

February Celiac Support Group Meeting Notes

- ❖ Tonight's presentation to the support group was by Heidi B Schwarz, who is a Neurologist with Unity Health System. She won the Patients Choice Award for 2008, 2009, and 2010.

- ❖ Dr. Schwarz talked to the group about a patient of hers that presented with persistent headaches, unsteadiness with walking, white lesions on the brain (found with MRI), as well as other health issues such as hypertension, diabetes, and hyperlipidemia. The patient had seen 4 other Neurologists and they could not find out what was causing the head aches to increase. It came to the point that the patient needed PT and OT and various meds were tried to stop the dizziness and headaches they were experiencing. The patient was having difficulty walking and focusing. Repeat MRI's showed that the brain lesions were worsening. During their struggle they had seen a doctor that said the patient had Celiac Disease. The patient tried the diet for a couple weeks and did not feel better, but mentioned this to their Neurologist. The Neurologist who was Dr Schwarz talked about the importance of staying on the gluten free diet and told her patient this was the only way to get better. Within a few months the patients head aches decreased in frequency, and their brain fog and dizziness improved as well. This shows that Celiac Disease and gluten sensitivity can present primarily with neurological symptoms.

- ❖ Dr Schwarz talked to us about the first time a small bowel biopsy was used to diagnose Celiac disease was in the 1950's. In the 1960's she stated that an association was made between CD and dermatitis herpetiformis. In 1966 the land mark paper on Neurological complications of celiac was written. It talked mostly about severe progressive neuropathy as well as gait ataxia.

- ❖ She talked to us about how many times Celiac Disease with GI involvement presents with things such as diarrhea, weight loss, abdominal bloating, fatigue, mouth ulcers, anemia, osteoporosis, IGA nephropathy, vitamin deficiencies, and is found on the small bowel biopsy.

- ❖ With Gluten Ataxia the person may present with things such as Ataxia, peripheral neuropathy, myopathy, dementia and seizures if severe, and the small bowel results are usually milder. The person often has malabsorption despite fewer GI symptoms, and cerebellar atrophy.
- ❖ In 2001 Dr. Hadjivassiliou described patients that had abnormal MRI scans. Of the patients 9 out of 10 got better when beginning a gluten free diet. In 2003 He found that close to 40 percent of those with unexplained ataxia had underlying Celiac Disease.
- ❖ Dr Schwarz talked about how the only treatment for Celiac disease and gluten ataxia was the gluten free diet. She mentioned that she often has to remind patients and their families that there is no magic pill they can take to make the reaction stop and the only way to feel better is to make sure your diet is gluten free, as well as your medicine and other household products such as toothpaste and cosmetics.

Thank you Dr Schwarz for your wonderful presentation and taking the time to come and talk to our support group!

- Kelly Odrzywolski ☺

Announcements & Upcoming Events

2011 Walk for Celiac Disease

Plans for the 2011 Walk for Celiac Disease are under way!

- ❖ www.rochesterceliacs.org/walk11.htm
- ❖ Saturday, May 21 at Brockport Middle School.
- ❖ Registration @ 9 am. Walk @ 10:30 am. Gluten-Free Food Fair @ 11:30-1:30 pm.
- ❖ We would like to thank Wegmans and Channel 8/Fox for their continued support. They are our presenting sponsors again this year.
- ❖ Online registration is now open (we already have 9 people registered!). Go to www.rochesterceliacs.org/walk11.htm to register.
- ❖ We will be posting fundraising aids on our website by the end of this week. You will be able to download posters, pledge sheets, coffee can wraps, and thank you notes.

- ❖ Visit the CeliacWalk.org website and where you can send emails asking your friends and family to support you, monitor your online donations, and print thank you notes.
- ❖ We are also looking for corporate sponsors - if you own a business or work for an employer who might be interested in supporting the walk, our sponsorship opportunities are posted on our website and you can also contact Cassandra Coffey.
- ❖ Please contact Cassandra Coffey if you are interested in volunteering at the walk.

March RCSG Meeting: Tuesday, March 15

- ❖ Speaker is Stephen Wangen, naturopathic physician, author of the book "Healthier Without Wheat".
- ❖ NO Admission Fee for the meeting, but you will need to RSVP via our website. We are requesting that people RSVP for this meeting due to expected large turn-out.
- ❖ Instructions will be sent out via email regarding how to RSVP for the meeting.
- ❖ Youth Group will be meeting with Dr. Wangen from 6:30 to 7:00, just before his main presentation. Please contact our youth group if you are interested in attending this youth-focused Q&A with Dr. Wangen, rochesterglutenfreeyouth@gmail.com

Jovial Cookies - Free Samples here tonight!

- ❖ Thanks to Jovial Foods for providing cookies for our meeting. There is a limited supply of the cookies available by the kitchen. First come, first served!
- ❖ If you took home a free sample of the Jovial pasta that was provided at the January meeting, and you have any feedback about the pasta, please see me tonight or send me an email (cmc.coffey@gmail.com). The representative from Jovial Foods was looking for feedback about the pasta.

VOLUNTEERS NEEDED!

Walk for Celiac Disease Volunteers

We need lots of help with advance planning of the Walk for Celiac Disease and volunteers to help run the event on May 21. Please contact Cassandra Coffey at cmc.coffey@gmail.com if you are interested in being a part of the team!

Book Sales/Resources Chairperson (need 1 volunteer)

This person would be responsible for book sales, including ordering books when needed, storing books, transporting books to meetings, selling books at meeting. This person would also help with other services/benefits we offer

our members. This position is a board position. Board meetings are held 6 times per year.

Newsletter Contributors

Tina Muto is looking for people to submit articles for our new quarterly newsletter. Please contact Tina at Tina.Muto@rochesterceiliacs.org if you would like to submit an article, restaurant review, or recipe for the newsletter.

Membership Committee Volunteer (need 1 volunteer)

This person would work with other membership committee volunteers to welcome new members, keep our mailing list up-to-date, and help with the new member meetings at 6:30 pm (just prior to our regular monthly meeting).

Refreshments Committee Members (Need 3-6 volunteers)

Kitchen volunteers are part of a team. The schedule is a rotating schedule, so that you only have to be at every third meeting. Committee members are responsible for:

- recruit volunteers to bring snacks
- set up the kitchen before the meetings
- make coffee
- set out snacks for serving after the meeting
- clean up the kitchen after the meeting.
- ❖ Need to arrive by 6:30 pm to set up, and will need to stay until kitchen is clean.
- ❖ Vice President of RCSG (currently Kathy Oaks) is chair of this committee.