



Information for Grandparents



Dear Grandparent,

Congratulations on your new grandchild, a child who will need your love, encouragement, and support more than ever. The fact that this child has Down syndrome has probably been shock to you and your family. You may be experiencing feelings of denial, anger and depression. You may be wondering about the future of your new grandchild. Will he walk? Will she talk? Will he even recognize you?

You as a grandparent must deal not only with your own feelings, but the feelings of your child who is experiencing parenthood differently than had been anticipated.

This packet of up-to-date, accurate information on Down syndrome can be helpful in dispelling the fears you and your family may have for this grandbaby. You will discover that this baby can be cuddled and loved like any other baby. In a short time you will see a unique personality begin to develop. You may even observe some of your own traits that have been inherited by this child.

You as a grandparent can have a unique role in your grandchild's life. You've already experienced being a parent and have discovered what's really important to a child - - like hugs, praise, cookies, junk food, giggles, the world of make believe and simple games.

This grandchild will have a special need from you - - to be his or her advocate in the community. This child will bring you joy and a new perception of Down syndrome. Please join us in spreading the word to others.

In this way you will give hope and encouragement to other grandparents and can be a link in improving quality of life for all people with Down syndrome. I promise you, your new grandchild will continue to surprise you by how much she is learning each day. Someday you may even wonder how life would have been without this child and the wealth of experience he has provided.

Sincerely,

Jeannette N. Lohner
A Grandparent



Down Syndrome

◆ Definition ◆

Down syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth.

◆ Incidence ◆

Approximately 4,000 children with Down syndrome are born in the U.S. each year, or about 1 in every 800 to 1,000 live births. Although parents of any age may have a child with Down syndrome, the incidence is higher for women over 35. Most common forms of the syndrome do not usually occur more than once in a family.

◆ Characteristics ◆

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one

person. Some common characteristics include:

- Poor muscle tone;
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds);
- Hyperflexibility (excessive ability to extend the joints);
- Short, broad hands with a single crease across the palm on one or both hands;



*is the
National Dissemination Center
for Children with Disabilities.*

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- Broad feet with short toes;
- Flat bridge of the nose;
- Short, low-set ears;
- Short neck;
- Small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

Individuals with Down syndrome are usually smaller than their nondisabled peers, and their physical as well as intellectual development is slower.

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are higher in individuals with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one third of babies born with Down syndrome have heart defects, most of which are now successfully correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.



Don't Be Shy!

All of our publications and resource lists are online—help yourself! Visit us at:

www.nichcy.org

If you'd like personalized assistance, email or call us:

nichcy@aed.org

**1.800.695.0285
(V/TTY)**

Children with Down syndrome may have a tendency to become obese as they grow older. Besides having negative social implications, this weight gain threatens these individuals' health and longevity. A supervised diet and exercise program may help reduce this problem.

✧ Educational Implications ✧

Shortly after a diagnosis of Down syndrome is confirmed, parents should be encouraged to enroll their child in an infant development/early intervention program. These programs offer parents special instruction in teaching their child language, cognitive, self-help, and social skills, and specific exercises for gross and fine motor development. Research has shown that stimulation during early developmental stages improves a child's chances of developing to his or her fullest potential. Continuing education, positive public attitudes, and a stimulating home environment have also been found to promote the child's overall development.

Just as in the normal population, there is a wide variation in mental abilities, behavior, and developmental progress in individuals with Down syndrome. Their level of retardation may range from mild to severe, with the majority functioning in the mild to moderate range. Due to these individual differences, it is impossible to predict future achievements of children with Down syndrome.

Because of the range of ability in children with Down syndrome, it is important for families and all members of the school's education team to place few limitations on potential capabilities. It may be effective to emphasize concrete concepts rather than abstract ideas. Teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has proven successful. Improved public acceptance of persons with disabilities, along with increased opportunities for adults with disabilities to live and work independently in the community, have expanded goals for individuals with Down syndrome. Independent Living Centers, group-

Other Helpful Things to Know

These NICHCY publications talk about topics important to parents of a child with a disability.

Parenting a Child with Special Needs

Your Child's Evaluation

Parent to Parent Support

Questions Often Asked by Parents About Special Education Services

Developing Your Child's IEP

All are available in English and in Spanish—on our Web site or by contacting us.

