

# WASHINGTON AREA CELIAC SPRUE SUPPORT GROUP MEETING NOTICE

**Date:** Saturday, April 17, 1999

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

**Location:** Dolley Madison Community Library, 1244 Oak Ridge Ave., McLean, Virginia  
(703) 356-0770

**Topic:** We will discuss the recent administrative changes to the group and provide an opportunity for you to meet our new chairperson Andrea Howe.

As usual, please feel free to bring gluten free snacks and recipes to share with other members.

**Something New!** Anyone interested in going out to eat after the meeting? Want to get tips on how to order a gluten free meal? Please join us for a group dinner at Ruby Tuesday's in Tysons Corner. Call Andrea Howe at 301-972-9263 if you are interested so we can make reservations and call ahead to inform the restaurant of our special diet needs.

## **DIRECTIONS:**

***From Maryland, points north:*** From the Beltway (495) take exit 11 to Rt. 123 N Chain Bridge Road. Proceed approximately two miles. After Crossing Old Dominion Drive, turn left on Ingleside Ave., the very next street. Drive one block on Ingleside. The library is the red brick building on the left. Turn left on Oak Ridge to enter parking lot.

***From DC, GW Parkway, points east:*** Take the route 123 exit toward McLean. Rte 123 (also Chain Bridge Rd, and later on, Dolley Madison Blvd.) goes through McLean. After crossing the traffic light at the intersection of Churchill Road and Dolley Madison Blvd., get into the right lane and proceed .3 mile. Turn right on Ingleside Ave. Drive on block on Ingleside. The library is the red brick building on the left. Turn left on Oak Ridge to enter the parking lot.

***From Virginia, Dulles Toll Road, points west:*** Take the Toll Road (rte 267) toward Washington. Take Exit 10B/ Rte. 123 North (Dolley Madison Blvd.) Get into the left lane as soon as possible. Proceed 1.3 miles, crossing two major intersections with traffic lights. After crossing Old Dominion Drive, the second intersection, turn left immediately at Ingleside Avenue. Drive one block on Ingleside. The library is the red brick building on the left. Turn left on Oak Ridge Ave. to enter the parking lot.

\*\*\*\*\* **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 newsletters prior to each February date.

\*\*\*\*\* **PASSOVER REMINDER!** \*\*\*\*\*

Many of the Passover food items that are in grocery stores now are very suitable for gluten free diets. Many items use potato flour or potato starch as wheat flour substitutes. However, be aware that items may contain matzah, which is made from wheat flour and water. Matzah cake meal is crushed matzah. Read labels carefully.

**MESSAGE FROM OUR NEW CHAIRPERSON:**

My name is Andrea Howe. I am the mother of two, Justin (almost 5) our celiac and Andrew (3). Justin was diagnosed 2 1/2 years ago and this group has been instrumental in helping him to get better. Without your support I would have cried many more hours and it would have been much more difficult to adjust to this diet.

When I came to my first meeting I was still mourning my son's diagnosis. I was sure his life would be difficult and unhappy. Seeing all the very normal, healthy and happy members of this group I felt much better. Everyone was kind and helpful and assured me that Justin would be just fine. He has been thriving and accepts his diet without complaint mostly, I believe, because I don't have that negative outlook anymore. Thank you!

During our meeting on February 20th, we agreed on our goals for this group. We as a group want to educate and lend support to newly diagnosed celiacs, provide support and information to our current members, educate the people around us, especially the medical community and keep current on product and medical information.

Several people have graciously stepped forward to help. Some of them are mentioned in this newsletter. We can always use more help of course. Mostly we would like members to attend the meetings, share with us the information they come across and support each other. Sometimes this can be hard. We have different views on so many things. Even though we may not agree on what is safe or not (ex. vinegar), I think it is important to show a united front and help each other cope.

Anyone with ideas, tips and / or advice please feel free to contact me at 301-972-9263 or at Andrea.R.Howe@gte.net.

Sincerely,  
Andrea Howe

### **CHAPTER NEWS AND ADMINISTRATIVE NOTES:**

--During the recent chapter reorganization, several volunteer committees have been created to divide up the work necessary to keep the group going and continue to achieve our goals. If you are interested in helping out in one of the committees or have ideas or information to add to any of the committees, the newsletter, or for upcoming meetings please contact Andrea Howe or one of the volunteers mentioned.

