

Dear CSA Members and Friends:

Since this will be my last "President's Letter," I just want to say "Thank You" to all of you who have helped our group grow in size and strength over the last two years. We are really getting the word out about our organization and about celiac disease/ gluten intolerance. So many of you have helped to expand our horizons by working with stores, restaurants, schools and businesses in our area to educate them about Celiac Disease and how to meet our needs. All of you have helped support other celiacs and their families.

Special thanks go to Jessica Farris for her leadership of the Cel-Kids group.

PS -- Don't forget to consider becoming a member of our parent group, the Celiac Sprue Association. The dues for membership are *tax deductible*, and are \$33 for New Members and just \$25 per year for Renewing Members. Contact me for a membership form or go to www.csaceliacs.org

Judy Bond
Email: JBond@kc.rr.com
Phone: 913-236-5659

UPCOMING EVENTS

- | | |
|--------------|---|
| Oct 14, 2007 | Restaurant Dining by Mary Scharff. Discussion of methods to help improve the safety of GF dining. |
| Nov 11, 2007 | Annual Thanksgiving Dinner
Elections of new President and Secretary. |
| Dec 9, 2007 | Annual Holiday Celebration |



Meeting topics for early 2008 will be determined after a new President is elected. The next issue of *KC Gluten-Free Advocate* will be published prior to the February meeting.

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.

Don't Miss the GF Thanksgiving Dinner and the Holiday Celebration

Our annual CSA **Thanksgiving Dinner** will be held on Sunday, November 11, at 2:00 p.m. There's always good food and fellowship. Turkey, Anna's famous dressing, mashed potatoes, beverages, and dinnerware will be provided. The rest of the meal is delicious potluck items brought by our members. We suggest the following potluck, grouped by the first letters of last names:

- A-H: Dessert
- I-P: Vegetable
- Q-Z: Salad



To help offset the cost of turkeys, we are asking for a donation of one dollar per person over the age of 18. Your donation can be made at the door when you arrive for the dinner.

Note: If possible, please notify **Judy Bond (913-236-5659 or jbond@kc.rr.com) regarding the number in your party (including yourself) who will attend.** This information is needed by October 26 to determine the number of turkeys to order. Also let Judy know if you could help with serving or cleanup at the event.

Our annual **Holiday Celebration** will occur on Sunday, December 9, at 2:00 p.m. This is your chance to show off your favorite gluten-free holiday snacks and treats. Beverages and dinnerware will be provided. There will be a face painter and games for the kids and bingo for the adults, with prizes provided by local stores.

We have a great time every year at these events and no one goes away hungry. You'll be glad you came. Your help in carrying out these events will be welcome. **Please notify Jessica Farris (816-353-7560) if you can help.**

For both events, please bring 30 or 40 copies of recipes to share or, at least, a single copy, and if you bring purchased items, please bring the original container (1) so gluten-free status can be verified and (2) so members with allergies to eggs, nuts, soy, dairy, and so on can determine what they're eating. **Please DO NOT bring items containing PEANUTS or PEANUT PRODUCTS (for example, read labels to be sure purchased items were not cooked in peanut oil).** Items with tree nuts will be placed on a separate table.

Disappointed in a GF Product You Bought?

Every celiac knows what it's like to try a gluten-free product and find taste or other quality disappointing. Many stores have customer satisfaction policies and will accept returns of items found unsatisfactory. There's no need to live with a product you don't care for. If enough people return the product, the shelf space may subsequently be allocated to a better gluten-free item.



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for.

Lost and Found (If yours, please contact Judy Bond at 913-236-5659)

- Large white Pampered Chef bowl with lid.
- Large Blockbuster Video bowl, gold with blue top, and lid

Time is Running Out to Help Your Group Win a Buffet Dinner

If you attend our support group, but have not enrolled in the national Celiac Sprue Association, please consider doing so before December 31, 2007. With your support, our group may win a gluten-free buffet dinner for up to 150 people at a local restaurant if we recruit the most new CSA members for 2007 (over and above 25 people). The dinner will be prepared by CSA's Chef Aaron Flores to celebrate CSA's landmark 30th Annual Conference.



