A Periodic Newsletter Published By The PKU Organization Of Illinois

35 Years of Service and many more to come...

This year marks the 35^{th} Anniversary of the PKU Organization of Illinois. The Board is busy planning an exciting meeting at Medinah Country Club to be held on November 6^{th} , 2004.

The keynote speaker this year is John Rolland, MD. He is the Co-Director and Co-Founder of Chicago Center for Family Health. He is Clinical Professor of Psychiatry at the University of Chicago Pritzker School of Medicine. At CCFH, he assumes primary training responsibilities in its unique and internationally recognized Families, Illness and Healthcare Program.

Dr. Rolland received his training in medicine and psychiatry at the University of Michigan and Yale University and earned a master's degree from the Harvard School of Public Health. He was the founding director of the Center for Illness in Families at Yale University, and continues as a Lecturer at Yale's School of Medicine. He is a Fellow of the American Psychiatric Association and the American Orthopsychiatric Association and former Fellow at the Institute for Social and Policy Studies at Yale.

For something different, the vendors will be presenting their line of products, not only during the breaks, but also as part of the meeting. The vendors will have time to talk during the meeting about new foods and formulas, along with old favorites. The cookie and snack exchange will take place during the reception after the meeting.

The Children's Program for 6-12 year olds is being planned and will be facilitated by Susan Ruohonen, MS, LPC, Clinician. She does such a great job with the children that we asked her to run the program again this year. It will coincide with the Parent Annual Meeting.

Being at Medinah, there will be an enforced dress code. Some clothing items **NOT** permitted are tee shirts, undershirts, athletic/sweat shirts, sweat suits, cutoffs, running shorts, short shorts, tennis attire, swimming attire, halter tops, fishnet tops, and tank tops. **JEAN OR DENIM MATERIAL OF ANY COLOR IS NOT ALLOWED** on the club premises by men, women, or children of any age.

Save the date and the Board looks forward to seeing you there.



SUMMER 2004

Registration is now here !!

2nd Annual BIG WIG Golf Outing for PKU

WHEN: September 18, 2004 WHERE: Popular Creek Golf Club Hoffman Estates, IL

Time to register your foursome (at least 2 must be women)

Fill out the attached form and send in your payment to make a reservation !!

For more information go to: <u>www.wiggolf.com</u> <u>www.pkuil.org</u>

**We are looking for prize donations for the silent auction. If you would like to donate a prize, please contact Steve Bennett at 847-359-0506.

Support of the set of	
Your Address:	Registration Form Saturday, September 18, 2004 (Tee times start at noon)
Your Address:	Your Name:
Your E-Mail (IMPORTANT!): Phone: *Preferred Foursome:	Your Address:
 *If you have a foursome you would like to play with, let us know who they are. If not, an extremely talented trio will be assigned to you. (<i>PLEASE NOTE</i>: IF SIGNING UP A FOURSOME WITH ONE REGISTRATION FORM, A CHECK OR CHECKS FOR EACH PERSON MUST ACCOMPANY THE REGISTRATION FORMS AND CHECKS (\$90 PER PERSON) ARE DUE AUGUST 24, 2004 Send your forms and check for \$90 made payable to Women In Golf, Inc. to: Women In Golf, Inc. c/o Jane Figiel 1332 Cove Drive Prospect Heights, IL 60070 We will be contacting you by e-mail (if possible) or phone with tee time and further BIG WIG information by September 1st. PLEASE CONTACT US AT wiggolf@wiggolf.com OR CALL JANE FIGIEL FORD AT (708) 226-0878 IF YOU HAVE ANY QUESTIONS REMEMBER TO CHECK OUT OUR WEB SITE AT WWW.WIGGOLF.COM 	Your E-Mail (IMPORTANT!):Phone:
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LOCATION East Bay Camp, Lake Bloomington in Hudson, Illinois. The organized event begins at 10:00 am Saturday and ends late morning on Sunday. You may come early Friday after 6:00 pm if you wish to begin your weekend early.

COST The PKU Organization of Illinois is underwriting most of the cost of this event. This year the cost is: Adult \$15, Child \$5. Anyone with PKU can attend at no charge. Payment is due at time of registration. For those wishing to help further offset the cost of the camp, any additional donations would be appreciated. **ACTIVITIES** Come enjoy crafts, games, swimming, hiking, good fellowship, evening campfire, fun for all ages, and planned PKU meals beginning at noon on Saturday.

