



Chapter of the  
**Celiac Disease Foundation**  
 csgmv-news ISSUE IV- 2  
 March – April 2004  
**WEB SITE -- [www.csgmv.org](http://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. 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

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*"I believe that friends are quiet angels who  
 lift us to our feet when our wings have  
 trouble remembering how to fly."*  
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2004 MEETING SCHEDULE  
 @ 10 AM New York Mills Library –  
 Sat., April 17, 2004  
 (MAY IS NATIONAL CELIAC  
 DISEASE MONTH)  
**ANNUAL WALK -May 15<sup>th</sup>**  
**@ 10 AM!**  
**Floyd Firemen's Field**  
 (this will REPLACE our regular  
 meeting)  
 Sat., June 19, 2004  
 Sat., July 17, 2004  
 Sat., August 21, 2004  
 Sat., September 18, 2004

(Registration is at 10:00 AM)  
 Plan on securing your pledges  
**-PLEASE TAKE NOTE-**

CSGMV will participate in the  
**3rd Annual Walk**  
 for Celiac Disease Research on  
**Saturday, MAY 15<sup>th</sup> 2004**  
 at **10AM** at the  
**Floyd Fire Department Field**  
 on Rte. 365, Floyd, NY  
 (Registration is at 10:00 AM)  
 ~ Plan on securing your pledges  
**and join us for a fun-filled time!!** ~

~MESSAGE FROM OUR  
 P R E S I D E N T ~  
 It's SPRING and the Robin's are back.  
 FINALLY! Winter sure was long...  
 Spring is a time of new beginnings. We  
 have many newly diagnosed people who have  
 joined our group this year. Welcome to All. The  
 CD diagnosis is in a way a new beginning, a new  
 way of life and eating. This is not a bad thing. It  
 may seem overwhelming at first but with support  
 and knowledge the transformation is much  
 easier. Our Motto "There IS Life After Diagnosis"  
 optimizes this fresh new beginning.  
 As we move into spring with our  
 refreshed attitudes lets look for new ways to help  
 our-selves and others deal with our gluten-free

trials and tribulations, thus increasing our support web.

Another new beginning for CSGMV, which has increased the support web, is our affiliation with the Celiac Disease Foundation this year. We are now officially a chapter of the foundation. This new marriage affords us many benefits, one of which is the 501c3 (non profit) status. Our new/updated name is CDF/CSGMV. Now we may accept monies from parties to use for our projects that were previously unavailable to us. This will be particularly helpful with our upcoming walk.

On May 15<sup>th</sup> 2004 we will again go out and "Make Tracks for Celiacs" at our 3<sup>rd</sup> Annual walk. We will be holding it again this year at the Floyd Fireman's Field on Route 365 in the Town of Floyd. Last year's event was excellent! The Department met our every need, the weather was perfect, the course was beautiful and the Shriner Clowns couldn't have been nicer. This year we plan to use monies raised to make donations to both the University of Maryland's Center for Celiac Research and the Celiac Disease Center at Columbia as well as further our local efforts to educate and spread the word about CD.

Please join us on May 15<sup>th</sup> and walk for a very worthy cause, one that affects 1 in every 133 Americans!

Pam



~ M o h a w k V a l l e y  
R . O . C . K . N E W S ~

**R.O.C.K.** held a meeting – March 13<sup>th</sup> – at the Oneida Public Library. **Becky Madeira** reported that a gentleman from Watertown came -- his son has Aspergers - a form of Autism. He is not indicating that Aspergers might be connected to CD. He wants to put his child on the GF diet. A very nice flyer for the meeting was made by the Library. A great deal of information was distributed to those attending the meeting.

Chocolate Chip cookies & Peanut Butter Bars with Chocolate were made and served by Tanya Clute & Becky Madeira to those attending. **Everyone is busy preparing for our 3<sup>rd</sup> Annual Walk for Celiac Disease Research Funding – to be held May 15<sup>th</sup>.**

There is a "Camp Celiac" in North Scituate, RI – for ages 7 – 16 – Aug. 15-20, 2004.

Contact Tannis Collard [csg@ix.netcom.com](mailto:csg@ix.netcom.com) for information.



