

WASHINGTON AREA CELIAC SPRUE SUPPORT GROUP NEWSLETTER



SEPTEMBER 2002

MEETING NOTICE:

Date: Saturday, September 14, 2002
Time: 2:00 p.m.
Location: Dolley Madison Library
1244 Oak Ridge Ave.
McLean, Virginia
703-356-0770

Guest Speaker: Marsha Davis, Dietitian,
Johns Hopkins Medical Center.

As always, please feel free to bring gluten free snacks to share at the meeting. Please make sure to include brand names of products used in recipes and try to be considerate of members who have other food intolerances.

Please ensure that all ingredients in both homemade and store bought items are confirmed to be gluten free by the manufacturer and are prepared in a gluten free environment.

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, Dolly Madison Blvd.) goes through McLean. After crossing the traffic light at the intersection of Churchill Road and Dolly 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 to Rte. 123 North (Dolly 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.

MESSAGE FROM THE CHAIR

Hi Everyone! As my year comes to a close I am thankful to all of you for your contributions to our group. I am extremely grateful that Juanita Ohanian has volunteered to become chair of the group as of our September 14 meeting.

In July, I had major surgery. Two weeks before the surgery I called the Dietitian at Alexandria Hospital. The Dietitian assured me that she had a list of the foods I could eat and would oversee my menu personally. The night after the surgery in came wheat crackers, no name soda, and broth full of gluten. The next day I spoke with her and all they really had that I could eat was a boiled egg and plain lettuce.

My husband was sweet to bring chicken breasts, sprite, jello, and potato chips. That is what I ate for the next two days. A good thing came out of all of this however - the Dietitian was so apologetic that she asked me to come back and review her food options and come up with a gluten free menu for Alexandria Hospital.

If you live near a hospital, please consider doing the same for October Awareness month. You would be helping a lot of people!

My complications from surgery prevented me from attending the crab pick and the manager I set it up with was off, so there was some con-

(Continued on page 2)

What's Inside?

| | |
|--|---|
| In Memoriam | 2 |
| In The News | 2 |
| Coolfont Resort and Spa | 2 |
| Food Allergen Consumer Protection Act (S 2499) | 2 |
| New WACSSG WEB site address. | 3 |
| How to Survive Hospital Food. | 3 |
| For the Newly-Diagnosed Celiac and DH'er | 4 |
| Product Information. | 6 |
| Recent Publications | 7 |
| The Online DC Area Support Group. | 7 |
| The Online Celiac Listserv Support Group | 7 |
| The Center for Celiac Research | 7 |



Message from the Chair *(continued)*

fusion. I hope that more of you will go to Captain Billy's in Popes Creek, it is very fun. They steam their crabs only in their own moisture and the seasonings are gluten free.

I would like to extend a special thank you to Carol Parrish, Nutritional Support Specialist for the University of Virginia, for making the long journey from Charlottesville to speak to our group in June. She was wonderful!

Please don't forget our next meeting with Marsha Davis, Dietitian at Johns Hopkins Medical Center.

Thank you all very much for your support and I hope all of us will be a great help to Juanita. The chair position is a lot of work, but very worth it to all of us.

Sincerely,

Hilari Moore
703-799-3764
hmoorefun@aol.com

In Memoriam

Sam Wylde Sr., the Founder and Chairman of Ener-G Foods passed away last week. He was 88 years old. The gluten free food company had been closed for a few days due to his passing, however, the company is now open for business.

In The News

- ◆ My Organic Market will be opening a new store in Alexandria, Virginia.
- ◆ Wu's Chinese restaurant in Bethesda will accommodate celiacs who bring their own soy sauce. For directions call 301-215-4668.
- ◆ The online store Gluten Solutions now sells Aunt Candice Foods that are both gluten free and casein free. The company offers cookies and cookie and cake mixes, pancake mix, and bread coating mix. For more information go to WWW.GLUTENSOLUTIONS.COM or phone 888-845-8836 for a catalogue.
- ◆ Amy's Kitchen has a frozen gluten free pizza, gluten free macaroni and cheese and frozen rice lasagna in the works. Look out for these products in your local stores.
- ◆ Thai Kitchen has reformulated their Savory Garlic Stir Fry Noodles and their Lemon Grass and Chili Rice Noodle Soup. They now contain WHEAT in a newly added soy sauce.

