



AUTISM/AUTISM SOCIETY ONTARIO
(YORK REGION CHAPTER) Autism Society
Ontario
PRESENT

THE E-NEWS

http://www.bbbautism.com/about_bbb.htm

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DE-MYSTIFYING THE GFCF DIET

Autism Interventions – Debate Rages On

Since I first started “surfing the ‘net’” to look for information and research on autism, I have come across a few topics that seem to push people’s hot buttons. Autism Interventions, without a doubt, is in the top three.

On message boards and news groups, debates rage over which is best, which one works, who has the ‘magic pill’ this month? **Debate is terrific, it can help you see someone else’s point of view and lead you to try something that you may not have thought of before. Thoughtful debate can lead to empathy and tolerance a couple of really great qualities to have.**

The GFCF diet is a very popular intervention for autism. Proponents believe that many cases of autism result from an immune-system dysfunction that affects the body’s ability to break down certain proteins and combat yeasts and bacteria. Many parents are convinced of the validity of dietary intervention for autistic individuals. Anecdotal evidence is, indeed, encouraging.

The purpose of this issue of the E-News is to present this topic in such a way as to de-mystify it. We have some terrific contributions from guests about their personal experiences, which contain information to help you get a clearer picture.

This issue is not about debate. We are not presenting pros and cons, but we *are* including an article from a parent who discontinued the diet and why, as well as the reasons why you might want to start. Our featured contributor this month has generously allowed us to peek into his life and the life of his child as they live GFCF. He has provided us with some great strategies and access to his personal journal, which details the “Changes in Attitudes and Changes in Latitudes” they experienced.

We are also thrilled to include contributions from authors Karyn Seroussi ("Unraveling the Mysteries of Autism and PDD") and Lisa Lewis ("Special Diets for Special Kids). These women have done much to help further research, while raising their own children with ASD, and they are an inspiration!

In talking to parents, who are our best source of information on this topic, we find that most of the children with the farthest measurable gains seem to be those who've enjoyed a nice combination of therapies, ones that have been enjoyable.

When I look at all the interventions out there, particularly the ones that parents swear by, I notice that they seem to have a common element. **All have a great deal of parent involvement.** Maybe that's the key. Maybe taking a viable idea and adding your loving touch to it makes it that much more successful... ☺

I hope you enjoy this issue and will join me in thanking the wonderful families who've shared their stories with us!

Bee Cool,



Liz

http://www.bbbautism.com/about_bbb.htm

Contact us at liz@deaknet.com

Are you wondering if your child might benefit from the GF/CF Diet? Take a few minutes to answer these questions!

http://www.bbbautism.com/candidate_for_gfcf.htm

BEE News Bits

Interested in Contributing to Upcoming E-News Issues?

Hi everyone! We love to receive contributions from our subscribers! Please take a look at the following list of potential topics and feel free to email us contributions. These could be in the form of:

- Short personal stories (1-2 paragraphs)
- Interesting links
- Recommended reading

Your ideas for e-news topics

Some potential future issues are:

- Acceptance and Denial
- How to Lobby for Effective Change
- Sensory Integration – part II
- Augmentative Communication
- How to help other parents with a new diagnosis
- Starting out – what to do
- Home Programming

- Autism and Enzymes
- Single parenting the child with ASD
- Autism and EFAs
- Going to the dentist
- ABA/IBI
- Dads' Issue
- Siblings
- Toilet Training
- Bits and Bites: A Potpourri of Information

Send ideas to <mailto:liz@deaknet.com>

Attention: Subscribers in the Greater Toronto Area!

We are expanding our Beginner's Guide to include clinics and private practitioners who perform diagnoses and assessments. Please send us: (answering as many questions as possible)

- ❖ The name of the place your child was diagnosed,
- ❖ The names clinician(s) involved,
- ❖ Year of assessment,
- ❖ The approximate length of time testing took,
- ❖ Names of tests used,
- ❖ Whether the information obtained was clear and useful,
- ❖ Approximate price and
- ❖ Whether a written report was included.
- ❖ Feel free to tell us if you think they delivered the news with as much empathy as possible!

This will be very helpful to parents seeking a diagnosis. Please reply to <mailto:liz@deaknet.com>. Replies are kept confidential!

Thanks!
BBB Autism and ASO York!



