



DEAR NEWBORN MEDICINE TEAM,

The Down Syndrome Program in the Developmental Medicine Center at Boston Children's Hospital offers multidisciplinary clinical evaluations for people with Down syndrome from birth until the age of 22. The Down Syndrome Program is more than a clinic; we strive to provide individualized resources, advocacy, and supports to all of our families. We appreciate your past referrals and look forward to working with you to support future patients.

As you know, Down syndrome is the most common genetic cause of intellectual disability and is associated with many possible medical concerns. However, in the past decades, the outlook for individuals with Down syndrome has changed greatly and the expectation for babies born with Down syndrome today should be for an active, full, and rewarding life as an integral part of their families, schools, and greater communities.

So, please do congratulate new parents! Like all parents, they are about to start an amazing journey. To get young children with Down syndrome off to a healthy start, there are several key evaluations to perform in the newborn period. We have enclosed a copy of the Health Care Guidelines for Individuals with Down Syndrome for providers. Also enclosed are a letter and materials you can share with new parents.

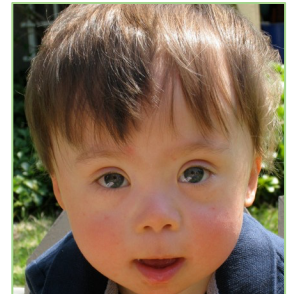
- Health Care Guidelines - parent checklist.
- Early intervention flyer.
- Handout on breastfeeding babies with Down syndrome.
- Massachusetts Down Syndrome Congress (MDSC) Parents First Call flyer
- Boston Children's Hospital Down Syndrome Program flyer

Please let us know if you would like more copies of any of these materials. We hope to serve as a resource to you and your families so please feel free to contact us with any questions.

Boston Children's Hospital Down Syndrome Program

Office: 857-218-4329, downsyndromeprogram@childrens.harvard.edu

www.childrenshospital.org/downsyndrome





DEAR PARENTS,

Congratulations on the birth of your baby! Because your baby has Down syndrome, the medical team will do a few special evaluations to assess for conditions that occur more commonly in babies with Down syndrome. There are many people who can help provide you with supports during your baby's first weeks and months. The list below notes some suggested resources.

Enclosed resources and supports:

Family Checklist provided from the AAP Health Care Guidelines for Individuals with Down syndrome

- Parent-friendly checklists for children newborn to one month and one month through age 1.
- Find parent-friendly checklists for all ages at www.healthychildren.org.

Early Intervention (EI)

- Provides your child with in-home therapies such as physical therapy, speech therapy, occupational therapy to promote the child's development.
- Ask hospital staff for a referral before your child's discharge home.
- 1-800-905-8437 or see directory at www.massfamilyties.org to find local EI.

Lactation support

- Babies with Down syndrome may need additional support but most can breastfeed. In addition to all of its other benefits, breastfeeding may assist oromotor development, which is important for babies with low tone.
- Ask for support in the hospital and after discharge home.

Massachusetts Down Syndrome Congress (MDSC)

- First Call program can match you with a trained parent volunteer for parent-to-parent support. www.mdsc.org
- The MDSC Annual conference is a great source of information and an opportunity to meet others involved in the Down Syndrome community.

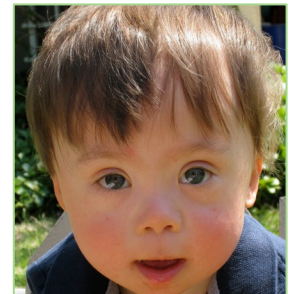
Boston Children's Hospital Down Syndrome Program

- Provides multidisciplinary evaluation for children with Down Syndrome.

Boston Children's Hospital Down Syndrome Program

Office: 857-218-4329, downsyndromeprogram@childrens.harvard.edu

www.childrenshospital.org/downsyndrome



Health Care Information for Families of Children and Adolescents with Down Syndrome

American Academy of Pediatrics

Introduction

Down syndrome is a common condition caused by having an extra copy of the 21st chromosome. These 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 may be common and visible, like the facial appearance. Other changes are less common or less visible but can still cause challenges or may need special treatments. The "special treatments" may include medicines, surgeries, or therapies. Each person with Down syndrome needs their own treatment plan. There are no medicines or therapies that can "cure" Down syndrome.

