NEW ENGLAND

The BEACON

A Publication of Scleroderma Foundation New England

Winter 2020

WELCOME NEW EXECUTIVE DIRECTOR LINDSAY DE SANTIS

The Board of Directors is pleased to welcome Lindsay De Santis to the directorship at Scleroderma Foundation New England. Lindsay's enthusiasm from the day of her arrival in December has resulted in a new wave of ideas and energy for which this organization is poised. She has begun to streamline many of the organization's upcoming events, most notably the Patient Education Seminar taking place on April 4, 2020.

Lindsay has been the Executive Vice President at the Massachusetts Pharmacists Association (MPhA) in Woburn and provided consulting services to small businesses allowing them to expand their reach by providing day-to-day administrative support.

Lindsay's business experience and energetic capabilities have shown that she can translate vision into meaningful action, moving an organization forward in alignment with current technology and reflection of constituent need.

Already working energetically with the SFNE Board of Directors and support group leadership, Lindsay has shown admirable compassion and diverse skills. We are thrilled to welcome Lindsay to our mission and look forward to her role in bringing us forward.

* * *

A MESSAGE FROM DEPARTING DIRECTOR JACK ARMITAGE

I am finding that retirement, as a concept, comes with ominous gravity. Looking back over nearly ten years of shepherding SFNE I am very grateful at having met and befriended so many of you whose lives are affected by scleroderma. Hopefully, I might have improved your circumstances, your access to care and your hopes for research success. What I carry away with me is diligent advancement of our mission and confidence in our shared achievements.

Time passes for all of us and we bear the marks of our lives in badges of visible change. Beyond our acceptance of life's ravages, we might choose to be in awe of the good that each day brings, finding more joy in the diverse and unpredictable bumps along life's path. And still, it is our shared directive to untangle the mysteries of the rare disease for which we are challenged to find a cure. My departure from this office will not diminish my zeal to work by your side to that end.

Marie Coyle figuratively plucked me from her garden to bring me in to direct the mission of this office. I had been hired to tend to her perennials when she mused about her need to initiate the search for an executive director at SFNE. I will never forget her polite chuckle when I told her that I would be interested in applying for the position. "But you are my gardener," she said, "how would this be possible?" Over time, Marie and I uncovered a shared understanding that all things are possible.

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IN THIS ISSUE

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

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Jack Armitage, *Editor*

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www.scleroderma.org/newengland

A MESSAGE FROM DEPARTING DIRECTOR JACK ARMITAGE

(continued from page 1)

In the ten years since that conversation, much has happened to bring possibility into play. Nothing is without cost, of course, and the tradeoffs for growth are growing pains – we have experienced much of both. Enjoying hindsight, I am thrilled to have been able to guide SFNE to this point. I look forward to my ongoing alliance with all of you and with this organization that holds onto its mission so tenaciously. We will find a cure for scleroderma. The "when" of that is the mystery. The "how soon" is the challenge for all of us. Stay the course, my friends, all things are possible.

I leave this position with great satisfaction. We have all worked together to bring change and research success. We have built accomplishment in both small and big ways. We will continue to influence the zeal of others in our shared mission.

Thank you for having partnered with me in recent years. What I leave behind is my heartfelt hope for all of you in our readership and a vision that we will all enjoy the outcome of shared possibility in our lifetime.

* * *

SUPPORT GROUP LEADER LUNCHEON, FALL 2019

Left to right: John Kittredge, Donna Bernier, Patty Kittredge, Cathy Green, Joan Kinsgbury, Mary McClay, Sandy Lunner, Roberta Mauriello, Jack Armitage, Jean Chapman, Tony and Bunny Cappellucci, Jane Ladas and Don Chapman.

As we have come to expect, there is a little cult growing up inside of SFNE! It is the enviable network of Support Group Leaders who work singlehandedly out in the field bringing together support group attendees, assuring them of continued support and representation through the course of their diagnosis.

This group of friends did not know one another at all five years ago. At that point, we instituted a twice annual support group leader luncheon. We invited the leaders and co-leaders and on occasion a group member or two who had become essential to the mission of the group.

Thinking back to that first meeting in 2015, they were a gathering of very shy leaders, nervous of showing vulnerability in their roles in a way that others could see. In very short

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FROM THE DIRECTOR'S DESK

by Lindsay De Santis

My connection to the Scleroderma Foundation New England chapter began as a result of a chance conversation nearly two years ago, but I will get to that shortly…

I have been managing non-profit organizations for the last fifteen years, specifically healthcare organizations. Of all the organizations I have had the pleasure to work with, I have never had a personal connection to the mission of those organizations. Until now.

