



# CSGMV Newsletter

## “If We Build It - Will You Come?”

At our Teaching Day, May 21, President Pam Fahy presented this rousing question - we have built a viable support group over the past 9+ years (and we plan to continue expanding our horizons)! Because of our growth, willing “hands” are needed to reach out to our area - the media, newly diagnosed Celiacs, and our health-care professionals. YOU can talk with your physician, family members, neighbors & friends about Celiac Disease - and your current status in your journey to a healthier life. When more people are aware that Celiac Disease is not rare, but rarely diagnosed, we become a stronger force in influencing others to be considerate of our absolute need for the availability of GlutenFree products.

This Spring we hosted an April fund-raiser featuring the Sail Cats & their music (including GlutenFree beer tasting!); participated in LifeLong Wellness’ Health Fair; held our May Celiac Teaching Day with Dr. Norman Neslin and Kristin Douglas, RD, as our featured speakers; we spoke to the staff at Outback Steakhouse (and enjoyed a wonderful GF meal as their guests); and we spoke to the North Utica Senior Citizens about CD in June.

We had Elizabeth Barbone (GlutenFree Baking & More) present an instructional program at our February meeting - and she provided bread for our meal at the Teaching Day.

We plan on more speakers at some of our meetings this Fall. We hope you will make an effort to come, join us.

Eleanor

**Make your plans NOW!**  
**November 9-11, 2006**  
*International Celiac Disease Symposium 2006*

November 9-11, 2006  
 Hilton New York  
 1335 Avenue of the Americas  
 New York, NY 10019

For additional information about this event, please contact Cynthia Beckman, Director of Development, at [cb2280@columbia.edu](mailto:cb2280@columbia.edu) or (212) 342-4529  
 Online registration begins Aug.1, 2005

Send in your thoughts/information/questions to:  
 Eleanor  
[elpar6@yahoo.com](mailto:elpar6@yahoo.com)  
 OR call:  
 315-736-6981

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### Special Interest -

?? *Columbia University News for ALL Health Care Professionals—Continuing Medical Education Symposium September 16, 2005*

+

?? *Patient Education Day September 17, 2005*

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## Meetings & Events

**3rd Saturday** of every month, **10 AM**,  
 at New York Mills Library –  
 corner of Main & Maple Sts.  
 (please use BACK entrance  
 off Maple St.)

**July, 16th, 2005**

**August 20th, 2005**

**September 17th, 2005**  
 Eileen Kinsella - speaker  
 Celiac Disease &  
 Neurological Involvement

**October 15th, 2005**

**November 19th, 2005**  
 Ready for Thanksgiving??

**December 17th, 2005**  
**LET'S CELEBRATE Holidays!!**

## PUBLISHING SCHEDULE

CSGMV Newsletter will now be published **4**  
times a year - seasonally!

You MUST notify Eleanor (315-736-6981)  
**OR** email at: [elpar6@yahoo.com](mailto:elpar6@yahoo.com)  
 if you desire to continue to have the Newslet-  
 ter mailed—**along with sending in one of the**  
**following:**

**DUES (\$12/year - pro-rated)**  
**DONATION (whatever you can afford )**  
**OR SPECIFIC REQUEST**  
 (if you truly cannot afford to contribute)

**EVERY DOLLAR HELPS!**

**Make check out to CSGMV/CDF** (including  
 name, address, phone #, and email address)  
 and send to:

**Lavinia Tilton, Treas. CSGMV**

**8801 Passer Rd. Blossvale, NY 13308**

## THANKS go out to -

**Harts Hill Inn**  
**Dr. Norman R. Neslin**  
**Ms. Kristin Douglas' RD**  
**Peter's Cornucopia**  
 (Peter, Phyllis, & Sherri)  
**Gluten-Free Baking & More**  
 (Elizabeth Barbone)  
**EnerG Products**  
**Pamela's Products**  
**Namaste**  
**Gluten-Free Pantry**  
 and **all** the CSGMV "helping hands"  
**Linda Buck, Terry DeCosty, Pam Fahy,**  
**Bonnie Goodman, Linda LaMonica,**  
**Debbie Servello, Vinnie Tilton, &**  
**Eleanor Wallace**  
 for the support and participation  
 received for our  
**2005 Celiac Teaching Day**  
**May 21, 2005**  
**IT WAS A GREAT DAY FOR ALL!!**



The "new look" of our  
 CSGMV "office" -  
 with special THANKS  
 to Eleanor's kids --  
 Carol, Scott, Shari, &  
 Wendy!!

