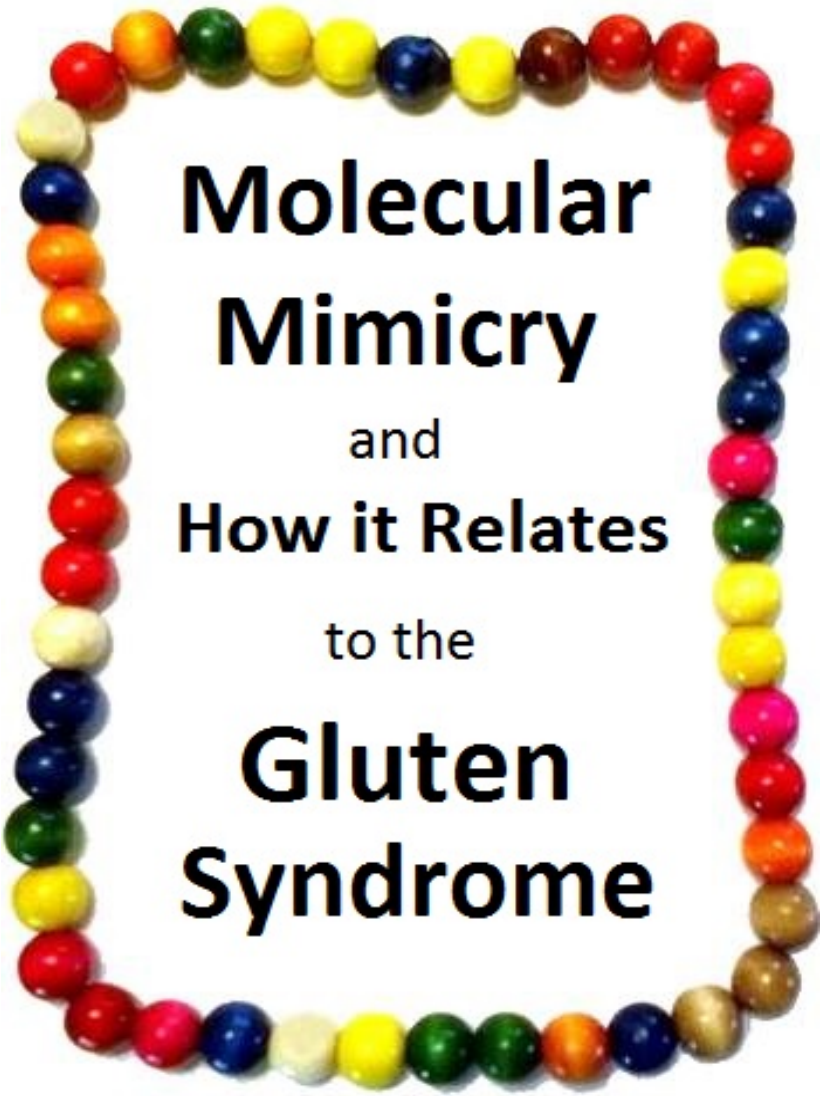

By Mrs. Olive Kaiser

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Healing the Symptoms Known as Autism SECOND EDITION

By Kerri Rivera, Kimberly McDaniel and Daniel Bender

Molecular Mimicry
What It Is & How It Relates to the Gluten Syndrome

by Mrs. Olive Kaiser

Who am I?

I am a married stay at home mom, blessed with a wonderful husband and seven fantastic kids. In 2003, after decades of searching, we learned about gluten reactivity through our daughter's nursing school training and eventually confirmed that we are a gluten syndrome family. Our daughter and my husband had the most obvious symptoms, but we all had manifestations and antibodies. Additionally our oldest son reacted to his MMR vaccination and probably other shots, which added high functioning ASD/ADD to the mix, and he developed type 1 diabetes at age 19. Two other sons had various shades of ADD/ADHD. My own school age vaccinations in the 1950's may have led to repeated bouts of strep throat until I reacted to a strep antibiotic injection about age 10. I developed PANDAS from that reaction (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus). What a struggle! Decades later it has responded somewhat to diet changes and now the CD/parasite protocol. I give thanks to God for His guidance along the way.

How did I get into this community and this health project?

We tested for gluten syndrome (we called it celiac disease back then) using standard tests recommended by celiac experts and received confusing results. Then, our daughter had a troubling experience with a gluten challenge that did not match the celiac story we'd been taught. I delved into medical literature and networked extensively with the gluten syndrome community looking for help. In that desperate discovery and prayer process I found practitioners and researchers who stepped outside the "villi damaged celiac only" box. They were able to explain why we received, in the midst of obviously gluten-induced

incidents, false negative results from our celiac blood tests and villi biopsy. Those tests significantly led us astray and eventually I put up a website...

www.TheGlutenSyndrome.net

...to warn others of discrepancies we stumbled upon in the diagnostic process.

What is Molecular Mimicry?

Molecular mimicry is a recognized medical theory which explains very nicely why gluten reactions may potentially inflame and damage so many different parts of the body, leading to very different symptoms in different people. It also clarifies why gluten antibodies may cross react with other foods and infections, and why it only takes a small exposure to trigger them.

When we understand molecular mimicry we are better equipped to deal with tempting social situations. Gluten syndrome has its own rules, which do NOT make sense unless this concept is understood.

The following is a brief introduction to Appendix 5, page 449, which goes into much more detail, along with references, about the following questions:

1. How does the gluten syndrome reaction actually damage our bodies?

Molecular mimicry. The molecular structure of gluten resembles the molecular structure of many of our body tissues. When the immune system attacks gluten it may also attack body tissues that "look like" gluten. Even if you do not read the other detailed answers, learn the details for this question on page 450.

