



Information for Friends/Relatives



Dear Friend / Relative,

The birth of a friend or relative's baby is exciting and joyous. It is a wonderful time in which many friends and families become closer. Everyone comes together to celebrate a miracle.

What happens then, when the baby is born with Down syndrome? Many of us are unsure of what to do or say. The usual response of flowers and congratulatory cards may feel inappropriate to us.

The DSAGC would like to share with you what might be helpful:

Celebrate - Celebrate the birth of this new life with your friends or family. Babies are just that – wonderful new persons to be welcomed into the world. Babies with Down syndrome are the same. Your family/friends will want to know that you welcome this new little one, and that you are there to love and support their child as you would any other baby.

Educate - It can be helpful, to you and your family and friends, to educate yourself about Down syndrome. The quality of life for children and adults with Down syndrome has improved dramatically in the past decade. Having accurate and up-to-date information is important. This packet was designed to educate you. In educating you, you can better support your friend or family member.

Understand - This may be a very difficult time for your friend or relative. The articles in this packet will give you an idea of some of the feelings your friend may be experiencing. If you are comfortable, allow your relative or friend to talk out their feelings with you and respond with support.

If you would like further information or have any questions, please call the DSAGC Monday through Friday, 10am to 4pm. You can also email us at dsagc@dsagc.com or visit our website at www.dsagc.com

Sincerely,

The Down Syndrome Association of Greater Cincinnati

Down Syndrome

by Siegfried M. Pueschel, M.D., Ph.D., J.D., M.P.H.

What is Down syndrome?

Persons with Down syndrome are first and foremost human beings who have recognizable physical characteristics and limited intellectual endowment that are due to the presence of an extra chromosome 21.

The estimated incidence of Down syndrome is between 1 in 800 to 1 in 1,100 live births. Each year approximately 3,000 to 5,000 children are born with this chromosome disorder. It is believed there are about 250,000 families in the United States who are affected by Down syndrome.

How do children with Down syndrome develop?

Children with Down syndrome are usually smaller, and their physical and mental developments are slower, than those who do not have Down syndrome. The majority of children with Down syndrome function in the mild to moderate range of mental retardation. However, some children are not mentally retarded; they may function in the borderline to low average range; and only a few children may be severely mentally retarded. There is a wide variation in mental abilities and developmental progress in children with Down syndrome. Also, their motor development is slow; e.g. instead of walking by 11 to 14 months as other children do, children with Down syndrome usually learn to walk between 15 to 36 months. Their language development is also markedly delayed.

It is important to note that a caring and enriching home environment, early intervention, and integrated educational efforts will have a positive influence on the child's development.



What are the physical features of a child with Down syndrome?

Although individuals with Down syndrome usually have distinct physical characteristics, generally, they are

more similar to the average person in the community than they are different. The physical features are important to the physician in making the clinical diagnosis, but no emphasis should be put on those characteristics otherwise. Not every child with Down syndrome has all the characteristics; some may only have a few, and others may show most of the signs of Down syndrome. Some of the physical features of children with Down syndrome include flattening of the back of the head, slanting of the eyelids, small skin folds at the inner corner of the eyes, depressed nasal bridge, slightly smaller ears, small mouth with narrow palate, decreased muscle tone, loose ligaments, and small hands and feet. About fifty percent of children with Down syndrome have one line across the palm, and there is often a wide gap between the first and second toes. The physical features observed in children with Down syndrome (and there are many more than described above) usually do not cause any significant disability in the child.

How many chromosome subtypes are observed in Down syndrome?

There are four main types of chromosome abnormalities in Down syndrome:

The vast majority of children with Down syndrome (approximately 95 percent) have an extra 21 chromosome. Instead of the normal number of 46 chromosomes in each cell, the individual with Down syndrome has 47 chromosomes. This condition is called trisomy 21.

The second type is called translocation. Here, the extra 21 chromosome is attached or translocated on to another chromosome, usually on chromosome 14, 21 or 22.

