a "connection" of the
Celiac Disease Foundation
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WEB SITE -- 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.
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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 –
Sat., December 20, 2003
-- In 2004 --
Sat., January 17, 2004
FRI., January 23, 2004 DINNER
<MA K E
RESERV A TI ON S
N OW!!>
Sat., February 21, 2004
Sat., March 20, 2004
Sat., April 17, 2004

IMPORTANT REMINDER!!!

Remember the **surveys** we passed out in the Summer - from the Columbia-Presbyterian Celiac Research Center in NY City??? We have returned 60% to them (and they commend us for that). However, they would like **EVERYONE** to get their form completed and returned…. Can we "earn a star" and do this??? (Remember, it's to help ourselves as much as helping research)… **IF you've "lost" yours, contact Eleanor at 315-736-6981 – we'll try to get you a form….**

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Congratulations to Arnoldine Bartoszek - who will continue to serve as Director of CSGMV for a term – ending in '06! We do deeply appreciate her work and dedication!

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PRESIDENTS MESSAGE

Happy Holidays!! 'Tis the season to eat "gluten free" and be merry… We all know how hard that can be. The good news is we have many new "good " products out there to enjoy. With December approaching we look forward to our December meeting where we will do a holiday goodie sampling. So bring your best holiday goodie to share – along with the recipe. It should be a delicious meeting on December 20th.

I received a news flash from the American Celiac Task Force on Friday November 21. The Senate HELP Committee passed the Food Allergen Labeling Legislation!!! This is 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 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."

The American Celiac Task Force attributes this huge step to our unified efforts. Our voices were heard and taken seriously. They say the next step is the Senate Floor!

Thank you to all who made your voice heard from our area. You make it better for all of us.

I would also like to talk about oats. At this time there are no national or local celiac groups that support the use of oats in the USA. This is due to the contamination factor. The oats on the market are considered unsafe. Some of the foreign oat producers say their product is pure but DO NOT certify a Gluten Free product. So from the perspective of the Celiac Support Group of the Mohawk Valley – We Do Not condone the use of oats in the gluten free diet. If you consume oats it is at your own risk.

We have again scheduled a dinner this year on Friday January 23rd 2004. The Franklin Hotel in Rome will be the place for our yummy event. We are working on the menu and expect it to be no less than excellent. The prices will follow last years lead. We will have an insert along with our newsletter so that you can make your reservations. If you went to or heard about the dinner last year, you won't want to miss it this year.

Hope your holidays are filled with Peace, Love and Joy!

Pam

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excerpts from Celiac.com

Winter 2003 edition of Celiac.com's
Scott-Free Newsletter

'There are many reports of learning problems in association with untreated celiac disease. A majority of children with celiac disease display the signs and symptoms of attention deficit disorder (ADD/ADHD)[1, 2] a range of learning difficulties[3] and developmental delays[4-6]. Many of the same problems are found more frequently among those with gluten sensitivity[7] a condition signaled by immune reactions against this most common element of the modern diet. Grain consumption can also cause specific nutrient deficiencies that are known to play an important role in learning. Grains can also cause problems with blood sugar/insulin levels resulting in reduced capacities for learning. Further, foods derived from grain are an important element in the current epidemic of hypoglycemia, obesity, and Type 2 diabetes[8-10].

Our growing understanding of the biological impact of cereal grain consumption must move educators to challenge current dietary trends.'

'Grains are a poverty food. As we increase our grain consumption, we cause deficiencies in other nutrients by overwhelming the absorptive and transport mechanisms at work in our intestines. For instance, diets dominated by grains have been shown to induce iron deficiency[22]—a condition that is widely recognized as causing learning disabilities[23-29]. This should not be surprising since iron is the carrier used to distribute oxygen throughout our bodies, including various regions of our brains. There is little room to dispute the hazards to learning posed by reductions in oxygen supply to the brain. Iron deficiency reduces available oxygen in the brain, revealing yet another dimension of gluten grains as mediators of learning difficulties.'

Neurology
May 27, 2003 (Volume 60, Number 10)
Celiac Neuropathy

Chin RL, Sander HW, Brannagan TH, et al. *Neurology*. 2003 (excerpted from Medscape)

'Celiac disease (CD) is classified as a chronic inflammatory enteropathy that results from sensitivity to gluten ingestion. Neurological dysfunction can result and occurs in approximately 10% of affected individuals. The most common neurological complications include ataxia and peripheral neuropathy. Chin and colleagues conducted an analysis to determine clinical presentation and incidence of CD in patients with neuropathy.

In total, 20 patients with neuropathy and biopsy-proven CD were identified. The majority of the patients had sensory neuropathy and normal or mildly abnormal electrophysiologic studies. Of the 20 patients, 6 exhibited only neuropathic symptoms without gastrointestinal

involvement, and neuropathic symptoms preceded other CD symptoms in an additional 3 patients.

The clinical presentation included burning, tingling, and numbness involving the hands and feet with distal sensory loss.

Nine of the patients had diffuse paresthesias of the face, trunk, or lumbosacral region, whereas only 2 patients developed weakness. The authors emphasized the common association between CD and sensory neuropathy and urged clinicians to consider the diagnosis even in the absence of gastrointestinal symptoms.'

excerpted from a study by Dr. Peter Green, Columbia-Presbyterian Center for Celiac Research

"The most striking feature of our study is that the risk for non-Hodgkin's lymphoma persisted despite diagnose and treatment with a gluten-free diet," Dr. Green said in an interview with Reuters Health. The non-Hodgkin's lymphoma included T-cell and B-cell types, and was found in gastrointestinal sites in five patients and extraintestinal sites in four patients.