NEW from Nancy Falini, MA, RD, LDN ---

"Gluten-Free Friends: An Activity Book for Kids"

ISBN 1889274-09-1 \$18.95

Get yours at [www.savorypalate.com](http://www.savorypalate.com) or [www.amazon.com](http://www.amazon.com) or call 800-741-5418 (Savory Palate Press)

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**Gluten-Free Diet** by Shelley Case, R.D.  
available - \$15.00

We have a NEW SUPPLY for those who are interested in purchasing this great guide (at reduced price).

Call Eleanor @ 736-6981 – OR get at our meeting!!

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**NEW NEWS**

Child gut disorder underestimated

**BBC NEWS**

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The number of young people affected by wheat intolerance may have been underestimated, research suggests.

A study by Bristol University has found as many as one in 100 children may have coeliac disease. Currently, fewer than one in 2,500 is treated for the disease, which is actually an intolerance to a substance called gluten found in cereal flour. The research, based on 5,470 seven-year-olds, is published in the **British Medical Journal**. The researchers found that although a large number of young people appear to have the disorder, many do not show obvious symptoms. (cont.) They believe that **coeliac disease is often triggered in childhood, but symptoms might not appear until years later**. The condition is caused by an oversensitivity to gluten of the lining of the small intestine. This leads to inflammation of the gut, and an inability to absorb adequate nutrition from food. **Symptoms** can include tiredness, anaemia, weight loss and diarrhoea. Researcher Dr Polly Bingley analysed blood samples collected from the children, looking for antibodies, which are markers of the disease. **A total of 54 children tested positive for the antibodies - but only four were on a gluten-free diet.** Girls were also more than twice as likely to have the antibodies as boys. **The children had only mild, if any, gastrointestinal symptoms.**

**Stunted growth:** However, Dr Bingley also found that on average the children with the antibodies were 2.7cm (1in) shorter and 1kg (2.2lb) lighter than those who did not. She said:

"This equates to about nine months' growth and weight gain in an average child around this age." It is not known whether this stunted growth is directly linked to coeliac disease. However, there is some evidence to suggest that babies born with the disorder tend to be smaller, suggesting problems may start in the womb. **Around 1% of the UK's adult population is known to have coeliac disease, but it is thought this is also underestimated.** Dr Bentley said: "We have found that the frequency of coeliac disease at age seven is the same as that we find in adults in this country, suggesting that the condition starts in childhood, even in individuals in whom it is diagnosed late in life. **"They don't suddenly develop coeliac disease - they've probably had it for years before it is eventually detected."** The researchers hope the study will lead to new studies into possible causes of the disease, looking at infant foods and influences on the baby in the womb. It could also pave the way for new treatments or prevention of the disease.

Story from BBC NEWS:

<http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/3461667.stm>

Published: 2004/02/06 01:29:10 GMT

Tuesday, 17 December, 2002, 00:56 GMT

#### **Birthday link to digestive disorder**

**Babies born during the summer months have a greater chance of developing the digestive disorder coeliac disease, research suggests.** Coeliac disease sufferers have an intolerance to gluten, a protein found in wheat, and similar proteins in rye, barley and oats. **Around three in 100 people in the UK are thought to be affected.** The only way to manage the condition is to eat a gluten-free diet. Scientists at Umea University in Sweden identified 2,151 children with coeliac disease from a national register of child health covering the period from 1973 to 1997. **They found the risk of coeliac disease was significantly higher for children born in the summer compared with the winter - but only in children who were under two when they were diagnosed.**

**Environmental key:** The researchers believe their findings suggest that the disease is linked to exposure to environmental factors that change during the year. **What these factors are remains unknown, but it is possible that the disease is linked to infection that is more likely to occur at some points in the year than others.**

**Writing in the Journal of Epidemiology and Community Health, the researchers say: "Children born during the summer, when there is an increased risk for coeliac disease, have been in utero mainly during**

**the winter when there is the greatest risk for infections in the mother. Furthermore, children born in the summer are introduced to a dietary gluten and also frequently weaned off the breast during the winter when the likelihood of becoming infected is greatest."** The researchers suggest that the best way to reduce risk is to introduce gluten-containing foods to a child's diet in small amounts while breastfeeding is still taking place.

**Complications:** Coeliac disease is often diagnosed in childhood, and can be characterised by a distended stomach and stunted growth. It can lead to serious long-term complications, such as the brittle bone disease osteoporosis, infertility and cancer of the small intestine. If people with the disease continue to eat gluten they are likely to suffer from anaemia and lethargy. Even though the disease is not uncommon, doctors can misinterpret these symptoms and diagnose the patient as suffering from chronic fatigue syndrome and irritable bowel syndrome.