To qualify, each new member must enroll as a member of the Celiac Sprue Association by calling 1-877-CSA-4-CSA or by visiting the website at www.csaceliacs.org. Currently, *tax deductible* fees for new members are \$33 and for renewing members, \$25, per year. If you know of other celiacs who don't attend our meetings, encourage them to join us and to become members of the national organization. **OUR CHAPTER IS THE BEST—WE CAN WIN!**

Sprue's in the News

Newsweek highlighted celiac disease in its September 17, 2007, issue. The informative article is another example of the increased focus in the media on gluten intolerance.

HOTLINE REPORT

by Helen Richards

HOT August and September. Twenty-three new contacts were made to our group in the past two months through the hotline, through email (president@csakansascity.org), through medical professionals, and through current members. We look forward to meeting you soon. Remember everyone is welcome at our meetings, so bring a friend, relative, dietitian, doctor. . . YOU are our most important "hotline."

Hotline Phone:

913-393-2400

\$\$\$ Treasurer's Report \$\$\$

by George Smiley

Beginning balance as of 12-31-06	\$2,471.37
Income	\$2575.38
Expenses	<u>\$3134.33</u>
Ending balance as of 9-15-07	\$1912.42

Thanks to your generous donations, our Chapter has operated over 20 years without requiring membership dues. An accomplishment to be

CSA of Greater Kansas City—Executive Board for 2007

President Judy Bond
913-236-5659; JBond@kc.rr.com

Former President Anna Scharenberg
913-962-0282; glutenfreeme@everestkc.net

Vice-President Mary Scharff
816-650-3649; papabearscharff@earthlink.net

Secretary and Cindy Faulkner
CSA Member-at-Large/Region 2
913-384-2276; cfaulknier@msn.com

Treasurer George Smiley
913-831-0031; georges@everestkc.net

Chapter Dietitian Karen Breshears
660-543-8737; kbreshears@ucmo.edu

Local website: www.csakansascity.org

Webmaster: Kris Koehler
kmkoehler@kc.rr.com

Chairpersons of Standing Committees:

Cel-Kids	Jessica Farris
Greeters	Lea Everist
Picnic	TBA
Hospitality	Rose Farris
	Sherri Garner
	Ann & George Smiley

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816-228-5704
meltonrp@sbcglobal.net

Product Information from Progreso Soups

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.

In an email from General Mills' Consumer Services Representative regarding Progreso soups: "It is our goal to help our consumers determine whether or not they can include our products in their diet. To accurately accomplish this, we believe it is best to refer to the specific ingredients listed on each product package.



"However, we do understand that ingredients can be confusing, so we want to assure you if the ingredient label does not list wheat, barley, rye, oats or gluten containing ingredients sourced from these grains, then the product would be gluten-free. Sources of gluten are listed on the label even if the source of gluten is part of another ingredient (such as flavoring or spice). Because ingredients may vary from one package to another due to product reformulation, you should use the product's ingredient label to provide you with current and accurate information."

The following Progreso soup flavors found at a Walmart and a Hy-Vee listed no gluten-containing ingredients in their labels as of August, 2007. When you buy, be sure to read the label to decide for yourself that the soup is gluten-free:

Creamy Mushroom
Garden Vegetable
Chicken Cheese Enchilada Flavor
Chicken Corn Chowder
Chicken Rice with Vegetables
Chicken and Wild Rice
Lentil
New England Clam Chowder
Southwestern Style Chicken
Split Pea with Ham

Gluten-Free Galas at Hy-Vees

Thursday, October 25th, 5:30 p.m. at the 23rd Street Hy-Vee in Independence, MO

Friday, October 26th, 5:30 p.m. at the Noland Road Hy-Vee in Independence, MO

October is Celiac Awareness Month. Join Megan Conrad, Hy-Vee dietitian, for a tasty gluten-free meal and learn about celiac sprue, what to avoid and best bets for going gluten-free. Gluten-sensitive individuals are encouraged to share recipes and ideas. Friends and family are welcome! Please pre-register for this event at customer service or contact Megan for more information. E-mail: 1261dietitian@hy-vee.com or phone at 816-836-1177 or 816-478-6557. Cost is \$5 per person.

