



Contact Us

For additional support and information, contact the CHARGE Syndrome Foundation at info@chargesyndrome.org



318 Half Day Rd. #305
Buffalo Grove, IL 60089
Office (516) 684-4720
Toll-Free (800) 442-7604
Fax (888) 317-4735
info@chargesyndrome.org
© 2021 CHARGE Syndrome Foundation

 CHARGE Syndrome Foundation
 @charge_syndrome_foundation
 @chargesyndrome

A better world for people with CHARGE syndrome.

The CHARGE Syndrome Foundation champions the lifelong potential of people with CHARGE syndrome through outreach, education and research.



What Is CHARGE Syndrome?

CHARGE is a complex genetic syndrome that is often obvious at birth due to the combination of physical and medical features. It also affects multiple sensory systems: vision, hearing, vestibular, olfactory, tactile, and proprioceptive.

Some of the Most Common Features of CHARGE Syndrome Include:

- Coloboma of the eye (iris, lens, optic nerve, and /or retina); vision loss
- Choanal atresia/stenosis and/or cleft lip/palate
- Cranial nerve abnormalities
 - Absent or decreased sense of smell
 - Facial palsy
 - Feeding and swallowing difficulty
- Ear abnormalities
 - External ear shape
 - Middle and inner ear anatomy
 - Absent or abnormal semicircular canals
 - Sensorineural and/or conductive hearing loss
- Neurodevelopmental challenges
- Tracheal or esophageal anomalies
- Airway obstruction
- Congenital heart defects

Developmental Features of CHARGE Syndrome Include:

- Challenging behaviors
- Psychiatric and social-emotional issues
- Anxiety
- Sleep disturbances
- Difficulties with identification and management of pain



What Causes CHARGE Syndrome and What Is Its Prevalence?

- CHARGE is a genetic condition most often caused by pathogenic variants in the *CDH7* gene.
- CHARGE occurs in about 1 in 12,000 births.
- Although it is most often sporadic, a number of families with more than one affected individual have been identified.



Understanding CHARGE Syndrome

- CHARGE is a medically and developmentally complex condition. Successful management of these challenges requires partnership between the individual, their family, and medical, therapeutic, and educational providers.
- There are many other conditions with features that overlap with CHARGE. Evaluation by a clinical geneticist and lab tests can help determine which condition is present.
- The CHARGE Syndrome Foundation provides support and resources to parents, professionals, and people with CHARGE syndrome. In addition, the Foundation's local, national, and international partners provide an array of services to assist the CHARGE syndrome community.