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# WASHINGTON AREA CELIAC SPRUE SUPPORT GROUP NEWSLETTER

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Late Fall 1999

## MEETING NOTICE:

**Date:** Saturday, November 20, 1999

**Time:** 2:00 p.m.

**Location:** Patrick Henry Library, 101 Maple Avenue East, Vienna, VA 22180, 703-938-0405.

**Topic:** Join us for a pre-holiday feast and an opportunity to discuss the challenges of getting through the holiday food maze and still come out gluten free.

We will also have samples from Glutino and the Gluten Free Cookie Jar to taste test. At this meeting we will initiate our new rating system on prepared gluten free food and mixes.

Several of the product lists from the last meeting will be available in addition to several new lists from McCormick, Giant, Fantastic Foods, Best's Kosher, Oscar Meyer, Health Valley, McNeil (Tylenol) and Land O lakes.

Please feel free to bring your favorite gluten free holiday dish and recipe to share with other members. We hope to see you there!

*Please note that our next meeting will be held on Saturday, February 5, 2000, at Davis Community Library in Bethesda. Directions will be included in the January newsletter. At this meeting we will be joined by the former owner of Ms. Robens gluten free mail order company who will share with us samples of recipes from her recent cookbook. Mark your calendar!*

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**Dinner after the meeting!** Anyone interested in going out to eat after the meeting? Want to get tips on how to order a gluten free meal from other celiacs? We will convene after the meeting and choose our restaurant in the Tysons Corner area.

## DIRECTIONS:

**From Beltway Inner or Outer Loop:** Take Exit 11 to Vienna. Follow Route 123 South. It becomes Maple Ave. Proceed 2.3 miles to Center Street. The library is a light brick building on the near left corner of Maple and Center Street, one block past Southern States.

***From I-66 East from Fairfax:*** Exit on Route 123 North and continue for 3.3 miles through Oakton to Center St. The library is a light brick building on the near left corner of Maple and Center Street, one block past Southern States.

***From I-66 West from Washington and Arlington:*** Follow I-66 West to the exit for Vienna which says "Nutley Street" (Route 243. Exit for Nutley Street, North. Turn right on Nutley Street and proceed for .9 miles to Route 123 North ( Maple Ave.)

### **NEW DUES SCHEDULE**

During the recent reorganization of the Chapter, the policy for the payment of dues has been changed. All dues for each calendar year will be accepted only during the **month of February**. This new policy will simplify the administrative confusion of having to coordinate individual renewal dates.

New members who join after the month of February will submit their first dues payment in February of the following year. If you have questions concerning this new policy please contact Andrea Howe. **A call for dues will be announced in the January newsletter.**

### **MESSAGE FROM THE CHAIR:**

I am happy to announce that our September meeting was a huge success – 54 attendees. I was a little under the weather, so I hope I didn't forget to call anyone afterwards! Since we had a larger number of attendees, we did run out of some of the product lists. I am very sorry. Our usual meeting size is 20, and I was ill prepared. We will have some of the same printed information at our next meeting. It was decided to donate funds to the Center for Celiac Research, and we had a good question and answer session. The food was great, too!

The meeting in November is traditionally our Holiday Feast. Most everyone brings a dish and it is a great time to bring the family. I would like to have an open discussion on how to deal with the approaching holiday season. This time of year can be especially difficult.

Several good ideas have been brought to me. Starting after the Summer of 2000, we will be meeting every other month. We plan to have social events during summer months and December.

I am looking for someone to host this year's Cookie Exchange. We also need hosts for future potluck get togethers. If anyone is interested in hosting or participating, please let me know.

There is also interest in buying foods in bulk as a group to lower the cost (of products and shipping charges). We would need someone to coordinate and receive shipments. Call me!

Looking forward to seeing you at the meeting!

Andrea Howe  
(301) 972-9263

### **FUTURE PLANS :**

#### **Taste Testing**

At the next meeting will be implementing our new rating system for prepared gluten free food and mixes on the Glutino and Gluten Free Cookie Jar samples. In doing this, we hope to save our members the time and money that they spend on purchasing expensive gluten free products and mixes that are disappointing and are too difficult and time consuming to make. Our rating system will include taste, ease of preparation, and cost.

At each meeting, we will have samples available for tasting, and hope that the members in attendance will rate the food before they leave. Some of our future taste tests will include cake mixes, brownie mixes, bread mixes, and even pizza mixes. In planning for our tastings, we only ask that members volunteer to help make the mixes for the meetings. The mixes will be purchased by the WACSSG, and volunteers will be given plenty of advance warning. Ratings will be published in the newsletter following each meeting.

