

PKU Press

WINTER 2004-2005

A Periodic Newsletter Published By The PKU Organization Of Illinois

President's note for PKU Press November 2004

HAPPY 35th ANNIVERSARY!!! That's right; this year our organization celebrated its 35th Anniversary. Over the past 35 years, our organization has developed a rich history:

- Founded in 1969 as an informal Parents Group
- We held our first Family Picnic in 1974
- Our first PKUIL Directory was published in 1976
- Our first newsletter was published in 1977
- Our first family camp was in 1981
- Our first Annual Meeting was in 1983
- We formally organized under state law in 1983
- Our first Raffle was held in 1984
- We received our "not-for-profit" status in 1985
- We awarded our first College Scholarship in 1996
- We now have a membership of 278 families

Our future will build on a great past; a past that was managed by committees to provide activities for you, our members. As six new board members join our organization, the six that will have completed their terms (and the board members who will complete their last term in 2005) can take a great deal of pride in what they accomplished in 2004. Here are some of the highlights our committees provided us with this past year:

THE ANNUAL MEETING COMMITTEE - this group selected the facility, arranged for the speakers, planned the workshops and cooking demonstration, and solicited prize donations.

THE COMMUNICATIONS COMMITTEE - this group updated our "directory" information (and raised donations and contributions to pay for a good portion of the cost), maintained and updated our website and voice mail, they saw to it our PKU Press was published three times in 2004, and they redesigned and rewrote our "UNDERSTANDING PKU" brochure (it is awesome).

THE EDUCATION AND RESEARCH COMMITTEE - this group planned the special PKU teen and adult cooking program, planned the annual cooking school, funded the creation and distribution of New Parent Packets through the clinics, sent three PKUIL members to the National Coalition Conference in Michigan, organized and planned the 2004 PKU Camp, and administered our College Scholarship program awarding two \$1,000 scholarships to two PKU young adults (it doesn't get any better than that).

THE FUNDRAISING COMMITTEE - raised over \$6,450 to be used exclusively for PKU research, started the news Carson's Days fundraiser which produced almost \$1,200 for our Organization, raised over \$2,100 from our 2nd annual golf outing hosted by the "WOMEN IN GOLF" (WIG), raised over \$14,000 from our annual raffle in 2003, and over \$20,000 from our raffle this year!, and secured a \$2,000 donation from North Western Mutual Life based on a presentation done by the Organization.

THE HOSPITALITY COMMITTEE - planned our 2004 Swim Party, and hosted one of the most popular events for new PKU families THE NEW PARENT COFFEE.

THE LEGAL COMMITTEE - reviewed our by-laws for changes and updates, served as the Registered Agent for the Organization, and ensured compliance with all Federal and State reporting requirements.

THE LEGISLATIVE COMMITTEE - involved in new born screening legislation and funding issues, organized our member letter writing campaign to the Governor to address the New Born Screening funding issue.

THE NOMINATING COMMITTEE - maintained a full board of directors during the year and actively recruited new board members for 2005 (generating the best response ever in recruiting new board members).

I couldn't be prouder of this team of fine parents. Everyone played a roll this past year. And, everyone contributed to giving our Board a reputation in the PKU Community as the place to turn to by our members and by other PKU families outside Illinois.

What's our future hold? One thing is for sure: the team that will direct our Organization in 2005 will "keep on keep'n on" with what's worked well in the past, and will listen carefully to what you, our membership, will want in the future.

Additionally, starting in 2005, our Organization will be reaching out to expand our scope to include and welcome allied disorders who have inborn errors of metabolism similar to PKU in some of our future activities. These disorders are:

Urea Cycle Disorders	Maple Syrup Urine Disease
Homocystinuria	Tyrosinemia
Glutaric Acidemia Type I	Methylmalonic Acidemia
Propionic Acidemia	Organ Acidemia

There are four key similarities to PKU: all require a medical formula, all require the maintenance of a low protein diet, all are conditions with a missing liver enzyme, and all share social and Psychological challenges just like PKU. Most of these diseases have little or no organized support group like us, but can benefit from the things we share in common. After all, at one time we were small too!

