



# Celiac Digest

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

Volume 5, Issue 1

online at [WWW.SouthernArizonaCeliacSupport.org](http://WWW.SouthernArizonaCeliacSupport.org)

September 2006

*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.*

## SACS is losing a founding member



MARY LOUISE CATURA

*especially to you people with whom I've formed strong attachments. I have been with this group since it re-formed in 1993 (I think). Pat Ewing did a great job bringing us together, Georgina was still a little girl, and Julia Kelly worked hard at keeping the group going also. Quite a long time ago, and now we've grown so much that some of you have no idea who I am. (!)*

*There are many people I could name, who have worked hard in this group and I am honored to have served in my capacity as Roundtable leader. There will be others who will "step up to the plate" and put this group on the Celiac map.*

*My best wishes go out to you all, and especially our new board president, Cheryl Wilson, and all the hard working board members.*

*I do expect to be at the next general meeting in September. We hope to move out of our house by the end of October.*

*With Love.....MLC*

**Mary Louise Catura has served SACS as President, past-president, member-at-large and nominating chairman. Additionally, she founded and ran the Wednesday Roundtable.**

**During these years, she has touched and improved the lives of literally hundreds of Celiacs. SACS would not be the group it is today without her hard work, leadership, vision and energetic personality. It goes without saying that we all will miss her immensely.**

## Five-star chef to speak at September 23 meeting

**Don't miss SACS general meeting slated for September 23<sup>rd</sup> at the Marshall Auditorium at Tucson Medical Center.** As usual, we'll open the door around 9 a.m., sign in and eat from the array of member-donated GF goodies and greet old friends.

Chef Fernando Espinosa, the 5-Star head-chef at Dos Silos Restaurant located at Tubac Golf Resort is our featured speaker. A former restaurant owner in Tucson, Fernando was one of the chefs participating in the Spring 2006 Gluten-Free cooking classes that

were held at the home SACS's member, Sande Smith, in Tubac.

While teaching the class some us attended in March, Chef Fernando expanded on his personal history of cooking gluten-free food for his uncle while growing up. Chef Fernando will share with SACS some of his tips and tricks for our holiday (and everyday) baking, including keeping the moisture in our GF baked goods, as well as some interesting alternatives to spice up our cooking/baking. Bring a notebook to jot down information.

He is a warm and entertaining speaker whom you will all enjoy getting to know. He will, of course, tell us more about Dos Silos in Tubac, where he designs unique menus and recipes to tempt the palates of one and all...and where we can enjoy GF meals!



Chef Fernando Espinosa

Please see **Meeting** page 6

# RAZ dazzles diners

**Delicious food, artful presentation**, the personal attention of the chef, and lots of laughs and conversation made our August 11<sup>th</sup> Lunch Bunch meeting at RAZ a great success. Twenty-eight people attended - which is a Lunch Bunch record - including at least four new members or prospective members.

Some entrées included the special



**MEMBERS ENJOY RAZ LUNCHEON** (Photo by Cheryl Wilson)

of the day, sea bass with lemon sauce, braised ahi (tuna) with raspberry sauce and wasabi on the side, made-to-order shish kebabs, broiled chicken served with purple potatoes, crispy salmon and several other dishes that were modified to be GF.

RAZ at 1929 E Grant Rd (NE corner of Grant and Campbell) serves

modern Riviera cuisine--a fusion of foods from Greece, Italy and France. Tucson native Chef Angel Fabian returned to Tucson from the Wynn Resort Las Vegas and is exceptionally creative.

This restaurant is pricey, but the food is excellent. You can get more information from their website at <http://www.razrestaurant.com/>.

They toned down the music when our group was there, but just before the last of us left, it was turned up.

If restaurant noise/music bothers you, you might want to just consider RAZ for lunch. It also has a full-service bar and an extensive wine list.

Another really excellent restaurant you might want to try is *Feast* at 4122 E. Speedway Blvd., location of Mary Louise's going-away party.



**Shop at Amazon.com through our website at [www.SouthernArizonaCeliacSupport.org](http://www.SouthernArizonaCeliacSupport.org). Go to our website and follow the links so SACS can get a percentage of whatever purchases you make from whatever (2) you buy at Amazon.com.**

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## Chapter 15 Notes

**Dannon Yogurt is GF ONLY** for the plain varieties. Any of the ones containing 'natural flavors' are not considered GF. They said, "...we cannot guarantee that the alcohol portion of the natural flavor system is *always* derived from corn and not from oats, rye and barley."

