

WASHINGTON AREA CELIAC SPRUE SUPPORT GROUP NEWSLETTER



MARCH 2002

MEETING NOTICE:

Date: Saturday, April 13, 2002
Time: 2:00 p.m.
Location: Dolley Madison Library
1244 Oak Ridge Ave.
McLean, Virginia
(703) 356-0770

Guest Speaker: Connie Sarros will be introducing her new cookbook, "Wheat Free Gluten Free Reduced Calorie Cookbook."

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.

MEETING AND EVENTS CALENDAR

May – National Walk for Celiac Disease, 10K, May 4, 2002, Fort Hunt Elementary School, Alexandria to Mt. Vernon.

June – June 29, 2002, WACSSG Meeting, Davis Library, Bethesda. 2pm.
Guest Speaker – Dietitian Carol Parrish, University of Virginia.

July – July 2002, TBA, Old Fashioned Southern Maryland Crab Feast.

DIRECTIONS

From Maryland, points north: From the Beltway (495) take exit 46B to Rt. 123 North Chain Bridge Road. Proceed approximately two miles. After Crossing Old Dominion Drive, turn left on Ingleside Avenue., 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 Rt. 123 exit toward McLean. Rt. 123 (also Chain Bridge Road, 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 Avenue. 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 (Rt. 267) toward Washington. Take Exit 10B/ Rt. 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 Avenue to enter the parking lot.

Message from the Chair

Hi! It's February already - I cannot believe it! Only 3 months to go before our 10K walk. Andrea Howe and the rest of the volunteers have been hard at work - if you have some free time or can collect pledges, they would really appreciate all you can do to help.

It seems that our hard work is paying off. In the last month, we have had six new celiacs diagnosed. The Walk will also help to bring about more awareness, I am sure.

Please remember all of our upcoming events. Your support and attendance makes this a great group. So, please come!

Special thanks to Santa Fe East in Old Town, Alexandria. They have been just fabulous to the group and have made the nights out a lot of fun. If you find yourself in Old Town, please patronize them and ask for Neal (mgr) or Edwin (chef). They said if you call them in advance they can provide you with a gluten free meal and you can even take out gluten free cheese cake (703-548-6900).

What a big thank you I owe to Linda Etherton for the terrific Pasta demonstration. She made

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Message from the Chair *(continued)*

it look so easy. And it was nice of Grandma Whimsey's Carol Roberts to include us in her business decisions.

If you have an idea for a meeting, space for it to take place or a restaurant for us to try, please call or email me.

Soon we will have all the information back from our surveys and will summarize them for you. See you at the next meeting on April 13!

Hilari Moore

8900 Battery Road
Alexandria, VA 22308
703-799-3764
email: hmoorefun@aol.com

Call For Dues

If you have not paid your dues for 2002, please send \$15 to Pam Tufts, 4719 Logwood Lane, Chantilly, VA 20151.

COMING EVENTS:

**March 3, 2002
CSA/USA Resource Unit #2074 Meeting
and Reduced Calorie Buffet**

The CSA/USA Resource Unit #2074 Meeting & Reduced-Calorie GF Buffet on Sunday, March 3rd, at 3:30p.m. will be held at the Key Bridge Marriott, 1401 Lee Highway Arlington, VA.

- Have you put on weight since going on a gluten-free diet?
- Do you need to cut down on fat and cholesterol intake?

Connie Sarros, the speaker for our meeting will address these questions and discuss her 2 self-published books: "Wheat-free Gluten-free Dessert" and "Wheat-free Gluten-free Reduced Calorie Cookbook." The reduced calorie cookbook contains 472 new recipes that are labeled as low fat, low cholesterol, low sodium and/or dairy-free. At our past meetings, this has always been a topic which many of us have requested information on.

The meeting will begin at 3:30 with a social mixer that will include GF snacks and appetizers.

Connie will speak from 4 to 5, and then, we will enjoy a fabulously prepared GF dinner buffet.

You'll have the chance to taste the delicious reduced calorie recipes before you buy the book!

Non-Alcoholic Beverages are included in the price below. GF Alcoholic Beverages will also be available at the cash bar (not included in the price).

Reduced Calorie GF Buffet! Cost: \$28 per adult (includes Tax & Gratuity)

All entrees will be prepared by Marriott Chef Kevin Halpin with recipes provided from Connie Sarros "Wheat-free Gluten-free Reduced Calorie Cookbook". Entrees include:

- Dilled Flounder
- Pork Roast with Apricot Stuffing
- Tapas
- Poached Salmon

- Raspberry Chicken
- Paella with Saffron Rice
- And Many More

Please RSVP by February 24th
Call 703-526-1682 email: oren.molovinsky@marriott.com or contact Chairperson Daniel DuBravec at 703-471-5047 or email: mvineyard40@aol.com

**March 3-4, 2002
Become a Patient Advocate**

by Cynthia Kupper, RD, CD, Gluten Intolerance Group

I was asked by the Executive Board of the Digestive Disease National Coalition (DDNC) to invite members of the celiac community to once again have the opportunity become patient advocates with the DDNC 2002 Public Policy Forum in Washington DC, March 3-4, 2002.

Last year the celiac patient advocates had an impact on the DDNC because of our number of patient representatives. They want to see us bring just as many people again this year. That is what we did right!

What we did wrong, was not understand the importance of speaking the same message. There is power in numbers and power in partnering with other patient groups. The DDNC provides us power by advocating with other organizations like ours that have similar issues and concerns. Sending a common message to congress shows credibility and value. If congress hears one message over and over, they get it. If we go with personal 'agendas' instead of a united message (even within the celiac community) we are not respected, often not heard and as a result, do more damage to our personal cause and that of the DDNC. If you want to advocate with a personal agenda, it is recommended by professional health advocates that you do it through personal visits not tied to a coalition group.

If we are to advocate as part of the DDNC, we must speak their message. As well, if we are to speak about celiac disease we must all be sending the same message. The national groups will work together to develop a common message about celiac disease.

If you are interested in advocacy, please support the Public Policy Forum. For more information write: gig@gluten.net

If you have an interest in participating in the advocacy efforts on the Hill, please contact Cynthia Kupper no later than February 22, 2002.

Cynthia Kupper, RD, CD
Exec. Director - Gluten Intolerance Group
Executive Board Member - DDNC

(Editor's Note: Last year we had several members attend this event. For those interested in attending this March, it would be extremely helpful if we were to organize and prepare a statement as a group. According to the by-laws of the WACSSG, we cannot lobby in the name of the group, but we can certainly lend our support to the DDNC and GIG.)

p.s. more information about the DDNC on page 5

May 3, 2002 Pre-Walk Rally

Special 10K Walk Dinner Rally and Discount Hotel Rates in Alexandria on May 3rd:

Our good friends at Santa Fe East, Pitt Street, Alexandria, VA, have offered to set up a pre-walk rally with gluten free food the night



before the walk. This will be great for people who are local and those who choose to stay the night before the walk in Alexandria. The details of the dinner are still being worked out, but will be sent out in the next newsletter.

Two area hotels have agreed to give us special rates for the night before the walk. The Hampton Inn (Richmond Highway off 95 and Rt. 1 exit) has given us a discount rate of \$109 for the night. Ask for Hilda when calling to make reservations.

Days Inn (right down Richmond Highway from Hampton Inn) has offered a \$60 per night rate if we reserve 10-15 rooms.

National 10K Walk for Celiac Disease on Saturday, May 4, 2002, Update:

The Center for Celiac Research has invited us to participate in the University of Maryland, Center for Celiac Research's First Annual National Walk for Celiac Disease. It will take place in cities across the country on Saturday, May 4th, 2002.

Celiacs from all over the U.S. need to unite to get celiac disease recognized in this country. This walk, along with national publicity the CFCR is planning, will be a giant step toward awareness.

