

*A New Parents' Guide To  
Down Syndrome*





## *Mission Statement*

*The Down Syndrome Society of Rhode Island (DSSRI) is dedicated to promoting the rights, dignity, and potential of all individuals with Down syndrome through advocacy, education, public awareness, and support.*

# *Dedication*

*This brochure is dedicated to our children with Down syndrome who have made us better parents, siblings, and people than we ever dreamed we could be.*

*We love you all,  
XOXO*



# *Congratulations to You and Your Family*

*We will address some of the questions most frequently asked by families during the first few months of their babies' lives. We hope this will give you a good start with your new baby.*

*We know that it may be painful to be told that your new and delightful baby has been born with Down syndrome. Whether this is your first child or your sixth, you may face many emotions, including anger, disbelief, guilt, depression, and anxiety. You will find that through knowledge and support you will gain understanding and control. This booklet offers some suggestions, facts, and ideas to help guide you through this confusing time. We want to help because we have been where you are now.*





# Where Do We Start?

*Since each family is unique, there is no single answer to this question. There are, however, five things that you can do immediately that will aid your peace of mind as you face the beginning of this new situation.*

*ENJOY your baby. These early months will pass very quickly. Do everything you had planned to do before you learned that your baby has Down syndrome. If you are facing some major health condition with your baby, you may have to postpone some of these things — but only temporarily. This little bundle is a baby first and foremost; he or she just coincidentally has Down syndrome.*

*TALK to other parents who have a child with Down syndrome. Another family who has gone through what you are now facing is better able to understand your feelings. You may wish to talk with another parent, visit another parent or have another parent visit you. The DSSRI office can provide you with a contact.*

*EXPLAIN Down syndrome to your relatives and friends simply and candidly. How you accept your new little person will be reflected in the way others accept him or her. The involvement of your family and friends can be a deeply supportive experience for you and a broadening one for them.*

*UNDERSTAND that it is not your fault that your baby was born with Down syndrome. Nothing in the mother's or father's activity, diet or emotional experience caused this. Down syndrome occurs in all races, religions, environments and at all economic levels. The chromosomal abnormality that results in Down syndrome happens most often during the development of the sperm or the egg before conception, or immediately after the sperm and the egg come together at conception.*

*BE MOM AND DAD first. As you learn more about your baby's condition and what you can do to help him or her to learn and grow, you will find yourself in many different roles. One mom said, "Before I knew it, I was so wrapped up trying to be his teacher, therapist, his nurse or doctor, that there didn't seem to be any time left just to be Mom. I really wish I would have just enjoyed him more and been more of a mom to him and let everything else be more secondary. . .*

*I felt like I always had to be 'working' with him. I know now that a normal, healthy family life is also so important to a child; a lot more so than a mother who is running herself ragged and not doing anybody any good." The key, then, is to strike a balance, keeping in mind that being a parent is your primary role.*

\* This section reprinted with permission from Getting a Good Start,  
Down Syndrome Association of Greater Cincinnati, Copyright 1992.

## *Down Syndrome - What Is It?*

*Down syndrome is the most common chromosomal anomaly. The presence of an extra chromosome gives an infant 47 chromosomes. This results in developmental delay, certain physical features and an increased risk for some health conditions. An individual does not outgrow Down syndrome.*

### *CAUSE*

- *Down syndrome results from the presence of an extra chromosome 21.*

### *OCCURRENCE*

- *About 1 in every 691 live births in the USA is a child with Down syndrome.*
- *Approximately 80% of all babies born with Down syndrome are born to mothers under the age of 35 years, although it is known that the chance to have a child with Down syndrome increases with maternal age.*

# *How Is The Diagnosis Made?*

*A baby with Down syndrome can usually be recognized by physical examination shortly after birth. The most common features of the face, hands and feet may be so apparent that the experienced doctor can make the diagnosis from appearance alone. Also commonly noticed are low birth size and weight, increased flexibility or limpness and heart murmurs. All children with Down syndrome have some of these features, but very few have all of them. Many of these features can be found in children who do not have Down syndrome.*

