

# impact

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HILARY JERICO, MD

## EXTRA-INTESTINAL MANIFESTATIONS OF CELIAC DISEASE

BY HILARY JERICO, MD

The first “classic” description of celiac disease, describing children with stunted growth, large protuberant abdomens, wasted bodies, atonic and flabby muscles, marked pallor and severe diarrhea, came from Samuel Gee, a London physician, in 1888.

Many advances have come about since that time, including the understanding that celiac disease is a complex autoimmune disease, triggered by the ingestion of gluten (the major storage protein in wheat, barley and rye) in genetically predisposed individuals. It is by now well known that celiac disease causes elevated titers of celiac-specific autoantibodies and results in variable degrees of small intestinal inflammation and a wide range of both gastrointestinal and extra-intestinal manifestations, and sometimes even completely asymptomatic states.

IT IS NOW CLEAR THAT CELIAC DISEASE CAN PRESENT IN MANY DIFFERENT WAYS, including “classic” gastrointestinal symptoms, “atypical” extra-intestinal symptoms, or asymptomatic forms.

Gastrointestinal symptoms are more common in younger patients, while the extra-intestinal symptoms occur more often in older patients. The more common gastrointestinal symptoms include vomiting, diarrhea, abdominal pain, bloating, constipation, poor weight gain, and constipation. On the other hand, the more common extra-intestinal symptoms include abnormal liver enzymes, arthralgia/arthritis, alopecia, fatigue, headache, anemia, mouth sores, muscle aches, psychiatric disorders including depression, rashes, seizures, neuropathy, short stature, delayed puberty, osteoporosis and infertility.

In a recent paper published at the University of Chicago Medicine by Jericho, Sansotta, and Guandalini, it was found that both children and adults have similar rates (~60%) of extra-intestinal symptoms with the three most common symptoms including short stature (33%), fatigue (28%) and headache (20%) in children and iron deficiency anemia (48%), fatigue

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(37%) and headache/psychiatric disorders (24%) in adults. I will further discuss short stature, iron deficiency anemia, and psychiatric disorders here.

Short stature is the most common extra-intestinal finding in children newly diagnosed with celiac disease and is a direct result of nutrient malabsorption. Once the patients start a strict gluten-free diet, though, the expectation is that they should achieve their expected adult height. An interesting finding from the above mentioned study from Jericho, et al, though, was that despite strict adherence to a gluten-free diet, 35% of children with short stature failed to have this “catch up” growth, as predicted. Upon further investigation, 28% of these patients were found to have another underlying condition contributing to their short stature such as inflammatory bowel disease, food aversion, Turner syndrome or growth hormone deficiency. This finding emphasizes the need to closely monitor these children. Failure to attain their expected height should prompt physicians to dig deeper for other possible underlying conditions that are contributing to their short stature.

Iron deficiency anemia related to celiac disease is a very common symptom in the adult population. It is often resistant to treatment with oral iron supplementation alone. This is secondary to the celiac-related small bowel inflammation that can cause persistent iron malabsorption, despite the supplementation. Once these patients start to follow a strict gluten-free diet in addition to the iron supplementation, the anemia resolves itself in roughly 84% of patients by 24 months. The iron supplement can typically be discontinued once one's celiac disease is under control.

As a whole, patients with celiac disease report “lower qualities of life” and have higher lifetime rates of depression (31%), anxiety (21%) and eating disorders (7%). These symptoms may be more complicated. They are thought to be initially a consequence of nutrient malnutrition. However, ongoing symptoms after strict adherence to the gluten-free diet may be caused by the decreased quality of life directly related to dietary restrictions. Ultimately, this can lead to school avoidance with falling grades, problems with relationships, poor performance at work, altered sleep, use of drugs and alcohol, and decreased adherence to the gluten-free diet. With strict adherence to the gluten-free diet,

up to 50% of adults and 83% of children report improved rates of depression. Those that continue to experience psychological problems should follow up with trained professionals for additional help.

When the article cited above compared extra-intestinal symptom resolution in children to adults, they found that children on a strict gluten-free diet have greater rates of symptom improvement for almost all the above listed extra-intestinal symptoms (71%) as compared to adults. The two exceptions were abnormal liver enzymes (88% vs 100%) and iron deficiency anemia (84% vs 85%) We also found that the single child with abnormal liver enzymes who failed to improve on the gluten-free diet had obesity-related fatty liver disease in addition to celiac disease. It was later determined that the fatty liver disease, rather than the celiac disease, was the cause of the abnormal liver enzymes. Of the patients with extra-intestinal symptoms that failed to improve on a gluten-free diet, further questioning revealed that 4% of children and 9% of adults reported that they were not actually strictly adhering to the diet.

