



a "connection" of the  
*Celiac Disease Foundation*  
**csgmv-news** ISSUE IV- 1  
 January-February 2004  
**WEB SITE** -- [www.csgmv.org](http://www.csgmv.org)

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**DISCLAIMER**

Information and dietary recommendations  
 Are intended for the benefit of our members and  
 other interested parties. Individuals should consult  
 with their physician before following any medical  
 or dietary recommendations.  
 No liability is implied by -- or assumed  
 for – the use of information contained herein.

**MISSION STATEMENT - CSGMV**

The CSGMV organized to provide support to  
 the diagnosed person (and family) with Celiac Disease  
 and Dermatitis Herpetiformis in the  
 form of current information, available  
 resources, and dietary management on an  
 initial and continuing basis. Further, to  
 serve as a resource for the general  
 community and medical professionals by providing up-  
 to-date information related  
 to the management of Celiac Disease.

Adopted 1/2000  
 Revised 5/2002

**MEETING SCHEDULE**  
 @ 10 AM New York Mills Library –  
 -- In 2004 --

Sat., February 21, 2004  
 Sat., March 20, 2004  
 Sat., April 17, 2004  
 Sat., May 15, 2004

**(MAY IS NATIONAL CELIAC  
 DISEASE MONTH)**  
**ANNUAL WALK – date to come!**  
 Sat., June 19, 2004

**Senate Committee Passes Food Allergen  
 Labeling Legislation**  
 (received Nov. 21, 2003)

This evening, the Senate HELP Committee  
 took a major step toward improving the nation's  
 food labeling laws. The Committee, led by  
 Senator Judd Gregg (R-NH) and Senator Edward  
 Kennedy (D-MA), unanimously passed legislation  
 requiring the top 8 allergens (peanuts, tree nuts,  
 eggs, milk, soy, shellfish, fish, and wheat) to be  
 listed on food labels by their common or usual  
 name, or by source of the ingredient.

The measure also requires the Secretary of  
 HHS to develop rules for using the term 'gluten-  
 free' on food labels. The "Food Allergen Labeling  
 and Consumer Protection Act of 2003" was added  
 as Title II to S. 741.

Today's action by the HELP Committee  
 demonstrates that our unified efforts are making  
 a difference. The UNIFIED voice of the celiac  
 community was heard, and taken seriously.

All of us deserve credit for getting this far.

**Next up, the Senate Floor.**

**Our Senators are:**

Sen. Charles Schumer  
 313 HART SENATE OFFICE BUILDING  
 WASHINGTON DC 20510  
 (202) 224-6542

[schumer.senate.gov/webform.html](http://schumer.senate.gov/webform.html)

Sen. Hillary Clinton  
 476 RUSSELL SENATE OFFICE BUILDING  
 WASHINGTON DC 20510  
 (202) 224-4451

[clinton.senate.gov/email\\_form.html](http://clinton.senate.gov/email_form.html)

Stay tuned for additional news. Thanks for  
 your help!

**American Celiac Task Force**

**CNYCSG Meeting News**

On **April 18, 2004 at 2:00 PM**, **Ann R. Lee** MEd, RD, CDE – author of *“Nothing Beats GF Cooking”* – will speak about Hidden Gluten in Drugs, Cosmetics, and Vitamins.

On **Feb. 15, 2004 at 2:00 PM**, Chef **Brenda Houde** will prepare a **Valentine Pizza Party**.

Meetings held in Conference Room at **NaturTyme, 5898 Bridge St., East Syracuse.**

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Bob & Ruth’s GF getaways in 2004 include:

- 5/24 – 26 Culinary Inst. of America New York Mini-getaway
- 11/6 – 20 The Wonders Down Under

membership fee required

Check out their site: [www.bobandruths.com](http://www.bobandruths.com)

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**PRESIDENT’S MESSAGE**

(written by Eleanor Wallace for Pam)

On January 23 – at the Franklin Hotel, in Rome – CSGMV hosted a GREAT buffet dinner! The food was excellent – the service was fine – and about 50 Celiacs, families and friends thoroughly enjoyed the evening. **Thanks** go out to **Melody Ernst** (bread & pasta), **Tanya Clute** (birthday cake for Isabella Madeira’s 4<sup>th</sup> birthday “celebration”), and **Pam Fahy** (bread) – AND to the **Franklin Hotel** for their understanding and generosity – all of which made the event one to remember.

