

# An Experimental Intervention For Autism

## Understanding and Implementing a Gluten & Casein Free Diet

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Samuel and Jacob Goldstein

### Introduction

In the five years since my son was diagnosed with autism, I have spent hundreds of hours in libraries, and connected to computerized databases and networks. Because I worked at a university, I had access to these resources, and the training and experience to use them. Through these media, as well as connection to the Internet I was able to gather together a great deal of information. Three years ago, I began a dietary experiment that has helped my son enormously. Because I spent so much time and energy searching for answers as to why this has helped him, and how to implement this diet, I decided to share it with other parents and professionals. I hope you will find this packet useful.

Please feel free to share it with others who may benefit or who are simply looking for more information.

### **What IS Gluten? Why Eliminate it From the Diet?**

Glutens are proteins found in the Plant Kingdom Subclass of *Monocotyledonae* (monocots.) These plants are members of the grass family of wheat, oats, barley, rye and triticale, and their derivatives. Derivatives include: malt, grain starches, hydrolyzed vegetable/plant proteins, textured vegetable proteins, grain vinegars, soy sauce, grain alcohol, flavorings and the binders and fillers found in vitamins and medications. Casein is a phosphoprotein of milk, which has a molecular structure that is extremely similar to that of gluten.

The following article was written by members of the [Autism Research Unit of the University of Sunderland](#) (Great Britain) and is reprinted with permission. [Text in brackets are my additions.]

#### **"The Use of Gluten and Casein Free Diets with People with Autism"**

These notes should be taken as observations. They do not constitute a recommendation or endorsement of a dietary method to alleviate the symptoms of autism. Any decision to undertake such a method must lie solely with the person with autism or with those having responsibility for their care.

Background In the early 1980's a number of researchers, including Herman and Panksepp, noted the similarities between the behavioural effects of animals on opioids, such as morphine, and the symptoms of autism. In a very speculative paper, Panksepp proposed a mechanism whereby people with autism may have elevated levels of opioids which occur naturally in the CNS (= brain) of humans. The best known of these naturally occurring opioid compounds is beta-endorphin (= endogenous morphine) and certainly there is a degree of correlation between the known effects of this compound and the symptoms of autism.

Just after this, Gillberg produced evidence of elevated levels of "endorphin like substances" in the cerebro-spinal fluid of some people with autism. In particular, elevated levels appeared in those children who appeared to feel pain less than

the normal population and who exhibited self-injurious behavior. At about the same time, Reichelt produced evidence of abnormal peptides in the urine of people with autism. We ourselves, like a number of other groups, attempted to replicate his findings. Although his technique was comparatively simple there were technical difficulties and these attempts were, initially unsuccessful. Later on we switched to a more sophisticated technique and have been able to confirm Reichelt's findings. **In the urine of about 50% of people with autism there appear to be elevated levels of substances with properties similar to those expected from opioid peptides.** [emphasis added]

The quantities of these compounds, as found in the urine, are much too large to be of CNS origin. The quantities are such that they can only have been derived from the incomplete breakdown of certain foods. Proteins consist of long chains of units known as amino acids. Normal proteins are digested by enzymes in the intestines and are broken down into these units. However, if for some reason, this digestion is incomplete, short chains of these amino acids (known as peptides) will result. It is proposed that these peptides may be biologically active and could result in the symptoms which we see in autism. The majority of these peptides will be dumped in the urine, which is where Reichelt and we are finding them. A small proportion will cross into the brain and interfere with transmission in such a way that normal activity is altered or disrupted. It may be that these compounds, themselves, have a direct effect upon transmission or that they will attach themselves to the enzymes which would break down our own naturally occurring enzymes. The consequences would be the same in either case. It is well known that casein (from human or cow milk) will break down in the stomach to produce a peptide known as casomorphine, which, as the name implies, will have opioid activities. Similar effects are noted with gluten from wheat and some other cereals [notably oats, barley and rye] in which the compounds formed are gluteomorphins [or gliadinomorphins.]

If this opioid excess hypothesis is correct, there are a number of strategies which can be adopted. Firstly the anti-opioid drug "naltrexone" could be considered and

promising results have been reported. [Note: a recent study of 41 children conducted by Magda Campbell, did not produce positive results with low doses of naltrexone. It is possible that doses were too low, but for now effectiveness of this medical intervention must be questioned.] Alternatively, a diet which excludes casein (milk and dairy products) or gluten (wheat and other grain products) could be considered. It may be possible to determine, from the pattern of the urinary peptides, whether casein or wheat [gluten] or both should be avoided, but such conclusions may be premature at this stage. It has been observed that those children whose autism appears at or around the time of birth may have a problem with casein whereas those whose autism becomes apparent at about two years of age, when a wheat based diet is more likely to be adopted, have particular difficulties with gluten. Some children may have difficulty with both.

Norwegian colleagues of Reichelt have published data which support the effectiveness of such dietary programmes but these studies cannot be considered as conclusive. There have been no other real attempts to demonstrate the effectiveness of such diets on a scientific basis. Numerous people have experimented on an individual basis and have reported successful responses but such evidence cannot be considered as, in any way conclusive. In Rimland's studies of parental reports, however, the results appear to be very much superior to those obtained with any drug based theory.

