



Volume 7, Issue 3

Celiac Digest

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

online at WWW.SouthernArizonaCeliacSupport.org

November 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.

More than just food at Nov. potluck

Our annual potluck will be held this year on Saturday, November 8th at 11 am. The new venue is **First Evangelical Free Church**, 4700 N. Swan Rd. (See map and details page 6) There will be a barrier with balloons and a sign to help mark the entry drive to the church.

This is going to be a great meeting. You will get to share wonderful food (all GF ☺) with wonderful people and hear all about the 2008 CSA National Conference from Board member and publicity chairperson Pat Hirsch.

Pat attended this year's CSA Conference as SACS representative. She also attended a special workshop on networking, promoting awareness and how to maximize a publicity budget.

Besides a side dish, it would be wonderful if you can bring **donations** for our raffle bags. These bags are so very much appreciated by those who are newly diagnosed as well as by the old-timers! Mostly, the SACS Board has been supplying all the raffle donations, but we need to broaden our donor base.

There will be a Cel-Kids table and special activities for the kids, as well as kid-friendly food and snacks. Of course there will be lots of info for parents of celiac children.

Probably the best opportunity is that you get to bring your favorite Thanksgiving side 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, iced tea and water will be provided, as well as table service. Interesting dishes like spinach soufflé, cranberry-apple quinoa and GF quiche 'might' be on the table.

Come early or plan to stay late and experience the opportunity of meeting and working with people in either setting up the potluck or helping clean up after.

NOTE: If you are *not* able bring a dish to the potluck, you are more than welcome to come anyway as we **always** have plenty of food.

Pizza pig-out at Picazzo's!

Lunch Bunch for November 14th will be at Picazzo's Pizza in Casa Grande, 105 W. Florence Blvd., Casa Grande. The restaurant is about four miles west of I-10.

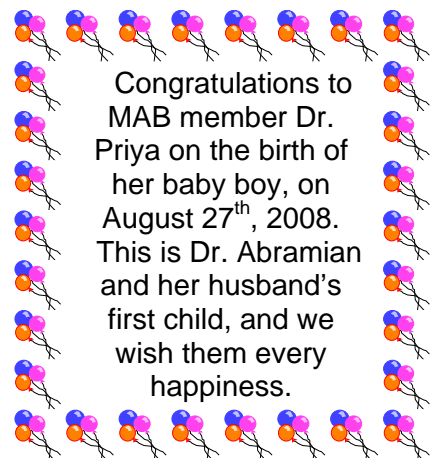
Picazzo's has delicious pizzas and an extensive GF menu. SACS will also have '2 for the price of 1' coupons to hand out, so the cost will be reasonable, too.

Because of the distance involved, we will meet between 10:00 and 10:15 at the Cortaro/I-10 Kohl's south parking lot and carpool. If you don't want

to carpool, we can meet you at Picazzo's between 11:00 and 11:30. The carpool will be informal with people deciding who will ride and who will drive when we get to the parking lot. Some are planning on doing some shopping at the Outlet Mall.

Call Eilene Ealey at 888-2935 to confirm as we need a final count by November 10th. If you

definitely **don't** feel comfortable driving on the Interstate, let Eilene know and we'll make sure you get a ride.



Congratulations to MAB member Dr. Priya on the birth of her baby boy, on August 27th, 2008. This is Dr. Abramian and her husband's first child, and we wish them every happiness.

Be an informed health-care consumer

By **LINDSEY PEARSON, NMD**

In 1997 David Eisenberg did a follow up to his 1990 study on the use of complementary and alternative medicine (CAM) in the United States and published the results in 1998 in *The Journal of the American Medical Association*. He found that the use of CAM therapies increased from 33.8% in 1990 to 42.1% in 1997, and the probability of patients utilizing a CAM therapy rose from 36.3% to 46.3%. With almost half of the population utilizing CAM therapies, it is imperative that one becomes an informed consumer when seeking out CAM practitioners.

