



# FXRFC Newsletter

News for Friends of the Fragile X Research Foundation of Canada

Winter 2007 • Volume #11 • Issue #1

## FXRFC Awards Three New Research Grants for 2007

*By Carlo Paribello, M.S.M., M.D., President, FXRFC*

*The Fragile X Research Foundation of Canada continues its drive to increase the number of scientists working towards finding a treatment for Fragile X. The FXRFC started off 2007 by awarding 3 new research grants and committing over \$100,000.00 for research aimed at finding a treatment or cure for Fragile X. The new projects at The University of British Columbia, University of Toronto, and McMaster University, will not only yield valuable information on the pathology of Fragile X, but will hopefully stimulate further research and encourage other researchers at these institutions to divert some of their scientific resources towards Fragile X research.*

*The following are brief descriptions of these new projects. If you would like to explore the entire portfolio of FXRFC funded research, past and present, please visit our website, [www.fragile-x.ca](http://www.fragile-x.ca) and click on “Fellowships and Grants awarded”.*

*Scientists are making significant progress in understanding Fragile X syndrome as a direct result of the work that we have funded with your generous donations – please keep them coming!*

FXRFC is a nonprofit, tax-exempt charity run by parents and volunteer professionals. Fragile X syndrome is the most common form of inherited mental impairment and developmental disabilities, affecting approximately 1 in 2000 males and 1 in 4000 females. FXRFC's goal is to accelerate research aimed at the treatment of Fragile X, by direct funding of promising research projects and by raising awareness of this disorder.

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## **The role of interactive protein relations and synaptic balance in Fragile X Syndrome**

**Principal Investigator:** Alaa El-Husseini Ph.D.

*Brain Research Centre, University of British Columbia*

**Postdoctoral Fellow:** Regina Dahlhaus Ph.D.

**Project Dates and Duration:** January 1, 2007

*\$45,000/Year for 3 years, in partnership with the CIHR*

The Fragile X Syndrome (FXS) is the most common inherited form of mental impairment in all races and ethnic groups. Affected individuals display a variety of intellectual deficits from learning problems to autism. FXS is caused by a loss of the FX protein (FMRP) that functions in local protein synthesis. A key advance in FXS research was the generation of a mouse model and an exciting discovery is that synaptic contacts of adult FMRP knockout (KO) mice display characteristics of an early development, indicating a deficit in synaptic maturation. Accordingly, the activity-induced increase in PSD95 – a locally synthesized scaffolding protein important for synapse maturation- is found to require FMRP, suggesting that deficits in local synthesis of PSD95 may lead to abnormal synapse development.

Importantly, our work indicates the relationship of scaffolding and adhesion proteins (e.g. NLGs) to regulate synapse development and specificity. Hence, we hypothesize that altered PSD95 expression leads to an altered balance of excitatory and inhibitory synapses (E/I ratio) and that a reconstitution of this relationship will be important to rescue synaptic balance. Thus, a comprehensive bio- and immunohistochemical analysis will be performed on KO mice to determine alterations in the expression or distribution of synaptic proteins. We will also quantify the E/I ratio and test if expression of PSD95 or other synaptic proteins in cultured neurons will rescue the E/I balance. NLG overexpressing mice are in frame for comparative studies and an in-vivo rescue experiment by crossbreeding.

The proposed studies will test a novel mechanism by which appropriate amounts of molecules are critical for synapse development and control of the E/I ratio. Thereby, important insights into synapse development and the relevance of the E/I ratio in FXS will be obtained. Furthermore, fundamental models of synapse development will be tested in vivo to find novel strategies in the therapeutic treatment of FXS patients.



