



Vol 10, Issue 1

Celiac Digest

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

online at WWW.SouthernArizonaCeliacSupport.org February 2011

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.



February 12 POTLUCK Features "Mini" Shop-a-Thon

SACS annual potluck will be held this year on **Saturday, Feb. 12th** at **The Journey Church**, 4700 N. Swan Rd, (just across the street from the three radio towers). See map on our website. There will be a barrier with balloons and a sign to help mark the entry drive to the church. We always look forward to this general meeting, so please try your best to come.

You will get to share wonderful gluten free food (all GF) with wonderful people. Children and non-member guests are always welcome. The business part of the meeting includes a report on SACS' activities as well as an outline of volunteer opportunities.

Copies of Melissa Diane Smith's newest book, Gluten Free Throughout the Year and Dr. Ford's book, The Gluten Syndrome and a video DVD of his presentation will all be available for sale, along with Recognizing Celiac Disease. All profits benefit SACS' educational programs and public outreaches.

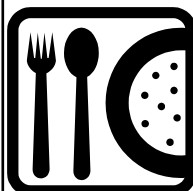
Due to the low turnout at our December 4th Shop-a-thon, we have invited a few of our favorite the vendors back for another chance to share their goods with our group. Please note that these vendors are donating a portion of their sales to support our ever growing Gluten Free Food Faire. Vendor items include gift baskets, hand-made cards, gourmet GF food, Tupperware and framed artwork.

Probably the best opportunity is that you get to bring your favorite GF dish or dessert to share with us. Don't forget to bring your recipe (or an ingredient list), so that those with multiple food intolerances can make wise choices. Coffee, tea and water will be provided.

Come early and plan to stay late! **NOTE:** If you cannot--for any reason--bring a dish to the potluck, please come anyway as we always have plenty of food!



**Shopping
Starts at
10:30am
(+ continues)**



**Eating
Starts at
11:00 am!**



Gastro Doc Sanner Surprises SACS Audience

Tucson Gastroenterologist, Dr Charles "Chuck" Sanner only lectured for about 30 minutes, but answered questions for at least that long (or longer). He started his lecture on "Trends in Celiac Disease" by relating that he has had an interest in CD since he started his medical training a few decades ago and internship in Pediatrics. At that time, CD was viewed as a childhood disease that was debilitating. When he transitioned to adult medicine it was stuck in his mind—he could not believe that it was limited to only children. He states that trends now are actually going in the other direction.

Dr Sanner went on to explain why some grains affect humans as they do. He showed an interesting grain chart outlining the connection between proline and glutamine levels and toxicity. The top three toxic grains are wheat, rye & barley and are the only proteins known to not be digested by the human gut.

Cont next page

Dr Sanner, Cont

Dr Sanner placed an emphasis on the importance of genetics in celiac research today. One somewhat 'surprising' statistic he brought up was the point that 1-5% of celiacs do NOT have either DQ2 or DQ8. He said that we (even doctors) *must* keep an open mind and cannot say someone does not have CD just because they don't have the genes! He said there are many genes now known to be associated with an increased risk of developing CD. He explained that HLA-DQ2 & DQ8 are highly associated with risk of CD because they control the antigen-binding proteins in the gut. The non-HLA genes suspected (but not confirmed) is now up to 13 that are also associated with increased risk of developing Type-1 Diabetes, Multiple Sclerosis, etc. Later in the lecture, Dr Sanner added that the DQ2 marker can be refined to help us identify those more at risk, especially in family studies. The research shows that those with two copies of the DQ2 gene are 5x more likely to develop CD than those with only one copy!

Dr Sanner's opinion that "EVERYONE who has gluten sensitivity has CD" elicited an audible response from the listeners. He was careful to state that it was his opinion only, but that it was based on research he had read, along with observations from his own practice. He then used a rather "busy" slide (as he called it) to explain why he believes that to be true. He detailed the processes by

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which antibodies are activated while explaining the whole 'leaky gut' mechanism involving zonulin. Some of you may have heard Dr Alessio Fasano speak on this very subject back when he guest lectured here in Tucson.

