**Questions About Down Syndrome (DS) That Kids May Ask**

**Why does Hannah have Down syndrome?**
Hannah was born with DS. Our bodies are made up of cells and every cell has 46 chromosomes. People with DS have an extra chromosome.

**Can I catch Down syndrome?**
No. If you weren’t born with DS you will never get it. You can’t catch DS from Hannah.

**Is there a cure for Down syndrome?**
No. There’s no medicine to make DS go away. Hannah will have it for the rest of her life.

**Why does Hannah seem so tired in class?**
All the muscles in Hannah’s body are very soft and flexible. She has to work extra hard to do the things you can do easily. This extra work makes her tired.

**What should I do if I can’t understand what Hannah is saying?**
Ask Hannah to say repeat what she said, have her show you what she is talking about or ask your teacher to help you understand each other.

**Why does Hannah leave the classroom with adults?**
Hannah works with some adults to get extra practice with her speech, math and handwriting. Some days she may have a helper here with her in class to explain what is being taught and help her understand everything.

**Why does Hannah sometimes scratch or hit others?**
Hannah has feelings just like you. Sometimes when she is upset she can’t find the exact words to tell someone how she is feeling. She might be feeling sad, afraid, or hurting, etc. This seems to be when this happens. Giving her personal space seems to help Hannah.

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**Hannah**

My name is Hannah and I am 7 years old. I enjoy doing a lot of the same things as other kids my age.

I jump on my trampoline. I can jump 70 jumps. I play kick ball and run. I play board games like Candy Land and my favorite card game is Uno. I love to play “Hide and Seek”. I read books and sing songs like “Jesus Loves Me.”

I have two brothers and two sisters. I love to spend time with my family. I ride the 3 wheeler with my brother, Aaron and run races with my brother, Michael. I go swimming with my sister, Marie and talk with my sister, Andrea, on the phone. I cook with my mom and play on the trampoline with my dad.

I am a lot like everyone else my age. One difference is that I have Down Syndrome. I can do everything everyone else can except sometimes it takes me a little longer to do it which is why I may sometimes need extra help or more time to do it.

My friends are very important to me. My friends help me learn. Thank you for being my friend.
October 2009

Dear Parent,

Some of you already know our daughter, Hannah. For those of you who do not, Hannah has Down Syndrome. She is excited to be in 2nd grade with your child. She is a cheerful student who loves school and to learn with her classmates.

Our expectations for Hannah are high, much like those you have for your child. We hope she will learn to the best of her ability, make lasting friendships, follow school rules, and be a contributing member of the classroom.

Your child’s role modeling and positive interactions with Hannah will help her to be successful in these areas. Today, your child was part of a brief presentation which highlighted and explained some challenges Hannah and others with Down Syndrome face along with some truths about Down Syndrome.

In addition, it hopefully gave some insight into her similarities to other children. We hope this helped answer some of the questions your child may have.

We hope you will contact us if your family has any questions. Children with Down Syndrome have unlimited potential when given opportunity and support.

Sincerely,
Jay and Jane Luthi

For more information on Down syndrome you can visit the Down Syndrome Guild of Greater Kansas City website at www.kcdsg.org. You can also contact the Executive Director, Amy Allison at 913-384-4848.

Myths & Truths
About Down Syndrome

Myth: Down syndrome is a rare genetic disorder.
Truth: Down syndrome is the most commonly occurring genetic condition. One in every 800 births is a child with Down syndrome. There are currently 350,000 people in the U.S. with Down syndrome, with 5,000 to 6,000 births per year.

Myth: Most children with Down syndrome are born to older parents.
Truth: Eighty percent of children born with Down syndrome are born to women younger than age 35 due to higher fertility rates. However, research has shown a link between the incidence of Down syndrome and maternal age.

Myth: Down syndrome is hereditary and runs in families.
Truth: Most cases of Down syndrome are sporadic, chance events. In general, Down syndrome does not run in families and a sibling or aunt has no greater chance of conceiving a child with Down syndrome.

Myth: People with Down syndrome have severe cognitive delays.
Truth: Most people with Down syndrome have cognitive delays that are mild to moderate. IQ is not an adequate measure of the functional status of people with Down syndrome. People with Down syndrome have great potential if given opportunities.

Myth: The life expectancy of people with Down syndrome is 30.
Truth: Thanks to advances in medical and clinical treatment and opportunities to thrive, as many as 80 percent of adults with Down syndrome reach age 55, and many live longer.

