

PKU Press

WINTER 2005-2006

A Periodic Newsletter Published By The PKU Organization Of Illinois

President's Note

Dear Members and Friends,

2005 was a very busy and successful year for the PKU Organization of Illinois. We introduced new programs, events, educational and family support materials, and products. For example,

New Programs:

The Mentoring Program

New Events:

Father-Child Grilling Day

The Pumpkin Patch Day

The Ginger Bread House Building Day

The Creative School Lunches Event

New Educational Support Materials:

PKU Care Index Cards (printing donated by Ideal Service of Lake Zurich, IL)

The DVD Katies Story (donated by SHS)

The DVD Network PKU (donated by Applied Nutrition)

At the 2005 Annual Meeting we were able to make new products available to our members such as the new cookbook Apples to Zucchini by Virginia Schuett and Dorothy Corry and What I can Eat, A Guide for Adults Living with PKU by Dianne Sullivan, Frances Rohr and Melissa Gennaccaro.

We also made some fun fundraising items available such as the PKU awareness wristbands and cupcake holders.

We were able to increase the Andrew Craig Memorial Scholarship program from two to four \$1,000 college scholarships in 2005.

During 2005, the Organization became a distributor of Polder and Ohaus brand gram scales and other related dietary management products, thus allowing the Organization to become the low cost provider of high quality dietary management products.

We also amended our bylaws to officially welcome the folks coping with Allied Disorders into our Organization as full members.

We awarded \$3,500 to Dr. Hoganson of UIC in support of his PKU brain function study.

We are financially sound and have a strong board of directors going into 2006 as we look forward to another bright year.

Best regards,
Joe Annunzio
President

Learning from Experience: A Multi-Age Panel

This year's annual meeting featured a stellar panel of participants that spanned every age and relationship in the PKU life cycle. Sarah Foster (PKU adult, moderator of the PKU adult listserv, organizer of the 2003 Adult and Teen PKU Conference, and Applied Nutrition representative) moderated the panel, which featured introductory remarks from panel participants and then active audience participation in a question-and-answer format. Some of the highlights of each of panelist:

Tom and Cris Gallagher, parents of a PKU toddler, reflected on getting the newborn screening results, coping with the initial diagnosis, and how they manage the toddler years. The Gallaghers admitted that at first, they were devastated by the PKU diagnosis, as they had no idea what PKU was or how it would affect their son's and their family's future. They believe it's important not to "get too far ahead of yourself" and to deal with PKU on a day-to-day basis, instead of thinking ahead to the future, which may seem overwhelming. They also stressed that we should all use the resources available to us: doctors, genetic counselors, dietitians, social workers, and especially, the PKUIL community as a whole. Those with more experience have a way of calming the fears of people new to PKU. Also, PKU is an indelible part of your child, accept them as they are!

Frank and April Salemi, parents of a preschooler, shared thoughts on handling PKU with sitters, day care providers, extended family, and at various social events. The Salemis noted that they do not look at PKU as a disease or disorder; it's simply a challenge that God gave their daughter, just as we are all given different challenges in life. They view themselves as a normal family, as PKU is their "normal". They started their daughter in daycare at 3 months, and put together a binder with information on PKU for the administrators and teachers their daughter comes in contact with. They encourage participation in the diet by their extended family, and even have a PKU potluck dinner once a year, in which they send out ingredients and recipes to family members, who then each bring the PKU-friendly dish to the party. It's something their daughter loves. Like the Gallaghers, the Salemis stressed the importance of using all available resources for support, including attending the annual meeting, going to PKUIL social events, and making use of the PKUIL directory when they have a question that could be answered by someone with more experience. Not only do they derive helpful advice from these events, but they are also left with the feeling that they're not alone in this, that others are facing the same challenges everyday, and are succeeding!

36th Annual Meeting Keynote Address

Alex Dorenbaum, MD

This year's annual meeting keynote speaker was Dr. Alex Dorenbaum, Medical Director of the PKU Program at BioMarin Pharmaceutical, Inc. A leading researcher in PKU treatment and the development of BH4 as a treatment option for PKU, Dr. Dorenbaum's speech was as entertaining as it was enlightening. He took what is a very complicated, scientific subject and made it understandable to everyone. Dr. Dorenbaum gave insight into the genetics and processes that cause PKU and how he and BioMarin are working hard to find treatment options.

Dr. Dorenbaum began by explaining what causes PKU. In a "normal" liver, when phenylalanine is ingested, the liver processes it into tyrosine, which it sends around the body, including to the brain, by using an enzyme called PAH that works in conjunction with a cofactor called BH4. In people with PKU, this enzyme action is either very limited, or inactive, so the normal processing cannot take place. Instead of sending the converted tyrosine to the brain, the liver sends the unprocessed phenylalanine, which accumulates, and causes brain damage.

For the past 40 years, treatment using a metabolic formula combined with a strict, low-protein diet has been very successful, but as we all know, causes some lifestyle restrictions. In addition, there are some people with PKU who do not respond well to the diet. In an effort to make the lives of PKU patients even easier, BioMarin is developing a treatment that uses large doses of BH4 to encourage the PAH enzyme to work better and digest the phenylalanine. All people with PKU have differing levels of PAH enzyme activity. So far, researchers have found that PKU'ers with the best PAH enzyme activity (reflected by off-diet blood phe levels on the lower end of the PKU scale, and/or a less severe genetic mutation for PKU) respond the best. Some patients, when treated with BH4, were able to come off the diet completely, while others were able to liberalize their diet.

So far, clinical trials have shown that BH4 is safe and effective for many individuals with milder forms of PKU. Trials are continuing, and a diet-controlled study in children was set to begin in December 2005 or January 2006. Dr. Barbara Burton of Children's Memorial Hospital is one of the researchers in these trials. Dr. Dorenbaum anticipates that BH4 could be available to PKU patients by the middle of 2007.

For those PKU'ers with more severe mutations (less enzyme activity and not BH4 responsive), researchers have found that another enzyme, called PAL, may be helpful in digesting phenylalanine. PAL is very similar to the PAH enzyme that in normal livers, will digest the phenylalanine. But while PAH is a human enzyme, and is produced in the body, PAL is not. When introduced into the body, the body will stage an immune response and reject the PAL. Researchers are trying to find ways to make PAL tolerable to the human immune system. PAL clinical testing is still in the beginning stages, and is in animal trials right now. Dr. Dorenbaum predicts that a treatment using PAL is still 3 to 5 years away.