## **Practical Aspects**

The theoretical processes described here are toxicological in nature rather than allergic. The results are akin to poisoning rather than an extreme sensitivity such as occurs in coeliac disease or sensitivity to certain food colourings [see discussion of coeliac disease below for another perspective on this topic.] Removal of gluten and/or casein containing products requires the active participation of all those concerned with the child's well-being. Tests have often been ruined by a well meaning relative who ignores parental instruction, or by

schools or therapists who feel that the proposals are rubbish. Carers must satisfy themselves that the diet is being adhered to before any evaluation is possible. Gluten and Casein free products, together with advice on their use, are available from Pharmacies [in this country health food stores will be the best source.] Nutritionists and dietitians would also be able to advise. Initially the reported effects may be negative, upset stomach, anxiety, clinginess and slight ill-temper. Experience would suggest that these are good signs and precursors of a positive response. Reichelt recommends a trial period of three months. If it has not worked within that time it is unlikely to do so. [Note: in electronic mail to me, Reichelt suggests a period of one year is necessary.] Experience also suggests that the results are more easily demonstrated in younger children. The effects in fully grown individuals appears less impressive. Given that there appear to be a number of possible causes of autism it is not unexpected that no unitary solution will be found for all cases.

## **Conclusions**

Although the hypotheses may appear "off the wall" in many respects, there are a number of pieces of evidence which support them. The ideas are compatible with virtually all the accepted biological data on autism and are worthy of consideration.

The dietary method must still be considered as experimental and no positive results can be promised or are claimed. The use of diet may well be far less harmful than other medical interventions or therapeutic regimes. We would be pleased to receive any feedback of a positive or negative nature from anyone utilising such dietary modification in the amelioration of autism.

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A quote from Reichelt in electronic mail sent to me: "In general we recommend a diet free of gluten and casein for autistic...patients. The reason for this is that opioid peptides from gliadin are almost of the same structure as casomorphins from casein. We also recommend addition of multivitamin with trace minerals and magnesium, cod liver oil and calcium."

"We usually remove casein and gluten both. Opioids from these proteins are very similar."

Gliadinomorphin (from gluten): Tyr-Pro-Gln-Pro-Gln-Pro-Phe Casomorphin (from bovine casein): Tyr-Pro-Phe-Pro-Gly-Pro-Ile

"Effects of diet if useful, tends to be cumulative. Must be tried for 1 year."

## Further Research

Mr. Shattock, along with colleague Dawn Savery, has recently written a paper which brings their work on this topic up to date. At the time of writing, Shattock and Savery had examined urine samples from nearly 1,000 subjects. While little other information about the subjects was collected initially, the study is now more formal and involves the collection of much more detailed behavioral and other information.

The theoretical model on which their study is based remains the same, relying heavily on the work by Reichelt and colleagues (Knvisberg and Waring.) To summarize:

...autism could be the consequence of the action of peptides of exogenous origin effecting neurotransmission within the Central Nervous System (CNS). We believe that these peptides result in effects which are basically opioid in nature....the CNS neuroregulatory role which is normally performed by the natural opioid peptides...would be intensified to

such an extent that normal processes within the CNS would be severely disrupted.

The presence of this intense opioid activity would result in a large number of the systems of the CNS being disrupted.... Perception; cognition; emotions; mood and behaviour would all be affected. ... Many and diverse symptoms by which autism is... defined would result. We believe that these peptides are derived from an incomplete breakdown of certain foods, and in particular, gluten... and from casein. ---- "Autism as a Metabolic Disorder," by Paul Shattock and Dawn Savery (1997)

### Related Articles

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## Sam's Story

My son Sam is nine years old, and was diagnosed as PDDNOS (autistic) at age three and a half. We believe that his development was normal for approximately the first 18 months of his life. By two and a half Sam was in an early intervention. County officials who ran this program never gave us a specific diagnosis, saying only that he had "sensory integration difficulties with some autistic characteristics." By three he was in a multiply-handicapped half-day preschool, and was receiving private speech therapy. Though he had language from an appropriate age (13 months), by age two it was far behind that of peers and was characterized by (appropriately placed) echolalic utterances. When Sam was three and a half, his father studied the DSMIII-R and realized that PDDNOS was the only diagnosis that fit our son.

After a neurologist confirmed my husband's diagnosis we sought an independent educational evaluation at the [Eden Institute](#) in Princeton, New Jersey. A placement more specific to autism was recommended, and Sam was accepted at the Douglass Developmental Disabilities Center (at Rutgers University) for the next year. Meanwhile, we had a summer to kill, and that summer was indeed a

killer. Sam's behavior became impossible, and for the first time aggression was prominently featured. I removed dairy from his diet, as an experiment. The aggression decreased, though it remained a significant problem.

Sam did very well at his new school, and behavior modification techniques (including mild aversives) were tried to eliminate his aggressive behavior. These behavioral interventions each helped for a time, but nothing really erased the behavior. Ultimately we were uncomfortable with aversive techniques and felt that they in fact escalated the behaviors; we thus withdrew permission for their use.

In June and July, 1993, Sam's aggression suddenly increased. The aggressions went to double digits during a five hour school day. Not knowing what else to do I decided to experiment again with Sam's diet. I chose to remove wheat because I knew it was a common allergen. After five days, Sam's aggressions dropped dramatically. For the remainder of the school year, his aggressions averaged 6.1/day. During the month he was on vacation, Sam did not aggress at all. When he returned to school in September, his aggressions dropped further, averaging 2.47/day over the next seven months. Sam also, for the first time, began to talk about his aggression. Even when he lost control he could now tell me "I don't want to hit or kick", and thus we could discuss his behavior with him, and suggest alternatives.

In November, 1993, I found Reichelt's and Shattock's papers and realized that gluten that was probably significant, rather than wheat. I had been using oat and rye flour, and both these grains have high levels of gluten. As of November, 1993, gluten was eliminated from Sam's diet. I didn't see the immediate change I'd seen when we removed wheat but certainly his growth continued. After removing wheat and other gluten grains from Sam's diet, we saw other changes too. For years we had struggled with Sam's reversed pronouns. We did drills at home, he worked on it at school and with his private speech therapist. Within a week of his dietary change, Sam's use of pronouns was suddenly and completely correct. His attention span increased and he responded more quickly to lessons

at school, home and in private speech and occupational therapies. His speech therapist referred to him as "my one-trail learner."

