

NEW ENGLAND The BEACON

A Publication of Scleroderma Foundation New England Summer2020



STEPPING OUT - BUT STAYING HOME

In the face of the COVID-19 pandemic, our lives are forever changed. As our communities begin to reopen and we hear about phases of implementation we must remember that for our community, the phases look very different for our friends with compromised immunity.

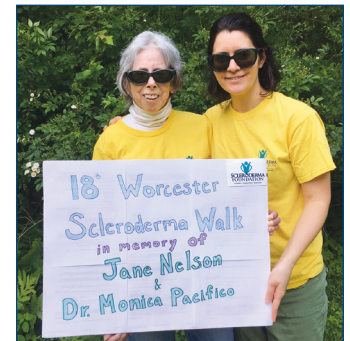
SFNE, as well as all Chapters and Affiliates of the Scleroderma Foundation, have made the necessary decision to cancel many of our fundraising events scheduled for 2020. To keep our community together, even at great distances, we will continue to host our Stepping Out to Cure Scleroderma Walks, but we will ask our members and supporters to walk on their own. We cannot miss a step in our fundraising, we have a promise to our patients and their families and caregivers to continue to fund research to find the cause and cure for scleroderma.

What is a virtual walk? The walking is real - it's the community that's virtual. You're probably familiar with local runs and walks held at a specific location. You've got to live close enough to get there by the start time - and parking can be a beast. With a virtual walk, you pick where you do it, who you do it with, and what time you start.

Our Stepping Out to Cure Scleroderma Virtual Walks are online fundraising initiatives that allow people to register and hold their own symbolic WALK while still raising money for SFNE! Can't walk on that specific day? No problem! Walk anytime and wear your favorite SFNE T-shirt proudly. We'll be sharing photos on our social media and hope you will too - but we'll be excited to hear about your walk whenever you do it.

#StepUp4SclerodermaNE

Our Worcester walk surpassed our virtual online goal! We can't be together, but we can still move forward! Please consider helping us meet (or exceed) our goals for our New Hampshire, Rhode Island, and Vermont virtual walks by August 29. Visit our website to donate or download a pledge form brochure.



Debbie Magnuson, team leader of Team Magnuson walks with her family in memory of two Worcester members Dr. Monica Pacifico and Jane Nelson.

HEALTHCARE HIGHLIGHT: Your Team at Boston Medical Center

Back in February the Scleroderma Community bid farewell to Dr. Robert Simms as he retired from his position at Boston Medical Center. Dr. Simms was a staple in our community and is greatly missed, but as we move forward so does the team at Boston Medical Center. I had the opportunity to speak with Tuhina Neogi, MD, PhD, Professor of Medicine and Chief of Rheumatology at Boston University School of Medicine/Boston Medical Center and Professor of Epidemiology at Boston University School of Public Health recently and pleased to share some updates from your team at BMC/BU!

SFNE: Can you explain the care plan and team approach that the Scleroderma Center can provide to its patients?

BMC: We are proud to be the largest scleroderma program in Northeast. Importantly for patients, the Scleroderma Program at BU/BMC provides

highly specialized care by rheumatologists who focus on scleroderma clinical care and research. We currently have three rheumatologists that specialize in scleroderma, all trained at top national scleroderma

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Scleroderma Foundation

New England Chapter

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***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.*

A MESSAGE FROM THE SFNE OFFICE

During these challenging times, I hope you and your loved ones are safe. Despite the uncertainties the pandemic has brought to all of us, our mission remains unchanged: to find the cure for Scleroderma and to support and educate our patients and their caregivers.

The pandemic has forced us to cancel critical fundraising events including this year's Patient Education Seminar back in April, our traditional Stepping Out to Cure Walks, our Annual Golf Classic in July as well as countless third party events hosted by our amazing volunteers and supporters. The Golf Classic alone raises more than 50% of our annual revenue.

As a result, our fundraising for 2020 looks vastly different, but we are committed to moving forward and have made some adjustments to the way we fundraise given the restrictions and limitations.

Our amazing Support Group leaders have started using Zoom to meet remotely. If you have ever considered joining a support group, but have been uneasy, the Zoom platform makes it accessible from the comfort of your home!

