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FACT SHEET

Gluten Intolerance Group in Utah estimates that 16,000 Utahns have undiagnosed Celiac Disease

Celiac Disease (also referred to as gluten sensitive enteropathy, gluten intolerance, or celiac sprue) is not as uncommon as once believed. In fact, medical researchers now say that celiac disease is the most widely under diagnosed illness in the U.S. today. One in every 133 Americans potentially has celiac disease.

Many people have no symptoms and are not aware of the potential, devastating affects of the disease. Others suffer painful and often baffling symptoms and spend an average of 11 years seeking a diagnosis. They often endure several uncomfortable procedures to rule out other illnesses before their celiac disease is diagnosed. Initial screening for celiac disease is with a fairly new blood test.

Definition:

Celiac Disease--a chronic, inherited disease which is the result of an immune-mediated response to the ingestion of gluten (found in wheat, rye, and barley) that damages the small intestine. Nutrients then quickly pass through the small intestine rather than being absorbed. Celiac means "pertaining to the abdominal cavity".

Common symptoms:

Celiac disease is a multi-symptom, multi-organ disease. Symptoms may include chronic diarrhea, abdominal bloating and pain, weight loss or gain, foul-smelling stool, seizures, dental enamel defects, edema, anemia, fatigue, a painful skin rash, headaches, inability to concentrate, and premature osteoporosis. It is a misconception that only emaciated people are gluten intolerant. Overweight persons may also have celiac disease. People are often misdiagnosed as having irritable bowel syndrome, spastic colon, or Crohn's disease.

Long-term health consequences of untreated celiac disease:

People with celiac disease are at greater risk to develop such disorders as osteoporosis, insulin-dependent diabetes, stomach cancer, Addison's disease, lupus, thyroid disease, anemia, eczema, fertility problems, premature menopause, Sjogren's syndrome, scleroderma, and dermatitis herpetiformis. Celiacs often develop other food sensitivities including lactose intolerance.

Patient profile and genetic link:

To develop celiac disease three conditions must be present: 1) you must inherit the gene, 2) consume gluten, and 3) have the gene triggered. Approximately 1 in 20 first-degree relatives of celiacs could have celiac disease triggered in their lifetime.

Celiac disease has long been commonly diagnosed in Europe. In Utah where so many residents have genetic links to Europe, it is safe to assume there are many celiacs (many undiagnosed) in our community.

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How celiac disease is triggered:

While some people are diagnosed as infants or children usually with glaring symptoms of malnutrition and failure to thrive, many people carry a propensity for celiac disease that can trigger any time in a person's life. Typical triggers include stress, surgery, pregnancy, giving birth, death of a loved one, divorce, loss of a job, viral infections, or any life altering or traumatic event.

Celiac disease is common, but under diagnosed in the U.S. and Utah:

- It is believed that 97 percent of Americans who have celiac disease are still undiagnosed. The U.S. Department of Health and Human Services/National Institutes of Health predicts that more than 2 million Americans likely have celiac disease but only about 60,000 have been diagnosed. Many more people suffer varying degrees of gluten intolerance.
- **In Utah, with a population of slightly over 2.2 million, the Gluten Intolerance Group in Utah estimates that nearly 17,000 Utahns have celiac disease, but only about 1,000 have been diagnosed. The Gluten Intolerance Group in Utah estimates that 16,000 Utahns are still undiagnosed. That's about 90 percent of Utah celiacs that are undiagnosed.**

Putting celiac disease in perspective:

The National Institutes of Health predicts that celiac disease affects 1 in 133 Americans for a total of more than **2 million Americans who likely have celiac disease**. Only about 60,000 Americans have been officially diagnosed. For contrast note the following illnesses and the number of Americans affected:

- Cystic fibroses affects 30,000 people.
- Multiple sclerosis affects 333,000 people.
- Alzheimer's disease affects 2 million.
- Type 1 diabetes affects more than a million people. (6 percent of those also have celiac disease)

The cure:

Completely avoiding foods that contain gluten is the only treatment. The small intestine will steadily heal and start absorbing the needed nutrients. Most patients report feeling better almost immediately, although complete recovery may take several months to years.

The disease is permanent. Children do not outgrow it as once thought. Damage to the small intestine will occur every time a person consumes gluten, regardless if symptoms are present. Gluten is a food additive and is present in many foods, as well as cosmetics and pharmaceuticals.

For more information: www.gluten.net or www.gfutah.org or www.nih.gov

About Gluten Intolerance Group in Utah

Utah County Gluten Intolerance Group®, the Salt Lake City Gluten Intolerance Group®, and the Northern Utah gluten Intolerance Group® are Branches of The Gluten Intolerance Group®, also known as GIG®, and are 501(c)(3) not-for-profit organizations. The Gluten Intolerance Group's mission is to increase awareness of and knowledge about this common, but under-diagnosed illness. To learn more, go to www.gfutah.org

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