

# Celiac Solutions

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

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WINTER 2008

## Gluten Free Holiday Food Expo

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The holidays got off to a great start at the Saint Barnabas Ambulatory Care Center as the Kogan Celiac Center hosted its first annual Gluten Free Holiday Food Expo with featured speaker/author, Jax Peters Lowell. A great time was had by all – several vendors commented that everyone in the room was smiling!

A variety of foods and vendors were represented. Some were restaurants that have added gluten free selections to their menus, some were manufacturers of gluten free products from dedicated facilities and some were there to showcase new microwavable preparation methods that add convenience and portability to gluten free foods. The companies in attendance were: Enjoy Life Foods, Schar, Calabria Pizzeria Restaurant, Cinderella Sweets, Joan's Great Bakes, Food Tek, Aunt Gussie's, Katz Gluten Free Bake Shop, Charlotte's Bakery, Miller's Gluten Free Bread Company, Legal Seafoods, and Jolie's Gourmet.

After everyone had their fill of gluten free goodies, we were treated to an uplifting



presentation by author and poet, Jax Peters Lowell. Diagnosed with celiac disease in 1981, Lowell was one of the first voices in the Celiac community to inspire and encourage fellow celiacs to navigate the gluten free lifestyle with patience, grace and humor. Her

*"The various food vendors' products were just super delicious!"*



pioneering first book, *Against the Grain*, is a true classic, and subsequent books, *No More Cupcakes & Tummy Aches* and *The Gluten-Free Bible* are equally popular with celiacs of all ages.

All in all, the first annual Gluten Free Holiday Food Expo capped off a very successful first year for the Kogan Celiac Center of the Saint Barnabas Health Care System!

# Welcome to Celiac Solutions

## Celiac Solutions

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

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Welcome to Celiac Solutions, Issue 3!

“In just two days tomorrow will be yesterday!” The unknown author of that quotation might very well have been a bug on the wall at our Center over the past few months! As we came to the end of 2008 and took a peek at what 2009 has in store for us, there was no doubt that the pace is picking up quite a bit and we hope you'll join us for the ride!

Page 3 offers important information about your health; individuals with celiac disease respond to the Hepatitis B vaccine differently from those in the general population. Consider this information carefully and don't hesitate to call us if you have any questions!

Each newsletter will

contain a recipe for you to try – one of the more popular ones is included in this issue. Zeppole, sometimes called funnel cakes or ribbon cakes, are frequently found at food fairs and amusement parks. Enjoy!



*“A big thank you for all you do for our celiac community . . . and me!”*

Our gluten free certification program has been progressing nicely – see Page 4 for an update on the steps we've taken so far!

Support group members are one of the best sources of gluten free information that is based on actual experience. One of the members from our adult group generously contributed her

description of a recent trip abroad – read more on Page 5!

Pages 6 and 7 have important information about our support groups. You can find our new 2009 schedule there and, due to popular demand, we will be having more “potluck” events! Also, please check out what is going on in the rest of the Ambulatory Care Center – there are wonderful and varied events happening here all the time!

Please keep those suggestions and contributions coming! We look forward to bringing many new and exciting programs to you in 2009!



# Journal review



Did you know that there is substantial evidence that individuals with celiac disease are significantly less responsive to the Hepatitis B vaccination than those in the general population? Since celiac disease is believed to occur in 1 in 133 individuals in the United States, it follows that there may actually be a significant number of people who are susceptible to infection with this very serious virus. As a matter of fact, the clinical protocol of the Kogan Celiac Center recommends that this phenomenon be tested in newly-diagnosed individuals.

Hepatitis B is a virus that can cause liver disease. It is transmitted via body fluids during sex, through sharing of contaminated needles or from an infected mother to her unborn child. The hepatitis B vaccination is offered to every child and at-risk individuals to stimulate the production of antibodies in the blood that offer protection against this disease.

Important studies have found that a significant percentage of vaccinated individuals with celiac disease may not develop the intended immunity against hepatitis B as compared with the general population. In a study by Ahishali et al., published in *Digestive Diseases and Sciences*, 32% of individuals with celiac disease were unresponsive to hepatitis B

vaccination, and another study by Noh et al., published in the *American Journal of Gastroenterology*, revealed a full 68% of “non-responding” celiacs.

The good news is that it appears that the gluten free diet helps to develop immunity against hepatitis B for celiacs. A study in Hungary - where routine hepatitis B vaccination of 14 year olds was introduced in 1999 – compared antibody production against hepatitis B in celiacs who were consuming gluten to that of celiacs who were not (Nemes, et. al., *Pediatrics*). They found that non-response to vaccination may not be permanent, and may be influenced by and improved with the exclusion of dietary gluten; this study also recommended revaccination after initiation of the gluten free diet.

