



Volume 6, Issue 4

Celiac Digest

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

online at WWW.SouthernArizonaCeliacSupport.org

January 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.

Pediatric dentist will speak at Jan. meeting

The first general meeting for 2008 is being held **Saturday, January 19th, 9 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).

From 9 to 10 we will have the usual meet and greet, some GF grazing, and then a business meeting.

The featured speaker will be **Dr. Priya Ramachandran** who will be discussing the diagnosis and treatment of the dental problems associated with celiac disease. Dr. Ramachandran is a pediatric dentist in practice in Tucson and a member of our Medical Advisory Board.

There will be a question/answer period after her presentation, so come prepared. As is customary, guests are always welcome.

If you would like to bring your favorite gluten-free snack (which we *all* appreciate), remember to bring the label, the box, or an ingredient list to accommodate those with multiple food restrictions.



DR. PRIYA RAMACHANDRAN

November Potluck a delicious success

Pass the turkey, pizza, ham, pea soup, shrimp salad, rice dishes, sausage casserole, sweet potatoes, pumpkin pie - oops, I'm too full to continue. Yes, it was SACS' annual Potluck held in last November to record

attendance. The food was fabulous.

The Potluck was held at Christ Community Church which has a commercial kitchen equipped with a steam table, ice table, convection ovens and serving facilities. This was

especially nice as it meant we could have freshly made GF pizza!

This potluck had a special program for children and was certainly the liveliest for it. Along with a jumping castle, generously donated by **KidzJump.com**, there was an activity room in the venue where children could do crafts and play under the supervision of

Cel-Kids' volunteers. There was food especially for the children, including Lil' Doggy Wraps, spaghetti and pizza.

One new member, one-year-old Brandy, who lives in Sierra Vista with her parents and older brother, came here all the way from Sierra Vista for the meeting. Mom and Dad were happy to meet the parents of other celiacs and are especially thrilled that she is no longer screaming most of the night with stomach pain. Four other 'new' people came and joined SACS, so it was nice to see all these fresh faces

President Cheryl Wilson gave a Power Point presentation on pie crust recipes and there was an ongoing slideshow of images from the September CSA Conference as well as our Executive Board members and

(Please see **Potluck** page 6)



Members **KATHLEEN JOY** (back) and **JAN TERRY** work to serve hungry SACS members at Potluck

CSA Conference report

By SHELLI HANKS, MD

This year's annual CSA Conference was held here in Tucson over September 28-30th at the *Westward Look Resort*. There was an interesting variety of presentations with speakers from all over the country.

Dr. Stefano Guandalini came to speak from the **Celiac Disease Center** at the University of Chicago. He presented a thorough overview of celiac disease. He discussed some interesting risk factors for celiac disease including exposure to the infant rotavirus (which increases the risk), breastfeeding (which decreases the risk) and the amount of gluten exposure early in life (increased gluten exposure leads to increased risk). He also confirmed that the anti-gliadin antibodies really have no role in testing for celiac disease at this point.

Dr. Detlef Schuppan from **Harvard** shared some very interesting information about emerging treatments for celiac disease. These included genetically modifying wheat so that Celiacs can consume it without generating an immune response, an oral enzyme called *Glutenase*, and a cellular permeability agent called *AY-1001*.

Once of the most interesting talks was given by a local Pediatric Dentist, **Dr. Laila Hishaw**. She shared information about pediatric dentistry

including an overview of the oral signs and symptoms of Celiac Disease. These include dental enamel hypoplasia, aphthous ulcers (canker sores), gum disease and dry mouth. She also stated that the effects of celiac disease can be seen prenatally.

People had previously thought that the effects of celiac disease were not seen until the permanent teeth are present, but Dr. Hishaw presented evidence demonstrating that the effects of celiac disease are seen long before that. Ridging of the teeth or patchy loss of tooth enamel can be seen in baby teeth as well as permanent teeth. Regular visits with a pediatric dentist trained in the effects of celiac disease on dentition are extremely important for all children with this disease.

Dr. Wataru Tamura, a local gastroenterologist and MAB member, gave one of the final talks, and it was about capsule endoscopy. He is using the "Pill Cam" to diagnose celiac disease as well as other small bowel disorders. He showed many cases of individuals with symptoms of celiac disease who had either negative antibodies and/or negative duodenal biopsies but who had CD identified by the pill cam. This device is probably the most exciting development in the diagnosis of CD since the development of the TTG test.

Chapter 15 Notes

Amaranth O's, by Nu World, is labeled gluten-free, since it is under 20ppm. The company says that it contains 16ppm of gluten. This may not be a problem for some less sensitive people, but, if you consume it every day or are very sensitive it might not be for you.

