



# The Down Syndrome Program at Boston Children's Hospital

The Down Syndrome Program offers specialized services for children with Down syndrome and their families. Program staff work closely with children, parents, medical specialists, community physicians, and educators. The program is a subspecialty service of the Developmental Medicine Center at Boston Children's Hospital.



**Boston  
Children's  
Hospital**

Until every child is well™



the **Developmental  
Medicine Center**

at Boston Children's Hospital

Institute for Community Inclusion



"Since our daughter was born, Boston Children's Down Syndrome Program has been there for our family and given us the information and support we so greatly needed. We are so grateful to the wonderful people in this program for helping us to give our daughter such a great start in life. They have given us hope for a very bright future."

—Maura,  
mother of Jennifer, age 4 1/2

## **Prenatal Diagnosis**

In collaboration with the Advanced Fetal Care Center, we offer prenatal consultation for families who receive a prenatal diagnosis of Down syndrome. These confidential appointments are held in the Advanced Fetal Care Center and offer an opportunity for families to meet with a physician from the Down Syndrome Program to learn about medical and developmental issues that may be associated with Down syndrome as well as resources in the community. Additional appointments such as cardiology, genetic counseling, or lactation support can be coordinated as needed. We can also offer prenatal connections to community supports and to parents of children with Down syndrome to learn about their personal experiences. To view a presentation "Navigating the Prenatal Diagnosis of Down Syndrome" and to learn of other prenatal supports available, please visit our website.

## **New Families**

For new families, we offer several supports. We offer an opportunity for a developmental pediatric visit to review medical issues, developmental questions, information and resources. For babies born in the Longwood medical area or hospitalized at Boston Children's Hospital, whenever feasible we offer visits from the Program Coordinator or a parent volunteer to provide support and information. For new families who would like to learn more about what to expect in the first year, please see the presentation on our website: "Your Baby's First Year: What You Should Know."

## **Infant-Toddler: Interdisciplinary Team**

The Down Syndrome Program clinic for children from 7 months to 3 years provides a comprehensive evaluation using an interdisciplinary team approach. With the exception of audiology, the interdisciplinary team convenes in clinic on Thursday mornings from 8:30-12:30. Throughout the course of the morning, each child has individual appointments with specialists in developmental pediatrics, a nutrition, physical therapy, speech-language pathology with expertise in feeding and swallowing, and dentistry. Immediately after seeing the team, the family proceeds to audiology where the child is seen by an audiologist with particular interest and experience in working with children with Down syndrome and also may go to the lab for any needed blood work. Children return for visits approximately every 8 months until around the third birthday.

## **School age: Individualized Multi-disciplinary Care**

For children age 3–21 years, we offer an individualized approach. We provide a comprehensive developmental pediatrics visit on an approximately annual



basis or more often as needed. Before scheduling the clinic visit, the Program Coordinator speaks with the family to determine each child's needs and family preferences. We can coordinate same-day appointments for other specialty care such as orthodontics, audiology, cardiology, physical therapy, ophthalmology, nutrition, etc. This is individualized for each family based on travel distances, schedules, and the child's tolerance for multiple visits in one day. We work with each family to make their visits as efficient and accommodating as possible.

### **Family Support in the Clinics**

For all of our clinics, the family is guided through the day by the Program Coordinator who is also the parent of a child with Down syndrome as well as the patient liaison who is a young adult with Down syndrome. The Program Coordinator and patient liaison provide information, resources and support as well as serving as role models and sharing their personal experiences.

