

impact

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STEFANO GUANDALINI, MD

INFANT FEEDING PRACTICES: WHAT WE KNOW AND WHAT WE DON'T KNOW

BY STEFANO GUANDALINI, MD

All new parents are concerned with their baby's welfare, and new parents in families with celiac disease are no exception. We frequently hear from expectant mothers and new mothers asking about the best protocol for infant feeding, to ensure the least likelihood of an at-risk child developing celiac disease.

Until recently, guidelines issued by the European Society for Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) suggested that parents introduce gluten to babies sometime between four and six months of age, and gradually increase this amount while still breast feeding. In 2010, *Impact* published an article on this very subject, summarizing the ESPGHAN guidelines. The guidelines emphasized that gluten introduction was to be done while breast feeding the baby. The idea behind this practice was to desensitize the baby to gluten gradually, and offer the baby the protective effects of the mother's immunities.

Because this topic is of such great interest, multiple studies have been done on it. Last year I, with a group of my colleagues from Italy and Spain, undertook to review the literature and assess the accuracy behind the guidelines. We found 149 related papers related to the association of the later development of celiac disease with breast feeding duration, breast feeding at the time of gluten introduction and the timing of gluten introduction. Forty-eight of these studies were considered, and 16 were found to fit the criteria for our review. Our conclusions, summarized in the article **Infant feeding and risk of developing celiac disease: a systemic review**, were published in *BMJ Open* earlier this year. (1,3)

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Spring Flours recap

Breast feeding and risk of celiac disease

Most of the 16 studies were prospective studies. Two of them were interventional, and the rest were observational. Interestingly nearly two thirds of the papers that investigated breast feeding on the risk of developing celiac disease concluded that the duration of breast feeding had no preventative effect. In fact one study even concluded the opposite, that increased breast feeding correlated with greater incidence of celiac disease, though the correlation was extremely small (2).

Breast feeding at gluten introduction and celiac disease

Two of the nine papers that examined this question found a preventative effect if the baby was being breast fed at the time of gluten introduction. However, these were retrospective control studies, that did not take into account the genetic predisposition or lack thereof of the subjects. The other papers did not report a positive effect from breast feeding at the time of gluten introduction.

Timing of gluten introduction and celiac disease

Eleven of the 16 papers reviewed dealt with the timing of gluten introduction. Eight of the 11 found that the timing of gluten introduction makes no difference in the likelihood of development of celiac disease later on. A more recent survey, that was not included in this study of original papers, came to the same conclusion: the timing of gluten introduction, whether at 16 weeks or 24 weeks or anywhere in between, has no bearing on later development of celiac disease. One study did find that waiting to introduce gluten until after six months of age did pose a slightly higher risk to the baby, but again the statistical significance was very small. Another showed an increase in celiac disease development for those babies fed gluten before three months of age.

At this point, “no studies are...available to explain the lack of a protective role of breast

feeding on the risk of [celiac disease].” (3) Even in the single study that did report a protective effect, it is possible that rather than truly preventing celiac disease, it only delays its onset.

One important point that did come out of this review is that one study indicated that girls with high genetic risk of celiac disease who were introduced to gluten at six months of age were more likely to suffer from it by age five than were their male counterparts. After a thorough review of the studies, this is the only possible exception to our conclusions: [that] there is currently no evidence to recommend avoiding either an early (at 4 months of age) or a late (at or after age 6 or even 12 months) gluten introduction in children at risk of [celiac disease].” (4,5) Therefore at this point in time, pediatricians cannot make any evidence-based suggestions on how to best prevent celiac disease in children at risk. And although breast feeding does not appear to offer a protective effect with regard to celiac disease, it certainly confers many benefits to newborn children, and should be encouraged whenever possible.

1. BMJ Open, Infant feeding and risk of developing celiac disease: a systematic review Marco Silano, Carlo Agostoni, Yolanda Sanz and Stefano Guandalini, Downloaded from <http://bmjopen.bmj.com/> on January 26, 2016 - Published by group.bmj.com.

2. Størdal K, White RA, Eggesbø M. Early feeding and risk of celiac disease in a prospective birth cohort. *Pediatrics* 2013;132:e1202-9.