We have transitioned our traditional Stepping Out to Cure Walks to Virtual Walks which you will read more about in this issue.

We are hoping to continue to use the Zoom platform to provide educational resources for our community. Our May Webinar: Self care at home for people with scleroderma was our first webinar. We are working to create additional resources to participate in live discussions or view in our video library.

We are all adapting to this new normal and finding alternative ways to do the simple things we may have taken for granted in the past. Now, more than ever, we need your support and ask you to consider helping SFNE to enable us to carry forth our mission without disruption.

➤ DONATE ONLINE OR MAIL

We recognize the financial hardship that many are facing during this unprecedented time of work layoffs and furloughs. A \$25 contribution

offers membership at the National and Chapter levels. If you are joining (or renewing your membership) and donating at the same time, the first \$25 covers your membership and each dollar above your \$25 membership fee is your tax-deductible donation. Membership awards you subscriptions to both the *VOICE* - the quarterly magazine from the Scleroderma Foundation and this quarterly *BEACON*. Contributions can be designated in memory of or in honor of a patient with the disease and will be acknowledged as such.

➤ PARTICIPATE IN VIRTUAL WALKS

Whether walking in the park, down the street or on a treadmill, we can make it work and have fun doing it! We cannot miss a step in fundraising this year and ask you to please #StepUp4Scleroderma

➤ CREATE ONLINE PEER TO PEER FUNDRAISER

Facebook makes it easy to ask your family and friends to support the cause of your choice. <https://www.facebook.com/fundraisers> and select the Scleroderma Foundation New England. Every little bit helps our cause!

Whether before, during, or after this pandemic, our Scleroderma community is defined by its' strength, its' resiliency, and its' unity. Thank you for your support and for all you do.

Stay safe and be well.

SFNE BOARD OF DIRECTORS WELCOMES NEW MEMBERS

At the end of 2019, SFNE elected Zak Karsan to the Board at our December Board of Directors meeting.



Zak has over 20 years of executive level experience in the technology industry with a focus on go-to-market strategy and business development. In 2004 he founded Vault America, a provider of compliant hybrid cloud data protection, archiving, and availability solutions. In 2016 he co-founded SecureEDEN, a cybersecurity company currently

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UPDATE ON CORBUS PHARMACEUTICALS TRIAL - LENABASUM

In May Corbus Pharmaceuticals, located here in New England in Norwood, MA, announced that the last subject in the Phase 3 study of Lenabasum for the treatment of Systemic Sclerosis completed their final visit. Topline results from the study are on planned for this summer. This is exciting news for our community as there are currently no FDA approved therapies for the overall treatment of Systemic Sclerosis.

"We would like to express our sincere gratitude to our staff, our clinical collaborators and the study participants for their commitment and dedication leading to the study completing on time in the midst of a global pandemic," said Yuval Cohen, Ph.D, Chief Executive Officer.

Corbus has been a partner of the Scleroderma Foundation and the New England Chapter as a supporter of our Patient Education Seminars and our Boston Stepping Out to Cure Scleroderma Walk. Many members of our New England chapter were participants in this important work! We look forward to seeing the information released soon.

SELF-CARE AT HOME: MEDITATION AND MINDFULNESS

We are all struggling with self-isolation and social distancing, and self-care is critical for us all during these challenging times. In May we were fortunate to host our first educational webinar presented by Christine Ciati, MS, OTR/L from Spaulding Rehabilitation focusing on self-care at home for people with scleroderma. It is available on our website to view and includes a meditation exercise.

SCLERODERMA FOUNDATION
NEW ENGLAND CHAPTER

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207-420-3337, slunner@aol.com
South Berwick Support Group

ONLINE
ScleroMen Support Group
ScleroMen@scleroderma.org

Support Group Meetings are being held via Zoom at this time, contact the SFNE office or group leadersto get more information and connect today!

Meditation is a wonderful way to relax your body and it is simple to do at home! Meditation has been found to not only reduce stress and feelings of anxiety, but to improve blood circulation and blood pressure and increase overall sense of well-being. Practice meditation at home following these tips or use an online app such as Headspace or the Calm app on your phone, tablet, or computer.

