

## A lot to Digest: All Things Gluten

By Syndy Sweeney

In the world of food trends, “gluten-free” seems to be the most popular celebrity lately on the red carpet. Giving up gluten-rich foods – like pasta or bread – even for a little while, promises quick weight loss. More and more manufacturers now clothe their food in new gluten-free labels and supermarkets dedicate shelf space to this gluten-free phenomenon. Gluten-free, however, is not just another diet fad destined to rise and fall like the oat bran, soy protein, or pomegranate trends of the recent past. Because while some people do lose weight when they eliminate gluten from their diets, for many others, gluten can be the deciding factor between good health and being very ill.

A gluey, elastic protein composite that gives baked goods and pasta their structural integrity and soft texture, gluten is found in rye, barley, wheat, and wheat-related grains, such as kamut, triticale, spelt, and farro. It can even be found in oats grown in rotation with wheat or processed in the same factory as wheat. In the form of the thickening agent dextrin, gluten also finds its way into powdered mixes like spice blends, bouillon, gravy and cocoa. It’s also in malt vinegar, vanilla flavoring, beer, some liquor, cured meats like bacon and sausage – and their vegetarian counterparts. Gluten has become ubiquitous in the American diet.

And that’s a problem. The same proteins that make food appealing and delicious are also responsible for wreaking havoc on the immune system, often resulting in celiac disease, non-celiac gluten sensitivity and even autism. Helping to increase the awareness of what gluten can do to the body, as well as ways to live a healthy, gluten-free life, locals from doctors and nutritionists to patients and food purveyors share both their experiences and knowledge.

### Celiac disease and non-celiac gluten sensitivity

According to Dr. William D. Chey, Director of the GI Physiology Laboratory and Co-Director of the Michigan Bowel Control Program at the University of Michigan, celiac disease (CD) is “a genetically-mediated disorder where patients experience an abnormal reaction of their immune system in the GI [gastrointestinal] tract in response to certain proteins that are contained by grains including wheat, barley, and rye.”

Chey says that while “one out of every 130, 140 people” have CD, people “really have to have the proper genetic make-up [the genes DQ2 and DQ8] to express the disease,” and they have to be eating gluten. However, it is still unknown what actually triggers the disease because there are many more people who carry the appropriate genes that don’t ever develop CD than those who do get sick. According to Chey, studies suggest that CD can occur in people with the right genetic markers if gluten is introduced into their diets at a very early age or if they suffer from a severe gastrointestinal infection that, in effect, “unmask[s] that genetic predisposition.”

Also, while CD is found everywhere in the world, Chey says, it “is more prevalent in northern Europe and it’s much less prevalent in Asia,” despite there being “tons of gluten in the Asian diet.” It also may be a matter of the type of wheat that people are eating. To achieve a softer texture in bread, Chey says, “What’s happened over time is that – it’s been suggested anyway –

that growers have selected for strains of wheat, for example, that contain more gluten and also, types of gluten that actually may be more toxic. So, there's been some sort of an emerging data to suggest that all gluten is not created equal and there may be certain types of gluten...that contain more of the proteins that are likely to cause the immune system to react abnormally." Dr. Malcolm Sickels, the father of two daughters with CD and a holistic medical doctor in Ann Arbor, agrees with this possibility. "Early in my practice," he says, "I came across a patient who couldn't tolerate wheat here but when they went to the Middle East, they could eat the wheat there."

Regardless of how CD develops, until recently, it was thought to express itself only in symptoms that affected the GI tract: diarrhea, weight loss, failure to thrive, constipation, bloating, and distension of the abdomen. Graduating from medical school in 1986, Chey says, "We were taught that the way patients with celiac disease presented was with malabsorption.... It was mostly diagnosed in kids and it was mostly kids with weight loss and diarrhea. And over time, what's become very clear is...the majority of patients with celiac disease don't have GI symptoms or only have very minimal GI symptoms."