### **After Clinic**

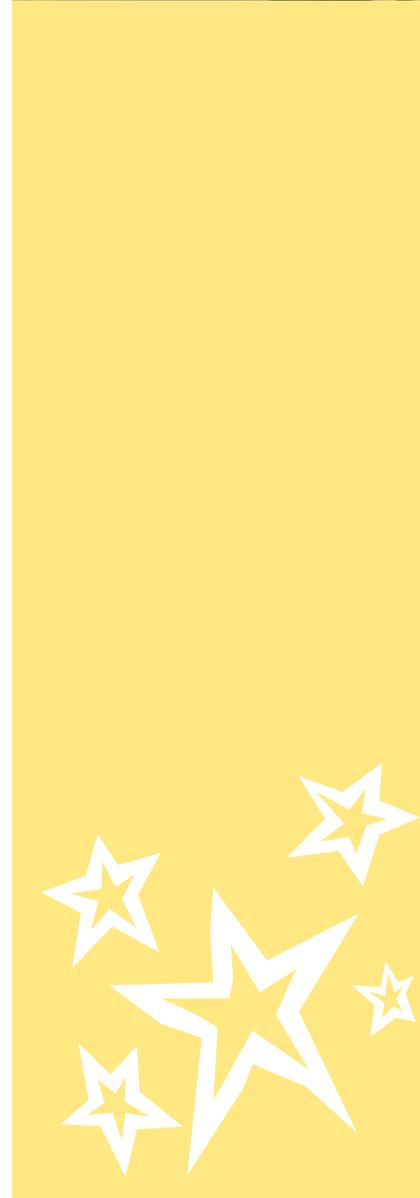
After each visit, the family and referring pediatrician receive individual reports from each of the specialists seen. Between clinic visits, the Program Coordinator and clinic providers are available for consultation by phone or email for families and referring pediatricians. We welcome questions about medical and other needs and will help find needed information and resources.

### **Specialty Care**

Boston Children's Hospital has internationally recognized care in multiple subspecialties. We work closely with physicians from departments across the hospital and we can help direct families to experts with particular interest and expertise in caring for children with Down syndrome.

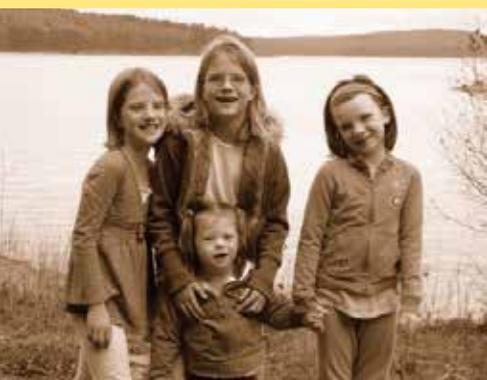
### **Allen C. Crocker Speaker Series**

The Allen C. Crocker Speaker Series provides quality information from experts on a range of topics related to Down syndrome. The series was created to provide information for families but is also relevant to providers and other community members. Talks are presented monthly at Boston Children's Hospital and are open to the public. The talks are presented monthly at Boston Children's Hospital and are open to the public. The talks are created to provide information for families but are also relevant to providers and other community members. The talks are simultaneously webcast and recorded so can be watched in real-time from anywhere with internet access (allowing remote viewers to participate in questions and answers at the end of the talk) and are archived on our website for future viewing.



“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.”

—Melissa Oddi Morrison,  
mother of Violet, age 2



## **Support Groups and Educational Workshops**

Based on family needs and interests, The Down Syndrome Program offers additional in-person supports including support groups (currently for Spanish speaking families and for families of children with complex needs), and workshops such as basic sign language and creating visual supports for learning and behavior. Upcoming events are posted on our website and facebook page and are announced by email to anyone who joins the DSP email list (email [angela.lombardo@childrens.harvard.edu](mailto:angela.lombardo@childrens.harvard.edu) to join).

## **Lending Library**

The DSP maintains a lending library of books, DVDs, videos, etc. that are available for families to borrow.

## **For Other Professionals**

### **Opportunities for Observation**

In keeping with the teaching philosophy of Boston Children's Hospital and Harvard Medical School, the Down Syndrome Program welcomes medical students, residents, and other healthcare professionals who are interested in learning more about Down syndrome. Observations can be arranged for a single day or an extended period of time based on individual interests and availabilities.

After permission has been secured from families, observers follow children with Down syndrome and their families as they come to clinic to meet various members of the interdisciplinary Down Syndrome Program team. Through this experience, observers learn more about the medical conditions associated with Down syndrome in addition to having an opportunity to engage with children with Down syndrome and their parents.

### **Pediatrician Support**

The DSP can provide supports to local pediatricians including access to current health care guidelines, consultation regarding clinical issues between visits, identifying local resources, etc. The program website has a section devoted to information for professionals. The DSP staff is also available to answer questions and to help facilitate referrals to other specialists when needed.

