Partners in Research

Creighton University Medical Center

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THE CREIGHTON UNIVERSITY OSTEOPOROSIS RESEARCH CENTER

# Living with Osteoporosis and Gluten-Enteropathy

*The Many Faces of Secondary Osteoporosis*

Osteoporosis, though multifactoral, is most often encountered as a result of risk factors such as inheritance, hormonal deficiencies, inadequate activity and nutritional intake, compounding age-related bone loss. There are, however, a number of secondary causes of osteoporosis which require unique work-up and treatment. If they are not ruled out in so called "typical" cases, important opportunity for timely and effective intervention is delayed if not completely over-looked. This issue will look at one of these secondary causes; gluten-sensitive enteropathy, also known as celiac sprue or celiac disease.

## What is celiac disease (CD)?

Celiac disease is a digestive disease that damages the small intestine and interferes with absorption of nutrients from food. People who have celiac disease cannot tolerate a protein called gluten, which is found in wheat, rye, and barley. When people with celiac disease eat foods containing gluten, their immune system responds by damaging the small intestine. Specifically, tiny fingerlike protrusions, called villi, on the lining cells of the small intestine are lost. Nutrients from food are absorbed into the bloodstream through these villi. Without villi, a person becomes malnourished--regardless of the quantity of food eaten.

Because the body's own immune system causes the damage, celiac disease is considered an autoimmune disorder. However, it is also classified as a disease of malabsorption because nutrients are not absorbed. Celiac disease is a genetic disease, meaning that it runs in families. Sometimes the disease is triggered--or becomes active for the first time--after surgery, pregnancy, childbirth, viral infection, or severe emotional stress

## What are the symptoms?

Celiac disease affects people differently. Some people develop symptoms as children, others as adults. One factor thought to affect when and how celiac appears is whether and how long a person was breastfed--the longer one was breastfed, the later symptoms of celiac disease appear and the more atypical the symptoms. Other factors include the age at which one began eating foods containing gluten and how much gluten is eaten.

Symptoms of celiac disease may or may not occur in the digestive system. For example, one person might have diarrhea and abdominal pain, while another person has irritability or depression. In fact, irritability is one of the most common symptoms in children.
Symptoms of celiac disease may include one or more of the following:

- recurring abdominal bloating and pain
- chronic diarrhea
- weight loss
- pale, foul-smelling stool
- unexplained anemia (low red blood cell count)
- gas
- bone pain
- behavior changes
- muscle cramps
- fatigue
- delayed growth
- failure to thrive (in infants)
- pain in the joints
- seizures
- tingling numbness in the legs (from nerve damage)
- pale sores inside the mouth, called aphthous ulcers
- painful skin rash, called dermatitis herpetiformis
- tooth discoloration or loss of enamel
- Reproductive issues (miscarriages, infertiltiy) missed menstrual periods (often because of excessive weight loss)

Anemia, delayed growth, and weight loss are signs of malnutrition--not getting enough nutrients. Malnutrition is a serious problem for anyone, but particularly for children because they need adequate nutrition to develop properly. Some people with celiac disease may not have symptoms. The undamaged part of their small intestine is able to absorb enough nutrients to prevent symptoms.

However, people without intestinal symptoms are still at risk for the complications of celiac disease.

## How Common is Celiac Disease?

CD is relatively common, affecting 1 of every 120-300 persons in Europe and North America. It is seen frequently in patients presenting with osteoporosis. Celiac sprue results from an inappropriate T-cell-mediated immune response against ingested gluten in genetically predisposed people. Initially it was thought that CD always manifested itself as intestinal symptoms. But now we recognize that approximately 50 percent of adult patients do not have clinically significant diarrhea. Iron-deficiency anemia is the most common clinical presentation in adults with gluten-sensitive enteropathy.

