/ L:ON LUMBIT I	19009
PERMIT NO.17	1/2
ΠΙΑΥ	11 11
JDATZOG .2.U	()]
NON PROFIT ORG	
040 113044 11011	WITA-140

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

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

2004 PKU Organization of Illinois Officers

Jim Critchfield - President Joseph Annunzio - Treasurer Angela Koster - Vice-President 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, Hazel Vespa

2004 Ex-Officio

Bruce Kimbrell

SPRING 2004

PKU Press

A Periodic Newsletter Published By The PKU Organization Of Illinois

LETTER from the Board



SAVE NOVEMBER 6th. Mark it in your calendar.

The 35th Annual Meeting is being held at a different venue this year. We are so excited to announce that this year's meeting will be held at Medinah Golf Club. We are still in the planning stages of the meeting, so more information will be in the next Press and the invitation that we send out in August. There will be a dress code.

The 2004 board has met twice and is busy lining up the year's activities along with overseeing the operations of the PKU Organization of Illinois. We have welcomed new board members and have a solid and excited group of individuals serving the Organization this year. We meet approximately every 6 weeks at the Children's Westchester clinic. We have phone conferencing available for those

board members who are unable to attend the meeting in person.

We have activities planned, some of which are highlighted in the Calendar of Events. We appreciate all of the support that we get from members that are willing to organize and host events. Without them, the events would not be possible. We also appreciate the support we get from the board members families by allowing each one to attend the meetings and take some of their personal time on planning for and attending meetings.

Feel free to provide input to the board anytime during the year. You can contact us through any board member, our voicemail, email, or regular mail.

Hope to see you at some of the events this year.

KEEP IN MIND... Andrew Craig Scholarship Application

This year the PKU organization will again award two \$1,000 scholarships to two qualifying individuals with PKU. The individuals with PKU have to be enrolled in an accredited college, university, or vocational school in the fall of 2004 and do not need to be newly enrolled. A student may win more than once, but not in consecutive years.

For the application and more information, after July 1st, please visit our website: www.pkuil.org or call Kate Chovanec at 847-854-4778 or write to the PKU Organization of Illinois, P.O. Box 102, Palatine, IL 60078-0102.

Sun, Fun, and a Little Fundraising!

Remember to mark your calendars!

2nd Annual BIG WIG **Golf Outing for PKU**

WHEN: September 18, 2004

WHERE: Popular Creek Golf Club

Hoffman Estates, IL



Start thinking about your foursome (at least 2 must be women)

More information coming soon!

Sponsored by: www.wiggolf.com www.pkuofil.org

Northern Minais Swim Party. Leaping into 2004

It was a fun time at this year's swim party. It was held at the Water Works in Schaumburg on February 29th. Families brought some fabulous PKU and non-PKU food dishes to share, including vegetable pizza, mini pizzas, muffins, pasta salads and chocolate covered marshmallow lollipops with cherries to name a few. Many thanks go out to SHS, Cambrooke Foods and Applied Nutrition for providing additional snack foods for families to sample, including various

cookies, fruit bars, crackers and low-protein chocolates. In addition to providing the snacks, our low protein vendors had various goodies for people to take home, including wafer cookies, fruit bars, pens, recipes and various literature. Once

fruit bars, pens, recipes and various literature. Once everyone had a chance to fill up on scrumptious foods, it was off to the pool to cool down a bit! Like last year, the PKU Organization of Illinois had a private pool rental, so there was plenty of space for 42 people to splash around and have fun. Thanks to the Egans, Buzzards, Ginters, Gallaghers, Bennetts, Kosters, Irgangs, Thompsons, Leafs, and Annunzios for coming out, bringing food, and making this event so great. It looked like everyone had a wonderful time! Many thanks go to Kristen Leaf for coordinating this year's event!



March 2004 NEWS FROM SHS NORTH AMERICA

SHS North America is offering a new pasta variety. Try our lasagna sheets in great recipe suggestions available through our Nutrition Support Department. The lasagna comes in packs of 250 g, the price is \$5.00/pack.

We also offer new 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.

Save the date: 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.

And don't forget the new 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.

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

The PKU Organization of Illinois Comparative Results of Operations for the Year Ended December 31, 2003 and 2002 Cash Basis

