

# Celiac Disease Digest Newsletter

September 2010

## Welcome

Welcome to the October edition of the Celiac Disease Digest Newsletter, a publication from the Celiac Disease Program at Children's National Medical Center. Our program is growing everyday and we are constantly expanding the programs and services we offer to patients to help support a gluten-free lifestyle.

In this month's newsletter, you'll learn all about how to manage Halloween on a gluten-free diet to ensure that all of the candy that you or your child eats is 100% safe. Also, be sure to take note of upcoming Gluten-Free Dinner Parties and how to cook up some delicious gluten-free meals. Happy reading!

---

## Upcoming Events for the Celiac Program

### Celiac Disease Challenge Grant

- Two generous donors have agreed to donate \$5,000 to support the Celiac Disease Program at Children's National Medical Center if the program can raise an additional \$5,000 from the public. We encourage you to give as little as \$5 or \$10, which will be extremely beneficial and helps us reach this goal. Contribute today by visiting: <http://www.firstgiving.com/ceciac>.

### Gluten-Free Shop for a Cause Macy's Fundraiser

- When: Saturday October 16th 10am-9pm
- Location: Macy's stores nationwide
- On Saturday, October 16, 2010, Macy's will host the 5th annual Shop for a Cause benefit. Since 2006, Shop for a Cause has raised more than \$34 million for regional and local charities across the country. This is your opportunity to be part of the excitement and help raise money for the Celiac Disease Program at Children's National Medical Center. Purchase your card in advance and enjoy amazing savings on October 16th at all Macy's stores nationwide.
- Cost: \$5 to purchase a shopping pass---all proceeds from the purchase of a pass go directly to the Celiac Disease Program. To purchase a card, contact Vanessa Maltin at [vanessa.maltin@gmail.com](mailto:vanessa.maltin@gmail.com) or Blair Raber at [blair.raber@gmail.com](mailto:blair.raber@gmail.com).

---

## Note From Lennie Clore, Celiac Program Coordinator

As the lazy days of summer slip away and we all start to look forward to cooler weather, the frenzy of back to school time begins. Between shopping trips for the perfect "first day outfit" and depleting Target's supply of #2 pencils, celiac disease may not be top of mind, but it should be something to consider as the school year gets underway.

Maybe your child was diagnosed this summer and will be gluten-free at school for the first time, or, maybe your child is transitioning from elementary school to middle school.

No matter the situation, sticking to a gluten-free diet at school can be challenging. You'll find dietary tips for school in this issue from Jessica, but aside from managing the food itself, the fear of being different than their peers is a significant stressor for children with celiac disease. Children may find it difficult to tell their friends about their diagnosis; however, a supportive peer group can provide an invaluable resource in the school setting.

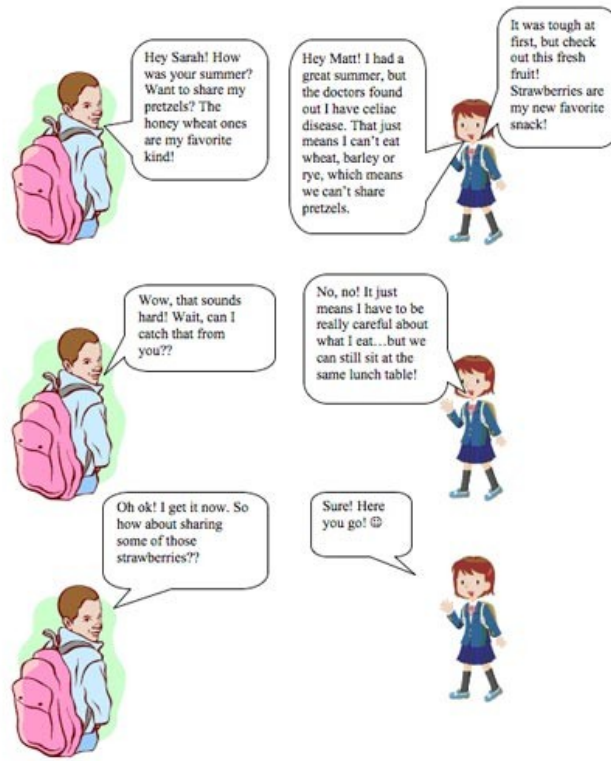
We want to empower our patients to speak as much or as little as they want about celiac disease. Their health information is private, and aside from a school nurse or perhaps a teacher, there is no one who needs to know about it. However, children may feel more comfortable taking about celiac disease if they can control who they tell and how that information is shared.

