



a "connection" of the
Celiac Disease Foundation
 csgmv-news ISSUE II-6
 November – December 2002
WEB SITE -- www.csgmv.org

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

ELECTION of OFFICERS
 held at the November 16th meeting -
 (officers for 2-yr. terms) results:

▪ **President – Pam Fahy**
 ▪ **Vice President – Louann Harto**
 ▪ **Secretary – Eleanor Wallace**
 ▪ **Treasurer – Lavinia Tilton**
 ▪ **Director**
 (class '05) – **Linda LaMonica**
 continuing in office are:
 (class '04) – **Eileen Kinsella**
 (class '03) – **Arnoldine Bartoszek**

ADVISORY BOARD

- Mark W. Adsit, MD
 Gastroenterologist
- Kathy Benjamin, MD 734-3161
 Pediatrician –
 Women & Children's Health
- Margaret Curtacci, RD 865-7498
 Curtacci Nutrition Care
- Sharon Hoff, RD 361-2028
 Oneida City Health Care Center
- Norman R. Neslin, MD 793-0205
 Gastroenterologist –
 Digestive Medicine of Central
 New York

CONGRATULATIONS to Louann Harto

– she was inducted into
 Sigma Theta Tau – Delta Pi chapter (an Nurses' HONOR Society). She also received a fellowship for her studies in nursing.

A SINCERE Thank-You

to **Peg Curtacci** for a great presentation on Chiari and Syringomyelia at our October 19th CSGMV meeting. She sponsored a fund-raiser on Nov. 2nd to increase awareness and provide monies to support research in this disease. **Over \$3,000 was raised at this event!!** (Congratulations – Peg!!) She explained that there are similarities between Chiari Malformation and Celiac Disease: it is rarely properly diagnosed; it is an autoimmune condition; funding for research is paramount to learning, more and being able to help more people who live with this disease.

Peg also stressed that she remains an available contact for our CSGMV members in view of the fact that she is a Registered Dietitian, and a member of our Advisory Board. She may be reached by phone at 865-7498 or e-mail at jtcpres@borg.com

The organization for this research is ASAP (The American Syringomyelia Alliance Project, Inc.) and you may contact the organization at **1-800-2727 (or write ASAP, PO Box 1586, Longview, TX 75606-1586)** for more information and/or to make a donation...The website for ASAP is www.asap4sm.org

"I am deeply concerned about products made by commercial bakeries and health food stores. They could be using the same scoop, the same sifter with rice flour as wheat, for example. So do rely on gluten free manufacturers for your products."

(Shelley Case, B.Sc., RD-report at Annual CDF Mtg.)

FROM THE "NET"

- "Depressive symptoms are a feature of CD; they are present to a similar extent in patients with childhood- and adulthood-diagnosed CD. The results underline the relevance of personal psychologic resources, which play a fundamental role in determining and sustaining depression."
- Celiac.com 11/27/2002 - According to recommendations made at the 127th Annual Scientific Meeting of the American Neurological Association (ANA), **a diagnosis of celiac neuropathy should be considered in patients with neuropathy of otherwise unknown etiology, including in patients without any gastrointestinal symptoms.**

Dr. Russell L. Chin and colleagues from the Columbia University College of Physicians and Surgeons in New York, New York reviewed the records of 20 patients who had neuropathy and biopsy-confirmed celiac disease and found that six had neuropathic symptoms with no gastrointestinal symptoms and three had the neuropathic symptoms before any symptoms of celiac disease appeared. All of the patients had burning, tingling and numbness in their hands and feet that included distal sensory loss, and nine had diffuse paresthesias that involved the face, trunk, and/or lumbosacral region. Two of these patients also exhibited weakness.

This article originally appeared at <http://hnn.us/articles/1125.html> and is reprinted here by permission of Richard Shenkman.

Celiac.com 11/27/2002 - New revelations that have appeared in the New York Times and the Atlantic Monthly, about John F. Kennedy's health have raised questions about his physical condition during his presidency. Robert Dallek, in the December Atlantic Monthly, described in "The Medical Ordeals of JFK" long standing medical problems that started in childhood. In Kennedy's adolescence, gastrointestinal symptoms, weight and growth problems as well as fatigue were described. Later in life, he suffered from abdominal pain, diarrhea, weight loss, osteoporosis, migraine and Addison's disease. Chronic back problems, due to osteoporosis resulted in several operations and required medications for chronic pain. He was extensively evaluated in major medical centers including the Mayo Clinic and hospitals in Boston, New Haven and New York. Among the multiple diagnoses were ulcers, colitis, spastic colitis, irritable bowel syndrome, and food allergies. His medications included corticosteroids, antispasmodics, Metamucil and Lomotil. However it is not clear that his physicians obtained a definitive diagnosis. Review of this medical history raises the possibility that JFK had celiac disease. Celiac disease is caused by ingestion of gluten, which is the main protein component of wheat and related cereals, rye and barley. The small intestine develops villous atrophy that results in difficulties in the absorption of nutrients. Diarrhea and abdominal pain are common symptoms. Elimination of gluten from the diet results in resolution of the inflammatory

