



Parents and Professionals "Why Does the Diet Work?"

(BBB Autism; PDF article #14)

Here is a simply written explanation of why the GFCF diet may help autistic children.

<<The theory is that many if not all autistic kids have a damaged intestine/gut - the damage may be there from birth but more likely comes from some immunological injury like a bad reaction to an immunization (not really sure - keep in mind this is mostly theory). Autistic kids seem to have weaker immune systems, and a lot seem to have digestive problems. Anyway, this "leaky gut" allows some food proteins to pass through into the bloodstream only partially digested - particularly the gluten from wheat/oats/rye/barley, and the casein from milk and other dairy products. These partially digested proteins form peptides which have an opiate-like affect (opioids is another term for them) -they can bind to the receptors and cause harmful effects in the brain (just like a regular opiate) - which either cause or magnify autistic symptoms. The opiates are a type of narcotic - there are receptors in the brain that they bind with to reduce pain, induce pleasure, but they also have harmful side effects. An example of an opiate is morphine or heroin.

So until we can figure out how to heal the "leaky guts" out there, many folks are going on the gluten free/casein free diets, and have reported good success with their kids. You can get a urinary test to see if the level of these peptides is high, which would show a need to at least try the diet. Note that this is not an allergy, and regular allergy testing will not tell you if there is a peptide problem.

There are also a few drugs which can block the opiate receptors before the opiates or peptides get to them. Naltrexone is one of these - that's why you might see this drug being discussed. However, studies have shown mixed results, so the theory is that the peptides and the receptors have a very strong attraction, that needs a stronger drug to overcome it.>>
(by Barb Byers)

This is a more complicated, yet more thorough explanation of the diet, written by a doctor. It also explores the relationship of the diet with the work being done currently by Johnson and Johnson:

<<there are some very interesting developments in autism research which are not yet published but have been presented in several meetings. Alan Friedman, PhD., is a chemist who works for a division of Johnson & Johnson. He was interested in the opioid theory of autism - first proposed by Panksepp, confirmed by Reichelt and Shattock - which held that children with autism had many abnormal peptides (small pieces of partially broken down proteins) in their urine, including casomorphine and gliadomorphin. This is where the rationale for the gluten-free, casein-free diet came from. Many children with autism (most but not all) do not seem to break gluten and casein down completely, but rather keep their metabolites casomorphine and gliadomorphin intact, which then get into the bloodstream (and therefore into the urine). Presumably this is because they have a leaky gut since normal people do not have significant amounts of these molecules in their circulation or urine. Many other abnormal protein fragments were found in the urine of these children, but the significance was not clear since the researchers did not have very high power equipment available.

Alan Friedman was able to use the multimillion-dollar technology of Johnson & Johnson to look into this area further. First of all he confirmed that almost all the autistic children studied had casomorphine and gliadomorphin unless they were on the diet. More importantly, he also found 2 other morphine-related compounds, dermorphin and deltorphin II, in the urine of these children. Dermorphin and deltorphin are compounds, which until now had only been found in the skin of poison-dart frogs in South America. Scientists had studied these frogs since they were known for their hallucinogenic properties - natives licked these frogs to get "high" and used them to tip darts to "stun" targets. These compounds turned out to be more than 1000 times more potent than morphine so were widely studied in the 1980s and early 90s since they were very different from the known morphine peptides. They bind to a different kind of receptor than



morphine or human endogenous opioids like the endorphins. Of great interest is the fact that it appears that these compounds are only found in the skin of these frogs when they are in the wild, but not when raised in captivity outside of their natural environment - in other words, it seems that it really is a bacteria or fungus on the skin which is making dermorphin and deltorphin.

So if autistic children have deltorphin and dermorphin, which have never been found in humans until now, it most likely is coming from a bacteria (or possibly a fungus) in their gut. The reason that it is clear that they are of "non-human" origin is that they contain a form of amino acid not found in mammals - a "D" amino acid instead of "L". D is for "dexter" or right and means that the amino acid is twisted to the right while all human amino acids are twisted to the left or "levo" amino acids.

