



# CanPKU News

Issue No. 6

Canadian PKU & Allied Disorders Inc. Newsletter

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**B:OMARIN**



Dear Reader,

During this busy season it is important to take a few minutes to yourself, so sit back, relax and read our newsletter! This edition has tons of interesting information and includes a personal tribute to Dr. Koch, a recipe for Low-Phe Christmas Stuffing, information about the ROSE award winner and many of our regular articles such as our PKU Profile, Ask Us, Hat's Off, Advocacy 101 and more! Click on the title to the left and it will take you directly to the article you are most interested in, or read them all in order so you don't miss anything!

As always, we welcome questions and comments about PKU and this newsletter so don't hesitate to email us if there is something you are curious about... Because Knowledge Leads to Better Health!

Sincerely,

Nicole Pallone

Mom of Rosie, 4, CPKU & Carmella, 1

Vice President, Canadian PKU & Allied Disorders Inc.

## [A Tribute to "Dr. PKU" Richard Koch](#)

[by John Adams](#)

*Los Angeles Times, October 08, 2011:*

*Dr. Richard Koch dies at 89; medical pioneer*

*After the World War II bombardier became a doctor, he changed the way the developmentally disabled were treated and made huge strides in fighting PKU, a disorder that can cause mental disability.*



Innovation in Nutrition

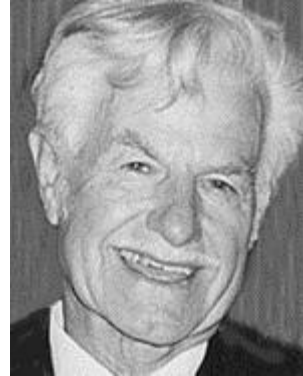
## RECIPE CORNER

### Rosie's Low Phe Stuffing



Christmas is almost here! Make sure your PKU loved one doesn't miss out on one of the best parts of Turkey dinner: **stuffing!** This recipe is EXACTLY the same as my family recipe except for the low phe bread cubes. If you don't have any of the Cambrooke Foods Artisan Loaves replace with whatever low-phe bread you do have (subtract 36mg of phe from the recipe total, and add in the phe amount of your bread).

With this on the table, the PKU people at your holiday table can enjoy everything but the turkey!(Bonus



Dr. Koch (pronounced "coke") had a heart condition and passed away Sept. 24 at his Los Angeles home.

Although I first met Dick and Jean Koch at a scientific conference in 2008 in Switzerland, we felt we already knew each other well through the global village of PKU. On an outing, Dick asked if he could hold my arm while walking up a hill, noting "I could use a little help. I had coronary bypass surgery three weeks ago." He was 86 at the time. There was no hill or mountain too challenging in his lifelong pursuit of better outcomes for people living with PKU. There is not a single person living with PKU anywhere in the world whose life and life prospects are not better because of what he contributed.

We became instant, good friends and three months later my PKU adult son and I stayed with them in their home. There was a creative plan behind that kind invitation: on the second day, Dick took us to see two group homes specializing in the care of older adults with PKU, who were born before the modern miracle of newborn screening and who had spent most of their lives in institutional care not on PKU diet. My son, then age 21 years and in university, had never met a group of untreated PKUers before. He was profoundly moved and could fully grasp what his life might have been like without the scientific and family pioneers of PKU.

In these group homes, the residents in their 50s and 60s were placed on the diet and some responded to Kuvan. Few had ever spoken; some could not walk. One woman in her 60s said her first word while we were present, according to the staff. Her first word was "coffee". In every case, behaviours and quality of life improved. Another woman made remarkable progress, had obtained an entry-level job in a

tips: replace the butter and milk in your mashed or whipped potatoes with olive oil, or a combo of phe-free margarine and rice dream , and thicken the leftover G. Washington broth from this recipe with some water & cornstarch for a phe-free gravy!)

