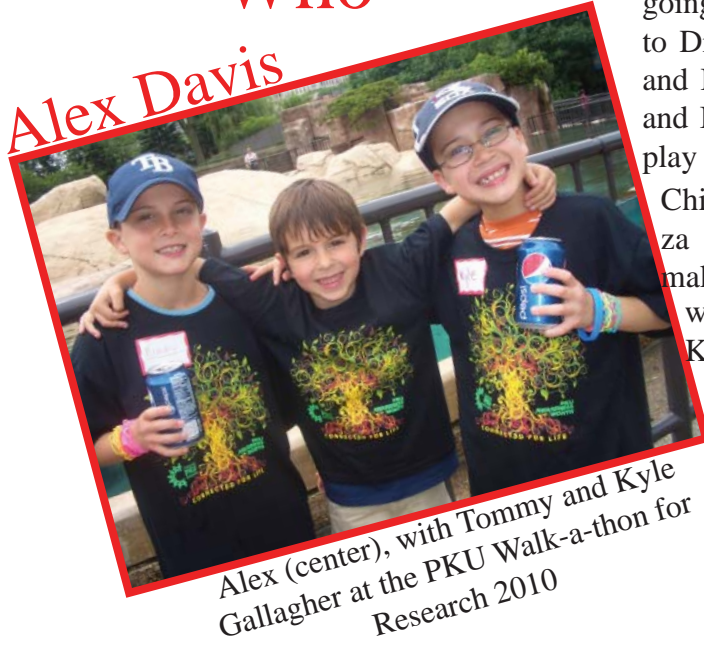


PKU Press

A Periodic Newsletter Published by the PKU Organization of Illinois

Who's Who in PKU



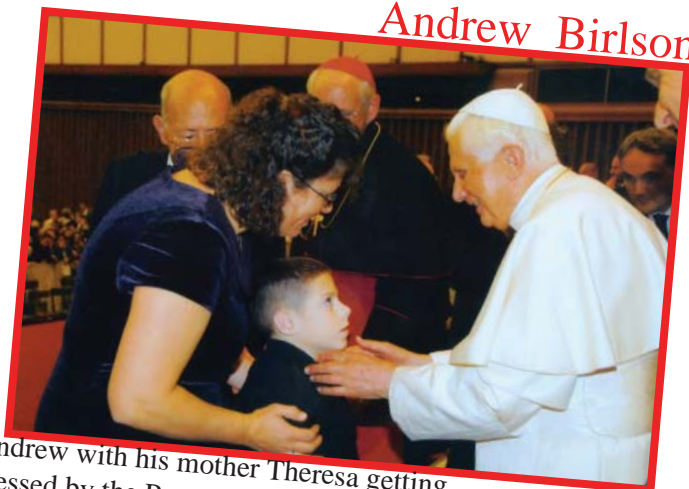
Alex (center), with Tommy and Kyle Gallagher at the PKU Walk-a-thon for Research 2010

Hi – my name is Alex Davis. I'll be 7 on August 24 and I'm going into 2nd grade at Alcott. I live in Chicago, very close to Dr. Burton's office. I like playing sports, playing guitar and I love to go swimming. I have a lot of favorite sports and I played baseball this summer on the Indians. I like to play tennis with my Dad too. My favorite foods are Lays Chips and chocolate Rice Dream. I also like pizza and the Cook for Love pancakes. I have fun making fruit salad with my best friend Harrison who lives downstairs from me. My friends Shayna and Kyle have PKU and I can't wait for PKU camp to hang out with them.

For more photo's from the 2010 PKU Walk-a-thon for research and all of our events go to www.PKUIL.org under Events!

Who's Who in AHD

Andrew is a very active and spirited ten year old boy—his passions are very diverse. From church, school, and reading to playing the drums, singing, and playing baseball, Andrew is always on the go. He reads at a second grade level and loves to ride his bike, go to the water park, and hauls logs to burn in his family's wood stove during the winter.
cont. pg 2



Andrew with his mother Theresa getting blessed by the Pope.

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PLEASE NOTE:

We have a NEW Phone number:
630-344-9PKU

Andrew's 10 year Journey with a UCD

He was diagnosed with Neonatal Onset Citrullinemia, one of several UCD's. Andrew's genetic code does not have the "recipe" to make a specific enzyme which is needed to digest protein. Without special Ammonia scavenging medications and specialized metabolic formula, the level of ammonia in Andrew's blood could escalate out of control, causing symptoms from tiredness and vomiting, to coma and even death from swelling of the brain. Below is a timeline which documents important milestones in Andrew's medical and personal life.

