



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.

Dynamic mother-daughter duo speak at August meeting

Only about 45 members and guests showed up for what was a terrific general meeting Saturday, August 25th at the Pima Community College District Office Campus. Dr. Shelli Hanks, a radiation oncologist specializing in the treatment of breast cancer and a member of Chapter 15's Medical Advisory Board spoke on: **How to Get Your Doctor to Listen to You.**

Dr. Hanks spoke from the perspective of a celiac patient and of a doctor. She candidly shared her personal and family health history with us, and there were many nods of recognition from her audience when she described the long road to finally getting that elusive diagnosis. They also chuckled at her exasperation over her extended family's reluctance to even consider testing for CD, even though some have obvious symptoms.

Her PowerPoint presentation out-

lined both the patient's responsibility and the doctor's responsibility in achieving good communication.

Patient Responsibilities •Bring a list of the medications you are currently taking •List medical illnesses and surgeries •Family medical history, •List of questions and concerns
Following the doctor visit:

- Follow your doctor's recommendations
- Keep accurate records
- Contact if there is a reaction to prescribed meds, symptoms don't improve or new symptoms develop
- Keep follow-up appointments
- Keep an ongoing list of questions and concerns.

Doctor responsibilities

- Provide adequate time for patient,
- Listen to patient •Address all of their concerns • Offer a plan of action for each concern •Recommend appropriate follow-up when needed
- Offer encouragement •Acknowledge what the patient is doing well •Refer the patient on when further expertise is needed from a specialist

The most useful and empowering information she gave was that you should, without guilt or delay, **seek a new doctor if the one you are seeing does not seem to care about you or is hard to talk to.**

Lindsey Hanks, Shelli Hanks' nine-year-old daughter and also a celiac, gave us a view of what living with CD is like if one is a child. Too often we look at compliance from our 'grown up' outlook and it was very informative



Lindsey Hanks speaks at meeting

to hear about the special challenges a younger celiac faces. Lindsey wrote her own speech and spoke about the importance of a good support system, saying that her mother and older sister were the two most important people in helping her stay GF.

She and her mother also encouraged attendance at Cel-Kids Network (formerly Tucson R.O.C.K.)The first meeting, a potluck and swim party, will be held at their home on Sunday, Sept. 9th.

Other meeting highlights include: ► Sande Smith's report on the Second Annual Gluten-Free Culinary Summit she attended in Denver where she met several nationally known chefs such as Chef Lee Tobin who introduced GF food to all of the Disney theme parks, and Chef Carol Fenster who has a Ph D in nutrition, and is the author of several GF cookbooks.

(Please see **Meeting** page 4)





CAUTION ! FAST FOOD AHEAD

ARBY'S - about the only thing you can have there is as follows:

Proteins, (without bread or buns) roast beef, ham, turkey, corned beef and **Grilled Chicken Fillet**.

[Breaded chicken fillet and tenders and the Diced-Grilled are NOT GF.]

Cheeses, natural and processed.

Peppered bacon.

Baked potatoes only [Plain, or with butter and gluten-free seasonings.

About 10% of Arby's restaurants offer baked potatoes.]

Fresh Fruit Cup.

Milkshakes

The other potato products are not safe because, in their cooking at the restaurant, there is the chance they will share fryer-space with wheat flour-based coated items.

Also, the Curly Fries are coated, and there is gluten added as a part of that formulation and preparation by the supplier. Their preparation in the same oil as that used for Homestyle Fries and Potato Cakes takes out all three as a GF option. [<http://www.arbys.com/> and select nutrition from the cover page for more detailed information on Arby's menu.]

McDONALD'S - probably due to the french fry flap of last year, has, maybe to remove all doubt and liability, added gluten to their fries. And, they have also removed their GF menu options. If you get Mickey D fries today, they will contain:

Potatoes, vegetable oil (partially hydrogenated soybean oil, natural beef flavor (wheat and milk derivatives)*, citric acid (preservative), dextrose,

sodium acid pyrophosphate (maintain color), dimethylpolysiloxane (antifoaming agent)), salt. Prepared in vegetable oil ((may contain one of the following: Canola oil, corn oil, soybean oil, hydrogenated soybean oil, partially hydro-



generated soybean oil, partially hydrogenated corn oil with TBHQ and citric acid added to preserve freshness), dimethylpolysiloxane added as an antifoaming agent). *CONTAINS: WHEAT AND MILK (Natural beef flavor contains hydrolyzed wheat and hydrolyzed milk as starting ingredients.)

