Pediatric Celiac Disease: Fact and Fiction

What Americans Misunderstand About Kids Getting Diagnosed and Living with It

A Report from Beyond Celiac | June 2024

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INTRODUCTION

Children and A Cure Are Our Future

It is hard enough being an adult with celiac disease, living in a world where the only option for avoiding sickness is following a strict gluten-free diet and having to consistently be on guard to make sure you don't accidentally "get glutened." It is even more challenging for children, especially those who are younger and do not understand why they cannot have the cake at their friend's birthday party.

About a year ago, Dylan Dreyer, NBC News meteorologist and co-host of the 3rd Hour of TODAY, announced that her six-year-old son, Calvin, had been diagnosed with celiac disease. Dylan soon realized that transitioning Calvin to a gluten-free lifestyle really meant changing nearly everything about how he lived. She chose to transform her entire household to gluten-free to ensure Calvin's safety.

Calvin's diagnosis was a shock to Dylan, especially since he had no gastrointestinal symptoms. Soon she realized that, like herself, parents with newly-diagnosed kids need help navigating the journey. Dylan teamed up with Beyond Celiac to help spread awareness and understanding of this serious autoimmune disease.

Alice Bast, Beyond Celiac founder & CEO, introduces Beyond Celiac 2023 Summit keynote speaker, Dylan Dreyer, NBC News meteorologist and co-host of the 3rd Hour of Today.

This led us to focus on pediatric celiac disease for this year's Beyond Celiac/ Harris Poll survey. As you will see in this report, we learned that parents of children under the age of 18 really do not know much more about celiac disease than Americans without children under 18 know.

Beyond Celiac vowed three years ago to drive the search for a cure by 2030. We continue to lead the way so that the 3.2 million children and adults diagnosed with the disease can live healthy lives and eat without fear of gluten exposure. I encourage you to be part of this mission by sharing this important report with family and friends and making a donation today.

Alice Bast
Founder & CEO

FIVE KEY TAKEAWAYS

from the 2024 survey by The Harris Poll on behalf of Beyond Celiac

To gain a better understanding of the knowledge and perceptions that Americans have about pediatric celiac disease, Beyond Celiac commissioned The Harris Poll to conduct a 2024 national benchmarking survey. The Harris Poll on behalf of Beyond Celiac was conducted nationwide January 9-11, 2024, among 2,074 U.S. adults ages 18 and older.

1. Nearly one-third (32%) of parents with a child under 18 mistakenly believe that it's fine for a child with celiac disease to eat food served at birthday parties, snacks after their sports team game, and other special occasion situations even though it is not gluten-free because it's not a daily occurrence. **32%**
2. Only 14% of parents with a child under 18 understand that many kids with celiac disease do not have stomach issues. **14%**
3. Just over one-third (38%) of parents with a child under 18 know that children who get accurately diagnosed with celiac disease and go on the gluten-free diet may still have co-related health conditions. **38%**
4. Only about a quarter of Americans (24%) realize that family members of people with celiac disease could have it without even knowing it. **24%**
5. Only one-fifth (21%) of parents with children under 18 are aware that the average time a person waits to be correctly diagnosed with celiac disease is 6 to 10 years. **21%**

BY THE NUMBERS

What we learned from the 2024 Survey

Getting Diagnosed

Stomach Issues

Many kids with celiac disease do not have stomach issues, yet only 14% of parents with a child under 18 realize that is the case. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**14%**
Without children under 18	**9%**

Race/Ethnicity

Hispanic	**14%**
Black (not Hispanic)	**11%**
White (not Hispanic)	**9%**

Gender

Male	**11%**
Female	**10%**

Age

18-34	**12%**
35-44	**12%**
45-54	**10%**
55-64	**11%**
65+	**7%**

BY THE NUMBERS

What we learned from the 2024 Survey

Ease of Diagnosis

When asked if they thought it was a true statement that doctors know what to look for and can easily spot a child with celiac disease, nearly one-fourth (24%) of parents with a child under 18 incorrectly believed it was true. Americans without children under 18 have a better understanding, however, with only 12% thinking the statement is true. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**24%**
Without children under 18	**12%**