So, if you have already received the hepatitis B vaccine and are wondering if you have developed the necessary immune protection, you may consider having your doctor check your blood for antibodies to this virus and discuss getting re-vaccinated or a booster shot based on the results. If you and/or your child are considering getting this vaccine for the first time, consider the above information and discuss any questions you have with your physician or the Kogan Celiac Center at 973-322-7272.

## Gluten Free Zeppole

(Special thanks to Vincent Masiello)

1 pkg. dry yeast	1/2 cup sugar
2 ½ cups warm water	1/4 tsp salt
4 cups gluten free all purpose flour mix	2 eggs
2 teaspoons xanthan gum	Canola oil, for frying
2 teaspoons baking powder	Honey for drizzling, or powdered sugar for coating



Mix dry yeast with warm water in a small bowl. In a large bowl, mix flour, sugar, cinnamon, xanthan gum, baking powder, sugar and salt. Make a well in this dry mixture with a spoon, and gradually add the eggs, water, and yeast, mix well. This mixture should reach the consistency of thick batter. If too thick, add water or milk to thin.

Cover and let rise in a dry warm area until at least double in size.

In a deep pan, pour oil to a depth of 2 inches and heat to 375 degrees. Fry dough by the large tablespoonful in hot oil. Drain on paper towels, drizzle with honey or dust with powdered sugar. Makes about 2-3 dozen.

## GF Certification Program (update)

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 its 6 acute-care hospitals and 9 long-term 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 comprehensive training. The Center will act as the focal point for this initiative by overseeing the implementation of the protocol and the training, as well as disseminating current and updated information.

Once the training and implementation are 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.



As we went to print, all of the Food Service Directors for every facility in the Saint Barnabas Health Care System received training (see picture above) and are implementing gluten free protocol in their kitchens. As soon as they have completed the implementation, System dietitians will be trained.

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



### Wanted: Focus Group Participants!

A major gluten free manufacturer is adding new bread items to its line of products and is forming focus groups to get your input! Here are some of the details:

- \* groups are scheduled to start in early 2009, location TBA,
- \* participants will sample several products and discuss taste, texture, flavor, and purchasing practices,
- \* compensation for participation will be \$50.00 plus product samples

If you are interested, please leave contact information with the Kogan Celiac Center at 973-322-7272.

# An American (or two) in Paris

Last spring, support group members Alex and Doris Schapira vacationed in Europe. Doris was kind enough to describe her experience from a gluten free perspective in the paragraphs below . . .

Little did I suspect in January 2008 when we paid for our first trip to London and Paris (scheduled for May) that in March I would be diagnosed with Celiac disease. After the diagnosis, it was hard to decide whether to cancel the trip. (I have also had a lactose intolerance all my adult life.) With encouragement and advice from Margaret Masiello, the dietitian I see at the Kogan Celiac Center, we decided not to cancel the trip.

The planned trip was an Elderhostel excursion to visit museums in the two cities and attend lectures on the cities and their art.



(Elderhostel has programs for participants 55 and older.) Most meals were included in the program. I contacted Elderhostel and they told me they would be able to

accommodate my food needs. I was apprehensive, but, as it turned out, I did not need to be.

Most of the included meals in London were in our hotel. The hotel staff was very accommodating and even ordered gluten free bread for me to have with breakfast. Breakfast was buffet style and I had plenty to eat from the buffet. Dinner in the hotel was served and they always brought me a special plate of gluten free, lactose free food. The hotel in which we stayed was the Jury's Hotel, Kensington.

I found that in London, they were way ahead of the US in knowledge of gluten and labeling. For some lunches, when we were on our own, we were usually rushed, so we ran into shops that had prepacked food. These were either grocery stores or places where you picked out a package and brought it to the counter. In both instances, the packages were clearly marked as having gluten or not. Occasionally we ate lunch in a museum and that was slightly more difficult, but I always found something I could eat. In Paris, we stayed in the lovely Holiday Inn Paris-République which must have been a chateau at one

time. They had an enormous breakfast buffet as well as a buffet for dinner. The breakfast buffet had so much on it that I had no problem finding plenty to eat. At dinner, they brought me a special plate with the main course, usually whatever was on the buffet for the main course, minus the sauce. I was able to get salad and fruit from the buffet.

*Won't you share your latest traveling experience?*

We traveled on Continental Airline and they did not have the promised gluten free meals for me on the trip to London. They did come up with a salad for me after I complained. I had brought snacks along and I was OK. On the trip from Paris to Newark, they provided me with a nice gluten free meal.

I would say that you should not hesitate to plan either an Elderhostel trip anywhere where they can promise gluten free meals, or a trip on your own to London and Paris.

~ Doris Schapira

## Reader Mailbag



**Q.** I was recently diagnosed with celiac disease and am doing pretty well on the diet. However, most of the gluten free specialty products that I see in the stores are so expensive, I don't know how I will be able to afford this for the rest of my life! Do you have any suggestions for how not to break the bank with this new diet?

