



FROM THE NATIONAL DIGESTIVE DISEASES INFORMATION CLEARINGHOUSE

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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Gluten-free Camp Reduces Stress and Improves Self-perception for Children and Adolescents with Celiac Disease

Researchers at the University of California, San Francisco, found that children with celiac disease who attended a gluten-free camp demonstrated an improvement in overall quality of life (QOL).

“A gluten-free camp that provides an environment of unrestricted foods can at least temporarily alleviate stress and anxiety around food and social interactions,” stated Melvin Heyman, M.D., M.P.H., professor of pediatrics and chief of pediatric gastroenterology, hepatology, and nutrition at the University of California, San Francisco, Benioff Children’s Hospital, and colleagues. “A gluten-free camp allows children with celiac disease to enjoy a camp experience without concern and preoccupation with foods they eat or the stigma of their underlying disease.”

Celiac disease is a digestive disease characterized by intolerance to gluten. Even minimal exposure to gluten causes small intestinal injury that can lead to a variety of symptoms, including weight loss, abdominal pain, diarrhea, and irritability. People with celiac disease must remain on a diet that completely excludes all forms of gluten, which is often difficult for economic, social, and practical reasons.

The researchers stated that a chronic illness such as celiac disease can reduce a child’s QOL at home, at school, and during extracurricular activities. Attending camps has been difficult for children with celiac disease because of their dietary restrictions. However, in an effort to



alleviate some of the isolation precipitated by the disease, camps that cater to children with celiac disease and who are on a gluten-free diet have recently been established across the United States.

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Researchers studied 77 campers who attended a 7-day gluten-free summer camp for children with celiac disease to see if the camp experience leads to improved QOL. QOL was evaluated through a survey intended to gauge campers' well being, self-perception, and emotional outlook. The results of the survey, which was given at the beginning and end of the camp week, showed improvement in each category by the end of camp.

“This is the first study to evaluate the short-term effect of a specialized summer camp on children with celiac disease in the United States,” the researchers stated. “We surmised that removing the hindrance of daily food choices allowed children to evaluate themselves without the burden of their chronic disease.”

The positive effects were more evident among campers who had been on a gluten-free diet for fewer than 4 years. Researchers suspected that children who had been on a gluten-free diet for 4 or more years had adapted more readily to that way of life.

Although researchers found that a gluten-free camp improved QOL, durability of these observations on return to daily life requires additional study.

The National Digestive Diseases Information Clearinghouse, an information dissemination service of the National Institute of Diabetes and Digestive and Kidney Diseases, has fact sheets and easy-to-read booklets about digestive disorders and celiac disease. For more information and to obtain copies, visit www.digestive.niddk.nih.gov and www.celiac.nih.gov. ■

Would you like to know more about NIDDK-supported research?

The National Institutes of Health (NIH) provides access to a variety of reporting tools, reports, data, and analyses of NIH research activities at the Research Portfolio Online Reporting Tools (RePORT) website, www.projectreporter.nih.gov/reporter.cfm. One of the tools available is RePORT Expenditures and Results (RePORTER), which allows users to search a repository of NIH-funded research projects and access and download publications and patents resulting from NIH funding. ■

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.

Please visit www.celiac.nih.gov/Newsletter.aspx to read or download a PDF version or to subscribe to the newsletter.

The National Institutes of Health Celiac Disease Awareness Campaign provides current, comprehensive, science-based information about the symptoms, diagnosis, and treatment of celiac disease, also known as celiac sprue, nontropical sprue, and gluten-sensitive enteropathy. The Awareness Campaign

is an initiative of the NDDIC, a service of the National Institute of Diabetes and Digestive and Kidney Diseases.

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.



Celiac Disease Is Associated with Restless Legs Syndrome

Restless legs syndrome (RLS) was found to be frequently associated with celiac disease, researchers reported in the June 2010 issue

of *Digestive Diseases and Sciences*. These findings

could lead doctors to screen for celiac disease in patients with RLS and diagnose and treat them for a disease they otherwise would have missed.