Chey continues, "Atypical symptoms are what most people with celiac disease actually present with." A 2010 study by Warde Medical Laboratory (*Keren, David F. Celiac Disease Panel Warde Med Lab 2010 21(1)*) confirms that "40% of patients with CD cases have atypical presentations in that they lack symptoms related to the gastrointestinal tract, but do suffer from chronic problems related to malabsorption such as iron deficiency, short stature and osteoporosis." Furthermore, the same study reveals that an additional "third of the cases are clinically silent." While this results in bowel damage, there are no clinical symptoms. Sickels elaborates, "'No clinical symptoms' doesn't mean no symptoms at all; it means, nothing enough to make them go to the doctor, or at least, they don't *perceive* as enough to go to the doctor.... People could have muscle aches; people could have headaches; people could have a rash; people could have all kinds of things."

Because the majority of CD cases can look like something else, it can be hard to diagnose. But, for "patients that have a wide variety of different types of clinical complaints and/or abnormal lab findings," Chey says, "You should be suspicious for celiac disease." According to Chey, patients with diabetes, Down's syndrome, problems with infertility, or who are extremely fatigued can often have CD, as well. CD can also affect the skin or in rare cases, the brain. Dermatitis herpetiformis causes scaly, blistery lesions on the skin usually around the elbows and knees. And gluten ataxia damages the cerebellum causing usually permanent problems with balance, swallowing, speaking and walking.

Confusing both the understanding and diagnosis of CD is non-celiac gluten sensitivity. According to Chey, "There is a larger population of patients out there that develop symptoms in response to eating gluten or wheat but they don't have celiac disease." Like with CD, these symptoms could present in the GI tract or elsewhere: migraines, headaches, joints, muscles and the immune system. A 2002 review in the New England Journal of Medicine (*Farrell, Richard J., Kelly, Ciara P. Celiac Sprue N Engl J Med. 2002 Jan 17; 346(3):184*) even lists lupus, schizophrenia and Addison's disease as "possible associations" of gluten-sensitivity.

Adding to this confusion is that a reaction to wheat itself and not gluten may be a bigger problem. “I actually think a better term is non-celiac wheat sensitivity,” Chey says, “Because when you label all these people as being gluten-sensitive, it implies that the symptoms they are experiencing...that they’re from gluten. And while in some patients, the symptoms clearly are from gluten; in other patients, they’re not related to gluten. They’re related to other characteristics of wheat that can still cause GI symptoms.”

“Wheat also causes symptoms,” Chey says, “because it’s a non-absorbable carbohydrate. Wheat is...the largest source of a non-absorbable carbohydrate – called fructan – in the U.S. diet.... A lot of people develop symptoms like bloating or cramping or even diarrhea after they eat a lot of wheat. And they assume it’s gluten. And sometimes it’s gluten. But other times, it’s got nothing to do with gluten at all. It’s purely because they’ve eaten a big load of carbohydrates they can’t absorb. And those carbohydrates are fermented by the bacteria in the colon and it causes all the problems that we just described.”

“So this is an important issue,” he adds, “because people think they’re ‘allergic’. They’re not allergic – it’s got nothing to do with allergy at all. This is a fermentation issue related to the fact that they can’t absorb fructans.”

The only way to know for sure whether a person has CD or gluten sensitivity is to test for it. Dr. Chey recommends a “simple blood test.” If the test is positive for celiac, Chey says, “Most people would advocate for doing a small intestinal biopsy to confirm the diagnosis of celiac disease.”

This biopsy test is not without controversy, however. Because the majority of CD occurs outside of the intestines, according to Judy Stone, the Director and Consulting Nutritionist of the Center for Functional Nutrition in Ann Arbor, the biopsy is “why so much gluten sensitivity gets missed.” It is also possible that a biopsy may come from a place on the small intestines where damage has not yet occurred, thereby showing a false negative for CD. And with someone with CD, the longer it takes to receive a proper diagnosis and treatment, the more damage can be sustained by the intestines.

Sickels explains, “The inside of the intestines normally have villi that increase the surface area. They look like little tiny fingers.... But with celiac disease, as it becomes more advanced, first they kind of get swollen and inflamed. And then, it looks like a lawnmower came by and just shaved it all off.” If a patient remains untreated, Sickels says, “they can then progress to the equivalent of third degree burns inside their gut and that may not heal.”

Furthermore, in an intestine damaged by CD, nutrients and food particles are not properly absorbed. They pass instead through the intestines into the blood stream. According to Coco Newton, a Functional Nutritionist at Lifetime Nutrition in Plymouth, “two-thirds *plus* of the immune system is located in the gut and it influences the entire body,” making the body prone not only to other diseases but to sensitivities and allergies to other types of food.

