



The Persisting Myths About Celiac Disease

Americans' Attitudes and
Understanding Are Falling Short

Table of Contents



3	Introduction
4	2023 Survey Results
4	Five Key Takeaways
5	By the Numbers
8	Facts about Celiac Disease
14	Leading the Way
19	About Beyond Celiac
19	Survey Methodology
20	References

Introduction

Solving the Mystery



It is a serious autoimmune condition, yet celiac disease remains a mystery. It is misunderstood, misdiagnosed, and there is no cure. Left untreated, it can lead to a number of serious, long-term health problems.

Last year the first nationwide benchmark report on celiac disease from Beyond Celiac revealed that only half of Americans know anything about celiac disease and/or gluten sensitivity. Earlier this year we again commissioned The Harris Poll to conduct a nationwide survey on behalf of Beyond Celiac, and uncovered additional eye-opening statistics that you will read about in this report. Celiac disease has come a long way in terms of awareness since I founded this organization in 2003 and we still have work to do to achieve our vision of a world in which people with celiac disease can live healthy lives, free from social stigma and fear of gluten exposure.

It's time for change. It is time to find a cure. Beyond Celiac is working diligently to drive treatments leading to a cure by 2030.

I understand the frustration of those who have symptoms but don't have a diagnosis. I understand what the 3.2 million Americans who have celiac disease experience even after they are diagnosed. I understand, because I have celiac disease. After visiting 22 doctors and still having no answers, it wasn't until I was speaking with a friend, a veterinarian, who suggested it could be celiac disease. So, I went to a 23rd doctor, asked for the blood test, and was finally diagnosed. That's why it is my passion and my mission to accelerate the quest for a cure. And, I too find it difficult to eat without fear.

Let us all commit to solving the mystery and to creating a future beyond celiac disease! If everyone whose life is touched by celiac disease – whether it be themselves, family members or friends – could make a donation today – we'd be well on our way to accelerating the discovery of a cure.

Alice Bast

Founder & CEO

Five Key Takeaways

From the 2023 Survey by The Harris Poll on behalf of Beyond Celiac

To gain a better understanding of the knowledge and perceptions that Americans have about celiac disease, Beyond Celiac commissioned The Harris Poll to conduct a 2023 national benchmarking survey. The Harris Poll on behalf of Beyond Celiac was conducted nationwide April 11-13, 2023, among 2,081 adults ages 18 and older.

- 1.** Only about a quarter of Americans (27%) realize that getting diagnosed with celiac disease is difficult because many people who have no stomach or digestion-related symptoms don't get tested for celiac disease and are misdiagnosed with something else.
- 2.** Only 40% of Americans know that left undiagnosed or unmanaged, celiac disease could lead over time to lymphoma or other cancers, additional autoimmune problems and/or a range of life-threatening medical conditions.
- 3.** Only 43% of Americans think that going to parties and other kinds of socializing are difficult when you are limited to gluten-free food.
- 4.** Over a quarter of Americans (28%) assume that people who eat gluten-free are just trying to get attention.
- 5.** One-third (33%) of Americans incorrectly believe that research to learn more about the causes of and a cure for celiac disease receives as much attention and funding as other serious diseases.

27%

40%

43%

28%

33%

By The Numbers

What We Learned from the 2023 Survey

Getting Diagnosed

Overall, 27% of Americans reported knowing that it is difficult to get diagnosed with celiac disease because many people have no stomach or digestion-related systems, don't get tested, and are misdiagnosed with something else. Here's how Americans answered this question, by demographic profile.

Race/Ethnicity

Hispanic **30%**
White (non-Hispanic) **28%**
Black (non-Hispanic) **21%**

Education

High School or Less **25%**
Some College **25%**
College Grad+ **30%**

Gender

Female **30%**
Male **23%**

Age

18-34 **33%**
35-44 **29%**
45-54 **27%**
55-64 **20%**
65+ **22%**

Household Income

Less than \$50,000 **24%**
\$50,000 - \$74,999 **27%**
\$75,000 - \$99,999 **28%**
\$100,000+ **29%**



By The Numbers

What We Learned from the 2023 Survey

Undiagnosed Celiac Disease

Only 40% of Americans know that left undiagnosed or unmanaged, celiac disease could lead over time to lymphoma or other cancers, additional autoimmune problems and/or a range of life-threatening medical conditions. Here's how Americans answered this question, by demographics.

