

# xpressions

## Fragile X Research Foundation of Canada Newsletter

### 1 | Latest News

Welcome to the first issue of the new FXRFC newsletter: **xpressions**

### 2 | Launch Event

The new look of the FXRFC was unveiled at The Drake in Toronto.

### 4 | Fundraising

High School students in Toronto, Seniors golfers in Thunder Bay, and Tupperware sales in Alberta all raised funds for research.

### 6 | Special People

An X-tra special athlete competes in his first triathlon.

**On October 27th, the new re-branding of the Fragile X Research Foundation of Canada was unveiled at a launch party at The Drake hotel in Toronto, Ontario.**

On October 27th, 2009 everything changed. The new FXRFC was unveiled.

**FRAGILE**

**By: Lori Beesley, Director, FXRFC**

The text that you see to the left was part of an invitation sent out last fall to 250 people across Canada. The invite was for a launch party to reveal the new brand of the Fragile X Research of Canada.

Almost a year ago, the FXRFC was dealing with a drop in donations due to the economic down turn. We knew we had to do something to turn things around. We wanted to take action and knew that meant overhauling the website and changing the dated look of the FXRFC.

The company that I work for as Studio Manager, Zync Communications, offered to have a look at our needs. What started off as a casual conversation at the office, quickly turned into a very generous offer to help the Foundation undergo a re-branding. Principals Marko Zonta and Brad Breininger own Zync, a premier branding and communication agency. Combining strategy and creativity, Zync's ideas help organizations define their voice and connect with their audiences.

The Board of Directors was very excited about working with the Zync team. A "wish list" was presented, at the top of which was the desire for a new website. That, along with the new logo - shown above - were unveiled at the launch party. Going live that same day, the new website is **[www.fragilexcanada.ca!](http://www.fragilexcanada.ca)**

It is extensive and full of useful information, thanks to the tireless efforts of the Zync team and the generosity of several companies. The new website will be a valuable resource to families, the medical community, therapists, teachers and the developmental sector.

Delighted with the new image, Dr. Carlo Paribello, President of the FXRFC, noted, "This new approach to brand marketing and communication gives a presence we've never had before. The new image is great, but its real purpose is to give us the tools we need to share information and raise money to fund our research—we must find a cure."

“A new brand and website.  
A reinforced commitment.  
A raising of awareness.  
Shouting from the rooftops.”

**We must find a cure** became the theme for the launch. Invited guests included members of the medical community and the developmental sector, current researchers, parents, donors, and the media. In taking the FXRFC to the next level, Brad Breininger said “The Fragile X Research Foundation of Canada is a group of volunteers and parents that had very little to use to raise awareness about the condition and elicit significant donations. Now they have the image, messages and resources to spread the word, educate the public and raise money – it’s a new day!”

## We must find a cure.

The fundraising team of Ian Shearer, Ryan Farquar, Jennifer Williams and myself thank our Title Sponsor for the launch event, **Williams Bros. Corp.** Their generosity allowed us to hold the event at the Lounge at the Drake Hotel. They also created the fabulous X Ornaments that went home with all the guests. There are other generous companies who helped to make the re-branding a success and we’d like to acknowledge them:

- **Party Packagers** for the colourful balloons that transformed the Lounge for our celebration.
- **Steve Frost**, owner of **Frost Photo** for the incredible pictures of the children used on the website.
- **Paul Russell, Bretenic Ltd.**, a professional writer whose great work helped ensure that the text on the website flowed.
- **Paralucent**, the website company who programmed and executed the designs that Zync developed. They continue to help with the development of the website.
- **Korax**, a web and domain name host company. They have generously offered to have our website [www.fragilexcanada.ca](http://www.fragilexcanada.ca) as a guest for as long as we’d like.
- **Bob Nicholson, Springfield Graphics**, who has educated many of his suppliers about the FXRFC. He is printing the new fundraising brochure and the stationery with the help of those suppliers.



Brad Breininger spoke of the process Zync went through in re-branding the FXRFC.



Ian Shearer, Board Member and FXRFC Fundraising Coordinator, spoke to the crowd about the importance of the fresh, new look and how it will invigorate us moving forward.



