
WASHINGTON AREA CELIAC SPRUE SUPPORT GROUP NEWSLETTER

Winter 2000

MEETING NOTICE:

Date: Saturday, February 5, 2000

Time: 2:00 p.m.

Location: Davis Community Library, 6400 Democracy Blvd, Bethesda, MD, 301-897-2203.

Topic: Join us for a special presentation by Roben Ryberg, the former owner of Miss Robens, a gluten free mail order company located in Frederick, Maryland. Ms. Ryberg will discuss her new cookbook, "*The Gluten Free Kitchen*", to be available soon, and bring samples of some of her favorite recipes (from the 140 found in her book!) to share with the group. She will also share with us a new product that doubles the length of time that baked goods can stay fresh.

As always, please feel free to bring gluten free snacks to share at the meeting.

DIRECTIONS:

From Maryland, points east: Go west on the beltway to the exit for Old Georgetown Rd. North. Go about ¾ mile to the traffic light at Democracy Blvd. (Wildwood Shopping Center is on right) turn left onto Democracy Blvd. Davis Library is on the left at the end of the first long block. Make the first left onto Bells Mill Road.

From Maryland, points north: Go south on Rt. 270. Take the right hand spur and exit onto Democracy Blvd. East. Go past the flashing yellow light and two stop lights to library on right, at Bells Mill Rd. (One block before Old Georgetown Rd.)

From Virginia, Dulles Toll Road, points west: Take the beltway to Rt. 270 spur. Take the first exit off 270 spur to Democracy Blvd. East. Pass the flashing yellow light and two stop lights to the library on the right, at Bells Mill Road (one block before Old Georgetown Rd.)

What's inside?

Blood Screening.....	3
Product Information....	4
Kid's Korner.....	7
Recipe Exchange.....	9
Safe Vinegars?.....	11
Questionnaire.....	insert

CALL FOR 2000 DUES

February has become our official dues month for both new and current members. A dues form has been included in the newsletter for your convenience along with our annual WACSG questionnaire.

Please take the time to fill out the questionnaire. This is the only chance we have to get feedback from our members and to update valuable information on local stores and restaurants. This information will be shared with members through future newsletters and the new member information packet that is presently being revised.

MESSAGE FROM THE CHAIR:

Happy New Year everyone! This will be a very busy year. I cannot believe almost one year has passed since I took over the chair position! Since my post will last for two years, I'd better get moving a little faster on my projects. 1999 was a productive year and hopefully 2000 will be more so. Sadly we lost one of our members last year. Natalie Stern died of a heart attack on September 27, 1999.

Our membership has grown some more and we are over 180 now. Dues will be collected in February and I encourage everyone to renew. We have seen some former members return and I am very excited about things to come. The more members we can reach, the stronger our voice will be in the community.

We are in the process of updating the new member packet and have designed a member questionnaire to assist us that is included in the newsletter. Please be as detailed as possible and add another page if necessary. This information will be shared with everyone after it is compiled, not just the new members.

There are so many new GF products that it is very overwhelming. I remember my first experience trying to find a GF spaghetti. I tried DE BOLES and hated it. Naturally I thought that this horrible tasting pasta was my son's fate - how depressing! Thankfully I found Pastariso and Tinkyada and life is good once again. It would be nice to help others find those "great" products a little faster and with less effort. We also get many requests for area doctors and restaurants. The revised member information will also be maintained on our web site for visitors to the area. Thank you for helping!

We have also included a renewal sheet for dues that provide areas to check if you are interested in being a volunteer. I know life is busy for everyone, but many of the volunteer positions are on a per project basis. We will also need help with typing labels and stuffing envelopes to send current information to doctors in our area. Please think about volunteering - we are Celiacs for life and need to help ourselves.

Finally, we are planning a blood screening as part of the University of Maryland's Center for Celiac Research Study. We are hoping to do this in April or May and plan to have many speakers and vendors present. Volunteers will be needed of course to plan and execute this. We are still looking for a location and date, but once we finalize the details, we will mail out information to all members.

We would like an idea of the level of interest ahead of time, and have an area provided on the renewal form for your feedback. First degree relatives that have not been tested are most important to the study, however, even those not diagnosed with Celiac

disease are invited. In fact everyone is welcome! Please share our plans with those who you think might be interested in participating in the study. Please contact me if you have any questions or if you would like to volunteer. I am always available to any member anytime.

