

CELIAC SOLUTIONS

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

Popular Potluck

Most would agree that special events and support group meetings at the Kogan Celiac Center are interesting and enjoyable, but our potluck events are quickly becoming a favorite. Our locations at the Saint Barnabas Ambulatory Care Center in Livingston and Monmouth Medical Center in Long Branch (now called KCC-N and KCC-S respectively) each hosted potlucks during the summer with great attendance. What a great way to share favorite recipes, tips and suggestions with fellow celiacs!

KCC-N took advantage of the picnic grove at the Saint Barnabas Ambulatory Care Center and had quite a feast outside on a lovely evening in July. KCC-S filled our meeting room at Monmouth Medical Center and stocked our buffet table with a great selection of favorite recipes and products from local specialty shops. Members were thrilled to expand their repertoires as they exchanged the recipes and ingredient lists of the wide variety of contributions.

The casual atmosphere of a potluck event is a wonderful way for celiacs of all ages to get together and enjoy food that is safe and delicious. (Cont'd on Page 4)



A beautiful evening for a gluten free picnic at KCC-N!



Our conference room at KCC-S was packed!



Gluten free goodies for all ages

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Welcome to Celiac Solutions

Celiac Solutions

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Now that the Center has been open for eighteen months, there is a new sense of continuity and staying power: opening our second location, getting involved in our second start to the school year, planning our second Holiday Food Fair and enjoying yet another potluck event. An eloquent phrase found in a recent newsletter from the American Dietetic Association says it all about what it takes to first develop and then maintain a clinically based nutrition program – one must “work *on* it, not just *in* it!” Truer words cannot be said about efforts at the Kogan Celiac Center as we continually measure what works and what doesn't as we address our mission *to offer testing, treatment and support to improve the health and well being of those who live with celiac disease.* Much of this issue details these ongoing efforts at our northern location in

Livingston and at our southern location in Long Branch, which we now call KCC-N and KCC-S.

Pages 1 and 4 are all about the sharing and friendship that accompany potluck events. We had great attendance at each location and, as you can tell from the pictures, a great time was had by all!

☀
“We are working on it,
not just in it.”

This issue's journal review discusses the growing awareness that early diagnosis of celiac disease can have a positive impact not only on the overall well-being of the patient, but also on overall expenditures for at-risk individuals by the health care system at large. Read the review on Page 3 for details.

See how our dietary education program is quantitatively evaluated and reported to the Saint Barnabas Health Care System on Page 5.

Views about what is acceptable on a gluten free diet are constantly evolving and we keep abreast of these changes! Our Reader Mailbag on Page 5 offers the latest information about a frequently debated ingredient.

As awareness about celiac disease and the gluten free diet grows, so do our choices for dining out! This issue's travel review is on Page 6, written by a new member of our children/teen support group.

Check out Page 7 for other activities and events that are happening this quarter in our Livingston and Long Branch facilities. Note the seminar about celiac disease and osteoporosis at the ACC in November!

Happy Fall!

Journal review



Celiac disease presents with varying symptoms that may occur in the digestive system or in other parts of the body. Diagnosis is difficult because these symptoms are similar to those of many other diseases, such as irritable bowel syndrome, inflammatory bowel disease, diverticular disease, chronic fatigue syndrome, intestinal infections, and others. Because recognition of this disease is difficult, recent studies have shown that the average time to diagnosis for patients in the United States is approximately 10 years.

Not only do patients suffer from the symptoms of undiagnosed celiac disease for so long, but there are related economic burdens to both the patient and our healthcare system. A retrospective study that examined how earlier diagnosis of celiac disease might help patients while reducing medical costs and services was published in the *Journal of Insurance Medicine* (“*Economic Benefits of Increased Diagnosis of Celiac Disease in a National Managed Care Population in the United States*”, *J Insur Med* 2008;40:218-228).

A team composed of Peter H. R. Green, MD and his colleagues from the Celiac Disease Center at Columbia University and individuals from CIGNA HealthCare analyzed patient data from a database of approximately 10 million patients from 1999 to 2003. They compared a group of confirmed celiacs with 3 separate control groups of patients who had symptoms that are associated with celiac disease but had no confirmed diagnosis -- one group had 1 symptom, another group had 2 symptoms and another group had 3 symptoms. Utilization of office visits, laboratory, imaging and endoscopy services were measured.