		2	003 Fund Activ	itv			:		
	General Fund	MPKU Fund	Education Fund	Research Fund	Spec. Assist Fund	200 Tota	-	200 Tota	
Receipts:									
Fund Raising:									
Jewel Shop & Share	440.67	_	-	-	_	440.67	1.0%	275.24	1.0
Dominick Benefit Days	15.99	-	-	-	-	15.99	0.0%	90.14	0.3
Meijer Give Away Program	-	_	_	_	_	-	0.0%	620.16	2.3
BIG WIG Golf Outing	1,200.00		_	_	_	1,200.00	2.7%	-	0.0
Pampered Chef Party	268.56			_	-	268.56	0.6%	_	0.0
Tastefully Simple Party	250.00	_		_	_	250.00	0.6%		0.0
Annual Appeal	3,296.00			_	_	3,296.00	7.5%	1,135.00	4.1
Donations & Grants	6,920.23	_	_	8,100.00	2,000.00	17,020.23	38.5%	8,638.02	31.5
Lapel Pin Sales	525.00			0,100.00	2,000.00	525.00	1.2%	0,030.02	0.0
T-Shirt Sales	1,395.00	_	_	_	-	1,395.00	3.2%	-	0.0
Hat Sales	140.00	_	-	•	-	140.00	0.3%	-	0.0
Other Product Sales	97.00	-	•	-	-	97.00	0.3%	72.50	0.0
	500.00	-	•	-	•	500.00	1.1%	72.50	0.0
T-Shirt Sponsorship PKUIL Directory Sponsorship		-	-	-	-	300.00	0.0%	1,225.00	4.5
	- 14 072 00	-	-	-	•				
Annual Meeting Raffle	14,972.00	-	-	9 100 00	2 000 00	14,972.00 40,120.45	33.8% 90.7%	10,879.00	39.6 83.6
SubTotal Fund Raising	30,020.45	-	-	8,100.00	2,000.00	40,120.45	90.7%	22,935.06	03.0
Event Receipts:									
Annual Meeting Registration	2,000.00	-	-	-	-	2,000.00	4.5%	1,800.00	6.6
Annual Meeting Sponsors	1,000.00	-	-	-	-	1,000.00	2.3%	1,450.00	5.3
PKU Camp Registration	640.00	-	-		-	640.00	1.4%	670.00	2.4
SubTotal Event Receipts	3,640.00	-	-	-	-	3,640.00	8.2%	3,920.00	14.3
Other Receipts:									
Bank Interest	379.88	-	-	-	-	379.88	0.9%	590.52	2.2
Honorariums	100.00	-	-		<u> </u>	100.00	0.2%	-	0.0
Subtotal Other Receipts	479.88	-	-	-	-	479.88	1.1%	590.52	2.2
Total Receipts	34,140.33	-	-	8,100.00	2,000.00	44,240.33	100.0%	27,445.58	100.C
Disbursements:									
Annual Meeting 2001	•	-	-	-	-	-	0.0%	4,809.50	17.5
Annual Meeting 2002	1,114.00	-	-	-	-	1,114.00	2.5%	6,754.19	24.6
Annual Meeting 2003	5,002.60	-	-	-	-	5,002.60	11.3%		0.0
Donations & Grants	1,202.73	-	2,000.00	1,650.00	1,142.37	5,995.10	13.6%	12,188.55	44.4
PKU Press	3,939.59	-	-	-	-	3,939.59	8.9%	3,087.12	11.2
Northern Illinois Swim Event	537.68	-	-	-	-	537.68	1.2%	399.74	1.5
New Parent Coffees	7.61	-	-	-	-	7.61	0.0%	50.00	0.2
Cooking Club	25.00	-	-	-	-	25.00	0.1%	-	0.0
Discovery Days	-	-	•	-	-	-	0.0%	350.00	1.3
Cooking School	-	-	-	-	-	-	0.0%	149.89	0.5
Southern Illinois Picnic	-	-	-	-	-	-	0.0%	145.00	0.5
PKU Camp	1,886.06	-	-	-	-	1,886.06	4.3%	2,468.20	9.0
Halloween Party	-	-	-	-	-	-	0.0%	459.00	1.7
Fund Raising	2,698.59	-	-	-	-	2,698.59	6.1%	16.91	0.1
PKU IL Directory	-	-	-			-	0.0%	1,808.00	6.6
New Parent Packets	573.87	-	-	-	-	573.87	1.3%	-	0.0
Administrative/Overhead	1,916.20				-	1,916.20	4.3%	1,905.34	9.6
Total Disbursements	18,903.93	•	2,000.00	1,650.00	1,142.37	23,696.30	53.6%	34,591.44	126.0
Foreign Currency Adjustment							0.0%	(36.16)	-0.1
Transfers Between Funds	(4,000.00)	-	4,000.00	-	-	-	0.0%	(30.10)	0.0
Net Surplus/(Deficit) for the year	11,236.40	-	2,000.00	6,450.00	857.63	20,544.03	46.4%	(7,182.02)	-26.2

PKU Organization of Illinois 2004 Central Illinois

DATE: Sunday, August 1, 2004

TIME: 1:00 am - 3:30 PM

LOCATION: 16036 Inverrary Lane, Bloomington, IL

(This is south of Bloomington)

Directions & Map will be provided upon RSVP

RSVP: If attending – (309) 827-4706 or bakimbrell@aol.com by July 23

HOST: Mary Jane Kimbrell

PROVIDED: PKU and non-PKU main dish, drinks, cups, and tableware.

We will determine menu as we get responses

BRING: - PKU dish labeled with Phe count per serving

and non-PKU dish

- Swimsuit

(If you would like to swim)

Picnic



Special thank you

The Board would like to extend a special Thank You to Lisa & Martin Irgang. Through the efforts of Lisa & Martin, the Organization received thirty-seven separate Donations and Annual Appeal contributions for a total of \$2,366.00during 2003!

The Board would like to extend a special Thank You toBoard Member Jayne Markham. Jayne single handedlyraised \$8,100.00 in research funds from twenty-one separate donors during 2003!

