

Celiac Disease News



Celiac Disease Awareness Campaign • www.celiac.nih.gov

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

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Celiac Disease and Reproductive Problems

Infertility, recurrent spontaneous abortion, and preterm delivery are among the reproductive problems that can affect women with celiac disease. Men with celiac disease can experience reduced fertility and sexual dysfunction. Read a feature article about celiac disease and reproductive problems at www.celiac.nih.gov/ReproductiveProblems.aspx. ■



NIH-supported Researcher Developing Celiac-safe Wheat Varieties

The National Institutes of Health (NIH) has awarded a 4-year, \$837,000 grant to Washington State University researcher Diter von Wettstein, Ph.D., D.Sc., to further his work on developing wheat varieties that people with celiac disease can safely eat.

Von Wettstein and his research team have discovered a mutant form of barley—another grain that people with celiac disease must avoid—that lacks gliadin-type proteins. Gliadin is the component of gluten that triggers the abnormal immune reaction of celiac disease. The discovery paves the way for development of gliadin-free wheat varieties.

In support of its research, the Washington State University team is partnering with the biotech company Arcadia Biosciences to identify specific gene mutations that affect gliadin-type proteins.

For more information about celiac disease research, visit www.celiac.nih.gov/research.aspx. ■

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NIDDK
NATIONAL INSTITUTE OF
DIABETES AND DIGESTIVE
AND KIDNEY DISEASES

Seven New Gene Regions Implicated in Celiac Disease

An international team of researchers has discovered seven additional gene regions that increase the risk for celiac disease, bringing the total number of known risk regions to nine. Four of the risk regions—*HLA-DQ*, *IL2-IL21*, *CCR3*, and *SH2B3*—are also implicated in the development of type 1 diabetes.

The team, led by David van Heel, B.M., B.Ch., D.Phil., M.R.C.P., of Barts and The London School of Medicine and Dentistry, built on its 2007 genome-wide association study that uncovered the second-known celiac risk region. The researchers studied more than 1,000 genetic markers in 1,600 people with celiac disease and 3,400 controls. Of the seven newly identified risk regions, six harbor genes that control immune responses.

“So far our findings explain nearly half of the heritability of celiac disease,” said van Heel. “Now studies with many more samples from individuals with celiac disease are needed to identify the precise causal genetic variants from each region and understand how these influence biological processes.”

Results of the study were published in the April 2008 issue of *Nature Genetics*. ■



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. Please visit www.celiac.nih.gov/News.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 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.



NIDDK Awareness and Prevention Series Wins NIH Plain Language Award

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) received recognition in this year's National Institutes of Health (NIH) Plain Language Awards Competition.

The NIDDK Awareness and Prevention Series, which includes a publication about celiac disease titled *Celiac Disease: What You Need to Know*, was honored with a gold award. An awards ceremony was held at the NIH campus in Bethesda, MD, on April 15.

The series, created for health fairs and similar events, presents brief overviews in English and Spanish of common health problems in a colorful, two-page format. Designed for people not yet diagnosed with diabetes or digestive, kidney, or urologic disorders, the handouts encourage readers to seek further information from the NIDDK or their health care provider.

The NIH created the Plain Language Awards to promote the NIH Plain Language Initiative, established in response to a 1998 White House memorandum calling for all Federal Government writing to be in an easy-to-read format.



Celiac Disease: What You Need to Know can be downloaded or ordered through the Celiac Disease Awareness Campaign website at www.celiac.nih.gov/Materials.aspx. ■

Upcoming Meetings, Workshops, and Conferences

Awareness Campaign Exhibits

The Celiac Disease Awareness Campaign exhibited at Digestive Disease Week in San Diego from May 18 to 22. About 300 conference attendees visited the exhibit booth to ask questions about the Awareness Campaign and pick up educational materials and promotional items.

The Awareness Campaign will have materials available at upcoming conferences:

American College of Gastroenterology Scientific Meeting

October 3–8 in Orlando, FL. For more information, go to www.acg.gi.org/acgmeetings.

31st Annual Celiac Sprue Association Conference

October 17–19 in La Vista, NE. For more information, go to www.csaceliacs.org/Conferences/2008AnnualCSAConference.php.

