



FXRFC Newsletter

News for Friends of the Fragile X Research Foundation of Canada

Winter 2009 • Volume #13 • Issue #1

On April 18th, participate in the 1st Annual Canadian Party for Fragile X Research!

The Canadian Party for Fragile X Research is a new and unique fundraiser. We are requesting **everyone** who receives this newsletter to participate! Instead of collecting pledges for an activity such as an organized walk, participants host a party to raise money. Guests are asked to bring a cash donation to the party and proceeds go to fund Fragile X research projects across Canada.

This does not have to be a large or formal affair. In fact, we encourage you to keep it simple, since the idea is to raise funds – not spend your own. You can serve hors d'oeuvres, wine and cheese and/or organize a board game or movie night and make popcorn!

Use your imagination to customize your party and make it your own. What's really important is that we all get together supporting research to find the cure for Fragile X.

Join the party today! Go to www.fragile-x.ca and download the Party Planner Kit - everything you need will be there, including invitations and donation forms. Then, phone five of your friends across Canada and ask them to commit to holding a party as well. Give them the website information and they'll be all set. Everyone on the FXRFC board of directors as well as our fundraising team has committed to asking five friends, and we need you to do this as well! Let's make this a Canada wide event, so call friends who live out of town to join in and host a party!

Anyone hosting a party will be eligible for a draw for one of 6 \$50 President's Choice gift cards generously donated by **Strike First Corporation**.

You have to submit your party donations by May 1st to be in the draw.

On April 18th 2009, Fragile X research will benefit from all of us.

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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FXRFC Recruiting Volunteers for first Canadian Clinical Trial to treat Fragile X

The first Canadian clinical trial to test a new treatment for Fragile X syndrome is underway at the Fragile X Clinic at Surrey Place Centre in Toronto.

Researchers have recently discovered that a drug called minocycline can reverse structural abnormalities seen in the brain cells of the Fragile X mouse model. Minocycline belongs to a group of antibiotics called synthetic tetracyclines, and it has been used in people for more than fifty years to treat Lyme disease, acne, and other skin infections.

With funding from FRAXA, and The Abe & Ruth Feigelson Foundation, Dr. Carlo Paribello and his team at the Surrey Place Centre Fragile X clinic in Toronto, Ontario, are running an open label trial to see if minocycline can improve learning and reduce anxiety and behavioral problems in people with Fragile X. Twenty participants between the ages of 13 and 35 years will take minocycline for two months. If the medication is helpful, they will have the option of continuing it for a year. Participants will need to travel to the Toronto clinic four times in the first two months of the study and will have two blood tests done over this period. This trial will be the beginning of a process to assess the value of minocycline in the treatment of Fragile X.

The FXRFC is currently recruiting participants for this clinical trial. In order to qualify, participants must be Canadian residents with Fragile X syndrome, between the ages of 13 and 35 and must be able to make regular visits to the clinic in Toronto.

Any interested participants can contact nurse practitioner, Leeping Tao at 416-925-2169 ext. 2326 for more information, or email her at Leeping.Tao@SurreyPlace.on.ca.

FXRFC Renews Funding Partnership with the Canadian Institutes of Health Research

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. Once again, the FXRFC has successfully renewed a Fragile X funding partnership with the federal agency known as the Canadian Institutes of Health Research (CIHR). The deal has been arranged through the Small Health Organization Partnership Program (SHOPP). This is a program aimed at strengthening linkages between the CIHR, health researchers, and not-for-profit and charitable organizations that share a common objective of improving the health of Canadians by supporting health research. The CIHR will match, on a dollar-for-dollar basis, the FXRFC's contribution. The money will be used to pay the salaries of four postdoctoral research scientists working in the field of Fragile X for up to three years. This could potentially amount to \$660,000.00 over the 3 year period, depending on the amount of money the FXRFC can raise, and the number of research grant applications we receive for the Fall grant competition.

The more money we make available for Fragile X research, the greater the number of scientists we can pay to work on the problem of Fragile X, and most importantly, the faster we will find a cure! Please help to make the most of our fundraising campaign!

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's X-tra Special person is Charlie Farquhar, written by Jill Cameron and Ryan Farquhar, Charlie's proud mom & dad.

Our son, Charlie, was diagnosed with Fragile X Syndrome just after his fourth birthday. Although we were very saddened by his diagnosis, in many ways the journey to get to that point was much more difficult than finally knowing what was going on.

On January 3, 2009, Charlie turned 5 years old. We celebrated his birthday by having a "Sportplay" party at a near-by gym. In addition to his big sister, Sarah, and his neighbourhood friends, we invited his whole Junior Kindergarten class.

As much as all kids love presents (Charlie being no exception), with the number of children invited to the party we felt that if everyone brought a gift it would simply be too much. As such, we asked the parents of his classmates not to send a gift along and told them that if they wanted to give something we had a special request.

