NEW ENGLAND
The BEACON
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DON'T EVER GIVE UP THE FIGHT!

By: Jack Armitage

Interviewing with SFNE board member Don Legere has been a delightful lesson in resiliency and personal mission to prevail. His story is really one of reflection over an eight year period from diagnosis through excellent care and astonishing treatment. It was Dr. Robert Simms at Boston Medical Center who initially advised him, "Don't let this disease change your lifestyle – rather, let your lifestyle change the disease!" Don took this advice to heart and has led with confidence and focus as is reflected in his day-to-day actions. With humor and grace, he is showing us all how lifestyle dictates personal success.

Don Legere (middle) with Dr. Burt (middle, right) and members of the SCT unit staff

Don's story is an example of the village that it takes to raise a person to excellence through teamwork, faith and attained goals. Starting with the careful directives of Drs. Lafyatis and Simms at Boston Medical Center, he initially participated in two trial studies, the second of which put him into a randomized protocol of a year of chemotherapy, called the SCOT Trial. At the point that the trial therapies began to falter, it was clear that the next line of treatment would be Hematopoietic Stem Cell Transplantation (HSCT).

So, in 2014, after a trip through the slalom course that is our health care system, Don found a way to meet the criteria for HSCT. The criteria were twofold: first, being at a level of health that kept him out of risk and second, enrolling in a health care program that found him eligible for coverage. It was neither easy nor quick to happen – Don's unrelenting persistence is what got him to treatment.

The process led Don, by this point quite ill, into the care of Dr. Richard Burt, Chief, Division of Immunotherapy at Northwestern University, Feinberg School of Medicine in Chicago. Don enrolled in the ASSIST II Trial Study with Dr. Burt on October 27, 2014. What followed was a rapid-fire series of medical procedures and events (see box on right). He emerged from the process on what he now refers to as his "HSCT Birthday."

Born in Athol, Massachusetts, Don and his family moved soon after to Maine, where he did most of his growing up. As a child, Don was determined and competitive. He attended St. Patrick's School in Portland, ME through grade

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DON'S STEM CELL SCHEDULE

2007 - Don's diagnosis with scleroderma

2007-2015 - Participation in clinical trials and treatment with various drugs and chemotherapy with limited success

10/27/14 - Eligibility tests for approval for Dr. Richard Burt's Assist II trial study at Northwestern University Feinberg School of Medicine

12/10/14 - Admitted for chemo and beginning of harvesting stem cells - 12 days total

12/25/14 - Home for Christmas!

1/14/15 - Back to Chicago for PICC line insert and final stage of HSCT therapy

1/14 to 1/20/15 - Five days of chemo, drugs, and intentionally diminished blood counts

1/20/15 - HSCT Birthday! Infusion of stem cells...

1/21 to 1/30/15 - After ten days, white blood count returns to 1.01

1/30/15 - Discharged from the hospital

2/5/15 - Back home again

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six. His extracurricular activities through his school years included gymnastics, ping-pong and pool. His positive attitude was amplified by his tendency to dream BIG! He relocated to Camillus, New York for his secondary education. There, he attended West Genesee Junior and Senior high School. He is the third of four children: an older sister and older brother and a younger brother after him. An early awareness to "watch out what you think about" surely led to his ability to visualize a positive outcome and to take control of challenges.

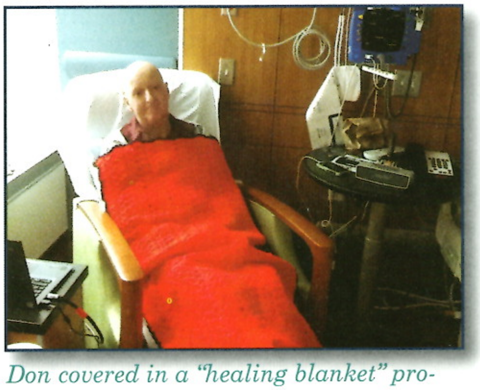
Meeting Cathy and subsequently marrying her in 1976 resulted in the expansion of his family. He soon had four children, Michael, Andrea, Maria and Nicholas. Don describes his family as his most important hobby and expands his interests to include water skiing, snow skiing, snowmobiling, golfing, hunting and fishing. As long as family is at the top of the list, the others come in no particular order of favoritism!

In his professional life, Don has been a dedicated insurance man. He worked for the Prudential Insurance Company for 25 years, followed by 14 years with Modern Woodmen of America – a Fraternal Insurance Company.

