

**Three Cheers for Golf, the Liberatis
and their family and friends**



Florence Coleman, Fran Babbage, Ellen Sharkey
& Janet Olszewski



Frank
Liberati



Rose Liberati & grandson,
Tullio Liberati III



Jim Morrin & Sam Pizzo



David Edens, Robby Edens,
Mark Popejoy, Malinda
Popejoy & Paul Urban

Three Cheers for Nicholas

Washtenaw County 4H Fair July 2006, three cheers for Nicholas Weber and the truck load of ribbons he earned. Nicholas won ribbons for his participation in horseback riding, swine and a rabbit showing for a whopping 17 "A" rating ribbons for his crafts and livestock presentations. XX

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

Platinum (\$1,000+)

Men's Wearhouse

Gold (\$500+)

Kenwal Steel Corp

Silver (\$250+)

Watson Engineering, Inc

Carl & Kathy Widdis

Bronze (\$150+)

Allen Park Adult Booster Club

Allen Park Football Committee

Arnaldo's Banquet Center

Jerry & Karen Bishop

Florence Coleman

Charlie Roy Management

Company

Direct Buy of Metro Detroit East

Downriver Italian American Club

Flagstar Bank

Family Dentistry

Freckle Face Candles

Italia Bakery

Stephen & Cynthia Kinch

Kiwanis Club of Allen Park

Lakeshore Utility

Law Offices of Miller & Miller, PC

Liberati & Sons Construction

Liberati's Italian Deli & Bakery

Lincoln Park Credit Union

McCarthy & Smith Construction

Mothers (and Fathers) of Twins Club

Francis Nazareno, MD

Pomponio Brothers Construction

Preferred Brands Produce

Silverton Skin Institute

Theresa Sternicki

Trenton Fire Fighters Charities

Weed Eraser, Inc

John Widdis

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

Anoir Agemy

Jim & Julie Bademian

Darrin & Ruth Best

Detroit Red Wings

Detroit Tigers

Father Saylor, Knights of

Columbus

Freckle Face Candles

Lori Friesner

Mary Hancock

Joe & Sharon Heltsley

George & Barbara Jakubik

Tony & Frances Jesue

Julian & Wanda Joseph

Leonard & Peggy Majeske

Ron & Laureen Majeske

Anthony & Dora Mangiapane

Bob Mannino

Jerry & Sally Nantais

Vince & Kristen Pattenaude

Kelly & Maria Pratt

Reale Cement

(Virginio & Anna Reale)

Roosevelt Lanes

Ken & Barb Sawicki

Dan & Lori Schrieber

Tony & Sue Shannon

Theresa Sternicki

Tom & Kathy Tubb

Lester & Lisa Voutsos

John & Nancy Warneck

James & Charlotte Westbrook

Todd Widdis

Mitch & Fran Wolski

Nazar & Sue Zain ✨

**Fragile X Association of Michigan
is a 501(c)(3) charitable organization.
(Fed. Tax ID# 56-2450171)**

Donations enable us to fulfill our mission by providing services and support to our families. They are welcomed throughout the year at PO Box 1414, Troy, MI 48099-1414.

Grief can be a gift

by Sally Nantais , Originally published:
August 1, 2004, *The News-Herald*

With the dog days of summer upon us, I was sitting at this silly computer trying to find the direction for a column. My mind wandered far from summer to a personal experience.

It's a unique experience that only a parent of a child with a disability can understand: the grief that one experiences with a diagnosis of a disability.

These thoughts were brought on by the images of Nancy Reagan having to be coaxed from her husband's coffin, so weary and grief-stricken. It's a vision some of us won't quickly forget.

It intensified with a column I read for the Grosse Pointe News by close friends Mary Beth Langan and Ted Coutilish on "D-Day," which had nothing to do with World War II. "D-Day" for them was "Diagnosis Day."

Having a child with a disability is not something one ordinarily chooses. The beginning, the diagnosis stage, is one of the most difficult.

We all have dreams for our children that may be shattered with a diagnosis of a disability, be it physical or developmental.

With the loss of those dreams comes grief and all the emotions that go with it: denial, fear, guilt, blame, anger, sorrow and acceptance. Grief doesn't exclude things we can't see or touch.

Grief over our shattered dreams can be as intense as that for the death of a loved one.

Denial came first. "They can't be right, look at what he can do, at how bright he is?" Why do they measure our children on what they can't do and not by what they are capable of doing?

Fear of the unknown is always present. As a parent, you want to know as much as possible and have all the answers. Unfortunately, you quickly discover there are no answers for the important questions.