While working with my last organization, I was fortunate to work with a wonderful woman who grew to be both a friend and a confidante. After a particularly stressful day I shared that my mother had been ill and that it had been taking its toll on my family, and my mother's mental well-being. As we talked more about what was happening with my mother, I explained her health struggles and gave a response I am sure so many people have used before, and one I have given more times than I can count – *"She has a disease you probably never heard of…it's called Scleroderma…"* and before I finished she looked at me in amazement and said, *"I have Scleroderma"*. That conversation set into motion my journey here.

In 2018, my mother was deteriorating in her mobility and suffered from inadequate care. At the urging of my friend who saw the despair she was in, she left her comfort zone and agreed to attend the 2018 Patient Education Seminar with my friend. From that day, she made the decision to change the direction of her care and agreed to take a chance on a new physician she heard speak at the Seminar (but made it ***very*** clear that if he wasn't as great as everyone said, she would not be trekking into Boston regularly). Within the first visit, and appropriate medications, she was able to move her arms again and walk freely without resting after 10 minutes. PS, she also said the food at the PES was delicious!

Nearly two years later, this same friend sent me a message on Facebook telling me that the same Foundation that held the Patient Education Seminar that helped my mother so much was looking for a new Executive Director. **And here I am**. I am so incredibly grateful that a simple conversation, one that wasn't uncommon to others I have had over the years, brought my mother the relief she so desperately needed, a care plan appropriate for managing her symptoms, and also brought me to this. It taught me that the right conversation and the right resources, **can be life changing** when you are struggling with your health or the health of a loved one. I truly hope to have these conversations with as many patients and caregivers as possible. It's my turn to pay it forward and I look forward to having the gift to do that daily through my role at SFNE.

This year my mom will be at the PES again, but this time I will be there managing the event. I hope she was right about the food! I hope to meet many of you there.

Outside of my passion for this new position, I have been married to my husband Sal for 13 years and we have two children Raymond, 9, and Stella, 7. We live in Boxford with our two crazy dogs, Guinness and Smudge. Life is loud, and crazy and I try to cherish every moment.

I look forward to meeting you - A cure is out there, and together we will get there!

Bancroft School sophomore volunteers at the Worcester Walk

CALL FOR VOLUNTEERS

2020 is shaping up to be a vigorous year of fundraising events. We will need volunteers in diverse assignments! If you review our schedule of events (page 9) and find any events that you'd be interested in attending as a volunteer, please let us know! At our April Patient Education Seminar, we will need greeters and setup help. We will need set-up and break-down help at any of our six Walks for a Cure, volunteers at registration and t-shirt sales and energetic volunteers to distribute signs along the route. The Golf Classic will need special skills in course setup, hole sitting and raffle distribution.

Call us at 978-887-0658 to sign up for the event that suits you best, especially if you are geographically close to it already!

We are a volunteer driven non-profit organization - thanks for making our events so successful.

FACING SCLERODERMA . . .
A GUIDE FOR PATIENTS AND THEIR FAMILIES

Dr. Marcy B. Bolster, MD

Dr. Bolster is a rheumatologist and the Director of the Rheumatology Fellowship Program at Massachusetts General Hospital. She is an Associate Professor of Medicine at Harvard Medical School. An established author on rheumatic diseases, she is a respected editor and reliable expert on scleroderma and other diseases including osteoporosis, lupus, and rheumatoid arthritis.

Facing Scleroderma, A Guide For Patients and Their Families is a recently published book reflecting up-to-the-minute patient-centric information. At first review, it strikes one as an exhaustive (in a very good way!) reflection of factual data, patient input, and unflinching content. It runs the gamut from graphically specific to deeply personal in its successful inclusion of aspects of symptomology, treatment, and psychological response. Editors Drs. Marcy Bolster and Theodore Stern include an impressive list of contributors to the content, all of whom are qualified practitioners and who write candidly in their areas of expertise. We are pleased to be able to recommend this user-friendly publication to our constituents. An interview with Dr. Bolster gives us a glimpse into the book, as follows:

INTERVIEW WITH DR. BOLSTER:

JA: Dr. Bolster, it is notable that you have made efforts at outreach to patients and support groups for people living with scleroderma. What have you learned in the less formal settings in which patients can be listened to in an unguarded capacity in the presence of their peers?

MB: *Our patients have many more day-to-day struggles than often get discussed with the physician. Patient discussions with peers provide a window into the patient's sense of wellness. These conversations often shed light on a patient's difficulties with daily activities, concerns about illness, effects on relationships, struggles in the workplace, fatigue, and times of feeling glum. In addition to learning more about daily struggles, I have witnessed the inspiration shared by patients with their families, friends and new acquaintances about coping, wellness, the important role of exercise, and the empowerment of having a positive outlook.*

JA: In one of the reviews of Facing Scleroderma, there is a welcome reference to your "caring and sensible approach to the emotional aspects of living with scleroderma and its complications." Can you expand on this?