In the spring of 1994, Sam was placed on a strict anti-yeast diet with high doses of the anti-fungal drug Nystatin. We were told that if this treatment was to be of benefit, we would first see a regression. We indeed saw a regression that lasted for three weeks and has been followed by a slow but steady improvement in language and behavior. During this period Sam's aggressions went back to pre-diet levels, but gradually decreased to a level of 2.47/day during the remaining school year. Fortunately, we saw no regressions in speech or other behaviors such as toileting.

Dr. Baker also ordered extensive testing of blood, urine, saliva and stool. While most were normal, Sam was deficient in eight amino acids, and was low in zinc. In order to put Sam's system into better balance, we added a vitamin compound, additional calcium and zinc to Sam's regimen. I later added molybdenum and magnesium, as well as essential fatty acids (evening primrose oil and flax seed oil.) at various times I have also experimented with DMG, L-Carnitine, a (milk-free) acidophilus powder, extra inositol, ginko extract, pycnogenol and octocosanol. I never saw any benefits from DMG, Carnitine, pycnogenol or octocosanol, so I discontinued their use.

Sam's diet and nutritional supplements are certainly not the only things that have helped Sam. He spent four years at an excellent special school, and attended weekly speech and sensory integration therapy for five years. For two years he wore yoke prism glasses and did visual therapy prescribed by Dr. Melvin Kaplan of Tarrytown, New York..

However, the change after removing wheat was both remarkable and undeniable, as is what happened on the occasions he accidentally ingested gluten. On several occasions Sam has ingested gluten without our knowledge, and the changes in him were fast and quite marked. In each case we were able to determine what had caused the sudden, and thankfully short-lived, regression.

While I cannot be sure what has helped Sam the most, I do have a daily record of his behavior and many of his utterances dating back to when he was three. I can therefore correlate changes with particular interventions. Because autism is likely a disorder with multiple etiologies, it is unlikely that every autistic person would benefit from this diet. I believe strongly, however, that the approach would help many children. Indeed, in the three years since I first wrote this paper it has helped thousands that I am aware of and no doubt countless others who have never contacted me. **It is certainly worth trying.**

For a child with a limited diet, I would start with lab tests to determine if he is likely to benefit from the diet (see below). All parents of children with very limited diets want to broaden the food choices the child accepts. However, if positive test results show that gluten and or casein could be causing damage to the CNS, changing the diet is critically important. NOTE: tests will not be valid once the child has had gluten and/or casein removed from his diet for any length of time. Because Sam responded so well to a g-f (and greatly reduced casein) diet, I feel frustration that more parents have not been willing to try this diet. However, I also know that I am lucky. My son is not a fussy eater, and accepts the various substitutes I provide for him. He can now monitor his own diet to a certain extent, refusing "regular" bread or cookies. He also eats a wide variety of foods, much of it healthful. He takes the vitamin supplements I give him with little trouble. Many people write and call me to discuss the issues covered in this paper. Without doubt, the question I am asked most often is "How is Sam doing now?" There is no simple answer to this question. In general we are gratified at the progress he has made and continues to make, but there are always 'glitches' along the way. As of this writing, Sam is about to turn nine and is finishing up second grade at a district school. He was transitioned to this school (from Douglass Developmental) last spring, with a great deal of support from the staff of his former school. This year he has attended "regular" school with the help of a personal aide who was also trained by the Douglass Developmental staff. Sam does his academic

work in a self-contained classroom, and most of it is one-on-one with his teacher or aide. He attends morning meeting, art, gym, lunch recess and other "specials" with his second grade peers. He uses a token economy system at school, earning money for good behavior and "buying" special treats or events.

Sam's attendance at this school has required a lot of patience on the part of school personnel, and a lot of adjustment on our parts. At times we have missed the extra attention and support we got as a family from his old school. And because we were a more integral part of the "team" at Douglass, we miss being able to offer the level of input we always contributed to his programming in the past. but Sam is so happy to have peers who respond to him! He loves his new school and there is no turning back now!

Though his behavior has been difficult at times (we still struggle with bouts of non-compliance and aggression at times) the year has been a great experience for everyone. He is well liked by staff and students. His peers try hard to help and understand him, and my husband worked with them at the start of the year so that they can understand Sam's struggles better. They are proud to help when they can, and they offer him encouragement whenever they can. Sam greatly enjoys the social times at school, is especially well-liked by his *female* classmates (!), and is learning to observe and copy their behavior and skills during their time together. His classmates have benefited from learning that not everyone faces the same challenges in life.

Sam continues to have a lot of trouble with visual processing, and reading remains a real challenge for him. It is a challenge he is meeting, however, and I am encouraged that he will read fluently in the not too distant future.

Sam's strength remains his verbal abilities, and as he grows he shows that he is able to generalize ideas and skills quite well. He clearly has a "theory of mind" and is improving at abstract thinking. His school provides two sessions of therapy per week, and one of Occupational Therapy. Nothing that Sam needed and benefited from input to his vestibular system, his OT obtained a weighted vest for

Sam. He wears it for much of each day, and teachers report it has a strong calming effect on Sam.

On the down side, Sam has shown a troubling and very predictable seasonal cycle. For the last three years, life gets increasingly difficult as late fall approaches. by mid-winter we are deep into a funk which includes a dramatic increase in the number of tantrums and difficult behavior. At this time of year, without medication, Sam will regress into terrible aggression and to a lesser degree, self-aggression. We have found that a small dose of the atypical neuroleptic drug Risperdal is necessary to get him through this part of the year. I doubt very much that Sam could get through a winter without this medication, and I am certain that he could not last, let alone succeed, at school.