Prep time: 10 minutes

Cooking time: 10 minutes

Oven time: 45-60 minutes

Total Phe: 8.86

exchanges or 133mg

Yield: 4 cups/servings

Phe per serving: 2.23exch

or 33.5mg

### INGREDIENTS:

2 tbsp butter

56g of raisins

100g of onion, chopped

100g of celery, chopped

170g of Cambrooke Foods Artisan Bread, cubed

1/2 tsp of thyme

1/2 tsp of sage

2 oz of prepared G.Washington Golden Broth

### INSTRUCTIONS:

Heat butter in saucepan over med-high heat. Saute onions and celery until soft and golden. Add raisins, sage and thyme; heat through. Add cubed bread and prepared broth. Stir thoroughly to coat bread with spices. Transfer to oven-safe dish and bake in oven until top is slightly crisp (about 45 minutes at 350 degrees). Tip: bake this beside the turkey or the day before, to ease the

school cafeteria and learned to take the bus on her own from the group home to the school. She was excited to bring home news of all the new things about food she was learning in the cafeteria.



*Jean and Richard Koch: lifelong learners and teachers at BH4 conference in Switzerland, March 2008; he presented early results of treating pregnancies of PKU moms with Kuvan, then the new drug for PKU based on BH4, tetrahydrobiopterin.*

One of Dick's missions in life was to get older PKUers out of institutional care and on to PKU treatments and community support services.

He had other missions. In World War II, he flew 13 missions over Nazi Germany in a B-24 bomber. In April 1944, Koch and his fellow crew members were shot down. While in the POW camp, he bartered for a typewriter and started a newspaper. He chose his life's work after reading one of the few books in the POW camp's meager library - the medical biography "The Doctors Mayo."

After the war, Koch obtained his medical degree from the University of Rochester School of Medicine and joined Children's Hospital of Los Angeles in 1951 as an intern in Pediatrics.

He was an early advocate against institutionalizing the developmentally disabled, which was commonplace in 1955 when Koch was named director of the hospital's newly established clinic for the study of mental disabilities.

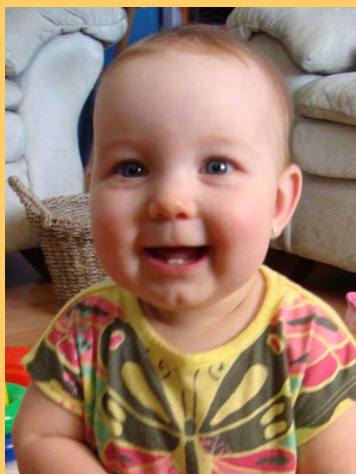
He pioneered mobile clinics that brought medical services to the disabled and helped lead a landmark effort to screen newborns for PKU. Koch was chief of child development at the Children's Hospital of Los Angeles and President of the

preparation of Christmas dinner!

## MERRY CHRISTMAS EVERYONE!!

### PKU Profile

#### Andréanne Ouellette



Andréanne Ouellette was born on December 17th, 2010 to proud parents Elsie and Serge, a beautiful 8lbs 8oz baby girl. "The first week was a bit hard" says Andréanne's Mom, Elsie. "She would be up all night and nap a bit during the day." On December 22nd, on their way back from their family doctor, the Ouellette's phone rang. It was someone at Children's Hospital of Eastern Ontario (CHEO) calling to say that Andréanne's newborn screening test came back showing elevated levels for PKU. "Not knowing what PKU was, the woman offered to explain," says Elsie. "She said 'PKU means Andréanne could be mentally retarded'; the explanation was longer but that's all I heard. I pulled over with tears in my eyes thinking they must have the wrong baby; my little girl was

California Association for Retarded Citizens when the California Governor signed the law in 1965 mandating that every newborn be tested for PKU.

The traveling clinics he created evolved into dedicated regional centers that enabled children to remain home with their families or live in a non-institutional setting. After Gov. Pat Brown signed legislation in 1966 to create a regional-center system in California, Koch served as the founding director of a Children's Hospital pilot facility now known as Frank D. Lanterman Regional Center. More than 20 were eventually established around the state.

As a researcher, Koch devoted much of his career to learning more about how to prevent disability in PKU. He was the Principal Investigator of two hugely significant clinical studies: the first was the Collaborative Study of Children Treated for PKU started in 1964 and the second was the Collaborative Study of Maternal PKU started in 1984. The first study ran until 1982 involving 16 clinics and developed the broad scientific evidence for a radical change in PKU management: Diet for Life.

But around 1980, health officials noticed that female PKU patients saved from disability were giving birth to babies with mental disabilities and other disorders. PKU mothers who followed a regular diet were developing high blood levels of phenylalanine that damaged the fetus.

