

CELIAC SOLUTIONS

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

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Teen Inspires Support Groups

On Tuesday, March 24, our teen and child support groups were treated to an uplifting presentation and discussion by Melanie Reider, a local teen who has been living with celiac disease for the past three years. Now fifteen, Melanie was diagnosed after several months of feeling sick and became a patient at the University of Maryland Center for Celiac Research. There, a dietitian taught Melanie how to follow a gluten free diet which led to a quick improvement in her health. She was so inspired by this experience that she decided to create a brochure about celiac disease targeted to newly diagnosed celiacs her own age. The double-sided tri-fold brochure, entitled "A Child's Guide to Dealing with Celiac Disease" contains tips about parties, school, travel, grocery shopping and dining out, as well as a view of the endoscopy from a child's perspective. Currently, the brochure is part of the starter packet that is distributed by the University of Maryland Center for Celiac Research to new patients. It is also available by contacting Melanie at kidsceliachelp@comcast.net.

Inspired, the members of the support groups at the Kogan Celiac Center are to begin creating their own kid-friendly list of tips and suggestions which will be available to download from the Kogan Celiac Center website. Topics under consideration are: favorite sports snacks and meal replacement bars, tips for attending parties, and suggestions for telling others about your diet. This project is currently a work in progress — look for further updates about this exciting contribution to the support services offered by our Center!

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A Child's Guide to
dealing with Celiac
Disease



From a
child's
perspective!

Welcome to Celiac Solutions

Celiac Solutions

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Spring has sprung and the Kogan Celiac Center is now one year old! This issue is full of news about all of the great new strides we've been making . . .

On Page 1, we report on a teen celiac who spoke to our teen and child support groups. Her original pamphlet, created for the Center for Celiac Research at the University of Maryland, was inspiration for the creation of our own patient handout for children and teens. Stay tuned as this project develops!

A recent study about the added expense of the gluten free diet is the subject of our most recent Journal Review. For most who follow a gluten free diet, no surprises here, just a clear mandate for further study into why and how these added costs exist.

Our recipe is not only gluten free but also dairy and nut free, perfect for family events where individuals with many different intolerances gather!


*"A big thank you for all you
do for our celiac community .
. . and me!"*
~ S.L., adult support group

One of our most exciting developments – the addition of a second location in Monmouth Medical Center – is described on Page 4. Many thanks to everyone who helped our program succeed thus far!

Read on page 5 for a report on the continued progress we are making toward

providing gluten free choices to all patients and guests in every facility of the Saint Barnabas Health Care System!

Our travel section covers a getaway spot right in our own state. A member of our adult support group shares her wonderful experience at a celiac-friendly Bed and Breakfast on Page 6.

Check out Page 7, which reports on topics covered in our January, February and March support groups, as well as other goings-on in the Saint Barnabas Ambulatory Care Center, Livingston, NJ.



Journal review



In addition to the many lifestyle changes brought about by the implementation of the gluten free diet, there is also a considerable financial impact to consider. The research paper published in the Journal of Human Nutrition and Dietetics, *Economic burden of a gluten-free diet*, by A.R. Lee, D.L. Ng, J. Zivin and P.H.R Green formally examined this important issue. Even though this article was published back in 2007, it seems even more appropriate and timely in the current economic environment.

The USDA Economic Research Service (ERS) develops hypothetical “market baskets” of food to evaluate trends and price fluctuations within our country's food supply chain. A market basket typically contains a selection of foods that is representative of a combination of current dietary recommendations, average consumption patterns, and current prices (see www.ers.usda.gov for more information). For the purposes of this study, the researchers created a hypothetical market basket that followed this template, but made gluten free substitutions for all gluten-containing products.

Once the market basket was created, price comparisons were made between the gluten free items and their gluten-based counterparts. Additionally, price according to shopping venue and geographic differences in availability were examined. Predictably, gluten free foods were uniformly more expensive than regular mainstream products, with the most difference found in snacks and convenience foods. Gluten free food was found to be

most available and more expensive via internet sites and in health food stores than in most upscale and traditional grocery stores, although this data was not statistically significant due to small sample size. New York and Portland offered the most availability of gluten free products, as compared to study cities in the middle of the country (Atlanta, Chicago and Rapid City).

Why not . . . identify stages in the supply chain that are responsible for added cost and lack of availability?

Most of the results in this study will not come as a surprise to anyone currently following a gluten free diet. Nor is the realization that there may be yet an additional expense of vitamin and fiber supplements for some celiacs, since gluten free products are frequently made from highly refined flours and are therefore deficient in many important nutrients. What is intriguing - and food for thought and possible future study – is the **reason** for the added expense and scarcity of these products. The ERS analyzes their market baskets in four different ways: retail price, farm value, farm-to-retail price spread and farm value share. Why not apply this analysis to gluten free food as it is converted from raw, gluten free grain to finished product? Such an exercise might identify stages in the supply chain that are responsible for added costs and/or lack of availability that can be addressed and changed according to consumer need and preference.

