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My G-Free Journey

I learned about gluten the hard way. I wrote this book so you don't have to.

Most people with celiac disease, like me, have a story to tell. My hope is that in reading mine, and the pages that follow, you will be able to begin your journey to a better body and a better self—without all the heartache (and bellyache!) that I endured for far too long.

I grew up in an Italian-American neighborhood in Providence, Rhode Island. There wasn't a single holiday that did not feature "Mama's" (my grandmother's) famous baked penne along with a thirty-inch loaf of fresh Italian bread. After dessert, my whole family would even sit around dunking any remaining bread into our coffee. My cousins and I would fight over who got the "end" of each loaf. I remember watching Mama slice into the loaf, waiting to see if it was my "day" or not.

The smell of more toasted Italian bread and butter would wake me up the next morning.

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In my childhood home, it was all bread, all the time—and that was just the way we liked it.

While some things haven't changed in my family—we still have baked penne at every holiday dinner—other things certainly have. Since 2002, for example, my mom has made *two* baked penne: one for everyone else, and one just for me, a gluten-free version that hurts neither my stomach nor Mama's feelings when she looks over and sees a plate devoid of our traditional family fare.

"What do you mean you 'can't have the penne'?" Mama would question me after we sat down at her table. Over and over, I would try to explain to my grandmother, whom I love with my whole heart, and hated to upset at all, that "I am allergic to the pasta."

"Since when?" she would immediately shoot back.

The answer to that was a bit more complicated.

The trouble began in early 1997, during the spring of my sophomore year of college. I went on two big trips that spring. The first, over winter break, was a three-week-long immersion/teaching trip to the village of Red Bank and the city of Dangriga in Belize. The second, a spring training trip, was within the United States, with my Boston College softball team.

I had been feeling a little under the weather since Belize, and shortly after I returned from the softball trip, I was diagnosed with a severe bacterial intestinal infection—residue, the doctor said, from my trip to Central America. I landed in the school infirmary for nearly a week, with an immensely distended belly and a 103- to 104-degree fever. My memories of that week are hazy at best: I can recall little more than opening my eyes to see my mom standing over the bed. And Tim, my college sweetheart and now husband, looking more than concerned.

Once the initial infection had subsided, I was incredibly relieved, thinking I was finally in the clear. As an athlete, I couldn't bear the thought of being "off my game" for more than a day or two. Little did I suspect that my game was going to be significantly "off" for quite some time…

After leaving the infirmary, I was eager to get my body back on track again, but my digestive system was seemingly shot. My efforts to regain some of the muscle mass I had lost during my convalescence went nowhere. And though I felt ravenously hungry *all the time*, the only dining hall option that looked even remotely appetizing to me was soft-serve vanilla frozen yogurt with Rice Krispies mixed in. Food just didn't appeal to me like it had before.

Regardless, I continued to eat, though nothing satisfied my hunger—and everything seemed to throw my stomach into a frenzy. Each meal left me bloated and gassy, with sharp, explosive pains in my abdomen. No matter what I ate, I would soon be doubled over with cramps, awful indigestion, diarrhea—or all of the above simultaneously. I soon became all too familiar with the location of any and all bathrooms. Half an hour later, I would be too lethargic to move.

What on earth was happening to me? I had always been filled with energy before, and now I wanted to crawl back into bed five times a day. I was always in pain, always uncomfortable—especially around mealtimes.

Food, for the first time to this pasta-loving girl, had become the enemy. I was at war with my own body, and it soon became obvious that I was losing each and every battle.

Early on, I (and everyone around me) attributed my difficulties to stress, combined with a lingering infection in my gut. But as time went on and I made my first career move out of school—working as a footwear designer for PUMA—my health only worsened. I was barely able to get through the day without being sideswiped by extreme pain and overwhelming fatigue. I would retreat to the bathroom every ten minutes or so, locking myself in a stall and pressing on my belly in an effort to get control of the spastic bouts in my intestinal region. To keep my colleagues from suspecting that I was under the weather *all the time*, I would strategically walk a different way to the ladies' room each time, to avoid passing the same person twice in a row.

My commute to and from the office was even more distressing. I was constantly pulling over to the side of the road: Intense pain in my lower abdomen made it nearly impossible for me to sit up straight and focus on driving. The pain typically worsened throughout the day. I would get home from work and try different strategies to "move" whatever was causing the pain. After numerous trips to the bathroom, I could only get relief by lying on my side in bed.

"Stress" was just not cutting it as the explanation for my pain. I was twenty-three and supposedly healthy, but I wasn't. Was I simply doomed to spend the rest of my life in digestive agony? Such a bleak conclusion was not acceptable. My gut instinct (pun intended) told me there was more to learn.