## MEMBER CONTRIBUTIONS

### Eating Right for Celiacs

Kristen Douglas, R.D., Nutritionist at Faxton-St. Lukes Health Care spoke at the May 21st Celiac Teaching Day. Her topic "CELIACS eat Right - Live Right", made a good point. To live healthy a person with Celiac needs to do more than eliminate gluten from their diet. The basis for her presentation was from MYPyramid.gov The new pyramid includes activity and uses a personalized approach. By logging on to MyPyramid.gov a person can find the kinds and amounts of food to eat each day for their individual needs. Much research has been done linking specific foods/food groups to lowering health risks. There is a greater focus on whole grains, vegetables and using more fish, beans, peas, nuts and seeds as protein. Using fish, nuts and vegetable oils as the major source of fat is also recommended. Staying within your calorie needs and being physically active for 30 minutes most days of the week is another recommendation.

Integrating gluten free foods with the new food pyramid can lead to a healthier lifestyle. Check out [MyPyramid.gov](http://MyPyramid.gov) to help get on the right track. If you do not have computer access, your local librarian can help you access the site. Best of Health to You, Peg Curtacci, CDN

### Our members help us out.

from Carolyn Trick -

An email from Alfred Carr, Consumer Affairs Rep. At 'Nature Made' to Carolyn (5/24/05) states that Nature Made Vitamin C 1000 mg. is gluten-free.

\* \* \* \* \*

from Phyllis Pratt -

5/11/05 email from the Jel Sert Company lists a number of products that are GF - contact her - Maureen Moore at <MMoore@jelsert.com> Products listed include: Mondo Fruit Squeezers; Comic Coolers; Fla Vor Ice, Lite, Plus; Pop Ice; Wyler's Light, Drink Mix; Fla Vor Aid; Royal Pudding & Pie Fillings; Royal Gelatins; Keebler Fudge Shoppe Fudge Pops; My T Fine Vanilla, Lemon, Butterscotch, Pumpkin, Tiramisu.

**Never neglect checking with companies yourself—it's**

**the safest practice to maintain "control" over your good health!!**



**Meetings are fun~  
Join us!!**

## NEWS FROM OTHER PLACES

excerpted from *Celiac.com* - 3/2005 -

'Results announced - findings from a survey of 200 Pediatricians, Family Practitioners, and Endocrinologists (The Children's Digestive Health and Nutrition Foundation (CDHNF) with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) reveal the lack of understanding about celiac disease (CD) in children.

The survey results supported the clear and urgent need to promote awareness of the individuals at risk, the associated conditions, the proper method of screening for celiac disease, and the necessary step of confirming the diagnosis with a small intestinal mucosal biopsy.

Regarding the diagnosis of CD, only 16% of respondents chose the most appropriate first line serological screening test for CD, which is the IgA-anti-human tissue transglutaminase antibody. If the patient has positive serology for celiac disease, the majority of the survey respondents did not recognize the need to confirm the diagnosis with an intestinal biopsy before starting a gluten-free diet. Some people unnecessarily are recommended a GF diet, while others at risk are not being properly screened, identified and placed on a GF diet.

**It is also of concern that the permanent nature of CD is not emphasized by our physician respondents. Less than 65% of respondents recognized that a life-long adherence to a GF diet had to be maintained.**

The survey also revealed there is a lack of awareness about associated conditions with CD. An average of 5% of people with Type 1 diabetes have CD. However, less than 50% of respondents were aware of the association and almost 30% were against screening individuals with Type 1 diabetes. In addition, greater than 75% of respondents were unable to identify the condition NOT associated with CD among a list of associated conditions.

"The level of knowledge of celiac disease is not what we like it to be. Clear educational initiatives are needed to promote appropriate testing of persons at risk for CD such as the recently released NASPGHAN Celiac Guidelines, NIH Consensus Conference, and our CDHNF Grand Rounds Program." - *Dr. Stefano Guandalini (survey co-author & Celiac Campaign Scientific Advisor - Univ. of Chicago)*

## RESTAURANT EATING

Gluten Free Menu Available at Outback Steakhouse -  
and soon to be offered at Symeon's.

