

See the Potential

A New Parent Booklet

**Prepared by The Down Syndrome
Association of Atlanta**

...you are not alone
**The most important thing for
you to know is that you are not alone.**

*...and that will happen
faster than you might think.*
**It will feel like a great accomplishment when
everything starts to fall into a routine again,
and that will happen faster than you might think.**

Dear New Parent:

Congratulations on the birth of your baby! Everything you are feeling is very natural and we know it can be overwhelming. Please know that you are not alone. The Down Syndrome Association of Atlanta (DSAA) is here to help and support you. For immediate information, please log on to our website at www.atlantadsaa.org. DSAA is comprised of parents, families, professionals, and friends who share many experiences with people who have Down syndrome. We have children of all ages, races, and ethnic backgrounds, yet we are all connected by the common link of loving someone with Down syndrome. We know first hand what you are going through.

If there is one thing that we can share with you right now, it is to enjoy your new baby! Your child has Down syndrome, but that diagnosis is far second to the excitement of having a new baby in your family. Your baby needs care, hugs, kisses, the sound of your voice, and that same unconditional love that all babies need.

Please take extra care of yourself, as well as the new addition to your family. Rest, let yourself laugh, cry, and share your feelings. Your life has changed in an unexpected way. You are beginning to walk a path you might not have expected, but it is a unique and wonderful experience. Your baby is special and we are here to celebrate with you and support you.

Sincerely,

Michelle Norweck
DSAA Member Parent



“Your life has changed
in an unexpected way.
You are beginning to walk a path
you might not have expected,
but it is a unique and
wonderful experience.”



Introduction

A message from the Down Syndrome Association of Atlanta

The Down Syndrome Association of Atlanta (DSAA) prepared this booklet to introduce you to Down syndrome. The feelings of disbelief, fear, sadness, and isolation that mothers and fathers normally experience when they are told that their baby has Down syndrome are frequently made worse because many new parents know very little about Down syndrome. Often it is not until weeks or months later that parents realize many of their initial fears were unfounded.

There is no profile for people who have children with Down syndrome. A child with Down syndrome can be born to anyone, regardless of age, race, socio-economic status, or where you live. The name Down syndrome comes from the English doctor John Langdon Down, who first described the syndrome in 1866. A syndrome is a collection of signs or characteristics.



DSAA Parent Corner:

“Most important thing to tell a new family; it’s going to be OK. It’s really difficult at first. You’re tired with any newborn, more exhausted when yours has a special need.”

“Don’t be ashamed of having a child with a handicap. Take her out. Show her off. Be proud of your baby. I keep telling myself that it is all going to be OK and, if I think about it, so far everything is OK. The most important thing for families to know is that heartbreak will give way to love and, believe it or not, intense enjoyment of your child who will turn out to be wonderful.”



DSAA was established many years ago by parents like you. Over the years DSAA has reached out and assisted parents through counseling, collective strength, and emotional support. DSAA promotes public awareness and advocates for the rights of people with Down syndrome. By addressing social policy issues and government legislation, people with Down syndrome become productive and important members of their community.

DSAA holds a bi-annual education conference that brings together parents and professionals with the latest information regarding health, research, therapies, and advocacy. Our website, at www.atlantadsaa.org, provides current updates on all aspects of DSAA, and a bi-monthly newsletter highlights personal interest stories, advocacy, clinical news, and events.

Characteristics of Down Syndrome

When a child is born, the health professionals present at delivery may suspect that the baby has Down syndrome because they observe characteristic physical features and low muscle tone. Facial features associated with Down syndrome are variable but can include upslanting eyes, epicanthal folds (small folds of skin at the inside corners of the eyes), a small nose, a tongue that tends to protrude, and small ears. Babies often have an extra fold of skin on the back of their neck and single creases across one or both palms.



However, each child is different, and you may or may not find each of these features in your baby. You should talk with your physician and get a referral to a medical geneticist or genetic counselor whose specialty includes Down syndrome. Write down your questions as they arise and ask to meet with individuals who can help you find the answers—your baby’s pediatrician, other professionals, and parents are available for you.



In addition to characteristic physical features, some babies with Down syndrome are born with medical problems including heart defects and/or abnormalities of the digestive tract. These are discussed under the section “The First Few Months” on page 6 of this booklet.

