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We would like to thank all of the
families who contributed to this book.

Welcome Letter

Dear New or Expecting Parents,

Congratulations!

This is an exciting time for both you and your family. From planning the nursery and adjusting to sleepless nights, a new addition not only brings lots of joy but also tons of diapers and late night feedings!!! Having a baby is a time for new beginnings and a time to mark milestones that will fill you with a love that you never imagined you could have for another.

We at Down Syndrome Alliance of the Midlands (DSA) share in your excitement and also in your anxiety and fear. You probably have questions about the health of your child and questions about what kind of life your child is going to have. You also may be mourning the loss of the child you thought you were going to have. The birth of your beautiful baby may bring some changes to your life that will seem difficult. While this new journey may be overwhelming at times, it will also enrich your life. Just like any baby, your baby will amaze you!

Your thoughts, feelings and fears about your baby's diagnosis are normal. Take the time to process your emotions. We are available at any time to provide support, resources and offer advice from parents who have experienced much of what you are going through. We are also here to listen.

If you need anything, would like to talk on the phone or in person, or would like one of our trained Parent to Parent support parents to reach out to you, please contact us at info@dsamidlands.org or call our office at 402.554.6095.

We can't wait to meet you!

Down Syndrome Alliance of the Midlands



MISSION STATEMENT:

DSA is committed to connecting those touched by Down syndrome through education, advocacy and support.

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What Is Down Syndrome?

Down syndrome is the most commonly occurring genetic condition. Individuals with Down syndrome have an extra, critical portion of the 21st chromosome 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.

It is estimated that one in every 691 births will result in a child with Down syndrome. There are approximately 400,000 individuals with Down syndrome in the United States today.

There is a wide variation in the abilities, physical development and behavior of individuals with Down syndrome. Each individual has his or her own unique personality, capabilities and talents. One should always use “people first” language. For example: a newborn is a baby with Down syndrome, not a Down’s baby.

With appropriate education, therapy, social support and opportunity, the majority of individuals with Down syndrome will lead fulfilling and productive lives.

The Genetics of Down syndrome

The human body is made of cells. All cells contain a center, called a nucleus, in which genes are stored. Genes, which carry the codes responsible for all our inherited characteristics, 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. Down syndrome occurs when some or all of a person’s cells have an extra full or partial copy of chromosome 21.

The most common form of Down syndrome is known as Trisomy 21. Individuals with Trisomy 21 have 47 chromosomes instead of the usual 46 in each of their cells. The condition results from an error in cell division called nondisjunction. Prior to or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate. As the embryo develops, the extra chromosome is replicated in every cell of the body. This error in cell division is responsible for 95 percent of all cases of Down syndrome.

Down syndrome also encompasses two other genetic conditions: mosaicism and translocation. Mosaicism occurs when nondisjunction of chromosome 21 takes place in one of the initial cell divisions after fertilization, causing a person to have 46 chromosomes in some of their cells and 47 in others. The least common form of Down syndrome, mosaicism accounts for only 1 to 2 percent of all cases.



There are more than 400,000 individuals with Down syndrome in the United States today.





Translocation, which accounts for 3 to 4 percent of all cases of Down syndrome, occurs when part of chromosome 21 breaks off during cell division and attaches to another chromosome, usually chromosome 14. While the total number of chromosomes in the cells remains 46, the presence of an extra part of chromosome 21 causes the characteristics of Down syndrome.

The cause of the extra full or partial chromosome is still unknown. We do know that it is not caused by environmental factors or anything the mother does before or during her pregnancy. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome resulting from non-disjunction. A 35-year-old woman has a one in 350 chance of conceiving a child with Down syndrome. By age 45, the incidence has increased to one in 30.

However, because younger women have higher fertility rates, 80 percent of babies with Down syndrome are born to women under the age of 35. Once a woman has given birth to a baby with Down syndrome, the chance of having a second child with Down syndrome is about 1 in 100, although age may also be a factor. Maternal age, however, is not linked to the chance of having a baby with translocation. Most cases are sporadic, chance events, but in about one-third of translocation cases, one parent is a carrier of a translocated chromosome. For this reason, the chance of translocation in a second pregnancy is higher than that seen in nondisjunction.

How is Down syndrome diagnosed in a newborn?

Even though there are many prenatal tests available for Down syndrome, most cases of Down syndrome are diagnosed after the baby is born. Doctors will usually suspect Down syndrome if certain physical characteristics are present. Some of the traits common to babies with Down syndrome include low muscle tone, a flat facial profile, a small nose, an upward slant to the eyes, and a single deep crease across the center of the palm.

Not all babies with Down syndrome have all these characteristics, and many of these features can be found to some extent in individuals who do not have the condition. Therefore, doctors must perform a special test called a karyotype before making a definitive diagnosis.

To obtain a karyotype, doctors draw a blood sample to examine your baby's cells. They use special tools to photograph the chromosomes and then group them by size, number and shape. By examining the karyotype, doctors can tell definitively whether or not your baby has Down syndrome.

How will Down syndrome affect my baby's development?

An additional chromosome means that there is excess genetic material in your baby's cells. While this will affect your child's development, it is important to realize that it is not a blueprint that determines his or her potential. Down syndrome is a condition your child has - it's not who your child is. As is true for all people, the skills and knowledge he or she acquires will be a unique combination of innate abilities and life experiences.

In most ways, your baby will be just like other infants. Every baby needs to be fed, held and most of all, loved. But there are certain health and developmental concerns commonly associated with Down syndrome that you should be aware of.

Individuals with Down syndrome are at an increased risk for certain health complications. Babies, in particular, are more likely to have heart problems, hearing loss and respiratory infections; however, advances in medicine have rendered the majority of these health problems treatable.

In addition, all people with Down syndrome experience delays in their cognitive and physical development. Cognitive delays are usually mild to moderate, and they are not indicative of the many strengths and talents that each individual possesses. Low muscle tone and other physical characteristics associated with Down syndrome can affect how soon your baby will be able to sit up, walk and speak. Rest assured, though, that your child will learn how to do these and many other activities, possibly somewhat later than his or her peers without Down syndrome.

Good medical care and early intervention can provide a strong foundation for your child's optimal development.



Good medical care and early intervention can provide a strong foundation for your child's optimal development.