Your child's primary care 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. 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.

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 clinical report for more details (the web address is given below).

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 into 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.

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 track 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.

National, state, and 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 childcare, etc. Your doctor's office may have names and contact information for groups in your area.

This document was created 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 and Adolescents with Down Syndrome" clinical report from the American Academy of Pediatrics, available here:

<https://publications.aap.org/pediatrics/article/149/5/e2022057010/186778/Health-Supervision-for-Children-and-Adolescents>

Health Care Information for Families of Children and Adolescents with Down Syndrome

Child's Age: Birth to 1 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, or if a diagnostic test was not performed before birth, then confirmation testing is 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.

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 may have feeding problems for various reasons. 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, ENT, and audiology).

Thyroid

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

Blood test

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

Stomach or bowel problems (reflux, constipation, blockages)

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

Infection

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

Developmental services

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

Resources

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

Health Care Information for Families of Children and Adolescents with Down Syndrome

Child's Age: 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. Your child's growth can be shown on the Down Syndrome Growth Charts. 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.

Blood tests

Tests for low iron (ferritin, serum iron, and other tests) and anemia (CBC and other tests if needed) should be done every year. Low ferritin can be associated with sleep problems, and your doctor may prescribe iron.

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.

Neurology

Children with Down syndrome have an increased risk for seizures including infantile spasms. Your child's doctor will ask about these symptoms.

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.

Counseling for chance of recurrence

Families should get counseling about the possible chance of having another child with Down syndrome, if they choose to have more children. While the chance 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.

WHAT IS Early Intervention?

Massachusetts Early Intervention (EI) is a program for infants and toddlers (birth to 3 years old) who have developmental delays or are at risk of a developmental delay.

EI services are designed to help support families and caregivers, and to enhance the development and learning of infants and toddlers through individualized, developmentally appropriate activities within the child's and family's everyday life experiences.

Early Intervention provides family-centered services that support the development of eligible children by assisting the child to:

- Develop positive social-emotional skills (building relationships).
- Gain knowledge and skills (learning).
- Use appropriate behaviors to meet their needs (developing independence).

And by helping families to:

- Know their rights.
- Communicate their child's needs.
- Help their children develop and learn.

Where can I learn more about Early Intervention?

Call the Central Directory at 1-800-905-8437, or visit massfamilyties.org for a listing of certified Early Intervention programs serving your city or town.



Massachusetts Department of Public Health
Bureau of Family Health and Nutrition
Division of Early Intervention Services

250 Washington Street
Boston, MA 02108

mass.gov/dph/earlyintervention

Call: (617) 624-6060



Massachusetts Department of Public Health
Bureau of Family Health and Nutrition
Division of Early Intervention
mass.gov/dph/earlyintervention



Who is eligible for EI?

Any Massachusetts family with a child under three years of age may be eligible for EI services if the child:

- Is **not reaching age-appropriate milestones** in one or more areas of development.
- Is **diagnosed** with certain conditions that may result in a developmental delay.
- Has a medical or social history which may put the child **at risk** for a developmental delay.

How is a referral made?

The process is simple. Anyone (a parent, doctor, care giver, teacher or friend) can find a certified Early Intervention program by calling 1-800-905-8437 or visiting the Family TIES website at massfamilyties.org. Referrals are made directly to a certified program. A prescription or insurance referral from a health care provider is not needed.

What happens after a referral?

An EI team will complete an evaluation to determine eligibility. The evaluation looks at all areas of a child's development as well as information about the child's birth, medical history and family. If the child is eligible, an Individualized Family Service Plan (IFSP) is developed in partnership with the family. An IFSP is a working document that outlines the early intervention outcomes and services to be provided with the child, family and other caregivers.

A meeting to write the IFSP occurs within 45 days of when the child was referred to the EI Program. A service coordinator is assigned to ensure that a family's priorities, needs and concerns are addressed and to coordinate collaboration among all EI and community team members.

