

“Making Tracks for Celiacs”

The Third Annual International Walk for Celiac Disease

Third International Walk
for Celiac Disease



What is celiac disease (CD)?

CD is a chronic autoimmune gastrointestinal condition. It is also called celiac sprue, gluten-sensitive enteropathy, coeliac disease or non-tropical sprue. Through a combination of genetic and other factors (some unknown), a celiac who ingests anything containing any form of wheat, rye, barley and possibly oats – even in small amounts – will experience a toxic reaction which damages the lining of the small intestine (the area responsible for the absorption of nutrients from food).

Chronic ingestion of the grains listed above leads to malabsorption of essential nutrients by the body. Calcium, iron and folic acid absorption are particularly affected, and the lack of these nutrients leads to serious secondary health problems.

There is a large range of symptoms associated with celiac disease; some of the most common ones include:

- diarrhea or constipation, or even both
- weight loss, sometimes severe
- abdominal pain and bloating
- dermatitis herpetiformis (a related skin condition, sometimes called “celiac disease of the skin”)
- thyroid problems (either hypo- or hyperthyroidism)
- chronic fatigue
- failure to thrive (in infants and children)
- osteoporosis and resulting bone fractures
- tooth enamel defects
- peripheral neuropathy (pain in the extremities)
- arthritis
- anemia
- infertility and/or recurring abortion
- headaches
- depression
- behavioral changes

Long-term effects from untreated celiac disease can be life-threatening, and have been linked to significantly increased risk of certain types of cancer, such as intestinal lymphoma.

The variety of this list sometimes makes it hard for doctors to diagnose celiac disease, as these symptoms are obviously common to a number of other ailments. CD has been called “the great mimic” in the medical literature. A significant number of celiacs don’t experience any clear symptoms at all after eating

foods containing wheat, oats, rye or barley. Many individuals have been known to eat gluten-containing foods for decades, without being aware of the damage occurring to the villi in the small intestine. However, the health of these “silent celiacs” is still seriously at risk.

Isn't this the same as a food allergy?

CD is sometimes confused with or referred to as a “wheat allergy”, although calling it an allergy isn't accurate. An individual can have one condition or the other, or both. In technical terms, the reactions and symptoms of each condition are associated with different proteins of the immune system, known as immunoglobulins. The immunoglobulins that are produced by a celiac exposed to gluten are different than those produced by an individual with a wheat allergy who is exposed to wheat.

What's the problem with wheat, rye, barley and oats?

These grains cause problems because they contain gluten. Gluten is the collective term for the proteins found in all forms of wheat (including durum, semolina and spelt), rye, barley, related grain hybrids (triticale, kamut, etc.) and possibly oats. (Oats are being studied, because it's still unclear as to whether the proteins found in this grain cause the same autoimmune reaction as that caused by wheat, rye and barley. The jury is still out on this one, so celiacs are generally advised to avoid oats.) Gluten is the protein that makes bread dough rise and become puffy before baking. Gluten is found in corn as well, but corn gluten is not harmful to those with CD. Ingesting the problem proteins sets up an autoimmune reaction that produces antibodies, which in turn attack and destroy the villi in the small intestine, causing the symptoms listed above.

How is celiac disease diagnosed?

Currently, the “gold standard” for diagnosing CD is an intestinal biopsy performed as part of an endoscopy. Usually performed under light anesthesia, a patient will swallow an endoscope – a long tube with a tiny camera at the end and a tool that can take a small bit of tissue from the inner lining of the small intestine. The gastroenterologist performing the procedure can look through the camera at the appearance of the intestinal lining for cracks and fissures that are characteristic of celiac disease. A pathologist examines the tissue sample microscopically, and diagnostic criteria are used to evaluate whether CD is present.

In addition, a blood test has been developed which measures levels of a certain set of antibodies. If levels of these antibodies are too high, CD is indicated and the biopsy should be performed. Research has been conducted over the past few years to make this test sufficiently specific and selective to use instead of the intestinal biopsy, making diagnosis less invasive, cheaper and faster.

How many people have CD?

The incidence of CD, or how often it occurs in the population, is much higher than was thought in the past 20-30 years. Recent research shows that as many as 1 in 133 people in the United States have this condition. These numbers mean that celiac disease, though uncommon, is certainly not a “rare” disease – it is likely that thousands of people are affected, many of whom may not even know it.

The situation in Europe is very similar – and the Europeans are a lot more familiar with celiac disease than we Americans! The incidence numbers across these countries are pretty much the same, with some statistical variations.

Not surprisingly, since there is a genetic component to most autoimmune conditions, approximately 6% of first-degree relatives (parents, siblings and children) of a celiac individual will also have CD.

