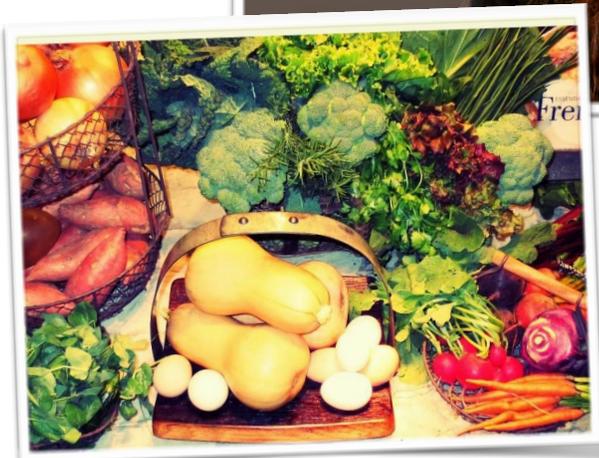
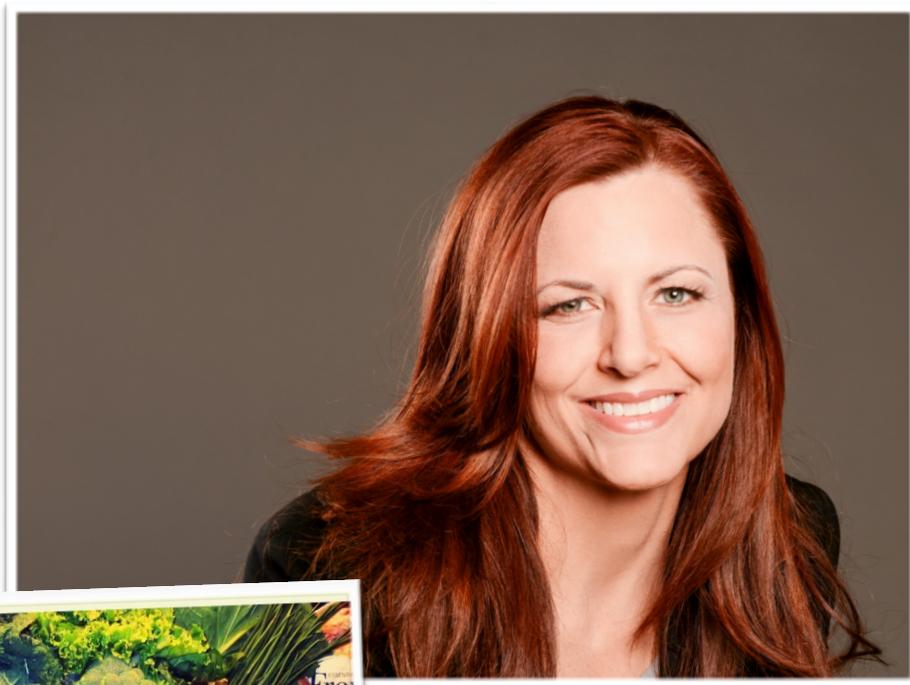


My Journey to Autoimmune Remission

Shannon Lea, the Autoimmune Foodie



PART ONE: AUTOIMMUNE SHIT SHOW

SEVEN AUTOIMMUNE DISEASES

I was 40 years old and I knew what I was going to die from. I was a successful professional. I had started my career 16 years earlier as a child psychologist. I also taught psychology at a four year university and worked for the university student counseling center. After 5 years, I switched careers and joined a Fortune 500 company as a sales representative. By the time I was 40, I had worked my way up the corporate ladder from sales to speciality sales to account management and was currently one of three national trainers for our oncology division. Although I loved the field of oncology, I was not happy in my career. But I felt trapped into staying with my company because my health was spinning out of control and I did not think I could find health insurance if I left my job.



ENDOMETRIOSIS

I was hiding in the bathroom stall, alone in the ladies room next to the study hall of my high school. My only hope was waiting for another student to come in. This would have been about 1987. Finally someone came in and I asked them through the stall door to please go to the office and have someone call my mother. Once again, I had bled so profusely, I had soaked my jeans with blood despite having on a tampon and an extra thick menstrual pad on.

My period had started at ten, along with monthly pain and heavy bleeding. At the age of 15, I was taken to the hospital for excruciating pain in my abdomen. Pain so bad I was given meds that caused hallucinations. That's when I started birth control pills to manage my monthly debilitating pain and hemorrhages. I remember first hearing the word "endometriosis" as a teenager and being told every year of my teen years, at my ob-gyn appointments, that I needed to "get married and have babies young if I was going to have any chance of having a family." I did not understand it at that age, but endometriosis had become my first autoimmune disease. Over the years, managing my endometriosis became a nightmare. I went from 7 days a month, to 14 days, to 21 days every month of extreme pain and significant bleeding. As an adult the bleeding and pain were enough to force me to stay at home at least 1-3 days a month. The pain would get so intense that even standing up was not an option. I actually had to have a calendar just to plan all vacations, girls nights out, and dinners for the one "good week" per month that my body allowed normal activities.

In February of 2002, I was taking a stroll through a park in Austin with my first husband. We had decided to move to Austin from Mobile. I

had secured a job transfer and we were visiting Austin for two days to find a house to rent. We were successful earlier that day and decided to take a walk and explore the town in the afternoon. I distinctly remember, as if it were yesterday, the “popping” sensation in my abdomen as I bent to pick something up. It was the most curious sensation I had ever experienced. It was as if a rubber band that had always been pulled tight had just been snipped. As we continued walking, I felt as if my insides were going to spill out. It was a sensation accompanied by dread. I kept instinctively grabbing my abdomen with both hands, my brain telling me that if I did not hold in the contents of my belly, that they were going to spill out. I honestly don’t remember if I had a lot of pain. I actually do think it was painful, but it was the sensation of “sloshing” and “imminent spillage” of my insides that dominates my memory.

It would become a recurring theme in my life: when something went very wrong with my body, it did not signal me to immediately call a doctor or go to an ER. So we flew home as scheduled the next day. I finally called my doc the following day to tell her something seemed very wrong. She told me to come in for an ultra sound that day. I will never forget the ultrasound tech taking one look at my tummy, turning white, putting the wand down, and walking out of the room without a single word. They are usually so stoic that I knew the behavior was not a good sign. Sure enough, the tech came right back in, with my doctor in tow. My doctor picked up the wand, took one look, and said I needed immediate surgery. Well, hell.

As it turns out, I had a major abdominal hemorrhage and my abdomen was full of blood and tissue. Hence the bizarre “sloshing” sensation as well as the sensation that things might “fall out.” I was immediately hospitalized and scheduled for surgery the next day. The

exact cause of that hemorrhage was never determined. Ectopic pregnancy was definitively ruled out. Bowel hemorrhage, large ovarian cyst rupture, and endometrial bleed were the top candidates. Regardless, once the blood and debris was cleared, the surgeons were able to see that I did have endometriosis. They ablated as much endometrial tissue as possible.

