University of Chicago
CELIAC
DISEASE PROGRAM™

Dx: CELIAC

THE NEWSLETTER OF THE UNIVERSITY OF CHICAGO CELIAC DISEASE PROGRAM

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OUR MISSION

The University of Chicago Celiac Disease Program seeks to improve the lives of celiac patients and to raise diagnosis rates by advancing research on celiac disease and increasing awareness among medical professionals and the general public.

DX: CELIAC

Dx is medical shorthand for diagnosis. When a medical professional makes this type of notation in a patient's medical chart, it means that he or she has been diagnosed with celiac disease—and we, the UCCDP, are a step closer to achieving our mission of raising diagnosis rates. Perhaps just as important, the newly diagnosed celiac patient—who has often suffered for years—is able to start the gluten-free diet and finally experience relief from debilitating symptoms.

FOR MORE INFORMATION ABOUT THE UCCDP, PLEASE CONTACT OUR PROGRAM OFFICE:

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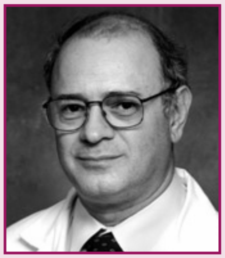
CELIAC DISEASE IN TYPE 1 DIABETICS:

CAREFUL USE OF SEROLOGIC TESTS ARE CRUCIAL

Stefano Guandalini, M.D., Director



Dr. Guandalini

The association between celiac disease and autoimmune conditions is well known. The strongest association is with type 1 diabetes. When these two diseases occur together, diabetes is usually the first to be diagnosed, 90 percent of the time. The high prevalence of celiac disease in type 1 diabetes has been documented in numerous studies over the past twenty years. Estimates from various parts of the world show that when patients with type 1 diabetes are screened for celiac disease shortly after their diabetes is diagnosed; approximately 8-10% of them have it. More recently, research has shown that when patients with type 1 diabetes who are negative at their initial screening for celiac disease are tested again in subsequent years, new celiacs are found, so that the prevalence of celiac disease in type 1 diabetics actually increases with time. As a result, it is now generally recommended that all type 1 diabetes patients be screened for celiac disease.

A recommendation to screen a particular population for celiac disease is not usually made unless there is evidence that patients may improve following the start of a gluten-free diet. Patients with type 1 diabetes have been found in studies to experience improvements in terms of symptoms, growth (in children), serum antibody levels, healing of the small intestinal mucosa and some level of control of diabetes.

There are, however, two areas of uncertainty: one is how often to rescreen patients who have tested negative for celiac disease initially, and the second and perhaps more important is to determine which tests to use and when to use them when screening a type 1 diabetic.

When to Screen Given the rate of new positive cases found in studies that have prospectively followed such patients, a reasonable conclusion would be to rescreen diabetic patients about every 3 years. In addition, as for Down syndrome patients or first-degree relatives, checking the HLA status (a genetic component of chromosome 6 where DQ2 and DQ8 are found) at the time of the initial screening would help to eliminate 60% of these patients. We know that about 40% of type 1 diabetics are DQ2-positive, which puts them at risk for developing celiac disease at some point in the future. But without the genetic HLA status for celiac disease, it is highly unlikely that a diabetic individual will develop the condition.

Continued on page 2

CELIAC DISEASE IN TYPE 1 DIABETICS

Continued from page 1

How to Screen The most sensitive test currently available to screen for celiac disease is the determination of the serum levels of the antibody anti-tissue transglutaminase (tTG). Its sensitivity is reported to be almost at 100%: in other words, the most likely explanation for a high tTG test in a person eating a diet with gluten is an autoimmune response commonly seen in celiac disease. Not surprisingly, this test is now universally recommended as "the" screening test. However, despite the efficacy of this test, a biopsy is still necessary to diagnose celiac disease.

There is a problem with using the tTG test to screen diabetic patients. It is widely believed that about 3 percent of diabetics have "falsely" elevated tTG levels. Thus, if we consider the average prevalence of "true" positive tests in type 1 diabetics (an average of 9 percent of patients in this population), it follows that one-third of type 1 diabetics testing positive for tTG do not have celiac disease. Patients with autoimmune thyroiditis and certain liver conditions face a similar situation.