MAKE YOUR RESERVATION Detach and Mail completed registration form and check (payable to PKU Organization of Illinois) by September 10, 2004 to Joseph Annunzio, 589 Picadilly Lane, Antioch, IL 60002. Space is limited for cabins and they will be assigned in the order that reservations are received. You may also come just for the daytime activities if you wish. Please indicate as such on the reservation form for our food preparation purposes. Additional information will be mailed to you after reservation is received. HOTEL Anyone not wanting to "rough" it sleeping at the campsite may stay at a hotel in Normal, IL. Motel

expenses and reservations are at the camper's own expense. Call us for hotel recommendations if you are unsure of where to stay.

QUESTIONS? Contact Michele Kowalski at (773) 745-4541.

------ Detach and mail the reservation form below to Joseph Annunzio, 589 Picadilly Lane, Antioch, IL 60002 -------

2004 PKU Family Weekend Reservation Form

We will attend the following day(s): Adults \$15, Child \$5	Friday - Sunday Saturday - Sunday Saturday only
There will be Adults and Chi	ldren in our group attending.
Total Amount Enclosed \$	
We will be staying in a : Cabin Tent Camper Hotel (cost is at your own	expense)

Listed below are the names of campers and ages of children whom will be attending. Indicate PKU with an (*).



The Markham Family once again graciously hosted the New Parent Coffee, held this year on Sunday, April 25th. Families with children aged two and under were invited. The Davis and the Smith families were welcomed by returning families including the Annunzios, the Burkes, the Gallaghers, the Irgangs, the Keegans, the Kosters, and the Thompsons. Childrens's social worker Hazel Vespa was on hand to give words of wisdom to all. Parents were able to share stories and swap advice while the kids played games and sampled homemade lopro treats, including vanilla cake, chocolate chip cookies, brownies, toffee bars, and a crowd favorite, Monkey Bread (from Virgina Schuett's Low Protein Bread Machine Baking for PKU). Families perused helpful publications, including Schuett's Low Protein Cookery for PKU and The Low Protein Food List for PKU, and were invited to take home bags of lopro goodies donated from companies including Ener-G Foods, Dietary Specialties, and SHS. Thanks to the Markhams for a great day of companionship and connections!



"Krafty" Macaroni & Cheese

Recipe given by Tracy Keegan

1 tbsp. butter

1 tbsp. (or less) corn starch

³/₄ cup total Coffee Rich/water combo (equal amounts of each) 1 tbsp (up to 2 tbsp., to taste) Fritos Mild Cheddar Cheese Dip LoPro Macaroni, cooked

Melt butter in small saucepan. Add cornstarch and stir with whisk until smooth. Add Coffee Rich/water combo while stirring constantly. Bring to boil, and then reduce heat until thickened. Stir in Cheese Dip. Pour over macaroni.

Phe per recipe, not including macaroni: 58 phe (approx)

I calculated the phe of the cheese dip, listed on can as 1 gm. (conservative phe estimate = 75 phe) per 2 tbsp serving, as 37 phe per tbsp.

PRIZE DONATIONS FOR RAFFLE NEEDED!

The PKU Organization of Illinois is asking its members for prize donations for the Annual Raffle to be held during our Annual meeting in November. The Annual Raffle is our biggest and most important fund-raiser, and its success in raising funds determines the kinds of programs we can offer to our members. If you know someone in your family, friend or business owner who would be willing to donate a prize for the raffle, please contact Joe Annunzio at 847-838-2706.

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
	(Yo	our Name)			*Note: Your employer may match your gift. Contact the Personnel or Community Relations Department of
	(A	Address)			your company for details.
(City)			(State)	(Zip)	

Thank you for your generosity. All contributions are tax deductible as allowed by law. Please make checks payable to the "PKU Organization of Illinois", and mail using the self addressed envelope provided. **We will acknowledge your donation.** Tax ID# 36-3320115.



<u>Reminder to</u> <u>College Students and</u> <u>High School Seniors:</u>

The application for the Andrew Craig Memorial Scholarship will be available on the PKU website, <u>www.pkuil.org</u>, from now until August 31. All applications must be mailed and postmarked by August 31, 2004. The two \$1000 scholarships will be awarded on November 6th at the Annual Meeting. All guidelines and procedures are with the applications. Just a reminder...the Organization updates the website quite often. Please visit our website periodically for event updates, the newest PKU Press, and new information. Thanks to Bruce Kimbrell for all his hard work for keeping our website updated and running. Website address is <u>www.pkuil.org</u>.



