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## **NIH Consensus Conference on Celiac Disease (2004) and NIDDK Celiac Disease Awareness Campaign**

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## Office of the Medical Applications of Research (OMAR), Office of Disease Prevention, NIH

■ <http://odp.od.nih.gov/omar>

The OMAR logo consists of the letters "OMAR" in a bold, blue, sans-serif font. To the right is the official seal of the U.S. Department of Health and Human Services, featuring an eagle and the text "U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES" and "NATIONAL INSTITUTE OF HEALTH".

**NIH Consensus Development Program**  
The Office of Medical Applications of Research (OMAR) within the National Institutes of Health (NIH) is the focal point for evidence-based assessments of medical practice and state-of-the-science on behalf of the medical community and the public.

**Office of Disease Prevention**  
Located in the Office of the Director, OMAR works closely with NIH Institutes or Centers and Offices to assess, translate and disseminate the results of biomedical research that can be used in the delivery of important health services to the public.

**Office of Rare Diseases**  
A major responsibility of OMAR is the coordination of the **NIH Consensus Development Program**. Under this program, OMAR organizes major conferences on complex issues of medical importance to health care providers, patients and the general public. These conferences are open to the public, broadcast on the Internet and free of charge to participants. The **NIH Consensus Statements and State of the Science Statements** produced by these conferences are disseminated widely to health care practitioners, policymakers, patients, the media and the general public.

**Office of Dietary Supplements**  
An evidence-based assessment is prepared for each conference topic. The assessment involves a systematic review of the medical literature to define the state of medical practice or science by using rigorous criteria for categorizing the strength of the available evidence.

OMAR routinely meets with scientists, clinicians, representatives from other Federal health agencies, and public representatives to discuss methods to further enhance the mission of the office.

In addition, through the **Medicine in the Media** program, OMAR seeks to enhance the ability of journalists to critically assess scientific reports and medical findings using an evidence-based approach, and to add content to make reports on research in the popular media more useful to readers.

OMAR is one administrative unit of the **NIH Office of Disease Prevention**. Other administrative units of ODP are the **Office of Dietary Supplements** and the **Office of Rare Diseases**.

For further information about OMAR activities.

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The Office of Medical Applications of Research (OMAR) is responsible for organizing major conferences on complex issues of medical importance to health care providers, patients, and the general public. The NIDDK worked with OMAR to convene the NIH Consensus Conference on Celiac Disease.



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## **Rationale for NIH Consensus Conference on Celiac Disease**

- The disease is relatively common in the United States, yet it is largely underdiagnosed (limited awareness)
- Protean manifestations require awareness in the general medical community
- Initial diagnostic steps and management suitable for general pediatrics, family medicine, and general internal medicine
- A highly effective treatment is available (gluten-free diet)
- New information is available about prevalence and diagnostic tests



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## **Format of Consensus Conference**

- Independent consensus panel of nonbiased scientists, physicians, and public interest representatives
- Presentations by experts in the field
- Analysis of scientific evidence by Evidence-Based Practice Group
- Solicitation of public comments
- Statement by independent panel to address the following questions:



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## **NIH Consensus Conference: Celiac Disease June 28 to 30, 2004**

- How is celiac disease diagnosed?
- How prevalent is celiac disease?
- What are the manifestations and long-term consequences of celiac disease?
- Who should be tested for celiac disease?
- How is celiac disease managed?
- What are recommendations for future research on celiac disease and related conditions?



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## Conclusions of Consensus Panel

- <http://consensus.nih.gov/2004/2004CeliacDisease118html.htm>



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The Consensus Panel concluded that heightened awareness of celiac disease is imperative and that education of physicians, registered dietitians, and other health care providers is needed. The Panel recommended

- education of physicians, dietitians, nurses, and the public about celiac disease by a trans-NIH initiative led by the NIDDK together with the Centers for Disease Control and Prevention
- standardization of serologic tests and pathologic criteria for diagnosing celiac disease
- adoption of a standard definition of a gluten-free diet based on objective evidence such as that developed by the American Dietetic Association
- development of an adequate testing procedure for gluten in foods and definition of standards for gluten-free foods in the United States to lay the foundation for rational food labeling
- formation of a federation of celiac disease societies, celiac disease interest groups, individuals with celiac disease and their families, physicians, dietitians, and other health care providers for the advancement of education, research, and advocacy for individuals with celiac disease



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## Consensus Conference Proceedings

- Full proceedings of the Consensus Conference published as a supplement to the April 2005 issue of *Gastroenterology*



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*Gastroenterology*, April 2005, Volume 128, Number 4, Supplement 1



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## **NIH Celiac Disease Consensus Conference Panel Recommendation**

- Education of physicians, dietitians, nurses, and the public about celiac disease by a trans-NIH initiative, to be led by the NIDDK, in association with the Centers for Disease Control and Prevention

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This recommendation by the Consensus Panel laid the foundation for the development of the Celiac Disease Awareness Campaign.

