

Kleefstra Syndrome Stats

Based on a recent international survey of 179 families affected by Kleefstra syndrome (June 2018)



AGE OF DIAGNOSIS



IT CAN AFFECT MANY FUNCTIONS OF THE BODY

29% were classed as non-verbal.
16% talk in sentences.

The rest use various methods of communication, such as sign language, to be understood.

They can understand more than they can express.

40% are diagnosed with an autism spectrum condition.



42% wake frequently during the night.

43% need additional equipment to help them get around.
And of those that can walk, 45% learnt to walk after the age of two.



57% are not toilet trained.
60% have constipation.

The following symptoms were experienced by at least 25% of people with Kleefstra syndrome:

- ◆ aspiration reflux
- ◆ hypermobility
- ◆ strabismus or unusual eye features
- ◆ heart condition
- ◆ microcephaly
- ◆ hearing impairment
- ◆ regression
- ◆ brain structure abnormalities



Children with Kleefstra syndrome are described as affectionate and they laugh a lot.

