



Celiac Digest

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

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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.

At-home finger-stick kit screens for CD, GF-compliance

Now you can monitor yourself for gluten-free diet compliance and/or screen children and others (like reluctant relatives) for Celiac Disease with the at-home Finger-Stick Rapid Test Kit for CD and Gluten Intolerance. It takes a drop or two of blood and about 10 minutes for results. Kits ship from York Labs in Florida for \$99 each, with quantity discounts, and are as accurate as a full Celiac Panel, which takes a full blood draw and weeks for results.

In the home test, the blood is “read” for the number of colored lines on the test strip – like a home pregnancy test. If no lines are present, the sample is IgA deficient or the kit is defective (and replaced by York Labs). There are two test strips included – one for Celiac Disease and one for Gluten Intolerance.

The tests, from Europe, are available only through York Labs but contain an insurance code and can be or-

dered by doctors/clinics as well as by individuals. Reliability tests were conducted in Spain, Italy, Hungary and Finland. (<http://www.medscape.com/viewarticle/513809> is the URL containing the technical article



CD test in 10-Pack kit for doctor's offices

on this new blood test from *Medscape*, a medical news publication.)

The patient must be actively consuming gluten for the test to be accurate, as with all current celiac serum tests. According to John Kernohan, director of York Labs, this test is considered accurate for people over 12

months who are consuming gluten. Before that age, antibodies acquired during breastfeeding can skew the results.

When asked about the difference between Celiac Disease and Gluten Intolerance, Mr. Kernohan said that Gluten Intolerance can produce the same symptoms and peripheral damage as Celiac Disease but that there is no intestinal damage to the villi involved.

York charges \$99 (includes shipping within the US) for each test but provides discounts – five kits for \$84 each, 10 for \$74 each, and 20 for \$64 each, provided they are shipped together. The kits are sold under the name *cdSCAN* IgA Tissue

Transglutaminase (tTG) Autoantibody Assay. The SACS governing board has not yet discussed this issue, but might consider a group purchase if there is enough demand. Contact any board member if you are interested in a group purchase.

Please see **CD Test** Page 6)

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General meeting slated for Jan. 28th at TMC

Don't miss the first general membership meeting of 2006, Jan. 28 from 9 a.m. -12 p.m. in the Rincon Room of the Alamo Building at Tucson Medical Center, north of East Grant Road at North Beverly Ave. in Tucson.

Food labeling changes implemented this month will be discussed. Come and learn about our new CSA Region VI Member-at-large Larry Schneider and his plans for the up-

coming year.

Bring along some of your favorite gluten-free snacks to share, if you wish. Since many of our members are sensitive to foods other than gluten, please list the ingredients or bring the wrapper from a purchased treat. (*Directions: Enter TMC at traffic light, turn left a first stop sign, follow curve and go straight to the end. Park in either lot, but enter lower level for Rincon Room. Map is available online at www.SouthernArizonaCeliacSupport.org.*)

Darryl Wong's *Lotus Garden* a winner with the GF Lunch Bunch

Colleen Beaman suggested we change the name of the GF Lunch Bunch to the *GF Glutton Group* after she surveyed all the polished platters at our Friday, Dec. 9th feast at Darryl Wong's *Lotus Garden Chinese Restaurant*. Darryl suggested we have a family style dinner so we could sample various dishes and ordered for us, which was a good choice.

Thirteen members gorged themselves on a family-style dinner that was not only delicious but totally GF. The meal started with *Hot and Sour Soup* and then we all devoured platters of *Chicken Fried Rice*, *Pineapple Delight with Chicken*, *Snow peas and Pork*, *organic Green Beans with Beef*, and, of course, an

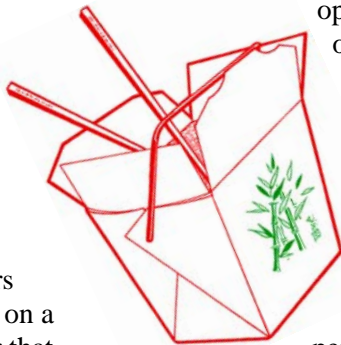
unlimited supply of steamed rice and hot tea. Darryl even brought out a bottle of wheat-free organic Tamari sauce in case anyone wanted extra seasoning.