Andrea Howe
(301) 972-9263
andreaowe@juno.com

WACSSG BLOOD SCREENING IN THE SPRING:

To assist in the study that is currently underway at the University of Maryland's Center for Celiac Research, we are planning to host a Washington area blood screening fair for our members and others in the community who are interested in furthering research on celiac disease. We are looking to test first degree relatives of celiacs, but the general public, and even those diagnosed with CD are welcome to get tested. We will be following all of the guidelines established by the Center for Celiac Research.

We haven't set a specific date yet, but we know it will take place sometime in April or May, and will be held at one of the area hospitals easily accessible for those who live in Maryland and Virginia. Our goal is to invite area doctors and researchers to speak at the fair, specifically those involved in the study itself and to showcase gluten free vendors. In addition, we would like to invite other area support groups (including other celiac groups) for diseases and conditions such as diabetes, down's syndrome and autism, where there has been shown to be a link with celiac disease.

As you can imagine, this is a big undertaking for our group, but one that we feel is extremely important. We are also asking for any help that you can offer. We especially need nurses to assist in the bloodwork part of the fair. In addition, we need volunteers to assist us the day of the fair. Above all, we would like to know whether you are interested in attending the fair with your family. Please take the time to let us know on the questionnaire included with this newsletter.

ADMINISTRATIVE NOTES:

Due to a printing error in the Fall newsletter, the list of gluten free Halloween candy got cut off. If you are interested in receiving the full list, please contact Debbie Byrne @ 703- 644-5863..

If you did not receive a roster of WACSSG members in the mail last fall and would like one, please contact Andrea Howe.

The WACSSG recently purchased the Louisville Blood Screening video that is available for members to borrow. The video was made by the Louisville, KY celiac support group to raise money for the Center for Celiac Research, and features many

speakers including Drs. Horvath and Fasano from Baltimore, a pediatrician and a dietitian. If you are interested in borrowing the video, contact Andrea Howe.

The WACSSG owns a bread machine that is made available to members who are unsure whether a bread machine is the best solution to their bread making needs before spending money to purchase their own. If you are interested in borrowing the bread machine, please contact Andrea Howe at 301-972-9263.

The WACSSG also has a variety of celiac related magazines, newsletters, and articles that are available to members, in addition to the article recently published in *Newsweek*, "The Perils of Pasta". Please contact Andrea Howe.

DO YOUR OWN RESEARCH ON THE INTERNET:

MEDLINE is the world's largest biomedical database with over 9,000,000 references to journal articles in all areas of related disciplines. It is also the first resort for most clinical and research questions. MEDLINE can be accessed online through MEDSCAPE (www.medscape.com). You will have to register (for free) but once you do, click on the icon to access MEDLINE to continue your research.

Johns Hopkins University sponsors a medical information website through INTELIHEALTH (www.intelihealth.com). As with MEDSCAPE, you will have to register (for free) and you will gain access to both MEDLINE and MDX HEALTH DIGEST, a medical index that includes over 200 peer reviewed medical journals, newsletters, popular newspapers, popular magazines, medical school and hospital publications for articles dealing with consumer health. All of their references include abstracts.

PRODUCT INFORMATION:

Gabrielle Pasta Products has come out with a wheat free polenta pasta made from cornmeal. The spaghetti pasta is flavored with sun dried tomato and basil and can be served with or without a sauce. For more information contact Gabriele Pasta Products, City of Industry, CA 91748

If you have been searching for a gluten free cocktail or horseradish sauce, try one of the following: Cross and Blackwell Cocktail Sauce, S&W Seafood Cocktail Sauce, Enrico's Cocktail Sauce, Golds Horseradish, Silver Springs Horseradish, Boars Head Horseradish, Manischewitz Grated Horseradish.

The following instant hot chocolate mixes are gluten free: Carnation (Nestle USA 1800-637-8534) Fat Free Rich Chocolate Cocoa, Fat Free Marshmallow, Double Chocolate Meltdown, Milk Chocolate Cocoa, and French Vanilla; Swiss Miss (Hunt Wesson 714-680-1431) all varieties are gluten free.

McCormick Spices (1800-632-5847) assures the celiac community that all of the ingredients contained in their spices are listed on their labels. This means that if they use wheat flour as an anti caking agent, it will be listed on the label. Their flavor

extracts: vanilla, almond, lemon, etc. are made from a synthetic alcohol and are therefore gluten free.

According to the company, the Jelly Belly jelly beans and Geolitz Confections Pectin, Mellocreme and Gelatin candies are gluten free and considered safe for the celiac sprue patient to consume. The source of the “modified food starch” is corn. All natural flavors are identified on packaging. The following flavors contain dairy products: chocolate pudding, hot chocolate, grandma’s pumpkin pie, caramel corn, buttered popcorn, carrot cake, strawberry cheesecake, key lime pie, and egg nog.