Race/Ethnicity

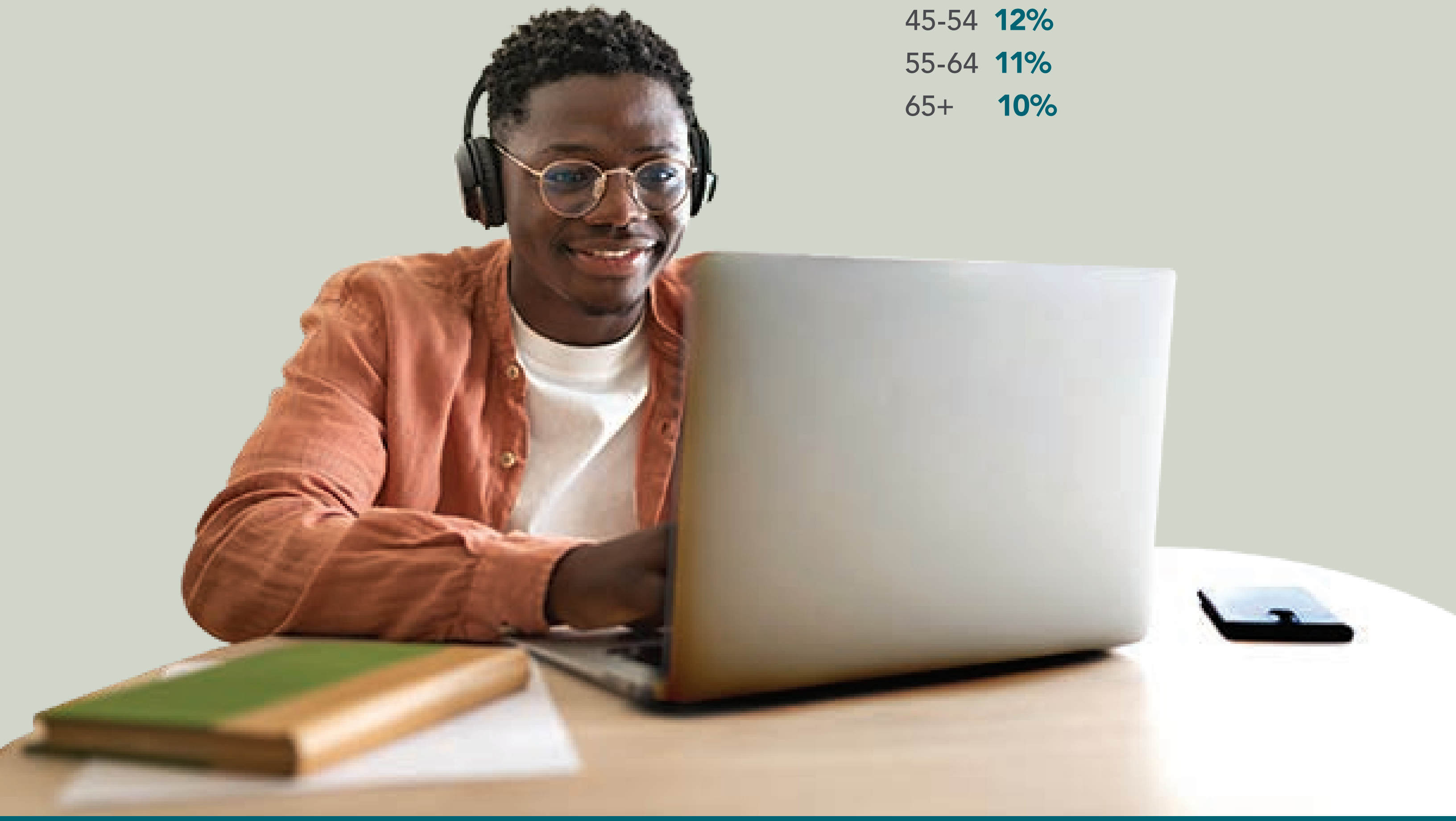
Hispanic	**18%**
Black (not Hispanic)	**27%**
White (not Hispanic)	**12%**

Gender

Male	**19%**
Female	**12%**

Age

18-34	**21%**
35-44	**20%**
45-54	**12%**
55-64	**11%**
65+	**10%**



BY THE NUMBERS

What we learned from the 2024 Survey

Undiagnosed/Misdiagnosed

Only about one-fourth of Americans (23%), whether they are parents or not, know that up to an estimated 83% of people with celiac disease are undiagnosed or misdiagnosed. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**25%**
Without children under 18	**23%**