3/23/2000-Andrew born (10 days late)

3/25/2000-Andrew was discharged at 48 hours old (had been vomiting)

3/26/2000-Andrew was readmitted to the ER at 60 hours old due to poor feeding, hypertonia, lethargy & unresponsiveness. -At 68 hours old Andrew had a plasma ammonia level of 1300 and was diagnosed with a Urea Cycle Disorder. He was admitted to Children's Memorial Hospital where he was given the specific diagnosis of Citrullinemia.

4/2000- After being treated with Buphenyl (Sodium Phenylbuterate) and Arginine and put on a low protein diet including essential Amino Acid formula, Andrew was released to home utilizing these treatments.

1st year- Andrew grew slowly (hugging the 5th % for height and weight) but his physical development was fairly normal... crawling at 9months and walking by 16months.

2nd year-Andrew hung on to the low end of the growth curve but taking his formula and meds by mouth was a constant struggle.

3rd year-Getting Andrew to consume all of his metabolic formula and meds became so difficult that we finally decided to have a G-tube placed. We were glad we waited until Andrew learned to eat table foods but it was definitely time! What a huge relief. Andrew could finally get 100% of his meds and formula every day. Also, when Andrew got sick, we could give him additional hydration and nutrition very easily. The G-tube also allowed us to treat mild hyperammonemic episodes at home.

4-7th year-Andrew was fairly healthy without any major hospitalizations until he turned 7 years old. During this time, however, he struggled developmentally. With hard work and persistence, his skills improved steadily. Behaviorally, Andrew also struggled, but a diagnosis of ADHD shed much light on these problems. It helped us to discipline him more effectively. To this day, he still struggles with listening and following through with directions.

8-10th year-Andrew was hospitalized over a dozen times in 2 years—requiring dialysis five times since his initial presentation as an infant. The hyperammonemic episodes were gradually becoming MUCH more frequent and they were occurring with no other inter-current illnesses (as they had in the past). It was only by the grace of God that we were getting him treatment in time.

4/2010- Andrew had a severe hyperammonemic episode and afterwards we sadly realized that he lost some of the math skills that he had worked so hard to acquire...that was it! We realized very vividly that a liver transplant was our only option to save Andrew's life and his quality of life.

5/10/10- After a liver transplant evaluation, Andrew was approved by the Transplant Team at Children's Memorial Hospital and officially put on the National Liver Transplant List. Because of his genetic disorder, he was given a PELD score of 30 out of 40, with 40 being the most in need of a transplant. Also, if he wasn't transplanted within 30 days of listing, his status would move up to a level 1B (Above 40 and just below emergency level-1A).

6/10/10- Andrew's status moved to a level 1B.

6/11/10- Andrew received an offer for a liver.

6/12/10- Andrew's new birthday- he received his new liver!

7/31/2010- Andrew is 7 weeks from his transplant, is home and is back to his normal physical self! He is eating foods he never tried in his entire life (eggs, hotdogs, yogurt, peanut butter...), he is riding his bike and he is even swinging across the monkey bars! THANKS BE TO GOD! *cont. page 3*



Andrew's 10 year Journey with a UCD

Along our ten year journey, we have had so much professional support...the NUCDF was a major factor in helping us make well informed decisions along the way...We attended the national conferences almost every year.

From the beginning of its inception, we enrolled in the longitudinal rare disease study for UCDs funded by the US Federal Government. Preliminary feedback from this UCDC study was very helpful. Many thanks to the other UCD patients who participated, to the private donors who gave additional financial support to the study and also to the professionals at Cleveland's Rainbow Babies Children's Hospital who followed Andrew over the past five years. We strongly recommend participation in research studies like these to ALL metabolic patients and their families...this is the KEY to understanding these disorders and in making progress for treatments of these disorders!

Last but not least was the OUTSTANDING care and love provided to our family by Dr. Joel Charrow, Dr. Barbara Burton, Kathryn Kim (genetic counselor), Heather (dietician), and the entire genetics team at Children's Memorial Hospital in Chicago. They are the blessings given to us by God who helped Andrew not only survive ten years, but helped him to have a good and happy life from his infancy until now without a liver transplant!

Many thanks, also, to the donor and the donor's family for giving Andrew a chance at life with a renewed sense of health and the opportunity for a newfound freedom and independence!



