



Volume 6, Issue 5

Celiac Digest

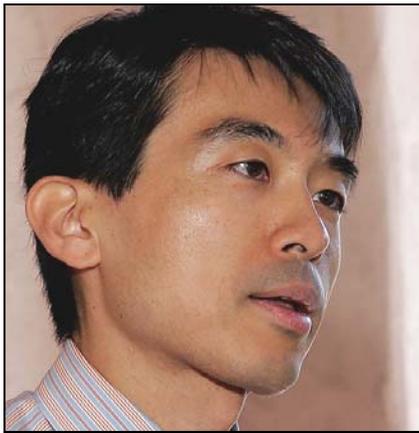
A publication of the Southern Arizona Celiac Support Group (SACS)

online at WWW.SouthernArizonaCeliacSupport.org

March 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.

Tour intestine March 29 with PillCam®



DR. WATARU TAMURA

Dr. Wataru Tamura will be the featured speaker for our March general meeting, and you do not want to miss this one. Dr. Tamura, member

of our Medical Advisory Board and a local gastroenterologist, will give an illustrated Power Point presentation featuring images of the small intestine taken with the PillCam®.

He will also explain the importance of testing for *all* food sensitivities as celiacs are especially prone to having more than just a problem with gluten.

There will be a question/answer period at the end of the presentation. Also, all guests are welcome, so bring anyone you think might be interested in these issues.

This event is **Saturday, March 29th, 8:30 to noon, at the Pima Community College District Office Campus, 4905 E Broadway, Bldg C**

(located just east of Swan, directly behind *TGI Friday's*. – Please see map p. 6 or our website at www.SouthernArizonaCeliacSupport.org).

Dr. Tamura was a featured speaker at the CSA Conference in 2007 and practices at Foothills Gastroenterology.

Also, what's a celiac gathering without food! If you wish to bring a GF snack, remember to bring the label, the box, or an ingredient list to accommodate those with multiple food restrictions. Coffee and tea are provided along with a half-hour period of meet and greet for members and newcomers alike. (*please note the time change: 8:30 not 9 a.m.*)

Volunteers get way more than they give

What do you get when you become a SACS' board member or just volunteer? Probably the most important thing you get is that good feeling of having helped another person. Another benefit is your own increased knowledge of CD, which will help keep *you* safer and healthier.

Another real plus is the new friends you make with other SACS members along with the camaraderie and just plain fun we have when interacting with the public.

SACS Bylaws recognize the benefit of the hands-on approach to learning about CD and provides for a complete

turnover of officers every two years, with an extra year added in case no one comes forward to take the post. If we kept the same officers year after year, we would not get new ideas, new energy and the group would become a private club for just a few. We sure don't want that.

SACS is at that point where each officer on the board has served beyond her term limits, and we need some new people to sign on. Plus, the group has grown so much in the last



Board member **LENORE THOMPSON** helps two shoppers at **New Life** with CD information

few years and has taken on so many outreach programs that we just need more people to help out.

There are few qualifications to be a board member. You have to be a

(Please see **Volunteer** page 6)

The myriad faces of CD

By **VIRGINIA MORGAN**

While at the National CSA Conference, I wrote down the symptoms and CD related diseases, compiling them from all the different speakers.

Please note that a person with gluten intolerance or CD may have only **one, lots of, or none** of these symptoms, making the diagnosis difficult.

Additionally, the blood tests are notorious for coming up with false negatives in people who have the disease and who are, as yet, untreated.

The symptoms fall into four basic categories. The list is not in any particular order of what is more common, nor is this list even complete!

Gastrointestinal Symptoms and associated diseases

Abdominal gas, bloating, cramping
Diarrhea
Constipation
Irritable Bowel Syndrome
Mild to extreme abdominal pain
Partial bowel obstruction
Hemorrhoids
GERD reflux disease
Fecal incontinence or leakage
Inflammatory bowel disease
Microscopic collagenous colitis
Eosinophilic esophagitis
Barret's esophagus
Schatzki ring (esophagus)
Intestinal cancers
Crohn's Disease

Malnutrition Symptoms and associated diseases

Vitamin deficiencies (folate, B12, iron, and others)

Iron deficiency resistant to oral iron
Osteoporosis and osteoparesis
Short stature and failure to grow in children

Delayed puberty
Fertility problems and miscarriage
Decreased teeth enamel
Low hemoglobin
Low good cholesterol (LDL)
Low weight
Chronic fatigue syndrome
Uncontrolled appetite
Multiple food allergies.

