



Social Aspects of Living with Celiac Disease

Social Life Is Affected in Far More Ways than Americans Realize

**A Report from Beyond Celiac
August 2025**





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Introduction

At Beyond Celiac, our mission is rooted in science, but it is powered by people. Every day, we hear from individuals and families navigating life with celiac disease—managing strict gluten-free diets, navigating social situations with uncertainty and too often feeling isolated or misunderstood. While much progress has been made in recognizing celiac disease as a serious autoimmune condition, the social realities of living with it remain widely overlooked.



Alice Bast, Beyond Celiac founder & CEO, and Elissa Hassman Waldstein, DO, pose for a photo at the 2025 Evening Beyond Celiac, the organization's annual fundraising gala.

This report shines a necessary light on the knowledge gap that still exists in the public's understanding of the social burden of celiac disease. It reveals that many Americans do not yet grasp the emotional, relational, and daily lifestyle impacts that come with the diagnosis. From the anxiety of dining out to the exclusion from shared experiences, living with celiac disease can quietly affect nearly every aspect of a person's life.

Understanding these challenges is the first step toward meaningful change—toward empathy, support, and ultimately, toward accelerating the search for treatments and a cure. This report is part of our ongoing effort to not only advance research but also to amplify the lived experiences of the celiac disease community.

Thank you for joining us in this important conversation. We invite you to read, reflect and help us spread awareness of the real human impact behind the diagnosis.

Alice Bast
Founder & CEO

Five Key Takeaways

from the 2025 survey by The Harris Poll on behalf of Beyond Celiac

This survey was conducted online within the United States by The Harris Poll on behalf of Beyond Celiac from April 8 -10, 2025, among 2,099 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.

1. Almost one-half (49%) of Americans don't realize that for someone with celiac disease, eating gluten-free is a necessity, not a lifestyle choice. **49%**
2. A third of Americans (33%) think that when someone with celiac disease says 'I can't eat or drink that' that they are exaggerating their condition. **33%**
3. Almost half (48%) of Americans know that it is common for people with celiac disease to choose to eat before they go to a social event or bring their own food where it's possible to do so. **48%**
4. Nearly three-fourths (71%) of Americans realize that for people with celiac disease, going to parties and other kinds of social events is difficult both physically and emotionally when you are gluten-free. **71%**
5. Almost 6 in 10 (58%) of Americans don't know that even if a restaurant lists a menu item as gluten-free, there is still a need for someone with celiac disease to question the waiter about the pan it is cooked in or how the food is prepared. **58%**

What We Learned from the 2025 Survey

Eating Gluten-Free: Lifestyle Choice or Necessity?

49% of Americans don't realize that for someone with celiac disease, eating gluten-free is a necessity, not a lifestyle choice.



Demographic Breakdown

GENDER

Female **42%**
Male **56%**

RACE/ETHNICITY

Black (not Hispanic) **67%**
Hispanic **63%**
White (not Hispanic) **40%**

AGE

18-34 **62%**
35-44 **48%**
45-54 **54%**
55-64 **44%**
65+ **35%**

What We Learned from the 2025 Survey

Gluten-Free Options at Restaurants

37% of Americans don't know that even if most restaurants have many gluten-free options on the menu, it doesn't necessarily make dining out an easy, safe option for someone with celiac disease.



Demographic Breakdown

GENDER

Female **31%**
Male **42%**

RACE/ETHNICITY

Black (not Hispanic) **44%**
Hispanic **41%**
White (not Hispanic) **34%**

AGE

18-34 **34%**
35-44 **42%**
45-54 **37%**
55-64 **36%**
65+ **37%**

What We Learned from the 2025 Survey

Gluten-Free Food in Airports and on Airplanes

55% of Americans don't know that people with celiac disease who travel by airplane may still need to take food with them because there aren't plentiful gluten-free food options in airports and on airplanes.



Demographic Breakdown

GENDER

Female **52%**
Male **59%**

RACE/ETHNICITY

Black (not Hispanic) **51%**
Hispanic **54%**
White (not Hispanic) **56%**

AGE

18-34 **45%**
35-44 **49%**
45-54 **56%**
55-64 **60%**
65+ **69%**

What We Learned from the 2025 Survey

Gluten-Free Menu Items

58% (almost 6 in 10) of Americans don't know that even if a restaurant lists a menu item as gluten-free, there is still a need for someone with celiac disease to question the waiter about the pan it is cooked in or how the food is prepared.