The most disheartening thing that you will probably be told is that your child will be developmentally delayed. All individuals with Down syndrome have delayed development, usually in the mild to moderate range, although the degree varies greatly from child to child. Sometimes you may hear the term developmentally delayed interchanged with mental retardation, and in the medical community it is abbreviated as MR/DD. Many parents ask if there is any way to know how their child will develop, but just as with any newborn, there is no reliable way to make these predictions early in life.

DSAA Parent Corner:

“When I first found out Justin had Down syndrome I was full of disbelief - after all, he looked ‘normal’ to me. Next a grieving period set in for all that Justin would not be. Finally, acceptance and thankfulness appeared.The first year is full of adjustments.”

“At first, I felt like every minute I was with him needed to be some kind of therapy session so I didn’t miss any opportunity to help him develop. Gradually came the realization that cuddle time is just as important and ‘playing’ is a great developmental tool.”

The Cause of Down Syndrome

In the United States, approximately 1 in 700 babies is born with Down syndrome. In the five county Atlanta area (Clayton Cobb, DeKalb, Fulton, and Gwinnett) approximately 70-80 babies with Down syndrome are born each year. As a woman gets older there is a greater chance of giving birth to a child with Down syndrome. This is particularly true for women in their mid-thirties and older. However, most babies with Down syndrome are born to women under 35 years of age because there is a higher number of younger women having babies.

The first thing to remember is that you did not cause your baby to have Down syndrome. Often, when parents first learn that their newborn has Down syndrome, they worry that something they did or thought before or during the pregnancy affected their baby. Nothing you did or thought caused your child to have Down syndrome. All individuals who have Down syndrome have it because they were born with extra chromosome material in their cells.

If the attending doctor thinks that a newborn has Down syndrome, a sample of the baby's blood is sent to a genetics laboratory for chromosome studies. Chromosomes are an important part of virtually every cell in the body because they carry the genes that determine our make-up. The normal number of human chromosomes is 46 and they come in pairs numbered 1 through 22, plus the two sex chromosomes, XX for girls and XY for boys (Fig. 1). Individuals with Down syndrome have an extra chromosome 21 in their cells. It can either be freestanding (standard trisomy 21) or attached to another chromosome (translocation). The extra chromosome carries another set of several hundred normal genes. Medical researchers around the world are working to discover how those extra genes cause Down syndrome.

Standard Trisomy 21 Down Syndrome

The most common cause of Down syndrome is standard trisomy 21 in which the individual has a total of 47 chromosomes including an extra free-standing chromosome 21 (Fig. 2). The extra chromosome material results from an error in cell division either in the egg or the sperm prior to conception or in the embryo very soon afterward. Approximately 95 of every 100 individuals with

Down syndrome have standard trisomy 21 in all of their cells that are tested. In rare cases (about one percent of Down syndrome) the child has a mixture of cells with standard trisomy 21 and cells with the normal number of 46 chromosomes. This is called mosaicism or (mosaic trisomy 21). Depending on the proportion of cells with an extra chromosome 21, mosaic individuals may be more mildly affected.

Translocation Down Syndrome

Four out of every 100 individuals with Down syndrome have a translocation between the extra 21 and another chromosome. These individuals have the normal number of 46 chromosomes but one of the chromosomes has an extra chromosome 21 attached (usually at chromosome 13, 14, 15, or 21). (Fig. 3). The physical characteristics and abilities of children with Down syndrome do not differ between trisomy 21 and translocation Down syndrome.

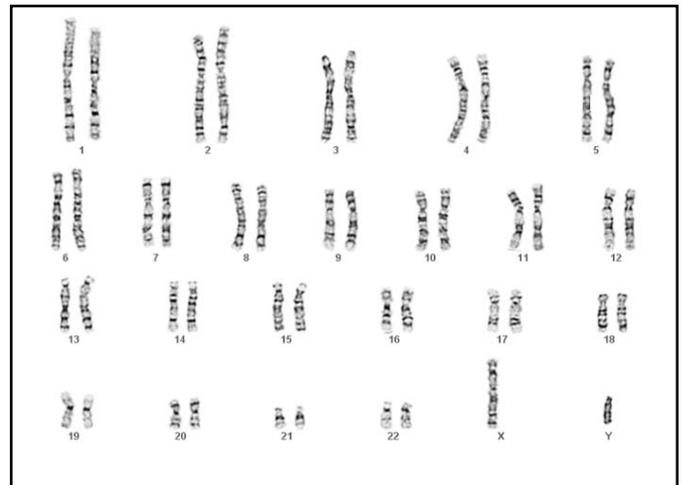


Figure 1: Normal chromosomes (male).

