

# PKU Press

SUMMER '08

A Periodic Newsletter Published By The PKU Organization Of Illinois

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## CALLING ALL TEEN GIRLS !!!

### 2008 MATERNAL PKU CAMP

**JULY 24<sup>th</sup>-JULY 27<sup>th</sup>**

*From Lauren Critchfield*

Registration time is running out on the Maternal PKU Camp. You need to call 608-263-0531 to try and get registered, and what a great Camp this is.

The PKU camp in Wisconsin is a MATERNAL PKU CAMP—just for teen age girls. It is important that PKU girls go to the camp not only to learn about maternal PKU, but also to try new foods. At camp we cook our own lunch and dinner. It is a good way to find new foods that you like. During camp, you a punch card to count how much phe you have; it is easy to keep track of because you have a folder with all the different foods for each meal, along with their serving size and phe. Also, another important reason why girls should go to camp is to meet other girls your age that have PKU too. Since all the girls can relate to each other on many different levels, such as formula, new foods, and techniques for staying on diet, you also become close with the girls at camp and make new PKU friends you

can email and stay in touch with. When you are with a bunch of girls with PKU, you all feel an instant connection with everyone because we know we are all going through the same things.

At camp we have many traditions that continue, and learn new things that will hopefully stay with us. Let me give you just some idea of how all the fun, and learning, comes together.

We start camp by doing "ice breakers". Ice breakers are little games we get to play to get to everyone's names. You have the option at the beginning of camp to take you blood so you can do a before and after analysis of levels. If you have high levels, I like to call the camp a "PKU Rehab", because we learn how to lower the levels and keep them down. There is "circle time"-- that's where we do all of our discussions. We also do activities, like go to the shopping mall, the zoo, the beach, and the pool: the activities are different every year, but they are all done together. There are always arts and crafts to do, such as making bracelets--always a big hit. Hopefully, this year, we will hold our 2nd annual "**CLUB PHE**" night. We spend a lot of time cooking of meals we can learn from for when we get home. At the end of camp we always split the camp up into groups, and each group makes up a song and skits about PKU, and they are always a lot of fun. We do have speakers come in to talk to us about adult PKU and maternal PKU. This helps out a lot, because there are always many questions asked and answered by the staff. This year I will not be becoming back as a camper; I will be coming back as a COUNSELOR.

All teen girls should attend this great event. I hope to see you there !!!

---

## **ANNUAL MEETING**

The Date is Set!

2008 Annual Meeting

November 8th, 2008

Medinah Country Club

We're planning now so you have ideas

send em in!

[info@pkuil.org](mailto:info@pkuil.org)

## Who's Who in PKU Illinois! Summer 2008 Profiles



DONENIKA, 11

Hi, my name is Donenika and I am 11 years old. I am in the 5th grade and I live in Cicero. My favorite Lo pro snack is Nachos and for formula I drink three different formulas, phlexy 10, phenex2 and mete amino acid. I am the only one in my family with PKU. I looking forward to summer because I really enjoy swimming. When I grow up I would like to a Veterinarian or a Zoologist.



RYAN, 3

Hi I'm Ryan and I live in Tinley Park. I was born in St. James of Chicago Heights. I don't have any family members with PKU but that's ok because that leaves more Aprotin spaghetti for me!!! It's my favorite food for dinner. I also really like to snack on Cinnamon twists because they give me energy for baseball. I get to play a lot now with Dad but in September I start preschool. Once I am done with school I am going to be a famous baseball player.



## FUNDRAISING 2008 Chicago Marathon Update

Attention!! If you or someone you know is running in the Chicago Marathon this fall, you can help raise funds for the PKU organization of IL. PKU Organization of IL is a registered charity of the Chicago Marathon and if you are already registered to run and have your ID# - they can still run on behalf of our organization. All you need to do is contact Mike and Christina at [info@pkuil.com](mailto:info@pkuil.com) and we'll set you up. Good luck runners and thanks for your support – we plan to register in 2009 now so future runners take note!

