

# PKU Press

A Periodic Newsletter Published By The PKU Organization Of Illinois

## Treatment Update Biomarin Press Release July 25th

from the Biomarin Website

### KUVAN RECEIVES PRIORITY REVIEW STATUS FROM FDA

PDUFA Date Set for November 25, 2007

NOVATO, Calif., July 25 /PRNewswire-FirstCall/ -- BioMarin Pharmaceutical Inc. (Nasdaq and SWX: BMRN) announced today that the U.S. Food and Drug Administration (FDA) has accepted for filing and granted priority review status to the New Drug Application (NDA) for Kuvan(TM) (sapropterin dihydrochloride). Under the Prescription Drug User Fee Act (PDUFA), the FDA is expected to take action on the application by November 25, 2007. Kuvan, an investigational oral small molecule for the treatment of phenylketonuria (PKU), a rare genetic metabolic disorder, is being developed in partnership with Merck Serono, a division of Merck KGaA, Darmstadt, Germany.

"We are pleased that Kuvan has been granted priority review status, a designation that emphasizes the significant need for an effective therapy to manage PKU. Over the next four months, we will work closely with the FDA to support their review of the NDA," said Jean-Jacques Bienaime, Chief Executive Officer of BioMarin. "We are preparing to launch Kuvan in the U.S. in December, if approved."

Priority review is typically granted to drugs that, if approved, will provide a significant improvement in the safety or effectiveness of the treatment, diagnosis, or prevention of a serious or life-threatening disease. Kuvan has also been granted orphan drug designation, which is conferred upon investigational products for diseases that affect fewer than 200,000 patients in the United States. Products with orphan drug designation that are the first to be approved for a specific indication have seven years market exclusivity in the U.S.

### About Kuvan

Kuvan is an investigational oral small molecule therapeutic for the treatment of PKU. The active ingredient in Kuvan, sapropterin dihydrochloride, is the synthetic form of 6R-BH4 (tetrahydrobiopterin), a naturally occurring enzyme cofactor that works in conjunction with phenylalanine hydroxylase (PAH) to metabolize Phe. Clinical data suggest that treatment with Kuvan results in significant reductions in blood Phe levels in BH4-responsive patients. It also may enable some patients to minimize or eliminate highly-restrictive dietary constraints by increasing Phe tolerance levels. BioMarin and Merck Serono estimate that Kuvan could be a potential treatment option for approximately 30 percent to 50 percent of the estimated 50,000 identified PKU patients in the developed world. Kuvan has received orphan drug designation from both the U.S. Food and Drug Administration (FDA) and the European Medicines Agency (EMA). If approved, it will receive seven years of market exclusivity in the United States and 10 years in the European Union for this indication. Additionally, the FDA has granted Kuvan Fast Track designation, which is designed to facilitate the development of new drugs that are intended to treat serious or life-threatening conditions and that demonstrate the potential to address unmet medical needs.

## PKU Community Summit 2006 - California

*Recap by Lisa Irgang*

This summer leaders from PKU organizations across the United States met at the headquarters of BioMarin Pharmaceutical in Northern California for the first PKU Community Summit.

The purpose of the summit was to discuss PKU community issues, to provide BioMarin with input on how the community will react if KUVAN (formerly called Phenoptin) becomes available, and to brainstorm on ways that BioMarin can partner with the PKU community to improve the lives of patients and families living with PKU.

## **PKU Community Summit 2006 - California** (continued)

### **KUVAN Discussion**

The meeting started with a brief history of the company and an overview of KUVAN, an investigational product. Alex Porter, MD, the Director of Medical Services at BioMarin, told us that KUVAN has been studied in 8 clinical trials in more than 690 patients at 40 universities and hospitals in 9 countries. The results of the clinical studies done suggest that KUVAN lowers blood Phe levels and increases Phe tolerance in some patients with mild, moderate and severe PKU.

