

# ***Rochester Celiac Support Group***

## ***July 15th, 2009 Meeting Minutes***

Cassandra Coffey called to order the regular meeting of the Rochester Celiac Support Group at 7:00 pm on July 15th, 2009 at the Brighton Reformed Church, Rochester, NY.

**Main Topic:** Announcements and GIG Conference Overview

**Meeting Chair:** Cassandra Coffey, President

**Note Taker:** Erin Collins, Secretary

### **Meeting highlights:**

- Tonight we **raffled off Sweet Sin Carrot Cakes**. They were leftover after the walk and have been in the freezer since the night of the walk. Thanks to Linda Howell for freezing these! They are delicious cakes and cost about \$25 each, I believe.
- **2009 Walk for Celiac Disease.**  
Donations have continued to trickle in since the walk, and our total funds raised to date are **\$38,000** and we had 652 people!  
There are still several **unclaimed lost-and-found items** from the Walk. Are you missing (1) Finding Nemo Baby Sunhat, (2) Event Bag + 2 Walk T-Shirts, (3) Insulated Lunch Bag, (4)
- **Celiac Awareness Day at Frontier Field** - Fri, Aug 7. We can purchase tickets as a group for \$5.50 each (need a minimum of 20 people to get the group rate/block). We'll be sitting in section 206. There are free fireworks immediately following the game. Need to RSVP/pay Cassandra Coffey by July 31. Please wear your walk t-shirt.
- **August RCSG Meeting - Families/Kids & Dealing with CD** - need a few more volunteers to share their experiences. Encouraging many families with kids to attend not only to share/learn, but to meet other families/kids with CD. There is interest in planning some kids activities - please contact me if you are interested in participating or helping to organize.
- **Introduction of new members.**
- **Italian Dinner Fundraiser at Biaggi's** (Eastview), Aug 23 @ 5 pm. Please see Nancy Wise to purchase your ticket tonight. 60 tickets are available - \$20 for adults, \$12 for kids. Menu includes. Event is a fundraiser, and funds raised will support the Rochester Celiac Support Group's operations and celiac awareness efforts. Go to the Biaggi's website to look for a description of the menu items.
- **32nd Annual Celiac Sprue Association Conference**  
Erie, Pennsylvania, Bayfront Convention Center  
October 30 – November 1, 2009.  
<http://www.csaceliacs.org/Conferences/2009AnnualCSAConference.php>  
Please let Cassandra 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.

- **We Need Volunteers for:**

- Table at Celiac Disease Awareness Day at Frontier Field (Aug 7). Need 4 volunteers for 6 - 7:05 pm. Also need volunteers for during the game (3-inning shifts).
- Organize/plan September Picnic.
- Helping to organize group dinners/events at restaurants.
- Helping to plan the 2010 Walk for Celiac Disease.

- **Highlights from the Annual GIG Conference**

By Susan Kath, Denise Copelton, and Karen Domenech

1. RDA is the recommended daily allowance for vitamins and minerals and they are for healthy adults and doesn't apply to people with Celiac Disease.
2. It is very important that you get screened for nutrient deficiencies, especially vitamin D and K.
3. Omega 3's are very important and we are often deficient in them.
4. Folic acid is one of the largest deficiencies in people with Celiac disease.
5. Lactose is absorbed by the top of the villi in the small intestine- it is the first
6. Fiber- 3 grams of fiber or greater means its an excellent source of fiber.
7. King Arthur has toaster bags that prevent cross-contamination and are great when you're travelling.
8. Cross-contact can be a better way to describe cross-contamination with gluten when talking with restaurants.
9. In reaction to the "G-Free Diet"- Dr. Green explained how we should embrace the exposure of Celiac Disease in the media.
10. Dr. Martin Kagnoff from UC San Diego talked a lot about Celiac Disease testing.
  - a. Antibody tests
    - i. IgA antibody tests are the most important for testing for Celiac Disease
    - ii. Some people with Celiac Disease have IgA deficiency and in this case, IgG will be tested
    - iii. IgA tTG (IgA tissue transglutaminase antibody)- 1<sup>st</sup> screening and each lab has a different normal range- measured by an ELISA assay
    - iv. IgA EMA (IgA endomesial antibody)- 2<sup>nd</sup> screening if necessary; requires tissue staining and is more subjective
    - v. IgA and IgG dGP (IgA or IgG deamidated gliadin peptide)
    - vi. IgA AGA (IgA antigliadin antibody)- not run as often anymore because it is not very specific or sensitive and is not very useful for diagnosis
    - vii. Sensitivity refers to the number of times a true positive result occurs whereas specificity refers to the number of times a true negative result occurs
  - b. Steps to diagnosis
    - i. Antibody test (usually IgA tTG and IgA EMA)
    - ii. If two of these antibody tests are positive, Celiac Disease is presumptive but biopsy is the gold standard;
    - iii. Biopsy
    - iv. Positive biopsy: diagnosis of Celiac Disease
    - v. Negative biopsy: will often repeat the antibody tests
    - vi. If on a gluten free diet, Dr. Kagnoff recommends a gluten challenge diet for one month
    - vii. Genetic testing can be done to rule out Celiac Disease; about 30% of the population has either the DQ2 or DQ8 genes which can indicate that Celiac Disease is a possibility, but if either or both of these are negative, Celiac Disease is not a possible diagnosis and can be ruled out