Celestial Seasonings (Warner-Lampert 1800-524-2854) makes herbal throat drops that soothe and calms sore throats and coughs. They come in a variety of flavors such as Harvest Cherry and Honey-Lemon Chamomile and all are gluten free.

Edy’s (888-837-4438, www.edys.com) has information on the gluten status of their ice creams on their website! Just click on “Freezer Case” and choose a flavor. The gluten status appears at the end of the nutritional information. As a general rule, any gluten in any of their ice cream, frozen yogurt, or novelty products is present only in added bakery products such as cookies or shortcake. The ice cream itself contains no gluten. The modified food starch that you may find listed in the ingredients is derived from corn and is therefore, gluten free. In addition, their entire Whole Fruit Sorbet line and all of their Fruit Bars are gluten free. The Dreamery flavors that are gluten free include Banana Boogie, Black Raspberry Avalanche, Caramel Toffee Bar Heaven, Cashew Praline Parfait, Chocolate Peanut Butter Chunk, Crème Caramel, Cuppa Joe, Galactic Chocolate Swirl, Harvest Peach and Vanilla.

Sargento is another company that lists their gluten free products on their web site! (1800-243-3737, www.sargento.com) All Sargento natural cheeses are gluten free with the **EXCEPTION** of the Imitation Mozzarella Cheese that contains a modified food starch which may contain gluten, and the Shredded Taco Cheese, Shredded Nacho and Taco Cheese, 6 Cheese Zesty Mexican Recipe Blend that contain wheat flour in the spice mixture. For obvious reasons the MooTown Snacks Cheeze and Sticks, Cheese and Pretzels, Cheeze and Crackers and Cookies and Cream are **NOT** gluten free. The company uses microcrystalline cellulose as an anti-caking agent on most of their shredded cheeses. This ingredient is a white odorless, tasteless, totally natural powder made from cellulose, a naturally occurring component of most plants. It is not derived from wheat, oats, barley or rye.

CHANGE OF GLUTEN STATUS: Hidden Valley Ranch dressing and KC Masterpiece barbecue sauce are no longer gluten free.

While many Giant brand Super G foods are gluten free, Giant will not publish a gluten free list. They are, however, extremely helpful in searching for the gluten status of their products on an individual per item basis and have been maintaining an ongoing list of food items that they have verified recently to be gluten free. This list is available upon request by calling 1888-469-4426 ext. 4365.

CURED PORK PRODUCTS:

Recently the US Department of Agriculture's Food Safety and Inspection Service amended federal regulations concerning the use of soy protein concentrate, modified food starch and carageenan as binders in cured pork products. The products affected are labeled as "ham with natural juices", "ham water added", and "ham and water product –x% of weight is added ingredients."

The first of the two amendments allows the use of soy protein concentrate, both singly and in combination with modified food starch or carageen as a binder in these products. The second amendment allows an increase in the permitted use level of modified starch as binder and states that manufacturers will be required to list the binders in the product ingredients. This will require modification of current labels. Unfortunately we will still have to verify added binders with manufacturers.

See <http://www.fsis.usda.gov:80/OA/fr/99-12882.htm> for the full ruling on "Ham water added". The following is an excerpt from the ruling:

Abstract: FSIS has reviewed the paperwork and record keeping requirements in this direct final rule in accordance with the Paperwork Reduction Act. This direct final rule requires manufacturers opting to use soy protein concentrate, singly or in combination with either modified food starch or carrageenan, as binders and extenders in certain meat products to revise their product labels and submit them to FSIS for approval. However, labels will not have to be revised for increasing the use level of modified food starch in "Ham and Water Product--X% of Weight is Added Ingredients" products that presently contain modified food starch, provided the increase in the use level does not change the order of predominance of the ingredients."

See <http://www.fsis.usda.gov:80/oa/fr/98-064.htm> for the full ruling on "Ham with natural juices". The following is an excerpt from the ruling:

"If a manufacturer decides to make a "Ham with Natural Juices" product that includes a binder, but which adheres to the PFF value for a "Ham with Natural Juices" product, it will have to be labeled accordingly. Modified food starch and the other permitted binders will have to appear in the ingredients statement to inform consumers of their presence."

ALTERNATE GRAINS:

(Please note that these grains are on the "grains to avoid" list published by the CSA. We are not endorsing them, only providing information for those celiacs who have made the decision to include such alternate grains in their diets.)