A Healthy Start

One of the main questions on the minds of many new parents is, “Will my baby be healthy?” Many babies with Down syndrome are born without any health problems. However, it is true that newborns with Down syndrome are at a higher risk for certain complications. While your baby may not have any of these potential complications, it is important to be aware of them so you can catch them early if they do occur.

Health Issues to Address at the Hospital or Soon After Birth

Children with Down syndrome are often at increased risk for certain health problems. Congenital heart defects, increased susceptibility to infection, respiratory problems and obstructed digestive tracts occur with Down syndrome. Fortunately, advances in medicine have rendered most of these health problems treatable.

As with all children, you must take an active role in ensuring the best health care for your child. Some steps that we recommend be taken soon after birth include:

- **Choose a pediatrician who has experience with children with Down syndrome or who is eager to learn.** The Down Syndrome Alliance does not endorse any health care provider. By contacting other parents, you can ask questions about how they selected a pediatrician for their child. You may also ask pediatricians for recommendations of colleagues with experience treating children with Down syndrome.
- **Obtain an echocardiogram.** It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echocardiogram in the first 2 or 3 months of life. Symptoms may present themselves as heart failure, difficulty breathing or failure to thrive. The symptoms may not be apparent at first. Most hospitals have the capability to perform an echocardiogram. It is often most convenient to take care of this before leaving the hospital.
- **Ensure that the diagnosis of Down syndrome is confirmed via chromosomal karyotyping.**
- **Have your pediatrician check for gastrointestinal blockage.** Some signs of gastrointestinal blockage include vomiting or absence of stools. Again, the symptoms may not present themselves for a period of time.
- **If your child has any feeding difficulties, consult a feeding specialist.**
- **Obtain a hearing test before leaving the hospital.** Some children with Down syndrome have hearing loss. With new testing procedures this can be detected early in newborns.



It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echocardiogram in the first 2 or 3 months of life.



What are the Down Syndrome Health Care Guidelines?

The Down Syndrome Health Care Guidelines follow an individual's development from birth through adulthood and provide information about potential health concerns at each stage. They are compiled by the Down Syndrome Medical Interest Group, a national affiliation of health care providers who specialize in caring for individuals with Down syndrome.

The guidelines help define the standards of quality care for individuals with Down syndrome. In addition to specific recommendations for screening tests, they include information about kinds of at-risk medical conditions for individuals with Down syndrome, suggestions for early intervention, diet, exercise, and other issues across the lifespan.

You can use the Health Care Guidelines to ensure that your baby is up to date on required and recommended screenings. While your pediatrician may be knowledgeable about the current recommendations, it is a good idea to provide him or her with a copy to place in your child's file. Also, because you are ultimately the person most concerned with your child's development, it is important for you to become familiar with the guidelines and communicate on a regular basis with your physician to make sure your baby is getting the best care possible.

Should I breastfeed or bottle-feed my baby with Down syndrome?

You may be aware of the tremendous benefits that breastfeeding provides to newborns. Breast milk contains natural antibodies that fortify babies' immune systems. This is especially important to infants with Down syndrome, who have higher rates of respiratory and other infections. Breast milk can also reduce bowel problems, which are more common in babies with Down syndrome, and it contains an ingredient known to promote brain growth and development. In addition, the physical process of breastfeeding strengthens babies' jaw and facial muscles, which helps lay a good foundation for speech and language development, and provides skin-to-skin contact, a form of sensory stimulation that creates neural connections that can facilitate future learning.

There are many great reasons to breastfeed, but whether or not to do so is a personal choice. Some mothers breastfeed exclusively while others bottle-feed. Still others combine the two. There are many factors that play into this decision, including whether or not you feel your body is producing enough milk, whether or not your baby has health complications, and whether or not you plan to return to work soon after delivery.

If you do plan to breastfeed, be aware of certain factors that might make it challenging. Babies with Down syndrome have low muscle tone, so it may be difficult for your baby to “latch on” to your breast at first. As these babies also tend to be sleepier than other infants, you will likely have to make an extra effort to raise your baby’s alertness and keep him or her awake throughout the entire feeding. Also, if your baby needs surgery, he or she may require a feeding tube for a short time.

Don’t worry, though. There are many organizations and individuals that can help you get started and provide tips for overcoming these and any other challenges you may encounter. These same specialists can help you learn how to pump, store and transport your breast milk, or how to select the right baby formula to meet your infant’s needs if you choose to bottle-feed.

When it comes to feeding, the important thing is to make the choice that is best for you. Feedings should provide quality time for a mother and her child to bond, so they should always be as comfortable and stress-free as possible for both individuals. A meeting with your hospital’s lactation specialist is a great place to start learning about what feeding option may be right for you.

What should I look for in a pediatrician?

For optimal health care, it makes sense to locate a developmental pediatrician or a specialist knowledgeable about Down syndrome, if any are available in your area. You can also contact NDSS to learn the location of the nearest Down syndrome specialty clinic. However, keep in mind that it is not always necessary to find an expert on Down syndrome. The most important thing when you have a baby with special health care needs is to find a doctor who is willing to learn about the condition and collaborate with you to ensure the best possible care for your child. One of the best ways to find a pediatrician is to ask families of other children with Down syndrome in your area for recommendations. Your local parent support groups can be a good source of referrals. As a parent, you have a right to interview potential physicians to find the best one for you. Find someone you feel comfortable with and with whom you can communicate freely. Also, do not be intimidated when speaking to physicians. A good doctor recognizes that parents are experts when it comes to their children. He or she respects their concerns and sees them as partners.



The most important thing when you have a baby with special health care needs is to find a doctor who is willing to learn about the condition and collaborate with you to ensure the best possible care for your child.

Health Care Information for Families of Children with Down Syndrome

Child's Age: Birth to 1 Month

American Academy of Pediatrics



■ Complete physical examination

If the diagnosis of Down syndrome was made before birth or suspected after birth, a complete physical examination should be done to confirm the known physical features and to check for any possible associated conditions.

■ Genetic testing

If prenatal testing gave a diagnosis of Down syndrome and if the exam after birth agrees, then no further testing is probably needed in the newborn period. If the physical examination after birth raises the possibility of Down syndrome, testing by rapid (FISH) confirmation and a complete chromosome analysis are needed. The rapid analysis results are typically available within 48 hours, whereas the complete analysis might take 3–5 days for the results. A complete chromosome analysis is needed to provide full information, but to ensure prompt results, both should be obtained unless the complete analysis can be done as quickly as the rapid analysis.

