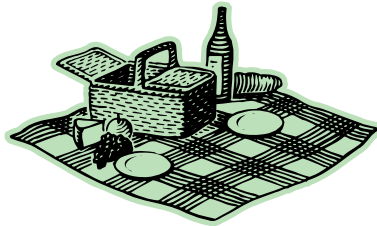


MADISON AREA GLUTEN INTOLERANCE CHAPTER M.A.G.I.C.

<http://www.madison.com/communities/gluten-free/>
CSA/USA, INC. – Madison Area Chapter #41 – Affiliated 1993

Next Gathering:
Saturday, July 8th – 4:30 pm
Potluck Picnic at Nancy Spencer's House
1110 Saalsaa Road
Madison
274-7121



Bring a dish to share & a folding chair
Plates, Utensils & Drinks Provided

Directions: Take Whitney Way south of the beltline. Go past Schroeder Rd. Turn right on Piping Rock. Take Piping Rock all the way down until it turns into Saalsaa Rd. (this happens just as you pass Chapel Hill). Nancy lives at 1110 Saalsaa (right hand side of street). Or if easier...take Schroeder Rd to Chapel Hill (approx. 1 block east of our meeting location at Prairie...) go south. Take a right on Saalsaa (if you turned left it would be Piping Rock).

*****No August Meeting—See you September 9th*****

MAGIC MEETING MINUTES June 10, 2006

Attendance:

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Russ and Lexy Austin, Leigh Barczi, Kathy Beringer, Kathy Borner, Teresa Braunsen, Hollee Cesar, Bob Coffin, Penny Coffin, Nancy Dott, Nancy Duerst, Sue Farrey, Emily Frigo, Sid Gomon, Barb Hennings, Margaret Kramer, Sean Lamb, Dan Moodie, Tammy Moodie, Ralph Musin, Kelly Olmstead, Patricia Pelletier, Betty Roberts, Deb Robbins, Carlos Rodriguez, Darlene Schulenberg, Meghan Shannahan, Brenda Schilke, Nancy Spencer, Joy Thompson, Judy Vinge, Julie Winding, Marge Westergard

Reports:

President's Report:

Nancy stated that she has been happy to have been the chairperson. Barb Hennings will be the new chairperson. A secretary is still needed.

The next meeting will be a picnic on July 8 at the Spencers' House at 4:30pm. Several members volunteered to cook some Pamela's products, so we may have a taste test at the picnic.

In the future, the Isthmus Annual Manual will have Barb listed as a contact under the health issues section.

At Char's Specialties, there will be a cooking demo on teff. Char has many new items, and she is always willing to get new products.

In the deli section at Woodman's, any item with a 'Dawns' label on it will indicate if it contains wheat.

Kathy Borner is compiling a doctor list because people often ask her for recommendations.

Treasurer's Report:

Bob recommended that you get hotel reservations for the CSA conference in Green Bay ASAP since it also happens to be a football weekend. Some rooms have been set aside by CSA. The price to attend the conference will increase after September 15. A direct mailing about the conference will be sent out in 2-3 weeks. At the August administrative meeting, it will be discussed whether our funds should be used to send a person to the CSA conference.

New Member Report:

Lexy and Russ Austin have a two year old son with celiac. Carlos Rodriguez is also a new member.

Library:

When you want to borrow a book, Marge asks that you remember to sign, date, and return the check out card to her. When you return the book, make sure to give it directly back to Marge, so she may record the book as checked back in.

Program

Meghan Shannahan, M.D., anesthesiologist at UW and former MAGIC member, spoke to group on how to talk to your doctor.

Meghan was in medical school from 1994-98 and she remembers seeing only a small paragraph on celiac sprue. There was not a lot of information out there and a lot of misinformation since celiac was perceived to be so rare. More recent data has shown that celiac has an estimated incidence of 1/133 people. You may have noticed that there is now more awareness. Since celiac requires dietary control (no medication), there is not a lot of money out there for research. A knowledge gap in medical communities still exists. Europe is ahead of the United States. Due to national health care programs, there is regular screening in Europe. Some physicians have come to the U.S. from Europe, which has contributed to more information out there.

Follow up testing:

The theory is that you should feel better and you should be fine once you follow the diet. This does not always work.

There are subsets of celiacs who do not have any symptoms when they eat gluten, and they will not know if they are healed. There are long term consequences if one does not completely follow the diet (i.e. osteoporosis, increased chances of certain types of cancer, etc.).

