

csgmv-news ISSUE IV - 5
September – October 2004
Chapter of the
Celiac Disease Foundation



WEB SITE -- www.csgmv.org

MISSION STATEMENT and GOALS - CDF/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. CSGMV is currently a chapter of the Celiac Disease Foundation – a non-profit public benefit organization dedicated 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

Revised 5/2004

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.

2004 MEETING SCHEDULE

@ 10 AM at New York Mills Library – corner of Main & Maple Sts.

(please use **BACK** entrance - off Maple St.)

- **Sat., Oct. 16, 2004**
action on bylaws & slate of officers
- **Sat., Nov. 20, 2004**
- **Sat., Dec. 18, 2004**
cookie/favorite foods sampling/exchange

PAY 2005 DUES – don't miss a newsletter!!!



CORRECTION (to NL IV 4) from Sue Goldstein, Westchester Support Group (we thank her!) re: kasha being GF -

KASHA is buckwheat and is ok (GF).

There are some prepared dishes, like "kasha varnikes," that are made with kasha and bow-tie noodles, often found in the deli department. These, of course, would not be gluten-free.

from Elaine Monarch, Exec. Dir. CDF 9/9/04:

MOST of the time maltodextrin is OK - it is derived from sugar. the name is suspect because of the "malto". (to be sure, call the manufacturer!)

letter received by member, Harold Wheeler

6/28/04 states " the following products are gluten-free:

Breyers "All Natural" Ice Creams: Vanilla, Chocolate, Chocolate Chip, Coffee, French Vanilla, Mint Chocolate Chip, Peach, Rocky Road, Strawberry, Vanilla Fudge Twirl, Vanilla/Chocolate/Strawberry, Take Two Vanilla/Chocolate, Frozen Yogurt Vanilla/Chocolate/Strawberry, Frozen Yogurt Chocolate, Light Vanilla, Light Mint Chocolate Chip, and Lactose Free Vanilla.

Other Breyers Ice Creams: Chocolate Rainbow, No Sugar Added Vanilla, No Sugar Added Vanilla/Chocolate/Strawberry."

Eleanor heard from **Byrne Dairy (re: the bulk sour cream used in the dressing at Symeon's)** – it is from Cabot's & is gluten-free --- so enjoy!

Eleanor received this from **Bumble Tuna 7/28/04:**

Thank you for taking the time to contact us about our Bumble Bee (Pouch) Chunk Light Tuna in Water.

All of our BUMBLE BEE Brand canned seafood products are gluten free. However, the crackers contained in our BUMBLE BEE Brand Ready-to-Eat Salads & Crackers, contain wheat flour.

We no longer use Hydrolyzed Proteins in any of our products. However, we do add a small amount of vegetable broth which may contain some of the following vegetables: carrots, peas, green & red bell peppers, onions, parsley, celery, garlic and sometimes soy.

MSG (mono sodium glutamate): is not added to any of our products and is not present in the vegetable broth.

PhillySwirl is making headlines AGAIN!

There is a **HUGE** article about the company on the front page of the Money Section of USA Today (August 20-22 Fri/Sat/Sun edition).

www.usatoday.com/money/industries/food/2004-08-20-phillyswirl_x.htm

Don't forget this is the company that is donating 50 cents off each box of its ice creams to Celiac Reseach! You just send in the UPC code to the Center for Celiac Research, and PhillySwirl makes a donation.

<http://www.celiaccenter.org/Phillyswirl.pdf> (cont.)

The ice cream is really tasty, and you can get it at Costco and Wal-mart. Info for local stores in on the PhillySwirl website -www.phillyswirl.com

BOOKS

"Wheat-Free Recipes & Menus" by Carol Fenster, PhD. – delicious healthful eating for people with Food Sensitivities – enjoy all your favorite foods without wheat OR gluten. This book is being offered by CSGMV to our people at a reduced price of \$15 (from the retail price of \$16.95). It is available at our meetings – and copies are being donated to the New York Mills Library & the Oneida Library.

