

xpressions

Fragile X Research Foundation of Canada Newsletter

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Read about ideas, or tools that make living with Fragile X a little bit easier day to day.

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This is the last *printed* issue of the FXRFC newsletter!

Due to increased costs involved in delivering this newsletter to families across Canada, we have made the decision to move to an **E-Newsletter format!**

Canada Post increased first-class postage prices significantly in recent years. This has had a financial impact on the FXRFC because it has increased our cost to mail out both our newsletters and tax receipts.

Due to this increase and other costs involved in delivering this newsletter in a printed format to families across Canada, we have made the decision to move to an **E-Newsletter format**. There was notification in the last newsletter, letting you know and providing time to sign up and send in your e-mail address. It's not too late!

Don't wait! Send your e-mail address please!

You can sign up to receive this newsletter via your email in-box moving forward.

We ask you to share an e-mail address with us, and you will receive a colour newsletter in an easy print-at-home pdf format! Or save a tree and read it on-line!

Just send an email to: **info@fragilexcanada.ca** with your preferred e-mail address and your next FXRFC newsletter will arrive via your in-box.

We promise not sell the email addresses to any organization.

Thank you for understanding!

The FX Tool Box

The Tool Box is filled with suggestions, helpful hints and coping strategies – tools to make living with Fragile X Syndrome easier. We invite you to send in your favourite tools to:

toolbox@fragilexcanada.ca for printing in future newsletters. On the FXRFC website, in **Coping with Fragile X**, you'll find a **Helpful Hints** page, where the Tool Box also appears.

We thought with school underway, we'd share some tools regarding cooperation skills and building friendships with classmates. Perhaps you can share this article with your child's teacher!

Learning to play and work with peers is a critical skill for developing friendships, doing group projects, and participating in extra-curricular activities. Cooperation skills also build the foundation for more complex social skills.

Create Roles – Teach children about cooperation through group activities that require skills such as waiting, turn taking, and following directions. Here are few fun ideas.

- **Cooking** – Small group cooking activities are a fun way to divide work and practice skills. Have a written or pictorial recipe with ingredients and steps presented in order. Assign roles to each child such as measuring the flour, counting the correct number of eggs, pouring the milk, and stirring. Children have to wait their turn, follow directions,

and share responsibility for creating something they can enjoy later.

- **Gardening** – Whether potting seeds or planting flowers, children can have individual responsibilities such as digging holes, counting seeds, putting seeds in the holes, patting dirt over the seeds, and watering. Gardening also provides the opportunity for continued cooperation and responsibility. For example, assign children days of the week to water plants or weed the garden.

- **Art** – Group art projects such as murals and collages provide an opportunity for dividing work and creating a lasting reminder of cooperation. Select a theme and have children individually look for specific pictures in magazines for the larger project. For example, if the goal is to create a community scene, assign roles such as drawing streets, cutting out pictures of buildings, locating pictures of community helpers, and drawing trees.

- **Literacy** – Paired or small group writing or printing assignments require children to share ideas and work together. Set guidelines about each child's specific role so they divide the task rather than having one child complete the majority of it. Have a buddy system to learn how to write their own names.

Let's hear from you! If you have any neat tricks, just drop us an email and we'll add it to an upcoming Tool Box.

Did you know...

Some female carriers (approximately 20-28%) experience Fragile X-associated primary ovarian insufficiency

(FXPOI) – menopause occurring prior to the age of 40.

Learn more at fragilexcanada.ca



Looking for children and youth ages 4 years and up
to participate in a memory research study



Memory Study in Children / Youth We need your help!

Researchers at the University of Alberta, Department of Pediatrics and Stollery Hospital are completing a study looking at memory in children with a neurodevelopmental disorder and control children.

