

Celiac Solutions

NEWSLETTER OF THE KOGAN CELIAC CENTER
THE SAINT BARNABAS HEALTH CARE SYSTEM

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Gluten Free Awareness in Schools

The task of increasing awareness about celiac disease doesn't stop with getting more people diagnosed – education about the importance of the gluten free diet and its challenges within the scope of daily activities is just as important. Parents of children with celiac disease will be happy to hear about the progress being made to educate personnel in schools, not only in our own backyard but on a national level as well.

On Monday, October 13, the Board of Education of the Washington Township Public Schools hosted a district-wide professional day and featured a presentation about celiac disease



Give us a call if your school is interested in learning about celiac disease and the services of the Kogan Celiac Center

by Margaret Weiss Masiello, RD, Clinical Coordinator of the Kogan Celiac Center. School administrators and nurses learned up-to-date information about symptoms, early diagnosis, the gluten free diet, and the education and support services provided by the Center. This presentation, and others like it scheduled in similar venues throughout the state this fall, are part of the Center's continuing mission to improve the health and well being of those who live with this autoimmune disorder.

Nationally, the American Celiac Disease Alliance (www.americanceeliac.org) is working

to guide parents through the complicated process of getting dietary accommodations for their children when they are in school. On their website you can find the results of a survey they conducted over the summer about gluten free offerings in schools across the country, as well as recommendations and sample documents that can be used when establishing and serving the dietary needs of a gluten free diet within the school setting.

The USDA is also accepting comments as they consider possible additions to the National School Lunch Program. The National Foundation for Celiac Awareness (www.celiaccentral.org) has information about how you can submit your input about including gluten free school lunches for those who need them.

If you are interested in more information about how a gluten free diet can be followed in schools, please call the Kogan Celiac Center at 973-322-7272.

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Welcome to Celiac Solutions

Celiac Solutions

A publication by
The Kogan Celiac Center
of the Saint Barnabas
Health Care System

Editor

Margaret Weiss Masiello, RD
Clinical Coordinator
The Kogan Celiac Center

Design and Editorial Contributors

Carrie Bogart, RN
Nurse Executive
Saint Barnabas Ambulatory
Care Center

Nancy Edelmann, RN
Administrative Director
Saint Barnabas Rehabilitation
Services

Medical Advisory Board

Glen Mogan, MD
Gastroenterologist
Director, Medical Affairs
Saint Barnabas Ambulatory
Care Center

Francis Sunaryo, MD
Gastroenterologist
Director
Pediatric Gastroenterology
Saint Barnabas Medical Center
Children's Hospital of NJ at
Newark Beth Israel Medical
Center

200 South Orange Avenue
Livingston, New Jersey
07039
www.koganceliacenter.com
Phone: 973-322-7272
Fax: 973-322-7528

Welcome to Celiac Solutions, Issue 2!

Summer is over, school has started and the Kogan Celiac Center is in full swing! We are seeing lots of enrollment in our dietary education program, new faces at support group meetings and more plans for awareness seminars in schools and business settings – all working towards our mission of providing a single-source, evidence-based support initiative for people with celiac disease in New Jersey. We are looking forward to continued growth and expansion.

Awareness in schools about the needs of children with celiac disease is growing. See Page 1 for information about work that is being done both on a national level as well as in our own backyard.

Most have heard that Disney in Orlando is very celiac-friendly, but have you heard that Busch Gardens in Williamsburg is making an effort to accommodate the gluten free diet as well? Read a chronicle from one of our support group members on page 4 that describes their experience in this wonderful vacation spot.

Our efforts to offer safe gluten free selections to patients and guests throughout the entire Saint Barnabas Health Care System are underway. See page 3 for details!

Support groups over the summer had a chance to sample a few recipes made with some new and interesting gluten free grains. Included on Page 3 is a great

recipe for muffins that are certain to pass muster with even the most discriminating palates!

Here at the Center we get lots of questions that pertain to diagnosis, support and, of course, the gluten free diet. If you have a question that you think suitable for our Reader Mailbag (see Page 5), submit it to us either by phone or online. Who knows, others may be wondering the same things too!

Keep checking our website for updates about our activities and events. We also welcome suggestions and comments about this newsletter—what changes can we make to fit YOUR needs?



GF Certification Program

As part of our mission to provide expert services that include early assessment, diagnosis, treatment, education and support to improve the health and well being of those who live with celiac disease, the Kogan Celiac Center of the Saint Barnabas Health Care System has begun implementing gluten free menu selections for patients and guests in every one of its 6 acute-care hospitals and 9 long- and short-term rehab centers throughout the state of New Jersey.