To start, CAM therapies include, but are not limited to, chiropractic, massage, herbal medicine, homeopathy, acupuncture, naturopathic medicine, and conventional practitioners such as medical doctors, osteopathic physicians, nurse practitioners, and physician assistants who practice outside the conventional scope of their respective practices.

I'm a consumer? Yes, like buying a car, a home, or a television you want to make sure you are getting what you are paying for. You want to make certain you get what you are offered. You want to make sure what you receive is effective and safe.

We are fortunate to live in the State of Arizona where most CAM professions are regulated and require licensure or registration and set standards for practitioners to receive the licensed or registered status. Though our state has more regulatory checks in place, you still want to check out the practitioner and therapy to make sure you are an informed consumer.

Here are some tips in becoming an informed consumer of CAM therapies:

Step 1: Choosing a practitioner

- Ask your current medical practitioner for a recommendation.
- Ask someone who has seen a particular CAM practitioner about him or her and the experience.

- (2) ● Contact state or national profes-

sional organizations; most are on the internet

- Contact the state regulating agency of the profession to check out if that practitioner has any complaints against him or her; this, too, can be found on the internet most of the time.

- Ask about the education of the practitioner:

- Where he or she was educated
- Check it out, see if it is an accredited program by an accreditation agency recognized by the U.S. Department of Education

- What kind of certification or licensing does he or she possess?

- Again, it is legitimate and recognized by a federal or state agency

- Advanced training

- In what areas does the practitioner specialize

- Certain disease or condition areas

- Treatment or modality area

- How long has he/she been in practice?

- How many patients has

he/she seen?

- How much do they charge?
- Does he/she accept insurance?

Step 2: Interviewing a Practitioner

Be prepared to interview the practitioner and have a list of questions prepared before you go to the office

- What benefits can I expect from this therapy?

- What are the risks associated with this therapy?

- Do the benefits outweigh the risks for my disease or condition?

- What side effects can be expected?

- Will the therapy interfere with any of my daily activities?

- How long will I need to undergo treatment? How often will my progress or plan of treatment be assessed?

- Will I need to buy any equipment or supplies?

- Do you have scientific articles or references about using the treatment for my condition?

- Could the therapy interact with conventional treatments?

- Could the therapy interact with any



Chapter 15 Notes

Heartland's Finest is no more. The message on their website reads: *Heartland Ingredients has closed its doors. Thank you for your support.*

The Picazzo's Pizza in Glendale is no longer owned by Dennis Daniel and, therefore, has lost its CSA certification as CSA contracted only with Mr. Daniel in terms of certifying the restaurant. Clue: if there is no CSA decal on the door of a Picazzo's, it's not CSA certified.

GF Cake Mix found at Costco. The brand is So'Fella Organic GF cake mix. Costco is also selling a rice cracker, **Crunchmasters**, that is certified GF. You get six packages of crackers for \$6.99, which is a good price. They taste good, too.

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.

herbs or nutrients? (Drug-Herb-Nutrient Interactions) ALWAYS BRING AN UP-TO-DATE MEDICATION AND SUPPLEMENT LIST WITH YOU TO THE VISIT. INFORM ALL OF YOUR HEALTH-CARE PRACTITIONERS, CONVENTIONAL OR CAM, OF EVERYTHING YOU ARE TAKING OR DOING

- Are there any conditions for which this treatment should not be used?

Step 3: Questions to ask yourself after interviewing a practitioner

(Recommended by National Center for Complementary and Alternative Medicine)

- Was the practitioner easy to talk to?
- Did the practitioner make me feel comfortable?
- Was I comfortable asking questions?
- Did the practitioner appear willing to answer them, and were they answered to my satisfaction?
- Was the practitioner open to how both CAM therapy /conventional medicine might work together for my benefit?

(Please see **CAM selection** page 6)

Raising celiac awareness: everyone's job

By CHERYL WILSON

As the 2008 National Celiac

Awareness month (October) comes to a close, we looked back on an unprecedented number of news features, radio and TV spots and articles about celiac disease—none of which were generated by our support group! Imagine that! It used to be that we had to initiate these type of public notices but are so thrilled to know that there are others out there helping us bring to the forefront the widespread affects and high susceptibility of CD.

