

John's Story

4 years old



It certainly was not the world's easiest pregnancy when I was carrying John. I was in the process of moving, switching jobs, taking care of a sick dog, and completing a fellowship on the East Coast while my husband completed his fellowship on the West Coast. But the pregnancy was going well, in spite of the turmoil that was going on all around me. John's ultrasounds consistently looked great and he was growing like a little bean sprout.

I have Rh-negative blood, and Dan has Rh-positive blood, so I needed to be immunized to prevent my body from rejecting subsequent pregnancies. At the same time, my blood work was starting to come back with high concentrations of antinuclear antibodies (ANA). In addition, I had to go to physical therapy because my joints were in such bad shape I couldn't walk, and the disks in my back were starting to bulge from the connective tissues stretching around my spine.

My obstetrician started doing non-stress tests every few days or so to monitor John and make sure he was still thriving. At 35 weeks, I was really feeling awful and I went in for a non-stress test as usual. I sat down, did my job pressing the little button, and the nurse came in about 20 minutes later. She looked at the chart, frowned, and pulled out a can of orange juice. After three cans of juice, I was quite awake but John was non-reactive.

The nurse called in my doctor and she immediately took me into the next room for an ultrasound. The doctor spent at least 20 minutes looking for any signs of activity, but saw no movement at all, not even breathing motions, kicking or even a twitch. If his little heart had not been beating on the screen, I would have thought the worst.

The doctor admitted me to the hospital. I was monitored around the clock until they could get the two of us

stabilized. My kidneys were starting to shut down; I was hypoglycemic, feverish, and retaining a tremendous amount of fluid.

After a couple days of intense watching and waiting, they were satisfied that John and I were on the right track and we were sent home. I went into labor two days later, and weighed 10 pounds more than the day before—all fluid. After 43 hours of labor, John was born with great Apgar scores (9 & 9) and a very robust cry. In fact, he cried, and cried, and cried some more. He didn't want to nurse—he just wanted to cry.

That evening, the nurse came into my room, and gently informed me that she was taking John out of my room and into the nursery because he was going to keep me awake (translation: he was keeping everyone on the entire floor awake with the constant high-pitched wailing). John had to be kept under the warmer for two days because he couldn't regulate his body temperature, and he was jaundiced, although apparently not badly enough to warrant attention.

In spite of the ominous beginning, John's development of language and motor skills was nothing less than astounding. He was rolling over from stomach to back at 21 days of age, spoke his first word ("hello") perfectly at 11 weeks, stood alone holding on to furniture at 15 weeks, sat unassisted at 20 weeks, and started walking the day after his 9-month birthday. John cooed, smiled interactively, babbled and made raspberries.

Shortly after 6 months, John had the first of six successive bouts of asthma, respiratory infections and otitis media during the spring and summer months of 2003. He was treated with antibiotics for each of these illnesses, and after the sixth ear infection, John's otolaryngologist performed a myringotomy and placed bilateral pressure equalization tubes in his ears.

For a while, we believed that his language acquisition abilities were adversely affected by his hearing deficit from the otitis, and we were encour-

aged when he started speaking again soon after the placement of the ear tubes. He learned to say words that approximated "fish" and "diaper," although none were as clearly enunciated or articulated as his first words.

In the meantime, John's motor skills continued to progress. At 10 months, he was able to go up and down stairs, run, kick a ball, and walk forwards, backwards and sideways. His balance, hand-eye coordination and concentration were quite impressive; he could ride his scooter and tricycle with ease, jump, walk (not crawl) up and down stairs unassisted, run through shopping malls, get in and out of laundry baskets, boxes and beds, build elaborate towers with his blocks, swing on his "big boy" swing and go up and down a slide, and play fetch with our dog.

