



FROM THE NATIONAL DIGESTIVE DISEASES INFORMATION CLEARINGHOUSE

Celiac Disease Awareness Campaign • [www.celiac.nih.gov](http://www.celiac.nih.gov)

A service of the National Institute of Diabetes and Digestive and Kidney Diseases, NIH

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## Making "Back to School" Healthy and Gluten Free for Children with Celiac Disease

**F**or families of children with celiac disease, the excitement of a new school year can be tempered by uncertainty. Parents, health care providers, and school staff all play important roles in the planning—and team approach—needed to ensure children stay healthy and gluten free at school.

Physicians can provide valuable advice and guidance to school staff members who may be unfamiliar with celiac disease. A letter or phone call from a physician to the school principal or nurse can explain what celiac disease is and discuss a child's special dietary needs. Physicians also can encourage families to make regular follow-up appointments during the school year to help parents make sure children are maintaining gluten-free diets and staying healthy. More information about how health care providers can help is available at [www.celiac.nih.gov/BacktoSchool.aspx](http://www.celiac.nih.gov/BacktoSchool.aspx).



Parents can also work with important school personnel—classroom teachers, the principal, the school nurse, and the cafeteria manager—to ensure that requisite staff are aware of the student's needs. Although in-person visits may not be possible during the hectic first weeks of school year planning, letters or prepared notes can explain the important steps in maintaining a gluten-free school environment. Celiac support

groups provide sample letters that parents can give to teachers, principals, and other key school staff members. Sample letters and other back-to-school resources are available at [www.csaceliacs.org/CelKidsSchool.php](http://www.csaceliacs.org/CelKidsSchool.php), [www.csaceliacs.org/SchoolMaterial/Principal.php](http://www.csaceliacs.org/SchoolMaterial/Principal.php), [www.celiac.org/kidskerner.php](http://www.celiac.org/kidskerner.php), and [www.gluten.net/publications.php](http://www.gluten.net/publications.php).

School personnel need to be made aware that "gluten free" is not limited to cafeteria meals or classroom snacks; gluten is also found in nonfood items including popular brands of clay, crayons, pastes, and paints. A discussion of school activities that may expose a child to gluten is at [www.gluten.net/downloads/print/studentflat.pdf](http://www.gluten.net/downloads/print/studentflat.pdf). ■

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## Research Finds Celiac Disease Is Four Times More Common Now than 50 Years Ago

Research supported by grants from the National Institute of Diabetes and Digestive and Kidney Diseases shows celiac disease (CD) is nearly four times more common now than it was in the 1950s. Moreover, people who had undiagnosed CD in the 1950s were four times as likely to have died during the following 45 years as were people without CD, according to principal investigator Joseph Murray, M.D., of the Mayo Clinic in Rochester, MN.



“Undiagnosed celiac disease may have a significant impact on survival. And this is a common enough disorder that this could be a significant public health issue.”

**Joseph Murray, M.D.**  
Mayo Clinic, Rochester, MN

The research findings, which were published in the July 2009 issue of *Gastroenterology*, have two major implications, Murray said. “First, celiac disease has become much more common than it was and we don’t know why that is. Second, the results suggest that undiagnosed celiac disease may have a significant impact on survival. And this is a common enough disorder that this could be a significant public health issue.”

Murray and his colleagues looked for CD-related antibodies in blood samples collected between 1948 and 1954 from 9,133 healthy young adults—nearly all male, with an average age of 20.5 years—at Warren Air Force Base in Wyoming. The researchers also looked at blood samples collected from two present-day

groups who had not been diagnosed with CD: one group of 5,558 men older than age 50 and another group of 7,210 younger men with an average age of 37.

Among the Air Force cohort, roughly 1 in 700—0.2 percent—had levels of CD-related antibodies high enough to constitute a diagnosis of CD. In the present-day groups, the prevalence of undiagnosed CD was at least four times as high—0.8 percent among those older than age 50 and 0.9 percent among the younger cohort.

