

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.

Delivering the Diagnosis

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

[Learn more >](#)

<http://www.brianskotko.com/documents/pressreleaseajmgnprenatalarticle.pdf>

Screening & Information about 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

[Learn more >](#)

https://www.acmg.net/docs/ACMG_Policy_Statement_NIPS_May2013_GIM.pdf

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

[Learn more >](#)

<http://ghr.nlm.nih.gov/condition/down-syndrome>

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.

[Learn more >](#)

<https://www.globaldownsyndrome.org/prenatal-testing-pamphlet/>

University of Kentucky, Interdisciplinary Human Development Institute (Brighter Tomorrows)

The Lettercase National Center for Prenatal and Postnatal Resources is part of the University of Kentucky's Human Development Institute and has free online learning modules for medical professionals on screening, diagnostic tests and evidence-based practices when delivering a diagnosis of Down syndrome.

[Learn more >](#)

<https://www.lettercase.org/education/medical-professionals/>

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

[Learn more >](http://pediatrics.aappublications.org/content/128/2/393) <http://pediatrics.aappublications.org/content/128/2/393>

Tennessee Early Intervention System

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

[Learn more >](https://www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html) <https://www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html>

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)

[Learn more >](https://vkc.mc.vanderbilt.edu/etoolkit/) <https://vkc.mc.vanderbilt.edu/etoolkit/>

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.

[Learn more >](https://www.childrenshospitalvanderbilt.org/clinic/down-syndrome-clinic) <https://www.childrenshospitalvanderbilt.org/clinic/down-syndrome-clinic>

Support and advocacy programs for children with Down syndrome

Tennessee-Based

B.U.D.S Being United & Developing Support

All inclusive to any family needing a community, Down syndrome or not. Based out of Dyer County and welcomes surrounding communities.

[Learn more >](https://www.facebook.com/groups/263764497605735) <https://www.facebook.com/groups/263764497605735>

Chattanooga Down Syndrome Society

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

[Learn more >](http://www.chattanoogadownsyndrome.org/) <http://www.chattanoogadownsyndrome.org/>

Clarksville Association for Down Syndrome

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

[Learn more >](https://www.facebook.com/CADSCCommunity) <https://www.facebook.com/CADSCCommunity>

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.

[Learn more >](http://www.dsagtn.org/) <http://www.dsagtn.org/>

Down Syndrome Association of Memphis and the Mid-South

An organization to support and empower individuals with Down syndrome and their families

[Learn more >](http://www.dsamemphis.org/) <http://www.dsamemphis.org/>

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 >](http://www.somethingextra.org/) <http://www.somethingextra.org/>

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.

[Learn more >](http://www.dsawt.com/) <http://www.dsawt.com/>

Friends Tri-Cities

Promotes community understanding and acceptance of individuals with Down syndrome in the Johnson City area

[Learn more >](http://www.dsfriends.net/) <http://www.dsfriends.net/>

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

[Learn more >](https://gigisplayhouse.org/nashville/) <https://gigisplayhouse.org/nashville/>

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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.

[Learn more >](https://www.childrenshospitalvanderbilt.org/clinic/down-syndrome-clinic) <https://www.childrenshospitalvanderbilt.org/clinic/down-syndrome-clinic>

Vanderbilt Kennedy Center

Training and resources for clinicians, students, researchers, and educators.

[Learn more >](https://vkc.mc.vanderbilt.edu/vkc/) <https://vkc.mc.vanderbilt.edu/vkc/>

National

Down Syndrome Diagnosis Network

Connect, support, and provide accurate information for families with a Down syndrome diagnosis

[Learn more >](https://www.dsdiagnosisnetwork.org/) <https://www.dsdiagnosisnetwork.org/>

National Down Syndrome Congress

Resources and educational materials for new and expectant parents.

[Learn more >](http://ndscenter.org/) <http://ndscenter.org/>

National Down Syndrome Society

Definitions, guides, informational brochures and fact sheets available in English and Spanish.

[Learn more >](http://www.ndss.org/) <http://www.ndss.org/>

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 >](https://www.somethingextra.org/siteDSAMT/assets/File/NDSA-AdoptionBooklet.pdf) <https://www.somethingextra.org/siteDSAMT/assets/File/NDSA-AdoptionBooklet.pdf>

Resources to help better educate families on their children's diagnosis

A Promising Future Together

A Guide for new and expecting parents published by the National Down Syndrome Society.

[Learn more >](http://www.ndss.org/wp-content/uploads/2017/11/NDSS-NPP-English.pdf) <http://www.ndss.org/wp-content/uploads/2017/11/NDSS-NPP-English.pdf>

An Extraordinary Life

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

[Learn more >](https://www.somethingextra.org/siteDSAMT/assets/File/DSAMT%20New%20Parent%20Book%2017%20-%20Final.pdf) <https://www.somethingextra.org/siteDSAMT/assets/File/DSAMT New Parent Book 17 - Final.pdf>

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 >](http://www.brightertomorrows.org/) <http://www.brightertomorrows.org/>

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 >](http://downsyndromepregnancy.org/) <http://downsyndromepregnancy.org/>

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.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx) <https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx>

Woodbine House

Publisher specializing in books about children with special needs

[Learn more >](http://www.woodbinehouse.com/) <http://www.woodbinehouse.com/>

Kids Health

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 >](http://kidshealth.org/parent/medical/genetic/down_syndrome.html) http://kidshealth.org/parent/medical/genetic/down_syndrome.html