In summary, there has been a dramatic increase in the understanding of celiac disease since it was first described in 1888. Among the many discoveries, it is now clear that celiac disease can present in many different ways, including “classic” gastrointestinal symptoms, “atypical” extra-intestinal symptoms, or asymptomatic forms. Overall, the rates of extra-intestinal symptoms appear to be equally distributed between children and adults, though children do appear to have better rates of symptom improvement as compared to adults on a strict gluten-free diet.



## THE UNIVERSITY OF CHICAGO MEDICINE

Celiac Disease Center  
[cureceliacdisease.org](http://cureceliacdisease.org)

Stefano Guandalini, MD  
FOUNDER & MEDICAL DIRECTOR  
*Section Chief* The University of Chicago Comer Children's Hospital, Pediatric Gastroenterology, Hepatology and Nutrition

Bana Jabri, MD, PhD  
*Director of Research*

Hilary Jericho, MD, MSCI  
*Director of Pediatric Clinical Research*

Sonia Kupfer, MD  
*Director of Clinical Genetic Research*

Carol Semrad, MD  
*Director of Adult Clinical Research*

Lori Rowell Welstead, MS, RD, LDN  
*Nutrition Advisor*

### STAFF MEMBERS

Carol M. Shilson, *Executive Director*

Ronit Rose, *Program Director*

Diane McKiernan, *Research Study Coordinator*

Trent Eisfeller, *Office Assistant*

### GENERAL OFFICE INFORMATION

5841 S. Maryland Avenue, MC 4069  
Chicago IL 60637  
773-702-7593

[www.CureCeliacDisease.org](http://www.CureCeliacDisease.org)

Facebook: [cureceliac](https://www.facebook.com/cureceliac)

Twitter: [@cureceliac](https://twitter.com/cureceliac)

Instagram: [uchicagoceliaccenter](https://www.instagram.com/uchicagoceliaccenter)

## SPRING FLOURS 2017

This magical evening will take place on April 28, 2017, at the Chicago Cultural Center's exquisite Preston Bradley Hall! Mark your calendar now—this event does sell out—and look for the Save-The-Date in the next few months for more information.

We are also looking for sponsors for this event. If your company is interested in a sponsorship, please contact us at

<http://www.cureceliacdisease.org/contact-us/>.



# DIETITIAN'S CORNER

By Lori Welstead, RD, MS

## ON THE ROAD TRAVELING ON A GLUTEN-FREE DIET

**ARM YOURSELF  
WITH SNACKS >**



I love to travel, and when I was diagnosed with celiac disease a little over a year ago, I worried about the impact on travel. But, following the advice I've given to hundreds of patients prior to being diagnosed myself, I've come to realize that traveling, whether for a long weekend, a quick business trip or an extended vacation, is a challenge but is entirely manageable with a little advance thought.

As I tell my patients, it is important to research options, including restaurants, grocery stores, and farmers' markets near your destination. This is work, but it's essential and thanks to the Internet, entirely doable. I can't imagine how difficult this process must have been 20 years ago, and am thankful that I was diagnosed in the era of smartphones and apps. Advance research will help you identify options and decrease stress. This is especially important if you are traveling to a new place.

Arm yourself with snacks. You may like savory or sweet snacks, or, like me, both. When I travel, I am sure to either make a trail mix or buy a gluten-free one to eat on its own or add to yogurt for a snack. Individual packets of nut butters are always helpful, and I add them to things such as bananas, carrots, celery, apples, gluten-free bread or gluten-free crackers. This helps give a boost of healthy fats and healthy protein to an otherwise only carbohydrate-laden snack or meal. Other snacks I might pack include hard boiled eggs, freeze dried cheese (often available at Starbucks), popcorn and snack bars. Dried fruits and vegetables are also a great option, and full of vitamins. I also try to squeeze in a visit to a grocery store as soon after arrival as possible, to make sure I have enough on hand and to allay any feelings of deprivation or desperation.

Keep it simple! Eating out can present many challenges and can raise stress levels. Let it



go...opt for something simple and reliable rather than an elaborate dish, if you have any doubts at all about its gluten-free status. I have experienced this first-hand in the past year since I was diagnosed, and have sometimes had to tone down my expectations. It is not the end of the world, and it is better to have a simpler meal than to become ill on a trip. Be sure to call ahead at an off-peak time to let the restaurant and chef know that you have celiac disease. Speak to the manager of the restaurant if necessary.

