Gluten free-dom: my journey to becoming an unintentional expert

Anne M. Hoyt, BBA

Anne Hoyt

Gluten: What is it? What does it mean to avoid it? How does it inevitably change one's life? My daughters and I stopped eating gluten. We took our experiences and morphed them into an entirely new life. One daughter, Taylor Nicholson, and I opened a gluten-free bakery called Unrefined Bakery, and the other daughter, Erin, has become a family physician, with

an emphasis on wellness and treating the body as a whole. Unrefined Bakery is an organic, non-GMO allergen-free bakery (gluten-free [100%], soy-free [100%], dairy- and corn-free [99%], egg-free [80%], grain-free, sugar-free, yeast-free, nut-free, etc.). At the bakery, we have the unique experience of learning about gluten from the stories of the people we come in contact with daily. We see the frightened look in their eyes when they enter and their joy as foods are brought back into their lives. This is such a current topic and our approach to food is so unique that we have been blessed with numerous articles being written about us in the *Dallas Morning News*, *New York Times*, *Living Without*, *Prevention Magazine*, and *D Magazine*, as well as numerous local print and online publications. This is how I became an unintentional expert on being gluten-free. This story has some basic facts regarding the what, why, and how of gluten and celiac disease, as well as about testing and treatment. But mainly this story is about the heart and soul of going gluten-free.

THE BEGINNING OF OUR JOURNEY: DIAGNOSIS AND SYMPTOMS

When our experience with celiac disease started is a tricky question, because symptoms were there long before we heard the word *gluten* or knew of celiac disease. A key event, though, was when my youngest daughter, Erin, fell in college and suffered a compound fracture in her ankle. The surgery to treat the fracture led to methicillin-resistant *Staphylococcus aureus* (MRSA), which settled in the bone marrow of her ankle. This led to harsh drugs and a severely weakened immune system. Even as she conquered MRSA, Erin became sicker and sicker. In essence, she failed to thrive, with multiple infections in the year following her MRSA

treatment. As always, her stomach hurt, only worse. She did the best she could with a bland diet of soda crackers, bread, and yogurt, which made her even sicker. Then she began bleeding internally, so to another doctor we went. Since we now know from our customers that they go to doctor after doctor, often never receiving a diagnosis, we were fortunate to receive a quick diagnosis by a relatively young gastroenterologist who asked her about her heritage. Hearing that she was a quarter Swedish, the first and only test he did for her was a biopsy of her small intestine, which found “smushed” villi—the hallmark sign for a diagnosis of celiac disease. Of course, we had been concerned that she had something much worse, so we were thrilled to find that all we had to do was stop eating gluten!

We are a family of nerds, so we researched what this gluten-free thing was all about. As I read *Living Gluten-Free for Dummies*, I was fascinated to learn that many symptoms I considered to be a natural part of aging fell into the category considered to be nongastrointestinal symptoms. I also discovered that my oldest daughter, Taylor, more than likely had celiac disease as well. As I read through the book, I saw my entire family in the pages. My daughters were seemingly symptomatic from birth. Between the three of us, we experienced many random and differing symptoms.

As early as I can remember, Erin had eczema, dry skin, rough elbows, horrific circles under her eyes, hair and nails that didn't grow, and constant stomachaches. From the moment she could talk, she talked of her stomach. It always hurt. She often threw up. It appeared to be *her* symptom. But she always grew, so the doctors weren't overly concerned. They chalked it up to stress since even at that young age she was already a perfectionist. In 1992, when Erin was 7, we took her to the Mayo Clinic due to her stomach. They only tested for and found an increased liver enzyme, which they deduced must have been an anomaly, but we know now is a symptom of celiac disease.

Taylor had been dairy-free since the age of 18 months due to chronic diarrhea. She had terrible colic until she was 6 months, when I finally introduced food. Based on a doctor's suggestion, I took dairy out of her diet and found an improvement. Today a doctor would most likely eliminate both dairy and gluten to

Corresponding author: Anne M. Hoyt, Unrefined Bakery, 718 North Buckner Boulevard, Suite 154, Dallas, TX 75218 (e-mail: anne@UnrefinedBakery.com).

determine the true nature of the diarrhea. We know now that gluten and dairy intolerances are often found together. Taylor also continued to have unexplained skin rashes and eczema and headaches. In later years, she described constipation followed by explosive diarrhea—irritable bowel syndrome (IBS)—and always feeling bloated and full, yet hungry.