Who can participate:

- Have a child aged 4 years and up
- Have siblings interested in participating together



What will we learn:

- Learn more about memory development in childhood
- Want to better understand memory of children with a neurodevelopmental disorder

What will you do:

- Children will do some fun and interactive learning and memory games
- Play a short online memory challenge from home on two separate days
- Caregivers will be asked questions about their child's health and development
- We may invite you to do genetic testing at a later date but agreeing to complete the memory game in **no way commits you to participating in genetic testing**

Contact: if you have any questions or would like to participate in this study please contact the study coordinator by calling 780-492-9461 or by emailing: memgame@ualberta.ca

**Project
deadline is
November
30, 2016**

The project is titled 'Identification of novel genes intellectual disability', and the principal investigator of this study is Dr. Francois Bolduc, MD, PhD, FRCPC in the Department of Pediatrics, University of Alberta, <http://www.bolduclab.com>

The 13th Annual Fragile X Family Fun Day - Amazing!

By: Lori Beesley & Jen Williams



On Sunday June 19th, we held our 13th Annual Fragile X Family Fun Day in Scarborough, ON at Variety Village. We appreciated that this date was also Father's Day and we heard that this had an impact on being able to attend. We will do our best to avoid this in the future if possible.

As we've had in the past few years, there were some very nice prizes and baskets of goodies that we raffled off. We would like to thank the numerous families and companies who stepped up and helped make the day a success. We'd especially like to give significant acknowledgement to **Party City**. Every year they have been very generous and their donation, arranged by parent **Ryan Farquhar**, makes a big impact on the success of the day.

Another special shout-out goes to **Nancy Cameron**. Nancy once again made a lovely quilt in honour of her grandson who has FXS. Nancy's quilt is eagerly anticipated every year and we look forward to her unveiling the new design upon its arrival. Every year the lucky raffle winner is excited!

This event would not be possible without a team of volunteers who help out before, during and after the 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 dedication to our event.

If you are interested in helping at next year's picnic, know someone who would volunteer or have a connection to a corporate sponsor, please email: picnic@fragilexcanada.ca It is never too soon to start planning for next year!

We hope everyone enjoys seeing the pictures of this amazing day - can you spot anyone you know?!





Fundraising News Update

Pub Night Fundraiser in Surrey, B.C. and the Scotiabank Marathon in Vancouver

Bree Greves, Carrie Lakatos and Marylène Allard hosted their first Pub Night Fundraiser for Fragile X Research on May 21st, 2016 at the Dublin Crossing Irish Pub in Surrey, BC. It was a great success and will definitely become a yearly event. The night included a 50/50 draw, toonie tosses and a silent auction.

The three moms of boys with Fragile X, put together gift baskets and were also given donations by The Keg Steakhouse and Bar, Save on Foods, Safeway and a few other corporations, as items for the silent auction.

These families also ran in the Scotiabank 5km, half and full Marathon, with their family and friends on June 26th.

Thank you to everyone that took part in both events and we look forward to another great fundraiser and run next year!



Thank you B.C.
If you live anywhere in Canada and want to fundraise, we can help with ideas and support. Contact us!



Thomson Reuters learns about Fragile X Syndrome

By Lori Beesley, Board of Directors, FXRFC

On September 7th, 2016, I was invited to go to one of the Toronto offices of Thomson Reuters. My sister-in-law, **Gloria Beesley** is employed as an Information Solutions Consultant, in the Legal, Tax and Accounting area. They have a sales blitz day once every month and invite one of a variety of charities to attend. I shared some of our own family story, told everyone about the Fragile X Research Foundation of Canada, and what we do. The employees are invited to donate part of their sales towards the charity that is featured that month.

Thank you very much to Gloria and Thomson Reuters for inviting the FXRFC to be a part of your day!



Gloria Beesley (2nd from left) and some of her fellow Thomson Reuters staff

Volunteer to Fundraise for the FXRFC!

The Fragile X Research Foundation of Canada is a 100% volunteer organization. How our membership contributes and how much time they fundraise differs from person to person. We value all of our fundraisers, however they choose to make a difference. Whether you're a family member of someone with Fragile X syndrome, a friend, or just a community-minded individual, we welcome your contribution of time and energy.

