The Gluten Syndrome: a neurological disease

Gluten just causes gastrointestinal and skin problems, doesn’t it? Not according to SACS general meeting speaker, Dr. Rodney Ford who hypothesizes that gluten can also adversely affect the nervous system. This New Zealand physician estimates that the Gluten Syndrome affects approximately 10% of the population—a startling statistic.

Dr. Ford will speak Saturday, November 7th on the subject of the neurological effects of gluten sensitivity. This general meeting is from 9:00 to noon, at the Pima Community College District Office Campus, 4905 E Broadway, Bldg C. (located just east of Swan, directly behind TGI Friday’s. – Please see map schematic p. 2 or our website at www.SouthernArizonaCeliac-Support.org)

A world-renown expert on what he terms the Gluten Syndrome, Dr. Ford continues to expand his knowledge base through treating patients at his Christchurch, NZ clinic. A prolific author (over 10 published books including The Gluten Syndrome), Dr Ford is a regular contributor to the Journal of Gluten Sensitivity (celiac.com). He also maintains a blog on his website (www.drrodneyford.com) and is in the process of opening what he is calling his “E-Clinic” where he can help individuals through his website.

Dr. Ford (MD, MB, BS, FRACP, Assoc. Professor) is in the US on a speaking tour that includes the CSA Conference, NASPGHAN Annual Meeting & Postgraduate Course (presenting continuing education for pediatric gastroenterologists) and three other speaking engagements in the US. The demand for his presentations underscores his credibility as a medical doctor, research pioneer and champion of those with symptoms of gluten intolerance. SACS is fortunate to have a speaker of his professional stature.

Please join us to listen to this very important message, and take time to

The following Abstract published online April 30, 2009 in Medical Hypotheses Journal, presents a brief synopsis of the lecture he will present:

Hypothesis: Gluten causes symptoms, in both celiac disease and non-celiac gluten-sensitivity, by its adverse actions on the nervous system.

Many celiac patients experience neurological symptoms, frequently associated with malfuncion of the autonomic nervous system. These neurological symptoms can present in celiac patients who are well nourished. The crucial point, however, is that gluten-sensitivity can also be associated with neurological symptoms in patients who do not have any mucosal gut damage (that is, without celiac disease).

Gluten can cause neurological harm through a combination of cross reacting antibodies, immune complex disease and direct toxicity.

These nervous system affects include: dysregulation of the autonomic nervous system, cerebella ataxia, hypotonia, developmental delay, learning disorders, depression, migraine, and headache.

If gluten is the putative harmful agent, then there is no requirement to invoke gut damage and nutritional deficiency to explain the myriad of the symptoms experienced by sufferers of celiac disease and gluten-sensitivity. This is called “The Gluten Syndrome”.

See Nov speaker page 2
Celiac disease affects twice as many women as it does men, and this statistic becomes even more upsetting when you consider that according to the Association of Family History of Autoimmune Diseases and Autism Spectrum Disorders, children who are born from mothers with untreated celiac disease are 3 times more likely to have autism. To learn more: see this website: www.jensglutenfreeblog.com/gluten-free-health/women-and-celiac-disease/

How long can that bottle of ketchup stay in your fridge before it goes bad? This site lists all kinds of foods and how to keep them fresh longer as well as when to get rid of them. If you have a question, click on the particular picture, and a whole list of stuff appears http://www.stilltasty.com/

Sunflower Farmers Market has opened a Northwest side market at 3860 W. River Road (Orange Grove and Thornydale intersection, where Thornydale becomes River). They have a decent selection of GF products and organic meats and produce. Phone: (520) 204-1787. Sunflower’s corporate website lists the location as ‘Marana’, but don’t expect to find it there.

CSA/USA: 877.272.4272, 9 a.m. to 4 p.m. Central Time. Their URL is: www.csaCeliacs.org. Membership changes? Notify us via the website or call 520.495.4829. Email the website if you wish to be added to or removed from our email notification list.

Nov Speaker (Cont. p. 1) invite your medical providers friends, family and anyone else who you believe might benefit – which would include everyone. Please do NOT miss this opportunity to learn from a world-famous researcher and an accomplished, entertaining presenter. As always, this lecture is free and open to everyone.

