# PKU Press

## A Periodic Newsletter Published By The PKU Organization Of Illinois

#### PKU Organization of IL 2005 Calendar of Events

<b>DATE</b>	EVENT	<b>LOCATION</b>	<u>TIME</u>	HOST/CONTACT
February 26	Carson Pirie Scott	Fox Valley Mall Community Days	TBA	Angela Koster (630) 551-0890
March 2	IDPH Conference	Oak Brook	7 am-5 pm	Joe Annunzio (847) 838-2706
March 20	Northern IL Swim	Schaumburg Water Works	6-8 pm	Lisa Irgang (847) 882-0298
April 24	Teen & Adult Bowling	Tivoli Bowling Alley Downers Grove	2- pm	Jonathan Springborn (815) 334-9834
May 1	Meet & Greet Coffee	Lake Zurich	1 pm	Patsy Thompson (847) 438-0204
May 16-18	Dominick's Benefit Days Jewel Shop-N-Share	Coupons in Spring Press Coupons in Spring Press		Gina Annunzio (847) 838-2706
June 12	Father/Child Grilling	Naperville	1-4 pm	Ruben Caro (630) 904-0702
July 1	Andrew Craig Scholarship	PKU Org. of IL Website	Beginning	www.pkuil.org
July 9	Creative School Lunches	Naperville	10 am-2 pm	Nina Neill (630) 904-4224
August 7	Cooking event	Wheaton	2-4:30 pm	Lisa Hughes (630) 653-6807
Summer	St. Louis Metabolic Summer Picnic/Swim	Clayton, MO	TBA	Laurie Sprietsma (314) 454-6261
August 31	Andrew Craig Scholarship	PKU Org. of IL Website	DEADLINE	www.pkuil.org
September 17	BIG WIG Golf Outing/ Silent Auction	Poplar Creek Golf Club	12 pm	Lisa Bennett (847) 359-0506 Hoffman Estates
September 23-25	PKU Family Camp	Lake Bloomington in Hudson		Michele Kowalski (773) 745-4541 Bruce Kimbrell (309) 827-4706
September	Apple Picking	TBA	TBA	Angela Koster (630) 551-0890
October	Pumpkin Picking	TBA	TBA	Alison & Tom Squillacioti (847) 577-7427
November 12	Annual Meeting & Snack Exchange	Medinah Country Club	9 am	info@pkuil.org or voicemail
November 14-16	Dominick's Benefit Days Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Gina Annunzio (847) 838-2706
December	Gingerbread houses	TBA	TBA	Dee Pratcher (708) 877-2761
December 5-7 December 12-14	Dominick's Benefit Days Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Gina Annunzio (847) 838-2706

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

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

## CARSON'S COMMUNITY DAY SALE

By Angela Koster

Thanks to everyone who helped make the Carson's Community Day sale a success! To date, we have raised \$562.83 from the 2005 spring event, which was held on February 26, 2005. We raised \$337.83 directly from Carson's and \$225.00 from sales of the coupons. \$842.00 was raised from the November, 2004 sale.

In the past year, PKUIL has been given the opportunity to raise funds by selling Carson Pirie Scott Community Day Sale coupon packets for \$5 each. We are able to raise money three ways:

- 1. We sell coupons in front of Carson Pirie Scott prior to the event. PKUIL is able to keep 100% of the proceeds from these sales.
- 2. We sell coupons individually. Again, the Organization keeps 100% of these sales.
- 3. If chosen via lottery, PKUIL may be given the opportunity to have volunteers "work" at Carson Pirie Scott at the Fox Valley Westfield Shopping Center in Aurora, IL on the actual day of the sale. Our Organization then shares the proceeds from coupons sold that day with the other non-profits chosen to "work".

We have been fortunate enough to have been chosen to work the last 3 events, which has been a wonderful addition to our current fundraising efforts.

The next Carson's Community Day Sale will be Saturday, November 19, 2005, just in time for holiday shopping. Coupons will be available for sale for \$5.00 per packet starting in September. Coupons generally include:

- One \$5 coupon towards any item \$5 or greater
- Six 20% off coupons
- One or two Bonus Buy items
- Entry for a drawing usually a vacation destination

Coupons may be used at any Carson's, Boston Store, Bergner's, Herberger's or Younkers location. Some restrictions do apply. If you're interested in purchasing coupons for the next Carson's Community Day, or want to volunteer to help us with this event, please contact Angela Koster at <a href="mailto:akoster3@yahoo.com">akoster3@yahoo.com</a>. Tickets also will be for sale at our Annual Meeting on November 12, 2005. Come help out your Organization while you shop 'til you drop!

# CREATIVE SCHOOL LUNCHES

The Education and Hospitality Committees would like to invite children ages 3-8 and their parents/guardians to a craft day with seminar. There will be an age appropriate craft and snacks for the children, while the adults participate in a seminar about school snacks and lunches. Mark you calendar for **JULY 9<sup>th</sup>** at **10 am 12 pm** in **Naperville.** For more information and to RSVP, please contact Nina Neill at 630-904-4224.

