

Consent to participate in the survey

The Celiac Disease Program at Boston Children's Hospital is working on a project to evaluate the effect of the COVID-19 pandemic on food insecurity in families with a child who is following a gluten-free diet. We hope that this work will help us understand the ability of families to access gluten-free foods prior to and during the COVID-19 pandemic.

This study will enroll approximately 700 families with a child ages 2-18 who is following a gluten-free diet. We will also ask that each family with a child who is gluten-free refer a peer family that does not follow a gluten-free diet to participate in the study so that we have a peer control group to compare our results.

What will your participation look like if you choose to participate?

We will ask your family to complete a short digital survey that asks questions about your ability to access food prior to and during the COVID-19 pandemic. You will also be asked basic demographic information questions, as well as about the availability of gluten-free products during the COVID-19 pandemic.

Additionally, through the survey, we will ask you to provide contact information for a peer family that does not follow a gluten-free diet to serve as a control group. This will help us compare what we find amongst gluten-free families to the general population. The peer family that you refer will be asked to complete a modified survey that asks about their experience accessing food prior to and during the COVID-19 pandemic. It would be great if you could let the peer family know to expect the survey in their email inbox.

This study will ask you to enter demographic information. The only personal identifiable information collected will be your ZIP code. Every precaution will be taken to secure participants' information to ensure confidentiality.

Participation in this study is voluntary and your decision will not affect the care that you receive. Please contact Vanessa Weisbrod at vanessa.weisbrod@childrens.harvard.edu with questions about this study. If you have questions about your rights participating in research or would like to speak to someone independent of the research team, then please contact the Institutional Review Board at 617-355-7052.

If you agree and consent to participate, then please click on the "Submit" button below to start the survey.

The Celiac Disease Program at Boston Children's Hospital is working on a project to evaluate the effect of the COVID-19 pandemic on food insecurity in families with a child who is following a gluten-free diet. We hope that this work will help us understand the ability of families to access gluten-free foods prior to and during the COVID-19 pandemic.

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Boston Children's Hospital

Celiac Disease Program

General Family History

Is there a child living in your household ages 2-18 who follows a gluten-free diet?

- ☐ Yes
☐ No

You have indicated that there is not a child who follows a gluten-free diet living in your household.

Does your child have a friend or peer who follows a gluten-free diet? If so, the survey that corresponds to this peer group can be found by following the link below:

Effect of the COVID-19 Pandemic on Food Insecurity in Pediatric Celiac Disease

If yes, how many?

- ☐ 1
☐ 2
☐ 3
☐ 4+

Is there an adult age 18+ living in your household who follows a gluten-free diet?

- ☐ Yes
☐ No

If yes, how many?

- ☐ 1
☐ 2
☐ 3
☐ 4+

Modified Hunger Vital Sign™ & US Food Security Questionnaire

We are interested to learn how the costs of a gluten-free diet affect you.

We also know that the COVID-19 pandemic has impacted budgets. Please answer the following questions considering your situation before and after the COVID-19 pandemic.

When answering the questions about someone ages 2-18 following a gluten-free diet, please consider any household in which the child spends a significant amount of time, if split among households.