As for me, I had developed IBS and anemia after my first pregnancy in 1982 and in my late 20s was diagnosed with fibromyalgia. I had significant joint pain that moved from area to area, seemingly without rhyme or reason. I was a migraine sufferer. By my mid 40s, I began having “foggy brain,” moments when I simply could not think. There were days at work, as I was pouring through numbers or intricate thoughts, that I would simply put the paperwork aside and go on to a different task. At times, I even turned the keys to the car over to my children because I couldn’t assimilate the fast-paced action of cars merging on interstates and changing lanes. I also had five miscarriages, two before and three after the births of my three children. I had attributed all of these failing processes to the simple fact of aging. I would never have gone to a doctor.

My son believes he has a gluten intolerance somewhere on the spectrum, but at this point he chooses to ignore it as he travels the world after being in the military. Many people find that as long as they keep eating gluten, they can continue eating it, even as it is likely causing silent but serious health issues that will raise their ugly heads later in life.

As we learned about gluten and its random and pervasive impact on the body, it seemed likely that all three of us had celiac disease. To be quite honest, at the time I didn’t care if I were celiac or somewhere on the gluten-intolerance spectrum, since the treatment is the same. Had I known my future, that I would become somewhat of an “unintended expert,” where I would tell my story over and over again, and that people would ask me to write my story, I most likely would have gotten tested. But, I believed I had an issue. I stopped eating gluten. Like many of our customers, Taylor and I were self-diagnosed and then we all became self-taught.

REACTIONS

Rather than feeling sorry for Erin or for each other, we felt an amazing sense of relief that Erin did not have Crohn’s disease, or colon cancer, or any of the other scary, life-altering diseases that had run through our minds. What she had was a disease that could be cured, or at least strongly improved by simply changing her diet. What an amazing outcome for a woman who had grown to be so very sick!

These are Erin’s words when I asked her to tell her tale:

I cannot explain the immense amount of relief I felt on my way home from that appointment [with the gastroenterologist who made the diagnosis]. A diet change? How easy is that! No matter how difficult this change would be, this was the best news I had heard in a long time. I was going to feel better. Until someone has felt what it means to be out of control of their day-to-day health, one cannot comprehend what it means to have some of that control given back, to be the one in charge of changing the

way you feel, for the better. The diet change was a little daunting at first (there were not many options in stores or restaurants in 2007), but within a couple of weeks, I was feeling much better. My energy improved, my weight went back to normal, and my hair stopped falling out. I felt better than I had in months. And nothing tastes as good as feeling healthy!

Taylor was thrilled that perhaps she too had found a way to change her health for the better. Due to an awareness of cause and reaction, Taylor had already self-selected her own diet by eliminating nearly 100% of bread and pasta. Taylor said,

With no formal knowledge of a gluten-free lifestyle, my body knew before my mind what was best for me and my overall health. I didn’t have the emotional transition that many experience, because for me, I felt so much better than I had my entire life, and nothing could make gluten worth it again. My practical approach was just that. Gluten made me feel badly; therefore I would no longer eat gluten.

I probably had the most difficult transition of the three of us. Not only did I love to eat baked food, I loved baking! I was thrilled to find such an easy solution to Erin’s failing health, and I jumped on board wholeheartedly. But I was sad. I was that person who got up on Thanksgiving morning and baked six pies just so they would be at their very best. I baked as an act of love. I truly grieved, not for the loss of the food as much as for the loss of baking. Nor was it easy to watch eating become a process. It became more like math—did I get enough nutrition through the proteins, fats, fiber, and carbs? It became a function of eating to live, eating for proper nutrition, rather than the social, joyful event of a meal shared. It became so tedious and difficult that it simply wasn’t worth going out. I hated to make a fuss. I had been that person who would eat anything, anywhere. I was a foodie. Now I had to be that challenging woman who seemed to make a fuss out of the simple act of ordering from a server! I hated being that woman. To this day, Erin still apologizes as she asks for servers to make special accommodations for her order at a restaurant.

I learned that *food defines us*. Take away one of the major food groups and you change a person forever. Few other dietary restrictions would cause such an emotional impact. For example, take away vegetables, and you end up with a person who is less healthy, but not mournful. Take away breads, cakes, etc., and you end up momentarily with an emotionally altered person. But, you also save a life or, at the very least, improve the quality of life and health. It is well worth the trade!

ACTIONS

Being the determined women we are, we simply read how to ferret out the hidden sources of gluten, and we stopped eating it. All together. All at once. And we never looked back. We read labels and we read labels and we read more labels. The positive impact, or should I say, the incredible cessation of sickness that we had all accepted as “normal,” was so sudden that not one of us even thought about eating it again. Okay, I may have had two individual pieces of pizza on two occasions within the next 3 years, but on each occasion the

impact was so severe and so immediate (threw up both times within 15 minutes!) that I have not done it since. And to my knowledge, the girls have never intentionally eaten gluten since we stopped in February 2007.