John could play various rhythms on his toy drum and hum familiar tunes like "Old McDonald Had a Farm" with us. On one occasion, John drew two pictures of an airplane on his Magnadoodle while watching "Jay Jay the Jet Plane" on television. He mastered every puzzle and shape sorter we gave to him, some within a matter of minutes. He also knew how to turn on (and turn off) and operate all of his electronic

toys and our electronic equipment including the VCR, television and radio. One of his speech therapists reported that in over twenty years of working with children, she had never seen a child as young as John master puzzles and spatial games as quickly and precisely as he did.

John was always interested in the tactile, concrete world. When we would hand John a new toy, he would initially approach the item like a little scientist or engineer given a specimen to study, rather than a child playing with a toy. Later, however, he would enjoy playing with his toys in an appropriate manner (i.e. pressing buttons to make animals pop up, turning the handle to open the cash register drawer, pushing cars and making car noises, etc.). He rarely

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threw or broke his toys or ripped pages in his books; he has always been gentle and contemplative when at play. If permitted, John was intrigued by taking things apart to see how they work; his favorite toy as a very young infant was an old dissembled remote control.

Since he was an infant, John enjoyed constant intellectual stimulation became bored with routine. Each new experience or activity we introduced was met with excitement, and his curiosity for the world around him was insatiable. During his infancy, he tended to move from toy to toy during the course of the day, never staying with any toy for any length of time. A friend commented that he "managed" his toys rather than played with them. His ability to recall specific places, pictures, and songs was exceptional.

Many who were getting to know John characterized him as spirited, adventurous and independent, always going after what he wanted rather than waiting for an adult to get it for him. Early on when John was hungry or thirsty, he would simply whine and cry until we figured out what he wanted, which initially took quite a long time. While other children might ask for or make the sign for a sippy cup, John walked into the kitchen and looked back and forth between me, the sippy cups and the microwave to indicate that he wanted me to make him something to drink.

John experienced feeding problems with oral aversion from a young age, and refused to put anything in his mouth (unless we were feeding him). He seemed to be afraid of anything that might potentially choke, gag or hurt him if ingested, and he had great difficulty learning to eat lumpy food. Since he was 12 months old, however, John has enjoyed feeding us crackers, cookies, and other stuff that he has refused to eat; thus, he understands that he is supposed to put those things in his mouth, but simply will not do so. When presented with a straw from which to drink, John had a tendency to bite the straw instead of suck fluid into it. John would drink from a regular cup, but he would only drink from sippy

cups that did not have spill-proof valves. His diet was limited to soft, mashed and pureed foods since he swallowed his food without really using his tongue or chewing. I had difficulty nursing John when he was young, and he would not take a pacifier.

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I believe these profound feeding problems stemmed dually from oral/verbal dyspraxia and from the gastrointestinal problems he experienced since birth. Even when he was an infant, he was irritable after every meal of breastmilk; he weaned himself early, and we were forced to replace breastmilk with formula. John was the type of kid that would rather starve to death than eat. We were not, able to get rid of the irritability, even after weaning from the breastmilk and supplementing with formula and solids. He would cry excessively and arch his back in pain; he was started on Zantac at four months for acid reflux. He was later switched to Prevacid, which only exacerbated his symptoms.

John's routine hemoglobin test at his 12-month check-up indicated mild anemia, so he began taking Poly Vi-Sol and ferrous sulfate iron supplements, with the thought that too much milk had prevented the absorption of iron from his formula. When his hemoglobin level was down even more after several months of iron, we conducted guaiac smear tests, which were positive for occult blood, meaning that he was bleeding internally, and nobody knew where or why.

Subsequently, John went in for an endoscopy and colonoscopy when he was 18 months old. The evaluation from the scope was unremarkable, and probably would have missed everything, but biopsies later revealed chronic gastritis and prominent lymphoid aggregates in his terminal ileum. Bloodwork conducted in tandem with the colonoscopy indicated neutropenia and elevated counts of lympho-

cytes and eosinophils.