McDonald's fries 'sort of' contain wheat, but they are still safe to eat- if you discount possible cross contamination issues. There is a flavoring that is used in the oil that is used to par-fry the potatoes. That flavoring has an ingredient that is *derived* from wheat. The flavoring itself is GF, with the protein having been removed. Like grain alcohol is, even if started with gluten grain. It is used in extremely small proportion in the oil; little of the oil is absorbed into the fries, so the proportion of the flavoring in the fries is exceedingly small. The fries themselves have been tested and have been found to be GF. In Canada, the Mickey D fries have NO wheat ingredients.

Mrs. Butterworth's Syrup is NOT gluten free according to Pinnacle Foods Group LLC. Their Log Cabin Country Kitchen Syrup is a GF product.

Gluten Free Creations products (from Lynn Rae Reis's bakery) are no longer being carried by Sprouts due to turnover problems.

Living Without magazine's mailings have been disrupted because the publisher has been ill with cancer. Since she has a very small staff, it was impossible to get all the issues out, but the magazine has not 'folded'. <http://www.livingwithout.com/welcome.htm> for more information.

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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RoundTable
Resumes Jan. 23

Developing celiac-safe grains

By VIRGINIA MORGAN



Dr. DAVID SANDS

Dr. David Sands is a phenomenal teacher, geneticist, and problem solver who is working on developing more gluten-free grains by studying ancient grains around the world and analyzing them for nutritional benefits. To date he has 17 patents. Most celiacs are familiar with Teff, which is now commercially available because Dr. Sands and others like him persuade farmers to grow these crops

Other products and grains that he helped developed are a high-lysine sour dough bacteria, a super protein which is three times higher than casein. Montina, Proatina, Timatina, Camelina, and Wrinkled Peas are also grains he developed. He likes Wrinkled Peas because it has such a low glycemic index for use in diabetic diets.

These specialty grains must be grown on smaller farms. For example, he now has 51 farms growing the perennial Montina, which is also known as rice grass. It is naturally gluten-free, high in fiber, iron, and calcium. It is a good source of balanced amino acids and is being grown weed-free. It can be purchased at www.amazinggrains.com.

Timotina is also known as Timothy Grass. It is easily grown, and, when baked into bread, it has a flavor better than wheat. Hopefully, it will soon be available along with the other grains at greatnortherngrowers.com.

He was excited about Camelina grain because it is a high omega 3 grain and is now being grown in the cold, poor soil of Montana. Dr. Sands mentioned that cold climates such as Montana's helps grain produce more unsaturated fats. Our American diet has a 25 to 1 ratio of omega 6 to omega 3 oils, which is pro-inflammatory. It should be a 2 to 1 ratio at the most. The camelina oil has 40% omega 3 oils. Most of this grain to date is being used to make biodiesel fuel and cosmetics, but it is also eatable and with great nutrition as it decreases the inflammatory response in our body.

Dr. Sands and his team constantly look over the fields of grain to spot natural mutants. He analyzes the mutant to see if it is superior or not and grows more of it if it shows promise. The grains with the most nutrients also are the most prone to insect in-

festations as insects and rodents, unlike humans, can recognize nutrient-laden foods. It also appears that grains that are resistant to insects also lack something our bodies need. For example, he found that if people who were deficient in zinc ate crops also deficient in this mineral, they tended to be more violent, aggressive, and have more mental illnesses.

Of the foods common in the diet of the average celiac, Dr. Sands singles out potatoes, rice and corn as being the poorest in nutritional values. White rice and corn starch are very deficient in protein and vitamins, while potatoes, brown rice and whole corn meal have a very poor balance of amino acids, so that we cannot absorb the proteins from it.

David Sands is a professor of Plant Pathology at Montana State University in Bozeman, MT.

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Lindsey publishes article in *Bear Essential News*

Hi. My name is Lindsey Hanks. I have Celiac Disease. You're probably wondering what Celiac Disease is. It's a disease where you can't eat a protein called Gluten. Gluten is contained in wheat, rye, malt, barley, oats, and many other things. This is my opportunity to tell kids and parents about my experience with Celiac Disease [CD]. Many parents, nurses, and even doctors have never heard of CD and don't know what to do about it. My mom and I go to support meetings. I learn a lot about what's going on in my body and stomach. I understand that gluten is bad for me. I know that I must only eat gluten-free [GF] food. I want other kids with CD to understand that gluten is bad for them and that it's not that easy, but it's not that hard.