Early on, I tried a gluten-free hamburger bun. It was shelf-stable for a year! It was made almost exclusively with white starches and white rice and was full of preservatives. Keep in mind that before the inclusion of preservatives and chemicals, bakeries sold day-old bread at a discount; bread was never intended to be shelf stable. The buns were so awful I simply threw them out. Like virtually everything available in 2007, they were highly processed carbohydrates: awful, empty, bad-for-your-body-in-every-way carbs. I wasn't going to eat a food that was dry, crumbly, tasted like cardboard, and had absolutely no positive nutritional value. So, we simply didn't eat baked goods in any form. We all ate sweet potatoes, beans, salads, meats, fruits, and vegetables. In the beginning, for Erin and me, the potatoes and beans were important as our bodies learned to live with a new and healthier form of carbohydrates. Taylor had long ago adjusted to a life without bread. Our experience showed us the need for our gluten-free-turned-allergen-free bakery.

THE BAKERY

Learning to bake again

Mom made everything from scratch. And she taught me to bake, as her mom taught her and her grandmother taught her mother. I passed it on to my kids, with a touch of "organic" already seeping into our food. As early as 1976, my sister called me a "granola head" and asked me why I was attempting to make a whole-wheat, carob chip cookie. Clearly, I always believed there had to be a way to eat "comfort food"—food that simply made you smile by eating it or thinking about the memories surrounding it—without having to pay an inherently horrible price with your body. What we eat definitely impacts our long-term health: we truly are what we eat!

I was so sad and so lost that for the first year I didn't even try to bake. Two holidays came and went. Taylor had begun playing with gluten-free granola bars. In the summer of 2009, she came up with one that was so great and nutritionally balanced that she called it a FoodBar. She is talented and clever. She figured out how to package it and seal it and even designed and produced a label for it. She gave it as a gift to overnight guests for her wedding. I was so proud of her, but a bit envious. I was like, "Well, if you can do that, then I can bake!" I had tried a few things in the previous 6 months from the collection of gluten-free cookbooks that were currently adorning my counters. The foods were awful. They landed in the trash. I was discouraged, but Taylor's determination and fantastic success spurred me on.

I had the realization that perhaps these were simply bad recipes. I had spent a lifetime borrowing great recipes or being thrilled to find one good one in a cookbook. Surely it was possible to come up with soft, tasty, healthy gluten-free breads that simply tasted like good food, as opposed to good-for-gluten-free food. My inquisitive mind delved yet again into research—this time, gluten-free flours. I read and read about the various

gluten-free flours and about the binders that were the essential ingredient in order to recreate the "magic" that gluten provides. (Gluten acts like a glue; it binds the ingredients together. In order to bake without gluten, a "binding" agent needs to be added. Gluten-free baking will never have the exact same texture as baking with wheat, but we have learned how to get pretty close.) After understanding the science behind baking without gluten, I proceeded. I had an old casserole bread recipe that I thought might work well with these new flours. I was right. It was fantastic, with perfect taste and texture! First the rolls worked. Then I tweaked the recipe a bit more and was able to make the round casserole loaf. Six months or so later, I was finally able to make this wonderfully old-fashioned-tasting bread into a sandwich loaf. It was an arduous journey of patience, frustration, failure, and finally success.

A perfect storm

We were a perfect storm of talents and experience, need and desire, and finally, incredible determination and perseverance. And, we had great family support and role models. Taylor's husband is an entrepreneur: he has started three medically based businesses. He has been a wonderful inspiration, not to mention fantastic cheerleader as well as a man willing to help us in any and every way. And, I came from a long line of self-employed men. My dad had owned multiple restaurants for 44 years. Taylor and I had grown up working in them and had been a part of long-range planning. We both had business degrees from college—mine was in economics; Taylor's was in accounting, finance, and management. I had the love of baking. I understood the essence and art and science of baking. Taylor understood how to eliminate the dairy, and she learned how to eliminate the eggs as we proceeded. Taylor had an exceptional understanding of nutrition. She is constantly reading about food and nutrition. And, most importantly, we were gluten-free.

We both quit our jobs in 2009, in the height of the worst economy since the Great Depression. We spent 6 months adapting old family favorites and learning how to go from home baking to commercial baking. We taught ourselves the various parts of a commercial business: packaging, labeling, food costs, and nutrition information per serving, not to mention the legal and administrative process of setting up a corporation. We designed our commercial kitchen and researched everything from the best ingredients to the proper equipment. It was a huge task.