We are starting **our 9<sup>th</sup> year of service** to the Celiac Community – and this begins our **4<sup>th</sup> year of our bimonthly newsletter!** Do you believe it?!? We currently are mailing newsletters to nearly 20 professionals and over 60 members. This is quite significant growth of our group over the years. We have also met with literally hundreds of people – not all of whom “return to our fold” – but if we have helped at all, it is SO worth our efforts.

There have been some comments made about the two **Teaching Days** offered by CSGMV in 2000 and 2001 – regarding “will CSGMV do this again?” People need to understand that this is a LARGE undertaking – people need to pitch in and work if this is to be done again! **Anyone interested?? Do let us know if you are!**

And don’t forget our **Annual Walk** - hopefully to be scheduled in **May** (we do not yet have a firm date – but keep tuned for further information).

**We need EVERYONE’s help! Pam**

**MAY 1<sup>st</sup> 2004**  
***Peter’s Cornucopia***  
 moving to their  
**NEW LOCATION!!**  
 in the  
**New Hartford Shopping Center**  
 ~ ~ stay tuned for MORE ~ ~

~~~~~  
**BE pro-active –**  
**NOT reactive.**  
**Eat RIGHT (GF) - & live well!!!**  
 ~~~~~

**PEANUT BUTTER CHOCOLATE BARS**

- ½ C. sugar
- 2 eggs
- ½ C. peanut butter
- 4 oz. chocolate chips

Mix sugar & eggs. Add peanut butter, mix. Bake at 325 degrees for 25 minutes. Immediately after removing from oven, sprinkle with chocolate chips and cover with tin foil for 3 minutes. Remove foil and spread chocolate.

**TANYA’S CHOCOLATE CHIP COOKIES**  
**(or Cake)**

- (GF Flour Mix: 4 C. white rice flour
- 1 ½ C. potato flour
- 2/3 C. tapioca starch)
- 2 ¼ C. GF flour mix (above)
- 1 tsp. baking soda
- 1 tsp. salt
- 1 tsp. xanthan gum
- 1 C. butter (softened)
- ¾ C. granulated sugar
- ¾ C. brown sugar
- 1 tsp. vanilla
- 2 large eggs
- 2 C. chocolate chips

Preheat oven to 375 degrees.

Combine flour, baking soda, salt & xanthan gum in small bowl. Beat butter, granulated sugar, brown sugar & vanilla in large bowl – until creamy. Add eggs, beating well. Gradually beat in flour mixture. Stir in morsels.

Drop by rounded tablespoon on ungreased cookie sheets. Bake 9-11 minutes or until golden brown – **OR** make bar cookies in 9”x11” pan **OR** 12” round pan – Bake 20-25 minutes...

**ENJOY!!**

## **NEW NEWS**

### excerpted news from celiac.com

"Celiac.com 12/19/2003 - According to Italian researchers, brief but recurring bouts of depression and other mood disorders are significantly more common in those with celiac disease than those without the disorder. The researchers conducted a study that looked at 36 clinically diagnosed celiac disease patients and compared them to 144 healthy controls. The study found that those with celiac disease had "significantly elevated risks for major depressive disorders," including major depressive disorders, dysthymic disorders, adjustment disorders and panic disorders. The researchers suspect malabsorption of tryptophan, which can lead to a decrease in serotonin synthesis, as a cause for the elevated mood disorder risk. Another possible cause is the cytokines, which are produced in immune reactions that may exert an effect on brain circuits related to mood regulation. More studies are necessary to determine the exact causes.