# Hospitality Committee Update

By Lisa Irgang

This year, the Hospitality Committee is an enthusiastic group. We are excited about the events we are planning, both old and new, and we hope to expand our event offerings by targeting various age groups, in addition to hosting a number of family events. The Northern IL Swim, held in March, was our first family event this year. For teens and adults, we're planning an afternoon of bowling at Tivoli Bowling Lanes on April 24th. Our annual Meet & Greet Coffee (formerly the New Parent Coffee) will be hosted by Patsy & Gerry Thompson for families with newborns and toddlers under age two, as well as for families new to our area. A number of cooking events also are planned, including a new Father/Child Grilling "class" hosted by Ruben Caro in June. Crafts for school-aged children are on the calendar for July, while the fall will bring apple- and pumpkin-picking days. Finally, toddlers and school-aged children will be sure to enjoy Dee Pratscher's Gingerbreadmaking party in early December.

Dates and locations for some of these events are still tentative, so mark your calendars now and keep an eye on the website for updates. In the future, we hope to create an e-mail system that can send out invitations/reminders.

We are already looking forward to planning events for 2006. If you have any suggestions, please free to contact me at (847) 882-0298 or via e-mail at <a href="mailto:lmi799@sbcglobal.net">lmi799@sbcglobal.net</a>.

Finally, I would like to thank my committee members for their enthusiasm and hard work: Gina Annunzio, Angela Koster, Kristen Leaf, Nina Neill, Jonathan Springborn, Tom & Alison Squillacioti, and Hazel Vespa.

#### Dear members,

I would like to take this opportunity to update you on our new officers for 2005. We have made the following changes for 2005:

20042005PresidentJim CritchfieldJoe AnnunzioVice PresidentAngela Koster

Angela Koster

Treasurer Joe Annunzio Gina Annunzio Christina Davis

Jim Critchfield, after two consecutive years as President and after finishing his second six-year tour of duty on the Board, will serve in an Ex-Officio capacity as an advisor-at-large to the current Board. We are all very grateful for Jim's efforts in moving our Organization forward. Jim previously served on the Board from 1992 1997 in the positions of Secretary, Vice President and President. Since our by-laws allow a board member to serve no more than six consecutive years, there was a need for change.

Joe Annunzio, after four consecutive years as Treasurer, will be the Organization's President for 2005. Our by-laws permit an officer to serve in the same position for no more than four consecutive years. Since Joe joined the Board in 2001 and has served as Treasurer since that time, there was, again, a need to change.

Angela Koster will remain as Vice President for 2005. Angela joined the Board in 2002 and became the Organization's Vice President in 2003.

Gina Annunzio, Secretary for the last two years, will assume the position of Treasurer. Gina joined the Board in 2001, served as acting Secretary in 2002 and became Secretary in 2003.

**Christina Davis**, a new 2005 Board member, has stepped up to take the position of Secretary on the 2005 Board.

Please join me in wishing our new officers the very best for a successful 2005!

Roet rogarde



# A quick reminder...

## The Andrew Craig Scholarship application process has begun for 2005!

The PKU Organization of Illinois will again award \$1,000 scholarships to qualifying individuals with PKU. This year, PKUIL will be awarding a minimum of four scholarships (increased from two in previous years). To qualify, applicants must:

- 1) have PKU
- 2) be a resident of Illinois
- 3) be enrolled in an accredited college, university, or vocational school in the fall of 2005
- not have been awarded the 2004 Andrew Craig Scholarship (individuals may win more than once, but not in consecutive years).
- 5) submit a complete application by August 31, 2005

All applications will be reviewed by the Board of Directors of the PKU Organization of Illinois, and winners will be selected. All winners will be notified by mail, and invited to the Annual Meeting on November 12<sup>th</sup>, 2005 to be formally recognized by the Board of Directors and the PKU community at large.

The 2005 application will be available from **June 1 to August 31**. For the application and more information, please do one of the following:

- visit our website at www.pkuil.org
- ➤ write to the PKU Organization of Illinois at P.O. Box 102, Palatine, IL 60078-0102
- > call Peter Neill at 630-922-9330 or email at pneill@odysseytel.com

## PKU Legislation Update:

House Bill 2583 is for prescription formula coverage and reimbursement up to \$2,500 for low-protein food per year. It went to the Rules Committee and was assigned to the Insurance Committee.

Senate Bill 1937 is for prescription formula coverage and reimbursement up to \$2,500 for low-protein food. It is currently in the Rules Committee.

