

Issue 40  
February 2008

## A Note from Our President

# KC Gluten-Free Advocate

Dear CSA Members and Friends:

I want to thank you for welcoming me as your new KC Chapter CSA President for 2008 and 2009. It is a great honor for me to step up to this leadership position, and I look forward to working with you all, helping to meet your needs, and growing stronger as a valuable support organization. What a great group to be a part of.

As a Hy-Vee registered dietitian, I invite you to please take advantage of my nutrition expertise. I do not have celiac disease but have counseled several individuals with the disease, understand the nutrition implications of celiac, have experience in gluten-free cooking, and am very familiar with gluten-free foods. I anticipate that we will all learn so much from each other.


Please feel free to contact me or talk to me at the monthly meetings with any questions, concerns and/or comments you may have. I want to get to know you all better!

Thank you again for accepting me as your new leader. I look forward to an exciting year together.

Your new President,

Courtney Keonin, RD, LD  
Home Email: [mkeonin@hotmail.com](mailto:mkeonin@hotmail.com)  
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Cell: 913-515-8802

### UPCOMING EVENTS

- 
- Feb 10, 2008 Report from the 2007 National CSA Convention by Cindy Faulknier
  - Mar 9, 2008 Discussion of osteoporosis by Beth Lucasey, RN MA, Endocrine Nurse Manager, KU Medical Center
  - Apr 13, 2008 Judy Bond will review the book, Recognizing Celiac Disease
  - May 11, 2008 To Be Announced

*All meetings from 2:00 to 4:00 p.m. on the second Sunday of each month. Unless otherwise noted, meetings are at the St. Joseph Hospital Community Center, I-435 and State Line. Availability of speakers could change schedules.*

## **2007 Expenses Exceeded Income—Your Help Will Be Important**

For the 2007 calendar year, our group's expenses exceeded its income. You can review the treasurer's report on page 3.

To continue providing the level of support to which our members are accustomed, your donation will be important. Most of our income is from member donations, so if you appreciate the information, support, and fellowship of the group, please consider making a donation. Our group does not require a membership fee because it is important that every celiac be able to enjoy the benefits of our organization.

We do not have statistics regarding how much our members give individually, but we estimate that a monthly gift of \$3 or an annual gift of \$36 per family may be adequate.

If you wish to give, you may mail a check to our treasurer, George Smiley, at 5119 Lowell Avenue, Overland Park, KS 66202. Make checks payable to "CSA of Greater Kansas City." Another option is to deposit your gift in the donation jar that is available at every monthly meeting.

Because expenses vary from year-to-year, here are approximated expenses that typically occur:

- Newsletter: \$2000
- Meeting room rental: \$1100
- Cel-Kids, children's activities: \$100 or more
- Hospitality and supplies: \$1200
- Food (such as Thanksgiving turkeys): \$300 or more

## **Keep Track of Donations for Tax Purposes**

**Tax law requires that donations claimed as tax deductions, such as those to the local chapter or the national Celiac Sprue Association, must be documented by receipts or annual statements from the organization or by bank records, such as cancelled checks.**

This applies to all cash donations, including those under \$250. Cash donations are reported on Schedule A, "Itemized Deductions." *(This is not tax advice. You should verify this information with your tax advisor to ensure accuracy as it applies to your situation.)*



Because of the record keeping required, our local CSA chapter cannot feasibly provide receipts or annual statements for single donations smaller than \$250. Consequently, we request that members make contributions by check when they wish to itemize their donations for tax purposes. Make checks payable to "CSA of Greater Kansas City" and hand them to George Smiley, our treasurer, at monthly meetings or mail them to George at 5119 Lowell Avenue, Overland Park, KS. 66202.

## Transitions in the Offices of President and Secretary

At the January meeting, Courtney Keonin was elected President of our KC Chapter of CSA and Julie Davis was elected Secretary, both for two-year terms. We welcome them to their new positions and we all look forward to working with them. Congratulation to both Courtney and Julie.