As with any new treatment, BH4 will be costly, but Dr. Dorenbaum predicts that the cost will come down as researchers find ways to use BH4 to treat other diseases. In all, the future looks bright for PKU treatment!

Learning from Experience:

A Multi-Age Panel (*cont.*)

Elena Caro, pre-teen with PKU, gave perspective into how she deals with PKU at home, at school, and in social activities. Elena is a competitive cheerleader, a coach to special needs kids, and gets good grades. Elena did a great job speaking in front of the general meeting, and said that to her, PKU is "no big deal". It's part of who she is, which is simply "a normal kid with a special diet."

Julie Kelly, young adult with PKU, gave insight into transitions: moving away for school and work, and changing PKU clinics and treatment programs. Julie recently moved to Chicago from New Mexico for school (working on her second degree!) and said her transition was fairly smooth, since there are far better PKU resources here than in New Mexico. Julie says that for her, the most difficult aspect of having PKU is drinking the formula. She went off diet for while (stuck to eating low-protein foods but didn't drink formula) and noticed the effects immediately: her speech slipped, her concentration wavered, she got migraines, and her hair thinned. At school, she was originally placed in a dorm with no kitchen, so she got a letter from her doctor asking for her to be placed in a dorm with one. Julie related that growing up, she often wouldn't keep track of her phe/formula intake, except when it came time for a blood test, so she would "cram for the exam". Julie recommends to parents that they should do "pop quizzes" every once in a while to keep better tabs on blood levels and diet compliance. In all, Julie says that PKU really doesn't make her feel "different". "Everyone is different in her or his own way, and that's what makes you unique and the person you are."

Jonathan Springborn, adult with PKU and PKUIL Board Member, gave an adult perspective on living with PKU, with thoughts on how his family, friends, and colleagues have shaped his current attitudes. Jonathan takes his formula to work, and has never been asked what it is, since these days, so many people are into health and healthy eating. He has been on diet for life, and says he views PKU as "no big deal," he just eats differently, echoing others in their sentiment that PKU is just a part of what makes him who he is.

Julie Lotterer, PKU adult, sister of Jonathan Springborn, and mother of two, had a different experience growing up with PKU than her brother did. Julie totally went off diet in high school, and says that the effects, especially on her relationship with her family during that period, were very obvious. She was moody, her grades slipped, and she generally didn't feel good. Julie has also had experience with maternal PKU, sticking to an extremely strict diet and formula regimen during her two pregnancies. Her children are completely healthy, happy, and normal in every way. Julie says that she prepared for pregnancy for at least a year each time (far longer than the recommended six months), by making sure her phe levels were in a safe range and that she had good control of her diet. Julie feels one of the keys to success for families dealing with PKU is having the child take over as much of the diet and formula preparation as early as possible so it becomes second nature, and not some mystery that only parents know how to deal with. Also, it gives the child the view that taking care of their PKU is not just something that their parents do, but that they can do, too.

A "PHE-nomenal" Children's Program

By Meghan Reilly

The children's program, which took place during the Annual Meeting, was a great success! Eighteen children between the ages of 6 and 12 participated in the all-day program.

The children spent time getting to know one another through ice breakers and social skills-building games. Next, they actively participated in the vendor fair, answering PKU trivia at each booth while exploring all the products. Many kids returned to the children's room with new products they shared with the group.

After splitting into two teams and competing in a game based on answering questions specifically related to a PKU food pyramid, the kids then explored the myriad of feelings that they have relating to having PKU and maintaining a strict diet. The children were especially engaged during this interactive activity, sharing with one another their successes as well as disappointments and frustrations with PKU. The kids' willingness to share in the group, especially the tough moments they have experienced with school peers, facilitated a very lively and supportive conversation!

A hay ride followed lunch...a mid-ride stop on the golf course for a quick game of freeze tag allowed everyone to work off some energy. Following the hay ride, the kids regrouped with facilitators and with great determination created some very clever "foods with moods." Who knew that simple PKU-friendly foods like bananas, oranges, kiwi, and cauliflower could be so easily morphed into bears, bunnies, dogs, sheep and octopi, all with different expressions conveying their moods?

Finally the kids shared with one another their favorite parts of their day spent together before saying good-bye until next time...most left the room proudly wearing their new PKU t-shirts boldly proclaiming the "phe-nomenal" futures ahead of them!

For those interested, books used during the children's program included:

HOW ARE YOU PEELING? FOODS WITH MOODS.

By Saxton Freymann and Joost Elffers
Scholastic Inc., New York
www.scholastic.com

DOG FOOD

By Saxton Freymann and Joost Elffers
2002

Arthur A. Levine Books
An Imprint of Scholastic Press/New York
Copyright by Play With Your Food, LLC
Published by Scholastic Press, a division of Scholastic Inc.

BABY FOOD

Saxton Freymann and Joost Elffers
2003
Arthur A. Levine Books
An Imprint of Scholastic Press

All Day Cooking Workshop

Co-Sponsored by
Taste Connections
and
CamBrooke Foods

Sunday, March 5, 2006
9:00 - 5:00

University of Illinois
Human Nutrition Department
1919 W. Taylor Street, Chicago

Each participant will take part in 3 hours of "hands on" cooking with Malathy Ramanujam and observe a 1½ hour cooking demonstration by Dianne Sullivan. There will also be a 1½ hour cooking demonstration by a local PKU parent/adult. Lunch is included. Kids and adults of all ages are welcome. Malathy asks that kids are able to follow directions and work independently.

The registration fee is \$15 per person. Sign up soon because space is limited!!

Name(s) please indicate those with PKU:

Phone number:

Please enclose a check made out to the PKU Organization of Illinois and mail the registration to: Lisa Irgang, 1926 Farnham Court, Schaumburg, IL 60194. Any additional questions can be directed to Lisa as well at (847) 882-0298.

Volunteers Needed

The Mentoring Program is up and running! Our new brochures debuted at the Annual Meeting and we have a number of families who have signed up to be Mentors. Many of you have probably served as unofficial "mentors" over the years because we are fortunate to have a great community here in Illinois. We would appreciate any help we can get so we can expand this program. Rest assured, the time commitment is not extraordinary. To sign up, please call Lisa Irgang at (847) 882-0298 or e-mail, lmi799@sbcglobal.net.

CONGRATULATIONS!