Celiac.com 11/26/2003 - The results of a study conducted by Dr. Joseph Murray and colleagues at the Mayo Clinic in Rochester, Minnesota indicate that an unusually high number of those with celiac disease do not develop immunity from the hepatitis B vaccine. The team looked at 23 clinically diagnosed celiacs who had been given a full series of hepatitis B vaccines. Out of this group they identified 19 who had been tested for hepatitis B Vaccine response, and of the 19 tested, 13 subjects did not develop long-term immunity to the vaccine, which was determined by utilizing the negative qualitative or quantitative anti-HBs antibody titer. The researchers are still uncertain of the specific cause of the failed immune system response in those with celiac disease.

Celiac.com 12/31/2003 - Italian researchers report in the journal *Gut* that their previous hypothesis which was based on their hospital study that reported a 1 in 80 incidence of celiac disease in pregnant women and an unfavorable pregnancy outcome for them needs to be revised."

### excerpted from CDF newsletter – Fall 2003 excerpted results of Survey presented at The American College of Gastroenterology – Baltimore, MD October 2003

'Celiac disease is a common disorder (up to 0.7%) but still infrequently diagnosed. In our recent survey of over 1000 patients with celiac disease, their primary physicians diagnosed only 6%. We sought to determine physician awareness of celiac disease presentations,

symptoms, associated disorders & diagnostic tests.' (Physicians in San Dimas, CA did this survey.)

'Over 50% of FPs (Family Practitioners) and GIs (Gastro-Enterologists) responded to the survey. Almost all physicians were aware that celiac disease involved sensitivity to wheat products, but only 33% of FPs and 35% of GIs knew that the onset of symptoms was much more common in adulthood than in childhood.

Celiac disease is common in patients with type 1 diabetes (2% - 6% prevalence), but only 13% of FPs, and 47% of GIs were aware of the association. there was more awareness of the association with thyroid disease (23% FPs, 53% GIs) and IgA deficiency (34% FPs, 59% GIs). When questioned on symptoms of celiac disease, almost all FPs knew that diarrhea was frequent, but symptoms resembling irritable bowel syndrome (68%), psychological disorders (43%) and fibromyalgia-like illness (39%) were less well appreciated. All GIs but less than one-half of FPs were aware of iron deficiency anemia and osteoporosis were manifestations of celiac disease, and few knew that untreated celiac disease may cause infertility (7% of FPs, 47% of GIs). On diagnostic techniques, all GIs and most FPs were aware of the use of small bowel biopsy; however, only 43% of FPs were aware of blood test to screen for celiac disease.

Despite an average of over 19 years in practice, less than one third (28%) of family physicians had ever diagnosed a patient with celiac disease. All GIs had diagnosed multiple patients with CD.' Data is consistent with surveys of patients reporting that their primary care physicians infrequently made the diagnosis of celiac disease. The survey results suggest a need to increase the awareness of celiac disease, particularly among primary care physicians, and particularly the recognition of adult presentations, the associated disorders, and the use of blood screening tests...

### ***New! Gluten-free pizza crust!***

"Here is some really exciting news! Hello Celiac Support Groups, I am proud to offer a new and exciting product for the celiac community. My wife Lisa and I are the proud owners and creators of Dad's Gluten Free Pizza Crust LLC. We offer a great pizza crust that you can enjoy with out the risk of cross-contamination. We hope that you will enjoy this product as much our local customers have for the past year and half. Please visit us @ glutenfreepizza.com. We look forward to helping you and your loved ones out. Please forward this on to the people in your support group so that they can also enjoy this product. You will not believe the quality and GREAT taste of this product until you try it. Thank you very much. We hope you have a safe and wonderful Holiday!

