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'EVERY DAY A NEW CHALLENGE'

Debilitating Lou Gehrig's disease fails to defeat Bernards mom

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BERNARDS TWP. – When Sonal Shah fell due to her right foot giving out just over four years ago, she had no reason to believe it signaled the start of a debilitating, fatal disease.

Then 60, the resident of The Hills development was an active working mom who had just run a door-to-door campaign as a Democratic candidate for the Township Committee.

But after the injury worsened in spite of physical therapy, Shah was diagnosed with amyotrophic lateral sclerosis (ALS), a neuro degenerating affliction commonly known as Lou Gehrig's Disease, after the New York Yankees baseball great who died from the disease in 1941.

Shah can no longer walk and now uses an electronically powered wheelchair to get around. But a passion to spread the word about ALS has kept her quite busy.

She's been involved in the annual Walk to Defeat ALS in Bridgewater Township as well as the annual Bike4ALS trip that runs from Basking Ridge to Washington, D.C.

She regularly joins an ALS support group at Robert Wood Johnson Medical Center in New Brunswick; and she's met monthly with a dozen or so local women in a "legacy group" that plans to help her write about her experience with the affliction.



Photo by W. Jacob Perry

Sonal Shah of Bernards Township, who was diagnosed in 2012 with amyotrophic lateral sclerosis, has devoted herself to raising public awareness of the crippling disease.

"It's a brutal disease and they have to raise awareness," Shah said in an interview at her home. "ALS doesn't discriminate – it catches anyone and everyone.

"We went through a lot of grieving the first couple of weeks after the diagnosis but I decided I'm not going to sit around in a corner and let ALS take over me," she added. "ALS is a part of me but I'm not a part of ALS. I will not allow it."

Mayor John Carpenter, as one of the cyclists in Bike4ALS, dedicated the last round trip to Shah.

"I find her to be courageous and inspirational," he said. "I admire her greatly for her positive outlook."

Victoria Zelin, a neighbor who is part of the legacy group, characterized Shah as tenacious and generous.

"She has such an authentic heart and openness," Zelin said. "It's never about Sonal. It's always about her family or her community."

ALS is often described as a cruel disease. It progressively affects nerves that reach from the brain and spinal chord to body muscles. Motor neurons die, and muscle movement is steadily lost, leading to paralysis.

Within two to five years of the diagnosis, patients typically die from an inability to swallow or breathe. Yet the mind is never affected, so the patient remains aware of what is happening. The cause of the disease is unknown, and there is no cure.

"ALS is one of those things where it seems pretty exotic but when you're in a group of any size, someone knows someone who's had it," said Carpenter, whose brother-in-law, Tom Shea, a 1986 graduate of Ridge High School, died from the disease two years ago.

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DAY: Family and friends help Bernards woman deal with disease

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'That's Me'

Shah, who smiles easily and looks younger than her 64 years, grew emotional when recounting the events that led to her diagnosis.

A native of India, she moved to the township in 2001 with her husband, Nirmal, and her daughter, Nirali, who was graduated from Ridge High School in 2008. Until recently, she worked as a manager in internal auditing for Telcordia Technologies.

In the winter of 2009-10, shortly after her campaign for the Township Committee, "I just fell," she said. Her right foot gave out and remained weak, but there was no pain, no swelling, and doctors found no break. Despite intensive physical therapy, the right foot failed to regain the mobility of her other foot.

She went to a foot and leg specialist and then to a neurologist who ran tests that proved inconclusive. Because she is a diabetic, doctors surmised that the problem was a diabetic neuropathy. But Shah said her sugar level was never high.

Over the next two years, the situation slowly deteriorated. After walking with a limp, Shah began to have trouble lifting her right leg, then could walk only while holding onto a rail or with assistance. By June of 2012, she needed a walker.

Around that time, she learned that her daughter's piano teacher had died from ALS at age 48.

"I didn't know what ALS was," Shah said. "I started reading about it, and when I learned the symptoms, I called my husband and said, 'That's me.'"

She, her husband and daughter went to Weill Cornell Medical College in New York and received the diagnosis of ALS, which was then confirmed by New York Presbyterian Hospital in July 2012.