Demographic Breakdown

GENDER

Female **54%**
Male **63%**

RACE/ETHNICITY

Black (not Hispanic) **63%**
Hispanic **60%**
White (not Hispanic) **55%**

AGE

18-34 **52%**
35-44 **51%**
45-54 **57%**
55-64 **64%**
65+ **66%**

What We Learned from the 2025 Survey

Eating Prior to a Social Event

48% (almost half) of Americans know that it is common for people with celiac disease to choose to eat before they go to a social event or bring their own food where it's possible to do so.



Demographic Breakdown

GENDER

Female **53%**
Male **42%**

RACE/ETHNICITY

Black (not Hispanic) **32%**
Hispanic **36%**
White (not Hispanic) **55%**

AGE

18-34 **46%**
35-44 **43%**
45-54 **47%**
55-64 **52%**
65+ **51%**

What We Learned from the 2025 Survey

Eating at a Business Function: Gluten-Free or Not?

51% of Americans don't know that people with celiac disease can't eat what they want at a business function that doesn't have gluten-free options just because it doesn't occur that often.



Demographic Breakdown

GENDER

Female **47%**
Male **55%**

RACE/ETHNICITY

Black (not Hispanic) **53%**
Hispanic **52%**
White (not Hispanic) **49%**

AGE

18-34 **46%**
35-44 **43%**
45-54 **48%**
55-64 **56%**
65+ **61%**

What We Learned from the 2025 Survey

Cross-Contamination of Gluten-Free Food

Only **39%** of Americans understand that even gluten-free food could be unsafe for those with celiac disease, unless it is prepared safely against cross-contamination.



Demographic Breakdown

GENDER

Female **44%**
Male **35%**

RACE/ETHNICITY

Black (not Hispanic) **33%**
Hispanic **29%**
White (not Hispanic) **45%**

AGE

18-34 **36%**
35-44 **37%**
45-54 **40%**
55-64 **39%**
65+ **45%**

What We Learned from the 2025 Survey

Kissing Someone Who Just Ate Gluten

Only **15%** of Americans think that if a person with celiac disease eats gluten-free when out on a date, but their date does not, they would not be able to kiss on the lips after the meal until their date thoroughly cleans their mouth or brushes their teeth.

**See further discussion on page 20.*



Demographic Breakdown

GENDER

Female	14%
Male	15%

RACE/ETHNICITY

Black (not Hispanic)	16%
Hispanic	20%
White (not Hispanic)	14%

AGE

18-34	24%
5-44	22%
45-54	15%
55-64	8%
65+	3%

What We Learned from the 2025 Survey

Eating Gluten-Free to Lose Weight

39% of Americans realize that some people who eat gluten-free food don't have celiac disease or gluten sensitivity, they do it to lose weight or for other reasons.



Demographic Breakdown

GENDER

Female **41%**
Male **36%**

RACE/ETHNICITY

Black (not Hispanic) **25%**
Hispanic **34%**
White (not Hispanic) **44%**

AGE

18-34 **35%**
35-44 **38%**
45-54 **41%**
55-64 **37%**
65+ **42%**

What We Learned from the 2025 Survey

Challenges of Attending Social Events

71% of Americans realize that for people with celiac disease, going to parties and other kinds of social events is difficult both physically and emotionally when you are gluten-free.



Demographic Breakdown

GENDER

Female **73%**

Male **69%**

RACE/ETHNICITY

Black (not Hispanic) **60%**

Hispanic **65%**

White (not Hispanic) **75%**

AGE

18-34 **64%**

35-44 **70%**

45-54 **72%**

55-64 **73%**

65+ **77%**

What We Learned from the 2025 Survey

Going to Bars or Restaurants with Peers

76% (three-fourths) of Americans know that having celiac disease makes it hard to be spontaneous or adventurous when going to bars or restaurants with peers.