By 2007 my endometriosis was so bad that I opted for a hysterectomy. I was 36 years old. I had to have counseling because I was still of child bearing age. I was divorced and had a new boyfriend. Brandon and I had only been together a year, and he was only 26, but he encouraged the surgery because he did not want me to live in increasing pain and near disability. The counseling went something like this: "Are you certain you want this surgery? You are young and do not have children and your boyfriend is young. What if one day he decides he wants to have children and leaves you?" Yes, the doctor said that.

Undeterred, I opted for surgery. The hysterectomy provided major relief from the endometriosis and gave me back a pretty normal life. I still had significant pain, but the birth control pills and anti-inflammatories kept it at a manageable level for the first time. And thankfully, the bleeding stopped for good. No more days that I had to stay home in bed because no tampon or pads on earth could hold back the volume of blood that I lost for several days each month. To celebrate, I burned my tampons in a tiny bonfire in my outdoor fire pit. Yes, that happened too. After the hysterectomy, I would have to stay on birth control pills for another 8 years in an attempt to keep the endometriosis at bay, before I finally said goodbye to this disease forever. (And as I write this, Brandon and I have been together for almost 12 years. We are deeply in love and doting parents to our cat babies.)

NARCOLEPSY PLUS

By 1998, I could no longer hold my head up all day. My daytime sleepiness was too bad to cope with. I could barely get out of bed and I could and would take unlimited naps - laying my head down to sleep anywhere and anytime that I had even one minute of spare time. I was drinking what seemed like a gallon of coffee per day. I was four years into my first career as a practicing psychologist. Several years earlier in graduate school, I had studied sleep disorders and I always suspected that I had a hypersomnia disorder, meaning a sleep disorder that caused extreme daytime sleepiness. So I talked to my doctor and he referred me to the sleep disorder clinic at the university where I taught psychology part time. An evaluation at the sleep clinic that lasted 24 hours confirmed that I had three sleep disorders: Narcolepsy, Restless Leg Syndrome (RLS), and Periodic Leg Movement Disorder (PLMD). RLS and Narcolepsy had just become my second and third autoimmune diseases.

RLS is a disorder where your legs move when you are awake and usually at rest. The movement is voluntary and can be controlled. However, the compulsion to move is so strong that controlling it is difficult. PLMD is a disorder where the legs move involuntarily during sleep. These movements do not wake up the person sleeping, but they definitely disrupt deep sleep. My sleep study revealed that I was kicked back into Stage 1 sleep (a light, non-restful state of sleep) about 100 times during the night. Meaning my sleep was severely fragmented and not restful. It also meant I was basically doing gymnastics in my sleep all night, waking my partner up constantly by dramatically shaking the bed.

Narcolepsy is a vicious disease that essentially means you never get restful sleep. Sleep stages move from Stage 1 to Stage 2 to Stage 3 to

Stage 4 to REM. Stage 3 and 4 sleep are deep, restful sleep. REM sleep is actually an “awake” or active brain state when you dream and experience muscle paralysis. With narcolepsy, you can slip straight into REM sleep from an awake state without going through the four sleep stages first. Hallmarks of narcolepsy include dreaming within minutes of falling asleep, hallucinations, and extreme exhaustion to the point that you can fall asleep while driving or talking to someone. You can have narcolepsy with or without cataplexy. Cataplexy is the symptom people most associate with narcolepsy. Cataplexy is “partial or total loss of muscle control, often triggered by a strong emotion such as laughter” (from www.sleepfoundation.org). Not everyone with narcolepsy has cataplexy. Sadly, it is thought that narcolepsy is astronomically more common than we know because people with narcolepsy without cataplexy are under diagnosed and not being referred for sleep studies (the only way to diagnose narcolepsy).

I like the definition of narcolepsy from <https://sleepfoundation.org/sleep-disorders-problems/narcolepsy-and-sleep>: “People with narcolepsy feel very sleepy during the day and may involuntarily fall asleep during normal activities. In narcolepsy, the normal boundary between awake and asleep is blurred, so characteristics of sleeping can occur while a person is awake. For example, [cataplexy](#) is the muscle paralysis of REM sleep occurring during waking hours. It causes sudden loss of muscle tone that leads to a slack jaw, or weakness of the arms, legs, or trunk. People with narcolepsy can also experience dream-like [hallucinations and paralysis](#) as they are falling asleep or waking up, as well as disrupted nighttime sleep and vivid nightmares.”

Of course the technical definition does not paint an accurate picture of what a nightmare it is to have these symptoms. For example,

two of the worst things about narcolepsy are the vivid nightmares and hallucinations. Vivid nightmares haunted me for years both at night and during naps. There were times that, despite my exhaustion, I dreading sleeping because the nightmares were exhausting. Now that my narcolepsy is gone, it is interesting to me to realize that this is not normal. I simply assumed that normal everyday sleep included terrible and vivid nightmares.

But while nightmares can be very scary, they are nothing like hallucinations. Nightmares can be vivid, but they eventually fade upon waking. And certainly your brain knows the difference between a dream and reality. Hallucinations are a different story. Hallucinations are the same as reality to your brain. They do not fade and there is no “waking” up from one because they happen while you are awake. You cannot discern if they actually happened or not. So, if the hallucination is that an intruder is in your house or that a snake bit you, you literally have to check yourself thoroughly for a snake bite or you must check your alarm system and doors and windows to try to figure out if someone was really just in your house. Thankfully I have pets. I learned to simply look and see if they were still sleeping. I could be sure there was no animal or person in my room if my cats or dogs were still sleeping peacefully on the bed or floor. But I have torn my bed apart looking for snakes and have picked up the phone to call 911 because hallucinations are so convincing.

The experience is terrifying. If anyone would like to read a riveting memoir, there is a book called WIDE AWAKE AND DREAMING by Julie Flygare that perfectly describes living with narcolepsy. I literally had tears streaming down my face when I read about her hallucinations. I had NO idea that this was not normal and that other people did not experience this. It is interesting that I never reported these experiences to a doctor

because I had no idea it wasn't normal. Of course if I had reported it, I'm sure I would have been called crazy.

The best way to describe living with narcolepsy is to remember what it was like to pull an all-nighter studying for an exam or what you felt like when you stayed awake all night due to insomnia. You know how you are just so exhausted you want to cry and hide in a hole and sleep for just a few minutes? How your brain is foggy and the world is dull and you just keep yawning? How you fight falling asleep while listening to someone talking or while driving? That's Narcolepsy. Every. Single. Day. There is no relief. Ever. No pill can induce deep sleep. You don't get a day off from that feeling. Ever. For years. It's one of the most terrible diseases you can imagine. I am going to tell you a truth: If you can't sleep, you will never have normal health or a normal life.

