

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 Meeting: Saturday, March 10

10-12 pm

Prairie Park Apartments—6530 Schroeder Rd.

PIZZA PARTY Prepared by Delitalia

Please RSVP to Nancy Spencer by Thursday, March 8th

Phone: 274-7121

MAGIC MEETING MINUTES

February 10, 2006

Attendance: Suzy Ardelt, Amelia Barczi, Leigh Barczi, Kathy Borner, Teresa Brausen, Penny Coffin, Bob Coffin, Nancy Duerst, Barb Hennings, Aimee Hennings, Sean Lamb, Ralph Musin, Charlotte Musin, Dan Moodie, Tammy Moodie, Bev Nelson, Kay Newton, Tara Nolley, Claire Poppe, Lynnette Reinfeldt, Betty Roberts, Jane Ross, Mary Lee Rossmassler, Darlene Schulenberg, Nancy Spencer, Walt Thieszen, Karen Thieszen, Joy Thompson, Judy Vinge, Marge Westergard, Julie Winding, Lynn Wood.

Reports

President:

There are free samples of Heartland's bean pasta available today. The Christmas cookie recipes are also available during the meeting today.

Delitalia pizza will be served during the meeting in March. Please let Nancy know if you have any allergies other than gluten, so that they can be accommodated.

Treasurer's Report:

Bob reported on the current status of the MAGIC bank accounts.

The May dinner out will be at Fife's Corner Bistro. There will be a fixed cost of \$18 per meal, and MAGIC will pay the remaining cost. Drinks will be available at a cash bar.

The CSA Annual Conference will be held in Green Bay in October. The facilities look very good. They have adequate resources, but might appreciate our assistance with registration and clean up. If you are interested in helping, please contact Bob Coffin.

Secretary:

There were no corrections to the minutes. We are in the process of looking for a secretary for next year. Please contact Nancy if you are interested. There is a possibility of sharing the position.

Librarian:

MAGIC will be purchasing a new edition of the Guide through the Medicine Cabinet. MAGIC may also purchase a copy of the GF cookbook being sold by the Charlottesville, NC chapter. Profits from their sales go to support the Celiac research program at the University of Chicago. If you would like a copy of this cookbook visit their website at www.Charlotte-celiac-connection.com .

Marge will be disposing of some of the product guides that are old.

New Member:

Clair Poppe has joined us this month. She has been diagnosed for some time, but just moved to the Madison area.

NEW BUSINESS

A motion was made to donate \$100 to the Prairie Park Apartments in appreciation for use of their meeting room. The motion was seconded and approved.

Upcoming meetings are scheduled on the second Saturday of each month. The May dinner out will be held during the week. The activities will be:

March – Pizza from Delitalia and a pasta making demonstration

April – Char from The Living Well Healthy Gourmet, and a panel discussion on kitchen organization

May – Dinner out at Fife's Corner Bistro.

June – TBD

July – Picnic at Nancy Spencer's house

August – Officer's meeting

ANNOUNCEMENTS

Cream Hiss Estates is a startup Canadian company that will be producing gluten free oats. They will be using dedicated fields and equipment. It was suggested that we could buy in bulk and then share among the group members. For more information on this company please go to their web site www.creamhillestates.com At least two other companies are being started in the US to provide gluten free oats. One is based out of Wyoming.

Gut Reactions, a documentary on Celiac disease, can be downloaded from the website <http://audible.com>. Search by title to find the video.

Carol Fenster has a web site with culinary tips. This month the tips are on getting bread to rise. www.carolfenster.com.

Food Fight does not seem to be progressing well in its attempts to adapt its menu to gluten free dinners. If you are interested in helping, please contact Nancy Spencer.

Breads from Anna's Pumpkin and Banana bread are very good.

Grandma Ferdon's cocktail rye bread is very good. It is available at The Living Well Healthy Gourmet.

Vin Santo's Italian restaurant will accommodate gluten free dinners. Call ahead for a reservation and let them know that you require gluten free food. They have rice pasta on hand and can serve it with almost any of their sauces. The restaurant is located on Hubbard Ave in Middleton. For more information, call them at 608-836-1880 or look at their web site, www.vinsanto.us.

Whole Foods has installed a hot bar. The food is labeled with ingredients and allergens.