Dr Sanner then moved to the subject of the prevalence of CD pointing out that those statistics have changed quite a bit even over the last few years. The incidence in Western Europe varies from 1:60 (Ireland) to 1:100, with the USA coming in at as little as 1:10, depending on the genetic pool you are researching.

Dr Sanner related that in studies where the siblings of celiac children were subjected to biopsies, of those who were DQ2+tTg positive AND totally asymptomatic, fully half of them will have villous atrophy.

The next portion of the lecture consisted of several charts outlining more changing trends in presentation of CD. It was interesting to note that in both children and adults, the "classic" (old) symptoms of diarrhea, gas/bloating and weight loss were the main symptoms doctors would look for back then. The only difference between the two was that adults would often present with iron-deficient anemia.

NEWER PRESENTATION OF CD SYMPTOMS IN CHILDREN
Short stature, Delayed puberty, Type 1 Diabetes, Dental enamel defects, Neurological disorders (seizures, ataxia), Chronic joint pain, Depression or Fatigue, Iron-deficient anemia.

NEWER PRESENTATION OF CD SYMPTOMS IN ADULTS:

IBS, osteoporosis, oral lesions (oral ulcers, glossitis, cheilosis), arthralgia/fibromyalgia, chronic fatigue syndrome, depression, infertility, spontaneous abortions, neurological disorders (neuropathy, ataxia), skins lesions (dermatitis herpetiformis, follicular keratitis-Vit A deficiency), abnormal liver enzymes (10% of people with CD will have sustained elevated liver enzymes, although there is more data for children than adults).

"Patient history is as important as serology!", Dr Sanner stated emphatically, then reported that he has changed the Antibody Tests that he uses in his own practice. After giving an in-depth explanation of the different serological tests available to patients, he asked the question, "is it really that they have early CD that cannot yet be proven by biopsy?"

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WANTED:
Creative Desktop Publisher

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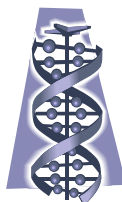
Consider joining our team as **Newsletter Editor** of **The Celiac Digest**. Requirements include having a working knowledge of MS Publisher and being willing to attend meetings occasionally. Please contact Cheryl Wilson at 520-298-5551 or via Email at so.az.celiacsupport@gmail.com.

Dr Sanner, Cont

One of the most impactful statements Dr Sanner put forth was his opinion on the “gold standard” in diagnosing CD. Traditionally, a positive small-bowel biopsy (proving villous atrophy) has been (and still is considered to be) the “gold standard” around the world. However, Dr Sanner said that, in his opinion, a patient showing improvement of symptoms on a GF diet is the gold standard for his practice. He was careful in issuing caveats stating that this is only his opinion, but judging by the reaction of the audience, it seemed it was a welcome approach. He no longer biopsies all of his patients being evaluated for CD. He believes that if there is strong enough evidence of CD with patient history along with serological pathology, they may not need a biopsy. He generally suggests that these patients begin a GF lifestyle. When he “offers” patients the option of doing the GF diet, he asks for an “absolute commitment of three months”.

Overall, Dr Sanner made some remarkable statements during his lecture and gave SACS listeners many new things to chew on. We so appreciate his dedication to researching all the trends in CD and for providing such compelling evidence.

Once again we are blessed, as a support group, to have such a high caliber of local physicians willing to spend some of their precious time sharing knowledge with us. We offer our sincerest gratitude to Dr Sanner.



The Value of Volunteers

By Kim Pebley

About two years ago, I was diagnosed with CD. Dazed and confused, I came upon the SACS website and just knew that I could obtain information through this group. There seemed to be a wealth of information at my finger tips.

Who put it there?



At my first food faire, I marveled at the sea of people and smiling volunteers that seemed eager to help point me in the right direction or talk to me about their own experience.

Who organized this amazing event?

