NEW ENGLAND

The BEACON

A Publication of Scleroderma Foundation New England Spring 2017

MAXIMIZING THE VALUE OF PATIENT INVENTION

In mid-March, Dr. Eva Guinan, a bone marrow transplant physician and translational researcher at Harvard Medical School, invited SFNE Executive Director Jack Armitage to be a presenter at a meeting of scientists and innovators. The presentation was sponsored by Harvard Catalyst, the clinical and translational science center at Harvard University, and a member of the National Institutes for Health Clinical and Translational Science Award Consortium.

The meeting itself was attended by representatives from thirteen foundations, twenty researchers and investigators from the Boston area (Harvard, Northeastern, BU, UMass) and twelve Harvard Catalyst members and representatives from Harvard Business School. The purpose of the meeting was to explore patient innovation versus strict scientist-driven inventions for people with challenges resulting from diagnosis. Dr. Guinan noted, "As the field of patient innovation continues to evolve, we are exploring ways to create partnerships that will support the development of patient and caregiver 'solutions' into more generalized tools to benefit patients, their disease communities and others with similar needs."

Jack speaking at Harvard Medical School

In response to this invitation, Jack introduced the topic: **Ideas, Innovation and Inventions… Is *Almost* Good Enough?** The leading inspiration in making this presentation was the frequent reports from many in SFNE's constituency regarding assistive devices that were not quite "enough" to resolve the challenges of the user.

SFNE sent out a request to our support group leaders asking support group attendees to offer feedback. Response was immediate and Jack was able to use many of the suggestions coming from these responses.

SFNE board president Don Legere accompanied Jack for the day. The other three speakers representing specific populations were Polly Dawkins from the David Phinney Foundation for Parkinson's, David Crandell, Director of the Amputee Program at Spaulding Rehabilitation Hospital and Andrew

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SERVE WITH LIBERTY AT SFNE

Serve with Liberty volunteers (l-r): Yigit, Andrea, Don, Cathy, Paul, Malini, Lana, and Lyndsey

We recently enjoyed an event initiated by the SFNE board of directors here at the office. Board member Andrea Mahoney, in her position as a manager at Liberty Mutual, arranged for us to have a "day of volunteers" through a program at her company. The volunteer program, called *Serve With Liberty,* was nothing short of incredible.

We arranged for a five-hour period on Tuesday, May 2. Six staff

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

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SPAGHETTI FOR SCLERODERMA 2017


2017 coordinator Allyson Favuzza and event originator Victoria Frazier

On the rainy Saturday evening of February 25, the sisters of Alpha Omicron Pi gathered with friends, family and guests for the 4th Annual Spaghetti for Scleroderma event held at the Bello Center at Bryant University in Smithfield, RI. This benefit event was hosted by Alpha Omicron Pi in memory of Wendy Frazier, the mother of alumna Victoria Frazier, and to raise funds for scleroderma programs and research.

There was a "photo wall" available, raffles, live music from a cappella group *The Bottom Line*, and a delicious spaghetti dinner. Several members of the Boston scleroderma support group attended. Member Mary McClay spoke to those attending about her journey with scleroderma as well as what SFNE offers to those living with scleroderma, their families and caregivers. Victoria Frazier also spoke of her experiences of having a family member struggle with scleroderma. She was deeply touched by the outpouring of support, even after she had moved on from college life. The sisters of Alpha Omicron Pi are an amazing group! Many thanks to this year's coordinator, Allyson Favuzza, for all her work on a successful event!

Boston Support Group members (l-r): Keisha Burton-Levy, Carol Taylor, Deanna White-Hebert, Mary Walsh Seabury, and Mary McCarthy.

This event is held each year in memory of Wendy Coleman Frazier.

FROM THE DIRECTOR'S DESK

By: Jack Armitage

The SFNE annual calendar of events is cyclical. As of this publication, staff and board at SFNE are caught up in the rapid-fire unfolding of the events that allow us to bring much needed endowment to research efforts. You'll remember that we were able to give $100,000 to eligible research projects in 2016, resulting from 15 events over ten months. We are proud of this end-of-year accomplishment and are mindful that it is support raised at the grass roots level by the individuals who attend and support our Walks for a Cure, the Golf Classic and our "third party" events. To our *BEACON* readership, thank you! We hope to see more of you at our events between now and October.