*Treasurer* - Collect dues every February and maintain member roster: Mary Perry

*Newsletter* - Collect and compile information into the newsletter 4 times a year before each meeting: Joany Janicki (202- 364-9703 jcjanicki@aol.com) , Debbie Byrne

*Meetings* - Research potential speakers, reserve meeting spaces in Maryland and Virginia, and post meeting dates on the internet: Danielle Clarke, Bea Newell, Becky Campbell, Sarah Barnett.

*Hospitality* - Provide refreshments, sign up sheets and name tags, and set up prior to each meeting: Debbie Byrne, Pearl Schwartz.

*Information* - Compile new product and medical information to share in newsletters and at meetings: Pam Tufts. If you have come across new information you would like to share, please forward it to Pam at 4719 Logwood Lane, Chantilly, VA 20151.

*New Member Packet* - Collect information for new member packet/ resource guide, ie. local products, local stores, local restaurants, mail order foods, local doctors, helpful websites, basic recipes, tips and advice, books. If you would like to add information to the new member packet or have anything you feel would have been helpful when you were first diagnosed or information you would like to share with a celiac visitor to the DC area, send it to Debbie Byrne at 7935 Orange Plank Road, Springfield, VA 22153, or by email byrnefp@aol.com or to Andrea Howe.

*Public Relations* - Community outreach, especially the local medical community and area celiacs who may not be aware of the local chapter. We are presently looking for a volunteer who would like to help out in this area.

--Mentor Program - We've recently had several members who have volunteered to help newly diagnosed celiacs with coping skills such as taking them food shopping for the first time to point out what brands we can actually eat at both regular grocery stores and local health food stores. We would like to continue this program, and will pair up new members with existing members in the same geographical area. If you are interested in becoming a mentor, or are newly diagnosed and would like some additional guidance yourself, contact Andrea Howe.

--We're in the process of compiling member email addresses for our membership list. If you would like your email address to be included, send your email address to Andrea Howe at Andrea.R. Howe@gte.net.

--Kathy Poneleit has been working on a WACSSG web page! We will let you know how to get access to the site when it is up and running.

--For chapter members and volunteers who have reimbursable expenses, please retain your receipts and give them or mail them to Mary Perry at 11520 Running Cedar Road, Reston, VA 20191.

### **FOOD FAIR VOLUNTEERS NEEDED:**

The Maryland Chapter is looking for non celiac volunteers to help out on the day of the food fair. They need individuals to watch the booths during the lecture portion of the fair. The volunteers will not be charged an entry fee. If you are interested please call Jim Scheder at 410-252-6777. If you have not received information on the food fair in **Baltimore on May 2**, you can pick up information at the meeting, or call Andrea Howe.

### **POTLUCK PICNIC IN JUNE!:**

Lynn and Rich Robbins have offered the use of their yard on **June 12 from 4:30-8:00 pm**. Everyone is welcome! Their house is located in Arlington and they have a covered section should the weather be rainy. Starting **June 1st**, please call Lynn at 703-276-3597 to RSVP and get directions to their home. Everyone should bring a dish with recipe (including brand names if possible). The recipes sampled at the picnic will be compiled and be available at the September meeting.

### **KIDS TACO PARTY IN JULY!:**

Lisa Cox will host the kids party on **July 17th at 4 pm**. This will be the only reminder, so call Lisa @ 301-438-9625 to RSVP and for directions. Tacos and fixings, drinks, and candy will be provided, but please feel free to bring a Mexican dish. Donations not required, but always welcome.

### **WACSSG INTERNET CHAT ROOM:**

There is a new web site chat room and bulletin board for the Washington area support group. Specific chat times will be arranged for individual groups, however, you can use the chat room message board 24 hours a day. There will be different places on the site for teens/ preteens, general discussion, parents, product information, medical information, etc.

*Parents of celiac children* - Through the chat room, we will be able to meet and discuss issues related to raising children on the gluten free diet, such as sibling issues, school concerns, birthdays, etc. The first chat will be on **Wednesday, April 21 at 8pm**. For those interested in signing up, please email Andrea Howe at [Andrea.R.Howe@gte.net](mailto:Andrea.R.Howe@gte.net) so she can send an invitation to get you started.

*Teen/ Preteen group* - If you are interested in forming a separate meeting in person, setting up a chat room, or email pals to share tips on how to deal with friends, dating, or for parents of teens, please call Andrea Howe.

The address for the message board is:

**<http://forums.delphi.com/m/main.asp?sigdir=wacssgparents>**

The address for the chat room is:

**<http://www.delphi.com/dir-app/chat/forumchat.asp?sigdir=wacssgparents>**

For those who don't have access to the internet call Andrea at 301-972-9263 to discuss setting up a formal group meeting for the parent and teen groups.