■ Counseling

The prenatal or newborn diagnosis of Down syndrome can cause many concerns for parents. Talking with a medical genetics team (medical geneticist and genetic counselor) or others recommended by your child's doctor may be helpful.

■ Feeding

Infants with Down syndrome sometimes have low muscle control, which can cause feeding problems. For this reason, infants should be closely watched for slow feeding or choking and for good weight gain. Breastfeeding is strongly encouraged, but extra attention may need to be given to positioning and to keeping the baby awake or alert.

■ Heart

An echocardiogram (an ultrasound picture of the heart) is needed to check for any evidence of heart disease. This should be done even if a prenatal echocardiogram was done. If issues exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

■ Hearing and vision

Infants with Down syndrome are at risk for sensory issues, such as eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmology and ENT).

■ Thyroid

Thyroid hormone levels can be too low in newborns and need to be checked (a TSH test). Thyroid hormone imbalance can cause a variety of problems that might not be easy to detect without a blood test.

■ Blood test

After birth, white and red blood counts can be unusually high in infants with Down syndrome. These blood counts need to be checked.

■ Stomach or bowel problems (reflux, constipation, blockages)

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

■ Infection

Because of an increased risk of infections (especially respiratory infections), infants should be protected from any unnecessary exposures to sick siblings, relatives, or others. It is also recommended to get checked quickly when any infection is suspected.

■ Developmental services

It is not too early in the first month of life to start to look for the developmental services (sometimes called "Early Intervention") that will be very important in early childhood.

■ Resources

Families of children with Down syndrome will need multiple resources, and now is a good time to start lining them up. Such resources might include specialized medical care, early intervention, physical therapy, and family counseling services.

Health Care Information for Families of Children with Down Syndrome

Child's Age: 1 Month to 1 Year

American Academy of Pediatrics

■ Regular well-care visits (check-ups)

While infants with Down syndrome might need multiple special visits to their doctor and specialty physicians, it is very important that they get regular well-care visits (check-ups). These visits will include checking your child's health, giving immunizations (shots), and building the relationships between the doctor and the family. Developing these relationships will help support the medical and other needs of the child and the family.

■ Monitor growth

It is important to check growth at every visit. Measurements include height, weight, weight for height, and head circumference. Discuss your child's diet, activity level, bowel and urine patterns, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

■ Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

■ Heart

If there were any signs of heart disease in the first month of life, heart monitoring is probably already in place. Heart problems could still worsen or new ones could arise. If concerns exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

■ Hearing and vision

Infants with Down syndrome are at risk for eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmologist and otolaryngologist/ear, nose, and throat doctor or ENT). The eyes should be tested at birth and again at 1 year or sooner if there are concerns. Hearing should be tested at birth and again every 6 months in early childhood to be sure that the baby's hearing is the best possible.

■ Thyroid

Thyroid hormone levels can be too low in infants and need to be checked (a TSH test). Low thyroid levels can cause a variety of problems that might not be easy to detect without a blood test. A TSH should be obtained at birth and again at age 6 months and 1 year.

■ Stomach or bowel problems (reflux, constipation, blockages)

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

■ Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done and the results are abnormal, your child may be referred to a spine or neck specialist. It is recommended that the neck be positioned properly for any medical procedures.

■ Developmental services

Developmental services (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.

■ Social support services

Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor the social services that may be available and their benefits.

■ Recurrence risk counseling

Families should get counseling about the possible risk of having another child with Down syndrome, if they choose to have more children. While the risk is usually low, other factors in the family history might be present, so counseling should be done after a complete review of the family history.



The Health Care Guidelines help define the standards of quality care for individuals with Down syndrome.



Health Care Information for Families of Children with Down Syndrome

1 Year to 5 Years

American Academy of Pediatrics



■ Regular well-care visits (check-ups)

At the one-year check-up, you should look at the checklists for newborns and infants to be sure everything has been done as recommended. Follow-up on known problems with specialists and be sure that reports are sent to your child's primary doctor.

■ Monitor growth

It is important to check growth at every visit. Measurements include height, weight, body mass index (BMI), and head circumference. Discuss your child's diet, activity level, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

■ Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

■ Heart

The need to see a cardiologist during this age is based on the child's health history and examination. Children with cardiac lesions may need to be monitored even after repair for remaining lesions and development of pulmonary hypertension (high pressure in blood vessels of the lungs).

■ Hearing

Hearing should be checked every 6 months, with audiogram and tympanometry tests until normal hearing is documented by testing of both ears separately (usually by 4–6 years of age). Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT). Higher risks of hearing problems can go with middle ear fluid and ear infections. Treatment of middle ear fluid often includes the use of ear tubes.

■ Vision

Vision should be checked at each visit to the doctor and with yearly checkups by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Crossing eyes or blocked tear ducts might be reasons for quicker action. Early use of eye patches, glasses, or both may help to fix eye crossing while lowering the need for surgery and the risk of vision loss.

■ Thyroid

The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in people with Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.

■ Blood test

Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.

■ Stomach or bowel problems (reflux, constipation, blockages)

Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition, and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:

- Very loose stools
- Hard to treat constipation (hard or painful stools)
- Slow growth/weight loss
- Belly pain or stomach swelling
- New or challenging behavior problems

Health Care Information for Families of Children with Down Syndrome

1 Year to 5 Years

American Academy of Pediatrics



■ Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:

■ Developmental services

Developmental services (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.

■ Social support services

Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor the social services that may be available and their benefits.

■ Recurrence risk counseling

Families should get counseling about the possible risk of having another child with Down syndrome, if they choose to have more children. While the risk is usually low, other factors in the family history might be present, so counseling should be done after a complete review of the family history.

- Stiff or sore neck
- Change in stool or urination pattern
- Change in walking
- Change in use of arms or legs
- Numbness (loss of normal feeling) or tingling in arms or legs
- Head tilt

■ Sleep issues

Obstructive sleep apnea is a common problem for people with Down syndrome, especially those with low muscle tone. Some symptoms are obvious (snoring, restless waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP guidelines recommend that every child with Down syndrome have a sleep study by the age of 4 years. (That testing may be hard to find in some parts of the country.) Treatment can include special breathing equipment or surgery.

