Celiac Disease

(pronounced SEE-LEE-ACK)

(Also known as Celiac Sprue, malabsorption disease, wasting away disease)

Often undiagnosed or misdiagnosed, Celiac Disease is a genetic disorder that affects children and adults in all stages of life. Persons with celiac disease are unable to eat foods that contain gluten contained in wheat, rye, barley, and possibly oats. The protein gliadin, which is found in gluten, sets off an auto immune reaction that causes the flattening and destruction of the villi in the small intestines.

Untreated celiac disease can be life threatening. Celiacs are more likely to be afflicted with problems relating to malabsorption, including osteoporosis, tooth enamel defects, central and peripheral nervous system disease, pancreatic disease, gastrointestinal organ disorders, and gynecological disorders.

Recent studies by the University of Maryland estimate 1 in 133 have celiac disease. A National Institute of Health study announced in July, 2004, indicate it may be as many as 1 in 100. Of that number, it is estimated that only 1-2% have been diagnosed. Research indicates celiac, once thought of as a rare disease, is twice as common as Crohn's, colitis, and Cystic Fibrosis combined.

Treatment for celiac disease is strict adherence to a gluten free diet for life.

This brochure was created and distributed by the Cincinnati Celiac Support Group.

How is Celiac Diagnosed?

When reviewing medical history and symptoms with a physician, consider the following: Family history of celiac, thyroid disease, or other auto immune disorders, and frequency and type of symptoms. Celiac disease is most often diagnosed by family physicians and gastroenterologists working together.

Symptoms

Physicians will look for symptoms such as emaciation, anemia, low blood pressure, dermatitis herpetiformis, easy bruising, signs of severe vitamin/mineral deficiency such as muscle spasms or bone tenderness, edema, irritable bowel syndrome, diarrhea or constipation, abdominal distention, and passing food largely undigested.

Diagnostic Tests

There are two main ways of diagnosing celiac disease. Endoscopy (EGD) with biopsy of the small intestine is an outpatient procedure performed under anesthesia. The endoscope is passed through a small tube inserted in the throat, through the stomach, and into the small intestine. A camera shows the condition of the villi and tiny pieces of tissue may be removed for further examination.

Blood tests, sometimes referred to as a celiac blood panel, can aid in diagnosis. Tests may include, but are not limited to, serologic tests such as AEA, AGA, AGG, total serum IgA, and tTG, and/or tolerance/absorption tests such as lactose tolerance and D-Xylose. While more labs are becoming familiar with these tests, the most reliable with respect to testing for celiac is still Prometheus Laboratories, Inc. in San Diego, California.

If You've Been Diagnosed

Don't panic. It's normal to feel scared, confused, and overwhelmed but now you can start the healing process. Don't be afraid to ask for help. Take advantage of as many available resources as you can. The more informed you are, the healthier you'll be. Read labels carefully EVERY time you purchase something. Formulas can change. Labels can be misleading. Some companies even use "gluten free" on the label but the ingredient statement may show some form of oats or a derivative of another forbidden grain. Note that some studies have shown oat gluten to be problematic, due to the content of the grain itself or cross contamination. Consuming oats is not recommended.

If you are zero tolerant about allowing wheat, rye, barley, or oat products in your diet but still have problems, consider the possibility of other allergies, food sensitivities, or insufficient nutrient absorption. Due to individual immune systems or intestine condition, it is not unusual for celiacs to have difficulty with other grains, dairy products, or yeasts and fungi. It is also possible that nutrients are not being absorbed at a level for optimum health. These sensitivities can be the cause of fatigue, nasal congestion or post nasal drip, dermatitis, or intestinal discomfort. Try eliminating one item (or group) at a time to see if it makes a difference. A clinical nutritionist can help with additional dietary modifications and supplementation.

Above all, don't "cheat." It isn't worth the consequences. Celiacs need to be gluten free forever. Just take it one day at a time and it will soon become second nature to you.

Cincinnati Celiac Support Group

The Cincinnati Celiac Support Group (CCSG) was formed as a 501c-3 non profit organization in 2001. With roughly 300 members, our purpose is to provide support for celiacs and their families and friends, to educate the general public and the medical community about celiac disease, and to raise funds for research and awareness activities. This brochure was paid for with funds raised by our annual Walk for Celiac.

We publish a member newsletter at least quarterly.

Our web site has information about:

- Upcoming meetings, cooking events, and restaurant gatherings
- R.O.C.K. (Raising Our Celiac Kids) our local subgroup for families with celiac children
- Walk for Celiac our annual 5K fundraising event held each May which benefits CCSG and the University of Maryland

There are also links to:

- Gluten free menus for local and national restaurants
- CCSG's online message board
- Other celiac-related web sites

To become a member, get information, or obtain more brochures, contact us by mail:

Cincinnati Celiac Support Group
PO Box 181611
Fairfield, OH 45018

Visit our web site-you can email us from there as well:
www.geocities.com/cinci_celiac

Other Resources

In Southwestern Ohio/Northern Kentucky
Local stores that sell gluten free foods include: Amy's Natural Nutrition, Bigg's, Cincinnati Natural Foods, Healthy Alternative, Jungle Jim's, Meijer, Susan's Natural World, Trader Joe's, and Wild Oats.

Restaurants

Many restaurants will prepare gluten free meals, and some even have GF menus. Ask the server or speak to the chef. Some celiac friendly restaurants include: Bahama Breeze, Bonefish Grill, Carrabbas, Don Pablo's, First Watch, Mitchell's Fish Market, PF Chang's, My Three Chefs, Outback Steakhouse, Smokey Bones, and Tony Romas.

Cooking at Home

Consult a cookbook by one of these authors: Carol Feinstein, Bette Hagman, Dana Korn, Karen Roberson, or Connie Sarros. Periodically, CCSG teams up with Jungle Jim's or other local cooking schools to conduct gluten free cooking classes for the public.

Helpful Publications

In addition to newsletters produced by CCSG, Celiac Disease Foundation (CDF), and Celiac Sprue Association (CSA/USA), good articles, recipes, and product ads are found in Living Without magazine, Gluten-Free Living, and Glutenfreeda online cooking magazine.

Sample Forbidden List

Below are some basic forbidden foods on a gluten free diet. It is not all inclusive. Please refer to celiac.com for an excellent list. Unsafe foods include anything made of, or made from derivatives of, wheat, rye, barley, and possibly oats. This includes: beer, brewer's yeast, bulgar, couscous, farina, kamut, malt, semolina, spelt, tabbouleh, teriyaki and soy sauces, triticale, and vegetable starch.

Gluten can be a hidden item used in the processing of items such as dextrins, caramel color, artificial or natural flavoring. You must read labels. Beware—gluten can be found in unlikely places such as in rice or soy beverages or cereal, grilled, fried, or toasted restaurant foods (due to contamination), medicines, ice cream, cosmetics, ground spices, stamps, envelopes, gummed labels, and bulk bins.

Notice what country your food comes from. Items that are gluten free when processed in North America may be unsafe when manufactured in other countries. When in doubt, call the manufacturer. Most are quite helpful.

On the Web

A wealth of good information can be found online. Since addresses may change, please search for the following sites: Celiac.com, Gluten Intolerance Group, Celiac Disease Foundation, University of Maryland Center for Celiac Research, Columbia University, University of Chicago, Gluten Free Mall, Celiac Sprue Association, Mayo Clinic, Silly Yaks, Delphi Forums, and Cel-Kids.