

Rochester Celiac Support Group

August 19th, 2009 Meeting Minutes

Cassandra Coffey called to order the regular meeting of the Rochester Celiac Support Group at 7:05 pm on August 19th, 2009 at the Brighton Reformed Church, Rochester, NY.

Main Topic: Round-table discussion with parents and children to discuss the issues impacting celiac kids and their parents

Meeting Chair: Cassandra Coffey, President

Note Taker: Erin Collins, Secretary

Announcements:

- **Celiac Awareness Day at Frontier Field Report.** It was great fun! There were 79 people sitting in the RCSG block of seats, plus additional celiacs attended on their own. They announced over the loudspeaker and on the screen that it was Celiac Awareness Night and lots of people stopped by.
- **Reminder: Italian Dinner Fundraiser at Biaggi's on Aug 23 @ 5 pm.** Deadline to sign up has passed, but if you registered, we look forward to seeing you there! Event is a fundraiser, and funds raised will support the Rochester Celiac Support Group's operations and celiac awareness efforts.
- Suggestion was made to have a "**kids time**" during the regular RCSG meetings. Perhaps the kids could watch a movie or have special snacks in one of the adjoining rooms. A way for them to attend the meetings and meet other kids with CD, while not have to listen to the whole adult meeting. We are looking for someone who would be interested in organizing this.
- **September RCSG Meeting** (Wednesday, September 16) is a family picnic here at the church (inside). Nick's Pizza will be provided, and we ask that you bring a dish to pass. Please RSVP to Kathy Oaks so that we can order the correct amount of pizza and plan accordingly. **Please note: the meeting will be held at 6 pm**, so that families with children can attend and have dinner early enough to get home and get to bed on time. Newcomers will still meet - but can meet after we eat.
- **RCSG at Health Fairs.** The RCSG will have a table at several health fairs this fall. We will have volunteers there to answer attendees' questions, our storyboard about celiac disease will be on display, and we will have GIG handouts on celiac disease, gluten sensitivity, dermatitis herpetiformis, and other issues related to celiac disease. Please contact Cassandra Coffey if you are interested in participating/volunteering.
 - Clyde Children's Health Fair, Saturday, September 12.
 - Hamlin Health Fair, September 26.
 - Alesi Health Fair at the Dome Fair & Expo Center, October 15.
- **4th Annual Gluten-Free Culinary Summit at The Culinary Institute of America in Hyde Park, New York on September 12 and 13, 2009.** The Gluten-Free Culinary Summit is a special annual opportunity for food aficionados in the national celiac community to become immersed in a scrumptious, one-of-a-kind gluten-free cooking and baking adventure that excites the mind and tastebuds at every turn. For event schedules, presenters and registration, please visit: www.theglutenfreelifestyle.com. Special Summit group lodging rates are available while rooms last. If anyone would like to enjoy 15% off the registration, call 303-368-9990 or email info@prchefs.com to make your reservation. This offer is not available online.

- Roundtable Discussions at the Celiac Disease Center at Columbia University in New York City on September 15, October 6, and November 3. Due to many requests, the Celiac Disease Center at Columbia University has decided to host a Roundtable on Celiac Disease that deals with individuals and their families' difficulties in living with celiac disease. Attendance will be limited to 30. There is no charge to participate.
 - September 15, 6pm–8pm. Topic: Individuals and their families' difficulties in living with celiac disease. Parents of young children with celiac disease are invited to attend.
 - October 6, 6pm–8pm. Topic: Adults with celiac disease.
 - November 3, 6pm–8pm. Topic: Teens and adolescence with celiac disease.
 - If you are interested in attending, please contact Cassandra Coffey (cmc.coffey@gmail.com) for more information.
- **32nd Annual Celiac Sprue Association Conference** in Erie, PA, Bayfront Convention Center. October 30 - November 1, 2009. www.csaceliacs.org/Conferences/2009AnnualCSAConference.php. Please let Cassandra Coffey know if you are interested in attending. She will keep a list of people who are attending and are interested in sharing rides/hotel rooms.
- **New member introduction** - many new members to this group this evening.