We have been building our mission from the educational perspective as well. Our support groups continue to serve our constituents regionally and our ongoing hope is that we are adequately reaching all who need assistance in the context of a scleroderma diagnosis, including families and communities. We've been especially proud this year to have been able to support two educational programs at area hospitals in New Hampshire and Maine. Our recent support group leader luncheon in Nashua was highly effective in empowering our dynamic regional support groups. Now might also be a good time for you to mark your calendar for our bi-annual Patient Education Seminar to be held in April 2018 at the Peabody Marriott Hotel. Specific date to be determined!

In our efforts to encourage research and to accelerate lab successes, we have partnered with Clara Health (*page 8*) to make access to clinical trials easy and dynamic. A recent Harvard Medical School presentation on innovations and inventions is featured on page 1 of this newsletter and will hopefully encourage more user friendly devices in the specific context of scleroderma. We also take a closer look at what it means when a researcher pursues funded research from a grant *(page 10)*.

Another partnership of which we are quite proud is with Liberty Mutual Insurance and their *Serve With Liberty* program, brought to us by board member Andrea Mahoney. Our board of directors continues to venture boldly into their increasing maturity and committee excellence. Excitedly, we are considering an expansion to bring in a third staff member in January 2018 – this will be a big step for us.

June is Scleroderma Awareness Month. We have been posting and raising awareness through the pledge driven campaign called *Hard Word, Harder Disease*. This social media campaign provides information throughout our contacts as a way to encourage sharing campaign-related posts on Facebook and Twitter. We are proud to join in this collaboration shared among the National Scleroderma Foundation, the Scleroderma Research Foundation, and the Scleroderma Society of Canada in the effort to increase awareness and commitment. Please join us in this shared effort to amplify our mission at *www.hardword.org*.

Of significant note, the National Scleroderma Conference will be held in Phoenix this year. *Discovery in the Desert* is the theme and the list of pharmaceuticals supporters continues to build excellence and high quality in the creative hands of the staff at the national office who make the impossible possible each year. Attending as well will be a broad representation of the scleroderma constituency, including an expanding group of adolescents through the effort of the National office to bring peerage and support to younger people living with scleroderma.

More locally, we thank our friends at the Alpha Omicron Pi Sorority at Bryant College for their ongoing loyalty to us in memory of Wendy Frazier *(page 2)*. As well, we tip our hat to Posie Mansfield for her dedication to survival and empowering others living with amputation *(page 5)*.

Finally, we congratulate our two "fifteenth" annual events, the Golf Classic for a Cure and the Worcester Walk for a Cure. The incredible people who had the vision in year #1 of these events surely have not received enough recognition and we are proud to offer it here. Eric and Debbie Magnuson, thank you for fifteen years of the Worcester Walk for a Cure. In those years you have raised more than $400,000! David Rosenberg, Bruce Gordon and Marie Coyle, Happy 15th for our Annual Golf Classic for a Cure. You are the proud promoters whose efforts have raised $1,900,000 cumulatively over fifteen years. Next year, we will cross the $2,000,000 mark. Persistence brings great reward - endless thanks to all of you.

Please join us in any or all of our events. Beyond being fun, they are essential to our success and outreach and, of course, we love seeing you there. *(For a list of upcoming events, see our events calendar on page 7 for dates and times).*

PATIENT INVENTION

(continued from page 1)

Berlin, Technical Staff Engineer at Draper Labs. A surprise attendee at the symposium was Lilly Stairs from Clara Health, the clinical trials access organization with which we have recently forged a partnership (*page 8*).

The speech presented the premise that the scleroderma patient is too often asked to be contented with innovations that, while somewhat helpful, more often come short in delivering complete satisfaction. Due to disease related loss of dexterity and tightened skin, well intentioned inventions are not completely effective specific to the obstacles presented in this mercurial disease. Jack challenged the audience to put the extra effort into creating user-specific tools that would meet the need of the scleroderma user at the 100% point. He stated, "Classically, *improvisation* is the behavior we most associate with our base of constituents in the regard of compensating around their challenges. I ask you to bring our constituents from improvisation to satisfaction." He offered examples of possible inventions that the attending audience might take on as challenges to improve the quality of life for any person with physical compromise resulting from scleroderma *(see insert, right)*.

Response to the day proved that SFNE had a very successful presentation and was well represented. The ideas came from a carefully collected list of suggestions submitted for the purpose of representing the people we serve out of the offices of SFNE. We can all be proud to have participated. SFNE has been invited to continue to work with this group of innovators and inventors.