Several of our SACS members have been keeping their eyes and ears open and have made several 'catches' this month. Georgina Rubal let us know that there was a radio program every Wednesday morning in October featuring CD. Eilene Ealey told us only this week of a CD segment on News 4@4. Fortunately, we were able to contact them ahead of time and get our website and phone number on the screen, which has generated calls. Thank you ladies for being so alert!

Our Cel-Kids Coordinator, Diana Knoepfle, heard about a small health fair being held at a local church where she was attending a MOPS (Mothers of Pre-Schoolers) group. Diana took it upon herself to put together a fine display of GF food, plenty of handouts, and borrowed our small table-top banner and she was ready to go. It turns out that her booth was one of the most popular ones and was very well attended. She was able to have many meaningful conversations and hand out a lot of information. (see photo).

You all know that our Executive Board actively seeks venues in which to increase awareness with our presence. We will have the opportunity in days to come at the Pima Council on Aging annual Health Fair (Nov. 6th), as well as an In-Service Presentation

for the Vail School District Health Care aids (Jan. 28th). We even received a call yesterday from the Basha's headquarters telling us that they are opening a brand-new farmers market in Oro Valley and they would like our 'input' on their gluten-free section to make sure they are 'going in the right direction'? WOW—that's a first, and we will help them.

So, what does this have to do with you, an average SACS member? Here's a hint. What do you carry around with you in your car, your briefcase, or perhaps your purse? How about a few of our quad-fold brochures that you can hand out to people when they overhear you ask "is this gluten-free"? Every time you ask a question at a restaurant or grocery store, or make a call to a manufacturer about ingredients, you are educating someone about celiac disease and/or gluten-intolerance. You even educate your doctor when you ask if that prescription they just gave you is gluten free. They may not know the answer (and it's likely they won't) but you have now put a new thought in their head. That's progress. Our brochures are available at any general meeting or by contacting any board member.

Keep your eyes and ears open for opportunities to increase awareness. For sure, if you learn of an event where we might be able to provide an information booth, let any board member know. And if you learn of an article or a TV or radio segment that is coming up (or has happened and you read / saw / heard it) please let us know. We cannot be everywhere, but you all are all over this country. Remember, the more people become aware of Cd and its only treatment, the easier it will be for us to get the care and products we need.

Here's another way to think of it: wouldn't you like to be able to save someone else from going through all you did to get to where you are now? Wouldn't you like to see them get a diagnosis or at least get help now? I know I would. With the average time for diagnosis in the USA still at between 9 to 11 years, wouldn't it be nice if people could go to *any* doctor in Tucson, and, after listening to someone describe his or her symptoms, the doctor said, "I think you should be tested for celiac disease".

Imagine that. I have and that's why I am reminding you that increased celiac awareness is not just my responsibility- it's *yours*.



Diana Knoepfle (behind the table) is a board member and chairperson of the Cel-Kids group. She is handing out literature and information about celiac disease at the MOPS 10/22/08 health fair at the El Camino Baptist Church.

Not *all* gluten is created equal

By NANCY SCHULLER, R.D.

When celiac patients are told to follow a gluten-free diet and to avoid wheat, rye, barley, and possibly oats, they often hear that rice and corn have gluten, also.

Gluten is a general term that refers to the storage protein in grains. The gluten in wheat contains *gliadin*, which contains a peptide chain of amino acids (the building block of protein) that cannot be totally digested and thus can cause damage for celiacs when transported across the lining of the small intestine. Rye con-

tains secalins and barley contains hordeins that are also polypeptide chains that can cause damage.

In plant taxonomy (the study of plant classification), Donald Kasarda has researched these grains for many years and states that corn and rice are *not* toxic to celiac patients.

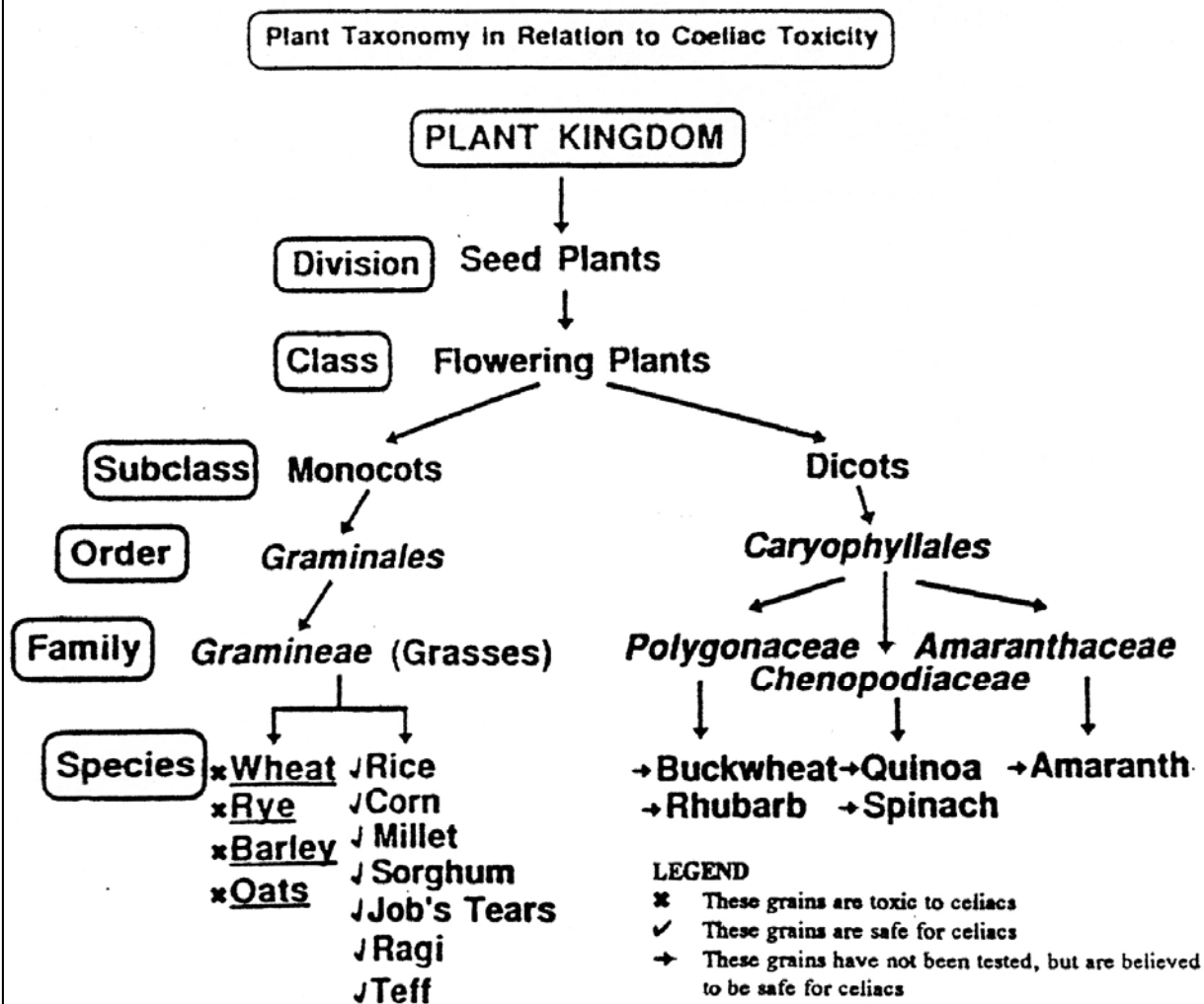
What follows is his *Table of the Taxonomic Relationship of Major Cereal Grains*. Dr. Kasarda also states "There is no reason for celiac patients to avoid plant foods that are very *distantly* related to wheat." (*emphasis ours*)



NANCY SCHULLER, R.D.

Plant Taxonomy in Relation to Celiac Toxicity

Courtesy D. Kasarda, Ph.D., USDA



From presentation by Donald D. Kasarda given at the Trinity College Dublin International Coeliac Symposium, 1992.

More complete information on grains and gluten, access this website <http://www.enabling.org/ia/ceiac/grains.html> which has more technical information from Dr. Kasarda.

Check GF status of Farmer's Market goods

Alert SACS members Jack

Cohen-Joppa and Phoenix Wheeler both notified the celiac community via our listserv that a vendor at the Farmer's Markets at Plaza Palomino, St. Phillip's Plaza and Oro Valley is selling products made with emmer, a progenitor of wheat, which the vendor insists is GF. In fact, emmer is **not** gluten free, and a major grower and several experts with CSA have written SACS to confirm that emmer, no matter how it is grown, is not GF. This vendor also uses barley water in her products, claiming that its gluten is neutralized by fermentation.

The good news is that several ven-

dors at the market do have safe, GF products; Mindy of Mindy's Miracle Munchies is one. She also prepares her products and mixes in a certified commercial kitchen.

Other safe products at the Market are fresh vegetables, jams/jellies and, of course, specialty honeys from Charles Shipp, former proprietor of **Naturally Healthy**.

Below is a letter Jack wrote to the listserv. Jack is in contact with the organizers of the Farmer's Market to see if they can curb misleading advertising.



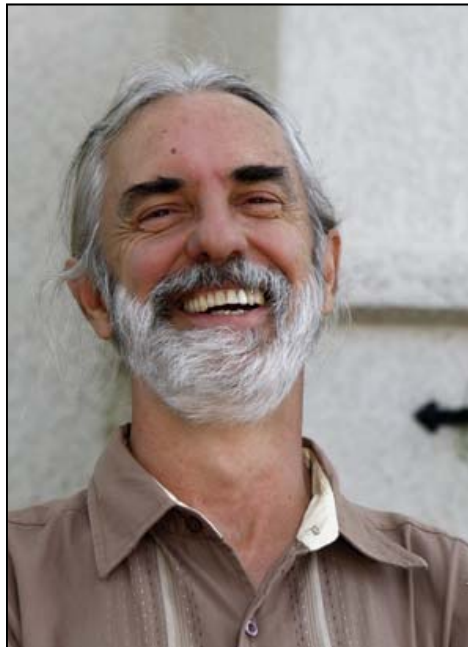
Mindy of **Mindy's Miracle Munchies**. Her company is a source of safe, delicious GF food and product mixes.

Dear Tucson Celiacs,

The last two Sundays I visited the farmer's market in St. Phillips Plaza, where I observed a couple in a stall selling emmer grain and baked goods made from emmer. Their sign proclaimed the grain to be "gluten free". I made a mental note last week, vaguely recalling the "ancient grain" emmer as NOT G-F, but I wanted to check my facts before asking questions.

So, yesterday I approached the stall from the side, asking a man behind the table if I could ask a question or two, because I had a concern. I indicated I did not want to disturb the commerce at the front of their table, where the other worker was speaking with a customer.

I noted that I was biopsy diagnosed with celiac, and after checking my facts at home this week, I was concerned that emmer is NOT G-F, and their sign could be misleading. I told him I had learned that several growers advertise pure emmer, but that different species were identified with that name, and asked where their product was grown. He told me theirs is triticum dicoccum from a clean, dedicated field in Aberdeen, Idaho. He went on to tell me that the woman working with him was researching a book on the subject, and among other things, they had deter-



SACS member Jack Cohen-Joppa

mined that how the crop is grown affects its protein makeup, and their crop was grown in the correct way (not supplementing nitrogen to the soil, as I recall) and was thus G-F!

