

Celiac disease remains tough to diagnose

Tara Caimi, For the Centre Daily Times ~

Tara Streno saw her family doctor once a month for about a year, and John Askey received aggressive treatments for a disease he may not even have had before arriving at what each feels is the correct diagnosis. From weight gain and weight loss, chronic fatigue, migraines, anemia, memory loss, joint pain, and insomnia to treatment for depression, irritable bowel syndrome, Crohn's, and even Lyme disease, the medical symptoms and health care experiences of an undiagnosed celiac patient sound like they belong in an episode of Discovery Channel's *Mystery Diagnosis*.

"I was basically told that I was crazy," said Streno, "like I had all these symptoms, and I brought them on myself." In truth, more than three hundred signs, symptoms, and disorders may be associated with celiac disease, according to the Celiac Sprue Association, making the detective work toward an accurate diagnosis that much more complicated.

Celiac disease is an autoimmune disorder triggered by gluten, which is found in all forms of wheat, as well as barley, rye, and to some degree, oats. When people with celiac disease ingest gluten, the small intestine is attacked and damaged by their bodies' own immune system responses. The damage with each ingestion is cumulative and negatively affects the body's ability to absorb nutrients. Over time, this can lead to an unfathomable variety of associated problems, including other autoimmune diseases like lupus or diabetes, osteoporosis, infertility, neurological disorders, and even cancer. The only known treatment for celiac disease is the strict elimination of gluten from the diet and lifestyle.

Adding to the complexity is the fact that gluten is found not only in cakes, cookies, breads, and other flour-based products, but is also hidden in seasonings, marinades, medications, and many other elusive places. Gluten is in more foods and products than most people would think to imagine, but Streno and Askey must think about those potential gluten sources multiple times every single day.

Over the course of the year prior to her diagnosis, Streno experienced migraines, depression, numbness in her hands, severe canker sores, and "every GI (gastric) symptom" in the book. She was diagnosed with anxiety, irritable bowel syndrome, stomach ulcers, Crohn's disease, and "intestinal cancer was a possibility," she said.

Despite frustration with her experiences, Streno had to admit she was

lucky to get an accurate diagnosis after only one year of illness. The average time from the onset of symptoms to a celiac disease diagnosis in the U.S., according to The University of Chicago Celiac Disease Center, is four years.

Askey wasn't so "lucky." In summer of 2005, he began noticing a tingling sensation or, what he referred to as pinpricks on his skin. Because Askey regularly handles agricultural pesticides at work, he received blood tests accordingly, but nothing showed up in the blood work to verify any relation between the pesticides and his symptoms.

Soon after, Askey began experiencing sleep disruptions. "I didn't sleep through the night from summer 2005 until February 2009," he stated. "Not one night."

Over the course of those four years, Askey would struggle with severe fatigue, headaches, memory loss, light sensitivity, dizziness, and brain fog. After countless blood tests, a sleep study, MRIs, and bone scans, Askey, in desperation, responded to an advertisement for Lyme disease treatment and began an exhaustive series of antibiotic therapy treatments that would last a full year and cost multiple thousands of dollars.

Throughout all that, Askey's symptoms persisted. He still couldn't sleep, had lost more than twenty pounds, and was coming to the end of his rope. "I thought I was dying," he said without pretense. "I thought, I'm dying and nobody knows why. And I accepted the fact that I'm probably just going to die."

It was then that Askey's neighbor, with whom he'd briefly spoken about his symptoms, was diagnosed with celiac disease. Knowing they'd suffered from similar symptoms, Askey's neighbor shared his story, prompting Askey to request the test as part of his regularly scheduled blood work. For the first time in almost four years of illness, Askey finally had something conclusive. His initial tests were positive for celiac disease.

Askey remembers getting the phone call with the blood test results. He'd just finished eating a piece of cake. "My heart just sank because I love to eat. And so ..." Askey's voice trailed off for a moment, "... I had another piece of cake."

Streno, a self-proclaimed "foodie" and practiced baker, had a similar experience. "When I first went on the diet, my best friend got married, and he got all these different cakes. I fell off the wagon completely, and I really paid for it. That was the last time I ever fell off the wagon," she said.

The same is true for Askey, who went completely gluten free after further testing led to a final, positive diagnosis in spring 2009. Though relieved to finally have a diagnosis, he knew his life would never be the same.

Both Streno and Askey describe the gluten-free diet as a complete lifestyle change, stressing the constant need for careful planning. Streno carries gluten-free snacks in her purse, packs her lunch for trips to the mall, and both wonder about the feasibility of future vacations.

At Askey's home, the whole family has switched to gluten-free pasta. They don't share a butter dish due to cross-contamination from crumbs or particles of gluten which may be left behind from buttering toast, and they now use squirt-bottles for all condiments.

Streno can tell by her body's reaction when she has unknowingly ingested gluten, but, she admits, the risk of cross-contamination through food preparation is high. While she has identified a few restaurants she feels are safe, Askey is more careful. He doesn't experience digestive upset when contamination occurs but knows that intestinal damage may result from the slightest contamination. "It only takes a little bit of gluten to undo months worth of abstinence," he said "so it's really imperative that you never get any."

With more gluten-free products hitting the shelves every day, celiac disease awareness is on the rise, according to Streno. "It's a lot easier for us now than it was twenty years ago," she said.

Still, both Streno and Askey share a desire for better education and support. Askey stressed the need for people to participate more actively in their own health care. "We need to ask questions," Askey said. "Sometimes we need to dig deeper on our own. I was guilty of thinking that doctors were all knowing, and that was my fault, not theirs. Sometimes it just takes persistence."

Askey recently attended a seminar presented by Dr. Alessio Fasano, Director of the Center for Celiac Research at the University of Maryland School of Medicine. "Dr. Fasano explained that out of all the autoimmune diseases the only one they know the trigger for is celiac disease, and if you remove the trigger it gets better. It's the only autoimmune disease that gets better," Askey said.

Once gluten is effectively eliminated, a person with celiac disease can lead a completely healthy life without supplemental medication or medical procedures. This, however, hinges on timely and accurate diagnosis and

treatment. According to the Celiac Sprue Association, untreated celiac disease increases the risk that other complications—some irreversible—will develop.

The State College Celiac Support Group has been a valuable resource, providing information and personal support for both Streno and Askey. Each has noticed health improvements and a reduction in symptoms since beginning the gluten-free diet. “The foggy brain got better,” Askey said. “I no longer feel like I’m dying.”

Streno is in the process of planning her wedding, and this time, she assures, the cake will be gluten-free.