

Spring 2010

PKU Press

A Periodic Newsletter Published By The PKU Organization Of Illinois

Who's Who in PKU



Matthew Squillacioti is our 7 year old Who's Who in PKU and AHD Illinois this Spring!

His birthday is October 4th and he is in first grade at Dryden Elementary. Matthew is the only one in his family with PKU, but he has a good friend with PKU – Sophia Salemi – that lives by him in Arlington Heights and goes to the same school! She is one year older than him and he has had her teachers. He sees Dr. Burton and drinks his Phenex II vanilla. Baseball is his favorite sport and he loves Monopoly and the movie High School Musical. His favorite food is his mom's yummy homemade pizza!

Table of Contents

Allied Disorders - Our Story	pg 2
Calendar of Events	pg 3
Register for June Walk	pg 4
Spring Cooking Fun	pg 5
New Website Launch	pg 6
Save the Dates!	pg 7
NPKUA Conference Recap	pg 8
Join NPKUA Form	pg 9
2010 Annual Meeting Preview	pg 10
How your donations help	pg 11
Support PKU with Ebay	pg 12
From the Board Room	pg 13
Transition Program at Children's	pg 14-15
Contact Your Legislators	pg 16

We Want to Hear from You

Do you or a family member want to be featured in our next Who's Who in PKU? Log onto our new website where you can find the forms and contact info to get to us! Or email info@pkuil.org for more information.

Allied Disorders Our Story

Dylan was born on March 17th, 2008 and after 4 days in the hospital we were sent home. That Friday did not turn out to be a normal first day home with Dylan. Dylan wasn't nursing very well and I was surprised at how well he was already sleeping. There was a massive snowstorm out of no where and then the phone call from the Pediatricians office stating that something on Dylan's new born screen came back false/positive and that he needed us to come into the office.

We drove over to the Pediatricians office not really understanding what was going on, but did what we were told. The Dr. tried explaining to us that false/positives happen all the time and not to worry there was a chance that this Maple Syrup Urine Disease would come up negative. But before the end of the night we were on our way downtown to Children's Memorial Hospital where all of a sudden blood tests were being drawn, questions about our 5 day old were being asked and we still didn't really understand what was going on. By 3 am the Fellow was talking as if it was not false positive any more and Dylan had MSUD - we were so lost.



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

We met Dr. Burton the following afternoon and we cried as she told us about the disease. After that Dylan spent 3 weeks in the hospital while we learned about how we will have to manage his diet and how all of a sudden we were in this world of a child with a disease that people never really heard of- even Dr's we new would comment "I remember learning about that in Medical school". Our family told us not to read the internet because we would get scared and that it was bad. However, after a week I did start searching the internet and joined the MSUD- Family Support Group right away. They were even having a Symposium in June and I was already thinking that we MUST go. With such a rare disease we have to be part of this community, where else would we get support and answers?

We attended the Symposium June 24-26, 2008 barely 4 months after Dylan was born and immediately became part of the MSUD family. Everyone was so friendly and open about talking about their child's story. We met a lot of people and learned a lot but the hot topic for us was the Liver Transplant. There was also a Symposium on Liver Transplants in August in Pennsylvania that we started talk-

ing about attending. There were some transplant recipients at the Symposium and we talked to those families. We were so overwhelmed by all the information we received at the Symposium and even thought neither my husband nor I would admit it yet we new that eventually Dylan would have the transplant.

We started to do our research on the transplant and I became involved in the MSUD community pretty quickly. First I organized a fundraiser for that fall and attended the PKU cooking class. I felt pretty passionate that even though we new that one day Dylan would be transplanted and basically cured of MSUD that MSUD would still be part of our family. It has had such an impact on our family that I am planning the MSUD Symposium for June 24-26th, 2010 at the Marriott Lincolnshire, IL. I talked to many different people about what they thought about the transplant, some post transplant families, some with older kids and our Dr's. Bottom line it was our choice and what we thought would be best for our child.

Dylan was placed on the UNOS list in January 2009 and transplanted August 8th, 2009 at the age of 16.5 months. He had his transplant at Children's Hospital of Pittsburgh and was the 37th MSUD child to be transplanted by them. It is now almost 6 months post surgery and he is doing amazing. We are extremely lucky with Dylan's success, he never had a metabolic crisis with the MSUD and as far as his transplant did not have any rejection or any other major complication. It's easy to say now that we do not regret our decision to have Dylan transplanted, but I do also respect all the families on both sides of the spectrum. I am very grateful to the PKU and MSUD communities for doing what they are doing for all these kids and their efforts in working together as a community. Even though we don't have to worry about the MSUD anymore like I said in the beginning MSUD is part of our life and I will support MSUD and PKU however I can.