## How is celiac disease diagnosed?

Diagnosing celiac disease can be difficult because some of its symptoms are similar to those of other diseases, including irritable bowel syndrome, Crohn's disease, ulcerative colitis, diverticulosis, intestinal infections, chronic fatigue syndrome, and depression. Recently, researchers discovered that people with celiac disease have higher than normal levels of certain antibodies in their blood. Antibodies are produced by the immune system in response to substances that the body perceives to be threatening. To diagnose celiac disease, physicians test blood to measure levels of antibodies to endomysium and tissue transglutaminase. If the tests and symptoms suggest celiac disease, the physician may remove a tiny piece of tissue from the small intestine to check for damage to the villi. This is done in a procedure called a biopsy: the physician eases a long, thin tube called an endoscope through the mouth and stomach into the small intestine, and then takes a sample of tissue using instruments passed through the endoscope. Biopsy of the small intestine is the best way to diagnose celiac disease.

**Screening for celiac disease** involves testing asymptomatic people for the antibodies (see above). Americans are not routinely screened for celiac disease. However, because celiac disease is hereditary, family members--particularly first-degree relatives--of people who have been diagnosed may need to be tested for the disease. About 10 percent of an affected person's first-degree relatives (parents, siblings, or children) will also have the disease. The longer a person goes undiagnosed and untreated, the greater the chance of developing malnutrition and other complications.

## What is the treatment?

The only treatment for celiac disease is to follow a gluten-free diet--that is, to avoid all foods that contain gluten. For most people, following this diet will stop symptoms, heal existing intestinal damage, and prevent further damage. Improvements begin within days of starting the diet, and the small intestine is usually completely healed--meaning the villi are intact and working--in 3 to 6 months. (It may take up to 2 years for older adults.) Vitamin D deficiency should be corrected. After 1-3 months the serum 25(OH)D level should be measured. Patients should consume approximately 12-1500 mg of elemental calcium daily. If serum iron levels are low patients may require iron supplements as well. The gluten-free diet is a lifetime requirement. Eating any gluten, no matter how small an amount, can damage the intestine. This is true for anyone with the disease, including people who do not have noticeable symptoms. Depending on a person's age at diagnosis, some problems, such as delayed growth and tooth discoloration, may not improve. A small percentage of people with celiac disease do not improve on the gluten-free diet. These people often have severely damaged intestines that cannot heal even after they eliminate gluten from their diet. Because their intestines are not absorbing enough nutrients, they may need to receive intravenous nutrition supplements. Drug treatments are being evaluated for unresponsive celiac disease. These patients may need to be evaluated for complications of the disease.

## The Gluten-Free Diet

A gluten-free diet means avoiding all foods that contain wheat (including spelt, triticale, and kamut), rye, and barley--in other words, most grain, pasta, cereal, and many processed foods. Despite these restrictions, people with celiac disease can eat a well-balanced diet with a variety of foods, including bread and pasta. For example, instead of wheat flour, people can use potato, rice, soy, or bean flour. Or, they can buy gluten-free bread, pasta, and other products from special food companies.

Whether people with celiac disease should avoid oats is controversial because some people have been able to eat oats without having a reaction. Scientists are doing studies to find out whether people with celiac disease can tolerate oats. Until the studies are complete, people with celiac disease should follow their physician or dietitian's advice about eating oats. A dietitian is a health care professional who specializes in food and nutrition.

Plain meat, fish, rice, fruits, and vegetables do not contain gluten, so people with celiac disease can eat as much of these foods as they like. Examples of foods that are safe to eat and those that are not are provided below.

The gluten-free diet is complicated. It requires a completely new approach to eating that affects a person's entire life. People with celiac disease have to be extremely careful about what they buy for lunch at school or work, eat at cocktail parties, or grab from the refrigerator for a midnight snack. Eating out can be a challenge as the person with celiac disease learns to scrutinize the menu for foods with gluten and question the waiter or chef about possible hidden sources of gluten. Hidden sources

of gluten include additives, preservatives, and stabilizers found in processed food, medicines, and mouthwash. If ingredients are not itemized, you may want to check with the manufacturer of the product. With practice, screening for gluten becomes second nature. A dietitian can help people learn about their new diet. Also, support groups are particularly helpful for newly diagnosed people and their families as they learn to adjust to a new way of life.

## What Are The Complications of Celiac Disease?

Damage to the small intestine and the resulting problems with nutrient absorption put a person with celiac disease at risk for several diseases and health problems.

