



# Fragile X News

MARCH 25, 2005

VOLUME 1, NUMBER 1

## Highlights:

Welcome	1
Upcoming Events	
FRAXA Gala	1
Golf tournament	1-2
Recent Events	
Kennedy Krieger	3

## Welcome

Hi and welcome to the Maryland Fragile X Resource Group's first newsletter. Our goal is to provide information on what the group is doing, our accomplishments, current events in the Fragile X world and articles that may be of interest to everyone. We will also provide an updated calendar of events.

Anyone interested in a particular subject, please let us know. We will do our best to obtain the most recent information or articles. Also, we are going to have a section "Smile-A-While" that would highlight any accomplishments that you and/or your child(ren) have obtained. We would also like to include any interesting, funny stories about our kids.

So, please send us your ideas, topics, funny anecdotes, and anything else "newsworthy"

### Contact information:

Kristen Head, President [kmhead129@aol.com](mailto:kmhead129@aol.com)  
Kathy Seering, Secretary [jseering@msn.com](mailto:jseering@msn.com)  
Shari Lewis [Meilia@aol.com](mailto:Meilia@aol.com)

## Upcoming Events

### **Eighth Annual FRAXA GALA**

The Eighth Annual Mary Higgins Clark dinner will be held in Washington at the Four Seasons Hotel on Monday, April 11th. Mary Higgins Clark will be a special guest, and Senator Chuck Hagel, the recipient of our 2004 Research Beacon award for his support of Fragile X research, will present this year's award. Roger Mudd will be the Host.

Invitations are ready to be mailed, and those desiring one or more, or further information, should contact Mary Beth Busby at [MBBBusby@aol.com](mailto:MBBBusby@aol.com) or at 202-462-2323.

Please come and join us for a wonderful evening. Meet the compassionate, dedicated people who work so diligently behind the scenes to move us forward in our quest to find a cure for Fragile X.

### **Fragile X Golf Classic**

I am pleased to announce that we will again be doing the Fragile X Golf Classic. For those of you that participated in 2003 (our inaugural event), thanks to your generous support, we raised over \$125,000 for Fragile X research and education.

Location: Tournament Players Club at Avenel

Date: Monday June 6<sup>th</sup>, 2005



PGA professional Fred Funk will again be the Honorary Chairman and attending the event. The Washington Post and Comcast have also generously agreed again to be our media sponsors for the event. Last year The Washington Post ran half page color ads for the event including The Sunday Post. Comcast aired a public service announcement with Fred Funk speaking about Fragile X Syndrome and the event that was filmed by the PGA. This aired throughout the region leading up to the tournament on Comcast stations in the Washington DC area. These media venues offered our corporate sponsors a tremendous opportunity to get high quality media exposure at a fraction of the cost if they had purchased this on their own. Not only was it an incredibly generous gesture on their part to support the event, it was also good business!

### **Sponsorship Opportunities**

#### Event Signature Sponsor- \$15,000

Only one available and already reserved

#### Gold Sponsor-\$10,000

Foursome to participate in golf clinic with Fred Funk, foursome for golf event, corporate name prominently displayed as a Gold Corporate Sponsor on all marketing, programs and promotion (includes Washington Post ads and Comcast public service announcements that air), six tickets to the evening awards banquet and auction

#### Silver Sponsor-\$5,000

Two slots to participate in golf clinic with Fred Funk, foursome for golf event, corporate name prominently displayed as a Silver Corporate Sponsor on all marketing, programs and promotion (includes Washington Post ads and Comcast public service announcements that air), four tickets to the evening awards banquet and auction

#### Corporate Banner Sponsor - \$2,200

Foursome to play in golf tournament, four tickets to evening awards banquet and auction, banner displayed at hole with company name as that hole's sponsor, company name as a hole sponsor in the program

#### Foursome-\$1,200

Greens fees, golf cart, dinner and prizes

#### Hole Banner Sponsor -\$1,000

Banner at hole displaying company name as hole sponsor

#### Individual Player - \$300

Greens fees, golf cart, dinner and prizes

We are also looking for auction items. Please let me know if you would like to donate something for the silent or live auction.

Please contact Mark & Marla Gruzin at [mgruzin@comcast.net](mailto:mgruzin@comcast.net)

## Recent Events

On March 12, 2005 Kennedy Krieger hosted our bimonthly meeting. They presented two seminars related to Fragile X Syndrome.

The first seminar was Pharmacotherapy for Children with Fragile X presented by Walter Kaufman, MD. Dr. Kaufman provided an excellent overview of the issues regarding drug-based treatment of boys with Fragile X. He also discussed the integration between pharmacologic and non-pharmacologic treatments and the areas that require more research.

The second seminar was on Aggressive Behaviors in Children with Fragile X. This was presented by Robert Gray, PhD. Dr. Gray discussed the variety of behavioral problems, including the scope and severity of aggression in boys with Fragile X. This presentation provided us an overview of the research findings regarding the characteristics and development of aggressive behavior; highlighted some potential causes; and addressed some of the treatment and interventions that have been used to reduce aggression.

Both speakers were wonderful, well-informed, and took a lot of time answering our myriad of questions. They have also offered to host other events, including business meetings, for our group.

We would like to extend our heart-felt thanks to those at Kennedy Krieger who worked so hard to make this happen.

To inquire about services, contact Kennedy Krieger Institute's Care Management Office at 443-923-9400.

Their website is [www.kennedykrieger.org](http://www.kennedykrieger.org)

The website for the Center for Genetic Disorders of Cognition & Behavior at the Kennedy Krieger Institute is: [www.gcbcenter.kennedykrieger.org](http://www.gcbcenter.kennedykrieger.org)

## Next Business Meeting

There will be a golf tournament planning meeting held on June 4, 2005 at 2pm. The meeting place will be at Mark & Marla Gruzin's. Please contact Mark at [mgruzin@comcast.net](mailto:mgruzin@comcast.net) for information.

**REMINDER:** We still need items for the silent and live auction. Some particular items include trips; restaurant vouchers; sports memorabilia; autographed items. We also need items for "goody" bags, items donated by a business with their logo such as flashlights, pens, etc.

The next business meeting will be held July 9, 2005 from 3p-4:30p at the Neelsville church. We hope to see you there!

Please contact Melissa Blount at [fragilexmom@comcast.net](mailto:fragilexmom@comcast.net) if you require daycare.

Maryland Fragile X Resource Group

P.O. Box 5255  
Laytonsville, MD 20882

301-774-1069

Kristen Head, President  
[Kmhead129@aol.com](mailto:Kmhead129@aol.com)

Web: [www.mdfragilex.org](http://www.mdfragilex.org)