Calendar of Events

April

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
April 24th	PKU Adult Meeting	Downers Grove, IL	11am	Lauren Leviton lleviton@childrensmemorial.org

May - PKU Awareness Month

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
May 1st	BioMarin waterpark townhall	Rockford, Illinois		psibley@bmrn.com Clocktower resort

June

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
June 1st	Andrew Craig Scholarship Application Process Opens	PKU Org of IL Website		www.pkuil.org
June 5th	PKU Awareness EVENT	Lincoln Park Zoo	11am	www.pkuil.org
June 13th	Child/ Father Grilling Event	Caro Family Home Naperville, IL	1-4pm	www.pkuil.org Rcaro19@comcast.net
June 24th, 25th, 26th	MSUD Symposium	Lincolnshire Marriott		Barbara Mudrick barbmd@yahoo.com

August

DATE	EVENT	LOCATION	TIME	HOST/CONTACT
August 7th	Propionic Acidemia Foundation Family Day	Children's Memorial Chicago	9:30 am – 3 pm	Jill Franks, 877-720-2192 pa@pafoundation.com
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

October

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

November

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



PKU AWARENESS FUNDRAISING EVENT AT CHICAGO'S LINCOLN PARK ZOO
SPONSORED BY BIO-MARIN

ILLINOIS PKU FUNDRAISING EVENT FOR PKU RESEARCH

EVENT IS FREE TO ATTEND WITH PRE-REGISTRATION
\$15 PER FAMILY DAY OF EVENT

WHERE: Lincoln Park Zoo- Chicago, Illinois Meet at the Foreman Pavilion
on the map legend- # 33, near the flamingoes-legend # 12 and near Cafe Brauer-legend # 20

WHEN: Saturday June 5th 11:00 AM-3:00 PM

WHY: To raise money for PKU research, detailed research funding information provided at the event.
Checks can be made payable to: PKU Organization of Illinois (a 501(c)(3) Tax ID: 36-3320115

HOW: DO I PRE-REGISTER? go to www.pkuil.org **OR** look for an email for us from constant contact
OR Detach and mail the bottom portion to address listed below

COST: No cost to attend for the event if you pre-register. \$15 per family day of event.
PKU as the password to get free parking at the zoo.
If you preregister, the only cost is any funds you wish to donate to research

WHAT: PKU picnic food will be provided. If you would like to bring a favorite snack to share please do.
Please bring beverages and any other non-pku for your family.

PKU Awareness shirts will be available for \$13.00 at the walk.

Tear off here

Tear off here

Names of those attending:

- | | | |
|----|----|----|
| 1. | 3. | 5. |
| 2. | 4. | 6. |

Address _____

Phone _____

E-mail _____ @ _____

_____ We will be attending.

_____ We cannot attend but have included our contact information and/or donation for research

mail to: Heather Ricca 2121 Willow Lakes Dr , Plainfield, IL. 60586

Thank you to all our sponsors:



2010 Spring Cooking Class

PKU Cooking Italian Style!

The 2010 Spring Cooking Class, sponsored by BioMarin/Patty Sibley and hosted by Eva Brandon and Michelle Brandon – was another huge success! Jeff Masse, owner of the Cooking Store, returned to provide a great hands-on experience for all – with some yummy Italian Main Dishes, Sides and Desserts. Cooking teams made their recipe and then passed around samples for everyone to enjoy!

Held at Dominican University in River Forest, approximately 40 people were in attendance – the cooking stations at our new local were huge – plenty of room to spread out to make that pizza/calzone dough! We raffled off many wonderful cooking items to complete our day of low-protein cooking for PKU and Allied Disorders.

Families were able to create and taste test the following low protein dishes from the “Apples to Zucchini” Cookbook –

- Basic Savory Dough for Pizza and Calzones**
- Gingered Orange Carrot Soup**
- Hawaiian Pineapple Pizza**
- Mushroom Strata**
- Italian Salad with Seasoned Baked Croutons**
- Fruit Bruschettas**
- Bread Pudding**
- Stromboli Italian Bread**
- Italian Calzones**
- Focaccia with Zucchini and Tomato Toppings**



Event Hosts Eva and Michelle take a well deserved break to chat with Julie and Hazel



Star Chef Michael Annunzio shows off his raffle winnings



The Bruno family's tasty Hawaiian Pizza Creations



Our happy cooks on their way home with great new recipes.