If translocation is found in a child with Down syndrome, it is important to examine the parents' chromosomes, since in at least one-third of the cases, a parent may be a carrier of the translocation. This form of chromosome error is found in 3 to 4 percent of individuals with Down syndrome.

Another chromosome problem, called mosaicism, is noted in about 1 percent of persons with Down syndrome. In this case, some cells have 47 chromosomes and others have 46 chromosomes. Mosaicism is thought to be the result of an error in one of the cell divisions after conception. Children with mosaicism Down syndrome usually have fewer physical characteristics and function better intellectually than those with trisomy 21 and translocation Down syndrome.

A very rare chromosome abnormality in persons with Down syndrome is called partial trisomy 21. Here, part of an extra chromosome 21 is usually attached to another chromosome.

What is the cause of Down syndrome?

Although many theories have been proposed, at the present time it is not known what actually causes Down syndrome. Some professionals believe that hormonal abnormalities, X-rays, viral infections, immunologic problems, or genetic predisposition may be the cause of the improper cell division resulting in Down syndrome, but there is no evidence that any of these conditions causes Down syndrome.

It has been known for a long time that the risk of having a child with Down syndrome increases with advancing age of the mother; i.e., the older the mother, the greater the possibility that she may give birth to a child with Down syndrome. However, most babies with Down syndrome (more than 85 percent) are born to mothers younger than 35 years of age. Recent studies revealed that if the mother has only one ovary, she also has an increased risk of having a child with Down syndrome.

The extra chromosome in trisomy 21 could either originate in the mother or the father. Most often, however, the extra chromosome comes from the mother.

What kind of information can be provided through genetic counseling?

Parents who have a child with Down syndrome have an increased risk of having another child with Down syndrome in future pregnancies. It is estimated that the risk of having another child with Down syndrome is about one in 100 in trisomy 21 and probably also in mosaicism. If, however, the child has translocation Down syndrome and if one of the parents is found to be a translocation carrier, then the risk of recurrence increases markedly. The actual risk depends on the type of translocation and whether the translocation is carried by the father or the mother.

What health concerns are often observed in people with Down syndrome?

Generally, the child with Down syndrome is in need of the same kind of optimal medical care as any other child. The pediatrician or family physician should offer support and counseling to the family, provide general health maintenance, immunizations, and attend to medical problems. There are, however, situations when children with Down syndrome need special attention.

Sixty to eighty percent of children with Down syndrome have hearing deficits. Therefore, audiologic assessments at an early age and follow-up hearing tests are indicated. If there is a significant hearing loss, the child should be seen by an ear, nose and throat specialist.

Forty to fifty percent of children with Down syndrome have congenital heart disease. Many of these children will have to undergo cardiac surgery and often will need long term care by a pediatric cardiologist. Persons with Down syndrome beyond adolescence often have mitral valve prolapse which is thought to be a benign condition.

Intestinal abnormalities also occur at a higher frequency in children with Down syndrome. For example, a blockage of the food pipe (esophagus), small bowel (duodenum), and at the anus (anal atresia) are not uncommon in infants with Down syndrome. These may need to be surgically corrected at once in order to have a normal functioning gastro-intestinal tract.

Celiac disease which is due to an intolerance to a particular part of protein in flour (gluten) is also more often observed in persons with Down syndrome.

Children with Down syndrome have more eye problems than other children who do not have this chromosome disorder. For example, 3 percent of newborn infants with Down syndrome have cataracts that need to be removed surgically. Other eye problems such as cross-eyedness (strabismus), near-sightedness, far-sightedness and other eye conditions are frequently observed in children with Down syndrome. Therefore, regular ophthalmological examinations are recommended.

Another concern relates to nutritional aspects. Some children with Down syndrome, in particular those with severe congenital heart disease, often fail to thrive in infancy. On the other hand, obesity is frequently noted during adolescence and early adulthood. These conditions can be prevented by providing appropriate nutritional counseling and dietary guidance.