Race/Ethnicity

Hispanic	**22%**
Black (not Hispanic)	**17%**
White (not Hispanic)	**25%**

Gender

Male	**20%**
Female	**26%**

Age

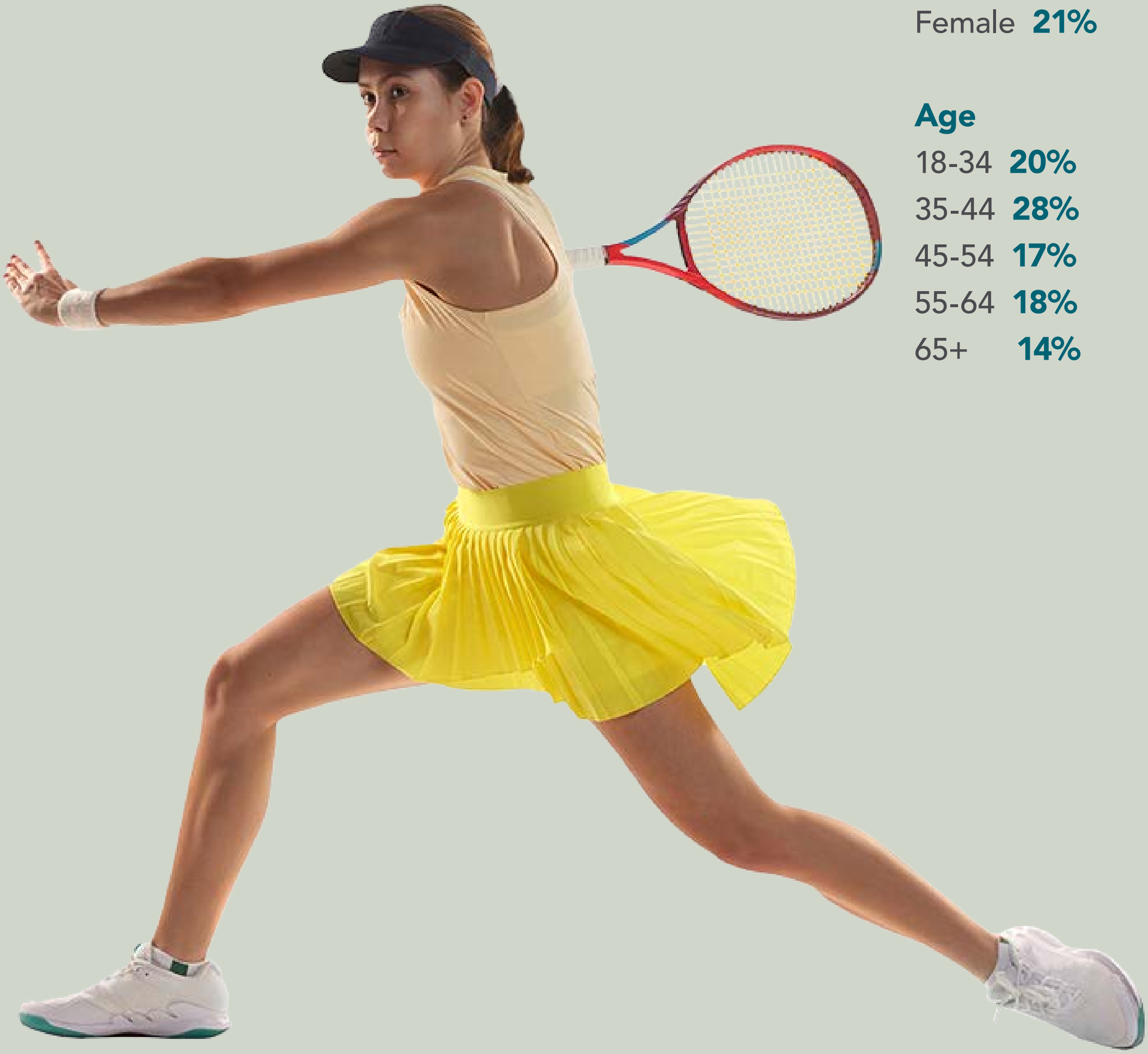
18-34	**25%**
35-44	**19%**
45-54	**24%**
55-64	**23%**
65+	**23%**

BY THE NUMBERS

What we learned from the 2024 Survey

Length of Time to Diagnosis

Only one-fifth (21%) of parents with children under 18, and 16% of Americans without children under 18, are aware that the average time a person waits to be correctly diagnosed with celiac disease is 6 to 10 years. Here is the demographic profile of how Americans answered this question.