The Board would like to extend a special Thank You our Vice President, Angela Koster for planning and coordinating the Pampered Chef and Tastefully Simple party fundraising events. These two events raised \$518.50 for the Organization in 2003. This is in addition to the Meijer Give Away fundraiser coordinated by Angela in 2002 which raised \$620.16 that year and the Carson's Days event which we expect will raise in excess of \$1,000 in 2004. The Board would like to extend a special Thank You to Steve & Lisa Bennett. Steve & Lisa were responsible for setting up the BIG

WIG golf outing in 2003. This event raised \$1,200 for the Organization. The Board would also like to thank Lori Knaub, Lisa's mom, and Jane Figiel Ford, Kathy Boldt and Ann Lyons of Women In Golf, Inc. (WIG) for including our Organization in this great fundraising event.

The Board would like to again express its appreciation to our top raffle ticket sellers in 2003: Tom & Christine Gallagher, Nelson Herschberger, Tom & Tracy Keegan, Dan & Beth Burke, Steve & Lisa Bennett. Each of these families raised in excess of \$1,000 through raffle ticket sales in 2003.

The Board would like to extend a special Thank You to our President Jim Critchfield for donating the PKUIL logo Baseball Hats to the Organization. We raised \$140 in 2003 with the Baseball Hats and still had 27 left at the end of the year for a \$270 in future fundraising potential.

and acknowledgment

To our PKU Parents, Families, PKU Press Subscribers, and Friends,

I am glad to report that the PKU Organization of Illinois had a stellar fundraising year in 2003. After running deficits in excess of \$7,000 for last two years, the Organization ran a surplus in excess of \$20,000 in 2003. We rose over \$40,000 from our fundraising events in 2003 as compared to less than \$22,000 in 2002. Our development of new fundraising alternatives has been very successful. However, we are still a small organization and need the continuing support of our members. Participation of our members in our fundraising events is crucial to their success. We do not want to grow complacent after a very successful fundraising year. Just a few years of deficits can wipe out the surplus. Support from you has even more importance because it indicates your desire for us to accomplish the goals of our Organization.

Just think of what we're all getting for our donation:

- No subscription fees for the PKU Press,
 3 times per year.
- Continuous/on-going educational events for us to attend so that we are up to date with successful diet management ideas.
- Social events to get parents and kids together to share ideas (new parent coffees, swim parties, snack exchanges, picnics, PKU Family Camp, Discovery Days and Cooking Schools).
- Educational grants for our PKU students. (Two \$1,000 grants per year)
- Active involvement by your board members at the State and National levels with legislation and new developments in PKU treatment (Board Members Gina Annunzio & Angela Koster, along with Fundraising Committee Member Lisa Bennett will attend the MACPAD conference in Detroit, MI in June of 2004).

- Our 24-hour voice mail (630) 415-2219 as well as our web site www.pkuil.org.
- Our Annual Meeting, which has attracted national attention for the quality of the presentations on PKU research and treatment, and which is longest continuous running event of its kind in the United States.

YOUR CONTRIBUTIONS ARE FULLY TAX DEDUCTIBLE #. REMEMBER, YOUR PKU ORGANIZATION IS AN ALL-VOLUNTEER PARENT ORGANIZATION. 100% OF ALL DOLLARS RECEIVED GO TO PROVIDE PROGRAMS AND SERVICES FOR PKU CHILDREN AND THEIR FAMILIES.

Many Thanks for helping to keep our Organization strong,

Joe Annunzio, Treasurer

Cut along line and return the bottom portion with your contribution

REMEMBER OUR CHILDREN AND THE FUTURE OF PKU

	E	nclosed	d is m	y con	tributio	n in	the an	nount	indi	cated belov	₩.*
[]	\$25	[] \$	50 []	\$75	[]_		_Other
	*						0.0			ne Personnel for details.	\or
Nar	ne:										
Add	lres	s:									
City	y: _						St	tate:		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." Send to: PKU Organization of Illinois, P.O. Box 102, Palatine, IL 60078-0102. We will acknowledge your donation.

Dominick's		Benefit Days Slip			
Monday, Tuesday, Wednesday	05/17/04	05/19/04			
re Dominick's Benefit Days For:		Date:			
P.K.U. Organization of III	inois	Ben# 0009	89		
Ven# 092848		Enter Sub7 Amount of			
Operator Number	Store Number	Dollars			
Thank you for Shopping At Dominick's		Customer's Signa	ature		

From the Jewel Shop & Share and Dominick's Benefit Days certificates included in the 2003 Annual Meeting folders:

The Jewel Shop Share event of November 17, 18, 19, 2003:

27 participants spent a total of \$3,404.16 and raised \$170.21 for the Organization. These funds are included in the 2003 financial report.

The Jewel Shop Share event of December 15, 16, 17, 2003:

20 participants spent a total of \$1,918.47 and raised \$95.92 for the Organization. These funds were remitted to the Organization in February of 2004 and are not included in the 2003 financial report.

The Dominick's Benefit Days events of November 17, 18, 19, 2003:

This event raised a total of \$39.41 remitted to the Organization in March of 2004, and therefore is not included in 2003 financial summary.

The Dominick's Benefit Days events of December 8, 9, 10, 2003:

This event raised a total of \$64.19 remitted to the Organization in March of 2004 and therefore, is notincluded in 2003 financial summary.

