

What is Celiac Disease, Really?

Your Questions Answered by a Highly Accredited Medical Professional of the Celiac Disease Center at Columbia University Hospital in New York City

The intent of this interview is to educate the world about Celiac Disease through an exclusive interview with a top medical professional of the Celiac Disease Center at Columbia University Hospital in New York City, one of the nation's only dedicated medical centers in America for funding research specifically for Celiac Disease. Columbia treats patients who have the disease, provides excellent nutritionist care by helping patients manage the gluten-free diet, and ultimately provides hope of finding a cure. If you think you may have the disease or know someone who may have it, please reach out to the Center and you will receive an informational packet about the disease, information about properly managing the gluten-free diet, and a guide to all of the 100% gluten-free restaurants and bakeries in the NYC area!

I encourage all people to listen to or read this interview because you are probably not as well-informed as you should be about Celiac Disease, and that's okay. But, it's also reality. If you have a cause that you believe in, I hope I can inspire you today to fight for that cause because the world deserves to be a better place for everyone to live in. That is why we are here to clear up any misconceptions, misunderstandings, and misinterpretations about Celiac Disease as well as to answer some extremely important questions. So, if you have Celiac Disease, know someone who has the disease, or even have a medical condition that is affected by gluten, you are in the right place!

Also, when Dr. Lebwohl mentions the term *trend*, he does not mean "to be trendy." The trend, or prevalence of those needing to be on the gluten-free diet is on the rise due to growing health reasons. **And we can all work together to find a cure.**

---Start Interview

Ariel: Hi everyone! I am Ariel, the owner and founder of Colored in Flour, and I am your resource for everything gluten-free for gourmet dessert recipes, articles, and travel with a strong emphasis on Celiac Disease advocacy and awareness. Sitting right here in front of me I have Dr. Benjamin Lebwohl of the Celiac Disease Center at Columbia University Hospital in New York City.

So, first things first, Dr. Lebwohl thank you so much for being here today and doing this interview with me. If you could introduce yourself to the world including your title and what you do that would be great!

Dr. Lebwohl: *Thanks so much for having me and for your efforts on behalf of the Celiac*

Disease and gluten-free community. So, I'm an adult gastroenterologist and I am the Director of Clinical Research at the Celiac Disease Center at Columbia University. My practice consists of office-based consultation primarily focused on the diagnosis and treatment of Celiac Disease and other gluten-related disorders. My research is also focused primarily on that topic. My research background is in epidemiology- counting patients studying population broadly thinking about the causes and consequences of Celiac Disease.

Ariel: How did it come about that you became a doctor who specializes in this condition?

Dr. Lebowhl: *I first learned about Celiac Disease when I was a pre-medical student in college. I happened to meet Dr. Peter Green, who is our Center's Founder and Director. This was in the late 1990s and I was looking for a research project for some experience in medical research. He told me about Celiac Disease, what it was, what gluten was, and he asked for his help setting up a clinical database because he had a growing number of patients who were coming to him with Celiac Disease. Then, as I progressed through medical school and then residency, fellowship, (these are all steps people take after they complete medical school) this sub-specialized into gastroenterology. I continued my relationship with Dr. Green and continued to write articles with him. I also gained research methodology skills so I got a Master's Degree at the School of Public Health at Columbia where I learned Epidemiology and Statistics and gradually honed my focus on Celiac Disease. Then, I joined faculty at the Center.*

Ariel: How many years specifically have you been treating patients with this condition?

Dr. Lebowhl: *Well, I joined a faculty and completed my training in 2010, so around 9 years. But, I've been thinking about Celiac Disease since I first met Dr. Green and I worked with him on a database in I believe was the summer of 1998. So, that's closer to 20.*

Ariel: How many people per year do you diagnose with Celiac Disease?

Dr. Lebowhl: *So, I don't personally do anything, it's all a **team**. So, typically what happens, is a patient will come referred because of an elevated antibody level and then I will participate in that diagnosis by doing an endoscopy and a biopsy of the small intestine. That biopsy is read by a pathologist. The endoscopy can't be done without the teamwork together with a nurse and a technician, sometimes an anesthesiologist. So, I really consider myself part of a healthcare provider community team. That's one way people get diagnosed. Even more frequently, because we are a referral center, people will be recently diagnosed with Celiac Disease and may be advised to try the gluten-free diet but have not seen an expert dietician. They might be having persistent symptoms, and then they come to our Center for another opinion- that's much more common. So, in terms of a fresh*

newly diagnosed patient, I might get a few a month, but, many more are coming having recently been diagnosed elsewhere looking for expertise either because of persistent symptoms or the need for an expert dietician.

Ariel:

So, to my audience, let me reiterate that... Dr. Lebwohl is a Celiac Disease *Medical Professional*. **He is a doctor that you should trust on this issue because he is very specifically knowledgeable about the condition.** He treats patients specifically with the disease, and here as a team, they are all here for people with the disease.

