



# Rochester Celiac Support Group

## Awareness and Support for those with Celiac Disease and Gluten Intolerance in the Greater Rochester Area

Welcome to Issue 2 of the Rochester Celiac Support Group's quarterly Newsletter. I am happy to report that I received positive feedback on our first issue. Please keep it coming. We want to keep you informed about local and national upcoming events as well as news of interest for those living a Gluten-Free life.

I am still looking for at-large reporters to contribute articles for

future editions. Please share your talent for writing as a one-time article or a regular column contributor. If you would like to review a restaurant, a new product, travel, share a recipe, etc., please contact Tina Muto at: [tina.muto@rochesterceliacs.org](mailto:tina.muto@rochesterceliacs.org)

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**FACT:** Celiac Disease is the number one autoimmune disease in the world. It is also the most under-diagnosed and misdiagnosed disease.  
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## Meet Kathy Oaks

*Kathy Oaks is the President Elect of the RCSG*

I was diagnosed with celiac disease in February of 2006. At the time I did not know much about the disease, even though my father had been diagnosed about seven years earlier. I also did not want to accept the diagnosis.

The major things I knew about celiac disease were that it caused severe intestinal problems and weight loss. I was told the only treatment was to adhere to a gluten-free diet. My father has Celiac Disease they live in Georgia so I did not see my father during the time he was diagnosed or pay much attention to the gluten-free diet he was required to follow. I regret that I did not make an effort during the times I hosted our family Christmas and other picnics to be sure he had something to eat that was gluten-free.

I had added my father's medical diagnosis to my family history with all of my physicians, but they never

really told me that some of my own medical issues might be related.

My major symptoms began in my mid-thirties - suddenly I was losing weight with no explanation. I did not have any intestinal problems and was eating a normal diet. Then, my hands started shaking and my heart rate increased. One of my sisters had told me that she was diagnosed with Graves' disease and that she had similar symptoms. I had a blood test that was positive for Graves' disease. After six months of treatment for Graves' disease my health was back to normal. Then, I started having problems with arthritis and the doctor suggested that I take Aleve for the pain. After starting on Aleve, I suffered from hives for four months without a reason. I thought I had a reaction to the medication. I read many articles on hives, but never saw celiac disease mentioned.

I went to an arthritis specialist because I could not take any of the NSAIDs usually prescribed. The rheumatologist ran many tests to detect nearly every autoimmune disease, but never tested for celiac disease, though it was in my family medical history. I was again put on a medication for the arthritis, which helped without causing the allergic reactions. During this time period I developed other allergies and asthma, which I had never had as a child.

In 2005, a rash developed on my neck and would not go away. In January of 2006, I went for a follow-up visit. It was only then, nearly ten years after my symptoms began, that my doctor decided to test me for celiac disease, since it can occasionally cause a persistent rash. She informed me there was a new, simple blood test that could detect the disease. I was sure I could not be positive for the disease. I was (continued on page 9)

## Volunteers Needed:

- **Membership Committee Volunteer:** Work with other membership committee volunteers to welcome new members, both through our website/cellist and at newcomer meetings (held at 6:30 pm each month just prior to our regular monthly meeting).
- **Resources Chairperson (Board Position):** Work with other group members on services/benefits we offer our members, such as book sales and group dinners. Serve as board member (board meetings held six times per year).
- **Refreshments Committee Members:** Join a team to help set up kitchen before meetings (make coffee, set out snacks, etc) and clean up after the meetings. Time commitment is **3-4 times/year** from 6:30 to 9 pm on meeting nights.
- **Youth Group Co-Chair:** This person will work together with the current co-chair to plan and run monthly meetings (held at the same time as our regular meetings), monitor youth email list, and organize fun events for youth. All volunteers working with youth are subject to a background check.
- **Health Fair Volunteer**  
Attend local health fairs and answer questions attendees have about the Rochester Celiac Support Group. You do not need to be a veteran member of our group or an expert on celiac disease - all you need is a friendly smile and the desire to talk with people. All materials are provided - you just need to show up for a couple of hours.