Survival Cooking for Teens and Young Adults

On Saturday, March 13, 2004 we had our first "Survival Cooking" course for teens and young adults. Our guest chef was Malathy Ramanujam from Taste Connections. Malathy came and demonstrated various scrumptious recipes that can be made from her TC - Low-Protein Bread Mix and TC - Low-Protein Multi-Baking Mix that she formulated. Malathy originally set out to make a good-tasting and lower-priced baking mix because her son has homocystinuria, which requires a low-protein diet, much like PKU, but requires a different medical formula. Malathy is currently continuing her education in nutrition and is writing her thesis paper on ways to improve the taste, texture and color of low-protein breads. We all received a mini-lesson on the differences between low-protein mixes and regular wheat flour and the reasons why they don't work alike.

For those interested in trying out the Taste Connections products, visit the website at <u>www.tasteconnections.com</u>. Or, call 310-371-8861 with any questions or to place an order. The bread mix and the multi-baking mix are each \$13.50 / 5 lb bag (not including shipping). Malathy is currently in the process of developing some new products that are expected to be on the market soon as well, like a versatile mix and cake mixes. Some of the recipes made included: drop biscuits, tortillas, chocolate chip cookies, bread, sapodillas, pancakes, low-protein refried beans, cilantro and mint chutney, and fritters.

Special thanks go out to Malathy Ramanujam for providing her baking mixes, nutritional knowledge and cooking expertise. Also, many thanks go to Pam Kowalczyk, Linda Kowalczyk, and the clinic staffs at the University of Illinois and Children's Memorial Hospital as well as everyone else who donated their time to make this day possible. Thank you Kelly Reilly for hosting Malathy during her time in Chicago.

Note: This is an shortened article from the last Press. The pictures were not ready to print and the Organization wanted to include the pictures in this Press.

CARSON PIRIE SCOTT COMMUNITY DAY SALE ~ MARK YOUR CALENDARS!

Once again, the PKU Organization of Illinois is participating in the Carson Pirie Scott Community Day Sale. The February Carson Pirie Scott Community Day Sale raised \$1,200, which has proven to be one of our best new fundraising events. **The date of the sale is November 20**, **2004**. How does it work? We sell coupon sheets for \$5.00 each prior to the sale, and the PKU Organization gets to keep the entire \$5.00 for each sheet sold. The coupons include:

- One \$5.00 off coupon for any single item worth \$5.00 or more (so right here you make your investment back!)
- Six coupons each good for 20% off of one item
- One or two coupons good towards "bonus" items that Carson Pirie Scott will disclose once coupons are for sale.

This is a great opportunity for the PKU Organization as well as those shoppers who want to beat the holiday rush! The coupons are good at all Carson Pirie Scott Stores as well as Bergner's, Herberger's, Younkers and Boston Store locations. The coupon sheets should be available sometime around September. If you're interested in purchasing coupons, please contact Angela Koster at 630-551-0890 for more information, or send a check for \$5.00 per coupon sheet (made out to "PKU Organization of Illinois") plus a selfaddressed stamped envelope to:

> PKU Organization of Illinois c/o Angela Koster 608 Northgate Drive Oswego, IL 60543

*** Please do not send checks prior to September, as the coupons will not be made available to organizations prior to that time. Thank you. ***

Or, if you prefer, we will also be selling the coupon sheets at our Annual Meeting on November 6,2004.

Thank you for your continued support and happy shopping!

Cambrooke Foods

Get the most out of summer foods with new recipes which feature foods that your kids already love - fixed in a brand new way. Get out of the recipe rut and try Ravioli Soup, Ravioli with Assorted Greens Salad and Lemon Grass Ravioli. All easy to prepare and perfect for a summer day! Are you looking for ways to take advantage of the luscious strawberries that are at the market? Try our Strawberry Shortcake recipe which uses MixQuick to make this old fashioned dessert favorite. Remember, pastas are great served cold in salads too, and we have many cold pasta salad recipes displayed. The Taboule salad is a garlicky favorite which is made using Cous Cous, vegetables and a garlic dressing. These recipes and many other new recipes are available on the Cambrooke Foods website under the recipes and tips tab.

Cambrooke is now carrying a variety of Aproten pastas. Our families of tasters enjoy these pastas and know that your family will enjoy using them in your favorite recipes as well. Yuca chips are now available in a variety pack. The variety pack has four sevenounce bags, one each of your favorite flavors; Original, Barbecue, Garlic 'n Cilantro, and Sour Cream'n Onion. A great way to try them all!

Have you been struggling to provide nutritious low protein lunches for your school age child? Now is the time to inquire about Cambrooke's School Lunch program so that you can get the necessary documentation to your School's Food Service Department in time for next semester. Ask us for the School Lunch Program packet which contains all the needed information so your child can join the school lunch line.