Nu-World Amaranth, Inc. is a supplier of a number of amaranth products. The only grain milled at their plant is amaranth, so there is no chance of cross contamination between grains in their facility. For more information contact Larry Walters, P.O. Box 2202, Naperville, IL 60567, 630-369-9819. Email – sales@nuworldamaranth.com
www.nuworldamaranth.com.

The Quinoa Corporation is a manufacturer of quinoa products, including Quinoa Flakes, which are 100% quinoa. Their quinoa is grown high in the Andes mountains of Bolivia and no wheat is grown anywhere around, so they can be assured that there is no possibility of contamination in the fields. Their warehouse contains only quinoa and they grind their own flour. Although they don't have their own machinery to make the flakes, they are confident that the company they use is very reliable and does extensive testing on each batch that they process. For more information please contact the Quinoa Corporation, P.O. Box 1039, Torrance, CA 90505.

KID'S KORNER

Gluten Free Camps !

The Massachusetts and Rhode Island Celiac Support Group for Children will host Camp Celiac 2000, July 21 throughout July 23, 2000. The weekend will take place at Camp Aldersgate, North Scituate, Rhode Island. The fun filled weekend will include lodging, canoeing, swimming, outdoor adventures, campfires and best of all, completely gluten free meals! This all inclusive weekend is open to children ages five and older with Celiac Sprue and will provide them with an opportunity to attend summer camp with fellow Celiac children. The weekend will give them an opportunity to enjoy the outdoors without the worry of adhering to their diets. Reservations are on a first come first serve basis and are expected to fill up quickly. For more information email Tanis Collard at csgc@ix.netcom.com or visit the soon to be updated website at <http://members.home.net/hkellyleech/ceciac/csgc.html>.

The GIG (Gluten Intolerance Group) Kid's Camp will take place in July 2000 at Camp Sealth, a CampFire Camp on Vashon Island in the Puget Sound. GIG is offering camping experiences that include 2 session lengths that includes gluten free cooking and volunteers that carefully monitor children's diets and provide educational information at the same time. The American Diabetes Association will attend the camp at the same time and will provide a large number of dietitians, nurses and doctors. 25 spots are reserved for celiac children, so you must act fast if you are interested. Scholarships are available on a need basis. For more information contact Nichole Marcotte, Camp Chair at the GIG at www.gluten.net or Andrea Howe @ 301-972-9263.

NEW COOKBOOK

"Cajun and Southern Gluten-Free Delights", a new cookbook, will be available in January 2000. Dishes in the book include jambalaya, crawfish pie, dirty rice, gumbo, etouffe, king cake, beignets, calas – a delicious rice cake made from left-over rice and many others. There is a vendor list in the back to order Cajun gluten free spices direct. (Tabasco hot sauce is gluten free!) These companies have gone to tremendous expense to insure that their products listed are gluten free. Call Aileen M. Bennett at 877-896-9334 to order. Cost is \$14.95 plus shipping and handling.

GLUTEN FREE DINING:

A WACSSG member recently had a very positive experience at a local restaurant in Arlington called Mediterranee (703-527-7276). It is located at 3520 Lee Highway about 1 block from Spout Run. The cuisine is French Algerian and features a lot of seafood. The chef rarely uses flour in his sauces although a few of the dishes were made with couscous and orzo, which are forbidden on the gluten free diet. Entrees are in the \$14 to \$16 price range. The chef said to always let the wait staff know that gluten is a problem and for them to write this on the order. Our member had an impressive meal of escargot and spinach and a smoked fish platter with lemon sauce. The paella and bouillabaisse were also represented as being gluten free.

Another member had a very positive experience at the Austin Grill in Bethesda. Because of the gluten free friendly menu worked out with the restaurant chain by Bob and Ruth's Gluten Free Dining and Travel Club, the wait staff and chef were familiar with gluten and extremely helpful in interpreting the menu. One waitress in particular, Adrienne, is the restaurant's expert, and can help guide you through the menu and let you know what substitutions can be made.

For those of you who visit the Rain Forest Café in Tysons Corner, please be aware that the french fries and hamburgers are **NOT** gluten free. For whatever reason the chain apparently dusts the fries and burgers with flour.

BARIUM BEWARE!

The barium used for the majority of radiological gastrointestinal medical procedures in the United States is not gluten free! The alternative, Barium sulfate USP (unflavored) is gluten free, however, many radiologists feel that this type of barium is not as effective and is difficult to take. If you plan on having any medical testing done that require the use of barium, consult your doctor to ensure gluten free alternatives. For more information regarding barium sulfate USP, contact Spectrum Chemical Manufacturing Corp. at 800-772-8796.