Coolfont Resort and Spa

by Juanita Ohanian

We recently took a trip to the Coolfont Resort & Spa at Berkley Springs, West Virginia with our granddaughters. I had read on our Yahoo listserv that the resort was very good about helping guests with the gluten free diet. We wanted to eat at their dinner buffet and made dinner reservations only after talking to the chef. He came out and talked with me, in the afternoon while they were not serving, and told me their menu for dinner that night and let me know what I could eat. He even told me that when we get there for dinner to ask for him and he would again go over the buffet with me and show me what I could eat. When we arrived for dinner, he came over to my table he took me around and explained all the dishes that I could eat—which was quite a few. Since they also cater to the Vegan diet as well, all the broths were vegetable-based—even in the rice and all of the vegetables, so there was no gluten to be concerned with. He made my soup from scratch in the kitchen and they brought it out to me without gluten because the soup that they offered at the buffet that evening was not gluten free.

The chef's name is Ned Sparks, Executive Chef, Coolfont Resort Spa & Wellness Center. He even has email: chef@coolfont.com and their website is: www.coolfont.com to check it out for a visit. They have cabins, lodges and houses that you can rent for a weekend or whatever. Since the drive is about 1 1/2 hours, we just drove up for the day and stayed for dinner. They also have an 800 number. 1-800-888-8768. The resort caters to healthy diets and holds seminars in their conference center on wellness, diets, quit smoking, how to reduce stress and many more. They have a spa center and swimming pool and give great massages.

I had a choice for dinner that night of: prime rib, mahi mahi, scallops with mushrooms and onions, salmon, mixed vegetables with squashes, brown rice, salad bar, oysters on half shell, boiled shrimp. For dessert, they brought me ice cream and a dish of fresh raspberries to top it off. I probably left out a few things that I forgot. It was certainly more things than I could eat. I do not eat red meat and do not care too much for fish, but the scallops were great.

The buffet costs \$23.00/person for adults and half of that for children. They also have a children's menu with things kids like to eat for much less under \$5.00. The meal includes tea and lemonade and coffee. They also serve wines at an additional cost (about \$5.00/glass).

Food Allergen Consumer Protection Act (S 2499)

There is a very important Bill that will be voted upon in the Senate Health, Education, Labor and Pensions (HELP) committee when the Senate reconvenes this Fall that could significantly improve the quality of life for those with food allergies and intolerances. The Bill was to be voted on in late July, but was postponed due to time constraints, so it is even more important to act quickly since we are getting a second chance to let our voices be heard on the Hill.



The Food Allergen Consumer Protection Act (S 2499) has been introduced by Senator Kennedy and Representative Lowry and in effect, would amend the Federal Food, Drug, and Cosmetic Act to require food labels to identify known food allergens contained therein or be deemed misbranded, without regard as to whether or not the presence of an allergen is intentional or unintentional. The language has specifically included gluten (in wheat, rye, oats and barley) as a known allergen, which is significant and a HUGE step forward for those with celiac disease.

Unfortunately, members of the food industry are inundating the Hill to kill the Bill, which is why it is critical for you, as a celiac, and your friends and family members, to help to push this Bill through committee and urge your Senate representatives on the HELP committee to support this Bill. The Hill has already been commenting on how many phone calls they have already been receiving, but the Bill is still at risk.

Because the food industry is already swarming the Hill, specifically targeting Democrats, it is even more critical in these last hours to collectively let our voice be heard. The Senators that should not be emailed or called are Kennedy (MA) and Clinton (NY), since they are both sponsors of the Bill.

You can contact your state Senator on the committee by going to www.congress.org, then click on U.S. Congress, then click on select a committee then scroll down till you get to Health Education, Labor and Pensions, select this and then hit go. This will give you the list of all senators on this committee.

If there are any senators from your state, you should contact them directly. If not, you should contact the ranking minority member or other senators in the HELP committee (ie. District residents). You can send an email message directly through this website. Just select the specific senator and it will take you to a new page with their information including a link to e-mail them if they accept e-mails. Otherwise you could telephone them to let them know how you would like them to vote. A phone call only takes a few minutes.