\* \* \* \* \*

As a Celiac, trying to maintain optimal health, you still need to ask specific questions in order to assure your food is not "cross-contaminated" in the preparation process. Remember, you are your own best advocate!

\* \* \* \* \*

Bard's Tale **GF Beer** - '**Dragon's Gold**' - is available  
through Marcy Discount Beverage Center -

315-736-3993

\* \* \* \* \*

### from Columbia University Celiac Disease Center

#### *Topics in Gastroenterology, Celiac Disease and Beyond*

**Friday, September 16, 2005 9 AM-5 PM**  
**Columbia University Medical Center**  
**Bard Hall**  
**Haven Avenue, New York City**  
**(between 168 & 169th Streets)**

This is a **Continuing Medical Education Symposium** that is open to all physicians, dietitians, nurse practitioners, physician's assistants & other health care providers. Topics include food allergies, celiac disease, sugar intolerances & compliances mechanisms.

**Online registration begins June 30, 2005.**

\* \* \* \* \*

#### *Patient Education Day*

**Saturday, September 17, 2005 9 AM-5 PM**  
**CMCU, Hammer Building**  
**701 West 168th Street (at Fort Washington)**  
**New York City**

This years program will feature sessions on **neurologic complications of celiac disease, diabetes & celiac disease, and research developments.**

There will be a **Teen Corner** which will feature coping strategies, socially navigating on the diet, and cooking. There will be a **Children's Corner** with entertainment.

**Online registration begins June 30, 2005.**

\* \* \* \* \*

Email [celiac@columbia.edu](mailto:celiac@columbia.edu)

Web site [www.celiacdiseasecenter.columbia.edu](http://www.celiacdiseasecenter.columbia.edu)

\* \* \* \* \*

*excerpted message from **Dr. Peter Green**, Director of Celiac Disease Center at Columbia University :*

**'You will appreciate the urgency of our task as you discover that celiac disease is very far from rare. An estimated 3 million Americans are afflicted - today; fully 97% of this population remains undiagnosed!**

In 2006, celiac disease will take center stage in New York City. The Celiac Disease Center will host the XII International Celiac Disease Symposium 2006, which will bring an unprecedented opportunity for each of you to help shape the future of celiac disease by participating - from Nov. 9-11, 2006, at the Hilton NY Hotel, New York City.

We approach our 5th anniversary with much enthusiasm - our physician and patient education programs are providing patients with better access to proper testing, diagnosis, treatment and follow-up care. Our nutritional programs are helping patients navigate life-long gluten-free eating habits.

?? *frequently asked questions:*

***Does celiac disease have a genetic predisposition?***

Yes. Celiac disease is a genetic disease, meaning that it runs in families. Sometimes the disease is triggered—or becomes active for the first time—after surgery, pregnancy, childbirth, viral infection, or severe emotional stress. Because celiac disease is hereditary, family members—particularly first-degree relatives—of people who have been diagnosed should be tested for the disease. About 10% of an affected person's first-degree relatives (parents, siblings, or children) will also have the disease. The longer a person goes undiagnosed and untreated, the greater the chance of developing malnutrition and other serious complications. This delay dramatically increases an individual's risk of developing other autoimmune disorders-including type 1 diabetes, thyroid disease, rheumatoid arthritis, liver

*(Continued on page 5)*

## RESEARCH NEWS

(Continued from pg. 4)

disease, lupus, or even cancer. The only treatment for celiac disease is to follow a gluten-free diet.

### ?? **Is it possible to outgrow celiac disease?**

No. It is a life long illness. There does appear to be a period in which people 'outgrow' the symptoms. This occurs when people who are ill with the disease are diagnosed and go on a gluten-free diet. After a period of time they find they can ingest gluten and not have diarrhea. **But in fact**, each time they are ingesting gluten, they are creating an **ongoing inflammatory process** in the intestine that may lead to the long term complications of celiac disease without ever having diarrhea again! This most frequently occurs in childhood celiac disease when it is known in adolescence that the ingestion of gluten may not cause the symptoms.

### ?? **When should children be tested for celiac disease?**

Children can be tested at any time for the gene (HLA DQ2/8) - this will determine if they have the possibility of ever getting celiac disease. To have the disease they need to be eating gluten. We recommend that children eat a regular diet and be tested at age 5 to 7 years, unless symptoms occur prior to that.'

