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who contributed
to this book.

Welcome Letter

Congratulations on the birth of your baby!

As parents who have experienced the birth of a child with Down syndrome, we know that this is a time of very mixed emotions. You may find that even though your baby is beautiful, you will need to grieve the loss of the baby you were expecting who didn't come. Yes, it is hard to learn that your beautiful child has Down syndrome . . . and there will be days of incredible sadness, of agonizing decisions, and of endless worry. But there will also be laughter, joy and thousands of little triumphs that will make the difficult times worthwhile.

Luckily the outlook for children with Down syndrome has improved tremendously in recent years. Advances in medical care and increased educational and vocational opportunities continue to benefit those with Down syndrome.

If you are one to dive in and gather information as soon as possible, search the internet and you will find many references to Down syndrome. If you want to take it one day at a time, do. Simply loving your baby is the most important thing you can do and if you need additional support along the way, please give us a call.

As parents we are amazed daily by our children's capabilities and accomplishments. We know you will be, too.

Down Syndrome Alliance of the Midlands



MISSION STATEMENT:

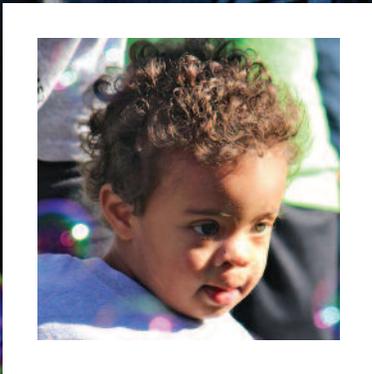
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& families
touched by
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What Is Down Syndrome?

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.

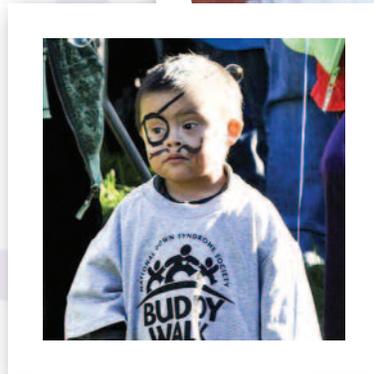
Individuals with Down syndrome are at an increased risk for certain health complications. Babies, in particular, are more likely to have heart problems, hearing loss and respiratory infections; however, advances in medicine have rendered the majority of these health problems treatable.

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.



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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 a 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.

Neonatal Healthcare Guidelines

Neonatal (Birth-1 Month)

(Based on "Health Supervision for Children with Down Syndrome" as published in *Pediatrics*)



- Review parental concerns. Chromosomal karyotype; genetic counseling, if not done prenatally.
- Check for signs and symptoms of gastrointestinal tract blockage (e.g., duodenal web, duodenal atresia, or Hirschsprung disease).
- Use typical growth charts from Centers for Disease Control (CDC), available at www.cdc.gov/growthcharts. Use weight/height assessment, as well.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Radiographic swallowing assessment if marked low muscle tone, slow feeding, choking with feeds, recurrent or persistent respiratory symptoms, failure to thrive. Consider feeding referral, if needed.
- Echocardiogram read by a pediatric cardiologist and referral to pediatric cardiology if abnormalities present. Subacute bacterial endocarditis prophylaxis (SBE), in susceptible children with cardiac disease. If a heart condition is identified, monitor for signs and symptoms of congenital heart failure.
- Car seat evaluation to evaluate for apnea, low heart rate, or oxygen desaturation prior to discharge from the hospital at birth if child is hypotonic or has had cardiac surgery.
- Complete blood count (CBC) to rule out transient myeloproliferative disorder (TMD) or polycythemia.
- Review feeding history to ensure adequate caloric intake. Children with Down syndrome can usually nurse, and many can breastfeed successfully. Consider lactation consultation.
- Thyroid function tests – check on results of state-mandated screening at birth. Add TSH is the state-mandated screening only included T4 results.
- Newborn hearing screen – auditory brainstem response (ABR) or otoacoustic emission (OAE) – to assess for hearing loss.
- Discuss risk for respiratory infections.
- Discuss complementary and alternative therapies.
- Discuss cervical spine positions, especially for anesthesia or surgical or radiologic procedures.
- Review signs and symptoms of myopathy. If myopathic signs exists, obtain neck X-rays (C-spine).
- Eye exam for cataracts.
- Discuss value of Early Intervention (infant stimulation) and refer for enrollment in local program.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.