3. BMJ Open, Infant feeding and risk of developing celiac disease: a systematic review Marco Silano, Carlo Agostoni, Yolanda Sanz and Stefano Guandalini, Downloaded from <http://bmjopen.bmj.com/> on January 26, 2016 - Published by group.bmj.com, p. 9

4. Lionetti E, Castellaneta S, Francavilla R, et al. Introduction of gluten, HLA status, and the risk of celiac disease in children. *N Engl J Med* 2014;371:1295-303.

5. Vriezinga SL, Auricchio R, Bravi E, et al. Randomized feeding intervention in infants at high risk for celiac disease. *N Engl J Med* 2014;371:1304-15.



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A Cure for Celiac Disease is possible ...

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CHICAGO CELIAC GROUP LAUNCHES!

If you've been searching for a local social group to meet and talk with other celiac patients, look no more. Registered dietitian Lori Welstead and Celiac Center research coordinator Diane McKiernan have started a new group known as Chicago Celiacs. The first meeting took place on at Chicago's Burger Bar on May 19, and future meetings will be quarterly. For more information, please contact Diane at dmckiernan@peds.bsd.uchicago.edu.



DIETITIAN'S CORNER

By Lori Welstead, RD, MS

OATS



There has been much confusion and controversy on safe consumption of oats for those with celiac disease. Despite the confusion, however, there are clear facts around oats and celiac disease. Let's outline what we know:

- Oats, by nature, do not contain gluten.
- Oats contain a protein called avenin, which may activate an immune response similar to gluten, but this occurs in an extremely small number of people (1).
- Oats are a good source of fiber. Increasing fiber intake may cause gastrointestinal (GI) symptoms that often mimic symptoms of celiac disease.
- Regular oats (known as commodity oats) are generally grown with other grains and often contaminated by gluten.
- Any product that contains oats needs to meet the FDA 20ppm Gluten Free Standard in order to be labeled Gluten-Free.

The prevailing consensus of the medical and scientific community is that the majority of people with celiac disease can tolerate oats as long as they are free of cross-contamination and are consumed in moderation. In fact, pure, uncontaminated oats may be consumed safely in quantities of 50 grams per day (1/2 c dry oats) (2). Some individuals are not able to tolerate oats regardless of gluten or celiac disease. These individuals often suffer from symptoms of gas and bloating that are the result of the presence of fermentable carbohydrates, which are commonly known as FODMAPs (fermentable, oligo-di, monosaccharides and polyols). It is important to note that anything more than 1/2 cup cooked oats consumed in one sitting is considered high FODMAP and may attribute to gastrointestinal symptoms (3).

The recent controversy about oats is surrounding the process used to eliminate cross-contamination in order to meet the FDA 20 ppm gluten-free standard. Some companies use what is referred to as a "purity protocol" which may include the following: using gluten-free seed; growing oats in fields without wheat, barley, or

rye in crop rotation for 2 or more years; walking fields to manually remove rogue gluten plants - multiple times - before harvest; using dedicated equipment for planting, harvesting, and transporting; using dedicated, gluten-free processing facilities; and extensive testing for gluten contamination. Other companies are now using a process that mechanically sorts, or "cleans" the oats from other grains after they are harvested. Regardless of the process, it is critical for those with celiac disease that the end product be tested to be less than 20 ppm of gluten.

The North American Society for the Study of Celiac Disease (NASSCD) issued a comprehensive statement on this issue, calling for rigorous testing and validation of all gluten-free oats (4).

Click here to read the full statement:
<http://www.nasscd.org/wp-content/uploads/2016/04/Oats-Statement-NASSCD-April-2016.pdf>.

We know that the Food and Drug Administration (FDA) does not inspect each food that is labeled gluten free. Rather, manufacturers who label gluten free are expected to adhere to the FDA Standard and conduct their own testing to ensure that the end product contains less than 20 ppm of gluten. The FDA standardized the definition of foods labeled gluten free in 2013. This rule requires that, in order to use the term "gluten free" on its label, a food must meet all of the requirements of the definition, including that the food must contain less than 20 ppm of gluten (5).

While the FDA Standard certainly has helped to ensure that products labeled as such are in fact gluten free, the system is far from perfect. Manufacturers may use various testing methods to assess the gluten-free status of raw ingredients, milled flour, and finished product. This information is not readily available. NASSCD, however, encourages manufacturers to have consistent, stringent, transparent and reliable testing methods to ensure that the end product is gluten free (below the FDA mandated level of 20 ppm). (6)



Ultimately, every individual with celiac disease should discuss oat consumption with his or her gastroenterologist and registered dietitian and should monitor anti-tissue transglutaminase (anti-TTG) levels. If symptoms believed to be caused by oat consumption persist or anti-TTG levels becomes elevated, review the diet with a fine-toothed comb to determine if an oat-containing product could be the culprit. Despite the FDA Standard, it is still important to always read labels before consuming any product as ingredients and suppliers may change, and to alert the FDA if you suspect a product labeled gluten-free is not meeting the standard.