2004 was also a great year for support from our vendors. The following companies have made financial contributions and provided product samples to underwrite some of the costs of our Annual Meeting and throughout the year:

Ross Products Division of Abbott Laboratories
VitaFlo USA, LLC
Applied Nutrition Corporation
Cambrooke Foods
Ener-G Foods
Dietary Specialties
ForMyDiet.com
Taste Connections

The following vendors made contributions to sponsor our updated PKU Organization of Illinois Directory:

SHS North America, Applied Nutrition, Cambrooke Foods, ForMyDiet.com, ENER-G Foods, The Dietary Shoppe, Dietary Specialties, Taste Connections, and Uncle Henry's Pretzel Bakery.

These are all wonderful companies, and we are extremely grateful for all of their support of our Organization going out of your way to support them; they are a tremendous lifeline to all PKU families.

I will be stepping down as your President. 2004 was my last term. The Board members I had the privilege of working with were awesome every one of them. They all had the commitment of making the quality of life a little bit better for our PKU kids, PKU young adults, and PKU parents. The caring for our families always came first and foremost with them, and I know this charge will continue in the future. Thanks for all the support you have given me over the years. I know I can count on everyone to give that same support to our new Board. Have a great holiday season, and a healthy and prosperous 2005.

THANK YOU!

Annual Meeting Keynote Address

By Tracy Keegan

Keynote speaker Dr. John Rolland is a Co-Director and Co-founder of the Chicago Center for Family Health. He is a Clinical Professor of Psychiatry at the University of Chicago Pritzker School of Medicine. Dr. Rolland addressed the many emotional issues that families face in dealing with a chronic medical condition. Dr. Rolland touched upon how sometimes families tend to focus only on the negatives. He suggests taking stock of your family's strengths--not comparing your family to others. Dr. Rolland also stressed the importance of prevention don't wait for problems to pop up. To that end, Rolland suggests a once-yearly "psychological check-up" to go over issues that the family is dealing with, and to work on them while they are still "simmering," not when there's a full-blown crisis. Dr. Rolland also suggests keeping illness in its place PKU is not the defining factor in your family though serious, it is but one part of the family as a whole. Rolland insists that the most psychologically healthy families dealing with chronic conditions are direct and open with each other, include siblings in the PKU dynamic so that they don't feel that their PKU sib is the "special one" (or that they are the "lucky one" and the guilt associated with that), and dispense with traditional gender roles when dealing with PKU (ie. the mom and dad try to take equal roles with the dietary, social, and psychological issues PKU presents.) This will help prevent primary caretaker "burnout". Finally, Rolland suggests that while the "why me" aspect of chronic conditions is common, it is unhealthy. We often try to find something to blame for our problems, and that, Rolland says, is toxic. A positive attitude yields positive results!



Cooking Demonstration at the Annual Meeting with Malathy Ramanujam

The Annual Meeting had something different this year...a cooking demonstration in the afternoon. The presenter was Malathy Ramanujam, who is the founder of Taste Connections. She showed the audience how to prepare quick and easy recipes, not only using her products but others as well. She prepared a lot of other food items the night before the meeting to share with the families. She demonstrated how to use a tortilla maker to make great tortillas. She talked about making breads and pancakes. Malathy has been cooking for a special diet for many years because her son has Homocystinuria. Her goal was to make a mix that would produce bread with the same texture and color as buying off the shelf. Malathy has achieved that goal, plus so much more. Check out her products and recipes at www.tasteconnections.com. The Organization would like to thank Malathy for her wonderful cooking demonstration and Barb Goss for hosting Malathy for the weekend.

Getting on Course with the Children's Program

Congratulations to the PKU Organization of Illinois on your 35th Anniversary! It was a privilege to be a part of this year's special annual meeting.

The children shared in the special programming and events once again this year. To "Get on Course", Mark and Jane from the *Kid Power* organization volunteered their time and talents during the morning sessions. Several arts and crafts projects were visibly enjoyed by the participants. Conversation flowed easily in the room. They got to know one another while creating their masterpieces and telling about them.

Each year, the children visit the vendor fair to discover new likes and, yes, dislikes also. They freely share with others their findings. It was exciting for the children to try all of the specially prepared food items by Malathy Ramanujam. There were many favorites from her table!