2. Does gluten always damage the villi of the small intestine as the celiac story teaches? Many other tissues such as thyroid, pancreas, liver, joint, brain, nerves, heart, bone, blood vessel walls, etc., are involved in this disorder. Does all that other damage only arise from poor nutrient absorption from injured gut villi?

No, according to published research, many researchers and practitioners believe the villi are not always damaged in an autoimmune gluten reaction. Where there is no villi damage, injury to other organs CANNOT be due to nutrient deficiencies caused by villi damage. Molecular mimicry provides a mechanism for direct autoimmune gluten damage to many other tissues and organs when the villi are fine, OR other tissues/organs, *including villi*, may be directly damaged through molecular mimicry.

Dr. Vojdani's abstract in his editorial *The Immunology of Gluten Sensitivity Beyond the Intestinal Tract*, supports that the villi are not always injured. To quote his editorial abstract, "Evidence has been accumulated in literature demonstrating that gluten sensitivity or celiac disease can exist even in the absence of enteropathy [gut/villi damage], but affecting many organs."

3. I don't have damaged villi, and my tTG/gliadin tests were negative, but I feel so much better gluten-free. Why?

The tests were likely false negative. That is very common. As gluten digests, it breaks into more pieces than we have tests developed to check them, and the immune system makes a separate antibody for each piece. Standard tests only check 2-3 antibodies. You may have others (Cyrex Labs tests 28 antibodies). Your villi may be fine, but you may be injured somewhere else—for example: thyroid, nerves, heart, etc.

4. Why do many gluten syndrome patients not only react to wheat, barley, and rye but also at times to other foods, particularly oats, milk, corn, soy, egg, yeast, coffee, sesame, rice, chocolate and others?

These foods "look like" gluten closely enough in their structure that the immune system may mistake them for gluten. This situation may also cause your gluten antibodies to run high after you go gluten-free. The immune system may misrecognize other foods, such as yeast, corn or milk, and others for gluten because they resemble gluten molecularly.

5. The diet seems excessively strict? Why does it take so little gluten to start a reaction?

Our perspectives are skewed. We accept that miniscule amounts of venom injected by a bee sting, or a tiny exposure to peanuts in allergic individuals can set off immediate life threatening allergic reactions. Many medications are contained in very TINY pills, but they have powerful effects in our bodies. Immune gluten reactions are also that sensitive. "Crumbs matter."

6. Why do many people react to gluten, proven by antibody tests, but they have few or no warning symptoms for a long time and then they crash with something serious, usually autoimmune?

Gluten is famous for slowly injuring nerves by molecular mimicry, and in many cases, the nerves are silenced by that injury. The patient does not realize there is a problem until the tissue or organ that those nerves supply begins to fail.

7. Why do so many of us react to gluten today, when for centuries most people appeared to be fine with wheat, barley, rye and oats? After all, wheat and barley are mentioned positively in the Bible and other historical documents.

Today's gluten is altered, violently, by nuclear radiation and chemical mutation within the past 60 years*, plus our toxic and poorly nourished bodies do not have optimal digestive capabilities to break it down. Weak, toxic, leaky body barriers/membranes, particularly leaky gut, set the stage for gluten induced molecular mimicry.

*Nina Federoff, *Mendel in the Kitchen*

8. Why do specialists and researchers insist that the gluten-free diet must be life long? Can't we heal this problem and go back to our beloved wheat bagels, croissants, and brownies?

Our scientists still insist that gluten-free is a strict lifelong commitment. I agree. For me it is not worth playing with today's wheat. There is something strange and unpredictable about it. The memory B cells in the immune system never forget what the enemy "looks like", and fresh exposure retriggers antibodies.

9. Traditional peoples soaked and/or sprouted their wheat berries and then made sourdough bread with them. Does that process alter the gluten sufficiently for gluten syndrome patients to safely consume this bread, particularly spelt or einkorn?

No. These processes and ancient wheat grains do make the bread more digestible, but not gluten-free and still unsafe.

10. Should I substitute all the gluten foods I routinely eat with gluten-free substitutes?

No, not routinely. The gluten-free community finds that they are still mainly expensive high carb processed food (i.e., junk food).

11. What are gluten withdrawals?

Occasionally, gluten breaks into specific "pieces" in the gut that resemble opiate drugs. When a person goes gluten-free, they may experience temporary, but unpleasant, withdrawal symptoms for a few days as these pieces disappear from the blood stream.

12. What are the risks of formal gluten challenges?

Many patients avoid these challenges. Occasionally a patient tries the gluten-free diet for an extended period of time and then the patient or doctor decides to run tests to confirm gluten reactivity. The standard advice to restart the production of antibodies is to consume gluten products 4 x per day for 4-6 weeks, and then run the standard blood test, followed by a villi biopsy if the blood work is positive. This is called a gluten challenge and has created some very dramatically unhappy reactions, some of them neurological/psychological.

Please see Appendix 5 (page 449) and www.GlutenSyndrome.net for more info and references. When we understand molecular mimicry our understanding of the gluten syndrome comes into focus. It explains why gluten-free diets and beyond are important tools to reduce inflammation and promote healing. As time goes on, gluten-free diets are easier to manage in public, tests are better and social awareness has grown. The Just Eat Real Food movement and others play into healthy gluten-free dining with wonderful recipes that avoid processed foods and incorporate healthy fats and nutrient density. This is a happy, encouraging era as we watch our children heal and adults find better stability in the midst of a health crisis. Bon Appetit!!!

Appendix 5

MOLECULAR MIMICRY
What It Is
&
How it Relates to
The Gluten Syndrome

by Mrs. Olive Kaiser

After reading the short answers in *The Diet* Chapter (page 64), we understand (simply) the basics of how some of these departments of the immune system function. It is easier to grasp how, through molecular mimicry, gluten can damage so many different tissues in different people, and sometimes cause other foods that *look like* gluten to also be reactive. Before we go any further, I would like to thank the following professionals for their contributions to our family's well-being and a wider understanding of the gluten syndrome and other related topics. If you would like to conduct further research into this topic, the body of work that the following professionals have contributed would be a great place to start. There is so much more to learn.