Parents of Children Under 18

With a child under 18	**21%**
Without children under 18	**16%**

Race/Ethnicity

Hispanic	**16%**
Black (not Hispanic)	**11%**
White (not Hispanic)	**20%**

Gender

Male	**14%**
Female	**21%**

Age

18-34	**20%**
35-44	**28%**
45-54	**17%**
55-64	**18%**
65+	**14%**

BY THE NUMBERS

What we learned from the 2024 Survey

Family Members

Family members of people with celiac disease could have it without even knowing it. Yet, only 27% of parents with a child under 18, and 23% of Americans without children under 18, are aware of this. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**27%**
Without children under 18	**23%**

Race/Ethnicity

Hispanic	**22%**
Black (not Hispanic)	**15%**
White (not Hispanic)	**25%**

Gender

Male	**21%**
Female	**27%**

Age

18-34	**22%**
35-44	**28%**
45-54	**26%**
55-64	**25%**
65+	**21%**

BY THE NUMBERS

What we learned from the 2024 Survey

Living with Celiac Disease

School Lunch

Nearly one-half (46%) of parents with a child under 18 believe that most children with celiac disease have to take their lunch to school because most schools don't offer a safe gluten-free option lunch. Nearly one-half (46%) of parents without children under 18 also said the statement was true. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**46%**
Without children under 18	**46%**

Race/Ethnicity

Hispanic	**46%**
Black (not Hispanic)	**34%**
White (not Hispanic)	**48%**

Gender

Male	**39%**
Female	**52%**

Age

18-34	**48%**
35-44	**42%**
45-54	**43%**
55-64	**49%**
65+	**49%**

BY THE NUMBERS

What we learned from the 2024 Survey

Emotional/Social Challenge

Children with celiac disease face emotional and social challenges due to having the disease because, in addition to their dietary restrictions, they feel left out or different from their peers. Some 44% of parents with a child under 18, as well as 43% of Americans without children under 18, agreed. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**44%**
Without children under 18	**43%**

Race/Ethnicity

Hispanic	**40%**
Black (not Hispanic)	**35%**
White (not Hispanic)	**45%**

Gender

Male	**38%**
Female	**48%**

Age

18-34	**44%**
35-44	**41%**
45-54	**40%**
55-64	**42%**
65+	**46%**

BY THE NUMBERS

What we learned from the 2024 Survey

Co-related Health Conditions

Children who get accurately diagnosed with celiac disease and go on the gluten-free diet may still have co-related health conditions. Slightly more than one-third (38%) of parents with a child under 18 understood that this is true. Americans without children under 18 had a similar understanding with 38% agreeing it is a true statement. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**38%**
Without children under 18	**37%**

Race/Ethnicity

Hispanic	**40%**
Black (not Hispanic)	**26%**
White (not Hispanic)	**39%**

Gender

Male	**34%**
Female	**41%**

Age

18-34	**43%**
35-44	**35%**
45-54	**38%**
55-64	**35%**
65+	**35%**

BY THE NUMBERS

What we learned from the 2024 Survey

Social Events

One-third (32%) of parents with a child under 18 incorrectly believe that it is fine for a child with celiac disease to eat food served at birthday parties, snacks after their sports team game, and other special occasion situations even though it is not gluten-free because it is not a daily occurrence. Americans without children under 18 were more likely to be aware, with only one-fifth (20%) incorrectly thinking it was true. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**32%**
Without children under 18	**20%**

Race/Ethnicity

Hispanic	**28%**
Black (not Hispanic)	**38%**
White (not Hispanic)	**20%**

Gender

Male	**29%**
Female	**18%**

Age

18-34	**33%**
35-44	**29%**
45-54	**19%**
55-64	**16%**
65+	**16%**

BY THE NUMBERS

What we learned from the 2024 Survey

A Little Bit of Gluten?

Nearly one-third (32%) of parents with a child under 18 mistakenly believe that a little bit of gluten won't hurt a child with celiac disease. Americans without children under 18 were more likely to be knowledgeable, as only 16% believed this was a true statement. Here is the demographic profile of how Americans answered this question.

Parents of Children Under 18

With a child under 18	**32%**
Without children under 18	**16%**

Race/Ethnicity

Hispanic	**29%**
Black (not Hispanic)	**30%**
White (not Hispanic)	**16%**

Gender

Male	**24%**
Female	**17%**

Age

18-34	**30%**
35-44	**26%**
45-54	**17%**
55-64	**13%**
65+	**12%**

FACTS ABOUT PEDIATRIC CELIAC DISEASE

Celiac disease is a misunderstood and misdiagnosed condition that affects a person both physically and emotionally. Until there is a cure or a treatment, the only option is to follow a strict gluten-free diet. However, there is still a possibility of "getting glutened" which means eating something unknowingly that contains gluten or accidentally consuming cross-contaminated foods. It is a burden to manage.

