

News (and Education) of Autism

by Thomas A. McKean (10/02/09)

There's been a bit of autism in the news recently, not much of it good.

In Florida, a teacher was found guilty of abuse when she placed hot sauce in a drink so she could "teach a child with autism a lesson."

In Edmonton, a father killed himself and his son with autism after his son had become violent and the father was unable to get help, despite going through the proper channels.

In Seattle, a 15 year old boy had his teeth cleaned and one tooth extracted. The next morning he was found dead due to an inappropriate dosage of medication.

A recent study showed those with disabilities (including autism) are 50% more likely to experience violent crime.

And it wasn't even all that long ago that a boy with autism was killed at a church when the congregation tried to "deliver him from the demons that caused his autism."

And don't get me started about how the autism community is at war even within its own self!

What this tells me is despite the dramatic rate in the increase of the diagnosis, and despite the ongoing advocacy of myself and others, the public continues to be uneducated on the fundamentals of the autistic disorder.

How many have walked in front of a car? How many have been drowned in backyard pools? How many have suffered at the hands of their teachers or caregivers (or even doctors and therapists) due to a lack of education on their part? Way too many!

With all of the political nonsense going on the autism community over a cure, the bottom line is *there is no cure*. Those of us who have it are stuck with it. Your children are stuck with it. I am not telling you anything here you don't already know.

So the question is, with these kinds of things going on, and with no cure, what can we do? There is only one thing we can do. The next best thing to a cure is education. We need to educate people on the disorder of autism.

I am not suggesting that we make like fundamentalists and tap people on the shoulder at the local Wal-Mart and start preaching the gospel of autism. If they do not have any connection to autism, they may feel they have other important things to worry about. They may be right.

But with the mantle of autism comes a responsibility. One that none of us want, yet one we must bare anyway. If we are to have doctors, nurses, educators, therapists, or even ourselves interact with your loved one with autism, they must be educated. And it is our job, our duty, and our *privilege* to do so.

No one else is going to do this for us. Even if they were, are you sure you would trust them to tell the truth? I personally have done more presentations than I can count. (So have a few others writing in this magazine.) All of them have been to educate about autism. I can't speak for the aforementioned others, but in my own case, I can only pray I was correct in what I taught. There is so much about autism that we don't know. I have had to change my talks over the years to account for new information that has come along. Those of us writing in this magazine are considered experts. But that doesn't mean we are always right. And that includes me. When it comes down to the health, safety, and general welfare of your child, the only person you can truly trust is yourself.

You, as parents, have the final word when it comes to your children. You have the right to decide which therapies, which medications, which education is right for your child. I believed this 15 years ago when I helped to write the *Parent Options Policy* for the *Autism Society of America*, and I believe it now. If your child is to get the best care possible, you as a parent must be educated yourself, and you must educate those who will be working with your child.

Every one of the problems at the top of this article could have been prevented, would have never happened, if the right people had the right education. They were all preventable.

I want to end with some good news. Just a couple of days ago, a child with autism here in town (she is non-verbal) was admitted to the hospital. She had an undiagnosed juvenile diabetes and her blood sugar was dangerously high. No one expected her to live to see the next sun rising.

But she did.

She was in mortal danger. Here was a girl who was going to die. But she fought her way through it to live. To me, this speaks to the strength of the individual with autism. There are many things she cannot do, just as there are many things I cannot do. But there is a quiet strength in the individual with autism. There has to be. It is the only way that person can survive.

It is this strength that brought her back from the dead. It is this strength (albeit a bit misplaced) that is causing the political uprising in the autism community. It is this strength that will, eventually, either lead to a cure, or to change things to the point where people with autism can live the quality of life they so desperately desire.

Until a cure comes along, education is the best tool we have. Let's make the most of it.