Forum

A child's journey away from autism

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Abstract

In the opinion of many parents, autism is a heavy metal and viral insult on the body of a young child. This insult affects the social and relational development of the child. Although mainstream medicine believes that there is no cure for autism, many parents are finding that bio-medical intervention can reverse symptoms of autism in their child. One mother tells the story of how early dietary and nutritional intervention and chelation helped her son progress beyond symptoms of autism. The story spans a 7-year period of time covering her pregnancy, when she discovered there was something wrong with her son, how she researched the area and how she facilitated her son's emergence from the autistic spectrum until today. This mother shares her resources and tips for helping a child with a neurological condition.

Keywords: autism, pervasive developmental disorder (PDD), developmental delays, ADD, ADHD, chelation, gluten casein free diet, (digestive) enzymes, Feingold diet, RNA therapy

Nathaniel Block is almost six years old (picture taken December, 2005). He is a beautiful boy with husky blue eyes and white blonde hair. He is charming, friendly, playful and smart. He will be attending public Kindergarten next September. Nathaniel's history is unique in that, at one point, he had many, many pervasive symptoms of autism including food allergies and gut issues. Today, you would never be able to tell this was part of his history. After 4½ years of intensive bio-medical, occupational and other therapies, he is indistinguishable from his peers. This is not to say that Nat is neurotypical because one out of six (or 17%) children under the age of 18 years are affected by one or more developmental disabilities that have an impact on cognitive function, language or learning ability, emotional state, sensory and motor function, a variety of behaviors, or physical growth (CDC 2004). Nat is still too young to know whether he will be a part of this statistic, but he no longer is among the children classified as having pervasive developmental delay (PDD) or autism. One thing is for sure. Nat is a strong and determined child and is interested in his own health, well-being and recovery. Nat's story began before he was even born.

After trying to get pregnant through *in vitro* 3 times while holding down a high stress job as in-house counsel at a large investment bank on Wall Street, I finally quit trying to get pregnant. Six months later, with a couple sessions of acupuncture, I found myself pregnant naturally. Four months prior to getting pregnant I got a Diptheria/Tetanus shot in the Emergency Room for a small cut on my finger. At that point, I had no knowledge of the issue of mercury in vaccines or the connection of mercury and autism. I had no clue that I would be haunted by the possibility and reality of autism in my own child.

The pregnancy was uneventful except for the fact that Nathaniel was breach and couldn't be turned. The only other event of note was the two jabs of RhoGAM. I received one at 8 months pregnant and one at the time of birth. I had always been a big sushi eater but only ate cooked tuna during my pregnancy. At this point, I had no idea about the connection between mercury and fish. In 1999, the government had not begun to warn pregnant woman not to eat fish. I don't think I ate too much fish, but I probably had tuna four to six times a month—sometimes a lot more, sometimes less. I didn't have any mercury fillings, but had one (along with my gold fillings) for about six years which I had removed probably two years prior to getting pregnant. Nat was born by planned C-section ten days before his due date and got a commendable 9 APGAR score. He did have slight jaundice.

At two weeks, Nat got the first of his childhood vaccine—Hepatitis B. One month later he got Hib and Pneumococcal. One month later he got DTaP and Polio (IPV). Six weeks later, he got DTaP again, Hib again and Polio again. Six weeks after these shots, he got DTaP again, Hib again, and Pneumococcal again.

At this point he was almost six-months old and every thing was fine with him except I thought he didn't really turn his head as much as maybe he should and he didn't really vocalize (but I didn't realize this until later). Nat had met all his milestones of sitting and crawling and he was a good eater. I breastfed Nat until 9½ months but he also was supplemented with formula. We introduced rice cereal after four months and foods starting after six months. Before his first birthday, he was eating yogurt, cheese, turkey, fruit and some veggies. As for the vocalizations, he screeched rather than cooed. I called him "the squeaker"

doi: 10.1588/medver.2006.03.00114

because he didn't have the intonation that an average baby would have.

At one-year old, he was administered the MMR and Varicella vaccines together. On this date, the pediatrician wrote in her files "waves, walks, babbling, loves books, Baby Einstein." Three months later, at 15 months, the pediatrician wrote "imitating a little bit, follows instructions rarely, no animal noises, no body parts, some pointing… once and then stopped, loves music, responds to games, babbles but not in context, funny noises, mom wonders if hearing is off. Needs hearing evaluation, if hearing is normal, needs developmental evaluation."

Sometime between 12-months and 16-months Nat developed chronic, smelly diarrhea. We would change his diapers ten times a day. He had only a couple words. Although he walked at 11-months, sometime between 12- and 18-months, he started tripping and falling a lot. He was extremely active and not engaged at all. He was in his own world. At music class he would run around the periphery of the room oblivious to everything except a fan in the corner. Then all of a sudden he would make a high-pitched scream and come crashing through the circle of singing mothers and children and crash his body into any mother. It didn't matter that it wasn't me, and it usually wasn't. His cheeks were always a ruddy red at this point. At 18-months the pediatrician wrote, "Understands well but does not speak much; no permanent words yet; no mama, no dada; please call to discuss." A month later I called in about a rash on his back. Rashes were a frequent occurrence at this point, but they didn't seem to bother him.

At 19-months I took him to a speech therapist. From a telephone conversation with her, the pediatrician wrote, "Rooting reflex, unsteady, balance is off, significant drooling, hypotonic, carries tongue in front, hyper extending/arching back, walks on tip toes. Recommends a neuro-evaluation. I agree. Left message for mom."

At this point, I was frantic because I knew something was very wrong with my child, but I didn't know what. He stopped pointing for what he wanted. In fact, he couldn't point. He could say "no" at this time, but he couldn't say "yes." He would hand-lead me to indicate his needs. He couldn't make eye contact anymore, either. In a move of desperation and being totally unfamiliar with the autism area thus far, I took the advice of a friend with celiac disease and started taking wheat and dairy out of his diet. Finally, I run a stool test for gluten and casein intolerance. The results indicated that his antigliadin IgA for gluten was 198. Negative is less than ten. His antitissue transglutaminase IgA for gluten was 84. Negative is less than ten. His anti-casein IgA antibody was 88. Negative again was less than 10. In a conversation with this gastroenterologist who specialized in celiac's disease, he told me, "I don't know what is going on with your child, but do yourself and him a favor and take him off of all wheat and dairy right NOW."