Democratic HELP Committee Members

Senator Christopher Dodd (D-CT) (202) 224-2823
Senator Tom Harkin (D-IA) (202) 224-3254
Senator Barbara Mikulski (D-MD) (202) 224-4654
Senator Jeff Bingaman (D-NM) (202) 224-5521
Senator Paul Wellstone (D-MN) (202) 224-5641
Senator Patty Murray (D-WA) (202) 224-2621
Senator Jack Reed (D-RI) (202) 224-4642
Senator John Edwards (D-NC) (202) 224-3154

Republican HELP Committee Members

Senator Judd Gregg (R-NH) (202) 224-3324
Senator Bill Frist (R-TN) (202) 224-3344
Senator Michael B. Enzi (R-WY) (202) 224-3424
Senator Tim Hutchinson (R-AR) (202) 224-2353
Senator John Warner (R-VA) (202) 224-2023
Senator Christopher Bond (R-MO) (202) 224-5721
Senator Susan Collins (R-ME) (202) 224-2523
Senator Jeff Sessions (R-AL) (202) 224-4124
Senator Mike DeWine (R-OH) (202) 224-2315

The following is a sample letter that you or your friends and family could email:

Dear Senator XXXXX:

I am writing to urge you to support passage of the Food Allergen Labeling Bill (S 2499 IS) as it is written.

The passage of Representative Lowry and Senator Kennedy's Bill, the Food Allergen Consumer Protection Act, is important to the health and safety, not to mention quality of life, of millions of persons suffering from food allergies and intolerances. This is especially important for the one in 150 people diagnosed with gluten intolerance (celiac disease.) I know (or I am one of) the many people who suffer severe consequences when they accidentally ingest gluten in store bought food due to poor labeling on packages. They (I) should be able to know exactly what is in the food they (I) buy.

Thank you for your support.

Or a simple phone call:

Hello, my name is _____. I am from _____(city), in _____(state). I would like Senator _____ to support S.2499 as it is written when it comes before the HELP committee next week. Thank you.

New WACSSG WEB site address

Please note that the WACSSG has changed its web site address. The site will still have current news for the group and past newsletters. The new address is: WWW.DCCELIACS.COM.

NOTE: The following two reprinted articles contain information this group may not agree with. If you have questions in regards to those items, please bring them up at a future meeting or call one of the group contacts.

How to Survive Hospital Food

by Kit Mooso, Dietetic intern diagnosed with celiac disease. Reprinted with permission from GrainWise newsletter of the Nashville Celiac Support Group, Vol., II, No. 1, Winter 2002 Issue.

As if a hospital stay isn't stressful enough, how does a Celiac guarantee the hospital food they are served isn't going to make them sicker?

As with any other dining situation – do your homework. The first step is to always double check with your physician to be certain he/she knows to order a gluten-free diet for you.

Then, call the hospital prior to your admission and ask to meet with your hospital's Registered Dietitian (RD) to review the gluten-free menu. Be aware that you may be charged for this meeting; it is quite possible that your phone conversation may be all that is required for the dietitian to prepare for your visit. Be ready to verify product brands, recipes, ingredient listings, and methods of preparation. Red-flag any questionable foods and preparation issues. The dietitian will make recommendations for your patient chart and inform the kitchen of your special dietary requirements. The hospital may have



the capability to save your dietary files for your next visit.

The dietitian should already be aware of your needs, but you will still want to be prepared by bringing along helpful information i.e. gluten-free product listings, forbidden ingredient listing (www.celiac.com/forbidden.html), gluten-free medicine listings. (However, this list may be misleading and confusing for a newly-diagnosed celiac.) The Celiac Sprue Association has a Health Professional Packet available free of charge by calling 402-558-0600 or ordering online at <http://www.csaceliacs.org/order.html>. The Gluten Intolerance Group also has a Hospital Guide available for \$15. You can Order by calling 206-246-6652 or online from <http://www.gluten.net/products.asp>.

Be aware that preparing celiac-safe food in a hospital setting can present some tremendous logistical problems in preventing cross-contamination. As a patient, you need to assume responsibility for initiating the communication between the departments, educating the staff of your restricted dietary needs, and being your own advocate to work toward this common goal.

A few hints for hospital safe dining include: Remember that Cream of Rice looks similar to Cream of Wheat and mistakes can happen in the kitchen.

- ◆ Consider all soups and stews as contaminated to avoid mistakes.
- ◆ Tossed salads with vinegar and oil dressings only (if vinegar is apple cider vinegar).
- ◆ Plain meats, rice, potatoes and vegetables are best.
- ◆ Avoid deli meats as many are contaminated with gluten-containing flavor enhances.
- ◆ Avoid seasonings except for the salt and pepper on your tray.
- ◆ Canned or fresh fruit and vegetables are acceptable.
- ◆ Avoid fried potatoes and French fries stick with baked or boiled (plain).
- ◆ Fresh or canned fruit is appropriate for dessert, avoid ice cream and sherbet as they contain milk (if you are lactose intolerant).
- ◆ Ask to be served butter, not margarine (if you are not lactose intolerant).