**The NIH through one of its institutes, the NIDDK**, has begun its Celiac Awareness Campaign as a result of its Consensus Meeting in 2004. The Awareness website is now up and running at [www.celiac.nih.gov](http://www.celiac.nih.gov). It's a start and might promote awareness in the medical community.

**The Oracle Road New Life Health Center Store** is located at 3954 N. Oracle instead of 4012 N. Oracle as it's listed in the new member packet.

**Lactose Intolerant?** According to Kraft, in natural cheeses the lactose is removed with the whey during processing. One of the best sources for information on lactose is your product label. If the ingredient statement contains milk, milk products, nonfat milk, milk solids or whey, this often means the product will contain some lactose." In other words, hard cheeses should give you no trouble.

**Cocoa Puffs by General Foods** *sometimes* has wheat starch as an ingredient. According to their spokesperson, the ingredients change depending on the 'buy' on the grains that go into the cereals. If wheat is cheaper for that manufacturing run, that's what they use. Read all the ingredients all of the time.

**Yeast bread failure?** Alton Brown on the Food Network show *GOOD EATS* said that a cause of bread failure is the chlorine in the water. It kills the yeast. He suggested that you run the water thru a charcoal filter or use bottled water...but not distilled water.

**Archway Coconut Macaroons** now have wheat starch in them. It's not labeled at the end as an allergen, but it's in there. Read the labels.

**Campbell's Soups has a GF product list.** Call the company at 800.257.8443, and they will send the list by snail mail.

Please see **Notes** page 6

# Vacancies on governing board a concern

At the May 20<sup>th</sup> General Meeting, attendees were introduced to the 'new' board of Southern Arizona Celiac Support (SACS) Group. Since that time, two of the newly-elected board members have stepped down, so we really only have one new member at this time, our President, Cheryl Wilson. However, several people have been approached about accepting positions on the board, so we are hoping to fill those positions soon.

Your board members currently are as follows: President - Cheryl Wilson; Vice-Pres./Membership - Sue Beveridge; Treasurer - Hetty Pardee; Past President - Georgina Rubal; Newsletter Editor - Shirley Curtis; Members-at-Large - Marilyn Ringer, Mary Massarotti, Jeannine Faidley, Elizabeth Rascon and Brenda Bryson.

**STILL NOT FILLED (BUT**

NEEDED!) are the following positions:

1. **President-Elect (4 yr commitment)** Attend board meetings, general meetings and special events, assist President, and prepare to be President in two years.
2. **Secretary** (needs to be able to attend board meetings monthly as well as general meetings, take notes at board meetings then type up these notes.



3. **Historian** (a board position) encompasses collection/storage/display of SACS history, speakers, events and

photos

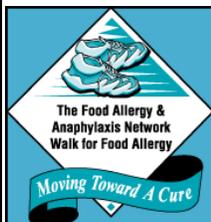
If you are interested in ANY of the above positions, PLEASE contact Cheryl Wilson (298-5551). All board positions require that you be able to attend monthly board meetings (usually held mid-town on Fridays), as well as the general meetings.

If you've never been involved in our group (other than to attend the occasional meeting), please seriously consider helping out--we need to spread the work out--after all, "many hands make light work". It's actually fun to be with such a great board, and you would get to help plan our events and have a say in what happens!

A real plus to working on the board is that you learn so much more about celiac disease and how to manage it. You actually 'get' much, much, more than you 'give'.

## Leadership Contacts

## Food allergy group hosts walk November 11



**Date:** Saturday, November 11, 2006

**Time:** 10 a.m. (check-in at 9 a.m.)

**Place:** Kiwanis Park, Tempe, AZ

**How:** 5k walk, including many family activities, D.J., the fire department, bounce houses, a "kidulance" & more

**Why:** To raise awareness and fund research on

## Vicki Holmes heads Roundtable

**Long-time member and past treasurer** Vicki Holmes will take on Mary Louis Catura's role as leader of SACS' monthly Roundtable.

Vicki is an experienced realtor with Long Realty at the River Road office. Along with that leadership experience, she has spent years coping with the GF diet.

The Roundtable meets at 1 p.m. every fourth Wednesday except during November and December. Make sure to come to the next one to welcome its new leader.