REFERENCES:

- 1 Hardy MY, et al., Ingestion of oats and barley in patients with celiac disease mobilizes cross-reactive T cells activated by avenin peptides and immuno-dominant hordein peptides, *Journal of Autoimmunity* (2014) <http://dx.doi.org/10.1016/j.jaut.2014.10.003>
- 2 "Celiac Disease." Evidence Analysis Library. Academy of Nutrition and Dietetics, 2009. Web. <http://www.andeal.org/topic.cfm?cat=3726>
- 3 Low FODMAP smartphone app. (2013; updated 2016). Retrieved June 08, 2016, from <http://www.med.monash.edu/cecs/gastro/fodmap/iphone-app.html>
- 4 North American Society for the Study of Celiac Disease. Summary Statement on Oats. April 2016. <http://www.nasscd.org/nasscd-publishes-oats-statement/>
- 5 "U.S. Food and Drug Administration." FDA Defines "gluten-free" for Food Labeling. 2 Aug. 2013. <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm363474.htm>
- 6 Thompson, T. (2016, May 18). Gluten Contamination Levels of Oat Products Labeled Gluten-Free: Summary Test Results from Gluten Free Watchdog. <https://www.glutenfreewatchdog.org/news/gluten-contamination-levels-of-oat-products-labeled-gluten-free-summary-test-results-from-gluten-free-watchdog/>



RESEARCH WRAP UP

Three Studies Are Enrolling Patients



A PILL TO TREAT CELIAC DISEASE?

Now enrolling patients in a clinical study!

This study is testing Montelukast (a drug that has been approved by the FDA for treatment of asthma) for the treatment of Celiac Disease. You may be eligible for this study if:

- > You are age 18 and older
- > You have celiac disease
- > You have been on a gluten-free diet for at least one year
- > You are willing to eat gluten (bread)
- > You live in the Chicago area or are willing to travel to Chicago up to six times a year

If enrolled, you will be given the drug or a placebo and asked to:

- > Come to up to 6 study visits
- > Have multiple blood draws, endoscopy with biopsy and brushings, and provide stool samples
- > Answer some questions regarding your health

All visits and treatment take place at the University of Chicago Medical Center. Subjects will be reimbursed up to \$160.00 if all visits are completed and will receive parking vouchers.

If you are interested, please contact Meaghan Peterson at 773-702-9743 or

mpeterson9@medicine.bsd.uchicago.edu

RESEARCH STUDY FOR THOSE SUFFERING WITH REFRACTORY CELIAC DISEASE TYPE II

The University of Chicago Celiac Disease Center is pleased to be partnering with Celimmune, which is working hard to find a treatment for those with the most difficult cases of celiac disease. In fact, it has launched a Phase II study to test an experimental therapy for those diagnosed with Refractory Celiac Disease Type II. RCD Type II is an extremely rare form of celiac disease, with only a handful of patients diagnosed with it in the United States. Refractory celiac disease is defined as persistent or recurrent intestinal atrophy and gastrointestinal symptoms despite adherence to a strict gluten-free diet for at least 6-12 months. In addition, the presence of aberrant (precursor of cancer) intraepithelial lymphocytes (IELs) is another hallmark characteristic of refractory celiac disease. Patients with a low proportion (<20%) of aberrant IELs, as determined by flow cytometry, are diagnosed with refractory celiac disease Type I. When the aberrant IELs exceeds 20%, the patient is diagnosed with refractory celiac disease Type II. For more information, please visit www.celimmune.com or contact info@celimmune.com.



ADOLESCENTS WANTED!

The University of Chicago Celiac Disease Center is currently conducting a research study for teenagers with celiac disease and their parents, to better understand the feelings and coping skills of our adolescent patients with celiac disease and how this affects their adherence to a gluten-free diet later in life. Our goal is to use this information to improve adherence to a gluten-free diet for these patients as they get older. If your child is between the ages of 12 and 18 and is a celiac patient at The University of Chicago Medicine, he or she may qualify. Parents should contact Celiac Center Research Coordinator Diane McKiernan by phone at 773-702-3572 or by e-mail at dmckiernan@peds.bsd.uchicago.edu for more information.

