



a "connection" of the
 Celiac Disease Foundation
 csgmv-news ISSUE III- 4
 July – August 2003
 WEB SITE -- www.csgmv.org

OFFICERS

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

Directors:

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

ADVISORY BOARD

Mark W. Adsit, MD 518-243-4492
 Gastroenterologist
 Kathy Benjamin, MD 734-3161
 Pediatrician –
 Women & Children's Health
 Margaret Curtacci, RD 865-7498
 Curtacci Nutrition Care
 Sharon Hoff, RD 361-2028
 Oneida City Health Care Center
 Norman R. Neslin, MD 624-7000
 Gastroenterologist – Digestive Disease
 Medicine of Central New York

DISCLAIMER

- Information and dietary recommendations Are intended for the benefit of our members and other interested parties. Individuals should consult with their physician before following any medical or dietary recommendations.
- No liability is implied by -- or assumed for -- the use of information contained herein.

MISSION STATEMENT - CSGMV

The CSGMV organized to provide support to the diagnosed person (and family) with Celiac Disease and Dermatitis Herpetiformis in the form of current information, available resources, and dietary management on an initial and continuing basis. Further, to serve as a resource for the general community and medical professionals by providing up-to-date information related to the management of Celiac Disease.
 Adopted 1/2000
 Revised 5/2002

Schedule of Meetings 2003

Join us.... AT 10 AM, THE 3RD SATURDAY OF EACH MONTH (schedule below – mark your calendars NOW!) AT THE NEW YORK MILLS LIBRARY, MAIN ST., NEW YORK MILLS, NY.....

- August 16th
- September 20th Sharon Hoff, R. D. Speaker
- October 18th
- November 15th
- December 20th

GREAT NEWS FOR THE GLUTEN INTOLERANT

Tufinit.com offers a line of products that are Gluten free and Lactose free. This well established company manufactures its chocolaty like treats under the strictest kosher supervision, known as Kosher Mehadrin. It uses only natural ingredients hence it avoids genetically modified inputs. In addition, its products contain no cocoa, no cocoa butter, no arousing ingredients and no artificial flavoring. Many of its products are SUGAR FREE as well.

Tufinit has recently established a presence in the US. Tufinit's products are currently available only via the Internet, on <http://www.TUFINIT.com> All orders are shipped in thermo-packages via express mail (overnight) or priority mail (1-2 days). Average shipping costs using priority mail are \$7.50

Detailed information about each product can be obtained by clicking on their respective images. For more information point your browser to <http://www.TUFINIT.com>

We look forward to servicing the needs of your Celiac Sprue Support Group members. Please pass this information along. Sincerely,

The Tufinit Team

President's Message

Hi everyone. Hope your summer is filled with the delicious locally grown fruits and vegetables that abound. We all benefit from this gluten free harvest!

I also have a very exciting opportunity to report that Dave and Sue Evans spoke to us at our June meeting about Nelson Farms. This is a new venture associated with the SUNY-Morrisville Auxiliary. Nelson Farms is in the process of renovating the old Nelson Inn in Nelson, New York.

The renovation will include the creation of six kitchens. One has been earmarked gluten free to produce gluten free products! The Celiac Support Group of the Mohawk Valley is being considered as a consulting capability.

The CSGMV committee members are Eileen Kinsella, Melody Ernst, Tanya Clute and myself. We are currently working with Dave and Sue to determine products that we "miss" most, and the equipment needed to produce these products. There are still many issues to discuss and get ironed out as this venture unfolds.

We are very excited about this new local opportunity to produce gluten free products. Our hope is to get Good wholesome gluten-free products at Reasonable prices.

Have a safe and Gluten Free Summer!!

Pam



M o h a w k
V a l l e y

R . O . C . K . N E W S -
from Tanya Clute

The Madiera & Clute families met at the Clute home on June 28, 2003. We discussed Nelson Farms and ideas for the Gluten-Free Kitchen. We also discussed Leanne Clute's project (see note below). It will be a lot of hard work, but we feel the rewards will be great because it will bring more attention to Celiac Disease!!

Leanne made Fudgy No-Bake Quinoa Flake Cookies that were out of this world! You really can't "eat just one". These cookies brought on a discussion about the use of Quinoa Flakes as a substitute for oatmeal.

We served G-F Pizza to those on a G-F diet - and Pepi's Pizza and wings to those NOT on a G-F diet.

As the sun went down, we started a fire and had S'mores for all. All you need is marshmallows, chocolate (the more the better) and Becky's G-F Graham crackers.

We need to give Becky a special "pat on the back" for all her strides in baking. Before Bella's diagnosis, Becky claims to have done very little baking. Since then she has made several kinds of G-F breads, desserts, and some of the BEST chocolate-chip cookies around. She does not hesitate to try something new in order for our Celiac girls to have what others are having! Congratulations, Becky! You are an inspiration to us all! We love you!!!

Our next meeting is scheduled for Sat., Aug. 9th, at the Madeira's. All are Welcome.....