"Incredible, Edible Gluten-Free Foods for Kids" a wonderful book for Celiac Children authored by Sheri Sanderson will be available at a discount, also – thanks to Sheri & Woodbine Press.
CSGMV has copies for sale at \$14.
Copies are being donated to the New York Mills Library & the Oneida Library.

NEW NEWS

email received 8/3/04

from the American Celiac Task Force:

Last night, President Bush signed

the Food Allergen Labeling and Consumer Protection Act (FALCPA / S. 741) into law. Every call, letter, meeting, petition, and crayoned picture paid off. Thanks to you --the celiac community -- we beat incredible odds and got this bill passed.

J Allergy Clin Immunol 2004;113:1199-1203. Celiac.com 07/30/2004 –

According to a study by Italian researchers published in the June edition of the Journal of Allergy and Clinical Immunology, the prevalence of atopic dermatitis is much more common in those with celiac disease. The researchers looked at 1,044 adults with untreated celiac disease at the point of their diagnoses, as well as 2,752 of their relatives, and 318 of their spouses. They also looked at the prevalence of allergies in celiacs after one year on a gluten-free diet. The subjects filled out a standardized questionnaire upon their diagnosis, and those who reported having an allergy were tested for it using a standard makeup of 20 antigens for serum specific IgE.

The researchers found that one celiac in 173 (16.6%) had at least one additional allergy, compared with 523 of their relatives (19%), and 43 of their spouses (13.5%). Patients with celiac disease were also more likely (3.8%) to have atopic dermatitis than their relatives (2.3%) or their spouses (1.3%). The amount of time that the celiac patients went undiagnosed and therefore untreated did not seem to influence the presence of allergy or atopic dermatitis. It is possible that a longer period of time on a gluten-free diet could influence the prevalence of allergy in those with celiac disease, and more research needs to be done to determine if being gluten-free longer can decrease allergies in those with celiac disease.

When: Saturday, October 23rd
from 8:30 AM to 3:30 PM

Cost: \$55/person \$110/family

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

Registration: call Hal Winfield @ 212-342-0251

Psychosomatics 45:325-335, August 2004
Celiac.com 07/30/2004 –

Past studies have reported a higher prevalence of depressive symptoms in adults with celiac disease, perhaps due to serotonergic dysfunction, and an increased prevalence of depressive and disruptive behavioral disorders in adolescence with the disease, especially before treatment. In an effort to further study any possible connections, researchers looked at 29 adolescents with celiac disease and 29 matched controls. The researchers used semi-structured psychiatric interviews and symptom measurement scales to examine all subjects. Their findings indicate that the subjects with celiac disease had significantly higher prevalence of major depressive disorder compared to the controls--31% versus 7%, and a significantly higher prevalence of disruptive behavior disorders--28% versus 3%. The researchers also found that most of the mental disorders occurred before the patients were diagnosed and treated with a gluten-free diet. The prevalence of current mental disorders was similar in both of the groups studied.

excerpted from updates on celiac.com

Cancer: Malignancy and Mortality in People with Celiac Disease: Population Based Cohort Study

BMJ. 2004 Jul 21

Celiac.com 08/09/2004 – In a study designed to quantify the malignancy and mortality risks associated with celiac disease, British researchers examined 4,732 celiac disease patients and compared them to 23,620 matched controls.

The researchers conclude that there is a modest increase in the rates of malignancy and mortality during the first year following a diagnosis of celiac disease. After one year, however, most of that increase quickly diminishes to a level that is only slightly higher than that of the normal population, presumably due to the effects of a gluten-free diet. In an unexpected finding the researchers also found a significant reduction in incidence of breast cancer in those with celiac disease, which warrants further study, as it could provide insight into the cause of the disease.

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Patient Education Day 2004 (from Hal Winfield at Columbia)

from Celiac.com – a 2002 study "**Low Serum Vitamin B12 is Common in Celiac Disease and is not due to Autoimmune Gastritis**" lists the following as 'conclusions':

Low B12 is common in coeliac disease without concurrent pernicious anaemia, and may be a presenting manifestation. B12 status should be known before folic acid replacement is started.

