

The Real James

"P.D.D.-N.O....what?" I asked the Neurodevelopmental Pediatrician. "Pervasive Developmental Disorder. It's on the Autistic spectrum." I couldn't believe what I was hearing, the word autism cut through my heart like a knife. Would someone please wake me up now, I am having a horrible nightmare that some evil doctor I just met is telling me that my beautiful, brilliant little boy has some dreadful disorder that I've never even heard of and that it's some type of autism. AUTISM, I'd heard of that though; the word kept repeating in my head like some bad jingle I heard on the radio but couldn't seem to shake from my memory.

I started reading everything I could get my hands on regarding this PDD and autism; I kept finding the same message- no cure, lifelong disability and only a very few people ever go on to lead independent lives. I felt as though my son had been given a death sentence. I went into mourning; horrible, grief stricken mourning. I cried everyday for what seem like months; I was inconsolable. All my hopes and dreams for my little boy were gone, wiped out by that awful word- Autism. Everything was different now, but was it really? Did that doctor uttering that one word suddenly change my son? Was the real James gone forever? It took me a long time to realize that the child I was grieving for does not exist and never has except in my grief stricken mind. The "Real James" never left me, he's been here all the time; I'm ashamed to admit it, but in my mourning I think I lost sight of this. What a rip-off for my son to have a mother who has been spending all her time grieving for another child, one who doesn't even exist when I have been blessed with a wonderful little boy like him.

I'm not saying that a diagnosis of autism, PDD-NOS or Asperger Syndrome is not emotionally painful; it is. We have a right to grieve, but we must remember that the hopes and dreams that we mourn are OURS not our children's. So we can mourn our lost dreams- cry, pray, curse the powers that be if necessary, but try not to stay there too long as it is time and energy that could be spent helping our children today, preparing for the future. It's hard to be strong, but we have so many real issues to deal with that dwelling on our lost expectations of what we thought our children's lives would be is pointless. I know my son James marches to his own beat and I'm not trying to change his tune, (I think that would be impossible!) but I feel it's my job as his parent to help him find a band that'll let him join anyway. Who knows, maybe he will be their leader!

Erin Duffy

Proud Mom of James age 4 Dx Asperger Syndrome

Member, ASPEN® , Middlesex/Union Counties Chapter

Although it is very challenging having 2 children with issues, they both have made much progress. I know I am blessed, as there was a time when I was not sure if James AS/Hyperlexic would ever be able to communicate. Then Justin came along with entirely different obstacles which affected his speech and his health; there were times I wasn't sure how much one family could take.

I live in a rather small boro, and from time to time I run into this family and their autistic son. About 2 years ago I wrote about the first time I encountered this child. The memory of what I took away with me that day is always pretty close at hand. I hope I never forget how far my son has come and how blessed I am. Here's part of the old post:

"That Look"

"A little while later we went to the library and while my boys were in the children's section with their Father, I was in line next to a man with an autistic child who was about 9 or 10 who had a harness around his waist with a line attached to his father wrist. The man was having a tough time as his son was getting very excited and jumping and flapping his arms and making really loud funny sounds. I tried to help as I had a pocket full of toys (As usual) and one in particular that caught the child's attention long enough for his father to take care of his business. I felt so bad for the man as I could see the pain in his eyes as everyone was looking at him and his child. When I tried to distract his child, I quietly turned to his

father and said, "I have a child on the spectrum." I wanted him to know that I wasn't making any judgments, that I understood. But you know, I almost felt guilty saying that, as James and that child were worlds apart yet I have dealt with the exact same behaviors in a lesser degree. James will jump when excited and many times James has made those loud goofy sounds to accompany his jumping. (This behavior was more common when James was younger) When I looked at that boy I recognized that look in his eye, as I have seen it in James, while only briefly, when he is on what I refer to as "Planet James" and he is very excited and bouncing off the walls. We passed them again as we were leaving and the man was having a difficult time getting his son into the car. I started thinking about that boy and his father and that "look". As we pulled away and my son began driving me crazy asking to go to every fast food joint known to man just for the toys, I was wondering if that man's son had ever asked him for anything, ever? Again I thought about that "Look," it is a joyful look, but it's the one I dread; it's the one I hope will someday disappear, for when I have seen it in my son's eyes when he is somewhere else, he is in a place that I have never been to. I wonder what is the differential that makes it possible for my boy to walk away from that place, that place within himself that he goes when he gets that look, and why that other boy may never leave. Parents and professionals may argue on what is or is not autism and I can tell you they will and have argued in regard to my son James (A.S/Hyperlexic), but something I can't argue or deny is that look that I recognized in that child's eyes."

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I wrote that 2 years ago. I saw that boy last week he is now taller than me and he must be around 12. When I saw him he was still wearing a harness around his waist, I said hello and receive no response. This child will soon be taller than his father and he is already larger than his mother. I believe this child is still totally nonverbal. My heart ached when I saw him, as I thought about his family and his future. I thought about my son James, now 6, in a regular 1st grade class and the remarkable progress he has made. Although we still have many struggles and life is not always easy, what my son has accomplished would seem like nothing short of miracle to that family, I hope I never forget that.

Regards,

Erin -Mom of James 6 AS/hyperlexic and Justin 4 A.D.C.O. (Attention Different, Chronically Oppositional) (A.D.O.C. is my own diagnosis of Justin- his official dx is still being debated)