As for me personally, I am a Celiac Disease advocate because well, I live with the condition. I deal with it on an everyday basis so I am going to be completely open and honest here... My quality of life is not great with this disease. Celiac Disease gives me a *gipped feeling that I have a reduced quality of life*. And honestly, I don't think there are too many people living without the disease who could fully walk a day in the shoes of someone with the disease because they don't understand what it feels like to not feel well every single day and simultaneously be robbed of the most basic human ability to eat freely. **Unfortunately, it's not safe to just walk into any restaurant and ask for something to be made gluten-free for you because if you're living with Celiac Disease or a wheat allergy you have to acknowledge that you are taking a risk with literally everything that you put into your body... including foods that are too often mislabeled gluten-free and I find that that's unfortunately common.** Why? Because there is a very, very apparent misunderstanding about why there is a need for the gluten-free diet. It's not to be trendy, and it should not be a money-making scheme.

I want to mention that with having Celiac Disease, just finding something to eat that isn't going to harm me is a daily challenge to overcome because wheat-gluten is everywhere... even things you wouldn't expect. And if you've ever had severe food poisoning or a severe stomach ache, that should give you a slight idea about what a Celiac reaction is like, except, with a Celiac reaction it's much worse and it comes with detrimental consequences such as intestinal cancer if you literally do not watch every single thing that goes into your body. **That stomach ache that you feel, that is a warning sign to your health.** It's scary because living with Celiac Disease is to acknowledge that I am taking a risk with everything that I put into my body... and yes, including foods that are too often mislabeled gluten-free. And I find that it is a common problem, Dr. Lebwohl.

Dr. Lebwohl:

*Yes. So, eating out particularly, outside of the world of packaged foods, every Celiac patient will tell you that this is a considerable source of distress. Every patient is different in terms of how sick they might feel acutely when they get exposed to gluten. Getting exposed to gluten though is merely universal simply because gluten is everywhere. And, to some degree, especially when eating out or traveling, it's **bound** to happen. With that said, the great majority of patients with Celiac Disease live healthy, long lives. **Intestinal cancer** is a concern. It is much more common in Celiac patients than people who don't have Celiac Disease. It is*

*thankfully still rare. We care about it, because we believe we can potentially prevent it. **Another cancer that Celiac patients are at an increased risk for is lymphoma, and that's more common. It is merely three times (3 x) more common in Celiac patients than it is in the general population.** Still, the great majority of Celiac patients don't get lymphoma and again, the great majority live a healthy life. Still, even those who don't get lymphoma are often living under the cloud of concern about being exposed to gluten, particularly when eating out. We've actually done studies about looking at the impact on gluten exposure on long-term outcomes and we have found that on-going, intermittent, even accidental gluten-exposure can have long-term health consequences as you mentioned. The two outcomes that we found were people with on-going intestinal damage were at an **increased risk for lymphoma** compared to people whose intestines have healed. People with ongoing intestinal damage were also at an increased risk for fractures likely related to **osteoporosis** or brittle bones, compared to people whose intestines have healed. Ongoing intestinal damage can be for a number of reasons, but we believe that it's most likely due to gluten-exposure, and eating out is a particularly hazardous situation when it comes to gluten-exposure. A one-time exposure might not cause intestinal damage. Intestinal damage likely is more a reflection of on-going intermittent exposure, the equivalent of a skinned knee that fails to heal because we keep skinning it again and again before we give it the opportunity to heal. **It is this uncertainty when eating out or systematic exposure because of beliefs about certain foods being safe that can cause this failure to heal.***

Ariel:

So, speaking of symptoms, sometimes people who do not experience anything after going out to eat at a restaurant where there is wheat-gluten being actively used in the facility will say “Oh I ate at *this restaurant* with a cross-contaminated kitchen and did not experience any symptoms. I feel fine.” Which is like, okay... I'll be honest, that was once me, when I was going out to eat carelessly in my “*I'm denying that I have Celiac Disease because this can't actually be my reality... I'll be fine*” phase. So, to clarify then, even if someone does not experience any symptoms, even after being in an environment where they are being exposed to cross-contamination, regardless of so-called safety measures taken, is it safe for people to risk their health like that?

Dr. Lebowhl:

*So, symptoms are not what we rely upon. There are people who do get very sick when exposed to gluten by eating gluten in sufficient quantities. **That could even be small amounts though, not even visible (the equivalent of just small barely visible bits of a piece of bread).** The amount of gluten it takes to cause symptoms can be that small. With that said, there also are people who can be exposed to that amount of gluten even on a regular basis and not get acutely ill, not feel symptoms, not get gastrointestinal distress. They might even feel fine. But if they are exposed on an ongoing basis enough, their intestines will show it and they will fail to heal, they'll have ongoing damage, and they are potentially at increased risk for these various outcomes. We actually did a study where we analyzed biopsy results (so, people who had their intestines sampled), and these are people with Celiac Disease largely who had ongoing symptoms of one sort or another and we asked the*

*question “Is there a specific set or type of symptoms that predict who has ongoing damage when we do the biopsy and who has healing and normalization?” and we found that there was no set of symptoms that was strongly predictive of that. **Symptoms are a poor predictor of intestinal damage.** We believe that the cause of intestinal damage is gluten and the treatment is time on a gluten-free diet. But, **if that time on a gluten-free diet is interrupted by frequent exposures to gluten, even in small amounts, that can interfere with the healing process.***

Ariel: Thank you for that explanation, and I bring that up because I have gone out to eat at “regular” restaurants before that offer gluten-free items, which, shouldn’t even be called that. **Instead they should be called “low gluten level containing items”.** For instance, I’ve been served things called gluten-free, like mozzarella sticks, and have been accidentally served to me wheat-breaded mozzarella sticks and I mean, I think it’s just out of control.