Gender

Women **43%**
Men **38%**

Region

Midwest **44%**
South **41%**
Northeast **39%**
West **37%**

Race/Ethnicity

Black (Non-Hispanic) **43%**
Hispanic **40%**
White (Non-Hispanic) **40%**

Gluten-Free

Americans attitudes and perceptions of the gluten-free diet vary.

61% of Americans strongly/somewhat agree that they assume people who follow a gluten-free diet have been medically diagnosed with a valid health reason to do so

57% of Americans strongly/somewhat agree that many people following a gluten-free diet are trying to lose weight

49% of Americans strongly/somewhat agree that people who eat gluten-free are generally healthier those people who eat gluten

28% of Americans strongly/somewhat agree that people who eat gluten-free are just trying to get attention

By The Numbers

What We Learned from the 2023 Survey

More About Celiac Disease

One-fifth (**22%**) of Americans believe that celiac disease is cured by following a gluten-free diet.

One-fifth (**20%**) of Americans think that celiac disease is a food allergy.

Living with Celiac Disease and Following a Gluten-Free Diet

One-half (**52%**) of Americans believe that because gluten can be found in many processed foods, sauces and condiments, that it can be challenging to find gluten-free options in grocery stores

Only **43%** of Americans realize that going to parties and other kinds of socializing are difficult when you are limited to gluten-free food

Only **39%** of Americans think that managing a gluten-free diet is hard because gluten-free food is more expensive

Only **38%** of Americans believe that traveling is difficult when you are limited to gluten-free food

Only **18%** of Americans consider that dining out is an easy, safe option for someone with celiac disease because most restaurants have gluten-free options on the menu

Celiac Disease Research

One-third (33%) of Americans mistakenly are under the impression that research to learn more about the causes of and a cure for celiac disease receives as much attention and funding as other serious diseases.

Facts About Celiac Disease

What is Celiac Disease?

Celiac disease is a serious genetic autoimmune disease triggered by consuming a protein called gluten, which is found in wheat, barley and rye. It damages the villi of the small intestine and interferes with the absorption of nutrients from food.

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

How Many People Have Celiac Disease?

One in 133 Americans, about 1 percent of the population, has celiac disease, according to the landmark prevalence study on the disease.¹ 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.²



Facts About 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. Due to the wide variety of symptoms that may present themselves, it can sometimes be difficult to diagnose celiac disease.

One person might have 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 doesn't mean they are avoiding long-term health complications.

These differences can make a celiac disease diagnosis extremely difficult to make, resulting in up to 83% of people with celiac disease being either undiagnosed or misdiagnosed with other conditions.³

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

Anemia

Anxiety

Bloating or gas

Brain fog

Constipation

Delayed growth in children

Depression

Diarrhea

Discolored teeth

Fatigue/tiredness

Infertility

Irritability

Itchy skin rash

Joint pain

Liver disease

Pale mouth sores

Poor weight gain

Thin bones

Tingling/numbness/neuropathy

Vomiting

Facts About Celiac Disease

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 your 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" in order to receive accurate test results.

Negative Results

If your blood tests come back negative there is still a chance you could have celiac disease. If you have other risk factors and still suspect celiac disease, or if you are continuing to experience symptoms after a negative blood test, talk to your 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.



Facts About Celiac Disease

Endoscopy

To confirm a celiac disease diagnosis, your doctor may recommend an upper gastrointestinal endoscopy. This procedure will allow your doctor to identify any inflammation or damage in your small intestines, which is a sure sign of celiac disease. Your doctor will take a small biopsy of your intestines during the endoscopy, which will help to confirm your diagnosis. In order for the endoscopy to be accurate, the patient must be on a gluten-containing diet. An endoscopy may sound like a big procedure, but it only takes about 15 minutes and is a low-risk procedure.

Non-Celiac Gluten Sensitivity

If your small intestinal biopsy results indicate that celiac disease is not present, but you and your doctor still suspect gluten is the cause of your symptoms, you may want to explore the possibility of non-celiac gluten sensitivity ('gluten sensitivity'). 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 for the rest of your life.



Facts About Celiac Disease

Genetic Testing

In order to develop celiac disease, you 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 it 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. It is recommended that relatives are given the blood test to determine if they have celiac disease. If the test is negative, it should be repeated every 2-3 years or sooner if symptoms occur because celiac disease can develop at any time. 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 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 years⁴ 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



Leading the Way

Dispelling the Myths and Driving Treatments for a Cure

Celiac disease is a misunderstood and misdiagnosed disease that does not receive as much attention or funding as other diseases that affect more people, even though it creates a lifelong burden for patients and affects both their physical and emotional health. 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.