FREE ONLINE NEWSLETTERS:

The Sprue-nik press is a very informative monthly newsletter put out by the Tri-County Celiac Sprue Support Group in SE Michigan. The current month's issue can be read online at <http://enabling.org/ia/ceciacs/sn/spnk9911.html>. You can also have a copy sent to you by email, by sending a message to LISTSERV@maelstrom.stjohns.edu containing this line: GET CELIAC SPNK9911. An index to the articles in all the past issues is also available at: <http://www.enabling.org/ia/ceciacs/sn/spnkindx.html>.

The Clan Thompson Celiac Newsletter is an monthly free online newsletter. To subscribe send an email to observer@nxi.com. The word SUBSCRIBE must appear in the subject line. Our own Andrea Howe was interviewed for this newsletter about the success of the WACSSG mentoring program.

FREE INTERNET ACCESS:

The internet is by far the best resource for valuable information on celiac disease and dermatitis herpetiformis. It is also our future and if you are not hooked up online yet and would like to be, there are several internet service providers that offer free and easy access to the internet in exchange for viewing selected advertisements. (Okay, nothing is “free”, but they are a good place to start to avoid costly monthly access fees). All you need is a computer and a modem. In addition, most, if not all, local area libraries provide free internet access to residents who don't have home computers.

If you are interested in hooking up at home, JUNO is a national internet service provider that offers free internet access. They can be reached at 1888-TRY-JUNO or www.juno.com. Locally, the television station WJLA also offers free internet access. For more information, call 1-877-835-6839, www.wjla.com.

If you have any questions regarding access to the internet or would like to get hooked up but don't know where to start, please contact Joany Janicki at 202-364-9703.

WINTER RECIPE EXCHANGE

Portuguese Potato and Kale Soup (adapted from a recipe found in Yankee Magazine)

¼ cup olive oil
1 large onion, chopped fine
1 or 2 cloves garlic, minced
3 pounds potatoes, about 6 large, peeled and thinly sliced
½ pound sausage, thinly sliced (ie. Hillshire Farms)
1 large bunch of kale (about 1 ¼ pounds)
salt and pepper to taste

Put the olive oil in a soup pot over medium heat. Add the onion and garlic and cook, stirring often, until limp but not colored about 5 minutes.

Add the potatoes and continue to cook until they start to turn golden, about 15 minutes. Pour in 8 cups cold water and cover the pan. When the water boils, reduce the heat to medium-low and

cook until the potatoes fall apart, about 20-30 minutes.

While the potatoes are cooking, fry the sausage in a heavy skillet over medium heat until browned. Drain on absorbent paper and set aside. Remove tough lower stems of kale and pile the leaves in stacks of 5 or 6 leaves each. Roll the stacks from point to base into tight rolls then cut crosswise into very thin ribbons no wider than matchsticks. Set aside.

When the potatoes are soft. Use the back of the spoon to mash them roughly into the soup. Add the sausage. Cook for 5 minutes or so, then add salt and pepper to taste.

Add the kale to the hot soup and cook just until it's bright green and tender, about 5 minutes more. Soup should be thick but not past; think with hot water if necessary, then serve at once. Makes 6 servings.

Mexican Tomato Lime Soup (adapted from a recipe in the Moosewood Cookbook)

3 garlic cloves, minced and or pressed
2 teaspoons ground cumin
1 tablespoons vegetable oil
6 cups tomato juice (46 oz. Can)
2 cups chopped fresh tomatoes
juice from 1 large lime (about ¼ cup)
3 tablespoons chopped fresh cilantro
Tabasco or other hot pepper sauce to taste (optional)
2 cups coarsely crushed tortilla chips
1 cup grated Monterey Jack cheese

cilantro leaves, whole or chopped (optional)

In a soup pot on low heat, sauté the garlic and cumin in the oil for a minute. B4 careful not to brown the garlic. Stir in the tomato juice, fresh tomatoes, lime juice, and cilantro. Bring to a simmer and continue to cook for several minutes. Add Tobasco to taste. If desired, place the tortilla chips at the bottom of large shallow bowls and ladle the soup over them. Top with grated cheese and cilantro.

TASTE TEST RESULTS!

The results are in! At our last meeting, we received several gluten free products from Glutino (800-363-3438, www.glutino.com) and the Gluten Free Cookie Jar (888-GLUTEN-0, www.glutenfreecookiejar.com). The following are member's comments on the food sampled:

Glutino:

Dr. Schaer Pizzirilli Crackers – good texture, crisp and tasty, overall very good. They taste like a cracker with “pizza spice” – my son adores these and we have already ordered more.