National Down Syndrome Society • www.ndss.org • info@ndss.org • 800-221-4602

Infant Healthcare Guidelines

Infant (1 - 12 Months)

(Based on "Health Supervision for Children with Down Syndrome" as published in *Pediatrics*)

- Chromosomal karyotype; genetic counseling, if not already done.
- Discuss chances of having another child with Down syndrome.
- Use typical growth charts from Centers for Disease Control (CDC), available at www.cdc.gov/growthcharts. Use weight/height assessment, as well.
- Radiographic swallowing assessment if marked low muscle tone, slow feeding, choking with feeds, recurrent or persistent respiratory symptoms, failure to thrive. Consider feeding therapy referral, if needed.
- At 1 year of age begin to check hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin if there is a concern for a diet low in iron or if hemoglobin < 11g.
- Eye exam for cataracts. Ophthalmology referral to assess for strabismus, nystagmus and cataracts.
- Delayed or irregular dental eruption, hypodontia is common. First dental visit by 1 year.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Discuss cervical spine positions, especially for anesthesia or surgical or radiologic procedures.
- Review signs and symptoms of myopathy. If myopathic signs exists, obtain neck X-rays (C-spine).
- Thyroid function tests at 6 and 12 months(FT4 and TSH).
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure, subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Well child care: immunizations including influenza.
- Newborn hearing screen follow-up and assessment by 3 months. Audiology evaluation at 6 months and every 6 months until "ear specific testing is accomplished and normal," at which point hearing screens can be done on an annual basis.
- Review signs and symptoms for obstructive sleep apnea.
- Discuss Early Intervention, including speech therapy, and refer for enrollment in local program, if not done already.
- Apply for Supplemental Security Income (SSI), depending on family income.
- Consider estate planning and custody arrangements; continue family support.
- Discuss complementary and alternative therapies.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.



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



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Healthcare Guidelines Record Sheet

Sheet #1: Birth to Age 12 Years

Name: _____

Birthdate: _____

		AGE, IN YEARS															
Medical Issues	At Birth or at Diagnosis	6-mo	1	1-1/2	2	2-1/2	3	4	5	6	7	8	9	10	11	12	
Karotype & Genetic Counseling																	
Usual Preventative Care																	
Cardiology	Echo																
Audiologic Evaluation	ABR or OAE																
Ophthalmologic Evaluation	Red reflex																
Thyroid (TSH & T4)	State screening																
Nutrition																	
Dental Exam ¹																	
Celiac Screening ²																	
Parent Support																	
Developmental & Educational Services	Early Intervention																
Neck X-rays & Neurological Exam ³							X-ray										
Pneumococcal Conjugate Vaccine Series																	

Instructions: Perform indicated exam/screening and record date in blank spaces.

The gray areas indicate that no action is needed at this time.

¹Begin Dental Exams at 2 years of age, and continue every 6 months thereafter.

²IgA antiendomysium antibodies and total IgA.

³Cervical spine x-rays: flexion, neutral and extension, between 3-5 years of age. Repeat as needed for Special Olympics participation. Neurological examination at each visit.

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 therapist 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	402-328-6446
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	402-557-2222
Papillion/La Vista Public Schools	402-898-0498
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.

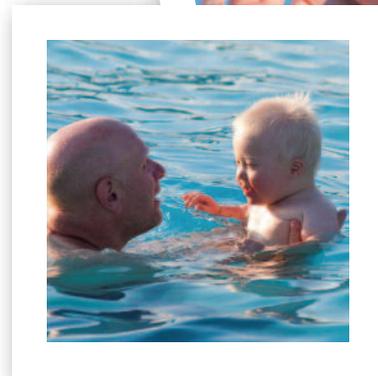


Once the assessment is done, a caseworker is assigned to coordinate the various services for which your baby and family qualify.