I immediately began making sure all gluten and casein was out of his diet and his stools immediately began improving. My nanny and I noticed the red around his anus disappeared and his balance dramatically improved as well. There was more babbling and there was less flushing of the cheeks and no incidents of spinning with his eyes pinned or head banging (although he didn't head bang on a daily basis). Nat also had more receptive and expressive language and volunteered a new word "key."

I started research on the Internet. I kept coming back to "autism." These were the symptoms that most closely matched the behaviors of my child.

Around this time (19-months old), I took Nat to his first Developmental Pediatrician appointment. She noted that "His mother feels relieved as Nathaniel was seen at the Regional Center for an evaluation recently. She was told that he had only speech delay and 'not to let anyone tell you he has autism.' This was of some concern to her because Nathaniel had some toe walking, spinning, some decreased eye contact, shaking of the head back and forth, and liked to be in small spaces." Frankly, it was not in the best interest of the Regional Center to diagnose any child with autism as they would be responsible for the cost of even more services. Multiple friends who have children diagnosed with autism were told by The Regional Center that their children did not have autism. The Developmental Pediatrician recommended speech therapy, occupational therapy, and a neurological evaluation. She noted delays across the board in all areas of development assessed.

In early April, Nat's little brother Declan was born. All was well with Declan except that he was the most colicky baby ever. From about 6-weeks old until about 10- or 12-weeks old, Declan's colic was unbearable to the family. The child was miserable. I exclusively breastfed Declan and my pediatrician recommended that I go on "The Elimination Diet." On this diet I could only eat a limited number of foods to start… lamb, turkey, millet, squash, pears, potato, rice and olive oil… and salt. It worked! Twenty four hours later he was an angel. I had to maintain a slightly expanded version of this diet for the next 10½ months while I breastfed. Declan was extremely casein and soy sensitive. He did not tolerate any formula very well. It was only when I started him on rice milk with protein powder at 10½ months that he slept 12 hours through the night for the first time in his life. He continued this pattern for the next couple years. Declan did not ever have wheat, directly or indirectly until he was 3 ½ years old.

Declan received the Hep B vaccine at 2-weeks old. At 6-weeks old, he got the DTaP, Hib, and Polio. He received the pneumococcal and Hep B at 8-weeks old. At 4-months, he received DTaP, Hib, and Pneumococcal. At 6 months old, he got DTaP, Hib, and Pneumococcal again. At 9-months old, he got Polio and Hep B again. And, 1-year, because of all I had learned from Nathaniel, I elected to not give Declan the MMR. I did give him the Varicella. Multiple doctors, who had reviewed Declan's lab results performed when he was 1 year old, agreed that not giving him the MMR probably saved his life. I also got two RhoGAM shots with Declan but these shots had minimal mercury. I did get a flu shot in my first trimester with Declan.

For Nat, I was getting speech therapy services twice a week through the Regional Center and occupational therapy once a week. The speech therapy didn't seem to make much of a difference but the occupational therapy was pivotal in evoking speech. Through movement, Nat really began to talk. The occupational therapist was very open to the fact that Nat was on a gluten-free/casein-free diet and felt that this really was facilitat-

doi: 10.1588/medver.2006.03.00114

ing his progress compared to his peers with whom she was also working.

Just prior to Nat's second birthday, my nanny had a cold sore. Although she was extremely careful, Nat got herpes around his eye. This was horrible because Nat just couldn't get a break. It was one issue after another, and why he would get herpes "through the air" was not clear. From later testing I realized that he had very weak viral immunity and this weak immunity is probably why Nat to had many recurrences in the ensuing months. We used Valtrex® (Valacyclovir HCl) and would protect his face from the sun. It was hard to get him to take the Valtrex® because the taste was so awful.

Six months after our first appointment, we went back to the Developmental Pediatrician. At this point Nat was 25-months old. She noted that Nat had "made very good progress [in speech] with many single word responses and imitation of two to three word utterances." Nat had about 150 words at 2-years old. He still was leading by the hand and not pointing. He still was unable to use the concept "yes," verbally or non-verbally. At this point, Nat had been on the GF/CF diet for five months. As his mother, I felt that the lion's share of his progress in speech was from the diet, as facilitated by the movement (i.e., occupational) therapy. I noticed that Declan was a very different baby than Nat. Declan was very demanding of attention; whereas, Nat was easy and did not imitate or really do much. I was beginning to see that there were differences from the beginning even though things really didn't get bad until Nat was around 16- to 18-months old. The Developmental Pediatrician noted that Nat's relative strengthens were gross motor and receptive language, even though they were still delayed. Nat was still "significantly delayed" in fine motor and expressive language, as well as visual comprehension, level of play, and he had low tone and motor planning issues. She also assessed Nat using the DSM-IV criteria for autistic disorder. Of the twelve diagnostic criteria, Nat had difficulties in five areas and was too young to be assessed in two other areas (i.e., failure to develop peer relationships and marked inability to initiate or sustain conversation). Because he had difficulties in five areas, he met the diagnosis criteria for PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified). Even though not able to assess conversation, the Developmental Pediatrician did note, however, that Nat's circles of communication were not frequent or elaborate enough for his age and recommended a therapist for this as well.

My pediatrician alerted me to NAET (Nambudripads Allergy Elimination Tehniques) for Nat's food allergies. NAET is an allergy elimination technique using acupressure to reprogram the body not to react to a particular substance. It is a form of energy medicine. I would take Nat to NAET every Wednesday and every Wednesday afternoon Nat would have diarrhea. An unintended benefit of this treatment was that Nat's eczema went away. For so long, Nat had ruddy red checks and a dry scaly chin. After 5 or 6 treatments for basic food allergies, I looked at him one day and saw that beautiful china white skin I hadn't seen in so long. I feel NAET had a beneficial (but hard to describe) effect. Even though I used NAET to clear food allergies, including wheat and dairy allergies, I wasn't going to remove Nat from the GF/CF diet because of NAET. I wasn't sure the treatments would be totally permanent. It is my experience years later that NAET, BIOSET and NMT are totally effective and beneficial, but not necessarily permanent.

