

Saville Kellner and The Scleroderma Research Foundation – A Serendipitous Path to Helping Patients

Las Vegas resident Saville Kellner is CEO of Lake Industries, an international leader in the wholesale supply of kitchenware. He's also a member of the Board of Directors at the Scleroderma Research Foundation—and a patient.

“About ten years ago, I had the pleasure of meeting celebrity chefs Susan Feniger and Mary Sue Milliken through a radio promotion one of my companies was involved in and we became good friends. Susan was a dear friend of Scleroderma Research Foundation (SRF) founder, the late Sharon Monsky, and a founding Board Member. Susan shared with me her passion for the SRF and asked how I felt about getting involved. I was happy to do so based on her enthusiasm, having no idea what scleroderma was or what the word even meant. So, we donated auction items and attended their gala *Cool Comedy – Hot Cuisine* events in Los Angeles; thrilled to participate. I listened to the keynote speakers and thought I understood...

Coincidentally, a short time later, I became aware that a schoolmate from Cape Town had been diagnosed with scleroderma. My friend had a kidney transplant and was really struggling. I introduced her to the SRF, and invited her and her husband to attend the Los Angeles event with us. We all had a great time and learned more about the disease. Again, I thought I understood.

Fast forward to November of 2011... I was diagnosed with scleroderma. Talk about a coincidence! The odds are amazing. The lottery would have been nicer. Scleroderma is not contagious or directly hereditary so this was a complete shock.

I had some symptoms but didn't make the connection. One evening on the soccer field, my fingers turned blue—an ink blue that scleroderma patients know well. My fingers then turned red—a deep, dark red. They then turned white. I thought I was having a heart attack. The blood wasn't flowing to my fingers. I was experiencing Raynaud's phenomenon, often one of the first signs of scleroderma. My hands became hard and I couldn't bend my fingers. I went to doctor after doctor, had test after test—arthritis? carpal tunnel?

Around the same time, we relocated our group of companies to the Las Vegas area and I went to see a new young doctor who took one look at me and said: “CREST Syndrome or Limited Scleroderma.” I thought I understood.

She referred me to a rheumatologist; I immediately called my friend Susan. After some crying and a lot of “I don't believe this,” Susan insisted that I see a specialist on the East Coast at one of largest and most respected scleroderma specialty clinics in the world. Only now do I realize why she insisted. The SRF plays a vital role in Centers like these. They recognize the power of bringing scientists and clinicians together and provide seed money not only to launch

these incredible Centers but also help sustain them. Because of research that so many have so generously supported, these doctors knew what treatments were likely to have success in suppressing my scleroderma. For now, my prognosis seems bright. I still have 70% of my lung capacity and my fingers can still grasp a pen.

Finally, I am beginning to understand. Thanks to the SRF and to all who so generously support them, I am one of the lucky ones.

Since joining the SRF team, I've committed to hosting one of their amazing *Cool Comedy – Hot Cuisine* events in Las Vegas, where all of the money raised will be funneled directly into research. Unlike choosing to make an investment in research at a single highly respected institution just because of its pedigree, the SRF is nimble enough and its reach is broad enough to seek out and find the best, most promising research—wherever it is being conducted (which, in the case of scleroderma research happens to include Dartmouth, Harvard, Johns Hopkins, Stanford, UCSF among others) and where it will have the greatest impact for patients. I'm excited that new research we're funding is showing promise not just for scleroderma, but for all autoimmune diseases.

At the SRF, more than half of research dollars go toward long-term “Big Difference” research aimed at a cure. Equally impressive, 40% of funding is allocated to helping patients today. By funding clinical centers and projects dedicated to improving the quality of life for patients like me, now, not just down the road, this program is unlike any other.

I've been given a clear view into the lives of scleroderma patients; I have seen many in waiting rooms at hospitals as I sat next to them; I've experienced a fraction of what many scleroderma patients go through. It's extremely frightening.

There will be many more people diagnosed with this debilitating disease this year and in the future. And despite how far we have come, too many will suffer. Others will die.