■ Skin

Discuss with your child's doctor if your child has very dry skin or other skin problems.

■ Brain and nervous system

Discuss with your child's doctor concerns about neurologic problems, such as seizures.

■ Dental

Delayed and missing teeth are common. Teeth often come in unusual order.

■ New treatments

Talk to your doctor about any new treatments or medications you may consider.

■ Recurrence risk counseling

Talk to your doctor about future pregnancy planning and chances of recurrence of Down syndrome and where prenatal diagnosis is available.

■ Developmental services (early intervention)

Review your child's development with your doctor. Referral to local early intervention services and other options for therapy may be needed. Speech progress can be very delayed in children with Down syndrome, but after some delays, most will learn to talk well. Until speech is easier for your child, he or she might need help finding other ways to communicate, such as using sign language, pictures, reading, or using electronic communication tools. Behavior problems are often linked to problems with communication, but may reflect other issues, including ADHD or autism. Language delays or hidden abuse are more common than autism but may be misdiagnosed. Talk with your doctor about how to explain social safety and "good and bad touch" as your child grows older.



Early Intervention

The first three years of life will be a critical time in your baby's development. All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, social and self-help skills that lay the foundation for future progress, and these abilities are attained according to predictable developmental patterns. Children with Down syndrome typically face delays in certain areas of development, so early intervention is critical. It can begin anytime after birth, but the sooner it starts, the better. This section provides details on the various kinds of early intervention available, and how to access services.

What is early intervention?

Early intervention is a systematic program of therapy, exercises and activities designed to address developmental delays that may be experienced by children with Down syndrome or other disabilities. These services are mandated by a federal law called the Individuals with Disabilities Education Act (IDEA). The law requires that states provide early intervention services for all children who qualify, with the goal of enhancing the development of infants and toddlers and helping families understand and meet the special needs of their children. The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, and occupational therapy.

How can early intervention benefit my baby?

Development is a continuous process that begins at conception and proceeds stage by stage in an orderly sequence. There are specific milestones in each of the four areas of development (gross and fine motor abilities, language skills, social development, and self-help skills) that serve as prerequisites for the stages that follow. Most children are expected to achieve each milestone at a designated time, also referred to as a "key age," which can be calculated in terms of weeks, months or years. Because of specific challenges associated with Down syndrome, your baby will likely experience delays in certain areas of development. However, you can expect your baby to achieve each of the same milestones as other children, just on his or her own timetable.

Each type of early intervention addresses specific aspects of your baby's development. Physical therapy focuses on motor development. For example, during the first three to four months of life, infants can be expected to gain head control and the ability to pull to a sitting position (with help) with no head lags and enough strength in the upper torso to maintain an erect posture. Babies with Down syndrome may have low muscle tone, and a physical therapist can illustrate exercises that you can do with your baby to help him or her achieve this milestone.



Children with Down syndrome typically face delays in certain areas of development, so early intervention is critical.



Before birth and in the first months of life, physical development remains the underlying foundation for all future progress. Babies learn through interaction with their environment. In order to do so, an infant must have the ability to move freely and purposefully. The ability to explore his or her surroundings, to reach and grasp toys, to turn the head in order to follow a moving object with the eyes, to roll over and to crawl in pursuit of a desired object - all of these behaviors are dependent upon gross as well as fine motor development. These physical, interactive activities foster understanding and mastery of the environment, stimulating cognitive, language and social development.

Another long-term benefit of physical therapy is that it helps prevent compensatory movement patterns that individuals with Down syndrome are prone to develop. These can lead to orthopedic and functional problems if not corrected.

Speech and language therapy is a critical component of early intervention. Even though your baby may not say his or her first words until 2 or 3 years of age, there are many pre-speech and pre-language skills that must be acquired first. These include the ability to imitate and echo sounds; turn-taking skills (learned through games such as “peek-a-boo”); visual skills (looking at the speaker and objects); auditory skills (listening to music and speech for lengthening periods of time, or listening to speech sounds); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving lips); and cognitive skills (understanding object permanence, and cause and effect relationships).

A speech and language pathologist can help with these and other skills, including breastfeeding. Because breastfeeding employs the same anatomical structures used for speech, it can help strengthen your baby’s jaw and facial muscles and lay the foundation for future communication skills.

Occupational therapy helps children develop and master skills for independence. When your child is an infant, the therapist can assist with oral-motor feeding problems or, in conjunction with a physical therapist, focus on developing your baby’s fine motor skills.

Once your child is a toddler and has more independent mobility, occupational therapy can help with abilities such as opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons, etc. Therapists also help children learn to feed and dress themselves, and teach skills for playing and interacting with other children.

Early intervention programs also offer many benefits to parents, including information, encouragement and support. Your therapist can teach you exercises and activities you can do at home with your baby to meet his or her specific needs and enhance development. The therapist can also provide reassurance that your baby is on track developmentally. Furthermore, early intervention centers give parents the opportunity to share their concerns with other parents.

How do I sign up for early intervention services?

Each state has its own set of laws governing early intervention services. You can call your local school district to set up an appointment. The program staff must schedule and complete an initial evaluation within a specified time. Once the assessment is done, a caseworker is assigned to coordinate the various services for which your baby and family qualify. Early intervention services are individualized to meet the specific needs of your baby. The caseworker, therapists and family members will determine the areas to focus on and set clear, measurable goals based on the developmental milestones. These will be recorded in a document called the Individualized Family Service Plan, or IFSP.

Local school district information

| | |
|-----------------------------------|--------------|
| Bellevue Public Schools | 402-293-4030 |
| Council Bluffs Public Schools | 712-328-6548 |
| Educational Services Unit 3 | 402-597-4800 |
| Elkhorn Public Schools | 402-289-2579 |
| Fremont Public Schools | 402-727-3000 |
| Gretna Public Schools | 402-332-3265 |
| Millard Public Schools | 402-715-8200 |
| Omaha Public Schools | 531-299-0303 |
| Papillion/La Vista Public Schools | 402-537-6200 |
| Ralston Public Schools | 402-331-4700 |
| Westside Community Schools | 402-390-2100 |

Who pays for early intervention?

All early intervention services are free of charge.



Once the assessment is done, a caseworker is assigned to coordinate the various services for which your baby and family qualify.