In March 2003, when Nat was 2-years and 9-months old and Declan was 1-year old, I went to my first DAN! (Defeat Autism Now) doctor. She ran a battery of tests that showed many nutritional deficiencies. Both kids had extremely high antimony and aluminum in the hair, and Declan also had high mercury. Both kids had strep and other pathogens in the gut and were deficient in the good bacterias. Declan's organic acid urine test was worse than Nat's. Almost all of Declan's indicators on the whole test were far out of the normal range. Nat's indicators were mostly out of the range as well, but not as bad as Declan's. Both had indicators of very low B-12, kidney stress, deranged fatty acid metabolism, deranged carbohydrate metabolism, abnormalities in the citric acid cycle, oxidative stress, deranged neurotransmitter metabolism, stressed detoxification indicators, and intestinal dysbiosis. Nat had so many food allergies that it was highly likely that he had leaky gut. Nat had many viral issues, too. Of note, his measles titer was 3½ times the reference range. He also had herpes, a need for digestive enzymes; his myelin basic protein was a bit elevated, and the varicella titer was only slightly high. A battery of other testing confirmed the compromised health status of both of my children.

I tested myself at the same time. I had "off the chart" mercury in my hair, but my body was handling the toxicity much better than the bodies of my young children. I had food allergies as well. I made an appointment with Dr. Jane Hightower, the nationally-known internist at UCSF who broke the story about mercury in fish. She noted that the hair test was a valid and accepted test for looking at heavy metal poisoning and that the levels of mercury in my hair (taking into account my RhoGAM shots and fish consumption) put me at risk while I was pregnant and breast feeding for neurologically adversely affecting my children. I was one of the 1 in 6 women who had high enough mercury to neurologically affect my child.

My first DAN! doctor required that, in addition to the GF/CF diet, her patients not eat soy. I took Nat off of all hidden soy. This made a huge difference in his eye contact. The week before I took soy out of his diet, the teachers at school told me that Nat really did not make eye contact with anyone. After the weekend and three days after removing all hidden soy from Nat's diet, the same teachers said, "Well, he seems to be making fine eye contact so that is no longer an issue." They were astounded at the rapid change. Under the guidance of my first DAN! doctor I also started heavily supplementing with vitamins, minerals and probiotics to make up for deficiencies in my children's bodies. Six months after starting this protocol, I noticed that their hair tests appeared to be a mess. Both my children were excreting a lot more metals in their hair. Antimony, aluminum, tin, arsenic, cadmium and lead were all popping up. For Declan, mercury was coming down as measured in his hair. Nat's hair tests were never as dramatic as Declan's, but antimony, aluminum, nickel and tin were all elevated. Also, four months after beginning supplementation, Declan grew incrementally. Since birth he was always in the 25th percentile for height. I always thought this seemed too small given the stature of his father's and my family. Also, it seems that siblings of children with autism sometimes have growth issues. At about

doi: 10.1588/medver.2006.03.00114

four months after starting supplementation for Declan, he grew from the 25th percentile in height to the 75th percentile. He has always maintained somewhere between the 50th and 75th percentile in height since then.

As part of my own treatment, the DAN! doctor started me on Alpha Lipoic Acid once a day and oral Allithiamine. This was causing me huge yeast issues which I had never had in my life and was not prepared for. Also, I had two occasions of severe stomach cramping. On the first occasion I went to the hospital because I didn't know if I was having appendicitis. It was as bad as labor cramps. I attribute this to possible redistribution of mercury to my gut at a time my probable body burden of Mercury was still high. Alpha Lipoic Acid and Allithiamine on their own shouldn't cause this type of reaction. I stopped this protocol and proceeded to do a lot more research on chelation before I would be willing to detoxify myself again or my children. I wanted to find the safest chelation protocol before I would proceed.

The fact that I got ill with supplementation made it harder for me to convince my husband that working with a DAN! doctor and doing bio-medical intervention was in the best interest of our children and might possibly cure our son. Bio-medical intervention can be a point of contention between spouses and certainly was for me and my husband. Because the government and Western trained medical doctors do not espouse bio-medical intervention for autism, one spouse often feels that parents doing bio-medical intervention are irresponsible or chasing a pipe dream. My husband justified what I was doing by deciding that it was a way for me to deal with my own anxiety and probably was not harmful to my children. The rift between parents that the disconnect between accepted autism protocols and effective autism protocols causes does affect a child's ability to be recovered from autism. If parents choose not to do bio-medical or other alternative treatments for autism, the prognosis is most likely that that child will always be autistic. The reality is that many children of parents doing bio-medical intervention have recovered. My husband has outwardly disapproved of everything I did for my son on a bio-medical level and even fought me on it, but ironically he let me do it all.

I wanted to chelate Nat, now 3½ years old, and had done substantial research through books, consultations and on the Internet. One of my primary resources was the Autism-Mercury chat group on www.yahoogroups.com. After reading his books and communicating with Andrew Hall Cutler, Ph.D., the moderator of this group and a mercury expert, I felt that his chelation protocol was the most conservative, and safe. I knew that the younger you start, the shorter you would have to chelate and the more chance of a full recovery, so time was of the essence. Andy Cutler performed a file review for my doctor of all the tests I had done on my kids to date and recommended, among other things, the Feingold diet. This particular diet was key to Nat's next developmental jump.

At this time, Nat was attending Marindale, a school for children with special needs. To qualify for this State-funded school, a child must be less than 15% in speech and language. When Nat entered in September he was probably just above 15th percentile. My OT and I fought to get him in because we wanted him to be supported and to continue to receive special services. But, by April 2004 before the school year had ended and after starting the Feingold diet in January 2004, Nat was 95% in speech and language. They could no longer keep him there. He was required to leave within a week. The administration at Marindale recommended that Nat be placed back into his regular preschool immediately so that he could be with his peers who were actually talking to each other and communicating and playing together.

Under the Feingold diet, we eliminated artificial colors and flavors and salicylates. Nat immediately stopped laying around on the floor, got potty trained, had a further language explosion and started using more complex language. We didn't really eat artificial colors or flavors at the beginning of the diet, so the elimination of salicylates itself was significant. For lunch at Marindale I would pack organic berries and after lunch he would be laying on the floor spaced out. Artificial colors, flavors, which are petroleum based products, and salicylates (a natural anti-pesticide occurring in some fruits which is chemically similar to artificial colors and flavors) have to be detoxified by the liver. If the liver is already under a lot of pressure, this added pressure might be too much for the body and cause symptoms such as hyperactivity, bedwetting, spaciness, ADD, ADHD, etc.

