



Volume 7, Issue 1

# Celiac Digest

A publication of the Southern Arizona Celiac Support Group (SACS)

online at [WWW.SouthernArizonaCeliacSupport.org](http://WWW.SouthernArizonaCeliacSupport.org)

July 2008

**DISCLAIMER:** This publication is intended as a general information resource for gluten-intolerant individuals. It is NOT intended for use in diagnosis, treatment, or any other medical application. Please consult your physician for professional medical advice and treatment.



## 2008 Food Faire a huge success

By CHERYL WILSON

**We did it again!** We doubled our expected attendance at the SACS' annual Gluten-Free Food Faire (GFFF) held May 10, 2008 at Christ Community Church. We were planning for about 300-400 attendees, but over 650 people participated!

Probably the most significant new element this year was our first ever free Celiac Blood Screening, made possible by test kits donated by Prometheus Labs. MAB members,

Georgina Rubal-Peace and Dr Priya Ramachandran, hosted the check-in table in an adjoining room. They, along with new MAB member Dr. Lindsey Pearson, oversaw the processing of hundreds of screening applicants who visited that day. Although there were only 100 free tests available, dozens more stopped by in hopes that they might get in and were put on a waiting list.

The blood draws were skillfully completed by volunteers from many different sources. There was an RN

from Christ Community Church and three phlebotomists from *Sonora Quest Labs*. There was also a 'celiac' RN from *Pima Medical Institute* who brought three of her advanced phlebotomy students with her. We feel that having these volunteer phlebotomists helped us establish a working relationship with local labs and the medical community at large.

We also added some new elements this year: "Dining out in Tucson" table, hosted by our webmaster, Gene Spesard, along with occasional help from our GF Lunch Bunch Coordinator, Colleen Beaman. There was also a table staffed by some of our Medical Advisory Board members where people could stop by and ask questions. Our thanks goes out to Nancy Schuller, Geri Bazzel and Diane Sheehey who graciously sat and answered question after question from attendees.

Also a first this year was a Cel-Kids table, complete with face painting and a jumping castle; both were a big hit! Cel-Kids coordinator, Diana Knoepfle, reported that she had 18 new sign-ups at the GFFF, which was very exciting for all of us on the board.



CHUCK CUSHMAN, father of SACS member Laura Dickerson-Cushman bravely submits to a blood draw for a CD screening.

(Please see **GF Food Faire** page 6)

# MAB member at GIG Conference



MAB member NANCY SCHULLER at our 2008 GF Food Faire

As the Morrison Healthcare Ambassador for CD, my paid attendance at the 2008 GIG Conference in Dallas this June 6-7 was one of the perks. GIG's theme was, *It's All About Food*, and they made it come true.

There are about 800 GIG members in the North Texas group, and they ran a very professional conference, a lot like the one CSA sponsored here last September.

We were lucky again to have Aaron Flores as the chef who provided wonderful meals. Many vendors were there, including LynnRae Ries from Gluten-Free Creations Bakery in Phoenix.

Carol Fenster talked about whole grains, Dr. Cathy Breedon talked about "Super foods", and Robin Ryberg talked about simpler G-F cooking as did Annalise Roberts. I bought

all three of their new cookbooks.

Dr. Joseph Murray spoke on the topic of *Refractory Sprue*, and it was worth the trip to see him line dancing at the Texas hoedown that night. Dr. Michelle Pietzak talked about *Celiac and Kids*, Dr. Ed Hoffenberg spoke on *Diabetes and Celiac Disease*, Dr. Jean Layton discussed *Probiotics*, and Dr. Megan Tichy spoke about gluten from a scientific approach.

I wish I could have heard all the speakers but there were concurrent sessions that prevented that. At the end of the conference, Aaron Flores suggested an "Iron Chef" contest at the next GIG Conference, which will be in Seattle next year.

Dr. Alessio Fasano was the speaker at the final banquet, and he gave a very funny talk about Celiac Disease. He said that he went to a meeting where they tried to see if CSA and GIG could resolve their differences, and since it seemed impossible, the *American Celiac Disease Alliance* was formed, an ad hoc group of 15 celiac leaders who came together to help persuade Congress to require food labels to include information about allergens.

