National Celiac Association Tennessee

GrainWise & GlutenFree

September 2020

NCA Tennessee (NCAT) -- serving those living gluten-free in Middle Tennessee

Our Next Meeting -- Saturday, Sept. 12th 1:00 – 3:00

The Gluten-Free College Experience

Valerie Kraft is a rising senior at Vanderbilt University studying Medicine, Health, and Society; Psychology; and Women's and Gender Studies. After being diagnosed with Celiac Disease in 2015, Valerie started a career of advocacy that included creating an international network for newly diagnosed Celiac teens, revolutionizing Vanderbilt's special diet program, designing the Nima College Ambassador Program, and working individually to help students navigate collegiate Celiac life.

Valerie is going to Zoom in from her home, as she is taking online classes this semester. She is also working part-time with the Picknic app, posting to their social media accounts and managing interactions with others through these accounts. Her personal familiarity with celiac disease is a plus in this position.

She is extremely passionate about being an advocate for one's self and hopes her story and advice can help empower the next class of gluten-free college students. So if you have students preparing to go to college, please have them join you for this Zoom meeting. Her story will interest all of us.

But How Are We Going to Meet? via Zoom!

In June, we used Zoom for the first time, as so many others are meeting at this time. We shared the PowerPoint presentation on Dining Out that we had to cancel back in March. I'll share some of the basics about that later, but since we still don't feel comfortable meeting in person yet, we have decided that we will meet once again via Zoom. This will permit Valerie Kraft to speak to us even though she is home this semester, taking online classes instead of being on the Vanderbilt campus.

If you haven't used Zoom yet, it is very easy. We will set up a meeting for September 12th 1-3 pm and then we will send you a link to that meeting and a password so only our members and guests can get in the Zoom classroom. You may use a computer, an iPad, or your smartphone to log into the Zoom meeting. You will enter with audio and video from your computer or phone. We will be able to see each other and we will be able to converse as we usually do. During the presentation, you will mute your audio so that no distracting noises interfere with the program, but you will be able to unmute the audio to ask questions as needed or at the end of the program. It's really almost like meeting in person except we are all at home and meeting virtually on the screen.

Our guest speaker at our September 12th Zoom meeting will be Valerie Kraft. She joined our NCAT when she came to Vanderbilt. She has worked to vastly improve the special dietary programs at Vanderbilt. She is now also working part-time doing social media management for the Picknic app that we learned more about at the June meeting.

June's meeting – Yes, You Can Dine Out Gluten-Free!

Our June Zoom meeting, which replaced our March meeting that we had to cancel, focused on how to talk to restaurant hosts, servers, managers, or chefs in order to assure that you have a pleasant gluten-free dining experience. First you have to select a restaurant using their website or an app that recommends gf restaurants. Then you can email or phone to make sure they can provide safe gf meals. Letting them know up front when you make reservations will allow the kitchen to prepare for your meals. If you don't make reservations, you should let the hostess know up front that you need gf options.

It pays to tell your server that you would become sick if your food contains or becomes cross-contaminated with wheat (rye, or barley). If the server doesn't seem to understand, ask to speak to a manager, or the chef to communicate your needs. Bringing a restaurant card explaining celiac and how to prepare gf foods in the kitchen can help. I have kitchen cards in English and Spanish to give out when we can meet in person. You can take one to your favorite restaurants to post in their kitchens for their staff.

We also went over tips for various ethnic cuisines and different restaurants so you could make safe choices from their menus.

If you have questions about specific restaurants or cuisine types, let me know and I'll share those tips in the next newsletter. **Call Carol Ann Baily at 615-478-9998 or email carolannbaily@gmail.com**

Check out the Picknic app, Nashville's Restaurant Search Engine for Celiacs

In June, we announced the Nashville-based startup Picknic app started by an NCAT member, Beau Bristow. With data for over 400 restaurants in Middle Tennessee, Picknic allows people with critical dietary restrictions such as food allergies and celiac disease to find restaurants and menu items that match their needs.

Picknic's most popular features among early users include allergy-friendly ratings for restaurants, details about a restaurant's food preparation process, and tips for eating there. Picknic also allows users to search by their dietary restriction (e.g. gluten-free, peanut-free, etc.) to see the menu items that match their needs.

