

Saratoga's Sandi Selvi stands up to MS

COVER STORY

Funny Lady

By Marianne Lucchesi Hamilton

Saratoga News, December 11, 2007

It's open mic night at The Improv in San Jose, and a succession of Robin Williams wannabes stumble through their routines. F-bombs and other expletives explode with tedious frequency, as jittery comics attempt to elicit any sort of response from the crowd.

Then Sandi Selvi bounds on stage. Subconsciously, the audience straightens up a bit. After the parade of mostly 20-something male comedians striving for "gangstah" coolness, Selvi is a revelation: female, late 40s, sporting both glasses and a sunny disposition. Her act quickly engages the crowd which, despite being two decades her junior, responds positively to her patter about her husband, kids and family life--and her multiple sclerosis.

On stage Selvi is fearless. Then again, once you've faced chemotherapy, radiation and an experimental stem-cell transplant, everything else is pretty much a walk in the park.

While going through the grueling treatments that freed her from the wheelchair looming in her future, Selvi made the choice to laugh. Since then she has dedicated her life to making others do the same.

The Saratoga resident has always been funny. Back when she was putting herself through San Jose State University by serving cocktails at a Capitola restaurant, a men's baseball team dropped in each Friday night after the game. Stacking paper bills in the center of the table, the team made a weekly promise to double the amount if Selvi could tell them a joke they hadn't heard. Accordingly, she made an urgent call each week to her father, who was then the San Jose Police Department's assistant chief.

"I'd call and say, 'Dad, Dad, gimme a new joke; I need the money!' " Selvi laughs. "I was all of 21, making these guys laugh. But they came in for about a year and a half, and they only caught me a couple of times."

After earning a degree in advertising, Selvi married husband Rob and settled into typical suburban life. When sons Jim and Tom entered Redwood Middle School, Selvi served as

head of the art docents program and coached AYSO soccer. She also ran an active side-business, painting murals in private homes under the "Off the Wall" shingle.

Always a fitness buff, Selvi studied tae kwan do at Studio Kicks in Los Gatos for many years. But while taking the exam for her black belt, things went terribly wrong.

During a spinning hook kick, Selvi inexplicably fell to the floor. When she tried to rise, she realized she was rooted in place. "I simply couldn't get up off the floor," Selvi says. "We'd all been training really hard, so I assumed I was just tired." Fifteen minutes later, Selvi once again attempted the move, with the same results. But this time, the entire left side of her face went numb. "I knew something was wrong; I totally panicked. Stupidly, I got in my car and drove home, then called my doctor."

A battery of tests followed. Selvi was told she was suffering either from Bell's palsy, a brain tumor or MS. "We were hoping for the Bell's palsy," she says. "That's temporary. Unfortunately, that wasn't the case."

The confirmation of MS was followed by a new and bewildering range of symptoms: double vision, numbness in Selvi's left leg, garbled speech and the loss of control of her left foot, which prompted constant tumbles. To stay vertical Selvi was forced to buy a cane; she used it for five years.

Her loss of motor skills brought an end to her business. "Suddenly I could no longer hold a paintbrush," Selvi says sadly. "I was broken; I didn't know what to do, or where to go. I felt like I wasn't worth anything anymore." Adding to Selvi's psychic pain was the necessity of enduring the weekly, toxic injections Rob had to give her to slow the progress of her disease. "We'd do it on Friday nights so he could watch the kids on the weekends, because I'd be sick as a dog for two days afterward. That was real fun."

The medication worked for a while. But eventually Selvi's disease began to shut down what remained of her motor skills and organ function. Her doctors recommended that the couple order a wheelchair; she was also advised to put her affairs in order.

Rob, now CFO at network security provider SonicWALL, was at the time a member of several companies' boards of directors. After one board meeting a colleague mentioned that his wife, who had MS, had just undergone an experimental stem-cell transplant and was still hospitalized, but that the progress of her disease presumably had been halted. As soon as the patient was released from the hospital, Sandi gave her a call.

"She told me that her MS had been killing her immune system," Selvi says. "The doctors essentially killed off the rest of her immune system, then built her a new one through an 'autologous' stem-cell transplant--one that used her own stem cells. I thought that made complete sense, so I made an appointment to consult with the medical team." The visit took Selvi to San Diego's Scripps Institute, where she consulted with the doctors, and was tested to gauge her suitability for participation in the experimental program.

