

Rochester Celiac Support Group (RCSG) Meeting
January 20, 2010 @ 7 pm
Brighton Reformed Church Fellowship Lodge

ANNOUNCEMENTS

- **Newsletter** was emailed to cellist and will be mailed out to membership within the next week. The schedule of meetings and special events was included in this newsletter and is also available on our website.
- **2010 Walk for Celiac Disease.** Saturday, June 12, 2010 at Oliver Middle School on the Brockport School District Campus. We need a co-chair to join Tina Muto. Tina has already begun the planning for next year's event with some exciting changes! Stay tuned for more details... We can't plan such a large event without the help of many volunteers. Please consider giving your time and energy to help organize and plan next year's Walk. Please contact Tina Muto (walk2010@rochesterceliacs.org) if you have more questions and/or are interested in joining the team.
- **RCSG Email List.** The RCSG has an active email list. It is a great way to stay on top of all things GF in Rochester. If you haven't already signed up and are interested, you may sign up tonight (see sign-up sheet on table by door) or you can sign up at <http://rochesterceliacs.org/cellist/index.asp>. The list is well-monitored by Joel Elias, so we do not get junk mail or an over abundance of messages on this list.
- **RCSG Library.** The RCSG has a library of books pertaining to celiac disease, gluten sensitivity, and the gluten-free diet. You may check out books (for free) at our monthly meetings. Checked out books are due one month later. We have a good selection of both cookbooks and reference books. I encourage you to take advantage of the library!

UPCOMING EVENTS

- Feb RCSG Meeting. Trish Kazacos, RD from Wegmans will be speaking about **"Living Gluten-Free with Wegmans"**.
- **Pancake Breakfast** to be held on March 20, 2010 at Clarkson Community Church in Brockport. More details to come.
- June 12, 2010. **9th Annual Walk for Celiac Disease.** Online registration and fundraising materials available soon on our website.
- **GF Cooking Class in 2010.** We will be having another GF cooking class in June, 2010. If you are interested in demonstrating how to prepare an item for the class, please contact Kathy Oaks (kathleen.oaks@gmail.com) who will be organizing the cooking class.

FEATURED TOPIC

Review of CSA Conference.

Speakers: Marlene Kier (MK), Katherine Barkley (KB), and Norma Bartlett (NB).

MK - emphasized how beneficial it is to attend conferences, and encouraged everyone to attend as many conferences as possible as there is so much to learn - and they're fun!

Tom Warth attended, but could not attend the meeting. He submitted the following comments regarding the conference, which MK read to the group:

CSA 2010 Conference Summary

By Tom Warth

I attended the Celiac Sprue Association Annual Conference in Erie, Pennsylvania with my 11-year-old daughter, Leah, October 2009. This was our first national CSA conference, but it definitely will not be our last. It was a very rewarding experience for both of us. We will be back because the research and knowledge about Celiac disease is progressing rapidly and we want to learn about these developments in the caring, enjoyable environment offered by CSA.

Leah is a Celiac, diagnosed about four years ago. I am not a Celiac, but suspect I have gluten sensitivity and, therefore, have been living gluten free for the past two years. Despite our years of living with Celiac disease, we were still relative novices to the issue knowledge-wise.

I was very impressed with the quality and communications skills of the presenters at the CSA conference. Doctors Peter Green and Rodney Ford are world-renowned for their knowledge and research. They and others explained to us the leading edge knowledge and research on celiac disease and gluten sensitivity issues. But unlike some elite experts in other fields, these doctors and scientists are also good communicators. They reviewed basics so that I could follow along, but they also shared with us the riddles and unknowns that remain to be solved. In other words, they are caring enough to do their best to make the science and research understandable, but respectful enough to avoid "dumbing it down" for us.

It is also clear that the good communication goes both ways. Nearly all of the presenters stayed around the entire three days and made themselves available to answer questions and take suggestions about their present and future research. It was clear from their presentations that their research is benefiting from the insights and suggestions offered by CSA members at this conference and from past conferences.

I learned a lot at the conference. Some of the biggest messages I came away with:

--celiac disease is not just a disease that affects the gut; in Celiacs and in those with gluten sensitivity, gluten can be harmful to multiple organ systems, including the brain.

--wheat is not a natural food; its use has evolved quite late in human history; there are ancient gluten-free grains and new gluten-free grains being developed that have more nutrients than wheat.

