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Autism and the GFCF Diet

by Tracy Noeske

(English 1102)

In the early twentieth century, autism was thought to be linked to the mental illness schizophrenia and was even blamed on the parents themselves. The outlook and hope for recovery was bleak, if not impossible altogether. Today, things have changed drastically. Not only has autism shown itself to be completely separate from schizophrenia and certainly *not* caused by the parents, every study conducted is bringing the world closer and closer to finding a true cause and ultimately a cure. A restricted, gluten-free, casein-free diet has been to many a pathway to just that. By eliminating gluten and casein from the diet, many children's symptoms of autism have disappeared or been reduced drastically. As a parent of a child with autism, that parent's duty should be to try any and every resource available to them. The gluten-free, casein-free diet has shown such dramatic effects that it seems almost irresponsible to ignore this potentially beneficial treatment.

Despite an occurrence in one out of every 150 children, autism is still something very few people know anything about. The Autism Society of America describes some of the characteristics of autism as:

Insistence on sameness; resistance to change, difficulty in expressing needs..., preference to be alone; aloof manner, tantrums, difficulty in mixing with others, not wanting to cuddle or be cuddled, little or no eye contact, spinning objects, sustained odd play, apparent over-sensitivity or under-sensitivity to pain, non responsive to verbal cues; acts as if deaf, although hearing tests in normal range, etc...

Not all children on the autistic spectrum will display these characteristics. In fact, most people have probably come in contact with someone of the autistic spectrum and have been unable to identify them as such. Many parents fail to take action when they sense something is wrong simply because their child has quite an abundant vocabulary. Unfortunately, many people are misinformed in that all autistic children cannot speak, when in fact many can and do, but other aspects of their personality land them on the spectrum instead.

In addition to the characteristics listed by the Autism Society of America, "anecdotal reports of disturbed gastrointestinal (GI) function and food intolerances from parents of autistic children have persisted since the early 1970's" (Johnson). In Johnson's article, she discusses a study of the GI tract of children with autism by Horvath *et al.*, who concluded "unrecognized gastrointestinal disorders... may contribute to the behavioral problems of the nonverbal autistic patient." "Constipation is the most common GI complaint, with up to 37% of ASD [Autistic Spectrum Disorder] children presenting with this problem" (Kirk).

In the past, many people would have never even considered that an occurrence of autism may be tied to issues in that child's gut. However, more and more people are beginning to recognize that some children with autism do have problems with food, which is in the end tied to the gut. Many of the parents of these children simply see them as picky eaters, but this is not always the case. Many children on the autistic spectrum have feeding problems including "selective acceptance of food or refusal to eat many or most foods with no known medical explanation" (Ledford and Gast). "The ASD children have a rigid pattern of interests and activities and an obsessive desire to cling to routines and order which is also reflected in food behavior. Repetitive eating patterns are common

and food choices are specific for texture, colour, and brand packaging” (Cornish). Because these children are so unwilling to adjust to changes in everyday life, it is easy to see how their need for routine could be transferred over to their food as well.

Still, the problem comes in the fact that many of these children crave the types of food that are causing harm to them in the first place. “Whiteley *et al.*...examined eating patterns in 100 autistic children...and identified categories of foods which were consumed excessively: cereal based foods, dairy produce and strongly flavoured foods” (Cornish). Cereal based foods and dairy produce are just what the gluten-free, casein-free diet removes.

So just what are gluten and casein? The average person knows them generally as wheat and dairy, respectively, though they are a bit more complicated than just that. Ives and Munro describe gluten as “a protein present in wheat, rye, barley and oats.” They describe casein as “a protein present in all dairy products.” While most people can tolerate gluten and casein just fine, some children with autism simply cannot. The effect of this intolerance, some people believe, is the appearance of the autism itself.

It’s a complicated process, but it all seems to come down to peptides in gluten and casein and how they are broken down in the body. In a 1979 article, Panksepp “noted that opiate administration in young animals produces abnormalities in social relatedness and behavior analogous to those seen in children with autism, and he proposed that components of autism may be due to excessive opiate activity” (Christison and Ivany). This excess opiate activity is coming from “two commonly ingested proteins [that] are known to break down into peptides that have opioid activity: casein and gluten” (Lewis). Ives and Munro explain that the opioid activity of these peptides is highly toxic. They go on to say that the average body is able take the peptides from gluten and casein and pushes them “through the gut and out of the system without any damage.”