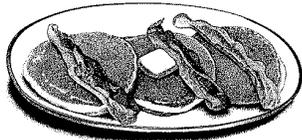
VICKI HOLMES

**barley, rye, triticale,  
spelt and most oats  
contain gluten**

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

# Pancakes pack protein power

This recipe is from Constance Powell who has a website 'Connie's Kitchen' which is devoted to new recipes and healthy living.



Combine in a blender:

- 1 Cup egg whites** (they are in the supermarket by the eggs)
- 1 Cup low-fat cottage cheese**
- 1 Cup uncooked regular oatmeal** (make sure it is GF! Quaker Oats is not GF)
- ½ teaspoon GF vanilla**
- ¼ teaspoon nutmeg** (Erika Williams uses cinnamon instead)

Blend to a smooth puree. Heat a non-stick skillet over medium heat. Spray with an aerosol vegetable shortening and pour the batter in skillet to make 4-inch rounds. Cook on one side (4)

for two minutes; flip over and cook for one minute more. This recipe serves two as a breakfast main dish. The batter can also be used in your waffle iron.

To make them even healthier, top with fresh fruit instead of jam or

syrup.

**Tips:** Recipe can be halved for one serving. Substitute 2 eggs + three egg whites if you can't tolerate the MSG in Egg Beaters. Bake waffles about a minute longer than usual. DO NOT substitute nut flours for the oats; even my dog would not eat the result.

## Mark your calendar

(See SACS Leadership box Page 3 for phone numbers/email addresses )

**Sept. 15** – Board meeting, Bookman's, Grant & Campbell, 2 -4

**Sept. 23** – General meeting, TMC, Alamo Bldg., Chef Espinoza 9-12

**Sept. 27** - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

**Oct. 13** – Lunch Bunch, Black Angus, Oracle & River, noon. RSVP @ 888-2935

**Oct. 25** - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

**Nov. 10** – Lunch Bunch, Dakota Cafe & Catering CO 6541 E Tanque Verde Rd, noon. RSVP @ 888-2935

**Nov. 18** – General meeting, St. Mark's Presb. Church, Potluck, noon. (no Roundtable in Nov. & Dec.)

**2007**

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

**Feb. 28** - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

**March 28** - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

**April 25** - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

**May 23** - Roundtable, 1 p.m. Ward Six City Hall at 3202 E. 1st St..

Southern Arizona Celiac Support  
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Cortaro, AZ 85652-0905

ADDRESS CORRECTION REQUESTED

First Class Mail



Sharing advice for a gluten-free life.

# CD specialist exposes medical ignorance, under-diagnosis of CD in US

By SHIRLEY CURTIS

In much of the world, CD is viewed as a common disorder. Doctors test for it, and GF food is readily available. In Dublin, 75 percent of the restaurants have a GF menu. In Finland, you can buy a GF Big Mac. Italy provides free GF food and a significant tax break. An ice cream shop in Buenos Aires posts the GF status of its offerings.

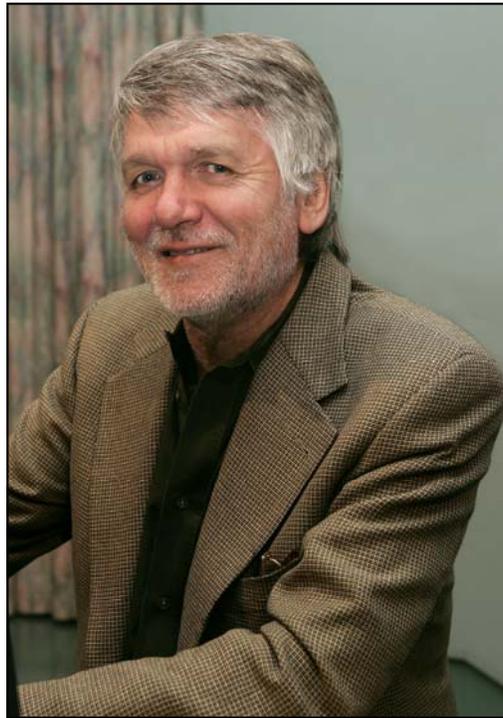
And that bit of news, my fellow Celiacs and friends, comes straight from one of the five top Celiac medical experts in the United States -- Dr. Peter Green. He is director of the Celiac Disease Center at Columbia University, New York City, and who also is the author of *Celiac Disease, a Hidden Epidemic*. Dr. Green, an Australian, and his four top-ranking Celiac expert colleagues in the US all are foreign born and educated, he pointed out.