There is no consensus on testing. However, there is consensus that there is no need for a follow up biopsy. Blood tests follow ups are not definitive, and more study is needed because the tests are not precise. The most common are EMA-IgA (anti-endomysial antibody test) and AGA-IgA or AGA-IgG (anti-gliadin antibodies). These tests look for immune responses. Meghan will contact Michelle (Univ. of Chicago Celiac Disease Program), but Meghan believes the tTG-IgA (anti-tissue transglutaminase) is the blood test currently in favor. How often you have the blood tests done is up to you—annually if you are feeling fine or more frequently if you are not feeling well, etc. You may have a hard time getting costs covered by your insurance. The high cost of medical care is a national issue.

Diagnosis:

A biopsy is the gold standard. You should never have a single biopsy—several should be taken. The tissue needs to be examined by pathology. However, many labs/pathologists may not be knowledgeable about celiac disease; it can be very subjective. Meghan will give a list of good labs to be printed in the newsletter.

Recommendation:

Older physicians may not know a lot about celiac. The best thing to do is to provide them some information. Keep a resource list of websites and give it to your physician. Websites are good because the information will be updated.

Summary of question and answer session:

1 What do I do if my doctor wants to continue to do biopsies on me?

Biopsies are the gold standard to make sure you are getting better. However, procedures have risks, and you need to weigh that and decide whether you are having symptoms, etc. Recommended approach—give your doctor information to help take control of your care. Have a conversation with your doctor

2 When I was first diagnosed, I had really high numbers from the blood tests. I continue to have elevated levels even though I am following the diet. What control do I have over these tests?

Bring your doctor information. Show doctor that these tests (AGA-IgA or AGA-IgG) don't work or are not the best. You don't have to be tested if you don't want to. You may be able to tell if you have symptoms. People who are asymptomatic may need to be more vigilant.

tTG-IgA is the test that is recommended. It is also an antibody test (blood test). Several years ago, there was talk of a saliva test. At this point doctors do not have new information.

3 In regards to hospital stays, most do not have procedures for celiacs regarding gluten free food. There is no awareness of cross contamination issues.

One solution is to create a group/taskforce to compile information and create a procedure manual. Meghan would be happy to help out with that.

4 How do you tell if you have a wheat allergy vs. celiac?

A skin test should indicate if you are allergic to wheat. Celiac is not a true allergy but an autoimmune reaction. If you are just allergic to wheat, your villi would not be damaged.

- 5 *Some people do not get a biopsy because they cannot get into the clinic, and they start the gluten free diet without a biopsy. Is there a need for a biopsy?*

That is an individual decision. Some people may need a definitive diagnosis to adhere to the diet. If you are already on the gluten free diet, you could do a gluten challenge. Doctors do not know how long you need to eat wheat for the villi to be damaged. Meghan does have information on a 'formula' that allows you to calculate how much gluten you should eat during a gluten challenge. She will try and attach this information to the newsletter.

- 6 *Is wheat starch safe?*

In Europe, they create wheat starch by removing the protein. I would be skeptical about it.

- 7 *What is gluten intolerance?*

Our bodies were not designed to eat wheat. Many people are gluten intolerant. For a celiac diagnosis, you need a blood test and biopsy. There is a genetic predisposition to celiac.

- 8 *I have been on the gluten free diet, but I am unsure whether I have an allergy to wheat or celiac. What do I do?*

Have a skin test to rule out an allergy. You could do a gluten challenge (minimum three weeks) and then have a biopsy. This way you would know if you face higher risk factors as related to celiac. Or you could simply adhere to the diet.

You may need a diagnosis in your medical records. Case in point--you may need to prove to your insurer that you need a specific gluten free medication.

- 9 *Should you list gluten as an allergy in your medical records?*

It is not a true allergy. List it as an adverse reaction. It is good to point it out because medical staff may not make a connection between celiac disease and the fact that you cannot eat gluten.

- 10 *What about children and testing/re-testing?*

The blood test is good for diagnosis but not good for follow up. The IgA is not as sensitive for children.

First degree relatives should be tested every two years or you could get a genetic test done.

- 11 *What about DH and celiac?*

Dermatitis herpetiformis (DH) is a different presentation of celiac.

*****Additional handouts from Meghan Shannahan***
will sent at a later date.**

Restaurant recommendations:

The **24 CARROT CAFE** (1325 Greenway Cross, Madison, WI) makes everything from scratch, and they are knowledgeable about what is in their food. The café serves breakfast and lunch.

Pasquals (Monroe St and Verona locations): the mole sauce is gluten free, but the green and red enchilada sauce is not safe.