What about the future?

IDEA, which regulates early intervention, also mandates that local school districts provide free preschool services for children with disabilities starting at the age of three. Your service coordinator or a local parent group can help you access these services and, if necessary, advocate for your child's needs when the time comes.



Finding Support

If you have recently learned that your baby has Down syndrome, you probably have a million questions, concerns and fears right now. That's okay. The most important thing to keep in mind is that the diagnosis is not as life-changing as the fact that you have a new baby. There will be challenges in raising your child, but there will also be many, many joys.

Is what I'm feeling normal?

Learning that your baby has Down syndrome is not an easy thing for anyone to face, and right now, you may be experiencing a roller coaster of emotions. While everyone handles the diagnosis in their own way, certain reactions are common in new parents of a child with a disability.

For the majority of parents, the period immediately following the diagnosis is filled with uncertainty and doubt. For example, you might worry about how the condition will impact your child's life and whether or not you are equipped to handle all the responsibilities of raising a child with a disability. If your child has health complications, you may have additional fears and concerns. It is natural to experience denial, anger, depression and other stages of grief as you adjust to the news that your baby has Down syndrome. Even for parents who knew they were at a higher risk of having a child with Down syndrome, acceptance can be difficult or, at first, seem impossible.

Know that whatever you may be feeling is normal. More importantly, know that you are not alone. There are many sources of support available to new parents of children with Down syndrome. In time, and with the right support, you can expect the intensity of painful emotions to subside, and new, positive feelings to take their place. One of the best places to turn to for encouragement and reassurance is other parents of children with Down syndrome. Often, other parents can help you look beyond your baby's diagnosis and delight in the joys of parenthood. They have been through what you are going through, and they can be an invaluable source of support.

How can I get in touch with other parents of children with Down syndrome?

One of the best ways to meet other parents is to join the Down Syndrome Alliance of the Midlands. DSA can provide you with an excellent forum for sharing your feelings and concerns as a new parent, and an opportunity to learn from the experiences of others who have been in your shoes. Learning more about Down syndrome can also help ease some of your uncertainty. In addition to providing emotional support, other parents can recommend useful Down syndrome resources and organizations and help you understand the new terminology.



DSA can provide you with an excellent forum for sharing your feelings and concerns as a new parent, and an opportunity to learn from the experiences of others who have been in your shoes.





What are some other things I can do to take care of myself?

Right now, you are very focused on taking good care of your baby. But remember that it's also important to take good care of yourself at this time. Doing so will keep you feeling healthy, strong and well-equipped to deal with your responsibilities as a new parent. It can also help you develop and maintain a positive frame of mind, which is necessary for meeting new challenges successfully. *Here are some tips many new parents have found helpful for reducing anxiety and stress:*

- **Be patient with yourself.** The road to acceptance is a process, so give yourself time to deal with your emotional responses. Some days you might feel like you're taking steps backward, but recognize that this doesn't mean you aren't making progress. If you feel it would be helpful, do not hesitate to contact a therapist. A therapist can help you find ways to cope and develop confidence in your ability to handle challenges.
- **Build a support system.** It may be tempting to keep to yourself at this time, but doing so can result in feelings of isolation. Reach out to trusted friends or family members. This allows your loved ones to understand what you're going through and gives them a chance to offer comfort and support. You can always let them know how much help you need or desire, and if you want time alone, don't hesitate to say so.
- **Schedule some alone time regularly, and use this time to "recharge."** Read a book, take a warm bath, go for a walk, or just watch your favorite T.V. show. Do something you enjoy and find relaxing, and let yourself enjoy it. Alone time may sound like a luxury, but it is necessary for good health and can do wonders for your productivity and mood.
- **Take care of your physical health.** Research shows that a healthy eating and exercise plan can reduce fatigue, irritability, and risk for certain diseases and health complications. Develop a plan that works for you and make an effort to stick to it, especially during times of high stress. Be sure to get regular medical check-ups, too.

- **Practice “living in the moment.”** While it is important to plan ahead, worrying about the future can easily lead to anxiety. Although it may be hard, try to focus only on what you can do realistically in the present. If you find yourself getting anxious about a particular situation, try this strategy:

- 1) Identify the problem.
- 2) Research your options.
- 3) Make a decision.
- 4) Set a date in the future to evaluate how your decision is working. In the meantime, just go with the decision you made and trust that it will work out.

- **Don't lose sight of “the important things in life.”** Nurture your relationships with your partner, children, friends and family. Communicate with each other, laugh, do fun things together, celebrate traditions, and be sure to spend quality time with your new baby that doesn't focus on his or her disability. The fact that your baby has Down syndrome is life-changing. But it doesn't change the things that are truly important in life!

Caring for your family

It's natural for new parents of a child with Down syndrome to wonder how this new person will impact family members and relationships. You might be asking yourself: How will having a brother or sister with Down syndrome affect my other children? Will having a child with a disability alter my relationship with my partner? How will my relationships with friends and relatives change? While each family's situation is unique, it may be helpful and encouraging to know that both personal accounts and research studies provide solid evidence that families of children with Down syndrome can be stable, successful and happy. This section provides information about things you can do to meet the needs of your entire family.

How will having a baby with Down syndrome affect my family?

One of the best ways to find an answer to this question is by speaking to family members of individuals with Down syndrome. In addition, there are many books and articles written by family members about their personal experiences. These accounts can offer a great deal of comfort and reassurance because, as you hear or read other people's stories, you will find that there is a consistent theme throughout the varied experiences. A message you'll encounter time and time again is that the positive impact of having a family member with Down syndrome far outweighs any difficulties or challenges that may come up. The majority of families share that they are stronger and closer as a result of the experience of dealing with a disability, and that they are



There is solid evidence that families of children with Down syndrome can be stable, successful and happy.





more focused on the things that really matter in life. There have also been many research studies that explore how having a child with Down syndrome affects families. These have shown that while these families do experience additional challenges, their levels of well-being are comparable to those of families who do not have a child with Down syndrome. Researchers say that what seems to determine if families are resilient and able to thrive is their ability to access individual, family and community resources.

How will having a sibling with Down syndrome affect my other children?