#### **Alternative Grains**

Alternative grains such as buckwheat, quinoa, amaranth, millet, wild rice, teff, and oats remain very controversial to those with Celiac Disease. While much evidence suggests that there is a strong botanical evidence that many of these grains are safe for those who are gluten sensitive, the decision to use these grains is still up to the individual. Because one of our goals as a support group is education, we would be remiss not to provide our members with current, up-to-date research regarding these alternative grains. In future issues, we will be including abstracts from research articles regarding these grains. Reader input is very important. If you stumble upon research information, please forward it to Andrea Howe.

### **PRODUCT INFORMATION:**

McCormick has some new spice blends and flavor medleys that are gluten free!. The Spice Blends come in Key West, Monterey Style, and Santa Fe blends, and the Flavor Medleys come in Garlic Herb, Italian herb, Lemon & Pepper, and Tomato Basil. The company phone number is 1-800-632-5847.

Fleischmann's margarine's are gluten free. These items are Fleischmann's Corn Oil Margarine, Chiffon, Blue Bonnet, Parkay, Move Over Butter, Touch of Butter. The company phone number is 1-800-988-7808. These products are distributed by Beatrice Foods.

Starbuck's Rhumba Frappuccino **DOES** contain gluten. However, the company has confirmed that all of the other coffee drink items are gluten free. For more information contact the company at 206-447-1575 ext. 2900, or email [info@starbucks.com](mailto:info@starbucks.com)

All of the Cabot Cheese products are gluten free. The company representative also assured that there is no possibility of cross contamination. Cabot Creamery Cooperative, 1-888-TRY-CABOT, [www.cabotcheese.com](http://www.cabotcheese.com).

For those of you who attended the September meeting, there was confusion over whether Rolling Rock beer was gluten free. The subject was raised because a member of the Baltimore group has been drinking the beer and put it on a gluten free list. Andrea Howe has contacted the Latrobe Brewing Company in Pennsylvania, makers of the beer, and it is definitely **NOT** gluten free. It has the same offensive ingredients that all beer has.

Neutrogena has confirmed that their new line of cosmetics is all gluten free with the exception of their mascara. 1-800-217-1136.

Best's Kosher hot dogs are gluten free, and are sold at all Costco refreshment areas.

### **KIDS CORNER**

The ***Celiac Support Group for Children*** is a support group for children with celiac disease and their parents that offers quarterly newsletters and new member packets that include a coloring book. The newsletters contain information for parents on lunch box ideas, starting school, and other issues that celiac children must cope with. We will have back issues of the newsletter available at the meeting for review. Membership is \$20 a year. For more information, or to join, please contact Janis Collard, President, 11 Level Acres Road, Attleboro, MA 02703. 508-399-6229, [csgc@ix.netcom.com](mailto:csgc@ix.netcom.com).

Giant Foods vanilla and chocolate ice cream cups are gluten free. These are great for birthday parties!

### **WHOLE FOODS ONLINE:**

Whole Foods (Fresh Fields) now has an online Gluten Free Products Guide. The web address is [www.wholefoods.com](http://www.wholefoods.com) Look in the Issues and Actions section. This list has been compiled with the assistance of Katie Atkinson of the Celiac Disease Foundation. Please note that this list is only a guide. There has been no research done on cross-contamination. Whole Foods is hoping that people will contact them on the web if they

see errors on the list. As always, manufacturers can change ingredients at any time, so the list will have to be periodically reviewed to keep it up-to-date. Gluten free lists should also be available at in-store kiosks located under healthinfo/ ingredients and labeling.

**CFCR RESEARCH UPDATE (from the internet , September 1, 1999):**

Currently, the Center for Celiac Research is involved in three critical research areas:

- Multi-Center Serological Screening Study to determine the prevalence of Celiac Disease in the United States.

We have tested 3,998 individuals as part of the Multi-Center Serological Study for the prevalence of Celiac Disease in the United States. Our preliminary findings indicate that 5.7% of first-degree relatives and 3.1% of second degree relatives of celiacs test positive for the disease. These results are similar to those reported previously in Europe, suggesting that Celiac Disease is currently under-diagnosed in the United States.

We are extremely encouraged by these preliminary findings; however, many more subjects need to be screened to put the study into full operations. Your financial help is pivotal to accomplish our goals.