### ?? **Follow-up Care Guidelines from Celiac Disease Research Center at Columbia University:** We recommend the following guidelines to follow.

1. Annual visits that include a physical examination
2. Periodic blood test to assess nutritional deficiencies & check celiac antibodies
3. Annual visits with an experienced dietitian that would review both the adherence to the gluten-free diet & nutritional quality of this diet
4. Appropriately timed follow-up biopsies
5. Advice regarding the assessment of potential complications of celiac disease
6. The timing of appropriate vaccinations
7. Advice concerning the screening of family members

## ENJOY LIVING YOUR LIFE

The gluten-free diet does offer tremendous variety! Actually, most foods are perfectly safe for you. A luscious bit of steak, a juicy pear, crunchy sugar-snap peas, or a baked sweet potato topped with a lovely little glob of butter will never trigger celiac problems. You must remember that when food has been processed, trouble can begin. Crusts, coatings, sauces and gravies are predominantly made with flour—although they don't have to be. Therefore, the plainer the food, the better!

### **"Go Ahead-Enjoy" list -**

- ?? **Meats, poultry, fish**
- ?? **All dairy products**
- ?? **All fruits**
- ?? **All vegetables**
- ?? **All beans & lentils**
- ?? **Every variety of nuts & seeds**
- ?? **In the starch category**—corn, potatoes, sweet potatoes, parsnip, turnip, yucca, and all the other tubers.
- ?? **AND Good News**—There are actually many delicious grains that pose **NO PROBLEM** for you either. They don't contain the same toxic protein sequence that wheat, rye & barley do.

### **The safe ones -**

- ?? **Buckwheat**
- ?? **Indian grass**
- ?? **Millet**
- ?? **Quinoa**
- ?? **Rice: brown, white, or wild**
- ?? **Teff**
- ?? **Amaranth**
- ?? **Corn**

### **The toxic ones -**

- ?? **Wheat in all its forms, including kamut, semolina, spelt, Triticale & others**
- ?? **Barley, including malt**
- ?? **Rye**

**The "jury is still out" on the subject of Oats—usually it is processed on lines which are contaminated. Although oats does not contain the same toxic protein as the above mentioned "no-no"s,**

*from "The Power's in the Fiber" - USA Today 6/19/05*

**FIBER** - good/safe sources are: brown rice, popcorn, wild rice, buckwheat, quinoa & amaranth. Just make sure these grains are "pure" - not contaminated!

# Mohawk Valley R.O.C.K. (RAISING OUR CELIAC KIDS)



## Contacts for Mohawk Valley R.O.C.K.

### Do you have (or know of) a Celiac child?

**Becky Madiera** -  
celiacparents@earthlink.com

315-337-7671

**Tanya Clute** -  
ADAMSCLUTE@aol.com

315-361-1150

**Bonnie Goodman**  
DOVE352000\_1999@yahoo.com  
315-337-8785

For information regarding meetings,  
assistance with helping your child  
remain Gluten Free, or particulars  
regarding activities for

**Mohawk Valley R.O.C.K.!!**

contact

Tanya, Becky, or Bonnie

(see #s above)

*excerpted from celiac.com - Journal of Pediatric Gastroenterology Nutrition July 2004 -*

‘The **best timing for a general screening children** for Celiac Disease is at age 2 1/2 yrs. This comes from a Spanish Research study. This study indirectly highlights just how many celiac disease diagnoses are missed - most people with celiac disease are still never diagnosed and must live with the disease and its associated problems for life. Those who finally get a diagnosis often spend years suffering before it is figured out. Many get lymphoma and die - which is why we must continue to advocate for celiac disease screenings for the general population - perhaps starting as early as 2-3 years of age.’

*excerpted from University of Chicago Celiac Disease Program Fact Sheets - 5/2005*

### ‘Follow-Up Testing - what does it do?’

Follow-up testing is done to ensure that antibody levels are returning to normal, indicating that the intestine is healing on the new diet. For this reason, repeat intestinal biopsies are no longer necessary. These tests also indicate the extent to which a celiac is avoiding gluten, and can detect when hidden gluten has entered the diet. New celiacs should receive follow-up testing twice in the first year after diagnosis. The first appointment should occur 3-6 months after diagnosis; and the second should occur after 1 year on the GF diet. After that, a celiac should receive testing on a yearly basis.

