

PKU Press

WINTER 2004

A Periodic Newsletter Published By The PKU Organization Of Illinois

PKU Annual Meeting

This year the members of the board of the PKU Organization of Illinois decided to highlight the annual PKU meeting by having a panel of young adults with PKU discuss what it is like living with PKU and to field questions about this experience from the audience. This turned out to be a huge success and was very educational and reassuring for the parents of children with PKU.

The members of the panel were Leah Orwig, 20, a student at SIUE, Cath Potaniec, 19, a student at Harper College, Julie Lotterer, 30, who works at Blue Cross Blue Shield and Jonathon Springborn, 32, who works in the information technology field. The moderator was Sarah Foster, who also has PKU.

The audience was very eager to ask questions and the panel had some interesting, encouraging and sometimes eye-opening answers for the audience. The following are some of the highlights of this discussion.

The panel was asked if they ever went off diet and what affects the high phe levels had on them. The effects they described were extreme fatigue, wanting to just sleep, inability to concentrate and becoming more emotional and rebellious. The panel was asked what challenges they face every day. They said that traveling or going off to college poses a challenge by having to bring the formula and trying to keep it cold but this did not stop them from doing what they wanted to do. Others find it sometimes challenging to be conscious of everything they eat and drinking the formula every day. The panel was also asked what was the best thing their parents ever did for them. The panelists' responses were that their parents didn't treat them different from their siblings without PKU and their parents started teaching them early to take charge of their own diet. They added that their parents didn't make a big deal out of it. Just like you brush your teeth every day, you



"Dr. Wong enjoys sharing with kids in the audience."

drink your formula and follow your diet. The audience asked what advice or words of wisdom they have for parents of children with PKU. They said to realize your child will be ok, don't feel sorry for your child, don't treat your child different and keep reinforcing the diet and encouraging them. The panel was asked what impact PKU has had on their social lives. Most responses were positive such as friends wanting to try their formula. One panelist said her boyfriend became a vegetarian. Another panelist said her husband got her back on diet.

One interesting highlight of the discussion was the experience one panelist had with managing her pregnancy with PKU. She described the experience as being the healthiest she has ever felt because she was so diligent about counting phes and doing blood levels weekly even before becoming pregnant. She also had ultrasounds every month. She delivered a healthy baby boy.

Thanks to this group of people who were willing to be so open and honest about how it is to live with PKU, the audience was able to take home a lot of valuable information.

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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email: www.pkuil.org

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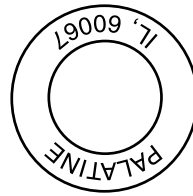
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A Children's Program was held once again this year during the Annual Meeting on Saturday, November 1, 2003. In conjunction with the adult programming, the *Back to Basics* theme was incorporated into the agenda for the children and youth.

It was wonderful to see many familiar faces and exciting to greet the newcomers. The "veterans" of the program were very instrumental in welcoming the first time participants. An "icebreaker" is always a fun way to start the day. The children and youth responded freely to a variety of "conversation starter" statements such as "what is your favorite appliance in your house and why?" or "In what ways is your family important to you?". This exercise enabled the participants to get to know each other and promoted interaction throughout the day.

The Vendor Fair provided an opportunity for the participants to find something familiar and discover something new. The dialogue was very energetic afterwards. There were suggestions for improving tastes, comparisons of likes and dislikes and an overwhelmingly positive response to the sampling of the perogies!

We were very fortunate to have the keynote speaker, Linda Gleason, participate in the Children's program as well. She effectively presented the "Science of PKU" using a theatrical format. She definitely captured the attention of everyone. Thank you, Linda, for sharing your knowledge with such positive energy!

The children and youth painted Paper Mache masks at various stages throughout the day. They were instructed to freely express themselves and had the opportunity to paint both the outside and inside of the mask. At the end of the day, each participant told a

story about his/her mask. The level of imagination and expression was very impressive, both in artistry and storytelling. Many of the concepts which Linda presented to them became a part of their creation. It was wonderful to hear the uniqueness of each story. A mask painted by the children was presented to Linda as a token of our appreciation.

Each year, I am very impressed with the discussions that become an integral part of the Children's Program. The children presented thought-provoking questions and provided suggestions and ideas about various PKU related topics and/or concepts. They mentor one another throughout the day and encourage everyone's participation in the learning process about PKU using formal presentations, art activities and games, which results in lots of fun.

It was a pleasure to plan and participate in the Annual Meeting Children's Program for the fourth year.

I would like to thank Adrienne Rice, Genetic Counseling Intern, from Children's Memorial Hospital for her valuable assistance throughout the day. There are always new challenges and opportunities worth exploring. The children themselves can be a vital resource for designing educational programs. Opportunities to interact with their peers provide the safe context to express themselves and practice conversing about PKU. From such experiences, support networks develop.

To the Board, staff, participants and their families, I sincerely thank you for your involvement and support of the Children's Program.