While having a sibling with Down syndrome may present unique challenges, it also provides many opportunities for children's positive growth and character development. Studies have shown that children who have a brother or sister with Down syndrome can benefit in many ways. For example, these children often exhibit a level of maturity above that of their peers and tend to have more highly-developed communication and social skills. The experience and knowledge gained by having a sibling with Down syndrome also seems to make children more accepting and appreciative of differences. They tend to be more aware of the difficulties that others might be going through, and often surprise parents, teachers and others with their wisdom, insight and empathy.

Brothers and sisters of individuals with Down syndrome are also very much aware of their sibling's challenges and often take a tremendous amount of pride in his or her accomplishments. In addition, parents often report that, no matter what issues siblings may have with their brother or sister with Down syndrome at home, outside the home they are typically very loyal to their sibling and do their best to defend and protect him or her.

How do I explain Down syndrome to my other children?

When telling your children that their new little brother or sister has Down syndrome, tailor your explanation to their age and ability to comprehend. An older child might be able to understand the genetics of Down syndrome, while a younger sibling might need a simpler explanation. Encourage your children to ask questions about whatever they don't understand and be sure to emphasize that the new baby will be able to do all the same things other babies do. Most children are able to grasp that a baby with Down syndrome may learn a little more slowly and need extra care, and they often take special pride in helping their new sibling.

Remember that your children will take their cue from you. If you are able to communicate excitement about their new sibling, they will be excited, too. Try to keep up family routines and traditions, and don't curb family activities out in the community any more than is necessary. This will help your other children come to terms with their sibling's condition while giving your new baby many new varied experiences. Brothers and sisters are often the first to realize that their new sibling is more like other kids than different, with his or her own unique personality, and that, like all members of the family, he or she will have strengths, challenges and much to contribute.

What are some tips for taking care of my other children's needs?

As discussed, your children may be doing an excellent job of helping with their brother or sister, but you want to make sure you are doing all you can to meet their needs as well. *Here are some tips for caring for siblings:*

- Be sure to acknowledge all emotions, not just the positive ones. If your children know that it is okay to express any feelings they may be having about their sibling with Down syndrome, negative emotions are less likely to turn up in other ways, such as behavior problems.
- While it can be beneficial for your other children to feel they can play an important role in caring for their sibling with Down syndrome, don't give them too many responsibilities in this area.
- Although your responsibilities may pull you in many different directions, pay attention to your children and any changes in their moods. If you notice symptoms of anxiety or depression, get your child the help he or she needs as early as possible.
- Make an effort to spend time with each of your children on a regular basis. Each child is unique, so don't worry about dividing your time equally. Instead, focus on what's important to an individual child, and dedicate time to those things that would make him or her feel loved and special. Remind your children that all members of your family are special in their own way.



Family and friends will usually want to support you, and if you are able to focus on positive aspects of caring for your new baby, they will likely share in your joy!



How can I keep my relationship with my partner strong?

There are many things you can do to keep your relationship strong amidst the added stresses that may come when raising a child with a disability. Two key strategies often mentioned by parents are maintaining good communication and spending time alone together. So take a few minutes every day to talk with your partner. Plan a regular “date night.” Take a vacation together. Even if you can’t get away as often as you might like, make an effort to keep your romance alive. Don’t let anniversaries or other special occasions go uncelebrated, and do little things to show your partner that you care and appreciate all of his or her hard work. A loving relationship is one of the best sources of strength and support for dealing with any challenges that come your way.

How do I share the diagnosis with other family members and friends?

New parents sometimes worry about telling friends and family members about their baby’s condition. However, it is recommended that you do it as early as possible. Parents report that the longer you wait, the harder it gets. Not only will waiting add to the stress that you may already be dealing with, but you will likely miss out on the comfort and support your loved ones might be able to provide during this time. Keep in mind, too, that others will follow your lead. Family and friends will usually want to support you, and if you are able to focus on positive aspects of caring for your new baby, they will likely want to share in your joy! You should also consider offering friends and family members information about the developmental aspects of Down syndrome so that they, too, can share in celebrating your baby’s accomplishments.

If someone does not react in the way you would hope, remember that he or she may have personal reasons for doing so that have nothing to do with you or your baby. The person may be uncomfortable because they don’t have accurate information about Down syndrome, or have never met someone with the condition. It is also a possibility that they may be dealing with their own grief or pain.

Grandparents, for example, may be dealing not only with the news that their grandchild has a disability, but also with the knowledge that their child is in pain. Just as new parents often go through the stages of grief, grandparents may also go through shock, denial and other emotions before they are able to accept the news. It is important to let them deal with their emotions at their own pace so they, too, can heal and begin to find joy in helping to raise their grandchild.

Support group membership is usually open to grandparents and other relatives, so you might consider letting them know that it’s an option available to them. Don’t be afraid

of sharing your emotions with your trusted friends and family members. Often, these people are eager to provide emotional support or other assistance. If you share your feelings honestly and openly, you create opportunities for them to do so. Remember that whenever you do turn to others for assistance, it's a good idea to be specific about how much help you want or need, and what your needs are.

A promising future together

Your child has been born, or is about to be delivered, into a world that offers more opportunities than ever before for people with Down syndrome to reach their full potential. Every day, we are expanding our knowledge about how individuals with Down syndrome learn and the best ways to support their development. Scientific research is constantly yielding new information about the causes of Down syndrome and associated conditions. Also, NDSS, NDSC, Global Down Syndrome Foundation, and many local and national advocacy organizations are working tirelessly to promote legislation that advances the rights of individuals with disabilities. All these efforts have opened up many doors for people with Down syndrome to pursue their dreams. This section discusses looking ahead to the future.

What does the future hold for people with Down syndrome?

There is still much progress to be made, but with the positive developments we've seen in recent years, you have every reason to be optimistic about your baby's future. For example, today the majority of children with Down syndrome are included in regular education classrooms alongside their peers, and research has shown that this inclusion has positive effects on both the academic and social experiences of students with and without disabilities.

Many individuals with Down syndrome are also graduating from high school and going on to college. The Individuals with Disabilities Education Act requires that your child have a plan in place to ensure a successful transition to life after high school, and many new postsecondary programs especially for people with disabilities are available. In addition, we are seeing an increase in the amount of meaningful, satisfying employment opportunities available to people with Down syndrome and more options for independent living. Many people with Down syndrome have jobs and live on their own. Some even have the opportunity to get married. The fact that these options are available today gives us reason to believe that for the next generation of people with Down syndrome - including your child - the future is even brighter.