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 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 mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people 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

666 Broadway
New York, NY 10012-2317
Tel. (800) 221-4602
www.ndss.org



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

1370 Center Drive, Suite 102
Atlanta, Georgia 30338
Tel. (800) 232-NDSC
www.NDSCcenter.org

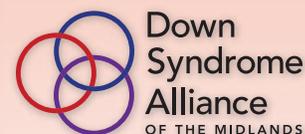


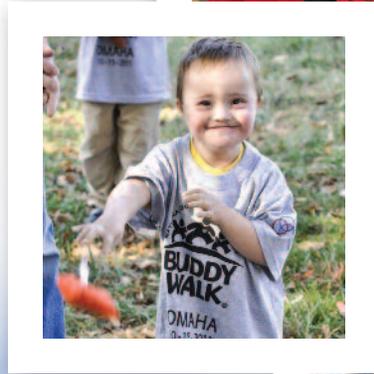
Phone:
402.991.1800

Website:
www.dsamidlands.org

Email:
info@dsamidlands.org

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.

Daniel Holm

Daniel is in 8th grade and enjoys video games, swimming, tennis, gymnastics, soccer, & Star Wars, and refuses to wear a shirt that doesn't have a skeleton or Star Wars on it. He is fluent in sign language and has signed songs for concerts at his school. He likes to sleep late (except on weekends when he is up at the crack of dawn), ride his bike, and, much to his parents' dismay, is learning how to ride a skateboard. When Daniel was younger he had two open heart surgeries. His parents worked full time and he went to daycare. These days he has to help with dishes & chores around the house. He has been known to get in trouble at home (and at school) for his attitude. And oh yes, he also has Down syndrome.

Mary McHale & Joe Holm

Kennedy Rocker

Right after Kennedy was born in August 2009, she was diagnosed with Trisomy 21. It was difficult because we had more questions than answers. However, we remember sitting together as a couple, making a commitment on that day to provide Kennedy with all the tools and advantages needed for her to lead as normal of a life as possible. And with every small progress, we were celebrating like 'heck.' When it was time for her to crawl, we were there clapping, videotaping, and shouting words of encouragement. It seemed like with every slight smile, grimace, sound, step, or new outfit she wore we were proud that she belonged to us. But guess what? She was going through the same growth accomplishments every kid undergoes. However, we were the ones celebrating and enjoying every small movement forward. Psst—here's what someone should tell you on day one: "your child will speak, walk, run, have caring feelings, make intelligent decisions, inspire you and challenge you in ways much more purposeful than you can ever imagine." We have a much more pointed and purposeful life because of our daughter Kennedy. So now it is your turn to be caring, patient, supportive, prepared and thankful to have this intense purpose and love-centered life for your child, your family.

April & Kenny Rocker





Nidal Sharif

Nidal is our oldest son and it is hard to believe that he will be turning 13 this December; he is counting the days to become an official teenager! Like most teenagers, he wants changes in his life like going to bed later, an increase in his allowance and less supervision from mom and dad! Nidal is a wonderful young boy who brings a smile to our faces every morning when he tells us that he loves us and that today is going to be a great day! Nidal enjoys riding his bike around the neighborhood and saying hello to all the neighbors. He loves to read, swim, and play soccer, basketball, and football. Exercising is very important to him, so he walks on the treadmill 30 minutes Monday through Friday after school while watching his favorite TV show. This year at middle school he has joined the reading, fitness and basketball clubs, and he is hoping to do drama next year. His favorite subject at school is Spanish which he practices a lot at home with mom and grandma. Because my husband and I come from two different parts of the world (South America and the Middle East), Nidal has had the opportunity to travel to different countries and enjoys the differences in cultures. When he grows up he wants to be a chef and a zookeeper to take care of the silver back gorillas!



Graciela & Ayman Sharif



Brady Shannon

In 2008 Brady popped into this world ready to teach us the true meaning of love. Having a child with Down syndrome has enriched our lives beyond words. It has slowed life down to a pace that allows us to enjoy each milestone and celebrate our hard work. Extra challenges accompany an extra chromosome, but when Brady smiles, our entire family is rejuvenated and motivated. Brady enjoys life to the fullest. He is currently attending preschool, learning to swim, and participating in the Young Athletes program. The future is bright and Brady is leading the way.