THE E-NEWS INTERACTIVE READER POLLS

To view the results of our first two polls, click here (or cut and paste into your browser): http://www.bbbautism.com/poll_1.htm

ARE YOU ON THE IBI WAITLIST IN YORK REGION???
Plan to attend the
PARENT INFORMATION NIGHT

Central East Preschool Autism Information Night for York Region

The evening will focus on the status of the Program and to overview IBI. It is an opportunity for parents awaiting services to ask questions and to dialogue with our Psychologist and our service providers. If you are interested in attending please contact the secretary at (905) 773-2362.

Date: MONDAY FEBRUARY 25, 2002

Place: Richmond Hill Public Library CENTRAL LIBRARY Meeting Room A & B1 Atkinson Street, Richmond Hill, ON 905) 770-0310 (south west corner of Major Mackenzie & Yonge St.)

Time: 7:00 - 9:00 pm

Please note: Our children our precious to us. We always substitute their real names for an initial or pseudonym (unless otherwise requested). Additionally, we never include last names of contributors (or any personal information) without permission.

BBB Autism and ASO York do not endorse any particular interventions, but we DO endorse your right to know about them! We strongly urge you to do your homework before starting any intervention. Here are some cautions:

- ❖ ***Any mention of 'cure', particularly if a large sum of money is mentioned in the next breath.***
- ❖ ***Anything that might harm your child – be smart.***
- ❖ ***Anything that states it works for all individuals with ASD.***
- ❖ ***Anything states it is the ONLY intervention you should try.***

If you have any trouble opening graphics or have any other questions, please let me know by email: <mailto:liz@deaknet.com>

A Typical Day In the Life of Jonathan – by Ronald

The room is full of six year olds hyped up as only a birthday party can get them. Balloons, streamers, party plates and bouncing balls decorate the hall. Most of the children are shoving pizza in their faces, smearing sauce on their cheeks, making their smiles into clown mouths and washing it all down with soda.

One boy at the table is eating from a lunchbox. He politely declines the offer of the pizza and chicken tenders. He pulls out an expensive waffle with tomato sauce and something orange on top of it, looks kind of like cheese. He eats one of the heartily and gets distracted by his friends.

Several minutes later a well-meaning parent clears the table of the food. Unknowingly she has just thrown out an expensive meal for that boy, and the only thing he can eat in the entire room. That boy is mine.

My son can't eat what others can.

He can't anything with wheat, oats, barley, rye or milk. He is on the Gluten Free Casein Free (GFCF) Diet.

I am always surprised at people's reaction to my son's special GFCF diet. "Isn't that a lot of trouble?" "How do you do it?" "What can he eat?"

"How can I not," I reply. If your child is sick, you give them medicine. This is the medicine he needs. I guess we have been doing this for two years now and it seems all routine, and really not that much extra work.

When we were first told about the diet, we freaked out a little, okay, a lot. It seemed so dramatic. After the detoxification stage, the majority of the extra work is done when we do our food shopping. We have a separate area in our pantry where we store only GFCF foods. He knows what snacks he can or can't have. It really isn't an issue now.

The other thing to remember is that when you are cooking for a GFCF diet that you prepare everything in separate pans. Cook the GFCF pasta while the pasta for the rest of the family is cooking. DO NOT stir them with the same spoon. This will cause cross contamination.

The attitude to take is to tailor several of the foods you will be putting on the table to be GFCF diet. In our home, we try to all sit down to similar meals at the same time. Just what makes up the meals is different. This way, all you are doing is adding two or three small side dishes to your preparation.

It is somewhere between 5:30 and 6:30 am when Jonathan wakes up. The house is dark and quiet. I think he likes the stillness. We have several GFCF cereals on a shelf in the pantry at ready access for Jonathan. Fruity and Cocoa Pebbles, Corn Pops and several organic cereals made from corn and rice. In the refrigerator, we usually keep two quarts of vanilla soymilk, chilled and ready for use. WestSoy and Silk are two of his favorites. He usually will help himself to juice while he watches TV or plays Nintendo.

Sometimes Jonathan will ask for several of his pancakes for breakfast. We will make a quadruple batch of his pancakes made from Arrowhead Mills All-Purpose Baking Mix ahead of time. We place the pancakes in freezer bags and they are marked GFCF pancakes. This way he can even enjoy them as a snack in the afternoon, for dinner, or for breakfast without too many hassles.