Board Members at the launch: Myra Sourkes, Raymond Jessome, Lori Beesley, Dr. Carlo Paribello and Barbara Byers

## Celebrate a new direction.

We encourage you to visit the new website at [www.fragilexcanada.ca](http://www.fragilexcanada.ca) and see what we have done. There is a lot of new information. We have built a website that will assist anyone who has a connection to Fragile X. There is content for both the newly diagnosed and for those families who have lived with Fragile X Syndrome for a considerable amount of time. You will find sections on medical issues, education, various types of therapy, life skills like toileting and dressing, long term planning for

adults with Fragile X Syndrome, fundraising, becoming a volunteer and much, much more. We urge you to tell everyone about the new FXRFC website and encourage them to visit it. Through awareness, more people will understand Fragile X Syndrome and the urgent need for support. That support will help lead to a cure for this devastating condition. **We must find a cure.**

Help the FXRFC  
save funds by  
receiving your  
newsletter  
electronically via  
email! See the back  
page for details.

### 12<sup>th</sup> International Fragile X Conference • July 21 - 25, 2010

Hosted by the National Fragile X Foundation - Detroit, Michigan

Every 4 years, families are invited to the International Fragile X Conference, hosted by the National Fragile X Foundation in the United States. This year's conference is being held in Detroit, Michigan in July.

For more information on this worthwhile conference, please visit [www.fragilex.org](http://www.fragilex.org) and click on the link for the conference.

Here is what you can look forward to:

- Discover the latest research by some of the world's leading Fragile X Syndrome experts
- Connect with researchers clinicians, educators, psychologists and parents
- Get the support you need
- Learn new techniques, behavioral interventions and coping strategies
- Start a new lifelong friendship and reconnect with old friends
- Sample the best of Motown, including a visit to the historic Henry Ford Museum



# High School Students open their hearts and wallets during their annual Christmas Cheer

By: Ian Shearer

Mowat Collegiate Institute is a high school in Scarborough, Ontario and they have an event called "Christmas Cheer" every year. Their goal is to try and help a worthwhile charity by raising as much money as possible over a 2 week period. Sarah Peltier is on Mowat's Student Council and has baby-sat our boys Will & Jack. She nominated the FXRFC this year as the Christmas Cheer charity. We were up against three other charities and much to our delight, the Student Council voted for the FXRFC.

On December 7th the "Christmas Cheer" assembly kicked things off with music, carols, cheerleaders, and a 20 minute PowerPoint presentation on Fragile X Syndrome. We know it went well because our neighbours told us their kids came home from school that day and went right for their piggy banks!

Over the next two weeks every student at Mowat was encouraged to participate in events like a pancake breakfast (\$3), penny drive (one class raised \$1,200 in pennies!)

and donations from students and faculty.

On December 18th the school held its final assembly before Holiday Break and presented the FXRFC with a cheque for \$13,400! Truly amazing!

A huge thank you to the students and staff at Mowat C.I. for their amazing help in funding important research for the FXRFC.

**Some of the Mowat Students present the cheque to Ian Shearer (centre in white shirt), the FXRFC Fundraising Co-ordinator.**



## How you can help!

The Fragile X Research Foundation of Canada is a non-profit tax-exempt charity run by parents and volunteer professionals. We need your support and there are various way you can help!

### Make a donation

### Volunteer

### Hold an event

### Spread the word

It's never been easier to make a donation. Simply log onto the new website and you'll see the large **Click here to donate now** button. We've partnered with CanadaHelps to process our online donations and provide you with an immediate tax receipt. Donating online is quick, easy and secure. It is also very cost effective, so your donation goes straight to work.

There are various way to donate:

- One-time donation
- Monthly
- Gift in memory
- Gift in celebration

In the **How to help** section of the website, you'll find information on areas such as:

- Corporate Giving
- Planned Giving, including gifts from Will bequests, Beneficiary designation, and Life insurance
- Tax-smart giving

However you choose to give, please know that the FXRFC appreciates every donation we receive.