- New Diagnostic Assay to develop a non-invasive diagnostic test for Celiac Disease.

Our scientists have been able to develop a more sensitive, non-invasive, and specific test for Celiac Disease based on the use of tissue transglutamines. We were able, for the first time, to clone the human tTG gene. Our preliminary results show that the human tTG assay performs much better than the commercially-available tests (including anti-endomysium antibodies and guinea pig-based transglutaminase assay).

- New Dot-Blot Assay

We have developed a human tTG dot-blot test based on the detection of anti-tTG antibodies in serum or in one drop of whole blood, which can be carried out within thirty minutes. The preliminary results of the dot-blot assay indicate that the assay is as reliable as the human tTG ELISA test, making the diagnosis of Celiac Disease possible at the physician's ambulatory site.

If the sensitivity and specificity of these tests can be confirmed on a large scale, a case can be made on the possible discontinuation of the invasive intestinal biopsy procedure as the "gold standard" for the diagnosis of CD. This would result in early identification and treatment for patients with CD at a significant cost savings. We will continue to validate these innovative tests during the future blood screenings.

**BLOOD SCREENINGS**

Blood screenings of first and second degree relatives have been conducted in California, Kentucky, Maryland, Montana, Pennsylvania, New Hampshire, New York, North Carolina, Rhode Island, Texas, and Washington state.

## FUND RAISING UPDATE

We are happy to report that as of September 1, 1999, the University of Maryland's Center for Celiac Research has received approximately \$369,494.00 in contributions and pledges. We thank all of you who have made a contribution or pledge.

As we reported in the June update, when we began this effort back in May of 1977, we suggested that if 1000 Celiacs, relatives or friends would make a commitment to pledge \$200 per year for three years, we would be on our way to funding this extremely important study.

For now, we cannot rely on any outside financial assistance. So please, help us to help you. Remember we are not asking you to make a contribution, but to make an investment in the well being of every celiac – now and in the future.

## DONATION CHECKS

Please make all donation checks payable to the University of Maryland Foundation, Inc. and send with the pledge form or a note saying that the donation is for the Center for Celiac Research. Since the University of Maryland Foundation, Inc. houses all the gift funds for the University, they are not permitted to deposit checks into the Celiac account if the check is not made payable to the University of Maryland Foundation, Inc. Thank you for your cooperation.

## UNITED WAY CONTRIBUTIONS

This is another great way to make a gift to the Center for Celiac Research and satisfy your employer's request to participate in the United Way Appeal. Please designate under Other The University of Maryland Foundation/ Center for Celiac Research, 511 W. Lombard St. Baltimore, MD 21201.

## WEB SITE

Our web site, [celiaccenter.org](http://celiaccenter.org) has been on line since the middle of June. The research and fundraising updates, as well as updates on the Ninth International Symposium on Celiac Disease, individual and group screening information, blood screening locations, and donation information will be posted on the web site.

## NINTH INTERNATIONAL SYMPOSIUM ON CELIAC DISEASE

The Center for Celiac Research at the University of Maryland School of Medicine, the University of Chicago, and the University of California, San Diego are please to announce joint sponsorship of the Ninth International Symposium of Celiac Disease to

be held August 10-13, 2000 in Baltimore, Maryland. A brochure outlining the program, and registration and hotel information will be distributed to all group leaders throughout the country, and additional brochures will be made available to them for distribute to their members. We anticipate a very large attendance so we advise you to register as soon as possible.

## OTHER WAYS OF GIVING TO THE CENTER

For many, providing for important research is an important aspect of their financial planning. If this is true for you, prudent and skillful investment planning can create rewarding opportunities for both you and the Center for Celiac Research. You may be interested to know, for example, that:

- Appreciated securities, held long-term, can be given to the Center without incurring a capital gains tax. And the full fair market value of the securities is available as a charitable education.
- Life insurance that is no longer needed for family or business protection can provide major support for the Center while producing important tax savings for you.
- Participation in a pooled income fund or the establishment of a charitable trust using appreciated securities, for the eventual benefit of the Center can be an excellent means of increasing your spendable income and minimizing income, capital gains, estate and inheritance taxes.
- The final opportunity to express your lasting commitment to the Center is through your will or revocable trust.
- Of course, charitable bequests are not subject to the federal gift tax and are not included in the "taxable estate" for federal estate tax purpose.