--a sound gluten-free diet does not just mean avoiding gluten; many Celiacs are not as healthy as they should be because they are not getting the nutrients they need or are getting more nutrients that they do not need (i.e., carbs, fat, salt).

--Celiacs need to be better advocates for themselves; while we are good at communicating with each other we need to be better about advocating with others for more research into the diagnosis and treatment of the disease and into the agriculture of developing gluten free alternative grains, more gluten-free food alternatives from the food industry, better food labeling, and better health coverage for diagnosis and treatment.

I also learned a lot of practical things. Like how to find gluten-free food while traveling and how to prepare easy gluten-free back-up provisions to take along, more insights on label reading and reliable and unreliable brands, and tips on making sure to keep up on certain nutrients often missing in gluten-free diets.

Leah had a great time. Like most 11-year-olds, she is shy with new people. But she became right at home with the dozens of children in her KidsZone group and the adults who organized the group. There were field trips to the Erie Zoo and to a local Wegmans, but I think she was just as happy taking part in the series of fun games, cooking activities, Halloween costume activities, and movie night that took place right down the hall from our conference activities. I knew she was having a great time, when she turned down offers to hang out with me during my afternoon conference breaks and after dinner so that she could stay with her new friends taking part in all of the fun activities organized by their adult chaperones. My feelings of rejection was healed somewhat by the knowledge that she was right down the hall and I could (and, indeed I did) pop in whenever I wanted. Every time I did pop in I saw she was under the supervision of adults who know how to manage fun for a big roomful of kids without it turning into mayhem.

Both Leah and I have always loved to eat. Every meal during the event was excellent. It was a real vacation for both of us to enjoy great food and the company of new friends without having to worry and/or negotiate over the content of our food. The breakfast buffets were our favorite because we both love waffles, pancakes, and other hot breakfast foods and have not found a place here in Rochester to partake of them confidently.

We also both loved the camaraderie of the event. I met and talked to people from all over the country, sharing stories. It was the same friendly atmosphere that I have enjoyed during dinners and meetings of the Rochester Celiac group. It was no harder to get along with the people at the national event, even though most lived a few hundred or few thousand miles away.

I encourage you to give it a try next year. If you have any questions, please do not hesitate to give me a call at 442-3518.

-Tom Warth-

Marlene, Katherine, and Norma continued with the discussion about the conference:

KB - the kids really had a wonderful time. For parents of celiac children, it's a great experience. It's hard on adults, but perhaps it's even harder for kids to have cd.

First speaker was Rodney Ford, prof of pediatrics at college in New Zealand. He has discovered that sometimes when you do the celiac tests, they come out showing that a person doesn't have it, but if they go on a gf diet, then their symptoms are healed. In many cases, once they've tried gf, they don't want to go back. He gave some stories of some of his patients that had various symptoms, but did not test positive for cd. He called it "medical heresy". He had a patient who had been unhealthy for 7 years, they tried gf, and she blossomed. The other doctors were saying "but she doesn't have cd", but it occurred to Dr. Ford that the tests do not always tell the whole story. He has done research with 30 people that had either brain, gut, or skin symptoms. Some had just one symptom, but many had 2 symptoms, and some had all 3. He talked a lot about gluten sensitivity. He said for every celiac, there are 10 other affected people. Many children when they go gf, they don't want to go back to foods that cause them problems. He said that half of what we think now will be invalid in 10 years. MK says she agrees because of how much has changed in the last 10 years. The older you are when diagnosed, the longer it takes to heal. He said that just because there are no gut symptoms doesn't mean that gluten is not causing damage. He had a list about brain/ceciac problems. Dr. Ford talked about testing for gluten sensitivity. If you have a negative celiac test, but go gluten free and feel better, then you probably have gluten sensitivity. They are saying that celiac disease is in about 1 in 100 people. Gluten sensitivity occurs in about 1 in 10 people.

Mark Dinga, RD. How to be healthy on a gf diet. Emphasized low fat, low salt, watch your cholesterol, etc.