When I attended General Meetings, Potlucks and other events, it began to sink in....**volunteers are needed to make all things possible!**

Although the Executive Board makes plans come to life throughout the year, without the support of the membership and VOLUNTEERS stepping forward to show their support, none of this would be possible.

Thank you to those who have supported SACS by volunteering. Please know that we appreciate your continued support! For those who are holding back, please come forward and experience the joy of volunteering. SACS wants to give you even more in the years to come.

We would like to hear from you as to what you would like to see happening with the group's outreaches and events.

Do you have a special skill or talent (or are willing to learn)? Please see the list in the next column then contact us!

Chapter 15 Notes

Membership changes?

Notify us via the website or call 577-6930 (Corene Johnson).

CSA/USA: 877-272-4272

9 a.m. to 4 p.m. Central Time. Go to www.csaCeliacs.org.

SACS GF Mentor Program

You can sign up online if you would like a mentor to help you navigate the sometimes confusing world of CD/DH or the GF lifestyle. We will try to match you with someone that lives on your side of town. You can also sign up to BE a mentor (diagnosed 1+yr). Go to our website and click on “Gluten-Free Mentor Program”.

SACS Volunteer Needs How Can YOU help?

In addition to the Newsletter Editor mentioned on Page 2, we are also in need of the following:

► **Cel-Kids Coordinator.** This person would assist us in the planning /execution of events for GF children, as well as answer questions that come to us via the web or phone calls. On-the-job training is provided!

► **Silent Auction Coordinator** for the 2011 GFFF. Again, on-the-job training will be provided by the 2010 Coordinator, who will also assist in coordinating the 2011 event (which will be held at the Holiday Inn Palo Verde on April 30, 2011).

► On going needs include clean up and/or set up for SACS general meetings or special events, as well as people to help assemble and mail the newsletter. You can volunteer to help for a specific date or any number of events. If you would like to know more or want to sign up right now, please contact our Volunteer Coordinator, **Celeste Harvey**, at 7216-6767 or lily_celeste@yahoo.com.



GLUTEN ATAXIA

A Neurological Condition Associated with Celiac Disease & Non-Celiac

Gluten Sensitivity

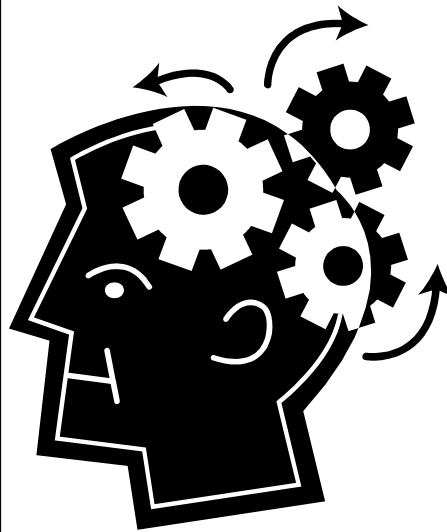
By Dr. Lindsey Pearson, NMD

As we learn more about celiac disease (CD) and non-celiac gluten allergies and/or sensitivities we become aware of more comorbid conditions associated with them. One of the more recently recognized comorbid conditions is gluten ataxia. First described in 1990, gluten ataxia is neurologic condition that is predominantly characterized by the loss of balance and coordination.

The medical term ataxia means a lack of coordination of muscle movements. Gluten ataxia is caused by anti-gliadin antibodies attacking and damaging Purkinje nerve fibers in part of the brain called the cerebellum. The cerebellum controls balance, motor control, and cognitive functions such as language and attention. When the essential nerve fibers of the cerebellum are damaged people may experience difficulty walking, balancing, talking, finding the correct

words in speech, motor coordination of the arms and legs, and cognitive decline such as mental foginess and mood changes. The damage is irreversible.