Dr. Alessio Fasano, MD, shook America awake on gluten awareness in the 1990's and in 2003 published a landmark paper[1] on one small subset of the gluten syndrome, villi damaged celiac disease. That study provided the impetus that brought gluten awareness to the table (or sadly, OFF many tables) across our nation.

Dr. Thomas O'Bryan, DC, Functional Medicine, and international gluten syndrome educator - www.thedr.com. Dr. O'Bryan is my functional medicine doctor. He taught me much of what I learned about gluten and other topics and led me to his mentor, Dr. Aristo Vojdani. Later Dr. O'Bryan's amazing research review seminars on gluten contributed hugely to my knowledge base and bolstered my confidence to manage our new lifestyle in a then difficult social era.

Dr. Aristo Vojdani, PhD., MsC, Immunologist, CEO owner of *Immunosciences Lab*, Los Angeles, CA. Dr. Vojdani is also chief scientific advisor of *Cyrex Laboratories*, Phoenix, AZ. Dr. Vojdani has published nearly 150 excellent research papers.[2,3,4] They fit the community like a glove.

Dr. Rodney Ford, MD, pediatric gastroenterologist, NZ, grasped the extent of neurological injury,[5] and "silenced nerves phenomenon."[6] This compellingly suggests why many of us do not recognize symptoms of gluten damage until we are in deep trouble. This builds on the previous work of Dr. Marios Hadjivassiliou, Professor of Neurology, Sheffield, UK.[7]

Dr. Kenneth Fine, MD, gastroenterologist, Dallas, Texas, owner of an investigative research lab, *Enterolab* (www.Enterolab.com). His lab ran the only accurate gluten antibody tests our family received back in 2004.

Without the courage of these astute researchers, we would still be wandering in the dark. Thank you all, and other individuals who thought outside the box. Kerri you are one of those thinkers. Thank you!

Lastly, special thanks to **LuEllen Giera**, my support group leader, for leading me to Dr. O'Bryan and Dr. Vojdani.

1. What is Molecular Mimicry? How does gluten damage us?

The structure of gluten resembles the structure of many of our body tissues. When the immune system attacks gluten or partly digested "pieces" of gluten it may also attack body tissues that "look like" those pieces of gluten. There may also be other processes that we do not yet understand.

What is gluten? - Gluten is a stretchy protein found in some bread grains. The problematic types are found in wheat, barley, and rye, and now early research suspects possibly rice, corn and oats (Dr. Peter Osborne, DC, CCN, www.glutenfreesociety.org).

What are proteins? - Proteins are a class of materials found in living tissues, such as hair, nerves, enzymes, etc. Molecularly, all proteins look like necklaces of beads strung into various color sequences. The different sequences make the proteins different, and the "colored beads" represent 22 separate amino acids. Our digestive system uses enzymes to cut up these necklaces into single beads so they are small enough to cross the gut wall properly and be restrung into new proteins. See image on page 452.

Unfortunately, many folks today are toxic and poorly nourished and do not have strong digestion, so the gluten "necklaces" may never completely break down. As weaker bonds between the beads break, "pieces", called "peptides," of gluten are formed. Gliadin is a well known gluten piece and there are many others.

Our immune system - has "departments" to protect us in various ways, including IgA, IgG, IgE, IgM, IgD and others. IgE can cause immediate allergic reactions to bee stings or peanuts, etc. IgA, IgG and IgM may react more slowly with less drama. They all manufacture "workers" or "soldiers", called antibodies, each custom designed to patrol our bodies, looking for the bead sequence of one particular enemy. When they find that bead sequence, they "tag or stick onto" it. Our killer white blood cells interpret the antibody tag as a condemned sign and know to surround and destroy that protein.

If an antibody test lists "Gliadin – IgA", "Gliadin – IgG", and"Gliadin – IgM" it means the test checked for gliadin antibodies in the IgA, IgG and IgM departments. If the antibodies are high it means the immune system is does not like gliadin and is working to destroy it.

Weak, leaky barriers - Our gut wall and other barrier membranes such as the skin, lung, placental, and blood brain barriers are held together with "tight junction proteins" that act like velcro. Inflammation, parasites, gluten, medications, infections, electrosmog, etc, may damage the "velcro" or open them up too much. Substances may slip through them into places they should not be and cause trouble.

Unfortunately if the gut wall does not hold together well, i.e., is "leaky", pieces of incompletely digested gluten strings (and others) may slip through and run into the immune system—our dutiful "guard dog" on the other side. Due to their too-large size "he" may raise the alarm. The invader strings are "frisked out" i.e., examined. If they are rejected, one or more of the immune departments make matching antibodies to "tag" them so the killer cells know to go after them.

It is at this point more problems may arise. A gluten antibody may "run by" a natural body tissue, for example a nerve in the heart. It may see in that innocent nerve tissue a sequence of "beads" that matches or partly matches the gluten sequence it was designed to "tag" and stick to that section of the nerve protein instead. This, unhappily, attracts killer cells to the misidentified nerve, resulting in autoimmune injury to the nerve. This is molecular mimicry.

Other foods and proteins beside gluten may also initiate molecular mimicry when they prematurely cross a leaky gut, and may prompt allergies (IgE) or intolerances (IgA, IgM, or IgG). However specialists agree that gluten's particular "bead" (amino acid) sequences are uniquely guilty in their ability to upset the immune system and instigate molecular mimicry between "their" antibodies and our tissues.