Dr. Schaer Grissini Sticks – crispy , the kind you find on the table while you wait for your dinner. Yuck, they are dry and flat tasting.

Glutino Corn Pizza Shells (attending members got to take one home) – my son loved it – we added spaghetti sauce, cheese, olives and Hormel pepperoni (says gluten free on the label!), and toasted it in the toaster oven and it was like his own personal pan pizza.

Glutino Vegetarian Pizza (attending members got to take one home) – very tasty, and easy to prepare – just pop it in the toaster oven, very crisp crust.

Gluten Free Cookie Jar:

Orange Chiffon Bundt Cake – good, nice flavor

Pumpkin Cookies – very good, but too sweet. Very good, delicious, really good.

Peanut Butter Cookies – very good, great, good peanut flavor, excellent.

We also had several bread items from the Gluten Free Cookie Jar – primo white bread, plain bagels, French rolls, pumpnickel bread, blueberry scones and brownies. We received no comments, and many members took these items home. If you have comments regarding these baked goods, please contact Andrea Howe.

While not part of the taste test, a member brought in a cranberry orange bread made from a *Gluten Free Pantry* mix, that received rave reviews. Special thanks to Mary Perry for the use of her microwave (second time around!), Joany Janicki for the use of her toaster oven, and Debbie Byrne and her family for being in charge of the hospitality at every meeting.

ARE ALL VINEGARS SAFE FOR CELIACS?

*Reprinted from GLUTEN-FREE LIVING, the Resource for People with Gluten Sensitivity. Subscriptions are \$29 for one year, \$49 for two years. Write to Gluten-Free Living, PO Box 105, Hastings-on-Hudson, NY 10706.**

Experienced scientists say yes!

Grain-based vinegar has been a controversial celiac issue in the United States, but not in other countries. Some US national support groups say it is safe; others say it is not safe. Rank-and-file Celiacs are left in the middle, trying to figure out what to do to stay healthy.

We have received many questions about vinegar here at *Gluten-Free living. But in our experience, the celiac community keeps asking scientists questions about the safety of vinegar and *rejecting the answers* -- so it could be pointless to research and report on this topic. Plus there have been misunderstandings not only about the ingredients used in making vinegar but also about the process itself. Here is what we were able to find out about vinegar.

There are several types of vinegar, most of which do not begin with wheat. In a recent letter, Jeannie Milewski, Technical Manager at The Vinegar Institute, wrote: "Gluten is not present in the starting material commonly used in the manufacture of vinegar. Apple, grape, corn and rice sugars are the most frequently used sources of alcohol that are fermented into vinegar."

The *Compliance Policy Guide* for vinegar from the Food and Drug Administration, which indicates what different vinegars can be made of, says the same thing. This guide includes no mention of wheat. It indicates that the single word "vinegar" on a label means apple cider vinegar. The Guide does say spirit vinegar, distilled vinegar and grain vinegar should be made from dilute, distilled alcohol. Traditionally, distilled alcohol has been the primary concern of celiacs because it has been thought that the source of the distilled alcohol could be wheat.

However, according to The Vinegar Institute and several vinegar producers, most distilled white vinegars are made from corn. Ms. Milewski says, "Alcohol manufacturers

and independent laboratories have tested alcohol produced from corn and have been unable to detect the presence of any protein. While it is possible for white vinegars to be manufactured from grains other than corn, it is uncommon. However, we suggest that gluten-sensitive consumers contact the manufacturer to ensure the vinegar is gluten free."

So the first reason why vinegar is not likely to be a problem for celiacs is that wheat is rarely used for this purpose. ***

How Vinegar is Made

Many of us have read complex explanations of how vinegar is made. If you aren't a scientist, you probably don't understand the explanations. If you are a scientist, you probably aren't worried about gluten in distilled vinegar.

Very simplistically, to make vinegar, some ingredient (probably not wheat) is fermented, and then the resulting alcohol is distilled. The distillation step has been the crux of the celiac matter with vinegar. According to the dictionary, "Distillation is the process of first heating a mixture to separate the more volatile from the less volatile parts, and then cooling and condensing the vapor so as to produce a more nearly pure or refined substance; non-volatile impurities remain in the residue."

Scientists say gluten molecules are heavy and non-volatile. They will not turn into steam and cross over into the end product. So they should "remain in the residue."

