

Coping With Celiac

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Five-year-old Fairfield native Ellie Stepanskiy probably knows more about celiac disease than your average American.

Ellie just won in the elementary division of the Celiac Sprue Association essay contest for her essay called "How I Survive and Deal with this Thing Called Celiac Disease."

"I can't eat wheat or gluten," said Ellie, who was diagnosed with celiac disease when she was 19 months old. "I can eat mom's food, but sometimes every kid has different food and sometimes it is very difficult because I can't eat it."

Celiac disease is a genetic autoimmune disease that interferes with the body's ability to absorb nutrients. Once a patient is diagnosed with the disease, he or she begins a diet that is free of wheat, barley, rye and oats, and immediately symptoms of the disease disappear, according to a Celiac Sprue Association press release issued on Jan. 10.

"Celiacs cannot digest the protein in wheat, barley, rye and oats or anything with gluten in it because the little hairs inside the intestines become dull and do not absorb the nutrients," said Loretta Jay Stepanskiy, Ellie's mom.

Each day, Ellie brings her own bag lunch to school, Jennings Elementary, because if Ellie consumes wheat, barely, rye, oats or any foods containing gluten, she will become severely ill. "I bring my own lunch to school, I can't eat hot lunch there."

"Ellie is a wonderful advocate for herself. She remembers what it is like to be sick, and she doesn't want to be sick," said Loretta Jay, who is chairman of the Connecticut Celiac Walk-a-thon, co-chairman of the CSA Greater New Haven Celiac Group children's group and also has celiac disease. "I tell Ellie that everyone's got something. We take it in stride, and it is tough at times."

"The good part is I get to eat Mom's food, and the bad part is eating others' food," Ellie said. "Sometimes I get confused about what to eat."

It is most difficult when Ellie has to eat out or over at a friend's house, according to Loretta Jay. "They're not sure what I can eat," said Ellie.

"My favorite food is tapioca pudding," Ellie said, and it is no wonder that Ellie's least favorite food "is some types of breads."

Undiagnosed people with celiac disease will exhibit a variety of symptoms, including, but not limited to, bloating, diarrhea, weight loss, mouth ulcers, fatigue or anemia. If undiagnosed, the disease can lead to more serious illnesses such as osteoporosis and bowel cancer. One out of

every 130 individuals will test positively for the disease, according to the CSA press release. Celiac disease is rarely fatal with treatment; however, if celiac disease goes untreated, it may increase the risk of developing intestinal lymphoma, a form of cancer, according to emedicinehealth.com.

According to Loretta Jay, other symptoms of the disease include migraines and infertility issues. "Many celiacs have given up [on getting diagnosed]," said Loretta Jay. "Sometimes it takes a celiac seven to 11 years to get diagnosed. "One percent of the population has celiac and 97 percent of celiacs don't know they have it and are walking around with misdiagnoses. Historically physicians thought the disease was very rare, when in reality it is very common. This is why we're working on increasing awareness and I entered Ellie into the contest."

"It was a struggle to get her diagnosed," said Loretta Jay. It took seven months before Ellie was correctly diagnosed, which is why she began awareness efforts for celiac, said Loretta Jay.

Dr. Alessio Fasano, who is a professor of medicine, pediatrics and psychology at the University of Maryland Center for Research, finally diagnosed Ellie with celiac disease. According to Loretta Jay, Fasano is known as the international authority on celiac disease, and he discovered that celiac disease was far more common than had been thought by physicians.

So far there is no medication for the disease and the only cure is to remove gluten from the diet, according to Loretta Jay. The most difficult time in a celiac's life is adjusting to this gluten-free diet, which typically takes three to four months to get used to, she said.

"There is no magic pill that will work for one meal," said Loretta Jay, "but I hope that within 10 years or so we can have a magic pill that will help us eat regular foods."

The walk-a-thon will take place on May 5 at 9 a.m. at Wharton Brook State Park in Wallingford. Loretta Jay expects more than 300 people to attend, and the event has raised more than \$75,000 for celiac disease over the past three years. Sponsors for the event include Brooks Community Newspapers, Newman's Own and B&B Catering, which have contributed more than \$1,000 to the event, according to Loretta Jay.

The money raised from the event has been donated to celiac research organizations and to local celiacs who may need assistance buying expensive gluten-free food. Scholarship funds are generated from the event as well, according to Loretta Jay, which gives Connecticut children the chance to attend Camp Celiac Camp for Kids, hosted by the CSA.

Loretta Jay also will be hosting the Gluten-free New York Style Pizza Making Demonstration on Feb. 4 from 2 to 4:30 p.m., and registration begins at 1:30 p.m. at the Mount Carmel Congregational Church, 3284 Whitney Ave., Hamden.

She also will be hosting the Children's Winter Party on Feb. 11 from 2 to 4 p.m. at the Connecticut Sportsplex, 150 Foxon Road, Branford. Call (203) 484-4383 for more information.