There is one treatment for celiac disease and gluten sensitivity, however: removing all gluten from the diet for the rest of one’s life. Chey says, “We know that a gluten-free diet makes

virtually everybody better.” Furthermore, by eliminating gluten and giving the gut a chance to heal, according to Chey, this also “mitigates all of the sort of downstream bad effects associated with untreated celiac disease: premature bone loss and osteoporosis, iron deficiency anemia, all of the GI symptoms that can go along with it, as well as an increased risk of cancer....

Identifying celiac disease and treating celiac disease properly with a gluten-free diet is critically important to prevent those things from happening.” For some people, removing gluten from the diet results in immediate improvement in the way they feel. For others, relief may take several months.

As awareness about gluten increases, Chey says the downside is that more and more often, he and other doctors are encountering people with GI symptoms who have diagnosed themselves with CD and gluten sensitivity. Then, with incomplete knowledge about gluten or nutrition, they have “put themselves on these highly restricted diets.” He warns, “They’ll do this for long periods of time, and after a while, patients will actually develop nutritional deficiencies.... People may actually be doing themselves more harm than good.”

Chey stresses the importance of being tested before removing gluten from the diet. “Once you go on that type of diet,” he says, “it markedly reduces the accuracy of the diagnostic test so that basically, a doctor can’t accurately tell you whether you do or do not have celiac disease. Basically, what you have to do as a physician...is to tell the patient to go back on a gluten-containing diet for some period of time. Now, here’s a problem: we don’t exactly know how long a patient has to go back on gluten before the testing becomes accurate again.”

Putting a patient back on gluten in order to confirm a diagnosis of CD would most likely result in more damage to the immune system. Sickels concurs, “If you can demonstrate that somebody has true celiac disease, then they have to be 100 percent off all gluten because it dramatically increases the risk, and by dramatically, I mean multiple times higher risk...of every autoimmune disease as well as carcinoma and lymphoma. So, essentially, for someone with celiac disease, every time they’re putting wheat [or gluten] in their mouth, they are risking their life.”

If it is possible to feel better after removing gluten from the diet, why is an official diagnosis even necessary? For one thing, there are financial benefits. In a treatment that requires a lifelong dedication to eating more expensive, gluten-free foods, Sickels says, “If we can establish a diagnosis of celiac disease...any testing, treatment or even therapeutic food – which for them would be a difference in price between a regular food and a gluten-free food – are tax-deductible.”

Also, receiving an official diagnosis not only establishes a timeline of the disease, it can help give a person with CD and gluten-sensitivity the resources she needs to change her diet and lifestyle in a healthy way. To help with this process, Chey recommends that patients seek the services of a nutritionist.

### **Living with CD and gluten-sensitivity**

When patients who must learn how to navigate their way in a gluten-free world visit Coco Newton, they’re not only getting a qualified nutritionist, they’re meeting someone who

intimately understands their needs and concerns. Both Newton and her husband have passed on the genes for gluten intolerance to their three children. Allergic to shrimp, eggs and dairy, Newton can actually eat gluten herself but for the sake of her family's health, she maintains a gluten-free household. It is this experience that informs the way she approaches her patients. Her goal is not only to educate them and their families about their own health and a gluten-free lifestyle, but to take away any sense of victimization they may be feeling.

Newton acknowledges that this life change can be very overwhelming. "So often with families," she says, "It's like, 'Oh, my gosh! I have this diagnosis. It's very depressing. It is restrictive'.... There are so many steps to this beyond just the food."

She and her patients discuss what gluten is and why it's a problem for them, but also what the day-to-day practical concerns are that they may encounter while living gluten-free. She teaches them how to recognize and avoid it in food and possibly even in cosmetic products such as lotion. Although Newton says, the proteins from gluten don't "end up in your blood from being on top of your skin," there is a possibility they can find their way through skin that is cracked or has a sore.