If you go to someone's home frequently for meals, or if you will be staying with someone and eating in, consider bringing a collapsible strainer to rinse vegetables and drain gluten-free pasta. I brought my own strainer and a very thin cutting board to my sister's home. She stores them for me, and they will be there to help me avoid cross contamination on future trips. If your children visit their grandparents or other relatives without you, this can be very helpful. Just mark everything with their name or a symbol so everyone in the household is aware that these are gluten-free items.

**TWO GREAT RESOURCES YOU CAN CHECK WHEN YOU ARE PLANNING A TRIP ARE:**

Find Me gluten-free:  
[www.findme glutenfree.com](http://www.findme glutenfree.com)

Gluten-Intolerance Group Foodservice locations with certified kitchens:  
<http://www.gffoodservice.org/wp-content/uploads/2015/02/GFFS-Certified-Eating-Establishments-11.15.16.pdf>



# RESEARCH WRAP UP



The University of Chicago is involved with a number of studies involving different aspects of celiac disease, from lifestyle issues to potential therapies and cures.

For more information about the individual studies, or to explore the possibility of participating in one of them, please visit

<http://www.cureceliacdisease.org/ongoing-studies/>.

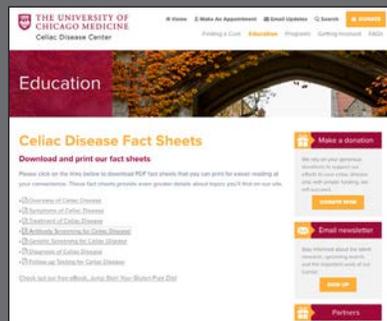
The University of Chicago Celiac Disease Center has released its annual Research Report, summarizing current research and new findings over the past year. You may have received the report by mail, and you can also read it on our website, at

<http://www.cureceliacdisease.org/research/>.

## FROM OUR WEBSITE

Did you know that we have an entire section of **factsheets** on different aspects of celiac disease on our website? We review and update the factsheets regularly, and add new ones as well. Our newest factsheet, For Family and Friends, discusses how to explain celiac disease to relatives and friends, how to emphasize the importance of proper food preparation for celiac patients, and why it is important for first degree relatives to get tested.

[cureceliacdisease.org/fact-sheets](http://cureceliacdisease.org/fact-sheets)



## PRECEPTORSHIP PROGRAM

On December 1 and 2, 2016, The University of Chicago Celiac Disease Center held its Preceptorship Program, bringing doctors, dietitians and nurse practitioners from around the country to study intensively for two days with celiac experts from The University of Chicago Medicine. The preceptors attended lectures, engaged in interactive discussions, shadowed our faculty in clinics and learned about celiac research initiatives at The University of Chicago Medicine from Director of Research, Dr. Bana Jabri. The University of Chicago Celiac Disease Center is committed to bringing this education to a much wider array of medical professionals through its online Preceptorship Course, which is currently in development. Doctors who take the online course will be able to earn continuing medical education credits for doing so. We will post more information about the course on our website as it gets closer to completion.



# CALENDAR of Upcoming Events:

**JANUARY 31 – FEBRUARY 2, 2017:** Dr. Guandalini will address the Middle East Course and the Saudi Arabian Society of Pediatric Gastroenterology, Hepatology and Nutrition (SASPGHAN)

**APRIL 28, 2017:** Spring Flours! Mark your calendars now for Spring Flours 2017, at the Chicago Cultural Center in downtown Chicago. Tickets will be available for purchase March 15.

**MAY 7, 2017:** Enjoy springtime ice skating at Celiac Skate, from 12:30 pm to 2:30 pm, at Centennial Rink in Highland Park, IL. Proceeds benefit research at The University of Chicago Celiac Disease Center. Please see our website in the coming months for more information.



## WILDFIRE WEEK: ANOTHER WONDERFUL SUCCESS

Wildfire Restaurants held its 7th annual Gluten-Free Week in early November, with a wonderful four-course meal and optional wine pairings. The event took place in its Oak Brook and Lincolnshire restaurants in the Chicago suburbs. The menu featured salmon pastrami and wild mushroom macaroni and cheese (for appetizers) and a salad, followed by a choice of seared branzino or pesto filet mignon, and topped off by an exotic olive oil cake. The wine pairings were perfect and the two evenings were lively and fun. Proceeds from the events support the important work at The University of Chicago Celiac Disease Center. Special thanks to Wildfire Restaurants Sales & Marketing Manager Laura Nessel and her team for their unwavering support over so many years. Special thanks as well to Founding Friend of Celiac Disease Center Susan Blumenfeld for working with Wildfire to create this special fundraising event so many years ago.

