

PKU Press

A Periodic Newsletter Published By The PKU Organization Of Illinois

Adult PKU Outreach Program – A Clinic Update

Many efforts across the country are being made to engage adults living with PKU with resources to support their PKU care. These efforts are being explored nationally as illustrated by the first International Conference for Adults and Teens with PKU and Allied Metabolic Disorders which took place in Chicago in August 2008. Many families affected by PKU in Illinois were able to attend this event.

In September 2008, the PKU Clinic at Children's Memorial Hospital initiated a formal multifaceted program to reengage adults with PKU. This program was implemented to connect adults who are living with diagnosis of PKU or hyperphenylalaninemia with resources to support their PKU care.

Goals for this program include:

- Outreach to individuals who are no longer actively involved with the clinic to share new information about the treatment of PKU
- Educate individuals about the neurocognitive and psychiatric consequences of elevated blood phenylalanine (PHE) levels in adults
- Link adult patients to comprehensive medical care
- Offer social support through networking opportunities with other adults with PKU.

As a part of this initiative, Children's Memorial Hospital continues to host a series of educational programs focused on the adult PKU population. Our first event was held in February 2009 at Children's Memorial Hospital. Dr. Burton, Director of the PKU Clinic, presented information about the "Neurocognitive and Medical Consequences of Elevated Blood PHE Levels in the Adult." Danielle Hartung, MS, Genetic Counselor,

PKU Clinic Coordinator, discussed the "Genetics of PKU and Maternal PKU." A second educational program was held in conjunction with BioMarin Pharmaceuticals Inc. in May 2009 at the Brookfield Zoo. Rich Dineen, MS, CGC, Genetic Counselor from the PKU Clinic at the University of Illinois in Chicago participated in this program and was able to provide connections with families who are followed at UIC; he presented information on "Points to Consider for the Adult with PKU." Many people have attended these educational programs and have had the ability to meet other individuals living with PKU.



Our next educational event will be held at the Peggy Notebaert Nature Museum in Chicago, IL on Sunday, October 11, 2009 from 2:00 – 4:00 PM. Presentations will cover PKU treatments pertinent to the adult population and include:

- Low phenylalanine diet and newly available medical formulas

- Medications available to treat elevated PHE levels (KUVAN and the investigational PEG-PAL)
- Large Neutral Amino Acids
- Managing PKU treatment as an adult

PKU friendly food, medical formula and low protein food product sampling and on-site blood PHE testing are provided at our educational programs.

Currently at Children's Memorial Hospital we are actively involved in several research studies. These include the Phase II of the PEG-PAL study involving individuals ages 16 – 55 and a PKU Registry for anyone who is currently taking Kuvan or has tried Kuvan in the past. We are also planning a project which will involve routine screening of our PKU patients for attentional deficits and psychiatric symptoms.

If you would like to learn more about the Adult PKU Outreach Program at Children's Memorial Hospital, research

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Who's Who in PKU



Hi I'm Kelly and I'm 15 years old. Living with MSUD can be difficult at times. Sometimes I would like to try foods that I know I can't eat. But what helps me to not try it is thinking about what will happen if I do. I know I will get really sick if I eat food that has a lot of protein and maybe end up in the hospital. Living with MSUD is not impossible. The older you get the harder it gets because you have temptations of food that you would like to try. But on the other hand the older you get the easier it is because you understand it more. You understand why you can't have protein. Even though living with MSUD can be hard at times it's not super hard. I get to eat things that a normal kid would eat for a snack but I get it for a meal. An example of that is french fries. I love french fries and I think any kid with MSUD would love french fries! It doesn't have too much protein. Even though it's not the most healthy choice at least it won't make you MSUD sick.

Adult PKU Outreach Program (continued)

opportunities, or the October 11, 2009 event at the Peggy Notebaert Nature Museum please contact Lauren Leviton, MA, LSW, Education Coordinator at 773-880-6960 or e-mail lleviton@childrensmemorial.org.

Meet one of our adult PKU patients!

Mary Lonski
Oak Lawn, Illinois

Mary is our gold star patient; she wins the award for "patient who has been seen for the most number of years!" The PKU Clinic at Children's Memorial Hospital applauds Mary for staying on top of her PKU treatment; she sends in regular blood PHE levels and schedules PKU follow up appointments. Meeting with the PKU team on a regular basis allows her the opportunity to address any questions or concerns about PKU directly with clinic staff. In addition, staying in regular contact with the PKU clinic team helps Mary to stay informed about available resources in the PKU community.

