

DATE: May 11th, 2006
TIME: 6:30 p.m.
LOCATION: Weschester
Meeting Opened: 6:50 p.m.
Meeting Closed: 9:00 p.m.
Next meeting will be 6/22 via conference call

Summary of Meeting Minutes**5/11/2006**

- 1) Lisa Irgang reviewed the updated status of PKU Awareness Month activities. Seven families total responded they are coming, all families are participating in the potluck. Lisa is not able to make it – however, Christina and Peter will assist with the set-up. Other families have raised money, however, not able to attend. T-Shirts are available for families who have raised money. In lieu of low attendance, discussed a different type of event for next year, possibly a walk-a-thon.
- 2) Logistics are being finalized for Matthew Koster memorial tree.
- 3) Reviewed 2006 Financial Statements, Joe Annunzio proposed moving money from checking account into money market account to procure better rate. Board agreed, provided a significant amount of funds were not immediately needed.
- 4) Joe Annunzio reviewed status of discretionary funds at UIC and Children's and finalized details with Hazel Vespa and Anne Kozek.
- 5) Board approved April minutes and reviewed and finalized remaining meeting dates as follows:
 - a. 6/22/06 – phone
 - b. 7/20/06 – Stuffing meeting – live
 - c. 8/24/06 – TBD phone or live
 - d. 10/5/06 – live stuffing meeting
- 6) Discussed annual meeting theme. Theme still not finalized, will enlist assistance from Tracey Keegan.
- 7) Annual Meeting Agenda – Reviewed Agenda as follows (Hazel Vespa presented Allied Disordered Presentation Agenda):
 - 8:30 a.m. – Registration (elections, administrative)
 - 9-9:20 a.m. – Opening Presentation
 - 9:20 – 10:10 a.m. – Vendor Presentations
 - 10:10-10:30 Break
 - 10:30 – Noon – Keynote Speaker
 - Noon – 1:30 – Lunch/Raffle
 - 1:30 – 2:00 p.m. – Clinic Updates by Physicians and/or staff
 - 2-2:20 p.m. – Claudia Nash – Newborn Screening Program, Experience w/ new disorders, Genetics and Metabolic Advisory Committee – Role of Present Representative
 - 2:20 – 2:40 p.m. – Break
 - 2:40 – 3 p.m. – What are Allied Disorders – Physicians
 - 3-3:45 – Allied Disorders Panel – will schedule a PKU teen/adult on the panel (possibly scholarship winner), April Salemi will moderate. Other participants will be represented as follows – The Jacob Foundation, Propionic Acidemia, Maple Syrup Urine or other Allied Disorders. There was discussion on how to ensure panel will have a broad enough appeal. The focus should be similarities of diet management – discuss similarities and differences.
 - 3:45 – 5 p.m. – Reception

- 8) Annual Meeting To-Do list was reviewed and tasks assigned out.
- 9) Annual Meeting Teen Program – discussed having speaker attend part of teen program for special Q & A session with our teens.
- 10) Children’s Program – Finalizing host for this program. Susan and Meaghan were mentioned. The host will receive honorarium.
- 11) Roller Skating Event – opened this event up as an all ages event. Discussed September 10 or 24th as possible dates.
- 12) Review of Adult Coffee/Socials – next event is at the end of June, first event was enjoyable and successful.
- 13) Status of Events – Swim had approximately 30 attendees. New Parent Coffee has a low turn out. Believe timing of other events was a factor. Lisa is considering pursuing a UIC family to host next year. Summer events include Father Son Grilling Event and a Networking Event Nina Neill is hosting.
- 14) Junior League is submitting a generous donation to PKU IL Org. April Salemi is waiting on donation.
- 15) Anne Kozek discussed an event at a local high school where students donate a dollar to wear dress down clothes to school and how it could be implemented for PKU IL. Christina relayed that her stepmom’s company had a similar event for PKU IL that generated approximately \$600 for the organization.
- 16) Big Wig Golf Outing – auction items are difficult to obtain. Frank has succeeded in getting goodie bags with PKU logo items donated. Peter relayed that he and Nina would donate a golf package and suggested the board could donate the other – board agreed. Capacity for outing is 60 and event is from 12-9 p.m
- 17) Mentoring Program – confirmed mentors are now in place and now need to aggressively market program as time permits. Brochures were printed.
- 18) Scholarship Materials – Peter completed all scholarship materials and they are posted.
- 19) Update – April will write article for Networking Event. Press will contain note about minute summaries available on website.