There was a live auction at the end and someone bid \$850 to have breakfast with Dr. Fasano! He said that he was glad that he went for more than the signed Dallas football which brought in \$500.

I had a lot of fun and am willing to share any of my notes with anyone who would like them.

## Chapter 15 Notes

### Enriched rice or other grains

questionable? In general, carriers in enrichment blends are considered incidental additives and as such do not have to be declared in the ingredient list. *However*, if the carrier in an enrichment blend contains wheat protein, under FALCPA it is no longer considered an incidental additive and as such must be declared on the food label.

**A 2007 Dutch study** concludes that there is a clear association between Hashimotos thyroiditis and celiac disease. Accordingly, it is recommended that patients with Hashimotos thyroiditis be screened for CD and that patients with known CD be screened for Hashimotos thyroiditis.

**CSA/USA: 877-272-4272**, 9 a.m. to 4 p.m. Central Time.

Their URL is:

[www.csaCeliacs.org](http://www.csaCeliacs.org).

**Membership changes?** Notify us via the website or call 742-4813.

## Mark your calendar

(See SACS Leadership box Page 7for phone numbers/email addresses )

**July 11**, noon Lunch Bunch, Jonathan's Cork, 6320 E Tanque Verde Rd. If you can attend, RSVP to (520) 888-2935.

**July 23**, 1:00 p.m. Roundtable, Ward Six City Hall at 3202 E. 1st St.

**August 27**, 1:00 p.m. Roundtable, Ward Six City Hall at 3202 E. 1st St.

**September 27**: General Meeting - 9 am, Pima Admin Campus, Georgina Rubal-Peace, Pharm.D will speak.

**October 16**: CSA Dieticians Day in La Vista, Nebraska (Omaha)

**October 17-19**: CSA Conference in La Vista, Nebraska (Omaha)

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Note: Store has closed

# Many Thanks

## These vendors sent in reps to participate in our 2008 GFFF

Arbonne (Tucson) \* Chebe Mix (Phoenix) \* Enjoy Life (Tucson)  
ExFuze7 (Tucson) \* Food Conspiracy (Tucson) \* Gluten-Free  
Creations Bakery (Phoenix) \* Juice Plus (Tucson) \* Lotus Garden  
Miracle Munchies (Tucson) \* Mixes from the Heartland (Amarillo, TX)  
New Life Health Centers (Tucson) \* Organic Bistro (Tucson)  
Sunflower Farmers Market (Tucson) \* Tastes Like Real Food (Iowa)  
Tom Sawyer's Flour (Sedona, AZ) \* Trader Joe's (Tucson)

## We received product and/or gift cards from these fine vendors:

Bob's Red Mill \* Dakota GF Coatings \* Ener-G Foods  
GF & Fabulous (pizza) \* Glutino \* Great Northern Growers  
( of GF oats) \* Jennies Macaroons \* Kinnikinnick \* *Living Without*  
Magazine \* Mama's Cooking \* Mary's Gone Crackers  
Mayacamas Gravy Mixes \* Melissa Diane Smith \* Namaste Foods  
Pamela's \* Picazzo's Gourmet Pizza \* Raw Indulgence \* Sprouts  
Sunflower Markets \* Toaster Bags

## Dr. Pearson new MAB member

SACS is excited to announce the addition of Dr. Lindsey Pearson to our Medical Advisory Board. Dr. Pearson first contacted us last August, shortly after he moved to Tucson.

Dr. Pearson, a licensed Naturopathic Medical Doctor (NMD), completed his graduate training and received his degree from Bastyr University School of Naturopathic Medicine in Seattle in 2003. Dr. Pearson has his undergraduate degree in Biology (Biochemistry) from The College of St. Scholastica, in Duluth, Minnesota.

Dr. Pearson says his interest in celiac disease began during his internship while working with a celiac patient. The patient had a gastroenterologist working with her on the diagnostics and management but did not have a practitioner working with her in the nutritional and daily health areas. "Celiac disease can cause a number of nutritional deficiencies which cause many people with celiac disease to experience complications", states Dr. Pearson. "With the disease in the gut, absorption is compromised."

