



Rochester Celiac Support Group

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

Welcome to the first edition of the Rochester Celiac Support Group's quarterly Newsletter. Our hopes are that we will keep you informed about upcoming events in our area and news of interest for those living a Gluten-Free life.

We would like your feedback on this new publication. It will only improve with member participation. Tell us what you would like to see!

I am looking for at-large reporters to contribute articles for future editions. If you would like to review restaurants, new products, travel, share a recipe, etc., please contact Tina Muto at: tina.muto@rochesterceliacs.org

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FACT: A positive attitude, 100% of the time, helps celiacs create a gluten-free lifestyle for themselves and their affected family member. (www.celiaccentral.org)

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Meet Cassandra Coffey

Cassandra Coffey is the current President of the RCSG

I was diagnosed with celiac disease in October 2006 at age 36. My family had moved here from Michigan, and it was a hard transition for me. I think the added stress of moving really kicked my celiac disease into full gear. I'd been experiencing some symptoms of celiac disease since my late teens, but in the year prior to being diagnosed, my main symptoms (anemia, chronic fatigue, weight loss, and intermittent GI symptoms) had gotten much worse. Luckily I found an internist here who was thorough. She did full bloodwork as part of my initial visit and found that I was severely anemic. We tried several high-dose iron supplements, but my iron status just kept declining. A dietician friend who knew of my symptoms asked me if I had ever been tested for celiac disease. That night I did a lot of reading about celiac disease and called my doctor the next day to request the blood test. My blood test

results came back positive, and I had a biopsy two weeks later, which was also positive. I started the gluten-free diet immediately. I did start to feel better very quickly, and my iron status was back to normal (even with no additional supplements) in six months time. Even though I recovered fairly quickly, I can honestly say that it took me about two years before feeling totally comfortable (to the point that I didn't have to think about it) with having celiac disease and following the gluten-free diet.

There conveniently happened to be a gluten-free tasting at Lori's just after I was diagnosed. I met Bert Garman there, who encouraged me to attend a Rochester Celiac Support Group meeting. I began attending meetings in November and volunteered to help plan the 2007 Walk for Celiac Disease. I enjoyed being involved in the planning of the Walk, and decided to chair the Walk the next year. I chaired the 2008 and 2009 Walks for Celiac Disease here in Rochester, during which time I served as a board member. I enjoyed being an active member of the board and really getting to know about all that the Rochester Celiac Support Group does here in Rochester, so I decided to step into the position of RCSG President after the 2009 Walk. During my term as president, I've really enjoyed being an integral part of RCSG and getting to know many newly diagnosed people. It's a great feeling to be able to share my experience with and help those who are just learning how to be gluten free.

Her tenure ends July 2011. In our next issue, we will meet Kathy Oaks - the new RCSG President effective July 2011.

Upcoming Meetings:

Tuesday January 18, 2011

Gluten-Free Bread Baking Class
Hosted by Marvin Becker
Learn gluten-free bread baking techniques from our panel of four experienced bakers.

Tuesday February 15, 2011

Celiac Disease and Neurology
Dr. Heidi Schwarz, Neurologist at University of Rochester Medical Center.

Tuesday March 15, 2011

Dr. Stephen Wangen, author of the book *Healthier Without Wheat*, will be our speaker for the evening.

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. 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.

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

Past meeting minutes available on our website.
www.rochesterceliacs.org

Gluten-Free Summer Camps:

Camp sign-up is just around the corner. Registration may begin as early as February.

- GIG sponsors 2 camps:

Camp Kanata, NC
August 7 - 13, 2011
Camp Sealath, WA
July 25 - 30, 2011
August 1 - 4, 2011

- CSA sponsored camp:

Camp Aldersgate
North Scituate, RI
August 7-12, 2011

- Georgia R.O.C.K.

Camp Will-A-Way at Fort Yargo State Park in Winder, GA (date TBA).

