

Celiac Support Group NEWSLETTER

 Children's
Wisconsin

WINTER 2023

We hope this newsletter finds you well and hope you are enjoying this holiday season! Thank you to everyone who participated in the support group events in 2023. We look forward to seeing more of you at next year's events. 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 would like to see in future editions!

Celiac Support Group Updates & Upcoming Events

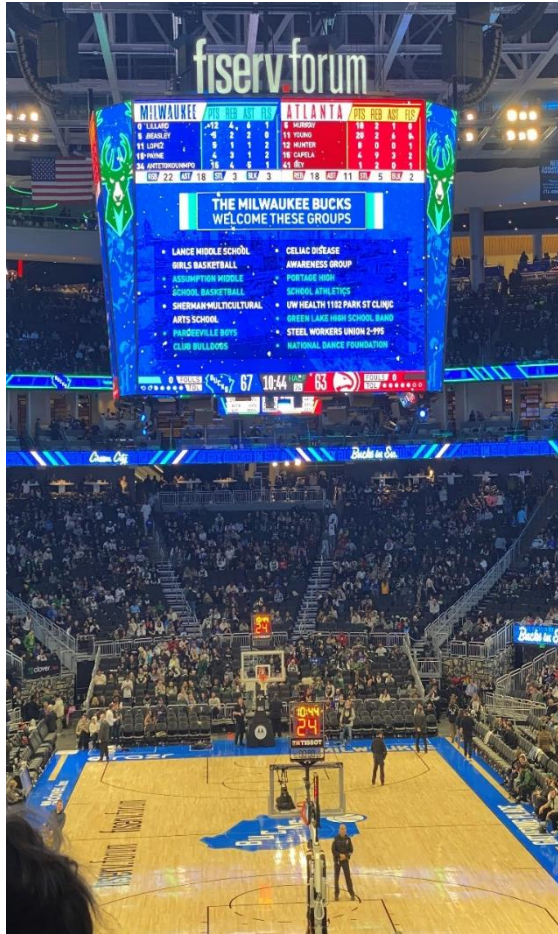
Milwaukee Bucks Celiac Awareness Night Event Summary

Thank you to everyone who came out to Celiac Awareness Night with the Milwaukee Bucks earlier this month! We were fortunate to have a great presentation by Dr. Stefano Guandalini along with a Q&A panel with local celiac experts. A total of \$1216 was donated to the Celiac Disease Foundation from this event.

The slides from the presentation and the Zoom recording were sent out via email earlier in the week. Here is the link for those that may have missed it: [Presentation and Q&A Panel](#)



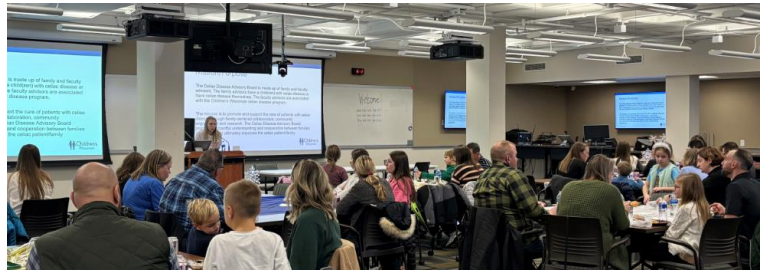
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Holiday Event Summary

We had a great time at our annual gluten free holiday dinner and treat exchange last week. We sampled 25 different holiday cookies and treats. See the attached recipe book for all the delicious treats we sampled!





A Year in Review: 2023 Support Group Events

- April- virtual cooking demonstration with Gloriosos's
- May- Milwaukee meet up
- June- Timber Rattlers game
- July- Milwaukee meet up (potluck)
- August- Rainbow camp
- September- Northeast meet up
- December- Milwaukee Bucks Celiac Disease Awareness event
- December- Holiday event & treat exchange

Upcoming 2024 Support Group Events

We are planning some exciting events for 2024! Please email us any ideas you have for events at celiacsupport@childrenswi.org.

In search of 1-2 new members to join our Celiac Disease Family Advisory Board

Please email us at celiacsupport@childrenswi.org if you are interested or have any questions about this opportunity!

Ask the Experts

RD Question: “Are most non-plastic straws made from wheat?

Is this one more thing we need to be aware of when dining out?”

Unfortunately, some of the eco-friendly straws and compostable paper plates may contain gluten. Most are made with wheat or corn starch. To be safe, those with Celiac should avoid using paper straws. Some tips to stay safe:

- Avoid using straws. When placing an order, tell staff you do not want a straw.
- Use straws made from gluten free materials, such as plastic, bamboo, stainless steel, silica, or glass. Consider bringing your own straws with you to a restaurant.
- Ask what type of straws are used when you place your order so you can look up if it is gluten free. Ask about the manufacturer so you can contact them directly.

MD Question: “What labs are required for follow-up testing of celiac disease?”