UPDATED & IMPROVED PKUIL WEBSITE

FEATURES INCLUDE:

- Links to vendors & PKU & AHD Resources
- Local & National Legislation Information
- Link to NPKUA & Current Information
- Register & Pay Online for the Big Wig Golf Outting
- Register & Pay Online for the Annual Meeting
- Donate Online with Google Checkout
- Illinois Clinic Information
- Interactive Calendar of Events
- Educational Scholarship Information
- Copies of the PKU Press
- Local & National PKU & AHD News
- Medical Conference News

And **LOTS** more!
WWW. PKUIL.ORG



SAVE THE DATE!!!
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:

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

Save the Date!

New this year: Download forms for the Andrew Craig Scholarship
at: www.PKUIL.org/scholarship

Scholarship applications accepted from June 1st- August 31st. See website for more details.
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. Winners will be announced at our Annual Meeting .

GET AND SUBMIT YOUR REGISTRATION MATERIALS FOR THESE EVENTS ONLINE THIS YEAR!

NPKUA

by Christine Brown

Update

In case you couldn't make it the inaugural conference, all of the videos, presentations and photos are now up on the web-site at <http://www.npkua.org/index.php/conference-update>. Please be sure to check it out – the amount of information that was presented at the conference was incredible.

Patient Power will be playing on their web-site and radio series a public service announcement about the NPKUA for two days in March, as well as for a week in May as part of PKU Awareness month.

Advocacy

We have our House Champion for the Medical Foods Equity Act! Congresswoman Tammy Baldwin (WI) has agreed to take the leadership role in the U.S. House of Representatives for the legislation. She sits on the Energy and Commerce Committee and is a member of the Children's Health Caucus. We are currently trying to help her office in locating more original co-sponsors for the bill. So far, Rep. Sarbanes (MD) and Rep. Edwards (TX) have agreed to co-sponsor, and we have several others we are waiting for final confirmation.

We really need your help getting more co-sponsors for the bill on the House side so it can be formally introduced. If you haven't done so, please contact your Representative and ask your members

to do the same. Talking points can be found at <http://www.npkua.org/index.php/talking-points>.

Due to the difference in rules between the Senate and House, I think the bill will move quicker in the House than in the Senate. The bill in the Senate remains in the Finance Committee.

Fundraising

Watch for more information soon on an exciting fundraiser for the NPKUA. Mike Esposito, a family friend of Dick Michaux, is an Iron Man competitor. Each year, he competes in one Iron Man competition and raises money for charity. This year, he has chosen the NPKUA for his charity! We are currently working on putting together some pages on our web-site so we can all cheer and follow "PKU Iron Mike" on his adventure.

The fundraising and executive committee has been hard at work looking at sustainable ways to raise funds for NPKUA operations for 2011 and beyond. After a series of conversations, three private donors have come forward with \$40,000 in donations to be used to hire a Development Consulting firm to help us in our efforts to create a development plan for the organization that includes foundations, corporate giving, individual donations, events, etc. A number of us have been working on finding the right firm to fit our needs and budget. This will be discussed more at our upcoming Board meeting on March 7.

PKU Awareness Month

Our t-shirt order was placed this month for the 2010 T-Shirts. Thank you so much for all of you that ordered shirts.

We ordered 2,484 shirts this year, including shirts to sell on our web-site.

The sponsors of this year's shirts are: BioMarin (\$1,500), VitaFlo (\$1,500), Nutricia (\$1,000), Applied Nutrition (\$500), Cambrooke (\$250), PKU Perspectives (\$250), Solace Nutrition (\$250).

Thank you all so much for all the activities that you do year-round to raise money for research. Together, the final amount raised for research in 2009 was \$213,634. And, all of our research awards will begin on March 1.

Administrative

I've been asked to become a member of the Long-Term Treatment and Follow-up Sub-Committee of the Secretary's Advisory Council on Heritable Disorders in Newborns and Children. The ACHDNC provides advice and technical information to the Secretary of the federal Department of Health and Human Services about newborn and childhood screening and for the development of policies and priorities to enhance the ability of the State and local health agencies to provide for newborn and child screening, counseling and health care services for newborns and children having or at risk for heritable disorders. This will be a wonderful opportunity for the PKU community to help shape federal policy and programs!

