

# THE DOWN SYNDROME PROGRAM AT CHILDREN'S HOSPITAL BOSTON

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 Children's Hospital Boston.







### THE DOWN SYNDROME PROGRAM | CHILDREN'S HOSPITAL BOSTON

"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 APPOINTMENTS

Parents who receive a prenatal diagnosis are given an opportunity to meet and talk with a developmental pediatrician about Down syndrome (DS) and ask questions. The Down Syndrome Program Coordinator will provide materials on DS and describe support services.

#### **NEW PARENTS**

The program provides guidance and information to all new families. Parents of new babies can meet with a developmental pediatrician for a New Baby Appointment. For babies born in the Longwood Medical Area, whenever feasible parents can meet with the Program Coordinator in person before discharge home from the hospital to provide support and to connect the family with appropriate resources. Otherwise, the Program Coordinator is available to talk with families by phone and will send resource materials through the mail.

### INTERDISCIPLINARY TEAM FOR CHILDREN UNDER 3 YEARS

The program provides a clinic with interdisciplinary services to children for the important period from birth to three years of age. The program focuses on medical and developmental monitoring. The family and child meet with a team comprised of a developmental pediatrician, physical therapist, nutritionist, speech pathologist, dentist, audiologist, and the Program Coordinator. The Program Coordinator, who is also the parent of a child with Down syndrome, distributes information about state organizations, local parent groups, and community groups.

The Down Syndrome Clinic takes place on Thursdays and runs from 8:30am to 1pm. Shortly after clinic, referring physicians and families will receive reports from each individual clinician. Families may wish to share the reports with other clinicians or therapists such as their schools or Early Intervention providers.

### INTERDISCIPLINARY TEAM FOR CHILDREN 3-18 YEARS

The program offers an interdisciplinary clinic for children with Down syndrome from age 3 to 18. The multidisciplinary team for this clinic includes experts in nutrition, developmental-behavioral pediatrics and genetics. Children will be followed annually for comprehensive review of health and development and more frequently as needed for specific issues that arise in between annual visits. The Program will ensure that visits are tailored to each child's needs and also include coordination of appointments in behavioral psychology, audiology, ophthalmology, dentistry, or physical therapy as needed, to occur on the same day of clinic visit when possible.

#### PARENT SUPPORT GROUP

The Parent Coordinator facilitates a parent support group which meets one evening each month at Children's Hospital. Meetings feature different topics and speakers. Parents who attend are a diverse group with children of all different ages. Families can receive notices about upcoming meetings by adding your contact information to our print or email lists. We provide refreshments and free parking vouchers to all participants.

### **Examples of topics during past meetings:**

- · Promoting Communication Skills in Children with DS
- Toilet Training Children with DS
- · Resource and Networking Night
- Talking to Siblings and Other Children about DS
- Feeding and Swallowing in Children with DS
- DVD viewing of "DS: The First 18 Months"

The program strives to keep families updated on new materials, upcoming events, and available resources in their community. Monthly mailings or emails are sent out to keep parents connected with happenings in the Down syndrome community.

### RECOMMENDATIONS

The Down Syndrome Program team members can provide recommendations to parents who are in need of a specialist for their child. We refer families to Children's Hospital Boston specialists or services as well as specialists in other settings.

### MATERIALS ON DOWN SYNDROME

All new families receive our welcome packet that has a wealth of information on DS as well as resources in the community. We also supply parents of new babies with a complimentary copy of the book *Babies with Down Syndrome, A New Parents' Guide*.

#### LENDING LIBRARY

The program has a lending library full of current books, informational videos, and DVDs on DS and related topics. All families receive a list of available materials in the welcome packet. Materials can be borrowed for a period of time and then returned to the program.

The lending library also has the *Signing Times* DVD Collections. Families interested in enhancing their child's ability and interest in sign language are welcome to borrow one or two volumes at a time.





"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





### FOR OTHER PROFESSIONALS

### **OPPORTUNITIES FOR OBSERVATION**

In connection with the teaching philosophy of Children's Hospital Boston 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 can 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 will 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 program can provide support to local pediatricians. The program supplies pediatricians with Healthcare Guidelines for Children with Down syndrome, growth charts, and other materials as needed. Our staff is also available to provide answers or information to pediatricians who have specific questions.

## 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 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 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.masshealth.gov

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 Forstermother 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

The Massachusetts Department of Public Health offers this program to families who have special healthcare needs. 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.ndsccenter.org

### NATIONAL DOWN SYNDROME SOCIETY

1-800-221-4602 | www.ndss.org

### MASSACHUSETTS ORGANIZATIONS

### MASSACHUSETTS DOWN SYNDROME CONGRESS (MDSC)

1-800-664-MDSC (6372) | www.mdsc.org

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 (search for 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

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

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

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.





### INFORMATIONAL WEBSITES

### DOWN SYNDROME HEALTH ISSUES

www.ds-health.com

Len Leshin, MD, a pediatrician who is also the father of a son with DS, runs this informative website.

### DOWN SYNDROME EDUCATIONAL TRUST, USA

www.downsed-usa.org

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

### DOWN SYNDROME RESEARCH AND TREATMENT FOUNDATION

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.

#### SIGN LANGUAGE GUIDE

www.commtechlab.msu.edu/sites/aslweb/browser.htm Look up a word and see how to do the sign for it!

#### SIGNING SAVVY

www.signingsavvy.com

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

### **DOWN SYNDROME PROGRAM TEAM MEMBERS**

Director | EMILY JEAN DAVIDSON, MD, MPH

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Dr. Allen Crocker with Rebecca

### FOR MORE INFORMATION:

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