Who provides EI services?

Services are provided by a team which includes the child's family. EI services may be provided by a developmental specialist, physical therapist, speech – language pathologist, psychologist, occupational therapist, social worker, nurse, and other specialty service providers.

The EI team believes in the importance of establishing relationships and equal partnerships with family members and caregivers so that activities and strategies can occur throughout the day to enhance a child's development.



Where and how are services provided?

Infants and toddlers develop and learn through meaningful everyday experiences and interactions with familiar people in familiar places. This may mean that services are provided at home, in early care and education programs, play groups, or within the family's community. Services work best when families and caregivers participate in home visit activities.

The Early Intervention process from the initial contact through transition out of the program, is collaborative, individualized and reflects the child's and family's priorities, learning styles, culture and community.

Who pays for EI?

Most health insurances cover EI services. There are no co-payments or deductibles or other costs to the family. The Massachusetts Department of Public Health, MassHealth and private health insurance cover EI services.



Nursing and Down Syndrome:

A short guide to breastfeeding your baby



Nicole Starr Photography

Congratulations! By following the advice in this brochure, you are taking an important first step toward successfully breastfeeding your baby with Down syndrome (DS). As with everything in life, being prepared is essential, and we want to help you have the best chance for a happy, healthy breastfeeding relationship.

Most babies with DS can breastfeed just like any other baby. There may be bumps in the road that can complicate breastfeeding or delay its onset, but in most instances, breastfeeding is possible. This brochure is designed to help you understand and prepare for some of the challenges you and your baby may face.

Benefits of Breastfeeding Your Baby with Down Syndrome

- Breast milk provides an ideal source of nutrition, is easily digested, and is well tolerated by babies.
- The physical act of nursing is a type of speech therapy, helping to shape the upper palate, and laying the groundwork for future speech.
- Babies with DS have a higher chance of being born early, with a less mature immune system. The antibodies in your breast milk provide some protection against illness.
- Breastfeeding can strengthen the important bond between you and your baby.
- Breastfed babies have a decreased risk of ear infections, respiratory infections, leukemia, sleep apnea, and celiac disease, all of which are more common in those with DS.

While You Are Pregnant

Tell your medical team about your intention to breastfeed and request that a note be placed in your chart so that all of your providers are aware of your wishes. Here are some other steps you can take:

- Enroll in a breastfeeding class to prepare for any challenges you may have.
- Contact the lactation consultants at the hospital where you are delivering to let them know that you want to breastfeed and that you may require extra assistance.

- Call your health insurance provider and ask if your policy covers a breast pump. If you are separated from your baby after birth, you may need a hospital-grade breast pump to establish your milk supply or to express breast milk long term.
- Ask your local DS organization to connect you with lactation professionals who have worked with babies with DS and with moms who may be willing to support you in this process.
- Direct your medical professionals to www.juliasway.org so they can better understand how to help babies with DS breastfeed successfully.

First Hours

After your baby is born, there are several things you can do to get breastfeeding off to the best start:

- Make sure everyone on the team is aware of your desire to breastfeed.
- Put your baby to breast as soon after birth as possible, preferably within the first hour.
- Practice skin-to-skin contact as much as possible. In addition to helping you establish a milk supply, skin-to-skin contact has several other benefits for both you and your baby.
- If your medical team wants to keep a close eye on intake, request pre- and post-breastfeeding weights to assess how much milk your baby is taking at each feeding. *(continued)*

If Your Baby Has Difficulties Breastfeeding:

Babies with DS do not seem to have a “window” in which they must learn to breastfeed. As long as you protect your milk supply by expressing your milk, you have a good chance of being able to transition your baby to the breast.

- If your baby can't breastfeed soon after birth, start expressing your milk, ideally within 1-3 hours of delivery. This will help you establish your supply and will stimulate ongoing milk production.
- Request assistance from the hospital's lactation consultants right away. They may have ideas or devices that can make breastfeeding more effective. Make sure that you know how to use these before leaving the hospital.
- Request a consultation with a speech pathologist or feeding team. They can collaborate with your lactation consultant to help your baby transition to the breast.