I also attended a summit at Emory University this month to provide input into the NBS Connect Program – an on-line patient registry for all disorders diagnosed through newborn screening. It will capture and analyze information related to these disorders in an effort to assess gaps in service, access to care, and to develop best standards of practice for clinical management.

As you can see, a lot continues to progress at the national level with PKU. We have made some incredible strides in the past few months, and I'd like to thank you again for your work and support in making this happen.

improving **LIVES**



research | education | support | advocacy

JOIN THE NATIONAL PKU ALLIANCE

The National PKU Alliance (NPKUA) works to improve the lives of individuals and families associated with PKU through research, support, education and advocacy, while ultimately seeking a cure. The NPKUA is the first national non-profit to unite adults, families, statewide organizations, the medical community and PKU-friendly businesses under one umbrella organization.

If you are interested in:

- helping find better treatment options
- supporting promising research for PKU based upon the recommendation of a Scientific Advisory Board
- expanding coverage on the federal and/or state level for medical formula and food
- meeting and networking with others affected by PKU
- discounted fees at our annual conference (our inaugural conference will be January 15-17 in Dallas)
- increasing awareness about PKU

We hope you will join us today. Together, we can change the history of PKU.

BOARD OF DIRECTORS

- ◆ **President**, Dick Michaux
The Michaux Family Foundation for PKU
- ◆ **Vice President**, Judy Griffith
The Mid-Atlantic Connection for PKU and Allied Disorders
- ◆ **Treasurer**, Rob Kerr
Maryland Alliance of PKU Families
- ◆ **Secretary**, Kelly McDonald
North Texas PKU Association
- ◆ Rhonda Connolly
Children's PKU Network
- ◆ Tanya Drake
Minnesota PKU Foundation
- ◆ Mike Foust
Ryan's PKU Foundation of Virginia
- ◆ Michael Franklin
Indiana PKU and Allied Disorders Assoc.
- ◆ Rachel Kaup
New England Connection for PKU and Allied Disorders
- ◆ Julie Kelly
PKU Organization of Illinois
- ◆ Sandy LaPrad
Michigan PKU and Allied Disorders
- ◆ Blythe Stanfel
Iowa PKU Foundation

Save the Date

Annual meeting; November 13th, 2010

“Agents of Change- New and Exciting News in the PKU & AHD World”

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

Speaker's bios:

Jeffrey R Lewis is a recognized leader in philanthropic entrepreneur with experience in the public and private sectors having helped create solutions to some of the nation's most difficult domestic policy problems. Specially focusing on health care/Rx and pension and retirement issues, he has learned to use the power of the marketplace to create change. He has a reputation for being a fine communicator and ambassador with proven ability as an innovative thinker. Mr. Lewis has been employed by the Heinz Family Office since May of 1991. He serves as Chief of Staff for Teresa Heinz, as President and Chief Operating Officer for the Heinz Family Philanthropies and Vice Chairman and President of Public/

Private Strategies for America's Health Care Future. Prior to joining the Heinz Family, Mr. Lewis was the Republican Staff Director for the late United States Senator John Heinz. He also worked for Senator Pete Domenici as the Deputy Staff Director for the U.S. Senate Special Committee on Aging, as a senior legislative assistant for Senator Bob Packwood, and as Senior Policy Advisor for Senator John Kerry. Mr. Lewis has worked at the state level having served as an assistant to Governor Victor Atiyeh, as well as in the private sector where he has and continues to work as a private consultant focusing on the development of policy strategies for clients. ¹

Denise Ney, PHD

Denise M. Ney is Billings Bascom Professor of Nutritional Sciences and a Waisman Center Investigator at the University of Wisconsin-Madison. Denise has an active NIH-funded research program in two areas. She conducts research in gastrointestinal physiology to develop improved treatments for individuals with short bowel syndrome who are dependent on parenteral nutrition and research in the nutritional management of PKU. The goal of the PKU research is to improve the PKU diet using glycomacropeptide (GMP), a protein in cheese whey that is naturally low in phenylalanine. Studies are being conducted in children and adults with PKU and results show that GMP holds promise to improve the PKU diet. ¹

¹Bios have been adapted from the NPKUA High Hope conference brochure.

To our PKU Parents, Families, PKU Press Subscribers, and Friends,

The PKU Organization of Illinois NEEDS YOUR FINANCIAL SUPPORT!