When I was five, I was diagnosed with CD. We lived in Ohio then. I got tested because my mom had it and wanted to get my whole family tested because sometimes CD runs in families. My parents told me after we moved to Tucson. Then it was hard to know what I could eat and why I couldn't eat everything else like most other people. It was confusing at school because I didn't know if I should eat something or not. But as I got older, it became easier and I know have favorite places to eat and grocery stores which sell my favorite GF foods. I have a pediatrician and a specialist for CD called a gastroenterologist. My favorite place to eat is Picasso's Pizza in Phoenix and my favorite GF store is New Life on Broadway.

People with CD visited Tucson for a conference and they had a special Kids Zone for Celiac Kids. There were nine or ten kids there. They came to the conference from all over the United States. The youngest was in 1st grade. One day we went on

a grocery store. We had to look for GF labels. My team won. Another time we went to buy all kinds of GF candy. We had to read the labels that time too. Then we did a piñata with the candy. We also got to swim and hike and we always had good GF snacks and meals. I still keep in touch

with one of the girls who went to the Kids Zone. She lives in Tucson but other kids came from other states

Allie, my best friend, always reminds our teacher Mrs. Singer when we have cupcakes or cookies, that I can't eat them if they have gluten in them. I am lucky to have Allie because sometimes it's hard for me to stand up for myself always. Once Allie and I were feeding her horses sweet oats. We wanted to try some but her dad said, "Stop, Lindsey! Those oats have wheat in them!" I was so glad he stopped me just in time, I couldn't believe I almost ate gluten! Allie understands that when I eat gluten it feels like the stomach flu and as long as I don't eat any, I don't get sick. We went to a GF potluck together. We met lots of kids at the Kids Korner. There was a jumping castle and a craft center. We had lots of fun.

I must read the labels on food packages. Before I could read my mom or sister did that for me. I am glad there are food labels so I don't accidentally eat some gluten. I never eat a food if the label says modified food starch. There are other ingredients I must avoid, too. A lot of people, like servers at restaurants have never heard of CD and don't know what food I must avoid. So, my mom and I have to explain it to them before I can order. It's not as hard as it used to be standing up for myself.

(Please see **Cel-Kids** page 6)



Back to front: **ALLIE, LINDSEY AND Lindsey's sister, DANIELLE** at the potluck last November

Lindsey's article was published in the December, 2007 issue of *Bear Essential News for Kids*.



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Thanks, kids!



Publicity Chair and Board Member **PAT HIRSCH**

When SACS president Cheryl Wilson asked me how the idea for a *real* celiac kid to write a *real* article on CD for all kids in a kids' *real* newspaper came about, three very smart, CD-informed people came to mind: Lindsey Hanks, Tyler New, and Katie Knoepfle.

All three young people are under 10 years old. Katie probably does not have CD, but she is the big sister of Emily who does. Katie was reading *Bear Essential News (BE)* during a Roundtable support group meeting. Everyone gets to speak at Roundtable, and Katie said it is a big sister's responsibility to make sure Emily eats GF. Katie was five then and Emily aged three.

I already had met Lindsey who is nine and dedicated to helping CD kids

and grown-ups be healthy. After she spoke at the SACS Aug. 2007 General Meeting to a crowd of more than 50 people, I asked her if she would like to write about CD in *BE News*. To my delight, she said yes!

Writing for BE news was a remarkable learning experience, and Lindsey and I are very grateful to Rachael Drozdoff, *BE's* Office Manager & Special Events Outreach Staffer, who coached us on how to meet deadlines and explained what the newspaper needed from us so that Lindsey's story would be published. Thanks to Rachael and *BE*, CD awareness is now on the minds of Arizona girls, boys, parents and teachers!

Tyler News is the first person I ever met who had CD. He was a healthy baby when he lived in Tucson but as a toddler, after the News family moved from Tucson to Colorado, he became seriously ill. The family and doctors struggled to find out how to make him well again. My husband Louis and I visited the News in Aug. 2005. Tyler was almost five, and the family had recently learned of his CD diagnosis.

By divine coincidence I had been having severe tummy trouble during our trip, and, when Tyler's parents compared his symptoms to mine

(and my history), we all concluded that I had CD, too. In three days I got a cram course in how to manage CD from Tyler, right down to seeing firsthand the frustrations of eating out! I also got to watch his big sisters be responsible yet fair and gentle guardians of Tyler's health, just like Katie is for Emily!

Louis and I learned so much from Tyler. We learned there were support groups like SACS. In following his example, I have become healthier than I can ever remember.