Dr. Chugh’s answer: Great question! Especially as this has been a moving target! As you may know, there are 2 main Pediatric GI societies that publish recommendations / guidelines (NASPGHAN and ESPGHAN) NA = North American, E = Europe. There used to be many follow up labs suggested in the past, but ESPGHAN published a position paper in 2022 that stated if the patient is doing well, then we just need the tTG IgA every 1-2 years. See below for the article clip/reference for more information!

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ESPGHAN Among Children and Adolescents With Celiac Disease

TABLE 1. Questions and recommendations on the follow-up of children and adolescents with celiac disease

Questions and recommendations

1. Is follow-up and management of celiac disease needed?

We recommend follow-up for children and adolescents after the diagnosis of CD has been established.

2. Who should do the follow-up of which patients and which is the role of the dietitian? What is the role of self-care and E-health?

The regular follow-up visits of children with CD are preferably carried out by a physician or a dietitian experienced in managing the disease. Local conditions and practices may determine how to apply these recommendations, but self-care treatment without access to adequate health care and dietitians is not recommended.

3. What should be the frequency of follow-up and what should be assessed?

3.1. The first follow-up visit should be scheduled 3–6 months after CD diagnosis, but with easy access to the celiac service if earlier advice is needed, and sooner review if there are concerns regarding how the family is coping with the diet, if there are ongoing issues with growth or persistent symptoms or a need to repeat bloodwork earlier. Subsequent visits should be every 6 months until normalization of TGA levels, and every 12–24 months thereafter.

3.2. During follow-up patients should be evaluated for:

3.2.I. Gastrointestinal and extraintestinal signs and symptoms.

3.2.II. Anthropometric measurements and growth parameters.

3.2.III. IgA-TGA using the same assay as at diagnosis as a surrogate marker for improvement/healing of the small-bowel mucosa. IgG based tests and RIA based IgA-TGA measurements are not suitable for follow-up in IgA sufficient patients. IgA insufficient patients with CD should be followed with IgG based tests.

3.2.IV. A complete blood cell count, micronutritional status (eg, hemoglobin, iron, vitamin B12, and vitamin D levels) and ALT measurements, should be performed after clinical evaluation at time of diagnosis. Any abnormality should be followed and deficiencies corrected until normalization. If abnormalities persist, additional diagnoses should be considered and appropriately investigated.

3.2.V. Screening for thyroid disease with TSH and thyroxine (and autoantibodies if indicated) may be considered during follow-up after clinical evaluation at the discretion of the clinician.

3.2.VI. Routine bone-density screening is not recommended.

3.2.VII. HBV antibody levels may be measured in previously immunized patients if this is considered important in the population. A booster dose should be given if inadequate levels are present.

If you have a question you would like answered in a future Ask the Expert section submit it to celiacsupport@childrenswi.org.



Patient Perspectives

If you have any tips, tricks, or advice to share with the support group, please email us at celiacsupport@childrenswi.org to discuss writing a future section of this newsletter.

New Products/Recalls

NEW! Coming January 3rd, 2024: Golden Gluten Free Oreos



RECALL: Playa Bowls Blueberry Flax Playanola GFCO has issued a product warning safety alert regarding Playa Bowls granola products because some display the GFCO certified product gluten-free mark even though they have never been certified. [Click here to learn more.](#)

RECALL: Shakespeare's Pizza

Shakespeare's Pizza is recalling all frozen pizzas from grocery stores as they contain wheat, but do not declare the presence of wheat on their labels. These pizzas were distributed in grocery stores throughout Missouri and in a small number of grocers in the Kansas City metro area. [Click here to learn more.](#)

Recipe

Breakfast Sausage Egg Muffins

Prep time: 10 minutes

Cook time: 20 minutes

Servings: 12

Ingredients:

12 Eggs
¼ Tablespoon salt
¼ Tablespoon pepper
1 cup sausage (cubed)
½ cup peppers and onion (diced)
½ cup spinach leaves (chopped)
2 cups shredded cheddar cheese
Cooking oil spray

Instructions:

- Preheat oven to 350°F
- Grease a 12 count muffin pan with cooking oil spray
- In a bowl, whisk eggs.
- Add salt, pepper, and cheese to bowl.
- Divide veggies and sausage evenly into cups and pour in egg mixture (fill ¾ of each muffin cup)
- Bake for 20 minutes.



Educational Opportunities

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!

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

GIG Cares Monthly Gift Box Program

In past newsletters, we have shared information on the GIG Cares monthly gift box program. This program provides a free monthly care package full of gluten free products for those who are struggling to afford the high cost of gluten free foods. At this time, the program is unfortunately not accepting new families as the demand is higher than they anticipated. They are currently working to raise more money to be able to support additional families. If you would like to learn more about this program or would like to consider donating to the program, please visit their website: <https://www.gigcares.org/>.

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

