



Evolving Diagnostic Criteria for Celiac Disease

BY DR. STEFANO GUANDALINI, MD AND RONIT ROSE

Medicine, like every other discipline, is constantly evolving. With new discoveries, both diagnostic techniques and treatments frequently change, improve and become ever more targeted and specific. Celiac disease is a perfect example of this phenomenon.

The ancient Greeks (Arathaeus from Cappadocia) first talked about it many centuries ago, and it was officially identified by Dr. Samuel Gee in the late 1800's, although gluten had not yet been identified as the cause. Only around World War II was this connection made. A highly popular treatment, originally prescribed by an American physician, was the banana and rice diet, and only more during the 60's, and after substantial controversy, did the gluten-free diet become the accepted treatment. As for diagnosis, celiac disease was for a long time only diagnosed through symptoms, until Dr. Margot Shiner in 1956 gave doctors the ability to extricate and examine the damaged intestinal lining through her invention of the biopsy capsule attached to a special tube (a sort of rudimentary endoscope, with no ability to visualize or to be advanced manually...).

Jumping ahead some years, in 1969, the newly created European Society for the Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) decided to take on the task of codifying the diagnostic criteria for celiac disease. These included an initial biopsy showing the damage, a gluten-free diet for one year, a second biopsy following this year and before the reintroduction of gluten to document healing on a gluten-free diet, and finally a third biopsy

after a few months of gluten reintroduction. Fortunately ESPGHAN, after a study conducted in Italy provided the necessary evidence for the possibility of simplifying this cumbersome process, reconsidered these criteria in 1990 and came up with the current criteria as we know them today: blood work, an intestinal biopsy revealing flattened villi and a positive response to the gluten-free diet.

Approximately 20 years later, prompted by substantial improvements in antibody testing, more specific blood tests, and readily available gene tests, ESPGHAN has revisited the issue, somewhat modifying its earlier criteria in certain cases. The new criteria are sensitive to the fact that today we know celiac disease is an immune disorder affecting not just the intestine, and that doctors see many more patients developing celiac disease who are either completely without symptoms or have symptoms that are far removed from the gastrointestinal tract.

The new ESPGHAN guidelines, which are about to be published, revisit diagnostic criteria both for the asymptomatic child and the one with symptoms, albeit not necessarily gastrointestinal symptoms. The guidelines for these two groups can be synthesized as follows:



A) For a child at risk for celiac disease because of a close relative with celiac or a related condition such as Down syndrome, Type 1 Diabetes, or short stature:

1. This child should have the gene test to determine if he carries the gene for celiac disease;
2. If so, he should have the tissue transglutaminase antibody (TTG-IgA) test and total serum IgA test;
3. If the result is greater than three times normal, he should be referred for a biopsy. If the result is positive but less than three times normal, he should:
4. Have the endomysial antibody (EMA) test. If that comes back positive, the child should be referred for a biopsy. If negative, there needs to be further investigation, while the child stays on a normal diet.

B) The new criteria for a child who has



FROM CARE TO CURE

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The University of Chicago Celiac Disease Center is dedicated to raising awareness and diagnosis rates and meeting the critical needs of people affected by celiac disease nationwide through education, research and advocacy.

The contents of this newsletter are not intended to diagnose or recommend treatment for celiac disease. Please consult your healthcare provider with questions about your condition. For more information about The University of Chicago Celiac Disease Center, please contact our office:

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suspected celiac disease because of clinical symptoms now allow for a definitive diagnosis without biopsy under certain strictly defined circumstances:

1. The TTG-IgA comes back highly elevated (greater than 10 times normal);
2. The EMA comes back at least 10 times normal;
3. The patient is positive for at least one of the two genes correlated with celiac disease (DQ 2 or DQ 8);
4. The patient has a positive response to the gluten-free diet

It must be stressed, in conclusion, that the diagnostic process remains essentially unchanged in the majority of cases, still requiring a huge degree of suspicion by the doctor (need for education!), running the right blood test, referring the patient with elevated antibodies to a pediatric gastroenterologist for the confirmatory biopsy. As we have seen, only in a few selected cases can this process be simplified by avoiding altogether the biopsy.

And what about adults? To date, there has not been a similar governing organization for adult gastroenterology to set forth specific diagnostic criteria for adults. However, the pediatric criteria were basically adopted for adults and published in the journal *Gastroenterology* in 2006, and are widely accepted as the adult standard as well. Those of us involved with celiac disease anticipate that the new criteria for children will apply for adults in the same circumstances.