The trouble for children with autism comes from something called a leaky gut. Some of these children have a problem with yeast overgrowth and yeast that excrete toxic by-products. “One of these toxic byproducts is an enzyme that allows the yeast to burrow into the intestinal wall...The yeast generated toxins literally drill holes through the intestinal wall and seep into the child’s bloodstream” (D’Eufemia P. *et al.* from McCandless). Remember those would-be harmless gluten and casein peptides? Well, instead of the body pushing them through the gut, “these peptides are able to leak through the walls of the gut and into the bloodstream. They then travel round the body and even penetrate the blood-brain barrier, where they cause all sorts of damage” (Ivas and Munro).

With all the havoc that gluten and casein are wreaking on the body, it’s obvious why a gluten-free, casein-free diet is worth a try. It’s non-invasive and extremely harmless. Parents of children with autism need to give it a chance.

Karyn Seroussi, a mother whose child benefited from the diet, explains that the first thing a parent should do is to “get the ball rolling.” Begin to order items that may be needed. Next, remove dairy from the child’s diet. “Removing dairy may be hardest for parents whose children self-limit only to foods containing dairy. The good news is that these children are most likely to show the fastest improvement, once on the diet.” After removing dairy, Karyn Seroussi suggests connecting with other parents. It may help to have a support group that understands and can relate. After this, it’s time to remove the gluten.

Parents should know that some children experience a “withdrawal” effect when being taken off of gluten, but given time and continuation of the diet, it should pass. Once gluten and casein have been strictly removed for some time, many parents still see very little difference. For some children the diet will, in the end, not be a big help. On the other hand, some children suffer from food allergies unrelated to gluten and casein. One way to check for this is to remove a certain food for a few days, then reintroduce it. Wait a few more days to see if there is a noticeable difference in behavior or health. If there is, the child may be allergic to this food.

The most important thing to remember about the gluten-free, casein-free diet is that it will not

work for every one. As Karyn Seroussi proposed:

Let's say that there are a thousand children with autism. Only one hundred of those receive an early diagnosis (before age two). Only ten of those have parents who find out about the diet soon after. Only five of those have parents who decide to try the diet. Only three of those have parents able to understand how to do it properly. Only one of those children is in the subgroup that will respond.

Also, in order for this diet to be effective, one has to be 100% diligent. This means reading labels and calling manufacturers in order to ensure that the food being fed to a child has absolutely no gluten or casein.

When it's clear that gluten and casein could be potentially poisoning certain children, some action needs to be taken immediately. Yes, there is evidence that children with autism are being affected by food, but does the gluten-free, casein-free diet actually help? Again, it will not work for everyone, but there are some brilliant success stories.

I went from being a babysitter to an applied behavior analysis (ABA) therapist for a young boy named Luke. At the time that I began therapy, Luke was two years old. He had begun developing as a typical infant, reaching all the milestones right on time, including language and social interaction. When he was about 15 months old and received his MMR vaccination, Luke began to regress. He no longer spoke any of the 25 to 50 words he had acquired, and eventually not only lost those words, but his ability to babble and coo as well. Between 18 months and two years, around the time he received his chicken pox vaccine, Luke really began to slip. He no longer made eye contact with anyone around him and would turn his back, preferring to be by himself. Pointing, a skill Luke had acquired quite early in life, also disappeared. His mother, Deborah, described a time where Luke would sit in a corner on his own, drooling and twirling a piece of fabric in his hands. For children on the autistic spectrum, that type of behavior is called a self-stimulatory behavior, or simply a stim. Two of the most important characteristics he began to exhibit less and less, according to his mom, were his sense of humor and his affectionate side.

Deborah's mother finally confronted her when Luke was two years old, telling Deborah she thought something was wrong. After taking him to his pediatrician, Luke's parents were told that his regression was simply because he was a boy and his mother was also pregnant; this was a time of adjustment for him. The doctor told them to wait; that things would be fine. Deciding to follow her instincts instead of the doctor's advice, Deborah began to research some of Luke's symptoms. Right away, the word "autism" appeared on her computer screen. Deborah spent night and day researching, some nights never sleeping at all.