The beautiful weather was an added bonus to our day. *Kid Power* put together an outdoor adventure for the children. Two teams were directed on a scavenger hunt. When the clue was given and the envelope &/or item found, a question relating to PKU needed to be answered before the team could venture on to the next station. Each team had five stations to discover.

To work up an appetite for lunch, several outdoor games were played. Each one incorporated a PKU theme. The morning was a delightful combination of education, fun and teamwork!

In the afternoon, we were able to "drive the range" on a Hayride. It was nice to have some of the youth join us and interact with the children. The time together was a great way to show one another the peer support that is an integral part of the meeting.

I am continually impressed each year at the questions that the children pose, the responses that they have to those questions and the support that they give one another. The children truly lead the events of the day. They have a wonderfully innocent way of freely discussing fears, thoughts and joys with one another while having a good time.

Each year, I feel honored to be a part of the Children's Program. It is always a pleasure to observe the mentoring and caring that each child uniquely displays throughout the course of the day. It is through the children that we develop the new challenges and opportunities to explore.

To the Board, staff, participants and their families, I graciously thank you once again this year for your continual support and acknowledgment of the value of the Children's Program.

Susan Ruohonen, M.S.
Licensed Professional Counselor

My Biggest Accomplishment

By: Elena Caro

Can you eat meat? No. Cheese? No. Anything? Of course! Yes that's right. When I was born I was tested for something called PKU (Phenylketonuria). We all were. When the results came in, I seemed to have it. I am not positive what PKU stands for, but I know that it means that my body can't tolerate too much protein. No, I don't get sick and drop dead if I take in too much protein. I might have a slight attitude change and talk back to my parents like any normal kid might do. Or I might just get hyper. That has never happened to me before.

As I got older I started making my own food choices and was getting used to it. It doesn't really bother me anymore because the choices I make are natural now. Once in a while I admit, I may walk by a food I can't eat, like meat or cheese, and want to try it. Other times I can just walk right by it and think to myself, "it looks gross anyway."

Some of the foods I can't eat are: meat, cheese, beans, some kinds of milk, or too many French fries. I always like to look on the bright side though. There are different companies that make replacements for some of the foods I can't eat. The things they make that I like the best are low protein peanut butter, pasta, and macaroni and cheese.

When it comes to the PKU Organization, they know it all! They have many events from overnight camps to cooking schools. I get to meet people from all over the country. It is a lot of fun to get to know the kids who have PKU just like me. At all of the meetings they have HUGE buffets just for "the PKU kids." Knowing we can have everything on the table, we ALWAYS PIG OUT!

It may seem like a big deal to all of those people who LOVE things that I can't eat, but I got over that along time ago. Now that I did that, I still want to be able to cook the things I can't eat when I get older. If I get married, my husband won't want to eat only the things that I can eat.

So having PKU is not so bad. I always take a chance to try new foods. Don't get me wrong; I still feel bad sometimes, but I am so thankful that I don't have A.D.D. or disabilities. Today doctors are working on a "cure" for PKU but it will probably not occur in my life time. I will always know not to be ashamed of PKU.

Vendor Updates from the Annual Meeting

By: Tracy Keegan

A variety of vendors attended the Annual Meeting to display and talk about some of their new offerings. Five vendors gave short presentations during the general meeting:

- **For My Diet. Com** - Ami Assayag gave a visual tour of their newest product, called For My Diet Manager. Available soon, the online service will help make managing a low-protein diet a little easier. It will offer a searchable food list, formula intake tracking, blood level tracking, and more. One of the more unique aspects of the service is that the user can give their nutritionist access to their online records so that the diet can be monitored quickly and easily. According to Assayag, the Diet Manager will be very inexpensive, and with a hoped-for NIH grant, may even be free.

- **Applied Nutrition** - Sarah Foster outlined their range of products available, including: Phenylade, which is a complete formula; Amino Acid Blend, which is low fat and tasteless, but not a "complete formula, so users need to supplement with a multivitamin; Phenylade 40, which comes in individual serving packets ideal for people on the go; Amino Acid Bar, which is a nice addition to a low-protein diet and can be substituted for some of the formula intake required in a day. Foster also announced the availability of a new DVD that profiles four people with PKU: a teenager, a twentysomething, a Maternal PKU adult, and the mother of two undiagnosed children with PKU. Also included with the DVD are some original, low-protein recipes created by Chef Chris, a well-known Denver, CO chef. DVDs are \$6 and are available through Applied Nutrition.