Dr. Barbara Burton, Director of the PKU Clinic at Children's Memorial Hospital in Chicago, and Elaina Jurecki, Regional Metabolic Nutritionist for the Northern California Region of Kaiser Permanente, told the audience about some of the patients that they had enrolled in the KUVAN clinical trials. Because there is no way to predict who will respond to KUVAN, both recommended that all patients with PKU try KUVAN to see if they can benefit from this treatment. Some of the patients they put on KUVAN were able to lower their Phe levels, and a few were able to lower their Phe levels enough so that more Phe could be added back into their diet.

The attendees advised BioMarin that there was concern about how KUVAN would be paid for:

? Members of the group believe that KUVAN is likely to be treated by health insurance plans very differently from formula and low-Phe foods. Because KUVAN would be a prescription drug (if approved by the FDA), it is expected that most health insurance plans will cover at least part of the cost.

? The group responded positively to the fact that BioMarin has established a service to help each and every person with PKU who wants to try KUVAN. BioMarin Patient and Physician Support, or BPPS, will enroll each patient who is referred by a physician and assign a personal case manager. This case manager will research insurance coverage to assist people with PKU to find the type of coverage and support needed to receive KUVAN.

### **Needs in the PKU Community**

We raised the following needs of the PKU Community:

? There is a need for treatment coverage legislation needs to be changed so that treatment for PKU is covered; including formula, food, drugs, and medical nutrition therapy. Restrictive riders on insurance policies should be removed.

? Research and money for treatment other than diet is needed

? Large scale fundraising to address legislation, to invest in research, and to provide families with assistance is needed

? There needs to be appropriate care of adults with PKU, preferably at adult-focused metabolic clinics that can address the unique needs of adults

? Comprehensive and standardized education for families, physicians in pediatric/primary care, nurses, and insurance companies is needed

? Treatment protocols should be standardized across states so that people with PKU are receiving consistent care throughout the US

? A Phe home monitoring device is needed

? Food lists with ingredients information, additional cookbooks, web-based PDA program to help with diet management, and better access to low protein foods are needed

? Need additional support from local PKU communities, including volunteers, fundraising efforts, legislation advocacy, social events, and cooking classes.

### **National PKU Organization**

Leaders from the PKU community expressed great interest in discussing the topic of forming a national PKU organization that would support the regional chapters in advancing national-level issues, such as research, insurance coverage and education. Advantages of a national organization that were discussed by the group are as follows:

? A national organization would centralize, organize, and unify all of the issues in the PKU Community that the group mentioned

? More funding for research, to address legislation, and for family assistance would be raised by a national organization

? There would be an increase in national and local awareness through the organization's activities and media relations

? The organization would build relationships with physicians, dietitians, politicians, insurance companies, newborn screening programs, etc

? A larger organization would advocate for PKU rights on both a state and a national level

? A PKU database could be developed to keep track of people with PKU

? The national organization has paid staff which will reduce burnout

? Support could be offered to individuals with PKU who live in an area without a support group

We discussed next steps for planning and implementation of a national organization, and these are underway.

Overall, the PKU community summit provided a great opportunity to discuss the issues that affect the PKU community.

## PKU Awareness Month - Another Successful Year

By Lisa Irgang

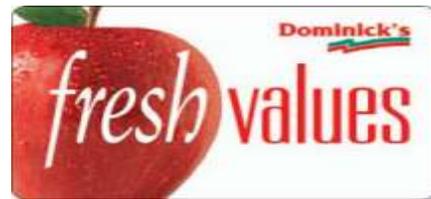
May 20th was probably the coldest day in May, but that did not stop our dedicated families from coming out to Busse Woods in Elk Grove Village. Over 20 families came out to walk for PKU research and enjoy food and children's games and events. Everyone enjoyed catching up with friends and meeting new members. Our youngest "walker" was only a couple of weeks old!