## Resources

### Do you know of a great resource in your area of Canada?

The FXRFC is always interested in gathering up to date resources from all across Canada. On the website, we will soon have a resource list of organizations and programs that provide leisure and therapeutic activities, related medical sites, government and support services and much more. The list is neither official nor exhaustive. Many of the listed programs are situated in the Toronto area, but we want to expand it with excellent programs from across the country. We are asking you, the readers of the newsletter, to let us know about programs that have helped you and your family, wherever you live.

Please send info. to the FXRFC at [newsletter@fragilexcanada.ca](mailto:newsletter@fragilexcanada.ca)

The list will be posted on our website shortly.

## Submit a story

### We Want Letters, Stories, Articles!

If you are planning or have organized a Fragile X fundraising activity or event in your area - big or small - we'd like to hear about it. Anything goes! If you have an announcement or request to make that is related to Fragile X, and would like other families to know about it, please e-mail the Foundation at [info@fragilexcanada.ca](mailto:info@fragilexcanada.ca), or fax the Headquarters at (905) 453-0095.

# Inaugural Thunder Bay Seniors' Golf Tournament is a success!

By: Bill Mokomela



On Thursday, September 17, 2009, the inaugural FXRFC Seniors' Golf Classic was held at Emerald Greens Golf Course in Thunder Bay. Grandpa Bill Mokomela, more affectionately known as "Grumps" to special grandson Ryan Kreczmer who has Fragile X Syndrome (pictured left), organized and ran the tournament.

Ryan loves riding with "Grumps" on his golf cart and hitting balls at the driving range with him. He is also his Grandfather's biggest critic when it comes to making shots out of the bunker! Grandpa and Ryan share a very special, loving relationship.

Jennifer and Justin, Ryan's parents send out a special "Congratulations Grumps" on a successful first FXRFC Seniors' Golf Classic.

The next Golf Classic has already been scheduled for September 9, 2010.

Because of this relationship, an idea emerged to hold a Seniors' Golf Tournament, which would benefit the Fragile X Research Foundation of Canada.

A total of 52 senior men, averaging over 70 years in age, participated in the event. Following a very spirited 18 holes of golf, a great meal was served at the Port Arthur Ukrainian Cultural Centre. All the golfers received prizes that were donated by local businesses and organizations.

We are proud to report \$900 was raised for the FXRFC!



Bill Mokomela, second from the left, with fellow golfers: Jack Zubec, Rod Boyd and Merv Dove.

## Focus on Funding

The Canadian Institute of Health Research 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 over the 3-year period, depending on the number of research grant applications we receive.

## Did you know...

Fragile X researchers have made

incredible progress in treatment in

recent years. In fact, they've learned

more about this disorder in the past

eight years than in the preceding 50.

Let's keep it up!

# XXX-tra Special Person

The FXRFC newsletter often publishes stories about the people that sparked the formation of the Foundation and inspire the ongoing growth and commitment of the FXRFC. If you have a story about a child or adult with Fragile X Syndrome, please send it to us along with a picture of the X-tra Special Person. Tell us a funny or heart-warming story, or share a success and allow it to inspire others. This newsletter's X-tra Special person is David Jessome and his story was sent to us by his very proud father, Raymond Jessome.

This story was originally printed in LE SAINT-LAMBERT, in Quebec in September, 2009 and written by Pierre Loiselle.

## A Special Olympics Athlete Participates in His First Triathlon

Pierre Loiselle

Wednesday, August 26, 2009

**Sports** - St. Lambert resident David Jessome became, on July 18, one of three South Shore athletes to participate for the 1st time in the triathlon organized by the city.

David and two of his friends who are living with an intellectual disability, Alain Lussier from Longueuil and Raphaël Van Damme from St. Hubert, all members of the South Shore Cougars, finished the Triathlon-Team in 1 hour, 47 minutes and 51 seconds!

David, 20 years old, swam 750 meters (30 pool lengths) in 21 minutes and 22 seconds, which is excellent (some regular triathletes did it in more than 20 minutes). Alain biked 20 km in 49 minutes and 57 seconds and Raphaël ran 5 km in 36 minutes and 33 seconds.

"These three guys made no mistakes either during the race or in transition zones. They were excellent, especially for their first participation", said Yolande Jessome, David's mom, who supervises his activities. David said "I am proud of myself, because I gave all I had. I was happy to be with my friend Raphaël. He is my alpine skiing partner". David took a couple of days to be ready for this event.