The findings were significant. Importantly, there was a significant downtrend in medical costs and utilized services over the study period in the celiac group, as compared to the control groups. The highest difference was

“Using these data we demonstrated economic benefit with the diagnosis of celiac disease.”

between the celiac group and the group with 3 symptoms, and this difference increased with the patient's age at diagnosis. The study also found that as the number of symptoms increased across the control groups, so did the number of diagnoses of celiac disease, underscoring the merit of structuring the control groups in this way. In other words, if a patient has more symptoms associated with celiac disease, he/she is more likely to be diagnosed after spending a longer period of time undiagnosed with a larger medical expenditure.

This study shows a clear economic benefit to early diagnosis of celiac disease. It raises several questions for further study: Are there significant economic benefits for mass screenings? Or, should we only screen those with symptoms or associated risk factors? If screenings are appropriate, what age is best? Italy, for example, screens all children by age 6 so that even asymptomatic celiacs are caught early – perhaps the answers to some of these questions lie in data from this population or others with similar screening practices.

Potluck (cont'd)

(Cont'd from Page 1) All contributors are instructed to follow strict cross contamination protocols and bring ingredient lists or recipes for each dish. If you haven't joined us for a potluck event yet, we hope you'll join us for the next one. See our schedule of meetings and events under the Support Groups tab on our website, www.koganceliacenter.com, or get on our email distribution list by calling the Center at 973-322-7272.



Lots of happy campers



. . . in both locations!

Gluten Free Chocolate Chip Bars

2 1/4 cups chickpea flour	2 eggs
3/4 cup granulated sugar	1 tsp. baking soda
1/2 cup peanut butter	1/2 tsp. salt
3/4 cup brown sugar	1 1/2 tsp. vanilla
1/2 cup (1 stick) butter	2 cups chocolate chips



Preheat oven to 375°. Combine dry ingredients. Cream together butter, sugars, and vanilla. Add eggs one at a time, beating after each addition. Gradually add flour mixture. Stir in chocolate chips. Spread in greased 13.x9 inch pan. Bake for approximately 15 minutes or until inserted toothpick comes out clean.

*Notes: * To make cookies, bake for 9 to 11 minutes*

** To make without peanut butter, substitute an additional stick of butter*

Check our website
frequently. We
post updates and
announcements all
the time!

Performance Improvement Studies at KCC

All departments at the Saint Barnabas Outpatient Centers participate in Performance Improvement initiatives and the Kogan Celiac Center is no exception. We constantly examine our processes, collect and interpret data, and put procedures into place to maintain performance gains. Our results are reported in a quarterly meeting to our

Performance Improvement Council and then reported to our physician leaders and the Saint Barnabas Outpatient Centers Board of Trustees.

All departments track outcomes related to at least one clinical monitor. At the Kogan Celiac Center, we re-evaluate the antibody levels in individuals who go through

our 6-month Steps to Success dietary education program. Our goal is a 50% reduction of tissue transglutaminase antibody levels at the end of the six months and we are proud to report that we have met that goal 100% of the time – in fact, the average reduction in antibody levels of all program participants is actually 88%!

Reader Mailbag



Q. I have heard that blue cheese is not safe for consumption on the gluten free diet because sometimes a gluten-based bread starter is used to grow the mold. Is this true? How much gluten would actually be transferred to the cheese in such a process?

A. Nobody really knows how blue (or Roquefort) cheese became the delicacy it is today, but there exists the classic tale of a French shepherd who left his meal of bread and cheese behind in a mountain cave while chasing his sheep — when he came back a few months later he found that the cheese was covered in mold and had a very strong but pleasing aroma and taste. This mold was called *Penicillium roqueforti*, named after the region in France where this phenomenon was believed to have first occurred.

So the question really revolves around whether or not mold that is grown on bread is contaminated with gluten when it is introduced to the cheese making process. In actuality, the mold and the medium it grows on is discarded and it is only the spores of the mold that are collected and injected into the milk mixture. During their growth and multiplying stages, these spores utilize gluten for fuel and also break down the gluten protein during fermentation, leaving little to no residual gluten left. The Food Research Division of Health Canada actually tested 3 cheeses with 3 separate tests and found absolutely no evidence of detectable gluten in any of the cheeses tested. (See the Canadian Celiac Association's March 2009 newsletter for more information).