Our success went beyond the day of our event. This year we were able to get media attention. In addition to helping organize the picnic, Beth Burke put a lot of energy into raising "awareness." She contacted a number of newspapers and television stations and was able to get a story in the Northwest Herald and the Village Life magazine for Huntley. She also arranged an interview on Channel 6 for their "Around the Grove" segment. Frank Salemi did a wonderful job representing the PKU Organization and community!

The amount of research funds earned from our organization continues to grow as of August, the walk-a-thon had raised over \$10,000 for PKU research. As of August 17<sup>th</sup>, the nationwide total had reached \$246,300! The PKU Organization is working together with a number of groups from other states in order to ensure that funds are distributed among the various researchers whose research projects have been reviewed and approved by MACPAD. These researchers include: Denise Ney from University of Wisconsin-Madison, Stephen Hunter from the University of Iowa Hospitals and Clinics, Reuben Matalon from the University of Texas, Ray Stevens from The Scripps Research Institute and Harold Trick from Kansas State University.

Thank you to everyone who helped make the 2nd Annual PKU Awareness Month a huge success. In particular, the organization would like to thank **Monica Cengia, Josh Prizer and Mike Prizer** from Vitaflo. Vitaflo co-sponsored the event and, as usual, provided wonderful information and games.

Thank you again for all of your support. We look forward to next May!



## Introducing the Dominick's eScrip Fundraising Partnership

By Mike McMahon -PKU Organization  
Fundraising Chairman

Our fundraising committee has exciting news regarding a new, simple way to raise money for our organization. Dominick's is now partnering with eScrip. According to their website, eScrip is program for fundraising where "participating business partners contribute a percentage of your grocery loyalty cards, credit card, and debit/ATM card purchases to the school, group or organization of your choice."

Dominick's parent company, Safeway Inc., has already donated over \$170 million for various charities and initiatives through eScrip. The Fundraising Committee is thrilled to bring this same opportunity to our area. The PKU Organization of Illinois is now participating and able to broaden their fundraising efforts with the help of eScrip, Dominick's and those with Dominick's Fresh Values cards!

Below are a few of the many benefits we will enjoy through the new Dominick's eScrip program:

**Ease of use** - we can simply encourage our neighbors, friends, co-workers and relatives (and of course ourselves!) to register their Dominick's Fresh Values Card at [www.escrip.com](http://www.escrip.com) and use it every time they shop at Dominick's. Dominick's will donate 4% of your purchase every time you shop and present your card it's that easy!

**Increased contributions** - because donations are generated year-round with every shopping trip your families make.

**Year-round program** - no date restrictions, slips to track or scheduling required.

**Online reports for organizations and families** - Our group will have access to monthly reporting show how well we are doing as an Organization.

**Monthly funds distribution** - to the PKU Organization of IL.

We invite you to join us in this powerful program by signing up for eScrip, and encouraging all of your family members, neighbors, co-workers and classmates families to register their Dominick's Fresh Values Cards as well to help the PKU Organization of IL easily raise funds throughout the year. Just go to [www.escrip.com](http://www.escrip.com), have your Dominick's fresh values card ready, and search for PKU Organization of IL.

If you have any questions about eScrip, - please visit [www.escrip.com](http://www.escrip.com). Together, we all benefit through the Dominick's eScrip program!

Thank you in advance for your help in making this program a success!

## Father/Child Grilling Outing 2007

By Jeff Davis



In June, the Caro family, for the third consecutive year, generously hosted dads and kids for their famous Father/Child grilling day. Ruben once again was the grill master, expertly preparing delicious, creative PKU recipes that can be easily made at summer grilling events or anytime PKUer's are looking to change up their regular meals. His fabulous recipes are printed here and we thank the Caro family for opening their home again this year for some PKU friendly summer grilling!

(NOTE: SOME PHE VALUES ARE ROUNDED)

### Grilled Artichokes:

Great as an appetizer or side dish!