Newton also discusses how to shop for gluten-free foods (including grocery store tours, if necessary) and how to eat out at restaurants where there is a greater chance for cross-contamination to occur. This cross-contamination could be as simple as a transference of crumbs from a knife used to cut both regular and gluten-free breads or from a deep fryer used to fry both regular and gluten-free foods. According to Dr. Chey, "most patients with celiac disease can tolerate small amounts of gluten" without a problem, but "there are some individuals...who are exquisitely sensitive and will react abnormally to...minute amounts of...cross-contamination."

Finally, Newton addresses the specific emotional concerns of her patients and their families – especially when it comes to children who must be put on a gluten-free diet. For example, how will a child deal with situations at school when a classmate may bring in a treat that he cannot eat – will he feel singled out? Or, how will the family educate several sets of grandparents who may be resistant to giving their grandchild gluten-free cookies and cake? Or, if the child's parents are divorced, can they put aside any remaining tension so they can provide her with the same gluten-free care at both homes?

"The teaching is gradual," Newton says. "The first thing I think is really important is to spend time educating and not putting the pressure of 'must turn over a new leaf by tomorrow, or else'."

After educating her patients and helping them to eliminate gluten from their diets, Newton works to restore balance to the gut. "I do not have a one-size-fits-all approach," she says. "I'm a very data-driven nutritionist." Rather than recommending supplements or enzymes out-of-hand that could be helpful to someone with gluten intolerance, Newton first collates information and lab results from her patients' primary-care physicians and any specialists they may have seen. "I like thinking in like terms of detective work and also looking for patterns and causes," she says, "I find it fascinating."

Depending on what she finds, she may then require more testing from her patients' doctors, such as a stool analysis. "That stool test," Newton says, "will let me know pretty clearly what I need to do to balance the bacteria...especially if a patient needs...good bacteria. It will help me know which herbs will get rid of which pathogenic bacteria or parasites or yeast.... If a person shows that they're not producing pancreatic enzymes for digestion, then I will know they will need to supplement digestive enzymes.... If I know someone's malabsorbing fat, then I know...to give herbs that are restorative to the GI tract lining."

Only after she receives the additional data, will Newton make recommendations. "I need to feel accountable to patients," she says. "When I give them their list of supplements I want them to take, I tell them what it's for, how long I want them to take it, and then I have data points of well, we either need to look at the symptoms after taking this or maybe retest this particular value.... It's all laid out. And that's really important. I want people to know exactly why they're taking what they're taking."

Despite their new diet and the supplements they must take, as their health steadily improves, Newton's patients "don't see it as a sacrifice as much as they see it as a way out of their misery. So, it's more like a gift than a sacrifice." Because she is able to help people not only adjust to a gluten-free diet but to restore balance to their lives, Newton says of her work, "I absolutely adore it."

Like Newton, two local women are also using their personal experiences with CD and gluten intolerance to help others make the switch to a gluten-free diet as painless as possible. Julie Rabinovitz is the owner of Tasty Bakery in Ann Arbor and Valerie Mates is the founder and moderator of the on-line support group, Gluten-Free Ann Arbor. Celiac disease runs in both of their families.

Although she suffered for years from infertility, depression, headaches, and fatigue that caused brain fog and memory loss, Julie Rabinovitz never entertained CD as a possibility until her mother was actually diagnosed first with the disease. "She didn't get sick until she was 69-years old," Rabinovitz says, "And for a year, they couldn't figure out what was wrong with her. And she just kept losing weight and it took them a year to figure out she had celiac disease. And then when I looked at the other symptoms, I started thinking, 'Well, maybe this is something I better get checked out.' So, that's what led me to it; otherwise, I probably wouldn't have known."

When Rabinovitz received her own diagnosis of CD in February, 2007, she also discovered that eliminating gluten from her diet was only the beginning. "The celiac created havoc in my body," she says, "and it became all these other things." Rabinovitz also had developed severe food allergies to beef, lamb, pork, dairy, eggs, corn, soy, yeast, sugar, and goat's milk. She recently also removed coffee from her diet. Since she's given up all of the foods her body reacts to, Rabinovitz says, "It's definitely helping. I definitely see a difference."

Although she could easily become depressed by her now limited diet, Rabinovitz says, "It just makes me want to create more foods that I can try myself."

