

Topic	Instrument	Question	Responses
Welcome back!	Thanks for your time so far...	Now we have a few more questions for you to include as a more complete picture of your celiac disease.	
Demographics	Sex	My biological sex (genotype) is...	Female (XX),Male (XY),Neither XX or XY (specify on next question)
Demographics	Sex	I describe my genotype as "Neither" because I have...	Turner syndrome (45,XO),XX male syndrome (also, de la Chapelle syndrome),Trisomy X (47,XXX),Klinefelter's syndrome (47,XXY),Jacob's syndrome (47,XYY),48,XXXY,48,XXXX,XXYY syndrome (48,XXYY),49,XXXXY, Penta X syndrome (49,XXXXX)
Demographics	Sex	According to my karyotype, I am...	Non-mosaic ,Mosaic,Don't know
Demographics	Sex	Enter the two (or more) chromosomal variations reported below...	

Demographics	Sexual Orientation	When describing my sexual orientation or preference, I think of myself as...	Straight, Gay or lesbian, Bisexual (romantic attraction, sexual attraction or sexual behavior toward both males and females), Asexual (or nonsexuality- the lack of sexual attraction to anyone, or low or absent interest in sexual activity), Pansexual (or omnisexuality- sexual attraction, sexual desire, romantic love, or emotional attraction toward individuals of any sex or gender identity), Polysexual (sexual attraction to multiple genders and/or sexes), Demisexual (do not experience sexual attraction unless a strong emotional connection is formed with someone), Do not
Demographics	Sexual Orientation	I describe my sexual orientation as "Other" because I am...	
General Health	Conditions	I am living with a condition or other health concern, or have in the past...	Yes, Did in the past, No, Don't know
General Health	Conditions	I have the following conditions or health concerns...	

General Health	Conditions	I have had the following conditions or health concerns in the past...	
General Health	Medical History	I have been hospitalized before...	Yes,No
General Health	Medical History	To the best of your recollection, list the years (or if multiple times during a single year, the approximate month and year) when you were hospitalized over the past 10 years...	
General Health	Medical History	I have been tested for...	Hepatitis A,Hepatitis B,Hepatitis C,None of the above,Don't know
General Health	Medical History	I have been vaccinated for Hepatitis A...	Yes,No,Don't know
General Health	Medical History	I have been vaccinated for Hepatitis B...	Yes,No,Don't know
General Health	Medical History	I have had a tuberculosis screening...	Yes,No,Don't know
General Health	Medical History	I had my last tuberculosis screening on...	
General Health	Medical History	The result of tuberculosis screening was...	Positive,Negative,Don't know
General Health	Medical History	I have had a sexually transmitted disease (STD)...	Yes,No,Don't know

General Health    Medical History    I have had any of the following problems <em>currently</em> or in the <em>past</em>...    Acid reflux (heartburn),Anemia, Arthritis,Asthma/emp hysema,Bladder infections,Chronic diarrhea,Diverticulosis,Diabetes,Emotional problems,Epilepsy or seizures,Gallstones,G onorrhoea/chlamydia, Gout,Heart disease,High cholesterol,Interstitial Lung Disease/Pulmonary Fibrosis,None

General Health    Medical History    I have had any of the following problems <em>currently</em> or in the <em>past</em>...    High blood pressure,Kidney disease/stones,Liver disease/hepatitis,Lung disease/pneumonia,L yme disease,Pancreatitis, Rheumatic fever,Skin disease,Sleep apnea,Stroke,Venereal disease/syphilis,Thyroid disease/goiter,Tuberculosis,Tumors/cancer ,Ulcers (stomach or intestinal),None

Anemia or blood  
 problems,Arthritis,As  
 thma,Cancer,Depress  
 ion/anxiety,Diabetes,  
 Ear problems,Eye  
 disorder/glaucoma,H  
 eadaches/migraines,  
 Heartburn  
 (reflux),Heart  
 disease/murmur/angi  
 na,High blood  
 pressure,High  
 cholesterol,Kidney/bl  
 adder problems,Liver  
 problems/hepatitis,L  
 ow blood  
 pressure,Lung  
 problems/cough,Lym  
 e  
 disease,Neurological  
 problem,Psychiatric  
 care,Seasonal  
 allergies,Seizures,Sh  
 ortness of  
 breath,Sinus  
 problems,Stroke,Swo  
 llen ankles,Thyroid  
 problems,Tonsillitis,U  
 lcer/colitis,None of  
 the above,Don't  
 know

General Health    Medical History    The following conditions  
 are currently being  
 treated or have been  
 treated in the past...  
 I am allergic to  
 penicillin or other  
 drugs...  
 Here is a list of my  
 allergies...  
 I have had surgery...