He lives with Fragile X Syndrome, is in his third year at Champlain College and studies in Adam's P.A.C.E. program. For six years now, he has been part of the South Shore Cougars team (Special Olympics). Not only does he swim, David also plays basketball, does alpine skiing, and plays hockey.

"Sport makes him happy, and develops initiative and persistence. He is continually surpassing himself, but learning he can also accept defeat. He has made strong friendships, and gained many values", says his mother.

Congratulations David and to your team mates!



## Un athlète des Olympiques Spéciaux participe à son premier triathlon

Pierre Loiselle

25 août 2009

**Actualités sportives** - Le Lambertois David Jessome, est devenu le 18 juillet, un des trois premiers athlètes des Olympiques Spéciaux de la Rive-Sud à participer au Triathlon de Saint-Lambert.

Lui et deux de ses camarades atteints de déficience intellectuelle, Alain Lussier de Longueuil et Raphaël Van Damme de Saint-Hubert, tous membres des Cougars de la Rive-Sud ont parcouru le Triathlon-Équipe en 1h, 47m et 51s.

David, 20 ans, a d'abord nagé 750 mètres (30 longueurs de piscine) en 21m 22s, un excellent temps (certains triathlons réguliers ont fait la même distance en plus de 20 m). Alain a ensuite roulé 20 km en vélo en 49m, 57s et Raphaël a couru 5 km en 36m, 33s. Ils ont terminé en 16e et dernière place, mais à seulement 11m de la 15e position.

«Les trois gars n'ont fait aucune erreur que ce soit en course ou dans les zones de transition. Ils ont été excellents, surtout pour une première», dit Yolande Jessome, mère de David qui supervise ses activités. «Je suis fier de moi, car j'ai donné mon maximum. J'étais content d'être avec mon ami Raphaël. C'est mon partenaire de ski alpin», ajoute David qui

s'était préparé pendant plusieurs jours pour cet événement.

David qui est atteint du syndrome de fragilité X, étudie en 3e année au Cegep Champlain Adam's P.A.C.E. program. Il est membre des Cougars de la Rive-Sud (Olympiques Spéciaux) depuis 6 ans. En plus de la natation, il pratique le basketball, le ski alpin, le hockey et l'athlétisme.

«Le sport lui apporte la joie, l'esprit d'initiative, la persévérance, le dépassement, l'acceptation de la défaite, l'amitié et une foule de valeurs humaines», dit sa mère.

# Fundraising with Tupperware in Alberta!

In October '09, the Befus family of Wetaskiwin, Alberta held a Tupperware fundraiser in honor of their wonderful little boy, Kyan, who received the diagnosis of Fragile X Syndrome at 2 and half years old. Jamie Befus, Kyan's mother, became a consultant so that her sales proceeds, in addition to the 40% from the Tupperware "fun" raising brochure, would go to the Fragile X Research Foundation of Canada. Between the proceeds from Tupperware sales and donations made directly to FXRFC they have raised over \$5,600.00, with the first \$1,000 matched by the Befus family!

They kicked off the event by holding an information session in their home on October 4. It included guest speakers Deb Lentz, Genetic Counselor, and Jane Carlson, Kyan's Family Wellness Worker from the Early Education and Family Wellness Centre. They received a lot of positive feedback from both the information session and the hand outs. The Befus family hopes that they can help others because of what they have been through and to educate people on the many strengths that a child with Fragile X Syndrome has and the joy they bring.



Kyan



Jane Carlson on the left, Jamie Befus in the centre, Deb Lentz on the right all enjoyed the event.

## The FX Tool Box

by Lori Beesley

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](mailto:toolbox@fragilexcanada.ca) for printing in future newsletters. On the new FXRFC website, in the **Coping with Fragile X** section, you'll find a **Helpful Hints** page, where the tool box also appears. Here are some helpful suggestions for use during gatherings or parties.

