

# PKU Press

WINTER '08

A Periodic Newsletter Published By The PKU Organization Of Illinois

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## The National PKU Alliance Update by Lisa Irgang

I am pleased to announce that efforts are well under way to form a National PKU organization!

Since July of 2007, a group of PKU individuals, parents, grandparents and leaders in the PKU community have been working to form a national PKU organization. The group's vision for a national PKU organization is to unify the PKU community, support local and regional organizations, and to focus on national issues, (such as advocacy for treatment coverage, peer reviewed research, awareness and education), where a national, unified effort leverages the capabilities of local organizations.

We are currently operating as a charter organization, “National PKU Charter Committee”, (NPOCC). Presently, the NPOCC has a membership made up of 53 members representing 15 states and Canada. The NPOCC has an executive committee; Chairman – David Donatucci (Florida); executive council members - Judy Griffith (MACPAD), Dick Michaux (Michaux Family Foundation), and Ray Stevens (The Scripps Research Institute); web site administrator - Rob Kerr (MAPKUF). There has been a tremendous amount of interest in joining the new organization and we are eager to receive requests for new membership from families, dieticians, researchers, and clinicians.

The group's vision is close to reality. We began fundraising efforts for start up costs last month with a goal of **\$30,000**. We have received **\$25,000** to date, and last week the charter committee chose the name **NATIONAL PKU ALLIANCE**, (NPKUA), for the new organization. The mission and by-laws are close to being finalized and our goal is to register a 501(c)(3) corporation in the first half of 2008.

Once the NPKUA is incorporated, we will begin working towards fulfilling the charter committee's vision of a permanent national PKU organization. Membership will be open to local and regional 501(c)(3) PKU organizations plus associate members who work closely with the PKU community, such as clinicians, research institutions, vendors, and pharmaceutical companies. No action is required at this time, and updates will be sent as accomplishments are completed.

Our proposed purposes are:

1. To advance research relating to the treatment and eventually the cure of PKU
2. To support local and regional PKU organizations
3. To educate others about PKU and the issues faced by individuals and families associated with PKU
4. To advocate for all individuals with PKU

As part of these goals, the NPKUA will work with national organizations of other allied disorders on issues relevant to the entire metabolic community (such as legislation for treatment coverage).

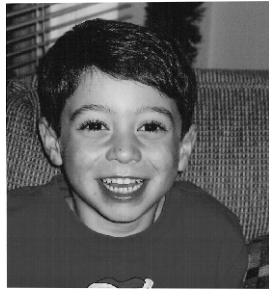
It has been an incredibly rewarding experience working with a dedicated group of people from all across the country giving their time in numerous meetings and calls to make a national PKU organization a reality. We invite you to share the information about the NPKUA with your patients and colleagues and hope you will support and participate in our efforts to build the National PKU Alliance into an institution that will serve the PKU community until there is a cure. If you have questions or would like additional information, please contact us at [nationalpkuorgcc@gmail.com](mailto:nationalpkuorgcc@gmail.com).

Sincerely,  
Lisa Irgang, Voting Member  
The National PKU Charter Committee

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

### CHRISTOPHER BRUNO

My name is Chris Bruno and I am 7 ½ years old. I am in first grade at Westgate Elementary School in Arlington Heights.



My Mom helps me manage my diet but I am learning to do it myself. Before I eat anything I know how to check the ingredients for protein and aspartame. My very favorite food is pasta. My mom knows how to make all different kinds of pasta. I like to bring pasta salad to school for lunch every day. I also like salads. For dessert I love Chocquitos!

In school my favorite things are reading, math, and gym. I love sports! I like to play baseball, basketball, football and golf. Right now I am working on earning my black belt in Taekwondo.

### MICHELLE BRANDON



Hello my name is Michelle Brandon. I am twenty years old and live in Riverside, Illinois. I am currently in my fourth semester at Triton College where I will receive an Associates Degree this spring. Come fall I plan to attend Dominican University where I will focus my studies on nutrition and dietetics. I love staying physically active by running, doing yoga, dancing and teaching gymnastics.

Some of my favorite foods are low-pro pasta with broccoli, bruschetta on Tapioca Bread, and my homemade low-pro bagels. One of my interests in drinking a variety of teas, I have about fifty different types!

In 2006 I participated in the Chicago Triathlon. It was so exciting and fulfilling. Having PKU has definitely kept me disciplined in everything I do. I am normally on-the-go so I always prepare my favorite foods in bulk. I find this more convenient than taking the cook book out everyday. I drink Vitaflo (tropical flavor) as my formula because it comes in packets and you can make it anywhere. I also like the taste and the fact that I don't have to drink a large quantity of it. Staying healthy is so important to me and should be for everyone else. Keeping a healthy, positive attitude is the key element for success dealing with PKU.