After explaining Charlie's diagnosis and a little bit about Fragile X Syndrome, we asked parents to make a donation to the Fragile X Research Foundation of Canada in lieu of purchasing a birthday gift. After all, the best gift he could ever hope to receive would be a cure for Fragile X.

We initially had concerns about telling the other parents about Charlie and in effect "labeling" our son. However, we decided that knowledge breeds understanding and acceptance, which is what we ultimately want and need for our son. The response was overwhelming. Not only did many families make donations in Charlie's name, we received many touching words of encouragement, support and understanding. Some of the parents have even talked about doing the same thing for their children's parties, with the proceeds going to the Fragile X Research Foundation in Charlie's name.

Perhaps most importantly, the party was a huge success. The kids had a wonderful time and Charlie was thrilled to have all of his friends and classmates help him celebrate his special day. (Charlie, front row, far left)



Charlie Farquhar



Paine Edmonds, Great People

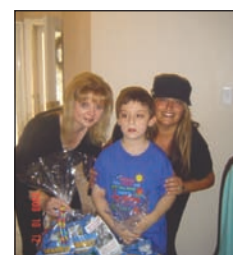
by Kirsten J. Madsen

Paine Edmonds LLP, Barristers & Solicitors, 1100 - 510 Burrard Street, Vancouver B.C.

I would like to thank the law office of Paine Edmonds LLP's Social Committee for choosing the Fragile X Research Foundation of Canada as the charity for our Christmas raffle. Thank you also to everyone who spent their hard earned money on raffle tickets to raise \$600. This is very, very meaningful to me and my family. The Fragile X Research Foundation of Canada is a 100% volunteer organization committed to finding treatments and ultimately a cure for Fragile X syndrome (FXS). FXS is the most common known cause of mental impairment in males and the only known cause of autism. 100% of all donations to the foundation goes to research to find a cure.

Fundraisers Get Popping!

Family members of Ben Ruffa held a fund-raiser during the month of November. They sold popcorn from Kernels and raised \$315 for Fragile X research. The amount was matched by Ben's parents (Dino & Connie Ruffa) bringing the total fund-raiser amount to \$630. Pictured with Ben are his aunts, Kim and Linda. Dino, Connie, and Ben would like to thank everyone for supporting such a very special cause. *Well done Ruffa family!*



Fragile X Family Picnic - Save the Date!

By Lori Beesley



Don't miss the Annual Fragile X Family Fun Day Picnic this year!

Sunday June 14th, from 11 a.m. to 2 p.m.

The Fun Day is held at Variety Village in Scarborough, ON.

This is a wonderful opportunity for families to meet each other, share experiences and let our children play together in a safe environment.

There is no cost for this event and you are encouraged to invite your whole family.

A small team of volunteers is already busy making plans & working on donations.

We hope this year will be the best Fun Day yet, filled with great surprises.

Please keep checking the Fragile X website for information on the picnic, as we'll post more details as they become available. www.fragile-x.ca

Details will also follow in our spring newsletter - but save the date on the calendar now!

If you are travelling from out of town & would like hotel information, please feel free to contact me at 416-261-2666 and I'd be happy to help - Lori Beesley



Registered Disability Savings Plan (RDSP)

Dr. C. Paribello, M.S.M, M.D., President, Medical Director

On December 1st, 2008 the Registered Disability Savings Plan (RDSP) officially became a financial savings mechanism in Canada. Similar to Registered Education Savings Plans (RESP), the RDSP would allow families to save money for their loved ones with a disability and help plan for future needs.

To qualify for the RDSP, an individual must qualify for the disability tax credit, which our children with special needs should already be qualified for, therefore there is no extra registration needed with the Federal Government.

The Ontario Government just announced in a press release that RDSP contributions do not affect eligibility for social assistance (ODSP) and that people on social assistance can take money out of an RDSP without affecting their social assistance (ODSP) benefits.

Due to the timing and requirements of the plan, there are only a few financial institutions prepared to issue the RDSP. The Federal Finance Minister Jim Flaherty has announced that any contributions made by March 2nd, 2009 will be considered 2008 contributions, and will be matched by 2008 Grants.

Here is a list of Financial Institutions who have been approved by the Federal Government to issue the plan to Canadians.

National

- Bank of Montreal (BMO Financial Group) began offering the Registered Disability Savings Plans on December 22, 2008. This is available through BMO to Canadians from across the country. To contact BMO and set up an RDSP you can call the BMO Investment Centre at 1-800-665-7700.

Regional

- Fédération des médecins omnipraticiens du Québec (Quebec Federation of General Practitioners) has signed an agreement with the Federal Government to offer the RDSP on behalf of the Desjardins Trust company (Desjardins is not currently offering the RDSP). FMOQ has indicated that it will offer the RDSP to its members (general practitioners) and their patients, and anyone referred to them by financial institutions who do not offer the plan (Québec residents only). To learn more visit: <http://www.fmoq.org/Accueil/Accueil/Index.aspx>

In the next year, it is expected that there will be 14 to 16 financial institutions issuing the RDSP. The RDSP web site created by PLAN is a comprehensive site for more information and can be accessed at www.rdsp.com.