***** from Leanne Clute *****

The Siemens Foundation is dedicated to providing scholarships and increasing access to higher education for talented mathematics,

science, engineering, and technology students in the U.S. A series of College Scholarships are awarded to people whose ideas place in the finals.

I am planning to create synthetic digestive enzymes in the small intestine and test them on foods that contain gluten.

I have had contact with Pam King, head of the research department at the University of Maryland in Baltimore, and with Dr. Fasano. Dr. Fasano says he is more than willing to work with me, with a few modifications to my idea. He will be getting back to me on dates when I will be traveling to the University of Maryland. The research will take place after July 1st, when he has met grant deadlines...

The following is from the "list-serv" - written by a former President of CSA - quite interesting - happy reading!

<<Disclaimer: Verify this information before applying it to your situation.>>

" Did you know that the gluten-free diet is the same for all celiacs in the U.S.? All of the national celiac organizations are now on the same page. Let's lay the past negative perceptions to rest.

Dietitians can access up-to-date gluten-free diet information in their 6th edition of their manual. CSA/USA, Gluten Intolerance Group, Celiac Disease Foundation, and American Celiac Society all subscribe to the same zero tolerance policy for gluten.

I want to share with you my opinions. Unfortunately, there are few absolutes in dealing with our diet. We celiacs should always avoid wheat, barley, rye, oats, spelt, triticale and kamut. Although there are various studies looking at oats for celiacs, the studies have not been long term enough to give definitive answers, just trends. However, there is likely contamination of wheat in the fields, storage, and/or processing. There is no pure retail source of oats in the U.S. at the present time. **No national celiac organization is advocating the liberal use of oats at this point in time.**

Many issues suggest certain answers at the present time depending on methods in manufacturing, agriculture, pharmaceutical practices, etc. At the present time corn (subsidized by the government) seems to be cheaper in many cases to that of wheat. The bottom line for companies is cost. There is no permanent answer to our questions.

We always have to be vigilant and investigate foods and ingredients for ourselves.

We thought the vinegar/alcohol issue was put to rest a couple of years ago when various scientists proved that little, if any, gliadin is allowed into the distillate in the distillation process. This means that most vinegars, except malt vinegar (where the flavoring from barley is added at the end of the process), are acceptable to most people on a gluten-free diet. The single word vinegar on food labels denotes apple cider vinegar. This all generally means we probably can order a vinaigrette dressing in a restaurant (not a creamy dressing) and not have to bother taking along our own bottle of salad dressing, as we once used to. Unfortunately, I have learned that the FDA also allows combinations of vinegars for some condiments, such as salad dressing (mayo type). It is best to find and use good brand names of companies who know the source of their ingredients.

Some celiacs tend to have other food sensitivities, even to vinegar. When these individuals have trouble with vinegar, therefore, it is probably not a gluten problem. Avoid any food that you cannot tolerate.

Canola oil that dietitians tout as being heart-healthy is no longer a perceived problem. Canola oil was developed in Canada, and now the companies that make canola oil have tested their products and say there is no gluten in this oil. If you have a problem with canola oil, it is probably not due to gluten. Red or white wine can be enjoyed by celiacs, unless they have individual sensitivities, possibly to sulfites. Of course, beer is forbidden.

Reacting to certain dyes is more likely to be an individual sensitivity rather than a gluten problem at the present time.

For best nutrition, we need to be eating a balanced diet using fruits, vegetables, protein (meat, poultry, fish, tofu, eggs), allowed starches, and limited fats. We celiacs can use flours from rice, potatoes, tapioca, cassava, nuts, beans, and Montina. All national celiac organizations believe that certain alternative grains and flours are inherently gluten free. These include quinoa, amaranth, buckwheat, millet and tef. Just be aware that some of the alternative grains could be contaminated with wheat, although quinoa and Montina are grown separately, not with wheat.

CSA now is dating all their publications. If your material does not have a date, it is probably old. I know a new Handbook is being written. Their Commercial Product List is revised every year. Write for updated material in which you are interested (www.csaceliacs.org).

CSA/USA believes that celiacs should use a three-step method for a gluten-free diet. The first stage is starting with unprocessed foods that are inherently gluten free. These would include all meat, fish, poultry, fruits and vegetables. Then add new products to your diet one at a time, judging how your body reacts to the new food. It is an excellent idea to keep a food diary with lists of the foods you try and your body's reactions, if any. Again, it is common for celiacs to have other food sensitivities, and by presenting one new food at a time, you will probably be able to ascertain if that food gives you a reaction. CSA says to wait to introduce the alternative grains into your diet at the end of the expanding stage 2, when you are more comfortable with the diet and realize how your body reacts to gluten. I believe using three stages is a reasonable approach to the gluten-free lifestyle that will benefit all celiacs trying to adjust. Yes, this approach might be considered a conservative view, but it addresses all levels of gluten sensitivity. When we are newly diagnosed, we don't know how sensitive we ultimately will become. Practically speaking, however, it may take a long time to expand your diet one food at a time. Another way to proceed for the average celiac is just to go strictly gluten free. Then if symptoms persist, go dairy free. If symptoms still continue, and you have reviewed your diet to ensure it is gluten free, then try the CSA 3-Step Diet approach.