Thyroid dysfunctions are more common in children with Down syndrome than in normal children. Between 15 and 20 per cent of children with Down syndrome have hypothyroidism. A few children may have hyperthyroidism. It is important to identify individuals with Down syndrome who have thyroid disorders and institute appropriate treatment, since it may compromise central nervous system functioning.

Skeletal problems have also been noted at a higher frequency in children with Down syndrome, including kneecap subluxation, hip dislocation, and atlantoaxial instability. The latter condition occurs when the first two neck bones are not well aligned because of the presence of loose ligaments.

Approximately 15 percent of people with Down syndrome have atlantoaxial instability. Most of these individuals, however, do not have any symptoms, and only

1 to 2 percent of individuals with Down syndrome have a serious neck problem (symptomatic atlantoaxial instability) that requires surgical intervention.

Other important medical aspects in Down syndrome, including immunologic concerns, leukemia, seizure disorders, sleep apnea, skin disorders, zinc deficiency, and Alzheimer disease may require the attention of specialists in their respective fields.

Can Down syndrome be medically treated?

Although many medications and various therapies including nutritional supplements have been touted as treatment for people with Down syndrome, there is no effective medical treatment available at the present time. However, recent advances in molecular biology make it feasible now to examine the genetic basis for Down syndrome. In the spring of 2000 nearly all genes on chromosome 21 were identified and their DNA was sequenced. However, at the present time we do not know how the triple genetic dose interferes with normal developmental sequences. Once we have more knowledge of the genes' function and how to counteract these genes, a rational approach to medical therapy could emerge.

What educational services and vocational opportunities are available for people with Down syndrome?

Today early intervention programs, pre-school nurseries, and integrated/inclusive special education strategies have demonstrated that youngsters with Down syndrome can participate in many learning experiences that will positively influence their overall functioning. Research has shown that early intervention, environmental enrichment, and assistance to the families will result in marked progress that is usually not achieved by those infants who have not had such educational and stimulating experiences.

Children with Down syndrome, like other children, can benefit from sensory and cognitive stimulation, specific exercises involving gross and fine motor activities, and speech therapy. Also, preschool nurseries play an important role in the young child's life since exploring the environment beyond the home enables the child to participate in a broader world.

Later, the school can give the child a foundation for life through the development of academic skills and physical as well as social abilities. School should provide an opportunity for the child to engage in sharing relationships with others and help to prepare the child to become a productive citizen. Contrary to some views, all

children can learn, and they will benefit from placement in a normalized setting with support as needed.

During adolescence, youngsters with Down syndrome should be exposed to prevocational training in order to learn good work habits and to engage in proper relationships with co-workers. Appropriate vocational counseling and job training will result in meaningful employment, and this, in turn, should lead to a feeling of self-worth and of making a contribution to society. In addition, post-secondary school educational opportunities should be made available for young people with Down syndrome.

What attitude should society have?

It is important that society develop attitudes that will permit people with Down syndrome to participate in community life and to be accepted. They should be offered a status that observes their rights and privileges as citizens, and in a real sense preserves their human dignity. When accorded their rights and treated with dignity, people with Down syndrome will, in turn, provide society with a most valuable humanizing influence.

Selected Resources

Organizations:

National Down Syndrome Congress
1370 Center Drive, Suite 102
Atlanta, Georgia 30338
Toll-free: 800-232-6372
Local: 770-604-9500
E-mail: info@ndsccenter.org
<http://www.ndsccenter.org>

National Down Syndrome Society
666 Broadway, 8th Floor
New York, New York 10012-2317
Toll-free: 800-221-4602
Local: 212-460-9330
E-mail: info@ndss.org
<http://www.ndss.org>

About the author: Dr. Pueschel, Professor of Pediatrics, Brown University School of Medicine, Providence, RI was awarded The Arc's 1990 Distinguished Research Award.