Molecular mimicry can take place between non-food proteins and body tissues also. Infectious microbe sequences such as strep, for example, are believed to partially match, (in the case of strep), heart and joint proteins and so injure the heart muscle or valves, and (rheumatic) joints. Ditto is suspected for root canal and cavitation infections that may circulate and injure specific tissues, including the heart. Flu microbe sequences can resemble gluten and may trigger or surface gluten syndrome. There are numerous other examples of mimicry between infections, foods and body tissues.

Consider the image below. An antibody may be made to seek the shorter "bead" sequence of a gluten piece that crossed the gut wall, but it might also recognize a similar sequence, a partial match, in the longer nerve protein sequence. The antibody "tags" or "sticks to", the part of the nerve tissue that matches the gluten piece that it seeks.

Gluten Peptide (and antibody) Sequence

Note: the different colors represent different amino acids.

					pink	blue	white	brown	brown	brown	red	red	green		

Nerve Sequence

orange	orange	yellow	green	red	red	blue	white	brown	brown	brown	red	orange	green	blue	yellow

It gets more complicated, but eventually the victim tissue is attacked by killer cells on an ongoing basis. This process may be slow but stealthy. In time, the nerve may malfunction and the organ it serves may also begin to fail; for example, heart failure. This is termed autoimmunity. The body attacks its own tissue.

Molecular mimicry can occur in hundreds of places in the body since gluten can break up into numerous pieces having amino acid sequences that partly match many of our natural tissues. This may explain why gluten syndrome presents so differently in different people.[2]

Once this process starts, like elephants who never forget, the memory B cells that manufacture the antibodies never forget the sequence of

the "invader" gluten pieces. If gluten is removed, antibody manufacture eventually stops, but any time the immune system sees even a tiny amount of that protein sequence, antibody production is retriggered. This is why specialists insist the gluten-free diet is strict and lifelong.

Gluten removal stops production of the initial antibody, which decreases the inflammatory process significantly. Literature shows the gluten-free diet may reverse or improve many serious conditions, but it may not always arrest an advanced autoimmune disease. Prevention is key.

Example: Once a ball is pushed down a hill, further pushing will only send it downhill faster, but it will roll on its own. To correlate, molecular mimicry between the gluten antibody and victim tissue starts the ball rolling. Removal of gluten stops pushing the process, and the sooner the better. The longer the exposure[8], and to other factors as well in a triad of autoimmunity (a. environmental stress, toxins, infections, etc.; b. a faulty blood brain barrier; and c. susceptible genetics), the higher the chance of autoimmune disease.

Dr. Vojdani comments, "If it is detected early enough and steps are taken early enough the condition may be reversed. If any condition is advanced enough you can reach a point when simple removal may not be enough. Autistic children generally have autoimmune reactivity rather than full-blown autoimmune disease, which is why they show great improvement upon the removal of gluten."

2. Does gluten always damage the villi of the small intestine as the celiac story teaches? Many other tissues such as thyroid, pancreas, blood vessels, joints, brain, nerves, liver, bone, etc. may be involved in this disorder. Does all that other damage arise due to poor nutrient absorption from injured gut villi?

No, according to published research many researchers and practitioners now believe the villi are not always damaged in an autoimmune gluten reaction.[2] Where there is no villi damage, injury to other organs cannot be due to nutrient deficiencies caused by villi damage. Molecular mimicry provides a mechanism for direct autoimmune gluten injury to many other tissues and organs when the villi are fine. It is also possible that several tissues and organs, *including villi,* may be injured and then nutrient deficiencies from poor villi absorption may affect other areas.

Dr. Vojdani's abstract in his editorial, *The Immunology of Gluten Sensitivity Beyond the Intestinal Tract,*[2] supports that the villi are not always injured. To quote his editorial abstract, "Evidence has been accumulated in literature

demonstrating that gluten sensitivity or celiac disease can exist even in the absence of enteropathy" [gut/villi damage], "but affecting many organs."

3. I do not have damaged villi, and my tTG/gliadin blood tests were negative, but I feel so much better gluten-free. Why?

The tests were likely false negative. That is very, very common. As gluten is processed in the digestive system, it can break into more pieces than we have tests developed to check them, and the immune system makes an antibody for each separate piece. The test probably missed your antibodies because they were different from the one or two the test checked. Many patients have proven this because they received negative results to the standard test, and then found a number of positive gluten related antibodies when they ran a more comprehensive panel. Cyrex Laboratories (www.cyrexlabs.com), runs 28 gluten related antibodies in 3 areas of the immune system.

Your properly performed* biopsy was probably negative because likely your gut villi are fine.** Your gluten injury may have targeted other organs or tissues, not the villi.*** For instance, if gluten has damaged the heart, snipping intestinal villi will not help find the heart injury. Damage in either place is not ok.

More detail on False Negative Tests

The blood and saliva tests - Standard celiac blood and saliva tests only check tissue transglutaminase IgA, (tTG – IgA) as an initial screener. Most doctors give up if that test is negative. However, the literature shows that standard tTG-IgA tests are only elevated when the villi are completely destroyed. Dr. Vojdani finds that form of tTG is often not found in other gluten injured tissues. Therefore the standard tTG-IgA test is a poor screener for most patients, and returns many false negatives. More forms of tTG have now been discovered.

Doctors might also order a standard test for deamidated gliadin IgA and possibly IgG. Unfortunately these tests also have a miserable failure rate for picking up gluten syndrome because many patients have other

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* If there IS villi damage it is possible for the biopsy to miss it if the damage is patchy or further down the duodenum than the villi samples are taken. Most good "gluten aware" gastroenterologists take a number of samples to try to avoid this possibility.

** It is possible that very early villi damage may slowly accumulate long before it shows up on a pathology report. An elevated IEL count, (intraepithelial lymphocyte, an early sign of inflammation) of the villi tissue indicates this process is underway. Ask the gastroenterologist to specify that the pathologist do an IEL count.