Susan Ruohonen, M.S.
Licensed Professional Counselor

The Children's Program Explores Back to Basics



Cooking School at the Hughes' House

It was a beautiful Saturday afternoon, July 19th, at the Hughes' House. Lisa opened up her door and kitchen to all that attended. There were 15 adults and 5 "taste testers" present. Lisa and her helpers (some of the moms that attended) made hot dogs, quiches, mushroom burgers, wheat starch dough hamburger and hot dog buns, and raviolis (Cambrooke Foods). Lisa also had a table full of goodies like, homemade zucchini bread, homemade white bread, cinnamon raisin bread (Cambrooke Foods), cream cheese (Cambrooke Foods), Uncle Henry's Pretzels, veggies, apple sponge cake (Angela Koster), blueberry muffins (Angela Koster), and so much more. Lisa used baking and cooking samples from a variety of vendors: Dietary Specialties, Cambrooke Foods, Ener-G Foods, Applied Nutrition, SHS North America, and Uncle Henry's Pretzel Bakery. Lisa had five test tasters at the cooking school: Julia and Laura Hughes, Lauren Annunzio, Ashleigh Ginter, and Marissa Pratscher. The girls tried to taste all the food, but they really liked the desserts. On the dessert table was an awesome chocolate frozen pie (Angela Koster), peanut butter cookies (Gina Annunzio), peanut butter balls (Gina Annunzio), white chocolate lollipops (Angela Koster), chocolate with mint mini candy bars (Gina Annunzio), and white chocolate peanut butter cups (Gina Annunzio). Thanks to Dietary Specialties, SHS North America, and Applied Nutrition for the recipes and samples that went into the desserts. Thank you so much to all the vendors for being so generous and in helping make our cooking school a huge success. A GREAT BIG THANKS TO LISA AND HER FAMILY. Thank you for opening your home, answering questions, making people feel so comfortable, and most of all, the hard work and preparation it took to make cooking school so memorable.

IDPH UPDATE

Kristen Leaf

Kate Seymore, who represented the Illinois Department of Public Health, spoke at our annual meeting on November 1. She updated the audience in three areas that are of concern to the PKU community. First, the distribution of formula to the family/individual will soon be via the vendors, and not the IDPH. This means little change to the families/individuals ordering the formula as they would still place the orders from the IDPH. However, since the formulas will soon be shipped from the vendors, orders must be placed well in advance in order for them to arrive as needed. Next, the IDPH is currently involved in legislation mandating insurance companies to pay for formula. Kate mentioned that the cost of formula alone for one individual per year averages around \$4000.00! Lastly, the Illinois Department of Public Health is now covering two new products - Phenylade Chocolate and Flexi-10 Tropical Surprise. Keep in mind, however, that a doctor's prescription is needed for these new formulas and that one cannot just try them out!

For the eighth consecutive year, the PKU Organization of Illinois has awarded two \$1,000 scholarships to individuals with PKU, who reside in Illinois, and who are enrolled in an accredited college, university or vocational school. This year's winners were Susanne McLaren and Anna Mezera. The board wishes to congratulate the winners and hopes these awards help support them in reaching their educational goals.

Cut along line and return the bottom portion with your contribution

REMEMBER OUR CHILDREN AND THE FUTURE OF PKU

Enclosed is my contribution in the amount indicated below.*

[] \$25 [] \$50 [] \$75 [] _____ Other

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

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

Basic Strategies for Managing PKU

by Bruce Kimbrell

This year's Annual Meeting keynote speaker was Linda Gleason, MS. RD. She is a nutritionist at Creative Nutrition Applications in Elm Grove, Wisconsin. She discussed a variety of information about managing PKU. This included hints, tips, and educational materials that we can all use as we live with PKU. There was something for everyone. A brief summary of this material is included in this article. The PKU Organization of Illinois appreciates the time and effort that Linda put into her preparation and presentation. It was an excellent presentation and received rave reviews and comments from the audience.

Talking about PKU. Linda covered various responses that children can give when responding to questions that they get about PKU. She encouraged us to empower children to respond confidently to the questions of others. This also covered how to say no (to foods) with style. This is saying no to foods in a respectful and polite way.

Educational Materials. She also has a variety of educational materials that are suited for different age groups. They all focus on giving children an explanation of what is PKU. The older the children are the more detailed the explanations get. Copies of T Rex, PKU, and Phe (5-7 year olds) and the Story of Phe and Me (8-10 year olds) were

available for the audience. She also described Give Me the Phe Facts (Middle School) and PKU Facts for now/Facts for the Future (High School).

Tracking Phes. Linda also discussed hands on activities for children to participate in tracking their Phe consumption during the day. These included the use of Phe Trees with leaves, using white boards, and a check off list.

The educational materials in the

“Kids need their parents to be advocates for them with teachers, school lunch programs, and insurance carriers. You need to help them plead their case.”

curriculum also include introducing the child to help with formula mixing and communication between family members on low protein food supply levels to know when to reorder. She covered information on how to handle children going on strike and not eating and how to handle food at group outings.

She stressed that for infants the impact of not properly following the diet can be devastating. As people get older and do not follow the diet properly, there are subtle differences that may be difficult to distinguish. There will be an impact that most often shows up in difficulty with concentration, organizing work, and remembering. Ms. Gleason indicated that an adult that is off diet may lose

Linda Gleason – Annual Meeting Keynote Speaker

one IQ point a year for each year they are off diet. Over time, this will really add up to a decrease in the level at which they can function.

Develop, keep, and teach good habits. Watch for slow phe level increase creep as the child gets older. Optimize the use of medical formula with 3-4 doses a day. Kids need their parents to be advocates for them with teachers, school lunch programs, and insurance

carriers. You need to help them plead their case. To do this you and your child should speak with authority. Also remember to ask for it in a respectable way and don't put them on the defensive. Be assertive, but not

defensive. Use other PKU families for guidance. The listserv is great for this purpose. Use your lifelines and phone a friend.

The materials Linda discussed were available on the internet until 12/31/2003 at

<http://www.waisman.wisc.edu/pku/>
They are excellent and can help all of us educate our children. If we learn of them being available on the internet in the future, we will communicate it to you in this newsletter.