Other studies have shown miniscule amounts of residual gluten in the final product, far below the proposed FDA threshold of 20 parts per million. Additionally, some manufacturers advertise that they use synthetic or non-gluten mold cultures which eliminates the problem altogether. Based on what we know about the making of blue cheese and the accuracy of the most sensitive gluten test kits available, it is reasonable to conclude that blue cheese is safe for celiacs to consume. Contact the Kogan Celiac Center at 973-322-7272 if you have any further questions.

Gluten Free in Jackson Hole, Wyoming

Dining out while traveling can be safe and fun — and can also provide the opportunity to try new foods! Hear one teen's vacation experience . . .

This past summer, my family and I vacationed in Jackson Hole, Wyoming. We were all very excited as it was our first time traveling to this destination. Jackson Hole, surrounded by the beautiful Grand Teton Mountain Range, had a real western feel but was still very cosmopolitan. During our week there, my family tried many new and exciting activities such as horseback riding overlooking the National Elk Refuge, white water rafting along the Snake River, and hiking through Yellowstone National Park. The diverse restaurants in Jackson Hole complement the picturesque landscape. Because I am a celiac and also have allergies to peanuts and eggs, eating out can sometimes be difficult. However, the resort that we stayed at, the Spring Creek Ranch, provided us with menus from nearby restaurants and I was able to determine what restaurant would be more suitable for me prior to our dinner. All of the restaurants we ate at fully accommodated my food allergies and gluten sensitivity.

My favorite restaurant was Burke's Chop House because of its relaxed environment, and very kind wait staff and chef. Since I couldn't have the french fries because the kitchen did not have a dedicated fryer, the chef made home fries with my delicious cheeseburger. I brought my own gluten free hamburger roll that our waiter gladly heated in aluminum foil in their oven. We really enjoyed ourselves at this restaurant.

Another night we ate dinner at The Granary, a pretty formal restaurant at the Spring Creek Ranch where I had the filet mignon with sauce Diane and spinach salad. My dinner was prepared perfectly and was delicious. The chef did not have to specially prepare this dish, as it was already peanut, egg, and gluten-free.

After a day of white water rafting we had dinner at The Gun Barrel Steak and Game house. We were quite tired and the amusing atmosphere at this restaurant was entertaining, as there were a stuffed bison and moose and elk heads hanging on all of the walls. As far as dinner went the chef said that I could have had any meat on the menu as long as it was grilled, and served without the sauce, because the chef could not

guarantee that the sauce was gluten-free, although the BBQ sauce on the table was gluten free. I decided to have grilled elk chop, because I'd never had it before and it was actually delicious. I also enjoyed a baked potato and grilled vegetables.

During the day that my family hiked in Yellowstone National Park, we stopped at the Old Faithful Inn, named after the famous geyser, to have a quick lunch. Because we were in a rush to continue sightseeing, my family ate at the buffet instead of ordering from the menu. I asked which items on the buffet would be safe for me and I decided to have a salad and the bison chili because I'd never tried it before. I would highly recommend trying new foods prepared safely at any of these restaurants, as they all turned out to be delicious.

When my family ate at the Blue Lion, the chef prepared a dish with brown rice pasta that I brought with me. They were very happy to accommodate my diet restrictions. I had Thai Shrimp Pasta, which was shrimp sautéed with artichoke hearts, red peppers, garlic, ginger, fresh cilantro, and Thai curry sauce, over the brown rice pasta. Yummy!

On the final night of my family's vacation, we ate at Nani's Cucina

Italiana, a typical Italian restaurant with red and white-checked tablecloths. For dinner I had risotto con porri, a risotto dish with leeks, mushrooms, and Fontina cheese. Personally, this was my favorite dish of our trip. It was gluten free naturally so it was served to me without any special preparations by the chef.

My family and I had a wonderful time during our summer vacation to Jackson Hole, Wyoming, and the fact that so many restaurants accommodated my dietary needs made the trip so much more relaxing and enjoyable.

One thing I always remember when eating out: ALWAYS explain my food allergies and gluten sensitivity to the waiter/chef and check the ingredients of the food I am ordering even if it has been recommended to me previously. Ingredients of a dish on the menu can always change so it's very important to check before you order.

~ Emily Mae Czachor, 13



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?

The information presented in this article is the opinion of the author solely and is for general information purposes. The Kogan Celiac Center makes no representations or endorsements with respect to the content of the article.

What's happening at our facilities this quarter?