## **Jake's Story**

Sam's brother [Jacob](#) was born when Sam was three and we watched his development very carefully. When Jake was nine months we were beginning to worry seriously. He showed little pre-verbal development; he did not babble and made very few sounds. About this time, the pediatrician said he was ready for milk. I was working full time and having trouble keeping up my own milk supply. I was happy to throw away the breast pump and the nasty smelling formula supplements. I bought some whole milk and Jake drank it with gusto. Cow's milk seemed to cause an immediate change in Jake. He got fussier and had more stomach upsets. Within a day I knew that this child was not ready for cow's milk. I went back to the store to buy formula. Then, in a moment that in retrospect seems like an epiphany, I bought soy formula instead. Within two days Jake was happier than he had ever been. Within three days he was saying "mamamamam" "dadadada" etc. On his first birthday Jake had about ten words; by 15 months he had 200; by 18 months he spoke in sentences. He continues to develop as an incredibly imaginative, verbally precocious little boy. At five, Jake calls himself a scientist and is fascinated by all sea creatures (especially sharks.) He wants to be an underwater photographer and to make nature films, but

agrees that perhaps kindergarten should come first. In addition to the joy he has brought to his parents, he is the best "therapist" Sam ever had! Did I "save" him from autism? From some other developmental disability? I'll never know.

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## Testing for Urinary Peptides

Because modification of the diet is far less invasive or harmful than most interventions, it would seem logical to try this method. Many autistic children, however, have such finicky eating habits that the idea of cutting anything they will actually eat out of their dietary repertoire, strikes fear the hearts of their parents. For this reason, some might prefer to test their child's urine for the presence of the urinary peptides found by Reichelt and others. If there are no peptides found, it is unlikely that the diet would help the child. However, if the peptides are present and are escaping from the gut into the bloodstream, it is believed that they can "mimic" neurotransmitters and thus result in the scrambling of sensory input.

There is only one laboratory in the US (that I know of) that is doing this testing. Because it is part of the lab's research, there is no charge for the testing.

Directions for the collection and shipment of the specimen can be obtained by calling Dr. Robert Cade at the University of Florida at Gainesville. His assistant, Malcom Privette can be reached at 352-392-8952. Please note: a few parents have told me that Dr. Cade is no longer testing urine; I spoke with his secretary in May, 1997, and **testing is still being conducted.**

If the test is positive for urinary peptides, you will still not know whether the problem is casein or gluten (or both). Dr. Cade asks that participants also have a blood test done (by another lab and at a cost of \$50) which should determine which protein is problematic. Mr. Privette can give you this information too. Blood serum is assayed for IgA and IgG antibodies to the following proteins: gliadin, gluten, lactalbumin, beta-lactoglobulin, casein and ovalbumin.

If you have already tried the diet you will not learn anything meaningful from the urine test. By eliminating gluten and casein from the child's diet, you have removed the source of the peptides. It can take a long time to build them back up to pre-diet (baseline) levels, and this is not advisable, especially if the diet has proven helpful.

## **What is Celiac Disease (CD) and Should I Test For It?**

"Celiac disease (also known as Celiac Sprue or gluten-sensitive enteropathy) is a chronic disease in which malabsorption of nutrients is caused by a characteristic...lesion of the small intestine mucosa. The lesion is produced, through unclear mechanisms, by protein constituents of some cereal grains". (J.S. Trier, 1993) Traditionally, doctors have suspected CD only when patients show poor growth, extreme gastrointestinal problems and fatty stools. It is now known that many patients with a sensitivity to gluten serious enough to damage the gut wall show no such symptoms!

In patients with CD, the intestinal wall is excessively porous; not only are nutrients improperly absorbed, but large molecules which should be contained by the gut wall are not. This could be the way in which improperly digested peptides pass into the bloodstream and then cross the blood-brain barrier. Thus, the speculation that CD is present in some autistic children who would benefit from a gluten free diet is not inconsistent with the opioid excess theory of Reichelt and Shattock.

Various experts on autism seem to have long ago dismissed the idea that gluten could be a significant causal factor. However, gluten exists as a "hidden ingredient" in many foods, medicines and even in the envelope glue we lick. It is possible that autistic children put on a so-called gluten free diet were inadvertently ingesting gluten in minute amounts. For those with full blown Celiac Disease, tiny amounts can be toxic; it is not so far fetched to imagine that in less severe forms of gluten intolerance, minute amounts could also cause harm.

When full blown CD is diagnosed, it can take more than a month on a gluten-free diet to see changes; again, it is not far fetched to assume that the same is true for people with gluten intolerance that have different outward symptoms. It may be then, that early researchers and parents who tried this intervention in the past simply gave it up too soon. Patients with full-blown CD often have terrible symptoms of gastrointestinal distress, fatigue, failure to grow or gain weight. Therefore, these symptoms are not ignored and the diet is changed when the child is relatively young. But it is possible that far less severe forms of CD exist and are, in fact, quite common. If so, these could go undiagnosed for years. Undiagnosed, the toxic effects of the ingested gluten could prove extremely damaging and could cause what is likely to be permanent damage to the central nervous system. According to Reichelt, there are fifteen opioid sequences in a single molecule of gluten!

According to an article by Dr. Alessio Fasano in a recent newsletter of the American Celiac Society:

In recent years there has been a noticeable change in the age of onset of symptoms and the clinical presentation of celiac disease. Because the typical symptoms of gastrointestinal dysfunction are frequently absent in older children, the diagnosis beyond the first two years of life is more difficult and often delayed. These cases are now regarded as having atypical or late onset forms of celiac disease.

