

# CHARGE Syndrome

## Background

CHARGE syndrome is a genetic disorder with a recognizable pattern of birth defects affecting a child's physical, sensory and behavioral needs. CHARGE syndrome affects multiple organ systems and can cause life-threatening cardiac and respiratory complications. Common features of this complex syndrome include:

- **C**oloboma ocular (a slit or groove in one of the structures of the eye that causes vision loss)
- **H**ear defects
- **A**tresia of the choanae (blocked nasal passage)
- **R**estriction of growth and development
- **G**enitourinary abnormalities
- **E**ar and hearing abnormalities

Additional physical conditions can include unique facial characteristics, low muscle tone, poor balance, pain, sleep disturbances, and fatigue. Behavioral conditions such as obsessive-compulsive disorder (OCD), attention-deficit/hyperactivity disorder (ADHD) and characteristics of autism spectrum disorder (ASD) may be diagnosed.

A child's intellectual ability is often underestimated because of their difficulties in communicating. Supporting the development of social skills is an important focus for children with CHARGE syndrome, as many experience delays in communication and social interaction.



## Top Takeaways for School

CHARGE syndrome is a medically and developmentally complex condition. It is the leading cause of congenital deafblindness.

Most children with CHARGE syndrome experience some degree of disability related to sensory impairment affecting vision, hearing, touch, temperature regulation, smell, taste, and balance.

Children with CHARGE syndrome often have decreased cognitive abilities, but intelligence is often underestimated due to sensory conditions.

Behavioral challenges associated with CHARGE syndrome may include repetitive and sensory-seeking behaviors, as well as difficulties with attention and concentration.

Creating opportunities for social development is important as children with CHARGE syndrome have been described as socially interested but socially immature.

## Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnoses: Imbalanced nutrition, impaired swallowing, ineffective breathing pattern, pain (acute/chronic) and fatigue
- Nutrition interventions and equipment (consider brand/size of feeding tube, tube replacement, water flushes, fluid intake goal and supplements); note school district policy on tube replacement and consider keeping backup feeding tube kit at school if applicable
- Elimination interventions and equipment (consider catheterization brand/system, French size, frequency, and cleaning techniques; location of procedure; level of assistance)
- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Equipment troubleshooting (consider equipment/device user manual, battery, charger)
- Consider emergency action plans (EAPs) and emergency evacuation plans (EEPs) related to special health care needs, including staff education/training

## Discussion Starters for the Educational Team

1. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
2. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
3. Does the student need additional adult support to access the academic curriculum in the least restrictive environment?
4. Can rest breaks, safe spaces or reduced stimulation times be built into the student's schedule?

## Resources

Kennedy Krieger Institute: Neurology and Neurogenetics Clinic  
[kennedykrieger.org/patient-care/centers-and-programs/neurology-and-neurogenetics-clinics](https://www.kennedykrieger.org/patient-care/centers-and-programs/neurology-and-neurogenetics-clinics)

The CHARGE Syndrome Foundation  
[chargesyndrome.org](https://chargesyndrome.org)

National Center on Deaf-Blindness  
[nationaldb.org](https://nationaldb.org)

Perkins School for the Blind: Impact of CHARGE on Communication and Learning  
[perkins.org/resource/charge-syndrome-impact-charge-communication-and-learning/](https://perkins.org/resource/charge-syndrome-impact-charge-communication-and-learning/)



For more information, please scan the QR code or visit: [KennedyKrieger.org/SHNIC](https://www.KennedyKrieger.org/SHNIC)

