



NEW PARENT WELCOME BOOKLET



The Down Syndrome Association of Jacksonville (DSAJ) aims to support families as they navigate the journey of supporting individuals with Down syndrome. The DSAJ offers support for each milestone of the lives of individuals with Down syndrome, from educating staff at local hospitals on better ways to deliver a prenatal or post-natal diagnosis, to making sure new babies receive the therapies they need, to ensuring better and sustainable career paths for adults.

Our Mission

The Down Syndrome Association of Jacksonville (DSAJ) is a non-profit organization committed to helping people with Down syndrome achieve their full potential and to creating a community that is educated, supportive and inclusive of individuals with Down syndrome.

Our Vision

We envision a community where all people with Down syndrome are actively included, given opportunities to participate and contribute as valued citizens, and have the choices to create their own paths to fulfillment and success.



Congratulations ON YOUR NEW BABY

Dear Parent,

Learning that your baby has Down syndrome can bring about many different feelings and emotions. Let me assure you that this is perfectly normal. The news fills most parents with countless questions and fears, but learning as much as you can about Down syndrome will help you embrace hope for a promising future.

The purpose of this booklet is to provide you with information and support to help you begin this journey. At first glance, it may seem overwhelming – but know that our team is available to answer any questions you may have.

When you are ready, please contact us, and we will send you additional materials and resources that will be beneficial to you and your family.

We look forward to hearing from you and having the privilege of sharing this journey with you!

Down Syndrome Association of Jacksonville

(904) 353-6300

info@dsaj.org



TABLE OF CONTENTS

About Down Syndrome	4
About the DSAJ	7
A Parent's Perspective	8-9
Caring for Your Family	10
Resources	12
Health Care Guidelines	14
What's Next?	23



ABOUT DOWN SYNDROME

Down syndrome is a genetic condition that occurs in 1 out of 792 babies. It affects people of all ages, races and economic levels and is the most frequently occurring chromosomal abnormality. Trisomy 21, the most common type of Down syndrome, occurs when there are three, rather than two, number 21 chromosomes present in every cell of the body. Instead of the usual 46 chromosomes, a person with Down syndrome has 47. It is this additional genetic material that alters the course of development and causes the characteristics associated with the syndrome.

Today, with early intervention, quality medical care, education programs and social acceptance, people with Down syndrome can live full, productive lives.



DOWN SYNDROME QUESTIONS AND ANSWERS

What is Down syndrome?

Down syndrome is a genetic condition that results when a baby is born with three rather than the usual two copies of chromosome 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.

How common is Down syndrome?

Down syndrome is the most commonly occurring chromosomal condition. One in every 792 babies is born with Down syndrome. Down syndrome occurs in people of all races and economic levels. There are approximately 250,000 people living with Down syndrome in the United States.

What comorbidities are associated with Down syndrome?

Approximately 40–60% of infants with Down syndrome have a congenital heart defect. Low muscle tone is common in people with Down syndrome, which may result in delayed gross motor development like crawling and walking. Constipation and gastroesophageal reflux are also common. Those with Down syndrome are at greater risk for childhood leukemia, sleep apnea, thyroid conditions, Alzheimer's disease, and diabetes. Many of these conditions are treatable, and most people with Down syndrome lead healthy lives.

What are the physical characteristics of an individual with Down syndrome?

Common traits include low muscle tone, small stature, an upward slant of the eyes, and a single, deep crease across the center of the palm. While there are similarities among people with Down syndrome, each person is unique and may possess these characteristics to varying degrees or not at all.

How long do people with Down syndrome live?

Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to over 60 today.

Will my child with Down syndrome go to school or work?

People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways. Many pursue post-secondary education and work in their communities.

How will Down syndrome affect my child's cognitive ability?

All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.

What types of programs are available?

Local and national agencies are available to provide quality educational programs, navigate healthcare, and increase inclusion at a multidisciplinary level. Social skill workshops, employment training, and health and wellness programs also enable people with Down syndrome to develop to their full potential and lead fulfilling lives.

What research has been done about Down syndrome?

Researchers, such as NDSS and GLOBAL, are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct or prevent many of the conditions associated with Down syndrome in the future.



Information from National Down Syndrome Society – www.ndss.org



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. There are, however, certain health and developmental concerns commonly associated with Down syndrome. Individuals with Down syndrome are at an increased risk for certain health conditions. Babies are more likely to have congenital heart conditions, hearing loss and respiratory infections; however, advances in medicine have rendered the majority of their health conditions as treatable.

