

DATE: May 12th, 2005

TIME: 6:30 p.m.

LOCATION: Weschester Clinic

Meeting Opened: 6:40 p.m.

Meeting Closed: 10:05 p.m.

Next Meeting: Next meeting will be held on Thursday June 30th at 6:30 p.m. This meeting will be a call-in meeting.

Summary of Meeting Minutes

5/12/2005

1. The Organization has received informational DVD's from SHS – the content is centered on the story of untreated PKU. It will be available to anyone who is interested at the annual meeting.
2. The Board has developed PKU index cards for PKU families. They are portable cards which allow the family to write down specific's of their child's diet and use for multiple situations including daycare, babysitters etc. They will be available at the annual meeting.
3. Recent updates to our financials include a donation from All-State and a board member's family.
4. We will be soon posting more information on the web site regarding our board meetings, including detailed agendas and schedules for the year. We will also be adding more detailed information on our positions and committees so members can be aware of how they can get more involved within the organization.
5. Our annual meeting agenda was discussed and finalized. We also discussed our discussion panel for the meeting, speaker's topics, raffle, and children's program. The annual meeting to-do list for board members was updated with deadlines and tasks.
6. The board reviewed ideas for inclusion in the PKU organization's next press, along with adding information on our website regarding current newborn screening issues in Illinois. We will be posting samples letters to representatives members can use to show their interest in protecting newborn screening funds.
7. The scholarship application will be posted on the website June 1st. The board will begin reviewing applications in September. An informational flyer for organization members was reviewed.
8. The board is developing a mentoring program for PKU individuals and families. The brochure and participant agreements were discussed and reviewed. Once all the literature is completed the program will be ready to launch.
9. The board would like to concentrate on three main fundraising efforts going forward: 1)Annual Meeting Raffle 2)Big Wig Golf Outing 3)Dinner with an Auction. We discussed details of planning a dinner with an auction in 2006. Fundraising will still include efforts such as Dominick's, Jewel and Carson Days.
10. Product sales such as gram scales and bread machines are currently available through the organization's website. Any proceeds will be distributed to needy Illinois PKU families.
11. The organization's bowling event was cancelled. Discussed recent Meet and Greet – there were two new PKU families. Upcoming events include grilling event and creative school lunches. Our hospitality committee is looking for a



- venue for a cooking event with Malathy of Taste Connections. The hospitality committee is drafting a needs assessment to distribute to members.
12. There is a legislative committee meeting on 5/18.