## ASK PKU Illinois – WINTER 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@pkuill.org](mailto:info@pkuill.org) 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 ISSUE'S TOPIC** – What are your thoughts on Kuvan? Are you or your child going to see if you/they respond? Why or why not? Have you already? If so, what were the results?



### Recipe Exchange

Doesn't look like Winter's going away soon! Warm up with our latest recipe!

#### “Italian Wedding Soup”

What you'll need:

30 grams Cambrooke Cous Cous  
1 package Organ Vegetable Soup Mix

1. Cook the cous cous as directed, prepare soup mix separately as directed.
2. Stir cous cous into soup broth and serve hot!
3. Approximately 7.5 mg phe per recipe (phe is rounded)

Tips:

Serve with a salad and a low protein dinner roll.  
Add shredded mozzarella as a topping (will increase phe depending on amount used!)

## Innovations in Fundraising

It started with a raffle and an annual appeal. Members of previous year's PKU Organization of Illinois' board of directors and the community we serve provided a solid foundation in fundraising with these two annual efforts – with generous members of our organization donating funds, prizes and time to assist. Other efforts were added, like shop and share initiatives with volunteers headed by Angela Koster spending long hours at malls soliciting donations. These efforts provided the charitable funds needed to begin and grow our organization and its support efforts - including the newsletter, the website, the annual meeting and hospitality events like PKU Camp. Then our fundraising events started to broaden and the funds received started to increase: the Bennett's pioneered and then significantly expanded the scope of the BIG WIG golf outing, PKU Awareness month was kicked off, April Salemi integrated us with the Junior League of Arlington Heights, corporate matching programs expanded, and the Gallagher family and Del Halter ensured we were the recipients of generous donations from the Handicapped Children's fund and the Carlos Rameriez Memorial golf outings.

As a result of this we've been able to expand PKU scholarships, further subsidize events and build a team dedicated to investigating where we can best allocate research funds now that we have an amount to donate that can make a real difference to the research project we decide to fund.

In 2008, building on our already successful slate of fundraising effort and events, Mike McMahon and Lisa Irgang have worked to add our organization to the list of official charities of the Chicago Marathon. See the sidebar on how you can get involved in this exciting event and help raise money for our organization! With the addition of this opportunity, our annual fundraising list is now as follows:

- PKU Awareness Month
- Annual Appeal Form for individual contributions within newsletter and on [www.pkuil.org](http://www.pkuil.org)
- Annual Meeting Raffle
- Corporate Matching programs and “Jeans Day” events
- BIG WIG Golf Outing
- Jewel Shop and Share Days
- Goodsearch
- Chicago Marathon

Please contact us if you have any questions about how to donate through any of these initiatives or if you'd like to volunteer to help – 312-968-7247 or [info@pkuil.org](mailto:info@pkuil.org):

### **The Chicago Marathon Running in the Chicago Marathon? Know anyone who is?**

The PKU Organization of Illinois is now an official charity of the Bank of America Chicago Marathon. What that means for us is runners in the marathon can collect donations on behalf of the organization. If you or someone you know is running in the marathon, contact us to find out how you can help benefit our organization.

Please contact [info@pkuil.org](mailto:info@pkuil.org) or Christina Davis at 312-968-7247 for more information.



## **Lil's Dietary Specialty Shop Where Everyone is Special**

2738 West 111<sup>th</sup> Street  
Chicago, IL 60655

### **MARCIE HARVEY**

President

#### **Hours**

Tues-Wed, Fri	10 AM – 6 PM
Thurs	10 AM – 7 PM
Sat	10 AM – 3 PM
CLOSED	Sunday and Monday

Phone: 773-239-0355

FAX: 773-239-0357

Email: [lilsdietaryshop@sbcglobal.net](mailto:lilsdietaryshop@sbcglobal.net)

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

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you can get low protein foods  
right off the shelf!

## **DATES TO SAVE – Check these Upcoming Events We'd love to see you there!**

### **PKU TEENS AND ADULTS - MARK YOUR CALENDARS**

Your international event is here  
in Illinois this year!