Neurological Symptoms and associated diseases

Headaches - frequent migraines
Epilepsy
ADHD
Psychiatric disorders including schizophrenia
Depression
Ataxia
Peripheral neuropathy
Hypotonia
Autism and related disorders
Multiple Sclerosis-like symptoms

Other symptoms or associated diseases that do not fit into any one category

Dermatitis Herpetiformis
Skin problems
Psoriasis
Arthritic diseases — including Rheumatoid Arthritis
Non-cardiac chest pain and arrhythmias and tachycardia

(Please see **Symptoms** page 8)

Chapter 15 Notes

Centrum Vitamins manufactured by Wyeth are no longer labeled GF. Ingredients now include 'modified food starch', and Wyeth can't guarantee where it comes from.

Barbara's Bakery & Puffins: "Puffins is the only Puffins cereal that contains no gluten in the ingredients but it is made in a facility that also makes products containing wheat. ... we cannot rule out the slight chance of cross contamination so we removed the gluten free designation from the packaging."

Hershey's Cadbury Cream Eggs have glucose in them based on wheat instead of the corn they have used in the past. However, the processing (akin to distillation) takes all the gluten out. So, they are *probably* safe to put in your Easter Basket.

Use Clan Thompson lists? There is a typo in the Ingredient Checker tool (part of the USA Food SmartList). Malt Extract is NOT gluten free. This will be corrected in the next update.

Hanaro's mini-sized sweet rice dumpling skins have wheat flour in them. Wheat is not listed as an ingredient nor are there any allergy warnings on the label.

MAB Member Erin Overgard, R. D. is resigning from our board as she has just accepted a position with the Mayo Clinic Hospital and will be moving to Phoenix. Congratulations and best wishes to Erin.

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.

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This is gluten intolerance?

By VIRGINIA MORGAN

This is a story of my husband Ray and his path to diagnosis. For many years he went to naturopathic doctors trying to find the cause to his mild and strange symptoms. He appeared to be super-healthy; he had perfect weight, exercised daily, had low blood pressure and cholesterol and took no medications other than a multi-mineral supplement. His diet was balanced and healthy with lots of fresh fruits and vegetables.

But every night he would wake up hungry and have to eat something before going back to sleep. He consumed lots of salt. He had dizziness when he stood up and this worsened. He felt that his memory was worsening. He was losing weight and down to 159 on a 6'2" frame. Because he has family members with CD, he was tested for CD multiple times, and each time it would be negative.

Further medical testing found that

his adrenals and thyroid were sluggish. His potassium was too low. He had a mild heavy metal level. When his blood sugar was tested in a four-hour test, it was found to be too low. He bought a home blood sugar testing unit and went on a low-glycemic diet.

When he tested his blood sugar during the day, he found it to be too high, even when he was hungry during the night. His doctor tested his level of chromium and found it to be zero. He was put on large amounts of potassium and chromium picolinate, and an herbal adrenal supplement and was treated for the heavy metals. This helped a little to absorb minerals.

He was given the gene test for DQ 2 or 8, and it came up negative. He then started to consume more whole wheat bread at lunch. Not deterred, his naturopathic MD continued to order celiac disease tests and finally a saliva test came back positive. Since

then, other blood relatives have confirmed the DQ1 gene for gluten-sensitivity.

He went on a gluten-free diet with me. It took two months before he noticed a bit of difference. And after four months, he is off his thyroid supplement and his blood sugar is normal, even after eating something sweet. He doesn't need the extra potassium or adrenal stimulants, and he's gained 10 pounds.

He is an example of why it is so difficult to diagnose celiac and gluten-intolerance diseases. His diffuse, mild symptoms were so different from the extreme GI symptoms that led to my own diagnosis.



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Follow-up Recommendations for Celiac Disease



DR. SHELLI HANKS

One of the confusing things about being a celiac is understanding what kind of follow-up is necessary once you have been diagnosed and

placed on the gluten-free diet.

Why do we need follow-up testing?

The most important reason is to ensure that antibody levels are returning to normal and that the intestine is healing. Once a celiac's antibody levels have returned to normal, these tests can also help to identify hidden gluten in the celiac's diet, which can increase antibody levels.

Another reason for follow-up testing is to rule out (or in) the role of gluten in other medical problems. When antibody tests are negative, it is unlikely that celiac disease is contributing to whatever symptom/medical problem you could be having.

How often do we need follow-up?

The recommendation of the University of Chicago is that newly diagnosed (biopsy proven) celiacs should have follow-up antibody tests twice in the first year after their diagnosis. The first appointment should be 3-6 months after diagnosis and the second should be after one year on the gluten-free diet. After that, a celiac should have follow-up testing on an annual basis.

