

Rochester Celiac Support Group (RCSG) Meeting
August 17, 2010
St. Anne Church

Announcements & Upcoming Events

Thanks to our new RCSG Volunteers!

0. Bridget Dugan is taking on the role of Health Fair Coordinator. If you are interested in volunteering at a health fair, please contact Bridget.
1. Celeste Kovachi is joining the New Member Committee. She will be helping to welcome and educate our new members.

We need more volunteers!

2011 Walk for Celiac Disease Committee Members (Need 7 volunteers).

2. Planning will begin soon for the 2011 walk, so we need volunteers NOW to make our 2011 walk a success! At this point, we have NO volunteers for the 2011 walk. We cannot have a walk with volunteers to plan it.
3. It's fun to work with a friend and it helps to spread out the work. Please volunteer and recruit others too!
4. Volunteer positions include the following areas: cash sponsors, in-kind donors, vendors, marketing, administration, finance, day-of-event operations.

Website Content Editor (Need 1 volunteer).

5. Will be responsible for keeping the content on our website current and relevant.
6. No knowledge of html or website editing is needed to do this job. Joel Elias is our website manager, and he will actually make the updates to the website. The website content editor just needs to forward to him the changes/updates that need to be made and he will implement them.
7. Will review all content currently on our website and update/edit.
8. Will stay informed of current news (news stories about CD or GF Diet, new restaurants that have GF menus, new shopping venues, etc.) and work with our website manager (Joel) so that these items can be added to our website.
9. Optional. Looking forward... Something we'd like to do in the future is have a quarterly newsletter that would be posted to our website and

emailed to our membership. This could be done by the Website Content Editor - or it could be a separate position = Newsletter.

Meeting Attendance + Sign-In Table (Need 1 volunteer or 2 to work as a team).

10. Bring sign-in sheets, clipboard, pens, and name tags to meetings
11. Arrive 30 minutes prior to the start of meetings (usually 6:30 pm)
12. Sit at sign-in table, welcome people, give them a name tag and make sure they sign in. Ask if they want to sign up for our email list.
13. Have first-time attendees fill out contact info cards (to be added to our mailing list) if they have not already signed up to be on our mailing list online. Give these cards to the person responsible for updating the mailing list.
14. Count and record the number of people in attendance and the number of newcomers at each meeting. Give these numbers to President.

Refreshments Committee Members (Need 2-3 volunteers).

15. Volunteer positions to begin in January 2011.
16. Committee members are responsible for the kitchen at monthly meetings:
 - a. recruit volunteers to bring snacks
 - b. set up the kitchen before the meetings
 - c. make coffee
 - d. set out snacks for serving after the meeting
 - e. clean up the kitchen after the meeting.
17. Need to arrive by 6:30 pm to set up, and will need to stay until kitchen is clean.
18. Vice President of RCSG (Kathy Oaks) is chair of this committee.

Ways & Means (Need 1 volunteer or 2 to work as a team).

19. Organize and run fundraising activities (like raffles) at monthly meetings.
20. Plan, organize, and run the primary annual fundraiser for RCSG.
21. Organize/plan other fundraisers throughout the year as desired/needed.

New Google Groups Calendar on our Website. Go to www.rochesterceliacs.org and click on the link on the left side that says

calendar. As we get the calendar updated, it will have all events in which RCSG is participating in the Rochester area, plus any other CD/GF-related events that we know about.

Celiac Awareness Day at Frontier Field-Recap. We had 85 people in our block of seats! The event was listed on their website and in the newspaper as "Celiac Awareness Day". They also announced it over the intercom and on the screen. We had a table with a display about celiac disease and information that people could take.

Gluten-Free Sampling Event at Holt Rd Wegmans. Saturday, August 21 from 11 am to 3 pm. It will be in the vestibule area before you enter the store. There will be numerous GF food samples, goodie bags and literature available. Be sure to stop by, enjoy some GF samples, meet the food reps and support Wegmans and their suppliers!

RCSG Family Picnic. Tuesday, September 21 at 6 pm. St. Anne's Church Social Hall. RCSG will be providing pizza and sausage from Nick's. Please bring a GF dish to pass. Please bring the recipe and clearly identify any other allergens.

Half-price Book Sale! At the September Family Picnic, we will be selling some of the books in our inventory (not the GF Grocery Guides or Dr. Wangen's book) at half-price.

GF Chinese Dinner at Golden Phoenix Chinese Restaurant. Tuesday, October 5. See Bert Garman for more information. There will also be a printable form on our website as the date gets closer.