#### **Ingredients:**

Baby artichokes, trimmed and halved  
1 Lemon  
3 Garlic cloves  
2 Tbsp olive oil, plus more for brushing  
Salt to taste



Preheat grill. Cut lemon in half and squeeze out the juice in bowl. Save for later. Cut remaining lemon into quarters. Boil artichokes in water with 2 tablespoons olive oil, garlic, lemon quarters. Cook until artichokes are just tender about 5-10 minutes. Remove from water and set aside to dry. Brush with more olive oil and place on grill. Grill for about 3 minutes or until they start to brown. Sprinkle with lemon juice and salt.

PHE = approximately 30 phes per ½ baby artichoke

### Grilled PB&J:

Back by popular demand!

#### **Ingredients:**

1 Low Pro Bread Slice (15 phe)  
Low Pro Peanut Butter (8 phe/2 Tbsp)  
Jelly - any variety (Free)

Cut the bread in half. Brush one side of the bread with olive oil and place on the plate oiled side down. Apply peanut butter and jelly to one of the sides. Cover with the other half. Grill both sides for a few minutes until the peanut butter starts to melt soft. Remove and enjoy.

PHE = approximately 23 phes per serving

### Asparagus Packets:

Great for the whole family!

#### **Ingredients:**

Asparagus - .62 phe/gm or 19 phe per 2-4" spears

Cut off thick ends and place in aluminum foil package. Sprinkle with olive oil and salt to taste. Grill for approximately 5-10 minutes turning once.

PHE approximately 10 phes per stalk



### Pepper Rice Boat:

Who comes up with these names!

#### **Ingredients:**

Red Bell Peppers - .29 phe/gm or about 10 phe per pepper

Olive Oil - just enough to brush the peppers

Low pro rice- 7 phes per 1/3 cup uncooked

Chicken broth - .39phe/gm (Vegetable or other broth can be used as a substitute)

Water

Make as much or as little rice as desired using double the amount of water and chicken broth to rice. Ex: If you make ½ cup rice, use ½ cup water and ½ cup chicken broth, ¼ to ½ stick Butter.

Cut tops off of peppers and remove seeds and membranes hollowing out the inside (larger peppers can also be halved). Set aside. Boil chicken broth, water and butter. Add rice to boiling liquid, cook on medium heat until the rice has fully absorbed the liquid or is "dry." When dry, add salt and pepper to taste. Shredded low protein cheese can also be added as a topping if desired. Fill pepper halves with rice.

While rice is cooking, place peppers, brushed with olive oil, on grill. Grill over medium heat until pepper feels soft. When peppers are done, remove from grill and fill with rice.

PHE Approximately 35-40 phes per filled pepper (Assumes approx. 25-30 phes per ¼ cup rice filling.)

### Grilled Low Pro Hot Dogs:

A must for summer BBQs!

#### **Ingredients:**

Country Sunrise Vegetable Hot Dog Mix - 35 phes per serving

Condiments to taste

Prepare hot dog mix according to the package directions and boil or bake first. Place on greased grill for a few minutes and turn until browned. Be careful not to overcook or hotdog will become dry. Served with desired hot dog condiments (ketchup, mustard, etc.). Buns (using homemade low protein bread or prepared buns) are optional!

PHE = 35 mg per hot dog



## Macaroni and Pea Salad

A perfect side dish for the hot dogs!

### **Ingredients:**

½ box low protein elbows - cooked, drained and rinsed (28 phe)

4 slices low protein American cheese - (29 phe/slice)

Frozen peas - 60g 2phe/gm (cut frozen green beans can be used as a lower phe substitute)

¼ cup Hidden Valley Spicy Ranch dressing - 16 phe

¼ cup Hidden Valley Light Ranch Dressing - 16 phe

½ Cup Miracle Whip Light Salad Dressing - 12 phe

Salt and Pepper to taste

Place cooked pasta in large bowl. Add salt and pepper to taste mixing well. Cut cheese into small cubes/pieces and add to pasta. Add frozen peas (no need to cook) and dressings then mix together well and chill. Note - the pasta tends to absorb the dressing so you may need to add a little more dressing to leftovers before serving again.

