

Autism:

DONNIE'S STORY

Like many new parents, we were excited to have our son, Donnie. We felt prepared because we had waited for five years after marriage to have him. We were so happy about this baby that we drove everybody around us crazy! We read every book we could possibly read on babies, and we asked other parents as many questions as possible. When we found out that we were going to have a boy, our excitement doubled. It would not have made any difference to us if it was a boy or a girl, but we wanted a boy first if it was possible. We threw a small party to announce to our close friends and our family that we were going to have a boy. We planned to have two children hoping that one would be a boy and the other a girl. For us, this was fifty percent of our prayers answered. If the next baby turned out to be another boy, we would still love him very much anyway.

There was no dull moment in our lives for the nine months of the pregnancy. The joy was so great, and the delivery was a touching and memorable experience for us. Bringing Donnie to this world was a miracle for us. We took several pictures every week just to capture and to compare every developmental stage of Donnie. The pictures looked different every week as he grew older, which was very exciting. As he grew daily, we were hoping to see changes based on what we read in the books, but his growth process did not seem to match what we had read. The doctor and other parents assured us that not every child would follow textbook format for developmental growth, and there should not be any reason for us to be alarmed or concerned. Donnie was so adorable; we were too happy with him to have the time to focus on some of the early cues or signs of autism. The

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assurance from others that every child may not necessarily follow the textbook format of growth was good enough for us to not worry too much.

We started paying more attention as he grew older and he became more and more difficult to console when he cried. He also stiffened whenever we tried to hold him, and he did not like to be held. We noticed that he was not very affectionate or attached to us the way some other babies in his age group were attached to their parents. We loved to take his pictures at every opportunity we had, but we noticed that it really upset him every time we tried to take his picture. My husband played it off that he was trying to be a typical boy and be really tough. By the time he was two, it was obvious that his growth was not following typical developmental milestones. The doctor started preparing us for the possibility that he may be autistic, especially with a lack of speech at age two. We started getting a little scared, because we thought all along that whatever was going on with Donnie was temporary, and he would snap out of it.

As young new parents, we were not interested in learning about childhood developmental problems. It never crossed our mind for a second that something could be wrong with our child. As far as we were concerned, we thought the odds were in our favor as parents because we were young and healthy, and we continuously maintained a very healthy lifestyle. By the time Donnie was two and a half years, the pediatrician gave Donnie a conclusive diagnosis of autism. We knew very little about autism; we had the basic knowledge that it was a childhood developmental disorder and that was about all we knew. The doctor spent time with us, explaining the possible future challenges we would likely face in raising Donnie. We were so shocked and overwhelmed by the initial outpouring of information that was given to us. Since then, we have learned nearly everything one can learn about autism. Our knowledge grew very quickly because we live with somebody with autism, our own child.

Donnie would have the most terrible and violent temper tantrums with no trigger or basis for it; he would throw things around the house and bang his head on the floor. Donnie was a picky eater; he wanted to eat the same thing for breakfast, lunch, and dinner. Any little change in his environment would upset him. He liked oatmeal, and he could not understand why he was not allowed to eat oatmeal three times a day. We insisted and maintained most of the time that he should eat other food, but we would end every meal with oatmeal, or at least a little oatmeal with every meal to keep us from deviating from his routine. Oatmeal literally became a dessert for Donnie. Occasionally, we would not have any luck with making him eat anything other than oatmeal, and we would have to give in and let him eat oatmeal instead of letting him starve.

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We started noticing a lot of unusual behavior with him, such as rocking himself in a chair non-stop for hours. He preferred solitary play and did not want to be hugged or be around anybody. He would spin and rock back and front endlessly in a chair. He did not show any emotion; his affect (facial expression) was completely flat and expressionless. We took every early intervention advice to try to stimulate his interest, so when he showed a little interest in animal toys, we went and bought a puppy. He treated the puppy more like an object, and paid very little or no attention to it. We cuddled the puppy, and gave a lot of attention to the puppy in his presence to model affectionate behavior to him, hoping that it would get Donnie's attention and help with his socialization skills, but it was a failed effort. When the puppy grew older and started barking a lot, Donnie became very resentful of the puppy. He became very violent with the dog whenever the dog barked continuously. We later realized that the barking sound was affecting his nerves and his hearing, and we were forced to give the dog away.

We also discovered that Donnie found a way to take the telephone off the hook. Friends and families were always complaining that our telephone line was always busy. We did not realize that the ringing tone of the telephone was like a sharp knife cutting through Donnie's ear, which was why he found a way to take the phone off the hook. We had to shop for a telephone with very low and more soothing ringing tone. We constantly made adjustments around the house to make the world a less hurtful place for him. He hated the sound of the vacuum cleaner; we had to make sure we vacuumed the house only when he was not home. He enjoyed exerting his energy at the park whenever the park was not too busy and noisy. He loved the swing and the slides. He hated the sound of the washing machine and the dryer; the buzzing sound of the dryer when the clothes were dry made him very angry. The sound of the doorbell also got on his nerves, so we changed the doorbell to a more soothing, musical sound, and we continuously made every possible effort to accommodate him. Something as simple as the sound of the bathroom vent and the air conditioner irritated him.