The PKU Organization of Illinois recognized the four 2005 Andrew Craig Scholarship winners at the November 12th Annual Meeting. This award was given to qualified and deserving students with PKU that have enrolled in College / University / Vocational Institutions for the fall of 2005. The four winners were selected from applications received between June 1st and August 31st, 2005, and each of them received a check for \$1,000 towards tuition and their pursuit of higher education. This year's winners include:

Benjamin Raffe from Shorewood, IL, who is attending Joliet Junior College

Robert Emerson from Libertyville, IL, who is attending Augustana College

Nicholas Ferguson from Wheaton, IL, who is attending the University of Illinois

Joshua Earnest from Rockford, IL, who is attending Rock Valley College

These four young men serve as an inspiration to PKU children and adults alike, and we wish them all the best in pursuing their dreams and aspirations. Make sure to watch for more information regarding our 2006 Scholarship Campaign next year!

What's Up, Docs?

The doctors from the three Illinois' clinics gave annual meeting attendees an update on what they're working on, and what's new at clinic:

Barbara Burton, MD, Children's Memorial Hospital, Chicago. Dr. Burton and staff are busy with the Phenoptin (BH4) clinical trials. They are preparing for the diet liberalization study, to start in late December or the beginning of January 2006. The study will focus on well-controlled, on-diet patients between the ages of 4-12. The study aims to see how relaxed the diet can get in Phenoptin responders. Dr. Burton announced some staff news as well, welcoming Heather Bausell as a full-time dietitian, announcing the November 21st arrival of another full-time dietitian, Melissa Edwards, the departure of dietitian Rhoda Pappanastassiou, and the happy arrival of genetic counselor Danielle Hartung's new baby boy, Jack! Congratulations!

Paul Wong, MD, Rush-Presbyterian St. Luke's Hospital. Dr. Wong thanked PKUIL for supporting an MPKU patient while insurance coverage was being worked out. The patient is now the mother of two healthy children. He also announced the arrival of a new genetic counselor, Keisha.

George Hoganson, MD, University of Illinois at Chicago Hospital. Dr. Hoganson announced his new, pilot study of PKU patients aged 6 and older. The study will use neuropsychological testing and functional MRIs to study brain activity and processing in people with PKU. Dr. Hoganson thanked PKUIL for donating the \$3,500 seed money to get the project rolling. He also touched on some of the therapies that are now being developed around the world: Dr. Savio Woo recently used a non-viral transport method of gene therapy to "correct" PKU in the PKU mouse. Also, Dr. Hoganson gave some insight on how stem cells might help PKU: if scientists can program stem cells to develop into liver cells and functionally integrate them into the liver of a PKU patient, then the future looks bright for a cure!

Vendors Visit the Annual Meeting

Four vendors gave presentations at this year's annual meeting:

Vitaflo: Monica Cengia and Josh Prizer announced that Vitaflo just launched a new product for PKU'ers ages 8 and older, The PKU Cooler. Designed to look like a foil sports drink with screw top, the Cooler is a fast, easy way of taking formula. It is very low in volume, offering 15 grams of protein in just 3 ounces, and is ready-made, with no preparation required. It keeps at room temperature, in the refrigerator, or in the freezer, and comes in purple and orange flavors. As always, Vitaflo continues to offer a range of metabolic products for PKU, including PKU Gel, for ages 8 and up, and PKUExpress, for ages 8 and up.

Applied Nutrition: Sarah Foster announced a new, low-protein chip, called Tangles. Available in Original, Salt & Vinegar, or BBQ flavors, Tangles are a tasty new option in low protein snacking. Applied Nutrition continues to offer their group of PKU metabolics, including Phenylade, for ages 1 and up, a "complete" formula that comes in vanilla, strawberry, chocolate, and orange cream flavors; Phenylade 40, for ages 8 and older, a lower-volume, lower-calorie option; and Phenylade Amino Acid Blend, which is not a complete formula (PKU'ers would need a vitamin/mineral supplement), but is great to add a protein burst to your existing formula.

SHS North America: Kristine Slaba announced the launch of www.myspecialdiet.com, a new website for PKU'ers packed with information on nutrition, products, recipes, and includes a "diet manager" and an online community. Kristine reminded meeting attendees of the wide range of metabolic products for PKU SHS currently offers, including, XPhe Analog, for ages 0-1; XPhe Maxamaid, for ages 1-8; Maxamum; Periflex, a fat-containing formula for ages 1-12; Phlexy-10, for ages 12+, a versatile metabolic product range that includes bars, capsules, and a drink mix; and LoPhlex, a low volume drink that offers 10 grams of protein per 2.5 oz. Kristine also reviewed SHS's food line, which includes pasta, cookies, cereal, and two baking mixes, Loprofin and Wel-Plan.

Ross Products: Chantal McFarlane brought 30 copies of Jean Koch's celebrated book on Dr. Robert Guthrie, inventor of the Guthrie blood spot test, which is now the standard for newborn screening around the country. Chantal also went over the range of products available to those with PKU, including Phenex-1 (for infants), Phenex-2 (for toddlers through adults), and new Phenex Chews, chewable tablets available in Chocolate Mint and Lemon Lime flavors. Phenex Chews offer 10 grams of protein per 25 tablets, and are a good additional source of protein for those on a low-protein diet. Chantal announced that there are "family kits" available for those using either of the Phenex formulas, which include drink bottles, coolers, and guides. Each family that signs up for a kit will receive a free case of formula. Ross also helps with patient financial assistance through www.helpingpatients.org.

State of the State

Kathryn Seymour visited from the Illinois' Department of Public Health and announced that they now cover the metabolic products for 324 children and adults with a range of disorders tested for in the state's newborn screening program. IDPH currently supplies 51 products from five companies, and is planning on adding new PKU metabolic products soon.

"2005 ANNUAL MEETING RAFFLE" The 2005 raffle raised \$14,795!

What made this year's raffle so successful? It's simple, member participation and involved parents generated these sales. No matter how much any of our members sold, in 2005 everyone seemed to contribute greatly towards this important annual fundraising event.

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

Tom & Christine Gallagher (\$4,000 in ticket sales)

Nelson & Anna Herschberger (\$1,410 in ticket sales)

Tom & Tracy Keegan (\$1,150 in ticket sales)

For their efforts, the Gallagher's, the Herschberger's, and the Keegan's received a \$100, \$50, and \$25 Cambrooke gift certificates respectively. Just think, over 60% of our raffle ticket sales came from these three families and over 70% from the top ten sellers
THANK YOU ALL!

