



National Celiac Association

Spring 2016 College Survey

Introduction

For some, the diagnosis of celiac disease provides the answer to a series of health questions. Why can't I lose weight? Why can't I gain weight? Why do I always feel awful after eating? Why do I have brain fog? Is this *normal*?

The diagnosis also comes with a set of rules for eating safely: consume no foods with gluten. No food that has been prepared using the same implements or cooking oil that has been used with "regular" food (containing gluten). Some with celiac disease will react strongly to being "glutened"; others may have no reaction even though the gluten will continue to damage their system.

And gluten hides in a variety of foods, such as sushi rice. If the rice has been prepared with malt vinegar, it contains gluten. Many with celiac disease have to play "detective" to find out why they get sick after eating out.

For adults, the process of refining one's diet, playing detective, keeping oneself safe, is challenging enough. For a young adult, who may have been recently diagnosed, or may be heading off to college for the first time, responsible for their own well being, the challenges can be overwhelming.

The National Celiac Association (NCA), then known as New England Celiac Organization (NECO), set out to document the issues faced by college students. The authors have lived this firsthand... "our daughter was diagnosed shortly before going off to school and had to advocate strongly for herself to be able to receive 'safe' food on a regular basis." Her experience is not uncommon in the celiac community.

The respondents reported significant, perhaps devastating, social and educational impact, at a point in their personal development when they are particularly vulnerable. First time away from home (and the parental and long term support systems), making new friends, trying to adjust to new social norms, taking on more challenging educational loads.

And boom...they get sick. Boom...they have to pre-order food. Boom...they have to eat separately from their new friends. Boom...they miss classes. Boom...they have to advocate for themselves. Boom...they end up double paying for food (no refund on

the meal service, no safe cooking facilities, not much more than junk food available outside the cafeteria).

As one measure of the impact, a full 60% of those with celiac disease would not be “very” or “extremely” likely to recommend their school to others with celiac disease. This question, phrased using the standard “NetPromoter Score” methodology, represents a failure on the part of those schools to meet the needs of their “customers...”

This is a recipe for personal and developmental disaster. Our research documents how broadly the problem exists and the extent of the impact.

NCA recommends the following actions:

- Schools and universities must acknowledge the extent of the problem and its impact.
- They need to take the problem seriously – gluten and cross-contamination will cause serious health issues, including cancer, for those with celiac disease.
- School administrations and food service organizations must properly develop and operate “safe eating practices,” ensuring that those with celiac disease can eat safely, with a choice of selections across the major food groups.

The data suggests that those that have been recently diagnosed are at greater risk as their answers skew towards “poorer” responses, reflecting greater impact as they are just learning about the disease, how to manage it, and how to advocate for themselves. Similarly, those with no other family members diagnosed with celiac show to be at substantially greater social and educational risk.

Methodology

NCA (then NECO) hosted an online survey instrument with SurveyMonkey and invited participation through a number of channels, including email, Facebook and other social media. The survey was opened on April 1, 2016 and closed 60 days later, on June 1, 2016. Participants were emailed multiple times to ensure participation and survey completion.

Summary of Findings

Of the 415 total respondents, just over half (215) completed the entire survey.

- 37% identified as having a formal celiac diagnosis
- 18% specified a gluten sensitivity

- 36% indicated that they choose to eat gluten free
- 8% reported an “other” need to eat gluten free

74% of the celiacs had been diagnosed five or more years ago, and 61% reported that one or more other family members also have celiac disease.

44% of those with celiac disease reported that eating gluten free had been a problem “the entire time I’ve been here.” Another 26% reported that it was a problem at first, but got better over time.

Only 30% of the those with celiac disease reported that their diet at school was “well-rounded,” while 48% of respondents choosing to eat gluten free reported that their diet was well rounded. Conversely, 16% reported that they are supplementing their diet with snacks, while only 5% of those choosing to eat gluten-free reported having to supplement.

20% of those with celiac disease reported that the food service needed more than 30 minutes to prepare gluten free food.

A full 40% reported that their eating experience on campus was “poor – challenging, frustrating.”

32% report that they still expect to be “glutened” once in a while. Almost 20% say that they simply stay away from the food service as it’s “not worth the risk.”

71% reported that their efforts to eat gluten-free were having some or major impact on their social life. The following are some of the verbatim comments provided by respondents:

I feel weird and bad when I have to keep being like 'yall I can't eat at any of these restaurants' or not being able to reliably eat at a certain dining hall and people get upset and then I feel like a bad person and some times end up going places where I can't eat anything.

People do not want to put in that little bit of extra effort to make sure that I can eat and eat safely. They think it's a joke and not a serious medical condition. I've been told to either eat before I go out or bring my own food along because no one else can be bothered to go to a restaurant where I can eat or make sure that I can have like a bag of chips at a party.

Many of my friends do not understand the severity of celiac disease. Because of this, I am often excluded from social events with friends, and I am rarely invited out to eat. If I am invited, I bring my own food, which leads to a further sense of social isolation. Friends and family will offer to make me food, but this gives me severe anxiety, because I do not know the state of their kitchen, or the segregation of ingredients or utensils. Because of this, I tend not to eat when going out with friends or when attending events at other people's houses.