The treatment for gluten ataxia is a strict gluten-free diet – just like in celiac disease, gluten sensitivity, and gluten allergies. Adherence to a gluten free diet will decrease the level of circulating anti-gliadin antibodies and thus halt the progression of gluten



ataxia – but not reverse it. A gluten-free diet will prevent further damage. It may take almost two years for all circulating antibodies to reach a level that is considered within normal range and thus halting the neurological destruction. If gluten is reintroduced into the diet, anti-gliadin antibodies will rise and further damage may

occur. Since gluten ataxia is caused by anti-gliadin antibodies it may be found in celiac and non-celiac gluten sensitive patients. Approximately 80% of celiac patients have anti-gliadin antibodies. IgG and IgA anti-gliadin antibody levels may be measured by a simple blood test and are often a part of comprehensive celiac screening panels along with tTG IgA antibodies (with total serum IgA levels), EMA IgA, anti-gliadin IgA and IgG antibodies, and deaminated gliadin peptide (DGP) antibodies. Since celiac and non-celiac gluten sensitivity have many of the same signs and symptoms, comprehensive screening panels should be utilized by physicians when either is suspected. In addition, patients with unexplained neurologic symptoms should be screened for celiac disease and non-celiac gluten sensitivity.

*Dr. Pearson is
the head of
SACS' Medical
Advisory Board
and practices
integrative
internal
medicine at*

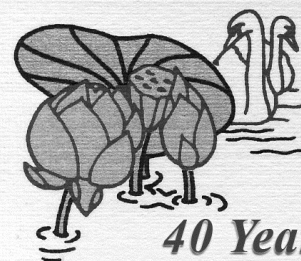


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Editors Note: There is a great article on Gluten Ataxia in this month's issue of *Living Without*. Included in the article are some real-life stories of people suffering with this disorder. We encourage you to read the article in full and learn about new options in treating gluten ataxia. Read it online at http://www.livingwithout.com/issues/4_12/ataxia-2366-1.html

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SACS in the Community

By Pat Hirsch

There's an encouraging upswing in publicity and awareness on eating out GF-safely! *The Arizona Daily Star's* dining and entertainment magazine, **¡Caliente!** had a great story, "Dining Without Gluten". Chef Andreas Andoniadis, owner of Opa Greek Cuisine, discussed his methods for ensuring safe GF menu items at all times. Inger Sandal's article was full of delicious looking photos of Opa's Gluten free food. The article states, "Star dining reviews will now mention if gluten-free fare is offered"! This story was in the Thursday, January 27 edition. It can be seen via SACS' website!

AND...Radio personality Matt Russell of **KJLL-AM 1330's On The Menu...Live!** spoke

with Chef Darryl Wong, owner of Lotus Garden, about the February 3rd Chinese New Year. They talked about what role foods play in the celebrations. During the hour-long show, discussion turned to GF food and how Lotus Garden can transform just about any traditional dish to GF without sacrificing flavor. Kudos to Matt for broadcasting the good news that caring chefs can simultaneously practice culinary artistry, provide excellent GF dishes and reap the benefits of having more customers patronize them. The radio show is heard at 5pm on Thursdays. SACS member Diana Knoepfle put Lotus Garden in touch with the show.

Thank you to **¡Caliente!** and **On The Menu...Live!** for telling everyone in southern Arizona this happy news.

► SACS outreach continues. We'll be at the huge YMCA Healthy Kids Day on April 16. Please contact me to help then; it's a great opportunity to advance CD/GF awareness and so much fun!

► SACS gives a big thanks to **Sprouts Farmer's Market** and the **Southern Arizona Women's Chorus (SAWC)**, as well as a few SACS volunteers who understand how important awareness is. Sprouts donated to SACS the ingredients to bake fancy desserts for **SAWC's** Christmas Concert, thus about 1,050 concert goers had the chance to sample delicious GF snacks while learning a little more about CD. We look forward to the spring concert season so we can do it again!

Here's hoping your new year of 2011 is prosperous and 100% gluten free.



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SACS Gluten Free Cooking Classes A BIG HIT!

The Southern Arizona Celiac Support Group (SACS) gluten-free cooking classes have been a great success. Our goal is to help our members create easy, healthy, GF meals. Our instructors (chefs) are friendly, helpful, and want you to learn in a casual and fun setting where every student is able to see, hear, and actively participate. Almost every class comprises a full meal, and, of course, we always eat what we cook!