Friday, October 26, 1-5 PM, Englewood Hy-Vee

Contact Nicole Kreber, RD, LD, 207 NE Englewood Rd., Kansas City, MO, (816) 454.4776, 1321Dietitian@hy-vee.com No cost.

Children Are Welcome, but Please Supervise

Children are welcome at our meetings, but they ***must be supervised*** by a parent or responsible adult or adolescent at all times.

Gluten-Free Turkeys

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.

For many of us, turkey is a major part of our Thanksgiving dinner. Here are four brands that have gluten-free turkey breasts and whole turkeys, but they may also have other varieties that are not gluten-free. It's important to read the label and/or call the manufacturer to be sure of gluten-free status and always remove the gravy packet, being careful to verify that the packet has not leaked. *(This is not a complete list of GF products marketed by these manufacturers.)*

Butterball: (by email from a Consumer Response Representative on 8-6-07)

“When there are dietary concerns, we advise purchasing Butterball Fresh Turkey and Butterball Fresh Breast of Turkey, which are all-natural and contain no added ingredients. The breast meat of Butterball Frozen Turkeys, including Butterball Frozen Stuffed Turkey, is moistness enhanced with a patented recipe of ingredients to yield a more uniformly juicy and tender turkey after cooking. Individual ingredients are specified on the labels of all Butterball Frozen Turkeys and Butterball frozen line extension products. (Although wheat and rye gluten-free, the recipe does include 0.5 ppm corn protein.)

“Because Butterball Frozen Stuffed Turkey (and Butterball Stuffed Frozen Breast of Turkey) is stuffed with a traditional bread stuffing, it does contain gluten. The gravy packets that come with some Butterball Turkey products also contain gluten.”

Honeysuckle White: (from website on 8-5-07—www.honeysucklewhite.com/faqs)

“Most of our products are Gluten-Free. However, our Italian Style Turkey Meatballs, Teriyaki Flavor Tenderloins and Asian Grill Marinated Turkey Strips do contain Gluten. All of our deli meats are also MSG and gluten free. We don't use flour on the conveyor belts in any of our Honeysuckle White® processing plants.”

Hy-Vee: (in an email from a Hy-Vee representative on 8-6-07)

“The following products are gluten free:
Hy-Vee Fresh Natural Whole Turkey
Hy-Vee Frozen Natural Whole Turkey
Hy-Vee Fresh Moisture Enhanced Whole Turkey
Hy-Vee Frozen Moisture Enhanced Whole Turkey”



Jennie-O: (from website on 8-5-07— http://jennio.com/turkey_faqs.asp)

“We are providing the following list of products as a general guideline for those presently produced and distributed in the United States with formulas that do not contain gluten in the form of wheat, rye, oats, and barley. Although our products are labeled in compliance with government regulations, it is always necessary to read the labels on the products to determine if the food product meets your required needs. Parents and individuals with food allergies and/or food intolerances are responsible for reading the label of all products they intend to use regardless of how the product is represented on this site. If you have any questions, please call our Customer Service Representatives at 1-800-523-4635.” The list includes several turkey products. Three are listed here. Please visit the website for the complete listing.

Jennie-O-Turkey Store Oven Ready Turkey Breast (the gravy packet DOES contain gluten)

Jennie-O Prime Young Turkey, fresh or frozen (the gravy packet DOES contain gluten)

Jennie-O Frozen Turkey Breast (the gravy packet does contain gluten)

Recipe: Gluten-Free Turkey Gravy

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.

