

impact



THE UNIVERSITY OF CHICAGO
CELIAC
DISEASE CENTER

IMPROVING LIVES THROUGH AWARENESS,
EDUCATION, AND RESEARCH

A Brief History of Celiac Disease

Long, long ago, man was a simple hunter/gatherer. His diet consisted of fruits, nuts, perhaps tubers and the occasional feast of meat. But eventually, he learned to cultivate plants, and the agricultural revolution began. Soon, the hunter/gatherer way of life was replaced by domestication of crops and animals.

As habits changed, some unanticipated problems arose. The human gut had developed, over more than 2 million years, into a sophisticated organ that could tolerate food antigens that were staples of the human diet over hundreds of thousands of years. But how would it react to new antigens, suddenly appearing in the diet? The agricultural revolution of the Neolithic period generated a whole battery of food antigens previously unknown to man, including protein from cow, goat, and donkey milk, as well as birds' eggs and cereals. Most individuals were able to adapt. Among those who could not, food intolerances appeared and celiac disease was born.

Some 8,000 years after its onset, celiac disease was identified and named. A clever Greek physician named Aretaeus of Cappadocia, living in the first century AD, wrote about "The Coeliac Affection." In fact, he named it "koiliakos" after the Greek word "koelia" (abdomen). His description: "If the stomach be irretentive of the food and if it pass through undigested and crude, and nothing ascends into the body, we call such persons coeliacs".

Another 17 centuries went by, and in the early 19th century a Dr. Mathew Baillie, probably unaware of Aretaeus, published his observations on a chronic diarrheal disorder of

adults causing malnutrition and characterized by a gas-distended abdomen. He even went on to suggest dietetic treatment, writing: "Some patients have appeared to derive considerable advantage from living almost entirely upon rice." Baillie's observations, however, went practically unnoticed, and it was for the English doctor Samuel Gee, a leading authority in pediatric diseases, to take full credit for the modern description of celiac disease some 75 years later, when he gave a lecture to medical students on the "celiac affection," the milestone description of this disorder in modern times.

Like Baillie, Gee sensed that "if the patient can be cured at all, it must be by means of diet." He added that "the allowance of farinaceous food must be small", and also described "a child who was fed upon a quart of the best Dutch mussels daily, threw wonderfully, but relapsed when the season for mussels was over; next season he could not be prevailed upon to take them." Thus he documents the improvement following the introduction of a gluten-free diet, and the relapse after reintroduction of gluten.

As the decades passed, there was still no clue as to what could be causing celiac disease and no hint (in spite of autopsies frequently performed given the high mortality rate) of



Dr. Stefano Guandalini, M.D.

the damage to the intestinal mucosa. Yet some of the present-day findings, which we tend to consider as recent advances, were indeed well known long ago, including that celiac disease could be present without diarrhea, the protective role of breast-feeding in the development and severity of celiac disease, only recently documented, and the increased incidence in families, particularly twins.

In the 1920s a new dietetic treatment erupted on the scene and for decades established itself as the cornerstone of therapy: the banana diet. In 1924 Sidney Haas described his successful treatment of eight children whom he had diagnosed with celiac disease. Based on his previous success in treating a case of anorexia with a banana diet, he elected to try to experiment with the same diet in these eight children who were also anorexic. He published ten cases, eight of them treated ("clinically cured") with the banana diet, whilst

>> continued on page 2



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Stefano Guandalini, M.D.

Founder and Medical Director

University of Chicago Comer Children's
Hospital Chief, Pediatric Gastroenterology,
Hepatology and Nutrition

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The University of Chicago Celiac Disease Center is dedicated to raising awareness rates and meeting the 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:

University of Chicago Celiac Disease Center
5839 S. Maryland Ave., MC 4069
Chicago, IL 60637-1470
Ph.: (773) 702-7593
Fax: (773) 702-0666
info@celiacdisease.net
www.celiacdisease.net

>> continued from page 1

the two untreated died. This paper encountered enormous success and for decades the banana diet enjoyed wide popularity. Indeed it benefited a large number of celiac children and probably prevented many deaths. The diet specifically excluded bread, crackers, potatoes and all cereals, and it's easy to argue that its success was based on the elimination of gluten-containing grains.

Haas was very proud of his insight that carbohydrates were the culprit and he was highly resistant to other viewpoints, no matter how well documented. Indeed, even as late as forty years later, well after Dicke, a Dutch pediatrician, had convincingly shown that wheat protein, not starch, was the only culprit, Haas still insisted that with his banana diet "all patients are cured by the specific carbohydrate diet, a cure which is permanent without relapse."

