

# PKU Press

SPRING '07

A Periodic Newsletter Published By The PKU Organization Of Illinois

## Research project update Spring 2007

*"Phenylalanine-free Protein Produced in Genetically Engineered Soybean";*

*Harold Trick, Department of Plant Pathology, Kansas State University (2/28/07)*

One of the projects in my laboratory is to produce a phenylalanine (PHE)-free protein in transgenic soybean as a source of dietary protein free of phenylalanine. This project is partially funded through MACPAD and the PKU Organization of Illinois and I would like to give a short update of our progress for the last six months.

Several individual plants from four 1st generation transgenic soybean lines have been grown in the greenhouse to establish homozygous lines, for progeny analysis, and for seed increase. Two of these lines contain the native gamma zein gene and two lines contain the PHE-free gamma zein gene. Molecular analysis was performed on these plants where DNA was extracted and the polymerase chain reaction (PCR) helped segregate the plants which contain the transgenes. Individual plants that tested positive for the selection gene and the gamma zein gene were maintained to the greenhouse for seed collection. Many of these plants are currently close to maturity and will be harvested later this spring. In addition, immature seeds were harvested from each line and PCR analysis was used to identify the homozygous plants. Immature seeds were also taken from these plants and protein was extracted for western blot analysis. Both the native gamma zein and PHE-free lines appear to be expressing the transgenic protein and homozygous plants from each of the transgenic lines have been identified.

Mature seeds from each of these plants will be used for additional seed increase, for amino acid analysis, and to begin the refinement of our protein extraction procedures. We anticipate performing amino acid analysis on the mature seeds as well as refining our extraction techniques of the zein protein from endogenous soybean protein later this spring into the summer. A notification to Biotechnology Regulatory Services (the office of USDA which implements the regulations for genetically engineered organisms) was sent informing them we intend to increase these lines in the field this summer. (This step is necessary to comply with federal regulations concerning field testing of transgenic crops.) By increasing seeds in the field we will be able to increase to amount of seed in greater

amounts than just growing in the greenhouse.

Rabbit polyclonal antibodies have been made to the gamma zein protein to aid in the detection of the protein as we refine the extraction methods. This antibody reacts to both the native gamma zein as well as the modified PHE-free gamma zein.

Seven new transformation experiments were also initiated in the fall of 2006. The purpose for these experiments is to create additional lines which may boost the amount of PHE-free zein protein in the soybean seed. Two different versions of the modified PHE-free protein were used in these transformations with one containing an additional DNA sequence which will facilitates protein extraction from the seed. Currently these cultures are under selection.

## *A quick reminder...*

The Andrew Craig Scholarship Application Process has begun for 2007!

This year the PKU Organization of Illinois will again award scholarships to qualifying individuals with PKU or an Allied Disorder. Qualifying individuals must:

1. have been diagnosed with PKU or Allied Disorder; and
2. be a resident of Illinois; and
3. be enrolled in an accredited college, university, or vocational school in the fall of 2007; and
4. not have been awarded a 2006 Andrew Craig Scholarship (*Individuals may win more than once, but not in consecutive years*); and
5. submit a complete application by August 31<sup>st</sup>, 2007.

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 PKU Organization of Illinois Annual Meeting on November 3rd, 2007 to be formally recognized by the Board of Directors and the PKU/Allied Disorder community at large.

The 2007 application will be available from June 1 to August 31 on our website at [www.pkui.org](http://www.pkui.org) OR you can write to us at PKU Organization of Illinois, P.O. Box 102, Palatine, IL 60078-0102.

