

Chapter of the  
Celiac Disease Foundation  
csgmv-news ISSUE IV - 3  
May – June 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

**2004 MEETING SCHEDULE**

@ 10 AM at New York Mills Library –  
corner of Main & Maple Sts.  
(please use BACK entrance  
off Maple St.)

Sat., June 19, 2004

Sat., July 17, 2004

Sat., August 21, 2004

Sat., September 18, 2004

Sat., October 16, 2004

*~the MOVE of Peter's Cornucopia~*

to the New Hartford Shopping Plaza on Genesee  
St., New Hartford, NY --- will be taking place **on**  
**or about June 15<sup>th</sup>** ---

more space, better parking and **MORE!!**  
He plans to have a **moving sale about 1 week**  
**prior to his move....**

**OUT-BACK STEAK HOUSE**

**will be opening around the middle of June**  
**in the "Orchards" – New Hartford.**

**They feature a Gluten-Free menu and are**  
**interested in working with CSGMV to educate**  
**their staff – this comes from Megan Gain**  
**who will be an employee AND is a member**  
**of CSGMV!!**

**Thank you, Megan!!**

**\*\*\*\*ALERT\*\*\*\***

to anyone who purchased the cheese puff  
snax at the Walk – They are NOT gluten-free  
– so feed them to your NON-celiac friends!!

**TESTING**

**Denver, CO, February 18, 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. Celiac disease is a chronic, autoimmune,  
gastrointestinal disorder. In genetically  
susceptible individuals, ingestion of gluten-  
containing grains, especially wheat, causes  
inflammation of the small intestine mucosa and  
leads to malabsorption. Long believed to be a  
rare disorder, **celiac disease is now known to**

be one of the most common, under-diagnosed diseases, affecting 1:120-1:300 individuals in European and North American populations. Early detection through antibody and genetic testing and subsequent elimination of gluten from the diet is essential in aiding prevention and treatment. 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). About Kimball Genetics, Inc. -- Kimball Genetics, Inc., is an independent genetic testing laboratory with a national reputation for combining the highest accuracy of testing with unparalleled turnaround time and excellent personal service. Founded in 1994 by Annette K. Taylor, M.S., Ph.D., Kimball Genetics has distinguished itself from other molecular diagnostic labs by its one-day turnaround time and unique emphasis on genetic counseling and education.

from Hal Winfield – Columbia Presbyterian Center for Celiac Research

#### **BUCKWHEAT** facts:

Although this grain may sound dangerous it really is gluten free and safe. Buckwheat is not related to wheat at all, in fact, buckwheat is part of the rhubarb family. It was originally grown in Asia and used as a common grain in China for many years. Buckwheat now is grown in the western states and used for both human consumption and feed. Buckwheat provides a good variety of nutrients in a very tasty form. This grain is rich in protein, magnesium, B complex vitamins and fiber. The best part is the taste. It has a full nutty taste that lends itself to baking and main dishes. Buckwheat groats, which is the buckwheat kernel, can be used in place of barley in soups and stews.

If the kernel is toasted it is called Kasha. Kasha is probably the most commonly used form of buckwheat, and used in many main dishes such as bowties and kasha (gluten free bowties of course). Buckwheat can also be enjoyed as a hot cereal. It is a wonderful replacement for oatmeal.

For more information please contact:

[www.mycustompack.com/healthnotes](http://www.mycustompack.com/healthnotes)

#### **Neurologic Complications of Celiac**

**Disease** (Dr. Green and his colleagues have a new paper published in the Journal of Clinical Neuro-muscular Disease (J Clin Neuromusc Dis 2004;5:129-137)

#### **Abstract:**

Neurologic complications of celiac disease include ataxia and peripheral neuropathy, which can be the presenting symptoms and signs. Early diagnosis and intervention could prevent development of further neurologic and systemic complications. Questions remain regarding the prevalence of the neurologic complications, the pathophysiological mechanisms and the effectiveness of therapy or response to a gluten-free diet.

