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**“Zero Tolerance, What’s this?”
My family’s testimony of health through diet.**

By Antoinette Bunce

I have discovered in my family, in the last year, some helpful information that I felt it my duty to pass on. Everyone biologically related in my immediate family, with the exception of our adopted daughter, has been confirmed as having Celiac Disease, including my husband! This means that my biological family has 100% prevalence. Plus there are six other relatives who have been confirmed on both sides. I would say this is pretty high, for a disease that is still considered to be “rare”, and just proves the hereditary component of this condition. If it hadn’t been for my infant daughter and high persistence on my part to hunt out doctors who would listen to me, she would have surely fallen through the cracks. It was obvious to me, she had Celiac Disease. At the time I had no idea every one of us had this, not even my self, but had a high suspicion. I suffered miserably from countless related conditions. For Celiac Disease is known as the “Great Mimic” of many gluten related conditions. The saddest was four miscarriages and years off feeling miserable, with no explanation or solution. On the most part most of my suffering ended at the age of 37, my husbands at the age of 38. This confirmation was given by our favorite doctor in Colorado Spring, Colorado, Scot M. Lewey D.O., who is a board certified gastroenterologist. My infant daughter is truly a messenger to her family, for if it wasn’t for her, we surely would still be slipping through the cracks with our laundry lists of problems. Our children are fortunate to have been diagnosed so early in life, before it took its toll on their bodies. Thankfully we didn’t have to die prematurely like many family members that walked down this ugly path before us, all who had symptoms, yet were devastatingly missed, for undiagnosed this disease doubles ones morbidity.

During our first year of eating our strict gluten free diet, we struggled to be symptom free. Our infant daughter had the most problems. We simply did not have the success promised by our strict gluten free diet. Driven by my daughter’s complications this is when I started my search for a better solution. I recently had many conversations with the Executive Director of the Celiac Sprue Association of the USA, Mary Schluckebier: (1-877-CSA-4-CSA). I told her of our struggles and discovered that they are suggesting ZERO Tolerance for all of us out there who have been confirmed with this condition, regardless of many of us claiming degrees of sensitivity. At this time she is saying that to go into remission: “Our organization believes in a zero tolerance approach, that is completely removing all wheat, barley, rye and oats, as well as all of their derivatives, from the diet of those affected by Celiac Disease and Dermatitis Herpetiformis, due to the fact that tolerance is so individual, that the only risk-free choice is total avoidance.” She went on to also state: “...there is a necessity of eliminating all sources of amino acid sequences known to evoke an immune response in people with celiac disease.” I went from there with my search for knowledge and learned so much.

Our two children suffer from Dermatitis Herpetiformis, a gluten sensitive rash, which only occurs with the ingestion of gluten containing foods. This condition has been a mixed blessing, for they appear to be very sensitive. For when they accidentally ingest just the smallest amount of gluten, just molecules, we get to know it with this awful rash. I still had unexplainable, yet occasional bouts of diarrhea, and irritable bowel like symptoms, accompanied with irritability, achy joints, depression, and even headaches or what I would like to call “foggy brain syndrome”. I wanted it to end, for this was not what I thought recovery would be like. I was desperate for my children’s suffering to stop

also. So this is what my family did that worked for us. After eliminating everything that could be the culprit of our symptoms, I unknowingly created the “paleo diet”, also known by some as the “garden of Eden” diet. Our symptoms all but vanished. I was surprised to learn that the diet I thought I had discovered had a label and that there is much information supporting its health advantages. In this diet one eats only whole foods such as, vegetables, fruits, meats, eggs and nuts. In order to stay well, I discovered through elimination diet, that we had to cut out all the grass grains, plus dairy. Every time we strayed from the paleo diet we suffered the consequences of having our celiac symptoms revisit us. Even though we felt much better eating this way I wanted to know why. In my quest for a solution I would like to share five reasons supporting what I discovered to be true about my family, and to why some of us diagnosed with Celiac Disease may not get the results we are wanting from our gluten free restricted diets. There is likely more, but these pertained to my family and our testimony. What I have discovered is disturbing and disappointing in the least:

My children continued to be symptomatic, not going into remission; our daughter continued to look and not grow well. Our son was growing well, yet would simply “just” get this rash and acted irritable and had recurrent diarrhea all the time. I was beginning to think it’s a myth about degrees of sensitivity, wondering if they are just fortunate to know when they are being “poisoned” and the majority of us like myself and my husband just don’t get to know it, but are affected never the less. After countless phone calls to many companies, this is what I discovered. Several companies who claim to make “gluten free” foods (some that are in the safe section of our product guides) are cross-contaminating as high as 200 parts per million, and at this time there is no way to test for ZERO. At best there is an Elisa Gliadin Test that can test down to 10 parts per million, yet there are no laws stating that a company has to do this to claim “GLUTEN FREE” on their label! At this time the only standard that our country goes by is the “Codac-Alimentarius”, which is an international standard, that is allowing as high as 200 parts per million. Lastly, the grain standards of the USDA, at this time is allowing as high as 5% contamination with weeds and what ever else, right there in our “gluten free” crops. At this time our country simply does not have a standard to keep the amount of cross-contamination at Zero.

I also discovered that our labels that list our food as “gluten free” are a catch all phrase. Research demonstrates that Gluten contains several dangerous proteins, the most common talked about are, GLIADIN and GLUTENIN. This means that if it is labeled “gluten free” it does not mean that it is glutenin free. For example, rice is not glutenin free yet is known by all to be “gluten free”. Most of us with Celiac Disease know that we definitely have a clear problem with Gliadin, which we all know is in wheat rye, barely and oats. You may have discovered this when you had your celiac panel drawn. Yet some of us have had questionable tests results when our blood was drawn, yet still tested positive for the Gold Standard EGD and biopsy of our small intestines. In my family we had negative looking celiac panels, meaning that it was not clear if we had a problem with Gliadin. Further examination showed that our two children where not IgG or IgA deficient, which can sometimes give false negatives. The doctors where surprised when our intestinal biopsies came back positive for Celiac Sprue. Needless to say Scot Lewey D.O. is one of the few doctors that has confirmed and validates that there are many people out there with negative looking Celiac Panels that still have CD. When I was confirmed, he told me he had personally confirmed over a half a dozen patients with CD who had negative celiac panels. At this time there is no blood work to accurately test for glutenin sensitivity. Better tests clearly need to be made. By doing an elimination diet I now know that my family clearly has a problem with most of the “gluten free” grains and gluten containing grasses. So it is either due to cross-contamination or an immune reaction to the protein glutenin or something else they we may discover in the future. Needless to say, complete avoidance to all grass grains is the only way we stay asymptomatic in our house.

At this time it is also being researched to see if some of the amino acid sequences known to evoke an immune response may be getting into our dairy and eggs. The verdict is still out; there is no definitive proof yet. Yet I would like to add, that in Australia right now they now have “gluten free” eggs, which they sell to their celiac community. Plus I would like to add, that I was told by my child’s pediatrician, nurse and lactation consultant, that if I was to continue breast feeding and giving my daughter the countless benefits of human milk, that I had to make certain that I was gluten free, in order for my milk to be gluten free. Why would this be any different with a chicken or a

cow producing our eggs and milk? We now have found eggs that are not fed gluten containing grains and are doing much better with them. We have yet to have success with milk and call it milk/dairy intolerance/sensitivity, but know it has to be avoided to feel are best.

It is also known that several of us with Celiac Disease, like my family, may also have other food intolerances that have to be ruled out before giving up and throwing in the towel and accepting it ones fate to never feel well. Many references I used, including, what the CSA-USA has to say, suggests elimination diets to discover the culprits and then rotating what we do eat for best results. It is easy to get stuck eating the same stuff day in and day out, but this needs to be avoided to have best results. At this time it appears that our problem with diary goes far beyond just lactose intolerance known to be related to Celiac Disease. I do believe it's the proteins in it, be it related to gluten amino sequences, or casein (a milk protein that is known to cause some people trouble). At this time the current tests for food intolerance are expensive and questionable, we have yet to go that route, yet some have claimed them to be very helpful.

