

DATE: January 18, 2007
 LOCATION: Westchester
 Meeting Opened: 6:40 p.m.
 Meeting Closed: 9:45 p.m.
 Next Meeting: Next meeting will be held on Thursday, March 1st at 6:30 p.m.

Meeting Minutes **1/18/07**

I. Roll Call/Introductions

IN ATTENDANCE:	NOT IN ATTENDANCE:
Joseph Annunzio	Christina Davis
Steve Bennett	Jeff Davis
Larissa Bruno	
Jim Critchfield	
Lisa Irgang	
Anne Kozek	
Mike McMahon	
Peter Neill	
April Salemi	
Jonathan Springborn	
Hazel Vespa	

II. Officer Reports

A. President's Report

- 1) Tracy Keegan will not be returning to the Board this year.
 - a. Need to e-mail Clinic staff for suggestions. Possibly approach members about a shared seat position.
 - b. Lisa will approach Josh Earnest
 - c. Legal minimum for an operable Board is 5 members. Our by-laws call for 11 members.
 - d. Jim brought up the perceived stigma about the necessary time commitment for serving on the Board.
 - i. Regular Board member vs. Executive Board member.
 - ii. Mike brought up the honor that he and Jennifer felt about serving. They viewed it as a way to learn more about the Organization.
- 2) Members were asked to review current committee list and make adjustments as necessary. The Hospitality Committee needs more members. Discussed looking outside of the Board.
- 3) PKU Awareness Month
 - a. Date is confirmed for May 20th at Busse Woods, grove #32 at 10:30 a.m.
 - b. Beth Burke is working with Lisa to organize the walk.
 - c. We will be sending a letter to the Mayor requesting a Proclamation.
- 4) Lisa had a meeting with the clinic staff from Children's and UIC in November.
 - a. Board members were asked for feedback about long-term goals for the Organization. We have a lot of "young" members which allows for time to tackle projects that will take longer.
 - i. Lisa would like to focus on education.
 - ii. Christina would like to focus on legislative issues and school education.
 - iii. Figures from Clinics regarding Spanish speaking families and Allied Disorder families
 1. Which literature, if any, should we translate? This needs to be discussed further.
 2. UIC
 - a. Spanish speaking families w/PKU = 5
 - b. Spanish speaking families w/Allied Disorders = 5
 - c. Bilingual families w/Allied Disorders = 2
 - d. English speaking families w/Allied Disorders (broken down by disorder)

i. Methylmalonic acidemia	2
ii. Propionic acidemia	6
iii. Isovaleric acidemia	6
iv. Urea cycle disorders	6
v. Tyrosinemia	3
vi. Maple syrup urine disease	9
vii. Homocystinuria	1
viii. Glutaric acidemia 1	5

3. CMH
 - a. Spanish speaking families w/PKU = 3
 - b. Spanish speaking families w/Allied Disorders = 15 – 18
 - c. English speaking families w/ classical PKU = 159
 - d. Allied Disorder break down wasn't available in time for the meeting
- iv. Allied Disorders
 1. Concerns were voiced about changing the name on products until interest and commitment from Allied Disorder families is evident
 2. We need to educate ourselves as to how we can help and how we can incorporate them into our Organization. Possibly invite a few families to a Board meeting to discuss these issues.
 3. Jim will contact Trish Mulalley and MACPAD about how these organizations have dealt with these issues.
- b. Education
 - i. Heather has developed a curriculum, which was passed around. Various members of the clinic staff took the responsibility for each section. The Board was asked to help with a few sections.
 - ii. The goal is to develop a binder that can be given to new, and existing, families with educational materials. A majority of the information will apply to all three clinics, with a section that can be personalized. Families will be asked to bring the binder to clinic appointments.
 - iii. The Board will be asked to help with the cost of printing the binders. A rough estimate would be approximately \$30 for each binder. Lisa brought up possible fundraising specifically for this project. Mike brought up the idea of approaching various vendors to advertise/help offset the cost.
- c. Clinic Wish List
 - i. Increase discretionary fund (which will be possible through the donation from Erin's Handicapped Children's Fund).
 - ii. Maternal PKU.
 - iii. Low protein guide at each clinic.
 - iv. Bags for new parent packets.
 - v. We ordered Low Protein Food Lists for new parent packets. This was more relevant for new families vs. the cookbook.
- 5) Request from the Evanosky Foundation for petitioning inclusion of lysosomal storage diseases in newborn screening.
 - a. We need to develop criteria for supporting various petitions.
 - b. Look to Drs. Burton, Wong and Hoganson for input.
 - i. Hazel mentioned that we can ask Dr. Burton to call in during a Board meeting and discuss the criteria that the doctors consider.
 - ii. Anne indicated that they will often look at whether or not treatment is available. It would be difficult for families if a disorder was identified, but there were no forms of treatment.
- 6) Request for support from STAPAD (South Texas Association for PKU & Allied Disorders). They are trying to organize a national campaign to change the federal law which allows PKU to be excluded from self-insured insurance plans.
- 7) Request form Organic Acidemia Association to write an article for their newsletter.
- 8) We received a few large donations in the last couple of months.
 - a. Erin's Handicapped Children's Fund for \$10,000 was secured by Tom & Cris Gallagher