Flourless Chocolate Cake

(for all occasions!)

8 oz. semi-sweet chocolate
8 eggs, separated
1 teaspoon vanilla

1/2 cup butter
1 cup sugar

Preheat oven to 325 degrees. Melt chocolate with butter over very low heat. Stir until smooth and set aside. Beat egg yolks with 3/4 cup sugar. Gradually stir in chocolate mixture and vanilla.

In a separate bowl, beat egg whites until soft peaks form. Gradually add in the remaining sugar and continue beating until stiff. Gently fold whites into chocolate mixture. It will be light and airy when you are done. Pour batter into a large, well greased springform pan and bake for 35 minutes. The cake usually looks as if it will burst out over the top when you pull it out of the oven, but usually settles back down as it cools. Serve with whipped cream and/or berries.



Our Center is Expanding!

*“Make service your first priority,
not success, and success will follow.”*
(Unknown)

It is now exactly one year since the grand opening of the Kogan Celiac Center. Much progress has been made toward our mission of 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. During this time, the Center has touched more than 2,500 lives through its outreach programs, screened over 100 individuals for celiac disease, offered dietary education to more than 75 patients and created monthly support groups for more than 150 adults, teens and children. As a result of this reception and unmitigated success, a second location will open and be celebrated with an event on Tuesday, May 19, 2009.

Intended to serve the southern half of New Jersey, the second location of the Kogan Celiac Center will be housed in Monmouth Medical Center, Long Branch. Services to be offered in the new location include dietary education with a Registered Dietitian, monthly support groups for all ages, and comprehensive community outreach programs and initiatives. Hours at the new location will be 8 a.m.—6 p.m. on Thursdays, and support groups will meet Thursday evenings from 6:30-8:00 p.m. (schedule TBA). Hours will be expanded based on demand.

We thank all of the wonderful people who have made such invaluable contributions to the success of the Center over this past year, and look forward to working with new patients and health care providers in our new location!

Check our website
frequently, we
post updates and
announcements all
the time!

Grand Opening—

Kogan Celiac Center at Monmouth Medical Center

- When:** Tuesday, May 19, 2009
- Where:** Monmouth Medical Center
300 Second Avenue, Long Branch, NJ 07740
Front Lobby
- Events:** Gluten Free Food Fair, 4pm-7pm, Front Lobby
Seminar, 7pm-8pm, Annalise Roberts, gluten free baker, author
Borden Auditorium (limited seating)
- Registration:** Registration is required by calling 1.888.SBHS.123 (1.888.724.7123)

GF Certification Program (update)

Over the next few months, significant progress will be made toward the system-wide implementation of gluten free choices and standardized cross-contamination protocol for celiac patients and guests.

In concert with the grand opening of the second location of the Kogan Celiac Center in Monmouth Medical Center, Long Branch, the food service and clinical nutrition staff at that facility will receive comprehensive training in the purchasing, preparation and serving of gluten free food.

Additionally, the Center will be collaborating with the SBHCS marketing department to deliver

targeted training and support to staff at the all System nursing homes, rehabilitation centers and assisted living residences. On Friday, April 30, food service directors and nutrition managers at these facilities will attend a seminar given by Margaret Weiss Masiello, Clinical Coordinator, Kogan Celiac Center, after which each facility will receive customized, hands-on support toward the implementation of safe, gluten free choices for their celiac patients.

Keep an eye out for our next update about this exciting and novel initiative!

Reader Mailbag



Q. Some people tell me that ketchup, mustard and other foods that contain distilled vinegar are not acceptable on the gluten free diet. Others tell me that it's ok to eat them. What is the real answer and why is there such disagreement?

A. Distillation is a process where ingredients are first heated to form a vapor and then cooled and condensed to form a final liquid product, called "distillate." For a very long time, it was believed that gluten followed this entire process and ended up in the final product, but we now know that it is too heavy a molecule for that to happen. Therefore, even if the original ingredients come from gluten-containing sources, the distillate will be gluten free.

For many years, celiacs were told not to consume distilled products unless they could ascertain the origin of the ingredients. This included most mustards, ketchups, salad dressings and distilled alcohols. Some of this information still exists on the Internet and guides those celiacs who have been following the gluten free diet for many years. Feel free to consume *distilled* vinegars and alcohols, but remember that *malt* vinegars and alcohols are **NOT** gluten free because they are made using an entirely different process. Give the Kogan Celiac Center a call at 973-322-7272 if you have any further questions about distilled products.