Mary spends her day working at Garden Center Services in Burbank, Illinois. Mary assists staff members with many administrative tasks including filling in for the receptionist and answering telephone calls. Garden Center Services hosted a variety show in July 2009 and Mary was the "Mistress of Ceremonies." Mary sang a duet with one of her friends.

In Mary's spare time she likes to play games on the computer, talk to her friends, read religious books, and pamper herself (she likes to get her nails done.) Her mom is the number one person in her life and she has many close friends. Mary is also a big fan of figure skater, Scott Hamilton.

Some of Mary's future goals include taking on more work responsibilities and transferring old diaries onto paper. Mary hopes to attend a future educational program for our adult PKU population. She feels it's important for individuals living with PKU to "not let it (PKU) stop you." Mary also urges individuals living with PKU to "try to live to the fullest in life." Great advice Mary!

Living With MSUD

When our daughter Kelly was born the state of Illinois did not have newborn screening for Maple Syrup Urine Disease (MSUD). The pregnancy was full term, no complications. The birth was a normal delivery, no complications. By the end of Kelly's first week of life, she was showing signs of poor appetite, lethargy (sleepy), and irritability. After many calls to the pediatrician because of our concern about dehydration, we brought her in to see her pediatrician. The pediatrician assured us she was fine, just a little sleepy, we should go home and force feed her with a bottle instead of breast feeding. We insisted on a blood test to check for dehydration and later that day we received a call that our baby girl was dehydrated and we needed to bring her in immediately. We decided to bring her to a university hospital instead of the community hospital where she was born. Kelly was nine days old. The hospital staff was very concerned as our daughter now was comatose, showed signs of lack of oxygen, and close to death. A CAT-scan of her brain showed tissue swelling. Our daughter had no brain stem reflexes. The neurologist couldn't tell us if our daughter would survive and if she did what her quality of life would be as she had sustained brain damage. At this point I (mom) was being questioned quite intensely by one of the physicians in the emergency room as to how often I fed Kelly and how much was she intaking. As we watched our baby girl being hooked up to all sorts of machines (heart monitor, IV tubing, oxygen monitor) and a breathing tube put down her airway we half expected the police to show up and arrest mom for negligence. Lucky for us Kelly's aunt worked at the university hospital and vouched for us as parents (Kelly has two older brothers).

After many blood tests and a muscle biopsy on day 16 of life Kelly was still in the ICU we were told Kelly had a muscle cell disease that was presenting very aggressively and she would only survive a few months. The next three hours were spent crying, praying with our priest, trying to make sense of what was happening, contacting family members, and of course spending time with Kelly. Then we were called in by the physicians and told that a blood test that had been sent out twice came back the second time with a different result. The doctors didn't want to give us a name yet for the disease but would be able to confirm it five days later. On Kelly's 21st day of life the doctors told us our daughter had Maple Syrup Urine Disease, but this too is a life threatening and difficult disease to live with, so don't get too excited. I saw this as our miracle!

MSUD is an inherited metabolic disorder that if untreated causes mental retardation, physical disabilities, and/or death. Mom and Dad must both carry the recessive gene in order for a child to have MSUD. Children/Adults with MSUD are missing an enzyme that breaks down the three branched-chain amino acids, Leucine, Isoleucine, and Valine. They must follow a very restricted protein diet for their lifetime. They are given a synthetic formula that provides them with most of their caloric and nutritional needs to grow. There are different types of MSUD, the two most common are classic

– the diet needs to be followed all of the time, and intermittent - the diet is followed when the child is sick). When children/adults with MSUD have high levels they may show signs of headache, dizziness, muscle weakness (may not be able to sit or stand up), slurred speech, vomiting, hallucinations. Without treatment they may develop cerebral edema (tissue swelling of the brain), become comatose and die. Children/Adults are often hospitalized and given IV fluid and nutrition when they become ill (especially stomach flu) as a preventive measure to avoid the more serious complications. When having surgery a MSUD person often is admitted the night before to get the appropriate amount of fluid and calories before surgery. Post-surgical stays are usually longer as the MSUD child/adult usually has elevated levels that need to be controlled before leaving the hospital. If a child can be treated at home they follow a "sick recipe" given to them by their physician.