Myth: Behavior problems and depression are just part of having Down syndrome.
Truth: Often, medical or mental health problems go untreated due to the assumption that it is typical of having this genetic condition. Complete examinations by appropriate health care professionals should always be pursued.

Myth: Children with Down syndrome are placed in segregated special education programs.
Truth: Children with Down syndrome are included in regular academic classrooms across the country. Students may be integrated into specific courses or fully included in the regular classroom for all subjects.

Myth: Adults with Down syndrome may be unable to work.
Truth: Businesses seek young adults with Down syndrome for a variety of positions. They are employed by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.
This booklet was designed by the Down Syndrome Guild of Greater Kansas City to help you welcome your new student. If you need additional resources on Down syndrome please call our office at 913-384-4848.
We are pleased to share our All About Me booklet with you. This booklet contains a lot of information about our child ____________ and our family. We hope that this information will help you to get to know our child and some of his/her interests, strengths and skills.

We have high expectations for our child as other parents do for their children. We hope he/she will follow school rules, perform to the best of his/her ability and be a contributing member of the class. Good teaching and positive peer role models will help our child be successful.

If you have any questions, please call us at home ______________ or at work ______________. The best time to reach us is__________.

We look forward to working with you this year.

Please let us know how we can help make this a great school year.

Sincerely,
When our child was born we worried about:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Our hopes for this year are:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Our lifetime goals for our child are:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Here are some ways we think you can help our child be successful:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
My name is: ______________________________________________________

My Mom’s name is: _____________________________________________

My Dad’s name is: _____________________________________________

I have _____ Brother(s)   Their names are: ________________________

I have _____ Sister(s)     Their names are: _______________________

We have a pet:_________   My pet’s name is: _______________________

Other family or friends that I want you to know about are:

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
Interesting Facts About Me!

My favorite activity is:_________________________________________

My favorite color is:___________________________________________

When I go outside, I like to:_____________________________________

My favorite hobby and other activities are:
____________________________________________________________
____________________________________________________________
____________________________________________________________

Three things that really motivate me are:
____________________________________________________________
____________________________________________________________
____________________________________________________________

When I grow up I want to:
____________________________________________________________
Here are some things you may need to know about my health:

Surgeries:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Current Medication (s):

________________________________________________________________________

________________________________________________________________________

I wear glasses: Yes No I wear hearing aides: Yes No

When I am not feeling well I might:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Other things you need to know about my health:

________________________________________________________________________

________________________________________________________________________
Things that make me feel happy:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Things that might upset me:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

It’s hard for me to:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Things I may be afraid of:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Here are some places that I like to go to with my family:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

_____________________________________________________________

My favorite vacation was when my family went to:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

My favorite places to go in my neighborhood are:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________
Here are some things you may need to know about how I communicate:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

My parents would prefer that you communicate with them by:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

If I am frustrated I might:

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Here are some things I do to help around the house:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Here is a list of things I do in the community on a regular basis:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Here are some things I can do if someone helps me:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Look What I Can Do!
Pictures of Me!
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Kids With Down Syndrome

More Alike Than Different

Focus on ability

October is National Down Syndrome Awareness Month. Down syndrome is a disability, but a lot of kids with it have many of the same capabilities as their peers, or kids of the same age. This week, The Mini Page learns more about Down syndrome.

What is Down syndrome?

Down syndrome (DS) is a condition that people are born with. It isn’t contagious, and kids don’t grow out of it. It happens because of an abnormality in the number of chromosomes*. Most people with Down syndrome have 47 chromosomes instead of 46.

*A different kind of cookie

An expert on Down syndrome explained it this way:

Suppose you’re making sugar cookies. You use flour, sugar, butter and other ingredients to make the cookies. But if you add chocolate chips to the batter, you won’t have sugar cookies anymore. All the cookies will have chocolate chips — you can’t take them out.

When that extra chromosome gets added in, it changes almost every cell of the body, just like the chocolate chips show up in every cookie.

You still have a cookie, but it’s a little bit different.

Look around your classroom at your schoolmates. One of the things you might notice is how different you all are. Other than age, you have many distinctive qualities. For example:

• Some of you have dark hair. Others have blond or red hair.
• Some kids are taller than others.
• You know good athletes, and other kids who would rather read a book or play an instrument.
• You might have kids in your class who were born with Down syndrome. Maybe you were born with it.