Rimland and Meyer noted as long ago as 1967, that children with the highest scores on Rimland's E-2 Diagnostic Checklist also showed many gastrointestinal symptoms. It has also been suggested that CD is an auto-immune disorder with gluten stimulating increased synthesis of some antibodies in CD patients. Ruth Sullivan noted that "though few children with celiac disease have autism, it seems a disproportionate number of autistic children have celiac. Why? Does malabsorption of the small intestine prohibit vital substances (like serotonin...)

from reaching the brain? If so, why do not all 'classic cases' have celiac? Or do they? (1975)"

A disorder very closely related to celiac disease, and necessitating the same dietary intervention, is a skin disease known as dermatitis herpetiformes (DH). According to the newsletter of the American Celiac Society, "Dermatitis herpetiformes is the skin manifestation of gluten sensitivity and 70-80% of DH patients have coexisting damage in the intestine." In many cases DH sufferers have no outward signs of intestinal difficulty, and yet at least 70% actually do suffer from CD! DH appears as a bumpy rash, usually on the arms, legs or buttocks. It is extremely itchy and may also burn.

My own son had such a rash on his arm and inner thigh. This rash first appeared at approximately age 2 (around the age his autistic symptoms also appeared) and was diagnosed by our pediatrician and two dermatologists as severe eczema. All prescribed cortisone creams but the rash did not improve. It was so itchy that my son would frequently scratch until he bled. We removed all synthetic fibers, dressing him in only 100% cotton washed in soap that had no colors or dyes. Nothing helped.

Then, as mysteriously as it appeared, the rash went away. Around the time that I changed my son's diet I began giving him evening primrose oil, which was said to help eczema. I credited the oil and bought several bottles. Then I stopped using it and the rash did not reappear. I now realize that the cause of the improvement was probably not the oil, but rather the removal of gluten from Sam's diet!

Though I cannot have the tests run (because he is been off gluten too long) I am convinced that he was likely showing signs of DH, which were unrecognized by the doctors who saw it.

New blood tests show latent and sub-clinical cases of CD. Because even latent celiac disease will cause damage to the intestinal wall, it makes sense to have these tests run. The relevant tests involve screening the blood for celiac antibodies. The tests are called endomysial IgA, gliadin IgA and reticulin IgA. The blood test can rule out or suggest Celiac Disease. If CD is not ruled out it can

only be confirmed via intestinal biopsy. If a gluten free diet has already been implemented, these tests will not be valid. While these tests will not reveal a possible sensitivity to casein, they should certainly be done on children who developed normally for up to two years (and who are thus more likely sensitive to gluten). Additionally, many autistic children toilet train late, which delays the possibility of collecting a 24 hour urine sample. Not all labs are equipped to run these tests. If a local lab cannot do it, you might want to contact Specialty Laboratories, Inc., in Santa Monica, CA at 310-828-6543

Although no child will willingly donate blood, all four tests can be performed following a single draw. While it is doubtful that all autistic people will turn out to have celiac disease, these tests should be performed to rule it out. Certainly CD causes a leaky gut; if various proteins are being improperly metabolized, such a gut would provide a pathway into the bloodstream for these peptides. Clearly these tests should be added to the battery that children undergo when a diagnosis of autism, PDDNOS or atypical autism is made.

Intestinal Permeability tests also exist, and should be performed, if possible [see section on the DAN! protocol, below.] This test requires a patient to ingest a sweet drink provided by the lab performing the test, then eat nothing for several hours. This is followed by a collection of all urine for the next 24 hours. This test must be ordered by a doctor, and will show whether or not the patient has a "leaky gut." If the child is not toilet trained, a bag (obtainable from your doctor) can be taped used to collect urine at each diaper change.

## Sulfur-Transferase Deficiency

Preliminary studies by Rosemary Waring, of the University of Birmingham, UK, suggests an enzyme deficiency in autistic children [Shattock has reported similar findings in children with ADD and ADHD.] This abnormality effects the sulfur-transferase system. With insufficient phenol sulfer-transferase (PST), individuals have an extremely low capacity to oxidize sulfur compounds. Children with this enzyme deficiency are unable to fully metabolize certain foods and chemicals

that contain phenols and amines. PST is necessary to break down hormones, some food components and toxic chemicals that we encounter daily. If the enzyme is deficient, the body cannot detoxify the system--that is, it will be unable to render these substances harmless.

If this happens, harmful substances that should be metabolized (broken down) would build up to abnormal levels. These substances include serotonin, dopamine and noradrenaline. The children most likely to show this deficiency (based on her small sample size) showed normal development for the first 18 months to two years of life, and also show family histories of asthma, skin problems and migraine, as well as sensitivity to foods (especially wheat, milk and salicylates.) Many metabolic processes can be disturbed by phenolic compounds and cause many physical problems that may not have been previously thought connected to autism (excessive thirst, night sweating, facial flushing, reddened ears etc.)

There are some tests which can identify whether an individual has a weak detoxification pathway. However, normal levels of PST have not been established for children under the age of twelve. Dr. Waring has a test for children, which uses acetaminophen (Tylenol®) as a "probe" for finding weakness in this enzyme system. Testing does require a 24 hour urine collection, which can be a nearly insurmountable difficulty if the isn't reliably toilet trained. For more information Dr. Waring can be contacted at: The School of Biochemistry, University of Birmingham, Edgbaston, Birmingham, B152TT England. Dr. Waring doesn't currently have Internet access. Dr. Robert Sinaiko, a San Francisco specialist in Allergy and Immunology, is working on perfecting a test in this country. Hopefully, such a test will be available soon.

