

Welcome
to the
DSCBA



Welcome

Welcome to the DSCBA, and congratulations on the birth or expected birth of your child! We know that having a child with Down syndrome probably wasn't in your plans, but we are so happy you're here.

We want to support you as you navigate your journey with your child. There will be wonderful highs and then the inevitable lows that come with parenthood. We'd like to reassure you that whatever you're feeling right now, the highs will outnumber and outweigh the lows. This wonderful child of yours will surprise and delight you in so many ways as they grow up!

And by the way, whatever you're feeling right now—give yourself grace. It's okay to be scared, sad, confused, or angry. It's okay to feel grief. It's also okay to be elated. Everyone processes unexpected news in different ways, and all of those ways are okay. Give yourself the time and space to feel whatever you need to feel. None of that bears on your love for your child.

When you're ready, this booklet will help you on your journey. You'll find general information about Down syndrome, tips on talking about Down syndrome and sharing the news with friends and family, and specific information about topics such as feeding and early intervention. You'll also find encouraging words from other families and individuals with Down syndrome sprinkled throughout.

And when you need more information, we're here. Contact our office any time at 925.362.8660 or email dscba@dscba.org. Our office is staffed for walk-ins five days a week, but we are available by phone or email when the office is closed, too.

Our Mission

To empower, inspire, and support people with Down syndrome, their families, and the community that serves them, while fostering awareness and acceptance in all areas of life.





About the DSCBA

The Down Syndrome Connection of the Bay Area (DSCBA) was started in 1998 by two mothers of children with Down syndrome who saw a need: there was no organization in the Bay Area dedicated to supporting families that included a person with Down syndrome. Now, the DSCBA is a thriving organization that implements programs and classes around the greater Bay Area. Our membership numbers more than 1,000.

The DSCBA offers family support, classes and connection groups for people with Down syndrome, workshops, and community events, as well as our Medical Outreach Alliance and Education Alliance, which support the medical and educational communities that serve our members.

Understanding the Diagnosis

Before anything else, we want to share with you the DSCBA's philosophy about your baby: Your baby is a baby first, with Down syndrome second. We want to assure you that the day will come when your child will be just your child, and the diagnosis will not consume every moment.

What Is Down Syndrome?

Down syndrome, sometimes known as Trisomy 21, is a condition in which a person is born with three copies of chromosome 21 instead of two. It is the most frequently occurring chromosomal condition, occurring in one of every 787 babies. There are estimated to be about 5,000 babies born each year with Down syndrome, and there are currently thought to be around 200,000 people living with Down syndrome in the United States.

An anomaly in cell division is the cause of the extra twenty-first chromosome. Ninety-eight percent of the time, Down syndrome is random and not hereditary. The chance of having a baby with Down syndrome increases with the mother's age; however, 80 percent of babies born with the condition are born to mothers under thirty-five years of age because younger women have more babies than older women do.

Down syndrome has nothing to do with race, nationality, socioeconomic status, religion, or anything the mother or father did before or during the pregnancy.



General Facts About Down Syndrome

- People with Down syndrome have intellectual delays, usually in the mild to moderate range. People with Down syndrome have a wide range of abilities that are impossible to predict. Despite these delays, every individual possesses many strengths and talents.
- Children with Down syndrome learn to sit, walk, play, communicate, and do most other activities, only somewhat later than their peers without Down syndrome.
- Under federal law, people with Down syndrome must be provided with a free and appropriate public education in the least restrictive environment through their public school system. This applies to individuals three to twenty-two years of age. Since the human and civil rights movements began in the 1960s, people with Down syndrome have been increasingly recognized as valued and contributing members of society.
- People with Down syndrome participate in school, religious groups, sports teams, and performing and visual arts programs. They have meaningful jobs and relationships and live full lives. A growing number of people with Down syndrome go to specialized college programs and live independently or semi-independently.

How Is Down Syndrome Diagnosed?

There are prenatal screenings to predict the likelihood of Down syndrome before a baby is born, as well as diagnostic tests that can confirm the diagnosis before birth. However, many parents who have a baby with Down syndrome are surprised at birth by the diagnosis.

