

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. Infants also face life threatening cardiac and respiratory complications. CHARGE syndrome is the leading cause of deaf-blindness at birth. A child's intellectual ability is often underestimated because of their difficulties communicating. Things like low tone, breathing difficulties, and poor spatial and body awareness can make speech or even manual signing difficult.

Although a genetic disorder, a diagnosis is made after assessing minor and major clinical characteristics. In 1981, the below 6 anomalies were identified. Today, there are up to 38 anomalies that further include cranial nerves affecting vision, smell, balance and swallowing, as well as sleep apnea, seizures, skeletal anomalies and cleft lip and palate.

C: Coloboma of the eye
(hole in one of the eye structures)

H: Heart defects

A: Atresia of choanae
(blockage of nasal passage)

R: Retardation of growth
and or development

G: Genital and/or urinary
abnormalities

E: Ear abnormalities



Multi-sensory impaired

Vision • Hearing • Touch • Temperature • Pain • Smell
• Taste • Proprioception • Vestibular

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
- TE Fistula
- Delayed/absent puberty
- Square face
- Abnormal facial symmetry

Physical problems

- Fatigue and sleep deprivations
- Digestive problems
- Pain
- Balance
- Self regulating (resting when tired)
- Low muscle tone
- Poor tongue movement

Suggested school accommodations

Behavior problems

- 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
- 1:1 support as needed

Environment

- Need sensory breaks, flexible schedule
- Offer a rest area
- Know behavior “signs” when break is needed
- Can be distracted by noise, glare, too much light
- Offer preferential seating and/or adapted furniture

Teaching

- Organizational strategies and aids
- Communicate clear expectations
- Use motivating materials
- Give choices
- Incorporate active and passive learning
- Keep predictable schedules and routines
- Pause time for response

SHNIC school nurses information:

Specific health issues for individual health care plans

- Diagnosis that is complete; noting all characteristics
- PT/OT/SLP/Vision services and hearing specialists / communication with staff
- 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.

Resources & Journals

The Charge Syndrome Foundation
<http://www.chargesyndrome.org/>

CHARGE Syndrome: Teaching Strategies for Children
<http://www.perkinslearning.org/videos/webcast/charge-syndrome-teaching-strategies-children>

American Speech Language Hearing Association
<http://www.asha.org/aud/articles/CHARGESyndrome/>

CHARGE Syndrome: Educational, behavioral & developmental aspects
http://texaschargers.org/professionals_21_2565743736.pdf