Francisco Leon, MD from Baltimore, MD. Works with Dr. Fasano doing medical research. He said it's never been as intense as it is now. At this point, there are 10 companies working on medicines for cd. It takes 3-5 years to develop a new medicine - it's very expensive and money is not readily available. For clinical trials, you have to have people who are diagnosed with cd go off the gf diet - so it's hard to get volunteers. He said you cannot eliminate gluten from wheat. For more information, go to www.clinicaltrials.gov. They are trying to develop some kind of a device that you can put into food to detect gluten, but they haven't found something like that yet that would be cheap and sensitive and reusable. They would like to develop something that you could take to counteract the effects of gluten, but they haven't found anything yet.

Peter Green, MD, from Columbia Univ. One of the papers he's written is on the economic benefits of increased diagnosis of celiac disease. In a case-finding study they found a 43 fold increase in the diagnosis of celiac disease.

Denise Copelton, sociology prof from Brockport. She spoke at the conference and was at our meeting, so she gave a summary of what her talk was about. It was very similar to her presentation to our group in Nov 2009. The social experience of celiac disease - families, dining out, relearn how to bake/cook/shop, etc.

Michelle Sullivan, DO and Bill Sullivan, DO, JD. Husband and wife team. Wife is a doctor. Husband is an attorney. They talked about inflammatory bowel disease. 29% of celiacs are affected with pancreatic enzyme insufficiency. Once you are on the diet if you are still having symptoms, you should ask your doctor about being tested for pancreatic insufficiency - you can just take a pill with each meal. Refractory celiac affects less than 2.5% of people - that's when you are sticking to the gf diet 100%, but there is no resolution of symptoms. Can result in small bowel cancers but not in all cases. You continue to lose weight, fatty stools, and diarrhea. Treatment is with tube feeding, steroids, immunosuppressives.

Dr. Kumar, PhD. Works at Immco Diagnostics in Buffalo - a lab. He talked in length about the testing for celiac disease. The results of the tests depend on the interpretation of the pathologist - it's subjective.

David Sands, from Montana State University. Is working to develop grains that are gluten-free and very healthy - very nutrient rich. He uses Indian Bunch Grass sold under the name Montana. He's got a passion for coming up with nutritious solutions. He's been working with several flours. A new one this year is Timothy Grass. They call it Timtana. They made flour out of it. It is high in protein, fiber, and nutrients. It doesn't need any other flour to mix with it - but you still add xanthan gum. It's brown in color. It's about \$5 per pound. Marlene made bread and brought some to share. They have a flour called proatina - made with oats - that they are experimenting with. Oats have about 12% protein, but proatina has 20% protein. They grow gf oats and make the proatina with the gf oats.

Diana Stuber, RD. Talked about diabetes and celiac disease. She talked about fact that the same genotypes are involved in type I diabetes and celiac disease. She talked about the normal diabetic menu and how to convert that to gluten free. If you are more interested, you can refer to their conference book.

Anne Lee, RD, from Schar Foods gave a presentation about gluten free lifestyle challenges. She will be the RCSG March meeting presenter.

Dennis Vidmar, MD - Dermatologist. He's trying to push dermatologists to think about celiac disease as more of a systemic disease and take a good medical history and look for chronic abdominal symptoms along with the skin symptoms. He says that kids who have eczema with no apparent reason might have celiac disease.

Ronnie Alicea, RD. She used to be here in Rochester and worked with Dietary Specialties. She's a dietician. She now prepares diets for people in institutional settings. First the doctor needs to write a prescription that the patient needs to be on a gluten free diet. She instructs people on how to make sure a person in a nursing home gets gf food. She said it's something we all need to know how to do.

At the end, they had a panel. They said that annually we should be tested with the celiac panel, vitamins B6, B12, and vit D.

Vendors/Exhibitors:

- Wegmans brought a busload of their employees to visit the vendors and try products.
- So many products are so much better today than in the past.
- Meisters sold a pre-mixed flour and they made angel food cake and it was just like wheat flour angel food cake. It was expensive, but we kind of have to expect that because it's a smaller market.
- DeFranco (??) was another pre-mixed flour that was really good.
- There were so many samples - just constant samples. The first day they had so many samples they skipped dinner!
- They also had cooking demonstrations.
- Crunch master multi-seed crackers - they are good - Wegmans and Lori's have them.
- There was a family that was making gravies, cheese sauce, alfredo sauce - they are called Full Flavor Foods - available at Red Bird Market in Fairport.
- Bread Machine - the flour comes in a bag - and you just pour it in and the bread is ready in an hour.