

# Celiac Sprue Association

## Celiac Disease Awareness Month

**“2.5 BORN EVERY MINUTE\*”**



2009 Packet

**\*“2.5 BORN EVERY MINUTE”**

Every minute 2.5 persons are born with the genetic predisposition for Celiac Disease.



## CELIAC DISEASE AWARENESS

"2.5 BORN EVERY MINUTE!"

The Celiac Sprue Association® (CSA), a member based, non-profit organization now in its fourth decade, is a leader in promoting awareness for celiac disease. CSA's membership has grown from 12 members in 1977 to its current membership of over 9,000 members and more than 125 CSA Chapters and Resource Units nationwide. With your help as a Chapter, Resource Unit or individual volunteer, the Celiac Sprue Association seeks to raise public awareness of celiac disease and dermatitis herpetiformis as it fulfills its mission of helping individuals with celiac disease and dermatitis herpetiformis worldwide through research, education, and support.

Since 1987, CSA has celebrated October as Celiac Disease Awareness Month by conducting national and local activities to increase awareness. This year, the CSA Celiac Disease Awareness Campaign theme, "2.5 Born Every Minute", emphasizes the potential impact of this genetically-based disease and the need for early diagnosis.

This packet is designed to help you plan and execute one or more Celiac Disease Awareness activities. It includes guidelines on how to plan an activity and get the best out of the effort. Whatever the event - big or small - everyone can help raise awareness. Everything you do to assist in this campaign benefits a broad spectrum of people - individuals with celiac disease, (both diagnosed and undiagnosed), physicians, dietitians, hospitals, nurses, businesses, your neighbors and the general public.

Senator Ben Nelson of Nebraska and Senator James M. Inhofe of Oklahoma will again jointly sponsor a Senate Resolution designating September 13<sup>th</sup> as National Celiac Disease Awareness Day. This date honors the birthday of Dr. Samuel Gee, who in 1888 first declared, "If the patient be cured at all, it must be by means of diet." Plan to celebrate Samuel Gee's 170<sup>th</sup> birthday this year on September 13!

Remember, you can enjoy extra publicity for your event(s) – AND help others - by sending details and photos to the CSA national office. Don't forget to include any press coverage you receive. We encourage you to take many photographs, as we plan to use the photos in future promotions, and they can also be entered in the Photo Competition. (See pages 20 and 21 for details.)

Talk to the students you know who are interested in celiac disease. Encourage their participation in the CSA Student Essay Contest (see page 22). CSA is searching for favorite, new, gluten-free (GF) recipes. Consider entering your favorite, original recipes in our new CSA Recipe Contest (see page 23 and 24).

Whatever you do, however you get involved to raise awareness, thank you for your continuing support in being "Celiacs Helping Celiacs." Enjoy and may you continue in good health.

Sincerely,

Mary A. Schluckebier  
Executive Director  
Celiac Sprue Association®  
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Omaha, Nebraska 68131-0700  
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celiacs@csaceliacs.org



## CELIAC DISEASE AWARENESS ACTIVITIES

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**Thank you for supporting the Celiac Sprue Association and our  
Awareness Month Activities!**

## What Is Celiac Disease

*Pronounced: (SEE-LEE-ACK disease)*

Celiac disease (CD), also known as celiac sprue, gluten-sensitive enteropathy or non-topical sprue, is a genetically linked autoimmune disorder that can affect both children and adults. Eating certain types of grain-based protein fractions sets off an immune response that causes damage to the small intestine. This interferes with the small intestine's ability to absorb the nutrients found in food, leading to malnutrition and a variety of other complications. The offending amino acid sequences are collectively called gluten and are found in wheat, barley, rye, and to a lesser extent, oats (WBRO).

### **CELIAC DISEASE IS:**

- common. It is estimated that as many as 1 in 130 may have celiac disease<sup>123</sup>.
- a genetic, inheritable disease.
- characterized by damage to the mucosal lining of the small intestine, which is known as villous atrophy.
- responsible for the malabsorption of nutrients resulting in malnutrition.
- reversible when wheat, barley, rye and common oats (WBRO) are excluded from the diet, in most cases.
- sometimes manifested in skin blisters called dermatitis herpetiformis (DH). (derm-a-TIE-tis her-pet-i-FOR-mis) with or without intestinal damage.

### **CELIAC DISEASE IS NOT:**

- a condition that can be treated with pharmaceuticals
- simply a food allergy.
- an idiosyncratic reaction to food proteins.
- associated with rapid histamine-type reactions (such as bronchospasms, hives, etc.).

### **SYMPTOMS OF CELIAC DISEASE**

The symptoms of celiac disease vary so widely among people that there is no such thing as a "typical" celiac. The type and severity of symptoms seem to be related to the level of intestinal damage and the length of time nutrient absorption has been abnormal. Some people with CD report having *no symptoms at all*. In general, adults and children can experience any combination of the following symptoms:

#### **PHYSICAL SYMPTOMS:**

- |  |  |  |
|--|--|--|
| • Abdominal cramping                           | • Flatus (passing gas)                           | • Pain in bones and joints   |
| • Anemia                                       | • Gluten ataxia (failure of muscle coordination) | • Smooth or geographic tongue  |
| • Appetite changes                             | • Infertility/miscarriages                       | • Abnormal Stools (loose/hard/small/large/foul smelling/light tan/gray/frothy) |
| • Constipation                                 | • Mouth sores or cracked lips                    | • Very dry skin  |
| • Decreased ability to clot blood              | • Muscle cramping (hands and legs)               | • Weakness   |
| • Decreased fat padding on feet/buttocks/hands | • Night blindness                                | • Weight loss (unexplained)  |
| • Dehydration                                  | • Osteopenia/osteoporosis                        |  |
| • Delayed puberty                              | • headache                                       |  |
| • Diarrhea                                     |  |  |
| • Edema  |  |  |
| • Electrolyte imbalance                        |  |  |
| • Fatigue                                      |  |  |

#### **EMOTIONAL SYMPTOMS:**

- |                                    |                |
|------------------------------------|----------------|
| • Depression                       | • Irritability |
| • Disinterest in normal activities | • Mood changes |
| • Inability to concentrate         |                |

### **IN CHILDREN:**

Children with CD may exhibit any of the above symptoms, as well as stunted growth, projectile vomiting and a distended abdomen. Older children may experience personality changes, irritability, crankiness, difficulty concentrating and poor memory.

### **DERMATITIS HERPETIFORMIS (DH)**

DH is a manifestation of celiac disease that occurs in the skin. It appears as small, itchy blisters, which commonly form in clusters at pressure points, such as:

- ankles/feet
- buttocks
- elbows
- face/neck
- knees
- sacral (base of spine)
- scalp
- shoulders

Many people with DH are able to predict the location of a new blister as much as 8 to 12 hours before the onset because of localized burning and itching. After 7 to 10 days, the blisters typically stop burning and itching and crust over.

