



Celiac Digest

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

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November 2005

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.

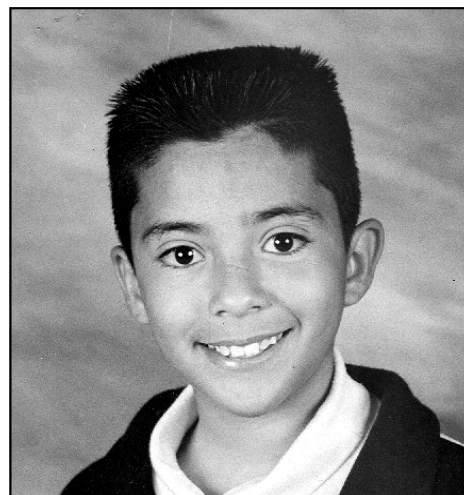
SACS 'adopts' Celiac Mexican boy, 12

SACS has "adopted" a 12-year-old boy, Oscar Ceron (AKA "Tito"), in Mexico who has Celiac Disease, Dermatitis Herpetiformis and lactose intolerance. His mother is having difficulty providing him with safe food and obtaining information about and treatment for his Celiac condition. As a group, SACS is sending and/or delivering packages of GF foods for him.

Because of the language barrier, it is hard to find out exactly what foods he likes to eat, but we did ascertain that he likes cereals and breads best of all. Any donations of 'kid friendly' GF foods *or* cash are appreciated. Bring them to any Roundtable or General Meeting. Mary Louise Catura, Shirley Curtis, or Sue Beveridge will be happy to hold the

donations until we can ship, via UPS, another box of goodies. Tito's family has provided us with an address on the US side of the border where we can send food.

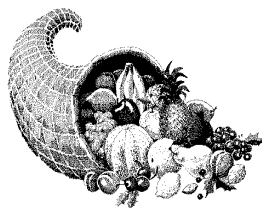
Since Tito's mother speaks only Spanish and has no Internet access, it is very difficult for her to cope. According to her, there are only three diagnosed Celiacs in Sonora, and one of them, a toddler, has already died. Understandably, his mother is extremely concerned about Tito, especially since it is almost impossible to buy GF processed foods in Nogales. Please contact any board member if you are fluent in Spanish and would be willing to drive down to Nogales to speak with Tito's mother, or if you would speak with her on the phone in order to give her



OSCAR DANIEL CERON ("Tito") is struggling with Celiac Disease.

advice or learn more about Tito's food preferences and CD problems.

Share GF holiday foods, conference updates Nov. 5



SACS members will share samples of their creative GF holiday recipes

such as pumpkin pie, stuffing, pumpkin-shaped cookies and cornbread when SACS holds its general meeting at **9 a.m. Saturday, Nov. 5th in the Alamo Room at Tucson Medical Center.**

Chris Maynard, manager at the Firecracker Bistro, 2990 N. Swan Rd., will share samples of GF menu favorites he has developed. Prizes will be

awarded in a fund-raising raffle. SACS members will also be asked to vote on amending the bylaws governing our group. These changes were discussed at the September meeting.

Nancy Schuller, R.D, dietician at St. Joseph's Hospital, a Celiac, and long-time advisor to SACS, will report on the Sixth Annual Stanford Celiac Conference held on Saturday, Oct. 8, 2005, at Stanford University, CA.

The conference was designed for primary care physicians, nurses, nurse practitioners, dieticians, and celiac patients.

Hetty Pardee, SACS treasurer, and

her husband, Stanley, will report on the 28th Annual CSA Conference held Sept. 30-Oct. 2, 2005 in Tysons Corner, a suburb of Washington, DC.

Even though the gastronomic theme of the meeting is "Holiday Harvest", any GF foods are welcome. As always, include the wrapper if you purchased the completed dish, or make a complete list of ingredients if the dish is home made. **Set the ingredients list next to the dish.** If feasible, bring copies of the recipes to share.

We need to display ingredients because many SACS members come with a variety of food sensitivities.