# Resources

## Recommendations for Families

### Initial connections:

- Begin Early Intervention (EI)
- Join Down Syndrome Program at Children's Hospital
- Connect with MDSC and Parent First Call Program
- Apply for SSI/MassHealth
- Sign up with the Department of Developmental Services

### Once you are settled a bit, you can then:

- Connect with other local parent organizations
- Connect with national organizations for information
- Participate in conferences or parent workshops

## Programs and Services

### Early Intervention (EI)

1-800-905-TIES | [www.massfamilyties.org/ei/eiwelcome.php](http://www.massfamilyties.org/ei/eiwelcome.php)

EI in Massachusetts is a statewide, integrated, developmental service available to all families of children between birth and three years of age. EI provides family-centered services that facilitate the developmental progress of children.

### Supplemental Security Income (SSI)

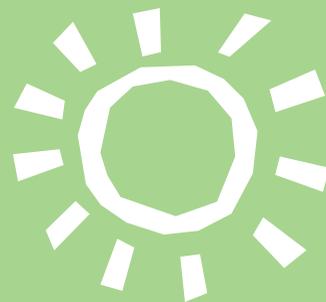
1-800-772-1213 | [www.ssa.gov/applyfordisability](http://www.ssa.gov/applyfordisability)

SSI is a federal program of the Social Security Administration that provides monthly cash benefits and automatic MassHealth coverage for a child with special medical needs. Families with low to moderate income and limited resources may be eligible for SSI.

### Medicaid: MassHealth/CommonHealth

1-888-665-9993 | [www.mass.gov/MassHealth](http://www.mass.gov/MassHealth)

The Medicaid program in Massachusetts is MassHealth. MassHealth pays for health care for certain low- and medium-income people. Some families will qualify for MassHealth Standard. Families whose income or resources exceed the limits of MassHealth Standard may be eligible for CommonHealth. CommonHealth is a state program that may charge a premium for MassHealth through a sliding fee based on income and family size.



"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."

— Rosalie Forster,  
mother of Hope, age 3

"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!"

—Nancy King,  
mother of Dylan, age 5



### **MassHealth Standard/CommonHealth Premium Assistance (MSCPA)**

1-800-862-4840

Once enrolled in MassHealth through the programs above, the child's family may be helped by MSCPA. MSCPA reimburses the employed parent his/her share of the premium for employer-based private health insurance. The reimbursement for premium payments for the family's health insurance helps to maintain health coverage for family members who are not covered by MassHealth. The private insurance coverage also remains the primary insurer for the child with disabilities.

### **Care Coordination Services**

1-800-882-1435 | [www.mass.gov](http://www.mass.gov)

The Massachusetts Department of Health offers supports through the Children and Youth with Special Health Care Needs Program. Their care coordinators can identify needs, explain range of available public benefits, identify community resources, and help families access specific programs and services for their child.

## **National Organizations**

National organizations for families of children with Down Syndrome also provide a wealth of information, support and learning opportunities, such as annual conferences. Each organization can provide informative parent packages to all new families. Call or email and request a parent package be sent to you.

### **National Down Syndrome Congress**

1-800-232-NDSC (6372) | [www.ndscenter.org](http://www.ndscenter.org)

### **National Down Syndrome Society**

1-800-221-4602 | [www.ndss.org](http://www.ndss.org)

# Massachusetts Organizations

## **Massachusetts Down Syndrome Congress (mdsc)**

1-800-664-MDSC (6372) | [www.mdsc.org](http://www.mdsc.org)

The MDSC is the preeminent organization in the state for information, networking and advocacy for and about Down syndrome. They have an annual conference, social events and other opportunities for families to come together. A wonderful part of this organization is their Parents' First Call Program, which is a volunteer network of parents who make themselves available as a resource to new families. Each new family gets a free one-year membership to the MDSC, a new parent package, and a phone call from a First Call Parent.

## **Massachusetts Department of developmental services (DDS)**

617-727-5608 | [www.mass.gov/dds](http://www.mass.gov/dds)

DDS (formerly known as the Department of Mental Retardation or DMR) offers a flexible array of supports to help families. These supports include community oriented resources, respite, special activities, and other supports. DDS provides these services through facilities and community-based state operated programs and by contracting with 235 private provider agencies.