**PKU Organization of IL 2007 Calendar of Events**

<u>DATE</u>	<u>EVENT</u>	<u>LOCATION</u>	<u>TIME</u>	<u>HOST/CONTACT</u>
February 18 <sup>th</sup>	Family Valentine party/dance	Sheffield Towne Clubhouse, Schaumburg	1:30 pm-4:30 pm	Lisa Irgang Patsy Thompson
March 3 <sup>rd</sup>	Meet & Greet Coffee	Oak Lawn	1 pm-4 pm	Cris & Tom Gallagher
March 28 <sup>th</sup>	IDPH Conference	Schaumburg	9 am-3 pm	Jonathan Springborn
<b>MAY</b>		<b>PKU AWARENESS MONTH</b>		
May 20 <sup>th</sup>	Walk-a-thon	Busse Woods, Grove 32 Elk Grove Village	10:30 am-4 pm	Lisa Irgang Beth Burke
May 21 <sup>st</sup> -23 <sup>rd</sup>	Jewel Shop-N-Share	Coupons in Spring Press		Mike McMahon
June 1 <sup>st</sup>	Andrew Craig Scholarship	PKU Org. of IL Website	Beginning	<a href="http://www.pkuil.org">www.pkuil.org</a>
Summer	Cake decorating class	Oswego	TBD	Annette Egan
June 10 <sup>th</sup>	Father/Child BBQ	Naperville	1 pm-4 pm	Ruben Caro
July	Beach party	Centennial Beach, Naperville	11 am-4 pm	Lisa Irgang
August 31	Andrew Craig Scholarship	PKU Org. of IL Website	DEADLINE	<a href="http://www.pkuil.org">www.pkuil.org</a>
September 15 <sup>th</sup>	BIG WIG Golf Outing/ Silent Auction	Tamarack Golf Club Naperville	TBD	Lisa & Steve Bennett
September 28 <sup>th</sup> - September 30 <sup>th</sup>	PKU Family Camp	Lake Bloomington in Hudson		Michele Kowalski Bruce Kimbrell
November 3 <sup>rd</sup>	Annual Meeting	Medinah Country Club	9 am -4 pm	<a href="http://www.pkuil.org">www.pkuil.org</a> or voicemail
November 12 <sup>th</sup> -14 <sup>th</sup>	Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Mike McMahon
December 17 <sup>th</sup> -19 <sup>th</sup>	Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Mike McMahon
February 2 <sup>nd</sup> or 3 <sup>rd</sup> 2008	Family Valentine party/dance			

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.**

## May is the 2nd National PKU Awareness Month

Continuing from last year, The Mid-Atlantic Connection for PKU and Allied Disorders, Inc. (MACPAD), has decided to promote May as National PKU Awareness Month. Their website, <http://www.macpad.org>, states "our vision is to have all PKU groups, plan and execute an event during that month that would increase awareness of PKU, while also raising money for research."

In honor of the 2nd Annual PKU Awareness Month, we have decided to do a Walk-A-Thon! On May 20, 2007 individuals with PKU, along with their family are invited to enjoy a fun-filled day at Busse Woods in Elk Grove Village. Registration will begin at 10:30 and the walk is scheduled to end by 12:00. Upon registration, each family will receive at least one water bottle (donated by BioMarin), a 2007 PKU Awareness Month t-shirt, education materials, and more! The day will also include face painting, PKU Bingo, games, and an inflatable. We are asking that families bring a PKU dish to share. Non-PKU food will be provided.

In honor of our event and to help raise awareness of PKU, Mayor Craig B. Johnson has declared May 20th PKU Awareness Day in the city of Elk Grove Village. We are honored that he is supporting our efforts to raise awareness locally. In addition, we want children with PKU to understand how special they are to all of us. The proclamation might also be useful for soliciting donations, endorsements, and furthering our educational goal.

We are asking IL families to help raise money and awareness throughout the month, even if you are unable to attend our event on May 20th. Packets were mailed in the beginning of March, so if you haven't received yours please contact either Beth Burke or Lisa Irgang. The packet contains more detailed information on how you can participate and include a registration form, pledge sheet, sample letter, and a press release to use in your local community. The registration form will help us plan for the total number of participants attending our event on May 20th. Donations can be solicited by anyone, whether or not you are attending the walk. With the help of our co-sponsors at VitaFlo, we will be sending one National PKU Awareness Month T-shirt to each family who raises money and may have additional T-shirts available for sale. The goal of including the press release is to encourage our community to help raise "awareness" of PKU. We are asking for each family to contact local TV and radio stations, magazines, newspapers, and any other group you can think of that might run a story on PKU during the month of May. If you are successful in getting an article written or the event mentioned somehow, let us know. We'd love to note it on our website. On an equally important level, consider approaching your child's school to organize an educational event. This could include reading a story about PKU (for example, *You & PKU* or *Everybody Has Something*), arranging for a fruit & vegetable snack day,

or science teachers can talk about recessive genes. Another idea would be to approach your doctors about displaying our **Understanding PKU** pamphlets in their office.

All of the money we raise this year will be donated to Professor Raymond Stevens at The Scripps Research Institute in California. The Scripps Research Institute is involved in three research projects focused on developing new therapeutics to treat PKU that will allow the current diet to be relaxed to a degree, allowing for more PHE intake. They maintain a website at <http://stevens.scripps.edu/pku-research.html>. Feel free to check it out for updated information.

We are very excited to be a part of this national event again this year and look forward to the support of our IL families.