1. Sit or lie comfortably. You may even want to invest in a meditation chair or cushion.
2. Close your eyes and make no effort to control the breath; simply breathe naturally.
3. Focus your attention on the breath and on how the body moves with each inhalation and exhalation. Pay attention to your body and focus your attention on your breath without controlling its pace or intensity. If your mind wanders, return your focus back to your breath.

Maintain this meditation practice for two to three minutes to start, and then try it for longer periods. <https://www.gaiam.com/blogs/discover/meditation-101-techniques-benefits-and-a-beginner-s-how-to>.

Scleroderma can be an overwhelming condition and it is important to find emotional support. SFNE can help! Please contact us and we can help you find the resources you need.

Make sure to follow the New England Chapter on Facebook to learn of upcoming free webinars!

SCLERODERMA AND NUTRITION

We have all heard the saying “You are what you eat”. But can what you eat make a difference in how your body responds to scleroderma? Including certain foods in your diet has been shown to help address symptoms associated with scleroderma including inflammation. The right diet can help ease pain associated with autoimmune diseases by focusing on fruits, vegetables, healthy fats and fish and ensuring ample consumption of important minerals and nutrients in your diet.

Some important elements to include in your diet include all the following:

Calcium is important for healthy bones. While milk and dairy products are good sources, some other sources include fish, dark green vegetables, seeds, nuts, and fortified cereals. If you are taking steroids your body’s calcium requirements are increased.

Vitamin D is obtained from sunlight and is needed to aide your body in absorbing and using calcium. In New England states, it is common to have a deficiency in the colder months. Vitamin D can also be found in certain fortified foods like eggs, butter, and cereals.

Iron can reduce the risk of anemia and can be found in red meat, poultry, fish, eggs, and dark leafy vegetables. Including a small amount of orange juice can assist in absorption; however drinking tea can reduce absorption so it would be best to avoid tea with meals.

Omega-3 Fats can help to protect against many diseases including heart disease. They can also reduce inflammation in the body. Add foods rich in Omega-3 fats such as oily fish (sardines, mackerel, salmon, and fresh tuna), walnuts, rapeseed oil, and fortified eggs.

Fruits, Vegetables and Spices

Fruits and vegetables not only help to reduce pain and inflammation, they are also a great source of fiber which

helps to regulate blood pressure and cholesterol. It is recommended to have 5 portions a day. Those suffering from acid reflux or chronic heartburn should avoid acidic citrus fruits.

Your balanced diet should also include **Beta-Glucan**. Beta-glucans appear to act as an immune system modulator and may also help auto-immune diseases. As well as eating more oats and shiitake mushrooms you can get supplements of purified beta-glucans. Choose those that contain (1-3) (1-6) beta-d-glucans. (<https://www.patrickholford.com/advice/auto-immune-disease>)

Ginger has been found to be a powerful antioxidant with anti-inflammatory properties. Ginger may inhibit pain producing prostaglandins (Prostaglandins promote inflammation, pain, and fever).

Turmeric contains curcumin, which is believed to have anti-inflammatory properties. Here’s a quick and easy recipe to add turmeric to your diet. People who have diabetes or who take blood thinners should talk to their doctors before trying any turmeric supplement, however.

Tart Red Cherries have been found to relieve pain and inflammation, suggested serving would be 20 a day.

Fresh Pineapple contains bromelain. People tend to use bromelain as a supplement for various health benefits, including relieving sinus problems, reducing inflammation, and improving digestion. Two to three slices a day can help with circulation and recovery.

References:

sruk.co.uk

<https://www.cleaneatingmag.com/clean-diet/eat-to-beat-autoimmune-diseases>

<https://www.patrickholford.com/advice/auto-immune-disease>

All content within this newsletter is provided for general information and should not be treated as a substitute for the medical advice of your physician or any other health care professional.



Consider joining our BEACON Legacies by making a major donation or creating a bequest provision to the Scleroderma Foundation New England Chapter in a will or trust.