Will my child have friends? Will my child be happy? Will my child be able to live independently when he's older? What will happen to my child when I'm no longer able to care for him?

Guilt and blame quickly followed, which for me was an easy trap to fall into. After all, my son's disability, Fragile X syndrome, is genetic.

Prior to his diagnosis (he was diagnosed when he was 4) I had no idea that I had a 50/50 chance of passing a developmental disability to my child.

Anger became apparent when I questioned why this happened to me. I wondered why I had to be the one to pass it on and not one of my sisters? It didn't seem fair, but is life ever fair?

At times, my anger has been misdirected. My son has a condition that he was born with and he will die with.

At least that's how one insurance company explained a denial of service to a parent of a child with Fragile X syndrome. At this time, it's not curable and it's not terminal.

There's no Make A Wish or Rainbow Connection for my child or other children like him. Sometimes it seems as though no one cares about the quality of his life, or others like him.

Sorrow was never as intense as it was in the beginning. It's difficult to explain the depth of your sorrow: It was, and at times still is, immeasurable.

Surprisingly, sorrow didn't occur immediately, but happened a little later when hearing the words "mentally retarded" used to describe my son's disability.

Grief may never completely end, but its intensity can subside. From time to time it will resurface and I've learned to welcome it, as it gives me the opportunity to be reborn.

In the movie, "Harry Potter and the Chamber of Secrets" there is a special bird called a phoenix. The phoenix has some unusual characteristics.

When he reaches the end of his life, he bursts into flames and is reborn from his ashes. His tears can heal the wounded and he has the ability to carry incredible loads.

There are times when I feel like the phoenix. I need to burn up so I can start over. From the ash comes additional strength and courage to go on and never give up.

My tears may not heal the wounded, but they do heal me. Lastly, it feels as though the weight on my shoulders is almost unbearable, but I've managed to carry it.

With the passage of time my grief has become a gift. Another door has opened in which my life has become more meaningful. One day, my husband asked me to imagine our lives without our son.

I could describe it with a single word: "shallow." I've found you can live a "shallow" life just as easily as you can drown in shallow water. It's only a matter of choice.

Strangely, many years ago "perfect" was something I strived for. Now, I strive for less than perfect.

All because of a child who may never be "perfect," who may never be "normal," but who will simply love me with all his heart, no matter what.

A lesson learned through the process of grief. ✖✖

Fragile X: A Family Affair

Presenter: Randi J. Hagerman, M.D.

Session Time: Friday, 7/21/06, 1:30 – 2:30 pm

These notes were taken by Mary Beth Langan at a session during the National Fragile X Foundation's 10th International Fragile X Conference, held July 19-23, 2006 in Atlanta, Georgia. Dr. Hagerman focused quite a bit of her session on issues which may affect female carriers, a newer area of research within the Fragile X community.

- there are a significant number of young male and female carriers who have autism and/or ADHD
- there are some carriers with high repeat numbers who actually present as someone with the full mutation/Fragile X Syndrome
- carriers with 70-110 repeats may have highest risk of FXTAS
- high repeat level female carriers may have lower risk of POF
- if females carriers with 90-100+ repeats pass on their affected X, they will nearly always have the gene expand to 200+ (full mutation)
- female carriers with numbness/tingling/sensory neuropathy often have steady symptoms and do not progress to full FXTAS
- some (but very few) women have classic FXTAS similar to male carriers
- female carriers have higher than typical incidence of autoimmune disorders
- 3 out of 105 female carriers have MS; this is higher than typical population
- one female carrier with MS dx actually had both MS lesions and FXTAS inclusions on the brain in autopsy results
- one study of 137 female carriers showed these symptoms/disorders:
 - 2.2% lupus
 - 3% optic neuritis
 - 21% thyroid issues
- 29% numbness/tingling
- 10% fibromyalgia
- 33% muscle pain
- Randi discussed a male carrier who presented with Charcot Marie Tooth, a neuropathy disorder; he really had FXTAS
- discussed one family of four sisters; all carriers between 36 & 50
 - all had anxiety/mood issues
 - two had FXTAS with tremor and ataxia
 - other two had occasional tremors and ataxia
 - one had lupus-like rash; her doctor thought she had fibromyalgia
- women with >100 repeats have higher rates of depression and interpersonal sensitivity
- stress can make you lose neurons and shrink your hippocampus
- 20% of carriers have POF; another 23% in menopause by age 45
- on average, those with 59-79 repeats begin menopause 2.5 yrs sooner than non-carrier women
- on average, those with >80 repeats begin menopause 4 yrs sooner than non carrier women
- 1/3 of female carriers can have OCD and/or anxiety; the rate is higher than the incidence in non-carrier females; male carriers also have a higher incidence of OCD and anxiety than non-carriers males
- what will help carriers stay healthy?
 - treat high blood pressure
 - reduce stress!
 - exercise daily for many reasons, including reducing stress
 - SSRIs (Zoloft/Prozac/Effexor) may help brain repair damage; take an SSRI if you have any of the psychiatric symptoms (anxiety, depression, OCD); these may help you stay healthy now and in the future
 - avoid general anesthesia as you age
 - consider taking folate, Vitamin E, B12, CoQ10