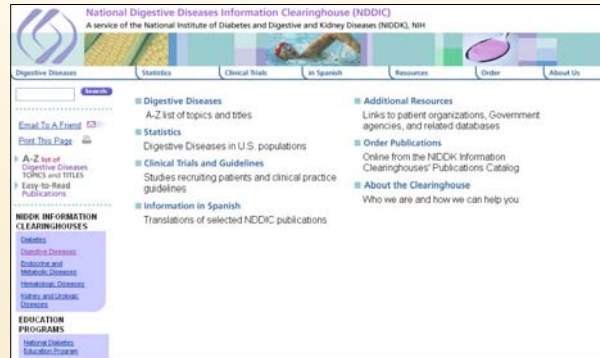




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## National Digestive Diseases Information Clearinghouse (NDDIC), NIDDK

■ <http://digestive.niddk.nih.gov>



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The National Digestive Diseases Information Clearinghouse (NDDIC) was given responsibility for developing the Celiac Disease Awareness Campaign. NDDIC is an information dissemination service of the NIDDK. The NDDIC was established in 1980 to increase knowledge and understanding about digestive diseases among people with these conditions and their families, health care professionals, and the general public. To carry out this mission, NDDIC works closely with a coordinating panel of representatives from Federal agencies, voluntary organizations on the national level, and professional groups to identify and respond to informational needs about digestive diseases.



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## Initial Planning Steps

- Form *Ad hoc* Committee made up of representatives from the research and celiac disease patient communities
- Identify preliminary components and structure of the Awareness Campaign

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Following the Consensus Conference, the NIDDK asked a small group of representatives from the research and celiac disease patient communities to help provide initial campaign planning direction. This ad hoc committee agreed that the Awareness Campaign should focus on the message that celiac disease is more common than previously thought and that its symptoms are broad.



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## Target Audiences

### Primary Targets

- Primary Care Providers
- Pediatricians
- OB/GYNs
- Physician Assistants

### Secondary Targets

- Endocrinologists
- Nurse Practitioners
- Hematologists
- Allergists
- Dermatologists
- Dentists

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The ad hoc committee agreed that primary care providers, those who are likely to see patients first and make timely referrals to a specialist, should be the primary target audience. The committee also identified secondary target audiences who, because of their specialties, might be likely to see patients with celiac disease and contribute to earlier diagnosis.

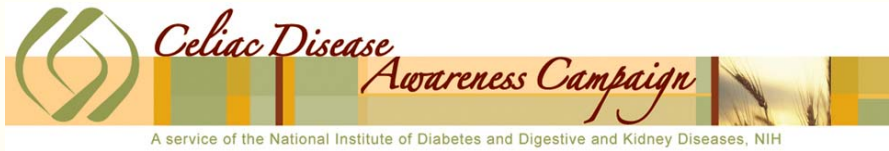


## Formative Research

- Intercept interviews with nurse practitioners and physician assistants, May 2005
- Focus groups with primary care providers, Fall 2005

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The ad hoc committee suggested conducting formative research with primary care providers to determine what they perceived to be the challenges to diagnosing celiac disease and what tools and information would be useful in overcoming those challenges. In May 2005, intercept interviews were conducted with nurse practitioners and physician assistants at the National Conference of Nurse Practitioners and the American Academy of Physician Assistants meetings. In Fall 2005, the NDDIC conducted eight focus groups in the four cities with primary care providers—family practitioners, internists, OB/GYNs, and pediatricians.



## Intercept Interviews

### Nurse Practitioners and Physician Assistants

- Most nurse practitioners and physician assistants had not been involved in diagnosing a person with celiac disease
- The majority rely on a variety of resources when seeking disease information
- Those interviewed suggested disseminating information about celiac disease through conference presentations, journal articles, one-page fact sheets, direct mail, and advertisements

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Most nurse practitioners and physician assistants interviewed said they rely on online subscription services, WebMD, medical journals, conferences, reference books, or consultations with colleagues when seeking disease information. They also recommended a quick reference guide and continuing education credits as useful ways of providing information and increasing awareness about celiac disease.