- ✓ Leave a gift in your will
- ✓ Name SFNE as a charity beneficiary of IRA
- ✓ Give charitable gift annuities

To find out more about your planned giving options, please contact Lindsay De Santis at 978-887-0658

SFNE BOARD OF DIRECTORS WELCOMES NEW MEMBERS *(continued from page 2)*

in its R&D phase of building the next-generation firewall which protects data on the network, from the network. SecureEDEN has been granted a U.S. patent for its IP which instantly reduces the surface attack area, making critical data on any network invisible and accessible by only those authorized.

In April, we were fortunate to elect two additional directors to join in our work.



Elysia Cappellucci is no stranger to the organization, having already served on our Board before departing due to professional conflicts. Elysia and her family have been staples of the SNFE community with her father Tony as a fellow Board member and her mother Bunny a member of our North Shore support group. The Cappellucci family are part of what this organization so wonderful. Elysia is a Nurse Practitioner working in the Department of Neurosurgery at Beth Israel Deaconess Medical Center since 2015. She received her undergraduate degree from Providence College and graduated with a Master of Science in Nursing from Simmons College of Nursing and Health Sciences.



Scott Winslow founded Winslow Technology Group, LLC in 2003, with the goal of providing better IT storage solutions to his customers - solutions that are easy-to-use, feature rich, and affordable. He has led the company to exponential growth that has been recognized by CRN, Boston Magazine, and Inc. Magazine. Today, Winslow Technology Group provides solutions from the desktop to the data center to the cloud. The company employs 55 people and has offices in Waltham, MA, New York, NY, and Charlotte, North Carolina. Scott holds a Bachelor of Science in Business Administration from the University of Connecticut, and an MBA from the J.L. Kellogg Graduate School of Management at Northwestern University. Scott lives in Wellesley, MA with his wife Valeria and two boys Nico and Sebastian.

We are incredibly fortunate for the skills and commitment of our diverse volunteer Board working to achieving our mission!

SFNE Membership & Donation Form

You can improve the lives of individuals with scleroderma and help search for a cause and cure.
To join or make a donation by credit card, visit our website www.scleroderma.org/newengland.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone : _____

Email address: _____

● Please check appropriate box(es): \$25.00 Membership Donation \$ _____

In Memory In Honor of _____

Send me information About Planned Giving

I would like to learn more about fundraising

To pay by cash or check, complete this form and mail to:

SFNE
462 Boston Street, Suite 1-1
Topsfield, MA 01983

Email us at Admin@SFNewEngland.org



HEALTHCARE HIGHLIGHT: Your Team at Boston Medical Center *(continued from page 1)*

centers, and two were trained by Dr. Simms. Specifically, Dr. Marcin Trojanowski heads the Scleroderma Program, Dr. Michael York is the Associate Director (and on the Board of SFNE), and Dr. Andreea Bujor is the lead clinical scientist performing basic science research in scleroderma. They work together as a team, thus enabling us not only to provide timely appointments for any new scleroderma patients, but to provide the best care due to their combined expertise. Individual patients are frequently discussed among the team to decide upon the best avenue of care for a particular patient.

We have a team of additional specialists who have a special interest and expertise on managing different aspects of scleroderma to provide high quality and timely multidisciplinary care. For example, we have specific specialist partners in Pulmonary Medicine, Cardiology, Gastroenterology, Dermatology, Nephrology, and OB/GYN, Nutrition, among others, that routinely jointly manage the various multisystem issues that can occur in scleroderma together with the Rheumatology scleroderma specialists. Patients can often be scheduled to see additional specialists on the same day as their Rheumatology appointment to facilitate closely coordinated multidisciplinary care. In this way, the Scleroderma Program at BU/BMC can provide a 'one-stop shop' for all specialty care required by people with scleroderma. We also partner with local rheumatologists and PCPs to help guide scleroderma care in between visits to our BU/BMC Scleroderma Clinic. There is a particular benefit for patients suffering from localized scleroderma (morphea) in that the visit can be a combined Rheumatology/Dermatology appointment with both specialists at the same visit.