Andrew playing baseball

Calendar of Events

August

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
August 31st	Andrew Craig Scholarship	PKU Org. of IL Website	DEADLINE	www.pkuil.org

September

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
September 18th	BIG WIG Golf Outing/	Tamarck Golf Club	12pm	Lisa & Steve Bennett (847) 359-0506
September 24-26th	PKU Family Camp	Lake Bloomington in Hudson		Christina Sciarrotta (312) 968-7247
September 30 th	Logo Contest	PKU Org. of IL Website	DEADLINE	www.pkuil.org

October

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
October 3rd	Carlos Galvez Memorial Golf Tournament	Broken Arrow Golf Club Lockport, Illinois		Jim Critchfield 847-341-1901

November

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
November 13 th	Annual Meeting	Medinah Country Club	9 am – 4:30 pm	www.pkuil.org or call 630-344-9PKU



Register Now!!!
2010 BIG WIG PKU Golf Outing

Sponsored By
**Women in Golf
 PKU of Illinois**

Date: September 18th 2010

Check-In begins 12:00 pm

**Register Your Foursome
 By September 4th!!**

**Where:
 Tamarack Golf Club
 24032 Royal Worlington Dr
 Naperville, IL 60564**

**Cost:
 \$130 per golfer**

For more info or to register online:
NEW! Pay & Register for BIG WIG on www.PKUIL.org **NEW!**
 Steven & Lisa Bennett|847.359.0506 Lori Knaub|630.837.0981
 Email: Bennett19@earthlink.net
 Subject line: PKU Golf Outing

2010 BIG WIG/PKU Registration Form

Registration Includes:
 - Windbreaker
 - Pre round lunch
 - Magaritas
 -1 hr Open bar
 -Silent Auction
 -Dinner during auction

Name: _____

Address: _____

E-Mail (IMPORTANT!): _____ **Phone #:** _____

*Preferred Foursome: _____

*If you have a foursome you would like to play with, let us know who they are. If not, an extremely talented trio will be assigned to you. Remember, this all goes to charity! (PLEASE NOTE: IF SIGNING UP A FOURSOME WITH ONE REGISTRATION FORM, A CHECK OR CHECKS FOR EACH PERSON MUST ACCOMPANY THE REGISTRATION FORM.)

Send your forms and check made payable to **PKU Organization of Illinois** to:

Women In Golf, Inc.
 c/o Lori Knaub
 1026 Bentley Lane
 Bartlett, IL 60103

OR

PKU Organization of Illinois
 c/o Steven Bennett
 4030 New Britton
 Hoffman Estates, IL 60192

Ruthie is a PKU Adult in Illinois running for Miss Illinois August 22; her platform is PKU Awareness and Education. Ruthie is dedicated to spreading PKU Awareness and is a board member of the PKU Organization of Illinois. If Ruthie wins the Pageant a portion of the money earned at the pageant will go to support PKU Research!



RUTHIE JAGER

Miss Oswego International 2011

My Platform:
PKU Awareness & Education

“I’ve learned to accept my diagnosis of PKU for it has made me a stronger woman by overcoming the obstacles I face every day from this genetic disorder.”

WHY AM I COMMITTED AND MOTIVATED TO ACTION?

- Living with PKU my entire life, I want to share my experiences with as well as educate other PKU teens, adults, and families about this disorder.
- Education is key to ensuring positive and productive mental health along with the proper diet of PKU needs.
- The consequences of mental retardation are irreversible and my brother suffers from developmental disabilities due to an inadequate diet as a baby. By educating families, I hope to ensure what happened with my brother does not happen to other families.



WHAT IS MY MISSION FOR PKU AWARENESS & EDUCATION?

My goal has been two-fold: to raise funds and educate others about the disorder. As a board member of **PKU Organization of Illinois**, a not-for-profit group dedicated to helping PKU families, I also serve as an advocate in my community.

Walk for Research 2010 Recap

Lincoln Park Zoo June 5th, 2010



The PKU Organization of Illinois Walk Committee

Thanks to all who attended the Walk for Research at Lincoln Park Zoo. The walk was a huge success and we raised over \$5,000 for Research for PKU. We had a little bit of rain in the morning but right at 11 when the walk started the skies cleared and it was a wonderful day to walk around the zoo and spread PKU Awareness!



The Irgang Ladies!



Craft time at the Zoo!



Walking at the zoo.....