On a final note, the treatments for Narcolepsy are their own special nightmare. First, narcolepsy usually takes years to diagnose. It is typically diagnosed as a psychiatric disorder, so I was given antidepressants and other drugs, to which I not respond well, for years prior to diagnosis. Even upon diagnosis, deep sleep cannot be induced with a pill so doctors threw a kitchen sink full of meds at me to put me to sleep and to wake me back up again. It became a merry-go-round of high dose stimulants, anti-depressants, bipolar drugs, anti-anxiety meds and sleep meds. On top of that, for PLMD, I was prescribed benzodiazepines, sedatives and a parade of medications for Parkinson's, all of which have significant and disturbing side effects including involuntary movements and anxiety.

Good times.

GASTRO DISASTER

I was in the ER being held up by two big burly nurses. I could not stand on my own, so they were trying to pin me by the arms up against an x-ray machine so the doc could see what was going on in my abdomen. It was the evening one day in August of 2002. It all started earlier that day when I had started bleeding from my rectum. The bleeding had been coming and going for hours and my insides felt like razor blades were eviscerating me. I'm a tough cookie and when something is really wrong with me, I tend to rationalize and refuse to go to the hospital. So just by consenting to the ER visit, I knew something was terribly wrong. I was currently debating this with the ER doc, who seemed to disagree. When the doc first came in, I begged him for something to relieve the pain. But the bleeding had stopped and he seemed unconvinced it had even happened. He said no pain killers would be given until I had an x-ray. But I refused to go to x-ray until he did something to stop the pain. He finally consented with a snarky, "Fine, but you are only getting a small dose of pain killer until we know what is going on."

Well, flash forward 30 minutes and I could no longer stand up from the powerful drug he gave me. Hence, the big nurses pinning me to the x-ray machine or I would have dropped to the floor. Holding me up was like trying to hold a noodle up straight by its arms. By the time I got back from x-ray, the profuse bleeding was on again and the the ER really got hopping. Apparently copious amounts of bright red blood squirting from a rectum gets an ER staff pretty excited. So I was prepped for a colonoscopy for the next morning which revealed "15 centimeters of complete loss of normal vascular markings, inflammation, and ulceration." In lay terms that's "6 inches of angry colon" y'all.

Diagnosis? "Severe Ischemic Colitis." The military term would be: CAFU:WKW (Colon All Fucked Up: Who Knows Why). I was put on a liquid diet of essentially nothing and lectured to rest and avoid stress with a warning that if it did not heal, I was looking at a colon resection. So I rested and ate liquids and eventually a repeat colonoscopy revealed that the ulcerations had healed.

As a funny side note, as I was waking up from the colonoscopy, the doctor who initially refused me pain meds came into the room and sat down on my bed. He said, "I owe you an apology. When you came into the ER, I thought you were a drug seeker. As soon as we gave you a relatively small dose of pain killer and you were almost incapacitated, I realized immediately that you had no tolerance to pain killers and were therefore were not an addict. I was wrong and I apologize for the assumption." I will never forget that because I learned two important lessons: (1) Stand up for yourself. I insisted on pain killer before that x-ray because I needed it and (2) an apology is one of the greatest gifts you can give or receive. That doctor was very rude to me when I landed at the ER. But he was humble and sincere when he apologized the next day. I have a lot of respect and admiration for anyone who is willing to acknowledge a mistake and apologize.

It was now October of 2002, two months post hospitalization. Thanks to the ischemic colitis, I had a new GI doc to call my own. I was at a follow-up and telling him that I was still having abdominal pains. Pain so bad that I would hold or rub my abdomen all day and often cry or double over from pain. So more tests were ordered and this time I was diagnosed with "severe gastroparesis," which means stomach mobility slows or stops. For the test, I had eaten a radioactive egg and after a significant amount of time elapsed the egg should have been digested.

However, my test revealed, "retained solid food contents, consistent with a severe gastroparesis." It confirmed that when I would eat, my stomach was not doing much of anything. After a small meal, I would feel full and sick for hours or days and eventually just throw up undigested food. I was also diagnosed with GERD, or acid reflux. I was prescribed a drug that promotes digestive movement. It was the second drug I took that caused frightening involuntary movements. After stopping that, I don't remember the doc giving me anything else to help, so I lived with gastroparesis off and on for another 13 years.

By November of 2002, a month later, I was still feeling terribly ill and having uncontrolled abdominal pain and IBS symptoms. I was sent for a gall bladder test which revealed that my gall bladder was not working properly. I was offered a surgery to have it removed, which I wisely declined.

After another month, in December of 2002, I was once again back with my GI doc telling him my abdomen was in exquisite pain. So I went in for my third colonoscopy in 5 months, plus this time, I got a bonus endoscopy. Diagnosis? "Severe gastritis." Do you love how all my diagnoses officially start with "severe?" As with the colitis and gastroparesis, no explanation was given as to why this happened and no suggestion was given as to how to stop it other than, "avoid gastro toxic medications." Ummm... ok. And I was told again that I had "Irritable Bowel Syndrome" with no additional information. Seriously? I mean, I get that my bowel is irritated. But WHY?

Beyond frustrated, I sought a second opinion from a new GI doc with a good reputation. He reviewed my history and examined me. I was on the exam table and he was having me do a series of different types of

sit-ups while reporting my pain level. He suddenly got animated and said he knew how to help me! I mean, he looked like a lightbulb had gone off right over his head as all the information fell into place. I was rippling with anticipation as he made this important announcement: "Your severe pain is from an inflammation in your abdominal wall muscle. I can give you a series of injections into your stomach muscles that will help."

Ummm....Next doctor!

So my parents generously paid for me to go to Mayo Clinic in 2003 for a complete GI workup. Now, if there is ever something in life that you do NOT want to do, it is go for a 9 day GI workup. Trust me. They essentially want to turn your GI tract inside out and have a good long look. But because that's not possible, they do ingenious and dastardly things to get as close as possible. Let's face it, there is just no fun way to have your GI tract investigated. On a funny note, I had two more colonoscopies that week and by the second one, I threw out the doctors orders for my colonoscopy "prep" and ordered my own preferred "prep" from the pharmacy. I marched right up to the counter and ordered my supplies with confidence, lol.

So, after 9 days, what were the findings? You know what's coming, right? "Irritable Bowl Syndrome." I mean here is a 32 year old woman who has been diagnosed with severe gastroparesis, severe gastritis, severe colitis, GERD and a gall bladder that is not functioning. And they have no idea why and they have no suggestions as to what to do about it, other than to give me a souvenir copy of the "Mayo Clinic Diet Cookbook" to follow. This did nothing for my symptoms. And now I've got "Irritable Person Syndrome" from the lack of answers or solutions!