May 21, 2011

## Rochester Walk for Celiac Disease

This year's RCSG Walk and Food Fair is fast approaching. Be sure to get registered soon so that you can benefit from all the events that will be taking place. We are very excited to have our walk at Brockport's AD Oliver Middle School again this year. We will be changing the walk route to be a 2-mile walk through the SUNY Brockport Campus.

One of the most popular parts of the event is the Gluten-Free Food Fair, which has expanded over the year to include around 40 vendors this year. With major financial sponsorship by Wegman's Food Markets, and also coordination of their Gluten Free vendors and Gluten Free Products, this year will be a great opportunity for Celiacs to sample Gluten free foods without the added expense of trying something you do not like.

In the fall we had made an announcement that our walk would need to be cancelled due to the lack of a coordinator. It was sad for us to cancel the walk as it is a beloved event for a lot of our members and the funds raised go to awareness and research on celiac disease. But organizing an event with more than 600 participants and vendors is no easy task for one person or even a few. After making that announcement, several people approached the RCSG Board and

wanted it to continue. We decided that we might be able to get volunteers for each of the committees needed and the Board would ultimately coordinate the walk. This new structure has allowed us to spread out the work, and also to save the walk. We are always looking for more volunteers and wanted to give our members a look at what each of the committee member's responsibilities are and why they got involved in the walk.

### **Cassandra Coffey - Overall Coordinator and RCSG President:**

Cassandra is the current president of our group and she was the walk chairperson for the 2008 and 2009 walks. She was instrumental in expanding the food fair portion of the walk. I asked her a few questions about the walk as one of the most experienced volunteers.

(1) How and why did you originally get involved with the Walk for Celiac Disease? How has it changed in the last few years?

I first became involved with the Walk for Celiac Disease in 2007 just a few months after being diagnosed and joining the Rochester Celiac Support Group. I volunteered to help with the planning of the walk because I love being involved with organizations of which I'm a member, and I also enjoy

planning and organizing events. I'm really glad I volunteered that year because it helped me get to know several people in the Rochester Celiac Support Group that I might not have gotten to know otherwise. Marvin Becker, who was the chairperson that year, asked me to coordinate the six vendors we had lined up to serve samples. At that time, there were no dedicated gluten-free bakeries in Rochester, and only a handful of restaurants had gluten-free menus. Boy how things have changed in just 4 years!!

I enjoyed helping to plan the 2007 event so much, that I chaired the Walk in 2008 and 2009. In those 2 years, the event grew by leaps and bounds because during that time there was such a dramatic increase in the number of people being diagnosed and the number of commercially-available GF products, awareness about celiac disease was growing, and more restaurants were becoming aware of the disease and accommodating GF diners. In those two years, Walk attendance and the number of vendors doubled! We found GF manufacturers were eager to share their samples with GF consumers, so we were able to offer participants a grocery bag full of free GF samples. The Walk was also featured in several radio and TV interviews, helping to growing the event and increase awareness about celiac disease in the Rochester community.

In 2010, we searched out a new location because the event had clearly outgrown the Perinton Park facility. We found Brockport Middle School and here we filled the a silent auction, lots of prizes and our 1st Annual Gluten-Free Food Fair. Channel 8/Fox and Wegmans both increased their involvement with the event and became Presenting Sponsors—it was very exciting to see commercials for our event on Channel 8! The event raised a

record \$41,000 last year!! It was definitely one of our most successful Walks for Celiac Disease!

And, now we're at 2011... We had actually cancelled the walk last fall because we did not have volunteers to lead the planning of the event. It is a big event, and as it's grown, so has the amount of responsibility in planning it. But, it's such a great event, and the Rochester site has had one of the most successful events since the very first Walk for Celiac Disease in 2002, and the funds we raise are so important for furthering research on celiac disease, that it was too hard to let it go. So, the Rochester Celiac Support Group Advisory Board decided to take on the planning as a team. Instead of having a single chairperson, we would work as a team. As soon as we announced that the Walk was back on, we had a resurgence in interest from volunteers, and now we have the biggest walk committee we've ever had working to plan the 2011 event! I can tell you that it is so great to be working with such a great group of people towards a common goal. Working as a team is definitely the way to do it, and I hope that we continue to have a great group of volunteers each year to plan this very special event.