All people with Down syndrome experience delays in their cognitive and physical development; however, 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, your child will learn to do these and many more activities, only possibly somewhat later than his or her peers without Down syndrome.



PROPER USE OF LANGUAGE FOR "DOWN SYNDROME"

Down vs. Down's – DSAJ uses the preferred spelling, Down syndrome, rather than Down's syndrome. While Down syndrome is listed in many dictionaries with both popular spellings (with or without an apostrophe "s"), the preferred usage in the United States is Down syndrome. This is because an "apostrophe s" connotes ownership or possession. Down syndrome is named for the English physician, John Langdon Down, who characterized the condition, but did not have it. The AP Stylebook recommends using "Down syndrome," as well.

People with Down syndrome should always be referred to as people first. Instead of "a Down syndrome child," it should be "a child with Down syndrome." Also avoid "Down's child" and describing the condition as "Down's," as in, "He has Down's."

Down syndrome is a condition or a syndrome, not a disease. People "have" Down syndrome, they do not "suffer from" it and are not "afflicted by" it. While it is unfortunately clinically acceptable to say "mental retardation," the more socially acceptable term is "intellectual disability". DSACO strongly condemns the use of the word "retarded" in any derogatory context. Using this word is hurtful and suggests that people with disabilities are not competent.

WHO IS THE DSAJ?

The Down Syndrome Association of Jacksonville (DSAJ), a 501 (c)(3) organization, is a network of individuals with Down syndrome, their parents, families, caregivers, advocates, volunteers, health care providers, educators, and friends. Collectively, we refer to all of these individuals as members. We provide members and the public with information, education, support, and assistance from birth through adulthood.



What counties do we serve?

The Down Syndrome Association of Jacksonville provides a variety of information, education, support and assistance to individuals with Down syndrome and their families in 7 counties throughout Northeast Florida and Southeast Georgia including Duval, St. Johns, Nassau, Baker, Clay, Camden and Glynn. Please note that the services, programs, and supports are not exclusive to the 7 counties highlighted. If you have an interest in a particular program or event that we offer, please do not hesitate to join us!

How many families do we serve?

Annually, we serve more than 2,500 individuals, families, and community professionals throughout 7 counties in Northeast Florida and Southeast Georgia.

What programs and services does DSAJ offer?

Over the arc of a lifetime — the DSAJ is the only agency in Northeast Florida and Southeast Georgia that assists families of those with Down syndrome from prenatal diagnosis, early intervention, the school-aged years, and throughout adulthood. Every step of the way, you have someone here to help. Our robust services provide a broad spectrum of opportunities for those in the Down syndrome community, no matter who you are. We want to help you become the best version of yourself.

How is the DSAJ funded?

It is only through the generosity of many individuals, corporations and grants that DSAJ is able to provide quality programs and services for individuals with Down syndrome and their families. DSAJ's largest fundraisers are the annual DSAJ Buddy Walk, and the DSAJ Charity Golf Classic.

FIND DSAJ ONLINE:

Website - www.dsaj.org

Facebook - @DownSyndromeAssociationofJacksonville

Instagram - @DSAJacksonville



A PARENT'S PERSPECTIVE

Welcome to Holland

BY EMILY PERL KINGSLEY

© 1987 BY EMILY PERL KINGSLEY. ALL RIGHTS RESERVED



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

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

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

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

But there's a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for awhile and you catch your breath, you look around...and you begin to notice that Holland has windmills... Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming from Italy... and they're all bragging about what a wonderful time they had there.

And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

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

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

A PARENT'S PERSPECTIVE

Welcome to Holland (Part 2)

BY EMILY PERL KINGSLEY

© 1987 BY EMILY PERL KINGSLEY. ALL RIGHTS RESERVED



I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned. I reflect back on those years of past when I had first landed in Holland.

I remember clearly my shock, my fear, my anger—the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its' tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

CARING FOR YOUR FAMILY

Research shows that families of children with Down syndrome can be stable, successful and happy. This section provides information on 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. A message from families that is echoed again and again is that the positive impacts of having a family member with Down syndrome far outweigh 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 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 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 BABY 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.



Photo by: Savannah Payne Photography

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 others might be going through, and often surprise parents 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 thus, 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 them.



WHAT ARE SOME TIPS FOR TAKING CARE OF MY OTHER CHILDREN'S NEEDS?

