



For additional information:

[www.chargesyndrome.org](http://www.chargesyndrome.org)

[info@chargesyndrome.org](mailto:info@chargesyndrome.org)

### ***About CHARGE syndrome***

- CHARGE syndrome is a complex genetic condition and the leading cause of congenital deafblindness worldwide.
- Occurring in approximately 1 in 12,000-15,000 births, CHARGE syndrome is most commonly caused by a new mutation in a single gene. The parents are typically not affected.
- CHARGE syndrome is a recognizable genetic syndrome with known pattern of features.
- CHARGE syndrome is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child.
- Babies with CHARGE syndrome are often born with life-threatening birth defects. They spend many months in the hospital and undergo many surgeries and other treatments.
- Swallowing and breathing problems can be lifelong challenges.
- Most individuals with CHARGE have hearing loss, vision loss, and balance problems that impact their development and communication.
- Individuals with CHARGE syndrome are truly “multi-sensory impaired,” having difficulties not only with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell, as well as problems with breathing and swallowing, eating and drinking, digestion, and temperature control.
- Cranial nerve abnormalities are also common, causing facial paralysis, swallowing difficulties, hearing loss, and a diminished sense of smell. Gut and urinary systems are also adversely affected.
- CHARGE was originally used as an acronym for the common characteristics of the disorder:
  - Coloboma of the eye
  - Hear defects
  - Atresia of the choanae
  - growth Retardation
  - Genital abnormalities, and
  - Ear malformations.
- Most children with CHARGE syndrome are considered medically fragile for many years.
- It’s common to leave the hospital with a feeding tube, an oxygen tank, and a print out of follow-up appointments. In practical terms, having a child with CHARGE syndrome means you are going to be at the hospital a LOT.

### ***About the CHARGE Syndrome Foundation***

- The CHARGE Syndrome Foundation is a charity run by parent and professional volunteers.
- The CHARGE Syndrome Foundation hosts conferences every two years. It’s the only chance many have to meet another family living with CHARGE.
- CHARGE syndrome conferences are unique in that families and professionals attend the same sessions and learn from each other.
- Over 90% of all money raised by our families and the people who care about them goes toward outreach, research, and conferences.