Jen & Jeff Shannon

Bailey Beightol

In 2004, just ten months after getting married, Larry and I gave birth to our first child, daughter Bailey Marie, on June 9th. Almost immediately after her birth, the doctor informed us that she suspected Bailey had Trisomy 21. Since Bailey was four weeks early, she was taken to NICU for all of the testing necessary for a diagnosis to be confirmed. She spent six days there learning to eat and regulate her temperature and oxygen. There were no heart problems or digestive issues. Learning that 1) your first child has Down syndrome and then 2) getting a crash course in all of the things that could be “wrong” with our daughter was obviously overwhelming.

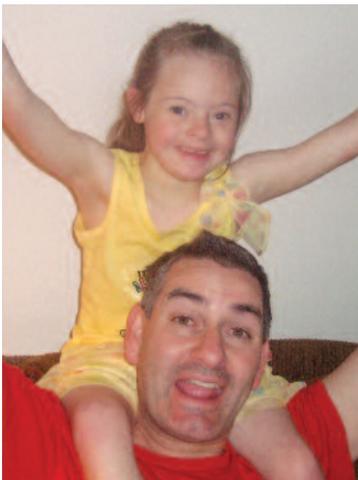
But the next day was better. And the next day was even better. By the time we took her home, we were realizing that we had a perfectly healthy 6 lb. beautiful baby girl—and oh yeah, she has Down syndrome.

We were fortunate that most people we encountered were positive, encouraging and optimistic about her future. There were those people that might have chosen the wrong words or just didn't know what to say to us. But overall, after getting over the initial “sucker-punch” at birth, we've come out of this experience stronger, smarter, more open-minded and even bigger advocates for our children.

Her diagnosis has changed the dynamics in our house but not our standards for raising children, not the expectations we have for our family, or how we live our lives daily. But we consider our future with Bailey and her siblings Brooke and Ryan, and what is best for them and their needs as our primary goal when making our big life decisions. If only there had been a crystal ball in the hospital room that sunny day in

June 2004, we would have felt much comfort and happiness in seeing a beautiful seven-year-old girl who shines when she swims, goes on field trips with her peers, loves spaghetti and ice cream, enjoys vacationing with her Nana in New Mexico and is our most easy-going, spirited child.

Buffy & Larry Beightol





Francesca Cogua

When Francesca was born and I looked at my new baby girl, the very first thing to cross my mind was, “Well . . . that’s not how I imagined her eyes would look!” but I thought nothing of it until after the medical team had done all the preliminary checks and the doctor came and put her hand on my shoulder. “I have something to tell you,” she said, and then came those life-changing words, “I think your daughter has Down syndrome.” I cannot describe in words the feelings that rushed through me in that moment, but it was as if my dreams for my daughter had suddenly been swept away and I was left with only the unknown. All my husband and I really could be sure of that early morning was that we loved our little girl and that one extra chromosome would never change that.

What we didn’t know then we are more than sure of now. Down syndrome has changed our life—it is richer, fuller, brighter. Francesca is pure joy. Her name means “smiling,” and her life brightens ours daily with smiles, delight at even the smallest accomplishment, and the best hugs ever! I have come to realize that my dreams before were just a shadow compared to the optimism that defines each day with my daughter. We are blessed because of our smiling Francesca.

You and your family are blessed, too.

Jaimie & Jose Cogua



Carson Butler

Our story begins at 12 weeks into our 3rd pregnancy. My husband John and I went for a regular checkup and QUAD screening which checks for Down syndrome. We were told that our baby had some of the facial signs of DS and they wanted us to see another doctor, who did another ultrasound at 14 weeks and confirmed that there was an abnormality in the thickness of our baby's neck. At 14 1/2 weeks we did an amniocentesis to be sure. On July 4th of 2010 we found out that we were having a baby boy who in fact did have Down syndrome.

