

October 1st 2005

Hello to everyone in School District 34. Another year has passed so once again it is time for me to send an All Staff e-mail to announce that October is designated Down syndrome awareness month by the National Association for Down Syndrome. www.nads.org I have been writing an e-mail like this for several years now because my first son, Flynn, has Down syndrome. Consider this a public service announcement if you will, or simply, someone up on their soapbox.

My wife, Beth, and I had lots to learn when Flynn was born. Besides being new parents we suddenly found that the new life we had been expecting was going to be a little different. In the Steve Martin and Mary Steenburgen movie "Parenthood" by Ron Howard, there are some scenes when Steve Martin's character has visions of being on a roller coaster. It is a metaphor of his life. He is not enjoying the ups and downs and this vision keeps coming to him each time an added stress rears up in his life. By the end of the movie the images have changed. The feelings of dread and fear that he had been experiencing, have been replaced with laughter and euphoria. He realizes that the unnerving sense of not being in control is just part of the ride. Beth and I both love roller coasters. Our life since Flynn was born has had its steep drops, blazing speed, thrills, and times when we realized that we were not in control. We have even had that sinking feeling that you get when you get to a ride and see that it is going to take a really, really long time to get on the train. The wait has always been worth it though.

People with Down syndrome - not Down's people, or Down children or Down's kids; they are people first so it is always nice to refer to people with Down syndrome or kids with Down syndrome or Children with Down syndrome in a way that recognizes them as a person first - are good people. Despite stereotypes, they are very individualistic. They do have some characteristics in common though. That is why this genetic disorder is called a syndrome. Flynn was evaluated at five days old by a geneticist that looked for 10 common traits among infants that have Down syndrome. I think he had 7 of them. They also drew blood and did a karyotype that allowed the doctor to see that he indeed had 47 chromosomes rather than the typical 46. The common characteristics of people with Down syndrome include low muscle tone or hypo tonicity, a softening of facial features which gave rise to the unfortunate terms

mongolism and mongoloid. These are terms today that are considered derogatory and insensitive to people with Down syndrome and true Mongols! People with Down syndrome may have a simian fold of their palm. This is a crease that crosses the entire palm. Your hand probably breaks into two folds. I am not up on my palm reading, but I think one would be your life line and the other your love line :) (I really don't know) This is one characteristic that Flynn does not have! There are some other cute characteristics such as an extra large gap between his big toe and his second toe. He will never have a hard time finding flip flops that fit. Also, his pinkie fingers look like they only have one joint in them instead of two. It is really quite bizarre! Finally the other characteristic that Flynn shares with most people that have Down syndrome is mental retardation.

Mental development is the characteristic that varies the most among people. I believe a person's intellect (cognitive development) is what varies the most between any of us. We are who we are based on the input our brains have received through our life experiences. There must be an infinite number of ways we can develop and the same is true for Flynn. It just happens that the experiences and actions that go into and out of his brain are developmentally delayed based on what we consider to be typical for typical people.

The term mental retardation is emotionally charged for some families that have kids with Down syndrome. They don't like it because they consider it derogatory. It is an accurate term however, when used appropriately. When used inappropriately it is quite mean and insulting to people that are mentally retarded. People will say "That is so retarded!" meaning it is something they don't like, or that they find repugnant. Sometimes people use it as a put down about themselves as in, "I am so retarded!" That could be the proper use of the term, but usually it is so negative there is no other way to take it other than as an insult. Retarded simply means slowed down, delayed, or limited. If the term were used correctly it might not be as offensive, but I don't see a future when the morning traffic reports might go something like this.

" Oh what a mess this morning folks! Retards are on all the major expressways! The Edens is the worst! Cars are retarded all the way back to Lake Cook Road because of an accident caused by a truck that retarded suddenly to avoid a tire changer in the center lane at the merge! And of

course this has caused a retard of outbound traffic as well. This retardation is going to be here for a long time. If you don't want to be tardy for work, use an alternate route!"