We've been successful in fundraising efforts these past years and shortly we'll have the ability to keep expanding our support to the community and consider significant donations to research. Please help us continue to attain these goals and continue to expand our capabilities to aid the community. Support from you has even more importance because it indicates your desire for us to accomplish the goals of our Organization. Just think of what we're all getting for our donation:

- Our parent directory which is updated and distributed every two years.
- No subscription fees for the PKU Press, published 3 times per year.
- Continuous/on-going educational events for us to attend so we're up to date with successful diet management ideas.
- Social events to get parents and kids together to share ideas (new parent meetings, networking events, grilling events, cooking classes and more for 2010!).
- Educational grants for our PKU students. (5) \$2,000 scholarships are awarded each year.
- Active involvement by your board members at the State and National levels with legislation and new developments in PKU treatment.
- Our 24-hour voice mail (630) 415-2219
- www.pkuil.org which has been redesigned free of charge by PKU board members.
- In addition to servicing the PKU community we ex-

panded our Organization to help those individuals and families with Allied Disorders.

- Our Annual Meeting, which has attracted national attention for the quality of the presentations on PKU research and treatment.

With your help, we can continue to provide the financial means necessary to continue to have outstanding Annual Meetings with speakers that benefit all of us. With your gift, we will add programs in the future that meet your needs and requirements. Whether you contribute \$25, \$50, \$75, or more you'll know you're making a difference in PKU for you, our kids, and the members of your family. PLEASE SAY YES in the box below, and pledge your financial support. Or NEW contribute on the webpage by clicking "DONATE via Google Checkout"

*****YOUR CONTRIBUTIONS ARE FULLY TAX DEDUCTIBLE**

REMEMBER, The PKU Organization of Illinois is an ALL-VOLUNTEER 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)

(Address)

(City) (State) (Zip)

Please make checks payable to the:

"PKU Organization of Illinois"; P.O. Box 102, Palatine, IL 60078-0102. We will acknowledge your donation.

*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.



Spring Cleaning???



Raise money for The PKU Organization of Illinois through



<http://www.ebaygivingworks.com>

Donate a percentage of your item to PKU Organization of Illinois and check out the great benefits below!

Check out these great benefits:

- **Attract more bids and higher prices.** Buyers are inspired to buy — and often pay more — for items benefiting a nonprofit. The "Giving Bar" at the top of your eBay Giving Works listing tells buyers all about your selected nonprofit and the percentage of the selling price you're donating.
- **Receive a fee credit when your item sells.** When your eBay Giving Works listing sells, we'll credit back your [Insertion and Final Value Fees](#) by the same percentage you donated. Giving 50% of your item's final sale price? You'll get back 50% of your fees. Giving 100%? You get back all of your Insertion and Final Value Fees.
- **Get extra exposure for your listing.** Buyers can find your item when they search on eBay, on eBay Giving Works, and on the About My Nonprofit page. It's like having three listings for the price of one!
- **Stand out from the crowd.** Each eBay Giving Works listing has the special charity ribbon next to it, catching buyers' eyes. Your listing stands out in search results and buyers see that their purchase helps you help a worthy cause.

It's easy- here's how:

1. Click the Sell button at the top of any eBay page—this will take you to the Sell Your Item form. You might be asked to sign in.
2. eBay Giving Works is in the "Choose how you'd like to sell your item" section. (Don't see this section? Under "Add or remove options" select "Donate percentage of sale" and then save your selection.)
3. Select the nonprofit that you'd like your sale to benefit. – PKU Organization of Illinois
4. Choose the percentage of your final sale price to donate if your item sells, from 10% to 100%. (The minimum donation is \$1.)
5. If you're never sold on eBay Giving Works before, you'll need to review and accept the [eBay Giving Works Terms & Conditions](#).
6. That's it! Now complete and submit your listing.