The walk in the DC area will take place on May 4th, at 8:00 am. The walk will start at the Fort Hunt Elementary School in Alexandria and will go to Mt. Vernon and back. The total distance is about 6.5 miles. There will also be a shorter walk available. We hope to see lots of WACSSG members walk with their family and friends. If you or friends (doctors, church, school, scout troop) cannot participate, please ask them to make a donation pledge for the cause. Your participation is very important. If we get a minimum of 300 participants, we will be able to get media coverage and further our goal of advocating awareness of Celiac Disease and to support the research being conducted at the Center for Celiac Research.

Registration before April 15th will be \$15, and \$20 after that date. All registrants will receive a T-shirt. Walk packets will be mailed out to all WACSSG members in March that will include an information sheet, registration brochure, pledge sheet, and current research updates from the CFCR. Also included will be our "What is Celiac Disease" brochure for you to use to educate those who you ask to participate on the Walk. This information will also be available on the internet at www.celiacwalk.org.

Media kits and sponsor packets are available to send to media outlets and local businesses. Please contact Andrea Howe at 301-391-6094 for information on receiving these items or if you have an address where you would like one mailed.

All registered walkers will receive a reminder card in the mail with directions for walk day. Free parking will be available at the school, and sign in will begin at 7:30 am. Programs with maps, water stations and porta-johns will be available. GF snacks and a raffle will follow the walk. Only registered walkers are eligible for water and food. Check out the internet at www.celiacwalk.org to see what other cities are participating!

Volunteers are also needed to work with local sponsors and the media and to help out on walk day. Volunteers will get a T-shirt and recognition for their efforts. If you would like to volunteer, please call Andrea Howe at 301-391-6094.

June 21–23, 2002 GIG Annual Education Conference – Winston Salem, NC:

The Gluten Intolerance Group (GIG) in Partnership with the North Carolina Triad GIG Partners

Presents its 2002 Annual Education Conference in Winston Salem, NC
June 21-23, 2002
Adams Mark Hotel

A special program for physicians and allied health care professionals will be held Friday, June 21. CME credits are pending on this program.

Friday, June 21 will offer:

Celiac Clinic - for persons who want to learn the basics, are newly diagnosed or never got much education. This 3-hour program will include overviews of the disease and diet. It will also include free screenings in the Health Screening Clinic. This is an excellent way to gain a basic understanding of the disease before learning more details in the main program.

Cooking Demonstrations - some of the leading cookbook authors, gluten free manufacturers, dietitians, and local chefs will conduct 3-hour workshops. We hope to have one just for kids.

Pre-Conference Reception - will be held in the exhibit area. This sneak preview will allow medical professionals, clients and vendors to join together to enjoy music, food, and good company.

June 22–23 Saturday and Sunday Programs - will provide a wealth of information with some of the leading celiac disease researchers and practitioners in the country. Learn about the latest research, associated diseases, dental concerns, Dermatitis Herpetiformis (DH), and associated skin diseases. Learn how to cope, work with the pharmacist and dietitian, and what to be concerned about and more.

Buy products on site - from over 20 gluten free vendors; have authors sign your books — and don't forget the health screening! Find out what your bone density is, are you at risk for diabetes and more.

Bring the Kids to GIG's Kids Day Camp - a 2-day program filled with fun learning activities, speakers, and special treats.

Don't miss this event. Information will go out in a few weeks. If you are not on our mailing list, watch for further announcements here or on the GIG website www.gluten.net.

If you want to participate as a sponsor or exhibitor, please contact the GIG office at 206-246-6652 or cynthia@gluten.net for more information.

August 23–25, 2002 Gluten Free Living Conference

How to Live a Happy Healthy Gluten-Free Life
August 23, 24, 25 at the Westin Hotel in Philadelphia, PA

Gluten-Free Living is proud to present the first conference customized for real celiacs who face the daily challenges of living gluten free in a gluten-filled world. The pages of Gluten-Free Living will come to life as experts lead you through the things you need to know to live a happy, healthy gluten-free life. You'll hear:

Alessio Fasano, MD, on the basics of the celiac disease: What it is, why you have it, how it is properly diagnosed, good follow-up care, what your future holds, and other pertinent, medically essential aspects of the disease. Bette



Hagman on how to cope with a gluten-free life, and how to bake delicious gluten-free breads and goodies. Nancy Patin Fallini, RD, on the basics of the diet and how you can follow it faithfully and safely and still get all the essential nutrients you need. Danna Korn, author of Kids with Celiac Disease, on how to raise a celiac child plus encouragement and tips for celiacs of all ages. Ann Whelan, editor/publisher of Gluten-Free Living, on suspicious ingredients, diet perspective, and happy, healthy gluten-free eating.

There will be workshops on many topics:

How to Raise a Celiac Child
How to Bake Gluten Free
How to Travel and Eat Out
How to Make Sure Your Prescriptions are Gluten Free
How to Handle Celiac Emotions
How to Live Comfortably With DH
How to Handle Celiac Disease and Type I Diabetes

Perhaps best of all, there will be gluten-free vendors of every stripe. You'll get to taste samples, ask questions on the spot, and collect take-home goodies.

We are planning a weekend you'll never forget in an exciting city at a cost you can afford. If you'd like to be one of the first to receive registration information, send your e-mail address to gfliving@aol.com.

Subscribing to Gluten-Free Living will give you a sneak preview of the kinds of things you will learn at the conference. This six-year old newsletter is the most authoritative source of reliable information on celiac disease and the gluten-free diet you can find. Subscriptions are \$32 for one year or \$54 for two years. Payment is by check or credit card. Be sure to include your mailing address and the length subscription you would like with your payment. You can send credit card information (Visa or Mastercard) to gfliving@aol.com or mail check or credit card information to: Gluten-Free Living, PO Box 105, Hastings-on-Hudson, NY 10706.

Celiac Research Subjects Needed:

For the past several years, Gary M. Gray, M.D. and Chaitan Khosla, Ph.D., both at Stanford University, have been studying the underlying causes of Celiac Disease, with an eye toward finding a therapeutic solution that would not require the strict adherence to a gluten-free diet. For the past two years, the Celiac conference at Stanford University has collected blood from Celiac volunteers for their research. Based on a series of studies involving animal tissue, Drs. Gray, Khosla, and coworkers have developed a hypothesis for the cause of the disease. Their findings in animal studies need to be confirmed on human tissue, and any differences in normal and Celiac intestine must be defined. The Stanford researchers are now in need of volunteers who are scheduled for a follow-up biopsy as part of their optimal care to provide intestinal tissue samples. Volunteers must be biopsy-diagnosed Celiacs who, as part of their care, will be undergoing an upper gastrointestinal endoscopy for recovery of small biopsies from the duodenum. For this research, two small (a few milligrams) of additional tissue will be taken during the biopsy, frozen immediately, and transported to Stanford. Please note that volunteers undergoing procedures at locations other than Stanford Hospital could participate. The small amount of additional tissue does not constitute a significant additional risk over and above that you will undergo due to the endoscopy and routine biopsies for the pathologist to examine. The research has been approved by the Human Subjects Committee at Stanford University Medical Center.

If you would like to participate in this study, please contact Kelly Rohlfs at 650-725-4771 or kellyr@bonair.stanford.edu. If you have questions concerning the risks and benefits of this study, please contact Dr. Gray at 650-725-3366 or gray@stanford.edu. Dr. Gray will coordinate the study with your gastroenterologist at the time of your endoscopy

AirSource:

At the last meeting Mike Ercole demonstrated a new air purification product called "AirSource". It is a state of the art air purifier produced by Shaklee USA and RGF Enterprises. This is a dual patent-pending device that uses Photo-Ionization and Electron Generation as its main components. AirSource is rated to clean the air in a 3000 square foot house or office. The cost of the AirSource is \$699.00 plus tax and shipping.

