



Celiac Support Group

NEWSLETTER



SUMMER 2024

We hope this newsletter finds you well and hope you are enjoying Summer! This summer is packed with opportunities to connect with others living with Celiac, learn and try new things, and have fun together! See below for updates on our latest events and upcoming opportunities! We hope you enjoy this edition of the newsletter, and please reach out to us at celiacsupport@childrenswi.org if there is anything else you'd like to see in future editions including a question you would like answered in the Ask the Experts section or if you want to share any recipes or recommendations, tips, or advice with the support group.

May was Celiac Disease Awareness Month

Here are a few facts you can share with your friends and family members to help them learn a little more about celiac disease:

- Celiac disease is estimated to affect 1 in 100 people worldwide
- About 80% of the people with celiac disease are undiagnosed
- People who have a first degree relative with celiac disease have a 1 in 10 chance of developing celiac disease themselves
- There are over 200 known symptoms of celiac disease

Celiac Screening

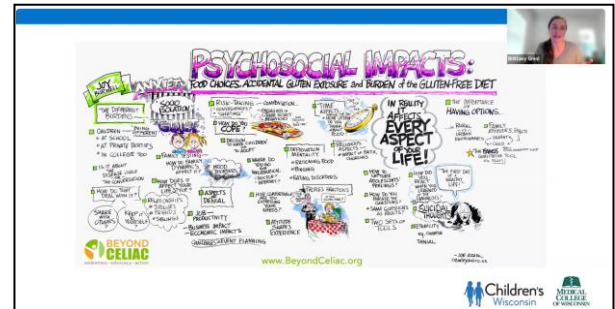
- We recommend that all immediate family members (parents and siblings) are screened for celiac disease.
- Contact your primary care provider and have them order the testing (Serum IgA level and Tissue Transglutaminase IgA (tTG IgA)).
- Remember that you would need to be consuming a gluten containing diet in order for the results of this screening lab test to be accurate.



Celiac Support Group Updates & Upcoming Events

April Support Group Event Summary

We learned so much about the psychological impacts of celiac disease at the virtual presentation by Children's Wisconsin GI Psychologist, Dr. Brittany Gresl. She is now available to see patients with Celiac at Main Campus or virtually! Please reach out to your GI team to discuss a referral if you're interested in individual support for things such as learning to manage thoughts, feelings and behaviors, coping and adjusting to your medical diagnosis, management of stress or anxiety, and other psychological concerns. If you missed the event on GI Psychology, the recording can be found [here](#)



May Support Group Event Summary

New this year, we held an event geared toward specific ages. May's event was for our littlest kiddos with Celiac at the Bug and Goose Play Café in Elm Grove where the kids played and parents were able to connect with one another about raising young children with celiac. For Celiac Awareness Month, they received gluten-free goodie bags!

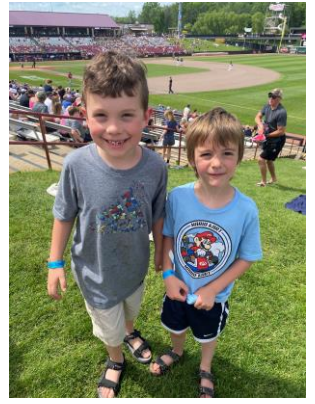
June Support Group Event Summary



Thank you to everyone that came to the Wisconsin Timber Rattlers Baseball Game in Appleton on June 2nd! We sold all 75 tickets in our reserved block of seats and had a great turn out at the tailgate, too! Children's Wisconsin (CW) and the Celiac Program were the Timber Rattlers Community Spotlight for the game! CW staff had a booth at the game and were able to spread

awareness about Celiac disease and share info about the CW Appleton Clinic before the game started. Luca (9 years old) was chosen to throw the first pitch at the game! The tailgate party included yard games, a grill out, and family fun! Special thanks to Missy Tate, a member of our Family Advisory Board, for all your help at this event!