#### **Key words:**

**ataxia** – incoordination of movement, unsteadiness of gait.

**peripheral neuropathy** - numbness, pain, burning, tingling or pins and needles in the arms and legs.

\*\*If you would like a reprint of this paper, please email:

[celiac@columbia.edu](mailto:celiac@columbia.edu)

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Celiac.com 05/25/2004 – (excerpted)

'The results of a study conducted by Dr. G. Richard Locke III and colleagues at the Mayo Clinic College of Medicine in Rochester, Minnesota do not show an association between irritable bowel syndrome (IBS) and celiac disease.' 'A 1 in 20 diagnosis of celiac disease in patients with IBS/dyspepsia is consistent with other studies, and is still high and suggests that testing for celiac disease should be done routinely on these patients. No studies have ever suggested that all or even most IBS patients have celiac disease, just that the incidence is higher than that of the normal population. I propose that if this study had been done on exactly the same people several years from now, the 2 people in the control group who were found to have celiac disease may well develop

symptoms that would put them in either the IBS or dyspepsia group, which would create a statistically significant result that would contradict this study's result. Last, perhaps the results of this study really support a **more broad conclusion: *Everyone ought to be screened for celiac disease, not just those with symptoms.***

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### **Congress Hears First Ever Testimony on Celiac Disease**

Today, for the first time, individuals with Celiac Disease testified before a Congressional Committee. Lisa Murphy, and her son, Colin, represented the ACTF before the House Appropriations Subcommittee on Labor, HHS, and Education. They did an outstanding job outlining what celiac disease is, who it affects, the need for NIDDK to develop a research plan for CD, as well as, the need for greater physician and patient education. (The Murphy family, of Chappaqua, NY, was featured in a Feb. 2004 Parents magazine article about CD). The Labor-HHS Subcommittee determines how much money NIH receives each year. Having individuals with Celiac Disease provide information about the disease is critical to securing funding for research. After hearing the testimony, Subcommittee Chairman, Ralph Regula (R-OH), asked if food labels were a problem for celiacs. Not missing a beat, Lisa offered an emphatic 'Yes,' then highlighted problems she has encountered. Rep. Nita Lowey (D-NY), sponsor of H.R. 3684, the Food Allergen Labeling and Consumer Protection Act, and member of the Subcommittee, noted the bill was drafted to help individuals like Lisa and Colin. The celiac community has waited a very long time for this incredible opportunity. The American Celiac Task Force is grateful to the entire Murphy family for graciously agreeing to share their story, and for helping to make this historic day possible.

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**from the "List-Serv" – Eileen Kinsella: promising testing being done in Italy** by the Institute of Paediatrics and Department of Clinical Science, University of Rome "La Sapienza" – it would seem a Transglutaminase Autoantibodies (tTG-Abs) saliva test (under development & testing) equals effectiveness of serum screening.

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**from the "List-Serv" – Eileen Kinsella:** To all that have inquired about baklava, spinach pie and GF phyllo (filo in Greek): If you're interested in these Greek delicacies, drop me an email at

dnworks@yahoo.com and I'll send you more info. Below is a list of the ingredients for those that may have additional issues beyond celiac disease - milk, egg, tree-nut allergies, etc. - I already posted the GF phyllo recipe a couple weeks back, and now, after a few trial runs to get the process down, I'm ready to take orders for GF baklava and GF spanakopita (spinach pie) made with my own, paper-thin, hand rolled phyllo that is indistinguishable from the wheat-based version. I've already shipped over 100 orders of both baklava and spanakopita across the country to rave reviews! I've also had people try them at celiac related events and was delighted by the look of wonder and surprise on their face to see and taste such treats. Thanks to Gluten Free Pantry and Schar whose wonderful GF flours make the phyllo possible!

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### **FOOD NEWS**

**\*\*corrected recipe from NL III-2\*\***

**~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 tsp. dill weed
1-2 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.