- | | | |
|----|--|--|
| 1 | Within the past 12 months (prior to the COVID-19 pandemic) we worried whether our food would run out before we got money to buy more | <input type="radio"/> Often true
<input type="radio"/> Sometimes true
<input type="radio"/> Never true
<input type="radio"/> Don't know/Refuse to answer |
| 2 | Within the past 12 months (prior to the COVID-19 pandemic) the food we bought just didn't last and we didn't have money to get more | <input type="radio"/> Often true
<input type="radio"/> Sometimes true
<input type="radio"/> Never true
<input type="radio"/> Don't know/Refuse to answer |
| 3 | Within the past 12 months (prior to the COVID-19 pandemic) we worried whether our gluten-free food would run out before we got money to buy more | <input type="radio"/> Often true
<input type="radio"/> Sometimes true
<input type="radio"/> Never true
<input type="radio"/> Don't know/Refuse to answer |
| 4 | Within the past 12 months (prior to the COVID-19 pandemic) the gluten-free food we bought just didn't last and we didn't have money to get more | <input type="radio"/> Often true
<input type="radio"/> Sometimes true
<input type="radio"/> Never true
<input type="radio"/> Don't know/Refuse to answer |
| 5 | Since the COVID-19 pandemic affected the area in which we live, we worried whether our food would run out before we got money to buy more | <input type="radio"/> Often true
<input type="radio"/> Sometimes true
<input type="radio"/> Never true
<input type="radio"/> Don't know/Refuse to answer |
| 6 | Since the COVID-19 pandemic affected the area in which we live, the food we bought just didn't last and we didn't have money to get more | <input type="radio"/> Often true
<input type="radio"/> Sometimes true
<input type="radio"/> Never true
<input type="radio"/> Don't know/Refuse to answer |
| 7 | Since the COVID-19 pandemic affected the area in which we live, "we could not afford to eat balanced meals" | <input type="radio"/> Often true
<input type="radio"/> Sometimes true
<input type="radio"/> Never true
<input type="radio"/> Don't know/Refuse to answer |
| 8 | Since the COVID-19 pandemic affected the area in which we live, did you or other adults in your household ever cut the size of your meals or skip meals because there was not enough money for food? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know/Refuse to answer |
| 8b | Since the COVID-19 pandemic affected the area in which we live, how often did your family have to skip a meal or cut down the size because there was not enough money for food? | <input type="radio"/> Almost every month
<input type="radio"/> Some months but not every month
<input type="radio"/> Only 1 or 2 months
<input type="radio"/> Don't know/Refuse to answer |

-
- 9 Since the COVID-19 pandemic affected the area in which we live, did your family ever eat less than you felt they should because there was not enough money for food?
- ☐ Yes
☐ No
☐ Don't know/Refuse to answer
-
- 10 Since the COVID-19 pandemic affected the area in which we live, were you ever hungry but did not eat because there was not enough money for food?
- ☐ Yes
☐ No
☐ Don't know/Refuse to answer
-
- 11 Since the COVID-19 pandemic affected the area in which we live, we worried whether our gluten-free food would run out before we got money to buy more
- ☐ Often true
☐ Sometimes true
☐ Never true
☐ Don't know/Refuse to answer
-
- 12 Since the COVID-19 pandemic affected the area in which we live, the gluten-free food we bought just didn't last and we didn't have money to get more
- ☐ Often true
☐ Sometimes true
☐ Never true
☐ Don't know/Refuse to answer
-
- 13 Have you or your child eaten gluten because there were no gluten-free options available?
- ☐ Yes
☐ No
-
- If yes, was this:
- ☐ Before COVID-19 pandemic
☐ Since COVID-19 pandemic
☐ Both before and since the COVID-19 pandemic
-

For the next two questions

Please consider where you shop. If you use a grocery delivery service like Instacart where the food is delivered from a local store, please count this as a “store” and not an online delivery from a warehouse.

-
- 14a Before COVID-19 pandemic:
What is the availability of gluten-free foods in your area?
- ☐ Readily available - I can usually get what I need at just 1 or 2 stores
☐ Available - I regularly shop at 3 or more stores to get what I need
☐ Limited availability - I often go without things I need and/or have to order online
☐ Very poor - I purchase most gluten-free foods online
-
- 14b Since COVID-19 pandemic:
What is the availability of gluten-free foods in your area?
- ☐ Readily available - I can usually get what I need at just 1 or 2 stores
☐ Available - I regularly shop at 3 or more stores to get what I need
☐ Limited availability - I often go without things I need and/or have to order online
☐ Very poor - I purchase most gluten-free foods online
-
- 15 Does your family have any additional dietary restrictions besides gluten-free?
- ☐ Yes
☐ No
-

Please use this space if you would like to share more with us related to your experiences in getting food before and after the COVID-19 pandemic.