Lastly according to a few doctors and research scientist in our world, lectin can also cause people some serious health problems. Surprisingly this protein is also known to cause intestinal damage and celiac like symptoms also. My family is still experimenting with some of the foods that contain Lectin. If you would like more information on lectin, this information can be found on the web. Some of this information is questionable but may be found to be legitimate and helpful to us and others.

On the most part my family is thriving and is having surprisingly wonderful results eating, the PALEO DIET. At first it is difficult, after years of being brain washed into believing you have to have x amount of servings of grain and milk, it can't help but make one feel a little deprived and sad at first. We clearly felt deprived, and even went through "withdrawal" and cravings, yet have now clearly discovered that the benefits out weight the cost of feeling lousy all the time. After going through the changes, food even tastes better, and the cravings do go away! We are slowly discovering what other foods are "safe". My infant daughter who once had failure to thrive, was only gaining three ounces a month, and not developing properly, may still be thin, yet by eating this way has shot up to the 80th percentile in height and is now developing normal and is healthy! I am also proud to announce that our son remains stable at the 90th percentile in height and all his, symptoms/behavior problems have vanished. Their height is a surprise to our families since there father only made it to 5 foot 8 inches, I am not tall and they come from a lineage of short people! When it appeared at one time our daughter would be short and petite, we use to say, being short was hereditary. Now we know, so is Celiac Disease. Their pediatrician, in Monument Colorado, Helen Danahey M.D. has been pleased with the results, and has been a huge help with offering information about nutrition, being of great support, plus validating our children's condition and our new way of living. By eating the paleo diet, we have discovered some very interesting, healthful, and very tasteful recipes out there to try! It has been far from boring or glum to say the least. It's a whole new world and culture to be discovered.

Until better information gets out there, or there is a cure, the healthful Paleo Diet may be the only alternative for some of us. In the mean while many of us are going to have to wait patiently for labeling to demonstrate zero parts per million when labeled "gluten free". We also will have to wait for better standards and laws to be passed by congress, for what "gluten free" truly means in respect with zero tolerance. For right now too many companies that are producing our "Gluten Free" foods, flours and starches, are disappointingly not complying with ZERO tolerance and may need to be avoided. In our home we had to put our "gluten free" product guide aside, for when we made phone calls we discovered this HUGE problem. If more people would call these companies and ask these questions, they will see a need to make changes sooner.

Needless to say, this may also mean that it may be safer for many of us to dine in. I know this is true for my family. If we are now learning this, I can bet the restaurants have yet to catch on. I know for a fact that many of our Restaurants that have a "Gluten Free" menu are clearly yet innocently, cross-contaminating by using these products. This also means that some of our books written with suggestions on to how to live a healthy and gluten free life,

written before this information on “Zero Tolerance” came out, may now have to be questioned. For I read in one of these books, that supports the health of celiac children, that Frito, Lays and Ruffles are “gluten free” and safe, when I know that they are not in my house. Plain and simple, “Zero Tolerance” is going to take time to catch on for all of us. I do not believe anybody is trying to do harm intentionally, but until progress catches up with us, the paleo diet is a solution that works. At this time we clearly have to take the responsibility of our health into our own hands. Only in this way we will feel better sooner.

If you are celiac and would like to talk to me feel free to write me. I am currently writing my book, and I would like to hear from you if you would like to share your story in the section “testimonials from others”. I know from personal experience how isolated and confused you may feel, you can e-mail me at: ajbunce@msn.com.

May it be known that the contents of this article has been read and approved by Scot M. Lewey, D.O., FACP, FAAP; from Colorado Springs, Colorado.

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Do various topic searches on: “paleo diet”, “cross-contamination”, and “symptoms of Celiac Disease”.