Your children may be doing an excellent job of helping with their brother or sister with Down syndrome, 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:

- 1** Be sure to acknowledge all emotions, not just the positive ones. If your children know that it is ok 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.

- 2** While it can be beneficial for your other children to feel that they can play an important role in caring for their sibling, don't give them too many responsibilities in this area.

- 3** 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.

- 4** 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 or special. Remind your children that all members of your family are special in their own way.

- 5** Read "Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters" by Brian G. Skotko and Susan P. Levine - www.brianskotko.com/publications

RESOURCES



BOOKS ON DOWN SYNDROME

Bloom: Finding Beauty in the Unexpected

Bloom is an inspiring and heartfelt memoir that celebrates the beauty found in the unexpected, the strength of a mother's love, and, ultimately, the amazing power of perspective. The popular blog, "*Enjoying the Small Things*", Kelle Hampton interweaves lyrical prose and stunning four-color photography as she recounts the unforgettable story of the first year in the life of her daughter, Nella, who has Down syndrome.



Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives

This commemorative 10th anniversary edition of *Gifts* includes 10 new personal stories, along with "where are they now" updates on many of the children and families featured in the first edition. *Gifts* is the much-loved collection of over sixty essays written by mothers who share their truths about raising children with Down syndrome. Powerful then and powerful now, it affirms over and over that a life with an extra chromosome is one worth living.

Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic

John and Martha Beck had two Harvard degrees a piece when they conceived their second child. When Martha learned her unborn son had Down syndrome, she battled nearly everyone over her decision to continue the pregnancy. By the time her son was born, Martha, as she puts it, "had to unlearn virtually everything Harvard taught [her] about what is precious and what is garbage."

Down Syndrome Parenting 101: Must-Have Advice for Making Your Life Easier

Down Syndrome Parenting 101 offers inspired takes on a host of important issues, from learning to recognize and celebrate your child's personality and gifts to finding a great teacher for him. The author advocates for your child to pull their own weight and also encourages giving appropriate space to your child as they grow and mature.

The Year My Son and I Were Born

In The Year My Son and I Were Born, Kathryn Soper takes us along on her personal journey through Thomas's tumultuous first year—as she strives to balance the loss of the child she thought she would have with loyalty for the baby she actually holds in her arms. Can she love Thomas for himself? Can she protect him from the world's insensitivity—and from her own doubts?



Road Map To Holland: How I Found My Way Through My Son's First Two Years With Down Syndrome

When Jennifer Groneberg and her husband learned they'd be having twin boys, their main concern was whether they'd need an addition on their house. Then, five days after Avery and Bennett were born, Avery was diagnosed with Down syndrome. This book is a resource, a companion for parents, and above all, a story of the love between a mother and her son—as she learns that Avery is exactly the child she never knew she wanted.

Please note Woodbine House Publisher www.woodbinehouse.com has a generous selection of books and DVDs on Down syndrome. You may also research your local library.

HELPFUL WEBSITES

Down Syndrome Association of Jacksonville
www.dsaj.org

Down Syndrome Pregnancy
downsyndromepregnancy.org/about-us

National Down Syndrome Congress
www.ndsccenter.org

National Down Syndrome Society
www.ndss.org

Global Down Syndrome Foundation
www.globaldownsyndrome.org



Photos by: Savannah Payne Photography



HEALTHCARE GUIDELINES

BASED ON “**HEALTH CARE INFORMATION FOR FAMILIES OF CHILDREN WITH DOWN SYNDROME**”
AS PUBLISHED BY THE AMERICAN ACADEMY OF PEDIATRICS

Introduction

Down syndrome is a common condition caused by having “extra” copies of genes on the 21st chromosome. Those extra genes change development during pregnancy, and they continue to have effects after birth and throughout a person’s life. Each person with Down syndrome is unique, having some of the many possible health, learning, and related differences that can occur with this condition.

Some of the differences in people with Down syndrome are common and visible, like the facial appearance. Other changes are less common or less visible but can still cause problems or may need special treatments. The “special treatments” may include medicines, surgeries, or changes in what you should expect. There are no medicines or therapies that are needed by all people with Down syndrome. There are also no medicines or therapies that can “cure” Down syndrome.