MB: *This comment touches on the depth of meaning this book may have for its readers. Each chapter is written with patients and their families in mind. While the book provides important information about the clinical manifestations and treatment options for people with scleroderma, it also addresses, in a thoughtful way, many of the emotional stresses that people with scleroderma may face. The chapters are written by rheumatologists who are very knowledgeable in the care of people with scleroderma. Many of the book chapters are co-authored by rheumatologists partnering with psychiatrists. The authors recognize the importance of both listening to and responding to their patients. This book provides an at-home reference that represents the caring approach taken by each of the book's authors in addressing the needs of people with scleroderma.*

JA: Our BEACON readership includes constituents who live in the far reaches of New England and for whom access to affordable and easily understood information is a challenge. Many do not use the internet and are reading what often feels like ancient texts. Explain why Facing Scleroderma will provide accessible and "digestible" information to our more geographically remote friends.

MB: *This book is written with all people with scleroderma in mind. People with scleroderma have different levels of accessibility to resources from which to learn more about their disease. It is our hope that this book reaches people to provide information to them in their homes. The information learned does not require a visit to a local rheumatologist or to a rheumatologist working in a scleroderma referral center. It is our hope that the information provided is written in an easy-to-understand format. There is an extensive glossary at the end of the book to provide clear definitions of many terms used throughout the book. There are many tables and figures to enhance the reader's learning. Additionally, there is a chapter devoted to helping people learn about other available resources to help with understanding and communicating about scleroderma.*

JA: Here at Scleroderma Foundation New England, we lead with the passionate mission directive that we will find a cure for scleroderma in our lifetime. Can you offer a medical

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NEWS BYTES

SECOND ANNUAL TEAM SKIPPY LOBSTER SHOOT

Michelle Monteiro is organizing friends and townspeople to raise funds for Worcester Walk's Team Skippy by hosting the Second Annual Lobster Shoot to honor the mission of Scleroderma Foundation New England. We are so grateful to Michelle for this creative and productive way to raise funds for our cause.

On Friday, March 20, Michelle's Second Annual Lobster Shoot for a Cure will open the doors of the VFW Hall, 3 Palmieri Drive, Hudson, MA at 6:30pm. As was the case last year, there will be a cash bar and a plentiful raffle with gift baskets creatively raised in the community. Part of the mission of SFNE is to raise awareness about this rare disease and it is Michelle's goal to do just that!

As Michelle's promotional poster describes it, "Raffle Silent Auction, Snacks, Lots of Laughs and MORE!" Admission to the VFW Hall is free. Game cards will be sold at $20 for ten shoot rounds for the games. Additional cards will be available for $2 each. If you have any questions, would like to make a financial donation or donate a raffle basket to become a part of this effort to raise awareness, feel free to contact Michelle at MJMJNM@MSN.com.

SCLERODERMA FOUNDATION
NATIONAL PATIENT EDUCATION CONFERENCE

BELLEVUE, WASHINGTON ~ JULY 17-19, 2020

ARE YOU ELIGIBLE FOR A NATIONAL CONFERENCE SCHOLARSHIP?

For first-time attendees, the National Patient Education Conference brings hope to those who thought they were alone in the fight against scleroderma. Thanks to generous support of many donors and chapters, conference scholarships will again be available to the 2020 National Patient Education Conference, which takes place July 17-19, in Bellevue, Washington, to the east of Seattle, across Lake Washington.

Conference scholarships are intended for first time applicants who would be unable to attend without outside financial assistance. At the National Foundation office, we regret we are unable to assist all who apply; however, the Foundation will use scholarships funds to assist as many applicants as possible. A patient-led committee will administer the award process based on available funds.

Conference Scholarship applications will open in January 2020. The deadline to apply will be in March. Decisions regarding scholarship awards will be announced in April.

If you have questions regarding the scholarship application process, please call **(800) 722-4673**.

THIRD PARTY EVENTS PLANNING. . .

Here at SFNE, we raise most of our research and budget funds through fundraisers. The singular Golf Classic for a Cure raises about half of our annual budget and we count on Walks for a Cure and third party events for the balance.

Third party events are run outside of SFNE by individuals or groups who find a theme that they feel can show a profit and be fun for their friends and community. Examples are Bowling for a Cure, Paint and Sip Evening, Spaghetti for Scleroderma, Southie Swims for a Cure, Fuddruckers Dine and Raffle, even the recently very successful Lobster Shoot!

We welcome third party events and we encourage that you let us know if you come up with an idea that you could turn into a small fund raiser for our benefit at SFNE. We would be glad to help you to launch the event and offer office support in some capacity. Typically, we can set you up with a registration page, offer some raffle items and a boatload of encouragement!!

If you find that an idea for a small fundraiser is percolating in your brain, call us at **978-887-0658** and we will gladly walk you through the process of setting up a third party event.

