

HEROES AMONG US



nfca

This month we recognize
the heroes among us.

**NATIONAL FOUNDATION
FOR CELIAC AWARENESS**

CELIAC DISEASE

A HIDDEN EPIDEMIC WORLDWIDE

THE MOST UNDIAGNOSED AND MIS-
DIAGNOSED AUTOIMMUNE DISEASE

THE TIP OF THE ICEBURG

- As a FCS professional, do YOU know the facts?
 - Why do I care?
 - Why should you care?

CELIAC SESSION OBJECTIVES

Participants will gain:

- An ability to take action, armed with knowledge to raise awareness of Celiac Disease.
- An ability to access, use and evaluate current Celiac Disease information to help raise awareness and curb the Celiac Disease epidemic.
- An ability to analyze and use Celiac Disease knowledge both PERSONALLY and PROFESSIONALLY to *advocate* for improved detection and CD outcomes.

Sources: Columbia and Johns Hopkins Universities, Mayo and Cleveland Clinics, NFCA, NCF, CD books, CD publications, research articles AND personal experience living with Celiac Disease

FACTS ABOUT CELIAC DISEASE

- Celiac Disease is a genetically based autoimmune disease that is triggered by the ingestion of gluten which includes Gliadin— a protein found in wheat, barley and rye and their derivatives
- An estimated 1 in 100-133 Americans has Celiac Disease (over 3 million) yet 83-99%, (depending on study) are either undiagnosed or misdiagnosed. 6-10 years is the average time a person “waits” to be diagnosed. Many wait much longer.
- Celiac Disease is a hereditary disease, expressed frequently in families carrying the gene or genes.
- 5-22% of people with Celiac Disease have an immediate family member who also has the autoimmune disease. Once removed relatives, too. (Often unaware of it)
- When a person with Celiac Disease eats gluten, it sets off an immune reaction that damages the villi (hair like projections) in the small intestine and interferes with the absorption of nutrients their entire life.

CD Facts, continued...

- There is no pharmaceutical cure for Celiac Disease. The only treatment is a strict, lifelong gluten-free diet. Researchers are working on “a pill.” (Duh!)
- Celiac Disease was once thought of as a childhood ailment that the child would outgrow. It is now known that the condition affects men and even more women of all ages and races, and can DEVELOP or express at any time, but you are BORN with it. You do not “catch or get it” any other way.
- REMEMBER: CD is NOT the same as “gluten intolerance.”

CELEBRATE THE DIAGNOSIS

AND A NEW LEASE ON LIFE GOING GLUTEN FREE

- Celiac Disease is a “life changer”--not for the worse, but for the better, because.....
- Celiacs can generally heal themselves by NOT eating or ingesting products containing wheat, barley or rye in any form. (foods, medications, some cosmetics, some sprays, etc.)
- Gluten triggers Gliadin which destroys the villi of the small intestine, resulting in lifelong malabsorption of vitamins, minerals, and nutrients, leading to many autoimmune diseases over a lifetime in Celiacs.

MISDIAGNOSIS FREQUENTLY LEADS TO A LIFETIME OF AUTOIMMUNE DISEASES

- Although it IS possible to diagnosis CD through testing at birth, as is done in some parts of the world, in the US most people are diagnosed with several to many autoimmune diseases over a period of several to many years before the correct diagnosis is made.
- The list of diagnosis of other conditions is long and is still being studied. Many are identified.
- The following list IS NOT comprehensive.

CELIAC RELATED DISEASES AND CONDITIONS

Infertility, miscarriage, still birth, menstrual and pregnancy problems

Migraine headaches

Peripheral Neuropathy

Osteoporosis, Osteopenia

Turner's, Williams Syndrome

Type 1 (and now type 2 diabetes)

Crohn's, Sjogren's Disease

Lupus, Multiple Sclerosis

Iron Deficiency Anemia

Thyroid Diseases (hypo and hyper)

Autism Spectrum, ADHD

Down Syndrome, other birth defects

Chronic Fatigue, Fibromyalgia

Anxiety, depression, mental illness

Dental defects, canker sores

Dermatitis Herpetiformis, skin issues

Irritable Bowel Syndrome

Intestinal and lymphoma cancers+

Liver Disease

Bloating and bowel problems

Slow growth in children

WHY ARE SO MANY DISEASES AND CONDITIONS RELATED TO THE UNDERLYING DISEASE, CELIAC?