All healthcare providers who are in contact with patients (nurses, dietitians, pharmacists, foodservice personnel, physical and occupational therapists) are included in this initiative and will undergo training via online learning modules, competency exams and

annual updating. The Center will act as the focal point for this initiative by overseeing the implementation of the protocol, documenting competencies and disseminating current and updated information. Once the training and implementation is complete, we will be certified by the National Foundation for Celiac Awareness, a premier national support organization dedicated to raising awareness and funding for celiac disease.

Comprehensive planning for this initiative started in early summer – look for kitchens and dietitians in all facilities to begin the certification process in early November, with the remaining staff beginning implementation in very early 2009!

*Sorghum Applesauce Oatmeal Muffins**

Ingredients

- 1/2 cup butter
- 3/4 cup brown sugar, packed
- 1 egg
- 1/4 milk
- 1 cup sorghum flour
- 3/4 tsp cinnamon
- 1 tsp baking powder
- 1/4 tsp baking soda
- 1/4 tsp salt
- 1 cup applesauce
- 1/2 cup golden raisins
- 1 cup gluten free oats

Streusel Topping

- pinch of salt
- 1/4 cup butter
- 1/2 cup sugar
- 1 teaspoon xanthan gum
- 1/2 cup sorghum flour

Heat oven to 350° F. Cream the butter; add the brown sugar; cream until light and fluffy. Add the egg and milk, beat well. Mix dry ingredients and add alternately with the applesauce to the creamed mixture, stirring well. Add the remaining ingredients. Spoon into well-greased muffin cups. Top with streusel topping. Bake 30 minutes.



*(developed by Barbara Kliment, Executive Director, Nebraska Grain Sorghum Board
www.sorghum.state.ne.us/)

A Vacation to Remember

As most people with celiac disease know, traveling is one of the most challenging aspects of a gluten free lifestyle. Refrigeration, storage, cross contamination and airline restrictions are all issues that must be confronted. Equally important, gluten free travelers want to have

"It was easier than we thought!"

fun and enjoy themselves too! Here, a family from our children's support group shared their wonderful, celiac-friendly experience at Busch Gardens in Williamsburg where they vacationed this past August.

Accommodations at the Kingsmill Resort and Spa were comfortable and clean with an efficiency kitchen, perfect to store and prepare dairy items and breakfast food. Some "just in case" items were brought from home: Annie's Mac & Cheese, frozen pancakes and waffles, Foods by George pizzas, cereal. The resort itself has six restaurants on site, and they were very forthcoming with ingredient lists and help with cross-contamination protocol.

Prior to the trip, the Kogan Celiac Center called the dietary department in the park and confirmed a list of gluten free foods that are available in the park itself (see below). Incredibly, one of the chefs in this department runs a local celiac support group—what a small world we live in! She was able to confirm the ingredients of every item in the park, giving our family a good level of detail and confidence as they enjoyed the attractions: first in Grogan's Grill where "it was easier than we thought!" and on the second day in Trapper's Smokehouse when "we had more confidence and brought fewer snacks with us." In both locations, our family "bypassed the regular line," and asked for a manager, who was ready, willing and able to discuss gluten free options and serve the plates straight from the kitchen to avoid cross contamination with



serving utensils. The Outback Restaurant in Williamsburg (www.outback.com) was "as wonderful as the one we go to in NJ," and the nearby Ukrops grocery store (www.ukrops.com) is a large, specialty foods store that has a good selection of gluten free food. In general, the trip was deemed a success, they all "felt fine during the whole trip," and "felt confident reading food labels" as a result of all of our discussions at support group meetings.

Gluten Free Choices in Busch Gardens (Williamsburg)

Grogan's Grill – speak with the manager to find out the GF daily specials
Trapper's Smokehouse – Grilled chicken and ribs (with BBQ sauce) are GF (but the individual packets of BBQ sauce are NOT)

Throughout the park – Hamburgers (without the bun), Icy Drinks, Soft Serve Ice Cream are GF
Personal Coolers – OK to bring into the park – they will store them in a refrigerator for you.

Won't you share your latest traveling experience?

Call

1-888-724-7123

to register for an upcoming support group meeting!

Send us your

suggestions and

comments about

this newsletter—

what changes can

we make to fit

YOUR needs?