She also recommends materials that focus on sibling support at www.thearc.org/siblingsupport

The 2003 Annual Meeting keynote presentations are now available on audio cassettes, CD's, video cassettes (VHS format) or DVD'S.

Just imagine being able view and hear the Panel of Young Adults with PKU discuss topics like:

- How they deal with PKU in high school, college, and with their peers.
- What's their time management like for making formula and sending in blood?
- How they can tell if phe levels are high.
- Their thoughts on "feeling left out" in a group meal setting
- What they like in the low-protein food lines available.
- Biggest challenges they face each day with PKU.
- Suggestions for when to drink the formula.
- Recommendations on how to keep kids from "cheating"
- Transitioning strategies for parents to get the kids tracking their diet
- Their advice to parents of infants with PKU – this is awesome!

AND, having the opportunity to get "BACK TO THE BASICS" with Linda Gleason's presentation, where she highlights how to handle practical day-to-day PKU issues like:

- Answering questions that friends, relatives, and co-workers have about PKU
- Kids saying "NO" in style, to foods that are off limits.
- How kids can ask questions about foods that aren't "obvious" off limits.
- PKU Websites available for everyone.
- Mixing formula and bonding along the way.
- PKU kids eating with a group of kids who do not have PKU.

All this, and MUCH, MUCH, MORE!

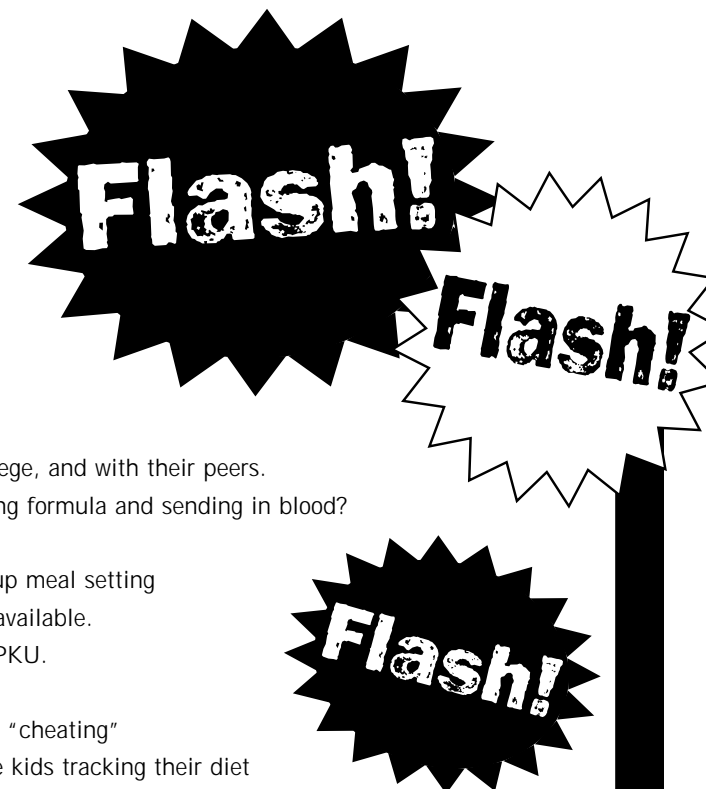
What ever format you choose, we know you will agree this is something that should be a part of everyone's home library. But, order fast, as supplies will be limited.

.....
**Cut along this line, and mail your order with a check made payable to:
PKU Organization of Illinois, PO Box 102, Palatine, Illinois 60078-0102**

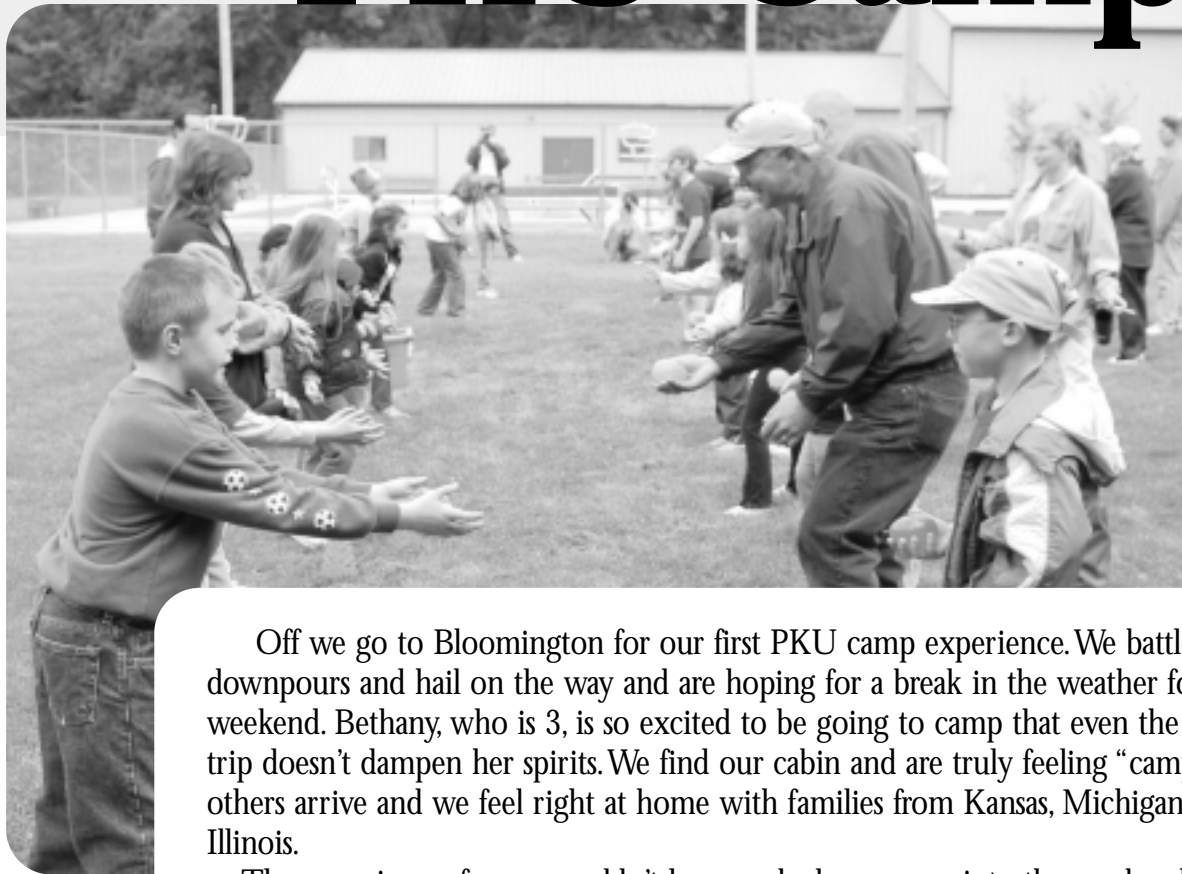
SHIPPING INFORMATION (very important)