After leaving her hometown of Lake City, Iowa, Courtney obtained her bachelor's degree in dietetics from Iowa State University and completed a 10-month dietetic internship program through ARAMARK in Kansas City, Missouri. Courtney joined Hy-Vee as a registered dietitian in October of 2006. In addition to promoting nutrition in the aisles, Courtney enjoys training for and participating in marathons and half marathons, strength-training, bicycling, hiking, swimming, cardio kick-boxing, playing tennis, water-skiing, being involved with church activities and service projects, and spending time with her family and friends.

Julie is retired from a career in civil engineering. She and her husband have two adult sons, one in the Marine Corps and one a junior in computer science at KU. Julie was diagnosed with celiac disease in April, 2007. She says, "Since being diagnosed with celiac disease, CSA has been a wonderful support group. I can't imagine how difficult it must have been over the past years for my fellow celiacs but I know that their work has made my transition to a gluten-free diet much easier. I look forward to being part of the tradition of 'Celiacs Helping Celiacs.'"

We extend sincere thanks and appreciation to Judy Bond who has led the group for the past two years. Judy helped our group continue to grow in its support for all celiacs, both the newly-diagnosed and the longer-term members. Thank you, Judy.

We also thank Cindy Faulknier for her dedicated service as Secretary for the past two years. Cindy continues to serve both our local group and the national organization as the CSA Member-At-Large for Region 2 (encompassing ten states). Thank you, Cindy.

### **HOTLINE REPORT**

by Helen Richards

The hotline received many calls as a result of the Star's December 27th article about local gluten-free food providers, with Olivia's Oven being featured. The need for information about gluten intolerance and gluten-free products is constantly increasing, with more people getting diagnosed daily. You can be a hotline by sharing such information and letting others know about our group which stresses "Celiacs Helping Celiacs."

**Hotline Phone:**  
913-393-2400

#### Chairpersons of Standing Committees:

Cel-Kids	Jessica Farris
Hospitality	Rose Farris
	Sherri Garner
	Ann & George Smiley
Newsletter	
Distribution	Mike & Jennifer Robert

#### *KC Gluten-Free Advocate*

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### **\$\$\$ Treasurer's Report \$\$\$**

by George Smiley

Beginning balance as of 12-31-06	\$2,471.37
Income	\$3,091.79
Expenses	<u>\$4,580.20</u>
Ending balance as of 12-31-07	\$ 982.96*

\*There are still outstanding bills for 2007 which exceed \$300. Known January expenses include a \$90 rental fee for the group's meeting room and approximately \$500 to publish the newsletter. Of the \$983 ending balance, \$400 are earmarked for Cel-Kids children's activities.

#### **CSA of Greater Kansas City—Executive Board for 2008**

President Courtney Keonin  
913-515-8802; [mkeonin@hotmail.com](mailto:mkeonin@hotmail.com)

Past President Judy Bond  
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Secretary Julie Davis  
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Treasurer George Smiley  
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Chapter Dietitian Karen Breshears  
660-543-8737; [kbreshears@ucmo.edu](mailto:kbreshears@ucmo.edu)

## Are Pringles Gluten-Free?

From the Pringles website on November 20, 2007: “Most Pringles versions **contain gluten**. ‘Wheat’ is called out on the label in the ingredient listing. Currently, a couple fat free Pringles are gluten-free: Original and Sour Cream and Onion. Please always refer to the label’s ingredient listing for the most up-to-date information.”

## Are Minute Maid Juice Bars Gluten-Free?

Verify gluten-free status of products before applying to your situation. Always read labels at the time of purchase because product formulations can change—a once gluten-free item may not always be gluten-free.

One of the online celiac discussion groups mentioned that someone had heard that Minute Maid Juice Bars are not gluten-free. I contacted Minute Maid and the email reply from their Consumer Affairs Department on December 14 states: “We are able to confirm that Minute Maid Juice Bars (Orange, Cherry and Grape) are gluten free.”

## Are HoneyBaked Hams Gluten-Free?

Until recently, HoneyBaked Hams have contained gluten. Thanks to a recent reformulation of the glazes, most hams are now gluten-free. **CAUTION:** *In an email dated December 10, 2007, from their Customer Service Department: Store shelves and catalog warehouses still have hams containing gluten. The company estimates that the gluten-containing products will be out of the system by approximately April, 2008. **Be sure to investigate before you purchase one of the hams.***



## Product Information from GeniSoy

A December 12, 2007, email from GeniSoy’s Consumer Affairs Department: “Thank you for taking the time to contact us with your request for information regarding gluten free products. We are dedicated to providing the highest quality products to our customers and we take your questions and concerns very seriously.