“This study presents the epidemiology of RLS in patients with celiac disease, and because an association between the two conditions has been newly recognized, further studies are warranted.”

Leonard B. Weinstock, M.D.

Department of Internal Medicine, Washington University School of Medicine, St. Louis, MO, and colleagues

“Screening for celiac disease in patients with idiopathic RLS may have importance because celiac disease is a commonly overlooked silent disease,” stated Leonard B. Weinstock, M.D., Department of Internal Medicine, Washington University School of Medicine, St. Louis, MO, and colleagues. “Thus, celiac disease may be an underlying correctable factor for some patients diagnosed with idiopathic RLS.”

RLS is a central nervous system disorder that is recognized by the compelling urge to move the legs that worsens at night. Previous neurological research has shown that people with RLS have an iron deficiency, and the greater the iron deficiency, the more severe the RLS. Research has also shown that people with celiac disease likely have an iron deficiency. The researchers used this link as a basis for their study. “The original rationale for this study was that both conditions often have concomitant iron deficiency,” the researchers stated.

However, researchers found that 50 percent of patients did not have iron deficiency, suggesting that alternative mechanisms for RLS and celiac disease may also be at play, such as an immune alteration as is shown in other celiac-associated disorders such as thyroid, ataxia, and other autoimmune disorders.

Researchers called celiac disease the “great modern-day imposter” because it is often clinically silent or has mild gastrointestinal (GI) symptoms and, therefore, may be undiagnosed for many years. Celiac disease symptoms include diarrhea, abdominal pain, weight loss, and constipation; however, celiac disease can occur

without GI symptoms. Celiac disease should also be considered in people with disorders such as osteoporosis, autoimmune diseases, infertility, and thyroid disease.

The study, the first to investigate the epidemiology of RLS in celiac disease, examined 85 people with celiac disease. Researchers found that 35 percent had RLS, compared with only 10 percent of the control group. The people who were identified with celiac disease began a gluten-free diet; 50 percent of them had a substantial improvement in their RLS symptoms. The researchers stated that this improvement could be due to improved iron absorption.

Showing the association between RLS and celiac disease could yield potential diagnosis and therapeutic benefits for both groups of people. Researchers hope that treatment with a gluten-free diet and aggressive iron replacement may improve the quality of life for patients with celiac disease who have RLS. The researchers concluded, “This study presents the epidemiology of RLS in patients with celiac disease, and because an association between the two conditions has been newly recognized, further studies are warranted.”

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Study Finds Gluten Contamination of Inherently Gluten-free Grains and Flours

Under the Food Allergen and Consumer Protection Act, the U.S. Food and Drug Administration (FDA) must issue a rule for the voluntary labeling of food as gluten-free. In the proposed rule, many single-ingredient foods, such as millet, are considered inherently free of gluten. Researchers tested a number of these “single-ingredient foods” and found that some were contaminated with gluten.



“Results of this analysis strongly suggest that not all inherently gluten-free grains, seeds, and flours are indeed gluten-free when they are market-ready for the consumer.”

Tricia Thompson, M.S., R.D. and colleagues

“This potential risk of contamination is a health concern for people with celiac disease, who must follow a gluten-free diet,” said researcher Tricia Thompson, M.S., R.D., and colleagues.

Researchers tested 22 inherently gluten-free grains, seeds, and flours that were not labeled gluten-free, including millet, white rice flour, buckwheat, soy flour, basmati rice, corn meal, and flax seed.

According to the results, 13 of 22 samples, or 59 percent, contained less than the limit of gluten quantification, which is 5 parts per million (ppm). Nine of 22 samples, or 44 percent, contained more than the limit of quantification, with mean gluten levels ranging from 8.5 to 2,925 ppm. Seven of 22 samples, or 32 percent, contained gluten levels that were greater than 20 ppm, which would not be considered gluten-free under the proposed FDA rule for gluten-free labeling. Products that had gluten levels greater than 20 ppm included two types of millet flour, millet grain, buckwheat flour, sorghum flour, and two types of soy flour.