## **ARC of Massachusetts**

781-891-6270 | [www.arcmass.org](http://www.arcmass.org)

The mission of The Arc is to enhance the lives of individuals with intellectual and developmental disabilities and their families. The state chapter provides education and advocacy while the regional chapters provide concrete services to families and individuals including early intervention, family and other types of in-home support, employment, housing, transportation and recreation.

## **Federation for Children with Special Needs (FCSN)**

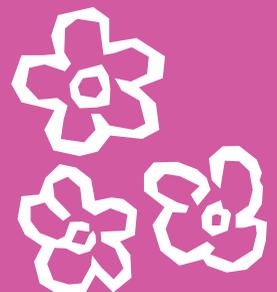
1-800-331-0688 | [www.fcsn.org](http://www.fcsn.org)

FCSN is a center for parents and parent organizations to work together on behalf of children with special needs and their families. They provide information, support, and assistance to parents of children with disabilities. They also offer free workshops about education and advocacy. This is a MUST for families of children who will be turning three soon to prepare for the transition to school.

## **Massachusetts Family Ties**

1-800-905-TIES (8437) | [www.massfamilyties.org](http://www.massfamilyties.org)

This is a statewide information and support network for families of children with disabilities. They offer information and resources, parent to parent program, workshops and conferences, and a wonderful Resource Directory. The resource directory can be obtained by mail or can be accessed online.



## **Down Syndrome Educational Trust, USA**

[www.downsed-usa.org](http://www.downsed-usa.org)

A leading research, information, and education services organization established to create new opportunities for people with Down syndrome.

## **Down Syndrome Education International**

[www.downsed.org](http://www.downsed.org)

Down Syndrome Education International is a leading international charity dedicated to raising levels of educational achievement among children with Down syndrome. They have been at the forefront of developmental and educational research and evidence-based services improving outcomes for children with Down syndrome for over 30 years.

## **Down Syndrome Research and Treatment Foundation**

[www.dsrtf.org](http://www.dsrtf.org)

A foundation whose mission is to stimulate biomedical research that will accelerate the development of treatments to significantly improve cognition for individuals with with Down syndrome.

## **Signing Times**

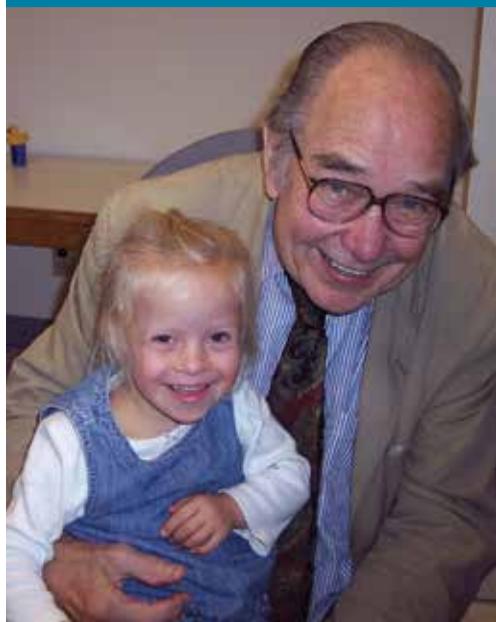
[www.signingtime.com](http://www.signingtime.com)

Signing Time products are highly recommended for families who would like to help their children learn sign language to support their communication development. We provide each new baby in our program with a complimentary Signing Time DVD (Baby Signs Volume 1).

## **Signing Savvy**

[www.signingsavvy.com](http://www.signingsavvy.com)

Most complete online American Sign Language dictionary, with several thousand videos.



Dr. Allen Crocker with Rebecca

## **For More Information:**

Angela Lombardo

857.218.4329

[angela.lombardo@childrens.harvard.edu](mailto:angela.lombardo@childrens.harvard.edu)

[childrenshospital.org/downsyndrome](http://childrenshospital.org/downsyndrome)

[www.facebook.com/bostondsp](http://www.facebook.com/bostondsp)

## **Down Syndrome Program Team Members include**

- Developmental-Behavioral Pediatrician
- Nurse Practitioner
- Physical Therapist
- Speech Pathologist/Feeding specialist
- Psychiatrist
- Psychologist
- Nutritionist
- Dentist
- Orthodontist
- Audiologist
- Research Coordinator
- Research Assistant
- Program Coordinator
- Community Case Coordinator
- Program Liaison (Parent Volunteer)
- Patient Liaison (Self Advocate)