I began to search for answers in earnest, but all my doctors' appointments stuck to the same script. An identical examination, followed by an identical diagnosis:

"IBS."

"Irritable bowel syndrome."

"IBS . . . It's becoming quite common."

Over and over again, that's what I was told. But the only accurate part of the term "IBS," in my opinion, was the "BS." Possibly, this diagnosis was "quite common"—because the doctors were *quite commonly missing the cause*. No mention of a food allergy ever came up, despite my repeated indications that I felt the worst immediately after eating. The doctors refused to see the connection between what I was eating and how I was feeling.

After more fruitless examinations than I care to remember, I was completely fed up. I was also in unbelievable pain around the clock. At that point, I was willing to try absolutely anything to get answers. After undergoing a "recommended" sigmoidoscopy—a minimally invasive intestinal procedure that yielded no clear diagnosis—I began to feel even worse. None of the medication I was prescribed for my stomach seemed to help, and I was tired of relying on doctors for solutions that never seemed to come. One doctor actually put me on an antianxiety pill. The reason? One of the

medication's side effects was that it numbed the stomach lining. The doctor had completely missed the mark.

That day set me, fuming, on a more determined search. There had to be a more direct means of treating whatever was going on with me. I refused to spend the rest of my life bouncing from doctor to doctor—or taking serious prescription drugs hoping for their side effects to kick in. If my own physicians were not helping me, I was going to get to the bottom of this mystery on my own.

From that day forward, I dove into research. I met with a holistic doctor in a neighboring state, who put me on a dairy-free, lactose-free, yeast-free program. Under his care, I went on a whole regimen of supplements and vitamins, and I lived off these special bars, which I was allowed to eat three times a day. I ate apricot seeds every day, as he told me they would help. The seeds were the most vile-tasting things I had ever tasted, but I kept on eating them in the hopes of feeling better. Even though they seemed to burn my tongue, I was willing to give them a shot. To my dismay, not even these extreme measures brought about any significant changes in my condition. Still, I resolved to do whatever it took. If that guy had told me to stand on my head for ten minutes every hour, I would gladly have done it for eleven.

As we were about to begin the phase of removing wheat from my diet, I applied to become a contestant on the reality show *Survivor: The Australian Outback*. Throughout the selection process, I hid my symptoms from the producers, saying nothing about the stomach pain that I was experiencing. As I went through extensive physical exams, I was amazed that no one could tell that the inside of my body was a complete disaster. I held back tears during one exam, which entailed the doctor pressing on my stomach. I held my breath as the doctor told me I was "good to go"... secretly counting the seconds until I could race to the bathroom.

Early the next morning, miraculously enough, I was picked as a contestant on *Survivor*, and so off I went, pain and all, into the Outback.

My Australian adventure was nothing short of life-altering. It was an incredibly rich, rewarding time—physically, mentally, and spiritually. Not surprisingly, it was the most physically grueling experience of my life. I was also given the most wonderful opportunity to investigate how my body works. Though exhausted on every level, I felt awakened. I learned how to live off the earth, to respect its boundaries, to work and bond with strangers, and to get by without any creature comforts. I also learned what mattered to me most, and what I relied on in extreme circumstances. One other remarkable thing happened to me Down Under, too: For the first time in about three years, I felt no pain in my stomach.

I remember thinking on multiple occasions, "Even though I haven't showered in thirty-nine days, I feel clean and pure." I was fairly certain that this sensation had nothing to do with my skin or hair or scent, and everything to do with my internal system. I was completely detoxified—without pain, without cramping or bloating, without any intestinal symptoms at all. I felt like I had before I had checked into the college infirmary so long ago. That person seemed to be nearly forgotten.

Shockingly, it took *starving* in the outback of Australia to feel like myself again. I remember joking that "I must be allergic to the United States." That was not the case.

I had lost about twenty pounds, but though my belly was empty, I left Australia full of answers. I left knowing that without God, I had nothing; that my family was the most incredible source of support; that I never again wanted to be away from Tim. I left knowing that for the past three years, my body had been fighting something that I was eating at home, and that if I didn't take it upon myself to figure out what that food was, no one else would do it for me.

Once I was back home, the scope of my quest narrowed.

Energized with the sense that I was on the trail of the culprit at last, and with a clean slate, I decided to reintroduce one item at a time back into my diet. But after thirty-nine days in near-starvation mode, I was absolutely ravenous, and I wasn't about to give up my

favorite foods without a fight. Soon, despite my best intentions, I had returned to my pre-Australia diet, and the consequences were dire. After the relief of having had my gut repaired, now I was suddenly feeling worse than ever, spending day after day in my room, unable to get out of bed, except to race to the bathroom.