“Results of this analysis strongly suggest that not all inherently gluten-free grains, seeds, and flours are indeed gluten-free when they are market-ready for the consumer,” the researchers stated. “Inherently gluten-free grains and seeds can become contaminated with wheat, barley, or rye anywhere from the field to the packaging plant.”

Crop rotation is one possible cause of grain and seed comingling. For example, a harvest of wheat, barley, or rye could be followed by a gluten-free crop. It is likely that errant wheat, barley, or rye seeds remain in the soil and result in gluten-containing grain harvested along with the gluten-free grain. Grain can also become comingled during shared harvesting, processing, or transporting.

The researchers pointed out that statements such as “all millet is gluten-free” can be misleading and potentially harmful to the consumer with celiac disease who requires a strict gluten-free diet.

The researchers concluded that the FDA may want to modify their proposed rule for the labeling of food as gluten-free, removing the requirement that manufacturers of inherently gluten-free grains, seeds, and flours state on product labels that all foods of that type are gluten-free.

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HHS Launches Healthy People 2020

The U.S. Department of Health and Human Services (HHS) officially launched Healthy People 2020 on December 2, 2010, at the George Washington University in Washington, D.C. The event marked the formal release of the decade's national health promotion and disease prevention objectives.



“[Healthy People 2020] should no longer be known primarily as a print-based reference book to be kept on the shelf for a decade. It should also be a Web-accessible database that is searchable, multilevel, and interactive.”

Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020

Each decade since 1980, the HHS has released a comprehensive set of national public health objectives. Known as Healthy People, the initiative has been grounded in the notion that setting objectives and providing benchmarks to track and monitor progress can motivate, guide, and focus action.

The HHS convened the Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020 to aid in the process of developing the next decade's guidelines. The Advisory Committee was charged with providing advice and consultation to the Secretary: 1) to facilitate the development and implementation of national health promotion and disease prevention goals and objectives, and 2) to inform the development of initiatives that will occur during initial implementation of the goals and objectives.

Healthy People 2020 should assist federal agencies in setting priorities and in providing funding and support to organizations and institutions that are able to help achieve the objectives. The Advisory Committee stated that Healthy People 2020 “should no longer be known primarily as a print-based reference book to be kept on the shelf for a decade. It should also be a Web-accessible database that is searchable, multilevel, and interactive.”

Healthy People 2020's overarching goals include eliminating preventable disease, disability, injury, and premature death; achieving health equity,

eliminating disparities, and improving the health of all groups; creating social and physical environments that promote good health for all; and promoting healthy development and behaviors across every stage of life.

Members of the public health community—especially federal, state, and local health agencies—have traditionally been viewed as the primary audiences for Healthy People. The Advisory Committee proposes that Healthy People 2020 be designed for use by a wider range of groups in both the public and private sectors. Tailored messages and products are needed to make Healthy People useful for this expanded audience-base, which should include the general public, voluntary organizations, faith-based organizations, businesses, health care providers, decision-makers, researchers, community-based organizations, grass-roots advocates, and others whose actions have significant health consequences.

The December 2 launch program included remarks by HHS Assistant Secretary for Health Howard K. Koh, M.D., and members of the Advisory Committee; an introduction and orientation to the Healthy People 2020 website and objectives; and a panel discussion about the uses of Healthy People 2020.

For more information about the Healthy People 2020 initiative, please visit www.healthypeople.gov/HP2020. ■

Administration Announces Regulations Requiring New Health Insurance Plans to Provide Free Preventive Care

The U.S. Departments of Health and Human Services (HHS), Labor, and the Treasury issued new regulations in July requiring new private health plans to cover evidence-based preventive services and eliminate cost-sharing requirements for such services. The new rules will help Americans gain easier access to services such as blood pressure, diabetes, and cholesterol tests; many cancer screenings; routine vaccinations; prenatal care; and regular wellness visits for infants and children.



