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“Neither domestic cereals nor milk from hooved animals is “natural” food in an evolutionary or physiological sense....If there is a single complex of events responsible for the deterioration of human health and ecology, agricultural civilization is it....”

-Paul Shephard, Coming Home to the Pleistocene

“Celiac Disease: Misconceptions, Education, and the Steps to Changing Your Life”

Celiac Disease is described as an inherited autoimmune disease that is triggered by eating foods that contain gluten, a protein that is found in wheat, rye, and barley. Specific tests are done to spot this deficiency in the body. Most common are the uses of blood tests, which tests for specific antibodies found in gluten and a small bowel biopsy. The biopsy can take small samples of the tissue to determine the presence or extent of the disease in a person. Many newly diagnosed individuals who go through these tests and then are told they have Celiac Disease can generally feel a sense of relief, because the therapeutic option for Celiac Disease at the present time is to permanently exclude gluten from their diet, and not be put on mind or body altering medications.

As I have come to learn throughout the semester through readings and case studies, Celiac Disease in fact shows itself early in many different ailments and manifests in more problems than one may ever think, when not properly treated. Why the disease goes so unnoticed though, is still a mystery. Currently approximately three million Americans are affected by this disease, but fully 97% of that figure still remains undiagnosed. For certain persons, it can feel like a common stomach ache, nausea, or

other abdominal discomfort symptoms. Very often a person may experience both ends of intestinal discomfort which makes it difficult to properly diagnose as well. These recurring feelings may lead someone to a gastroenterologist's office, which in many cases may lead to a misdiagnosis. Many times, the symptoms will warrant diagnoses such as Crohn's Disease, Colitis, or Irritable Bowel Syndrome and go untreated for Celiac's. The topic of concern with these misdiagnoses are the long term side effects one can develop from Celiac Disease, and if left untreated can lead to nutritional deficiencies, neurological disorders, and even cancer. An in depth description of potential side effects include, but are not limited to: Gastrointestinal issues, persistent anemia, weight loss, infertility. Autoimmune disorders can manifest in stomatitis or ulcers in the body, arthritis, thyroid diseases (Graves Disease), and various skin disorders. Lastly, and on an even more serious level than the first two groups of side effects would be the possibility of developing Malignancies such as Non Hodgkin lymphoma, Esophageal carcinoma and Papillary Thyroid cancer. Of course, these are the most serious of side effects if Celiac Disease is not treated or spotted early enough where the sufferer won't continually cause damage to his or her self while thinking they have some other issue.

In my own personal instance, I was another pre-teen who was not eating properly and always feeling sick and pale, but after numerous trips to the doctor, was simply diagnosed as a "hyper, typical kid who didn't want to eat much". As those around me began to grow or gain weight, I stayed the same, if not lighter, which then became a cause for greater concern. After going for numerous tests and taking medications I may or may not have had to take, I had been diagnosed with Crohn's Disease, which was in me, an inflammation and irritation of the small intestine, the same exact general area that

Celiac Disease also resides. For a span of ten years I was taking two different medications prescribed to me, in hopes of slowing down the development of the Crohn's. What was not known at that moment though, was while they were attempting to combat this diagnosis, I had gradually become sicker as I would continue to eat meals constantly with the gluten ingredient, feel sick, but pass it off as Crohn's Disease in this case.

As a twenty-two year old I believed at that point I had enough of constantly feeling sluggish, enduring the mental stress and anxieties that had developed with constantly feeling sick and not wanting to be out for fear of sickness issues taking place. As symptoms progressed again, I visited a new doctor, who thought a little bit differently of these symptoms and had me tested for something new that was being noticed, a disease called Celiac's. Blood tests showed that I was positive, so I immediately began a gluten free diet. At the time, in 2000, gluten free food was not as prevalent as it is today. Now you can walk in to any Starbucks and find a rack of Gluten Free cookies or snacks, and many specialty food stores are loaded with aisles and freezers that cater to those with a gluten sensitive diet. Testing new foods was a horrible idea, but what I did not realize that I now do, is that most foods, in their plainest form, are gluten free. Besides eating anything wheat-filled, I was still OK to eat grilled chicken, hamburgers had to be eaten without the bun, but they could still be eaten. The trade off for feeling great was an easy one to accept, and as the years have passed now, there are more and more restaurants that cater to Celiac Disease sufferers as well. In my quest to understand more about the disease and its effects I have come across more people with similar stories than I could ever imagine. Ranging from stay at home moms with children already affected by the

disease, to world travelers in search of wellness through various doctors, the common bond of despair to hope was all there.