**Testing needed: #1 tTG-IgA** - This test result should be negative (the numerical value of the test doesn’t matter as long as the result is negative).

**#2 Anti-gliadin IgA** - This result should have a very low negative value - in this case, the numerical value does matter because a high negative test result still indicates that a patient is eating gluten. A low negative indicates that the diet is working well.

\*It’s never too late to begin follow up testing and to learn from the results. Food manufacturing practices change often, and even the most diligent celiac cannot keep up with all the changes. Also, some celiacs find that current health problems may be related to celiac disease - such as anemia or bone density. The reverse is also true - some find that current health problems they’ve attributed to celiac disease are NOT related, because their antibody levels indicate that celiac disease isn’t active. In either case, the patient and physician have received valuable information.’

*from Celiac Disease Center - Columbia Univ.*

“**You’ll Make a Great Teacher** ~ Parents can safely assume that very few people know the principles of a safe celiac diet. Education is desperately needed. And there’s so much you can do!

Basic informational pamphlets & booklets are available from the Center & various support groups. Grab an armful, and be generous with them. Distribute them in school, share them with your friends, and especially, get them into the hands of anyone expected to come into contact with a child with celiac disease.

Providing a specific list of allowed, safe foods to anyone and everyone who may be offering the child something to eat is a very effective way to decrease the stress and insecurity of social situations for your kid.

Getting others aware and involved will take time, patience, and a LOT of repetition. BUT it can make a big, positive difference in your child’s life!!”

## FROM THE UNIVERSITY OF CHICAGO CELIAC DISEASE PROGRAM

### The Importance of a Second Opinion ~

It may be the understatement of the century to say that receiving a diagnosis of celiac disease is often difficult and frustrating. Finding a gastroenterologist who can and will perform the diagnostic tests for celiac disease is a big step forward. Yet many patients find they have inconclusive results—positive tTG or EMA tests, and a negative biopsy. Others receive conflicting information—their doctors may suggest a trial of the gluten-free diet before testing, or order different blood tests and not recommend a biopsy.

It is understandable that many people in this situation would pursue the gf diet before receiving a diagnosis, especially those who live in small towns or have restrictive health insurance plans.

Before taking this step, there is another to consider—seeking a second opinion. The purpose of a second opinion is to have an outside perspective, from an experienced physician, to determine if the test ordered, the biopsies taken, the patient's medical history and clinical exams support the diagnosis that has been given. (OR, if no diagnosis had been given, can one reach a diagnosis with the information presented?)

Most people with celiac disease would inject a healthy dose of skepticism at this point—and understandably so. However, there are steps every person can take to know as much about their health as possible. It takes some additional work but this can bring a great peace of mind!

#### **Step 1: Request Copies of all of your medical records**

You have the right to request copies of all blood tests and the biopsy report (if you had one). Keep a file of all test results as a matter of course for every person in your family. This information will help you to know how a second opinion can best help you.

#### **Step 2: Select a Doctor for a Second Opinion**

A physician who is providing you with a second opinion must be outside the practice or hospital where you have been treated. This helps to ensure that you will receive a truly independent review of your medical care. When you make the appointment, ask about the procedure for sending your biopsy slides for review.

For many people, this will require travel to another town. Use the recent NIH consensus statement on celiac disease to educate your insurance company about the standard of care for diagnosing celiac disease. If you can show that your doctor has not provided the standard of care, you've established why it is necessary for your

Insurance company to pay for 'care out of network'.

If you or your child has a complex medical situation, consider making an appointment at a celiac center like the University of Chicago, Columbia University, or the University of Maryland. There are often low-cost lodging facilities (like Ronald McDonald house for children) and low-cost airfares on airlines.

#### **Step 3: Consider a Second Opinion with a Pathologist**

Patients with a strong family history or symptoms that are highly consistent with celiac disease, who have been told that their biopsies were negative, should consider having the slides re-read by a pathologist. While it is possible to send the slides without a doctor's appointment (depending on the celiac center) we would recommend making an appointment and having the slides sent along as well. At the University of Chicago, we prefer having both an expert pathologist's view, and an expert gastroenterologist's opinion about a patient's condition. An expert pathologist can often find subtle signs of celiac disease that are otherwise missed.

If you have questions about how to seek a second opinion, call the University of Chicago Celiac Disease Program at 773-702-7593.

