Pre-Assessment...

What you think you know?

QUIZ TIME!
*Which of the following is acceptable for a person with a diagnosis of celiac disease to consume?

Personal Communications
“I have been searching & searching for any research on CD & athletes, & I came across your article in the JAT. I am the captain of the men’s soccer team at X University & I was just dx w/ CD. I have had 2 injury filled & frustrating yrs as I pushed myself through my muscle fatigue, weight loss, & weakness. I have high hopes to return to my former health. I am wondering how hard to train & whether there are supplements that celiac athletes should take? I am desperate for some kind of help. Any information would be appreciated!”

“I found your web abstract on CD. I have a 20 yr old daughter who is a basketball player at the national level. She had a 3 week episode of serious leg cramps & is now hospitalized for vertigo & cramps that go on for 2 hrs at a time. She has had so many tests, but nothing has been found. She has lost weight, but denies an ED. Please help!”
Communication from Finland

Other Advances for Patients w/ CD:
“New store in Everett [MA] focuses on gluten-free food: New business aims to make life easier for people with special dietary needs” (Boston Globe, 2011)
“Celiac & osteoporosis link uncovered”
Consequence of CD, failure to absorb vitamin D & Ca+ (New England Journal of Medicine, 2009)

Celiac disease and athletes...do you really know what you think you know? An evidence-based discussion affecting clinical practice
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“Celiac disease is a rare disorder...” [c. 2003]
Session Overview

Celiac disease (CD) was once thought to be a rare disorder primarily affecting children; however, recent evidence has brought the full magnitude of this disorder to light. **Athletic trainers’ work with diverse groups of people all over the world** and while prevalence estimates vary, approximately 1 in 100 people may have the disease, athletes notwithstanding. This research helps to address an important gap in the evidence for athletes with CD. Additionally, this session will provide **evidence-based data** focusing on potential athletes with celiac disease, including prevalence estimates and dialogue pertaining to recognition, referral, and management best practices.

Presentation Goals & Objectives

**After attending this workshop participants should be able to:**

*Identify* the key features of celiac disease, such as signs and symptoms;
*Discuss* the differences among celiac disease and related disorders, such as non-celiac gluten sensitivity (NCGS);
*Examine* current trends and fads related to celiac disease;
*Describe* ways to identify, treat, and manage athletes and physically active populations with celiac disease;
*Apply* knowledge of celiac disease to advance clinical practice and best practices.

A Brief Hx of Celiac Disease

**Case Study**

Starters...
Boston Marathon & body temperature
Common sense
Focus on *patient* relevance v. *clinical* relevance
What works!
“*Zebra’s & horses*”
Recognition skills
Clinical decision making [ethics]
ED example
Do we not still tx people w/ sx’s even though they may not have a definitive dx?

**FEAR**

Let’s Consider...
Stomach pain/upset/cramping
Gas/flatulence/bloating
Diarrhea
Weight loss
Arthralgias
Mental “cloudiness”
Mood disturbances
Fatigue/malaise
Stomach pain/upset/cramping
Virus
Food poisoning (bacterial)
Pancreatitis
Hepatitis
Hernia
Appendicitis
Ulcers
Diverticulitis
Colitis
Gallstones
IBS
Crohn’s disease
Constipation
Pregnancy
Gas/flatulence/bloating
Food poisoning (bacterial)
Excess fiber
Colitis
Antibiotics
IBS
Crohn’s disease
Constipation
Menstruation
Diarrhea
Viruses
Bacteria
Proctitis
LGV (Lymphogranuloma Venereum – STI)
Often confused w/ IBD!!!
Parasites
Medications
Lactose intolerance
Fructose
Artificial sweeteners
Crohn’s disease
Ulcerative colitis
IBS/IBD
Menstrual cycle
Weight Loss
Exercise
Eating Disorder
Stress/psychiatric
Parasite
Infection (virus/bacteria)
Diarrhea/malabsorption
Drugs & medications
Diabetes
Cancer
Endocrine dysfunction
Age
Neurological disease
Kidney dysfunction
Arthralgias
Stress/psychiatric
Infection (virus/bacteria)
Cancer
Endocrine dysfunction
Age (degeneration)
Neurological disease
Arthritis (Osteo, Rheumatoid, etc.)
Lupus erythematosis
Lyme disease
Gout
Physical trauma
Mental “Cloudiness”
Stress/psychiatric
Age (degeneration)
Neurological disease
Drugs/medications
Dehydration
Concussion
Fatigue
Poor nutrition
Mood Disturbances
Stress/psychiatric
Age (degeneration)
Neurological disease
Drugs/medications
Dehydration
Fatigue
Poor nutrition
Concussion
Eating Disorders
Injury
Menstruation/PMS
Fatigue/Malaise
Stress/psychiatric
Infection (Flu)
Age
Mononucleosis
Drugs/medications
Dehydration
Poor nutrition
Concussion
Eating Disorders
Lyme disease
Injury
Menstruation/PMS