Managing a gluten-free diet becomes even more complicated when a child under the age of 18 is diagnosed with celiac disease. Parents of children under 18 who have celiac disease have quite a challenge as well, especially when first learning of their child's diagnosis. They have many questions, including 'where do I start?'

This section contains facts about pediatric celiac disease and provides access to further resources.

What is Celiac Disease?

Unlike wheat allergy or gluten intolerance, celiac disease is a serious genetic autoimmune condition triggered by consuming gluten, which is found in wheat, barley and rye. For someone with celiac disease, eating gluten damages the villi of the small intestine and interferes with the absorption of nutrients from food. So, like with all autoimmune conditions, the body mistakenly attacks itself.

A systemic autoimmune disorder, celiac disease can be chronically debilitating, a fact which is often misunderstood. Left undiagnosed or unmanaged, celiac disease can lead to lymphoma or other cancers, additional autoimmune problems and a range of life-threatening medical conditions.

FACTS ABOUT PEDIATRIC CELIAC DISEASE

At What Age Do Symptoms of Celiac Disease Show Up?

The symptoms of celiac disease can appear at any age. In children, symptoms can appear as early as six months old.

By the time symptoms appear, some reversible damage to the child's small intestine has already occurred. Parents who think their child may have celiac disease should contact their pediatrician immediately.

Use the Celiac Disease Symptoms Checklist on the Beyond Celiac website to check all symptoms that apply. Hit the submit button and receive an email of results that can be shared with a physician. Some individuals with celiac disease do not have any outward symptoms. Individuals with certain risk factors, like having a family member with celiac disease, should be tested even if symptoms are not present.

FACTS ABOUT PEDIATRIC CELIAC DISEASE

What Are the Symptoms of Celiac Disease?

There are more than 300 known symptoms of celiac disease. Celiac disease symptoms may vary among different people. Symptoms of celiac disease in children are not necessarily the same as in adults. Due to the wide variety of symptoms that may present themselves, it can sometimes be difficult to diagnose celiac disease.

For example, one person might experience diarrhea and abdominal pain, while another person has irritability or headaches. Some patients develop symptoms of celiac disease early in life, while others feel healthy far into adulthood. Some people with celiac disease have no signs or symptoms at all, but that does not mean they are avoiding long-term health complications.

These differences can make a celiac disease diagnosis extremely difficult to make. In fact, up to 83% of people with celiac disease are either undiagnosed or misdiagnosed with other conditions.[1]

Left untreated, people with celiac disease can develop further complications such as other autoimmune diseases, osteoporosis, thyroid disease and certain cancers.

Common Signs and Symptoms of Celiac Disease in Children

Abdominal Pain
Anemia
Bloating/Gas
Canker Sores
Constipation
Decreased Appetite
Diarrhea
Discolored Teeth
Fatigue
Delayed Growth or Puberty
Distended Abdomen
Irritability
Joint pain
Obesity
Short Stature
Skin Rashes
Thin Bones/Frequent Fractures
Vomiting

FACTS ABOUT PEDIATRIC CELIAC DISEASE

How Many People Have Celiac Disease?

One in 133 Americans, about 1% of the population, has celiac disease, according to the landmark prevalence study on the disease.[2] That equates to about 3.2 million people in the U.S. The study also determined that 60% of children and 41% of adults diagnosed during the study were asymptomatic. Further, only 35% of newly diagnosed patients had chronic diarrhea, dispelling the myth that diarrhea must be present to diagnose celiac disease. And while the estimate is that approximately 1% of the population has celiac disease, some researchers believe that prevalence may now be as high as 2.4% based on newer studies.[3]

What Kind of Testing Is Done for Diagnosis of Celiac Disease?

Blood Tests

Blood tests are the first step in a diagnosis of celiac disease. A doctor will order one or more of a series of blood tests to measure the body's response to gluten. It is important to remain on a normal, gluten-containing diet prior to testing for celiac disease. Do not change to the gluten-free diet before being tested for celiac disease. If the blood tests and symptoms indicate celiac disease, a physician will likely suggest a biopsy of the lining of the small intestine to confirm the diagnosis.

Keep in mind that going gluten-free before being tested for celiac disease can prevent diagnosis. However, people who have already adopted the gluten-free diet without having been tested for celiac disease can undergo a "gluten challenge" to receive accurate test results.