Could another test be used instead? The classic anti-Endomysium antibody test (EMA) is generally regarded as somewhat less sensitive than tTG; but there is no doubt that its specificity is superior, and this holds also in presence of other autoimmune conditions, type 1 diabetes included. But it does cost more, however, and raises concerns about the use of primate tissue (EMA is measured in cells obtained from monkey esophagus).

A winning strategy for screening the type 1 diabetic is the following: Check diabetic patients first with a tTG and HLA gene test. Then if both genes are positive – before scheduling a biopsy with a gastroenterologist – do an EMA test. With a positive EMA test, the endocrinologist or gastroenterologist can be sure that a patient has a high enough probability of having celiac disease to refer and/or perform an endoscopic biopsy. Follow-up testing in type 1 diabetics found to have celiac disease should similiarly avoid relying solely on the tTG test, for the same reasons noted above.

OUR HEARTFELT THANKS TO A SPECIAL DOCTOR

In 2001, Brianna Wolin, now 10, was diagnosed with celiac disease. Her parents, Dr. Lawrence Wolin, an ophthalmologist in Arlington Heights, and his wife, Stacey, received a care package to help Brianna. Since then, the Wolin family has actively participated in many of our events, and has repeatedly donated gluten-free products to the Care Package Program. This year, Dr. Wolin made another donation as well. He is an expert in LASIK surgery, and decided to donate his services for one LASIK operation to the silent auction. His generosity, not to mention his professional skills, resulted in a $4,200 donation to the UCCDP. Brianna also participated in the silent auction, triumphing over several enthusiastic bidders for another unique item, a gluten-free potato clock. We greatly appreciate the Wolin family's generosity and their involvement and dedication to our cause. Thanks again!

Dr. Lawrence Wolin

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.

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NEW DIRECTORS AT THE HELM

Since its founding in 2001, the University of Chicago Celiac Disease Program (UCCDP) has been skillfully guided by Dr. Stefano Guandalini and a dedicated Advisory Board. For its first three years, the board has been led by Robin Steans, chair, Leonard Gail, vice chair, Mary Lassila, secretary and Mark Achler, treasurer.

New board officers (left to right) Brian Israel, Mary Lassila, Cessy Roth and Leonard Gail, with Dr. Guandalini, center.

At a recent advisory board meeting, a new slate of officers was unanimously elected. Mary Lassila, who has celiac disease, became the new board chair. She has been involved with UCCDP since the beginning, as board secretary as well as chair of the benefit committee. She works at the Harris Bank, where she is Vice President and Training Manager for the Residential Mortgage Division. Our new board treasurer, Brian Israel, is using skills that he honed in two decades as a mortgage banker, primarily at the Harris Bank as well, to streamline our program operations. Brian has wasted no time in his new position by creating some very useful spreadsheets and management tools for our organization.

Leonard Gail, who remains vice chair, is an attorney. He has three daughters, one with celiac disease, and was a cofounder of the program. Cessy Roth is the new secretary of the UCCDP advisory board. Cessy is an employee benefits attorney in Chicago, and the mother of three children. One of her sons has celiac disease. The University of Chicago Celiac Disease Program has benefited greatly from the leadership of its past board officers and looks forward to working with its newly elected leaders.

THE COMPLICATED QUESTION OF COMMUNION

The issue of communion for celiac Catholics has dominated the media's attention in recent weeks, and we've received many calls from celiacs wanting to know about the low-gluten host and if it is an option for them. While the need to follow a strict gluten-free diet and the desire to participate in communion with a low-gluten host may seem contradictory, they really are not. For those Catholic celiacs who follow a strict gluten-free diet, receive regular follow-up testing, and are not exquisitely sensitive to gluten, the low-gluten host may be appropriate with some additional guidance.

First, it is important to address what "low-gluten" really means, and which low-gluten host we are talking about. The low-gluten host that is approved by the Catholic Church is made by the Benedictine Sisters of Clyde, Missouri. They have been working for over a decade to create a host bread that has the smallest amount of gluten possible in order to be approved by the Catholic Church. (Whether or not this requirement should exist is not something that will be addressed here.)