Don’t forget to bring your GF goodies to share and maybe plan to purchase some raffle tickets to help support SACS. The ‘meet and greet’ portion of the meeting will be from 9-9:30 with the presentation starting after that. (If you wish to bring a GF snack, remember to bring the label, the box, or an ingredient list to accommodate those with multiple food restrictions. SACS provides the coffee and tea.)

Pres. CHERYL WILSON speaks at the September 26 general meeting

Map to Nov. 7 meeting

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Do you want to be part of the GFFF’s 2010 ‘A’ Team? Then we NEED you! SACS needs someone to be the Vendor Coordinator for our April 24, 2010 GF Food Faire here in Tucson.

You will be reporting to President Cheryl Wilson as you make contact with vendors and then follow up with them until the GFFF event. It’s not a difficult job as SACS has the forms you need to get started, and we will then supply a list of vendors to you. There will also be plenty of help and backup if you have questions.

This job requires maybe one or two hours a week until about March, and then it will be a bit more time consuming as we approach the date of the GFFF itself. Most of the initial vendor contacts will be made via email and then possibly followed up via phone call. Our Vendor Coordinator needs to have Internet access in order to send reports to SACS, as well as make contact with vendors. If you don’t have email access, you can still assist the Coordinator by volunteering to make phone calls, so let us know. Two people can share this important job.

Please contact Cheryl Wilson (520-298-5551 or email: so.az.celiacsupport@gmail.com) if you can join the team. It is critical that we get started contacting vendors as soon as possible.

GFFF coordinator needed for 2010

Chapter 15 Notes

Celiac disease affects twice as many women as it does men, and this statistic becomes even more upsetting when you consider that according to the Association of Family History of Autoimmune Diseases and Autism Spectrum Disorders, children who are born from mothers with untreated celiac disease are 3 times more likely to have autism. To learn more: see this website: www.jensglutenfreeblog.com/gluten-free-health/women-and-celiac-disease/

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No Roundtable in Nov. or Dec.
Uh oh. It is October, and here comes Halloween! Here it comes, followed by all those other confounding food–centered holidays for the GF, like Thanksgiving and Christmas.

Halloween especially can be hard for children who are GF. Friends talk of going door-to-door for Trick or Treating, there is candy at church Harvest festivals, and parties at school. Chances are, a lot of the candy offered is NOT GF, yet the parent does not want to deprive the GF child of the freedom of experiencing the Halloween holiday the way a child should. What to do? And which candies ARE GF?

Having dealt with this for a number of years now, we have developed what our family is comfortable with for our GF child. There are basically two approaches to this problem. Both of these ideas can help make the Trick or Treating experience more enjoyable for the GF child and her parents.

A common suggestion for this dilemma that one finds on the Internet, is to take some pieces of GF candy to the home of “designated” neighbors ahead of time, perhaps the day before, letting these neighbors know what the child’s costume looks like or have a ribbon or badge on the costume. On Halloween, have the GF child Trick or Treat only at those neighbors, that way it is a sure thing that the child comes home only with GF candy. This idea does have merit, as children sometimes are tempted to sample along the way. It may give the parent of the GF child peace of mind. This procedure will work best when the child is young, and is not so aware of feeling “different”.

Our GF daughter has just turned six years old. She is a Trick or Treating veteran in our child-friendly neighborhood. Of course, not all the people in our area know this is a GF child coming to their door, nor may they recognize her in disguise as she takes her flashlight and goes out with her sister, friends, and the accompanying adults on Halloween night. As this group goes door to door, she does not really want her father to hold her back when the other children go up to a house that is not designated GF. She does not want to be different, and has said so. What do we do about this conflict in food safety versus what the neighbors are handing out?

At home, we stand ready with many, many bags of commercial GF candy, a short list of which is included in this article. Some is handed out as children come to the door with their parents, but approximately half of each bag is saved for when our own happy group comes back to our house. My husband, who accompanies our daughter, makes sure that no candy is eaten while the children are out.

Then, of course once home, like any other family, the inspection of candy for tampering begins. At this time, our GF daughter begins sorting her collected candy into a known GF pile, and the not GF pile.

After this, she is allowed to trade the latter pile for the candy bags of commercial GF candies that have been saved for this purpose. She happily chooses what she wants instead, adding it into her GF pile. She thinks this is great fun, and it gives her the freedom to accompany her sister, friends, and father around the neighborhood. Additionally, this method is helping her to learn to keep a gluten lifestyle on her own. Her father will eventually take the non-GF pile in a bag to work, where it quickly disappears. Poof! Halloween magic, and all involved are happy.