In a newborn, Down syndrome is usually identified by certain physical traits, including low muscle tone, a single deep crease across the palm of the hand, a slightly flattened facial profile, and/or an upward slant to the eyes. The suspicion of Down syndrome may be confirmed with a karyotype chromosomal analysis. A small blood sample is taken from the baby in order to perform the karyotype. The results can take up to two weeks to come back.



Types of Down Syndrome

A karyotype will confirm the type of Down syndrome your baby has. There are three types of Down syndrome:

Trisomy 21: By far the most common, Trisomy 21 accounts for 95 percent of cases of Down syndrome. In Trisomy 21 (or T21, as many call it), three copies of chromosome 21 are created during cell division. The typical number of copies is two, so babies born with T21 are often said to have “a little something extra!” The extra chromosome is present in every cell of the person’s body.

Translocation: This is the only inherited form of Down syndrome, though only one-third of translocation cases are inherited—two-thirds occur spontaneously, just like Trisomy 21 and mosaic Down syndrome. In this type of Down syndrome, part of chromosome 21 breaks off and attaches itself to another chromosome. Usually—but not always—that is chromosome 14. Translocation is rare, accounting for only 2 to 3 percent of cases of Down syndrome.

Mosaicism: Mosaic Down syndrome is also very rare, accounting for only 2 percent of cases. In this type of Down syndrome, only some cells possess an extra twenty-first chromosome. It’s impossible to know how many cells in the body are affected, but the extra chromosome is not present in every cell, as is the case in Trisomy 21.

While awaiting the karyotype results, some parents find themselves hoping their child has mosaic Down syndrome. After all, fewer affected cells means fewer challenges, right?

Not necessarily. It is impossible to predict how a person with Down syndrome will develop over their life. People with any type of Down syndrome experience developmental delays, but the degree of delay varies from person to person. Just like people in the general population, people with Down syndrome have strengths and challenges unique to them.

Appropriate medical care for children and adults with Down syndrome is important and can strengthen their physical and intellectual capabilities. The American Academy of Pediatrics has published healthcare guidelines for physicians to follow in caring for individuals with Down syndrome. We can provide you with a copy of these guidelines.

Health Concerns

Upon receiving a diagnosis of Down syndrome for your child, you may be concerned by some of the health issues brought up by your medical provider. As healthcare providers, their job is to alert you to some possible concerns. However, one benefit of Down syndrome being the most common genetic condition is that the medical community is well-versed in how to treat the health issues common to Down syndrome.

You may be told that your baby is likely to have a heart defect. In reality, the number of children with Down syndrome born with a heart condition is approximately 40 percent. For the vast majority of these children, the condition is successfully treated with surgery.

Congenital heart defects are the most common serious health concern associated with Down syndrome, but you may hear about other issues as well. Some children with Down syndrome are born with digestive concerns. As with heart conditions, the vast majority of the time these issues can be successfully treated. Low muscle tone is another health concern you might hear mentioned. This affects nearly every baby with Down syndrome, but it is not cause for concern. It just means your baby will feel a little “floppy” compared to a typical baby and will have to work harder to learn skills such as sitting up, crawling, and walking. The level of tone varies in each person with Down syndrome, but rest assured that low tone will not prevent your child from doing anything. They learn to compensate very well, especially when supported with the proper therapies. Side bonus: Babies with low tone are the best snugglers out there!

The bottom line is that people with Down syndrome have an increased risk for certain medical conditions, including respiratory issues, hearing problems, sleep apnea, thyroid conditions, and heart issues, but it’s important to note that an increased risk does not mean that your baby will have these issues. Also, most of these are now treatable, and the majority of individuals with Down syndrome lead healthy lives. In fact, people with Down syndrome rarely develop certain cancers or suffer from heart attacks or strokes.

How to Talk About DS

You might be wondering about the proper terminology to use when talking about Down syndrome. Communicating about individuals with Down syndrome using both positive and accurate language is important in education and advocacy. Knowledge is key, and we've put together a simple guide so you can help others speak in ways that are respectful and empowering, avoiding hurtful and offensive language.



Person-First Language

The emphasis should always be on the person first, not the disability. Terms such as *Down's baby* or *Down syndrome child* put the disability first. When phrases like *baby with Down syndrome* are used instead, it puts the person first and lets the disability remain in the background—an important distinction.

