

**SCR**

**16**

<TARGET><BILL>SCR 16</BILL><SUBJECT>SCR  
16</SUBJECT><COMM>HHSS27</COMM></TARGET>

# ALASKA STATE LEGISLATURE

716 W 4<sup>th</sup> Avenue  
Suite 460  
Anchorage AK 99501-2133



State Capitol  
Juneau AK 99801-1182  
907-465-4843  
Fax: 907-465-3871  
800-892-4843

## Senator Cathy Giessel Senate District P

### SPONSOR STATEMENT FOR SCR 16

*“Proclaiming May 2012 to be Celiac Disease Awareness Month.”*

SCR 16 designates May 2012 as Celiac Disease Awareness Month.

Celiac disease - often referred to as gluten intolerance - affects an estimated 3 million men, women and children in the United States. It is one of the most common genetic diseases in the world and affects an estimated 1 in 133 Americans. Assessments indicate that over 5,300 Alaskans (according to the 2010 Census, Alaska’s population is 710,231) are living with this disease and, sadly, 97% (nearly 5,200) don’t even know it.

Misdiagnosis is common and costly. Individuals who are incorrectly diagnosed and not treated for celiac disease can face health care costs averaging \$5,000-\$12,000, not including lost work time. The average length of time for a person to be correctly diagnosed is 6-10 years; left undiagnosed and untreated, Celiac disease can lead to cardiovascular disease, diabetes, autoimmune diseases, malnutrition, vitamin deficiencies, loss of calcium, osteoporosis, lactose intolerance, infertility, certain forms of cancer, depression, and neurological complications. There is no known cause or cure for this disease. It is treated by maintaining a strict, lifelong adherence to a gluten-free diet.

While no cure has yet been found, researchers are hard at work looking for a way to combat and eliminate this genetic disorder. Prestigious institutions like the University of Chicago Celiac Disease Center – which is seeking to find a cure by 2026 – and the University of Maryland Center for Celiac Research are sponsoring teams of scientists and doctors who are tirelessly searching for ways to fight and eventually end Celiac disease.

SCR 16 would observe Celiac Disease Awareness Month by promoting awareness of this prevalent disease, leading to early detection and correct diagnosis. It also provides an opportunity to honor our dedicated health professionals and to recognize individuals and their families whose lives have been affected by this disease.

# FISCAL NOTE

**STATE OF ALASKA**  
**2012 LEGISLATIVE SESSION**

Bill Version SCR 16  
 Fiscal Note Number 1  
 (S) Publish Date 2/8/12

Identifier (file name) \_\_\_\_\_ Dept. Affected \_\_\_\_\_  
 Title SCR 16 CELIAC DISEASE AWARENESS MONTH Appropriation \_\_\_\_\_  
 Allocation \_\_\_\_\_  
 Sponsor Senator Giessel  
 Requester (S) State Affairs OMB Component Number \_\_\_\_\_

**Expenditures/Revenues** (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

	FY13 Appropriation Requested	Included in Governor's FY13 Request	Out-Year Cost Estimates				
			FY14	FY15	FY16	FY17	FY18
<b>OPERATING EXPENDITURES</b>	<b>FY13</b>	<b>FY13</b>	<b>FY14</b>	<b>FY15</b>	<b>FY16</b>	<b>FY17</b>	<b>FY18</b>
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants, Benefits							
Miscellaneous							
<b>TOTAL OPERATING</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

<b>FUND SOURCE</b>		(Thousands of Dollars)					
1002	Federal Receipts						
1003	GF Match						
1004	GF						
1005	GF/Prgm (DGF)						
1037	GF/MH (UGF)						
1178	temp code (UGF)						
<b>TOTAL</b>		<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

<b>POSITIONS</b>							
Full-time							
Part-time							
Temporary							

<b>CHANGE IN REVENUES</b>							
---------------------------	--	--	--	--	--	--	--

**Estimated SUPPLEMENTAL (FY12) operating costs** \_\_\_\_\_ (separate supplemental appropriation required,  
 (discuss reasons and fund source(s) in analysis section)

**Estimated CAPITAL (FY13) costs** \_\_\_\_\_ (separate capital appropriation required;  
 (discuss reasons and fund source(s) in analysis section)

**Why this fiscal note differs from previous version (if initial version, please note as such)**

Prepared by (S) State Affairs  
 Division \_\_\_\_\_  
 Approved by /s/ Senator Wielechowski, Chair  
 \_\_\_\_\_

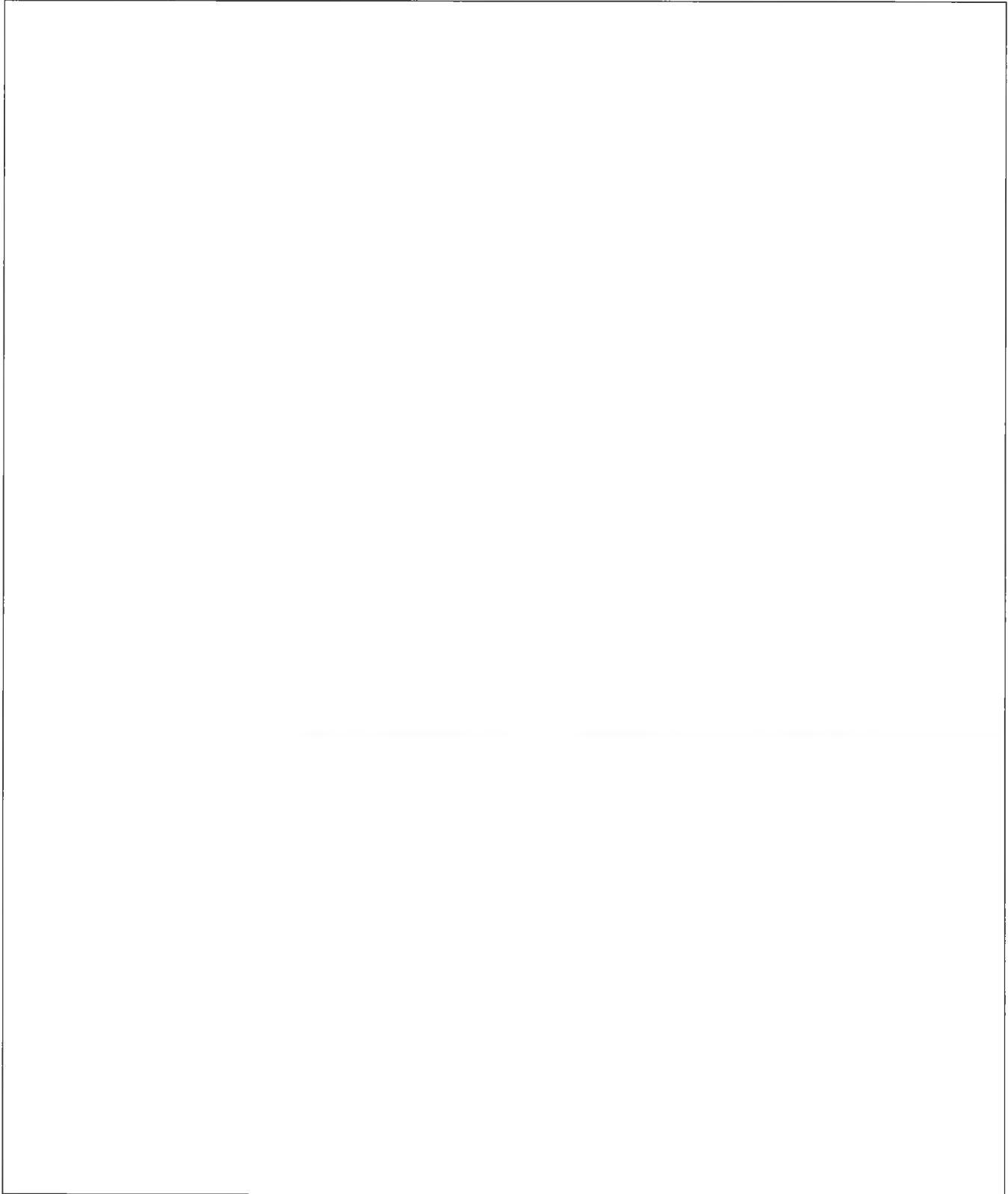
Phone 465-2435  
 Date/Time 2/7/12 12:00 AM  
 Date 2/7/2012