So let's talk about celiac for a moment. By this time, all of the GI docs I saw were convinced that I had celiac. I had 5 colonoscopies and two endoscopies with biopsies and every time the docs were dumbfounded that I did not have any sign of celiac. Fast forward to 2013 when I was STILL having constant and severe abdominal pain as part of my everyday life. (Just imagine, 11 years of chronic and severe pain every day with no relief and no one knew why). So, finally, I went to a GI doc that was supposed to be the best around. He specialized in celiac and told me that there was no doubt that I had celiac and he explained that many doctors fail to diagnose it correctly. He scheduled me for colonoscopy and endoscopy with biopsies and assured me that when it was over, I would be diagnosed celiac. I will never forget waking up to see him with a puzzled and irritated expression as he said, "Well, you don't have celiac. I was sure you would. I'm not sure what is causing your symptoms." F*ck.

On a final note, as I review my notes from Mayo from all those years ago, I see that I did have indication of a "gluten sensitivity." On the Mayo Clinic labs, I had a flag for "Immunology AG, Gluten Sensitivity AG, Gliadin IgA." I was only told at the time, that I did not have celiac, therefore, I should NOT avoid gluten. I believe this will become critical to my recovery story and my success in leaving GI issues behind forever.



RESPIRATORY DISTRESS

I was sure I would die before I reached the hospital. Actually, that happened three times. On the first occasion I was 18 years old. We were visiting SMU as a potential college option for me. Dallas was my original home town and I was interesting in returning. I was given an antibiotic prescription earlier that day at a walk in clinic for strep throat. During a break in sessions at SMU, our family had stopped at the pharmacy for my antibiotic before heading for pizza. After placing our order, I took a pill with my soda. Before our pizza arrived, I had turned bright red and was having trouble breathing. There was a hospital around the corner so we raced for the car. By the time we got to the hospital, just minutes away, my lungs would not expand, I felt hot and trapped, and I started to panic. I was certain I would die, as I was not getting much air in.

I remember being on a gurney and doctors and nurses telling me I would be ok but I thought they were lying, I was so panicked and certain that I would die. I have no other memory after that. But the feeling of terror of that night lingers. My mother tells me that I had an anaphylactic reaction to the antibiotic and that the doctor told her my entire GI tract had blistered and that I might have lifelong trouble as a result. She says she will never forget her shock at the doctor telling her this and that she has always felt that this still effects me today. On a side note, that was my first of three anaphylactic reactions to antibiotics. When I woke up from my hysterectomy, my doc handed me a piece of paper with the name of a drug written on it. She said, "you had a severe reaction to the antibiotic we gave you. Put it this way, we were thankful you were already intubated and had an IV because it was bad." Yikes.

In December of 2012, I learned that you could drink dexamethasone. Funny what you notice in an emergency. I was fighting for my life and I was thinking, "I only thought dexamethasone came in pills." Earlier that day, I was so proud to finally have qualified for the "Level 8" ski school. We were skiing in Beaver Creek for the fourth year in a row and I was determined to conquer some tough double black diamond mogul runs. But for the first time ever, I seemed to have no stamina. I had to keep stopping on the slopes to catch my breath while the other ski students kept having to wait for me. My chest was tight and I was feeling odd. Never having had this experience, I kept pushing myself. Finally at the end of one run, I sat down and could not get back up. I urged my group to go on without me. They were worried, but I convinced them I was fine and that I would just pop into the lodge in front of us for a drink. They agreed to go up for another run and come back for me.

Unfortunately I was far from fine. I virtually crawled into the lodge, got some water, and collapsed. When they came back for me, I could not stand up. Perseverance is my middle name and I would leave a limb on the slope before quitting, so I was shocked that I could not will myself to get on with it. I called my boyfriend Brandon who was on the slopes elsewhere and he came to get me. It took about two hours to ski me home with constant rests. My chest was burning and I was having trouble breathing but I would not let him call for help. Getting dragged home by the Ski Patrol? Not happening. By the time we got to our hotel, I was wheezing and in respiratory trouble. Panic set in as my airway continued to restrict. Brandon had asthma and knew what was happening, so he coached me how to breathe and how to remain calm.

There was literally an emergency clinic at the foot of the hill of our hotel so he grabbed the car and rushed me there within minutes. By the

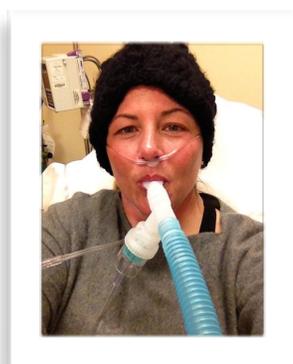
time we arrived, I was not getting any amount of adequate air and was once again convinced I would die. Tears were streaming down my face as I drank that first dose of dexamethasone and was given a breathing machine. That when I had the bizarre thought about its curious liquid form.

I ended up needing three doses of dexamethasone before the symptoms started to resolve. I remember hearing the doctor tell the nurse after the second dose, "We can only try to give her one more dose. Call for the medevac helicopter to be on standby. If the next dose does not work, we have to get her to the medical center." Those are NOT words you ever want to hear while you are struggling to breathe. Thankfully the final dose worked. I love the technical jargon on my report: "Diagnosis: Acute Asthma. Asthma: Asthma is a disease where the small air passages within the lung go into spasm and restrict the flow of air. Inflammation and swelling of the airways cause further restriction. During an asthma attack, these factors cause difficulty breathing, wheezing, coughing, and chest tightness." I would add that these factors also cause "extreme distress and terror of death."

The third time I thought I would die from not breathing was in 2012. I was flying 4-5 times a week for my job, and I was always running from airport to airport. On this day, I was hurrying to my plane at a fast walk, trying to be sure my asthma would not get set off from running. But just walking fast had set it in motion. I was coughing by the time the plane took off and it became uncontrolled in the air. We were only going from Houston to Austin, so by the time the wheezing really got going, it was faster for the plane to get to Austin as scheduled than to try an emergency landing anywhere else. The flight attendants were so nice and paged for a doctor (there was not one on board) and kept bringing me

water and talking to me to keep me calm. They wanted to call an ambulance to be waiting at the airport, but I'm stubborn and refused, horrified at the scene I was already causing. So I just kept taking hits off my emergency inhaler. When we finally landed, I went on "illness autopilot" which consists of denial and determination to ignore or downplay the seriousness of the situation and get through the crisis. I walked from the plane straight to my car and sped to the ER about 5 miles away. By the time I arrived, I was once again afraid that I was not going to make it. I was crying and praying not to die. Thankfully I made it. Again.

On a side note, I did not develop Asthma until I was in my late 30's, but I have always been plagued by allergies. I took allergy shots for 12 years and had two sinus surgeries to try to control my trifecta of misery: congestion, post nasal drip and chronic sinus infections. I'll bet I've taken enough antibiotics, antihistamines, and nasal sprays to fill a swimming pool. Eventually, I obviously developed asthma as well. After that, my chest always felt tight. Cold, exercise, dust, or even fast walking would set off an asthma attack. I was using an inhaler twice per day. I had 7 emergency inhalers stashed in my drawers and purses and I was using those emergency inhalers multiple times a week. It wasn't until 2016 that I was confident and courageous enough to throw out my last emergency inhaler, convinced my asthma was never coming back.