Shop& Share	SHOP & S	HARE IDENTIFICATI	ON SLIP AMOUNT OF PURCHASE
	0431155 GROUP NUMBER	STORE NUMBER	DOLLARS CENTS
	DUP: PKU Organ	ization of Illinois s: 05/17/2004, 05/18/2004, 05/19	9/2004
SIG	NATURE		<u></u>
PARTICIPA	NTS CAN MAKE PURC	N IT IN TO YOUR CHECKER WHEN YOU SHO HASES AT ANY JEWEL-OSCO ON THE DATE A TO BE DISTRIBUTED IN FRONT OF ANY JEWI	ABOVE.

The PKU Organization of Illinois would like to acknowledge and thank the following contributors for 2003. The Organization raised \$17,020.23 in donations from thirty-nine donors in 2003.

Those who gave \$5,000 or more:

1. Mr. Craig Hudson

Those who gave \$2,000 to \$5,000:

- 2. Mr. & Mrs. Ruben & Jodi Caro
- 3. Automatic Switch Company

Those who gave \$1,000 to \$2,000:

- 4. The Arkin Foundation, Inc.
- 5. United Way/Crusade of Mercy Chicago Area Camp & United Way of Decatur, IL

Those who gave \$500 to \$1,000:

- 6. Mr. & Mrs.Edward & Jennifer Tilly
- 7. T.A. Sporer
- 8. State Farm Companies

Those who gave \$100 to \$500:

- 9. Mr. & Mrs. Lawrence & Sandra Zabinski
- 10. Bank One Corporation
- 11. Ms. Christine Tenerelli
- 12. Mrs. Rosalie Stimac
- 13. Mr. & Mrs. Tom & Tracy Keegan
- 14. UBS Warburg
- 15. Mr. & Mrs. Donald & Jane Gralen
- 16. Mr. & Mrs. Jon & Patricia Stickney
- 17. Mr. & Mrs. Bradley & Dana Eilertsen
- 18. Mr. & Mrs. James & Jeanne Perry
- 19. Mr. & Mrs. Joseph & Susan Vasselli
- 20. Mr. & Mrs. Mark & Melinda Green
- 21. Mr. & Mrs. Lorne & Marylee Burke
- 22. Mr. & Mrs. H.J. & L.K. Vandenbergh
- 23. Mr. Conrad A. Riemer, Trustee
- 24. U.S. Refrigeration Corp.
- 25. Mrs. Anne Gebka
- 26. Ms. Karen Schilling
- 27. Mr. & Mrs. J. Ralph & Patricia Seaton
- 28. Kathleen Knoring Designs
- 29. Mr. & Mrs. Richard & Cathleen Sporer
- 30. Mr. Peter Tschultz
- 31. Mr. & Mrs. ennis & Maureen Slott
- 32. Simply Flowers
- 33. Mr. James X. Maude

Other generous donors:

- 34. Mr. & Mrs. Tim & Ann Singer
- 35. Mrs. Marie Berthold
- 36. Mr. & Mrs. John & Sandy LaPrad
- 37. Midwest Physical Therapy Center
- 38. Mr. & Mrs. Brian & Mary Schultz
- 39. Mrs. Mary David

Great handmade bread recipe

bread

Great



Great handmade bread recipe • Great handmade

Given by Tracy Keegan

(It was originally posted by Sharon on the Listserv – thanks for the recipe, it's the best!)

Low Protein Bread

By Lois and Fred Roods

- 400 grams wheat starch
- 36 grams Metamucil
- 2 tsp methylcellulose
- 2 tbsp sugar
- 2 tsp yeast (Red Star Active Dry works best)
- 1 tsp salt
- 370 grams warm water
- 2 tbsp oil

Mix dry ingredients with fork. Add water/oil mixture and mix well with a spatula to get the edge of the bowl clean. Let rise 30 minutes in a warm oven (preheat to 150 then turn off.) Knead by hand for three minutes on a surface floured with wheat starch. You may need to add more wheat starch gradually as you knead. Place in oiled 10-inch loaf pan. Let rise in warmed oven again. When it gets a little above the rim of the pan, place in a hot oven preheated to 350 degrees. After it is in the oven for 15 minutes, brush the top with melted butter. Let bake 10 more minutes. Place on a wire rack and let cool 15 minutes. Put in a brown paper grocery bag to retain moisture, until completely cooled. Slice into individual slices, wrap in Saran Wrap and place in freezer-proof container in the freezer. Stores well.