Ironically, if it weren't for CD, Rabinovitz may not have ended up a baker. This married mother of one says, "My mother and my grandmother always said I should get into like some kind of cooking profession.... But I was always afraid...if I do something I love I'd end up hating it – if I make it 'work' .... And then I found out I have celiac and well, you know, it just kind of came to me. Give it a try, see if I can experiment and make a go of it."

In May of 2009, Tasty Bakery was born. Selling her baked goods at the Ann Arbor Farmers Market and local coffee houses, Rabinovitz is hoping to expand to her own storefront. For now, she rents a dedicated area in a commercial kitchen (she's the only one who bakes there).

All of Rabinovitz' baked goods are gluten-free. But as she's uncovered her own "layers of allergies," Rabinovitz also offers vegan, dairy-free, and sugar-free versions of her cakes, pies, cookies, and other treats.

Because she sells her goodies at the farmers market, Rabinovitz does not have to legally list her ingredients. But from the beginning of her business, she has. Besides, she wants her customers to know that she uses excellent ingredients – like coconut flour, organic coconut nectar and fair-trade, soy-free, Mindo chocolate from Dexter – and that her baked goods are for everyone, not just those with food restrictions. "My goal," she laughs, "was that anybody who was going to be eating with the [gluten-free] person was going to eat my stuff and enjoy it just as much, and not say, 'Oh, God. We have to eat a gluten-free cake!'"

Rabinovitz' table at the farmers market has also become a place for information exchange. Her customers share their own stories about what gluten and their food allergies have done to their health. "There's no way you can deny what's happening to people," she says. "The more I've been doing this, the more I'm seeing and hearing from people that it's so out there and so prevalent."

It is this prevalence; however, that ultimately prompts Rabinovitz into further experimentation with her baked goods. "I get so much gratitude out of what I do because people are so excited.... To be able to offer all those things and kind of hit as many allergies as possible...it's just really gratifying."

When Valerie Mates started the Yahoo! group Gluten-Free Ann Arbor on February 19, 2005, she also couldn't have predicted the response that she received from other people like her and her family. "I thought it would be a good place to connect with all three celiacs in town, all three gluten-free people," she laughs. "If we ever got up to like nine people on the list, I thought it would be really huge! Today, right this minute, we've got 740 people.... Just the idea that there are 740 people in Ann Arbor who've gone and found this e-mail list about being gluten-free is really amazing to me!"

Mates' experience with gluten intolerance began decades before she was even born. Her paternal grandfather had died young from intestinal cancer and then, when her parents married in 1955, a wedding guest took Mates' mother aside and told her that her new husband, as well as his brother, had been celiac babies. Back then, Mates says, "People thought that gluten-sensitivity

and celiac was a childhood condition that people outgrew.” Consequently, Mates says her father was never put on a gluten-free diet and he often “spent a lot of time in the bathroom.”

But it wasn’t until 2000 when CD took a dominant position in Mates’ life. Her one-year old niece began throwing up after every meal and losing weight. “Nobody could figure out why,” Mates says. “And they [the doctors] had the ‘Grand Inquisition’ with my sister: ‘Are you intimidating your child? Are you scaring her at mealtimes? Are you treating her wrong?’ It wasn’t any of those things! My sister was being kind and gentle.” Her niece was in the hospital, “getting sicker and sicker,” Mates says, until a friend of her sister who was also a doctor finally correlated all of her niece’s test results. She was positive for CD. “They gave my niece a gluten-free meal and...she ate it and kept it down and everybody was just amazed. She got healthier and gained, I think it was, three or six pounds in a few weeks, and it was just really clear that gluten had been the problem.” Now age 12, Mates says her niece is “thriving,” and has become a “great mentor to other kids who are new to the gluten-free diet.”

A few years later, when Mates’ own daughter was gaining weight very slowly, she also suspected a problem. “I talked to her doctor about it and he said, ‘Oh, she’s fine. Bright-eyed. She’s cheerful. You know, she’d look really sick if she had a problem’.... It took a year of pestering the pediatrician to send her to the gastroenterologist. And the gastroenterologist did the tests for celiac and they came off-the-scale positive.”

Then, it was Mates’ turn. Less than a year after her daughter’s diagnosis – and after several years of suffering from digestive problems and feeling what she calls “tremendously sick” – Mates decided to give herself a birthday present. She says she thought, “‘I’m going to just see if I can make myself healthy for one day,’ and I dropped all gluten from my diet for that one day and I felt almost immediately better. It was a life-changing change. I felt so much better.”