Honorable Mention Raffle Ticket Sales:

Steve and Lisa Bennett \$1,045

Dan and Beth Burke \$ 800

Peter and Nina Neill \$ 480

Cindy Stuart \$ 460

Alison & Tom Squillaciotti \$ 450

Angie Cobb \$ 400

Gerry & Pasty Thompson \$ 300

Del and Carla Halter \$ 220

There were also 25 families that sold \$100 to \$200 worth of tickets.

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

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

• **Medinah Golf Outing** The Critchfield Family

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

• **\$100 American Express Gift Card** The Caro Family

• **\$100 Tiffany's Gift Certificate** The Keegan Family

• **\$100 Mary Kay Gift Basket** The Kiscellus Family

• **\$50 Borders Gift Card** The Burke Family

• **\$50 Lettuce Entertain You Gift Card** The Thompson Family

• **\$50 Lettuce Entertain You Gift Card** The Gallagher Family

• **\$50 Lettuce Entertain You Gift Card** The Gallagher Family

• **Mary Kay Satin Hands Gift Bag** The Wurster Family

• **Homemade Crocheted Afghan** Donna Guarni, Grandmother of Lauren Annunzio

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

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

The individual prize-winners of the 2005 Annual Meeting Raffle are listed separately in this newsletter.

THANK YOU TO EVERYONE WHO PARTICIPATED BY SELLING TICKETS, BUYING TICKETS, AND CONTRIBUTING PRIZES.

Announcing The 2006 PKU Organization of Illinois Board of Directors

The following board members will not be returning in 2006, we thank them for their service:

Angela Koster Vice President in 2005

Kristin Leaf

Greg McDanial

New board members for 2006, we welcome them to the board:

Jim Critchfield Ex-Officio in 2005

Steve & Lisa Bennett (Shared Seat)

Frank & April Salemi (Shared Seat)

Our continuing board members for 2006:

Joe Annunzio

Gina Annunzio

Christina & Jeff Davis (Shared Seat)

Lisa Irgang

Tracy Keegan

Anne Kozek (UIC)

Peter & Nina Neill (Shared Seat)

Jonathan Springborn

Tom & Alison Squillaciotti (Shared Seat)

Hazel Vespa (CMH)

Officers for 2006 will be selected by the board at the January board meeting.

RAFFLE WINNERS AND SELLERS

November 12, 2005

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

- One Week Trip to Puerto Rico The Caro Family: Hotel, PKU IL: Airfare up to \$1,000
WINNER: Cody Reilly SELLER: The Reilly Family
- Medinah Golf Outing The Critchfield Family
WINNER: Tom Neill SELLER: The Neill Family
- Charter Air Service to Champagne Breakfast at Lake Lawn Resort in Lake Geneva for 4 people - Tim Koster from Midwest Avtech (Through Angela and Brad Koster)
WINNER: Ray and Lorraine Kapela SELLER: The Burke family
- \$100 American Express Gift Card The Caro Family
WINNER: Jessie and Chris Volpe SELLER: The Burke Family
- \$100 Tiffany's Gift Certificate The Keegan Family
WINNER: Dale Craig SELLER: Dale Craig
- Mary Kay Gift Basket The Kiscellus Family
WINNER: Stan Kapka SELLER: The Bennett Family
- \$50 Borders Gift Card The Burke Family
WINNER: Pat LeBeau SELLER: The Stuart Family
- \$50 Lettuce Entertain You Gift Card The Thompson Family
WINNER: David Vecchione SELLER: The Gallagher Family
- \$50 Lettuce Entertain You Gift Card The Gallagher Family
WINNER: Chris Park SELLER: The Cobb Family
- \$50 Lettuce Entertain You Gift Card The Gallagher Family
WINNER: Drew Elwood SELLER: The Santillian Family
- Mary Kay Satin Hands Gift Bag The Wurster Family
WINNER: Bern Gallagher SELLER: The Gallagher Family
- Homemade Crocheted Afghan Donna Guarni, Grandmother of Lauren Annunzio
WINNER: James Kowalczyk SELLER: The Kowalczyk Family
- Four Lower Box Tickets for April/May Chicago White Sox
WINNER: Maria DeRush SELLER: The Davis Family
- Two One-Day Admission Tickets Six Flags Great America
WINNER: The Gallagher Family SELLER: The Gallagher Family
- Four VIP Tickets Shedd Aquarium
WINNER: Fred SELLER: The Herschberger Family
- Four Tickets to the Planetarium Adler Planetarium
WINNER: The Kiscellus Family SELLER: The Kiscellus Family
- Clubhouse Admission and Reserved Box Seats for 6 Arlington Park Racecourse
WINNER: Mark Muller SELLER: The Gallagher Family
- Lunch or Tea for Two American Girl Place
WINNER: Clara DeFilippi SELLER: Tricia Cox
- Four Loop Walking Tour Passes Chicago Architecture Foundation
WINNER: Bob Furlong SELLER: The Gallagher Family
- Two Adult and Two Children Tickets Emerald City Theatre Company
WINNER: Mary Miller SELLER: The Herschberger Family
- Four Complimentary Admission Passes The Hancock Observatory
WINNER: Kori Wamboldt SELLER: The Bennett Family
- Two Adult and Two Children Tickets The Notebaert Nature Museum
WINNER: Rebecca Steiner SELLER: The Squillaciotti Family
- Admission for Two People The Second City
WINNER: Dan Haumann SELLER: The Neill Family
- Admission for Two People The Second City, etc.
WINNER: Carol Guinn SELLER: The Stuart Family
- Twenty Swedish Dollars Gift Certificate Ann Sathers Restaurant
WINNER: Marilyn Sieradzki SELLER: The Kruvalis Family
- Autographed Picture of Chicago Cubs Centerfielder Corey Patterson Chicago Cubs
WINNER: K. C. SELLER: The Keegan Family
- Picture of Tyson Chandler and Chicago Bulls Yearbook Chicago Bulls
WINNER: Kathy Yankovich SELLER: The Gallagher Family

"Thank You"

Thank You

I would to thank you for the continued support of our efforts:

SHS - For their many product donations throughout 2005 in support of our events, including the Katie's Story DVD, and to Kristine Slabe for coming to the Annual Meeting and making a presentation.

Applied Nutrition - For their many product donations throughout 2005 in support of our events, including the Network PKU DVD, and to Sarah Foster for moderating the panel discussion and making a presentation.