Unfortunately, there is not any standardized, recommended treatment for PST deficiency. Two approaches may be taken--you can try to increase the body's ability to detoxify itself, or you can try to decrease the toxic load to which you subject the system. Neither approach is 100% effective. To quote [Developmental Delay Registry](#) founder Kelly Dorfman:

Some parents have used diets that remove all known phenol components (such as Sara's Diet) to take the pressure off the PST-P system. While sometimes helpful, these diets are extraordinarily difficult to implement long-term, as naturally occurring phenols are in every food with color. Except in extreme cases, a diet reducing toxic load from the most concentrated sources...appears to be the best. That is...reduce juices (or limit to pear juice) and eliminate all artificial colors and flavors.

Unfortunately, no amount of intervention...can totally unburden the PST-P enzymes....That is why it is critically important to improve the efficiency of the faulty enzyme system while attempting to lessen the load. Several nutrients may help. They include Vitamin C, reduced L-glutathione and N-acetylcysteine. All of the antioxidants (including selenium and bioflavonoids) are valuable for detoxification in general.

--from *New Developments*, Winter 96-97, a DDR publication.

Autism researchers have been intrigued by the fact that a PST deficiency can cause the improper metabolism of some neurotransmitters (serotonin, dopamine and noradrenaline.) It has been known for years that autistics often have abnormal levels of serotonin, at least as is measured in the blood. but the buildup of serotonin may be less significant than another outcome of PST deficiency--namely, the effect this deficiency would have on the permeability of the intestinal lining. One outcome of an improperly operating sulfur-transferase system is insufficient connective tissue in the gut wall. Thus, this deficiency could be yet another reason (besides Celiac Disease and other gastrointestinal ailments) that the gut wall would be "leaky." As stated above, when improperly metabolized proteins (such as gluten or casein) are able to escape the gut lining into the bloodstream, they can cross the protective blood-brain barrier.

I noted above that my son's urinary amino acid tests reveal a deficiency in eight amino acids. Five of these are sulfur-carrying amino acids. I am informed, by Dr. Baker, that this is a pattern he sees very frequently in autistic patients. Because the sulfur-carrying amino acids are involved in the detoxification of the body of both exogenous and endogenous pollutants, disturbances in these systems indicate disturbed immune systems. Considering how frequently these children suffer from numerous infections and allergies, this is not an unlikely assumption. In some parts of the country immunological approaches are being taken with some benefits to autistic children, and it is possible that for some the cause of autism may be an auto-immune disorder.

Though it cannot yet be proven, there is good evidence that a diet that eliminates gluten and or casein may indeed be beneficial. In an unpublished (1993) manuscript, Waring and Reichelt state "We think that the demonstrated peptides may be central to the aetiology of the disease. Exorphins not only increase social isolation in animal models, but may cause CNS inhibition of maturation." Another observation is equally intriguing: "...because most bioactive peptides are found in different chain lengths, but with very similar activity, different peptidase defects would cause similar but not identical symptom profiles and peptide profiles." They believe that this indicates that such "effector peptides" would be the "final common path of several clinical subtypes involving different lengths of peptides. It would also suggest that other diseases may show autistic symptoms if peptides are involved, as is seen for coeliac disease."

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## **Gluten and Casein Free Products and Sources or... How to feed your family without going nuts!**

There is a large population in this country of celiac sufferers; they are experienced in food substitutions and can be a great source of information. Five organizations that have newsletters and lots of information are:

**American Celiac Society**

201/325-8837 (New Jersey)

**Celiac Sprue Association/USA**

402-558-0600 (Omaha, Nebraska)

**Canadian Celiac Association**

905-567-7195 (Toronto)

**Gluten Intolerance Group of Florida**

12733 Newfield Drive

Orlando, Florida 32837

Internet: Celiac@ispace.com

**Gluten Intolerance Group of North America**

P.O. Box 23053

Seattle, Washington

407-856-3754

**Celiac Disease Foundation**

13251 Ventura Blvd. Suite #3

Studio City, CA 91604

818-990-2354

*The Gluten-Free Baker Newsletter* is published quarterly, and gives recipes for sweet and savory baked goods. Write to 361 Cherrywood Drive, Fairborn, Ohio, 45324-4012 for subscription information.

To subscribe to the Internet Celiac mailing list contact [Mike Jones](#), the list administrator. All recipes posted to the list have been [archived](#), and can be seen by anyone with Internet access.

**Mail Order Sources**

David's Goodbatter--bread, cake and cookie mixes, 717-872-0652. Great chocolate cake mix.

The Really Great Food Co.--pancake, gingerbread, cornbread, pizza crust etc.,  
516-593-5587

[Ener-G Foods](#). Call for a complete list of products. They sell xanthan gum  
(essential for giving gluten free baked products the proper texture). 800-331-  
5222

[The Gluten Free Pantry](#) (EXCELLENT)--mixes for breads, cookies and  
pancakes, cakes, even bagels, 860-633-3826.

[King Arthur Flour](#) tapioca flour, white rice flour, potato starch flour, Jowar flour,  
xanthan gum. These flours are slightly more expensive than what you can get at  
your local health food store. 800-827-6836.

Pamela's Products, Inc.--Mixes for pancakes, very good (but expensive) cookies.  
These can often be found in health food stores, but they also run a mail-order  
business. 415-952-4546.

[Kinnikinnick Foods](#) has everything necessary, including ingredients, mixes,  
condiments and baked goods.