The researchers also evaluated mortality among the Air Force cohort and found that those with

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### CELIAC DISEASE News



*Celiac Disease News*, an email newsletter, is sent to subscribers by the National Digestive Diseases Information Clearinghouse (NDDIC). The newsletter features news about celiac disease, special events, patient and professional meetings, and new publications available from the NDDIC and other organizations.

If you would like to subscribe, send an email to [celiac@info.niddk.nih.gov](mailto:celiac@info.niddk.nih.gov). Please visit [www.celiac.nih.gov/Newsletter.aspx](http://www.celiac.nih.gov/Newsletter.aspx) to read or download a PDF version of the newsletter.

To meet the need for comprehensive and current information about celiac disease, the NDDIC, a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), launched the Celiac Disease Awareness Campaign. The Awareness Campaign is the result of the

combined ideas and efforts of the professional and voluntary organizations that focus on celiac disease, along with the NIDDK, the National Institutes of Health, and the Centers for Disease Control and Prevention.

Visit [www.celiac.nih.gov](http://www.celiac.nih.gov) to learn more about the Awareness Campaign.

**Executive Editor: Stephen P. James, M.D.**

Dr. James is the director of the Division of Digestive Diseases and Nutrition within the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). As director, Dr. James oversees planning, implementation, and evaluation of a national research effort focused on gastrointestinal, pancreatic, hepatobiliary, and nutrition diseases and conditions. Before joining the NIDDK in 2001, Dr. James directed the division of gastroenterology at the University of Maryland’s School of Medicine for 10 years.



## Small Business Grant Will Enable Researchers to Pursue Celiac Disease Treatments

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has awarded a Small Business Technology Transfer Research (STTR) grant, titled “Drug Engineering of Transglutaminase 2 Inhibitors,” to fund a collaboration between Chaitan Khosla, Ph.D., a Stanford University biochemical engineer, and Numerate, Inc., a California-based biotechnology company.

“Our results create a foundation for dissecting the process by which the autoantibody response to TG2 is induced in celiac disease patients.”

**Chaitan Khosla, Ph.D.**  
Biochemical Engineer,  
Stanford University

Transglutaminase 2 (TG2) is an enzyme that plays a key role in the biological process that causes gluten to trigger an immune response that damages the lining of the small intestine in people with celiac disease. The collaboration is an extension of Khosla’s research, which focuses on TG2 and celiac disease. Using techniques that allowed him see to the physical structure of TG2, Khosla found that the flexible molecule undergoes a substantial rearrangement in the early stages of the gluten-induced immune response.

“Very few proteins have been observed to undergo this type of large-scale transformation,” Khosla said. “Our results create a foundation for dissecting the process by which the autoantibody

response to TG2 is induced in celiac disease patients.”

Khosla’s work makes it possible to see the TG2 structure on the scale of individual atoms. Numerate will use that structural information to develop candidate “inhibitors”—molecules that bind to specific TG2 sites and block the chain of biological events that leads to immune system damage to the intestine.

The NIDDK STTR program allows a small business to partner with a research institution on projects that will lead to a commercial product. More information about the program and other funding opportunities is available at [www2.nidk.nih.gov/Funding](http://www2.nidk.nih.gov/Funding). ■



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undiagnosed CD were nearly four times as likely to have died by 1997 as those without CD.

Reasons for the increased prevalence of CD are not clear, Murray said, but a change in inherited predisposition is not likely. “Human genetic changes in response to environmental challenges are extremely slow,” Murray said. “The most likely explanation may be environmental, such as a change in the quantity, quality, or processing of cereal.”

Whatever its cause, the increase in prevalence of CD—and the increased mortality among people with undiagnosed CD—might justify a change in approach to diagnosis of the disease, Murray said. “Our finding suggests that CD is emerging as a substantial public health concern in the United States. Maybe our strategy ought to be looking for celiac disease in the general population like we do for problems with cholesterol or blood pressure.” ■

## Study Finds Diagnosis of Celiac Disease Associated with Lower Health Care Costs

In a study published in the December 2008 issue of the *Journal of Insurance Medicine*, researchers from Columbia University and CIGNA HealthCare report that diagnosis of celiac disease substantially reduces subsequent health care costs. The research group, led by Peter Green, M.D., at Columbia, looked at medical records for 10.2 million CIGNA managed care members and identified four study cohorts:

- patients with a primary or secondary diagnosis of celiac disease—that is, patients identified with ICD-9 code 579.0, which includes celiac crisis, gluten enteropathy, nontropical sprue, and a few other conditions associated with malabsorption—made in 2000
- patients reporting one primary symptom of celiac disease but not diagnosed with celiac disease during 2000
- patients with two celiac disease symptoms but no diagnosis
- patients with three or more celiac disease symptoms but no diagnosis

The two main findings over the study period were the following:

- The rate of celiac disease diagnosis increased annually during the 4-year study period. Rates of new diagnosis more than doubled

over the study period, with rates among women and older adults rising faster than those among men and younger patients.

- Compared with undiagnosed patients with symptoms, those patients diagnosed with celiac disease had lower subsequent medical costs and service utilization rates. The researchers compared annual cost of health care utilization over 12-, 24-, and 36-month periods among the four groups. Those diagnosed with celiac disease had substantially lower health care costs during each follow-up period. Relative economies were greatest when comparing diagnosed patients with those having the greatest number of primary symptoms but no diagnosis. ■



## Researchers Find Irritable Bowel Syndrome Associated with Increased Likelihood of Celiac Disease

Celiac disease is four times as likely in patients diagnosed with irritable bowel syndrome (IBS) as it is in people without IBS, according to a report in the April 13, 2009, issue of the *Archives of Internal Medicine*.

Celiac disease is four times as likely in patients diagnosed with irritable bowel syndrome (IBS) as it is in people without IBS.

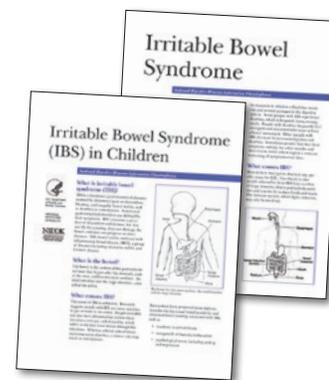
A group of investigators headed by Alexander Ford, M.D., at the Health Sciences Centre, McMaster University, Hamilton, Ontario, Canada, searched databases containing studies published from 1950 through mid-2008 and identified 14 studies that involved patients diagnosed with IBS, tests for antibodies associated with celiac disease, and biopsy-confirmed celiac disease. The studies were then evaluated through meta-analysis—a statistical approach that analyzes a single set of pooled data from numerous small studies designed to investigate similar hypotheses. In this case, the researchers assessed the likelihood of biopsy-proven celiac disease or positive findings for celiac antibodies—antigliadin antibodies, or either endomysial or tissue transglutaminase antibodies—in patients diagnosed with IBS.

The research group included investigators from McMaster University; the University of Michigan, Ann Arbor; the Mayo Clinic Florida in Jacksonville; the Mayo Clinic Rochester in Minnesota; and the UCLA School of Medicine.

The studies included 4,204 people, of whom 2,278—or 54 percent—met diagnostic criteria for IBS. Analysis showed that prevalence

of celiac disease in IBS patients was 4.1 times the prevalence in patients without IBS. Positive anti-gliadin antibodies were 4 times as likely and positive endomysial or tissue transglutaminase antibodies were 1.6 times as likely in IBS patients as in those without IBS.

The National Institute of Diabetes and Digestive and Kidney Diseases has fact sheets and easy-to-read booklets about celiac disease and IBS at [www.digestive.niddk.nih.gov/ddiseases/a-z.asp](http://www.digestive.niddk.nih.gov/ddiseases/a-z.asp). ■



## Germino Appointed NIDDK Deputy Director



National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Director Griffin P. Rodgers, M.D., M.A.C.P., announced the appointment of Gregory G. Germino, M.D., as the NIDDK's deputy director. Germino came to the NIDDK from The Johns Hopkins University School of Medicine, where he held dual appointments in the Division of Nephrology and the Department of Molecular Biology and Genetics.