Down Syndrome

In the past, it wasn't unusual to use the names *Down's Syndrome* or *Downs*. The name of the syndrome is *Down syndrome*, after Dr. John Langdon Down, who first identified Down syndrome. It is not a possessive (*Down's syndrome*); it is simply *Down syndrome*. At least in the United States, anyway. There are certain other countries where it is referred to as *Down's syndrome*, but not in the US.

Developmental Delay

This is the accepted term for describing delays in development and the learning process, such as speaking and walking.



Intellectual Disability

This is the legislative term that replaced the outdated and offensive term of *mental retardation*. Very, very occasionally you will still find medical or government forms that use the term *mental retardation*. Feel free to point out to the party in question that in accordance with Rosa's Law, they must change their wording to *intellectual disability*.

Disability

On a similar note, the term *disability*, which used to be considered troublesome, is now preferred over *special needs*. People with disabilities have consistently said that they have no problem identifying as disabled, but they do not like to be considered to have "special" needs. Their needs are unique to them, just as every person's are.

Typically Developing

This term is used to refer to people who do not have Down syndrome or another intellectual disability, as opposed to using the word *normal*. As they say, normal is nothing but a setting on the washing machine!



Positive Word Choices

People have Down syndrome; they are not suffering from it or afflicted by it. We must instill a sense of pride and self-esteem in all children, so we should ensure that we communicate that Down syndrome is not harmful, terrible, or something to be ashamed of.

Stereotypes and Generalizations

If you got a nickel for every time you heard “They’re always so happy!” about people with Down syndrome, you’d be able to retire young and set up a tidy ABLE account for your child! This is probably the most common of many stereotypes floating around about Down syndrome. It’s a safe assumption that most of the generalizations you’ll hear—including that one—are false. People with Down syndrome experience a full range of emotions, just like anyone else.

Severity

At some point in your journey, someone will ask you if your child is “high functioning” or “just has a little bit of Down syndrome.” These questions, while they might be well intended, are pointless and not helpful. People either have Down syndrome or they don’t. And, like the general population, people with Down syndrome have areas where they excel and areas where they struggle. People in general are masters at adapting to cover their specific challenges, and people with Down syndrome do the same.



Sharing the News

When sharing the news with friends and family, remember that your baby is a baby first, and a baby who happens to have Down syndrome second. Although your baby’s birth may inspire a range of emotions, it is a milestone to celebrate and share.

We suggest that you not wait to tell friends and family members about your baby having Down syndrome. You might feel afraid to tell others or you may be afraid of their responses. But generally, the longer an announcement is put off, the harder it can be, and in our experience most people find great support when sharing their baby’s diagnosis. We do, however, have a couple of tips we’ve learned over the years.

First, most people know very little about Down syndrome, so education is important. Some people might think back to people with Down syndrome that they knew as children. Their thoughts tend to be outdated because today society is more accessible to and accepting of people with Down syndrome, and therefore people with Down syndrome are accomplishing more than they did in past generations. Children born with Down syndrome today have more inclusive educational and community opportunities available to them than those born even a decade ago.

Second, we’ve found that friends and family will follow your lead. If you announce the news with celebration, they will be more inclined to do the same. Some families have found it helpful to be very upfront about their baby and how they want others to respond to the news. Here is one example of such an announcement:

*Dear Friends and Family,
Our beautiful baby boy, Elias, was born January 13th. In addition to sending out this adorable photograph of him, we wanted to add this personal note to let you know that Elias was born with Down syndrome. In the past few days, we’ve been learning a lot about Elias’s needs as well as a great deal about the positive ways he will affect our family. Elias is a beautiful and responsive baby who happens to have an extra chromosome. We want you to share in the joy of his birth and his progress along the way. Though his progress might be slower than some, we know that our lives will be enriched by having Elias—as they already have. Please celebrate his birth with us.*

Another family chose to take a humorous route, sharing with friends and family:

Our daughter was born with a little surprise—an extra chromosome. We ask that you share in our joy and not express sadness or grief. We’ve had a few people ask what they can do. If you really want to do something for us, send cookies. We love cookies.

That family ended up having a freezer full of cookies!

