

Celiac Solutions

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

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SPECIAL POINTS OF INTEREST:

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- Is Gluten hidden in some of the medications you take? Page 4
- Read about the signs, symptoms and treatment of Celiac disease from our very own Dr. Mogan! Page 5

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Kogan Celiac Center Opens



On April 2, 2008, Saint Barnabas Health Care System officially opened The Kogan Celiac Center, located at the Saint Barnabas Ambulatory Care Center in Livingston, New Jersey. A crowd of over 350 celebrated with special gluten-free food vendors, cooking demonstrations, and heart-felt presentations from Alice Bast, Executive Director of the National Foundation for Celiac Awareness, Ritu Verma, MD, Director, Children's Celiac Center, Children's Hospital of Philadelphia, and Margaret Masiello, RD, Clinical Coordinator of the Kogan Celiac Center.

Ronald J. Del Mauro, President and CEO of the Saint Barnabas Health Care System speaks to the over 300 people at the opening of the Kogan Celiac Center.

The Kogan Celiac Center is dedicated to providing expert services including 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.

Welcome to Celiac Solutions

Welcome to the first issue of Celiac Solutions! We have had many exciting developments in the few short weeks since our kickoff event in April.

A number of newly diagnosed patients are already enrolled in our dietary education program, Celiac Steps to Success, and are well on their way to implementing a gluten free diet into their busy lives.

The Café in the Saint Barnabas Ambulatory Care Center and the foodservice at Saint Barnabas Medical Center are now offering gluten free menu selections and have put cross-contamination protocols in place – we'll keep you up to date as the rest of the facilities in the Saint Barnabas Health Care System follow suit!

Our first support group meetings are taking place, and we are now offering individual, customized screening appointments for individuals who do not wish to wait for our quarterly community screenings.

Please visit our website:
www.koganceliaccenter.com

frequently as these and other developments are posted and updated on a regular basis.

A large part of this issue is devoted to the kickoff event which was incredibly successful with record-breaking attendance and remarkable community interest. Without a doubt, there is significant demand for a single-source, evidence-based support initiative for individuals with celiac disease and our Center is now the only program of its kind in New Jersey! Thanks to all who participated with such enthusiasm and dedication.

Each quarterly issue will also have regular features. A “recipe of the month” will be showcased, either from our own sources or from our readers, so please send us your contributions for possible inclusion in a future issue! Each issue will also address a special point of interest; look here for research developments, current trends or changes in dietary recommendations that readers will find applicable to their daily

activities. Other features under development are a calendar of events in and around New Jersey, “what’s new at the Kogan Celiac Center,” a reader mailbag, “Celiac Tip of the Week,” and many others.

Our journey has just begun! We have a vision of a world with MORE -- more awareness, more and quicker diagnoses, and more gluten free food with understandable and accurate labels. Send us your comments, suggestions and contributions and join us as we serve our mission to provide 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!



Gluten Free Food for all!



Chef Jesse Kraft, CIA prepares a dish for the opening of the Kogan Celiac Center.

Guests at Celiac Awareness Night, at the Saint Barnabas Ambulatory Care Center on April 2, were treated to a health and wellness fair and a gluten free cooking demonstration by Chef Jesse Kraft, CIA. Fifteen exhibitors displayed food samples and information about their gluten-friendly travel companies, camps and magazines.

While preparing a delicious, crustless spinach quiche, Chef Jesse provided a

running commentary about shopping for ingredients and other intricacies of cooking gluten free. Samples and printed recipes were available for all with a lively question and answer period at the end.

Below is a recipe that Chef Jesse demonstrated at the Celiac Awareness Night.



Spinach Squares

Ingredients:

- * One 9-ounce package of frozen chopped spinach, defrosted, squeezed or drained well
- * 1/3 cup minced onion
- * 8 ounces grated sharp cheddar cheese
- * 2/3 cup GF flour
- * 1/2 teaspoon oregano
- * 1/4 teaspoon freshly ground black pepper
- * Pinch of salt
- * 2 large eggs, separated, plus 2 egg whites
- * 1 cup milk
- * 4 tablespoons melted unsalted butter or vegetable oil

Lightly grease a 9" x 9" or 8" x 13" inch pan. Mix spinach, onion, and cheese together in one bowl, mix flour and spices in another bowl. Blend egg yolks with milk and butter and add to cheese mixture. Combine with flour mixture. Beat egg whites until stiff and fold in. Spread entire mixture into prepared pan and bake in preheated 375 degree oven for 30-35 minutes. Cut into squares when cool. May be served at room temperature or wrapped and frozen. Reheat frozen squares at medium-high heat for 10 minutes.

Gluten Hidden in Your Medications

On Friday, April 11, the National Foundation for Celiac Awareness and the American Society of Health-System Pharmacists co-sponsored a seminar about Gluten in Medications in Bethesda, Maryland for pharmacists, pharmaceutical manufacturers and other healthcare providers. The event began with lectures about current definitions of “gluten free,” pharmaceutical parallels with current food labeling laws, and the use of inert ingredients in medications (usually fillers, colors or flavors, called excipients). A two-hour stakeholder meeting followed, where pros, cons and practical issues about the future of medication labeling were discussed.