VitaFlo - For their financial support and to Monica Cengia and Josh Prizer for coming to the Annual Meeting with their new products and for their presentation to our membership.

Ross Products - For their financial support, for the Robert Guthrie Story books, and to Chantel McFarlane for her presentation at the Annual Meeting.

Cambrooke Foods - For their PKU food donation for lunch and snacks and to Dianne Sullivan for the cooking demonstrations at the Annual Meeting.

To **ENER-G Foods, Uncle Henry's Pretzel Bakery** and **PKU Perspectives** for their product donations in support of the Annual Meeting.

Dr. Dorenbaum - For his very informative presentation as well as his enthusiastic participation and support of our Annual Meeting.

Dr. Burton, Dr. Hoganson and **Dr. Wong** for the ongoing and continuing support and participation in our activities.

To our many volunteers, event hosts that keep the Organization running year after year.

Steve & Lisa Bennett for the annual BIG WIG Golf outing

Ruben & Jodi Caro for the new Father Child Grilling

Event
Gerry & Patsy Thompson for the New Parent Meet & Greet

Lisa & Mike Hughes for another great Cooking School

Event
Nina & Peter Neill for the new Creative School Lunches

Mary Jane and Bruce Kimbrell, Michele and Vince Kowalski, Anne and Mike Kozek for their continued hard work on PKU Camp

Alison & Tom Squillaciotti for the new Pumpkin Picking Day

Dee Pratcher for the new Gingerbread House Day

Lisa Irgang for the Northern Illinois Swim Day

Angela Koster for being a great VP and for bringing in the product distribution business

Anne Kozek and Hazel Vespa for all their hard work and continuing support for our Organization

Christina Davis for serving as Secretary of the Organization

Gina Annunzio for serving as Treasurer of the Organization

Tracy Keegan - For her work in coordinating and writing many of the articles for the Press

Jonathan Springborn - For his year long contribution to the board

Jim Critchfield - For once again offering Medinah as a venue for the Annual Meeting

Thanks to all,
Joe Annunzio
President

Hospitality Committee Update Winter 2005

Happy Holidays! We hope that you had a wonderful Thanksgiving celebration and enjoy a peaceful and joyous Christmas and/or Hanukkah.

In preparation for the Christmas holiday season, Dee Pratcher hosted a Gingerbread House social. Since this article was written prior to this December 3rd event, we hope it was a success and will update everyone in our Spring issue. Since our last newsletter, we have hosted a number of very successful events. Nina & Peter Neill hosted by The Creative School Lunch program which was co-sponsored by Vital/Monica Cengia and CamBrooke. Twelve families attended and received information on Illinois law and the school lunch program. Monica's niece and two of her friends were in charge of the activities, which included racing around with a blueberry on a spoon and a banana on the head. And your mom always told you not to play with your food!!

Again, Lisa Hughes did a wonderful job teaching about ten individuals (including two teens) some new recipes. We made burritos, chili, and enchiladas. PKU Perspectives donated the Hot Dog mix, Country Sunrise Scrambled Egg mix, and Frosty mix for us to experiment with. The Egg and Frosty mix were a big hit. Additional Fall events included the BIG WIG Golf outing. It was great to see pictures from this year displayed at the Annual Meeting. Thanks again to the Bennett's for organizing and hosting this wonderful fundraiser/social event. Unfortunately, we had to cancel the Apple Picking outing scheduled for September. Nine families had a wonderful time pumpkin picking at Goebbert's Farm in South Barrington. Each family took home a pumpkin and enjoyed a pony ride. Thank you Alison & Tom Squillaciotti for organizing this event.

Our plans for 2006 are already in the works. As you will see on the enclosed calendar, we already have two cooking events scheduled. Our goal is to organize a minimum of 4-6 cooking events this year. In April, we scheduled the annual swim at Water Works in Schaumburg. This year the event is on a Saturday night in hope that more families will be able to attend.

May has been designated as **PKU Awareness Month**. The PKU Organization of IL is working with MACPAD and other state organizations to raise funds for PKU research. In addition, we have scheduled social events that will appeal to different individuals and families so as many people as possible can participate in at least one event during the month.

We're looking forward to a great 2006 and hope to see you all at our educational, social, and fundraising events.

**IN LOVING MEMORY & JOYFUL CELEBRATION
OF THE LIFE OF
LILLIAN K. WACHTEL**



Lillian Wachtel, former volunteer, at Children's Memorial Hospital and with the PKU Organization of Illinois passed away on October 31, 2005. A role model for young and old, Lillian came every Tuesday to volunteer her skills, time and energy. She began on November 11, 1979 and "retired" on June 19, 2001. The official volunteer log recorded 5,992.48 hours of volunteer service but in reality these hours were even more, because she would add a full Saturday once a year and attend the PKU Organization of Illinois Annual Meeting assisting in any way she could so parents could attend the presentations.

She also volunteered with Elizabeth Han Fung, Ph.D., Hemophilia Service.

Lillian Wachtel's social work experience began during the Depression over 70 years ago upon her graduation from the University of Chicago in Social Services. Her initial employment was with the Chicago Relief Administration as a caseworker and later a supervisor. After several years the Social Security Act was passed and she became a district supervisor for the Division of Old Age Assistance. She put her career on hold to raise three of her own children and two nephews of a deceased sister. In 1979, her daughter, who was by then a social worker herself, showed Lillian a magazine article which sought volunteers with social work backgrounds to assist at Children's Memorial Hospital... The Director of Volunteer Services believed Hazel Vespa and Lillian Wachtel would work effectively with one another and so she became her supervisor and mentor.

Given Lillian's professional experience, she provided social work consultation and interventions in many ways, including working with Dr. Margaret O'Flynn, former Chief of Staff and Medical Director of the PKU Program in an ambulatory medical unit that trained pediatric residents. The team shared information about families, their financial or emotional needs, problems among parents or siblings, or the lack of adequate day care.

Being a Chicagoan and a professional in the field, she knew the city's many resources. In addition to these daily undertakings, Lillian attended staffing meetings at various agencies and annual meetings for agencies and associations with whom she interacted. Due to her knowledge and excellent listening skills, she facilitated parent groups at some of these gatherings.

Her volunteer work and contributions were celebrated informally and formally throughout her 22 years of service. In 1991 she received the *Classic Senior Achievement Award*; in 1995 *Chicagoans of the Year award*; and in 1997 an *Heroes in our Midst* recognition from the National Hemophilia Foundation.