WE ARE ALWAYS LOOKING FOR **interesting topics of concern to celiac patients** TO EXPLORE AND COVER IN OUR NEWSLETTER.

Let us know your ideas.

PLEASE SEND THEM TO
WWW.CURECELIACDISEASE.ORG/CONTACT-US



CALENDAR of Upcoming Events:

SEPTEMBER 15, 2016: Online Registration for Free Screening opens.

SEPTEMBER 20, 2016: Dr. Carol Semrad will address the Janesville, Wisconsin, Celiac Disease Support Group.

OCT. 5-7, 2016: Dr. Guandalini will address the World Congress of Pediatric Gastroenterology in Montreal, on "Diagnostics and spectrum of gluten related disorders".

OCT. 22, 2016, 9 AM - 1 PM: Celiac Education Day, at The University of

Chicago Celiac Disease Center. It will feature lectures, a Q & A Panel and a free blood screening. Please visit our website for more information.

NOV. 18, 2016: Dr. Guandalini will address the Italian Society of Pediatrics in Florence on "New Frontiers in Functional Foods"

NOV. 21, 2016: Dr. Guandalini will speak at National Digestive Week in Mazatlán, Mexico, on "Finding and treating Celiac Disease in 2016"; and "Gluten trouble: celiac disease and what else?"

DECEMBER 1 & 2, 2016: Annual Preceptorship Program at The University of Chicago Celiac Disease Center, for medical professionals. Please visit <http://www.cureceliacdisease.org/preceptorship-program/> for more information and a link to the application.

APRIL 28, 2017: Spring Flours Gala. More information available on our website in the coming months.

MAY 7, 2017: Celiac Skate, in Highland Park, IL. More information to follow on our website soon.

wheat's END

Wheat's End Owners Amelia Fonti and Susan McMillan did not anticipate careers in the food business. Amelia was an opera singer by training, and Susan, who also had a degree in voice, was a lawyer, homemaker and volunteer. But somehow the food business, in particular the gluten-free end of it, found them. Their first venture together, Senza, made history in gluten-free dining by attaining the first Michelin star for a gluten-free restaurant ever. It repeated the feat the following year but unfortunately shut its doors shortly thereafter. However, rather than become another empty storefront in Chicago's Lakeview neighborhood, the space, which had already been operating in the mornings as a gluten-free café, reopened as Wheat's End, a wonderful café and lunch spot with lines out the door every weekend.



Wheat's End Café offers so many baked goods one could easily forget that the menu is gluten-free. Among the many choices are panini, popovers, and English muffins. All bread products are produced in their offsite bakery, also in a dedicated gluten-free facility, and outside food, even gluten-free food, is banned in both the bakery and the café. In addition to supplying the café, the offsite bakery also supplies a number of other restaurants and hotels in the Chicago area with gluten-free baked goods, including Spring Flours partner LYFE Kitchen, and fills special orders for retail customers. Local customers can pick up orders at the café, but don't despair: Wheat's End does ship around the country, and recently opened up an online Etsy site as well. For more information, or to order, please visit wheatsend.com.

Wheat's End also tries hard not to be just another bakery, albeit a gluten-free one. "We try really hard to make sure all our products have protein and fiber, and that



they are as nutrient-full as possible," says Susan. Indeed all products and menu items are largely made from organic ingredients. It strives to accommodate other allergies and food preferences, but commits only to delicious gluten-free dining, suitable for customers who are seeking a gluten-free meal as much as for those who are simply seeking a healthy meal in a cheery setting.



SPRING FLOURS

GLUTEN-FREE GALA 2016

The stations were back! And the event was sold out—Spring Flours 2016 was a raging success by any measure, but most importantly by the money raised to support research for a cure at The University of Chicago Celiac Disease Center. Director of Research Dr. Bana Jabri and Dr. Sonia Kupfer honored all the lab researchers, and talked about current initiatives. Everyone enjoyed this spectacular evening at the beautiful Chicago Cultural Center, and we look forward to next year's event, on April 28. More information to come soon, but mark your calendars now. For photos of this year's event, <https://uchicagoceliaccenter.shutterfly.com/pictures>



PARTNERS:

The University of Chicago Celiac Disease Center is required to raise its own funding, for all research and programming, each 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>.



KING ARTHUR FLOUR