### **Fragile X Family Picnic - Save the Date!**

*by Lori Beesley, Member, Board of Directors, FXRFC*

*After a break of a two years, our Fragile X Family Fun Day/Picnic is back this year!  
The picnic will be held at Variety Village in Scarborough on*

***Sunday June 24th, from 11 a.m. to 2 p.m.***

*This is a wonderful opportunity for families to meet, share experiences and let our children play in a safe environment. There is no cost for this event and you are invited to bring your whole family. Details will follow in our spring newsletter - but save the date on your calendar now!*



## **Effects of Astrocyte FMRP and mGluR Expression on Neuronal Survival and Maturation Background**

**Principal Investigator:** Laurie Doering Ph.D.

McMaster University, Hamilton, Ontario

**Project Dates and Duration:** March 1, 2007/\$15,000.00

FMRP, the protein absent in Fragile X Syndrome (FXS), is thought to be produced primarily in neurons. However, very little research has examined the role of FMRP in cells of non-neuronal lineages (called astrocytes or oligodendrocytes) in the CNS (Central Nervous System). This project will examine the role for FMRP in astrocytes during CNS development.

Historically, astrocytes have been viewed as secondary cells, providing structural and trophic (nutritional) support to neurons. However, emerging evidence suggests highly important roles for astrocytes in the proper formation, maturation and maintenance of synapses. Astrocytes may also influence dendritic spine morphology of neurons and play a role in synaptic pruning, a process that is abnormal in FXS.

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## **Testing Metabotropic Glutamate Receptor and GABA Ligands in Fragile X Syndrome Mice**

**Principal Investigator:** David R. Hampson, Ph.D.

Leslie Dan Faculty of Pharmacy, University of Toronto

**Project Dates and Duration:** July 1, 2007, \$42,500 for one year.

Fragile X syndrome (FXS) is a genetic disorder caused, in most cases, by an inherited mutation of the FMR1 gene, which in turn prevents the production of its corresponding protein. The FMR protein encoded by this gene is normally operative in neuronal branches (*dendrites*) where it controls local protein synthesis. The FMRP is involved in binding and transporting genetic messages to the synapse where they are held in an inactive state until needed. The loss of this protein in FXS causes many defects including seizures in about 20% of FXS patients and abnormal dendritic spine formation and the inhibition of synaptic growth, and interference with learning and memory. It is believed that the defects in neuronal morphology may underlie many of the symptoms seen in the animal models and in patients with Fragile X.

This lab will test the hypothesis that drugs that stimulate the mGluR receptors of neurons (called group I *mGluR agonists*) will exacerbate the pathological features and seizure susceptibility of the disorder while drugs that suppress mGluR receptors of neurons (called *Group I mGluRs antagonists*) will ameliorate seizures and pathology. It will also test compounds that bind to another type of neuronal receptor believed to be affected in Fragile X Syndrome, known as the GABA receptor. The primary emphasis will be on testing various drugs and compounds for use as potential therapeutic treatments.



## Physician Awareness of Fragile X

Even though Fragile X is the most common inherited form of mental impairment, and the most common known cause of autism, it is still goes unrecognized by many physicians. In addition to funding research aimed at finding improved treatments, and ultimately a cure for Fragile X, the FXRFC constantly seeks opportunities to disseminate information about Fragile X to the public and to Canadian physicians.

*The Parkhurst Exchange*, is a monthly clinical journal read by over 40,000 Canadian physicians, mainly family practitioners. It has a column called **Clinical Case Conundrums**, which discusses diseases that are relatively uncommon, but will be presented to a family physician. Dr. Paribello, President of the Fragile X Research Foundation of Canada (FXRFC) was recently requested to write a feature article on **Fragile X Syndrome**.

It will be published in the March 2007 issue of *The Parkhurst Exchange* and provides a wonderful opportunity for the Foundation to expand its education of the medical profession with regards to Fragile X. It will discuss key practice points -- clinical signs and symptoms, diagnosis, differential diagnosis, management, schooling and teaching advice and recommendations, genetic testing, prenatal diagnosis, and new research directions.