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**re: Panera's – Commercial Dr., New Hartford the following was obtained by Arnoldine & Stan Bartoszek 4/29/04**

**"The locals may create their own creation but only the ones she lists are Gluten Free, e.g., the New Hartford Panera Bread had a Garden vegetable Soup and showed that it was free of gluten by their listed contents but when the soup arrived, it had BB size pasta balls.**

**If you look at the list, there is no Garden Vegetable soup on Tracy's list.**

**The list is not long but they are a bread-based cafeteria like food server so you can't really expect more."**

**GLUTEN FREE LIST – Panera Bread**

**Salads: (including the salad dressing)**

(source of modified food starch is corn)

- Greek Salad
- Fandango Salad
- Caesar Salad (**without croutons**)
- Asian Sesame Chicken Salad (**without**

**Won Ton noodles)**

- Classic Cafe' Salad

**Soups:**

- Moroccan Tomato Lentil
- Santa Fe Roasted Corn
- Vegetable and Sirloin Beef
- Vegetarian Black Bean
- Vegetarian Lentil
- Mesa Bean & Vegetable

**Salad Dressings:**

- Balsamic Vinaigrette
- Caesar
- Greek
- Poppy seed
- Raspberry Vinaigrette
- Sesame Vinaigrette

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from Megan Cain - Uncle Ben's "Redi-Rice" (white & Spanish) is gluten-free.

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from Hal Winfield at the Celiac Disease Center at Columbia-Presbyterian in New York City:

**Conclusion of a study done -**

\* Our results indicate that the quality of life of individuals with celiac disease in the United States is less than non-affected controls. It is negatively impacted by several factors that include adherence to a gluten-free diet, ability to travel, dine out, work, and presence of symptoms, though it improves with time. In contrast to previous studies there were no differences between genders in relation to the negative impact of the diet on quality of life. Presence of other medical conditions did not adversely affect quality of life.

\* There has been a lot of activity on the legislative front. On April 27<sup>th</sup> for the first time, individuals with celiac disease testified about it before a Congressional Committee. Lisa Murphy and her son, Colin, represented the ACTF before the House Appropriations Subcommittee on Labor, HHS, and Education. They did an outstanding job explaining what celiac disease is and focusing the need for research into it.

\* On May 4<sup>th</sup>, Tommy Thompson, Secretary of HHS, sent a letter to House Speaker Dennis Hastert sharing the Department's views on new food labeling, (S. 741), and requesting the House 'move expeditiously to adopt this legislation.'

A similar letter was sent to Rep. Joe Barton, Chairman of the House Energy and Commerce Committee. It is well known that our community is intended to benefit from passage of the Food

Allergen Labeling and Consumer Protection Act.

\* We recommend that the celiac community capitalize on the work of the ACTF. Do something! Contact the American Celiac Task Force.

[www.celiaccenter.org/taskforce.asp](http://www.celiaccenter.org/taskforce.asp)  
[actf@fogworks.net](mailto:actf@fogworks.net)

**\* NIH CONSENSUS DEVELOPMENT CONFERENCE ON CELIAC DISEASE NIH, WASHINGTON, DC 28<sup>th</sup>-30<sup>th</sup> JUNE, 2004**

The program is available at:

<http://consensus.nih.gov/cons/118/ceciabackground.html#overview>

The conference is open to the public. Registration is required and is available at this site:

<http://www.meetinglink.org/omar/ceciac/registration.htm>

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Celiac Disease Center at Columbia  
 Columbia University College of Physicians and Surgeons  
 New York – Presbyterian Hospital  
 161 Fort Washington Avenue  
 New York, NY 10032

**"Hold the Dates"**

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**What:** [Celiac Disease CME for Professionals](#)

**When:** Friday, October 22<sup>nd</sup>  
 from 8:30 am to 3:30 pm

**Where:** Milstein Hospital Building's  
 Clark Conference Center  
 177 Ft. Washington Ave

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**What:** [Patient Education Day 2004](#)

**When:** Saturday, October 23<sup>rd</sup>  
 from 8:30 am to 3:30 pm

**Where:** Health Science Campus of  
 Columbia University in the Hammer  
 Health Sciences Building at  
 701 West 168th Street, NY City, NY