*I said I wasn't interested in arguing about the science (I'm not a plant scientist), and asked if an ELISA assay had been done on the product they sell. At this point, the female vendor turned around to engage me, so I repeated my question. She told me the ELISA tests are "bull****" and before going off too far on that point, I*

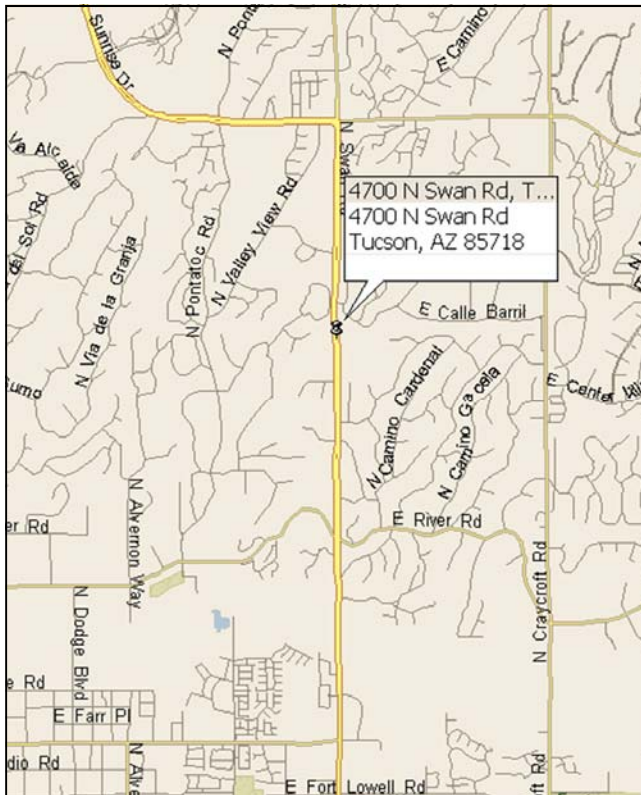
repeated that I was not there to argue about the science of the test - I just wanted to know if it had been done on their product. She again used the same language without simply answering my question, and I repeated again that I was not interested in arguing about the validity of the test - I just wondered if it had been done and what value it revealed in ppm. She told me she can tell if the product is G-F by mixing the flour with water; if the dough breaks instead of stretching, it's gluten free, and the visual test is all that matters! (At this point, I resisted the urge to let my chin actually drop as far as it might have) Once again, her response included scorn for the question that was still unanswered plus the barnyard epithet, so I concluded the conversation by saying I still was not interested in arguing, and because she kept using 'fighting words' about it, I would just carry on with my shopping.

Has anyone else engaged this vendor on the subject? I was quite surprised that someone trying to sell me something would be this rude, but then, quacks routinely demean professional opinions to sell their products or services, so maybe this factor was at play.

Let the buyer beware!

Jack Cohen-Joppa

Potluck at new venue—see maps



To the left, a street map of 4700 N Swan Rd and to the right is a bird's eye photo of the First Evangelical Free Church. As you can see, it is located about 800 feet east of Swan. Since the church cannot be seen from Swan, turn east directly across from the three radio towers located on the west side of Swan.

Our potluck will be held in building F (marked on the map), so park accordingly.

CAM selection

(continued from page 2)

- Did the practitioner get to know me and ask me about my condition?
- Did the practitioner seem knowledgeable about my specific health condition?
- Does the treatment recommended seem reasonable and acceptable to me?
- Was the practitioner clear about the time and costs associated with treatment?