Dr. Lebowhl: *And this can certainly ruin a dining experience not only if someone eats and feels sick but even if they recognize it before they eat it, you know, the whole process of sending it back and having to do your on-the-spot education to the wait staff while it might be helpful in the long-run for future people who are eating there, you know, you came there to have a good time with your friends and **you deserve to be treated in a safe way by food handlers.***

Ariel: And trust me, to those who are listening with the condition, I understand the need to feel normal with taking the everyday pleasures of going out to eat, but **please listen to me when I say that risking your health is not going to be worth it if you have Celiac Disease. But honestly, I think this has a lot to do with gluten-free labeling laws that need to be improved and made stricter.** So, my next question is, what in your professional medical opinion, should be done to improve gluten-free labeling laws here in America?

Dr. Lebowhl: *Well, there are a few areas in need of improvement. I should say, that it’s better now than it was 10 years ago when there was no gluten-free definition or standard. Right now there is a definition and standard defined by the Food and Drug Administration that issued a federal standard by what it means for packaged foods to be gluten-free and that definition relies on the 20 parts per million (ppm) concentration. That concentration was cut-off at 20 because below that concentration, it’s impractical and unrealistic to expect that amount of gluten to be eaten so as to cause intestinal damage. But, above that concentration, if you eat it in normal portions, you would expect to see intestinal damage. We believe that is likely the great majority the threshold of symptoms of feeling ill when they get exposed to gluten. So, it is better in that right now, **when we see a food item that is labeled gluten-free, we at least know what that means. But there are problems. First of all, there have been multiple instances that have been called out in which companies have packaged foods that say gluten-free but when you look at the ingredients, there are ingredients that obviously contain gluten and they are basically disregarding the definition of what it means to be gluten-free and then***

*slapping the label. So, the approach for citizens, patients, and watchdogs to call this out and bring it to the FDA's attention. The FDA is supposed to investigate each instance. It would be in my opinion preferable for these not to be reaching the consumer and not to be left to such advocates. **We are thankful for such advocates but it would be great if these foods did not label as such and erroneously labeled gluten-free in the first place.***

***The other area in need of improvement is the question of gluten in medications.** So, this has been a source of considerable concern for many patients because of the idea that medicines contain not just active drug but, also a filler. In many cases, that filler is cornstarch, but it is possible for a filler to be made with wheat starch. Wheat starch, in and of itself, does not necessarily contain the protein that's in wheat, which is gluten. So, something could in theory could be wheat starch and be gluten-free, but because of the possibility that something that is derived from wheat could contain trace amounts of gluten, this has been a source of **considerable concern**. Whether this is a widespread cause of damage to patients in true harm, to me, I have not seen the evidence. I see patients with Celiac Disease all the time and the number of times where I found it was clearly a medication that contained gluten is vanishingly rare. It is much more of a theoretical concern than an actual concern. **But still, if you have a patient with Celiac Disease who is still not feeling well and we're not sure why they're not feeling well, they shouldn't have to be worrying and eyeing a suspicion about the medication they are using. Medication should be gluten-free. Period.** The fact that it even remains a theoretical possibility, remains a source of distress. Now there are resources out there; there is glutefreedrugs.com, for example, in which the manager of that site has gone through the work of reaching out to companies finding out the gluten-free status of each drug. But that requires constant updating and is, again, a citizens' work, and is something that really shouldn't be necessary, but it is necessary in this day and age. There shouldn't be gluten in drugs, in my opinion, and the fact that it's still a remote and theoretical possibility is a great source of anxiety for many of our patients.*

The last area I would mention, is restaurants.** We talked about the FDA, and there is a rule for what gluten-free labeling that really only applies to packaged foods. It does not apply to foods that are labeled as gluten-free on a menu in a restaurant that is not packaged foods. So, what the FDA states is that any violations of the gluten-free labeling would be welcomed to be referred to the FDA. But, that rule doesn't apply specifically to restaurants. I think we should be looking elsewhere. **We should be looking abroad for advice and I've heard from my patients and also my colleagues who study Celiac Disease in other countries, that there is a more standardized way, whether it be for single certification mechanism from a national society for restaurants to abide into, or other more strict regulations that would allow restaurants to only report gluten-free on the menu if they have had the appropriate training, and if their food strictly is gluten-free, and if this is strictly enforced.