	Quantity	Price	Total
_____ (Your name)			
_____ (Shipping address)			
_____ (City, state, zip code)			
Audio Cassette	_____	\$ 5.00	\$ _____
Audio CD	_____	\$ 8.00	\$ _____
VHS Video	_____	\$25.00	\$ _____
DVD Video	_____	\$25.00	\$ _____
Shipping/ Handling		\$ 5.00	
TOTAL			\$ _____

Note: Due to technical difficulties experienced during the recording process, there is some distortion in the audio, and clarity in the video, that could not be prevented. Allow 3-5 weeks for delivery.



PKU Camp in Illinois 2003



Off we go to Bloomington for our first PKU camp experience. We battle heavy downpours and hail on the way and are hoping for a break in the weather for the weekend. Bethany, who is 3, is so excited to be going to camp that even the 400 mile trip doesn't dampen her spirits. We find our cabin and are truly feeling "campy". Soon others arrive and we feel right at home with families from Kansas, Michigan and Illinois.

The organizers of camp couldn't have packed any more into the weekend! We had a hayride, swimming time in the indoor pool, campfires, fishing (even though the fish didn't cooperate!), games, and a dance. And of course LOTS of different PKU foods to try and take home.

As the mom of a young child I can see how this camp will only get to be more important as my daughter grows. She is too young to realize that the variety of foods to taste was amazing! It saves time and money trying these samples, just in case she didn't like them.

I spent a lot of time talking with other parents and kids about recipes, difficult times, formula tips, favorite foods and just life in general.

I want to thank all of the parents, dieticians, kids and others who obviously work very hard to make this weekend a success. You should all be proud. We plan to return next year and I would recommend this great opportunity to anyone in the PKU community.

Sincerely,

Sandy, John and Bethany LaPrad
Midland, Michigan



PKU families and friends enjoyed the games, hayride, crafts and many other fun activities throughout the weekend.



Coping with PKU in the Early Years (Ages 1-5)

by Tracy Keegan

Approximately 15 families attended the Coping with PKU in the Early Years (Ages 1-5) workshop, facilitated by Children's Memorial Hospital social worker Hazel

Vespa. Attendees ranged from parents to grandparents, aunts, uncles, and supportive friends. Each family was given the opportunity share their experiences with PKU so far, and learned different tips and techniques for managing the diet from others. Topics included educating other family members about the diet, and dealing with the diet in a range of situations, including at daycare/with babysitters and while traveling. Families also discussed ways that their transition to being a PKU family could have been made easier.

Suggestions included assigning mentor families, meeting and/or talking on the phone with a more experienced family soon after diagnosis, and even a babysitting exchange. Keynote Speaker Linda Gleason sat in on part of the meeting, and attendees were able to take home her teaching tool, **T-Rex, PKU & Phe**, an illustrated handout explaining PKU from a young child's perspective. The workshop ended with a viewing of a wonderful video, **Really Living with PKU**, produced by the PKU Action Group in Washington State.

Copies of the video are \$5, and can be obtained by calling Children's PKU Network at 1-858-509-0767 or emailing pkunetwork@aol.com.



Sun, Fun & Golf!



Well, September 20, 2003 turned out to be a wonderful day. Sunny, not a cloud in the sky, a great day for golf and that's exactly what we did! The first annual BIG WIG golf outing for PKU. Forty eight people played a best ball/scramble tournament at the Village Green Golf Club in Mundelin, Illinois. This tournament had its own set of rules, or shall we say "WIG Don't". For each violation, the golfer had to donate an additional dollar to the pot. The day ended with dinner and silent auction. A great time was had by everyone!

This tournament raised \$1200.00 for the PKU organization. A special thanks goes out to organizers and hosts of the tournament Jane Figel-Ford and Lori Knaub (Grandmother of Joshua Bennett, son of Steven and Lisa Bennett).

MARK YOUR CALENDARS !!

Women In Golf, Inc.