FISCAL NOTE #1

STATE OF ALASKA  
2012 LEGISLATIVE SESSION

BILL NO. SCR 16

**Analysis**



# FISCAL NOTE

**STATE OF ALASKA**  
**2012 LEGISLATIVE SESSION**

Bill Version SCR 16  
 Fiscal Note Number \_\_\_\_\_  
 () Publish Date \_\_\_\_\_

Identifier (file name) SCR16-LEG-SESS-03-27-12 Dept. Affected Legislature  
 Title "Proclaiming May 2012 to be Celiac Disease Awareness Month." Appropriation Legislative Council  
 Allocation Session Expenses  
 Sponsor Senator Giessel, Representative Kerttula  
 Requester Health & Social Services OMB Component Number 783

**Expenditures/Revenues** (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

	FY13 Appropriation Requested	Included in Governor's FY13 Request	Out-Year Cost Estimates				
			FY14	FY15	FY16	FY17	FY18
<b>OPERATING EXPENDITURES</b>	<b>FY13</b>	<b>FY13</b>	<b>FY14</b>	<b>FY15</b>	<b>FY16</b>	<b>FY17</b>	<b>FY18</b>
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants, Benefits							
Miscellaneous							
<b>TOTAL OPERATING</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**FUND SOURCE** (Thousands of Dollars)

1002	Federal Receipts							
1003	GF Match							
1004	GF							
1005	GF/Prgm (DGF)							
1037	GF/MH (UGF)							
1178	temp code (UGF)							
<b>TOTAL</b>		<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**POSITIONS**

Full-time							
Part-time							
Temporary							

**CHANGE IN REVENUES**

--	--	--	--	--	--	--	--

Estimated **SUPPLEMENTAL (FY12) operating costs** \_\_\_\_\_ (separate supplemental appropriation required)  
 (discuss reasons and fund source(s) in analysis section)

Estimated **CAPITAL (FY13) costs** \_\_\_\_\_ (separate capital appropriation required)  
 (discuss reasons and fund source(s) in analysis section)

**Why this fiscal note differs from previous version (if initial version, please note as such)**

Initial Version

Prepared by Jessica Geary, Finance Manager  
 Division Legislative Affairs Agency  
 Approved by Pamela Varni, Executive Director  
Legislative Affairs Agency

Phone 465-6626  
 Date/Time 3/27/12 1:17pm  
 Date 3/27/2012

FISCAL NOTE

STATE OF ALASKA  
2012 LEGISLATIVE SESSION

BILL NO. SCR 16

**Analysis**

This Legislation has zero fiscal impact on the Legislative Affairs Agency.



January 24th, 2012

Alaska State Legislature  
120 4th Street, State Capitol  
Juneau, AK 99801-1182

Dear Committee Members of the House and Senate,

As a diagnosed celiac, I am writing to ask you to join with Senator Cathy Giessel (R-AK) by co-sponsoring SCR 16, which endorses May as Celiac Disease Awareness Month.

Celiac Disease affects 1 in 133 individuals in the United States or roughly 1% of our population. This equals over 3 million Americans, including more than 5,000 Alaskans. These facts were confirmed in 2004 by the National Institutes of Health, yet 97% are undiagnosed with this autoimmune disease because of the lack of awareness and research.

Your support and passage of this resolution will encourage screening and early detection thereby eliminating costly medical expenses from delayed diagnosis and unnecessary years of suffering with a compromised quality of life. The average length of time from symptoms onset to diagnosis is 6-10 years. I was diagnosed after 9 years of misery. This resolution will also serve to align the United States with South America, Europe and Australia for the international observance of May as Celiac Disease Awareness month.

As a celiac who desires to decrease the number of those undiagnosed and hurting, I thank you in advance for your support.

Sincerely,

A handwritten signature in black ink that reads "Brandy Wendler". The signature is written in a cursive, flowing style.

Brandy Wendler, RN, MSN, ACNP-BC  
St. Elias Specialty Hospital Director of Infection Control and Employee Health  
Founder/Executive Director, A Spoonful of Wellness  
Leader of the Anchorage CDF Gluten-free Support Group



# Celiac Disease Foundation

Raising Awareness since 1990

A Nonprofit Corporation

## BOARD OF DIRECTORS

MARC RICHES  
President

RICHARD TASOFF  
Vice President

MARILYN GELLER  
Treasurer

TENAYA CUSTER  
Secretary

MARVIN BERMAN

CHAD HINES

PAMELA ROWE

ELLIOTT TAFT

MICHAEL WEISS, M.D.

## MEDICAL ADVISORY BOARD

MARVIN AMENT, M.D.

Central California Children's Hospital

BOB ANDERSON, PH.D., FRACP

The Walter & Biza Hall Institute, Australia

BETTY BERNARD, M.D. (Retired)

University of Southern California

A LUCIA CALVO, M.P.H., R.D., C.D.E.

SHELLEY M. CASE, B.Sc., RD

PAUL J. CICLITRA, M.D. Ph.D.

St. Thomas' Hospital, London

ERIC ESRAIJIAN, M.D., M.P.H.

University of California, Los Angeles

ALESSIO FASANO, M.D.

University of Maryland, Baltimore

PETER H. R. GREEN, M.D.

Columbia University, New York

NADINE GRZESKOWIAK, RN, CEN

IVOR D. HILL, M.D.