“Getting access to early care and screenings will go a long way in preventing chronic illnesses like diabetes, heart disease, and high blood pressure.”

Michelle Obama
First Lady

“Today, too many Americans do not get the high-quality preventive care they need to stay healthy, avoid or delay the onset of disease, lead productive lives, and reduce health care costs,” said HHS Secretary Kathleen Sebelius. “From the Recovery Act to the First Lady’s Let’s Move Campaign to the Affordable Care Act, the Administration is laying the foundation to help transform the health care system from a system that focuses on treating the sick to a system that focuses on keeping every American healthy.”

Chronic diseases, such as heart disease, cancer, and diabetes, are responsible for seven of 10 deaths among Americans each year and account for 75 percent of the nation’s health spending—and often are preventable. Nationally, Americans use preventive services at about half the recommended rate. An estimated 11 million children and 59 million adults have private insurance that does not adequately cover immunization, for instance. Studies have shown that cost sharing, including deductibles, coinsurance, and copayments, reduces the likelihood that people will use preventive services.

“Getting access to early care and screenings will go a long way in preventing chronic illnesses like diabetes, heart disease, and high blood pressure,” said First Lady Michelle Obama. “And good [preventive] care will also help tackle an issue that is particularly important to me as First Lady and as a mother—and that is the epidemic of childhood obesity in America today. These are important tools, and now it’s up to us to use them.”

“One of the best ways to improve the quality of your life—and control health care costs—is to prevent illness in the first place,” said Second Lady Jill Biden. “Focusing on prevention and early treatment makes more sense than trying to play catch-up with a potentially deadly disease. Quite simply, these [preventive] services will save lives.”

Under the recently issued regulations, new health plans beginning on or after September 23, 2010, must cover preventive services that have strong scientific evidence of their health benefits, and these plans may no longer charge a patient a

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NIH Pays Tribute to the First Woman Appointed Director of an NIH Institute, Ruth L. Kirschstein



Current and former National Institutes of Health (NIH) scientists and staff, as well as members of Congress, honored Ruth L. Kirschstein, M.D., the first woman appointed director of an NIH Institute, for the positive impact she made as a leader in the scientific community.

“Ruth Kirschstein was a legendary scientist and administrator.”

David Obey
U.S. Representative, Chairman
of the House Appropriations
Committee

“Ruth embodied the spirit of NIH. She was an icon. She was loved and admired by so many at the NIH, across the medical research community, among hundreds of members of Congress, and around the world. There are few at the NIH who have not been touched by her warmth, wisdom, interest, and mentorship,” said Francis S. Collins, M.D., Ph.D., director of the NIH.

Kirschstein, who passed away in 2009, was honored in 2010 with a tribute and symposium in her honor that featured four sessions with 11 featured speakers and ended with a reception. Scientists and researchers who received funds from the Ruth L. Kirschstein National Research Service Award presented the sessions. The awards have supported the work of thousands of researchers, and the quality of their research has elevated the program to the ranks of Fulbright Awards and Rhodes Scholarships.

As the first woman director of an NIH Institute—the National Institute of General Medical Sciences (NIGMS)—Kirschstein was known for mentoring young researchers, especially women and minorities. In 1993, Kirschstein became acting director of the NIH, and then served as the deputy director under NIH Director Harold Varmus for the next 6 years. She was acting director again from 2000 to 2002.

A Brooklyn native, Kirschstein wanted to be a doctor from a young age and fulfilled her dream

after graduating *magna cum laude* in 1947 from Long Island University. She then went to Tulane University School of Medicine, where she was one of 10 women in a class of 100 men.