In addition to his world-class scientific expertise and perspective as a National Institutes of Health (NIH) grantee, Germino's management experience, commitment to mentoring the next generation of researchers, and work with professional and patient advocacy organizations makes him especially well suited to help the NIDDK advance research on many of the most serious health issues affecting the public.

Germino identified *PKD1*, the primary gene involved in autosomal dominant polycystic kidney disease. He also developed novel methods for detecting altered genes and for characterizing the *PKD1* protein and its role in cell signaling pathways and cell-cycle regulation.

After graduating *summa cum laude* in biology from Loyola University of Chicago, Germino earned his medical degree from the Pritzker School of Medicine at the University of Chicago. He served his internship and residency in internal medicine and completed a clinical fellowship in nephrology at Yale University before spending a research year at Oxford University in England.

Germino has been an NIH grantee since 1994. He has written more than 70 peer-reviewed publications and has authored more than a dozen book chapters. He has been a visiting professor and invited lecturer across the United States and around the world. ■

## Kranzfelder Appointed Director of NIDDK Office of Communications and Public Liaison



Kathy Kranzfelder has been named director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Office of Communications and Public Liaison (OCPL). As director, Kranzfelder will serve as a member of the NIDDK's senior leadership team and provide advice and guidance on external communications to the NIDDK director and the Institute.

Kranzfelder came to the NIDDK to cover "intramural," or on-campus, basic and clinical research from a similar post at the National Institute of Neurological Disorders and Stroke. In 1993, she was named director of the NIDDK's national health information clearinghouses and in 1994, she launched the NIDDK's website—one of the first Institute websites at the National Institutes of Health.

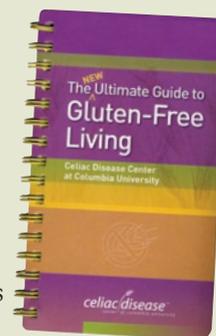
As OCPL director, Kranzfelder will oversee staff managing the NIDDK's response to the media, its online health information for the public,

and its other award-winning national education and information programs, which include the National Diabetes Education Program, the National Kidney Disease Education Program, and the Weight-control Information Network. In addition, she will continue to serve as director of the NIDDK's three national information clearinghouses until a successor is found.

To learn more about the NIDDK Information Clearinghouses, visit [www.niddk.nih.gov](http://www.niddk.nih.gov). ■

## Featured in the NIDDK Reference Collection

*The New Ultimate Guide to Gluten-Free Living* is a pocket-sized guidebook designed to help people with celiac disease follow a gluten-free diet with ease and confidence. The guidebook includes seven sections: living gluten-free; getting started, including how to avoid contamination in the home kitchen; grocery shopping; restaurant guidelines; travel tips; a glossary of grains; and religious observances. Each section features a brief introduction, lists and charts of practical suggestions, recommended food items, and pitfalls to avoid. The guidebook, printed on heavy-duty laminated stock and spiral bound, is designed to go anywhere for immediate reference. Short sections throughout the book allow readers to make notes and individualize the information. A final section describes the mission and activities of the Celiac Disease Center at the Department of Medicine at Columbia University.



*The New Ultimate Guide to Gluten-Free Living* is available for \$20 from Columbia University Medical Center, Harkness Pavilion, 180 Fort Washington Avenue, Suite 934, New York, NY 10032, [celiac@columbia.edu](mailto:celiac@columbia.edu), [www.celiacdiseasecenter.org](http://www.celiacdiseasecenter.org).

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Reference Collection is a free, online database that helps health care professionals, health educators, patients, and the general public find educational materials not typically referenced in most databases. The NIDDK does not control or endorse the information contained in this collection; the information is provided as a convenience to our visitors. ■

## Additional Resources

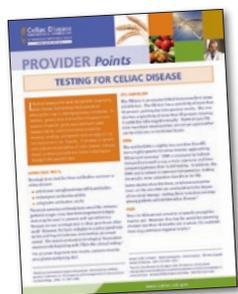
### Provider Points Fact Sheet about Testing for Celiac Disease Now Available

*Testing for Celiac Disease*—the second in the National Institutes of Health Celiac Disease Awareness Campaign's new Provider Points Series—is now available for download at [www.celiac.nih.gov](http://www.celiac.nih.gov).