## Products Available in Health Food Stores

While the home baked bread recipes in More From The Gluten Free Gourmet  
produce loaves far superior to anything that can be purchased, there are times  
when you just have to buy a loaf of g-f bread. Ener-G (white rice, brown rice or  
tapioca) breads are generally found in the freezer section of your health food  
store. It isn't terrific tasting, and it's expensive, but toasted and "battered" with  
soy or canola margarine it is passable. It also "grills" when filled with Soymage  
"cheese". Note: most soy or tofu based cheeses contain casein. Soymage does  
not, and is available in "cheddar" and "mozzarella" style. Some of these breads  
are also yeast free, so if you are avoiding yeast read the labels carefully.  
Fearn's brand brown rice baking mix is available at health food stores, and even  
some supermarkets (in the flour section.) This mix makes very good waffles and  
pancakes. You can make extra pancakes and waffles to freeze. They "nuke" very

well. For those mornings when you can't get it together, try to find Van's brand frozen wheat-free waffles and pancakes. They're expensive but taste great and are wonderful to have in a pinch.

For those avoiding sugar, 100% Pure Vegetable Glycerin is a coconut based product that makes a good sugar substitute. It is very sweet, very expensive, a little hard to find and an acceptable sweetener on a yeast-free diet. Don't get less than 100% pure; lower grades are available for cosmetic uses, but not for eating! It can be used to sweeten foods, and can also be used to make a faux maple syrup by adding Frontier brand maple flavoring. Frontier flavorings are available at many health food stores, contain no alcohol or preservatives..

If you are going to make quick breads, cookies, yeast breads or muffins you will need a variety of flours. Quinoa is a good gluten free flour that adds good body to baked goods; if used alone it tastes rather odd, so use it as part of your flour, not all. Some celiac groups maintain that quinoa isn't gluten free, but most agree that it is a safe food. Soy flour is also good when used as part of a recipe's flour content, adding a slightly nutty taste and a bit of moistness. Brown and white rice flours are the basis of most gluten free baking. White rice flour is harder to find at times, since many health food stores have a "no refined products" policy.

Arrowhead Mills makes a very nice white rice flour; since almost all health food stores (and many supermarkets) carry this brand, you should be able to get the store manager to order the white rice variety. Asian grocery stores are also good (and cheap) sources for anything made from white rice, including flour! While Indians and Pakistanis might laugh at the idea that it is "new," [Jowar](#) flour has recently been stocked by various mail order houses as a gluten free flour alternative. The flour is made from sorghum and if xanthan gum is used, is interchangeable with wheat flour in most recipes. It can be found in Indo-Pak groceries, generally in larger packages (and thus cheaper) than is available from most mail order companies.

In general, you can't go wrong with the Gluten-free Flour of Bette Hagman (see references below.) This can be used as a direct substitute for white flour. The

Gluten-free flour proportions are given in the recipe section below. You should keep some of this mixture on hand at all times, as it works with nearly any recipe calling for white flour. To give breads the body and stretchiness you get with wheat, you must add either xanthan gum or guar gum. It can be hard to find; if your local health food store doesn't carry it you can order it from King Arthur Flour. Guar gum has a laxative effect for some people, so xanthan gum is generally preferable. It is expensive at \$20 a jar, but a little goes a long way as you only use a tsp. or two at a time. Potato Starch Flour is available in health food stores and shouldn't be confused with Potato flour. The potato starch generally found in the "Jewish section" of the supermarket works just as well. Baking powder should be gluten free. Some brands, such as Featherweight, are specified "gluten free," but others (e.g. Rumford) specify corn starch and are also acceptable.

Many health food stores stock Rice Pizza Crusts but most frozen pizzas, even those made with rice crusts and soy cheese, contain casein. Recipes for breads and pizzas can be found in the Hagman books (see below), and several of the mail order companies make excellent pizza crust mixes. For variety, use corn tortillas and the toppings of your choice, to make inexpensive individual sized tortillas (try topping with browned meat, beans, salsa and tomato.)

Vary the diet by borrowing from other ethnic cuisines that are rice based. Go to the library and check out cookbooks on Chinese, Japanese, and Indian cuisines (did you know most public libraries have a huge cookbook collection?) Even familiar foods, such as rice, are prepared very differently in different cultures. Arborio rice makes risotto, a delicious change from plain rice. Check out some books on Mexican cooking, where corn and rice together with beans can be used to create nutritious dishes that contain no wheat. Learn to thicken sauces with sweet rice flour (at Asian groceries) and marinate using wheat free soy sauce (health food stores.) Learn about the many uses of tofu and the products made from it. Excellent dried pastas in various shapes are made from corn, quinoa and rice and can be found at the health food store. Did you know you can make a

delicious crust out of cooked spaghetti? Make corn spaghetti, boiling only to the al dente state. Add two beaten eggs, mix it well, and place in a pie pan. Fill with whatever you like--browned meat with marinara sauce is good--and bake. Hol Grain brown rice crackers can be ground and make an excellent substitute for matzo meal. Organic brown rice cereal (the "Cream of Wheat type) also makes an excellent filler, breading or matzo meal substitute. I used it his Passover for gluten free "knaidlach" (matzo balls) and they were delicious.

Be careful to check all labels. For example, frozen French fries and "tater tots" generally contain wheat starch. Many prepared foods and sauces contain wheat, and other foods have gluten. Anything containing "modified food starch" is suspect. Rice Syrup, a common sweetener, usually has extracts from barley.

[Lundberg Farms](#) has a form of brown rice syrup that does not use barley enzymes, but when rice syrup is used as an ingredient in another product, there is no way to know its source.

Many people have asked about spelt and kamut flours--these are close relatives of wheat and are NOT permissible. Soy milks make good substitutes for dairy, but most are sweetened with barley malt or rice syrup that contains barley. Read the ingredients carefully. Vance's DariFree is delicious, and has a potato base; very few people cannot tolerate potatoes! Call A&A Amazing Foods at 1-800-497-4834. Available in a powder, it mixes easily and works very well in breads and other baked goods. It is also available in a liquid form. If these substitutes just won't "go down" at first, try mixing a little into regular milk. slowly add more until you are left with nothing but the substitute. If all else fails (and only then) Nestlé's Quick is gluten-free.