**WHAT:** The International Conference for  
PKU Teens and Adults  
**WHEN:** The conference is being held on  
August 15 and 16, 2008  
**WHERE:** The Embassy Suites  
Chicago O'Hare  
**CONTACT:** Annaliese Martinec  
[annaliesemm@gmail.com](mailto:annaliesemm@gmail.com)  
Sarah Foster [pkuadult@aol.com](mailto:pkuadult@aol.com)

A small group of PKU Teens and Adults from the US, Canada, and the UK have acted as a steering committee to organize the meeting with the strong support and advice of Susan Waisbren, Clinical Psychologist for the metabolic programs at Boston Children's Hospital, along with NCC Transition to Adult Care National Workgroup.

The conference is open to PKU teens age 13+ and PKU Adults, parents of PKU teens/adults, spouses, and metabolic health care professionals, etc. Topics for the conference include, but are not limited to: transition to adult care, adult clinics, maternal PKU, daily dietary management, nutrition management issues for adult PKU, insurance, and current research.

There will also be time to visit with vendors and free time in the evenings to relax, socialize and have fun!

To learn more about the discounted hotel room rates and conference registration fee details please contact Sarah or Annaliese at the info above or talk to your clinic.

We look forward to seeing many of you there!

Sarah Foster  
PKU age 37  
Boston, MA

### ***New Parent Meet and Greet***

Join us to meet the new parents in our organization – and come share your tips, hints and greatest hits and sample some great PKU goodies!

**WHEN:** March 15, 2008, 1-4 p.m.  
**WHERE:** The Gallagher's Residence -  
5325 W. 107TH STREET,  
Oak Lawn, IL  
**RSVP:** To Cris Gallagher (708) 424-7351  
If you'd like, you can bring your favorite PKU dish to share!

### ***The Date is Set!*** ***2008 Annual Meeting***

November 8<sup>th</sup>, 2008  
Medinah Country Club  
We're planning now  
so if you have ideas send em in!  
[info@pkuil.org](mailto:info@pkuil.org)

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### **BIG WIG Golf Outing – Ready for another successful Year! Scheduled for September 20<sup>th</sup>, 2008**

Join Us for Golf, Dinner and Fun!  
Don't Golf? No problem – no experience required – it's all for fun and for the PKU Organization of IL, not to mention there's great prizes and all kinds of fun!  
This event has been wildly successful in fundraising for our organization – come join the fun!  
Questions? Comments? Want to reserve early?

Contact Steven Bennett at [bennett19@earthlink.net](mailto:bennett19@earthlink.net)  
Sponsored by Women in Golf

### **VOLUNTEERS NEEDED**

Hey Everyone! Planning on attending this year's International Conference for PKU Teens and Young Adults? Consider volunteering! We need help with everything from food preparation the Wednesday and Thursday before the conference, to envelope stuffing of mailers and registration documents to help planning a Friday evening social event. Any amount of time you can spare would be a great help – please contact Sarah Foster or talk to your clinic staff if you can join us in making this year's conference a smashing success for all!



# 2008 Calendar of Events

Our calendar is still being worked on so events are still to come and some dates are tentative, but here's what our wonderful new Hospitality Chair Eva Brandon has put together to date! For more dates and events – see our save the date information on pages 4-5.

## Cooking School Spring

**When:** Saturday April 13<sup>th</sup> 2008

**Where:** Eva's Brandon's Home  
182 Northgate Rd.  
Riverside, IL 60546

**RSVP:** To Eva – [eva.brandon@worldnet.att.net](mailto:eva.brandon@worldnet.att.net)  
(708) 285-1685  
11 am – 3 pm



## Cooking School Summer

**When:** Saturday August 23<sup>rd</sup> 2008

**Where:** Eva's Brandon's Home  
182 Northgate Rd.  
Riverside, IL 60546

**RSVP:** To Eva – [eva.brandon@worldnet.att.net](mailto:eva.brandon@worldnet.att.net)  
(708) 285-1685  
11 am – 3 pm



*Also in the works – a “PKU Snooze Em” night at the  
Museum of Science and Industry for Late 2008!  
Stay Tuned!*

## **To all interested in applying for the 2008 Andrew Craig Scholarship!**

We've been receiving quite a few inquiries about the scholarship dates and process – the information is below!

### 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 2008; and
4. not have been awarded a 2007 Andrew Craig Scholarship (*Individuals may win more than once, but not in consecutive years*); and
5. submit a complete application by the deadline which will be in August, the specific date to be published with the application in June.

The 2008 application will be available beginning June 1 on our website at [www.pkuil.org](http://www.pkuil.org) OR you can write to us at PKU Organization of Illinois, P.O. Box 102, Palatine, IL 60078-0102.

