

Fragile X

They tell us that they want to be a firefighter and a tow truck driver, they want to have a family and a job, they understand that's what people do. They have dreams and we will support them in anything they choose ... We love them for who they are, who they want to be and neither of us would have it any different.

The parents of twins Conor and Zach, who have fragile X, taken from <http://fragilex.ca/sons.html>

Fragile X is a genetic disorder, so called because of a fragile site on the tip of the long arm of the X chromosome where, although not quite separated, it looks as though the end is broken off. It is diagnosed by DNA testing on a sample of blood.

The student with fragile X will often have an unusual facial appearance characterised by large protruding ears, a long nose and a high forehead. Many may have flat feet and generally exhibit a 'floppy' gait owing to poor muscle tone. Learning needs can range from mild to severe, with girls usually less affected. The student with fragile X is often described as impulsive, acting before thinking, wanting everything straight away, having impaired concentration and being dependent on following a consistent routine. The student may appear uncooperative at times and exhibit oppositional type behaviours.

Other behavioural habits include hand-biting/flapping, rocking and gaze avoidance. However, those with fragile X are interested in others and enjoy social contact on their own terms in a 'safe' environment. Inappropriate behaviours are triggered by an inability to select and organise sensory information from the environment, which causes the student to become overwhelmed by the mass of sensory input. Typically, more males are severely affected than females.

It is important to remember, however, that while students with fragile X may share common traits, each student has individual and unique characteristics that need to be considered when devising learning and teaching programmes.