In addition, during the International Celiac Disease Symposium of 2011, held last June in Oslo, a new celiac organization was created, which is now in the process of incorporating (please see next article for more information). This organization, the North American Society for the Study of Celiac Disease (NASSCD) will serve, among other things, as a resource to look to for the best and most current diagnostic criteria. Thus the criteria that the NASSCD eventually approves will be applicable for adult patients and will set forth guidelines most likely highly compatible with the new pediatric guidelines.

North American Society for the Study of Celiac Disease

Many people have long felt that the lack of a single, comprehensive organization to guide the cause of celiac disease in the U.S. has slowed progress in terms of finding better treatments and a cure. This all changed with the formation of the North American Society for the Study of Celiac Disease (NASSCD), which was born at the International Celiac Disease Symposium in Oslo, Norway last June. This organization, initially headed by Dr. Guandalini, is currently in the process of incorporating. Its goals are to foster the study of celiac disease in young investigators, to be a clearinghouse for major issues in celiac disease as well as major research initiatives, and to help guide precious resources and funding to those research projects that appear to be the best designed, with the greatest chance of a positive outcome, as determined by peer review.

We are so pleased to be working with the very best minds in North America and welcome the opportunity to set the very highest standards and best practices for physicians in this field to follow. Stay tuned in the coming months for more information about the NASSCD as it becomes available.

Check Out our New Website



The University of Chicago Celiac Disease Center has redesigned and relaunched our website, to make it more informative and user-friendly, and to emphasize our search for a cure. Our new tagline, "From Care to Cure," summarizes our mission in just four words.

→ Please visit us at www.CureCeliacDisease.org and let us know what you think.

You can also friend us on Facebook at <http://facebook.com/cureceliac> and follow us on Twitter at <http://twitter.com/cureceliac>. We always post announcements and updates to our events on Facebook and Twitter, so please check them regularly for all the latest happenings at the University of Chicago Celiac Disease Center. Our Facebook page is updated daily.



Annual Preceptorship Program 2011

Last month, 34 doctors, dietitians and nurses from all over the U.S. gathered at the University of Chicago Medical Center for our 6th Annual Preceptorship Program. Participants heard lectures from Dr. Bana Jabri, Director of Research at the University of Chicago Celiac Disease Center, Dr. Guandalini, Dr. John Hart, leading pathologist at the UCMC, Dr. Bob Anderson, founder of Immunosant, a leading developer of a celiac vaccine, our adult celiac specialists, Drs. Semrad and Kupfer as well as many others including dietitians and chefs. In addition to the lectures and case presentations, preceptors took a tour of Dr. Jabri's research lab and heard her keynote address at our annual Preceptor Dinner at the Intercontinental Hotel which was graciously underwritten by Thermo Fisher Scientific. We are confident that the knowledge these professionals gained during the two-day course will advance awareness and diagnosis rates across the country.



THE 2011 PRECEPTOR CLASS, WITH DRs. GUANDALINI AND JABRI (FRONT ROW CENTER) AND CELIAC CENTER AND MEDICAL CENTER STAFF.

Research Wrap-Up

We still have room for 10 more patients in a study to evaluate the performance of a new test for the antibodies associated with celiac disease. Typically, people with celiac disease have elevated levels of certain antibodies in the blood, including tissue transglutaminase (tTG), anti-endomysium antibodies (EMA), and deamidated gliadin peptides (DGP). Subjects who agree to participate in this study will have about one teaspoon (three ml) of blood drawn at the University of Chicago Medical Center. To qualify for this study, *you must be a patient at the University of Chicago Medical Center*. You must have recent positive blood tests for the antibodies associated with celiac disease, or have been recently diagnosed by a scope with biopsies (upper endoscopy). Participants in this study receive \$50 in the form of a check.

In another project, Dr. Guandalini is investigating the health-related quality of life for children with celiac disease. Patients at The University of Chicago Medical Center who are between 8 and 17 years old and have been diagnosed with celiac disease by an upper endoscopy with biopsy can qualify for this study. Qualifying research participants and their parents will be asked to fill out a brief questionnaire online.

If you are interested or have further questions about either of these studies, please email or call our Research Coordinator, NurAlima Grandison, at ngrandison@uchicago.edu or (773) 702-3572.

We have two more studies in the pipeline that should begin enrollment in the next few months, so please check our website (<http://www.cureceliacdisease.org/research-news/finding-a-cure/news>), Facebook, and Twitter pages to stay updated!