We retested the stool several months later, and the smear tests were still positive, presumably because nothing had been done to actually treat the underlying problem. In May 2004, John had an upper GI series and small bowel follow through with barium contrast, which was normal. At this point, his gastroenterologist offered a diagnosis of lymphonodular hyperplasia, although again, no course of treatment was suggested.

John was getting sicker by the day, and his subsequent blood reports were showing even more decreased levels of neutrophils, very low glucose (57 mg/dl), and elevated levels of lymphocytes, eosinophils, platelets, and thyroglobulin. His sedimentation rate was also elevated (15 mm/hr). All of this pointed to some substantial inflammatory process going on somewhere in his body.

At the same time that all of this mess was going on with his gut, John's developmental skills were starting to suffer. He was referred by his pediatrician for a developmental evaluation when his language development failed to keep pace with the development of his gross and fine motor skills. He was evaluated at 21 months by a developmental pediatrician for being socially withdrawn and failing to progress in his language development.

John was not given a formal diagnosis by the developmental pediatrician; her evaluation notes indicate that John had some features of autism, including social aloofness and poor language development, but he did not demonstrate a full range of autistic-like behaviors during the evaluation.

A few weeks later, he was re-evaluated by a speech language pathologist in the home to establish recommendations for speech and augmentative communication therapies, and she noted that he has understood language better than his speech and language difficulties have allowed him to express, and that he needs structured practice and

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expectations to use speech, signs and symbols to communicate in his daily routines. Ultimately, her diagnosis was a speech and language disorder with some atypical language and social behaviors, but not autism per se. John's occupational therapist believed John had significant issues with praxis and motor planning, and all of his speech therapists have stated unequivocally that John struggles with oral/verbal dyspraxia.

John started direct speech language therapy at 24 months (two times per week) with a focus on speech and language and use of signs, symbols and voice output to help increase his language and functional communication skills. He also started working with an occupational therapist to address his oral aversion and feeding issues, including brushing his teeth, feeding himself with a spoon, and chewing of solid food. His occupational therapist started by using the Wilbarger Protocol (deep pressure and proprioceptive techniques with oral tactile stimulation) to help decrease John's sensory defensiveness regarding his mouth, including his pattern of food avoidance, fear, and anxiety about eating. This technique made visible improvements in John's overall anxiety level, and he demonstrated greater use of eye contact and increased his attention span, but he was still not talking or interacting normally, nor was he eating, chewing, or using his tongue in any functional way.

John started attending a wonderful structured playgroup at the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) Center at 26 months. In the beginning, he could only say a handful of words, none perfectly. He could make a sound like a cow, sheep and horse, and could point to the animals to identify them. He didn't know how to share, made little eye contact, and could not sit for any length of time to perform a simple task. Everything was on his terms, and he was not interested in interacting with any other people other than Mommy and Daddy. But by the time the first

semester ended, he knew all of his letters (upper case and lower case), colors, shapes, and numbers up to 10. He doubled his vocabulary and mastered many tasks that required complex fine motor and planning skills. He became interested in animals, pretend play, and singing with the group.

At 28 months, I hired a wonderful young woman to come to the house for 10 hours per week to work with John intensively, one-on-one, on social skills and communication. Within a month he was sharing his toys, drawing pictures with his Magnadoodle, and increasing his vocalizations. She worked on two-word combinations, and by Christmas he could say "thank you," "big truck" and "push please." Those two played games together, took turns, made choices, and sounded out words together several days per week. She also designed a series of games tailored for John's interests and worked on creative projects, including painting, drawing and coloring.

Nobody around here knew how to fix John's tummy, so I started searching all over the world to find an expert in lymphonodular hyperplasia. At the beginning of December 2004, John's new doctor put him on anti-inflammatory medications to get the colitis to calm down and start healing. He also adjusted John's diet to eliminate a variety of foods, including glutens and caseins, although at that point we didn't know yet exactly what we should avoid. We also started supplementing with probiotics (to replenish the good bacteria that were depleted during multiple courses of antibiotics), DMG, and essential fatty acids.