Because she and her family have been restored to health after removing gluten from their diets, Mates wanted to help others in similar situations. Her online forum has databases for gluten-free recipes, grocery store and restaurant reviews, medical information, and overall support for those with CD and gluten-sensitivity.

## **Autism**

By amending the diets of children with autism spectrum disorder (ASD), there is a good possibility that not only will many of their symptoms be alleviated but that some may recover from autism.

Dr. Tony Boggess, a Physical Medicine & Rehabilitation physician and Medical Director of the Natural Balance Wellness Medical Center in Ann Arbor, has spent the last five years working with children with ASD. According to him, while the exact cause of autism is unknown, it is recognized as being “multi-factorial” in which “genetic predispositions meets environmental factors.” He says, “Very few physiological systems remain unaffected by what seems to be a widespread activation of immune reactivity and increased sympathetic activation.”

This sympathetic activation in children with autism, leading to “what’s described as activation of the fight-or-flight parts of the nervous system,” he says, “include propensities to have sensory ramp-up.... They’re more sensitive to noises and sounds, things like that.” This is a defense mechanism, Boggess says, “And we know through various physiological mechanisms, that when the fight-or-flight system is ramped up, the immune system is also ramped up.”

He adds, “The story would be incomplete if we didn’t also know the digestive system of most kids with ASD is also stressed.”

When that stress occurs, this may result in a leaky gut. According to Boggess, leaky gut is the laymen’s term for “the gut being too permeable.” More specifically, it is “the tendency for the integrity of the digestive system to be changed, such that, the basic nutrients that would otherwise be absorbed in a totally intact gastrointestinal system” instead, pass into the bloodstream as partially digested food particles. If that food contains gluten, casein (milk) or soy proteins, then their natural morphine-like byproducts which are necessary for protein digestion in a healthy gut – called exorphines – also pass into the bloodstream in what Boggess calls “greater than physiological amounts.” These exorphines are neurotoxic and addictive. “They’re very irritating to the immune system,” Boggess says.

In a separate yet related issue, Boggess says that once the immune system reacts “at the level of the gut-blood barrier, there can be an almost mirror image inflammatory reaction” at the blood-brain barrier and likely, even in the brain itself. This reaction, Boggess says, “creates more trouble for the nervous system.”

While acknowledging that the issue of “neurotoxicity, GI-permeability, and immune reactivity is not the only mechanism by which we classify kids as having autistic features,” Boggess says, “It’s a major one.”

And because it is, the first intervention Boggess often requires for his patients is to restrict the three major exorphines-producing foods from their diet. Called the GCSF (gluten/casein/soy-free) diet, it removes all gluten, casein, and soy proteins from a child’s diet. Boggess takes the time to educate the parents about the value of such a diet and to meet with the clinic’s dietician to “make it very easy for them.” Although this diet does require dedication from the parents, the possibility of positive changes in their child keeps them motivated. In his clinic alone, Boggess estimates that in “60 to 70 percent” of the children who are placed on the GCSF diet, parents see an immediate improvement in them.

For children on the more subtle end of the autism spectrum that may have problems with focusing and a need for constant stimulation, after switching their diets, Boggess says that need diminishes noticeably. But for children with ASD “who are on the severe end,” Boggess says, “You’ll see everything from resumed eye contact [and] starting to spit out words.” Parents will also notice that there is “more awareness, the digestive problems are not as bad, the constipation has improved, and just generally speaking, they know their child [is] better,” since the diet was changed.

Boggess will then begin adding other interventions to his patients' care specific to each individual depending on the results of various tests he runs. These may take the form of select nutraceuticals which are high-grade supplements, medicines, or hyperbaric oxygen. While these nutraceuticals support neurotransmitters in the brain, detoxification pathways in the body and the immune system in general, Boggess says they also help to "return the digestive system to its native ecology".

As the digestive system returns to health and the behaviors associated with ASD consequently begin to lessen, Boggess says, "We get to celebrate kids improving rapidly – and [in] some cases, going from completely disabled to mainstream.... It's not a 'once severely autistic, always severely autistic' thing. It's a treatable, often resolvable condition."

