

Symptoms or Behaviors

Sensory impairments
(vision, hearing)

Heart defects (often
complex and difficult to
correct)

Cleft lip or palate

Tracheo-esophageal
(TE) fistula or
esophageal atresia

Genital abnormalities

Kidney problems

Characteristic face

Hockey-stick hand
crease

Developmental delays

Low muscle tone

Vestibular
system/balance
impairments

Skeletal anomalies

Sensory integration
difficulties

Revised 2012

About the Disorder

CHARGE syndrome is a complex genetic condition seen in about 1 in 10,000 births. The name “CHARGE” is an acronym stemming from some of the features seen in many children with CHARGE: **C**oloboma, **H**ear, **A**tresia of the choanae, **R**etardation of growth and development, **G**enito-urinary, **E**ar anomalies and hearing loss.

CHARGE syndrome is no longer diagnosed using the acronym features. A diagnosis of CHARGE syndrome is made using **Major** and **Minor** clinical features or by finding a mutation in the CHD7 gene. CHARGE syndrome is a genetic condition most often caused by a new change (mutation) in the CHD7 gene on chromosome #8. It is usually sporadic, with no other affected family members. It is found in every ethnic group all over the world.

Major features of CHARGE syndrome are:

Coloboma: Coloboma is a cleft of the eyeball. It can result in a keyhole-shaped pupil (iris coloboma) and/or abnormalities in the retina or optic nerve. Colobomas of the retina or optic nerve can cause vision loss or blindness.

Choanal atresia or stenosis: a blockage or narrowing of the airway from the back of the nose to the throat. Many individuals with CHARGE also have apnea or other breathing problems.

Cranial nerve abnormalities. Most individuals with CHARGE syndrome have abnormalities of the cranial nerves (nerves for the head and neck), especially facial palsy (partial paralysis of the facial muscles), swallowing difficulties, and decreased or absent sense of smell. The swallowing problems can be severe and require tube feeding for many years to get adequate nutrition and avoid aspiration pneumonia.

Characteristic CHARGE ears: Most individuals with CHARGE syndrome have unusually formed ears. They are often short, wide (cupped) ears with little or no earlobe. Sometimes the outer fold is missing. They are often very floppy. Most people with CHARGE syndrome have **hearing loss**, ranging from mild to profound and inner ear problems leading to **poor balance**.

Other features of CHARGE syndrome may include growth deficiency, poor upper body strength, sleep difficulties, and typical behaviors (perseverative behavior, obsessive-compulsive disorder).

Recommended Educational Considerations

Communication

Most children with CHARGE have both vision loss and hearing loss (dual sensory impairment: Deaf-blindness). Most benefit from a **total communication** approach. Total communication means incorporating anything and everything: gestures, simple signs, print/Braille, facial expression, symbols, and PECS (Picture Exchange Communication System) in addition to speech and sign language. The modes for each child are highly individualized and the entire team (including the family) needs to participate in developing and consistently instituting the plans.

Impact of Sensory Loss

It is important for the team to take careful notice of the functional vision of the child as well as the hearing loss, the impact of hearing loss on communication and the total effects on day-to-day functioning. Consultation with vision and hearing specialists and/or DeafBlind teacher can be helpful in determining appropriate accommodations.

Instructional Strategies & Classroom Accommodations

- Provide a comfortable structure and routine; prepare for transitions and changes in schedule
- Develop an organizational system with materials and approach to tasks (Left to Right, Top to Bottom), including checklists, assignment logs, coded folders, etc.
- Initially focus on successful, functional activities that are motivating to the student
- Break tasks into smaller steps
- Provide multi-modal sensory input, such as verbal/auditory/visual cues
- Provide breaks during and between activities
- Modify the curriculum to meet the unique needs of student
- Provide strategies to prevent/deal with sensory overload and stress
- Allow opportunities for student choices

Note: Document all accommodations on the student's IEP

Resources

CHARGE Syndrome Foundation, Inc.

Phone: (516) 684-4720
800-442-7604 (families)
Email: info@chargesyndrome.org
<http://www.chargeysndrome.org>

Minnesota DeafBlind Technical Assistance Project

<http://www.dbproject.mn.org/education.html>

American Speech-Language Association (ASHA)

www.asha.org/Publications/leader/2006/.../f061017a.htm

Minnesota Low Incidence Projects

<http://www.mnlowincidenceprojects.org/pi.html>