Demographic Breakdown

GENDER

Female **77%**

Male **75%**

RACE/ETHNICITY

Black (not Hispanic) **69%**

Hispanic **70%**

White (not Hispanic) **79%**

AGE

18-34 **70%**

35-44 **74%**

45-54 **77%**

55-64 **81%**

65+ **81%**

What We Learned from the 2025 Survey

Isolation or Anxiety in Social Situations

77% (over three-fourths) of Americans understand that it is common for people with celiac disease to have feelings of isolation or anxiety in social situations because they have to be so particular about what they eat and drink.



Demographic Breakdown

GENDER

Female **79%**

Male **75%**

RACE/ETHNICITY

Black (not Hispanic) **70%**

Hispanic **70%**

White (not Hispanic) **81%**

AGE

18-34 **68%**

35-44 **77%**

45-54 **79%**

55-64 **81%**

65+ **83%**

What We Learned from the 2025 Survey

"I Can't Eat or Drink That"

33% (one-third) of Americans think that when someone with celiac disease says 'I can't eat or drink that' they are exaggerating their condition.

Demographic Breakdown

GENDER

Female **28%**

Male **38%**

RACE/ETHNICITY

Black (not Hispanic) **39%**

Hispanic **43%**

White (not Hispanic) **29%**

AGE

18-34 **37%**

35-44 **44%**

45-54 **39%**

55-64 **20%**

65+ **24%**



What We Learned from the 2025 Survey

Sharing Health Needs Publicly

77% (more than three-fourths) of Americans understand that sharing their health needs publicly in social and business situations when food is involved isn't what people with celiac disease want to do, it is what they have to do.



Demographic Breakdown

GENDER

Female **79%**

Male **75%**

RACE/ETHNICITY

Black (not Hispanic) **71%**

Hispanic **72%**

White (not Hispanic) **81%**

AGE

18-34 **69%**

35-44 **73%**

45-54 **80%**

55-64 **84%**

65+ **84%**

This survey was conducted online within the United States by The Harris Poll on behalf of Beyond Celiac from April 8 - 10, 2025 among 2,099 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.

How Social Life Changes on a Gluten-Free Diet

For those with celiac disease, eating gluten free is not a trend or fad. The gluten-free diet is currently the only available treatment for celiac disease. And food is an integral part of social life. Gluten exposure can occur anywhere and anytime – when dining out, in shared cooking spaces and while consuming processed foods and other products like medications.



The Burden of Eating Gluten-Free

The substantial burden of the gluten-free diet often includes a significant negative impact on quality of life by limiting social activities as well as educational and employment opportunities. For example:

- Eating out always carries a risk of gluten exposure.
- The constant focus on finding safe food on the gluten-free diet reduces time and energy for other aspects of life.
- Traveling for fun or work carries the extra stress of needing to find safe food.
- The whole family, not just the person who has celiac disease, is affected.

All of these impacts on daily living also impact quality of life.

The Celiac Community Talks about the Burden of Gluten-Free

Beyond Celiac [surveyed](#) 1,532 people with celiac disease about their experience with the gluten-free diet and learned:

1. What they miss the most about life before celiac disease? Respondents cited freedom, spontaneity, eating out, socializing and convenience.
2. 68% have a kitchen mixed with both gluten-free and gluten-containing foods
3. 12% intentionally eat gluten at least some of the time, putting their health at risk
4. 57% are concerned or embarrassed about eating in front of other people, which might contribute to intentional cheating
5. 49% have sacrificed a life experience because they would have to explain their gluten-free needs and/or celiac disease.

Kissing Someone Who Just Ate Gluten

Can a person with celiac disease kiss someone who just ate gluten, or will you make them sick? A [study](#) by the Celiac Disease Center at Columbia University presented at this year's gastroenterology research conference, Digestive Disease Week, looked into whether or not kissing someone who has eaten gluten would make a person with celiac disease ill. The study concludes that they can indulge without worry. To be extra safe, the study recommends drinking water before smooching.