COMMON CHALLENGES

These challenges may seem overwhelming at first, but most can be overcome with time and support.

- Prematurity
- Heart or other medical conditions
- Low muscle tone
- Poor endurance
- Weak suck
- Excessive sleepiness

If You Need to Pump

Pumping can be tiring, and it may be challenging to establish your milk supply if your baby cannot nurse directly, but it can be done!

- Hand expression can be more effective at milk removal in the first 24-48 hours. Your lactation consultant can instruct you on how to do this.
- Pump 8-10 times every 24 hours to establish an adequate milk supply, including at least once overnight. This will ensure that you will have the opportunity to transition your baby to breast in the future.

- Remember that when establishing your milk supply, more frequent pumping is more beneficial than longer pumping sessions.
- Massage your breast for a few minutes before you start pumping to encourage let down and help maximize your milk supply.
- Listening to relaxing music while pumping, especially while looking at photos of your baby, has been shown to have a positive effect on the quantity and fat content of milk.
- Try the “milk shake”! Lean forward, let your breasts hang down, and gently shake them back and forth. This is thought to help release the milk droplets from the walls of the ducts.

Going Home

You may find it easier to concentrate on your breastfeeding relationship once you are home. To help with the transition:

- Track your baby's feeding and wet/soiled diapers in a journal or smartphone app to ensure enough intake.
- Consider renting a digital scale to do pre- and post-breastfeeding weights at home to ensure that your baby is transferring enough milk.
- Find a comfortable chair and a good pillow to support you and your baby. Good positioning will help your baby latch better and allows for optimal milk transfer.

Further Resources

In addition to this brochure, Julia's Way has created the book, *Breastfeeding & Down Syndrome: A Comprehensive Guide for Mothers and Medical Professionals*. Our book:

- Is written by experts in their fields using the latest evidence-based research.
- Offers advice on everything from preparing to breastfeed, to breastfeeding after heart surgery, to getting to the breast after tube feedings, and much more.
- Includes everything you need to know to successfully breastfeed your baby, including dozens of mothers' stories to help reassure you that babies with Down syndrome CAN breastfeed.

Because we have a deep commitment to helping mothers breastfeed their babies with Down syndrome, our book is available to download free of charge. Proceeds from any print copies go directly to Julia's Way to help us continue our work supporting mothers who want to breastfeed their babies with Down syndrome.

To download or order your book or to learn more, visit www.juliasway.org/book or email love@juliasway.org

Connecting with Parents First Call

The MDSC makes First Call parent connections based on:

- Geographic area
- Ethnic background
- DADS network
- Religious background
- Similar health issues
- Primary language

For all First Call connections, please call 800.664.6372 or email firstcall@mdsc.org.

About MDSC

The Massachusetts Down Syndrome Congress (MDSC), established in 1983, is a not-for-profit organization made up of parents, individuals with Down syndrome, educators, health care providers, and others interested in gaining a better understanding of Down syndrome.

The MDSC is the premiere resource for Down syndrome information, advocacy and networking in Massachusetts. We do this through established programs and services including:

- Parents First Call
- Annual Conference
- Educator's Forum
- Buddy Walks across the state
- Advocates in Motion
- Legislative Advocacy



“For months after I was informed that my son had Down syndrome I was angry with the world. I did not know how to calm my negative feelings. Fortunately we reached out to the MDSC’s First Call Program. Kim (a First Call parent) invited us into their home, and it was then that I finally began to accept my son for who he is. Our First Call put us on the road to recovery. Meeting their daughter touched our hearts and from that moment on, I knew things would be OK.”

– New Parent (Whitman, MA)

Reach Out

When you are ready, whether you are an expectant parent or a new parent, make the MDSC your first call:

1.800.664.MDSC (6372)

You can also visit us on-line at www.mdsc.org or e-mail the Family Support Director at firstcall@mdsc.org.

Did You Know?...