*When a doctor suspects that a baby has Down syndrome, a blood sample is taken to perform a chromosomal analysis in order to confirm the clinical diagnosis.*

## ***POSSIBLE VISUAL FEATURES***

- Slight upward slant of eyelids with folds of skin over the inner corners of the eyes (epicanthal folds)*
- Light spots within the edge of the iris (colored part) of the eyes (Brushfield spots)*
- Small nose with flat bridge between eyes*
- Mouth often open with tongue showing*
- Ears slightly small and the upper part of the ear is folded over*
- Broadened neck due to excess skin*
- Hands with a single palmar crease; unusual finger print patterns*
- Little (5th) finger curved inward with single crease or 2 close creases*
- Increased space between 1st and 2nd toes with a crease between 1st and 2nd toes*



*In addition, many children with Down syndrome have vision problems. Some may be born with cataracts. An ophthalmological exam is recommended during the baby's first year of life.*

*It is important that all infants with Down syndrome have hearing and vision evaluations between six and twelve months of age or earlier if problems are evident.*

\* This section excerpted with permission from An Introduction to Down Syndrome, Medic Publishing, Co., Copyright 1993.

## *Will My Baby Be Healthy?*

*Children with Down syndrome may face health problems beyond the usual childhood illnesses. Problems such as some congenital malformations of the heart and intestine can be life-threatening. Others are of less significance.*

*More than 40 percent of children born with Down syndrome have congenital malformations of the heart; therefore, every newborn baby with Down syndrome should have an echo-cardiogram and be examined by a pediatric cardiologist. The diagnosis of a heart problem does not necessarily mean the baby is, or will become, seriously ill. The significance of heart problems varies greatly.*

*A high percentage of children with Down syndrome experience some degree of hearing loss, most often due to frequent ear infections or fluid accumulation in the middle ear. Adequate hearing is critical to the development of good language skills; therefore, periodic medical check-ups should include visualization of the ear drum to ensure that no infection is present.*

\* This section, excerpted with permission from A Baby First, National Association For Down Syndrome, Oak Brook, IL.

# *How Do I Feed My Baby?*

*All babies vary in their enthusiasm to feed. Some are eager and hungry and seem to know immediately how to suck effectively either from breast or bottle. Others are sleepy, less enthusiastic, or tire quickly when feeding. Mothers learn their babies' feeding habits and adjust the times and amounts of feeds so that their babies thrive appropriately.*

*Babies with Down syndrome are no different than many other infants who do not have Down syndrome. Some feed enthusiastically whereas others take longer to feed and may require more encouragement. It can be worrying and tiring to spend long periods of time feeding your baby - especially if you have other young children at home. But perseverance pays off as one learns the tricks of tickling cheeks, chin and feet or of changing a diaper in the middle of a feed, to remind a baby to wake up.*

*Here are some points to help you in the area of feeding:*

- When bottle feeding, you can tell how much your baby has taken at a feed and that is useful.*
- When breast-feeding, you may need to express milk in order to maintain sufficient supply if your baby has a weak suck and provides little stimulation to the breast.*
- Tongue position is crucial for proper feeding of any baby. The tongue must be under the nipple and not stuck to the roof of the mouth. It is important to check at the beginning of a feed that nipple and tongue are properly positioned; otherwise, your baby may start to suck, get no milk and give up feeding.*
- Holding your baby fairly upright during feedings may also be helpful in preventing regurgitation of milk.*

- *If possible, allow your baby to feed as long as he or she wants to. This way the baby will pace him or herself and take the amount that he or she needs.*
- *Remember, your baby may not gain weight at the same rate as other babies. Do not be alarmed; this slower weight gain is to be expected in some babies with Down syndrome, in particular if congenital heart disease is present.*
- *The nurses in postpartum units and in the nurseries will help you if your baby has difficulties feeding. Please share any concerns you may have with them so that the Visiting Nurse can also be informed. They often will start visiting you soon after you and your baby go home.*
- *The local LaLeche League may also be able to help you with suggestions for successful breast-feeding.*

*The Down Syndrome Society of Rhode Island has many members who have had successful and satisfying experiences nursing their babies. Call the office for a referral to a parent or for more information.*

\* This section excerpted with permission from *A Practical Guide for Parents of Babies with Down Syndrome*, The Canadian Down Syndrome Society, 1993.