INTERVIEW WITH DR. BOLSTER *(continued from page 4)*

perspective on the accomplishments in research as they are playing out in day-to-day patient care?

MB: *Physicians who provide care for patients with scleroderma and our scientist colleagues join our patients in the mission to find a cure for scleroderma in our lifetimes. Research in this disease is part of a fertile area in the study of fibrosing diseases. Much more is being learned every day about fibrosis, and it has become apparent that fibrosis is a disorder underlying many diseases, not just scleroderma. Researchers are putting together small pieces to form the building blocks upon which future discoveries will be helped; this will hopefully lead us closer to finding a cure. Research however cannot only include that which is performed at the scientific bench (basic research), but importantly, must include clinical information, genetics, and medication responses to advance our goals of discovery for cure.*

JA: You have led scleroderma focused clinics and have helped to train rheumatology fellows in the specific symptomology and characteristics of scleroderma. Thank you for this. We continue to feel the need of such education in the medical community in an expansive capacity. What frustrations (if any) do you experience as you work to bring scleroderma into the mainstream medical conversation?

MB: *I find audiences to be open and interested in learning more about scleroderma. It is a privilege to be able to train fellows in the care of patients with scleroderma, and I welcome the opportunity to see patients with my fellows in training to enhance the care provided as well as to build on a strong foundation of education to enhance future care delivery. I am fortunate that my experience with providing care for patients with scleroderma has led to invitations to speak and to write journal articles and textbook chapters about this disease. I have not found frustrations with bringing scleroderma into the mainstream of medical conversation, as audiences, whether readership or in-person, are welcoming to learn more from those who take care of patients with scleroderma. Ideally, each of the fellows whose training I have touched will be well-prepared to enter the rheumatology workforce*

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SOUTHIE SWIMS FOR A CURE

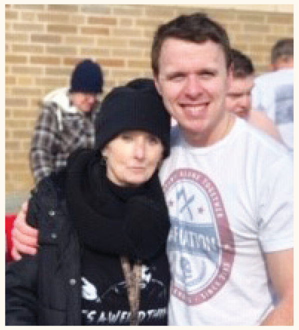
It is for certain that Paul Lombard and his family and friends in South Boston didn't have a slow lazy morning on New Year's Day. While we were all being cozy in our pajamas Paul and 30 other brave souls were tempting fate as they dove into the ocean for the umpteenth Southie Swims for a Cure for Scleroderma in honor of Paul's mother, Liz Lombard. Carrying the tradition initiated by his uncle Kevin Conroy (Liz's brother), Paul and friends joined the Polar Plungers at the L Street Bath House in South Boston for a daring immersion in the frigid waters of the Atlantic.

Paul had the following to report, *"The swim was a complete success. We had about 30 people get in the water and many more join us after the fact. The water was cold but the sun was shining and the energy was great."* This optimistic report is a measure of the bravery of these participants.

After the swim, all participants met at Touchies Shamrock Pub for a beverage (warm, one hopes), a 50/50 raffle and four raffle gifts. In all, Paul was successful in raising $18,085 for SFNE!

Paul is dedicated to making his mark in the efforts to eradicate scleroderma. Of the day, he said, *"We are so happy to be able to present you with this and we hope to keep the big numbers up for years to come. We have seen first-hand for over 20 years what this disease does, so anything we can do to fight it, we will! Next year we hope for an even bigger and better event."*

To Paul and Liz and Kevin, we extend our sincere thanks for your many years of dedication to our mission. Thank you.



Paul Lombard and his mother, Liz

A hearty group of swimmers, 2020

Shane Begin, Ace O'Loughlin and Tom Cole

Scleroderma Foundation
Support · Education · Research
New England Chapter
www.scleroderma.org

PATIENT EDUCATION SEMINAR

Saturday, April 4, 2020
Boston Marriott Peabody
Peabody, MA

Scleroderma Foundation
New England
Support ★ Education ★ Research

SAVE THE DATE!

SFNE's 2020 Patient Education Seminar is scheduled for Saturday, April 4, 2020 at the Boston Marriott Peabody Hotel in Peabody, MA

We are excited to present a day filled with a selection of expert speakers, vendors, great food and company!

Register today to reserve your spot! Registration can be completed online at the SFNE website, *https://www.scleroderma.org/PES2020*, or complete the information below and mail or fax the form to our office at 978-887-0659. Registration is $15.00 per person and includes our luncheon. Please contact the SFNE office at 978-887-0658 or *admin@sfnewengland.org* with questions. We hope to see you there!