The next three hours were spent crying, praying with our priest, trying to make sense of what was happening, contacting family members, and of course spending time with Kelly.

Our daughter Kelly has the classic MSUD. When she would become ill with childhood illness, ear infections, colds, stomach flu, etc., she had to go on a "sick recipe" or sometimes be hospitalized. Her "regular recipe" currently consists of a synthetic formula called Maxamum MSUD, Duocal, a little Valine and Isoleucine. Depending on the age of the child the recipe changes as to what is added and of course quantity. Kelly is followed closely by a geneticist and dietitian. Kelly was given a G-tube (gastric feeding tube) at the age of two because she stopped drinking the milk (formula) on her own. The smell and taste was pretty bad (a different formula than the one she currently takes). She stills has the G-tube and prefers to take her milk and any medicines through the G-tube, but can eat and drink normally the food she is allowed. Her diet is similar to a vegetarian only stricter as she is not allowed the soy, peanuts, or high protein foods. Obviously she cannot have dairy, meat, fish, chicken, real chocolate, or peanut butter Her diet is high in carbohydrates and is allowed unlimited sugar, although she is not a big candy person. French fries and potatoes are a staple of her diet. She follows a 3-day window diet with exchanges. One gram of protein equals 3 grams of leucine. She seems to tolerate 15-24 grams of protein on any given day, but cannot intake 24 grams each day in a 3-day window or her levels

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Living With MSUD (continued)

will elevate. Leucine is the amino acid that we need to watch closely. We do finger-stick blood draws at home and mail them into her doctor to check her amino acid levels. When she was a baby she needed weekly blood work and we had to go to a lab to draw blood. Now she tries to send in blood monthly to monitor her levels. We also monitor her at home by using ketone sticks. If her urine shows ketones we know her protein level is elevated and she should not eat any protein and begin her “sick recipe”. Too much leucine in her body is toxic and she can have a metabolic crisis.

Kelly also has cerebral palsy and spinal kyphosis. She ambulates with a walker and wears leg braces (AFOs). We are proud to say that Kelly gets around her HUGE high school with her walker. Although she has an individualized education plan (IEP) she is in regular education classes. She has had multiple orthopedic surgeries and therapies through the years to help her walk and correct her spinal kyphosis. Kelly has joined different clubs through her school years (drama, chorus, art,) and volunteers as a religious education teacher at our church and in the health office at her high school. She likes to hang around with her girlfriends and loves to go to the movies.

Our next MSUD symposium is being held June 24-26, 2010 at the Marriott Lincolnshire, Lincolnshire, Illinois. The MSUD families get together biannually to hear speakers with updates of the latest treatment options, research, and history of MSUD. Please join us next summer. Go to our website www.msudfamilysupportgroup.org for further information.

Our 40th Annual Meeting is November 7th!

The meeting’s theme is “Being Prepared then and Now” – with Susan Waisbren providing our keynote address.

Susan Waisbren directs a research program on the behavioral and developmental aspects of phenylketonuria and other inborn errors of metabolism. Her current research focuses on intergenerational considerations in PKU and the developmental implications of a statewide newborn screening program. She has been a leader in developing national and international networks to address the needs of youngsters and their families with inborn errors of metabolism.

Other highlights include a Newborn Screening Panel, Breakout Sessions, a Cooking Demonstration and our Children’s Program.

Our breakout sessions this year are:

Allied Health Disorders

School Age PKU Topics

Adults and Maternal PKU

If you haven’t registered or need a registration form, please contact us at info@pkuil.org or **312-968-7247**.

2009 PKU Illinois Family Camp

The dates – September 25th – 27th. The place – Hudson, IL. The event – PKU Camp! If you’ve never had a chance to join us at camp – it’s a great family weekend with loads of activities and all kinds of low protein food and treats. Campers stay in cabins, tents or a nearby hotel. There is a main cabin where we eat, play ping-pong, do crafts or just hang out. A pasta lunch is served on Saturday and this year’s dinner was a grill out with Brooklyn Dogs and Camburgers. A big breakfast is served Sunday morning before everyone packs up and heads out. Some annual activities include fishing, swimming, dancing in the rec room, critter cabin, bonfire and games. After the outcome of the games this year, we’ll have to re-name that event “Boys vs. Girls – The Rematch” or maybe “Girls Win All – the Sequel” for next year! Mary Jane Kimbrell was brave enough to give boys and girls, young and old alike a hammer and nails for the craft she organizes each year and as always, everyone pitched in to help and had a great

time! Next years dates are already set – September 24-26th 2010. If you’ve never gone and would like more information – please email us at info@pkuil.org .