### Jewel Shop n Share

Attention shoppers - PKU Organization of IL still participates in Jewel shop n share!! See coupons and dates in this issue – we have dates in late August perfect for back to school shopping, and dates in November and December – perfect for pre-holiday stocking up. Print out your coupons and support our organization this year for things you already need! Thanks again for your previous and continued support!

### Recycle your Gold and raise Funds for PKU

Do you have any old, broken or unwanted gold jewelry? Host a fundraiser where attendees can get old and broken gold appraised and receive the appraised the value for and 10% will go to PKU. It's the party where you don't have to buy anything! For more information call Christina Davis at 312-968-7247.

### SAVE THE DATE – TEEN AND ADULT CONFERENCE

On behalf of the Planning Committee for the International PKU Teen and Adult Conference, I am pleased to let you know the conference registration form and the agenda are complete and we are now opening up the conference for registration.

The conference is open to people with PKU age 13 and older, their parents/spouses, metabolic healthcare professionals, etc. and is scheduled for Friday, August 15 and Saturday, August 16th 2008 at the Embassy Suites Chicago O'Hare. Additionally, weather permitting, an informal trip to The 50th Annual Chicago Air and Water Show downtown is being planned for Sunday, August 17th.

A link to the pdf files for the registration form and the conference agenda is available on the main page of the website [pkuworldlink.org](http://pkuworldlink.org). Many of the details regarding the conference are on these pdf's but please feel free to email [pkuadult@aol.com](mailto:pkuadult@aol.com) with questions.

Sarah Foster  
PKU Adult, Boston, MA  
[www.pkuworldlink.org](http://www.pkuworldlink.org)

## Orzo Salad

Great refreshing salad for hot summer days!

- 1 cup LP orzo or small pasta noodle
- 1/2 cup finely chopped celery
- 1/2 cup shredded carrot
- 1/2 cup chopped, seeded cucumber
- 1/3 cup olive oil
- 1/2 cup dried cranberries
- 1/4 cup balsamic vinegar
- 2 tablespoons finely chopped shallot
- 1 teaspoon sugar
- 1 teaspoon dry mustard
- 1/2 teaspoon fennel seed
- 1/4 cup chopped green onions

Cook orzo according to package directions. While orzo is cooking, chop all necessary ingredients and place in medium bowl, preferable with sealable lid. Add spices and oil and vinegar. When orzo is complete drain and add hot orzo to chopped veggies.

Cover and chill for 4-24 hours.

Yield: 5 serving Phe: 102mg Calories: 588



## Ice Cream Pie

I scream, you scream we all scream for LP deserts!

- 6oz semi sweet chocolate morsels
- 3 tablespoons butter or margarine
- 1 1/2 cup rice krispies
- 1 pint sorbet

Over stove at medium heat, melt butter and chocolate. Add rice krispies, stir thoroughly and remove from heat. Scoop chocolate mixture into 9" pie pan. Freeze for 2 hours. Add slightly softened pint of sorbet to rice krispie crust.

Yield: 9" pie Phe: 439mg Calories: 1542



## Tzatziki Dip

Cucumber dip for that last minute BBQ

- 8oz Sour Cream
- 1/3 cup thinly diced cucumber
- 1 clove garlic
- 1 teaspoon white pepper
- 2 tablespoons dill

Dice cucumber and garlic very finely. Mix all ingredients in a medium sized bowl, chill for 2 hours. Serve with slices of cucumber, carrots or LP Rusks or similar cracker/ pita.

Yield (dip only): 1 1/2 cups Phe: 301 Calories: 426

## Authentic Greek Salad

Eat like the Greeks do all year long!

- 1/2 cup diced green bell pepper
- 1/2 cup diced cucumber
- 1/2 cup diced tomatoes
- 1/2 cup diced red onion
- 1/4 cup black olives
- 1 teaspoon oregano
- 1 teaspoon basil
- 1 teaspoon pepper
- 1/2 lemon, squeezed on salad
- 2 tablespoons olive oil
- 2 tablespoons red wine vinegar

Chop all necessary ingredients into bite size pieces, toss in medium bowl add spices and squeeze lemon juice. Cover ingredients with oil and vinegar, stir and enjoy!