Professor Paul Cicilitira is a Consultant Gastroenterologist at St Thomas' Hospital in London and has been leading a three-year study, funded by leading medical charity Action Research, to look specifically at coeliac disease and inheritance patterns. He said: "The observation that coeliac disease affects more babies born in the summer is clearly of interest. "One must assume this suggests that either the infants are weaned differently or that they may suffer a precipitating infection. "Clearly it would be of interest to determine whether the observation can be confirmed in another group and attempt to identify any other associated phenomena such as evidence of gastroenteritis or a difference in their diets." **I was so pleased to see the results of the Avon Longitudinal Study of parents and children (ALSPAC) which confirm what many people working with adult coeliacs have suspected for a long time - that coeliac disease is likely to be a lifelong condition beginning in childhood. However I was surprised that the authors described the association of short stature and childhood coeliac disease as a "striking observation" suggesting that they were possibly unaware of the well-recognised association of short stature and untreated coeliac disease(1). I am surprised that screening for coeliac disease is rarely included in the work-up for failure to thrive and short stature in children, but hopefully the results of the ALSPAC study may help to change this.** from: Margaret E Lupton, General Practitioner  
*Parkview Surgery, 23 Ribblesdale Place Preston PR1 3NA*



The Celiac Disease Center at Columbia is pleased to update major events and information. If you have any questions, please feel free to contact Hal Winfield at 212-342-0251 or email: [celiac@columbia.edu](mailto:celiac@columbia.edu).

#### 1. INFORMATION ON GLUTEN FREE PRODUCTS

In our attempt to make sure patients with celiac disease remain aware of the variety of grains that are gluten-free and available to them, we would like to pass along this information on Montana and Teff.

A) We have obtained this information **about Montana.**

Montina is a gluten free grain that many people with celiac disease may not know about. It is produced by Amazing Grains, headquartered in western Montana. Within this dedicated Gluten Free facility Montana™ flour is milled from a native grass seed called Indian ricegrass (*Achnatherum Hymenoides*). The name is somewhat misleading for Indian ricegrass has nothing to do with rice. Re-discovered as a nutritionally beneficial and gluten free grain by Montana State Universities Plant Science Dept. in the mid-1990's **Amazing Grains** is now developing and expanding the availability of Montana™ throughout the country. The seed is about the size of a sesame seed only dark brown to black in color and has an extremely hard outer hull or seed coat. When milled this coating is the source of the very high fiber content in the resulting flour. Montana™ is the registered name for this unique flour that is not only high in fiber but protein, iron and most importantly flavor. Montana™ is, in fact, so high in fiber that it needs to be blended with other Gluten Free flours like potato, rice and/or tapioca flours. Extensive testing has determined that the substitution of 15% to 20% Montana™ for other Gluten Free flours in a recipe will result in an exceptional baked product. Montana™ is **available in its pure form known as Montana™ Pure Baking Supplement or as Montana™ Baking Flour Blend, which is a blend of White Rice, Tapioca and Montana™ flours to create an all-purpose flour that can be used as a one for one substitution for any flour needs.**

For additional information, please contact: [www.montina.com](http://www.montina.com) , or call toll free at 1-877-278.

B) **Teff: Ivory and brown teff are sweet tasting grains unlike any other.**

Teff has a subtle hazelnut, almost chocolate like flavor and a moist texture similar to millet. Originally from Ethiopia, teff now grows and thrives in Idaho. Tinier than a poppy seed, teff is

a nutritional powerhouse. An eight-ounce serving of teff yields 32% of the USRDA for calcium, 80% for iron, and 28 grams of protein. It is also a good source of fiber, the B complex vitamins, phosphorous and potassium. It is sometimes called the perfect woman's grain because it has so many of the nutrients women need. **Teff grain and teff flour are wonderful alternatives to wheat, rye and barley.**

**They perform well in recipes for everything from pancakes to pastry and back to stuffings and stew.**

**For more information about Teff - you can contact:**

**The Teff Company**  
POBox A Caldwell, ID 83606  
(208) 455-0375 [teffco@earthlink.net](mailto:teffco@earthlink.net)

C). From a colleague of ours comes this statement from **Merck & Co. concerning GLUTEN CONTENT OF MEDICATIONS.**

"Currently those oral dosage forms of Merck products that list starch as an inactive ingredient contain either corn starch, pregelatinized starch, or sodium starch glycolate. According to our supplier, our pregelatinized starch is derived from corn, and sodium starch glycolate is a substituted and cross-linked derivative of potato starch.

