



**WEB SITE --** [www.csgmv.org](http://www.csgmv.org)

**MISSION STATEMENT and GOALS - CDF/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. CSGMV is currently a chapter of the Celiac Disease Foundation – a non-profit public benefit organization dedicated 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  
Revised 5/2004

**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.

**2004 MEETING SCHEDULE**

**@ 10 AM at New York Mills Library –  
corner of Main & Maple Sts.**

**(please use BACK entrance -  
off Maple St.)**

**Sat., August 21, 2004  
Sat., September 18, 2004  
Sat., October 16, 2004  
Sat., November 20, 2004  
Sat., December 18, 2004**



**IF YOU ARE RECEIVING  
THIS NEWSLETTER - AND YOU SEE  
A 'C' ON THE MAILING LABEL  
this means you are receiving a  
'courtesy mailing'.**

**Any small contribution you are able to  
make to CSGMV helps us "spread the word"  
to those who are in need of learning more  
about Celiac Disease – both in the medical  
profession AND the community!!**

**WILL YOU HELP??**

Make checks payable to CDF/CSGMV and  
send to:

Lavinia Tilton, Treas.  
8081 Passer Rd.  
Blossvale, NY 13308

**THANK YOU**

**for your CONTRIBUTIONS!!**

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**LOOKING FOR VOLUNTEERS**

We are hoping to be able to host a "special  
event" in the spring. May is officially  
"Celiac Disease Month" -- and would be a  
good time to do this. BUT – "many hands  
make light work" so we need YOUR help!  
Please contact Eleanor @ 315.736.6981 if  
you are willing to work in this area. It  
really can be very rewarding!

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from Hal Winfield @ Columbia University

**Food Labeling Bill Awaits  
President Bush's**

**Signature**

On July 20th, the Food Allergen Labeling and  
Consumer Protection Act (FALCPA) received final  
approval by the House of Representatives.

**Thanks to the leadership and determination  
of Representative Nita Lowey (D-NY), this  
bill is on its way to the President.**

In eight months S. 741 has cleared the Congress  
with simple voice votes.

**An UNBELIEVABLE feat!**

And the following words, say it all . . .

" Before I close, I hope the Speaker and my  
colleagues will indulge me for just a moment.  
This bill has been a work in progress for 4-plus  
years. There are many people who worked  
diligently behind the scenes to craft it and secure  
its implementation. . .

The Food Allergy Initiative, American Celiac Task  
Force, Food Allergy and Anaphylaxis Network and  
so many others also deserve thanks for their  
continued dedicated advocacy."

**Representative Nita Lowey July 20, 2004**

Floor Statement on the Food Allergen Labeling  
and Consumer Protection Act

FOOD

Are you going out to eat at the **Outback Steak House??** If you order the candied yams (sweet potatoes) be sure to ask that they use **ONLY** the butter & cinnamon – no brown sugar **UNLESS** they are sure a slice of bread has **NOT** been placed in the container (to keep the brown sugar soft) -- as it would contaminate the sugar!!

**Symeon's – Byrne Dairy sour cream** is used in their 'dressing' (e.g. – Souvlaki Platters, etc.) – and this is being checked into as to GF status (from consumer affairs @ Byrne Dairy). As of "press time" – no answer!

BOOKS

(excerpted from GF LIVING vol.9 #1)  
\*\***LynnRae Ries** authored a book in 2002 – "**What? No wheat?**" (subtitled "A lighthearted primer to living the gluten-free, wheat-free life"). She puts a happy face on celiac disease & the gluten-free diet. Ann Whelan (of *Gluten-Free Living*) with others was a contributor to the books contents –

and says 'Her method of coping was unique. She told her doctor she was going to write an easy-to-understand book on celiac disease!' Since her book, she has been involved in many avenues of reaching out – including working with local restaurants, started the GF Cooking Club to help others learn how to cook, bake & shop GF. established a lecture series, opened a small baking service for the GF community, recipe book, mailings to over 600 AZ doctors, and the list goes on! Proof that anyone CAN make a difference... Profits from the book go back into the celiac community.

Go to [www.whatnowheat.com](http://www.whatnowheat.com) OR call 1-800-777-1242 to learn more.

\*\* **"Wheat-Free Recipes & Menus: Delicious Healthful Eating for People with Food Sensitivities"** by Carol Fenster, Ph.D. (Carol is an internationally recognized expert, speaker, and consultant on food sensitivities & gluten-free living.)

This book has been updated – and we are looking into purchasing some copies at a substantial discount off the regular price of \$16.95. "Stay tuned" for developments! Better yet --- **COME TO OUR MEETING!!**

**re: GF BEER**

Kevin Seplowitz is the President and Co-founder of the Bard's Tale Research Company, LLC and organization that researches the correlations between nutrition, diet, and autoimmune disorders. Bard's Tale Research owns and operates Bard's Tale Beer Company, LLC ([www.bardsbeer.com](http://www.bardsbeer.com)) a company that develops commercial gluten-free beers. Mr. Seplowitz is a diagnosed Celiac.

