

Exercise

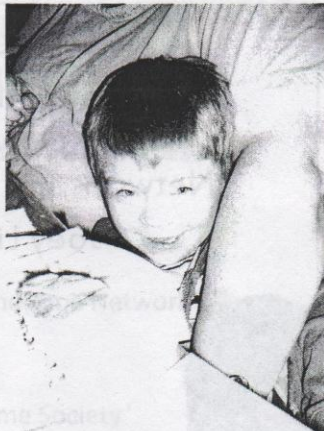
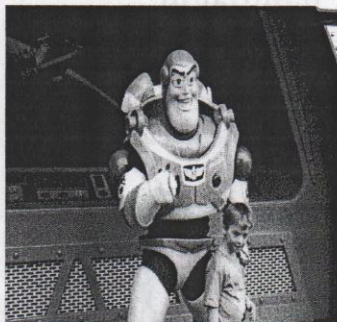
- We have passed out baggies with M&M. **DO NOT EAT THEM YET**
Each bag contains the DNA for your child. Some of you may have to share.
- The bag contains about 46 M&Ms- 23 from each parent . Colors being:
 - yellow-8
 - orange-8
 - blue-6
 - brown-6
 - red-9
 - green-9
- Sex is determined by red/green pairings: more red=boy, more green=girl
- Hair color is determined by yellow/orange pairings: more yellow=blond, more orange=brown
- Eye color is determined by blue/brown pairings: more blue=blue eyes, more brown=brown eyes.

Ellen Lindsey
 President of the Champaign
 County Down Syndrome
 Network and this is my son,
 Joey Lindsey.



- First I am the mother of a brilliant seven year old boy with Down Syndrome. He is the light and reason for my life. Without him, I wouldn't be able to stand up here in front of you and talk, it would have scared me beyond belief. Truly. He is the reason I do what I do.
- He has had over 10 surgeries in his seven years. The first 9 before he was 7 weeks, yes, weeks old. His first surgery before he was a week old. In the hospital we had only positive people around us and it set a precedent that I have followed since. Don't tell us that Joey can't do something, he WILL do it in his own time. Now there are things he won't be able to do for safety or whatever, but don't tell us he won't do something.
- When you have a Special Needs child you throw out the timelines, you throw out the books that tell you at blank your child should be doing this or that. We do it in our own dang time!
- We didn't know that Joey had Down Syndrome or DS as I may refer to it. It didn't matter to us.
- Joey attends a Cross Category First Grade class at Thomas Paine in Urbana. We have had great teachers and therapist working with us. This is the foundation of our start in his education. He has had an IEP since he was three starting at Washington Early Childhood.

This is Joey



We went to Florida in 2010.

Champaign County Down Syndrome Network

We support families and individuals with Down Syndrome. We refer to individuals with Down Syndrome – Self Advocates once they are old enough to advocate for themselves.

We have monthly meetings for our families with educational topics and speakers as well as some fun topics. We have had someone come in an talk about how Yoga can benefits our children. Kids love it and it was fun for the parents too!

We meet the third Thursday of each month at 6:30 pm at the DSS building by Kraft on Bradley Ave in Champaign. You are welcome to come and join us.

Since the DSN is mainly a parent and volunteer organization our main source for raising funds for our group is the Buddy Walk.

We walk to promote inclusion and acceptance of those with Down Syndrome. We have fun all day.

There are informational booths, carnival games, bounce houses, food and ice cream. You can to www.Champaigndsn.org to find out more.

We need volunteers to pull this wondrous day off. Joey is seven and has recognized the Buddy Walk Logo for a few years now. He knows that logo means something important for him and something fun.

We also have an Inclusion Week in Nov/Dec to promote inclusion in the classrooms. We usually give a game or book to the schools that our kids are in and then some of the other schools too.

We also try and sponsor conferences in the area on safety, inclusion and other topics relative to our parents and students.

We help to sponsor the SPREAD THE WORD TO END THE WORD with Best Buddies and Special Olympics. It is in March and we always can use volunteers for this. We try and get into the schools and set up on the u of I Campus. One year we actual had some u of I students walk up to some self advocates at the table and call them retards!

Tell me how you could say such a mean thing to this face?



Down Syndrome Fact Sheet

- Down Syndrome is also known as Trisomy 21.
- Down syndrome occurs when an individual has three, rather than two, copies of the 21st chromosome. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.

- Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies is born with Down syndrome.
- There are more than 400,000 people living with Down syndrome in the United States.
- Down syndrome occurs in people of all races and economic levels.

- The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.

- A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.
- Life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today.
- People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways.

- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives.
- Researchers are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

Volunteering

What we want you to know

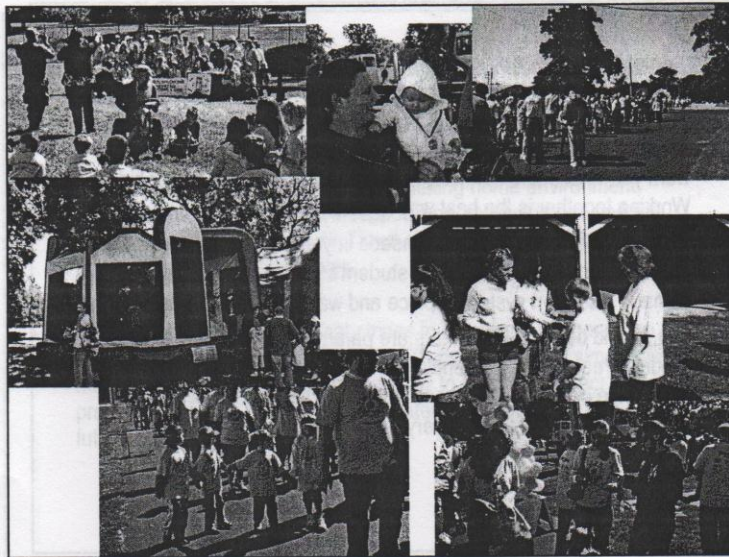
- One of the things we want you to know, is our kids with Down Syndrome are just like other kids, they want the same things as typically developing kids. To be loved, to learn, to communicate and to be accepted.
- Most parents want you to know that we are willing to answer questions you have about our lives and how our kids function and what they need. We are willing to go the extra mile to get what is best for our kids.

- Inclusion Week - making schools more inclusive for all students
- The campaign to Spread the Word to End the Word
 - This campaign asks you to take a pledge not to use the word and encourage others not to use it as well.

- We want to work with you, not against you in the classrooms. We want you to educate our kids, we want to educate you on our kids. Working together is the best way to get this done.
- If you have a child with special needs in your classroom, make a special effort to get to know the student's parents and family. Most of us have a support system in place and want you know understand it.
- You should be aware that there are parents that do not want their children treated any differently than mainstream and will not seek assistance or help from anyone with their child, "they will be fine." Yes it is true, fairly rare, but very true.

- If you have an idea about working with our students, then find a way to explain it to us. To excite us and show us that this could be life altering.
- By the time our kids get to school, most have had three years of therapies in home, possibly numerous surgeries and appointments. We have learned to communicate with our children by learning systems like PECS or American Sign Language. I mark that as a language on Joey's paperwork for school. So explaining another system for us to work on is a little overwhelming.

People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways.



Volunteering

- Volunteering with any organization gives meaning to what you do and you can help make a difference. We rely on our volunteers for support in getting our projects done.
- Some of the things we do in the community are:
 - Set tables up at the Disability Expo and have a table there with information. Saturday, October 22
 - Hold conferences or workshops and include the other disability groups in the area bringing in topics of interests.
 - Have a float in the 4th of July parade.
 - Inclusion Week making schools and children aware that our kids are more alike than different.
 - The campaign to Spread the Word to End the Word
 - This campaign asks you to take a pledge not to use the r-word and encourage others not to use it as well.

We need you!

- We would love to have you come to the Buddy Walk as a volunteer or as someone to participate. Joey's Jesters is a great team to be on!

- Thank you for having me and finding out more about the Down Syndrome Network, Down Syndrome and Joey and me!
- If you have questions now or later, please email me at ellen.lindsey.dsn.president@gmail.com or email president@champaigndsn.org anytime and ask for me and they can forward to me. I am happy to answer any questions for you. I believe in pay it forward.

Some Resources

- NDSC National Down Syndrome Congress Center
– www.ndscenter.org
- Champaign County Down Syndrome Network
www.champaigndsn.org
- NDSS National Down Syndrome Society
www.ndss.org