“While we do not include grain protein (gluten) in the manufacture of many of our products previously available on a gluten free list, our products are not produced on dedicated lines or in dedicated facilities. As a result, traces of gluten can sometimes be found in our products.

“The FDA has proposed new guideline as to what constitutes a ‘gluten free’ product. Only 20 parts per million of gluten can be found in any product labeled ‘Gluten Free’. We are re-evaluating our ‘gluten free’ label so as to be in compliance with the new FDA guidelines since some of our products are testing slightly higher than the 20 parts per million.. **We therefore no longer have a gluten free listing of products.** *(emphasis added)*

“If you ever have questions or concerns as to **whether you should consume one of our products, it is best to choose not to** and to consult your physician or dietitian.” *(emphasis added)*

Editor’s note: GeniSoy’s website continues to list “wheat-free” products. Wheat-free is not the same as gluten-free, because the wheat-free product may contain other unsafe grains or their derivatives (barley, malt flavoring, etc.)

## In Your Grocer's Freezer Section

Verify gluten-free status of products before applying to your situation. Always read labels at the time of purchase because product formulations can change—a once gluten-free item may not always be gluten-free.

Here is a list of gluten-free products that appear in many food retailers' freezers. Not all varieties from every manufacturer are available. Other brands may also appear in some stores. If you see something listed that you may like and it's not in your store, ask the management to consider stocking the item.

### Ian's Natural Foods

Products: Wheat Free, Gluten Free Fish Sticks; Chicken Nuggets; Popcorn Hotdogs; French Toast Sticks; Kids Meals; and Alphas. These products do not contain any wheat, gluten, egg, dairy, soy or nuts. Website:

[www.iansnaturalfoods.com](http://www.iansnaturalfoods.com)

### Van's Waffles

Products: Waffle flavors including: original, blueberry, apple-cinnamon, flax, buckwheat, and mini. Website:

[www.vanswaffles.com](http://www.vanswaffles.com)

### Glutino

Products: macaroni and cheese, pizzas, penne pastas. Website: [www.glutino.com](http://www.glutino.com)

### Lean on Me Baking Company

Products: quiche, corn bread, cheesecake, carrot cake, chocolate mousse. Website:

[www.leanonmebakingcompany.com](http://www.leanonmebakingcompany.com)

### Kinnikinnick

Products: sandwich breads, hamburger and hotdog buns, muffins, waffles, bagels, donuts, pizza crusts.

Website: [www.kinnikinnick.com](http://www.kinnikinnick.com)

## Update on Research for Drugs to Assist in Digesting Gluten



As previously reported, a company called Alba Therapeutics is conducting research on a pill that will assist celiacs in digesting gluten. Subsequent information was published by [Celiac Digest](#) and distributed by Celiac Listserv in October, 2007: Alba Therapeutics is running clinical trials aimed at using the drug on a regular basis and with each meal. However, people may want to use the drug only as a "safety net" when they are not completely in control with the food they eat (business trips, vacations, on a flight, eating out at restaurants or at friend/family household not really familiar with the gluten free diet, going to college, etc). The drug will block gluten molecules from being absorbed before they are broken down into amino acids that can be safely absorbed as nutrients. Absorption of other desirable nutrients will occur normally.

It is important to keep in mind that clinical trials of this drug are still being conducted and, if proven successful and safe, the drug will not be on the market for a long time, possibly years. Other similar research is being conducted by Stanford University and by Leiden University in the Netherlands and, in their cases too, it will be a long time before satisfactory results and marketable products will be available. While there are enzyme products currently on the market that claim to help in the assimilation of gluten, anyone interested in these products may wish to inquire into the scientific and medical validations supporting the products' safety and effectiveness. **Regarding Gluten-Ease**, the Celiac Sprue Association recently quoted Dr. Detlef Schuppan of the Beth Israel Deaconess Medical Centre in the January, 2008, issue of [Lifeline](#): "There is very strong scientific data and evidence that **this product is deceiving and potentially dangerous.**"

## **Recipe: Ann's Lasagna** *Recipe provided by Ann Smiley*

Verify gluten-free status of products before applying to your situation. Always read labels at the time of purchase because product formulations can change—a once gluten-free item may not always be gluten-free.