2020 PROGRAM TOPICS INCLUDE:

- **Dental Care in Scleroderma**
  David Leader, DMD, Department of Comprehensive Care
  Tufts School of Dental Medicine
- **Navigating Your Healthcare**
  Nicole M. Orzechowski, DO, Dartmouth Hitchcock
- **Systemic Sclerosis and Mental Health**
  Judith A. Restrepo, MD, Psychiatry,
  Massachusetts General Hospital
- **Utilizing Occupation Therapy in Managing Scleroderma Symptom**
  Christine Caiati, MS, OTR/L, Spaulding Rehabilitation Center
- **Management of Systemic Sclerosis: A Dermatologist's Approach**
  Christina Lam, MD, Medical Director, Dermatology Clinic,
  Boston Medical Center
- **Clinical Trials Update**
  Flavia V. Castelino, MD, Director, Scleroderma Program,
  Massachusetts General Hospital

To register by mail, please fill out, clip and return this form to SFNE in the attached envelope with payment.

PATIENT EDUCATION SEMINAR RESERVATION FORM

☐ YES, I/We plan to attend the Patient Education Seminar on Saturday, April 4, 2020 - 8:00am - 3:00pm

Name: ______________________ Phone: ______________ Email: ________________

Address: ______________________ City, State, Zip: ______________________

Please reserve ________ seats @ $15.00 each Number of people attending: __________

Luncheon Selections (For multiple registrations, please indicate quantities)

_____ **Chicken Madeira:** *Seared chicken breast with Maderia demi-glace* _____ **George's Bank Cod:** *Fried Cod baked with buttery Ritz cracker crumbs*

Please contact our office with any special accommodations or dietary restrictions.

PAYMENT OPTIONS:

☐ Check (*Payable to SFNE*) ☐ VISA ☐ MasterCard ☐ AMEX ☐ DISCOVER

CARD #: ______________________ Expiration: _______/_______ Security Code: _______

Name on Card: ______________________ Signature: ______________________

SUPPORT GROUP LEADER LUNCHEON, FALL 2019

(continued from page 2)

time, they became an empowered, close-knit group of friends who now look forward to these luncheons at which they can catch up, compare notes and successes, and renew friendships. And eat.

This year's SGL luncheon was double-themed. First, we held it in memory of Marie Coyle, the inimitable leader of our cause. Second, we were proud to show a film presented by Lindsey Smith from Corbus Pharmaceuticals featuring 8 members of the SFNE constituency discussing their life experience as people diagnosed with scleroderma. It was powerful and, hopefully, the beginning of a more visible prominent representation of those living with a diagnosis (visit our web site to view the film). We offer great thanks to Lindsey and Corbus for their brave venture with us.

In the old days, I would arrive with a tightly scripted agenda for the day with speaking assignments and suggested topics for conversation. We would sit in a circle and shyly ask this group to create a support environment just like they would in their monthly meetings. It was only briefly excruciating – and today, there is little (if any) need for structure. This vibrant group of old friends are enthusiastic about spreading their stories and challenges, and to uplift one another.

Attending the Fall SGL Luncheon was a classic collection of old friends. They are, left to right: John Kittredge, Donna Bernier, Patty Kittredge, Cathy Green, Joan Kingsbury, Mary McClay, Sandy Lunner, Roberta Mauriello, Jack Armitage, Jean Chapman, Tony and Bunny Cappellucci, Jane Ladas and Don Chapman. The empty seat was for Marie Coyle and the mystery guest behind the camera will go unnamed! Carla King and Tim Gray are missing from the photo as are Don and Cathy Legere, Tom and Tricia Legere, Lindsey Smith from Corbus Pharmaceuticals, David Murad and Angel Soto (SF National office), and our great friend Carol Taylor, six-year leader of the Boston Group. Support Group Leaders who couldn't make it to the luncheon are: Ilene Wax, Blythe Leonard, Nancy Velleco and Andrew Botieri.

BOLD GOVERNANCE AT SFNE IS OUR TRADEMARK

With deserved pride, we enjoy very solid and enviable governance here at SFNE. Because we honor term limits and refresh our pool of skills regularly, we can assure our constituents and supporters that their faith in us is met through smooth internal oversight.

In recent months we have welcomed new members to our Executive Board. Board President Don Legere has been joined on committee by Jane Ladas (Vice President), Jeff Daddio (Treasurer) and Steve Lang (Clerk). Members of the Executive Board have served on the board of directors before advancing to these positions. All have special leadership qualities that bring ongoing excellence to SFNE. Our Board general membership is proudly served by Joan Meissner, Chris Simms, Tony Cappellucci, Andrea Mahoney, Brenda Brown and Zak Karsan.

We are very grateful to retiring board members Peter Hart, Kate Bedard and Tim Hagan for their years of service to us. Sadly we lost Marie Coyle, our founder, former Board president and board historian nearly a year ago.

We are represented on the Board by constituents (members who are diagnosed with scleroderma, caregivers and those who bring first-hand relevance to our work). Additionally, many skills are represented, ranging from a certified public accountant, an attorney, a retired pharmaceuticals representative, a pastor, two insurance professionals, a financial investments manager and several other skillsets. Beyond being strict about term limits, we embrace the diversity of professions, autoimmune disease representation, and social strata. This regulated turnover keeps the board fresh and enthused.