Do I need a follow-up biopsy?

In the past, it was felt that a follow-up biopsy after a reasonable amount of time on the gluten-free diet was needed to confirm healing of the small intestine. This is no longer felt to be necessary.

Which antibody test is best for follow-up?

Guidelines from the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition state that the tTG-IgA should be used for follow-up testing. It is important to have a NEGATIVE test

but the actual numerical value doesn't matter (for example, if normal is less than 7, it doesn't matter if the result is 2 or 6; it is still negative). Although the anti-gliadin antibodies are no longer felt to be important in diagnosing celiac disease, the University of Chicago does feel that they are important for follow-up.

Some individuals with autoimmune disorders like Type 1 diabetes and thyroid disease will have unreliable tTG results. For this reason, they recommend anti-gliadin IgA and IgG be checked at follow-up as well. In this case however, the numerical amount IS important. They should be as close to zero as possible as this indicates a minimal antibody response to gluten.

A word of caution regarding interpreting these test results: different laboratories have different reference levels for normal and laboratories sometimes change their reference levels. Make sure you and your doctor read the test results carefully including the reference ranges. A result that was previously "negative" may not be with a new test.

What other tests should I have?

All patients with CD should have a bone density test and a blood test to check for anemia at diagnosis. Patients who have osteoporosis or osteopenia should have annual bone density tests until this test is normal. Once the test normalizes, bone density should be checked every 2-3 years. A test for anemia should be done annually.

There is controversy regarding tests for other vitamin and mineral deficiencies. Some believe that as long as antibody tests are negative and a patient is asymptomatic, additional testing is unnecessary. Others believe that things such as iron, calcium, folic acid, fat soluble vitamins (A, D, E and K) and zinc should be tested annually as well. This is probably best left to patient and physician preference.

Should my family members be tested?

Although many family members may be reluctant to be tested (usually insisting they have no symptoms of CD), the recommendation is that every first degree relative of someone with CD should be tested. First degree relatives have a 10-15% chance of having CD (although about 50% of them will be asymptomatic). This risk increases if more than one family member has celiac disease.

Family members who test negative should consider genetic testing for HLA-DQ2 and HLA-DQ8. If they test negative for the gene, they do not need further follow-up. If they test positive for either gene, they should undergo repeat testing for CD every five years.

On that note, be sure to look for the announcement regarding our upcoming Community Screening for Celiac Disease at the May 10th Food Faire. Look for more information online at our website.



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GEORGINA RUBAL-PEACE

Free CD blood screening test for SACS members

There will be an announcement at the March 29th general meeting regarding registration and requests for volunteers to help with the screening.

Information on applying for these free celiac blood tests will be posted on our website as soon as the details are finalized. The patient must be age 18 or over (for liability reasons) and actively consuming gluten for some time prior to the blood draw. Applicants must also be first-degree relatives of diagnosed members

If you are a nurse or phlebotomist who could help draw blood and/or have access to phlebotomy chairs we can borrow, please contact MAB Coordinator Shelli Hanks, M.D. at shelli.hanksmd@yahoo.com

Specifically, we are looking for approximately 20 volunteers who are trained to draw blood, and have experience doing so. You may be a physician, PA, nurse or paramedic, or

maybe even some designation we have not mentioned, but we need at least 20 trained volunteers to work in shifts drawing blood. Please email Dr. Hanks or so.az.celiacsupport@earthlink.net if you are able to assist us. Or, if you know of a non-member who might donate his or her time and expertise, please let them know of this worthwhile volunteer opportunity.

We also need a couple of experienced and fast data entry people who will enter the blood-draw information into an *Excel* database *during* the screening process.

This is an ambitious project made possible by *your* membership support and, of course, your generous donations of time and talent.



Thanks to Medical Advisory Board member and former SACS president Georgina Rubal-Peace, Prometheus Labs (www.prometheuslabs.com/) has agreed to donate 100 tests for our first, and hopefully annual, Community Screening for celiac disease.

The screening will be held in conjunction with our May 10th Food Faire at Christ Community Church and will focus primarily on family members of SACS members already diagnosed.

Jan. meeting has sparse turnout

About 25 members showed up for our January 19th general meeting where pediatric dentist Dr. Priya Ramachandran was the featured speaker. Dr. Ramachandran is also on our Medical Advisory Board.

An especially nasty flu season was responsible for many of the empty seats in Pima College's auditorium that day.

