



# FXRFC Newsletter

News for Friends of the Fragile X Research Foundation of Canada

Spring 2006 • Volume #10 • Issue #2

## 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 negotiated 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) which replaces the **Health Research Partnership Fund (HRPF)**. 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 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!

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

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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## **Progress Report on the novel use of non-verbal tasks to assess cognitive function in Fragile X affected males**

*One problem with early clinical trials is a lack of appropriate IQ tests that are suitable for individuals with Fragile X. The traditional tests that have been used depend on written or verbal responses. However, many patients with Fragile X syndrome are non-verbal or have problems with these kinds of tests because of their intense anxiety, perseveration, and difficulty with word retrieval.*

*With the hope of dealing with this problem, the Fragile X Research Foundation of Canada, in partnership with the Canadian Institutes of Health Research, awarded a fellowship grant to Dr. Isabelle Boutet to assess the use of various non-verbal tasks designed to measure cognitive functioning and ability to learn. The progress of her research is described below and we believe that her findings will lay the groundwork for a more accurate assessment of treatments used in future clinical trials.*

### **Progress Report**



***Dr. Norton Milgram, Ph.D., Principal Investigator  
Dr. Isabelle Boutet, Ph.D., Postdoctoral Fellow  
University of Toronto at Scarborough,  
Division of Life Sciences***

Over 90% of males affected by the Fragile X Syndrome (FXS) suffer from severe learning disabilities, with intelligence quotients (IQ) in the mild to moderate retardation range. Individuals with FXS often display signs of impulsivity, hyper-arousal, anxiety, and in some cases, autistic features. While there is currently no cure for FXS, numerous pharmacological and behavioural interventions are currently being investigated to deal with the behavioural and cognitive difficulties present in affected individuals. However, clinical trials that evaluate the potential benefits of new interventions are limited because there are no suitable measures to evaluate improvements in cognitive function in FXS.

Assessment measures that are currently available can rarely be administered to individuals with intellectual handicaps and attention deficits. The proposed project examined the feasibility of using a novel battery of non-verbal tasks that are not limited by these factors. All the tasks are based on a simple reward principle. Participants are shown two objects, one of which hides a reward. Where the reward is hidden is determined by a specific rule. The participant can figure out what the underlying rule is by trial-and-error. These tasks are advantageous because they are simple and motivating. Our study indicates that these tasks can be successfully used in FXS individuals. Furthermore, our results indicate that males affected by FXS display strengths in object recognition and spatial abilities, alongside weaknesses in cognitive flexibility and response inhibition.

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We have presented these results at two international conferences and the response has been so positive that some of one of our tasks is now being used in a clinical trial. We are currently trying to determine if the profile of strengths and weaknesses we observed is unique to FXS, by comparing performance of individuals affected by FXS with individuals suffering from Down Syndrome.

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## **Dr. Paribello of the FXRFC to speak at the National Fragile X Foundation's 10th International Fragile X Conference in Atlanta Georgia, U.S.A.**

Dr. Paribello, President of the Fragile X Research Foundation of Canada, has been invited to speak at The National Fragile X Foundation's biannual international conference hosted by The Fragile X Association of Georgia in Atlanta U.S.A. July 19-23, 2006.

Dr. Paribello will provide information on Fragile X from a unique dual perspective; from a father's point of view and a physician's point of view. He will begin his presentation by giving an overview of the Fragile X syndrome. It will include a clinical description of how Fragile X interferes with learning and will review the strengths and idiosyncrasies of the Fragile X individual. It will provide newly diagnosed families with guidelines for the medical management of patients with Fragile X and outline the recommended interventions by allied health professionals. The molecular and cellular defects that occur in Fragile X will be described in a family friendly way and will be correlated with the clinical symptoms. Finally, there will be a concise explanation of how the newly identified "therapeutic targets" hold the potential for specific new treatments of Fragile X in the near future.

This conference is highly regarded and is well known for bringing together families, researchers, medical personnel, therapists, and educators in a setting that is specifically designed to optimize interaction among families and professionals. Increased collaboration between researchers, improved treatment skills of professionals, optimized development of individuals affected by Fragile X, and increased understanding of those impacted by the syndrome are the most significant outcomes often cited by previous conference attendees.