# *When Should I Tell My Family About My Baby With Down Syndrome?*

*Do not wait to tell your family and friends about your baby, although it may be painful to do so. The longer you wait, the harder it will become. You will be surprised how much these people will appreciate your forthrightness and, in the long run, the explanation will avoid unnecessary embarrassment. Many people know very little about Down syndrome except that the children have a disability. It can be useful to share your baby's accomplishments as they occur so that your friends and relatives can learn that the same exciting signs of progress occur in all babies - such as sleeping through the night, smiling and laughing.*

*Try to remember that like you, close family members may feel upset and angry at times. It is important to be tolerant and understanding of each other at these times and to remember that working together will make life easier for everyone in the long run. If you feel that you need to talk to someone outside your circle of family and friends, please feel free to contact DSSRI for guidance.*

*Try to be open and truthful with other children in your family. Answer their questions honestly, just as you would answer any questions from your child.*

\* This section excerpted with permission from *A Practical Guide for Parents of Babies with Down Syndrome*, The Canadian Down Syndrome Society, 1993.



# *How Is Family Life With A Baby Who Has Down Syndrome?*

*Today, most children with Down syndrome live with their families; attend school, social events, and religious activities; and lead full and productive lives.*

*Your child with Down syndrome is a member of your family who deserves love, respect and dignity. We must remember that each child is a unique and caring human being. Not all children will do everything, but all children will have success. No dream or goal should be automatically deemed impossible.*

*A large majority of children with Down syndrome are being successfully included into school systems with their peers. Some people with Down syndrome have their drivers' licenses, graduate from high school or college, and hold jobs in the private sector.*

*Family life takes on a whole new dimension when a child with Down syndrome is born.*



# Welcome To Holland

by Emily Perl Kingsley, Mother of Jason Kingsley who has Down syndrome.

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*I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...*

*When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.*

*After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."*

*"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."*

*But there's been a change in the flight plan. They've landed in Holland and there you must stay.*

*The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.*

*So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.*

*But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."*

*And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very, very significant loss.*

*But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.*



## *Where Do I Go From Here?*

*The prospect of caring for a baby with Down syndrome at times can be overwhelming. The job of parenting may seem suddenly complicated and unfamiliar. Many parents doubt their ability to raise a child with special needs. It is important to remember that there are many resources available to you. Expect a Visiting Nurse to contact you at home soon after you are discharged from the hospital.*

*The Early Intervention Program in Rhode Island is administered by the Executive Office of Health and Human Services (EOHHS). Early Intervention Programs include a wide variety of services provided by specialists in early childhood development. Among the services most often required by children with Down syndrome are speech, physical, and occupational therapies.*

*In addition, children with Down syndrome benefit from many of the same community programs and services as other children such as play groups, nursery school classes, swimming and music lessons, story times at the library, and other social activities.*

*Aside from the expertise of professionals, parents can find information and support from the Down Syndrome Society of Rhode Island. The office has an extensive resource library available to provide parents with guidance and up-to-date information.*





# *Speaking Of Your Baby*

*Words do matter. Although breakthroughs have been made in many areas for persons with Down syndrome, such as early intervention, heart surgery (for those who need it), and inclusion in community activities, our language continues to reinforce false stereotypes. It is most important to remember that your baby is a unique person.*

*Your baby is not a “Down’s” or a “Down syndrome baby” (words you might hear even from some professionals). Your child is a baby who happens to have Down syndrome. Your baby will have a unique personality, with different strengths, capabilities, and talents. Proudly acknowledge your child’s individuality and accomplishments while emphasizing the person first.*

