

NYC Conference Report: Nov. 2, 2002 “Patient Education Day” at Columbia-Presbyterian Celiac Research Dep’t. (attended by Pam Fahy & Eleanor Wallace)

Dr. Peter Greene: There is an absence of knowledge re: CD among Pediatric GIs

Those also needing to have an increased interest in CD are Rheumatologists because of the incidence of Metabolic Bone Disease

The #s at Columbia are skyrocketing d/t screening of family members

Those with autoimmune/connective tissue diseases, neurological disease, osteoporosis, osteopenia and malignancies have a 10% incidence of CD.

Males & females seem to have about the same % of CD.

Differences in numbers between Europe & the US – due to genetics and the amount of gluten found in foods. There needs to be a stronger collaboration between MDs involved in bone metabolism, Neurology, pathology and immunology. Centers involved in CD research are found at Columbia-Presbyterian, Univ. of MD, Univ. of Chicago, Princeton, Cedars Sinai (in LA), and Westchester Med. Center.

Osteoporosis affects men MORE severely than women! Fosomax increases bone density about the same as a GF diet.

Peptidase has a questionable affect on OTHER peptides.

MDs should talk to other MDs the SAME as they talk to their patients (to educate). The best (perhaps ONLY) way to reach doctors is to have articles published in professional journals. Patients need to participate – through philanthropy, support centers AND research.

Future Programs under consideration: GF Diet; Food Labeling; Child/Adolescent life with CD; Life Outside the Home; Formation of a NATIONAL CD Foundation.

Dr. John Zone (from Utah): stated he is “obsessed” with DH – all diagnosed with DH do have CD – and a wide range of symptoms & spectrum of severity – from a mild intestinal - to severe skin involvement. GF diet DOES affect improvement.

DH has variable clinical presentations. Most c/o general discomfort, scratching, little spots w/persistent itching. Psoriasis occasionally clears on a GF diet. Those with CD are generally at risk for other skin conditions.

To diagnose DH, there needs to be a biopsy investigation of areas surrounding lesions (as opposed to the lesion itself) - w/immuno-fluorescence to assure correct diagnosis. Laboratories vary in assessments – the more testing they do, the more reliable the results may be.

DH is familial – not rare. Gene Therapy is a consideration for the future. It IS rare in Asians & Blacks.

People who develop DH tend to have chronically UNTREATED CD.

Don Kasarda, PhD (USDA – Columbia Univ. CD Program): Expression (triggering CD) requires genetic predisposition + environmental factor (gluten protein ingestion) = other environmental factors (viral infection; severe stress; etc.). CD is a multi-gene disease (2 or more genes) DQ2 or DQ8 heterodimer.

Proteins are polypeptides. Proline & Glutamine are involved in the damage to the intestines.

Wheat NOT clean in separation results in contamination. Oats are not toxic in CD – BUT this does NOT deal with the contamination factors.

Anne Roland Lee, RD, CDE: Gluten – determine the labeled, hidden AND “let’s move on”!!

Gluten from rice, potato, corn, tapioca, amaranth, quinoa, buckwheat, millet are OK. Amaranth is a good source of Vit. B-6 & Iron. Buckwheat & Millet are sources of Riboflavin, Vit. B-6, and Zinc; Quinoa provides Iron.

Labels stating “caramel color”, maltodextrin, & glutinous rice (in USA) are safe.

MSG is OK ONLY if from USA. Vanilla is OK.

Questionable are: emulsifiers; modified (food) starch.

Hidden sources of gluten can be listed as: HVP; HPP; Dairy substitute. Also of concern are: prepared frostings; packaged foods (including frozen vegetables)

Questionable, too, is lipstick; finger-paints; play dough....

What we have/need to gain is the labeling of nutrient content of foods – **write to reps re: legislation and STRESS that complete labeling is a serious health issue/need for YOU!!**

Dr. Norman Latov, MD: (Peripheral Neuropathy & CD)

Symptoms of neurological involvement include weakness, depression, & lack of coordination.

2-3% of patients with Peripheral Neuropathy ARE Celiacs. In Celiac Disease, neuropathy is from small fiber damage.

Pericarditis (inflammation of heart covering) can also be present with CD.

Dr. Bruce Roseman, MD: (Pediatric Neurological problems & CD)

CD can cause a REVERSIBLE type of brain damage – Lily (patient name) had acute paraplegia; 2 weeks into the GF diet she started to walk; and after 3 weeks she started to talk!!

Down Syndrome affected people have a higher chance of having CD - & NOT being diagnosed. If they ARE diagnosed, their quality of life is greatly improved.

Children diagnosed EARLY with CD – the chance of developing other autoimmune diseases is equal to the general population. Neuropathy can cause joint pains; Reynaud's Disease (hands change color in the cold); Sjogren's Syndrome (dry eyes, dry mouth, etc.).