The change in selection at Copp's and Pick & Save is due to a change in distributors and will be permanent.

Rice Crunch-Ums are available at Whole Foods.

PROGRAM

Gluten Free Pasta

This month's program allowed everyone to sample a variety of gluten free pastas. Recipes for the pasta dishes will be included in the newsletter.

Tex-Mex Pasta Salad

(prepared by Barb Hennings, using Pastariso Macaroni)

10 oz. pasta, cooked, drained & rinsed in cold water	1 c cubed cooked chicken, optional
14.5 oz. can black beans, rinsed & drained	1 c medium spiced salsa
1 c frozen corn kernels, thawed	½ c plain yogurt or low-fat sour cream
1 red bell pepper, seeded & chopped	3 T g.f. mayonnaise
3 green onions, chopped	2 t ground cumin
	Salt & pepper to taste

Combine drained pasta, black beans, corn, pepper, green onion, and chicken, if used. In a separate bowl, combine salsa, yogurt or sour cream, mayonnaise, cumin, salt & pepper. Pour over pasta mixture and stir to blend. Refrigerate until ready to serve. Serves 8.

Baked Macaroni w/ Ground Beef

(prepared by Nancy Spencer using Heartland macaroni)

1 lb ground chuck	¾ t basil
½ c chopped onion	¾ t oregano
1 green pepper chopped	½ t garlic powder or chopped garlic
1 can diced tomatoes, un-drained	½ t salt
1 8 oz. tomato sauce	¼ t pepper
	8 oz. cooked macaroni
2 c (8 oz.) shredded mozzarella cheese	

Saute meat, onion, and green pepper in large skillet until onion is tender and beef browned. Drain fat, add tomatoes, tomato sauce, basil, oregano, garlic, salt & pepper. Stir well. Stir in macaroni and 1 c cheese, put into a 2 ½ qt. casserole. Top with 1 c of cheese. Bake at 350 degrees for 25-30 minutes or until hot and bubbly. Serves 6.

Cold Spaghetti Salad

(Prepared by Leigh Barczi using R& P's Fresh Pasta—Wheat Free-Gluten Free Linguini)

8 oz. cooked spaghetti or vermicelli, drained
1 med. tomato diced
1 cucumber, diced
1 med. green pepper, diced
½ c Parmesan cheese
½ jar McCormick's Salad Supreme seasoning
1 bottle Italian dressing

Combine tomato, cucumber, green pepper in a large bowl. Add McCormick's Salad Supreme seasoning, Italian dressing and parmesan cheese. Add Spaghetti, mix well. Chill 4 hours or overnight. Serve cold.

Dreamy Spaghetti Casserole

(Prepared by Leigh Barczi using R & P's Fresh Pasta—Wheat Free-Gluten Free Linguini)

Serves 6-8

1 8 oz pkg thin spaghetti	1 c cottage cheese
2 lbs ground beef	1 8 oz pkg cream cheese, softened
Salt & pepper to taste	½ c sour cream
2 8 oz cans tomato sauce	1/3 c minced green onions
¼ c minced green peppers	

Cook spaghetti and drain. Brown ground beef, drain, add tomato sauce, salt and pepper. Remove from heat. Combine cottage cheese, cream cheese, sour cream, green onions, green pepper. Mix well. In 9" x 13" pan, spread the cooked spaghetti and cover with cheese mixture. Spread tomato meat sauce over top.

Chill for at least 1 hour. Remove from refrigerator 20 minutes before baking. Bake at 350 degrees for 45 minutes to 1 hour.

Recipe may be assembled the day before and stored in refrigerator.

Optional: Cook meat with clove of garlic

LAZY DAY LASAGNA (microwave recipe)

(from Jo Ann Willoughby/prepared by Kathy Borner)

1 ½ lb. ground beef or venison	1/4 teaspoon garlic powder
1 (14 ½ oz.) can tomatoes, un-drained	2 cups cottage cheese
1 (6 oz.) can tomato paste	1/4 cup Parmesan cheese
1 (4 oz.) can tomato sauce	1 egg
3/4 cup water	2 to 3 Tablespoons parsley flakes
1 teaspoon salt	lasagna noodles, uncooked (used EnerG)
1 teaspoon dried oregano leaves	2 cups mozzarella cheese

