

**Statement of  
LISA MURPHY  
on behalf of the  
AMERICAN CELIAC TASK FORCE  
Before the Subcommittee on LABOR, HHS, and EDUCATION  
of the  
Committee on Appropriations  
U.S. House of Representatives  
April 27, 2004**

Thank you for inviting me. My name is Lisa Murphy and I am here today on behalf of the American Celiac Task Force, the 80,000 Americans with celiac disease, and the estimated 2 million at risk. Colin, my 15 year old son, also a celiac, has joined me today. I would like to thank Representative Lowey, for her efforts to raise awareness about celiac disease.

Celiac disease is considered by many to be the most common genetic disorder of mankind, yet, in the United States few people know what it is. As recently as 5 years ago, it was believed that only 1 in 10,000 Americans had the disorder. In February 2003, a multi-center prevalence study, revealed that approximately 1 in 133 Americans were at risk for developing this genetic disorder.

When a person who has celiac disease eats gluten, a protein found in wheat, rye and barley, the immune system responds by attacking the small intestine and blocking the absorption of key nutrients into the body. Undiagnosed and untreated, celiac disease can lead to the development of other autoimmune disorders, as well as osteoporosis, infertility, neurological conditions and in rare cases, cancer.

Digestive problems were something that I lived with most of my life. In my 20's, I saw several doctors with complaints of bloating, stomach pains, and frequent diarrhea. Repeated tests, including a bone marrow extraction, showed nothing definitive so physicians categorized the problem as irritable bowel syndrome, gastritis, colitis, or even stress. After the birth of my third child, twelve years ago, I became quite ill. Eating caused significant pain, the diarrhea was constant. I began to lose weight, and my hair was falling out.

By sheer coincidence, my gastroenterologist had just returned from a conference on celiac disease. He ran the required blood tests, which showed high levels of the antibodies associated with celiac disease. An endoscopy revealed that the villi in the small intestine were severely blunted. Within several months on the gluten-free diet, I started feeling significantly better.

[Three] years later, I gave birth to my fourth child. Early on, Eamon was sickly, and failed to meet developmental milestones. At two and a half he still was not speaking, and later started having seizures. Even though I had celiac disease, a genetic disorder,

no one considered this might be the source of Eamon's problems. I read about a study\* that showed family members of individuals with celiac disease have a 1 in 22 chance of having it, too. The study also indicated that 40% of affected adults, and 60% of affected children exhibited no symptoms. Our four children were tested, Eamon and Colin required follow-up biopsies which confirmed both had celiac disease. There was more bad news. Further testing revealed that Colin, who had no outward symptom, had osteoporosis in his spine, and left forearm. Osteopenia, a precursor to osteoporosis, was found in his hip. He was only 11 years old. Colin's body had not been absorbing calcium, and vitamin D, leaving him at high risk for fractures. Celiac disease is the leading cause of osteoporosis in men. The most common symptom leading to diagnosis – anemia.

Our story is not unusual. Celiac disease is not thoroughly covered in medical schools; pharmaceutical companies pay little attention because the only treatment is a strict-gluten free diet. With no 'drugs' to market or ongoing testing required, celiac disease is not a moneymaker for the health care industry.

The costs associated with the disease are staggering. On average, it takes 11 years for an individual to be diagnosed in U.S. In that span of time, individuals will have endured repeated office visits, CT scans, blood tests, X-rays, tried various prescriptions, had miscarriages, and even been hospitalized. In addition, there would be days and days lost from work due to illness. Colin, who was asymptomatic, developed osteoporosis of the spine during those 11 years.

Research has also demonstrated that the delays in diagnosis, dramatically increases an individual's risk of developing additional autoimmune disorders like Type 1 diabetes.  
[ADD STATS ON AUTOIMMUNES]

Research on celiac disease in the U.S. lags well behind that of other countries, in part because physicians still believe it only affects children. The NIH has organized a consensus conference on celiac disease for June 2004. Recommendations from the consensus panel are not binding on the NIH. However, we strongly **recommend that NIDDK to carefully consider any research recommendations made by that panel in determining future funding decisions for celiac disease research, and in developing its budget for FY 2006.**

Education and awareness among health professionals is inadequate as is demonstrated by the 11 years it can take for diagnosis. The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) will release practice guidelines on the treatment of CD later this year. Guidelines, such as these, are desperately needed NOW to help educate primary care physicians, as well, specialists. With more physician education, someone else's 11 year-old son will be saved from osteoporosis; or 2 ½ year-old from seizures and delays in cognitive development. It is imperative that while NIDDK develops a clear, research agenda for celiac disease,

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\* **Prevalence of Celiac Disease in At-Risk and Not-At-Risk Groups in the United States A Large Multicenter Study** *Arch Intern Med.* 2003;163:286-292

awareness efforts must be expanded. Although celiacs are responsible for their own 'treatment', we face obstacles each day because physicians, or food manufacturers do not have a complete understanding they are putting us in harms way.

**We strongly recommend that NIDDK provide funding, as soon as possible, for programs to educate health professionals about CD. In addition, because management of CD lies almost exclusively with the patient, we further recommend that any educational efforts provide guidance to patients on managing the condition.**

On behalf of the American Celiac Task Force, and our family, thank you for the opportunity to present our testimony today.

## **ADD**

ε Type 1 Diabetes affects 1,177,500 people; 6% (70,650) of those diagnosed also have celiac disease.

ε 610,000 women in the US experience unexplained infertility; 6% (36,600) of these women might never learn that celiac disease is the cause.

ε 350,000 people in the United States are living with Down Syndrome; 12% (42,000) of them also have celiac disease.

ε The number of people with celiac disease in the U.S. is roughly equal to the number of people living in the state of Nevada.