Principles and expansion

Our bakery began with the basic principle of being 100% gluten-free while being as healthy as possible. We were negating the impact on our bodies of our modern diet: a diet full of preservatives, highly refined and genetically modified ingredients, and overuse of sugar, fats, and salt. We reduced the sugar, used only heart-healthy fats, and used organic ingredients where it was feasible. Over the past 3 years, the bakery has turned into so much more due to customer requests as well as an increased understanding of the incredible severity and impact of food allergies. Immediately we became soy-free and decided to remain as dairy-free as possible. Within the first 6 months, we took the

corn out of all but four products, two of which were cornbread. After 18 months, we reduced the sugar in all of our yeast breads by 50%, and we offered some tapioca-free breads, a line of anti-Candida (yeast-free, sugar-free) breads, and a paleo line of products free of grains, sugar, dairy, and legumes. Nineteen items turned into 160 or so! If it is a chemical/preservative or an allergen that makes people sick, we can and do keep it out. We couldn't be more proud of the range and quality of bread products that we have developed to serve the varying needs of our customers. Our referrals at this point come from word of mouth, our Facebook page, the unsolicited press that we have received, or doctors. Can you imagine doctors sending patients to a bakery?

Fast forward to 2010 and you'll see that the *Dallas Morning News* titled their article about us "Building a Better Bakery." I take that as a true compliment! Clearly, Taylor and I have always thought that food was in integral part of health, while baked food is a key to a person's happy place. We put our thoughts into action.

Stories from inside the bakery

If the walls could talk inside our bakery, your heart would melt. Tears from mothers, or smiles from the children, as we bring some sense of normalcy back to even the sickest of our customers, are equally emotional and inspirational. If you could only hear these tales, you would feel more than blessed to have only a simple gluten allergy, or even a gluten and dairy allergy. We have babies who enter this world allergic to gluten, eggs, dairy, and soy. Consequently, their nursing mothers come to us to buy our food so their milk is acceptable for their babies. We also have children, one in particular, the 4-year-old son of an otolaryngologist, who is still suffering from incredible eczema despite years of testing and doctors and adhering to the most stringent of diets. At the age of 4, before they found us, he was still living on bottled formula. I wish you could watch that wonderful little boy eat a cupcake that is free of gluten, soy, dairy, eggs, and all chemicals and preservatives. The smile on his face, and the always-thankful love we receive from his mother, are enough to keep us moving forward to continue to develop recipes that allow the severely allergic to eat with some amount of normalcy. Or there is the 11-year-old boy who never had a birthday cake until they found us. Or the cancer patients (and the cross-fitters—those who are extremely aware of the causal relationship between diet and exercise and their health) who come to eat our most specialized products: the paleo, which is free of grains, dairy, sugar, and legumes. It is anti-inflammatory and ultra-low carb. It is incredibly nutritious given it is made from eggs, nuts, seeds, and fruit.

Some of our customers can eat only our most limited breads: the anti-Candida, which is truly allergen free, with no gluten, soy, dairy, eggs, nuts, yeast, or sugar. It has been a god-send to these people, many of whom are autistic, who eat this bread. It has the taste and texture of bread, which is so important for autistic children. Autoimmune disorders are no stranger to us at Unrefined Bakery: there is a huge correlation. We have never done a scientific study, but we have more than a few with lupus,

Sjogren's, Hashimoto's/Graves', multiple sclerosis, muscular dystrophy, diabetes, autism, etc. (Taylor has a thyroid condition and another family member with celiac disease has lupus.) We hear their stories. We offer a shoulder. Often we learn as well.

We have become a collection point of information; more than that, we have become a family of random people with shared experiences. We share information regarding great doctors and nutritionists. This is a safe place not only for food, but for helping a customer who has become a friend. Sadly, but realistically, some of our customers get more and more sick. But in the meantime, they continue to come to us for a cookie or cupcake or a paleo loaf. They come to us because we are one of them. We get it! We offer a safe haven with food that brings a smile!

AN OVERVIEW OF GLUTEN AND CELIAC DISEASE

The National Institutes of Health indicated that, on average, "a diagnosis of celiac disease is not made until more than a decade after symptoms begin" (1). This was clearly true for me and my daughters. According to the Celiac Support Association, 3 million Americans are undiagnosed. Untreated celiac disease increases the risk of cancer 200% to 300% and increases the risk of miscarriage 800% to 900%. Individual health care costs for untreated celiac disease are \$5,000 to \$12,000 annually—a total of \$14.5 to \$34.8 billion for the United States (2).