Here’s to a happy and safe Halloween. All families will do what each is comfortable with, and I hope that these suggestions will help. Below is a short list of the many GF commercial Halloween candies available and some web sites with more candies listed. For further help or information, do feel free to email me at diana.knoepfle@gmail.com.

Cel-Kids Tucson 2009 GF Halloween Commercial Candy List:
Airheads Pops
Airheads Whistle Pops
All Tootsie brand candies
Clark Bar
Dum Dum Pops
Extra Gum
Farley’s Atomic Fireball
Farley’s Jawbreakers
Hershey’s Kisses (milk chocolate)
Hubba Bubba Gum
Jelly Belly Jelly Beans
Jolly Rancher Hard Candies
Jolly Rancher Laffy Taffy
Just Born Hot Tamales
Lifesavers Fruit, Pops, Gummies
Necco Wafers
Nestlé Baby Ruth
Nestlé Nips
Nestlé Butterfinger (not Crisp or Stixx)
Nestlé Raisinettes
Peeps Marshmallow Candies
Smarties
Starburst Fruit Chews
Swedish Fish
Sweetarts
Welch’s Fruit Snacks
Wonka Pixy Stix
Wonka Laffy Taffy
Wonka Nerds
Wonka Fun Dip, Fun Dip Sour
Wrigley Spearmint Gum
Wrigley Doublemint Gum
York Peppermint Patties

GF Candy List Web Addresses:
Tucson dermatologist Dr. Gerald Goldberg prepared and delivered a fascinating talk on Dermatitis Herpetiformis (DH), the fairly rare skin manifestation of CD, for our September 26 general meeting. His collaboration with leading USA DH researcher, Dr. John Zone, Chairman of the Dermatology Department at the University of Utah School of Medicine, brought us the latest findings, treatments and statistics. Because of the value of this information, Celiac Digest will summarize the content in more depth than usual:

Dermatitis Herpetiformis was first discovered/described in 1884 by Dr. Louis Duhring, a dermatologist at the University of Pennsylvania, but it took another 83 years until DH was tentatively linked with CD in 1967. Only 19 years later, the link between CD and DH was established via immunology studies. Blood tests to identify CD and DH markers for both the skin and the gut became widely available in 2003.

Just as in CD, DH is most common in people of Northern European ancestry and afflicts about one in every 10,000 people, roughly 10-15% of all CD patients. The mean age of onset is in the 30s (40.1 years for men and 36.2 years for women) but it has appeared in people from ages two through 90. Childhood onset DH is rare. While CD is more prevalent in women, men with DH outnumber women by two to one.

Since DH is an expression of CD, virtually all patients must have the gene HLA types: DQ2 or DQ8 but 90% of DH patients express HLA DQ2 while 8% have DQ8. Like CD, just having the genes does not mean you have DH. Also, as with CD, there is a familial link with 10% of first degree relatives of DH having CD or DH.

DH is an extremely itchy skin condition, but over 90% of DH sufferers also have evidence of gluten-sensitive intestinal damage - ranging from mild to severe loss of intestinal villi. However, only about 20% of DH patients have the GI symptoms of CD and the severity of their skin disorder has no relationship to the severity of their gut damage. They may be covered with DH lesions but have a relatively healthy intestine or vice versa. Like all CD sufferers, the severity of the symptoms is not necessarily linked to the internal damage wrought by the disease. This makes strict adherence to the GF diet imperative.

A full 60% of DH patients have ‘silent CD’ with no GI symptoms at all even though their gut is suffering continuous damage.

A definitive diagnosis is made by labeling of antibodies or antigens in the skin sample with fluorescent dyes. False negatives may occur if abraded skin is biopsied or if the pathologist reading the slide is inexperienced.

Both CD and DH are hard to diagnose because the blood tests available

See DH Lecture page 5
to us today show a high frequency (up to 20%) of false negatives. The true incidence of CD is much higher than the existing blood screening tools suggest. However, there has been an increase in diagnosis recently, not only because of ease of performing blood tests to confirm a diagnosis, but also because of an absolute increased prevalence of CD in the greater population. Dr. Joseph Murray proved this with his study of blood samples taken from Army recruits 60 years ago. (See Sept. issue of Celiac Digest)

Diseases associated with DH include thyroid abnormalities, and pernicious anemia. Addison’s disease is uncommon but known and T cell lymphoma (a type of cancer) prevalence is increased. There is some information to suggest the lymphoma is reversed by a GF diet. The link of osteoporosis with DH is unknown. Conditions like immune linked skin/mucous membrane diseases (such as non-male pattern hair loss, psoriasis, and oral canker sores) have been reported to reverse with a GF diet.