(2) What do you feel is the most beneficial aspect of the walk other than the opportunity to raise funds for CFCR?

The funds raised at the Walk for Celiac Disease benefit both research and awareness programs at the University of Maryland's Center for Celiac Research and the local awareness efforts of the Rochester Celiac Support Group.

Dr. Alessio Fasano is the director of

the Center for Celiac Research, and his team published the landmark study in 2003 that established the prevalence of celiac disease at 1:133. Since then, he's continued to direct research that aims to answer fundamental questions about celiac disease. One of their current top priorities is to determine what causes celiac disease.

Raising funds to support Dr. Fasano's research or the Rochester Celiac Support Group's awareness efforts are both great causes and great reasons to attend and support our Walk. But, our event is even more than this! We also offer the Gluten-Free Food Fair, which features local bakeries, markets, restaurants, and GF food manufacturers offering free samples of their GF specialties. It's a great way to sample some of the many GF products that are now available before purchasing them or even to learn about GF products that you've never seen or heard of before. Our goal is to make this year's Gluten-Free Food Fair the biggest and best yet!

Besides these, attending the walk is a great way to connect with LOTS of other people in the Rochester area that also follow a gluten-free diet. Imagine being surrounded by 600 people that understand what it means to be on a gluten-free diet!

**Tina Muto – Raffle/Auction Chair:**

Tina was the walk chairperson for the 2010 Walk. She has returned to the committee as chair of the raffle/auction items. Tina had the following to say about her event:

"We have a great committee this year working on the raffle and silent auction. there are many exciting and new prizes this year. Be sure to stop by the raffle and auction area when you attend this year's walk"

**Bridget Dugan – Local Vendors Chair:**

This is what Bridget had to say about her committee:

"I am organizing the local Vendors for the Gluten Free Food Fair at the Celiac Walk. We are showcasing local businesses, bakeries and eateries who offer gluten free food. So far we have confirmed 9 local businesses as Vendors. They will be joined by 30 other Vendors (businesses that sell their products at Wegmans grocery chain). We are very excited that this year's Gluten Free Food Fair will be the biggest and most diverse one we've had at the Celiac Walk!"

**Kathy Oaks – Coordinator for Wegman's Vendors and Brockport Walk Location Chair:**

" I am so glad we were able to have the walk this year. I remember my first walk just after being diagnosed in 2006. It was the first time I tried pizza that actually tasted good. Even though the event was still small that year, to me it was huge. We have now expanded to between 500 and 600 people at the walk. Last year I coordinated the change of location to the Brockport Middle School and it has allowed us to expand our offerings of vendors. This year will be the most diverse food fair we have had yet. The change in our walk route was required due to some construction on Main Street in Brockport. The route we have chosen takes the walkers on a tour of the SUNY Brockport Campus. It is a beautiful campus and will be a very pretty spring walk.

I am so excited to be working with Wegman's as our major vendor this year. Wegman's has been a great asset to the local Celiac community with their allergen labeling and the offerings that they have in their Gluten free Section. They have also been a financial sponsor of our walk

for many years. I don't think I could have survived the gluten free diet without Wegman's. Be sure to stop by their booth and also to thank them for all they offer. I encourage everyone to get their friends and family to attend the walk with them this year. Even those without CD can benefit from the walk. My sister came with me a few years ago and she said she learned so much from coming to the walk. Hope to see you at the walk on May 21<sup>st</sup>, and I would love to have more volunteers for next year's walk as well.

**Andrea O'Keefe and Erin Noel are Co-chairing the Kid's Zone:** Andrea and Erin currently are the leaders of the RCSG Youth Group. When Andrea was asked about her involvement in the walk and the plans for the kid zone, she responded with excitement.