- **SHS** - Cristy Ferguson went over the array of products available including the Phlexy-10 system, which offers users a choice between mixes, bars, capsules, and tablets. One of SHS's newest offerings is Lophlex, which is a low-volume formula powder that users mix with 2.5 oz of water. SHS is also offering holiday candy.

- **Taste Connections** - Malathy Ramanujam, mother of an adult son with Homocystinuria, which like PKU, also requires a low-protein diet, founded her company last year and currently offers two low-protein mixes for baking an array of breads, cookies, bagels, and more. Taste Connections will soon be offering a mix for pancakes and waffles, in addition to packaged cookies. Ramanujam, who has a BS in chemistry, has dedicated herself to improving the products and recipes available for a low-protein diet and will soon be completing her masters in Nutritional Science with an emphasis on the low-protein diet. Ramanujam offered a variety of delicious samples made from her mixes and recipes and gave an entertaining and informative cooking demonstration in the afternoon. TC Bread Mix (for yeast recipes) and TC Multibaking Mix are available through www.tasteconnections.com.

- **VitaFlo** - Mark Riser explained how though his company is new to the US, the company has many years of experience in metabolics in Europe. VitaFlo was the first company to offer single serving packets that mix with water to make a low-volume (3 oz. per serving serving) formula. Riser said people with PKU who use VitaFlo average 12 oz. of formula consumption per day. Though VitaFlo is not yet available through the state of Illinois, Riser says VitaFlo is working on getting through the state qualification process, and is looking for a PKU "test" family to help them with that. VitaFlo is currently available in the US only through CamBrooke foods. www.cambrookefoods.com.

LETTER FROM THE BOARD

Dear Members,

The 35th annual meeting of the PKU Organization of Illinois was a great success. We had a total of 138 attendees, including medical staff, vendors, and speakers, and raised \$20,140 through our annual raffle. The centerpiece of this year's activities was an address by our keynote speaker, Dr. Rolland. Dr. Rolland is the Co-Director and Co-Founder of the Chicago Center of Family Health. He is Clinical Professor of Psychiatry at the University of Chicago Pritzker School of Medicine. At CCFH, he assumes primary training responsibilities in its unique and internationally recognized Families, Illness and Healthcare Program.

During 2004, the Organization sponsored a full calendar of events in addition to our annual meeting. Regular members and board members of the Organization hosted all of these events:

New Parent Coffee John and Jayne Markham

Teen and Adult Cooking Program

The Kowalczyk Family, The Reilly Family,
Rhonda Papanastassiou, and Hazel Vespa

Northern Illinois Swim James and Kristen Leaf

Cooking School Barb Goss

Big Wig Golf Outing Lori Knaub, Jane Figiel

Ford, and Steve and Lisa Bennett

Carson Pirie Scott Community Days

Fundraisers Angela Koster

PKU Family Camp Anne Kozek, Michele

Kowalski, Mary Jane and Bruce Kimbrell,

Ruben and Jodi Caro, and Neil Brown

We hope that you were able to attend as many of these events as possible, if not this year, then perhaps next year.

The board endeavors to keep in contact with the membership via variety of means such as our web page at www.pkuil.org where a great deal of current information on the Organization's activities is kept along with registration forms and other related informational documents and applications. With the web page and our e-mail address at info@pkuil.org, the Organization is in contact with individuals and other organizations from around the world.

We would also like to acknowledge and thank Jim Critchfield. Jim has served on the PKU Board for many years. He has served two terms as President, and has served as the Organization's Vice President and as the Secretary in the past as well. Jim will be serving as an Ex-Officio board member in 2005 and will stay very involved with the Organization. His dedication and hard work is an example to all of us. Thank you Jim for everything you have done to make our Board and Organization what it is today.