"The main implication [of these results] is that patients with [celiac disease] need to be followed closely after diagnosis," Dr. Green explained. "In addition, it raises the possibility that despite the patients adhering to a strict gluten-free diet they may in fact be consuming gluten," he noted. "This is because it may be very hard in the U.S. to be on a strict gluten-free diet [because] gluten is frequently present in processed food and in food that is prepared out of the home."
Am J Med 2003;115:191-195.

excerpted from e-mail from Howard Winfield at Columbia Presbyterian Cellac Research Center:

Celiac Disease Finally Moves to Primetime in the United States

'**Disclosures**:
Alessio Fasano, MD Baltimore, Tuesday, October 14, 2003 – Celiac disease (CD) was one of the featured topics during today's scientific sessions at **the annual meeting of the American College of Gastroenterology**.
CD is an immune-mediated enteropathy triggered by the ingestion of gluten-containing grains (including wheat, rye, and barley) in genetically susceptible individuals. Discussion during a fully attended breakfast session and findings reported in several abstracts helped counter the common belief that CD is so rare in the United States that it is very unlikely for gastroenterologists to encounter a case during their professional career. A series of such tenets capitulated following today's presentations.

Epidemiology: The Global Village of CD
The general perception that CD is rare in the United States had not been substantiated by any large epidemiologic study. However, this controversy regarding prevalence has been put to rest by a series of recent reports[1] suggesting that **CD is as frequent in this country (prevalence in the general population of 1:133)[2] as it is in Europe. The bottom line is that if you search for it, you will find it.**

Clinical Presentation: Not Only Intestine
CD can manifest itself with a previously unappreciated range of clinical presentations, including the typical malabsorption syndrome (chronic diarrhea, weight loss, abdominal distension) affecting children, as well as in a spectrum of symptoms involving potentially any organ system. Recent epidemiologic studies showed that adult-onset, extraintestinal forms of CD are much more frequent than classical pediatric forms of the disease.[3] **Because CD often presents in an atypical or even silent manner, many cases remain undiagnosed and thus carry the risk of long-term complications, including osteoporosis,[4] infertility, neurologic disorders, or cancer.**
Diagnosis: From Stool Testing to Genomics
The mainstay of CD diagnosis is a small intestinal biopsy showing the typical celiac enteropathy followed by clinical (and, in selected cases, histologic) remission after treatment with a gluten-free diet.[5] Until the early 1980s, the diagnostic tools available for CD were rudimentary at best, being based on nonspecific tests. During the past 2 decades, however, a number of serologic tests have been developed that now have a definite role in the diagnostic process.
The antigliadin antibodies (AGA; both IgG and IgA class) developed in the early 1980s have been followed by development of the more specific antiendomysium antibody (EMA) tests. The technical difficulties associated with the EMA assay, along with the identification of tissue transglut-aminase as the target antigen for the EMA,

paved the way for development of the latest generation of serologic tests for CD -- the human anti-tissue transglutaminase (tTGA) antibody assay, now widely used as the main screening study for CD.

Management: Don't Abandon Your Patient
Complete lifelong abstinence from gluten ingestion remains the cornerstone of treatment for this disease.[8] Adherence to this diet requires the ongoing education of patients and their families by both physicians and dieticians**. Regional CD support groups are instrumental sources of information and emotional support.**
The general acknowledge-ment among patients with CD is that once diagnosed, one set of problems often ends while another series of challenges begins.
In this context, what is particularly frustrating is the limited information regarding what constitutes a gluten-free diet, what is safe and what is not, how to check for compliance, identifying the complications of untreated CD or of a delayed diagnosis, and how often it is necessary to follow up with the Gastro-enterologist, among many other issues.'

Why We "Missed the Boat"

'If CD is so common in the United States, one must question why it is not diagnosed more frequently. The most obvious explanation is that if physicians perceive that CD is rare, they are less likely to test for it. Additionally, the failure of clinicians to fully appreciate that many individuals initially present without gastro-intestinal symptoms may offer another explanation as to why CD testing is not performed as frequently. A survey among primary-care physicians and gastroenterologists presented during these meeting proceedings confirmed the limited level of awareness (mainly among primary-care physicians) regarding several aspects of CD, specifically concerning its variable clinical presentations, diagnostic algorithms, and approach to management.[10] The exclusive use of the more widely known but less sensitive and specific AGA assay instead of the EMA and tTGA tests could also result in missed/inappropriate diagnoses. Even when gastrointestinal symptoms are present and a gastrointestinal endoscopy is performed, endoscopists do not always obtain intestinal biopsies that could demonstrate the presence of CD.
Finally, if pathologists do not recognize early features of CD (Marsh stages 1, 2, and 3a), further confounding and missed diagnoses may result.

Due to the high morbidity and mortality related to untreated CD and the prolonged delay in diagnosis in the United States,[2] serologic testing of at-risk patients (ie, case finding) should be considered the best strategy for maximiz-ing our current knowledge regarding CD, alleviating unnecessary suffering among patients, preventing complications, and improving the quality of life of the many individuals with CD.'
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Anxious to "make a difference"?? Share the above information with YOUR physician – and help us all!!

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RECIPE

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.

Gluten-Free Diet **by Shelley Case, R.D. available at CSGMV meetings - $15.00**

~ Mohawk Valley R.O.C.K. NEWS –

Publication of a Children's Cookbook by the Celiac Disease Center
Title: ***Nothing Beats Gluten-Free Cooking***
Authors: Anne Roland Lee, Susan Cohen & Laura Leon
To purchase online for $25 (including shipping): www.cdcc.hs.columbia.edu