It would seem that this information -- wheat is rarely used to make vinegar and even if it were used, gluten peptides would not survive the distillation step -- would end any celiac concern about vinegar.

But the concern has lingered for three reasons. First, some celiacs say large-scale distillation might not be as precise as small-laboratory distillation, so gluten peptides might sneak through the distillation into the distillate used to make the vinegar. Although this concern would seem to defy science and the vinegar-making process itself, it has lingered.

Second, some celiacs say they "react" to distilled white vinegar and conclude that it must contain gluten. Since vinegar is not consumed alone, how these celiacs know distilled white vinegar causes their reaction is not clear.

Third, there is no absolute guarantee that the starting material isn't wheat, so conservative celiacs say all celiacs should avoid all vinegars known to be started from wheat or for which the starting source is unknown.

*On the first reason, that something could go wrong with the distillation, of course things do go wrong in the real world. But in this case, what is being distilled is most likely not wheat, and whatever the original material is, by the time it's fermented, it's alcohol, not the original material. Although a small percentage of the original material could remain in the alcohol, in the unlikely event that the starting material was wheat,

scientists say any gluten peptides that survived fermentation would not survive distillation. Furthermore, they indicate that should something go wrong during distillation, even the wrongest wrong would still produce a product that is safe for celiacs (see following).*

On the second reason, celiacs have been told time and time again that what one celiac experiences with certain GF foods is not applicable to all celiacs. Those who react to distilled white vinegar should avoid it.

As far as a "conservative" approach to the diet is concerned, no doubt that is a healthy approach. But avoiding a class of products because something toxic "could" be there, even though all indications are that it is not, does not sound healthy. And if we are going to worry about what "could" be in certain foods, we should be consistent. The mind boggles at what we would be avoiding if we carried this thought to a logical conclusion. The first thing that comes to mind is all processed foods not produced in a dedicated facility.

But forget all the explanations, all the doubts and all of the fears that the vinegar question has generated. The best answer to questions about the safety of vinegar *was given over 10 years ago* by J.A. Campbell, Ph.D., then chairman of the Nutrition Advisory Board for the Canadian Celiac Association, and a scientist who had done some pertinent research.

Dr. Campbell wanted to determine the effectiveness of the distillation process in eliminating residual solids. He was as interested in alcoholic beverages as he was in vinegar. So whatever he found about alcoholic beverages would be even more true about vinegar since vinegar would use a smaller amount of distillate than alcoholic drinks and the distillate would be more dilute (read even less gluten in the unlikely event some was there).

Dr. Campbell's data indicated a residue of less than 0.2 mg per liter (1.06 quarts) of distillate, and he noted that these distillates are never used at full strength, so the above number would be even smaller. He compared this amount of potential gluten to the lowest amount considered to be toxic to some individuals (1-2 mg gliadin, the amount still quoted today). Then he wrote:

"To expose a celiac patient to this level of gliadin would require the consumption of at least 20 liter (21.2 quarts) potable spirits a day. The patient would undoubtedly be more at risk from alcohol than from gluten toxicity. When distilled grain alcohol is used in the production of white vinegar...the dilution factor is still greater and the possible concentration of gluten-like substances even less."

So it would be literally impossible to consume enough vinegar to even get close to the lowest amount considered to be toxic to some individuals, assuming some toxic material was present.

Other scientists agree with Dr. Campbell, most notably Don Kasarda, a respected American grain chemist who has provided scientifically- and research- based guidance

to American celiacs for many years. Dr. Kasarda has been asked again and again about vinegar. His answer is always the same:

"I agree with Dr. Campbell on this. Amino acids, peptides and proteins are of such low volatility compared to the high volatility of ethyl alcohol that they should not be found in the distilled alcohol. There is no scientific evidence for gluten peptides in alcohol or vinegar that I am aware of. *I have never encountered a single chemist who thinks there are gluten peptides in distilled alcohol from wheat grain*. I have not personally researched this matter because it is such an unlikely possibility and to prove the absence of gluten peptides that might be present in minute amounts is likely to be a major, costly undertaking and not at all easy. I realize that some celiac patients may have a disagreeable digestive response to white vinegar...but if it doesn't bother you don't worry about it. If it does bother you, don't ingest it. (Malt vinegar is the only vinegar that I think might contain harmful peptides.)"

Some *Still* Say No!

Despite all this credible evidence (there is plenty more), the US celiac community has continued to equivocate about gluten in vinegar, which has several harmful consequences.

First of all, it casts doubt on a long list of common foods that contain vinegar, the obvious, like salad dressings, and the less-than-obvious, like ricotta cheese. This doubt adds what are almost certainly unnecessary restrictions to a limited diet that is already very restrictive.