*Reprinted with permission from the University of Chicago Celiac Disease Program*

### KEY MESSAGES

- ?? Celiac disease affects as many people as Alzheimer's disease in the United States.
- ?? In **NY state**, based on the 2003 census figures of 19,190,115 people—144,286 have celiac disease and 97% of them (139,957) don't know it. In **Oneida County**, of 234,373 people in the 2000 census, 1,762 have CD and 1,709 do not know this. In **Utica**, again based on the 2000 census, 456 people have CD—and 442 are unaware! This is based on the factor of 1 in 133 people living with CD.
- ?? The most common risk factors in adults include anemia that does not respond to iron therapy, IBS-type symptoms and conditions like infertility.
- ?? The most common risk factors in children include growth problems (children are short or underweight), bloating, muscle wasting and diarrhea.

## RECIPES to ENJOY!

### Cole Slaw

(Eileen Kinsella)

- 1 16 oz. pkg. Cole slaw mix
- 1 med. Red pepper – chopped
- 8 oz. can water chestnuts  
(drained – may chop a little)
- ½ C. chopped onion
- Sauce: ½ C. oil
- ½ C. vinegar
- ¼ C sugar
- 1 tsp. salt
- 1tsp. pepper

**MIX TOGETHER – ENJOY --  
especially on warm summer days!**



### HAWAIIAN SALAD:

(from Helen Garlock)  
1 C. rice (cooked;  
rinsed in cold  
water; drain well)

- 1/3 C. sugar
- 1 egg
- 1 T. G-F flour (OR cornstarch)
- dash of salt
- 1 lg. Can crushed pineapple
- 1 lg. Can mandarin oranges  
(OR 3 fresh oranges)
- 1 jar maraschino cherries
- 5-6 oz. Cool Whip
- add slivered almonds
- Drain juices from fruit – and save.
- Mix fruit juices with sugar, egg,

### CREAMSICLE FUDGE

(from Melody Ernst)

- 1 ¾ c. sugar
- 1 ½ c. Nestle white choc. morsels
- 2/3 c. evap. Milk
- 20 Large marshmallows
- Combine first 4 ingredients in heavy saucepan, bring to a boil over medium heat, stir constantly while boiling 5 mins. Remove and add marshmallows and morsels and stir

### DELICIOUS Chocolate Cake:

- 1 ¾ C. G-F flour mix
- 2 eggs
- 1 ½ t. baking soda
- 1 t. salt
- 1 C. milk
- 1 ½ t. baking powder
- Sift together above ingredients.
- 2 C. sugar
- ¾ C. G-F baking cocoa
- 1 ½ t. Xanthan gum
- ½ C. vegetable oil
- 1 C. boiling water
- 2 t. vanilla

flour, salt – and cook until mixture comes to a boil.

Pour juice mixture (will be rather thin) over rice – AND cool overnight.

Mix Cool Whip, fruit, and rice before serving.

May add a little orange juice OR more Cool Whip to get the texture you prefer.

**ALWAYS CHECK YOUR  
INGREDIENTS TO ASSURE  
THEY ARE GLUTEN-FREE!**

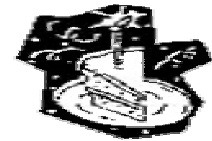
until all melted and smooth texture. Stir in vanilla (and nuts if desired). Pour 2/3 into buttered glass cake pan. Add orange extract and orange food coloring to remaining 1/3 fudge mixture until proper orange color. Drizzle orange over white mixture and pull a knife through to cut the orange into the white. Cool and then cut.

Combine dry ingredients in large mixing bowl. Add eggs, milk, oil and vanilla. Stir in boiling water.

Batter will be thin. Pour into greased & floured 13" x 9" x 2" pan.

Bake for 35-40 min. in 350 degree oven, or until cake tester comes out clean. Cool.

Frost – OR dust with confectioner's powdered sugar. OR top with whipped cream!!! **ENJOY.....**



### CORN-FLAKE COOKIES

(from Gaile Lepper)

**(MAKE SURE ALL INGREDIENTS ARE G-F)**

- 1 stick oleo
- 1 large bag marshmallows (G-F)
- 2 tsp. green food coloring OR red OR any color
- 4 ½ C. Cornflakes (G-F)
- 1 tsp. Vanilla

Melt butter, marshmallows – add food coloring. Add cornflakes. Mix – spoon onto greased cookie sheet or waxed paper. Decorate (if desired) w/colored sugar. Let cool...