Dig Dis Sci. 2004 Apr;49(4):546-50

Celiac.com 08/27/2004 – Dr. Peter Green and colleagues at the Department of Medicine, Columbia University College of Physicians and Surgeons, New York, New York, conducted a study designed to determine the sensitivity of the various serological tests used to diagnose celiac disease. To do this they looked at 115 adults with biopsy-proven celiac disease who fulfilled strict criteria which included serological testing at the time of their diagnosis, and a positive response to a gluten-free diet. Out of those studied, 71% had total villous atrophy, and 29% had partial villous atrophy. Serological results indicated that only 77% of those with total and 33% of those with partial villous atrophy actually tested positive for celiac disease, and it did not matter whether the patients presented with classical or silent symptoms. All patients who were positive for anti-tissue transglutaminase had total villous atrophy.

The researchers conclude: "Seronegative celiac disease occurs. Endomysial antibody positivity correlates with more severe villous atrophy and not mode of presentation of celiac disease. Serologic tests, in clinical practice, lack the sensitivity reported in the literature."

excerpted from Celiac.com 08/09/2004

HOLLYWOOD, FL - York Nutritional Laboratories has announced it will now provide the saSCAN Secretary IgA Food Intolerance Kit, which can conveniently be administered in the comfort of one's own home or in the privacy of a doctor's office. Unlike competing tests, which require a full blood draw, the saSCAN can be performed by means of a simple saliva collection mechanism. Originally developed by Diagnos-Techs, the saSCAN screens the four most common culprit foods involved in IgA-mediated food allergy (e.g. - Egg, Gluten, Milk and Soy).

According to John Kernohan, Director of York Nutritional Laboratories, "We're very excited over our new strategic alliance with Diagnos-Techs and our ability to provide the saSCAN Secretary IgA Food Intolerance Test. It's a wonderful compliment to our foodSCAN IgG ELISA Food Intolerance Finger-Stick Test, which when used in conjunction with each other, allows physicians and patients alike to have an accurate, reliable and cost-effective means to screen for both IgA-mediated and IgG delayed onset allergic reactions."

For more information contact John Kernohan, York Nutritional Laboratories Inc., 2700 North 29th Avenue, #205, Hollywood, Florida 33020 USA, (888) 751-3388, info@yorkallergyusa.com www.yorkallergyusa.com

excerpted from the Westchester Newsletter 4/04 – summarized by Rory Jones

"Celiac Disease is NOT a food allergy – but part of a misdirection of the immune system. Genetic makeup is only part of the picture – you need the predisposition, BUT environment plays a part.

TYPICAL symptoms of CD include:

- early onset (children stop tolerating gluten when it is introduced
- malabsorption (food goes through us undigested enabling bacteria to turn it into gases & foul, smelly stools)
- failure to thrive (seen on growth curve charts; they are important to plot at each MD visit)
- muscle wasting
- distended belly (the 'text-book' case)
- irritability
- weakness
- sleep disturbance

NOT-SO-TYPICAL symptoms of CD include:

- unexplained anemia
- unexplained abnormal liver function tests
- osteoporosis & fractures
- dermatitis herpetiformis
- constipation
- IBS (irritable bowel syndrome; patients can have BOTH CD & IBS)

In short – there are many 'faces' of Celiac Disease!"

also excerpted from the Westchester Newsletter 4/04:
from

"so What Should the Term 'Gluten-Free' Mean?"

'A recent abstract presented at the Annual Meeting of the American Academy of Allergy, Asthma & Immunology showed that up to 1/5 of common grocery foods labeled 'wheat-free' or 'gluten-free' may actually contain significant amounts of wheat protein. As reported on the St. John's Celiac Listserv, **Deland Bakery's** line of millet breads (appearing to be GF based on the ingredients listed on the ingredient labels & on their website) was independently tested by AIB International of Manhattan, KS – and was found to have a gluten content of greater than 10%! This result was confirmed by a second independent testing lab, which went so far as to say that the primary grain in the bread sample tested was in fact wheat. They have now removed the "GF" designation from their website. Please contact the local FDA office if you happen to have any physical evidence (bread wrappers) of GF labeling by Deland Bakery.'

