

**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).

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
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Family Dentistry
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
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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 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:

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eXtra, eXtra

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