Research has shown that stimulation during early developmental stages improves a child's chances of developing to his or her fullest potential.

shared and supervised apartments, and support services in the community have proven to be important resources for persons with disabilities.

◇ Resources ◇

Cunningham, C. (1999). *Understanding Down syndrome: An introduction for parents* (2nd ed.). Cambridge, MA: Brookline. (Phone: 800.666.2665. Web: www.brooklinebooks.com)

Pueschel, S.M. (Ed.). (2001). *A parent's guide to Down syndrome: Toward a brighter future* (2nd ed.). Baltimore, MD: Paul H. Brookes. (Phone: 800.638.3775. Web: www.brookespublishing.com)

Unruh, J.F. (1994). *Down syndrome: Successful parenting of children with Down syndrome*. Eugene, OR: Fern Ridge Press. (Phone: 800.816.5679. Web: www.fernridgepress.com/)

Woodbine House (Phone: 800.843.7323, Web: www.woodbinehouse.com) publishes a series on Down syndrome, including:

- *Babies with Down syndrome: A new parent's guide*
- *Differences in common: Straight talk about mental retardation, Down syndrome, and life*
- *Down syndrome: The first 18 months (DVD or Video)*
- *Early Communication skills in children with Down syndrome: A guide for parents and professionals*
- *Fine motor skills in children with Down syndrome*
- *Gross motor skills in children with Down syndrome*
- *Medical and surgical care for children with Down syndrome: A guide for parents*
- *Teaching reading to children with Down syndrome*

◇ Organizations ◇

National Down Syndrome Congress
1370 Center Drive, Suite 102
Atlanta, GA 30338
770.604.9500; 800.232.6372
info@ndscenter.org
www.ndscenter.org

National Down Syndrome Society
666 Broadway
New York, NY 10012
212.460.9330; 800.221.4602
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The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Springs, MD 20910
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Grandparents Get Tips on Offering Support

When a child is born or diagnosed with disabilities, parents are not alone in their concerns. Grandparents are anxious, too, for their grandchild and for their child whose life is affected by the baby. Many grandparents and parents have been interviewed to ask how grandparents can best help their children and grandchildren. Here are some tips:

- ❖ Offer support, but don't hover. Unconditional love and support are very important for the parents.
- ❖ Ask how you can help in practical matters. If the grandparents don't know how to help the family, please say so. Ask what the family needs help with. Sometimes it's the very practical matters in which the grandparents can assist.
- ❖ Learn as much about the disability or diagnosis as possible. Becoming informed will show you want to be involved.
- ❖ Offer opinions only if asked. One parent felt that grandparents thought she wasn't doing enough, or doing the right things. Do your best to let your children know they are doing a good job as parents.
- ❖ Accept your grandchild as he or she is. First and foremost, he or she is a child who should be loved unconditionally.

As grandparents, you can offer your children much love and support through this difficult time. You will even find that there are many positive aspects that you may not have expected to find.





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.

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FOCUS ON GRANDPARENTS

The impending birth of a child fills the entire family with anticipation and delight. The hopes and joys of the prospective parents and grandparents are dashed however, when the eagerly-awaited baby is born with a disability. The most heart-rending task of all falls to the new parent who must break the news to the grandparents that the child has been born with a disability.

Both parent and grandparent experience similar feelings of sadness, shock and grief. The grandparents' reaction however is doubled – the grandparents are concerned not only for their newborn grandchild, but for their own child as well. As the grandparent of a grandchild born with Cerebral Palsy commented, “I worried, of course, about the welfare of my grandchild, but my heart broke even more for my son and daughter-in-law for what they were going through and for not being able to experience the normal joy of becoming a parent.”

In this handout we will focus on dealing with grief issues; how to go on to develop fulfilling relationships between parent and grandparent, grandparent and grandchild; and the best ways for the grandparent of a special grandchild to provide support.

Initial Reactions

Both parent and grandparent share the universal reactions of grief. The initial reaction to the birth of a child with a disability is *numbness*. The numbness is an *actual* physiological response, and is nature's way of protecting us from feeling unbearable pain. The short-lived stage gives us time to develop ways of coping.