Wake Forest University, North Carolina

EDWARD J. HOFFENBERG, M.D.

The Children's Hospital, Denver

MARTIN F. KAGNOFF, M.D.

University of California, San Diego

DONALD D. KASARDA, Ph.D. (Retired)

U.S. Department of Agriculture

STEPHEN G. LEVINSON, MD.

TED MALAHIAS, D.D.S.

Columbia University, New York

NICOLE MEADOW, MPN, RD

JOSEPH A. MURRAY, M.D.

Mayo Clinic, Rochester, MN

MICHELLE M. PIETZAK, M.D.

University of Southern California

CYNTHIA S. RUDERT, M.D.

DAN W. THOMAS, M.D.

Children's Hospital Los Angeles

EVELYN TRIBOLE, M.S., R.D.

KIMBERLY UPTON, R.D.

WILFRED WENSTEIN, M.D.

University of California, Los Angeles

JOHN J. ZONE, M.D.

University of Utah

## EXECUTIVE DIRECTOR/CEO

RITA T. HOPKINS

## FOUNDER

ELAINE MONARCH

January 26, 2012

Alaska State Legislature  
120 4th Street, State Capitol  
Juneau, AK 99801-1182

Dear Committee Members of the House and Senate,

As the Executive Director/CEO of Celiac Disease Foundation, and on behalf of the millions our organization serves, I am writing to ask you to join with Senator Cathy Giessel (R-AK) by co-sponsoring SCR 16, which endorses May as Celiac Disease Awareness Month, aligning the United States with Australia, Europe and South America for the international observance of May as Celiac Disease Awareness Month.

Celiac Disease, a chronic, genetic, multi-system, multi-symptom, autoimmune disease, affects nearly 3 million people in the United States – 1 in 133, including children – as confirmed in 2004 by the National Institutes of Health. Yet 95% of those affected are undiagnosed or mis-diagnosed because of lack of awareness and research. Undiagnosed Celiac disease can lead to early-onset osteoporosis, delayed growth or onset of puberty, spontaneous miscarriages, infertility, depression, among other conditions.

Your support and passage of SCR 16 will encourage screening and early detection thereby eliminating costly medical expenses from delayed diagnosis and unnecessary years of suffering with a compromised quality of life.

I thank you in advance for your support.

Sincerely,

Rita T. Hopkins

13251 VENTURA BLVD, SUITE 1 • STUDIO CITY • CALIFORNIA 91604-1838  
818/990.2354 • FAX 818/990.2379  
cdf@celiac.org • www.celiac.org

Celiac Disease Foundation  
**TEAM**  
gluten-free™

February 4<sup>th</sup>, 2012

To Our Honorable Senate State Affairs Committee Members:

Celiac Disease is a known and increasingly common, although "invisible" autoimmune disease that leaves it's victims without the ability to consume most common foods enjoyed by the "average" person. Celiac Disease causes the body to attack the lining (microscopic villi) of the GI tract when exposed to gluten, a primary protein in foods containing a variety of grains including but not limited to wheat and barley. This includes both the obvious foods such as breads and pastas, and the non-obvious sources of gluten including soy sauces and various medications that include gluten-containing binders. Not to mention possible unintentional exposures to gluten, due to cross contamination... such as using the same knife that cut a regular piece of bread to cut special "gluten free" bread products. Due to the "invisibility" of this disease, most persons with gluten issues see 8 healthcare providers during an average of 10 years before having a "name/diagnosis" (and "treatment plan") to put with their various and often inconsistent symptoms... in addition to their chronic pain, mental anguish and suffering, daily excruciating gastro-intentional track discomforts, and poor overall health status (due to GI villi damage and thus micro-nutrient deficiencies) by the time they are diagnosed. Due to my field of nutritional expertise as a Registered Dietitian in Anchorage, I commonly instruct, guide and sympathize with my patients who are knowledgably managing this disease (along with their other health conditions).

However with your assistance, and the State of Alaska's support for SCR 16 to increase the awareness of Celiac Disease (with May as the Month of Awareness), we can not only increase exposure about this "invisible" disease, we can increase awareness that exposure to various food elements may be considered "risky" for many within our Alaska state. With this raised awareness, we may be able to raise "safer" restaurant and grocery store atmospheres, by increasing voluntary actions by these facilities to increase choices that are Gluten-Safe and do not risk or compromise their health. This will ultimately increase Alaska's local community positively by promoting a voluntarily safer atmosphere for persons with Celiac Disease and others suffering from gluten-sensitivities.

My Sincere Appreciation for Your Time and Consideration,

DJ Moberly, MPH, RD, LD, CDE  
Registered Dietitian and Certified Diabetes Educator

DJ Moberly  
10260 Valley Park Drive  
Anchorage, AK 99507



January 27, 2012

Alaska State Legislature  
120 4<sup>th</sup> Street, State Capitol  
Juneau, AK 99801-1182

Dear Committee Members of the House and Senate:

The Center for Celiac Research at the University of Maryland has been recognized for the past 15 years as a world leader in the field of celiac disease and gluten sensitivity. The Center houses a comprehensive, multidisciplinary program covering clinical care for adults & children, support services, education and scientific research. The paramount goal of the Center is to increase the awareness of celiac disease and gluten sensitivity in order to provide better care, better quality of life, and more adequate support for the gluten-free community.

It is very important for the following reasons that May is designated as Celiac Awareness Month in the state of Alaska, as it is in Maryland and many other states.

- millions of individuals and their family members are facing the challenges of living with celiac disease; and
- celiac disease is a lifelong autoimmune intestinal disorder found in individuals who are genetically susceptible; people with the disease cannot tolerate certain proteins found in common cereal grains such as wheat, barley and rye; and
- when a person with celiac disease eats foods containing these proteins their immune system responds by damaging the small intestine, which can lead to malnourishment; if left untreated, this damage can be chronic and life-threatening; and
- researchers at the Center for Celiac Research have determined that celiac disease affects 1 in 133 Americans, and it is now considered to be the most common genetic disorder in the world; research indicates that there are approximately 2.5 million people with celiac disease in the U.S., yet only approximately 120,000 of those have been diagnosed; and
- Celiac Disease Awareness Month provides an opportunity to recognize individuals and their families whose lives have been affected by this disease, honor dedicated health professionals and researchers, and raise public awareness.

Sincerely,

Alessio Fasano, M.D.  
Professor of Pediatrics, Medicine, and Physiology  
Director, Center for Celiac Research and Mucosal Biology Research Center  
University of Maryland School of Medicine

Office of Senator Cathy Giessel  
State Capitol Room 7  
Anchorage, AK 99801

Dear Senator Giessel,

My name is Deb Wheaton and I have Celiac Disease.