From Board the Room

BOARD MEETING SCHEDULE 2010

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

May 27th | July 8th (conference call)
August 26th | September 30th

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

BOARD OF DIRECTORS - OFFICERS AND COMMITTEE LEADS 2010

All of our wonderful volunteers for 2010 – if you'd like any information on how to help out or get involved – email info@pkuil.org or check out our new web site

PKU Organization of Illinois – Officer and Committee Positions

A non-for-profit Illinois corporation qualified under Section 501(c)(3) of the Internal Revenue Code for tax-deductible contributions

President
Christina Sciarrotta

Vice President
Eva Brandon

Treasurer
Joe Annunzio

Secretary
Heather Ricca

Board of Directors – 11 Voting Positions and 3 Non-Voting Positions

Current members – Joe Annunzio, Eva and Michelle Brandon (shared seat), Jim Critchfield, Christina Sciarrotta, Steve Bennett, Jill Franks, Ruthie Jager, Julie Johnstone, Gary Krasno, Mike McMahon, David and Heather Ricca (shared seat) Barb Goss (Honorary), Hazel Vespa (Honorary), Ex-Officio – vacant 2010

COMMITTEES

<p>Annual Meeting Committee</p> <p>Plans and implements the annual meeting, manage task list for annual meeting, report ideas and agenda to board for approval</p> <p>Christina Sciarrotta Hazel Vespa Barb Goss</p>	<p>Education Committee</p> <p>Manages scholarship program, works with clinics on needs for any of their educational programs</p> <p>Julie Johnstone Lauren Levitton Hazel Vespa</p>	<p>Hospitality Committee</p> <p>Plans social events (coffees, picnics, camps, cooking events); assists with new member orientation upon diagnosis</p> <p>Michelle Brandon Ruthie Jager</p>	<p>Vendor and Product Management</p> <p>Liaison with all food and formula vendors, single point of contact to communicate and solicit vendor product, donation and representation needs, ensures vendor information sent to comm. committee. Manages org inventory of products</p> <p>TBD</p>	<p>PKU Awareness Month Committee</p> <p>Manages PKU Awareness Month events, marketing and communications</p> <p>Eva Brandon Heather Ricca David Ricca</p>
<p>Communications Committee</p> <p>Manages publication of <i>PKU Press</i>, Illinois Directory, and other org. marketing material, PKU website; other clinic communication needs, manages google doc site</p> <p>Gary Krasno David Ricca Julie Johnstone</p>	<p>Fundraising Committee</p> <p>Manages and plans fundraising goals and activities each year – serves as liaison for any fundraising events planned outside board</p> <p>Mike McMahon Steve and Lisa Bennett Jim Critchfield</p>	<p>Legal and Legislative Committee</p> <p>Ensures compliance with legal and tax requirements; maintains insurance coverage; protects member interests in health care and insurance legislation, follows local legislation for communication to community</p> <p>Joe Annunzio Jim Critchfield</p>	<p>NPKUA Representative</p> <p>Represents Illinois on NPKUA Board, makes recommendation to board on how Illinois should be contribution time and funds to NPKUA, reports on NPKUA activities</p> <p>Julie Johnstone</p>	<p>Allied Disorder Committee</p> <p>Manages all events for Allied Disorders, manages any material or communication needs specific to Allied Disorder community</p> <p>Jill Franks Hazel Vespa Barb Goss</p>

aVoice

Reprinted with permission from Children's Memorial Hospital

Translating Transitions

At Children's Memorial Hospital, a variety of programs help patients and their families prepare for a longer life

BY JULIE JUNG

Children's, our patients have a social worker, a nutritionist, a genetic counselor, but working with an adult doctor, they probably won't have that team of people working on their case anymore."

>>> ■ <<<

WHEN TALKING ABOUT hospital social workers, Vespa likes to cite Richard Cabot, a progressive doctor and medical reformer from the early twentieth century, who said that their role is "a translator and communicator between two sides with differing perspectives."

Based on her research and case experience, Vespa created the first family intake evaluation for PKU at Children's in the early 1970s. Now a senior social worker in the Division of Genetics, Birth Defects and Metabolism, and Family Services, Vespa sees newly diagnosed PKU and rare metabolic patients. One of her patients dubbed her "the grandmother of PKU," an honor she clearly enjoys.

Rubovits, a cardiology/heart transplant social worker, works with the Mended Little Heart Support Group at Children's, a program sponsored by the



Social workers Sandy Rubovits (left) and Hazel Vespa have helped create Children's Memorial Hospital's transitions programs.

MOST PEOPLE in the United States transition from a pediatrician to an adult care internist around their teen years. But for children who have grown up with chronic illness, it's not so easy.

It's not that internists do not want to help these patients. But many simply don't have the experience or training with adults with these illnesses. Until fairly recently, most children with chronic diseases such as spina bifida or cystic fibrosis did not live through puberty, let alone into their teen years and beyond. Certain illnesses that lead to retardation, such as phenylketonuria (PKU), were recognized as early as 1930, but until the 1960s there was no effective prenatal testing and accurate preventative care.