Family

Many parents are concerned about how a child with Down syndrome will affect their family, their relationships, and any siblings. It is natural to feel worried or even sad when you have a baby with Down syndrome. A baby with special needs is not usually something people plan for. You might find yourself grieving the baby you did not have (the one without Down syndrome that you were expecting), and you now have to learn about your baby's unique needs. There may be additional medical, educational, and financial challenges to address. The paperwork alone involved in parenting a child with a disability can feel overwhelming.

Every family is unique and may deal with the birth of a baby with Down syndrome differently. Remember, there is no one right way to react to your baby's birth and diagnosis. Despite potential challenges, personal stories and studies show that most families that have a child with Down syndrome are stable, successful, and happy.



Siblings

Siblings of children with Down syndrome often report having increased compassion and empathy. A major 2011 study of more than 2,000 families that have a child with Down syndrome revealed that 95 percent of respondents said their children without Down syndrome have a good relationship with their child with Down syndrome. The study also showed that 94 percent of older siblings to a child with Down syndrome are proud of their sibling.

This is not to say that your child's siblings are always going to get along with your child with Down syndrome. Just like with typical siblings, there will be rivalries and arguments. In addition, some children feel resentment when their sibling with Down syndrome takes up family time with therapies or medical appointments. Kids with Down syndrome can also attract a lot of attention—far from being outcasts, they are often quite popular at school! This can lead to typically developing siblings feeling jealous.

All of this is natural. Be open and honest with all your children about their sibling with Down syndrome to help them feel included and important. And make sure your typically developing children have parts of their own lives that do not include Down syndrome. You will quickly learn that you don't have to eat, sleep, and breathe Down syndrome twenty-four hours a day, but that lesson sometimes comes a little slower for children. It helps to make sure your typically developing children have time to themselves, too.

Recommended Reading:

- *47 Strings: Tessa's Special Code* by Becky Carey is a great book to explain Down syndrome to your child's young siblings.
- *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters* by Brian Skotko and Susan P. Levine is an excellent book for older children about having a sibling with Down syndrome.

Self-Care

While taking care of your new baby and their siblings, don't forget to take care of you. We often put ourselves last where care is concerned, but you can't care for your family if you don't take care of you.

Your form of self-care is unique to you—some people enjoy exercising, others meditate, and still others have a pastime such as painting or scrapbooking. Whatever it is that refuels you, make sure you continue to do it. And when people offer to help, take them up on it! We have found in general that people want to help, and you only need to accept it or ask for it.

Feeding

With a newborn, feeding is obviously your number-one goal. One of the misconceptions about Down syndrome is that babies with DS cannot breastfeed. That is not true. If you want to breastfeed your baby, it is possible. It may require some additional support, but it is doable. Here are a few tips to get you started:

- Newborns with Down syndrome are notoriously sleepy, especially if they also have a heart condition. Know that you may have to wake your baby to eat and work to keep them awake while feeding. You can have your baby wear just a diaper during feedings, to keep them cooler and more alert. This brings the added benefit of skin-to-skin contact. You can express a few drops of milk into your baby's mouth before feeding to increase interest. You can also run a cool, damp cloth over your baby's skin if they're starting to fall asleep while nursing.
- Try other positions if the traditional cradle hold doesn't work well for your baby. Low muscle tone makes babies with Down syndrome a little floppy, and sometimes another hold, such as the football hold, can be easier.
- Make sure your baby's tongue isn't getting in the way when you try to have them latch onto the breast. Babies with Down syndrome sometimes have protruding tongues, and you might need to use your finger to help position it correctly in the beginning.

Above all, do not get discouraged if your baby does not exclusively breastfeed right away. It's not uncommon to have to supplement feedings for the first few weeks or even months, while your baby builds up oral strength and the skills necessary to breastfeed. There are specialized feeding systems and supports that can help you ensure that your baby is adequately nourished, either with expressed breastmilk or with formula.

We cannot stress enough the value that a certified lactation consultant who has experience with babies with Down syndrome can bring. They have many tricks up their sleeve to help families learn to breastfeed a baby with Down syndrome.

None of this is to say that you must breastfeed your child. That is a personal choice, and many babies with Down syndrome have grown up happy and healthy on formula! Make the choice that feels right for your family, and know that you have support whatever you choose.