BLOOD TESTS FOR FOOD ALLERGIES ARE NOT RELIABLE IN CD PATIENTS!!

Elizabeth Shane, MD: (Osteoporosis & CD)

CD skeletal manifestations most common are Osteoporosis (low bone density) & Ostopenia (level of bone density falls between "normal" and osteoporosis). A RARE occurrence is "Osteomalacia" (bones hurt; legs ache (tender to touch; bones bend because they're softer).

A fracture is often the 1st symptom of Osteoporosis.

Diagnosis is obtained by a DXA or DEXA scan – measuring the lumbar spine & hips bone density.

The WHO (World Health Org.) has the following categories:

	normal is a "T" score of -1.0
Osteopenia	" -1.0 to -2.5
Osteoporosis	below -2.5

A study found fractures in CD at 25%+; and in the control group at 8%+ -- numbers relative to early or late diagnosis. A GF diet reduced incidence of fractures.

Early diagnosis of children reclaims bone density and normal growth.

ESSENTIAL tests include: Calcium, Phosphate, Alkaline, Phosphatase, Vit. D (25 hydroxy-vitamin D), Parathyroid Hormone (PYH), Urine Calcium.

HELPFUL tests include: Bone Turnover Markers, Calcium Citrate (1500 mg. daily), Vitamin D, Magnesium, and exercise are all highly recommended in CD "living".

Amy DeFelice, MD & Joseph Levy, MD (Pediatric Celiac Disease):

Celiac Disease is PERMANENT!! Children CANNOT "outgrow" it!! They ARE genetically "pre-disposed" for developing CD. There is a need for exposure to gluten proteins for its expression. It is often associated with other autoimmune disorders (Diabetes; Thyroid disease; Dermatitis Herpetiformis; Lupus).

In a "text-book case" – the child is OK until introduction of gluten. There may be chronic, foul-smelling diarrhea, weight loss, abdominal distention, Dermatitis Herpetiformis with itching. In atypical cases, there is tooth enamel defects, arthritis, bone problems.

Physicians'/parents' "antennas" should go up then the following signs are noted:

Short Stature/Delayed Puberty; Osteoporosis; Dental Enamel Defects; Dermatitis Herpetiformis; Anemia; Brain Calcifications; Ataxia (unsteady gait); Seizures; Psychiatric & Mood Disorders.

Development of Autoimmune Disorders is directly related to duration of exposure to gluten – under 2 years old it is 5%.

Approximate Risk Factors for CD diagnosed relatives:

Identical twin – 70% Non-HLA matched sibling – 10% Child – under 10%

Identical HLA matched sibling – 30-40%; Parent 5-7%

It is NOT KNOWN if breast feeding OR delaying gluten ingestion influences the onset of CD.

Diagnosis – the sooner, the better! There is an NEED for increased awareness of atypical manifestations of CD.

The GOAL should be NOT to begin the GF diet BEFORE referring to a GI Pediatrician & DIAGNOSIS!!

“Take-Home Messages” :

CD is MORE common than generally recognized – NOT RARE. **CD is the ONLY autoimmune disease for which we know the cause & cure!**

Early recognition will have major impact on preventing autoimmune disorders.

“Throw out the “IGG” test ----- USE the TTG test.

A child MUST learn to advocate for self!! “You ARE the master of you MOUTH!”

Carol Semrad, RD: (Oats & how much gluten is allowed?)

Gliadin is MANY different proteins.

Tests have shown 10 mg. Gliadin = 20 mg. Gluten = 250 mg. Wheat Flour – OR there are 10 mg Gliadin in 1/8 tsp. Wheat Flour (not toxic to most) while 5 mg.

Gliadin IS toxic to some patients!

STANDARDS ARE NEEDED FOR LABELING “Gluten-Free”.....

Anne Lee, Dr. Semrad, and Dr. Kasarda: (Oats/Gluten)

Non-gluten-free foods – diet has a **huge impact on “eating out”**.

DO pick a restaurant that you like and “work on/with them”.... **KEEP IT SIMPLE!!**

The titer height (blood test) = the severity of small intestinal damage (villous atrophy).

By relying on only ONE serology (blood) test , 30% of those having CD are MISSED!!!

Conrad Gilliam, PhD: (The search for the genetic answer)

There is a strong genetic component in key immune system genes (HLA). There is the environmental component.

Family studies reveal 1 or more non-HLA component. Identical twins – are 70% concordant for CD. Non-identical twins – are 25% concordant.

HLA siblings – are 30% concordant.

HLA genes DQ2 & DQ8 are “risk factors” for CD.

Autoimmune genes are DIFFERENT from allergy genes.