SACS founder to receive philanthropy award



PAT EWING at the CSA Conference in OK City, 2004

Pat Ewing, who was a primary founder of SACS 20 years ago, will be among 27 volunteers from various organizations to be cited at noon, Nov. 4. They will receive *Spirit of Philanthropy Awards* from the Association of Fundraising Professionals

during a luncheon at the Westin La Paloma Resort.

SACS members and friends who wish to attend the luncheon should contact Georgina Rubal, chapter president. Nov. 4 is National Philanthropy Day 2005.

Pat was nominated by SACS in recognition of her leadership, vision, time and effort she provided to create and build the organization over the years, starting with about eight members meeting in her home.

Georgina said, "Pat Ewing was determined to help other individuals like her, who were diagnosed with CD. She helped them learn about what they were permitted to eat on a strict gluten-free diet. Pat did this by inviting other Celiacs to her home to guide and comfort them as they began to make a lifestyle change with the GF diet."

Health news to use

Celiac 'Pill' holds promise

Australian doctors have developed a substitute for the missing enzymes to offer sufferers relief and a broader diet. Researchers at RMIT University in Melbourne have developed a treatment that restores the gluten-processing enzymes, ending a very long wait for patients.

"This use of enzymes is quite a breakthrough because patients have only had use of a gluten-free diet for the last 50 years," biochemist and Professor Hugh Cornell, from RMIT, said.

Jennifer Angwin took part in the first trial of the supplement at the Royal Melbourne Hospital. She took the pills just before eating foods high in gluten and found the reaction was reduced.

"To have the opportunity to take the capsules and know the likelihood of an attack is far diminished would be wonderful," Ms Angwin said.

The new treatment is *not designed to replace* a gluten-free diet. But researchers say it could be used as a safeguard when patients do not know what is in the food they are eating. After the success of the first trial, the treatment will be tested on a bigger group of volunteers.

Doctors hope it will be available at the end of next year.



Zonulin blocker in trials

Alba Therapeutics Corp. announced in Sept. 2005 that it has begun first human dosing of AT-1001, an orally administered zonulin receptor antagonist that is being developed for the treatment of Celiac Disease (CD).

The double blind, placebo controlled dose escalation study will evaluate the safety, tolerability and pharmacokinetics of AT-1001 and is being conducted in twenty-four nor-

Please see *Health news* page 3

Chapter 15 Notes



Volunteers are needed to design and construct a portable and durable presentation board on Celiac Disease that can be displayed at health fairs or other awareness events. Contact any board member if you can help.

Up-to-the-minute Celiac news is available on our website via a news-feed script supplied by Celiac.com. Check out the site often.

Quinoa flakes substitute pretty much cup for cup for oatmeal. Take a regular oatmeal cookie recipe and any GF flour blend that substitutes cup for cup and start baking. The quinoa flakes also work well in fruit crisp toppings that call for oatmeal

Buy a five-year membership in SACS for \$50 and save \$10. The regular price is \$12 per year.

CSA/USA: 877-272-4272, 8 a.m. to 3 p.m. Central Time. Their URL is: www.csaCeliacs.org.

Change of address/phone number: Change of email: Notify us via the website or call 742-4813

Subscription discounts are available if at least 10 new readers sign up for *Living Without* magazine. Contact Mary Louise Catura at 298-1038.



Members enjoy savory dishes, sample baked goods at September Potluck

Savory gluten-free dishes ranging from a highly-spiced African recipe to an eggplant lasagna to chicken salad to cheesecakes satisfied appetites of some 30 attendees at the Sept. 25th Potluck in Reid Park. The lasagna recipe is on Page 4

Those attending the potluck endured an hour's wait in the late-summer heat waiting for park officials to unlock the facility. The administrative mishap resulted in a \$32-refund from the park.

There was some disappointment due to the cancelled appearance by the featured speaker, LynnRae Ries a GF baker and author, but members enjoyed samples from Celiac Specialties, a Chicago-based GF bakery that provided donuts and cookies that were certainly popular.