For those with celiac disease, gluten makes them sick. Gluten is a protein found in wheat, barley, and rye. This is the common simple explanation, but it is so much more complicated than that—it has to do with the peptides within the gluten protein, glutenin and gliadin, and how in the autoimmune form, celiac disease, the villi become damaged. The villi play the important role of absorbing nutrients from food. With damaged villi, malabsorption occurs, and the body ceases to function properly. Why is it so challenging to live without? Gluten is simply everywhere. It's in the expected offenders—breads, crackers, pastas, pastries—and in less typical places like your spice cabinet and seasoning mixes. It also hides in cosmetics and medicines. It is used as a filler and a binder/thickener in our highly processed society.

Celiac disease and nonceliac gluten sensitivity are both treated by 100% elimination of gluten from the diet. This is a bit harder than it seems. It is not like sugar, where less is definitely better. It has to be 100% elimination. This means no crumbs from toasters or shared butter or jelly jars. It means avoiding cross-contamination inside a deep fryer at a restaurant, where french fries are fried in the same grease as the chicken strips. It means you have to learn scientific words like maltodextrin and modified food starch that are found in processed foods. You have to learn to read labels. It is hard to find all the hidden places. It takes a while. This is why our customers come in with that deer-in-the-headlight look! But, there are books and blogs and support groups and people like us who have been there, done that.

Table 1 summarizes some basic information on celiac disease (3–6). Although I am not a medical expert, I continue to study this disease and found the following points interesting.

History and increasing prevalence

For humans' first 2+ million years, we were hunters and gatherers. Our gut developed with a specific diet. Then, somewhere around 10,000 to 15,000 years ago, our lifestyle and diet evolved: we began to grow wheat and to domesticate animals. Our food changed, and so did the demands on our gut. As Dr. Stefan Guandalini noted: "The agricultural revolution of the Neolithic period generated a whole battery of food antigens previously unknown to man, including protein from cow, goat, and donkey milk,

as well as birds' eggs and cereals. Most individuals were able to adapt. Among those who could not, food intolerances appeared and celiac disease was born" (7). Although it would seem that gluten is "suddenly" on the scene, it was first documented in 200 AD by Aretaeus of Cappadocia, who wrote about "The Coeliac Affection." Dr. Guandalini noted that Aretaeus "named it 'koiliakos' after the Greek word 'koelia' (abdomen). His description: 'If the stomach be irretentive of the food and if it pass through undigested and crude, and nothing ascends into the body, we

Table 1. Basic facts about celiac disease*

Category	Comment
Elements of pathogenesis	<p>"The prevalence of (serologic screening detected) celiac disease correlates with the carrier state of the major genetic predisposition (HLA-DQ2>HLA-DQ8) and a high wheat consumption" (4). Other aspects:</p> <ul style="list-style-type: none"> • Serum autoantibodies • Gliadin reactive T cells • Innate immunity to wheat proteins • Autoantibodies and intraepithelial lymphocytes • Gliadin receptor(s) on intestinal epithelial cells (4)
Epidemiology and prevalence	<ul style="list-style-type: none"> • Occurs primarily in those of northern European ancestry • Prevalences of 1:70 to 1:300 in most countries • Increasing prevalence with age • "First-degree relatives of patients with celiac disease have a 10% to 15% risk of celiac disease" (4).
Clinical manifestations	<ul style="list-style-type: none"> • "Patients with celiac disease may present with classic symptoms related to malabsorption, including diarrhea, steatorrhea, weight loss, and nutrient or vitamin deficiencies. However, the majority of patients with celiac disease exhibit only minor gastrointestinal complaints, have nongastrointestinal manifestations, or are asymptomatic" (4). • Nongastrointestinal manifestations: infertility, rheumatic disorders, vitamin D and calcium deficiency, osteomalacia, osteoporosis (4). • Neuropsychiatric disease: association with "headache, peripheral neuropathy, ataxia, depression, dysthymia, anxiety, and epilepsy" (4).
Associated conditions	<p>"Numerous autoimmune conditions are frequently associated with celiac disease including dermatitis herpetiformis, type 1 diabetes mellitus, and autoimmune thyroiditis. Patients with celiac disease should therefore be screened for these conditions" (4).</p>
Diagnosis	<ul style="list-style-type: none"> • "If total IgA levels are abnormally low, an IgG-based assay should be used to test for celiac disease. The IgG antigliadin assay has been traditionally used in this circumstance but is not ideal since it yields frequent false positive results. Thus, serum IgG tTG or IgG DGP tests are preferable. Negative results upon testing for HLA DQ2 or DQ8 can also help exclude the diagnosis in this setting. • "In addition to serologic markers, the diagnosis usually requires a small bowel biopsy, which can be obtained during upper endoscopy. Exceptions are patients with compatible serologic findings and biopsy-proven dermatitis herpetiformis in whom the diagnosis can be established without a small bowel biopsy. A hallmark on histology is the presence of villous atrophy. However, villous atrophy can be patchy, and may also be present in a variety of other disorders that should be considered in appropriate clinical settings. Four to six biopsies in the duodenal bulb and second and third portion of the duodenum should be obtained to maximize the likelihood of detecting villous atrophy" (5).
Six key elements in patient management following the acronym CELIAC	<ul style="list-style-type: none"> • "Consultation with a skilled dietitian • "Education about the disease • "Lifelong adherence to a gluten-free diet • "Identification and treatment of nutritional deficiencies • "Access to an advocacy group • "Continuous long-term follow-up by a multidisciplinary team" (3).
Additional comments on patient management	<ul style="list-style-type: none"> • Test for deficiency of vitamins (A, D, E, B12), copper, zinc, carotene, folic acid, ferritin, and iron. • Evaluate for bone loss using a dual energy x-ray absorptiometry scan and appropriate therapy instituted based upon the results. • Offer pneumococcal vaccination since celiac disease is associated with hyposplenism. • Follow patients clinically and with serologic testing to determine response to dietary therapy. • Obtain a meticulous dietary history to ensure compliance with a gluten-free diet. • Recognize that some patients do not respond despite adherence to a gluten-free diet, including those with clinical or histologic features caused by other disorders; concurrent conditions, refractory sprue; ulcerative jejunitis or intestinal lymphoma (6).