Child's Gluten-Free Diet

Please answer the following questions about your child who follows a gluten-free diet.

If multiple children in your household are gluten-free, please answer the questions about your child who has been gluten-free the longest.

People eliminate gluten from their diet for many reasons. What is the reason(s) that your child follows a gluten-free diet (check all that apply)?

- ☐ Celiac disease
- ☐ Non-celiac gluten sensitivity or allergy
- ☐ Wheat sensitivity or allergy
- ☐ Irritable bowel syndrome (e.g., Low FODMAP diet)
- ☐ Autism or behavior problems
- ☐ Other, please describe

If "Other" selected above, please describe:

Has your child had an intestinal or duodenal biopsy to look for celiac disease?

- ☐ Yes
- ☐ No
- ☐ Not sure

Has your child had a blood test for antibodies associated with celiac disease?

- ☐ Yes
- ☐ No
- ☐ Not sure

Which method(s) were used in diagnosing your child with celiac disease? (check all that apply)

- ☐ Blood serology (elevated tissue transglutaminase TTG, positive endomysial antibody EMA, positive deamidated gliadin antibody DGP)
- ☐ Genetic testing (HLA-DQ2/HLA-DQ8)
- ☐ Intestinal biopsy (endoscopy)
- ☐ I don't know

How old was your child when they began following a gluten-free diet?

(years old)

How long has your child been on the gluten-free diet?

- ☐ Less than 1 month
- ☐ 1-3 months
- ☐ 3-6 months
- ☐ 6-12 months
- ☐ 1-2 years
- ☐ More than 2 years
- ☐ Never been on a gluten-free diet

What is your relationship to your child who follows a gluten-free diet?

- ☐ Mother/Stepmother
- ☐ Father/Stepfather
- ☐ Other relative or legal guardian

If "Other" selected above, please tell us your relationship to the child:

Child's Demographics

What is your child's age in years?

(years old)

What is your child's gender?

- ☐ Female
☐ Male
☐ Other

If "Other" selected above, please share the gender your child identifies as:

Where you live affects what resources are available to you. What is the ZIP code of your child's primary neighborhood?

(5 digit zipcode only (e.g. 02115))

What type of education is your child currently receiving?

- ☐ Public School (in-person, remote or hybrid)
☐ Private School (in-person, remote or hybrid)
☐ Charter School (in-person, remote or hybrid)
☐ Home School
☐ Daycare
☐ Not currently enrolled in school or daycare
☐ Other

Self Demographics

Please answer the following questions about yourself.

What is your gender?

- ☐ Female
- ☐ Male
- ☐ Other

If "Other" selected above, please share how you identify your gender:

What is your marital status?

- ☐ Married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Single (never married)

What is your highest level of education?

- ☐ Grade School (K-8)
- ☐ Some High School (No diploma)
- ☐ High School diploma or equivalent (e.g., GED)
- ☐ Some College (No degree)
- ☐ Undergraduate degree (Associate or Bachelor's)
- ☐ Graduate or Professional degree
- ☐ Professional/Technical degree

What is your race?

- ☐ American Indian/Alaska Native
- ☐ Asian, Native Hawaiian or Other Pacific Islander
- ☐ Black or African-American
- ☐ White
- ☐ More than One Race
- ☐ Unknown/Not Reported

What is your ethnicity?

- ☐ Hispanic or Latino
- ☐ NOT Hispanic or Latino
- ☐ Unknown/Not Reported

What is your age?

- ☐ Under 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65 or older

Which of the following categories best describes your employment status?

