

Rochester Celiac Support Group

November 18th, 2009 Meeting Minutes

Cassandra Coffey called to order the regular meeting of the Rochester Celiac Support Group at 7:00 pm on November 18th, 2009 at the Brighton Reformed Church, Rochester, NY.

Main Topic: "The Social Experience of Celiac Disease: From Diagnosis to Dietary Management" w/ Denise Copelton, PhD

Meeting Chair: Cassandra Coffey, President

Note Taker: Erin (Collins) Harner, Secretary

Announcements:

- We now have a new "happy belly" logo for our group. It conveys a positive, uplifting image which aligns with the role the RCSG plays in many members' lives. Many are overwhelmed and struggling when first diagnosed and the group is here to foster them through the transition to a gluten free diet as peers. The message symbolized by the "happy belly" is that, often after years of discomfort, a healthy GI system can be attained with diagnosis and adoption a gluten-free diet. The symbol's common iconic form also communicates that we are a group that serves all people. Thanks to Amy Van Dussen for designing the logo.
- 2010 Walk for Celiac Disease update. We've chosen the date and location for the 2010 Rochester Celiac Walk. It will be on Saturday, June 12th, 2010 at Oliver Middle School in the Brockport School District. We are still looking for more volunteers for the walk committee. We need a co-chair to help Tina Muto with the walk as well as a few other positions. Please contact Tina Muto if you are interested in helping out! 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.
- We need a few volunteers to help set-up and clean-up for our monthly meetings. If you would like to help, please contact Cassandra Coffey. Responsibilities include: arrive one hour prior to start of meeting to set up. Meetings generally begin at 7 pm, so you would arrive at 6 pm. Set-up tables and chairs before the meeting. The tables are heavy, so we do need people who are capable of lifting heavy items. After meetings, we need to take down tables and chairs, sweep the floor, and help tidy up building before leaving for the night. Clean-up is usually complete by about 9:30 pm.
- Our RCSG e-mail list is easy to join and is loaded with lots of great information. Go to www.rochesterceliacs.org to sign up if you are already not on this list. The list is well-monitored by Joel Elias, so we do not get junk mail or an over abundance of messages on this list.
- 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!
- Our next RCSG meeting is on Wednesday, December 16th at 7pm. Please bring 3 dozen gluten free cookies as well as recipes with lists of ingredients for people with other food allergies and intolerances. Also, remember to bring a container to take your cookies home with you.
- January 12th, 2010 is a gluten free cooking class at the Pittsford Wegmans. To sign up, go to the Wegmans website or stop in at the store.
- RCSG will be having another gluten free cooking class in 2010. If you would like to help out, please contact Kathy Oaks.

Main Topic of the Meeting:

- **Denise Copelton, PhD, Assistant Professor of Sociology, The College at Brockport, State University of New York**
“The Social Experience of Celiac Disease: From Diagnosis to Dietary Management”

Main points of talk (please see the slides posted on the RCSG website)

- The lay standards and medical standards of diagnosis for Celiac Disease differ
- The medical guidelines for diagnosis starts with antigliadin antibody testing, followed by tissue transglutaminase antibody testing, followed by antiendomysial antibody testing, followed by biopsy which is still the gold standard for diagnosis and improvement on a gluten free diet.
- Many physicians will ask patients who have already gone gluten free to do a gluten challenge before testing in order to get a positive result.
- There has recently been an emergence of Direct to Consumer (DTC) testing for Celiac Disease with varying levels of scientific validity.
- Post-diagnosis, there are a lot of learning curves to deal with on the gluten free diet such as shopping, cooking, baking, and learning to like the gluten free problems.

Upcoming Events:

- **December 16th, 2009**- The next RCSG meeting is our annual gluten free cookie exchange.
- **January 12th, 2010**- Gluten Free cooking class at the Pittsford Wegmans.
- **January 20th, 2010**- RCSG meeting and review of Celiac Sprue Association Conference.

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