She interned in medicine and surgery at Kings County Hospital in Brooklyn and completed residencies in pathology in Detroit, New Orleans, and the then new NIH Clinical Center. In 1957, Kirschstein joined the Federal Government, beginning a 15-year stint as an experimental pathologist at the NIH Division of Biologics Standards, now known as the U.S. Food and Drug Administration (FDA) Center for Biologics Evaluation and Research.

In her first major accomplishment as a scientist, Kirschstein led the development of a safety test for the polio vaccine in the 1950s and 1960s. Ultimately, her work led to widespread adoption of the Sabin oral vaccine, especially in developing countries. Kirschstein continued to develop tests for the safety of vaccines for other diseases, including measles.

In 1974, after 2 years with the FDA, Kirschstein was appointed director of the NIGMS, a post she held for nearly 20 years. One of her most significant accomplishments as NIGMS director was her dedication to funding HIV/AIDS research and helping to establish the Genbank nucleic acid sequence database, which has been a

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copayment, coinsurance, or deductible for these services when they are delivered by a network provider. Specifically, these recommendations include the following:

- **Evidence-based preventive services.** The U.S. Preventive Services Task Force, an independent panel of scientific experts, rates preventive services based on the strength of the scientific evidence documenting their benefits. Preventive services with a “grade” of A or B—such as tobacco cessation counseling and screenings for breast and colon cancer, vitamin deficiencies during pregnancy, diabetes, high cholesterol, and high blood pressure—will be covered under these rules.
- **Routine vaccines.** Health plans will cover a set of standard vaccines recommended by the Advisory Committee on Immunization Practices. Such vaccines range from routine childhood immunizations to periodic tetanus shots for adults.
- **Preventive care for children.** Health plans will cover preventive care for children recommended under the *Bright Futures* guidelines, developed by the Health Resources and

Services Administration with the American Academy of Pediatrics. These guidelines provide pediatricians and other health care professionals with recommendations on the services they should provide to children from birth to age 21 to keep them healthy and improve their chances of becoming healthy adults. The types of services that will be covered include regular pediatrician visits, vision and hearing screenings, developmental assessments, immunizations, and screening and counseling to address obesity and help children maintain a healthy weight.

- **Preventive care for women.** Health plans will cover preventive care provided to women under both the Task Force recommendations and new guidelines being developed by an independent group of experts, including doctors, nurses, and scientists, which are expected to be issued by August 1, 2011.

More information about the Affordable Care Act’s new rules on preventive care can be found at www.healthcare.gov/law/about/provisions/services/index.html.

The regulations can be found at www.healthcare.gov/center/regulations/prevention/regs.html. ■

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critical tool for biomedical research. She championed myriad programs in basic biomedical research and research training that have helped to transform biomedical research.

“Ruth Kirschstein was a legendary scientist and administrator . . . a pioneer . . . a champion for the advancement of women and minorities in biomedical research . . . a strong advocate for research training, especially interdisciplinary

predoctoral programs,” said U.S. Representative David Obey, chairman of the House Appropriations Committee.

Kirschstein remained active at the NIH in her later years as a senior adviser; she was on a conference call with NIH Director Collins a week before her death. Kirschstein embodied the spirit of the NIH and was responsible for the career development of innumerable scientists and administrators. ■

Nurik Appointed Director of NIDDK Information Clearinghouses

Jody Nurik has been named director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Information Clearinghouses. She will oversee long- and short-range plans and operations for the NIDDK's three national health information Clearinghouses and manage the Clearinghouses' support contract. Nurik will also manage the update and production of more than 300 award-winning print and online publications and three national awareness campaigns—bladder control for women, celiac disease, and bowel incontinence.



"Jody is extremely detail-oriented and gifted in big-picture-planning too."

Kathy Kranzfelder

Director, Office of Communications and Public Liaison, NIDDK, NIH

The Clearinghouses disseminate science-based health information to the public, health professionals, and the media. In 2009, the Clearinghouses handled nearly 79,000 information requests, received 6 million visitors to the NIDDK health information website, and distributed more than 1 million publications.