Yield: 3-4 serving Phe: 90mg Calories: 187

## COMMUNITY CORNER

What's Going on in our  
PKU Community This Quarter

Goodbye and Good Luck Melissa Edwards!!

Melissa Edwards, beloved dietician at Children's Memorial Hospital, is leaving to pursue other opportunities effective June 25th. We wish her well – Melissa we will greatly miss your warmth, assistance, support and expertise – GOODLUCK!! From Melissa:

*PKU of IL families. I want to thank you and say farewell. I have learned so much from everyone including a love for metabolic nutrition. I have accepted a metabolic position at Seattle Children's Hospital so Brian and I will be heading west. We are looking forward to being closer to our families (and the mountains) but will miss everyone back here in Illinois. Thanks again I am so grateful to have worked with such wonderful families.*

**ASK PKU Illinois –  
SUMMER 08**

Every newsletter we'll pose a question to the PKU Community – maybe a hot topic, maybe a seasonal topic – to get the buzz in the community and share thoughts with the organization. Send your thoughts and answers to [info@pkuilorg](mailto:info@pkuilorg) and we'll publish them in the next issue. Don't forget to include your name and city if you'd like! Don't have email? Don't worry call Christina Davis at 312-968-7247 – we'd still love to hear from you!

**THIS ISSUES TOPIC** – Are you an estimator or is diet management an exact science for you? Do you keep a daily diet log? Do you weigh and measure everything –even low phe items? How exactly do you manage PKU?

### **Reminder – Stipends Available for PKU Teen and Adult Conference**

A reminder to any teens or adults who want to attend the PKU Teen and Adult Conference – stipends are available through your clinic if you are in need of financial aid to attend this event. Please contact your clinic for more information.

### **THANK YOU DONORS**

None of our accomplishments would be possible without the support of our donors. If you donated to our organization, past and present, in any amount, at any time, know that you've contributed to our organization being able to:

- Host Hospitality Events at no to low costs to our community - everything from New Parent Coffee to Cooking Classes to our Annual Meeting

- Sponsor PKU college scholarships
- Produce the newsletter and maintain our website
- Donate funds to local and national research projects
- Subsidize a portion of the annual PKU Illinois Camp Costs

Thank you again, on behalf of the Board and everyone in our community for your continuing generosity. We appreciate all that you do!

### ***It's a GIRL for Michele Paxson!!!***

The PKU Organization of IL sends our congratulations and best wishes to Michele Paxson – new Mommy! The letter she wrote to our organization is below:

3/28/08

To whom it may concern:

Hello! My name is Michele Paxson and I am a 35 yr old with PKU.

On February 7, 2008 I was blessed with a beautiful baby girl! She is my miracle baby. I was not on diet when I conceived so it was a very critical pregnancy.

But, thank God she came out normal!

I would like to thank the PKU team at Children's Memorial for all their help. I really appreciate my PKU team. Dr. Burton, Heather, Daniell and Hazel, who has been there since I was a little girl.

And yes, I am still on diet! My beautiful girl is Hasia Irene Logemann. She was 5lbs., 5 oz., 16 ¾ inches at birth.

Sincerely  
Michele Paxson

The **PKU PRESS** is published three times a year as a service of the PKU Organization of Illinois. In conjunction with the three Illinois clinics, we are working together to provide information, offer support, highlight achievements, and provide services for the benefit of the PKU community.

