

Attitudes toward genetic testing for celiac disease

The Celiac Disease Center of Columbia University invites you to participate in a research study looking at individuals' knowledge of genetic testing of celiac disease and their opinions regarding such testing. The goal of this study is to increase understanding of the factors associated with making an informed decision regarding such testing and to better provide the necessary information to make such a decision.

The survey takes approximately 5 -8 minutes to complete. The survey is anonymous; no identifying information is collected.

Your time and participation in completing the survey is appreciated.

1. Your Gender:

- Male Female

2. Your age

- 18 - 25 41 - 50 71 - 80
 26 - 30 51 - 60 > 80
 31 - 40 61 - 70

3. What best describes your level of education?

- Less than 9th grade Some college Graduate or professional degree
 Some high school Associate degree
 High school graduate or equivalent Bachelor's degree

4. What is your marital status?

- Single Divorced Widowed
 Married/Domestic Partner Separated

5. What is your state of residence?

State:

6. Do you have children?

- Yes No

7. Do you have celiac disease?

- Yes No Uncertain/Evaluation in progress

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8. If yes, age at diagnosis.

9. Was diagnosis confirmed by biopsy?

- Yes No

10. If no, how diagnosed? (check all that apply)

- Blood Test (antibody testing) Stool Test Self-Diagnosed

11. If you do not have confirmed celiac disease, do you have a gluten-sensitivity?

- Yes No

12. Are you on a gluten-free diet?

- Yes No

13. Have you seen a nutritionist?

- Yes No

14. Do you have a family member(s) with biopsy-proven celiac disease?

- Yes No

15. Do you have a family member(s) with gluten-sensitivity?

- Yes No

16. If yes, check how they are related to you?

- Child Sibling Parent Grandparent Aunt/uncle Cousin Other

17. Are you aware genetic testing is available for celiac disease?

- Yes No

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18. If yes, how did you hear about genetic testing for celiac disease? (check all that apply)

- | | | |
|---|---|--|
| <input type="checkbox"/> Newspaper/ Magazines | <input type="checkbox"/> Doctor/Health Professional | <input type="checkbox"/> Support Group |
| <input type="checkbox"/> Television | <input type="checkbox"/> Dietician | <input type="checkbox"/> Friend/Family |
| <input type="checkbox"/> Internet | <input type="checkbox"/> Laboratory | <input type="checkbox"/> Other |

Other (please specify)

19. Do you plan to have genetic testing for celiac disease?

- Yes No Already tested

If you answered yes or no, please state why.

20. If you have children, do you plan to have your children tested?

- Yes No

21. Please check if you agree or disagree with the following statements.

	Agree	Disagree
Ruling out the diagnosis of celiac disease is beneficial to an individual.	<input type="checkbox"/>	<input type="checkbox"/>
The accuracy of genetic testing when on a gluten-free diet is important.	<input type="checkbox"/>	<input type="checkbox"/>
Reassurance that a child is not at risk for celiac disease is beneficial.	<input type="checkbox"/>	<input type="checkbox"/>
Knowledge that a child or other relative is at risk for celiac disease is beneficial.	<input type="checkbox"/>	<input type="checkbox"/>

22. The reason to have gene testing for celiac disease susceptibility is:

	True	False
To determine if I am at risk for celiac disease	<input type="checkbox"/>	<input type="checkbox"/>
To determine if periodic celiac blood testing is needed	<input type="checkbox"/>	<input type="checkbox"/>
To learn about my children's risk	<input type="checkbox"/>	<input type="checkbox"/>
To take better care of myself if positive	<input type="checkbox"/>	<input type="checkbox"/>
To go gluten-free if positive	<input type="checkbox"/>	<input type="checkbox"/>
To further research	<input type="checkbox"/>	<input type="checkbox"/>
Recommended by doctor/health professional	<input type="checkbox"/>	<input type="checkbox"/>

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23. Are you aware of GINA (Genetic Information Non-discrimination Act), a Federal law passed in 2008, which protects people against health insurance or employment discrimination with respect to their genetic information?

Yes

No

24. Please indicate your agreement or disagreement with the following statements.

	Strongly disagree	Disagree	No Opinion/Not Applicable	Agree	Strongly Agree
I want to know if I am at risk for developing celiac disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have considered genetic testing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have had celiac genetic testing and found it beneficial.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about the cost of genetic testing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about testing's impact on my health care and/or insurance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about confidentiality and/or public access to testing information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing for celiac disease will cause anxiety about developing the disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing for celiac disease diagnoses the disease in a person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing will result in relief upon knowing my risk status.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Positive genetic test results will cause strained family relations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If genetic test results are positive one must inform family members.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic test results can cause guilt due to chance of passing on the gene to offspring.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am aware of the availability of genetic counseling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The risks and benefits of gene testing have been explained to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cheek cell sample as an alternative to blood for genetic testing is an advantage for me or my family members.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Test results will cause stress about dietary restrictions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Test results will enable me to make informed decisions about my medical care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family may have access to this information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My insurance company may have access to this information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My employer may have access to this information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Where did you fill out this survey?

Doctor's office

Genetic Testing Laboratory

Support Group Meeting

Online