"I started crying," Shah said. "It's like, Oh my God, will ALS take my life? What about my husband, my daughter, my siblings, my dear friends and my relatives?"

It took a few weeks to absorb the news. But once she did, Shah made a point of exercising as much as possible and getting involved in ALS treatment efforts.

Last June, she appeared at the Walk to Defeat ALS fund-raiser at TD Bank Ballpark in Bridgewater. She helped raise about \$7,000 for the ALS Association Greater New York Chapter as some 80 friends and relatives walked on her behalf.

In September, she met some two dozen Ride4ALS cyclists as they prepared to leave downtown Basking Ridge for the 400-mile round trip to Washington, D.C.

'I think God gave me ALS, but he also gave me a lot of love from people.'

SONAL SHAH

Basking Ridge resident

Her daughter, Nirali, later greeted the cyclists outside the White House.

Mayor Carpenter said he did not know Shah until the 2009 Township Committee contest, when he served as the campaign manager for her two Republican opponents.

"It seems funny now to be such good friends and have this common bond," he said.

Shah also became a supporter of the Joan Dancy and People with ALS (PALS) Foundation, a Red Bank-based non-profit group that serves ALS patients.

Legacy Group

The women's legacy group was formed last October. Zelin said she knew Shah wanted to make a lasting difference for others, so they started a conversation about what to do.

Another dozen or so women in their fifties and sixties soon became involved and started meeting with Shah on a monthly basis.

"I always admired her can-do spirit and willingness to do something for the community," said one of the women, Caroline Roi, who once served on the township's Municipal Alliance. "Legacy is very important to everyone – what's important in our lives and what we want to leave behind."

Said Zelin, "People think they have forever to do what they're going to do, and you don't. We thought we'd get together and have that conversation ... I think it's a conversation that's valuable to Sonal and valuable to us."

Zelin said Shah chose to write about the challenges of living with ALS.

"In some ways it will be an empowering story because she has used creativity to do things she otherwise couldn't," Zelin said. "It's exciting for her to figure out these kinds of things."

Shah was familiar with Gehrig's story, including "The Pride of the Yankees" movie and the famous speech in which he called himself "the luckiest man on the face of the earth."

But the public, Shah said, never really saw Gehrig's life as he dealt with ALS.

She vividly recalled the night she walked home from dinner and, needing to go up only two steps, "my leg just wouldn't take

the step. It had no strength." She had to be carried inside.

"My life changed" after the need for a wheelchair in late 2012, she said. "It's a big thing – the whole mindset changes."

The paralysis also began to weaken and curl her fingers, but she taught herself to keep typing through the use of one finger. "It takes a long time, it gets frustrating, but I have to live with that," she said. "I used to write so fast."

Use of the electronic wheelchair, which was provided by the ALS Association, has improved her quality of life, she said, "but ALS is still hard, emotionally, physically and financially – it's an expensive disease."

"The most expensive thing is the care-giving," she explained. "My husband has a job and can't sit with me all day. We have to hire people."

Emotionally and physically, "every day starts with a challenge," she said. "Every month the condition changes."

Shah is prepared for further challenges. Aware that ALS eventually affects the ability to swallow, she had a feeding tube put in her stomach in December. She has been told she may need to use it in six months to a year.

Nevertheless, "people say I look better than other ALS patients," she said. "The reason is my exercise, my activity, my involvement, my reading, and number one, my family and friends."

She said she continues to enjoy good food and music and celebrates holidays, birthdays and weddings.

'A Lot Of Love'

She spoke warmly of the support from her husband and daughter, as well as from her sister, Rajal, her brother, Vaishal, and their spouses. The affection was mutual.

"I'm very proud of her and how brave she is, and how graceful she has been throughout this whole situation, and how she holds her spirits high," said her husband, Nirmal.

Added her daughter, Nirali, "She is probably the strongest person I know. Just coming home and spending time with her is what I look forward to doing. She's been the best mother. She's always been my rock."

And then there are those outside the immediate family.

"I never knew I had so many friends," Shah said. "Friends in the real sense, who showed love and caring."

"I like to see a lot of people around," she added. "It gives me strength."

In that sense, she said, her situation has resulted in some good things. "I think God gave me ALS but he also gave me a lot of love from people."