Why do autistic children have these compounds circulating when "normal" people do not? There is an enzyme in the small intestines called DPP IV (dipeptidyl peptidase four) which seems to be responsible for breaking down morphine-related peptides in the gut and also plays a role in the immune system, especially in turning on T cells. Something is wrong with this enzyme in autistic children. At this point it seems that there may be some children who are missing this enzyme (maybe the autistic-from-birth subset) while there are other children who make the enzyme but who also have an inhibitor which makes the DDP IV very ineffective (the group who regress?). Rats who are missing this gut enzyme exhibit very abnormal behavior and finally die when fed gluten. It is quite possible that the "bug" producing the dermorphin and deltorphin is something that everybody has in their gut but these kids are unable to handle it because of lack of normal DPP IV function.

It seems as if there might be a 3-pronged approach to dealing with this problem. No one knows what the "bad bug" in the gut is at this point, but it certainly is possible that an antibiotic or antifungal might be able to knock down the amount (but we don't know which antibiotic or antifungal). Somehow replacing DDP IV or blocking the inhibitor might enable these children to break these abnormal morphine peptides rather than having them circulate. Blocking the opioid receptors in the brain so that whatever does get into the circulation wouldn't have CNS effects would be the other part. Deltorphin and dermorphin bind to different opioid receptors than morphine, which is why naltrexone is only a little effective in children with autism. There are some possible candidates for this, but none currently available (because there never has been a need for them).

When you look at what dermorphin and deltorphin do when they have been injected into animals, they interfere with memory, attention (can't filter out the "background" from the important stuff), behavior (causing hyperactivity as well as stereotypic activity), temperature control (lowers basal body temperature), and cause abnormal EEGs. Opioids which bind to the same receptors as dermorphin also play a role in auditory processing (although I can't find anywhere that these compounds have specifically been looked at for this). Sound familiar?

Johnson & Johnson plans to have a test available in the very near future to look at these compounds. There is a commercial lab, which for the past 3 months has been measuring casomorphine and gliadomorphin on a single 10cc urine sample (previously a 24 hr collection was needed or the sample had to be sent overseas). Prior to Alan Friedman's first presentation of his findings, they decided to measure dermorphin as a negative control along with the other morphine peptides, since it had never been found in humans. They were very surprised when the autistic children were all positive for dermorphin and thought that maybe they were doing something wrong, so they stopped marking where it was on the test results. However, those of us who sent urine samples on patients when the test first came out know where to find the dermorphin in the results if it is there. (They eventually will have this test result commercially available again at some point, but it is not clear when.) The test costs \$ 90 and it is doubtful that insurance will cover it since the lab clearly states that it is for research use only. Personally, I think \$ 90 is not too bad to find out if your child would benefit from a gluten-free, casein-free diet considering how much trouble it is to do the diet.

While the information about secretin (and it is not yet clear how secretin plays a role in this) certainly made a few people



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in the medical establishment think about autism as a biochemical problem related to the gut, I think that the medical establishment will be turned on its head when this information is published. Just the fact that Johnson & Johnson is involved will lend credibility to research in this area far beyond what has occurred in the past. I am incredibly excited about the possibilities for medical intervention and will keep everyone posted about new developments as they occur.>>
(by JE)

Here is another parent's explanation of why the diet might work from an allergy standpoint.

<<There are two reasons why this diet may be helpful for some children. Dr. Reichelt and Paul Shattock PhD (both from Europe) have hypothesized that some children are missing some enzyme that allows them to fully digest the proteins in these foods. Instead they partially digest these proteins down to peptides that look like morphine. Which might explain why our kids are "addicted" to some foods. (There is a general belief among those who believe in food allergies that we crave the foods that are bad for us personally.)

The other more general reason is that there might be a food intolerance or sensitivity (Feingold, Dr. Doris Rapp, etc.) It just so happens that gluten and casein are likely candidates for this kind of food allergy.

