

xpressions



Fragile X Research Foundation of Canada Newsletter

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The FXRFC Expands its Research Grant Program

The Fragile X Research Foundation of Canada (FXRFC) offers a grants and fellowships program designed to accelerate research aimed at finding a specific treatment for Fragile X Syndrome.

Most of the research funded by the Fragile X Research Foundation of Canada has been financed with money raised privately by the parents, families, and friends of individuals with Fragile X Syndrome. However, part of the FXRFC's strategy to increase the amount and quality of research done in this field is to advocate for more government funding for work on Fragile X Syndrome.

FXRFC GRANTS AND FELLOWSHIPS PROGRAM

The Fragile X Research Foundation of Canada (FXRFC) offers a grants and fellowships program designed to accelerate research aimed at finding a specific treatment for Fragile X Syndrome.

The Foundation now offers grants in two categories:

1. Postdoctoral Fellowships of \$45,000 per year will be offered to support postdoctoral fellows who want to pursue research in Fragile X (includes salary plus research travel allowance). Grants are awarded for a period of one year, but may be renewed yearly to a total of three years if satisfactory progress is made.

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2. Program Grant awards of up to \$65,000 are also available to fund investigator initiated research projects. These grants will be awarded to applicants proposing innovative pilot studies aimed at developing, characterizing and testing new therapeutic approaches for the treatment and ultimate cure of Fragile X Syndrome. Program Grants are awarded for a period of one year, but may be renewed yearly if satisfactory progress is made.

New applications are considered once a year, and the next deadline for applications is **November 1, 2015**.

Families are invited to attend The Fragile X Conference in Victoria, B.C. on November 7th, 2015

The newly established Fragile X and Related Disorders Clinic in Victoria B.C. is hosting their first Fragile X Syndrome Conference on Saturday, November 7th, 2015. This conference is part of their mandate to provide assessments for individuals with Fragile X and / or Fragile-X related disorders. They also provide ongoing education and support by connecting families, health care providers and support workers with appropriate resources across Vancouver Island and Lower Mainland communities.

The conference is open to Fragile X families, educators, health care providers, support workers and students. For those that cannot travel, video-conferencing will be used to reach out to communities across B.C.

They have a dynamic, wide-ranging and multidisciplinary team of speakers including:

Tracy & Mouse from Developmental FX in Denver, Colorado,

Dr. Carlo Paribello, President & Medical Director of the Fragile X Research Foundation of Canada,

Dr. Elena Lopez-Rangal, Clinical Assistant Professor, Division of Developmental Pediatrics, University of British Columbia,

Kirsten Madsen, former Director for the Developmental Disabilities Association of B.C., active volunteer with the Fragile X Research Foundation of Canada, as well as parent to her son Adam who has Fragile X Syndrome; and

Dr. Gudrun Aubertin, Clinical Geneticist & Director of the Fragile X and Related Conditions Clinic, with support from the FXRFC clinical team.

Although the conference will be open to the general public, it will be geared towards individuals with Fragile X Syndrome and related conditions, family members, physicians and other health care professionals as well as support networks within the community.

For further information contact: **Molly Perry**, Project Coordinator - Victoria Fragile X Clinic, Queen Alexandra Centre for Children's Health, A015B - 2400 Arbutus Road, Victoria, B.C.

Phone: 250-519-5390 Ext: 36956, email: Molly.Perry@VIHA.CA

Did you know...

Fragile X Syndrome

is the most common INHERITED form of mental impairment.

1 in 4,000 males & 1 in 6,000 females

are affected worldwide, from all ethnic & socio-economic backgrounds

Study Focused on Men with the Fragile X Premutation

A California research team is searching for men who are carriers of the Fragile X premutation between the ages of 40 and 75 to participate in a longitudinal U.C. Davis research project, studying changes in brain and cognition associated with aging. For men who have not yet been tested, FMR1 DNA testing is completed to help determine eligibility for the study. The study involves three 2-day visits over the course of five years, and each visit includes:

- Pictures of the brain, taken while engaged with different tasks
- Testing of thinking and memory skills
- Blood samples for testing related to the FMR1 gene
- Interviews and questionnaires focused on health history

Participants will be compensated \$200 for each 2-day visit (\$100 for completing each day), and there is travel and lodging reimbursement. Participants are also given a picture of their brain. Feedback can also be provided on cognitive strengths and weaknesses.

Please contact the researchers listed below if you or someone you know may be interested in participating.

For more detailed information please contact:

Jessica Famula, MS,

David Hessel, Ph.D.,

Susan Rivera, Ph.D.

(916) 703-0470 or email: trajectories@ucdmc.ucdavis.edu

Access 2 Cardholder Updates and Reminders



In our last newsletter, we introduced the Access 2 Entertainment card. Easter Seals has issued this update and reminder to all cardholders: As the number of cardholders continues to grow and as the Access 2 program continues to partner with new venues all across Canada, we wish to remind members of the terms and conditions when using the card, to ensure the continued success of the program.