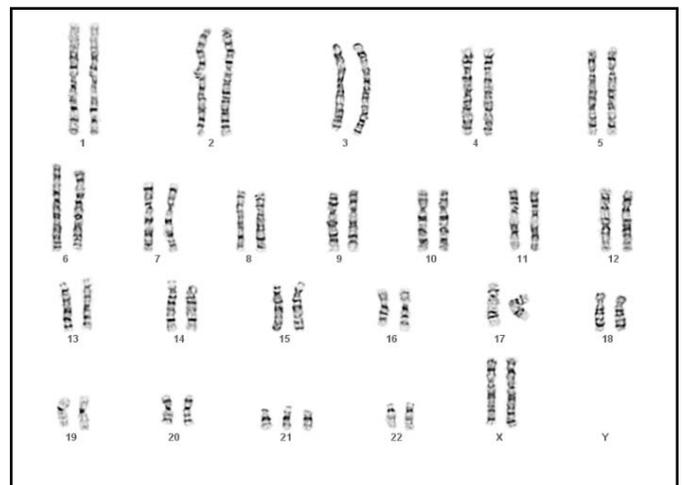


Figure 2: Trisomy 21 Down syndrome (female).

What is the Chance that Down Syndrome Will Occur Again?

Although the newborn period is chaotic and parents are focusing on their baby, most couples eventually ask whether they have an increased chance for having another child with Down syndrome. The answer to this question depends on the type of chromosome 21 abnormality present. For standard trisomy 21, the chance is estimated to be about one percent, that is, out of 100 couples who have one child with Down syndrome, one will have a second affected child. For women in their late thirties or forties, the chance is somewhat greater than one percent and is usually based on the woman's age at the time of the second pregnancy.

The chance for recurrence is different when Down syndrome is caused by a translocation of chromosome 21 onto another chromosome. Both parents should have their chromosomes studied. In about one-fourth of cases where the child has a translocation, one of the parents has a similar translocation although they have it in a "balanced" form that does not cause them to have Down syndrome. In three quarters of the cases, the translocation just happened for the first time in that one child and neither parent is a carrier. If one parent is a carrier of the translocation, there is a substantially

greater chance of having a second child with Down syndrome. The actual risk depends on the type of translocation. If neither parent carries the translocation, the chance of another child having the same translocation is very low.

Couples who have had one child with Down syndrome (either standard trisomy 21 or a translocation) are encouraged to meet with a geneticist or genetic counselor. A professional can discuss the chance of recurrence and explain about options for chromosome testing during a pregnancy.

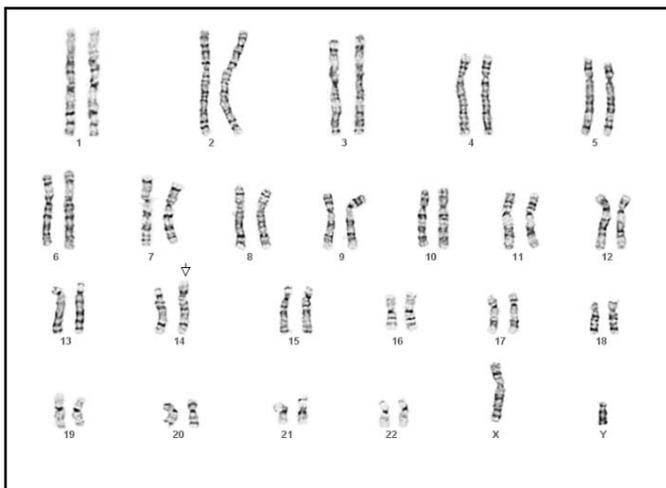
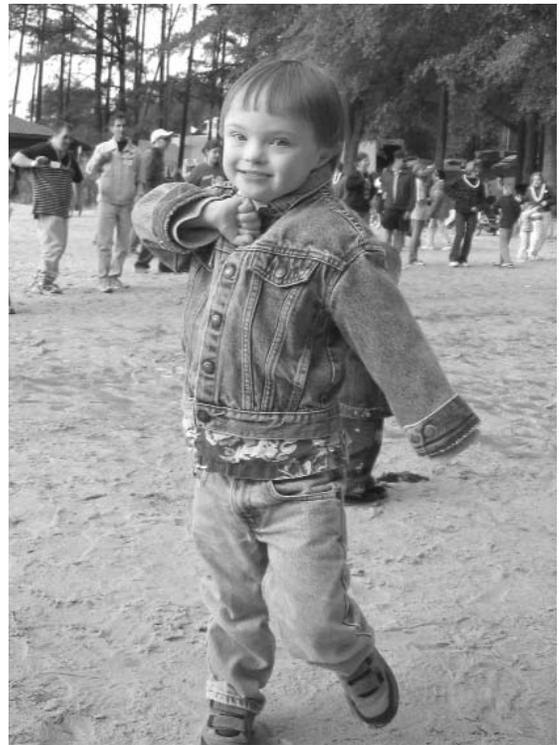