How the Study Was Conducted

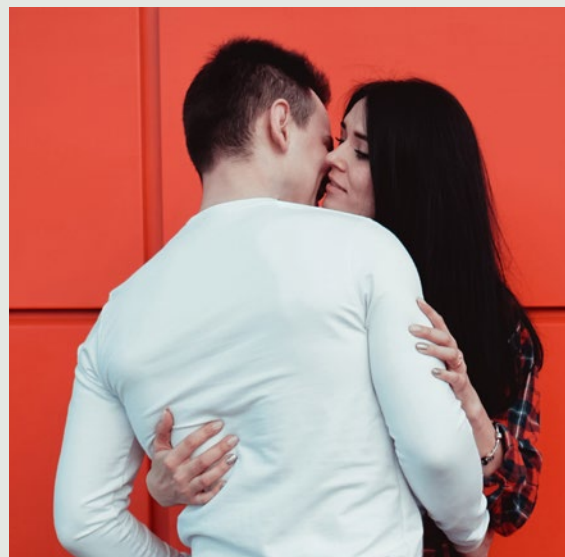
The study recruited only 10 couples which is a small sample size. One partner had celiac disease and one did not. The partner who did not have celiac disease ate 10 crackers with a total of nearly 60,000 parts per million (ppm) of gluten. Foods that contain 20 ppm gluten or more are not considered safe on the gluten-free diet. Then they did two tests with saliva collections in between. For the first test, the couples waited five minutes after the gluten was eaten. For the second test, the partner who did not have celiac disease ate gluten again, then drank 4 ounces of water before they started kissing.

Gluten was detectable in the saliva of both kissers. Most of the partners who had celiac disease had less than 5 ppm of gluten in their saliva, though two exposures had more than 20 ppm, including one with about 154 ppm after a kiss that came five minutes after the partner ate the crackers. The partners who did not have celiac disease and ate the gluten containing crackers had a range of gluten from 19 ppm to more than 2500 ppm in their saliva. Still, when they drank 4 ounces of water before kissing, the amount of gluten in the saliva of the partner with celiac disease was always less than 20 ppm.

Comments from Some Members of the Celiac Community

After the study was released, members of the celiac community online shared personal anecdotes of getting glutened after kissing someone. No symptoms were reported post-kiss by any of the study kissers who had celiac disease. However, celiac disease has so many symptoms, and people react very differently to different amounts of gluten.

Beyond Celiac applauds the fact that a study was conducted. However, with such a small sample size, it's hard to say definitively that people with celiac disease don't have to worry about kissing someone who just ate gluten. Anyone with celiac disease has to make their own decisions about their health.



Cross-Contamination

People with celiac disease have to take cross-contamination seriously. It can happen when utensils or cooking surfaces are used to prepare gluten-containing foods or when they make direct contact with one another. Even if it's minimal contact or the gluten-containing item is removed, the cross-contact can trigger a celiac reaction, sending the body into attack mode and often making the person sick.

Examples of How Cross Contamination Happens

One way to understand the full impact of cross-contamination is to think of gluten as something sticky that hangs around and gets on everything it touches.

Here's how it happens:

- If croutons accidentally end up on a salad, it's a no-go for people with celiac disease, even if the croutons are removed.
- If eggs are cooked on a griddle that just had pancakes on it, the (naturally gluten-free) eggs are likely to make a person with celiac disease sick, even though the pancakes are long gone.
- If a gluten-free pizza crust is baked in the same oven as gluten crusts, the person with celiac disease can get sick even if the gluten crust had already been removed from the oven.

All of those examples of cross-contamination will have the same effect on the person with celiac disease as if they ate the croutons, pancakes or gluten pizza themselves.



Dining Out

A survey of the celiac disease community by Beyond Celiac reveals that nearly 73% of people with celiac disease are exposed to gluten every year, resulting in symptoms. The survey also showed that 91% of people with celiac disease say that dining out is difficult due to lack of gluten-free options, creating an even bigger barrier to socializing and living normally.

If you have celiac disease, you have to advocate for yourself when dining out. Calling ahead to a restaurant or talking to the waiter to inquire about how their gluten-free dishes are prepared is the best method to determining if it might be safe to consume.

Beyond Celiac has several resources to help with this process, including:

Dining Tips – A tool from Beyond Celiac on how to best communicate your gluten-free needs before and at the restaurant.

Gluten-Free Restaurant Card – You can hand this card to a waiter or chef when you dine out to explain the extent of cooking and preparing gluten-free food.

Gluten-Free Restaurant Safety – This is a useful resource for restaurants in following safe gluten-free food preparation.



Facts about Celiac Disease

Celiac disease is a misunderstood and misdiagnosed condition that affects a person both physically and emotionally. Until there is a cure or 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.



What is Celiac Disease?

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

It 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.

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.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

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.