The most frequent coping mechanism that follows is *denial*. Feelings of unreality, that this really didn't happen or is some kind of a misdiagnosis, are common examples of this stage. Grandparents who are removed from first hand experiences with the newborn or who live at a distance frequently cling to denial reactions, hoping against hope that their grandchild is somehow miraculously outgrowing the disability. In extreme situations, the grandparent may avoid visiting or even calling, thus not having to come to terms with the truth. Unfortunately, this type of behavior can be mistaken for disinterest, compounding the new parents' sorrow and taking away their much-needed support.



Grief Reactions

It is important to recognize that clinging to denial is one way of not having to grieve. Persistent denial, as understandable as it is, will only backfire because we *must* grieve in order to heal. Grief is the natural expression of all the emotions we feel when faced with tragedy. Not allowing oneself to work through these feelings can often result later on in depression, stress-related physical illness, insomnia and other emotional problems.

Paradoxically, the only way to relieve grief is to permit the sorrow and pain to surface. Feelings of grief shared with someone else – spouse, counselor, clergy – gradually lessen in duration and intensity. Grandparents who believe they are being strong by denying or suppressing their grief feelings run the risk of compromising their ability to function and be of any assistance.

Sometimes the grandparents and new parents are unable to communicate to each other exactly how they feel. Both sides may feel vulnerable or wish to protect each other. However, sharing feelings honestly and openly will bring the family closer together. Sympathetic words or tender encouragement can go a long way at this point.

One of the most frequent reactions to a stressful circumstance is *anger*. This can be a generalized response such as “Why did this happen to me?” or can be directed to others such as the doctor or the hospital where the child was born. Anger in its extreme form can manifest itself as uncontrollable rage, thus paralyzing and frightening at the same time.

Sometimes anger is displaced and serves as a way of assigning blame to others, especially to the doctors and therapists. At times misplaced anger is directed towards the child with the disability themselves and this unhappy situation can result in rejecting the child altogether.

Unfortunately, there is no easy answer to dealing with anger. Although anger is understandable, it is ultimately non-productive. As one young parent told the grandparents, “My anger went away when one day I looked down at my child and thought not ‘Why me?’ but ‘Why him?’”

Tips for Parents

In most cases grandparents who have a grandchild with a disability want to shoulder some of the responsibility and help out as much as they can. Sometimes they are upset themselves, and their good intentions can become overbearing or interfering.

Be honest. If you feel the grandparents are out-of-bounds, let them know as calmly and gently as possible. If, on the other hand, you feel the grandparents have distanced themselves, perhaps because they “don’t want to get in the way”, then let them know that you welcome their calls and visits. In any event, open communication and an honest expression of wants and needs work best. If the grandparents ask how they can help, tell them as explicitly as possible: Can you go to the grocery store? Take the other children for a weekend? Take my car in to be serviced? Suggest whatever will make things easier. Most grandparents would be delighted with a little bit of direction.

Asking for help. Subtle hints often lead to misunderstandings and hurt feelings. If you are in need of financial assistance for example, *discuss this openly*. In many cases, young couples with an infant or young child strive to be as independent as possible. However, having a child with a disability can strain both financial and emotional resources. Being honest about your situation and your feelings is the best bet, whenever asking for needed assistance.

Educate your parents about their grandchild’s disability. Send them literature, pamphlets or books about the specific disability. Have them accompany you and their grandchild to the child’s doctor, therapist, clinic, etc. Let them ask the doctor or teacher questions so they can learn *firsthand* the nature and extent of the grandchild’s

needs. The more educated the grandparents become, the better able they are to help you *and* their grandchild. Sometimes grandparents have hidden fears or misconceptions about the nature and the course of their grandchild's disability. Gaining knowledge can dispel many unfounded anxieties. The more grandparents know, the less likely they are to offer unwanted advice about "cures," diets and the like.

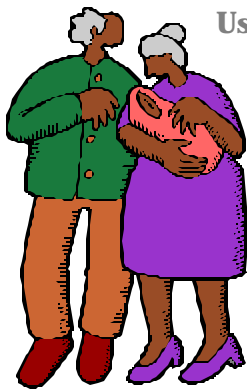
Help your parents to feel comfortable with caring for their grandchild. In many cases grandparents hesitate to babysit or provide respite because they are fearful of doing something wrong or harmful. Your explicit instructions and hints will enable the grandparents to relax, enjoy and bond with their grandchild. Giving grandparents the opportunity to hold close and nurture their grandchild deepens love and family ties.

