



**PKU Organization
of Illinois**
P.O Box 102
Palatine, Illinois
60078-0102

PKU Organization of Illinois- Board Meeting

DATE: August 3, 2016

TIME: 7:00 p.m.

LOCATION: Call in

Call in Info: (630) 874-7007 Pass code: 12041

Meeting Agenda

8/3/16

I. Roll Call:

Danae' Bartke
Matt Bartke
Grant Smith
Ben Wagner
Pam Kowalczyk

Not in Attendance

Joe Bonucci
Katie Paskewicz
Dean Seppelfrick
Ami Vanderhoof
Eric Sartain
Kim Kowalyck
Andrea Hall

On the phone:

Mary Lonski
Hazel Vespa
Soo Shim

II. Officer Reports

- A. President's Report** – Focusing on the annual meeting.
Grant Smith will be organizing the Panel, while Danae' focuses on the agenda for the day, the cooking demo, and the keynote speaker.
- B. Vice-President's Report-** Grant – Focusing on the raffle portion of the annual meeting and panel.
- C. Treasurer's Report-** Andrea – P&L to date.
- D. Secretary's Report-** Matt – Minutes approved.
- E. NPKUA Update** – Kim –
I apologize again for not being able to make this meeting (both in person or even on the phone), but I just wanted to email you with some updates from the NPKUA meeting that we had in person the day before the conference.

- Maternal PKU training took place right after the conference and they will have more information soon about how to join that program

- The senate passed the national defense authorizations act, which included medical foods coverage for military families! We understand that obviously not every PKU family is a military family, but it is a step in the right direction.

- We are also presenting the medical nutrition equity act to congress by Senator Casey (PA) which will require all insurance companies to cover medical foods. THIS IS HUGE! However, we need a republican to co-sponsor this movement to continue with the movement, and the NPKUA is asking all state chapters to write to their state representative to support this bill. **I am going to work on a cover letter that we can send to all PKU families in IL. Maybe we can email it along for everyone to print, sign, and send to our rep?**

-We are looking for a new venue for the NPKUA conference 2018, preferable in a Hilton because we have a contact with Hilton rewards and it will be MUCH cheaper than the conference we just had at the Westin in Indy. If anyone has any ideas, I will pass it along to NPKUA.

-At our meeting, we were learning about writing grants to pharmaceutical companies to obtain royalties for the production of these PKU drugs that we have funded (and a bunch of other legal jargon that I reallllyyyyy do not understand). However they are asking any other members of our state chapters to help step up if they have any back ground in grant writing. I do not, but maybe one of our members does? They posted slides explaining more about it, but I can not get them to load right now otherwise I would attach them to this email. **If anyone at the meeting is interested, let me know and I will call Christine Brown for more information about how to get involved with this.**

Also, I was curious about how much our chapter usually donates to the NPKUA? I was inspired to run my own fundraising event for our own organization, so I am going to look into how to get started. Maybe a 5K race? I have never done something like this before so that will be interesting and will probably take several months of planning.

III. Committees 2015 –

A. Hospitality Committee

Family Camp – September 23-25, 2016, East Bay Camp
24248 Ron Smith Memorial Hwy, Hudson, Illinois East Bay Camp
Friday, Sept. 23 check in at 5:00 pm – Sunday, Sept. 25 check out at noon
Camp includes fishing poles.
Pricing and Agenda is on website.

– Mike from Nutricia will be doing the fishing Derby.

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Donations:

- Pasta from Nutricia and any other food.

B. Fundraising Committee -

Wine event: October 15, 2016 - 2144 W Division St, Chicago, Letizia's Natural Bakery – Lets make sure that the chart is up to date!

Carlos R. Galvez Memorial Golf Tournament: Sunday Oct 2nd and Oct. 9- Broken Arrow Golf Club 16325 Broken Arrow Dr., Lockport, IL 60441

-This year we need someone there and speak. Grant will be in attendance.

C. Education Committee:

Scholarships – We are now excepting scholarships – help spread the word!

Andrea and Pam will review them once they are in.
So far we have 2.

Cooking classes-

Nutrica – August 13, Chicago & September 17, 2016 - Naperville

Grocery Store Tour – Luries and Biomarin at Lil's – August 10th

D. Communications Committee

Fall PKU Press- Is out!

PKU Press will be in full color and \$5 an issue going forward.

IV. ANNUAL MEETING! - November 12, 2016 - Oak Brook, Hilton Conference Center

We are always looking to save money, but we need to raise prices to offset the deficit the annual event continues to puts us at. We will continue to raise prices by no more than \$10 a year until we break even. This year the annual meeting will be \$35 per person. Last year it was \$25.

- a. Dr. Olaf Bodamer - Novel therapeutic approaches for inborn errors of metabolism including phenylketonuria, homocystinuria and others.

- Looking to the future...

- b. Cooking Demo. – Brenda from Cook for Love!!!

- c. Panel style discussion
Panel –lead by grant

Who will our experts be?

Grant – Moderator

- Dr. Hoganson
- Dietician – Lauren Kime? Or Andrea Paras
- Social Worker – Soo Shim
- Elementary - Gallagher - to be confirmed
- High School/College –
- Maternal – Heather Ricca – to be confirmed
- Allied Disorder – Danae’ Bartke

- Topics we should make sure they can cover?

d. Vendors – POA, Vitaflo, Biomarin, Nutricia, Mead Johnson has confirmed they will be in attendance!

V. PKU NATIONAL CONFERENCE

	February	March	April	May	June	July	August	September
Danae	Jewelry Set	Jewelry Set	Cello Wine Rack	Music Box	PKU Shirt w/ Original Framed Artwork			
Matt	Crochet Set	Crochet Set	Danae/Matt Gift Basket					
Andrea	Wine Basket	Sky High Sports						
Grant	Bears Tickets							
Pam/Ben	Crème Brulee Dessert Kit	Iphone Running band						
Ami	Wine Basket valued at 175	Amazon Echo (its valued at \$180)	Zoo Society pass					
Katie	Scentsy	Usborne Books						
Joe								
Dean	Starbucks Basket	Starbucks Basket						
Kim	Coffee Maker	Late Milk Steamer	Veggie Mandolin					
Eric								
Hazel	Knitting Class	Tea Set	Natural Elements					