SFNE is a high functioning chapter (one of more than 20) of the National Scleroderma Foundation. We are proud of our role in the network of chapters that covers the nation with accessible care and counsel. Interviews and vetting are ongoing for interested candidates and we expect to add at least one new member in the next quarter. Please consider how your qualifications might ensure your eligibility to serve with us as we look to the future.

Recently we have welcomed Lindsay De Santis to the directorship of the organization. Lindsay's vibrant understanding of board function and the interrelationship with the office staff has made her a most welcome contributor to the ongoing role that the Board of Directors holds.

As the representative group serving the New England scleroderma constituency via care and solid governance, we have every reason to be very proud of our board of directors and we thank them daily for their guidance.

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OCCUPATIONAL THERAPY AT THE NORTH SHORE SUPPORT GROUP

by Roberta Mauriello

Group attendees: Tom Legere, Joan Kingsbury, Joan Powers, Roberta Mauriello, Tricia Legere , speaker Christine Caiati, Pat Weisberg, Bunny Cappellucci, Janel Rogers, Donna Ahern, Jack Armitage, Kim Tebbets and Fran Mauriello.

The North Shore Support Group recently hosted speaker Christine Caiati, MS, OTR/L, an Occupational Therapist from the Spaulding Outpatient Center located in Gloucester, MA.

Several Members of the Group have hand involvement issues and wanted information on hand exercises, treatments, etc., so we were pleased to invite Christine to present on the topic.

The reaction and response from group members were very positive. Ms. Caiati illustrated various hand exercises and demonstrated how to measure and monitor range-of-motion. She also showed us special cup holders that she made that are beneficial for those who have difficulties holding a cup. Packets were given to us showing hand exercises and helpful products to assist us.

Her message to us was to continue using these techniques to keep our hands and fingers limber.

We felt she was an excellent speaker and was very knowledgeable with the subject matter. We hope to have her return with updates in the future.

Christine Caiati will be a presenter at the April 4 Patient Education Seminar.

• SAVE THE DATE •

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SCLERODERMA FOUNDATION
NATIONAL PATIENT EDUCATION CONFERENCE

SEATTLE, WASHINGTON ~ JULY 17-19, 2020

Visit the National Scleroderma Foundation web site for further information on the 2020 National Patient Education conference

www.scleroderma.org

SAVE THE DATE 2020 EVENTS

☐ **Team Skippy's Lobster Shoot**
VFW Hall, Hudson, MA
Friday, March 20, 2020

☐ **2020 Patient Education Seminar**
Peabody Marriott Conference Center
Saturday, April 4, 2020

☐ **Eighteenth Annual Worcester Stepping Out for a Cure Walk**
Bancroft School, Worcester, MA
Sunday, June 14, 2020

☐ **Fourth Annual Stroll for Scleroderma**
Deer Island, Boston, MA
Saturday, May 16, 2020

☐ **NCRS/NE Corvette Day**
Larz Anderson Auto Museum
Brookline, MA
Sunday, June 14, 2020

☐ **Eleventh Annual Maine Stepping Out for a Cure Walk**
Riverbank Park, Westbrook, ME
Saturday, June 6, 2020

☐ **Laugh in the Face of Scleroderma Comedy Night**
Hanson Athletic Association
Hanson, MA
Saturday, June 27, 2020

☐ **Eighteenth Annual Golf Classic for a Cure**
Salem Country Club, Peabody, MA
Monday, July 13, 2020

☐ **Fuddruckers Raffle & Dinner Night**
Fuddruckers, Saugus, MA
Date: TBD

☐ **Lynda Fernandes Golf Tournament**
Midville Country Club
West Warwick, RI
Saturday, September 5, 2020

☐ **Sixteenth Annual North Shore Stepping Out for a Cure Walk**
Proctor School, Topsfield, MA
Sunday, September 13, 2020

☐ **Montaup Golf Classic**
Portsmouth, RI
Sunday, July 26, 2020

☐ **Eleventh Annual Westfield Stepping Out for a Cure Walk**
Stanley Park, Westfield, MA
Date: TBD

☐ **Fifth Annual Boston Stepping Out for a Cure Walk**
Artesani Park, Boston, MA
Sunday, September 27, 2020

20 Years Reaching for the Cure
SCLERODERMA FOUNDATION
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SCLERODERMA FOUNDATION RESEARCH AWARDS

As reported in the Scleroderma *VOICE*, Winter 2019 issue, *"In 2019, the Scleroderma Foundation awarded seven research grants totaling more than $1 Million. Award recipient work covers a range of scientific topics including understanding fibrosis and vascular processes, immune system involvement, gene involvement and protein processes. These areas of study are intended to discover the underlying causes of scleroderma, to understand the disease mechanisms within the body and to develop therapies to overcome scleroderma forever."*

The importance of research in our mission driven work is never diminished, especially when we are given results that bring us closer to the very good news that we all hope will come soon. Please read the review in the winter edition of the Scleroderma Foundation *VOICE*.