### NEWBORN SCREENING PROCESS DATA 2005 FROM THE GENETIC AND METABOLIC ADVISORY COMMITTEE

Often times we get asked "how many new PKU kids are born in Illinois." Well, the Illinois Department of Public Health maintains a lot of records on all newborn screening that you may find interesting.

Data for the calendar year 2005 has just been released, which tells the number of cases for each disorder, the elapsed time from birth to diagnosis using by newborn screening, and other nice to know information, and is summarized below:

During 2005, from birth to diagnosis of PKU, took 14 days; it took 53 days for Fatty Acid Oxidation, and 82 days for Organic Acid. While I do not have the information from 2004, the summary note from IDPH indicated the time was slightly greater in 2005. For just about all of the allied disorders (including PKU), it takes slightly longer than one day from the time IDPH receives the blood sample until the doctor is notified.

In 2005 it took 6.6 days from the time the doctor was notified to final diagnosis--other amino acid disorders were only 3.3 days, and other allied disorders were over 45 days.

There were 27 diagnosed cases of PKU, 31 diagnosed cases of Fatty Acid Oxidation, and 6 diagnosed cases of Organic Acid. For PKU, it is interesting to note that 3 of the 27 cases were re-evaluated, and found to be normal; but, 1 of the cases "refused follow-up."

All Classical PKU cases received treatment within 10 days--hyperphe's took slightly longer. As a member of this committee, I am also involved in sub-committees on the development and standardization of educational materials available immediately at diagnosis for the the families. Our committee only meets 2 times per year. However, you would be very impressed with the depth of this committee and the action that takes place as some of the key pulse points of newborn screening are analyzed.

Jim Critchfield, Member  
Representing PKU Organization of Illinois  
Illinois Genetic and Metabolic Diseases  
Advisory Committee



## **May is the second annual National PKU Awareness Month!**

### **Come Walk with us and enjoy a day of fun for PKU Research!**

May 20<sup>th</sup>, 2007  
10:30 – 4:00

Busse Woods, Grove 32  
Elk Grove Village

You can view a map of Busse Woods at [http://www.fpdcc.com/tier3.php?content\\_id=66](http://www.fpdcc.com/tier3.php?content_id=66). Enter off of Arlington Heights Road. The cost is \$10 per family.

Registration begins at 10:30 and the walk will begin at 11:30. The rest of the day will be filled with food and fun! There will be games, an inflatable, and more!

We are asking families to raise money through family, friends, and company sponsorship. Their tax deductible donations will be donated to Professor Raymond Stevens at The Scripps Research Institute in California. The Scripps Research Institute is involved in three research projects focused on developing new therapeutics to treat PKU that will allow the current diet to be relaxed to a degree, allowing for more PHE intake. They maintain a website at <http://stevens.scripps.edu/pku-research.html>. Feel free to check it out for updated information. Each family that raises money will receive a National PKU Awareness Month t-shirt. For more information or to register, please contact Lisa Irgang or Beth Burke \_\_\_\_\_

This event is co-sponsored by:



# PKU Organization of Illinois – Committee and Officer List 2007

*A non-for-profit Illinois corporation qualified under Section 501(c)(3) of the Internal Revenue Code for tax-deductible contributions*

**Lisa Irgang**  
*President*

**Jim Critchfield**  
*Vice President*

**Jonathan Springborn**  
*Treasurer*

**Christina Davis**  
*Secretary*

## Board of Directors

Lisa and Steve Bennett, Larissa Bruno, Jim Critchfield, Jeff Davis, Jennifer and Mike McMahon, Nina and Peter Neill, April and Frank Salemi, Jonathan Springborn, Lisa Jones, Anne Kozek (Honorary), and Hazel Vespa (Honorary),  
Joe Annunzio and Gina Annunzio (ex-Officios)

## C O M M I T T E E S

If you'd like to volunteer to assist on any committee or have any ideas – please contact the PKU Organization of IL.