**from:** Bob & Lisa @ glutenfreepizza.com"

**ERROR CORRECTED !!**

In the last newsletter an error was made (inadvertently) in the amount of lemon juice in the recipe for Black Bean Salad. It is **correct as printed below.**

**Black Bean Salad:**

- 1-16oz. can drained rinsed black beans
  - 2 C. cooked brown rice
  - ½ C. chopped/cooked red & green peppers
  - 1 small red (or sweet) onion – chopped
  - ½ C. chopped parsley
  - 1 can (6-11 oz.) mandarin oranges – chopped
- Stir to mix well. Add dressing, stir, and refrigerate (covered) for a few hours to blend flavors...

**Dressing:** ¼ C. oil; 2-1/2 T. lemon juice; 1 T. juice from oranges. Salt to taste.

**MuNcHiEs**

**Roll-Ups:**

- 2 slices GF lunch meat
  - 2 pieces GF cheese
  - GF mustard
  - + thinly sliced vegetables
  - thinly sliced avocado
  - romaine **OR** iceberg lettuce
- Lay lettuce flat and top with ingredients (modify to taste). Roll lettuce leaf like a burrito & bite!!

**Kreamy Krunchies:**

- 1 rice cake
  - sliced avocado
  - GF Cream Cheese
  - sliced vegetables
- Spread cream cheese on rice cake, add vegetables, and enjoy!!

**Pigs in a Blanket:**

- Chebe` Bread Mix
  - vegetable spray
  - GF cocktail wieners (Tofu-Pups for vegetarian)
- Heat oven to 350 degrees & coat cookie sheet with vegetable spray. Mix Chebe` Bread according to directions. Spray hands lightly with vegetable spray & form 1-inch balls with dough. Flatten & cut into pie shape wedges. Place cocktail wiener on large side of dough & roll. If using Tofu-Pups, cut into halves before rolling. Bake for 15 minutes -- or until golden in color & slightly crisp on the outside...

**Wheat-Free Playdough**

- ¾ C. cold water
  - 1 T. food coloring
  - ½ C. corn starch
  - 1 C. salt
- Mix water & food coloring in medium size saucepan. Add salt & cornstarch. Cook over medium heat until the mixture sticks together & forms a ball. Wrap dough in paper towel until cool. (cont.)

Knead until pliable and smooth – approximately 5 minutes. Form into shapes; let dry and decorate.

**MENU IDEAS for CELIACS:**

**Breakfast -**

- Egg, hash browns, orange juice
- GF cereal with yogurt OR milk of choice – topped with fruit & nuts
- GF breakfast bar, fruit smoothie

**Lunch -**

- Tuna salad on bed of lettuce, sweet potato fries
- Chili, corn chips, veggies & dip
- GF bagel with nutbutter, baby carrots, fruit

**Dinner -**

- Poached salmon, roasted potatoes, garlic spinach
- Tofu OR beef stir fry with veggies (use WF-tamari), brown rice
- Grilled chicken, corn, tomato & basil salad

**Sweets -**

- GF cookies with tea, coffee, or milk of choice
- Sorbet topped with fresh berries
- Ice cream or other frozen dessert with almonds, banana, chocolate sauce.

**Here's How YOU Can Help People Living with CD ---**

**Talk to everyone!**

**Make contacts at your local health food store, doctor's offices, newspapers, and libraries.**

**Do research on the Internet to be informed on Celiac Disease – and share information!**

**ALWAYS REMEMBER -- YOU ARE IN CONTROL OF YOUR HEALTH – SHARE THIS WITH OTHERS**

source: RealSimple (from CDF Fall 2003 Newsletter)

'If you want to be happy for an hour – take a nap.

If you want to be happy for a day – go fishing.

If you want to be happy for a month – go on a honeymoon.

If you want to be happy for a year – inherit a fortune.

**IF YOU WANT TO BE HAPPY FOR A LIFETIME -- HELP OTHER PEOPLE !!!'**



**Did you know??**

Celiac Disease is considered a condition which disqualifies a person for military service?