Luke did not get much sleep, either. He would wake up in the middle of the night screaming and crying after thrashing about from what his mother called "night terrors." As Luke was a normally affectionate child, Deborah knew something was wrong when he would not even allow her to physically touch him in order to be of comfort.

One night, Deborah came in contact with another mother of a child with autism, who explained the gluten-free, casein-free diet and supplemental enzymes. Deborah figured that it could not hurt to try it, and decided to remove casein first. Once the milk was gone, so were the night terrors. Within one to two days, Luke's focus and attention span were noticeably improved, while his need to stim decreased significantly.

Deborah feels that the diet, supplemental enzymes, and ABA therapy went hand in hand to help cure her son of autism. Today, Luke is five years old and no one in his life, besides those closest to him, know of his past. He is ahead in school and is considered by his teachers and classmates to be "brilliant." He has many friends and leads a normal, happy, and healthy life. He was able to go off the diet and now can eat any type of food with no problem at all. Deborah explains that "the diet

helped give him back the ability to pay attention and allowed his gut to heal so that he could relearn all the skills he had lost.”

Karyn Seroussi tells her son, Miles’ story in her book, *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother’s Story of Research and Recovery*. Like Luke, Miles began developing normally until he received his vaccinations. After that, things went downhill. He no longer reached the milestones Karyn and her husband had seen in his past development. He could not point and would not respond to his name. Like Luke, Miles began to engage in stimming. He also experienced chronic diarrhea. Miles was eventually diagnosed with autism. He started with therapy treatments similar to what Luke experienced. After reading a book on autism that mentioned a potential allergy to dairy, Karyn tried removing it from his diet. Once the dairy was removed, Miles began to make some progress. It was at that point that Karyn realized how much Miles had craved milk since he was a baby. It was all he would drink and often drank it in excess amounts.

One day, Miles began to “shut down.” His parents could not figure out what could possibly be causing another regression until they received a note from his teacher the next day at school: “I forgot to let you know – Miles got hold of a piece of cheese yesterday morning. When we realized, he had already eaten most of it. Sorry!” Eventually, Karyn became convinced that gluten needed to be eliminated as well. A few days after it was taken out of Miles’ diet, he had his first normal bowel movement in months.

Miles was one of the children on the autistic spectrum who was found to have various other food allergies in addition to gluten and casein. Once these were all removed from his diet, just like Luke, Miles began to prosper. He eventually grew into a bright young boy with amazing intelligence and charm. Karyn realized that while Miles’ therapies and the diet worked together, it is the diet that opened Miles’ mind up once again:

As much as the discrete trial therapy and the physical therapy had helped Miles to catch up, neither of them would have been one-tenth as effective if he had not been on the diet. I simply knew this to be true. On the rare days when he had been contaminated with dairy, or even corn or soy, Miles’s therapy was a complete waste of the county’s money.

Not only are there personal stories to show the success of the diet, research is beginning to back it up as well. A study done by Knivsberg et al. took 20 children and placed ten on the gluten-free, casein-free diet, and used the other ten as a control group. The children were “matched pair-wise,” that is, they tried to partner a child in the diet group with a child in the control group that closely matched their characteristics. “A child’s total impairment consists of scores related to resistance to social interaction and scores for strange or unusual behavior.”

The children were followed for one year and then assessed. “In the diet group, resistance to communication and interaction had disappeared completely for eight out of the ten children during the experimental period.” The control group showed “an insignificant improvement.” After a year, seven children in the diet group were communicating in a “normal way.” Nine children in the control group still had problems after one year, and one had no problem with communication to begin with. Six of the ten children in the diet group showed a “significant reduction of strange behavior,” while the control group had an insignificant change. “Calculations showed a significant decrease in the autistic behavior of individuals in the diet group.”

The authors of this study, Knivsberg et al., stated that:
Behavioral changes were marked and significant for the group of children randomly assigned to the diet group. The development for these children was better than the development for the children in the control group... In the diet group, resistance to

communication, social isolation, and strange behavior decreased significantly, whereas willingness and abilities to communicate increased significantly.

This study is a perfect example that this diet can and has helped many children.