The Sisters had the bread tested by food scientists, which found the level of gluten to be "undetectable." Another nun who is also a doctor of pharmacy tested it and determined that the host contains 37 micrograms of gluten. This is equivalent to 1⁄16 of a grain of rice.

Why should it be acceptable to consume such a small amount of gluten when every celiac has been taught to follow a 100% gluten-free diet? The answer lies in follow up testing and the clinical and research experience of experts around the world. Dr. Guandalini's view is that this infinitesimal amount of gluten would likely be destroyed by the digestive process before it reached the small intestine, and any remaining amount would not provoke an immune response. This perspective is based on scientific studies and experience with a low-gluten diet in Europe.

The standard gluten-free diet for European celiacs allows for a small amount of wheat starch. These diet guidelines have been in effect for over 30 years. A very important study by a leading Finnish researcher on low-dose wheat starch in a European gluten-free diet found that the diet containing the wheat starch was as good as a completely gluten-free diet in 54 patients. This study included intestinal biopsies to measure damage. The amount of gluten allowed per day for European standards is significantly higher than 37 micrograms.

The decision whether or not a person with celiac disease should participate in communion with a low-gluten host is based on that individual's current health (how well they follow the diet) and the comfort level of the person and their physician. If a decision is made to explore this possibility, these are the steps we recommend that the celiac take:

Continued on page 4

THE COMPLICATED QUESTION OF COMMUNION

Continued from page 3

1. See your doctor for follow-up blood testing (all celiacs should receive follow-up testing once a year). Establish with the tTG and the anti-gliadin IGG and anti-gliadin IGA testing that the levels of antibodies in your blood stream are well within the negative range. If not, consuming a low-gluten host is not an option until antibody levels are lowered.
2. If test results are good, discuss your desire to participate in communion with your doctor, and schedule a special follow up appointment for six months after you start using the low-gluten host.
3. Order the low-gluten host from the Benedictine Sisters (800-223-2772) and work with your local parish to receive the host during services. We would recommend using only a portion of the host (for instance, 1⁄4 of a host) for each Sunday service.
4. See your doctor for follow-up testing to determine if your antibody levels have changed. If they are higher, evaluate the amount of host received or discontinue using. If they are the same, the option exists to continue receiving the same amount, providing that your physician agrees. Return for testing in six months.

Call our program office if you have any questions: 773-702-7593.

WORD OF THE ANNUAL BENEFIT SPREAD LIKE WILDFIRE!

The 4th Annual Gourmet Gluten-Free Luncheon took place on April 17 at Wildfire Restaurant in Chicago. The event was a smashing success by just about every measure. Tickets sold out in advance, and dozens of people had to be turned away (note to self: reserve early next year!). The event netted over $38,000, to support our programs and services.

Wildfire's incredible spread...

The chefs at Wildfire outdid themselves with a gorgeous, gluten-free gourmet spread that featured Wildfire's signature chopped salad, cedar planked salmon, Roumanian skirt steak and pizza topped with fresh tomatoes, basil and three cheeses. The delectable appetizers and side dishes included chicken and Portobello mushroom skewers and wood-roasted asparagus. The desserts, including a decadent flourless chocolate cake and mouthwatering key lime pie, were scrumptious. A special thank you goes to the Gluten-Free Market in Buffalo Grove, IL, for donating the gluten-free pizza crusts and to Gluten-Free Delights in Cedar Rapids, IA, for donating the gluten-free graham cracker crusts for the pie.

For the first time, the event also included a silent auction, which proved to be very popular. The auction committee, spearheaded by Andrea Hosbein, worked tirelessly to come up with nearly a hundred items. The items ranged from a bread maker to a case of gluten-free beer from Ramapo Valley Brewery to a custom-made gluten-free birthday cake from Ched's Kitchen to tickets for great sporting and theater events. There were personal services such as massages and makeovers, lots of tours and gift certificates and some very unique artwork, including an oil painting by board member and professional artist Susan Bennett. The auction was a lot of fun, and bidding was fast and furious on many of the items, raising some $12,000.