<p><i>Lisa Irgang</i> (Chairperson), <i>Jeff Davis,</i> <i>Hazel Vespa,</i> <i>Anne Kozek,</i> <i>Jim Critchfield,</i> <i>Jonathan</i> <i>Springborn</i></p>	<p><b>Annual Meeting Committee</b></p> <p>Plans and implements the annual meeting logistics with input from board</p>
<p><i>Christina Davis</i> (Chairperson) <i>Bruce Kimbrell</i> <i>Cathy Lorimer,</i> <i>Gina Annunzio</i></p>	<p><b>Communications Committee</b></p> <p>Publishes <b>PKU Press</b>, Illinois Directory, PKU brochure; updates PKU website; coordinates other communications to members</p>
<p><i>Jonathan Springborn</i> (Chairperson) <i>Heather Bausell,</i> <i>Lisa Irgang, Anne Kozek, Michele Kowalski, Hazel Vespa</i></p>	<p><b>Education Committee</b></p> <p>Gathers and distributes information to members dealing with PKU; coordinates educational activities; assist with maternal PKU educational issues</p>
<p><i>Mike McMahon</i> (Chairperson) <i>Steve and Lisa Bennett, Jim Critchfield, Jeff Davis, Peter Neill, Frank and April Salemi</i></p>	<p><b>Fundraising Committee</b></p> <p>Plans and conducts fundraising events (raffle, shop-n-share, product sales); coordinates fundraising appeals to members and donors</p>
<p><i>Lisa Irgang</i> (Chairperson) <i>Melissa Edwards, Jennifer McMahon, Hazel Vespa, Cris Gallagher</i></p>	<p><b>Hospitality Committee</b></p> <p>Plans social events (coffees, picnics, camps, cookie exchanges); assists with new member orientation upon diagnosis</p>
<p><i>April Salemi</i> (Chairperson) <i>Jodi Caro, Jim Critchfield, Jonathan Springborn</i></p>	<p><b>Legal Committee</b></p> <p>Ensures the organization complies with legal and tax requirements; maintains insurance coverage; protects member interests in health care and insurance legislation</p>
<p><i>Jim Critchfield</i> (Chairperson) <i>Steve Bennett, Jodi Caro, Christina Davis, Bruce Kimbrell</i> <i>Jonathan Springborn</i></p>	<p><b>Legislative Committee</b></p> <p>Work through state and local politicians to achieve mandatory insurance coverage of foods and formulas</p>
<p><i>April Salemi</i> (Chairperson) <i>Jim Critchfield, Larissa Bruno, Frank Salemi</i></p>	<p><b>Research Committee</b></p> <p>Investigate viable options to channel research funding from this organization and be viable done of funds to research, responsible for growth and management of research funds</p>

# Annual Meeting Update

*Mark Your Calendars*

PKU Organization of IL Annual Meeting

November 3, 2007

Medinah Country Club

More information to follow!



## Father/Child Grilling Event

*Hosted by the Caros*

**June 10, 2007**

1-4 p.m.

Naperville

RSVP Ruben Caro

What if my favorite charity had a penny for every time I search the Internet...

Now it can!

# GoodSearch

There is new and easy way to raise money for the PKU Organization of IL just by searching the Internet with GoodSearch.com.

It's simple. You use GoodSearch.com like any other search engine (the site is powered by Yahoo!) but each time you do, money is generated for the Organization just by filling in "PKU Organization of Illinois" in the "Who do you search for?" Box.

We hope that not only will you use GoodSearch as your main search engine from here on out, but will also pass this message on to your friends and family. The more people who use this, the more money will go to the PKU Organization of IL. The following link (<http://www.goodsearch.com/About.aspx#faq16>) provides ideas for promoting GoodSearch to your friends, family, and colleagues.

## ANNUAL APPEAL CONTRIBUTION FORM

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)

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

\_\_\_\_\_  
(City)

\_\_\_\_\_  
(State)

\_\_\_\_\_  
(Zip)

\*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.**

# BIG WIG/PKU Golf Outing

Sponsored By  
Women In Golf  
PKU Organization  
of Illinois

*All the proceeds go  
towards research for a  
better treatment!!*

## Outing Highlights

Date: September 15, 2007

Time: 11:00 AM

*Reserve your spot Today !*

### Where:

Tamarack Golf Club  
24032 Royal Worlington Dr  
Naperville, IL

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

### Registration Fees:

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

For more information or to register call:

Steven & Lisa Bennett  
Lori Knaub

- ? Pre-Round Lunch
- ? Shotgun Start!
- ? 1 Hr. open bar with appetizers
- ? Dinner
- ? Cash bar during and after dinner
- ? Both Silent and Live Auctions
- ? Raffles Prizes
- ? AND MUCH MORE !!