Brown ground beef/venison in microwave 5-6 minutes. Drain. Add tomatoes, tomato paste, tomato sauce, water, salt, oregano leaves and garlic powder. Stir. Microwave at FULL POWER 4 to 5 minutes; until boils. In separate bowl, mix cottage cheese, Parmesan cheese, egg and parsley flakes. In 9 x 13 pan, layer as follows: 1½ cups tomato sauce 4-4½ uncooked noodles, ½ of cottage cheese mixture; ½ of mozzarella cheese, ½ of remaining meat sauce, 4-4½ uncooked noodles, remaining cottage cheese mixture, remaining mozzarella and remaining meat sauce. Cover with plastic wrap. Microwave 15 minutes at FULL POWER. Turn pan. Microwave at MEDIUM (50% POWER) for 15-20 minutes. Remove wrap. Sprinkle with Parmesan cheese; microwave 2 minutes until melted. Let stand 10 minutes before cutting into squares. Makes 9 servings.

If pressed for time, use your favorite GF spaghetti sauce (32 oz.). Also, this may be covered and cooked in oven, 350 for 1 hour. Be sure and cover. Check before taking from oven. Then add the Parmesan cheese. Let rest before cutting. May be made ahead of time.

Kathy Borner's NOTE: I've not made the microwave version. Have only made the oven baked lasagna using 1 lb. ground beef.

Samples of gluten free, New Grist Beer were also available. This beer is made by the Lake Front Brewery in Milwaukee, using Sorghum. The beer can be purchased at Whole Foods. The cost is \$7.49 for 6 bottles.

Calories:	189.22 cal/12 fl. oz.	Total Fat:	0
Total Carbs:	19.03 g/12 fl. oz.	4 Weight Watchers Pts (per Mary Lee's calculations)	
Alcohol by Volume:	5.75%		
Alcohol by Weight:	4.49%		

Focaccia

(Carol Fenster's: Wheat-Free Recipes and Menus)

1 ½ t dry yeast	2 large
¾ c warm water	Eggs
1 t sugar	2 T olive oil
1 c brown rice flour	½ t cider vinegar
¼ c potato starch flour	1 T cornmeal
¼ c tapioca flour	<u>Topping</u>
1 ½ t xanthan gum	1 t Italian seasoning
1 t unflavored gelatin	¼ t salt
1 t dried rosemary	1 T olive oil
½ t onion powder	Cooking spray
½ t salt	

Dissolve sugar in warm water. Sprinkle yeast into water and stir until yeast dissolved. Set aside to foam, about 5 minutes.

Combine flours, xanthan gum, gelatin powder, rosemary, onion powder, and salt in a small mixer bowl. Whisk eggs, olive oil, and vinegar into the dissolved yeast and stir the mixture into the flour. Beat dough with mixer for 2 minutes using a spatula to keep stirring down the dough on the mixer beaters. The dough will be soft and sticky.

Transfer dough to 11 x 7 inch nonstick pan coated with cooking spray and cornmeal. Poke with fork.

Sprinkle with Italian seasoning, salt and olive oil. Cover with aluminum foil and let rise in warm place for 30 minutes. Preheat oven to 400. Bake for 15 minutes.

Alternate Toppings:

Herb: ½ t rosemary, ½ t dried sage, ½ t thyme, ¼ t black pepper and 2 T Parmesan cheese

Sun-dried tomato and olive: ½ c chopped sun-dried tomatoes in oil, ¼ c chopped black olives, and ¼ c chopped onion sautéed until translucent in 1 t olive oil.

Pesto: Puree in food processor just until smooth—1 C fresh basil leaves, 1 garlic clove, ½ c pine nuts. Slowly drizzle in ¼ c olive oil through the feed tube. Add ¼ C Parmesan cheese and a dash of freshly ground pepper.

Travel Opportunities

Celiac Ranch Family Vacation

Two Bars Seven Ranch, Wyoming

Contact the ranch to find out 2006 Celiac week date, new date hasn't been posted yet

www.twobarssevenranch.com . For more information, email schaffer@vcn.com (307) 742-6072.

TPI Travel Celiac Vacations

See website for gluten free vacation listings and dates: www.tpiworldwide.com/sidneyclaretpi For more information, call Sidney Oare (604) 741-7823 or email: sclare@tpi.ca

Bob & Ruth's Travel Club

www.bobandruths.com or (410) 486-0292

Disney World GF Vacation

Disney can cater to many dietary restrictions. All sit down restaurants can handle g.f. meals. Make reservations ahead of time www.disneyworld.com Priority seating restaurant reservations (407) 939-3463.