He could not tolerate places with lots of noise, like an amusement park. It took some harsh experiences for us to figure out some of his dos and don'ts. We took him to see the fireworks on the Fourth of July one year; he hated it so much and reacted as if we were putting a knife through his throat. We had to take him back home as quickly as possible. He liked hiding in unusual places such as under the sofa, between the mattress and the box springs, and between the sliding closets doors that usually fold. We tried very hard to keep Donnie engaged, and made a conscious effort to interrupt him from escaping into his own private world. Living in his own world was exactly what he wanted to do all the time if we let him.

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We realized that we had to prepare him for school and to encourage socialization as much as possible. We took him to speech therapy five days a week; we also went to social training and a behavior modification program. We gave him positive reinforcement whenever he responded to and got involved in his environment. One of the keys to our success with Donnie was that we took the warning from his therapist and his doctor very seriously that we must not allow him to be alone too frequently. The therapist emphasized that part of the symptoms of his illness was to shut the rest of the world out and to keep to himself in his own world. Keeping him engaged and involved was very draining on us, but we loved him so much that we would do anything as parents to help Donnie develop his socialization skills as much as possible. We kept Donnie very busy and very structured until his bedtime.

Donnie's difficulty with communication made us result to trial and error most of the time in order for us to pinpoint his wants and needs, and it was especially difficult for us when he became aggressive. When he had some of the normal childhood illnesses like a headache, earache, or stomachache, he sometimes acted out because he could not communicate his problems to us. Donnie would walk around with a cut on his foot for days before we would finally notice the cut. We made sure we did a head-to-toe check on him daily. Donnie was fixated on the color green, and we tried as much as possible to buy mostly green clothes and green toys for him.

It was difficult to introduce any form of change to him, and making him accept that he could not wear the same clothes everyday was a big struggle. Donnie was very talented with drawing; he drew on everything in the house—walls, books, plastic bottles, clothes, and anything that he could possibly draw on. We spent a lot of time trying to work with him to draw mostly on a board and paper. Donnie's artistic talents really came out whenever he visited a place that interested him, or saw something that interested him. He would come home and reproduce what he saw in a beautiful art. He would see something on a billboard while we were driving and draw it exactly as it was on the billboard when we got home. We encouraged his artistic talents a lot. Donnie was also amazing with numbers.

With early intervention and unconditional love, Donnie did well, and he was able to mainstream into a regular school. We continued to keep him structured and involved with the rest of the world. We were very lucky with the wonderful teachers he had; they were always willing to work with him. He had some behavioral problems, especially with temper tantrums; we worked with him by setting firm limits and making sure there were no external triggers for his outburst. He got into a lot more trouble at lunch time in the school cafeteria, and

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we figured out that the noise in the cafeteria would trigger his outbursts. The teacher gave him an exception to get his food early from the cafeteria and to eat it at the back of the classroom. That took care of the cafeteria problem. He also got into trouble a lot at the gym whenever he experienced sensory overload; the noise in the gym irritated his nerves badly and made him act out. The gym teacher always picked up on the cue, and he would send him to the classroom where he quickly settled down.

We faced different challenges everyday with Donnie; one morning he went on a rampage of breaking things in the house because we ran out of oatmeal, and we could not give him oatmeal for breakfast. Donnie just could not deviate from his routine, and he would need a lot of preparation if there was going to be a change in his routine. We had to constantly prepare Donnie before school was out for the holidays and to reinforce it repeatedly to him that he would be on vacation soon, and he would not be going to school for some time. We also had to start preparing him long in advance to go on a family vacation.

Donnie has some limitations, but he has been able to live close to a normal life because of early intervention and extensive therapy. No matter how strong you are, you still wonder why this has happened to your son. It is a lot of financial and emotional stress. You give up so much in search of a close-to-normal life for your child. You also have to live with the rest of the world, because there are those who have no patience to understand your pain and your frustrations. We joined a support group and found out how lucky we are even with Donnie's limitations. There are a lot of other children with autism in the support group who are not responding very well to therapies and different interventions like Donnie. We found out that Donnie's autism is one of the milder ones. Donnie is responding well to medication and therapies.

To us, Donnie is our miracle, and we would not trade him for any other child in the world. We have learned a lot about life by being his parents. We love him unconditionally, and we are happy that Donnie is part of our lives. Despite the good and the bad times, we went on with our original plans to have another child. Our second miracle is a girl; we got exactly what we had hoped for. Our daughter's name is Charlene, and she is beautiful. We are grateful that she has no autism, and even if she did, we would not love her any less.

If you have an autistic child, do not give up or lose hope. Get help for your child. Behind the autism are wonderful beings and precious gifts from God. We hope and look forward to a day that there will be a cure for autism. We always allow Donnie to participate in research in search of a cure for autism. We hope that one day Donnie can look back and say, "I was one of the many autistic children who helped to find a cure for this illness."