

**Three Cheers for Golf, the Liberatis  
and their family and friends,  
our volunteers and a beautiful day!**



From left: Kim Young, Frank Liberati, Sally Nantais,  
Mary Beth Langan, Mark and Malinda Popejoy



**Saturday, November 3, 2007, Support Meeting**

We will have an honored guest at the November meeting. Don Bailey, Ph.D., who's been a part of numerous fragile X research projects - some of which have included research participants from our FXAM family.

Bailey is a Distinguished Fellow at RTI International. For 27 years, he was on the faculty of the University of North Carolina at Chapel Hill, where he was a Professor of Education and Director of the Frank Porter Graham Child Development Institute. For nearly 20 years, Bailey has studied children with fragile X syndrome, the leading inherited cause of intellectual impairment, and their families. He has an extensive record of publications, with more than 170 peer-reviewed articles, chapters, and books on a wide variety of topics related to early education, early intervention, and family support. Currently, Bailey directs several projects funded by the National Institutes of Health and the Centers for Disease Control on various aspects of fragile X and broader issues surrounding the ethical, legal, and social consequences of genetic discoveries and the disclosure of genetic information to families. In 2006, he received the Career Research Scientist Award from the Academy on Mental Retardation. He is President-Elect of the Board of Directors of the National Fragile X Foundation ([fragilex.org](http://fragilex.org)).

Come to the meeting, meet Dr. Bailey and learn more about his new project, detailed in this newsletter. ✕✕

Our sincere gratitude goes to the following businesses, organizations and individuals for their generous donations:

**The Tiger (\$1,300+)**

Men's Wearhouse

**The Palmer (\$500+)**

Kenwal Steel Corp.

**The Watson (\$250+)**

Trenton Fire Fighters Charities

**The Player (\$150+)**

Allen Park Adult Booster Club  
Allen Park Football Committee  
Ameriprise Financial  
Arnaldo's Banquet Center  
Jerry & Karen Bishop  
Charlie Roy Management Company  
Cohen Family  
Florence Coleman  
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Father Saylor, Knights of Columbus  
Flagstar Bank - Gary Swinney  
& Walter Tyslicki 313-381-8900  
Freckle Face Candles  
Joan Grab  
Gary & Lori Gassmann  
Groh Enterprises  
Italia Bakery  
Kiwanis Club of Allen Park  
Lakeshore Utility  
Langan-Coutilish Family  
Law offices of Miller & Miller, PC  
Papa & Mama Rose Liberati  
Liberati & Sons Construction  
Liberati's Italian Deli & Bakery  
Lincoln Park Credit Union  
Maracle Family  
Sandra & Douglas McClennen  
Nantais Family  
Preferred Brands  
Pomponio Construction  
Romeo Country Store  
Silverton Skin Institute  
Theresa Sternicki  
John & Nancy Warneck  
Watson Engineering  
Weed Eraser, Inc.  
Wurth Family

We would also like to thank the following businesses, organizations and individuals for their donations:

Terry Adams  
Agemy & Sons Market  
Dave & Fran Babbage  
Cathy Bartolotta

Joe Batayeh  
Darrin & Ruth Best  
Brennan Jewelry  
Bob Callahan  
Kerry & Isolina Carlini  
William & Shirley Cavataio  
Sheryl Fellows  
Brian & Annette Foley  
Tony & Leanna Foresi  
Mark & Tina Gaworecki  
Karen Goulasarian  
Freckle Face Candles  
Rose Guerra  
J. Goulasarian Contracting, Inc.  
Craig Hawker  
William & Kim Holdsworth  
Dave Jakobowski  
George & Barbara Jakubik  
Julian & Wanda Joseph  
Levon & Gloria King  
Malcom Kurepa  
Jim Lada  
Ray Lalli  
John & Emma Langan  
Michelle Laske  
Jimmy & Deborah Lee  
Trina Lengyel  
M-Den  
Leonard & Peggy Majeske  
Ron & Laureen Majeske  
Tony & Dora Mangiapane  
Bob Mannino  
Jerry & Sally Nantais  
Steve Obermier  
Vince & Kristen Pattenaude  
The Perfect Wedding Box  
Jerome & Jeannette Pearsons  
Sam & Grace Pizzo  
Kelly & Maria Pratt  
Joe Procopis  
Douglas & Lois Rich  
Joe Salisz  
Lori Schrieber  
Tony & Sue Shannon  
Glenn & Sarah Smith  
Susan Stearns  
Keith & Wendy Stephens  
Theresa Sternicki  
Susin Construction Co.  
Tony Theodore  
This is Zip Printing  
Lester & Lisa Voutsos  
Weight Watchers  
James & Charlotte Westbrook  
Larry & Coleen Wurth  
Nazar & Sue Zain ✕✕

## Participate in the first national Survey for Families of Children with Fragile X Syndrome

This survey will look at how Fragile X affects families, including medical and nutritional needs of children with Fragile X, use of educational services and supports, and the cost of raising a child with Fragile X. The survey will be the first to gather national data from families that can be used to change policy and improve practice.

