

Down Syndrome

TIPS AND RESOURCES FOR FAMILIES



What causes Down syndrome?

Individuals with Down syndrome usually have an extra copy of chromosome 21. Although some cases may have a slightly different cause, all cases involve chromosome 21. Down syndrome occurs in about 1 in every 700 to 1,000 births. The chance of giving birth to a baby with Down syndrome increases if the mother is over 35 years old. Down syndrome affects both males and females of all ethnic and socioeconomic backgrounds. It is the most prevalent chromosomal cause of intellectual disability, and most cases are not familial (heritable).

What are the effects of Down syndrome?

Down syndrome results in higher-than-normal risks for many medical conditions, most notably congenital heart disease (most correctable by surgery), hearing and vision impairments, gastrointestinal problems, leukemia, and Alzheimer's disease. It is characterized by an expected life span (55 to 60 years on average) that, although shorter than the general population, has quintupled over the last century. Persons with Down syndrome should see a physician to monitor these medical conditions.

Individuals with Down syndrome have distinctive cognitive, language, and behavioral profiles. In general, they have higher levels of adaptive behavior (e.g., self-care, getting along with others) than of intelligence. For most persons with the syndrome, expressive language, grammar, and speech articulation are particularly challenging. Most individuals are able to function successfully in integrated school, living, and work environments.

Can Down syndrome be treated?

Early intervention is the best treatment for young children with Down syndrome. Children should begin physical therapy and developmental education as soon as possible. With appropriate supports, students with Down syndrome can be educated in general education classrooms with typically developing peers. High-quality early intervention, education, and supports for work and community living enable most individuals with Down syndrome to live long, productive lives.

What are the special needs of my family?

Family supports are helpful. Membership in organizations such as a local Down Syndrome Association chapter or The Arc helps families connect with others facing similar issues across the life span. Training programs are available to help parents understand special education law and to become effective advocates for their children. Support groups may be helpful to siblings or other family members. A broad range of adult community services are available, including centers for independent living and self-advocacy programs.

Please see reverse for resources.



Down Syndrome

RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center** (VKC) works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers. Contact vkc.vumc.org, (615) 322-8240, toll-free (866) 936-8852.

Down Syndrome Clinic

The Monroe Carell Jr. Children's Hospital at Vanderbilt offers a clinic for children referred by their primary care provider. The Clinic provides comprehensive medical care that includes a variety of specialty services. A Vanderbilt Kennedy Center social worker meets with families to provide information about related therapeutic and educational services. Contact (615) 343-3696 or toll-free (866) 900-3696.

Next Steps at Vanderbilt University

Individualized, inclusive 4-year program of postsecondary study for persons ages 18-26 with intellectual disabilities on the Vanderbilt campus. Contact NextSteps@vanderbilt.edu or (615) 322-3978.

Vanderbilt Kennedy Reading Clinic

This clinic provides intensive, evidence-based instruction and assessment for students in kindergarten through middle school. Contact readingclinic@vumc.org or (615) 936-5118.

Sibling Programs

Support for siblings who have a brother or sister with a disability, chronic health care issue, or mental health concern. *SibSaturdays*, ages 5 to 12 and *Tennessee Adult Brothers and Sisters* (TABS), ages 18+. Contact info.tabs@vumc.org.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has more than 3,000 agencies searchable by Tennessee county and

service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Two Easy Ways to Take Part in Research

Babies, children, and adults, with and without disabilities, are invited to participate in studies. We provide two ways to find out about such opportunities. **StudyFinder** is a searchable database that lists current VKC studies, including autism research; see vkc.vumc.org/studyfinder/. **ResearchMatch** is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, you will be contacted if you're a possible match for the research study. See www.researchmatch.org.

Best Buddies

Best Buddies Colleges, an international organization, pairs people with intellectual disabilities in one-to-one friendships with college students. For chapter, see <https://anchorlink.vanderbilt.edu/organization/bestbuddiesvandymed>

Other Resources

- Down Syndrome Association of Middle Tennessee, www.somethingextra.org, (615) 386-9002.
- Health Library, Jr. League Family Resource Center, Monroe Carell Jr. Children's Hospital at Vanderbilt www.vanderbiltchildrens.com/healthlibrary
- International Mosaic Down Syndrome Association www.imdsa.org, 1-888-IMDSA-21
- KidsHealth information for kids, teens, and parents www.kidshealth.org
- National Down Syndrome Congress www.ndsccenter.org, (800) 323-6372
- National Down Syndrome Society
Tennessee chapters: Chattanooga, East Tennessee, Memphis and Mid-South, Middle Tennessee, plus other affiliated organizations. www.ndss.org, (800) 221-4602
- The Arc US, www.thearc.org, (800) 433-5255
- The Arc Tennessee, www.thearctn.org, (800) 835-7077 or (615) 248-5878. See also Tennessee chapters.
- STEP (Support & Training for Exceptional Parents) www.tnstep.org, (800) 280-STEP
- Tennessee Developmental Disabilities Network www.tennddnetwork.org

