Lupus

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lems. In particular, Black women with lupus have more problems with seizures, strokes and dangerous swelling of the heart muscle. Overall, nine out of ten adults diagnosed with lupus are women aged 15-45.

Matz experienced symptoms of lupus, including a mild stroke, for at least 20 years before being officially diagnosed in 2012.

She says she had a lot of fevers as a child, which she later found out was an early sign of the disease. When she was 13 or 14, she had kidney issues, which required special medicine.

From 1991-95, her and her husband had three children, each pregnancy was high risk, and finally after her third she was advised to not have more. Although high-risk pregnancies and miscarriages are also considered early signs of lupus, no one made the connection during this time either.

About a year after the birth of her daughter in 1995, Matz suffered a mild stroke. Her mouth was the only part of her body that she could move. Doctors ran a number of tests and said her condition was lupus-like, but began rigorous treatment for her symptoms.

Matz was in college in California at the time and had to put her education on hold as she went through physical therapy and learned to walk again. The family didn't have a lot of money and chose to move to Oregon in 2001 because it was cheaper to live and that's where her husband's family was located.

The first year in Oregon was really difficult, she said. She switched to BlueCross BlueShield and found her insurance to be expensive and ineffective. Eventually, she had to choose between paying for her lupus medication and medicine to treat her children's asthma. Matz chose to take care of her children and her condition worsened.

After her husband got hired by the state in 2003, she switched to Kaiser and at first she did not connect with doctors. Coordinating care was too hard to do while also raising her children and working so she chose not to see a rheumatologist.

In 2010, she had a bad flare and had to have emergency surgery. Matz was so anemic that she met the criteria for a blood transfusion. While this surgery normally takes two hours, doctors found a tumor attached to her uterus so it took five. After the surgery, doctors told Matz they were surprised she was even standing.

Following the surgery, she was again referred to a rheumatologist to manage her lupus, but she felt invisible and unheard.

"Doctors aren't always as sensitive as they could be or should be," says Matz. "I think there are cultural nuances that they aren't aware of. I think that if you're young and brown, it makes it harder."

This rheumatologist put her on Plaquenil. 30 days into the new medication, she began getting bad headaches, dizziness and spikes in her blood pressure. During one episode, her primary doctor had her taken to the hospital by ambulance. Her regular rheumatologist was out that day and a stand-in said that this was an issue previously seen in Plaquenil and requested Matz get off of the drug.

Her regular rheumatologist disagreed.

One of the contributing issues, according to Matz, is that that United States doesn't have a standard of care for lupus like the international community. There also isn't coordination of care, which means lupus patients have to coordinate and manage all of their different doctors and medicines on their own.

> Black women with lupus have more problems with seizures, strokes and dangerous swelling of the heart muscle

Ultimately, Matz didn't go back to Plaquenil, but was put on prednisone. However, she was still experiencing problems like vision changes, ulcers and rapid weight loss coupled by an inability to get hungry so the rheumatologist suggested Imuran.

Matz didn't take the Imuran and when she went to get blood work done, her white blood cell count was low. The rheumatologist thought that it was because of the medication but Matz didn't tell her she wasn't taking it.

"I didn't tell her I wasn't taking the Imuran because I didn't like her and I didn't trust her, which is not good," she says.

The Walk to End Lupus Now, at Oaks Park on June 2

"African American women are really (skeptical) and for good reason. We have Tuskegee. We have Henrietta Lacks. We have a long history of the medical system abusing people of color. It doesn't excuse it, but it makes it understandable."

Her worsening symptoms and need to find a trusted primary doctor and allergist/immunologist in Kaiser was what inspired Matz to begin reading the LFA website and start a support group. She read through message boards, did her own research on lupus through resources on the site, and finally made the decision to switch rheumatologists.

LFA has partnered with the American College of Rheumatology, the US Department of Health and Human Services, and other organizations to create curriculum called the Lupus Initiative - Eliminating Lupus Health Disparities. According to the LFA, it is designed to improve the diagnosis, treatment, and management of lupus in patient populations disproportionately affected based on race, ethnicity, and gender through the education of medical professionals in training and in practice. One of the hopes of the Lupus Initiative is that addressing the health inequities of lupus will help to address other health inequities that are endemic to the poor and people of color.

Before Matz began working with her new rheumatologist, she had an honest conversation about her last experience. She says she was on board when the new doctor suggested trying Imuran again because this doctor listened to her fears as well as feedback from other doctors.

