



# GF UTAH Gluten Intolerance Group

Spring 2007

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## Upcoming Events

- April 5, Utah County GIG**, Food Storage, Diane Bell, owner of Against the Grain will be presenting gluten free ideas for 72-hour kits and long term food storage.  
Timpanogos Regional Hospital  
(750 West 800 North, Orem) Main Floor, Cafeteria Classroom
- April 10, SLC GIG**, St Mark's Dieticians, giving a presentation on healthy eating on a gluten free diet. How is it we can eat healthier?  
St. Mark's Hospital, 1200 East 3900 South, SLC  
Women's Pavillion, Auditorium
- May 3, Utah County GIG**, Travel tips  
Timpanogos Regional Hospital  
(750 West 800 North, Orem) Main Floor, Cafeteria Classroom
- May 8, SLC GIG**, Dr. P.J. Pedersen, SLC GIG Medical Advisor will be speaking.  
St. Mark's Hospital, 1200 East 3900 South, SLC  
Women's Pavillion, Auditorium
- May 19, GF Utah presents, the 3rd Annual Walking Feet without Wheat Walk @ Wheeler Farm.**  
Registration form in this newsletter.  
Pre-registration April 30th Deadline!  
See [www.gfutah.org](http://www.gfutah.org) for further details.
- June 7, Utah County GIG**, School Lunches,  
Timpanogos Regional Hospital  
(750 West 800 North, Orem) Main Floor, Cafeteria Classroom
- June 12, SLC GIG**, Italian Favorites, Potluck meeting, bring your favorite Italian side dish. Discussing easy BBQ ideas for your summer gatherings. Be prepared!
- June 13, Northern Utah GIG**, Wednesday GF Night BBQ for families, location to be announced, (6-8pm) Contact Tammy Ward to sign up for the potluck & RSVP, [wcheftammy@msn.com](mailto:wcheftammy@msn.com)  
For further questions , [GIGNorthernUtah@yahoogroups.com](mailto:GIGNorthernUtah@yahoogroups.com)
- June 17-23**, Sunday-Saturday, Children's GF Camps *Summer Camp Session 1*  
(Grades 3-9) [www.fcyd-inc.org](http://www.fcyd-inc.org)
- June 24-30**, Sunday-Saturday, Children's GF Camps, *Summer Camp Session 2*  
(Grades 2-6) [www.fcyd-inc.org](http://www.fcyd-inc.org)



## Celiac Disease Research Briefs

### Diagnosing Celiac Disease

#### Sources :

Green, P. et al., (2004). False Negative Serological Results Increase with Less Severe Villous Atrophy *Dig Dis Sci Apr: 49(4): 546-50*

Craig, D; Robins G. Howdle P. (2007), Advances in Celiac Disease, *Curr Opin gastroenterol. ; 23(2):142-148.*

Dr. Peter Green reported that celiac disease that did not test positive with the EMA blood tests was more likely to be found with severe villous atrophy. It did not appear to make a difference if the patient had classical symptoms or silent symptoms. Dr. Green also reported that the results of this study did not show that EMA was as sensitive as previous researchers had found. The researchers found that with serious villous atrophy the EMA test still missed about 25% of the biopsy diagnosed patients. With only partial villous atrophy, EMA resulted in false negatives for 70% of the patients.

In the March, 2006 issue of *GUT* another group of researchers reported that patients who have a negative EMA and biopsy positive celiac disease may have severe villous atrophy. These researchers suggested an hypothesis that the serum autoantibodies disappear in long-term severely damaged cases.

Both researchers found that the EMA test missed diagnosing celiac disease. One with low levels of villous atrophy and one with severe levels villous atrophy.

#### Positive blood tests, but negative or unclear biopsy

Silent celiac disease is being given more recognition  
Silent celiac disease occurs when the patient is symptom free but is diagnosed by blood and biopsy.

#### Screening

The debate is still whether or not there is any advantage to diagnosing patients who have no symptoms and whether or not the costs are worth the benefits. One group was identified where the screening might have value. Women who have undiagnosed celiac disease had more adverse fetal outcomes such as low weight babies and more c-sections. Four years after diagnosis (and presumably gluten-free) the mothers did not have worse outcomes than the general population. Studies in Sweden

had the previously described results, but the UK studies did not find the same results.

#### New types of blood screening are being tested.

Point of Care Testing involves a 30 minute blood test done in the office. Sensitivity and specificity were both in the high 90 percentiles in the initial trials in Finland. The developers suggest that this test could be used to monitor compliance, whether or not the patient is getting gluten in their diet, and for diagnosis. The test consists of a four pronged stick. This test will also identify IgA deficiency.

A second type research on testing involves identifying the activity that is taking place in the intestinal cells prior to villous atrophy. The results are mixed as to whether these indicators will have value in predicting who will develop celiac disease.