Mike has offered to donate \$50.00 to the WACSSG from each sale of an AirSource air purifier to our members. When purchasing a unit, just tell him you are a member and he will make the donation to our operating fund.

For more information contact Mike Ercole at 703-780-5901.
Email: mercole1@cox.rr.com

IN THE NEWS

Celiac Disease: It's Not What You Think!

(The following article is a reprint from the January 2002, Newsletter for the National Association of School Nurses, written by Carole Moore. The National Association of School Nurses has given permission to distribute copies of the article.)

Many school nurses and other healthcare providers in the community believe that celiac disease is rare and have seldom, if ever, had a student or patient with celiac disease. Current research shows that it is not rare; it is one of the most common genetically-based diseases, with an average worldwide incidence of 1:266. The majority of cases go undetected—**it is one of the most commonly missed diagnoses in the U.S.**

What is it? Celiac disease (CD) is an autoimmune disorder in which the mucosa of the small intestine is damaged after ingesting dietary gluten (proteins found in wheat, rye, oats, and barley) in genetically predisposed individuals. The development of CD requires a genetically predisposed person who is eating gluten. Even if these two factors are present, CD may not develop until a "trigger factor" starts the abnormal immune response. Exposure of the intestinal mucosa to gluten destroys and flattens the villi, resulting in malabsorption. Early diagnosis is key, because data suggests that the prevalence of other autoimmune diseases among patients with CD is proportional to the time of exposure to gluten.

What are the symptoms? Because of a wide range of symptoms, CD can be difficult to diagnose. Research indicates that almost 50% of CD patients recently diagnosed did not present with gastrointestinal symptoms. For each child with symptoms, four children have CD without symptoms.

Stunting of growth may be the only symptom. Other symptoms may include: weight loss, diarrhea, weakness, constipation, iron-deficiency anemia, stomatitis, abdominal pain, lactose intolerance, vitamin deficiency, reduced bone mineral density, osteoporosis, dyspepsia, dental enamel hypoplasia, arthritis, delayed onset of puberty, neurologic problems, and fatigue. Gluten sensitivity has also been linked to migraine headaches in some studies.



How is it treated? The only treatment for CD is a life-long gluten-free (GF) diet. For most people, following the GF diet stops symptoms, allows the intestine to heal, prevents further damage, and results in optimal health. The diet requires ongoing education of celiac patients, families, dieticians, school staff and other caregivers. A gluten-free diet means avoiding all foods that contain wheat, rye, barley and oats—most pastas, cereals, breads, and many processed foods, including foods and sauces containing wheat flour or modified food starch made from wheat. Many sources of gluten are “hidden” on food labels, so education about reading labels is crucial. Wheat-free foods may not necessarily be gluten-free. Medications must also be checked for GF status.

Despite these restrictions, people on a GF diet can eat a wide variety of foods and enjoy a very healthy diet: meats, fish, vegetables, fruits, and rice. Many celiacs enjoy purchasing a variety of delicious GF foods available at stores, online, and mail order, including cereal, breads, pastas, cookies, pancakes, pizzas, donuts and other snack items and baked goods.

Who should be screened? Current research shows that serologic testing is indicated for people who have symptoms suggestive of CD, but also for those with CD-associated diseases. This is where astute school nurses can be of assistance in the referral process. Some particularly at-risk include: first and second degree relatives of people with CD; patients and relatives of patients with Type 1 diabetes; those with autoimmune thyroid disorders, Sjogren syndrome, Down syndrome, or Turner syndrome; those with selective IGA deficiency, alopecia areata, or rheumatoid arthritis. A single negative serologic result does not rule out the possibility of CD later in life.

How can school nurses help? Be alert to who should be referred for screening or in-depth testing. Educate celiac students and families about the GF diet, or refer to someone knowledgeable about the diet. Refer students and their families to local celiac support groups, GF camps, GF food vendors, and celiac conferences. Share resources listed below with them. Develop IHPs for celiac students to ensure a GF diet and promote success at school.

Resources:

Book *Kids with Celiac Disease: A Family Guide to Raising Happy, Healthy, Gluten-Free Children*, by Danna Korn, founder of an international celiac support group, R.O.C.K. (raising our celiac kids).

Celiac listserv: <http://www.enabling.org/ia/ceeliac/>

<http://www.celiac.com>—very comprehensive site with information on CD, recipes, GF food vendors, scientific articles

Celiac Sprue Association (CSA): <http://www.csaceliacs.org>;

Phone: 402-558-0600

Gluten Intolerance Group of North America: <http://www.gluten.net>

Phone: 206-246-6652

Carole Moore, RN, BSN, NCSN, school nurse at Grace School in Houston, Texas, is professional development chair of the Private and Parochial School Nurses of NASN as well as the Texas Assoc. of School Nurses.

BOOKS AND GUIDES AND INTERNET RESOURCES:

■ The following internet site offers a pharmacy resource that is updated regularly: www.geocities.com/HotSprings/Spa/2679/gluten.html.

From the folks that published Danna Korn’s book, “Kids with Celiac Disease”, comes a new cookbook out in May, “Incredible Edible Gluten Free Food for Kids”, written by Shari L. Sanderson. This is the first cookbook to provide delectable gluten-free recipes formulated especially for children with gluten sensitivities due to a condition such as celiac disease. For more information, contact Woodbine House Publishing at www.woodbinehouse.com.

Clan Thompson Online Data Base of Gluten Free Foods - This food database now includes gluten free menus for 14 restaurants including Boston Market, Dairy Queen, Outback Steakhouse, Starbucks, Subway, Taco Bell, TCBY, Tony Romas, and Wendy’s. 340 new items were added to the food database this month for PC’s and Palm OS handhelds. To download a Free Palm or PC demo go to www.clanthompson.com.

Clan Thompson Online Database of Gluten Free Drugs - 227 new items have been added to this database this month. New personal care items have been added such as cosmetics, skin care, soaps etc. For more information go to www.clanthompson.com.

Bette Hagman’s new cookbook, “Gluten Free Gourmet Makes Desserts,” can now be found on Amazon.com. The cookbook features over two hundred recipes for delicious cakes, cookies, pies and other desserts.

The Coeliac Society of UK publishes a “World Travel Guide” underwritten by Schar. It is a valuable resource for those travelling abroad and includes helpful phrases, local restaurants, hotels, etc. For more information, go to: www.coeliac.co.uk/index_flash.html.

THE ONLINE DC AREA ONLINE 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.

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

Digestive Disease National Coalition Public Policy Forum: see page 2 for dates

Q: What does the DDNC do?

A: DDNC is a group for professional and patient organizations that come together for the purposes of:



1. Informing the public and health care community about digestive diseases and nutrition including research, health care and education programs, costs and social implications, as well as services available to those suffering from these diseases.

2. To participate with the National Digestive Diseases Education and Information clearinghouse, other government agencies and the private sector in the National Digestive Disease Education Program.

3. To heighten the awareness and knowledge of federal and state legislators and administrators about digestive diseases and nutrition.

4. To represent the interests of member organizations regarding federal and state legislation and programs that effect research, health care, training and education in digestive disease and nutrition.

Q: Who is a part of DDNC?

A: Member organizations include such groups as the American Liver Assoc., Colorectal Cancer Network, and the Crohn's & Colitis Foundation of America. Gluten Intolerance Group has been a member of DDNC for many years. A few years ago the Celiac Disease Foundation also joined the Board. Last year CSA and American Celiac Society also joined - so now all the national celiac patient support groups are represented.

Q: What has the DDNC done recently?

A: It is partly through the work of the DDNC that so much attention has been given to colorectal cancer, irritable bowel syndrome (IBS) and other such conditions.

Q: Do you need people to go to D.C. that weekend?

A: This advocacy work is on a national level. Our primary goal is to represent DDNC and the need for continued funding for research, awareness, and education regarding digestive diseases. Our secondary goal is to briefly share how this funding would help persons with celiac disease.