Hopefully the new labeling law will help us to know for sure that a product is GF – meantime **BE AWARE!!**

from Carolyn Trick (member) 7/28/04:

I spoke with the **Bath & Body Works** company today and they informed me that that the new Fall Fragrances (this fall '04) are NOT gluten free...specifically Green Apple and Pumpkin. They also said the Aromatherapy Hand Soaps were NOT gluten free. # 1-800-395-1001

from Louanne Harto, V.P. (rec'd. 8/4/04) -

Just a line to let you know I am here **in Florida** getting settled in. You had asked for something in writing pertaining to my current position with the group. I am no longer available to act as Vice-President of the group due to my relocation. Thanks so much for everything, really. I do love you guys and have met a lot of really nice people.

My address is:

922 Florida Ave. Dundee, FL 33838

New phone #: 863-439-3877

Well, bye for now. Will keep in touch.

Louanne

We wish you all the very best, Louanne, and thank you for your years of great service to CSGMV! Please do come see us when you're "in town"!!

from Lou Parrotta – Splenda is Gluten Free (from the company) There is no gluten in SPLENDA(R) Brand Sweetener. Sucralose, the sweetening ingredient in SPLENDA(R) No Calorie Sweetener is made from sugar. There are no wheat-derived ingredients or proteins in SPLENDA(R) Brand Sweetener. > >The maltodextrin in SPLENDA(R) No Calorie Sweetener is derived from corn and is known to be well tolerated by Celiac patients. > >We value hearing from our consumers. Please feel free to call us with any additional comments or questions on our toll-free number 1-800-7-SPLENDA (1-800-777-5363), Monday through Friday from 9:00 AM to 5:00 PM, Eastern Time.

8-year-old's first Holy Communion invalidated by Church

By JOHN CURRAN

The Associated Press BRIELLE, N.J. - An 8-year-old girl who suffers from a rare digestive disorder and cannot consume wheat has had her first Holy Communion declared invalid because the wafer contained none, violating Catholic doctrine. Now, Haley Waldman's mother is pushing the Diocese of Trenton and the Vatican to make an exception, saying the girl's condition - celiac sprue disease - should not exclude her from participating in the sacrament, in which Roman Catholics eat consecrated wheat-based wafers to commemorate the last supper of Jesus Christ before his crucifixion. "In my mind, I think they must not understand celiac," said Elizabeth Pelly-Waldman, 30. "It's just not a viable option. How does it corrupt the tradition of the Last Supper? It's just rice versus wheat." It's more than that, according to church doctrine, which holds that communion wafers must have at least some unleavened wheat, as did the bread served at the Last Supper. The Diocese of Trenton has told Waldman's mother that the girl can receive a low-gluten host, drink wine at communion or abstain entirely, but that any host without gluten does not qualify as Holy Communion. Pelly-Waldman rejected the offer, saying even a small amount of gluten could harm her child. Gluten is a food protein contained in wheat and other grains. "This is not an issue to be determined at the diocesan or parish level, but has already been decided for the Roman Catholic Church throughout the world by Vatican authority," said Bishop John M. Smith. "Hosts that are completely gluten-free are invalid matter for the celebration of the Eucharist," Smith said in a prepared statement released Thursday by the diocese. Celiac sprue disease, an autoimmune disorder, occurs in people with a genetic intolerance of gluten. When consumed by celiac sufferers, gluten damages the lining of the small intestine, blocking nutrient absorption and leading to vitamin deficiencies, bone-thinning and sometimes gastrointestinal cancer. It isn't the first such communion controversy. In 2001, the family of a 5-year-old Natick, Mass., girl with the disease left the Catholic church after being denied permission to use a rice wafer. Some Catholic churches allow the use of no-gluten hosts, others don't, according to Elaine Monarch, executive director of the Celiac Disease Foundation, a Studio City, Calif.-based support group for sufferers. "It is a dilemma," said Monarch. "It is a major frustration that someone who wants to follow their religion is restricted from doing so because some churches