In 2004, Nurik oversaw the transition and establishment of all NIDDK Clearinghouse support contract operations to Circle Solutions, Inc., where she served as project manager. "Jody is extremely detail-oriented and gifted in big-picture-planning too," noted Kathy Kranzfelder, director, Office of Communications and Public Liaison, NIDDK, National Institutes of Health, and former director of the Clearinghouses. "From inquiry response to materials development to inventory database management to exhibit staffing and scheduling to reporting—the Clearinghouses will definitely benefit from new perspective and deep experience from Jody."

Prior to joining the NIDDK, Nurik was director of product marketing at Resolution Health/WellPoint, Inc., where she developed and managed health communications for health care providers and the public. In this role, Nurik led plain language initiatives, outreach campaigns, and market research with physicians and consumers to improve content and design.

Nurik has also managed an information center for the Health Resources and Services Administration, also part of the U.S. Department of Health and Human Services, and has launched adult and pediatric diabetes disease management programs at one of the largest home health companies in the United States. Nurik began her career as a nurse, moving up to supervise urology units of a hospital affiliated with Baylor College of Medicine.

To learn more about the NIDDK Information Clearinghouses, visit www.niddk.nih.gov. ■

New Fact Sheets

The National Digestive Diseases Information Clearinghouse (NDDIC) has published the following new fact sheets:

- *Colonoscopy* (Spanish)
- *Flexible Sigmoidoscopy* (Spanish)
- *H. pylori and Peptic Ulcers* (Spanish)
- *Liver Biopsy* (Spanish)
- *Lower GI Series* (Spanish)
- *Upper Endoscopy* (Spanish)
- *Upper GI Series* (Spanish)
- *Virtual Colonoscopy* (Spanish)

These publications are available at www.digestive.niddk.nih.gov.

Updated Fact Sheets

The NDDIC has updated the following fact sheets:

- *Chronic Hepatitis C: Current Disease Management*
- *Digestive Diseases Statistics for the United States*
- *Gastritis*
- *H. pylori and Peptic Ulcers*
- *Liver Transplantation*
- *Microscopic Colitis: Collagenous Colitis and Lymphocytic Colitis*
- *NSAIDs and Peptic Ulcers*

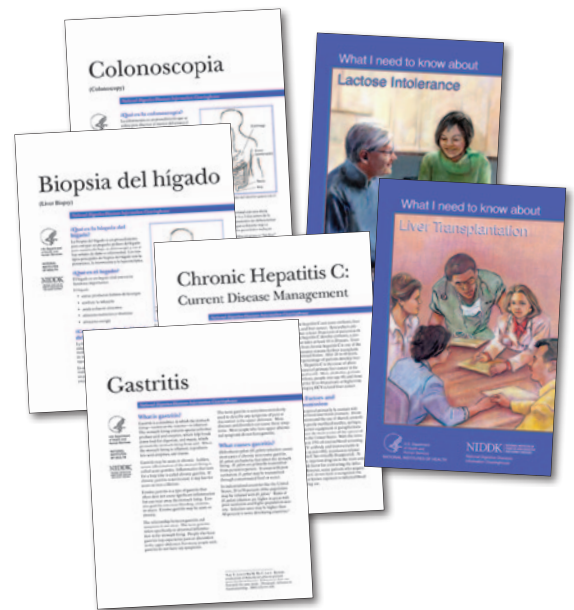
These publications are available at www.digestive.niddk.nih.gov.

Updated Easy-to-Read Booklets

The NDDIC has updated the following easy-to-read booklets:

- *What I need to know about Lactose Intolerance*
- *What I need to know about Liver Transplantation*

These publications are available at www.digestive.niddk.nih.gov. ■



Upcoming Meetings, Workshops, and Conferences

The National Institute of Diabetes and Digestive and Kidney Diseases Information Clearinghouses will exhibit at the following upcoming event:

Digestive Disease Week

May 7–10 in Chicago.

For more information, visit www.ddw.org. ■