We go to Washington DC to meet with our Congressional representatives and senators as a member of a team representing the DDNC. The teams are coordinated and the meetings scheduled through the DDNC. The DDNC offers a briefing meeting and reception on Sunday, March 3rd, starting at 4:00 at the Washington Court Hotel. At this meeting we learn about the focus and priorities for the forum, as well as what is currently happening in research.

Monday, March 4th a breakfast is offered and a briefing in preparation for congressional visits. The teams get back together for lunch and a guest speaker, then the teams complete the Congressional visits in the afternoon. GIG helps to arrange GF offerings for these meals.

Q: What do we have to do to get more recognition for celiac disease?

A: We got the attention of the DDNC, NIH and a number of other powerful groups last year by the sheer number of people representing celiac disease. Being willing to continue to be a visible part of the DDNC Public Policy forums is very important. Visits are very short - no more than 10-15 minutes, so the messages must be precise and concise.

But more importantly, we must not only be a team player for the DDNC (they are our best ally and resource for increased awareness and research money) but also we must all be saying the same thing and sharing the same information. The celiac community, including the national groups, is not currently respected on the Hill because we don't work together. This should be the one place we can set our differences aside and "speak with one voice". Until we do this, we will not be taken seriously.

What else can we do? Simply work together, draw off current research that will benefit celiac disease awareness (even when the research is not solely focused on celiac disease), provide information that is accurate and research based, and speak with one voice.

Q: Who can advocate for celiac disease?

A: Anyone can advocate. Children often make the best advocates, or those who have suffered from the disease. Even if you have never been an advocate before, you can do this. It is not difficult. The script is written for you.

You are the messenger.

Q: What are the national celiac organizations doing to help us work together for advocacy?

A: The DDNC has asked that all organizations submit the handouts they want to use during the Public Policy Forum. They will then work with us to present a unified message. What this means is we will probably only use something like the Fact Sheet used last year, that lists all the national organizations, rather than individual organization brochures. CDF has offered to update the Fact Sheet for this year.

Q: What can I do to help if I can't attend the forum?

A: We have another opportunity to advocate in Washington DC. The Skin Disease groups and NIAMS advocate on the Hill April 16 & 17th. You can help us then also. GIG is the only celiac organization currently doing advocacy for persons with DH. We need to have representatives at this advocacy effort too. We are also offered the opportunity to write letters asking to testify before Congress. These letters are usually written in December. Congress will then decide who they are going to invite with those testimonies and they are generally in the spring each year.

If you have an interest in participating, please contact Cynthia Kupper no later than February 22, 2002.

Cynthia Kupper, RD, CD
Executive Director
Gluten Intolerance Group
www.gluten.net or cynthia@gluten.net
Executive Board Committee - DDNC
206-246-6652

RECIPES!

Brazilian Cheese Puffs

4 cups tapioca starch (substitutes don't work well)
1 cup milk
1 cup water
1 cup cooking oil
7 eggs
1 1/2 cups grated Parmesan cheese

Preheat oven to 375 degrees. In a pan, bring the milk, water and oil to a boil. In a large bowl, place the starch. Add the hot liquids, mixing well. When the mix has cooled somewhat, add the eggs one by one. Add the cheese.

Put a little bit of butter, cooking oil or cooking spray on your hands. Make little balls of approximately 1 1/2 inches. Bake for about 20-25



minutes, or until the tops turn golden brown. This recipe makes a very large quantity. The dough can be stored in the refrigerator and can be baked in batches.

Gluten Free Pasta, *courtesy Linda Etherton*

3/4+ cup GF flour (I use Bette Hagman's mix)
1/2 tsp. Salt
1 Tbsp. Guar Gum
2 eggs
1 Tbsp. Oil

Food processor method:

Put dry ingredients in food processor bowl and pulse to mix. Add the eggs and oil and mix until a ball forms. If dough is wet, add more flour - about 1 teaspoon at a time until the dough cleans the sides of the bowl. Stop and scrape the bowl if necessary. If it is too dry (forms small balls in the processor) add a few drops of water. Process about 1 minute to knead.

Hand method:

Mix dry ingredients in a bowl. Add egg and oil and mix with a fork. Knead about 3 minutes until firm and not sticky. Add more flour or water as needed.

For both methods:

Cover the dough with plastic wrap and let it rest for 15 minutes. Roll and cut the dough by hand or using a pasta machine. Cook in lots of boiling water and test for doneness. Fresh pasta will cook fast. The amount of time depends on the size and thickness of the pasta.

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.

There has been recent concern on the Listserv regarding the practice of dusting the packaging of frozen vegetables to aid in the packaging process. **Bird's Eye** does not dust their packaging. Although they do not have a gluten-free listing, they assure the celiac community that all of their plain vegetables and Comstock/Wilderness pie fillings are gluten free. Of course, their products that contain sauces or pasta may contain gluten.

None of **Wal-Mart's** Great Value frozen vegetables or fruits contains gluten.

The following is a statement from Cynthia Brown of General Mills Consumer Services regarding their **Muir Glen** product line: Our primary goal is to provide accurate information, and we believe this is best accomplished by referring to the specific ingredients listed on each product package. Look at the ingredient label for wheat, barley, rye, or other sources of gluten. If you don't see any of these listed, then the product would be gluten-free; as are our current formulations of yogurt products. Again, if grains or their derivatives are not listed, there is no gluten. We do not 'hide' gluten in other ingredients (i.e. Natural Flavors). This is the most current information for your needs.

■ **Green Giant** states that if they use any gluten it will be on the ingredient list even if it is only used in the packaging or processing of the product. 800-998-9996.

■ **Shaw's Supermarkets** is a grocery store chain in the New England area of the US. They claim that occasionally, dusting may occur in the packaging of their frozen vegetables.

■ **Kroger Supermarkets** uses cornstarch in the packaging of their frozen vegetables.

The following **Bacardi** products are gluten free: Bacardi Carta Blanca, Bacardi Breezer, Bacardi Rigo and Metz.

■ **Brookfield Farms** corned beef brisket is gluten free and is available at Costco.

All of the stuffed sausages by **Casual Gourmet** are gluten free. They can be found in the refrigerated section of many health food stores and are sold at Costco.

■ The following information is from **Kraft**:

We understand how important it is for people who have been medically diagnosed with gluten sensitivity to have accurate information about foods to help plan their meals and diets. Therefore, all Kraft and Nabisco products now list items that contain gluten on the package ingredient statement. These items will be listed using commonly known terms such as Wheat, Barley, Oats or Rye. For other ingredients that contain gluten, the phrase 'contains gluten' will appear in parenthesis after the ingredient name. Other ingredients that contain gluten are: Triticale, Spelt, Kamut, Mir or Farina (also known as Far or Farro).

■ **Ikea** now carries gluten free torts (GLUTEN FREE is written on the package) in their specialty foods section of the stores. They are produced by a company in Sweden called Almondy and are presently not being distributed by American distributors. For more information or to encourage the company to find an American partner, go to www.almondy.com.

■ All of **Pond's** products are gluten free, EXCEPT the following: Nourishing Lotion with Sunscreen contains wheat amino acids
Nourishing Lotion contains wheat amino acids
Nourishing Overnight Cream contains wheat amino acids
Nourishing Cream contains wheat amino acids

■ All of **Duncan Hines** frostings are gluten free EXCEPT the Homestyle Vanilla frosting which contains malt syrup. The company is in the process of reformulating this flavor to remove the malt (for us celiacs!), and it will be several months before it will be available on the shelf. 800-845-7286.

■ **Splenda** sweetener is gluten free.

■ **Worlds Finest Chocolate**, the bars sold through school fundraisers, are NOT Gluten free due to the problem of cross contamination from the barley malt in the rice crispies used in one of the bars. The company does NOT wash the equipment between runs. 773-847-4600.