To all our constituents: please continue to bring ideas to the table. We might just change the world, one small invention at a time!

* * *

SOME OF YOUR SUGGESTIONS:

- *Because of my hardened skin and cold fingers due to Raynaud's, the fingertip oxygen sensor at doctors' offices often cannot "read" my stats. If scleroderma fingertips are not a good and accurate transmiter of data, what device can be invented to ensure accuracy?*
- *Easier access to clinical trials. We often feel isolated and confused by the process. If we are willing contributors to the efforts for a cure, can innovations be put in place to make it easier to do so?*
- *I have found that battery-operated gloves are great for cold days, but they don't keep my thumbs warm. Also, the batteries are very bulky and hard to handle. Is there anything new with lithium ion batteries? Warming gloves are essential to me as I attend lots of soccer games for my children.*
- *Is there an extendable device that would help me to get up from a kneeling position? Perhaps a handle that would fit in the pocket (like a jacknife) and extend in a "T" shape to push off the floor?*
- *Is there a portable stylus for touch screens? They do not always react to my touch. Perhaps it could attach to a person's glasses.*
- *How about a small pocket container (like Chapstick) that would have a tacky substance that I could use to help me turn the pages in the newspaper or a book?*

Save the Date!

19th Annual Patient Education Conference
July 21-23, 2017
Sheraton Grand at Wild Horse Pass
Chandler, Arizona

The Annual National Patient Education Conference, July 21-23, offers educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends and includes special programming for juvenile patients.

Workshops, panel discussions and other educational sessions are led by leading scleroderma researchers and healthcare professionals. Whether you are newly diagnosed or have had scleroderma for many years, the National Conference is a great way to learn about the disease and become connected with others that are dealing with scleroderma.

For registration information go to *www.scleroderma.org/conference*.

LIMBITLESS POSSIBILITIES WITH POSIE MANSFIELD

By: Jack Armitage

The SFNE North Shore Support Group was very lucky to have a visit and presentation from Posie Mansfield in April of this year. Posie is the President and Certified Peer Visitor for the COP Amputee Association out of Wenham, MA. She runs an amputee support group which has the unique goal to train "seasoned" amputees to mentor and coach.

Posie's story is one of strength, courage and grace – three words which she has incorporated into the insignia for her organization. In her presentation to the group, Posie reflected all three attributes with humility and uniquely gifted storytelling for the benefit of our attendees, some of whom have had digital amputations due to calcification and subsequent deformity of their fingers.

Posie's story unfolded in a very stark way. In 2010, Posie's husband died as a result of a massive heart attack. Six months later, after a total knee replacement, she contracted MRSA, the virulent staph infection, resulting in the amputation of her leg above the surgery point. Posie's question coming out of the surgery was, "How do I move on from these two losses?"

She made the following points, "The focus of my life was forever changed; I spent a lot of time with the Boston Marathon survivors; I began to see my situation as an opportunity, finding the good in it."

Posie Mansfield speaks to the North Shore Support Group

Addressing the support group attendees, Posie said, "Any loss of a limb is a big impact in life, whether it is the tip of a finger or a whole limb. One should never minimize the impact of relative loss of any part of the body. If one does, the chance to learn and grow from it could be lost. What may seem like a simple toe amputation, for example, is devastating to balance and confidence, no less so than what I have lost." This was an astonishing revelation to members of the group who might have otherwise felt less relevant in their circumstances. Additionally, it brought this group of people who are challenged by life's circumstances closer together.

Posie continued to be frank in her story. "I need crutches," she said, "but I refuse to use a wheelchair. I want to keep my independence. When you make these adjustments, you have to make choices to either live with it or fight it. Choosing to live with it pays off and, in my case, I HEALED faster!

"When you have a disability, you tend to offset it by compensating with other limbs and with compensating activities. This can further confuse your body. Be patient – the body seeks balance!

"I am very lucky in life. I am an EMT instructor. I ski on one leg. I spent two days skiing this winter! I also water ski on one leg. I participate in adaptive sports. Spaulding Rehabilitation Hospital accommodates my limitations – they assist when I cannot do something. I have learned that sometimes your limitations are placed on you by yourself!"