BUT WAIT, THAT'S NOT ALL

The lymph nodes in my groin had swollen to the size of golf balls. They were so giant and sore that I could not put on pants. I had been bitten by a tick that week and developed a rash and flu like symptoms. This was 20 years ago, but you know where this story is going. I was diagnosed with Lyme and subpoenaed by the CDC to provide all my medical details, as they were tracking the progression of Lyme in the US at that time. I took antibiotics and had my titers monitored for two years but the titers stayed high and I finally stopped antibiotics and forgot about it. No one was talking about "chronic lyme" back then and I had no idea that discontinuing follow-ups with my infectious disease doctor might have long term consequences.

So, how much does Lyme play a role in my health problems? I don't know. In 2015, I had a Multiplex PCR test for Lyme (negative), Lyme IgG/IgM Western Blot (Inconclusive), and IFA, B Burgorferi G/M/A test (Equivocal). Meaning that after thousands of dollars paid for a Lyme specialist and for Lyme tests, it could not be determined if I still have Lyme. Certainly, I had my first one or possibly two autoimmune diseases prior to getting Lyme Disease. But I may never know what role it is played in my subsequent diagnoses or what role it still plays today in my health.

At some point around 2007, I was diagnosed with autoimmune thyroiditis and started meds for hypothyroid. That was my fourth autoimmune diagnosis.

I was also diagnosed with psoriasis along the way, which effected my feet and toes for a number of years. That was my fifth autoimmune diagnosis.

LUPUS

I almost collapsed in front of 50 people. I was one of four national trainers for our cancer division. My colleagues and I were asked to prepare and conduct a week-long training session in Boulder, Colorado. It was July of 2011 and we were excited for this big opportunity. My first session went great and my colleague congratulated me on a great class. But by that afternoon, I did not feel well. And people were noticing. A parade of colleagues had approached me saying, "You don't look well. Are you ok? Maybe you need to lie down." My former manager was most adamant, saying "You look really ill. You should go rest and you may even need to go to the hospital." For sure, I felt really strange. Surreal even. But as you can guess by now, my stubborn won out. I'm no quitter. So I started teaching my second session. And it did not go well. I started losing touch with reality. I was sweating. The room was not staying still. My heart was pounding. My face was red. Then I forgot what I was saying. As I stood there struggling for words, the room tilted and I grabbed a chair to keep from hitting the floor. Then the room went dark.

I don't remember anything after that, but I know I was helped to my room. People say I looked like death. I know people checked in on me and begged me to go to the hospital, but I refused, of course. At about midnight, I woke up with "an elephant sitting on my chest." That is literally the most spot-on definition of a sensation ever uttered. My chest was being crushed. I could not breathe. Once again, I was terrified. I was sure I was having a heart attack and would be dead within minutes. I grabbed the phone and called 911. I threw on clothes and rushed downstairs. Once I was out of bed, the crushing sensation stopped, but the severe horrifying pain had bloomed like a mushroom cloud in my chest. I was so

scared. The hotel staff was so nice and talked to me to keep me calm. But the ambulance never came. The staff urged me to call someone I from my company to get me to the hospital. So I called my colleague and she rushed me to the ER. I later found out from the hotel staff that the ambulance never did come. Scary.

By the time we arrived, I could not speak because of the pain. My colleague explained to the front desk that I was having chest pain. The woman at reception calmly pulled out a blood pressure cuff and measured my blood pressure. Then she equally calmly picked up the phone and called a cardiac code. The next thing I knew, I was being rushed to the back. I had been at the hospital for about two minutes. All I could think to ask the woman who was rushing me to the back in a wheelchair was, "Don't you need my name? Insurance?" She looked at me like I was crazy and said, "Honey, let's worry about that later." When a hospital doesn't want your insurance card before rushing you back for treatment, you know your condition is serious.

I later found out that my blood pressure had been something over 200/120. It was higher than that but I don't want to guess so I'll keep it at that. Tests revealed that I was not actually having a heart attack but my pain was so intense that I was in danger of having one. They needed to get my pain down in order to get my blood pressure down, so they ended up giving me morphine while they ran tests all night. I remember my friend and the nurse trying to cheer me up at 2 am before the morphine kicked in. I was in the worst pain of my life and terrified. They started telling the funniest jokes but when I laughed the pain was excruciating. I burst into tears and begged them to please, please stop making me laugh. To this day, just thinking about that level of pain is traumatic. With morphine finally on board, the next thing I remember is

waking up the next day with my parents in the hospital room. I will never know how they got from Memphis to Boulder between 2 AM the night before and Noon of that day, but I'm so blessed to have parents that made it happen.

The hospital eventually ruled out that I had or was having a stroke but they were convinced that I had a clot - a pulmonary embolism or DVT (Deep Vein Thrombosis). A long line of specialists was called in for the next two days as the search for the clot was on. In the meantime, they started me on Lovenox which is a hard core anticoagulant that triggered bloody, projectile diarrhea and terrible bowel pain. Finally after two days of futile searching, and a lot of head scratching, they called in a cardiologist from Denver to run more tests. All this time, I was on the cardiac ICU which is its own special hell. You are watched and monitored 24/7 and if you so much as fart, they come flying in with a crash cart. Not to mention that in the Cardiac ICU, they serve you food devoid of flavor, color, or texture. Completely sodium-free-cardiac-unit-approved food is the equivalent of eating paper products.

Thankfully, the new cardiologist quickly determined that I had pericarditis and pleurisy, not a clot. Pericarditis is an inflammation of the pericardium, which is the sac surrounding the heart. As a complication, I also had fluid between the heart and pericardium called a pericardial effusion. I also had pleurisy, which is an inflammation of the lining (pleura) of the lungs. When the linings of your heart and lungs are inflamed, every heartbeat and every breathe are excruciating. It is a pain so severe that I can't describe it. Every heart beat, every breathe is torture. And, when you have fluid around your heart, that fluid is dense and restricts your heart from expanding. So your heart is trying to beat and is hitting a density it should not be hitting instead of an expansive muscle. So your chest feels

tight, your heart races, and you feel like you are on the verge of a heart attack with every heart beat.

I don't know what it says about me, but when the doctor came in and said we finally had a diagnosis and that my life was not in imminent danger, I did not immediately ask what pericarditis was. I did not ask what pleurisy was. I did not ask how to fix it or how long I would be sick. I did not even ask how serious it was. What I asked first was, "Can I eat something that's not on the cardiac ICU menu now?" Yes, seriously. The doc laughed and said yes, and my Dad took off to find me a burger. My second questions was, "Can I stop taking that damn Lovenox?" Again the doc laughed and said yes. Whew!

I was on heavy morphine in the hospital, as well as heavy duty pain killers for a long time after my release. So my memory is fuzzy on the details of that time, and my brain was not putting pieces together at the time as to why I had these issues with my heart and lungs. But the one thing I remember from this episode was the doctor saying upon discharge, "You need to see a rheumatologist when you get home." I remember thinking, "A rheumatologist? Why? I don't have arthritis. How bizarre." So I put it out of my mind for the next 6-8 weeks as I healed.