If you don't feel comfortable eating hospital food, you can suggest they purchase already prepared gluten-free meals that are sealed and just need to be heated. These will reduce the risk of cross-contamination during preparation. Sources for prepared meals include Dietary Specialties, 937-895-4446, www.dietspec.com; Dining by Design, 402-327-8880, www.diningbydesign.com; Specialty Food Shop, 416-977-4360, www.specialtyfoodshop.com. You can also consider supplying your own food. During your meeting with the dietitian, you can verify storage availability and cooking arrangements.

If you will be on a clear liquid or full liquid diet, you will need to verify those food items as well to avoid gluten-containing products. Be wary of the broth served as part of a clear liquid diet. It might contain gluten. Fruit juices and Jell-O are safe, as is soda and many other drinks. A full liquid diet includes milk, pudding, yogurt, milkshakes, ice cream, etc. Beware of regular milkshakes, custards, puddings, etc. Most of these purchased through food service companies

will contain gluten. Ask the dietitian for Ensure liquid and pudding nutritional supplements because they are gluten-free. Avoid Ensure with Fiber as it contains oat fiber. Nutricia also has a gluten-free, nutritionally complete, elemental diet called E028 Extra available at SHS North America 800-365-7354 or online at <http://www.shsna.com/html/gastrointestinal.htm>

A hospital setting is a difficult place to serve safe, nutritious and balanced meals to a celiac patient. As a patient, a few important things to remember are:

1. Order your food as plain as possible.
2. Avoid foods whose ingredients must constantly be verified, like mayonnaise, salad dressings, deli meats, puddings, ice cream, etc.
3. Request that "Note Celiac Food Restrictions/Gluten-Free food only" be placed in your file and on your chart.
4. Make sure you have someone present with you after surgery to be your advocate for gluten-free food in case you are still groggy from the anesthesia.

Don't forget that medications can also contain gluten. Discuss this issue ahead of time with your physician then contact the hospital pharmacist and make him/her aware of the problem. Ask the pharmacist to verify all your medications with the manufacturer before dispensing. Take a copy of the Stokes Pharmacy "Celiac Disease: A Guide Through the Medicine Cabinet" with you. You can purchase it for \$39.95 at 800-754-5222 or online at <http://www.stokesrx.com>. CSA also has a Drug Information Guide online at <http://www.csaceliacs.org/pharmaceuticals.html>

And last but not least, if you have Dermatitis Herpetiformis, you may want to check into any topical medications, adhesive bandages (glue), or lotions if you react through skin contact. Remind your physician of your sensitivity and talk to your nurses about it. Nurses are always a great resource for your care.

Sources:

Janet Lowery, Nashville, TN
Glenda Dixon, M Ed, R.D., L.D.N., The Thomas
F. Frist, Sr. Heart Wellness Center,
Centennial Medical Center

For the Newly-Diagnosed Celiac and DH'er

Step-by-Step: Beginning the Gluten-Free Lifestyle

The following outline is reprinted with the permission of the Houston Chapter and is written by Janet Y. Rinehart and Lynn Rainwater.

BEGIN

- ◆ A definite diagnosis of Celiac Disease (screening blood tests plus endoscopic biopsies) and/or Dermatitis Herpetiformis (skin biopsy) requires your lifetime commitment to a gluten-free diet.
- ◆ Take full advantage of your local celiac chapter membership. Their group leaders and contacts have experience with the gluten-free diet. They can help you acclimate to the changes in your lifestyle. They welcome your questions.



- ◆ Order the CSA Cooperative Gluten-Free Commercial Products Listing (\$10)

It will greatly simplify your task of identifying gluten-free products. Join our parent organization, CSA/USA, P. O. Box 31700, Omaha, NE 68131-0700. The full membership (\$28) includes a quarterly newsletter, Lifeline, and an extensive Handbook, which can be an important part of your orientation.

- ◆ Start a Food Diary with notations about both investigated “good” brands and those which do not seem to agree with you. Write down every thing you put into your mouth - food, liquids, and medications - and questionable ingredients, as well as your body’s reactions. You may see a pattern indicating other food sensitivities.
- ◆ Sort out your Pantry and refrigerator. Stock with approved goods and produce. Give away non-gluten-free items — like baked goods, pasta, soups, etc., or keep them on separate shelves for family members who are not gluten intolerant. You may want to use special stickers to differentiate gluten-free items.
- ◆ Learn to read all labels to discern possible gluten.
- ◆ Understand that you will make unintentional mistakes as you are learning and may cause some symptoms to reoccur. Unfortunately, that’s part of the process. Just get back to basics and do the best you can. Gluten is hidden in so many products.