Posie puts her words where her beliefs are – the subtitle of her organization is *Limbitless Possibilities*. Posie paints a perspective of realism as she advises the group, "You cannot prepare for this – you must adapt. Looking around this room, I see that none of you have given up – **good for you**!"

In comparing other challenges she shares with members of our group, Posie went on to say, "Physical therapy helps with balance. But when PT ends, you have to go home. In my situation, I go home to another batch of challenges. I also have gastroparesis disorder and digestive problems."

Chuckling, she goes on to say, "Look, after my surgeries, I had some stark choices. One of them was to decide if I was going to be a victim or a victor. You KNOW which one I chose! I adjusted all sorts of things – my methods of eating not the least of them. I learned a few tricks. I trained myself not to feel different. 'Different' is a judgement! In the regard of judgements, adults are the WORST! Kids adjust spontaneously."

If Posie's parting remark was to suggest that we all try to look at life's challenges the way that a child does, she may have planted a very significant nugget of skill in this group. Acceptance and growth go hand in hand. This was a very powerful support group meeting for all who attended. In subsequent weeks, in conversation with our members, I have learned that Posie has colored their outlook with hope and determination. Thank you Posie – we are a better organization because of you.

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Falling down is part of life.
Getting back up is living.

~Anonymous
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2017 SPRING WALKS REVIEW

WORCESTER WALK - CELEBRATING 15 YEARS!

What can we say about the 15th year of the Worcester Walk? The day started with mermaids and mascots, and improved from there. 2017 marked 15 years since founder Eric Magnuson, then a Bancroft School sophomore, had an idea to create a walk in honor of his mother Debbie, who lives with scleroderma. The school joined in and the Worcester Walk was born.

To mark the 15th anniversary, all participants received a commemorative pin. Three young ladies made an appearance in Disney princess costumes, and the mascot of the Worcester Bravehearts baseball team joined the festivities along with Mayor Joseph Petty to honor the day.


The royal court!

This walk hosts lots of great teams, and this year raised $23,830 towards SFNE's programs and research for scleroderma. With the help of raffle coordinator Martha Pierson, her family, the Worcester Support Group, Debbie Magnuson and volunteers who brought baskets, this year's raffle was HUGE, with over 54 chances to win a prize, plus a vibrant silent auction.

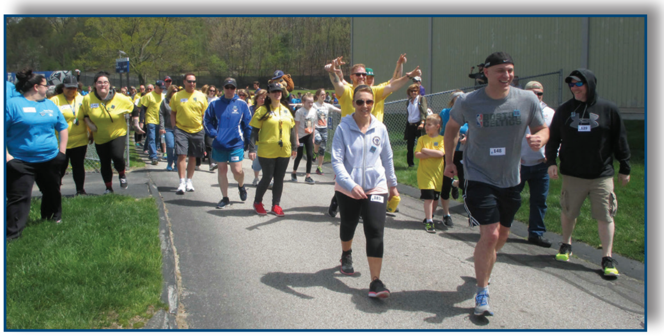
There were hamburgers and hot dogs, pizza, chips, Table-Talk pies and delicious brownies to help celebrate the event. There was also music throughout the day, DJ'd by Glenn Petrucci. Our sincere thanks go to Debbie, Eric and David Magnuson, Gail LeBlanc, Nancy Valleco, Martha Pierson, Betty Belevick and the Worcester Support Group, Mayor Petty, Glenn Petrucci, Kathy Moriconi, the Bancroft School, and all our volunteers.


Nancy Valleco spoke to the crowd about Mary Ann and Vivian.

This walk was held in fond memory of two amazing individuals: Mary Ann Persson and Vivian Killoran. We were honored to have had them as part of the Worcester Walk and support group for many years. Looking to 2018, we anticipate many more Worcester Walks in the future!


Debbie and Eric Magnuson received an award for fifteen years of the Worcester Walk.


The Worcester Support Group gave their support to the Walk


The Walk started with a bang! Over 205 walkers completed the course on a chilly May afternoon.

Go Team Skippy!

MAINE WALK

Sandy Kneeland, Donna Dodge, Lori Chason, Sue Zemla and Michelle Noyes

Thank you Hardy Mainers for an amazing walk on a beautiful day. The temperature was just right for 122 walkers and guests to come out and enjoy a beautiful walk in the park while supporting programs and research for scleroderma.

The Walk was followed by a lunch of pizza from Westbrook House of Pizza and a raffle with lots of winners!