We are ALWAYS open to serve you. Call tollfree, (866) 4 LOW PRO / (866) 456-9776 or visit our website at www.cambrookefoods.com. If this is not convenient, you can mail (2 Central Street, F r a m i n g h a m, M A 0 1 7 0 1), e - m a i l (<u>orders@cambrookefoods.com</u>) or fax your orders to us at (978) 443-1318.

Greetings from Dietary Specialties!

The last six months have been full of exciting changes at Dietary Specialties. More space was needed to accommodate new products so the corporate office and warehouse was moved to Whippany, NJ. A few old friends left the company to pursue other interests and some new faces were added. Roger Jones, General Manager, was hired to steer DS towards continued success in its 43rd year of Mary and John, Customer Service operation. Representatives, are available to answer questions and take your order. Lou D'Amelio has taken over as Office Manager and Event Coordinator and Joann D'Amelio, RD has been brought on board for clinical expertise, recipe development, and as the company's trade show representative.

The DS chocolate and vanilla cake mixes continue to receive rave reviews! They're great for birthday cakes, muffins and cookies. Visit the website for a delicious new Chocolate Crinkle Cookie recipe using the chocolate cake mix. Look for new products and old favorites from Dietary Specialties coming soon.

Call center hours have been expanded to 8:00am 6:00pm, EST Monday through Friday. For further information or to place an order, call toll-free 888-640-2800 or log on to <u>www.dietspec.com</u>.

Applied Nutrition, in conjunction with The Children's Hospital of Denver, is proud to announce **"Network PKU Event and Conference"** October 15-17, 2004 Denver, Colorado

The Network PKU Event and Conference is a fun filled, family weekend that will focus on daily living techniques to make life easier for those with PKU. The Conference will include hands on cooking demonstrations by professional chefs on the prestigious campus of Johnson & Wales Culinary Institute. This event will feature innovative recipes and cooking techniques to teach you how to make PKU meals go from the ordinary to the extraordinary. The conference will also feature a screening of the award winning "Network PKU" video and break-out sessions for both children and young adults with PKU, their parents and professionals. The Network PKU Event and Conference will grant you the opportunity to meet, share ideas, and get to know other people and families that live with PKU from across the nation.

This event is sure to be the <u>PKU Event of the Year</u>!

Register to receive more information at <u>www.medicalfood.com</u>.





Ener-G Foods, Inc. Toll-FREE 1-800-331-5222 Internet web site: www.ener-g.com Orders, Nutritional Information, Full product info.

Low Protein Products

Our extensive line of low protein products are full of flavor and are perfect for anyone on this restrictive diet.

Flours, Mixes & Baking Ingredients Pasta Cheese Milk & Egg Substitutes Candy & Chocolate Pizza Shells & Soups/Broth LP Bulk items/Sample Kit

Low Protein Insurance As a provider of low protein foods, Ener-G Foods accepts assignments from state agencies and private insurance companies.

PhenylAde40[®] - Taste the Difference!

PhenylAde40 Drink Mix is quickly becoming one of the most versatile PKU formulas available. Each single serving pouch can be combined with as little as 4 oz of cold water, for a quick, low fat, low volume formula. This new product from Applied Nutrition is available in both Citrus and Unflavored varieties, which allows for endless taste options. Both flavors can be customized by adding a splash of your favorite flavor or drink. "One of the most popular mixtures is PhenylAde40 Unflavored combined with 6 oz of Sunny Delight", remarks Sandra Maltzman, Registered Dietitian for Applied Nutrition.

The combinations are endless, so creating a great tasting formula to meet your needs is just one step away.

PhenylAde40 Citrus Blend

1 pouch* PhenylAde40 Citrus 3 oz water 1 oz pineapple juice (contains 2.5 mg of phe) Shake or blend combination until powder is fully dispersed.

PhenylAde40 Ice Cream

1 pouch* PhenylAde40 Unflavored 4 oz non-dairy creamer (Rich's) Strawberry: add 2 Tbsp strawberry syrup Vanilla: add ½ tsp vanilla extract

Blend on high and place in freezer for 1-2 hours.

*1 pouch (25g) PhenylAde40 Drink Mix = 10g Phe-free Protein equivalent

For more recipe ideas visit Applied Nutrition's website at <u>www.medicalfood.com</u> or call 1-800-605-0410.

For MyDiet.com

Helping people with metabolic disorders manage their diets better.

ForMyDiet.com is a new website designed to make living with and managing a metabolic disorder diet a whole lot easier.