### **REGISTRATION INFORMATION**

Online registration forms for the 10th International Fragile X Conference are available at [www.nxf.org](http://www.nxf.org). Registration forms will also be published in NFXF Quarterly Journals beginning January 2006. Registration fees for NFXF Members are \$350(U.S.) for individuals and \$575(U.S.)for couples (2 parents). Non-member registration fees are an additional \$60(U.S.) per registration. Registration includes a welcome reception, luncheon, and banquet dinner.

## HOTEL INFORMATION

The conference will be held at the **Omni Hotel at CNN Center, Atlanta, Georgia**. Rooms are available for attendees of the conference for a special rate of \$134(U.S.) per night, plus taxes. To make a reservation, please see the contact numbers below. Be sure to let them know that you are with the 10th International Fragile X Conference to get the special room rate!

### Direct Hotel Reservations:

Phone: 404-659-0000 or Fax: 404-525-5050

### Central Reservations

1-800-843-6664 or 1-800-the-Omni

Web: <http://www.omnihotels.com/FindAHotel/AtlantaCNNCenter.aspx>

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## Please Save Your Supermarket Receipts!

If you live in Ontario, you can raise money for Fragile X research just by shopping for your weekly groceries! The FXRFC is enrolled in the "Save-a-Tape Program" run by A&P, Dominion, and Ultra Food & Drug stores, and can now earn \$1.00 for every \$450.00 in cash register tapes we collect. The FXRFC can raise a maximum of \$1,000.00 over a 12 month period.



Please forward your tapes to the FXRFC along with a note with the tape total written on it. We will redeem the tapes and receive a cheque made out to the Foundation once per year. The Save-A-Tape Program will come to a completion on December 31, 2006, so please get all of your tapes to us by then.

If you know of a similar program in place at the community grocery store in your province, please contact us regarding registering the FXRFC with these stores.



## **The Fragile X Awareness Wristbands are Here!**

*Our bright green silicone wristbands say “Support Fragile X Research” and show the FXRFC logo. It’s a great way to raise public awareness about Fragile X and raise money for research at the same time!*

*Order 1 - 4 wristbands at \$3 each or save, and order 5 or more wristbands at \$2 each. Try selling them at work as a fundraiser or use them as a great gift idea for teachers, day care staff, babysitters, friends and family.*

*Just call the FXRFC headquarters at (905) 453-9366 and order yours today!*

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## **FXRFC Bulletin Board**

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 [fxrfc@on.aibn.com](mailto:fxrfc@on.aibn.com), or fax us at (905) 453-0095. You can also check out our website at [www.fragile-x.ca](http://www.fragile-x.ca).

The Website is an integral part of the Foundation. Not only does it provide scientists with information about our research grant program, but it also allows us to educate the public about Fragile X and keep you updated on the research that your donations are funding. We also have back issues of the FXRFC newsletters posted so you can read interesting articles you might have missed. With a click of the mouse button, you can access a multitude of useful links related to Fragile X, learn about the research projects that we fund, and find out about events in your area.



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## **Send in your Articles**

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

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! Perhaps it could be a brunch, lunch, or dinner party, a car washing event, football party, bowling, a walk or run, bake sale, cocktail party, a jar for coin collection, garage sale, benefit night at a local fast food restaurant, arranging with local merchants to match any funds raised, etc.

Please e-mail your article for the newsletter to [fxrfc@attglobal.net](mailto:fxrfc@attglobal.net). The deadline for submissions to the next newsletter is July 7, 2006. If you have any questions, please feel free to call us at (905) 453-9366.



## On The Lighter Side



*By Barbara Byers  
(re-printed by request - from Spring 1998)*

### ***Just point me in the direction of home...***

There are times when I wonder about people's perception of my parenting skills, such as the other day, as I watched my three year old peddling his trike up the street, suitably attired with bike helmet, snorkel, and mask. Or when my very proud six year old, who had just dressed himself, marched out of the house with his shoes on the wrong feet. Somethings you overlook; others you don't notice until it's too late. Whatever the symptoms, the condition is called "being a parent"!