The breakthrough that Haas chose to downplay was to change forever our view of celiac disease. Dicke had noticed that during bread shortages in the Netherlands caused by World War II, children with celiac disease improved. He also saw that when Allied planes dropped bread into the Netherlands, they quickly deteriorated. A few years later, working with others, he produced a series of seminal papers, documenting for the first time the role that gluten from wheat and rye plays in celiac disease.

The next major breakthrough came in the mid-50s, when Margot Shiner described a new jejunal biopsy apparatus with which she successfully reached and biopsied the distal duodenum. This -- and the development of the less cumbersome capsule developed shortly after by the American Lieutenant Colonel Crosby -- finally allowed doctors to link the disease with a specific, recognizable pattern of damage to the proximal small intestinal mucosa.

Thus, at the dawn of the 60's we had three important elements: the knowledge that gluten is the triggering agent for celiac disease; the notion that there was a remarkable and easy identifiable mucosal lesion; and finally the availability of an instrument to obtain biopsies and begin to unravel the mystery of celiac disease pathogenesis (see below).

In the mid to late 60's, it had become clear that CD could be diagnosed with the jejunal biopsy showing atrophy of the villi. However, since that lesion could have other causes, the medical community urged doctors not to diagnose CD until it could be proven that gluten was indeed the cause of the mucosal atrophy. The steps were manifold: First, a

complete clinical remission on a gluten-free diet, followed by the documentation of the normalization of the lesion, and finally by its recurrence once gluten was reintroduced into the diet. These criteria were formalized in 1969 by a panel of experts in the newly born European Society for Pediatric Gastroenterology (today ESPGHAN) as the "Interlaken criteria" which for over 20 years served worldwide as the accepted diagnostic standard.

The Interlaken criteria, however, overlooked an important discovery made a few years earlier: that celiac children presented in their blood antibodies caused by the ingestion of gluten. The first category to be discovered were the anti-gliadin antibodies, detected and reported by Berger in 1964. Seven years later Seah et al. identified for the first time not an anti-food protein, but an actual auto-antibody in the serum of celiac children: the anti-reticulins, although it took however several years before their diagnostic utility was fully appreciated.

During the 1980's it became increasingly clear that CD could be associated with other conditions, mostly autoimmune disorders such as type 1 diabetes, but also some syndromes such as Down. It was also apparent that CD was changing patterns of presentation, becoming less an intestinal disorder, and more a variety of extra-intestinal symptoms and signs.

In the late 80's, a large multicenter Italian study that I conducted demonstrated that by relying on strict clinical and laboratoristic criteria, a correct diagnosis of CD could be reached in 95% of cases by limiting to the one initial biopsy, and new diagnostic guidelines were published in 1990 by ESPGHAN, guidelines that stand to this day.

After 1990, CD was increasingly accepted as an example of an autoimmune disease, associated with a specific gene (either DQ2 or DQ8) and the missing autoantigen was finally identified in the enzyme "tissue transglutaminase". At long last, there was universal acceptance that celiac disease is an autoimmune condition whose trigger (gluten) and autoantigen (tissue transglutaminase) are known.

What the future will bring is in the hands of the gods: we can be sure, however, that we won't have to wait 17 more centuries before the next earth-shaking discovery in celiac disease will be made. I'm confident the future is being prepared for us right now in the minds and hands of the many brilliant investigators passionately working in this field.

Memoirs of a Celiac: Benefit Luncheon at Ben Pao

Our 6th Annual Celiac Disease Center Benefit Luncheon, titled “Memoirs of a Celiac,” was a fabulous event. It was held at Ben Pao, a Chinese restaurant in downtown Chicago, owned by Lettuce Entertain You Restaurant Group, known for its early adoption of gluten free menus.

The luncheon featured wonderful food, a fun-filled raffle and silent auction and our first ever live auction, emceed by Chicago celebrity newscaster Joel Daly.

The day, which proved a success by every measure, was our biggest fundraising event yet. Nearly 300 people attended and all the funds raised will support the Celiac Center’s programming initiatives. This year we had a record number of corporate sponsors and donors to the event. That list includes:

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Goodsearch Names University of Chicago Celiac Disease Center as “Charity of the Day!”

Goodsearch.com is a search engine, powered by Yahoo, that donates approximately half of its revenue to designated charities. The University of Chicago Celiac Disease Center has been a designated charity for well over a year, and has received funding from Goodsearch. On June 28, Goodsearch.com designated the Celiac Center as “Charity of the Day,” with a link on its homepage for all to see.

If you use a search engine (and who doesn’t), take a minute to sign up for Goodsearch. It’s easy—just go to www.goodsearch.com and follow the instructions. Download the Goodsearch toolbar by clicking on the link, and add the University of Chicago Celiac Disease Center as your designated charity. Then, start searching! The Celiac Center will receive a donation for every search you run. It’s a simple way to show your support with no cost to you at all!