I am writing you today to add my support to SR 16, your bill to designate May as Celiac Disease Awareness Month in Alaska. Last year I worked closely with the Celiac Disease Foundation and California State Senator Robert Huff to achieve the designation for California. As you may know, May has already been recognized as National Celiac Awareness Month, and states such as California, New York, Oregon, No. Carolina and Ohio have recently come on board. Such designations on the state level allows for increased awareness of the *"#1 Disease You've Never Heard Of"*.

**My personal crusade:**

- Early diagnosis is a personal crusade/passion for me. After being sickly most of her young life, my daughter, Amy, was finally diagnosed in her early 20's. The delay in diagnosis for both of us was over 10 years, which is typical for most Celiacs. This is a genetic disorder and although a simple blood or gene test is all that is needed, somehow it is almost always the last test a Dr. will do. My mother died at age 62 from a Celiac related disease – without ever being diagnosed. On a Gluten-Free diet, my daughter and I are each living a normal healthy life. We have our lives back! And how different all of our lives might have been, if we only had the knowledge. So, my goal is to help raise awareness, which will increase the likelihood that our kids ....their parents, and their grandparents will be tested.

We know that our best hope to raise awareness is through word of mouth and the media. Raising awareness will increase diagnosis and saves lives. Declaring May as Celiac Awareness Month in Alaska will help bring attention to the disease and facilitate that goal.

- *Celiac Disease is the #1 autoimmune disease in the United States. It is a genetic disorder, affecting 1 in 133 Americans, requiring a life-time commitment to a strict gluten-free diet. Ingestion of even a crumb of wheat, rye and/or barley can cause a severe reaction.*
- According to Dr. Peter Green, Director of the Celiac Disease Center, Columbia University, and author of *"Celiac Disease: The Hidden Epidemic"*, Celiac is the #1 genetic autoimmune disease in the country as well as the most common in the world. It is also the most under-diagnosed and/or misdiagnosed with **the average delay in diagnosis being 10 years.**
- ***There is no cure. The "cure" requires a life-time commitment to a strict Gluten-Free diet. Ingestion of even a crumb of wheat, rye and/or barley can cause a severe reaction. Left untreated related diseases include Type 1 Diabetes, Rheumatoid Arthritis, Osteoporosis and Thyroid Disease, and certain types of cancer.***

Thank you for helping us shine a light on *"The #1 disease that you've never heard of"*.

Sincerely,

Deb Wheaton

[www.notevenacrumb.com](http://www.notevenacrumb.com)

*"Raising Awareness, One Crumb at a Time"*

PO Box 20385  
Juneau, AK 99802-0385  
February 7, 2012

The Honorable Cathy Giessel  
Alaska State Senate  
State Capitol, Room 7  
Juneau, AK 99811

Dear Senator Giessel,

Thank you for being so gracious on Saturday evening when I interrupted your dinner at the Baranof. As I mentioned, I was planning to write to thank you for introducing SCR-16, proclaiming May 2012 as *Celiac Awareness Month* and to let you know how grateful I am.

On September 16, 2008, I was diagnosed with Celiac Disease after both a blood test and corroborating biopsy. As SCR-16 notes, while there is no cure, I was glad the treatment was to “merely” give up gluten. I soon learned, however, that the “merely” was forever, and the “gluten” wasn’t as easy to eliminate from my diet as I had hoped. As you know, a world without wheat, rye, (oats) and barley isn’t only about living without some of the grains in breads and cereals, but rather, learning how gluten is hidden in so many other products – such as soy sauce, malt and licorice (really!). And, to make it even more frustrating, it’s discovering that gluten free is not just about eating foods without gluten, but about making sure the gf foods haven’t been *cross-contaminated* with gluten-laden fare.

After reading it, I’m not sure I can add anything to this truly comprehensive resolution, but if you can think of something, please let me know. I so appreciate your efforts in helping to make people realize that eliminating gluten by choice is far different than having to do so.

I’ll be sharing this email with my delegation: Senator Egan and Representatives Kerttula and Muñoz, with the hope they’ll be supportive of your effort.

Sincerely,

Sharon Gaipman

Sharon Gaipman  
PO Box 20385  
Juneau, AK 99802-0385



# Celiac Disease Facts and Figures

Celiac disease is an inherited autoimmune disorder that affects the digestive process of the small intestine. When a person who has celiac disease consumes gluten, a protein found in wheat, rye and barley, the individual's immune system responds by attacking the small intestine and inhibiting the absorption of important 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.

## Prevalence of Celiac Disease in the United States

- In average healthy people: 1 in 133
- In people with related symptoms: 1 in 56
- In people with first-degree relatives (parent, child, sibling) who are celiac: 1 in 22
- In people with second-degree relatives (aunt, uncle, cousin) who are celiac: 1 in 39
- Estimated prevalence for African-, Hispanic- and Asian-Americans: 1 in 236
- In the landmark prevalence study on celiac disease, investigators determined that 60% of children and 41% of adults diagnosed during the study were asymptomatic (without any symptoms).
- During the prevalence study, researchers found that 21% of patients with a positive anti-endomysial antibody test could not receive a biopsy due to the refusal of their physician to perform the procedure or the insurance company to pay for it.

- Only 35% of newly diagnosed patients had chronic diarrhea, dispelling the myth that diarrhea must be present to diagnose celiac disease.

Source: A multi-center study on the sero-prevalence of celiac disease in the United States among both at risk and not at risk groups. Fasano et. al., Archives of Internal Medicine. February 2003.

- Celiac disease affects at least 3 million Americans.
- The average length of time it takes for a symptomatic person to be diagnosed with celiac disease in the US is four years; this type of delay dramatically increases an individual's risk of developing autoimmune disorders, neurological problems, osteoporosis and even cancer.

Source: Characteristics of adult celiac disease in the USA: results of a national survey. Green, P.H. et.al. American Journal of Gastroenterology. 2001, 2006.

- The incidence of autoimmune diseases in the general US population is 3.5%.

In a 1999 study, Ventura, et.al. found that those diagnosed with celiac disease between 2-4 years of age had a 10.5% chance of developing an autoimmune disorder. Additional findings are outlined in the table below:

Age at diagnosis	Chance of developing autoimmune condition
4 – 12 yrs of age	16.7%
12 – 20 yrs of age	27%
Over 20 yrs of age	34%

- Early diagnosis of celiac disease thus is important, as it might prevent complications, and awareness is the key. A recent study in North America shows that an active case-finding strategy in the primary care setting is an effective means to improve the diagnostic rate of Celiac Disease: by screening with the blood test all subjects belonging to known “at-risk” groups such as those listed above, the diagnosis rates increased more than 40-folds.