One of the named awards, of particular interest to us at the New England Chapter, is the Marie Coyle Award. The 2019 recipient is Patricia A. Pioli, Ph.D. at Dartmouth College. This two-year grant in the amount of $150,000 will assist in her research to identify mechanisms that regulate microphage activation in systemic sclerosis.

Watch for the announcement of the 2020 research recipients in the Spring.

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SCLERODERMA FOUNDATION
NEW ENGLAND
SUPPORT ★ EDUCATION ★ RESEARCH

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: Mary McClay
sclerodermaboston@gmail.com

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
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 Saturday of each month
12:30 - 2:00 pm
Scarborough Campus of Maine Medical Center
*Next meeting will be in March 2020
Group Leader: Sandy Lunner
207-420-3337
slunner@aol.com

South Berwick Support Group
Meets the 1st Thursday 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 visit the Scleroderma Foundation page on **Inspire.com** for online support.

MAJORITY OF EMPLOYED PATIENTS WITH SCLERODERMA REPORT UNMET WORKPLACE NEEDS

This article was recently published in the Scleroderma Foundation e-newsletter. It was originally published in the Healio Rheumatology newsletter and offers a compelling perspective on workplace accommodation.

Arif Jetha, PhD Jetha A, et al. *Arthritis Care Res*. 2019;doi:10.1002/acr.24123.

Approximately 61% of patients with systemic sclerosis who are employed report unmet workplace support needs, and more than 80% identified extended health benefits as their most needed workplace support, according to findings published in *Arthritis Care & Research*.

Approximately 61% of patients with systemic sclerosis who are employed report unmet workplace support needs, and more than 80% identified extended health benefits as their most needed workplace support, according to findings.

“Our study is one of the first to provide evidence regarding the importance of employer-led interventions in promoting work productivity of employed adults living with scleroderma,” Arif Jetha, PhD, of the University of Toronto, told *Healio Rheumatology.* “The workplace supports that were reported as being most needed by participants with scleroderma included extended health benefits, special equipment for work, and flexible scheduling. These workplace supports have the potential to address the impact of the disease on employment engagement.”

To analyze the relationship between unmet workplace support needs and lost productivity among workers with SSc, as well as examine whether symptom severity, fatigue, active disease periods and activity limitations in the workplace impact that relationship, Jetha and colleagues conducted a cross-sectional survey. The researchers recruited 110 participants primarily from the Toronto Scleroderma Program, a health network comprising three hospital-based SSc clinics affiliated with the University of Toronto. All participants were aged 18 to 70 years, with a confirmed SSc diagnosis and employment within the last 5 years.

The 25-minute, telephone surveys asked participants about productivity loss — including absenteeism, presenteeism and job disruptions — as well as the need, availability and use of workplace supports. The researchers also collected information on symptom severity — including workplace activity limitations, active disease periods and fatigue — as well as demographic, health and work characteristics. To assess the link between unmet workplace support needs and each productivity loss outcome Jetha and colleagues used three Bayesian path models. Symptom severity variables were analyzed as mediators in each model. According to the researchers, 61% of participants reported unmet workplace support needs. Among the most needed workplace supports, 84% identified extended health benefits, while 63% cited special equipment and 59% named flex time. In addition, path models demonstrated significant indirect links between unmet workplace support needs and work productivity loss. Workplace activity limitations mediated this relationship in all models.

“Our analytical models indicated that the relationship between unmet workplace support needs and lost productivity was most significant for those who experienced greater workplace activity limitations,” Jetha said. “Meeting workplace support needs has the potential to address activity limitations and minimize the number of workdays missed due to scleroderma and the extent to which a person reports working while unwell and health-related job disruptions.”

– by Jason Laday

Disclosure: The researchers report no relevant financial disclosures.

* * *

“Be not afraid of life.
Believe that life is worth
living, and your belief
with help create the fact.”