Issues of the *Parkhurst Exchange* can be viewed online at: [www.parkhurstexchange.com](http://www.parkhurstexchange.com)

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## Recreational Activities List for Kids with Fragile X Syndrome



By Myra Sourkes M.D.  
Member, Board of Directors, FXRFC



I am a Fragile X parent and Board Member, and I have compiled the following list of organizations, programs and suggestions for leisure activities for Fragile X kids. This list is not official or exhaustive, and neither I nor the Board endorse any of these programs. Most of the information comes from my own experience, that of other parents on the Board or our friends, or word of mouth. Because I live in Toronto, many of the listings are in Ontario, but I am sure that similar programs exist across the country. I have often been frustrated that there is no central body that provides this kind of information, and I hope that readers will find some helpful ideas in the list. If you know of any programs or organizations in your province, we would be happy to include them in future issues. One of the reasons we publish the newsletter is to share information between families across Canada, so please feel free to contact us and let us know how you spend time with your family.

This information will be put on the FXRFC website, and will be updated periodically.

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## GENERAL

### ART AND OTHER ARTS CLASSES



Visual art classes can be good opportunities for integration, fun, creativity, improving fine motor skills and pride of accomplishment. Other arts classes can also open up new worlds, dance, singing, music, etc. There are trained therapists in these disciplines. For instance, music therapy programs, in small groups or 1:1, can help children improve coordination, rhythm, counting and other math skills, expressive language, articulation and imagination, as well as learn about music.

### BOOKS

Good old fashioned book reading is a wonderful pastime that should not be forgotten. Children who cannot read or cannot read well can still enjoy being read to or reading with someone's help. Public libraries have appealing children's programs.



### COMMUNITY DANCES

Some wonderful individuals and organizations run social dances for teenagers and young adults with special needs. Check with your local Community Living Organization.

### COMPUTER EDUCATIONAL PROGRAMS AND GAMES

There are companies who have developed educational software and games that are especially helpful for children with special needs. There are also many websites that have easy and educational games and puzzles. Edmark is a source, as are the Close Pro, Clicker, and Premier softwares.

### GAMES

There are many classic and new games, which are fun and educational. An adult may have to spend a lot of time teaching them, and some children may require an adult's ongoing participation. Some examples are Apples to Apples Junior, Architex, Bingo and variations, simple card games like Fish, color-by-number pictures and variations, Cranium, Cadoo, Discovery Toys company products, dominoes and triominoes, jigsaw puzzles, Junior Scrabble, Kerplunk, LeapPad Learning System, Memory games and variations, Monopoly and variations, sequence cards, Snakes and Ladders, Sorry and Sorry Card Revenge, Super Mind from Leisure Learning Products, Twister, and Wedgits.



### RECREATIONAL SPORTS

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. Adapted programs for many sports exist, some of which are mentioned elsewhere in this list.

### 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.

## **CAMPS & RESIDENTIAL PROGRAMS**

There are many day and overnight camps, some integrated, some special needs only. I have listed a few examples below. Other camps are mentioned in other places in this list.

### **BLOOMING ACRES**

Ontario 705-487-3076 • [www.bloomingacres.com](http://www.bloomingacres.com)

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](http://www.ccamping.org) • This website provides links to provincial associations.



### **CAMP KENNEBEC**

Ontario 1-877-335-2114 • [www.campkennebec.com](http://www.campkennebec.com)

An integrated residential summer camp including children with LD, ADHD and behavioral needs.

### **CAMP KIRK**

Ontario 416-782-3310, 1-866-982-3310 • [www.campkirk.com](http://www.campkirk.com)

Residential summer camp for children with learning disabilities and Asperger's Syndrome. Owned by the Lion's Club.

### **CAMP KODIAK**

Ontario 905-569-7595, 1-877-569-7595 • [www.campkodiak.com](http://www.campkodiak.com)

An integrated, non-competitive, residential summer camp, including tutoring, for children, teens and young adults with and without learning disabilities and ADHD.