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Things to Say and NOT to Say

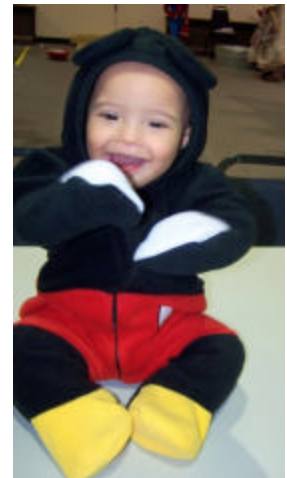
We have received many e-mails from aunts and uncles of children with Down syndrome who are trying to get more information about the new child in their family. We can not stress enough how important it is for family to support the new parents at this time. This is a frightening time for the new parents and they often wonder how their family will treat the new baby. Showing how much you love them and their new baby will help to alleviate these fears. Make sure to pick up the baby, fuss over him/her, play with the baby.

Sometimes you may not know the right thing to say or what you say, is in fact, the wrong thing. We would like to give some suggestions about what not to say and what to say. The following suggestions are based upon the input of many parents of children with Down syndrome.

Things NOT to say

These are the things that parents have said really upset or angered them:

- **"I'm sorry" or any form of pity.**
Pity is not what new parents want or need. What they need is love and acceptance of their new baby.
- **"God gives special parents special children" or any variation.**
The new parents probably don't feel very special right now. Also, some parents may be a little mad at God. Trying to make them feel better with words like these might be appreciated by some parents and not by others. It is best to avoid this.
- **"They're such loving children."**
This is a stereotype of children with Down Syndrome and demonstrates that you really don't know much about Down Syndrome.
- **"Do they know how serious it is?" or any variation.**
Again, this is a demonstration of a lack of knowledge about Down Syndrome. Some parents may be angry and want to reply with, "How serious is it? Well, every single cell in his body has an extra chromosome... is that serious enough?"
- **"You are handling this better than I could."**
This is an invitation for the new parents to say something like, "No, you would be wonderful." Suddenly, the conversation has switched to you instead of the parents and their new baby. Plus, you don't really know how the new parents are handling it, do you?



Things TO say

These are the things parents have found comforting or made them feel good:

- **"Congratulations."**

They just had a baby! What better response to show that you love them and their baby than to say congratulations. It made us feel like 'normal' parents when someone said that to us. If the hospital allows it, a bottle of champagne could be greatly appreciated.

- **"He/She looks just like you."**

The baby probably does look like someone in the family. All of the baby's genes are from the family. My son looked exactly like my daughter did when she was just born.

- **Friends and family who actually 'did' something like read about the disability (or find information on the web!)**

This really means something to the new parents. It shows love and concern for the baby. The day after we told Mikey's uncle about Mikey having Down Syndrome, he came to visit us with a handful of papers dealing with Down Syndrome he had gotten from the web. That showed us that he really cared.

- **Offer to babysit.**

It is a fear of the new parents that their family will not accept the new baby. By saying something like, "Well, when are you going to let me babysit?" you are showing the new parents that you want to be part of the baby's life. This will be a great relief to them.

- **"He/She will do fine."**

The new parents are probably pretty worried. They might not know much about Down syndrome and they may be concerned about possible medical problems. Having a positive attitude will rub off on them. They don't need pessimism or negativity from their loved ones.

- **"We'll all learn from him/her."**

This is another good way to show that you intend on being part of their lives. After all, how can you learn from their new baby if you are ashamed of him/her? Their new child will be an opportunity to learn about love, acceptance, and respect for the disabled.

- **"We will always be here to help."**

Another very good way to show that you are going to be there. Let the new parents know that you intend on being part of their lives.



A Baby is a Baby First **by Kate Sefton**

There is nothing quite like a baby...there's a lurch in the heart when we touch the beginning of a life in the small person of an infant. For some parents, the lurch is made more poignant, even painful, by the fact of their baby's diagnosis of Down syndrome.