Gluten in Medicine

Did you know that gluten is sometimes used in medications? The FDA is now looking into the issue and wants your opinion. Please check out the survey at:

www.CeliacCentral.org/Survey

Separately, remember to check with your pharmacist to make sure your drugs are gluten free. Another great resource is www.glutenfreedugs.com.



Care Package Program

We are starting a new year of the Care Package Program. This program has grown from humble beginnings into a well known, renown resource for newly biopsy-diagnosed patients. We thank all of our Care Package sponsors, as well as the many donors who have made this program possible. If you are newly diagnosed with a biopsy and need to receive a Care Package, please contact our office at (773) 702-7593. We will determine your eligibility for the Care Package, and will then send you a link to the form, with a temporary password.

Apple's Bakery and Gluten-Free Kitchen

Bakery on Main

Betty Crocker

Bhuja

Bob's Red Mill

Bready

Cabot Creamery

Chebe

Crunchmaster

Dr. Lucy's Cookies

Dr. Schär

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Enjoy Life Foods

Glutino Food Group

Kettle Cuisine

Lärabars

Lifeway Foods

Lucini Italia

Namaste Foods

Progresso

Rice Chex

Rudi's Gluten-Free Bakery

San-J

Upcoming Events

February 1 – 6, 2012: Dr. Guandalini will be speaking and consulting in Riyadh, Saudi Arabia, on celiac disease.

Saturday, February 18, 2012, 11 am to 4 pm: The South Florida Gluten-Free Expo at the South Florida Fairgrounds in West Palm Beach, FL. We will be there along with many of our corporate sponsors and friends. Please stop by our booth for information on our services and research. Admission is \$5 per person or \$15 per family. For more information, please visit: www.cdfsouthflorida.org.

Skate For Celiac, February 26, 2012, 12:30 pm to 2:30 pm (skating starts at 1 pm) at Centennial Rink, Highland Park, IL. Tickets are \$15 in advance, \$20 at the door. It includes skate rental depending on availability, so bring your own if you have them. There will be a silent auction, food and fun! Please visit our events page at www.CureCeliacDisease.org for more information or to order tickets online.

Pediatric Symposium in Gastroenterology: The Spectrum of Abdominal Pain in Childhood. **March 1, 2012**, Dublin, Ireland. Dr. Guandalini will be speaking on celiac disease.

March 28 – 31, Florence, Italy. Dr. Guandalini will be speaking at an international symposium on celiac disease.

The Gluten-Free Expo, at the Westin Lombard in Lombard, IL, April 14 - 15, 10 am to 4 pm. Ticket prices are \$20 for adults, \$5 for children, or \$75 if you wish to attend a cooking class (early bird price per class). There will be two cooking classes each day. Over 100 vendors attend, and we will have a booth as well. Please stop by! For more information, go to www.gfafexpo.com.

Spring Flours, April 20, 2012, at the Sheraton Chicago Hotel & Towers, from 6 pm to 10 pm. Tickets are \$175. The University of Chicago Celiac Disease Center's annual fundraiser, with over 25 restaurants participating. We'll have a martini bar, a silent and live auction, and the best gluten-free food you can possibly imagine. For more information, please visit: www.CureCeliacDisease.org.

Celiac Disease Foundation's Annual Education Conference & Food Fair, April 28, 2012, 7:30 AM – 4:30 PM, at the Hilton Hotel, Los Angeles/Universal City, \$95 admission for CDF members. Dr. Guandalini will be a keynote speaker. Please visit www.celiac.org for more details.

Digestive Disease Week, May 19 to May 22, 2012, at the San Diego Convention Center. A number of doctors from the University of Chicago Medical Center will be attending and speaking, and we will have a booth as well. For more information, please go to www.ddw.org.

American Dietetic Association/Food & Nutrition Conference & Expo, Oct. 6 – 9, 2012. This event gives us the opportunity to meet dietitians from around the U.S. and many other countries, to let them know about the resources we offer for their patients and their own education about the gluten-free diet. Dr. Guandalini will be speaking. For more information, visit: www.eatright.org.

Annual Free Blood Screening, October 13, 2012, 8:30 am - noon, at the University of Chicago Medical Center. Registration will open on August 20th, and it is mandatory. You may register by calling our office at (773) 702-7593 on or after August 20. No early registrations can be accepted. You need to have a risk factor for celiac disease and be on a regular, gluten-containing diet for at least 12 weeks prior to the screening.

ICDS 2013 – International Celiac Disease Symposium, September 22-25, 2013 For more information, please visit www.icds2013.org. You can sign up there for regular updates on the International Symposium.