ead recipe • Great handmade breac

PKU ORGANIZATION OF ILLINOIS

2004 Calendar of Events

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
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 847-740-5415
March 13	Cooking Program for Teens	Conant High School and Young Adults	9 am – 3 pm	Hazel Vespa 773-880-4486 Schaumburg
Spring	Metabolic Spring Picnic	Eastern MO/Southern IL	Clayton, MO	Laurie Sprietsma 314-454-62
April 25	New Parent Coffee	Barrington Hills	1:00 pm	Jayne Markham 847-382-8955
May 17 - 19 May 17 - 19	Dominick's Benefit Days Jewel Shop-N-Share	Coupons in Spring Press Coupons in Spring Press		Joe Annunzio 847-838-2706
July 17	Cooking School Dianne Sullivan	Still in the planning stages Check the website in May for more details		Gina Annunzio 847-838-2706
Summer	St. Louis Metabolic	Clayton, MO Summer Picnic/Swim		Laurie Sprietsma 314-454-626
August 1	Central Illinois Picnic	Bloomington, IL	1-3:30 pm	Mary Jane Kimbrell 309-827-4
Sept. 18	BIG WIG Golf Outing, Silent Auction	Poplar Creek Golf Course Hoffman Estates, IL	12:00pm	Jane Figiel Ford 708 226-0878 www.wiggolf.com
Sept. 24-26	PKU Family Camp	Lake Bloomington, Hudson		Michele Kowalski 773-745-45 Bruce Kimbrell 309-827-4706
October	Halloween Event	Chicago vicinity		
November 6	Annual Meeting & Cookie Exchange	Medinah Golf Club Medinah	9 am	info@pkuil.org or voicemail
Nov. 15 - 17 Nov. 15 - 17	Jewel Shop-N-Share Dominick's Benefit Days	Coupons for both in Summer Press and Annual Meeting Folders		Joe Annunzio 847-838-2706
Dec. 6 - 8 Dec. 13 - 15	Dominick's Benefit Days Jewel Shop-N-Share	Coupons for both in Summer Press and Annual Meeting Folders		Joe Annunzio 847-838-2706

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.

Survival Cooking for Teens and Young Adults

On Saturday, March 13, 2004 we had our first "Survival Cooking" course for teens and young adults. It was held at Conant High School from 9:00 am to 3:00 pm and 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 lowerpriced 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.

All in all, 36 people attended the survival cooking class. This included Ann Kozek, Barbara Goss and Mary Niewinski from the University of Illinois, and Hazel Vespa, Rhoda Papanastassiou and Danielle Hartung from Children's Memorial Hospital. Also included were Gina Annunzio and Angela Koster from the PKU Organization of Illinois and various teens, young adults, their moms and a grandmother. We were split up and each assigned a kitchen to cook in. Each kitchen had two recipes to make.

"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."

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. Some of the kitchens had some "technical difficulties" with some of the recipes, but there were many recipes that were very tasty. As many have heard, the bread is very good. As it turns out, most of the "technical difficulties" had to do with the amount of water added to the recipe. Due to the differences in climate, sometimes the water amount

needs to be adjusted. Other than that, everyone seemed to have a good time cooking, then eating.

For those interested in trying out the Taste Connections products, visit the website at www.tasteconnections.com.

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.

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.

The PKU Organization of Illinois would like to acknowledge and thank the following participants in the 2003 Annual Appeal. The 2003 Annual Appeal raised \$3,296 from forty-six contributors.

THOSE WHO CONTRIBUTED \$1,000 OR MORE:

1. Blum-Kovler Foundation c/o Brian Burke

THOSE WHO CONTRIBUTED \$100 TO \$500:

- 2. Attorney's Liability Assurance Society c/o Mark Gralen
- 3. Mr. & Mrs. Brad & Angela Koster
- 4. Ms. Loretta Knaub
- 5. Mr. & Mrs. Robert & Karen Michael
- 6. Mr. Ronald Yannone
- 7. Ms. Dora Mazza
- 8. Mr. & Mrs. Melvin & Anna Weintraub
- 9. Mr. & Mrs. Martin & Lisa Irgang
- 10. The John A. Hartford Foundation matching contribution on b/h of Mr. Samuel Gische

OTHER GENEROUS CONTRIBUTORS IN ORDER RECEIVED:

- 11. Mr. & Mrs. Joseph & Karen Sadilek
- 12. Mr. & Mrs. Travis & Kathy Jerke
- 13. Mrs. Marilynne Irgang
- 14. Ms. Patricia O'Connor
- 15. Mr. & Mrs. Phillip & Katie Dermer
- 16. Wolniak Funeral Home
- 17. Ms. Hilda Schaffer
- 18. Mrs. Ann Speranza
- 19. Ms. Alda Descenza
- 20. Ms. Lorraine Nodiff Gurtler
- 21. Mrs. Mary David
- 22. Ms. Gertrude Kahn
- 23. Mr. & Mrs. Irwin Klein
- 24. Ms. Barbara Birnbach25. Ms. Elaine Brownstein
- 26. Mr. & Mrs. Maury & Hedy Siegel
- 27. Ms. Fanny Yannone
- 28. Ms. Ruth Waldman
- 29. Mr. Samuel Gische
- 30. Mr. & Mrs. Walter & Danielle Landzettel
- 31. Ms. Grace Sammarco
- 32. Mr. & Mrs. Keith & Julie Youngmann
- 33. Mr. & Mrs. Morris & Rea Hause
- 34. Ms. Dorothy Shapiro
- 35. Mr. & Mrs. Milton & Miriam Lukaczer
- 36. Ms. Dorothea Brust
- 37. Mr. & Mrs. Kevin & Lori Mendenhall
- 38. Ms. Shirlee & Ellen Schwatzman
- 39. Ms. Renee Neschis
- 40. Ms. Michelle Marzouk
- 41. Mr. & Mrs. Jerome & Marla Zimmerman
- 42. Ms. Ilse Dellheim
- 43. Mrs. Judith Deer Springborn
- 44. Mr. & Mrs. Ted & Mary Dec
- 45. Ms. Nicole Marzouk
- The Angelina Speranza Trust

APPLIED NUTRITION IS PROUD TO INTRODUCE

A New PKU Formula for Teens and Adults

As a person with PKU grows and develops, their formula and medical foods needs may change. For this reason, Applied Nutrition has created PhenylAde,40.