XX

Were you unable to attend the conference but want to learn more?

Please visit the National Fragile X Foundation website at www.fragilex.org. Under "Conferences" select "Prior Conference Proceedings". In the near future, there should be a link to the 2006 Proceedings, which will have handouts, Powerpoint presentations and scientific abstracts from the numerous sessions. Soon after, a hardcopy version will be available for purchase. If you do not have internet access, call 800-688-8765 for details. As of the printing date of this newsletter, this is not yet available. In addition, for the Fragile X listserv, Sally has compiled notes from numerous parents who attended sessions, contact Sally if you'd like a copy in pdf format.

Between the Lines
Featured Book

Fragile: Handle With Care
(Revised Edition 2000)
by Marcia L. Braden, Ph.D.

As noted by the National Fragile X Foundation, this book captures the essence and the characteristics of fragile X at all developmental stages. Good for parents and those who want a basic, thorough introduction to fragile X by a well-known expert.

Whether you are new to the diagnosis or needing the insight of an expert who truly understands the developmental, social, sensory, behavior and adolescence/adult issues as they relate to Fragile X, this book will provide answers. It should be a part of every Fragile X library. ✕✕

Through the Maze
Featured Website

Marcia Braden, Ph.D., P.C.
www.marciabraden.com

Marcia Braden is a licensed psychologist with a clinical practice specializing in children and adolescents. She has been working with individuals with Fragile X since the 1980s. She has created behavioral and academic programs to benefit children and adults with Fragile X.

Her website has products you may purchase: DVDs on behavior, educational issues and sexuality, and educational programs she's created - the Math-Equivalence Board, Logo Reading System, and Token boards.

There are files (previous columns printed in the National Fragile X Foundation's quarterly newsletter) free to download which are easy, and a must, for you to share with family, schools and your professional team who may work with your family member with FXS. A few of our favorites, must-reads, are: Putting the "I" Back into the BIP, Oppositional or Merely Anxious, Have Purpose will Transition.

In addition, the website provides Dr. Braden's lecture schedule and the ability for individuals to purchase her lecture series in a DVD format.

If you are struggling to understand behavior as it relates to Fragile X, Marcia Braden is the expert whose advice you need to seek. ✕✕

From the President's Desk
By Lauren Majeske

After a long summer break, it was nice to see so many of you at the golf fundraiser. We raised nearly \$10,000 and were able to make a \$5,000 donation to the National Fragile X Foundation. A big thank you to Men's Wearhouse and all of the people who continue to sponsor us year after year.

The money helps to support our Michigan families through support group meetings, our quarterly newsletters, local conferences, scholarships and much more.

Carefully read this newsletter and upcoming issues for information on all our events and programs. Watch your mailbox for an updated directory this fall/winter.

Looking forward to seeing you at an upcoming meeting. ✕✕

VOLUNTEERS NEEDED
Special Committee Meeting

January 13, 2007, 2 p.m.
Beaumont Hospital

We need your help! Please come to a meeting to discuss our 2007 programs.

Come volunteer your time, ideas and organization skills. Everyone can contribute! We will be discussing many of our events, especially our premier fundraising event, our golf outing.

RSVP to Mary Beth at 313-881-3340 or
mblangan@hotmail.com.

✕✕

Quote for the Quarter

**In the face of uncertainty, there is
nothing wrong with hope.**

O. Carl Simonton

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:

Dec 9: Holiday Potluck Party, 5 p.m.
Cohen Family home, more details will be
provided later via email or mail

Jan 13: Committee Meeting, 2 p.m.
Please read about this meeting on page 5

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.

Feb 3: NFXF Adolescent and Adult Project
Discussion led by Arlene Cohen

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

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eXtra, eXtra

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Association of Michigan

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