

**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, November 11, 2006  
10a.m. – 12 p.m.  
Prairie Park Apartments—6530 Schroeder Rd., Madison**

**Bob Coffin Presents  
“Celiac Quackery”**

**Magic Meeting Minutes  
October 14, 2006**

**Attendance:** Aaron & Charlene Avery, Kathy Beringer, Kathy Borner, Teresa Brausen, Sue Caldwell, Penny & Bob Coffin, Tom & Jean Consigny, Nancy Dott, Jennifer Du, Ellen Fitzsimmons, Jacki Friend, Barb Hennings, Jill Kessler, Brenda Landerud, Tammy & Dan Moodie, Ralph Musin, Kay Newton, John Ollinger, Claire Poppe, Katie Ronk, Sarah Rose, Mary Lee Rossmassler, Sharon Schrank, Darlene Schulenberg, Nancy Spencer, Ralph & Linda Stauffacher, Walt & Karen Thieszen, Judy Vinge, Marjorie Westergard

**Announcements**

Delicious jelly roll cakes were provided by Char from C's Specialty Foods and great chocolate chip cookies by Aaron and Charlene Avery (recipe included in newsletter).

We're still looking for a Secretary and will tap someone attending the meeting to take notes until someone (or two) volunteers to take on the responsibility. We just ask that the minutes be written up and delivered to Leigh, the newsletter editor, within a few days of the meeting so the newsletter can get out in a timely manner. If interested, please contact Barb Hennings @ 241-9510.

**Reports**

**Treasurer's Report:**

Bank balance as of October 13, 2006 is \$ 4,152.03. Adjustments against that are:

- \$75 of new members' dues not yet deposited.
- \$ 210 (est.) for monthly expenses: newsletter & new members for end-of-October net of approx. \$4,020.

Currently have 61 members renewed for 2006 – 2007. At the time of last year's October meeting, 78 had renewed.

Dues are payable for next year ~ July 1 to June 30, 2007.

#### **New Member Report:**

Kathy Borner introduced the new members who were present: Sharon Schrank, Ellen Fitzsimmons, Tom Consigny, Jill Kessler and Ralph Stauffacher. At the close of the meeting Ralph expressed his appreciation for the existence of this support group.

It was noted that the new NIH statement and booklet have come out, we continue to have more publicity on Celiac Disease, there is more education about CD, and there is an increase in diagnosis as is evidenced by the number of calls Kathy is receiving from newly diagnosed people.

#### **Newsletter Report:**

To help contain costs it is preferred that you receive your newsletter by Email but we are happy to send it by regular mail if requested.

#### **Librarian Report:**

Marge Westergard mentioned new additions to our library and asked to have overdue books returned. She has one copy of Carol Fenster's *Wheat Free Recipes and Menues* available for \$10.00.

## **Program**

### **Member Discussion and Review of CSA Conference in Green Bay Oct 5-8**

**Mary Lee Rossmassler** spoke about the conference in general, how great it was to eat everything available without being concerned about the safety of the food, all the information on Celiac Disease available, and how all participants were interested in sharing stories on the same topic, and how no one felt different. She felt that the Conference committee had done a good job of providing a book of slides by all the presenters and a sturdy tote for each participant.

**Barb Hennings** explained that Thursday, October 5 was Dietitians Day with about 60 dietitians and health care professionals participating. The purpose was to assist dietitians in helping the newly diagnosed celiacs with setting up their kitchens to be GF, in dealing with the challenges of eating out and in coping with the diet in general.

The importance of having enough fiber in the GF diet was emphasized at Dietitian's Day and throughout the conference. Pea hull fiber was introduced as an excellent source of fiber. Also information was given on how to search out hidden sources of gluten and how to read labels. It was mentioned that it can take considerable time to heal depending on the extent of damage. More than one appointment with the dietitian is appropriate.

**Nancy Spencer** reported on the speakers.

Dr. Henry Bone from the Michigan Bone Clinic spoke on the effects of Celiac Disease on Bone Metabolism including the malabsorption of Vitamin D, calcium and other supplements and medications. For the absorption of calcium we need a healed intestine, sunlight, calcium supplements 3 times daily with meals and lots of water and Vitamin D (1.25 dihydroxyvitamin), and milk. Wait to add drugs until you assess the response to the above.