Ariel:

I am actually glad that you brought that up as that was my next question. Are you familiar with other countries' awareness and action that is being taken to aid people living with Celiac Disease in terms of quality of life and providing assistance to those living with the disease? For instance, **there are certain countries where, if patients can prove through medical forms that they have Celiac Disease, those patients are allowed to purchase specific gluten-free items at half the cost of what they are priced at? Or in other countries, gluten-free foods are offered through prescription?** As those countries see Celiac Disease as a serious health issue and I mentioned that and I'm glad you brought that up because I strongly feel this is something that **we should see happening in our own country here where due to the high cost of the gluten-free diet, aid and assistance should be given as priority to those with Celiac Disease.** What do you think?

Dr. Lebowhl: *I agree that the economic burden of Celiac Disease is **considerable**. Gluten-free substitute items, whether it be packaged foods, or restaurants, are considerably more expensive than their gluten-containing counterparts. The question is, how to address that? **And I think this is particularly relevant for middle and lower income people who are dealing with this condition because then you really shouldn't have to decide between your health and your pocket book.***

*So, there are some countries who have for example, given an income subsidy so as to compensate for the increased annual average cost of the gluten-free diet. I know Finland at least a decade ago was doing that. Actually, when that allowance was made and it required a physician's note that this patient has a diagnosis of Celiac Disease, it actually resulted in increased awareness and increased diagnosis rates. So there was that benefit that patients were going from undiagnosed to diagnosed because there was that economic incentive. As far as eating out, I hear about this from my patients certainly who, when navigating this or when preparing for a trip they meet with our dietician, Anne Lee, or Jessica Lebovits, give them country-specific guidance about how to figure whether restaurants are safe. Certainly not for every country, but countries particularly, in Europe, where there is a more systematic and more reliable way when determining restaurants that are safe for people eating gluten-free food whereas in the United States, it's really restaurant by restaurant, and it's anecdotal, and it's based on prior experience with regard to talking to specific staff with whom you can trust. When you're coming to our dietician and you want to know where in the New York City area or the immediate surrounding area are safe places, but it's not really scalable. People around the country needing to be gluten-free and some of them are going to chain restaurants that might have a gluten-free menu or gluten-free options and **we need to have a more uniform way to ensure that those menus are safe.***

Ariel:

What is the history of Celiac Disease? How did it develop and why is it becoming more and more prevalent?

Dr. Lebowhl:

So, Celiac Disease was defined in ancient times by ancient Greek physicians as an affliction of the intestines. Whether people were said to have Celiac Disease and are the same kind as people who have it now, in

other words, whether they have the same architecture of their small intestines, we can't be sure, but **it's been around for more than 1,000 years**. For a long time, it was thought to be a disease primarily of children, who were failing to absorb what they were eating so they looked like they were starving. They had very bony features and also swollen bellies, which is a feature of children who are living through famine. The reason the bellies are swollen is because they are full of fluid because the fluid is leaking out because they don't make enough protein. So these are children who are starving, sometimes even starving to death. In the early 20th century, the theory that it was a dietary cause finally started to gain traction. There was a Dutch physician named Gee who's theory that wheat, or the component of wheat, was the primary cause of Celiac Disease, who was ultimately proven to be correct. The gluten-free diet which became more widespread around the 1950s became life-saving for these children. Still, we didn't have a way to diagnose it apart from proof that these children got better, and then proof that their intestinal damage also got better, and went on a gluten-free diet. But, it started in the 1980s the discovery of antibody tests, these are tests where you can check in the blood for components of gluten became available, and while these are not perfectly reliable for Celiac Disease, they certainly linked corroborating evidence Celiac Disease and a way to start the process so if a kid or adult had an elevated antibody then the suspicion was that maybe they had Celiac Disease and they would then undergo the procedure of an endoscopy with a biopsy. Then closer to the year 2000, there was another test that developed called tissue transglutaminase, or (t-Tg-IgA), which is even more reliable as a marker. Around that same period of time, a link to the necessary gene for having Celiac Disease was discovered. **So, all of these diagnostics came together and with those improved ways to diagnose Celiac Disease came the awareness that there was a lot more Celiac Disease than we had initially thought.** So it turns out that if you screen the general population of the United States, close to 1% of people have Celiac Disease. **So, nearly 1 in 100 people have Celiac Disease.** But, it turns out, that most of those people that were tested, didn't know that they had it and were eating gluten on an ongoing basis. Some of them were having considerable symptoms, not all of them, some have no symptoms so there is that variability. That realization happened in the first decade of the 21st century so in the early 2000s we realized that close to 1% of people with Celiac Disease had it, even though most were undiagnosed. **As the decade progressed, studies started to come out that showed that actually, that 1% figure, is not a static figure, that it's been moving.** If you look back to 1950 at blood that's been store in a freezer and you thaw that blood and test that blood for antibodies, that it was much less than 1% who had Celiac Disease antibodies back then. **So, Celiac Disease is on the rise.** It's perhaps risen four-fold since 1950, not just in the United States, but elsewhere. In other countries it's actually more common. In Finland, it's more common it's actually closer to 2%.