- Michigan Capital Celiacs/DH
Camp Manitou-Lin/Lake Barlow, Middleville, MI
2011 dates TBA

GIG Sponsors Chef to Plate Event

Once again this year, Gluten Intolerance Group will sponsor Chef to Plate: Celebrating Restaurants Serving Up Gluten Free Awareness. Chef to Plate will occur during the month of May. The RCSG will be approaching restaurants in the Rochester area that are willing to display table tents and posters. Please participate in this event by supporting the restaurants involved. More information will be available soon.



Recipe Corner

Contributed by Erin Harner

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

Vegetable Quinoa Pilaf

Prep Time: 15 minutes
Cooking Time: 20 minutes
Yield: 4-6 servings

Ingredients:

2 tbsp oil
1 large onion, chopped
2 stalks celery, chopped
3 carrots, chopped
1 cup quinoa (red or white)
2 cups water or GF vegetable stock
2 bay leaves
1 tbsp lemon juice
1 cup frozen peas, thawed
Sea salt, to taste
Black pepper, to taste

Directions:

1. In a medium saucepan, heat oil. Add onion, celery, and carrots and stir for about 5 minutes or until veggies are tender.
2. Rinse the quinoa in a fine mesh strainer, drain well, and stir into the vegetables. Add the water or stock, bay leaf and lemon juice and bring to a boil.
3. Cover, reduce heat to medium low, and simmer for 15 minutes or until all water is absorbed.
4. Discard the bay leaf, stir in the peas, season with salt and pepper, and serve.

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FACT: CD affects more people in the US than Crohn's Disease, Cystic Fibrosis, Multiple Sclerosis and Parkinson's disease combined.
(www.celiac-disease.com)



GLUTEN FREE SURVIVAL

One Step At A Time (reprinted with permission from GIG Education Bulletin 12/2009)

The Internet, the news, and papers... Your family and friends, doctors, and co-workers...they all have advice these days. We are inundated with health information...what is healthy, what isn't, what to do, what not to do. It is all so overwhelming! What do you believe and what is just hype? That is health in general! Now add a chronic disease that is "unknown to most doctors", may have taken years to figure out, and is treated by diet alone. BUT WHAT A DIET!

Welcome to the world of gluten intolerance (celiac disease, dermatitis herpetiformis). Many are relieved to know what makes them or their child feel so poorly. Yet the diet seems unmanageable. Avoiding a food or two is not difficult. But this diet is more than that. It's avoiding those foods, things made from them...and the list seems endless. It's no wonder people throw their hands in the air, with tears in their eyes saying, "so what CAN I eat?"

Yes, there is a lot to know about foods, ingredients, and changes in lifestyle and cooking. This gluten free diet is no easy thing to master in 'one easy step'. So take one step at a time. Elaine Hartsook, Ph.D., RD, once used an upside-down triangle to illustrate the point that there are obvious things that make those with gluten intolerance ill and there are the not so obvious things. Let's use this upside-down triangle as a model to take one step at a time. Tackle the obvious things first, then fine tune more and more. Remember Rome wasn't built in a day...no one expects you to know this diet all at once.

Step One - Omit the obvious foods from your diet. These are foods that can easily be identified as containing the grains to be avoided (wheat, rye, oats, and barley). Cereals, breads, pasta, desserts. Avoid beers and ales. Try eggs, cream of rice, or cornmeal mush for breakfast. Substitute rice cakes, rice, potatoes, or corn tortillas for the breads and pastas you have usually eaten. Have sherbet or fruit for dessert. Use vinegar and oil on salads. Drink milk, 100% fruit juice, coffee, or teas. This step is a huge change from the 'normal' diet. Now sit back and breathe! Yes, it is not fun, but you can still eat. Now you are ready to move on to step two.