2nd Annual BIG WIG Golf
Outing For PKU

WHEN: September 18, 2004

WHERE: Village Greens Golf
Club, Mundelin, IL

For more information:
www.wiggolf.com

LETTER FROM THE BOARD

Dear Members,

NOVEMBER 15, 2003

The 34th annual meeting of the PKU Organization of Illinois was a great success. We had a total of 133 attendees, including medical staff and speakers, and raised \$14,972 through our annual raffle. The centerpiece of today's activities will be an address by our keynote speaker, Linda Gleason, MS. RD, is a nutritionist at Creative Nutrition Applications in Elm Grove, Wisconsin. Linda has a wealth of information she will share, that improves the quality of life for PKU kids and their parents. Linda's career focus on PKU spans over 20 years, and her rewards are measured in the satisfaction she gets in working with families who face the daily challenges of diet management.

During 2003, the Organization sponsored a full calendar of events in addition to our annual meeting. Regular members and board members of the Organization hosted all of these events:

- NEW PARENT COFFEE - *John and Jayne Markham*
- COOKING SCHOOL - *Lisa Hughes*
- NORTHERN ILLINOIS SWIM - *James and Kristen Leaf*
- COOKING DAYS - *Dee Pratscher*
- BIG WIG GOLF OUTING - *Lori Knaub, Jane Figiel Ford, and Steve and Lisa Bennett*
- PAMPERED CHEF AND TASTEFULLY SIMPLE FUNDRAISERS - *Angela Koster*
- PKU FAMILY CAMP - *Anne Kozak, Michele Kowalski, Mary Jane and Bruce Kimbrell, Ruben Caro, and Neil Brown*

We hope that you were able to attend as many of these events as possible, if not this year, then perhaps next year.

The board endeavors to keep in contact with the membership via variety of means such as our web page at www.pkuil.org where a great deal of current information on the Organization's activities is kept along with registration forms and other related informational documents and applications. With the web page and our e-mail address at info@pkuil.org, the Organization is in contact with individuals and other organizations from around the world.

We would also like to acknowledge and thank very much Bruce Kimbrell. Bruce has served on the PKU Board for many years. He has served as President, Vice-President, and Secretary (some years he held two offices at a time) during his terms on the Board. Bruce will be serving as Ex-Officio this upcoming year and will maintain our website. His dedication and hard work is an example to all of us. Thank you Bruce for everything you have done to make our Board and Organization what it is today.

Sincerely,

The Officers and Directors of the PKU Organization of Illinois

NORTHERN ILLINOIS SWIM EVENT

*Come Join A Fun Filled
Night of Jumping and
Swimming*

WHERE:

The Water Works

A facility of the Schaumburg Park District
505 N. Springinsguth Road,
Schaumburg • 847-490-2509

DATE:

February 29, 2004

TIME:

4 - 9 pm

We have a private room from 4 - 6 pm
And private swimming from 6 - 9 pm
Bring your favorite bathing suit and towel

Please bring two food items to
share, one PKU and one Non-PKU
(Beverages will be provided).

Please RSVP to Kristen Leaf at
847-265-8275, by February 22nd.



CAMBROOKE FOODS

NEW PRODUCTS: As a partner to our delicious new Portabella Mushroom and Spinach Ravioli, Cambrooke is pleased to bring you Pierogi. This is a fresh frozen pocket of dough filled with whipped potatoes and cheddar cheese that can be boiled, sautéed or fried. From the freezer, to the pan, to the table, Pierogi are easy to prepare and delicious. Try dipping the Ravioli, Pierogi or your favorite pasta in our new Alfredo Sauce Mix - delicious! The dessert lovers in your house will love our new Gourmet Chocolate Chip Cookie Dough. This scoop-and-bake delight comes to you in a convenient three-pound tub for your freezer - perfect for a cookie baking and eating family experience. Calling all salty snack lovers! Yuca chips are here in Original and three seasoned flavors; forty percent lower in fat than traditional potato chips too.

VITAFLO FORMULA: Cambrooke is excited to announce that we are now carrying Vitaflo metabolic formulas for patients with PKU, MSUD and HCU. These complete formulas are lower in volume, convenient and better tasting. Have your doctor or dietician send us a note giving us permission to send you a sample. A doctor's prescription will be needed to order the products once you have gone through the approval process with your insurance company.

LOW PROTEIN SCHOOL LUNCH PROGRAM: Have your child join the school lunch line! We have designed a new program which features the medical forms, menus, nutritional information and recipes to guide parents and school Food Service Departments through the process of supplying children with a nutritious low protein lunch. Please contact us for a copy.

INVITE DIANNE TO YOUR NEXT EVENT: Need help trying to figure out how to use low protein products or how to get your recipe to turn out just right? Cambrooke is pleased to continue providing support to the metabolic community, by providing Dianne's services to your next event. Dianne Sullivan, low protein chef extraordinaire, has joined forces with Cambrooke to bring her ideas and cooking talents to you. Ask your clinic or metabolic group to contact us to arrange for a cooking demonstration or event featuring Cambrooke's delicious low protein food.

We are ALWAYS open to serve you. Call toll-free (866) 4 LOW PRO / (866) 456-9776 or visit our website at www.cambrookefoods.com. If this is not convenient, you can mail, e-mail or fax your orders to us at orders@cambrookefoods.com - (630) 839-7413 (fax), 2 Central Street, Framingham, MA 01701.



SECOND CALL - *Live outside of Illinois?*

We are very happy to be able to send our newsletter to individuals and families that live outside of Illinois. We do not charge you anything for this, because we feel that we are all part of one large PKU family.