McDonald's In the News...Are McDonald's French Fries Gluten Free or Not?

McDonald's Media Statement - 02/20/2006

McDonald's Fries are "Gluten and Allergen Free," According to Expert

"We understand the concern that individuals in the Celiac community and others with food allergies may have regarding foods that meet their individual needs. That is why we are eager to provide them with the most factual information we can.

"Scientific evaluation by one of the world's leading experts on gluten sensitivity and allergenicity, Dr. Steven Taylor of the Food Allergy Research and Resource Program of the University of Nebraska, has confirmed again that our fries are gluten free and allergen free.

"Based on this analysis, we believe the lawsuits filed are without legal merit."

Jack Daly, Senior Vice President, McDonald's

The following is a comment from Cynthia Kupper, a registered dietitian, Executive Director of the Gluten Intolerance Group and has worked with Outback (along with other companies) to develop gf menus.

"This is a case of McDonalds following the letter of the law, but without the FDA having the exceptions in place - it is causing confusion. This is a perfectly safe ingredient. People should not be blasting McDonald's for doing what they are told they have to do, but instead forcing the issue of the pan fry to file an exemption for their product. (notice that thus far the FDA has not made a ruling on any exemptions filed...that doesn't help)

Of or course the pan fry company could certify their product. This would mean they are regularly testing the product to show it's purity. The law is good, but the cart was put before the horse."

Cynthia Kupper, RD, CD
Executive Director
Gluten Intolerance Group of NA
15110 10 Ave SW, Ste A
Seattle WA 98166-1820
206-246-6652; F: 206-246-6531

The following is from Lani Thompson of ClanThompson...

Date: Tue, 7 Feb 2006
From: Lani K. Thompson celiac@CLANTHOMPSON.COM
Subject: McDonald's French Fries

"I just got off the phone with McDonald's. According to them, the French Fries haven't been changed and are still the same "recipe" that was in use last year. However, one of the processing agents (called par fry) contains wheat. The manufacturer of par fry told McDonald's that the wheat was removed from the par fry prior to use. However, McDonald's states that the new food regulations require them to state that the French Fries (or anything else processed with par fry) contains wheat if wheat was ever an ingredient of the processing agent - and even if it was "removed."

Best wishes,
Lani K. Thompson
www.clanthompson.com

Eating Out

Even though the following restaurants have gluten-free menus on their websites, don't assume the wait and cook staff are familiar with it or gluten-free food prep and handling. Please exercise caution and voice your needs clearly and carefully. Some of these restaurants are not in the Madison area, however may be useful when traveling.

Carrabba's Italian Grill, www.carrabbas.com/menu.asp

Click on Gluten-Free Menu.

P.F. Chang's, www.pfchan2s.com/cuisinelmenLLSpec.jsp

Outback Steakhouse, www.outbackcom/ourmenu/index.asp

Click on Gluten Free Menu.

Pei Wei, www.peiwei.com/glutenfreeMenu.jsp

Subway, <http://subway.com/subwayrootlMenuNutrition/Nutrition/pdf/AllergenChartpdf>

Wendy's, www.wendys.com/food/U5.J1utritiorLtopics.jsp#gluten

Bonefish Grill, www.Bonefishgrill.com/tastybites.asp

Click on Download our Gluten-Free Menu.

McDonald's, www.mcdonalds.com/app/controller.nutrition.categories.gluten.index.html

Chick-fil-A <http://chick-fil-a.com/gluten.asp>

Dairy Queen, www.dairyqueen.com/en-US/Menus+and+Nutrition/Special+Dietary+Needs/default.htm

Click on Gluten-Free Products.

Burger King, www.bkcom/Food/Nutrition/NutritionInfo/index.aspx

Click on Allergens link

Steak & Shake.

www.steaknshake.com/nutritionalinfo/index.asp?p=10

Don Pablo's, www.donpablos.com/fooddrinklp_fooddrinkcfm Click on Nutritional Information. PDF has GF menu on last page.

Arby's, www.arbys.com/nutrition/ClickonArby.s U.S. Nutrition Information link Allergen and Ingredient info is on page 5 of PDF.