Many people assume that because these children are on a diet without gluten or casein their nutrition will suffer. This is simply not true. There are many enzymes available in addition to nutritional supplements. A nutritionist or a doctor who specializes in autism is the best source to go to when beginning this diet. They can provide helpful information and help select the best enzymes and supplements for a particular child. As with autism, each child is different and will benefit from separate regimens.

As a parent, it is important to never feel that all this work has to be done alone. There are numerous resources available. The internet has many great sites, such as <http://www.autismndi.com> for is the Autism Network for Dietary Intervention. The official gluten-free, casein-free diet support group is located at <http://www.gfcfdiet.com> and offers many free products, such as shopping guides for gluten-free, casein-free food and even an interactive CD-ROM explaining the diet and how it works. There are also great books available, including Karyn Seroussi's book and two books by Lisa Lewis, *Special Diets for Special Kids* and *Special Diets for Special Kids Two*.

The gluten-free, casein-free diet has been a life saver to many. Without it children with autism could be "lost" forever. This diet is too important a resource to simply ignore or postpone. Steps toward implementing the diet need to be taken as soon as information about the diet is received. There is simply no time to waste.

Works Cited

- Autism Network for Dietary Intervention. 2007. *ANDI*. 02 May 2007 <<http://www.autismndi.com>>.
- Autism Society of America. 2007. *Defining Autism*. 02 May 2007 <http://www.autism-society.org/site/PageServer?pagename=about_what_is_characteristics>.
- B., Deborah. Phone Interview. May 2, 2007.
- Christison, George W. and Kristin Ivany. "Elimination diets in autism spectrum disorders: any wheat amidst the chaff? (Treatment)." *Journal of Developmental and Behavioral Pediatrics* 27. (2006). *Expanded Academic ASAP*. InfoTrac Web. Coll. of D.P. Lib., Glen Ellyn, IL. 08 April 2007.
- Cornish, E. "Gluten and Casein Free Diets in Autism: A Study of the Effects on Food Choice and Nutrition." *Journal of Human Nutrition and Dietetics* 15. (2002): 262. *Health Source: Nursing/Academic Edition*. EBSCO. Coll. of D.P. Lib., Glen Ellyn, IL. 26 Mar 2007.
- GFCF Diet, The. 2007. *The GFCF Diet Official Website*. 02 May 2007 <<http://www.gfcfdiet.com>>.
- Ives, Martine and Nell Munro. *Caring for a Child with Autism*. London: Jessica Kingsley, 2002.
- Johnson, Teresa W. "Dietary Considerations in Autism: Identifying a Reasonable Approach." *Topics in Clinical Nutrition* 21. (2006): 215. *Expanded Academic ASAP*. InfoTrac Web. Coll. of D.P. Lib., Glen Ellyn, IL. 08 April 2007.
- Kirk, Patricia L. "Autism-associated disorders can lead to nutrition deficiencies. (Mental Health)." *Family Practice News* 36. (2006): 41. *Expanded Academic ASAP*. InfoTrac Web. Coll. of D.P. Lib., Glen Ellyn, IL. 08 April 2007.

- Knivsberg, Ann-Mari, Karl-L. Reichelt, Torleiv Høien, and Magne Nødland. "Effect of a Dietary Intervention on Autistic Behavior." *Focus on Autism and Other Developmental Disabilities* 18. (2003): 247-256. *Health Source: Nursing/Academic Edition*. EBSCO. Coll. of D.P. Lib., Glen Ellyn, IL. 26 Mar 2007.
- Ledford, Jennifer R. and David L. Gast. "Feeding Problems in Children With Autism Spectrum Disorders: A Review." *Focus on Autism and Other Developmental Disabilities* 21. (2006): 153. *Expanded Academic ASAP*. InfoTrac Web. Coll. of D.P. Lib., Glen Ellyn, IL. 08 April 2007.
- Lewis, Lisa. *Special Diets for Special Kids*. Arlington: Future Horizons, 1998.
- . *Special Diets for Special Kids Two*. Arlington: Future Horizons, 2001.
- McCandless, Jaquelyn. *Children with Starving Brains: A Medical Treatment Guide for Autism Spectrum Disorder*. N.C.: Bramble, 2003.
- Seroussi, Karyn. *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research and Recovery*. New York: Broadway, 2002.