will not allow it." "It is an undue hardship on a person who wants to practice their religion and needs to compromise their health to do so," Monarch said. Haley Waldman, a shy, brown-haired tomboy who loves surfing and hates to wear a dress, was diagnosed with the disorder at 5. "I'm on a gluten-free diet because I can't have wheat, I could die," she said in an interview Wednesday. Last year, in anticipation of the Brielle Elementary School third grader reaching Holy Communion age, her mother told officials at St. Denis Catholic Church in Manasquan that the girl could not have the standard host. The church's pastor, the Rev. Stanley P. Lukaszewski, told her that a gluten-free substitute was unacceptable. But a priest at a nearby parish contacted Pelly-Waldman after learning about the dilemma, volunteering to administer the sacrament using a gluten-free host. She said she won't identify the priest or his parish for fear of repercussions from diocese. On May 2, Waldman - wearing a white communion dress - made her first Holy Communion in a ceremony at the priest's church. Her mother, who also suffers from celiac and had not received communion since her diagnosis four years ago, also received.

But last month, the diocese told the priest that Waldman's sacrament would not be validated by the church because of the substitute wafer. "I struggled with telling her that the sacrament did not happen," said Pelly-Waldman. "She lives in a world of rules. She says 'Mommy, do we want to break a rule? Are we breaking a rule?' Now, the mother is seeking papal intervention. She has written to Cardinal Joseph Ratzinger, prefect of the Congregation for the Doctrine of the Faith in Rome, challenging the church's policy. "This is a church rule, not God's will, and it can easily be adjusted to meet the needs of the people, while staying true to the traditions of our faith," Pelly-Waldman said in the letter. For her part, Pelly-Waldman - who attends Mass every Sunday with her four children - said she is not out to bash the church, just to change the policy that affects her daughter. "I'm hopeful. Do I think it will be a long road to change? Yes. But I'm raising an awareness and I'm taking it one step at a time," she said.

[August 12, 2004](#)

*"Strangers are just family you have yet to come to know!"
~ 'the Blue Man'*

After years and many requests Wegman's Market Buyers have authorized the sale of certain Glutino Products for the Natures Market departments of their stores. The stores will not necessarily bring in all (or any) items unless there is a perceived demand. It is recommended that you contact the Natures Market Manager at your local Wegman's and let them know which items you would like to purchase. To make your request easier I have included the available items and codes for you to give to the dept manager.

Enjoy those bagels and breads,

Mike Lodico

www.GLUTENFREEINWNY.com

a Branch of Gluten Intolerance Group

Wegman Item # Vendor Item # Pack Size

Description

266607	356253	12/4.4oz	Glutino
Dreams cookies		(cont.)	

chocolate 266608 356170	12/4.4oz	Glutino Dreams
cookies shortcake 266610 356238	12/4.4oz	Glutino Dreams
cookies vanilla 266611 356196	12/4.4oz	Glutino Dreams
cookies zebra 266612 264630	6/19.0oz	Glutino Gluten Free
Bread, Corn 266613 264747	6/20.2oz	Glutino Gluten Free
Bread, Fiber 266614 264671	6/22.6oz	Glutino Gluten Free
Bread, Cinnamon Raisin 266615 264655	6/21.2oz	Glutino Gluten Free
Bread, Flax Seed 266616 264697	6/13.2oz	Glutino Gluten Free
Pizza Crusts(cont.) 266617 395673	6/22.9oz	Glutino Gluten Free
Bagels, Plain 266618 395699	6/22.9oz	Glutino Gluten Free
Bagels, Sesame Seed		

* Visit the Celiac Web Page at
www.enabling.org/ia/celiac/index.html *

from Eileen Kinsella -
In the Current issue of 'Time Out New York' (#464, Aug 19-26) there is an excellent article about Celiac Disease, especially wonderful because this is a really popular listings-type magazine especially attractive to young people. There is a website which I presume will give access to the article: www.timeoutny.com Nancy in nyc

BE AWARE

Castlewood no longer has a 'dedicated fryer' for their **French Fries** – **SO** they are not acceptable on a GF diet!!



RECIPES thanks to Celiac.com
Zucchini Bread

from Esme Smith -

This recipe makes one loaf.