Yes,No,Don't know  
 Yes,No

General Health	Medical History	To the best of your recollection, list the years (or if multiple times during a single year, the approximate month and year) when you had surgery over the past 10 years...	
General Health	Medical History	I am currently on a medication...	Yes,No
General Health	Medical History	Here is a list of my current medications...	
General Health	Medical History	I am aware of my family history...	Yes,No,Somewhat
General Health	Medical History	Anyone in my family (including grandparents, parents, brothers, sisters, or children) has had any of the following conditions...	Yes,No,Don't know
General Health	Medical History	Other condition(s) that my family member(s) has (please list the conditions)...	
General Health	Medical History	The 'other' conditions listed in the previous question affect...	Maternal grandfather,Maternal grandmother,Paternal grandfather,Paternal grandmother,Father, Mother,Child(male),Child(female),Brothers,Sisters

General Health	Medical History	I use any of these tobacco products...	Cigarettes, Pipe, Cigar, Snuff, Chew, None
General Health	Medical History	I smoke cigarettes _____ per day...	Less than 1 pack, 1 pack, 2-3 packs, 4-5 packs, >5 packs
General Health	Medical History	I drink alcohol...	Yes, No
General Health	Medical History	On average, I drink _____ (number of) glasses per week...	
General Health	Medical History	I drank alcohol in the past...	Yes, No
General Health	Medical History	I have used any of these recreational drugs...	Marijuana, Cocaine, Stimulants, Narcotics, Diet pills, Other, None
General Health	Medical History	List 'other' recreational drug(s)...	
General Health	Medical History	I am sexually active...	Yes, No
General Health	Medical History	I practice safe sex...	Yes, No
General Health	Medical History	I exercise regularly...	Yes, No
General Health	Medical History	I exercise _____ per week...	30min-1hr, 1hr-2hr, 2hr-3hr, 3hr-4hr, 4hr-5hr, 5hr-6hr, 6hr-7hr, >7hr
Background	Education	I am currently in school...	Yes, No

Background	Education	My highest level of education is...	No schooling completed,Some primary or high school (no diploma),Regular high school diploma,Special Education Certificate,GED or alternative credential,Some college, but less than 1 year,1 or more years of college, no degree,Vocational, trade school or associate's degree,Bachelor's degree,Master's degree,Professional degree beyond a bachelor's degree,Doctorate degree
Background	Education	The highest grade level I completed...	Preschool,Kindergarten, Grade 1,Grade 2,Grade 3,Grade 4,Grade 5,Grade 6,Grade 7,Grade 8,Grade 9,Grade 10,Grade 11,Grade 12 - No Diploma



Background	Education	My mother's highest level of education completed is...	No schooling completed,Some primary or high school (no diploma),Regular high school diploma,Special Education Certificate,GED or alternative credential,Some college, but less than 1 year,1 or more years of college, no degree,Vocational, trade school or associate's degree,Bachelor's degree,Master's degree,Professional degree beyond a bachelor's degree,Doctorate degree
Background	Education	The highest grade level my mother completed...	Preschool,Kindergarten, Grade 1,Grade 2,Grade 3,Grade 4,Grade 5,Grade 6,Grade 7,Grade 8,Grade 9,Grade 10,Grade 11,Grade 12 - No Diploma

Background	Education	My father's highest level of education completed is...	No schooling completed,Some primary or high school (no diploma),Regular high school diploma,Special Education Certificate,GED or alternative credential,Some college, but less than 1 year,1 or more years of college, no degree,Vocational, trade school or associate's degree,Bachelor's degree,Master's degree,Professional degree beyond a bachelor's degree,Doctorate degree Preschool,Kindergarten, Grade 1,Grade 2,Grade 3,Grade 4,Grade 5,Grade 6,Grade 7,Grade 8,Grade 9,Grade 10,Grade 11,Grade 12 - No Diploma
Background	Education	The highest grade level my father completed...	
Background	Language	My preferred method(s) of communication is (are)...	Sign Language,Spoken Language,Written Language,Non-Verbal English,Spanish,Creole,Chinese,Tagalog,French,Vietnamese,German,Korean,Russian,Arabic,Other
Background	Language	The language I most frequently speak at home is...	
Background	Language	The language I most frequently speak at home is...	