Beyond Celiac is the leading catalyst for a celiac disease cure and the premier celiac disease nonprofit funder of research globally. Beyond Celiac engages with the top scientists in the field and makes the right investments in research that will lead to the 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

Driving treatments for a cure by 2030

The Science Plan

Two 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

Leading the Way

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, Beyond Celiac will continue educating our community about the importance of participating in trials. We also will 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.



Leading the Way

Grant Funding for Critical Celiac Disease Research

Beyond Celiac has committed more than \$3M to directly fund celiac disease research in the last several years as part of its comprehensive Science Plan to have treatments toward a cure by 2030. This includes \$1.6M in research funding announced in March 2023 to prestigious institutions in five countries, making Beyond Celiac the premier nonprofit funder of celiac disease research worldwide.

Research projects selected for grants this year address non-invasive/minimally invasive biomarkers of celiac disease, the microbiome and restoring/inducing immune tolerance to gluten antigens.

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 8,000 patients are registered and have connected with the celiac disease community to share resources and participate in celiac disease studies.

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

Leading the Way

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.

Frustration, Fear, and Luck Play a Role When a Celiac Disease Diagnosis Is Pursued

Beyond Celiac research has found that frustration and distress about symptoms lead most people with celiac disease to seek a diagnosis. These findings were presented by Beyond Celiac on May 9, 2023, at Digestive Disease Week (DDW).

Results from the qualitative study of 2,500 responses from adults who participated in surveys in the *Go Beyond Celiac* registry also found that fear and embarrassment prompted some participants to seek support from friends and family on their path to diagnosis. However, those same factors had the opposite effect on others, preventing them from seeking social support.



Leading the Way

Health Diversity, Equity and Inclusion

Beyond Celiac believes in a world where we all can live healthy lives free from bias and barriers. Across our work, we must engage diverse perspectives and promote equity in our community to realize our vision of a world Beyond Celiac. Our diversity, equity and inclusion mission includes fostering a sense of belonging by elevating underrepresented voices as we work together for a cure. We seek to be a community that welcomes diverse perspectives and provides meaningful opportunities to empower marginalized populations. At the heart of our vision is a world in which all people have equal access to good health choices, healthcare, and health outcomes.

Our work is dedicated to finding treatments and a cure for celiac disease, and part of that effort is focused on reducing disparities, both in diagnosis and access to resources. Achieving health equity comes from ensuring equity of opportunity and access in all facets of life for all members of the celiac disease community.



As a result, our ongoing commitment is to continue advocating for access to healthcare and the right for everyone to live their healthiest life, especially communities that are disproportionately affected by systemic, longstanding inequities of any type. We recognize that only by working with and listening to people of all races, backgrounds, ethnicities, sexual and gender orientations, abilities, and cultural backgrounds can we truly understand and appreciate one another and fulfill our mission of a world Beyond Celiac. Our work in all areas reflects this important truth – in science, in events and community resources, in partnerships, and in all of our interactions with the celiac disease community.

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 April 11-13, 2023 among 2,081 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 +/- 2.8 percentage points using a 95% confidence level. For complete survey methodology, including weighting variables and subgroup sample sizes, please contact cbaker@beyondceliac.org.