Step 4: Researching the CAM Professions and Treatments

- PubMed: www.ncbi.nlm.nih.gov/entrez
 - Web searches
 - Textbooks on the subject area
 - National Center for Complementary & Alternative Medicine (National Institutes of Health): www.nccam.nih.gov
 - Information on Treatments: www.nccam.nih.gov/health/bytreatment.htm
 - Information on Selecting a Practitioner: www.nccam.nih.gov/health/practitioner/index.htm
- (6) • Safety of Herbal Supplements:

www.nccam.nih.gov/health/supplement-safety

• 10 Things to Know About Evaluating Medical Resources on the Web:

www.nccam.nih.gov/health/webresources/

• Office of Dietary Supplements: dietary-supplements.info.nih.gov

Tips for the Savvy Supplement User:

• Making Informed Decisions and Evaluating Information:

www.cfsan.fda.gov/~dms/ds-savvy.html

• University of California, San Francisco. Study of Naturopathic Medicine:

www.futurehealth.ucsf.edu/pdf_files/naturo2.pdf

• Health Notes: www.gnc.com/healthnotes

• Herb Med: www.herbmed.org

• Dr. Andrew Weil: www.drweil.com

With studies like Eisenberg's demonstrating an increased frequency of CAM therapies and well as the number of visits to CAM practitioners exceeding the total number of visits to U.S. primary care physicians in 1997, it is essential you become active, educated, and empowered as a consumer of complementary and alternative medicine.

Mark your calendar

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

2008

Nov: 8: 11 a.m. Potluck, First Evangelical Free Church, 4700 Swan,

Nov: No Roundtable during Nov/Dec

Nov 14: Lunch Bunch Pizza Run—Meet at Cortaro/I-10 Kohl's S. parking at 10:00-10:15 for carpool. Call 888-2935 to confirm.

Dec 12: 11:30, Lunch Bunch, Location TBA

2009

Jan 16: 1 p.m., Board meeting, Ward Six City Hall at 3202 E. 1st St.

Jan 24: 9 a.m. General meeting, MAB panel discussion, location TBA

Jan 28: 1:00 p.m. Roundtable, Ward Six City Hall at 3202 E. 1st St.

Feb 25: 1:00 p.m. Roundtable, Ward Six City Hall at 3202 E. 1st St.

Roundtable

resumes Jan. 28



From left: Aline Horan, Audrey Dunham, Vicki Holmes (moderator) and Joyce Kvanbeck. Audrey is sampling Vicki's homemade GF cupcakes. You can also see other goodies spread out around the table.

SACS Roundtable, held at 1 p.m.

every fourth Wednesday of each month (except for Nov/Dec) at the Ward Six City Hall at 3202 E. 1st St. is a SACS tradition. The meeting, moderated by Vicki Holmes, is an informal gathering with no fixed agenda.

Participants (you do not have to be a SACS member to attend) discuss recipes, sample new foods, and share advice on living gluten free. Many bring a GF treat to share, but it is not required. There is no charge.

At the October meeting, Vicki brought delicious homemade cupcakes and promised to bring copies of her chicken enchilada recipe but then remembered that Roundtable's next meeting was in January. So, here is her recipe:

Easy Chicken & Cheese Enchiladas

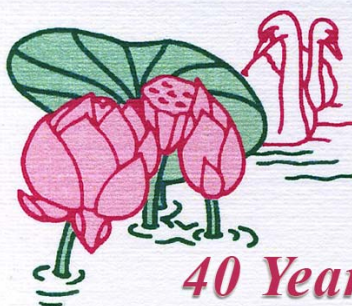
- 1 can 10 ¾ oz G-F Cream of Chicken Soup (Amy's or Health Valley)
- ½ cup sour cream
- 1 cup Pace Picante Sauce
- 1 tsp chili powder
- 2 cups chopped cooked chicken
- ½ cup shredded Monterey jack cheese
- 6 flour tortillas 6" size, warmed
- 1 green onion sliced

1. Stir the soup, sour cream, picante sauce and chili powder in a medium bowl.
2. Stir 1 cup picante sauce mixture, chicken and cheese in a large bowl.
3. Divide the chicken mixture among the tortillas. Roll up the tortillas and place them seam-side down in an 11"x 8" shallow baking dish. Pour the remaining picante sauce mixture over

- the filled tortillas. Cover the baking dish.
4. Bake at 350 for 40 minutes or until the enchiladas are hot and bubbling.
5. Top with tomato, onion and extra cheese for the last 5 min. of baking.

Leadership Contacts

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



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