**[\\*Registration information to be announced for both days\\*](#)**

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from listserv – Eileen Kinsella

**Video: Celiac Disease Often Undiagnosed**  
<http://cf.nbc4columbus.com/col/sh/video/player/video.cfm?id=3313324&owner=col>  
 Transcript

**Genetic Disease Quietly Destroys Intestines**  
<http://www.nbc4columbus.com/health/3305336/detail.html>

**If anyone would like to see the TV interview that San Diego's NBC affiliate did**

last week, it can be viewed online at <http://nbcсандiego.feedroom.com/iframeset.jsp?ord=760260> -- the host, Bill Menish, did an AWESOME job, covering all the highlights (he was well prepared by one of my local ROCK moms, Karen Fine). The interview was live, and lasted a few minutes -- a LOT of time in the TV world. The station told me they were not going to put this link on their site, but they had dozens of calls that morning after the piece ran, so they added it to the site -- LOTS of interest in celiac disease!  
 Danna Korn (founder of R.O.C.K.)

R.O.C.K. (raising our celiac kids) – Mohawk Valley



~WALK for Celiac Disease Report~  
 from - Becky Madeira

At the walk we had a great turn out. R.O.C.K. made \$40 on the raffles we offered.

The following won: 2 Baskets of Cookies - one went to Emily Allen and the other went to James Farrell; the chocolate cookie cake went to Emily Allen; the chocolate covered peanut butter bars went to James Farrell; the box of breakfast bars (made by Envirokids) went to Arnoldine Bartoszek. Thank you to everyone that supported the R.O.C.K. group. We all had a great time at the walk and met a lot of new people.

I made chili - the recipe is below - the original recipe came from Tanya Clute...

I have changed it a little:

CHILI

- 2 lbs of ground beef
- 1 onion (med-large)
- 2 bell peppers (any color is good)
- 1 16 oz can of each Pinto, Kidney and great northern beans
- 1 28 oz diced tomatoes
- minced garlic (fresh or dried will work)
- chili powder (to taste) (cont. next page)
- onion and garlic powder (to taste)
- red pepper (to taste)
- olive oil (1 tbsp)

Dice onion. Sauté onions in the olive oil until they are clear. Once they are clear, fry up ground beef and some of the seasoning above with onions. While the meat and onions are cooking, cut up the bell peppers & put in crock-pot with tomatoes (DO NOT

drain) and the 3 cans of beans (drained not rinsed). Drain the ground beef/onion mixture free of grease, add to crock-pot. Add some more of the seasonings above to the crock pot mix to taste. After adding a little seasoning here and there, you might want to taste and add more if desired. Start this process early to allow the bell pepper to cook thoroughly. RED HOT sauce may be added to crock pot mixture or the individual bowl as desired.

I like to add crushed up tortilla chips to my chili.

Tanya added a few other ideas: eat with corn bread, add sour cream or plain yogurt or even cheddar cheese.

ENJOY!

Tanya and I are really glad you liked it.

Becky Madeira

315-337-7671 home

315-525-5048 cell

celiacparents@earthlink.net



BOOKS

Gluten-Free Friends: An Activity Book for Kids

is designed for approximately 4-11 year old children with gluten sensitivity. It also describes methods to eliminate casein making it useful for the autistic community. Through an enticing, delightful, optimistic story and abundant multi-sensory learning activities the child becomes empowered with the ability to independently make gluten-free food choices even in the face of peer pressure. Methods to manage the fundamental intricacies of the gluten-free diet are addressed as well as good overall nutrition. The book may also be use by not only parents, but healthcare providers, educators and therapists. Nancy Patin Falini, MA, RD, LDN a dietitian in private practice specializing in celiac disease and the gluten-free diet is the author.

