



Volume 6, Issue 6

Celiac Digest

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

online at WWW.SouthernArizonaCeliacSupport.org

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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.

GF Food Faire Extravaganza 2008!

That may seem like an over-the-top term, but this year the Gluten-Free Food Faire is so packed that it really can be called that!

After the unexpected record crowd at last year's event, the SACS Executive Board decided to plan the 2008 GFFF applying a different model. Not only will there be lots of donated food samples from your favorite GF vendors, but many of them (around 15 at last count) will actually be there in person passing out samples and information which is a first for our chapter. If you've ever attended a CSA Conference, this will be very

much like the Exhibitor's Hall that they have every year. There will be so many GF goodies to taste that



your eyes will glaze over!

Some of the vendors planning to personally attend include Tom Sawyer, Enjoy Life, Mixes from the Heartland, GF Creations Bakery (LynnRae Ries), Organic Bistro, Tastes Like Real Food, Chebe, Arbonne, ExFuze7, Lotus Garden, Juice+, Sunflower Markets and New Life Health Centers. Some of these reps will be cooking/baking right there, so you will be served fresh samples (yum!). Many more, like Kinnikinnick, Mary's Gone Crackers,

(Please see **Food Faire** page 3)

LATEX AND BANANAS - the new and improved PillCam lecture



DR. WATURA TAMURA

...At the March 29th general meeting, Dr Tamura wowed the crowd with lots of new slides and info that he added to his PillCam Presentation.

He stated that the endoscopic

study with biopsies can be negative, but the PillCam with its greater resolution and ability to reach the entire gut, can find many more cases. He showed pictures of other problems causing intestinal inflammation including Crohn's disease, NSAIDs inflammation, and radiation burns among others.

He focused on the importance of dealing with any cause resulting in inflammation in the gut because he feels that these are a trigger for a host of other auto-immune diseases.

When he sees someone come into his office with many different diagnoses, he looks for a cause originating in the gut somewhere. The long list of auto-immune diseases include all forms of arthritis, thyroid disease, gall bladder

dysfunction, frequent cystitis, colitis, and hyperlipidemia to name just a few.

The inflammation could be caused by celiac disease or food allergies. He tests all his patients for food allergies/intolerances, because he is finding this to be a common problem. It is very prevalent in those who have celiac disease. The symptoms may be similar to those we had when we first got diagnosed with CD. He personally thinks that food allergies and intolerances are a bigger problem than acknowledged and have a huge impact on health.

Dr. Tamura finds that people with food allergies may actually *crave* the food that is harming them. They

(Please see **PillCam** page 6)

Fair booth has big impact

By TALITHA RIECK



Photo: Diane Perrine

Ann and Bruce Kurth have volunteered at the County Fair every year.

We were reaching people, even people from other states. That is certainly what happened at the County Fair. No matter how many came by the booth, every family and every individual makes a difference. Due to SACS efforts, think of the changed lives from these brief encounters!

(These are just some of the lives reached by a warm "Hi" and "Have you ever heard of Celiac Disease?" from our SACS volunteers at the Pima County Fair this year.)

"...It has been a life saver for me and I have felt good all year." (A woman commenting on how last year's booth encounter changed her life)

"... a great way to provide information about celiac disease/gluten intolerance to many people who might not otherwise learn about the disorders. I spoke to many people who found the information helpful. Although we have no way of knowing what people actually do with the information we provided, just having the information is certainly a necessary first step toward diagnosis for many individuals." (Christina Pheley regarding the SACS Fair booth)

Reaching people who were long searching for that right diagnosis and hoping maybe Celiac would explain it all.

"One gentleman was very concerned about his wife who was having fairly serious but non-specific symptoms that had the doctors stumped."

"A 37-year-old woman with a little baby in a stroller, read the lists on the display and ticked off all the things she is suffering with. She seemed very discouraged because she is so young and yet constantly tired, and constantly dealing with a number of health issues. She had never heard of Celiac Disease. After talking with her and sharing our literature, she felt it very important to go back to her PCP to investigate if there is a connection between her fatigue, her other conditions, and Celiac Disease."

"This young military mother had never heard of CD until she came to the SACS booth. She spent about 30 minutes sharing her medical history with us, and then completed the "Celiac Score" sheet. After recognizing how many of the symptoms she currently has, she ended up filling out the registration form for the blood screening. She was very touched (to the point of tears) by our concern for her health and our purposefully-directed

(2) conversation." →

(Please see **County Fair** on page 5)

Chapter 15 Notes

Honey Baked Ham Co. has four corporations and four *different* shipping facilities and unfortunately they do not all carry/produce the same products. You still have to check the ingredients in the HB Ham available in your area to see if it is safe to eat.

General Mills Rice ChexR has been reformulated and is now GF! Look for the new Rice ChexR with the red gluten-free check mark on the front of the box. Thank you to General Mills for bringing more Celiac awareness to the market place.

Hundreds of Crock Pot recipes and many are easy to make GF at this site <http://crockpot365.blogspot.com/>.

This is especially helpful as you can make ahead and freeze portions for easy meals.

Rosarita Refried beans (traditional) are no longer on Rosarita's gluten free list.

CSA/USA: 877-272-4272, 9 a.m. to 4 p.m. Central Time. Their URL is: www.csaCeliacs.org.

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

Mark your calendar

(See SACS Leadership box Page 6 for phone numbers/email addresses)

May 10 — 9:00 a.m. Annual GF Food Faire and **First** Annual Community CD Screening program. Christ Community Church, 7801 E. Kenyon

May 28 — Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

June 25 — Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

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

'Normal' eating possible for celiacs?

By SHELLI HANKS, MD

Another possible treatment for Celiac Disease is in the works in the Netherlands. In the January issue of *Gut*, the Leiden University Medical Center published an article looking at the efficacy of an enzyme to treat gluten intolerance in an artificial gastrointestinal tract.

The enzyme, a prolytic endoprotease, has been shown to breakdown gluten proteins and peptides in laboratory experiments. The enzyme has a pH that is compatible

with stomach acid so it is not broken down by gastric juices. This allows it to remain intact in the GI tract where it can break down gluten.

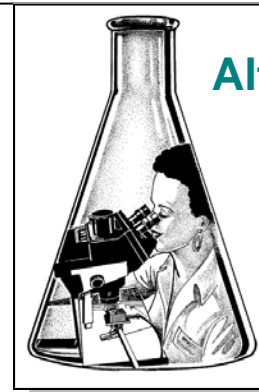
Dr. Mitea, from Leiden University, tested the enzyme in an artificial system designed to closely mimic the human gastrointestinal tract. They found that the enzyme accelerated the digestion of the glutenins and gliadins found in white bread. After 90 min-

utes, the gluten proteins could no longer be detected. Without the enzyme, the glutes persisted for at least 120 minutes. Similar results were found when a fast food meal was tested instead of white bread.

More importantly, the enzyme also completely abolished T-stimulatory activity in the untreated samples. During the time food is normally in the stomach, the enzyme led to a complete disappearance of T-cell stimulatory

peptides of gliadins and glutenins.

Researchers are hoping to proceed with human trials in the future. They believe the enzyme, which is readily available in large quantities, should undergo clinical trials to determine if it can eliminate 100% of gluten toxicity. If it works as they expect, it may provide a way for celiacs to stray from their diets without symptoms or long-term health consequences!



Alternative testing for Celiac Disease

The American Celiac Disease Alliance (ACDA) has this to say about stool/saliva tests for CD:

"There are well accepted criteria for the detection and diagnosis of celiac disease. The tests used to fulfill these criteria have been subjected to scientific scrutiny and validation. **To our knowledge tests of antibodies in stool or saliva have not been validated as a robust test for the diagnosis of celiac disease.**

Many insurance companies base their decision to cover the costs of testing on the scientific evidence that supports the testing of that individual (indication) and the actual test used (validation).

Food Faire

(continued from page 1)

Bumblebar, Glutino/GF Pantry are donating product samples for us to hand out to attendees.

This year, for the first time, we have a Cel-Kids Korner that will include hand-outs, face-painting and a jump-

ing castle! There will also be an opportunity for attendees to join the Cel-Kids group (free, of course). There will be moms of celiac children there to answer your questions or give you suggestions for what to feed your picky eater.

Probably the most exciting and different aspect of the Faire this year is the FREE celiac blood screening.

This is the first time in the history of

SACS that there has been a blood screening at any of our events. It is also the first such public celiac screening held in all of southern Arizona. You need only be 18 years of age and fill out/sign the registration form available on our website, or at the Faire. Preference will be given to those who pre-register, as well as those who are first degree relatives of those with biopsy-proven CD.

If you can help set up, tear down or pass out samples to the estimated 300-400 attendees, please contact Kathleen Joy (885-4514) to volunteer. This event truly fulfills the CSA mission statement of "Celiacs Helping Celiacs", and you can be a part of it.

Be **sure** to make a point of coming to the Food Faire and bring your friends, family and any others you think might enjoy tasting GF Food.

