

Information for Teachers

What is Noonan Syndrome?

Noonan Syndrome was first named by Dr Jacqueline Noonan, an American paediatric cardiologist, who in 1963 recognised that an unusual congenital heart defect, was often accompanied by short stature and a characteristic facial appearance. The Syndrome itself is a complex one with over 200 features recognised. Most children with Noonan Syndrome do not possess every feature, but each characteristic can be expressed to a differing degree within a child. Thus, some children are mildly affected and cope well in mainstream. Others are more severely affected in one area or in several, and require provision at an MLD school. Each individual has differing needs. Many children are at Stage 3 of the Code of Practice. Some, at Stage 5, have support from an NNEB or Special Support Assistant (SSA). It is not known how many children are receiving support nationally.

The incidence of Noonan Syndrome is between one in 1,000 to one in 5,000 of the population. Half of all cases run in families. So far there is no clinical test for it, and diagnosis has to be made by a geneticist. However, recent advances in genetics show that the gene for Noonan Syndrome is located on chromosome 12. Up to one in every hundred people could be carrying the gene, but because of the complexity of the condition, many cases remain undiagnosed and untreated. Noonan Syndrome has been called 'the most complex genetic condition', since it can affect the heart, growth, blood, sensory, physical and mental development.

Physical Effects

- Abnormal birth weight
- Early sucking and feeding problems
- Dental problems
- Poor sleep patterns
- Major delay in the developmental milestones of sitting, crawling, walking, talking, etc
- Low immunity to colds, coughs, chest infections, tonsillitis, etc
- Susceptibility to easy bruising and profuse bleeding

Facially, children have a recognisable appearance:

- Low set ears
- Drooping eyelids
- Large downward slanting eyes
- Eyes spaced wide apart
- Broad, flat bridge of the nose
- Short neck
- Excess skin on the back of the neck
- An unusual, low hairline

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