SACS MEMBERS tuck in at the annual Potluck at Reid Park.

An informational handout on Celiac after care from the University of Chicago Celiac Disease Program was available at the Potluck and is included in this newsletter. Members are encouraged to make this information available to their health care

providers.

President Georgina Rubal also explained proposed changes in SACS bylaws that will require a vote by the general membership on Nov. 5 at our next general meeting.

Leadership Contacts

Send an email to: info@southernarizonaceliacsupport.org for contact information.

Sweet rice flour makes a passable thickener, white sauce

Do you have foods requiring sauces that you plan to freeze or refrigerate prior to serving? Sweet rice flour is touted as "...is a superior thickening agent especially good for recipes to be refrigerated or frozen. It inhibits

liquid separation." or so claims the folks at *Authentic Foods*.

Basic White Sauce:

- 4 Tablespoons butter or margarine**
- 1 1/2 cup milk**
- 1/4 teaspoon salt**
- 1/8 teaspoon pepper**
- 2 1/2 Tablespoons sweet rice flour**
- 1/4 cup milk**

Over low heat melt margarine or butter in 1 1/2 cup milk, salt and pepper. Make a smooth paste of 2 1/2 Tablespoons sweet rice flour and 1/4 cup milk and add slowly to heating mixture. Stir over heat until thickened.

Health news

(continued from page 2)

-mal volunteers.

"The data we plan to generate from this and subsequent Phase 1 studies will educate us on the safety and tolerability of AT-1001, in addition to quantifying the impact of this novel compound on intestinal permeability," stated Dr. Blake Paterson, CEO of Alba "It is a great day for celiac patients and we look forward to rapidly generating the clinical data necessary for the continued development of AT-1001 as a potential therapy for CD and other autoimmune diseases."

Dr. Alessio Fasano is the discoverer of Zonulin and co-founder of Alba Therapeutics.

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New member's specialty— Eggplant Lasagna

VIRGINIA MORGAN developed this healthy, GF lasagna that uses no noodles .

Eggplant Lasagna

Make eggplant 'noodles'

Peel eggplant (optional if the vegetable is young and tender)

Slice thinly

Soak slices at least ½ hour in salt water and then drain and dry

Dip the dried slices into a **well-**

beaten egg mixture

Then, **dip** in **GF corn meal**

Fry these slices in **oil** over medium-high heat for about one minute per side

Use these 'noodles' in layers for the lasagna

Sauce:

1 pound hamburger, *sautéed* with the fat drained off

One **25 to 28 oz. jar of GF spaghetti sauce** (Italian style) or homemade spaghetti sauce

Heat together and season to taste with more **salt, pepper, oregano and garlic**

Assembly: Layer, in the order given, in large baking dish, making thin layers several times:

Fried eggplant slices

Hamburger sauce mixture

1 pound grated mozzarella cheese

1 pound ricotta cheese

1 cup grated parmesan cheese

(optional layers might include 1 pound chopped spinach or small slices of broccoli stems and flowerets)

Bake uncovered in a 350 F oven for 30 minutes. **Refrigerate**. Reheat the next day for the best flavor and serve hot. It may be microwaved before serving the next day.

Mark your calendar

(See **SACS Leadership** box Page 3 for phone numbers/email addresses)

Nov. 5 - General Meeting, TMC, Alamo Bldg. CSA Conference Update, 9-12

Nov. 11-GF Lunch Bunch, *Paco's Tropical Café*, 5819 N Oracle Rd, Noon. RSVP @ 888-2935

Dec. 9- GF Lunch Bunch, *Lotus Garden*, 5975 E Speedway Blvd, noon. RSVP @ 888-2935

(no Roundtable in Nov. or Dec.)