American Dietetic Association Food and Nutrition Conference and Expo

October 25–28, Chicago. For more information, go to www.eatright.org/cps/rde/xchg/ada/hs.xsl/7539_ENU_HTML.htm. ■

NDDIC Hosts Digestive Diseases Coordinating Panel Meeting

The National Institute of Diabetes and Digestive and Kidney Diseases' National Digestive Diseases Information Clearinghouse (NDDIC) convened a meeting of the Digestive Diseases Coordinating Panel on June 11 on the National Institutes of Health campus in Bethesda, MD. Panel members, who represent professional and voluntary organizations concerned with digestive diseases, come together annually to learn about Clearinghouse programs, provide guidance for upcoming projects, and share news about their organizations' activities. Along with the Clearinghouse, several groups concerned with celiac disease education and advocacy presented highlights of their work.

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Kathy Kranzfelder, NDDIC director, noted that the Celiac Disease Awareness Campaign will be 2 years old in July and highlighted the campaign's publications for consumers and professionals. The fact sheet *Celiac Disease* and the easy-to-read booklet *What I need to know about Celiac Disease* are among the Clearinghouse's most popular products.

The gluten-free diet is a new "hot topic" on the American Dietetic Association (ADA) website, said Jennifer Weber, manager of policy initiatives and advocacy for the ADA. The topic is available at www.eatright.org/cps/rde/xchg/ada/hs.xsl/nutrition_16994_ENU_HTML.htm. The ADA's Evidence Analysis Library® for members and library subscribers includes a Gluten Intolerance/Celiac Disease and Nutrition project that studies what constitutes a gluten-free diet and analyzes the evidence about its effectiveness in combating complications of celiac disease.

Alice Bast, executive director of the National Foundation for Celiac Awareness (NFCA), reported on the NFCA's public awareness campaign, which features the *Do I Have Celiac?* brochure and an online symptom checklist that visitors can complete, print out, and take to their doctor. The campaign has also released public service announcements and a podcast called "Appetite for Awareness." Among its other

activities, the NFCA is conducting a physician awareness program and a continuing pharmacy education program to help pharmacists address patient questions about gluten in medications.

The Celiac Disease Foundation (CDF) is also undertaking a physician awareness campaign titled "Is Your Patient the One?" said Elaine Monarch, CDF founder and executive director. As part of the campaign, the CDF disseminates brochures to internists, family practitioners, and osteopaths, and in 2007, the foundation ran a monthly full-page ad in the journal *Practical Gastroenterology*. The CDF is also working to secure insurance reimbursement for dietitians who counsel patients with celiac disease and sponsoring events that raise money for scholarships to send children with celiac disease to gluten-free camps.

The Celiac Sprue Association (CSA) promotes two key messages, reported Mary Schluckebier, CSA executive director: the gluten-free diet is a medical necessity and diagnosis before starting a gluten-free diet is crucial. The CSA connects newly diagnosed people with local health care professionals, provides thank-you notes for people with celiac disease to give to restaurants offering gluten-free options, and supports research through its Peer Review Research Grant program, among other activities. ■

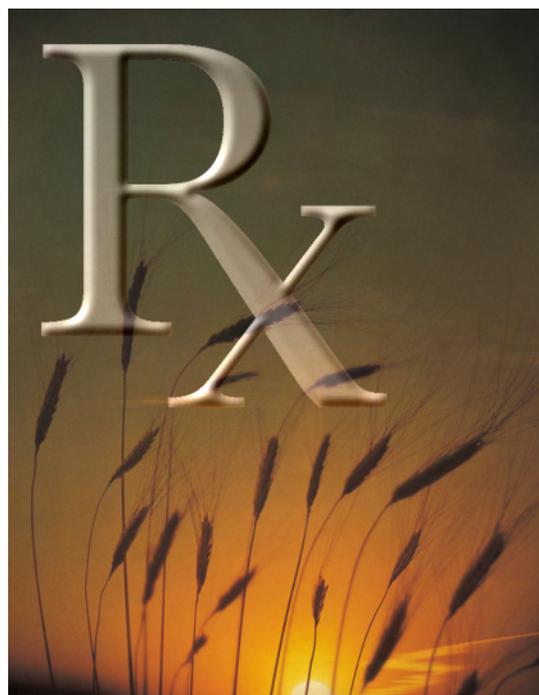
National Foundation for Celiac Awareness Hosts Gluten in Medications Educational Session

The National Foundation for Celiac Awareness (NFCA) and the American Society of Health-System Pharmacists (ASHP) hosted an educational session and stakeholders meeting about gluten in medications on April 11 in Bethesda, MD. Pharmacists, pharmaceutical company representatives, and people with celiac disease attended the session.