When asked what NCAT members can do to support Picknic, Bristow said the following: "The most valuable thing to us right now is feedback about Picknic: what users like, don't like, and what we can do better. We also need help spreading the word to others with food allergies and celiac disease, especially in Middle Tennessee."

To learn more about Picknic and search for restaurants, visit https://picknic.app. If you have feedback, you are welcome to email Beau directly at beau.bristow@picknic.app.

Gluten Intolerance Group (GIG) creates a new GF symbol

The Gluten Intolerance Group, based in Seattle, announced in a recent online meeting that they have designed a new certification mark that will be displayed on products that meet that organization's safety standards that **test for gluten to less than 10 parts per million (ppm).** They are announcing this new certification mark to help consumers choose products that meet their standards. You may want to watch for their GFCO Certified Gluten-free mark on the packages you buy. This new certification mark will be on store shelves soon.

Old GIG logo

New GIG logo

New Small GIG logo

The National Celiac Association (NCA), our parent organization, has a certification program **testing gluten to less than 5 parts per million (ppm).** Using this symbol, you can look for products you are purchasing that may be even safer for you, with much less possible gluten.

CELIAC DISEASE: IS IT OK TO CHEAT ON YOUR GLUTEN-FREE DIET?

One misadventure with gluten will stick with your body for a while. So, the answer is NO.

U.S. News and World Report, May 25, 2020.
Tamara Duker Freuman, MS, RD, CDN; May 25, 2020

from the *Houston Celiac Perspective*, Summer Issue 2020

When people with celiac disease consume even trace amounts of gluten – a protein naturally found in wheat and its close relatives like spelt, barley and rye – their bodies launch a self- directed immune system attack that can cause damage to the intestinal lining and result in a variety of health problems beyond the digestive tract.

A meticulously strict gluten-free diet for life is the only treatment for celiac disease, and when people with CD adhere to this diet for the long term their guts typically heal fully.

Having worked with hundreds of patients with celiac disease over my years as dietitian in a gastroenterology practice, I've gotten an insider glimpse at how different people with celiac disease live with the condition.

To some, their celiac disease diagnosis is a welcome explanation for years of feeling miserable and sick, and the inconvenience of a gluten-free (GF) diet is a small price to pay for being able to feel consistently healthy and well. Even minute amounts of exposure to gluten make them feel so awful for days, that they take painstaking measures to avoid it at home, as well as when eating out, traveling and celebrating special events.

But even with the growing popularity of gluten- free lifestyles and increasing availability of gluten- free packaged foods and restaurant menu items, it can still be quite inconvenient to follow a strict, GF diet.

Vigilance Fatigue

When you really want pizza or pasta, it sucks to have to order a salad when dining out because it's the only gluten-free menu item. It can be embarrassing to grill restaurant servers about menu items and prep methods when dining out, especially if sharing a meal with work colleagues or out on a date.

It's annoying to have to bake your own gluten- free birthday cakes because there's no gluten-free bakery in your area. It's also sad to miss out on your mom's famous fill-in-the-blank-of-your-favorite- nostalgic-dish because it's made with flour, and her attempts at gluten-free substitutes just don't taste the same. Trust me, I get it: I've been living with celiac disease for the past 12 years.

For any/all of these reasons, many of my patients seem to experience a "vigilance fatigue" after months or years of strict attention to avoiding cross-contamination, reading labels and always erring on the side of caution when eating out. It may result in laxity with adhering to the GF diet: not grilling their servers about ingredients when dining out, ignoring the likelihood of soy sauce in a dish or opting for the side of French fries, knowing that they likely shared a deep fryer with battered or breaded menu items. Still others knowingly "cheat" on their GF diet with various degrees of frequency – from just once in a while to once a week.

My patients with celiac disease who only experience mild symptoms when consuming gluten – and especially those who have "silent celiac disease" and experience no noticeable symptoms at all – can find it especially hard to stay motivated to consistently follow their medically-necessary GF diet.

Beyond the fatigue factor, some people with celiac disease don't fully understand what actually happens inside their bodies when they eat gluten, and how one random bite of cake or stolen moment with a croissant can have longer-lasting impact than just the duration of the bloating, stomachache or diarrhea it provokes.