### **CAMP PROSPECT**

Ontario 705-735-0129 • [www.campprospect.com](http://www.campprospect.com)

Residential summer camp and year round programs for people of all ages with complex special needs.

### **CAMP WINSTON**

Ontario 416-487-6229 • [www.campwinston.com](http://www.campwinston.com)

A residential summer camp for children with complex neurological disorders.



### **CIRCLE SQUARE RANCH**

905-332-6400, ext. 3310, 1-800-539-9598 • [www.csranch.ca](http://www.csranch.ca)

These integrated summer camps are across the country. They are Christian-based, but welcome children and youth of any faith.

## **RECREATION PROGRAMS**

### **BLOORVIEW KIDS REHAB CENTRE FOR THE ARTS**

Toronto 416-425-6220, ext 3317 • [www.bloorview.ca/centreforthearts](http://www.bloorview.ca/centreforthearts)

This centre offers visual arts, performing arts, music and multimedia programs year round for children and youth of all abilities. The programs are integrated, with priority given to those with special needs.

### **GUIDES AND SCOUTS**

Many children enjoy these programs, and a respite worker can help ensure success.

### **CHIRP CHICKADEE OWL MAGAZINES**

416-340-2700 • [www.owlkids.com](http://www.owlkids.com)

These Canadian magazines for children of different ages focus on nature, science, discovery and fun. They are colorful, attractive, informative and educational.

### **GYMBOREE LEARNING PROGRAM**

Alberta, BC, Ontario • [www.gymboreeclases.com](http://www.gymboreeclases.com)

This 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**

Toronto 416-973-4600 • [www.harbourfront.on.ca](http://www.harbourfront.on.ca)

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

### **SOUTHPAW ENTERPRISES**

1-800-228-1698 • [www.southpawenterprises.com](http://www.southpawenterprises.com)

This is a US catalog of equipment, products and toys for sensory processing disorders.

### **SUPER DUPER PUBLICATIONS**

1-800-277-8737 • [www.superduperinc.com](http://www.superduperinc.com)

This is a US catalog of fun and educational materials for speech-language pathologists, teachers, parents and caregivers, which is geared to kids with reading, language and social skills problems.

### **UPSTAIRS AT LOBLAWS**

Loblaws has children's cooking classes that welcome kids with special needs.

### **SPORTS PROGRAMS**

#### **CARD**

Community Association for Riding for the Disabled • Toronto 416-667-8600 • [www.card.ca](http://www.card.ca)

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.

#### **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.

#### **ONTARIO TRACK 3 SKI ASSOCIATION**

Ontario 416-233-3872, 1-877-308-7225 • [www.track3.org](http://www.track3.org)

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

#### **LAURA HUNTER'S STEPS PROGRAMS**

Ontario 905-642-8001 • [www.stepsprograms.com](http://www.stepsprograms.com)

STEPS stands for specialized therapeutic education for physical skills. Laura runs gym, biking, horseback riding and lifeskill programs, year round, for toddlers to young adults with intellectual and/or physical disabilities.

#### **THE Y**

Ys have many activities and camps that include kids with special needs.



### **POINTE-CLAIRE AQUATIC CENTRE**

Montreal 514-630-1202 • [www.ville.pointe-claire.qc.ca/En/Services/aquatic/Adaptive/Adaptive.asp](http://www.ville.pointe-claire.qc.ca/En/Services/aquatic/Adaptive/Adaptive.asp)  
There are 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**

1-888-888-0608 • [www.specialolympics.ca](http://www.specialolympics.ca)  
This is a community-based organization across Canada that provides sport training and competition opportunities for children and adults with an intellectual disability.



### **SUPPORT SERVICES**

#### **ACCESS 2 ENTERTAINMENT CARD**

[www.access2.ca](http://www.access2.ca) • The Access 2 Entertainment™ Card allows people with a disability to receive either free admission or a significant discount for their support person at most movie theatres across Canada.