PHE Approx. 38 phe/¼ cup serving.

## Grilled Vegetable Sandwiches:

Who said we can't be creative!



### **Ingredients:**

Low pro bread - 15 phe/slice depending upon recipe/brand purchased

Yellow squash - .40 phe/gm or 4 phe per 10gm slice

Zucchini - .40 phe/gm or 10 phe per 25 gm slice

Eggplant - .42 phe/gm or 8 phe per 20 gm piece

Olive Oil

Low pro cheese slices (American or Swiss) - 29 phe/slice (use ½ slice per sandwich)

Cut vegetables lengthwise into thin slices. Brush with olive oil and desired spices. Grill vegetables until tender. Cut bread in half and place on grill for a few seconds until hot. To assemble sandwich, put one piece of bread on plate, and top with vegetables and cheese. Finish sandwich with the other bread half or leave to enjoy open faced. Add condiments or marinades to taste.

PHE = 52 PHE per sandwich assuming 1 slice of bread, ½ slice low protein cheese and 1 slice of each different type of vegetable)

## Brown Sugar Grilled Plums and Apricots with Lemon Sorbet:

Yum, yum!

### **Ingredients:**

Cooking spray

Brown sugar

Butter

Ground Cinnamon

Plums, halved and pitted - 1 plum = 11 phe

Apricots, halved and pitted - 1 apricot = 31 phe

Lemon Sorbet - 3 phe per ½ cup



Coat the grill with the cooking spray and preheat to medium heat. In a small bowl, whisk together melted butter, brown sugar and cinnamon. Brush mixture all over fresh fruit. Grill plums and apricots, flesh side down, for 5 minutes or until soft. Serve fruit with lemon sorbet. Enjoy.

PHE = 14 phes for 1 whole grilled plum with ½ cup sorbet; 34 phe for 1 whole grilled apricot with ½ cup sorbet

## Ruben Tips for a successful PKU BBQ:

? Have children help choosing, cutting, and weighing veggies and fruits

? Use pre-cut veggies and fruit as a shortcut

? Substitute ingredients to suit your child's tastes or lower PHE counts

? Don't be afraid to experiment with seasonings, sauces and ingredients

? Enjoy and have fun!

## **PKU Profile Call for Entries**

We would like to start including in the PKU Press as a regular feature - profiles of PKUer's in our IL community. So all you PKUer's, young and old, send us your story! Tell us all about yourself where you live, your hobbies, your favorite PKU foods! If you have a picture we'd love to include that as well. Send all information to [info@pkuil.org](mailto:info@pkuil.org).

## PKU Organization of IL 2007 Remaining Events

**The year's almost over come join us at one of our events soon to meet and have fun with other members of our wonderful PKU Community!**

<u>DATE</u>	<u>EVENT</u>	<u>LOCATION</u>	<u>TIME</u>	<u>HOST/CONTACT</u>
November 3rd	Annual Meeting	Medinah Country Club	9 am-4 pm	<a href="http://www.pkuil.org">www.pkuil.org</a> or voicemail
November 12th-14th	Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Mike McMahon
December 17th-19th	Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Mike McMahon
February 2008	Family Valentine party/dance			

Have an idea for an event for 2008 or interested in hosting an event? Please contact us at [info@pkuil.org](mailto:info@pkuil.org)!!

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>

**The calendar is subject to change.**  
**As events are scheduled the calendar will be updated and put on the website.**

## 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.**

## PKU Organization of IL Board of Directors looking for participants

The board will have two vacant positions for the 2008 term. Please email [info@pkuil.org](mailto:info@pkuil.org) 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:

- The Annual Meeting
- The PKU Press
- PKU Awareness Month Activities
- Hospitality Events for the Community
- PKU IL Camp
- Our website
- Fundraising Events
- Donations to research
- ....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. Please consider volunteering today!