- Lymphoma and adenocarcinoma are types of cancer that can develop in the intestine.
- Osteoporosis is a condition in which the bones become weak, brittle, and prone to breaking. Poor calcium and vitamin D absorption is a contributing factor to osteoporosis.
- Miscarriage and congenital malformation of the baby, such as neural tube defects, are risks for untreated pregnant women with celiac disease because of malabsorption of nutrients.
- Short stature results when childhood celiac disease prevents nutrient absorption during the years when nutrition is critical to a child's normal growth and development. Children who are diagnosed and treated before their growth stops may have a catch-up period.
- Seizures, or convulsions, result from inadequate absorption of folic acid. Lack of folic acid causes calcium deposits, called calcifications, to form in the brain, which in turn cause seizures.

## Diseases linked to Celiac Disease

People with celiac disease tend to have other autoimmune diseases as well, including

- dermatitis herpetiformis
- thyroid disease
- systemic lupus erythematosus
- type 1 diabetes
- liver disease
- collagen vascular disease
- rheumatoid arthritis
- Sjögren's syndrome

The connection between celiac and these diseases may be genetic.

**Dermatitis Herpetiformis (DH)** *is a severe itchy, blistering skin disease caused by gluten intolerance. DH is related to celiac disease because both are autoimmune disorders caused by gluten intolerance, but they are separate diseases. The rash usually occurs on the elbows, knees, and buttocks. Although people with DH do not usually have digestive symptoms, they often have the same intestinal damage as people with celiac disease. DH is diagnosed by a skin biopsy, which involves removing a tiny piece of skin near the rash and testing it for the IgA antibody. DH is treated with a gluten-free diet and medication to control the rash, such as dapsone or sulfapyridine. Drug treatment may last several years.*

## THE GIFT OF GIVING

***Consider a donation in honor of a loved one to the Osteoporosis Research Center***

Just mail this form to: Osteoporosis Research Center
601 North 30th Suite 5766
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A Contribution is enclosed to the Recker/Pappajohn Osteoporosis Research Center Endowment

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# May is Osteoporosis Awareness and Prevention Month

During the month of May we are celebrating Osteoporosis Awareness and Prevention Month. To help increase the awareness of Osteoporosis we will be offering courtesy bone density scans. There will be no cost to you and it will only take one hour of your time. You must be at least 20 years old and have not had a scan within the past two years at the Creighton Osteoporosis Research Center. Call by May 31, 2007 to schedule your appointment. There is no obligation to join a research study, but information will be available. 402-280-BONE(2663)

Osteoporosis Research Center

Creighton University Medical Center
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# *The Honor Roll*

**Karen Rafferty, R.D., L.M.N.T.,** senior research dietitian for the Osteoporosis Research Center at Creighton University Medical Center, has been awarded the 2006 Joan Werblow Nutrition Education Award. The award, which recognizes exceptional leadership in nutrition education by promoting the health benefits of dairy foods, was presented by the American Dairy Association and Dairy Council of Nebraska at the organization's annual meeting. Rafferty is an award-winning author and respected voice in calcium nutrition, food fortification, and mineral bioavailability, the council noted in presenting her with the award. Her published research on potassium and calcium served as supporting documentation for the 2005 U.S. Department of Agriculture's Dietary Guidelines for Americans and earned her the American College of Nutrition's "Best Scientific Paper of the Year" honor in 2005. Rafferty is a member of the American Dietetic Association and a speaker for the Nutrition Working Group of the American Society for Bone and Mineral Research. (You Rock Rafferty!)

**An Endowed Professorship in Nephrology** has been established through a joint effort of Creighton University School of Medicine's Division of Nephrology and DCI (Dialysis Clinic, Inc), the largest nonprofit dialysis provider in the United States. The professorship has been named in honor of J. Dan Egan, M.D., a senior nephrologist, master clinician and recognized expert in the diagnosis and treatment of metabolic bone disease. Dr. Egan has devoted his life to serving others and does so with grace and charm. He continues to teach and provide care to patients at the Omaha Veterans Administration Medical Center in addition to the Creighton Osteoporosis Research Center. (We love ya, doc!)