Speakers identified many nonfood sources of gluten that people with celiac disease must consider—drugs, vitamins, nutritional supplements, and cosmetics and health and beauty aids. Inactive ingredients in these products, such as binders, suspending agents, and thickening agents, may contain gluten. In reading product labels, people with celiac disease should be suspicious of “starch” whose source is not specified, “natural ingredients,” “flavors,” and “fragrance.”

Starch is a common excipient—a substance that provides suitable size or consistency—in medications, but most labels that include starch don’t include its botanical source. For example, corn starch is safe for people with celiac disease, but “modified starch” or “pregelatinized starch” may or may not originate from wheat, rye, or barley. When the source of any ingredient is in doubt, people with celiac disease should contact the manufacturer or check an online source of information such as www.glutenfreedrugs.com.

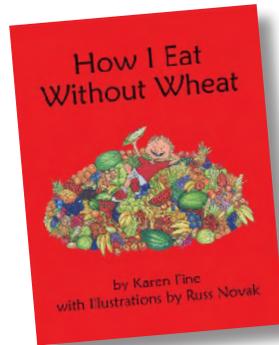
The U.S. Food and Drug Administration currently has no requirements for labeling gluten risk in medications. Next year, ASHP leadership will vote on a proposed professional policy that would encourage manufacturers to declare the name and derivative source—meaning the botanical, animal, or other original source—of all excipients on drug product labels. The ASHP further seeks to educate health-system pharmacists about celiac disease and the exacerbating effects of gluten in drug products and foster definitive research on the influence of gluten in drug products on celiac disease.



NFCA Director of Programming and Communications Vanessa Maltin, who has celiac disease, offered a patient’s perspective on the challenge of finding safe medications. She showed the group a prescription written for her 3 days earlier that she’d been unable to fill because, despite her best efforts, she couldn’t determine whether it contained gluten. Her advice to pharmacists who encounter patients with celiac disease is to 1) determine the inactive ingredients in the prescribed medication and 2) if the source of an ingredient is uncertain, contact the manufacturer. Maltin further called for drug manufacturers to make this information readily available to physicians, pharmacists, and patients. ■

Featured in the NIDDK Reference Collection

How I Eat Without Wheat



This colorful children's book tells the story of a little boy who was happy and healthy but then started to have digestive troubles—even losing weight and failing to thrive. The story follows his journey as he is diagnosed with celiac disease

and learns to identify gluten-free foods that will not make him ill. The book also briefly addresses what to do when a friend or classmate offers a food that has gluten in it.

The story is illustrated with full-color line drawings of the little boy and his family and their activities. The book is designed for toddlers and young children who have diets that restrict them from eating gluten-containing foods.

The book is available for \$10.90 from Author House, 1663 Liberty Drive, Suite 200, Bloomington, IL 47403, www.authorhouse.com.

"Kids and the Gluten-Free Diet"



This journal article helps nutritionists and gastroenterologists counsel families who need to follow a gluten-free diet for a child with celiac disease. The authors review some of the unique challenges for children and their families. Despite

rapid improvement of a child's symptoms upon accurate diagnosis and treatment, compliance with the diet may be less than optimal.

The authors focus on the strategies of frequent follow-up and monitoring, along with the use of educational resources and support groups, as ways to aid families in maintaining the gluten-free diet. Specific suggestions are provided for empowering children, incorporating safe snacks and treats, making good school lunches, and coping with the gluten-free diet on a college campus.

The article is available in the February 2007 issue of *Practical Gastroenterology*, www.practicalgastro.com.

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. To find more celiac disease resources, visit www.catalog.niddk.nih.gov/resources. ■