When Dena Sabou, the mother of three, was told six years ago that her 14-month old son had autism, she mourned. She says, "When you're pregnant and you're planning on having a baby, and you start dreaming of: What could they be? What will they be? What will they like? What will he want to do? What will he be really good at it? Will he be funny? Will he play sports? What will he do? And [then] that diagnosis comes, and it just takes *all* that away from you. Immediately. And it's a really hard thing to go through."

Sabou did not mourn for long, however. "I immediately started doing research," she says, "And one of the first things that I came across was how gluten reacts in the body, crossing the blood-brain barrier and what neurological effects it can have on somebody with autism." This information made sense because her son's digestive system had been taxed since birth. Born with gastro esophageal reflex disorder (GERD) – which Sabou discovered in her research can often be a precursor to an autism diagnosis – her son lived a 24-hour cycle in which, Sabou says, he would, "eat, throw up, sleep; eat, throw up, sleep; eat, throw up, sleep."

Sabou decided to share her research with her son's neurologist and she was surprised by the amount of resistance she received. "He told me, 'This won't work. These aren't proven. These aren't tried.' He was very patronizing: 'Save your time. Save your money. Let's focus on accepting who he is and what his limitations will be.' He pointblank told me, 'If you're changing his diet, it's not going to help him. Save your money because it's likely when he gets older and too big for you to manage, then he'll have to go into a home.'" The neurologist even tried to prepare Sabou for what her son's limitations would be. According to Sabou, he said her son was "never going to talk. He's never going to be potty-trained. He's never going to ride a bike. He's never going to bond with you. They gave me my list of 'nevers' and I am very proud to say that I didn't listen. I went way out of the western medicine paradigm and I tried a bunch of things that are not proven [in double-blind studies]."

But her interventions worked.

She says, "We went ahead and removed gluten out of his life, out of his diet completely and it doesn't happen overnight." Sabou decided not to share with her extended family what she was doing – if there were any changes to come in her son's behavior, she wanted her family to perceive them on their own. And six months later at Thanksgiving, Sabou says, "People were noticing."

Until then, her son had been “non-verbal, no eye contact, very cloudy. He was very removed from all of us.” And she says, her son would behave “like a nervous little baby monkey...we would walk into a room and he would do everything to get like to the top, the highest part of my shoulder and he kind of just like didn’t want anything to do with any of it.” But, at that Thanksgiving celebration, for the first time, her son climbed down from her shoulder, walked over to his cousins and was able to be in their space, playing with his own toys. Sabou says, “My aunts were saying, ‘Wow! What did you do? It’s amazing!’”

Based on her research and with an aim to heal her son’s gut, Sabou continued to intervene in her son’s diet. She says, “He responded so well to [removing] gluten that we then, in two to three months, took away casein. I made the decision at the time of taking casein away that we would not substitute with soy.... And he responded even better!”

While her son’s interventions have also included neurofeedback, Vitamin B12 and nutraceuticals, changing his diet so drastically from the beginning of his diagnosis, in effect, has helped him to recover from autism. His mother says, “He has met all of those milestones that he wasn’t supposed to meet and now he’s in first grade with no aide. He has friends. He is social. He goes to parties. He plays at recess. He’s a regular kid.” Like many seven-year olds, his goal this summer is to ride his bike without the training wheels.

And as far as feeling any stigma because he eats differently than his classmates, Sabou says, “I have went out of my way to make sure that he never feels excluded, so when he’s invited to a pizza bowling party, I make him a gluten/casein-free pizza and I take it fresh out of the oven with me to the party. I bring him his own cupcakes...I have found very good replacements for all the things so he never feels left out.” Her son even trick-or-treats at Halloween, trading his brother and sister who are now too old to participate, his stash of regular candy for the organic, gluten/casein-free candy he can eat. “We make a game out of it,” Sabou says.

Sabou and her son’s journey together have also given her a career. Now an advocate for autism awareness, Sabou works at the Natural Balance Wellness Medical Center counseling parents who may be mourning their child’s diagnosis. While she acknowledges that autism is different for every child and that “they may not get fully recovered,” Sabou says, “I am certain that they are going to get a better quality of life with therapies and interventions than they will without it.” With her own son as proof that eliminating gluten can lessen the effects of autism and even restore health to an autistic child, Sabou is able to give these other parents the benefit of her experiences, the resources she’s accumulated, and more importantly, hope.