She received the green light, and was scheduled to become the second MS patient in the U.S. to undergo the revolutionary procedure (Italian medical teams have routinely performed the procedure for three decades; Japan has begun to embrace the practice as well). But she and her husband paid a high price--literally. Since insurance would not cover the procedure, the Selvis were forced to plunk down \$100,000 out of their own pockets. "There were absolutely no guarantees that I'd be cured, or have any positive results at all," Selvi says. "But considering the alternative, it seemed like a good choice."

On March 15, 2000, Selvi celebrated her 40th birthday by having a port implanted in her chest, facilitating the delivery of IV medications and other necessary procedures. The port also enabled doctors to draw the blood needed to collect Selvi's stem cells.

"Different parts of the blood, such as red and white cells, platelets, and stem cells, separate at different levels when they're spun around in an apheresis machine," she explains. "I'd been given medication to produce more stem cells; those were collected and frozen. After four hours a days for four days, they were able to gather over 11 million stem-cells."

High-dose chemotherapy and full-body irradiation followed the stem cell harvest. So did the side effects. It was at this point that Selvi turned to comedy for comfort.

"I was constantly nauseated, I was bald and down to 97 pounds," she recalls ruefully. "Because I was so sick I needed something to laugh at. I bought a tape at Costco that had 10 comics on it and started listening to it every day. After a few months, I thought, 'I could do that.' "

Selvi's indomitable spirit--combined with the success of her transplant--eventually enabled her to fulfill that wish. Within six months she suspected her newly implanted stem cells had driven back her disease; after a year most of her symptoms had vanished completely. Her triumph over MS gave her the courage (not to mention the material) needed to attempt stand-up comedy. But instead of glossing over her illness, Selvi chose to make it the centerpiece of her act.

"I have to laugh at it, because if I weren't laughing I'd be crying ... and I don't have time to cry," she says.

For a year Selvi worked with a comedy coach, who helped her refine her jokes and polish her delivery. She has since been making the rounds of Bay Area comedy clubs and coffee houses, delighting audiences with her bemused account of her diagnosis and treatment.

"I had no idea what MS was," she begins, "so I went home and Googled it. But because I'm dyslexic, I typed in SM; pretty soon I thought, 'Wow, I have a really cool disease!' Of course I had to buy some new accoutrements: I showed up at my first support group meeting wearing thigh-highs and a leather collar.

"The director kept looking at me like I was crazy. That went on through the entire meeting," Selvi continues innocently, then, taking the perfect beat, she adds, "and then

at breakfast the next morning, where he was standing because he'd been a very naughty boy." Given Selvi's soccer-mom looks, the crowd explodes with laughter.

Seven years later, Selvi is convinced she has a relatively normal, healthy future ahead of her. Though fatigue still brings on the odd tremor or misstep, she is mostly symptom-free. She works daily on her comedy act, writing and rehearsing. She also revels in (and draws inspiration from) the success of her family: Son Jim is now a sophomore at Santa Clara University, and Tom is a 4.0 senior at Saratoga High School.

Additionally, Selvi is collaborating with an editor to polish (and eventually publish) the journal she maintained during her treatment and recovery. Says Selvi, "I knew there would be people after me who would want to know what was going to happen to them. When I told the doctors at Scripps about what I was doing, they were thrilled."

Their enthusiasm was short-lived, Selvi adds. "Right after I had my transplant, President Bush banned all stem cell research because he didn't understand you could use your own. His veto of funding, which was all about his religious views on embryonic stem cells, has basically squelched the program."

Selvi aims to continue spreading the word about the benefits of autologous stem cell transplants. Someday she hopes to visit Washington and plead with Congress to put aside its concerns about embryonic-based research, and fund the studies that would enable more MS patients to participate in a program such as hers. In the meantime, she actively networks with other MS sufferers via e-mail and phone--and she keeps on laughing.

"Sure, the whole transplant process was horrible and painful for a while, and it was really hard on my family," she says. "But I'm feeling great these days, and just thrilled with life. It was so worth it."

Sandi Selvi welcomes the community's inquiries about multiple sclerosis and/or her treatment. She can be reached at sandiselvi@yahoo.com ; more information is available at www.sandiselvi.com .