Recently, I've had the great pleasure of holding a number of soft, beautiful babies who have Down syndrome. Their parents want to find out what it all means, what they can do, what to think about the future. The first professionals to talk to the parents of babies with Down syndrome tend to discuss the differences parents may see, difficulties babies will encounter. Armed with information about what milestones their child may not reach, what problems she may have, what services they should obtain to avoid potential problems, new parents want to help their babies as soon as possible. So they come to me (and to numerous others) to get this help...to find therapy, activities, and solutions to problems that may or may not exist.

We just don't know, at an early age, in exactly which ways Down syndrome may affect a child. She may be really good at cognitive activities, but have significant delays in movement... thereby falling behind her peers in playground and paper-and-pencil activities. He may be fairly good at gross motor, excelling in sports. Ocular control may be an area of need, or may be perfect. Language may be good, or may need lots of work. However, one thing we know for certain... babies don't deal with these things no matter what their chromosomes look like. They lie down and expect to be carried, cuddled, talked to, fed and generally catered to. They learn they are lovable, cute, and the center of the universe. They begin to know who their family members are, and who is the soft touch in the house in the middle of the night.



If these adorable creatures have Down syndrome they are at risk for certain physical and cognitive delays. It behooves parents to keep an eye open for problems that could arise. It's important that they know something about their child's diagnosis so that they can be alert and helpful. But my belief is that the most important things that parents of babies with Down syndrome can do are exactly those things that all parents do. You know: they cuddle, feed, sing and love. Not the kind of things you need a Developmental Therapist for... or any other therapist, for that matter. I want to be clear. Young



children with Down syndrome often show delays that need to be remedied so that these kids can be happy with themselves and do their very best. Very young babies with Down syndrome have specific concerns about early development. And doubtless, parents will find themselves driving this child about for ear infections, speech therapy, developmental evaluations, etc. But the main advice I have for parents of new babies with Down syndrome boils down to this: **You have a beautiful new baby. There will be some areas that need work, but what you have right now IS PRECIOUS AND PERFECTLY RIGHT.**

Reprinted with permission from the April 1993 issue of the Down Syndrome News, the newsletter of the National Down Syndrome Congress, www.ndsccenter.org. Ms. Sefton is a Master Developmental Therapist.



Educating Children About Disabilities

More and more children with and without disabilities are engaging in inclusion. Inclusion is when people with disabilities and people without disabilities are in relationships with each other. Examples of inclusion are: when a child with Down syndrome is included in a regular education classroom; when a girl with Cerebral Palsy is included to be a part of her school's Girl Scout troop; when a boy with a developmental disability is invited by his neighbors to play baseball.

With inclusion come questions from children *without* disabilities. "What's wrong with that boy?" or "why does she talk that way?" are some usual questions that children ask, and parents are unprepared for. How *do* you explain to a child why his classmate or neighbor is different? We went to special education experts for some suggestions:

- **Never ignore someone's disability.** A common reaction is to pretend the disability isn't there. The best approach is to "be straight with your kids when they ask about differences," advises Deidre Hayden, Executive Director of the Parent Educational Advocacy Training Center in Alexandria, Virginia. "Kids are often far more comfortable with the concept than adults are."
- **Explain that everybody is different.** Just as people have different interests, they also have different abilities. "What's most important is seeing the disability as just *one* quality of the person rather than the *only* defining quality," says Doug Biklen, Ph.D., author of Schooling Without Labels (Temple University Press, 1992).
- **Help them focus on similarities.** Whether it is baseball cards, music or a favorite television show, all kids share some common interests. People with disabilities are different in a few ways, but they are the same in a hundred ways.
- **Reassure them that disabilities aren't contagious.** "Younger kids may worry, 'If I touch him, will I become blind'" says Virginia Roach, Director of The Center on Teaching and Learning at the National Association of State Boards of Education, in Alexandria. Assure kids that holding hands, hugging, and sharing toys are all okay. You cannot catch Down syndrome from someone who has it. It is something you are born with.