Dr. Pearson proposes that "to increase celiac awareness, I think there needs to be more screening at the primary care level and that clinicians need to be educated more about food allergies, autoimmune diseases, and conditions like celiac disease. Once educated, they will be more likely to not look past subtle signs and symptoms and be more mindful of the prevalence and the many presentations of celiac disease. Educating not only physicians, but nurses, NP, PA, DDS, OT, PT, and other healthcare providers is essential. In today's healthcare delivery system, patients are having more contact time with other practitioners than a medical doctor. Providing a multidisciplinary education model would



From left, DR. LINDSEY PEARSON talks to a GFFF participant about CD blood screening. Dr. Pearson worked as the physician in charge at this event when Dr. Shelli Hanks was unable to attend.

be effective in educating those the patient will come in contact with."

Dr. Pearson says that the biggest stumbling block to increased diagnosis is "...Education. Many practitioners are not aware of celiac disease beyond what was talked about in pathology class or a gastroenterology lecture. For being a disease with a prevalence of 1 out of 120-300 people and its association with other autoimmune conditions, patients that I have screened stated they were not asked by their other clinicians about celiac disease nor was it suggested to them they should be screened. If the clinicians aren't educated then there is little hope for detection and proper management."

As for following the gluten free diet, Dr. Pearson likes to be involved in helping his patients make healthier lifestyle choices, especially since his opinion that personalized education and lifestyle counseling is lacking for most patients. It isn't just about a gluten-free diet. "Food and eating habits are some of the hardest areas to work with patients. It goes beyond micro- and macro-nutrition. It includes teaching patients how to choose foods that are nutrient dense, healthy, well balanced, enjoyable to eat, and easy enough to prepare. It's about setting them up to succeed and not becoming overwhelmed," says

Pearson.

Dr. Pearson is very clear on his reasons for wanting to be a part of the SACS Medical Advisory Board, and that reason is very closely aligned with our mission statement. "Overall, education is the key to success in diagnosing, managing, and living with celiac disease. A multidisciplinary approach, I believe, will be the most effective is designing and disseminating the information for both patients and practitioners. It will take a multidisciplinary approach to over all the bases and all areas of healthcare to provide celiac patients with comprehensive care. Getting practitioners of different disciplines on board is the most effective approach. The more information you have, the better educated everyone can be."

Dr. Pearson currently practices Family and Sports Medicine at Tucson Natural Medicine Center, 8230 East Broadway Blvd, Suite E2. He has many patients who are gluten intolerant and is committed to raising awareness. The biggest surprise? He makes hospital rounds personally, something that most doctors no longer do.

If you did not have a chance to meet Dr. Pearson at the Gluten-Free Food Faire, make sure you greet him at our next meeting on September 27.

# Coming soon —a standard for gluten-free labels

By GENE SPESARD

## FALCPA

The Food Allergen Labeling and Consumer Protection Act of 2004 (FALCPA) mandated allergen labeling starting on January 1<sup>st</sup>, 2006 which required the disclosure of wheat as an ingredient in food. Now, coming in August 2008, the law also requires the Food and Drug Administration (FDA) to set a standard for **gluten-free** labeling

We've all become familiar with scanning labels for a "Contains..." statement or for "wheat" in the ingredient list. However, the allergen labeling that was initiated in 2006 does not require the disclosure of barley, rye or oats. Nor does it address in any way the problem of inadvertent cross-contamination. Some companies have dealt with cross-contamination by using "Made on equipment with..." or "Made in a facility with..." statements, but in many cases these seem to be there more as a legal disclaimer than as useful information for consumers.<sup>1</sup>

## Gluten-free labeling

The FDA is required to set a standard for voluntary gluten-free labeling by August, 2008, which is just a month away! This is a voluntary standard, meaning that food manufacturers can use the label "gluten-free" (or "free of gluten", "without gluten" or "no gluten") if their product meets the standard **and they wish to do so**. Currently there is no standard for the use of "gluten-free" in food labels. The FDA does require that labels be "truthful and not misleading" but doesn't define that in terms of gluten-free labeling.

The FDA issued their proposed standard in January 2007 based on 20 parts-per-million (ppm) or less of gluten from wheat, barley or rye (referred to as "prohibited grains"). For comparison, our parent organization, CSA/USA, requires a level of 3

ppm to qualify for their Seal of Recognition. [Oats were not included. The issue of oats for those with celiac disease is a topic beyond the scope of this article, but note that **cross-contamination** in oats or any product containing oats is addressed, since the final product would have to have less than 20 ppm of gluten from any of the prohibited grains.]