Both bills can be found on this page http://www.ilga.gov/legislation/default.asp

Also, if you want the history or wording of Illinois legislation, or names of the House/Senate members that have sponsored it in the past, the information is now accessible from the links.

http://www.pkuil.org/legislation.htm

### **Book Review**

By Tracy Keegan



What Can I Eat?: A Guide for Young Adults Living with PKU has a great mix of ideas and recipes for making the PKU diet more manageable. Authors Dianne Sullivan (PKU chef extraordinaire and mom to two adult PKU'ers), Frances Rohr (nutritionist at Children's Hospital Boston) and Melissa Gennaccaro geared the book to the adult returning to diet. It features a variety of sections, including bread-making tips (did you know you can use the bread machine with your oven for a picture-perfect loaf?), sandwich ideas, menu ideas (for a cocktail party, a dinner party, a fiesta, a barbecue, and more), ideas for what to order when eating out in different types of restaurants and at the movies, and of course, lots of recipes: soups, salads, main dishes, vegetables, breads, and desserts. One very user-friendly part of the book is called the "Everyday Cooking Survival Guide". It starts with a meal idea (like fajitas), and then lets you choose from a list of add-ins, with instructions on how to cook it all. I would highly recommend What Can I Eat? to everyone, including parents looking to expand their kids' menu and recipe choices. It's definitely a worthwhile addition to anyone's lo-pro cookbook shelf.

To order, send your name and address with \$20 per book and \$5 for shipping to:

Fran Rohr Metabolism Clinic Children's Hospital Boston 300 Longwood Avenue Boston, MA 02115

Or email: frances.rohr@childrens.harvard.edu

#### **Blueberry Pie**

Courtesy of Dianne Sullivan, What Can I Eat?: A Guide for Young Adults Living with PKU

2 cups fresh or frozen blueberries plus 2 cups fresh blueberries 1 cup sugar

3 tbsp cornstarch dash of salt

<sup>1</sup>/<sub>4</sub> cup water

1 tbsp butter

Cook 2 cups of blueberries (fresh or frozen) with the sugar, cornstarch, salt, and water, in a saucepan until thick. Remove from heat and stir in butter. Let cool. Bake a 9-inch pie shell (see recipe below) and let cool. Put the 2 cups fresh blueberries in the cooked pie shell. Pour cooled sauce over the fresh berries and chill. Top with whipped topping.

Serves 8

Per serving (pie filling only): 10 mg phe

Per serving (filling and Swiss Pastry dough pie crust): 23 mg phe

#### **Swiss Pastry Dough**

Courtesy of Dianne Sullivan, What Can I Eat?: A Guide for Young Adults Living with PKU

6 tbsp butter

2 cups low-protein baking mix

<sup>1</sup>/<sub>4</sub> cup heavy whipping cream

<sup>1</sup>/<sub>4</sub> cup water

Blend butter into baking mix with your fingers. Add heavy cream and some of the water, blending until mixture forms a nice dough ball. Refrigerate the dough for about an hour. Roll dough (sprinkle with lp baking mix and place between two sheets of wax paper) or press with fingers into a pie plate. (Dough should be as thick as a "regular" pie crust. When baking crust without pie filling, prick the crust with a fork and bake at 375 degrees until lightly browned.