If Tyler can help one person like me, then others like Lindsey and Katie can help many more people, too. When children speak on serious life experiences like CD, we all should listen for they have earned dignity and wisdom. They are concerned that others be spared the suffering they have known. Thank you, kids.

Attention: Cel-Kids!

Cel-Kids Tucson would like to thank all who came to our event this past November, making it such a success. We would also like to thank KidzJump for generously donating the use of their jumping castle at that event.

Please join us at the next SACS general meeting on January 19th, while we sit in and listen to Dr. Priya Ramachandran's lecture regarding pediatric dentistry and celiac disease.

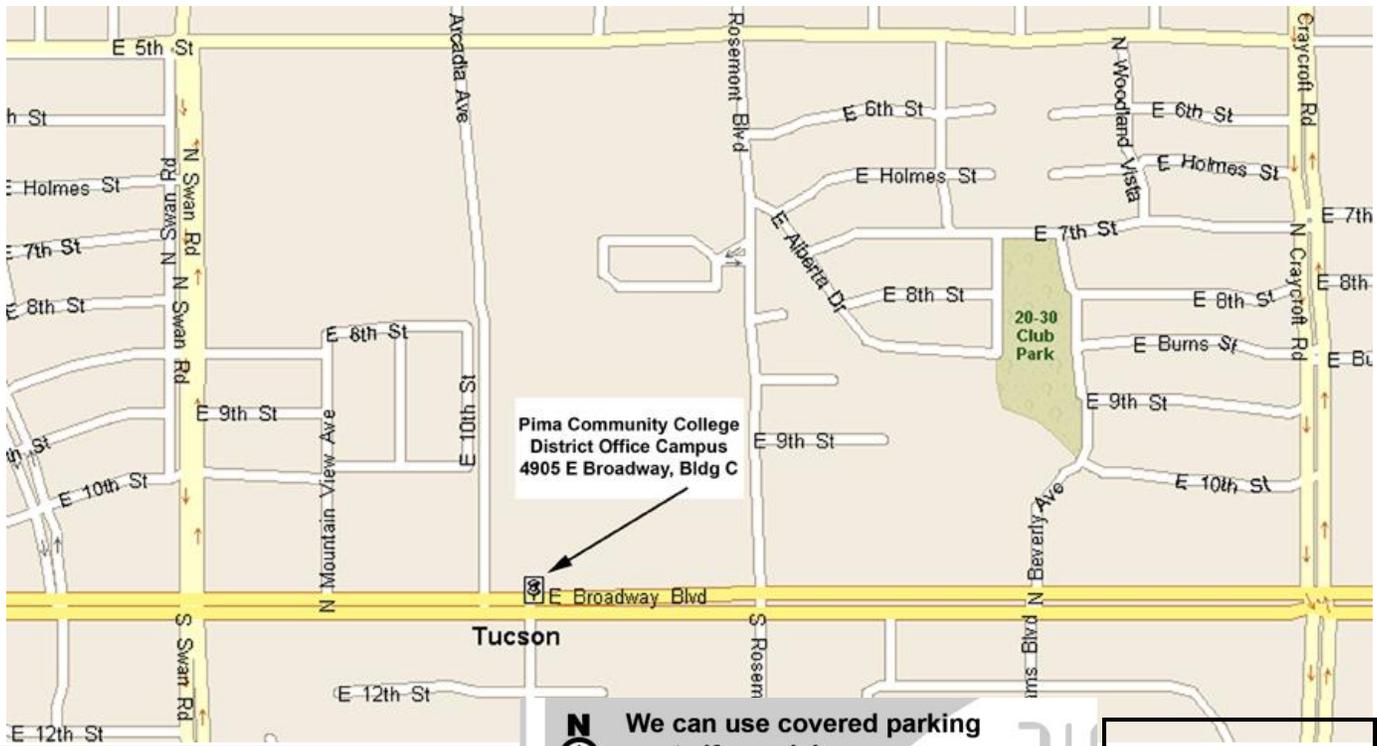
We also will have a table with useful information and a signup sheet specific to Celiac-Kids Tucson so that we can organize a get together near the end of February.

Contact Diana Knoepfle [diana.knoepfle@gmail.com] or phone her : 520.574.0777 for more information about Cel-Kids.