■ According to Liberty Richter, the US distributor for **WASA**, the Gluten free **WASA** crackers will no longer be sold in the United States. The principle reason for the discontinuation is the fact that **WASA** has lost control of the plant in Switzerland where the product has been manufactured. So far no solution has been found in finding another manufacturing location with the strict controls necessary for this product.

■ As of this writing, all of the **Bush's** products are gluten free except the **Bush's Best Chili Beans** products and the **Bush's Chili Magic** line. The company advises that they are constantly expanding their product line and many add new products that contain gluten. In order to ensure that a product is gluten free, call their office at 865-558-5445.



■ **Amy's Kitchen** has come out with a frozen rice Mac and cheese! Many of their products can be found at local Giant and Safeway stores and area health food stores, and My Organic Market in Rockville sells the new rice Mac and cheese. The following Amy's products are gluten free:

Shepherd's Pie
Mexican Tamale Pie
Cheese Enchiladas
Black Bean Enchiladas
Cheese Enchiladas, whole meal
Black Bean Enchiladas, whole meal
Rice Mac and Cheese
Asian Noodle Stir Fry
Thai Stir Fry
Teriyaki Stir Fry (skillet meal)
Lentil Soup
Cream of Tomato Soup
Black Bean and Vegetable Soup
Split Pea Soup
Spicy Chili
Medium Chili
Chili With Vegetables
Black Bean Chili
Tomato Basil Sauce
Family Marinara Pasta Sauce
Garlic Mushroom Pasta Sauce
Puttanesca Pasta Sauce

The following three items should be on store shelves in the next 3-4 months: Brown Rice and Vegetables Bowl, Teriyaki Bowl, Santa Fe Enchilada Bowl.

■ **Dowd and Rogers Inc.** announces that its line of premium wheat free & gluten free cake mixes are now available in select markets throughout the U.S. Addressing the needs of individuals intolerant of gluten and those allergic to wheat, the mixes contain a gourmet blend of fine white rice flour, imported Italian chestnut flour, and tapioca flour.

The mixes are available at the following : Whole Foods/Fresh Fields stores: 8402 Old Keene Mill Rd. in Springfield, VA; 1416 Seminole Trail in Charlottesville, VA; 6548 Little River Turnpike in Alexandria, VA; 2700 Wilson Blvd. in Arlington, VA; 11660 Plaza America Dr. in Reston, VA; 143 Maple Ave. East in Vienna, VA; and 1440 P St. in Washington D.C.

The mixes are also available online at www.dowdandrogers.com.

The mixes contain only the finest, all-natural ingredients and come in three flavors:

Dutch Chocolate - A tender and flavorful cake made with imported Dutch cocoa and finished with a light touch of pure vanilla powder.

Dark Vanilla - A wonderfully moist cake that features pure vanilla powder to give the unmistakable taste that only natural vanilla can.

Golden Lemon - An indulgent cake featuring pure lemon oil with hints of lime oil and bergamot oil.

Nearly one out of every 150 Americans suffers from celiac disease, according to a new study by the University of Maryland Center for Celiac Research in Baltimore. Individuals with celiac disease are unable to eat foods that contain gluten, a protein found in wheat, barley, rye, and oats. Research also indicates that celiac disease is

twice as common as Crohn's disease, ulceric colitis, and cystic fibrosis combined.

Dowd and Rogers Inc. is a Sacramento, CA based manufacturer of premium products for the wheat free and gluten free market. More information about the company can be obtained by visiting www.dowdandrogers.com.

■ **Purdue** Fresh ground turkey is gluten free. The natural flavors is rosemary.

■ The following products from **Whitehall-Robins** are gluten free as of August 2001:

Advil Caplets
Advil Cold & Sinus Caplets
Advil Cold & Sinus Tablets
Advil Flu & Body Ache
Advil Gel Caplets
Advil Liqui-Gels
Advil Migraine Liqui-GeIs
Advil Tablets
Anacin Caplets
Anacin Tablets
Anbesol Cold Sore Therapy Gel
Anbesol Gel Cool Mint, Alcohol Free
Anbesol Liquid Cool Mint, Alcohol Free
Axid AR Tablets
Baby Anbesol Grape Teething Gel
Caltrate 600
Caltrate 600 + Soy
Caltrate 600 + Vitamin D
Caltrate Plus
Caltrate Plus Chewables - Cherry Tablets
Caltrate Plus Chewables - Fruit Punch Tablets
Caltrate Plus Chewables - Orange Tablets
Centrum Focused Formulas Energy
Centrum Focused Formulas Heart
Centrum Focused Formulas Mental Clarity
Centrum Focused Formulas Stress
Centrum Kids + Extra Calcium (Cherry Flavor)
Centrum Kids + Extra Calcium (Fruit Punch Flavor)
Centrum Kids + Extra Calcium (Orange Flavor)
Centrum Liquid
Centrum Silver Tablets w/ Lutein (DV)
Centrum Tablets w/ Lutein (DV)
ChapStick Lip Balm Cherry
ChapStick Lip Balm Medicated Stick
ChapStick Lip Balm Medicated SqueezeTube
ChapStick Lip Balm Mint
ChapStick Lip Balm Regular
ChapStick Lip Balm Strawberry
ChapStick Lip Balm Sunblock 15
ChapStick Lip Moisturizer SPF-15, Stick
ChapStick Lip Moisturizer SPF-15, Tube
ChapStick Lip Moisturizer, Squeeze Tube
ChapStick Lip Moisturizer Vanilla Mint SPF-15
ChapStick Lip Moisturizer Vanilla Raspberry SPF-15
ChapStick Petroleum Jelly Plus
ChapStick Petroleum Jelly Plus Cherry
ChapStick SlimStick Lip Moisturizer SPF-15
ChapStick Sun Zone Ultra 30 Summer Berry
ChapStick Ultra SPF 30 Lemon-lime



Children's Advil Fruit Chewable Tablets
Children's Advil Fruit Suspension
Children's Advil Grape Chewable Tablets
Children's Advil Grape Suspension
Children's Advil Infant Drops Fruit
Children's Advil Infant Drops Grape
Children's ChapStick Flava Craze- (Blue Raspberry)
Children's ChapStick Flava Craze- (Fruit Punch)
Children's ChapStick Flava-Craze (Grape)
Children's ChapStick Flava-Craze SPF 15 (Passion Fruit)
Children's ChapStick Flava-Craze SPF 15 (Strawberry Twist)
Children's ChapStick Flava-Craze SPF 15 (Watermelon Splash)
Children's ChapStick Flava-Craze SPF 15 (Wild Crazeberry)
Denorex Advanced Formula
Denorex Extra Strength Medicated Shampoo
Denorex Extra Strength Medicated Shampoo with Conditioner
Denorex Medicated Shampoo and Conditioner
Denorex Medicated Mountain Fresh Scent Shampoo
Dimetapp Cold & Congestion Caplet
Dimetapp Cold & Fever Suspension
Dimetapp Decongestant Infant Drops
Dimetapp Decongestant Non-Drowsy Liqui-Gels
Dimetapp Decongestant Plus Cough Infant Drops
Dimetapp DM Cold & Cough Elixir (Reformulation w/ PSE)
Dimetapp Get Better Bear Sore Throat Soother, Cherry Flavor
Dimetapp Get Better Bear Sore Throat Soother, Grape Flavor
Dimetapp Get Better Bear Sore Throat Pops, Cherry Flavor
Dimetapp Get Better Bear Sore Throat Pops, Grape Flavor
Dimetapp NightTime Flu Syrup
Dimetapp Non-Drowsy Flu Syrup
Dristan 12-Hour Nasal Spray (Non-Thimerosal)
Dristan Long Lasting Mist (12-Hour Nasal Spray)
Dristan Nasal Spray
Dristan Sinus Caplets
Fibercon
Flexagen Caplets
Jr. Strength Advil Chewable Tablets Fruit Flavor
Jr. Strength Advil Chewable Tablets Grape Flavor
Jr. Strength Advil Coated Tablets
Maximum Strength Dristan Cold Non-Drowsy Caplets
Maximum Strength Anacin Tablets, Micro-Coated
Maximum Strength Anbesol Gel, Alcohol Free
Maximum Strength Anbesol Liquid, Alcohol Free
Maximum Strength Aspirin Free Anacin Tablets
Orudis KT Tablets
Preparation H Cooling Gel
Preparation H Hemorrhoidal Cream
Preparation H Hemorrhoidal Suppositories
Preparation H Hydrocortisone Cream
Primatene Mist
Primatene Tablets
Riopan Plus Double Strength Suspension
Riopan Plus Suspension
Robitussin (Guaifenesin Syrup, USP)
Robitussin CF
Robitussin Cold (Cold & Cough Liqui-Gels)
Robitussin Cold (Cold, Cough & Flu Liqui-Gels)
Robitussin Cold (Night-Time Liqui-Gels)
Robitussin Cold (Severe Congestion Liqui-Gels)
Robitussin Cold (Cold & Congestion) Caplet
Robitussin Cough & Congestion