### **LOCAL AREA PRODUCT INFORMATION:**

Frookie has come out with three flavors of organic, gluten free cookies: peanut butter, chocolate chip, and double chocolate. They are presently being sold at My Organic Market in Rockville, Md. For more information call Frookie @ 1-888-FROOKIE. Samples of the cookies will be available to taste test at the meeting along with mail order forms.

Area Fresh Fields stores now carry a brand of gluten free rice pasta made by a Canadian company called Tinkyada. The pasta comes in spaghetti, spiral, shell, fusili, and elbow shapes. You can reach the manufacturer at Food Directions, Inc., 150 Milner Ave., Units 21-23, Scarborough, Ontario, M1S3R3 Canada.

Papadini makes a gluten free, hi-protein, pure lentil bean pasta. Four shapes are available and they are presently being sold at My Organic Market in Rockville, Md. For more information contact Adrienne's Gourmet Foods, 849 Ward Drive, Santa Barbara, CA 93111, 1-800-937-7010.

Annie's Naturals, the same company that makes a variety of interesting salad dressings, many of which are gluten free, has come out with a pourable Vermont Cheddar Cheese Cooking Sauce that is gluten free. The sauce is perfect for topping a broccoli filled baked potato. Look for it at your local health food store, or contact the company at Foster Hill Road, North Calais, Vermont 05650, 1-800-434-1234. The company publishes a list of all their gluten free, dairy free and vegan products.

**PUBLICATIONS AND WEB SITES:**

“Special Diet Celebrations”, by Carol Fenster, 1999. Carol Fenster’s newest book is available through Barnes and Noble.com and other bookstores. ISBN 1889374067

WWW.ISLEUTH.COM - this site is a comprehensive search engine for locating company phone numbers and addresses.

**GLUTEN FREE GETAWAY VACATIONS from Bob and Ruth’s Gluten Free Dining and Travel Club:**

Bob and Ruth invite you to join them and others at the Super Clubs Adult Only All-Inclusive Breezes Bahamas Resort Hotel, Cable Beach, Nassau, November 15-21, 1999. At every meal special gluten-free items will be prepared, as well a regular menu items changed so that they are available to us as well. Pizza, muffins, cakes, french fries, pies, cracked conch, conch chowder and much, much more - all gluten free.

They would also like to remind members of the Gluten Free FAMILY Getaway to Boscobel Beach, Jamaica August 2-8, 1999. Time is of the essence on this trip, as they need to confirm all reservations by mid April.

For cost and detailed information either call Bob and Ruth at 410-486-0292 or email [boblevy@erols.com](mailto:boblevy@erols.com)

**CFCR SEROLOGIC STUDY UPDATE (CFCR internet update as of Jan 31, 1999))**

**Progress of study:** We have tested 1,579 samples as part of the Multicenter Serological Study for the prevalence of celiac disease in the United States. Our preliminary findings indicate a 5.8% positive finding of first degree relatives and a 3.2% positive finding of second degree relatives of celiacs. These findings are in the same range as were found in most of the European studies done in previous years.

As we initially stated in our protocol, we will need to test a total of 45,000 blood samples. The six (6) regional centers have begun minimal screening of study participants. Now we need the necessary dollars to put the study into full operation. Blood testing, supplies, and shipping charges will increase significantly in direct proportion to the samples processed.

**Progress of fund raising:** As of January 31, 1999, the University of Maryland’s Center for Celiac Research has received approximately \$231,000 in contributions and pledges. We thank all of you who have made a contribution of pledge.

As we reported in the September 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 (3) years, we would be on our way to funding this extremely important study. As of September 1st, we had received only 122 pledges in the amount of \$70,335. To date, we have received only 8 additional pledges; however, we did receive a significant number of cash contributions for which we are very grateful. "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.

We wanted to advise everyone that due to circumstances beyond our control our voice mail line 410 706-2715 crashed December 20th. The problem was corrected on January 11th; however, all messages that were left during that time were lost. We apologize for any inconvenience this may have caused:

***What you can do:***

1. If you have not made a pledge or contribution, please consider making one 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.
2. If possible, increase your current pledge or make another gift at this time.
3. Discuss the importance of this study with fellow celiacs, relatives, friends or whoever might be in a position to help. Ask them to contribute.
4. Organize discussions and/or fund-raising efforts with your local support group. For example, Tri-County Celiac Sprue from Walled Lake, MI organized a bake sale and the Greater Louisville Celiac Sprue Support Group organized a Walk/run event. Both donated the proceeds to the Center.
5. Help us to identify possible organization, companies, trusts or foundations that might be in a position to help. Please contact Pam King @ 410 706-8021 if you have any questions or need any assistance.
6. Send money contributions to the Center for Celiac Research in honor or in memory of a friend or loved one. Make a gift to the Center in honor of the new year.