Ted's Montana Grill,

www.tedsmontanagrill.com/nutriti04luterL..free.html

Yum Brand Restaurants. Click on Food Allergens and Sensitivities link at each of the following websites.

Taco Bell, www.yum.com/nutrition/allergen/allergenLtb.asp

A&W Restaurants, www.yum.com/nutrition/menu.asp?brandID.-Abbr=4.-AW

KFC, www.kfc.com/kitchen/nutrition.htm or www.yum.com/nutrition/menu.asp?brandID.-Abbr=2J<FC

Pizza Hut, www.yum.com/nutrition/menu.asp?brandID.-Abbr=1PH

Long John Silvers www.yum.com/nutrition/menu.asp?brandID.-Abbr=3JJS

MANAGING THE PATIENT WITH CELIAC DISEASE

By Cynthia S. Rudert, M.D., FAC.P., At/anta

Presented at GIG Annual Education Celiac Conf, June 2005

Overview

- **Explanation.** Celiac Disease is the most common inherited autoimmune disorder in America. About one in every 133 individuals, based on recent data published by the University of Maryland, will be a celiac. Dr. Alessio Fasano states that if you take all the people with ulcerative colitis, Crohn's disease and Cystic Fibrosis and double that number, those are the estimated amount of individuals with Celiac Disease. Therefore, you are looking at over one million celiacs in the United States.
- **Special dietary management for Celiac Disease.** This is a disease that has specific dietary management. The treatment is strict adherence to a gluten-free diet.
- **Follow-up for possible complications and monitoring after diagnosis.** There has been an explosion in the amount of research publications about CD within the past two years. Physicians are gradually going to become more aware on how to diagnose CD and treat celiacs. According to a publication by Dr. Peter Green, his studies showed that a celiac patient might take up to 11 years before correct diagnosis.

Explanation

Cause: Celiac Disease is an immune reaction to the presence of gluten in the small intestine. It is partially genetic. In identical twins, there is a 70% concordance; i.e., if one of the twins has CD, there is a 70% chance that the other will also develop CD. Ninety-five (95%) percent of celiacs have the HLA DQ2 haplotype; however, this haplotype is present in 33% of Americans. Five (5%) percent of celiacs are HLA DQ8.

Intestinal Function

Vitamins and minerals in food are absorbed in the small intestine. The human body needs 72 vitamins, minerals and amino acids for full function. When the small intestine is inflamed, nutrient absorption is impaired. Therefore, it is very important that the CD patient come back for a follow-up visit to check the CBC (Complete Blood Count), and a complete metabolic panel (blood sugar, liver tests, kidney test, cholesterol). These tests can be ordered by any primary care physician. Also, as part of Dr. Rudert's evaluation, she orders an RBC folate level to check the amount of folic acid and B-12 level. It is thought in some studies in Scandinavia that the birth defect spina bifida in babies is related to deficiency of folic acid in mothers and possible unknown CD. Damage in the small intestine can cause severe fatigue, depression, etc. The small intestine can be healed by strict adherence to a gluten-free diet. Other tests (blood and/or x-rays) may need to be ordered and each patient may have unique needs to be addressed in follow-up.

Dietary Management

- The doctor and dietitian should give the celiac or DH patient hope of recovery. Celiac Disease is not a devastating diagnosis. You do not need to take medication. and there's no chemotherapy involved (unless the rare patient has refractory sprue) - just eating good appropriate food.
- There is a learning curve; assimilation of all the details of the GF diet takes time. Join both national and local support groups. Go to a national conference.
- There are no dangerous medications involved, but you need to check the gluten status of all your medications and supplements. Gluten and lactose may be used as carriers in some medications. Some sites for investigating medicines are: www.stokesrx.com or www.clanthompson.com or www.glutenfreedrugs.com (by Steve Plogsted, who has a Ph.D.

in pharmacology and runs the website -the only free drug information site).