Featured Presentation:

Tonight we have the honor of hearing from our charter members. These women really laid the foundation for what our group has become. We must thank them for their hard work in the beginning, when things were not nearly as easy as they are today. With us tonight are:

22. Karen Meyers
23. Marlene Kier
24. Norma Bartlett

25. Bert Garman
26. Carol Becker
27. Katherine Barkley

The History of Celiac Disease and the Rochester Celiac Support group.

– Presentation given by Carol Becker, Karen Meyers, Norma Bartlett, Bert Garman, Marlene Kier, and Kathlyn Barkley

- ❖ The first Rochester Celiac support group meeting was held at Rochester General. In the beginning they only met a few times a year.
- ❖ At the early meetings they had fewer members. The turn out was anywhere from a few people to 30 to 40 people. The earlier members shared experiences of having to walk all around the hospital following arrows while one person led the way around the hospital. Everything they needed for their meetings they had to carry with them, including water for coffee.
- ❖ At one of the early meetings they hired a grief counselor to come and speak to them, as they were giving up many of the foods they enjoyed. When the counselor arrived they thought they had the wrong room, as they heard everyone in the group laughing and talking with one another.
- ❖ The meetings were later moved to Strong hospital. The members talked about their experiences here, and how for parking they could only attend the meeting if they had a special green parking sign. This held true for all seasons.
- ❖ The meeting place was then held at a church in Webster for a little while, and later changed to the location on Blossom rd.

- ❖ In 1994 the Rochester Celiac Support group had their first pizza party. At this time there were no pizza places that sold a gluten free pizza, and none were sold at the stores. The group got together and made their own and had a party.
- ❖ In 1996 Joel Elias started the Rochester Celiac Support Group website
- ❖ In 1998 the group was expanding and they wrote up their mission statement. They created the Board, and made sure to have an uneven number of board members so that when it was time to vote on something there would not ever be an even vote.
- ❖ In 2000 and in 2003 the group helped out with a study being done by the University of Maryland. The study was to see how prevalent celiac disease was and involved getting blood samples from about 380 different people who were having symptoms suggestive of celiac disease. Several people were diagnosed from this study.
- ❖ The first Walk for Celiac Disease was held in 2002, and raised \$27,000. 230 people participated in it.
- ❖ In 2003 the group decided that they needed a logo, which ended up being a loaf of bread with steam rising out of it, it was used up until the current logo was selected.
- ❖ The group organized a Chinese Dinner at Golden Phoenix. They spoke with the owner of the restaurant at the time and came up with a whole menu of gluten free items. This was the first place in Rochester with a gluten free menu. Our October dinner this year will be held at the same place.
- ❖ In 2007 the Rochester Celiac support group became a branch of GIG.
- ❖ The presenters talked about various speakers they had that came and spoke to their group about Celiac disease. Among them were, Dr. Shaw, Dr. Decross, Dr. Furman, Freda

Hanafraw, Peggy Wagner, Jane Andrews, and Colleen Wegman.- (I apologize for any misspellings of their names)

- ❖ The Celiac support group came up with the idea of the Gluten free Auction when they became low on cash. Each year everyone would bake something, and people would bid on the items at one of the meetings. Everyone came to learn each year who made the best apple pie or lemon meringue pie and it was quite a success. The profits went to the group.
- ❖ The celiac support group also had a pasta dinner to raise profits for the group.
- ❖ The members of the group felt like holiday times were especially difficult for them, and they created a cookie exchange around the holidays where they would all bring in gluten free cookies and exchange them at the meeting.
- ❖ They also organized a gluten free Christmas party, so they could go to one of the member's houses and everything they would have there would be safe for them to eat.
- ❖ The support group worked with a student who went to Nazareth and one of the cooks there to develop a plan for her to be able to eat the foods at the college. The cook would prepare them for her in a place separate from the other gluten containing foods, and she was able to eat at the college.
- ❖ The Rochester Celiac Support Group also worked with The University of Columbia, who has a gluten free menu for their students with Celiac disease and gluten intolerance.
- ❖ At the end of their presentation they encouraged everyone to attend at least one of the National conferences for celiac support.
- ❖ The presenters said they found the more they gave their time and help to others with Celiac Disease, and more they got back.

- ❖ The size of the group has grown incredibly since 1989, when there were 39 members. The group now has 1,037 people on the cell list!

Thank you for the wonderful presentation on the history of Celiac disease and the Rochester Celiac support group Ladies!