Now notice how much you’re all really alike. For instance:

• Your classmates like to play with friends, go to camp, see movies or try new sports.
• All of you probably enjoy watching TV shows and playing games — even your friends with Down syndrome.

Violinist Riggo Carillo lives in California. People with Down syndrome develop musical talent, become good at sports, or work toward other goals, just as their peers do.

Down syndrome was named for John Langdon Down, a doctor in England who described the condition in 1866. In 1959, a French doctor discovered its cause.

Chromosomes are the parts of our cells that carry genes. Genes provide the information that decides the details about us — our hair color, how tall we are, etc.
What’s the Difference?

Health problems

Down syndrome causes challenges for kids and adults in a few different ways.
 About half of babies born with Down syndrome have a problem with their heart. Some of these troubles can be corrected with surgery or with medicine. Some correct themselves as the child grows older.

Many kids with DS also have trouble with their vision and hearing. These, too, can often be corrected.

Learning

Kids with Down syndrome may learn more slowly than their peers. The condition can affect intelligence, but it’s different with each child.

Most kids with the condition are able to learn all the same subjects and skills as their friends; it just may take them a little longer.

Swimming and working for a cause

Swimmer Karen Gaffney was on a relay team that swam the English Channel in 2001. She has won two gold medals in Special Olympics.

Five years ago, Karen swam the length of Lake Tahoe in Nevada — 9 miles in 59-degree water. She did it to raise money for the National Down Syndrome Congress and to show others that people with Down syndrome are more like everyone else than different.

Karen is the founder of the Karen Gaffney Foundation, which focuses on the potential of people with Down syndrome.

On the surface

You may notice that people with Down syndrome look a little different from others. Their faces may be flatter, and their eyes usually slant upward.

Kids with Down syndrome grow more slowly than their peers. Sometimes poor muscle tone makes it hard for them to speak clearly.

Meeting the challenge

According to experts, most kids who start to get help when they’re very young can achieve almost any goal. They can run, jump, bike, swim or dance. They can do well in school and graduate from high school and college.

Adults with Down syndrome hold jobs, live on their own, and have romantic and friendly relationships.

Ready Resources

The Mini Page provides ideas for websites, books or other resources that will help you learn more about this week’s topics.

On the Web:
• youtube.com/watch?v=4D3HU0iwZE8&feature=plcp
• youtube.com/watch?v=Jg2ZBPw2LyE&feature=related
• msnbc.msn.com/id/21134540/vp/22397724#22397724
• specialolympics.org/Common/Special_Olympics_Program_Locator.aspx

At the library:
• “My Friend Has Down Syndrome” by Amanda Doering Tourville
**Mini Spy . . .**

Mini Spy is helping her friend Gary on the playground. See if you can find:
- cheese wedge
- dragon
- carrot
- number 7
- seahorse
- butterfly
- pencil
- frog
- caterpillar
- hammer
- toothbrush
- heart
- word MINI
- cat
- needle

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**Rookie Cookie’s Recipe**

**Good-for-You Cookies**

You’ll need:
- 1/4 cup butter, softened
- 1 cup light brown sugar
- 1/2 cup applesauce (no sugar added)
- 2 egg whites
- 1 teaspoon vanilla
- 1 1/2 cups whole-wheat flour
- 1 teaspoon baking powder
- 1 teaspoon ground cinnamon
- 1/2 teaspoon salt
- 2 cups quick-cooking oats (1 minute)
- 1 cup golden raisins
- 1/2 cup chopped walnuts
- 1/2 cup dark chocolate chips

What to do:
1. Cream butter and sugar until well mixed; stir in applesauce.
2. Add egg whites one at a time and beat well.
4. Combine flour, baking powder, cinnamon and salt.
5. Stir flour mixture into wet mixture.
6. Add oats, raisins, nuts and chocolate chips; mix well.
7. Drop by teaspoons onto ungreased cooking sheet. Flatten slightly.
8. Bake for 10 to 12 minutes at 350 degrees. Makes 3 to 4 dozen cookies.

You will need an adult's help with this recipe.

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**Meet Ben Gundersheimer**

Ben Gundersheimer, better known as Mister G, is a singer and songwriter. His latest album, “Chocolalala,” has songs in English and Spanish. Mister G also plays guitar, banjo and percussion, or rhythm instruments. He has given free concerts in schools in Mexico, Guatemala and Colombia. He also gives free concerts to charitable groups in the United States, including a children’s cancer hospital and a center for disabled kids.