Sincerely,

The Officers and Directors
of the PKU Organization of Illinois

ANDREW CRAIG SCHOLARSHIP WINNERS

The board members of the PKU Organization of Illinois are pleased to announce this year's winners of the Andrew Craig scholarships. The winners are Pamela Kowalczyk and Aga Leszkiewicz. Pamela is attending Loras College in Dubuque, Iowa. She is majoring in special education with a minor in Spanish. Aga is attending the University of Illinois at Chicago. Each winner received \$1,000.00 to go towards their college expenses. We would like to congratulate both Pamela and Aga and wish them the best.

Cooking School With Dianne Sullivan

It was a rainy Saturday afternoon, July 17th, at Whole Foods Market in Wheaton. Even with the rain it was a great day for PKU cooking. The PKU Organization of Illinois invited Dianne Sullivan to demonstrate her awesome cooking talents. With the company of Fran Rohr, MS, RD, Children's Memorial Hospital in Boston, Dianne came to Chicago to share her tips and shortcuts to some PKU recipes. She showed the 30+ attendees how to making cooking PKU style quick and easy. Dianne made stir-fry and rice, using Cambrooke Rice. She made coucous and cabbage, using Cambrooke Coucous. There were sweet potato buns, fettuccini alfredo, and for dessert...chocolate chip cookie sandwiches with Cool-Whip in the center. Fran discussed Maternal PKU to the audience and answered questions. The Organization would like to thank Barb Goss for making all the arrangements for the cooking demonstration. She hosted Fran and Dianne during their stay. Thanks to Hazel Vespa for taking Fran and Dianne back to the airport. A BIG thank you to Cambrooke Foods for donating the food that was used by Dianne for the cooking demo. Many thanks to Dianne and Fran for coming to Chicago and sharing their experiences with us.

“2004 ANNUAL MEETING RAFFLE IT KEEPS ON GROWING”

2004 will go down in our history as the best year ever for our largest fundraising event, “**THE RAFFLE**”. The 2004 raffle raised \$20,315! This is a 36% increase over the 2003 total \$14,972.

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 2004 everyone seemed to contribute greatly towards this important annual fundraising event. Seventy-nine families sold raffle tickets this year.

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

Tom & Christine Gallagher (\$5,320 in ticket sales **AWESOME - 2nd year in a row as #1!**)

Dan & Beth Burke (\$2,624 in ticket sales **TERRIFIC JOB!**)

Nelson & Anna Herschberger (\$1,926 in ticket sales - **A Top Seller As Always**)

For their efforts, the Gallagher's, the Burke's, and the Herschberger's received a \$100, \$50, and \$25 American Express gift certificates respectively. Just think, nearly 50% 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:

Tom & Tracy Keegan	\$1,500	Kim Sopko	\$ 352
Del & Carla Halter	\$1,010	Gerry & Patsy Thompson	\$ 330
Steve & Lisa Bennett	\$ 820	Angie Cobb	\$ 304
Tom & Alison Squillacioti	\$ 446	Cynthia Stuart	\$ 300
Brad & Angela Koster	\$ 444		

Martin & Lisa Irgang, Peter & Nina Neill, Ruben & Jodi Caro, and Mike & Lisa Hughes each sold \$200 or more worth of tickets. There were also 18 families that sold \$100 or more.

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)
- **Mill Creek Hotel in Lake Geneva 1 night** (Through Angela and Brad Koster)
- **Chicago Cubs Tickets** The Critchfield Family
- **\$100 American Express Gift Certificate** Jodi and Ruben Caro
- **\$100 US Savings Bond from United Community Bank** (Through Angela Koster, and Angela's Sister, Tracy Skopec)
- **Sapphire and Diamonds Earrings** (The Keegan Family)
- **Sterling Silver Bracelet** (The Keegan Family)
- **Pink and Ivory Hand Crocheted Afghan** (Donna Guarni, Gina Annunzio's mother)
- **Blue Hand Crocheted Afghan** (Donna Guarni, Gina Annunzio's mother)
- **\$50 Pottery Barn Gift Card** (The Burke Family)
- **\$50 Lettuce Entertain You Gift Card** (The Thompson Family)
- **\$25 American Express Gift Certificate** (The Keegan Family)

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

Many of our vendors contributed product samples for everyone to try. A special “thanks” goes to our good friends at Ross Products (represented by Ann Levin, Chantal McFarland, and Mario Pierre-Jerome), Applied Nutrition (represented by Sarah Foster), SHS North American (represented by Cristy Ferguson), ForMyDiet.com (represented by Ami and Laura Assayag), Taste Connections (represented by Malathy Ramanujam), and VitaFlo (represented by Mark Prizer and Cynthia Chavez) for being there to personally answer questions and to allow our families to sample their new products. Also, the Organization would like to thank Cambrooke Foods, Ener-G Foods, and Q's Cookies for donating samples of their products for the Annual Meeting.