Support Group Minutes

Check out Joan's Great Bakes for English muffins, bagels and pizza crust "like the real thing," www.gfgreatbakes.com . . . A really great place to see what's new out there is the "New Products" tab at www.glutenfreemall.com; recent finds there are GF licorice whips, granola bars and crisped rice chocolate bars . . . If you're tired of rice and corn side dishes, try some gluten free grains off the beaten path. In July, our support groups tried dishes prepared with millet, sorghum and quinoa and loved them . . . Until now, most gluten free products were made with highly refined flours and lacked the enrichment of important vitamins, minerals and fiber that their gluten-containing counterparts enjoyed. Some gluten free manufacturers are enriching their products now, keep an eye on those labels to find out which ones . . . Most blogs and listservs are not considered consistent and reliable sources of information, but there is one out there now that you can rely on: Tricia Thompson's blog on www.diet.com, posted weekly on Tuesday mornings **Calling all teens!** Are you or do you know of a teen with celiac disease? Give us a call and let us know your availability, this group is starting . . . Lots of discussion about diseases and conditions related to celiac disease; did you know that although 3 percent of the general population is affected by autoimmune disorders, it is believed that approximately 30 percent of individuals with celiac disease are affected? Discuss with your healthcare provider your need to be screened accordingly . . .



Please note these changes to the support group schedule: November support meeting **FOR ALL GROUPS** will be at 6:30pm on November 11 ("Dealing with Feelings of Deprivation" with Clinical Psychologist Dr. Gary Goldberg) and the December meeting **FOR ALL GROUPS** will be at 6pm on December 8th (Holiday Food Expo and presentation by author and poet Jax Peters Lowell). Groups will not meet at their regular meeting times for these two months! **Don't forget to register for these exiting events at 1-888-724-7123!**

Reader Mailbag



Q. I was diagnosed 6 months ago by chance (I was asymptomatic) and went on the gluten free diet. The diet was very depressing and I went off of it several times and experienced no celiac-related symptoms. Are there any studies about NOT following a gluten free diet and still living a healthy life?

A. Studies have shown that undiagnosed celiacs (or non-compliant ones) are at an elevated risk for developing other autoimmune conditions and/or lymphoma. Even without symptoms, an individual with celiac disease still experiences the stimulation of the immune system and the intestinal damage that is responsible for the risks and conditions mentioned above. It is strongly recommended that all diagnosed individuals follow a strict, lifelong gluten free diet. The Kogan Celiac Center of the Saint Barnabas Health Care System offers free monthly support groups that are geared towards improving the lifestyle of individuals with celiac disease and we strongly urge you to take advantage of what could be a very helpful part of your treatment.

SAINT BARNABAS
HEALTH CARE SYSTEM
The Kogan Celiac Center



The Kogan Celiac Center
Saint Barnabas Health Care System
200 South Orange Avenue
Livingston, New Jersey 07039

Phone: 973-322-7272

Fax: 973-322-7528

E-mail: koganceliaccenter@sbhcs.com

Website: www.koganceliaccenter.com

The Kogan Celiac Center of the Saint Barnabas Health Care System offers comprehensive testing and treatment for celiac disease for adults and children. The Center is dedicated to providing expert services that include early assessment and diagnosis, treatment, education and support to improve the health and well being of those who live with celiac disease.

Services include:

- Initial screening and diagnosis
- Initial and ongoing nutrition counseling
- Support groups and education
- Physician Referral

The Kogan Celiac Center of the Saint Barnabas Health Care System is made possible through the generous support of Mr. and Mrs. Richard Kogan.

Before You Cut Back, Test for Celiac!

It is often tempting to “try” a gluten free diet if you feel that you have symptoms of celiac disease, such as diarrhea, change in bowel habits, nausea, abdominal bloating, failure to thrive, fatigue, anemia,, infertility, joint pain, depression or irritability. If you do have celiac disease when you do this, you may see a noticeable improvement of symptoms because you will stop or slow down the inflammatory process that is characteristic of this disease. However, you will also



affect the presence of antibodies in your blood and/or the kind of damage in the small intestine that we look for in order to diagnose this disease. As a result, screening or testing may be inaccurate. At

the Kogan Celiac Center, we strongly advise individuals to wait until they have been positively diagnosed with celiac disease through currently accepted and established protocols before implementing a gluten free diet.

Information regarding current diagnostic protocols, screening opportunities through our Center, and dietary education can be found on our website (www.koganceliaccenter.com) or by calling us at 973-322-7272.