I was on STRICT bed rest. Absolutely NO getting out of bed expect to go to the bathroom. Period. Not even baths. I was sent home with several bottles of waterless body cleaner and told to use that to bathe. So I stayed on the couch or in bed - flat on my back - for weeks and weeks on end on heavy pain killers and anti-inflammatories as the inflammation and the fluid around my heart slowly, slowly, slowly started going away. Not that I would have gotten up anyway. The tiniest movement sent

paralyzing pain through my heart and chest and I remember trying not to breathe deeply or move a single muscle to keep the pain at bay.

When I was finally back on my feet, I went to see a rheumatologist. He ran tests and said I had fibromyalgia. That made complete sense. I had developed horrible body pain. Sometimes just touching me made me jump out of my skin like I had been hit with a cattle prod. I hurt all over and was miserable. So fibromyalgia became my sixth autoimmune diagnosis.

The rheumatologist also said I possibly had systemic lupus. Wait. What? What was lupus? I'd heard of it but had no idea what it was. He explained that I had the hallmarks of lupus: The pericarditis and pleurisy were lupus symptoms, which is why the cardiologist had told me to see a rheumatologist upon discharge. I also had ulcerations packed in my mouth and throat. I would lay awake most nights unable to sleep from throbbing ulcers. It was painful to eat or to talk much of the time. I was at my wits end, but had no idea how to stop them from forming. I was also losing massive amounts of hair. I could just run my hands through my hair and pull wads of hair out. And I had been running a fever for a year and my PCP was simply stumped. He ran every blood test available and finally diagnosed me with chronic EBV (Epstein Barr Virus).

Another odd thing was my interesting face rash. I would get face flushing on my nose and cheeks, sometimes in a rectangular pattern. Sometimes it looked like a lumpy rash and other times it was almost a pretty flush, but it did not look like any type of face flushing I had ever seen. My doctor could not tell if the rash was a lupus malar rash or if it was rosacea, so he asked me to go to my dermatologist the next time it appeared. So I talked to my dermatologist and she said, "Next time it

happens, just pop in and let me take a look.” So that’s what I did. The next time it appeared, I went to my dermatologist’s office. The nurse came out and said, “The doctor is at her station. Just pop back there so she can have a look at you.” I will never forget as I rounded the corner in the hallway to her station, she was standing there waiting for me. Before I could even say, “Hi,” she popped out with, “Oh, yes. That’s lupus, my friend. I’m sorry.” After that I had a follow-up so she could examine it further, but it was already determined.

At my next visit with my rheumatologist, he informed me that my ANA and other lupus blood work had come back positive. It finally made sense that, for a number of years, I had been having abnormal labs for my blood work. A few years prior, my PCP had been so concerned that he had referred me to a hematologist. Every time I went for blood work, something was off. I appreciated it very much when the hematologist finally said to me, “Something is wrong. I don’t know what, though. Anytime you have abnormal labs, there is always a reason. But the reality is that we don’t always know the reason and we don’t always know how to find the reason. But I will acknowledge that something is wrong and I’m willing to keep working with you to try to determine what that is. But I don’t know if or when we will find the answer.” Well two years after that conversation, I learned that lupus was the answer. It had been attacking my blood and causing abnormal findings. So, with the blood work back, I was one symptom short of an official lupus diagnosis. My doc started treating me for fibromyalgia and instructed me to come in every three months for complete labs and monitoring.

A few months later I went to the beach for a girls’ weekend. I had never gone away for several days with the girls and I was so excited. We were having an amazing time when we hit the beach the second day.

About an hour after plopping down our towels, I realized I was coming down with the flu. I was running a fever, getting chills, and I was horribly nauseous. I could barely stand up and my friends were alarmed. I don't remember anything else that day other than hiding in a dark room and asking my friend to bring me a Slurpee from the 7-11 next door. It was the only thing I thought I could hold down. I don't remember a lot of that trip, other than feeling as sick as I had ever felt in my life.

I recovered from the trip and, that same summer, I went with my family on our annual beach trip to Florida. Once again, I came down with what I thought was the flu and spent the entire week in bed in darkness. Shortly after returning home, it became more and more obvious that every time I was exposed to the sun, I felt like I had the flu. At that time, I had been promoted to manager for the state of Texas. I took my team on a retreat, but fearful of the sun, I scheduled a canoe trip down a river for twilight. The sun was setting and it was difficult to see. I had on shorts and a t-shirt. One of my employees suddenly says, "Oh my gosh, Shannon, you're blistering!" I looked down, in very fading light, and sure enough, I could see my legs were burned and starting to blister. I had been outside for 15 minutes in near darkness. I had developed extreme UV sensitivity.

UV sensitivity robbed me of life. I became freakishly sensitive to sunlight and fluorescent light. The bizarre thing about lupus UV sensitivity is that you react to both UVB and UVA rays. UVB rays (think: burn rays) are what give people tans or sunburns. These rays do not penetrate windows, so you typically do not burn in your car or house from sunlight. UVA rays (think: aging rays) will age the skin but they don't cause a reaction or burn. These rays will penetrate windows and fabric, you just don't realize it. With lupus, you can start reacting to UVA rays so you can burn sitting in

your car or house. I spent thousands of dollars having UV tints put on my home and car windows and bought two layers of curtains for every window. People would always say, "Your house is so dark. Please open the curtains!" But I could not. Even with tints and blinds and blackout curtains, if light was coming through, I was getting "zapped." So, every morning when light would filter into my bedroom, I would crawl out of bed and coat my body in zinc. Then I would get back in bed, pull up the heavy covers, and put a pillow on my head to try and stop the UV bombardment. UV light exposure meant fever, disease flare, and itchy painful burns.

Of all the symptoms of disease I have experienced, UV sensitivity is by far the hardest one for anyone to comprehend. If you have not experienced it, I simply cannot paint an accurate picture for you. But of course I will try: Imagine that if you can see sunlight - if there is any light filtering into your hours or penetrating the darkness outside - that light is filled with deadly poison and you need to flee. Sunlight becomes kryptonite and exposure in any dose will zap you of all strength. This is the most life-robbing, depressing thing I ever experienced. I grieved more over this symptom than any other. I had to say goodbye forever to walks outside, beaches, and sunlight on my face or body. I came to hate and fear the sun above all else. I relished darkness and only felt my anxiety drain away when the sun was long gone for the night. I became a recluse and only felt coolness and normality at home in darkness. I cried more over losing my entire "daylight life" than I ever cried over anything. In Part 2 of my story, I will share a story of how the lowest point in my disease history was related to this symptom.