Wine Tasting & Silent Auction Recap

Webster's Wine Bar August 6th, 2010



A Special thanks to everyone who came to our 1st Annual PKU Wine Tasting and Silent Auction. It was a fun evening for Adults with PKU, parents with Children with PKU, PKU staff and friends and family.

A special thank you to our donors who donated items to the Auction.

Auction items included:

Cubs Tickets

Sox Tickets

Dave Matthews Band Tickets

Medinah Golf outing

Leather office desk chairs

Salon gift baskets

Art work and Framing services

Restaurant Gift Certificates

and much more!



We hope you can attend next year!



Annual Meeting

Save the Date

November 13th, 2010
Medinah Country Club

*“ Be your own Advocate in the Changing world of PKU
and Allied Health Disorders”*

This year register online: www.PKUIL.org

Preview:

- Legislative & Health Care presentation by Jeff Lewis
- Special Speaker for Allied Disorders
- Kids Program
- Teen and Young Adult Program
- Vendor Presentations
- Clinic Updates
- Special PKU Presentation by Denise Ney
- Raffle
- And lots more!



At this year's Annual Meeting we will be selling raffle tickets for a commemorative PKU T-shirt quilt. This quilt was made by a PKU Adult and her mom out of popular PKU awareness shirts

NEW LOGO CONTEST



PKU Organization of Illinois Logo contest

This year the PKU Organization of Illinois is looking for a new logo and we want your help, just as we did 10 years ago when Maggie Fischer with PKU made our current logo in our logo contest. We want to do the same thing again this time to help us freshen up our look.

As you know PKU is for life and we want a logo that the PKU Organization of Illinois and Allied Disorders is here to help everyone with PKU at every age.

Interested? You have until Sept 30th to create your own design and send it to us. All entries will be reviewed by the Board of Directors prior to the Annual Meeting. Based on applications we will narrow down the entries to 5. At the Annual Meeting we will enlarge your entry to be voted on by all of the PKU & Allied Disorders community in attendance. If your logo is selected it will be used on our stationary, signs and website*.

We wish you all the very best luck!!

*Visit the website for more details



LOGO CONTEST RULES:



1. Your logo can be any shape you like; it does not have to be square.
2. You can use markers, crayons, color pencil, paint or your computer to make the logo.
3. All work submitted must be your own.
4. Create a logo that includes all ages since PKU is for life!
5. Logo may have words or abbreviations or neither.
6. Allied Disorders may be included in the title, but it is not required.
7. Fill out form completely & mail to the address below by September 30th 2010.
8. You can use the area below to create your logo or attach it to this sheet

Questions: email JulieJ@PKUILL.org or call 630-344-9PKU

Name:

Address:

Phone:

Email:

Age:

Circle one: PKU-AHD-N/A

Please mail this sheet to:

Julie Johnstone 1451 N. Bosworth Ave #3R Chicago, IL 60642

TOGETHER

We Can Impact PKU



National **PKU** Alliance



Join Us: **Membership that Pays for Itself**

Join the National PKU Alliance (NPKUA) and become a part of the Member Discount Program to help you save money on low protein food, while supporting our work in improving the lives of individuals with PKU while pursuing a cure.

For a \$25 membership fee, you will receive:

1. 10% off an order from Applied Nutrition
2. \$100 off coupon on a Cambrooke Foods order and a chance to win an iPod Touch
3. 5% discount on Country Sunrise products at PKU Perspectives
4. Free box of Vitabites from Vitaflor

P.O. Box 501,
Tomahawk, WI 54487

Tel 715.437.0477

Fax 715.453.7670

www.npkua.org

Donate more than your membership fee to help us continue our four signature program areas that have the most significant returns for those who live with PKU: research, education, support and advocacy. Families and adults created the NPKUA to serve a dual mission: improve the daily lives of those individuals and families affected by PKU and accelerate the timeline for a cure by investing in targeted research.

VISIT NPKUA.ORG FOR A MEMBERSHIP FORM!



CONNECT WITH US: **DONATE, BECOME A MEMBER**

The NPKUA's mission is to improve the lives of individuals and families with PKU and pursue a cure.

Yes! I'd like to become a member of NPKUA today! When you become a NPKUA member, you will receive the member discount benefits valued at \$125 for tax purposes. *(In accordance with Internal Revenue Code requirements, this disclosure statement is to inform you that the amount of your contribution that is tax-deductible is limited to the amount of the contribution you made less the value of any goods or services that were provided in return. The law requires us to furnish you this statement and a good faith estimate of the value of goods and services provided to you in connection with this gift.)*

Yes! I'd like to donate but not become a member. Your entire contribution will be tax-deductible as allowed by law.