Step Two - Begin reading labels for hidden sources of gluten in food. Learn what to watch for on labels. Avoid anything you think is suspect for having gluten. Keep in touch with a contact person, the GIG® office or one of the support groups. This step can be very confusing. You will learn new words, and look at food and food preparation in a new way. It's usually here that people will panic. This is a natural feeling. The reality of your situation is setting in. If need be, break this step into 'baby steps'. Only read labels on a certain group of products, such as condiments or frozen foods. Carry a pen and paper with you. If you find a product that appears to be safe write it down. Once you have a few items in a category of foods add another to your list, so that eventually you have a number of foods you feel comfortable buying. You can quickly review the label each time you purchase it. You still

don't know it all, but you are closer and haven't made yourself and those around you crazy in the process.

Step Three - Reach out and touch someone. Now it is time to try calling or writing to a manufacturer. In doing this make sure you are using the proper terms and being very specific in what you are asking. Look at the sample letter in the diet instruction as a guide. When you can do this, you have just about mastered the diet. You don't have far to go.

Step Four - Continue to fine tune. Now start looking at the things you may have never thought of...medicines, mouthwash, and toothpaste. Consider cross-contamination issues - such as toasters, shared foods products like mayonnaise, margarine, and jam. What about your chewing gum or breath mints?

We never stop learning if we choose to keep our eyes and minds open. Be thankful for a diagnosis and someone to lean on. Take one step at a time and learn and grow healthy!

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FACT: Celiac Disease occurs in:

- 3.9 -12.3% of people with Type 1 Diabetes
- 5 -12% of people with Down syndrome
- 20% of people with collagenous colitis
- 4.5% of first degree relatives of people with Celiac Disease.

This newsletter is published by the Rochester Celiac Support Group for the benefit of our members. The information, recommendations, dietary suggestions, product news, menus, recipes, and related data is not qualified medical advice. Individuals should consult with their physician/professional health care provider before following any medical or diet recommendations contained in this newsletter. Opinions expressed are those of the editor or identified contributor and are not necessarily endorsed by GIG. Food manufacturers' products are subject to formula change at any time and these changes may not be reflected on labels. Products mentioned or omitted do not constitute endorsement. No liability is implied by or assumed for the use of information contained in this newsletter.



Restaurant Review

Contributed by Tina Muto

On a recent Saturday night in December, my husband and I enjoyed a dinner at Luna Piena, 564 Merchants Rd, Rochester. (<http://lunapienarochester.com/>)

We had been intending to try out this restaurant - and after a restaurant review in the Rochester D&C (dated 12/2/2010) we had to try it.

Luna Piena is tastefully decorated with approx. 15 tables. The wine list includes many Italian wines as well as domestic. My husband enjoyed the potato gnocchi (not GF) in a slightly spicy sauce. I had the GF veal scaloppini - sauteed veal, sausage and shrimp served with roasted potatoes and steamed vegetables. Both were delicious. Unfortunately, they were out of their GF Chocolate Mousse Cake. A great reason to return again.

We received prompt service. Our server was new but more than willing to check on the GF status of any menu items. While there, be sure to say hi to owner John Sebaste - a RCSG member.

30% of people newly diagnosed with celiac are over 60

Celiac disease is a genetic, autoimmune disorder that affects roughly 1% of the population. When people with celiac disease ingest gluten; the protein in wheat, barley and rye; their body reacts. This reaction prevents the body from properly absorbing the nutrients from the food eaten. Consequently all body systems may be affected. The list of symptoms is long, from diarrhea to migraines to fatigue and more. Celiac disease affects people of all ages, from young babies to the elderly. Once celiac is treated with a gluten-free diet, symptoms typically resolve and the affected feel better.

Once diagnosed

You are not alone in following a gluten-free diet and there are resources to support you. A diagnosis of celiac disease requires lifestyle adjustments. No medication or surgery is needed. The good news is that it can be controlled just by following a special diet. Gluten-free foods can be found in most grocery stores.

Attitude is everything

Like anything new, it takes time to adjust to the gluten-free diet and learn this lifestyle. Stay focused on all the foods you can eat.

Gluten-free Diet

Eating gluten-free can seem overwhelming, but as you learn what to look for, how to read food

labels and prepare food, the diet becomes easier. Naturally gluten-free delicious and healthy foods are plentiful, such as fresh fruits, vegetables, dairy, eggs, poultry, fish, meat and legumes.