Health Care and AAP Guidelines

While some children with Down syndrome will have additional medical needs, others will not. However, as your child grows, it is important to monitor for certain issues and health concerns that are found in people with Down syndrome. The American Academy of Pediatrics (AAP) has published health care guidelines for children with Down syndrome. These guidelines, known as "Health Care Information for Families of Children with Down Syndrome," can be found online, but we have reproduced them here for your convenience. We encourage you to share these guidelines with your pediatrician when your child is at the appropriate age. We also suggest that you read and digest these guidelines only when your child reaches a particular age group. Reading about the health needs of a young adult can be overwhelming when you're just entering the infant stage!





Birth to One Month

- **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.

One Month to One Year

- **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.

One Year to Five Years

- ❑ **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 check-ups 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 tests:** Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.
- ❑ **Stomach or bowel problems (diarrhea, constipation):** 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
- ❑ **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:
 - 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.



Five to Thirteen Years

- ❑ **Regular well-care visits (check-ups):** It is important to have yearly well-care check-ups. These visits will assist in checking your child's health, giving shots, and answering your questions about your child's health.
- ❑ **Monitor growth:** It is important to check growth at every visit. Measurements include height, weight, and body mass index (BMI). 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 (heart doctor) during this age is based upon a child's health history and examination. About half of children with Down syndrome are born with differences in how their heart is formed. Children with normal newborn testing for heart problems may not need more evaluation at this age.
- ❑ **Hearing:** Hearing testing is needed every 6 months, until each ear can be tested alone. When a child can respond to testing in each ear alone, testing may be done every year. Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT).
- ❑ **Vision:** Vision should be checked at each well-care visit. It is also important to have an exam at least every two years by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Visits may be needed more often if your child has known eye or vision issues.
- ❑ **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 tests:** Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.
- ❑ **Stomach or bowel problems (diarrhea, constipation):** 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
- ❑ **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 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:
 - Stiff or sore neck
 - Change in stool or urination pattern
 - Change in use of arms or legs
 - Head tilt
 - Change in walking
 - Numbness (loss of feeling) or tingling in arms or legs
- ❑ **Sleep issues:** Obstructive sleep apnea is a common problem for people with Down syndrome. This is a sleep problem that can affect a child's behavior and ability to pay attention. It can also affect the heart. Some symptoms are obvious (snoring, restless sleep, 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 four years. (That testing may be hard to find in some parts

of the country.) Treatment can include special breathing equipment or surgery. Let your child's doctor know if your child is having:

- Loud breathing
- Snoring
- Waking up often at night
- Daytime sleepiness
- Restless sleep (moving around a lot)
- Uncommon sleep positions (like sitting up to sleep or sleeping with neck arched back)
- Pauses in breathing during sleep
- Behavior problems

□ **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.

□ **Behavior and mental health:** Some children with Down syndrome can have behavior or mental health issues that affect how they play and work at home, at school, or in the community. Let your child's doctor know if your child is having problems that make it hard for them to function in the home, community, or school, including:

- Anxiety
- High activity level
- Wandering off
- Not listening
- Other behavior concerns
- Attention problems
- Sad mood or lack of interest in activities
- Loss of skills (not being able to do the things they used to do)
- Obsessive compulsive behaviors (behaviors that are repeated frequently)

□ **Development:** As for all children, your child's well child visit is a chance to discuss his/her development, including:

- School progress and development: discuss your child's development, school placement, and service needs
- Transition: Children can need extra support at times of transition: discuss transition from elementary to middle school
- Social/independence skills: discuss developing social skills, self-help skills, and a sense of responsibility. Discuss working toward independence (doing things by him- or herself) with bathing, grooming, and self-care

□ **Sexuality and puberty:** Children need help to learn appropriate touch in social situations and correct names for body parts. Puberty can bring many changes. As your child approaches and enters puberty, discussions can include:

- Changes in puberty
- Managing sexual behaviors (such as masturbation)
- Gynecologic (women's health) care for girls with Down syndrome, including periods and mood changes related to (menstrual) periods.
- Fertility, birth control, prevention of sexually transmitted infections
- Risk for a person with Down syndrome having a child with Down syndrome