Oh, well, after reading all the stuff that's in them, who wants a french fry anyway!

Chapter 15 Notes

Honey Rice Puffins Cereal from Barbara's Bakery is the *only* Puffins cereal that contains no gluten. However, it is made in a facility that handles wheat products. The lines are scrubbed between runs, but there is no guarantee it is totally GF.

Sees Candies are GF even

though the packaging says 'wheat' on some of them as they are using up preprinted packaging. "...our Quality Assurance Manager has advised that we have reformulated our products and we have eliminated wheat as a direct ingredient in all of our candies packed in standard boxes."

Rice Dream rice milk is now GF

as they have eliminated the small amount of barley they had used before. The new formulation and new packaging *should* say 'Gluten-Free' on the package.

A new clinical study has finally

tested the safety of white sorghum. It concludes sorghum demonstrates no harmful effects and confirms its safety and palatability in the gluten-free diet.

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.



If you would like to be on SACS' email distribution list, send an email to our website or to the

newsletter editor. If you are on the email distribution list and don't want to be on it, notify us, too.

Remember, we can't send out notices or electronic copies of the newsletter without valid email addresses. Once an address is bounced back, it's permanently removed from the list, and it's up to you to supply us with the correct one.



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Allergen advisories: Do they matter?



By: GENE SPESARD

The July-August issue of *Food Allergy News* (FAAN) discusses a paper on the issue of voluntary allergen advisories, what they mean and the effect they have on consumers.

First, to set the context, we need a brief discussion of FALCPA (The Food Allergen Labeling And Consumer Protection Act of 2004). FALCPA took effect in January 2006 and requires that labels state the presence of any "major food allergens." This can either be as part of the ingredients list "Ingredients: Enriched flour (wheat flour..." or as a separate statement "Contains Wheat." It only addresses the ingredients in an item. It does not address cross contamination in any way. As a result food manufacturers have added advisories that state things like "Manufactured in the same facility with...", "Manufactured on shared equipment with..." or even "May contain..." to alert consumers of allergy issues. These are not required by law and there are no legal standards for them. The format may vary and the policy on when to use them is unique to each manufacturer. This of

course makes it very difficult to understand what they mean.

The paper first reviews surveys on consumer behavior that show that in 2003 85% of consumers with food allergies never purchased items with allergen advisories, but by 2006 this had dropped to 75%. Clearly, people are becoming more comfortable with these advisories and pay less attention to them.

And now for the test results: The study focused on peanut contamination, which may or may not be a suitable surrogate for contamination by wheat. Two-hundred food items were tested using two samples of each. 179 of them had allergen advisory labels of some sort (the others listed peanuts as a "minor ingredient"). Overall, 13 items with allergen advisory labeling contained detectable levels of peanuts (7%). The highest level measured for items with an allergen advisory was 4000 parts per million (ppm).

The results by type of advisory:

- "May contain" labeling: 2 of 51 items were contaminated (4%). The range of contamination was 53-81 ppm.
- "Shared equipment" labeling: 3 of 57 items were contaminated (5%). 3-4 ppm.
- "Shared facility" labeling: 7 of 68 items were contaminated (10%) 3-4000 ppm.
- Other unique labeling: 1 of 3 items were contaminated (33%) 99-107 ppm.

It's not perfectly clear how well this translates into contamination by wheat. The lower limit of detection in the study was 2.5 ppm, which is very close to the 3 ppm used by CSA as the lower limit for detection of gluten in their "Gluten Free" labeling program.