The Houston enzymes were the other intervention (started in October of 2003) which I feel propelled Nat's development while in Marindale. I had read Karen DeFelice's book, *Enzymes for Autism and Other Neurological Conditions*, and the experience of starting enzymes was just as she stated in the book. There was a 21-day adjustment period probably caused by die-off and detoxification in which behavior and gut issues were exacerbated. Both children were bouncing off the walls and had variable stools. After the 21 days, they both were sleeping better, calmer and happier—just as predicted by Karen DeFelice in her book.

An interesting thing happened with Declan around this time. He was about 14 months old. He had had severe, itchy eczema around his neck and it was not getting better. My husband said "I know you hate Western doctors, but you need to take him to the dermatologist. He is miserable." So I did and she prescribed a series of steroid creams. However, when I'd back off the cream, the eczema would come back. I recalled that with NAET, Nat's eczema had gone away. I found a NAET practitioner in my neighborhood and called for an appointment. He said he had never worked on kids but he'd give me two free appointments. I said I'd show him how the other guy worked on kids. His muscle testing showed that although Declan had never had wheat and hadn't had dairy in probably six months (i.e., mother's milk or small amounts of formula), he was weak to wheat and dairy. The first week he cleared wheat in a 20 minute, tapping on the back, acupressure appointment that he performed on me as the surrogate for my child, who I was physically touching. The next day 60% of the eczema was gone. A week later, we did the same treatment for dairy. The next day 100% of the eczema was gone and never came back … and I am writing this 2½ years later.

I had a couple NAET treatments around this time and once, while being treated for allergies to my dog, I went from a violent allergy attack to clear breathing during the 20 minute appointment even though I had my head face down in a cradle. It

doi: 10.1588/medver.2006.03.00114

was incredible to feel the actual allergy symptoms quickly and completely leave my body.

As soon at I got the news from Marindale, that that Friday was to be Nat's last day, I called his old school and told them we were ready to come back. At the end of the last year, they recommended that I hold Nat back one year but were happy when I said I was going to send him to Marindale. They said that he could come back as soon as he was ready. No problem. When I called to ask that he be admitted on May 1st, they didn't want him there. They had numerous reasons. The first was that he wouldn't be ready for the year end circus performance. I had learned that I am my child's only advocate and if I didn't stand up for him, no one would. I said, "Well, since we are holding him back one year and he has already performed once in this circus last year, he will be better prepared than any other child there as he will have a second time to practice what he already knows." Then they said, "Well, the other children will be thrown off if another child is introduced into preschool so late in the year." This time I responded, "Well, these children are 3-years old and 3-year olds are some of the most flexible, forgiving humans on the face of the earth. Also, these are all neighborhood children who know Nat and who Nat knows so it will not be such a big transition for these kids or Nat." Then they threw out the idea that it might not be in Nat's best interest. At this point, my blood was boiling. This was preschool for goodness sake. I said, "I am Nat's mother and I know what is in his best interest more than any one on this planet. I believe it is in his best interest to be in his peer group at school. Besides, five professionals from Marindale who work with children with special needs and have a cumulative experience of over 85 years all believe that he should be placed back in a mainstream preschool right away."

Nat was doing great at this point. He was now almost four years old. He was still delayed but he was holding his own. He was not delayed enough to be in a special school. In fact, he wasn't in the autism class there. He was in the highest functioning class at Marindale. But, he was still not nearly neurotypical.

I was ready to start chelating Nat and Declan. I got on the Internet autism chat groups and got the names of the best, most reliable DAN! doctors in the country. I would go anywhere. The one stipulation from my husband was that the doctor must be a M.D. and Western trained in a mainstream medical university. Dr. Usman, hands down, fit this bill. In fact, she had also run the Pfeiffer Clinic in Chicago and had been on the cutting edge of treating children with metabolic difficulties for years. I made my appointment and traveled to Chicago with my two children and their nanny in July 2004.

I spent the morning at Dr. Usman's clinic and she examined both children and reviewed their medical files, which were each a couple inches thick. She listened to their history and reviewed their many labs. She expertly distilled all this information and made recommendations for some adjustments in the supplementation. She said they were ready and in shape to be chelated and wrote me a prescription. Although Transdermal DMPS had just become available, I asked her if I could chelate with oral DMPS according to Andy Cutler's protocol. I wanted to use a protocol that had been being used for a long time, one which I had studied and been familiar with and one which I believed to be extremely conservative given its low and tight dosing schedule. Dr. Usman was familiar with Dr. Cutler's work and agreed to this protocol for my children. I felt a sense of relief that I was in competent hands and could finally begin to detoxify my children.

In the airport on the way home from Chicago, I accidentally gave Nat a juice box which I thought was pear juice, but which was actually apple juice, a salicylate. It was like Dr. Jekyll and Mr. Hyde. He started chewing through his shirts as he used to do at Marindale. His shirt was immediately soaking wet and I had to change it. We got onto the airplane and Nat could not sit still. This reminded me of a gluten infraction after a child has been on the GF/CF diet for a while. Once the body was clear of the offending foods, just a little bit of the food could set off a disastrous set of events. Nat started bouncing off the bulk head, sliding under his seat belt and bumping into the guy next to him. Luckily I had my nanny there so that she could take care of Declan while I tried to restrain Nat. It got to the point where I had to physically, but gently, restrain him. Everyone in the airplane around me was extremely nice and sympathetic as they could see this was not just an undisciplined child. The woman across the aisle started praying out loud for me. She told me I must be a saint, for God does not give us things we cannot handle. I wanted to cry. Finally after about a two hour struggle, Nat fell asleep out of exhaustion.

At the end of July 2004, I started chelating. This was not ideal as school was starting soon and Nat was going to be going through the initial stages of chelation in school. Because every child's situation is different, I will not go into the specifics of the protocol I used for chelation. Each parent should work under the supervision of an experienced doctor if they are going to chelate themselves or their children. The most crucial aspect of chelation is the timing of dosing and the vitamin and mineral support. I will, however, relate the benefits and pitfalls and the general progress I saw from chelation. To start, Round 1 was great. Nat was more focused and more applied at task. However, on the first day of Round 2, Declan had a reaction to the chelation agent I gave him and it concerned me enough that I decided not to use the DMPS again for Declan, or for Nat and me for awhile. So, for the next 20 rounds, the three of us used only alpha lipoic acid (ALA) as a chelator. Again, I would like to reiterate that I would not even give your child ALA if you are not under the supervision of a qualified doctor. If proper dosing and schedule is not followed, there is the risk of redistribution of mercury and heavy metals rather than elimination of these dangerous metals. I know this from reading as well as my own experience. Please be careful.