- The Access 2 card is meant to provide 1 free or significantly reduced admission ticket for the cardholder's support person. The card does not provide free admission for the cardholder.
- When a cardholder presents the Access 2 card at a participating movie theatre or selected attraction across Canada and pays the standard admission fee, the support person is then given one free admission or a discounted admission for the purposes of accompanying the cardholder. The cardholder must pay the regular admission price and the two tickets must be issued during the same transaction.
- Photo Identification is NOT necessary, however the theatre or attraction may ask to see a second piece of photo identification to verify the identity of the cardholder.
- The cardholder and support person must attend the movie or attraction together and the two tickets must be for the same performance, date, and time.

For full program terms and conditions, or to learn about how the card works, please visit www.access2card.ca

The 12th Annual Fragile X Family Fun Day - a Big Hit!



By: Lori Beesley & Jennifer Williams

We held our 12th Annual Fragile X Family Fun Day at Variety Village in Scarborough, ON on Sunday June 21st. It was a special day this year since it was Fathers Day as well as the Family Picnic Day. This year Variety Village had a new outdoor playground for the families to enjoy. We were one of the first groups to get to make use of this equipment and we noticed that the large swing was a huge hit with many of our families.

Together with some of our special Fragile X families and some very generous businesses we approached, we were able to secure some wonderful donations. We put together great prizes and baskets of goodies in order to hold a raffle. We would like to thank the numerous families and companies who stepped up and helped make the day such a success.

A special thank you goes out to Nancy Cameron. Nancy once again made a lovely quilt in honour of her grandson who has Fragile X Syndrome. Nancy's homemade quilt is eagerly anticipated every year and we look forward to her unveiling the new design upon it's arrival. We also look forward to learning who the lucky winner will be, who gets to take home this work of art. This year Nancy very generously made both Jennifer Williams and Lori Beesley their own quilts and presented them to the Fun Day co-chairs, as a thank you on behalf of the families. *Nancy, both Jen and myself were extremely moved by this incredible gesture and we both treasure our quilts, as you know.*

This event would not be possible without a team of volunteers who help out before and during the Family Fun Day. Many, many thanks go out to all of the volunteers and people who were so generous with their time and effort. We really appreciate your loyal dedication to our event.

If you are interested in helping at next year's picnic, know someone who would volunteer or has a connection to a corporate sponsor, please email us at picnic@fragilexcanada.ca. We are always eager for teenage helpers, looking to earn their high school volunteer hours. It is never too soon to start planning for next year!





Fundraising News Update

Disneyland & a Garage Sale

By: Laura Devonport

What do these two things have in common?
Hilary Brown and Laura Devonport!

Hilary took part in 3 events over 3 days at Disneyland to raise money and awareness for FXRFC. Friday, September 4th was a 5k run, Saturday, September 5th a 10k run and Sunday, September 6th was a half marathon! All this just as she was recovering from a bout of pneumonia, what a super star!

Meanwhile Laura and her family held a weekend long garage sale, where they also sold popcorn, baked goods, and had an old fashioned lemonade stand. The total raised from these two events, championed by long-time friends Hilary and Laura, is currently at \$2,316 and is still growing!

The FXRFC would like to thank both of these amazing women for all their time and effort. We hope they serve as inspiration to other families to get creative and hold their own fundraisers!



FXRFC Tumblers are Here!

The FXRFC tumbler made its debut at the Fragile X Family Fun Day held this past June and was a big hit with the families attending.

They are \$20 each if you purchase a single tumbler. If you purchase two or more at the same time, they become \$15 each. Postage must be paid by the recipient in advance. They are a great gift idea for loved ones, teachers, EA's, bus drivers, babysitters and daycare staff. Why not get creative and tuck a gift card inside or fill one with chocolate kisses to make the gift extra special! They can hold either hot or cold beverages, and with their double wall technology, there's no condensation! They are decorated with an illustration of two children, a boy and girl, holding up a banner that has the FXRFC logo and website. All tumblers are the same. If you'd like to place an order, please contact Jennifer Williams at: fundraising@fragilexcanada.ca

FXRFC is on Facebook - check it out!

Please go to our page and "Like" Us! Our FB page has become a great forum for our Fragile X families all across Canada. It's a great way to connect with each other, share ideas and info, and support one another. Feeling isolated? Maybe there is another FXRFC family near by - make a connection!

For anyone in the Toronto area, keep checking out our FB page to see details for Team Toronto and the Scotiabank Run on October 18th. Join the team!!!



Top 10 Things a Teacher Should Know About Fragile X Syndrome

We came across this great list and asked the author if we could reproduce it in our newsletter. We hope many of you will find this helpful and pass this along to your children's school and teachers.

The #1 thing teachers should know about students with Fragile X Syndrome is that they are prone to hyperarousal and anxiety.