*So once again, CONGRATULATIONS to you and your family, as you begin this journey with your precious new baby.*



# A Special Thank You



*Natalia & Family*



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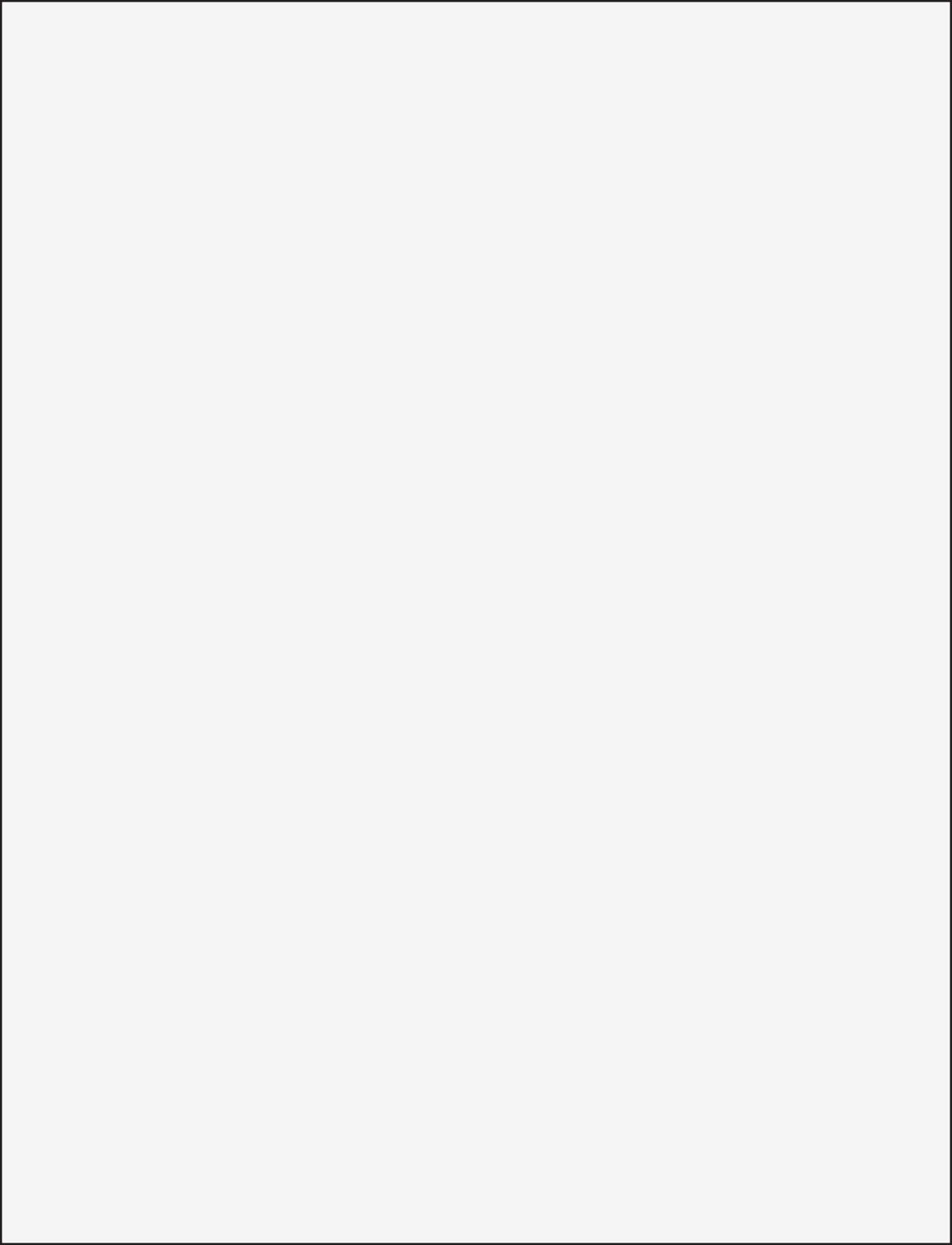
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Third Edition 2015