FACTS ABOUT PEDIATRIC CELIAC DISEASE

Negative Results

If blood tests come back negative there is still a chance celiac disease could be present. If other risk factors exist or if symptoms continue to persist after a negative blood test, talk to the doctor about performing further tests such as an endoscopy or genetic screenings. Continued testing is encouraged to establish an accurate diagnosis, whether for celiac disease, non-celiac gluten sensitivity, or other diseases with similar symptoms.

Endoscopy

To confirm a celiac disease diagnosis, the doctor may recommend an upper gastrointestinal endoscopy. This procedure will identify any inflammation or damage in the small intestines, which is a sure sign of celiac disease. The doctor will take a small biopsy of the intestines during the endoscopy, which will help to confirm diagnosis. For the endoscopy to be accurate, the patient must be on a gluten-containing diet.

Non-Celiac Gluten Sensitivity

If small intestinal biopsy results indicate that celiac disease is not present, but the doctor and/or the patient still suspect gluten is the cause of symptoms, the next step is often to explore the possibility of non-celiac gluten sensitivity ("gluten sensitivity"). However, currently there are no accepted methods of testing for gluten sensitivity.

Follow-Up Testing

Celiac disease damages the villi, which are finger-like projections in the small intestine. Villi are responsible for absorbing nutrients from food. Because of this, it is highly likely that people with celiac disease will be deficient in essential vitamins and nutrients when diagnosed. Laboratory tests should be done within three to six months following a diagnosis and annually to monitor nutritional absorption.

FACTS ABOUT PEDIATRIC CELIAC DISEASE

Genetic Testing

To develop celiac disease, a person must have either the HLA-DQ2 or HLA-DQ8 genes. Without one of these genes, it is virtually impossible to develop celiac disease. The celiac disease genes alone are not enough to develop celiac disease. Up to 40 percent of people have these genes, yet only a very small percentage of these people go on to develop celiac disease. That is because an environmental trigger is necessary. This trigger can be a stressful event, illness, surgery, pregnancy, etc.

Because having the genes does not automatically lead to celiac disease, genetic testing can only rule out celiac disease. It cannot concretely diagnose celiac disease. Genetic testing is beneficial for relatives of people diagnosed with celiac disease. Since it is a genetic (hereditary) autoimmune disease, family members are also at risk for developing it. Relatives should have the blood test to determine if they have celiac disease. If the test is negative, it should be repeated every two to three years or sooner if symptoms occur. Those with negative test results can go on to get the gene test. If the gene test is negative, the relative can stop with regular screening.

FACTS ABOUT PEDIATRIC CELIAC DISEASE

Is It Necessary to Have an Endoscopy if the Blood Test Comes Back Positive?

Undergoing an endoscopy to gather tissue for a biopsy is the final step in diagnosing celiac disease. Yet, 30% of patients who screen positive in the blood test for celiac disease never get the endoscopy/biopsy to confirm the diagnosis, according to recent research conducted by Beyond Celiac. For children, that number is even higher, jumping to about 50% who never obtain the biopsy after screening positive in the blood test.

The reason children get an endoscopy and biopsy less frequently than adults is not certain, but it may be due to parents' worry about children having an invasive procedure, the study says. Children from one to 10 were the least likely to have the follow-up procedure.

During an endoscopy, a very thin, flexible tube is snaked from the mouth to the small intestine, and a small tool is used to take tissue samples, called biopsies, from the wall of the intestine. Patients are sedated, with the type and amount of sedation dependent on age and any other co-existing medical conditions. Guidelines from U.S. organizations for gastroenterologists recommend that a positive blood test should lead to an endoscopy and biopsy, currently the gold standard for diagnosis of celiac disease for adults and children.

FACTS ABOUT PEDIATRIC CELIAC DISEASE

How Long Does It Take to Be Diagnosed?

It has long been reported that the average time a person waits to be correctly diagnosed with celiac disease is 6-10 years[4] with newer research noting that the delay to diagnosis of the disease is as long as from three to 13 years.[5]

How is Celiac Disease Treated?

There are no FDA-approved drugs to treat celiac disease. At the present time, following a strict, 100% gluten-free diet is the only way to avoid experiencing symptoms, but the gluten-free diet does not treat the condition. It is best to transition your child to a gluten-free diet as soon as possible after diagnosis. The sooner your child is gluten-free, the sooner he/she will stop suffering and start healing.

My Child Has Been Diagnosed with Celiac Disease. Now What?

Parents of a child with celiac disease have the unique challenge of teaching the child about celiac disease and eating gluten-free, as well as cooking them food they can safely eat. This may seem like an overwhelming challenge at first, but parents often say that it gets easier with time.

