

the up side of dōwns

*Supporting & Celebrating
Down Syndrome in Northeast Ohio*

Understanding the Diagnosis

A Guide for Parents





**Use this booklet
as a guide to
answer the
questions that
you may have.**

Dear Parent,

You may have just been told that your baby most likely has Down syndrome. You probably have a million questions, concerns and fears right now. **That is okay.** The most important thing to remember is that this diagnosis is not as “life changing” as the fact that you will have a new baby. And in most ways, your baby will be just like other infants. Every baby needs to be fed, held and most of all, *loved*.

There will be challenges in raising your child, but there will be many, many joys also. It is normal to be nervous about what lies ahead, but remember, Down syndrome is a condition your baby may have, it is not who your baby is. This guide is to help give you some information about Down syndrome and let you know what resources are available to you.

We have a wonderful *New Parent Support* program that offers phone calls, home and/or hospital visits or e-mail contact. We also have a comprehensive website and online Family Support network. We offer infant and toddler playgroups, family social events, youth activity programs, parent educational programs, family grant program, and help with accessing benefits programs through the Ohio Benefits Bank.

The Up Side of Downs wants you to know that you are not alone. We support over 900 families in sixteen counties in Northeast Ohio. We are here to support you and provide you with information to help you on your journey.

What is Down Syndrome?

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

Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies is born with Down syndrome.

There are more than 400,000 people living with Down syndrome in the United States.

DOWN SYNDROME OCCURS IN PEOPLE OF ALL RACES AND ECONOMIC LEVELS.

The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.

People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.

A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.

LIFE EXPECTANCY FOR PEOPLE WITH DOWN SYNDROME HAS INCREASED DRAMATICALLY IN RECENT DECADES - FROM 25 IN 1983 TO 60 TODAY.

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

All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses. There are many people with Down syndrome who have made great accomplishments in their lives, including graduating from high school, going on to college, living on their own and getting married. Please see this website to read about many of these individuals: www.thepreciouslivesgroup.org. One such individual is Jason Kingsley, who is one of the authors of the book *Count Us In*. He graduated from high school with a regular diploma and passed all his New York State Regents Competency exams. His mother is Emily Perl Kingsley, the author of the poem, "Welcome to Holland".

Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives. People with Down syndrome date, socialize and form ongoing relationships. See the story of Carrie Bergeron, a national advocate, and Sujeet Desai, an accomplished musician who plays 6 instruments on his website at www.sujeet.com who got married in 2006.

Another accomplished young woman with Down syndrome is Karen Gaffney. Karen has received her high school diploma and she completed requirements for an AS degree and a certificate to be a teacher's aide at Portland Community College. Karen even swam the English Channel! You can visit her website at www.karengaffneyfoundation.com.

Researchers are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.



What Causes Down Syndrome?

First of all, you need to know that nothing that you or your partner did before or during your pregnancy caused your baby to have Down syndrome. In every cell in the human body there is a nucleus, where genetic material is stored in genes. Genes carry the codes responsible for all of our inherited traits and are grouped along rod-like structures called chromosomes. Normally, the nucleus of each cell contains 23 pairs of chromosomes, half of which are inherited from each parent.

There are three 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 since 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 three to four percent of the individuals with Down syndrome. Another chromosome problem, called mosaicism, is noted in about one percent of individuals 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 cell division soon after conception.

All persons with Down syndrome have an extra, critical portion of chromosome 21 present in all or some of their cells. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.

Once a woman has given birth to a baby with Trisomy 21, it is estimated that her chances of having another baby with Trisomy 21 is 1% greater than her chances by age alone.

The age of the mother does not seem to be linked to the risk of translocation. Most cases are sporadic-that is, chance events. However, in about one third of cases, one parent is a carrier of a translocated chromosome. The risk of recurrence of translocation is about 3% if the father is the carrier and 10-15% if the mother is the carrier. Genetic counseling can determine the origin of translocation.

More information about Down syndrome can be found on our website, www.usod.org or the National Down Syndrome Society's website at www.ndss.org. If you do not have access to the internet, please contact our office at 216.447.USOD (8763) and we will be happy to get you that information.

How will this affect our family?

Many parents are concerned about the potential impact of a child with Down syndrome on their families. Indeed, raising a child with any disability, including Down syndrome, poses some unique challenges, which can require more time, cost and patience. On the other hand, parents report that children with Down syndrome can have a positive impact on their entire family and increase their appreciation for humanity and empathy for others. Studies also reveal that the parents of children with Down syndrome, in fact, have a lower divorce rate than couples who do not have a child with Down syndrome.

Brothers and sisters of individuals with Down syndrome report that the positives typically outweigh the negatives in the relationships with their siblings. According to some studies, siblings of children with Down syndrome tend to be more compassionate and well adjusted than their other peers. Additionally, a large number of siblings report close relationships with their brother or sister with Down syndrome into adulthood, and many of these siblings choose careers in the health care, support services and education fields.



Next Steps for New and Expectant Parents

Contact the Up Side of Downs (USOD) at 216.447.USOD (8763)

- Request an Expectant Parent and/or New Parent Packet.
- Speak to our New Parents Coordinator who can help you through this sensitive time.

Get on the web

- www.usod.org
Access links, learn about USOD services and read archived copies of the weekly Sunburst e-newsletter or bi-monthly Sunburst News publication.
- **Parent-to-Parent Network**
Join the USOD Online Family Support Network, a social network for USOD families to share resources and support.
- www.ds-health.com
Created by a pediatrician and parent of a child with Down syndrome, this website can address many of your medical questions.
- www.ndss.org and www.ndscenter.org
These websites were created by the two national Down syndrome organizations.

Contact other parents

- The USOD has an excellent Parent to Parent Mentoring Program that connects families over the phone, in person or by email. Geographic area, age of parents, birth order of baby, medical complications, multiple births or single birth, are all considered when creating a match of new parent or mentoring parent.
- Seek out people on your own that are connected to a person with Down syndrome whether at church, work or in the community, and ask them to tell you about their lives.
- Visit bulletin boards to read questions and comments from new and expectant parents. Go to the USOD Online Parent to Parent Network for support from local families.

For Expectant Parents

- Make an appointment for genetic counseling or testing at University Hospitals 1-866-UH4-CARE, and Cleveland Clinic 1-800-223-CARE.
- Research genetic testing on your own. Try www.kidshealth.org and search for Down syndrome.

For Parents of Newborns

- Talk with your doctor about scheduling a special heart test called an echocardiogram soon after birth. Forty percent of babies with Down syndrome are born with a heart defect. The USOD can provide you and/or your pediatrician a list of recommended health care guidelines for people with Down syndrome.
- Help Me Grow (www.ohiohelpmegrow.org) Contact the “Early Intervention” in your county for information about the many helpful services they offer free of charge to help minimize delays and maximize development.

For adoption information

- Contact the National Down Syndrome Adoption Network (NDSAN) at 513.213.9615 or www.ndsan.org. NDSAN provides information and support to birth parents throughout the United States in order to ensure that every child born with Down syndrome grows up in a caring family.

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We at The Up Side of Downs want you to know that we are here to provide you with whatever support and information that you may need.

We are committed to building a community where people with Down syndrome are independent and have the opportunity to reach their fullest potential.

Membership is free and open to anyone; families, grandparents, educators, medical professionals and friends.

Please contact us at
216.447.USOD (8763)
or www.usod.org.



USOD'S MISSION

To provide support, education
and advocacy for people with
Down syndrome, their families
and communities.

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