[PICTURED ABOVE] Brad Wermager (Wine & Spirits Director), Laura Nessel (Director of Marketing & Sales), Moreno Espinoza, (Divisional Executive Chef), Camilo Castillo, (Kitchen Manager—Lincolnshire Wildfire), Susan Blumenfeld, Celiac Center Founding Board Member, and Humberto Morales, (Wildfire Lincolnshire Executive Chef)

## PARTNERS:

The University of Chicago Celiac Disease Center is required to raise its own funding, for all research and programming, every year. Our partners are an important part of this effort. We are pleased to partner with the companies listed below, and we thank them for their support.

If your company is interested in partnering with us, please email us at

<http://www.cureceliacdisease.org/contact-us>.



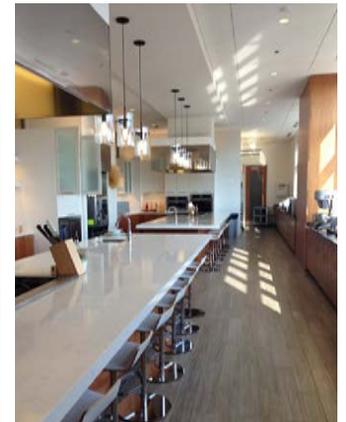
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**END**  
ARTISAN FOODS

# GAME CHANGER: BARILLA® GLUTEN-FREE PASTA

Walk into Barilla's American headquarters in Northbrook, IL, and you will experience a different kind of company. The corporate bicycles parked outside, for all to use, are the first hint of a lively, welcoming spirit that pervades the building. The conference rooms, each named for a different kind of pasta, are welcoming and comfortable, and the public spaces are all flooded with natural light, stunning photos and white boards proclaiming employees' anniversaries with the company, or their thoughts and comments on a particular issue. The company's test kitchen is gleaming, and its storage room holds boxes and boxes of pastas, all in that distinctive royal blue signature Barilla carton.

In September, 2013, Barilla, headquartered in Parma, Italy, at last introduced its long-awaited gluten-free pasta to the Italian and U.S. markets. The addition of Barilla to the market truly changed things for the better for celiac patients everywhere. Suddenly, gluten-free certified pasta was widely available, for lower pricing, than ever before. Today, Barilla has a total of five different cuts of gluten-free pasta (spaghetti, fettucine, penne, rotini and elbows) available in the U.S. Since the beginning of 2016, all Barilla gluten-free pasta sold in North America has been produced in the company's GFCO-certified facility in Iowa. Sales of gluten-free pasta in the U.S. have enjoyed a growth rate of over 110 percent, and have already captured 31 percent of the gluten-free pasta market. Barilla has truly achieved its goal of "creating gluten-free pasta that tastes and performs like a gluten-containing pasta," says Enrico Cademarti, Vice President for Research and Development and Quality at Barilla America®, Inc.

With all this delicious gluten-free pasta readily available, do celiac patients need to worry about gaining weight? Absolutely not, according to Barilla dietitian Ana Rosales, as long as portions are controlled, to about one cup cooked, or the size of a baseball: "The Mediterranean diet is healthy, and helps BMI stay under control," explains Rosales. "People who eat pasta regularly are more likely to stay on the Mediterranean diet\*." For healthy ideas incorporating gluten-free



pasta, visit the [Recipe Builder](#), suggests Rosales.

Because Barilla's U.S. headquarters is located near Chicago, it has been an important partner for The University of Chicago Celiac Disease Center since its first gluten-free products hit the supermarket shelves. In fact this year, Barilla will enjoy its 140<sup>th</sup> anniversary, coinciding with its 20<sup>th</sup> anniversary in

the U.S. The University of Chicago Celiac Disease Center congratulates Barilla and Barilla America on these important achievements, and looks forward to many more years of working together.

[\\*http://www.nature.com/nutd/journal/v6/n7/full/nutd201620a.html?WT.mc\\_id=FBK\\_NUTD\\_1606\\_PASTA\\_PORTFOLIO](http://www.nature.com/nutd/journal/v6/n7/full/nutd201620a.html?WT.mc_id=FBK_NUTD_1606_PASTA_PORTFOLIO)