- The gluten-free diet is challenging but is achievable. Thank goodness for the amount of good information available on the Internet and tram support groups nationwide. Be selective and remain informed - not all information is correct.
- Keep a folder up to date with your tests, dates of tests, X-rays, etc. Develop a page of your medical history to make it easier for your physician to see the whole picture. If you're following a GF diet, after 6 months to a year your celiac blood tests are going to be normal. You should repeat celiac antibody tests yearly or sooner after diagnosis depending on your symptoms. Minor dietary indiscretion will not be picked up.
- In addition to the panel of blood tests, Dr. Rudert always gets a serum IgA level. Serum IgA helps to fight infection. With low levels of serum IgA you could be prone to repeated GI infections. One that is pretty common is giardia, a microscopic parasite. It is very common in the summer and it isn't killed by chlorine. If you happen to have had giardia, that fact raises suspicion that you might have low levels of IgA. Low levels of IgA can also be seen with sinus infections. Ten percent of celiacs have low IgA levels. Knowing the IgA level is important to interpret the results of the celiac antibody tests. If you have low levels of serum IgA, your blood tests (if you are newly being screened and not yet on a GF diet) could be falsely normal. If you're concerned about a family member, be advised that a negative blood test does not rule out 100%, that you don't have CD. It is thought that 10 to 15% of people may be "seronegative".
- The biggest challenge is to get family members screened. A first-degree relative has about a 1 in 22 chance of getting CD. Second degree relatives are about 1 in 39. The good news is most probably do not have it CD, however, can run in families. One family member might have CD and the other present with Dermatitis Herpetiformis, which is more often seen in men.
- You are not alone. According to new research heard at the recent 2002 International Celiac Symposium in Paris, celiacs are in one (1) percent of the worldwide population. especially where there is a high consumption of wheat.

Roles - Cooperative Efforts

The Patient

- Gaining expertise in doing the gluten-free diet should be a team effort with the patient, physician, dietitian, family, pharmacist (if possible) and support groups.
- You should apprise all your professional contacts with your CD reports, including your OB/GYN, cardiologist, endocrinologist, etc. They need to know about your whole medical history and the complications that might result.
- The patient needs to understand the importance of the GF diet to gaining overall health for life.
- The more that person knows about food issues, the more successful he/she will be.
- Celiacs need to recognize the stages of grief in celiacs - for example, denial, anger, overcompensation, and finally acceptance with energy directed toward doing the best GF diet you can.
 - Some patients may need to keep a food diary so that a knowledgeable doctor or dietitian can analyze and see if there are problems with inadvertent gluten (accidental) consumption.
 - It's just a fact that there will be temptation to cheat in some patients. Our whole world's social activities revolve around food. Seek out support when you need it

The Dietitian

- . Expert dietary advice is critical to a newly diagnosed celiac. Cynthia Rudert gives dietary consultations to her new celiac patients. More and more dietitians are becoming knowledgeable regarding the diet
- . The dietitian must have up-to-date information, however; to give the best advice.
- . The dietitian should review current eating habits (diet diary) and suggest comparable GF substitutions.
- . The dietitian should tailor his/her program to the individual patient's age and education level.
- . The dietitian should enlist family members in terms of education and support for the celiac.
- . The dietitian should give the patient a good list of resources for national and local support groups.
- . The dietitian should follow up with the celiac patient and monitor his/her progress.

The doctor

The gastroenterologist should make the diagnosis by doing the blood antibody test, then the gold standard biopsies (multiple tissue samples) if the blood work comes back positive. Dr. Rudert commented that the average patient in her practice has probably seen a minimum of 6 to 12 physicians prior to correct diagnosis. She sees that number dropping as more physicians are becoming better educated.

- . Most gastroenterologists will diagnose the CD and then just say don't eat wheat and come back in a year. There's so much more involved in a GF Diet and these folks need more help.
- . Dr. Rudert takes at least 6 to 8 tissue samples with the endoscope instrument for analyzation.
- . The doctor should explain fully what Celiac Disease is, and make the patient comfortable with the diagnosis. The doctor should identify the complications. Generally CD patients start feeling better from weeks, to months, to the rare patient that might take a year or longer. Good results on a GF diet depend on the length of time you've been symptomatic before the diagnosis was made.