As I touched on a bit earlier, some of the most major effects that have been reportedly linked to untreated Celiac Disease, is the possibility of developing Non Hodgkin Lymphoma and Esophageal carcinoma as well as Papillary Thyroid cancers. A case study that I was able to use, that provided two of these three medical issues was my mother. Over the last few years as her health worsened my mother had years of other issues that were viewed as isolated bodily issues, with no connection to anything else, but as one would go away another would come up. First, in her case, she developed ulcers, which lead to bleeding ulcers, something that can be a direct effect of Celiac's disease. She was never tested for Celiac's disease, and continued her normal diet and lifestyle, consuming gluten filled items, which may have continued the breakdown in her body. Though the ulcers got progressively worse, it was continuously just pushed off as stress. With continued medication not solving the issue, she was back again at the doctor, now being tested for esophageal issues, a potential bi-product of untreated Celiac's. This visit was a blessing in disguise though, as she was being treated for this issue and had tests run, they soon discovered masses throughout her lymph nodes. After being tested for this, it was found that she in fact had cancer in the form of Non-Hodgkin Lymphoma., after a multitude of tests. Though that may have been enough to trigger a look into something being the initial cause of this, she was then diagnosed with Lichen Planus, which is a rare esophageal disorder, that actually thins out the esophagus over time and seems to combine a malignancy with a skin disorder, as it is also likened to an internal skin disorder. With this, and various other tests, she was lastly tested for Celiac Disease,

because her ability to intake and hold nutrients was becoming less and less, and at the same time more and more uncomfortable. I believe that if Celiac Disease is spotted early, for instance, when one of these side effects first shows, that it can slow the possibility or even take away the possibility that someone may have to suffer through multiple issues because of an inability for their body to process gluten. It is not to say these issues would have never appeared, but with what we know that comes out of Celiac's, a case can be made for it.

A gluten-free diet is not a fad or a trend in finding a way to lose weight, it is something that must be strictly adhered to by the person with Celiac Disease or they can develop potentially fatal side effects.

The psychological aspect that can be affected when diagnosed and dealing with Celiac Disease is something that every single sufferer will agree is the hardest to deal with. As stated in different publications, depression can settle in as a side effect of having Celiac's or be a symptom from not finding it soon enough. When the disease is not found early, constant sickness and sluggishness can occur. That can turn itself into feelings of hopelessness that one will always feel this way. Even on the other side of the spectrum when Celiac Disease is spotted early, it can still set off a psychological reaction that can bring down a person's psyche. In that instance, it becomes a mental strain on a person to think they have a life long "disease" or something they will never defeat. As a young person it can be even more demeaning. A young child can develop Celiac Disease and that can be handled easily at home, but curbing and cutting out foods from their diet. The issue then becomes more social, as they will have to face their friends and attend parties not being able to eat the same things as everyone else. This brings with it the potential to

be ridiculed, and that can be crushing to a child or an adolescent who craves nothing more than to just fit in. Pizza parties are the norm for kids, and even that is not an option. That becomes a strain for parents as well, knowing that they may feel as if their child is deprived.

For children who develop Celiac's, early training in the diet and self-empowerment is crucial for their mental development. Maximizing their acceptance of the diet and the illness is something a parent can most certainly help with, because they can not necessarily change their children's personality or characteristics. It is important to instill in them early that they learn how to enjoy and embrace this disorder, and it can be a speed bump rather than a lifelong issue.

As a person who developed and was diagnosed with Celiac Disease at 22 years old, my reactions were obviously different than that of a child, because I was able to process what the disease meant and what the next steps were. The thing that remains constant, whether in a child or not, is the effect it already takes on your mind. For me it did not become as much of a social aspect as it did a constant state of anxiety of being sick. That triggered multiple reactions of social disorder, especially because I became someone of an outcast with every single group of friends, no matter where we went out to eat. It becomes almost embarrassing, in a Celiac patient's mind, to be that person with special needs, because of their health. Again for me, as someone who was non stop moving and enjoyed athletics, it almost became a death sentence. I constantly thought "How is someone who can't load up with pasta or someone who has an eating disorder play sports?". Questions like this were non-stop, until I ultimately removed myself from a lot of activities, simply to avoid those situations, which I thought I would not be able to

handle and be a part of. I, like so many other people I know with Celiac Disease, was told repeatedly by therapists, psychologists, and anyone who claimed to be a professional, that we were simply depressed and stressed. Multiple times I was prescribed anti-depressants as well as other medications to off-set what I was experiencing. Fortunately for me, I felt sick enough that I did not want to take a synthetic substance, and refused to torture myself even more. Many people with Celiac Disease can recite the exact same story. Their sickly bodily feelings persist, they remain sluggish, with joint aches, headaches and no motivation or energy to move. All too often when speaking to fellow Celiac sufferers, they are told the same, and even pushed towards the same or similar medications.

