



a "connection" of the Celiac Disease Foundation
 csgmv-news BIMONTHLY ISSUE 11-2
 March - April 2002

WEB SITE -- www.csgmv.org

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 Gastroenterologist –
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MISSION STATEMENT - CSGMV

The CSGMV organized to provide support to the diagnosed person (and family) with Celiac Disease in the form of medical, dietary, and food preparation information on an initial and continuing basis. Further, CSGMV provides the general community and medical professionals with direct information about this elusive malady.

Adopted 1/2000

EXECUTIVE BOARD

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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.
 No liability is implied by -- or assumed for -- the use of information contained herein.

**CALL
 Manufacturers !!
 &
 READ Labels !!**

**MEETING
 SCHEDULE**

April 20, 2002

MAY 4, 2002
1st Annual WALK
"Make Tracks for Celiacs"
@ Sangertown Square -
8 AM – 10 AM

let's go!!



May 18, 2002
 June 15, 2002
 July 20, 2002
 August 17, 2002
 September 21, 2002

October 19, 2002
"Annual Event"

November 16, 2002
 December 21, 2002

*** May 4th "Walk" *
 t-shirts will arrive
 the end of March!!**

GET THEM at the APRIL meeting...

Do you have an e-mail address that we don't have??

Please send it to elpa1@juno.com so that we may contact you in that manner, if necessary. Thank you.

IF you do not have the current address/phone #s for the following in your paperwork, please NOTE:

**Colgate (tooth paste):
1-800-468-6502**

**Dietary Specialties:
1248 Sussex Turnpike Unit C-1
Randolph, NJ 07869
1-888-640-2800**

**Hannaford:
1-800-213-9040**

**Heinz Foods:
1-800-577-2823**

**Hellmann's/Best Foods:
1-800-338-8831**

**Syracuse Support Group:
Ruth Wyman (315) 463-4616**

A GOOD IDEA – keep ALL your information on Celiac Disease &/or dietary needs in a loose-leaf notebook OR folder. That way, you can have it easily accessible! This IS what we need to lead a life that is as healthy as possible.

GET READY FOR OUR WALK

May 4th, 2002

"Making Tracks for Celiacs" t-shirts will be available at the April 20, 2002 meeting!!

Be sure to come – and get yours!!

Good News

Local endocrinologists are checking patients for CD when they present with thyroid problems!!

Eileen Kinsella, Pam Fahy, and Eleanor Wallace have been invited to speak to a meeting of the Gastrointestinal Nurses, April 6, at the Radisson Hotel in Utica. We welcome another opportunity to "get the word out" on living healthy with Celiac Disease!!

Karen Huxtable is presenting – on WKTV Channel 2 –

a segment on Celiac Disease & CSGMV – featuring Dr. Mark Adsit & Pam Fahy. It will be taped on April 24th, and "air" on the same day – BARRING "BREAKING NEWS" of another event – at 5 OR 6 PM...

Please BE CONSIDERATE –

In our current world, MANY people are extremely sensitive to MANY things – fabrics, dyes, odors, foods, etc.!!

When you attend ANY gathering (including meetings, religious services, being at work in confined areas, caring for the sick) be kind enough to NOT wear heavily scented perfumes/powders/makeup.

Amazingly enough, this can cause a severe reaction in some people.

Thank you for your consideration...

Spring is



around the corner!!

HONEST!!

"Celiac Friendly" places to eat ---

Pickle Barrel Country Inn
French Rd., Utica

Castlewood
Oneida St., Washington Mills

Kirker's Seafood & SteakHouse
Off the Northway near Albany

Symeon's – on Commercial Drive
You STILL have to ask the "right" questions & make responsible choices!!