**Merck does not use wheat in the starch or in any other excipient in our products.**

As suppliers for our inactive ingredients may occasionally change, please check with **The Merck National Service Center (1-800/672-6372)** periodically for an update on the source of starch in Merck products."

#### 2. RECENT LITERATURE ON CELIAC DISEASE

A) A new celiac disease study has been published in the British Medical Journal, (BMJ), by the University of Bristol, in the United Kingdom.

A description follows:

**Coeliac Disease - the Tip of the Iceberg.**

While fewer than 1 in 2,500 children is treated for the disease in the UK, the study shows it probably affects 1 child in 100, although most have no overt symptoms.

The figures appear to indicate that celiac disease is triggered in childhood, although the symptoms might not appear until years later. An author said: "The children had only mild, if any, gastrointestinal symptoms. A striking observation was that they were shorter and lighter than antibody negative children matched for date and place of birth.. This equates to about 9 months' growth and weight gain in an average child around this age. We have found that the frequency of celiac disease at age 7 is the same as that we find in adults in this country.

**Adults don't suddenly develop celiac disease - they've probably had it for years before it is eventually detected."**

**"Our Editorial comment.** We noted this study revealing 1% of children in the UK have celiac disease is identical to the figure of 1% of Finnish school children having celiac disease, from a study published in the New England Journal of Medicine. It is in line with another study from the UK of adults published in Gut and the study from the US published in Archives of Internal Medicine. This later study revealed about 0.8% of those studied had celiac disease.

Our **Dietitian, Anne Roland Lee, MEd, RD, CDE,** was invited to contribute an article by the American Dietetic Association to their journal, **Clinical Connections, The newsletter of Dietitians in General Clinical Practice, vol. 23, # 3, Winter 2003** The paper is titled: **Nutritional Assessment of the Individual with Celiac Disease.**

The article is a **guide for the dietitians** to use in the treatment and care of individuals with celiac disease. The article gives a description of symptoms, prevalence, and complications. Detailed charts are used to guide the dietitian through a complete nutritional analysis with emphasis **on potential nutrient deficiencies** of the individual with **celiac disease and DH.** It also **details the gluten-free diet.** Allowed grains, food labeling tips and importance of melding the diet to the individuals social-emotional life is stressed.

**A second chart details the various handouts and key points to include while counseling patients with celiac disease and DH."**

### **3. UPCOMING SPEAKING ENGAGEMENTS OF THE CELIAC CENTER'S MEMBERS.**

A) **June 28-30, '04, Dr. Green along with other authorities will be speaking at the National Institutes of Health (NIH) Consensus Development Conference on Celiac Disease,** at: Natcher Conference Center National Institutes of **Health Bethesda, Maryland.** You may find additional information and register for the Conference by going to **their website** at :

<http://consensus.nih.gov/cons/118/celiacbackground.html>

Please consult the NIH website calendar for the program schedule: <http://calendar.nih.gov/>. You may also visit the NIH Videocast website for a live web cast of the conference.

B) **April 28 - 30, 2004, 11th International Symposium on Celiac Disease, at Waterfront Hall, Belfast, Northern Ireland.**

Please consult the **website: www.happen.co.uk/iscd2004** for details. The main scientific symposium is open to patients and patient organizations. However they will

need to register. The organizers would consider a reduced registration fee for patients and patient associations. A special patient day is on Saturday.

#### **4) OTHER CONFERENCES :**

A) **Gluten Intolerance Group® (GIG®) Annual Education Conference.**

Where: Doubletree Hotel, Lloyd Center, **Portland, OR**

**When: June 4, 5, 6, 2004**

Exhibits: June 4, 5, 2004

B) **2004 CSA Annual Conference** Expanding the Knowledge

Where: Marriott Downtown Hotel, **Oklahoma City, Oklahoma**

**When: October 21-24, 2004**

5) **NOTHING BEATS GLUTEN FREE COOKING** (a children's cookbook)

A publication of the Celiac Disease Center at Columbia.