2006 Events

Jan. 14 - tentative date for general meeting. Topic TBA

March—Rice Innovations Spaghetti Dinner fundraiser, details TBA

May—Food Fair and Elections, details TBA

Southern Arizona Celiac Support
Chapter 15, CSA/USA
P.O. Box 0905
Cortaro, AZ 85652-0905

ADDRESS CORRECTION REQUESTED

First Class Mail



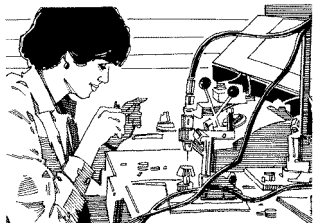
Sharing advice for a gluten-free life.

UNIVERSITY OF CHICAGO CELIAC DISEASE PROGRAM

Fact Sheets about Celiac Disease

What does follow-up testing do?

Follow-up testing is conducted to ensure that antibody levels are returning to normal, indicating that the intestine is healing on the new diet. **For this reason, repeat intestinal biopsies are no longer necessary.** These tests also indicate the extent to which a celiac is avoiding gluten and can detect when hidden gluten has entered the diet.



How often should follow-up testing occur?

New celiacs should receive follow-up testing twice in the first year after their diagnosis. The first appointment should occur three to six months after the diagnosis, and the second should occur after one year on the gluten-free diet. After that, a celiac should receive follow-up testing on a yearly basis.

What tests are needed at follow-up appointments? How are they interpreted?

New guidelines on the diagnosis and treatment of celiac disease by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition state that tTG-IgA testing should be used for follow-up care. Interpreting this test result is straightforward – a celiac on the gluten-free diet should have a negative test. The numerical value of the test is not important.

Follow-Up Test #1:

tTG-IgA: This test result should be negative.

The numerical value of the test doesn't matter as long as the result is negative.

The University of Chicago Celiac Disease Program recommends additional testing because the tTG test can sometimes be inaccurate in people with autoimmune disorders like Type 1 diabetes and thyroid disease. In addition, the tTG can sometimes become negative before a celiac has actually experienced significant healing.

For these reasons, Anti-Gliadin Antibodies (AGA) are also important. These are two types that need to be run: AGA-IgA and AGA-IgG. In this circumstance, the numerical values of the tests are very important. The numbers should be as close to zero as possible, indicating a minimal antibody response to gluten. The additional advantage of these tests is that the blood can be drawn by any physician and sent to any laboratory.

Follow-Up Test #2

Anti-gliadin IgA: This result should have a very low negative value.

In this case, the numerical value does matter, because a high negative test result still indicates that a patient is eating gluten. A low negative indicates that the diet is working well.

I was diagnosed 15 years ago, and have never received follow-up testing. Why should I start now?

It's never too late to begin follow-up testing and to learn from the results. Food manufacturing practices change often, and even the most diligent celiac cannot keep up with all the changes. In addition, some celiacs find that current health problems may be related to celiac disease, such as anemia or bone density. The reverse is also true – some find that current health problems they've attributed to celiac disease aren't related because their antibody levels indicate that celiac disease isn't active. In either case, the patient and the physician have received valuable information.



While follow-up testing is especially important for people in the first five years after diagnosis (this is when the most serious complications of celiac disease can occur) testing can help all celiacs know that they are doing well with the diet or need to make changes to protect their health.

I worry that I might be feeding my child the wrong foods, and I can't tell if her stomachaches are from celiac disease or something else.

For concerned parents, and for anyone who worries if they are making the right food choices for themselves or their child, follow-up testing can be very helpful. Negative test results reinforce that the family's approach to a child's gluten-free diet is working well.

I've been having joint pain, and I think it's from celiac disease. I follow the diet very carefully.

Follow-up testing is important and can be performed when there is a question about whether or not a health condition, like joint pain, could be related to celiac disease. A series of positive antibody tests (indicating gluten in the diet) may indicate that a complication of celiac disease exists, in this case, joint pain. When antibody tests are negative, indicating a strong level of compliance with the diet, it is unlikely that celiac disease is contributing to the worrisome condition. While this is not an exact science, follow-up testing can often clarify whether or not a health condition could be a complication of celiac disease.

Questions?
Call the University of Chicago Celiac Disease Program
773-702-7593
Monday – Friday
9 am to 5 pm Central Time