

# 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.

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# Delivering the Diagnosis

## **Delivering the Diagnosis**

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

[Learn more >](http://www.brianskotko.com/documents/pressreleaseajmgprenatalarticle.pdf) <http://www.brianskotko.com/documents/pressreleaseajmgprenatalarticle.pdf>

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# 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) [https://www.acmg.net/docs/ACMG\\_Policy\\_Statement\\_NIPS\\_May2013\\_GIM.pdf](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) <http://ghr.nlm.nih.gov/condition/down-syndrome>

## **Prenatal Testing & Information**

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

[Learn more >](https://www.globaldownsyndrome.org/prenatal-testing-pamphlet/) <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/) <https://www.lettercase.org/education/medical-professionals/>

# Treatment and care for pediatric patients with Down syndrome

## **American Academy of Pediatrics**

Health Supervision for Children and Adolescents With Down syndrome, Volume 149, Issue 5, May 2022 e2022057010

[Learn more >](#)

<https://publications.aap.org/pediatrics/article/149/5/e2022057010/186778/Health-Supervision-for-Children-and-Adolescents>

## **American Medical Association**

Medical Care of Adults With Down Syndrome: A Clinical Guideline JAMA. 2020;324(15):1543-1556. doi:10.1001/jama.2020.17024

[Learn more >](#)

<https://jamanetwork.com/journals/jama/fullarticle/2771907?guestAccessKey=821dfafe-2109-4af9-be04-4dd2b4f51ea2>

## **Tennessee Early Intervention System**

A voluntary educational program for families with children birth up until age 3 with disabilities or developmental delays.

[Learn more >](#)

<https://www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html>

## **IDD Toolkit**

A website hosted by the Vanderbilt Kennedy Center to give primary care providers electronic access to best practice tools enabling physicians to more readily serve adults with intellectual or other developmental disabilities.

[Learn more >](#)

<https://iddtoolkit.vkcsites.org/>

## **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>

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# 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>

### **The Down Syndrome Community of Greater Chattanooga (DSCGC)**

Made up of 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**

To educate and create a support network for individuals with Down Syndrome, their families, and the community.

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

### **Down Syndrome Awareness Group of East Tennessee**

Bringing families and professionals together through support and information about Down syndrome.

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

### **Down Syndrome Association of Memphis & the Mid-South**

Promotes the inclusion of all people with Down syndrome by providing families and our communities with up-to-date information and education. To that same end, we strive to foster positive attitudes and enhance public awareness within our society of the inherent worth, value and contributions of people with Down syndrome.

[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 serving East Tennessee and Southwest Virginia.

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

## **GiGi's Playhouse**

Provides free programs that are educational and therapeutic in nature to individuals with Down syndrome from birth through adulthood, their families and the community.

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

## **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>

## **Vanderbilt Kennedy Center**

To facilitate discoveries and best practices to improve the lives of persons with developmental disabilities and their families.

[Learn more >](https://vkc.vumc.org/vkc/) <https://vkc.vumc.org/vkc/>

# National

## Black Down Syndrome Association

Connects Black families in the Down Syndrome community with resources to improve their lives in a more meaningful way by addressing the many inequalities present that increase barriers to access, support, and education.

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

## The Brett Boyer Foundation

Organization which raises awareness and provides funding to further research in the area of Congenital Heart Disease (CHD) for individuals with and without Down syndrome.

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

## 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/>

## Global Down Syndrome Foundation

A network of affiliate organizations that work closely together to improve the lives of people with Down syndrome through Research, Medical Care, Education, and Advocacy.

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

## Lumind Down Syndrome Foundation

Accelerates Down syndrome research to increase availability of therapeutic, diagnostic, and medical care options and we empower families through education, connections, and support.

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

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

## **An Extraordinary Life**

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

[Learn more >](#)

<https://www.somethingextra.org/resources/new-expecting-parents/an-extraordinary-life-guidebook-for-new-and-expecting-parents/>

## **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/>

## **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>

## **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)

## **Lettercase Prenatal and Postnatal Resources**

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.lettercase.org/>

## **DSC2U: A Personalized Care Plan**

DSC2U is a way for families to get up-to-date, personalized health and wellness information for their loved one with Down syndrome.

[Learn more >](#)

<https://www.dsc2u.org/>