As a rule, Jonathan carries his lunch every day to school. This is a great help and keeps him from being tempted by "bad" foods. His lunch will contain either a juice box or a soy milk box, a peanut and butter (Fleischmann's margarine) sandwich made on rice bread or a Van's Wheat free waffle, fruit cup or apple sauce container, and a sweet of some type, GFCF cookies or a non-dairy pudding. We also provide him shelf stable snacks to have in his class at school for special and unexpected occasions.

When he gets home from school he usually has a snack, a bowl of cereal, a pancake or two or maybe some chips. Dinners are more fun. Tonight, we are having Fettuccini Alfredo with chicken and broccoli and garlic bread; nothing Jonathan could or would eat.

For his meal we will start by preparing the chicken. The chicken for Jonathan is sautéed in a little Fleischmann's margarine after being rolled in white rice flour or even your basic cornstarch. The chicken is cut in to medium to small nuggets and seasoned with salt, pepper and poultry seasoning. It only takes a few minutes, and his chicken is done and set aside. The rest of our chicken goes into a bigger pan and is seasoned with some Jane's Crazy Salt and garlic or garlic salt.

Next, come the pastas and broccoli. All three are put on the boil at once on three different burners. Tonight, we are using corn pasta for Jonathan. We will make sure to add extra water, so that the cornstarch will not make the water too thick. As we are waiting for the water to boil, we will take some Fleischmann's margarine in a small bowl and a little garlic salt into the microwave to melt along with a bowl containing some butter and garlic salt. On a cookie sheet we place several slices of regular bread along with two slices of white rice bread. Each is coated with its garlic sauce and put in the oven to bake.

Adding the pastas and broccoli to their pans as the water boils; it is time to start heating the Alfredo and spaghetti sauces. The Spaghetti sauce is one without wheat flour or modified food starches used as an emulsifier. The pastas are strained in separate colanders placed in bowls and put on the tables. We have to make sure we wash the colander out first very well. We have to make sure there are no gluten proteins on the colander. Then we strain the broccoli. When the Alfredo sauce is ready, we add the chicken and broccoli.

Tossing some cheese on our bread and soy cheese on his bread, the garlic toast is finished, as well as the rest of the meal.

The key to these extra steps is having the meal planned out and all of the components available. Do not be afraid to experiment. Learn how to cook the GFCF foods. Know what is GFCF and what isn't. And then experiment. Live and enjoy!

(Read Ronald's Journal by clicking here:

http://www.bbbautism.com/gfcf_ronalds_journal.htm)

Gluten, Casein and Cod Liver Oil by Ronald



What is gluten? Gluten is the glue stick protein that you find in wheat, rye, barley, oats and malt. It is what makes bread dough elastic and rise to be light and fluffy. It is ideal for pastas. Any flour or starch extract from any of these sources contains gluten. Gluten is everywhere it seems. It is in a lot of the foods we eat and do not even think about. Many times, wheat flour is added to our gravies, soups, and other liquids to thicken them up as an emulsifier.

Casein is an insoluble protein found in cow's milk and all milk products: milk, ice cream, butter and cheese.

Vitamin A is found in two different forms, solid and liquid. Solid Vitamin A is different in molecular structure than liquid. Your multi-vitamin and your cereal contain solid Vitamin A. Liquid vitamin A is found in fish oils, like Cod Liver Oil. I can feel you cringe reading that. I did, too.

Being gluten free, casein free and a good source of Vitamin A are the most important things you can do for your child with Pervasive Developmental Disorder. At first it seems like an impossible task. When you read food labels for everything in the grocery store you will find wheat flour, milk products, sodium caseinate, emulsifiers, etc on the labels. All of these food products must be removed from the home.

Bread – The Key question, Make or Buy? By Ronald



We started off making bread. We also tried making bread from the blending of rice flours, starches and Xanthan gum. I found the Oriental Grocery Store in town and they carry white rice flour, sweet rice flour, potato and tapioca starch. These were 99¢ a pound to a \$1.50 for the sweet rice flour. Xanthan gum runs about \$12 for half a pound. Several of the loaves made from these combinations were edible but were far from delicious.

Next, we tried some of the store-bought mixes. We ordered several bread mixes from Miss. Robens, The Gluten-Free Pantry, and picked several up from the local health food store. These mixes varied in price, anywhere from \$4.50 to \$6.00. Initially, we started baking the bread in the oven. The breads were very dense and crumbly. It was difficult to cut these in to sandwich slices. The breads molded quickly, with about a four-day shelf life.