Dr. Frank Hamilton from NIH gave some history of what the NIH has done beginning with their Celiac Awareness Study in 1992 through the 2004 Consensus Conference which come out with several recommendations for the future. They recommended the tTG and biopsies containing several samples obtained from the second portion of the duodenum. This is not a rare disease but it will take 10 to 15 years to get physicians educated about Celiac Disease. For children under 5 years of age the tests are not reliable. To keep abreast of current information go to [www.NIH.gov](http://www.NIH.gov)

Dr. Joseph Murray from Mayo Clinic said 14 to 20% of the general population has some type of food allergy. He stated that there is a need for better testing tools. Three times more people are being diagnoses with CD today. It is important to be tested before you stop eating gluten! 1/3 of people diagnosed are over 65. CD can present at any age and to either sex.

CSA is still questioning the safety of eating oats. There was a hand out available on oats for Celiacs and there are now three companies in the US and Canada producing noncontaminated oats. Using oat flour will make a moist cake that will rise higher than the traditional rice flour cakes and provide more fiber. But they cautioned to go slowly when introducing oats in your diet.

### **Eating Out and Traveling GF**

Recommended web site [www.glutenfreerestaurants.com](http://www.glutenfreerestaurants.com)

Make sure to check sauces, flour dusting of meats, stocks and broth, marinades, garnishes, pasta, dumplings, cross contamination of cooking oil, fryers, boiling water, prep boards and utensils.

Dr. Gail Pyle from Stanford talked about enzyme therapy saying that there is nothing on the market at this point and it will likely be 5 to 10 years or longer before we see something in this area.

Dr David Sands from Montana spoke about Montana flour and said they are also working on producing flours from other grasses to provide higher nutrient value in addition to fiber. He addressed the problem of obesity in this country.

Maria Brown from Rush Medical Center in Chicago emphasized the importance of daily exercise to avoid osteoporosis. She said it is important to remember that like everyone else Celiacs are still at risk for heart disease so we should keep our cholesterol under 200 and know the difference between good and bad cholesterol. We should watch our blood pressure, making sure it is under 130/80, and eat plenty of fiber and drink plenty of fluids. She also advised us to cut back on sugar and caffeine, get sufficient sleep, and join a support group!

If iron deficient, do not drink tea with milk.

She recommended the following tests for monitoring your health for at least the first two years after diagnosis:

- complete blood count
- metabolic panel which includes calcium level
- bone density
- thyroid level - TSH
- B12 level
- satuated ferritin and ferritan level
- folic acid test

There is a dipstick available to test for gluten but it is costly at this point and only used commercially. It needs to be priced so it is available to the average consumer.

**Aaron and Charlene Avery** talked about the excellent food that was provided through out the Conference. Hopefully Natural Feast Pies will come to our area soon. Montana is making a delicious stick pretzel that we hope to see soon. Cream Hill Estates and two companies in Wyoming and Montana are selling noncontaminated oats. Foodtech is making products good for travel. Just add water, mix and microwave. Woodchuck Draft Cider and New Grist Beer were mentioned. And Expandex is recommended for better baked goods.

**Bob Coffin** mentioned that CSA is by far the largest Celiac organization but they are losing membership, possibly because they are unwilling to join the alliance of Celiac organizations to speak with one voice for the Celiac community.

**Dan Moodie** talked about how exciting it was to be at this Conference in Green Bay and gave some of the statistics about Lambeau Field and the Packers.

The CSA conference will be in Tuscan next year.

Molly's Bakery in Pewaukee was mentioned. Kathy recommended their Danish's. All of their products are GF. They are open Wednesday through Saturday.

The meeting ended with the drawing for door prizes.

## **In The News...**

### **POTENTIAL LINK BETWEEN CELIAC DISEASE AND COGNITIVE DECLINE**

Clan Thompson Celiac Newsletter, Issue #89 September 21, 2006  
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Newswise — Mayo Clinic researchers have uncovered a new link between celiac disease, a digestive condition triggered by consumption of gluten, and dementia or other forms of cognitive decline. The investigators' case series analysis -- an examination of medical histories of a group of patients with a common problem -- of 13 patients will be published in the October issue of Archives of Neurology.

"There has been very little known about this connection between celiac disease and cognitive decline until now," says Keith Josephs, M.D., Mayo Clinic neurologist and study investigator. "This is the largest case series to date of patients demonstrating cognitive decline within two years of the onset of celiac disease symptom onset or worsening."

Says Joseph Murray, M.D., Mayo Clinic gastroenterologist and study investigator, "There has been a fair amount written before about celiac disease and neurological issues like peripheral neuropathy (nerve problems causing numbness or pain) or balance problems, but this degree of brain problem -- the cognitive decline we've found here -- has not been recognized before. I was not expecting there would be so many celiac disease patients with cognitive decline."