The following cartoon depicts one possible way for your child to handle discussing celiac disease with his or her friends. This is certainly not the only

## In this Issue:

- [Welcome](#)
- [Upcoming Events for the Celiac Program](#)
- [Note From Lennie Clore, Celiac Program Coordinator](#)
- [Packing a Gluten-Free Lunch: Nutrition Tips From Jessica Sargood, MS, RD](#)
- [Dining Out: Will We Ever Feel "Normal" Again?](#)
- [Recipe of the Month: Homemade Macaroni & Cheese](#)

way, but hopefully it helps start a conversation with your child about this important topic.



If you and/or your child have questions or concerns about how to navigate celiac disease and the gluten-free diet in the school setting, let us know! As always, our program is here to provide the support that you need!

--Lennie Clore, MSN, RN, CPNP Celiac Disease Program Coordinator

---

## Packing a Gluten-Free Lunch: Nutrition Tips From Jessica Sargood, MS, RD

With the start of a new school year, the books, pencils, and school lunches need to be packed! Although it is exciting, it can prove difficult for those trying to provide healthy, and yummy gluten-free snacks and lunch items to students. Here are a few tips to ensure your child gets back to school and stays healthy during lunchtime.

- Make sure you discuss the importance of not sharing food so your child can avoid gluten exposure from friends and classmates.
- Packed lunches are common and it can be a challenge to include gluten-free items. Choose fruits and vegetable, which can be easily washed, packed, and eaten as they are. Vegetable sticks such as baby carrots, celery, or squashes are easy to prepare and pack. Many dips, such as peanut butter, hummus, and yogurt are healthy sidekicks to many fruits and veggies. Dried fruit may also be a quick ready-to-go snack, be sure that the fruit hasn't been dusted with a gluten-containing flour. Applesauce cups, string cheese, and many fresh surprises from local farmers markets can easily be packed in lunches.
- If you choose to eat at school, it is recommended that you talk to the kitchen or catering manager for the school and/or nursing staff to be sure safe gluten free items can be provided. Developing a good relationship with these food representatives can be a beneficial experience for all involved. Consider including "emergency" gluten-free treats to be kept in a freezer at school for classroom events or parties involving food.

Overall, thinking ahead will help to provide healthy and safe gluten-free lunches and snacks for students as well as grant a delicious start to the new school year.

Happy Gluten-Free School Year! Jessica Sargood MS, RD and to working with you!

---

## Dining Out; Will We Ever Feel "Normal" Again?

By Blair Raber, Celiac Program Founder & Board Member

During the first year of my daughter's diagnosis, it was nearly impossible for me to hold back my tears when chefs told me they couldn't accommodate our needs. What I could never muster myself to say was that our greatest need

was to feel “normal” again.

I wanted my daughter to be able to walk into a restaurant with her friends and eat from the communal pizza on the table or order her favorite dessert, apple pie, and dig in while everyone else enjoyed their chocolate cakes or ice cream.

Those easy-eating flashbacks are no longer our reality and we’ve had to make many adjustments.

After that first year of dabbing my tears while asking strangers about dedicated toasters, I now feel empowered to talk with authority to chefs about our needs.

Thankfully, what we’ve learned has enabled us to take back our night’s out on-the-town again and experience a “new normal.”

An enjoyable evening at a restaurant doesn’t just happen – pre-planning must take place.

Here is our family’s ABC strategy when planning to visit a new restaurant or one of our familiar eateries:

**A) Advocate.** You must be your child’s advocate and state your needs clearly and in detail. Be sure to tell the person who takes your reservation over the phone that you will need a gluten-free meal.

- Speak to the maître d’ when you arrive at the restaurant (maître d’s will often note special diets on their reservation lists)
- Explain gluten-free once more for the server when placing your order, and if your server doesn’t acknowledge the special preparation, ask to speak with the chef directly.
- When your food arrives, confirm that your meal is gluten-free (GF)
- If you don’t want to be repetitive in front of others at your table, take the owner/maître d’ aside upon your arrival to remind them of your needs.
- It’s always a good idea to confirm that your meal is gluten-free when it arrives at your table.

Some restaurants will allow you to bring in your own food, such as gluten-free pasta, and they will cook it for you so don’t hesitate to ask in advance.

Make sure the chef knows about issues of cross-contamination and that the pasta will need its own pot of fresh water. Remind the chef that preventing gluten contamination is just like preventing salmonella poisoning!

Keep your food simple to avoid tricky ingredients like soy sauce in the marinade. Make sure that the restaurant can broil/bake fish or meats without breading, sauces, etc. If they can’t, consider ordering something else, or trying another restaurant that can accommodate your request.

