Fragile X syndrome

What is Fragile X syndrome?
Fragile X syndrome is an inherited condition which may affect many areas of a child’s development. While the disorder can affect both males and females, it is an X chromosome linked genetic disorder which means that males may be more frequently and severely affected.

What are the common characteristics of children with a diagnosis of Fragile X?
The majority of males and approximately one third of females with Fragile X syndrome are typically diagnosed with an intellectual disability. Children may have physical characteristics, such as larger ears, longer face. Children with Fragile X syndrome can experience some difficulties in the following areas:

- Learning
- Attention and concentration
- Communication
- Processing sensory information (e.g. upset by loud noise, hand flapping)
- Social/emotional development

Some children with Fragile X syndrome also have a diagnosis of Autistic Disorder or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

How is it diagnosed?
Fragile X syndrome can be detected via blood testing arranged through a paediatrician or geneticists.

How can I support my child with Fragile X syndrome?
Parents report that it can be very helpful to obtain a clear picture of their child’s developmental strengths, sensory preferences and areas of concern to assist in focusing on relevant goals to support their child. Families are encouraged to consult their Maternal Child Health Nurse, Paediatrician or Early Childhood Intervention Practitioner for more information on further supports. Tuning in to your child’s interests and supporting them with exploring their world is a great way to build on your child’s ability to move, communicate, behave and learn.

Providing lots of opportunities for you and your child to have fun in your everyday routines; sharing praise and encouragement, using visuals, communicating with your child using simple language and instructions are some examples of strategies that have been shown to be effective in promoting learning and development. Providing sensory calming activities can be used to support your child learning and promotion of positive behaviours.

Resources and References:
Fragile X Alliance Inc: www.fragilex.com.au
The Fragile X Association of Australia: http://www.fragilex.org.au
Visual resources are available on the resources hub on the EPIC website: www.epic.edu.au
Department of Education and Training: (DET): www.education.vic.gov.au
Early Childhood Intervention Australia (ECIA): www.eciavic.org.au
Raising Children’s Network: www.raisingchildren.net.au

Prepared and Collated by the Education Program for Infants & Children Inc.
Visit www.epic.edu.au for resources and training information.