



there IS Life After Diagnosis!!

a "connection" of the
Celiac Disease Foundation
csgmv-news ISSUE III- 5
September – October 2003
WEB SITE -- www.csgmv.org

OFFICERS

President – Pam Fahy 865-4247
V. President – Louann Harto 865-8551
Secretary – Eleanor Wallace 736-6981
Treasurer – Lavinia Tilton 337-8841

Directors:

Linda LaMonica ('05) 337-3870
Eileen Kinsella ('04) 363-4632
Arnoldine Bartoszek ('03) 768-8290

ADVISORY BOARD

Mark W. Adsit, MD 518-243-4492
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 624-7000
Gastroenterologist – Digestive Disease
Medicine of Central New York

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 –

Sat., October 18, 2003

Sat., November 15, 2003

Sat., December 20, 2003

-- In 2004 --

Sat., January 17, 2004 – DINNER(?)

Sat., February 21, 2004

Sat., March 20, 2004

Sat., April 17, 2004

Sat., May 15, 2004

Sat., June 19, 2004



~ MOHAWK VALLEY
R.O.C.K. NEWS ~

We had our R.O.C.K. meeting yesterday -- (8/30/03) -- at Delta Lake.

In attendance was: Joe, Becky, Josh, Anthony, Derick, Isabella Madeira - and John, Tanya and Cassandra Clute.

We also had a birthday party for John who turned 40 years old 8/29. We started with chips- Isabella tried Cheetos for the first time , she really loved them and her hands were really orange. Her and Cassandra pretty much ate the whole bag and of course they are GF. We grilled hotdogs, hamburgers, sausages and peppers, clams, snappy grillers. We also brought salt potatoes and baked beans w/bacon all for lunch/dinner. We then went to the beach where the kids all played in the water. The weather got bad so we went to the Madeira's house and had a chocolate cookie cake was made by Tanya and a chocolate pie in a GF graham cracker crust was made by myself. Everything was GF, but we did have gluten buns for those who are not Celiacs. The main thing talked about was the GF snappy grillers they are very good, John indicated that they are best when grilled. We also talked about Wegman's and that they carry breakfast bars made for children, which are really nice for on the go families. Isabella has the peanut butter and chocolate flavors. They also have a berry flavor that she has not tried yet. We have not heard from any families with children w/CD. We will continue to have our meetings and hope that someone else will show up. I will continue to e-mail all the contacts that I have, and receive in the future. The next meeting has not been scheduled.

Thank you – Becky Madeira

Celiac.com 09/03/2003 - *The results of a study conducted by Dr. Peter Green and colleagues at the College of Physicians and Surgeons in New York City indicate that, despite a gluten-free diet, people with celiac disease still have an elevated risk of getting non-Hodgkin's lymphoma. The good news is that the risk of getting other types of cancers like small intestinal adenocarcinoma, esophageal cancer and melanoma were reduced in patients who adhered to a gluten-free diet, as was the overall risk of getting non-Hodgkin's lymphoma. The study looked at 381 celiac disease patients, out of which 43 were diagnosed with cancer (11%). The vast majority—34—were diagnosed at or before their celiac disease diagnoses, so it is safe to say that they were not following a gluten-free diet.*

The results of this study emphasize the importance of adhering to a strict gluten-free diet, and of getting regular checkups by your doctor. Cancer screenings may also be advised, especially in cases where unexplained symptoms continue after going gluten-free. There is currently, however, no specific test for non-Hodgkin's lymphoma, so one must learn about its warning signs and be on the lookout for any symptoms. - Scott Adams

The researchers conclude: "Children with coeliac disease have antibodies to oat proteins at significantly higher levels than reference children. The absorption test did not indicate a cross-reactivity between the prolamines of wheat and oats. The method will be employed for repeated sampling of anti-avenin antibodies during a prospective interventional study with a gluten-free diet supplemented with oats." An emphasis should be added to the last sentence, as it appears that they will now perform a study on celiac children who actually eat oats, and most other major studies of this type have shown no intestinal damage caused by the avenin oat prolamines in people with celiac disease. It is interesting that this study shows a different response to oats in those with celiac disease, but it remains to be seen if this response is actually harmful to celiacs.....

HANNAFORD (Commercial Dr., N. Hartford) is adding G-F products to their stock continuously. Prepared foods (heat & eat) are in the freezer area of "Nature's Place" on Commercial Drive. If there is a product you'd like them to check into, just take the wrapper to Dennis!

Upcoming programs at the Central NY CSG – in the Community Room of Natur-Tyme (5898 Bridge St., Syracuse) : **October 26th** – Co-Authors Donna Washburn & Heather Butt – professional home economists (have taught at the college level) will speak. Their new cookbook is "125 Best Gluten Free Recipes".