For now I just ask kids that I hear using the term incorrectly why they are going to be slowed down. It usually takes a little explanation, but these opportunities are nice teachable moments. The poster in my room reads "Say what you mean. Mean what you say."

Flynn's delays are noticeable. He is ten years old now. Speech is his biggest delay. The low muscle tone makes it hard for him to form words. He worked on about 25 sight words last year and can recognize most of those words now. His counting improved greatly, and this year he just learned his phone number! It would be pretty tough for most people to understand him when he says it, but he can also write it down somewhat legibly...if he feels like it. In Flynn's world he has told me his phone number. He remembers that he has told me his phone number. If I ask him to tell me his phone number, he might not because he has already told me before so why should he tell me again. What's my problem...can't I remember it? Flynn was in a basketball camp this summer and had a great time. One of the drills was dribbling down the court. Flynn did it twice and decided that he thought that was enough.

He goes to school at Richmond Grade School and is in a 4th grade classroom with a one on one aide. The support he has received from our school district has been awesome. There were about 10 people at his P/T conference last year. We were all waiting to go into the classroom in the hallway. The parents coming out felt terrible because they thought they had backed up the schedule. I reassured them by saying "No, no. We are all here just for the next conference." You should have seen the look on there face then! :) It was a great decision to have Flynn start attending RGS in third grade last year. He made lots of friends despite his delay in speech development. For his birthday this summer some classmates went with us to see a movie. It was great to see them interacting with Flynn and just having a great time together. For any of you that might be wondering if 10 year olds think Hot Wheels are fun, the answer is yes. We lost one car temporarily, we are lucky no one lost an eye! This summer at the local parade kids I didn't even know were yelling to Flynn from their floats as they saw him sitting by the side of the road. He is playing recreational soccer this year and having a fun time. Sometimes

he kicks the ball and sometimes the ball just bounces off his foot. The other kids work really well with him though. This past summer he was in the Special Olympics and made it to the State Games for the second year in a row! He got a Silver medal in the 50 m dash and a Silver medal in the tennis ball throw. He had a great time!!

Flynn has two younger brothers, Will and Reed. If you need a way to remember their names they make a sentence. Flynn Will Reed. I can't really say we did that on purpose, but when the opportunity presented itself Beth and I took the optimistic approach. The three boys have a great time together. This year they all come home from school on the bus together. Sometimes they add bumps to the track of the roller coaster, or maybe it is me adding bumps to the track of their roller coaster, but in any case we all have fun together.

Thank you for reading and thank you for being a little more aware of Down syndrome. If you ever have any questions ask any time! Feel free to pass this on to anyone you would like to. I think that would be great.

This is a link to a great read about Down syndrome.
<http://www.nads.org/pages/ruletheworld.htm>

These are links to pictures of Flynn. They are on our shared server. If you forward this, the links won't work. These are big files so you will need to zoom out if they don't resize automatically.

[Flynn at the beach](#) [Boys in Chicago](#) [The Silver Medalist](#) [Birthday 1](#)
[Birthday 2](#) [Birthday 3](#) [Birthday 4](#)

There are more pictures of the Marshall Boys in this folder as well. [Marshall Boys](#)

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PROUD FATHER OF FLYNN DAVID MARSHALL

PS (The techie stuff) (I am probably encroaching on Dave Downing's hint of the day) This is a big e-mail and I am sure our servers can handle it, but if I had attached those picture files instead of making links to them on the S: drive Dave Downing would be extremely displeased with me. Big files bog down the e-mail server so I also sent this e-mail during an off peak time like in the evening. (are you still reading this???? You are really good!!) Sending stuff to All Staff or a building staff really taxes the system so if you ever need to send files to large numbers of people it is much better to post them to the S: drive and then give people the link. It is easy to do. Instead of inserting a File you just insert a Hyperlink. A window comes up and you can browse to the S: drive and your are done in just a few mouse clicks. (Still here? Golly!) It is a great way to share things and instead of sending an e-mail that says to look for something on the S: drive you can actually get them to see what you want with one click! Pretty cool. Have a great day.