Robitussin Cough Drops - Cherry Ovals
Robitussin Cough Drops - Cherry Squares
Robitussin Cough Drops - Honey-Lemon (Base Brand Optimization)
Robitussin Cough Drops - Honey-Lemon Ovals
Robitussin Cough Drops - Honey-Lemon Squares
Robitussin Cough Drops Extra Strength-Menthol Eucalyptus Ovals
Robitussin Cough & Cold Infant Drops
Robitussin DM, Alcohol Free
Robitussin DM Infant Drops
Robitussin Honey Cold Syrup
Robitussin Honey Cough Syrup
Robitussin Honey Cough, Cough Drops Natural Herbal w/ Natural Honey Center
Robitussin Honey Cough, Cough Drops Natural Herbal Almond w/ Natural Honey Center
Robitussin Honey Cough, Cough Drops Natural Herbal Honey Grapefruit
Robitussin Honey Cough, Cough Drops Natural Honey Lemon Tea
Robitussin Liquid Center Cough Drops Honey Lemon Tea
Robitussin Honey Flu Syrup
Robitussin Honey Flu Nighttime Mix
Robitussin Honey Flu Non-Drowsy Mix
Robitussin Maximum Strength Cough Syrup
Robitussin Maximum Strength Cough & Cold Syrup
Robitussin Multi Symptom Cold & Flu Caplets
Robitussin PE
Robitussin Pediatric Cough
Robitussin Pediatric Cough & Cold
Robitussin Pediatric Night Relief
Robitussin Sugar-Free Cough Drops - Cherry
Robitussin Sugar-Free Cough Drops - Ice blue Peppermint
Semicid Contraceptive Suppositories

The following is from SAFEWAY grocery stores:

While we are somewhat familiar with the malabsorption syndrome, we do not presume to prescribe any of our products for any specific diet(s). On the other hand, we are happy to provide what information we have which might be useful to you.

For your information, we have over 5,000 different products in our Safeway private label product line and we do not have a listing of ingredients available for the general public on each of these items so we are not able to comply with all requests. We do suggest that you read carefully all ingredient labeling information on products that you purchase.

We can tell you that our frozen vegetables and fruits should be okay since they do not contain any other ingredients but the vegetables or fruits themselves. The exception to this would be our frozen vegetables in sauce.

Another group of items that would be acceptable are non-breaded seafood items, poultry that has not been breaded or stuffed, and our Lucerne/SELECT eggs. In other words, all fresh meats, seafood's and eggs.

Acceptable dairy items would be all fluid milks, except chocolate milk when starch is added and the source is not listed, cottage cheese and natural cheeses. Most bakery items we believe would not be acceptable for use in this diet.



We have taken the initiative to solicit all of our suppliers for lists of their products that are gluten free. This list is attached for your easy reference.

As near as we can determine, the above information is correct; however, we cannot guarantee that changes will not occur from time to time in our ingredient listings, or vendor changes that would affect processing methods or raw ingredients. We do appreciate your interest in our Safeway Brand products and hope that we have been of some help to you.

Sincerely,

Shannon Healy
Customer Service Representative

Celiac Sprue – (gluten-free food products)

SELECT Brand

BBQ Sauce (Honey Mustard)
Carbonated Beverage, Clear Sparkling Water (all varieties)
Chocolate Chips
Dressings (Basil Ranch, Roasted Red Pepper & Garlic Vinaigrette, Raspberry
Vinaigrette, Blue
Cheese, Cranberry/Orange, and Harvest Vegetable)
Enchilada Sauce (vinegar distilled w/wood, pulp)
Flavored Coffees
Gourmet Dipping Sauces (Plum and Honey Mustard)
Jams/Jellies
Mayonnaise (Regular, Reduced Fat and Fat Free distilled w/wood)
Mustard (Classic/Country Dijon)
Refrigerated Pasta Sauces (Classic Pesto, Creamy Parmesan Basil, Garden
Vegetable & Herb, Light Alfredo, and Roasted Garlic & Mushroom)
Sausage, Chicken (Apple, Parmesan, Basil, and Tomato)
Sausage, Turkey (Italian)
Steak Sauce
Southwest Salsa (all varieties)
Truffles (Chocolate/Raspberry, Mocha, Butterscotch, and Milk
Chocolate)
Tuna (Tongol)
Verdi Marinara Sauce
Winners Thirst Quencher (Lemon Lime, Lemon Ice, Orange, Lemon,
Tropical, Fruit Punch, Glacier Wave, Tangerine Freeze, and Amazon
Freeze)

ENLIGHTEN Brand

Dressings (Honey Mustard, Roasted Sweet Pepper &
Garlic Vinaigrette, Garden Italian, and Balsamic & Red Wine
Vinaigrette)

HEALTHY ADVANTAGE Brand

Corn Chowder
Split Pea w/Ham
Vegetarian Chili

SAFEWAY Brand

Apple Sauce (Cups, Natural and Sweetened)
Aspartame Sweetener
Black Olives
Canned Beans (Pork & Beans, Light & Dark Red Kidney, Pinto,
Blackeye, and Chick)
Cashews, Halves & Pieces and Whole
Cereal* (Corn Nuggets, Corn Flakes and Fruity Nuggets)
Cheese Curds & Cheese Puffs
Cheese Spread, Aerosol (American, Cheddar and Sharp)
Chicken Broth
Coconut (Sweetened)
Corned Beef Hash
Corn Starch
Cranberry Sauce (Whole and Jellied)
Cream Style Corn
Deluxe Mixed Nuts
Dried Beans (Pink, Great Northern, Lentils, Black, Blackeye,
Small White, Large Lima, Small Red, Green Split, Light Red Kidney,
Pinto, Baby Lima, and Navy)
Dried Fruit (Prunes, Raisins, Apricots, Peach, Apple, and Cherry)
Extracts & Pure Spices** (if gluten, ingredient statement will declare)
Fruit Snacks
Grated Parmesan Cheese (3, 8 & 16oz.)
Instant Rice
Hot Cocoa Mix (with and w/o Marshmallows and Fat Free)
Honey (Pure and Creamed)
Instant Breakfast
Instant Puddings and Instant Gelatins
Iced Tea Mix
Jams/Jellies
Juices (Tomato, Lemonade, Pineapple, Apple, Orange, Prune, White/Pink
Grapefruit, Ruby Red, Grape, Cranberry, Cranberry/Raspberry,
Cranberry/Apple, and Cranberry/Grape)
Ketchup
Lemon Juice
Limeade
Maraschino Cherries
Marshmallows
Microwave Popcorn (all varieties)
Milk (Sweetened, Condensed)
Mixed Nuts w/ Peanuts
Mustard
Oils, edible
Onion Soup Mix
Peanuts, Dry Roasted and Roasted/Salted Spanish
Pudding Snack Cups (Banana, Butterscotch, Chocolate Fudge, Tapioca,
Chocolate, and Vanilla)
Peanut Butter (Reg. & Reduced Fat Smooth and Crunchy)
Popcorn Cakes**
Salad Dressing (Light & Regular Zesty Italian, Creamy Italian, Light
& Regular Ranch, Ranch w/Bacon, FatFree & Regular 1000 Island,
and California)
Sauerkraut
Splash (Tropical, Strawberry/Kiwi, and Berry)
Sugar (Granulated, Powdered, and Brown)
Sugar Free Mixes (Iced Tea, Lemonade, and Raspberry)
Syrup (Old Fashioned, Light, and Butter Light)
Tomato Juice
Tomato products (all canned)
Tortilla Strips, Nacho Cheese, and Golden Chips (Casa del Pueblo)