#### **CAMPBILL COMMUNITIES ONTARIO**

705-424-5363, [www.camphill.on.ca](http://www.camphill.on.ca) • Camphill is a lifesharing community including adults with special needs, in group residential and work environments

#### **CANADIAN ASSOCIATION FOR COMMUNITY LIVING**

[www.cacl.ca](http://www.cacl.ca) • This is a Canada-wide association of family members and others working for the benefit of people with an intellectual disability.

#### **GENEVA CENTRE FOR AUTISM**

Toronto 416-322-7877 • [www.autism.net](http://www.autism.net)  
This is an autism info. and education centre, with many courses, lectures and workshops about autism and developmental disorders, given by professionals with different kinds of expertise. The centre also provides multidisciplinary assessments, has treatment programs, and runs social skills groups and respite programs.

#### **MIRIAM FOUNDATION**

Montreal 514-345-1300 • [www.miriamfoundation.ca](http://www.miriamfoundation.ca)  
This is a not-for-profit organization which supports rehabilitative, vocational and residential services (English and French) for children and adults with intellectual disabilities.

#### **LEAPS AND BOUNDS**

905-727-2273 • [www.leapsandboundsservices.com](http://www.leapsandboundsservices.com)  
This organization provides a range of services for individuals with autistic spectrum disorders, developmental disorders and learning disabilities, including individualized programming, behavior management, behavior therapy, social, communication and life skills, tutoring, and family respite. Services are available across the country.

#### **ONGWANADA**

Kingston 613-548-4417 • [www.ongwanada.com](http://www.ongwanada.com)  
This organization offers a wide range of individualized services and community supports to people with developmental disabilities and their families. It is affiliated with research programs at Queen's University.

## **LEARNING DISABILITIES ASSOCIATION OF CANADA**

613-238-5721 • [www.ldac-taac.ca](http://www.ldac-taac.ca)

Many people with Fragile X Syndrome fit the definition of a learning disabled person. This organization has chapters in each province, provides information, publishes guides and manuals, organizes conferences and advocates for its population.

## **INTEGRA**

Toronto 416-486-8055 • [www.integra.on.ca](http://www.integra.on.ca)

This children's mental health center is for children and adolescents with learning disabilities, who experience social, emotional and behavioral problems. Services include counseling, group programs, parent groups and a therapeutic summer camp.

## **REACH FOR THE RAINBOW**

Ontario 416-503-0088 • [www.reachfortherainbow.ca](http://www.reachfortherainbow.ca)

Reach for the Rainbow provides integrated recreational and respite opportunities for children and young adults with disabilities, arranging 1:1 support in existing day and residential summer camps and year round community programs. Many of the programs in this list are affiliated with Reach for the Rainbow.

## **REENA**

Toronto region 905-889-6484, 1-877-324-4114 • [www.reena.org](http://www.reena.org)

This social service agency is dedicated to integrating people with developmental disabilities into the community. Services include residential supports, and day and evening programs for older children, teens and adults that focus on recreation, social skills, work skills development and job placement. Reena emphasizes Jewish culture and values, but welcomes people of all denominations.

## **RESPIRESERVICES.COM**

[www.respiteservices.com](http://www.respiteservices.com)

This is an online registry in Ontario, which coordinates a network of agencies and organizations providing respite services to people with all kinds of disabilities and their families. Its objectives are to provide information about services, to allow families to access respite care at home and in the community, and to facilitate creative respite options that meet each person's needs.

## **SPECIAL SERVICES AT HOME**

Ontario Ministry of Community, Family and Children's Services

[www.children.gov.on.ca/cs/en/programs/SpecialNeeds/](http://www.children.gov.on.ca/cs/en/programs/SpecialNeeds/)

Through this program, the Ministry in Ontario provides financial support to families with special needs children, independent of income. For children with Fragile X Syndrome, this can translate into thousands of dollars, which can be used to pay for respite programs such as those on this list, among other things. The Ministry provides additional funding to low-income families. Similar programs may exist in other provinces.