- There are more than 210,000 individuals with Down syndrome in the United States
- Down syndrome occurs in approximately one in every 790 live births
- Around 80% of babies with Down syndrome are born to mothers under the age of 35
- Down syndrome affects people of all ages, races and economic levels
- Early Intervention services through the state help children with Down syndrome develop to their full potential
- Children with Down syndrome often participate in regular classrooms, learn to read and enjoy many integrated community activities
- Children with Down syndrome really are “more alike” other children than different

mdsc
Massachusetts Down Syndrome Congress



Parents First Call Program

For expectant and new parents of children with Down syndrome



www.mdsc.org | 800.664.MDSC (6372)



www.mdsc.org | 800.664.MDSC (6372)



Welcome New Parents

Congratulations! The most important thing to remember is that your baby is a baby first and is not defined by his or her diagnosis of Down syndrome. Right now there may be a lot of emphasis on how your baby may be different and possible medical problems he or she may face, but try to take things one day at a time. You will soon find that children with Down syndrome are more alike than different from other children.

And Expectant Parents

Learning that your baby has Down syndrome is an overwhelming and emotional experience for most parents. You may initially feel confused, frightened, angry, saddened, and/or isolated. We have information, resources and connections available that can help you make important decisions for your family.



“I would never be the person I am today if it wasn't for Kelly (a First Call parent) being there for my family and I as we went through the very confusing and emotional time after my daughter was born. Kelly had calming words, great information and all the encouragement I needed to just let me enjoy my new child. She was a tremendous support to us during that trying time in our lives and I treasure our friendship today. I could never thank her enough!”

– New Parent (Westport, MA)

You Are Not Alone

A dedicated group of experienced parents of children with Down syndrome are available state-wide to offer you support and information through the Parents First Call Program, sponsored by the Massachusetts Down Syndrome Congress (MDSC).

Parents First Call Program offers:

- Accurate information about Down syndrome for expectant and new families
- The opportunity to talk with other parents about your concerns and questions
- A chance to meet other children with Down syndrome and their families
- Support groups for parents, including a network specifically for fathers
- Assistance locating helpful medical and early intervention services
- Referrals to local and national resources including: books, websites and other helpful organizations
- Special support to families who have a child that will undergo heart surgery
- Access to the MDSC's full range of resources, programs, and community events



Partnering with Health Care Professionals

The MDSC partners with the Massachusetts Department of Public Health, health care providers, hospitals and other groups throughout Massachusetts to develop ways to best serve expectant and new families.

The MDSC has a Medical and Scientific Advisory Council which guides the MDSC to ensure that the MDSC membership has access to accurate up-to-date medical and scientific information and resources pertaining to Down syndrome. The Council also facilitates communication amongst health care providers and scientists in Massachusetts who are interested in working together to develop best practices in providing medical care, therapies, and research related to Down syndrome. Council members are available to present for Grand Rounds at MA hospitals on a variety of topics. Please contact the MDSC for more information.



The Boston Children's Hospital Down Syndrome Program

"The program is a place where everyone feels at home. It is a wonderful resource for parents. The topics for each meeting support the growth and development of these special children along with the families that are blessed to have them!"

— Parent of child, age 17

"This program has become an extension of our family. They have helped with our family face any obstacle our daughter may have with love and knowledge rather than fear and sadness. Without this program we and other families would be disconnected from important information, doctors, and human connections that help us move forward in a positive direction, knowing our children are getting the best care and guidance we could ever provide them."

— Parent of child, age 11

The Boston Children's Hospital Down Syndrome Program, founded in 1967, is one of the oldest and largest Down Syndrome Programs in the United States, serving as a model for programs across the US and around the world. The clinical program offers highly specialized medical services and provides individualized management of complex challenges for patients with Down syndrome through an interdisciplinary clinical approach. The program has developed innovative care coordination, family resources, and holistic programming. The Boston Children's Hospital Down Syndrome Research Program is a comprehensive research program closely aligned and integrated with clinical care in our mission to help all individuals with Down syndrome reach their fullest potential.



