Understand your pediatric patient’s Down syndrome diagnosis

Up-to-date, accurate resources that may be useful to providers who are providing services to new or expecting parents who have received a Down syndrome diagnosis.

https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html
This information is being provided pursuant to the Down Syndrome Information Act of 2018, Tenn. Code Ann. §§ 68-1-2601 et. al.
Delivering the Diagnosis

How to Deliver the News? New Advice for Doctors Diagnosing Prenatal & Postnatal Down Syndrome

ACMG statement on noninvasive prenatal screening for fetal aneuploidy
Anthony R. Gregg, MD, S.J. Gross, MD, R.G. Best, PhD, K.G. Monaghan, PhD, K. Bajaj, MD, B.G. Skotko, MD, B.H. Thompson, Md and M.S. Watson, Phd; are The Noninvasive Prenatal Screening Work Group of the American College of Medical Genetics and Genomics

National Institutes of Health (NIH)
Comprehensive resource regarding Down syndrome, screening, development and genetics and links to additional information including fact sheets in English and Spanish

Prenatal Testing & Information
The Global Down Syndrome Foundation and the National Down Syndrome Congress have teamed up to publish the second edition of the groundbreaking Prenatal Testing Pamphlet for Down syndrome, available in English, Spanish and Icelandic.

University of Kentucky, Interdisciplinary Human Development Institute (Brighter Tomorrows)
Resources for families and physicians including videos, and information on screening, diagnostic tests and evidence-based practices when delivering a diagnosis of Down syndrome

https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html
Treatment and care for pediatric patients with Down syndrome

American Academy of Pediatrics
Health Supervision Guidelines for Individuals with Down syndrome, Pediatrics, Vol 128, No.2, August 1, 2011, pp 393-406

Tennessee Early Intervention System
A voluntary educational program for families with children birth through age two with disabilities or developmental delays.

IDD Toolkit
A healthcare toolkit, supported in part by the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Grant #90DD0595, Administration on Developmental Disabilities, ACF, HHS)

Monroe-Caroll Jr. Children’s Hospital at Vanderbilt Down Syndrome Clinic
Provides comprehensive care and professional services to children and teens with Down syndrome. The clinic staff assists patients in finding therapeutic services and educational/behavioral support and providing a multidisciplinary approach to treatment.

https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html
Support and advocacy programs for children with Down syndrome

**Tennessee-Based**

**Chattanooga Down Syndrome Society**
People who have Down syndrome, their family members, and others who care about them in the Chattanooga region

**Clarksville Association for Down Syndrome**
A support network for individuals with Down Syndrome, their families, and the community in the Clarksville area.

**Down Syndrome Awareness Group of East Tennessee**
A parent-initiated organization developed to provide information and support to families of individuals with Down syndrome (DS) and to raise awareness within the community about the abilities of individuals with DS and the benefits of their inclusion into society.

**Down Syndrome Association of Memphis and the Mid-South**
An organization to support and empower individuals with Down syndrome and their families

**Down Syndrome Association of Middle Tennessee (DSAMT)**
A community of parents, grandparents, siblings, physicians, educators, professionals, friends and self-advocates from forty counties in Middle Tennessee who celebrate and support individuals with Down syndrome and their families

[Learn more >](https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html)
Down Syndrome Association of West TN
Enhances the lives of individuals with Down syndrome by providing programs and support, information, and education to those individuals, their families, professionals, and the communities that make up the West Tennessee region.

Friends Tri-Cities
Promotes community understanding and acceptance of individuals with Down syndrome in the Johnson City area

GiGi’s Playhouse
Provides free educational, therapeutic-based and career development programs for individuals with Down syndrome, their families and the community, through a replicable playhouse model

Monroe-Carroll Jr. Children’s Hospital at Vanderbilt Down Syndrome Clinic
Provides comprehensive care and professional services to children and teens with Down syndrome. The clinic staff assists patients in finding therapeutic services and educational/behavioral support and providing a multidisciplinary approach to treatment.

Vanderbilt Kennedy Center
Training and resources for clinicians, students, researchers, and educators.
National

Down Syndrome Diagnosis Network
Connect, support, and provide accurate information for families with a Down syndrome diagnosis.

Learn more >

National Down Syndrome Congress
Resources and educational materials for new and expectant parents.

Learn more >

National Down Syndrome Society
Definitions, guides, informational brochures and fact sheets available in English and Spanish.

Learn more >

Down Syndrome Adoption Network
Helps families with an adoption plan and assist families who are looking to adopt a child with Down syndrome.

Learn more >
Resources to help better educate families on their children’s diagnosis

**A Promising Future Together**

[Learn more >](https://wwwaddon.org/resources/parents/pfut/)

**An Extraordinary Life**
Guidebook for new and expecting parents published by the Down Syndrome Association of Middle Tn.

[Learn more >](https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html)

**Brighter Tomorrows**
Information for families and physicians; includes videos, printable resources, screening, diagnostic tests and evidence-based practices when delivering a diagnosis of Down syndrome.

[Learn more >](https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html)

**Diagnosis to Delivery**
Program administered by the National Center for Prenatal and Postnatal Resources at the University of Kentucky's Human Development Institute providing honest, compassionate, medically-reviewed, and informative support for those preparing for the birth of a baby with Down syndrome.

[Learn more >](https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html)

**Health Care Guidelines for Parents of Children with Down Syndrome**
Family friendly information about development from birth through adulthood that includes information about potential health concerns for which individuals with Down syndrome are at risk.

[Learn more >](https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html)

**Woodbine House**
Publisher specializing in books about children with special needs

[Learn more >](https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html)

**Healthy Children**
Information for parents about Down syndrome. This site also contains explanation of Down syndrome at a young person's level of comprehension, and includes movies, games and recipes

[Learn more >](https://www.tn.gov/content/tn/health/health-program-areas/mch-cyshcn.html)