However, it's far below the 20 ppm proposed by the FDA as their standard for gluten free labeling. In all but one case, the amount that would be ingested in one serving falls below the 10 mg per day that is currently believed to safe for celiacs. However, this assumes that you would only consume one serving (quite likely unrealistic considering that most food manufacturers use serving sizes that are rather small) and that this was the only gluten you consumed all day. One item tested, a nutrition/meal bar with "Shared facility" labeling would have delivered 180 mg in one serving.

The mechanism by which peanut contamination occurs may not be the same as that for wheat, so these results can only give us an approximate idea about the dangers of ignoring allergen advisory labels. However, it's certainly clear that ignoring them can lead to significant ingestion of wheat and the likelihood of resumption of the symptoms of celiac disease and possibly long term health consequences. Eat at your own risk!

*The paper discussed is: Susan L. Hefle, Terence J. Furlong, Lynn Niemann, Heather Lemon-Mule, Scott Sicherer, and Steve L. Taylor. "Consumer attitudes and risks associated with packaged foods having advisory labeling regarding the presence of peanuts." *Journal of Allergies and Clinical Immu-**



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Naturally Healthy in the Northwest

OK, so you live on the far Northwest side of Tucson and you need a safe vitamin supplement or a GF cake mix or just want some bread or cookies and don't have time to make them yourself. In the past, that meant a trip all the way to Wild Oats, Sprouts or even further down Oracle to New Life's store. Now, there is a close and convenient place to shop for your dietary needs.

You can find Charles and Fay Shipp's *Naturally Healthy* specialty food and supplement store tucked in the strip mall directly north of Mountain View High School at Thornydale and West Linda Vista on the far Northwest side of Tucson. While the store is small, Mr. Shipp has a well-stocked and clearly marked GF section, and, best of all, he carries Kinnikinnick frozen bread products with fresh deliveries each Wednesday.

He is also forming a Juice Club, a co-op where members can buy fresh fruits and vegetables in bulk to use in making their own raw juices from these sources as well as share recipes and techniques. Along with their products, Charles and Faye offer expert advice on using diet and supplements to cure or help physical problems.

Charles and Faye along with their nine-year-old son Sheldon are recent transplants to the Tucson metro area. They moved here from Washington, DC in June, 2005. Charles took an early retirement from the

Federal Reserve Board, and, along with his wife Faye, decided that he had had enough of the East coast.

Charles began his journey into Natural and Holistic health when, in his early twenties, he was periodically plagued with kidney stones and all of the pain and unpleasantness associated with them. Taking matters into his own hands he began to read, study, and research as to the why of this particular ailment. He noted that his father and brothers were similarly affected. With his new found knowledge, he began to incorporate various herb and vitamin supplements into his dietary regimen and changed his diet to incorporate more natural fruits, vegetables, and grains.

Correspondingly, he eliminated fast foods, colas and other soft drinks from his diet. It was also during this time that he began to experiment with vegetarian diets. With a dramatic improvement in his health, (actually the stones went away) he began to research and study the effects of a natural health lifestyle on himself. Increasingly, family members and friends sought his advice and wisdom about information on a healthy lifestyle. Now, you can, too.

Naturally Healthy, 9725 N. Thornydale Rd. Tucson, Arizona 85742 (520) 579-7757 **E-mail:**
cshipp@naturallyhealthyaz.com



Charles Shipp holds some Pamela's cookies in his *Naturally Healthy* store.

Meeting

(Continued from page 1)

- ▶ Lisa Lopez gave a report on Oscar and said that the proceeds of the raffle would go to buy GF food for him. He is still having difficulty with maintaining his diet, especially during his long school days.
- ▶ Diane Knopfle, co-chairman of both Cel-Kids and Children's Dietary Group spoke briefly about her experience as a mother of a child diagnosed with CD and gave the website address of a group that discusses the special dietary needs of children.
- ▶ Member Joy Fields has a line of prepared GF baked goods, including crescent rolls and hotdog wraps that were for sale at the meeting. Call her at 546 7944 for more specific information on buying these items.
- ▶ Pat Hirsch, publicity chairperson for SACS, brought and played a CD of the chapter's recently recorded Public Service Announcement
- ▶ President Cheryl Wilson encouraged everyone who could to attend the CSA Conference at the end of this month. She explained what financial assistance was available.