"Logically, we should have thought of it," Koch told The Los Angeles Times in 1996. "But I think we were so enthused about these first PKU patients even being normal. That in itself was a shock."

Unable to bear the thought that "a small army of patients that had been saved from this condition was producing a new flock of disabled children," Koch secured a grant to deal with the problem.

With Koch coordinating the effort, Children's Hospital served as the hub to collect data on adult PKU patients and encourage those who were pregnant to return to the low-protein diet to increase their chances of having a healthy baby.

It is largely because of these two multi-centre, multi-country studies that he is known in the USA and internationally as Dr. PKU. The license plate for his car said, "Dr. PKU". Says Colleen



perfectly healthy." The family was told to rush to CHEO as soon as possible for another blood test. It took them an hour ride to get to the hospital and they arrived there 15 minutes before the blood lab closed, which meant they had to wait until the next day to get the results. The next morning, they received a phone call from the hospital telling them to pack a bag for Andréanne because she would likely be hospitalized for 1 night for testing (CHEO is one of the many clinics that does a BH4 load to rule out Bipterin Deficiency). On December 24th, at 7pm, Andréanne was discharged and the Ouellette family celebrated Christmas at home, surrounded by loved ones. "It was hard at the beginning but I was happy that I could still breastfeed my little girl half of the time," says Elsie. "It wasn't always easy breastfeeding, pumping, mixing formula but we got through it." Andréanne is now a year old and eating solids, and Mommy and Daddy have gone through all those stages that first time PKU parents find stressful... the beginning of solids, stressful because of new calculations and level fluctuations; teething, when babies sometimes don't want to eat at all and getting in the right amount of Phe each day can be hard, and finger food, making it a huge challenge to figure out exactly what was consumed! Elsie describes Andréanne: "She is such a happy, expressive baby and she's growing normally. She is just like any baby her age. She puts a smile on our faces every day." In September, the Ouellette's decided to organize a fundraiser for their

Azen, the biostatistician on Koch's research team: "Dr. Koch pretty much defines the field of PKU research."

Almost until the end of his life, Koch continued to treat PKU patients whom he first saw as infants decades ago, seeing them at his home near the hospital he retired from.

"He was the most unassuming, gracious, gentle, kind-hearted man," said Dr. Linda Randolph, head of medical genetics at Children's Hospital. "You would never know how great he was and what a tremendous contribution he made in the fields of disabilities and PKU from a casual conversation. He never tried to impress anybody."

He was born Nov. 24, 1921, in Dickinson, North Dakota, the sixth of nine children of Valentine Koch, a sheep farmer, and his wife, Barbara. His family moved to Petaluma, California when Richard was 7.

After graduation in 1941 from high school, he soon found himself in the US Army Air Force. At a USO dance, Koch met his future wife, who was playing marimba in the band. He headed off to war soon after they married in 1943.

With his family, he often backpacked, once hiking 110 miles round-trip from Mineral King in Sequoia National Park to Mt. Whitney and trekking 150 miles on the John Muir Trail.

He took a leave of absence in 1970 to spend a year in Peru with his family as a medical volunteer with Project Hope. Well into his 70s, the dedicated environmentalist could be spotted riding his bicycle down Sunset Boulevard to work, his tie flapping in the wind.

Dr. Koch's passion for PKU research and health care extends to his wife, Jean Koch, who authored a biography entitled Robert Guthrie: The PKU Story A Crusade against Mental Retardation.

In addition to his wife, Koch is survived by three daughters, Jill, Christine and Leslie, all of Los Angeles; two sons, Tom and Martin, both of Ridgecrest, Calif.; 10 grandchildren and nine great-grandchildren.

PKU Clinic at CHEO. In the previous two years, Elsie had participated in a fundraiser for the Walk for Women's Cancer in Ottawa. This year it was cancelled, so with the help of family members they decided to organize a fundraiser at the Rideau Carleton Raceway for a cause that affects someone close to them... their beautiful daughter. They had a lot of help from Andréanne's grandmothers, her great-grandmother, and other PKU families in the area, and they had a great turn-out at the fundraiser. They raised \$6598, an impressive total by all accounts!! The Ouellette's find it helpful to talk with other PKU families, and they have great support from their dietitian. "All that is important to us is that she was diagnosed early enough to have a normal life with a healthy diet," says Elsie. "We wouldn't change her for anything in the world, we love her so much!"