Authors: Anne Roland Lee, Susan Cohen & Laura Leon

To purchase either online or by mail for \$25 (including shipping) please go to: [www.cdcc.hs.columbia.edu](http://www.cdcc.hs.columbia.edu)

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**Hyde Park/NY-Gluten-free Baking one-day class**

The **Culinary Institute of America in Hyde Park, NY** is offering a one-day course on Gluten-Free Baking. This course focuses on gluten-free breads, cookies, and elegant, yet easy, desserts. Don't miss out. You've gone without long enough!\*\* from **Linda Buck (THANK YOU!)** -- Here is the information I have on the Culinary Institute of America in Hyde Park, N.Y.

The one day **Course on Gluten -Free Baking** is filled up for **April 24th.** They've added a class because of this. The date is **May 8, 2004.** The phone number to call is:

**1 (800) 888-7850** - that is the Continuing Educ. Dept. **The time of the class is from 9:00 to 3:00 and the cost is \$160.00.**

(Chef Richard J. Coppedge, Jr.)

**Reach them for a catalog at 1-800-CULINARY (285-4627).**

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**3 recent articles concerning celiac disease Parents Magazine, February, 2004**

pp. 83-89.

**Woman's Day, February 17, 2004**

pp. 58-64.

**Reader's Digest, February, 2004**

pp. 123-124.

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**CNYCSG Meeting News**

On **April 18, 2004 at 2:00 PM,**

**Ann R. Lee MEd, RD, CDE** – author of **"Nothing Beats GF Cooking"** – will speak about 'Hidden Gluten' in Drugs, Cosmetics, and Vitamins.

Meetings held in Conference Room at  
NaturTyme, 5898 Bridge St., East Syracuse.  
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-- FOOD FACTS --

from Nestles in response to inquiry by Lou Parrotta: 2/7/04 Most of our products contain some form of gluten or a derivative of gluten. Also, many of our vendor-sourced ingredients may contain a "hidden" source of gluten of which we would not be aware, due to the proprietary nature of some formulations. Please understand that it would be virtually impossible to analyze every ingredient in every product for these >hidden sources of gluten. At Nestlé, we are dedicated to you and your family throughout every phase of your lives. Your feedback is valuable to us, as it helps us to improve our products and services. We appreciate your interest in our products and hope you will visit our website often for the latest information on our products and promotions. Sincerely, Kathleen Hayes - Consumer Response Ref: 9294773

from Hillshire Farms (Eleanor Wallace called): 2/10/04 "Our products are Gluten-Free EXCEPT for Beer Wurst."

-- CORRECTION --

(from Tanya Clute – look for "gluten-free" on the box!)

**ALL Celestial Seasonings teas are not gluten-free – beware!!**

Hello Everyone:

Baffled when it comes to bread baking?

Perplexed about making the perfect piecrust?

For the latest in gluten-free cooking, subscribe to my FREE monthly e-newsletter called

Carol's Culinary Cues by going to

<<http://www.savorypalate.com/>> .

You'll learn about the newest ingredients to make your gluten-free baking even better. For

example, the February issue tells you how to use healthy oils in place of butter or margarine,

In coming issues, you'll learn the secrets of perfect piecrust, when you should use Dutch versus regular cocoa, and why you should defy convention and start some breads baking in a COLD oven. If this sounds like information you can use, go to [www.SavoryPalate.com](http://www.SavoryPalate.com)

<<http://www.savorypalate.com/>> .

See you there!

**Carol Fenster, Ph.D. - President  
Savory Palate, Inc.**

8174 S. Holly, #404, Centennial, CO 80122  
{Award winning books, cooking consultant for food sensitivities  
Subscribe to FREE e-newsletter and order books at [www.CarolFenster.com](http://www.CarolFenster.com)}

Carol Lydick - Subject: Frito-Lay info site  
<http://www.fritolay.com/nutrition/freelist.html>

'My daughter just sent me this Frito-Lay site. It has all the allergy information for all its products, including, gluten, soy, peanuts, corn, MSG, etc. Wow, I think we are making progress. This is especially great for me, because I have so many other intolerances besides CD and checking the GF status is not enough to declare a food safe for me and many of our family.'