Dr. Priya Ramachandran gave a very interesting presentation, using Power Point slides (from the new digital project that we voted to buy last November) on tooth development in children and how anything, from prenatal nutrition to ventilation tubes could disrupt tooth development.

She was also kind enough to participate in a question-answer period from the audience, many of whom were young mothers. Member Karen Luce,



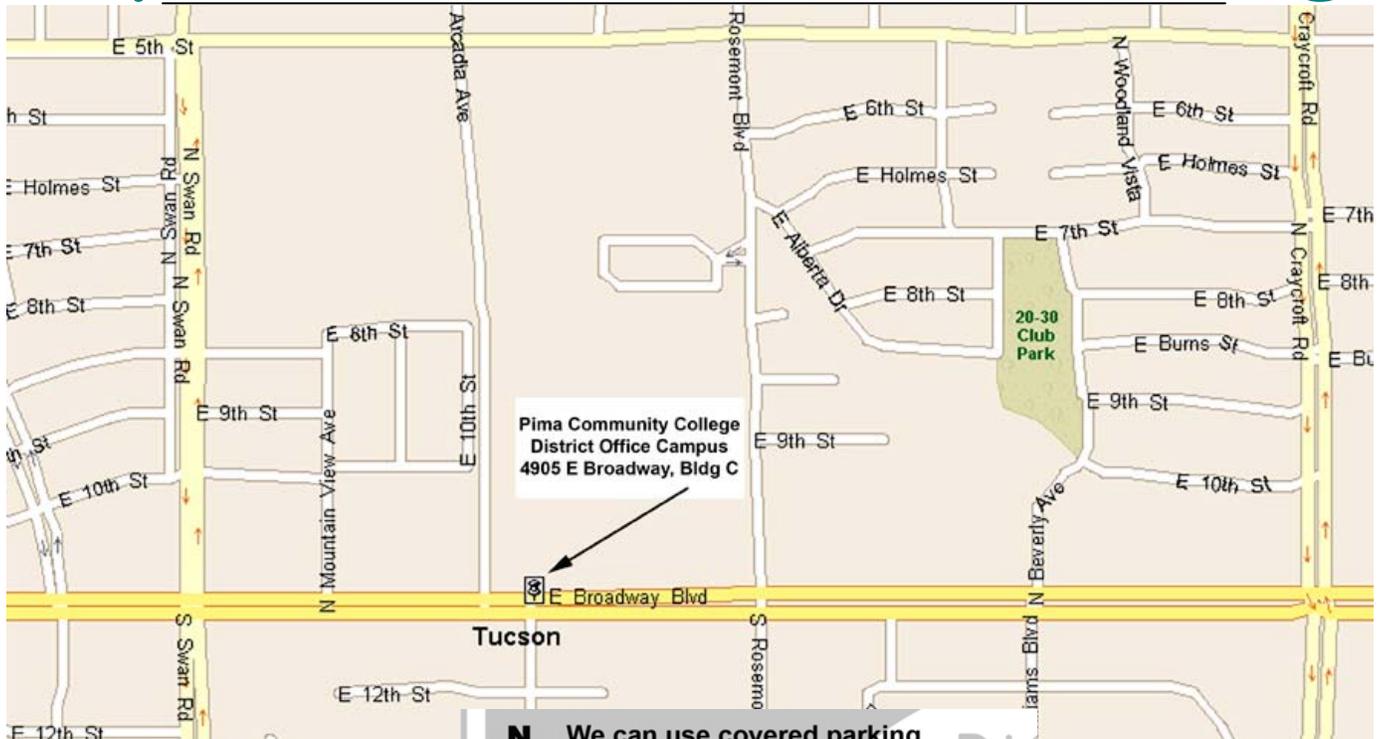
(From left) **Speaker DR. PRIYA RAMACHANDRAN, SACS President CHERYL WILSON and member KAREN LUCE, DDS share a few laughs before the meeting began.**

who is also a dentist, explained how some OTC medicines could affect mouth tissues.

Katie Knoepfle, whose sister Emily is a celiac and whose mother is the co-chair of Cel-Kids, gave a brief talk about how she could help keep her sister gluten-free.

Her mother Diane Knoepfle gave a report on the progress of the Cel-Kids Chapter. Because of low participation rates, the chapter is suspending organized activities until they have a broader member base. She did say that her website is quite active with requests for information.

Map to the March 29th meeting



Volunteers

(continued from page 1)

member of SACS and be able/willing to use email because 90% of our communication is conducted that way. Each board member must make a good faith effort to attend one board meeting a month (vacations and emergencies are understood) on a Friday from 1:30 to 3:00 at the Ward 6 City Hall building.