Single ingredient foods that are



inherently gluten-free (milk or fruit, for example) could carry a label indicating all such foods are gluten-free ("milk, a gluten-free food"). The proposed standard is online at <http://www.fda.gov/OHRMS/DOCKETS/98fr/05n-0279-npr0001.pdf>. The FDA also has a frequently asked questions web page at <http://www.cfsan.fda.gov/~dms/glutqa.html>.

Note that the new gluten-free standard does **not** apply to drugs (either OTC or prescription) or to food served in restaurants.

## International Standards

For many years the Codex Alimentarius standard for gluten-free food has been 200 ppm. In November of 2007 it was agreed to revise the Codex standard down to 20 ppm for gluten-free labeling. However, this has not been implemented yet. There will also be a label (as yet undefined,

maybe "gluten reduced") for foods that have 20-100 ppm gluten. It's good that the Codex is moving to be consistent with the proposed US requirements, because it appears that the United Kingdom was planning to protest the different standards as a violation of free trade agreements.

## What does this mean to me and what is safe?

In 2007 a study was published that indicated that 10 mg per day of gluten was safe for celiacs, but that 50 mg per day resulted in detectable damage to the intestine.<sup>2</sup> This was a small study and the changes detected were slight, so the results aren't absolutely definitive. In fact, one participant withdrew because of "typical signs of relapse (vomiting, diarrhea, and abdominal distension)." There's no way of knowing if they were reacting to accidental gluten exposure unrelated to the testing or to the 10 mg they were taking as part of the test protocol. So it's possible that 10 mg per day may be too much for *some* people.

## How does 20 ppm relate to a safe level?

In a nutshell, if you eat 500 grams (17.6 ounces) of food containing 20 ppm of gluten in one day, you will reach the 10 mg "safe" level. You would reach the 50 mg level if you ate 2500 grams (88.2 ounces or 5.5 pounds). Of course, things aren't quite that simple, but, fortunately most of the complications work in our favor. Many of the foods we eat are completely gluten-free (apples, eggs and milk, for example), so we won't count them at all. Also, the 20 ppm limit is the maximum allowed. Any prudent food manufacturer would set a target level considerably below that to insure compliance. That should raise the amount of gluten-free labeled food you can safely eat. (continued →)

(Please see **Labeling laws** page 6)

# GF Food Faire

(continued from page 1)

the costs associated with putting on this event. Scores of people and/or companies generously donated items for both the raffle and silent auction, and many were exceedingly generous with their bids. Thank you! SACS made nearly \$1,700 on the silent auction alone, which is important as the GFFF is about our only source of income.

Right around noon, Darryl Wong of Lotus Garden brought in plenty of GF Chinese food for everyone to enjoy. What a special way to end the GFFF. Thanks, Darryl!

The day would not have gone anywhere near as well as it did without the assistance of so many of YOU. We had over 20 SACS members who volunteered to help in different capacities. Many of you helped open boxes and put food out on a table, some assisted at the sign-in tables out front. Some of you cooked pizza, sliced it

and then brought it back out to the main floor (it was a big hit, too!). Some of you sat at a computer and entered data for the blood screening. Thank you ALL for investing in the lives of others during this outreach!

As I walked around the floor and talked to people, so many of them told me how wonderful it was to have all this GF food in one place. Others liked that they could taste things first

before buying, or they discovered a new favorite. It is truly gratifying to know that SACS is fulfilling its mission statement in such a fun way! If you have not had the chance, view the photos of the 2008 GFFF on our website at [www.SouthernArizonaCeliacSupport.org](http://www.SouthernArizonaCeliacSupport.org).



From left, MAB member GERI BAZZEL, RN advises Fair participants on the medical aspects of celiac disease. The MAB is an invaluable part of SACS.

# Labeling laws

(continued from page 5)

The hope is that with a definite standard, more food manufacturers will be willing to make the commitment to supplying gluten-free food. And of course we should hope that all our old favorites will meet the new standard.

It's interesting to note that a food product could be required to list wheat as an ingredient and could still qualify to be labeled gluten-free if the wheat was processed to remove the gluten and tested below the 20 ppm level. If you are highly sensitive to gluten this could provide you with a way to further screen food labeled gluten-free.

