



Mary Schluckebier, BS, MA

Executive Director

Prepared for DDNC Public Policy Forum

2009



Celiac Sprue Association
2009

The Mimic

- Non-tropical Sprue
- Celiac Sprue
- Gluten Enteropathy
- Celiac Disease



Reality of living with celiac disease

Undiagnosed -- untreated

- Risk of cancer 200-300%
- Risk of miscarriage 800-900%
- Healthcare costs \$14.5 - \$34.8 mil. annually
- Average of 10 years from symptoms to diagnosis



What are the symptoms of celiac disease?



- No “typical” celiac
- No discernable symptoms
- Co-exists with other autoimmune disease at rate of 6-10%
- Sjögren’s has highest correlation
- Autoimmune liver disease 6-8%
- Idiopathic dilated cardiomyopathy



Patients newly diagnosed symptoms:

- Chronic diarrhea: 35%
- Joint pain: 29%
- Abdominal pain: 28%
- Fatigue: 26%
- Constipation: 20%
- Asthma: 7%
- Type 1 diabetes mellitus: 7%
- Osteoporosis: 6%
- Peripheral Neuropathy: 5%
- small fiber neuropathy 16%

– Neurology Russell Chin, MD; Norman Latov, MD; Peter HR Green, May 2003

• "Prevalence of Celiac Disease in At-Risk and Not-At-Risk Groups in the United States," Archives of Internal Medicine, Feb. 10, 2003



Symptoms of celiac disease

- Abdominal cramping/bloating
- Abdominal distention
- Acidosis
- Anemia
- Appetite (increased to the point of craving)
- Back pain
- Bone pain or loss



Celiac Sprue Association®

Celiac Sprue Association
2009

Symptoms

- Constipation / Diarrhea
- Decreased ability to clot blood
- Dermatitis herpetiformis
- Depression / mood change
- Dehydration
- Edema
- Electrolyte depletion



Symptoms

- Fatigue
- Feet (reduced fat padding)
- Flatus (passing gas)
- **Gluten ataxia**
- Infertility / delayed puberty
- Malnutrition
- Migraine like headaches



Celiac Sprue Association®

Celiac Sprue Association
2009

Symptoms

- Mouth sores or cracks in the corners
- Muscle cramping (especially in hands/legs)
- Night blindness
- Peripheral neuropathy
- Rheumatic conditions
- Skin (very dry) / skin irritations



Celiac Sprue Association®

Celiac Sprue Association
2009

Symptoms ... about 300 in all

- **Stools** (loose, hard, small, large, foul smelling, frothy)
- **Thyroid hyper/hypo**
- **Tongue** (smooth or geographic – like continents)
- **Tooth enamel defects**
- **Villous Atrophy**
- **Weakness**
- **Weight loss / gain** (unexplained)



Celiac Sprue Association®

Celiac Sprue Association
2009

Symptoms – children

- Delayed puberty
- Difficulty concentrating
- Diarrhea / constipation
- Personality changes
- Projectile vomiting
- Slow growth / short stature
- Sickly -- tired



At diagnosis

- 1/3 had celiac disease
and no gastrointestinal symptoms

- H.P. Green, MD



Celiac Sprue Association®

Celiac Sprue Association
2009

May become active for the first time after. . .

- Surgery
- Pregnancy or childbirth
- Viral infection
- Severe emotional distress.

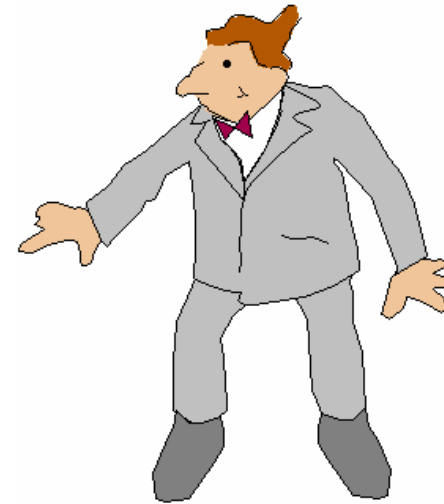


National Institute of Diabetes, Digestive and Kidney Diseases.

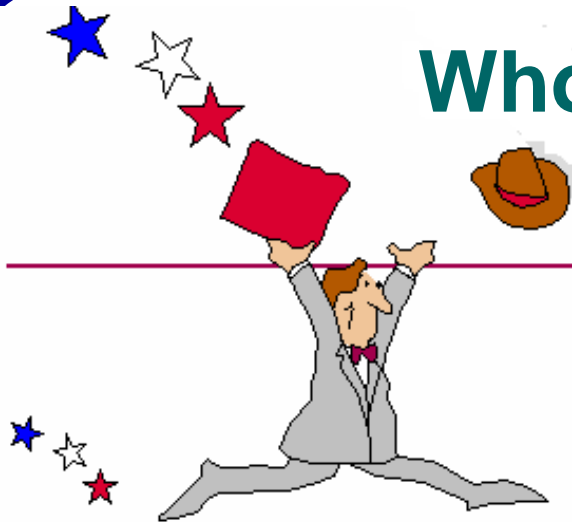


What is celiac disease?

- Digestive disease
- Genetic
- Inflammatory
- Autoimmune



Who catches celiac disease?