Per recipe: 101 mg phe

# PKU Organization of Illinois Comparative Results of Operations for the Years Ended December 31, 2004 and 2003

Receipts   Fund Raising   Javed Stop & Share   285.43   0.7%   146.77   114.67   0.3%   15.99   Cascon Price South Fundraisar   2,000.60   2,000.00   2,000.00   4.6%   15.99   Cascon Price South Fundraisar   2,000.00   2,000.00   4.6%   15.99   Cascon Price South Fundraisar   2,000.00   2,000.00   4.6%   15.90   Cascon South Fundraisar   2,000.00   2,000.00   4.6%   15.90   Cascon South Fundraisar   2,000.00   2,000.00   4.6%   15.90   Cascon South Fundraisar   2,000.00   2,000.00   36.06.55   0.2%   2.90   Cascon South Fundraisar   2,000.00   2,000.00   3.00   3.00   2.90   2.90   0.0%   2.90   2.90   0.0%   2.90   2.90   0.0%   2.90   2.90   0.0%   2.	
Fund Raising:	- 1
Jewold Snop A Share   286.43	
Duminick's Brancht Days	1.0%
Carson Prie Scott Fundraiser   2,040,26   -   2,040,26   4.7%	0.0%
NAMM   Specials Fundraiser   2,000.00   - 2,000.00   4.6%   1,200.00   1,200.00   4.6%   1,200.00   1,200.00   4.6%   1,200.00   1	0.0%
Big Wild Fundraiser   2,100.00   - 2,100.00   4.8%   1,200.00   2,200.00	0.0%
Candle Salling Fundraiser	2.7%
Pampered Chal Fundraiser	0.0%
Tasisfully Simple Fundraiser	0.6%
Arrural Appeal 1.815.00 - 1.815.00 4.2% 3.286.00  Considers & Grants 6.306.03 100.00 2,000.00 6.405.03 19.4% 17,020.25 Lapiel Pin Sales 90.00 - 2.000.00 19.4% 17,020.25 Lapiel Pin Sales 225.00 - 225.00 0.5% 1,395.00 Lat Sales 60.00 - 60.00 1.4% Lapiel Pin Sales 60.00 - 60.00 0.1% 140.00 Cookie Raffic 27.00 0.1%  DVD & VHS (2003 A.M.) Sales 150.00 - 150.00 0.3% 97.00 Charl Product Sales - 0.0% 500.00 PKUIL Directory Sponsorship 885.00 - 150.00 0.3% 500.00 PKUIL Directory Sponsorship 885.00 - 20.140.00 2.000.00 38.418.84 98.5% 40,120.45  Event Receipts: Low Pro Cooking School Regist. 65.60 - 2.040.00 2.000.00 38.418.84 98.5% 40,120.45  Event Receipts: Low Pro Cooking Sponsors 1,850.00 - 1,850.00 4.3% 1,000.50 Annual Meeting Registration 1,860.00 - 1,850.00 4.3% 1,000.50 Annual Meeting Sponsors 1,850.00 - 1,850.00 4.3% 1,000.50 SuDTotal Event Receipts 4.505.60 - 4,505.60 10.4% 5,640.00  Other Receipts:  Brick Interest 491.10 - 491.10 1.1% 379.86 Horizonarium's - 491.10 1.1% 379.86 Horizonarium's - 491.10 1.1% 379.86 Horizonarium's - 491.10 1.1% 379.86 Total Receipts 491.10 - 491.10 1.1% 379.86 Total Receipts 493.31 - 50.00 2.000.00 3.86% 5,002.60 Annual Meeting 2002 - 5.000.00 2.000.00 5.2% 5,000.80  Disbursementa:  Annual Meeting 2002 - 5.000 2.000.00 5.2% 5,000.80  Annual Meeting 2004 8,303.16 - 9.0% 3,003.16 5.00.80  MACP AD Conference 515.91 1.4%	0.6%
Denations & Grants	7 6%
Lapel Pin Sales	38.5%
T-Shirt Sales	1.2%
Had Sales	3.2%
Chookie Raffile	0.3%
DVD & VHS (2003 A.M.) Sales   150.00	0.0%
Other Product Sales         -         0.0%         97.00           T-Shrt Sponsorship         885.00         -         0.0%         500.00           PKUIL Directory Sponsorship         885.00         -         20,140.00         2.0%           Armual Meeting Raffle         20,140.00         -         20,140.00         46.4%         14,972.00           SubTotal Fundralsing         36,318.84         100.00         2,900.00         38.418.84         98.5%         40,120.45           Event Receipts:         -         20,140.00         2,900.00         38.418.84         98.5%         40,120.45           Event Receipts:         -         -         20,140.00         38,418.84         98.5%         40,120.45           Event Receipts:         -         -         65.60         -         65.60         0.2%           Annual Meeting Registration         1,880.00         -         1,889.00         4.3%         2,000.00           Annual Meeting Registration         710.00         -         -         710.00         1,6%         490.00           SubTotal Event Receipts         4,505.60         -         -         4,505.60         10.4%         3,640.00           Other Receipts:         491.10         - <td>0.0%</td>	0.0%
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PKUIL Directory Sporsorship   885.00   - 885.00   2.0%   Annual Meeting Raffle   20,140.00   - 20,140.00   46.4%   14,972.00   SubTotal Fundralsing   36,318,84   100.00   2,000.00   38,418.84   88.5%   40,120.45	1.1%
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Event Receipts:	90.7%
Low Pro Cooking School Regist   65.60	30.7 .2
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Annual Meeting Sporsors 1,850.00	4.5%
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Other Receipts         4,505.60         -         4,505.60         10.4%         3,640.00           Other Receipts:         Bank Interest         491.10         -         491.10         1.1%         379.86           Honerariums         -         -         491.10         1.1%         379.86           Sublotal Other Receipts         493.10         -         -         491.10         1.1%         479.88           Total Receipts         41.315.54         -         100.00         2,900.00         43,415.64         100.0%         44,240.33           Disbursements:           Annual Meeting 2002         -         -         -         9.0%         1,114.60           Annual Meeting 2003         1,564.75         -         -         9.0%         5,002.60           Annual Meeting 2004         8,303.16         -         -         8,303.16         19.1%           Donations & Grants         250.00         2,000.00         -         2,250.00         5.2%         5,995.10           PKU Press         3,903.70         -         815.91         1.4%         -         815.91         1.4%	1.4%
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Back Interest         491.10         -         -         491.10         1.1%         379.86           Honorariums         -         -         -         -         0.0%         100.00           Sublotal Other Receipts         491.10         -         -         491.10         1.1%         479.88           Total Receipts         41.315.54         -         100.00         2,000.00         43,415.54         100.0%         44,240.33           Disbursements:           Annual Meeting 2002         -         -         -         9.0%         1,114.60           Annual Meeting 2003         1,564.75         -         -         1,564.75         3.6%         5,002.50           Annual Meeting 2004         8,303.16         -         -         8,303.16         19.1%         -           Donations & Grants         250.00         2,000.00         -         2,250.00         5.2%         5,995.10           PKU Press         3,903.70         -         -         615.91         -         -         615.91         -	
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	B.9%
Northern Illino's Swim Event 644.09 644.09 1.6% 537.68	0.0%
	1.2%
New Parent Coffees 0.0% 7.63	0.0%
Cooking Club 0.0% 25.00	0.1%
Low Protein Cooking School 540.68 540.68 1.2% -	0.0%
Regular Codking School 67.46 67.46 0.2% -	0.0%
PKU Camp 2,287.86 2,287.86 5.3% 1,886.06	4.3%
Halloween Party 0.0% -	0.0%
Fund Halsing 824.51 824.51 1.9% 2,699.59	6.1%
PKU IL Directory 977.00 - 977.00 - 977.00 -	0.0%
Presentation Materials 2,111.10 2,111.10 4.9% 573.87	1.3%
Agministrativa/Overhead 1,519.63 1,519.63 3.5% 1,916.20	4.3%
Total Disbursements 23,609.85 - 2,000.00 - 25,609.85 59.0% 23,696.30	53.6%
Net Surplus (Delxii) 17,705.69 - (2.000.00) 100.00 2,000.00 17.805.69 41.0% 20,544.03	46 4%