They say that every cloud has a silver lining, and this horrible time finally clued me in to the cause of my long illness. I noticed that the moment I ate a starchy food, all the symptoms returned, and with even more fury than before. I went on the Internet to research what this reaction might mean, and soon after thought I had discovered the cause: *Wheat!* Out it went from my diet.

There were some days when I didn't feel so bad. Still, every so often, I would get tripped up after eating sushi or teriyaki chicken, and I couldn't put my finger on what was making me sick. After more and more online research, I stumbled upon some information about gluten intolerance and celiac disease. In 2002, *five* years since the onset of my symptoms, I diagnosed myself with celiac disease, an autoimmune condition triggered by gluten, the protein found in everything from pasta to bread to cookies. The only known treatment for celiac disease—which can cause acute damage to the small intestine and the digestive system as a whole—is a lifelong gluten-free diet.

Since celiac disease seemed to cover each of the symptoms that had been plaguing me for so many years, I set about eliminating all wheat, then barley, oats, and rye—the main gluten-containing foods—from my diet. In the beginning, the road was rocky: There was so much I still had to learn about gluten, and finding desirable alternatives was not as easy as it is today. I also found myself repeatedly rebelling against my self-diagnosis, and bingeing on gluten-containing foods just to prove that I could have them if I wanted to. Despite these repeated slipups, I nevertheless persevered . . . And my body would soon thank me.

Even after this breakthrough, doctors resisted my self-diagnosis. Though I was convinced that I had celiac disease—and armed with

plenty of specific examples to back up my claim—I still could not find a physician who would run the necessary diagnostic tests on me. Dismissing the theory that my diet could cure me, doctor after doctor kept on prescribing medications that did little more than mask my symptoms, if even that.

I began to wonder why so many doctors ignored my theory—and why I had to spend months learning about celiac disease on my own. There had to be a reason why such a common disease, which affects an estimated 1 out of every 100 to 200 people worldwide, was not on medical radar at all. The more I thought about it, the more I came to believe that there was no money in researching gluten intolerance, because there was no medication to treat it. No noise, no advertisement, no call to diagnose. Was this the result of some conspiracy? Neglect? Straight-up ignorance? Whatever the explanation, I had to struggle for eight long years before I found a physician who was willing to listen, willing to run proper tests, and willing to join me on the voyage that I'd been on since 1997.

Ironically, I had to travel all the way to Australia to gain real insights into what was hurting me in the United States, and when I moved to New York City, it was an Australian, Dr. Peter Green, the director of the Celiac Disease Center at Columbia University, who confirmed what I'd suspected for years. The moment he told me I had a disease—celiac disease—I enthusiastically thanked him. This reaction might seem a little bit odd, but I had been searching for a clear-cut diagnosis for almost a decade by then! I had consulted innumerable experts in the hopes of finding out what was wrong with me. For all those years I had waited in vain for an explanation that made sense. Dr. Green was the first doctor to look for the cause, not simply treat the symptoms. My gratitude to him is beyond measure.

Once Dr. Green confirmed that I had celiac disease, I became even more committed to what I called the G-free lifestyle. With Dr. Green's help, I deepened my knowledge of where gluten is found, and how I could most effectively avoid it. With the encouragement of my loved ones, I became more adept at shopping for and prepar-

ing delicious G-free alternatives to what had once been my favorite foods.

In no time at all, I found that living G-free wasn't so bad at all! In fact, I've never felt better in my life. I cannot imagine *ever* returning to eating gluten—even if I *didn't* have celiac disease. The G-free diet gives me the stamina and strength I need to manage my increasingly hectic life.

It turns out I have a lot of company! Apparently, I am not alone in benefiting from the G-free diet: According to the University of Chicago, 1 out of every 133 otherwise healthy adults in the United States has celiac disease—that's nearly 3 million of us.

But a gluten-free lifestyle can help countless others as well. People suffering from a wide range of diseases—from autism to osteoporosis, from diabetes to rheumatoid arthritis—can often benefit from this change in diet. Even people with no health issues have a great deal to gain by giving up gluten. The G-free diet can help with weight management. It can elevate your energy levels, improve your attention span, and speed up your digestion.

Whatever your motivation for going G-free—whether you have celiac disease or a gluten intolerance, or a basic desire to live a healthier, longer life—this book will help you achieve your goal. It's an all-inclusive, easy-to-read survival guide to living without gluten and *loving* it. I will define gluten in all its particulars, and teach you how to spot it in the unlikeliest places. I will also help you navigate social situations, and instruct you in the art of reading both food and beauty product labels. You will learn how to target gluten-free products, both at restaurants and your local supermarket, how to stay on your diet even in a foreign country, and even how to keep your kids G-free in the school cafeteria. By the end of this book, you will be equipped with all the information you need to get through the world without gluten. My guess is that you will only wish that you had done it sooner!