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**NIH Consensus Panel Finds Celiac Disease Under-Diagnosed**  
*Panel Recommends Six Key Strategies for Disease Management*

**Bethesda, Maryland** — Celiac disease is considerably under-diagnosed, according to an independent consensus panel convened this week by the National Institutes of Health (NIH). The panel, charged with assessing all of the available scientific evidence on celiac disease announced today its recommendations for the appropriate diagnosis and management of this disease, which was previously believed to be rare. Celiac disease may affect 3 million Americans. The disease is present in 0.5 to 1% of the U.S. population, ten times higher than previous estimates.

"We know that celiac disease is caused by an immune response to the gluten in certain common grains, so we have a very effective treatment — a gluten-free diet — but if physicians don't recognize when to test for the disease, patients are going to suffer needlessly", said Charles Elson, MD, of the University of Alabama at Birmingham, and chair of the consensus panel. He added, "Because the disease has been thought to be rare, testing for it may not occur to many physicians. We hope that this conference will help to increase physician awareness."

The panel found that increasing physician awareness of the various manifestations of celiac disease and appropriate use of available testing strategies may lead to earlier diagnosis and better outcomes for celiac patients.

Based on its assessment of an extensive collection of medical literature and expert presentations, the panel identified six elements essential to treating celiac disease once it is diagnosed:

- C** - Consultation with a skilled dietitian,
- E** - Education about the disease,
- L** - Lifelong adherence to a gluten-free diet,
- I** - Identification and treatment of nutritional deficiencies,
- A** - Access to an advocacy group, and
- C** - Continuous long-term follow-up.

The panel released its findings in a public session this morning, following two days of expert presentations and panel deliberations. The full text of the panel's draft consensus statement will be available following the conference at <http://consensus.nih.gov/>. The final version will be available at the same Web address in three to four weeks. Statements from past conferences and additional information about the NIH Consensus Development Program are also available at the Web site, or by calling 1-888-644-2667.

The panel's statement is an independent report and is not a policy statement of the NIH or the Federal Government. The NIH Consensus Development Program, of which this conference is a part, was established in 1977 as a mechanism to judge controversial topics in medicine and public health in an unbiased, impartial manner. NIH has conducted 119 consensus

development conferences, and 22 state-of-the-science (formerly "technology assessment") conferences, addressing a wide range of issues.

The conference was sponsored by the Office of Medical Applications of Research and the National Institute of Diabetes and Digestive and Kidney Diseases, of the NIH. Cosponsors included the National Institute of Child Health and Human Development, the National Cancer Institute, the National Institute of Allergy and Infectious Diseases, the U.S. Food and Drug Administration, and the U.S. Department of Agriculture.

The 13-member panel included practitioners and researchers in gastroenterology, pediatrics, pathology, internal medicine, endocrinology, a dietitian, a geneticist, and a consumer representative. The panel reviewed an extensive collection of medical literature related to celiac disease, including a systematic literature review prepared by the University of Ottawa Evidence-Based Practice Center, under contract with the Agency for Healthcare Research and Quality (AHRQ). A summary of the Evidence Report on Celiac Disease is available at <http://www.ahrq.gov/clinic/epcsums/ceciacsum.htm>. The full report will be available later this summer.

The archived videocast of the conference sessions will be available shortly at <http://consensus.nih.gov/>.

**Note to TV Editors:** The news conference at 2 p.m. today will be broadcast live via satellite on the following coordinates:

Galaxy 3 Transponder 07 C-Band  
Orbital slot: 95 degrees West  
Uplink Freq: 6065 Vertical  
Downlink Freq: 3840 Horizontal  
Audio 6.2/6.8  
Test time: 1:30 - 2:00 p.m. ET  
Broadcast: 2:00 - 3:00 p.m. ET

**Note to Radio Editors:** An audio report of the conference results will be available after 4 p.m. today from the NIH Radio News Service by calling 1-800-MED-DIAL (1-800-633-3425).

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