There is still much progress to be made, but with the positive developments we've seen in recent years, you have every reason to be optimistic about your baby's future.



How can I give my baby the best chance at a promising future?

No one can tell you your child's potential, but there are many things you can do to give your child the best chance at a successful and happy life. First and foremost, your child will need lots of love, affection and support for healthy development. Just like all kids, children with Down syndrome will have their own unique talents and abilities, and it is important to recognize and celebrate those accomplishments. During the first few years of life, your child will likely receive many early intervention services, including physical, speech and language, and occupational therapy. Still, instead of emphasizing what your child can't do, focus on what he or she can do! We are used to doing this with typically developing children, and it should be no different for kids with disabilities.

Of course, babies and children with Down syndrome will have certain developmental challenges that will need special attention. In addition to providing your baby with varied experiences and constant opportunities for growing and learning, you'll also want to learn as much as you can about Down syndrome.

There are many successful strategies for addressing specific challenges, but often, it's up to parents to track them down. Fortunately, there are many organizations and resources available to you that can provide information on specific topics.

Lastly, although your child with Down syndrome may need more attention from time to time, do your best to treat him or her the same as your other children and have similar expectations. Inclusion starts in the family. By going out into the community and enjoying all the same activities that other families enjoy, you will be teaching your child that he or she has the same right as everyone else to live a full and active life. You will also be showing others that people with Down syndrome are more like the rest of us than they are different.

As a parent, you are a natural advocate for your child. You will probably come across many people who do not know very much about Down syndrome, and you'll be able to share information with them about your child's abilities and the potential of people born with this condition. As you become more comfortable in your role, you may find that you want to advocate for people with Down syndrome in more formal ways, and there are many opportunities to get involved!

National Down Syndrome Resources



NDSS has worked since 1979 to benefit people with Down syndrome and their families through national leadership in education, research, and advocacy.

Mission

The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome.

Vision

The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

For more information, contact:

THE NATIONAL DOWN SYNDROME SOCIETY

8 E 41st Street
8th Floor
New York, NY 10017



The National Down Syndrome Congress (NDSC) is a not-for-profit organization founded in 1973. The purpose of the NDSC is to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information dissemination on all aspects of Down syndrome. The NDSC is financially supported primarily through membership dues and individual contributions.

Mission

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

For more information, contact:

NATIONAL DOWN SYNDROME CONGRESS

30 Mansell Court, Suite 108
Roswell, GA 30076
Tel. (800) 232-NDSC
www.NDSCcenter.org



The Global Down Syndrome Foundation is dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy. Formally established in 2009, Global's primary focus is to support the Linda Crnic Institute for Down Syndrome, the first academic home in the United States committed solely to research and medical care for people with Down syndrome. Since Down syndrome is the least-funded genetic condition in the United States, fundraising and government advocacy to correct the alarming disparity of national funding for people with Down syndrome is a major goal.

Mission, Vision and Values

Our goal is to significantly improve the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy. We work to educate governments, educational organizations and society in order to affect legislative and social changes so that every person with Down syndrome has an equitable chance at a satisfying life.

For more information, contact:

GLOBAL DOWN SYNDROME FOUNDATION

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DSA is proud to be affiliated with both national Down syndrome organizations.



Meet Our DSA Families

Allow us to introduce a few local children through the stories their parents wrote.

Joey Bear Poole

It was a long journey for us to get pregnant and when we finally did we were ecstatic. We decided to do the early screening test so we could find out the gender of our baby at 11 weeks. We didn't even consider that anything else would come up positive. We found out we were having a boy and we also found out that there was a chance he would have Down syndrome. I have never had such a roller coaster of emotions in my life, literally all of the feels....good and bad. We were so excited to be pregnant but so scared at the same time. At 16 weeks we did the amniocentesis and it was confirmed that Joey Bear did in fact have Down syndrome. Looking back we were so lucky to have the time before his birth to process it all. Before my own experience I never understood what it would mean to “prepare” yourself after a diagnosis. I always thought to myself what is there to prepare for? I will love my baby no matter what. And yes thats totally true but the unexpected part are the emotions that you can't control and don't expect. What it meant for us was to grieve the loss of the child we thought we were going to have and give us time to realize it was all going to be ok, and actually way better than ok.? We are so thankful that we had that time and when it came to his birth we were ready. We were able to have a day that was full of excitement and joy (and maybe just a little fear because he decided to arrive 5 weeks early). We had a very quick C-section and the first thing I said when he came out was “he's big”. Our 5 lb 14 oz boy was here. We spent some time in the NICU and came home 2 1/2 weeks later. Joey Bear was healthy and strong. We had such a great birth experience and made so many connections with everyone who took care of him.

We joke that we didn't do anything “typical” in our pregnancy and so why would he be? We love to be different and celebrate that Joey Bear is who he is. He is almost 17 months old now. He is jabbering, standing on his own and working on signing and walking. He is our perfect baby boy and we are the luckiest family around. Joey Bear brings our whole family joy. He lights up a room with his smiles and gives the best snuggles. We can't wait to see what he accomplishes in life. We love that we get to celebrate all of the milestones big and small. This kid is going to change the world (some say he already has).

Joe and Nicole Poole





Emilee Schmidt

When we learned at our twenty-week ultrasound that our baby had markers for Down syndrome, we were in disbelief and the vision of our family's future was shattered. We opted to have the amniocentesis to confirm and the results came back positive that our baby had Down syndrome. As we came to terms with our new reality, we spent the remainder of the pregnancy regaining our bearings by doing research and thinking about all the ways this was going to impact our lives. We worried about the different surgeries and medical hurdles she would have to endure, how her older brother would deal with having a sister with special needs, what would we do when she was out of high school, and so much more. Our previous roadmap to life had to be thrown out the window, replaced by one featuring a lot of unknown landmarks, pitstops and a pocket medical dictionary.

Once Emilee arrived and the initial flurry of medical procedures passed, including surgery for duodenal atresia on day two and AVSD heart repair at three months, we started to settle into our new normal. We went back to work, Emilee went to an in-home daycare and we were able to continue our normal day to day activities. Yes, there was what felt like a never ending calendar of doctor's visits for almost every system of her body and therapies for every developmental milestone, but along with all of it came new friendships, personal strength we didn't know we had in us, and a renewed hope for Emilee's future.