## WHAT CAN YOU DO?

If you have not made a pledge or contribution, please consider making gone at this time. Please make checks payable to the UM Foundation, Inc. Center for Celiac Research, Attn: Pam King, 700 W. Lombard St. Room 206, Baltimore, MD 21201. These funds are administered by the University of Maryland Foundation, Inc.

- If possible, increase your current pledge or make another gift at this time.
- Discuss the important of this study with fellow celiacs, relatives, friends or whoever might be in a position to help. Ask them to contribute.
- Organize discussions and/ or fund-raising efforts with your local support group.
- Help us to identify possible organization, companies, trust of foundation s that might be in a position to help. Please contact Pam King at 410-706-8021 if you have any questions.

- Send contributions to the Center in honor or in memory of a friend or loved one.  
Make a gift to the Center in honor of the holidays.

**WACSSG CONTRIBUTION:**

At the September meeting, the members in attendance voted to contribute \$1000 from the funds of the Washington Area Celiac Sprue Support Group to the Center for Celiac Research.

**NUTRITIONIST:**

If you are looking for a nutritionist, Deborah A. Redman PhD, ND, C.N.C., is a naturopath and certified nutritional consultant who has celiac disease herself. She specializes in assisting those with celiac disease with nutritional advice in our area. She can be reached at 202-544-4006.

**FALL RECIPE EXCHANGE**

**Gluten Free Pizza – no Yeast!**

- 1 cup rice flour
- ½ cup Argo corn starch
- 1 teaspoon baking powder
- ½ teaspoon salt
- ¾ cup milk
- ¼ cup corn oil
- 1/3 cup prepared gluten free pizza sauce
- 1 cup (4oz) shredded mozzarella cheese

Preheat oven to 425 deg. In a medium bowl combine rice flour, corn starch, baking powder and salt. Stir in milk and corn oil to form a very soft dough. Spread on cookie sheet to form a 10 inch circle ¼” thick. Bake 12-14 minutes or until lightly browned around edge. Remove from oven. Spread sauce over crust, sprinkle with cheese. Bake 5-7 minutes or until cheese is bubbly.

**GLUTEN FREE PRESCRIPTION DRUG GUIDES:**

As we approach cold and flu season, celiacs can have considerable difficulty in finding medications to relieve their symptoms. There are two pharmaceutical guides available to Celiacs that provide the gluten status of a variety of over the counter and prescription medications:

1. The Clan Thompson Pocket Guide to Gluten Free Prescription Drugs. \$3.50  
Mail requests to Clan Thompson, 951 Maine St., Stoneham, ME 04231,  
<http://www.idsl.net/ceciac>

2. Stokes Pharmacy publishes "Celiac Sprue, A Guide Through the Medicine Cabinet", \$19.00.  
1-800-754-5222. [www.stokesrx.com](http://www.stokesrx.com)

### **Y2K PREPAREDNESS:**

The recent hurricanes that have swept through our area and the ice storms this past winter that left many of us without power for several days have created unique challenges for those of us with celiac disease. Even without the impending problems that Y2K might bring forth, celiacs should be prepared for such natural disasters.

No one can really predict the extent of problems, if any, that might arise with the Y2K transition. In an emergency, however, preparation means everything. Most emergency planners suggest having enough supplies to last you and your family for three days to a week for weather-related events.

However, because of our dependence on special foods and foods that are imported from other countries, celiacs might want to plan for longer periods of time. Do you know where your tapioca or rice flour comes from? Experts are predicting that many third world countries might be significantly less prepared for Y2K than the United States and this might create longer term complications with international distributors.

It might be advantageous to stock up on your gluten free staples, or have a store of baked goods to last several months after Y2K problems are corrected. In addition, if Y2K creates disruption in the transportation of food products within our own country, our familiar, and confirmed, gluten free brands of non perishable items might not be available on our grocery store shelves.

If there is such a need to go to a Red Cross shelter, celiacs must bring their own food. The Red Cross suggests having a two week supply of specialized food on hand and not to depend on emergency relief food to see to our needs.

The following are just a few suggestions to help in making up a celiac disaster kit (food in the kit should be rotated every three to six months to ensure freshness). Note that this list pertains to our specialized needs only. Refer to the contact list for further information regarding the basics for disaster planning and more information on Y2K:

- Medication – Make sure that you have an adequate supply of required medications. Place in proper air tight containers. Store an adequate supply of gluten free pain reliever.
- Vitamins – Store enough to last you several weeks.
- Water -- Water should be stored in plastic containers. Avoid containers that break if you need to transport them to different locations. Store one gallon of water per person per day: Two quarts for drinking, two quarts for food preparation/ sanitation.