UV sensitivity meant I even had to buy an all new wardrobe of UV protective clothes, arm covers, gloves and headwear from special

companies that cater to people who have lupus and skin cancer. I literally ONLY wore clothes from these catalogues. I mourned by lost wardrobe, but I had no option. I was still working and my job necessitated that I work outside at least 3 days per week. But, despite wearing heavy zinc, hats and special clothes, I ran a fever every single day. I literally collapsed in near delirium after work each day during this period. When I was not working, on the weekends, I slept most of the time and I did not leave the house until it was pitch dark.

I am thankful in hindsight that, not long after this started, I lost my job. At the time, this was the lowest point in my life (second to my divorce). But I was thankful that I could finally get away from the sun. That year I did not leave my house, from June through August, a single time until after it was dark. I was sick all the time and getting sicker. And I seriously asked Brandon if we could move to England. Sadly, UV rays are also in fluorescent lights, so I would burn at stores, or when using my computer or phone. My face would blister just using an electronic device. Beyond the fevers and burns, which felt like itchy rashes or chemical burns, the sun was flaring my lupus out of control.

Photosensitivity was the final symptom needed for an official diagnosis: Systemic Lupus Erythematosus had become my seventh autoimmune diagnosis. I was immediately started on Plaquenil to try to stop Lupus from progressing. To understand lupus, let me first say that autoimmune comes in two flavors: organ-specific and systemic. In organ-specific disease, the immune response is directed against one organ such as the pancreas in Type I Diabetes or the thyroid in Hashimoto's thyroiditis. In systemic autoimmune disease, the autoimmune response is directed at multiple targets. In lupus, the immune system can turn against the heart, lungs, kidneys, GI tract, salivary glands, liver, kidneys, thyroid,

brain, blood components, the linings of the body, or even your own DNA. So I had to go every 3 months for blood work to monitor for early signs of my immune system mounting an attack on any of these organs.

I started dreading those check ups. I would lose sleep waiting to see what my lupus was going to attack next. During that time, Plaquenil was lowering my immune defenses and I became a walking germ absorption pad. If I walked outside and someone sneezed a mile away, it would whisk on the wind and up my nose in 2 seconds flat. I was sick all the time.

By 2014, I had gained a lot of weight and my hair had started going gray. It was coming out by the fistful and clogging all the drains. I was horrified to go in public because it would fall out all over the place and get on people. To cook, I had to have a hair net. The ulcers lined my mouth and throat relentlessly. I could not set foot in daylight. I had full body pain and could not tolerate to be touched. I ran a constant fever. My brain no longer comprehended anything. My joints hurt too much to move. My right elbow was so degenerated that my orthopedic doc said my right arm must be immobilized for 6 weeks in a sling or he would put it in a cast. I developed neuropathy so bad that I had no feeling in part of my hand. And my blood work showed progressive lupus. My doctor was talking about steroids and chemo. I looked up lupus on wikipedia and under the noted people with lupus, almost every entry ended with "died from complications of lupus." The thought that haunted me day and night was, "I am 40 years old and I know what I am going to die from."

**2011
Lupus Malar Rash
Sometimes Pretty,
Sometimes Not**



NOW WHAT?

At the height of my symptoms, in July of 2014, Brandon and I decided to go on a vacation to Seattle and Portland. We had an amazing time. We considered ourselves “food tourists” and enjoyed hitting as many coffee and foodie stops in Portland as possible. We also walked for miles all over both beautiful towns. It was our perfect vacation: an urban outing filled with daylight, food, and movement. Unfortunately, such simple pleasures were too much for my body to bear. Upon our return, I was so sick I simply stopped getting out of bed. My body could no longer function in any way. I was done. I felt hopeless. I was out of fight. My defining characteristic is determination. Call it stubborn, call it perseverance, call it single-mindedness, I do not quit. As you can see from my story, I’m no wimp. Twice I lost so much blood (from my ulcerated colon and my abdominal hemorrhage) that upon finally going to the hospital, my blood pressure was dangerously low. Twice I was sternly lectured about getting to the hospital sooner when something catastrophic happens to your body. I just don’t give in easily.

I had navigated six autoimmune conditions over 30 years. And I was phenomenally successful. I had been the psychologist who helped abused children. I had been the psychology teacher with the highest student ratings at a four year university. I had climbed the corporate ladder from sales person to account manager to corporate trainer to being one of only 2 female managers in my company, managing the second most important territory in our oncology business. And all the while battling endometriosis, gastrointestinal chaos, asthma, narcolepsy, fibromyalgia, lyme, and the long onset of lupus. I could have declared

myself disabled from anyone one of these diseases. Narcolepsy alone is enough to keep anyone from having any type of normal life.

My motto has always been "obstacles fear me." I will knock down, go around, or go over any obstacle in my path. But the harder I tried, I could not defeat lupus. By August of 2014, I felt defeated. I could not go on, literally. I was physically out of energy. For the first time in my life, I admitted defeat. I knew deep in my soul that lupus would kill me and I was afraid it would be soon. I cannot describe the depth of my despair. Lupus was the obstacle that I could not overcome by sheer will. Putting one foot in front of the other was too hard to do. As I write this, I am crying. Because to write this, I have to put myself back there. And it was a desolate place to be.

My job was gone after 15 years. I was too sick to work. I was 43 and disabled. I looked 20 years older than I was. I was overweight and my hair was dry and falling out. I could not imagine my boyfriend still being able to love someone so sick. I could no longer take care of myself or my house. I was a recluse. I had no meaning or purpose. I thought, "So this is it. I had a meaningful career 15 years ago. And then I spent the last 15 years chasing achievement at a company I did not like. I have no joy in my life. I have neglected my friends and family to chase a career. I have never followed my dreams. I have completely neglected Brandon and our relationship. And now my life may end with nothing meaningful to show for it and no hope on the horizon for a second chance." I was literally living in the dark, hiding from the sun. But my thoughts were dwelling in much, much deeper darkness. It was an abyss. I was falling with nothing to grasp onto and no bottom in sight.

THE BEGINNING OR THE END?

"I bought this for you in January because I love you and I care about you and I want you to get better. I feel this is the right time to give it to you." It was August of 2014. We had returned from the cruise and I was hopeless. Curious as to what Brandon would buy me and keep from me for 8 months, I was puzzled. He pulled out a book and continued, "I don't want to upset you. But I feel this will help you." It was called "The Wahls Protocol: A Radical New Way to Treat All Chronic Autoimmune Conditions" by Dr. Terry Wahls. He was right, my first reaction was not positive. I was defensive and skeptical. But I was also defeated. My feisty nature was gone. So I simply said, "At this point I'm willing to try anything."

FEAR

But he knew me so well. That morning after giving me the book, he headed to work. Despite my defensive perimeter, I sat down and started reading. Dr. Terry Wahls had secondary progressive MS and developed a protocol to heal herself at the cellular level using food and functional medicine. She went from a wheel chair to reclaiming her health. Theoretically it worked for any autoimmune disease, by rebuilding every cell of the body over time. Could it really work? By the time Brandon returned home for work, I pledged to give it a try. There was a glimmer of hope. But my heart, soul, and my mind were angry and rebelling.