For Christmas, my in-laws bought us a bread maker. This made making the bread easier, but it still had the problems with crumbling, molding, and slicing. It also did not rise as well as the old fashioned way you make bread. Removing the loaf from the cooking tube was also difficult. Either way, we were throwing out one loaf out of four.

I'll never forget my mother saying, "Oh making bread is easy." She went in and tried several of the tricks she learned from her mother to make the bread light and fluffy. When it collapsed in on itself like a black hole, we threw it out and smiled at the loss of a \$5 mix.

We finally found several frozen breads available at our local grocery store. The store has a special foods section catering to organic and special dietary food requirements. Food For Life has several wheat and gluten free rice breads. This bread is kept frozen and has a shelf life of over 2 weeks. I can tell you the exact length because it is eaten up well before it molds. Each loaf contains about 15 slices. The different flavors are White Rice (\$3.59 a loaf), Rice Pecan Bread (\$3.99 a loaf) and Rice Almond (\$4.39 a loaf). My son devours eats this. We make cinnamon toast, sandwiches and use it for pizza.

Another commercially available bread product is the Van's Wheat Free Waffles. These waffles come in regular and apple-cinnamon. We will make peanut butter sandwiches from the waffle. If we don't have any bread thawed, we even use them for pizza.

Recently, we discovered Arrowhead Mills Wheat Free All-Purpose Baking Mix. This mix runs around \$4.60 for a 24-ounce box. We use this to make anything from pancakes and some cakes. It is very easy to use, and everything turns out very tasty. One day we made pancakes for my son and gave them to my daughter (who is not on the GFCF diet). She thought they were delicious. You should have seen the look on her face when I told her they were made from the GFCF mix.

There is a recipe for an orange cake that was very good. Each box has a recipe book included. This includes recipes for biscuits, cakes, waffles and pancakes. We usually make a quadruple batch of pancakes and freeze them. This allows us to give my son a pancake as a snack at anytime.

- ❖ Arrowhead Mills, Inc., P.O. Box 2059, Hereford, Texas 79045
- ❖ Food For Life Baking Co., Inc., P.O. Box 1434, Corona, CA 91718
- ❖ The Gluten-Free Pantry, P.O. Box 840, Lastonbury, CT 06033
- ❖ Van's International Foods, Torrance, CA, 90501

Pastas *By Ronald*



There are several different alternatives in pastas. The two major choices are made from rice or corn. Both are different in texture to wheat flour pastas, but both are tolerable. The local specialty food store only had one brand of pastas on the shelf when I went to look. The DeBoles brand provides both rice and corn pastas in Angle Hair, Spaghetti and Fettuccini. The cost is the same, \$1.99 (U.S.) for an eight-ounce box. There is also elbow macaroni made from corn flour available, \$2.39 (U.S.) for a 12-ounce box.

It has been my experience that when cooking corn & rice pasta add extra water. The water will get thick and soupy from the cornstarch and rice starch. Remember cornstarch is used to thicken the juices from meats to make gravy. It only makes sense that it would thicken the boiling water cooking the pasta the same way.

DeBoles Nutritional Foods Corporate Headquarters, The Hain Celestial Group, Uniondale, NY 11553

The Journal Of Ronald E.



Preface

The purpose of this journal is to provide a written documentation to my son's progress and to record my thoughts and feelings.

My son has been diagnosed with PDD. Over the last two years, labels to describe his difficulties have ranged from autistic to Asperger's Syndrome. We recently took Jonathan to see Dr. Mary Megson. After a physical exam and looking at our family histories, Dr. Megson believes his problems result from improperly digested Vitamin A.

Vitamin A exists in two forms, a solid, which is in our multi-vitamins and our cereals and a liquid form, as found in Cod Liver Oil (CLO). Both our children were recommended 2 teaspoons of CLO a day.

One of the things this journal is aimed at is to chronicle my observations. The other objective is to give me a chance to express my feelings. Let me qualify anything I write here by saying that I love my wife immensely; however, she does drive me nuts! ☺

Please note: You can access this entire inspirational journal by visiting:
http://www.bbbautism.com/gfcf_ronalds_journal.htm

A Different Point of View:

IMPROVEMENTS, BUT NO MIRACLE CURE FOR US!