For Nat, the first ten rounds of chelation brought more engaged and complex speech. With both chelators (i.e., DMPS and ALA), he was more sound sensitive, biting, spacey, and tantrumy between rounds of chelation. He was having stool accidents but then getting to the potty. He also started laying on the floor again and spitting, just as he had done prior to going on the Feingold Diet. At Round 7, Nat had an incident of herpes on the eye and stool smearing. He had had a few incidents of stool smearing prior to going on the Feingold Diet as well. I attribute this to gut flora imbalances. So again, these are old behaviors that had reemerged after a long time of improved behaviors prior to chelation. I believe that the ALA and some NAC I was giving were beginning to create a yeast problem. By

doi: 10.1588/medver.2006.03.00114

Round 8, between rounds he was starting to put his head in the sand again at the park and had diarrhea. By Round 10, he had the red ring around his anus and I knew I had to start getting aggressive with an anti-yeast campaign. I have only used natural anti-yeast agents. All three of us had yeast and I had known from the internet support groups that around Round 10, yeast would start to become problematic. I think this issue was compounded by the fact that we were all doing ALA only, a sulfur compound known to possibly create yeast in the mercury toxic population. Also, on Round 10 Nat's glands on the side of his neck, which are always a little bit swollen, were more swollen. He was soaking his diapers at night. This is generally viewed as a positive sign—a sign of detox. Also, he was getting a recurring dry patch on his face next to his mouth. Nat's usual activity of getting into my space, hanging on me, leaning on me, and not initiating his own activity were being exacerbated by the chelation process. But, his mental processing was up a notch. For example, he asked me what the word "insert" meant and he then said, "So, what does "outsert" mean?" Of all the negatives with chelation, no behavior ever came about that we hadn't seen in Nat before chelation.

During Rounds 11 through 20, we saw a lot of soaking wet pull-ups in the morning and lots of urine and stool accidents. Shirt chewing, dilated pupils, and visual stimming were also prevalent. He was refusing to participate in school as well. Around Round 13, Nat had a red bumpy rash all over the trunk of his body. On the positive side, Nat was becoming more jealous and affectionate. He was building more with his toys; whereas, before he only knocked things down. He was getting his clothes on better. Also, Nat started Tae Kwon Do at the same time he started chelating. I watched as Tae Kwon Do got more and more difficult for him and he became more engaged with the pieces of tape on the floor rather than with what was going on in class. Nat's Tae Kwon Do teacher, whose own child had autism, was talking to me as if Nat had autism. It was interesting because his autistic symptoms had been long gone until the beginning of chelation, when he started spinning more, spacing out more, and becoming less engaged in what was going on around him. By Round 20 he was getting better at Tae Kwon Do. At this point, he was actually participating 85% of the time and only stimming once or twice. His coordination was improving again.

Because the behavior was getting so bad and the yeast so problematic, I started up with DMPS/ALA for Nat (and myself) on Round 21. I kept Declan on ALA only. With this combination, Nat's lips were a little bit red. By Round 24, Nat started having good days in school again. He rode the tricycle, which he hadn't done at all that year. Because of how bad things had gotten for a while, I had the occupational therapist and speech therapist from Marindale come to Nat's nursery school to observe him. They noted that he wandered during free time and didn't apply himself. Also, they noted that he did not really know where his body was in space and had vestibular type issues. Round 26 of chelation marked the first time I didn't have to participate in tiny tot Tae Kwon Do with Nat to keep him engaged. This was truly liberating for me as I didn't have to hold his hand and do snake pulls myself and act like a cheerleader to keep him going.

At this point, I had my first assessment with at a home-schooling neurodevelopmentalist program called *Help With Learning* (www.help-with-learning.com). *Help With Learning* is a wonderful program in which highly qualified specialists assess the child using tools from many different disciplines and create a home program for the child. The benefits of a home program are that the child gets a little bit of very consistent therapy every day and you don't have to spend hours in the car taking your child for 50-minute sessions here and 30-minute sessions there. Because of the consistency, it is very effective. Because parents are doing it themselves, it is very economical. Through this program, we started a strict discipline program at home. This discipline program consisted of having a car seat up in the boys' rooms. If the children did not listen when we asked something of them, we would automatically put them in the car seat for 3 to 5 minutes for the 3 year old and 5 to 10 minutes for the 4 year old. The idea was that if we started to negotiate with them or count to three, then we had behavioral issues rather than pure compliance and tuning in. Nat was starting to get his clothes on without a problem and listening intently the first time. The discipline program gave us a lot more leverage with the children to get done the million things we needed to do every day. Marilee Coots, the neurodevelopmentalist, had a point! If we made allowances for our kids with disabilities then we are discriminating against them. They have to learn to survive equally as well as any neurotypical child and if we don't require them to take care of themselves to the best of their ability, even if it is hard for them, then we are reinforcing a sense for them that they have special needs rather than helping them to learn to overcome them.

Round 30 of chelation was concurrent with Declan's birthday party in April 2005. We were 9 months into chelation. At this party, Nat was indistinguishable from his peers. He was totally interacting with the children and responding to the puppet show. It was the best day of his life so far! He was far more social than he had ever been even before chelation. The next day, as I was driving down the highway and heavy tears of joy were streaming down my face…. "I did it," I cried out loud. I had found the way to get Nat out of his shell. We still had a long way to go but we were on the road to recovery.

At some point in chelation, Nat's breathing patterns at night improved. He used to always have a very labored, strange breathing pattern at night, but at one point in chelation his night breathing became normal.