- 1 cup walnuts, chopped
 - 1½ cups freshly shredded zucchini
 - ½ cup vegetable oil
 - 1 cup sugar
 - 2 eggs
 - 2 teaspoons vanilla
 - ½ teaspoon baking soda
 - ½ teaspoon cinnamon
 - ½ teaspoon salt
 - ¼ teaspoon baking powder
 - 1½ cups [GF flour mix](#) **
 - 1 teaspoon xanthan gum for each cup of flour (cont.)
- Shred the zucchini and chop the walnuts in a food processor and set them aside.

Use a mixer to beat the eggs and add the sugar, oil and vanilla. Add the baking soda, cinnamon, salt and baking powder. Slowly pour in the flour and xanthan gum until well mixed. By hand, mix in the zucchini and walnuts. Pour in greased & floured loaf pan and bake at 350F degrees for 75 minutes. Let cool.

If flour is the only ingredient that contains gluten, then you can convert it to a GF recipe. Just replace the flour with ** *Bette Hagman's GF flour mix:*

- 2 parts white rice flour**
- 2/3 part potato starch flour**
- 1/3 part tapioca flour and 1 teaspoon of xanthan gum**

Beware of spices which contain wheat flour! Many manufacturers use wheat flour to keep spices from clumping.

Apple Strawberry-Rhubarb Crisp

Fruit Filling:

- 1 jar (12 oz) strawberry preserves
- ¼ cup granulated sugar
- 2 tablespoons [GF flour mix](#)
- 1 lb (3 medium) Granny Smith apples
- 3 cups rhubarb, cut into ½ inch pieces (cont.)

Streusel Topping:

- 1/3 cup butter or margarine, melted (cont.)
- 6 or 7 Pamela's Pecan Shortbread cookies (1 ¼ cups chopped)
- ½ cup chopped almonds
- 1/3 cup [GF flour mix](#)
- ¼ cup brown sugar
- ½ teaspoon cinnamon (cont.)

Mix preserves, sugar, and flour for filling in small bowl. Peel, core and slice apples, then cut in half crosswise. Coat apples and rhubarb with preserves mix and spoon into 8-cup baking dish.

For topping, mix chopped cookies, almonds, flour, sugar and cinnamon. Add melted butter and mix well. Sprinkle evenly over fruit filling. Microwave on high 13-15 minutes or (cont.) until apples are tender, turning dish after 7 minutes. Let stand about 30 minutes. Serve warm with ice cream or whipped topping.

Can be cooked in the oven - add 1 tablespoon flour to fruit mixture and bake at 350F for 45-50 minutes.

Variation:

Pine-Apple Crisp - Substitute pineapple preserves for strawberry, omit sugar and reduce flour to 1 tablespoon. Omit rhubarb and use 2 pounds Granny Smith apples. For more tropical flavor, use coconut macaroons for some of the cookies and nutmeg instead of cinnamon.

*thanks to Celiac Disease Center –
Columbia University*

Quinoa Vegetable Stew

- ¾ C Quinoa
- 1½ C water
- 1 C fresh (or frozen) corn kernels
- 1 C. chopped onions
- 3 garlic cloves (minced or pressed)
- 1 T. olive oil (cont.)
- 1 chopped bell pepper
- 2 C chopped zucchini or yellow squash

- 5 C. fresh or 3 C undrained canned tomatoes (28 oz.)
- 1 T. chopped fresh cilantro
- 1 T. chopped fresh basil
- salt & ground black pepper to taste
- a few cilantro or basil sprigs

Thoroughly rinse the quinoa in a fine mesh strainer under cool running water & set aside to drain. Combine the quinoa & water in a saucepan, cover & simmer for 15 – 20 minutes, until tender & fluffy. When the quinoa is cooked for about 10 minutes, stir in the corn, cover, & continue to cook.

Meanwhile, in a non-reactive or nonstick skillet, sauté the onions & garlic in the oil for 5 minutes, until the onions begin to soften. Add the bell peppers & zucchini (or yellow) squash & sauté for 5 more minutes. Stir in the tomatoes, cilantro, & basil – cover & simmer for about 10 minutes until the vegetables are tender. Add salt & pepper to taste. Fluff the quinoa mixture, spoon it onto individual serving plates, ladle on the vegetable sauce, and garnish with cilantro or basil sprigs. Serves 4.