Written by "Pro"

When we first heard that our 15-month-old son had some 'soft' signs of autism, I immediately went out and read anything I could find on autism. The first book I found was the one by Karyn Seroussi in which she details how her son 'recovered' from autism using a special casein-free gluten-free diet. I got very excited, bought a bunch of CFGF recipe books and went headlong into the diet even though my husband, being a physician, questioned the science behind the diet. We figured it couldn't hurt him so why not try? At the same time, we started speech therapy, occupational therapy and ABA/IBI, and perhaps more importantly we changed the way we interacted with our son.

Within a week of removing casein, our son, who had stopped babbling at 12 months, started making sounds again. Next we removed gluten. Over the next few months, he began to sleep better, began to eat a greater variety of foods, began to walk and seemed much calmer over all. His bowel movements became more regular and softer and less painful to pass. However, even after 10 months on the diet he is still on the autism spectrum. No miracle cure for us.

The diet is very strict, even to the point of recommending a separate toaster for the CFGF bread. Luckily, I found a fair number of health food stores, including my local grocery store that carried CFGF foods. I became obsessive about my son's food and carried it with me everywhere including to Chicago for a family wedding. The diet is expensive but not impossible. There are many good recipes and I'm sure that my son is healthier because he was eating organic and homemade food with no preservatives.

We ran special 'allergy' tests that came back negative for casein and gluten which would seem contradictory but isn't if you understand the theory behind the diet. However the tests came back positive for many of the things he was allowed (corn, soy, pea etc). I felt overwhelmed because it seemed impossible to remove so much from his diet. We removed some of the offending foods for several weeks and saw no change in his behaviour. This made us question whether or not he needed to stay on the CFGF diet.

A month ago we began to challenge our son first with gluten and then eventually with casein. In fact one day, he accidentally drank an entire bottle of milk (not his). We kept it a secret from his therapists and even they saw no change in his behaviour. Now he is about 50% back on gluten and has some casein every day. He seems OK.

I don't understand exactly what has happened with my son but some theories are that he may have begun improving because of all the other therapies that began at about the same time as the diet. Also we had started adapting our interactions with him so that may have also contributed to his improvements. My pet theory is that by removing the foods he had self-limited himself to (cheerios, yogurt, milk, wheat raisin bread) he had no choice but to eat what we offered him with the CFGF diet. He probably felt better and calmer because he was eating better. Too much milk can cause ear infections, hard stools etc so again; he may have begun to feel better because milk was removed.

I don't regret having put my son on the CFGF diet. It gave me hope when all seemed hopeless. My advice to any parent is to be careful to attributing improvements to any one thing. Do everything in your power that might help but won't harm your child.

I'm sure that KS's son and others like him improved to the point that they were no longer autistic but I don't think the CFGF diet helps every child to the same extent. If you decide to go ahead with the diet, know what you are getting into. Document every change you see as well as what else has changed in your child's life besides the diet. Give the diet a trial period of about 9 to 12 months but if you're going to do it, no cheating. It's not something that should be done half-heartedly or randomly. Remember to read every label on every food. Best of luck.

We continue to see amazing changes in our son as he grows. We know that he loves us and is happy. It's enough for now but we continue to hope for much much more.

Frequently Asked Questions about Dietary Intervention for the Treatment of Autism and Other Developmental Disabilities

by Karyn Seroussi, Co-Founder, Autism Network for Dietary Intervention, Author, "***Unraveling the Mystery of Autism and PDD: A Mother's Story of Research and Recovery***" ***Click Here:*** <http://www.autismndi.com/faq.htm>

Other FAQs: <http://www.autismndi.com/faq.htm>

WHY DIETARY INTERVENTION FOR AUTISM?

*From the Living Sensibly Foundation
(Reprinted with permission)*

Written by Lisa Lewis, Ph.D.

Why would anyone think that a gluten and casein free (GF/CF) diet could help a child who has a developmental disorder? The idea of dietary intervention has its origins in 1980, when scientist Jaak Panksepp observed that autistic children had many traits in common with people addicted to opioid drugs. Addicts are often "in their own world," and frequently exhibit stereotypic behaviors (e.g. rocking). Generally, opiate addicts are insensitive to pain and have serious gastrointestinal problems. Panksepp proposed that autistic children might have elevated levels of naturally occurring opioids in their central nervous systems.