**Sylvan Border Farms carries a G-F General Purpose Flour Mix -- Call 1-800-297-5399 for information.**

NOTE (thanks to Armoldine Bartoszek)  
**As of Jan. 2004, KELLOGGS Corn Pops has "wheat starch" as an ingredient! This is listed as such in the ingredients. This is due to a reformulation by the company – Corn Pops produced prior to Jan. 2004 do NOT contain wheat. You may call them @ 800-962-1413 from 8 AM – 5 PM Mon. – Fri. to check for yourself!**

*tasteadventure* says: all of our products are gluten free except the Minestrone soup. We are sorry to learn that you have had difficulty purchasing our products at Hannaford's, we will look into this matter. In the interim, there are store locations in the following upstate regions that our carry our products: Ithaca; Piermont; Pearl River; Larchmont; Peekskill, Bayshore, New Paltz, Troy, Watertown, Oswego, Pleasantville, E. Setauket, High Falls, Albany, Fishkill, Katonah, Schenectady, Ardsley, Rocky Point, Rochester, Liverpool, and Webster.



RECIPES

~Potato Salad with Herbs~  
(from Margaret Angell)

½ lb. red potatoes (2-3) 1 stalk celery – minced  
½ small onion – minced ½ red pepper – finely chopped  
1 T. minced parsley 1 T. dill weed  
½ T. sweet pickle relish salt & pepper to taste  
\*¼ - ½ C. dressing (see below)  
\*(Grapeseed Oil Vegennaise) \*Margaret used Nasoya Nayoanise\*  
Steam potatoes (cooked but firm) 15 – 18 minutes. Peel; allow to cool. Place celery, onion & peppers in bowl. – add parsley, dill & cooled potatoes.  
Mix ingredients together – add dressing (a little at a time). Add relish, salt & pepper. Mix well.  
Cool & refrigerate. Serve cold. Serves 2.

**Shopping during Passover** (at a Jewish market) may be a benefit! Foods made for Passover are **usually** prepared with potato flour (be sure to ASK) -- and can range anywhere from chicken coating (which can be used to make matzo balls) to a wide variety of baked goods made with and without sugar for the celiac with diabetes.

Take advantage – stock up!!



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**PETER'S CORNUCOPIA**  
**MOVE will take place the**  
**FIRST PART of JUNE!**

**Peter is very busy – getting ready for his**  
**move to the New Hartford Shopping Center**

**\*\*MORE ROOM**

**\*\* MORE Gluten-Free STOCK**

**\*\* BETTER PARKING & ACCESS!!!**

**WATCH FOR “MOVING SALE”**

at current 52 Genesee St. location  
 (in New Hartford)  
 to New Hartford Shopping Center

around the middle of May!!

Phone: 315-724-4998



excerpted from CDF WINTER NEWSLETTER --  
 Jackie Rosenblum

*“suggestions to make being gluten-free easier:*

- 1) **Understand** that it is sometimes difficult for family members to acknowledge that your diagnosis of celiac disease is an INHERITED AUTOIMMUNE DISEASE. Parents can have a problem accepting that they may have been the one who gave their child the disease. Other family members may be afraid that they, too, have the disease. Spouses may be angry that your lifestyle will change OR fear the unknown.
- 2) **Be honest with your friends.** Hopefully, they will want to know more about celiac disease, and the kinds of food you can and can't have.
- 3) **Find a dessert that you get compliments on,** and volunteer to bring it when visiting a friend's house for dinner – or that you can share at a school or social function.

4) **When dining at a friend's house,** ask what will be served – and plan on bringing something similar for yourself. Never count on the host providing a gluten-free meal UNLESS they offer to. If you are not comfortable with bringing something, eat before you go. Choose from the meal what you think is appropriate. This applies to children as well. If they are newly diagnosed, and embarrassed, get them a treat before or after the function – and LET THEM KNOW YOU ARE PROUD OF THEM for not eating something that contains gluten!!

5) **Knowledge is power.** Learn as much as you can from a QUALIFIED AND up-to-date source – i.e. National support groups, doctors, and dietitians. Be wary of internet CHAT ROOMS about Celiac Disease. The amount of information is overwhelming AND not always accurate, causing more frustration. There is, however, a lot of useful information, particularly sites with recipes & food preparations.

6) **VOLUNTEER!** By focusing on OTHER PEOPLE & THEIR NEEDS, you will, in time, realize how fortunate you are – that you have Celiac Disease – and not something else....



With a population now of over 292 million people, calculations show 2.2 million celiacs in the U.S. Since 97% are UNDIAGNOSED, that translates to over 2.1 million undiagnosed celiacs. If ever there was a reason to work hard to get the word out to physicians, pediatricians, and gastroenterologists – AND to push for meaningful labeling legislation, it is these statistics!!!