Lillian brought creativity, compassion, consistency and wisdom to all of those with whom she came in contact. We miss her presence but share with her family and friends the wonderful memories of a woman who helped hundreds of children and families and made a difference in their lives and ours.

ANNUAL APPEAL CONTRIBUTION

Cut along line and return the bottom portion with your contribution

REMEMBER OUR CHILDREN AND THE FUTURE OF PKU

[] **YES**, I want to help continue the programs provided by the PKU Organization of Illinois. Enclosed is my contribution in the amount indicated below.*

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

(Your Name)

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(State)

(Zip)

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

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

The Recipe Exchange

By Tracy Keegan

Begin your day with a delicious corn muffin, toasted, with a pat of butter and jam. These muffins have incredible texture, and freeze well. And what better way to welcome a long winter's night than with a dish to warm you from the inside out? This simple potato soup recipe is creamy and satisfying, and you won't believe there's not an ounce of cream in it. Even better, it's a recipe that can feed the whole family from one pot! Top it all off with some cinnamon Snickerdoodles. Stored in a tight container, they retain their chewiness long after baking day.

Keegans' Potato Soup

380 gm onion, quartered
1200 gm potatoes, quartered
20 gm celery leaves from the stalk (a little stalk is ok, too much makes soup stringy)
6 cups water
3 tbsp butter

Combine first four ingredients in a large pot. Bring to a boil, and then reduce heat to medium. Cook until potatoes are soft, about 25 minutes. Ladle broth with vegetables into a blender with butter and puree. (You may have to fill the blender a few times.)

PKU portion: Serve with seasoned salt, if desired.

Family portion: Serve with seasoned salt, if desired, and shredded cheddar and/or crumbled bacon on top.

Total weight per recipe: 2706 gm
Total phe per recipes: 1191
Per gram: .44



Katie's Corn Muffins

1 cup Baking Mix (I use CamBrooke's)
½ cup (54 gm) cake flour
½ cup (64 gm) corn meal
½ tsp. Xanthan gum (available at www.ener-g.com)
2 tsp. Egg Replacer
2 tsp baking powder
½ tsp baking soda
¼ tsp. salt
½ cup sugar
½ cup oil
¾ cup non-dairy creamer and water mixed together in equal parts
2 tbsp. applesauce
1 tbsp. orange juice

Mix all dry ingredients. Make a well, add wet ingredients, and mix until combined. Bake in paper-lined, 12-cup muffin tin at 375 for 15 minutes.

Total yield: 12 muffins
Total phe: 480
Phe per muffin: 40

Katie's Snickerdoodles

1 ½ cups (150 gm) baking mix (I use CamBrooke's)
¾ cup (80gm) cake flour
¾ tsp. Xanthan gum
¼ tsp cream of tartar
1 ½ tsp. Egg Replacer
¼ tsp. baking powder
¼ tsp. baking soda
½ tsp. salt
1 cup sugar
½ cup butter
½ tsp vanilla
2-3 tbsp. non-dairy creamer



Topping: 1 ½ tbsp. sugar + ½ tsp cinnamon

Heat oven to 375. Line cookie sheets with parchment paper. Beat butter and sugar until creamy. Add vanilla and 2 tbsp. creamer. Add dry ingredients. Dough should form a stiff ball...if not, add more creamer. Form 1" balls and chill in freezer for 30 minutes. Roll balls in cinnamon sugar topping and bake for 8 minutes. Cool on pan for 1 minute.

Total yield: 36 cookies
Total phe: 368
Phe per cookie: 11



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Women In
Golf, Inc.

Every year it just gets better !!!!!

It was another glorious day and everyone was just having a ball! The 3rd Annual BIG WIG Golf Outing for PKU occurred on Saturday, September 17th and the sun couldn't have been brighter! Over forty golfers and non golfers alike had some good old fun at Poplar Creek Country Club in Hoffman Estates, IL. With the tremendous help from Jane Ford and Lori Knaub from Women In Golf, Poplar Creek Country Club, and our auctioneer Jim Critchfield, we raised \$3,800.00 for the organization. Lets try for even more in 2006! Remember this is all for fun and for a great organization! We hope to see more of you next year!

Some new changes are in the works for next year's event.... Details later!

MARK YOUR CALENDARS !!! – 4th Annual BIG WIG Golf outing for PKU

When : September 16, 2006

Where: Poplar Creek Country Club, Hoffman Estates, IL



PKU Organization of IL 2006 Calendar of Events

<u>DATE</u>	<u>EVENT</u>	<u>LOCATION</u>	<u>TIME</u>	<u>HOST/CONTACT</u>
March 4th & 5th	Cooking Workshop	University of Illinois	9 am-5 pm	Lisa Irgang (847) 882-0298
March	IDPH Conference	Oak Brook	7 am-5 pm	Joe Annunzio (847) 838-2706
April 29 th	Northern IL Swim	Schaumburg Water Works	6 pm-9 pm	Lisa Irgang (847) 882-0298
MAY PKU AWARENESS MONTH				
May 7	Meet & Greet Coffee	Lake Zurich	1 pm	Patsy Thompson (847) 438-0204
May	Dominick's Benefit Days Jewel Shop-N-Share	Coupons in Spring Press Coupons in Spring Press		Gina Annunzio (847) 838-2706
May 20 th	Skate-a-thon	Rocket Ice, Bolingbrook	5:30 pm-9 pm	Lisa Irgang (847) 882-0298
June	Father/Child Grilling	Naperville	TBD	Ruben Caro (630) 904-0702
June 1	Andrew Craig Scholarship	PKU Org. of IL Website	Beginning	www.pkuil.org
August 31	Andrew Craig Scholarship	PKU Org. of IL Website	DEADLINE	www.pkuil.org
September 17	BIG WIG Golf Outing/ Silent Auction	Poplar Creek Golf Club Hoffman Estates	12 pm	Lisa Bennett (847) 359-0506
September 29th- October 1st	PKU Family Camp	Lake Bloomington in Hudson		Michele Kowalski (773) 745-4541 Bruce Kimbrell (309) 827-4706
November	Dominick's Benefit Days Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Gina Annunzio (847) 838-2706
December	Dominick's Benefit Days Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Gina Annunzio (847) 838-2706

For more information of these events call our voicemail at (630) 415-2219 or via e-mail at info@pkuil.org
Watch for updates in the PKU Press and check out our web site <http://www.pkuil.org>

This is an incomplete calendar. As events are scheduled the calendar will be updated and put on the website.