Tuna, Chunk Light
Vinegar, White Distilled

SAFEWAY Brand Refrigerated

Aerosol Whipping Cream (Light and Non Dairy)
Butter
Cheese, Processed Sliced
Cooked Ham, 95% Fat Free
Cream Cheese (soft, bars, onion/chive, strawberry, garden vegetable, light, Neufchatel, fatfree, whipped spread)
Dips (French Onion, Clam, Bacon Onion, Green Onion, Ranch, Avocado, Guacamole)
Margarine
Milk Drinks (Mocha Cappuccino, Chill'n Chocolate, Very Berry Strawberry, Marvelous, and Vanilla Shake)
Orange Juice
Soups (Potato Leak, Fire Roasted Tomato, Hearty Vegetable Beef, New England Clam Chowder, and Minestrone)
Vegetable Oil Spreads, 70%, 37% Light, and 70% 1/4 lb sticks (Homestyle)
Whipped Topping (Regular and Light)

MANOR HOUSE

Turkey

LUCERNE Brand

Buttermilk
Cream Cheese, Regular/Fat Free Neufchatel
Egg Nog
Half & Half
Sour Cream, LowFat/NonFat
String Cheese
Whipping Cream (Regular/Light/Heavy)
Yogurt, Pre-Stirred LowFat/NonFat

SAFEWAY Brand frozen

Hash Browns (Shredded and Southern Style)
Potatoes (Crinkle Cut, French Fried, O'Brien, Restaurant style Crinkle Cut, Shoestring, Steak Cut, Twice Baked)
Orange Juice Concentrate

SELECT/Safeway/Lucerne Brand

Frozen Desserts - Ice Cream (w/o inclusions)
Sorbet and Sherbet

DELI

Salsas
Primo Taglio Deli Meats - All
St. Louis BBQ Ribs

SAFEWAY/SELECT Non-Food

Antacid Tablets (Peppermint, Fruit, Wintergreen)
Calcium Tablets (500mg corn starch; 600mg potato starch)
Central-Vite w/Lutein

Children's Chewable Vitamins (All)
Maximum Strength Suphedrine
Micro Coated Aspirin
Night Time Cold Medicine (Nyquil)
Nutritional Supplement
Orange Flavored Natural Vegetable Powder

Must avoid cereals where Malt Syrup/Malt Flavorings are used - these malt products are generally derived from Barley.

Spices not run on dedicated line - Popcorn Cakes, w/the exception of White Cheddar, are Gluten-free; however, these products are not run on a dedicated line. White Cheddar is run last with a thorough line clean at end of production.

The following is from GIANT grocery stores:

We can research any Super G items with which you may have a concern. We do not have a complete list, the products in this letter are products which have been recently checked. Please note that we anticipate supplier changes in the next year, so check back with us if these items are of continued interest. Always read the label - ingredients change. We cannot be held responsible for individual reactions to a product.

We have been told by our suppliers that these products ARE GLUTEN FREE:

Bread, Bakery products

Coconut macaroons

Dairy

American sliced cheese food (yellow and white)
Cheddar cheese, regular and reduced fat
Cream cheese, all varieties
Feta cheese
Margarine, corn oil sticks
Mozzarella cheese (shredded or block)
Muenster chunk cheese
Natural slices, all except Swiss 4x4
Pasteurized processed cheese food slices
Pasteurized processed cheese products slices and shreds
Pasteurized processed cheese spread slices
Ricotta cheese, all varieties
Sour cream
Whipping cream
Yogurt

Deli

Frankfurters (beef and kosher beef)
Ham, imported (service deli)
Ham, honey, Livingston Farms (service deli)
Provolone cheese, Bel Gioioso (service deli)
Roast Beef, Italian (service deli)
Swiss cheese, domestic (service deli)
Turkey Breast, Homestyle smoked (service deli)



Frozen

Citrus pops
 Combo cremes ice cream bars
 Dreamy Tofu
 Ice cream (all flavors except cookies and cream and chocolate chip cookie dough)
 Ice cream bars, chocolate coated
 Ice cream cups, vanilla
 Lemonade concentrate
 No-sugar added fudge bars
 Sherbet (all flavors)
 Tator tots
 Twin pops

Grocery

Fruit snacks
 Gelatin (regular and sugar-free)
 Hot Sauce
 Instant mashed potatoes
 15% maple syrup
 Maraschino cherries
 Mustard
 Popcorn, Bagged butter flavored
 Olives, ripe (black)
 Pickle Relish
 Pickles
 Pie filling, cherry and apple
 Pork and beans, vegetarian beans
 Pudding mix (all flavors - regular and instant)
 Raisins, Seedless (packaged)
 Rice cakes
 Sodas, all flavors
 Taco seasoning
 Tomato sauce (regular and no-salt added)
 Vegetable shortening
 Whole bean coffee (chocolate and vanilla flavor)
 Worcestershire sauce

Meat

Corned beef brisket
 Ham (shank, butt)
 Turkey, whole (frozen and fresh)

Over the Counter Products

Buffered aspirin, coated tablets
 Extra Strength calcium/antacid tablets
 Extra Strength Pain Reliever gel tabs (acetaminophen)
 600 mg calcium with or without D
 Stress Formula with iron

Please note the following caveats from some of our suppliers: Our pasteurized process cheese products supplier advises that you check the label to be sure no wheat products are added. Our salad dressing supplier said they could not 100% guarantee their vinegar sources, so if you have been told by your doctor to avoid distilled vinegars with a possible wheat base you should not use those items. The supplier for our Super G green olives with pimento says the vinegar is distilled three times, but can be from a wheat source. In a distilled vinegar there is

not likely to be any gluten, but some physicians may still want you to avoid it. Our maraschino cherry supplier also said they cannot guarantee that the source for their flavorings won't change.

The following products have also recently been checked and contain gluten or could be contaminated with gluten: bagged cheddar cheese popcorn, barbecue sauce, bulk dried fruits, catsup, corn flakes and crispy rice cereal, grated Parmesan cheese, grated fat free Parmesan and grated Romano blend, creamed corn, fudge bars, chocolate ice cream cups, Neopolitan ice cream brick, mayonnaise, spaghetti sauce and vanilla extract.

Paulette Thompson, M.S., R.D.
 Food And Nutrition Coordinator

LOCAL RESTAURANTS:

■ The following is a reply from the **Chipotle** restaurant chain on the availability of gluten free menu items: "You should be able to eat everything freely, except for the tortillas for burritos and the soft flour tacos. The crispy tacos are fine, or you could try a "naked burrito", which is a burrito without the tortilla. There is no wheat flour in the crispy corn tacos. There is no flour in the vegetable shortening we use in our fryers, and we don't fry anything in the fryers that contains wheat flour. The corn chips and the corn shells are fried in the fryer, and we don't fry them anywhere else. Our cheese is gluten free and our hot red tomatillo salsa does not use white vinegar. The other salsas use lemon juice. Our chicken, steak, and barbacoa are seasoned with an adobada salsa-marinade that doesn't contain gluten or flour. For more information, contact jstupp@chipotle.com.