Board member Dr. Mark DeMeo (right) enjoying conversation with Michelle and Randy Eaton from Kansas City

Many thanks to the hard-working benefit committee, chaired by Mary Lassila, and to Susan Blumenfeld, who was instrumental in bringing the event to Wildfire Restaurant. Thanks also to Wildfire and its staff, to the Gluten-Free Market for its sponsorship of the event, and finally, to all our guests and donors who supported the event and helped make it such an incredible success.

NEW FOOD LABELING LAW!

The American Celiac Task Force (ACTF) is pleased to announce that the president has signed the food labeling legislation that has been championed by organizations and individuals who care about the challenges that families face when shopping for food that is safe. The legislation will go into effect on January 1, 2006.

The University of Chicago Celiac Disease Program, a member of the ACTF, feels that the legislation offers a huge step forward in terms of clarifying the nature of the ingredients in food items. The labeling law will improve the lives of families in several ways, by:

1. Providing uniform guidelines, developed by the Food and Drug Administration, for companies who wish to claim that their food or vitamin product is gluten-free. These uniform guidelines will help to prevent the use of the term gluten-free when a product actually contains gluten.

2. Requiring food or vitamin manufacturers to declare the presence of wheat (and the other top allergens) in their products by requiring a declaration under the ingredients listing that says CONTAINS WHEAT. For the family shopping for gluten-free items, this simplifies the process because so many ingredients contain derivatives of wheat. Rye and barley are listed much more simply on a food label.

ANNUAL BLOOD SCREENING: OCTOBER 23

The UCCDP's fifth annual celiac blood screening will take place on Saturday, October 23, 2004, from 8 a.m. to 12 noon at the University of Chicago Hospitals. Last year nearly 400 people underwent screening for celiac disease. Many participants had close family members with celiac disease; others had celiac symptoms or other risk factors. Some drove as far as seven hours to get to Chicago for the screening, either because their doctors didn't want to do the tests themselves or their insurance wouldn't cover it.

The screening is free, but preregistration is required. To register, please call our office at (773) 702-7593. Registrants will be prescreened to determine their eligibility. Risk factors include:

- A close relative who has celiac disease;
- A related autoimmune disease, such as Type 1 diabetes or Hashimoto's Thyroiditis;
- Early onset osteoporosis or, for children, failure to thrive

The blood screening test is the tissue transglutaminase test. The test results will determine whether further testing for celiac disease is indicated at this time.

TAMING TEMPTATION: PRACTICAL STRATEGIES FOR MAINTAINING A 100% GLUTEN-FREE DIET

The Taming Temptation speaking tour has already visited six cities around the U.S. In the coming months, the presentation will go to the following areas:

Sept. 3:	York, Gettysburg and Harrisburg, PA.
Sept. 18:	Arkansas and Missouri Celiac Support Groups
Sept. 25:	Milwaukee Area Celiac Support Group
Oct. 2-3:	Erie and Pittsburgh, PA.
Oct. 6-9:	Dallas, Austin, San Antonio and Houston, TX
Oct. 10:	Indiana Gluten Intolerance Support Team, Lafayette
Nov. 6:	Richmond, VA
Nov. 13:	Madison Area Gluten Intolerance Group

We hope to see you there!

NEWS ABOUT OATS

We've recently learned that Quaker Oats, a company that we had previously recommended as having oats that were safe for celiacs, has changed its manufacturing standards. It now allows 1% wheat and 1% barley into its final oat product. We certainly find this disappointing, but have since learned that McCann's Irish Oatmeal is often recommended by experts in celiac disease across the U.S., and based on the experience of our colleagues, we feel comfortable suggesting the same.

Ultimately, it is up to the individual celiac to determine whether or not to include oats in his or her diet. We would encourage anyone who eats oats (or for that matter, every celiac following a gluten-free diet) to receive regular follow up testing to determine that their antibody levels are within a safe range. Without this information, celiacs cannot know if their food choices are safe for them. If you have questions about follow up testing, please feel free to call us at 773-702-7593.

COMPANIES WHO CARE: TINKYÁDA PASTA

Tinkyáda Pasta does one thing, and they do it very well. According to founder Allen Lau, Tinkyáda has many times been asked to expand its offerings beyond rice pasta, to include pasta made from corn or other grains. But Allen wants to be able to guarantee that Tinkyáda Pasta is pure rice, without any risk whatsoever of cross contamination, and so has refused to move beyond what he knows best.