We felt our world come to a stop. All I could do was cry. My tears, however, were not of sadness, defeat or even a "why me?" feeling. The tears were more from having an answer and of no longer having to live in the "what if?" world. Then we got excited. *We were having another boy!*

Our doctor made sure we knew that with a positive result for Down syndrome we were going to have many ultrasounds to check for some of the common health problems. Around 20 weeks we checked his stomach for a double bubble. Sure enough our little man had Duodenal Atresia. They let us know that he would need surgery within the first days of life to fix his blockage and 6 to 8 weeks of NICU for recovery. This blockage caused my amniotic fluid to build. At 32 weeks and a 54" waist I had to have an amniocentesis done to reduce my fluid level and get our first round of steroids to boost baby man's lung development. Our doctor thought my pregnancy would not last much longer.

Thursday, November 25, 2010 Carson James was born by emergency C-section. He was 4 1/2 weeks early and was rushed to the NICU. Once stabilized, he was transferred to another NICU to undergo surgery and finish his recovery. Carson spent 36 days in the NICU. Now he is a strong, happy, healthy baby boy!

Carson has brought great joy, a sense of calm to my life and more love than any mom and dad are ready for. Our five year old said it best: "Just because he is different does not mean I won't love him."

Enjoy your blessing!

Julie & John Butler





Eisley Rich

Eisley was born in January of 2010 and like all the snowflakes falling during that time, she is beautiful and unique. Shortly after birth we discovered Eisley not only had Down syndrome, but an AV canal (a common heart defect of children with DS) and pulmonary hypertension (something any newborn can experience). Together, this bought us a 6-week ticket to the NICU. Eisley came home with a g-button to give tube feedings through and eventually had open heart surgery at 4 months to repair her little heart.

Since then, wow has she grown! Little E has graduated from the intensive feeding program at Munroe Meyer and now attends feeding therapy on a weekly basis. She is quickly learning the joy of eating and will soon be saying bye-bye to the button. Now her determination is aimed at physical therapy each week (as well as climbing the stairs at home!).

Eisley is the perfect addition to our family. Thanks to her, we've learned to appreciate the small things and celebrate them all. She has a brother and two sisters who are the best motivators, coaches and therapists anyone could ask for. Although Eisley has taken us on a few roller coaster rides, she's taught us to buckle up and hold your hands high—it's the best way to enjoy the ride!

Come follow our journey: www.richvisions.blogspot.com

Anne & Sean Rich



Jacob Gehringer

Hello! We are the Gehringer Family. We are a busy family of six going a million miles an hour, doing a million different things, going in a million different directions. Our youngest son, Jacob, who happens to have Down syndrome, is no exception. As a matter of fact, he just may be busier than the rest of us. Jacob lives a very full “teenager” life. Jacob is a member of his high school marching band and bowling team. He wears his school colors proudly and enjoys the interaction and friendships he has with his typically developing teen peers. Jake also plays soccer, baseball, basketball and swims competitively along with his big circle of pals that also happen to have Down syndrome. Lately Jake has been enjoying exploring his culinary interests in cooking class and has had the chance to perform in a couple of play productions in our community. He can often be found chanting “U.N.O.” at the Qwest center as he is quite the hockey fan and please don't bother him during a Tiger's baseball or Husker football game because his is a dedicated supporter. Jake is looking forward to going to college someday like his brothers. Who knows what he will be involved in next? The sky's the limit with this guy!

Denise & Jeff Gehringer

Cael Campin

We have been blessed with Cael Ryan Campin for almost 8 years! Cael was born eight weeks early, and has beaten the “DS myths” since that day. Due to his prematurity, we were told our baby would probably arrive very listless, pale, and probably unresponsive. Thank goodness no one knew he had Down Syndrome, or I am sure the outlook would have been more grim. Contrary to those beliefs, Cael arrived kicking and screaming and his color couldn't have been any better. Since then, he continues to be a strong willed, ambitious, outgoing, and smart child. He is in the 2nd grade at Standing Bear Elementary and loves math and reading. Cael is as rambunctious as any other seven year old and gives his brother quite a match in wrestling. He also plays organized baseball through the Suburban Athletic Association, and loves to play soccer through the TOPSoccer league.

Cael is blessed with two older siblings. Hannah is in 7th grade and strives to pick on her little brother as much as possible. Colin, a 5th grader, roughhouses with him all the time every day. When push comes to shove, though, Hannah and Colin won't let anyone mess with their little brother! We have always and continue to treat Cael like our other two children, and he continues to amaze us each and every day.