Purifying agents might also be necessary if you are dubious of your local water supply.

- Food

Dried foods- powdered milk, coffee, tea, cocoa, eggs, cornmeal, rice, gluten free flours, instant potatoes, gluten free cereal.

Canned or jar fruits and vegetables - Small cans are best. Canned vegetables do not require heating. Applesauce, high protein beans such as chickpeas or kidney, Nutella, (make sure you have a hand operated can opener)

Juices –available in single serving boxes or cans, Gatorade, V-8 Juice – many of their drinks are not gluten free – check with the company, Minutemaids with Calcium is gluten free and comes in individual boxes.

Milk- Powdered or canned.

Canned meat/ fish – Salmon, tuna fish, chicken, canned chili - Hormel, canned chunk ham, canned stew – Dinty Moore.

Canned or instant gluten free broths: Powdered type can be mixed with only water for a nutritional soup. The commercially available gluten free broths are Health Valley (both the chicken and beef), Herb Ox bouillon cubes, Dominiques, Campbell's Healthy Request Chicken, Shelton's Chicken Broth, Kitchen Basics (both the chicken and beef), Trader Joe's has its own brands of broths.

Staples – sugar, salt, pepper, rice, gluten free pasta, bread – EnerG makes a bread that keeps very well on the shelf. Gluten free bread can be baked in canning jars in the oven. As soon as the jar comes out of the oven, the boiled jar lids and then the rings are applied. These should keep for about 6 months. Gluten free pancake mix that can be used for pancakes made on a camp stove.

High energy foods – Jelly, peanut butter on gluten free crackers, nuts, raisins, protein bars.

Stress and comfort foods – Cookies, hard candy such as Lifesavers, tortilla chips and other such snacks.

Rice cakes – these will no doubt last forever.

Dehydrated foods – AlpinAire Foods manufactures packaged freeze dried foods for backpackers and several of their items are gluten free. Call 1-800-322-6325 for their gluten free list. [www.alpinairefoods.com](http://www.alpinairefoods.com)

If you have your own dehydrator, take advantage of it and package up some foods for your kit, gluten free jerky, dehydrated soup mixes. The Tamarind Tree Company

makes several Indian style gluten free entrees that are shelf stored and can be heated in boiling water.

Baby food – Much of it is gluten free, stores well and comes in individual containers. This might be your only option if you find yourself in a shelter with no food.

- Utensils, plates and pots and pans – if you have to go to a shelter or someone else's house and are concerned about cross contamination.

#### APPROXIMATE SHELF LIFE OF FOODS STORED AT 70F:

<b>Item</b>	<b>Shelf Life</b>	<b>Information Source</b>
Refined Flours	1 year	Grain Process Enterprises Ltd. (800) 387-5292
Unrefined Flours	6 months	Grain Process Enterprises Ltd. (800) 387-5292
White Rice	2 years	Lundberg Family Farms (530) 882-4551
Brown Rice	6 months	Lundberg Family Farms (530) 882-4551
Dry Beans	5 years	Utah State Univ. Extension Services (801) 370-8460
Dry Corn	5 years	Utah State Univ. Extension Services (801) 370-8460
Powdered Milk	2 years	Utah State Univ. Extension Services (801) 370-8460
Canned Fruits, Veg., & meats	2-3 years	Utah State Univ. Extension Services (801) 370-8460
Sugar/ Honey, Salt	indefinitely	Utah State Univ. Extension Services (801) 370-8460
Shortening	2 years	Utah State Univ. Extension Services (801) 370-8460
Baking Pder, soda	1 year	Utah State Univ. Extension Services (801) 370-8460
Xantham Gum	indefinitely	Ener-G Foods, Inc. (800) 331-5222
Yeast	1 year	Red Star Yeast (800) 445-4746
Peanut Butter	1 year	Skippy Peanut Butter (800) 338-8831

FOR MORE INFORMATION ON Y2K PREPAREDNESS CONTACT THE FOLLOWING:

- Presidents Council on Year 2000: 1-800-USA-4-Y2K, [www.y2k.gov](http://www.y2k.gov)
- The American Red Cross: 703-248-4222, [www.redcross.org/disaster/safety/y2k.html](http://www.redcross.org/disaster/safety/y2k.html)
- Federal Emergency Management Agency, [www.fema.gov/y2k](http://www.fema.gov/y2k)

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