**WORDS from our President – Pam Fahy**

We owe a very large 'Thank You' to those in our group who always seem to "step up to the plate". This includes, of course, our officers – but, behind the scenes are special people like Margaret Angell & Linda LaMonica – on hand to greet our folks at every meeting; Karen Mierzwa who sends out cards and oversees our refreshments; Arnoldine Bartoszek who manages our scrap book & photo albums – covering our events. Also thanks to all who inform us of calls to companies, experiences in the community, contacts with new Celiacs, the stores who are giving us more & more access to GF foods (quite tasty, for the most part), and the MDs & PAs who are increasingly looking for Celiac Disease in their patients! Our appreciation is hard to put into words! We can only strive to continue to help people – and in that venue, GROW.

We will be revising our bylaws in order to have the terms of officers staggered (and not have all new people in office the same year) – also being considered will be having some assistants for the busiest officers. This will be presented to our meeting – hopefully in September. Please plan to attend and be heard!

**One huge point on being heard... The collective efforts (voices) of the celiac community have been heard!!! On 7/20/04 the Food Allergen Labeling and Consumer Protection Act was passed by voice vote by the House of Representatives. The next step is a signature from President Bush!!! The American Celiac Taskforce is actively working on legislation to make May the official Celiac Awareness Month. Currently there are 16 sponsors. Please go to [www.capwiz.com/ceeliac](http://www.capwiz.com/ceeliac) and support this legislation with your voice to your representative. IT DOES MAKE A DIFFERENCE!!**

**R.O.C.K.** (raising our celiac kids) – of the **Mohawk Valley**



As with most summers, everyone is VERY busy – so the group has been unable to schedule any special plans. We hope some events will be more possible in the near future. Do be in touch with **Becky Madeira (337-7671)** with any questions, thoughts or ideas! Form letters regarding CD children's needs are available for children starting school or day care.

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the new Peter's is  
OPEN!!

and how wonderful it is!!  
"Mega" parking spots, wide aisles,  
shopping carts, a Gluten-Free section  
with expanded product lines, and – of  
course – the beautiful people who are  
there!!

CHECK IT OUT!!

store hours: 9 AM – 8 PM Mon. – Fri.

9 AM – 6 PM Sat.

(Closed Sundays during July & August)

Sept. thru June Sunday hours are

12 Noon – 5 PM

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"The Nurse Practitioner" – a journal for N.P.s  
Vol. 29/No.7 – had an excellent 4-pg. (#42 – 45)  
article on 'Celiac Sprue Treatment in Primary  
Care' – we who live with Celiac Disease are most  
pleased to see the increase in coverage in  
professional journals!

(Thanks to Angie Sosa, N.P./Gastroenterology at  
Slocum Dickson Clinic, for bringing this to our  
attention!)

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### **Eating While Hospitalized**

(guest

column)

**Margaret (Peg) Curtacci  
Certified Dietitian-Nutritionist**

Should an illness necessitate a hospital  
stay, special attention needs to be paid to dietary  
restrictions. When the patient is too ill to self-  
advocate, a family member should be present at  
all meals to assist.

Prior to admission (if possible) contact the  
dietitian to discuss your needs and concerns.  
Providing a written copy of your meal plan may  
be helpful. It is the doctor's responsibility to  
order the diet - and the dietitian's job to plan  
your meal. Several other staff members, nurses,  
cooks, servers will be involved before your meal  
reaches you. My point is that there is a lot of  
places where errors might happen. Do not  
hesitate to question anything appearing to be a  
problem. Remember that dietary supplements  
and medications may also contain gluten.  
Persons with Celiac Disease might consider  
ordering single item foods – foods that have not  
been mixed or seasoned. Gluten free pastas and  
breads may be difficult to identify unless they are  
packaged and sealed. A second option is to have  
family bring in gluten free foods.

The same holds true for other dietary restrictions,  
e.g. - lactose intolerance, diabetes and  
cholesterol-lowering diets. In my opinion gluten  
free and allergy diets are some of the most  
difficult to serve with accuracy.

Dietitians are the trained professionals - but you  
are the person who lives daily with your  
restrictions. The American market is flooded daily

with new food products. Keeping abreast of the  
nutrient content of new foods is very difficult.  
Those of you experienced in planning your own  
restricted diets know this to be only too true.  
Should you need assistance contact myself or  
another CSGMV board member.

**My best advice is three fold:**

- Educate yourself
- Advocate for Yourself
- Stay Healthy !!!!

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Anyone interested in submitting a "piece" for  
future newsletters is most welcome to do so.

You may email it to: [elpa1@juno.com](mailto:elpa1@juno.com)

OR send it to: Eleanor Wallace

10 Clinton St. Apt. 715

Whitesboro, NY 13492

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### NEWS "BITES" -- G-F

Megan Cain (due to a shoulder injury) is  
no longer able to work at OutBack - and this is a  
loss for CSGMV. However, we can (and should)  
still stress our dietary needs when we go there to  
enjoy eating out! Best of Luck, Megan! She also  
checked on Hellman's Classic Deli Potato Salad &  
their salad with bacon & chives - Hellman's says  
they are GF!