The next step in the research will be to investigate the measure and nature of the connection between the two conditions. "It's possible it's a chance connection, but given the temporal link between the celiac symptoms starting or worsening and the cognitive decline within a two-year time span, especially the simultaneous occurrence in five patients, this is unlikely a chance connection," says Dr. Josephs. "Also, these patients are relatively young to have dementia."

Theories to explain the connection between celiac disease and cognitive decline include the following, according to Dr. Murray:

- Nutritional deficiency
- Inflammatory cytokines -- chemical messengers of inflammation that could contribute to problems in the brain
- An immune attack on the brain that may occur in some patients with celiac disease

The cognitive decline that occurred in three of the celiac disease patients studied, according to Dr. Josephs, is relatively unique in its reversal in two of the patients and stabilization in one patient. Typically, cognitive decline continues to worsen, he says. "This is key that we may have discovered a reversible form of cognitive impairment," he says.

William Hu, M.D., Ph.D., Mayo Clinic neurology resident and study investigator, says that the reversal or stabilization of the cognitive symptoms in some patients when they underwent gluten withdrawal also argues against chance as an explanation of the link between celiac disease and cognitive decline.

Currently, the investigators do not know which celiac disease patients are at risk for cognitive decline; this deserves future investigation, says Dr. Hu.

Dr. Murray suggests that recognizing and treating celiac disease early will likely prevent most consequences of the disease, including symptoms in the gut or the brain. For celiac disease patients who have already developed cognitive decline, closely following a gluten-free diet may result in some symptom improvement, he says. For those with cognitive decline without a confirmed diagnosis of celiac disease, he does not recommend a gluten-free diet, however.

Physicians can play an important role in keeping alert to a potential celiac disease and cognitive decline connection, says Dr. Hu. "For patients who come in with atypical forms of dementia, we need to consider checking for celiac disease, especially if the patients have diarrhea, weight loss or a younger age of onset -- under age 70," he says.

To conduct this case series analysis, the researchers identified 13 Mayo Clinic patients with documented cognitive impairment within two years of onset of symptoms or severe exacerbation of adult celiac disease. All celiac disease had been confirmed by small-bowel biopsy, and any patients for whom an alternate cause of cognitive decline could be identified were excluded from the analysis. Patients included five women and eight men, with a median onset of cognitive decline at age 64 that coincided with onset or worsening of symptoms of diarrhea, the presence of excess fat in the stools and abdominal cramping in five patients. The most common reasons for seeking medical help were amnesia, confusion and personality changes. The average score on the Short Test of Mental Status among the 13 patients was 28 out of 38 possible total, indicating moderate cognitive impairment. Ten patients experienced loss of coordination and four experienced symptoms of peripheral neuropathy. Four patients demonstrated deficiency in folate, vitamin B-12, vitamin E or a combination of these deficiencies, although supplementation did not improve the patients' cognitive decline. Three patients' cognitive decline either improved or stabilized when they completely withdrew from gluten consumption. A brain autopsy or biopsy was completed in five patients, and there was no evidence of Alzheimer's disease or any other well-known causes for dementia.

Celiac disease occurs in 1 out of 133 people and predominantly affects Caucasians, according to Dr. Murray. Symptoms can include intermittent diarrhea, abdominal pain and bloating, or no gastrointestinal symptoms at all. It can also manifest in weight loss, fatigue, anemia, general

weakness, foul-smelling or grayish stools that may be fatty or oily, osteoporosis or stunted growth (in children only). The condition may also cause symptoms far outside of the gut. Nine out of 10 times, the disease is not discovered due to the vague nature of the symptoms, according to Dr. Murray. The treatment for celiac disease is a gluten-free diet. For further information on celiac disease, see <http://www.mayoclinic.com/health/celiac-disease/DS00319>.