*** I am careful to specify the "villi of the gut". There may actually be gut damage, but not to the villi. There are many types of tissue in the gut, such as nerves, for instance. The villi may be fine, but it is still possible that some other gut tissue may be damaged by molecular mimicry or other processes we do not yet understand. For instance, if the nerves that control peristalsis (wave like gut motion) are injured, it could result in chronic constipation.

antibodies beside those two. The gluten "string" can break up into many other pieces, plus other "departments" of the immune system may react.

Villi biopsy vs. positive antibodies for diagnosis? - To add insult to injury, even if antibodies are discovered, many celiac, villi focused specialists may still insist that the villi biopsy is the final word for "celiac" diagnosis and they trust a negative villi biopsy over positive antibodies. Many folks have positive antibodies and suspicious symptoms, including improvement upon gluten removal, but no apparent villi damage. Their doctors assure them they can eat gluten! This is a serious mistake for many patients.

More on the villi biopsy – By now it is easy to understand why even properly performed* villi biopsies are only useful for the relatively small subset of patients in which the villi of the duodenum are injured. Most patients do not happen to have damaged villi. Their damage is somewhere else in their body, other organs, nerves, etc., or some enzyme or functional item has been damaged by gluten antibodies. Scientists such as Dr. Aristo Vojdani[2,3,4,] do NOT recommend villi biopsies for gluten syndrome diagnosis (there may be other reasons to scope the gut, such as tumors, etc). Dr. Vojdani explains that if there are elevated antibodies to gluten, the immune system is screaming "I do NOT want this substance! I am manufacturing antibodies to tag and destroy it." That is sufficient reason to remove gluten from the diet. It is less expensive to check an extensive array of gluten antibodies than undergo an endoscopy anyway, and is much less invasive.

4. Why do many gluten syndrome patients not only react to wheat, barley, and rye but also sometimes to other foods, particularly oats, milk, corn, soy, egg, coffee, sesame, yeast, chocolate and others.

These foods have similar amino acid sequences to gluten. Now that we grasp molecular mimicry, this is logical. The immune system may misrecognize them for gluten, causing cross reactions which may keep the gluten antibodies running high even on a gluten-free diet. Happily, this does not always occur. Cyrex labs, Array # 4, checks a list of cross reactive and gluten substitute foods, IgA and IgG.

5. The diet seems excessively strict? Why does it take so little gluten to start a reaction?

We understand that miniscule amounts of bee venom, or peanut, can trigger emergency allergic reactions, and very tiny medication pills can cause major effects on our bodies. This is also true of gluten reactions, both immediate allergic IgE, and delayed IgA, IgG, and IgM.[3] "Crumbs matter." The difference is that delayed reactions are not as obvious as the allergic reaction. They may go unnoticed for hours to decades, but may be a long, slow, serious process. Their lack of drama robs these reactions of the compliance respect they deserve.

6. The silent syndrome - Why do many people react to gluten, proven by antibody tests, but they have few or no warning signs, or seemingly unrelated symptoms they do not recognize or connect with their diet for a long time. Then they crash with something serious, often or usually autoimmune?

Gluten is famous for slowly injuring nerves[5] by molecular mimicry, and in many cases the nerves are silenced by that injury.[6] The patient does not realize there is a problem until the tissue or organ that those nerves supply begins to fail. Furthermore some areas of the body do not contain many pain nerves, so we may not feel the damage. Slow silent damage is understood in other diseases. Heart damage, cancer, and aortal aneurysms are examples of conditions that develop silently and then suddenly flare. Prevention is best.

For years, celiac literature recognized 2 neurological conditions, peripheral neuropathy and gluten ataxia. In the wider perspective of gluten syndrome, nerve damage may be one of the most important areas of injury.[5]

Dr. Rodney Ford, MD, suggests in his book, *The Gluten Syndrome: Is Wheat Causing You Harm*,[6] that this is primarily a neurological disease[5], injuring and in some cases silencing nerves, compromising the health and function of the tissues they serve. This idea was reinforced by an astute observation made by Dr. Ford of one of his patients, an elementary school child who had not achieved bowel control. After she went gluten-free, the problem resolved. Dr. Ford realized the child now recognized the signal to visit the toilet, and accidents were avoided. The nerves in the lower bowel apparently "woke up" once the antibodies that injured them disappeared. This is an interesting and logical theory to explain "silent gluten injury", and it fits the community. Here is an abstract of Dr. Ford's published paper which discusses a possible widespread neurological focus:[5]

The Gluten Syndrome: A Neurological Disease, by R.P. Ford

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 malfunction 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."[5]

7. Why do so many of us react now, when for centuries most people appeared to be fine with wheat? After all, wheat is spoken of positively in the Bible and many other historical documents.

There may or may not be a conclusive answer to this question, but a few factors may play a role.

a. Many folks have higher toxin levels now, their nutritional status is worse, and digestive strength is weaker.

b. Today's wheat is different. Gluten grains have been subjected to a lot of changes, some genetically violent, according to Nina Federoff, a pro GMO scientist. She asserts in her book, *Mendel in the Kitchen*, that gluten grains were altered with nuclear radiation and chemical mutation by the 1950's – 1960's.[9] Recently a stash of old blood samples from that era, stored in a freezer by the military, were checked with standard celiac antibody tests. The incidence of positive antibodies was much less in those samples than is typically found in the general public today.

c. Wheat seed is sometimes treated with mercury. Might this play into unintended results?

8. Why do specialists and researchers insist that the gluten-free diet must be life long? Can't we heal the gut and go back to our beloved wheat bagels, croissants, and brownies?

Our scientists insist that gluten-free is a strict lifelong commitment. The memory B cells in the immune system never forget what the enemy "looks like." Today's gluten is a violently altered substance according to the very scientists who defend genetic alterations.[9] It is not worth playing with today's wheat. There is something strange and unpredictable about it. Even if a leaky gut has healed, future circumstances, toxins and stress might injure it and retrigger the syndrome, perhaps silently. Researchers say gluten creates leaky gut for a few hours in everyone.