1 10-oz package Tinkyada brand Lasagna Organic Brown Rice Pasta

### **Hamburger Layer**

2 pounds hamburger  
2 cloves garlic, chopped  
2 tablespoons parsley flakes  
(McCormick, Tone's, Durkee)  
1 medium onion, chopped  
½ teaspoon oregano (McCormick,  
Tone's, Durkee)  
½ teaspoon sweet basil (McCormick,  
Tone's, Durkee)

½ teaspoon Italian seasoning  
(McCormick, Tone's, Durkee)  
½ teaspoon granulated sugar (C&H)  
1 6-oz can tomato paste (Hy-Vee,  
Contadina—**do not** use Contadina Italian  
Tomato Paste with Italian Herbs which  
contains gluten)  
2 8-oz cans tomato sauce (Contadina)  
¼ cup water

Cook lasagna, drain, and set in oblong pan of cold water. Cook hamburger and onion and drain. Stir into the hamburger mixture the garlic, parsley flakes, oregano, sweet basil, sugar, tomato paste, tomato sauce, and water. Heat uncovered in sauce pan until boil stage is reached (or in microwave for 6-12 minutes).

### **Cottage Cheese Layer**

Combine the following in a bowl:

1 24-oz container GF cottage cheese (A-E, Roberts Dairy)  
1 large egg, slightly beaten  
2 tablespoons parsley flakes (McCormick, Tone's, Durkee)  
½ teaspoon salt  
¼ teaspoon black pepper (McCormick, Tone's, Durkee)  
½ pound grated mozzarella cheese (Hy-Vee, Kraft) (Can also use Hy-Vee  
grated mix  
cheese)



### **To Assemble** (Preheat oven to 350° F)

1. Spread ⅓ of the hamburger layer in the bottom of a slightly oiled 13x9x2-inch glass or metal baking dish. (Glass works better for lasagna.) Carefully add one layer of noodles (three laid lengthwise). Add ⅓ of the cottage cheese mixture.
2. Add another layer of hamburger, another layer of three noodles, another layer of cottage cheese, and top off with the last 1/3 of the hamburger.
3. Sprinkle ⅓ cup grated Parmesan cheese on top.
4. Bake for 30 minutes at 350° F. Place slices of mozzarella cheese on top and bake for 15 minutes longer. Let stand 15 minutes before cutting.

*Note: There are more than six noodles in the Tinkyada package. You can boil only six, but I usually have one or two break while boiling, so I boil about eight.*

## **Jessica Farris Honored for Outstanding Service**

At the Cel-Kids party on December 16, Judy Bond presented Jessica Farris with the Celiac Sprue Association "Spirit of Service" award for all her hard work as our Cel-Kids coordinator. Jessica is a college student at a local community college. She has been accepted for an internship by Disney College. For the spring semester 2008, she'll be in Orlando working at one of the four Disney Parks. While Jessica is in Florida, Diadra Harnden will be coordinating the Cel-Kids group. Diadra's email address is [dhardenrd@aol.com](mailto:dhardenrd@aol.com)

## **Grains to Avoid When Gluten-Intolerant**

The following grains must be avoided by celiacs. Many are seldom seen on product labels, but it is useful to know their names when we run across them. For more information about each grain, visit the CSA website at [www.csaceliacs.org](http://www.csaceliacs.org)

Barley  
Bulgur  
Couscous  
Dinkle  
Durum  
Einkorn  
Emmer  
Farina

Fu (*not to be confused with tofu which is made from soy*)

Graham flour  
Kamut  
Matza, Matzo, Matzah  
Mir  
Oats  
Oat bran



Oat fiber  
Oat gum  
Rye  
Seitan (*found in vegetarian and Asian dishes*)  
Semolina  
Spelt  
Triticale  
Wheat  
Wheat berry  
Wheat germ  
Wheat germ oil  
Wheat grass  
Wheat gluten  
Wheat nut  
Wheat starch

## **Alerting Pharmacists to the Risks of Gluten in Medications**

At a December 2007 national conference, The American Society of Health-System Pharmacists (ASHP) alerted 8000 pharmacists who work in hospitals and health systems about the safety risks that unlabeled gluten in medicine pose for patients with celiac disease. They also advised pharmacists to consider malabsorption due to undiagnosed celiac disease as a possible reason why a patient's drug therapy may not be working as expected. Additionally, ASHP is in the process of developing official organizational policy calling for drug manufacturers to label botanical sources of starch used in medications.