Thank you to all our families for coming, helping and making camp such a success!

Egan Family
Davis/Sciarrotta Family
Irgang Family
Gallagher Family
Jerke Family
Wurster Family
Kimbrell Family
Pratscher Family
Kowalski Family
Ruthie and Matt Jager
Shannon Lester



Adity and Mia Wurster go for the top fishing prize



Alex Davis’s favorite part of camp – the PKU treat table!”\



Matthew, Tommy, Alex and Kyle hanging out



All our Happy Campers



Ian supervises the boys at tug of war – they need your help Ian!

2009 PKU Illinois Family Camp



The girls – kicking some butt at tug of war – guess who won...



Colin, Annette, Ariadne, and Quin Egan at lunch



Matt Jager catches one!



Everyone anxiously awaits the critters.



Dee and Matt eating dessert



Lisa Irgang introduces Shanya and Becca to the group



Our fabulous grilling chefs – Vince and John!



This must be when the girls plotted the strategy for their big games win...



Ruthie and Alicia hanging out at the rec hall



Annual after lunch tradition of the younger kids risking head injuries to jump on the pillars!

Fall Low Protein Cooking with Chef Jeff Masse

The PKU Organization's 2nd 2009 cooking class sponsored by Biomarin was Fall Soups – timed just right for the chilly weather coming in slowly but surely! On October 17th at the Oakbrook Marriott our PKU Chefs welcomed Jeff Masse back and followed his lead in creating new, fun and yummy soup recipes from Virginia Schuett's Apples to Zucchini cookbook. Some of the wonderful soups simmering that day were Honey Tomato Bisque, Simply Apple Pumpkin, Mexican Tortilla and Autumn Harvest with Butternut Squash. We also learned some tricks for a new twist on Ants on a Log and Apple Smileys and got to sample low-protein Teriyaki Tortillas. Prizes were raffled off and the Honey Tomato Bisque soup was the most popular – being voted into the cooking demonstration at the annual meeting.

Thank you to Eva and Michelle Brandon for all of their hard work in organizing and coordinating this amazing event.

Special thanks to Jeff Masse, Patty Sibley, Vitafto, Nutricia and Biomarin.



The Brunos and Persheys the crowd favorite Tomato Bisque



Asher learns some knife skills from his dad Cameron



Getting some tips from Chef Jeff



Chris, Becky, Michelle and Christina put the finishing touches on Lemongrass Soup



Stir frying veggies for tortillas

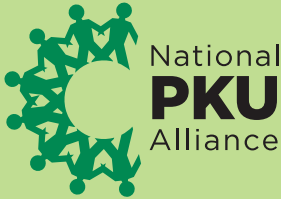


Elena, Chris, Frankie Asher, Michelle and Elizabeth show off their pumpkins



Hard at work chopping veggies for Teriyaki Tortillas

Coming together is what makes things happen...



High HOPES

Inaugural NPKUA Conference • January 15-17, 2010 • Dallas, TX
Embassy Suites Dallas - DFW International Airport South



The Inaugural NPKUA conference promises to be a landmark event

Parents and Grandparents of people with PKU, people with PKU and all who serve, work with or supply the PKU community are invited. Coming together is what makes things happen!

Enjoy meeting distinguished guests

Dr. Richard Koch, Dr. Charles Scriver, Dr. Ray Stevens, Dr. Rani Singh, Dr. Susan Waisbren, Dr. Ira Fox (University of Pittsburgh Medical Center's Transplant & Stem Cell Center), Jeff Lewis (Heinz Philanthropies), Dr. Barbara Burton and Kathryn Moseley, RD will join other leading experts in the fields of PKU research, clinical care, diet, nutrition and advocacy to provide the latest information, answer questions, stimulate discussion and offer hope. Celebrate with us as we honor Dr. Koch and Dr. Scriver with the first PKU Hero Awards for their extraordinary and legendary service to the PKU community.

And...plenty of opportunities for networking, socializing and fun!

From Friday and Saturday night dinners and entertainment to Sunday "take away" lunch, the PKU community will be together! There will even be a little magic on Saturday night—a reminder to dream and imagine.