Thirteen to Twenty-One Years or Older

- **Regular well-care visits (check-ups):** It is important to have yearly well-care check-ups. These visits will assist in checking your child's health, giving shots, and answering questions about your child's health.
- **Monitor growth:** It is important to check growth at every visit. Measurements include height, weight, and body mass index (BMI). These measurements are very important to assessing the overall health of the child. Discuss diet, activity level, and growth. Your child's doctor can help with question 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 (heart doctor) during this age is based on a child's health history and exam. Let your child's doctor know if your child is having increasing fatigue (low energy) or shortness of breath at rest or during activity. If new symptoms appear, an echocardiogram (an ultrasound picture of the heart) may be needed.
- **Hearing:** Hearing testing is recommended at least every year. This may be needed more often if your child has hearing or ear problems.
- **Vision:** Ophthalmology examination by an eye doctor is recommended at least every three years or more often if there are known eye or vision issues.
- **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 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 tests:** Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.
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 - Hard to treat constipation (hard or painful stools)
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- Anxiety
- High activity level
- Wandering off
- Not listening
- Other behavior concerns
- Attention problems
- Sad mood or lack of interest in activities
- Loss of skills (not being able to do the things they used to do)
- Obsessive compulsive behaviors (behaviors that are repeated frequently)

□ **Sexuality:** Young people need help to learn the right kind of touch in social situations and the correct names for body parts. Puberty brings many changes and it may help to talk with your child's doctor about several things. Discussions may include:

- Changes in puberty
- Managing sexual behaviors (such as masturbation)
- Gynecologic (women's health) care for girls with Down syndrome, including periods and mood changes related to (menstrual) periods.
- Fertility, birth control, prevention of sexually transmitted infections
- Risk for a person with Down syndrome having a child with Down syndrome

□ **Transitions:** Discussion topics may include:

- School placement and goals for education. These should plan for transition and vocational (job skills) training.
- Guardianship and long-term financial planning.
- Adult work and places to live: family relationships, group homes and independent living opportunities, workshop settings, and other community-supported employment
- Working toward independence with bathing, grooming, self-care, and skills of community living
- Places for health care as an adult

□ **Aging:** Discussion of special health problems for adults with Down syndrome. This includes a tendency to early aging and higher risk for Alzheimer disease in some people.



Early Intervention

If you haven't already heard the term *early intervention*, it will soon become part of your everyday language. Early intervention refers to the services provided to infants and toddlers from birth to age three, and to their families. Early intervention generally includes:

- **Physical therapy:** This therapy works on gross-motor skills and muscle development used for activities such as sitting, standing, walking, and running.
- **Occupational therapy:** This therapy works on fine-motor skills, such as manipulating objects with one's hands, self-feeding, and pre-writing skills.
- **Speech therapy:** This therapy works on communication, language, and sometimes feeding issues.

Early intervention can help your child develop skills and meet milestones. Children with Down syndrome typically meet every milestone that typically developing children do, but at a delayed rate. The following table, adapted from the National Down Syndrome Society (NDSS), will give you an idea of milestone ranges for children with Down syndrome, as compared to typically developing children.

Milestone	Range for Typically Developing Children	Range for Children with Down Syndrome
Gross-Motor Milestones		
Sitting Unassisted	5–9 months	6–30 months
Crawling	6–12 months	8–22 months
Standing	8–17 months	1–3.25 years
Walking Unassisted	9–18 months	1–4 years
Social/Self-Help Milestones		
Responsive Smiling	1–3 months	1.5–5 months
Finger Feeding	7–14 months	10–24 months
Drinking from Cup Unassisted	9–17 months	12–32 months
Using Spoon	12–20 months	13–39 months
Toilet Training	16–42 months	2–7 years
Dressing Unassisted	3.25–5 years	3.5–8 years
Language Milestones		
First Word	1–3 years	1–4 years
Two-Word Phrases	15–32 months	2–7.5 years



Regional Centers

Here in California, early intervention is provided first by the Regional Center. Simply by virtue of having Down syndrome, your child will be a Regional Center client for life. The Regional Center provides different supports and services as each client ages. For the moment, you'll be most interested in early intervention.

Regional Centers help plan, coordinate, and access an array of supports and services that are needed or recommended when your child has a developmental disability. The first step is getting an initial assessment and intake; these are provided for free. If your family is above a certain annual income level, you may be assessed a co-pay (called Family Cost Participation) for the services you receive through the Regional Center. However, the income level is quite generous, and a great many of our families receive Regional Center services at no cost to them.