#### Vocabulary for Understanding Research

**Selectivity** - a test is positive for the targeted disorder with few false negatives, but because it is picking up a broader range of indicators there may be false positives. Anti-tissue transglutaminase (TTG) is highly selective so there may be false positives.

**Specificity**- a test is positive for the targeted disorder with few false positives, but because the test is finding a narrower range of indications may miss some diagnoses so there are false negatives. Endomysial Antibody(EMA) is highly specific and will have more false negatives.

**Silent celiac disease**- a patient has no identified symptoms, but has a biopsy with evidence of villous atrophy

**Latent celiac disease**- a patient has positive blood tests, but has no change or minimal changes in the biopsy that may or may not be celiac disease The results of research are still not clear as to whether this group of patients will develop celiac disease.

**Review** when researcher combines the results of several other researchers to try to find an overall conclusion.

**Medical Fact** research can not be considered to have found a “fact” unless the research can be repeated in other locations by other researchers and get the same results. When the results are different more research has to be done to figure out why.



## SLC GIG Meeting Highlights

### Gluten on the Go

The SLC GIG shared a discussion on traveling with a gluten-free diet. The following is a list of some information that was offered by the members.

- Carry a doctor's note to verify your medical need for the gluten-free diet
- Favorite travel gadgets included: Food Tek molds, silicon bakeware, can opener, coolers that plug into a car power source or other source of electricity, small insulated lunch bags and coolers
- Favorite snacks to carry while traveling: Kozyshack puddings, Midel Ginger Snaps, Nana's cookies, Sunflower Bakery, Running Rabbit GF licorice, K-Too cookies, Cliff Nectar, Lara Bars, Crunchmaster Rice Crackers in a homemade GF "Lunchable"
- Individual condiments can be ordered on line from [www.minimus.com](http://www.minimus.com)
- Airlines that provided GF diet: Virgin, Atlantic, United, American, British, Delta, Quantas
- Favorite GF Destination- Disneyland and Disney World
- [www.InnSeekers.com](http://www.InnSeekers.com) listings of beds and breakfasts including a sublist that is GF

### Travel Resources on the Internet

[www.bobandruths.com](http://www.bobandruths.com)  
[www.triumphdining.com](http://www.triumphdining.com)  
[www.glutenfreeda.com](http://www.glutenfreeda.com)  
[www.glutenfreepassport.com](http://www.glutenfreepassport.com)

### Celiac 101

SLC GIG hosted an educational group for people who were newly diagnosed with celiac disease. Heather Khader from St. Mark's Hospital and our group's assisting dietician created a Power Point presentation that reviewed the basics. The room was filled with questions from people who were beginning the diet. There were even a few familiar faces that snuck in for a review. At present the tentative plan is to present this group quarterly. If you or someone you know is interested in participating contact the SLC leadership. [saltlakegig@gmail.com](mailto:saltlakegig@gmail.com)



## SLC GIG Branch Updates

We would like to say thank you to our Walking Feet without Wheat Walk Core committee for volunteering their time to make this walk possible.

Utah County GIG, Kathy Chilcote, Branch Manager

Utah County GIG, Robert Lee, GF Utah WebMaster & his son, Robert Lee & scout troop

Marcie Coda, SLC GIG Branch Manager

Melissa & Ryan Park, SLC GIG Members

Barb Shelley, SLC GIG Marketing & Public Relations contact for GFUtah

Stephanie & Preston Lockwood, SLC GIG Members, (Library Contacts)

Justine Sheedy, (SLC GIG Member)

Christie Vantassell, (SLC GIG, Auditor)

We are looking forward to another wonderful walk event and should you be interested helping this year contact [slcgig2006@comcast.net](mailto:slcgig2006@comcast.net).



## Gluten Free Product Updates

**Mariani** products, all of their dried fruit products are gluten free.  
(Researched 3.06, shared by Darylee Ishimatsu SLC GIG)

**Uncle Ben's Ready Rice**, the ready to go bags you put into the microwave, flavors that are gluten free are the 'Chicken wholegrain' and the 'whole grain brown'. The "Garden Vegetable" contents are gluten free; however, there is cross contamination. (Researched 3.06, shared by Darylee Ishimatsu SLC GIG)

**Clan Thompson's Mini-List** Verified Information on Gluten Content

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This Month's Tip: Gluten can "hide" in lipsticks and lip pencils. Don't forget to check cosmetics and other non-food items, like toothpaste, that come in contact with your mouth. The manufacturers of the following products reported them to be GLUTEN FREE when we contacted them between January and February, 2007:

Vicks DayQuil Liquid	Vicks Cough Drops - menthol
Children's Advil Fruit Suspension	Children's Advil Infant Drops Grape
Cough-X Lozenges	Cepacol Sore Throat Dual Relief Spray (cherry or citrus)
Cepacol Sore Throat and Coating Relief Lozenges	Vicks Sinex Regular Spray
Vicks NyQuil Adult Liquid	Halls Cough Drops - Cherry
Halls Cough Drops - Kiwi Apple - Sugar Free	Halls Cough Drops - Assorted Mint Flavors - Sugar Free
Halls Plus Cough Drops - Cherry	Halls Plus Cough Drops - Honey-Lemon
Halls Plus Cough Drops - Mentho-Lyptus	Triaminic Chest and Nasal Congestion - liquid
TheraFlu Flu & Chest Congestion Non-Drowsy	Hot Liquid Formula
TheraFlu Nighttime Severe Cold	Hot Liquid Formula

Clan Thompson's Celiac SmartLists are a series of programs which make it easy to find gluten information on thousands of items. Our SmartLists are the ONLY software that contains VERIFIED information, and a "Comments" field is included to provide even more information. Download a FREE DEMO, at <http://www.clanthompson.com/> In addition, you may always subscribe online to our free email Newsletter which includes new Gluten Free food lists, The Cook's Corner, Ask the Doctor, Ask the Nutritionist and more.



## Restaurant Reviews

The **Mazza Restaurant** is a 'Must-Eat-At' for those with Celiac disease. The Mazza specializes in middle eastern food, mainly Lebanese. There are now two locations. The original is on 15th South and 15th East; and in keeping with the same theme, the second location is on 9th East and 9th South. The 9th & 9th location seems to be about three times the size of the original, but at the time of this review, is only open from 5pm to 10pm. The gluten-free menu is delivered in the \*same leather cover\* as the regular menu. The dishes are naturally 95% gluten free so you get a good selection of nearly everything on the menu. At a quick glance it easy to compare a regular menu with the gluten menu. The pita bread is replaced with a buttered rice (Yum-O), but may have a small additional charge depending on the meal ordered.

One must eat the hummus, it is delicious with cucumber slices. THE FRIES ARE GLUTEN FREE and are second to none.

If you have been newly diagnosed and think you are now a social outcast who will be relegated to TV dinners labeled gluten free. This a location where you can take your friends along with you. and enjoy the whole experience. Your taste buds and friends will thank you.

Written by Preston Lockwood, SLC GIG Member and Librarian Contact

**Pier 49** in downtown Salt Lake City only is serving a gluten-free pizza. You must call ahead about 20-30 minutes to order and to be sure that they have the crusts because they were sold out after our last SLC GIG Meeting. Owner Don Herrera promised that he would continue to restock his gluten free crusts. The pizza was fabulous and cooked in the pizzeria oven then generously topped, with the toppings of choice and all with a great taste to match. The convenience of being able to call ahead and then pick up this pizza was a tradition we had not experienced in quite some time.

Written by Tim Coda, SLC GIG Co-Chair

**All young adults interested in meeting up to have a slice of pizza and great conversation should contact Keri Apodaca, saltlakegig@gmail.com**



## Celiac Disease in the News

### This item was found posted on an international listserv Celiac group

Very interesting & informative article from Cinthia Kupper & Laurie A Higgins:

<http://www.healthsystem.virginia.edu/internet/digestive-health/nutritionarticles/KupperArticle.pdf>

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Combining Diabetes and Gluten-Free Dietary Management Guidelines

### PROBIOTICS

Mayo Clinic.com explains that probiotics are dietary supplements or foods that contain beneficial or “good,” bacteria normally found in your body. These microorganisms assist with digestion or help to protect against some harmful bacteria.

These supplements are increasingly being researched. Researchers in Chile have reported that bacterial overgrowth can interfere with absorption of nutrients from food. Dr. Peter H. Green and Rory Jones in *Celiac Disease: A Hidden Epidemic* describe bacterial overgrowth as a common concern among people with celiac disease that may contribute to continued problems that do not resolve with the gluten-free diet.

Another team of researchers is reporting that a special research developed form of lactobacilli when used in a sour-dough leavening for bread may eliminate gluten from cross contamination. If combined with the agricultural research being done on developing varieties of grain with lower gluten levels, the researchers believe that the types of food available for those who eat gluten-free will be expanded.

### ***What is Celiac Disease?***

Celiac disease is an autoimmune disease of malnutrition induced by gluten in the diet and the prevalence of this disease in the United States is 1 in 133 people. There is no cure for the disease and no medicine that will thwart it but the absence of gluten in the diet can bring about complete restoration of the villi and maintenance of good health. Once diagnosed, the patient does not outgrow the disease as was formerly thought by doctors. The diet is a lifetime commitment.