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Bulk buying for lower prices



Board member Elizabeth Rascon selects some Lundberg Rice Chips at the **ShopNatural** retail store on Toole Ave.

Finding the *ShopNatural Cooperative* retail store at 350 Toole Avenue was a bit of an adventure, but SACS' board members Elizabeth Rascon and Shirley Curtis grabbed water bottles and headed off into the scorching Tucson summer in search of more places to shop for GF food. Due to the construction on I-10, getting there from the Northwest side was not easy, but it was worth it.

General Manager Reggie Smith gave them a personal-

ized tour of the small retail shop and the huge warehouse to which it is attached. The bulk of *ShopNatural's* business is in wholesale supply and online shopping. Reggie gave SACS members a special code so they can get 10% off all online orders. Go to <http://shopnatural.com/> and enter the code **CSASAZ** in the coupon code field during checkout for 10% off any order. This coupon is good through 12/31/07. Their web site and search engine is fast, comprehensive, and easy to use.

ShopNatural also sent a representative to our August general meeting to talk a bit about the store and bring two huge boxes of Pamela's Cookies and Mary's Gone Crackers samples and a display of brochures and catalogs. These catalogs will be available at our November Potluck, too.

The retail store offers the usual array of GF products, most of which are displayed in one area for easy selection. They have a full assortment of organic fruits and vegetables as well as freezer cases stocked with specialty frozen food. Best of all, they are always interested in carrying new products and will listen to customer requests and recommendations. The retail store also offers many non-food organic items and numerous supplements and vitamins.

ShopNatural is the online division of the *ShopNatural Cooperative* which has been in business in Tucson for over 30 years as a distributor of organic and specialty foods. They deliver to and service a region of seven states in the West, so they have both variety and quantity to sell.

ShopNatural Cooperative is operated as a cooperative. It is owned by its members, who participate in purchasing products and providing input and feedback as to the products and services the company should carry. The firm believes in and practices cooperative principles and is proud of its long history as a successful cooperative in the natural foods business.

If you want to find out exactly how to navigate the construction maze and shop at their retail store, you can call them at 520-622-3911 for directions. Membership in the cooperative is also offered. Contact information for that is: Phone: 520-884-0745 or Email: customerservice@shopnatural.coop

Free Initial Consultation

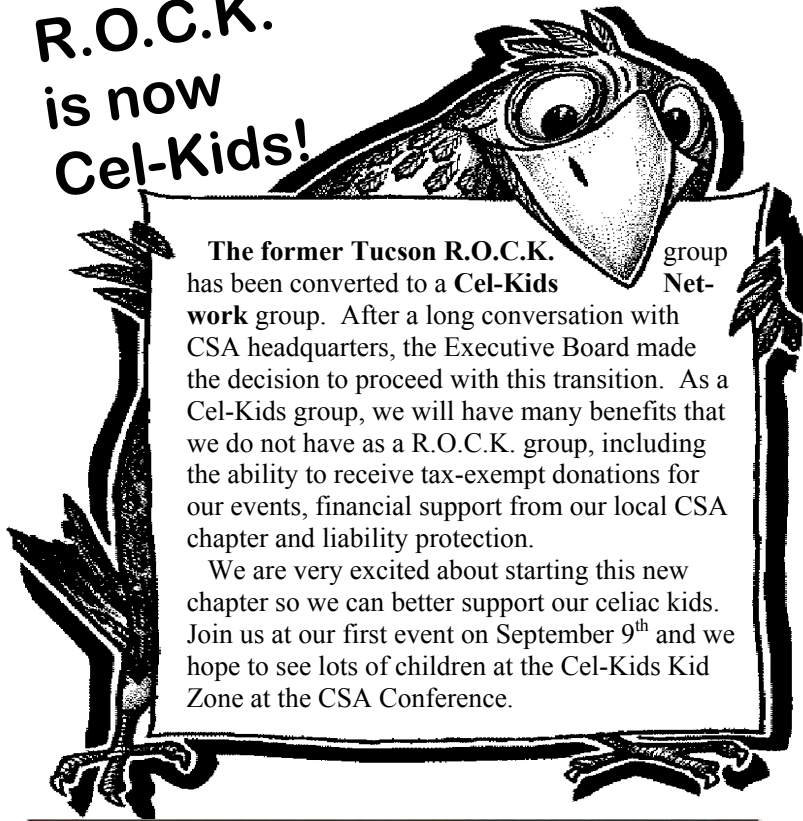
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Roundtable
4th Wednesday of each month

R.O.C.K.
is now
Cel-Kids!