In Rounds 31 through 40, we saw a continued strong cognitive development. At Round 33, one mother in Tae Kwon Do said that Nat's changes since she saw him there were "outstanding." At Round 35, he had a rash on this trunk again and was spitting a lot. He woke up dry and all of a sudden he was ready for big boy underwear at night. He had become so cute and interactive. He was delighted about things I was doing and he started using the term "may you this and may you that" to be polite. He was able to blow bubbles all of a sudden and had better conversation. He was very interested in playing with other children but he didn't have the right social skills to break into groups, so he still had a hard time. All this time, he still had the sucking reflex at night. There were other infantile reflexes he still had as well, which were further indication that his system was still immature. He still liked to lean and put pressure

doi: 10.1588/medver.2006.03.00114

on his head. Also, he still had the occasional OCD (Obsessive-Compulsive Disorder) behavior, but we could usually reason him out of this behavior or merely point out the behavior and ask him to stop, and he would.

Rounds 41 through 50 marked continued improvements. Nat stopped head shaking by Round 41. He was also getting better about not shoving food in his mouth. He still had motivation issues. At summer school, the teacher had no idea that he had any "issues" and said he was the brightest child in the class. We still were dealing with alternating normal bowel movements and diarrhea. He still had periods of OCD behavior. I started a couple rounds of HBOT in a 1.3 ATA soft-sided chamber. I only got in nine sessions of HBOT so I have no opinion as to this particular intervention. At my neurodevelopmentalist quarterly appointment, she noted that Nat made a year of progress on auditory processing in four months. I also started introducing goat milk with enzymes to see if the kids would tolerate it. I was getting them ready for the school year next year. At Round 47, something amazing happened. For the first time ever, Nat did not lean on me when he was holding my hand and walking with me. It was the first time I wasn't tripping over his feet or pulling him up or getting dragged down. It was an absolutely amazing feeling to walk with my child and have him hold his own body up himself. The next round he wanted to scribble with his crayon. This was something he had never before done.

Round 51 corresponded with Nat's first week of school at a two-year Kindergarten program at a Waldorf based school. I noticed a new interest in pretend play at this time. I had been so excited all summer than Nat was going to go to a new school and was particularly excited that it was a Waldorf school where they focus on the development of the child from a very organic point of view. At the first interview for school, things were not looking so good because my husband and I were so at odds with each other as to how to handle the interview. This was early in the summer and we wanted to talk about Nat's developmental issues without setting off alarm buttons. I asked my husband to let me do all the talking. He came in late and started telling them how Nat couldn't do this and he couldn't do that and how he himself was not creative and was unable to write or draw and had a hard time in school as a kid. We did not come off very well. After not hearing back from the school for a good while we made some telephone calls and were able to secure a new interview. At this point, six weeks after the first interview, Nat was more centered and so were we as parents. This interview occurred after Round 36 of chelation. Based on this interview, Nat got into this school. I had been furiously chelating him all summer to get him ready for school in September and I chelated him right up until the day school started.

Before Nat had even been there a day, my husband said I hope Nat lasts at school and they don't kick him out. I couldn't believe he would even think that way. It wasn't very supportive of Nat on an energetic level and it was just a bad vibe. Two days later the teacher called and said that she couldn't see him being able to stay at the school. I knew that I could make it work if she just gave me time. I needed about a month. I offered to pay for an aide if it was really too tough for her, which she indicated it was. She said he was perfectly charming and sweet, but that he needed to be one-on-one with the teacher and they didn't have that type of resource. She said that he did not sustain independent play on his own and he was too peripheral. I knew these were old traits. I was trying to figure out what was going wrong because Nat was performing above this level but had regressed some how. I realized that his vitamin levels, particular Vitamin B-6 had gotten too high. I cut all his vitamins back. It would take a while for his body to adjust. At the beginning of the second week of school, the teacher called to say, "So, how about if next Friday is Nat's last day but I will need an aide until then." I was devastated. I was just sending out invitations to the first fund-raiser for my new not-for-profit to raise money for autism. It was a stressful night because I was embarking on a huge ordeal and Nat's and my life were getting turned upside down. My friends were sitting in the kitchen stuffing envelops with me and I said to the teacher, "Why should next Friday be his last day, why wait?" "Oh, because I am not ready to let him go," she said. "Ok," I said. Then she said "Well, can I have him until this Friday?... Oh, no, how about Thursday… If we go to the park on Friday, I won't be able to handle him." I was flabbergasted. He was so easy in the park. She really just did not want to make any effort at all and she did not want to get to know my kid. In fact, the Friday before I drove carpool for a school outing and Nat was playing so well with another boy. I was talking to this boy's mother who carpooled with me and she could not believe that Nat had the history he had. She thought he looked perfectly normal. I thought everything would be fine after that day. I agreed to leave Nat at the school through the following Thursday, but the next day I could not bear to take him to school. I decided to keep him home with me.

This event precipitated a new round of visits to a couple Developmental Pediatricians and a psychiatrist who my husband wanted us to see. By the time we got into see the first, more traditional Developmental Pediatrician, things had started normalizing for Nat again. We had an appointment with her in which my husband and I went through Nat's history and answered her questions. Then she had an appointment with Nat and me, followed by another appointment with Nat alone. Then we had a final appointment in which she sat down with Steve and I to tell us her conclusions. First, she concluded that Nat was "amazing." I asked her for some more technical conclusions than just that he was simply "amazing." She said she expected something totally different given the history and the fact that the school asked him to leave. She said that she could give him no diagnosis whatsoever… not even ADD as he sat for 25 minutes at a chair and went through an exercise book with her. She did say that she saw shadows of behaviors that may be vestiges of prior symptoms or characteristics of autism, but that he was doing amazingly well. She did recommend that he be in a school where they are willing to support him and that he be reevaluated in six months or so. Nat was still behind in writing (and still is today). But at this appointment, Nat had enough self-confidence to pick up a pencil and write his name; whereas, he had refused to ever even try before. I told him which way to draw the lines in order to form the letters of his name and he did it. Prior to this he would only do what he called "scribble scrabble." To this point, if you asked him to draw or write he would say he couldn't do it.

As for the psychiatrist, my husband wanted to make sure Nat didn't need psychotropic drugs. After quizzing me for some

doi: 10.1588/medver.2006.03.00114

time, the psychiatrist decided that everything that I was doing seemed reasonable and helpful and that Nat looked like he was doing great. He said that I seemed to know more than he did and that there was nothing more he could recommend. He said that he certainly did not recommend drugs. My husband asked me if the psychiatrist then wanted to speak to him and I said, "No, he is satisfied with what I told him."