Conference topics include:

PKU Research, PKU Drug Therapies, Diet and Nutrition, Breakouts by PKU age groups, Clinic updates and developments, PKU advocacy (insurance & politics), Stem cell research, PKU and bone density, PKU and brain function.

To register for the conference, request a partial sponsorship, or to sponsor another member of the PKU community, just fill out the enclosed form or log on to www.npkua.org and click on "Conference". Registration fee is \$99 per family (up to two adults and children). Conference registration check-in begins at 2 p.m., Friday, January 15, and conference concludes 11:30 a.m. Sunday, January 17. Detailed conference schedule available at www.npkua.org. **Registration deadline is Dec. 24, 2009.**

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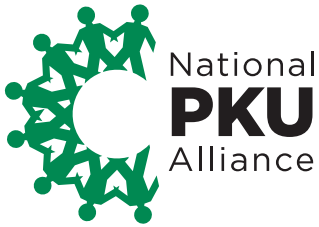


BOOK Your TRIP!



The NPKUA has reserved a block of rooms* at **\$99/night** at the Embassy Suites Dallas – DFW International Airport South. Please call 1-800-934-7972 and reference PKU/NPKUA to get this special rate. You can also reserve rooms on-line at www.esdfwsouth.com. Put in the dates of the conference, hit Go and there will be a section called, "Special Accounts". Click on the one named, "Group/Convention Code" and put in the letters PKU. Hit the continue button which is right below and the discounted rate will apply. Transportation to and from DFW will be provided by the hotel. *All hotel rooms are equipped with refrigerators.
Deadline for discounted room rate is Dec. 24, 2009.

Learn...Share...Get Involved...Be Inspired...*Enjoy!*



Coming together is what makes things happen...

High HOPES

Inaugural NPKUA Conference • January 15-17, 2010 • Dallas, TX
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REGISTRATION

Registration fee*: \$99

* For up to two adults and immediate children. Includes Programs, Lunch & Dinner, Networking Sessions & Awards Ceremony. Child care will not be provided. Registration deadline is Dec. 24, 2009.

I am a:

- Parent of a child with PKU
- Adult with PKU
- Relative
- Friend
- Medical or Educational Professional
- Corporation

Travel costs and overnight accommodations must be arranged separately. **The NPKUA has reserved a block of rooms at \$99 / night at the Embassy Suites Dallas – DFW International Airport South.** Please call 1-800-934-7972 and reference PKU/ NPKUA to get this special rate. You can also reserve rooms on-line at www.esdfwsouth.com. Put in the the dates of the conference, hit "Go" and there will be a section called, "Special Accounts". Click on the one named, "Group/Convention Code" and put in the letters PKU. Hit the "continue" button, which is right below, and the discounted rate will apply. All hotel rooms have refrigerators. Transportation to and from DFW will be provided by the hotel. **Deadline for discounted room rate is Dec. 24, 2009.**

Name: _____

Address: _____

City/State: _____ Zip: _____

Phone: _____ Email: _____

Please list any professional credentials: _____

I/We would like to request a partial sponsorship**

I/We would like to sponsor _____ additional participants

Names of those attending:	Age:	PKU?
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No

Please note any other dietary needs: _____

Check or Money order: Make payable to NPKUA

Credit Card: Visa Mastercard Amount: \$ _____

Card #: _____ Exp. Date: _____

CW Code: _____ (The three-digit number located on the back of the credit card, to the right of the signature.)

Signature Authorization: _____

Credit Card Billing Address: (Same as Above)

City/State: _____ Zip: _____

**Scholarships available through the generosity of Nutricia and The Michaux Family Foundation for PKU

Fax to 715-453-7670 or Mail Registration form and payment to:

**NPKUA
PO Box 501
Tomahawk, WI 54487**



Coming together is what makes things happen...

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SCHOLARSHIP APPLICATION

The National PKU Alliance (NPKUA) has a limited number of partial scholarships available to assist PKU individuals and families in attending our inaugural conference in Dallas. Applications will be considered on a rolling basis. Scholarships will be awarded based on quality of the submitted documents and demonstrated financial need. Please submit the application to Christine Brown, Executive Director at christine.brown@npkua.org, or fax to 715-453-7670. Please contact Christine with questions by email or by calling 715-437-0477.