### **DIAGNOSIS**

The American Gastroenterological Association recommends the following three steps leading to diagnosis of celiac disease:

1. A thorough **physical examination**, including the celiac blood panel for gluten antibodies--IgA antiendomysial antibody (EMA) and the IgA tTGA – anti-tissue transglutaminase. In addition deamidated gliadin peptide (DGP IgA and DGP IgG) testing is useful for detecting potentially IgA deficient celiacs. Many studies demonstrate a specificity of IgA tTGA greater than 95% and sensitivity in the range of 90%-96%. The EMA has a slightly lower and variable sensitivity but an excellent specificity (99.6%)
2. Upper GI (gastrointestinal tract) Endoscopy with a **small intestinal biopsy**. For those with DH, skin biopsies will be taken.
3. The pill cam diagnostic technique for viewing the entire digestive tract may also be used.
4. Implementation of the **gluten-free diet** with follow-up to confirm diagnosis and manage compliance

The process is complete when symptoms subside and the intestinal lining normalizes.

NOTE: to ensure an accurate diagnosis, the gluten-free diet is to be implemented only after the first two steps have been completed.

### **TREATMENT**

At this time, the only treatment for celiac disease and dermatitis herpetiformis is the life-long commitment to a strict gluten-free lifestyle. This means eliminating any contact with the offending amino acids found in wheat, barley, rye and common oats<sup>6</sup>, or their derivatives and crosses. Many of these grains or their derivatives are found in processed foods, medications (prescription and over the counter) and personal care products. Research confirms that the fewest complications are experienced by those who follow the strictest form of the gluten-free diet.

Studies are inconclusive regarding the inclusion of oats in the gluten-free diet. Clinical studies indicate that uncontaminated oats may be tolerated by some people with celiac disease while other studies demonstrate that some people with celiac disease react to oats (avenin). Currently there is no way to identify which people with celiac disease may tolerate oats. CSA strongly advises caution when considering the use of uncontaminated oats in a GF diet. At this time, the use of oats is not a risk free choice for all those with CD/DH.

Self-management is the key to living a gluten-free lifestyle. It is important to become

familiar with the places gluten “hides” and comfortable with informing family about the requirements of the gluten-free lifestyle. Meeting and sharing with others in a celiac support group helps increase both knowledge and confidence when transitioning into and maintaining a gluten-free lifestyle. Working with a gastroenterologist and a registered dietitian who are well versed in the specifics of CD/DH is another part of the self-management process.

#### **ON THE HORIZON**

Possible treatments for celiac disease are in clinical trials. Alba Therapeutics has developed a “permeability inhibitor”, larazotide acetate (AT-1001) which appears to reduce the transport of antigens across tight junctions in the intestines and mitigates or prevents inflammation. The altered intestinal permeability (“leaky gut”) that may be both a cause and consequence of CD facilitates transport of gluten which then triggers an inflammatory response, resulting in tight junction dysfunction which can be blocked by tight junction modulators such as

AT-1001. Alvine Pharmaceuticals has developed an orally administered combination of two proteases (enzymes) engineered to digest gluten. Development is based on research conducted at Stanford University. ALV003 consists of a glutamine specific cysteine protease (EP-B2) and a proline specific prolyl endopeptidase (PEP). Also, a new enzyme called “AN-PEP” which was originally developed for food processing, has been found by a team in the Netherlands to break down whole gluten molecules, as well as the T-cell stimulatory peptides that evoke damage characteristic of celiac disease. Although early clinical trials have produced promising results for both of these potential treatments, it is still too early to assess the impact for those with celiac disease.

## CELIAC SPRUE ASSOCIATION

### A HISTORICAL PERSPECTIVE OF CSA

- In 1977-78, Pat Murphy Garst of Des Moines, Iowa, a celiac and cookbook author, was instrumental in forming the Midwestern Celiac Sprue Association (MCSA). By October of 1978, MCSA held its first annual celiac conference. *Lifeline*, MCSA's (and now CSA's) quarterly newsletter, was launched.
- On January 30, 1985, MCSA officially incorporated as the Celiac Sprue Association-United States of America (CSA/USA). Six regions formed the basic structure, each with a regional director and member-at-large on the CSA Governing Board. Equipped with chapters, officers, members, resource units, and medical and dietitian advisors, CSA was in a position to move forward as a national organization.
- CSA was designated an IRS 501(c)(3) charity in 1986. With "Revised Articles of Incorporation" the IRS Determination Letter was re-issued in 2002.

### CSA TODAY—"CELIACS HELPING CELIACS"

- As "Celiacs Helping Celiacs" CSA members and staff fulfill its stated mission:

The Celiac Sprue Association® (CSA) is a member-based 501(c)(3) non-profit organization dedicated to helping Individuals with celiac disease and dermatitis herpetiformis worldwide through research, education, and support.

- The purposes of CSA include:
  - To provide and actively distribute educational materials on celiac disease and dermatitis herpetiformis to individuals with such conditions, their families, health care professionals and other interested persons.
  - To serve as a vehicle for providing mutual support opportunities to individuals with celiac disease and dermatitis herpetiformis, and their families, by, among other things, encouraging, establishing and supporting volunteer units for such individuals throughout the country.
  - To keep abreast of and publicize current research on celiac disease as related to the conditions of celiac disease and dermatitis herpetiformis.
  - To provide information regarding the clinical diet recommendations for celiac disease.
  - To work with both industry and government to improve labeling practices for ingredients which affect individuals with celiac disease and dermatitis herpetiformis.
  - To exchange information and sponsor programs with other public and private organizations regarding celiac disease and dermatitis herpetiformis.
  - To solicit funds through memberships, private and corporate donations, foundation and estate contributions for the purpose of supporting the above-referenced programs and activities.

- With over **9,000 members**, in more than **125 CSA Chapters and Resource Units**, CSA is the largest 501(c)(3) non-profit, support, information and referral organization representing the celiac community in the United States. A dedicated force of volunteer officers and committee members serves the organization.
- Key offerings include:
  1. A national toll-free phone line to personally answer questions concerning celiac disease
  2. Informational website featuring links to related topics
  3. Print material for patients, dietitians and other health professionals
  4. Annual CSA Educational Conference
  5. The CSA Recognition Seal Program for WBRO-free products and menus
  6. CelKids® Network and Camp Celiac Programs
  7. The CSA Peer Review Research Grant program for the support of research on celiac disease
  8. *The CSA Gluten-Free Product Listing* updated and published annually
  9. A Speakers Bureau for presentations at local, regional and national events
  10. The CSA Celiac Disease & Gluten Sensitivity Physician Education Program (CSA-PEP)
- CSA maintains active relationships for celiac disease research, education and support by participating in the following organizations and government outreach entities.
  - Associations:
 

<ul style="list-style-type: none"> <li>▪ American Autoimmune Related Disease Assoc. (AARDA)</li> <li>▪ American Celiac Society (ACS)</li> <li>▪ Digestive Diseases National Coalition (DDNC)</li> <li>▪ Dietitians in Gluten Intolerance Diseases (DIGID)</li> <li>▪ Food Allergy and Anaphylaxis Network (FAAN)</li> <li>▪ National Organization of Rare Diseases (NORD)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Genetic Alliance (GA)</li> <li>▪ FDA Alliance</li> </ul>
Government Outreach	
<ul style="list-style-type: none"> <li>▪ National Digestive Diseases Information Clearinghouse (NDDIC)</li> <li>▪ National Institute of Arthritis, Muscular &amp; Skeletal Diseases (NIAMS)</li> <li>▪ National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)</li> </ul>	
- Worldwide participation with celiac associations in the following countries:
 