### ***What are the symptoms?***

Celiac disease is often overlooked by physicians as the symptoms are so diverse and frequently misdiagnosed. Common symptoms include:

Anemia	Allergies
Diarrhea	Constipation
Irritable bowel	Spastic colon
Osteoporosis	Infertility
Weight loss	Small stature
Chronic fatigue	Mental fatigue
Lactose intolerance	Reflux



### ***How is it diagnosed?***

Research has made it possible for signs of celiac disease to be found through a simple blood test. The patient is then referred to a gastroenterologist for an endoscopy for verification before going on the lifelong gluten-free diet.

### ***Why Support the Walk?***

It is estimated that for each person diagnosed with gluten intolerance, celiac disease and dermatitis herpetiformis, 90 are undiagnosed and suffering. Help GIG support those affected by the diseases with support, resources and research funding. All contributions are tax deductible. Please make checks payable to SLC GIG 2809 E Commonwealth Avenue SLC UT 84109.

### ***Registration***

A pre-registration fee of \$16.00 per registered walker (one volunteer hour) or \$18.00 pre-registration without volunteering. Mail payment along with the registration form by April 30th. Registration forms are available at all Utah Wild Oats Markets or on-line at [www.gfutah.org](http://www.gfutah.org) starting April 1st. Registration will also be available the morning of the Walk for a \$20 per walker fee.

Walkers will receive a Walk T-Shirt and Goodie Bag full of gluten free products and information.

### ***Schedule, May 19th, Saturday, 2007***

- 8:30am** Registration & Continental Breakfast sponsored by Wild Oats.  
The Continental Breakfast is \$2.00 per adult & \$1.00 per child under age 6 if you're not registered for the walk event.
- 9:30am** Walk in the Park (1K trail)  
Health Awareness Fair & Gluten Free Food Exhibitors
- 11:30am** Prize Drawings provided by our sponsors - must be present to win!

*Children's Play Area will be available from 8am to 11am - parent/guardian supervision required. Entertainment will be announced soon!*

### ***Location***

Wheeler Historic Farm is located at 6351 South 900 East in Salt Lake City.  
Take I-215 and exit at Union Park Avenue, or Exit 9.  
The Farm entrance is located on the east side of 900 East.



**\*\*Submit this form before April 30<sup>th</sup>, and receive ongoing communication for the walk.\*\***

Registration NEW! Options for 2007: Each pre-registration includes the walker bag, brochures of the latest GF information, a list of vendors involved in the walk, a Prometheus Laboratory Inc. tTG blood test, and the great T-shirts we offer every year. Special gift for the first 40 pre-registered for this event! Deadline April 30th for pre-registration.

- \_\_\_\_\_ @ \$16.00 ( per Pre-Registration / Volunteering a minimum of 1 hour at the event)
- \_\_\_\_\_ @ \$18.00 (Pre-Registration / Unable to volunteer, but will be at the event, Pre-Registering)
- \_\_\_\_\_ @ \$20.00 (Registering Day of the walk)

walking as a team, Name of Team \_\_\_\_\_ Name of Captain \_\_\_\_\_

**NEW!** Additional t-shirts available:

**Adult T-shirt size** (Write the number of shirts needed next to your selections)

\_\_\_\_\_ Small \_\_\_\_\_ Medium \_\_\_\_\_ Large \_\_\_\_\_ X-Large \_\_\_\_\_ XXLarge

**Kid T-shirt size** (Write the number of shirts needed next to your selections)

\_\_\_\_\_ Small \_\_\_\_\_ Medium \_\_\_\_\_ Large \_\_\_\_\_ X-Large

\_\_\_\_\_ \$10.00 per shirt/ \_\_\_\_\_ Total Number of shirts

**Extra** GF Walk Breakfast Admission(s) For those not 'registering for the walk event'

\$2 / per Adult \_\_\_\_\_

\$1 / per Child \_\_\_\_\_

**Total for this Pre-registration \$** \_\_\_\_\_

**The GF Walk Breakfast:**

**Prices for extra breakfast armbands are \$2.00 per adult and \$1.00 per child over age 5.**

**If you are 'registered' for this event the breakfast is already included.**

Senior Citizens over age 65 and children under age 5 do receive this breakfast free of charge. Let us know if either applies for this registration.

*Breakfast will include waffles, breads, 'fresh pancakes' being cooked on site, and many great breakfast items. The meal is sponsored by over 8 vendors and Wild Oats will be the Platinum Sponsor again this year!*

On May 19<sup>th</sup>, 8:30 am at Wheeler Farm, Breakfast begins and the walk will begin at (9:30am)

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Day Phone \_\_\_\_\_ Evening Phone \_\_\_\_\_

E-Mail \_\_\_\_\_

*(Volunteers be sure to list both a phone & email for contact about the walk)*

To pre-register, mail this form and registration fee by April 31<sup>st</sup> to:

**SLC Gluten Intolerance Group, 2809 E Commonwealth Ave., Salt Lake City, UT 84109**

Registration available the morning of the Walk for a \$20 per walker registered walker.