Book Review

By Tracy Keegan

Apples to Zucchini: A Collection of Low Protein Recipes by Virginia Schuett, MS, RD (Editor, National PKU News) and Dorothy Corry (mom to an 18-year-old with PKU) is what avid cooks in the PKU community have been longing for! The book features 562 fresh, healthy recipes that make use of generally available foods, including heavy emphasis on fruits and vegetables, and very limited use of special, low protein products. Most of the recipes are ones that you'll be able to serve to the whole family, which saves precious time and money. The book is divided into easy-to-use chapters including 12 recipe sections which include:

Salad Celebrations
Soup's On
Bread & Beyond
Vegetables for All Seasons
Rice from East to West
Pasta, Please!
Hot off the Grill
Where's the Beef?
The Adventurous Cook
Company's Coming
Sweet Delights
And Everything Else

There are recipes for comfort foods, gourmet meals, and quick meals, spanning all phe levels, so people with differing tolerances will all find something delicious. The book includes hard-to-find recipes including "Peanutty Butter", "Lo-Pro Sausage," various recipes for chili, caramel apples, French toast, tortillas, and much more. Phenylalanine counts are included for each recipe, along with other, helpful nutritional information. Other chapters include information on diet management, menu ideas, produce information, tips for food storage, resources, and much more!

My family has tried many recipes from this book in the few weeks we've owned it, and all dishes have been fabulous. I highly recommend this cookbook to anyone looking to expand their low-pro cooking repertoire with easy, healthy meals the whole family can enjoy.

Winter Fruit Salad

Courtesy Virginia Schuett & Dorothy Corry,
Apples to Zucchini

"This colorful mix of fruits, available year-round, can be served either as a salad or a light dessert. Use a nice, crisp apple, such as Fuji or Granny Smith."

¼ cup orange juice

¼ tsp. vanilla extract

½ medium apple, unpeeled, cored, and cut into ½ inch pieces (75 gm)

½ cup seedless red grapes, halved (75 gm)

2 medium oranges, peeled and sectioned with membranes removed (230 gm)

2 medium kiwi fruit, peeled, cut in half lengthwise, then cut crosswise into ¼" thick slices (150 gm)

1. Combine orange juice and vanilla in a bowl.
2. Stir in fruit and mix gently. Refrigerate until ready to serve.

Makes 3 cups

½ cup per serving

23 phe per serving

Help us help you

The Fall 2005 issue of the PKU Press included a survey to get a better idea of what the members of our community are looking for in terms of educational and social events. At the suggestion of Dee Pratscher, and with Bruce Kimbrell's hard work, the survey is now available on our website. Please take a few minutes to fill it out. Your feedback is valuable to us. The Calendar of Events for 2006 is still in the works and we can definitely incorporate your ideas. THANKS!!

Get in the Swim!

Join us for our annual PKUIL swim event!

Where: The Water Works
A facility of the Schaumburg Park District
505 N. Springinsguth Road, Schaumburg
847/490-2509

Date: April 29, 2006

Check the calendar at www.pkuil.org for more information as the date approaches!



Brown Bag Lunches

Adapted for those with inborn errors of metabolism by Monica A. Cengia, MSEd, RD, LD, CDE, VitaFlo Dietitian

Here are some quick and easy tips to help you pack a safe and healthy lunch join the “make your own lunch” bunch!!

Make it Safe

Use an insulated lunch bag with a freezer pack to keep cold foods cold. Holding perishable foods at room temperature for longer than two hours allows bacteria to grow and could make the food unsafe to eat.

Freeze well-wrapped sandwiches at the beginning of the week or the night before. Pack them in the morning; they will be thawed by lunch. Good “freezers” are low protein cheese spreads and low protein bread items. Raw vegetables do not freeze as well. Pack those separately and add when ready to eat.

Store your low protein sandwich bread or low protein tortilla wrap in the freezer. Using frozen bread to make your sandwiches in the morning will help keep your sandwich filling colder and fresher until lunch.

Freeze fruit juice jugs, gelatin cups or fruit cups. Wrap in foil and use as an ice pack in the lunch box or bag. They will help keep foods cold and taste refreshing at lunch which means they are more likely to be eaten.

Make it Healthy

Use your list of allowed foods to plan your lunch. Include at least 2 servings of low protein bread or grains and 2 servings of the fruits and vegetables for a balanced meal. Include a treat like **VitaBites** (low protein snack or treat bar). Pack the midday protein drink like **VitaFlo!** Just empty the packet contents into a water bottle or small juice jug, shake 60 seconds & drink it down to be sure that all vital nutrients are included at lunchtime. It's fast, easy, tasty, mixes smooth, does not require refrigeration & is a small amount to drink.

Go for variety. Try low protein bagels, crackers, pita bread, tortillas, quick breads or muffins paired with your favorite low protein cheese spread or slices or veggie fillings. Keep an assortment of fruit cups and alternate like: fruit cocktail, pineapple chunks, pear bits and applesauce cups. Put some whipped topping in a small plastic cup or container to dip fresh or canned fruit. Be creative and lunch will be fun!

Make small sandwich bags of low protein items like: low protein tortilla chips, pita chips, cookies and pretzels at the beginning of the week and store in an airtight container for easy packing all week long.

Pack fruit that is easy to eat. Grapes, strawberries, chunks of melon, apple wedges, and orange sections are all good choices. Cut up fruit to makes it more appealing and a finger food. Keep fruit rollups handy.

Raw vegetables such as baby carrots, celery and bell pepper strips are more likely to be eaten if they are packed with a container of ranch dressing or salsa. Look for individual packages in the produce section.

Sneak vegetables in wherever you can. Try grating a carrot into your sandwich or salad. Add fresh crispy leaves of spinach or romaine lettuce to your sandwich. Pack a low protein pasta salad with vegetables or a thermos of vegetable soup. Carrot or zucchini low protein muffins make a healthy sweet treat.

Creative tasty ideas can be found on websites like www.cambrookefoods.com where low protein items that taste good and are handy for busy families are the job #1!!

Make it Fun for Kids

Involve your child in planning and preparing lunches. Provide some choices and let them decide what to pack that day. Let them help pack the lunch, especially items that can be packed the night before.

Make a “lunchable” using a divided plastic container. Use as lots of colors to fill each section.