Children playing in the jumping castle at the November general meeting

Map for the January 19th meeting

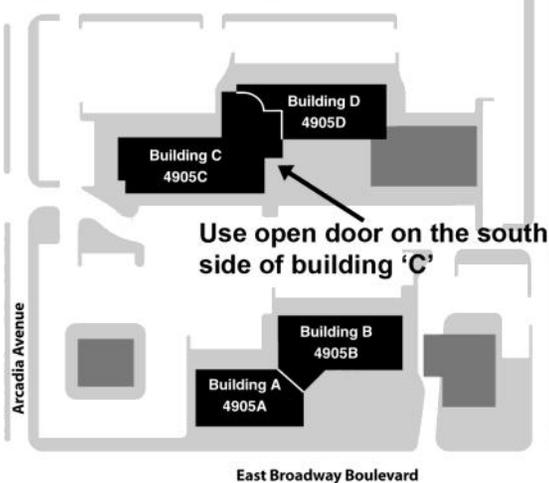


Cel-Kids

(continued from page 4)

I'm not embarrassed about myself because I know how important it is. I know in order for me to be healthy I must be and eat gluten-free. For more information on CD and support groups visit <http://www.southernarizonaceliacsupport.org> or call Diana at 488-7738. For more information on the CEL-KIDS which is a support group just for kids with CD..... Diana runs the celkids website and kids korner. There is a celkidstucson@googlegroups.com

N We can use covered parking spots if we wish



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.

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Potluck

(continued from page 1)

Medical Advisory Board members.

Under new business, it was proposed and unanimously passed that SACS purchase a digital slide projector as so many of our presenters rely on media presentations. Past President Georgina Rubal-Peace handed out a questionnaire concerning GF pharmaceuticals and there was some discussion of the 2008 Food Faire, which is going to be the biggest and best ever.

Breakfast Casserole

- 2 pkgs. (16+ oz. each) frozen hash browns, thawed (or substitute refrigerated-style)
- 2 C. chopped cooked ham
- 1 C. sliced green onions
- 3 C. shredded cheddar cheese
- 10 eggs, beaten
- 1 to 2 Cups milk (Cheryl uses 2)
- 1 tsp. salt
- 2 tsp. dry mustard
- Dash cayenne pepper
- Paprika to taste



Preheat oven to 350 degrees.

Layer bottom of 13 x 9 pan with hash browns. Sprinkle ham, green onions and cheese evenly over potatoes. In bowl, combine eggs with milk, salt, mustard and cayenne. Pour over all. Sprinkle with paprika.

Bake in pre-heated oven for 40-45 minutes or until firm. You can add additional ingredients, such as mushrooms, peppers, etc., but then allow about 60 minutes to bake. Makes 12 large servings.

Note: Casserole can be assembled the night before, covered and refrigerated until ready to bake.

In Memoriam
Anna Lillian Leonard
1918 - 2007

Anna Leonard passed away November 18, 2007 of metastatic lung cancer. She was a registered nurse and served as a Sergeant in the Army Nurses Corps during the Japanese Occupation in Tokyo.

Anna brought her nursing skills to the celiac group and together with Pat Ewing, who also passed away in 2007, started what is now our SACS group in the early 80's. She was very active throughout the years as a local board member.

She also served as a regional chair of CSA National and attended many of the national CSA Conferences.

Anna was an extremely warm and friendly person who was always willing to help out newly diagnosed celiacs. She helped make the Tucson celiac group into what it is today, and she will be greatly missed.

In Memoriam
Carol Bailey

SACS member, Carol Bailey passed away December 31st at her home in Benson, AZ. We extend our heartfelt condolences to her family.

Leadership Contacts

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

RoundTable
 Resumes Jan. 23

NOTE THIS URL: <http://youtube.com/watch?v=QR2LvQmoF1Y>

It is an excellent 90 minute video on the full spectrum of celiac disease, and it's available on **YouTube**. It's best to have a high-speed Internet connection to view this. It is also a valuable link to send to relatives and friends who just don't 'get' CD.

Free Initial Consultation

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Part of the crowd at the November Potluck

Mark your calendar

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

2008

Jan. 19— 9:00 a.m.: General Meeting, Dr. Priya Ramachandran, pediatric dentistry and CD.

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

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

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

March 29— 9:00 a.m.: General Meeting, Dr. Wataru Tamura.

Location TBA

April 17-27: SACS booth at the 2008 Pima County Fair

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

May 10 — 9:00 a.m.: Annual GF Food Faire – bigger ‘n better than ever!



LUNCH BUNCH SCHEDULE

January 11th *Opa Greek Cuisine & Fun* (2990 N Campbell) a new restaurant in town

February 8th *Old Pueblo Grille* (Alvernon N of Broadway)

March 14th *Casa Blanca* (283 N.Stone Ave & Franklin- the old MO Club- now more of a dance club)

(As always, call Eilene Ealy at 888-2935 to confirm you are coming)