



Fragile X News

FALL 2005

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Welcome

Hi and welcome to the Maryland Fragile X Resource Group's second 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"

As an apology from the editor.....I was attempting to put together a summer newsletter that included some special needs camps. I received a good number of responses, with some great recommendations. I was trying to verify some of the other camps, and well, the late spring, early summer just went by too fast. The information that I received will be included in the Spring 2006 newsletter. If anyone has any suggestions for summertime fun things to do with our children, please send me your recommendations. I would love to be able to include those in the Spring edition.

The next newsletter will be in December. Please let me know of any events, notices or special things that you would like included.

Contact information:

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Upcoming Events

Oct 8, 2005 Potluck dinner at the Swerdlin's home in Brookeville. The event will start at 6:00pm. This is an adults only event. For more information and to RSVP, please contact Laura at lauraswerdlin@comcast.net or at 301-774-0674.

Oct 9-11, 2005 Pediatrics Conference at the Washington DC Convention Center. The National Fragile X Foundation will have a booth set up and need volunteers to assist. Please contact Kristen Head at kmhead129@aol.com.

Oct 14-15, 2005 1st Annual Pennsylvania Fragile X Gala & Auction in Harrisburg, PA. For more information, please contact Deborah & William Parker at 717-541-1500 or jacobscrib@aol.com.

Nov 12, 2005 Maryland Fragile X Resource Group Business Meeting
Neelsville Presbyterian Church

Nov 12-16, 2005 Society for Neuroscience Conference
This event will take place in Washington, DC.
FRAXA will have a booth there and volunteers are needed to assist. Please contact Mary Beth Busby at mabbusby@aol.com.

Also relating to this FRAXA has also asked for assistance with obtaining a trade show display and video projector. If you know of any companies that may be willing to donate either (or both) items, please contact Katie Clapp at KClappFRAXA@comcast.net.

Recent Events

Fragile X Golf Classic

The 2nd Golf Tournament was held on June 6, 2005 and was a huge success. We had a great time and so did the golfers! The proceeds were donated to FRAXA and to the National Fragile X Foundation.

Thank you to the many volunteers who worked so hard to make this event such a success. Your hard work and dedication is Awesome! Special thanks to Mark Gruzin for coordinating this event, Marla Gruzin for all of her support and help (and for offering up her husband), Michael and Lisa Kelly did a fantastic job with the set-up and dinner, Melissa Blount for coordinating the Silent Auction, and Kristen Head for doing everything else.

2005 Fragile X Classic Volleyball Tournament

The volleyball tournament was held on Sept 17th and 18th. This was also a huge success and is truly a fun event. Thanks to all of the volunteers who came out to help. Special thanks to Bill Pribac for coordinating these events for the past four years.

Other News

Moms Day Out

There has been some interest expressed in having get-togethers for our moms. This would provide a forum for us to offer support, discuss any issues, exchange ideas and techniques that have worked for others, and a chance for us to get to know each other better. Liz Pribac has graciously offered the use of her home for these get-togethers. Please contact Liz if you would like more information at EPribac@comcast.net.

It is time to update our membership list. This will ensure that we have accurate data to send out emails and other information. Everyone will be receiving a Maryland Fragile X Resource Group Membership Application. Included in the application are areas to notate whether you are interested in participating in one of the MDFX committees and also a survey that will help the group determine some additional needs. Please complete the form and return to Kristen Head.

Hey....check out our updated website at www.mdfragilex.org and a big welcome and thanks to Dennis Hasley for volunteering to be our webmaster. For any comments, additions, or suggestions please contact Dennis at Magnum54o2@aol.com.

Of Interest

As we go into another school, the journey of the IEP begins. For some of us this can be an intimidating process. There are 6 – 8 of “them” and 1 or 2 of “us”. During this process many unfamiliar terms may be thrown about, and of course in the interest of time and not wanting to appear “uninformed” we do not interrupt to ask questions. So I would surreptitiously write them all down, to go home after the meeting and begin searching books and the internet.

The goals start flying around the table, interventions, modifications, how to measure, what to measure. What will work, what won’t work, is this appropriate for my child? So many decisions, so many questions. Am I agreeing to the right things? Is there more that should be included?

Included at the end of the newsletter is a Glossary of terms and some websites to help us become more involved and proactive during the IEP development process. And just like the “Never-ending Story” we have begun the “Never-ending Journey”

Next Business Meeting

The next business meeting will be held on Nov 12, 2005 from 3p-4:30p at the Neelsville Presbyterian church in Germantown. Please contact Melissa Blount at fragilexmom@comcast.net if you require daycare.

Maryland Fragile X
Resource Group

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