There is an entire section on Celiac Disease and Children on the Beyond Celiac website. When transitioning to a gluten-free diet, remember that each child will react to the gluten-free diet differently. Some see improvement within a few days; other take months before symptoms subside. The important thing is to always maintain a 100% gluten-free diet. Review A Guide to the Gluten-Free Diet for Kids on the Beyond Celiac website.

Other resources that will be helpful are:
- Parent Resource Guide for Supporting Children with Celiac Disease is available for download on the Beyond Celiac website
- Articles & Resources for Parents of Children with Celiac Disease
- FAQs with Answers from a Pediatric Gastroenterologist

FACTS ABOUT PEDIATRIC CELIAC DISEASE

How Will My Child Stay Gluten-Free at School?

There are several ways to help ensure your child's success, safety and happiness at school. Meet with your child's teacher at the beginning of each school year to discuss celiac disease and the need to stay gluten-free. Teachers can be your child's ally in the classroom.

There are two other ways to keep your child safe in school – an Individualized Healthcare Plan (IHP) and a 504 Plan.

- An IHP is a medical document describing your child's basic needs and outlining how those needs will be addressed. All children with celiac disease should have an IHP at a minimum. It is usually obtained by contacting the school nurse.
- A 504 plan is a legally-binding agreement that is part of the Americans with Disabilities Act (ADA). Celiac disease qualifies for a 504 plan. It can be carried with the child throughout the college years and can be customized to your child's needs.

Start by reading this article comparing IHPs and 504 plans.

Gluten-free kids can miss out on the moments their peers take for granted, such as eating a cupcake or pizza to celebrate a classmate's birthday. If this upsets your child, validate their feelings and talk with them about it. Consider sending alternatives to school with them so they can eat the same type of food as their peers. The gluten-free diet is more than just food. It really is a lifestyle, so it can affect children's confidence and their emotional and social health, too.

FACTS ABOUT PEDIATRIC CELIAC DISEASE

What Does My Teenager with Celiac Disease Need to Be Aware of Heading Off to College?

No matter how long your teenager has been living gluten-free, there are considerations to think about when heading off to college. The Beyond Celiac website has a section on Information for College Students that covers topics such as gluten-free accommodations on campus and talking to university staff. The section also includes a downloadable Gluten-Free in College Student Toolkit.

BLUEPRINT FOR A CURE

Beyond Celiac was created 20 years ago to make sure that people get diagnosed accurately and after diagnosis, that they have an advocate in their corner to push for treatments beyond the gluten-free diet, while also creating a community of understanding and support.

We are the leading catalyst for a celiac disease cure. As the premier celiac disease nonprofit funder of research globally, we engage with the top scientists in the field and make investments in research that will lead to the cure. Earlier this year we announced the creation of Beyond Celiac Investments (BCI), an investment program to accelerate the development of treatments and a cure for celiac disease by leveraging the speed and scale of venture capital and capital markets. We have mapped out our blueprint and will continue to innovate and push forward until there is a cure.

To Beyond Celiac, a cure means real treatment options so those with celiac disease can live healthy lives and eat without fear.

How Beyond Celiac is Leading the Way

The Science Plan

Three years ago, Beyond Celiac developed and began implementing a strategic Science Plan to accelerate a celiac disease cure by 2030.

The Plan addresses and seeks to overcome the many barriers to finding an effective treatment or cure. Current barriers to a cure for celiac disease include:

- Poor understanding of celiac disease by the medical community
- Limited support for early career scholars/researchers
- Serious nature of the disease is underappreciated
- Too many people remain undiagnosed
- Lack of funding and strategic focus for research
- Assumption that the gluten-free diet is enough

BLUEPRINT FOR A CURE

Here are our scientific priorities underway that will lead to a cure.

1. *Evidence Generation: Highlighting the seriousness of celiac disease*
   Through our patient registry, Go Beyond Celiac, and other initiatives, we are collecting and analyzing comprehensive data on the burden of celiac disease and gluten sensitivity. With this information, we can increase awareness and make a compelling case for larger investments from government agencies, pharmaceutical companies, biotech and more.

2. *Translational Research: Accelerating scientific progress toward a cure*
   We are funding promising research quickly translates from scientific investigation to clinical use, speeding the development of treatments for patients.

3. *Clinical Trials: Enabling faster approval of treatments*
   As the nation's top recruiter for celiac disease clinical trials, we will continue educating our community about the importance of participating in trials. We will also work with pharmaceutical companies to ensure trials are designed with patient perspectives in mind.