*Source: *UpToDate* articles on celiac disease (3–6).

call such persons coeliacs” (7). It was another 1600 or so years, the late 1880s, before modern science began delving more deeply into the correlation between our gut and what we put into it.

It seems clear—from the labeling of products on supermarket aisles, to magazine and newspaper articles, to the latest professional athlete seeking to find an edge—that gluten is on the brain and on the rise. An article from the Mayo Clinic summarizes current thought based on interviews with Joseph Murray, MD:

Mayo Clinic research suggests the disease is becoming a major public health issue. Although the cause is unknown, celiac disease is four times more common now than 60 years ago, and affects about one in 100 people. According to Mayo studies, undiagnosed celiac disease can quadruple the risk of death. Mayo researchers are working to discover the causes and improve diagnosis. Their effort . . . “tells us that whatever has happened with celiac disease has happened since 1950,” Dr. Murray says. “This increase has affected young and old people. It suggests something has happened in a pervasive fashion from the environmental perspective.” . . . Mayo researchers learned that those whose gluten intolerance had not been diagnosed in the 1950s were four times likelier to have died. “Having undiagnosed celiac disease is not good for you,” Dr. Murray says. “It may take 20 to 30 years for that risk to become apparent. But there’s a good chance it’s a problem.” . . . About one-third of the population carries the genetic background for gluten intolerance—but only 1% of people have it. Before causes can be tested in the lab, researchers must develop an animal model with celiac disease.

Dr. Murray lists several possible environmental causes of celiac disease. The “hygiene hypothesis” suggests the modern environment is so clean that the immune system has little to attack and turns on itself. Another potential culprit is the 21st century diet. Although overall wheat consumption hasn’t increased, the ways wheat is processed and eaten have changed dramatically. “Many of the processed foods we eat were not in existence 50 years ago,” Dr. Murray says. Modern wheat also differs from older strains because of hybridization. Dr. Murray’s team hopes someday to collaborate with researchers on growing archival or legacy wheat, so it can be compared to modern strains (8).

Again, these views are not hard to find, or to believe, but as a layman, it is simply better to put in the views of a highly qualified health professional.

Obtaining a diagnosis

As indicated by The University of Chicago Celiac Disease Center (9), it can be useful for patients to be tested for celiac disease and have an official diagnosis rather than just attempting a gluten-free diet, as Taylor and I did. The term “gluten intolerance” is used when discussing the whole spectrum of conditions associated with gluten-related illnesses. The different conditions—celiac disease, nonceliac gluten sensitivity, wheat allergy, sensitivity to foods rich in FODMAP (fermentable oligosaccharides, disaccharides, monosaccharides, and polyols)—have differing mechanisms of action, severity of damage, and complications. “Plus, autoimmune diseases tend to cluster together in one individual

and celiac disease is an inherited disease, so we believe it wise to understand the health risks for your other family members” (9).