Home Away From Home—The Raritan Inn

When we think of vacations, most of us dream of going to faraway places to get a break from everyday stresses and activities. However, it is also nice to know that a wonderful retreat exists right in our own backyard, and it is celiac-friendly too! Support group member Janice Chapin described her very positive experience at the Raritan Inn.

I heard about The Raritan Inn in Califon, New Jersey from a friend. We stayed there before I was diagnosed with celiac disease and loved the place. I arranged an English Tea Party there with some friends this past February and when I called the inn to make the arrangements, I described my dietary needs and they knew exactly what to do.

For guests with celiac disease, the inn uses gluten free ingredients and recipes to provide the same varied menu plan enjoyed by everyone else. According to innkeeper Margy DeWitt, “no one knows the difference! We also provide brownies, chocolate chip cookies or cheese, crackers and fruit for when guests arrive. We like to say that the Inn is a place where you can rest, relax and unwind, and we want that to be true for our gluten free guests as well.”

If you look on the web site for special events, it will give you the English Tea Menu. To adapt the English Tea Party menu to my diet, a GF English muffin was used for sandwiches and she made fruit dipped in chocolate for dessert. Since Margy knew what I was talking about from the beginning of the conversation and had the supplies already on hand, I assumed she knew what to do, and she did. The kitchen is wide open to the rest of the inn, not hidden away, so I was able to see that everything was fine. During our stay Margy told us that the first celiac she had had at the inn was George and his wife from [the well known gluten free manufacturer] Foods by George. They had explained everything to her ahead of their visit and as far as she knew they were very pleased.

I would go back again in a heart beat, and actually we are hoping to plan another event there in May or June. It's really an amazing place and Margy is a wonderful host! It's in such a lovely setting too. The Columbia Trail runs behind the property—it's a great bicycle or hiking trail. And a branch of the Raritan River runs right through the property. There are farms all around and rolling hills - truly a lovely, lovely place.”

~ Janice Chapin



Won't you share your latest traveling experience?

Send us your suggestions and comments about this newsletter—what changes can we make to fit YOUR needs?

Support Group Minutes

Did you know that part of the cost of gluten free food qualifies as a deductible medical expense on your taxes or can be reimbursed from your company-provided Flexible Spending Account? In January we talked about strategies for keeping track of these expenses for tax year 2009 and beyond . . . Like many manufacturers of gluten free food, Schar Foods has strict cross contamination protocols in place to ensure the safety of their products, and their National Nutrition Manager described those during our February meeting. Ask the manufacturers of *your* favorite foods to describe their production procedures so that you feel comfortable purchasing their products. . . . In March's meeting we discussed the many gluten free products that are available during the Passover holiday. Observers of this holiday avoid wheat, barley, oats, rye and spelt so celiacs can take advantage of many of the cakes, cookies, candies and baking ingredients that are available at this time.



As always, the patient education material distributed at each monthly support group meeting can be found on our website at www.koganceliaccenter.com.

What else is going on in the ACC this quarter?

*Here are some events scheduled to take place at the
Saint Barnabas Ambulatory Care Center
200 South Orange Avenue
Livingston, NJ 07039
973-322-7000*

Adult Diabetes Self Management Classes, May 20 and May 27, 9:30-11:30 a.m. These classes offer guidance on topics associated with living with diabetes. This program is fee-for-service and Medicare reimbursement is accepted. For more information, call 1-888-724-7123.

Laparoscopic Gastric Band Support Group, May 20, 6:00-7:30 p.m. A free support group for laparoscopic gastric band surgery patients. Led by a professional, discussions feature topics such as healthy cooking, stress management, exercise, behavior modification, eating out and other helpful topics. Call to register at 973.322.2458.

Bariatric Support Group, May 27, 6:00-7:30 p.m. A free support group for bariatric patients who have had surgery more than a year ago. Please call 973.322.2458 to register.

Liquid Facelift, June 2, 6:30 p.m. Dr. Eric Joseph, M.D., will present his revolutionary Liquid Face Lift. Look years younger with no downtime, without the expense and inconvenience of a surgical facelift. Join Dr. Joseph for a live demonstration. To register, call 973.325.1155

Treatment of Peripheral Vascular Disease, June 22, 4:00 p.m. The Saint Barnabas Ambulatory Care Center will offer a community event about the treatment and management of peripheral vascular disease. Registration is requested by calling 1.888.724.7123.

Cancer Wellness Yoga, May 21, 28, 6:00-7:00 p.m. Yoga is a comprehensive system of mind-body techniques. This class is tailored to Cancer Survivors. To register, please call 973.322.7444.



**SAINT BARNABAS
HEALTH CARE SYSTEM**

The Kogan Celiac Center



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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.