[excerpted from the Jan 17 2002 New England Journal of Medicine]

- True prevalence of Celiac Sprue is difficult to ascertain – many patients have atypical symptoms OR none at all.
- Atypical Celiac Sprue is usually seen in older children or adolescents, who often have no overt features of malabsorption. In addition to recurrent abdominal pain, there may be arthralgia, defects in dental enamel, and behavioral disturbances (depression, irritability, and poor performance in school).
- In patients with Celiac Sprue, there is greater prevalence of occurrence of type 1 diabetes and autoimmune thyroiditis. Unexpected episodes of hypoglycemia or diarrhea should alert clinicians to the possibility of coexisting Celiac Sprue in patients with type 1 diabetes.
- Approximately 50% of adult patients do NOT have clinically significant diarrhea. Iron-deficiency anemia is now the most common clinical presentation in adults.
- Abdominal discomfort & bloating often lead to the mistaken diagnosis of Irritable Bowel Syndrome.

Recaps from CDF newsletter/annual meeting:

SCREENINGS:

- Research concludes that people with EITHER CD or Diabetes have a higher incidence of developing (and should routinely be screened for) the other disease.
- Persons with CD may also be at increased risk for developing diabetes OR other endocrine disorders, such as thyroid disease.
- BE PROACTIVE – Educate your physicians, demand initial & ongoing screenings.

INTERESTING but TRUE:

- CD is not a “rare disease” – it’s rarely diagnosed!!
- It is VERY important to have a GOOD knowledge of your FAMILY HEALTH HISTORY...

A FEW WORDS to our families & friends:

CD is **NOT** contagious – **AND** the **treatment is simple & clear** –

a strict gluten-free diet!! **NO cheating!!**

Please don’t ask us to try “just a little something” which contains gluten ---- it can definitely do more than “a little harm”.....

Unnecessary, too, are remarks like “How can someone who looks so healthy be ill?”

We look well BECAUSE we follow a STRICT gluten-free diet....



some “food facts” from the Winter 2002 CDF Newsletter

Ongoing controversy– re: oats and their gluten “status” --- regardless of recent research findings, it is still recommended that oats (along with wheat, barley and rye) be avoided in order to maintain a gluten-free diet.

OK are pure buckwheat , quinoa, flax, millet, and amaranth.

Buckwheat is a fruit (part of the rhubarb family). It is a high source of protein, iron, B vitamins & zinc.

Quinoa is also classified as a fruit and is in the same family as spinach. You can buy it as seeds, flakes, flour or pasta. It has more high quality protein as other grains & cereals – the quality compares to dried skim milk. It is high in iron, magnesium, phosphorus, potassium & zinc – also a source of many B vitamins, calcium & dietary fiber.

Amaranth is part of a broadleaf plant family. High in protein, dietary fiber, magnesium, phosphorus & zinc - & a source of calcium & B vitamins.

Flax is available as a seed or ground as flax meal. It is rich in the essential Omega 3 Fatty Acids – may be beneficial against heart disease & cancer. To get benefits, you must consume it ground. As a seed, it acts as a laxative.

Hydrolyzed Plant Protein (HPP) – can be contained in some luncheon meats, baking powder, bullion cubes, soups, soy sauces, seasoning mixture, rice crispies, licorice & corn flakes. **Most HPP is from corn, soy, wheat & sometimes from peanuts.** The U.S. Code of Federal Regulations says that the **source** of the protein **MUST be identified.**

Starch means corn unless identified otherwise as “potato starch,” “tapioca starch,” “wheat starch,” etc. “Modified food starch” is not, however, identified specifically. **Wheat starch contains varying amounts of gluten. You can find it is some baking powders & some seasoning mixes.**

Check with manufacturer!

Dextrin is partially hydrolyzed starch., used as a thickener & binder. It is almost always made from corn in North America. **To be 100% sure – check with manufacturer!**

Malto-dextrin is used in a variety of foods – it can come ONLY from potato, corn or rice. IT IS NOT A PROBLEM!!