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When we got the next round of bloodwork back in January, we thought they had mixed up his file with someone else's. It was like looking at a completely different kid—not one of his numbers was off, not even the blood sugar. We also noticed that John had not had an asthma attack or ear infec-

tion since October.

In January 2005, John continued to do speech therapy, occupational therapy, the communication therapy at home, and we started him on hippotherapy one day a week to strengthen his abdominal muscles, which had atrophied since John avoided any activities that would engage his tummy area. Everyone we knew was starting to remark about his progress. He was counting to twenty, and we could now understand much of what he was saying. Up to then, he had been counting with one-to-one correspondence. He was adding more shapes and colors to his repertoire, and attempting to say every word he heard. He wasn't just making his toy animals walk around—now, they were having fun, eating snacks, taking baths, and chasing each other. He was performing song games, like "itsy-bitsy spider" and "head, shoulders, knees and toes." He was suddenly absorbing information faster than we could feed it to him.

Three months before he turned three, we discovered quite haphazardly that John was, in fact, able to read. Although he could not say the words, he matched pictures of animals perfectly with the corresponding words, and was able to repeat the feat consistently, much to the amazement of everyone in the room. I started testing to see how much he could actually read, and it was truly amazing. I went right up to our computer and made a spelling activity for him, and he could spell most preschool three- and four-letter words with ease. The great thing about this is that it was not hyperlexia; he understood what he was reading. Even now he sits down and reads by himself, and when he doesn't know a word, he sounds it out. Many people look at John and smile, thinking that he's merely pretending to read. In reality, he is reading, although what's coming out of his mouth doesn't always make sense to those around him.

In the fall of 2005, John started school with neurotypical kids at a Montessori school near our house. It seemed like a good plan; he could move at his own pace, and since academically John is way ahead but socially behind, that self-paced strategy might have just worked. And so,

he was scheduled to attend every morning of every day for three hours like the other kids, although for the first month, that didn't work out at all. He was easily exhausted and started acting out after only an hour, and was ready to come home and collapse for the rest of the day.

His diet had been completely overhauled to accommodate the results of a series of highly sensitive allergy tests that revealed he was allergic or sensitive to nearly forty different foods, many of which he ate on a regular basis, so he also could not eat the same foods as the other children (nor could he chew yet).

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In late August, we began giving John shots of methylcobalamin (methyl-B12) every three days in an attempt to boost his immune system and give him some help getting through the day. We all need that vitamin to be able to complete the methylation process and get rid of nasty toxins in our bodies. In autistic kids, this process gets jammed up because of the exposure to heavy metals and environmental insults. By injecting kids with additional methyl-B12, we're giving them the chance to jump-start this process and relieve the oxidative stress of inflammation to detoxify.

Almost immediately after starting the shots, everyone noticed a big change in John. He was happier, more alert, laughed at jokes, etc. His teachers at school began to guess (correctly) the day of the shot cycle by his demeanor in class. After evaluating his progress, Dr. Neubrander determined that he was a "class 5 responder," meaning that he had the potential to benefit greatly from high dose, high frequency methylB12 shots. He started him on shots every day at Thanksgiving and recommended that we begin hyperbaric oxygen treatments.

In the meantime, his gastroenterologist began John on a course of pred-

nisonone to see if this would have a cognitive effect; in kids with autism, sometimes calming the neuroinflammation is enough to pull them off the spectrum. It was worth a try, but it could not be a long-term solution because of the side effects.

Up to that point, those six weeks on the prednisone were the best weeks of John's life—he was like a different kid, and his teachers were astounded. This was enough to make a believer out of his doctor—he put John on a low dose of 6MP, a drug that was designed to combat leukemia, but is also useful for calming severe cases of inflammation without the side effects of corticosteroids. All we could do was wait and see if it worked...