Name _____ Relation to PKU _____

Address _____ City _____ State _____ Zip _____

Phone _____ Email _____ Membership/Donation Amount \$ _____

Check enclosed OR Credit Card Name _____ Cardholder name _____

Number _____ Exp. ____/____ Security Code _____

From the Board Room



(Left to right) Steve Bennett, Jim Critchfield, Julie Johnstone, Mike McMahon, Heather Ricca, Gary Krasno, Eva Brandon, Jill Franks, Christina Sciarrotta, Barb Goss, Michelle Brandon, Hazel Vespa, David Ricca, Ruthie Jager. (Joe Annunzio absent)

MEETING SCHEDULE 2

Our board of directors meeting schedule for 2010 is as follows:

August 26th – invitation stuffing meeting

October 7th – at Children’s Westchester Clinic

November 4th – at Children’s Westchester Clinic

Anyone is welcome to attend – for more information or minutes or agendas – please contact Christina Sciarrotta at 312-968-7247

Call for Board Member Volunteers!

Interested in volunteering on the PKU Org of IL Board? We will have open seats for 2011. Elections will be held at our annual meeting on November 13th. Consider volunteering – it is only as big of a time commitment as you can contribute. Email info@pkuil.org or call us at 630-344-9PKU.

**Come One, Come All to the 29th Annual PKU IL Family Camp Weekend
September 24 - 26 2010**

WHAT IS PKU FAMILY CAMP?

The PKU Organization of IL has been hosting Family Camp Weekend for 29 years! It's an entire weekend of nostalgic camp activities. From Friday night unpacking, to Saturday morning fishing through Sunday morning breakfast at the main dining cabin, it's an entire weekend of organized fun.

WHERE IS PKU FAMILY CAMP LOCATED? East Bay Camp, Lake Bloomington in Hudson, Illinois. The PKU Org has a reserved site every year with 12 rustic (they have showers and rest rooms – but bunk cots require your own sheets/sleeping bags) cabins, areas for tents, a bonfire pit, picnic tables, plenty of space for outdoor games and a main cabin for meals. The main cabin features recreation space, room for dining or just relaxing and kitchen facilities including refrigerator, sink, oven and coffee maker. There is parking adjacent to the site.

WHAT DO WE DO AT PKU FAMILY CAMP? Friday night there are no organized activities except unpacking/socializing. Saturday begins with morning fishing, lunch at the camp's main hall, indoor swimming, kid's activities/crafts, dinner at our camp site, dancing and games in the gym and an evening bonfire. Sunday wraps up with breakfast at our camp site and kids games and races. All meals include low-protein options and low-protein snacks and treats are available all day in the camp site main cabin.

DO WE HAVE TO COME FOR THE WHOLE WEEKEND - DO WE HAVE TO STAY ONSITE? No, you can register for all 3 days, just Saturday & Sunday or just Saturday - indicated on your registration form. There are several lodging options - you can opt to stay in one of the available cabins (cabins are assigned on a first come, first serve basis in the order registrations are received), stay in a tent on the site or stay in an area motel. Please contact us for recommendations. **Motel expenses and reservations are at the camper's own expense.**

WHAT DOES IT COST? Each year The PKU Organization of Illinois uses funds to underwrite most of the cost of this event. The cost is: Adult \$15, Child \$5. **Anyone with PKU can attend at no charge.** Payment is due at time of registration. For those wishing to help further offset the cost of the camp, any additional donations would be appreciated. The cost is the same for those staying on or off site.

HOW DO I REGISTER? Detach and Mail completed registration form and check (payable to PKU Organization of Illinois) by **September 20, 2010** to **Christina Sciarrotta 2853 N. Burling, Chicago, IL 60657**. Or register and pay online at www.pkuil.org. Additional information will be emailed to you after your registration is received.

QUESTIONS? Contact Michele Kowalski at (773) 745-4541 or Christina Sciarrotta at (312) 968-7247

----- Detach and mail the reservation form below to **Christina Sciarrotta 2853 N. Burling, Chicago, IL 60657** -----

2010 PKU Family Weekend Registration Form

We will attend the following day(s):
_____ Friday - Sunday
_____ Saturday - Sunday
Adults \$15, Child \$5, PKU FREE _____ Saturday only

There will be _____ Adults and _____ Children in our group attending. Total Amount Enclosed \$_____

We will be staying in a :
_____ Cabin
_____ Tent
_____ Hotel (cost is at your own expense)

Family Name, Address, Phone #, Email

Listed below are the names of adults & children (w/kids ages) camping this year. Indicate PKU with an (*).