# Sun, Fun, & Little Fundraising!

**Mark Your Calendars!** 

## 3rd Annual BIG WIG Golf Outing for PKU

WHEN: September 17, 2005

WHERE: Popular Creek Golf Club

Hoffman Estates, IL

For more information go to:

<u>www.wiggolf.com</u>

<u>www.pkuil.org</u>

## DADDY AND KIDS GRILLING DAY

#### HOSTED BY RUBEN AND FLENA CARO

WHEN: JUNE 12<sup>TH</sup>, 2005

TIME: 1 4 P.M.

WHERE: 2203 WICKLOW ROAD

**NAPERVILLE** 



JUST IN TIME FOR THE GRILLING SEASON TO BEGIN!!!

DADS COME AND LEARN SOME NEW TRICKS WITH THE GRILL.

KIDS COME TO TASTE SOME GREAT FOOD.

PLEASE RSVP BY MAY 29<sup>TH</sup>
630-904-0702
SPACE IS LIMITED, SO RSVP EARLY

#### To our PKU Community,

I am happy to report that the PKU Organization of Illinois had another stellar fundraising year in 2004. After S е n

20 co ar οι fui im th	2003 and in excess \$17,000 in 2004. We raised more than \$38,000 from our fundraising events in 2004 as empared to \$40,000 in 2003. Our development of new fundraising alternatives continues to pay off. However, we see still a small organization and need the continuing support of our members. Participation of our members in our fundraising events is crucial to our success. Let's not grow complacent after two very successful andraising yearsjust a few years of deficits can wipe out the surplus. Support from you has even more apportance because it indicates your desire for us to accomplish the goals of our Organization. We are all very lankful for the great number of people who support our Organization: in 2004, there were sixty-five dividual donors, twenty-nine Annual Appeal contributors, donations from four product vendors in support of our new
di Ju • • • e	rectory, including the new three-ring binder covers donated by SHS North America.  Ist think of what we're all getting for our donations:  No subscription fees for the PKU Press, 3 times per year.  The PKUIL Directory.  Continuous/on-going educational events for us to attend so that we are up-to-date with successful diet anagement ideas.  Social events to get parents and kids together to share ideas (new parent coffees, swim parties, snack x c h a n g e s ,  PKU Family Camp, Discovery Days, and Cooking Schools). We are adding new events in 2005.  Educational grants for our PKU students. We are expanding our scholarship program to fund four \$1,000 grants
• d D O • a	2005.  Active involvement by your Board members at the state and national levels with legislation and new e v e I o p m e n t s i n P K U treatment (Board Members Angela Koster & Joe Annunzio represented the Organization at the 2005 Illinois e p a r t m e n t o f Public Health Genetic Conference. Jim Critchfield remains active as our national representative. The r g a n i z a t i o n i s active in the legislation pending in the Illinois General Assembly pertaining to insurance coverage. Please see the Legislative Update.  Our 24-hour voice mail (630) 415-2219 as well as our web site www.pkuil.org.  Our Annual Meeting, which has attracted national attention for the quality of the presentations on PKU research n dtreatment, and which is the longest continuously-running event of its kind in the United States.
	OUR CONTRIBUTIONS ARE FULLY TAX DEDUCTIBLE#  Cut along line and return the bottom portion with your contribution  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.*  [ ] \$25 [ ] \$50 [ ] \$75 [ ]Other
_	(Your Name)  *Note: Your employer may match your gift. Contact the Personnel or

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Thonkyoufory		All contributions are	toy doductible of	allowed by low	Diagon make abacka navable to the "DKLLOrgan

Thank you for your generosity. All contributions are tax deductible as allowed by law. Please make checks payable to the "PKU Organization of Illinois", and mail using the self addressed envelope provided. **We will acknowledge your donation.** Tax ID# 36-3320115.

The PKU Organization of Illinois would like to thank the following donors to the 2004 Annual Appeal. The **2004 Annual Appeal raised \$1,815** from twenty-nine contributors.