■ The following information comes from the **Guapos** restaurants in the DC area - Any dish that contains corn tortillas would be a good choice - for example, Crispy Tacos, Enchiladas made with corn tortillas and all of the chef Recommendations (salmon, pollo lupita, mariscade). Stay away from the Chimichangas, Burritos and Quesidillas because they contain flour.

■ The following statement comes from **Baja Fresh**: We do not have any information on the gluten content of our food at this time.

The following restaurants have been recommended by members:

■ **Café Dalat**, a Vietnamese restaurant on Wilson Blvd., in Clarendon (Arlington). It is a very unassuming place and most of the items on the menu are gluten free.

■ **Ghin Na Ree**, a Thai restaurant a mile from the Ballston metro in the Lee-Harrison Shopping Mall (Arlington). Almost everything on the menu is GF. If you get the satay, ask for no toast.

KID'S CORNER

R.O.C.K.

R.O.C.K (Raising Our Celiac Kids) is a new group that has been formed for parents of celiac kids or children on the GF diet (this might include food allergies or autism). The group was the brain child of Danna Korn, author of the book, "Raising Our Celiac Kids." The Washington group is co-chaired by Jill Arends and Andrea Howe.

The next R.O.C.K. meeting will be held at Andrea Howe's home in Damascus, Maryland, on Sunday, March 17th, at 2 pm. Please bring a dish to share with ingredient listings. This goal of this meeting will



be to plan the meetings and parties for the rest of 2002. Please call Andrea to RSVP- 301-391-6094.

BEN'S CAMP!

Friends of Celiac Disease Research is delighted to announce its second annual summer camp for children with celiac disease in the Midwest. "Ben's Friends Camp 2002" will take place August 6th through August 9th, 2002. The camp will be held at Camp Courage in Maple Lake, Minnesota. The focus of this camp is to provide a well-monitored situation where children with celiac disease and their sibling's, ages 8-17, can enjoy a real summer camp experience.

The trained counselors and program staff live in the cabins with the campers, direct daily activities, supervise diets, and provide excellent role models for young campers. A doctor, three licensed RN's, certified lifeguards, as well as program specialists, round out the staff. Camp Courage is fully accredited by the American Camping Association. For more information on Camp Courage, please visit their website at www.couragecamps.org.

The professional staff at Camp Courage will carefully monitor all children and provide a wonderful once in a lifetime experience of outdoor adventure that your child will talk about all year until "Ben's Friends" meets again in 2003. Children will be able to partake in a plethora of age appropriate recreational activities such as swimming, water-skiing, tubing, canoeing, sailing, fishing, nature hikes, and wagon rides. Weather permitting an overnight campout will take place, which will include a good old-fashioned gluten-free meal served fireside.

Bev Lieven, Director of Education for Friends of Celiac Disease Research and Coordinator of Milwaukee Celiac-Sprue Crew, will be working with the Camp Courage staff to ensure a gluten-free menu and to oversee food preparation. Bev has been gluten-free since her diagnosis 19 years ago. Two of her children, now young adults, are also celiacs so Bev has experienced the gluten-free diet both as a patient and as a parent.

To request further information, please contact Dana Tehako-Esser, Executive Director of Friends of Celiac Disease Research, at 414.540.6679 or via e-mail at friends@aero.net, in the subject line please indicate "Ben's Friends Camp 2002". Financial assistance is available.

Don't delay registration for the first Midwest camp will fill up fast!!!

Happy Gluten-Free Camping!

GIG KID'S CAMP 2002!

Camp dates are August 2 through 5 and August 6 through 9, 2002. Kids can sign up for one or both sessions. There are a number of special camp programs during these sessions, but even the general program is filled with fun! Camp Fire's Camp Sealth (on Vashon Island, WA) and GIG Kid's Camp enroll kids going into the 2nd through 12th grades. A diabetes care team will be available to support those children attending with diabetes and celiac disease.

GIG Kid's Camp is a mainstream camping experience. Our children attend camp with nearly 300 other kids, enjoying "just being a kid." GIG Staff does all the cooking for our children in a separate kitchen. We become the hit of camp, because we make the best food! Even other campers come begging for brownies and those special GF

Twinkies! Our campers get the chance to share a special dessert with their cabin mates, showing them our food is good.

The children attending camp come from all over the country. Several return year after year. About 80% of our children attend camp on partial to full scholarships. If you wish to sponsor or provide a gift camper-ship for a child, please contact GIG.

This camp is very popular and fills fast. If you would like information about GIG Kid's Camp, contact GIG at 206-246-6652 or gig@gluten.net. Scholarships are available for travel and camp registration.

Submitted by:

Nancy
Seattle, WA

CAMP CELIAC

The Massachusetts and Rhode Island Celiac Support Group for Children is pleased to announce the opening of registration for Camp Celiac 2002. Camp dates are August 11 through August 16, 2002. Camp is held in N. Scituate, RI for an all inclusive fee of \$250.00 per camper. Registrants must be 6 years of age to 16 years of age to enjoy this five-day sleepover camp. The camp is entirely gluten-free and closed to other sleep over groups during our stay. Children enjoy an array of activities from swimming, canoeing, arts and crafts, adventure programming, field events, nature walks, cooking classes and much more. Activities and sleeping arrangements are set by age and gender. Don't miss this wonderful opportunity to enjoy a week of gluten-free meals, friendship, nature, and so much more. Last year 65 children from 18 states across the USA attended. Register early as we are expected to fill up quickly. For more information and to print out registration forms, visit the newly updated CSGC web site at <http://members.cox.net/nowheat/index.html> or email Tanis Collard at csgc@ix.netcom.com.

LUV POPS-

American Candy Company's Mickey Mouse Luv Pops are gluten free, and can be found at Wal-Mart stores.

ICEES-

Coca Cola (the company that makes all of the Icee syrups) states that all of its flavors are gluten free.

YORKSHIRE FARMS-

Dinosaur shaped chicken bites are gluten free and also work with the Feingold Diet. They are easy to heat and taste and look like Burger King chicken nuggets. The website has many other gluten free meat items. www.yorkshirefarms.com.

FRUIT LEATHERS-

Stretch Island makes 8 (soon to be 9) gluten free flavors of their 100% fruit snacks. They can be found at area Fresh Fields stores. For more information, contact, custservice@stretch-island.com.



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. Juanita Ohanian.

CONTACTS:

| | | | |
|-----------------------|--------------------|----------------|-------------------------|
| Chairperson: | Hilari Moore | (703) 799-3764 | hmoorefun@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 | | |
| Hospitality Director: | Danielle Clarke | (301) 620-0075 | pianodc@aol.com |
| Virginia Contact: | Hilari Moore | (703) 799-3764 | hmoorefun@aol.com |
| Maryland Contact: | Andrea Howe | (301) 391-6094 | andreahowe@juno.com |
| District Contact: | Joany Janicki | (301) 581-1155 | jcjanicki@earthlink.net |
| N. Shenandoah, VA | Ruth Arcuri-Kovacs | (540) 536-4165 | rakovacs@visuallink.com |

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

CELIAC HOTLINE COMMITTEE:

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

| | | |
|--------------------------------|-----------------------|--------------------------------------|
| Joany Janicki, Bethesda, MD | (301) 581-1155 | Has celiac disease |
| Andrea Howe, Germantown, MD | (301) 391-6094 | Mother of celiac child |
| 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 Fickensch, suburban MD | (301) 972-6045 | Daughter w/ Down Syndrome and CD |
| | LFlickensch@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