Beware of "fast food" restaurants: if breaded chicken or fish go into the same oil as French fries, the fries are not G-F! Gluten can transfer from a dirty griddle (for example, eggs cooked immediately after pancakes can be contaminated.)

Cross-contamination can take place at home, when one uses the same utensils in safe and then unsafe foods (e.g. spreading jam on wheat toast and then using the same knife or jam for g-f bread) or toasters. Caramel coloring is questionable;

if it is an American made product, the caramel is acceptable. That may or may not be true for imported foods. Hydrolyzed vegetable protein is used in many products (labeled HVP). Sometimes it is derived from casein.

Many people use Tofutti as a non-dairy "ice cream," but be warned, it is not gluten free. Rice Dream non-dairy frozen desserts are OK, but not those coated with carob or chocolate. Some baking yeast is grown on a wheat substrate---use Red Star or Saf brands when doing gluten-free baking. The Red Star yeast company will send you a booklet on baking without gluten--call 1-800-4 CELIAC and leave your name and address.

### **The Great Bread Machine Debate**

No, you don't *have* to go out and buy a bread machine. Will you be happy if you do? You bet! the difference in taste and texture between homemade g-f bread and what is commercially available will amaze you. the machine is pricey, true, but at over \$4/loaf, buying bread is not bargain.

Models change all the time, but two brands known for their good g-f bread results are those made by Zojirushi and Welbilt. both brands have programmable cycles that can be set to bake gluten free loaves. The recipe booklet that comes with the Welbilt has several excellent g-f recipes (this is the brand I own) and I assume the Zoj does too.

If you can take the time to make bread, it won't be punishing to be gluten free. While the store bought breads are only barely acceptable, the homemade versions really are good. Many of the books listed below can be found at public libraries, or for purchase at a health food store that stocks books (most do.) Bette Hagman's *More From the Gluten Free Gourmet* has bread recipes that have been adapted for today's bread machines.

### **Some Good Cookbooks**

*The Gluten Free Gourmet, More From the Gluten Free Gourmet* and *The Gluten Free Gourmet Cooks Fast and Healthy* by undisputed G-F Guru Bette Hagman

are published by Holt. All are excellent. Each has over 200 gluten free recipes for bread, cookies, pizza, chicken pot pie, cakes etc. It's also full of advice about adapting regular recipes and what to use as substitutions. If you can buy only one cookbook, make it one of Bette Hagman's.

Other useful and excellent cookbooks include: *Allergy Cooking With Ease* by Nicolette Dumke and *The Allergy Self-Help Cookbook* by Marjorie Hurt Jones. For those who are limiting yeast, *The Candida Control Cookbook* by Gail Burton is a very good source of recipes.

*Full of Beans* by Kay Spicer and Violet Currie has recipes using beans and bean flour. These "odd" ingredients make wonderfully moist and delicious baked goods. *No-Gluten Children 's Cookbook* by Pat Cassidy is available for \$25.50 from RAE Publications, PO Box 731, Brush Prairie, WA 98606. The *Practical Gluten-Free Cookbook* by Arlene Stetzer is available from Main Street Systems (608) 534-6730.

**There are MANY others--check bookstores and libraries or shop [on-line!](#)**

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## Where Do We Go From Here?

Everyone agrees that autism is a puzzle. It seems at times, that all the pieces are black and we are trying to put it together in the dark! Everyone has to do what they think is best for their children, and for their families. For forty years parents have been given false hopes and empty promises. There are still few definitive answers, and there are still lots of promises being made.

I hope that the reader of this paper does not believe that special diets fall into this category. I do not believe that dietary intervention will "cure" anyone (or at least, not very many.) But it can help, and it can help a lot. It probably won't help everyone who tries it. Should you decide to try, be serious about it and be scrupulous about it too.

But what else should you look at? If we all know now (no thanks to the late Bruno Bettelheim) that this disorder is an organic rather than an emotional problem, why has so little been done to find a medical answer? Fortunately, things are changing. In January of 1995, Dr. Bernard Rimland convened the first Defeat Autism Now! (DAN!) conference in Dallas, Texas. It was a gathering of serious researchers who want to find a way to help autistic children now, not in twenty years. A major undertaking of the group was the writing of a medical protocol to be used by physicians who treat autistic patients. Called "Clinical Assessment Options for Children with Autism and Related Disorders: A Biomedical Approach," it represents a consensus report of the participants. The protocol was written up by Drs. Sidney Baker and Jon Pangborn, and approved by all but one of the practitioner participants. It has recently been revised, and includes a list of doctors who are willing to use the protocol.

The DAN! protocol as it is called, is available from Dr. Rimland's organization, for a cost of \$25.00. It is a somewhat daunting document, but it is very well worth the effort to buy the protocol and go through it with your child's doctor. No one expects that parents will do every test in the protocol. But when you study it you will find those tests that seem most likely to give you information that is relevant to your child. It is a valuable document, and I highly recommend that you contact Dr. Rimland's organization, the Autism Research Institute. Their address is 4182 Adams Avenue, San Diego, California 92116.

I was lucky to have been one of four parents who were invited to join in the first meeting of the DAN! Since that time, Dr. Rimland has convened another conference aimed at training of doctors and informing parents. One of the other parents who attended both DAN! conferences, decided that it was time to do something positive to save our children. She and her husband started another organization, the [Cure Autism Now Foundation](#) (1-213-549-0500). This group is dedicated to raising money for badly needed, innovative research. It is vital that we all join this effort!