December 7th – Laurel Prisco, R.D. CNYCSG new dietitian/advisor - will speak on Weight Control on the Celiac Diet --- also taking place will a cookie exchange & sale!

Upcoming - CONFERENCES

November 2nd – CDF Annual meeting & Education Conference & Food Faire - in LA, California – info - cdf@celiac.org

November 15th – 2nd Annual Patient Education Day at **NY Columbia-Presbyterian Medical Center** – for info, call Hal Winfield 212-342-0251 - or go to www.cdcc.hs.columbia.edu

June 4-6th (2004) GIG Annual Conference in Portland, Oregon - e-mail info@gluten.net

TESTING for CD – DQ2 or DQA is used when the IgA test has come back negative AND celiac disease is still suspected.

CONTACT your legislative representatives in Washington, D.C. to ENCOURAGE them to act quickly AND positively on the bill pending for BETTER FOOD LABELING!!!

Points to emphasize –

- **Current food labels are too difficult to read, and determine if the food is safe to eat.**
- **People with celiac disease & food allergies risk getting sick each day – we need BETTER labeling to stay healthy.**
- **Close by thanking the staff for their time.**

Do your part to help us all live better –
Gluten-Free....

(from Gluten-Free Living Vol.8, No. 2)

Maltodextrin --

"WHEAT has to be noted on the label because the definition of *maltodextrin* lists ONLY corn, potato or rice."

HVP (hydrolyzed vegetable protein)—

A 1993 FDA law states that manufacturers MUST identify the "vegetable" in HVP – labels SHOULD reflect this!! If not – call manufacturers!!

Our President's Message

Happy Fall to All! This is my favorite season. The air is cool and crisp, the leaves beautiful and hardly any bugs!

The celiac community is abuzz with all of the things happening over that last few months. Most importantly is the big push to educate Congressional members and to ask for accurate food labels. Andrea Levario, Co-Chair of the Legislative Project of the American Celiac Task Force reported that New Yorkers had the largest number of e-mails and letters to their Senators. Congratulations New York for its vocal inhabitants. We need to keep up the good work, as October is Celiac Awareness Month. **The E-Advocacy site is (www.capwiz.com/celiac).** Please visit the site and make your voice heard!!! These lawmakers need to keep hearing about celiac disease, how common it is and who it affects. Andrea points out: **"that the Representatives and Senators pay attention to YOU, their constituents so -- Let's really show them our stuff!"**.

If you were able to attend our September meeting you would have heard Sharon Hoff give a nice talk about the new gluten free guidelines, and introduce a new book by Shelley Case, R.D., outlining these guidelines. Sharon says it is her gospel when it comes to working with celiac patients. The CSGMV has ordered a case of these books to be sold at our meetings. If you are interested they will be sold on a first come first serve basis.

We are currently working on a dinner again this year. It is tentatively scheduled for January 17th, 2004 at the Franklin Hotel in Rome. We hope to be able to secure this date and location soon. Information will follow with the menu and other particulars. The media has been doing a great job in getting information out on CD. The October issue of the MV Health insert of the Observer Dispatch had a wonderful article. Also, some huge news – GIG is launching a public awareness campaign with advertisements for magazines, newspapers, signs and even buses. They are proposing that local support groups try to participate by utilizing their ads. We will need to investigate this prospect for our area.

See you at the October meeting!! Have a cool and Gluten Free Autumn!!

Pam

When freezing foods for future use, it is wise to separate foods into individual servings to avoid thawing entire amount repeatedly. This way, you can thaw just what you are going to eat at one meal.

from the University of Chicago Celiac Disease Program – *Myths and Facts:*

Myth – Only one or two biopsy samples are needed to diagnose CD, because the physician can see if CD is present.

Fact– The standard for diagnosing CD is at least 4 biopsy samples, which need to be properly oriented in order to be read by the pathologist. CD in a vast majority of cases is a microscopic condition. The physician cannot see celiac disease during the endoscopy procedure.

Myth – One cannot be diagnosed with CD if one is overweight, or has constipation.

Fact – Weight is not a significant indicator for whether or not an individual has CD – nor is the presence or absence of constipation. Roughly 8-10% of people have constipation upon diagnosis; only 35% of those diagnosed in the prevalence study had chronic diarrhea.

Myth – Every person with CD has symptoms.

Fact – In the study, only 40% of children and only 59% of adults diagnosed had symptoms. The rest had NO symptoms at all!!

