

PKU Press

FALL '08

A Periodic Newsletter Published By The PKU Organization Of Illinois

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Rich and Rewarding! **Abundant, Diverse and Relevant Topics** **contribute to Teen and Adult Conference** **Overwhelming Success**

— by Julie Kelly

The International PKU Teen and Adult Conference was held in Rosemont, Illinois on August 15th and 16th. It was a huge success and provided great information for everyone in attendance. Sarah Foster, an adult with PKU from New England and a well known member of our PKU community, was one of the main coordinators and pioneers of this event – the first of its kind to gear its focus to adults and teens.

The conference provided thorough information and a great variety of topics pertaining to adults. Speaking as an adult with PKU, I know sometimes going to a clinic at a children's hospital can be frustrating, and this was a pleasant adult and teen only environment to really learn about PKU in mature setting. The conference was broken up into many fascinating session – but with enough time still set aside to converse with vendors and learn about new adult-focused foods and formulas.

Diet management was discussed at length, especially as it related to the correlation between PKU and Osteoporosis. From this, we took away that calcium must be an integral part of the low protein diet to avoid the weakening of our bones. Melissa Edwards discussed the importance of eating properly with sports. Maggie Davis gave a fascinating study on successful weight loss with PKU.

No one was better suited than Dr. Koch to give a wonderful presentation on the history of PKU. Michael Petros gave an update on Newborn screening in Illinois, discussing new screening that Illinois will soon be providing, hopefully leading the way for other states to follow in our footsteps.

Dr. Burton discussed treatment with Kuvan and Heather Bausell spoke on how to incorporate Kuvan into your PKU diet management. Dr. Christenah Sarkissian from Montreal then spoke on what your options are if you are not responsive to Kuvan/BH4.

Psychological effects and their correlation with PKU and diet management were discussed by Dr. Susan Waisbern and Dr. Lisa Irgang. They provided valuable information to everyone regarding self esteem and the effects of high phe levels can play on social and psychological levels in our lives.

Amy Cunningham from Tulane University gave a great presentation on what to do in the event of a disaster. She discussed important things to consider inspired by her experiences with PKU diet-management following Hurricane Katarina. It would be hard to imagine what to pack in such an event but my Formula and Kuvan would be right next to my cat in my suitcase! She explained how this not only affected current patients but also the newborns that were recently screened. Other topics included medical home and care coordination.

Self-advocacy was discussed by Hazel Vespa and Monica Giovanni talked about the soon-to-come adult clinics!

The days ended with break out sessions that allowed everyone to exchange ideas on topics from college to spouses, maternal PKU, late diagnosis and everything in between.

Who's Who in PKU Illinois! Fall 2008 Profiles



Sophia Salemi

Hi, my name is Sophia and I am 6 years old and I just started 1st grade. When I grow up I want to be a pet doctor because I love hamsters. My favorite Lo pro snack is cracker and my favorite lo pro meal is tacos. I have been in dance and gymnastics since I was 4 years old, when I am not flipping and twirling in the air I enjoying creating beautiful art.



Zachary Raitz

Hi, I'm Zachary and I live in Hoffman Estates but I was born in Royal Oak, Michigan. I have a baby sister Madison who is only 7 months old. When I am not entertaining my sister I love playing baseball. I also really enjoying telling stories. I drink Phenex 2 and love to eat spiral noodles with cheese to keep me strong and healthy for baseball. Here I am at the PKU walk-a-thon snacking on my favorite treat, apples!



FROM THE "BOARD" ROOM

REMAINING MEETING SCHEDULE 2008

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

- October 23rd (folder assembly meeting)

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

LOOKING FOR RECAPS?

All of our board meeting minutes are available online – check out www.pkuil.org for meeting minutes past and present.

Come Join Us!

PKU Organization of IL Board of Directors Needs Volunteers!

The board has 3 vacant positions for the 2009 term. Please email info@pkuil.org or call Christina Davis, 312-968-7247, if you are interesting in serving on our board.

THANK YOU 2008 BOARD MEMBERS!