The Lotus Garden is located at 5975 E Speedway Blvd. and open 11:30 to 10 p.m. Since over 80% of their food is made to order from primary ingredients, they can easily substitute ingredients.

Make sure you **contact Darryl Wong personally** via his cell phone (907-2427) before you come in so he can

personally oversee the food preparation. Take out is available.

The next GF Lunch Bunch meets Friday, Feb. 10th at **Elle Wine Country Restaurant**, 3048 E Broadway Blvd at Country club and Broadway. Contact Eilene Ealey at 888-2935 to reserve a seat.



Neuropathy related to CD

According to Reuters Health, some patients with celiac disease have small-fiber neuropathy, based on a case series of skin biopsies reported in the October issue of the *Archives of Neurology*.

"Painful small fiber neuropathies sometimes are caused by diabetes, but often no cause is found," lead investigator Dr. Thomas H. Brannagan told Reuters Health. "Celiac disease may be an important cause of small fiber neuropathy."

Dr. Brannagan of Weill Medical College of Cornell University, New York and colleagues report on findings in 8 such celiac disease patients.

Neuropathy began at points ranging from childhood to 59 years. Celiac disease was diagnosed in 5 of the patients after their neuropathy began. The others were referred for evaluation before the diagnosis.

In the 7 patients who underwent a glucose tolerance test, there was no sign of diabetes. Nerve conduction studies were normal in 7 patients and 1 had mildly reduced sural amplitudes. Epidermal nerve fiber density was reduced in 5 patients and was at the low limit of normal in the other 3.

One patient had no improvement with a gluten-free diet and symptoms developed in 2 while receiving a gluten-free diet. However, 4 responded and reported improvements while on a gluten-free diet.

Overall, the researchers observe that the findings point to a sensory ganglionopathy or an immune mediated neuropathy.

Dr. Brannagan concluded that "celiac disease, which is now increasingly recognized in North America, is important to identify" and thus allow treatment by means of a GF diet.

Chapter 15 Notes

Trader Joe's chicken taquitos are once again GF. The new ingredients label says "Rice starch" instead of the old label which said "wheat starch". The beef taquitos are NOT GF. Read the label to make sure you have the new formulation.

In products made OUTSIDE the USA, citric acid can be made from wheat. Read the labels carefully on juices/fruits produced outside the US.

Ocean Spray indicates that Craisins® Trail Mixes and Craisins® Chocolate Covered Cranberries *may* contain gluten. Their other Craisins products are GF.

Boomi Bars will no longer be available through Costco Road Shows. However, they *are* available via their website *or* for home delivery. Contact Michael Williams at boomiaz@yahoo.com for details.

Pad Thai noodle boxes from *A Taste of Thai* are no longer GF. Always check labels, even if the product is one you've safely used before.

Think Thin from Prime Health is a nutrition bar containing 20 gms of protein and is *labeled* wheat and gluten free. Elizabeth Rascon found them at Trader Joe's and says they are delicious.

Starkist Tuna Packets: *Except* for the *crackers* in the Lunch-To-Go kits, the *Herb & Garlic Tuna Creations* and the new pouch *Light Meat Teriyaki Tuna Fillets*, all Starkist Tuna Creations are GF. Some contain soybeans but *not* soy sauce.

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.

New Location for ROUNDTABLE !!!

Roundtable in new location for 2006

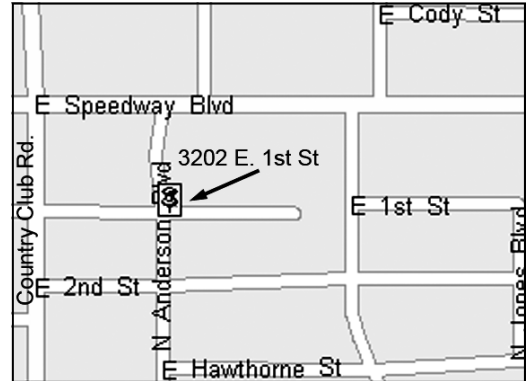
The Roundtable forum meeting place has been changed to the **Ward Six City Hall at 3202 E. 1st St.**

This is one block east of Country Club and one block south of Speedway. (see the map) We hope this location is more convenient for members from the Northwest.