READING LABELS

- ◆ DO USE: Flours from rice, corn, potato, nuts, beans, tapioca, sorghum, or quinoa.
- ◆ AVOID ALWAYS: Wheat, barley, rye, oats, spelt, triticale and kamut.
- ◆ HVP (hydrolyzed vegetable protein), HPP (hydrolyzed plant protein), and TVP (texturized vegetable protein) may contain wheat. If source is not shown, investigate.
- ◆ The terms “modified food starch”, “modified starch” or “gelatinized starch” should always be investigated unless the source of starch is included, or the food item has been investigated.
- ◆ The word “starch” alone on a food label is supposed to indicate that corn is the source of the starch.
- ◆ The word “vinegar” alone on a food label should denote apple cider vinegar.
- ◆ These ingredients contain gluten: Bran, bread crumbs, bulgur, cereal extract, couscous, cracker meal, durum, durum flour, enriched flour, farina, gluten, graham flour, high gluten flour, high protein flour, malt or cereal extract, malt vinegar, matzo, matzo meal, semolina, soft wheat flour, pastas, gluten flour, vital gluten, wheat (bran, germ, gluten, malt, starch), whole wheat berries, whole wheat flour, barley grass, orzo (rice-shaped pasta).
- ◆ These items usually contain gluten and should be questioned: Most soy sauces, brown rice syrup, flavorings in meat products, coating mixes, communion wafers, imitation seafood (surimi), marinades, roux, sauces, self-basting poultry, canned soups and soup bases, stuffings, thickeners.
- ◆ AVOID: Malt flavoring, a very common ingredient in cereals and elsewhere, is usually from barley. Do not use products with malt or malt flavoring.

- ◆ AVOID: Roquefort or Bleu cheeses that may be contaminated from its bread starting material.
- ◆ QUESTION: Dextrin, MSG if product is imported, vegetable starch; perhaps artificial or natural flavorings.
- ◆ Other Sensitivities: Certain products are questionable for celiacs, not because of gluten, but some other issue having to do with an individual sensitivity. For example: New fat replacers Olean and Olestra are not recommended for people with digestive problems; they may have a laxative effect. Similarly, guar gum does not contain gluten, but larger amounts may have a laxative effect. Celiacs tend to have other food sensitivities.
- ◆ Cross contamination is a real problem in terms of manufacturing, conveyor belts or shipping; at restaurants and at home with bottled/canned products everyone uses (use one implement for dipping and another for spreading), toaster, cooking; in restaurants on grills, using same spoons, picking off croutons instead of none to start with, etc. Be aware and vigilant.
- ◆ Note that manufacturers may replace fat in some no-fat or low-fat products with starch of indeterminate source. Therefore, no-fat products are probably not a good choice.
- ◆ If in doubt, leave it out! Wheat free is not necessarily gluten free.
- ◆ Always read all labels! Manufacturers may change ingredients frequently based on the lowest cost provider.

WAIT

- ◆ You may want to wait 2 to 4 months to use milk products. Many newly-diagnosed celiacs are intolerant to lactose (with similar symptoms to gluten ingestion). The lactose in milk does not damage the villi, but the damage to the intestine may interfere with the production of the enzyme lactase, the enzyme used by the body to break down lactose (milk sugar). After the gut heals, celiacs who were not lactose intolerant before developing CD usually regain the ability to tolerate lactose.
- ◆ Wait to use fatty foods like bacon & ham. Sick celiacs tend not to digest fats well.
- ◆ Wait to try any ‘pseudograins’ like millet, amaranth, buckwheat.. Although these grains in pure form are probably gluten free, these may be contaminated with wheat. There are so many great recipes using the common substitutes that you need not use any of these at the beginning.
- ◆ Celiacs tend to be susceptible to other food sensitivities. After milk, the most common one is soy intolerance.

