

Connecticut Post

May 19, 2006

Section: Lifestyle

Womanwise

Article ID: 3840898

Against the grain

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Keeping her family healthy is challenging for Loretta Jay Stepanskiy. The 39-year-old Fairfield mother of two and her children all have **celiac** disease. The illness is a genetic disease that leaves one unable to digest gluten, the protein in wheat, barley, rye and oats.

Because of their illness, Stepanskiy and her children - aged 5 and 3 - have to eat only gluten-free products. That means the little ones often can't indulge in the cake at a friend's birthday party or partake in other gluten-filled treats they might encounter at school or in social situations.

Also, Stepanskiy was diagnosed as an adult, which meant she had to radically change her diet to accommodate the disease. It's a challenge - but not as challenging as getting the disease diagnosed. Her older daughter, Ellie, now 5, was the first one to present symptoms, which appeared when she was about a year old. When Stepanskiy suggested to her pediatrician that it might be **celiac** disease, the theory was quickly dismissed. "The pediatrician said 'Oh no - that's much too rare,'" said Stepanskiy, now co-chair of the Connecticut Children's **Celiac** Group and member of the board of directors of the Greater New Haven **Celiac** Group.

After consulting a specialist in Baltimore, Stepanskiy learned that her hunch was right and that Ellie had **celiac**. She was then diagnosed with the disease and, eventually, her son Mickey was, too. Stepanskiy has since learned that **celiac** disease is more common than originally thought - one in 133 people have it.

May is **Celiac** Awareness Month and, in honor of that, Stepanskiy is chairing the third annual Connecticut **Celiac** Walkathon, which takes place 10 a.m. Saturday at Wharton Brook State Park in Wallingford. The walk raises money for **celiac** disease research, and Stepanskiy - also one of the event co-founders - hopes the walk will raise the disease's profile as well.

Doctors now are more educated about the disease, and are more aware of how common it is. "The experience I had four years ago is very rare now," Stepanskiy said.

But there are still plenty of people who don't know about **celiac**. In fact, many people with the disease go undiagnosed. That was especially common a few years ago, said Fairfield gastroenterologist Dr. Julie Spivack.

In those days, she said, the only way to diagnose **celiac** was to biopsy the small intestine. Now, the diagnosis can be made using a blood test. "That has made it so much easier to diagnose," said Spivack, a partner in Gastroenterology Associates of Fairfield County.

Spivack said **celiac** disease is basically an allergy to gluten. In those with the illness, gluten triggers anti-bodies and inflammation in the small intestine. The small intestine is what allows the body to absorb vitamins and nutrients, such as iron.

When people with **celiac** disease eat gluten, it eventually affects their ability to absorb these crucial nutrients, which can result in malnutrition. Classic **celiac** symptoms include abdominal pain, bloating and loose stool.

There is no medication for **celiac** disease - the only treatment is to change one's diet. Stepanskiy said, though this is less disruptive than, say, being on regular medication or having surgery, it's still hard, particularly for children.

"It's tough for kids to go to birthday parties or school events and they have to eat separate foods," she said.

Spivack said there's also the matter of shopping. Though a number of stores, including Stop & Shop, now carry gluten-free products, they're generally more expensive than products that include gluten. Plus, a surprising number of foods contain gluten - including beer, some salad dressings and other condiments - so it's difficult to avoid, Spivack said. "It's not just 'I can't have bread and I can't have pasta,'" she said.

The Connecticut **Celiac** Walkathon raises money through pledges from participants. Money raised goes to the University of Maryland Center for **Celiac** Research and the **Celiac** Disease Center at Columbia University. Since the Connecticut walkathon began, it has raised a total of about \$50,000 and drawn about 300 participants a year. That includes Anne-Marie Alderman of Milford. The mom of three has participated in the event since it began, as both her 10-year-old daughter, Katie and her husband Kendall have **celiac**.

Her dream is that, eventually, money raised through the event will help fund a cure for **celiac**. "My hope is that, when Katie goes to college there will be some pill she can take so that she can eat what everybody else is eating," Alderman said.

The Connecticut **Celiac** Walkathon takes place 10 a.m. Saturday, with registration starting at 9 a.m. For details, visit www.connceliac.org or call Stepanskiy at 254-0190.

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