These observations led to research in Norway, Great Britain and the United States. In all locations, abnormal peptides were found in the urine of autistic children. These findings ultimately resulted in the postulation of what is now called the "opioid excess theory" of autism*. Briefly, this hypothesis suggests that autism and its associated symptoms result from the incomplete breakdown of peptides derived from foods that contain gluten and casein, and to excessive absorption of these peptides (due to a "leaky gut"). According to the theory's proponents, the presence of these peptides causes disruption to biochemical and neuroregulatory processes in the brain.

Recent research at Johnson & Johnson has confirmed the presence of these substances in the urine of autistic subjects. Perhaps more significant, another urinary compound was found and identified in autistic subjects. Known as dermorphin, this highly hallucinogenic substance was not found in the urine of any non-autistic person.

How on earth did this get into the urine of autistic children? One theory is that it is a fungal metabolite in other words, there is a fungal infection and dermorphin is the byproduct of the metabolism of that organism. This may be why some children with autism respond well to a low-sugar, anti-yeast diet and treatment with anti-fungal medications.

In the future the enzyme or enzymes that are inactive or insufficiently active to metabolize these common dietary proteins may be identified. For now, however, all these researchers have one thing in common all recommend that gluten and casein be removed from the diet of autistic spectrum children. Until researchers discover why these proteins are not broken down, removal of the proteins from the diet remains the only way to prevent further damage. Some children, who were diagnosed with autism and started on the diet before the age of two, have lost their labels and no longer need their services! For children who started the diet at a later age, this level of recovery may be out of reach. Even so, thousands of parents around the world will attest to the dramatic improvement that can be achieved by implementing a GF/CF dietary program.

*For more information see: "A Gluten-Free Diet as an Intervention for Autism and Associated Spectrum Disorders: Preliminary Findings," by Whiteley et. al. Autism: Vol. 3 (1), March 1999.

The Living Sensibly Foundation needs the help of parents of children with autism (and anyone else willing to help) to distribute the publication directly to other parents, to schools with special programs for children with autism to give to other parents, to doctors, etc. The publications can be obtained at no cost from <http://www.vancesfoods.com> at their online store or by calling 1-800-497-4834.

From THE ANDI NEWS, Volume III, Issue 1

When Can My Child Go Off the Diet?

by Karyn Seroussi

(Reprinted with permission from the author)

We were recently told this story by a mother in Massachusetts:

Four years ago I helped to start a support group in my area for parents doing the diet, and I was adamant that this was a lifetime treatment plan, with no excuses for “cheating” or giving up as long as the child was improving and doing well. My son responded extremely well to the removal of gluten and casein at age five, and by age nine, he had lost his diagnosis of autism and had done wonderfully in a regular third-grade classroom without supports.

In years past, any trace of contamination led to diarrhea, screaming, return of autistic behaviors, and multiple other problems, so we were very careful not to re-introduce those foods. However, last June my son ate some regular pizza and, presto, nothing happened. Had his gut healed? Had his immune system kicked in and repaired the root of the problem?

At that point, it seemed unfair to keep a healthy child on such a restricted diet, so we let him have ice cream, bread, cereal, the works. For at least a month, we congratulated ourselves on “fixing” the problem. But then things began to fall apart. My son started complaining that he was seeing things, and then that he was hearing voices in his head. By August, he had been hospitalized twice for violence and delusional behavior, and he was diagnosed with schizophrenia.

As you can imagine, we put him back on the diet, and he is slowly returning to normal. But he was unable to attend fourth grade with his friends, and he has been set back by many months in his development and education.

Unfortunately, this seems to be a common account. Lisa and I have heard similar stories several times, and it is always heartbreaking. One theory of this phenomenon is that the gut does indeed “heal,” keeping undigested gluten and dairy proteins out of the bloodstream, should they be re-introduced. However, if the child still has high IgG titers to gluten, it creates an autoimmune reaction similar to that in Celiac Disease, and before long it damages the lining of the gut wall. This is only a theory—it may be that something else is damaging the gut wall, and that, given enough time, a return to gluten and casein filled food will also mean a return to the leaky gut syndrome and the problems associated with it.

We would all like to let our kids eat regular food, I know. But let’s face it—the diet really isn’t that hard, once you get used to it. Although we have some ideas about it, we just don’t fully understand the mechanisms by which these foods are doing their damage, or how to fix it, and until we do, it is better just to hang in there.