Main Topic of the Meeting:

- **Round-table discussion with parents and children to discuss the issues impacting celiac kids and their parents**
 - Things learned from the parent/child panel tonight:
 - A great book for toddlers is "How I eat without wheat"
 - Going to college on a Gluten Free diet- sign-up with student disability services, the hardest part about going to college is explaining to others about Celiac Disease, talk to the dining hall about your dietary needs, and the easiest way to do it is to cook for yourself but this can be tough at college.
 - If someone in your family has Celiac Disease, it is pretty likely that someone else may have it as well.
 - Try replacing foods in your child's diet that they really like with Gluten Free substitutes.
 - If your kids go to sleepovers, send food with them or plan ahead about what they are going to eat.
 - It is great to cook the way you used to, but switch the foods over to Gluten Free foods.
 - Empowering kids is important so they can speak up for themselves and look out for themselves- you will not always be there.
 - It is important to talk to your child's school or preschool about your child's gluten intolerance and educate the teachers and administrators.
 - Celiac Disease is covered under the American's with Disabilities Act so school districts are obligated to help the kids out to the best of their ability.
 - In middle school, cooking classes and paper mache
 - It is easiest for kids/parents to pack lunches for school. That way going through the lunch line will not be such a big deal and you can pack Gluten Free foods that the child likes.
 - Sleepover camps for Gluten Free kids are great- they are a great place to go where the kids can fit in, be part of the group, and not be different.
 - 504 Plans can be really useful for school districts. It gives a lot of information to the teachers and administration about the child's special needs like Gluten Free foods or accommodations. You only need to set this up once and you will be all set.

- **Useful internet links and printable PDF's for children and Celiac Disease and the Gluten Free Diet**
 - GIG: "Understanding Your Student":
<http://gluten.net/downloads/print/Students%20with%20Celiac%20Disease.pdf>
 - GIG: "Students with Celiac Disease":
<http://gluten.net/downloads/print/Students%20with%20Celiac%20Disease.pdf>
 - National Foundation for Celiac Awareness: "Navigating the School System" (plus several links at bottom of page): <http://www.celiaccentral.org/Resources/Support-for-Patients/Kids-Youth/Navigating-The-School-System/209/>
 - Children's Hospital Boston Celiac Disease Program & Support Group - Celiac Family Health Education:
<http://www.childrenshospital.org/clinicalservices/Site2166/mainpageS2166P12.html>.
Comprehensive site and very useful.
 - Video: Children's Hospital Boston, Family Health Education Series: Raising Your Celiac Child- Guidelines for a Gluten-Free Life, available for \$29.99. Individual clips are available online for free:
<http://www.childrenshospital.org/clinicalservices/Site2166/mainpageS2166P12.html>.
 - "Kids and the Gluten-Free Diet," *Practical Gastroenterology*, February 2007:
<http://www.healthsystem.virginia.edu/internet/digestive-health/nutritionarticles/SharrettArticle207.pdf>
 - <http://www.healthsystem.virginia.edu/internet/digestive-health/nutritionarticles/SharrettArticle207.pdf> Celiac Sprue Association: "Getting Along at School": www.csaceliacs.org/CelKidsSchool.php

- Many interesting points learned from visiting these websites:
 - 504 Plans can be useful if school staff is reluctant to accommodate your child.
 - It is really important to have a letter or documentation from your child's physician.
 - Get to know your school nurse/food service staff/teacher.
 - When setting up your child's school lunch account, go into the food service office and sit down with them to set up the account. They should be able to set it up so that the child is only allowed to purchase items which are safe.

Upcoming Events:

-August 23rd at 5pm at Biaggi's Restaurant, we will be having a fundraiser so please save the date. We would like you to come and bring family and friends. Please see the flyer below.

-September 16th at 6pm is our annual picnic with Celiacs and their families. Nick's pizza will be provided and we ask that you bring a Gluten Free dish to pass. Please RSVP to Kathy Oaks (vice president) so that we can order enough Gluten Free pizza.

-September 20th from 6-8pm, Lori's Natural Foods in Henrietta will be offering a food tasting (Gluten free and other).

-October 6th, Chinese Dinner at Golden Phoenix chaired by Bert Garman, more details to follow.

-October 21st at 7pm is a membership meeting, more details to follow.

-November 18th at 7pm is a membership meeting chaired by Denise Copelton, PhD, Asst. Professor of Sociology, The College at Brockport, State University of NY. The topic is "The Social Experience of Celiac Disease: From Diagnosis to Dietary Management".

The minutes are respectfully submitted by Erin Collins, Secretary of RCSG. Thank you.

