

Key Facts about Kleefstra Syndrome

| Kleefstra syndrome is named after the clinical geneticist Dr Tjitske Kleefstra. |
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| Kleefstra syndrome is caused by a missing piece of information (deletion) on the long arm of <u>chromosome 9</u> |
| The <u>early signs</u> of Kleefstra syndrome vary between individuals |
| Most individuals with Kleefstra syndrome will have a moderate level of <u>intellectual disability</u> |
| Over half of individuals with Kleefstra syndrome are born with structural heart defects |
| Motor development is often delayed in Kleefstra syndrome |
| Many children with Kleefstra syndrome are reported to show ASD characteristics |
| Children with Kleefstra syndrome often prefer to be with adults rather than children |
| Some children with Kleefstra syndrome show problematic sleep patterns, which change with age |
| Mood swings tend to increase during puberty for children with Kleefstra syndrome |
| Speech skills may improve with time in some individuals |

The information on this website was developed in collaboration with www.kleefstrasyndrome.org. This is the parental support group for Kleefstra, a well-developed community with an active facebook group and parent support conference. Please visit their website for further information and to get in touch with families of individuals with Kleefstra syndrome.