**At least 2,500 families are needed for the survey; your participation is very important!**

### Enrollment

- August through December 2007
- Takes 20 minutes to complete
- Can be done on the Internet or by calling toll free
- Asks for basic information about your family

### The Survey

- Begins in January 2008 (you will be reminded 2 weeks before the survey begins)
- Asks more in-depth questions about your family
- Takes 35–40 minutes to complete
- Can be done on the Internet or by calling toll free
- All responses will be kept confidential and no personally identifying information will be published in any report or given to any individual or organization

**Dr. Don Bailey**, an established Fragile X researcher at RTI International, is the Project Director. Do you have questions? **Come to the support meeting on Saturday, November 3, and ask Dr Bailey.**

Questions can also be directed to **Melissa Raspa**, Project Manager, at 866-860-5229

For more information or to enroll, visit [fragilex.rti.org](http://fragilex.rti.org) or call 866-860-5229

## Fragile X Fun Run & Walk and Picnic 2007

This year, we combined our annual family picnic with a Fun Run & Walk, appropriately held on Sunday, July 22, National Fragile X Awareness Day. The events were held at Independence Oaks County Park in Northern Oakland County. We had a spectrum of participants at the Fun Run & Walk – competitive runners and families pulling children in wagons. Our sincere gratitude goes to the following individuals for their generous donations to the awareness event:

Rachael & Scott Albaugh  
Michele & Gerald Jankowski  
Cynthia Koch  
Emma & John Langan  
Therese Langan  
Jean & Roger Laske  
Romy & Michael Patterson  
Michelle Peterson  
Laurie & Steve Willis

After the Fun Run & Walk, we went on to more fun and food. Children loved the twin bounce houses which were added this year. FXAM provided much of the picnic food, with families bringing a dish to pass. As always, we had plenty of food and a lot of fun! A big thank you to Kim and Mike Young for organizing the whole day, with assistance by other members.

XX

## From the President's Desk By Lauren Majeske

This year's Fragile X conference at Beaumont Hospital was a wonderful experience. The dedicated families and professionals who attended were a wonderful reminder of how we work together to help our children and family members live a full and productive life in the world we live in. I know I always go home with a renewed sense of love and awe at the wonderful human beings we are helping to raise. Thank you to Dr. Marcia Braden and Erin Carmany for the terrific job they did on their presentations. Special thanks to the National Fragile X Foundation, Beaumont Hospital and Eaton Corporation for their generous support, making the conference possible. Hope to see you all at our November meeting with our very special guest, Dr. Don Bailey. XX

*Quote for the Quarter*

**We make a living by what we get,  
we make a life by what we give.**

*Sir Winston Churchill*

## Mark Your Calendar

### Support Meetings:

**When:** November, February and March  
First Saturday of the month.

**Time:** Business Meeting: 6 – 7 p.m.  
Support Meeting: 7 – 9 p.m.

**Where:** Beaumont Hospital, Royal Oak  
Admin Building, Private Dining Room

### Special Events:

**Nov 3: Don Bailey, Ph.D., Guest Speaker**

**Dec 8: Holiday Potluck Party, 5 p.m.**  
Cohen Family home, more details will be  
provided later via email or mail

Electronic copies of our newsletter are available on our  
website. If you would like to share them with family,  
friends or professionals, please share  
our web address with them.

**Reminder: NO Support Meeting in  
DECEMBER or JANUARY**

### Contact Information:

Phone: 313-381-2834

E-Mail: [fraxmich@hotmail.com](mailto:fraxmich@hotmail.com)

Web: [www.Fragilex.org/html/michigan.htm](http://www.Fragilex.org/html/michigan.htm)

*eXtra, eXtra*

Editors:

Mary Beth Langan 313-881-3340  
[mblangan@hotmail.com](mailto:mblangan@hotmail.com)

Sally Nantais 734-282-7910  
[sallyn423@juno.com](mailto:sallyn423@juno.com)

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P.O. Box 1414  
Troy, MI 48099-1414