We welcome your input and ideas. Requests for additional copies or correspondence should be addressed to:

**PKU PRESS Editor**  
P.O. Box 102, Palatine, IL 60078-0102  
Email: [www.pkuil.org](http://www.pkuil.org)

**2008 PKU Organization of Illinois Officers**  
Jim Critchfield - Vice-President/Acting President  
Frank Salemi - Treasurer  
Christine Davis - Secretary

**2008 PKU Organization of Illinois Board Members**  
Lisa and Steve Bennett, Larissa and Frank Bruno, Jeff Davis, Mike and Jennifer McMahan, Julie Kelly, April Salemi, Eva and Michelle Brandon

**2008 PKU Organization of Illinois Honorary Members**  
Anne Kozek and Hazel Vespa

**2008 PKU Organization of Illinois Ex-Officio Members**  
Gina Annunzio and Joseph Annunzio



**The Andrew Craig Memorial Scholarship Fund is looking to help qualified and deserving students enrolling in College / University / Vocational Institutions in the Fall of 2008!**

**Applications are available between June 1<sup>st</sup> and August 31<sup>st</sup>, 2008 on the [www.pkuil.org](http://www.pkuil.org) website, and must be mailed and postmarked by August 31<sup>st</sup>, 2008.**

**We want to hear about you, you're experiences with PKU, and your future aspirations. This year, five \$2,000 Scholarships will be awarded at the PKU Organization of Illinois Annual Meeting on November 8<sup>th</sup>, 2008.**



*For more details: Visit [www.pkuil.org](http://www.pkuil.org) OR Write PKU Organization of Illinois at P.O. Box 102, Palatine, IL 60078-0102.*

# Andrew Craig Memorial Scholarship Guidelines & Procedures

For the eleventh consecutive year, the PKU Organization of Illinois has elected to award scholarship dollars for education to qualifying individuals with PKU or Allied Disorders. This year, \$2,000 scholarships will be awarded to five individuals with PKU or an Allied Disorder, who reside in Illinois, and who are enrolled in an accredited college, university, or vocational school in the fall of 2008. A student may win more than once, but not in consecutive years.

## **Guidelines:**

The applicant must submit a complete application and,

- ▶ Show proof that he/she will be enrolled in classes during the school year for which the scholarship is being awarded
- ▶ Have been diagnosed with PKU or an Allied Disorder
- ▶ Show proof of primary residence in Illinois
- ▶ Submit a short essay
- ▶ Will apply scholarship funds to College/University/Vocational school expenses (i.e. course fees, textbooks, room & board)

## **Procedures:**

- ▶ An application should be obtained via our website ([www.pkuil.org](http://www.pkuil.org)) OR by writing to us at :  
PKU Organization of Illinois  
Attn: Andrew Craig Memorial Scholarship  
P.O. Box 102  
Palatine, IL 60078-0102
- ▶ The application will be available from June 1<sup>st</sup> to August 31<sup>st</sup>.
- ▶ **The application must be completed and mailed/postmarked by August 31<sup>st</sup>.**
- ▶ The application will be reviewed by the Board of Directors, and ALL applications meeting the required criteria will be presented to the Board of Directors for consideration and selection.
- ▶ The winners of the scholarships will be notified by mail, and invited to attend the PKU Organization of Illinois Annual Meeting to be recognized by the Board of Directors and the PKU/Allied Disorder Community at large.

## ***PERSONAL ESSAY:***

Include a short essay describing yourself, your experiences with PKU/Allied Disorder, and your future aspirations.

## ***ADDITIONAL INFORMATION:***

1. Proof of enrollment (i.e. copy of class schedule)
2. Proof of residence (i.e. copy of Drivers License or school ID)

# PKU Organization of Illinois 2008 Andrew Craig Memorial Scholarship Application

Please complete ALL information requested (Print clearly or Type)

Completed form is to be mailed by August 31<sup>st</sup> to:

PKU Organization of Illinois  
Attn: Andrew Craig Memorial Scholarship  
P.O. Box 102  
Palatine, IL 60078-0102

## **APPLICANT DATA:**

Name: \_\_\_\_\_  
                    First                                    Middle                                    Last

Birth Date: \_\_\_\_\_

Permanent Mailing Address: Street: \_\_\_\_\_  
  City: \_\_\_\_\_  
  State: \_\_\_\_\_  
  Zip: \_\_\_\_\_

Contact Telephone Number: (\_\_\_\_\_) \_\_\_\_\_  
  (Area Code)

Email Address: \_\_\_\_\_

The undersigned hereby acknowledges that the prescribed criteria for eligibility for award of scholarship funds of the PKU Organization of Illinois have been met, and that the information provided within this application is correct.