"I'm thrilled to be a part of planning our 10<sup>th</sup> Annual Walk for Celiac Disease and Gluten-Free Food Fair! It's especially exciting because this will be my first Walk. I'm working with Erin Noel (my co-chair for the Rochester Gluten Free Youth Group) to create the Kids' Zone, a unique way for our youth to celebrate their own Walk experience. We'll have all kinds of fun activities and even some surprises. Parents, be sure to accompany your children when venturing to the Kids' Zone - you shouldn't miss it! I've been enjoying collaborating with all those who volunteered to help get the Walk going this year - We've got a tremendous team. While I eagerly await getting outdoors on May 21<sup>st</sup> and walking with pride for our cause, I admit I'm equally anticipating visiting the GF Food Fair! Get ready, Rochester - It's going to be a blast!"

Erin is equally excited about the walk. Here are her comments.

"This year's walk will be my second walk and I'm more excited than ever! It's great to be part of the planning process and work with so many people dedicated to making May 21<sup>st</sup> an amazing experience for everyone! I don't just live with Celiac disease, I work with it. I am the social worker for the Pediatric GI office at Strong, a sponsor for this year's walk. I am also a co-chair for the Rochester Gluten Free Youth Group and am really excited about this year's Kid's Zone - a space where kids can be kids! We'll have some hands on activities, face painting, clowns, and much more. We'll look forward to seeing you on May 21<sup>st</sup>.

**To Register for the 2011 Rochester Walk for Celiac Disease:**

Go to: [www.RochesterCeliacs.org](http://www.RochesterCeliacs.org)  
Click on 2011 Walk  
Follow the instructions.

**To donate to the 2011 Rochester Walk for Celiac Disease:**

Use the fundraising aids available at [www.RochesterCeliacs.org](http://www.RochesterCeliacs.org). Send an email or ask your friends, family and co-workers to make a donation.

Go to <http://celiacwalk.kintera.org/> and 'Sponsor Participant' or make a 'General Donation'

Bring your check made out to 'Center for Celiac Research' to the walk.

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**FACT:** Celiac Disease is the only disease in the world completely controlled by diet.  
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## Rochester Celiac Support Group (RCSG)

Meets the 3rd Tuesday of every month at 7pm. Newcomer orientation at 6:30pm prior to the general meeting.

St. Anne's Church  
1600 Mt. Hope Ave.  
Rochester NY  
585-861-4065

Meeting topic schedule and past meeting minutes available on our website.  
[www.rochesterceliacs.org](http://www.rochesterceliacs.org)

## GIG Sponsors Chef to Plate Event

Gluten Intolerance Group (GIG) is sponsoring Chef to Plate: Celebrating Restaurants Serving Up Gluten Free Awareness during the month of May. Local restaurants will display posters and table tents to raise awareness about Celiac Disease. Participating restaurants include:

- The Owl House - Marshall St, Rochester NY
- Simply Crepes - Schoen Pl, Pittsford and 101 S Main St, Canandaigua
- Agatina's - 2967 Buffalo Rd, Rochester NY
- Livingston County Pizza Company - 212 Rochester St, Avon NY
- Blue Cactus Mexican Grille - 5 Liftbridge Ln E, Fairport NY
- Casa Moreno - 200 Park Point, Rochester NY

Please participate in this event by supporting the restaurants involved.



## QUINOA WITH CHICKEN, SPRING PEAS AND ASPARAGUS

Serves 4

Quinoa is a nutty flavored grain that is very high in protein. This gluten free recipe blends the quinoa nicely with chicken, asparagus, peas and other ingredients.

### Ingredients

1 cup quinoa  
2 cups water  
1 tablespoon extra-virgin olive oil  
1/2 cup finely chopped red onion  
1/2 pound (about 1/2 bunch) asparagus, woody ends snapped off and discarded, spears cut into 1-inch pieces  
2 cloves garlic, finely chopped  
1 cup fresh peas or frozen petite peas, thawed  
1 cup shredded cooked chicken  
[Note: if using rotisserie cooked chicken, remove the skin]  
1 cup thinly sliced baby spinach leaves  
Sea salt and freshly ground pepper to taste

Rinse quinoa under cold running water and drain. Combine water and quinoa in a medium saucepan and bring to a boil.

Reduce heat to a simmer, cover and cook until quinoa is tender and all the water is absorbed, 15 to 20 minutes.

In a large skillet, heat the olive oil over medium heat.

Add the onion and asparagus. Cook for 4 to 7 minutes, stirring often, until the asparagus is tender and bright green.

