

Autistic Spectrum Disorder (ASD)

Watch the video above to hear parents of children with Kleefstra syndrome describe their experiences of ASD characteristics. However, not all of these children have a diagnosis of an Autism Spectrum Disorder.

Many children with Kleefstra syndrome show behaviours which are described as characteristic of Autism Spectrum Disorder, including:

- Poor or unusual social interaction skills
- Delayed development or difficulties in verbal and non-verbal (gestures, pointing, showing etc.) communication
- The presence of repetitive behaviours

The severity of ASD experienced by individuals with Kleefstra syndrome varies greatly. Some individuals will exhibit repetitive behaviours and difficulty in social situations while others are reported to be very sociable. Much more research is needed in this area.

Some individuals may also show autistic catatonia, which can result in the individual not speaking or moving at all for long periods of time.

Research conducted at the University of Birmingham has looked at Autism Spectrum Disorder in Kleefstra syndrome. This research is in its early stages and has not yet been published in a scientific journal, which means it has to be interpreted very carefully. However, so far this research suggests out of 10 people aged 4-16 years with 9q34 deletions, 9 met criteria for an Autism Spectrum Disorder on a screening questionnaire. Six of these individuals met the more stringent criteria on this screening questionnaire that suggested they may have autism.

The information on this website was developed in collaboration with www.kleefstrasynndrome.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.