Seasonings -- a subject causing the most grief. There is **no specific regulation** for the word “seasoning” in U.S. or Canada. It is most important to confirm the components of the ingredients of these foods. Also know that **PURE spices are gluten-free** ---- problems occur when these spices are added with other ingredients to create a **seasoning “mixture”!!**

Flavorings – another problem as they are complex mixtures that can be composed from over 2,000 substances. Current requirements do not require that components be listed, when listing the ingredients of the food. It will just say “flavoring”. Gluten containing grains are occasionally used in flavorings (meat products, products containing meat, deli meats, beef jerky, and imitation bacon bits) – may also be found in soy beverages & cereals which use barley malt flavoring or extract. This may not always be described on the label.

Vinegar – the only vinegar that is at issue is Malt Vinegar (it’s fermented). Distilled vinegar is OK....



Be thankful for -
Family & friends -
Their love & support!
A Diagnosis - now you
know
how to improve your health
& feel better!
Our freedoms to
strongly & repeatedly urge
Legislators to act quickly
& responsibly - labeling
laws are needed!
The Professionals who
know about Celiac Disease
- AND those willing to
learn and test for, and
diagnose Celiac Disease!

 a complete panel of blood tests for Celiac Disease
 includes:

- anti-Endomysial antibodies
- anti-Reticulin antibodies
- anti-Gliadin antibodies
- anti-Tissue Transglutaminase antibodies

www.immcodiagnostics.com

1-800-537-8378

OR

www.specialtylabs.com

1-800-421-4449

**Share this information with
 your doctor!**

[excerpted from *Gluten-Free Living*
 Nov./Dec. 2001]

Article by Joseph Murray, MD

There is a relationship between Celiac Disease and other autoimmune disorders. *Relationship* means two diseases may occur together in the same individual because of genetic similarities.'

This is not a certainty, but the *risk* for it happening is somewhat bigger than for those not having an autoimmune disorder. Usually an autoimmune disease is diagnosed *before* Celiac Disease.

Doctors are finding that newly diagnosed celiacs, especially children, have autoantibodies to other parts of their bodies that go away when the child adopts a gluten-free diet. Diagnosing Celiac Disease at a young age might prevent those autoantibodies from forming and thus prevent other and more serious autoimmune problems.

Untreated Celiac Disease can interfere with treatment of other autoimmune problems.

A celiac patient of any age should not be overly concerned about developing another autoimmune problem.

Follow diet religiously; report symptoms to your physician rather than trying to self diagnose them, and adopt a positive outlook on life!!'

'An autoimmune disease is one in which the person's immune system attacks part of the body in an uncontrolled fashion.'

Condensed Milk Frosting

1 can condensed milk 1 Tbs. Water
 2 oz. Baking Chocolate 1 tsp. Vanilla
 dash of salt

Heat condensed milk & water over low/medium heat (OR in double boiler) stirring continually.
 Melt baking chocolate – add to heated condensed milk. Stir and bring to low boil (when it bubbles) until it thickens.
 Remove from burner. Add Vanilla. Cool. Frost cooled cake.

(OR fudge, if you prefer!)

FOR FUDGE – use 1 can condensed milk + 3 C. chocolate chips + dash of salt. Melt together in microwave. Place in wax paper-lined pan. Chill thoroughly. Cut. Keep chilled to retain "fudginess".....

"Mom's" Lemon Pie Filling

baked 8" pie shell

In saucepan, bring to boil 1 C. sugar + 2 C. water.
 Add 8 Tbs. Cornstarch mixed in 1 C. water. Add 2 slightly beaten egg yolks & mix well.
 Stir constantly until thickened.
 Remove from heat & add 1T. oleo (butter). Add 4-5 Tbs. ReaLemon (or 3 lemons – rind & juice).
 Pour into baked pieshell.

Meringue: 2 egg whites – beat well until stiff peaks appear; add 5 tsp. Sugar + 1 tsp lemon juice. Bake @ 325 deg. 15 min.

Enjoy!!