Add the garlic and peas, and continue cooking for another minute. Season with a little salt and pepper.

Stir in the cooked quinoa, then the chicken – just until mixed together.

Add the spinach and stir until it wilts, about 2 to 4 minutes.

Serve immediately.

## Recipe Corner

Contributed by

Bridget Dugan

In this section we will feature members' favorite recipes - not necessarily what your mom made.

## Upcoming Meetings:

Tuesday April 19, 2011

Gluten Free Cooking Class  
with Kathy Oaks

Tuesday May 17, 2011

Discussion of Celiac  
Disease  
with Dr. Anthony Baratta

Tuesday June 21, 2011

### Two Topics This Month:

You Choose Which Session  
to Attend

\* How to Advocate for  
Your Celiac Child at  
School

\* Going Off to College  
Gluten-Free

## RESTAURANT DINING:

### 7 Tips for Staying Gluten-Free

(reprinted with permission from GIG Education) Bulletin 4/2009)

*Tips for dining away from home*

#### 1. Selection of eating establishment.

Your success at gluten-free dining will be determined by a number of factors, including the type of restaurant you choose.

Be careful in restaurants where language may create a communication barrier. Food service workers may not easily understand your dietary restrictions.

Allow extra time to discuss your needs for a gluten-free meal. Fast food, quick-service restaurants, and

those with a standard menu may have little time to thoroughly check ingredients.

Finer dining establishments offer a less-hurried atmosphere and usually have more time to meet your needs. Call the restaurant the day before or earlier the same day. Speak to the chef to discuss your meal options. This will increase the quality of your dining experience. The chefs in finer dining establishments are generally aware of gluten and can be very helpful.

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## 2. Dine early or late.

Time your meal earlier or later than the busiest meal time. You will have more time and easier access to the people who can help you. Even the most cooperative server may not have the time you need during “rush hour.”

## 3. Explain your dietary restrictions briefly.

Example: (smile) “Hi, I may need your help with my menu selection. I am on a medically restricted diet and am unable to eat grain products. This includes wheat, rye, barley and foods made with these grains. I have some questions and need your help.” Enlisting the interest and cooperation of your server is essential. They can be your ally or your biggest stumbling block. Medic alert bracelets help to give credibility to the seriousness of your diet restrictions.

## 4. Ask detailed questions.

Use the GIG restaurant card. Ask that the card be taken to the chef for more assistance in selecting safe menu items. The only person who really knows what went into a dish is the person who made it! You may need to ask extensive questions about the foods and preparation. Be very specific in your questions about each item. Below are some foods and the potential problems involved with them:

- **Salads:** The possibility of contamination lies in the cleanliness of the boards used to chop ingredients and the addition of croutons or salad dressings containing unsafe ingredients. Ask for dressing to be served on the side. No croutons or other bread products.
- **Salad Dressings and Marinades:** Salad dressings and marinades may contain thickeners or other unsafe ingredients. Try ordering a lemon wedge and oil on the side,

wine or balsamic vinegar and oil, or bring a small container of dressing from home if you are unsure of the restaurant’s salad dressing.

- **Soups and Sauces:** Soup bases are often used as a foundation for soups and sauces. Bases contain ingredients comparable to bouillon or broth, i.e., hydrolyzed vegetable protein, natural flavors, etc., and should be carefully checked. Roux (pronounced “roo”) is the thickening for most sauces and is a combination of butter and flour. It is safest to avoid sauces. Canned sauces are also used in restaurants, so you may be able to check the ingredient listing. Soup base will sometimes appear in sauces.
- **Prime Rib and Other Meats:** If prime rib is too rare for the customer’s taste, the cook may “cook” it in a pot of au jus until it reaches the desired doneness. Au jus may come from a can or mix and contain unidentified hydrolyzed vegetable protein (HVP). Seasoning is often used in preparing meats; their ingredients should be verified. Self-basting turkeys and imitation bacon bits may contain HVP or textured vegetable protein (TVP) and need to be checked for safety before using.
- **Fried Foods:** The oil used to deep-fry foods may be used for both breaded and non-breaded items, in which case they should be avoided. In large restaurants where French fries are cooked in separate fryers, there is less chance of contamination.
- **Rice, Starches, and Hash Browns:** Many hash browns are frozen and pre-packaged with starch added. Ask what other ingredients have been added while cooking them. Many rice pilafs may have seasonings or added ingredients that you may need to avoid. Plain steamed or baked rice cooked in water is a good choice.