#### Those who gave \$500 or more:

#### 1 David & Halina Skopec

#### Those who gave \$100 or more:

- 2 John & Jeanette Consgrove
- 3 Dora Mazza
- 4 Melvin & Anna Weintraub
- 5 Thomas Brennan
- 6 Willard & Carol Sudduth

#### Those who gave \$50 or more:

- 7 Marie Berthold
- 8 Follett Corporation
- 9 Fred & Sheila Marzouk
- 10 Martin & Lisa Irgang
- 11 Mary David
- 12 Myron & Joan Irgang
- 13 Nicole Marzouk
- 14 Robert & Victoria David
- 15 Ronald Yannone
- 16 Ruth Jansen

#### Other generous contributors:

- 17 Angelina Speranza Trust
- 18 Dave & Jennifer Sprinzen
- 19 Dorothea Brust
- 20 Grace Sammarco
- 21 Irwin & Dorothy Klein
- 22 Joseph & Karen Sadilek
- 23 Kevin & Lori Mendenhall
- 24 Maury & Hedy Siegel
- 25 Ruth Waldman Revocable Trust
- 26 Steven Wistreich
- 27 Barbara Birnbach
- 28 Dorothy Shapiro
- 29 Milton Lukaczer

## Big News on Diet Related Product Sales

Effective April 1, 2005, the **PKU Organization of Illinois** will become a distributor of Ohaus and Polder brand scales as well as other related products for use in PKU diet management.

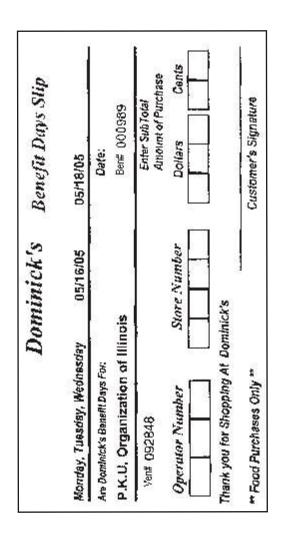
We are taking over the distribution function from the **New England Coalition for PKU and Allied Disorders** who will no longer be a distributor of these products effective April 1, 2005.

Products can be ordered by mailing the enclosed order form, with a check made payable in U.S. dollars to the **PKU Organization of Illinois**, to:

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

ATTN: Diet Products Department

This form is also available on our web site at www.pkuil.org



## The Recipe Exchange By Tracy Keegan

Editor's Note: Finding tasty PKU recipes that you can serve as or along with the family's meal is sometimes a challenge. While there are several PKU cookbooks out there, many times the best recipes are adaptations of our own recipes or of those found in "regular" cookbooks. This new column will hopefully serve to share some of those tried-and-true recipes that can't be found in an official lo-pro cookbook. So, if you have a family recipe you'd like to share, or found a keeper in a cookbook or on the Listserv, send it in! (Just give credit to the creator if it's not you.) Each issue, we'll give one contributor (chosen at random) a \$10 CamBrooke gift certificate! Send your recipes to: PKU Press Editor, PO Box 102, Palatine, IL 60078-0102, or via email: tkeegan42@yahoo.com.

With the warm weather approaching, thoughts turn to easy meals that you can enjoy on the deck with family and friends. On nights you grill, why not serve your PKU'er a delicious veggie burger, and the whole family some potato salad and chocolate mousse with raspberry sauce?

Veggie Burgers Credit: Dianne Sullivan/Boston Children's Hospital Resource Mothers Book

1 cup (150 gm) cooked rice

1 cup (63 gm) fresh lp bread crumbs

1 Tbsp. olive oil ½ cup (75 gm) chopped onion 1 Tbsp. (6 gm) minced garlic

3 cups (241 gm) fresh mushrooms, trimmed and sliced

2/3 cup (75 gm) grated carrots

Egg Replacer mixed for 2 eggs Heat oil in nonstick skillet over medium heat. Add onions and garlic. Saute until the onions are soft, about 3 minutes. Add mushrooms and carrots and cook for 3 more minutes. Remove pan from heat, add rice. Blend in food processor until mixture has a mealy consistency. Add bread crumbs, and mix well. Add seasonings and egg replacer. Shape into 10 (58 gm) patties and fry them in hot oil over medium-high heat so they brown quickly. Place on cookie sheet and bake for 25 minutes at 350. They freeze well, and reheat quickly! 46 phe per patty

1/4 tsp pepper

1/2 tsp salt

American Potato Salad Credit: Cook's Illustrated

816 gm (3-4 medium) russet potatoes, peeled and cut into 3/4" cubes 2 tbsp. distilled white vinegar

50 gm celery, chopped

25 gm minced red or sweet onion 3 tbsp. sweet pickle relish ½ cup (115 gm) mayonnaise

3/4 tsp. powdered mustard

34 tsp celery seed

2 tbsp. minced fresh parsley (or 2 tsp. dried)

1/4 tsp. black pepper

½ tsp. Salt

Cover potatoes with water to cover by one inch. Bring to boil over medium-high heat, add 1 tbsp. salt and reduce to a simmer stirring once or twice, until potatoes are tender, about 8 minutes. Drain potatoes and transfer to a large bowl. Add vinegar and, using rubber spatula, toss to combine. Let stand for 20 minutes, until potatoes are just warm. Meanwhile, in small bowl, stir together celery, onion, relish, mayo, mustard, and spices. Using rubber spatula, gently fold dressing into potatoes. Cover with plastic wrap and refrigerate until chilled, about one hour.

