

SUMMER 2002

PKU Press

A Periodic Newsletter Published By The PKU Organization Of Illinois

DISCOVERY DAY 2002:

HARVESTING YOUR PHES

Did you know that certain types of plants grow well together because they need the same things to be healthy? Did you know that beans, peas and other "legumes" actually help fertilize the soil to make other plants healthy by "fixing" nitrogen in their roots? And did you even know that certain herbs and flowers such as marigolds will help defend your vegetable garden from harmful insects because insects think they smell "stinky"?

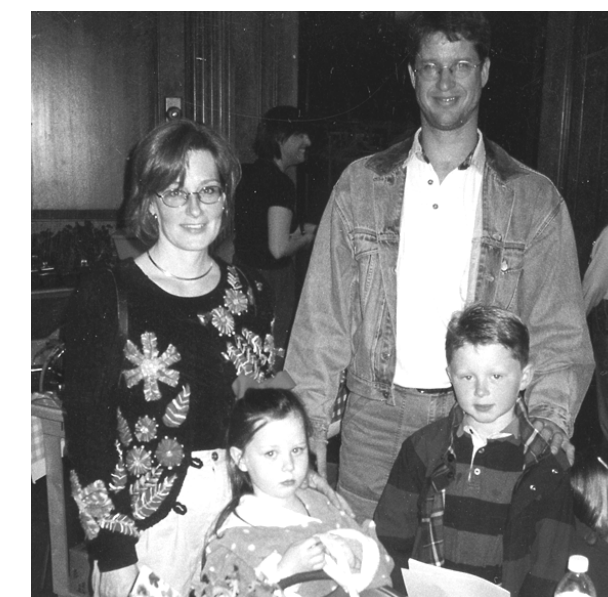
Much to the delight of our PKU kids, the answers to these questions were *discovered* in a hands-on *Garden Play* activity offered by *Garden Play* Specialist, Robbi Hursthouse, HTR at Children's Memorial Hospital, Chicago, Illinois. "When you plant a garden of plants that help each other to be healthy you are planting a *Companion Garden*," Ms. Hursthouse explained. "You don't have to have a lot of space. Your garden can be as simple as a container or flower pot sitting on your porch."

Our young gardeners chose five kinds of plants and/or seeds from an assortment of vegetables and flowers that are compatible because they need the same type of soil, fertilizer and even the same amounts of water and sunshine. A special "soil-free" potting mix provided the appropriate balance of nutrients and our kids provided the TLC.

Through special games and activities relating to gardening, fruits and vegetables, Susan Ruohonen,

Clinician; Danielle Perron, Genetics Counselor; and Rhoda Papanastassiou, Dietician helped children explore the parallels between the particular care needed by their *Companion Gardens* and the special care our kids give themselves and support to each other.

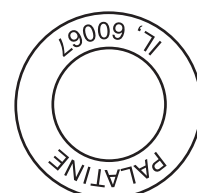
The *Garden Play* program, now in its 18th year, began as a collaborative effort between the Child Life Department of Children's and the Chicago Botanic Garden. *Garden Play* is offered on a weekly basis to the inpatients of Children's as well as special seasonal programming for outpatients.



Susan, Jim, Lauren and Sean Haney

DISCOVERY DAY 2002! DISCOVERY DAY 2002!

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

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

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PKU Medical Products and IDPH

You may have recently received a letter from IDPH stating that they need updated prescriptions on you/your child in order to send out the medical product. If you have been to see your PKU specialist within the past 6 months, you/your child will have an updated prescription at IDPH. So, you do not need to do anything at this time. As long as IDPH has an updated prescription, you/your child will not have an interruption in the delivery of medical product.

If you have not been seen by your PKU specialist within the past 6 months, you need to contact your specialist to schedule clinic visit as soon as possible. Once you/your child has been seen by the PKU team, an updated prescription can be sent on to IDPH and medical product can be ordered/delivered without any questions.

Since there are so many products available now, it is becoming a challenge to know exactly how much of which products to order. By having current prescriptions at IDPH, they can better guesstimate how much product they need to order. That way we can be sure that there is enough product available throughout the year for everyone.

If there are any other questions, please contact your PKU team.

INFORMATION

Cooking Day

**Saturday,
September 14th, 2002
1:00 - 4:30 pm**

651 E. 166th Street
South Holland

**R.S.V.P: Dee Pratscher
708.877.2761 by
Sunday, September 8th, 2002**



*Bring take home containers,
scale, measuring spoons & cups!*

Halloween at the Farm!