<ul style="list-style-type: none"> <li>▪ Argentina</li> <li>▪ Australia</li> <li>▪ Belgium</li> <li>▪ Bermuda</li> <li>▪ Bosnia and Herzegovina</li> <li>▪ Brazil</li> <li>▪ Bulgaria</li> <li>▪ Canada</li> <li>▪ Chile</li> <li>▪ Croatia</li> <li>▪ Cuba</li> <li>▪ Czech Republic</li> <li>▪ Estonia</li> </ul>	<ul style="list-style-type: none"> <li>▪ Faroe Islands</li> <li>▪ Finland</li> <li>▪ France</li> <li>▪ Germany</li> <li>▪ Hungary</li> <li>▪ Iceland</li> <li>▪ Ireland</li> <li>▪ Israel</li> <li>▪ Italy</li> <li>▪ Latvia</li> <li>▪ Liechtenstein</li> <li>▪ Lithuania</li> <li>▪ Luxembourg</li> <li>▪ Malta</li> <li>▪ Netherlands</li> </ul>	<ul style="list-style-type: none"> <li>▪ New Zealand</li> <li>▪ Norway</li> <li>▪ Paraguay</li> <li>▪ Poland</li> <li>▪ Portugal</li> <li>▪ Romania</li> <li>▪ Slovenia</li> <li>▪ South Africa</li> <li>▪ Spain</li> <li>▪ Sweden</li> <li>▪ Switzerland</li> <li>▪ United Kingdom</li> <li>▪ Uruguay</li> </ul>
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## CSA LEADERSHIP

### CURRENT CSA OFFICERS

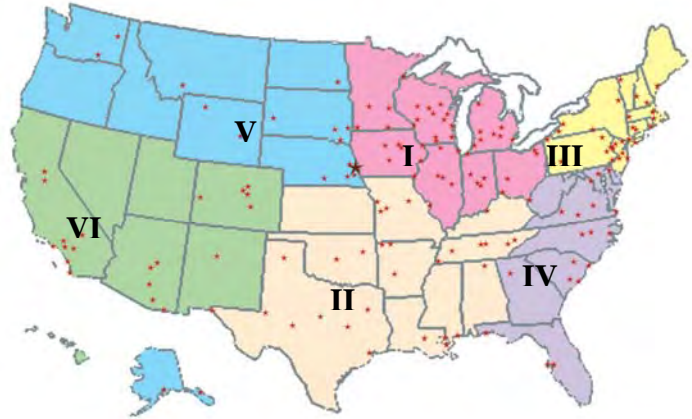
- CSA Executive Director
  - Mary Schluckebier - NE
- Current CSA President
  - Bill Eyl - CO
- CSA President Elect
  - John Libonati - PA
- CSA Treasurer/Comptroller
  - Clark Kolterman - NE
- CSA Recording Secretary
  - Joanne M. Schwartzott – NY
- Past CSA President
  - Gary Powers - PA

### CSA REGIONAL DIRECTORS

- Region I
  - William Morris - WI
- Region II
  - Heather Mahieu Cline - OK
- Region III
  - Cliff Hauck – NY
- Region IV
  - Sandra McCravy - SC
- Region V
  - Juliann Becker – ND
- Region VI
  - Joan Van Loozenoord - CO

### CSA MEMBERS-AT-LARGE

- Region I
  - Position open
- Region II
  - Carolyn McKinley - MO
- Region III
  - Linda Pickett – NJ
- Region IV
  - Rebecca Godfrey – SC
- Region V
  - Mimi Frerichs - NE
- Region VI
  - Diane Craig – CA



### AACSA Foundation

- President
  - Diane Eve Paley – NJ
- Vice President
  - Thomas Sullivan – MI
- Secretary
  - Mary Neville – PA
- +Treasurer
  - Clark Kolterman - NE

### CSA AND THE FUTURE.....

- The Affiliated American Celiac Sprue Association Foundation (AACSA Foundation) was launched in 2004 to aid and assist in the support of the activities of CSA. You can help promote the mission of AACSA Foundation by making a donation to help fund the programs supported by AACSA Foundation and the Celiac Sprue Association as a whole.
- The CSA Celiac Disease & Gluten Sensitivity Physician Education Program (CSA-PEP) was launched in 2008 with the goal to increase the rate of assessment, diagnosis and treatment of celiac disease and gluten sensitivity in the U.S. through provision of a comprehensive set of educational materials on celiac disease and gluten sensitivity to 70,000 physicians and medical students by 2012. Through working partnerships with the mainstream medical community, physicians and medical students will be introduced to CSA, its national programs, resources and patient support chapters.

## The Aims of Awareness Month

- **Raise awareness of the importance of early diagnosis of celiac disease.** Advocate for early diagnosis among physicians and healthcare professionals through support of the CSA-PEP Program. Raise awareness of the need for early diagnosis of celiac disease at a local, state and national level through a mass media campaign. Encourage people with symptoms of celiac disease to be tested.
- **Request legislation to require generic drugs to disclose presence of WBRO and other major allergens.**
- **Support local Celiac Disease Awareness Month activities.** Encourage local chapters to take part in activities, promotions, contact legislative representatives, act as case studies and create Celiac Awareness displays in libraries, hospitals or schools.

## THE THEME: "2.5 BORN EVERY MINUTE"

"2.5 Born Every Minute!" The Celiac Disease Awareness Month Theme refers to the 30% of the United States population genetically predisposed to celiac disease by carrying the major celiac genetic markers (predominantly DQ2 and DQ8)<sup>1</sup>. Using this formula, it can be calculated that every minute approximately 2.5 children are born carrying this genetic predisposition. Although not all genetically predisposed people will develop celiac disease, this staggering statistic succinctly displays the ever-increasing need to promote awareness and strengthens the resolve of CSA to provide accurate and up-to-date information on celiac disease to the celiac community, those at-risk for development of celiac disease, and the population at large.

It is further estimated that 1 in 130 people in the United States would test positive for celiac disease. Most of these celiacs are undiagnosed. It is clear that a greater effort is needed to raise awareness. Unfortunately, the average time from onset of celiac symptoms to diagnosis is 11 years.

As a result, the Celiac Sprue Association has implemented the theme of "2.5 Born Every Minute" to remind people of the potential number of those with celiac disease in the United States. We invite you to join CSA in the push to increase awareness of celiac disease and to promote earlier detection of the disease all year long.

## AWARENESS IDEAS

There are three target audiences for the awareness campaign. These are healthcare professionals, governmental representatives and the general public. Here are some ideas of ways you can get involved.

### HEALTHCARE PROFESSIONAL

- With the permission of your local hospitals and pharmacies, **build a celiac disease information display** using materials available from the national office. Ask if the hospital or pharmacy will allow you to leave the display up for at least a month.
- **Circulate the CSA health fair brochure “CD-The Basics”** and other materials to your local clinics and hospitals – don’t forget to include your local dental offices as mouth ulcers are a recognized symptom of celiac disease.
- **Nominate your physician**, pharmacist or dietitian as a case study of best practices for the CSA “Spirit of Service” Award.
- **Write letters** to physicians to explain your diagnosis and its impact on your health and lifestyle.

### GOVERNMENT REPRESENTATIVES

- **Invite** your local city/county governmental agency to join the campaign by signing a Celiac Disease Awareness Month Proclamation.
- **Promote Celiac Disease Awareness Month** with a photo event of the official signing.