- **Dairy Products:** Non-dairy products are sometimes used instead of dairy products in restaurants. The three most frequently used non-dairy products are non-dairy creamer, non-dairy “sour cream” topping, and non-dairy whipped topping. Verify if the ingredients in the non-dairy substitute are okay.

## 5. Have your food prepared on a clean cooking surface, with clean utensils.

Check if breaded or gluten-containing foods have been cooked on the surface beforehand. Suggest using foil to cook on if this is a problem.

## 6. Confirm your order before eating.

Is it the “special” meal you ordered? Were your instructions followed?

## 7. Thank your food server.

Leave a generous tip for good service and if you have an extra GIG brochure, leave it with the management for their information. Return. Patronize the establishment again!

## Helpful aids:

- **GIG Restaurant Card** – *The English version is a plastic credit card-sized card to carry with you at all times. It is simple yet provides helpful information to the chef and other staff.*
- **Foreign Language Restaurant Help** – *GIG offers similar information in several languages. Many languages appear on one sheet.*
- **Quick Start** – *A fast and easy way to learn about the gluten-free diet.*
- **GIG’s Gluten-Free Diet Instruction** – *A very detailed diet guideline.*

# Family Ties: How I Spread the Word and How You Can, Too

By: Andrea O'Keefe

Whether you were diagnosed a few weeks ago or decades ago, you likely understand that having Celiac Disease or being gluten intolerant has its share of complications. Is this dessert safe for me to taste? Does that salad dressing contain gluten? What kind of food will be served at his birthday party? Thanks for thinking of me, Grandma, but do you mind if I don't eat that special pie you made? Oh no... have I just been "glutened"?

Of course, that's just the beginning of a long list of questions associated with having CD. I've considered them all, especially during 2007, the year I was diagnosed. At age 27, I was the first in my family to learn that such a disease even existed. I found that I was up against a lot of disbelief about the disease itself as well as my diagnosis. Some of that

came from my own naivety and inevitable lack of information. And so I did what many in my position would do: I got a second opinion. I also had my genes screened. Nevertheless, it all pointed to the same result: positive for Celiac disease.

I became quite vocal about my needs even before I truly began to understand what they were. I did my best to harness my family members around the facts and realities of my having CD, and occasionally I felt disappointment when my efforts were not immediately embraced. Then came the day I realized that it isn't just about me; that because I have Celiac, it's more likely that others in my gene pool may have either CD or gluten intolerance. And the notion that my aunt's digestive woes maybe could be alleviated, my father's headaches maybe could dissipate, or my cousin's infertility struggles possibly could disappear? To this day, those are tough thoughts to curb knowing what I know.

But my aunt, my father, my cousin... They don't know what they don't know. That is to say, they hadn't learned what I had learned, so how could they know any better? So then, I figured, don't I have some sort of responsibility to help educate them about CD and the fact that it could possibly be in their medical repertoires too, particularly since they are experiencing symptoms that are associated with CD and gluten intolerance?

The answer was a stark "yes." At first, I revisited the topic with those closest to me: immediate family, friends I saw frequently, coworkers

with whom I ate lunch. Through light conversation, I found that nearly all were curious and had lots of reasonable questions—a few even asked for specific information about symptoms and diagnosis. However, to date I know of only one relative who requested that her doctor order the Celiac blood test. These past few years, I have learned of even more relatives and friends struggling with various symptoms—nearly all of which could merit their being tested for CD or gluten intolerance.