PhenylAde, 40 is a complete, phenylalanine free PKU formula, designed specifically for older people with PKU. PhenylAde,40 is a low fat, reduced calorie formula. One serving mixes easily with only 4-6 oz of cold water, which allows you to meet your prescribed protein need in less liquid volume. As an added bonus, PhenylAde40® is packaged in easy to use, single serving pouches to make drinking formula easy for the active person with PKU.



Looking for a great tasting formula? PhenylAde40® (teens and adults) is available in two great tasting varieties, Citrus and Unflavored. PhenylAde® Drink Mix (ages 1 and up) is available in Chocolate, Vanilla, Strawberry, and Orange Crème. Try some today!

To request a sample of PhenylAde, 40 or PhenylAde® Drink Mix, speak to your dietitian or call 1-800-605-0410. Please visit our website at www.medicalfood.com for a list of our other PhenylAde, products for the dietary treatment of PKU.

Greetings from dietary specialties!

Dietary Specialties has been serving the low protein community for more than 42 years. We offer a wide variety of baking mixes, cookies, pastas, and sauces. At DS we strive to provide our customers with quality products, easy recipes, and top-notch service to make living with low protein diets more manageable. To place orders, call our toll-free telephone number at 1-888-640-2800 or visit us on the Web at www.dietspec.com.

It was right under our noses!

Creating new low protein recipes can be a challenge. But sometimes you can find the ingredients you need right in your own home! We found a delicious recipe for our Almost Hot Chocolate by combining two staple products with a little "kick". Try this new treat today!

ALMOST HOT CHOCOLATE

- 1 rounded cup Vance's Dari-Free
- 2 cups warm water
- 5 tablespoons Dietary Specialties Almost Chocolate Sauce Mix
- 1 cup cold water
- 1 teaspoon Vanilla Extract
- Mini Marshmallows



In a blender or a container with a secure lid, combine Vance's Dari-Free and warm water. Blend or shake vigorously until thoroughly mixed. Note that stirring alone will not be adequate to combine mixture.

In a saucepan, mix Dietary Specialties Almost Chocolate Sauce Mix with cold water. On medium heat, gradually whisk in prepared Vance's Dari-Free. Add vanilla extract to taste. Pour into mugs and top with mini marshmallows. This recipe makes three 8oz servings.

tip

For a warm weather treat, prepare above recipe and pour mixture into ice pop molds for a delicious frozen dessert kids will love!

PER SERVING:

Calories: 110
Protein: >1g
Fat: 0g
Cholesterol: 0mg
Sodium: 125mg
Potassium: 50mg
Phenylalanine: .06mg

This recipe can be prepared in advance and refrigerated for up to one week. Just heat and enjoy! Look for new recipes coming soon!

LAST 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.

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. We will be purging the mailing list, so please respond by June 1st. 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

----- DETACH AND RETURN THE FORM BELOW TO REMAIN ON OUR MAILING LIST

PKU Organization of Illinois Mailing List Verification

lame:			
ddress:			
City:			
State:	ZIP/Postal Code:	Country:	

Good news! Yuca Chips are now available to order through Cambrooke Foods. These new salty snacks, comparable to potato chips are made from cassava, a potato-like tropical vegetable. Forty percent lower in fat than regular potato chips, these snacks have .5g of protein per serving and 10-15 mg of phe – depending on the variety. Yuca Chips are available in Original, Barbecue, Sour Cream 'n Onion, and Garlic 'n Cilantro flavors. They are sold in 7 oz. bags — 12 bags to a case. These crunchy chips are great for school lunches and snacks!

Many new recipes are available on the Cambrooke web site. You will be delighted to see the many new and delicious recipes under the "Recipes and Tips" tab. Try the Chocolate Chip Cookie Tart recipe which features the new Gourmet Chocolate Chip Cookie Dough or the Carrot Cake with Cream Cheese Frosting which features the Baking Mix and Cream Cheese.

Vitaflo metabolic formulas for patients with PKU, MSUD, HCU and TYR are available through Cambrooke Foods. These complete formulas are lower in volume, convenient and better tasting. Samples are available to both clinics and individuals. If you would like samples, contact us to request a Consumer Sample Request form. (Your doctor or dietician will need to sign this to give us permission to send you a sample.)

If you would like to switch over to a Vitaflo

MBROOKE FOOD

product and are receiving payment benefits for formula through your insurance company, please contact Cambrooke Foods to set up direct billing. A doctor's prescription will be needed to order the formula once you have gone through the approval process with your insurance company.

Are you interested in having your child join the lunch line this semester? A reminder that Cambrooke has a 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 Cambrooke for a copy if interested.

Are you interested in the convenience of purchasing Cambrooke products at your favorite health food/grocery store? Our marketing department has worked with other individuals and support groups to help bring Cambrooke products closer to home. If this program is of interest to you or your support group, call us at (866) 456-9776, ext. 1007. 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 (2 Central Street, Framingham, MA 01701), e-mail (orders@cambrookefoods.com) or fax your orders to us at (978) 443-1318.