**GO TO <http://capwiz.com/ceciac/home/>**  
**a reminder ~**

**NIH Consensus Development Conference**  
**on Celiac Disease ~**  
**June 28-30, 2004**

2 ½ day conference in Bethesda, MD will assess prevalence of celiac disease, its diagnosis, long-term manifestations, management - & explore directions for future research. Experts in the field will present the latest in research findings to an independent panel, who will then prepare a consensus statement addressing six key questions. Proceedings will be webcast live. Check [www.celiac.org](http://www.celiac.org) for more details.

**Celiac.com 03/04/2004** - Kimball Genetics is pleased to announce availability of the One-Day Celiac Disease DNA Test for cheek cell specimens in addition to blood. Cheek cell specimens are popular with both patients and physicians because they eliminate the need for a blood draw and are convenient to collect and ship. Kimball Genetics' unique ability to perform celiac disease testing on cheek cells enables direct-to-consumer marketing of this service.

Due to the extremely variable presentation of disease symptoms and severity, diagnosing celiac disease is difficult. Antiendomysial and tissue transglutaminase antibody test results can be equivocal depending upon diet adherence and stage of disease. Kimball Genetics' One-Day Celiac Disease DNA Test is a reliable and critical tool for accurately diagnosing celiac disease. Kimball Genetics' One-Day Celiac Disease DNA Test includes highest accuracy of testing, one-day turnaround time, detailed test reports, free genetic counseling for physicians and patients, and excellent personal service

For more information about the Celiac Disease DNA Test, please contact Juli Murphy, M.S. at (800) 320-1807 or at [jamurphy@kimballgenetics.com](mailto:jamurphy@kimballgenetics.com).

**Celiac.com 03/16/2004** - According to Dr. Erika Jensen-Jarolim, professor of medicine and immunology at the University of Vienna, there may be a connection between the development of food allergies and the use of antacids. Dr. Jensen-Jarolim presented her team's preliminary findings at the World Allergy Congress on September 10, 2003. Individuals who take medications that reduce or neutralize the acidity in the stomach may be at a higher risk of developing food allergies, possibly caused by normally harmless food proteins passing in tact through the digestive system. Normally acid and pepsin break down food proteins before they pass into the digestive tract, and if Dr. Jensen-Jarolim is correct, interrupting this process could cause serious, lifelong consequences. Dozens of over the counter and prescription medications suppress acid production or neutralize it.

The Austrian research team conducted experiments on mice which were fed hazelnut proteins and other allergens. The normal group of mice did not develop allergies to these foods, while mice that were given the ulcer drugs omeprazole (Prilosec) or ranitidine (Zantac) with the foods they ate did develop allergies to those foods. The animal results were further backed by data on 153 human patients who are taking part in a Hungarian acid-suppression therapy study. One interesting finding in their study was that

mice only developed food allergies in response to novel foods that were introduced, not to their regular daily diets. Since an estimated ten percent of the population is taking acid-suppression/neutralization medications, Dr. Jensen-Jarolim recommends that these people should not try eating any novel foods during their treatment.

### **Altering Diet May Ease Fibromyalgia**

by Keith Mulvihill

Fibromyalgia.com 11-07-2001 *excerpted*

'Lead investigator Dr. Joel S. Edman of the Center for Integrative Medicine at Thomas Jefferson University Hospital in Philadelphia, Pennsylvania, presented the findings at the annual meeting of the American College of Nutrition in Orlando, Florida, earlier this month. "People [suffering with fibromyalgia] don't need to completely change their life, but food may be a contributing factor to their condition," Edman told Reuters Health. In the study, Edman and colleagues reviewed medical charts of 17 fibromyalgia patients who agreed to eliminate common foods from their diet such as corn, wheat, dairy, citrus, soy, and nuts. After two weeks without eating any of the potential food allergens, nearly half of the patients reported "significant reduction of pain," and 76% reported a reduction in other symptoms such as headache, fatigue, bloating, heartburn, and breathing difficulties, according to Edman. Two patients experienced an increase in symptoms.

After the food elimination phase of the study, the patients were then instructed to reintroduce a particular food every two or three days, and monitor their reaction to the food.

Some of the reactions to foods were pain, headache, and gastrointestinal distress, Edman noted. The most common problem-causing foods or ingredients for the patients in this study were corn, wheat, dairy, citrus, and sugar. "It's a preliminary study...but (the findings) do support the idea that food may play a role in fibromyalgia and more research in this area should be conducted," he said. ~~~~~