## Oats in the Gluten Free Diet

Practical Gastroenterology, Sept 2006

Whether or not oats can safely be included in a GFC has been a subject of debate over the past 50 years. Historically, oats were categorically excluded from the diet because it was thought that avenin (the storage protein found in oats) was also toxic to gluten intolerant individuals. However, recent research in Europe and the U.S. has revealed that when consumed in moderation, oats are well-tolerated by most children and adults with CD and do not contribute to abdominal symptoms, serological or mucosal relapse, nor prevent small bowel healing. The majority of these studies used oats that were specially processed to ensure that they were free from cross-contamination with gluten-containing grains. It should be noted that the regular oats that are commercially available to consumers are frequently contaminated with wheat or barley. A study by Thompson in the United States and another by Storsrud in Sweden tested multiple commercially available oat products and found varying levels of gluten contamination. Because uncontaminated oats have not been widely available, most celiac support organizations did not recommend oats in the past as part of a gluten free diet. However, "pure, uncontaminated" oats have recently become available from several companies in the US and Canada. These companies process oats in dedicated facilities and test their oats for purity. Many celiac support organizations, research centers, and health professionals have revised, or are revising, their recommendations to allow moderate amounts of pure, uncontaminated oats in the gluten free diet.

The following are manufacturers that provide pure, uncontaminated oats and oat products:

Manufacturer (Web site, Contact info)	Notes
<b>Cream Hill Estates</b> (Canada) <a href="http://www.creamhillestates.com">www.creamhillestates.com</a> 866-727-3628 or 514-363-2066	These oats undergo a three step purity process Oat products from Cream Hill Estates are available under "Lara's"
<b>Gluten-Free Oats</b> (U.S.) <a href="mailto:sales@glutenfreeoats.com">sales@glutenfreeoats.com</a> 307-754-2058	Specific procedures are used to ensure purity Oat products test under 10 ppm
<b>Gifts of Nature</b> (U.S.) <a href="http://www.giftsofnature.net">www.giftsofnature.net</a> 888-275-0003	Oats undergo 3 <sup>rd</sup> party inspection and testing by Gluten Free Certification Organization visit <a href="http://www.gfco.org">www.gfco.org</a> for more information.
<b>Farm Pure Foods</b> (Canada) <a href="http://www.farmpure.com">www.farmpure.com</a> 306-791-3770	Projected availability late 2006

## The Cook's Corner...

Beginning with Halloween and ending with New Year's Eve, we are about to embark on two months of partying, celebrating, and yes... eating. Eating all kinds of delectable, seasonal treats. Below is a pudding recipe that is perfect for autumn and for your Thanksgiving table. Find more quick and easy recipes like this in the *Wheat-free Gluten-free Cookbook for Kids and Busy Adults* at [www.gfbooks.homestead.com](http://www.gfbooks.homestead.com).

### **PUMPKIN STREUSEL PUDDING**

by Connie Sarros, Clan Thompson

#### **Pudding Ingredients**

1 can (15 oz.) pumpkin  
1 can (14 oz.) sweetened condensed milk  
1 egg  
1 tsp. cinnamon  
1/2 tsp. nutmeg  
1/4 tsp. ground cloves  
1/2 tsp. ginger  
1/2 tsp. salt

#### **Topping Ingredients**

1/4 cup brown sugar  
1/4 tsp. cinnamon  
2 Tbsp. GF flour mixture  
2 Tbsp. cold butter  
3/4 cup chopped walnuts

Preheat oven to 425 degrees. In a large bowl, whisk together all of the pudding ingredients. Pour mixture into a greased 9-inch pie plate. Bake for 15 minutes, then remove from oven. While pudding is baking, mix the brown sugar and cinnamon with a fork. With a fork, blend in the flour mixture, then the butter until the mixture is crumbly. Stir in the walnuts. Sprinkle topping over the hot pudding. Reduce oven temperature to 350 degrees and bake pudding for 40 minutes or until a knife inserted in center comes out clean. Cool pudding completely, then refrigerate for 3 hours or more before serving to set.

### **CHOCOLATE CHIP COOKIES**

Modified from the Nestlé Toll House Cookie Recipe

Submitted by Aaron & Charlene Avery

1 1/8 c. brown or white rice flour	3/4 c. granulated sugar
1 1/8 c. soy flour	3/4 c. firmly packed brown sugar
1 1/2 - 2 tsp. baking soda	2 tsp. GF vanilla extract/flavoring
1 tsp. salt	2 eggs
1 c. (2 sticks) butter, softened	12 oz. (2 cups) chocolate chips

Preheat oven to 375° F. In small bowl, combine flour, baking soda and salt; set aside. In large mixer bowl, beat butter, sugar, brown sugar and vanilla until creamy. Beat in eggs. Gradually beat in flour mixture. Stir in chocolate chips. Drop by rounded measuring tablespoonfuls onto ungreased cookie sheets. Bake 9-11 minutes until edges are golden brown. Makes about 3 dozen 2 1/2-inch cookies.