Matz has been taking Imuran every day since and has had blood work done consistently. While she hasn't had too much nausea she says the fatigue has been pretty intense. The medications have improved her ability to eat, walk and feel more human again, she says.

Matz hopes it continues to work but understands there are side effects to chemotherapy. Being in the presence of people who are sick or who have just taken live vaccines can be very dangerous for her. When her daughter had H1N1, Matz was sick for an extended period of time and lost ten pounds in one week. She notes that it's not usually the lupus, but infection or kidney or heart failure that kills people.

"If someone gets me sick I could die from that," says Matz. "I could do everything right, and still not live."

She also notes that lupus isn't an inexpensive disease. It's estimated to cost $20,000 a year, she says. In addition to that, Matz says most patients will go through four to eight doctors before they are even diagnosed.

Not everyone has the luxury to afford all of the medications and various therapies that lupus can entail and that's why Matz says she and others are walking Sunday.

"Just by having lupus you have a higher risk for cardiovascular disease," she says. "You have a higher risk of having hypertension. You have a higher risk for having kidney failure. Life becomes precarious and more precious all at once and we need allies to not only hold our hands, but to fight for a cure."

To see more photos from the "Walk to End Lupus Now," go to *The Skanner News* Facebook page.

Spices

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needed to ensure high product standards. Saturday Market, which leases its space from the city's Parks Department, is dedicated to promoting artists and artisans who hand-craft unique products.

"Nine other vendors have taken the workshop visit and passed it," Verhoeven said, then clarified that one business has yet to submit required documents. "He's been notified and re-notified and now he's here in disregard of the No-Sell notice. He's disregarding it."

To get his spot back, Verhoeven said, Groves must complete the workshop visit and show his year's worth of receipts. The rule does not require Groves to reveal his trade secrets, Verhoeven said.

"You don't have to show your recipe."

Saturday market has rules about everything from incense and smoking (banned), to introducing new products (a committee must approve each one). One soap vendor said body care product vendors also are required to have workshop visits. But they did not have to show a year's worth of product receipts.

Groves says the market board is dominated by a tight cabal who invent rules so they can force out anyone they don't like. He says two other artisans – a cupcake baker and a couple who make tie-dye t-shirts—were pushed out. And as one of just two African Americans who currently sell at Saturday market – the other business is My Brother's Barbecue – he feels unfairly targeted.

> 'You've heard the expression judge, jury and executioner. Let's add to that complainant, prosecution and witness'

"It's a policy they made up this year," he says. "They want to see everything. They've never done this before and I think they are doing this to get me out."

Some might say Groves is taking this too personally? Not Steven Gifford. Gifford says he was evicted from the market for no good reason.

Cross over to the other side of the light-rail tracks and you can find Gifford's stall. He moved his tie-dye t-shirt business from Saturday Market to the Skidmore Fountain market, which includes imported goods.

Gifford says he can't charge as much for his tee-shirts at this spot, even though he hand dyes everything he sells. That was at the crux of his dispute with the Saturday market board. Members of the product committee told him they'd received a complaint that his tee-shirts were simply bought from a catalogue. They wouldn't supply any more details, he says, but asked to visit his workshop.

During the visit, Gifford said the board members pronounced the workshop too clean to be a real dye space, and refused to look in his product cabinet.

"They said the floor was too clean," he says. "But they weren't even looking at the area where I do the work. They said I was lying. They were willing to do anything to get me out of there."

Gifford calls vending at Saturday market, "an Animal Farm, situation." After he was pushed out another tie-dye artist who had left the market returned, he said.

"You've heard the expression judge, jury and executioner. Let's add to that complainant, prosecution and witness. These people who were going to judge me were the ones who complained about me; they investigated me; they prosecuted me; they juried me; they executed me. They kicked me out of the market."

Groves has another reason for feeling targeted. Three years ago the board slapped him with a series of infraction notices, alleging he'd left his booth 5 minutes early and parked his vehicle in the street before the allowed time of 5 p.m. Those complaints were dropped after a photo of Groves' parked vehicle was shown to be taken after 5 p.m., and a vendor survey found most believed the rules were unclear.

Since, then Groves' relationship with the board has remained cool. Now, with an eviction notice from the board and no sign of willingness to compromise, he says he needs to find a lawyer to take the case.