But lest you should think that all rice pasta is the same, visit the Tinkyáda webpage (www.tinkyada.com). The webpage lists 18 different varieties of rice pasta. Five are certified organic, two are flavored with vegetables, one is from white rice, and the remaining varieties are all different shapes of brown rice pasta.

These 18 different varieties of pasta help Tinkyáda's parent company, Food Directions, fulfill its mission of giving joy to people who cannot consume wheat pasta. Food Directions has donated almost 500 bags of Tinkyáda pasta to the UCCDP Care Package Program, enough so that every care package contains one bag of Tinkyáda. The care packages also contain information on ordering Tinkyáda, which is made in Canada from rice grown in the U.S. Most major health food stores and many supermarkets carry Tinkyáda pasta. In the Chicago area, you can find Tinkyáda pasta at Whole Foods, Wild Oats, Jewel (Albertson's) and Sunset Foods, as well as the Gluten-Free Market in Buffalo Grove.

Food Directions is an outstanding company that has demonstrated an extraordinary commitment to people with celiac disease. Tinkyáda has a special place in our hearts as the first company to give so generously to our care package program.

SPECIAL GIVERS

The UCCDP is entirely supported through the generosity of its many donors from across the United States. We appreciate every donation, each financial contribution, every gift of gluten-free food for the Care Package Program and the precious time of our volunteers. In recent months, we have been most fortunate to receive the special generosity of several donors, all under the age of 13. The kids that donate to our program really do so from the heart. They could use their money for anything they wanted: the latest computer game or a movie or some other special treat. But these young people instead choose to show their generosity by saving their money and sending it to support the mission of the UCCDP.

Last fall, Lindsay Gordon celebrated her bat mitzvah, a coming-of-age ceremony for Jewish adolescents. The traditional gift on this occasion is money. In the true spirit of the Jewish tradition, Lindsay decided to donate two thirds of her gifts to philanthropic causes. Lindsay, who has celiac disease, presented us with a generous contribution of $700, to sponsor a UCCDP educational program for a support group. Lindsay and her mother, Debbie, will attend the "Taming Temptation" educational tour in Madison, WI, in November to see firsthand how her donation will be put to use.

Lindsay Gordon with her mother Debbie and Dr. Guandalini.

Evan Kasal, a 6th grader, also shows that philanthropic bent despite his young age. Evan came to the April luncheon at Wildfire, and gave a generous donation of his own savings to support testing for celiac disease for a family of four.

Brian and Hannah Rabinowitz show support for their cousin, Julie (center).

Our littlest contributors, Brian and Hannah Rabinowitz, are learning about philanthropy very early. Brian, 5, and Hannah, 3, are learning about the Jewish tradition of tsedaka (charity) as well. Each week they put aside money to be donated to a charitable cause that they choose. They are aware that their older cousin Julie, 9, has celiac disease. Wanting to do something to support her, they recently chose to make the UCCDP the lucky recipient of their tsedaka.

Lindsay, Evan, Brian and Hannah have all found creative and meaningful ways to support a cause they care about—and their parents are establishing a tradition of charitable giving early on. Their efforts will help another person find out that he or she has celiac disease and start on the road to recovery. Their gifts are truly from the heart.

COMPANIES WHO CARE: CHĒBĒ BREAD

After many years in the international food industry, Dick Reed decided that he needed a change. He had spent a lot of time in Brazil, both for business and pleasure, and had many times enjoyed the ubiquitous snack there called pão de queijo, or cheese bread. Dick, who had never even heard of celiac disease before he did a feasibility study on the potential market for gluten-free cheese bread, realized there was a substantial market for such a product, and launched his company.

Chēbē Bread (an abbreviation of cheese bread) is an all-natural gluten-free, dairy-free, yeast-free bread dough made with manioc flour, a very common tuber, or root, in South America. Since its founding in 1999, Chēbē Bread has taken the basic ingredients of cheese bread and created an entire manioc-based gluten-free product line of breads and doughs. Chēbē now offers all natural, gluten-free, preservative-free mixes for bread sticks, pizza crust and cinnamon rolls, as well as frozen dough. The cheese bread mix itself leaves the cheese out, to be added by the user, so that it can remain preservative-free.