- Genetic predisposition
- Exposure to an environmental “trigger”
- Consume foods containing specific amino acids most prevalent in wheat, barley, rye and to a lesser degree oats

Celiac disease

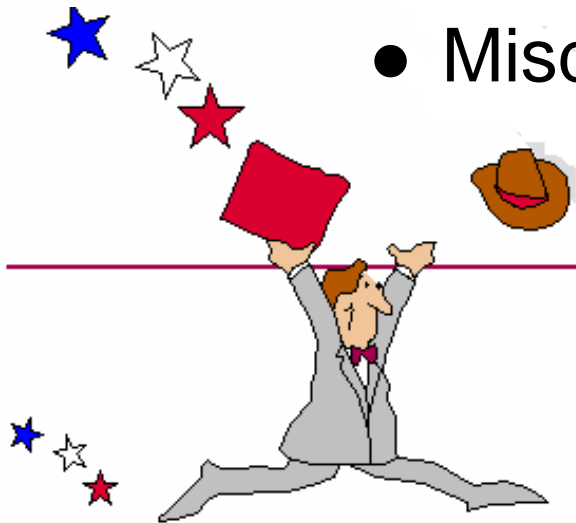
- Is lifelong
- Has no cure
- Remission for patients who are diagnosed early and maintain the medically prescribed diet

Early diagnosis means few, if any, additional health complications related to celiac disease



Who has celiac disease?

- 1% of population world wide
- 10-11 years delay in diagnosis
- Misdiagnosed symptoms mimic other diseases/disorders
 - Undiagnosed



Diagnostic resistance to test

- Suspicion
- Test at risk population?
 - Family
 - With pre-mature osteopenia
 - With nutrient deficiencies
- Test for co-existing diseases
- Test the chronically ill



Road to diagnosis

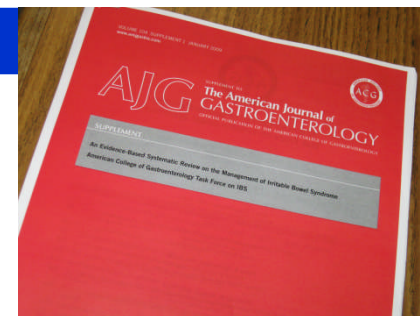
- Awareness
- Suspect celiac disease



Test IBS patient for celiac disease?

Supplement

Am J Gastroenterol 2009;
104:S1–S35; doi:10.1038/ajg.2008.122



An Evidence-Based Position Statement on the Management of Irritable Bowel Syndrome

Routine serologic screening for celiac sprue should be pursued in patients with IBS-D and IBS-M (Grade 1B)

Cost effective - serologic screening for celiac sprue in IBS patients as long as the prevalence of celiac sprue exceeded 1 % (81,82)



Celiac Sprue Association
2009

Undiagnosed celiac children fail to respond to hepatitis B vaccine

- NY 53.9%, vaccine failure, a rate 8.33 times greater than controls
- Turkey 68% failure in untreated celiacs
- Hungary 97.3% booster **success** for those on diet
- *Clinical trial in Israel began Oct 2008 on alternative vaccine delivery for greater success*



Celiac Sprue Association®

Celiac Sprue Association
2009

Disclosure of excipients in drug products



“To advocate that manufacturers declare the name and derivative source of all excipients in drug products on the official label.”

Note: Derivative source means the botanical, animal, or other source from which the excipient is originally derived.

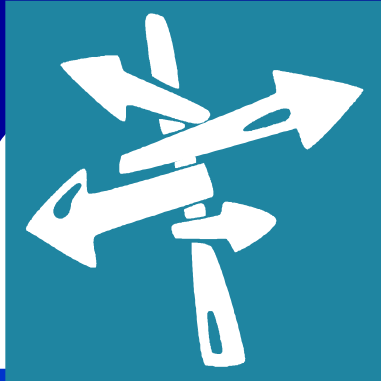
American Society of Health-System Pharmacists

Policy Statement 0808 Council on Pharmacy Practice



Celiac Sprue Association®

Celiac Sprue Association
2009



The Medici Effect:
Confluence of many seemingly
unrelated fields working toward
common goal

Working Toward **Common Goals** – **Solving Digestive Diseases Mysteries**

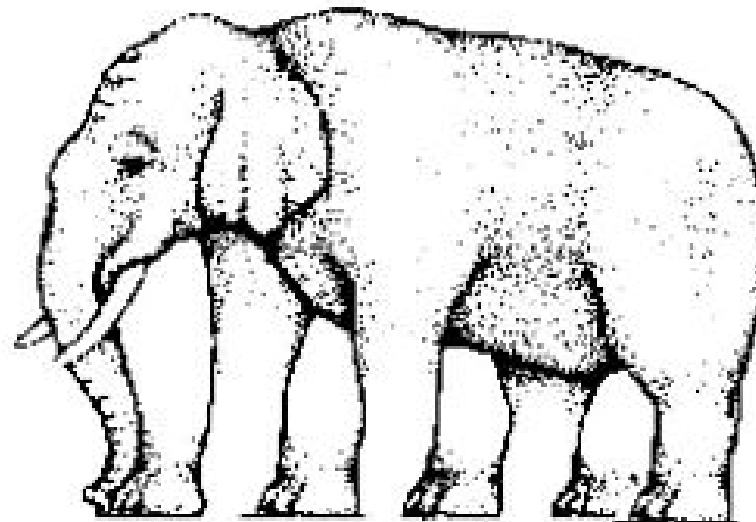
- Health Interest Groups: awareness for early diagnosis / cure
- Research:
 - Precise analysis of food
 - Digestive micro flora -- animal models
 - Pharmaceutical efforts
- Genetics:
 - Human genome project
 - Plant breeding for foods with health benefits
- Legislative:



Celiac Sprue Association®

Celiac Sprue Association
2009

Working Toward Common Goals – Solving Digestive Diseases Mysteries



How many legs does this elephant have?



Celiac Sprue Association®

Celiac Sprue Association
2009



**Celiac Sprue
Association®**

P.O. Box 31700
Omaha, Nebraska 68131
1-877-CSA-4-CSA
www.csaceliacs.org

**Mary Schluckebier, BS, MA
Executive Director**