Canadians with Disabilities Win Another Historic Transportation Access Battle

Council of Canadians with Disabilities Press Release

On November 20, 2008, the Supreme Court of Canada denied Air Canada and WestJet's request to appeal the decision of the Canadian Transportation Agency which requires the airlines to accommodate persons who need additional seating space because of their disability. The Council of Canadians with Disabilities (CCD) launched this action in 2002 to remove a long-standing barrier to the travel of persons with disabilities. People with disabilities who required an attendant in flight to assist them with services not provided by flight attendants and persons with disabilities who required additional seats were having to pay for two fares. This decision now brings planes into line with other modes of transportation such as rail, bus and marine who do not charge for additional seats. The airlines were given one year to implement the policy.

"We celebrate this decision and are thrilled to see the removal of another long-standing barrier to our mobility and travel," said Pat Danforth, Chair of CCD's Transportation Committee. "What continues to be a concern, however, is that we are being forced to pursue legal action to ensure accessibility of our national transportation system. Where is the federal government's leadership on this issue? We urge the Government of Canada to regulate access standards for persons with disabilities on all federally regulated transportation systems," said Danforth.

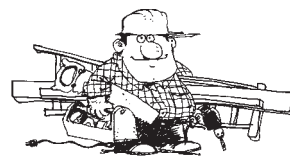
"We have been victorious in two major transportation access battles in the past 8 years," said Marie White, Chairperson of CCD. "First we fought VIA Rail's purchase of inaccessible passenger rail cars all the way to the Supreme Court of Canada and now we have made the airlines more accessible as well," said White. "These victories are to be celebrated but they could have been more appropriately handled through the development of access regulations by Transport Canada," said White.

CCD urges the Government of Canada to move away from voluntary codes of practice and regulate the industry to ensure that the equality guarantees of the Charter are made real and that Canadians with disabilities have equal access to the goods and services of Canada. CCD urges the airlines to speedily implement this decision. Access for Canadians with disabilities has been denied long enough.

Canadians with Fragile X or other disabilities take heart that the Courts have upheld, and continue to uphold, the equality rights of persons with disabilities.

The FX Tool Box

by Lori Beesley



What is The FX Tool Box? The Tool Box is filled with suggestions, helpful hints and coping strategies – tools to make living with Fragile X easier. We invite you to send in your favourite tools to: fxrfc@on.aibn.com for printing in future newsletters. Here are some suggestions:

- 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.

Fragile X poet finds his voice – and his audience!

article by Paul Russell

The Toronto Public Library gets hundreds of submissions each year for *Young Voices* – its annual magazine of teen writing and art. So when Toronto Fragile X teen Eric Lewin, submitted his poem – *Rose, where did you get that red?* – to the publication, the odds of it getting published based on numbers alone were stacked against him.

But wonderful things happen sometimes in the world of art and literature. Toronto Public Library youth services librarian Susan Kernohan had received a letter with Eric’s submission, advising her that Eric was a special needs student. On a hunch, she decided not to pass this information on to the editorial team that made the final selection.

Her hunch was well founded. The editorial team selected Eric’s poem for publication with no knowledge of Eric or his condition, meaning the selection was based solely on the merit of the poem alone.

Needless to say, when the call came to let Eric know that his poem had been chosen for publication, he was thrilled. Kernohan said that of the hundreds of families that she has contacted over the years, this was “the happiest house full of people I ever called.”

Eric and his family and friends attended the magazine launch party in October, then held a private party a few days later to celebrate. Eric continues to write poetry – and enjoys the freedom of the form. It’s clear that his writing will be both an important means of expression in the future and a great discussion topic and icebreaker when he interacts with other people.

And with more than 18,000 copies of *Young Voices* distributed annually through library branches, schools and community agencies in Toronto and surrounding area, it’s clear that this Fragile X teen has not only found his voice, he’s found his audience as well!

Rose, where did you get that red?

by Eric Lewin

reprinted from Young Voices ‘08

*magic spells could say make it work
 paint it yellow orange green pink red
 we need paint brushes with long brown handles
 we need brushes and paint cans
 we need to open the cans
 mix the paint
 swimming oceans of red
 we need long brushes
 we need paint to make it pink
 we need 60 paint brushes and long strokes of red on the rose
 the rose is marvelous
 the rose is exquisite
 the rose is perfect*

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. We currently have a need for support groups in Manitoba and Nova Scotia. 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. Please become a Friend of The FXRFC in supporting research aimed at treatment for Fragile X. Friends of the FXRFC receive this quarterly newsletter and are welcome to participate as active volunteers.

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FXRFC Newsletter

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