Depression is obviously common when attached to any chronic illness or disease, that is why Celiac is common as well, because it is no exception. In Celiac Disease, the issue of malabsorption of nutrients becomes an issue, and it can also interfere with neurotransmitters that regulate mood in anybody. Some studies showed that there was a possible link between the brain function, malabsorption, and depression because of the food factors involved. They also showed that depression and anxiety could be secondary to reduced neural production of monoamines, which are serotonin, dopamine, and noradrenaline, items that were being depleted by a changed diet. Another study also showed that depression is related to the immune response in Celiac Disease. In this instance, fatigue and depression were associated with the activation of the inflammatory response. In general, then body's response to getting sick, is to shut down. People fighting off regular illness will go to sleep, lie in bed, develop a fever, all to fight off whatever is ailing them. A prolonged ill feeling will produce a prolonged sickness response, and then depression may be related to the processes needed to heal. The

inflammatory agents implicated in several studies were the cytokines that are involved in the immune response of the body. One study interestingly showed that some antidepressants actually impair the release of pro-inflammatory cytokines and then enhance the expression of the anti-inflammatory cytokines.

As research data continues to show that depression is characterized by both neuroendocrine and immune changes in the body, one can correlate those directly to someone with Celiac Disease, as they fit the mold. The antidepressants that I spoke of earlier, that are so common to be prescribed rather than a deeper research into internal causes for the depression are used to send serotonin to the brain. Unfortunately for a patient with Celiac Disease the bulk of serotonin is found in the small intestine, which is where the disease itself manifests. Overall, having this serious medical condition that requires lifelong dietary and lifestyle restrictions can provoke many different psychological responses. Some people say that before being diagnosed they felt there was no hope, that they were in a constant fog, or felt overwhelming anxiety. Some people say that after they are diagnosed they have an even more elevated level of angst, knowing that they have to be strictly confined to this forever. Though depression and Celiac Disease are completely separate from one another, the ongoing similarities between patients diagnosed and misdiagnosed can not be ignored.

Eating at restaurants is a test, as I have found in a lot of cases, a quick “no that doesn’t have gluten in it” is common place, when in fact the server may have little to no clue what gluten actually is. In some instances when food has been ordered specifically without a bread product, bread products were included despite strict orders that it’s an allergy issue not a diet thing. Most times a restaurant will take the food back, as dealing



with an allergic reaction is not something they are prepared to fight, but in some cases I have had the food speedily returned to me, and then told repeatedly it is a whole new meal, when in fact the bread was just removed. This sort of thing is something to deal with daily and forever, as long as the gluten intolerance is an issue. Being vigilant while trying to go out and enjoy a meal at times takes from the freedom and enjoyment of going out to eat, but in the world of Celiac Disease, you are trapped in this prison, and can not be free to choose foods as you like. Each persons reactions are different, but each persons steps must be the same, and a person who has Celiac Disease must know where gluten is found most, how to read labels of ingredients on foods and how to avoid cross contamination as well. Cross contamination also includes the fryers, pans, and utensils foods are cooked with, because more often than not the same deep fryer that cooked your gluten-free french fries just cooked someone else's gluten-filled onion rings.

The commonality of peoples responses everywhere is "oh that sucks" or "oh I would kill myself" when they hear that I can't eat a food product with gluten, due to Celiac Disease. That isn't exactly the most sensitive approach a person could take when reacting, but it is also something they are not familiar with and have no clue how hard it is to live daily without the luxury of picking up a slice of pizza when you are hungry or getting a #1 from a drive through on your way to work. From the outside looking in it almost seems like a joke, and this upsets me in a way not that I get angry, which I do at times, but that the level of awareness today is not where it should be. Having dealt with Celiac Disease for over ten years now, I would have hoped in 2000 that by now it would be common knowledge what the disease was about. According to studies by the Columbia University Celiac Disease Research Center, fully 97% of the population is

undiagnosed. Many doctor's are quick to diagnose stress or IBS to a person who is feeling symptoms of Celiac, without even going further in depth, due to lack of education on the subject.

