

October 1st 2006

I am going to take a guess that many of you reading this are doing so on Monday morning. If so, I apologize for the length of this e-mail in advance. I hope you will find the time to read this when you are comfortable and not rushed to deal with the myriad tasks that are more urgent for your attention.

Ahhh...I hope your day is going well now.

For the detail conscious people out there I did not actually send this at 7:00 AM on Sunday morning. My computer sent it. I was on my bicycle starting a 124 miles ride to raise funds for Special Olympics Illinois. Well that is my plan anyway...I am actually writing this on Friday night! This is getting harder to follow than the timeline of "Back to the Future" 1 2 & 3!! Well since I am all over the space-time continuum let me back up to 1995.

In 1995 my first son, Flynn, was born. About 45 minutes after the greatest event of my life our doctor came back into the room and informed my wife, Beth, and me that Flynn had some characteristics of a child with Down syndrome. "Really?" I said. Dr. Stan had tried to give me the news by pointing out the simian fold on Flynn's palm. I remember pointing out to the doctor that I could make the crease across my palm into a single line if I held my palm just so. Slowly the news sank in. Beth and I talked a little. It was about 4:30 in the morning. Flynn was sleeping. Beth wanted to sleep. We decided I would go home and get some sleep too. We had already shared the wonderful news of Flynn's Birth with our parents. Beth's mom and dad would be at the hospital in the morning. My parents would be driving up from Decatur in a few days. Now what else would we say? I called my mom when I woke up and told her that Flynn might have Down syndrome. I cried.

Beth and I learned a great deal in the next week. On Flynn's fifth day we took him to Rockford for a series of tests that included a blood draw to look at his chromosomes. A genetic counselor also evaluated Flynn for 10 characteristics of children with Down syndrome. I think he expressed 6 or 7 of the 10. In two weeks the karyotype confirmed that Flynn had 47 chromosomes instead of the typical 46 chromosomes in humans.

45 minutes... five days... two weeks... I don't know when I realized it, but at some point I realized that I did not feel any differently about the fact that Flynn was my son and that nothing would change the feelings of love and devotion, awe and wonder that I had for him the very first time that I held him. Flynn is my son. He is the oldest of my three sons, and as my second son, Will, said in the title of his book that he authored for the Young Authors contest at his school last year, My Brother Flynn is Mostly Like Me.

The National Association for Down Syndrome designates October as Down Syndrome Awareness Month. I have been sending out an e-mail for several years now to raise the awareness of my colleagues about Down syndrome and many people tell me they like to get updates about Flynn. I am amazed every year by the connections that are made just by sending

out a few (?) lines of information. For all the veterans out there I thank you for your encouragement and patience as I repeat some things you already know.

An extra 21st chromosome causes Down syndrome, or Trisomy 21. Typically people have 23 pairs of chromosomes that tell your body how to grow. The extra chromosome gives extra information and causes a range of characteristics for people that have it. Extra chromosomes can cause other genetic disorders, and sometimes trisomies of certain chromosomes result in miscarriages. The important thing to remember about people with Down syndrome is that they are people first. Flynn is a child with Down syndrome, not a Downs child. With 46 out of 47 chromosomes the way they are supposed to be they really do have more in common with the rest of the world than differences!

Flynn is 11 now and is in 5th grade at Richmond Grade School. He has a one on one aide that is a Saint and a group of teachers and therapists that work very hard for him and are very dedicated to what they do! We just signed him up for band and he is trying his hand at percussion! It is going to take lots of practice!! This is his third year at RGS and we are very pleased with his socialization and academic progress. It is heartening to sit on the side of the road during local parades, or to be in parades, and hear kids yelling "Hi Flynn" and waving like mad so he will see them and wave back! Flynn started playing soccer last Fall on a Under 9 team, even though he was 10, and had a great time. More often than not the ball went right past him, but as more people got to know him, the whole crowd would cheer whenever he connected and kicked the ball! He even played goalie and made some good saves with the help of a strong defense! His biggest delay is still his speech. He definitely has more words, but they can be pretty hard to understand sometimes. We are working on getting him to extend his verbal sentences. He has been working on sight words and can recognize sentences that he has practiced with. In a sense I can say Flynn can read. Beth and I named our second son Will, and when we had a third son we decided that Reed would be a good name to reflect our optimism that Flynn Will Reed.

Thanks for reading this far. If you would like any of my old e-mails I am happy to share them. The last thing I have are some links to our shared s drive. As a favor to Dave Downing I do not send pictures contained in this e-mail or even attached files because it would be too much data for the server to handle. (He could give you the particulars if you are interested) So enjoy the pictures and please feel free to share this e-mail. If you forward it to someone out of the district the links won't work so ask me to send you the files and you can attach them if you want to. Take care and have a great year!

[11th Birthday](#) [Laughing](#) [Mayflower](#) [Pool Picture](#) [Flynn with Two Cheeseburgers](#)
[Beach I](#) [Reed](#)
[Beach 2](#) [Beach 3](#)
[Flynn flying a Kite](#) [Will Flying a Kite](#) [Reed Flying a Kite](#)

P.S. When these open they will be big I think! The easy way to shrink them should be by rolling the scroll wheel on your mouse.

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