As for the second Developmental Pediatrician we saw, she was a traditionally trained pediatrician who had an autistic son. She found that nothing in Western medicine could help her son and she found a book on Waldorf and anthroposophical medicine. She was able to heal her son primarily through movement and nutrition. She studied Handel, Brain Gym, and Eurythme in Europe and brought a whole new refreshing view to autism and related developmental difficulties. She recommended that I do movement classes to get Nat's vestibular and proprioceptive system more integrated. She also recommended a cranial sacral therapist who worked on an energy level. This particular D.O. went through the full Upledger training for cranial sacral work and studied for seven more years with Jim Jealous, for the highest possible certification in this field.

At this point, it was October 2006, and Round 55 of chelation corresponded with the first fund raising event of The Ryder Foundation, my new not-for-profit corporation. My co-founders and I hosted an amazing cocktail party and silent auction at my house. We had over 220 people. Our two speakers, Dr. Lynn Meilke, a DAN doctor, and Dr. Lyndi Woodard, a local alternative pediatrician), and one of my co-founders, Jenny DeMaria brought so many people in the crowd to tears with their personal stories. Many people approached me afterwards and said they had a new understanding of autism. The day before this wonderful event, I was speaking with Declan's preschool teacher and mentioned that Nat was not in school anymore. It just so happened that another mother was going to send her son to this Waldorf preschool and had arranged for an aide for her son, but then decided to go elsewhere. The timing was right. Declan's teacher said, "If you want to start Nat on Monday, he can come with this aide." I said, "Done."

The first day at this new school, Nat knocked over a glass of water and said to the teacher, "Will I be able to stay here at MorningSong? I knocked my water over at Greenwood and I got kicked out of school." The teacher called me that night and said, "Wow, I can see that Nat is an extremely intelligent child and very sensitive. We cannot fail him this year. We will make this a positive experience for him so that he can build his self-esteem." It was so refreshing to have someone on my side and interested in really creating a positive experience for my child. This school year proved to be extremely beneficial to Nat and his confidence has grown throughout the school year.

During Rounds 51 through 60, I saw that Nat had more desire for interaction and asked me to play with him. He also played really well with an older kid in the neighborhood who used to be mean to him and exclude him. He had a reoccurrence of that red patch of skin next to his mouth at Round 51 and again at Round 58. At Round 59, Nat had become quite charming. He was always loving but he was not also quite so charming. He was constantly declaring his love for me. He also was not throwing his body around so much, which he had been doing again during a couple of the prior rounds. Around Round 57, he was upside down again a lot and chewed on his shirt and laying around on the floor. Again, this was another behavior that had improved dramatically, but had re-emerged again through the process of chelation.

I had started using nasal methyl B-12 (without folinic acid) around Round 60 and I noticed that Nat would sometimes hum when on this. If I talked he would hum. I would ask him not to do it and he could stop. At Round 61, I noted that he had a new expression in his face. On Day 1 of Round 63, I bribed Nat to draw pictures of the family. For the first time ever, he actually drew an image. He drew me, my husband, himself, his brother and our dog in five separate drawings. I was so excited because they were detailed drawings including eyes, pupils, eye lashes, etc. Although the maturity level of these images because of the large heads and small bodies indicated he was still about 2½ years behind in his ability to draw (drawing ability can show the maturity level of a child's body), he at least had the confidence to draw. He felt great about himself that day. After he went to bed that night, he later came downstairs and said, "Mommy, I had a great day today."

Over the last 15 Rounds of chelation, Nat's stools had become very normal. Prior to this he, his brother, and I (all of us were chelating) had lots of diarrhea. I believe this was from strep and other pathogens in the gut. We were using homeopathic remedies for strep as well as lots of Xylitol (as a partial replacement for sugar) and at some point something shifted and we all had normal eliminations. I also noticed that, unlike at the beginning of chelation, we had very little indication of yeast. From time to time, Nat might get a little bit of a red anus or a little diarrhea, but the outward obvious signs of yeast were no longer present. I do still believe yeast is an issue and this might be the cause of some of the upside down and other behaviors that would come and go throughout chelation. But, at least by this point in chelation, yeast was manageable without being on an anti-yeast protocol as we had been on for the first 9 months of chelation and in the years prior to chelation.

As of February 8, 2006, Nat completed 63 rounds of chelation. I had been waiting to get to this number, which although arbitrary, was a goal for me given the great things other parents on the internet had reported at or around this Round. Round 63 also marked approximately 18 months of chelation. My first goal was just making it to Round 10 and then to Round 35, which was approximately the 9 month mark, and then Round 63. I did one more round of chelation and then decided to take a long break from chelation to see where we were.

At my last visit to the anthroposophical Developmental Pediatrician, we discussed that the Eurythme classes were not effective to get Nat's vestibular system orderly. It was better but not good enough. After talking to a couple people, the Eurythme teacher I used wasn't known for working with small children. Apparently, with movement classes the child must be fully present in their calm (parasympathetic nervous system) in order for the brain to learn what just happened through movement. The parasympathetic nervous system is known as the "rest and digest" or "budda" state. On the other hand, the sympathetic nervous system is known as the "flight or fight" reaction. Apparently, autistic children operate, for the most part, in their "flight or fight" reactive state. If we can shift them into a calmer chemical state, then they can finally integrate and organ-

doi: 10.1588/medver.2006.03.00114

ize the various systems of their body using movement therapy. It is a real talent to work with children and if you get them into the right state of mind to do the movements, there can be a profound and immediate shift. I also put Nat into Feldenchrist classes called The Anat Baniel Method. After a series of these classes, Nat asked to draw and wanted to try to color within the lines (which he couldn't do, but he tried). Nat's new willingness to draw and write is a good sign of things to come. I can see his body is integrating. However, I haven't had a huge immediate shift as I have heard other people report. For us, it has been slow and steady improvement.

Slowly throughout the school year, I discontinued the gluten/casein free diet for my children. They have been freely eating wheat and dairy for the last eight months. I have not, however, discontinued the Houston enzymes, which they still take with each meal. I still feed my children nearly 100% organic foods and I prefer raw cow's milk and raw butter. I still use ghee (clarified butter) and will choose low-gluten grains such as spelt if I have this option. I will always be Stage II Feingold, which means that we avoid artificial colors and flavors and preservatives, but my kids can freely drink apple juice and eat berries, etc.