**A.** Yes, it's true, gluten free food can be very expensive. Some ways to reduce costs are: find manufacturers that give discounts or "frequent flyer" points when you buy in bulk, make some of your own food in large quantities and freeze for future use, purchase gluten free private label products that are available in some stores, and make better use of naturally gluten free foods that don't have the gluten free premium built into the price.

Also, look on our website in the Support Groups section for information about tax breaks associated with gluten-free food!

## 2009 SUPPORT GROUP SCHEDULE

All groups meet at the Saint Barnabas Ambulatory Care Center  
200 South Orange Avenue, Livingston, NJ 07039  
6:30pm-8:00pm

**January 2009**

**Celiac-related tax information and Section 504 accommodations in schools**

Adults: Tuesday, 1/13  
Children: Tuesday, 1/20  
Teens: Tuesday, 1/27

**February 2009**

**Tuesday, February 17— (all ages) GF Manufacturing Procedures and POTLUCK**—How exactly does a manufacturer of gluten free products ensure that products are safe? What systems do they put into place? Come hear Anne Lee, Director of Nutritional Services for Schär products, discuss this very important issue. If you care to bring a gluten free dish, follow this schedule:

A-G: appetizers/snacks/side dishes  
H-N: entrees/side dishes  
O-Z: desserts

**March 2009**

**Passover bonanza**—Passover is a time of plenty for anyone following a gluten free diet. Let's talk about why and how to stock up at this time.

Adults: Tuesday, 3/10  
Children: Tuesday, 3/17  
Teens: Tuesday, 3/24

**April 2009**

**Travel Tips, Ideas and Gluten Free Vacation Spots**

Adults: Tuesday, 4/14  
Children: Tuesday, 4/21  
Teens: Tuesday, 4/28

**May 2009**

**Gluten Free Awareness Month – TBA**

**June 2009**

**NO SUPPORT GROUP MEETINGS**

**July 2009**

**Tuesday, July 14, Summer Picnic Potluck!** Bring a GF dish per below:

O-Z: appetizers/snacks/side dishes  
A-G: entrees/side dishes  
H-N: desserts

**August 2009 NO SUPPORT GROUP MEETINGS**

**Sept. 2009**

**Gluten Free on a Budget**

Adults: Tuesday, 9/08  
Children: Tuesday, 9/15  
Teens: Tuesday, 9/22

**Oct. 2009**

**Gluten Free Weight Loss Products**

Adults: Tuesday, 10/13  
Children: Tuesday, 10/20  
Teens: Tuesday, 10/27

**Nov. 2009**

**Topic TBA and POTLUCK**

Adults: Tuesday, 11/10  
Children: Tuesday, 11/17  
Teens: Tuesday, 11/24

**Dec. 2009**

**HOLIDAY FOOD EXPO, DATE TBA**

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

The theme of our November meeting was “Feelings of Deprivation During the Holidays,” and Dr. Gary Goldberg offered inspired coping strategies and empowering solutions. The following are his “anti-craving strategies” to help change your mindset during those times when temptation is the greatest:



- **Label it**: Tell yourself, “This feeling is just a craving, uncomfortable but not an emergency.”
- **Stand firm**: Tell yourself that you’re absolutely not going to eat the food that you’re craving; consider whether giving in to this craving will be worth the momentary pleasure you’ll get from eating or undermining your diet and health.
- **Don’t give yourself a choice**: The emotionally painful part about a craving is the struggle you feel. Once you can tell yourself with total conviction, NO CHOICE, the craving will diminish.
- **Imagine the aftermath of giving in**: Measure the short period of gratification you will get from eating the food you are craving against the longer period of time when you might experience symptoms and/or discomfort—when you look at the whole picture, not eating the food seems the better choice.
- **Remind yourself why you want to learn to withstand cravings**: Giving in to cravings can affect your quality of life . . .and worse!

## What else is going on in the ACC this quarter?

January, February, March—Project Healthy Bones, an exercise and education program for people at risk for, or who have osteoporosis. For more information, please call The Osteoporosis Center at 973-322-7430

January—Lasik laser Vision Correction Seminar—Dr. Charles Rassier, M.D. explains the Lasik blade-free procedure and see if Laser vision Correction is right for you. For more information, please call the Refractive Surgery Center at 973-322-7285

January 20—“How to Achieve and Maintain Your Health Goals through Integrative Wellness”—Sponsored by the Siegler Center for Integrative Medicine. For more info, call 973-322-7007

February 22, 2pm-4pm—Multiple Sclerosis, “Ask the Doctor” MS conference, speaker TBA. For more information please call the Multiple Sclerosis Comprehensive Care Center at 973-322-7484

January, February, March—Our Health and Wellness Department now has personal trainers and a new arthritis program! For more information about availability, dates and times, please call Laura Depaola at 973-322-7453.

April 19—MS Walk. Come join team Leslie and the MS Center Steppers for this fundraising opportunity! Registration is required, call 973-322-7484 for more information.

**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](http://www.koganceliaccenter.com)) or by calling us at 973-322-7272.