We started hyperbaric oxygen therapy (HBOT) in January 2006. This is a treatment that has been used for years to speed healing in burn victims and athletes, but has only recently been found to be of help to autistic children—this is probably because researchers only recently discovered the substantial amount of neuroinflammation in children diagnosed with autism.

The increased pressure in the HBOT chambers allows blood plasma to absorb additional oxygen (Henry's Law of Physics—under pressure, gas dissolves in liquid) and greatly increase the uptake of oxygen by cells, tissues, and glands in the body.

This allows for greater circulation to areas with swelling or inflammation, including the brain. At the same time, the increased pressure decreases swelling and inflammation.

After the first HBOT session, we noticed some subtle, but very real differences in John—better articulation, more interaction, etc. After the second round in early February, John was a different kid. His thought processes were faster, he was asking questions, pointing out things of interest, not just counting to 100, but recognizing all the numbers; starting

“...the increased [hyperbaric] pressure decreases swelling and inflammation..”

to tell time, reading without hesitation, etc. It was truly amazing to watch.

Following the second round of HBOT, we had a very interesting (and wonderful) encounter

with his pediatrician, who had not seen John since October 2005. She walked into the room, and John gave her a hug—she looked at me, stunned, and said jokingly, "Who is this child?" I said, "You don't know the half of it."

Then, she looked him over and started talking to him about clocks, squirrels, cats, colors, numbers, anything and everything. He was playing nicely with the toys in the office, paying attention to our conversation, and attentively responding to her requests to breathe deeply and open his mouth. At the end of her exam, she said, "How did you do this?"

I said, "You don't want to know," but she emphatically replied that she did. I looked her right in the eye and said, "I spent the past two years treating him for heavy metal poisoning and neuroinflammation and now he's finally recovering." She took a deep breath and said, "I've never seen anything like this. John's functioning completely within normal limits for a three-year old. Wait here."

Five minutes later, every member of the staff who was in the medical office that day was in that tiny room taking notes and asking questions

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about John and our treatment regimen. After they had cleared out, she told me she wanted every book, every article, the name of every specialist, every treatment protocol, EVERYTHING so that she could give the other kids in her practice a chance. She could not bring herself to believe that an entire generation of children suffering from similar symptoms could be helped...until that day when she saw John laughing and talking to her, and realized that the cure for "autism" in many children was simply to get rid of the oxidative stress caused by the neurotoxins that were

stuck in their brains.

Since starting hyperbaric oxygen therapy, John has been physically and emotionally able to successfully attend preschool for the full morning session, every day. He is amazing. He reads, writes, counts, sings, draws, spells, pretends, tells stories, speaks in complete sentences, chews food (!!!!), and generally gives his teachers a run for their money. His teachers have said repeatedly that each time he returns from the HBOT sessions, a "new child" walks through the door.

I can't express the joy that we are feeling now that John is truly on the road to recovery; we are so relieved

and excited to see what will be in store for him next! We still have work to do, and he'll probably have to be on the various therapies for quite some time, but that is all minor compared to the happiness we are experiencing.

Doctor's notes:

Key point 1: This child had significant autistic characteristics though not an official diagnosis of autism. However, HBOT does not know the difference between "traits of" and "definite diagnosis" of autism so it is my opinion that any family whose child has some of the symptoms of autism owes it to their child to do a

clinical trial of HBOT.

Key point 2: The father is a world-renowned scientist and very famous. As a scientist he must say that everything he sees is anecdotal. However, as a parent he says there is no doubt what he has seen happen for his child is undeniably real. First methyl-B12 made significant and undeniable changes, and later mild HBOT also made remarkable and undeniable changes. Therefore, though science has not yet performed the studies necessary to "prove" that methyl-B12 or HBOT works for children with autism or autistic tendencies, parents and teachers can see "undeniable proof".

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