Source: Duration of exposure to gluten and risk for autoimmune disorders in patients with celiac disease. SIGEP Study Group for Autoimmune Disorders in Celiac Disease. Ventura A, et.al. *Gastroenterology* 1999 Aug;117(2):297-303. Rampertab SD et al. Trends in the Presentation of Celiac Disease *Am J Medicine* 2006 Catassi C et al. Detection of Celiac disease in primary care: a multicenter case-finding study in North America. *Am J Gastroenterol* 2007

Celiac disease affects 1% of healthy, average Americans. That means at least 3 million people in our country are living with celiac disease—97% of them are undiagnosed.

#### Chronic Illness in the United States

Below is a list of some commonly known chronic illnesses and the number of people affected in the United States:

- Epilepsy affects 2.7 million
- Cystic Fibrosis affects 30,000 people
- 17,000 people are living with hemophilia
- Parkinson’s disease affects 1,000,000 individuals
- Ulcerative colitis affects 500,000 people
- Crohn’s disease affects 500,000 Americans

- 2.1 million Americans are living with rheumatoid arthritis
- Lupus affects 1.5 million people
- Multiple sclerosis affects 400,000 people in the United States

#### Putting Celiac Disease in Perspective

- Type 1 Diabetes affects 3 million people; 6% (180,000) of those diagnosed also have celiac disease.
- 610,000 women in the US experience unexplained infertility; 6% (36,600) of these women might never learn that celiac disease is the cause.
- 350,000 people in the United States are living with Down Syndrome; 12% (42,000) of them also have celiac disease.
- The number of people with celiac disease in the U.S. would fill 4,400 Boeing 747 airplanes.
- It would take 936 cruise ships to hold every American with celiac disease.
- Americans with celiac disease could fill Comiskey Park (now US Cellular Field, with 40,000 seats) to watch the Chicago White Sox 55 times.
- U.S. fans with celiac disease could fill Soldier Field, the home of the Chicago Bears, 37 times.
- 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.
- Alaska, Delaware, Washington DC, Hawaii, Idaho, Maine, Montana, Nebraska, New Hampshire, New Mexico, North Dakota, Rhode Island, South Dakota, Utah and Vermont all have populations that are less than 2,200,000 the number of people living with celiac disease in the United States.

#### Facts about the Gluten-Free Diet

- In 2004 the Food Allergen Labeling and Consumer Protection Act became law. This legislation went into effect in 2006 and makes it possible, for the first time, for people with celiac disease to read a food label and determine in a few easy steps if a product is safe to eat. The University of Chicago Celiac Disease Center helped to pass this law.

- There are more than 2,000 gluten free food items available in the United States, and consumers are more likely to find these foods in regular grocery stores.
- From 2004 – 2005, sales of gluten-free foods increased by 77.8 million dollars (a growth of 14.6%).
- The US Department of Agriculture projects that the gluten-free industries revenues will reach \$1.7 Billion by 2010.

Data from [www.bakingbusiness.com](http://www.bakingbusiness.com) August 2005.

**For more information contact the  
University of Chicago Celiac  
Disease Center at 773.702.7593  
or [www.CeliacDisease.net](http://www.CeliacDisease.net).**



**For release:** immediate

## **Multi-Million Dollar Commitment Spurs First-Ever Mouse Model Studies at University of Chicago's Unique Celiac Disease Center**

*University of Chicago Celiac Disease Center Advisory Board Campaign Aims to Uncover New Treatments for World's Most Common Genetic Autoimmune Disease*

**CHICAGO (May 27, 2009)** – The University of Chicago Celiac Disease Center Advisory Board has partnered with The University to launch a two million dollar campaign to support the first-ever mouse model for celiac disease, the world's most common genetic autoimmune disease. Celiac disease affects approximately three million Americans and is triggered by the consumption of gluten--a protein found in wheat, barley and rye.

For the first time, researchers at the University of Chicago Celiac Disease Center will examine the underlying causes of the disease, test new therapies and identify new targets for treatment through mouse model research. Currently a gluten-free diet is only known treatment for celiac disease, offering only partial alleviation of symptoms.

At least ninety-seven percent of people with celiac disease have not been diagnosed. The symptoms are numerous, ranging from intestinal symptoms to neurological and psychological disorders. If undiagnosed and untreated, it can lead to osteoporosis, infertility, neurological conditions, and cancer. In addition, patients with celiac disease have a significantly higher chance of developing other autoimmune diseases, in particular Type-1 diabetes.

Bana Jabri, M.D., Ph.D., Associate Professor, University of Chicago Medical Center, one of the world's leading celiac disease researchers, will develop the new mouse model with the goal of identifying new remedies and preventive treatments aimed at children of families with celiac disease history. The studies will also shed new light on events triggering the development of Type-1 diabetes.

The University of Chicago Celiac Disease Center is the first of its kind in the country. It has been dedicated to raising awareness and meeting the needs of those affected by the disease nationwide through education, research and advocacy since 2001.

- more -

“There is a critical need to provide the proper resources to those who suffer from celiac disease,” said Stefano Guandalini, M.D., professor of pediatrics at the University of Chicago Medical Center, founder and medical director of the Celiac Disease Center. “This commitment from University of Chicago Celiac Advisory Board reaffirms the Celiac Disease Center’s mission to bring cutting edge research, education and encouragement to those affected by the disease”.

Dr. Jabri believes it is essential to create a mouse model of celiac disease to better understand the chain of events leading to celiac disease, its link to autoimmune diseases, and provide sustainable funds to continue programming for many years to come.

**About the University of Chicago Celiac Disease Center**

The University of Chicago Celiac Disease Center has fundamentally improved the care, diagnosis and awareness of celiac disease. In addition, it provides the infrastructure and support that is needed to advance cutting-edge celiac research, including investigations into structure of gluten peptides and the mechanisms by which gluten modifies self molecules. The University of Chicago Celiac Disease Center is a 501-c3 non-profit organization, completely funded by donor contributions.

For more information please visit: [www.celiacdisease.net](http://www.celiacdisease.net)