If you are interested in fundraising with the Foundation please go to the **About Us** section, then the **Committees** page 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

A Little Brother and his Team's Big Win!

Submitted by proud father, Steve Lawrence

Our average son Derian plays baseball for the Whitby Chiefs Tier 4 Mosquito Rep Team. In June, the team competed in a weekend tournament in London, Ontario. After a long day of baseball we headed back to the hotel so the boys could swim and the parents could socialize. A wedding reception was being held at the same hotel. A parent on the team, Mike D. bet the boys on the baseball team if they could get a bridesmaid to have her picture taken with the coach, Garry Reay-Leider, he would give the boys \$500. The boys were excited and up for the challenge! The team of 12 boys ages 11 & 12 were determined to win. The boys came up with a plan. They got a bridesmaid to come over to have her photo taken with the coach. Mike said "How do I know she's not just a guest attending the wedding?" So the boys went and got a second bridesmaid to have their picture taken with the coach. The boys won the bet! Great team work by the boys. But they had another decision to make. Did they want to split the \$500 up amongst themselves, buy something for the team or did they want to donate the money to a charity of their choice?

It didn't take long for the boys to decide that they wanted to donate the \$500 to charity. The charity they choose was the Fragile X Research Foundation of Canada in honour of Derian's oldest brother Kody who has a full mutation of Fragile X Syndrome. Not only did they donate the money, they made Kody a part of the team as their official bat boy, #18. Kody takes his job as bat boy very seriously. He never misses a game because he says "I don't want to get fired". When our son Derian made the rep. team we were very proud of him, but we could never have imagined that two of

our sons would make the team! We are overwhelmed with the support and understanding we have received for Kody, not only from the boys on the team but also from all the coaches and parents! We can't thank the Whitby Chiefs T4 team and our new baseball family enough for such a memorable 2016 baseball season.

Go Chiefs Go!!!



Derian at the baseball field above left, while Kody proudly wears his team uniform, and poses with Mike Densham, who made the \$500 donation.



In Memory of May Tait

On Easter weekend of this year, **Mrs. May Tait**, a long time supporter of the Fragile X Research Foundation of Canada passed away, just weeks short of her 98th birthday. May's great-grandson is the son of Lori and Chris Beesley. Lori is a senior member of the FXRFC Board of Directors.

As per her daughter, **Bonnie Beesley's** wishes, donations were made to the FXRFC in lieu of flowers. In addition to this, Bonnie also donated the proceeds of the Estate Sale to the Foundation. We send our condolences to the entire family and our heartfelt appreciation.



E-Receipts are Quick, Easy & Fast and Save Us \$!

Did you know you can help to reduce the financial impact on the FXRFC and eliminate our cost to mail out income tax receipts?

How can you help?

By going to our website when you want to make 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 in 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.

Thank you!



“Like” Us on Facebook!

The Canadian Fragile X Research Foundation is on Facebook! Please go to our page and “Like” Us! Our page is a great forum for our Fragile X families. What a great way to connect with each other, share ideas and info and support one another. Feeling isolated? Maybe there is another Fragile X family near by. Check out the page and make a connection in your area!

For anyone in the Toronto area, why not post to our Facebook page a location of a “Cheer Squad” for Team Toronto during the Scotiabank Run in October. Cheer on the team!!!

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Mark your calendar

Please 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 issue.

Toronto Scotiabank Waterfront Run for FXRFC

October 16th - come & participate!

Fragile X Team needs you! Run the marathon, half marathon or 5k run/walk is a lot of fun for the whole family. To join our Fragile X Team contact: Ian Shearer or Jennifer Williams at: fundraising@fragilexcanada.ca or call 416-419-7108 and find out how.

If you are not able to join us, please consider helping by sponsoring a FX Team member. Ian and Jen have all the info. about this event.

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