Andrew Craig Memorial Scholarship Guidelines & Procedures

The PKU Organization of Illinois has elected to award dollars for education to qualifying individuals with PKU or Allied Disorders. This year, \$2,000 scholarships will be awarded to five individuals with PKU or an Allied Disorder, who reside in Illinois, and who are enrolled in an accredited college, university, or vocational school in the fall of the upcoming school year. A student may win more than once, but not in consecutive years.

Guidelines:

The applicant must submit a complete application and,

- Show proof that he/she will be enrolled in classes during the school year for which the scholarship is being awarded
- Have been diagnosed with PKU or an Allied Disorder
- Show proof of primary residence in Illinois
- Submit a short essay
- Will apply scholarship funds to College/University/Vocational school expenses (i.e. course fees, textbooks, room & board)

Procedures:

- An application should be obtained via:
 - Our website (www.pkuil.org/scholarship)
 - PKU Press
 - writing to us at :
 - PKU Organization of Illinois
 - Attn: Andrew Craig Memorial Scholarship
 - P.O. Box 102
 - Palatine, IL 60078-0102
- The application will be available from June 1st to August 31st.
- **The application must be completed and mailed/postmarked by August 31st.**
- The application will be reviewed by the Board of Directors, and ALL applications meeting the required criteria will be presented to the Board of Directors for consideration and selection.
- The winners of the scholarships will be notified by mail & email, and are invited to attend the PKU Organization of Illinois Annual Meeting to be recognized by the Board of Directors and the PKU/Allied Disorder Community at large.

PKU Organization of Illinois Andrew Craig Memorial Scholarship Application

Please complete ALL information requested (Print clearly or Type)

Completed form is to be mailed by August 31st to:

PKU Organization of Illinois
Attn: Andrew Craig Memorial Scholarship
P.O. Box 102
Palatine, IL 60078-0102

APPLICANT DATA:

Name: _____
 First Middle Last

Birth Date: _____

Permanent Mailing Address: Street: _____
 City: _____
 State: _____
 Zip: _____

Contact Telephone Number: (_____) _____
 (Area Code)

Current Email Address: _____

The undersigned hereby acknowledges that the prescribed criteria for eligibility for award of scholarship funds of the PKU Organization of Illinois have been met, and that the information provided within this application is correct.

Applicant Signature: _____

COLLEGE/UNIVERSITY/VOCATIONAL INSTITUTION DATA:

Name of Institution: _____

Address of Institution: _____
 (City) (State) (Zip)

Month and Year of first semester attended: _____

RELEASE OF MEDICAL INFORMATION:

Patient: Complete the upper portion of this form, and forward to your physician who will in turn complete the lower portion. Your physician should then forward this form to the PKU Organization of Illinois.(You may wish to assist your physician by including a pre-addressed envelope).

I, _____, do hereby request and authorize
(Name of Patient)

_____ to release medical information indicating the
(Physician's Name/Institution)

Diagnosis of PKU / Allied Disorder concerning _____
(Name of Patient)

to the PKU Organization of Illinois Andrew Craig Memorial Scholarship Program.

(Patient Signature) _____

(Guardian Signature) _____
(Required if Patient if a Minor)

I, _____ do hereby attest that _____
(Physician's Name/Institution) (Patient Name)

has been diagnosed with PKU or an Allied Disorder.

(Physician/Institution)

(Address)

(Physician Signature)

(Date)

Communication Preferences

Website- PKU Press- Email Newsletter

How would you like us to communicate with you?

In order to keep you informed with news from the PKU Organization of Illinois we have several options available. We can send you the PKU Press in the mail or in PDF format in an email, we also have been sending Electronic Newsletters and Event Invitations we send out via email and all our current information is on our website.

Please detach and mail back or return at the annual meeting. Please select all that apply so that we can keep you informed:

- I would like to receive the PKU Press in the mail
- I would like to receive the PKU Press in a PDF via email
- I would like you to add me to the email list so that I can get the PKU Newsletter and Event Invitations

How often do you visit our website: (circle one)

Once a week 1-2 times a month Every 6 mo. Once a year Never

Name:

Address:

City: State: Zip:

Email:

Any other comments for us: