



Volume 5, Issue 5

Celiac Digest

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

online at WWW.SouthernArizonaCeliacSupport.org

May 2007

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.

CSA President Elect main speaker at March meeting

The draw of our speaker, Bill Eyl, and the lure of fresh GF breads from GF Creations Bakery brought about 60 people to our March 24th general meeting. Cheryl Wilson entertained members with a photographic slide show of the Westward Look facilities in a preview of what we can expect during the Sept. CSA Conference.

Membership Chair Sue Beveridge reported that have 179 members and are growing monthly. Phoenix Wheeler spoke about the progress of a group effort to organize a GF residence facility. While this group uses SACS's email list, and we work closely with it, it is not officially a part of SACS or CSA due to our non-profit status and mission charter.

Member Sande Smith spoke briefly about holding GF cooking classes in

Tucson and asked for a show of hands as to who would be interested in signing up for it. The classes would cover comfort foods, bread baking and a kids' class. Watch for future updates and notices on these classes.

Bill Eyl, the Celiac Sprue Association's (CSA) President-elect, is passionate about the idea of Celiacs helping Celiacs and believes that joining this national organization is the best way to do that. Assisted by a Power-Point presentation, Bill outlined the goals of CSA to Provide: • Educational materials • Mutual support • Promote research community • Provide clinical diet information • Work to improve labeling practices • Promote awareness, and • Solicit funds to make it all possible.

He related a humorous anecdote



BILL EYL, CSA President Elect, speaks at our March meeting.

about CSA's attempts to reach members of congress with CSA's concerns in re food labeling laws. Evidently, it was more mentally and physically demanding than any of them anticipated.

(Please see **Bill Eyl** on page 4)



Food Faire at *new* location!

Don't miss this year's annual Food Faire which will be held May 19th - 9 to noon at Christ Community Church in the Oasis Auditorium, 7801 E. Kenyon Dr., Tucson. [CCC is located on the NW corner of Pantano/Kenyon. Park along the north driveway or in the back for better access to this building. We will have signs up. SEE DETAILED MAP PAGE 2 or click on links at our website.]

Author LynnRae Ries will be giv-

ing an update on her work, along with offering some of her most popular baked goods (from *Gluten-Free Creations Bakery* in Phoenix) for sale to attendees. Ms Ries will be available to autograph copies of any of her books. (see related story page 3)

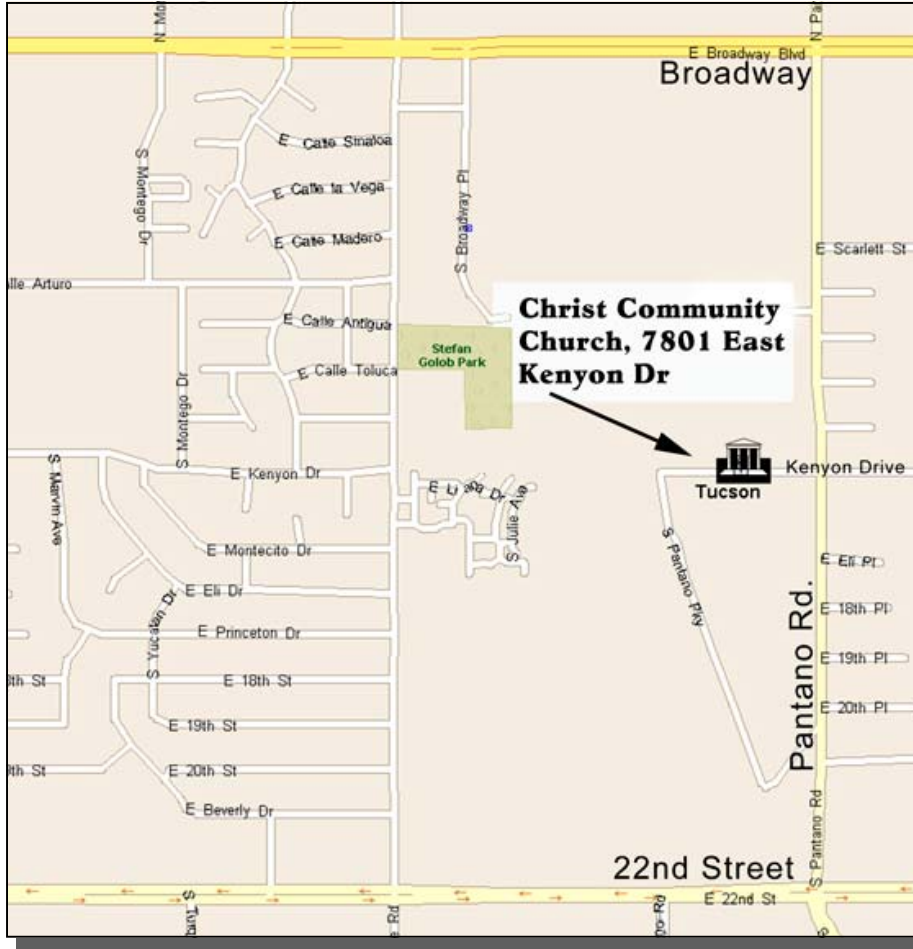
Also at the Food Faire will be Celiac Sprue Association (CSA) Executive Chef, Aaron Flores, an entertaining speaker who is extremely knowledgeable about the special techniques

used in gluten-free cooking. He will be giving a sneak preview of the menu for the CSA Conference to be held in Tucson this September.

We will also have a Silent Auction fund raiser (see page 6) as well as some fabulous raffle prizes. Bring your check book *and* your appetite.

Remember, this is the one event where **YOU** don't bring in any GF foods to share. This is an opportunity to sample new GF products on the market. And, it's free!

Map to the May 19th Food Faire



Chapter 15 Notes

See's Candies as of 2006 are GF except for some flavors which contain malt. Since they are no longer using wheat in any of the formulations, cross contamination is also no longer an issue.

In-N-Out Burgers have GF fries and their burgers are, too, if ordered *protein style*, which means wrapped in lettuce. They are located at 3711 E. Broadway Blvd, just east of El Con.

Bragg Liquid Aminos is an all-purpose seasoning made from soy protein. It looks, smells and tastes like 'regular' soy sauce which is usually made from fermented wheat. See www.Bragg.com for more uses and health information.

RiceWork chips ARE GF even though oat fiber is listed on the ingredient list. They printed the packages and then changed the formulation, omitting the oats. An independent company tested the product and certified it GF

The Cheesecake Factory (three locations in the Phoenix metro area) reports that the only GF cheesecake they offer is their Godiva Cheesecake. However, since all their cheesecakes are produced in the same facility on shared equipment, cross contamination is a possibility.

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

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

R.O.C.K

Raising *Our Celiac Kids* group is starting up again. See details and phone numbers on our website at www.SouthernArizonaCeliacSupport.org.



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GF Creations will close May 18th!

Lynn Rae Ries, co-owner of *Gluten Free Creations* announced May 3rd that she will be closing her bakery by May 18th unless an investor comes forward to help with the next growth step. If not, the bakery is up for sale - hopefully to a gluten-free buyer. She is actively looking for a way to keep this business going, so contact her if you or someone you know can invest in or otherwise help this company.

This is really bad news for celiacs in Arizona as she has the only dedicated GF bakery in the state. What makes it doubly hard is that she undoubtedly makes the very **BEST** gluten free pastries/breads that any of us have ever tasted.

Lynn Rae is planning to come to



SACS members eagerly line up to buy GF bread supplied by **Gluten Free Creations** owner Lynn Rae Ries. All of the product sold out within minutes.

the Food Faire on May 19th and will have some product to sell. Please contact her directly to determine quantity and type. Her phone number is: 602.485.8751 and email address is: glutenfreenews@cox.net

(Yes, it's **three** repeated 'E's in the email address.)

SACS earned over \$40 from Lynn Rae's donation of wholesale GF goodies which were sold at the March 24th general meeting.



Shelli Hanks, MD

New MAB member an asset to SACS's educational programs

She's a celiac, the mother of a celiac and a medical doctor - any one of which makes her uniquely qualified to teach others about celiac disease.

Shelli Hanks, a new member of our Medical Advisory Board (MAB) drew on all three experiences while speaking on April 18th to an audience of TUSD School Nurses at a meeting sponsored by Laurel Kruger, Coordinator Staff Development for TUSD Health Services.

While Shelli covered the medical aspects of CD, Cheryl Wilson did a polished presentation on aspects of the GF diet. Both of them fielded questions from the interested audience of RNs.

Dr. Hanks is on leave of absence from her position as a radiation oncologist. She has four girls ranging in age from two to 16, so it's not hard to imagine all the demands on her time. She's going to be working with the ROCK group, too.

Win a gluten-free buffet

The CSA chapter that recruits the **most** new CSA members (over and above 25 people) for the year 2007 will win a buffet dinner for a maximum of 150 people. Chef Aaron Flores will work with a local restaurant in the area, adapting a celiac-style menu for the event..

Join CSA/USA now and get a substantial discount on the Sept. Conference, help us win a GF dinner, **and** help other celiacs, too! Join online at <http://www.csaceliacs.org/>



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Gluten Free Creations
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SACS spreads Celiac scoop

By VIRGINIA MORGAN

Working at

the Celiac booth during the Pima County Fair is a stimulating experience! People stop to read the attractive and well-designed posters, and then all we have to do is ask a simple question such as "Do you have any of these symptoms?."

That opens up a conversation about celiac disease and its myriad symptoms. We are able to reach some people who have the disease, but who do not know about our group.

We encourage others, who are undiagnosed, to talk to their doctor or to see Dr. Tamura for testing concerning their medical problems. Some come for information to give to a friend or relative who has celiac disease.

There is a display of gluten-free food to show people that we are not deprived on this diet. We also distribute handouts and a bag to put them in, giving people the opportunity to read the information at home.



SACS member Virginia Morgan explains celiac disease to an interested visitor at our booth at the Pima County Fair which ran April 19-29.

Of course, we can also refer people to our web site where they can get more information.

SACS's goal is to reach the many thousands in Tucson who have the disease, but are as yet undiagnosed, and to encourage those with the disease to join our support group.

We accomplish that goal by our presence at the County Fair.

With two of us manning the booth, we had the ability to take brief breaks so that it wasn't tiring. Each person who volunteers knows he or she is doing our community a much-needed service.

Next year, we hope more of you volunteer. It is an easy, fun, and rewarding activity which entails only about four hours of your time.

Bill Eyl

(Continued from page 1)

CSA has softened its original (pre 2003 position) that the only acceptable standard for a GF label would be 0 ppm which is no gluten at all. Due to more sensitive tests like the ELISA R Biopharm RIDASCREEN®, CSA has accepted the standard of 3 ppm as being essentially 'Gluten Free' and provided a CSA Seal of approval which is reproduced on this page.

Bill disagreed with the present allowance of 200 ppm of gluten in items that are labeled GF as he said there is no way to determine the long-term health consequences of ingesting gluten at that level.

Bill Eyl will be at the Conference in September and is looking forward to (4) meeting you all again there.

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Celiac Sprue Association®

The manufacturer of this product is pleased to be recognized by the Celiac Sprue Association® (CSA®). The use of this Seal on an article means that the manufacturer has agreed to adhere to CSA's standards in representing this article to be free of wheat, barley, rye, oats, their crosses and derivatives in product, processing and packaging.

Visit CSA at www.csaceliacs.org or call toll-free 877-CSA-4-CSA.

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JAMES R. BEAMAN
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What're you packin' for protein power?

Every celiac carries them. You know, the emergency supplies of food in case you get stuck somewhere and have no way of getting safe food.

Luckily for us, GF energy bars come in a great variety. *Here are some of the favorites.*

Boomi Bars (nuts/fruit) – Pros: delicious, healthy, safe and they don't melt. Cons: expensive, low in protein and only available via mail order.

Bora Bora Bars – Pros: available in a three-flavor pack at Costco, inexpensive and tasty. Cons: contains nuts and 1/3 of the bars in the pack have oatmeal in them. Labeled GF.

Bumble Bars – Pros: available in most health food stores, safe, don't melt and come in various flavors. Cons: there isn't much protein in them and some people don't like the texture in terms of all the seeds.

Larabars – Pros: available in a three-flavor box at Costco, labeled GF, and tasty. Cons: low protein and high sugar nut and fruit bars with mostly dates as the base ingredient.

Pure Fit Nutrition Bar – Pros: no dairy, wheat or gluten, tastes OK and does not melt. Cons: lots of soy in it and it can have a bit of a gritty texture.

Some of the lower sugar, GF varieties for those who are conscious of the glycemic index:

Impact Meal Alternative Bar by

Vitapath - Smores and Peanut Butter flavors with 14 gms protein and 1 gm sugar. These are only available online. Go to the Amazon link from our website.

Nutiva Flax Seed and Raisin has 7 gms of protein and 8 gms of sugar



and can be purchased locally. And, Nutiva Hempseed organic bar with 9 gms of protein and 5 gms of sugar **Ruth's Very Berry Flax Power** with 7 gms protein and 4 gms sugar is available locally.

Think Thin – Pros: available locally, tastes like a candy bar and has lots of protein. Cons: it melts easily and contains soy and dairy. It is available in several flavors.

*The following are **not** labeled GF, but members report no problems with them.*

America's Protein Bar - Pure Protein High protein double layer bar, Country Blueberry Pie or Strawberry Shortcake with 2 gms sugar and 20

gms of protein. These are available locally and have a good flavor.

Power Bars Nut Naturals Mixed Nut flavor or Fruit and Nut Flavor 10 gms of protein and 8-9 gms of sugar. These have whole oats listed as a trace ingredient but may not cause you any problems.

South Beach Diet Meal - Vanilla Cream or Cinnamon Cream flavors with 19 gm protein and 1 gm sugar. Always read labels since these can change. Others flavors may have a gluten ingredient. They are tasty enough.

Outreach

(Continued from page 8)

The Fair booth idea was initiated by Cheryl last year and was an even bigger success this year. This is the most labor intensive and depends upon the hard work of member volunteers over a 10-day time period. (see story page 4)

Right near the end of the County Fair, Cheryl hosted **another** booth, this time at the **Spring Health and Safety Fair** sponsored by Barnes and Nobles. This was well attended and gained us a new member.

On May 4th, at the Arizona Dietetics Association Conference at the Marriott Starr Pass, Dr. Tamura and Nancy Schuller both gave wonderful PowerPoint presentations that complemented each other's area of expertise. SACS's big banner was behind the presenters, reinforcing the symptoms of CD for the audience and our presence in the community. Cheryl, Sue Beveridge and Shelli Hanks were there, video taping the presentations and hosting an informational booth for attendees.

Remember, it's your membership, your donating the time to volunteer, and your financial support that makes all this possible.

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Get incredible bargains at Silent Auction

Colleen Beaman, organizer of this year's Silent Auction said this is just a partial list of the items available for you to bid on. All proceeds, of course, go to benefit SACS.

The main reason for this year's fund raising is to help members with a portion of their fees for attending the CSA Conference in September. Bring your checkbook to the May 19th Food Faire! All donations are tax deductible.

Autographed book *The Celtic World* (12.95) donated by author Patrick Lavin

Darryl Wong's *Lotus Garden* \$25 gift certificate

Elephant Bar and Restaurant in

Peoria, AZ \$25 gift card
Gift cards from *Applebee's* (3)

Gift cards from the *Tire Corral* (3) (each totaling a value up to \$479 in services)

Gift certificate for *Last Will and Testament* (donated by law offices of James R. Beaman)

Gift certificate from *Fronimo's Greek Café* \$20

Office Ultimate 2007 – sells for \$562.99 (at Amazon.com) – Donated by

Microsoft Corporation

One *Hypnosis Therapy Session* of Your Choice -Value \$150.00 (by Dr Eric Horowitz)

One *Private or 5 Dance Classes* with Colleen Kelly Beaman (value \$50)

One *Private Piano Lesson* with Colleen Kelly Beaman

Painting by Western Artist *Alvin Carroll* value \$400 (donated by Catherine Devine)

T-shirts (2) from the *Moja 2 Running Team* (donated by Saul Soto)

- Office Word 2007
 - Excel 2007
 - PowerPoint 2007
 - Outlook 2007 (with Business Contact Manager)
 - Publisher 2007
 - Accounting Express 2007
 - Access 2007
 - Groove 2007
 - OneNote 2007
 - InfoPath 2007
- Sealed box, licensed for noncommercial use on up to three computers w/ XP or Vista



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Fresh faces and fresh ideas?

It's that time of year again and SACS does not have a nominating committee this year, so we would like *you* to nominate someone (like yourself?) you believe might make a good officer on our Executive Board.

We have some members who would like to retire, but naturally, we are not letting anyone go until after the conference in September. Please put your thinking caps on.

We truly need members that will commit to attending the monthly board meetings (11x/yr) and the general meetings (5x/yr). No experience is required, and, remember, you get more out of this than you will put in. (Contact Cheryl - see page 7)

In order to offset increased printing and mailing costs, the **Celiac Digest** is accepting advertising on a limited basis. The costs are for one year (six issues).

Business card size = \$60
1/4 Page = \$150
1/2 Page = \$300

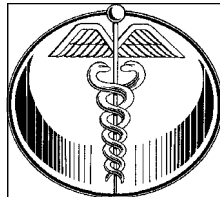
Contact Connie Beuerlein at connie@chbdesignlink.com or 520.615.9494 for details.

ADVISORY: Please be aware that, although the ingredients may be gluten free, the owner told us that there are **no** dedicated prep or cooking surfaces in Lovin' Spoonfuls (including a toaster). We recommend that no celiac have his or her GF bread toasted (make sure you advise your server), and remind the server that whomever is preparing your food needs to change plastic gloves before touching your food, We also recommend that you do not order peanut butter & jelly sandwiches, since they use the same PB & J jars for all customers (so there may be gluten crumbs in them). If you consider yourself a 'sensitive' celiac, please be advised (6) that there *may* be cross-contamination issues that *could* cause a gluten reaction.

Medical news to use

A negative blood test means you don't have celiac disease? Don't assume so says a study carried out at Columbia University College of Physicians and Surgeons in New York. They found that sensitivity studies performed in clinical practice varied a great deal from studies carried out by the manufacturers of the tests themselves.

In a 2004 investigation of 115 adults, the study authors found that the blood test was only positive 77% of the time with patients with **total** villous atrophy (flattened villi from severe, long-term celiac disease) and positive only 33% of the time with those with **partial** villous atrophy (villi



that still had some length).

If you or your reluctantly-tested relatives come up as negative on the blood test, encourage your doctor to look further in terms of a biopsy with the tissue examined with an electron microscope or a full-intestine scan with a PillCam®.

The abstract from PubMed (a service of the National Library of Medicine and the National Institutes of Health) is below. The full text of the article can be purchased online.

