

# 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. CHARGE is an acronym; its letters stand for several of the common features of this complex syndrome:

- **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, fatigue, pain, low muscle tone, poor balance and sleep disturbances. Behavioral conditions can include obsessive compulsive disorder (OCD), attention-deficit/hyperactivity disorder (ADHD) and characteristics of autism spectrum disorder (ASD), as children struggle to self-regulate. A child's intellectual ability is often underestimated because of their difficulties in communicating. Promoting social skills for children with CHARGE syndrome has been emphasized, as these children can experience delays in effective communication and social skill development.



CHARGE syndrome is a medically and developmentally complex condition. It is the leading cause of d/Deaf\*-blindness at birth.

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

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

Behavior challenges associated with CHARGE syndrome can include repetitive and sensory-seeking behaviors and difficulty 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.

\*Kennedy Krieger Institute recognizes that the word "deaf" can refer to both a condition and a culture. Kennedy Krieger spells the word as "d/Deaf" to be inclusive of both hearing status and cultural identity.

## Discussion Starters for Educational Team

## Top Takeaways for School Considerations

## Kennedy Krieger Institute's Specialized Health Needs Interagency Collaboration

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



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## Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of imbalanced nutrition: less than body requirements, impaired swallowing, ineffective breathing pattern, pain (acute/chronic) and fatigue
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Respiratory interventions and equipment needs
- Nutrition interventions and equipment needs (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 needs (consider catheterization brand/system, French size, cleaning procedure and frequency of catheterization); note location of procedure
- 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 care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

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 Clinics  
[kennedykrieger.org](http://kennedykrieger.org)

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

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

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



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