Not only that, it can be difficult to search for the source of a vinegar used as an ingredient in other foods. You can call the food processor, who may or may not know which vinegar was used in which product. You can ask other celiacs, who may know no more than you. You can consult the GF food lists, all of which indicate that the information they contain may not be valid at the time you are reading it. So there are no reliable ways to check for the sources in all the various vinegars used in products like ketchup and salad dressings.

The continuing controversy about the possibility of gluten in some vinegars also casts doubt on initial basic guidance about the gluten-free diet. If some respected group leaders say vinegar is safe and other respected leaders say it's not safe, who should a new celiac believe?

Worse yet, all the controversy about vinegar seems to send newly diagnosed patients off on a search for vinegar in products rather than a search for gluten. They set off on the wrong gluten-free foot, looking for a needle in a haystack, even though the needle probably isn't there, and worrying about which kind of vinegar is in which product, when they should be looking for the more obvious mountain of gluten in their diet so they can weed it out.

All celiacs lose credibility with food processors about their own diet when they continue to worry about the possibility of gluten in some vinegars. Why should food companies

take our valid questions about gluten freeness seriously when we don't take the answers their well- paid scientists give us seriously.

Furthermore, in the face of such rigidity, some companies are forced to say things about ingredients that seem to fuel the initial questions! At the beginning of this article, you read what The Vinegar Institute says about the possibility of gluten in vinegar. Initially it says, "Gluten is not present in the starting material commonly used in the manufacture of vinegar." But at the end adds, "However, we suggest that gluten-sensitive customers contact the manufacturer to ensure the vinegar is gluten free." You can read the end of the response as contradicting the beginning -- and answers like this are very common.

Celiacs will never get definitive answers about ingredients in processed foods as long as they continue to question valid answers that are supported by science.

Finally, continued doubt about ingredients such as vinegar could cast doubt on the very strong probability of living a long, healthy life once diagnosed with celiac disease and on the gluten-free diet. Why feel confident when there are so many perceived unknowns, so much conflict and so much confusion?

Since there seems to be no firm basis for avoiding vinegar, it would be best for all celiacs if the controversy about this product was laid to rest (some groups are moving in this direction). Then we can get on to more important things and help all celiacs feel more confident about their diet and their health.

*** The one vinegar about which celiacs might have some concern is malt vinegar, which is made from "an infusion of barley malt or cereals," according to the Compliance Policy Guide." Also, a few vinegars do have flavoring or something else added back in after distillation. If so, that would be indicated on the label.

WACSSG GROUP CONTACTS

Chairperson:	Andrea Howe	(301) 972-9263	andreahowe@juno.com
Treasurer:	Mary Perry	(703) 860-2012	mperry@ucsworks.com
Newsletter Editor:	Joany Janicki	(202) 364-9703	jcjanicki@aol.com
Mailing List:	Debbie Byrne	(703) 644-5863	debmom4@aol.com
Virginia Contact:	Julia Patchan	(703) 709-1465	bernjulia@aol.com
Maryland Contact:	Andrea Howe	(301) 972-9263	andreahowe@juno.com
District Contact:	Joany Janicki	(202) 364-9703	jcjanicki@aol.com

WACSSG Website address: www.erols.com/stataid/dcceliacsupport.htm

Celiac Hotline Committee: Do you have a celiac question? Call a hotline member:

Joany Janicki, Washington, DC.....(202) 364-9703..... Has celiac disease
Andrea Howe, Germantown, MD.....(301) 972-9263..... Mother of celiac child
Bea Newell, suburban MD(301) 365-6261..... Maintains a Kosher gluten
free diet
Daneille Clarke, Frederick, MD..... (301) 620-0075..... Has celiac disease
Pianodc@aol.com
Pam Tufts, suburban VA.....(703) 968-7192..... Dermatitis Herpetiformus
PtTufts@erols.com
Julia Patchan, suburban VA..... (703) 709-1465..... Mother of celiac child
Bernjulia@aol.com

MEMBER PARTICIPATION:

If you have any information that you would like to see included in the newsletter such as local restaurants, new gluten free products you've found at your health food store, or current medical information you've come across please forward it to:

Joany Janicki, 202-364-9703, jcjanicki@aol.com, 5410 Connecticut Ave., NW #408, Washington, DC 20015.

DISCLAIMER: As always, the information contained in this newsletter is provided solely for the benefit of the reader without endorsement or recommendation. Please verify all information.