## Big Wig PKU Golf Outing Raises over \$15K for PKU Research

This year's Big Wig/PKU Golf Outing, sponsored by Women in Golf and the PKU Organization of Illinois was an incredible success again this year.

Held at Tamarack Golf Club in Naperville, over 130 people came out to support our organization, golf and have some fun!

Thanks to the generosity of the sponsors, those who donated prizes and time and our golfers the event raised over \$15,000, which will be allocated to PKU Research for treatments.

The organization would like to thank all the attendees, sponsors and everyone who donated their time and funds to make this event a success especially Steven and Lisa Bennett and Lori Knaub who work extremely hard to organize this event yearly and who pioneered this event for our organization. In the past two years, the amount of money raised by the outing for PKU Research has more than tripled. THANK YOU all and we look forward to another great time in 2008!

## Feedback on PKU Organization of Illinois Hospitality Events

One of the benefits our organization provides the Illinois PKU community is organizing numerous events throughout the calendar year for PKU children, teens, adults and their families to get together and exchanges ideas, stories, recipes and PKU food and have some fun! The Hospitality Committee works hard to plan a calendar of events each year tailored to the needs of the Illinois PKU community. In order to ensure we're planning events in which all members have an opportunity and would like to participate in, we'd like your feedback!! Please review the questions below your feedback and any general comments can be emailed to [info@pkuil.org](mailto:info@pkuil.org). Please be sure to include your contact information! Thanks for your help in ensuring our Hospitality Events are a success!

1) What events have you been able to attend, if any?

2) What type of events would you like to see the organization plan? (i.e. holiday themed, educational events, family, toddler, cooking classes, any others?)

3) Is there sufficient communication regarding events we plan and RSVPing?

4) What is the best way to communicate invites and reminders for events?

5) Are you interested in volunteering on the Hospitality Committee or planning an event for the organization? If so, please let us know! We can always use volunteer help, in whatever amount of time fits your schedule.

Thank you for your feedback!

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

Our sincere thanks to Cathy Lorimar for donating her time over this year in order to maintain our website Cathy has done a great job taking over for Bruce Kimball, who has supported our website in past years.

Here are just a few things that you will find on our website.

- Calendar of Hospitality Events.
- Board meeting information
- Information on Fundraising
- Link to update your PKU Org. of IL information in our directory
- Recipes
- PKU links, the PKU Index Card
- More!
- If you have any feedback or ideas on what you'd like to see on our website, please email us at [info@pkuil.org](mailto:info@pkuil.org)



# Ghoulish Goodies



## APPLE CIDER DOUGHNUTS

- 1 cup (100 gm) Cambrooke Foods MixQuick
- 2/3 cup apple cider
- 1/2 tsp ground cinnamon

Combine the MixQuick, apple cider, and cinnamon in a mixing bowl and mix with a fork until blended. Drop batter into electric doughnut maker and cook until browned. Cool on a wire rack. Sprinkle with sugar and cinnamon mix if desired.

Makes 5 doughnuts. Each doughnut = 0.2 mg phe

## BLACK PUNCH\*\*

- 1 envelope unsweetened grape drink mix
- 1 envelope unsweetened orange drink mix
- 2 cups sugar
- 3 quarts cold water
- 1 liter ginger ale, chilled



Stir together drink mixes, sugar, and water until dissolved. Combine with ginger ale just before serving.

Makes about 4½ quarts. One cup (8 oz) serving = 0 mg phe

## EYEBALL ICE CUBES\*\*



- 12 purple seedless grapes
- 4 drops green or red food coloring
- Ice cube tray

Peel most of the skin off of the grapes, leaving bits for red color. Tint cold water with a few drops of food coloring. Pour into ice cube tray and place a peeled grape in each section. Freeze until solid and serve in beverage of choice. The "eyeballs" will be most visible in a fairly clear beverage, such as ginger ale.

Makes 12 ice cubes. One ice cube = 1 mg phe

\*\*Recipes from *The Seattle Times*, October 25, 2003.



# PKU Camp 26 years and still going strong!

*By Christina Davis*

It was a beautiful Indian Summer weekend for the PKU Family Weekend held at East Bay Camp for the 26<sup>th</sup> straight year. The weather couldn't have been more perfect for getting together with friends and family and enjoying the outdoors and wonderfully coordinated camp activities.

This was our family's first year attending PKU Camp, but it will definitely be the first of many years to come. It is a great time to spend getting know families in the PKU community, sample excellent PKU cooking and have some good old summer camp style fun.

PKU families stay in Woods Camp, a spacious outdoor area with cabins, a dining hall with kitchen facilities, picnic tables, a bon fire area and plenty of space to play and mingle outdoors.

On Saturday there was fishing in the morning then lunch in the main dining hall, where PKUer's and non PKUer's alike enjoyed pasta and dessert, then off to the petting zoo followed by swimming in the camp's indoor pool. There was just enough time to grab a

PKU snack, with many homemade treats such as low-phe pumpkin bars available brought in by families attending, before it was time for a hay ride. Dinner was a "make-your-own pizza" buffet for PKUer's, the delicious homemade crusts courtesy of Mary Jane Kimball. Anne Kozek, working hard in the kitchen, prepared low phe puddings with a variety of toppings to choose from. After dinner the kids lined up for hat and animals from the balloon artist and then headed over to the dance hall. The evening ended with what else? Marshmallow roasting and relaxing by the bon fire.

Michelle Kowalski, Bruce Kimball and Anne Kozek, and all those that help out and attend, do a fabulous job of making this such a well organized and fun weekend for PKU families. There is so much to do, so many families to meet and chat with and of course, the added bonus of great PKU meals and snacks readily available. For those who haven't had a chance to drive out yet and join the fun, mark your calendar for next year, you don't want to miss this PKU event.



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

Now it can!



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.



# SHOP & SHARE IDENTIFICATION SLIP

AMOUNT OF PURCHASE

0411155

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GROUP NUMBER      STORE NUMBER

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DOLLARS      CENTS

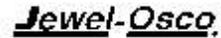
GROUP: **PKU Organization of Illinois**

YOUR SHOP & SHARE DAYS: **November 12, 13, 14, 2007**

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.

IDENTIFICATION SLIPS ARE NOT TO BE DISTRIBUTED IN FRONT OF ANY JEWEL-OSCO.



# SHOP & SHARE IDENTIFICATION SLIP

AMOUNT OF PURCHASE

0411155

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GROUP NUMBER      STORE NUMBER

--	--	--	--	--

DOLLARS      CENTS

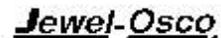
GROUP: **PKU Organization of Illinois**

YOUR SHOP & SHARE DAYS: **December 17, 18, 19, 2007**

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

### 2007 PKU Organization of Illinois Board Members

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

## ***SAVE THE DATE!!***

### **The PKU Organization of IL Annual Meeting PKU & Allied Disorders - A Family Focus November 3, 2007 Medinah Country Club**

What's on the Agenda for November?

- Keynote Address discussing the "family focus" of metabolic disorders
- Late morning presentation - **"Making the Most of Adolescence... How teens and families can successfully navigate their way to a healthy future"**
- Lunchtime informal roundtable - traveling with a metabolic disorder
- Breakout sessions around diet management, sports nutrition and allied disorders
- Final Keynote focusing on ongoing considerations for family management of diet
- Vendor presentations, clinic and research updates
- Children's and sibling's programs
- Raffle, scholarship presentation, samples, products and much more!

For those selling raffle tickets for the event - if you need more tickets, please email [info@pkuil.org](mailto:info@pkuil.org)

See you in November at Medinah!!

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