Remember that some people can be allergic to corn and derivatives, which is a staple in the basic diet. Everyone's gluten-free diet will differ in the same light that everyone's menus will differ.

Reading labels for gluten is an acquired skill. There are about 20 companies who have full disclosure in terms of the top eight allergens, including wheat. Calling consumer toll-free phone numbers on food products is one way to ascertain the gluten status. Using the CSA/USA Commercial Product list can give you a head start. Lists are also published by Clan Thompson on the Web, the Denver CSA chapter, and the Tri-County Michigan chapter. **There is help available.**

Lactose intolerance is closely associated with celiac disease because the lactase enzymes are generated at the tips of the villi, and it is, of course, the villi that are damaged by gluten.

Thus the lactase enzymes do not have full function to digest the milk sugar (lactose).

Fortunately for us, ingesting lactose (if one is lactose intolerant) does not damage the small intestine - it just makes us uncomfortable.

Beyond gluten and lactose, celiacs might be sensitive to soy. Just be aware that other food sensitivities may cause digestive distress as well as gluten. All gluten type symptoms may not really be attributed to gluten. Most celiacs who continue to have digestive problems after going on a gluten-free diet may in fact not be vigilant enough or know enough.

Dr. Peter Green of Columbia University Celiac Disease Center says that if you find yourself having recurring gluten-type problems, the likely answer is in your diet itself; you are not being strict enough, possibly because you do not know enough or products have changed ingredients.

Review your diet. Review your diet.

Review your diet. Nothing is all black or white. The GF diet is essentially the same for all celiacs, but people themselves are different and have different levels of sensitivity, different associated disorders, different concurrent allergies, etc. The other celiac organizations do not specifically advocate a three-step approach to the gluten-free diet. However, the ultimate goals and foods allowed are the same. The point is that you have options and choices in the way to proceed.

Basically, all the celiac organizations have the same GF diet, but the manner in which they get to the end is a little different. No big deal! This is my understanding.

Because every little bit of gluten is damaging the villi in the small intestine, it behooves us to eliminate all the gluten we know about; we are inadvertently getting gluten particles in areas where we are unaware. **We ourselves are responsible for our own gluten-free lifestyle.** Our best health should be restored in time on a strict gluten-free diet.

I have been attending celiac conferences (CSA, GIG, Am.Celiac Society, or CCA) for the last 15 years, when I was rediagnosed. I have been a leader in various capacities for CSA/USA, I have collaborated with other celiacs, and I am currently chairman and newsletter editor for the Houston CSA chapter, as well as CSA TX State Coordinator. I have heard many, many lectures from well respected physicians and dietitians.

This is where I am coming from. I firmly believe in Celiacs Helping Celiacs. We all need each other.

--Janet Rinehart, Former President,
CSA/USA, Inc. www.houstonceliacs.org

Strawberry Dessert

(from Helen Garlock)

1st Layer

2 cups GF pretzels crushed
3/4 cup melted butter (or margarine)
3 TBS. sugar
Mix together, spread and pat in 9x13 pan.
Bake at 400 degrees for 7-10 minutes.
Cool for 1 hour.

2nd Layer

Cream 8 oz. cream cheese with 1 cup sugar -
Blend in one large container of Kool Whip.
Spread cream cheese mixture on pretzels.

3rd layer

Dissolve 2 regular packages of Strawberry Jello with 2 cups boiling water. Add two 10 oz. pkg, frozen strawberries (thawed) with one large can crushed pineapple (drained).
Spread Jello mixture over cream cheese mixture.
Cool till set.

(Enjoy!! Delicious!!)

CornFlake Cookies

(from Gaile Lepper)

(MAKE SURE ALL INGREDIENTS ARE G-F)

1 stick oleo
1 large bag marshmallows (G-F)
2 tsp. green food coloring OR red OR any color
4 1/2 C. CornFlakes (G-F)
1 tsp. Vanilla

Melt butter, marshmallows – add food coloring.
Add cornflakes. Mix – spoon onto greased cookie sheet or waxed paper. Decorate (if desired) w/colored sugar. Let cool... Enjoy!

(Hint -- grease spoon to drop cookies).

GFRAP

(Gluten-Free Restaurant Awareness Program)
sponsored by the
Westchester Celiac-Sprue Support Group
is "up & running".

More information is available at

www.glutenfreerestaurants.org

Is this of interest to anyone in CSGMV?? There has been previous discussion regarding trying to get restaurants/groups involved. Let us hear from you! They are looking for donations, and people who want to volunteer. The program is now "reaching out" nation-wide.

Pat McGregor is available to answer questions –
as Program Chairperson – 914-248-7377 or
email: pmacgf@aol.com