Whether you manage the diet of your child or yourself, a special medical diet can be a challenging situation. Our goal is to bring you everything you need in one place to make your life easier. Here are some of the features you can find at ForMyDiet.com:

- ✓ Get medical information about specific disorders from reputable sources.
- ✓ View the weekly easy-to-make recipe column that includes phe, protein, and calorie information.
- Share your experiences with others with metabolic disorders in the ForMyDiet Message boards. We have created a range of forums that fit your interests from recipes and food recommendations to parenting ideas.
- ✓ **Find food nutritional information in seconds** with the searchable online food list, which allows you to retrieve nutritional values of disorder-specific nutrients.
- ✓ Let the online nutrient calculator do all the calculations for you.
- ✓ Shop for pocket scales, bread machines, and other items you need for day-to-day meal preparation. We are certified by Verisign to provide you with a safe shopping experience.

For My**Diet**.com is dedicated to providing support to the special diets community by bringing together people living with similar dietary restrictions.

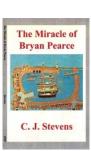


10% OFF

COUPON

Newborn Screening Video Tape - Free

One out of every 1,500 babies born in the U.S. has a disorder detectable through newborn screening! Courtesy of Save Babies Through Screening Foundation, this FREE educational video teaches about comprehensive screening.



The Miracle of Bryan Pearce - \$11.99

This book by C.J. Stevens depicts the story of Bryan Pearce, born in 1929 with an *undiagnosed Phenylketonuria*. This is the beginning of one of the most astonishing adventures in twentieth century painting.

Visit **For** My**Diet**.com to for all this and more!

Special offer: Save 10% on your next ForMyDiet.com Online Purchase. Coupon expires August 15th, 2004 Enter Coupon code "PKUIL74" when ordering at ForMyDiet.com



SHS NORTH AMERICA P.O. Box 117 Gaithersburg, MD 20884-0117 Tel (301) 795-2300 (800) 365-7354 Fax (301) 795-2301

June 2004

NEWS FROM SHS NORTH AMERICA

SHS announces the launch of an exciting new PKU medical food, **Lophlex**. **Lophlex** is a low volume, great tasting PKU drink mix, packed with all the vitamins and minerals needed for healthy growth and development. One sachet provides 10 g of protein equivalent and mixes easily with water for a final volume of 2.5 fl oz or less. That's only 12 - 15 fl oz a day for adolescents or adults! Ask your dietitian for samples of the berry and orange flavored product.

Have you heard about the latest addition to the Phlexy-10 System, **Phlexy-10 Tablets?** Each tablet contains double the amount of amino acids in comparison to one **Phlexy-10** Capsule, decreasing the necessary intake of pills by half. **Phlexy-10** is designed for a standard PKU diet. It includes drink mixes (blackcurrant/apple and tropical surprise flavor), a bar, capsules and now also tablets. Try it! Ask your dietitian or physician for a sample.

Tired of the taste of your medical food? Call our Nutrition Support Department for **metabolic formula recipes**. Check out the simple, mostly one-ingredient recipes as well as the fancy ones and make your daily drink mix more interesting. Talking about recipes: SHS also carries a line of low protein foods, **Loprofin**. Call us for great recipe suggestions.

As a reminder: The **SHS Metabolic Conference**, in cooperation with Children's Hospital of LA will be held October 1, 2004 in Long Beach. Topics are maternal PKU and other interesting issues. Teleconferencing will again be available.

For more information and a complete listing of SHS' products, please visit SHS North America at <u>www.shsna.com</u> or call 1-800-365-7354, Mo-Fr 8:30 am 5:00 pm EST.

Jewel Shop and Share

Twenty-seven people participated in the Jewel Shop and Share of May 17th, 18th, and 19th. The amount spent was \$2,324.62, thus raising \$116.23 for the Organization. The results of the Dominick Benefit Days are not know as of this Press. Thank you to everyone who participated.

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PKU ORGANIZATION OF ILLINOIS P.O. BOX 102 Palatine, Illinois 60078-0102

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: <u>www.pkuil.org</u>

2004 PKU Organization of Illinois Officers

Jim Critchfiled *President* Angela Koster *Vice-President* Joseph Annunzio - *Treasurer* Gina Annunzio Secretary

2004 PKU Organization of Illinois Board Members Patrice Bedenk, Beth and Dan Burke (shared position), Kate Chovanec, James Leaf, Kristen Leaf, Tom Keegan, and Tracy Keegan.

2004 PKU Organization of Illinois Honorary Members Anne Kozek and Hazel Vespa

2004 PKU Organization of Illinois Ex-Officio Bruce Kimbrell