Carolyn Trick told us that **TIME**  
magazine had an article in the **7/19/04 issue** –  
titled "Allergic to Wheat?" by Michael D.  
Lemonick. In the article, it is stated that 'some 3  
million Americans may suffer from the illness - 10  
times as many as doctors once thought.'

'The trick now is to teach Primary-care doctors to  
recognize the symptoms and test for the disease.'

Dr. Elliott, director of the Celiac Clinic at  
the University of Iowa medical center, suggests  
(if you have received a diagnosis of celiac  
disease) consulting a professional dietitian about  
how to rid your diet of gluten. While we in  
CSGMV realize there is a distinct advantage to  
consult with a dietitian, we also feel there is  
strong validity in our Support Group – we LIVE  
with a gluten-free diet every day.

**Traveling?** Try packing enough food  
to 'keep you going'; book rooms with  
kitchenettes; call/check with a local support  
group in the area you are visiting for information  
&/or assistance; freeze bread/baked goods to  
preserve shelf life. Take along GF snacks to have  
as needed. Check out fast-food restaurants  
ahead of time to know if they have food  
available that is GF. Many times, if you check  
with the company you plan to travel with/by,  
they may be able to accommodate you (or tell  
you if they can't). **Planning IS the key!**

**Foods that travel well include:**  
dry cereal; nuts; raisins; GF energy bars; GF  
candy (check with manufacturers); freeze-dried  
foods for camping; nutrition drinks (e.g. –  
Ensure).

There is a 'light-hearted' web site – CeliacChicks.com - much about various travel locations & eating. 2 young New York City girls have designed it. Lovely pictures – and some commentary!

**Pure spices** are GF – Bottled spices often contain something to keep the spice free flowing. Usually it's silicon dioxide – but you should read the label (or call the manufacturer) to be sure.

**Remember** – there are now pre-mixed flour blends! Amongst others, Sylvan Border Farms has this available. Check it out – it can make our baking experiences much easier – yes?!?

We cannot say often enough – there are so many great tasting GF foods/mixes out there. **Please do concentrate on what you can eat – not what you can't!!**

**Always read labels** – Product ingredients are subject to change at any time. You can then make informed choices.

**Exclude** foods containing wheat, barley, rye or oats. Also exclude foods that have derivatives from durum, wheat flour, graham flour, kasha, wheat germ, bran & bulgar, triticale, kamut, spelt or mir.

**Include** foods that contain starches from rice, corn, potato, arrowroot, tapioca, soy & legumes.

**Seek specialty information** from reliable sources – GF cookbooks, GF food items (labeled as such); check for UPDATED newsletters, web sites & support groups (make sure the source is reliable!).

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**from Dr. Guandalini – Univ. of Chicago (Spring 2004 CDF newsletter)**

'Most newly diagnosed celiacs start to experience a reduction in symptoms after following the diet for 2-6 weeks. Complete recovery can take 6-12 months depending on the extent of the damage done to the intestine. Also, the duration and severity of the gastrointestinal symptoms before beginning the diet can impact recovery time.'

**Celiacs in college** – should provide the college with a note from the doctor stating you have CD and any other medical conditions present. Meet with the head cafeteria staff and others involved in the meal plan to explain to them about CD – bring information with you. If you feel comfortable that they can meet your needs – try it. Otherwise you might want to have your meal plan reduced – or be excused from it altogether. Then make other arrangements where you can prepare your own food.

## **SOURDOUGH STARTER** (from CDF Spring 2004 Newsletter)

**#1** 1 C. low-fat milk & 5 Tbs. plain yogurt. Choose a yogurt that lists 'Living Yogurt Cultures' as ingredients. Sterilize a 1-qt. jar. Heat the milk to 90 degrees. Remove from heat & stir in the yogurt. Pour into glass container. Cover with plastic wrap & let stand in warm place for 24 – 48 hrs. – or until the starter is the consistency of yogurt. If some liquid rises to the top, stir it back in. If the liquid turns pink, discard & start again. **#2** Add ½ C. of Sylvan Border Farm Flour to the starter. Stir until the starter is smooth. Cover with plastic wrap & let stand in warm place until the mixture is full of bubbles – 2 to 3 days. This mixture is called a **sponge**.

### **PIZZA DOUGH**

½ - ¾ C. Sylvan Border flour  
¾ tsp. salt  
¼ C. dry milk powder  
1 tsp. xanthan gum  
1 ½ C. **sponge**  
1 pkg. yeast dissolved in ¼ C. warm water  
1 T. olive oil

Combine the flour, salt, dry milk powder, & xanthan gum & set aside. In large bowl combine the dissolved yeast, **sponge** & olive oil. Add dry ingredients & mix with a dough hook for 3 minutes.

Sponges vary in consistency so the amount of flour added can vary. Let the dough sit for 20 minutes. Spread on greased pizza pan with an oiled rubber scraper. Cover with favorite sauce & toppings.

**BAKE** at 400 degrees for 25 – 30 minutes.

### **ENJOY!!**

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### OFFICERS:

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