- William James

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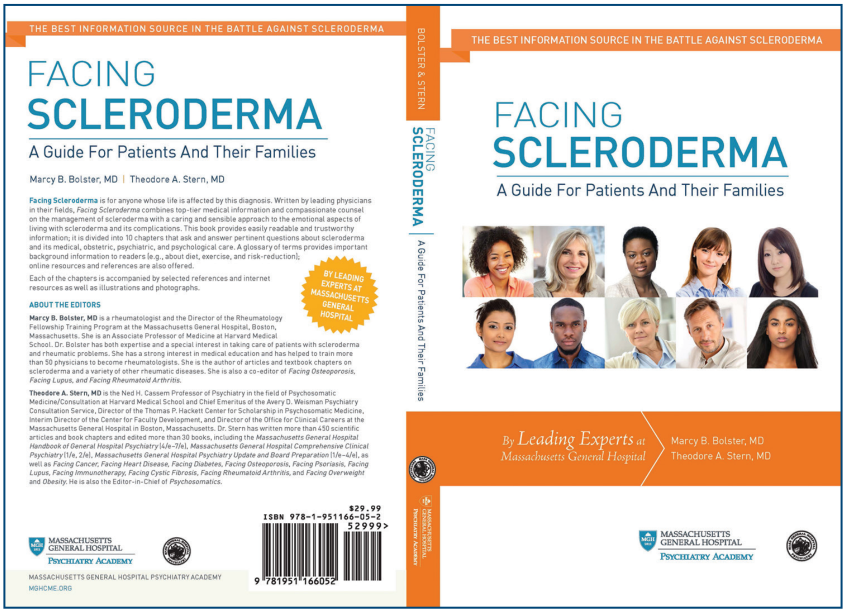
INTERVIEW WITH DR. BOLSTER

(continued from page 6)

and provide excellent care to those with scleroderma. I view the fellows, for whom I take part in their learning, as ambassadors to help educate and care for patients with scleroderma.

Additionally, fortunately, we have seen recent publications to advance the care of internal organ involvement, particularly for those patients with lung disease. Keeping scleroderma on the front burner for pharmaceutical companies is an important challenge as we continue to make efforts to advance the treatment of this disease. The more we see in publication of successful treatments, the more opportunities we should envision for making scleroderma part of the mainstream of medical conversations.



THE BEST INFORMATION SOURCE IN THE BATTLE AGAINST SCLERODERMA

FACING
SCLERODERMA
A Guide For Patients And Their Families

Marcy B. Bolster, MD | Theodore A. Stern, MD

Facing Scleroderma is for anyone whose life is affected by this diagnosis. Written by leading physicians in their fields, *Facing Scleroderma* combines top-tier medical information and compassionate counsel on the management of scleroderma with a caring and sensible approach to the emotional aspects of living with scleroderma and its complications. This book provides easily readable and trustworthy information; it is divided into 10 chapters that ask and answer pertinent questions about scleroderma and its medical, obstetric, psychiatric, and psychological care. A glossary of terms provides important background information to readers (e.g., about diet, exercise, and risk-reduction); online resources and references are also offered.

Each of the chapters is accompanied by selected references and internet resources as well as illustrations and photographs.

BY LEADING EXPERTS AT MASSACHUSETTS GENERAL HOSPITAL

ABOUT THE EDITORS

Marcy B. Bolster, MD is a rheumatologist and the Director of the Rheumatology Fellowship Training Program at the Massachusetts General Hospital, Boston, Massachusetts. She is an Associate Professor of Medicine at Harvard Medical School. Dr. Bolster has both expertise and a special interest in taking care of patients with scleroderma and rheumatic problems. She has a strong interest in medical education and has helped to train more than 50 physicians to become rheumatologists. She is the author of articles and textbook chapters on scleroderma and a variety of other rheumatic diseases. She is also a co-editor of *Facing Osteoporosis, Facing Lupus, and Facing Rheumatoid Arthritis.*

Theodore A. Stern, MD is the Ned H. Cassem Professor of Psychiatry in the field of Psychosomatic Medicine/Consultation at Harvard Medical School and Chief Emeritus of the Avery D. Weisman Psychiatry Consultation Service, Director of the Thomas P. Hackett Center for Scholarship in Psychosomatic Medicine, Interim Director of the Center for Faculty Development, and Director of the Office for Clinical Careers at the Massachusetts General Hospital in Boston, Massachusetts. Dr. Stern has written more than 450 scientific articles and book chapters and edited more than 30 books, including the *Massachusetts General Hospital Handbook of General Hospital Psychiatry* (4/e–7/e), *Massachusetts General Hospital Comprehensive Clinical Psychiatry* (1/e, 2/e), *Massachusetts General Hospital Psychiatry Update and Board Preparation* (1/e–4/e), as well as *Facing Cancer, Facing Heart Disease, Facing Diabetes, Facing Osteoporosis, Facing Psoriasis, Facing Lupus, Facing Immunotherapy, Facing Cystic Fibrosis, Facing Rheumatoid Arthritis,* and *Facing Overweight* and *Obesity.* He is also the Editor-in-Chief of *Psychosomatics.*

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FACING SCLERODERMA | A Guide For Patients And Their Families
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The book is also available on Amazon for Kindle or paperback.
https://www.amazon.com/Facing-Scleroderma-Guide-Patients-Families/dp/1951166051/ref=sr_1_1?keywords=facing+scleroderma&qid=1579298290&sr=8-1

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