**An Endowed Chair in Nursing** (the first in nursing) was inaugurated May 2nd installing one of the Osteoporosis Research Centers primary investigators, Joan Lappe PhD, RN, MS '85 as the first chair holder. (GO NURSING!)

# Opportunities to Participate

***The Creighton University Osteoporosis Research Center is conducting the following studies. If you have any questions, please call 402-280-BONE (280-2663) or Toll-free 1-800-368-5097.***

### INTERESTED IN JOINING A NUTRITIONAL SUPPLEMENT STUDY?

This is a 6 month study evaluating the potential effectiveness of a nutritional supplement on bone density.
Eligible participants will receive at no cost to them a pre-study health screening which includes a bone density scan.
Requirements:

- Female, age 45-55
- Caucasian
- Post-menopausal for 1 to 3 years and no hysterectomy
- Not currently taking any hormones
- Not currently taking osteoporosis medication
- Not currently taking long term steroid therapy
- No cancer, except for basal or squamous cell skin cancer

For more information, contact our research associates at 280-BONE (2663) or 1-800-368-5097, ext. 2663

### HAVE YOU HAD A BROKEN BONE?

You may qualify for a bone mineral density scan to evaluate your bone health at no cost to you. The study involves no medication.
Do you meet the following criteria?

- Ages 20-48
- Having regular menstrual cycles
- Not currently on treatment for osteoporosis
- The broken bone occurred after age 18

For more information, please contact Jeanette LeMaster, RN, CCRC at 280-4839 or 1-800-368-5097 or e-mail jml@creighton.edu

### THE MILK MINERAL STUDY

*Milk, calcium supplements, Vitamin D and bone density scans provided at no cost. Stipend available. Only 4 visits in 6 months for those who qualify.*

- Women over age 50
- Past menopause for more than 5 years but less than 10 years
- Dairy intake of 1 serving or less a day
- Must be willing to drink 3 servings of milk a day for the duration of the study or take a calcium supplement
- Not currently taking steroids, calcium supplements, hormone replacement or prescription osteoporosis medication

If interested contact Julie Stubby, Project Manager, at 280-BONE (2663) or 1-800-368-4958 and mention “milk mineral” study.

### RELATIONSHIP BETWEEN GENES AND RISK OF SUFFERING A HIP FRACTURE

*You must be a woman age 50 or above and have broken your hip. The study includes:*

- Bone density scan at no cost for qualifying individuals
- No medication
- One visit with one blood draw

For more information, please contact Jennifer Larsen, RT (R) (BD) (ARRT), CDT at 280-4489 or 1-800-368-5097 or e-mail jennyl@creighton.edu

# The Omaha Nuns Project

It all started in 1967 when Dr. Heaney and Rita Ryan recruited nearly 200 healthy young Omaha-area nuns, age 35-45 to participate in a prospective study of calcium metabolism. The data collected in this study have been a font of information. It showed that calcium balance is influenced by such variables as body size, vitamin D and estrogen levels, age, race, the source and quantity of calcium as well as other nutrient interactions. It has provided the principle scientific basis for the National Institutes of Health, recommendations for adult calcium intake, and have established the gold standard measurement of calcium absorption using a radioactive tracer method. Originally the studies involved and eight-day in-patient stay, but now is cost-prohibitive. The women, now in the 70’s and 80’s, still return to the unit for calcium absorption measurements and bone density scans. With their generosity of time, good humor and good will, they continue to shape our understanding of the interrelated factors that play a role in the calcium balance equation of women’s health. The Osteoporosis Center hosted a fortieth Anniversary celebration at a reception April 25th here at Creighton. Memories and stories were shared and a good time had by all.