4. *Drug Repurposing: Leveraging existing solutions for our community*
   We will invest significant resources to identify treatments that have been investigated or approved for other purposes but might also benefit celiac disease patients, reducing risk, cost and time to market for potential celiac disease treatments.

BLUEPRINT FOR A CURE

Beyond Celiac Investments (BCI)

To fulfill the fourth phase in the Science Plan, Beyond Celiac launched Beyond Celiac Investments (BCI) in February of this year. It is the first investment program for celiac disease therapeutics to focus on accelerating treatments and a cure.

Starting with an initial funding of $2 million with additional capital raised through donations, BCI leverages the speed and scale of venture capital and capital markets.

Beyond Celiac research uncovered no venture funds with a specific focus on celiac disease or autoimmune disorders, though many venture funds invest in companies that have the potential to address it. BCI plans to invest significant resources to identify promising treatments under development as well as those that have been investigated or approved for other purposes that also might benefit celiac disease patients.

BCI is using the Development Catalyst business model, designed to increase development and commercialization activity across the Celiac treatment spectrum. The model enables drug development through nonprofit means. Using donated funds also means that all financial returns from BCI's investments return to Beyond Celiac to be used for future investments and grants to benefit Beyond Celiac's cure acceleration mission and celiac disease population.

Because BCI uses donated funds through a venture philanthropy model, investing began immediately. BCI's Development Catalyst investment strategy will focus dollars for the greatest impact on the most promising investments.

BLUEPRINT FOR A CURE

The Beyond Celiac Coalition

Two years ago, Beyond Celiac formed a first-of-its-kind coalition – the Beyond Celiac Coalition – to accelerate clinical research in celiac disease and to assure that the patients' voice is always heard.

The Beyond Celiac Coalition is composed of members from pharmaceutical, biotech, diagnostic companies as well as leading researchers and clinicians in the field. Beyond Celiac formed this precompetitive partnership with the overarching goal of addressing significant roadblocks on the path to a cure for celiac disease, with a particular emphasis on breaking down barriers to patient engagement in clinical trials.

A key project of the Coalition was meeting with representatives of the FDA in May of this year to address major patient barriers to accelerate clinical trials for celiac disease.

Online Patient Registry

Go Beyond Celiac is the organization's online patient registry and app that collects data to accelerate research for celiac disease. More than 9,000 patients are registered and have connected with the celiac disease community to share resources and participate in celiac disease studies.

Beyond Celiac is the nation's top recruiter for celiac disease clinical trials and works with pharmaceutical companies to ensure that trials are designed with the patient perspective in mind.

BLUEPRINT FOR A CURE

Health Inequities in Diagnosis of Celiac Disease

Beyond Celiac is leading the way in documenting and bringing greater awareness to health inequities in celiac disease. Research suggests that disparities in healthcare access may result in underdiagnosis of celiac disease in non-white Americans. Original research using Medicare data from a partnership between Beyond Celiac and the National Minority Quality Forum (NMQF) was presented May 9, 2023, at Digestive Disease Week (DDW), the largest international gathering of physicians, researchers and academics in the fields of gastroenterology, hepatology, endoscopy and gastrointestinal surgery.

The analysis included median income, race, urban areas and proximity to a celiac disease center. The results showed that as the median income increased, so did the prevalence of celiac disease. The research presented at DDW found that a higher income, living in an urban area and living close to a celiac disease center are all positively correlated with celiac disease prevalence, while being Black or Latino/Hispanic is negatively correlated. Meanwhile, the percent of Latino/Hispanics with Medicare claims for celiac disease decreased as the percentage of relative celiac disease increased. For Black people, this was also largely true.

ABOUT BEYOND CELIAC

Founded in 2003, Beyond Celiac is the leading catalyst for a celiac disease cure in the United States, serving as a patient advocacy and research-driven organization working to drive diagnosis and accelerate the discovery of new treatments. By engaging with the top scientists in the field, making the right investments in research and supporting the broad community of those with celiac disease and gluten sensitivity, Beyond Celiac envisions a world in which people can live healthy lives and eat without fear – a world Beyond Celiac. www.BeyondCeliac.org.

SURVEY METHODOLOGY

This survey was conducted online within the United States by The Harris Poll on behalf of Beyond Celiac from January 9-11, 2024, among 2,074 U.S. adults ages 18 and older. The sampling precision of Harris online polls is measured by using a Bayesian credible interval. For this study, the sample data is accurate to within +/- 2.5 percentage points using a 95% confidence level. For complete survey methodology, including weighting variables and subgroup sample sizes, please contact acrist@beyondceliac.org.

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