I have a couple friends who have been treating their children exclusively with Dr. Yasko's protocol. I got interested in this protocol because she attacks autism from the viral side and says that doing so causes the children to dump heavy metals. She says that, for survival, the viruses hold onto the heavy metals in order to immuno-compromise the body. I decided I needed an exit strategy from chelation in case my son was a child who would tend to re-accumulate metals if I stopped chelating. Also, I was interested in taking another swing at autism from the other side. I had attacked it from the metals side. Now I could have the opportunity to attack it from the viral side and possibly dump more metals. Even after 18 months if chelation, Nat's measles (Rubeola) titer was still 3 ½ times the reference range and his German measles (Rubella) titer was slightly elevated. I read all of Dr. Amy Yasko's books and watched three or four of her videos. I did genetic testing on myself and both my children. Nat's genetic testing indicated that he has CBS (cannabinoids) upregulation which would cause more ammonia. He also, was COMT++, which meant that he might have less tolerance for methyl donors. He had the MTHFR (C677T) mutation (++) which meant that he needed the 5-methyl-tetrahyrdrofolate form of folic acid. He also had the MTRR ++ mutation which indicated that he had a problem recycling the much needed methyl form of vitamin B-12. He had a couple other mutations. I have since tweaked his supplementation according to these findings. I am not convinced that Dr. Yasko is correct on every one of her interpretations as genetics is a complicated and infant field of study. However, she does have a success record and children are recovering using her protocol. I started my children on the RNA drops in hopes of by-pass genetic mutations which might be compromising detoxification. I did use some RNA drops towards the end of chelation and Nat did seem to slightly increase his excretion of heavy metals compared with prior testing. I don't know if it is due to the RNA drops or not.

This week I was about to start Dr. Yasko's Metals I drops to address the measles virus. However, Nat and Declan had gone camping with their dad two weeks earlier. Nat had a rash on his knee that looked suspiciously like a Lyme disease rash. One doctor said she didn't think it was Lyme disease. The other doctor said maybe it was. Given that Nat just "got out of the woods" of neurological insult, my husband thought it prudent to treat him with antibiotics. This is the first course of antibiotics Nat has ever been on in his life. After he is done, I will start up again with the Metals I RNA drops and see if I can bring down his titer and cause him to excrete more heavy metals.

Nat's self-esteem is flourishing. Also, Nat is so incredibly smart and intuitive that he has known all along what has been going on with him. Early on I decided to talk to him as an adult. I explained to him that a portion of his childhood was taken away from him and that he has had to grow up more quickly than other children his age because of his challenges. I also explained to him that, although life may seem harder right now, he has received the gift of awareness. Ironically, as he has recovered, he has recovered his childhood. He loves to play. I say to Nat "What is your job?" He says "My job is to play mommy" and runs off and plays with his brother and friends.

It was only recently that I was struck by the fact that Nat's name, Nathaniel, means "gift from God." We only picked this name because we couldn't agree on any other name and we both liked the sound of it. Nat's struggles and my journey to help him recover has taking me on my own spiritual journey. I am not religious but I have become very spiritual. It is beautiful to watch a child develop. However, it is magnificent to watch a child who was robbed of this natural, God-given progression to finally blossom in ways it seemed unlikely given prior circumstances. That is absolutely magical. I mourn the fact that my own child's illness is what was required for me to finally stop and look hard at life, our environment and why we are all here. Nat has instilled in me a sense of wonder and awe for life itself. I honor Nat and the whole generation of children who have sacrificed all or a part of themselves to be our teachers.

The most important things to do consist of the following:

1. Don't be in denial if there are signs that something is wrong.
2. Don't wait for a Western trained Developmental Pediatrician to tell you your child has autism.
3. Don't decide your child is not going to have problems if the Developmental Pediatrician tells you your child does not have autism.
4. Do look into the alternative DAN! protocol for autism or Dr. Yasko's genetic protocol for autism whether or not a third party tells you your child has autism. Autism is the tip of the iceberg and chances are that the therapies for autism can help your child if he has any type of developmental or learning disability.
5. Do start the gluten/casein/soy-free diet early.
6. Do use Houston Enzymes
7. Do use a basic multivitamin (I like *Child's Essence* and *Pure Kids*) and supplement with methyl B-12 (try the nasal form or use very high levels of oral methyl B-12)
8. Consider chelation (after research and under the supervision of a qualified doctor).
9. Do get on an internet support group. At www.yahoogroups .com there is GFCF Kids, Enzymes and Autism, Autism-Mercury and Chelating Kids 2 among others. Dr. Yasko's support group is at www.autismanswer.com.

doi: 10.1588/medver.2006.03.00114

10. Do read books. I liked *Amalgam Illness* by Dr. Andy Cutler, which I read three times to absorb all the information and it helped inform me on the specifics of chelation and helped me overcome the fear of starting to chelate. I like *Enzymes and Autism* by Karen DeFelice because it is covers a broad spectrum of issues in a very easy to understand fashion. Although a bit off topic, I like *Nourishing Traditions* by Sally Fallon because it informs you regarding nutrition. When you are trying to go alternative in the foods your kids can eat, you can often find yourself in the trap of using processed foods which are actually more dangerous. I like Amy Yasko's books because although technical, they give a good overlay on a metabolic level of what can and does go wrong in autism and how this affects the body and how you can supplement to help it. These two books are *The Puzzle of Autism: Putting it All Together* and *Genetic By-Pass: Using nutrition to Bypass Genetic Mutations*. Available at www.autism answer.com Although I haven't read it yet, I understand that *The Out-of-Sync-Child has Fun* by Carol Stock Kranowitz is a great book for helping your child integrate his body. I recommend reading *Autism: Effective BioMedical Treatments: Have We Done Everything We Can For This Child* (2005), available at www.autismre searchinstitute.org. Also, Amy Lansky's book *The Impossible Cure* is a great read related to homeopathy.
11. This is your child. Because no one is taking responsibility for the autism epidemic and the epidemic of children with learning difficulties, you need to take responsibility for your child's health. Don't let anyone discourage you. Only by addressing your child's needs will you know what can be changed and what cannot be changed. I have heard hundreds of stories on line and at the last DAN! conference of how parents have released their children from a life time of physical pain and symptoms of autism. Autism is not a natural state for any one or any child.

Declan (left) and Nate (right) in Costa Rica, December 2006

doi: 10.1588/medver.2006.03.00114