Attention Illinois families!

It is that time again to update the PKU Organization of Illinois Directory. It has been two years since the last directory was printed and it needs a little work. Please help us by filling out the form below and mailing it back before May 15th. If we do not receive a form from you, we will keep your name in the directory as it appears in the last directory.

Thank you for your time and understanding.

Detach a	and mail to the address below
O I have changes	be added to the 2004 Directory for the 2004 Directory be taken out of the 2004
Last Name:	
First Name(s)	
Of Parents/Guardians	
Or Self:	
Address:	
Phone:	
	help the Organization keep in better touch with families)
Clinic:	
List all the children in y Please mark PKU childr	our household and their birthdates. en with an asterisk (*).
Please mail forms to:	Kristen Leaf PKU Directory 619 West Galeton Drive

619 West Galeton Drive Round Lake, IL 60073

847-740-5415

During 2003, the Organization offered PKUIL logo Lapel Pins, T-Shirts and Baseball Hats as premiums for donations of \$5, \$15 and \$10, respectively.

Following is the result of these fundraisers:

			_			
	3					
200		2.26	_			
			9	74		
	5	2.76				
reak-Even						90
d to Break-E	ven					
		Qty		Cost/Unit	Total	Cost
	_	95		2.26	5	214
		2				
	Ξ	97				
Qty		Frice		Total		
93	9	15.00	9	1,395		
200		7.42		1,484		
		(2.50)	(500)		
	9	4.92	9	904		
			9	411		
			_			
	5	10.00				
mak.From						88
	ven					,
		Gty		CostiUnit	Tate	Dog
	_			7.42	5	794
Original		Sold	Re	maining		
20		- 1	4	a		
20			9	18		
15		1	3.	2		
20			3.	17		
35		4	5	20		
50		1	9	31		
35		-		14		
5			-	1		
200		9	3	107		
Qty		Price		Total		
Qly 14	\$	Price	9	Total 140		
	9		5			
	Gty Oty P3 200 Cask-Even d to Break-E- Original 20 15 20 35 36	Gty Gty Original Conginal Congin	105 \$ 5.00 200 2 26 \$ 2.75 **eak-Even d to Break-Even Qty 93 \$ 15.00 200 \$ 7.42 (2.50 \$ 4.92 \$ 10.00 **eak-Even d to Break-Even Gty **Original Sold 20 1 20 15 1 20 35 1 36 2	105 \$ 5.00 \$ 200 \$ 200 \$ 5 276 \$ 5 276 \$ 5 276 \$ 5 276 \$ 5 2 276 \$ 5 2 276 \$ 5 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	105 \$ 5.00 \$ 525 200 2 26 461	105 \$ 5.00 \$ 525 200 2.26 461 5 74 5 2.76 5 2.76 95 2.26 8 200 97 Gity Price Total 93 \$ 15.00 \$ 1,395 200 \$ 7.42 1,464 (2.50) (500) 5 4.92 \$ 904 5 451 5 10.00 Gity Cost/Unit Total 93 \$ 15.00 \$ 1,395 200 \$ 7.42 1,464 (2.50) (500) 5 4.92 \$ 904 5 451 9 10.00 Gity Cost/Unit Total 107 7.42 \$ 019 Cost/Unit Total 108 Cost/Unit Total 109 Cost/Unit Total 100 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0

Ener-G Foods, Inc.

LOW-PROTEIN PASTA OPTIONS... THESE HAVE RECEIVED RAVE REVIEWS.

Low Protein/Gluten Free

- Large Shells
 - Lasagna
 - Macaroni
 - Small Shells
 - Spaghetti

Our mission at Ener-G Foods as one of the country's foremost producers of foods for diet-restricted individuals is to provide a wide range of ready-made foods and mixes that are wholesome, nutritious, risk free and good tasting. We are constantly responding to the demand for special diets with research, innovative products, and convenience foods.

New formula Low Protein Lemon and Chocolate Sandwich Cookies

We have reformulated our Low Protein Cookies, they were quite hard before and now they are a wonderful crisp texture with scrumptious fillings like Lemon Crème and Chocolate.

> Phe for Lemon Crème Cookies 0.0 mg per 100g (1) serving 36g Phe for Chocolate Crème Cookies 0.57 mg per 100g (1) serving 36g

Low-Protein/ Gluten-Free **CINNAMON COOKIES**

THE GLUTEN FREE. LOW PROTEIN ANSWER TO THE CLASSIC SNICKERDOODLE. THESE CRISP SUGAR COOKIES WITH A SUBTLE CINNAMON FLAVOR HAVE BECOME A FAVORITE. THIS COOKIE AS MANY OF OURS IS USEFUL IN RECIPES CALLING FOR COOKIE CRUSTS. CRUMBLED AND USED AS A CLASIC CHEESECAKE CRUSTS WILL TRULY PLEASE. THE TEXTURE IS LIGHT, CRISP AND SATISFYING.

INTRODUCING!!!

NEW LIGHT BROWN RICE BREAD NEW LIGHT TAPIOCA BREAD NEW LIGHT WHITE RICE BREAD

Our New Light Breads are an amazing development for the gluten - free and low protein bread industry! This bread is light as air with fewer carbohydrates than our regular bread. Perfect for sandwiches, delicious toasted! The reviews have been exciting.