The reason for that rise is really unknown. **There must be something in the environment that is triggering people to lose their tolerance to gluten and we don't know what that is, but we are trying to study it.** In addition to the 1 in 100 people that have Celiac Disease, there are many people, more than 1%, who are on a gluten-free diet for other reasons. That trend has increased even more rapidly than the rise in Celiac Disease. There has been a rise of Celiac Disease. Some do it because they experience symptoms such as abdominal pain or diarrhea and intestinal problems or the non-intestinal things that you hear in Celiac Disease might not be present in those with Celiac Disease yet when they start a gluten-free diet, **they feel ill.** We don't really understand the biology behind that. We don't know why or how **gluten is making them sick.** It's probably a mixed number of causes. In some people, it's not gluten necessarily, but it's something closely related to gluten that when they start the gluten-free diet, **they feel better.** In some people it might be an issue with a **related nutrient.** For some people it might be **fiber content.** For other people it might be a degree of a **placebo effect.** If that were the case, it would more of a short-term improvement that doesn't last very long. With others it might be something that's related to the **immune system.** We've studied that, that some people with non-Celiac gluten sensitivity when they eat gluten, they have signs in their blood in increased immune activation. There are many on the gluten-free diet simply because of the belief that it promotes wellness. This is much more shaky ground. This has not been established. A gluten-free diet is not intrinsically more healthy than a gluten-containing diet, if you don't have symptoms or if you don't have Celiac Disease. Awareness of gluten is on the rise but as real work has shown, there is showing there is a double-edged sword there, **even if there is more availability and interest in gluten-free food, that may lead to more options that could paradoxically cause people to advertise themselves as gluten-free but they are not taking the appropriate precautions.**

Ariel: What is gluten, specifically? Because there are still many people who do not know what it is.

Dr. Lebowhl: *Gluten is a protein, the principle protein that is present in wheat, rye, and barley. It's actually a collection of closely related types of proteins. It is what gives bread it's texture, it's sort of stickiness. **The most obvious gluten-containing foods tend to be breads, pizza, cookies, muffins, that type of thing. But, trace amounts of gluten can be found elsewhere. The most common example given is soy sauce.** Small amounts of gluten can be present as a sort of thickener to the soy sauce. Not all soy sauce has gluten in it, but certain brands do. So, the educated Celiac Disease patient will know how to navigate that and figure out how to avoid these hidden sources of gluten.*

Ariel:

So, speaking of the term hidden, Celiac Disease has been referred to as “**A Hidden Epidemic**” as described by Dr. Peter Green, who you mentioned earlier. Gluten, is causing a lot of health issues not just in people with Celiac Disease but with other conditions as well. I know that some people who have thyroid conditions are on the gluten-free diet and it has even been recommended for children with autism to start a gluten-free diet which is just fascinating to me because gluten is everywhere and it causes many, many health problems so I think it is definitely a hidden epidemic especially with Celiac Disease.

Is gluten a natural protein found in wheat flour or is it a man-made protein?

Dr. Lebowhl: *So, it exists in nature, it is a component of wheat. Man-kind did not synthesize or invent gluten. I am always hesitant to use the term “natural” because everything that exists is compatible with nature. Wheat, of course, is something that mankind has cultivated since the advent of domesticated agriculture 10,000 years ago. There’s a lot more wheat now than there was in prehistoric times. The wheat that we are eating now is going to be different because of selective hybridization. So, farmers through the millennia selectively bred that kind of wheat crop that is most likely high yield, most likely to withstand whatever the elements most likely to grow tall and easiest to harvest. So, it’s going to be different compared to how it was a millennia ago. Does that mean it’s less safe? Does that mean it’s making people sick? There’s zero proof for that. We do know that there’s just as much gluten now in any given amount of wheat than there was 100 years ago that’s been evaluated. There’s a lot of interest in what is it that’s making people more intolerant of gluten now than a generation ago. My theory is that it’s related to the Hygiene Hypothesis- we’re being exposed to fewer germs and more antibiotics now than we were 100 years ago. So, that might be changing the relationship we have with the world around us and it might be changing our developing immune systems, might make our immune systems go in a path that we didn’t intend, like not tolerating and having an immune response to gluten which should otherwise be innocuous.*

Ariel:

I’m curious to know if one person’s case of Celiac Disease is more severe than another person’s Celiac Disease? In other words, is Celiac Disease, Celiac Disease?

Dr. Lebowhl: *Everyone’s experience with Celiac Disease is different both in terms of the burden of the diet. Some people seem to have very little difficulty, other people tend to have a great deal of difficulty. It has nothing to do with the wear-with-all intelligence or anything constitutional about the individual but it affects everyone very differently. It is also likely that some people are going to be more sensitive not just in terms of symptoms but also in terms of damage to their intestine with regard to trace amounts of gluten that is likely to be the case like with any other condition, there is going to be variability in spectrum and that might be why some people have less difficulty for example when they’re eating out. They might not feel ill and also if you take a repeat biopsy, things might look fine and for them it’s more a walk in the park than for others. I would say that eating out tends to be an ordeal for the*

majority of patients. As for how patients do in the long-term there is also a lot of variability. For some people, Celiac Disease is just an asterisk to what they have been living with and they make the adjustment and they're perfectly fine. They live to an old age and they have no issues. Other people seem to have one related problem after another whether it's ongoing intestinal symptoms or other autoimmune diseases that come along or Celiac-related cancers. So while thankfully while the latter is rare, it tends to weigh out people's consciousness and can be a great source of worry and for those unlucky few who do have those outcomes it can really curtail life expectancy and quality of life. So, not all Celiac Disease is the same.

