



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,

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

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 kidstheir 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

"Raising Awareness, One Crumb at a Time"



Celiac Disease Foundation

Raising Awareness since 1990

A Nonprofit Corporation

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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

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Celiac Disease Foundation
TEAM
gluten-free
Always inspect the Date of Receipt on Celiac Disease



UNIVERSITY of MARYLAND
CENTER FOR CELIAC RESEARCH

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Baltimore, MD 21201
410.706.8021
www.celiaccenter.org

January 27, 2012

Alaska State Legislature
120 4th 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