**Enjoy a hayride, corn maze, kiddie train,
farm train, haunted barn, & petting zoo.**



Saturday
October 19th • 1:00 - 4:00 pm

R.S.V.P Dee (708) 877-2761



**Chili, Chips, Soda and Cupcakes will be served and a pie Pumpkin
be given to each child to paint at home. Available for purchase
at the farm are carving pumpkins, apple cider, pickles, kettle corn,
cotton candy, pocorn balls, as well non pku foods.**

Cottonwood Farms 17250 S. Weber Road, Lockport IL

www.ourpumpkinfarm.com

1.800.304.3276

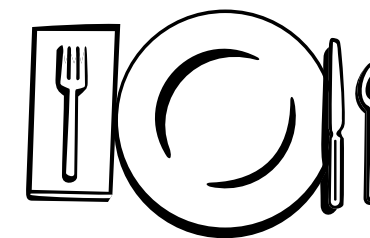


2002 Swimming Party!

This year, instead of trying to work around the weather, we took the picnic indoors. The Northern Illinois Picnic turned into the Northern Illinois Swim Party. We had about 50 adults and children come out to the Schaumburg Water Works. We had a room full of food and pleasant conversation. Plus, everyone had a blast in the water works. There were slides, fountains, waterfalls, and a lot of splashing and good fun. Thanks to Patty Cosgrove who arranged the whole party. Thanks to all the families who participated and made the day fantastic.



The Cooking Day



We cooked up a feast. The group was small therefore we were able to make extra large batches so everyone went home with full recipes of peanut butter, nuggets, breadsticks, tortillas, as well as a few pizza crusts, pretzels and bagels. Cambrooke Foods also donated Cream Cheese and Focaccia Sticks which were sent home for our little PKU test tasters to evaluate. If you have not yet tried these products they do come highly recommended from dieters and chefs alike. The Cream Cheese is excellent in Kim Graylen's Lasagna Roll Up Recipe which was printed in a previous PKU Press.

Two of our chef's met at the cooking day, discovered they live within 20 minutes of each other and have kindled a friendship. They went

shopping together to stock their pantries with PKU needed ingredients and plan to get together regularly to cook. I would say the day was a success.

If you would be interested in participating in a Cooking Day please contact Dee Pratscher 708 877.2761 or dpratch1@ameritech.net The next day will be in Aug. or Sept. the date to be determined by availability of those wishing to attend. Reservations for the kitchen must be made 3-4 weeks in advance so please check your calendars and get in touch with me promptly. The menu will also be determined by those in attendance so relay your wishes and ages of who your cooking for.

NATIONAL COALITION FOR PKU & ALLIED DISORDERS METABOLIC CONFERENCE

WHEN: Thursday October 3, 2002 with full access to World Congress on Disabilities 10/3-10/6

WHERE: Orange County Convention Center, Orlando, FL

We will have our own meetings on 10/3 which are disorder specific and open only to our attendees. Over the course of the next couple of days, our families have the option of attending any one of the 160 scheduled breakout sessions at the World Congress on Disabilities, including the huge exhibition area.

If interested in receiving a registration form or with questions contact coalition4pkquad@aol.com or Phone 877-996-2723.

Attention!

**PKU FAMILIES
AND FRIENDS!!!!!!**

SHOP AT MEIJER STORES AND EARN \$\$\$ FOR
THE PKU ORGANIZATION OF ILLINOIS !!!

\$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$

Collect all original Chicagoland Meijer Store receipts from 5/21/02
through 9/23/02 and mail them by September 25, 2002 to:

*PKU Organization of Illinois
P.O. Box 102
Palatine, IL 60078-0102*

The PKU Organization of Illinois will receive a donation from
Meijer Stores in proportion to the total receipts received from the organization.

**This is a great way to earn money to help fund the many
activities we plan each year for you and your families –
and it's easy! Start collecting receipts from everyone you
know now and send them in as often as you can!**

\$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$ \$

Chicagoland store locations: Algonquin, Aurora, Bolingbrook,
Champaign, Elgin, McHenry and St. Charles.

**THE PKU ORGANIZATION
OF ILLINOIS NEEDS YOUR
FINANCIAL SUPPORT!**

**Remember, your PKU Organization is an All-Volunteer Parent Organization. 100% of all
Dollars Received go to Provide Programs and Services for PKU Children and their Families.**

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)

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

(Address)

(City)

(State)

(Zip)

Thank you for your generosity. All contributions are tax deductible as allowed by
law. Please make checks payable to the **"PKU Organization of Illinois", and
mail to PKU Organization of Illinois, P.O. Box 102, Palatine, IL 60078.
We will acknowledge your donation.**



IDPH NEWS

**The big news is July 1, we are
expanding screening. Also, we will
be moving June 20th. Our phone
number is the same, but our
mailing address will be:**

Ridgely Building
500 E. Monroe St.
Springfield, IL 62701
Fax number: (217) 557-5396

**Andrew Craig
Scholarship Application**

This year the PKU organization will again award two
\$1,000 scholarships to two qualifying individuals with
PKU. The individuals with PKU have to be enrolled in an
accredited college, university, or vocational school in the fall
of 2003 and do not need to be newly enrolled. A student
may win more than once, but not in consecutive years.