Tracy & Casey Campin





Marcus Amua-Sekyi

One might have known with the way he made his entrance into the world that life with Marcus Kojo Amua-Sekyi would be nothing less than fast and furious. It seems like only yesterday that 11 minutes of labor and 3 pushes brought him into the world—and now he’s about to become a teenager. Shortly after his birth Marcus began to lose oxygen and within 48 hours we had the results that he had Trisomy 21, which put Preston and me on a whirlwind adventure of being first-time parents, and to a child with a disability that we knew little about. It was time to do our research and call on family and friends to join us on our journey. After those first 48 hours his oxygen stats stabilized and for the next two weeks we worked on his feeding in order to get him ready to leave the NICU at Children’s Hospital and go home. Once at home we started Early Intervention Services with Bellevue Public Schools and have continued with services from BPS ever since. Marcus’ resilience never ceases to amaze me. He truly is a boy who can and will do anything. Not only has he had the hurdles of his disability to tackle but he’s also lived the life of a military child, withstanding his mom’s overseas tour and several deployments. This is probably why he was named as an Air Force Finalist for Military Child of the Year in 2011! He’s grown into a fine young man who loves to play soccer, read, and play Wii games with his little brother, Bryce. He’s been mainstreamed during his elementary school years and now in middle school, allowing extra time for reading and math. He enjoys playing in the school band. When asked what he wants to do when he grows up he says he wants to be a cop, so he can catch the bad guys.

From the day he was born,
I’ve looked at Marcus and seen
nothing but a road of endless
possibilities. Yes, the road has
had potholes and needed
construction, but we keep
traveling on to each new day!

Amy & Preston Amua-Sekyi



Erika Lundquist

Seven years ago I received the most precious gift ever when I was united with my daughter through adoption. She was 2¾ years old and I named her Erika Lynn. She was living in foster care in Texas, where she was born. Her first two years of life were difficult due to being born prematurely weighing 2 pounds, 3 ounces, having Down syndrome, and having prenatal drug exposure. She had multiple significant medical problems related to those issues and spent much of her first year in the hospital. Starting in her second year she lived with a wonderful foster family who nursed her through the problems and got her relatively healthy. Then they gave her to me, even though they loved her dearly. Although significantly improved, she still has some medical problems, including feeding difficulties. She communicates with vocalizations, sign language and an augmentative communication device. She is now almost ten years old and attends our neighborhood school. She is mainstreamed into a third grade classroom, with an assistant to help her for much of the day. The administrators, teachers, staff, students, and parents at the school have been awesome and she loves going to school.

Erika is amazing, beautiful, funny, smart, determined, easy-going, and treasured. She loves Elmo, her iPad, roller coasters (the bigger the better), swimming, horseback riding, playing soccer, music, bowling, the Children's Museum, watching videos (especially of herself), and ice cream. She doesn't like arts and crafts, fancy clothes, tights, eating (except ice cream), going to the dentist, going to baseball games, candy,



getting her picture taken, or pretend play. Every milestone met is a miracle, especially since so little was expected from her when she was young. She is absolutely the best part of my life. Each night I tell her that she makes me the luckiest and proudest mom ever, forever, and always. And I know it is true.

Diana Lundquist





Brooklyn Tonjes

Brooklyn is 6 years old and attends Kindergarten at Picotte Elementary in the Omaha Public School district. She is in an inclusive classroom and only leaves for a couple short periods during the school day for resource and speech. Brooklyn is currently in Daisy Girl Scout Troop 42125 and enjoys playing TOPSoccer through the Omaha Football Club. Her favorite things to do include singing into a microphone, playing with her doll Ariel, and watching movies and sports with her dad.

Brooklyn was diagnosed with Down syndrome after delivery. She has no other diagnosis and is a healthy little girl. I cannot imagine what we would have done without the support of our family and friends as well as the support from local resources. I have grown a lot with patience, gratitude and love for myself and others.

Brooklyn has an older sister, Taylor, who is 8, and a brother, Jake, who is 18. We are a very happy family and wouldn't change anything.

Roberta & Jason Tonjes