Your child’s doctor should be your starting point. Your child needs regular doctor visits and a few special tests. Medical specialists may also need to be involved. The medical issues for a child with Down syndrome change with age. For this reason, this document is divided into several age groups. Each age group includes a list of issues that may be important to your child at that age. Your doctor can check the full AAP guideline for more details (<http://pediatrics.aappublications.org/content/128/2/393.full>). The information within each age group is sorted by the parts of the body that are affected (heart, ears, etc.). Many tests only need to be done once. Some areas might need to be looked at again, or even many times, as the child grows to an adult.

This document focuses on medical topics that affect physical health. Other issues can affect social and school success, which may not need doctors or other medical resources but are still important issues for children with Down syndrome. Many people with Down syndrome understand more than they can say. They may need help to communicate in other ways. Most have good social skills, especially if they have friends with typical behavior as models. Respect for and attention to their abilities are often important missing pieces and may be enough to make a big difference in performance and behavior.

The information in these guidelines has grown with the help of families, Down syndrome clinics, and doctors around the world. Most of the information is easy to follow. However, some tests or specialists might be needed that are not available in your area. Your doctor can help to sort out the best next-steps when something can’t be done quickly or nearby.

When you visit the doctor, you might want to bring a notebook to write down information from each visit. A notebook will help you keep all of your child’s medical information in one place. This will be valuable when you meet with new doctors or with others involved in your child’s care. Local parent support groups can be a very good place to learn about doctors, therapists, and other providers in your community. They may also be able to help with questions about daycare, preschools and schools, other local developmental programs, problems with behavior, help with child care, etc. Your doctor’s office should have names and contact information for groups in your area.

Complete Physical Examination:

If the diagnosis of Down syndrome was made before birth or suspected before 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.



INFANT (1 MONTH TO 1 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.

CHILDHOOD (1 YEAR TO 5 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 checkups by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Crossing eyes or blocked tear ducts might be reasons for quicker action. Early use of eye patches, glasses, or both may help to fix eye crossing while lowering the need for surgery and the risk of vision loss.

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

Blood 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 new or challenging behavior problems, as well as:

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

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.



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.

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.

ADOLESCENCE (5 YEARS TO 13 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 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 during this age is based on the 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 important to have an exam at least every 2 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.

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.

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 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.)* 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
- 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
- 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

YOUNG ADULT (13 YEARS TO 21 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 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 overall health of the child. 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. 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 3 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 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 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. 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 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.) 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 youth 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 him or her to function in the home, community or school, including:

- Anxiety
- High activity level
- Wandering off
- Not listening
- 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)
- Other behavior concerns



Sexuality and puberty: 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
- 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 towards 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 of Alzheimer disease in some people.

“Health Care Information for Families of Children with Down Syndrome” was created in July 2013 by the American Academy of Pediatrics (AAP) to give parents and families information about the special health care needs for children with Down syndrome. This document should be used together with the care given by a child’s doctor.

This information is based on the “Health Supervision for Children with Down Syndrome” clinical report from the American Academy of Pediatrics, available here: <http://pediatrics.aappublications.org/content/128/2/393.full>

The “Health Care Information for Families of Children with Down Syndrome” Ad-Hoc Writing Committee:

Marilyn J. Bull, MD, FAAP (Chairperson) Richard J. Robison, PhD George T. Capone, MD

W. Carl Cooley, MD, FAAP Philip Mattheis, MD, FAAP Robert A. Saul, MD, FAAP

Maria A. Stanley, MD, FAAP Paul Spire (AAP Staff)

WHAT'S NEXT?



FUTURE TO-DO LIST

- 1. Become a member of DSAJ to get information on programs and resources available.** Membership is free! Please complete a membership application which can be found on the DSAJ website at www.dsaj.org/become-a-member
- 2. Get connected to other parents by attending a Little Stars social event hosted by the DSAJ.**
(more information can be found on the DSAJ website)
- 3. Set up an appointment with your pediatrician.** Don't forget to take your Physician Folder with you (enclosed)!
- 4. Contact your county's Early Intervention Services (EI), also known as Early Steps.** You can find your county's contact information at floridaearlysteps.com/contact/.
- 5. Check eligibility for Supplemental Security Income (SSI)** – a Federal income supplement program funded by general tax revenues designed to help aged, blind, and disabled people, who have little or no income, and provides cash to meet basic needs for food, clothing, and shelter at www.ssa.gov/ssi.
- 6. Do you need immediate support? If so, don't hesitate to call Debbie Revels, the DSAJ Executive Director, today at (904) 353-6300.**