This concise fact sheet summarizes available serologic and genetic tests used to evaluate patients who may be candidates for biopsy, the gold standard for celiac disease diagnosis.

The first Provider Points fact sheet provided information about dermatitis herpetiformis, a blistering skin rash associated with celiac disease.

The Provider Points Series is designed to aid primary care physicians in recognizing the symptoms and complications of celiac disease. Most health care professionals must choose among multiple sources of information to keep up to date about the myriad conditions they see in their practices. The series allows health care providers to access essential information in a concise and practical format. Additional planned topics in the Provider Points Series include celiac disease in children and the relationship of celiac disease to other autoimmune disorders.



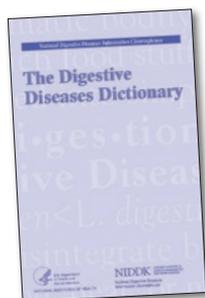
### Newly Revised

#### *The Digestive Diseases Dictionary*

Expanded and revised, *The Digestive Diseases Dictionary* defines more than 400 terms and includes a pronunciation guide and illustrations that help explain dictionary entries. *The Digestive Diseases Dictionary* is available from the

National Institute of Diabetes and Digestive and Kidney Diseases at [www.digestive.niddk.nih.gov/ddiseases/a-z.asp](http://www.digestive.niddk.nih.gov/ddiseases/a-z.asp).

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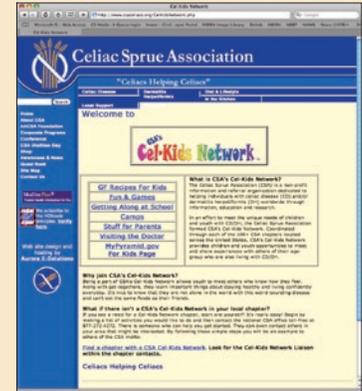


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## Featured Website

### CSA's Cel-Kids Network

The Cel-Kids Network, a program developed by the Celiac Sprue Association (CSA), provides children and youth with celiac disease opportunities to meet and interact with other children who have the condition. Cel-Kids activities are coordinated through more than 100 CSA chapters in the United States. Among other resources, the Cel-Kids Network website provides children and adults—parents, teachers, and school staff—with information and support materials to help ensure a healthy and gluten-free environment at school. See [www.csaceliacs.org/CelKidsNetwork.php](http://www.csaceliacs.org/CelKidsNetwork.php). ■



## Upcoming Meetings, Workshops, and Conferences

The National Institute of Diabetes and Digestive and Kidney Diseases Information Clearinghouses will be exhibiting or displaying materials at the following upcoming events:

### American Association of Diabetes Educators 36th Annual Meeting

August 5–8 in Atlanta.  
For more information, go to [www.diabeteseducator.org](http://www.diabeteseducator.org).

### American Dental Association 150th Annual Session (Celiac Disease Awareness Campaign exhibit only)

September 30–October 4 in Honolulu.  
For more information, go to [www.ada.org/ada/150th](http://www.ada.org/ada/150th).

### American Academy of Family Physicians 2009 Scientific Assembly

October 14–17 in Boston.  
For more information, go to [www.aafp.org](http://www.aafp.org).

### American Dietetic Association's Food and Nutrition Conference and Expo

October 17–20 in Denver.  
For more information, go to [www.eatright.org](http://www.eatright.org).

### American Academy of Pediatrics National Conference and Exposition

October 17–20 in Washington, D.C.  
For more information, go to [www.aapexperience.org](http://www.aapexperience.org).

## Celiac Disease—Broadening Horizons

The American Gastroenterological Association Institute will host a 2-day conference focusing on celiac disease September 11–12, 2009, at the Fairmont Chicago Millennium Park Hotel. The conference will examine the basic science behind the latest clinical advances in the diagnosis, management, and treatment of celiac disease. Future options for treatment will also be discussed. More information is available at [www.gastro.org](http://www.gastro.org). ■