

CHARGE SYNDROME

What is it?

CHARGE syndrome is a genetic disorder with a pattern of co-occurring birth defects affecting a child's physical, sensory, and behavioral needs. CHARGE is an abbreviation for several of the common features of this complex syndrome, some of which are distinctive at birth: Coloboma ocular (a slit or groove in one of the structures of the eye causing vision loss), Hear defects, Atresia of the choanae (blocked nasal passage), Restriction of growth and development, Genitourinary abnormalities, and Ear and hearing abnormalities. CHARGE syndrome affects multiple organ systems and life-threatening cardiac and respiratory complications can occur at birth. Other characteristics are not apparent until the child develops. CHARGE can be the cause of multi-sensory impairment including pain, vision, hearing, touch, temperature, smell, taste, and balance. A child's intellectual ability is often underestimated because of their difficulties communicating.

What are the characteristics or complications?

Characteristics of CHARGE syndrome can greatly differ between children. The signs and symptoms are highly variable and mimic those of similar conditions. In addition to the CHARGE mnemonic, other major diagnostic criteria exists.

Major characteristics	Small eyes, narrowed or blocked nasal passage, swallowing problems, mild to profound hearing loss, facial paralysis, unusually shaped ears, affected sense of smell
Minor characteristics	Heart defects, slow growth, cleft lip/palate, developmental delay, tracheoesophageal fistula, delayed or absent puberty, square face, abnormal facial symmetry
Physical	Fatigue and sleep deprivations, digestive problems, pain, balance, self-regulating (resting when tired), low muscle tone, poor tongue movement
Behavioral	OCD, ADHD, characteristics of ASD, sleep disturbances



NIH: U.S. National Library of Medicine, CHARGE syndrome



Kennedy Krieger Institute

The Specialized Health Needs Interagency Collaboration (SHNIC) program is a collaborative partnership between the Kennedy Krieger Institute and the Maryland State Department of Education.

Suggested school accommodations

Most children with CHARGE syndrome experience some degree of development disability related to the dual sensory impairment of deaf blindness. This combination of hearing and vision loss does not mean total hearing or vision loss as residual hearing and/or vision remains. PT/OT/SLP and hearing/vision evaluations should be considered. The following information could aid the team in developing a 504/IEP to meet the student's unique needs.

Behavioral	Obsessive-compulsive behavior, tantrums, outburst, difficulty sharing, difficulty seeing other points of view, executive function disorders
Communication	Hearing and vision impairments; consider size and font; incorporate their use of gestures, signs, symbols, drawings; assistive technology; repeat signs often in natural communication; encourage sharing for peer interactions; keep daily schedule; slow down, repeat; extra adult support
Teaching	Organizational strategies and aids, communicate clear expectations, use motivating materials, offer choices, incorporate active and passive learning, maintain predictable schedules and routines, pause time for response
Environment	Need sensory breaks, flexible schedule, offer a rest area, know behavior "signs" when break is needed
Training	Peer support, staff education/training, Emergency Evacuation Plan (EEP)

Specific health issues for Individualized Healthcare Plan

- Diagnosis including all characteristics
- Nutrition orders
- Feeding protocol and/or supervision required
- Feeding tube orders for use and replacement, if applicable
- Catheterization orders including size and type, times, position
- Baseline cardiac assessment with parameters
- Rest breaks
- Safety restrictions regarding balance
- Supervision for hallways, stairs, transitions, etc.
- Communicate with school staff, parents/guardian, and provider any changes or concerns about the disease
- Emergency Care Plan(s) (ECP) related to medical needs in the school setting and staff education/training as appropriate for each

Resources & Manuals

National Institute of Health: U.S. National Library of Medicine– CHARGE syndrome
<https://ghr.nlm.nih.gov/condition/charge-syndrome>

The CHARGE Syndrome Foundation
<https://www.chargesyndrome.org/>

Perkins School for the Blind– CHARGE syndrome teaching strategies for children
<https://www.perkinslearning.org/videos/webcast/charge-syndrome-teaching-strategies-children>