



## Getting a Proclamation For Celiac Awareness Month

Having the Governor or Mayor issue a proclamation for awareness month definitely helps raise the visibility of celiac disease. How can you make it happen? In many cases, a citizen needs to just ask. This is a wonderful project for local support groups or students.

Remember, elected officials and their staff want to be helpful and look forward to educating the public, particularly on health issues, whenever possible.

*Make it happen where you live by following the steps below.*

### **STEP 1: Where to start? Identify a Contact**

- Up to 8 weeks in advance, identify a contact in the Governor or Mayor's office to assist in obtaining the proclamation.
- City or state government websites often list a public affairs or communications office. This is a good place to start. The official's administrative assistant may also be helpful in directing you to the right person.
- Prepare a brief statement highlighting the significance of Celiac Awareness Month, to share with the contact person. Include local statistics, where possible and known.

### **STEP 2: Get the Details and Ask Questions!**

- Does the official need to hear from other constituents in support of the Proclamation?
- Offer to provide the text or background information for the document.

### **STEP 3: Prepare the Paperwork**

- Prepare a letter (or email message) to the official explaining that your group or organization, along with the hundreds of others across the United States (and millions worldwide!), will be observing Celiac Awareness Month in May.
- Include the statement from Step 1 along with background information and key statistics about celiac disease.
- Ask the official to aid in raising awareness by proclaiming May as Celiac Awareness Month in their city or state. Provide a draft Proclamation for consideration along with your contact information.

- Hand-deliver or email the letter, draft Proclamation and other supporting materials. It's good to include brochures or handouts about Celiac Disease since not all officials are well versed on the condition.

#### **STEP 4: Media Magnifies the Message**

- After you learn the Proclamation is in the works, ask about an official presentation to your group. The media (TV, newspaper, blogs) cover such events all the time.
- A week before the event, send an email with details to local TV stations and newspapers. Call to confirm receipt and offer to answer questions.
- Media attention helps magnify the importance of causes like ours. Giving them a heads up is important.

#### **Step 5: Thank Those Who Made It Happen**

- Send a note of thanks to the official and each of the individuals who assisted in obtaining the Proclamation.

***If you need assistance along the way, we're ready to help!***

*TEMPLATE*

**CELIAC AWARENESS MONTH 2012**

**BY THE GOVERNOR OF THE STATE (COMMONWEALTH) OF \_\_\_\_\_**

**A PROCLAMATION**

Whereas Celiac Disease, a genetic autoimmune disease, affects 3 million people in the United States;

Whereas 200,000 people have been diagnosed with Celiac Disease;

Whereas 95% of Americans with Celiac Disease remain undiagnosed;

Whereas delays in diagnosis of Celiac Disease are costing the health care system millions of dollars;

Whereas failure to diagnose Celiac Disease can lead to the onset of other autoimmune disorders including Rheumatoid Arthritis, Systemic Lupus, and Sjögren's syndrome;

Whereas one in eight persons with Type 1 Diabetes also have Celiac Disease;

Whereas individuals with Down's syndrome are at increased risk of having Celiac Disease;

Whereas Celiac Disease is a serious chronic condition that affects children, women and men;

Whereas 30% of newly-diagnosed celiacs are over the age of 60;

Whereas 50% of men diagnosed with Celiac Disease will have iron deficiency anemia;

Whereas 10% percent of people with Celiac Disease suffer from associated neurological conditions such as peripheral neuropathy and ataxia;

Whereas the only known treatment for Celiac Disease is strict adherence to a gluten-free diet;

Whereas the lack of a standard for gluten-free foods and labeling of products places poses ongoing health risks to persons with Celiac Disease;

WHEREAS, increased recognition and awareness of Celiac Disease will have a significant positive impact on the quality of life of people with Celiac Disease;

NOW, THEREFORE, I, \_\_\_\_\_, Governor of the State (Commonwealth) of \_\_\_\_\_, do hereby proclaim May 2012, "CELIAC AWARENESS MONTH" in [ NAME OF CITY / STATE ] and commend its observance to our citizens.



## May is Celiac Awareness Month Help Spread the Word!

Around the world, and here in the United States, May is recognized as Celiac Awareness Month, with events and activities to educate the public about one of the world's most common genetic conditions. The goal is quite simple -- get more people tested and diagnosed and focus attention on the need for additional research to find a cure.

**Celiac Disease is one of the most common genetic disorders of humankind.** In the United States, the number of people living with Celiac Disease is estimated at 3 million, yet less than 200,000 have been accurately diagnosed. The multi-system, multi-symptom condition affects children, women and men across the age spectrum.

**Symptoms mirror other conditions.** In the United States, it can take years for an adult to be properly diagnosed. Why? The symptoms – diarrhea, osteoporosis, anemia, infertility, depression, peripheral neuropathy and migraines -- often mirror those associated with other medical conditions. Delays in diagnosis place the individual at increased risk of developing other autoimmune disorders such as Fibromyalgia, Graves' disease, Lupus, Sjögren's syndrome and Rheumatoid Arthritis. Without treatment the condition can be life-threatening and has been linked to an increased risk of certain types of cancer, especially intestinal lymphoma.

**There is no cure for Celiac Disease.** Individuals with Celiac Disease are unable to eat foods containing gluten, a protein found in wheat, rye and barley. For them, gluten sets off a reaction that causes damage to the small intestine. This damage impairs the body's ability to absorb vital nutrients. Quite simply, the body starves. By following the gluten-free diet, symptoms will abate and, in time, the small intestine will begin to heal.

### Putting Celiac Disease in Perspective

- ◆ Type 1 Diabetes affects over 2 million Americans; 1 in 8 also have Celiac Disease.
- ◆ Each year 610,000 women in this country experience unexplained infertility; 6% (36,600) may never learn that celiac disease is the cause.
- ◆ 400,000 people in the United States have Down's syndrome; about 12% also have Celiac Disease.
- ◆ Almost 50% of men diagnosed with iron deficiency anemia will be diagnosed with Celiac Disease.
- ◆ 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.