From birth onward various amounts of damage along the 22 ft. long small intestine continue to wear away villi, leading to malabsorption unequally so various systems are affected, causing disease and other autoimmune conditions.

The OTHER diseases are generally more commonly tested for and more obvious in their presentation to doctors

According to my doctor, most doctors are not trained in this country to look for Celiac Disease. It has it's own specific tests.

Treatment for Celiac is done by the Celiac, not by medicine or by the doctor, other than to follow your progress.

Resistance from those standing to loose money!!! (Many)

WHAT ARE CELIAC SIGNS AND SYMPTOMS

- A 2012 survey found that 35% of people at risk for Celiac Disease had ***no reason*** to suspect that the symptoms they were experiencing may be due to undiagnosed Celiac Disease.
- Classic symptoms include diarrhea, anemia, weight loss or growth failure (especially in children.)
- Non-classic symptoms include constipation, abdominal pain, and foul-smelling and bulky stools.
- Other symptoms include skin rash, unexplained infertility, fatigue, headaches and nutritional deficiencies.
- Many people with undiagnosed Celiac Disease experience no symptoms at all. It's common to go 50, 60, 70 years without getting a proper diagnosis. May have a dozen other diagnosis instead.

HOW IS CELIAC DISEASE DIAGNOSED?

Accurately diagnosing Celiac Disease can be quite difficult largely because the symptoms often mimic those of other diseases as mentioned earlier.

The **correct** blood tests are the first step in a diagnosis of Celiac Disease. A doctor must order the correct, specific series of blood tests to measure your body's response to gluten.

Therefore, you must continue to eat Gluten until you are tested or the antibodies may not show up. False negatives are fairly common. Retesting may be needed.

Recommended blood tests include: Total IgA, IgA-tTG, and IgA-EMA

If IgA is deficient, it is recommended that the IgG/IgA-DGP also be ordered. At the discretion of the doctor, IgG-AGA can also be ordered.

Genetic testing can tell if the person carries the gene(s). They must to have Celiac. They test for HLA genetic markers, **HLA-DQ2** (95% have) and **HLA DQ-8** (5%have)

A biopsy of the villi is the “gold standard” for assessing/diagnosing Celiac Disease.

WHAT MIGHT NEWLY DIAGNOSED CELIACS EXPECT?

Adjusting to a Celiac diagnosis takes some time

- Sense of loss, fear of unknown, worry are common.
- Insecurity, anger, denial, resistance, acceptance
- Learning curve steep, lots to learn. Many resources.
- Family, others don't understand, appreciate CD.
- Healing takes time, patience and persistence.
- Your coping style matters (positive, flexible, adaptive)
- Mastering the gluten free diet—OK-NOT OK foods
- Shopping takes longer and is more expensive. (taxes)
- Avoiding cross-contamination at home, a must.
- Many non-food items also contain gluten.
- Challenges of eating out, away from home.

YOU can heal yourself by lifelong compliance.

A CLOSER LOOK AT CELIAC ADJUSTMENT

Read, read, read and find knowledgeable persons to consult.

Find Resources: National Celiac Awareness Foundation;
Research hospitals, centers; books, Celiac magazines;
Celiac support group; reliable online Celiac information

Most people in US know very little or nothing about Celiac and misinformation abounds. Many believe it to be a “fad.” (for some, going gluten free may be, but NOT for the Celiac)

“Gluten Intolerance” is not the same as Celiac Disease and there is no definitive test for it. Celiac Disease is not an allergy (which is a fast acting reaction to something) but many people do feel better when they don't eat gluten. Research has shown gluten has addictive properties.

For Celiac's, it's a lifelong condition requiring NO GLUTEN!

MYTHS SURROUNDING CELIAC

Myth #1: You can outgrow Celiac Disease. Although symptoms may disappear, with proper GF adherence, once a diagnosed Celiac you ALWAYS have Celiac.

Myth #2: A little bit of gluten now and then won't hurt. Research indicates it WILL, even in very small amounts. (20+ ppm does damage)

Myth #3: Vinegar contains gluten. Distilled is OK. Only MALT vinegar has gluten.

Myth #4: Distilled alcohol has gluten. Distilling removes gliadin, so it is GF. Only spirits made from wheat, barley or rye and related flavorings contain gluten

Myth #5: Gluten is absorbed through the skin. Gluten MUST be ingested to affect the villi of the small intestine. The condition dermatitis herpetiformis that Celiac's may get is caused by eating gluten, not creams or lotions ON the skin.

Myth #6: You can get CD through a blood transfusion. The antibodies found in blood cannot cause Celiac Disease in another person.

LEARNING TO LIVE AS A CELIAC

The eating learning curve.....

Your toolbox should include.....

An understanding of which grains, ingredients and foods are safe and which are not.

Finding the products you need in stores or online. ASK manager to stock items.

The ability to read and understand labels. Look for the new GF label as of Aug. 2014

Storage, contamination, “oops” issues. Needs careful attention. A trace does matter.

A knowledge of the areas of the GF diet still being researched enabling you to make educated choices (oats, etc.) Standards vary around the world (US: 20 ppm).

The ability to advocate for GF safety with waiters, hostesses, caterers, school lunch.

Patience—with family, friends and strangers who may or may not cope well with the GF diet. They don't realize how important it is or HOW GOOD the food tastes.

Keep the focus on EATING HEALTHY, not just on eating gluten free.

ANALYZING AND USING CELIAC DISEASE KNOWLEDGE

How can CD knowledge be used PERSONALLY?

Consider your own risk by taking the “Do I have Celiac.org” assessment tool. IF indicated, talk to your doctor about testing, but be certain she/he is up to date on Celiac by talking about your concerns. Seek another opinion if this doctor scoffs at testing. Only the correct blood test can start the process.

If another member of your family could benefit from being checked out, work with the person to try to get them tested.

Keep learning about Celiac Disease in order to share accurate information when appropriate. We can't share what we don't know—or CAN WE?

How can CD knowledge be used PROFESSIONALLY?

Make it a goal to educate others accurately about the Celiac Epidemic: In the classroom, in clubs and organizations, churches, conferences. Especially important is including a unit in secondary and higher education FCS settings to raise awareness of the hidden epidemic of Celiac Disease, helping to unmask it for the benefit of future generations.

FINDING CD RESOURCES

A real plethora of CD resources today—but not all are created equal! BEWARE

Reliable Resources

Research hospitals: Columbia and Johns Hopkins Universities; Mayo and Cleveland Clinics); Celiac Centers: National Celiac Foundation and Celiac Awareness Foundation; peer reviewed articles; Celiac GF magazines.

Online: FDA, CDC, USDA, ADA,celiac.com, American Celiac Disease Alliance, Celiac Foundations, Research Hospitals and Clinics, Triumph Dining, etc.

Books: Celiac Disease: A Hidden Epidemic. Peter H.R. Green, M.D., Director of the Celiac Disease Center and Rory Jones, Columbia University, NYC, NY, 2010. (Very educational)

The Gluten Free Bible. Jax Peters Lowell, forward by Anthony DiMarino St. Martin's Press, NY, NY, 2005 (Very practical and helpful)

Artisanal Gluten Free Cooking. Kelli and Peter Bronski, Workman Publishing Co., Inc, NY, NY, 2012 (Excellent-Best of the “cookbooks”)

Magazines: Simply Gluten Free, Gluten Free Living, Living Without

THE CHALLENGE TO Family and Consumer Science Professionals

Unless FCS professionals care about, understand and teach about Celiac Disease we will leave out critical information that could help many individuals and families improve their health and well-being across their life span.

FCS professionals DO HAVE a great opportunity to help unmask this worldwide epidemic so future generations will be aware and knowledgeable about Celiac Disease.

Make a PLAN and TAKE ACTION!

**THANK YOU FOR THE IMPORTANT
ROLE YOU WILL PLAY!**

Next Steps

IT'S UP TO YOU!