If you have further questions about Goodsearch, go to Goodsearch.com or call our office at (773) 702-7593.

WORK OFF POUNDS BY EXERCISING FOR CELIAC DISEASE

You can raise money for the University of Chicago Celiac Disease Center and get in shape at the same time. We’ll make it easy for you. Just sign up for a walk, run, swim, race or any other athletic event in your community. Give us a call and we can mail you a pledge kit, with a sample request letter, pledge sheet, and sample thank you note, and tee shirt to wear the day of the event. When you’re done, send in the pledge money you raised, along with the pledge sheet with everyone’s name and address, so that we can thank everyone individually.

If you are a solo exerciser, you can set up your own personal goal, and ask your friends, family and coworkers to support you in it. We’ve had runners, bikers and tri-athletes who have run or ridden up to 2,000 miles in the course of a summer, to raise money to support our programs. So get moving! Call us at (773) 702-7593 or check out “Going the Distance” on our website, www.celiacdisease.net to learn more or to get your pledge kit.

New Leadership

Last February, the Celiac Disease Center welcomed its new Executive Director, Carol McCarthy Shilson. Carol, who has celiac disease, comes to the Celiac Center from the publishing world.

She served as the Senior Vice President and General Manager of Imagination Publishing, the Midwest's largest custom publishing firm, for the last seven years. Prior to that, she was with *Chicago Magazine*, where she developed their public relations department. Previously, Carol served as deputy press secretary to the Lieutenant Governor of Illinois. Additionally, Carol has been active in the nonprofit sector, serving on many boards. If you'd like to talk to her about a particular issue or just to introduce yourself, call our office at (773) 702-7593 or email her at: info@celiacdisease.net.

One of our first orders of business under the new leadership was our name change. We will henceforth be known as The University of Chicago Celiac Disease Center. The Celiac Center is leading the nation in awareness, education, patient care and research. In addition

to our many successful programs we now boast a diverse network of doctors and specialists at the University who collaborate for comprehensive diagnosis and care. They include:

David P. Cohen, M.D.
Associate Professor of Obstetrics/Gynecology
Chief, Reproductive Endocrinology and Infertility

John Hart, M.D.
Professor of Pathology

Rebecca Lipton, M.D.
Associate Professor of Endocrinology
Community Health Sciences, The Institute for Molecular
Pediatric Sciences

Nancy McGreal, M.D.
Gastroenterology Fellow

Vesna Petronic-Rosic, M.D., MSc
Assistant Professor and Clinic Director
University of Chicago Section of Dermatology

Louis H. Philipson, M.D., Ph.D.
Professor of Medicine
Division of Endocrinology, Diabetes and Metabolism

Raymond P. Roos, M.D.
Marjorie and Robert E. Straus Professor in Neurological
Science Department of Neurology

David Rubin, M.D.
Assistant Professor of Medicine
Department of Medicine, Division of Gastroenterology
Program Director, Fellowship in Gastroenterology, Hepatology,
and Nutrition

Mala Setty, M.D.
Instructor Pediatric Gastroenterology, Hepatology and
Nutrition

Peter Joseph Smith, M.D.
Assistant Professor of Pediatrics
Developmental and Behavioral Pediatrics

Darrel Waggoner, M.D.
Assistant Professor of Human Genetics and Pediatrics
Medical Director, Department of Human Genetics

We hope our new, integrated approach to celiac disease will serve as a model for other Centers across the nation.

SPONSOR A CARE PACKAGE!

Remember how much it meant to you when you got a care package from the Celiac Center when you were first diagnosed? How your child's face lit up when he opened his box and saw what was inside? Would you like to bring that same relief and joy to someone else? You can, simply by becoming a Care Package Sponsor. Just clip the coupon below, and send in to our office with your payment. Or donate directly on our website.



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Please mail your payment to: University of Chicago Celiac Disease Center, 5839 S. Maryland Ave., MC 4069, Chicago, IL 60637-1470 The cost of a sponsorship is \$250. If you want to sponsor this Care Package in someone's honor, please send the name and address so that we can send an acknowledgement.

Celiac Blood Screening

Mark your calendar: On October 6, 2007, The University of Chicago Celiac Disease Center will hold its annual Blood Screening, sponsored by Prometheus Laboratories. During the event, we will also have a panel of experts speaking on celiac disease, and you'll have an opportunity to ask your questions of them.

Both events are free, and will take place in the Center for Advanced Medicine at the University of Chicago Medical Center. The screening is open to anyone who has a risk factor for celiac disease, either a close relative with celiac disease, a related condition such as type 1 diabetes, or symptoms. Note: Preregistration for the screening is required. **You must call our office at (773) 702-7593 to register.** Registration opens on August 15. In the meantime, check our website for more information on these two events.