Be aware – Castlewood Café no longer has a “dedicated fryer” for their French Fries – THEREFORE the fries are NO LONGER GF!

CSGMV encourages its members to join CDF (Celiac Disease Foundation) – this will result in \$ benefits to CSGMV. There is a form included in this newsletter – CDF Dues are \$35/yr. – you receive a wonderful initial packet + quarterly newsletters!! ***Check it out !!***

Carryout containers from wheat? Yes!?!

September 3, 2004 (from Eileen Kinsella)

Lightweight, biodegradable containers for taking home your fast-food meal or leftovers from your restaurant dinner can be made with wheat starch, ARS scientists have shown. So, too, can cups, bowls and plates. See the September issue of Agricultural Research magazine, available online at:

<http://www.ars.usda.gov/is/AR/archive/sep04/wheat0904.htm>

Check with candy companies to assure GF Halloween treats!!!

Ideas for Healthful Nutritious Lunches:

(thanks to CNYCSG newsletter)

- >1% or fat-free milk – good source of calcium (as is low-fat yogurt & calcium-fortified orange juice)
- >Use turkey, chicken, lean roast beef or low-fat ham instead of bologna, salami, pastrami or corned beef – OR use peanut butter
- >Add lettuce, tomato, and/or cucumber whenever you can (or carrot, celery sticks)
- >Cold GF pasta salads OR tossed salads with protein toppings (grilled chicken is good!)
- >Include 1 fruit every day – preferably fresh!
- >Baked chips, low fat popcorn, GF pretzels or rice cakes rather than full-fat items (do NOT use products made with olestra (Olean) – a fat substitute that can cause abdominal cramps)

>Pack water, or 100% fruit juice

from Journal of Pediatrics May 2004 –

Italian researchers studied samples of serum from 39 celiac disease patients with 32 controls. Salivary transglutaminase autoantibodies were detected in 97.4% of the patients with CD and in 100% of their corresponding serum samples. All the healthy controls tested negative for both serum & saliva transglutaminase autoantibodies. **The researchers conclude that it is possible to detect salivary transglutaminase autoantibodies in celiac disease with a non-invasive, simple to perform, reproducible and sensitive method.**

from Dr. Levy (Director of the Children’s Digestive Health Center of the Children’s Hospital of New York-Presbyterian in NY & a Professor of Clinical Pediatrics at Columbia University College of Physicians & Surgeons – 3/7/04) – excerpts:

- Since individual tests may look normal, & are based on IgA antibodies, it is recommended to measure total IgA antibodies to identify CD in symptomatic patients who happen to be IgA deficient.
- Blood tests alone may not be conclusive, but are worth re-doing if they do not correlate with the physical exam & history.
- Possible additional symptoms may include: Seizures; Brain Calcifications; Neuropathies; Psychiatric manifestations; Behavior changes (e.g. – hyperactive children); learning disabilities.
- ‘Celiac Disease is the ONLY autoimmune disease for which we have the cause & the cure.’

HORMEL – have a question about their products??
Call 1-800-523-4635

• **OFFICERS:**

President – Pam Fahy 865-4247
Secretary – Eleanor Wallace 736-6981
elpa1@juno.com
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Eileen Kinsella (‘04) 363-4632
Arnoldine Bartoszek (‘06) 768-8290

• **R.O.C.K. (Raising Our Celiac Kids) Co-chairs:**

Becky Madiera 337-7671
celiacparents@earthlink.net
Tanya Clute 361-1150

• **ADVISORY BOARD:**

Kathy Benjamin, MD 734-3161
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Oneida City Health Care Center
Norman R. Neslin, MD 624-7000 Gastroenterologist –
Digestive Disease Medicine of Central
New York

GLUTEN-FREE PASTA DINNER

"Who Needs WHEAT??"
at
St. Mark's Episcopal Church
17 White St.
Clark Mills, NY

Sunday November 7th
12:00 noon – 2:30 PM

\$6.00 Adults
\$4.00 Children 5-12 yrs.
Under 5 FREE!

