

CHARGE Syndrome

TIPS AND RESOURCES FOR FAMILIES



What causes CHARGE syndrome?

CHARGE syndrome is thought to be caused by a mutation in the gene CHD7 on chromosome #8. It occurs in 1 out of every 10,000 births and is not thought to be inherited. CHARGE syndrome affects males and females at equal rates and has been diagnosed in all ethnicities and socioeconomic backgrounds.

What are the effects of CHARGE syndrome?

While every individual is unique in how they look and act, people with CHARGE syndrome have some traits in common. They may have some or all of these characteristics, which include:

- Coloboma of the eye and possible vision loss

- Missing or decreased sense of smell, touch, pain, or balance
- Swallowing difficulties
- Short, wide ear with little or no lobe
- Hearing loss
- Heart defects
- Cleft lip or cleft palate
- Short stature
- Low muscle tone
- An exceptional ability to learn and to retain information
- A determined nature

Can CHARGE syndrome be treated?

Any medical issues that arise should be monitored closely by physicians. Children with CHARGE syndrome may require multiple surgical interventions. The most common is to treat congenital heart defects.

While there is currently no cure for CHARGE Syndrome, individuals will benefit greatly from early intervention. While developmental delays are common, involvement in physical, occupational, and speech therapies will assist many children with CHARGE syndrome in reaching their developmental potential. Some individuals with CHARGE may be diagnosed with an intellectual disability, but many will not. Children with CHARGE syndrome will benefit from special education services.

Please see reverse for resources.



CHARGE 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.

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 over 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

The Vanderbilt Kennedy Center serves families through research studies. StudyFinder is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See kc.vanderbilt.edu/studyfinder, (615) 936-0448. Research Match is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

Contact the Vanderbilt Kennedy Center
Nashville (615) 322-8240
Toll-Free (866) 936-VUKC [8852]
Web: vkc.vumc.org
Email: kc@vumc.org

Other Resources

• CHARGE Syndrome Foundation

The Foundation provides support to individuals with CHARGE syndrome and their families, gathers, develops, and distributes information about CHARGE syndrome, and to promote awareness and research. (800) 442-7604

www.chargesyndrome.org/index.asp

• CHARGE Syndrome Listserv

An online forum for individuals with CHARGE syndrome, family members, caregivers, medical professionals, therapists, or anyone interested in CHARGE Syndrome.

<http://health.groups.yahoo.com/group/CHARGE/>

• Genetic and Rare Diseases Information Center

A collaborative effort of two agencies of the National Institutes of Health, The Office of Rare Diseases Research, and the National Human Genome Research Institute to help people find useful information about genetic conditions and rare diseases.

<http://rarediseases.info.nih.gov/GARD/>

• The Arc US is the world's largest grassroots organization of and for people with intellectual and developmental disabilities. (301) 565-3842

www.thearc.org

• The Arc Tennessee

(800) 835-7077 (615) 248-5878

www.thearctn.org

• Tennessee's Early Intervention System (TEIS)

TEIS is a voluntary educational program for families with children ages birth through two years of age with disabilities or developmental delays. (800) 852-7157

tn.gov/education/teis

• Tennessee Division of Special Education

The Division's purpose is to promote educational services and programs for all Tennessee's children with special education needs that will enable them to lead productive and independent lives. (888) 212-3162 www.tn.gov/education/spced/

• Health Library, Jr. League family Resource Center, Monroe Carrell Jr. Children's Hospital at Vanderbilt, www.vanderbiltchildrens.com/healthlibrary