There are some tests you could do that might help you decide whether to try this diet or not. Dr. Robert Cade (Malcolm Privett) at the Univ. of Florida in Gainesville and Dr. Reichelt can do urine tests to see if your child has these morphine-like peptides in their urine. The test can determine the quantity of the morphine-like proteins but not the source (gluten or casein). For that, you had to do a blood test from Alletess Labs in MA that measured your child's immune response to gluten and casein. Based on the blood results, you might decide to eliminate one or the other or both.

Or you could do general food allergy testing on blood. Don't bother with scratch tests for food allergies since they are notoriously bad at detecting food allergies (except for anaphylactic reactions like to peanuts). The skin tests only measure histamine reactions--those that cause hives and are usually immediate reactions. Behavior changes due to food allergies can occur up to 2 days later. Blood testing can be done with very little blood on many foods at once. There are two labs that do this testing: Better Health (ImmunoLabs) in Ft. Lauderdale, FL and Meridian Valley Labs in Kent, WA. These tests are not cheap and may not be covered by insurance. However they will test around a hundred foods and spices and send you the results plus a suggested rotation diet.>>

(by Jean on the Autism List)

And finally, here is Paul Shattock's explanation of why we see the reactions we do from our children as we follow the course of a GFCF diet.

<<Of course we are learning about the effects of removing gluten from the diet all the time and certainly are nowhere near understanding all the consequences or processes involved.

We expect to see the effect that Todd Moody described after a period of time. When the person first goes gluten (or casein) free we do seem to get these exaggerated responses when infringements occur. Then, after a period of time - 3 months to two years depending upon the individuals - this doesn't happen any more and the odd infringement goes unremarked. What surprised us more was the exaggerated almost "allergic" response in the early days. I know we always bang on about the effects being basically of toxicity rather than allergy but there are lowish levels of anti gliadin and anti casein antibodies circulating in the blood of our children.

In the absence of continual gluten challenge they will diminish over time and infringements would not result in allergic type responses at all.



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At the same time, we visualize the situation as follows. The body cannot break down these peptides yet they are absorbed into the blood stream and dumped as quickly as possible into the urine. This rate of dumping is finite so levels build up and the peptides are stored in the tissues of the body. In the Celiac literature it talks of gliadin/antibody complexes persisting in the tissues for up to seven years. So, why not in autism?

When a person goes GF/CF the body takes the opportunity to dump these things in the blood/urine again. That is why we see them in the urine for some time afterwards and why GF/CF adults do not go "cold turkey" and have more drawn out but milder side effects. Little children do, more or less, go "cold turkey" as they don't have these levels in their systems to make the decrease more gradual. That's why these little ones have such serious withdrawal effects but they don't last long.

One of the major milk peaks (beta casomorphin 1-7) almost disappears from the peptide profiles within about two days after CF and re-appears just as quickly when milk is reintroduced. We reckon that a lot of people with autism have sort of spotted this and know that milk makes them feel funny so don't touch the stuff. With wheat it is more insidious so tends not to get noticed.

Our most recent trial included 3 boys who had been gluten free for at least two years. When gluten was re-introduced, one of the boys had a fit the next day but it could well have been just coincidence. However he was back GF the next day just in case. The other two showed no immediate effects whatsoever but over a period of months the parents and teachers independently reported increases in stereotypies, hyperactivity and poorer sleep patterns. I am not sure but I think they all went back to GF after a while.

We really don't know what we are playing with in some ways and such interventions are not just games. We can only remain vigilant and monitor our children and do our best.

By the way, we get a lot of instances where the benefits are non-existent to minimal to not worth the effort and we don't know why this should be (yet). Sometimes we know it is not being imposed too strictly for whatever reason and sometimes it is later found out that someone has deliberately been sabotaging the diet! Sometimes, however, everything seems perfect and yet nothing happens. I am aware of some parents who have persisted for up to two years (in Norway, not England) before seeing results but I am not sure that I could do that myself.>>

(by Paul Shattock)

From the gfcf mail list

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