### GENERAL PUBLIC

- **Contact** your local supermarket managers for permission to display literature and talk to customers. Very successful events have been held at several local stores by chapters and volunteers.
- **Be a case study** – If you’ve have a good story to tell about how long it took to be diagnosed and/or how diagnosis has changed your life, you can contact the national office toll-free at 877-CSA-4-CSA with your story. Be a part of “My Story” on the CSA website.
- **Approach the media** directly with good case studies – use the publicity guidelines (p.14-19) as a guide or call the national office toll free for more assistance.
- **Put yourself forward** to talk about celiac disease on local radio, TV, or cable channels.
- **Promote the CSA Photo, Student Essay and Gluten Free Recipe Contests.** (Refer to details in this packet on p. 20-24)
- **Set up displays** in libraries or at local health fairs to promote celiac disease awareness.
- **Make public service announcements** Public service announcements and press releases from the national office are available for local radio, TV, cable and print media outlets in your area. (See p. 18 for examples)
- Utilize the **CSA Spirit of Service Award** (p. 25) to recognize supporters of the celiac community.

## **NATIONAL CELIAC AWARENESS DAY**

The third annual Celiac Disease Awareness Day Resolution was passed in September, 2008 by the United States Senate (S.Res. 657). This resolution, again sponsored by Senator James Inhofe of Oklahoma and Senator Ben Nelson of Nebraska, made September 13, 2008 National Celiac Disease Awareness Day. The date of September 13 was chosen because it honors the birthday of Samuel Gee, MD a British physician and pediatrician. Dr. Gee published the first modern description of the clinical picture of celiac disease and is credited with being the first to identify the link between celiac disease and diet. One of Gee's famous quotes on celiac disease is "if the patient can be cured at all, it must be by means of diet." CSA is again working with Senators Inhofe and Nelson to have Dr. Gee's birthday, September 13<sup>th</sup>, nationally recognized as Celiac Awareness Day. CSA personally encourages you to contact your United States Senators and encourage them to co-sponsor this important resolution which helps to increase national awareness of celiac disease.



**Dr. Samuel Gee**

### **IDEAS FOR HOW TO CELEBRATE CELIAC AWARENESS DAY**

- **Sponsor a party complete with gluten-free cake.**
- **Contact your local newspaper, television and radio stations inquiring about a story on Samuel Gee.**
- **Have a gluten-free baking contest.**
- **Talk to a local class telling them about Samuel Gee and his contribution to medicine.**
- **Create a display in a public library, clinic or shopping area and promote Dr. Gee's 170th birthday!**

### **SUGGESTED WEB SITES REGARDING SAMUEL GEE**

Information regarding the life and work of Samuel Gee can be found at:

<http://osiris.sunderland.ac.uk/~cs0rel/hist.htm>

[http://en.wikipedia.org/wiki/Samuel\\_Gee](http://en.wikipedia.org/wiki/Samuel_Gee)

[http://www.coeliac.co.uk/coeliac\\_disease/68.asp](http://www.coeliac.co.uk/coeliac_disease/68.asp)

<http://www.whonamedit.com/doctor.cfm/1312.html>

[http://www.aim25.ac.uk/cgi-bin/search2?coll\\_id=7101&inst\\_id=8](http://www.aim25.ac.uk/cgi-bin/search2?coll_id=7101&inst_id=8)

## **APPROACHING LOCAL/STATE OFFICIALS**

Write to your local officials and state representatives to encourage their support of Celiac Disease Awareness Month. A sample letter on page 11 is available for your use. **Send these letters in August or September to coincide with other awareness month publicity.**

### **CSA CELIAC DISEASE AWARENESS MONTH PROCLAMATION PROMOTION**

A generic sample of a Celiac Disease Awareness Month proclamation is shown on page 12.

The idea of an official proclamation is not a new one, but very popular. Many local chapters and individual members can use this sample for their own community, county, parish or designated area.

Any Celiac Disease Awareness national resolutions and proclamations will be handled by the national office. All proposed state resolutions or proclamations should be coordinated with the national office, to avoid duplication, and to make sure that everyone is included in the promotion process.

Please send any photos or news publicity using a proclamation to the CSA national office for use on the website as well as in *Lifeline*. Contact CSA by mail at: PO Box 31700, Omaha, NE 68131, or by email at [celiacs@csaceliacs.org](mailto:celiacs@csaceliacs.org).

Date

The Honorable \_\_\_\_\_  
Office Building  
City, State, Zip

Senator / Representative / Mr. / Mrs. / Ms. \_\_\_\_\_:

As one of your constituents, I would like to bring to your attention that October is National Celiac Disease Awareness Month. I am calling for measures to promote the earlier diagnosis of celiac disease.

As you are probably aware, celiac disease is an autoimmune disease caused by the reaction to gluten, the protein fractions found in wheat, barley, rye and oats. It is one of the most common lifelong disorders in the USA. There is no cure; the only reliable treatment is a strict lifelong diet free of wheat, barley, rye and oats. Celiac disease affects as many as 1 in 130 Americans, but nearly five out of six people are undiagnosed. In fact, an average of three individuals is born every minute with a genetic predisposition to celiac disease.

Celiac disease has a myriad of symptoms which can vary greatly; as a result the disease often goes unrecognized for years. Left untreated, it can result in chronic ill health and susceptibility to complications such as osteoporosis, infertility, other auto-immune diseases and an increased risk of malignancy, particularly lymphoma. Healthcare costs per untreated celiac in the United States range from \$5,000-\$12,000 annually, and total healthcare costs for all untreated Celiacs in the United States can approach \$34 billion each year.

The Celiac Sprue Association (CSA) is currently coordinating an Awareness Month under the campaign banner "2.5 Born Every Minute" to draw attention to the need for early diagnosis. CSA, the largest celiac disease patient support organization in the United States, has the support of its membership to promote awareness of celiac disease.

I hope that you will add your name to this Celiac Disease Awareness Month proclamation to help raise awareness of this widespread but still largely unknown disease.

Sincerely yours,

Chapter Contact Information  
CC: Celiac Sprue Association (CSA)  
Toll Free: 877-CSA-4-CSA  
[www.csaceliacs.org](http://www.csaceliacs.org)

## Proclamation for Celiac Awareness

**Whereas**, *Celiac Disease, also known as Celiac Sprue, is an autoimmune disorder that affects as many as one in every 130 Americans;*

**Whereas**, *Every minute approximately three children are born with a genetic predisposition for celiac disease;*

**Whereas**, *Celiac Disease, a reaction to the ingestion of gluten, a storage protein found in wheat, barley, rye, oats and their derivatives, damages the lining of the small intestine preventing the proper absorption of nutrients into the body;*

**Whereas**, *some of the symptoms of Celiac Disease include fatigue, anemia, headache, and gastrointestinal distress;*

**Whereas**, *the disease was first described in the second century but the cause and treatment were not described in medical records until the twentieth century;*

**Whereas**, *Celiac Disease covers a wide spectrum of physical, neurological, and immunological conditions;*

**Whereas**, *the inconsistent, mysterious and mimicking nature of Celiac Disease makes it a diagnostic puzzle;*

**Whereas**, *the Celiac Sprue Association is the largest member-based non-profit organization helping the celiac community in North America;*

**Whereas**, \_\_\_\_\_ is a Chapter of the Celiac Sprue Association, with their national headquarters in Omaha, Nebraska, and with all its affiliates have made tremendous strides in raising public awareness of Celiac Disease; and;

**Whereas**, 2009 marks the beginning of the fourth decade for the Celiac Sprue Association, and;

**Therefore, I**, \_\_\_\_\_, do hereby proclaim

\_\_\_\_\_, 2009 as “Celiac Disease Awareness Month”

**In Witness Whereof**, I have hereunto set my hand and caused the Great Seal of \_\_\_\_\_ to be affixed.

Done at \_\_\_\_\_ in the \_\_\_\_\_ this \_\_\_\_\_ day of \_\_\_\_\_ in the Year of Our Lord two thousand nine.