Name: _____

Address: _____

Phone: _____ **Email:** _____

Relation to PKU: _____

Please use as much space as needed to answer the following questions fully:

1. What do you hope to gain in attending the NPKUA High Hopes Inaugural conference?
2. Do you have a state or regional PKU organization in your area? If so, are you involved in their work or have you attended any of their events?
3. What will you plan to do with the information you receive from the conference?
4. What sort of financial assistance do you need to attend the conference? Please note that the NPKUA, with support from our generous sponsors, will be able to provide partial assistance in travel hotel or registration fees. Any scholarships for travel will be done on a reimbursement basis.

Please sign here to indicate that, if you receive a scholarship to attend the High Hopes Inaugural Conference, you will commit to active participation, which includes attendance at all keynote and breakout sessions, completion of the program evaluation and proof of travel for the meeting. If you are emailing this document, please write your name in place of your signature.

Signature

Date

NPKUA Embarks on Historic National Legislation to Cover Medical Foods for PKU

The National PKU Alliance launched an effort this past summer in Congress to mandate insurance companies to cover the cost of medical foods (i.e. formula) and foods modified to be low in protein. Hundreds of PKU adults and families contacted their Congressional representatives and shared their personal stories of the difficulty of getting their insurer to cover their medical foods. Our efforts are beginning

to pay off. In September, Senator Kerry (MA) announced he would sponsor such legislation, and his office hopes to introduce the Medical Foods Equity Act of 2009 on the Senate floor very soon. The bill would mandate insurance companies (including self-funded plans and federal plans) to cover a minimum amount each year for medical foods (i.e. formula), foods modified to be low in protein, supplemental vita-

mins and amino acids, as well as the equipment needed to administer such foods for inborn errors of metabolism, such as PKU and designate the Secretary's Advisory Council on Heritable Disorders in Newborns and Children (ACHDNC) as the entity responsible for carrying out the legislation. To learn more, and keep updated on our efforts, please visit our web-site at www.npkua.org.

Donor Appreciation

The PKU Organization of IL and our members would like to extend our sincere appreciation and gratitude to all our generous donors this year.

All of our donors will be recognized and listed in our Winter 2010 PKU Press.

We would like to recognize our two largest fundraising events and the tireless efforts of those who organize and host these events and put so much time into their success:

2009 BIG WIG GOLF Outing

Raised over \$9,000 for the PKU Organization of IL
Thank you to Steve and Lisa Bennett and Lori Knaub

2009 Carlos R. Galvez Memorial Golf Outing Raised over \$10,000
for the PKU Organization of IL

Thank you to Dr. Carmencita Galvez and the Halter Family

Board of Directors Update

PKU Organization of IL

The Board of Directors for 2010 includes the following members of our PKU Community:

Joe Annunzio
Steve Bennett
Eva Brandon
Michelle Brandon
Jim Critchfield
Jill Franks
Julie Kelly
Mike McMahon
Heather Ricca
David Ricca
Christina Sciarrotta
Hazel Vespa – Honorary
Barbara Goss – Honorary

We still have two openings for the 2010 year. Serving on the board requires attending board meetings and volunteering on a committee of your choice. Our board is made up of volunteers and the overall time commitment required is only based on what our volunteers can accommodate. Our committees include Annual Meeting Planning, Education, Hospitality, Communications, Fundraising, Allied Disorders and Legislation. Please contact us at info@pkuil.org if you are interested in serving on the board.

LIL'S DIETARY SPECIALTY SHOP—Where Everyone is Special!

In 2003, Marcie Harvey opened the doors of Lil's not sure what to expect. Well, six years later, the store is growing in leaps and bounds. What started as one smaller store front expanded this Fall to more than double the original size. Half of Lil's is 100% gluten free while the other side offers the low protein foods options, as well as some low carb, sugar free foods.

Customers comment daily on how they can't believe all the offerings Lil's has under one roof. Marcie's goal is to bring in more low protein food options from overseas. She wants the low protein world to have easy access to a wide variety of high quality low protein foods. We are currently awaiting the arrival of foods from Spain and Italy. Ordering from Lil's is easy. By offering so many choices without minimum or maximum orders, allow families to obtain their favorites in one-stop shopping which also minimizes shipping and handling costs. If you are ever in the Chicago area, stop in at 2738 W. 111th Street. We love to meet all the families! As of November 1, 2009, Lil's will now be open on Mondays from noon to 7p.