(6) As with the original FALCPA

allergen labeling, this gluten-free labeling will be a significant help for celiacs. However the standard is less strict than we might have hoped for. Since gluten-free foods currently aren't required to meet a specific standard, we should be better off with this new legislation.

<sup>1</sup> Susan L. Hefle, Terence J. Furlong, Lynn Niemann, Heather Lemon-Mule, Scott Sicherer, and Steve L. Taylor. "Consumer attitudes and risks associated with packaged foods having advisory labeling regarding the presence of peanuts." *Journal of Allergies and Clinical Immunology* 120, no.1 (July 2007) 171-176.

<sup>2</sup> Carlo Catassi, Elisabetta Fabiani, Giuseppe Iacono, Cinzia D'Agate, Ruggiero Francavilla, Federico Biagi, Umberto Volta, Salvatore Accomando, Antonio Picarelli, Italo De Vitis, Giovanna Pianelli, Rosaria Gesuita, Flavia Carle, Alessandra Mandolesi, Italo Bearzi, and Alessio Fasano. "A prospective, double-blind, placebo-controlled trial to establish a safe gluten threshold for patients with celiac dis-

ease." *American Journal of Clinical Nutrition* 85 (2007) 160-166

# Last Issue

of the **Celiac Digest** for those members who have not yet renewed. Go to our website to download a membership form or call Sue, our membership chair, at (520) 742-4813.

# CD and 'Leaky Gut Syndrome'

By VIRGINIA MORGAN

*Member Virginia Morgan is interested in and researches many aspects of CD and diet.*

When we had celiac disease, but did not know it and were eating gluten, we had a 'leaky gut'. There is no proven medical test for this type of theoretical damage, but it may affect us long after the celiac disease is under control.

Our intestines, when damaged by gluten, lose their mucous protective barrier. This probably allows abnormal particles of food and chemicals to cross the intestinal lining in a larger form. The body sees these large particles as foreign substances and may set up an immune reaction to them. Antibodies and other alarm substances called cytokines are produced to alert the lymphocytes to battle the particles, and inflammation occurs.

Increased intestinal permeability leads to a host of symptoms that we associate with celiac disease. Not only does gluten damage the villi and intestinal lining, but now other foods and chemicals can pass through into our blood stream in a form that the body cannot address and this might result in food and chemical allergies in some people.

We can also get an imbalance of good bacteria in the gut and too much bad bacteria. Good bacteria are called probiotics. Acidophilus, for example, is one of the good bacterias.

When we stop eating gluten, the intestinal lining heals, but the antibodies for certain foods and chemicals can still be in the blood stream. Now food allergies come to the forefront and we have to deal with new physical problems with diverse symptoms. Elimination of allergic foods is a big step toward healing completely. Unfortunately the foods we loved the most and ate the most of, now are usually the very foods that we must eliminate.

Many of us also need to deal with the imbalance of bacteria and take probiotics. Some studies on the bacteria in the gut in children with celiac disease show the need for probiotics. Each time we take antibiotics, we might need to restore the healthy flora to our gut by taking probiotics after our session of antibiotics is over.

(Note: From MAB member Nancy Schuller: *There is emerging evidence*

*of probiotic's benefits, but not everyone is the same! There is also information that you should not use probiotics with pancreatitis and that it can be dangerous, even fatal if patients develop an ischemia (restricted blood supply) in the intestine. As always, check with your health care professional before taking any OTC supplement or medicine.)*

## GF Pizza? Here?

CSA Region 6

Director, celiac,

and entrepreneur

Larry Schneider

has launched a

new business called **Gluten Free and Fabulous** (<http://www.glutenfreefabulous.com>).

You can buy his products through Amazon.com (use our website portal to help the group) or from Sprouts.

Larry assures us that his frozen GF pizza will soon be available in most Fry's supermarkets throughout the state, also. Samples of **Gluten Free and Fabulous Pizza** were handed out at the GFFF this May.

Call or contact the manager of your local Fry's to see when these pizzas will be available. You might also want to call Sprouts to see if they are now carrying it.

Remember, the market responds to demand, so demand more GF foods from your local grocer!



### Leadership Contacts

For email and phone contact info on any SACS' leaders, please email this website.



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