condition in the intestine and the associated symptoms and prevention of the complications of the disease. A life-long gluten free diet is then required. People with celiac disease, providing they adhere to the diet have normal longevity. Celiac disease can present at any age. In infancy and childhood it may cause chronic diarrhea, abdominal pain, and growth, behavioral and development problems. In older individuals the presentation of celiac disease is frequently due to the development of complications of the disease. These include anemia, osteoporosis, skin rashes or neurologic problems. The neurologic problems include neuropathy, epilepsy, ataxia (balance disorders) and migraine. While the disease is more common in females, men are affected as well. Osteoporosis is common in patients with celiac disease, men often are more severely affected than women. Gastrointestinal symptoms in celiac disease persist for many years prior to diagnosis and are often attributed to an irritable bowel syndrome or spastic colitis. Patients typically see many physicians prior to the diagnosis of celiac disease. Autoimmune disorders occur more frequently in patients with celiac disease than the general population by a factor of ten. Frequently the autoimmune disorder assumes greater clinical significance than the celiac disease and as a result is diagnosed first. The associated autoimmune disorders include thyroid dysfunction, psoriasis, dermatitis herpetiformis (an intensely itchy skin rash), Sjogren's syndrome, and Addison's disease. Relatives of patients with celiac disease have a greater risk, not only of celiac disease, but also of other autoimmune diseases.

**-MAKE YOUR RESERVATION -
-NOW-**

DINNER at HART'S HILL INN

Saturday, January 4th, 2003

at 6 o'clock in the evening

a hot Gluten-Free buffet will be held for members and their friends and family at Hart's Hill Inn.

Reservations ARE necessary by Dec. 22!!.

Use form on colored page of this newsletter.

Cost (including tax & gratuity) will be: \$13.00 per adult;

\$11.50 per person (age 10-16)

\$9.00 per child (age 5-10);

\$6.25 per child (age 2-5).....

make checks payable to CSGMV

& MAIL TO: Lavinia Tilton

8081 Passer Rd.

Blossvale, NY 13308

GF Menu: Fruit salad; tossed garden salad; baked chicken; oven-browned potatoes; hot vegetable; wild rice & veggies; sausage & peppers; cold roast beef; beverages; butter/ bread; dessert!!

Eileen Kinsella spoke to the **CNYCSG** meeting, **October 20th**, and she may be invited to address **Medical Students** at Syracuse SUNY, in Spring 2003. This is a wonderful avenue to pursue – and we sincerely **"Thank"** her for her **efforts** in helping to educate the Medical

community, as well as working with our "sister" support group!! "You go, girl!".....

SPRITZ COOKIES

1 ½ C. margarine	1 C. sugar
1 egg	4 C. white rice flour
1 t. vanilla	1 t. baking powder
1 t. almond extract	¼ t. salt

Sift together the flour, baking powder and salt. Cream butter until very soft. Work in sugar, egg and extracts. Add flour mixture gradually. Form cookies with press or cookie shooter on ungreased cookie sheets. Decorate as desired and bake at 400 degrees F. for 8-10 minutes. Makes 7 ½ dozen cookies.

'GLUTEN CHALLENGE' – yes or no??

A "gluten challenge" (eating large amounts of gluten and then following up with re-testing for CD) is **ONLY necessary** when a person has uncertain/negative antibody tests – or when diagnosis is "iffy".

It is NOT a recommendation, as a general rule.

On November 13, 2002 –

Suzanne Elinskas "manned" a booth (with fellow student Audrey Harris) for **Celiac Disease** at the **SUNYIT Health Fair** – several "handouts" were offered. About 50 people stopped by to learn about Celiac Disease – (AND 4-5 faculty and/or maintenance workers ARE Celiacs!).

CSGMV offers our heartfelt thanks to her for this effort!! It lightens the "load" on our "regular" workers.....

She is currently working toward a Bachelor Degree in Nursing– and we wish her great success in her endeavors – **AND** welcome her to our "fold"!!



- Mohawk Valley

R.O.C.K. NEWS –

Mohawk Valley R.O.C.K. met on 11/23 - the Maderia and Clute families were in attendance. We completed the ROCK flyer to send to doctors' offices, grocery stores, anywhere we can make it known that we are here. We will get copies and be sending or hand delivering these soon. We also have a rough draft of a press release. Tanya spoke to a contact at the Rome Sentinel who will help get it in when we are ready. We served Chebe Bread pizza with lactose free mozzarella and everyone (including the non-Celiacs) agreed that this is the best GF pizza crust yet! We also served Chocolate Topped Peanut Butter Bars - always quick and delicious. (see recipe below) We had a relaxing evening discussing GF products (ie: Goya Rice Mixes - not the cheese ones), lactose free cheeses, trading recipes and stories. We enjoy each others company and find it reassuring that we can lean on each other anytime. We hope that our flyer and press release will get the word out and more families can join us. We will meet again after the holidays in January. Remember to spread the word! Contact Becky at 337-7671 -

celiacparents@earthlink.net or Tanya at 361-1150 - tsuadaclu@yahoo.com for more information.

Have a wonderful holiday season!

Chocolate Topped Peanut Butter Bars

1/2 C. sugar	2 eggs
1 C. Peanut Butter	4 oz. chocolate chips

Beat sugar and eggs. Beat in peanut butter. spread into 8 X 8 greased pan. Bake at 325 for 25 minutes. Remove from oven and immediately sprinkle chocolate on top and cover lightly with foil. Let stand

3-5 minutes. Spread chocolate and cut bars. ENJOY!