Dr. Green, who has practiced in New York for 30 years, let these factoids slip out in his charmingly Down-Under accented speech, May 13, 2006, when he addressed about 200 Celiacs at the Carolinas Medical Center Auditorium in Charlotte, NC. (I was in NC on very important business -- visiting, Johnny, my grandson.)

Dr. Green told the crowd that when he asks Canadian celiacs if they would take a pill with meals rather than follow the gluten-free diet, only about 10 percent say they would. In the US, he said, "the proportion is just the opposite." According to Dr. Green, 90 percent of the Americans would take the pill and forget about the diet. Dr. Green attributed this disparity to the simple fact that GF food is not readily available making it very difficult to be a

Celiac in the USA.

Dr. Green placed the blame squarely on our political system. He claims that as long as we have "government by lobbyists", we will



DR. PETER H. R. GREEN

focus on drugs and high-cost medical procedures instead of prevention or diagnoses. Since the main source of continuing education for doctors is the pharmaceutical industry, Celiac Disease never gets mentioned as there's "no money in it." Drug companies, Dr. Green maintains, provide 78% more funds for doctor education than does the National Institute of Health (NIH).

The long delay between symptoms and diagnosis is the fault of the physicians, Dr. Green said. He added that many doctors fail to realize that *most* Celiacs do NOT have diarrhea, and *most* do NOT lose weight. In fact, Dr. Green said, that only 30 per-

cent of newly diagnosed Celiacs follow the "classic" symptoms of CD. Celiac Disease as it presents in the US today, he pointed out, manifests itself with an "enormous spectrum of symptoms in a multi-system disease" which delays the diagnosis. The frequency of diseases and how they make themselves known change over time as the environment changes, he explained.

Dr. Green further stated that doctors will *NOT* read the information local Celiac groups send to them. And, he maintains that the older the doctor, the less likely he or she is going to listen to laymen about Celiac Disease. To further complicate matters, he added, doctors are reluctant to even consider Celiac Disease because compliance to the diet is so low (a world-wide phenomenon) that they feel it would do no good to diagnose it. People who are in support groups do better, overall, than those who manage it alone, Dr. Green stated.

Dr. Green did suggest that support groups get accurate information out to politicians, teachers and school nurses. About the only thing that will get the attention of medical doctors, Dr. Green claims, is published research and that research is funded by money from support groups like ours.

We have obtained permission (in writing) for SACS to reproduce the diagnostic questionnaires Dr. Green included in his concise and very readable book.

Other points Dr. Green made in his talk:

► Breast feeding an infant is protective against CD. Formula might have gluten in it and the child is sensitized

Please see **Green** page 6

# Green

(continued from page 5)

to gluten via a GI infection before the immune system is developed. The baby, at four months, should also be exposed to tiny amounts of gluten while still consuming breast milk.

► We did not evolve to eat grains, and **nobody** digests gluten fully as the proteins are not fully broken down.

► Low over-all cholesterol and low HDL cholesterol are indicative of CD. Anyone with these test results should get a CD workup.

► Early diagnosis of CD results in better heart health later in life as celiacs are prone to problems with irregular heartbeats.

► People with CD show unusual facial structure, with a longer, more prominent forehead. He showed slides to illustrate his point.

► The worst thing a person can do is to not continue with the diet once the symptoms are 'cured'. Asymptomatic Celiac can do every bit as much damage as the symptomatic kind.

► Blood tests are valuable but not infallible as they are only 85 percent accurate. Plus, they can be negative one year and positive the next!

► More than 30 percent of Celiacs have another auto-immune disease. He believes that CD might be the first and then the others develop because of the leaky gut.

► Celiacs have an increased risk of cancer, even if they are GF. Small

intestine, thyroid and esophageal cancers are prevalent along with an increased risk for melanoma.

► Dr. Green is not a fan of the pills being developed that will block either enzymes, gliadin or the immune system. But, they **will** be developed because there is money in it, not because they are good for people.

► Stool and saliva tests for CD are, according to Dr. Green, not accurate, not replicated, and not reported in reputable medical journals.