## FUNDRAISING IDEAS

Raise awareness and funds at the same time! Here are some ideas to get started:

### AT HOME

- Entertain your friends with a gluten-free meal, morning coffee, or a wine and cheese evening etc. Ask for donations in support of the CSA chapter, the CSA Peer Review Research Grant Program, or the CSA-PEP Program.

### AT SCHOOL

- Propose a "hat or cap day" at school – charging everyone a fee (dollar) to wear a cap or hat for a day, with proceeds going to celiac disease research or a CSA camp scholarship.
- Have a penny campaign to assist in celiac disease research. Place collection canisters throughout the school and community.

### AT WORK

- Bake gluten-free goodies and ask for donations in the office. Distribute CSA awareness brochures in the coffee lounge.
- Do a blind tasting test – which cake tastes the best and see if the gluten-free ones win. Charge a donation for the privilege!

### OUT AND ABOUT

- Arrange a meal at a local celiac-friendly restaurant.
- Get fit and help raise money too! Organize a sponsored walk or bike ride. Check with your local police and city government for local regulations, etc.

Don't forget to contact the local newspaper, radio, TV, and cable channels about your fundraising efforts!

**Contact the CSA national office early in the planning process for your fund raising events to assure that your efforts are in compliance with 501(c)(3) regulations for non-profit organizations.**

## **APPROACHING THE MEDIA**

These guidelines will help as you approach the media to secure coverage on Celiac Awareness Month.

### **LOCAL NEWSPAPERS**

Regional newspapers are always interested in good, exciting, local stories. To achieve coverage in local press you can either interest them in covering an 'event' or increase awareness through a local case study.

Remember, the press like good photo opportunities so choose your event or subject wisely in order to secure the best coverage. Children make good pictures, but check with their parents first! Send your press release with details of your event or subject and a fact sheet to all local newspapers, addressed to the news editor.

When using the general press release template (p. 13) change the wording to add your own local information. Send with a fact sheet to either the editor or features editor with a cover letter offering someone as a case study. Give interesting information on your case study in the letter.

*If at any time the media wants more detailed information on celiac disease or dermatitis herpetiformis than you are able to give, please refer the media to the CSA office, (toll free) 877-CSA-4-CSA, [www.csaceliacs.org](http://www.csaceliacs.org), or email CSA at [celiacs@csaceliacs.org](mailto:celiacs@csaceliacs.org).*

### **LOCAL TELEVISION, RADIO AND CABLE**

Use the same rules as suggested for local newspaper. Do some prior research. Contact the television or radio stations by writing to the Producer of the program you think would be the best fit with either your event or awareness story. If it is an event you wish to promote, you can also send your information to the news editor for possible inclusion in their local news. In all cases, offer yourself or a representative as a possibility for an interview.

If you know a doctor or dietitian who has a special interest in celiac disease, perhaps he/she would participate in interviews and volunteer as a possible spokesperson. Some members of the Celiac Sprue Association Medical Advisory Board have also offered to speak for Celiac Awareness Month.

## NOTES AND HINTS FOR APPROACHING THE MEDIA:

- Verify that it is acceptable to send press information and photos via e-mail BEFORE sending anything.
- Always ensure you have your contact telephone number on any press release.
- Once you have sent the release, it is wise to call and check that it has been received. This also gives you an excuse to discuss your story and sell it.
- Invite the media to your event and ask them to bring a photographer/camera crew, radio news reporter etc.
- Choose a case study who is positive – someone with an interesting job, or someone who travels extensively or a mom/dad with celiac children. For newspapers, choose someone who will make a good picture.
- Use your Q&A's (p. 21-22) to help with any press quotes/interviews.
- Share the Q&A's with your interviewee to ensure a cohesive message.
- Talk about the support that the Celiac Sprue Association offers. Remember, "You are CSA!"
- Have Celiac Sprue Association helpline phone number available (toll free) 877-CSA-4-CSA and give it out to the media. Alternatively, refer people to the website [www.csaceliacs.org](http://www.csaceliacs.org).
- Mention *The CSA Gluten-Free Product Listing* and give details of how to purchase it.
- Finally, if you do get media coverage, share it with the national office and the rest of the membership!

## HOW TO WRITE A PRESS RELEASE

- Use the examples below in this packet to guide you.
- Basic rules for a press release are:
  - Keep it short and concise and communicate clearly.
  - Give it a snappy title to catch media attention.
  - The release should always include: 'who', 'what', 'where', 'when', 'why' and 'how'. This information should be in the first paragraph.
  - Put in a quote from the organizer, as it makes the story more local and human and adds a finishing touch.
  - Offer an opportunity for a reporter, photographer etc to attend your event.
  - Include opportunities to talk to case studies if appropriate.
  - Always include a contact phone number.
  - Print the release on official stationary of your Celiac Sprue Association chapter.
  - Include a fact sheet (p. 20) with each press release

## GENERAL PRESS RELEASE TEMPLATE

Local press contact:

Date:

Tel:

E-mail:

Website:

### **[Details of local activity/body of press release]**

Volunteers in [town/city] are [doing what? ex. working with local schools to provide gluten free meals] as part of Celiac Sprue Association® (CSA) "2.5 Born Every Minute" campaign to promote Celiac Disease Awareness. Brochures on celiac disease [and other literature?] giving information about the disease will be displayed in clinics and libraries in the [town/city].

It is estimated that 1 in 130 people – men, women and children – have celiac disease. Celiac disease is an immune mediated response to gluten, significantly reducing the body's ability to absorb nutrients. The 2009 Celiac Disease Awareness Month Theme refers to the fact that 30% of the United States population is genetically predisposed to carry celiac genetic markers<sup>1</sup>. Using this formula, it can be calculated that every minute approximately 2.5 children are born carrying this genetic predisposition. This staggering statistic succinctly displays the ever increasing need to promote awareness of celiac disease and strengthens the resolve of CSA to provide information regarding education, awareness and research for our membership and individuals dealing with celiac disease.

Five out of six people with the disease have yet to be diagnosed by their physician, and are unnecessarily suffering uncomfortable and sometimes embarrassing symptoms including bloating, diarrhea, weight loss, mouth ulcers, fatigue, or anemia. If undiagnosed, the disease can lead to more serious illnesses such as osteoporosis and intestinal cancer. Once diagnosed, a diet free of wheat, barley, rye and oats will alleviate the symptoms, usually within weeks, and will help prevent the onset of related illnesses.

[Spokesperson] says: "We are concerned that so many people in [town/city] could be undiagnosed, as celiac disease has a massive impact on daily life if you don't know you have it. Our campaign's aims are to get people talking about celiac disease, with the hope of getting people diagnosed more quickly than in the past."