Ariel: And to me, in a way, feeling symptoms is actually better than not feeling any symptoms at all because at least your body is able to let you know that there is something wrong... that at least you can get yourself checked and start the gluten-free diet whereas **if you are not experiencing any symptoms, you could end up with serious health complications.**

Dr. Lebowhl: *I have had patients tell me that they don't have symptoms that they wish they had some sort of early warning symptom so that they could modify their diet or behavior or dining practices accordingly and when that's not the case we have to rely on other things. We have to rely on the dietician's assessment, we rely on bloodwork, antibody normalization and we rely on how the intestine actually heals on repeat biopsy.*

Ariel: My cousin's grandmother on the other side of her family was diagnosed with intestinal cancer. **She was informed that it was caused by Celiac Disease, which she didn't even know she had it because she didn't feel any symptoms.** Now, here she is, dealing with that and it's **literally caused by food** and it's just tragic.

Dr. Lebowhl: *And it's a rare, but a devastating complication of Celiac Disease. We've studied this particular kind of lymphoma, there's not a lot of it out there but the treatment is not satisfactory. **There's no good treatment for it and according to our calculations, it has been on the rise and is parallel with Celiac Disease.** Typically when we diagnose it, it's often in people who were diagnosed with Celiac Disease at an older age. While we don't have definitive proof, it stands to reason that it can be a long standing consequence of Celiac Disease, and ongoing exposure.*

Ariel: So, are people dying from Celiac Disease?

Dr. Lebowhl: *There have been a number of studies of mortality risk in Celiac Disease. When talking to patients I try to reassure that there are patients who live a long healthy life. But when you study it and look at large population you see a signal. **You do see an increased rate of death compared to the general population.** So, one large study out of Sweden found there was a 39% increase in rate of death compared to the general population. That doesn't mean that 39% of Celiac's die young, or early,*

*it means that if you follow people over time and look at their life expectancy, we all die eventually, but the rate at which the population will die will be somewhat increased. It's not double, so that would have been a 100% increase. **But overall, it's a 39% increase.** The good news, is that rate changes over time with more time after diagnosis presumably because of the gluten-free diet, that increased rate is not as high and so **it does appear that being on the gluten-free diet is likely good in terms of long-term life expectancy in people with Celiac Disease.***

Ariel: What is your take on items that are gluten-removed?

Dr. Lebowhl: *So, that's a term that makes a lot of us uncomfortable because it implies that this is a product that had gluten and then removed. The question is, has it been removed in such a way that the product you are now facing has less than 20 ppm of gluten? **In general, when a product says gluten-removed, it often is a red flag, because it implies that it's not gluten-free.** If it were truly gluten-free, then it would say gluten-free regardless of whether gluten used to be present and has now been removed. A product could be potentially harvested from a source that had gluten in it and the gluten was truly removed and that product is now gluten-free, but if that's the case, that product should be labeled gluten-free. If it's not, then we have to worry that they're trying to bypass the FDA rule and it implies that maybe it's not gluten-free. So, it's a red flag.*

Ariel: I read an article a little while back about gluten-removed beer where there was a study done by The University of Chicago's Celiac Disease Center who tested patients who consumed **gluten-free beer vs. gluten-removed beer.** The studies indicated that patients with Celiac Disease who drank the gluten-free beer, did not experience any symptoms and there was no antibody reaction found. **However, when they drank the gluten-removed beer, they experienced no symptoms, however, their blood was detecting a reaction. In other words, they were having a silent attack and the person didn't even know they were having one because they experienced no symptoms** which is interesting, but actually really scary, if you think about it. For me personally, this is actually why I will not ever eat or drink anything gluten-removed, **including oats**, actually, because I don't trust the safety of anything labeled gluten-removed.

Dr. Lebowhl: *So, as I said gluten-removed is a red flag and why isn't it being called gluten-free? Even if gluten was removed from a naturally gluten containing item, if that gluten has truly been removed, it should be labeled gluten-free and if it's not it's a red flag. Now, for a specific brand, I always urge my patients to talk to an expert dietician because as we talked about, the labeling is not perfect and something can be labeled gluten-free illegal and the item can actually contain gluten. So, if there's potential concern or suspicion, run a specific brand by a dietician you can trust.*

Ariel: I'm glad you clarified that because I get sick all the time from eating foods and I don't know if they're actually gluten-free or not but it's just not a quality of life that anybody should experience.