The Organization would like to express our gratitude to the following vendors for the monetary donations given in support of the Annual Meeting totaling \$1,850:

➤ Ross Products Division of Abbott Labs	\$1,000
➤ VitaFlo USA, LLC	\$ 500
➤ Applied Nutrition Corporation	\$ 200
➤ Cambrooke Foods	\$ 150

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 2004 Annual Meeting Raffle are listed separately in this newsletter.

THANK YOU TO EVERYONE WHO PARTICIPATED BY SELLING TICKETS, BUYING TICKETS, AND CONTRIBUTING PRIZES YOU MADE THIS YEAR'S RAFFLE THE BEST EVER.

RAFFLE WINNERS AND SELLERS

NOVEMBER 6, 2004

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: Dave Schutt SELLER: The Gallagher Family
- Medinah Golf Outing The Critchfield Family
WINNER: Daren Herschberger SELLER: The Herschberger 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: Carol Sudduth SELLER: The Sudduth Family
- Mill Creek Hotel in Lake Geneva 1 night (Through Angela and Brad Koster)
WINNER: Tess Ramos SELLER: The Halter Family
- Chicago Cubs Tickets The Critchfield Family
WINNER: Ann Bahnsen SELLER: The Jarvis Family
- \$100 American Express Gift Certificate Jodi and Ruben Caro
WINNER: Janet Griffiths SELLER: The Koster Family
- \$100 US Savings Bond from United Community Bank (Through Angela Koster, and Angela's Sister, Tracy Skopec)
WINNER: The Kiscellus Family SELLER: The Kiscellus Family
- Sapphire and Diamonds Earrings (The Keegan Family)
WINNER: Leona Ream SELLER: The Burke Family
- Sterling Silver Bracelet (The Keegan Family)
WINNER: Lyle P SELLER: The Herschberger Family
- \$50 Pottery Barn Gift Card (The Burke Family)
WINNER: The Caro Family SELLER: The Caro Family
- \$50 Lettuce Entertain You Gift Card (The Thompson Family)
WINNER: Fred Etzel SELLER: The Squillacioti Family
- \$25 American Express Gift Certificate (The Keegan Family)
WINNER: Dave Schutt SELLER: The Gallagher Family
- Hand Crocheted Afghan (Pink and Ivory) (Donna Guarni, Gina Annunzio's Mother)
WINNER: The Thompson Family SELLER: The Thompson Family
- Hand Crocheted Afghan (Blue) (Donna Guarni, Gina Annunzio's Mother)
WINNER: James Lapera SELLER: The Halter Family
- VIP Package for 12 people Hawthorne National Race Course
WINNER: Richard Appel SELLER: The Gallagher Family
- Two One-Day Admission Tickets Six Flags Great America
WINNER: G. Borrelli SELLER: The Gallagher Family
- Four Tickets to the Planetarium Adler Planetarium
WINNER: The Edel Family SELLER: The Burke Family
- Admission for Four People The Museum of Science and Industry
WINNER: C. Burke SELLER: The Burke Family
- Four Admission Passes to Zoo and Four Passes to Hamill Family Zoo Brookfield Zoo
WINNER: Peggy Mellenthin SELLER: The Thompson Family
- Family One Year Membership Chicago Botanic Garden
WINNER: Ron Serpe SELLER: The Gallagher Family
- Four Loop Walking Tour Passes Chicago Architecture Foundation
WINNER: Ruben Caro SELLER: The Caro Family
- Four Admission Tickets The Field Museum
WINNER: The Schuman Family SELLER: The Irgang Family
- One Day Family Pass Peggy Notebaert Nature Museum
WINNER: Lyle P SELLER: The Herschberger Family
- Admission for Two People The Second City
WINNER: Bob Mulchrone SELLER: The Gallagher Family
- Admission for Two People The Second City, etc.
WINNER: Dorothy Flynn SELLER: The Flynn Family
- Twenty Swedish Dollars Gift Certificate Ann Sathers Restaurant
WINNER: Dr. Don Mammano SELLER: The Sopko Family
- Autographed Picture of Joe Paterno, Head Football Coach Penn State
WINNER: Lisa Short SELLER: The Gallagher Family

"Thank You"

2004 CAMP

Sept. 24-26
Bloomington, IL





Golfing and Fundraising, Can't get any better than this !!!