**FOR BEER-LOVERS**

We are emailing you regarding the Celiac community. We are a brewery in New York. We produce Gluten-Free Beer. It is called Gluten-Free Honey Lager. This beer will be carried year round!

The beer features a bright golden color and has an alcohol content of around 5.5%. To make to beer gluten-free, no barley or wheat is used. It includes honey notes and touch of molasses in the flavor. Only "noble" hops are used for flavor and aroma. Brewed in dedicated fermenters using kosher yeast.

The brewery ships out the beer by the case. Which is 24 (12oz) bottles. The price is \$35 plus shipping.

In the future we will be traveling to different parts of the country due to the great demand. If you have any questions or would like to place an order, you may call us directly.

Thank you, Ramapo Valley Brewery  
www.ramapovalleybrewery.com  
[glutenfree@optonline.net](mailto:glutenfree@optonline.net)  
122 Orange Ave  
Suffern, NY 10901  
845-369-7827

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For those who receive the CDF newsletter:

Eleanor --  
**PLEASE caution your group that just because something is on the Listserv it isn't necessary correct.**

**My best to you and your family in the New Year**

**Elaine Monarch Director CDF**  
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(from Eileen Kinsella) Yes, our **Manny's White Corn Tortillas are gluten free** and they are made in a separate facility.

Hope this helps!  
Thank you for purchasing our products!  
Dennis Lancaster  
Director of Sales  
Mexican Accent, Inc.

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from Lou Parrotta -- I wanted to let the group know that Good Earth Teas are gluten free as are Celestial Seasons Teas.

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**The Celiac Disease Center at Columbia** is pleased to update major events and information. If you have any questions, please feel free to contact **Hal Winfield at 212-342-0251 or email: [celiac@columbia.edu](mailto:celiac@columbia.edu).**

1) While we do not encourage alcohol consumption to excess, we get many questions regarding what forms of alcohol can be safely consumed by people with celiac disease. We think the following information is of interest, and reinforces the concept that a gluten free diet should have a sound scientific basis. As you may know, whiskey, such as Scotch, is fine to drink because the distillation process keeps out the harmful products. We have received the following about Scotch Whiskey and a new beer.

**A)** Dr. Bill Lumsden, the master distiller of Glenmorangie Scotch, has written that due to the nature of the distillation process, he ensures that no gluten is present in the final product which is Malt Scotch Whisky or Blended Scotch Whisky. Moreover, nothing is added back in after distillation. This applies to all Scotch Whiskey.

**B)** From a brewery in New York, comes a Gluten-Free Honey Lager. The beer has an alcohol content of around 5.5%. To make this beer gluten-free, no barley or wheat was used. The brewery ships out the beer by the case.

**Ramapo Valley Brewery**  
**www.ramapovalleybrewery.com**  
**glutenfree@optonline.net**  
**845-369-7827**

2) Following is the latest information we have from the American Celiac Task Force, the celiac community's lobbyists in Washington.

In June 2003, Drs. Fasano, Catassi, Horvath, Guandalini, and Green, submitted testimony to Congress discussing connections between celiac disease and type 1 diabetes. The statement, while brief, was historical. It was **the first time celiac disease was discussed as part of a Congressional hearing.**

Congress is expected to show greater interest in celiac disease this year, due to the **pending food labeling legislation**, and the **upcoming NIH Consensus Conference.**

3) You may **contact the American Celiac Task Force at: [American Celiac Task Force <actf@fogworks.net>](mailto:AmericanCeliacTaskForce@fogworks.net)**

4) On **November 15th** over 500 patients and health care providers attended **Patient Education Day, put on by the Celiac Disease Center at Columbia.** There were talks on multiple topics related to celiac disease. The guest speakers included John Zone, Chairman of Dermatology, University of Utah, who spoke on dermatologic manifestations, and Drs. Norman Latov, Cornell University and Bruce Roseman,

