

DOWN SYNDROME

T I P S A N D R E S O U R C E S



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 information about Vanderbilt Kennedy Center programs.



DOWN SYNDROME

HOW WE CAN HELP

Who We Are and Who We Serve

The Vanderbilt Kennedy Center works with and for people with disabilities and family members, service providers and advocates, researchers and policy makers. It is one of only eight centers in the nation to be both a University Center for Excellence in Developmental Disabilities Education, Research and Service and a national Developmental Disabilities Research Center. The following are some of the ways the Center's programs and staff can assist families.

Explorers Unlimited Academic Camp

This camp is a summer day program for students with Down syndrome. The Camp involves activities that promote academic and social development. It is jointly sponsored with the Down Syndrome Association of Middle Tennessee, the Frist Center for Visual Arts, and University School of Nashville. Contact kccamps@vanderbilt.edu, (615) 322-8529 x3.

Camp Shriver Transitions and Sports Camp

Camp Shriver provides opportunities for adolescents and young adults with developmental disabilities to practice skills needed to prepare for life after school. Contact kccamps@vanderbilt.edu, (615) 322-8529 x3.

SibSaturdays

SibSaturdays provide siblings who have a brother or sister with a disability with the opportunity to play games, meet friends, and participate in group discussions. Contact (615) 936-5188, UCEDD@vanderbilt.edu.

Vanderbilt Kennedy Reading Clinic

This clinic provides intensive, systematic, evidence-based tutoring and assessment for students in kindergarten and early elementary grades, including students with Down syndrome. Contact (615) 936-5123, readingclinic@vanderbilt.edu.

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. A clinic for adults also is available. Contact (866) 900-3696, (615) 343-3696.

Vanderbilt Bill Wilkerson Center

This Center offers a variety of pediatric speech-language assessment and treatment programs. Contact (615) 936-5000, vbwc.info@vanderbilt.edu.

Best Buddies

Best Buddies Colleges, an international organization, pairs people with intellectual disabilities in one-to-one friendships with college students. For chapter, see www.vanderbilt.edu/bestbuddies.

Family Outreach Center

This center provides families with a single point of entry into the many services and supports of the Vanderbilt Kennedy Center, Vanderbilt University, and the community, including research projects, clinics, social work services, and recreational and arts programs. Contact familyoutreach@vanderbilt.edu, (615) 936-5118

Taking Part in Research—StudyFinder

Research on Down syndrome is a Vanderbilt Kennedy Center priority. Representative topics include early communication, speech processing, adolescents and their families, and siblings. The StudyFinder website lists studies. It tells you what you would be asked to do if you choose to take part. See www.kc.vanderbilt.edu/studyfinder, (615) 936-0448.

Tennessee Disability Pathfinder

Pathfinder provides free phone, web, and print resources in English and Spanish that connect the Tennessee disability community with service providers and resources. It is a project of the Vanderbilt Kennedy Center and the Tennessee Council on Developmental Disabilities. See www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636

Other National and Local Resources

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.com, (888) 637-5465 or (979) 828-4177

KidsHealth information for kids, teens, and parents www.kidshealth.org.

National Down Syndrome Congress, www.ndscenter.org, (800) 323-6372

National Down Syndrome Society, www.ndss.org, (800) 221-4602
Tennessee chapters: Chattanooga, East Tennessee, Memphis and Mid-South, Middle Tennessee, plus other affiliated organizations

The Arc US, www.thearc.org, (301) 565-3842

The Arc of Tennessee, www.thearc.org, (800) 835-7077, (615) 248-5878. See also Tennessee chapters.

STEP (Support & Training for Exceptional Parents), www.tnstep.org, (800) 280-7837, (423) 639-0125

Tennessee Developmental Disabilities Network, www.tennddnetwork.org

Please see reverse for facts about Down syndrome.

Contact the Vanderbilt Kennedy Center
Nashville (615) 322-8240
Toll-Free (866) 936-VUKC [8852]
kc@vanderbilt.edu