Again, we are verifying that our mailing list contains valid names and addresses since we use a non-profit mailing rate and do not receive notification back on undeliverable mail. **We need you to respond if you wish to continue to be on our mailing list.** This will help us to reduce costs.

You can respond by email to: info@pkuil.org or fill out the form below and mail to:
PKU Organization of Illinois, P.O. Box 102, Palatine, Illinois 60078-0102

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Parenting the Young Adult, & Beyond.

This back to the basics workshop gave many excellent suggestions for the young PKU adult—especially those living away from home. Some of the key points were:

The parents must give enough of a foundation of good habits while the kids are living at home, to have kids be able to implement the basics on their own. The biggest issues for the teens and young adults are preparing formula, counting fees, and being responsible to take blood when they are away from home. Some of the key points made for those living with PKU at college or away from home, were:

Analyze the college rules/exemptions before going there. Mandatory meal plans may not be cost effective for PKU diets if they lack variety. Some students have even gotten keys to the kitchen when living in a dorm.

The young adult needs to take control if living away from home, since it takes planning, organization, and yes they may even need to learn how to cook.

Federal guidelines for school lunch mandates for elementary and high school ages may not apply to colleges, especially the private ones.

Alcohol issues—if the young adult drinks, remember, dark beers are higher in phe (regular 12oz = 40 mg; lite beer 12oz = 20 mg phe. Wines are “free”, or trace.

Be creative-pre-measure formula in baggies before leaving home for ease in mixing at school, have the proper mixing utensils, and know how to measure (nested measuring cups, spoons, storage containers, gram scale, etc.). If possible, have a refrigerator, microwave, hot plate or stove, popcorn popper, etc. More variety is available with low protein foods, but many still require some food preparation.

Establish benchmarks to help them remember, like drawing blood on a day of the month that corresponds to their birthday (if your birthday is on the 28th day of September, then every 28th day they draw blood).

For Convenience, make things/prepare certain foods, and freeze them. We reviewed and discussed the fast and easy recipes available from Dianne Sullivan.

Weight gain was discussed, and an alternative is using an amino acid only product to prevent weight gain, with portions/ingredients designed by your dietitian.

The issue of adult PKU clinics as alternatives to the pediatric clinics was discussed. Currently, the only ones available are in Washington State and Utah. These have not caught on more due to the high cost to operate. The idea would be to develop such a clinic with a strong team approach covering areas like nutrition, social work, nursing, genetics, counseling, gynecology, etc. for overall care and to address insurance company issues.

It Was **TASTEFULLY SIMPLE** and **DELICIOUS...**

She did it again...Angela Koster hosted another wonderful fundraiser. She hosted a *Tastefully Simple* party on October 3rd at her house in Oswego and some of the profits were donated to the Organization. Angela baked her little heart out and prepared different kinds of dips. The representative was Michelle Lopez, who was very personable, handed out the delectable goods one tray at a time. There was the famous Beer Bread, Spinach Dip, Bacon Bacon Dip, Cheddar Potato Soup, and Chai Tea, just to name a few items that were taste tested, along with plenty more. Those that attended had a great time laughing and EATING and EATING and EATING. The party raised \$250. Thanks to all those that participated and ordered products. MANY THANKS to Angela for opening up her home and making this party a big success.

2003 Annual Meeting Raffle...

It keeps on growing!

2003 will go down in our history as one of the best years ever for our largest fundraising event, "THE RAFFLE". The 2003 raffle raised \$14,972! This is a 38% increase over the 2002 total \$10,879.

What made this year's raffle so successful? It's simple, member participation and involved parents generated these sales. No matter how much any of our members sold, in 2003 everyone seemed to contribute greatly towards this important annual fundraising event. Seventy-nine families sold raffle tickets this year.

Certain members in our organization "went the extra mile" in raffle ticket sales. This year's top producers were:

Tom & Christine Gallagher (\$1,940 in ticket sales – **AWESOME - and in the 1st year!**)

Nelson & Anna Herschberger (\$1,670 in ticket sales – **GREAT JOB - As Always**)

Tom & Tracy Keegan (\$1,650 in ticket sales – **WOW, in the top 3 - in their first 2 years**)

For their efforts, the Gallagher's, the Herschberger's and the Keegan's received a \$100, \$50, and \$25 American Express gift certificates respectively. Just think, over 35% of our raffle ticket sales came from these three families and nearly 70% for the top ten sellers – THANK YOU ALL!

Honorable Mention Raffle Ticket Sales:

Dan & Beth Burke	\$1,502
Steve & Lisa Bennett	\$1,143
Brad & Angela Koster	\$ 826
Craig & Cindy Stuart	\$ 506
Frank & April Salemi	\$ 410
Gerry & Pat Thompson	\$ 370
Martin & Lisa Irgang	\$ 348

Ruben & Jodi Caro, James & Kristen Leaf, Mike & Lisa Hughes and Frank & Larissa Bruno each sold \$200 worth of tickets. There were also 20 families that sold \$100 or more.