Figure 3: Translocation Down syndrome (male). An extra chromosome 21 is attached to a chromosome 14.

DSAA Parent Corner:

"We sent our immediate family members information that we received from the Down Syndrome Association. We included pamphlets with pictures of young children and everyone was happy to receive the information.."

"It is just the unknown, the fear of taking the step to speak out for your child. You learn a lot real fast and you learn to speak up to educate others. As they understand and hear you speak frankly, they are much more accepting."

"The most practical advice I could give would be treat your child as you would any other....Give your child a lot of love and attention and you will be amazed at what he can achieve."

Informing Family and Friends

Many parents find this to be difficult and they feel apprehensive telling the grandparents, the baby's siblings, and friends that their new baby has Down syndrome. Experience has shown that using a forthright approach and providing up-to-date information sets a positive tone and allows family and friends to become involved from the start.

The First Few Months

Your baby will have a physical examination soon after birth and if any problems are suspected, specialists will be consulted. All infants, whether or not they have Down syndrome, need a general pediatrician for routine care. Well-baby exams, immunizations, and treatment for routine childhood illnesses are taken care of by your child's pediatrician. This person does not have to be a "Down syndrome specialist." It is more important for you to choose someone you are comfortable with and whom you believe will give your child the best medical care.

The American Academy of Pediatrics and the national Down Syndrome Medical Interest Group have developed Healthcare Guidelines for individuals with Down syndrome. One of the first recommendations is for new parents to schedule an appointment in a general genetics

DSAA Parent Corner:

"Doctors, hospitals, testing, therapy, service coordinator, Down Syndrome Association meetings - very exhausting, emotionally and physically-[but] very rewarding - every 'new venture' was so meaningful."

"My advice is to get involved! Find out what's available to you and do it. Some of the nicest people I have met are parents of children with Down syndrome. There is also an unspoken bond and sense of familiarity and sensitivity that exist. You are not alone!!"

clinic or a special Down syndrome clinic. A geneticist or genetic counselor familiar with Down syndrome will explain your baby's chromosome report, discuss the development of individuals with Down syndrome, assess your child's medical and developmental needs, direct you to community services, and answer your questions. Follow-up visits can be scheduled to monitor progress.



Because approximately 40-50% of all babies with Down syndrome are born with a heart defect, the national Healthcare Guidelines recommend that each newborn have an echocardiogram and an evaluation by a cardiologist with follow-up if needed. Heart defects range from those that disappear by themselves to more serious problems that require surgery.

Ten percent of infants with Down syndrome are born with a gastrointestinal abnormality. The majority of these are detected soon after birth. The most common is duodenal atresia, a narrowing of a portion of the small intestine. Surgery is usually required in these cases.

There are several other problems that occur occasionally in infants with Down syndrome. By following the national Healthcare Guidelines, neonatologists, pediatricians, and geneticists remain alert for possible problems and can refer a child to the appropriate specialist. Of course, if you have any concerns about your child's health you should discuss this with your child's physician.