This close collaboration with highly specialized experts in scleroderma has also been a major reason why the Scleroderma Program at BU/BMC



Your Rheumatology Team at BMC

has been able to contribute to major developments in scleroderma care, including demonstrating that treatment using oral immunosuppressive therapy (cyclophosphamide) can slow disease progression to performing autologous hematopoietic stem cell transplantation for scleroderma. We continue to actively engage in all levels of research to improve the lives of people with scleroderma, from clinical trials to basic science and translational research studies. In this way, patients with scleroderma who come to our Center for care can be confident that they are not only receiving the best care possible, individualized to their needs, but that they are also helping to advance the science leading to new developments and breakthroughs in scleroderma research.

SFNE: What are your goals for the center as we move forward?

BMC: Our goals for the BU/BMC Scleroderma Program include ongoing expansion of the care and services we provide to improve the lives of people with scleroderma in terms of their functioning and quality of life, and minimizing the complications of their disease. We have increased the number of rheumatologists who specialize in scleroderma care in the last couple of years and continue to train the next generation of "sclerodermologists". We continue to engage in clinical trials to provide opportunities to our patients to gain access to promising therapies. One of the ways in which I would like to support and strengthen our

Scleroderma Program is by extending the ways in which patients can help us learn more about scleroderma, which in turn can enable us to help our patients with better testing and treatments. I envision doing this by asking patients to consider signing up to have their routine doctor's office visits with their rheumatologist to be analyzed as part of research efforts, such as understanding how the skin score changes over time, or if their Raynaud's symptoms might be related to their lung function down the road, as examples. In this way, patients with scleroderma can become direct partners in research to help improve the lives of their fellow scleroderma patients. We can also engage in a patient advisory group to help us think about the best way to use these data to address questions that are of importance to patients. By learning directly from our patients what is happening in their individual disease courses, we can inform other avenues of research that will accelerate insights and innovation that would otherwise be difficult to achieve.

SFNE: Has the COVID-19 crisis changed the way patients are receiving care?

BMC: Most definitely, yes. We are in the midst of a historic pandemic that has led to the loss of more lives in just 3 months than this country has lost in wars. It is definitely a challenging time. We acted very

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HEALTHCARE HIGHLIGHT: Your Team at Boston Medical Center *(continued from page 6)*

quickly at BU/BMC to convert in-person clinic visits to telemedicine visits to keep our patients as safe as possible, particularly as many patients who see rheumatologists, including those with scleroderma, are on immunosuppressive medications that can make them more prone to become infected. On the other hand, there are many patients that do need to be seen in person, and often those are the sickest patients at highest risk. We therefore implemented an urgent care clinic for those patients that do need to be seen in person, ensuring all steps to minimize risk, and to minimize the number of people who are in the clinic at any given time. We are fortunate that our risk mitigation strategies have been largely successful with only a handful of rheumatology patients at BU/BMC needing to be admitted to hospital, and none of our physicians

or staff having been infected. We are now moving to Phase 1 with a mix of in-person visits and ongoing telemedicine visits. We know that we would like to continue offering telemedicine visits particularly for those who travel from a far distance who may otherwise be stable but primarily need a check-in for refills and labs, for example. We are working on ways to have labs done locally closer to one's home with results sent to us to facilitate telemedicine visits when a thorough physical examination may not be needed at that particular time. How long we will be able to offer telemedicine for will depend primarily on insurance companies continuing to cover those types of visits.


More broadly, the COVID19 pandemic has laid to bare unfortunate systemic inequities, with certain groups of people being disproportionately af-

ected by this disease. We are proud to be at an institution whose mission is to serve the underserved.

SFNE: What are some areas you are most excited for, or would like our constituents to know about the team at BMC?

BMC: I think we've touched upon the major areas for your constituents to know: we strive to continue providing excellence in scleroderma clinical care and research, and will continue to expand and innovate in both areas. For a rare disease like scleroderma, patients with scleroderma can have confidence that they are receiving the highest quality care guided by the latest and best evidence from research at our Center where scleroderma is not rare to us!

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The New England Chapter Board is looking for new Board members with accounting and financial skills. Please let us know if you are interested. Contact [LDesantis@sfnewengland.org](mailto:LDesantis@sfnewengland.org)