People living in [town/city] can support the campaign by:

- Taking part in any local events
- Writing to [insert name of governmental representative] asking the government to raise public awareness of this disease and promote measures to aid in the diagnosis of celiac disease.

Please visit the CSA website at [www.csaceliacs.org](http://www.csaceliacs.org) or call toll free 877-CSA-4-CSA for more information about the "2.5 Born Every Minute" campaign.

ENDS – Additional Information for editor's use only.

## Notes to Editors

- Celiac disease is caused by an immune mediated reaction to gluten, a protein found in wheat, barley, rye and oats, yet it can be treated very successfully by excluding from the diet foods with these grains. The disease can lead to far more serious conditions such as osteoporosis, infertility and gastrointestinal cancer if left untreated. The symptoms are very individualized, but can include tiredness, anemia, diarrhea, abdominal discomfort, weight loss, vomiting, and mouth ulcers. Celiac disease in children can result in stunted growth and has a significant impact on a child's overall development.
- Newly diagnosed people are joining CSA every month. Members receive up-to-date materials, quarterly newsletters, opportunities to network in local chapters and at national conferences, and donate to research projects related to celiac disease.

For further information please contact [insert details]

## Quotes You Can Use From the National CSA Officers and Executive Director

According to Bill Eyl, CSA President, "CSA is the largest member-based nonprofit celiac disease organization in the United States, with over 9,000 members dedicated to helping individuals with celiac disease and dermatitis herpetiformis through research, support, and education."

Jean Guest, CSA's Dietitian Advisor, states, "Clients should develop and implement a diet that is free of wheat, barley, rye and oats (WBRO-Free) as well as utilizing evidence-based resources such as the Celiac Sprue Association."

CSA Executive Director, Mary Schluckebier says, "It is important to become familiar with the places gluten 'hides' and be comfortable with informing family about the requirements of the 'WBRO-Free' lifestyle."

"The motto of the Celiac Sprue Association (CSA) is "Celiacs Helping Celiacs". CSA has over 125 local CSA Chapters and Resource Units across the United States to assist anyone with concerns and requests," according to Diane Eve Paley, Affiliated American CSA (AACSA) Foundation President.

## **SAMPLE AWARENESS MONTH RADIO PUBLIC SERVICE ANNOUNCEMENTS**

### **A Possible Script for a Half-Minute Public Service Announcement (approx. 30 seconds)**

Wait a second. . . In that second 2.5 more children were born in the United States with a genetic predisposition for celiac disease. October is celebrated as national Celiac Disease Awareness month. Find out more about celiac disease by contacting the Celiac Sprue Association toll-free at 1-877-CSA-4-CSA or visiting their website [www.csaceliacs.org](http://www.csaceliacs.org). Don't wait another second.

### **A Possible Script for a One Minute Public Service Announcement (approx. 60 seconds)**

Got symptoms? Fatigue, weakness, anemia, abdominal cramping, bloating, diarrhea—It could be celiac disease. This lifelong autoimmune condition affects 1 out of every 130 people in the United States. To find out more about celiac disease call the Celiac Sprue Association toll free at 1-877-CSA-4-CSA and a friendly voice will provide up-to-date information on diagnosis and treatment with a gluten-free diet. Don't delay, call today or visit the Celiac Sprue Association website [www.csaceliacs.org](http://www.csaceliacs.org). You could soon be symptom-free.

A disc of radio public service announcements, complete with background music, is available for distribution to radio stations and promotional use at no charge. To obtain a copy of the promotional disc, contact the CSA office.

## **AWARENESS MONTH TELEVISION PUBLIC SERVICE ANNOUNCEMENT**

A DVD of a 30-second television public service announcement featuring Gary Powers, CSA Past President, is also available from the CSA office. Contact the CSA office to arrange delivery.

## **RADIO PRESENTATION AVAILABLE "GUT REACTION"**

The Celiac Sprue Association is happy to offer the radio broadcast, "Gut Reaction-The Human Face of Celiac Disease", which was funded by member donations through the CSA Peer Review Research Grant Program in 2004.. The broadcast is available in both one hour and half-hour segments. This professional presentation, by Richard Paul, with music by Lenny Williams, presents the issues individuals face with celiac disease. It is presented through personal testimony and interviews. To obtain a copy of the disc to be broadcast in your area, contact the CSA office at 877-CSA-4-CSA. The disc is free of charge.

## PHOTO TIPS

If you've been unable to get the press to your event, you might be able to send them your own photos and get them published if it meets their standards. Here are some tips for taking the perfect photo:

**Composition:** A little care before pressing the button can ensure a good photo. Zoom in on a group of people in a shot. Stage a photo in an interesting way – but don't photograph up people's nostrils or below their chin, as it's very unflattering. Instead, ask your subject to look directly at the camera or photograph them slightly from above. Eye contact, big smiles and photos of children are always good too.

**Focus on the prize:** Most cameras have razor sharp auto focus – but only if you put the subject in the middle of the frame. Aim the camera at the real subject and put a little pressure on the shutter button to lock in the focus. Then reframe your picture, being careful to keep a little pressure on the button. Once happy with the way your subject is framed, simply take the shot.

**Steady as you go:** Take a little breath before you press the trigger, just to stop any shakes. This also avoids a common problem with digital cameras: blurring caused by the delay between pressing the shutter button and taking the picture.

**Lighting is key:** Keep light behind you as you take the photo so that it lights up your subject well. Auto flash should kick in if needed indoors.

**It's behind you:** Focus on the subject, but be aware of what's in the background. Watch out for trees or lamp-posts sticking out of heads and try not to photograph against patterned wallpaper or carpets, as you might lose your subject in the pattern.

**Finally:** Get written permission of those in the photo to use the photo publicly.



## CSA PHOTO COMPETITION 2009

### Promoting Celiac Disease Awareness Month

We have all heard that "one picture is worth a thousand words." Everyone looks forward to seeing photos and hearing stories. As a result, this year CSA is sponsoring a photo contest to promote Celiac Disease Awareness Month. Entries may be submitted until December 1<sup>st</sup>. Capture fun moments and action ---promoting celiac disease awareness -- - and demonstrating that individuals diagnosed with celiac disease lead normal lives. Prizes will be awarded, and the winning photos will be prominently featured in *Lifeline* and the CSA website. This contest is open to all ages.

#### Contest Rules:

- All photos must be accompanied by an entry form (see page 20 or download from website)
- Snapshots/collages are welcome from any event or activity such as summer picnics, fall meetings or CSA Chapter activities
- Pictures should be as high resolution as you can accomplish with your camera
- Photos can be black and white or color
- NO PHOTOS WILL BE RETURNED
- No limit on photo entries, but each should be accompanied by an entry form
- No larger than 8" X 10"
- Ideally, you should save your picture in the largest size you can
- If you save your photo as a jpeg and email to [celiacs@csaceliacs.org](mailto:celiacs@csaceliacs.org), be sure to add that the photo is for the competition. Be sure to include the entry form
- Be sure you obtain permission from all persons in the photo before you submit
- Winners will be notified after December 1<sup>st</sup>

#### Photo Ideas:

- Group meetings/speakers
- Group activities/programs
- Individuals finding success through the "WBRO-Free diet"/CSA CelKids®/Leaders /Families
- Action photos such as a walk-a-thon, bike-a-thon, cooking demo, BBQ, bake off, etc

Send photos and entry forms to:  
CSA Photo Contest  
PO Box 31700  
Omaha, NE 68131-0700

OR

Email photos and entry forms to:  
[celiacs@csaceliacs.org](mailto:celiacs@csaceliacs.org)



**CSA PHOTO COMPETITION 2009**

**PROMOTING CELIAC DISEASE AWARENESS MONTH**

**ENTRY FORM**

Name: \_\_\_\_\_ Membership#: \_\_\_\_\_

Street Address: \_\_\_\_\_

Apartment Number (If Applicable): \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: ( \_\_\_\_\_ ) \_\_\_\_\_ Email: \_\_\_\_\_ @ \_\_\_\_\_

Local Chapter name and number: \_\_\_\_\_

Please describe the activity depicted in the photo including the date and name of the activity:

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I give permission for CSA to use this photograph in print and electronic media in the interest of increasing awareness of celiac disease and dermatitis herpetiformis. **I have obtained permission from all parties in the photo** to submit this photo for display on CSA's website and *Lifeline* newsletter.