Upcoming Event: Holey Mackerel Mini Golf on July 25th at 5-7pm

An opportunity of children/teens (age 10+) and their parents/caregivers to get together and have an open conversation about celiac and the gluten free lifestyle. Small fee of \$5/player for unlimited mini golf, 2 tokens to the batting cages, and gluten free snacks in Greenfield. Please **RSVP by July 18th** to CeliacSupport@childrenswi.org

Upcoming Event: Rainbow Day Camp on August 14th in Fredonia

Day camp with sports, swimming, boating, climbing tower, archery, and arts and crafts for Children's WI Celiac patients and their siblings, ages 5-18. No cost to you! Transportation, beverages, and a gluten-free lunch provided. Bus from Main Campus will leave at 9am and return at 4pm. Bus from Appleton Clinic will leave at 8:15am and return at 4:30pm. If you are driving your child, please drop off by 9:30am and pick up at 3pm. **RSVP by August 1st** by emailing CeliacSupport@childrenswi.org with your child's name, age, transportation (bus/driving), and completed permission form.



Ask the Experts

Are children with Celiac Disease (CeD) at higher risk for developing a mental health disorder compared to their non-CeD peers?

GI Psychologist, Dr. Brittany Gresl answers: Yes, children with CeD are at higher risk for developing a mental health disorder. The burden of strict adherence to a gluten free (GF) diet along with the psychosocial impact of the disease is associated with increased symptoms of anxiety, depression, and behavior problems which can lead to decreased quality of life, challenges with adherence to GF diet and more stress for both children and caregivers in the long-term. Moreover, there is evidence that this treatment burden does not necessarily decrease after diagnosis, suggesting that management of the GF diet does not get easier over time.

While mental health concerns can occur independently from CeD, it is important to consider the above factors that may be impacting the child's functioning and recognize the benefits of seeking mental health support early on. One way we are doing this at Children's Wisconsin is starting to incorporate psychological health and wellbeing screenings with a psychologist specializing in pediatric GI. This multidisciplinary approach to care will allow us as a team to monitor psychosocial functioning over time, target problem areas before they cause significant impairment, and integrate psychosocial health into a comprehensive CeD treatment plan. For more information about the Children's Wisconsin Celiac Program, visit our website at: [Celiac Disease Clinic | Pediatric Celiac Specialists | Children's Wisconsin \(childrenswi.org\)](#).

Patient Perspectives

Tips for how to navigate social scenes with Celiac

Shared by Lexi Van Den Heuvel, a past patient of Children's WI and current member of the Children's WI Celiac Family Advisory Board

Navigating social scenes with celiac can be eased tremendously by thorough preparation. Several suggestions for planning ahead include:

- **Communication with the Host:** Communicate your food intolerances to the host of the event so the individual can prepare food for you or recommend you bring your own. From personal experience, I recommend always bringing a snack in case the host forgets, is not careful, or does not have your preferred option. Sometimes it is easier to just bring your own dish!
- **Bring a Dish:** Consider bringing a dish to social scenes with necessary protein and carbs to ensure you are well fed.
- **Practice the Art of the Decline:** Never apologize for your celiac; it is essential to advocate for yourself confidently, whether that be through education, politely declining an option that is not safe, or learning to say no, if pushed.

It is also important, again, to cultivate a group of friends that prioritize your health and wellbeing; friends should understand and respect the severity of celiac.



New Products/Recalls

NEW!

- Canyon Bakehouse Cinnamon Raisin Bread
- Crunch Master Avocado Toast Crackers
- Chips Ahoy Original Cookies
- Taste Republic Egg Noodles
- Glutino Dill Pickle Pretzel Twists
- Blake's Seed Based Breakfast Bars
- Garden Veggie Flavor Burst Nacho Cheese and Zesty Ranch flavors
- Glutino 3 new flavors of sandwich cookies (mint, lemon pie, swiss miss hot cocoa)
- Simply Nature PB&J Bites are back while supplies last at Aldi!
- BFree Gluten Free products have a new look!



