

# 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, educators and service providers, researchers, students, and policy makers. Faculty and staff engage in interdisciplinary research, training, service, and information dissemination and work in collaboration with local, state and national networks and partners. (615) 322-8240, toll-free (866) 936-8852, [vkc.vumc.org](http://vkc.vumc.org)

### Tennessee Disability Pathfinder

Provides free information, referral sources, and help with navigating services via phone, email, and website. Assistance is available to individuals of all ages, all types of disabilities, and all languages spoken. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and is partially funded by Tennessee Council on Developmental Disabilities and other state agencies. (615) 322-8529, toll-free (800) 640-4636, [DisabilityPathfinder.org](http://DisabilityPathfinder.org)

### Two Easy Ways to Take Part in Research

StudyFinder is a searchable database that lists current VKC studies. Studies seek people of all ages with and without developmental disabilities. See [vkc.vumc.org/studyfinder](http://vkc.vumc.org/studyfinder). Research Match is a secure place for volunteers and researchers to connect. See [researchmatch.org](http://researchmatch.org)

### Contact the Vanderbilt Kennedy Center

**Nashville (615) 322-8240**  
**Toll-Free (866) 936-VUKC [8852]**  
[vkc.vumc.org](http://vkc.vumc.org)  
[kc@vumc.org](mailto:kc@vumc.org)

### Local and National 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](http://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](http://www.thearc.org)

- **The Arc Tennessee**

(800) 835-7077 (615) 248-5878  
[www.thearctn.org](http://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 [www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html](http://www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html)

- **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/student-support/special-education.html](http://www.tn.gov/education/student-support/special-education.html)

- **Health Library, Jr. League family Resource Center, Monroe Carell Jr. Children's Hospital at Vanderbilt,** [www.vanderbiltchildrens.com/healthlibrary](http://www.vanderbiltchildrens.com/healthlibrary)