Recent significant advances in medicine, prevention, and genetic testing have allowed an entirely new group of patients with a variety of illnesses to

survive to adulthood, where patients have to learn how to navigate issues such as managing their health in school and/or in the workplace. Children's Memorial Hospital in Chicago has been a trailblazer and is one of a handful of hospitals that are responding to this growing need with the development of transition programs for children aging out of pediatric care.

Hazel Vespa and Sandy Rubovits, both alumnae of SSA's master's program, Class of 1968, are among the doctors, nurses, nutritionists, and therapists who have helped create Children's transitions programs. With intensive training in long-term counseling for chronic illness, they have helped hundreds of patients and their families meet the challenges of finding adult-level care and social supports.

"As social workers, we are learning how to build bridges for children who grow up and have to work with an adult doctor," Rubovits says. "At

Hospital social workers guide families through both practical and psychosocial issues during the process of critical care. They do intake and discharge planning, provide psychosocial services, arrange for language translators, help families navigate the labyrinth of insurance and disability forms, and provide a constant, friendly face for families who often see many different doctors. "Social workers help families to cope as best they can," Vespa says.

During her master's fieldwork at the Jewish Family and Community Services, Vespa wrote her first research paper for a class taught by Professor Mary Lou Somers that framed the family unit as a small group—a unique perspective for its time. She says that this early research enabled her to later develop Children's programs for patients with PKU, a genetic condition where children cannot metabolize the protein phenylalanine. Treatment is entirely diet modification.

Division of Cardiology in conjunction with the American Heart Association. She helps parent support group leaders to secure speakers such as psychologists, cardiologists, and therapists to talk to patients and families facing organ transplantation. Groups such as Mended Little Heart give families the opportunities to build and provide a network of support.

Rubovits says that Children's legacy of hospital social work is due to its decades of field placement programs and student interns from schools such as SSA and hospital social work pioneers, including Betty Butler, Bernece Simon, Karen Teigiser, Shelton Key and Phyllis Wexler—SSA graduates and instructors during the 1940s through the 1970s. SSA has provided particularly strong consultation and direct field instruction to the student unit. "It has been a wonderful opportunity for students to learn—and to the benefit of the patients," Rubovits says.

Rubovits' own internship was at Children's, working with the "caring

from the Field

and insightful” Betty Butler. “We did groups on the medical floors with patients in ward service, at times with a mixture of medical diagnoses. First- and second-year SSA students attempted to help patients express their feelings and responses about medical procedures, isolation of hospitalization, and fears evoked by their respective illnesses,” she says.



RUBOVITS’ INITIAL TRANSITION PROGRAM, which she led for five years,

Children’s is developing transition programs across the multiple specialties of chronic diseases, including liver transplant programs, Marfan syndrome (a genetic disorder that affects the connective tissue), epilepsy, juvenile rheumatoid arthritis, spina bifida and PKU.

“By empowering patients during adolescence, we believe that they will be set up for success in managing their condition not only in the adult medical care setting but also in real life situations.” says Sarah Ahlm, the program manager in the hospital’s Epilepsy Center and a 1999 SSA graduate.

a patient who’s been through this can relate to others in the same position. My job is to bring these people together so that they feel as if they have a community and a circle of support,” Rubovits says.

Rubovits says her job provides enormous satisfaction, such as when a former heart patient came back to Children’s to mentor and support younger patients. Now seventeen, the young man wrote a letter about how he was thankful for his care and that because his younger brothers had been tested, they did not have to endure what he did.

Vespa, whose PKU parent group held their 40th annual meeting this year, also says that watching her patients become part of the hospital’s family is part of what she enjoys about the work. Her oldest PKU patient is in their 50s now, and she has watched many grow up to have their own children.



LAUREN LEVITON MANAGES the Adult PKU Outreach Program for individuals living with PKU at Children’s, which was funded by a grant from BioMarin Pharmaceuticals Inc. Initiated by Dr. Barbara Burton, M.D., the program’s goals include educating adult patients about the neurocognitive and psychiatric consequences of elevated blood phenylalanine levels, sharing new treatment information, providing referrals to comprehensive medical care and linking patients to networking opportunities with other adults with PKU. So far, the clinic has connected with 59 patients previously lost to follow up care.