- 15-16 turkey necks, browned in skillet
- 2 large onions, quartered
- 2 ribs celery cut into 1-inch lengths
- 2 full-size carrots, quartered and cut into 1-inch lengths
- 3 garlic cloves, quartered
- 2 bay leaves (McCormick)
- 2 teaspoons dried thyme leaves (McCormick)
- 12 whole peppercorns (McCormick)



After turkey necks are browned, put all ingredients in stock pot and cover with water (about 8 to 10 cups). Bring to boil, then reduce to simmer. Simmer for 3 to 4 hours. Strain through sieve and discard solids. Cool turkey stock and refrigerate.

To make gravy, blend 3 or more tablespoons (use judgment) corn starch into $\frac{1}{4}$ cup turkey stock; then blend into total volume. May add drippings from roasted turkey, if available.

Not 100% Gluten-Free? Is It OK to Cheat or Take Chances?

Some of us have no noticeable reaction after eating gluten. Others have only minor reactions. Sometimes we accidentally consume gluten at restaurants. Is it OK to cheat intentionally or to live with exposures at restaurants? No—these actions are dangerous. Once diagnosed with celiac sprue, the 100% gluten-free diet must be carefully and continuously followed. When untreated, the disease can cause life-threatening complications. A delayed diagnosis or non-compliance with the diet places the patient at risk for developing associated conditions such as infertility, miscarriage, osteoporosis, fractures, certain types of intestinal cancer, lymphoma, or other autoimmune disorders. Continued consumption of gluten increases the chance of gastrointestinal cancer by a factor of 40 to 100 times that of the normal population.

Diseases and Conditions Associated with Celiac Disease

- Alopecia (hair falls out)
- Anemia
- Autoimmune diseases
- Autoimmune hepatitis
- Lactose intolerance
- Dermatitis herpetiformis (a burning, itching, blistering rash), and other skin disorders
- Type 1 diabetes
- Thyroid disease
- Crohn's disease
- Low pancreatic enzymes
- Down syndrome
- Sjogren's syndrome (dry eyes, dry mouth, dry internal organs)
- Thyroiditis (low or high)
- Unexplained infertility
- Microscopic colitis
- Miscarriage
- Osteoporosis or osteopenia
- Certain types of intestinal cancer
- Neurological conditions
- Autoimmune disorders such as rheumatoid arthritis and systemic lupus erythematosus

Restaurant: Red Robin (email from Red Robin on 8-8-07))

Eating out is always risky for celiacs and readers must decide for themselves how to apply this information to their situations.

“Thank you for your inquiry. Below is a list of gluten-free food item options from the Red Robin menu. Red Robin will do its best to customize orders to meet dietary needs. Hopefully there's something on this list you'll enjoy.

Produce Items

- Cheese.
- Guacamole
- Salsa
- Black Beans
- Turkey Breast Meat
- Beef patty
- Lettuce Wrap Burger
- Carnitas meat
- Grilled Chicken Breast Fillet
- Egg
- Turkey patty
- Grilled Salmon
- Rice
- Side of cooked vegetables

Current Entrees Revised

- Cobb Salad, no bacon
- Crispy Chicken Salad, substitute crispy chicken with grilled chicken, no bacon
- Fajita Pollo, minus corn strips.

General Information

- Red Robin will customize orders to meet dietary needs.
- Salad Dressings and mayo do contain vinegar in the ingredients list. The vinegar is not malt vinegar.
- The Red Robin Seasoning is sprinkled on the beef patty after cooking. The Seasoning does not contain wheat, barley, oat or rye glutes. It may contain naturally occurring glutamates. The beef patty can be ordered without Red Robin Seasoning. Please inform your server if you desire no seasoning.
- Corn strips, Bacon and Fries may be cooked in a common fryer.

“Please bring this list of gluten free menu items with you when you dine with us and inform your server so that he/she can help meet your dietary needs.”

Gluten-Free Halloween Treats for Celiac Goblins

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.