Coexisting sensitivities and food allergies

As Vikki Petersen, DC, CCN, indicated, gluten-sensitive patients often don’t tolerate dairy products. She listed three main reasons: enzymes, allergens, and morphines (10). The Celiac Disease Center noted, “It’s possible to be intolerant to other substances as well as gluten, but intolerance for one does not necessarily cause or occur with the other more frequently. Many who have celiac disease are also lactose intolerant, but it often resolves after the gut has a chance to heal” (11).

Awareness of food allergies has been important in our bakery. The top food allergies, which account for about 90% of allergic reactions, are milk, eggs, peanuts, tree nuts (almonds, cashews, walnuts), fish, shellfish (such as crab, lobster, shrimp), soy, and wheat (12). According to Food Allergy Research and Education:

Researchers estimate that up to 15 million Americans have food allergies. This potentially deadly disease affects 1 in every 13 children (under 18 years of age) in the U.S. That’s roughly two in every classroom. The economic cost of children’s food allergies is nearly \$25 billion per year. According to a study released in 2013 by the Centers for Disease Control and Prevention, food allergies among children increased approximately 50% between 1997 and 2011. The number of people who have a food allergy is growing, but there is no clear answer as to why (13).

Gluten and neurological symptoms

The bestselling book *Grain Brain* (14) has brought public awareness to the impact of grains, gluten, and sugar on inflammation and its long-term effect on the human body. The author, David Perlmutter, MD, stated his argument in the introduction to his book:

I believe that the shift in our diet that has occurred over the past century—from high-fat, low carb to today’s low-fat, high-carb diet, fundamentally consisting of grains and other damaging carbohydrates—is the origin of many of our modern scourges linked to the brain, including chronic headaches, insomnia, anxiety, depression, epilepsy, movement disorders, schizophrenia, attention deficit hyperactivity disorder (AHDH), and those senior moments [including Alzheimer’s]. (14).

He related the link to inflammation: “All of the neurodegenerative diseases are really predicated on inflammation” (15).

Dr. Perlmutter calls himself the Empowering Neurologist. I have learned through my own experience and the experiences of my family and customers that there is indeed power in changing what we eat and watching our health reappear.

Dr. James Hamblin, medical editor for *The Atlantic*, interviewed Dr. Perlmutter for his article, “This is Your Brain on Gluten” (15). Dr. Hamblin expressed skepticism that any one factor can be the end-all, be-all, cure-all to neurologic disease. In his explanation, Dr. Perlmutter commented:

People say “What you’re promoting here is really outside the box. Is that your mission?” I try to explain that, no, my mission

is to make this inside the box. To make the box bigger. So that mainstream medical professionals will begin to discuss the importance of these factors. Because it's already there. In the peer-reviewed literature. It's been there for decades. There's nothing proprietary about this. Every peer-reviewed article is available in the "Science" section of my website (15).

The idea of medicine being integrative was once implicit. Why is it thought of as "outside the box" or alternative for people to look at the totality of their diet, exercise, and/or stress as possible factors in their overall health? How did we ever think that what we eat or drink or how we do or do not exercise wouldn't impact our long-term health?

Hamblin's article also quoted Dr. Perlmutter on gluten insensitivity's wide-ranging effects, of which all physicians need to be aware:

The gastroenterologists don't seem to realize that gluten insensitivity far exceeds their area of focus. According to the work of Dr. Marios Hadjivassiliou in England, there are a large number of people who have reactions to gluten that have absolutely nothing to do with the gastroenterologist. Manifestations can occur anywhere in the body. The work of Dr. Alessio Fasano at Harvard indicates that perhaps all humans have some negative reaction to gluten. Gluten induces this cornerstone of brain degeneration: inflammation. It causes leakiness of the blood-brain barrier (15).

This passage from the *Journal of Gastroenterology and Hepatology* also speaks to the impact of gluten on the brain:

Neurologic manifestations are among the most common extraintestinal features of celiac disease. . . . While celiac disease continues to be underdiagnosed in the West, a low index of suspicion among physicians in the developing world has led to gross under-recognition of the disease elsewhere. Celiac disease can affect multiple organ systems, and its tremendously varied clinical presentation implies that physicians of all specialties should keep this condition in mind when evaluating patients (16).

MY WORDS, MY BELIEFS, MY SUMMARY

I know so many readers have their own story, their own frustrations and losses. To you I ask: please listen and know that my success was confirmed long before we opened our bakery. It was nearly immediately apparent when I made the conscious decision to stop eating gluten. As Erin said after finding out she had celiac disease, "Nothing tastes as good as feeling healthy." A wonderful side effect of going gluten-free was awareness of nutrition labels. I realized the "junk" that is actually in the food of a typical 21st-century American diet. My diet gradually morphed into being cleaner and more organic.