You will work with the Regional Center to identify your child's strengths and challenges and to create a plan to help your child reach their next developmental level.

A list of Regional Centers by county can be found in the Additional Resources section of this book.

Every child with Down syndrome has individual development needs, but most children with Down syndrome will benefit from occupational, physical, and speech therapy during their first three years. (Speech therapy typically starts around age 18 months, but the other two can start much younger.) Because children with Down syndrome typically understand more language than they can speak (their receptive language is higher than their expressive language), part of speech services may include an assessment and plan for "oral motor placement therapy" or "alternative and augmentative communication (AAC) systems." The DSCBA has additional information and resources available to learn about the complex communication needs of children with Down syndrome and would be happy to help you learn more about these options.

Regional Center therapies may be provided in your home, in a therapy center, in a center-based program with other babies/toddlers, in childcare, or in another natural setting. You may want to discuss your options with your Regional Center case manager, the DSCBA, other parents, and your family to decide what is best for you and your child. There is no one right placement or approach, and it is important to find the best match for your family situation.

Preschool Years

When your child reaches the age of three, educational and therapeutic services shift from the Regional Center to your local school district. The planning and preparation for this transition should begin happening by the time your child is two-and-a-half years old. Your child will remain a Regional Center client after age three, even after these services have shifted to the school district, and your family will remain eligible for certain Regional Center services. These services may include ongoing service coordination; support during and after transition to the school district; attendance at Individualized Education Plan (IEP) meetings; consultation with specialists on staff to discuss behavioral, medical, or educational issues; respite services; coverage for diapers; and workshops about various topics of interest to families. Your Regional Center caseworker may also know about other community and/or recreational opportunities that might be a good match for your child.

School district personnel will work with you and possibly other specialists in your child's life, such as therapists, Regional Center caseworkers, and so on, to develop your child's IEP. The range of available preschool services and settings varies from district to district. Most districts will provide some designated services, such as occupational therapy, speech therapy, physical therapy, and adaptive physical education. They will also offer a special day classroom setting or a more inclusive setting, such as integration into a public preschool program, like Head Start.

Some districts have been known to support (financially and/or just with designated services) students who attend private, general education preschools. We have also seen families who opt to structure a combination of a public special day class preschool setting and a private general education preschool. Work with your district, talk with other parents, visit classrooms, and consult with the DSCBA and other trusted specialists who know your child well to understand the range of options available. It's important that your child's team work together to create a plan for an appropriate preschool setting and program for your child.

Decades of research have repeatedly shown that children with Down syndrome benefit from being educated with typically developing peers. Typical peers can be motivating models of appropriate play, language, and behavior. Most students with Down syndrome at this young age need extra support in the classroom, but the level and type of support depend on the individual child. Every child is different. Specialists from your child's early intervention services, school district personnel, and the DSCBA can assist you. We have training materials and resources to support educators and families with these transitions.

Finally, know that you have rights where your child's education is concerned. If you feel the decisions made by the school district are not in your child's best interests, contact the DSCBA. We can help you understand your child's rights and help support you as you pursue them.



Additional Resources

Because Down syndrome is a relatively common genetic condition, there is a lot of support available for families! We hope that the DSCBA will provide you with local support and connections that will last a lifetime! In addition, we'd like to share some other resources available to you.

National and International Organizations

- National Down Syndrome Congress (NDSC) (ndscenter.org). NDSC is a national organization dedicated to providing support and information to people with Down syndrome and those touched by it. They hold an annual conference with many dozens of workshops on anything and everything related to Down syndrome. They also advocate for legislation that will help improve the lives of people with Down syndrome and other intellectual disabilities.
- National Down Syndrome Society (NDSS) (ndss.org). NDSS is a human rights organization that, like NDSC, advocates for policies and legislation that will improve the lives of people with Down syndrome and other intellectual disabilities.
- Global Down Syndrome Foundation (globaldownsyndrome.org). Global is dedicated to significantly improving the lives of people with Down syndrome through research, medical care, education, and advocacy.
- LuMind IDSC Foundation (lumindidsc.org). LuMind seeks to stimulate biomedical research that will accelerate the development of treatments to improve cognition, including memory, learning, and speech for individuals with Down syndrome.
- Down Syndrome Diagnosis Network (dsdiagnosisnetwork.org). DSDN works to improve the diagnosis experience for families receiving a Down syndrome diagnosis and provides an online support network consisting of more than 10,000 parents worldwide.
- Down Syndrome Education International (dseinternational.org). Down Syndrome Education International, based in the UK, supports scientific research and delivers evidence-based advice and information to improve educational outcomes for children with Down syndrome.