It was another glorious day and the ball just kept on rolling! The 2nd Annual BIG WIG Golf Outing for PKU occurred on Saturday, September 18 and the day couldn't have been nicer. Forty golfers and non golfers alike set out to have 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 \$2100.00 for the organization. That is almost double the amount we raised in 2003 ! We hope to see more of you next year!



TM©2003
Women In
Golf, Inc.

MARK YOUR CALENDARS !

3rd Annual BIG WIG Golf outing for PKU

When: September 17, 2005
Where: Poplar Creek Country Club
Hoffman Estates, IL

The New Board Members are Here!

After a delicious lunch and an extremely successful Raffle, it was time to take care of business Board business that is. Each year the Board is required to elect members to fill vacant Board seats. The Board of Directors of the PKU Organization of Illinois consists of 11 voting members in addition to ex officio and honorary members. The Board meets periodically throughout the year to plan all of the events our families enjoy. Once the general membership elects the Board, the Board will then elect four officers (President, Vice President, Treasurer and Secretary) at the first Board meeting. Board members are elected to a two-year term, with a limit of three consecutive terms.

The following Board members have 1 year left on their term and will be returning to service next year:

Tracy Keegan
Angela Koster

The general membership re-elected the following returning Board members:

Gina Annunzio
Joe Annunzio
Kristen Leaf

The general membership elected the following new Board members:

Jeff and Christina Davis
Lisa Irgang
Greg and Christina McDaniel
Peter and Nina Neill
Jonathan Springborn
Tom and Alison Squillacioti

The Honorary and Ex-Officio Board Members for 2005 will be:

Jim Critchfield Ex-Officio
Anne Kozek UIC - Honorary
Hazel Vespa CMH - Honorary

The PKU Organization would like to thank the following members of the 2004 Board for their contributions to the Board as they will not be returning next year:

Kate Chovanec
Bruce Kimbrell
Jim Leaf
Beth Burke
Tom Keegan
Patrice Bedenk

**We appreciate your dedication and hard work on behalf of all of our children and families!
Congratulations to the 2005 Board.**

Cut along line and return the bottom portion with your contribution

REMEMBER OUR CHILDREN AND THE FUTURE OF PKU

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

\$25 \$50 \$75 _____ Other

(Your Name)

(Address)

(City)

(State)

(Zip)

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

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

Tax ID# 36-3320115.

PKU ORGANIZATION OF ILLINOIS 2005 Tentative Calendar of Events

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
March 20	Northern Illinois Swim	Schaumburg Water Works	6 - 8 pm	Lisa Irgang 847-882-0298
May 1	New Parent Coffee	Lake Zurich	1:00 pm	Pat Thompson 847-438-0204
May 16,17,18	Dominick's Benefit Days	Coupons in Spring Press		Joe Annunzio 847-838-2706
May 16,17,18	Jewel Shop-N-Share	Coupons in Spring Press		
July	Cooking School			
Summer	St. Louis Metabolic Summer Picnic/Swim	Clayton, MO		Laurie Sprietsma 314-454-6261
July	Central Illinois Picnic	Bloomington, IL	1:00 pm	Mary Jane Kimbrell 309-827-4706
Sept. 17	BIG WIG Golf Outing, Silent Auction	Popluar Creek Golf Club Hoffman Estates, IL	12:00pm	Lisa Bennet 847-359-0506 www.wiggolf.com
Sept. 23-25	PKU Family Camp	Lake Bloomington, Hudson		Michele Kowalski 773-745-4541 Bruce Kimbrell 309-827-4706
October	Halloween Event	Chicago vicinity		
November	Annual Meeting & Cookie Exchange		9 am	info@pkuil.org or voicemail
Nov. 14,15,16	Jewel Shop-N-Share	Coupons for both in Summer		Joe Annunzio 847-838-2706
Nov. 14,15,16	Dominick's Benefit Days	Press and Annual Meeting Folders		
Dec. 5,6,7	Dominick's Benefit Days	Coupons for both in Summer		Joe Annunzio 847-838-2706
Dec. 12,13,14	Jewel Shop-N-Share	Press and Annual Meeting Folders		

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 on the website.