Triggers

- . You inherit the tendency for the autoimmune system to malfunction. A trigger; however; is needed to activate the gene if you carry the genes (HLA DQ2 & DQ8, etc.). Triggers may include stress of pregnancy, overuse of antibiotics, and general stresses of life (death in family, divorce, etc.). Put your stresses into your medical history. Dr. Rudert likes to understand the start of symptoms and if possible the trigger to see how long the patient has been symptomatic. Children tend to bounce back faster than adults.
- . A rare percentage of adult celiacs can have refractory celiac disease. Despite a good GF diet, the patient does not improve. (This rarely, if ever; occurs in children.)
- . Fatigue is the 99% universal complaint of people with gastrointestinal symptoms. Other symptoms are diarrhea, constipation, obesity, severe weight loss, bloating, and mental foginess, joint pain, gas, loose stools, etc.
- . Follow-up blood tests for compliance, even as good as they are, are not sensitive enough to show slight dietary indiscretions. If you are continuing to have symptoms, go back to the doctor for repeat tests.

- . Bacterial overgrowth is common for celiacs, but is commonly missed. If a person needs to take an antibiotic, that medication might destroy both the bad and good bacteria in your gut. You may develop symptoms similar to CD. Dr. Rudert mentioned the possibility of taking a "probiotic" (one a day with breakfast, like acidophilus or lactobacillus capsules, available at most health food stores. Even diarrhea associated with traveling may be helped with probiotics. Pediatric gastroenterologists are usually very familiar with probiotics and their use for children.
- . Irritable Bowel Syndrome is a common diagnosis, but there are few specific tests for IBS. Many of Dr. Rudert's IBS patients turn out to have CD or bacterial overgrowth, rather than spastic colon/IBS.
- . There may be pancreatic insufficiency, with symptoms very similar to CD. The doctor may want the patient to have a short course of prescription pancreatic enzymes.
- . "Standard of Care" - One out of 30 referrals to a GI, for any reason, may have CD. Screening for CD in GI patients is not considered routine standard of care. Even when a GI physician does an endoscopic procedure for any reason, they do not think of taking biopsies in the small intestine for CD. Much Celiac Disease is hidden in the unbiopsied duodenum. Ooseph Murray, M.D.- Mayo Clinic)
- . The doctor should refer the patient to local and national celiac support groups. Support Groups . There are over 200 support groups to help celiacs in their locality. There is a celiac Listserv and other websites to give information. There are many good newsletters from which to gain further knowledge.

Life After Diagnosis

The gluten-free lifestyle is very interesting, healthy, and challenging. But eat out with care. There are many good tasting GF specialty foods available. You can even travel safely with Bob & Ruth's GF Dining and Travel Club.

Common Pitfalls in the Gluten-Free Diet

- . We know we should avoid wheat, barley and rye. Regular corn flakes and rice krispies are not GF because of malt flavoring from barley. Avoid wheat-like grains like spelt, kamut and triticale.
- . Oats are probably safe, but controversial, due to cross contamination with wheat. No national support group is recommending the use of oats at this time. There is no pure source in the U.S. at the present time.
- . Investigate the source of gluten in HVP, modified starch, vegetable gum, natural flavorings, etc. . Don't eat "WOW" Chips; olestra will cause loose stools. Sorbitol in sugar free products like candy & gum) and guar gum may have a laxative effect
- . Investigate unexpected sources of gluten in medications, glues and pastes (glue on envelopes), play putty, communion wafers, airborne flour, cross contamination: and topical glutens in lotions, shampoo, makeup (especially lipstick that we tend to eat off).
- . Contamination Possibilities
 - a. Processing, including conveyor belts & packaging
 - b. In store open bins with general scoopers
 - c. Use separate implements for condiments, butter; peanut butter and jelly .
 - d. Use separate toasters at home or a toaster oven that can be more readily cleaned

Follow-up Routine Tests

Bone density tests (DEXA) for everyone. Sixty to 80% of adults at time of CD diagnosis have an abnormal density, indicating some bone loss or Osteoporosis. Get a bone density test to use as a baseline for further tests and to determine about calcium and vitamin D replacement whether they are candidates for other medications to prevent continued bone loss.

- . Check Vitamin B-12 level.
- . TSH (Thyroid Stimulating Hormone) - this test monitors the function of the thyroid.
- . Iron level.
- . Carotene level. If this test is low, you may still be malabsorbing.
- . RBC folate test If you are planning to get pregnant, take folate acid before you get pregnant
- . CBC (Complete Blood Count) and Complete Metabolic Panel.
- . ANA - non specific antibody (may be elevated in CD and other autoimmune disorders).
- . In a gluten-free diet, all malabsorption conditions should improve.