Currently, there are no requirements for labeling gluten or common allergens found in drug ingredients. Further, labels do not need to provide precautions for people with celiac disease. Potential sources of gluten in medication are the excipients whose effects are not well-recognized by health professionals or patients. Excipients include bindings, coatings, fillers, colors, flavors, preservatives, and other ingredients other than the active ingredient. Sources: [www.medicalnewstoday.com](http://www.medicalnewstoday.com) and listserv

For information regarding whether a particular drug is gluten-free, call the manufacturer, visit the website [www.glutenfreedrugs.com](http://www.glutenfreedrugs.com), or call KU's Drug Information Center at 913-588-2328. Formulations can change with each lot manufactured, so call the manufacturer each time the medication is purchased to verify gluten-free status.

## **In Fond Memory**

We are saddened to report that Lea Everist, our gracious and friendly greeter at the door each month, passed away on December 31. She was a fine lady and will be missed. We extend our condolences to her family and we thank them for suggesting memorial gifts to our organization.

## **Merchants Continue to Learn about Gluten-Free**

From the Raleigh, NC, [News and Observer](#):

Sales of packaged foods labeled "gluten free" are booming. For example, they have doubled in the past year within the Kroger Company. Sales of gluten-free products in the U.S. rose from \$210 million in 2001 to \$696.4 million last year, according to market research firm Packaged Facts. The company projects that sales will continue to rise at a 25 percent annual clip, reaching \$1.7 billion in 2010. SPINS Inc., a market research and consulting company in the natural products arena, has tabulated more than 3,000 products labeled gluten-free.

Sales of gluten-free products have traditionally been concentrated in health and specialty food stores. Much of the growth in the sales of gluten-free products, however, is coming from traditional grocery stores and mass merchandisers such as Kmart, according to SPINS.



The variety of products has improved. The number of companies making products has increased. For the most part, gluten-free products are produced by small and midsize companies. The industry giants are sitting on the sidelines until the Food and Drug Administration develops a standard for labeling a product as gluten-free, according to Packaged Facts. The FDA has proposed a standard that would allow a trace amount of gluten -- 20 parts per million, the equivalent of a crumb in a loaf of bread -- and is supposed to issue its standard in August. Consequently, many products on grocery shelves contain no gluten but don't advertise it.

There was a time when the Harmony Farms natural food store in North Raleigh, which has a wall devoted to gluten-free products, bought virtually any available gluten-free product, co-owner Steve Long said. Now there are so many products, the store has the luxury of picking and choosing. Its most popular gluten-free selections are pastas made from brown rice flour or other alternative ingredients. "The next big thing you are going to see is pre-made dinners that are wheat- and gluten-free," Long said. "We're just starting to see them."

The consensus among people who observe a gluten-free diet is that the quality of packaged foods has been upgraded considerably over the years but still has room for improvement.

More restaurants offer gluten-free menus or accommodate the diet. Simon Wong, general manager of the Red Bowl Asian Bistro, which opened in March in Cary, NC, said three or four people each week ask for the restaurant's gluten-free menu. He said he expects the menu to become a bigger draw as word spreads.

## **Besides Bread, Where Do We Find Rye?**

Celiacs know we must avoid rye, but how likely are we to encounter rye? Based on an internet search, the following uses for rye have been identified: breads, rye bran, rye milk substitute, fermented alcoholic beverages (vodka, whiskey, gin, ale, lager, kvas [a low-alcohol Slavic beer]), rye malt for some German beers, traditional Polish soups, and some recipes for borscht, a beet-based soup. *Note: There may be other uses that the web search did not identify.*

## **Welcome to Celiac Foreign Exchange Students**

Anna Scharenberg, our former President, and her husband, Carl, are hosting two foreign exchange students who are celiacs. Mara Milena Suter is from Bern, Switzerland, and Karin Tornvall is from Stockholm, Sweden.

