



# CHARGE Syndrome

## Resources:



[New Diagnosis](#)



[Get Support /  
CHARGE Foundation](#)



[Find your state  
Deaf-Blind  
Project](#)



[Audiology  
Considerations for  
CHARGE](#)

- CHARGE is a recognizable genetic syndrome most often caused by mutations in the CHD7 gene. There is no relationship to sex, race, nationality, religion, socio-economic status, or prenatal exposure.
  - It occurs in about 1 in every 10,000 births.
- **Distinctive features:** Most individuals with CHARGE have:
  - Coloboma - a hole or missing tissue in one or both eyes at birth.
  - Choanal atresia - occurs when the nasal passages are blocked by abnormal tissue or bone at birth.
  - Ear abnormalities - malformed inner, middle and/or outer ears which may cause hearing loss.
  - And/or other birth defects - <https://www.chargesyndrome.org/overview/signs-symptoms/>
- **Common challenges:** Difficulty with hearing, vision, and balance. This results in delayed motor development and communication.
- **Deafblind diagnosis:** Most children with CHARGE will be considered deafblind, even though most of them retain some usable hearing and/or vision. Children are considered to be deafblind (and eligible for deafblind services) when the combination of their hearing and vision loss causes such severe communication and other developmental and educational needs that they require significant and unique adaptations in their educational programs.
- **Expanded medical team:** CHARGE syndrome is a complex condition, yet each child is unique and should be treated as such. You will likely have many doctors as part of your medical team. Management, coordination and good record keeping will be essential as your child develops.
  - It is important to know the medical issues associated with CHARGE and share that information with your child's medical team. Do not be afraid to ask questions.
- **Determination:** Despite these very tough challenges that look really hard to overcome, children with CHARGE Syndrome often far surpass their medical, physical, educational, and social expectations. One trait that is often overlooked is the determination and strong character these children display.
- **Resources:** Every state has a Deaf-Blind Project (DBP) to provide services from birth to 21.
  - The IL DBP provides technical assistance, information, and training to address the early intervention, special education, related services, and transitional service needs of children with DeafBlindness.

05.2024 CHARGE