THE OFFICES OPEN ARE:

(detailed descriptions available at our website under Bylaws)

President-Elect. The president sets the agenda and presides over the board meetings and general meetings. The new president would *not* have to do all of the outreach programs that Cheryl has been doing. He or she would also get plenty of help from the Past-President. Also, he or she would have an entire year to learn the ropes.

Membership This person keeps track of the membership and is responsible for sending out renewal notices and a mailing list for the newsletter. This person should have a modest knowl-



edge of *Excel* or an equivalent database software.

Treasurer The treasurer keeps track of the money, pays the bills and reports to the board once a month.

Members-at-Large These board members attend every month and lend their experience and vote on issues before the board. They also help out at most functions. (Other perks for board members is that someone almost always brings GF goodies to the meeting, custom-made business cards are provided and there is *always* lots of laughter.)

FREEWAY?

Just a reminder that all freeway exits are closed until 29th street. So, if you are coming from the northwest side of Tucson, take an alternate route. Oracle to Ina to Skyline to Swan is one route to consider.

The Pima County Fair is coming up in April and then the Food Faire in May. Both these events need plenty of volunteer help. If you don't feel you can manage a board position, please consider volunteering for one or both of these events. Contact any board member from the list on page 7.

Sign-up sheets will be available at our March meeting for times to work at the Pima County Fair and the Food Faire in May. We always have at least two people assigned to a booth.

You'll get way more out of volunteering than you put in. Honest.

Dear SACS members,

On behalf of the entire Caffarella family, please accept my sincere gratitude for your outpouring of concern, condolences and sympathy at the passing of my father, LeRoy Caffarella, as well as my nephew, Jared Caffarella on Sunday, March 2.

I cannot adequately express our appreciation for the time and effort that SACS extended to provide food for our the double Memorial Service last Saturday. Having SACS members there to serve us was so unexpected, I can only say that my entire family was deeply moved and impressed with your servant hearts.

With the very warmest regards,

Cheryl A. Wilson



ROY CAFFARELLA shown teaching respiratory therapy during the 1960s

Leadership Contacts

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

PillCam® works!

ROCHESTER, Minn., Feb. 27 / PRNewswire-USNewswire/ -- Mayo Clinic researchers have found that capsule endoscopy can provide a magnified view of the intestinal damage caused by celiac disease. This new information can help physicians detect and diagnose celiac disease, as well as measure intestinal healing following treatment. These findings are published in this month's issue of **Clinical Gastroenterology and Hepatology**.

It's official. What Dr. Tamura has been saying for years has finally been 'discovered' by the major names in CD research. Maybe this will mean an easier time getting insurance coverage for the procedure.

In Memoriam

LeRoy E. Caffarella
1920 - 2008

Surrounded by family, Roy E. Caffarella passed away March 2, 2008 of complications associated with congestive heart failure.

He was a respiratory therapist at St. Mary's Hospital and Tucson General Hospital, as well as a Minister of Music at three local Nazarene churches. He also taught respiratory therapy.

Roy was a long time member of SACS, along with his wife Thelma and seven children, one of whom is SACS president Cheryl Wilson. We shall miss his presence at our meetings.

Free Initial Consultation

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SACS' dues going up ?



The SACS board voted at its March 14th meeting to raise the membership dues from \$12 to \$15 dollars yearly, beginning July 1st of this year. This will not affect the dues of those members who have paid for five years in advance.

President Cheryl Wilson cited the increased postage and printing fees for the newsletter and also the fact that SACS has staged no major fund raiser for several years. Our outreach and educational programs have also increased, which leads to higher revenue outlays.

The general membership will vote to approve this price increase at the March 29th general meeting.
(8)

Symptoms

(continued from page 2)

Fibromyalgia
Idiopathic dilated cardiomyopathy
Cardiac valve involvement
Liver and biliary track diseases includes gall bladder malfunction
Autoimmune hepatitis
Thyroiditis, Graves' Disease
Recurrent pancreatitis
Sjogren's syndrome
Type I Diabetes
Lymphoma
Melanomas
Down, Turner's, and William's Syndromes

Mark your calendar

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

2008

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

March 29— 8:30 a.m. General Meeting, Dr. Wataru Tamura., Pima College District Office Campus, 4905 E Broadway

April 11, 1:30 p.m. Board Meeting, Ward Six City Hall at 3202 E. 1st St
April 17-27: SACS booth at the 2008 Pima County Fair. Volunteers are desperately needed!!!

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

May 2, 1:30 p.m.: Board Meeting, Ward Six City Hall at 3202 E. 1st St

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