It is how their nervous systems are wired. Most recommendations that follow are geared to maximizing focus and cooperation by minimizing hyperarousal and anxiety:

1. **Don't force eye contact**
Eye contact will come naturally as the student becomes more comfortable with you.
2. **Expect inconsistency**
Engagement and performance is likely to vary greatly; it can be difficult to discern why. Try to accept this to avoid frustration; your student will pick up on frustrated energy and that will exacerbate anxiety.
3. **Students are "simultaneous" vs "sequential" learners**
Students with FXS are good sight word learners, but have a terrible time with phonetics. They are motivated by the end result, and impatient with the process. Use backward rather than forward chaining; use checklists to show progress toward an end result.
4. **Allow and/or encourage frequent breaks**
Accommodate attention deficits by keeping tasks brief. Keep up a good pace – power breaks are short breaks.
5. **Verbal expression is cognitively taxing**
Provide some non-verbal alternatives for students to show what they know, such as following directions and pointing to visual representations.
6. **Think "INDIRECT"**
There are times when students with FXS enjoy attention, but most often they are adverse to the limelight. Give compliments in the 3rd person about the student to others within earshot; use incidental learning; include the student in a small group while directing instruction to a peer; avoid direct, open-ended questioning: prompt "The Prime Minister of Canada is....." vs. "Who is the Prime Minister of Canada is?"
7. **Prepare for transitions**
Give 10 and 5 minute prompts. Allow students to be at the head or back of the line. Use social stories about routine transitions. Provide a purposeful errand so the focus is on the outcome (e.g. delivering an envelope) rather than moving from one place to another.
8. **Work with an OT knowledgeable about sensory integration (S-I). Embed S-I strategies into the day.**
Students with FXS are prone to hyperarousal and anxiety which undermines focusing ability - learn what S-I techniques are calming for your student - heavy work like re-arranging desks, cleaning windows, moving stacks of books? Vestibular input, like going for a walk, doing wall push-ups, swinging, using a skateboard? Integrate these activities throughout the day to sustain a calm, regulated nervous system.
9. **Notice environmental triggers**
Students with FXS often have sensory sensitivities to sound, light, textures, taste, and smell that provoke hyperarousal. Make adjustments to the environment (dim lighting, allow use of muting headphones) as much as possible.
10. **Know FXS strengths**
Common strengths associated with FXS are a good visual memory, sense of humor, desire to be helpful, empathic nature, and gift for mimicry. Use visual cues, make learning fun, provide opportunities to be of assistance, encourage providing emotional support to peers, use modeling as a primary teaching technique - embed academics into useful and practical tasks, such as taking attendance (counting) or ordering from a menu (reading) - **and ENJOY YOUR STUDENT WITH Fragile X Syndrome!**

Important Information

Canada Post increased first-class postage prices significantly in March 2014. This has had a financial impact on the FXRFC because it increases our cost to mail out both our newsletters and income tax receipts. How can you help? There are two ways:

By going to our website when you want to make a donation: fragilexcanada.ca

Just click on our Donate Now button, and you are linked to Canada Helps where you are able to make a safe and secure donation on-line. You can even designate who your donation is in honour or memory of. You will receive a speedy electronic tax E-receipt and this will keep associated administrative costs to a minimum, allowing more funds to be directed to the scientific research we fund. You can also sign up to receive this Newsletter via your email in-box. We encourage you to share an email address with us to receive a colour newsletter in an easy print-at-home pdf format!

Just email info@fragilexcanada.ca and be patient, it might take us an issue for the switch to occur.



Fundraising and Volunteering

The Fragile X Research Foundation of Canada is a 100% volunteer organization. How our volunteers contribute and how much time they contribute differs from person to person. We value all of our volunteers however they choose to give their time. If you are interested in volunteering with the Foundation please contact us or go to the **Volunteering** page on the **How to Help** section of the FXRFC website. You can also contact our National Fundraising Coordinators, Ian Shearer and Jennifer Williams, by sending an email to fundraising@fragilexcanada.ca or volunteer@fragilexcanada.ca

We are currently seeking volunteers who can help with the FXRFC newsletters and the Annual Reports. We are in need of a graphic designer & a writer to assist.

FRAGILE

This newsletter is published 3 times/year by Fragile X Research Foundation of Canada and sent to our supporters. You can view/download a PDF of the newsletter on our website at www.fragilexcanada.ca by clicking on Resources. If you do not receive our newsletter regularly or would like us to mail a copy to someone you know, send an email with a complete mailing address to newsletter@fragilexcanada.ca

The Fragile X Research Foundation of Canada (FXRFC) is a national, nonprofit, tax-exempt charitable organization run by parents of children with Fragile X syndrome and volunteer professionals. Permission is granted to reproduce or distribute this newsletter for non-commercial purposes. We accept donations on-line through our website at www.fragilexcanada.ca or by mail or phone at our National Headquarters in Brampton, Ontario.

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Please Remember to...

Keep checking the FXRFC website for upcoming events. If you have an event planned in your area, let us know and we'll include it on the site and in our next **xpressions** newsletter.

www.fragilexcanada.ca
& FXRFC on Facebook
Check us out!

We're looking for a
Graphic Designer
and a Writer to
assist the FXRFC.

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