Tips for Grandparents

Most grandparents who have more financial resources and leisure time at their disposal find great pleasure in the relationships they develop and the activities they share with their grandchildren. In many cases grandparents have a more relaxed attitude towards their grandchildren; they are not as pressured or fearful of spoiling the child as when they were young parents themselves. Tales of doting grandparents who indulge their grandchild's every whim are legendary, however; allowing grandchildren forbidden sweets, staying up late or ignoring family rules, although prompted by the most loving of intentions, can create family friction – especially when the child has special needs.

Grandparents can avoid hard feelings by sitting down beforehand and requesting careful explanations regarding their grandchild's care, including, for example, what activities are over-stimulating, what activities are most beneficial, hints on handling and dietary needs.

By becoming as expert as possible the grandparent will be able to provide consistent care and help when and where it is most needed.



Use leisure time to your grandchild's best advantage. Because grandparents are removed from the day-to-day care of your child that can be tiresome at times, they are better equipped to do and say the little things that enrich the quality of their grandchild's life. The grandfather, for instance, who patiently tosses the ball back and forth to help with coordination, or the grandmother who spends hours teaching shoelace tying is providing a loving service that delights both grandparent and grand child. The best gift a grandparent can offer is the gift of time.

Providing actual financial gifts however, requires careful evaluation. Many well-meaning grandparents leave bequests or send funds to their grandchild, not realizing that often this is *not* the best way to provide for the child's needs. In many states, having funds in one's own name and right disenfranchises the individual from vital services and benefits, including Medicaid, Social Security Income, living on one's own and more. Grandparents and parents should seek the advice of an attorney or agency expert in the field of leaving gifts, trusts, and wills. Regulations vary from state to state.

Dos and Don'ts

Do be aware that most schools, agencies and parent support groups welcome attendance by grandparents. Some associations even have grandparent groups. This is a good way of keeping abreast of your grandchild's specific disability and, more importantly, indicates your support.

Do avoid the pitfalls of cliché-ridden advice. Pollyanna statements about things not being as bad as they seem, or this was meant to be may sound condescending to the parents, and may not provide the comfort you wish to imply.

Do remember that if you have a positive, tender, loving attitude towards your grandchild, others in the family will feel the same way. The more support from family members, the better the young parents feel.

Do remember that non-verbal expressions – a loving pat to your grandchild's head, a warm hug to your son, daughter and their spouses – convey what words cannot express. By the same token, pitying glances and an anxious tone of voice may be conveyed as disappointment.

Do be aware of any heightened sensitivity in the parents. Be careful about what you say, and remember that your most well intentioned remarks can be taken the wrong way. Handle this with grace and humor.

Do let your children know that they can rely on you in good times or bad. Many grandparents have flexible schedules that can be arranged to meet the needs of the grandchild. Just knowing that this kind of help is available can lessen anxieties and strengthen family bonds.

Do offer to visit or help out with your grandchild regularly. Sometimes staying at a nearby hotel can ease the logistics and make the visit even more rewarding for all involved.

Don't allow any frictions between yourself and your children interfere with your relationship with your grandchild. The bonds of love between grandparent and grandchild are genuine and profound. The relationship can enhance and nurture the grandchild's feelings of self-esteem and self-worth.

Do be aware that there are revolving cycles of grief. Feelings of depression, anger, non-acceptance or sorrow usually surface around stressed times or milestones, such as when your grandchild should have been walking or talking. Knowing this ahead of time can prevent the reaction from becoming extreme.

Do remember that above all the relationship of a grandparent to a grandchild is unique, and the love that is generated is freely given and like no other. Your grandchild with a disability is first and foremost a *child* – more like other children than not unlike. The needs of a child with a disability differ only in degree, not in kind. Your grandchild responds to your love, your jokes and games, your abiding affection exactly like any of your other grandchildren.

Adapted from the March/April 1990 issue of Special Parent/Special Child. 2001.



Can I Imagine Life Without Beth?

By Jeannette Lohner

It's been eight years since Beth made her debut into this world. Thinking back I cannot imagine what life would have been without her. She's stubborn, devious, imaginative, forgiving and loving. In fact, we often remark that she never holds a grudge.