Signed: \_\_\_\_\_  
Photographer

Date: \_\_\_\_\_



## The CSA Student Essay Contest

### TO BE ME. . . AND GLUTEN-FREE!

Students in grades kindergarten through college are invited to share their unique personalities and experiences with celiac disease and the gluten-free lifestyle through a special essay contest.

The contest is open to students diagnosed with celiac disease or students who are members of a family dealing with celiac disease.

The essay should be either written in ink or typed and approximately 500 words or less. Pre-writers may dictate their thoughts to an adult scribe.

In the **upper right hand corner** include:

- Name
- Address
- City
- State
- Phone number
- Parent/Guardian Name
- CSA local chapter name/number
- School
- Grade
- Age (if under 21)
- Entry date

The essay will be evaluated on the six traits of writing: voice, ideas, word choice, organization, sentence fluency and conventions. It should include an introduction, topic development, support and structure.

Awards and prizes will be given in appropriate divisions including grades K-4/elementary, 5-8/middle school, 9-12/high school, and college. With permission, winning essays will be printed in *Lifeline* and on the CSA website.

The essays will be judged by a panel from the National Council of Teachers of English (NCTE), Nebraska Affiliate-the Nebraska English Language Arts Council (NELAC) and CSA staff. All essays will become the property of CSA; submission of an essay constitutes permission for use by CSA.

Entries will be accepted at any time until the contest closes on **December 1**. Winners will be notified and announced in CSA publications and on the website.

**Mail essays to:**  
**CSA Student Essay Contest 2007**  
**PO Box 31700**  
**Omaha, NE 68131-0700**

Or

**Email essays to:**  
[executivedirector@csaceliacs.org](mailto:executivedirector@csaceliacs.org)



## THE 2009 CSA GLUTEN-FREE RECIPE CONTEST

For 2009, the Celiac Sprue Association is introducing a gluten-free recipe contest. Send CSA your favorite and most original recipe for the competition. CSA will select a winner who will win free membership to CSA for one year and three books from the CSA cookbook collection. Recipes can be mailed to CSA at PO Box 31700 Omaha, Nebraska 68131 or email the recipe to [celiacs@csaceliacs.org](mailto:celiacs@csaceliacs.org). All entries must be received by noon on December 1, 2009. All recipes postmarked after that date will not be considered. We encourage you to spread the word to your fellow CSA members and we will see who has the most innovative and delicious recipe! Please refer to the following criteria when selecting which recipe to enter:

- Send us up to three delicious, creative, gluten-free recipes. The recipes can include breads, salads, soups, entrées or desserts. **Recipes must be your original creation: not from restaurants, cookbooks, or previously published.**
- **All recipes must include a title, a list of ingredients with exact measurements and complete instructions with all cooking/baking times and temperatures.**
- **Recipes must be typed or printed.**
- **The judges' decision is final.**
- **Awards will be based on number of entries.**
- Recipes will be judged on taste, appearance, originality, creativity, ease, healthfulness and cooking time.
- Photo is optional.

### OFFICIAL JUDGES FOR THE CSA RECIPE COMPETITION:

- Clark Kolterman – CSA Treasurer and a man who knows his food!
- Mary Schluckebier – CSA Executive Director and Home Economist.
- Linda Flyr – Editor of *Lifeline* and a cooking expert for individuals with celiac disease.
- Jean Guest – CSA Dietitian Advisor.
- Joan Gloystein – CSA Dietitian and Patient Support.





## THE CSA SPIRIT OF SERVICE AWARD

Create interest and awareness about celiac disease by honoring those who exemplify and live the CSA motto of "Celiacs Helping Celiacs" with certificates of recognition.

Our deep appreciation goes to those individuals who work toward and are dedicated to the mission of CSA, assisting individuals diagnosed with celiac disease. This certificate can be presented to health professionals, teachers, chapter officers, advocacy group leaders, community service project leaders, food service handlers or any others that have demonstrated exemplary support of the mission of CSA. For example, you may want to honor the volunteer leader in a fund raiser or an outstanding programming chair person.

To assist in recognizing such individuals, a certificate has been prepared that can be presented to the individuals to be honored. The recognition certificate is signed by the CSA President and the CSA Executive Director. The certificate (8<sup>1</sup>/<sub>2</sub>" by 11") can easily be framed for the presentation to the honored individual.

This "Spirit of Service Award" is available at any time during the year, but special emphasis on those who serve should be made during Awareness Month. Designation of the award is entirely up to the presenters and no documentation is required by the national office before certificates are sent. Local press releases are encouraged when giving the Spirit of Service Award, as well as press releases to the national office to be included on the CSA website.

To obtain certificates, contact the national office by toll free phone 877-CSA-4-CSA, by email at [celiacs@csaceliacs.org](mailto:celiacs@csaceliacs.org) or mail at PO Box 31700, Omaha, NE 68131-0700, and ask for "Spirit of Service" award certificates. They will be mailed to you complete with presidential and executive director signatures, and ready for you to fill in.