Fast forward three and half years and those days of worrying have faded into the rearview mirror. Emilee attends two different preschools during the day and her vocabulary is exploding, as well as making up ground in many other areas. She adores her older brother and is even warming up to her newborn baby brother asking to hold him and even helping change an occasional diaper. She is incredibly social and will smile and say "hi" to everyone she meets. She's quickly taking the role of lighting up any room with love and joy when she enters. We can't wait to see Emilee start school and blossom into a beautiful and intelligent young woman. She makes us proud every day and we are truly blessed to be her parents.

Kyle and Stacy Schmidt

Kyle and Stacy Schmidt

Cadie Albin

Cadie Maxine made her way into the world fast and furious by arriving 7 1/2 weeks early and in only 3 pushes. She weighed just 4 lbs, had troubles breathing and needed oxygen but she pressed onward. She has carried that attitude into her teenage years with many of her interests and pursuits such as her love for hip-hop dance and reading at book club. She continues to amaze us each and every day with her outgoing personality and independence shining bright performing with her Sparkles Cheer Squad. Cadie is a vibrant 18-year-old with big life dreams and loves everyone she meets.

Cadie is surrounded by family, including her two brothers, cheering her on. Connor, who is older and attends college, and Chase, who is younger and also has special needs. They let her think she's the boss and love her dearly despite her sass. Cadie has made great strides throughout her life that will always continue to amaze us. She loves to be involved in the community socializing with friends, helping others and is involved in various programs. We are blessed to have her in our lives and are sure she is headed for success-paving her own way.

Russell and Cheri Albin





Sam Thunker

Sam came into the world in October of 2017 and from the moment that the doctor handed Sam to me, I knew that he would change our lives forever; in ways that I couldn't even imagine or wrap my head around at the time. I knew immediately that he had Down syndrome. My husband Mike and I had chosen to do the 13 week screen with Sam and there were no signs or suspicions of any chromosome abnormalities. Regardless of those results, Sam would have still very much been a part of our family, but I am not one that likes surprises. Prepared is my middle name! Sam threw us for a big loop that day, and continues to do so each and every day, but in some of the most amazing, joy-filled, positively life-altering ways.

For the most part, Sam is a very typical child. He is a 16-month-old child that loves playing, eating, throwing things, wrestling his older brother, smiling, laughing, waving (to everyone), clapping and did I mention smiling? He is crawling, pulling to stand, cruising along furniture and working on walking. There is nothing that Sam likes more than interacting with people. He has a gift for making everyone around him feel loved. His joy comes without limit and knows no bounds.

Has Sam changed what I had imagined for our family? Absolutely! Sam works a lot harder than his brother did to accomplish the same tasks. Sam comes with therapy and doctor appointments that I never saw coming. However, the ways that Sam has

impacted our family in a positive way has far surpassed all of those challenges! He changes the way we see life and makes us excited about the little things. He has helped us learn to embrace the unexpected and see the challenges as just part the process. He has made us stop trying to plan out what life should be and to be excited about what it has become. Sam truly is the greatest gift! A gift that we never knew to ask for, but are so glad to have received.



Welcome to this awesome club!

Kendra, Mike, Ty and Sam Thunker

Daniel Holm

Daniel is in his last year of Transition at Omaha Public Schools and is looking forward to moving out of the house, having his own apartment, working at a job, having fun with his friends and dating. If you would have told us that we, as parents, would also be looking forward to those things for him when he was born in 1998, we would have told you that was not possible.

Since Daniel was born, so many things have changed for someone with a disability. DSA was not in existence at that time. As it became an organization and grew to the outstanding resource it is for parents and families today, those items started to become dreams and then become a reality for him.

We celebrated (and continue to celebrate) the milestones that he achieves, just like any other parent would. Whether it was sitting up, walking, reading, learning sign, getting suspended from school for behavior (maybe that wasn't really a celebration but it definitely was a milestone). He enjoys movies, weight lifting, basketball, video games, likes to work, likes to make money (who doesn't?), and wants to live on his own (just like his cousins do). Working towards that goal, he has learned to cook, vacuum, clean, dust, make meals, wash clothes—all of those same skills that anyone needs to be independent.

We are confident that Daniel will excel at whatever he chooses to do and we will be there cheering him on.

Mary McHale and Joe Holm





Joseph Tran

Congratulations, welcome to a journey of intense purpose and love! Let me start by telling you a little about our Joseph. Joseph is our five year old little boy, he came into our world two days after Christmas with many gifts and qualities. He has a very confident and determined personality. He's an amazing and protective older brother. He loves all sports, especially those with a ball. He has the most contagious smile and joyful laugh. He loves to go to Creighton Bluejay games and dance in the aisles. He can look at his books or play with his puzzles for hours at a time. He also happens to be living with Down syndrome, a diagnosis that our family received shortly after his birth.

The diagnosis of Down syndrome feels like it comes with many unknowns, you can feel like you have more questions than you do answers. These questions will stir up fear and worry, but also pride and triumph. The unknowns will be filled in with moments of heartwarming celebration when they meet a milestone, soul-stirring vigor for inclusion, and a deeper meaning of love and patience. It's an adventure, no doubt, please know you won't be alone! There are many supportive organizations and families in our community that are willing to be right there along side you on this journey if or when you need them.

Christine and Tin Tran



Aiden Keckeisen

After two years of trying to get pregnant, we were elated when we finally did. About 10 weeks in, we found out our baby had a heart defect, likely associated with a chromosomal disorder, and later found out our baby screened positively for Down syndrome. We struggled with the diagnosis, or, more adequately put, the change in our expectations of what our lives would look like. We worried about what “could” happen (health issues, development, etc.) and it was hard, but it didn't change the fact we were finally having a baby, and there was still so much to be joyful for. We're learning those worries don't go away, but they are no different for our friends whose kids don't have Down syndrome, so we try to take life one day at a time. Our sweet Aiden came into our world on May 8, 2018, and changed it forever. His name means “little fire” and it fits him so perfectly. After a brief NICU stay, a major heart surgery, and a lot of lessons learned along the way, we have a ten-month old who is full of life, joy, smiles, and yes, fire. He is perfect!

Ranae and Chris Keckeisen