Thank you for all your time and effort devoted to the PKU Organization of IL -

Lisa Irgang
Jim Critchfield
Frank and April Salemi
Christina Davis
Steve Bennett
Mike and Jennifer McMahon
Julie Kelly
Eva and Michelle Brandon
Jonathon Springfield
Jeff Davis
Gina and Joe Annunzio (ex-officios)
Hazel Vespa (honorary)
Anne Kozek (honorary)
Barb Goss (honorary)



Back to School Cooking

Low Protein Hot Dogs

- 4 slices low pro bread, crumbled fine
- 60 gm fresh onion, chopped fine
- 165 gm cooked carrots, mashed
- 120 gm cooked potatoes, mashed
- 1 clove garlic and 1 tsp garlic powder
- 1/4 cup ketchup
- 1/4 tsp paprika
- 1 tsp seasoned salt
- 1 tsp vinegar
- 1 tbsp lard or vegetable shortening
- 1 tbsp Ener-G egg replacer
- 3 drops red food coloring
- 3 drops green food coloring

Combine all ingredients. Divide into 10 equal parts and shape into hot dog shape. Fry in scan amount of vegetable oil, turning often.

Great with Virginia Schuett's recipe for buns! or just ketchup!
 Source: PKUListserv
 Yield 8 hot dogs mg phe: 48

Pumpkin Pie Filling

- 1 Can (15 oz) pumpkin
- 5 tablespoons cornstarch
- 6 tablespoons brown sugar
- 1 cup coffee rich
- 4 tablespoons vanilla cook type pudding
- 3 tablespoons butterscotch cook type pudding
- 1 teaspoon pumpkin pie spice

Preheat oven to 425 degrees, mix all ingredients over heat on the stove till thick. Pour pie filling in shell bake 20 minutes.

Source: Virginia Schuett modified by S. Kelly
 Yield: Pie mg phe:140



Quick College Meals

One Dish Past a Dinner

- 1/2 c. Ragu (or other) Spaghetti Sauce
- 1 c. Water
- 1/4 tea. Oregano
- 1/4 tea. Garlic Powder
- 1 c. Wel-plan short cut spaghetti pasta
- 1 1/2 tbsp. Cheddar Cheese Soup- undiluted
- 5 Sliced green olives



In a skillet with a tight lid, combine all ingredients (uncooked noodles), except cheese soup and olives. Heat to boiling. Reduce heat; cover and simmer until noodles are tender, about 15 minutes. Stir in cheese soup and olives; cover and simmer 5 minutes.

Source: S. Kelly
 Yield: 2 cups mg phe: 108

COMMUNITY CORNER

What's Going on in our
PKU Community This Quarter

Welcome Maryam Naziri!!

Maryam has just joined the metabolic clinic staff at Children's Memorial Hospital. We are thrilled to welcome Maryam to our community and those of us at Children's look forward to meeting and working with her! From Maryam:



My name is Maryam Naziri and I am the registered dietitian that recently joined the metabolic team at Children's Memorial Hospital. I previously worked at Swedish Covenant Hospital with adult and pediatric patients in an inpatient setting. As an intern I worked with the Children's Memorial Hospital metabolic team at the PKU annual meeting in 2005. I am particularly interested in working in metabolic nutrition and am thrilled to be a part of this great team. I look forward to meeting and speaking with you at upcoming PKU events.

Annual Meeting - Invites are Out!

The annual meeting invites for November 8, 2008 at Medinah should have arrived! There topics are varied this year from Research to Kuvan to School Lunches - there's something for everyone! Please contact Christina Davis at 312-968-7247 if you have not received an invite.

ASK PKU Illinois -
FALL 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@pkuil.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 ISSUES TOPIC - How do you manage pre-school and school? Did you work with the school lunch program or do you just send lunch everyday? How do you manage phe counts with either option? Don't forget we are having a school lunch break out session at the annual meeting where you can discuss questions and ideas with other parents and PKU and Allied Disorders adults!

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:

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P.O. Box 102, Palatine, IL 60078-0102
Email: www.pkuil.org

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

2008 PKU Organization of Illinois Board Members
Lisa and Steve Bennett, Larissa and Frank Bruno, Jeff Davis, Mike and Jennifer 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



PKU Awareness Month Recap

Our third annual Illinois PKU Awareness Month Event was a Walk-a-Thon held in Elk Grove Village on May 17th. We had a great turn out and many new faces as children and adults with metabolic disorders from all over the state of Illinois walked to raise awareness of PKU and raise money for PKU research in this national effort.

The month of May was declared the Annual National PKU Awareness Month, and our event, along with events held around the country worked to raise awareness and financial support for research and PKU families.

Our event along raised over \$3500.00 for PKU!! Special thanks to:

Eva, Don and Michelle Brandon
Lisa Irgang
Patty Sibley and BioMarin
VitaFlo
Nutricia
Twilight Party Rental

See you next May!



