

October 1st 2004

Hey!! There is new stuff in here!!! I don't copy and paste each year!!! Thanks for reading. It only looks long because it is a big font...well maybe it is kind of long, but I hope you will read it.

Dear Friends and Colleagues, welcome to October!! October is my favorite month of the year. Many of you know why! Some of you might remember with a little reminder. The rest of you may be wondering about the color of this font. I hope all of you will continue to read and allow me to stand on my electronic soap box to pass on what I consider to be vital information. Thank you in advance for your time...

I think this is the 5th e-mail that I have sent to ALL STAFF in District 34 on October 1st. This date has significance to me because October is designated by the National Association for Down Syndrome as National Down Syndrome Awareness month. (For those of you with keen skills of observation, yes that does make the acronym NADS. It does take a little while to get used to mail coming to your house with a big return address that says NADS, but you get used to it. It is now a ubiquitous word in our household.☺)

Well, as this is Down syndrome awareness month I would like to spread some awareness. Here is a little history... I have three sons whose names are Flynn Will and Reed. I tell people the easy way to remember their names, is to say them as a sentence. Cool huh? Yes my wife and I sort of planned that. Right after we found out she was pregnant for a third time and we realized we would need a third name. Before that the plan was just to have two kids. Ah Reed, the little trickster, was even born on the appropriate date of April 1st!! Well, we thought making the sentence was a cute and optimistic way to set a goal for our oldest son Flynn. Flynn you

see was born with Down syndrome. He is now 9 years old and has brought an immeasurable amount of joy into our lives. So, I started sending out e-mails in October to talk to our staff about Down syndrome. I have continued because I have information to share with the “rookies” to make them *aware*, and because the veterans tell me that they like to get the updates about Flynn. Thank you from everyone that responds to me. I have saved the replies from previous years and they mean a great deal to me.

Down syndrome is very interesting. It is not a disease. It is a genetic disorder caused by the presence of an extra chromosome in all of Flynn’s cells. You (should) have 46 chromosomes. Flynn has 47. There are 23 pairs of chromosomes present in a typical person. The 21st pair of Flynn’s chromosomes has an extra hitchhiker that was picked up when one of the gametes formed. (I am trying to keep this rated G so you can share it if you want to. If you would like more info please ask☺) This extra chromosome causes up to ten or so characteristics that may or may not be expressed by individuals with Down syndrome. The most common characteristics are developmental delays AKA mental retardation, low muscle tone, and flattened facial features. Finding out that Flynn had Down syndrome about 45 minutes after he was born was tough for both Beth, me and even our doctor, but now I am ok with the probability that he is not going to be the next genius like Einstein, body builder like Arnold, or actor with a chiseled face like Robert Redford. Flynn is who he is, just like all of us, which means he is very special.

Something to be aware of is that people with Down syndrome are people first and that is how they should be referred to. Flynn is not a “Downs child”. He is not part of a Downs group. People with Down syndrome are not Downs people. That

pesky little s comes from the possessive form of the doctor that first described the syndrome. He was Dr. Down. In the very first e-mail like this I said Flynn is not a Downs child unless he is sitting on the floor or is sad about something, and even then there is a grammatical error with that statement. 😊 Flynn, and other people with Down syndrome are people first, or children first, or babies first.

I talk to my students about Flynn at the beginning of the year about the meaning of the word retarded. Just yesterday I heard a girl calling another kid a retard and I asked her what she meant. She said that the other kid was a “weirdo”. I told her that not what retarded means. At this point the lesson that I had talked about in class about a month ago sunk in. The State of Illinois changed the terminology used by special education teachers a few years ago to describe a student’s designation that has a mental delay back to “mentally retarded”. Some people were upset by this. They did not think it was sensitive or politically correct. I think it is very descriptive and conveys a meaning that is easily understood. Unfortunately, there is a definition amongst students in all grades and even in adults that pervades our society. Weirdo. Flynn has delays because of his mental retardation. It takes him longer to learn how to do things. His development is *slowed* down. That is the real meaning of retarded, and that is not a weird thing. I am not sure if I have ever asked this before but this year is different because Flynn is now in our home school, Richmond Grade School. What I would ask of you is if you hear one of your students use the word, retarded, if the opportunity is there just ask the student what they mean by it. Educate them if they need it. Try to get them to realize that their words have meaning and to be careful about what they say. Thank you!! It would mean a great deal to me.

Here is the update part. Flynn has had a great year!!! We were very excited when he turned 8 in July of 2003 because he was eligible to participate in the Special Olympics. He competed last Spring in the 50 meter dash and the tennis ball throw. He qualified for the State games held in June and competed in Bloomington to win two bronze medals!! Here is a picture of Flynn getting the Bronze for the tennis ball throw. We were very proud of him and put him in the Richmond Round Up Days parade in August. He had a great time. As I mentioned earlier Flynn is now in Richmond Grade School. He is mainstreamed into a 3rd grade classroom and has a great teacher and a wonderful aide. He came from a SEDOM classroom that he had been in for three years. It was an adjusted learning kindergarten class that had 8 students and about 8 adults in it most of the time!! He now has 27 classmates but has adjusted well and is starting to learn all of their names. Pretty much any time he sees someone he thinks could be in his class he just calls them “boy”. I have not seen him approach a girl outside of school, but I don’t think he calls them “boy”. They asked the students to sign up to be his lunch buddy and made a list with room for ten names. 16 kids signed up!! Beth and I really thought about this decision, but we are very happy he is where he is. One of the traditions at RGS is the kindergarten milk trolley. The kindergarten teachers have an old tricycle that has a basket in the back that the students take turns riding down to the cafeteria to get milk for snack time. One of Flynn’s jobs is to help load up the tricycle every day. He loves it!!

Flynn’s biggest delay is still speech. He can let us know what he wants at home and we have been able to figure out what he says most of the time. His big thing this summer was to say “Mom, (or Dad depending on who was around at the time) Shrek two movie again.” Beth was the one that figured this out. Imagine how that sounds with no beginning sounds

and mostly vowel syllables and that is what it sounds like. Still, the meaning behind it is awesome. He loved that movie and he let us know on a daily basis, sometimes an hourly basis that he wanted to see it again. His other two phrases that developed this summer were “What do you mean?” and the ever present toddler phrase “Why?” Usually these two are put together in wicked combination and rapid succession as I try to explain why having ice cream every day is not something that his mother and I want to expose his digestive system to. To facilitate his communication at school he has an amazing speech synthesizer that has a touch screen that he continues to learn to use. He likes to use it to tell knock-knock jokes and riddles as well as to “talk about” what he is doing in class.

Another speech phrase he learned was how to tell us that he liked going on the Viper roller coaster at Six Flags in July. He would point to this [picture](#) and say “Daddy. Flynn, scared. Again!!” He was scared silly, but isn’t that the point!! He loved it and we did get to go again last weekend and he ran right up to the line without and hesitation or apprehension. The picture did not turn out as well, but his eyes were just as big!!

Well I think that is it for this year. Thank you very much for taking the time to read this if you made it this far. There are more pictures of the boys in this folder on the shared server so feel free to browse them. Just click on this link.

<\\\\209.174.46.250\\shared\\Marshall Boys> That should work.

Thank you again and have a great October!! ☺ ☺

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