

MAY 2022

## The Mystery of Celiac Disease: *The Need for Greater Awareness and Accelerating the Quest for a Cure*



A REPORT FROM  
BEYOND CELIAC

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# INTRODUCTION



CELIAC DISEASE IS MISUNDERSTOOD, OFTEN MISDIAGNOSED, SOMETIMES NOT DIAGNOSED FOR AS LONG AS 10 YEARS OR MORE, AND THERE IS NO CURE.

People can have celiac disease without even knowing it. Even those who don't have symptoms may have celiac disease.

It is one of those conditions in which, because every person is different, symptoms vary greatly from person to person.

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 national benchmarking survey. The Harris Poll on behalf of Beyond Celiac was conducted online February 8-10, 2022 among 2,039 adults nationwide. It provides insight into how much Americans know about gluten sensitivity and celiac disease.

Celiac disease affects an estimated 3.2 million Americans, and it is time for greater understanding of the facts of the disease and of the need for finding a cure.

This report reveals what the survey shows regarding how much Americans don't know about celiac disease, presents the facts about the disease, and outlines how Beyond Celiac is taking steps to accelerate the quest for a cure.

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# WHAT WE LEARNED FROM THE 2022 BEYOND CELIAC SURVEY

## SIX KEY TAKEAWAYS

1. **Only half of Americans (50%)** report knowing anything about celiac disease and/or gluten sensitivity.
2. **Only one-third (32%)** realize that 50% or more of people with celiac disease are undiagnosed.
3. **Nearly two-thirds (61%) of Americans** are “not at all sure” about conditions that untreated celiac disease can lead to, such as depression and anxiety; anemia; brain fog, migraines and other neurological disorders; infertility; some types of cancer; osteoporosis or osteopenia; and delayed growth in children.
4. **Only one-fourth (24%)** of Americans understand that celiac disease is an autoimmune disease.
5. **Only half of Americans (53%)** recognize that following a strict, 100% gluten-free diet (no wheat, barley or rye) is the only way someone with celiac disease can currently control it. Almost one in five (18%) incorrectly believed there is medicine that prevents a gluten reaction, while one in ten (10%) incorrectly thought there is a medicine that cures celiac disease.
6. **Only 49% of Americans** know that someone with celiac disease who strictly follows the gluten-free diet still has to worry about experiencing celiac disease symptoms or health conditions caused by it.





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# WHAT WE LEARNED FROM THE 2022 BEYOND CELIAC SURVEY

Only half of Americans (50%) report knowing anything about celiac disease and/or gluten sensitivity.





# WHAT WE LEARNED FROM THE 2022 BEYOND CELIAC SURVEY

Awareness/Experience with Celiac Disease and/or Gluten Sensitivity

**50%** DON'T KNOW ANYTHING ABOUT CELIAC DISEASE AND/OR GLUTEN SENSITIVITY.

AND

**50%** REPORT HAVING AN AWARENESS OF CELIAC DISEASE AND/OR GLUTEN SENSITIVITY.

**2%**

HAVE BEEN DIAGNOSED WITH CELIAC DISEASE BY A MEDICAL PROVIDER

**4%**

HAVE BEEN DIAGNOSED WITH GLUTEN SENSITIVITY BY A MEDICAL PROVIDER

**10%**

HAVE NOT BEEN MEDICALLY DIAGNOSED WITH EITHER CELIAC DISEASE OR GLUTEN SENSITIVITY BUT FEEL BETTER ON A GLUTEN-FREE DIET

**37%**

HAVE NOT BEEN MEDICALLY DIAGNOSED WITH EITHER CELIAC DISEASE OR GLUTEN SENSITIVITY BUT KNOW ABOUT CELIAC DISEASE AND/OR GLUTEN SENSITIVITY

## WHAT WE LEARNED FROM THE 2022 BEYOND CELIAC SURVEY

### Don't know anything about Celiac Disease and/or Gluten Sensitivity:

#### Race/Ethnicity

63% Black (non-Hispanic)  
49% Hispanic  
47% White (non-Hispanic)

#### Gender

52% Male  
48% Female

#### Age

18-34 - 45%  
35-44 - 47%  
45-54 - 48%  
55-64 - 57%  
65+ - 55%

#### Education

High School or Less - 61%  
Some College - 48%  
College Grad+ - 40%

#### Household Income

Less than \$50,000 - 58%  
\$50,000 - \$74,999 - 49%  
\$75,000 - \$99,999 - 51%  
\$100,000+ - 43%





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# WHAT WE LEARNED FROM THE 2022 BEYOND CELIAC SURVEY

## About the Diagnosis

Only **32%** of Americans know that 50% of people with celiac disease are undiagnosed

Only **21%** of Americans realize that celiac disease often runs in families

Only **18%** of Americans understand that 6-10 years is the average time a person waits to be correctly diagnosed with celiac disease

## Why Managing Celiac Disease with a 100% Gluten-Free Diet is Difficult

**55%** of Americans realize that eating at a restaurant, at parties or dining with friends can be difficult due to lack of gluten-free items and risk of cross-contamination

**53%** of Americans say that foods are not always clearly labeled as “gluten-free” or not

**53%** of Americans know it can be hard to find gluten-free food options when away from home, such as when traveling or at school

**37%** of Americans believe that gluten-free food is expensive

**19%** of Americans believe it is not difficult to always follow the diet



## Conditions That Untreated Celiac Disease Can Lead To

Only 20% of Americans realize it can lead to depression and anxiety



Only 17% of Americans realize it can lead to brain fog, migraines and other neurological disorders



Only 15% of Americans realize it can lead to anemia



Only 12% of Americans realize it can lead to osteoporosis or osteopenia



Only 11% of Americans realize it can lead to some types of cancer



Only 11% of Americans realize it can lead to delayed growth in children





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## WHAT WE LEARNED FROM THE 2022 BEYOND CELIAC SURVEY

Only 9% of Americans realize that  
celiac disease can lead to infertility.