###

# Celiac Disease

*National Digestive Diseases Information Clearinghouse*



U.S. Department  
of Health and  
Human Services

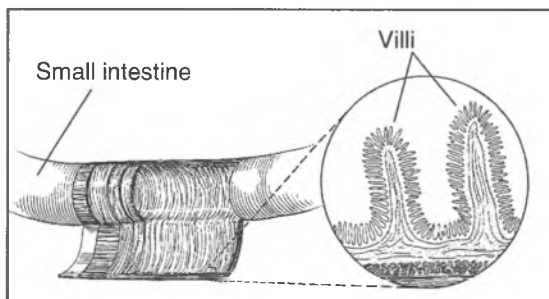
NATIONAL  
INSTITUTES  
OF HEALTH

**NIDDK**  
NATIONAL INSTITUTE OF  
DIABETES AND DIGESTIVE  
AND KIDNEY DISEASES

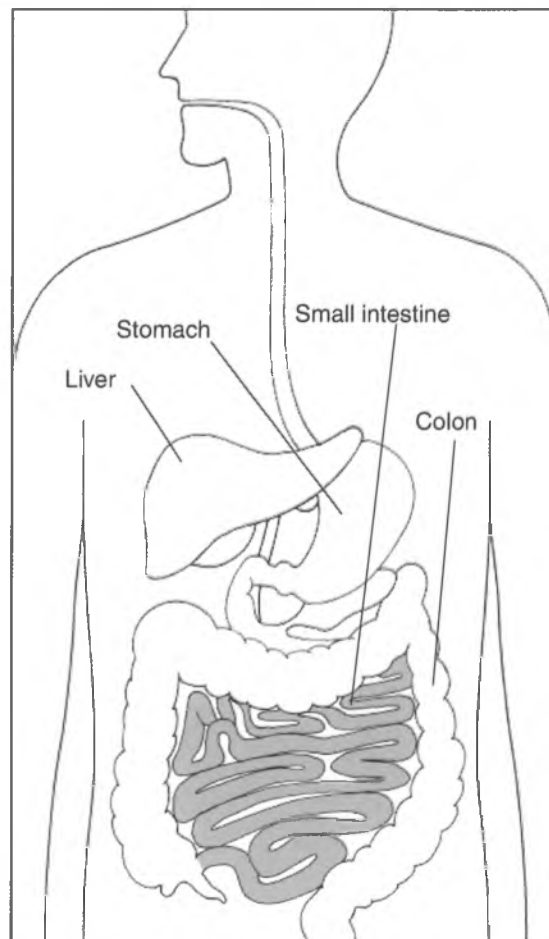
## What is celiac disease?

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 gluten, a protein in wheat, rye, and barley. Gluten is found mainly in foods but may also be found in everyday products such as medicines, vitamins, and lip balms.

When people with celiac disease eat foods or use products containing gluten, their immune system responds by damaging or destroying villi—the tiny, fingerlike protrusions lining the small intestine. Villi normally allow nutrients from food to be absorbed through the walls of the small intestine into the bloodstream. Without healthy villi, a person becomes malnourished, no matter how much food one eats.



Villi on the lining of the small intestine help absorb nutrients.



The small intestine is shaded above.

Celiac disease is both a disease of malabsorption—meaning nutrients are not absorbed properly—and an abnormal immune reaction to gluten. Celiac disease is also known as celiac sprue, nontropical sprue, and gluten-sensitive enteropathy.

Celiac disease is genetic, meaning 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 of celiac disease?

Symptoms of celiac disease vary from person to person. Symptoms may occur in the digestive system or in other parts of the body. Digestive symptoms are more common in infants and young children and may include

- abdominal bloating and pain
- chronic diarrhea
- vomiting
- constipation
- pale, foul-smelling, or fatty stool
- weight loss

Irritability is another common symptom in children. Malabsorption of nutrients during the years when nutrition is critical to a child's normal growth and development can result in other problems such as failure to thrive in infants, delayed growth and short stature, delayed puberty, and dental enamel defects of the permanent teeth.

Adults are less likely to have digestive symptoms and may instead have one or more of the following:

- unexplained iron-deficiency anemia
- fatigue
- bone or joint pain
- arthritis
- bone loss or osteoporosis
- depression or anxiety
- tingling numbness in the hands and feet
- seizures
- missed menstrual periods
- infertility or recurrent miscarriage
- canker sores inside the mouth
- an itchy skin rash called dermatitis herpetiformis

People with celiac disease may have no symptoms but can still develop complications of the disease over time. Long-term complications include malnutrition—which can lead to anemia, osteoporosis, and miscarriage, among other problems—liver diseases, and cancers of the intestine.

## Why are celiac disease symptoms so varied?

Researchers are studying the reasons celiac disease affects people differently. The length of time a person was breastfed, the age a person started eating gluten-containing foods, and the amount of gluten-containing foods one eats are three factors thought to play a role in when and how celiac disease appears. Some studies have shown, for example, that the longer a person was breastfed, the later the symptoms of celiac disease appear.

Symptoms also vary depending on a person's age and the degree of damage to the small intestine. Many adults have the disease for a decade or more before they are diagnosed. The longer a person goes undiagnosed and untreated, the greater the chance of developing long-term complications.

## What other health problems do people with celiac disease have?

People with celiac disease tend to have other diseases in which the immune system attacks the body's healthy cells and tissues. The connection between celiac disease and these diseases may be genetic. They include

- type 1 diabetes
- autoimmune thyroid disease
- autoimmune liver disease
- rheumatoid arthritis
- Addison's disease, a condition in which the glands that produce critical hormones are damaged
- Sjögren's syndrome, a condition in which the glands that produce tears and saliva are destroyed

## How common is celiac disease?

Celiac disease affects people in all parts of the world. Originally thought to be a rare childhood syndrome, celiac disease is now known to be a common genetic disorder. More than 2 million people in the United States have the disease, or about 1 in 133 people.<sup>1</sup> Among people who have a first-degree relative—a parent, sibling, or child—diagnosed with celiac disease, as many as 1 in 22 people may have the disease.<sup>2</sup>

Celiac disease is also more common among people with other genetic disorders including Down syndrome and Turner syndrome, a condition that affects girls' development.

---

<sup>1</sup>Fasano A, Berti I, Gerarduzzi T, et al. Prevalence of celiac disease in at-risk and not-at-risk groups in the United States. *Archives of Internal Medicine*. 2003;163(3):268–292.

<sup>2</sup>Ibid.

## How is celiac disease diagnosed?

Recognizing celiac disease can be difficult because some of its symptoms are similar to those of other diseases. Celiac disease can be confused with irritable bowel syndrome, iron-deficiency anemia caused by menstrual blood loss, inflammatory bowel disease, diverticulitis, intestinal infections, and chronic fatigue syndrome. As a result, celiac disease has long been underdiagnosed or misdiagnosed. As doctors become more aware of the many varied symptoms of the disease and reliable blood tests become more available, diagnosis rates are increasing.

### Blood Tests

People with celiac disease have higher than normal levels of certain autoantibodies—proteins that react against the body's own cells or tissues—in their blood. To diagnose celiac disease, doctors will test blood for high levels of anti-tissue transglutaminase antibodies (tTGA) or anti-endomysium antibodies (EMA). If test results are negative but celiac disease is still suspected, additional blood tests may be needed.

Before being tested, one should continue to eat a diet that includes foods with gluten, such as breads and pastas. If a person stops eating foods with gluten before being tested, the results may be negative for celiac disease even if the disease is present.

### Intestinal Biopsy

If blood tests and symptoms suggest celiac disease, a biopsy of the small intestine is performed to confirm the diagnosis. During the biopsy, the doctor removes tiny pieces of tissue from the small intestine to check for damage to the villi. To obtain the tissue sample, the doctor eases a long, thin tube called an endoscope through the patient's mouth and stomach into the small intestine. The doctor then takes the samples using instruments passed through the endoscope.