TM©2003 Women In Golf,

**2007 BIG WIG/PKU Registration Form**

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

PKU Organization of Illinois  
c/o Steven Bennett

**OR**

We will be contacting you **by e-mail** (if possible) with tee time and further information seven days prior to the event. Please contact us at: \_\_\_\_\_

**OR**

CALL: LORI KNAUB: / STEVE BENNETT :

IF YOU HAVE ANY QUESTIONS

**REMEMBER TO CHECK OUT OUR WEB SITES**

**[WWW.WIGGOLF.COM](http://WWW.WIGGOLF.COM) / [WWW.pkuil.org](http://WWW.pkuil.org)**



**PKU Organization of Illinois  
Financial Statement 2006**

**Comparative Results of Operations for the Years Ended December 31, 2006 and 2005**

	General Fund	MPKU Fund	Education Fund	Research Fund	Spec. Assist Fund	2006 Actual YTD		2005 Actual	
<b>Receipts:</b>									
<b>Fund Raising:</b>									
Jewel Shop & Share	136.89	-	-	-	-	136.89	0.2%	165.96	0.4%
Dominick Benefit Days	50.15	-	-	-	-	50.15	0.1%	41.30	0.1%
Carson Pirie Scott Fundraiser	-	-	-	-	-	-	0.0%	562.83	1.3%
BIG WIG Fundraiser	10,370.00	-	-	-	-	10,370.00	13.5%	3,800.00	9.0%
Erin's Golf Outing	10,000.00	-	-	-	-	10,000.00	13.0%	-	0.0%
Carlos R. Galvez Memorial Golf	-	-	-	9,800.00	-	9,800.00	12.8%	5,000.00	11.9%
Margarita Party Fundraiser	2,550.00	-	-	-	-	2,550.00	3.3%	-	0.0%
Home Party Fundraisers, All	-	-	-	468.00	-	468.00	0.0%	-	0.0%
Skate-A-Thon	-	-	-	4,735.00	-	4,735.00	0.0%	-	0.0%
Annual Appeal	1,565.00	-	-	-	-	1,565.00	2.0%	650.00	1.5%
Donations & Grants	10,031.77	-	-	-	-	10,031.77	13.1%	8,891.36	21.2%
Matthew Koster Memorial	-	-	-	5,075.00	-	5,075.00	6.6%	-	0.0%
Lapel Pin Sales	60.00	-	-	-	-	60.00	0.1%	35.00	0.1%
PKU Logo T-Shirt Sales	105.00	-	-	20.00	-	125.00	0.2%	105.00	0.2%
PKU Awareness T-Shirt Sales	5.00	-	-	-	-	5.00	0.0%	-	0.0%
Hat Sales	50.00	-	-	-	-	50.00	0.1%	10.00	0.0%
Cookbook Sales	560.00	-	-	-	-	560.00	0.7%	1,575.00	3.7%
Cup-A-Cake Sales	57.00	-	-	-	-	57.00	0.1%	201.00	0.5%
Wristband Sales	-	-	-	192.00	-	192.00	0.3%	546.00	0.0%
Diet Product Sales	1,680.00	-	-	-	-	1,680.00	2.2%	1,282.00	3.1%
Other Product Sales	3.00	-	-	-	-	3.00	0.0%	35.00	0.1%
T-Shirt Sponsorship	-	-	-	500.00	-	500.00	0.7%	-	0.0%
Annual Meeting Raffle Prior Year	850.00	-	-	-	-	850.00	1.1%	200.00	0.5%
Annual Meeting Raffle	11,347.00	-	-	-	-	11,347.00	14.8%	14,045.00	33.4%
SubTotal Fund Raising	49,420.81	-	-	20,790.00	-	70,210.81	91.6%	37,145.45	88.4%
<b>Event Receipts:</b>									
Low Pro Cooking School Regist.	735.00	-	-	-	-	735.00	1.0%	-	0.0%
Annual Meeting Registration	1,960.00	-	-	-	-	1,960.00	2.6%	2,140.00	5.1%
Annual Meeting Sponsors	1,500.00	-	-	-	-	1,500.00	2.0%	1,100.00	2.6%
PKU Camp Registration	650.00	-	-	-	-	650.00	0.8%	515.00	1.2%
SubTotal Event Receipts	4,845.00	-	-	-	-	4,845.00	6.3%	3,755.00	8.9%
<b>Other Receipts:</b>									
Bank Interest	1,503.90	-	-	-	-	1,503.90	2.0%	1,098.42	2.6%
Honorariums	100.00	-	-	-	-	100.00	0.1%	-	0.0%
Shipping & Handling	-	-	-	-	-	-	0.0%	8.00	0.0%
Subtotal Other Receipts	1,603.90	-	-	-	-	1,603.90	2.1%	1,106.42	2.6%
Total Receipts	55,869.71	-	-	20,790.00	-	76,659.71	100.0%	42,006.87	100.0%
<b>Disbursements:</b>									
Annual Meeting 2004	-	-	-	-	-	-	0.0%	1,000.00	0.0%
Annual Meeting 2005	1,000.00	-	-	-	-	1,000.00	1.3%	6,409.23	16.5%
Annual Meeting 2006	6,875.70	-	-	-	-	6,875.70	9.0%	-	10.5%
Donations & Grants	3,007.67	-	4,000.00	-	-	7,007.67	9.1%	6,938.75	16.5%
PKU Press	2,665.44	-	-	-	-	2,665.44	3.5%	4,417.18	10.5%
PKU National Conference	268.00	-	-	-	-	268.00	0.3%	-	0.0%
Northern Illinois Swim Event	380.00	-	-	-	-	380.00	0.5%	360.00	0.9%
New Parent Coffees	-	-	-	-	-	-	0.0%	-	0.0%
Beach Party	110.00	-	-	-	-	110.00	0.1%	402.45	1.0%
Low Protein Cooking School	-	-	-	-	-	-	0.0%	-	0.0%
Regular Cooking School	1,519.99	-	-	-	-	1,519.99	2.0%	7.70	0.0%
Central Illinois Picnic	-	-	-	-	-	-	0.0%	-	0.0%
PKU Teen/Adult Bowling Event	-	-	-	-	-	-	0.0%	110.06	0.3%
PKU Camp	2,284.87	-	-	-	-	2,284.87	3.0%	2,009.14	4.8%
Skate-A-Thon	-	-	-	714.25	-	714.25	0.9%	-	0.0%
Halloween Party	527.81	-	-	-	-	527.81	0.7%	118.70	0.3%
Fund Raising	2,177.23	-	-	-	-	2,177.23	2.8%	892.72	2.1%
Cost of Product Sales, All	2,818.63	-	-	-	-	2,818.63	3.7%	2,495.66	5.9%
PKU IL Directory	645.00	-	-	-	-	645.00	0.8%	-	0.0%
Presentation Materials	1,484.38	-	-	-	-	1,484.38	1.9%	1,115.94	2.7%
Administrative/Overhead	1,863.31	-	-	-	-	1,863.31	2.4%	1,918.06	4.6%
Total Disbursements	27,628.03	-	4,000.00	714.25	-	32,342.28	42.2%	28,195.59	67.1%
Contra Cash Collection (A/R)	60.39	-	-	-	-	60.39	0.1%	(15.39)	-
Transfers Between Funds	(4,000.00)	-	4,000.00	-	-	-	0.0%	-	0.0%
Net Surplus/(Deficit)	24,302.07	-	-	20,075.75	-	44,377.82	0.58	13,795.89	32.8%