► Kimball Labs are best for cheek swab DNA tests to see if a person **can** develop CD.

► The most common symptom of CD is depression.

► The spleen atrophies with CD giving us an increased risk for pneumonia. Take the vaccine every five years.

► Testing for food allergies is not reliable because *everything* shows up as a reaction.

► Citracal calcium citrate or its generic equivalent is the best form of calcium to take as it dissolves into a form the body can absorb. The other varieties often 'pass through' untouched.

► Celiacs diagnosed in later adulthood sometimes *never* completely heal their intestines, even if they are reliably GF.

Dr. Green believes everyone should eat a wide variety of foods so he or she will not develop sensitivities to frequently consumed staples. Do your best to be GF but don't be paranoid and don't worry excessively about cross-contamination. He believes that we **will** get accidental

**dients list next to the dish.** If feasible, bring copies of the recipes to share.

We need to display ingredients because many SACS members come with a variety of food sensitivities. You do not have to be a member to attend, and you certainly do **not** have to bring a GF dish to share. Everyone is welcome. (*Directions to Marshall Auditorium: East bound on Grant, turn north on Craycroft and access the east side of the campus. Map is available online at [www.SouthernArizonaCeliacSupport.org](http://www.SouthernArizonaCeliacSupport.org). Signs will be posted.*)

exposure to gluten, but an otherwise healthy body will shrug it off. He compared it to getting a skinned knee. It will heal up and life will go on. But, real problems will develop if you continually irritate it and don't let it heal. So it is with the intestine.

Dr. Green's parting message was to relax and live life to its fullest - without ever letting your disease dictate your life.

(Cheryl Wilson has copies of Dr. Green's book for sale or you may order it from Amazon.com - through our website.)

## Chapter 15 Notes

(continued from page 2)

► **Yogi Tea has barley malt** in 5 of their 56 flavors. It is *in* **Calming Tea, Stomach Ease Tea, Fasting Tea, Kava Stress Relief Tea** and the **Decaffe Roast Tea**. The rest *are* GF

► **XII International Celiac Disease Symposium** 2006 is November 9-11, 2006 at the Hilton New York 1335 Avenue of the Americas New York, NY. For additional information about this event, please contact Cynthia Beckman, Director of Development, at [cb2280@columbia.edu](mailto:cb2280@columbia.edu) or (212) 342-4529.

► **Red Star Baking Powder is GF** but is not produced in a GF environment.

► **Mrs. May's Naturals are currently NOT reliably GF** as the rice malt they are using contains small portions of barley. In September, they are switching to a 100% rice syrup which is GF. Read the labels before purchasing these nuts.

► **Traveling by air** and can't use a frozen gel pac to keep things cold? Use a Zip Loc bag filled with frozen peas or spinach in place of the commercial ice.

► **CSA/USA:** 877-272-4272, 8 a.m. to 3 p.m. Central Time. Their URL is: [www.csaCeliacs.org](http://www.csaCeliacs.org).

► **Change of address/phone number or email:** Notify us via the website or call 742-4813

# Meeting

(continued from page 1)

(PLEASE NOTE: Due to Chef Fernando's schedule, he will start speaking promptly at 9:30 AM--so please don't be late--you don't want to miss what he has to say!)

As always, include the wrapper if you purchased the completed dish, or make a complete list of ingredients if the dish is home made. **Set the ingredients** (6)

**Roundtable every fourth  
Wednesday - 1 p.m.**

# Oscar needs our help

By SHIRLEY CURTIS



13-YEAR-OLD OSCAR CERON, AKA 'TITO'

Early this month, Elizabeth Rascon and I went to Nogales to take Oscar some GF foods and talk to his mother about how he is faring with his diet. The news is not encouraging. Oscar has continued intestinal inflammation and has developed softening of his bones. According to Lisa Lopez, Oscar also has an intestinal tumor that will have to be removed, and may have other malabsorption issues. She is trying to arrange for him to see a doctor in Tucson, something that is complicated by Oscar's alien status. (They have passports and can travel freely across the border.) Lisa also wants to have Oscar stay with her for a while so he can see that Celiacs can eat normally and do not have to have an unhealthy focus on their disease.

Oscar was diagnosed as a Celiac when he was four-years-old, and his symptoms are severe. When he eats gluten, he vomits. As a result, he does not like to eat and is seriously underweight. He's also a very picky eater and has been sick a great deal, which has led his mother to be anxious and not thoroughly support dietary compliance. This is totally understandable when a child is very ill.