McCormick's Spices/Extracts

Single Spices & Extracts from McCormick are Gluten-Free – per a phone call to the company in September by Eleanor!

from CDF newsletter – Summer 2003

Celiac Disease & Infertility/Miscarriage

- * 2.2 million people in the US are living with CD – AND 97% are undiagnosed.
- * CD is associated with infertility in BOTH MEN & WOMEN.
- * Women with infertility test positive for CD at 10x the rate of the normal population.
- * Up to 50% of women with un-treated CD experience miscarriage - or unfavorable pregnancy outcome.
- * The US lags far behind Europe in the diagnosis, treatment, and awareness of CD.
- * Doctors are taught that CD is a *rare* condition, leaving many undiagnosed and receiving non-effective treatment.

SOY – does NOT contain gluten. However, some soy sauces DO contain wheat. Read the label to find one which contains ONLY SOY. It is possible for some people (celiac or not) to be sensitive to soy.

SPELT is NOT ALLOWED – despite what some bakers may say!! It contains the same amount of gluten as does wheat. It is NOT G-F!!

2nd Dinner Dance for ASAP

Peg Curtacci's 2nd Dinner Dance for ASAP

will be Saturday, November 1st, at the Holland Patent American Legion, 7 'til 11 PM. Paul Gleba Rated Productions D.J. and Karaoke will provide the entertainment. A buffet dinner, raffle, door prizes and a cash bar will be included. Tickets are \$15.00, children twelve and under free.

Call 865-7498 for further info. The event is sponsored by the Curtacci, Heburn, Lemieux and Niedzielski families. Proceeds to benefit research and education for people with Chairi Malformation, Syringomyelia, Fibromyalgia and related disorders.

A local ASAP support group was started in March, contact Peg at 865-7498 for further info.



Let's Put Some SUPPORT into OUR Support Group!!

We need your presence at our meetings. We need you to BE INVOLVED in our activities – volunteering is NOT a dirty word...

We need you to continue talking with your physicians, family, and friends in order to gain understanding concerning Celiac Disease – and hopefully increase awareness in the medical and social communities!

We look forward to have refreshments (G-F, of course!) at our meetings – so call Karen Mierzwa (@724-8347) to say that you can bring something to share, and specify which meeting, please. Veggies & G-F dip are always welcome!

Linda LaMonica is working on the plans for a dinner in January, 2004 ----- call her to HELP -- @ 337-3870.

Old, old sayings – but oh, so true:
Many hands make light work
AND –

A chain is only as strong as it's weakest link.

Let's help to make CSGMV the best it can be!!

Easy Meal–

Sauté` in vegetable oil 1/2 C. sliced onion, 2 tsp. minced garlic, sliced zucchini (or Italian squash); add 4 zap. can (or fresh) cut-up mushrooms, 8 oz. diced or stewed tomatoes and 6-8 oz. meat of choice (pork, chicken, etc.) cooked & cut into small pieces – Simmer 15 minutes.

Serve over cooked rice – Serves 2-3!!

from CDF Summer Newsletter – & Mrs. Leeper's Pasta

Radiatore in a creamy sauce of 3 cheeses:

- 12 oz. Mrs. Leeper's Corn Vegetable Radiatore
- 1 pt. Whipping cream
- 8 oz. smoked cheese, grated
- 6 oz. mozzarella cheese, grated
- 4 oz. Parmesan cheese, grated (or well-flavored vegetarian cheddar)
- Salt & freshly ground Pepper to taste

Pour cream into a heavy-based saucepan over medium heat. When the cream begins to steam (but is NOT boiling) add the cheese. Raise the heat a little as it begins to melt. Meanwhile, cook the Mrs. Leeper's Corn Radiatore according to instructions on the package. Bring the sauce to a boil, stirring constantly. Reduce heat to a simmer and cook sauce until smooth and slightly thickened, about 5 minutes. Season to taste. Pour over prepared pasta, sprinkle with parsley, and serve at once. Preparation time: 15 minutes. Makes 4 servings.

**a Repeat Favorite –
Deep, Dark Chocolate Cake
(mix in 5 minutes!)**

- 1 3/4 C. flour mix
- 2 C. sugar
- 3/4 Hershey cocoa
- 1 1/2 tsp. baking soda
- 1 1/2 tsp. baking powder
- 1 C. boiling water
- 1 tsp. salt
- 2 eggs
- 1 C. milk
- 1/2 C. oil
- 2 tsp. vanilla
- 1 1/2 tsp. xanthan gum

Combine dry ingredients in large mixing bowl. Add eggs, milk, oil & vanilla. Stir in boiling water. Batter will be thin. Pour into greased & floured 13x9x2 pan.

Bake for 35-40 minutes, or until cake tester comes out clean. Cool.

Frost with favorite G-F frosting – OR top with whipped cream!!