- **Set Expectations:** Whether you are going out or having guests come to your home, let your child know ahead of time what is going to happen. Show them pictures of, or talk about, the different people they will meet. Set behavioural expectations and discuss activities that may be difficult for them to cope with. At birthday parties, for example, they will have to wait for the celebrant to open the gifts, in any order they choose to. Educate family members as well on what to expect from you child. We let our son open all his gifts first on Christmas day. He always receives a new movie and is happy to disappear, away from the group, to watch it. There is nothing wrong with being happy and content, while getting a break during the busy day. And no one will be upset that you are not following the usual social decorum! This makes for a happier experience for everyone.

- **Give Responsibility:** Have older children carry gifts or cards when visiting others. If people are visiting you, ask the child to be the official greeter/announcer or coat person if they are able to handle this. Since children are often excited at the start of an event, a task early on can channel their energy into something productive.
- **Encourage Manners:** With children who are able, encourage them to greet and say good-bye to others. Older children can hold doors and demonstrate more advanced manners. Teach them polite words and helpful actions by modeling the behavior and offering praise when they demonstrate it. Other people may serve different foods or have different routines, so remind children to respond to differences with respect.
- **Keep them busy:** Bring along a favourite toy or activity if you are visiting and aren't sure what is planned or available. If your child is occupied and happy, the whole visit will be a better experience for everyone.

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.

## FXRFC Provincial Contacts

Our provincial contacts provide local support to Fragile X individuals and their families across Canada. Please connect with the contact person nearest you for information on what's happening in your area. We are also very interested in connecting with other provinces and territories not listed below and will provide assistance to anyone able to help out. If you would like to network with other parents, to share information regarding local resources like recreational activities or to exchange stories of family experiences, please contact any of the people below. We also encourage groups or individuals to raise awareness and fundraise in support of the FXRFC.

Ontario (Toronto) Dr. Carlo Paribello T. (905) 453-9366 E. info@fragilexcanada.ca	Quebec (Baie d'Urfé) Evelyn Lockett T. 514-457-3284 E. elockett@fragilexcanada.ca	Saskatchewan (Saskatoon) Jamie Fast T. 306-374-2225 E. jfast@fragilexcanada.ca
Ontario (Kitchener-Waterloo) Teresa Burch T. 519-894-3689	Alberta (Calgary) Beverly Delion T. 403-256-8252	British Columbia (Vancouver) Kirsten J. Madsen T. 604-607-5480 E. kjmadsen@fragilexcanada.ca

If you are interested in being a contact person in your area, please contact the FXRFC Headquarters at 905-453-9366 or [info@fragilexcanada.ca](mailto:info@fragilexcanada.ca)

## Fundraising and/or Volunteer

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. 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 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, listed below.

Ian Shearer and Jennifer Williams - FXRFC National Fundraising Coordinators  
E. fundraising@fragilexcanada.ca  
E. volunteer@fragilexcanada.ca

This newsletter is published quarterly by Fragile X Research Foundation of Canada and mailed to all our supporters. You can view/download a PDF of the newsletter on our website at [www.fragilexcanada.ca](http://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](mailto: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 can accept donations on-line through our website at [www.fragilexcanada.ca](http://www.fragilexcanada.ca) or by mail or phone at our National Headquarters in Brampton, Ontario.

Charitable Registration Number: 88643 3762 RR0001.

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C O M P A N Y I N C .

## Important Information

Help the FXRFC save on printing and postage costs of our newsletter:

Our newsletter is printed and mailed out to four times a year to over 1,250 supporters. You can choose to have it delivered to your email account and save the Foundation printing and postage costs. Simply send us your name and email address and we will coordinate removal of your "snail mail" address from our database. Also include a phone number in case we need to contact you for any clarification.

Please be patient, as it might take one or two issues for the switch to occur.

Send your email request to:  
[info@fragilexcanada.ca](mailto:info@fragilexcanada.ca)

## Mark your calendar

Please keep checking the new 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.

### April, 2010

**The Canadian FXRFC Fundraising Parties**  
Time: you choose! It's not too early to be thinking about holding a Spring Party! More info. to come - keep checking the website for details to be posted in March.

### June 13, 2010

**Fragile X Family Fun Day**

Time: 10 am - 2 pm

Location:

Variety Village, Scarborough ON.

More details will follow in the next issue.

Plan on attending - save the date!

# FRAGILE

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