- **Practice what you preach.** Without realizing it, we've all been insensitive to individuals with disabilities at some time. By either averting our eyes when a person with a disability walked by or staring at the person, or parking in handicapped spot "just for a minute." Remember: what you do and don't do sends stronger messages to your kids than anything you say.

Excerpts reprinted with permission from the handout, "Mom what's wrong with that boy?" by Lynn Prowitt.



Questions and Answers About Down Syndrome

Why should we be concerned about Down syndrome?

Chromosomal abnormalities are a widespread medical problem, with Down syndrome being the most common genetic condition. One in every 800 to 1,000 children is born with Down syndrome.

More than 50 percent of miscarriages are caused by a chromosomal abnormality. As many as 25 percent of all miscarriages are caused by a trisomy, which is the presence of three copies of a particular chromosome, rather than the normal two.

The most common form of Down syndrome is called Trisomy 21, because it involves an extra copy of the 21st chromosome. Twenty to 25 percent of children conceived with Down syndrome survive past birth.

What impact does Down syndrome have on society?

Individuals with Down syndrome are becoming increasingly integrated into society and community organizations, such as school, health care systems, work forces and social and recreational activities. Individuals with Down syndrome possess varying degrees of mental retardation, from very mild to severe. Most people with Down syndrome have IQs in the mild to moderate range of mental retardation.

Due to advances in medical technology, individuals with Down syndrome are living longer than ever before. In 1910, children with Down syndrome were expected to survive to age nine. With the discovery of antibiotics, the average survival age increased to 19 or 20. Now, with recent advancements in clinical treatment, as many as 80 percent of adults with Down syndrome reach age 55, and many live even longer.

In the United States, approximately 350,000 families are affected by Down syndrome. Approximately 5,000 children with Down syndrome are born each year. As the mortality rate associated with Down syndrome is decreasing, the prevalence of individuals with Down syndrome in our society will increase. Some experts project that the number of people with Down syndrome will double in the next 10 years. More and more Americans will interact with individuals with this genetic condition, increasing the need for widespread public education and acceptance.

Is Down syndrome transmitted from the mother or father?

The additional genetic material which causes Down syndrome can originate from either the father or the mother. Approximately five percent of the cases have been traced to the father.

Who has the highest risk of having a child with Down syndrome?

Down syndrome affects people of all races and economic levels. Women age 35 and older have a significantly increased risk of having a child with Down syndrome. A 35-year-old woman has a one in 400 chance of conceiving a child with Down syndrome and this chance increases gradually to one in 110 by age 40. At age 45 the incidence becomes approximately one in 35.

Since many couples are postponing parenting until later in life, the incidence of Down syndrome conceptions is expected to increase. Therefore, genetic counseling for parents is becoming increasingly important. Still, many physicians are not fully informed about advising their patients about the of incidence of Down syndrome, advancements in diagnosis and the protocols for care and treatment of babies born with Down syndrome.

Why is it important to raise children with Down syndrome at home?

A greater understanding of Down syndrome and advancements in treatment of Down syndrome-related health problems have allowed people with Down syndrome to enjoy fuller and more active lives. Children raised at home and included in all aspects of community life can best reach their potential and function in society with a greater degree of independence. Parental love, nurturing and support, as well as early intervention programs, educational opportunities and community involvement, have a direct relationship to the degree that a person with Down syndrome is able to achieve his/her potential.

Why are medical researchers following Down syndrome work so closely?

Down syndrome is a developmental disorder. As researchers learn more about the molecular genetics and other aspects of Down syndrome, they also obtain valuable information about human development and can advance the study of many biological processes.

In addition, individuals with Down syndrome have a higher incidence of certain medical problems and the study of Down syndrome may yield important breakthroughs in those areas. Research in Down syndrome provides a way for looking at many important problems:

Heart disease: Up to 50 percent of individuals with Down syndrome are born with congenital heart defects. The majority of heart defects in children with Down syndrome can now be surgically corrected with resulting long-term health improvements. However, scientists continue to search for the cause of this problem and look for means of prevention.