11. GIG (Gluten Intolerance Group) is a great organization and you can join their group and support them with a \$35 annual membership. Visit GIG at their website at [www.gluten.com](http://www.gluten.com). You will also get quarterly magazines with a lot of information about Celiac Disease.
  12. Re-check your prescription drugs to make sure that new formulations do not contain products made from wheat such as starch and hydroxycellulose. View more information on [www.stokesrx.com](http://www.stokesrx.com)- they will compound gluten free medications.
  13. Be careful of gluten in vitamins and supplements.
  14. The pharmacist also recommends 50mg per day of Vitamin B12 for people with Celiac Disease.
  15. The average adult should get about 35 grams of fiber per day. Make sure that you are eating lots of fruits, vegetables, nuts, seeds, and legumes to get more fiber in your diet.
  16. Hypothyroidism can be related to Celiac Disease. Pay attention to your energy levels.
  17. It is really important to incorporate lots of whole foods into your diet. There are lots of gluten free grains such as quinoa, buckwheat, millet, etc.
  18. Make sure that you get checked for osteoporosis or osteopenia because this is highly prevalent in people with Celiac Disease.
  19. From the "Gluten Free Girl"- baking
    - a. Most Americans don't bake anymore, so many people fear baking gluten free because of the
    - b. Baking disasters- awful cookies can make good pie crust and mishappen bread can make great bread crumbs
    - c. GF flours- you need to mix at least three different flours together and generally in equal parts; base flour: brown rice or sorghum, second: starch such as tapioca, arrowroot, cornstarch, third: personality flour: amaranth for cookies, quinoa flour for crusts, sweet rice flour for starchy dishes
    - d. The flour you use will produce similar qualities in the finished product.
    - e. If the recipe calls for 1 cup, generally use 1 ¼ cups of GF flour
- Additional handouts presented at the meeting will be posted on the website:
    - Shopping Gluten Free in 6 Easy Steps
    - GF on the Go
    - GIG Annual Education Conference Notes

### **Upcoming Events:**

**-August 7, 2009** (Friday) will be a new event for Celiac Awareness Day at Frontier Field. They have concessions with gluten free food at the stadium. We ask that our members wear their walk t-shirts.

**-August 19<sup>th</sup>** is a membership meeting where we will have a round-table discussion with parents and children to discuss the issues impacting celiac kids and their parents.

**-August 23<sup>rd</sup>** 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 16<sup>th</sup>** at 6pm is our annual picnic with Celiacs and their families. More details to follow.

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

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



**Rochester Celiac Support Group  
Fundraiser**



**Gluten-free Italian Dinner  
Sunday, August 23, 2009 at 5pm  
Biaggi's Ristorante Italiano,  
818 Eastview Mall, Victor, NY  
585-223-2290**

*Italian Buffet including:*

- \*Pizza Appetizer*
- \*House Salad*
- \*Rigatoni alla Toscana*
- \*Unlimited non-alcoholic beverages*
- \*Pasta Marinara*
- \*Farfalle Alfredo*
- \*Dessert*

*Adults - \$20*

*Children 3 to 11 - \$12*

*RSVP by 8/8/08, along with check payable to RCSG, to:*

*Nancy Wise*

*276 Ross Street, Batavia, NY 14020*

*585-343-5707*

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*RCSG Gluten-free Italian Dinner Reservation*

*Name:* \_\_\_\_\_

*Phone Number:* \_\_\_\_\_

*# of Adults* \_\_\_\_\_

*# of Children (3-11)* \_\_\_\_\_

*# of Children (under 3)* \_\_\_\_\_

*Total Paid:* \_\_\_\_\_