## ***Annual Appeal Letter***

### ***To our PKU Parents, Families, PKU Press Subscribers, and Friends,***

I am writing to ask for your donation to our Annual Fundraising Drive.

**The PKU Organization of Illinois NEEDS YOUR FINANCIAL SUPPORT!** We're a small organization and can only raise so much from our Annual Raffle and other donations to support the programs we provide for our PKU children and their families. The balance of our financial requirements must come from all us with this Annual Appeal. Support from you has even more importance because it indicates your desire for us to accomplish the goals of our Organization.

Just think of what we're all getting for our donation:

Our parent directory which is updated and distributed every two years.

No subscription fees for the PKU Press, published 3 times per year.

Continuous/on-going educational events for us to attend so we remain up to date with successful diet management ideas.

Social events to get parents and kids together to share ideas (new parent meetings, snack exchanges, picnics, camp-outs, Discovery Days and Cooking Schools).

Educational grants for our PKU students. **We increased the scholarship amount available from \$2,000 to \$4,000 in 2005.**

Active involvement by your board members at the State and National levels with legislation and new developments in PKU treatment.

Our 24-hour voice mail (630) 415-2219 as well as our web site [www.pkuil.org](http://www.pkuil.org).

In 2005, we **expanded the Organization** to now include those individuals and families with Allied Disorders.

Our Annual Meeting, which has **attracted national attention** for the quality of the presentations on PKU research and treatment.

Speaking of our Annual Meeting, we have begun planning another great meeting for this year. **BUT**, this meeting continues to be our single largest annual expense. With your help, we can continue to provide the financial means necessary to continue to have heavy hitting Annual Meetings with speakers that benefit all of us.

With your gift, we'll add programs in the future that meet your needs and requirements. Whether you contribute \$25, \$50, \$75, or more you'll know you're making a difference in PKU for you, our kids, and the members of your family. **PLEASE SAY YES** in the box below, and pledge your financial support.

#### **YOUR CONTRIBUTIONS ARE FULLY TAX DEDUCTIBLE\*\*\***

**REMEMBER, YOUR PKU ORGANIZATION IS AN ALL-VOLUNTEER PARENT ORGANIZATION. 100% OF ALL DOLLARS RECEIVED GO TO PROVIDE PROGRAMS AND SERVICES FOR PKU CHILDREN AND THEIR FAMILIES.**

Many Thanks for helping to keep our Organization strong,  
Lisa Irgang  
President

-----  
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)

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

\_\_\_\_\_  
(City)

\_\_\_\_\_  
(State) (Zip)

\*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.**

## Annual Appeal Donors 2006

The **PKU Organization of Illinois** would like to thank the following donors to the **2006 Annual Appeal**. The **2006 Annual Appeal** raised **\$1,565 from ten contributors**.

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

Mr. and Mrs. Gary Woehlke  
Mr. and Mrs. Thomas Keegan

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

Mr. and Mrs. David Skopec  
Mr. and Mrs. Robert Graham  
Mr. and Mrs. James Jansen

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

Mr. and Mrs. Mark Gralen  
Mr. Daniel Moore

### Other generous contributors:

Ms. Hilda Schaffer  
Ms. Dorothea Brust  
Ms. Lorraine Nodiff-Gurtler



## Recipe Exchange

### Quick and Easy Cous Cous

#### Ingredients

1/3 cup Cambrooke Cous Cous  
3 teaspoons Cambrooke Chicken Consomme  
Seasoning  
1 TBS Butter

Cook Cous Cous as directed on package, drain. Add seasoning and butter and stir while still hot. Serve immediately. A great alternative to pasta to change things up a bit!

Phe 16 phe per 1/3 cup serving.  
The phe can be lowered by using olive oil instead of butter!

## Firstgiving

Firstgiving Instructions to assist in communicating to potential donors about fundraising events! This is an excellent idea for raising money during the 2nd Annual PKU Awareness Month in May.

Directions for setting up a personal website at Firstgiving:

1. Log on to [www.firstgiving.com](http://www.firstgiving.com)
2. Click on Start Fundraising
3. Click on Create Your Page
4. Click on Sporting
5. It will ask you, "What kind of event are you doing?" (Walks), and "When is it?" ( May 20, 2007) Then click Continue
6. If "Walk for PKU" is not found on the event list, then type in "Walk for PKU PKU Organization of IL" and click Continue
7. It will prompt you for the organization's name. Type in PKU Organization of Illinois and then click Search
8. The PKU Organization of Illinois should come up as a choice on the next page, so click Select
9. Enter your email address, and then choose the "New to Site" button and then click Continue
10. Enter your website registration info, which includes your name, address, etc., and click Continue
11. Now you can create your own fundraising page. You can personalize all yellow areas on the page, which includes the name of the page, the fundraising target, a personal message and thank you note, and a picture and caption.
12. Check out a completed page at [www.firstgiving.com/teamkatiekeegan](http://www.firstgiving.com/teamkatiekeegan). It includes some good information about PKUIL that you may want to cut and paste and add to your own page.
13. Finish your page, and then email the link to family and friends!

Donations 2006

The **PKU Organization of Illinois** would like to thank the following contributors for 2006. The Organization raised **\$12,099.77 in donations from forty-nine donors in 2006.**

**Those who gave \$4,000 or more:**

Arlington Heights Junior Woman's Club

**Those who gave \$1000 or more:**

Mr. and Mrs. Thomas Keegan  
Mr. and Mrs. Manuel Doria

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

The Allstate Foundation  
State Farm Insurance Company  
Biomarin  
Blum-Kovler Foundation

**Those who gave \$250 or more:**

Mr. and Mrs. Derek Cobb  
FM Global Founadtion  
Ms. Christine Tenerelli  
Ms. Joy Sciarrotta  
UBS Matching Gift Program  
St. Rene Goupil School  
Mr. and Mrs. Derek Cobb  
FM Global Founadtion

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

Ms. Anne Gebka  
Mr. and Mrs. George Tighe  
Ms. Karen Schilling  
Ms. Amy Swab  
Mr. and Mrs. Frank Salemi

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

Mr. and Mrs. Martin Irgang  
Mr. and Mrs. Fred Marzouk  
Ms. Lynn Cirrincione  
Ms. Marian Lucheckko  
Mr. and Mrs. Lawrence Hopman  
Ms. Robin Rapp  
Mr. and Mrs. Carl Vespa  
Mrs. Mary David