Enjoy!

(Hint -- grease spoon to drop cookies).

### EASY Chocolate Frosting

- 1 can Condensed milk
- 2 squares unsweetened baking chocolate (melted)
- 1 tsp. vanilla extract
- 1 Tbs. water

Over LOW heat, constantly stirring, bring to simmer—continue until it starts to thicken. Remove from heat—add vanilla. Allow to cool—frosts 1- 8" square cake!

## MEDIA ARTICLES -

*excerpted from "Prevention" magazine  
June 2005:*

**"GAUGE RISK** - Only 1% of Americans are estimated to have celiac disease - but one family member has it, the immediate family is 10% more likely to have it also, even if they show no signs of it. Relatives who already have an autoimmune disease are 25% more likely to get celiac disease.

### **RECOGNIZE SYMPTOMS** -

They can include chronic diarrhea, abdominal bloating and pain, weight loss, foul-smelling stool, seizures, edema, and a painful skin rash.

**GET TESTED** - Your doctor can give you a panel of blood tests to assess the levels of certain antibod-

ies that are typically high in people with celiac disease. If the tests are positive, the physician may perform a biopsy to sample tissue in your small intestine - the only sure way to diagnose the problem. The biopsy is done with an endoscope, a long thin tube that's eased through the mouth and stomach into the small intestine. Hospitalization is not usually required.

### **FIND THE RIGHT TREATMENT - ONLY ONE APPROACH WORKS -- ELIMINATE GLUTEN!"**

'Diagnosis takes an average of 11 years - in many cases, a person is symptom-free even while the illness destroys the intestinal lining (preventing absorption of vital nu-

trients for the body). These nutrients include calcium, vitamin D, folic acid & iron. Left untreated, the disease can cause osteoporosis, anemia, infertility, miscarriages, and lymphoma.'

'There's no magic pill to cure the problem - just PERMANENT elimination of gluten sources from the diet including cereals, pasta, flour products, bread, cold cuts, prepared foods, and soy sauce.'

But today there are available some great gluten-free "replacements" in the line of cereals, bread, pastries, pasta., prepared mixes - Manufacturers are also more aware of the gluten free needs of celiacs. Celiacs can eat well - and healthily!

## MORE INFORMATION in Print -

*taken from LABMEDICINE \* Volume 36  
Number 6 June 2005 (provided by Gerry  
Wilklow, CSGMV member)*

*Michael Nimmo, MD University of British  
Columbia Hospital, Vancouver, Canada*

"Traditionally, celiac disease was considered to be an uncommon disease characterized by gastrointestinal symptoms, predominantly diarrhea. The introduction of new serologic tests and better understanding of the protean manifestations of celiac disease have helped identify

celiac disease as a relatively common, multi-system disease that may occur at any age. ---

Management of Celiac Disease therapy is strictly adhering to a gluten free diet, which should only be recommended after appropriate testing. Gluten free equates to eliminating wheat, rye, barley and oats from the diet - as well as their byproducts. In some writings, oats would appear to be acceptable. HOWEVER, oats may often be contaminated by glu-

ten during processing. Management of individuals with celiac disease involves consultation with a skilled dietitian, education, monitoring for nutritional deficiencies, and continuous long-term follow-up."



[It may be noted that a couple of CSGMV members have tried eating oats in the past - and became very ill following their experience.]

## More Recipes ~

### Impossible Coconut Squares

*(from Jean Williams, CSGMV member)*

- 2 C. milk
- 1/4 C. margarine or butter  
(softened)
- 4 eggs
- 3/4 C. sugar
- 1/2 C. Pamela's baking mix
- 1 1/2 tsp. vanilla
- 1 C. flaked/shredded coconut

Grease 9"x9" pan.

Stir all ingredients until well-blended. Pour in pan. Bake 40-50 minutes—until golden brown & knife inserted in center comes out clean.

Refrigerate any remaining food in pan.

\*(Recipe may be doubled for a 9"x13" pan.)

**ENJOY a cool desert!!**

Send your favorite  
"people-tested" recipes to  
Eleanor at  
elpar6@yahoo.com  
to see them here -  
And share them with our  
members!

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Visit our Web Site at:  
[www.csgmv.org](http://www.csgmv.org)

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Gluten-Free & Sugar-Free Products

**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.