References

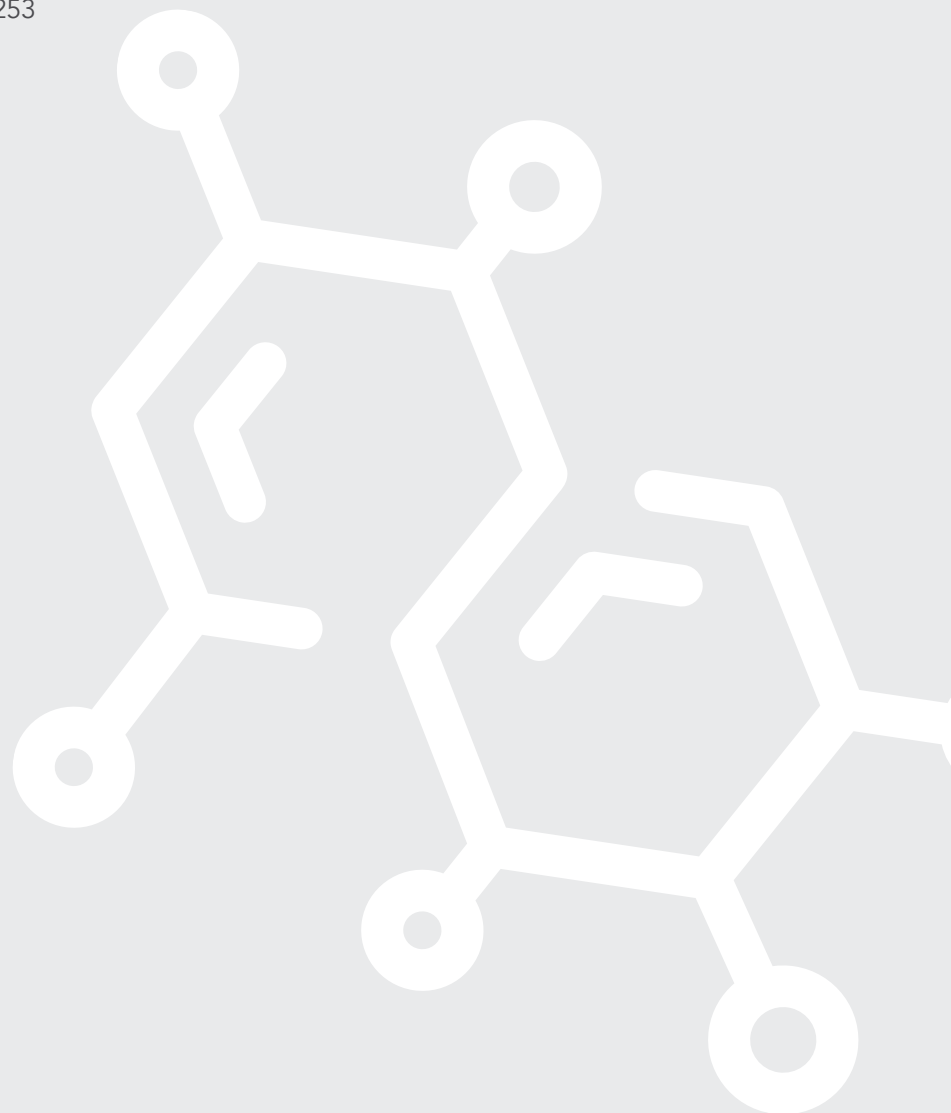
¹Choung, R. S., Unalp-Arida, A., Ruhl, C. E., Brantner, T. L., Everhart, J. E., & Murray, J. A. (2017). Less hidden celiac disease but increased gluten avoidance without a diagnosis in the United States. *Mayo Clinic Proceedings*, 92(1), 30–38. <https://doi.org/10.1016/j.mayocp.2016.10.012>

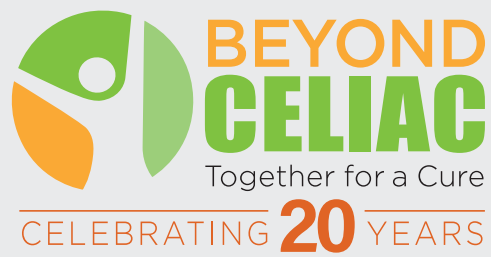
²Beyond Celiac. (2022, April 18). Marisa Stahl, MD: Mass Screening Outcomes for Pediatric Celiac Disease; Beyond Celiac 2022 Summit [Video]. YouTube. <https://www.youtube.com/watch?v=S8P03i7O76E>

³Whitburn, J., Rao, S. R., Paul, S. P., & Sandhu, B. K. (2021). Diagnosis of celiac disease is being missed in over 80% of children particularly in those from socioeconomically deprived backgrounds. *European Journal of Pediatrics*, 180(6), 1941–1946. <https://doi.org/10.1007/s00431-021-03974-8>

⁴Norström, F., Lindholm, L., Sandström, O., Nordyke, K., & Ivarsson, A. (2011). Delay to celiac disease diagnosis and its implications for health-related quality of life. *BMC Gastroenterology*, 11, 118. <https://doi.org/10.1186/1471-230X-11-118>

⁵Fuchs, V., Kurppa, K., Huhtala, H., Mäki, M., Kekkonen, L., & Kaukinen, K. (2018). Delayed celiac disease diagnosis predisposes to reduced quality of life and incremental use of health care services and medicines: A prospective nationwide study. *United European Gastroenterology Journal*, 6(4), 567–575. <https://doi.org/10.1177/2050640617751253>





BEYONDCELIAC.ORG