**Other Generous donors:**

Ms. Roberta Berthold  
Mr. and Mrs. Hugh Swager  
Mr. and Mrs. Jerome Zimmerman  
Allstate Giving Campaign  
Ms. Jamie Wenz  
Ms. Patricia O'Connor  
Mr. and Mrs. Travis Jerke  
Ms. Angelina Speranza  
Ms. Rebecca Weber  
Mr. and Mrs. Robert Ege  
Mr. and Mrs. Michael Kozek  
Mr. and Mrs. John Peterson  
Anonymous  
Ms. Jeannette Kunstmann  
Mrs. Dorothy Shapiro  
Ms. Mary Beth Sotak  
Ms. Diane Morgiewicz  
Ms. Leigh Schade  
Ms. Nancy Rieck  
Ms. Barbara Chorba  
Ms. Janice Hamby  
Mr. and Mrs. John Pratscher  
Mr. and Mrs. Mark Gralen

Dear Members & Friends,

I would like to start out by thanking Tracey Keegan for all of her hard work, particularly on the PKU Press, over the past couple of years. Unfortunately, she needed to resign her position on the Board. Her presence will be missed, though we can continue to look forward to her wonderful contributions in The Recipe Exchange. At our March 1<sup>st</sup> Board Meeting, we welcomed Lisa Jones as our newest Board Member. We are very excited to have Lisa, who is an adult with PKU, and her perspectives on diet management, particularly around issues involving maternal PKU.

The Board of Directors has been very busy since we last saw you at the Annual Meeting in November of 2006. Our website has been changing weekly with updates on our various events, updated Board minutes and information, scholarship program, and current legislation issues that are being presented in Illinois. Kudos to Cathy Lorimer for volunteering to help our wonderful web designer, Bruce Kimbrell, in maintaining our site. It looks wonderful! I encourage you to check our website frequently ([www.pkuil.org](http://www.pkuil.org)).

There are a few major events that I would like to bring to your attention.

- ✓ The 2<sup>nd</sup> Annual PKU Awareness Month this May
- ✓ The 5<sup>th</sup> Annual BIG WIG Golf outing in September
- ✓ The 26<sup>th</sup> Annual PKU Family Camp in September
- ✓ Our 38<sup>th</sup> Annual Meeting on November 3, 2007

The level of dedication and energy that our Board Members commit to organizing these events continues to amaze me. We are fortunate this year that many general members have also stepped forward to help and participate in committees. Our sincerest thanks to The Gallagher family, Beth Burke, and Michele Kowalski for helping with the events I've noted above. If you are interested in helping in any capacity, please feel free to contact any our current Board members (see the Organization chart).

Well, that's all for now. We look forward to seeing you in May!


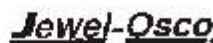
Sincerely,  
Lisa Irgang



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## Is [www.pkuil.org](http://www.pkuil.org) bookmarked on your Favorites?

Our sincere thanks to Bruce Kimbrell for donating his time over the past few years in order to maintain our website. We have certainly used his expertise this past year as the Organization has moved toward expanding the information and resources available. A sincere "thank you" to Cathy Lorimar, as well, for recently volunteering to help Bruce with our website. Cathy has done a great job, especially with some fun graphics.

Here are just a few things that you will find on our website. Information on PKU Awareness Month. Board meeting agendas and a summary of the minutes from 2005 and 2006 are available. We are continuously updating our calendar of events. In addition there is a copy of the PKU Care Index card, a link to update your information for the directory and/or mailing list, fill out a Hospitality survey, and get information on fundraising (including our newest additions GoodSearch and Firstgiving) and so much more.

	<b>SHOP &amp; SHARE IDENTIFICATION SLIP</b>		AMOUNT OF PURCHASE	
	0411155	<input type="text"/>	<input type="text"/>	<input type="text"/>
GROUP NUMBER	STORE NUMBER	DOLLARS	CENTS	
GROUP: <b>PKU Organization of Illinois</b>				
YOUR SHOP & SHARE DAYS: <b>May 21, 22, 23, 2007</b>				
SIGNATURE _____				
PLEASE SIGN THIS SLIP AND TURN IT IN TO YOUR CHECKER WHEN YOU SHOP. PARTICIPANTS CAN MAKE PURCHASES AT ANY JEWEL-OSCO ON THE DATE ABOVE.				
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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)

**2007 PKU Organization of Illinois Officers**

Lisa Irgang - President  
 Jim Critchfield - Vice-President  
 Jonathan Springborn - Treasurer  
 Christine Davis - Secretary

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Lisa and Steve Bennett, Larissa Bruno, Jeff Davis, Mike and Jennifer McMahon, Nina and Peter Neill, April and Frank Salemi

**2007 PKU Organization of Illinois Honorary Members**

Anne Kozek and Hazel Vespa

**2007 PKU Organization of Illinois Ex-Officio Members**

Gina Annunzio and Joseph Annunzio

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