There was a great showing of teams, with Team Heather B joining the group and raising the most funds this year! Team Ambrose was second followed by Chason a Cure, but contributions flowed in from all our teams, raising a total of $13,857! Many thanks go to all teams, walkers, donors and volunteers, including Sandy Lunner, Terri Ireland, Sandy Kneeland, Matt Dube, Lori Chason and our onsite helpers, Saad and Mohammed. We couldn't have done it without all of you!

We were honored to walk in memory of Deb LeHouillier and Heather Bshara, and took a moment of silence before the walk to remember their impact to so many. Thank you everyone and we hope to see you next year!

Family and friends walked in loving memory of Debbie LeHoullier.

Team Heather B sporting their own team shirts in memory of Heather Bshara.

Some Hardy Mainers!

Even Rocky Balboa came out of retirement to show his support!

SAVE THE DATE

2017 EVENTS

☑ **The Polar Plunge**
L Street Tavern, Boston, MA
Sunday, January 1, 2017

☑ **Spaghetti for Scleroderma**
Bello Center, Bryant University
Smithfield, RI
Saturday, February 25, 2017

☑ **Fifteenth Annual Worcester Stepping Out for a Cure Walk**
Bancroft School, Worcester, MA
Sunday, May 7, 2017

☑ **Eighth Annual Maine Stepping Out for a Cure Walk**
Riverbank Park, Westbrook, ME
Saturday, May 20, 2017

☑ **Ninth Annual Plymouth Stepping Out for a Cure Walk**
Nelson Beach, Plymouth, MA
Sunday, June 11, 2017

☑ **NCRS/NE Corvette Day**
Larz Anderson Auto Museum
Brookline, MA
Sunday, June 11, 2017

Strolling for Scleroderma
Deer Island, Boston, MA
Sunday, June 24, 2017

SFNE Golf Classic for a Cure
Salem Country Club, Peabody, MA
Monday, July 17, 2017

Lynda Fernandes Golf Tournament
Midville Country Club
West Warwick, RI
Saturday, TBD, 2017

Thirteenth Annual North Shore Stepping Out for a Cure Walk
Proctor School, Topsfield, MA
Sunday, September 10, 2017

Seventh Annual Westfield Stepping Out for a Cure Walk
Stanley Park, Westfield, MA
Sunday, September 17, 2017

Third Annual Boston Stepping Out for a Cure Walk
Artesani Park, Boston, MA
Sunday, October 1, 2017

CLARA HEALTH FOR CLINICAL TRIALS

In 2015, a young woman named Lilly Stairs contacted SFNE to offer tickets to a comedy show in Boston for any of our clients who would enjoy the event. These no-cost tickets would make life just a bit more fun for them. Lilly spoke passionately about the importance of continuing to see to the "whole" needs of our constituents – a night out on the town with some laughter would be good medicine!

Lilly Stairs

That conversation and generous gift made an impression on us and when Lilly called again a year later to tell us that she had joined a team of entrepreneurs whose mission would be to walk people with autoimmune disease through the process of eligibility and participation in clinical trials, we jumped at the chance. The organization is Clara Health (*https://clarahealth.com*) and Lilly is their Head of Patient Advocacy.

In the months since, Lilly has contacted many of our support group leaders and has made presentations to our constituents about how they can be a part of research and trials to find a cure.

Lilly assures us that Clara will always be free to patients. Their revenue stream comes from researchers and biotech companies who want to partner with Clara to recruit for their trials. She states, "Our plan is to support patients throughout the entire process of a clinical trial, from search through trial completion." Follow this link to see Lilly's video presentation to our constituents: *https://drive.google.com/file/d/0B6PrUc1u1_6bbWk2bTQ3RmxWNkE/view?usp=sharing*.

SFNE is now partnered with Clara Health with the shared goal to bring the clinical trial process closer to home. Lilly is our guide in making the process easily understood and accessible. Because of this alliance, we are able to involve our support group leaders and members in the clinical trials process from beginning to end. We are at the very beginning of this journey and the feedback that we are getting is enthusiastic and hopeful. Anything that we can do to enthuse research excellence is key to our mission and success.

SERVE WITH LIBERTY

(continued from page 1)

members from Liberty Mutual arrived at 9 am to a scleroderma tutorial and a big box of doughnuts. What started as an overview on the disease quickly became a passionate discussion, as one of the attendees had lost her mother to scleroderma. Don Legere (Andrea's dad) spoke about his own challenges with scleroderma and Cathy Legere offered a caregiver's perspective.