Background	Income	My total family income is...	Less than \$10,000 (USD), \$10,000 - \$14,999, \$15,000 - \$19,999, \$20,000 - \$24,999, \$25,000 - \$29,999, \$30,000 - \$34,999, \$35,000 - \$39,999, \$40,000 - \$44,999, \$45,000 - \$49,999, \$50,000 - \$54,999, \$55,000 - \$59,999, \$60,000 - \$74,999, \$75,000 - \$84,999, \$85,000 - \$99,999, \$100,000 - \$149,999, \$150,000 - \$199,999, \$200,000 - \$249,999, \$250,000 and above, Decline to provide
Background	Income	Including me, the number of persons that live in my household is...	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, More than 12
Background	Job Status	I am currently working (full time, part time, paid or unpaid)...	Yes, No, on disability, No, retired, No, other
Background	Job Status	The other reason I am not currently working is...	
Background	Job Status	My usual job or main occupation during my lifetime has been...	
Background	Job Status	I stopped work because of my health...	Yes, No
Background	Job Status	Occupation I had before I stopped working because of my health was...	

Background	Marital Status	My current marital status is...	never married, Married, Living as married, Widowed, Separated, Divorced, Remarried
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Quality of Life	About this section...	This section contains 29 questions for adults that are designed to evaluate general health and well-being in seven health domains: physical function, anxiety, depression, fatigue, social roles and activities, sleep disturbance, peer relationships, and pain.	
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Quality of Life	Physical Function	I am able to...	Without any difficulty, With a little difficulty, With some difficulty, With much difficulty, Unable to do
Quality of Life	Anxiety	In the past 7 days, I felt...	Never, Rarely, Sometimes, Often, Always

Quality of Life	Anxiety	In the past 7 days, I found it hard to focus on anything other than my anxiety...	Never, Rarely, Sometimes, Often, Always
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Quality of Life	Anxiety	In the past 7 days, my worries overwhelmed me...	Never, Rarely, Sometimes, Often, Always
Quality of Life	Depression	In the past 7 days, I felt...	Never, Rarely, Sometimes, Often, Always

Quality of Life	Fatigue	During the past 7 days, I felt fatigued...	Not at all, A little bit, Somewhat, Quite a bit, Very much
Quality of Life	Fatigue	During the past 7 days, I had trouble <u>starting</u> things because I was too tired...	Not at all, A little bit, Somewhat, Quite a bit, Very much
Quality of Life	Fatigue	In the past 7 days, on average, I...	Not at all, A little bit, Somewhat, Quite a bit, Very much
Quality of Life	Sleep Disturbance	In the past 7 days, my sleep quality was...	Very Poor, Poor, Fair, Good, Very Good
Quality of Life	Sleep Disturbance	In the past 7 days, my sleep was refreshing...	Not at all, A little bit, Somewhat, Quite a bit, Very much
Quality of Life	Sleep Disturbance	In the past 7 days, I had a problem with my sleep...	Not at all, A little bit, Somewhat, Quite a bit, Very much
Quality of Life	Sleep Disturbance	In the past 7 days, I had difficulty falling asleep...	Not at all, A little bit, Somewhat, Quite a bit, Very much
Quality of Life	Ability to Participate in Social Roles and Activities	I have trouble doing all of my regular leisure activities with others...	Never, Rarely, Sometimes, Often, Always
Quality of Life	Ability to Participate in Social Roles and Activities	I have trouble doing all of the family activities that I want to do...	Never, Rarely, Sometimes, Often, Always
Quality of Life	Ability to Participate in Social Roles and Activities	I have trouble doing all of my usual work (include work at home)...	Never, Rarely, Sometimes, Often, Always

Quality of Life	Ability to Participate in Social Roles and Activities	I have trouble doing all of the activities with friends that I want to do...	Never,Rarely,Sometimes,Often,Always
Quality of Life	Pain Interference	In the past 7 days, pain interfered with my...	Not at all,A little bit,Somewhat,Quite a bit,Very much
Quality of Life	Pain Intensity	In the past 7 days, on average, I would rate my pain as...	
Quality of Life	About this section...	This section contains 25 questions that are designed to evaluate general health and well-being in six health domains: physical function, anxiety, depression, fatigue, peer relationships, and pain interference.	
Quality of Life	Physical Function & Mobility	In the past 7 days, I could do sports and exercise that others my age could do...	With no trouble,With a little trouble,With some trouble,With a lot of trouble,Not able to do
Quality of Life	Physical Function & Mobility	In the past 7 days, I could...	With no trouble,With a little trouble,With some trouble,With a lot of trouble,Not able to do
Quality of Life	Physical Function & Mobility	In the past 7 days, I have been physically able to do the activities I enjoy most...	With no trouble,With a little trouble,With some trouble,With a lot of trouble,Not able to do