Is there a cure for CD?

Unfortunately, there is no absolute cure for CD. To prevent the damage to the intestine and secondary health problems, celiacs must adhere to a carefully monitored, gluten-free diet. Even if the food a celiac eats starts out as gluten-free, preparation has to be just as carefully monitored, because if a food item comes into contact with non-gluten free food, it has to be considered contaminated (from a celiac perspective). Since gluten molecules are large, gluten can't be absorbed through the skin, but it is easy for a celiac to touch something containing gluten, put fingers or hands in the mouth, and ingest it. The good news is that as long as a celiac avoids the problem grains and stays carefully and consistently on the diet for life, he or she can basically lead a healthy life.

So what does a person with CD eat?

There's no question that the gluten-free diet is difficult, as everything ingested – food, medications, and supplements – must be carefully checked for anything that might contain sources of gluten. Food labels don't necessarily tell the whole story, either, as current FDA labeling requirements permit manufacturers to not mention certain processing ingredients. (Ever seen an “emulsifier” on an ingredient label? This ingredient can be wheat based, which is not gluten free, or corn based, which is gluten free. Celiacs have to know for sure before eating that product.)

Baked goods are tricky, as breads, cakes, cookies, etc. must be made with flour comprised of substitutes for wheat. Celiacs use rice flour, potato starch flour, tapioca starch flour and bean flours in baking; gluten-free baking techniques are a whole different ball game for a newly diagnosed celiac to learn.

Going out to eat can be a minefield, and celiacs often wind up playing “20 questions” with restaurant servers to make sure what they order and how they order it is what gets served up. For example, salads can be gluten free, but a celiac had better make sure that it doesn't get piled with croutons!

The up-side is that so many fresh, unprocessed foods are available in the diet, and celiacs can eat very well – meats, poultry, seafood, fruits and vegetables, and gluten-free grains (including rice, potatoes, corn, quinoa, millet, amaranth and buckwheat) are all inherently gluten-free. In addition, there are a number of vendors and distributors who sell gluten-free food products by mail order - the UPS man is truly the friend of the celiac. More and better ingredients and products have been developed over the past decade and more are appearing over time.

Why haven't I heard of this condition before?

Great question! We keep asking our doctors and scientists the same thing.

In all seriousness, there is a significant lack of education among the United States health care community about celiac disease. Because CD has historically been considered a “rare” disease (which it isn't), very little attention is paid to it in the training of doctors. The average individual with celiac disease spends 11 years and is seen by a number of doctors before obtaining a correct diagnosis and being placed on a gluten-free diet.

Over the past few years, however, as more and more celiacs are correctly diagnosed, the word is slowly getting out and more health care professionals are being educated about CD. We want to help that educational process along, so that everyone who should be diagnosed with celiac disease is diagnosed and can get healthy.

What resources are available to celiacs and their families?

Local support groups have been of great help to celiacs in learning about and adjusting to a gluten-free lifestyle. All manner of physical and emotional issues confront a newly-diagnosed celiac, and celiacs helping celiacs is one of the best resources.

A few national organizations exist to provide materials.

The Internet has been a boon to so many people living with chronic conditions, and celiacs are no exception.

In addition, a website is available for the central Ohio region: www.columbusceliac.org. The site serves as a clearinghouse for local-regional information for celiacs, their friends and their families.

An ever-increasing list of food manufacturers and distributors exists from which celiacs can obtain gluten-free food and other products by mail. Here in Columbus, there are a few local stores that carry various gluten-free products.

Last, but not least, is the Gluten-Free Gang of Central Ohio – the local support group for celiacs.

What is The Gluten-Free Gang of Central Ohio?

The Gluten-Free Gang is a non-profit organization that provides support and education to people in the Central Ohio region. The group consists of both adults with CD and parents of celiac children, and was formed:

- (1) to provide active support to Central Ohio celiacs and their families;
- (2) to share practical information on successfully living a gluten-free lifestyle in the Central Ohio area;
- (3) to educate the lay and medical community about CD;
- (4) to raise awareness about CD in the central Ohio area; and
- (5) to raise funds to support local CD initiatives and international research

Mary Kay Sharrett, MS RD LD CNSD, a dietitian with over ten years' experience with celiac disease, assisted in originally forming the support group, and continues as the Gang's liaison with Children's Hospital.

What activities and events are supported by the Gluten-Free Gang?

