**RESOURCES: Fragile X Syndrome**

http://www.fragilexcanada.ca

Website includes information regarding:

- **What is Fragile X Syndrome**
  - Symptoms
  - Testing for Fragile X
  - How Fragile X is inherited

- **Coping with Fragile X Syndrome**
  - Finding a Genetic Counselor
  - Where to Get Help
  - Informing Family Members
  - Living with Fragile X Syndrome in preschool (0-3 years), school-age (4-12), adolescence (13-20), and adulthood (21+ years)
  - Helpful Tips *(see below appendix 1)*

- **Treatment**
  - Therapies
  - Fragile X Clinic
  - Medication
  - Medical Complications

- **Resources**
  - Useful Links *(see below appendix 2a and 2b)*
  - Online Discussion Groups
  - Fact Sheet *(see below Appendix 3)*
  - Newsletter – available online

- **Contact Information**

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  Phone: 905-453-9366  info@fragilexcanada.ca
What is Fragile X syndrome?

The term Fragile X refers to a group of conditions due to defects in a gene on the X chromosome:

- Fragile X syndrome (FXS)
- Fragile X-associated Tremor Ataxia Syndrome (FXTAS)
- Fragile X-associated primary ovarian insufficiency (FXPOI)

Fragile X syndrome (FXS), first known as Martin-Bell syndrome, is the most common inherited form of mental impairment. FXS affects 1 in 4,000 boys and 1 in 6,000 girls of all races and ethnic groups. While Fragile X individuals have a normal life expectancy, most will need support and care for their entire lives.

A single gene in the brain cells shuts down, causing Fragile X syndrome. In 1991, scientists discovered the defect in a gene on the X chromosome (called FMR1) that causes FXS. In affected individuals, this gene is shut down and cannot manufacture the protein it normally makes – a protein vital for normal brain development and functioning.

Large-scale population studies of Fragile X still need to be done, but it is clear that this is one of the most common genetic diseases in humans. Most people with Fragile X are not yet correctly diagnosed.

Research is aimed at developing effective treatments. In addition, this research is leading to better understanding and treatments for other conditions, such as autism, and Alzheimer's Disease.

Appendix 1.

Helpful tips

Buy socks with coloured heels and toes to help your child know how to pull them on correctly.

Hang outfits together in the closet so your child knows what clothes go together and can get dressed more independently.

Mom B.B. suggests: The store HomeSense sells canvas sectioned hangers that you would usually put shoes or hats in. We stuff a day’s worth of clothes in each cubby box - underwear, socks, jeans, t-shirt and hoodie - and there are 6 compartments so it covers every day of the school week. My son just takes out an outfit and gets dressed. He no longer spends hours getting dressed, has a sense of independence, and as a bonus - his dresser drawers don’t get messed up!

Going to the dentist? Take some time to educate the people at the office about Fragile X syndrome. Book extra time and take along a Game Boy type of toy or earphones plugged into music or go to a dentist that has a tv/dvd player mounted up high on the wall to distract them.

When trying to teach something new or difficult, take frequent breaks and use a very simple task they have success with (like a puzzle they have mastered) in between the difficult tasks. Your student will gain confidence and be ready to go back and tackle the tougher one.
Fill a wheel barrel with water in the summer and let them carry it back and forth across the lawn - the lawn gets watered, the weight and pressure is calming and if they get wet, who cares - how refreshing! Our son carries his little sister around in ours and they both have a blast!

Get a bean bag chair for them to relax in or simply watch TV.

Small but silent vibrating toys are great help during school assemblies or whenever they are expected to sit quietly for a long period of time.

Purchase an inexpensive tape player with music cassettes that they can play with/rewind to their hearts content.

Freezies seem to help with the oral self-stimulation. Make your own out of watered down juice so they are healthier than store bought.

Put a dot of the inside, insole of their boots or shoes with bright red nail polish (make sure you let it dry completely) and tell them that the red dots have to be together (side by side) before they put on their boots/shoes so that they go on the correct feet. This has been very helpful and gives a sense of independence!

Use social stories with pictograms. Social Stories are personalizable children’s books that engage children in a fun and creative way while addressing social skills, safety skills, and communication skills. You can personalize them to help in almost any situation. If you want to learn more about social stories, there are free ones available on the internet at: www.sandbox-learning.com

Use praise for anything your child does well. As you move through your day, tell your child how happy you are that they listened, followed directions or were quiet while you were on the phone. We are quick to criticize when they don’t behave, so make it a habit to be equally quick to sing their praises. This shows your child they will get as much or even more attention for behaving than when they don’t.

Frustrated with shoe laces? Tired of the time it takes to do them up? Try to purchase shoes that are velcro close only. If you can’t find them in larger sizes, since they can be difficult to find, use bungee shoe laces. They are available at Payless and other major shoe retailers, come in various colours and work very well!

To reduce anxiety causing sounds such as noise generated while on the bus or in a crowd, let your child wear headphones and listen to music that they enjoy. They can focus on one sound source and they have control over the volume and the music selection. There are lots of different headphone styles available to suit your child.
Appendix 2a

Recreational Sports Programs

Special needs kids can benefit from competitive and solo sports. Physical fitness is important in this population. Examples include bike riding, skating, hockey, soccer, skiing, swimming, and horseback riding.