Particularly since gluten appears to be the "bad boy" that predisposes to other intolerances, I prefer to walk away for life and concentrate on other nutrient dense foods. However, it is wise to consume whole foods rich in B vitamins, (ex., liver or bee pollen), and silica (the herb horsetail, "equisetum hymale" species, is a source,) as gluten grains contain those nutrients.

9. Traditional peoples soaked and/or sprouted their wheat berries and then made sourdough bread with it. Does that process alter the gluten sufficiently for gluten syndrome patients to safely consume it today, particularly organic spelt and einkorn?

No. These methods make bread more digestible, but the fermented products and ancient gluten grains still contain gluten and can trigger reactions in research trials. Even if there are no visible reactions, silent injury cannot be ruled out without long term research. Additionally, the preparation process before fermentation is completed is definitely gluten based, so significant cross contamination issues come into play in the kitchen. Healing the gut is a challenge. Other areas crop up that need cleanup too, such as the parasite issues. Gluten specialists advise us to go gluten-free, stay that way, and move on.

10. What are gluten withdrawals?

Rarely, a few days to a few weeks after going gluten-free, or after being glutened, a patient may experience a few hours to a couple of weeks of a parade of varied and unusual symptoms including dizziness, black pit depression, crying, physical or emotional exhaustion, even as in difficulty getting up to use the rest room, and other odd symptoms. In severe cases they may experience an inability to socialize, make eye contact, make decisions or hold a normal conversation. Children or teens may act out in extreme ways during this situation. Often patients cannot bring themselves to discuss this experience afterward. However, a patient reluctantly described her experience 2 years later as "encountering an empty white board with nothing on it." The rest of life around her seemed to be "across the Grand Canyon." This appears to be a temporary crisis that resolves anywhere from a few hours to a couple of weeks or so according to folks who contact me about them. It is assumed that this phenomenon is due to particular pieces of gluten strings called gluteomorphins with amino acid sequences which resemble opiate drugs. When these gluten pieces disappear from the blood stream the patient may experience "withdrawal," very much like a drug withdrawal. Another theory for why this may happen involves changes in blood flow to the brain that may create a temporary neurological crisis. Autistic children may suffer these withdrawals and may take longer to stabilize, but they usually make nice gains after the crisis passes. Happily, once withdrawal is over the patients are usually much better, and they are VERY vigilant with their diet.

In the rare event that this type of reaction might occur, family and friends of the person do well to understand that the person may (or may not) be able to prepare their own food, for instance, but not be able to verbally communicate much, make eye contact, hold a conversation, answer

questions, and may be uncharacteristically snappy particularly if others attempt to communicate with them. Family members may wish to be quietly and unobtrusively nearby until the person passes through this stage. If the patient has children to care for, help may be needed, and also solitude, rest, and simply prepared "real" nourishing food that is gluten-free and easy to digest such as bone broth. Probiotics or old fashioned fermented raw veggies or sauerkraut from the refrigerated section of the health food store may be helpful. Family and friends should not take the person's temporarily withdrawn personality personally.

For details on these unstudied rare reactions, or if you need support during a crisis, see...

www.theglutensyndrome.net /Adverse_reactions.htm

...or contact me at *jka8168@sbcglobal.net*. I collect testimonials, so feel free to contribute if you have experienced this type of reaction. We hope these reactions will eventually be studied.

11. Should I replace all the gluten foods I routinely eat with gluten-free substitutes?

No, most gluten-free substitutes are still mainly expensive processed food (aka junk food). For the first few weeks it is normal for newbies to look for substitutes to replace their "old gluten friends" and it helps them make the very real emotional transition, but there are better, more nutrient dense food choices. The substitutes are still high carb, (potato, corn, tapioca, rice), and most contain sugar, processed gums, GMOs and ingredients that do not help us get well. We may actually eat more of them BECAUSE they are gluten-free. Additionally they are expensive and not always easy to prepare at home.

Many experienced gluten-free folks gradually wean themselves off a constant diet of the rather junky substitutes in favor of other real unprocessed foods, such as meat, eggs, veggies, fruits, nuts, fermented vegetables, bone broths, and so on according to their digestive abilities. The gluten-free substitutes become the occasional treat, such as pizza crust. Gluten free families are wise to find the healthiest GF versions of just the items they miss the most, and skip the rest. For example, at our house, I had served gluten spaghetti for years, but when I dropped that habit, no one noticed. However, my husband wanted his breakfast toast, so we found a gluten free brand he liked and continued that tradition. Each family works out these adjustments for themselves.

Lettuce wraps are crunchy and yummy instead of sandwiches. Hamburger patties without the bun but with onion for the onion lovers, are still tasty and they feel better afterward. In our family we now use watermelon or a watermelon basket for birthday "cake", complete with candles and a bow in the summer. Fruit pizza with a nut flour or nut/date crust, avocado chocolate or other dairy-free or fruit based pudding for the sauce, and an artistic fruit/coconut topping works for parties. There are lots of ways to celebrate happy healthy gluten-free, junk free birthdays.

12. Warning! Formal gluten challenges for testing purposes – risky!

A word of caution. Antibody tests must be performed while the patient is still consuming gluten or shortly after going gluten-free. Sometimes doctors advise patients who are already gluten-free to go back on gluten, 4 slices a day for 4-6 weeks to restart the antibodies for testing purposes. Patient experience has shown that once the system is fairly clean of gluten, going back to perform a formal gluten challenge for testing purposes may be risky. The secondary reactions for some individuals can be significant, particularly neurologically. Challenges have been known anecdotally to trigger psychological black pit crashes, fibromyalgia, and other organ injury. Autistic children may have a hard time when they just go gluten-free initially or consume gluten accidentally. A planned challenge for them may be very unwise.