- **Bi-monthly meetings.** The Gluten-Free Gang meets every other month through most of the calendar year. Meeting topics cover a broad range of issues relevant to the celiac community, and are a prime opportunity to ask questions, share information and ideas, and to support and be supported.
- **Annual Celiac Workshop.** Children's Hospital sponsors our annual conference, held in November, which offers a noted guest speaker, other experts in the field, and smaller workshops on issues related to CD. This conference is a full day, packed with information and is a great opportunity to meet and socialize with other celiacs and their families (adults and children both). Various vendors bring

products for sampling and purchase. The 2003 Conference was our most successful event yet, with over 425 people in attendance.

- **“Making Tracks for Celiacs”**. The second annual international walk for celiac disease was held May 3, 2003, and locally over \$8,000 was raised to fund research projects conducted by the Center for Celiac Research. The third annual event, scheduled for Saturday, May 1, 2004, and to be held at Beekman Park on the campus of The Ohio State University will again benefit our local efforts and support the Center for Celiac Research.
- **Annual Celiac Golf Outing**. The first annual golf outing for celiac disease will take place on June 26, 2004 and all proceeds will benefit the Gluten-Free Gang’s local awareness and educational programs.

What is the Center for Celiac Research (CFCR)?

The CFRC, based at the University of Maryland, Baltimore, is the first multidisciplinary institution in the United States to be thoroughly engaged in clinical care, diagnostic support, education and research in celiac disease. We have attached more detailed information from the Center’s website (www.celiaccenter.org) for review.

Why are the efforts of the CFRC important?

Prior to the first “Making Tracks for Celiacs” event, the Center had already raised approximately \$450,000 in funds from individuals in the celiac community, not from large corporate donations. As described in the attached materials, the results of the epidemiology study have been crucial in establishing how many people are affected by celiac disease – we now can accurately demonstrate that CD is not rare. However, scientific research takes time and is not cheap; there is so much more to be done. Current initiatives of the CFRC include:

- **Celiac Prevalence Study** was published in the Archives of Internal Medicine showing that CD is not a rare disease and may affect as many as 2.5 million people in the U.S.
- **Media awareness** of CD was increased dramatically by working with many media outlets. *The Today Show* has aired a segment on the disease, *The Washington Post* has published a front page article and CD was included in over 50 other media outlets, including *The Wall Street Journal*.
- Organized the **2nd Annual International Walk** for CD. Participation increased to 30 cities and 5 countries.
- Created the **American Celiac Task Force** to focus on an issue affecting the daily life of every celiac – the need for a clear and understandable food labeling policy. Senate HELP Committee unanimously passed S. 741 which included the food labeling provisions and the House introduced H.R. 3684, the Food Allergen Labeling and Consumer Protection Act.
- Initiated a **Case-Finding Study** to estimate the change in incidence of adult CD resulting from routine serological screening and to evaluate the cost-effectiveness of a case-finding strategy for CD.

- Established a Fellowship Program to train the next generation of health care professionals in CD.
- Created a **New and Improved Website** - www.celiaccenter.org

What is the “Making Tracks for Celiacs” Event All About?

Saturday, May 1, 2004 is the date for the third local event held to benefit the celiac community. Literally thousands of celiacs around the world, their friends and family members have already committed to walking miles to raise money to support ongoing and future education and research relating to celiac disease.

Local support groups, like The Gluten-Free Gang of Central Ohio, will organize the event in their own cities and regions. Each local group may choose to retain up to 25% of funds raised to fund local education efforts. The Gluten-Free Gang is using funds raised the past two years to develop educational materials and host educational sessions for health care providers and their staffs. The CFCR will receive the remaining 75% to fund new projects and work relating to develop a permanent treatment for celiac disease.

How Can I Help?

1. Come walk with us.

Join us on Saturday, May 1, 2004 at Fred Beekman Park (corner of Lane Avenue and Kenny Road) on the campus of The Ohio State University. It's a great way to enjoy the outdoors, get some exercise, and support your local celiac community at the same time.

2. Come shop with us.

Browse the myriad choices of our Silent Auction, part of the festivities at Fred Beekman Park on Saturday, May 1, 2004. Shop til you drop — it's for a good cause!

3. Make an additional donation to the Gluten-Free Gang of Central Ohio.

Your contribution will be tax deductible, as the Gang has currently filed for 501(c)3 non-profit status. Please make your check payable to **The Gluten-Free Gang of Central Ohio.**

Or

You may also make your check out directly to **UMB** (University of Maryland at Baltimore) and they will reimburse the Gluten-Free Gang its 25% of the total donation.

4. Help us find matching or additional sponsorship for the walk.

Do you know of any companies or individuals who could assist with monetary or material support? We would appreciate the opportunity to speak with anyone who can help us make this event a success, through direct funds raised or items for our silent auction, the proceeds of which will boost our efforts.