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

Expression of Phenylalanine-free Zein Protein in Transgenic Soybean as a Value-added Trait for PKU Patients

information provided by Harold Trick & Bryan E. Hainline

Trick, Harold N.; Muthukrishnan, Subbaratnam. Kansas State University, Department of Plant Pathology, 4024 Throckmorton Plant Science Center, Manhattan, KS 66506; USDA/NRI \$227,280; 3 years

Longterm objectives and specific goals. The long-term objective of our research project is to provide phenylketonuria (PKU) patients a more nutritious, versatile, and palatable source of dietary protein free of phenylalanine as well as providing an alternative market for soybean through the production of a value-added (nutraceutical) trait. Recombinant phenylalanine (PHE)-free gamma zein protein produced in soybean, whose nutritional content is stable to heating/baking, is one possible solution. These objectives will be attained in three phases; Phase I: the production and molecular characterization of transgenic soybean plants expressing the PHE-free gamma zein gene; Phase II: seed increase of selected transgenic lines, the large scale extraction of the PHE-free gamma zein protein and nutritional and digestibility studies of the PHE-free gamma zein protein; and Phase III: commercialization. The proposed work is the first phase of this project. In our current proposal we will: (1) complete the construction of expression vectors for soybean seed-specific expression of a recombinant phenylalanine-free gamma zein protein; (2) perform particle bombardment of soybean embryogenic cultures with the zein gene vector constructs and isolate fertile plants, and (3) perform genetic and protein analyses on transgenic plants.

Side note: This grant is a continuing collabo-

orative effort initiated by Bryan E. Hainline, MD, Ph.D. (Section of Pediatric Metabolism and Genetics, J.W. Riley Hospital for Children, Indianapolis, IN). The above grant would not have been possible without the help and expertise of Dr. Hainline and collaborator Dr. Bruce Hamaker (Purdue University) whose initial research has given us preliminary data to show the feasibility of the project. Both Drs. Hainline and Hamaker will continue to be involved with this project as we will need to perform nutritional and digestibility studies in their laboratories. The Kansas Soybean Commission has supported our efforts in soybean transformation for the past several years and was also crucial for us to obtain this recently awarded, three-year USDA/NRI competitive research grant to begin on Phase I of our project. The KSC will continue to be involved as this project evolves.

The Jewel Shop & Share from 5/20-5/22 raised \$194.02 for the Organization. Fifty-two people participated and spent a total of \$3,880.34. The Organization received 5% of the gross amount spent.

Thank you to everyone who participated. Our next Shop & Share event will be 11/18-11/20 and 12/09-12/11.

Best regards,
The Officers and Directors
of the PKU Organization of Illinois



PKU Resource Mothers Training - Cambridge, MA April 26-28, 2002

By Michelle Kowalski

I was given a wonderful opportunity to go to Cambridge, MA for the PKU Resource Mothers Training. This was with the backing of the PKU Org of IL and Hazel Vespa, Social Worker from Children's Hospital. I went with a wonderful group of PKU Mothers; Kelly Reilly, Liz VanArsdell, Judy Raffé, and Cindy Bouk. The coordinators attending were Hazel Vespa, of Children's and Barb Goss, of U of I. Also attending were wonderful women from across the country. These women had children with PKU ranging in age from 2-41 years of age. They are deeply committed to helping the young PKU women with their diet before and during pregnancy.

The role of the Resource Mothers is to help women with PKU to gain metabolic control before and/or during pregnancy by providing social support and promoting a positive outlook on life through home visitation. The Resource Mothers are all women with children with PKU and thus understand the diet and hardships associated with PKU.

On Friday, Dr. Harvey Levy presented case studies on women with PKU and their pregnancies. Today there are 4,000-5,000 young women with PKU who are at age where they can reproduce. There is a generation of PKU women who did not stay on diet due to various circumstances. These young PKU women are faced with the daunting task of getting back on diet if they are considering becoming pregnant or are pregnant. They are hearing the frightening repercussions of being pregnant and not being on diet. The results on the fetus of PKU women who have high phe levels, above 2-6mg/dl are:

- Mental Retardation
- Congenital Heart Disease
- Microcephaly (small head size)
- Low Birth weight
- Low Development
- Language Deficits

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PKU women can have healthy children if they maintain a strict diet prior to and during pregnancy. If the diet is not started prior to pregnancy there is a risk of congenital heart disease in the fetus. The heart begins to form within the first 30 days of gestation, thus the first trimester is the most critical.

With what these women are facing is extremely difficult. So in addition to the doctors, clinics, and dieticians giving them support, they also can receive the support of the PKU Resource Mothers. In addition to the Resource Mothers Program we need to start the

education process when these girls are too young to consider pregnancy. We need to support the camps for these young women so they become aware early of the importance of diet for life.

A woman with PKU in her 30's spoke at the training. She stated she had no contact with others with PKU as she was growing up. This made her feel isolated. Therefore, if you're a teen or

young adult with PKU you need to let the PKU Organization of Illinois know what type of programs and activities you would like to see. We need to keep the connection with others in the PKU community alive. The organization needs your feedback.

A big perk during the weekend is having Diane Sullivan provide us with recipes and cooking demonstrations. There was also the introduction of Cambrooke Foods Quick Mix. This mix makes some wonderful foods that are very easy to make.

It was a wonderful weekend as I learned a great deal and met some wonderful coordinators and PKU mothers.