For the next three hours, we accomplished the near-impossible! We built 32 raffle baskets for our walks and made 133 snack bags for our golfers at the upcoming Golf Classic for a Cure. Pizzas and salad were delivered from Alex's House of Pizza in Topsfield by our friend Tim. We are very grateful to Liberty Mutual Insurance Company for creating this volunteer opportunity. To Andrea, Malini, Lana, Paul, Lyndsey, Yigit, Don, Cathy and Rebecca, THANK YOU!!

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ON THE BOARD

Board members Marie Coyle and Jane Ladas discuss the history of Scleroderma Foundation New England

Longtime Friends, Shared Vision

SFNE founder and board member Marie Coyle meets with returning board member Jane Ladas to review historic documents for preservation and future use. Beyond being old friends since the mid-1980s, Marie and Jane share a passion for research and strict oversight of research dollars. Marie and Jane have been admirably invested in the mission of our work and bring endless experience and vision to our goal to find a cure for scleroderma in our lifetime.

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NEWS BYTES

EVERETT HEALTH FAIR

Roberta and Fran Mauriello hand out information at the Everett Health Fair

North Shore Support Group Leader Roberta Mauriello and her husband, Fran, participated again at the annual Everett Health Fair. During the fair, many people stopped by to ask questions and took brochures. The Everett, Mass. Public TV station also interviewed Roberta about scleroderma. This helps to spread awareness about scleroderma and inform the public of the organization's help and support. Thank you!

BOSTON WALK VOLUNTEERS

Boston Walk coordinator Carol Taylor is looking for additional volunteers for the Boston Walk on October 1st. If you are interested in helping coordinate or volunteering at the Boston Walk along the Charles River at Artesani Park in Brighton, MA, contact Carol at 774-233-0558 or cvsing@comcast.net. If soliciting for raffle items, please contact SFNE for solicitation letters.

SCLERODERMA INFO KIT FOR EMERGENCY MEDICAL RESPONDERS

Scleroderma is such a rare disease that there is a chance that some emergency service professionals haven't encountered a patient with the condition. They may not understand some of the intricacies of the disease and how best to approach caring for the patient.

The Scleroderma Foundation created a downloadable booklet for emergency medical responders to help them better understand how to manage scleroderma patients. It highlights some of the challenges they may face. One example is that the use of a pulse oximeter may not work accurately if the patient has Raynaud's Phenomenon. Another example is that blood pressure readings may seem abnormally high due to the patient taking ACE-Inhibitors for renal problems.

You can download this booklet from the Scleroderma Foundation New England site at *www.scleroderma.org/newengland*. Go to the local resources page and click on *download a scleroderma info kit to have on hand for Emergency Medical Responders*.

15TH ANNUAL SFNE GOLF CLASSIC

From our office in Topsfield, we prepare ourselves for the 15th Annual Golf Classic for a Cure for Scleroderma, to be held on July 17 at the Salem Country Club. This year there is a fair amount of sentimentality attached to these preparations. The Golf Classic is the backbone of our financial readiness to find a cure. Its consistent success is measured by the dedication of three people: David Rosenberg, Bruce Gordon and, of course, Marie Coyle. To all three we offer our endless gratitude and we honor their vision by making this annual event a model of success. We are over halfway enrolled as of this printing of *The BEACON*. This year, the Classic will feature a new toy – a golf ball cannon! Marie has generously sponsored the cannon, which is powered by compressed air and which will shoot a golf ball up to 325 yards with no recoil whatsoever. Watch for pictures in our next issue of *The BEACON*.

To all who support our Golf Classic, thank you. We are able to do what we do because of your ongoing support and belief.

RESEARCH SPOTLIGHT

By: Rebecca Dube

Dr. Bradley Maron receives the 2017 Marie A. Coyle Research Grant

Dr. Bradley Maron

Our bodies are made up of so many inter-related functions which, when the body is running optimally, all work together in good health and efficiency. When any singular part of this "machine" slips out of synch or function, it can affect a host of other functions throughout the body. One of the goals of researchers is to isolate specific causes of such dysfunction so they can identify solutions and guide others to take steps to treat the larger problem. As with all classic research, each discovery uncovers new challenges and the process is often made increasingly complex, revealing the need for even more research and discovery. A researcher often finds that the excitement of discovery is mitigated by the resulting need for more research.