The former Tucson R.O.C.K. group has been converted to a Cel-Kids Network group. After a long conversation with CSA headquarters, the Executive Board made the decision to proceed with this transition. As a Cel-Kids group, we will have many benefits that we do not have as a R.O.C.K. group, including the ability to receive tax-exempt donations for our events, financial support from our local CSA chapter and liability protection.

We are very excited about starting this new chapter so we can better support our celiac kids. Join us at our first event on September 9th and we hope to see lots of children at the Cel-Kids Kid Zone at the CSA Conference.

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ADVISORY: Please be aware that, although the ingredients may be gluten free, the owner told us that there are **no** dedicated prep or cooking surfaces in Lovin' Spoonfuls (including a toaster). We recommend that no Celiac have his or her GF bread toasted (make sure you advise your server), and remind the server that whomever is preparing your food needs to change plastic gloves before touching your food. We also recommend that you do not order peanut butter & jelly sandwiches, since they use the same PB & J jars for all customers (so there may be gluten crumbs in them). If you consider yourself a 'sensitive' Celiac, please be advised that there may be cross-contamination issues that could cause a gluten reaction.

(6)

Medical Advisory Board holds second meeting

The Medical Advisory Board met on August 21st to discuss a variety of issues including preparation for the upcoming CSA Conference, which all of the board members are planning to attend.

Two of our board members, Wataru Tamura, M.D. and Nancy Schuller, R.D. will be speaking at the conference. The board discussed various aspects of their talks, and we will be very excited to hear the presentations.

We also discussed possible board activities for National Celiac Awareness Month which is October. Our primary mission continues to be focusing on supporting our local chapter in whatever ways needed and promoting education about diagnosis and treatment of Celiac Disease in the medical community. Our next meeting will be held in November.

(Contributed by Dr. Shelli Hanks, MAB Coordinator)

Vt. D builds bone and helps curb cancer cells

In a landmark study conducted earlier this year at Creighton University School of Medicine in Omaha, Neb., vitamin D was found to play a major role in breast cancer prevention. The four-year study followed more than 1,000 healthy postmenopausal women.

Your age, ancestry and the latitude at which you live can also influence your body's ability to convert sunlight into vitamin D. Production of the vitamin is lower in older adults, individuals with dark skin and people who live in northern areas.

To reap all the cancer-protecting benefits of vitamin D, many nutrition experts now recommend taking a daily supplement of at least 800 IU. According to the Institute of Medicine, the safe upper limit of vitamin D is 2,000 IU and that is the dose that translates to a meaningful reduction in cancer risks.

Vitamin D-3, also known as cholecalciferol, is derived from animal sources. It's been shown to be far more potent than Vitamin D-2 and is more beneficial.

Medical news to use

Alba Therapeutics testing new drug for Celiac Disease

Alba Therapeutics will publish the results of a Phase I study of AT-1001 next month in the *Journal of Alimentary Pharmacology & Therapeutics*. AT-1001 is a drug that inhibits permeability (the passage of substances between cells). In this study, 12 mg of AT-1001 was given to patients with celiac disease to determine the safety and tolerability of the drug. Determining the safety and tolerability of a drug is the sole purpose of a Phase I study, which is the first step in testing a new drug for use in humans.

Effects of the drug were also studied in comparison to a placebo (non-drug agent). After eating gluten, patients who took AT-1001 had no increase in intestinal permeability while

patients who did not receive the drug had a 70% increase in intestinal permeability. Patients who received the AT-1001 also had less increase in inflammatory agents and gastrointestinal symptoms after eating gluten. The study concludes that the AT-1001 is well tolerated and appears to decrease intestinal leakage, inflammatory reaction and gastrointestinal symptoms after ingestion of gluten in patients with celiac disease.