“This is a very sharing community,” she says.

### **Buying and Eating Gluten-free Food**

(Please see the sidebar for additional resources)

According to Coco Newton, when it comes to a gluten-free lifestyle, Ann Arbor is “a conscious area”.

Kevin Sharp, the Marketing and Member Services Manager of the People's Food Co-Op in Ann Arbor, agrees, "The general public is becoming more aware of their own need or response to eating gluten." When the co-op participates in off-site health and wellness events, Sharp says, "It's one of the most common questions I get asked.... Do we carry some gluten-free products and is that sort of a specialty of ours?"

"In the last three to five [years] in particular," Sharp says, the request for gluten-free foods has "really picked up steam."

The co-op carries gluten-free pasta, bread, tortillas, and baked goods, and for people who prefer to do their own gluten-free baking, it carries the Bob's Red Mill product line. Sharp says, "We do make a very conscious effort to respond to product requests and to keep something available throughout the store so somebody can come in and shop just about every department and find something – and something good, not just a suitable alternative."

"We're not going to lower our standards for gluten-free," he adds, "It's got to be good *and* gluten-free."

Besides selling prepackaged items, the co-op bakery also makes its own gluten-free baked goods. "We always have at least a gluten-free cake and...at least one other gluten-free baked good that we make in addition to our usual offerings. All of our cupcakes that we make are gluten-free and vegan and they're really, really good. We have a chocolate cake – we call it 'Nothing but Chocolate', a bête-noire – and that's gluten-free. We always have at least one gluten-free cookie that we make a day."

Sharp cautions that the small size of the co-op bakery does not allow for a separate area to prepare the gluten-free baked goods. Despite wiping the space down, handling and storing the gluten-free items separately, and preparing them at different times from the regular baking, Sharp says, for people with "a very high intolerance for gluten, our baked goods wouldn't meet their need.... For people wanting to avoid it or with relatively low sensitivities, we've got that covered."

Like the co-op, Silvio's Organic Ristorante e Pizzeria also has limited space to prepare its gluten-free pizza crust and desserts but according to owner Silvio Medoro, they "use it consciously." To avoid cross-contamination, the staff triple washes the equipment using fresh cloths and soap. Medoro says they prepare the gluten-free items "two hours before starting the rest" of the prep work or "after everything has been cleaned up for the night."

Combining Bob's Red Mill Gluten-free Mix with rice, amaranth and tapioca flours, Medoro says that while his pizza crust is "three times more expensive" to make than regular wheat crust, it's worth it. His customers, he says, "love the crust and say it's the best they've ever had, and keep coming back for more."

His customers were actually the driving force behind Medoro creating a gluten-free crust. When this married father of four and grandfather emigrated from the Abruzzo region of Italy to the United States 16 years ago, he already knew the value of organic, pesticide-free food. Seven

years ago, he took that knowledge and applied to his then-new restaurant. He says, “It is nice to provide healthier food for my patrons, the same as I would put on my dinner table.”

Almost immediately after the restaurant opened, Medoro’s customers began requesting a gluten-free crust. Medoro experimented and by his second year in business, he had his crust. He says, “It has undergone a few different changes over the years as we realized some who are gluten-intolerant have broader sensitivity.”

Medoro, who has “a passion for pleasing any patron”, does recommend that if his customers order a gluten-free crust, to “please be patient if coming during a busy time so we can prepare it as safely as possible.”

People who are extremely gluten-intolerant can still eat out safely. The Gluten-Free Restaurant Awareness Program® (GFRAP) has developed a gluten-free certification program for restaurants and bakeries. Customers can go to [www.gluten.net](http://www.gluten.net) and plug in their city and state or zip code to locate restaurants in their area that have received this gluten-free certification. In Ann Arbor, these restaurants are The Melting Pot, Outback Steakhouse and Seva Restaurant.

While some people may approach a gluten-free lifestyle as just another food trend, it doesn’t really matter. For those many others suffering from celiac disease, gluten-sensitivity and autism, in the words of Coco Newton, “It’s no fad.” For them, going gluten-free is the way forward to a healthy life.