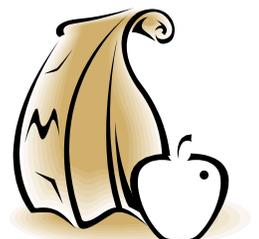
Make a homemade “happy meal” by including a special note, sticker or a mix of gumdrops and jelly beans.

Make It Easy

Keep lunch-making supplies together in one place in the kitchen. Include lunch bags, sandwich bags, juice jugs, small storage containers or cups for dips or whipped topping, plastic silver wear and quick foods like such as individual cans of fruit or **VitaBites**.

Pack your lunches the night before so you can avoid that early morning rush.

Write down lunch menu ideas for one week. After planning 2-3 weeks worth of lunches you can rotate the menus throughout the year. Lunch will always be a welcomed meal and more likely to all be eaten too!!



Tips to Help Kids Eat Their Veggies

Adapted for those with inborn errors of metabolism
by Monica A. Cengia, MSEd, RD, LD, CDE,
VitaFlo Dietitian

Getting children to eat vegetables can be a challenge. Here are a few tips to help your child get 4 to 6 servings of vegetables each day in a fun and positive way!

Make It Fun

Use color, shapes and different sizes
To grab your child's attention and curiosity.



Start with these ideas...

- Create faces, boats, houses & other pictures using low protein bread, crackers, pita bread, or a bagel as the base. Spread with low protein cream cheese (plain, cream cheese, cheese wizard or herb garlic via www.cambrookefoods.com). Decorate with chopped veggies.
- Let them make their own robots, cars, faces, animals, etc. using toothpicks and a variety of veggies. Scoop creations into a vegetable dip or dressing.
- Make "ants on a log". Wash celery sticks, spread low protein cheese down the middle and top with raisins.
- Create a "veggie bowl". Simply hollow out a tomato, fresh peppers, acorn squash, baby pumpkin, or zucchini. Fill with veggies or other foods.
- Dip it! Kids love to "dip" finger foods. Good dip choices for veggies include salsa, ketchup, low protein cheese dip or ranch dressing.

Make It Visible

- Keep ready-to-eat vegetables such as baby carrots, celery sticks, cherry tomatoes, broccoli, radishes, sliced onions or red and green pepper sticks in the snack bin of the refrigerator.

Make It Simple

Preparing vegetables doesn't have to be a chore. Use canned, frozen, or pre-packed vegetables for quick and healthy meals or snacks.



- Add chopped broccoli, carrots, or frozen mixed veggies to cooked low protein rice or pasta.
- Top frozen low protein pizza crust with cooked frozen vegetables like chopped green peppers, spinach, onions, tomato bits and thin carrot strips.

Make It Interactive

- Take an adventure to the grocery store or farmer's market and let your child help you decide which ones they would like to eat. Plan and plant a garden together this summer!
- A child is more likely to eat what they help prepare. Children can help you measure, chop, and mix. Remember to use kitchen safety and always have an adult around to supervise when children are using appliances or knives.
- Laugh, have fun and enjoy your child positive memories in the kitchen with parents and other special people will translate into more positive feelings about eating vegetables!



Chicago Bulls vs. Boston Celtics

United Center, Chicago, IL

When Monica Cengia, VitaFlo Consultant Dietitian, contacted John Paxson in August, 2005 requesting over 100 tickets to a Chicago Bulls game she called it a "dream event" for the IL PKU families. Paxson, a "Dream Team" player himself, promptly responded "I respect what you are trying to do for this special group", and he promptly arranged for 234 free tickets to the October 15, 2005 game at the United Center! Monica called on social worker Hazel Vespa and Peggy Cleveland (Children's Medical Center) and dietitians Anne Kozek and Barbara Goss (U of I Chicago) to help get the ball rolling as they teamed up and sent invitations to IL families. VitaFlo arranged for permission to distribute special low protein snack bags at the game. Hazel states, "We met 2 goals with this event to bring the young adults and teens back together for an event they would enjoy and to include those with other metabolic problems beyond PKU." IL families, clinic staff and their families and VitaFlo managers and dietitians sat together and enjoyed the excitement of the game, cheered for the team and were delighted with the Bulls victory. This event brought many special people together it was definitely a "slam dunk" winner!

Special thanks go to the U of I Chicago - especially Anne Kozek and Barbara Goss and Children's Medical - especially Hazel Vespa and Peggy Cleveland for the many hours spent on invitations and careful handling the 234 tickets (\$11,700 worth of tickets!). The IL PKU organization is very blessed to have 2 health care teams who not only care for our children and adults - but also take the time out to have a good time at events like these! Their support is what made this event possible and so successful!



PKU Organization of Illinois Family Camp 2005

September 23-25, 2005



CONTACT:
Ulrike Reichert
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SHS North America Reformulates Maxamaid® Product Line In Accordance with New Dietary Reference Intakes (DRIs)

Rockville, Md. (August 26, 2005) SHS North America (SHS) of Rockville, Md., USA, a leader in clinical nutrition, has reformulated its Maxamaid® product line in accordance with the new Dietary Reference Intakes (DRIs). The Food and Nutrition Board of the Institute of Medicine, which publishes the DRIs, recently made new recommendations for the dietary intake of vitamin and mineral nutrients. The Maxamaid® product line is indicated for the dietary management of children one to eight years of age with various metabolic disorders.

Features of the new Maxamaid® product line include:

- ? Updating the formulations in accordance with new DRI recommendations
- ? Enhancing the flavor of all Maxamaids
- ? Availability of XPhe Maxamaid® in a new refreshing strawberry flavor

SHS will continue to offer both current and new formulations for a limited time to ease patient adaptation to the new formulation. A two-can sample case of the new formulation will be available to patients, along with a guide to help with transitioning. For questions, contact our Nutritional Specialists at the toll-free SHS Product Information Helpline at 1-800-365-7354 Monday through Friday, 8:30 a.m. 5:00 p.m. EST.

SHS continues to be committed to bringing the metabolic community the best in clinical nutrition products.

About SHS International and SHS North America

A global leader in clinical nutrition, Liverpool-based SHS International specializes in the manufacture, marketing and distribution of medical foods and infant formulas for the dietary management of rare genetic, metabolic, allergic, gastrointestinal and neurological disorders.

SHS North America (SHS) is the North American division of SHS International, a division of Royal Numico. SHS was established in 1983 and has offices in North America on the Human Genome Sciences Campus just outside Washington, D.C. and near Montreal, Quebec, Canada.

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

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