



## What is Fragile X Syndrome?

Fragile X Syndrome is the leading cause of inherited mental impairment. This impairment can range from learning disabilities to severe cognitive or intellectual disabilities. Symptoms can include characteristic physical and behavioral features and delays in speech and language development.

Fragile X is also the leading known cause of autism. Approximately 5% of people with autism turn out to have fragile X and 30% of children with fragile X - meet the diagnostic criteria for autism.

Fragile X is a genetic disorder that affects about one in 4000 individuals. As many as one in 130 women and one in 800 men may be carriers of the faulty gene. This gene is located near the bottom of the X chromosome and gives it a “fragile” appearance.

Because it is an X-linked disorder, female carriers have a 50% chance of passing the syndrome on to their children. Male carriers never pass on the syndrome to their sons, but will pass on the faulty gene to all their daughters. For New Zealand’s population of just over 4 million people, this means that around 1000 families are affected by fragile X and 8000 New Zealanders are carriers of the gene.

Although there is currently no cure for fragile X syndrome, a recognised diagnosis can lead to appropriate management and intervention that helps affected individuals reach their full potential. The information obtained from the test can help identify other family members at risk of carrying the gene change and having children with fragile X.

Fragile X can be passed on in a family by individuals who have no apparent signs of this genetic condition. In some families a number of family members appear to be affected, whereas in other families a newly diagnosed individual may be the first family member to exhibit symptoms.

## About the New Zealand Fragile X Trust

The Trust is a parent-led charitable organisation that supports families affected by fragile X syndrome and raises awareness about this genetic disorder.

The Trust offers a toll-free support line, a website and a library service, publishes a regular newsletter, and runs annual family gatherings and workshops where information can be shared in a supportive and family atmosphere. We employ a part-time administration officer to assist our volunteers; we provide training and support for our volunteer workers; we are in the process of setting up a fragile x clinic where families can have their FX child assessed and given specialist support.