City Parks and Recreation Departments

There are a wide range of programs, and there are special needs representatives. It all depends on the size of your community and the type of programs available. Larger cities have more and varied opportunities.

Community Association for Riding for the Disabled (CARD)

www.card.ca

Toronto ON 416-667-8600

This is a therapeutic horseback riding program for children and adults with disabilities. Its goals are to improve balance, coordination, confidence, self esteem and social skills.

Gymboree Learning Program

www.gymboreeclasses.com

Programs offered nationally

This program offers a progression of developmentally appropriate play, music and arts classes for infants and young children and their parents. The website has interesting links.

Harbourfront Centre

www.harbourfrontcentre.com

Toronto ON 416-973-4600

A wide range of programs are offered throughout the year for children.

Laura Hunters STEPS Programs

www.stepsprograms.com

Stouffville ON 905-642-8001

STEPS stands for Specialized Therapeutic Education for Physical Skills. Laura runs gym, biking, horseback riding and lifeskills programs year-round, for toddlers to young adults with intellectual and/or physical disabilities.

Martial Arts

Martial arts may be beneficial to children with learning or developmental disabilities because they have an individualistic bent, so even an uncoordinated, unfocused person can be successful. They can improve self-esteem and confidence.

Ontario Track 3 Ski Association

www.track3.org

Ontario 416-233-3872, Toll Free 1-877-308-7225

This organization teaches downhill skiing and snowboarding to children and youth with all kinds of disabilities.

Pointe-Claire Aquatic Centre

www.ville.pointe-claire.qc.ca

Pointe-Claire QB 514-630-1202

The Centre has adaptive programs for special needs children with low staff:student ratios. These are non-competitive swim and gym programs, with activities focussing on coordination, fine motor skills and social skills.
Special Olympics Canada
www.specialolympics.ca
Toll Free 1-888-888-0608
Programs offered nationally
This is a community-based organization across Canada that provides sport training and competition opportunities for children and adults with an intellectual disability.

The Y
www.ymca.ca
Programs offered nationally
Ys have many activities and camps that include kids with special needs.

Appendix 2b

Camps & Residential Programs
These are day and overnight camps, some integrated, some special needs only.

Blooming Acres
www.bloomingacres.com
Barrie, ON 705-487-3076
A residential community for children and teens with complex special needs, offering residential care, respite and a summer camp.

Canadian Camping Association
www.ccamping.org
This website provides links to provincial associations.

Camp Kennebec
www.camptkennebec.com
Arden, ON 1-877-335-2114
An integrated residential summer camp including children with LD, ADHD and behavioral needs.

Camp Kirk
www.campkirk.com
Kirkfield, ON 416-782-3310 1-866-982-3310
Residential summer camp for children with learning disabilities and Asperger’s Syndrome. Owned by the Lion’s Club.

Camp Kodiak
www.campkodiak.com
McKellar, ON 905-569-7595 1-877-569-7595
An integrated, non-competitive, residential summer camp, including tutoring, for children, teens and young adults with and without learning disabilities and ADHD.

Camp Prospect
www.campprospect.com
Loretto, ON 705-735-0129
Residential summer camp and year-round programs for people of all ages with complex special needs.
Camp Winston
www.campwinston.com
Kilworthy, ON  416-487-6229
A residential summer camp for children with complex neurological disorders.

Circle Square Camp
www.csranche.ca
905-332-6400, ext. 3310
1-800-539-9598
These integrated summer camps are across the country. They are Christian-based, but welcome children and youth of any faith.

Appendix 3

10 things you should know about Fragile X syndrome

Below are 10 quick facts about Fragile X syndrome that you need to know.

If you’d like to print a pdf of the fact sheet, click here.

1. It’s genetic – caused by a defect in the X chromosome.
2. It is the most common inherited form of mental impairment. 1 in 4,000 males and 1 in 6,000 females are affected from all ethnic and socio-economic backgrounds.
3. It’s a spectrum disorder, with symptoms varying from mild learning disabilities (including shyness and social anxiety) to severe cognitive impairment (mental impairment) and autism.
4. The effect on boys tends to be more severe. Most boys have mental impairment and approximately 1/3 have autism. Girls generally exhibit a milder form of Fragile X syndrome because they have two X chromosomes – one that works properly and one that doesn’t.
5. Fragile X syndrome does not shorten lifespans. People affected by it do not suffer from major medical problems because of the syndrome and thus are generally healthy – but often require special care for life.
6. If a man is a carrier (1 in 800 men are carriers), he will pass it only to his daughter(s), and they will always be carriers.
7. If a woman is a carrier (1 in 260 women are carriers), she has a 50/50 chance of passing the defective gene on to her son(s) or daughter(s); the child will either be a carrier or be affected by Fragile X syndrome.
8. Some male carriers (and rarely women) will be impaired by Fragile X-associated Tremor Ataxia Syndrome (FXTAS) later in life. This is a neurological disorder that can involve tremors, balance irregularities, difficulty walking and dementia – and may be misdiagnosed as Parkinson’s disease and/or Alzheimer’s disease.
9. Some female carriers (approximately 20-28%) experience Fragile X-associated primary ovarian insufficiency (FXPOI) – menopause occurring prior to the age of 40.
10. Fragile X syndrome can be detected through a simple blood test. Testing should be considered for any individual with otherwise unexplained developmental delay, mental impairment or autism. Testing is also recommended if there is any family history of developmental problems.