Celiac disease can be found at any age. It is also showing up more frequently in older adults, who often present with different symptoms than those diagnosed at an earlier age. Fatigue, constipation, anemia, osteoporosis and neuropathy are common and often dismissed as signs of "old age and of no consequence." The absence of classic celiac disease symptoms can delay diagnosis.³

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.

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

If someone has undiagnosed or misdiagnosed celiac disease, then they are not being treated for celiac disease and, therefore, could be susceptible to complications of celiac disease, such as other autoimmune diseases, osteoporosis, thyroid disease and certain cancers.

Common Signs and Symptoms of Celiac Disease

Anemia	Diarrhea	Liver disease
Anxiety	Discolored teeth	Pale mouth sores
Bloating or gas	Fatigue/tiredness	Poor weight gain
Brain fog	Infertility	Thin bones
Constipation	Irritability	Tingling/numbness/ neuropathy
Delayed growth in children	Itchy skin rash	Vomiting
Depression	Joint pain	

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.

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.



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.



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.

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.

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 to avoid experiencing symptoms, but the gluten-free diet does not treat the condition.

Studies have shown that people with celiac disease on the gluten-free diet continue to have symptoms, elevated antibodies to gluten detected in blood tests and damage to the nutrient-absorbing lining of the intestine, with the result being possible long-term health consequences. In fact, over half of individuals diagnosed with celiac disease who adhere to a gluten-free diet will remain symptomatic after five years, regardless of mucosal healing.⁶



Accelerating Treatments and a Cure

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

How Beyond Celiac is Leading the Way

We are focused on advancing the science of celiac disease because we know the gluten-free diet does not reliably and thoroughly work. In order for our community to be able to eat without fear and avoid the host of other serious medical issues celiac disease can cause, we must shatter the myth that the gluten-free diet is enough and focus on the research and clinical trials that will produce the treatments we so desperately need.



Beyond Celiac is 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.

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

The Science Plan

The Beyond Celiac Science Plan addresses and seeks to overcome the many barriers to finding an effective treatment or cure.

Current Barriers to a Cure for Celiac Disease

- 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

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

1. *Evidence Generation: Highlighting the seriousness of celiac disease*

Through 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 that 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.

Beyond Celiac Investments (BCI)

To fulfill the fourth phase in the Science Plan, Beyond Celiac launched Beyond Celiac Investments (BCI) last 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 can begin immediately. BCI's development catalyst investment strategy will focus dollars for the greatest impact on the most promising investments.

The Beyond Celiac Coalition

The Beyond Celiac Coalition is a multidisciplinary group 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.

Last year the Coalition met with representatives of the FDA to address major patient barriers to accelerate clinical trials for celiac disease. A February 2026 workshop is scheduled to discuss celiac disease across the lifespan and considerations for pediatric clinical trials. The Coalition also is hosting a clinical trial coordinator workshop this year to help better understand the barriers and challenges to clinical trial recruitment from the perspective of clinical trial coordinators. The Coalition continues to work on other drug development priorities for celiac disease such as symptoms, histology, biomarkers and endpoints.

Go Beyond Celiac Insights

Open to all people affected by celiac and non-celiac gluten sensitivities as well as parents and caregivers, Go Beyond Celiac Insights administers surveys and collects data to provide researchers with information about the celiac disease community. By participating in these studies, celiac disease community members are helping to accelerate research for celiac disease.

Additionally, 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.

Delays in Diagnosis Research Presented at Digestive Disease Week

A study conducted by Beyond Celiac in partnership with Weill Cornell Medicine researched the delays in diagnosing celiac disease. This data was first presented at Digestive Disease Week 2025—and honored as a Poster of Distinction—as part of our commitment to ensuring that future patients receive timely diagnoses and the care they deserve.

Delays in Diagnosis of Celiac Disease

The study found that delays are longest among:

- Women compared to men
- Older adults compared to younger adults and children
- Non-white individuals compared to non-Hispanic white individuals
- Residents of the Southern United States compared to those in the Northeast and West

The research also revealed that the average delay in diagnosis is three years. While this delay is deeply concerning and underscores the need for more efficient diagnostic practices, it's worth noting that these figures show improvement compared to a decade ago, when diagnosis delays were estimated to be between five and nine years.