He grew up in the Philadelphia area and now lives near Northampton, Mass. He got his first guitar when he was 9 and says he began writing songs at once.

Mister G loves playing baseball and was captain of his college baseball team. His college degrees are in English and elementary education.

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**Goldie Goodsporth’s Report**

**Supersport: Sloane Stephens**

- Height: 5-7
- Weight: 135
- Birthdate: 3-20-93
- Hometown: Plantation, Fla.

Look into the future of tennis, and you might see Sloane Stephens. Just 19 years old, she has a game full of power and promise. At the U.S. Open, she opened fans’ eyes with a big first-round upset and her No. 44 world singles ranking.

With powerful ground strokes and a serve that sizzles in the 120 mph range, Stephens is the youngest player ranked in the top 50. She also was selected to play on the U.S. 2012 Fed Cup team.

Stephens began swinging a racquet at 9 years old, thanks to her mother’s encouragement. Sports runs deep in the family. Her mom, Sybil Smith, was an All-American swimmer at Boston University, and her late father, John Stephens, played pro football. Now, keep an eye on Sloane.

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**Mini Jokes**

All the following jokes have something in common. Can you guess the common theme or category?

**Mary:** What do mountain climbers do when they get bored?
**Maddox:** Climb the walls!

**Monroe:** Why did the old man refuse to climb the mountain?
**Madison:** He was already over the hill!

**Minnie:** What is the sleepiest mountain in the world?
**Maurice:** Mount Everest!
Friends First

A big change

When your parents were schoolkids, many children with Down syndrome didn’t go to class with their peers. Instead, they were sent to different schools or even lived in special homes with other disabled people.

Today, most kids with Down syndrome learn in regular classrooms with other kids. They may get some extra help, or go to a few special classes, but they are part of the school community.

Focus on ability

When you describe your friends to people who don’t know them, you probably tell something about how they look or what they do well. For example: “You know my friend Emily. She’s a soccer player, with long dark hair. She’s a great singer.”

Kids with Down syndrome like to be identified by their abilities, too, rather than by their disability. Jack might have Down syndrome, but he’s also on the swim team and tells funny jokes.

Feelings

Sometimes kids with Down syndrome are made fun of or called names. This hurts their feelings, just as it would hurt yours. If you see a kid bullying another, don’t laugh or join in. Tell the bully it’s not funny.

Being a good friend

Your friends or classmates with Down syndrome can do most of the activities that you and others enjoy. But they may need your patience and help along the way.

For instance, if you and your buddies plan to go hiking, ask your friend with DS to come along. You might have to hike a little more slowly — and as a result, you might have a chance to see an animal or an interesting plant that you would have missed without your friend.

Giving back

You can care for your friends with Down syndrome by organizing events or clubs that include them. Your family could help you plan an outing for once each school quarter, maybe going out to eat, going ice skating or seeing a movie. Your group might finish the year with a dance party at school.

Students can also volunteer for Special Olympics. One volunteer who is now in college began helping when she was in the second grade.

The Mini Page thanks Jennifer Carroll, resource specialist for the National Down Syndrome Congress, for help with this issue.

Next week, The Mini Page is all about algae.

The Mini Page Staff

Betty Debnam - Founding Editor and Editor at Large  Lisa Tarry - Managing Editor  Lucy Lien - Associate Editor  Wendy Daley - Artist
Peer Presentation Activities

Simon Says- Various Learning Styles Exemplified

When I do the Simon Says game I stand at the front of the room and say "Simon Says put your hands on your head" while I say this I actually put my hands on my stomach instead. The kids who are visual learners watch me and put their hands on their stomach because that is what they saw. The kids who are auditory learners listen to what was said and put their hands on their heads as that is what they heard. I go on to explain that some people learn by watching and others by hearing what is said. Some need to put both the auditory and visual directions together. We talk about kids with DS being visual learners who may need to see something 10-20 times before they can model it back to them.

Weights- Muscle Hypotonia Highlighted

I buy the weights for your wrists that have Velcro on them. I then have the students put both weights on their wrists and then try to zip up their jacket, button their shirt and tie their shoes. (any fine motor skill will work) This exemplifies how hard students with DS have to work to compensate for their muscle hypotonia. It also helps the kids understand why the paper of the student with DS may look different and why it may take them longer to finish a task.