Applicant Signature: \_\_\_\_\_

## ***COLLEGE/UNIVERSITY/VOCATIONAL INSTITUTION DATA:***

Name of Institution: \_\_\_\_\_

Address of Institution: \_\_\_\_\_  
  (City)  (State)  (Zip)

Month and Year of first semester attended: \_\_\_\_\_

# RELEASE OF MEDICAL INFORMATION:

Patient: Complete the upper portion of this form, and forward to your physician who will in turn complete the lower portion. Your physician should then forward this form to the PKU Organization of Illinois.(You may wish to assist your physician by including a pre-addressed envelope).

I, \_\_\_\_\_, do hereby request and authorize  
(Name of Patient)  
\_\_\_\_\_ to release medical information indicating the  
(Physician's Name/Institution)  
Diagnosis of PKU / Allied Disorder concerning \_\_\_\_\_  
(Name of Patient)  
to the PKU Organization of Illinois Andrew Craig Memorial Scholarship Program.

(Patient Signature) \_\_\_\_\_

(Guardian Signature) \_\_\_\_\_  
(Required if Patient if a Minor)

-----

I, \_\_\_\_\_ do hereby attest that \_\_\_\_\_  
(Physician's Name/Institution) (Patient Name)  
has been diagnosed with PKU or an Allied Disorder.

\_\_\_\_\_  
(Physician/Institution)

\_\_\_\_\_  
(Address)

\_\_\_\_\_  
(Physician Signature)

\_\_\_\_\_  
(Date)



## 2008 BIG WIG PKU Golf Outing

Date: September 20, 2008

Check-In begins 12:00 pm

Register Your Foursome By  
September 1st !!

Where:

Tamarack Golf Club  
24032 Royal Worlington Dr  
Naperville, IL 60564

[www.Tamarackgc.com](http://www.Tamarackgc.com)

Registration Fees:

\$115.00 For Women Golfers  
And  
\$125.00 For Men Golfers

***The proceeds will  
go towards research  
and the PKU  
Organization of IL !!***

For more info or to register call:

Steven & Lisa Bennett 847.359.0506  
Lori Knaub 630.837.0981

Email: [Bennett19@earthlink.net](mailto:Bennett19@earthlink.net)  
Subject line: PKU Golf Outing

## Outing Highlights

- ***Pre-Round Lunch –12:00 pm!***
- ***Shotgun Start - 1:30 pm !***
- ***Appetizers with 1 Hr. open bar***
- ***Dinner***
- ***Cash bar during and after dinner***
- ***Silent and Live Auctions***
- ***Raffle Prizes***
- ***AND MUCH MORE !!***



TM©2002 Women In Golf

# 2008 BIG WIG/PKU Registration Form

**Due By September 1, 2008**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

***E-Mail (IMPORTANT!):*** \_\_\_\_\_ ***Phone #:*** \_\_\_\_\_

\*Preferred Foursome: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\*If you have a foursome you would like to play with, let us know who they are. If not, an extremely talented trio will be assigned to you. Remember, this all goes to charity! (PLEASE NOTE: IF SIGNING UP A FOURSOME WITH ONE REGISTRATION FORM, A CHECK OR CHECKS FOR EACH PERSON MUST ACCOMPANY THE REGISTRATION FORM.)

### **Cost Per Person**

**\$115.00 - Women Golfers**

**\$125.00 – Men Golfers**

\*If signing up more than one person on a registration form, please include addresses and e-mails for each participant.