TOOLS

- ◆ Invest in good gluten-free cookbooks. The CSA cookbooks, Bette Hagman’s Gluten-Free Gourmet series, and Carol Fenster’s series (with food values and substitutions) are excellent resources. There are many more. If your child is the celiac in your family, collect a variety of cookbooks and teach him/her to cook. Engage your spouse to learn to shop and cook gluten free. In order to stay committed on any special diet, you will be more satisfied with a variety of foods. Try at least one new recipe a week.
- ◆ Get used to calling manufacturers. An important tip when investigating products is to first ask whether the product contains wheat, barley, rye or oats, or any derivatives - rather than asking initially whether something is gluten free. (Some manufacturers lump corn



gluten into a big “gluten” category, and that complicates the picture.) You will find most company representatives are friendly and helpful. However, many companies don’t want to be committed to saying something is gluten free because of possible litigation.

- ◆ Manufacturers can and do change ingredients and suppliers at any time and without warning, so always read the labels! Unfortunately, at this time the label cannot be the final determination of what truly is gluten free and what’s not. Some companies have full disclosure on labels, but not many.
- ◆ Medications - You can’t necessarily tell by labels whether a medication is gluten free. Investigate with a manufacturer the source of any starch in both active and inactive ingredients. “Celiac Disease: A Guide Through the Medicine Cabinet” is available from Stokes Pharmacy, 639 Stokes Road., Medford, NJ 08055; phone 800/754- 5222; or order on line at www.stokesrx.com. The current edition is based entirely on information received directly from the manufacturers. Price: \$39.00 each plus \$3.95 shipping.

SYMPTOMS

Diarrhea:

If you’re still having diarrhea, perhaps try a softer diet of mashed potatoes, bananas, well-cooked soft vegetables, apple sauce, GF bread (warmed in microwave or toasted), soft cooked chicken or fish, eggs, etc., for a couple of weeks. Avoid fatty foods like bacon or ham. Avoid milk products and ingredients. A short course of the over-the-counter medication Imodium may be helpful. If symptoms persist, consult your GI specialist.

Constipation:

If you’re suffering with constipation, gradually add more “al dente” vegetables and fruits that contain fiber. If possible, begin a walking plan. Exercise will help digestion. You may find Metamucil will balance out the system, as needed.

Dermatitis Herpetiformis:

Skin eruptions for celiacs with DH usually take longer to disappear than the digestive symptoms. Work with your dermatologist to ensure you use the smallest amount of dapsona possible to provide relief from symptoms. Remember that the GF diet must be strictly followed to achieve remission. Iodine (in salt, some fish, etc.) may exacerbate symptoms.

MEAL PLANNING

. Plan meals before you get to the grocery store. The first couple of months will be frustrating when going grocery shopping because you are new at reading labels. Yes, gluten-free specialty products are more expensive; that’s just a fact.

- ◆ To save time and trouble, plan to make as much of the meal gluten free as possible. The celiac will appreciate not feeling different, and the cook will not have to make two meals. The “civilians” in the family can add gluten- containing bread or dessert items as they want.
- ◆ Start out with simple meals, rather than combination dishes.
- ◆ Pay attention to all food sensitivities of your family.
- ◆ Make a rough draft of your meals for the next week, taking into consideration the family’s schedule. Plan for the main entree, veges, fruit & salad. Plan one new interesting GF dessert per week.
- ◆ Use the CSA Commercial Product List to evaluate brand names of

products. Then draw up a brand-name grocery list based on the recipes you plan to use. Working on a weekly basis helps you eliminate extra trips to the grocery store, which will in turn cut down on the frustration of looking at labels again and may save money.

- ◆ Be sure to plan for the family’s snacks, both gluten free and non-GF. When you have GF items readily available (like nuts, popcorn, fruit, raw cut-up vegetables, etc.), you will be less tempted to “cheat” when you are starving.
- ◆ Try at least one new gluten-free recipe a week. Mark your cookbooks with comments, or develop a list of your favorites with the cookbook page noted. Include the family in meal planning. What kind of meals do they like? Try to find good gluten-free substitutes.
- ◆ Make good use of your freezer. Freeze single portions of dinner main dishes to use as lunch items. Freeze dessert items for snacks.
- ◆ There are many companies that manufacture gluten-free specialty products. These products are more expensive than the comparable; that’s just a fact. However, many of the mixes, frozen meals, and already-baked goods are quite good and make your life easier. See the CSA Products booklet for a listing of some of the specialty food manufacturers. (The DC area has several health food store chains: Fresh Fields/ Whole Foods Market, Healthways, My Organic Market, in addition to several individually owned health food stores.) On the Web there are several on-line grocery stores with extensive GF product lists. You may want to consult support group members to get their opinion of some of the products before you invest in a big order.

ALWAYS READ ALL LABELS!!!