Westchester Medical Center who spoke on neurological complications of celiac disease. Also, Dr. Bana Jabri and Dr. Carol Semrad both from the University of Chicago spoke on the potential for non dietary therapies and **the role of small amounts of gluten in the diet as causes of persistent damage.** From Columbia, Dr. Elizabeth Shane addressed issues concerning **celiac disease related bone damage.**

Anne Lee, the Center's nutritionist, addressed trends in dietary management, while Dr Peter Green hosted the event and gave an update on recent research in the field. There was also a talk given on **dental and oral abnormalities seen in celiac disease,** and, in addition, there was an **update on recent legislative activity on a food labeling bill that is currently under consideration in Washington, DC.**

**This was the second annual patient education day run by the Center. The large attendance is a reflection on the growth of the Celiac Disease Center at Columbia, the increased rates of diagnosis of this common condition and the strong desire of patients to be involved in the management of their disease.**

**5) AUDIO TAPES OF PATIENT EDUCATION DAY 2003.** To purchase the set of tapes for \$50, either online or by mail, please go to: [www.cdcc.hs.columbia.edu](http://www.cdcc.hs.columbia.edu).

**6) NOTHING BEATS GLUTEN FREE COOKING** (a children's cookbook)

A publication of the Celiac Disease Center at Columbia.

Authors: Anne Roland Lee, Susan Cohen & Laura Leon

To purchase either online or by mail for \$25 (including shipping) please go to:

[www.cdcc.hs.columbia.edu](http://www.cdcc.hs.columbia.edu)

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(this was emailed to those with addresses – as the next newsletter will not be out before 1/29)  
"Dear Friend,

You are receiving this information in the hope that you will share it with your gluten-free support group and friends and help us get the word out about this exciting program. (cont.)

This January and February, Nu-World Amaranth, the Celiac Sprue Association, the Gluten Intolerance Group of North America, the Celiac Disease Foundation, R.O.C.K. (Danna Korn), Celiac.com and cookbook authors Carol Fenster, PhD. and LynnRae Ries are ringing in the 2004 New Year with a complete lifestyle makeover for healthy, gluten-free living and more. Gluten-free is no longer just about eating tasteless, safe foods---it's about eating healthy and delicious gluten-free foods, trying new recipes, and incorporating new ideas and tips for maintaining a gluten-free lifestyle.

We've come together to share news, information and recipes with you. In addition, we are conducting an exclusive live on-line chat on January 29<sup>th</sup> at 7:30 P.M. CST (8:30 P.M., 6:30 P.M. MST, 5:30 P.M. PST), inviting you to post your personal commitment to living a gluten-free lifestyle and giving 1 lucky family the chance to win a complete pantry and kitchen makeover with a registered dietitian! A great second prize includes a phone or e-mail consultation with Danna Korn. There are also gift baskets of products and books.

**Visit:**  
[www.nuworldfamily.com/glutenfreeandmore](http://www.nuworldfamily.com/glutenfreeandmore) to LEARN more, ENTER TO WIN, REGISTER for the LIVE CHAT this coming Friday, January 29<sup>th</sup> (spots are limited but there is still time to sign up!) or post your **PERSONAL PLEDGE to help set your course or to give inspiration to others.**

We're all very excited about this program and hope you will be too. Here's an opportunity to renew your pledge to a gluten-free lifestyle, to gather more helpful information, try delicious new recipes, win a gift basket and learn about some of the wonderful support avenues available; all with a chance to win a pantry and kitchen makeover with personalized recommendations from a registered dietitian. Hope you will join us!

Wishing each of you a Happy and Healthy New Year!

Sincerely yours,

**Diane Walters**

Vice President of Marketing and Education  
Nu-World Amaranth Inc.

630-369-9524"

[diane@nuworldfamily.com](mailto:diane@nuworldfamily.com)

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*Recent Publications with Articles about Celiac Disease &/or GF Diet – check them out!!!*

**Parents Magazine Feb. '04 pages 83-89**  
**Woman's Day Feb.17 Pages 58-64**  
**Reader's Digest Feb.'04 Pages 123-24**