One night after dinner, my husband and I sat at the table wearily surveying the mess. In walked our middle son, busily affixing charity return address labels to his books and the appliances. Smiling, he came over and gave me a big hug. It was two hours until the kids' bath, and bedtime so I decided to fill the time at the local aquarium store. The kids eagerly jumped into the car for the outing. Once inside the store, I selected yet another fish net and handed it to the little guy. I hadn't realized how strong he was getting until we reached the back of the store and he showed me the remodelled circular net handle. Both kids were really taken by the shark tank and I smiled at everyone who smiled at me, thinking they were all sharing in my children's excitement.

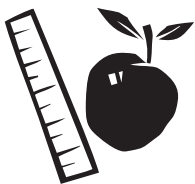
We took our black mollies and neon tetras to the front counter to pay for them. I ran interference as my kids unscrewed the dried tubeworm food, fearing they would quickly turn the place into a bulk food outlet. What a great evening I thought. The kids were amused, the store staff seemed so merry, and an hour had melted away. It wasn't until I got home and walked towards the aquarium, past the hall mirror, that I realized why there were all those amused grins. There on the back of my pink shirt, sticking out like quills, were a bunch of curled address stickers! It's okay, I thought. I'm just a parent. If anyone had asked, I would have simply requested that they read the labels and point me in the direction of home.



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## FXRFC Fundraising Cook Books

*Wondering what might make a perfect end-of-school-year gift  
for your child's teacher or daycare staff?*



At the FXRFC, we would like to suggest you consider making a donation in someone's name as an alternative to buying a gift. It might be a teacher, education assistant, school librarian, or anyone who has helped make this year special for your child. Some of our families do this on an annual basis, with both the sender and the recipient getting a letter from the Foundation, making them aware that the donation has been received.

If you would like to include a small gift along with the donation, may we suggest a FXRFC cook book that you could inscribe with a personal message.

All the compiled recipes were sent in by friends and families touched by Fragile X. Cookbooks are available for \$10 by contacting the FXRFC headquarters at (905) 453-9366 or by e-mail at: [fxrfc@attglobal.net](mailto:fxrfc@attglobal.net).



## **Holland**

*I am often asked to describe the experience of raising a child with a disability; to try to help people who have not shared the unique experience.*

*To understand it and to imagine how it would feel, I tell them - it's like this:*

*When you are going to have baby.*

*it is like planning a fabulous vacation to Italy.*

*You buy a bunch of guidebooks and make your wonderful plans.*

*You dream of the Coliseum, the Sistine Chapel, the gondolas in Venice.*

*You may even learn some handy phrases in Italian. It's all very exciting.*

*After months of eager anticipation, the day finally arrives.*

*You pack your bags and off you go. Hours later, the plane lands, the stewardess comes in and says, "Welcome to Holland."*

*"Holland?" you say. "What do you mean Holland? I signed up for Italy."*

*But there's been a change in the flight plan.*

*They've landed in Holland and there you must stay.*

*The thing is, they haven't taken you to a horrible, disgusting place full of famine and disease. It's just a different place.*

*So now you must go out and buy new guidebooks.*

*And now you must learn a whole new language.*

*And now you will meet a whole new group of people you would never have met.*

*Holland is slower paced than Italy, it's less flashy than Italy.*

*But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.*

*But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there.*

*And for the rest of your life you will say,*

*"Yes, that's where I was supposed to go. That's what I planned too."*

*The pain of that will never, ever, go away because the loss is a very real, very significant loss.*

*But if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very lovely, the very special things about Holland.*

## **FXRFC Support Groups - We are Growing!**

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](mailto:fxrfc@attglobal.net)

### ***Quebec Support Group***

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

### ***Ontario***

#### ***Kitchener-Waterloo Fragile X Support Group***

Teresa Burch, Co-ordinator  
62 Corfield Drive, Kitchener,  
Ontario N2A 3W9  
Phone: (519) 894-3689  
Fax: (519) 894-6333

### ***British Columbia Support Group***

Pam Winthrope  
7968-112A Street  
Delta, BC V4C 4Y6  
Phone: (604) 590-6822  
E-mail: [pwinthrope@hotmail.com](mailto:pwinthrope@hotmail.com)  
Web:  
<http://fragilex.bc.tripod.com/fragilex.bc/>



*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.*

## **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, Ontario, Canada L6Y 1M5  
*Come visit our site on the web at: <http://www.fragile-x.ca>*