Recently, I met a new patient who continued eating gluten for four years after a celiac disease diagnosis. She did so believing that her mild symptoms of temporary gas and bloating after eating gluten meant that she didn't have it "as bad" as her brother, who got violently ill with even trace exposure. Although she had such severe iron deficiency anemia that it required intravenous iron infusions, no doctor had ever pointed out the connection between her ongoing gluten consumption and the likely nutrient malabsorption as a result of it. Damage was being done to her gut with each exposure, even when it didn't feel so bad.

So in recognition of celiac disease awareness month, I think it's important for those of us with celiac disease to understand why maintaining ongoing vigilance in our gluten-free diets remains important month after month, year after year.

The Lasting Effects of Gluten

"The inflammatory response when a person with celiac disease is exposed to gluten starts within just a few hours, and involves the propagation, migration and invasion of white blood cells into the gut's lining," explains my gastroenterologist colleague, Dr. Eric Goldstein of East River Gastroenterology and Nutrition in New York City. But the duration of this inflammatory process set off by even a single, seemingly small intake of gluten will far outlast the particular digestive journey of the food itself.

Start to finish, the cascade of inflammatory reactions isn't hours-long or even days-long, but more likely weeks-long. "The lymphocyte (white blood cell) invasion of the gut's tissues stimulated by that bit of cake doesn't just disappear immediately; it can be going on even a week later. And once the storm is over, it can take another week to re-grow the damaged gut cells – and then those cells may take several more days to mature and start producing their normal levels of digestive enzymes."

Exposure Just Once or Twice a Year?

Let's say you have celiac disease, you pay close attention to your gluten free diet, but you still have one or two accidental, isolated exposures per year. According to Dr. Goldstein, there will be plenty of time for your gut to heal between these exposures.

But if you're chronically lax with your gluten- free diet and have intentional or unintentional exposures even a few times per month, "you're piling on additional injury while the gut is still going through the previous injury. The gut never gets a chance to heal before the next exposure, and this leads to chronic inflammation ... and this is the case even if you are following your gluten-free diet 'most of the time.'"

The risks of poorly-managed celiac disease are well-documented. They include: Iron deficiency anemia; · Osteoporosis due to chronic malabsorption of calcium; Developing small intestinal bacterial overgrowth (SIBO); · Infertility and/or miscarriages; · Neurological symptoms and injury; · A variety of digestive system complaints.

People with celiac disease are also at elevated risk for developing certain cancers of the small intestine, and there's the strong suggestion – but not conclusive data – that better adherence to the gluten-free diet may reduce this risk. So as much as I miss some of the goodies from my old, pre-celiac life, the fleeting pleasure of a stolen bite of croissant isn't worth sacrificing my long-term health for.

Upcoming Events for NCAT— NCA to offer monthly webinars in the fall. Our Next Meeting on November 14!

We will send you email notice of the webinars offered by NCA this fall as soon as we get news about them. Although our Holiday Potluck is usually our meeting event for November, we are thinking that we will not be able to meet in person and share food this year. Would you like a cooking sharing session with ideas and recipes for the holidays? If so, please contact us via email with suggestions. I have a couple of ideas about people who might be able to share some recipes and show us some gluten-free holiday ideas.

NCA expands Feeding Gluten-Free program

NCA has restructured its gluten-free food assistance program. Because the national need has been so great, and growing, the decision was made to close our in-person Gluten-Free Food Bank in order to maximize efficiency. A local MA food pantry has decided to take it over and continue serving GF food to the whole state of MA. Also, to better reflect what NCA is doing, they changed this initiative from "Giving Gluten-Free" to "Feeding Gluten-Free."

They have **identified over 36 different food banks/pantries** around the country who are willing to accept gluten-free food and deliver it to those with this specific need. The total **value of food donated** exceeds $320,000! While this has all been donated, NCA has paid for some of this food to be shipped to where it is needed. They continue to call food assistance organizations to find the need for GF food assistance and **have already called more than 135 of them**. At the same time, they are responding to individuals who are calling in for help, trying to get them a longer-term solution for their food insecurity.

NEW ONLINE Nourished Festival

The Nourished Group is launching an online Gluten-Free & Specialty-Diet Festival.

The 3-day live event will be on September 24 - 26.

- Coupons
- Giveaways
- Virtual Presentations
- Cooking Demos
- Discover New Brands
- Purchase Products
- ...and more!

For details about the festival, contact: glutenfree@findmeglutenfree.com