We will still meet the fourth Wednesday of each month starting

in January, 2006. They have very nicely booked us in for the whole year and the time remains the same, from 1 pm to 3 pm. **The first meeting for this year is Wednesday, Jan. 25.** See you there!

If there are any questions please call Mary Louise Catura at 298-1038



Nancy Schuller reports on the Stanford Celiac Conference

Stanford Conference a let down

Member and Dietician Nancy Schuller reported on the Sixth Annual Stanford Celiac Conference at our Nov. 5, 2005 meeting at TMC.

According to Nancy, the best part of the conference was hearing Mayo's Dr. Joseph Murray speak. He said that after being GF for an entire year, a 'Celiac' can drop the word 'disease' from the diagnosis as they are considered 'cured'. Celiac disease is the only auto-immune disease where a person can literally cure himself without pills

or medical intervention.

She regretted that Dr. Gary Gray had only a limited time for his presentation and felt that CSA and/or GIG offered more information at their conferences than did Stanford's.

No audio materials were made available for reference or teaching and question/answer time with presenters was limited.

Safe or not?

Having trouble figuring out which personal care products contain gluten? It's not surprising as the ingredient labeling is a bit confusing.

This list gives the standard industry names for ingredients as found in the International Cosmetic Ingredient Dictionary:

- Hydrolyzed Wheat Protein
- Avena Sativa (Oat) Kernel Flour
- Cyclodextrin
- Dextrin
- Dextrin Palmitate
- Hydrolyzed Oat Flour
- Hydrolyzed Vegetable Protein
- Hydrolyzed Wheat Flour
- Hydrolyzed Wheat Gluten
- Hydrolyzed Wheat Protein
- Hydrolyzed Wheat Protein/PVP Crosspolymer
- Hydrolyzed Wheat Starch



- Maltodextrin
- Secale Cereale (Rye) Seed Flour
- Triticum Vulgare (Wheat) Germ Extract
- Triticum Vulgare (Wheat) Germ Oil
- Triticum Vulgare (Wheat) Gluten
- Triticum Vulgare (Wheat) Starch
- Wheat Amino Acids
- Wheat Germ Glycerides
- Wheat Germamidopropalkonium Chloride
- Wheat Protein
- Wheatgermamidopropyl
- Ethyldimonium Ethosulfate
- Yeast Extract

New Location for ROUNDTABLE !!!

Leadership Contacts

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

Elect email delivery of *Celiac Digest* to help us save money

Postage costs went up by another 2¢ this month, which means it is that much more expensive to mail out the *Celiac Digest*. Printing costs have increased also, despite liberal application of discounts and coupons to offset the expense.

The SACS Board requested that anyone who *can* receive the newsletter electronically, please do so. It will be sent in Adobe PDF format and can easily be printed out if you want to keep a hard copy for future reference.

If you have a dial-up Internet connection, it will take about five minutes for the entire newsletter to download. If you have a broadband connection (cable or DSL) it will take about 30 seconds.

To get on the electronic mailing list and suspend the paper copy for the

next issue, contact us via the website at www.SouthernArizonaCeliacSupport.org and request electronic delivery.



Of course, if you don't have an Internet connection or a printer or just don't feel comfortable downloading

and printing out the newsletter, SACS will cheerfully continue to send the *Celiac Digest* to you by snail mail.

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now @ 
WILD OATS

Mark your calendar

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

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

Jan. 28 - General Meeting, TMC, Alamo Bldg. Labeling Laws, CSA Report 9-12

Feb. 3 – Board Meeting, Bookman's Grant & Campbell, 12:30 – 3:00

Feb. 10-GF Lunch Bunch, at Elle Wine Country Restaurant, 3048 E Broadway Noon. RSVP @ 888-2935

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

March 3 - Board Meeting, Bookman's Grant & Campbell, 12:30 – 3:00

March – General Meeting TBA

March 10 – GF Lunch Bunch TBA

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

April 7 - Board Meeting, Bookman's Grant & Campbell, 12:30 – 3:00

April 14 – GF Lunch Bunch TBA

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

May 5 - Board Meeting, Bookman's Grant & Campbell, 12:30 – 3:00

May 20 – General Meeting, 9-12, TMC, Alamo Building

May 24 - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

**New Location for
ROUNDTABLE !!!**

(4)

CSA Conference reports given by members

By HETTY PARDEE

Stan and I attended the 28th Annual CSA Conference, September 30-October 2, 2005 at the Sheraton Premiere at Tyson's Corner, Vienna, Virginia. The theme was "Capitalize on the Knowledge."