This year's raffle was also very successful because of raffle prize contributions from our member families. Specifically:

One Week Trip to Puerto Rico – The Caro Family: Hotel, PKU IL: Airfare up to \$1,000

Medinah Golf Outing – The Critchfield Family

Charter Air Service to Champagne Breakfast at Lake Lawn Resort in Lake Geneva for 4 people – Tim Koster from Midwest Avtech (Through Angela and Brad Koster)

Mill Creek Hotel in Lake Geneva – 2 nights (Through Angela and Brad Koster)

\$500 Gift Certificate for Miceli Drapery Company – John Miceli Jr. (Through Frank and April Salemi)

14 Karat Two Tone Necklace (\$125 value) from Daniel's Jewelry, Glenview, IL – Valery Keller (Through Martin and Lisa Irgang)

Chicago Cubs Tickets – The Critchfield Family

\$100 American Express Gift Certificate – Jodi and Ruben Caro

\$100 US Savings Bond from United Community Bank (Through Angela Koster, and Angela's Sister, Tracy Skopec)

\$30 Gift Certificate for Mario Tricoci – The Burke Family

Extreme Scooter – Hazel Vespa

\$50 Certificate to Des Plaines Golf Center – Des Plaines Golf Center (Through Steve and Lisa Bennett)

\$25 Gift Certificate for Rosati's Pizza – Nick and Gina Scannicchio (Through Steve and Lisa Bennett)

The Board would like to express our deepest thanks to all these families that contributed prizes for the raffle.

Many of our vendors contributed product samples for everyone to try. A special "thanks" goes to our good friends at Ross Products (represented by Dr. Barbara Marriage, Herman Miller, and Mario Pierre-Jerome), Applied Nutrition (represented by Sarah Foster), and Cambrooke Foods (represented by Diane Sullivan) for being there to personally answer questions and to allow our families to sample their new products.

The Organization would like to express our gratitude to the following vendors for the monetary donation given for the Annual Meeting:

Applied Nutrition Corporation	\$500.00
Ross Products Division	\$500.00

Next year's raffle is right around the corner – if you have prizes that you can contribute or know of companies or organizations that will contribute a prize, or would be willing to help write the raffle prize solicitations, LET US KNOW.

The individual prize winners of the 2003 Annual Meeting Raffle are listed separately in this newsletter.

THANK YOU TO EVERYONE WHO PARTICIPATED BY SELLING TICKETS, BUYING TICKETS, AND CONTRIBUTING PRIZES – YOU MADE THIS YEAR'S RAFFLE ONE OF THE BEST EVER.



Doctor's UPDATE

This year's annual meeting gave us the opportunity to hear from the doctors at Rush-Presbyterian St. Luke's Hospital, University of Illinois at Chicago Hospital, and Children's Memorial Hospital. Dr. Wong of Rush-Presbyterian St. Luke's Hospital reported a couple of new hyper-phe cases that required no treatment. Dr. Hoganson of the University of Illinois at Chicago Hospital reported 10 new hyper-phe cases that needed no treatment. He also discussed the bone study which was looking for changes in bone mineralization. So far, this study has shown no significant differences in bone mineralization between PKU

2004 Board Election

On November 1, our membership elected five members to the PKU Board of Directors for two-year terms. As is our tradition, the election took place at lunch and the new directors were elected unanimously by a show of hands. Angela Koster was re-elected for a new term. She served as vice-president this past year, is on the fundraising committee, and was the primary person that did the work to update our last organization directory. Joining Angela, as new members to the Board are Beth Burke and Dan Burke (sharing one position), Tracy Keegan, and Tom Keegan. These newly elected directors join seven returning members: Gina Annunzio, Joseph Annunzio, Patrice Bedenk, Kate Chovanec, Jim Critchfield, James Leaf, and Kristen Leaf. We wish to express our appreciation to Larissa Bruno, Jayne Markham, and Ruben Caro three of last year's directors who have stepped down from the Board. Bruce Kimbrell will serve as an Ex-Officio board member.

There are plenty of opportunities for all members to get involved with the organization. There are smaller items and committees that would not take much time and will greatly help the organization. If you are interested in finding out more about this or assisting the Board, please telephone the PKU voice mail box or send an email to us at info@pkuil.org

patients and non-PKU patients. Dr. Burton of Children's Memorial Hospital reported new classical and hyper-phe patients this year. Dr. Burton also discussed the BH4 study she is conducting. The study is of PKU patient's ages 3 years and up. Twenty-seven patients have been tested for BH4 responsiveness. So far, 3 patients have responded to the drug, 2 hyper-phe cases and 1 classical case. Nine more patients will be tested for responsiveness as she is looking for at least 4 to 6 responsive patients. At that point, a one year treatment trial will be conducted to see if they are responsive to the drug over the long term to determine how much diet liberalization is possible. On behalf of the PKU Organization, many thanks to Dr. Wong, Dr. Hoganson and Dr. Burton for keeping us informed!