However, some of these diseases may simply be caused because of the same genetic pre-dispositions which allow the CD and/or DH. Or, as Dr. Goldberg said, they could be caused by chronic stimulation of the immune system by gluten.

Dr. Goldberg summarized the options for treating DH in order of their preference:

- A Gluten-Free Diet
- A Gluten-Free Diet
- A Gluten-Free Diet

Dr. Goldberg says most dermatologists, including himself were trained with the mantra of “Patients will not adhere to a GF Diet”, or the “Life is too short not to eat bagels!!” philosophy.

Dapsone taken orally, while it might subdue the symptoms of DH, does NOT affect the GI disease progression. Patients can also use topical steroids and should avoid any foods containing iodide.

Since DH clears rapidly on Dapsone (a sulfonate antibiotic also used to treat leprosy) and suppresses inflammation in the skin, many DH patients choose to take Dapsone chronically and not restrict gluten intake despite knowing that gluten is causing their condition and destroying their intestine. Also, long-term use of Dapsone is not without side effects, some of them serious. Dr. Goldberg sees those people who refuse to follow a GF diet as an opportunity to study the long-term metabolic and immunologic effects of CD in the absence of a GF diet.

He clearly stated that treating DH with drugs without addressing the underlying cause, Celiac Disease, is neither smart nor healthy.

Dr. Goldberg finished his lecture with a public service announcement concerning the danger of sun exposure and skin cancer. He treated his audience to some sobering photographs of skin cancer/sunburn victims, which served as an incentive to cover up, limit exposure during midday and to wear sunscreen.

SACS appreciates his concern, his expertise and his professionalism.

Dr. Goldberg practices at Pima Dermatology (5150 E. Glenn Street, Ph. 520.795.7729) and provides adult, pediatric and cosmetic dermatology as well as laser and skin surgery. Check out his website at http://www.pimaderm.com/ and see videos and before/after photos which demonstrate his surgical expertise.
So here you sit, with something funky called gluten intolerance. You know it’s serious because you feel like you’ve been run over by a train most days… and because your doc just told you, “Look, get off the gluten or die,” in so many words. You certainly understand the need to stay away from the Scary Four: Wheat, (non-GF) Oats, Rye, Barley – but how do you communicate that need effectively to your family and friends?

Some of them look at you like you’ve got a highly contagious virus that you’re just waiting to pass on. Some of them snort and laugh it off with an asinine comment or 10 about you and your freaky diet fads. Some of them pat you on the back and make mac ‘n cheese, ‘because it’s made with white flour, not wheat.’ And some just stare in horror – after all, everyone knows that they always bring the peach pie to the picnic. And they have to bring the peach pie! And the peach pie is your favorite. You always eat peach pie! YOU DON’T LOVE MY PEACH PIE!??!! HOW COULD YOU DO THIS TO ME???

Ahem.

If you’re wondering why people seem to freak out about this new disease you’ve got, and you’re wondering how to help them help you, you’ve come to the right place. The truth is, your loved ones are grieving the loss of their former lives just as much as you did when you were first diagnosed. In fact, you might still be grieving yourself. Never being able to eat gluten again may not seem as big a deal as losing a pet or a loved one… but in reality, it is. Our culture intertwines food and love so tightly into tradition and memory that the thought of changing is horrifying.

Here are the five stages of celiac grief.

1. **Anger**—When control is taken from a person, he or she tends to get angry. Sometimes really angry. Sometimes people direct the anger toward the person they blame for upsetting the order of things -that would be you -or the doctor who threw this in their face… or even the Almighty. Anger gives an illusion of control – A person can storm and rage and pull the silent treatment, and it helps the pain, at least temporarily. In celiac disease this looks like:
   - “You’re always flying off with some new fad diet!”
   - “Don’t think I’m going to change our Thanksgiving menu, just to suit your needs!”
   - “I can’t believe how expensive this is! This is just a scam – a big ripoff from people trying to make money from us!”
   - “What kind of loving G-d would do this to me?!”