Those with gluten intolerance need to be their own advocates. Read and research. Teach yourself. Even teach your doctors. Don't take no for an answer. Don't be afraid of losing the gluten. Life without it is a great life. Health is priceless—so much better than a slice of pizza or a cinnamon roll (my two weak spots).

Doctors, please listen to your patients. The scope and variety of symptoms are so expansive, so seemingly random and unrelated that a person can feel a bit crazy when trying to put them all together. I ask you to be the one who helps your patients find the answers they so badly need. Please help us help ourselves. The science behind the various foods that we eat will be left for the researchers and scientists to ultimately discern. I predict it will be a long time before we have answers. Perhaps, as with all medicine, the "answers" might still be the best guess with the best intention after correlating the best research from the brightest minds.

My philosophy that carried us through these huge changes is this simple: Life works in mysterious ways. For me, I have found that life is what it is: I take the "givens" that land in my lap; I learn as I go; I focus on the positive; I share my gifts and talents. My daughters seem to do this too. We three have learned that these "bumps" can be the best thing ever. It is part of what makes us unique. Living gluten-free has brought us the gift of health.

1. National Institutes of Health. Genetics home reference: celiac disease. Available at <http://ghr.nlm.nih.gov/condition/celiac-disease>.
2. Celiac Support Association. Celiac disease facts. Available at <http://www.csaceliacs.info/celiacdiseasefacts.jsp>.
3. Kelly CP, Dennis M. Patient information: celiac disease in adults (beyond the basics). In LaMont JT, Section Editor; Grover S, Deputy Editor. *UpToDate* (current as of March 2014). Philadelphia, PA: Wolters Kluwer Health.
4. Schuppan D, Dieterich W. Pathogenesis, epidemiology, and clinical manifestations of celiac disease in adults. In LaMont JT, Section Editor; Grover S, Deputy Editor. *UpToDate* (current as of March 2014). Philadelphia, PA: Wolters Kluwer Health.
5. Kelly CP. Diagnosis of celiac disease. In LaMont JT, Section Editor; Grover S, Deputy Editor. *UpToDate* (current as of March 2014). Philadelphia, PA: Wolters Kluwer Health.
6. Ciclitira PJ. Management of celiac disease in adults. In LaMont JT, Section Editor; Grover S, Deputy Editor. *UpToDate* (current as of March 2014). Philadelphia, PA: Wolters Kluwer Health.
7. Guandalini S. A brief history of celiac disease. *Impact* [a publication of the University of Chicago Celiac Disease Center] 2007;7(3):1–2. Available at http://www.cureceliacdisease.org/wp-content/uploads/2011/09/SU07CeliacCtr.News_.pdf.
8. Celiac disease: on the rise. *Discovery's Edge—Mayo Clinic's Online Research Magazine*, July 2010. Available at <http://www.mayo.edu/research/discoverys-edge/celiac-disease-rise>.
9. The University of Chicago Celiac Disease Center. Why do you insist I eat gluten for a diagnosis when I feel better on a gluten-free diet? Available at <http://www.cureceliacdisease.org/archives/faq/why-do-you-insist-i-eat-gluten-for-a-diagnosis-when-i-feel-better-on-a-gluten-free-diet>.
10. Petersen V. Gluten and casein intolerances. Available at <http://www.glutenfreefox.com/articles/gluten-and-casein.html>.
11. The University of Chicago Celiac Disease Center. Frequently asked questions. Available at <http://www.cureceliacdisease.org/archives/faq/do-some-with-celiac-disease-also-have-lactose-intolerance>.
12. Mayo Clinic. Food allergies: understanding food labels. Available at <http://www.mayoclinic.org/diseases-conditions/food-allergy/in-depth/food-allergies/art-20045949>.
13. Food Allergy Research and Education. Facts and statistics. Available at <http://www.foodallergy.org/facts-and-stats>.
14. Perlmutter D. *Grain Brain: The Surprising Truth About Wheat, Carbs, and Sugar—Your Brain's Silent Killers*. New York: Little, Brown & Company, 2013.
15. Hamblin J. This is your brain on gluten. *The Atlantic*, December 2013. Available at <http://www.theatlantic.com/health/archive/2013/12/this-is-your-brain-on-gluten/282550/>.
16. Mahadov S, Green PH. Celiac disease: a challenge for all physicians. *Gastroenterol Hepatol (N Y)* 2011;7(8):554–556.