13. Intermittent infractions (aka cheats) are seriously unwise and may increase injury.[10]

This is not a fad, or cheater's diet. The gluten-free diet is a medical diet to treat or control serious autoimmune, inflammatory, and often neurological diseases. There is no room for casual infractions. Research suggests that repeated, intermittent cheats, even every few weeks, over time may actually influence mortality rates.[10] This is not a reason to avoid the diet, but to take it seriously. Once the strictness of the diet is embraced the patient or family adjusts and discovers that it is doable. Gluten-free food bars, nuts, a packet of gluten-free soy sauce, and GlutenEase™ or other brands of DPP IV enzymes are good to keep in the glove compartment or backpack to handle emergencies. NOTE: DPP IV (pronounced DPP 4) digestive enzymes help break down gluten but they do not stop a reaction and are NOT a reason to cheat. However if there is a possibility of exposure it makes sense to take them for whatever help they might afford. In the case of a confirmed gluten exposure, take the enzymes, keep the bowels moving, stay calm and deal with it. Worry and drama makes everything worse.

14. Discrepancy – The celiac focus uses villi biopsy for diagnosis. The wider perspective relies on positive antibodies or improvement on the diet. Question? How did villi damage become the gold standard?

The first place the medical profession found conclusive damage by gluten in the 1950's – 60's was to the villi of the gut. After the endoscopy tool was developed, villi damage and subsequent healing upon gluten removal could be observed. They concluded that gluten damaged the villi. This was true. The particular subset of cases they scoped had villi damage, but their conclusion that the villi were the only target of damage for everyone with gluten syndrome was too narrow according to research today.[2] In most patients the target damage was NOT the villi, but the bones, joint lining, heart, thyroid, pancreas, liver, brain, almost any organ, blood vessel walls, nerves almost anywhere in the body, and so on. The patients might even have injury to multiple tissues, BUT NOT NECESSARILY ALWAYS TO THE VILLI. When the villi biopsy was declared the gold standard for gluten syndrome diagnosis, it cut out most of the patients who were reacting to gluten. Snipping villi does no good if the damage is in the thyroid or brain. For the next 60 years very few patients were prescribed a gluten-free diet because most of them did not have damaged villi, (or the doctor never thought to look at all). Their gluten-induced injury was somewhere else in their body, so they were never diagnosed.

15. Discrepancy - The villi damaged celiac disease story teaches that celiac disease is autoimmune and much worse than "non autoimmune" non-celiac gluten syndrome (NCGS). The wider gluten syndrome perspective teaches that both are autoimmune and serious.[2,3,4]

A significant disagreement exists over the autoimmunity of non-celiac gluten syndrome (NCGS). In the beginning, antibodies to gluten could not be found in NCGS patients, therefore it was assumed that NCGS was not autoimmune. However, Dr. Vojdani insists NCGS IS autoimmune. The NCGS patients have plenty of antibodies, just different ones than the standard tests check. His tests, which check and find more antibodies,**** the illnesses these patients develop, and recoveries or improvements on the diet all prove his point. He also asserts that NCGS can indicate a gut wall in worse shape than the celiac villi damaged subset.[2,3,4] The damage is simply somewhere else, not to the villi. See the link below for diagrams of these reactions, and compare the condition of the gut wall in the celiac diagram with the gut wall in the gluten intolerance diagram.

www.TheGlutenSyndrome.net/ VojdaniDiagrams.htm

**** Dr. Vojdani's research found several more forms of both tTG, and gliadin antibodies, (alpha, gamma, omega), gluteomorphins, glutinins, and others. His saliva and blood panels check 12 separate antibodies in 3 different immune departments and 2 mediums, totaling 28 gluten related antibodies. The two panels, run together, nearly always find antibodies if they are present in the patient, translating to far fewer false negatives.

This disagreement fosters confusion among NCGS patients that villi damaged celiac disease is the "big bad boy" to avoid (true, it is bad), but that NCGS is less severe, not autoimmune. This translates in real life to gluten birthday cake for the Friday night party and then back on the gluten-free bandwagon Saturday morning, "so I won't eventually develop villi damaged celiac disease." Yes, that could happen also, particularly if the person seesaws on the diet, but the notion that NCGS is not as bad as villi damaged celiac disease is a misunderstanding according to Dr. Vojdani.[2,3,4] To repeatedly seesaw off and on gluten indiscriminately is unwise according to medical literature,[10] and community experience. Gluten exposure needs to be an accident, which happens occasionally even to the most vigilant. Casual cheats are a more risky mindset, usually meaning "more frequent."[10] Take it seriously, nerves, blood vessels, and organs are precious.

Gluten Tests with a Good Track Record

Some families cannot afford to test or good tests are not available. In the case of autism this protocol and most others require gluten-free and that is the end of the matter. Kerri takes this position partly due to cost and the miserable record of false negatives that standard tests return. The protocol does not work without the diet. Period.

Some adults are also willing to go gluten-free without a test. Their bodies tell them what they need, they listen, and are happy to find answers. Social pressure does not sway their decision or ability to comply.

In many other situations, a positive test is very meaningful. It gives patients confirmation that gluten-free is right for them, silences critics, and helps them comply with the diet. In the case of children it provides proof to the other parent, grandparents, therapists, doctor, etc. It may also come in handy if the child turns into an invincible teen who doubts he ever needed the diet in the face of pizza and beer, ditto for his future spouse and in-laws. The catch is that the test must be adequate. A false negative misvalidates the skeptics. These are decisions every individual or family must evaluate for themselves. Thankfully there are test panels with good track records now.

Absolutely, regardless of any test result, if the body is able to communicate a reaction to gluten or its removal, then that is the final answer. Be grateful and go gluten-free.

This testing section is for those who wish to test for their own confirmation or social support.