Our efforts to raise awareness about celiac disease in public, academic and clinical settings are making a difference. Research like this provides valuable insights into where and why diagnosis delays occur, helping us strengthen our initiatives to increase screening and reduce diagnosis times even more.



Beyond Celiac Presents Neurological Symptom Research at American Academy of Neurology Annual Meeting

Beyond Celiac original research showing that the majority of celiac disease patients get symptoms such as brain fog, headaches and migraines after being exposed to gluten was presented at the American Academy of Neurology Annual Meeting this year.

This is another example of the work we have been doing for years – validating patients’ experiences with data through research that is often underfunded or overlooked. By sharing our findings with the clinical and academic communities, we aim to improve the diagnosis and treatment of patients.

Beyond Celiac and American Gastroenterological Association Launch Research Award

Beyond Celiac is partnering this year with the American Gastroenterological Association (AGA) to establish the AGA-Beyond Celiac Pilot Research Award in Celiac Disease. The one-year, \$40,000 grant supports independent scientists at any career stage who are researching new directions in celiac disease and gluten-related disorders.



About Beyond Celiac

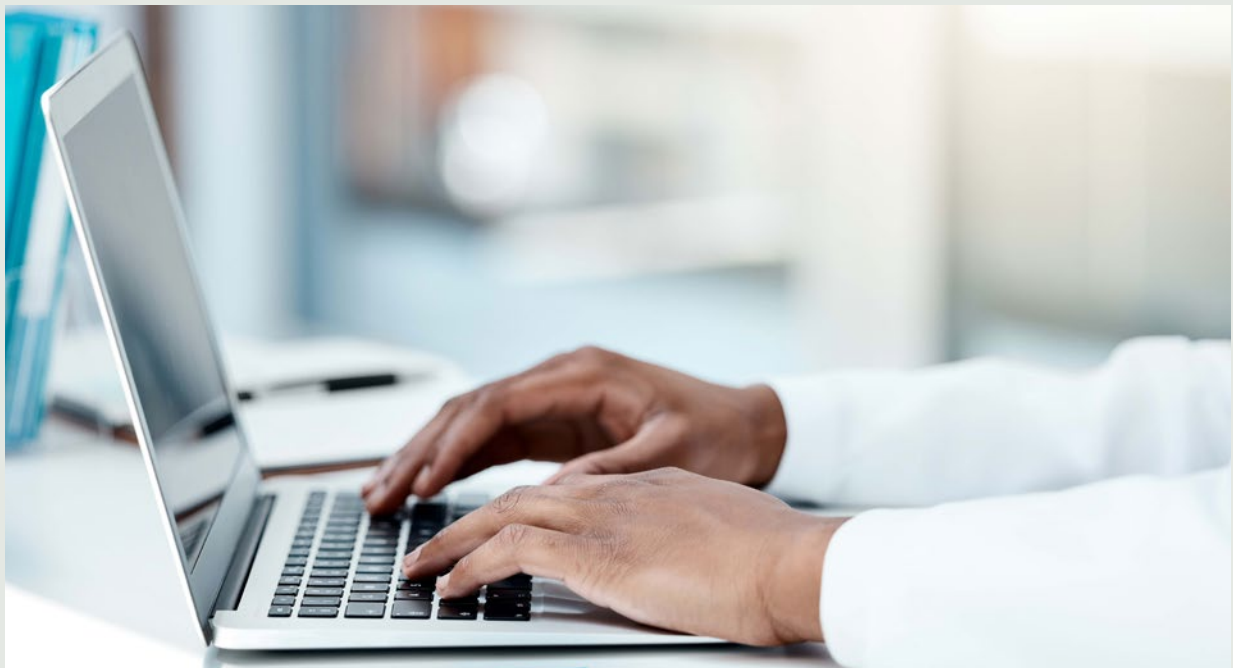
Founded in 2003, Beyond Celiac is the leading catalyst for a celiac disease cure in the United States, serving as a patient advocacy and research-driven organization working to drive diagnosis and accelerate the discovery of new treatments.

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. A 501(c)(3) non-profit organization, Beyond Celiac is based in Philadelphia. BeyondCeliac.org.

Survey Methodology

This survey was conducted online within the United States by The Harris Poll on behalf of Beyond Celiac from April 8-10, 2025, among 2,099 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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