SUPPLEMENTS

- ◆ Find a gluten-free multivitamin; for example, Freeda brand, Nature Made or others.

CONCLUSION

Continue your education about Celiac Disease and the Gluten-Free Diet. Attend a national celiac conference. Former Surgeon General Dr. C Everett Koop has said, “The best prescription is knowledge.” Your success in going gluten free will ultimately get you back to good health. Don’t cheat. Every single bit of gluten is doing some damage in your small intestine and promoting inflammation. Never give up. You can do it. Foster a support system within your family and local celiac support group. Don’t forget to utilize your sense of humor; some day a guest will ask for your recipe (GF)! Stem depression by thinking of, reaching out to, and helping others. Do unto others as you would have them do unto you.

Product Information

The following items have been verified for their gluten content, but as ingredients can change, please read labels. The consumption of alcohol is a personal choice and the inclusion in this newsletter is for informational purposes only.

- ◆ All of TGI Friday’s Blenders and On the Rocks drinks are gluten free. 800-767-3123.
- ◆ Vlassic pickles, sauerkraut and peppers are gluten free. For those celiacs concerned about vinegar, these products are made with corn vinegar.
- ◆ Wrigley chewing gums are gluten free.



- ◆ All flavors of Ore Ida's new Funky Fries are gluten free. They include Sour Cream and Jive, Crunchy Rings, Cocoa Crispers, Kool Blue and Cinna-sticks. 800-892-2401.
- ◆ Pillsbury does not offer gluten free lists of their products, however, the company states that "all sources of gluten such as wheat, rye, malt, barley and oats are declared on Pillsbury Brand labels if they are used as part of the product ingredients. This includes gluten such as wheat, rye, malt and barley and oats that is present as part of another ingredient, such as natural or artificial flavors, natural or artificial colors and spices." Pillsbury uses shared equipment when producing their products.
- ◆ Both the vanilla and chocolate softserve ice cream at Dairy Queen are gluten free.
- ◆ Malt-O-Meal currently produces four products to be gluten free. These include: Malt-O-Meal Puffed Rice cereal, Malt-O-Meal Corn Bursts® cereal, Malt-O-Meal Fruity Dyno-Bites™ cereal, Malt-O-Meal Cocoa Dyno Bites™ cereal. These products may be produced on the same production line as a gluten containing cereal. However, our lines are shut down and sanitized in between each production run to prevent cross contamination. Please remember to check ingredient statements each time you purchase a product to ensure no changes have occurred.

Recent Publications

- ◆ *Celiac Sprue in Current Concepts*, New England Journal of Medicine (Jan. 17, 2002, Vol. 346, No. 3, pp. 180-88.) This article, by Richard J. Farrell, MD and Ciaran P. Kelly, MD, gives you an in depth explanation of celiac disease, clinical manifestations, diagnoses, treatment, etc.
- ◆ There is an article in the August 2002 issue of a dental hygiene magazine called Access that is written specifically for hygienists and dentists on the precautions that they must take when treating celiac patients.

The Online DC Area Support Group

Events and information of interest to people with Celiac Disease/Sprue or parents of children with Celiac Disease in the Washington, DC, Northern Virginia or Suburban Maryland area.

To subscribe, send an email to the following address:

DCCeliac-subscribe@yahoogroups.com

Or go to www.groups.yahoo.com/group/DCCeliac.

Also, you must have a Yahoo! ID in order to access the Group Website. Establish a Yahoo! ID by going to <http://groups.yahoo.com/convwiz>.

The Online Celiac Listserv Support Group

To subscribe, send an Internet email to the following address:
LISTSERV@MAELSTROM.STJOHNS.EDU

In the body of the email put the following:
SUB CELIAC followed by your first and last name

For example: SUB CELIAC JANE DOE

The Center for Celiac Research

University of Maryland Center for Celiac Research is an institution engaged in clinical care, diagnostic support, education, and clinical and basic science research in Celiac Disease.