## Dermatitis Herpetiformis

Dermatitis herpetiformis (DH) is an intensely itchy, blistering skin rash that affects 15 to 25 percent of people with celiac disease.<sup>3</sup> The rash usually occurs on the elbows, knees, and buttocks. Most people with DH have no digestive symptoms of celiac disease.

DH is diagnosed through blood tests and a skin biopsy. If the antibody tests are positive and the skin biopsy has the typical findings of DH, patients do not need to have an intestinal biopsy. Both the skin disease and the intestinal disease respond to a gluten-free diet and recur if gluten is added back into the diet. The rash symptoms can be controlled with antibiotics such as dapsone. Because dapsone does not treat the intestinal condition, people with DH must maintain a gluten-free diet.

<sup>3</sup>Rodrigo L. Celiac disease. *World Journal of Gastroenterology*. 2006;12(41):6585–6593.

## Screening

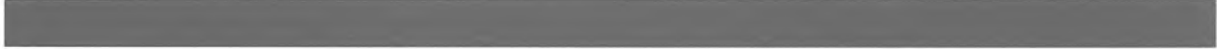
Screening for celiac disease means testing for the presence of autoantibodies in the blood in people without symptoms. Americans are not routinely screened for celiac disease. However, because celiac disease is hereditary, family members of a person with the disease may wish to be tested. Four to 12 percent of an affected person's first-degree relatives will also have the disease.<sup>4</sup>

## How is celiac disease treated?

The only treatment for celiac disease is a gluten-free diet. Doctors may ask a newly diagnosed person to work with a dietitian on a gluten-free diet plan. A dietitian is a health care professional who specializes in food and nutrition. Someone with celiac disease can learn from a dietitian how to read ingredient lists and identify foods that contain gluten in order to make informed decisions at the grocery store and when eating out.

For most people, following this diet will stop symptoms, heal existing intestinal damage, and prevent further damage. Improvement begins within days of starting the diet. The small intestine usually heals in 3 to 6 months in children but may take several years in adults. A healed intestine means a person now has villi that can absorb nutrients from food into the bloodstream.

<sup>4</sup>Ibid.



To stay well, people with celiac disease must avoid gluten for the rest of their lives. Eating even a small amount of gluten can damage the small intestine. The damage will occur in anyone with the disease, including people without noticeable symptoms. Depending on a person's age at diagnosis, some problems will not improve, such as short stature and dental enamel defects.

Some people with celiac disease show no improvement on the gluten-free diet. The most common reason for poor response to the diet is that small amounts of gluten are still being consumed. Hidden sources of gluten include additives such as modified food starch, preservatives, and stabilizers made with wheat. And because many corn and rice products are produced in factories that also manufacture wheat products, they can be contaminated with wheat gluten.

Rarely, the intestinal injury will continue despite a strictly gluten-free diet. People with this condition, known as refractory celiac disease, have severely damaged intestines that cannot heal. Because their intestines are not absorbing enough nutrients, they may need to receive nutrients directly into their bloodstream through a vein, or intravenously. Researchers are evaluating drug treatments for refractory celiac disease.

## **The Gluten-free Diet**

A gluten-free diet means not eating foods that contain wheat, rye, and barley. The foods and products made from these grains should also be avoided. In other words, a person with celiac disease should not eat 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. They can use potato, rice, soy, amaranth, quinoa, buckwheat, or bean flour instead of wheat flour. They can buy gluten-free bread, pasta, and other products from stores that carry organic foods, or order products from special food companies. Gluten-free products are increasingly available from mainstream stores.

## New Food Labeling

The Food Allergen Labeling and Consumer Protection Act (FALCPA), which took effect on January 1, 2006, requires food labels to clearly identify wheat and other common food allergens in the list of ingredients. FALCPA also requires the U.S. Food and Drug Administration to develop and finalize rules for the use of the term “gluten free” on product labels.

“Plain” meat, fish, rice, fruits, and vegetables do not contain gluten, so people with celiac disease can freely eat these foods. In the past, people with celiac disease were advised not to eat oats. New evidence suggests that most people can safely eat small amounts of oats, as long as the oats are not contaminated with wheat gluten during processing. People with celiac disease should work closely with their health care team when deciding whether to include oats in their diet. Examples of other foods that are safe to eat and those that are not are provided in the table on page 8.

The gluten-free diet requires a completely new approach to eating. Newly diagnosed people and their families may find support groups helpful as they learn to adjust to a new way of life. People with celiac disease must be cautious about what they buy for lunch at school or work, what they purchase at the grocery store, what they eat at restaurants or parties, and what they grab for a snack. Eating out can be a challenge. When in doubt about a menu item, a person with celiac disease should ask the waiter or chef about ingredients and preparation or if a gluten-free menu is available.

Gluten is also used in some medications. People with celiac disease should ask a pharmacist if prescribed medications contain wheat. Because gluten is sometimes used as an additive in unexpected products—such as lipstick and play dough—reading product labels is important. If the ingredients are not listed on the label, the manufacturer should provide a list upon request. With practice, screening for gluten becomes second nature.

## The Gluten-free Diet: Some Examples

In 2006, the American Dietetic Association updated its recommendations for a gluten-free diet. The following chart is based on the 2006 recommendations. This list is **not** complete, so people with celiac disease should discuss gluten-free food choices with a dietitian or physician who specializes in celiac disease. People with celiac disease should always read food ingredient lists carefully to make sure the food does not contain gluten.

Allowed Foods		
amaranth	legumes	seeds
arrowroot	millet	sorghum
buckwheat	nuts	soy
cassava	potatoes	tapioca
corn	quinoa	teff
flax	rice	wild rice
Indian rice grass	sago	yucca
Job's tears		
Foods to Avoid		
wheat		barley
• including einkorn, emmer, spelt, kamut		rye
• wheat starch, wheat bran, wheat germ, cracked wheat, hydrolyzed wheat protein		triticale (a cross between wheat and rye)
Other Wheat Products		
bromated flour	graham flour	self-rising flour
durum flour	phosphated flour	semolina
enriched flour	plain flour	white flour
farina		
Processed Foods that May Contain Wheat, Barley, or Rye*		
bouillon cubes	French fries	seasoned tortilla chips
brown rice syrup	gravy	self-basting turkey
candy	imitation fish	soups
chips/potato chips	matzo	soy sauce
cold cuts, hot dogs, salami, sausage	rice mixes	vegetables in sauce
communion wafers	sauces	

\*Most of these foods can be found gluten-free. When in doubt, check with the food manufacturer.

Source: Thompson T. *Celiac Disease Nutrition Guide*, 2nd ed. Chicago: American Dietetic Association; 2006. © American Dietetic Association. Adapted with permission. For a complete copy of the *Celiac Disease Nutrition Guide*, please visit [www.eatright.org](http://www.eatright.org).