What to look for on the label

Gluten is listed using 5 words on a label: wheat, barley, rye, malt, and oats. Read ingredient lists very carefully. If you see any of these words you will know a food contains gluten. By law, wheat used as an ingredient or processing aid must be listed as an allergen. A food described as "wheat-free" may not necessarily be gluten-free. If you are unsure if a food is gluten-free, avoid it until you are able to investigate it further.

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How to stay healthy with your new diet

While removing gluten from your diet will help your body heal, you also need to focus on maintaining optimum nutrition. Choose gluten-free whole grains and foods with nutrients such as iron, B vitamins, fiber, zinc and calcium. For a nutritious diet include fresh fruits and vegetables, brown rice, dairy products, meat/fish/poultry, eggs, and gluten-free grains (such as buckwheat, cornmeal, and quinoa). A supplement may be recommended if you are not getting enough nutrients; make sure it is gluten-free.

Gluten in personal care and household items

Gluten must be ingested or swallowed in order to cause a problem. Therefore, items like shampoo and cleaners with gluten-containing grains are safe for someone with celiac disease unless they have a secondary allergy or sensitivity to those ingredients.

Gluten in Medication

Oral medication must be gluten-free. There are no labeling requirements for the source of ingredients in medications. Few drugs contain gluten, but because some DO contain gluten - the source of ingredients in all medications must be verified.

Brand name medications and generic equivalents may have different inactive ingredients and could contain gluten.

Either brand name or generic drugs are acceptable as long as the ingredients have been checked to insure that they are gluten-free. Ask your pharmacist to investigate the medication's ingredients - this should be checked when the prescription is refilled in case the

ingredients changed, and also if the drug manufacturer changes. Physicians and pharmacists are not always alert to the risk that gluten in medication poses to the person with celiac disease.

When you need a little help: Hospitalizations or Assisted Living

Involve family members in the details of your diagnosis and diet. Provide them with a copy of this guide along with a list of current medications and the name and address of all healthcare providers.

To ensure the best possible care during your stay keep a copy bedside and give this brochure to your healthcare providers to help communicate your dietary requirements and have it entered into your chart:

- Dietitian, pharmacist, physician
- Pre-admission nurse and nurse manager

Request a written physician's order for a gluten-free diet that identifies you as having an "allergy" to wheat, rye, barley and oats so that all personnel in the hospital will be aware of your dietary restrictions. Make an appointment to see someone in the nutrition services and pharmacy departments prior to your admission to determine the facility's ability to safely accommodate your gluten-free needs.

Request an allergy wristband. You may also request that

"Celiac Disease: All foods and medications must be verified gluten-free" be printed in **BOLD** writing on your chart, at your bedside, or on the front of your door.

Ask if you may use medication and food from home. If allowed, mark with your full name, date and room number.

Fast, easy and nutritious snacks and meals.

- Yogurt with a fresh (or frozen) fruit topping
- Corn tortillas wrapped around turkey and cheese
- Fresh fruits and vegetables
- Scrambled eggs with spinach and cheese (or just a hardboiled egg)
- A handful of mixed nuts and a piece of fruit makes a great healthy, balanced snack.

If the source of the following ingredients is not specified, ask your pharmacist to call the manufacturer:

- Starch
- Pregelatinized starch
- Dextrates
- Dextrimaltose
- Modified starch
- Pregelatinized modified starch
- Dextrin
- Caramel color

If a prescribed medication does have gluten in it you may:

- Ask your pharmacist for an equivalent medication that is gluten-free, but is made by a different manufacturer.
- Request an alternative medication from your healthcare provider.
- Go to a compounding pharmacist to have the medication made without gluten.

Printable guides for the gluten-free diet can be found online at:

www.CeliacCentral.org
www.gluten.net

Printable reproductions of this brochure are available online at:

www.gluten.net/downloads/print/Over60brochure.pdf