Send your forms and check made payable to **Women In Golf, Inc.** to:

Women In Golf, Inc.

c/o Lori Knaub

1026 Bentley Lane

Bartlett, IL 60103

**OR**

PKU Organization of Illinois

c/o Steven Bennett

4030 New Britton

Hoffman Estates, IL 60192

We will be contacting you **by e-mail** (if possible) with further information seven days prior to the event. Please contact us at: **Bennett19@earthlink.net**

**OR**

CALL: LORI KNAUB: 630-837-0981 / STEVE BENNETT : 847-359-0506

IF YOU HAVE ANY QUESTIONS

**REMEMBER TO CHECK OUT OUR WEB SITE**

**WWW.PKUIL.ORG**

**WHERE TO SEE AND BE SEEN IN PKU : )**  
**PKU Organization of IL – 2008 Calendar of Events**

<u>DATE</u>	<u>EVENT</u>	<u>LOCATION</u>	<u>TIME</u>	<u>HOST/CONTACT</u>
June 1 <sup>st</sup>	Andrew Craig Scholarship	PKU Org. of IL Website	Beginning	<a href="http://www.pkuil.org">www.pkuil.org</a>
August 3-8 <sup>th</sup>	13 <sup>th</sup> Annual M PKU camp	California	deadline 5/16	Norah Ojeda (510) 412-1504
August 15 <sup>th</sup> & 16 <sup>th</sup>	International Teen Adult Conference	Embassy Suites Chicago O'Hare (Rosemont)		<a href="http://www.pkuil.org">www.pkuil.org</a>
August 23 <sup>rd</sup>	Cooking School Spring	Riverside	TBD	Eva Brandon (708-285-1685)
August 23-31 <sup>st</sup>	5 <sup>th</sup> annual PKU family Camp	Antelope, Oregon		Sandra Maltzman 1-800-605-0410 <a href="mailto:snadra@medicalfood.com">snadra@medicalfood.com</a>
Aug 25, 26, 27	Jewel Shop-N-Share	Coupons in Summer Press		Mike McMahon (630) 416-3170
August 31 <sup>st</sup>	Andrew Craig Scholarship	PKU Org. of IL Website	DEADLINE	<a href="http://www.pkuil.org">www.pkuil.org</a>
September 20 <sup>th</sup>	BIG WIG Golf Outing/ Silent Auction	<b>Tamarack Golf Club Naperville</b>	TBD	Lisa & Steve Bennett (847) 359-0506
September 26 <sup>th</sup> - September 28 <sup>th</sup>	PKU Family Camp	Lake Bloomington in Hudson		Michele Kowalski (773) 745-4541 Bruce Kimbrell (309) 827-4706
September 28 <sup>th</sup>	GOMEZ golf outing	Illinois	TBD	Mike McMahon (630) 416-3170
November 8 <sup>th</sup>	Annual Meeting	Medinah Country Club	9 am – 4:30 pm	<a href="http://www.pkuil.org">www.pkuil.org</a> Christina (312) 968-7247
Nov 17, 18, 19	Jewel Shop-N-Share	Coupons in Fall Press and Annual Meeting Folders		Mike McMahon (630) 416-3170
Winter TBD	Winter PKU snooze em	Chicago, Museum of Science and Industry	TBD	TBD
Dec 8, 9, 10th	Jewel Shop-N-Share	Coupons in Fall Press and Annual Meeting Folders		Mike McMahon (630) 416-3170

For more information of these events call our voicemail at (630) 415-2219 or via e-mail at [info@pkuil.org](mailto:info@pkuil.org)  
 Watch for updates in the PKU Press and check out our web site <http://www.pkuil.org>

**This is an incomplete calendar. As events are scheduled the calendar will be updated and put on the website.**



## 27th Annual PKU Organization of Illinois Family Weekend September 26 - 28 2008

**LOCATION** East Bay Camp, Lake Bloomington in Hudson, Illinois. The organized event begins at 10:00 am Saturday and ends late morning on Sunday. You may come early Friday after 6:00 pm if you wish to begin your weekend early.