Stan spoke on the presentation by Dr. Sue L. Hefle of the University of Nebraska Food Allergy Research and Resource Program (FARRP). Her topic was *Testing and Controlling for Gluten in the Food Manufacturing Environment*.

Status of Food Allergen Testing:

Many companies test in-house or contract labs using ELISA (Enzyme-Linked Immunosorbent Assay), or dipstick type, is the preferred method. Food lawyers consider using allergen ELISA test kits to be the "Standard of Care" in the US.

Good manufacturing practices and regulatory limits by government agencies should be based knowledge of threshold levels. Presently, the FDA does not have a definition for gluten free. The generally accepted level of gluten is 200 parts per million (ppm), but the testing threshold lower limit is now 20 ppm. Canada uses 20 ppm for their gluten free threshold and the United States is considering 20 ppm too. Dr. Hefle stressed that the gluten free threshold should not be so stringent that manufactures become discouraged, and opt not to produce *any* gluten free products.

Home Tests: These kits are not accurate because they are water based, and they need to be alcohol based.

Food Labeling Law: The law will go into effect January 2006. The goal is to list ingredients more accurately and make them more understandable with less ambiguity. Dr. Hefle also spoke of trace contaminants and how they can be introduced into a product during harvesting, milling and proc-

essing. She used several anecdotes of her plant visits to illustrate her points.

One of the speakers I gave details about at the meeting was **Dr. David Sands**, Professor of Plant Pathology at Montana State University and co-founder of Montana Turfgrass Technologies. He developed Montana flour from Indian ricegrass, which is high in iron, fiber, and a good source of



Stan Pardee gives CSA report

calcium. Four additional gluten-free high protein crops in the making are Proatina, Timotina, C-Lina and Teff.

Also, **Lee Tobin** from **Whole Foods Market** cooked with alternative grains such as quinoa, millet, buckwheat groats, hominy grits and had samples for all that were there to try. If you are interested in any of the recipes, I can make copies to hand-out.

Donna Washburn and **Heather Butt**, authors of two GF Cook Books, **The Best Gluten-Free Family Cookbook** and **125 Best Gluten-Free Recipes**, spoke about cooking with alternative flours. Rice flour, which has a low protein content, is high in carbs and low in fiber, iron and calcium. Some of the flours they talked about were:

Amaranth-mild, nutty, slightly sweet flavor, high in fiber and iron, good in

bread and muffins. Use as a thickener with soups and stews.

Quinoa-most nutritious, has a nutty flavor, high in protein and iron, use with banana recipes.

Sorghum-sweet and earthy flavor, use with pumpkin, molasses, chocolate and date recipes

Garfava-doesn't have a strong "beany flavor", use with applesauce and pumpkin recipes

Crunchy Flaxseed Cookies

1/3 c. sorghum flour
 1/4 c. garfava flour
 1/4 c. tapioca starch
 1/4 c. ground flaxseed
 2/3 c. cracked flaxseed
 1 tsp. Baking soda
 1 tsp. Xanthan gum
 1/4 tsp. Salt
 1/2 c. butter, softened
 1/2 c. packed brown sugar
 1/3 c. sugar
 1 egg
 1/2 tsp gf vanilla
 2/3 c buckwheat flakes

In a medium bowl combine dry ingredients except buckwheat flakes. Mix well and set aside.

In a large bowl with electric mixer, cream butter, sugars until combined. Add egg and vanilla and cream until fluffy.

Slowly beat in dry ingredients until combined. Stir in buckwheat flakes. Roll into 1-inch balls. Place 2 inches apart on prepared baking sheets and flatten with a fork or bottom of a drinking glass. Bake in preheated 350 degree oven for 10-15 minutes or until set. Remove from baking sheet and cool on rack.