The paramount goal of the Center for Celiac Research is to increase the awareness of celiac disease in order to provide better care, better quality of life, and more adequate support for the celiac disease community. In order to achieve these goals the Center for Celiac Research has the following primary missions:

- 1 To support cutting-edge, innovative, interactive, multidisciplinary research in all aspects of celiac disease including (1) epidemiology research to establish the prevalence of the disease worldwide; (2) basic research (pathophysiology, autoimmune mechanisms, inflammatory processes, genetics); (2) clinical research (clinical spectrum of celiac disease, association with other autoimmune diseases, complications including infertility, osteoporosis and malignant transformation); (3) challenges of treatment of the disease (psychological impact of the diagnosis on family dynamics and on the acceptance of the gluten-free diet, toxicity of traces of gluten in both symptomatic and asymptomatic patients);
- 2 Increase the awareness of the disease among (1) health care professionals including primary and subspecialty physicians, nurses, nutritionists and dietitians; (2) public and private health care providers; (3) food regulatory agencies; (4) legislators; (5) general population;
- 3 To provide state-of-the-art education opportunities for medical students, graduate students, post-doctoral fellows and visiting scientists in one or more of the broad areas outlined as mission 1; to offer educational exchange opportunities to international students, clinicians and scientists particularly from the developing countries
- 4 To provide consultation in the area of basic and clinical aspects of celiac disease, advise on the most appropriate algorithm for diagnosis and treatment of the disease
- 5 To implement the diagnostic tools for celiac disease including newly developed diagnostic strategies and international implementation of the standardization of these tools
- 6 To provide expert consultantship or committee membership to both national and international agencies as well as industry engaged in activities in celiac disease

For more information:

University of Maryland
Center for Celiac Research
22 S. Greene Street, Box 140
Baltimore, MD 21201
410-328-6749
www.celiaccenter.org



THE WASHINGTON AREA CELIAC SPRUE SUPPORT GROUP

Membership dues are \$15 annually, payable during the month of February each calendar year. The newsletter is published four times a year and provides support for celiacs, parents of celiac children, and patients with dermatitis herpetiformis. We currently have over 300 members within the Washington DC Metropolitan Area. Reproduction of any material is allowed, but please indicate the source. Membership information is solely for our members and is not to be used for any other purpose

Newsletter printing courtesy of Nebel Printing, Inc. 12160 Nebel Street, Rockville, MD, 301-881-4016, www.nebelprint.com.

CONTACTS:

| | | | |
|--------------------|--------------------|----------------|-------------------------|
| Chairperson: | Juanita Ohanian | (301) 881-4019 | jaonebel@aol.com |
| Treasurer: | Pam Tufts | (703) 968-7192 | ptufts@erols.com |
| Newsletter Editor: | Joany Janicki | (301) 581-1155 | jcjanicki@earthlink.net |
| Mailing List: | Joanne Zins | (703) 378-8116 | |
| Webpage Editor: | Kathy Poneleit | (301) 309-0912 | poneleit@hotmail.com |
| Hospitality: | Danielle Clarke | (301) 620-0075 | pianodc@aol.com |
| Virginia Contact: | Hilari Moore | (703) 799-3764 | hmoorefun@aol.com |
| Maryland Contact: | Joany Janicki | (301) 581-1155 | jcjanicki@earthlink.net |
| N. Shenandoah, VA | Ruth Arcuri-Kovacs | (540) 536-4165 | rakovacs@visuallink.com |

NEW WACSSG Website: www.dcceliacs.com

CELIAC HOTLINE COMMITTEE

Do you have a celiac question? Call a hotline member:

| | | |
|---------------------------------|----------------|---|
| Joany Janicki, Bethesda, MD | (301) 581-1155 | Has celiac disease |
| Bea Newell, Bethesda, MD | (301) 365-6261 | Has CD and follows a Kosher diet |
| Daneille Clarke, Frederick, MD | (301) 620-0075 | Has celiac disease Pianodc@aol.com |
| Pam Tufts, suburban VA | (703) 968-7192 | Has Dermatitis Herpetiformis and CD Ptufts@erols.com |
| Hilari Moore, suburban VA | (703) 709-1465 | Has CD and mother of celiac children hmoorefun@aol.com |
| Debbie Fickenscher, suburban MD | (301) 972-6045 | Daughter w/ Down Syndrome and CD LFlickenscher@erols.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, current medical information, or an article you would like to write for the newsletter on a personal experience, please forward it to:

Joany Janicki
5805 Phoenix Dr.
Bethesda, MD 20817
Email: jcjanicki@earthlink.net
301-581-1155.

DISCLAIMER: As always, the information contained in this newsletter is provided solely for the benefit of the reader without endorsement or recommendation. This newsletter is a general information resource not intended for use in medical diagnosis or treatment. Questions should be directed to your personal physician. Please verify all information.



**Washington Area Celiac
Sprue Support Group**

Postmaster: Please return undelivered copies to:
JOANNE ZINS, 4723 Logwood Lane, Chantilly, VA 20151