Let's all support this great effort!!

Rochester Celiac Support Group
hosting **GF Luncheon** - at
RIT Inn & Conference Center
5257 West Henrietta Rd.
Henrietta, NY
Saturday, Oct. 16 11 AM –
2 PM

Speaker: Dr. Alessio Fasano
World-Renowned Celiac Research MD
at University of MD

He will speak on what the Univ. of MD Research
Center has done, AND what the future may hold
for those who are living Gluten-Free!!
call Ruth Wyman @315-463-4616
for information – **Reservations Necessary!**

CNYCSG Meeting

Sun., Nov. 14th
2 – 4 PM
at

NaturTyme Conference Room
5898 Bridge St.
East Syracuse, NY
315-488-6300

Speaker: Chef JoAnn M. Jones
Bread-Making Demonstration

+
**Tips on Avoiding Cross- Contamination in
Kitchen**

& will introduce a **brand new
GF Bread** – Manna from Anna
-- Samples served--
*Claimed to be better than
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**1-day Workshop
G-F food preparation
Nov. 13th OR Dec. 4th
(on Saturdays)
\$ 160 fee**

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1-800-888-7850, or e-mail
ciaprochef@culinary.edu.

WORDS from our President

– Pam Fahy

Hi all – Fall is here and the bustle of activity has begun! We
all have our list of obligations to carry us through to spring.
Whether it is, family and the seemingly endless sports,
parent teacher meetings & lessons or participation in civic

organizations which means meetings – meetings – meetings. And don't forget the holidays! I just don't know how we do it all. But do it though we must. It seems the busier we are the more we do.

The CSGMV has grown to 86 paid members this year. This membership growth is a huge indicator of the importance of our group to the celiac, medical and general communities. We provide the link to recovery. With the above mentioned growth our organization needs people to help it to continue and to grow. There are so many things we could do and want to do. We need help in this pursuit. I know – You're already too busy – but as I mentioned earlier, the busiest people find the time for the things that mean the most to them. Maybe it isn't an officer position, maybe it's just coming to the meetings or lending a hand with a dinner or refreshment, a health fair or during celiac disease awareness month in May. **"Many hands make light work"**

Some of the things we have done in the past and would like to do this year include:

-After holiday gluten free dinner – Excellent!

-Grass roots awareness – including health fairs, speaking engagements and letters, editorials etc... to the media – Critical!

-Teaching Day in May 2005 to correspond with the national celiac disease awareness month.

A support group is there to support those in need.

CSGMV is a strong support group thanks to the volunteers who give, give, give. Volunteering is very rewarding. The **benefits** go beyond the initial effort. **It is like the pebble in the pond. You find that the little thing you did ended up helping to create a big wave.**

This has a very therapeutic effect for both parties. It allows you to take your mind off of your problems for a while and helps you to see the positive side of things. **There are so many good things that come from getting involved – So Please Do!!**

treats to place in their desk or a cabinet. Advise the teacher that this is to be given to your child anytime there is a special event, such as a birthday or a holiday party. Make sure the treats are something your child really loves so that they will not feel left out.

They may feel even MORE special!!

****A site specifically for Celiac Teens – check it out!****

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

Need ideas for a GF lunch???

(thanks to Westchester CSG newsletter)

thermos of GF soup
cheese & crackers
lunchmeat wrapped around cheese stick
Vans waffles used for PB&J sandwich
apples & peanut butter
left-over spaghetti/mac & cheese in a thermos
tuna salad & GF crackers
Kinnick's cheese bread with marinara sauce
GF muffins
Individual applesauce cups/fruit cups/or fresh fruit with yogurt for dipping
small box of raisins
GF pretzels (may coat with melting chocolate)
Sunkist fruit roll-ups

ENJOY LIFE!!!

Gluten FREE!!!

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



A tip to all the R.O.C.K.ing parents who are sending your celiac child to school for the first time. After speaking to your child's teacher about the Gluten-Free (GF) requirements, give the teacher a bag of GF