All of this combined has made it, at least for me, a passion to work with and educate persons affected with this auto-immune disorder, as it can effect a lot of other aspects of their life, but it is not a life sentence like many people will comment. While visiting the Center at Columbia this past week, I was able to discuss the potentiality of an event in New York City to raise awareness. Not surprisingly, there had not been anything put together by an outsider or any major event to raise awareness. Conversely, there had been many other events and enormous amounts of donations for other similar diseases that had been brought to light in the press. Being a person who deals with Crohn's Disease as well, the amount of literature and donation requests from those charities versus ones for Celiac's disease does not even compare, as Crohn's disease is something made well more aware in the public eye today, To me that is where the insensitivity and lack of knowledge can be bridged, if it was brought to light just as much as another disease. Where people may think "oh you can't eat bread, that sucks", what they don't realize is that its not a food allergy, but an auto-immune disorder, that can potentially break your entire body down and potentially cause diseases that are untreatable, and at times, fatal.

When discussing the difficulties with them, I used myself as a case study in two separate instances, as this past week our season started, and we were away for 2 straight weeks on the road, but before that I had the pleasure of eating with staff from Columbia University's Research Center. First, before I had left, I was able to go out to dinner with

staff from the Celiac Disease Research Center, at Columbia University. They picked the restaurant, and they wanted to see how I ordered and dealt with the waiters, as neither of them were Celiac Disease patients, but interested in watching and learning the process. Though it was common for me to order and speak with a restaurant staff member, they sat in fascination listening to the questions about how the food is prepared, where it is prepared, or what the seasoning is prepared in. While their fascination struck me as different, I also really began to realize the lack of awareness and in many cases the lack of sensitivity to the situation at hand. For most people, their order is their order, as it was with the guests I was with. To them, watching me take an extravagant meal and break it down to a grilled chicken with potatoes was something they rarely see as well.

The second study was more personal to me, as I was ready to leave New York for weeks, but not looking forward to the potential food issues I would face outside of the city. Not being in areas that I am familiar with, or areas that I know have local restaurants or food markets that offer gluten-free products can be challenging at times too. Aside from a bag of snacks and bars that I know are gluten-free, I generally have to go over a restaurant's menu twice to make sure the sauces and the marinades being used won't touch my meal. Now, I don't want this to sound like it is impossible and every single item on every single menu is filled with bread or gluten, because many wholesome foods, vegetables and fruits are naturally gluten free, it is the cross contamination when being out that causes another unseen problem. Celiac's Disease causes people to become vigilant, not complainers about the foods they could once eat. Upon arriving for both team meals, one in Baltimore, one in Richmond, Virginia, I was disappointed to see the usual, trays filled with pasta, meat balls, and breads, as athletes need to "carb up" before

performing. Back to the menu for me! The great thing about this for me was, once I asked for a menu, and dealt with laughs and the joking that I was too good for spaghetti and meatballs, I was able to break it down for an entire table, why I had to order outside of their meal and let them know what exactly Celiac Disease is. There were even a couple people who interjected they should have a family member checked because they're always sick when they eat. Those are the responses I value most, because it shows that the potential misdiagnosis is right there, all around us. The following week in Virginia, when entering the restaurant, there was the same set up for the meal, but this time the staff had ordered a plate of grilled chicken and salad for myself, knowing ahead of time the issues that I would have. The awareness made me just as happy as the gesture, and is something I appreciated greatly.

In going forward with my desire for Celiac Disease awareness throughout a community, especially with youth who may have to deal with a cut down diet, or teasing by other children, I am looking forward to putting together an awareness event for New York City. Using my sports background as a platform, I am hoping to reach out and help educate as many people as possible. Even if it takes an instance of being ribbed for a few minutes only to educate an entire group of people, it is extremely worth it. Knowing that there are a few centers like Columbia University's makes it comforting to know as well, as I can see that this is slowly, but hopefully surely, becoming a mainstream thing to bring awareness too. More importantly, and to me more importantly in younger people, the need to know that though this disease will effect your daily life, it is not an end or a life sentence.

One of the main focuses when dealing with a Celiac patient is the concern of a healthy diet, and adding in vitamins, supplements or any minerals that can offset what a sufferer may be lacking in their diet due to restrictions. As I have mentioned in previous postings, most sports related meals or pre-game meals are always thought of as a time to “carb up” for the performance about to take place. In the dining area or restaurant will always be trays of pastas and breads for the team to eat before playing. For myself as a Celiac patient, I usually travel armed with snacks like protein bars, flax seed bars, or anything else that would sustain my energy in place of having a pasta loaded meal.

