ongoing support of our mission to find a cure for scleroderma in our lifetime!

GOLF CLASSIC, 2019 (continued)



The raffle table reflected Tony Cappellucci's success in raising items. It made for a robust display and the table represented north shore businesses, sponsor generosity and traditional gifts. The Salem Country Club donated a foursome with carts and there was an abundance of sports items including autographed pictures of Stephon Gilmore and Julian Edelman and multiple sets of Red Sox tickets. The SFNE Board of Directors donated a plentiful wine basket and member Jane Ladas' Newburyport getaway basket added greatly to the day! Individual sponsorships from board members Joan Meissner and Tim Hagan were generous and greatly appreciated. Special thanks to our event photographers, Tom Curran, Donna and Sean Ahern and Jane Ladas. By the time the players emerged from the course and into the Club House, there were some tired, thirsty and hungry guests. The sit-down dinner was enjoyed by 165 diners, most of whom had played, others joining them for the meal and live auction. All volunteers stepped back into action and orchestrated the welcoming of guests, directives at the raffle and live auction and the end of day cleanup.

By the time the day concluded, and the cleanup was underway, we had raised an astonishing \$177,900 in gross receipts. To Bruce Gordon and David Rosenberg, we extend our gracious thanks for 17 years of support. To the Rosenberg family, we offer our support in Ira's memory. And in memory of Marie Coyle, our founder and inspiration, thanks for the memories!

STROLL FOR SCLERODERMA, DEER ISLAND

Beautiful and scenic Deer Island in the Boston Harbor is a stunning vantage point for watching the comings and goings of this busy seaport and a truly stunning recreation area. Somehow the beauty of this island is an ironic cover for its function as the recycling center for the city of Boston's waste. It is a very successful outcome of a plan to invest form and function in a most practical capacity.

We at SFNE are so lucky to have this location as the eye-popping backdrop for the annual Stroll for Scleroderma, hosted by Maria and Jacek Bartoszewicki and the extended Legere clan.

On June 15, more than 100 walkers

joined forces to walk the perimeter of the island to raise funds to support the mission of SFNE. Maria saw to every detail and brought an infectious energy to the day and shared credit for the outcome with her extended family, their co-workers and an ever-growing number of children and surprise attendees. Dr. Jonathan Garlick brought several of his interns from Garlick Labs at Tufts, to join in. Members of our constituency walked, enjoying the early summer weather. Carla King and friends walked the 3-mile route. Board President Don Legere and board members Tony (and Bunny) Cappellucci, Jane Ladas and Chris Simms attended with gusto!



The raffle table was loaded with tempting options for all ticket buyers and by the time the day ended, no one left without a complete satisfaction with the day. This was year #3 for the Stroll and we hope that it will continue long into the future. A BIG thank you to all who generously participated!

Total funds raised at this Walk for a Cure are \$15,000. We are sure to enthruse this event into the future and we invite one and all to join us in 2020!

NATIONAL CORVETTE RESTORERS SOCIETY OF NE, LOYAL FRIENDS!

On June 9, we were very lucky to enjoy the proceeds gathered at the annual National Corvette Restorers Society of New England meeting at Larz Andersen Auto Museum. Don and Jean Chapman have become our annual Corvette Day representatives and each year Jean looks more relaxed and settled in. Don loves cars, so he is scarce at the information table, leaving Jean to fend off the throngs of car restorers seeking rare disease information.



2017 - Corvettes displayed on the Larz Anderson lawns.

We value this group who have loyally supported our mission for more than 15 years! Great thanks to Don and Jean for always representing the SFNE mission with such vigor and delight. And to the many friends at NCRS/NE, THANK YOU again from all of us at Scleroderma Foundation New England.



Jean holds down the fort!



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



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
 donnab2@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
 carla.king@comcast.net
 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.



CONFERENCE VIDEOS ON YOUTUBE

During the 2019 National Conference, 14 workshops and presentations were video taped. Those videos are now being posted on the Scleroderma Foundation's YouTube channel, www.YouTube.com/sclerodermaUS.