One reason some parents take their children off the diet is because, after a trial period, they are not certain it has had any effect. Here are my thoughts:

1. For the kids who self-limited their diets or had bowel problems before the diet, giving up might still be a bad idea. Although this subgroup is not the only one to benefit from the diet, it describes the children who almost always respond well.
2. Are you sure your child is actually on the diet? Is there casein in the soy cheese or tuna fish? Is there malt in the breakfast cereal? What's really in and on the chewing gum? This is a good time to list every food that goes into your child's mouth, and do a bit of detective work. Just a trace can make a world of difference in your results.
3. Have you tried removing soy and/or corn as well? For some kids, taking away these and other allergens seems to be necessary to achieve results. Allergy testing, both by skin (IgE testing) and by blood (IgG testing) may yield some answers.

If you have considered the above and really want to stop doing the diet, after a fair amount of time (at least three months, preferably a year) this is certainly reasonable. We suggest proceeding carefully. First thing in the morning, give your child a nice big serving of Lactaid milk or another lactose-free dairy food *on an empty stomach*, then put him back to the diet for three or four days and watch carefully for any changes. If there are none, proceed with caution; recording any changes in your child's sleep patterns, behavior, and bowel movements.

For those of you whose children's autism is not coming from these foods, do not give up your search for answers. Test immune function, look at issues like yeast and bacteria in the gut, and perhaps even look into homeopathy, which seems to be helping many autistic children for reasons that are not fully understood. Remember, autistic behaviors are not a disease; they are a symptom, and there is no such thing as a symptom without a cause.

GFCF – Thoughts from Parents	
Khris	We did some preliminary testing with a DAN doctor, and even though no dairy products showed up in his blood allergy profile and gluten had only a slight reaction, we decided to go GF/CF as well as eliminating all the other foods that he reacted to. After 3 months of being off all offending foods we slowly rotated the least offenders back in (except for gluten). After 3 more months we rotated the rest of the offending food back in (except gluten and casein) with good success. When we tried gluten and casein independently, there was no noticeable reaction, so we slowly increased his intake and found that as long as we rotated all foods there was no problem. We continue to rotate his diet just by mentally tracking what he's eating and offering a variety.
Bernie	We tried the diet for about 6 months. I didn't see a significant change in A's behavior to continue.
Jean	Some people are also on this diet for digestive problems. We have not seen any behavioral changes in my son but digestive problems have decreased. We think he has an intolerance to dairy and have him almost 100% off this and have cut out a majority of wheat products along with sugar products. Just another thought about why people use this diet.
Kim	I don't know a whole lot about this area yet. But, I'm thinking that if my son has any sort of digestive/dietary problem, there would be some physical symptoms. He doesn't appear to have any health problems at all, never has. It seems like a lot of trouble (and more expense)

	<p>to do this diet. I would do it in a minute if I thought I had good reason. It seems like it's worked really well for a whole lot of people. Do most kids who respond to this also have physical symptoms that get better? How do you know (especially for a 2 yr.old) if it's the diet that worked or something else? This is something I have not yet researched fully, because I have too many other things to learn about right now. So I guess my question is, "Is there a good chance this will be helpful with my son's autism, even though he shows no other signs of needing a dietary change?"</p>
Dana	<p>We have been gfcf for over 2 years. I have three of my four kids with dietary restrictions. My son was VERY low functioning. It took him maybe 13 months to have all the gluten removed from his body and I saw some good things, but he was still very low functioning, although better.</p> <p>I learned that he does not tolerate basically any foods. So I started him on digestive enzymes from HNI. They help with most foods but not all, so he is still gf, but no longer cf, plus he still can't have cane sugar, some nuts and fruits, and most supplements.</p> <p>Now I am chelating him, plus my other kids also. He tolerates more foods now than he did before. I am hopeful that when we are finished chelating the metals out, he will be able to eat all foods without restrictions.</p> <p>The best thing is now with diet and enzymes and chelation, my son no longer qualifies as autistic. He started very low functioning and has a dx of "classic genetic Kanner's autism", the pediatric neurologist who diagnosed him told me "he might be able to live in a group home someday". Now he is basically a typical kid of a younger age than his chronological age. So I am very happy about that, it appears that he can be independent when he is adult.</p> <p>Some kids do just fine with enzymes and not diet. Some kids do just fine with chelation and not diet. Some kids do not benefit from diet/enzymes/chelation. But I am very glad I found what my son needed. Here is his story, as well as other stories of recovery, for anyone interested. http://www.autismchannel.net/dana/recover.htm</p>