After celiac goblins make their rounds and come home to sort through their goodies, here are some gluten-free treats they can safely consume: Almond Joy, Andes Mints, Baby Ruth, Blow Pops, Butterfinger, Charms Pops, Cheetos (puffy and crunchy), Cracker Jack, Dum-Dum Pops (by Spangler), Fritos chips, Goobers, Heath, Hershey plain and almond (full-size and snack-size; not miniatures), Hershey Kisses, Jolly Rancher hard candy and lollipops, Junior Mints, Lay's potato chips (regular, wavy, and ruffles—but NOT KC Masterpiece BBQ flavored), M&Ms plain and peanut (but NOT crispy), Mars bars, Mounds, Nerds, Pay Day, Raisinets, Reese's Peanut Butter Cups, Rolo, Russell Stover products (EXCEPT cookie products such as S'Mores and Cookies and Cream), Skittles, peanut Snickers (not Snickers Cruncher), Starburst, Starburst Fruit Chews, Starburst Jelly Beans, Sweet Tarts, Tootsie Rolls, Tootsie Pops, York Mint, Wrigley chewing gum. **Avoid products containing crispies**, such as Snickers Cruncher and crispy M&M's. Treats other than those listed here may also be gluten-free, so contact manufacturers regarding the ones you're not sure about. **NOT GLUTEN-FREE:** Hershey's miniatures (as opposed to snack size), Milky Way, 3 Musketeers, 100 Grand Bar, Kit-Kat, Krackle Bar, Crunch Bar, all Brach's, most licorice (and others too numerous to list here).

Did You Know...?

- More hope for celiacs: Alvine Pharmaceuticals, Inc., is a San Carlos, California, based biopharmaceutical company dedicated to developing therapeutic drugs that target both detoxification of food-borne gluten before it can do harm, as well as drugs to block the gluten-induced immune- and inflammatory responses in the intestines that characterize celiac sprue disease. Even patients who are able to maintain a strict dietary regimen suffer from celiac sprue due to inadvertent or background exposure to gluten. Consequently, new therapies to treat this disease represent a significant, unmet medical need.
- According to Dr. H. Mitchell Hecht in Pennsylvania's www.timesleader.com, once internal bleeding has been ruled out, "the most common cause for iron deficiency anemia...is malabsorption in the small intestine from a condition known as 'celiac sprue.'"
- Researchers in Sweden have found that children with celiac disease are three times more likely to develop Type I (insulin-dependent) diabetes, often before age 20. In an unrelated study, Danish researchers also found a correlation between celiac disease and Type 1 diabetes and recommend that celiacs have periodic screenings for diabetes if they exhibit symptoms such as increased thirst, increased urination, weight loss, and fatigue.

(Source: http://www.medindia.net/news/view_news_main.asp?x=15875)

Cookies from FoxRidge Bakeries

Our scheduled speaker for September was unavailable, so we were fortunate to have Peggy Thoennes of FoxRidge Bakeries in Mission, Kansas, present to tell us about her varieties of gluten-free cookies which are available in several HyVee stores. Peggy has applied for the CSA Recognition Seal for her products. FoxRidge is working on making cookie dough available in tubs so that celiacs can bake fresh gluten-free cookies as needed. For more information, contact www.foxridgebakeries.com

Gluten-Free Treats for the Holiday Season

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.

The following are summaries from prior editions of this newsletter. According to the manufacturers, the following treats are gluten-free, but verify for yourself prior to purchase:

- Russell Stover candies, except products containing cookies, such as S'mores and Cookies and Cream. www.russellstover.com
- Topsy's Old Fashioned Popcorn: cinnamon, buttered, and caramel flavors. NOT gluten-free: cheddar cheese flavor. Call 816-523-5555
- Blue Diamond Almonds, except the BOLD Wasabi and Soy Sauce which contain wheat. www.bluediamond.com

Calcium and Vitamin D

Because of malabsorption, osteoporosis, or other problems associated with celiac sprue disease, some celiacs may need more calcium than normal. Vitamin D helps our bodies absorb calcium and some celiacs may wish to supplement their diet (Oscal+D, for example) and/or get a few minutes of sunshine each day. You may find it appropriate to ask your physician to check your vitamin D level. The body can absorb only a limited amount of calcium at one time, so intake should be spread over the course of the day. Your doctor can recommend a regimen that is best for you.

