Have you been diagnosed with CD?

- Yes
- No

Has your child been diagnosed with CD?

- Yes
- No

What is the age of the person on behalf of whom you are completing this survey?

- 0-7 years old
- 8-12 years old
- 13-18 years old
- 19-25 years old
- 36-45 years old
- 46-55 years old
- 56-65 years old

In the past ONE month, how much has each of the following been a problem for you or your child? Select not at all, slightly, moderately, quite a bit, a great deal.

- I feel limited by this disease.
- I feel worried that I will suffer from this disease.
- I feel concerned that this disease will cause other health problems.
- I feel worried about my increased risk of cancer from this disease.
- I feel socially stigmatized for having this disease.
- I feel like I am limited eating meals with coworkers.
- I feel like I am not able to have special foods like birthday cake and pizza.
- I feel that the diet is sufficient treatment for my disease.
- I feel that there are not enough choices for treatment.
- I feel depressed because of my disease.
- I feel frightened by having this disease.
- I feel like I don't know enough about this disease.
- I feel overwhelmed about having this disease.
- I find it difficult to travel or take long trips because of my disease.
- I feel like I cannot live a normal life because of my disease.
- I feel afraid to go out because my food may be contaminated.
- I feel worried about the increased risk of one of my family members having celiac disease.
- I feel like I think about food all the time.
- I feel concerned that my long-term health will be affected.

For each of the following questions, select none of the time, little of the time, some of the time, most of the time, or all of the time.

- Have you been bothered by pain or discomfort in the upper abdomen or the pit of the stomach during the past 4 weeks?
- Have you been bothered by nausea during the past 4 weeks?
- Have you been bothered by rumbling in the stomach during the past 4 weeks?
- Has your stomach felt bloated during the past 4 weeks?
- Have you been bothered by diarrhea during the past 4 weeks?
- When going on the toilet, have you had the sensation of not completely empying your bowels during the past 4 weeks?
- Have you been bothered by hunger pains during the past 4 weeks?
- Have you been bothered by low energy levels during the past 4 weeks?
- Have you been bothered by headaches during the past 4 weeks?
- Have you had food cravings in the past 4 weeks?
- Have you had loss of appetite during the past 4 weeks?

For each of the following questions, select excellent, good, fair, poor, or terrible.

- Related to celiac disease, how is your health?
- Overall, how is your health?

For each of the following statements, select strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree.

- I am comfortable.
- I am as healthy as anybody I know.
- I am able to follow a gluten-free diet when dining outside my home.
- Before I do something I carefully consider the consequences.
- I do not consider myself a failure.

How important to your health are accidental gluten exposures?

- very important
- somewhat important
- neutral/unsure
- a little important
- not at all important

Over the past 4 weeks, how many times have you eaten foods containing gluten on purpose?

- 0 (never)
- 1 to 2
- 3 to 5
- 6 to 10
- more than 10

Do you or your child eat gluten voluntarily?

- Yes, a normal portion
- Yes, often just a taste.

- Yes, rarely a taste.
- No, AND I will NOT tell the person who is cooking about my disease.
- No, AND I WILL tell the person who is cooking about my disease.

Do you or your child check the labels of package food?

- No, I or they do not check.
- Yes, I or they do check and will ONLY eat package food certified by a glutenfree certification body.
- Yes, I or they do check and a package food does NOT have to be certified by a glutenfree certification body.

How often do you check the ingredients in non-food and non-beverage products such as medications, lipstick, toothpaste and hand and body lotions before ingesting or applying?

- never
- almost never
- sometimes
- often
- almost always

As an infant, how were you or your child fed? If breastfed, please tell us the estimated length of time.

- breastfed only
- formula fed only
- both
- I don't know

As an infant, how were you or your child fed? If breastfed, please tell us the estimated length of time. IF BREASTFED, PLEASE SPECIFY LENGTH OF TIME

- Free text response

Do you know how old you or your child were when gluten was introduced into the diet?

- Yes
- No

Age of gluten introduction?

- Free text response

What was your or your child's mode of birth?

- emergency c-section
- scheduled c-section
- vaginal birth
- I don't know

Growing up, did you or your child use antibiotics often?

- Yes
- No
- I don’t know

Please think about the primary environment or setting in which you or your child grew up. Which is the best description?

- Urban
- Rural
- Neither urban nor rural
- I don't know

Did you or your child have pets (of any kind, either indoor or outdoor) growing up?

- Yes
- No

How were you or your child diagnosed with celiac disease?

- Clinical diagnosis by a physician
- Self-diagnosed

Please tell us what, if any, tests were used to diagnose you or your child with CD. Select all that apply.

- Blood test
- Endo and biopsy
- HLA typing / genetic test
- gluten challenge
- I don't know.

If you know the specific names of the blood tests used, please specify.