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# THE 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.[i] 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.[ii]



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# THE 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.[iii]**

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 include:**

**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**



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## THE FACTS ABOUT CELIAC DISEASE



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

A retrospective study found that 44% of screened first-degree relatives of people with celiac disease also had celiac disease.<sup>[vi]</sup>

Despite following a strict gluten-free diet, currently the only treatment, 44% of those with celiac disease report accidental exposure to gluten at least once a month, often causing ongoing symptoms and/or additional intestinal damage.<sup>[vii]</sup>

Recent research also reveals damage to brain structures in people with celiac disease and gluten sensitivity which may worsen the longer a person remains on a regular gluten-containing diet.<sup>[viii],[ix]</sup>





# HOW IS CELIAC DISEASE TREATED?

There are no FDA-approved drugs to treat celiac disease. However, the good news is that there are currently 15 pharmaceuticals for celiac disease being tested in clinical trials in the U.S.

At the present time, following a strict, 100% gluten-free diet is the only way to control celiac disease.



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# DRIVING A CURE FOR CELIAC DISEASE



**Evidence is increasingly showing that even those who follow the gluten-free diet strictly are exposed to some gluten from cross-contact and other inadvertent sources.**

Because Beyond Celiac has seen the mounting data indicating that the gluten-free diet is not enough, we have made it our mission to accelerate research to find new treatments and a cure. Those with celiac disease should be able to live life to the fullest, free from symptoms and long-term damage to their bodies. Researchers, scientists and drug companies are finally interested in understanding this disease and finding new treatments. Beyond Celiac is committed to highlighting the patient perspective while championing this research.

Beyond Celiac launched a strategic science plan in 2021 to change the future for the millions of Americans living with this serious genetic autoimmune disorder. The only treatment now available, the gluten-free diet, does not protect the large, diverse celiac disease community or allow patients to fully enjoy a healthy life. Even on the gluten-free diet, celiac disease patients have ongoing nutritional deficiencies, risk of mental health issues, other health conditions and greater odds of early mortality.

The science plan focuses on funding research, amplifying the patient voice, connecting those patients with researchers and clinical trials, and bringing together a team of scientists and collaborators to lead the way. To accomplish that goal, Beyond Celiac is laser-focused on addressing the many current barriers to a cure.





# DRIVING A CURE FOR CELIAC DISEASE

Those barriers to a cure for celiac disease include:

- Celiac disease is poorly understood by the medical community.
- There is limited support for early career scholars/researchers.
- The serious nature of the disease is underappreciated.
- Too many people remain undiagnosed.
- Compared to other gastrointestinal diseases, celiac disease has been underfunded and under-researched[x]

# DRIVING A CURE FOR CELIAC DISEASE

Beyond Celiac is committed to addressing the many current barriers to a cure through four scientific priorities: evidence generation, translational research, clinical trials and drug repurposing.

Through our patient database Go Beyond Celiac, working with scientists exploring the disease's non-GI symptoms, and initiatives such as our partnership with the National Minority Quality Forum to address health disparities in diagnosis and treatment, Beyond Celiac is collecting and analyzing comprehensive data on the burden of celiac disease and gluten sensitivity. This evidence generation will increase awareness of both the nature and scope of celiac disease, making a compelling case for larger investments from government agencies, pharmaceutical companies, biotech and more.

Beyond Celiac is funding promising translational research that will quickly move from scientific investigation to clinical use, speeding the development of treatments for patients.

As the nation's top recruiting partner for celiac disease clinical trials, Beyond Celiac continues to educate the community about the importance of participating in trials and work with pharmaceutical companies to ensure trials are designed with patient perspectives in mind.

Beyond Celiac is also focused on identifying treatments that have been investigated or approved for other purposes but might also benefit celiac disease patients. This drug repurposing reduces risk, cost and time to market for potential celiac disease treatments.

**Beyond Celiac has the strategic science plan, the people and the passion to accelerate treatments leading to a cure. We firmly believe that with a strategic approach to targeted research, an effective treatment or cure is possible by 2030.**





## HARRIS POLL SURVEY METHODOLOGY

This survey was conducted online within the United States by The Harris Poll on behalf of Beyond Celiac from February 8-10, 2022 among 2,039 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](mailto:cbaker@beyondceliac.org)

## 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 is creating a future in which people can live healthy lives and eat without fear – a world Beyond Celiac. [www.BeyondCeliac.org](http://www.BeyondCeliac.org).



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