

October 1st 2007

Dear Friends,

Please allow me to share with you something that is important to me. October is Down syndrome awareness month. I know many of you already know this because you have received an e-mail like this on October 1st for about the last 6 years. I like to pass on information about Down syndrome because when my oldest son, Flynn, was born, my wife, Beth and I found out he had some physical characteristics of babies that have Down syndrome. In about two weeks, genetic testing confirmed he had Down syndrome, but by that time we had fallen in love with him so he was ours for keeps. The hospital said they did not accept returns without original receipts and original packaging and we had thrown those out, so...I'm kidding!!!!!! Actually, I can remember holding Flynn for the very first time after he was born and feeling so very proud and amazed. The feeling of responsibility and knowledge that I would do anything for him filled me up. It was great.

So, Flynn has Down syndrome and he is now 12 years old. I am going to try to keep this a little shorter this year so I am going to direct you to some web sites for the technical aspects of Down syndrome. They really do a great job of informing people, so I hope you take some time to view them.

People with Down syndrome may or may not have certain physical and mental characteristics caused by an additional, or 47th, chromosome in all of their cells. There is a wide range of abilities in people with Down syndrome in the same way that there are a wide range of abilities in people that have only 46 chromosomes. It is the additional copy of the 21st chromosome that causes these characteristics, which I liken to an extra page in a set of blueprints. The blueprints are read, but that extra page is not always treated the same way by different people. In other words, people with Down syndrome are individuals just like everyone in the whole world. (Did I say I was going to keep this shorter? Wait... I said try.)

This past Friday a student in my 6th grade science class used the word retarded. I seized the moment and asked the class what retarded meant. I got a really good definition of "It means someone does not learn things very fast." That was after another attempt which was "Stupid or mental" (The attempt was not stupid or mental, that was the definition they gave me!!) I agreed that that was a common definition, but I also told them that it was wrong. I told my students that Flynn is mentally retarded which basically just means that he is slowed down. It takes him longer to learn things in school, but it does not mean he is stupid. I reminded my students of the line from *Forrest Gump* ... "Stupid is as stupid does". Flynn has many thoughts and ideas going on in his head; he just has a hard time getting it out. Speech is his biggest delay. It is very hard to understand what he says, but he has a pretty big vocabulary. He can play Star Wars Lego II on our game system. He loves to look at books. He likes to hide things around the house, and he loves to set out his favorite things and just put them in order on the floor. I asked my kids to not use the word retarded as an insult because it is usually not what they mean and it is not very nice. I have mentioned this in previous years too. It just seems like a topic that keeps coming up. Maybe if you happen to have a teachable moment sometime in October you could talk to your students, or kids, or even your friends!

Flynn has a busy school year. He attends two schools each day. He goes to Johnsbury Junior High for an adjusted learning program, but he ends his day at Nippersink Middle School doing different jobs. He has stamped books in the library and he is also a hall monitor. He has a card that says "Excuse me, may I see your pass?" I don't know what he does if a student does not have a pass. Flynn is still able to see his friends that he made in 3rd, 4th and 5th grades. The friends he has in Johnsbury are some of the students he attended school with before he returned to Richmond in 3rd grade. He will also continue these friendships in high school because Johnsbury and Richmond-Burton work together and the students meet at least once a week. We are very pleased with Flynn's schedule, and he likes it too. He is really enjoying school and we are hoping for some big academic gains.

Flynn is still riding at Main Stay Therapeutic Riding Stables. In the last month his instructor has had him taking the reins of his horse and independently controlling where the horse (Classy) goes in

the arena. Up to this point he has always had a lead walker and a side walker. It is really great to see his progress, and I think he is really making a connection between what he has to do and what he wants Classy to do.

Speaking of riding, I got a tandem bicycle and Flynn and I have a good time riding that around town, out to Main Stay, on the bike trails and even on Lake Shore Drive back in May for Bike the Drive. Flynn also plays soccer. Our league lets him play down in a younger league so I am able to have Flynn, Will and Reed all on the same team. He does ok. Sometimes he plays goalie and he does ok. Usually the other kids really turn up their defense, so that is good! I can honestly say Flynn is happy whether he is on the field or on the sideline. He just loves being a part of the yellow team.

I hope you have enjoyed this little (?) e-mail. I don't know if it is up to snuff in comparison to years past, but here is one more anecdote. Figuring out what Flynn says is very challenging at times. Beth is better at it than me, but we all have our moments. A few weeks ago I asked Flynn how his day at school had been. He usually says "good". I can get more info by asking yes or no questions. This night I asked if he worked in the library and he said "yeah", but then he became very excited. He was saying something but I could not make it out. This turned into the Monday Night Mystery!! I asked him to say it again so I could try to narrow it down. Flynn's brothers sometimes get involved but these guesses are not always helpful. (Try playing 20 questions with a 2nd grader and you will get an idea of what I mean. I was asking general questions, and they were asking very specific questions.) Flynn's response to Reed when he gets tired of these queries that are way off base is a terse "no" followed by three rapid syllables of "top i Reed!" (Stop it Reed!). Sometimes he mixes it up and it is "Reed! Top i !" (Reed! Stop it!) Well, it was Beth to the rescue when she finally figured out that he was saying High School Musical Two. He was so excited that the library had received a new copy of the book that day and he had been one of the first kids to see it. He was so glad that we had figured it out, and now we had a new "phrase" to try and keep in our vocabulary.

If you have questions feel free to ask. Thanks for all the support! Have a great October! Feel free to pass this on to anyone you might think would like to read it.

Web sites

National Down Syndrome Society

http://www.ndss.org/index.php?option=com_content&task=view&id=1962&Itemid=233

National Association for Down Syndrome

<http://www.nads.org/>

Tech note and something to keep me on Dave Downing's good side: I did not include any pictures because it makes the file too big and may crash the e-mail server. It is not a good idea to send a big e-mail to All staff. I will have some pictures on the shared drive that you can view if you are in the district. [Click here](#). Or look in the Marshall Folder on the S drive. If you are out of district 34 e-mail me and I will send some pictures of the boys to you directly.

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