Mara is in the 12<sup>th</sup> grade and her favorite subjects are Spanish, PE, and U.S. history. The most surprising thing she noticed upon arriving in the U.S. is how big everything is—the cars, houses, schools, and portions at restaurants. What she likes most is her high school and how nice people are. Mara was diagnosed with celiac disease at age 14 and is the only member of her family who is a celiac. She sometimes attends a support group in Bern, but believes that people in the U.S. may be more familiar with celiac sprue than in Switzerland. Mara thinks that there may be a better selection of gluten-free foods in Switzerland, but that restaurants in both countries are about equal in their accommodation of the gluten-free diet.



Karin's favorite subjects as a 12<sup>th</sup> grader are band and orchestra. She, too, was struck by how big everything is in the U.S.—“the cars, the stores, and the size of your drinks!” She likes the nice people she has met and all of her new friends. Karin was diagnosed with celiac disease at age two. Her father is also a celiac, but they do not attend a support group in their hometown. Karin says there are more diagnosed celiacs in Sweden and that more people are aware of what a gluten-free diet means. Eating out in Stockholm is not a problem for celiacs. Restaurants accommodate the diet very well—you can have a gluten-free hamburger bun at McDonalds and at Burger King. Restaurants almost always have gluten-free bread and many cafes serve gluten-free sandwiches. There are bakeries dedicated solely to gluten-free breads, cakes, cookies, pies, etc. Swedish stores have gluten-free sections with a large variety of brands and products to choose from and “it just keeps getting more!”

Some of our members may have met Mara and Karin at our group's Thanksgiving Dinner. We're pleased that they are visiting our country and we wish them the very best of futures when they return home.

## **Part of Your Amazon.com Purchase Can Be Donated to the CSA**

When you shop for food, books, and equipment through Amazon.com, a portion of your sale can be donated to the Celiac Sprue Association. To take advantage of this option, go to [www.csaceliacs.org](http://www.csaceliacs.org) and connect to Amazon.com to make your purchase. Some manufacturers, such as Gluten-Free and Fabulous, donate a portion of all sales to CSA **and** are available on Amazon.com. Then your purchase results in: (1) no greater cost to you, (2) a donation to CSA from Amazon.com, and (3) a donation to CSA from the manufacturer.

Tell your family and friends about this opportunity to help The Celiac Sprue Association. It supports the organization's programs and services without adding to the cost of the online purchase.

## **IHOP Omelets Contain Gluten**

IHOP pancake house adds wheat flour to their omelets. When ordering, specify that the flour must be omitted from yours and that you request a clean cooking pan or griddle and a clean spatula. Inquire about the cooking process to determine whether you should include other instructions for the kitchen staff.

## **Gluten-Free Cooking Class**

The Johnson County Extension office is offering a class "Everyday Meals for a Gluten-Free Kitchen" on Tuesday, March 25, 6:30 -8:30 PM. Fee: \$20 Sample dishes include German 'pasta', Greek Dolmas, and sloppy Joes with a twist. Register by calling (913) 715-7000.

## **Disclaimer**

Efforts are made to verify the gluten-free status of products named in this newsletter, but manufacturers can change formulations without notice and once gluten-free products may not always be gluten-free. **It is the responsibility of every person to verify the gluten-free status of products he/she purchases and not to rely solely on the information provided in this newsletter.** Citing brand names is for reader convenience and does not constitute endorsement of products or imply that these are the only suitable gluten-free products available.

The information provided in this newsletter is not intended to be a substitute for individual medical advice in diagnosing or treating a health problem. Please consult your healthcare provider about your health concerns.

All recommendations, information, dietary suggestions, menus, recipes, and related data generated by the Kansas City Chapter of CSA/USA, Inc., are intended for the benefit of our members and other interested parties. The text has NOT been submitted for approval by the CSA/USA, Inc., medical board. No liability is assumed for the use of this information.

### **KC Gluten-Free Advocate**

*Celiac Sprue Association of Greater Kansas City*

*Chapter 4*

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**Celiacs Helping Celiacs**