## PKU Organization of Illinois – 2008 Board Members

*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*

*Frank Salemi  
Treasurer*

*Christina Davis  
Secretary*

### Board of Directors

Lisa and Steve Bennett, Larissa and Frank Bruno, Jeff Davis, Jennifer and Mike McMahon,  
April Salemi, Julie Kelly, Eva and Michelle Brandon, Anne Kozek (Honorary), Hazel Vespa (Honorary), Gina and Joe Annunzio (Ex-Officios)

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

<p><i>Lisa Irgang (Chairperson) Jim Critchfield, Jeff Davis, Frank Salemi, Anne Kozek</i></p> <p><b>Annual Meeting Committee</b></p> <p>Plans and implements the annual meeting, managed task list for annual meeting, report ideas and agenda to board for approval</p>	<p><i>Christina Davis (Chairperson) Cathy Lorimer</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>Julie Kelly (Chairperson) Heather Bausell, Hazel Vespa</i></p> <p><b>Education Committee</b></p> <p>Gathers and distributes information to members dealing with PKU; coordinates educational activities;</p>	<p><i>Mike McMahon (Chairperson) Steve Bennett, Jim Critchfield, Jeff Davis, Frank Bruno, Frank Salemi</i></p> <p><b>Fundraising Committee</b></p> <p>Plans and conducts fundraising events coordinates fundraising appeals to members and donors</p>	<p><i>Eva and Michelle Brandon (Chairperson) Anne Kozek</i></p> <p><b>Hospitality Committee</b></p> <p>Plans social events (coffee, picnics, camps, cookie exchanges); assists with new member orientation upon diagnosis</p>	<p><i>April Salemi (Chairperson) Jim Critchfield,</i></p> <p><b>Legal Committee</b></p> <p>Ensures org complies with legal and tax requirements; maintains insurance coverage; protects member interests in health care and insurance legislation</p>	<p><i>Jim Critchfield (Chairperson) Steve Bennett, Eva Brandon</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 (Chairperson) Larissa Bruno</i></p> <p><b>Research Committee</b></p> <p>Follows research efforts and make recommendations to board on how to appropriate research funds</p>	<p><i>Lisa Irgang (Chairperson) Eva Brandon</i></p> <p><b>PKU Awareness Month Committee</b></p> <p>Coordinates activities for PKU Awareness Month</p>
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**Come Join Us!**  
**PKU Organization of IL Board of Directors Needs Volunteers!**

The board has one vacant position for the 2008 term. 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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***Available Now!***

**Dianne Sullivan's Easter Candy**

Dianne continues to make fabulous and inventive candy  
for many holidays.

Easter Candy is now available – beautifully wrapped  
bunnies and foil eggs and lots of PKU goodies.

List of all Phe counts are included with each order.

Order bags and individually –all in themed wrapping –  
perfect for easter baskets and treats!

To order – contact Dianne via email – send her your email  
address to get on her mailing list!



1473 Hollywood Terrace  
The Villages , FL 32162  
[lophechef@capecod.net](mailto:lophechef@capecod.net)  
352.350.2032

**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've been successful in fundraising efforts these past two years and shortly we'll have the ability to keep expanding our support to the community and consider significant donations to research. Please help us continue to attain these goals and continue to expand our capabilities to aid the community. 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, 3 times per year.
- Continuous/on-going educational events for us to attend so we're up to date with successful diet management ideas.
- Social events to get parents and kids together to share ideas (new parent meetings, networking events, grilling events, cooking classes and more for 2008!).
- 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 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 and soon we'll be in a position to significantly aid those needing research funds.

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 make us 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.**

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**

Lisa Irgang - President  
Jim Critchfield - Vice-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 McMahon, 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**

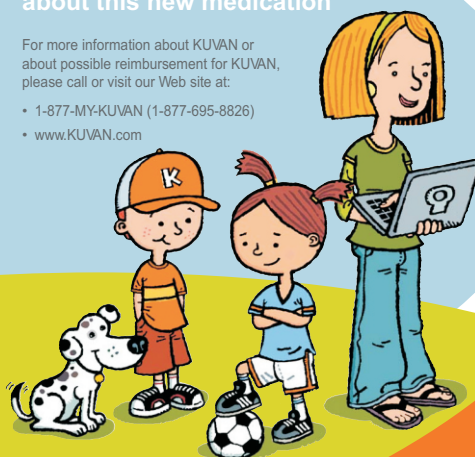
Gina Annunzio and Joseph Annunzio

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- 1-877-MY-KUVAN (1-877-695-8826)
- [www.KUVAN.com](http://www.KUVAN.com)



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