Though I generally take these vitamins daily, for myself and most Celiac patients, it is still recommended to take the daily requirement, because there are side effects of trying to overdo the dosages, thinking we need to over compensate for lack of nutrition. To me, getting the optimal amount of nutrition comes together with working with a nutritionist, as is suggested when a person is diagnosed with Celiac. A normal meal that anyone can eat for breakfast, such as egg whites, with potatoes, juice and a piece of fruit is naturally gluten-free, and this can be a great start to any day. Following that, a snack usually consisting of another fruit with peanut butter is common, to keep the protein intake flowing.

Lunch is usually the most difficult on any given day, because of different daily schedules, different areas that we may be traveling in or not having the ability to stop and eat somewhere. Though quick and easy meals like fast food are not an option, it is still important to load the body with healthy replacements that will continue to help when it comes time to take the field. Most establishments will have salads available, and its easy to add grilled chicken to that, but to make sure that the chicken itself isn't marinated or

glazed with anything that may be contaminated. Burgers of any kind are great too, as long as they are ordered without the bun. The only problem that I have come across and that would be an issue for others would be the cooking of French fries in oil that is also used to cook onion rings, and other fried, breaded products. You don't always have to directly consume something to feel the effects of gluten in your system!

Dinners can be a good time to load up on anything you may have missed in your diet throughout the day, like a raw or crunchy-cooked vegetable, and a healthier portion of whatever you want, but again being cautious for glazes and sauces, as being vigilant comes with the territory, now that a person has Celiac Disease. In snacks for people with Celiac, the issue of foods containing more fats and oils due to the absence of gluten, the universal binder. Again, watching your intake of these types of foods can help keep a healthy and balanced diet, as it is very possible to perform at your peak, even with an auto immune disorder like Celiac Disease. All of this, plus supplements can ensure excellent anaerobic or aerobic performance for athletes in any category.

Personally I feel as if I had been performing as well as I possibly can, but within our two-week break, it is also equally as easy to relax and not exercise or eat as healthy. Even on a gluten free diet, eating unhealthy is just as easy as eating healthy. Watching some athletes at higher levels in different leagues though, has shown me that I can curb my diet even more to obtain a higher level of strength and conditioning. Being a full time student and traveling and trying to graduate simultaneously is not something many people in other sports deal with, but at the same time, they don't deal with Celiac Disease as well, so it becomes even more of a challenge, or a goal to achieve. With the infusion of a nutritionist now and a lot more knowledge thanks to the Research Center at Columbia, I

feel like I have taken my diet to another level, something that I was confident I had been at already, but quickly learned after these readings that I was far from that.

In the case of athletes and Celiac Disease, not much has been made publicly, because there have not been too many athletes that have stepped up to speak about Celiac Disease. Though that may be the case, the issues remain the same, and I see this first hand. Playing a sport where food intake equates to energy, which will equate to performance, discipline is again a key factor to this diet. Dietary supplements and vitamins are sometimes needed to make up for what is lost in eating certain foods. Though companies are extremely good at posting on their products that they are “gluten free” this does not necessarily mean your body may react to the potency of the vitamin you will take, if it has a deficiency. In the world of sports, specifically my sport, football, pre-game meals are generally laced with trays and trays of pastas, breads and all the carbohydrates that make an athletes engine run. Unfortunately for a person like myself, the focus to know and stay away from these foods is a must.

My pre-game meals consist of a bottle of water, a banana, and a protein bar to make sure I take in as much as I can without the worry of being sick. Road trips become even more difficult, as there is not much time to go grocery shopping for the right foods. More often than not I will pack foods that will not go bad, mainly boxes of pastas and cans of vegetables, and prepare these before games for myself, knowing that there will be no added ingredients that can cause a reaction. At the beginning of my involvement with football I had even consulted with a dietician to make sure I would be getting the proper vitamins and minerals in my body that I would need to have peak performance. Newer

companies and newer ingredients are always coming out, and though one may be able to tolerate certain things, it does not always translate to the same for others with the disease.

Even Gluten Free cookbooks are on their fourth and fifth editions for a reason, because ingredients keep changing and new things are always being found out about Celiac Disease and what can and can't be tolerated. Successfully adapting your diet and especially your lifestyle to living gluten free takes years to work towards and sometimes cannot be achieved because of the ever changing diet of a Celiac's Disease patient. This is not to say it is not attainable, but lack of attention to these details can be more life-threatening than any person without the disease could ever imagine.

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