

# 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

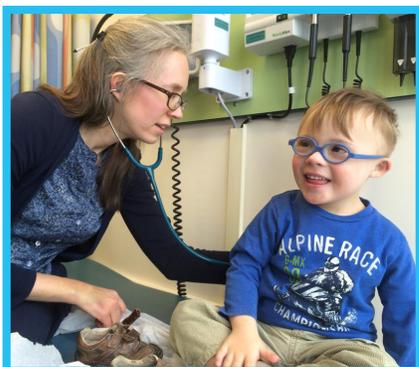
Confidential prenatal consultations are provided in the [Maternal Fetal Care Center](#) for families who receive a confirmed or suspected prenatal diagnosis of Down syndrome. These consultations allow families to learn more about the diagnosis of Down syndrome, potential medical and developmental issues, 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

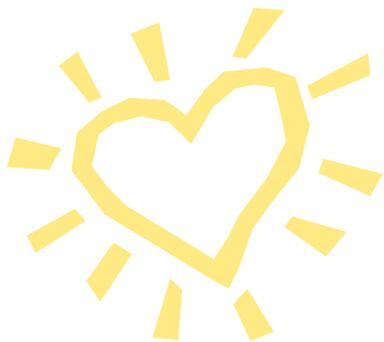
The Boston Children's Hospital Down Syndrome Program offers individualized and intensive care coordination to assist families in accessing services, appointments and resources. Care is coordinated with many of Boston Children's Hospital's top specialty programs and providers such as cardiology, neurology,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



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## 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 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:

Director: Nicole Baumer, MD, EdM

Program Coordinator: Angela Lombardo

Office: 857-218-4329 Fax: 617-730-0252

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

Scheduling inquiries: [downsyndromescheduling@childrens.harvard.edu](mailto:downsyndromescheduling@childrens.harvard.edu)

Research inquiries: [downsyndrome.research@childrens.harvard.edu](mailto:downsyndrome.research@childrens.harvard.edu)



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