**COST** The PKU Organization of Illinois is underwriting most of the cost of this event. This year the cost is: Adult \$15, Child \$5. Anyone with PKU can attend at no charge. Payment is due at time of registration. For those wishing to help further offset the cost of the camp, any additional donations would be appreciated.

**ACTIVITIES** Come enjoy crafts, games, swimming, hiking, good fellowship, evening campfire, fun for all ages, and planned PKU meals beginning at noon on Saturday.

**MAKE YOUR RESERVATION** Detach and Mail completed **registration form** and **check** (payable to PKU Organization of Illinois) by **September 14, 2008** to **Christina Davis 2853 N. Burling, Chicago, IL 60657**. Space is limited for cabins and they will be assigned in the order that reservations are received. You may also come just for the daytime activities if you wish. Please indicate as such on the reservation form for our food preparation purposes. Additional information will be mailed to you after reservation is received.

**HOTEL** Anyone not wanting to "rough" it sleeping at the campsite may stay at a hotel in Normal, IL. Motel expenses and reservations are at the camper's own expense. Call us for hotel recommendations if you are unsure of where to stay.

**QUESTIONS?** Contact Michele Kowalski at (773) 745-4541.

----- Detach and mail the reservation form below to **Christina Davis 2853 N. Burling, Chicago, IL 60657** -----

### 2007 PKU Family Weekend Reservation Form

We will attend the following day(s):                     Friday - Sunday  
     Saturday - Sunday  
 Adults \$15, Child \$5     Saturday only

There will be  Adults and  Children in our group attending.

Total Amount Enclosed \$

We will be staying in a :	Family Name, Address, Phone #
<input type="checkbox"/> Cabin	_____
<input type="checkbox"/> Tent	_____
<input type="checkbox"/> Camper	_____
<input type="checkbox"/> Hotel (cost is at your own expense)	_____

Listed below are the names of campers and ages of children whom will be attending. Indicate PKU with an (\*).

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# PKU & Allied Disorders: A Family Focus - The Children's Program – 2007 Recap

By Phoebe Nitekman  
Susan Ruohonen

2007 marked the 8<sup>th</sup> year that school aged children with metabolic disorders [which included Maple Syrup Urine Disease (MSUD), Propionic Acidemia (PA), and PKU] have participated in a full- day program in conjunction with the Annual Meeting. This year was especially exciting because it was the first that their brothers and sisters were included as well! We welcomed back many returning participants and enjoyed getting to know several new children, including siblings, this year. As always, the day was full of education and fun as they children got to know each other and share their thoughts and feelings.

Susan Ruohonen, MS, LPC  
Phoebe Nitekman, LSW, CCLS  
Rachel Katz, LSW  
Jennifer Bassin, Art Therapy Intern

Worked with Lauren Leviton, Social Work Intern and Hazel Vespa, LCSW, Social Worker, to plan this event.

In celebration of the 2007 theme *A Family Focus*, the PKU Organization of Illinois provided copies of the *The Moon Balloon* [a full-color picture book that has been used as a valuable communication tool for thousands of children, families and caregivers throughout the US, Canada and Europe] to all families who attended the meeting.

This unique program provides opportunities for children to support one another, discover new ways to manage therapeutic diets within their families, communicate with peers and handle social situations. Guided by the expertise of various professionals, all of the children are encouraged to ask questions, explore experiences and learn more about themselves and others as they cope with the challenges of metabolic diets.

During the morning session, all of the children participated in an activity based on the book *The Moon Balloon* by Joan Drescher. *The Moon Balloon* is described as 'A journey of hope and discovery for children and families.' Children join together on an imaginary balloon ride during which they explore their feelings. As a group, we created and discussed four different balloons: giggle, anger, fear, and wish.