## Points to Remember

- People with celiac disease cannot tolerate gluten, a protein in wheat, rye, and barley.
- Untreated celiac disease damages the small intestine and interferes with nutrient absorption.
- Without treatment, people with celiac disease can develop complications such as osteoporosis, anemia, and cancer.
- A person with celiac disease may or may not have symptoms.
- Diagnosis involves blood tests and, in most cases, a biopsy of the small intestine.
- Since celiac disease is hereditary, family members of a person with celiac disease may wish to be tested.
- Celiac disease is treated by eliminating all gluten from the diet. The gluten-free diet is a lifetime requirement.
- A dietitian can teach a person with celiac disease about food selection, label reading, and other strategies to help manage the disease.

## Hope through Research

The National Institute of Diabetes and Digestive and Kidney Diseases conducts and supports research on celiac disease. Researchers are studying new options for diagnosing celiac disease, including capsule endoscopy. In this technique, patients swallow a capsule containing a tiny video camera that records images of the small intestine.

Several drug treatments for celiac disease are under evaluation. Researchers are also studying a combination of enzymes—proteins that aid chemical reactions in the body—that detoxify gluten before it enters the small intestine.

Scientists are also developing educational materials for standardized medical training to raise awareness among health care providers. The hope is that increased understanding and awareness will lead to earlier diagnosis and treatment of celiac disease.

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. For information about current studies, visit [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov).

## **For More Information**

### **American Celiac Disease Alliance**

2504 Duxbury Place  
Alexandria, VA 22308  
Phone: 703-622-3331  
Email: [info@americanceeliac.org](mailto:info@americanceeliac.org)  
Internet: [www.americanceeliac.org](http://www.americanceeliac.org)

### **American Dietetic Association**

120 South Riverside Plaza, Suite 2000  
Chicago, IL 60606-6995  
Phone: 1-800-877-1600  
Email: [knowledge@eatright.org](mailto:knowledge@eatright.org)  
Internet: [www.eatright.org](http://www.eatright.org)

### **Celiac Disease Foundation**

13251 Ventura Boulevard, #1  
Studio City, CA 91604  
Phone: 818-990-2354  
Fax: 818-990-2379  
Email: [cdf@celiac.org](mailto:cdf@celiac.org)  
Internet: [www.celiac.org](http://www.celiac.org)

### **Celiac Sprue Association/USA, Inc.**

P.O. Box 31700  
Omaha, NE 68131-0700  
Phone: 1-877-CSA-4CSA (272-4272)  
Fax: 402-558-1347  
Email: [celiacs@csaceliacs.org](mailto:celiacs@csaceliacs.org)  
Internet: [www.csaceliacs.org](http://www.csaceliacs.org)

### **Children's Digestive Health and Nutrition Foundation**

P.O. Box 6  
Flourtown, PA 19031  
Phone: 215-233-0808  
Fax: 215-233-3918  
Email: [mstallings@naspghan.org](mailto:mstallings@naspghan.org)  
Internet: [www.cdhnf.org](http://www.cdhnf.org)  
[www.celiachealth.org](http://www.celiachealth.org)

### **Gluten Intolerance Group of North America**

31214 124th Avenue SE  
Auburn, WA 98092-3667  
Phone: 253-833-6655  
Fax: 253-833-6675  
Email: [info@gluten.net](mailto:info@gluten.net)  
Internet: [www.gluten.net](http://www.gluten.net)

### **National Foundation for Celiac Awareness**

P.O. Box 544  
Ambler, PA 19002-0544  
Phone: 215-325-1306  
Email: [info@celiaccentral.org](mailto:info@celiaccentral.org)  
Internet: [www.celiaccentral.org](http://www.celiaccentral.org)

### **North American Society for Pediatric Gastroenterology, Hepatology and Nutrition**

P.O. Box 6  
Flourtown, PA 19031  
Phone: 215-233-0808  
Fax: 215-233-3918  
Email: [naspghan@naspghan.org](mailto:naspghan@naspghan.org)  
Internet: [www.naspghan.org](http://www.naspghan.org)

## **The Celiac Disease Awareness Campaign**

To meet the need for comprehensive and current information about celiac disease, the National Digestive Diseases Information Clearinghouse (NDDIC), a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), launched the Celiac Disease Awareness Campaign. The Awareness Campaign is the result of the combined ideas and efforts of the professional and voluntary organizations that focus on celiac disease, along with the NIDDK, the National Institutes of Health, and the Centers for Disease Control and Prevention.

Visit [www.celiac.nih.gov](http://www.celiac.nih.gov) to learn more about the Awareness Campaign.

You may also find additional information about this topic by visiting MedlinePlus at [www.medlineplus.gov](http://www.medlineplus.gov).

This publication may contain information about medications. When prepared, this publication included the most current information available. For updates or for questions about any medications, contact the U.S. Food and Drug Administration toll-free at 1-888-INFO-FDA (463-6332) or visit [www.fda.gov](http://www.fda.gov). Consult your doctor for more information.

## National Digestive Diseases Information Clearinghouse

2 Information Way  
Bethesda, MD 20892-3570  
Phone: 1-800-891-5389  
TTY: 1-866-569-1162  
Fax: 703-738-4929  
Email: [nddic@info.niddk.nih.gov](mailto:nddic@info.niddk.nih.gov)  
Internet: [www.digestive.niddk.nih.gov](http://www.digestive.niddk.nih.gov)

The National Digestive Diseases Information Clearinghouse (NDDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health of the U.S. Department of Health and Human Services. Established in 1980, the Clearinghouse provides information about digestive diseases to people with digestive disorders and to their families, health care professionals, and the public. The NDDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about digestive diseases.

Publications produced by the Clearinghouse are carefully reviewed by both NIDDK scientists and outside experts. This fact sheet was originally reviewed by Ciaran Kelly, M.D., Beth Israel Deaconess Medical Center; Mitchell Cohen, M.D., Cincinnati, Children's Hospital Medical Center; Walter Reed Army Medical Center; National Foundation for Celiac Awareness; Celiac Disease Foundation; Celiac Sprue Association/USA, Inc.; and Centers for Disease Control and Prevention staff. The gluten-free diet chart was reviewed by Alice Bast and Nancy Dickens, National Foundation for Celiac Awareness; Cynthia Kupper, R.D., C.D., Gluten Intolerance Group; and Elaine Monarch, Celiac Disease Foundation.

This publication is not copyrighted. The Clearinghouse encourages users of this fact sheet to duplicate and distribute as many copies as desired.

This fact sheet is also available at  
[www.digestive.niddk.nih.gov](http://www.digestive.niddk.nih.gov).



U.S. DEPARTMENT OF HEALTH  
AND HUMAN SERVICES  
National Institutes of Health

NIH Publication No. 08-4269  
September 2008