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Volume IV, Issue 1; January 2008

Mark Your Calendar

Support Meetings:

When:

February, March, April, first Saturday of the month.

Time:

Business Meeting: 6-7 p.m. Support Meeting: 7-9 p.m.

Where:

Beaumont Hospital Royal Oak Campus Administration Bldg Private Dining Room

Special Events:

Feb 26-27:

Advocacy Day in Washington D.C. More details on pg 2

Jul 23-27:

11th International Fragile X Conference, St. Louis, Missouri

Fragile X Association of Michigan

Contact Information:

313-381-2834

fraxmich @hotlinemail.com

Fragilex.org/html/michigan.htm

9 to 4 with Eric Zachary Wagar

By Jill Schodde

ric is working today. He starts his job as a courtesy clerk with Glen's Market in the northwest Michigan town of Petoskey at 9:00 a.m. sharp. calls me at 7:00 a.m. to let me know that he already walked and fed Reggie, his dog, and that he will shower, shave and dress for work, then bring Reggie to my house for "doggie day care" while he is at work. He walks Reggie again as he heads the four blocks to my house.

He is running a little late today. It's only 8:00 but he likes to have breakfast at the nearby Big Apple Bagel so he can visit with friends and co-workers before he clocks in at the store. He rushes to my garage where he stores his bright red 50cc motor scooter.

He got his license last year. He always jokingly says "Third time's a charm" because he passed the test on his third try.

Glen's Market is on Hwy 31 in town about 6 miles away. He gets to the bagel shop and orders a muffin and coffee that they pour into a cup they keep there for him. It has "Eric" written on it and Eric loves

that none of his friends have their own cup there. Just him.

When he clocks in at his job he goes right to work bagging groceries and bantering with the many customers he

has gotten to know over time. He is quick with a grin and a genuine "How ya doin'?"

When he clocks out from work at 4 p.m., he buys me a newspaper and brings it over when he comes to pick up Reggie. He doesn't tell me much about his day but that's okay. We live in a small town and I usually end up hearing about his day from my many "sources".

Once, when he went to the movies he said that he didn't see the movie he was planning to see. When I went to the hair salon the next day one of the hair dressers said she'd seen Eric in the theater but didn't wave to him because the movie had already started. I told Marcy that he'd said he hadn't seen the movie. Well, she said, she thought he might have been shy about telling me because there were some racy parts in the movie. When I told him Marcy



had seen him in the movie he said "Oops" with a grin on his face.

Eric will be going to Tae Kwon Do tonight. He goes three times a week and is currently working towards his green belt. He is in the adult class and, since he is a camel belt, he spars with the other athletes. He is totally fun to watch. can't help but crack up when he tells his sparring partner "to take it easy" or "come on now". (They get a kick out of it too) He keeps his eyes on the prize, that's for sure. He tells me: "Next green, then red, and then black belt!" instructor wants him to go to an area competition in February. It would be fun to go and watch. They have a special division for differently-abled athletes, from what I understand.

We drive Eric back to our house from his class and tonight we will have dinner together. Then he and his dog Reggie walk home.

Eric is thirty-seven years old.

Fragile X Advocacy Day, Feb 26-27, 2008, Washington D.C.

Agenda:

Advocacy Training from 1 p.m. to 5 p.m. on Tuesday, February 26.

Capitol Hill meetings will take place anytime between 9 and 5 p.m. on Wednesday, February 27.

Specific meeting times will not be available until your arrival in DC. Where to learn more:

fragilex.org/html/public_policy_legislative_advo.htm Contact NFXF Public Policy Chair Jeffrey Cohen at: 734-407-2413 or j.cohen@fragilex.org Conference Hotel:

The Melrose Hotel

2430 Pennsylvania Ave. NW Washington DC, USA 20037

For reservations call: 1-800 MELROSE

Ask for the NFXF Conference Rate: \$239.00 plus tax.

ROOM RESERVATIONS MUST BE MADE BY FEB. 1, 2008.

Diagnosis experiences of women with Premature Ovarian Failure (POF).

Krista Charen is finishing her Master's in Public Health at Emory University. She is currently recruiting women for her thesis research project, which will examine the diagnosis experiences of women with Premature Ovarian Failure (POF).

Participation in this study will entail completing a questionnaire about your diagnosis experiences with POF. The questionnaire will take approximately 15 minutes to complete and can be completed online. All participants must be at least 18 years old and have received a diagnosis of POF from a medical professional.

If you are interested in participating or if you would like additional information about the study, please contact Krista at:

404-778-8479 or Kcharen@genetics.emory.edu.

Participants must be 18 or older, and have a diagnosis of POF from a medical professional.

Participants do NOT have to be Fragile X premutation carriers.

From the President's Desk

Happy 2008!

We are moving into the new year with an exciting agenda -- new families, new fundraisers, new energy! Thank you so much to all of you for your hard work over the past year.

We welcome any of *your* new ideas for this coming year and we look forward to seeing you! Don't forget our business meetings proceed our support meetings. All are always welcome and we can use additional volunteers.



Research Study

Are You a Teen or Young Adult Affected by an

Autism Spectrum Disorder?

Do You Know Someone that is?

We Want to Hear From You!!

WAYNE STATE UNIVERSITY

SCHOOL OF SOCIAL WORK

r. Jozefowicz-Simbeni and Rebecca Thompson from Wayne State University are conducting a research study about the experiences of adolescents and young adults affected by Autism.

They are interested in conducting focus groups and interviews with individuals affected by Autism, their families, and the professionals that work with them. Discussions would focus on the successes and struggles experienced during adolescence

and the transition to adulthood, experiences with school, work, social relationships, interests, hobbies, and use of services. If you are interested in learning more about this study, please contact us.

Contact Rebecca Thompson at

313-577-2262 or

rebthompson@gmail.com

Fragile X Research News ...

Fragile X has been in the news a great deal during December and January. May this trend continue through 2008.

One of the best articles written on the latest news is available at Time.com, titled "A New Approach to Correcting Autism". One drug that has in the animal-model research studies, reversed some of the symptoms of Fragile X and improved cognitive ability, has begun Phase I human clinical trials late December 2007.

Dr. Mark Bear, Picower Professor of Neuroscience at the Massachusetts Institute of Technology and Investigator, Howard Hughes Medical Institute, has founded a company called Seaside Therapeutics that hopes to begin human safety tests of another drug as early as this year.

Follow the research at:

clinicaltrials.gov neuropharm.co.uk seasidetherapeutics.com fragilex.org fraxa.org



Hosted by the Fragile X Resource Center of Missouri

Online registration for the 11th International Fragile X Conference will be available January 31, 2008.

The conference will be held at the Hyatt Regency St. Louis at Union Station.

Full details are available online at fragileX.org or by calling the National Fragile X Foundation at:

800-688-8765

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Fragilex.org/html/michigan.htm



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