Makes 3 1/2 dozen

From *The Best Gluten-Free Family Cookbook*- by Donna Washburn & Heather Butt.

(Continued on the next page)



Laura Weinreb shares her experience of the Oct. 2005 CSA Convention with the general membership at our Nov. 5 meeting. Laura has attended two CSA conferences.

New Location for ROUNDTABLE !!!

CSA reports

(continued from page 5)

Tips on baking with Gluten-free flours:

- Stir GF flours before measuring
- Measure accurately
- Mix flours and starches well
- Mixing time is critical
- Batter standing time improves texture

There are more tips with each recipe in their cookbooks.

For their recipes go to www.bestbreadrecipes.com or if you want to contact Donna and Heather email them at bread@ripenet.com.

Next year's CSA Conference will be October 6-9, 2006 in Green Bay, Wisconsin. See their website for more details

Clueless people award

British author Lynne Truss planted her foot firmly in her mouth with a comment she made on page five in her recently released book, *Talk to the Hand* - a diatribe on the rudeness of everyday life.

She states, **"I now can't abide many, many things, and am actually always on the lookout for more things to find completely unacceptable. Whenever I hear of someone being 'gluten intolerant' or 'lactose intolerant', for example, I feel I've been missing out. I want to be gluten intolerant too."**

This comment is her way of suggesting Celiacs are self-centered malingerers. One can only hope she gets her wish and develops Celiac disease or gluten intolerance.

CD Test

(Continued from Page 1)

European health care providers are using this test to monitor compliance with the GF diet and to screen patients for Celiac disease. Florida-based York Labs has promotional material aimed at medical professionals and will email or snail mail them upon request. <http://www.yorkallergyusa.com/> is the URL of their website. Or, you can contact them toll-free at (888) 751-3388.

Directions from the kit are included below to help you determine how it works and what to expect if you buy it.

The procedure is very simple:

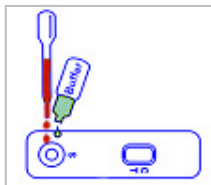
1. Bring CD1WB & CD2WB cassettes to room temperature.
2. Remove CD1WB & CD2WB from their sealed bag just before using and place each on a flat surface.
3. The collection and placement of the blood sample must be done quickly in order to avoid coagulation in the micro-pipette. Clean finger with alcohol swab and allow to air dry. Position the hand with the palm facing upward.

Blood should be collected by finger puncture (refer to included lancet instructions). Massage finger from base and work towards puncture mark in order to start a blood flow. Use the correct micro-pipette with the correct cassette:

* 30ul Micro-pipette (Red Dot) is for the CD1WB cassette

* 15ul Micro-pipette is for the CD2WB cassette

Hold micro-pipette horizontally and touch opened end to blood. Capillary action will automatically draw blood to the fill line and stop. Test sample immediately by squeezing the bulb at the end of the micro-



pipette so to place blood into round hole with an arrow located on each cassette.

It is important to use the 30ul micro-pipette with the CD1WB cassette and the 15ul micro-pipette with the CD2WB cassette.

Wait 1 minute after placing blood into the cassette's well and then re-use the 15ul micro-pipette to add 3 drops of buffer solution to the round hole with the arrow).

CD1WB RESULTS:

Negative – Only one BLUE band appears across the result window close to the "C" letter (Control Line).

The BLUE band must ALWAYS appear.

Positive – In addition to the BLUE control band, a PINK-RED band also appears across the results window close to the "T" letter (Test Line) . *

CD2WB RESULTS:

Negative – Only one BLUE band appears across the result window close to the "C" letter (Control Line).

The BLUE band must ALWAYS appear.

Positive – In addition to the BLUE control band, one or two PINK-RED bands also appear across the results window close to the "T1" and "T2" letters (Test Lines) . *T1 Line

Only: Positive IgA tTG

T2 Line Only : Positive IgA Gliadin

Both T1 & T2 Lines: Positive IgA tTG and IgA Gliadin
* Please Note: The intensity of the PINK-RED line(s) depends on the antibodies concentration in the sample.

If no BLUE line appears, the test is INVALID due to the test not being performed correctly. Also, any line or color appearing after 15 minutes has no diagnostic value.