***SYMPOSIUM ON CELIAC DISEASE (from the internet)***

The University of Maryland's Center for Celiac Research, the University of Chicago's Medical Center, and the University of California, San Diego are pleased to announce joint sponsorship of the 9th International Symposium on Celiac Disease to be held **August 10-13, 2000 in Baltimore, Maryland**. For the first time this prestigious meeting that attracts the world's most renowned and respected experts on celiac disease will convene in the United States. Leaders and members of celiac communities from around the world will also be in attendance. A very large attendance is anticipated and additional information will be released by the CFCR as it becomes available.

\*\*\*\*\* SPRING RECIPE EXCHANGE \*\*\*\*\*

***Hazelnut Pavlova with Coffee Cream*** (from March issue of *Better Homes and Gardens*)

4 egg whites  
1 tsp. vanilla (gluten free)  
1/4 tsp. cream of tartar  
1 1/3 cups sugar  
1 cup ground hazelnuts (filberts)  
2 oz. semisweet chocolate squares  
3 Tbsp. margarine or butter, softened  
1 3-oz. pkg. cream cheese, softened (gluten free)  
1 cup whipping cream  
3 Tbsp. coffee liqueur (if you know of one that is gluten free)  
or 3 Tbsp. concentrated instant coffee  
1/4 cup coarsely chopped hazelnuts (filberts)

Preheat oven to 300 deg.F. Draw two 8-inch circles on a foil-lined baking sheet. In a large mixing bowl combine egg whites, vanilla, and cream of tartar. Beat egg white mixture with an electric mixer on medium speed until soft peaks form (tips curl). Gradually add 1 cup of the sugar, a tablespoon at a time, beating about 7 minutes on high speed until stiff peaks form (tips stand straight) and sugar is almost dissolved. Gently fold in the 1 cup nuts. Spread half of egg mixture over each circle on baking sheet. Bake 35 minutes. Turn off oven. Let meringues dry in oven, with door closed, 1 hour.

To assemble, in a small saucepan melt chocolate and 1 tablespoon of the margarine or butter over low heat, stirring constantly. Set aside to cool. In a medium mixing bowl beat cream cheese with remaining margarine until smooth; beat in remaining sugar. Gradually add cream, beating at low speed until combined, then at medium speed just until soft peaks form. Stir in coffee. Carefully peel meringues from foil. Place on serving plate. Drizzle with the chocolate. Spread with half of shipped cream mixture. Place second meringue on top. Spread with remaining cream mixture. Sprinkle with 1/4 cup coarsely chopped nuts. Cover loosely. Chill for 2 to 24 hours. Serves 12 to 16.

***Matzah Crispbread*** (for celiacs - submitted by Bea Newell from "The Complete International Jewish Cook Book" by Evelyn Rose)

1 1/2 oz. (40 g, 1/3 cup) ground almonds  
2 pinches salt or salt substitute  
2 1/2 oz. (65 g, 1/2 cup less one level tbsp.) potato flour  
1 oz. (25g, 2 tbsp.) soft margarine  
2-3 tbsp. cold water  
more potato flour for rolling out

Preheat the oven to Gas No. 8 (450 deg F, 230 deg C). Put the almonds, salt and potato flour into a mixing bowl. Add the margarine and rub in with the fingers until the mixture resembles fine breadcrumbs. Add 2 tablespoons of the water and mix to a stiff paste with a fork. Add more water if required, then knead gently to a soft dough.

Continue to knead until the dough comes clean away from the bowl, sprinkling with extra potato flour if at all sticky. Roll out to the thickness of crispbread or matzah and cut into squares or triangles. Use a spatula to place these on baking sheets covered with silicone paper or foil. Prick evenly all over with a fork. Bake for 8-10 minutes, or until a pale gold in color.

Take off the baking sheets and allow to cool and crisp on a wire rack. Store in an airtight container. Makes 8-10 crispbread; quantities may be doubled. Hints: press dough down hard and make it thin.

**\*\* 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.