

May Rochester Celiac Support Group Meeting Notes

At the beginning of the Meeting Cassandra announced that Wegmans will have Rudi's hamburger buns shortly.

She informed us that Weight Watchers is now also doing a gluten free option, and a New Brand of gluten free yellow cake is out at the supermarkets. The brand is Hodgins Mill.

Cassandra talked about how the Walk for Celiac Disease has been going on for ten years in Rochester, and that Bert got the walk going in the beginning and has raised over 20,000 dollars over the past ten years for research on celiac disease!

The speaker at tonight's meeting was a local Gastroenterologist named Dr. Baratta. He has worked at Rochester General Hospital and now is working at Highland Hospital. He was voted to be in the top 5 Gastroenterologists in Rochester, NY, and has received this honor two times.

He started the presentation out about talking about Celiac disease and stating that it is an immune mediated disease in genetically susceptible people. The environmental precipitant is gliadin. The villi are attacked in celiac disease and when they are completely wiped out it is called villous atrophy. Patients improve with a gluten free diet.

He talked about the prevalence of celiac in first degree relatives of those currently diagnosed which was 1:22, and the prevalence in second degree relatives to be 1:39.

Of those that are symptomatic 1:56, and overall 1:133.

The classic symptoms of celiac disease are things such as: diarrhea, weight loss, bulky stool, bloating, vague abdominal discomfort, and flatulence.

Some current day symptoms he mentioned are Iron deficiency anemia, asymptomatic, a family history, abnormal liver enzymes, infertility, and DH.

Some Extra intestinal manifestations are amenorrhea, seizures, peripheral neuropathy, ataxia, arthritis, oral ulcers, failure to thrive, and dental erosions.

Some other conditions and diseases associated with Celiac disease are Diabetes type 1, Down Syndrome, Migraine, MS, Anxiety and depression, and Fibromyalgia.

Dr Baratta then talked about tTg and how it is released by inflammation and endothelial cells. He said it crosslinks gluten proteins. Celiac is diagnosed by having an upper endoscopy with a biopsy. Individuals that are highly suspected of having Celiac are those with things such as Anemia and a family history. These individuals should have a biopsy because the blood test could be negative in early conditions. If the doctor has a lower degree of suspicion for Celiac he may order the initial string of blood tests. If the patient has Celiac they avoid gluten for life, and they begin to feel better.

Initial Management for Celiac includes things such as: Attending a support group, going to Dietician, GF and Lactose free diet, Understanding the complications of the disease, screening first degree relatives, self education, and also screening second degree relatives.

Once diagnosed with Celiac the gluten free diet will reduce cancer risk, prevent immune disorders, diabetes, and thyroid issues, and improve pregnancy outcome.

Some cancers associated with Celiac Disease are Lymphoma, small intestine cancer, cancer of the pharynx and esophagus. Within 5 years time you can decrease the risk of these cancers associated with your Celiac disease if you follow the gluten free diet. It will then be the same risk as the general population.

Dr Baratta made mention that meds can contain gluten, as well as lipstick, toothpaste, and shampoo and lotion. He said unless you are swallowing the shampoo or lotion they would be considered safe even if they contained gluten.

Some causes for poor response to the Gluten free diet were that the person was still ingesting gluten, they have IBS, Lactose intolerance, Microscopic colitis, pancreatic insufficiency, or Bacterial Overgrowth.

People with celiac disease who have Osteoporosis have a 50 percent increase in fracture risk. The GF diet may decrease the risk. The gluten free diet is low in calcium however and vitamin D. A DEXA scan can be done after one year on the gluten free diet to look for osteoporosis.

Dr Baratta likes to do annual follow ups with his patients with celiac. He checks their weight, symptoms, chem. Profile, CBC, folate, ferritin, and transglutamine. At this time he also recommends screening relatives. He says that the tTg usually becomes in the normal range between 3 to 12 months on the gluten free diet. Persistent elevation indicates gluten exposure. A normal tTg does not mean that the person with celiac can eat gluten again. It is important to clarify the diagnosis so that relatives can then be checked.

Non Celiac Gluten intolerance was then discussed. He mentioned a study with 34 patients that did not have celiac, but rather IBS and a prior response to the gluten free diet. One group of people got gluten in the form of bread, and the other group got gluten free bread. They did this for 6 weeks. Of those receiving gluten 68 percent had symptoms vs only 40 percent on the placebo. The public perception is that non celiac gluten intolerance is pretty common.

At the close of the presentation Dr Baratta stated that of those in the United States that have celiac disease, only 5 percent have been diagnosed.

Thank you Dr Baratta for your wonderful and informative presentation!

I would like to let everyone know that this is my last month as Secretary of the Rochester Celiac support group. It has been a pleasure getting to know everyone and I will still attend as many of the meetings as possible. Hope to see you all there!

- Kelly Odrzywolski