SERONEGATIVE CELIAC DISEASE: INCREASED PREVALENCE WITH LESSER DEGREES OF VILLOUS ATROPHY.

Abrams JA, Diamond B, Rotterdam H, Green PH., Department of Medicine, Columbia University College of Physicians and Surgeons, New York, New York, USA.

*Our aim was to assess differences in the sensitivities of serologic tests used for the diagnosis of celiac disease among patients with varying degrees of villous atrophy. Among 115 adults with biopsy-proven celiac disease who fulfilled strict criteria, including serologic testing at the time of diagnosis and response to a gluten-free diet, 71% had total villous atrophy and 29% partial villous atrophy. Endomysial antibody was positive in 77% of those with total villous atrophy, compared to 33% with partial villous atrophy (P < 0.001). There was no difference in sensitivity when the type of presentation (classical vs. silent) was compared. Endomysial antibody-positive and negative patients did not differ with respect to age at diagnosis, duration of symptoms, mode of presentation, or family history of celiac disease. All anti-tissue transglutaminase-positive patients had TVA on biopsy. Seronegative celiac disease occurs. Endomysial antibody positivity correlates with more severe villous atrophy and not mode of presentation of celiac disease. **Serologic tests, in clinical practice, lack the sensitivity reported in the literature.***



In Memoriam
Pat Ewing
1932-2007

When Pat Ewing was diagnosed as a celiac in 1982, she and her husband Randy started investigating what was "out there" in terms of help. They found the year-old CSA/USA then called *Midwestern Celiac Association* based in Omaha, Nebraska.

Pat and Randy started forming a local group which over the years grew to almost 100 members. It was a very active group until Randy Ewing's long illness and subsequent death. Then the group meetings were put on hold until they were later resumed as the very active group we have today.

Pat suffered a fatal stroke in April and, at her request, no services were held. We shall miss her.

In Memoriam
Jim and Mike Franklin
1940 & 1943—2007

Jim and Mike (Mary Michaelen) Franklin long-time residents of Tucson and SACS members died April 15, 2007 in the crash of their private plane near Sedona, AZ.

We will miss their participation and smiling good humor. Services were held April 23rd at St. Mark's Church, in Oro Valley, AZ. (7)

Leadership Contacts

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

SACS does 'reach and teach'

Under the energetic leadership of President Cheryl Wilson, SACS has been hitting the road and dispensing our message at numerous high-profile venues.

The first one was a lecture on **Gluten-Free Food Choices**, where Cheryl explained GF available foods and some aspects of CD to an audience at Sprouts Farmers Market this March. Other SACS members hosted a table and distributed handouts for

the rest of Sprout's 10-day spotlight on GF foods.

Then, Dr. Shelli Hanks and Cheryl gave a tandem presentation to the TUSD Nurses in April (see p.3) This was so well received that they have been invited to the AZ School Nurses Assoc. annual conference which will be held in July in Phoenix.

The Pima County Fair has become another important outreach program. (Please see **Outreach** on page 5)

Mark your calendar

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

May 19 - 9:00 a.m. to noon: Christ Community Church, 7801 E. Kenyon Dr See map p. 2 this issue. **ANNUAL FOOD FAIRE** - Bring your appetite only as vendors send food. **SILENT AUCTION**, so bring your checkbook.

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

June 27- Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

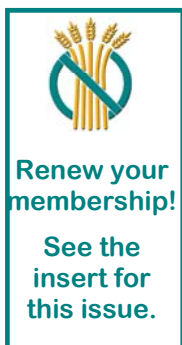
July 25 - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

August 22 - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

September 26 - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

September 28-30 - CSA Annual Conference, Westward Look Resort, Ina/ Oracle.

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(8)

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(Check here if you are **UNWILLING** to let us publish the above information in our chapter directory)

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Physician's name: _____ Gastroenterologist's name: _____

Year diagnosed: _____ Current member of National CSA/USA, Inc.? _____

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