

Subject: Minutes of the September 18, 2004 Maryland Fragile X Resource Group Business Meeting

Present: Kristen Head, Kathy Seering, Rita Furst Seifert, Mark Gruzin, Melissa & Al Blount, Shari Lewis, Dennis Hasley, Mary Beth & David Busby, Liz & Bill Pribac

Treasurer's Report presented by Al Blount for the period 1/1/04-9/18/04

Total Inflows: \$12,491.00
Total Outflows: 1,640.78
Overall Total: \$10,850.22

Old Business:

Certificate from the NFXF

Kristen Head shared a certificate that the Maryland Fragile X Resource Group received from the National Fragile X Foundation thanking the group for all of their help with the 2004 Conference. The certificate will be put in the group memory book.

New Business:

Volleyball Tournament

The 2004 Fragile X Classic Volleyball Tournament will be held Columbus Day weekend. The dates are: Friday, Oct. 8th, Saturday, Oct. 9th, and Sunday Oct. 10th at St. John's College High School on Military Road in Washington D.C. This is the 3rd annual tournament. **Volunteers are needed to make this event a success.** Volunteers are needed to cover the door and refreshment stand. Volunteers are needed during the following times: Friday 5:30-10:00, Saturday 11:00-10:00, and Sunday 8:30-5:00. At all times we need at least 4 volunteers. Please let Bill Pribac know what hours you will volunteer. Bill's email address is Bpnordic@comcast.net. Even if you can only spare a couple of hours.....we really need your help. Besides do you know of any better cause?

Genetics Conference

Robert Miller of the National Fragile X Foundation is also looking for volunteers to help with their table at the National Society of Genetic Counselors meeting October 7-10, 2004 (Wed.-Sun.). It is being held at the Hyatt Regency on Capital Hill. The NFXF has purchased an exhibit booth and is in need of volunteers to setup, staff and take down. Please contact Kristen Head at KMHead129@aol.com to volunteer.

Rotation of Business Meeting Location

The idea of rotating the location of business meetings was discussed. It was decided to hold the March business meeting in/near Baltimore. We hope that by doing this that more of our 60 some families will be able to attend a meeting and get involved in group activities. We decided to have Baltimore be the first meeting site because we seem to have a lot of families that live closer to Baltimore. More information on the location will be sent out later. So Baltimore area families mark your calendars for March 12th. We look forward to meeting you.

FRAXA Gala

The next FRAXA Gala will be on April 11, 2005 at the Four Seasons Hotel in Washington D.C. Tickets are \$350 per person. For more information contact Mary Beth Busby at MBBBusby@aol.com.

Potluck at the Heads

A potluck dinner and cookie swap will be held at the Head's home on December 4, 2004. More information to come.

Calendar of Events

The calendar of upcoming events was discussed and an updated version will be sent out shortly.

Nominations for Office

Voting on Offices will be done in November. If anyone would like to nominate someone for office please let Kristen Head know at KMHead129@aol.com. The offices are President, Treasurer, and Secretary. Only people who have filled out a membership application are eligible to vote. Membership applications will be sent out to those who have not filled one out in the past.

The next business meeting will be on November 13, 2004.

Guest Speaker

Our guest speaker was Dr. Walter Kaufmann from Kennedy Krieger Institute in Baltimore. Dr. Kaufmann discussed Fragile X research being done at Kennedy Krieger. Please check out the website at www.gcbcenter.kennedykrieger.org.