She loves McDonald's, Arby's and most fast food items and one of her favorite games is "drive through." As a sight-reader you can imagine which words she recognizes immediately. The "yucks" in her life include rice, peas, stew and cornbread. Her favorite movie is "The Wizard of Oz." She loves to play the part of Dorothy while relegating others to the role of the Scarecrow, the Lion or the Tin Man.

Since I take her to school every morning, I have observed some very "typical" behavior. She absolutely refuses to let me walk into the school building with her. "I'm a big girl, mam-ma," she insists. As she strives for independence, I hold my breath as she pours her own juice and milk while reminding me firmly, "I do it myself."

She has known her colors since she was three, but we thought she would never learn to count to ten. But she did, and even to fifty (sometimes) and now is constantly counting everything. She still has no concept of time, but then a lot of other people I know don't either. She attends public school and is in a special education class. Because her behavior has sometimes been a problem, she has gotten to know practically all the teachers, and especially knows the principal!

Someone once asked me, "Don't you sometimes yearn for the child that Beth might have been if she didn't have Down syndrome?" I thought about that for a moment – a child who would probably have mastered her ABCs early and could have counted to 100 by the time she was five or maybe even four. A child who would have barreled down the street on a two-wheeler at an early age while I worried about her safety. A child who would have probably been a little more sophisticated than the other kids so that when she misbehaved she wouldn't always have gotten caught. But a child who would still have loved McDonald's and Arby's and "yucked" at rice, peas and stew. No, I don't yearn for the child that might have been or for the persons my own sons, who do not have a disability, might have been. I accept Beth as her very own person, unique in every way, just as she accepts all of us, even when we are less than perfect. I consider it a privilege to be Beth's grandmother and I see her as one of the rainbows in my life. She can be a challenge, a help and sometimes a pain-in-the-neck. But looking back over these past years I cannot possible imagine my life without Beth.



Grandparent Group

Grandparents of children with Down syndrome are welcome to attend the DSAGC Grandparent groups. Grandparents of children of all ages gather quarterly for dinner at an area restaurant to share experiences, joys and of course, pictures of their beautiful grandchildren!

For information on the Butler County Group, please email Joan at jeve@fuse.net or contact her at 513.931.8630 .

For information on the Northern KY Group, please email Dottie at tdjo@fuse.net or contact her at 859.586.4035 .

Grandparents from all counties are welcome

Come join us for a fun evening!



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

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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Words of Wisdom from Grandparents of a Child with Down Syndrome

She makes me smile...she makes me laugh...she makes me feel proud. She is Elizabeth. She just happens to have Down syndrome.



Ashley's smile has brightened many days for all of us.

Having Matthew as part of our family has taught us patience and brought us all closer together. We have all learned the true meaning of challenge and determination.

Down syndrome is powerless to trespass into our grandson's personality. He is as unique and fascinating as any child.

I think at first grandparents get a double blow—you are upset because you worry about your child and you also worry about your grandchild. But as time goes on and your love grows, you wonder why you ever were so upset. Just take one day at a time.

Our grandchild has been a true blessing. Enjoy the smiles, love, adventures and accomplishments that you will share. He has been a wonderful source of joy in our lives. We've met and made so many new friends at the Grandparent Group.



Provide support to your children, be there to listen and help when needed.

Each accomplishment is a stepping-stone to be cherished.

With love,

Grandparents of the Down Syndrome Assoc. of Greater Cincinnati

Things to Say and NOT to Say

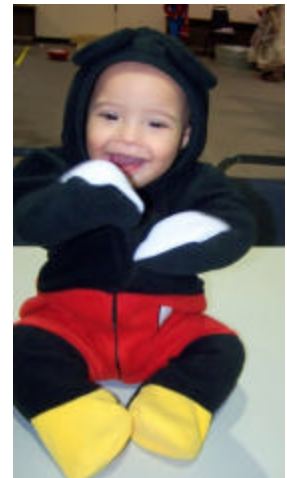
We have received many e-mails from aunts and uncles of children with Down syndrome who are trying to get more information about the new child in their family. We can not stress enough how important it is for family to support the new parents at this time. This is a frightening time for the new parents 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.

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.



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.ndscenter.org. Ms. Sefton is a Master Developmental Therapist.