Saint Barnabas Ambulatory Care Center 200 South Orange Avenue Livingston, New Jersey 07039

Diabetes Self-Management Classes, offered in September and November. Topics include glucose monitoring, nutritional management, physical activity, medications, psychological adjustment. To register or to get more information, dates and times call 1.888.724.7123

Laser Vision Correction Seminar, September 16, 6:00pm, Conference Rooms A&B. Join Dr. Shawn Klein for a seminar on laser vision correction surgery. Please register at 1.888.724.7123

Completely Natural Rhinoplasty, September 22, Conference Rooms A&B. Join Dr. Eric Joseph, MD, Facial Plastic Surgeon at a seminar where he discusses his revolutionary Completely Natural Rhinoplasty. Please call 973-325-1155 to register.

Are You Balanced? A Falls Risk Assessment, October 8, 11:30am-12:30pm, Conference Room B. Discussion about fall risk factors, tips for fall prevention and a personalized fall risk assessment using Biodex Balance System. Call 973.322.7830 to register

Mom to Mom Interactive Series: Handling Weight Issues in Children, September 24, Conference Rooms A&B. Debra Gill, Ph.D., Director, Weight Management Program, SBMC, will moderate a session about handling weight issues in children. Call 1.888.724.7123 to register.

Tell a Friend About Women and Heart Disease, September 24, 6:00 pm. Join Janie Baranyay, RN, APN for a review of women and cardiovascular disease risk factors. Register at 1.888.724.7123

Breast Cancer: Reality vs. Myths—September 30, 6:00 pm, Conference Rooms A&B. M. Michele Blackwood, MD, FACS will discuss the Breast Center's Triple Assurance protocol for screening mammograms and the latest technology and treatment of breast cancer. Call 1.888.724.7123 to register.

Celiac Disease and Osteoporosis, November 12, 11:30am-12:30pm. Three million people in the US have celiac disease and only 3% know it. Hear a discussion about this disease, its relationship to Osteoporosis and paths to diagnosis for those at risk. Call 973.322.7830 to register.

Monmouth Medical Center 300 Second Avenue Long Branch, New Jersey 07880

Free Prostate Cancer Screening, September 21, 4:30 pm. Leon Hess Cancer Center, BBR 4. Men age 50 and over who have never had a prior prostate screening, who have never had a prior urology work-up, have never been diagnosed with prostate cancer and are not under the care of a urologist are eligible to participate. Men with a family history of prostate cancer or African-American men should begin screenings at age 40. Call 1.888.724.7123 to register.

Minority and Multicultural Health Fair-Take Control of Your Health: Managing Chronic Disease, September 23, 11am- 1pm, ground floor lobby. Free info (English and Spanish) about cancer, cardiovascular disease, diabetes, obesity, HIV/AIDS, infant mortality, unintentional injuries.

Parenting Education Series: Gang Violence, September 25, 6-8pm, Borden Auditorium. Presented by Rosendo Perez, Detective, Monmouth County Prosecutor's Office, the discussion will cover New Jersey and National perspectives. Call 1.888.724.7123 to register.

STEP (Systematic Training for Effective Parenting of Young Children), September 16,23,30, October 7, 14, 7-9pm, \$75/person, \$100/couple. Five-session program focuses on understanding the behavior of children, communication, cooperation, discipline and nurturing children from infancy to six years. Call 732-923-6990 to register.

Safe Sitter, September 26, 9am-4pm, \$50/child. Presented by certified Safe Sitter instructors, 11-13-year-olds learn to be responsible babysitters with emphasis on how to handle emergencies. Call 1.888.723.7123 to register.

Shingles Vaccination Program—The FDA approved a shingles vaccine for people age 60 and older which may cut your risk of developing shingles in half. To schedule an appointment call 1.888.724.7123 or call 732-923-6111 for more information.

 **SAINT BARNABAS
HEALTH CARE SYSTEM**

The Kogan Celiac Center



Two convenient locations:

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and

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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. The Center's comprehensive array of public education strategies includes nutrition education programs, support groups, school and retail outreach and other health and wellness initiatives.

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 have celiac disease when you do this, you may see 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 changes in the small intestine that we look for in order to make a diagnosis.

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 about current diagnostic protocols, dietary education, and screening opportunities at either of our two locations can be found on our website(www.koganceliaccenter.com) or by calling us at 973-322-7272.