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## Focus Groups

### Primary Care Providers

- do not trust claims of a 1-percent prevalence of celiac disease
- are unsure of the sensitivity and specificity of blood tests
- do not perceive underdiagnosis of celiac disease to be problematic or have long-term consequences
- are already overwhelmed with information

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Physicians participating in the primary care provider focus groups answered a wide range of questions to assess awareness of celiac disease and barriers to diagnosis. Many of the physicians said they were already “overwhelmed” with information and that celiac disease was a “third-tier” disease. They were more concerned with “first-tier” diseases they see much more often, such as diabetes, hypertension, and cardiovascular disease.



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## **Campaign Goal**

### **Educate the medical community about the**

- prevalence of celiac disease
- issues of blood testing and its validity
- health consequences of celiac disease
- need to view celiac disease as *not only* a gastrointestinal disease



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## **Strategies for Reaching Primary Care Providers**

- Develop tools to help primary care providers recognize, diagnose, and manage celiac disease
  - Website information
  - Journal articles
  - Presentations at national meetings
  - Textbooks and medical curriculums
- Develop health information tools for primary care providers to distribute to patients





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## **Communication Channels**

- Campaign website, [www.celiac.nih.gov](http://www.celiac.nih.gov)
- Consensus statement
- *Celiac Disease News*
- Other publications/Awareness Campaign articles



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## Celiac Disease Awareness Campaign Website

■ [www.celiac.nih.gov](http://www.celiac.nih.gov)



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The Celiac Disease Awareness Campaign, featuring the Awareness Campaign website, was launched in July 2006.



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## **Campaign Website Features**

- Campaign news and events
- Practice guidelines and tools
- Educational materials and resources
- Celiac disease research
- Celiac disease organizations



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## ***Celiac Disease News***

- Communicate with the celiac disease community about Awareness Campaign developments, features, resources, and upcoming events
- Subscribe online at [www.celiac.nih.gov/news.aspx](http://www.celiac.nih.gov/news.aspx)

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The website features the current issue of *Celiac Disease News* and an archive of past issues.



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## **Publications**

- *Celiac Disease* fact sheet
- *What I need to know about Celiac Disease* easy-to-read booklet
- Awareness Campaign articles

## **Other Publications from the NIH**

- *What People With Celiac Disease Need to Know About Osteoporosis*

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*What People With Celiac Disease Need to Know About Osteoporosis* was produced by the National Institute of Arthritis and Musculoskeletal and Skin Diseases and is available at [www.niams.nih.gov/bone/hi/bowel/celiac.htm](http://www.niams.nih.gov/bone/hi/bowel/celiac.htm).

# Celiac disease: It's common, and commonly misdiagnosed

Updated 11/1/2006 9:04 PM ET

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By **Mary Brophy Marcus**, Special for USA TODAY



[Enlarge](#) By John Zich, USA TODAY

The Libreris: Aldo, left, Pietro, Claudio and Lucio, in front row, all have celiac disease. Mom Rosalia, Angela, Ignazio, Rosalba and father Luciano do not.

Lucia Libreri, 16, stopped growing when she was 8. Four years later after a battery of tests and visits with medical experts, her parents, Rosalia and Luciano, finally found a doctor who pinned down her problem: celiac disease, a condition scientists say is much more widespread in the USA than previously believed.

This summer, the National Institutes of Health launched the Celiac Disease Awareness Campaign to educate physicians and the public about the prevalence of the disease, the myriad of symptoms it can cause and the tests that can detect it.

People with celiac disease can't digest gluten, a protein found in wheat, rye, and barley — grains commonly used in bread, pasta, cookies and beer. Oats don't contain gluten, but U.S. oats are considered contaminated due to crop rotation and milling.

Less than a decade ago, it was thought celiac disease affected one in every 10,000 Americans, says Michelle Pietzak, clinical assistant professor of pediatrics at the University of Southern California Keck School of Medicine in Los Angeles and founder of website [glutenfreemd.com](#).

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In addition to being mentioned in a November 1, 2006, article on celiac disease in *USA Today*, a national newspaper that reaches 5 million readers, the Awareness Campaign received press from WABC New York Radio, which has 250,000 listeners in the New York metropolitan area; PR Newswire, which reaches more than 4,700 newsrooms, 3,600 websites and online databases, and 80,000 journalists nationwide; and *NIH News in Health*, a monthly newsletter mailed to 6,500 senior centers, medical libraries, and community health clinics around the country. The online version of the newsletter receives about 20,000 hits per month.