Clearly the issue of gluten in medication is crucial for individuals with celiac disease. Whether a prescription is filled for a short course of antibiotics or for long-term maintenance medication, ingredients must be questioned with the same vigilance as with food. In recent past, the FDA initiated its landmark food labeling bill that has made significant headway towards ensuring understandable, accurate ingredient labels for individuals with celiac disease and other food allergies. The pharmaceutical industry is now beginning to address this issue and will, in fact, be voting on the following policies in June 2009:

- that manufacturers declare the name and derivative source of every ingredient on the label of a drug product,
- that health system pharmacists be educated about celiac disease and the effects of gluten in food and drugs,
- that definitive research be undertaken to determine the effects of gluten in drug products.

Until that time, try calling the manufacturer directly or have your pharmacist call to check the source of the following ingredients: modified starch, pregelatinized starch, pregelatinized modified starch, sodium starch, glycolate, dextrans, dextrin, dextrimaltose, caramel coloring, any unspecified flavoring or coloring.

Since labeling regulations and research about gluten in pharmaceutical products are constantly changing, use the following resources to find up-to-date information: www.glutenfreedrugs.com, www.celiacmeds.com, www.celiaccentral.org, www.ashp.org/gluten.

Call

1-888-724-7123

to register for an
upcoming support
group meeting!

Kogan Celiac Center Support Group Meeting

The first support group meeting of the Kogan Celiac Center was a huge success! Thirty-two people attended and were treated to “Penne Vodka” and Italian biscotti from Calabria’s of Livingston, and Mama’s Restaurant and Café Baci of Hackettstown provided coupons and a \$25 gift certificate which we raffled off at the end of the meeting. Lots of other celiac-friendly restaurants were discussed and recommended and nobody left hungry!

So much was discussed that we agreed that a summary of the meeting would be posted on the Center’s website (www.koganceliaccenter.com) for future reference and for those unable to make meetings.

Support groups are now meeting from 6:30-8:00pm, at the Saint Barnabas Ambulatory Care Center, 200 South Orange Avenue, Livingston, NJ, according to the following schedule:

- ✦ Adults: 2nd Tuesday of the month, next meeting 7/8
- ✦ Children 1-10: 3rd Tuesday of the month, next meeting 7/15
- ✦ Teens (11-18): 4th Tuesday of the month, next meeting 7/22

Special Meetings, times/dates to be announced, based on interest: Gluten Free/Lactose Free, Gluten Free/Diabetic. Please call if interested in these or other special interest groups.

Registration is requested for all support group meetings through our registration number, 1-888-724-7123.

Other activities of the Kogan Celiac Center were discussed:

- Individual screenings assessments *are now available* with a Registered Dietitian, with same day screening bloodwork if indicated.
- The Kogan Celiac Center of the Saint Barnabas Health Care System was featured statewide in an article in the Star Ledger on May 13!
- Our neighbors, the Greater Philadelphia Area Celiac Support Group are co-sponsoring a Celiac Awareness Day with the National Foundation for Celiac Awareness at a Phillies home game in Citizens Bank Park on Sunday, July 27. Lots of gluten-free goodies will be available!

Does Your Child Have Celiac Disease?

Signs, Symptoms and Treatment

By: **Glen R. Mogan, MD**, Board certified gastroenterologist,
On staff at Saint Barnabas Ambulatory Care Center & Saint Barnabas Medical Center

The following is a summary of an article by Glen R. Mogan, MD, Board Certified Gastroenterologist, on staff at Saint Barnabas Ambulatory Care Center & Saint Barnabas Medical Center, recently published in the May issue of Healthy Child magazine. To read the complete article, please visit our website, www.koganceliaccenter.com.

Celiac disease is no longer considered rare, but remains frequently undiagnosed because its symptoms can be varied and can resemble symptoms of other diseases. It is a genetic, autoimmune intolerance to gluten that causes damage and inflammation in the small bowel, affecting the absorption of nutrients from food. Bloating, gas pain, loose stools, failure to thrive, delayed weight gain and growth retardation are frequently seen in children. Neurological manifestations, osteoporosis, menstrual irregularities, skin rashes, bleeding tendencies and a higher incidence of malignancies are some systemic, non-gastrointestinal symptoms of this disease.

Screening blood testing measures the production of antibodies to gluten and a biopsy of the small intestine via endoscopy confirms the diagnosis of celiac disease. Once diagnosed, the only treatment is a gluten free diet, a diet that eliminates wheat, barley and rye and any ingredient derived from these grains.

A recent growth in awareness about celiac disease has resulted in a proliferation of new products, websites and restaurants that cater to individuals following a gluten free diet. Education from the physician and an experienced Registered Dietitian is extremely important for the newly diagnosed, as are support groups and other allied healthcare providers who are knowledgeable about the disease and the gluten free diet. Education about reading food labels, self-advocacy in public settings and general coping strategies for the myriad lifestyle changes associated with the gluten free diet are paramount for the newly diagnosed.

Screening children with symptoms and increased risk factors for celiac disease can substantially reduce the time it takes to make a diagnosis.



Pictured here are some of the 350 people who attended the reception for the opening of the Kogan Celiac Center. Here they are enjoying the gluten free menu provided by Sodexo Food Services.

**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

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 will stop or slow down the characteristic inflammatory process in the small intestine and you may see a noticeable improvement of symptoms. 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, so screening or testing may be inaccurate and unreliable. 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.koganceliacenter.com) or by calling us at 973-322-7272.