Local Organizations

- Charlie's Clinic at UCSF Benioff Children's Hospital Down Syndrome Clinic (Oakland)
- Center for Down Syndrome at Lucile Packard Children's Hospital (Palo Alto)

- Family Resource Networks (various throughout the Greater Bay Area; see www.frcnca.org/frcnca-directory to find the one nearest you)
- Regional Center (various depending on county):
 - Alameda and Contra Costa Counties: Regional Center of the East Bay (rceb.org)
 - Marin, San Francisco, and San Mateo Counties: Golden Gate Regional Center (ggrc.org)
 - Monterey, San Benito, Santa Clara, and Santa Cruz Counties: San Andreas Regional Center (sanandreasregional.org)
 - Napa and Solano Counties: North Bay Regional Center (nbrc.net)

Books

- *The Parent's Guide to Down Syndrome: Advice, Information, Inspiration, and Support for Raising Your Child from Diagnosis through Adulthood.* Jacob, Jen, and Mardra Sikora. Avon, MA: Adams Media, 2016.
- *47 Strings: Tessa's Special Code.* Carey, Becky. Mineral Point, WI: Little Creek Press, 2012.
- *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives.* Lynard, Kathryn. Bethesda, MD: Woodbine House, 2016.
- *Unexpected: Stories of a Down Syndrome Diagnosis.* Jacob, Jen, and Joelle Kelly. 2014.
- *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters.* Skotko, Brian, and Susan P. Levine. Bethesda, MD: Woodbine House, 2009.

Letters from parents...



Congratulations on your little miracle! I know this time can feel incredibly overwhelming, but along with the fear of the unknown and worry will come the most beautiful introduction to looking at the world in a whole new way. Your new bundle will teach you to slow down, take some breaths, and savor even the smallest of moments as pure gold. Their smiles are magic—just wait and see, and welcome to the most amazing community you never knew you wanted to join.

- *Stephanie*



Haley is such a joy in our family! When she was born, I remember feeling like, How I am going to do this? I wondered if she would ever be able to swim, dance, play soccer, ride a bike, and even wear makeup! She can do all these things. When she was a baby we would always say, “She will be able to do all the things we can eventually, but it will take more time.” I am so glad I made it through the first few emotionally hard years, because it’s so worth it and there is so much joy and happiness that these children bring into our lives!

- *Brooke*



Hi friends. Welcome to this beautiful life with your baby! We found out at five months pregnant that our girl had Down syndrome. Since then, we have learned so much. The most important takeaway so far is that Cadence has so much more to teach us and others than we could ever hope to teach her. We’re so lucky that she picked us.

- *Karen*



Welcome to a very unique and special parenthood of moms and dads who have, over time, learned how incredibly blessed they are to have been entrusted with a child diagnosed with Down syndrome! I understand that right now this may not feel like much of a blessing—we have all been there. But I promise that with time, you will see the miracle that sometimes hides for what seems like a lifetime! You will without a doubt be faced with challenges unique to your new little angel, but I assure you that for every challenge there will be great recompense! Please call us if you have any questions or simply need an empathetic ear to cry to, without the fear of judgment! This is not the end of a dream; this is just the beginning of a new adventure!

- *Susana*



Congratulations! All children are a gift and all children grow and develop at different ages. Your baby needs what all babies need—to be fed, held, changed, and most of all LOVED. Set high expectations for your children, and they will achieve great things. Celebrate the milestones and persevere when life gets hard. This child will bless your family and teach you many wonderful life lessons. You are one of the lucky few.

- The Drucker Family



My name is Nora, and I like to read, dance, and play with my friends. I can jump. I can sing. I can write my name. Whatever my big brother does, I want to try. And I love going on adventures with my family.

- Nora



Down Syndrome Connection of the Bay Area
Empower - Inspire - Support