Alzheimer's disease: Estimates vary, but it is reasonable to conclude that 25 percent or more of individuals with Down syndrome over the age of 35 will develop the clinical signs and symptoms of Alzheimer's-type dementia.

Leukemia: Individuals with Down syndrome have a 15 to 20 times greater risk of developing leukemia. The majority of cases are categorized as acute megakaryoblastic leukemia, which tends to occur in the first three years of life, and for which there is a high cure rate. A transient form of leukemia is also seen in newborns with Down syndrome, disappearing spontaneously during the first two to three months of life.

Why hasn't Down syndrome received much attention in the past?

Even though Dr. Jerome Lejeune discovered in 1959 that it was an extra 21st chromosome that caused Down syndrome, it is only in the last few years that a focus has been placed on the study of the 21st chromosome.

In May 2000, researchers completed sequencing the approximately 225 genes on the 21st chromosome - only the second chromosome to be fully sequenced at this time. Although these findings will not have an immediate impact on the Down syndrome community, they will open the door to valuable research on this small set of genes.

Researchers continue to look for the genes related to the development of intelligence and the physical characteristics associated with Down syndrome. Once identified, it is hoped that the biochemical process which causes Down syndrome can be decoded, leading to the development of an intervention and cure. See the Research section of this Web site for more information about sequencing the 21st chromosome.

What is the National Down Syndrome Society doing to further research?

NDSS is currently sponsoring three scientists through the NDSS Science Scholar Award Program initiated in 1983. Under this grant program, each researcher receives \$35,000 a year for two years to carry out scientific research into the causes and/or amelioration of Down syndrome. To date, more than 20 scholars have been supported by this program.

NDSS also sponsors a series of annual symposia focusing on Down syndrome research. This sharing of information, technology and the collective knowledge of the world's foremost researchers is expected to produce an acceleration of advancements in a variety of areas. The proceedings of these scientific symposia are published annually and are available through NDSS.

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Down Syndrome: Myths and Truths

Myth: Down syndrome is a rare genetic disorder.

Truth: Down syndrome is the most commonly occurring genetic condition. One in every 733 live births is a child with Down syndrome, representing approximately 5,000 births per year in the United States alone. Today, Down syndrome affects more than 350,000 people in the United States.

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 35-years-old. However, the incidence of births of children with Down syndrome increases with the age of the mother.

Myth: People with Down syndrome are severely retarded.

Truth: Most people with Down syndrome have IQs that fall in the mild to moderate range of retardation. Children with Down syndrome are definitely educable and educators and researchers are still discovering the full educational potential of people with Down syndrome.

Myth: Most people with Down syndrome are institutionalized.

Truth: Today people with Down syndrome live at home with their families and are active participants in the educational, vocational, social and recreational activities of the community. They are integrated into the regular education system, and take part in sports, camping, music, art programs and all the other activities of their communities. In addition, they are socializing with people with and without disabilities, and as adults are obtaining employment and living in group homes and other independent housing arrangements.

Myth: Parents will not find community support in bringing up their child with Down syndrome.

Truth: In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.

Myth: Children with Down syndrome must be placed in segregated special education programs.

Truth: Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The degree of mainstreaming is based in the abilities of the individual; but the trend is for full inclusion in the social and educational life of the community.

Myth: Adults with Down syndrome are unemployable.

Truth: Businesses are seeking young adults with Down syndrome for a variety of positions. They are being employed in small and medium sized offices: by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry, in clerical positions and in the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.

Myth: People with Down syndrome are always happy.

Truth: People with Down syndrome have feelings just like everyone else in the population. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Truth: People with Down syndrome date, socialize and form ongoing relationships. Some are beginning to marry. Women with Down syndrome can and do have children, but there is a 50 percent chance that their child will have Down syndrome. Men with Down syndrome are believed to be sterile, with only one documented instance of a male with Down syndrome who has fathered a child.

Myth: Down syndrome can never be cured.

Truth: Research on Down syndrome is making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

Reprinted with permission from the National Down Syndrome Society, www.ndss.org.