Clinical Care

Prenatal Consultations

Confidential prenatal consultations are provided in the Maternal Fetal Care Center for families who receive a confirmed or suspected prenatal diagnosis of Down syndrome. These consultations allow families to learn more about the diagnosis of Down syndrome, potential medical and developmental issues, and available resources. Advanced diagnostic imaging, including prenatal echocardiography and fetal MRI, is available through the Maternal Fetal Care Center as well as additional consultation with cardiology, genetics, neurology, lactation support, and other subspecialists as needed.

Comprehensive Clinical Visits

Children are seen longitudinally for comprehensive visits addressing medical and developmental issues in children, adolescents, and young adults. The Boston Children's Hospital Down Syndrome Program has expertise in the management of patients with complex medical needs and co-occurring neurodevelopmental disorders, such as Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder. Care is individualized to meet the needs of each patient and family. Extensive neurodevelopmental and behavioral assessments and carefully designed psychological testing are available to target and individualize developmental therapies and educational interventions for optimal development.

Intensive Care Coordination and Specialty Care

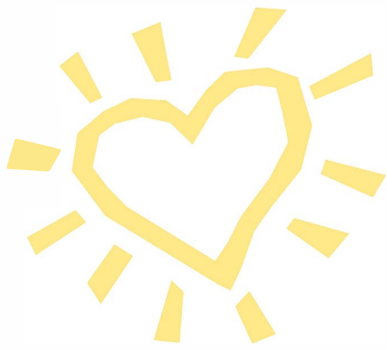
The Boston Children's Hospital Down Syndrome Program offers individualized and intensive care coordination to assist families in accessing services, appointments and resources. Care is coordinated with many of Boston Children's Hospital's top specialty programs and providers such as cardiology, neurology, gastroenterology, nutrition, sleep medicine, ophthalmology, dentistry, orthodontics, otolaryngology, audiology, and more.



**Boston
Children's
Hospital**

Where the world comes for answers





Additional Programs and Support

Beyond the clinical visit, the Boston Children's Hospital Down Syndrome Program offers unparalleled family support including resource specialist services, workshops, inclusive wellness, exercise, and yoga programs, literacy outreach, and support groups. The Boston Children's Hospital Down Syndrome Program works closely with local and national organizations, and the website houses additional patient resources including webinars through the Allen C. Crocker Speaker Series, informational guides, and educational programs.

Supporting Transition and Employment

The Boston Children's Hospital Down Syndrome Program is dedicated to preparing adolescents and young adults for successful transition to adulthood. Transition services are offered to support access to resources, adult services, and adult providers. Medical and psychological assessments and social work consultation are coordinated for those pursuing guardianship or other options.

The Boston Children's Hospital Down Syndrome Program is committed to promoting employment and job training for people with Down syndrome. In addition to employing young adults with Down syndrome, the Boston Children's Hospital Down Syndrome Program has a two-year internship program for young adults with Down syndrome to learn and practice job skills.



"To walk into the DS clinic and see Nathan contributing in such an important way is inspirational to me as a mother. I am also so happy for him as it seems like a perfect place for him to build confidence and career skills that he can build upon for the future."

— Parent of child, age 5

Research in The Boston Children's Hospital Down Syndrome Program

Research is critically needed to help improve the lives of individuals with Down syndrome. The Boston Children's Hospital Down Syndrome Research Program is a comprehensive research program that is dedicated to studying neurodevelopment and health outcomes in Down syndrome. In partnership with the Laboratories for Cognitive Neuroscience and the Translational Neuroscience Center at Boston Children's Hospital, and through involvement in the Intellectual and Developmental Disabilities Research Center (IDDRC), the Boston Children's Hospital Down Syndrome Program is engaged in cutting-edge research for individuals with Down syndrome to better understand neurobiological mechanisms of learning, memory, and behavior, to use new tools to study development, and to explore novel educational, behavioral, and medical interventions.



"Each visit to the DS clinic offered us a wonderful opportunity to ask questions, learn important information and share Hope's story with a team of professionals who truly care."

— Parent of child, age 16

CONTACT US:

Office: 857-218-4329

Fax: 617-730-0252

Website:

childrenshospital.org/programs/down-syndrome-program

Scheduling inquiries:

downsyndromescheduling@childrens.harvard.edu



Where the world comes for answers