Last year, Vespa and Leviton co-wrote a supplemental grant request to the PKU Organization of Illinois. As a result, the hospital has been able to support payment for medical services for some of the most vulnerable patients in the program—those in their 20s who are not insured, either because they’ve aged-out of state insurance or

are no longer eligible to be on their parents’ insurance plan.

Leviton, who graduated from SSA with a master’s in 2008, is one of a small army of social workers trained by Vepsa and Rubovits over the years. “People really need to have first-hand experience with patients as there are so many things that play into critical care,” says Leviton, who also credits Assistant Professor Malitta Engstrom’s Family Systems: Health and Mental Health class for providing a framework in how the course of illness applies to living with a diagnosis.

Leviton says she would like to see the PKU program evolve by creating separate meeting tracks for patients who learned they had PKU as a result of available newborn screening and for families of individuals who were diagnosed with PKU before newborn screening was available because some of their concerns and perceptions about their disease are different. She also believes that giving pre-adolescents opportunities to meet one-on-one with their doctors (and without their parents) will help them to take further ownership of their own health care.

Family-centered care, new innovations in counseling and a more evolved understanding about how to deliver chronic care has altered the domain of hospital social work. Vespa says that in training younger social workers, for example, she’s finding that she can build on their Internet savvy and strengths in social networking to optimize the one-on-one social worker to patient relationship. This is particularly important because insurance companies are either severely restricting or do not allow for long-term counseling for chronic care.

“As social workers, we are able to give parents and children comprehensive care and help families to feel not so helpless,” Rubovits says. It seems that hope, in the absence of a cure, is one of the best medicines. ■



was a group for heart transplant patients who were graduating from high school. Starting in 1999, Rubovits helped the members of her group explore what their next steps could be in job training settings, in finding employment and in peer-group self reflection, with the focus on what was to be expected as an emerging adult needing continual care of a transplanted organ.

Building from the heart-transplant group and other similar programs, Children’s has instituted an institutional dictum over the last decade to prepare all patients early for transition in care. These transitions programs specifically aid patients in their move to adulthood and in dealing with adult self-care issues, such as cooking for themselves if a patient has special dietary needs.

A patient starts and may utilize a transition program at different times depending on their particular developmental needs. The program for a disease such as PKU starts early, initially teaching parents how to properly feed their newborns and later teaching pre-adolescents (ages 11-13) how to make healthy choices on their own. In contrast, an adult PKU patient who was not diagnosed early and faces cognitive problems will need ongoing counseling to address at-home care and employment or disability options.

Social workers also help parents deal with chronic grief. Some of this work is done in transition program forums of support for families and patients during diagnosis and treatment, such as Children’s all-volunteer ParentWISE program. “Only a parent or

Spring 2010

PKU Press

A Periodic Newsletter Published By The PKU Organization Of Illinois

Contact Your Legislators!

PKU Members: Help Make a Difference in the Future of PKU.

The **Kakkis EveryLife Foundation** has just made it even easier to contact your legislative representatives to support the **Medical Foods Equity Act**. The Kakkis EveryLife Foundation is dedicated to expanding access to treatment for patients with very rare diseases by improving the predictability of the FDA regulatory process through science driven public policy that includes better understanding of new surrogate measures of disease, new clinical study designs, and new organizational focus at the FDA. In effort to ensure access to treatments for patients with rare diseases, the Foundation also supports the legislative efforts of our patient organization Partners.

Please visit <http://www.congressweb.com/cweb4/index.cfm?orgcode=kaki>

and click on the NPKUA headline under "Our Issues." You can either write your own letter or use a pre-filled one that you can personalize to your legislators. CongressWeb will then email your letter to your legislators or give you an option to print out your letter and mail it yourself.

Contacting your legislators has never been easier! Your representatives need to hear from you if we want this legislation to move forward that would require all health insurance companies and federal programs to cover the cost of formula and food for all ages!

PKU PRESS

The PKU PRESS is published two 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

2010 PKU Organization of Illinois Officers

Christina Sciarrotta - President
Eva Brandon - Vice-President
Joe Annunzio - Treasurer
Heather Ricca - Secretary

2010 PKU Organization of Illinois Board Members

Joe Annunzio, Eva and Michelle Brandon (shared seat), Steve Bennett, Jim Critchfield, Jill Franks, Ruthie Jager, Julie Johnstone, Gary Krasno, Mike McMahon, Heather and David Ricca (shared seat), Christina Sciarrotta

2010 PKU Organization of Illinois Honorary Members

Barbara Goss and Hazel Vespa