In class, you will receive all the recipes, friendly instruction, and answers to any of your questions about cooking gluten-free. Please browse our website for schedules and menus.

February's class will feature the Gourmet Girls, Mary Gibson and Susan Fulton. They will be teaching the class how to cook bruschetta, pasta, brussel sprouts, and sweetheart cupcakes, all gluten-free.

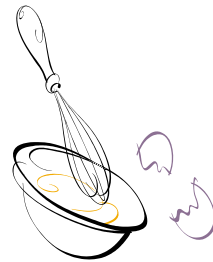
March's class will feature long-time SACS member

Joyce Kvanbeck. She will be sharing with the class her favorite lasagna recipe, breadsticks, and a dessert. Sign up early for class, space is limited and fills quickly. Meet your fellow GF eaters, ask questions, and have fun while learning new ways to enjoy food again. Call Corene Johnson at (520) 577-6930 to enroll. Must be over 14 years and pay a \$20 fee for supplies.

What Students are saying:

Theda Doak said, "Thanks to Corene for the great idea of a GF cooking class and inviting us into her lovely home to create wonderful and exciting recipes. Each month we are provided with new ideas, good organization and lots of laughs. Looking forward to next month."

Joyce Kvanbeck said, "I enjoy it! I learn something new each class. It is great being with other people who eat gluten-free, and I do not worry about contamination."



Linda Walker said, "I love it, it's a great thing."



WHAT:

March 5
GF Cooking Class:
Lasagna
Breadsticks
Dessert

WHY:

To learn how to cook easy, healthy, GF meals

WHEN:

March 5
from
10am-12:30p

WHERE:

4662 E. Don Jose Drive
Tucson, AZ 85718
Corene Johnson, Hostess

WHO:

Anyone over age 14
(limit of 10 per class)

GF Cooking Class:

Saturday

March 5, 2011

10:00am to 12:30pm



COST:

\$20.00 per person

HOW:

Call Corene Johnson
(577-6930)
to reserve your
space for the fun!



Dr Sanner visits with SACS MAB members, Dr Pearson and Meg Roop, before the meeting began.



The audience follows Dr Sanner's power point presentation closely.



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Leadership Contacts

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AVAILABLE
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**(print version
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 Through
 Paid SACS
 Membership)**

In Memoriam

Condolences to the families of
Seymour Saltzman
 who passed away in 2010

~and~

Elton Gosse
 who passed away in January 2011

Both were long-time key members of our group who will truly be missed



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

PLEASE FORWARD IF NECESSARY



Sharing advice for a gluten-free life.

Save the Date!

**Saturday
April 30, 2011**

**SACS Annual
Gluten-
Free
Food Faire**

**Holiday Inn @
Palo Verde
9am — 1pm
GF Vendors
Silent Auction**

(8)

Donations for our **Silent Auction** at the GF Food Faire on April 30. Contact Kim Pebley, 219-7076 or kimpebley@gmail.com

GFFF volunteers needed to pass out samples, assist at sign-in tables, etc. Contact Volunteer Coord. Celeste Harvey, 721-6767, lily_celeste@yahoo.com

Do YOU have connections to a GF vendor? **Tell Kim!** We are competing with other GFFF around the country and so are especially interested in showcasing local vendors who are endeavoring to address the needs of those following a GF lifestyle. We like to hear when there is a another new GF option!

Mark Your Calendar

February 11 — Noon, GF Lunch Bunch, Zona 78, 78 W River Rd, RSVP Corene 577-6930, corene-robert@comcast.net

February 12 — 11am Potluck + Mini Shop-a-Thon @ The Journey church, 4700 N. Swan Rd*

March 5 — 10am, GF Cooking Class, RSVP 577-6930*

* = more info inside newsletter

SACS Roundtable
Fourth Wed each Month
(except Nov/Dec)

GF Lunch Bunch
Second Friday each Month

GF Dining Out
Fourth Friday
Evening
each Month