Don first noticed a change in his health and body when, in 2007, he was aware that his hands and feet were swelling. He sought medical follow-up right away and saw many doctors until he was finally diagnosed with scleroderma a year later. Don's perception is that his disease progressed slowly and it was 4½ years before there was any sign of internal involvement. The effect on his life was significant. Early in the progression Don was compelled to give up some of his favorite pastimes including snowmobiling and heavy yard work – such as cutting firewood. All were affected by his Raynaud's disease – a condition often paired with scleroderma.

Don and his family members adjusted to the reality of his new challenges and all stepped up to the plate to take a proactive role in his care and protocol – all wanting to help and all being very understanding and supportive. Cathy, Don's incredible wife, was constant and steadfast in his personal care and advocacy – best friends, these two! Their family had the usual fears and questions, especially concerns about heredity of this disease. Don was able to assure them that there are no hereditary links and they did not have to live with concerns about themselves and their children. There is so much to learn early on.

On January 20, 2015, Don celebrated a birthday. As he describes it, "Stem Cell Transplantation hit my 'reset' button and gave me new life." His transition from precipitous decline in health to spontaneous rebound and recovery was remarkable.



Don covered in a "healing blanket" provided by the facility chaplain's church

Clearly, Don's personal commitment and attitude make this transition all the more compelling as his energy and his renewed enthusiasm have blossomed. His openness to helping others through the process, combined with his tireless self-representation regarding HSCT reveal him to be

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a missionary with generosity and unstoppable goodwill. An example of his outcome measures, beyond his greatly improved health, includes a willingness to help others to navigate the pathways to wellness. Some obstacles for others going through this process include lack of insurability (Don can help you with that), advice on the process and the logistics (Don will get you up to speed with that), knocking down the roadblocks to insurance coverage (Don's specialty) and outreach and self-representation as a teaching tool (Don is a gifted speaker and teacher).

Don's distilled philosophy about his challenges with scleroderma is simple: **Don't Ever Give Up The Fight!** To that personal reflection, Don is always quick to add that he will personally help anyone diagnosed with scleroderma to never give up the fight. You may see a new scleroderma support group arriving in the Concord New Hampshire area soon – and as surely, Don's name will be attached to it.

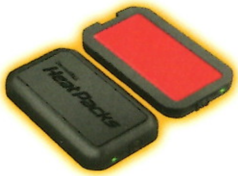
Our great thanks go out to Don and Cathy and their remarkable family for raising the bar on goal setting and for encouraging personal success in others faced with the challenges posed by a diagnosis with scleroderma.

* * *

Don poses with another HSCT patient, Michelle, on his discharge day.

THERMACELL AND SOLETICS REVIEWS

By: Jack Armitage



Thermacell hand warmers

Preliminary reports on the early testing of two different warming devices for people with Raynaud's Disease seem, while still in the testing stages, quite positive as we anticipate their application for alleviation of symptoms of Raynaud's. The two companies whose products are being considered are Soletics (teamsoletics.com) *and* Schawbel Technologies LLC (heat.thermacell.com).

To date, both companies have had a target audience in cold weather outdoor activities, essentially for people whose primary objective is to stay warm under what we would consider "normal" conditions. These thermostatically controlled devices seem to be enjoying great success in that description but sensibly, their inventors have stretched their imaginations to include a new frontier: medical application for people suffering with Raynaud's Disease.

Surely, in the broad context of scleroderma, we have no shortage of candidates! So recently, with the blessing of Arthur Schawbel, principal at Schawbel Technologies, we gave four sets of warmers to four of our constituents. With the gifts, we required that a 30 day report be submitted with an objective assessment of the success or failure of the warmers to alleviate symptoms of Raynauds. Three of the recipients reported back in thirty days with glowing reports on their success. All were notably impressed with this product that has three settings, is thermostatically controlled and rechargeable. Our fourth recipient has not reported back yet – we are guessing due to other stresses.

Soletics is in an earlier stage of development. Our representative inventor there, Vanessa Gore, keeps us up to speed on her progress in the lab as they continue to design and implement a complex glove that has individuated finger sensors which will set the temperature for each as called for by the person wearing the glove. The glove looks like something that would be worn in a Dick Tracy world and promises to be as sophisticated!

Soletics glove prototype being built

We applaud both companies for their heightened sensitivity of our needs and look forward greatly to continuing our emerging relationship with them. We will be looking for a funder in the five to ten thousand dollar range to assist us in making these devices affordable and available to us in the future. Early indicators are very good with both companies and, knowing what Raynaud's sufferers endure daily, there is no shortage of urgency to make these products accessible and available.

Thank you to Vanessa Gore at Soletics and Arthur at Schawbel Technologies LLC, and especially to our testers Tricia, Donna and Joan!

* * *

By a simple show of hands, who here is wearing gloves?

~ Jarod Kintz