> Phe for Light Brown Rice Bread 135 mg per 100 g (1) slice = 19 gPhe for Light Tapioca Bread 168 mg per 100 g (1) slice = 19 gPhe for Light White Rice Bread 179 mg per 100g (1) slice = 19g

Contact Us:

www.ener-g.com Ener-G Foods. Inc.

P.O. Box 84487, Seattle, WA 98124-5787

Phone: (206) 767-6660 Toll-FREE: 1-800-331-5222 FAX: (206) 764-3398

To place an order or receive a FREE catalog contact us:

www.ener-g.com Ener-G Foods, Inc.

5960 First Avenue South, P.O. Box 84487, Seattle, WA 98124-5787

Toll-FREE: 1-800-331-5222 FAX: (206) 764-3398 Phone: (206) 767-6660

Traditional Vegetable Lasagna

2 This polive oil I clove gerfic, crushed

75g (3 oz) shullots, chapped 50g (2 oz) celery, sliced

75g (3 to) carrot, dicad 65g (2 % oz) cardifforeer, roughly chopped

25g (Jog) zwyshini, diood

400g (14 oz) chapped to to ten dried mixed herby

% vegetshie bouillon cube 50 mt. (2 fl nv) hot water

Salt and pepper to taste

250 ml. (8 fl ov) Lapentia Drink Mix 120 mL (1 fl og) clost vegetable broth 2 Thap + 2 tap constauch

9 cheets Leprofin Laugne

\$" x \$" shallow haking dish

Meat the olive oil in a covered pan and santi the partie, shallots, eclery and curret, over medium heat for 3 minutes, stirring occasionally.

Add the equiliflower, brougeli and equalities and equilifier 3 more minute Stir in the chopped transities, herbs, bouillos cube and water. Biring to a boil, then cover and reduce

hour. Simmer 5 minutes, stirring occasionally.

To proper the sauce: Combine the vegetable both and the Leptelin Drink Mix mixture.

Continue the parastanth with a small amount of orld water (about 2 fl og) and add it to the mixture firing to a boll and add the salt, popper, and notineg to tasks.

Spoon about a quarter of the vegetables over the base of the overspeoof dish. Cover with a layer of

Loprofin Lasagne sheets, breaking them to fit if necessary.

Repeat with one or two more layers, finishing with vegetables, then cover with source

Place the Lassgue is a preheated over for 25 minutes, until the top is golden brown. If desired, sprinkle with chapped fresh before serving.

Phonelstaning, mg Per serving 321

Stuffed Pasta Shells with a Gingerbread **Wine Sauce**

100g (4oz) zaochini 100g (4oz) carrot

125g (5og) onlens or locks 1 Thup-cooking oil

2 Thus ginger, minced

Salt and pepper 5 sheets Loprofie Lavagne

1 Thep cooking oil

1 top salt

Tg (L/2 Thep) butter

Tg (1 Thsp) Laprafia Baking Mis. 225 ml. (8 fl ur) clear vegetable broth

50 mL (2 fl oz) dry white wine 1 Thup ginger, minced

Probable you to 400° F.

- 1. Using a potato pecler page 8 slices, lengthways, from the psechini. Repeat the process with the sarror (do not use the first two slices as they will be narrow.) Reserve the 8 slices of the zuzobini
- Finely chop the onion or leek with the rensi ning zucchiel and carrot
- Heat the oil in a saucepan. Add the chopped vegetables, and cover and cook over medium to low heat for 4-5 minutes, until just softening. Ser consistently during cooking. Next, stir in the ginger
- and searching to taxes. Set aride until negative.

 To propore the posts: Fift a large pan three-quarters with water. Add 1 They off and 1 top sell, and hings to a beil. Individually place 1 Lagrentin Langue shorts in the boiling water and cook for 5 minutes, over medium heat. (Check during cooking to ensure the posts where sho not wisk to each
- 5. Carefully remove each lassages sheet from the pan onto a flat surface. Repeat the cooking process with the remaining lawagne sheers. Meanwhile, blanch the vacchini and carrot saips in hoiling salted water for 2 minutes. Drain and cover with cold water.
- To prepare the sauce: melt the better in a clean stracepan. Stir in the Logrofta Baking Mix, br while wire and ginger. Bring to a boil while stirring.

 7. To assemble the rolls: place a slice of zwednini and curret next to each other on a flat surface, and
- cover with a sheet of Israges. Spread 1.9 of the chopped vegetables over the center of the pasts and carofully roll up to form a tube. Repeat with remaining vegetable strips, pasts and chopped vegetables to give 8 rolls.

 Pour a thin layer of sauce into the balling dish and arrange the stuffed pasta rolls on the top. Pour
- the remaining source over the rolls and cover the dish with aluminum foil. Bake for 25 minutes in preheated over. Serve immediately.

Calories Pretries a Phraylafanian, ma Per serving 4.3

PKU Cooking School with Diane Sullivan!

Lasagna Recipes

From SHS North America

To be held on July 17th, 2004

The Board is still planning this event. We are looking for a facility at which to hold the event. Please check the website in May for further details or call Gina Annunzio at (847)838-2706.