Down syndrome is a chromosomal condition which is caused by an extra copy of the 21st chromosome. We have developed the following 21 facts to enlighten you about the capabilities and unique contributions of individuals with Down syndrome:

- Down syndrome is the most commonly occurring chromosomal genetic disorder resulting in 1 in every 733 births.
- "I am Patrice. I have a job, I pay taxes and I do volunteer work. I have Down syndrome."
- "I am Lisa and I live in my own apartment. I have Down syndrome."
- The average life span has risen from 9 years in 1925 to 65 and beyond in 2008.
- "My name is Kevin and I am a professional artist. I have Down syndrome."
- Down syndrome occurs across all economic and cultural levels.
- "I am Marty and I am an Eagle Scout. I have Down syndrome."
- 350,000 American citizens have Down syndrome.
- "I am Robert and I love to read and use the computer. I have Down syndrome."
- "I am Mac and I attend classes at NKU. I have Down syndrome."
- Children with Down syndrome learn to sit, walk, talk and play only somewhat later than their peers.
- "I am Andrew and I am married to a beautiful girl named Sarah who also has Down syndrome."
- Siblings of children with Down syndrome are more well-adjusted, mature and responsible than their peers.



- "My face has many characteristics of other people with Down syndrome but I look like my dad too."
- Parents of children with Down syndrome do not have a higher rate of financial hardship or divorce.
- The average age of a mother giving birth to a baby with Down syndrome is 28.
- A woman with Down syndrome ran for the Texas State Board of Education.
- Families continue to enjoy typical leisure activities such as vacations, going to restaurants and movies.
- There are over 200 families waiting to adopt a child with Down syndrome.
- Most children with Down syndrome are educated in their neighborhood public schools.
- It is important that individuals with Down syndrome have an opportunity to let their voices be heard.

Language Guidelines

Language is a reflection of how people see each other. We believe that when referring to an individual with Down syndrome it is important to use language which is both accurate and respectful of the individual.



People with Down syndrome should always be referred to as people first. Instead of “a Down syndrome child,” the correct wording is “a child with Down syndrome.” This is known as Person-First language. It places the individual before the disability. Placing the person before the disability emphasizes the person first and the disability second. Person First language emphasizes respect

for the individual.

Avoid using the term “Down’s child” or describing the condition as “Down’s,” as in, “He has Down’s.” A baby born with Down syndrome is not a “Down’s baby” or a “baby with Downs.” He/she is a baby with Down syndrome.

Down syndrome is named for the English physician Dr. John Langdon Down, who characterized the condition, but did not have it. We use the preferred spelling, Down syndrome, rather than Down’s syndrome as is common in England and other parts of Europe. While Down syndrome is listed in many dictionaries with both popular spellings (with or without an apostrophe s), the preferred usage in the United States is Down syndrome. This is because an “apostrophe s” connotes ownership or possession. The AP Stylebook recommends using “Down syndrome” as well.



It is also important to use correct terminology. People “have” Down syndrome, they do not “suffer from” it nor are they “afflicted by” it. It is not a disease. Down syndrome is a chromosomal condition resulting from an extra copy of the 21st chromosome. Similarly,

when referring to peers, the correct term is “typical” peers as opposed to “normal.” Although it is acceptable to use the term, “mental retardation,” it is more acceptable to use the term “intellectual or cognitive disability.”

People with Down syndrome are sometimes portrayed as being happy and loving all the time or frequently as angels. However, avoid casting every person with Down syndrome as a superhuman model of humanity. They are unique individuals with unique personalities just like everyone else.

You can help others use responsible language which reflects the dignity of people with Down syndrome. Words can create barriers and reinforce stereotypes. Therefore, the DSAGC strongly believes in the importance of ensuring that correct language is used. A child is much more than a label. Help to educate others about the preferred way to refer to individuals with Down syndrome.

This statement was adapted from the Down Syndrome Society of Rhode Island.