For those patients, and for myself, I'm committed to helping the SRF grow and am very excited to partner with my friend Susan Feniger, owner of Border Grill restaurants in Los Angeles, at Mandalay Bay and, soon, at Caesars Palace, to bring *Cool Comedy – Hot Cuisine* to Las Vegas.”

Cool Comedy – Hot Cuisine:

Since 1987, *Cool Comedy – Hot Cuisine* events in Los Angeles, New York and San Francisco have raised more than \$14 million for scleroderma research. The event combines a celebrity chef prepared multicourse meal, the “hot cuisine,” with headlining entertainment by some of the biggest names in comedy along with special musical guests. The SRF has never once paid a talent fee—instead taking great care of all artists and their support teams so much that they often volunteer to lend their time and talents again. Previous performers include Sheryl Crow, Ellen DeGeneres, Jay Leno, John Mayer, Conan O'Brien, Jerry Seinfeld, Robin Williams... The list goes on. *Cool Comedy – Hot Cuisine* is typically hosted by fellow Board Member, actor/comedian Bob Saget, who lost his sister to the disease.

Scleroderma:

Scleroderma (systemic sclerosis) literally means ‘hard skin,’ but the disease is much more—often affecting the internal organs with life-threatening consequences. Four out of five patients are women, most between the ages of 30 and 50, but the disease also strikes men and children across all ages and ethnic boundaries. Scleroderma has one of the highest mortality rates of the rheumatic diseases. It is characterized by widespread vascular abnormalities, an impairment of the immune system, leading to an unregulated immune response and a scarring/thickening of the connective tissues. The resulting fibrosis often affects multiple organs, including the skin, kidneys and lung. Much work has been done to manage the symptoms of scleroderma. Unfortunately, universal treatments to fully arrest symptoms and stop disease progression have been limited by a lack of understanding regarding the underlying cause(s) of the disease.

The Scleroderma Research Foundation:

Founded by patient and activist Sharon Monsky in 1987, the Scleroderma Research Foundation (SRF) is America’s leading nonprofit investor in medical research aimed at finding improved therapies and a cure for people living with scleroderma. The SRF oversees a growing acclaimed national research program focused on extending lifespan as well as improving quality of life for patients and has increased awareness of this life-threatening illness. Until a cure is found, the SRF will lead the way – working to help scleroderma patients everywhere live longer, fuller lives.

The Foundation has put together a diverse portfolio of projects enabling progress in understanding and treating scleroderma’s most pervasive symptoms. The SRF hosts an annual Scientific Workshop where funded investigators, new applicants and other experts are able to share their latest data and ideas. Also, the Foundation continues to invest in growing Scleroderma Centers of Excellence across the United States as well as continuing to forge partnerships with academia and industry that pave the way for new treatment options.

What makes the Scleroderma Research Foundation unique?

- ***Collaboration is at the core of the SRF research program.*** There is tremendous power in bringing top scientists and clinicians together both to improve quality of life *and* provide life-saving results for patients everywhere.
- ***The SRF research program accelerates progress.*** A majority of SRF funding is dedicated to long-term fundamental discoveries. The end goal is halting and even reversing damage, a process that SRF-funded researchers have proven possible in a laboratory setting in late 2013. Beyond the laboratory, the Foundation invests resources to launch and sustain Scleroderma Centers of Excellence —where patients receive comprehensive care, clinicians can partner with frontline scientists and the next generation of experts can be trained.
- ***The SRF has a world-class Scientific Advisory Board.*** The SRF research program is guided by an Advisory Board comprised of some of the nation’s most highly regarded

scientific leaders who select a prestigious roster of grantees dedicating large portions of their careers to scleroderma research. The advisors also leverage their networks and knowledge to bring new partnerships together for the benefit of scleroderma patients as well as others with life-threatening disorders.

- ***The SRF is a highly responsive organization with broad reach.*** The SRF seeks out and funds the best research *wherever* it is being conducted and where it will have the *greatest* impact for patients. SRF-funded research is showing promise not just for scleroderma patients but, also, for patients with other autoimmune diseases.