RECALLS:

- Gluten-Free Watchdog tested the Best Express Foods Organic Aussie Bites in May and found well above 20ppm of gluten. Find out more [here](#)
- Abundant Life Foods Gluten-Free Mixes recalled due to undeclared gluten which were distributed to a distribution center in Minnesota. Find out more [here](#)
- Feel Good Foods issued a voluntary recall of Gluten-Free Cream Cheese Stuffed Mini Bagels in April. Find out more [here](#)
- Texas Pecans issued an allergy alert on undeclared tree nuts, soy, dairy, sesame, and wheat not named in products. Learn more [here](#)

Recipe

Slow Cooker Pulled BBQ Chicken

Cook time: 3-5 hours

Serves 4-6

Ingredients

Chicken:

- 1 small onion, chopped
- 2 cloves garlic, minced
- 1 cup ketchup
- ¼ cup molasses
- 2 Tablespoons apple cider vinegar
- 1 teaspoon freshly ground black pepper
- 2 pounds boneless skinless chicken breasts or thighs
- Salt and pepper to taste
- Gluten free hamburger buns

Coleslaw(optional):

- ¼ cup mayonnaise
- 1 teaspoon apple cider vinegar
- ½ teaspoon salt
- ½ teaspoon granulated sugar
- ¼ teaspoon freshly ground black pepper
- 2 cups coleslaw salad blend

Instructions

1. In a small bowl, mix together onion, garlic, ketchup, molasses, vinegar, and black pepper. For a smooth sauce, blend in a blender or food processor.
2. Place the chicken in a 6-quart slow cooker. Pour sauce evenly over the chicken and place lid on slow cooker.
3. Cook for 3 hours on high or 5 hours on low. The chicken should come apart when touched with a fork.
4. Transfer chicken to a cutting board. Shred chicken using two forks or a hand mixer. Return the chicken to the slow cooker. Stir to coat with the sauce. Season with salt and pepper to taste.
5. Serve on toasted hamburger buns with coleslaw, if desired.
6. Coleslaw: combine mayonnaise, vinegar, salt, sugar, and pepper in a small mixing bowl. Stir until smooth. Add the coleslaw salad blend. Stir to combine.

Recipe from: <https://www.glutenfreeliving.com/recipes/main-dish/slow-cooker-pulled-bbq-chicken/>



Educational Opportunities/Resources

NEW! Children's Wisconsin Celiac Disease and the Gluten Free Diet Education Module is now available on the [Celiac Disease Foundation's website!](#)

Children's WI Celiac [Webpage](#)

Browse the website to learn more about the Celiac Program, Frequently Asked Questions, Nutrition resources and more!

Children's WI Electronic Education [Module and Resources](#)

Review the electronic education course or share with family, friends, teachers, and caregivers!

The National Celiac Association (NCA) offers virtual events every month geared towards elementary aged children, middle-schoolers, and high-schoolers. If you are interested in attending one of these events here is the calendar of upcoming events: <https://nationalceliac.org/nca-events/>

We will continue to share information on our 2024 support group events with you by email. We also want you to be aware of educational opportunities that are being held by other celiac disease centers, as we do not want to recreate something that others are already doing. We will be sharing these educational opportunities on our private Facebook group (Celiac Support Group of Wisconsin). Please reach out to us at celiacsupport@childrenswi.org if you need instructions on joining our Facebook group!

Gluten Free Care Packages

Festival Foods offers Gluten Free Care Packages: If your child was diagnosed with Celiac in the last 12 months and is interested in seeing what your local Festival Foods store has to offer for gluten free products, use this [link](#) to sign-up for a gluten free care package and possible tour of the store!

Nick's Snack Packs: If you have a child who is 12 years old or younger and diagnosed with Celiac, sign up using this [link](#) to request a free box of free gluten-free products from Nick's Snack Pack. They typically release 25 snack packs each month and are mailed on a first-come, first-serve basis. Learn more here: <https://www.nickssnackpack.com/>

Everyone at The Bonnie Lynn Mechanic Celiac Disease Clinic at Children's Wisconsin wishes you a great Summer!