COURAGE

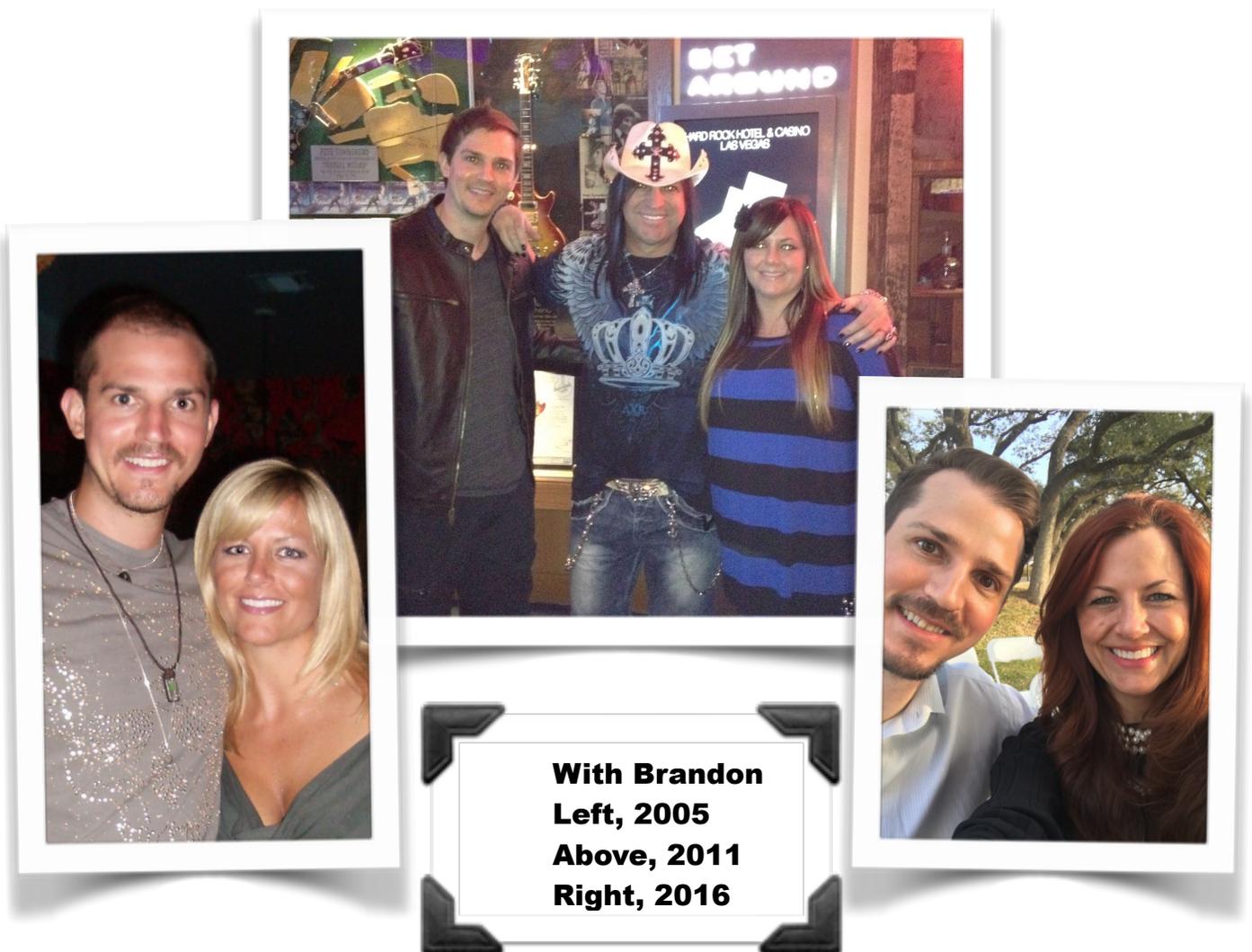
I was still stewing over the book, even as I pledged to try it. I know myself pretty well. I knew I had a deep fear of something that I could not put my finger on. I knew that I needed to process it out loud with Brandon to name it and deal with it head on. So we talked for a long time that night. And we got to the root of my fear: the most terrifying thing I could imagine was HOPE.

That's right. I was fearful of hope. What if I allowed myself to believe healing was possible and it wasn't? Wasn't it better to have no hope than to have hope dashed? I was already moving through the stages of grief. Why renew hope only to have to face the grief cycle all over again? And to add to that, I resented that I needed help. I had always figured out how to win every fight. Why could I not win this on my own? I felt like a failure. And another thing, if this worked, why had I never heard of it? Why hadn't any of my dozen doctors ever mentioned this?

But Brandon's wisdom and courage infused me. And deep, deep down, there was something else. Like that tiny Who from Whoville that only Horton could hear, there was a tiny but distinguishable voice crying out from deep within me. It was not to be extinguished: "Don't give up." It had taken me throwing in the towel to hear that voice that was still within me.

I was a fighter after all. I had been knocked down many times in life. But I knew one thing: It's not about how many times you have been knocked down. It's not even about how many times you have been knocked out. It's about how many times you get back up. And despite my time in bed in despair, I knew deep down I would never give up or give

in. And I knew that Brandon had a genius for discerning the right path to health. If he said The Wahls Protocol was the way, I knew he was right. I had found my voice of courage from deep within and now I had the right tool with which to fight back. If Brandon had given me that book anytime prior to August of 2014, it would have gone in the trash. No doubt about that. But his timing was perfect. I had an ally. It was time to find my second chance.



COMMITMENT

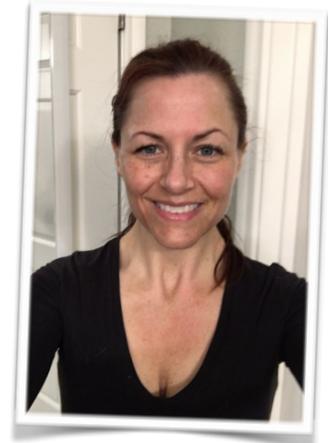
I bought a brand new teal leather journal just for this new commitment. Actually, I made two commitments and wrote them down:

1. I would try the Wahls Protocol for 30 days to see what happened. If I felt any better at all, then,
2. I would do a three year trial of the protocol.

I'm going to be honest: I hoped it would not go well so I could say, "I told you so," give up on the diet, and go back to my misery. I secretly wanted to PROVE that I had been right: this was NOT going to work.

Well, I did feel better in 30 days. So the commitment for the three year trial was on. And as I write this, that 3 year trial period ended several months ago. The past three years have been a wild ride. I simply could never have imagined the events that would unfold during that time.

See the continuation of my story in **PART 2: AUTOIMMUNE RECOVERY** to read about my how I clawed my health back from the abyss and created the miraculous "Second Chance Life" that I never would dreamed was possible just a few short years ago.





**Sick & Inflamed
2010-2014**

**Healing
2016
45 Years Old!**