There is a pressure of knowing what I know about Celiac and wanting to share that knowledge with others, in the hope that they would seek advice, possibly request that they be tested or, at the very least, be willing to educate themselves about CD with my help. I am still advocating for my family and friends to raise their awareness of CD. I E-mail them once a year, reminding them that I have Celiac and encouraging them to view some of the resourceful links I include, especially if they suffer from any of the symptoms that I list. I also include a disclaimer that while I don't mean to be pushy or prompt panic, I am writing out of concern because Celiac is a serious disease that has the potential to do major damage if undiagnosed or untreated...and because rather than subscribing to pills or surgery, having Celiac Disease requires maintaining a gluten-free diet—a tactic much easier (and likely to yield better results) than what several of my relatives have done and do now for their some of their symptoms in question. This is not to say that there aren't situations where taking medicine and having surgery aren't warranted. After all, certainly not  
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## Gluten-Free Conferences/ Events:

### **Gluten Intolerance Group (GIG) National Conference**

June 30 - July 2, 2011  
Gaylord Palms Hotel &  
Convention Center  
Kissimmee FL  
Visit [www.gluten.net/](http://www.gluten.net/)

### **Celiac Sprue Association (CSA) National Conference**

September 15-18, 2011  
San Diego, CA  
Visit [CSACeliacs.org](http://CSACeliacs.org)

### **Celiac Disease Foundation**

May 14, 2011  
Hilton Hotel Los Angeles/  
Universal City, CA  
Visit [www.celiac.org](http://www.celiac.org)

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everyone with intestinal cramping or fatigue has Celiac Disease. Yet, when we consider the reality of a genetic relative experiencing symptoms, why not encourage them to have a simple blood test, or at the very least, become informed about it?

All of my "campaigning" for Celiac awareness came to light when my husband was diagnosed last October, almost three years to the day after my own mystery was solved. He, too, was the first in his family to investigate the possibility of having CD. Soon after, one of his sisters learned that she is gluten intolerant. Another sister is about to be tested, having some associated symptoms herself. His family has also been questioning whether my father-in-law, who passed away after a long battle with non-Hodgkin's lymphoma, might have, in fact, had Celiac Disease.

While I remain the only member of my gene pool diagnosed, and one

of only two so far having been tested, I continue to reach out to my family. As the saying goes, "you can lead a horse to water, but you can't make him drink." I take comfort in knowing that should a relative or friend ask for my advice, I will be ready to give it. I am happy to be involved with my local support group, and on a team for our upcoming Walk for Celiac Disease to support research in this field. I see that my relatives and friends have begun to understand and accept my modified lifestyle, some of them even making bold (and delicious) attempts at gluten-free recipes, or forwarding me current articles that they've come across. Occasionally I will be asked about symptoms and diagnosis procedures. I respond in a friendly manner, careful to separate fact from fiction as much as I can. If your experience has been anything like mine, or if you are just now considering the potential implications that your own health awareness could have on your family, take a deep breath. Don't feel like you have to go out and preach the news, or convince your

entire family to get tested right away. Just don't let it stop you from helping your friends and relatives gain awareness. Find ways that work for you (and them) to provide information. Do you have a sibling or grown child who's in need of, yet hesitant about getting tested? Recommend a doctor and offer to accompany them to their first appointment, or start slowly by inviting them to our Walk. Got a wonderful but stubborn relative who you believe is at risk? Consider showing them this article. In the meantime, think about simply being there for others who have been diagnosed or who are curious. Maybe even sign up to volunteer with your local Celiac support group. After all, where might you be today if the person or thing that made you get tested hadn't crossed your path?

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**FACT:** According to NIH, celiac disease affects one in 133 people in the U.S. Premier researchers at Colombia University believe the actual number is closer to one in 80.  
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overweight at the time, and believed, like many, that the disease resulted in an emaciated appearance.

I was on vacation when my doctor called. I tested positive for celiac disease. As my husband and I drove back from Florida, I was unsure of what I was able to eat. I was mentally ready to accept the disease at the time, but it was hard to do practically. When we returned home, I started searching the Internet for information on the disease. I e-mailed my family members (I have 9 sisters and 1 brother) to let them know I had been diagnosed and that, in my opinion, I

did not have any of the symptoms besides the rash.

Finding foods I could eat was one of the toughest hurdles. Someone told me that Wegman's had a gluten-free section. The first month, I lived on Tostitos chips, Perry's Ice Cream, and hamburgers because those were the few things I knew I could eat.