New Gluten-Free Cookbooks

Bon Appetit—Without the Wheat, by Julie Ambrose, contains over 175 gluten-free and wheat-free recipes from appetizers to desserts. All of the recipes use premixed gluten-free flour and ingredients that can be found at any grocery store. Julie Ambrose, the author, is a registered dental hygienist who is completing an educational program to raise dental hygiene students' awareness of symptoms and appropriate treatment of celiac patients in the dental office. Price: \$19.95, plus \$4.50 shipping. Available through INFINITY PUBLISHING (www.bbotw.com), 1094 New Dehaven St, Suite 100, West Conshohocken, PA. 19428. Toll Free (877) BUY-BOOK. Fax: (610) 941-9959.

The Gluten-Free Vegetarian Kitchen, by Donna Klein, offers over 225 recipes that make good use of vegetarian foods that don't contain gluten such as fruits, vegetables, eggs, dairy, tofu, beans, oils, legumes, rice, and gluten-free flours. With appealing recipes and food options, vegetarians can maintain a satisfying, well-balanced diet. Available at Amazon.com for \$12.89, plus shipping.

New Online Resource: "Raising Your Celiac Child"

"Raising Your Celiac Child," an online resource from Children's Hospital Boston, (www.childrenshospital.org/ceciac) contains 12 interactive modules covering topics such as keeping your kitchen organized and safe, shopping for and cooking gluten-free foods, preparing your child for school, ordering and eating out at restaurants, planning activities and travel, and adjusting and coping. It also provides resources and support for families and features celiac kids talking about living with the disease. Other useful information for families can also be found at the website. Physicians, dietitians, and other health care professionals may wish to recommend this resource to newly-diagnosed families as a first step in learning how to cope with the disease.



Gluten-Free/Low-Gluten Wafers for Holy Communion/Holy Eucharist

Protestant celiacs who wish to participate in Holy Communion can order Ener-G brand gluten-free Communion wafers (50 per box) for \$8.00, plus shipping, from <http://www.churchpartner.com/store/customer/product-1026.html>. The telephone number is 1-800-572-0550. You may wish to discuss with your pastor a procedure for receiving the elements. If your church uses whole loaves of bread, an option is to provide a gluten-free loaf to share with the entire congregation.

Catholic celiacs wishing to participate in Holy Eucharist which requires some gluten can order low-gluten wafers at http://www.benedictinesisters.org/english/site.php?use=low_gluten. Order by email at altarbreads@benedictinesisters.org or by calling 1-800-223-2772. Prices approximate \$5.00, plus \$1.75 handling charge, plus shipping. Sample packs are available. The Catholic Church has ruled that the wafers may be validly used at Mass in the diocese of the United States with appropriate permission. The Center for Celiac Research advises that the 0.01% gluten content would be safe for most celiacs. If you and your priest choose this option, you may wish to purchase a pyx container at a religious article store. One option is that celiacs come to the altar to receive the low-gluten host before the rest of the congregation. If you are very sensitive to gluten, you may want to ask to remove the wafer from the pyx yourself after it is presented to you by the priest.

Trusting a Restaurant's Gluten-Free Menu

Restaurants' gluten-free menus can be suspect. If you have doubts, ask to see recipes of questionable items. One of our members recently visited a local restaurant whose gluten-free menu listed cheesy baked potato. Upon reviewing the restaurant's recipe, it was discovered, much to the manager's horror, that the product contained flour. This incident was particularly significant because the celiac is very sensitive to gluten and had recently had surgery that would have been negatively affected by a reaction to gluten.

This experience emphasizes (1) that eating out is always risky for celiacs and (2) that celiacs must always be vigilant.

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*

14409 W. 123rd Terrace

Olathe, KS 66062