Quality of Life	Anxiety	In the past 7 days, I felt like something awful might happen...	Never,Almost Never,Sometimes,Oft en,Almost Always Never,Almost
Quality of Life	Anxiety	In the past 7 days, I felt nervous...	Never,Sometimes,Oft en,Almost Always Never,Almost
Quality of Life	Anxiety	In the past 7 days, I felt worried...	Never,Sometimes,Oft en,Almost Always
Quality of Life	Anxiety	In the last 7 days, I worried when I was at home...	Never,Almost Never,Sometimes,Oft en,Almost Always
Quality of Life	Depressive Symptoms	In the past 7 days, I felt everything in my life went wrong...	Never,Almost Never,Sometimes,Oft en,Almost Always Never,Almost
Quality of Life	Depressive Symptoms	In the past 7 days, I felt...	Never,Sometimes,Oft en,Almost Always
Quality of Life	Depressive Symptoms	In the past 7 days, it was hard for me to have fun...	Never,Almost Never,Sometimes,Oft en,Almost Always
Quality of Life	Fatigue	In the past 7 days, being tired made it hard for me to keep up with my schoolwork...	Never,Almost Never,Sometimes,Oft en,Almost Always Never,Almost
Quality of Life	Fatigue	In the past 7 days, I got tired easily...	Never,Sometimes,Oft en,Almost Always
Quality of Life	Fatigue	In the past 7 days, I was too tired to do sports or exercise...	Never,Almost Never,Sometimes,Oft en,Almost Always
Quality of Life	Fatigue	In the past 7 days, I was too tired to enjoy the things I like to do...	Never,Almost Never,Sometimes,Oft en,Almost Always
Quality of Life	Peer Relationships	In the past 7 days, I felt accepted by others my age...	Never,Almost Never,Sometimes,Oft en,Almost Always

Quality of Life	Peer Relationships	In the past 7 days, I was able to count on my friends...	Never,Almost Never,Sometimes,Oft en,Almost Always
Quality of Life	Peer Relationships	In the past 7 days, my friends and I helped each other out...	Never,Almost Never,Sometimes,Oft en,Almost Always
Quality of Life	Peer Relationships	In the past 7 days, other kids wanted to be my friend...	Never,Almost Never,Sometimes,Oft en,Almost Always
Quality of Life	Pain Interference	In the past 7 days, when I felt pain, it was hard for me to...	Never,Rarely,Someti mes,Usually,Always
Quality of Life	Pain Intensity	In the past 7 days, on average, my pain was...	
Relationship with Research	Interest In Participating In Research	Aside from this survey, I have taken part in research projects related to my health or to the health of a family member...	Yes,No,Don't know
Relationship with Research	Interest In Participating In Research	If it was quick and easy to do, I would be willing to update my health profile on a regularly scheduled basis...	Definitely would want to do this ,Very likely ,Somewhat likely ,Uncertain ,Somewhat unlikely ,Very unlikely ,Definitely not
Relationship with Research	Interest In Participating In Research	My preferred method(s) to receive questions and respond with periodic updates in this sort of program would be...	Text message,Email,Phon e call,From a computer browser,Mail (Postal Service)



Relationship with Research	Interest In Participating In Research	If I could control who saw the information, I would be willing to ask my health provider(s) to communicate updates to my profile and/or link all or some portion of my health records to it...	Definitely would want to do this, Very likely, Somewhat likely, Uncertain, Somewhat unlikely, Very unlikely, Definitely not
Relationship with Research	Interest In Participating In Research	I am interested in taking part in research in general...	Definitely would want to do this, Very likely, Somewhat likely, Uncertain, Somewhat unlikely, Very unlikely, Definitely not
Relationship with Research	Interest In Participating In Research	I am interested in giving a blood sample that would be used to study my DNA...	Definitely would want to do this, Very likely, Somewhat likely, Uncertain, Somewhat unlikely, Very unlikely, Definitely not

Relationship with Research	Interest In Participating In Research	I am not interested in participating in research because...	Do not want to be a "guinea pig",The project was not recommended by a doctor ,Results may not be kept private or confidential,The project will take a lot of time,Not paid for taking part,The project involves medical tests, Like drawing blood or having x-rays,The research might reveal something bad,No obvious benefit to self or family,Worried about privacy,Don't know,Would rather not say
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Relationship with Research	Interest In Participating In Research	I would be more likely to take part in research if it were run by...	Personal doctor,A medical school or hospital,The US government (like the National Institutes of Health),A non-profit foundation (such as the American Diabetes Association),A tobacco company,A drug company,An insurance company,Private research institute
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<p>Thank you for  
completing this survey.  
We appreciate your  
contributions.

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<p>

Please check your email  
for regular updates on  
how your participation  
is helping in the fight  
against celiac disease.  
To contact us about this  
survey, or any other  
matters, please use the  
"Give Feedback" link  
below.

In conclusion... Thanks again! </p>