I don't have a social life LMAO sorry I stay in the classroom during meals and work through them. It's a better use of my time than going up to the dining hall only to find there's nothing to eat.

It's frustrating because all my friends have meal plans and want to eat at the cafeteria, but I rather not. But, I also don't have access to a kitchen and cannot afford to go out to eat and end up eating minimal meals at the cafeteria.

Long wait time to get gf food, limited Options, no gf food at social events or food trucks on campus, friend complain they don't want to dine with me as it takes too much time

I rarely can eat out with friends off or on campus because of incredibly limited selection and perpetual risk of cross contamination.

A lot of the academic events and social events provide food, which I usually cannot eat. This means that either I have to bring my own food or eat before/after. I can only be accommodated at one dining hall on campus, thankfully it is the main one, but this severely limits my meals "out" on campus with friends.

I can't enjoy going out, unless to a place I know is safe for me to eat. My friends are considered of where I can eat, but I feel awkward always choosing the places to eat.

I have to request food in advance and have to wait for it to be prepared. This leaves me alone or away from my friends for part of our meal time.

My friends won't wait for me to get my food. So I have to eat alone.

I avoid community gatherings because I know there will be no gluten-free options.

Feeling awkward or isolated because of my dietary needs.

I hold back from going to certain events because everyone is eating and I hate being that awkward person just standing around

Making me feel excluded Making my friends not want to be around me because I'm sick

Conversely, only 4% of those choosing to eat gluten-free felt a substantial social impact.

32% indicated that having to find gluten-free food is having "some" impact on their educational success, while 5% indicated that it was having a "major" impact.

I have wasted a lot of my time, that I could have spent studying or with friends, meeting with the cafeteria staff and emailing them.

At times food wasn't able to be prepared in the time frame I had and was forced to eat prepackaged snack food for the day

When I first came here and lived on campus, I was getting sick frequently and had to miss a few classes. I haven't had any problems lately

After being glutened, the brain fog I experienced often made concentrating in class nearly impossible. Those days I may as well not been in the classroom.

I am extremely sensitive to gluten and it causes major brain fog, belly aches, diarrhea to the point I have to miss classes.

I have had to miss class from being "glutened" more than once, without a doctor's note excusing me for that day specifically, I get points deducted from my average for missing class.

23% of those with celiac disease report skipping 1-2 meals a week due to gluten concerns, while 30% report skipping 3-5 meals a week.

25% reported that they worked with the food service to improve the situation. The largest percentage, however, 30%, indicated that they found no solution, they were just "winging it."

58% of those with celiac disease report that the food choices at school are "limited and repetitive."

8% report that they are glutened "frequently," while 17% report being glutened at least a couple of times each month.

Over half, 51%, had no idea whether the food service workers had been properly trained in food preparation (with regard to cross contact). Another 18% guessed that perhaps one or two workers had been properly trained.

Family Matters

Those with other family members with celiac disease handle the situation better at school, reporting that access to gluten-free food is better. 38% of those with a family history of celiac disease report having a well-rounded diet, versus only 17% of those with no other family members.

Those with family members more actively advocated for themselves and reported better results. 66% of those with family members reported that having to eat gluten-free was having "some" or "major" impact on them socially, while a full 80% of those with no other family members reported this impact.

Clinical Support

From Dr. Alessio Fasano, Director of the Center for Celiac Research and Treatment at MassGeneral Hospital for Children
Boston, Massachusetts

The results of the New England Celiac Organization's (NECO) recent survey paint a troubling picture for many college students who cannot consume gluten-containing foods (who have a diagnosis of celiac disease or non-celiac gluten sensitivity) to be

medically “safe.” Not only are their dietary needs not being met safely or adequately, there is also a spillover effect into the social and academic life of many of these students, particularly for those students diagnosed with celiac disease.

The survey findings from NECO present a challenging picture not only for those who work in college dining halls and kitchens, but also for the administrators of these institutions.

I support NECO’s call to action for colleges and universities to acknowledge this problem and develop safe eating practices for students with celiac disease and non-celiac gluten sensitivity.

I also urge college and university administrators to undertake an awareness campaign about celiac disease and gluten-related disorders to help eliminate the social stigma faced by some of these students. This would demonstrate to all students that eating gluten free is not a “fad diet” for students with these disorders, but indeed, it is a medical necessity.

July 10, 2016

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I strongly support NECO’s initiative, a call to action by colleges and universities to support their students with celiac disease and non-celiac gluten sensitivity. College is a particularly important transition time in life when a person on a medically necessary gluten-free diet may have the least amount of personal control over the food he/she eats. It is imperative that our educational institutions stand up and eliminate the inconveniences and social burden of managing a special diet on campus, offer well balanced gluten-free alternatives to the general menu, and protect their students from gluten exposure that will negatively affect their brains and bodies. I’ve heard from many students over the years about their campus eating experiences – there are some great strides being made out there but it needs much more attention.

“ Special Thanks to Ian’s Natural Foods for support of this survey”