Alba Therapeutics will be launching



to a Phase II study (the second level of testing in humans) of AT-1001 to determine the efficacy of multiple doses of AT-1001 in preventing intestinal permeability changes. This will be a multi-center study. Patients will remain on a gluten-free diet throughout the duration of the study, and they will receive either AT-1001 or a placebo 15 minutes before each meal for 6 weeks. They will also receive gluten tablets or placebo 15 minutes before meals. Changes in intestinal permeability will be measured in all groups. For more information on this exciting trial contact clintrials@albatherapeutics.com. You can also find more information about these studies on the NIH website: <http://www.clinicaltrials.gov/>.

(By: SHELLI HANKS, MD, SACS Medical Advisory Board)

Failure to Respond to Hepatitis B Vaccine in Children with CD

A study published in the *Journal of Pediatric Gastroenterology and Nutrition* in April of 2007 looked at whether or not the hepatitis B vaccine built antibodies in children with celiac disease compared to non-celiacs. The hepatitis B vaccine became available

in 1980, and it is now standard to administer it to all infants.

Hepatitis B is a disease caused by a virus that affects the liver. The study consisted of 26 celiac children and 18 non-celiacs with an average age of nine-years-old. All of the children had received the series of three doses of vaccine at least nine months before the hepatitis B antibody testing.

The study demonstrated that a significantly higher proportion of subjects in the celiac disease group (14 out of 26), failed to respond to the hepatitis B vaccine. Only 2 of the 18 non-celiacs failed to respond to the vaccine. This study also looked at whether or not the celiac children responded to other vaccines, including rubella, tetanus, and the flu vaccine. However, there was no difference in the number of children who responded to these vaccines between the two groups.

The study concluded that more than 50% of celiac children failed to respond to the hepatitis B vaccine. The reason for this is unknown. Since it is believed that as many as 1 in 133 Americans may be affected with celiac disease, the current hepatitis vaccine may need to be reassessed.

In a similar study performed by Nol et. al, 19 of 23 adult celiacs failed to produce long-term immunity with the hepatitis B vaccine. In order to know if the hepatitis B vaccine worked for you, you can ask your doctor to draw a titer. This blood test will tell you whether or not your body responded to the hepatitis B vaccine.

Park, S, Markowitz, J, Pettei, M et al. "Failure to Respond to Hepatitis B Vaccine in Children with Celiac Disease." *Journal of Pediatric Gastroenterology and Nutrition*. Apr 2007; 44(4): 431-435. (By: GEORGINA RUBAL-PEACE, PHARM D, 2008, SACS Medical Advisory Board)

Leadership Contacts

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

Nutty Nice Rice

Make-ahead wild rice pilaf

- 1TB. extra-virgin olive oil
- ½ cup chopped onion
- ½ cup chopped celery
- 2 ½ cups GF chicken broth
- 1 cup uncooked wild rice (Or, use brown & wild rice to make 1 cup)
- ½ cup chopped walnuts (or pecans)
- ½ cup dried cranberries

In a medium saucepan, heat oil. Sauté onion and celery until soft, about 5 minutes. Add broth and rice. Bring to a boil, reduce heat, simmer 50-60 minutes or until rice is tender and the liquid is absorbed. Add walnuts and cranberries. Toss, serve warm.

The recipe reheats nicely, can be made ahead, and freezes well. It can also be used as a stuffing for chicken or game hens.

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Mark your calendar

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

Sept. 14— Lunch Bunch, noon at *Sam Hughes' Place Championship Dining*, 446 N. Campbell Ave. RSVP 888-2935 by 9/12/07

Sept. 15 — Health Fair, Wild Oats Marketplace, Oracle/Ina Road— emphasis on Celiac disease

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

September 28-30 - CSA Annual Conference, Westward Look Resort, Ina/Oracle.

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

Nov. 17— SACS Annual Potluck; 11:30-1:30, Christ Community Church (7801 E Kenyon Dr) Kenyon and Pantano—Family Life Center (front of property – different building than Food Faire)

Roundtable is suspended for November and December