So, I'm going on 28 years old now, and **I remember the lack of competence of my doctor who diagnosed me in my late teens.** I remember word for word him telling me "Oh a little bit of wheat here and there won't hurt you. You can cheat on your diet. You'll be fine." **There are doctors who are still not well-educated about the disease who are still informing their patients that it's okay to cheat on their diet.** Can you please tell everyone what happens when someone who has Celiac Disease cheats on their diet?

Dr. Lebowhl: *When someone is exposed to gluten, on purpose or by accident, there is great variability. Some people don't feel anything acutely **but the gluten is being recognized by that patients' immune system which then recruits other white blood cells to the intestinal wall and attacks.** That collateral damage is the intestinal wall. The intestine itself can be potentially damaged. In some people, they really feel it. They feel terribly ill. Others don't feel a thing. For most people, it's somewhere in between those two extremes. This happens, even someone trying to be 100% strictly gluten-free. This is almost for sure going to happen at some point in their life, simply because gluten is everywhere. If someone attempts 100% gluten avoidance, hopefully these instances will be rare and won't amount to ongoing intestinal damage. In other words, even if the intestine has some degree of damage from exposure, that will rapidly heal. **But, if you continue to expose and expose without giving the chance for intestine to heal, then you'll have ongoing damaged villi- these flat projections which are no longer tall but are flat. That's what's been linked to dead outcomes in the long-term.***

Ariel: What advice can you give to doctors who are not well-educated about Celiac Disease?

Dr. Lebowhl: *Avail yourself of the resources that are out there. There are several books that have been written by our group and others on Celiac Disease, there are continued medical educational conferences that are available including ones that we put up at the Celiac Disease Center at Columbia. There are sessions on Celiac Disease at the Major Gastrointestinal Societies' annual meetings. Thankfully, many of the Primary Care Societies also have educational materials related to Celiac Disease. **It's all of our responsibilities as healthcare practitioners to educate ourselves, to be up on the latest, and not to pass along perhaps, old advice that turns out to be incorrect.** The idea that "Oh you can cheat every now and then is okay and that Celiac Disease isn't serious."*

Ariel: I listened to an interview that you were in on NPR where you had mentioned that gluten is **toxic** to those with Celiac Disease. So, **please don't advise** anyone with Celiac Disease that it's okay to cheat on their diet.

Dr. Lebowhl: *Yes, and our **Hippocratic Oath** says do no harm. If you do diagnose someone with Celiac Disease, gluten is toxic to them and you should urge them to attempt 100% gluten avoidance, even though gluten-exposure is bound to happen at some point by accident. If you attempt 100%, those exposures will be rare enough that the long-term outlook will be good.*

Ariel: I have also heard this one before as well because someone told me this recently... “Oh, my Celiac Disease went away. I no longer have it.” Can you clarify, can Celiac Disease just “go away” like that?

Dr. Lebowhl: *Usually not. Whether that’s impossible, there is a little bit of uncertainty in that there have been case reports and I mean like 1 patient described and then another patient described, not groups, but really sporadic reports of someone having not just the antibodies being elevated but also intestinal damage from gluten and then somehow no longer having that damage and are now eating gluten. That is **vanishingly rare**, maybe more common in certain children than in adults, though the common scenario you’ll find in children are being monitored because they are high risk and develop elevated antibodies and they never develop Celiac Disease. It just goes away. But, most of those cases, they never had the intestinal damage. **As a rule, once the damage occurs in the intestine, it’s irreversible in that the gluten will always be toxic to them. The intestinal damage itself will reverse if they go gluten-free but if they eat gluten again, they’ll have damage.** So, it’s the cat’s-out-of-the-bag phenomenon. There have been exceptions, but they are really exceptions that prove the rule.*

Ariel: When you are diagnosing someone with Celiac Disease, you perform an endoscopy through the small intestine. What does Celiac Disease look like? How can you tell that somebody has it? **Would you be able to describe what the damage looks like?**

Dr. Lebowhl: *Well, to the naked eye on endoscopy, there is no tell-tale sign. There are few things that have been described. So called scalloping of folds or decreased visible folds that you can count when you’re looking on the monitor when you have a scope in the intestine, but really, that’s not reliable. **For many people with Celiac Disease, it will look normal.** It’s principally, a diagnosis that’s made under the microscope of biopsy specimens. You take very small sample of tissue and you take several different numbers of them, 4-6 of them from the multiple portions of the duodenum, which is the beginning of the intestine and then those specimens are examined under a microscope by a pathologist. **Instead of long, slender villi which are the microscopic projections which allow for the surface area absorption of nutrients-they become flat or short, and that’s how the diagnosis is made in a proper context.***

Ariel: Why is there no cure for Celiac Disease yet?

Dr. Lebwohl: *Like many diseases, they are more complicated than right now by a medical science is able to tackle. **But we've cured other diseases where we've developed treatments for other diseases that are as complex. We primarily haven't gotten there with Celiac Disease because there is not enough financial support for the research.** Reasons for that are complicated but principally boils down to a combination of not a lot of federal funding, from the **National Institute of Health**, and also not a lot of support from the **Pharmaceutical Industry** which funds a lot of biomedical research in this country and that's because there isn't a drug for Celiac Disease.*

Ariel: So, there is not even a medication for Celiac Disease? No form of aid for symptoms even caused by cross contamination?

