

Celiacs need more than a diet

By Alice Bast

We were going to name her Emily. I didn't know that the constant migraines, extreme stomach pain, and diarrhea that I developed after my first daughter, Elizabeth, was born would impact my second pregnancy. In my ninth month, I noticed the baby was no longer moving. I was told I was worrying needlessly. I wasn't. I had a full-term stillbirth.

After three subsequent miscarriages, I had another viable pregnancy. I was on bed rest for months. I was desperate to have that baby. One day at 33 weeks, she stopped moving.

I had an emergency C-section, delivering two-pound Linnea. Day by day, she got stronger. I didn't. I struggled with debilitating symptoms for eight long years.

Finally, I happened to run into our family veterinarian, who suggested that my multitude of symptoms might be connected to my diet: "Some animals can't tolerate grains. Have you been screened for celiac disease?" My 23rd doctor ordered the blood test that ultimately led to a positive celiac disease diagnosis.

Celiac disease affects one in 133 Americans. It is largely misdiagnosed or undiagnosed, leading to stories like mine, and worse, including an increased risk for some cancers. I did not want others to go through this same journey, so I founded Beyond Celiac, which is now based in Amler. We were dedicated to improving the rate of diagnosis and increasing access to what remains the only treatment for celiac disease, gluten-free food.

But research now shows that the gluten-free diet is not a cure-all. People are still getting sick no matter how strictly they follow the diet. Their mental health is affected by the constant strain of policing ev-



Alice Bast (center) on vacation with family in 2018. She endured years of severe health problems, including miscarriages and a full-term stillbirth, before finally being diagnosed with celiac disease. Courtesy of Alice Bast.

ery bite of food. Some have damage to their systems even years after adopting the gluten-free diet. People with celiac disease often share their stories with Beyond Celiac, and we've worked over the last decade to amplify the patients' voice, which is crying out loud and clear: We need options beyond a difficult diet that is not always effective. Creating this better care starts with prioritizing patient voices.

The first Beyond Celiac multidisciplinary summit in 2015 was the first step in including the patient voice in the research process. From that meeting, we created an aggressive research agenda, includ-

ing building a patient database called Go Beyond Celiac, hired a chief scientific officer, and created a science department and advisory council to award Beyond Celiac grants to the best and brightest in the field with emphasis on new areas of inquiry. Within celiac research, there are now more than a dozen drugs being investigated by academic researchers and pharmaceutical companies.

But there is more to do. Through our 2019 Research Summit on Friday, our patient community will

again be able to tell their stories directly to researchers, as well as pharmaceutical and health insurance company and Food and Drug Administration officials. It's critical that patients participate in research.

In addition to participating fully in the proceedings, nearly 5,000 people with celiac disease and parents of children with celiac disease responded to a survey we sent out in advance of the summit. We will share the numbers from our results along with the voices of patients on two summit panels, to help tell the full story of celiac disease. We expect the outcomes of this summit to provide the final push for finding viable treatments and a cure. We will be webcasting the morning sessions of the summit, and invite anyone with an interest in patient engagement to get the link to watch live or later: www.BeyondCeliac.org/researchsummit.

My heart will always ache for the daughter I lost. But I'm more determined than ever to get help our community eat without fear and live life to the fullest.

Alice Bast is CEO of Beyond Celiac, a national patient advocacy and research-driven celiac disease organization driving awareness, diagnosis, and the discovery of treatments and a cure.

A gluten-free diet isn't always successful for people with celiac disease. A cure is needed.