

Amanda's Story

4 years old



There is a universal desire for parents to want what is best for their children. From the moment a newborn comes into the world, a pledge is made by parents to do all that is possible to protect, nurture, and care for the young life. For us, our promise to our daughter Amanda has been no different.

At two years, 7 months old, our Amanda was diagnosed with Autism Spectrum Disorder—Progressive Developmental Delay, Not Otherwise Specified (PDD, NOS) after she experienced a rapid decline following a routine doctor's visit.

Following is an account of our experience over the course of the past two years, contained within it a hopeful message for all those currently living the nightmare we have and continue to experience.

Words cannot properly convey the pain, worry, fear and frustration felt every day as parents of a sick child. When Amanda was first diagnosed, we were told that PDD is a "fairly common" form of Autism. And in so many words, we were told, by both our pediatrician and county-appointed child psychologist to be prepared for a life of Applied Behavioral Analysis therapy (ABA) and special education programs. We were told Amanda could, with these therapies, have the chance of someday leading a productive life.

This did not sit well with us because up until two years of age, Amanda was speaking in two languages (English and Spanish), making eye contact, laughing, interested in reading, singing along to nursery rhymes and engaging in creative play. We knew that her ability to speak and communicate was buried deep within her, and we vowed to do everything possible to bring her back.

Let us explain of what "everything" consisted. Within three days of Amanda's diagnosis, we immediately began intervention. We hired an ABA therapist to come to our home while awaiting services to be provided through the school district. Although

we knew the growing costs associated with health care, we could have never imagined the true capitalism in medicine. In a short amount of time, we have found that many practitioners have placed their own Hippocratic oaths second to exploiting an area of medicine that is not usually covered by insurance.

For example, our first appointment with one of the foremost New York experts treating adolescent autism was nothing short of disappointing. We were charged \$650 for a 25-minute consultation, and were given less advice than we received browsing the Internet.

Being New York City Detectives, my husband and I spent countless hours investigating all available evidence for a change of recovering our Amanda. After researching the subjects of autism, autism spectrum disorder, basic biological principles, nutritional background—and even mercury poisoning—we became well-acquainted with the Autism Research Institute (ARI), Defeat Autism Now! (DAN!) and its many practitioners.

We followed their many protocols, Regimens, and new approaches to the letter, with no improvement. My husband became well-versed on these subjects, often educating Amanda's many doctors on the new studies conducted, the effects of these studies, and many times requesting prescriptions in an effort to rule out different types of viruses, genetic disorders and diseases.

All the while, Amanda endured countless laboratories' analyses, consisting of regular blood, urine, hair and stool sampling.

By this time, my husband Michael had been attending several physician conferences to listen to the many panels of doctors, who were debating the causes of autism and unveiling new treatments in the fight for recovery.

After almost two years of following various, highly recommended biomedical regimens—which consisted of an extremely strict gluten/ casein/ yeast/ egg/ soy-free diet, oral DMPS chelation, probiotics, cod liver oil,

routine B-12 injections, daily glutathione therapy (IV and nebulizer mist), anti-viral medication, Actos (for anti-inflammatory purposes), weekly cranial-sacral therapy, infra-red sauna, consumption of every supplement available from AK A to Zincs, 36 hours weekly of ABA therapy—there was still not "dramatic" or "significant" improvement.

Amanda continued to regress, losing the little bit of language she had left, no longer repeating, and showing less interest in her therapies. Her sleep pattern also began worsening by the day and her mood consisted of daily crying. Our Amanda was an extremely unhappy child.

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Then, by a stroke of grace, at a recent Long Island, NY conference in April 2006, our situation changed when we met an IHA spokesperson, Shannon Kenitz, who shared with us her own experience as a "mom in the dark". She told us about her daughter Grace and about the only treatment—after having tried many—that saved her daughter, Hyperbaric oxygen Therapy.

On behalf of the IHA, we were invited to bring Amanda to the Wisconsin Integrative Hyperbaric Center (WIHC) in Fitchburg, Wisconsin, where Amanda could try this new form of therapy—commonly referred to as 'dives'. Within 6 days, and no hesitation, we packed and relocated to Wisconsin.

When we arrived at the WIHC, Amanda was four years old. She was no longer imitating sounds. She rarely engaged in creative play, her eye contact was poor, and she rarely laughed or smiled. Amanda suffered crying episodes that sometimes lasted for hours, with no visible known explanation. She could not jump off the ground clearing both feet.

Above all these things, she virtually never slept. She slept through the night one or two nights per week at most. The rest of the nights were spent screaming, crying for hours, or just sleepless from 1 am to 7am in the morning. This new dark world was taking a tremendous toll on us: affecting our jobs—to which it was

becoming difficult to get, and if we did manage to make it to work, we were running late; affecting our finances—we have taken every possible loan available and have begun dipping into our retirement funds; and affecting us emotionally—we were slipping further and further into depression with no sign of hope. We were truly desperate.

Today, we are pleased to share that after 80 sessions— 'dives' of Hyperbaric Oxygen therapy in a steel wall chamber at 1.5 atmospheres of pressure, Amanda now sleeps through the night. She imitates sounds. She is repeating or is eagerly attempting to repeat what is asked of her. She clearly understands what we tell her.

She can jump off the ground clearing both feet. She can climb in and out of her car seat as well as the car itself. She does not mind having her little brother, Michael around, or having him touch her, and at times she smiles with him. She is smiling a lot, laughing appropriately.

The most significant breakthrough we have witnessed since all of this began happened during a trip to the indoor playscape at the local mall—after the completion of 80 HBOT sessions.

When we arrived at the play area, Amanda's face lit up. She had a big gleaming smile. She ran independently towards the playscape, and just like the other children there, Amanda began climbing on and off the various stations, running, crawling—engaging in play for hours with laughter, smiles and wonder. We couldn't believe our eyes. My Husband and I were truly amazed. The dark cloud of Autism is starting to lift.

As I write this, we are preparing to leave Wisconsin, continuing on our journey for Amanda's recovery. Before our visit to the center, we were slowly losing hope. But, seeing the improvements in Amanda over the course of the past two months has given us a new found sense of faith, belief in others, and has reassured us of what we knew all along: Amanda was deep down inside that little body—and she's finally healing, showing herself to us again.

For those parents experiencing the world of autism, I have some advice, as my husband and I have learned several things through this journey.

"...you have to trust your instincts and question treatment providers, who may not place your child's interest first."

First, we have learned to be our own advocates, because you have to trust your instincts and question treatment providers, who may not place your child's interest first.

Second, we learned that anyone, regardless of education, could learn about biological science, autism and other developmental disorders through the vast articles, resources and information available in textbooks and over the internet.

Lastly, after going through a very dark time, we have learned that there is hope, there is faith, and there are good people in the world who want to help our children and who are not driven by the mighty dollar. With persistence, perseverance, and the help of people like those at the Hyperbaric Center, you can improve your child's situation. We are living proof.



Thank you IHA and WIHC for your generosity, unconditional devotion, and friendship. God bless you for your kindness and compassion. You have done more for us than you will ever know.