Currently, Chēbē Bread products are available online (www.chebe.com), at the Gluten-Free Market in Buffalo Grove, IL, at some Wegman's markets in the Northeast, and at other online stores such as www.glutenfreemall.com. The company is looking for a larger distributor, and hopes to become available at chain health food stores around the country soon.

Dick Reed and Chēbē Bread have been long-time supporters of the UCCDP Care Package program. Every care package that goes out contains a Chēbē Bread mix in it, to introduce the recipient to this delicious gluten-free bread product. If you haven't tried Chēbē Bread yet, try it soon! You don't know what you're missing!

BRENDEN'S TELEVISION DEBUT

In April, Channel 7, a Chicago television station, featured the UCCDP in a 12-minute segment on *Healthbeat*, a weekly news magazine. The segment featured interviews with Dr. Guandalini and with Stacey Slomka, mother of Brenden, 2 ½, who has celiac disease. The segment provided information about the disease and the gluten-free diet. It also showed a confident Brenden climbing up on the exam table and asking Dr. Guandalini for a bandaid. He positively stole the show!

NATIONAL INSTITUTES OF HEALTH HOLDS CONSENSUS CONFERENCE ON CELIAC DISEASE

The National Institutes of Health (NIH) is a government agency which is charged with conducting medical research in a wide range of diseases and conditions, as well as to help set health policy on current and emerging issues in medicine. While the NIH is not the single largest funder of research in some diseases, NIH funding could make a significant difference in the number of researchers and the nature of scientific investigation in celiac disease. Yet, for the most part, the NIH and its related institutes have propagated the belief that celiac disease is very rare.

In the past several years, the NIH has come to realize that the commonly held beliefs about celiac disease in the agency and among the medical community seem not to be true. The watershed moment was the publication of the Prevalence of Celiac Disease in At Risk and Not At Risk Populations in the United States, in the Archives of Internal Medicine last year. This groundbreaking work, led by Dr. Alessio Fasano with coinvestigators from across the country (including our very own Dr. Stefano Guandalini), found that celiac disease affects 1 in 133 average Americans.

A consensus conference is held when the NIH has recognized that physicians and researchers are not working from the same information, and patients are being treated differently in some parts of the country than others. The purpose is to identify a panel of experts to review the most current scientific understanding on a given topic, and with the input of experts in the field, to write a consensus statement that informs physicians and researchers about every aspect of a disease, and the means for its detection, diagnosis, treatment and follow up.

Michelle Melin-Rogovin, program director for the University of Chicago Celiac Disease Program, was present for the entire conference, and we've developed a report on the proceedings, which were very exciting and meaningful. If you would like to receive a copy of this report, please call us at 773-702-7593 and we will mail it to you.

Companies Who Care: Savory Palate, Inc.

If you are on a gluten-free diet, Carol Fenster has probably made a difference in your life. Carol has been working with gluten-free food for nearly two decades. She became interested in gluten-free food in response to her own food intolerances, and in the years since, she has created thousands of recipes and created a cookbook called *Wheat-Free Recipes and Menus: Delicious Dining without Wheat or Gluten* (www.savorypalate.com), which has just been updated and published by Penguin. She has also written numerous articles promoting the gluten-free diet for people with celiac disease, and she creates new gluten-free products and recipes for Bob's Red Mill Natural Foods, Inc. and several other companies.

Carol has generously donated over a thousand cookbooks to the UCCDP for use in the Care Package program. For two years now, each newly diagnosed person with celiac disease has received one of Carol's invaluable cookbooks, full of familiar dishes made with gluten-free ingredients. Every family that attended Family Fun Day received one as well. The feedback we've received on the cookbooks has been enthusiastic and appreciative. One woman called to tell us that she had been reading and underlining in it, and was about to start trying recipes. Another wrote simply: "The cookbook was extremely helpful."

We express our deep appreciation to Carol for her outstanding dedication, and encourage celiacs and their families to check out all of her cookbooks for great gluten-free recipes, and to sign up for her online newsletter, on the Savory Palate website.

COMING UP ON OCT. 23: THE UCCDP CELIAC DISEASE SCREENING DAY! MORE INFORMATION INSIDE.

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