In the giggle balloon, the children talked about things that make them laugh. We heard meaningful stories about friends and families as well as funny songs and cartoons. The anger balloon gave the children a safe environment to talk about things that make them frustrated and/or mad. They shared important issues such as teasing, tattling and not sharing. The fear balloon consisted of what was scary to the children, including snakes and spiders, hearing footsteps at night and people sneaking up on them. Finally, the group took a ride on the wish balloon. The children shared their wishes about what they wanted to be, wanted to have and wanted to do. Diet related issues were a common theme on the wish balloon. Children with PKU and other metabolic disorders wished they could eat whatever they wanted and wished they did not have to stay on their diet. The children supported each other by giving examples on how to learn and adapt to skills in managing these situations.

After lunch, it was time to get creative! All of the children made and decorated their own personal balloons. For this project, we assembled into two separate groups. This format provided a forum for the siblings to get together and talk about their common issues and concerns related to having a brother or sister with a metabolic disorder. Siblings asked many questions for the expert, Danielle Hartung, Genetic Counselor, Children's Memorial Hospital. Thanks to Danielle, the siblings have a better understanding of metabolic disorders and felt included in this important annual get-together.

To celebrate the end of the day, the children had the wonderful opportunity to explore the grounds of Medinah on a hay ride! The hay ride is always a popular, fun way to conclude the day, and the weather held up for us again this year.

We look forward to the Children's Program next year as it continues to expand!

Phoebe Nitekman  
Susan Ruohonen



For more information visit [The Moon Balloon Website: www.themoonballoon.com](http://www.themoonballoon.com) or contact: Hazel Vespa, Social Worker, Children's Memorial Hospital (773) 880-4486 or [Hvespa@childrensmemorial.org](mailto:Hvespa@childrensmemorial.org).

# FROM THE “BOARD” ROOM

## REMAINING MEETING SCHEDULE 2008

Our remaining board of directors meeting schedule for 2008 is as follows:

- August 7
- September 25<sup>th</sup> (envelope stuffing meeting)
- October 23<sup>rd</sup> (folder assembly meeting)

Anyone is welcome to attend – for more information or minutes or agendas – please contact Christina Davis at 312-968-7247.

## LOOKING FOR RECAPS?

All of our board meeting minutes are available online – check out [www.pkuil.org](http://www.pkuil.org) for meeting minutes past and present.

## *Come Join Us!*

### *PKU Organization of IL Board of Directors Needs Volunteers!*

The board still has vacant positions for the 2008 term and will into 2009. Please email [info@pkuil.org](mailto:info@pkuil.org) or call Christina Davis, 312-968-7247, if you are interesting in serving on our board.

Volunteering on the board is rewarding and doesn't require an excessive time commitment. The board holds meetings every six weeks throughout the calendar year and is responsible for overseeing, organizing and maintaining:

- o The Annual Meeting
- o The PKU Press
- o PKU Awareness Month Activities
- o Hospitality Events for the Community
- o PKU IL Camp
- o Our website
- o Fundraising Events
- o Donations to research
- o ....and more!

As a member of the board you can serve on one or more of our various committees, such as communications or education and be involved in whatever area of supporting the PKU community you prefer. You can help us shape new events or fundraising ideas, help contribute to our Press or Website, get involved in educating our community or helping with research initiatives – whatever interests you. Consider volunteering today!

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## REMEMBER OUR CHILDREN AND THE FUTURE OF PKU

**YES**, I want to help continue the programs provided by the PKU Organization of Illinois. Enclosed is my contribution in the amount indicated below.\*

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\*Note: Your employer may match your gift. Contact the Personnel or Community Relations Department of your company for details.

\*\*\*Thank you for your generosity. All contributions are tax deductible as allowed by law. Please make checks payable to the “ PKU Organization of Illinois”; P.O. Box 102, Palatine, IL 60078-0102. **We will acknowledge your donation.**



# SHOP & SHARE IDENTIFICATION SLIP

AMOUNT OF PURCHASE

0411155

GROUP NUMBER

STORE NUMBER

DOLLARS

CENTS

GROUP: **PKU Organization of Illinois**

YOUR SHOP & SHARE DAYS: August 25<sup>th</sup>, August 26<sup>th</sup> and August 27<sup>th</sup>, 2008

SIGNATURE \_\_\_\_\_

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