- TTG
- DGP
- EMA
- AGA
- I don't know.
- Other - specify

In years, what was the age you or your child when diagnosed with celiac disease?

- Free text response

When diagnosed, were you or your child told you would outgrow celiac disease?

- Yes
- No

What signs, symptoms or conditions did you or your child experience before the celiac disease diagnosis?

- another autoimmune disease, such as Type 1 diabetes, Thyroiditis, or Inflammatory Bowel Disease (IBD)
- ataxia
- bloating, gas, abd pain
- bone loss
- constipation
- delayed growth or puberty
- depression or anxiety
- diarrhea
- discolored teeth or loss of enamel
- dry mouth
- elevated liver enzymes
- fatigue
- foul smelling, hard to flush or bulky stools
- headaches or migraines
- indigestion
- IBS
- irritability or behavior changes
- itchy skin rash
- lactose intolerance
- low albumin
- low copper
- low folic acid
- low iron / anemia
- low vitamin B12
- low vitamin D
- low zinc
- malabsorption
- mouth ulcers
- pain in multiple joints
- short stature (children)
- unexplained infertility or miscarriages
- weight gain
- weight loss
- none - asymptomatic at diagnosis

From the time your or your child's symptoms began, how long did it take to receive a proper diagnosis of celiac disease?

- I don’t know
- Free text response

Who first diagnosed you or your child with celiac disease?

- Pediatrician
- Primary care provider
- Gastroenterologist
- Dietitian or nutritionist
- Other

Who first diagnosed you or your child with celiac disease?

- Free text response

Please think about your or your child's current overall health such as energy, mood and physical health. Generally, how do you or your child feel since diagnosis?

- Better
- Worse
- The same

Who do you consider your or your child's main healthcare provider when it comes to managing celiac disease?

- Pediatrician
- Primary care provider
- Gastroenterologist
- Dietitian or nutritionist
- Other
- Free text responses

In the past 5 years, have you specifically visited about or discussed management of your or your child's celiac disease with a healthcare provider? This may include talking about symptoms, the gluten-free diet or complications of celiac disease.

- No
- I don't remember
- Not applicable - Diagnosis occurred within past 5 years
- Other

If yes, estimate of how many times person/child has visited with HCP in past 5 years about celiac disease.

- Free text response

If you haven't visited a healthcare provider within the past 5 years to specifically discuss or manage your or your child's celiac disease, what are your reasons? Please select all that apply.

- I haven't had a reason to see my healthcare provider.
- I don't trust healthcare providers.
- I haven't found my or my child's healthcare provider(s) to be knowledgeable about celiac disease.

- I haven't found previous visits to be helpful.
- I believe I am or my child is doing a good job of managing celiac disease on my/their own.
- For financial reasons - I am uninsured.
- For financial reasons - I am insured, but the co-pay is too high.
- I have visited a healthcare provider within the past 5 years.
- Other reason

Do you or your child have any other autoimmune or other diseases? Please check all that apply.

- Type 1 Diabetes
- Dermatitis Herpetiformis
- Thyroid disease (hypo/hyperthyroidism)
- Autoimmune Liver Disease
- Rheumatoid Arthritis
- Psoriasis
- Sjogren's
- Osteoporosis Or Osteopenia
- None
- Other - Specify

Other than you or your child on behalf of whom you're completing this survey, have any of your blood relatives been diagnosed with CD?

- yes
- no
- I don't know

If other blood relatives have been diagnosed with celiac disease (excluding the person on behalf of whom you're completing this survey, e.g. your child), please identify the relation.

- None have been dxed
- Mother
- Father
- Sibling
- Other Child
- Aunt
- Uncle
- Niece
- Nephew
- Grandfather
- Grandmother
- Cousin
- Half-Sibling

Have any of your blood relatives been diagnosed with any of the following autoimmune or other diseases? Please select all that apply.

- Thyroid disease (hypo/hyperthryoidism)
- Autoimmune Liver Disease
- Type 1 Diabetes
- Dermatitis Herpetiformis
- Rheumatoid Arthritis
- Psoriasis
- Sjogren's
- Osteopenia or osteoporisis
- None
- Other - please specify

Have any of your blood relatives been diagnosed with the following illnesses or conditions? Please select all that apply.

- Lymphoma (a cancer of a part of the immune system called the lymph system)
- Small intestinal cancer
- Esophageal Cancer
- Pharyngeal Cancer
- Thyroid Cancer
- Colon Cancer
- Pancreatic Cancer
- Hematologic cancers (such as leukemia or myeloma)
- None

What is your or your child's sex?

- male
- female

What is your race?

- White or Caucasian
- Hispanic or Latino
- Black or African American
- Asian or Pacific Islander
- Indian
- Native American or American Indian
- Other
- Prefer not to say

What is your state of residence?

- Free text response