

**Anne's notes from GIG's Annual Educational Conference, June 2010,
Minneapolis, MN**

Joseph Murray, MD
Julianne Karow
Tom O'Bryan, DC, CCN, DACBN
Christine Doherty, ND
Bonnie Presti
Jillian Sarno Teta, ND
Stephen Wangen, ND
Dr. John Neustadt
Daniel Leffler, MD, MS
Rodney Ford, MD, MS, BS, FRACP
Cynthia Kupper, RD

Joseph Murray, MD

Latest Research News in Celiac Disease and Gluten Sensitivities.

The prevalence of CD in the general population is about 1%. Has the prevalence of undiagnosed CD changed over the past 50 years? Recently Dr. Murphy was given the opportunity to run tests for CD on stored serum collected from 1948-1954 and compares them to tests run on a similar current population.

The prevalence of CD in the frozen serum was 0.2% (1 in 714). The fresh samples were taken from two groups. The first group were those who were born at the same time as the soldiers who had the serum frozen. It showed a prevalence of 0.8% (1 in 127). The second group were soldiers who are now the same age as the soldiers were when the samples were taken. Prevalence was 1.0% (1 in 98). There has been a 4-5-fold increase in prevalence of CD over the last 50 years. Only population where CD is less than 1% is in those who are over 80.

This study also looked at mortality of the soldiers from the 1948-1954 group. It was found undiagnosed celiac disease is associated with a nearly 4-fold increase risk of death over the 45 years follow up. There are other studies that show no increased mortality with CD.

If a person is double positive – both tTG and EMA positive - they have CD.

Recent paper linking c-section to increased incidence of CD

Something has changed in our environment – What is causing the increase in CD, autoimmune diseases and type 1 diabetes?

Mucosal recovery – Dr. Murray rebiopsies everyone to make sure there is recovery.

Children – 95% will have mucosal recovery within 2 years
Adults – Mucosal recovery is less certain and can take years.

There is no association between clinical response and mucosal recovery. Persistent mucosal damage may be present in the absence of antibodies in the serum.

He said the equivalent of one cookie with gluten per month is enough to keep one from healing.

Possible reasons for persistent villous atrophy

- Inappropriate food labeling
- Late intervention
- American lifestyle – easy access to fast food
- Limited availability of GF food and high cost of GFD
- Persistent gluten ingestion – only 66% report good compliance

Predictors of failure to heal

- Persistent gluten ingestion
- Diagnosis of CD during adulthood
- Positive serology at follow-up
- Low plasma albumin at follow-up
- Total villous atrophy at diagnosis
- Severe CD

Clinical Implications

- Persistent mucosal damage after GFD is frequent and may not be benign
- Systematic follow-up with intestinal biopsies may be advisable in patients diagnosed with CD as adults.

Refractory celiac disease is very rare but is associated with poor prognosis. This must be treated at a celiac center.

Microscopic colitis is a common cause of new onset diarrhea in treated CD. Often needs steroids. Cause is unknown but drugs could play a role – he mentioned statins.

Because of time constraints, Dr. Murray did not talk about gluten sensitivity and skipped his last few slides.

He asks if screening for CD is helpful and will people accept testing and will they go on a GFD? Will they stay on a GFD and does it help them in the long run.

New treatments being tested are worms, probiotics, vaccine, enzymes, and drugs to block permeability and drugs to block immune response.

Dr. Murray asks what you want in a new treatment

- Freedom to eat gluten
- Increased safety of gluten free diet from low level contamination
- Would you take it every day?
- What risks would you accept?
- What cost?

Julianne Karow

Wrote Celiac Resource Guide: Helping to Navigate Life's Detour
www.celiacresourceguide.webs.com

Successful Strategies for Starting GF Life/Emergency Preparedness

When she first went GF she used both the library and the Internet.

She talked about taking 3-6 months to transition into living GF.

Learning to live gluten free takes time. You will need to do a kitchen clean out, get some new kitchen items and do some reorganization. (If you feel you need more help in getting started with a GF life, GFCA has a 101 session to make the transition easier.)

Gluten free products that replace non-gluten free products are more expensive. You can save money by:

- Plan meals in advance
- Buy in bulk
- Can seasonal items
- Purchase from local farms
- Order from the internet
- Form a buying club
- Look for coupons on the internet and in the newspaper
- Cook from scratch
- Attend GF expos or meetings where there are vendors

When traveling:

- Find a place with a microwave and fridge
- Use dining cards
- Bring your own sauces and dressings <http://www.minimus.biz/> has small individual packages
- Take along snacks

If your medical deductions are greater than 7.5% of your adjusted gross income you can deduct this from your taxes. Gluten free food, travel to get the food, restaurant surcharges, shipping fees of GF food may all be deductible. Deduction for food is the difference between the GF item and a similar non-GF item. Keep all receipts.

For more information about deducting expenses talk with your tax advisor and read http://www.celiac.org/index.php?option=com_content&view=article&id=116&Itemid=207

Julianne talked about having a GF food emergency kit. Please let me know if you want more details about this.

Tom O’Bryan, DC, CCN, DACBN

Living Life to the Fullest – How Gluten Affects Neurotransmitters, Depression and Anxiety

<http://www.thedr.com/index.html>

Dr. O’Bryan started out by sharing personal information about his family. He talked about his father who probably died from folate deficiency. The family has hyperhomocystinemia. He told the story of his aunt with liver failure, his mother with metabolic encephalopathy and a young child with Tourette’s. All were gluten sensitive and helped by changing to a GF diet.

- The brain is the primary system affected by gluten – not the gut.
- This kills people.
- For every patient with GI symptoms, there are 8 without GI symptoms
- Gluten is the gasoline on the fire of autoimmune diseases

He asked people to raise their hands if gluten had affected their brain – about 50% of the attendees raised their hands.

He mentioned a new test that will look for antibodies to 12 gluten proteins. The lab is www.cyrexlabs.com the site is new and under construction.

He believes support groups need a social worker or psychologist working with children as children on a GF diet often have difficulty with social issues. Support groups are critical to the success of living gluten free. Grass roots groups will make the difference.

Dr. O’Bryan showed a PowerPoint presentation called Living Life to the Fullest. He quoted a series of articles that support gluten affects the brain. He received a standing ovation.

From the book Genetic Nutritioneering by Jeffrey S. Bland, Sara H. Benum:
“Throughout your life the most profound influences on your health, vitality and function are not the Doctors you have visited or the drugs, surgery, or other therapies you have undertaken. The most profound influences are the cumulative effects of the decisions you make about your diet and lifestyle on the expression of your genes”

Dr. O'Bryan said he has given up his practice in order to dedicate his time to lecture to doctors about gluten sensitivity. He does an 8 hour course and has a list of doctors who have completed this at

<http://www.conquergluten.com/glutenfree/index.html>

Christine Doherty, ND

Including Aspects of a Mediterranean Diet to Supercharge the GF Diet

http://www.naturopathicexperts.com/index.php?show_aux_page=111

Christine was not able to come to the meeting and but she was able to talk with us through a phone. She went into naturopathic medicine because of her many chronic health problems.

Blue Zone and the "Power of 9". There are 9 behaviors that can lead to a healthier life. This is taken from a book, Blue Zones by Dan Buettner <http://www.bluezones.com/about> Christine said, "Dan looked at many cultures around the world who lived to be healthy and vibrant and quite commonly living to be over 100 years old."

1. Exercise
2. Stop eating when you are full
3. Don't eat refined food
4. Drink red wine in moderation
5. Define your purpose
6. Relax often
7. Have a spiritual practice and community
8. Family first
9. And what clan you belong to is critical (we are in the Gluten Free Tribe)

She said that exercise is at the base of the pyramid of the Mediterranean diet. You may have up to ¼ cup of olive oil per day. Eat nuts and dairy daily. She loves Brebis cheese. Red meat is eaten only once a month.

Egg allergy often worse to raw eggs.

All Atlantic salmon is farmed

She recommends buying free-range chicken.

Up to 50% of celiacs may still have multiple nutritional deficiencies up to 10 years gluten free and may need IV vitamins.

Another recommended book is The Mediterasian Way by Ric Watson and Trudy Thelander. She says this book can be easily adapted to be GF.

<http://www.mediterrasian.com/>

Bonnie Presti

Controlling Metabolic Syndrome

The way Americans Eat

- Fast food
- Ready-made meals
- On the run – 45% of meals are eaten away from home
- Irregular or skipped meals
- Social and emotional eating
- Mindless eating

This adds up to the Standard American Diet or SAD

- Hydrogenated oils
- High fructose corn syrup
- Caffeine
- Alcohol
- Salt
- Processed food
- <12gm of fiber a day
- Low-nutrient-density

About 90% of our budget is spent on processed food. 1000 new processed foods are brought into the market each year.

Metabolic syndrome is having 3 or more of these risk factors

- Abdominal obesity
- Triglycerides over 150
- Low HDL
- Blood pressure over 130/85
- Fasting glucose over 100
- On medication for lipids, high BP or blood sugar

Many Americans are obese and this includes those on a GF diet. A study of 371 people over a 10-year period who were gluten free showed 5% were underweight and 69% were either overweight or obese. After 2 years GF 81% gained weight.

We need to make wise food choices. She recommends mindful eating, control portions, balance meals, add variety, small frequent meals, water and plant based diet.

She talked about the healthy fats, proteins, vegetables, starches and grains (limits to one serving a day), fiber.

Jillian Sarno Teta, ND

Inflammation and Health

Inflammation is both good and bad. Inflammation is a normal, predictable response by the immune cells. But our immune system can become underactive, overactive or dysfunctional.

In people with CD, gluten causes inflammation in the intestine that destroys the villi.

“What you put into your mouth is 85% responsible for how you feel. So increase foods that help and decrease foods that hurt.

Foods that increase inflammation:

- Sugar
- Refined carbohydrates (including baked goods)
- Trans fats
- Additives
- Synthetic flavors and colors
- Artificial sweeteners (stevia and sugar alcohols are OK)

We have been eating processed foods for only the past 40-80 years.

Exercise and inflammation: Long duration, low intensity exercise like jogging promotes inflammation. Short duration, high intensity movement and resistance training is anti-inflammatory.

Proper sleep is crucial for decreased inflammation.

“Supplements should be managed by a doctor. “

Curcumin can shift immune system away from autoimmunity

Probiotics quiet inflammation

Fish oil is anti-inflammatory

Get a vitamin D test.

L-glutamine can help repair the intestine

In some people, caffeine will increase inflammation.

Add ½ tablespoons of organic cocoa powder to water or milk and sweeten.

Coconut is a functional food

Sugar decreases immune surveillance and may increase number of colds and flu.

Stephen Wangen, ND

Allergies, Celiac Disease and Gluten Intolerance – What's the Difference?

Wheat is a relatively new food.

Most, but not all, who are reacting to wheat are reacting to gluten.

Oats are not a gluten issue but there may be a peptide in oats that is similar to a peptide in wheat gluten.

Testing for CD

If blood tests are positive, having the biopsy will not change the treatment. He feels the biopsy has a significant potential for false negative. Tissue transglutaminase is the best blood test for CD. Gliadin antibodies are not specific for CD.

Some people will feel better off gluten even with all tests negative.

He does not do genetic testing as he does not think it adds useful information.

If there is no villous atrophy, it is not celiac disease.

Non-Celiac Gluten Intolerance

Over 200 known conditions related to gluten and celiac disease (villous atrophy) in only one of the 200.

Stool testing tests for SIgA antibodies and these are not the same as IgA in the blood. SIgA is found in mucous membrane. This is not better than a blood test but it is “an interesting tool”. Saliva tests are SIgA tests too.

What is the prevalence of gluten intolerance? No one knows. In Dr. Wangen’s experience it is at least 10% but there are reports as high as 30%.

Important Points

- It is not normal to have an immune reaction against food
- If you have elevated gliadin antibody levels, they are meaningful
- There are many studies on the relationship between health problems and elevated gliadin antibody levels

When Dr. Wangen sees a patient he does not ask if the patient’s symptoms are on the list of 200 disorders related to gluten. He tests everyone. He showed slides of these 200 health problems.

It is a myth that CD is the worst form of gluten intolerant. It is a myth that CD is the end-stage of gluten intolerance.

One does not have to have villous atrophy or digestive problems to have malabsorption.

If you don’t improve on a gluten free diet, that does not mean that gluten is not a problem. It is not easy to truly eliminate all gluten and it has to be done for a long enough time to notice improvement.

Gluten is just one of the many possible foods that cause problems. He uses food panels in his practice.

Eat

- Vegetables
- Healthy proteins
- Healthy fat

“Simpler than you think!”

Dr. Wangen has a newsletter and a blog. <http://ibstreatmentcenter.blogspot.com/>
Both are excellent as is his book “Healthier Without Wheat”.

Dr. John Neustadt

<http://www.montanaim.com/about.html>

<http://www.nbitesting.com/about.html>

Dr. Neustadt posts on The Huffington Post

Osteoporosis: Fracture Proof your Bones – The Most Important Nutrient isn't Calcium

Bone mineral density is not dangerous – fractures are what are dangerous.

Osteoporosis is low bone mineral density. A T score of ≤ -2.25

Osteopenia is a T score of -1 to -2.5

Bone loss occurs from age, poor absorption of nutrients and medications.

Celiac doubles the risk for osteoporosis. Any premenopausal woman or man diagnosed with osteoporosis who be tested for CD.

Where do fractures occur? 73% were no in the spine and 71% occurred in woman. In those who are over 65 years old, 20% of those who have a hip fracture will die within a year.

Hal of all hip fractures occur is women who have osteopenia.

Bone is a complex living tissue. The two major components are cartilage and minerals. Bone scans don't tell anything about the health of the cartilage.

Risk factors include age, smoking, family history, nutritional problems, low physical activity, poor vision, medications low body weight, and many diseases.

Prevention includes medication, diet, exercise, environmental modifications and target nutrients (Calcium, D, K and strontium)

Bisphosphonates (Fosamax, Actonel, Boniva) account for only about 4-28% reduction in vertebral fracture. All the studies are about vertebral fractures. There is

no information for hip fracture. These may increase fracture risk after 4-7 years of use.

There can be a 16% decrease in risk for fracture with use of Vitamin D and Calcium.

He talked about the need for vitamin K2 (Menaquinones). This is more active than the K1 we get from vegetables. K2 is found in some cheeses, fermented foods, organ meats, and eggs.

MK7 and MK4 are two forms of K2.

- MK7 – there are no clinical trials showing decrease in fractures.
- MK4 multiple clinical trials show it to decrease fractures by 80%

Dr. Neustadt said K2 helps the collagen in the bones.

Calcium carbonate will not be absorbed with low acid in the stomach.

Strontium is used as a prescription drug in Europe for treatment of osteoporosis and it compares favorably with the other currently marketed anti-osteoporosis medications.

The radiologist must correct for use of strontium when a DEXA scan is done or it will not be accurate.

Daniel Leffler, MD, MS

Director of clinical research of The Celiac Center of Beth Israel Deaconess Medical Center

Owning the Gluten Free Lifestyle: A Holistic Approach to Life with Celiac Disease

This is not a disease of the intestine. It is a disease of the body.

He went through the history of CD and the diagnostic testing.

Nutritional deficiencies are common:

Vitamin D, Iron, B12, Zinc, Calcium.

Related conditions should be assessed for by testing bone density, thyroid and liver function.

All patients should be referred to an experienced RD.

Encourages participation in a support group.

Less than 50mg of gluten (1/30th of a slice of bread) can cause significant, sustained mucosal inflammation.

There are treatments that are undergoing clinical trials. None of these will allow people to eat gluten freely.

Larazotide is the zonulin inhibitor.

ALV-003 is an enzyme that can break down ingested gluten.

Nexvax is like an allergy shot. It may last up to 3 years and is good for only a single protein. Gluten is made up of hundreds of proteins. The screened 20,000 proteins and found 3 that seem to cause 90% of the reactions in CD. Interesting that an injections in the arm gave people symptoms of being glutened.

He does not do a follow up biopsy if a person with CD has a normal tTG and is feeling well and nutritional values are good.

Rodney Ford, MD, MS, BS, FRACP

www.drrodneyford.com

A Gluten Free Planet

Dr. Ford is calling for a gluten free planet by 2050. At the very least he believes there should be warning labels of toxicity on products with gluten just as there are warning labels on cigarettes and alcohol.

Who does he test – everyone! He uses the antigliadin antibody test as that picks up those with gluten sensitivity. The tTG, EMA and DGP are tests for celiac disease.

He quoted Dr. Hadjivassiliou: “To improve diagnosis rates, the perception of physicians that gluten sensitivity is solely a disease of the gut must be changed.”

He quoted Dr. Fasano: Many patients report that their symptoms resolve once they embrace a gluten free diet even when celiac disease has been ruled out.

Growing clinical evidence suggests that these cases are related to gluten sensitivity, a new form of food reaction.”

Dr. Ford says

- Treat symptoms – not gut tissue
- Gluten illness is a brain disease
- Celiac tests do not identify gluten sensitivity.

You can also friend Dr. Ford on Facebook and join his Facebook group for a [Gluten Free Planet](#).

Cynthia Kupper, RD

“ADA Nutrition Recommendations for Celiac Disease & Label Reading: Putting it all Together”

Cynthia Kupper is the Executive Director of GIG.

The ADA has published some guidelines for the gluten free diet for those with celiac disease. This information was compiled by reviewing over 800 articles. There was concern that the GF diet was not adequate. Top medical experts in CD reviewed the final report. Sadly, the section on gluten sensitivity was pulled but nearly all the recommendations could apply to those with gluten sensitivity as well as CD.

Questions researched:

- How does the inclusion of oats impact the effectiveness and acceptability of the GFD?
- How does inclusion of wheat-starch based GFD impact the effectiveness and acceptability of the GFD?
- What is the long-term effectiveness of the GFD on bone density?
- What is the effectiveness of the GFD on iron deficiency anemia?
- What is the effectiveness of the GFD on villous atrophy?
- What is the effectiveness of following a GFD on pregnancy outcomes?
- What is the effectiveness of the GFD on neurological symptoms?
- What is the effectiveness of the GFD on gastrointestinal symptoms?
- What is the impact of the GFD on quality of life?
- Is the GF diet nutritionally adequate?

Here is some of what the recommendations included:

- Medical nutritional therapy from a Registered Dietitian
- Bone density screening
- Assess GI symptoms and look for other associated diseases
- Advise people to eat whole or enriched GF
- Supplements for reduces iron deficiency and reduced bone density
- Advise, educate and give resources about the GFD
- Monitor dietary compliance and quality of life issues
- Evaluate other potential causes of persistent symptoms

Cynthia said that people think they are compliant with the GFD but are often less strict in social situations. Dietitians and support groups need to make the GFD livable.

Reading labels

The FDA and the USDA have different rules.

FDA says the top 8 allergens must be on the label of food and this includes dietary supplements. The 8 allergens are soy, dairy, eggs, peanuts, tree nuts, fish, shellfish and wheat. Barley, rye and oats are not in this list.

There is still no FDA rule for labeling GF food. The proposed rule would be voluntary and GF would be defined as <20ppm gluten.

Whenever oats, other than GF certified oats, were tested for gluten by www.gfco.org the results were 500-1500ppm gluten. If you include oats in your diet make sure they are certified GF.

Statements that say “May contain...” or “Processed in.....” are not allergy statements.

Getting all the nutrients in the GFD. She mentioned food sources for:

- Niacin, Folate
- B12
- Calcium
- Vitamin D
- Phosphorus
- Iron
- Zinc
- Fiber

Weight management

Gluten free is not calorie free. The GFD is not a weight loss diet. Many people gain unwanted weight.

In summary, the registered dietitian is an essential part of the team. Get involved with a support group. Add a variety of naturally GF foods. Supplement with nutritional supplements if needed. Rest/sleep. Exercise. No cheating on the diet!