Early Intervention

Soon you will begin to hear about “early intervention”. Years ago, new parents were given a poor outlook for their newborn with Down syndrome. Parents and professionals did not take an active role in promoting the infant’s development. Fortunately, times have changed and we realize that much can be done very early in life to maximize a child’s potential.

Beginning soon after birth, early intervention specialists including physical, occupational, and speech therapists should become involved in your baby’s care. In Georgia, each county has services for children with Down syndrome and there are private sources as well. You should make sure your child’s pediatrician or geneticist refers you to the appropriate resources in your community.

Resources

There are many resources available to help new families learn about Down syndrome and reach the services they need. We have included with this booklet a separate list of specialty clinics, books, websites, national and local organizations, and government agencies. A warning: the internet has some valuable sites related to Down syndrome, but parents should exercise caution and be alert for sites that make unfounded statements.

In the beginning it is easy to feel overwhelmed. In addition to doctors you will encounter social workers, physical therapists, early intervention teams, and other parents who will suggest community resources to investigate, books to read, websites to visit, and a host of other things. Keep in mind that you do not have to do everything at once. You may want to keep a journal—if you do not feel up to doing this at first, ask a friend or family member to help. New parents are often bewildered by the sheer number of individuals with whom they come in contact. Always be sure to ask for business cards and write on the back when and where you met the person. Keep all of this material together, deal with the immediate issues, and worry about the rest later.



Meeting Other Parents Who Have Children with Down Syndrome

Some parents want to talk to another family as soon as possible after hearing their baby has Down syndrome, and they later say that this was one of the best decisions they made. Others wait before taking that step. There is no right or wrong way. You should take the approach that makes you comfortable. DSAA is always ready and waiting to help with this step.

DSAA Parent Corner:

“We take such a great joy and so much pleasure from Jenna and each success. She enjoys other children, attends Easter Seals of North Georgia daycare, and receives physical, occupational, and speech therapy.”

“Chris is 9. He is in a regular second grade class receiving resource help. He also receives speech and occupational therapy. Chris loves, gymnastics and cub scouts. Frustrations are the constant educating of others...”

How Will My Child Grow and Develop?

New parents usually want to know what the future will hold for their child. Health problems in the newborn period were discussed earlier, and aside from these, babies and children with Down syndrome are very much like other children in their health needs. Colds, earaches, and other common childhood illnesses are to be expected. Some children with Down syndrome will have more trouble with these than other children. In a few cases, more serious medical problems can arise, but these are not common. You'll find that several of the newer books (we have included a separate list of reading materials in this folder) about Down syndrome have very good explanations of health needs and problems that may arise.

Many new parents do not have a good idea about how a child with Down syndrome develops and, therefore, they tend to think the worst when they are told that their child will be developmentally delayed. First of all, each child is different and there is no way to predict an individual's course of development. Children with Down syndrome develop very much like other children especially during the first few weeks and months of life.

Large motor skills like sitting, crawling, and walking may develop at a slower pace, but early intervention programs and physical therapy help maximize abilities. Speech delay is common, but once again therapy can be extremely effective. In some cases parents encourage the use of sign language to decrease their child's frustration of not being understood.

DSAA Parent Corner:

"He is 12. He has been fully included in a regular class since third grade (he is now in 5th). I wish we had known to do this in kindergarten! This has made the biggest impact on him and our family.."

"Most important - treat your child with Down syndrome as you would any child. Introduce him or her to all types of activities and experiences. Talk to your child, explain things, love, hug, cuddle.... Encourage your child. Your child will do everything that other children will so - it may or may not take longer - just don't give up! Every success is so great."



Most children attend their local schools either in special classes or as part of an inclusion program in typical classes with extra help. Sports, summer camps, hobbies, playing musical instruments—children with Down syndrome, like anyone, can accomplish a great many things with determination and persistence.

Because this booklet is primarily for new parents, we refer you to other sources as you look to the future. In addition to investigating the reading and resource lists enclosed, we encourage you to attend functions of the Down Syndrome Association of Atlanta to meet older children, teens, and adults with Down syndrome and talk with their parents. The goal for children with disabilities is to achieve the highest level of independence by adulthood, and this goal can be met through teamwork and a plan for the future.



Down Syndrome Association of Atlanta

www.AtlantaDSAA.org

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