PKU Camp

For 27 years – a great weekend for family fun

If it's the last weekend in September the place to be for PKU families is at East Bay Camp near Normal IL. 2008 was another fun-filled weekend – with well organized activities and games and meals and snacks featuring a huge array of PKU foods – including many wonderful homemade PKU dishes.

This was the first year in many without Anne Kozek – our camp coordinator extraordinaire – but with Bruce and Mary Jane Kimball, Lisa and Martin Irgang and Michelle Kowalski – camp activities, accommodations and meal times were smooth running and a fabulous time was had by all. A special thanks to Cris Gallagher for transporting (to and from camp) all of our camp supplies!

The weather cooperated and it was great to see familiar faces and meet others for the first time. Everyone at camp not only participates and has fun, but helps out with set up and clean up and its overall success – many, many thanks to our 2008 camp families – and we hope to see everyone next year – September 25-27, 2009.

Josh Earnst
Kimball Family
Hamby Family
Irgang Family
Pratscher Family
Kowalski Family
Halter Family

Dent Family
Thompson Family
Gallagher Family
Egan Family
Davis Family
Shrouse Family
Jerke Family



PKU Cooking from A-Z

Our 2nd 2008 cooking class explores recipes from V. Schuett's wonderful cookbook

The Illinois PKU community assembled for our 2nd cooking class this year – on August 23 at “Real Time” in Elk Grove Village. Hosted and organized by Eva Brandon and sponsored by BioMarin Pharmaceutical's Patty Sibley – the event offered a wonderful hands on cooking experience to it's over forty participants.

The workshop featured Jeff Masse - a well known chef from Wisconsin. Jeff split up the group into working stations, allowing the group to get their hands dirty and have some fun while finding new recipes to spice up their PKU meal time experiences. Then our master PKU chef's fabulous creations were served as a family style/buffet for all to share and enjoy.

Many thanks to –

- Cambrooke / Anne Kozek for donating many of the products that made this event successful. Cambrooke generously donated buns, pasta, and tortillas.
- Patty Sibley from BioMarin for her participation and sponsorship
- Jeff Masse contributing his expertise and skills and ensuring all had a great time
- Eva Brandon for all her hard work in making this event happen

Our menu featured fabulous recipes - From the Virginia Schuett Apples to Zucchini Cookbook – and executed by our talented PKU chefs -

- Jicama Salas with Orange & Avacado pg. 38
- Broccoli and Cauliflower Toss with a kick! pg. 318
- Mushroom Sloppy Joes's pg. 294
- Family Style Burritos pg. 295
- Penne with Butternut Squash pg. 219
- Tropical Fruit Quesadilla's pg. 318



Donations 2007

The **PKU Organization of Illinois** would like to thank the following incredibly generous contributors for 2007 – many, many thanks from the PKU Community!

Those who gave \$10,000 or more:

The Handicapped Children's Fund sponsored by the Gallagher Family
The BIG WIG Golf Outing sponsored by Steven and Lisa Bennett and Lori Knaub
Carlos R. Galvez Memorial Golf Outing sponsored by Dr. Carmencita Galvez and Del and Carla Halter

Those who gave \$1000 or more:

Mr. and Mrs. Tom Keegan
Dr. Carmencita Galvez
Dr. and Mrs. Manuel I. Doria
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Michael and Jennifer McMahon
BioMarin

Those who gave \$200 or more:

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The Pampered Chef Fundraiser

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Tom and Cris Gallagher
Feltz Family
Beth and Steve Northcott
William Erickson
Reynard and Carol Russo

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

<u>DATE</u>	<u>EVENT</u>	<u>LOCATION</u>	<u>TIME</u>	<u>HOST/CONTACT</u>
November 8 th	Annual Meeting	Medinah Country Club	9 am – 4:30 pm	www.pkuil.org Christina (312) 968-7247
Nov 17, 18, 19	Jewel Shop-N-Share	Coupons in Fall Press and Annual Meeting Folders		Mike McMahon (630) 416-3170
Dec 8, 9, 10th	Jewel Shop-N-Share	Coupons in Fall Press and Annual Meeting Folders		Mike McMahon (630) 416-3170

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

CORRECTION

The 2008 Calendar of Events listed the Carlos Galvez Memorial Golf Outing on our Calendar of Events with an incorrect name and with incorrect dates – this event was held on 10/5. Our sincere apologies to the Galvez and Halter families for this error and inaccurate information listed for their wonderful event.

 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)

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 (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.**



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