PKU ORGANIZATION OF ILLINOIS
2004 Tentative Calendar of Events

<u>DATE</u>	<u>EVENT</u>	<u>LOCATION</u>	<u>TIME</u>	<u>HOST/CONTACT</u>
February	Candle Selling Fundraiser	Winter Press Advertisement	Whole Month	Tricia Cox 815-224-1208
February 29	Northern Illinois Swim	Schaumburg Water Works	4-9 pm	Kristen Leaf 847-265-8275
Spring	Eastern MO/Southern IL Metabolic Spring Picnic	Clayton, MO		Laurie Sprietsma 314-454-6261
April 29	New Parent Coffee	Barrington Hills	1:00 pm	Jayne Markham 847-382-8955
May	Dominick's Benefit Days	Coupons in Spring Press		Joe Annunzio 847-838-2706
May	Jewel Shop-N-Share	Coupons in Spring Press		
July	Cooking School			
Summer	St. Louis Metabolic Summer Picnic/Swim	Clayton, MO		Laurie Sprietsma 314-454-6261
July	Central Illinois Picnic	Bloomington, IL	1:00 pm	Mary Jane Kimbrell 309-827-4706
Sept. 18	BIG WIG Golf Outing, Silent Auction	Village Greens Country Club Mundelein, IL	12:00pm	Jane Figiel Ford 708 226-0878 www.wiggolf.com
Sept. 24-26	PKU Family Camp	Lake Bloomington, Hudson		Michele Kowalski 773-745-4541 Bruce Kimbrell 309-827-4706
October	Halloween Event	Chicago vicinity		
November	Annual Meeting & Cookie Exchange		9 am	info@pkuil.org or voicemail
November	Jewel Shop-N-Share	Coupons for both in Summer Press and Annual Meeting Folders		Joe Annunzio 847-838-2706
November	Dominick's Benefit Days			
December	Dominick's Benefit Days	Coupons for both in Summer Press and Annual Meeting Folders		Joe Annunzio 847-838-2706
December	Jewel Shop-N-Share			

For more information on these events:

- Call our voicemail at (630) 415-2219
- Email us at info@pkuil.org
- Watch for updates in the PKU Press
- Check our web site www.pkuil.org

This is an incomplete calendar. As events are scheduled the calendar will be updated and put into the Spring Press.



Raffle Winner & Sellers

One Week Trip to Puerto Rico - The Caro Family: Hotel, PKU IL: Airfare up to \$1,000
 WINNER: The Herschberger Family SELLER: The Herschberger Family

Medinah Golf Outing - The Critchfield Family
 WINNER: Lynn Cirrincione SELLER: The Bennett Family

Charter Air Service to Champagne Breakfast at Lake Lawn Resort in Lake Geneva for 4 people - Tim Koster from Midwest Avtech (Through Angela and Brad Koster)
 WINNER: Cassie Stevens SELLER: The Stevens Family

Mill Creek Hotel in Lake Geneva - 2 nights (Through Angela and Brad Koster)
 WINNER: Debbie Guerra SELLER: The Davis Family

\$500 Gift Certificate for Miceli Drapery Company - John Miceli Jr. (Through Frank and April Salemi)
 WINNER: Dan Schael SELLER: The Herschberger Family

14 Karat Two Tone Necklace (\$125 value) from Daniel's Jewelry, Glenview, IL - Valery Keller (Through Martin and Lisa Irgang)
 WINNER: Dan Schael SELLER: The Herschberger Family

Chicago Cubs Tickets - The Critchfield Family
 WINNER: John Jesse SELLER: The Herschberger Family

\$100 American Express Gift Certificate - Jodi and Ruben Caro
 WINNER: Andrew Gingerich SELLER: The Herschberger Family

\$100 US Savings Bond from United Community Bank (Through Angela Koster, and Angela's Sister, Tracy Skopec)
 WINNER: Pat Thompson SELLER: The Thompson Family

\$30 Gift Certificate for Mario Tricoli - The Burke Family
 WINNER: Bob Furlong SELLER: The Gallagher Family

Extreme Scooter - Hazel Vespa
 WINNER: Bruce Kimbrell SELLER: The Kimbrell Family

\$50 Certificate to Des Plaines Golf Center - Des Plaines Golf Center (Through Steve and Lisa Bennett)
 WINNER: Don Glennon SELLER: The Bennett Family

\$25 Gift Certificate for Rosati's Pizza - Nick and Gina Scannicchio (Through Steve and Lisa Bennett)
 WINNER: Alisa Spangler SELLER: The McLaughlin Family

Two Nights and Continental Breakfast - Hilton Chicago and Towers
 WINNER: Jerry Hoyer SELLER: The Keller Family

VIP Package for 12 people - Hawthorne National Race Course
 WINNER: Mike Hisler SELLER: The Keegan Family

Concert Gift Certificate - Metro Chicago
 WINNER: Doris Benjamin SELLER: Doris Benjamin

Clubhouse Admission and Box Seats for 6 People - Arlington Park Race Course
 WINNER: The Murphy Family SELLER: The Burke Family

Two One-Day Admission Tickets - Six Flags Great America
 WINNER: Mark Renn SELLER: The Bennett Family

Four Tickets to the Planetarium and Theater Presentation - Adler Planetarium
 WINNER: Carol Thompson SELLER: The Thompson Family

One Free Visit Family Pass - Chicago's Children Museum, Navy Pier
 WINNER: Evelyn Fuhrman SELLER: The McLaughlin Family

Admission for Two People - The Second City
 WINNER: Joe Mestan SELLER: The Gallagher Family

Admission for Two People - The Second City, etc.
 WINNER: Tom Keegan Sr. SELLER: The Keegan Family

Gift Certificate for Two and Free Video to MBC NewsCenter Broadcast - MBC NewsCenter
 WINNER: The Breslin Family SELLER: The Hughes Family

Twenty Swedish Dollars Gift Certificate - Ann Sathers Restaurant
 WINNER: Joe Stockhausen SELLER: The Caro Family

Kyle Farnsworth Autographed Picture - Chicago Cubs
 WINNER: Val Keller SELLER: The Irgang Family

Carlos Lee Autographed Picture - Chicago White Sox
 WINNER: Michael Murphy SELLER: The Gallagher Family

Magglio Ordonez Autographed Picture - Chicago White Sox
 WINNER: Pat Thompson SELLER: The Thompson Family

The PKU Organization of Illinois gratefully acknowledges the persons and companies (at left) who contributed raffle prizes or made donations which helped us bring this year's Annual Meeting to you: