

I support Deafblind children

95% of what we learn is through our **eyes** and **ears**. Imagine what it is like to be **deafblind**.

Deafblindness is a unique disability that combines **varying degrees** of both **hearing** and **visual impairment**. All individuals who are deafblind experience extreme challenges with communication and mobility and most have additional physical and medical conditions. Persons with deafblindness face neglect and discrimination owing to their inability to communicate and relate to the world. They are thus denied even the basic human rights like education, medical care, amongst other needs that are taken for granted by most of us.

There is very little awareness about deafblindness amongst the government, general public and other NGOs working in the area of disability. Due to this situation many deafblind children and adults are left without support and even considered severely mentally retarded incorrectly. What most people do not know is that deafblind children and adults can become active members of society if provided with the right care and support.

Causes of Deafblindness

There are multiple causes for deafblindness. Pre mature birth, Low birth weight, Birth injury, Respiratory distress such as hyperoxia and hypoxia, Jaundice, Fits, Nutrition, Infections such as Meningitis and Encephalitis are some of the common causes during birth that may lead to deafblindness

Rubella or German measles can be transmitted from an affected pregnant mother to its foetus. The Usher Syndrome, with varying degrees of severity and progression of symptoms, is a genetic disorder characterised by hearing impairment and an eye disease called retinitis pigmentosa. Another cause for deafblindness is a syndrome known by its abbreviation CHARGE which is, Coloboma, Heart defects, Atresia, Retarded Growth, Genital differences, Ear anomalies. The incidence of CHARGE is about 1 out of 10,000-12,000 births.

Deafblindness can also be caused by Cytomegalovirus, belonging to the herpes virus group, if contracted by a pregnant mother can be transmitted to their unborn child. Poor nutrition, unbalanced diets and trauma during pregnancy can cause birth defects leading to multiple disabilities.

There could be many high risk factors leading to deafblindness. Some of the main causes are: RUBELLA (German measles) Rubella, also known as German measles, causes a group

of congenital defects known as congenital rubella syndrome (CRS). The disease is easily transmitted from the pregnant mother to the unborn foetus. If the infection is contracted in the early months of pregnancy, the risk for the foetus is greater.

Usher Syndrome Usher Syndrome is a genetic disorder that is characterized by hearing impairment as well as an eye disease called retinitis pigmentosa. Types of usher syndrome: Usher syndrome type 1 (US1) People with US1 are profoundly deaf from birth and have severe balance problems. These children usually begin to develop vision problems by the time they are ten. Visual problems most often begin with difficulty seeing at night, but tend to progress rapidly until the individual is completely blind. Usher syndrome type 2 (US2) People with US2 are born with moderate to severe hearing impairment and normal balance. Retinitis pigmentosa is characterized by blind spots that begin to appear shortly after the teenage years. The visual problems in US2 tend to progress more slowly than the visual problems in US1. Usher syndrome type 3 (US3) Children born with US3 have normal hearing and normal to near-normal balance. Hearing worsens over time. Children develop noticeable hearing problems by their teenage years and usually become deaf by mid to late adulthood. Retinitis pigmentosa in the form of night blindness usually begins sometime during puberty.

CHARGE Syndrome CHARGE association (or syndrome) is an acronym referring to children with a specific pattern of birth defects viz. Coloboma, Heart defects, Atresia, Retarded Growth, Genital differences, Ear anomalies. The incidence of CHARGE is about 1 out of 10,000-12,000 births. It affects males and females of all races equally. Besides the above, recent research has shown that CHARGE children may exhibit a wider range of characteristics such as Nerve dysfunction, Cleft Lip / palate and Feeding difficulties. As a result of all these factors, children with CHARGE commonly have delays in development.

Common Factors during Pregnancy Nutrition: Poor nutrition and unbalanced diets during pregnancy can cause low birth weight or premature births. Infants who survive these conditions are more likely to have mental retardation, cerebral palsy, epilepsy and respiratory disease. Trauma: Trauma during pregnancy can injure foetus in the mother's womb. This can also lead to premature birth and/or bleeding. Emotional trauma too can affect development of foetus.

CYTOMEGALOVIRUS (CMV): This is a potential prenatal cause of deafblindness. It is a commonly occurring virus that belongs to the herpes virus group. If a pregnant woman contracts CMV, the virus may be passed on to the developing fetus. Some of the common causes during child birth are: Premature birth: Birth before 37 weeks of pregnancy is considered as premature birth. Pre mature birth is one of the common causes seen in deafblind children identified in India. Low birth weight, Birth injury, Respiratory distress such as hyperoxia and hypoxia, Jaundice, Fits, Nutrition, Infections such as Meningitis and Encephalitis are some of the common causes during birth that may lead to deafblindness.

Common causes during childhood: Severe malnutrition, Trauma or accidents leading to brain damage, Infections such as Meningitis and Encephalitis are some of the other causes that can affect children during their childhood.