Never assume anyone knows as much about your child’s needs as you.

Expressing those needs in an informative and clear manner is imperative.

**B) Befriend the chef/owner/maître d’/staff.** Once you’ve found an establishment that can safely accommodate your needs, develop a relationship with them.

After the meal, introduce yourself, shake the chef’s or owner’s hand and let them know how delicious the meal was and thank them for their responsiveness.

If you decide to go back, call in advance and remind them of your previous gluten-free experience there.

Most importantly, get names!

Request the same server if he/she was responsive to your needs and if it was a successful outing.

Write them down so you can request to be seated at their table the next time, or so you can greet the chef or owner personally.

Let them know that because of their impeccable service and attention to your needs, you will be a loyal customer.

After a few interactions, they’ll remember you, your graciousness and, perhaps, most of your needs (however, never assume they’ll remember all of your needs).

**C) Call Ahead:** Restaurants need advanced notice of your needs to be sure they can serve you safely and seamlessly.

Call at a time when the restaurant is not very busy.

There are a few questions you should ask in advance:

1. Does the restaurant have a GF menu?

2. If they do not have a GF menu, can they accommodate GF requests?
3. How do they prevent cross-contamination?

It's best to speak to the chef or owner about these questions.

Always go to the top.

Get the name of the person with whom you speak and find out if they will be working when you arrive for your reservation.

Touch base with them when you arrive and remind them of your conversation.

At first, these pre-planning steps may seem like a lot of work, but I'm happy to say that they quickly become second nature, especially after a positive experience.

Once you become skilled at asking the right questions for your situation, you can be richly rewarded by a wonderful and delicious evening out.

With careful pre-planning and advocacy, you may even start to feel "normal" again!

---

## Recipe of the Month: Homemade Macaroni & Cheese

*Recipe from Vanessa Maltin  
Makes 8 servings*

All kids love the blue box of macaroni and cheese, but with a celiac disease diagnosis, the childhood favorite, is all of a sudden off limits. However, just because the store-bought brands aren't gluten-free friendly, doesn't mean mac & cheese has to become a distant memory. Ahead you'll find a basic recipe for gluten-free macaroni and cheese. For the kids it's absolutely perfect! For mom and dad, spice it up by throwing in some sautéed ground turkey, your favorite vegetables and some seasonings like cumin or chili powder.

**Basic Gluten-Free Macaroni & Cheese Recipe:**  
*Makes 8 servings*

1 pound gluten-free brown rice macaroni pasta, cooked to package specifications  
½ cup butter  
¼ cup corn starch or potato starch  
3 cups milk  
3 cups grated cheese  
Salt, to taste  
Pepper, to taste  
1 cup gluten-free breadcrumbs (Options: Kinnikinnick Panko Style Breadcrumbs, Glutino Breadcrumbs, or Gillians Breadcrumbs)

1. Cook gluten-free macaroni pasta according to package specifications. Drain and set aside.
2. In a medium-sized saucepan, melt butter over medium heat. Add corn or potato starch and whisk rapidly until the mixture is smooth. Bring to a boil; reduce heat and whisk in milk. Whisk constantly until mixture comes to a boil and begins to thicken.
3. Add grated cheese and stir until completely melted and smooth.
4. Season with salt and pepper.
5. Preheat oven to 350 degrees F.
6. Put cooked pasta into a large mixing bowl and pour ¾ of cheese sauce over the pasta. Stir gently.
7. Pour macaroni and cheese into a Corning Ware baking dish and smooth out the top with the back side of a spoon. Pour remaining cheese sauce over the top and sprinkle with breadcrumbs.
8. Bake for 30 minutes until golden brown on top and bubbly.

\*\*Are you searching for gluten-free recipes? If the answer is yes, email your recipe needs to Vanessa Maltin at [vanessa.maltin@gmail.com](mailto:vanessa.maltin@gmail.com) and check back in the next newsletter to see your recipe created.

 [Join us on Facebook](#) |  [Follow us on Twitter](#) |  [Watch us on YouTube](#)

Children's National Medical Center | 111 Michigan Avenue, NW Washington, DC 20010

888-884-BEAR (2327)

If you would like to [unsubscribe](#) from Celiac Disease Digest [update your preferences](#). You will be taken off the list immediately. Thank you!

If you would prefer to be removed from all future mailings [optout here](#).

Copyright© 2004-2010 by Children's National Medical Center. ALL RIGHTS RESERVED. Text, graphic, and code are protected by U.S. and international copyright laws.