NOTE: If a patient has been ill for a very long time it is possible for the immune system to be so worn out that few antibodies are manufactured. Lower antibody counts might show a false negative but not prevent injury to innocent tissues. Also, due to the wide variety of antibodies a patient may happen to make, it is possible to run any antibody panel and miss those particular antibodies. The more antibodies that are checked the less likely this may occur, but should be considered in the event of a negative test that the patient or practitioner questions. In this case a gene test may be helpful.

Enterolab - Stool and 1 part gene tests

For 10 years Enterolab's mail in home collection research stool test stood in the gap for thousands of patients who received false negative standard tTG and gliadin blood tests. It has saved many lives, and gave our family the social confirmation we needed. This unpublished research test checks stool for tTG-IgA and gliadin-IgA only. The use of stool as the testing medium appears to pick up those antibodies most of the time, much much more often than standard tTG or gliadin IgA blood tests. However, since only two antibodies are checked, it may miss in some cases.

Dr. Fine's lab also offers a one part gene test which he believes is adequate for a reasonable price. Dr. Fine finds if a gene is present, nearly always so are the antibodies, and two genes are worse. Villi damaged celiac specialists recognize only HLA DQ 2 and 8 as gluten related, but Dr. Fine includes 1 and 3 and their subsets 5, 6, 7 and 9. In fact according to Enterolab, HLA DQ 4 is the only DQ gene that does NOT correlate with gluten syndrome. According to him, a patient needs 2 copies of the HLA DQ 4 gene to miss the predisposition. This translates to 81% of the Caucasian population with a predisposition to trigger gluten syndrome at some point in their lifetime, including before they are born.

Cyrex Labs - Better blood and saliva tests

Cyrex Labs (www.CyrexLabs.com) opened their doors in 2010 in Phoenix, Arizona. They run much more complete antibody panels designed by Dr. Aristo Vojdani, PhD., their scientific advisor, an immunologist, and researcher. Dr. Vojdani found a wider variety of gliadin antibodies, (alpha, gamma, omega) and variations of tTG in other tissues, plus gluteomorphins, and several others. He also checks an IgM antibody due to possible malfunctions in that system. Cyrex blood and saliva panels, Array #1 and #3, combined, test for 28 gluten related antibodies between 3 immune departments, 2 mediums,

plus IgA insufficiency. They rarely miss a diagnosis because they look for so many antibodies. (Note: Vojdani believes stress, toxins and infections, i.e. environment, can trigger a gluten reaction without the genes.)

Gluten Free Society - Two Part Gene Test

A third approach espoused by Dr. Peter Osborne, *The Gluten Free Society*, Sugarland, Texas, (www.glutenfreesociety.org), is to run only the gene test, since any antibody panel may theoretically miss the particular ones the patient may have. He uses a 2 part test, the most complete method, and looks for both celiac and gluten sensitivity genes. A positive gene test does not prove a current immune response as do antibodies, but predisposition to it. Presence of 2 genes indicates a more severe case. Gene tests have an advantage in that they can be run anytime, gluten consumption is unnecessary, and depending on the results, useful information can be gleaned for immediate and extended family members.

Elimination Diet

The elimination diet is inexpensive. Often/usually it demonstrates improvement upon removal of gluten, or worsening upon reintroduction. Many "heads up" practitioners accept this as reason enough to go gluten-free.

There are occasional complications or interpretation issues for the elimination diet as follows:

a. Reintroduction of gluten (gluten challenge) can trigger stronger, sometimes risky reactions.[10] Stop a challenge upon negative symptoms, including depression and emotional instability, or best, don't challenge. An accidental infraction may come up that provides insight.

b. Occasionally it takes several months to see the difference, or a silent reaction may mask symptoms.[6]

c. If the patient later decides to test and is already "clean" on the gluten-free diet, blood tests will not work unless gluten is reintroduced for many weeks.[10] No! Stool/gene tests are safer.

d. There is no lab confirmation to silence naysayers.

Other Related Tests

Cyrex Labs Array # 2 - Intestinal Permeability Panel focuses on specific causes of leaky gut. This helps strategize treatment, and is an improvement over the old lactulose/mannitol test.

Cyrex Labs Cross Reactive Foods and Gluten Substitutes, Array # 4. - This specific list checks foods that commonly cross react with gluten and also foods commonly used to replace gluten. It helps customize an anti-inflammatory diet.

Cyrex Labs Predictive Antibody panels determine if or which tissues are currently under antibody attack. This predicts autoimmunity years ahead of time and gives the patient advance notice in order to address trouble spots.

Enterolab (www.Enterolab.com) offers several stool based food antibody panels and gut related stool tests.

What are the lab instructions?
Do I need to consume gluten for testing?

Antibody tests, (blood, saliva, stool), prove a reaction and require recent gluten consumption. Ideally, test first, then go gluten-free. If the patient is off gluten, call the lab for advice on the time window before the test will not work.

Cyrex Labs (www.CyrexLabs.com) tests require prescriptions and a saliva specimen and/or blood draw. If a doctor is needed to write the script, check www.thedr.com for a partial list of practitioners who are familiar with Cyrex Labs. Results are sent to the prescribing doctor.

Enterolab stool specimens are ordered online, kits are sent, home collected and mailed. No prescription is required. Results arrive on email. Enterolab's test works for several months after going gluten-free.

Gene tests do not require gluten consumption or a script and can be run at any time. Genes prove a predisposition to gluten reaction.

Enterolab's gene test is a relatively inexpensive "one part" test. It is a mail in cheek swab and reports the patient's actual genes.

Gluten Free Society (www.Glutenfreesociety.org) gene test is a "two part" (more complete) mail in cheek swab and reports yes or no for both celiac and gluten sensitivity genes.

For information on testing (I have no financial interests) see:

www.TheGlutenSyndrome.net

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