Call 773-239-0355 to place an order or order on-line 24/7 at lilsdietary.com.



PKU ORGANIZATION OF ILLINOIS
Serving The Needs Of Pku And Allied Disorder Families

PKU ORGANIZATION OF ILLINOIS
SERVING THE NEEDS OF PKU AND ALLIED DISORDER FAMILIES

PKU and Allied Disorder Families!

Register with the PKU Organization of Illinois! Registering will add your information to our mailing list and family directory and ensure you receive notifications of all our events and updates and the Press. You can also register online at www.pkuil.org .

Please help us by filling out the form below and mailing it to address at bottom.

----- Detach and mail to the address below -----

Last Name : _____
First Name(s) of Parents/Guardians or Self: _____
Address : _____
County: _____
Phone: _____
Email: _____

** (Providing an email address will help the Organization keep in better touch with families)**

Clinic: _____
PKU or Allied
Disorder: _____

List all the children in your household and their birthdates. Please mark children with PKU or Allied Disorder with an asterisk (*):

Please mail forms to: Christina Sciarrotta, 2853 N. Burling #2N, Chicago, IL 60657

www.pkuil.org

P.O Box 102 Palatine, Illinois 60078-0102 Phone 630-415-2219

Affiliated With Children's Memorial Hospital University Of Illinois Hospital Rush University Medical Center A Not-for-profit Organization Federal I.D. #36-3320115

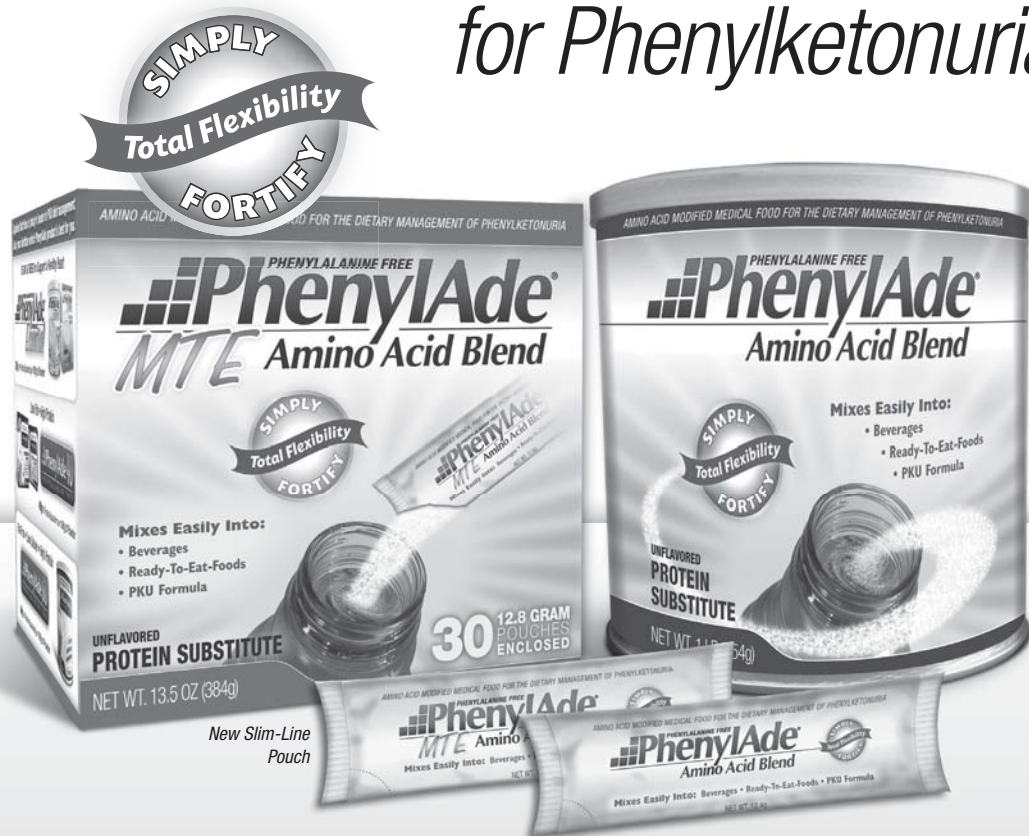
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or visit medicalfood.com to request a sample **TODAY!**