Case Study #1
Celiac Disease Symptoms in a Female Collegiate Tennis Player:
A Case Report
Treatment: The athlete underwent a series of blood & allergen tests to confirm/refute a dx of CD. When CD was suspected, dietary modifications were made to eliminate all wheat-based & gluten-based products from the athlete’s diet.
Uniqueness: The athlete was able to fully compete in a competitive NCAA D-I tennis program while experiencing the debilitating effects associated w/ CD. The immediacy of sx onset was notable because the athlete had no hx of similar complaints.

Case Study #2
Celiac Disease in an Elite Female Collegiate Volleyball Athlete:
A Case Report
Background: Athlete lost 8.1 kg during the first 20 days of training; initially suspected an eating disorder.
Found she did not have psychological sx's indicative of an ED.
Results of routine blood tests revealed critically high platelet counts; in conjunction w/ physical findings, the athlete was referred to a gastroenterologist.
Treatment: Tx w/ a GFD, which excludes wheat, barley, & rye.
Uniqueness: The presence of active CD may not be uncommon. However, elite athletes who face CD present a new challenge for the AT. The AT can help guide the athlete in coping w/ lifestyle changes associated w/ a GFD.

Athlete’s Blood Panel

Discussion of Case Studies
One presents w/ clinically significant sx’s
Again patient relevance v. clinical relevance
Other presents w/ underlying sx’s (anorexia n.)
BOTH are likely CD, but high functioning (as most athletes are!)
Different ways in which they were managed

Many doctor’s have little experience with CD, particularly in athletes

How to identify CD
gas
recurring abdominal bloating and pain
chronic diarrhea
pale, foul-smelling, or fatty stool
weight loss / weight gain
fatigue
unexplained anemia (a low count of red blood cells causing fatigue)
bone or joint pain
osteoarthritis, osteopenia
behavioral changes (Schizophrenia)
tingling numbness in the legs (from nerve damage)
muscle cramps
seizures
missed menstrual periods (often because of excessive weight loss)
infertility, recurrent miscarriage
delayed growth, failure to thrive in infants
**pale sores inside the mouth, called aphthous ulcers**
tooth discoloration or loss of enamel
itchy skin rash called dermatitis herpetiformis

Non-Celiac Gluten Sensitivity [NCGS]
An agreed upon definition of NCGS does not currently exist.

Celiac Disease & Domains of AT

**Defining the Disease**

*Background*

Body sensitivity to *gluten*

CD is an abnormal reaction to a normal food substance

Autoimmune response

Cellular damage results (even w/out sx’s)

Small intestine

Nutrient Absorption

**Common Differential Dx with CD**

*Normal vs. Pathological Villi*

**Comparison**

*Marsh Lesions (stages)*

**Research & Theories**

What we know...

CD is the most common & one of most under-dx, hereditary autoimmune conditions in U.S. (Green & Jones, 2010; Kumar et al., 2001)
Affects 1% of U.S. pop. [1 in 100 people]; 97% of them are undiagnosed! (Ciacci et al., 1995; Lebenthal et al., 2008)
Of 2.1 million people w/ Type I DM → 8-10% have CD
Average time to dx = 9 YEARS!

In Athletic Training?
Lacking research/epidemiology

It is a significant medical condition & a life-long illness! (Green & Jones, 2010)
Geographic & Regional Factors
CD is common in European countries: Ireland, Italy, Sweden, & Austria.
Northern Ireland, for example, one in every 100 people has CD.
In Finland, prevalence may be as high as one in every 50 persons.
CD also occurs in N. America where the prevalence has been estimated at one in every 3000 people.

Geographic & Regional Factors
Most population studies underestimate the prevalence of CD because many patients who develop CD have few or no sx’s until later in life. (van Dijk & Klinkhamer, 2009)
Iceberg model
A recent study in the U.S. suggests that the prevalence of CD in the U.S. is similar to Europe.
CD may be↑; 4 fold↑ over past 50 yrs (Lohi et al., 2007)

The Impact of CD in Athletics*
NCAA reports approx. 380,000 athletes**
If 1:3000 = 127 athletes
If 1:250-300 = 1267-1520 athletes
If 1:100-150 = 2533-3800 athletes
Approximately 7.2 million H.S. athletes in U.S.*
If 1:3000 = 2400 athletes
If 1:250-300 = 24,000-28,800 athletes
If 1:100-150 = 48,000-72,000 athletes

CD: Signs & Sx’s

Identification & Treatment Options
Identification
ELISA panel test
Immunoglobulin A (IgA)
anti-tissue transglutaminase (tTGA)
IgA anti-endomysium antibodies (AEA)
Fecal samples
Genetic testing
Oral swabs
Treatment
Strict GFD
Tx for skin issues
Dapsone
Vitamin & mineral supplementation
Gene therapies
Vaccinations
Dx: Gold standard is intestinal biopsy (Presutti et al., 2007)
Serologic tests often lack sensitivity (Walker et al., 2010)
Normal biopsy doesn’t exclude CD for life (Green & Jones, 2010)
If skin biopsy (+) for DH $\rightarrow$ CD is confirmed (Salmi et al., 2011)
Autoimmune disorders affect ~3% of general population, but affect 30% of people w/ CD (Cosnes et al., 2008; Green & Jones, 2010; Neuhausen et al., 2008)
Assure all prescription & OTC meds, vitamins & supplements are GF (Green & Jones, 2010)
Children & 1st degree relatives of patients should have blood tests even if no sx’s (Greco et al., 2002; Neuhausen et al., 2008)
Make sure to get good info!
Cross-contamination is a HUGE issue (Catassi, et al., 2008; Leone, 2009)
Reassess what you eat; you do not need to eliminate everything & start over (Green & Jones, 2010; Leone, 2009)
CD patients need to not only focus on GFD, but also eating healthy (Green & Jones, 2010; Kupper, 2005)
Many products are devoid of fiber, have high fat content, & the intestines now WORK! (wt. gain)
Ask for “naked food”
GFD is difficult, particularly for adolescents (Treem, 2004)
Consider psych aspects of CD (Ciacci et al., 2002)
Sense of loss & grief (AT role) (Leone, 2009)

The future...
- Greater awareness
- Ease in obtaining GF food
- More normal lifestyle
- Better dx, prognosis, & tx

Essentials of the GFD

Celiac Disease Today

Important to follow Celiac “Medical Checklist”
- Dietary counseling
- Assessment of nutritional deficiencies
- Medication assessment
- Bone density assessment (males & females)
- Pneumovax vaccination q 5 yrs.
- Screen family members
Follow-up blood antibody levels (yearly)
Repeat biopsy
Malignancy screening at appropriate ages
Weight & cholesterol assessment
Yearly physical & celiac evaluation

If Symptoms Persist
Still getting gluten?
Ongoing inflammatory process...
Common associated condition that needs tx
Something else wrong?
True refractory sprue (rare)
Wrong dx & do not have CD
? NCGS

Consequences
Stunted growth
Failure to thrive
Loss of key minerals & nutrients
Vit. K, Na+, Ca+
Weight Loss
Seizures
GI ulcers/CA (adenocarcinoma)
Death...

Be an AT CSI

The Diversity of Celiac Disease
Psychological Management...
DOES MATTER!
Helping athlete to cope
Support systems
Sense of loss

Summary for the Clinical Management of CD:
The ATC’s role:
Know what it is! (first things first!)
Challenge your clinical thinking/paradigm
Educate your colleagues; including physicians!
Be aware of physical signs:
Mouth sores
Unexplained weight loss
Skin reactions
Abnormal blood panels

Celiac Disease & Domains of AT
Take-Home Points:
People w/ CD can’t eat foods or use items w/ gluten
CD harms the sm. intestine.
People w/ untreated CD can’t get needed nutrients.
W/out tx, people w/ CD can develop other health problems.
CD is dx by blood tests & biopsy of the sm. intestine.
A GFD must be followed for life.
A dietitian can help people choose the right foods.

“Eating to live...versus living to eat!”

“Djokovic Attributes Diagnosis of Celiac Disease to new found Form”
April 27, 2011
World No. 2 Novak Djokovic, who was recently diagnosed with celiac disease, told the Serbian media earlier this week that his health and movement around the court have improved tremendously since he’s changed his diet.
Celiac disease, which damages the lining of the small intestine and prevents it from absorbing parts of food that are important for staying healthy, is caused by a reaction to eating gluten, which is found in wheat, barley, rye, and possibly oats. Djokovic gave full credit to his nutritionist for figuring out the problem.
“He’s done a great job in changing my diet after we established I am allergic to some food ingredients like gluten,” Djokovic said of his nutritionist.
“It means I can’t eat stuff like pizza, pasta and bread. I have lost some weight but it’s only helped me because my movement is much sharper now and I feel great physically.”
Djokovic, who is currently riding a 26-match winning streak, will begin his clay-court season this week at his hometown event in Belgrade, Serbia. Djokovic is also a part owner of the tournament.

Health Questionnaire
Meaning...
If one or more lines checked in either Section I or II & have any of the illnesses in Section III → consider testing for CD;
If you have checks in all three sections, you & your doctor definitely should explore a dx of CD!

The “only” type of wheat permissible for a celiac...

Select Resources
Resources

Celiac Disease Awareness Campaign
National Digestive Diseases Information Clearinghouse
2 Information Way
Bethesda, MD 20892–3570
Phone: 1–800–891–5389
Fax: 703–738–4929
Email: celiac@info.niddk.nih.gov
Internet: www.celiac.nih.gov

American Celiac Society
P.O. Box 23455
New Orleans, LA 70183–0455
Phone: 504–737–3293
Email: info@americanceliacsociety.org
Internet: www.americanceliacsociety.org

American Dietetic Association
120 South Riverside Plaza, Suite 2000
Chicago, IL 60606–6995
Phone: 1–800–877–1600
Email: knowledge@eatright.org
Internet: www.eatright.org

Celiac Disease Foundation
13251 Ventura Boulevard, #1
Studio City, CA 91604
Phone: 818–990–2354
Fax: 818–990–2379
Email: cdf@celiac.org
Internet: www.celiac.org

Celiac Sprue Association/USA Inc.
P.O. Box 31700
Omaha, NE 68131–0700
Phone: 1–877–CSA–4CSA (272–4272)
Fax: 402–558–1347
Email: celiacs@csaceliacs.org
Internet: www.csaceliacs.org

Gluten Intolerance Group of North America
31214 124th Avenue SE
Auburn, WA 98092
Phone: 253–833–6655
Fax: 253–833–6675
Email: info@gluten.net
Internet: www.gluten.net

National Foundation for Celiac Awareness
P.O. Box 544
Ambler, PA 19002
Phone: 215–325–1306
Email: info@celiaccentral.org
Internet: www.celiaccentral.org
Select References
Select References (cont.)
Select References (cont.)

**QUESTIONS?**
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Website: [http://jleoneatc.googlepages.com/home](http://jleoneatc.googlepages.com/home)

**THANK YOU for ATTENDING**