LINKS

Kirkman Laboratories: Guide to Intestinal Health in ASD:
http://www.kirkmanlabs.com/Publications/Books/Gut_Protocol.pdf
ANDI: <http://www.autismndi.com/>
An Experimental Intervention For Autism Understanding and Implementing a Gluten & Casein Free Diet by Lisa S. Lewis, Ph.D. <http://members.aol.com/lisas156/gfpak.htm>
GFCF Diet and Food: http://www.bbbautism.com/dan_gfcf_diet.htm
Nutritional Approaches to ASD/PDD: http://www.bbbautism.com/nutrition_contents.htm
BBB Autism E-News; Chelation Issue: http://www.bbbautism.com/volu_2_iss_5_chelation.htm
The Living Sensibly Foundation: <http://www.livingsensibly.org/index.html>
GFCF in Canada: http://www.bbbautism.com/gfcf_canada.htm

Interested in Information about Epsom Salts and ASD? Join us in the tub!

E-mail <mailto:liz@deaknet.com> for a parent guide on this topic!



RECOMMENDED READING – BY PARENTS



Unraveling the Mystery of Autism and Pervasive Developmental Disorder by Karyn Seroussi
ISBN: 0684831643; Simon and Schuster (dietary intervention for autism)

Diet Intervention and Autism Implementing the Gluten Free and Casein Free Diet for Autistic Children and Adults - A Practical Guide for Parents by Marilyn Le Breton ISBN: 1853029351;
Jessica Kingsley Publishers (dietary intervention for autism)

Special Diets for Special Kids by Lisa Lewis ISBN: 1885477449; Future Horizons (dietary intervention for autism)

New! Special Diets For Special Kids TWO, by Lisa S. Lewis, Ph.D. ISBN: 1885477813, Future Horizons, Incorporated

Is This Your Child?: Discovering and Treating Unrecognized Allergies in Children and Adults
by Doris J. Rapp ISBN: 0688119077 Morrow, William & Co

Biological Treatments for Autism and PDD by William Shaw, Great Plains Laboratory Inc; ISBN: 0966123816

The Yeast Connection Handbook: How Yeasts Can Make You Feel Sick All Over and the Steps You Need to Take to Regain Your Health by William G. Crook ISBN: 0933478240 Professional Books/Future Health, Inc

WHERE TO BUY PRODUCTS

Gluten Free Pantry locations: <http://www.glutenfree.com/stores.htm>

Miss Roben's Online: <http://www.missroben.com/>

Ener-G Foods: <http://63.249.18.35/Index.tmp>

Kinnikinnick Foods: <http://www.kinnikinnick.com/welcome.html>

Glutino: <http://www.glutino.com/english/index.cfm>

Special Foods: <http://www.specialfoods.com/>

Juice Plus +: <https://www.juiceplus.com/>

Note: Inclusion here is not an endorsement by BBB Autism/ASO York

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- Art Therapy** ~ Nancy Wood, Art Therapist **TUESDAY, MARCH 5, 2002**
- Siblings of Children with Autism** ~ Victor Predo, TRE-ADD **TUESDAY, MARCH 26, 2002**
- Autism & Sexuality** ~ Deanna Pietramala, Leaps & Bounds **TUESDAY, APRIL 9, 2002**
- Social Skills** ~ Deanna Pietramala, Leaps & Bounds **TUESDAY APRIL 23, 2002**
- School Discipline & The Exceptional Student** ~ Lindsay Moir **TUESDAY, MAY 7, 2002**
- Behavior Management** ~ Deanna Pietramala, Leaps & Bounds **TUESDAY, JUNE 4, 2002**

ALSO:

Finalizing details on:

- 8-week Behavior Management Courses
- Hanen's More than Words Course

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**CONTAIN PRACTICAL INFORMATION BY PARENTS FOR
PARENTS**

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1. Halloween
2. Epsom Salts
3. Pros and Cons of telling your ASD child his/her diagnosis
4. How we advocate for our children

AS ALWAYS, WE LOVE TO HEAR YOUR SUGGESTIONS AND INPUT!

Past Issues

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