Total phe: 861 Total yield: 1015qm Phe per gm: .85

> Chocolate Mousse with Raspberry Sauce Adapted from Mrs. Fields' I Love Chocolate Cookbook



1/4 cup non-dairy creamer

40gm Nestle's semisweet chocolate chips

110 gm Cool Whip ½ tsp. vanilla extract

Heat creamer in small saucepan over medium heat. When hot, remove from heat, and add chocolate chips. Cover, and let sit for 5 minutes until chips are melted. Stir until smooth and pour into a bowl. Let cool slightly and then add about 1/3 of the Cool Whip and the vanilla extract to lighten it. Fold in the remaining Cool Whip. Spoon into serving dishes, refrigerate, and enjoy topped with Cool Whip and raspberry sauce (recipe below)!

Total phe per recipe: 176 Total yield: 190gm Phe per gram: .92

Lower phe version:

2 cups Rich's Whip Topping (liquid)

1 tsp. vanilla extract

6 oz. (168 gm) chocolate almond bark (grated)

In a small saucepan over low heat, bring 1/2 cup of the Whip Topping to a simmer. Remove from the heat, stir in the bark, and cover. Set aside for 5 minutes and then stir until smooth. Transfer this chocolate cream to a large bowl.

Beat the remaining 1-1/2 cups Whip Topping with vanilla until soft peaks form. Fold 1/3 of the whipped cream into the chocolate mixture to lighten it. Gently fold in the remaining whipped cream.

Total phe per recipe: 240 Total yield: 512gm Phe per gram: .47

Raspberry Sauce

12 oz pkg unsweetened frozen raspberries 1/4 cup sugar 1 tbsp. orange juice

Drain the berries in fine-mesh sieve set over a bowl; press gently on the berries with a spoon to remove as much juice as possible. Transfer the juice to a small saucepan and simmer until reduced to about 1/3 cup (5-10 minutes). Return the reduced juice to the bowl and stir in the sugar and orange juice. Serve over the mousse.





## 2005 March of Dimes Perinatal Conference

On March 2, 2005, Angela Koster and Joe Annunzio attended the 30<sup>th</sup> Annual Illinois Department of Public Health Genetics Conference as an exhibitor. This year, the conference was sponsor by the March of Dimes. The conference was held at the DoubleTree Hotel in Oak Brook, IL.

There were over 500 attendees at the conference and it was a great opportunity for us to increase awareness of PKU and our Organization as in integral part of the larger PKU community. We were also able to meet and talk with officials from the Illinois Department of Public Health and The March of Dimes.

We had a display booth were we were able to use our new tri-fold display and from which we were able to distribute our literature (the last two issues of the <u>PKU Press</u> and our new <u>Understanding PKU</u> brochures). In addition to our literature, we were able to distribute pens and PKU related literature provided to us by Cristy Ferguson of SHS North America and PKU candies provided to us by Sarah Foster of Applied Nutrition Corp.

We would very much like to thank Cristy Ferguson and SHS as well as Sarah Foster and Applied Nutrition for their support of our efforts at the Conference. Both SHS and Applied Nutrition have always been very supportive of our Organization and we are deeply appreciative of this fact.

# Announcing the PKUIL Mentoring Program By Lisa Irgang

The Board of Directors has approved a proposal that will allow the PKU Organization of Illinois to set up a Mentoring Program. The goal of the program is:

To connect individuals and families with an immediate and ongoing support person/family. The mentor will serve as an additional source of information (in conjunction with the clinic team, PKU Organization of IL and Listserv) and support through the early adjustment stage, as well as over the course of time as the mentee family/individual faces new issues/challenges at various life stages (e.g., starting solids, starting school, teaching PKU child to handle diet management, going to college, etc).

As we are all aware, there are many challenges along the road in living with PKU. Therefore, mentors will be available not just for newly-diagnosed families, but for current PKUIL members as well.

The first step in setting up this program is to find individuals and families who are willing to serve as mentors: PKU teens, PKU adults, and parents (moms and/or dads) of PKU kids.

Once we have a list of volunteers interested in serving as mentors, we'll be compiling a list of individuals and families who would like a mentor. If you're interested in becoming involved in the program in any capacity, please fill out the form below and send it to me.

Additional questions, comments, or feedback can be directed to Lisa Irgang, program coordinator, at (847) 882-0298 or via email at <a href="mailto:lmi799@sbcglobal.net">lmi799@sbcglobal.net</a>.

