

FRAGILE X SYNDROME

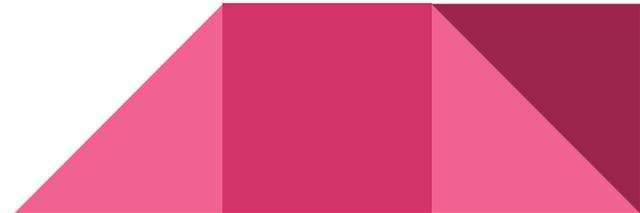
The what, the why, the who and what we can do.

What is Fragile X Syndrome

Fragile X refers to a group of conditions which are due to a defect in a gene in the X Chromosome.

Fragile X Syndrome (FXS) is the most common form of mental impairment. It was previously referred to as Martin-Bell Syndrome.

A single gene in the brain cell shuts down causing Fragile X Syndrome. Due to the shut down in the gene, it cannot produce the protein it normally does for normal brain development and functioning.



Who does it effect?

FXS is said to be the most common genetic disorder however most people are not diagnosed. It affects 1 in 4 000 boys and 1 in 6 000 girls.

Girls tend to have milder symptoms than boys with many of the girls (over half) having normal IQs.

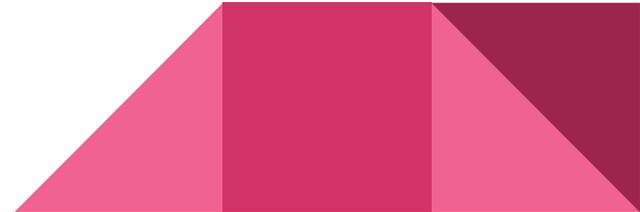
About 30% of boys with FXS meet all characteristics for Autism.



Testing for Fragile X Syndrome

A reliable DNA test can be done to identify affected individuals. The test itself was developed in 1992 and can be ordered by a physician. The testing can also indicate if the individual is a FXS carrier.

Testing should be considered if unexpected developmental delay, mental impairment of Autism is present.



Medical Treatment of Fragile X Syndrome

There has been much development over the past decade in regards advancements in medical treatment. Experimental drugs have been used in trials with success. Currently, there is not a cure for FXS but there is medication to help manage the symptoms.

Some individuals with this syndrome appear to prone to Ear infections, ADHD, Autism, Mitral Valve Prolaspe, Seizures, Strabismus, Hernias, Joint problems, Depression, Connective tissue issues, Scoliosis and flat feet. Regular medical check-ups are important to ensure that these conditions are prevented or managed early on. Life expectancy is normal.



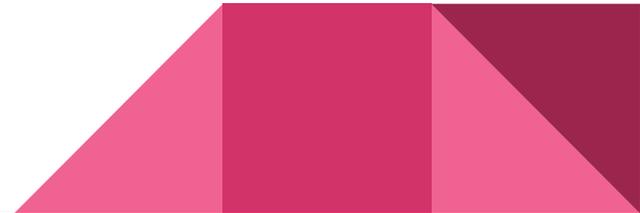
Symptoms of Fragile X Syndrome

- Intellectual disabilities ranging from mild to severe
 - Attention difficulties and hyperactivity
 - Anxiety and unstable mood
 - Sensory sensitivities
 - Speech delay with expressive but more severely receptive language
 - Seizures
 - Long face, large prominent ears, flat feet (more so after puberty)
 - Hyperextensible joints especially fingers
 - Low muscle tone
 - Males may end up having larger testes after puberty
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What can parents do (years 0-3)?

Early interventions are the key which is why it is so important for families that have a child who isn't hitting milestones, to follow up with their family physician. Some early interventions that may be required or utilized are

- Assistive technology (devices a child might need)
- Audiology or hearing services
- Speech and language services
- Counseling and training for a family
- Medical services
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services



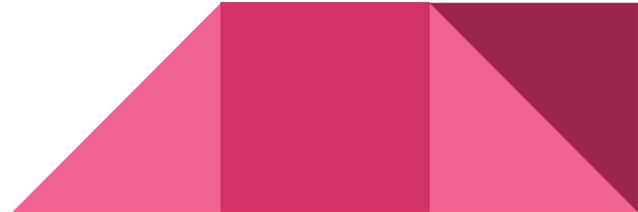
What can educators do?

Identification is key in terms of fully understanding what a student struggles with and much like for parents, early identification goes a long way for overall student academic success.

An Individualized Education Plan can be put in place to ensure that the students needs are met.

Teacher should work with speech and language pathologist, occupational therapists and the special education teacher to use communication tools and scaffolding strategies that can assist students with FXS communicate and learn more easily. Also important to remember that there is comorbidity with Autism and FXS.

Teachers should try to create an environment which is calm and quiet most of the time. Teach students how to request a break, smaller groups



What can educators do now?

- Teachers should try to create an environment which is calm and quiet most of the time
- Teach students how to request a break
- Smaller group or one to one instruction
- Explore use of calming strategies within the classroom (calming zones, distraction tools)
- Give ample time for processing
- Visual schedules (class and individual)
- Use both high and low technology teaching strategies
- Use manipulative
- Play on strengths of students
- Use backward chaining to have students finish the task

Use the great teaching strategies you are already doing !



Resources

<https://www.fraxa.org/fragile-x-syndrome>

<https://fragilex.org/#home>

<http://www.fragilexcanada.ca/index.php?home&lng=en>

<https://fragilex.org/wp-content/uploads/2012/08/Educational-Guidelines-for-Fragile-X-Syndrome-General2013-Sept.pdf>