Jump into SPRING...

NORTHERN ILLINOIS SWIM EVENT

Come Join A Fun Filled Night of Jumping and Swimming

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

Date: March 20, 2005

Time: 6 - 8 pm

Please RSVP to Lisa Irgang at 847-882-0298, by March 13th, space is limited.
 No food or beverages will be available.

A Special Thanks:

The Board would like to thank **Jodi Caro** and **Looking Glass Networks, Inc.** for the use of the Company phone-bridge for our board meeting. The phone bridge allows board members to use the phone to conference into board meetings when they cannot attend in person. This feature has proved to be an invaluable tool to the Board and it is greatly appreciated.

Additional Fund-Raising Acknowledgments:

In addition to the Raffle, the Organization conducts many other fund-raising activities throughout the year. The Board would like to acknowledge and thank the following members of our Organization for their very important and beneficial fund-raising activities in 2004:

Steve & Lisa Bennett - In Addition to \$820 in raffle sales, Steve & Lisa Bennett coordinated and helped plan the 2004 BIG WIG Golf Outing which raised \$2,100. Additionally, it was Steve Bennett who opened the door at Northwestern Mutual Life allowing the Organization to make a presentation to the charitable committee thus yielding a donation of \$2,000. All told, Steve & Lisa Bennett raised \$4,920 for the Organization in 2004.

Martin & Lisa Irgang - In addition to \$282 in raffle sales, Martin & Lisa Irgang raised an additional \$805 through their efforts in promoting the 2004 Annual Appeal. That is a total of \$1,087 for the Organization in 2004 through the efforts of Martin & Lisa Irgang.

Brad & Angela Koster- In addition to \$444 in raffle sales, Angela Koster started the new Carson Pieri Scott Community Days fund-raiser. In February alone this event raised \$1,198 with the second event scheduled for November 2004. That is a total of \$1,642 in 2004 with more to come before the end of the year!

The Board would also like to thank **Angela Koster** for procuring the following donations in support of our new directory:

SHS North America Donated over 400 PKUIL logo 3-ring binders

Applied Nutrition	\$200
Cambrooke Foods	\$150
ENER-G-FOODS, Inc	\$100
The Dietary Shoppe, Inc.	\$100
Taste Connections	\$ 50
Dietary Specialties	\$ 50
Uncle Henry's Pretzel Bakery	\$ 35
Total Directory Support	\$685

The total gross cost to print the directory was \$977, between the financial contributions from our vendors and the 3-ring binders from SHS, the net cost of the new directory was only \$292 thanks to Angela's efforts.

The Board would also like to acknowledge and thank **Gina Annunzio, Angela Koster** and **Kristen Leaf** for their work in updating the directory information.

The Board would also like to acknowledge and thank **Gina Annunzio and Tracy Keegan** for their efforts in rewriting and redesigning the new Understanding PKU pamphlet. The new pamphlets cost \$756. The cost was held down substantially through the work of Gina & Tracy.

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

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The **PKU PRESS** is published three times a year as a service of the PKU Organization of Illinois. In conjunction with the three Illinois clinics, we are working together to provide information, offer support, highlight achievements, and provide services for the benefit of the PKU community. We welcome your input and ideas. Requests for additional copies or correspondence should be addressed to:

PKU PRESS Editor
P.O. Box 102, Palatine, IL 60078-0102
Email: www.pkuil.org

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, Kate Chovanec, James Leaf, Kristen Leaf, Tom Keegan, and Tracy Keegan.

2004 PKU Organization of Illinois Honorary Members

Anne Kozek and Hazel Vespa

2004 PKU Organization of Illinois Ex-Officio

Bruce Kimbrell