Dr. Lebwohl: *At this point, there has been no medication that has been proven to prevent or treat damage from gluten. Some people will anecdotally say, "Well, I take Pepto Bismol if I get stomach distress if accidentally eating gluten" and that's fine it might work for some patients. But for example, there are these advertising for gluten-digesting enzymes. **None of that's been proven to work for people with Celiac Disease.** There are several drugs that are in the pipeline being tested at various phases in people with Celiac Disease to prevent gluten-related damage. **But, none of them have been sufficiently proven at this stage.** We have some promising ones, but they need to be subject to rigorous human trials. Hopefully, in the coming 5-10 years, we'll have such drugs available. But, it's hard to predict in the future with certainty.*

Ariel: Finding a cure is definitely something that is my passion. In life, I feel it is my purpose. Dr. Lebwohl, has so much compassion for what his patients are going through and I say this because there is a **continued ignorance and lack of compassion** for those living with the condition which I truly think stems from others not having the condition themselves or they don't know what Celiac Disease is, or if they have never heard of it they do not really know what entails of it because **it's a lot more than just being on the gluten-free diet** which is extremely difficult and then on top of that it comes with **detrimental health consequences** so others cannot relate if they don't have it. For those who represent the FDA, the NIH, Pharmaceutical Industry, you could help people with this condition. We should all be sensitive to what others are going through, right? What do you think Dr. Lebwohl?

Dr. Lebwohl: *The experience of living with Celiac Disease can be very difficult. **There really is an unmet need.** We need to support our patients, we need to hear from them, listen to them, and hear what are the major issues and **we need to pay attention to this condition because it's serious, it's common, and right now the gluten-free diet is not an adequate treatment** for so many patients because gluten is everywhere. It's so hard to maintain a strict diet because of limitations adhering to that diet.*

Ariel: When I research the internet and type in, "What is Celiac Disease?" I get many, many different search results that appear, as well as many definitions that

inaccurately describe Celiac Disease by referring to it as an “intolerance”. Dr. Lebowhl, I would like for you to define Celiac Disease for those listening to and reading this interview.

Dr. Lebowhl: *Celiac Disease is an immune based condition. It is a disorder related to the bodies' immune system that's triggered by eating gluten and people who are susceptible to it. There is a genetic component that run in families and there are genes that are necessary for the development of Celiac Disease. One can develop Celiac Disease at any age. It is characterized by the development of antibodies in the blood that **apply immune activation and damage of the intestines when eating gluten.** It's diagnosed by a biopsy, an analysis of specimens of the duodenum, which is the beginning of the small intestine, and is treated with a gluten-free diet.*

Ariel: So, he answered **What is Celiac Disease, Really?** That is the best answer that you'll get. If you listen to this interview, I wouldn't rely much on the internet in other terms in that sense. So, thank you for that definition.

What is the future of Celiac Disease?

Dr. Lebowhl: *The future of Celiac Disease could play out in a few different ways, but I'm an optimist in that I think it's going to look very different in the coming years. Hopefully we will have better diagnostics, better ways to pick up who is at risk for Celiac Disease, identify them early, and diagnose and treat them properly. I am also hopeful that we will have alternatives to the gluten-free diet so that there will be for a subset of people who need it, ways to treat Celiac Disease in addition to or instead of the gluten-free diet, **I'm also hoping that we as a society will get better about labeling and eating out so that people who need to navigate the gluten-free diet can do it in an easier, more user-friendly way. But, we can't take it for granted. For that to happen, we need research support, we need the government, the pharmaceutical industry, and philanthropy support on the kind of research that has to be done. We also need patients to volunteer and to be engaged and be activists.** So, I'm an optimist, and I think that will happen. But, we can't take it for granted.*

Ariel: How can people support the Celiac Disease Center's research efforts in finding a cure?

Dr. Lebowhl: *Everyone is different in terms of what they bring to the table. One patient might volunteer to be a participant in a clinical trial. One patient might attend a rally or lobby Congress for increased funding. One patient might use their families' wealth to support a large donation to support a research program. One person might fill out a questionnaire and **there's so many different ways people can help out large or small, but every bit helps.***

Ariel: Well, there you have it. To those who are listening, this is just a start. There's going to be more coming from me. For more information on Celiac Disease, the Celiac Disease Center, including ways to donate to the center and contributing to finding a cure, or simply if you want to learn more, **please visit celiadiseasecenter.org**.

Thank you again Dr. Lebwohl for this interview. It means so much. We can all work together to find a cure because living with Celiac Disease is not easy and even if you don't have the disease, well, I encourage you to contribute and help make the world a better place to live in because that's all we can ask for right, Dr. Lebwohl?

Dr. Lebwohl: *Yes, and I appreciate the opportunity to talk to you about this.*

Ariel: Thank you so much.

Dr. Lebwohl: *Thank you.*

--End Interview