## **VIA RAIL TRAVEL**

Via Rail's policy is that if a person of any age with special needs cannot travel alone, then the accompanying person travels free. You must have a medical certificate when you purchase your tickets.



## Third Annual Reunion of Fragile X Families

*By Beverley-Ann Lee, Geneticist, Member, Board of Directors, FXRFC*



This November, 2006, Hôpital Rivière-des-Prairies hosted the 3rd annual reunion of Fragile X families. Although a tremendous amount of information on Fragile X is available on the internet as well as numerous other sources, no support is greater and more meaningful than the sharing of experiences among families. Older families especially are an inspiration for younger ones.

During the reunion this year, everyone quickly found their common ground, sharing practical experiences,

coping strategies, and stories of their challenges, their courage and victories. In this milieu of trust and understanding, families also shared their deepest emotions, their heartfelt concerns and their ultimate hope for the future.

People tell us that with support, their sense of isolation and discouragement dissipates. Having support allows them to feel more confident and to stay the course with a sense of optimism, humour, pride and joy.

Since last year, two members of our support group began to develop written materials in French, to raise awareness about Fragile X. These were displayed during the family reunion. One booklet is currently in progress and the other is ready for publication and will soon be ready for distribution. The booklet titled "Adam Has Fragile X" will be the first on Fragile X written in Quebec and, as far as we know, the first also for Canada.

We are extremely proud of all the families who support one another in spirit, at reunions and through their ongoing efforts to promote research and public awareness.

At Hôpital Rivière-des-Prairies, we look forward to continuing our support by bringing everyone together and providing ongoing information. We also share in the hope that one day a treatment or cure will be found to relieve all the debilitating effects of this syndrome.



**Adam a l'X fragile**

Adam a le X fragile est un petit livre rempli de belle photos où une maman partage avec nous les beaux sourires de son enfant atteint du syndrome X fragile. En toute simplicité, elle y présente les problématiques et les réussites vécues par son enfant. À la portée de tous, il est parfait pour expliquer les caractéristiques et les implications quotidiennes du syndrome... Ce précieux document deviendra certainement une référence importante pour tout enfant atteint du syndrome X fragile.

## XXXX-tra Special People!

The FXRFC Newsletter often publishes stories about the people that have sparked the formation and inspired the growth of the FXRFC. If you have a story about a child or adult with Fragile X, please send it to us and a picture of the X-tra Special Person to share with our readers. Tell us a funny or heart-warming story, or share a success.

This newsletter we have several X-tra Special people. The first is Nicholas Paribello, of Brampton, ON.

**THE OLYMPIAN** - By Barbara, mother of Nicholas.

The weekend of February 1-4, 2007 may have been a cold and blustery one for most people in Owen Sound, but things were really “cookin” for extra special person Nicholas Paribello! Nicholas was competing in the Ontario Special Olympics Winter Games, as a member of the Barrie Snow Striders Cross Country Ski Team. Only in his rookie year, Nicholas qualified to join the Region 6 Team to compete with skiers from across the province. The group were bused to the Meaford Army Barracks and spent four days that started with Opening Ceremonies at the Harry Lumley Community Centre, attended by the Owen Sound Attack of the OHA and the Owen Sound Police Department, complete with pipers and torch ceremony. The team received generous sponsorship from Royal Bank, Roger’s Communications, and the O.P.P. The town of Owen Sound businesses from McDonald’s to Staples and the Brick had welcome signs out for the athletes and their families. There were over 400 people from the community volunteering at this very well organized event!



*Nicholas shows off one of his gold medals*



*Striding to the finish line!*

Nicholas had an extremely successful time, winning two Gold Medals in his Division for the 1 km and 2.5 km events. Though the snow was flying and the wind chill was -25C, Nicholas blasted towards the finish line, double polling like a machine. We, as his parents, were jumping for joy as he charged past the finish line! His entire family is so very proud of his accomplishments! We highly recommend the opportunities afforded to athletes by the Special Olympics organization. Keep posted to their website for information about the Canada Games to be held in Quebec City in 2008!