I/we are interested in	(	) becoming a mentor.	(	) receiving a mentor.
Name:				
Address:				
Phone number:				
E-mail:				

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# PKU Organization of Illinois 2005 Central Illinois Picnic

Date: Sunday, July 24, 2005

Time: 1:00 am - 3:30 PM

Location: 16036 Inverrary Lane, Bloomington, IL

This is south of Bloomington

Directions & Map will be provided upon RSVP

RSVP if attending: (309) 827-4706 or bakimbrell@verizon.net by July 17

Host: Mary Jane Kimbrell

Provided: PKU and non-PKU main dish. We will determine menu as

we get responses, Drinks, tableware, cups

PKU dish labeled with Phe count per serving and non-PKU dish

Swimsuit (If you would like to swim).





The PKU Organization of Illinois would like to thank the following contributors for 2004. The Organization raised **\$8,406.03** in donations from sixty-five donors in 2004.

Those who gave \$500 or more:

- 1 Automatic Switch Company
- 2 Tamaraw Golf Organization
- 3 State Farm Companies Foundation

Those who gave \$100 to \$500:

- 4 Anne Gebka
- 5 Michael Styve
- 6 Christine Tenerelli
- 7 Emily Mazurek
- 8 Tom & Tracy Keegan
- 9 MDC Products ATTN: Randall Gebka
- 10 Jim & Peggy Critchfield
- 11 David & Patricia Parker
- 12 Sleepeck Printing ATTN: Ginger Gebka
- 13 Steve & Lisa Bennett
- 14 Margot Flanagin
- 15 Thomas & Patricia Keegan
- 16 Robert & Karen Michael
- 17 James Moles
- 18 Frank & Larissa Bruno
- 19 Karen Schilling
- 20 Joan Parker
- 21 Constance M. Mazurek
- 22 Thomas & Patricia Keegan
- 23 George & Shirley Tighe

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

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Joseph Annunzio - President Angela Koster - Vice-President Gina Annunzio - Treasurer Christine Davis - Secretary

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Jim Critchfield, Jeff Davis, Lisa Irgang, Tracy Keegan, Kristen Leaf, Greg McDaniel, Nina Neill, Peter Neill, Jonathan Springborn, Alison Squillacioti, Tom Squillacioti

#### 2005 PKU Organization of Illinois Honorary Members

Anne Kozek and Hazel Vespa

#### Other generous donors:

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# Northern Illinois Swim Party March 20<sup>th</sup>, 2005

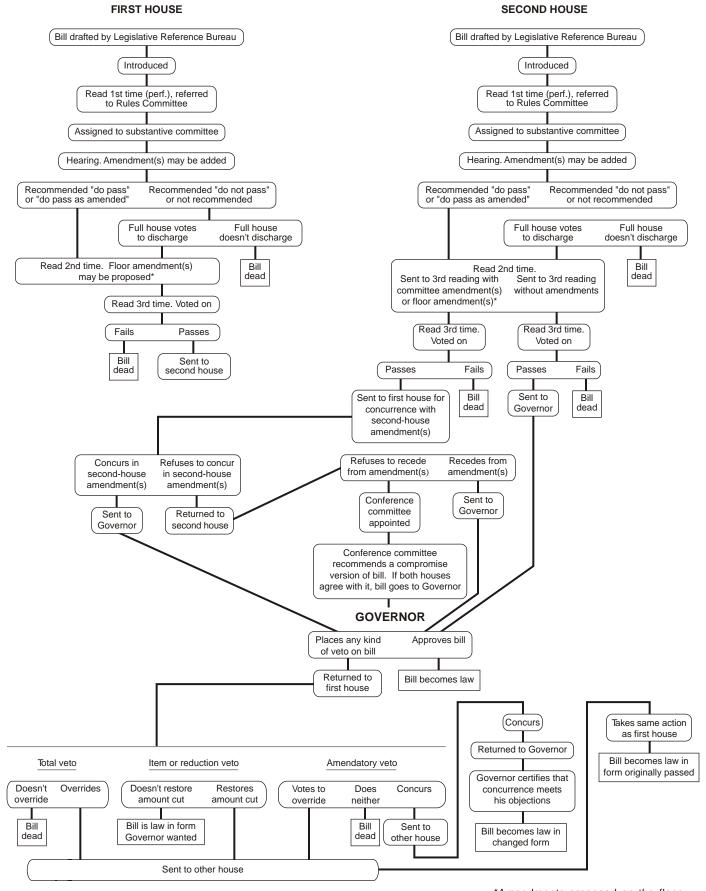
It was a fun time at this year's swim party. It was held at the Water Works in Schaumburg on March 20th. The PKU Organization of Illinois had a semi-private pool rental, so there was plenty of space for 35 people to splash around and have fun. Thanks to the Buzzards, Ginters, Gallaghers, Bennetts, Irgangs, Thompsons, Squillaciotis, Annunzios, and Rhoda Papanastassiou, from Children's Memorial Hospital, with her family for coming out and making this event so great. It looked like everyone had a wonderful time!







#### **How A Bill Becomes Law in Illinois**





\*Amendments proposed on the floor must go to the Rules Committee for approvalbeforebeingconsidered.

PKU ORGANIZATION OF ILLINOIS P.O. BOX 102 Palatine, Illinois 60078-0102

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