So, Oscar will only eat certain things or will cheat on his diet and get very sick. His mother gets very worried and cannot force or discipline him *because* he's sick. And, he's sick *because* he hasn't developed self-discipline. It's a vicious cycle and hard to break as the entire focus of the family is on keeping Oscar alive. Because he's been so

sick for so long, Oscar does not have a 'pack' of friends like most teenagers and usually stays indoors or close to cousins or his sister. Appealing to his 'desire' to be a healthy person would not be productive, as he has no concept of what that would be like.

So, what can *we* do? Well, it's impossible to force someone to eat what he or she does not want to eat, especially when that person associates eating with vomiting and pain. But, Oscar *does* like certain GF foods and will eat them. However, his family cannot *afford* to buy them



EVANGELINA CERON holding a sheaf of papers containing Oscar's medical records.

even *if* they were available in Nogales.

We can donate GF foods he will eat (see list on the next page) and/or donate money to Lisa Lopez who will purchase foods and take them down to Oscar. Bring the items to any Roundtable or general meeting, and they'll get to Lisa.

Continued on the next page

**A combination of medical, social, psychological,** and economic factors mean that 'our boy' Oscar is facing an uphill battle with Celiac Disease. As many of you recall, our group has 'adopted' a 13-year-old Celiac, Oscar Ceron (AKA Tito) who lives in Nogales, Sonora with his mother, father and sister.

As individuals and as a group, we have donated GF food for him that would be impossible for his family to find in Mexico or afford in the US. One generous member donated a bread machine for the family. Lisa Lopez and her mother-in-law, Hortensia Lopez, have not only donated a refrigerator to the Ceron family but have spent much time and money out of their own pocket to try to help Oscar.

# Oscar's Wish List— clip and save

## Trader Joes

Christophers- Assorted Fruit Jellies  
Fruitti Gummi Chewies  
Cheese Puffs  
Envirokidz- Gorilla Munch  
Envirokidz- Peanut Butter Panda Puffs  
GF bread mixes

## New Life

Envirokidz- Crispy Rice Bar (Peanut Butter)  
Mi-Del- Arrowroot Cookies (Animal Crackers—  
which are his favorite)  
New Morning- Cocoa Crispy Frosted Rice  
Glutino- Cereal Honey Nut  
Mi-Del- Chocolate Sandwich Cookies  
Thia Kitchen- Instant Rice Noodle Soup  
Glutino-Vanilla Dreams  
Glutino- Cream Sandwich Cookies

Pamela's Gourmet Cookies- Anything with  
Chocolate & Shortbread Swirl

Lisa said, "I also like to buy Vitamins for Oscar that they sell at Costco and Trader Joes - Lil Critters- Gummy Vites, Calcium or Vit C. **Safeway** gift cards are also useful, because that is where Oscar's mom is able to buy his milk , chips, Cracker Jacks, chicken, vegetables and other GF items available at Safeway. He loved the chocolate soy milk from there as well."

Note: **Wild Oats** has a 10% Senior Discount Day every Tuesday, so if you are over 60, take advantage of that to stock up on supplies for Oscar.



## What we can do to help (continued)

Or, if you want to make a tax-deductible donation, send the money to our treasurer, Hetty Pardee, and note that the money is for Oscar.

Or, you can buy gift cards at New Life, Trader Joe's, Wild Oats or Sprouts and send them to Lisa Lopez.

Or, if you are fluent in Spanish and willing to travel to Nogales or even talk to Oscar's mother on the phone, that would be of great help, too. Right now, Lisa Lopez is doing a great deal for him, so some relief help would be

much appreciated. Elizabeth Rascon will certainly help all she can, but she is facing some serious medical procedures over the next year and will not be able to travel.

I know that Oscar's mom is profoundly grateful for the assistance she has received and thanks you all. Lisa Lopez stated that Evangelina makes her promise to tell everyone 'thank you' for all the food and emotional support.

One thing we *can* do is show Evangelina Ceron that we do care and will help all that we can as she's truly desperate to save her child's life and hasn't the resources to cope with it alone.



(From left) EVANGELINA CERON AND ELIZABETH RASCON Elizabeth listens sympathetically as Evangelina describes her family's challenges with Oscar's medical problems.