Our next Xtra-Special Person is Andrew Ballard, of Pickering, ON.

## A Safe Ride

Andrew’s mom Dagmar Ballard writes: Andrew loves to ride with his favourite “Uncle Randy” on his Harley Davidson. Uncle Randy used to bring Andrew to tears when Andrew was a toddler. He was so afraid of Randy...



must have been the deep voice and long beard. Randy really is just a big pussy cat. Andrew so enjoyed the ride with Randy that Dad went out and got his own Harley last spring. Now Andrew enjoys a ride with Dad (Chris) around the neighbourhood. In the beginning when Chris ventured out alone Andrew would tell him to “Ride Safe”. Seems to be fail-safe. Chris never leaves for a bike ride before hearing that phrase from Andrew.

*And last but certainly not least...*

## **An Alternative Birthday Present For Sebastian's 4th Birthday**

*Less than one year ago Sebastian was diagnosed with Fragile X Syndrome, the world's most common inherited developmental disorder. For Sebastian's 4th Birthday, we would love for all of our family and friends to help us support the Fragile X Research Foundation of Canada. Any donation made on Sebastian's behalf would be greatly appreciated. As Sebastian has many toys, and with Christmas so close, we feel that a donation to support research would be a wonderful birthday present for Sebastian.*

*Thank you for your support! Thomas, Liz, Sebastian & Marcus*

We raised \$370 for the FXRFC and Sebastian had a wonderful day with his family and friends!



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## **FXRFC Support Groups**

We are very interested in starting support groups in the other provinces and territories and will provide assistance to anyone able to help out. If you would like to network with other parents of children with Fragile X, or if you would like to volunteer for fundraising events in your area, please contact any of the people below.

### **National Headquarters**

167 Queen St. W. Brampton,  
Ontario, Canada L6Y 1M5  
Phone: (905) 453-9366  
E-mail: fxrfc@attglobal.net

### **Quebec**

Evelyn Lockett  
32 Lakeview, Baie d'Urfe, Quebec  
H9X 3B1 Phone: (514) 457-3284  
E-mail: evelyn\_lockett@hotmail.com

### **Ontario**

#### **Kitchener-Waterloo**

Teresa Burch, Co-ordinator  
62 Corfield Drive, Kitchener, Ontario  
N2A 3W9 Phone: (519) 894-3689

### **British Columbia**

Pam Winthrop  
7968-112A Street, Delta, BC  
V4C 4Y6 Phone: (604) 590-6822  
E-mail: pwinthrop@hotmail.com  
Web: <http://fragilexbc.tripod.com/fragilexbca>

### **Fundraising and Public Awareness Contacts**

Kirsten J. Madsen  
4022 West 28th Ave. Vancouver BC  
V6S 1S8 k.j.madsen@telus.net  
cell 604-607-5480  
office 604-683-1211 (collect calls accepted)

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## **FXRFC Newsletter**

This newsletter is published regularly and is sent to friends of the Fragile X Research Foundation of Canada (FXRFC). Permission is granted to reproduce and distribute this newsletter for noncommercial purposes.

The Fragile X Research Foundation of Canada (FXRFC) is a national, nonprofit, tax-exempt organization; charitable # 88643 3762 RR0001. You can become a friend of the FXRFC for a tax-deductible donation of \$35 or more per year. The FXRFC is a 100% volunteer organization run by parents and professionals - which means more of your donation goes directly towards research. We now accept VISA and Mastercard payments; simply phone (905) 453-9366 and pass on the details. You may send your cheque or money order to:

The Fragile X Research Foundation of Canada • 167 Queen St. W., Brampton, ON, Canada L6Y 1M5

*Come visit our site on the web at: <http://www.fragile-x.ca>*