Dr. Bradley Allen Maron, M.D., who was recently awarded the 2017 Marie A. Coyle Research Grant, has been doing just that. As a cardiologist/ vascular biologist, and a member of the research group at Brigham and Women's Hospital in Boston, Dr. Maron has been studying how greater levels of aldosterone (*see insert*) in patients with pulmonary arterial hypertension (PAH) contribute to lower levels of necessary bioavailable nitric oxide. The resulting "pulmonary vascular oxidant stress" contributes in part to increased pulmonary vascular dysfunction.

Dr. Maron proved in animals that this oxidant stress modifies three receptor cysteins that are needed to produce the nitric oxide synthesis required to keep everything in balance. This research can then help to steer scientists in a direction to look for possible treatments of this dysfunction. They can now try looking into a way to inhibit the overproduction of aldosterone, thereby restoring balance and preventing/reducing pulmonary vascular dysfunction in PAH.

Having been awarded the Marie A. Coyle Research Grant from the Scleroderma Foundation Peer Review Research Program, Dr. Maron can now undertake a similar funded study that looks at the role of proteins in systemic sclerosis and how they communicate between cells within lung arteries. What, if anything, do they do to increase collagen that contributes to pulmonary arterial hypertension?

Such individual and ongoing research endeavors can add up to possible breakthroughs in treatment of some of the major attributes of systemic sclerosis, and perhaps one day could be a contributing element to an overall cure. Scleroderma Foundation New England is proud to be able to, provide funds to support Dr. Maron and other researchers in their ongoing, painstaking quest to find answers, treatments, and ultimately a cure. Our ability to to do so is a direct response to your generous contribution to our research mission! Thank you.

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> ***Against all odds, a seed rises from darkness and beautifies the universe.***
>
> ***~Matshona Dhliwayo***

What is aldosterone?

Aldosterone is a steroid hormone that is essential for sodium conservation in the kidney, salivary glands, sweat glands and colon. It plays a central role in the regulation of the plasma sodium, the extracellular potassium and *arterial blood pressure.*

What is nitric oxide?

Nitric oxide is an important cellular signaling molecule involved in many physiological and pathological processes in mammals (including humans). Research into its function led to the 1998 Nobel Prize for discovering the role of nitric oxide as a *cardiovascular signalling molecule.*

Dr. Maron is a recipient of the Scleroderma Foundation's Established Investigator Grant. This grant is for established investigators both inside and outside the field of scleroderma (SSc) research who wish to propose pilot studies to obtain preliminary data dealing with a highly innovative and/or highly relevant theme related to SSc. This grant supports pilot research that is likely to lead to more substantial research pilot grants from federal or non-federal sources. Applicants may request up to $75,000 per year for up to two years. Recipients of an Established Investigator Grant must have been a Principal Investigator on grants from either the Scleroderma Foundation or other national, private, or government agencies.

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SUPPORT GROUP LEADER LUNCHEON

Back row (l-r): Rebecca Dube, Jack Armitage, Don Chapman, David Magnuson; Middle Row (l-r): John Kittredge, Patty Kittredge, Brenda Promowicz, Donna Ahern, Tricia Legere, Debbie Magnuson, Carla King, Don Legere, Cathy Legere; Front Row (l-r): Christine T. Maroney, Jean Chapman, Joan Kingsbury, Carol Taylor. Video Screen: Lilly Stairs of Clara Health.

Twice annually, SFNE hosts an appreciation luncheon for our support group leaders and their guests. In the four years that we have been "growing" this new idea, it has morphed under its own power to being a powerful opportunity for education and organizational inspiration - a force within SFNE.

On April 14th, 18 of us met at The Country Tavern Restaurant in Nashua for what has begun to feel like an annual summit conference. We kicked off the meeting with a video created by Lilly Stairs of Clara Health, a start-up clinical trials access organization from Boston. SFNE has recently partnered with Clara Health in the effort to make participation and access to clinical trials less complex for our constituents. Lilly has since visited two of our support groups for presentations with more planned in upcoming weeks. We anticipate a very good relationship with Clara Health going forward.

