

CHARGE Syndrome Foundation, Inc.

www.chargesyndrome.org

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What Are The Facts About CHARGE Syndrome??

- ▶ CHARGE syndrome refers to individuals with a specific set of birth defects and medical problems.
- ▶ CHARGE syndrome is a genetic condition. The first gene for CHARGE (CHD7) was discovered in 2004. It is usually sporadic with no other affected individuals in the family. There are rare families with multiple affected individuals. CHARGE syndrome is not caused by any known exposures during pregnancy. It is not related to sex, race, nationality, religion or socio-economic status.
- ▶ There is a DNA test (CHD7) that can confirm the diagnosis of CHARGE syndrome in many cases. Because not all people with CHARGE have a detectable DNA change, CHARGE is still primarily a clinical diagnosis based on physical features. The diagnosis should be made by a medical geneticist who is familiar with CHARGE syndrome.
- ▶ The incidence of CHARGE is about one in every 8-10,000 births. The frequency is the same in males and females.
- ▶ There is a wide variation in the physical and mental abilities among individuals with CHARGE.
- ▶ Although there are many problems, children with CHARGE can survive and become healthy, happy citizens.
- ▶ Appropriate therapies and educational intervention must take into account any hearing and vision loss which is present. The intelligence of children with CHARGE is often underestimated due to the combined hearing and vision issues.
- ▶ Individuals with CHARGE need supportive, loving homes, early intervention, appropriate and challenging educational and vocational programs, and preventative medical care.