# Bone Appétit

*Gluten-Free Recipes*

## Featherlight Rice Flour Rolls

*(Betty Hagman/Sandi Allen)*

**Flour Mix:**

3 cups rice flour
3 cups cornstarch
3 cups tapioca flour
3 Tbsp potato flour

**Rolls:**

4 ½ tsp dry yeast
4 cups Featherlight Flour Mix
2 tsp unflavored gelatin
1 tsp salt
1 tsp vinegar
1 egg
¼ cup sugar
1 Tbsp xanthan gum
2 tsp egg replacer
½ cup dry milk powder
4 tsp honey
2 Tbsp powdered egg whites (do not dilute)
2 cups lukewarm water, 110-115 degrees, divided
1/3 cup buttter, melted and cooled to room temperature

Dissolve yeast in 1 cup of lukewarm water to which you have added 1 tsp of the sugar. Allow to proof.

Combine the remaining sugar with the flour mix, xanthan gum, gelatin, egg replacer, salt, and powdered egg whites. Mix together well. Mix dry milk powder, vinegar and honey with remaining cup of warm water. Add dry ingredients along with the yeast mixture, egg and melted butter. Mix until smooth. (I use a KitchenAid Mixer and a regular hook.)
To shape rolls, drop walnut size dollop of dough into a bowl of rice flour. Shake dough until completely covered with flour. Place on greased Teflon cookie sheet and flatten with fingers to ½ inch. Allow to rise in warm place until double. Bake at 350 degrees for 15 minutes. Use same dough flattened more for pizza shells.

## Deviled Eggs

Hard boiled eggs
Lea & Perrins Worcestershire sauce (few drops)
Hellmann's Dijonaise mustard
Hellmann's mayonnaise
Salt & pepper
Paprika

## Taco Salad

*(Kathy Hayes)*

1 ½ lbs hamburger
3 tomatoes, chopped
Lettuce – almost 1 head, shredded
16 oz or less Catalina salad dressing
1 can kidney beans
1 ½ cups shredded cheese
1 cup toasted corn chips

Fry hamburger, drain. Add beans and refrigerate for a few hours or overnight. Add lettuce, tomatoes and cheese. Add corn chips just before serving. Add dressing and toss. Makes 10-12 servings.

## Crispy Baked Chicken

3 Tbsp margarine or butter
¼ cup grated Parmesan cheese
¼ tsp pepper
2 ½- to 3-pound broiler-fryer chicken pieces
1 ¼ cups Betty Crocker Potato Buds mashed potatoes (dry)
1 egg, beaten
½ tsp salt

Heat oven to 425°. Heat margarine in 13x9x2-inch rectangular pan in oven until melted. Mix potatoes, cheese, salt and pepper. Dip chicken into egg; roll in potato mixture. Place skin side up in pan. Bake uncovered 50 minutes or until thickest pieces are done and coating is crisp. 6 servings. High Altitude (3500-6500 ft): Bake about 1 hour.

## Vanilla Cream Pudding

*(Sandi Allen)*

1 Tbsp sweet rice flour
2 Tbsp cornstarch
2 cups milk
1 tsp flavoring or orange or lemon zest
1/3 cup sugar
½ tsp salt
2 egg yolks, beaten
1 Tbsp butter

Combine first four ingredients. Stir in milk and cook until thick, stirring constantly. Blend a little of the mixture with the eggs to temper. Then add to pan. Heat and boil 1 minute, stirring constantly. Remove from heat.
Add remaining ingredients.

## Yellow Cake with Raspberry Sauce

*(Carol Fenster/Adopted by Sandi Allen)*

**Sauce:**

2/3 cup sugar
¾ cup cold water
2 cups raspberries
2 Tbsp cornstarch
1 Tbsp lemon juice

Combine first two ingredients in saucepan. Add water and cook until thick. Stir in lemon juice and fold in raspberries.
Pour into bottom of 7x11 baking dish. Top with cake batter.

**Cake:**

6 Tbsp butter
1 ¾ tsp grated lemon or orange zest
1 cup white rice flour
2 Tbsp tapioca starch
¼ tsp baking powder
1/3 tsp salt
1 cup sugar
2 large eggs
6 Tbsp potato starch
½ tsp xanthan gum
¼ tsp baking soda
¾ cup buttermilk

Cream butter and sugar. Mix in eggs and zest. Combine dry ingredients. Add buttermilk and dry ingredients alternately to cream mixture, beginning and ending with dry ingredients. Pour on top of raspberry sauce.
Bake at 325 degrees for 35 minutes.