- ☐ Employed, working 40 or more hours per week
- ☐ Employed, working 1-39 hours per week
- ☐ Not employed, looking for work
- ☐ Disabled, not able to work
- ☐ Student
- ☐ Stay-at-home parent
- ☐ Retired
- ☐ Other

If applicable, what is the employment status of the other parent/guardian responsible for your child(ren)?

- ☐ Employed, working 40 or more hours per week
- ☐ Employed, working 1-39 hours per week
- ☐ Not employed, looking for work
- ☐ Disabled, not able to work
- ☐ Student
- ☐ Stay-at-home parent
- ☐ Retired
- ☐ Other

How much total combined money did all members of your HOUSEHOLD earn last year?

- ☐ \$0-\$15,000
- ☐ \$15,001-30,000
- ☐ \$30,001-45,001
- ☐ \$45,001-60,000
- ☐ \$60,000-80,000
- ☐ \$80,001-100,000
- ☐ More than \$100,000
- ☐ Prefer not to answer

What type of housing do you and your family currently reside in?

- ☐ Homeless/shelter
- ☐ Staying with friends/family
- ☐ Subsidized housing
- ☐ Rental
- ☐ Mortgage/own home
- ☐ Other

If "Other" selected above, please share how you identify your housing type:

How many family members currently live in your same household?

(number)

Additional Information

A control group is important to our research to help us understand if a diagnosis of celiac disease and the requirement to eat gluten-free foods contributes to the rate of food insecurity.

Please enter the email address of a peer family with a child who does not have celiac disease that may be willing to complete a modified version of this survey.

A peer family is defined as a family that is of similar age, background, and socioeconomic status, and that does not have a family member with celiac disease or follow a gluten-free diet.

Thank you for your interest

We thank you for your interest in completing this survey; however we are recruiting families with children who are following a gluten-free diet.

Please enjoy the rest of your day,

Boston Children's Hospital Celiac Disease Program

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Boston Children's Hospital Celiac Disease Program

Food Insecurity Resource List

Thank you for completing the survey to help our team better understand food insecurity for families with a child who follows a gluten-free diet. We know that accessing food has become incredibly difficult for many families. Below are several resources that offer food assistance programs in Massachusetts and across the United States.

A document containing these resources can be downloaded at the bottom of this screen for your convenience as well.

Food Equality Initiative

The food Equality Initiative is one of the nation's leading organizations working to increase access to allergy-friendly and gluten-free foods for individuals who need them the most. In 2015 FEI launched the nation's first allergy-friendly and gluten-free food pantry and today ships food to families in need across the country. To access food, physicians must submit a prescription diet order form to confirm the diagnosis requiring food as a treatment. For more information, please visit: <https://foodequalityinitiative.org/>

- Medical Provider Prescription Form for Referral:

https://foodequalityinitiative.org/wp-content/uploads/2020/04/RX-Diet-Order-Form_2020.pdf

Feeding Gluten-Free from the National Celiac Association

Feeding Gluten-Free is a pilot initiative of the National Celiac Association to help get gluten-free food to people who need it across the United States by connecting gluten-free food companies with area food pantries. The project currently supports food pantries in many states.

<https://nationalceliac.org/gluten-free-food-pantries/>

Project Just Because

Massachusetts residents are able to access the PJB Gluten-Free Food Pantry weekly at 109 South St in Hopkinton Monday-Thursday from 9:30am-3:30pm. We no longer have online forms. Come to our location and select perishable and non-perishables food items.

<http://projectjustbecause.org/>

The Friendly House Neighborhood Center

Offers meals for children at various times throughout the week with gluten-free options available. Please check the website for weekly mealtime and locations.

<http://www.friendlyhousema.org/>

Weymouth Food Pantry

The Weymouth Food Pantry collects and distributes gluten-free items and although it is more difficult during COVID since they are prepacking items and people can't freely shop, they will place the gluten-free items on top of bag, as requested.

<https://www.weymouthfoodpantry.org/>

[Attachment: "Food Insecurity Resources.pdf"]