Monitoring

- In the first month after going on a GF diet, the person's GI symptoms should diminish somewhat.
- . In 3 to 6 months, there should be correction of nutritional deficiencies and the patient should feel the improvement
- . Within 6 months, the serologic tests should show a reduction in celiac antibodies.
- . At 1 year, a follow-up biopsy might be necessary in certain individuals who are not doing as well as expected.
- . Have regular celiac serological tests every year to test for compliance on your GF diet

The Asymptomatic Celiac - Silent Celiac Disease

- . No over typical GI symptoms, but patient might have ataxia (difficulty walking), short stature (children), and many other problems seeming unrelated to the gut
- . A gluten-free diet will
 - a. reduce the risk of lymphoma
 - b. reduce subtle symptoms
 - c. stop bone disease
 - d. stop growth retardation in children

The Non-Responsive Celiac

- . If the symptoms persist, check your diet, again, and again for inadvertent gluten ingestion.
- . There may be a condition called lymphocytic colitis present. There may be pancreatic insufficiency.
- . There may be bacterial overgrowth - take a probiotic first
- . If the gall bladder has been removed, about 100% of patients may develop bile salt diarrhea, that is treated with medications to bind the bile (medicine called "Carafate" may be used).
- . Some celiac patients will have episodes of urgency, some so severe in the beginning, that they will not leave the house. Often this condition is treated with probiotics and other antispasmodic drugs that will take the cramping away so that you can make it to the bathroom. One prescription is called "Nulev" (unknown GF status). This urgency should not continue, and you need to find out the reason it does continue. Usually this condition improves within 6 months on a GF diet and with the additional help of the medications named.
- . Consider Refractory Sprue (RS), although RS is rare.

Follow Up with Physician

- . Review detailed food diary with symptoms marked.
- . The doctor should ask. "How many times in the last 3 months did you knowingly eat contaminated gluten-containing foods?" We all have human frailties. Let the physician know if you have some continued gluten ingestion, because that knowledge could prevent further diagnostic studies.
- . All celiacs are worried about developing lymphoma, but being on a GF diet decreases that risk to that of the normal population.
- . Serologic testing
 - a. Antigliadin IgG and Antigliadin IgA
 - b. Tissue transglutaminase (IgA)
 - c. Antiendomysial antibodies (IgA)
 - d. Serum IgA
- . Tropical sprue is an infection, different from Gluten Intolerance. "Sprue" is a Dutch word meaning pain. "Celiac" or "Coeliac" means of or pertaining to the abdominal cavity.
- . Lactose Intolerance may be aggravating the condition by continuing GI symptoms. The lactase enzymes are generated at the tips of the villi. Without the full function of these enzymes, we develop Lactose Intolerance. Sometimes people are incorrectly diagnosed solely with Lactose Intolerance because that enzyme is temporarily gone, when they also should be screened for CD. The villi return to normal on a GF diet, as does the enzyme function in many celiacs.
- . Your doctor should follow you regularly and consider repeating the small bowel biopsies (according to your symptoms) in approximately one (1) year. Colonoscopies may need to be scheduled but this is individualized.

Refractory Sprue (also called Collagenous Sprue)

- . Refractory sprue (RS) is usually seen in older patients
- . RS is associated with lymphoma
- . Rarely do physicians *see* evidence of Celiac Disease on X-rays. (By the way, check out the barium used for X-rays as to possible gluten.)
- . Ulcerative jejunitis
- . Lymphocytic enterocolitis
- . Get a CT Scan and extended endoscopy with molecular studies on the intestine

Treatment for Refractory Sprue (person does not improve on GF diet)

- . Nutritional support
- . Steroids
- . Cyclosporin
- . Azathioprine

Dermatitis Herpetiformis (DH)

- . Dapsone is the usual medication prescribed for DH patient to help them to help suppress the itching and rash. Try to take the smallest possible dose needed because of serious side effects of this drug.
- . Eventually a gluten-free diet should get the skin condition under control.
- . A carbon monoxide detector should be used in the home if taking Dapsone since the presence of CO2 will trigger the side effect of hemolysis (breakdown of red blood cells).
- . 75% of DH patients get off Dapsone within 12 months of a GF diet
- . The GF diet will heal any intestinal lesions and reduce the risk of complications.