Dr. Alessio Fasano, MD, an internationally renowned pediatric gastroenterologist wrote the Forward. It sells for \$18.95 with a price reduction for 10 or more orders. **It's available from [www.amazon.com](http://www.amazon.com) and the publisher Savory Palate at [www.savorypalate.com](http://www.savorypalate.com) or 800-741-5418.**

Eating Gluten-Free with Emily - A Story for Children with Celiac Disease

Written by Bonnie J. Kruszka

Fully illustrated with whimsical watercolors by artist Richard S. Cihlar that your child will love! ISBN: 1-4010-8949-6

This is the story of Emily, a happy, active five year old, who suddenly becomes ill. Emily describes the process through which she is diagnosed with celiac disease, and chronicles real-life situations that all children with dietary restrictions inevitably face. She then recounts the lifestyle changes necessary to manage her disease in terms that young children can understand. To order your copy today for \$14.99 plus shipping, visit:

[http://www.xlibris.com/](http://www.xlibris.com/EatingGlutenFreewithEmily.html)

**EatingGlutenFreewithEmily.html**  
**OR call 1-888-795-4274**

**CSGMV continues to have Shelley Case's "Gluten-Free Resource Guide" available for \$15 – as well as the 2<sup>nd</sup> revised edition of "CSGMV Favorite Recipes" for \$5 --at meetings OR contact Lavinia Tilton at 315-337-8841**

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**~WALK for Celiac Disease Report~**  
**from our President – Pam Fahy**

**Our 3<sup>rd</sup> Walk for Celiac Disease was a success** - Here is some information on the results of our walk to raise funds for Celiac Disease from Melody Ernst, our very effective co-chair of the event.

- over 100 people attended the event, including "Happy the Clown" who made figurine balloons for children and adults including a puppy with a baby inside, an apple with a worm and a bumblebee!

-Attendees came from throughout the Mohawk Valley Region, including Utica and parts south, Rome, Blossvale and West Leyden (north of Rome) and as far away as Watertown! Several people at the walk were newly diagnosed with Celiac Disease and came to support the cause and obtain information to get on the road to recovery.

- About half of those in attendance participated in the one mile "Nature Walk", including two different parents with children in strollers! A small group took the extended distance Nature Trail. Although we did not see any deer this year, we DID see deer tracks, lots of birds and butterflies!

-The R.O.C.K. (Raising Our Celiac Kids) group staged a booth and several families with their Celiac children were on hand to enjoy the fun and answer questions. They offered free face painting at the booth and held a raffle for several prizes involving gluten-free goodies. (see the article by Becky under the "ROCK" banner!)

- The rain held out until the event was over!

- over \$2,500 was raised thus far, with **funds still being collected until June 17, 2004.**

We'd like to offer a special "Thank You" to the Town of Floyd for grooming our trails and providing a wide and dry trail for us all to enjoy. And also a Big Thank You to the Floyd Fire Department for being wonderful and accommodating hosts, as usual!

Lastly, we would all like to THANK YOU Carl Eilenberg, for so generously covering our event in your publications and giving us so much extra exposure! It really means a lot to us and certainly helps our cause. So, again, thanks so much to all who participated in any small way! (Melody)

CSGMV has a strong presence in our community – but we have much room to grow. In the future, we are hoping to reach out in areas such as participation in local Health Fairs, courtesy mailings to professionals, and many other ideas are in the "hatching" phase – WE NEED THE HELP of EVERYONE!!! Don't be shy – there is always room for you to be involved!!

In October, we will be electing officers – do you have a bit of time, talent, networking contacts that you can provide CSGMV?? Then, please contact me. We really want as many as possible of our members to be involved.

Below is a list of winners of **Prizes at the Walk Drawing:**

Kraft Picnic Basket	Emily Allen
Peter's Cornucopia Basket	Michelle Farrell
Symeon's Gift Cert.	Happy the Clown
Rome Comm. Theatre Gift Cert.	The Madiera Family
A.C. Moore Gift Cert.	Pam Dudeck
Set of Knives	Happy the Clown
Set of Knives	Peg Ward
G.F. Cookie Mix	Jim Ward

Again, **our sincere thanks to everyone** – and do plan to attend our **next meeting, Sat., June 19<sup>th</sup> at 10 AM.** See you there!

Pam Fahy, President