2. **Denial**—Coping with the idea of dying or losing someone is a hard concept to grasp. The mind can only handle so much new information. It can only adjust so quickly. When too much change is afoot, our survival mechanisms kick in. The mind just shuts down – refuses to accept the new data. At this stage, people often convince themselves that you heard the doctor incorrectly, that the doctor may have misread the test, or that the whole thing is just some sort of cosmic misunderstanding that will evaporate with the morning fog. Denial often looks like this:
   - “That seems like a really low number. If the tests were really bad, wouldn’t the numbers be higher?”
   - “But the Doctor said you had a mild intolerance, right? That means you’re not really extremely allergic, so a little won’t hurt you, right?”
   - “Maybe they gave me the wrong test.”
   - “Maybe you ate too much gluten before the test and it skewed the results.”
   - “I think all these tests are just for doctors to make more money, for the drug companies.”
   - “But you don’t look sick. They must be wrong!”

3. **Bargaining**—When the brain has had time to reconsider the new information – when reality continues to hammer it with inescapable data, it will adjust by seeking out ways to understand and make sense of the new data. Often the brain will seek cultural cues to help formulate coping strategies. Most cultures have an un-
derlying philosophy – we’ll call it The Law of Returns. This theory says that good things happen to good people. When someone does something good, they earn a reward. When someone does something bad, they reap a consequence. This can also apply to interpersonal relationships. In China this is known as Guanchi, in Russian speaking countries it is known as Blat. In our culture, the concept is expressed as, ‘you scratch my back, I’ll scratch yours.’ The idea is that anyone can turn a situation to their good (or to a mutually acceptable outcome) with a simple exchange of favors or compromises.

The idea that loss is somehow related to mistakes or wrong actions is very deeply ingrained. You or your loved ones may believe that this ‘bad’ has happened because of a misstep or misbehavior. You may believe that prayers or actions may negate this situation. Bargaining often looks like: “If only you hadn’t overeaten so much bread, you wouldn’t have developed an allergy.”

“If only I hadn’t had you vaccinated”
“If I pray hard and fast every Saturday, perhaps G-d will take this burden from us.”
“If we just eat a little gluten – only on holidays! – perhaps it won’t cause damage.”

4. Depression—Once people realize that there is nothing to be done about their state, they become depressed. This stage involves despair, constant crying, fatigue, and feelings of sadness. They realize it is inevitable and begin focusing on feelings of great loss. Often, during this stage people will say:

“Life’s not worth living if I’m going to be a freak!”
“You’ll never be able to enjoy normal food again!”
“I’ll never get better.”

5. Acceptance—This is the final stage of mourning. Accepting the fact that the loss has occurred and cannot be undone. The person experiences closure and can now move on with their life. It is at this stage that people begin to make adjustments to lifestyle. Attitudes improve, and often the person becomes proactive in seeking solutions to challenges brought to his or her attention and to adjusting to the new life. This looks like:

“Maybe I could try that new gluten-free pasta!”
“We’ll use another recipe that does not use canned tomato soup.”
“Did you make sure to call ahead and let them know it has to be gluten free?”

People move in and out of these stages of grief – some faster than others. Sometimes a person will regress to an earlier stage of grief. Eventually, though, most people are able to move to Acceptance.

In your interactions with your loved ones, ask yourself, “What stage of grief does this sound like?”

1. Anger: Be patient. Let your loved one vent. Don’t take their venting personally, either! Remind yourself that this, too, shall pass.

2. Denial: Be firm, but stay calm. Combat denial with data, not emotion. Continue to state what you know to be true. Be consistent in living a GF lifestyle!

3. Bargaining: Once again, be firm but polite. Stick to the truth. This is the time to introduce cooperative strategies that don’t compromise your health - offer to bring GF pasta to a meal, take the initiative in calling ahead to make arrangements. Show your love and reinforce your relationship with your loved one.


5. Acceptance: Enjoy this new life and all it has to offer. Bring your loved ones into this new life with joy. Always show your gratitude in words, actions, and acts of service.

6. Seek out Others… and help them make this journey, too.
Too busy to bake for the holidays? Remember, we can ship your order via UPS Overnight to Tucson.

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Muffins Breads Pizzas Low-fat Donuts Brownies Cakes Cookies - and more!

All of them divinely delicious and wheat and *gluten-free

- Many items dairy, soy or egg free  - All enriched with folic acid and B vitamins

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