- b. Carlos Galvez Men Golf Tournament for \$9,800. This event was organized as a memorial for Carla Halter's father. We discussed that a representative from the Board would attend the outing this year.

B. Vice-President's Report

- 1) Nothing to report.

C. Treasurer's Report

- 1) Official "changing of the guard" from Joe to Jonathan. Jonathan, Lisa and Jim signed new signature cards for the checking account. Due to Christina's absence, she will not be a signer. We can add her later on.
- 2) 2006 Financial Statements – Joe proposed moving some funds from checking to a money market to get a better rate of return.
- 3) Need to get the sales tax exemption forms (in the "legal" file) to April.

D. Secretary's Report

- 1) Board Meeting schedule:
 - a. 3/1/07 - Hazel is unavailable. Possible location is the Schaumburg library meeting room.
 - b. 4/19/07
 - c. 5/31/07
 - d. 7/26/07 – stuff invitations for the Annual Meeting
 - e. 9/6/07
 - f. 10/18/07 – folder stuffing
 - g. Board meeting following the Annual Meeting to ramp up for '08
 - h. Executive officer meeting in December to ramp up for '08

III. Committees

A. Annual Meeting

- 1) Critique of 2006 meeting
 - a. The agenda flowed well.
 - b. Many Board members expressed that they were very happy with Dr. Sarkissian's keynote address.
 - c. The panel was very informative.
- 2) Potential dates are November 3rd or 10th.
- 3) Debated location. Jim will put the dates on hold at Medinah. Lisa suggested looking at alternative sights, e.g. the Hyatt Lodge at Hamburger University.
- 4) Topics and suggested speakers
 - a. Focus will be more social-emotional this year. Discussed organizing more breakout sessions. April indicated that we don't want to lose out on research updates, considering that there are a number of important projects right now. This could be covered by the clinic updates. Specific topics for the break out sessions will be reviewed at the next meeting.
 - b. Hazel suggested contacting Michael Rapoff from Kansas University Medical Center. He has a great book out and addresses the developmental stages of children with a chronic illness from a family oriented perspective.

B. Hospitality Committee

- 1) An early version of the 2007 calendar is available. The committee needs to meet and flush this out.
- 2) We may not participate in the IDPH conference this year. Joe reported that we would be charged a \$250 fee to have a table. In the past we have received \$100.
- 3) Martin Irgang and Josh Earnest working to develop an all day cooking workshop at Kendall College. A solid date has not been scheduled yet.

C. Fundraising Committee

- 1) Jim will take over as chairperson. Peter will send him a list of strategies from 2006.
- 2) Dominick's benefit days are being restructured in May. We have dates for set for April. Jewel dates have been set for the year.
- 3) Mike suggested contacting our bank to sponsor PKU Awareness Month. One possibility would be t-shirts.

D. Education and Research Committee

- 1) Peter asked that the Board consider increasing the number and/or amount of scholarship money for 2007. He will put together a proposal and e-mail it to the Board.
- 2) April suggested possibly developing a contest to sponsor teens and young adults to go to various events. This could hopefully encourage them to take over diet management.
- 3) Other items on the agenda were deferred until the March meeting.

E. Communications Committee

- 1) Christina had indicated (prior to the meeting) that she was willing to taking over editing the Press.
- 2) The first deadline is March 2nd in order to allow for advertising PKU Awareness Month.
- 3) Additional deadlines will be determined at the next meeting.
- 4) Tracy had suggested (in an e-mail to Lisa) including Disney information on our website as a service to the PKU community. This is a common topic on the PKU list serv.
- 5) Need to come up with guidelines for allowing links on our website.
- 6) Other items on the agenda were deferred until the March meeting.

V. Other Business/Open Discussion – N/A