Joan Kingsbury reported on Posie Mansfield's visit to the North Shore group (*page 5*). Carol Taylor updated us on the Boston Walk and the Boston Support Group. Don Legere offered a personal reflection on his health and then spoke about a recent SFNE gift he will hand-deliver to Dartmouth Hitchcock Medical Center to enthuse patient care, education and awareness there. Debbie Magnuson updated us on the Worcester Walk and invited all leaders to join in. Fall River/Bristol County's Christine Maroney enthused the meeting with discussion about an education program being planned for her group. Jean Chapman and Carla King spoke about the direction of the Hampstead group and have undertaken plans to have Lilly Stairs visit with a presentation.

Perhaps most relevant in this meeting was the opportunity to discuss inventions and innovations ideas for the presentation being made at Harvard – maximizing the value of patient invention. Lots of ideas came forth and would be represented later in the month at the Harvard Medical School Symposium. Tricia Legere expressed the urgency for solutions regarding compromised hands and emerging challenges for those living with scleroderma.

We are witnessing the emergence of a powerful group of people whose individual and collective contributions to our mission are significant – thank you Support Group Leaders!

SFNE SUPPORT GROUPS

Maine

Maine Support Group
Windham Public Library 11 am - 1 pm
Meets the second Friday of most months
Co-Leaders: Lori Chason, 207-892-7323
chason.lori@yahoo.com
Sandy Lunner, 207-420-3337
slunner@aol.com

Massachusetts

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

Fall River/Bristol County Support Group
Meets the 3rd Tuesday of every month
6:30 - 8:30pm
Co-Leaders: Donna Bernier
Donnabdab2@hotmail.com, 774-488-6775
Christine T. Maroney, 508-675-4152

North Shore Support Group (Topsfield)
Meets the 2nd Wednesday of most months
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
Group Leader: Nancy Velleco
508-869-2997

New Hampshire

Granite State Support Group (Hampstead)
Meets the last Saturday of every month
Co-Leaders: Carla King, 978-884-4866
granitestate@scleroderma.org
Jean Chapman, chappybear@charter.net

Central NH Support Group (Bow)
Meets the first Wednesday of the month
Baker Free Library, 10 am - 12 pm
Co-Leaders: Don & Cathy Legere
603-566-3145, donlegere@comcast.net

Vermont

Burlington Vermont Support Group (Williston)
Meets the 3rd Tuesday of most months
Group Leader: Blythe Leonard
802-878-0732, b.leonard@myfairpoint.net

Brattleboro Area Support Group
Meets the 2nd Wednesday of every month
Brattleboro Memorial Hospital, 6:00 - 7:30pm
Group Leader: Ilene Wax
802-464-5847, ilenewax@gmail.com

SCLERODERMA FOUNDATION
NEW ENGLAND
SUPPORT ★ EDUCATION ★ RESEARCH
New England Chapter
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Quips!

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It's great to be great, but it's greater to be human.

Never have a battle of wits with an unarmed man.

Pride is the only poison that is good for you when swallowed.

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Renew your SFNE membership and you will not miss out on the New England *BEACON* or the National *Scleroderma VOICE*, both of which feature updates on the latest research and treatment, stories of hope from fellow constituents, and reviews of fundraising events large and small.

Your $25 membership fee also helps support Scleroderma Foundation New England, its programs and publications, and increases available research funds. Your subscription end date is on the bottom of your mailing label (above).

PUZZLE ANSWERS

Congratulations to Deb Mall, the winner of our Winter BEACON puzzle! She will receive a box of Harbor Sweets chocolates in the mail. See the correct answers below.

a. 12 = S. of the Z.	Signs of the Zodiac
b. 88 = P.K.	Piano Keys
c. 4 = Q. in a G.	Quarts in a Gallon
d. 24 = H. in a D.	Hours in a Day
e. 29 = D. in F. in a L.Y.	Days in February in a Leap Year
f. 64 = S. on a C.	Squares on a Checkerboard
g. 52 = C. in a D.	Cards in a Deck

NEW PUZZLE

The last three letters of each word in the puzzle are already in place. Insert the blocks of letters below into the remaining squares - without rearranging any letters - to complete eight nine-letter words reading across. Each block is only used once. Once filled, two of the columns reading down will spell a pair of bonus words.

AMP DAR EDE ENF GNO HES HOU LIT
MAT OCR ORC PRO RIA SEW THE WOM

						T	R	A
						S	I	S
						O	L	K
						U	D	E
						I	F	E
						R	C	H
						A	C	Y
						V	I	L

Send us your answer, and you could win a prize!