The Food Faire is held from 9am-1pm at the Family Life Center of Christ Community Church (see map page 6 or our website)

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County Fair

(Continued from page 2)

Reaching people whose children died or faced major life changes like autism and/or diabetes in the wake of delayed diagnosis.

“One baby son was so ill that he weighed less than when he was born. It took so long to get the right diagnosis that he almost died. He came through this trial left with autism and diabetes.”

“One family with an autistic child has been gluten-free, and they say he has improved markedly. They were aware of our website but not the Food Faire.”

“A young mother stopped by the booth to speak to me because she had been reading our display and saw the term “miscarriages/infertility”. She began to relate her story to me which started with her losing her two-year-old son to pancreatic cancer 13 years ago. I was immediately empathetic because I had never even heard of a 2-year-old having pancreatic cancer. She subsequently had a miscarriage of her next pregnancy. The good news is that she now has a healthy two-year-old.”

Reaching people who found that they, or someone they knew, shared these symptoms, so just maybe it could be Celiac.

“I heard many cases where CD was suspected or diagnosed in the family member or friend of a co-worker. I was pleased with how folks showed love and concern enough to take a brochure or GF FF invitation to share with that co-worker on behalf of someone they didn't even know.”

“The display with the lists of how CD might manifest itself caught another person's eye because he suffers with several of the things listed. He also told me how he pops Zantacs after every meal. I think the information and literature shared with him will be of help as he pursues answers to his health issues.”

Reaching People excited to be pointed to doctor who could do a good job getting the right diagnosis!

“One woman stopped by the booth who had been diagnosed perhaps a couple of months ago by Dr. Craig Gross. I was gratified for a couple of reasons; one is that Dr Gross diagnosed a friend of mine who is a member of SACS, and two, he is one of the two GI docs that we recommend (Dr Tamura being the other). It's nice to hear about when GI docs are catching CD.”

“She then told me that she was diagnosed with Hashimoto's approximately a year ago, and had 3-4 surgeries in the last year. At only 32-years-old, I told her that she

(5) was way too young for that type

of medical history! She went on to explain that she waited five months to have an appointment with an endocrinologist who was supposedly the best in Tucson. She was disturbed by the fact that she heard from us that CD is significantly correlated to Hashimoto's, yet this doctor never mentioned CD as being a part of the picture. Even worse, he felt that having Hashimoto's was ‘no big deal’ – not that serious! (She said that all of her other doctors felt that it is a serious diagnosis). I quoted to her the statement that Dr Fasano made when he spoke to SACS in 2004: “Hashimoto's is what you get when you don't treat your CD.”

“Many took a card for Dr Tamura, especially after expressing that their doctor did not seem to want to pursue a diagnosis, or they were still having problems while on a GF diet.”

Reaching people who work to heal people in the medical profession.

“Several in the medical profession who had heard of Celiac were glad to find out where to send people for help. Some showed us that SACS is getting the word out”

“A TUSD nurse said, “Hi,” and told me what good work SACS is doing from her perspective. I thanked her, suggested she take a handful of brochures and she said, ‘No, we already have quite a few at school.’!”

“Celiacs helping Celiacs” - diagnosed or not.

“One lady had been diagnosed, but said she ‘cheated’.”
“Even those individuals who have been diagnosed with celiac disease often do not understand the importance of being careful about what and where they eat.”

“I was surprised the number of people who had stopped by who knew about Celiac and had family members who had it. I gave at least six people the website, but most of them just really wanted to know where to purchase gluten-free food. I also handed out the sheet regarding the Food Faire; I invited all of them to come and join the group.”

“A young girl stopped who just got diagnosed with DH, and really didn't seem to know anything about the diet or SACS. Meeting people like this makes it all worthwhile.”



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Food Faire map



Leadership Contacts

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

PillCam

(Continued from page 1)

often follow patterns: for example, casein and egg are a common allergy duo. If one is allergic to one nut, they may be allergic to other nuts and seeds. He also mentioned that if one is allergic to latex, there is a common group of fruits that they will frequently be allergic to. Tree pollens are similar with related common food allergies. He is finding that pineapple is a very common allergy.

He recommends that everyone with celiac disease or *any* autoimmune disease get tested for food allergies. He uses the E95 basic and A95 extended food panel blood tests.

(6) _____

In his PowerPoint presentation he did include pictures of scarring, polyps, and a rare cancer of the small intestine. He recommends that those with celiac disease fol-

low up in a year or two after diagnosis with a PillCam, which now costs \$1,000, including the reading of the images and diagnostic report.



DR. TAMURA talks to PHOENIX WHEELER and other SACS members after his March 29th presentation.