On my first visit to the store after the diagnosis, I spent a lot of money on gluten-free foods. I did not think I could buy normal food. When I got home, I tried some of the gluten-free foods. They tasted terrible. Every time I went to the grocery store, I was in tears by the time I left. I was not sure what I could eat. I had

trouble reading the labels and knowing for sure whether something was gluten-free. I was always a name-brand shopper, bought the same brand of everything, and rarely changed. Suddenly, most of the brands I used either contained gluten or I was not sure if they contained gluten. Hershey's Chocolate with Almonds bars are my favorite candy bars. The day I found out that they were gluten-free, I began having a positive outlook on living with celiac disease.

I was referred to a nutritionist who really helped me get a perspective on food. She showed me the food pyramid and told me I could eat  
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everything except the items in the bread group. It was a great visual, and helped me realize I could eat much more than I originally thought - I just had to learn a different way to cook. Around that time, I joined the Rochester Celiac Support Group. A representative from Wegman's was at the first meeting I attended and spoke about their new labeling system requiring all store-brand, gluten-free items to be marked with a 'G'. They had researched the manufacturers and the items would be safe for a celiac diet. They also provide a gluten-free food list at [www.wegmans.com](http://www.wegmans.com). I changed from a name-brand shopper to a Wegman's-brand shopper very quickly. It was so easy and safe. Over the last few years, Wegman's has introduced many more items with the 'G' on them.

After my diagnosis. I encouraged my ten siblings to be tested. A few of them spoke to their doctors, but their doctors would not order the test since they either did not present any known symptoms or they were overweight. I could not believe it. I was shocked and disappointed in the lack of knowledge about the disease among the medical profession. In my opinion, if you have a family member who has celiac disease, you and your children should be tested every year.

A few siblings tested negative, but one sibling tested positive. Then the dermatologist I saw in March told me that the rash I had was not from celiac disease. He said it was psoriasis and gave me medication for it, but did not take a sample of the rash. I questioned him about it,

but he said that the celiac rash was rare and he knew what my rash was.

I doubted the celiac blood test and its accuracy. I decided to contact my doctor to find out if I could see a gastroenterologist for a biopsy. By the time I went to see the specialist, I was on a gluten-free diet for 3 months. The gastroenterologist gave me two options. I could either take the biopsy right then, or return to a diet containing gluten for six weeks and then do the biopsy. I decided to have the biopsy then, rather than wait. The biopsy was negative for celiac. I had to go back to eating gluten and schedule another biopsy in the fall.

After one week of eating gluten, I recognized the symptoms of celiac disease. During the four months I was on a gluten-free diet, my arthritis symptoms lessened. But as soon as I went back on gluten I felt the difference. I would wake up every morning with stiff joints. I also felt bloated and uncomfortable and I began to gain weight.

I scheduled a new biopsy in October. This time, the biopsy was positive for celiac disease. I knew that I had to adhere to a gluten-free diet for the rest of my life. I approached the diet with a new attitude. I did not cry when I went to the grocery store anymore. I looked at my favorite recipes and realized by changing a few things, my husband and I could eat normal meals again. I realized I didn't have to buy expensive specialty foods all the time.

After sharing my story with others, I was surprised how many people

have celiac disease. Everyone that I meet who lives with the disease has helped me a little bit and I have been able to help others as well. Part of living with the disease is sharing your struggles and your successes and making a difference. The support group has been really important for me. When I first started attending the meetings, my husband joked and asked when I would be in charge. I told him I did not plan to take a leadership role, I just wanted to go for more information. Well the group was so helpful to me that I wanted to give back. I had some ideas that I thought would be great for the group like cooking demonstrations and if you have an idea you need to be willing to follow through and do it. So that was the start of my involvement. I was then asked if I would like to be Vice President and then move into the role of President when the current term was done. I hesitated at first but I feel I received so much more back from the support group that devoting a few years to this group would be a rewarding experience. I have learned so much and have been able to encourage so many people and in the process I have been the one who has benefitted most.

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Next month you will meet Erin Noel (Huston), our next RCSG Vice President.