

Friday, October 01, 2010

Dear Friends, Colleagues, Acquaintances, Family, and any other Readers of this e-mail,

Happy October! Again I find myself taking the time to spread the word about Down Syndrome since October is Down Syndrome Awareness Month. I take this assignment on each year because I have a 15 year-old son that has Down Syndrome. Flynn has a great story, and I have shared much of his life in previous years. The earlier e-mails are here. <http://www.antioch34.com/webpages/jmarshall/october.cfm>

I will share new information shortly, but first I am borrowing some information from the National Down Syndrome Society's web site.

Join NDSS this October to Celebrate National Down Syndrome Awareness Month

Down Syndrome Awareness Month is marked by national programs to promote awareness for the abilities and achievements of those with Down syndrome.

New York, NY - October 1, 2010. This October the National Down Syndrome Society (NDSS) invites the country to celebrate Down Syndrome Awareness Month in recognition of the many achievements and abilities of people with Down syndrome. People with Down syndrome are living longer than ever before. The life expectancy of individuals with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today. Children with Down syndrome are often fully included in social and educational settings and increasingly go on to graduate high school and attend postsecondary education programs. While placement in the workforce remains a struggle, the situation has improved and adults with Down syndrome have attained a variety of positions, bringing enthusiasm, reliability and dedication to their jobs. Down syndrome is the most commonly occurring genetic condition, one in every 733 live births is a baby born with Down

syndrome, and it is the most commonly occurring chromosomal condition. Advancements in education, research and advocacy have had a tremendous impact on the opportunities that individuals with Down syndrome have to live healthy and fulfilling lives. People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways. http://www.ndss.org/images/stories/NDSSresources/pdfs/dsam_press_release.pdf

Flynn had a good year. He participated in the Special Olympics program *Run With The Law* which is a new program that I helped organize in Antioch last November. About 30 people ran with Law Enforcement Personnel from Lake County including students from my school. It was a great event and Special Olympics Illinois hopes the program will grow across the state. Flynn also ran in the Bigfoot Beach State Park Turkey Trot. He won his division, and that is all I will say about that! :) He also participated in his 7th year of Special Olympics. He did not make it to the State Games this year, but he is developing his competitive spirit.

Flynn had a summer of firsts. He spent a whole week away from home at Camp Red Leaf. He enjoyed the ratio of three counselors to one camper. It also helped that they were girls, girls with long hair also described by Flynn as "long hairs". Only pretty girls are given this distinction. This was the first summer that Flynn had a season pass to Six Flags Great America. Flynn was able to enjoy the rides and the shows. We saw *Show Stoppin'* more than a dozen times, probably because of the "long hairs" in the cast. On his 15th birthday we went to the show and had his picture taken with the cast. He has some great memories from the summer.

Flynn has had an exciting start to his new school year. He attends Richmond-Burton Community High School and is now back

with the group of students that he was included with from 3rd through 5th grades. We wondered what would happen to the friendships when he started attending middle school in another district, but we are happy to report his friends were excited to see him again. While Flynn attended Johnsburg Junior High he was still able to participate in track at Nippersink Middle School. This activity helped him stay connected. Beth was surprised to discover how many of her juniors remembered him from the old days.

Flynn has become quite popular. He was voted onto the Homecoming Court by the freshman class. When Flynn was introduced at the pep assembly last week, he received more applause than the King and Queen. While Flynn enjoyed the festivities, he was a little overwhelmed when the student body chanted his name. Flynn attended the Homecoming dance with a group of friends. He was able to have a typical teenager experience: pictures, dinner and of course lots of dancing. Beth might even say too much dancing based on the details Flynn shared.

This week some of Beth's juniors asked if she had seen Flynn's fan page on Facebook. She had no idea so she checked it out. One of the junior football players who eats lunch with Flynn created the page *Flynn Marshall is the man!* Currently there are over 200 fans. With his newfound popularity Flynn has become more confident and is using his communication device to interact with people. Since Flynn has friends on the football team he enjoys attending the games. Flynn is running the track with a spirit flag that is bigger than he is. The best part for Flynn is that he hangs out with the cheerleaders (more "long hairs").

Flynn has also gained confidence at Main Stay Therapeutic Riding. He is riding his horse independently and completing obstacle courses. We are looking forward to watching Flynn develop friendships, improve his communication skills with his device, send email and update his status on Facebook with Beth's guidance. He already wanted to invite all of his

friends over to our house for a movie. Beth says we don't have room for 75 students in our basement.

We are fortunate to have so many people that accept Flynn for who he is. Thank you for taking the time to read and share this. Please feel free to pass it on.

Jay Marshall

Antioch Upper Grade School October 1st, 2010 (Thank you to my wife, Beth, who co-authored this year's letter.)

Here is some basic information from the National Association for Down Syndrome web site.

What is Down Syndrome?

Down syndrome is a genetic condition that causes delays in physical and intellectual development. It occurs in approximately one in every 800 live births. Individuals with Down syndrome have 47 chromosomes instead of the usual 46. It is the most frequently occurring chromosomal disorder.

Down syndrome is not related to race, nationality, religion or socioeconomic status. The most important fact to know about individuals with Down syndrome is that they are more like others than they are different.

Diagnosis

Down syndrome is usually identified at birth or shortly thereafter. Initially the diagnosis is based on physical characteristics that are commonly seen in babies with Down syndrome. These include low muscle tone, a single crease across the palm of the hand, a slightly flattened facial profile and an upward slant to the eyes. The diagnosis must be confirmed by a chromosome study (karyotype). A karyotype provides a visual display of the chromosomes grouped by their size, number and shape. Chromosomes may be studied by examining blood or tissue cells.

Cause

Down syndrome is usually caused by an error in cell division called nondisjunction. It is not known why this occurs. However, it is known that the error occurs at conception and is not related to anything the mother did during pregnancy. It has been known for some time that the incidence of Down syndrome increases with advancing maternal age. However, 80% of children with Down syndrome are born to women under 35 years of age.

Learning & Development

It is important to remember that while children and adults with Down syndrome experience developmental delays, they also have many talents and gifts and should be given the opportunity and encouragement to develop them.

Most children with Down syndrome have mild to moderate impairments but it is important to note that they are more like other children than they are different. Early Intervention services should be provided shortly after birth. These services should include physical, speech and developmental therapies. Most children attend their neighborhood schools, some in regular classes and others in special education classes. Some children have more significant needs and require a more specialized program.

Some high school graduates with Down syndrome participate in post-secondary education. Many adults with Down syndrome are capable of working in the community, but some require a more structured environment.

Health Issues

Many children with Down syndrome have health complications beyond the usual childhood illnesses. Approximately 40% of the children have congenital heart defects. It is very important that an echocardiogram be performed on all newborns with Down syndrome in order to identify any serious cardiac problems that might be present. Some of the heart conditions require surgery while others only require careful monitoring. Children with Down syndrome have a higher incidence of infection, respiratory, vision and hearing problems as well as thyroid and other medical conditions. However, with appropriate medical care most children and adults with Down syndrome can lead healthy lives. The average life

expectancy of individuals with Down syndrome is 55 years, with many living into their sixties and seventies.

http://nads.org/pages_new/facts.html