Oven Mitts- Fine Motor/Gross Motor Issues

Ask students to put oven mitts on both hands. Give them a marker that they have to take the lid off of without assistance. Then ask them to put the marker in the hand they do not write with and spell their name on a write on-wipe off board. The kids typically fumble with getting the lid off and then write their names large and sloppy on the board. Explain to them that their friend with Down syndrome may have fine motor skill issues which make it hard for them to remove lids on pens and write in small spaces or lines on paper. This is why their paper may look different than yours and why it may take them longer to finish a worksheet.

Braille Cards- Accommodations

The Braille cards are handed out to kids and we ask them to "read" the cards. They of course cannot do this unless we give them help and show them what the dots mean. We talk about how reading words on paper can be difficult for students with DS so they may need extra help with reading. Students with Down syndrome may have adapted work and a paraprofessional to help them learn better.
**Marshmallows-Speech Intelligibility**

Give each student a large marshmallow and ask them to put it on top of their tongue and then turn to their neighbor and say “Hi my name is _______ and my favorite flavor ice cream is __________” While doing this exercise the students will typically giggle and laugh at how funny their words sound. I tell them to chew and swallow the marshmallow or spit it out at that point. Ask the students if it would be frustrating to try to communicate with people and not have them understand you.

Then discuss the jaw structure of a person with Down syndrome and how it is smaller and that their tongue may be larger and set back further in their mouth. This causes issues with speech being understood. Suggest ways the students can encourage their friends with Down syndrome to communicate such as:

- Speak more slowly
- Can you show me what you are talking about?
- Can you please say it again?
- Can you write down what you are trying to tell me?
- Show students any sign language signs the student uses regularly

Encourage the students to respect the processing time of their peers with Down syndrome. Ask them something and wait 10 full seconds before asking another question or giving another prompt. This gives them time to process information and respond.

**Earmuffs- Hearing Deficits**

Have students put ear muffs on and then go to a corner in the room that is farthest from where you are presenting. Then give them a 3 step instruction to follow in a hushed voice. The students won’t be able to hear you or follow directions. Encourage them to keep stepping closer until they can hear you. In most cases they will have to be right next to you to hear you and sometimes they still cannot hear you. Explain that many students with Down syndrome have hearing loss. Be sure to speak to your friend with Down syndrome while they are close to you and you are making eye contact with them as that will give you the best chance for successful communication.
Please fill this out with your STAR and return it to the DSG.

All About Me!

STARS
Special Teens Achieving Real Success

1984-2014 30 years

DSG
Down Syndrome Guild of Greater Kansas City
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Please let us know how we can help make this a great school year.

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_________________________________________________________________
_________________________________________________________________

Our hopes for this year are:

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_________________________________________________________________

Our lifetime goals for our child are:

_________________________________________________________________
_________________________________________________________________
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_________________________________________________________________
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My favorite vacation was when my family went to:

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________________________________________________________________________
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________________________________________________________________________
Communication

Here are some things you may need to know about how I communicate:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

My parents would prefer that you communicate with them by:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

If I am frustrated I might:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
Common behaviors to be aware of: (good and bad):

_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

Skills I am working on to help reduce behaviors:

_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

These are things that help me calm down and/or refocus:

_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
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____________________________________________________________________
____________________________________________________________________
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Myth: Behavior problems and depression are just part of having Down syndrome.
Truth: Often, medical or mental health problems go untreated due to the assumption that it is typical of having this genetic condition. Complete examinations by appropriate health care professionals should always be pursued.

Myth: Children with Down syndrome are placed in segregated special education programs.
Truth: Children with Down syndrome are included in regular academic classrooms across the country. Students may be integrated into specific courses or fully included in the regular classroom for all subjects.

Myth: Adults with Down syndrome may be unable to work.
Truth: Businesses seek young adults with Down syndrome for a variety of positions. They are employed by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.
3-2-1

Three Facts I Learned

Two Questions I Still Have

One Opinion I Now Have
Most people have 23 pairs of chromosomes for a total of 46, but a person born with Down syndrome has a third copy of chromosome 21. They have 47 chromosomes.

Down syndrome is named after Dr. John Langdon Down, who first identified the syndrome in 1866.

Down syndrome is not a birth defect, it’s not a disease, it’s not contagious like a cold, you can’t catch it and you can’t cure it. You will have it your whole life.

Kids with Down syndrome go to school and learn just like you, but they may need extra time or help.

It's easy to be friends with someone who has Down syndrome, just treat them like any other kid.

Down Syndrome Guild of Greater Kansas City