## FACT SHEET ON CELIAC DISEASE

- Approximately 2.5 babies are born every minute that carry a genetic predisposition to celiac disease.
    - The 2009 Celiac Disease Awareness Month Theme refers to the 30% of the United States population genetically predisposed to celiac disease. Using this formula, it can be calculated that every minute approximately 2.5 children are born carrying this genetic predisposition. This staggering statistic succinctly displays the ever increasing need to promote awareness of celiac disease and strengthens the resolve of the Celiac Sprue Association in its mission to provide research, education and support for individuals dealing with celiac disease.
  - Research indicates that at least 1 in 130 people<sup>1</sup> might have celiac disease in the US – most without knowing it
  - Celiac disease is NOT an allergy, however many people believe this to be the case. An allergy is Immunoglobulin E (IgE) immune response. Celiac disease is Anti-gliadin antibody (IgA), T-Cell mediated immune response
  - People who think they have irritable bowel syndrome may have undiagnosed celiac disease
  - People can be diagnosed at any time in their lives. The most common age of diagnosis is 50
  - Currently, in the United States, it averages 11 years before an individual learns they have celiac disease from the onset of symptoms
  - Naturally gluten-free food can be contaminated by crumbs in toasters, jam, butter, on knives, breadboards and other utensils
  - If you are a person who is highly sensitive, even living next to an operational flour mill or going to a bakery can bring on symptoms
  - Dermatitis herpetiformis, or DH, is a skin manifestation of celiac disease
  - The term “gluten” is, in a sense, a generic term for the storage proteins that are found in grains. In reality, each type of protein—gliadin in wheat, hordein in barley, secalin in rye, avenin in oats, zein in corn and oryzenin in rice—is slightly different from the others. The “gluten” in wheat, barley, rye and a much lower amount in oats (WBRO) contain particular amino acid sequences that are harmful to persons with celiac disease. It is important to note that the gluten found in corn and rice does not cause harm to those with CD.
  - On January 23, 2007, the United States Food and Drug Administration (FDA) proposed a definition for “gluten-free” to be used in voluntary labeling. Final regulations were slated for 2008, but the definition remains in draft form as of this date. The FDA definition states that for a food to be labeled “gluten-free” it must **not** contain **any** of the following:
    - An ingredient that is any species of the grains wheat, rye, barley, or a crossbred hybrid of these prohibited grains
    - An ingredient that is derived from a prohibited grain and that has not been processed to remove gluten (e.g. wheat flour)
    - An ingredient that is derived from a prohibited grain and that has been processed to remove gluten (e.g. wheat starch), if the use of that ingredient results in the presence of 20 ppm or more gluten in the food
- Or
- 20ppm or more gluten
  - Average healthcare costs per untreated celiac in the United States range from \$5,000-\$12,000 annually and total US healthcare costs for all untreated celiacs are estimated to range from \$14.5 billion - \$34.8 billion annually.

## QUESTIONS AND ANSWERS

### **“How common or widespread is celiac disease?”**

Studies have suggested that approximately 2.5 babies are born every minute with a genetic predisposition for celiac disease, and that as many as 1 in 130 people may have celiac disease in the US<sup>1</sup>.

### **“So what exactly is celiac disease?”**

Celiac disease is one of the most common genetically linked diseases. It is a cell mediated response to amino acid sequences found in wheat, barley, rye and oats. Celiac disease is a life-long condition, which affects the whole body. It also damages the intestine, preventing normal digestion and absorption of food. If undetected in the long term it can lead to, among other things, anemia, poor bone health and weight loss because the body is not absorbing nutrients properly. If you are born with the genetic predisposition, symptoms can be triggered at any time in your life – for example during illness, stress, or after an accident, but the majority of people are diagnosed in their mid-life.

### **“What harm does the disease do – I mean how dangerous is it, or is it contagious?”**

It's not contagious although it does run in families. There is an increased risk when celiac disease exists in a family, so anyone who has a family member with celiac disease should be extra vigilant. Thankfully, the health risks associated with celiac disease are minimized as long as a gluten-free diet is adhered to. However, it can have long-term serious effects if left undiagnosed until later life as the risk of osteoporosis and cancers of the digestive tract is increased.

### **“What are the symptoms, what should we be looking out for?”**

The symptoms are variable but can include tiredness, diarrhea, anemia, abdominal discomfort, weight loss, vomiting, and mouth ulcers, but some people don't have any symptoms at all. Children with celiac disease can present with the same symptoms, but if left untreated, can suffer from weight loss and stunted growth. Dermatitis Herpetiformis (DH) affects the skin and usually the intestinal villi. People with DH react to gluten by developing itchy, sore blisters on the skin – particularly on the elbows, knees and buttocks.

### **“What should people do if they suspect they might have celiac disease?”**

See a doctor. Diagnosis involves having a blood screening test which the physician can do, followed by an upper endoscopy with biopsy of the small intestine (a tube passed down your throat through your stomach and into the small intestine) done under sedation by a gastroenterologist. If you think your symptoms are consistent with celiac disease persevere with your physicians and ask for a celiac blood panel test. NEVER CHANGE YOUR DIET UNTIL YOU HAVE A DIAGNOSIS!

### **“How is it treated? What's the management of the disease?”**

Treatment is a diet free of WBRO for life. When you are first diagnosed, a dietitian may help guide you through the steps of changing your diet. It may take a while to get your diet sorted out, but with perseverance you will get there. The intestinal villi have been damaged by taking in gluten for quite some time. By switching to a gluten-free diet, the intestinal villi will start to heal but this healing can take up to two years. However, most people start to feel better in the first week or two.

### **“What is the difference between allergy and intolerance?”**

Marsh uses the term 'Food sensitivity' to describe a range of abnormal responses to foods. Food sensitivities include immune system allergies and celiac disease. Food

sensitivities without an immune base include food intolerances (eg. lactose or gluten intolerance).

**Celiac disease** is a cell mediated auto immune disease. It is life-long, symptoms vary widely among individuals, and damage is cumulative. Celiac disease is diagnosed through a special celiac blood panel test and an upper endoscopy with a small intestinal biopsy. Diagnosis of **gluten allergy** is based on diet history, detection of IgE antibodies and other laboratory tests. Anaphylactic shock is symptomatic of a true food allergy.

**Gluten intolerance** is a non-immune response for which there are no diagnostic tests at this time. Intolerances are confirmed through an elimination diet. Symptoms and treatment for all three conditions may be quite similar.

#### **“What kinds of food have gluten in them?”**

Foods and ingredients based in or derived from the grains wheat, barley, rye and oats have “gluten” that triggers the immune response in celiacs. Gluten can be found in breadings, coatings, processed foods, sauces, soups and gravies. Even corn and rice based cereals often contain barley malt. Label reading for potential sources of gluten is essential in maintaining a gluten-free lifestyle.

#### **“What about eating out?”**

Contact the local CSA chapter or the national office for a “dining card” with suggestions on how to handle specific situations. Local CSA Chapters and Resource Units often have suggestions and ideas as to “safe places” to dine.

#### **“And what about going on vacation or even going abroad?”**

CSA offers a restaurant card and a variety of travel tips. Contact area CSA Chapters or Resource Units to assist you when traveling in specific areas of the United States. Many countries have celiac associations that offer assistance to foreign travelers. Contact CSA for the websites of celiac organizations in countries you will be visiting.

#### **“What research has CSA funded?”**

For a complete listing of the CSA-funded research studies, contact the CSA office by calling toll free 877-CSA-4-CSA or visit the website at [www.csaceliacs.org/research](http://www.csaceliacs.org/research).

#### **“What is The AACSA Foundation?”**

The Affiliated American Celiac Sprue Association Foundation is the support foundation for CSA. The foundation was proposed in 1990 created in 2000 and incorporated in 2004 in order to support the mission and work of the Celiac Sprue Association.

#### **“What specifically does The AACSA Foundation do?”**

The stated intent of The AACSA Foundation is to:

- Aid and assist CSA, including the operation of a national office, programs and projects that CSA supports and operates, by and through the solicitation and administration of gifts, grants, contributions, funds, devises and bequests of money and property for the benefit of said organization.
- Aid and assist in the support of activities of CSA and the care and outreach by and through the solicitation and administration of gifts, grants, contributions, funds, devises and bequests of money and property for the benefit of said institutions.
- Aid and assist the CSA membership with educational programs affiliated and approved by CSA and through the solicitation and administration of gifts, grants, contributions, funds, devises and bequests of money and property for the provision of scholarships, grants and other activities as so selected by CSA
- Promote and encourage the support and financial contributions of the membership of CSA by good management of funds and by providing educational support, materials and resources to the CSA membership on the activities of CSA and the Foundation.

## WORKS CITED

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