*It goes without saying that the Ouellette's went above and beyond their call of duty, organizing such an impressive fundraiser with their PKU daughter less than a year old. Good job Elsie & Serge!*

**FREE CAKE!!**



Click on the above logo and sign up for the Maddy's Birthday Club! Applied Nutrition will send you a free can of Maddy's Cake Mix



Excerpts from an interesting news story:

#### **Race Against Time**

**A generation ago, Dr. Richard Koch made his mark saving PKU babies. Now he's trying for another miracle: saving the children of his first patients.**

September 15, 1996 | SHARI ROAN | LOS ANGELES TIMES

**Dr. Richard Koch remembers that first miracle baby like it was yesterday. That was 30 years ago...**

Koch was chief of child development at the (Children's) Hospital and president of the Assn. for Retarded Citizens. A bill had just been signed by Gov. Pat Brown ordering hospitals to screen every California newborn for a disorder called phenylketonuria (PKU), a metabolic disease that eventually can cause mental retardation but that can be treated with a special no-protein diet. "We haven't had a case of a baby institutionalized since then," Koch says. "The program has been remarkably effective."

But after decades of success, a disturbing twist has emerged in what has been one of medicine's happier stories. It turns out that the first generation of PKU patients, now adults who are in their prime childbearing years, may still be at risk.

What's more, the offspring of women with PKU are in danger of being born with mental retardation or other birth defects if the mother does not return to the special diet--which most adults discontinued years ago--before conception or early in

in time for each birthday!



### ROSE Award Winner

The Applied Nutrition ROSE Award (Recognition of Service Excellence) recognizes individuals who consistently demonstrate outstanding service and selfless work to help improve the health and welfare of those with PKU or MSUD. There are many in the metabolic community who work tirelessly to make a difference in the lives of those with PKU or MSUD. We received many nominations for people that have done wonderful things, but we can only have one winner.

Please join us in congratulating...



**Kristen Vanags**

Kristen has demonstrated outstanding leadership within the PKU community as President and founding member of Georgia PKU Connect. This grassroots organization was started by Kristen and other local parents to bring families from all over Georgia together as a community to share in the care of those impacted by PKU. Kristen is also

pregnancy.

"You have 600 patients with normal intelligence [treated since 1966 in the California program] who are out in society," Koch says. "Half of these people are women. We are very interested in finding these women."

"We have a tremendous potential for prevention here. One mentally retarded baby costs society \$1 million."

### 2011 Event Recap

#### June 11th: AB PKU Day, Red Deer, AB

Our 2011 Event Series started with our **Prairies PKU Day** organized by **Sandra Harland** and was a success with a total headcount of 78 people! This included PKU patients and families, medical professionals, CanPKU representatives, metabolic vendor reps and our keynote speakers. Attendees were wowed with the wisdom and knowledge provided by **Dr. Jerry Vockley** and **Dr. Steven Yannicelli**, and brought to tears with a powerful presentation by our very own **John Adams** on the history of PKU treatment, and the important role families play in pushing doctors and scientists to strive for better treatments. We asked each registrant to introduce themselves to the group and found it to be a great ice-breaker and the kids all had a blast at the on-site daycare (which is standard at all our events, give or take a magician!)

#### July 8-10: ON PKU Day, Polo-4-Kids & CanPKU AGM



This 3-in-1 weekend was organized by our very own **Cristian Baiggoria** and **Janine Anderton** and was a great success! A reception Friday night included refreshments and good conversation as well as a fantastic demonstration by

an active member of the NPKUA Advocacy Committee. In her personal time, she travels to Washington, DC to help promote the Medical Foods Equity Act and lobbies on behalf of all PKU families.

Her dedication to the PKU community on both a national and state level is unyielding. Kristen not only donates her time and energy to the community, but has also excelled at fundraising for Georgia PKU Connect to support Emory University's Metabolic Nutrition Program, the National PKU Alliance Research Program and local community support and advocacy programs. In 2009 the Ultimate PKU Day, created and directed by Kristen raised over \$6,000. Two years later, the fundraising event has grown in size and impact, raising more than \$16,000.

Kristen will be recognized with a \$1000 donation to the Georgia PKU Connect in her honor. In addition, we will hold a special event in Georgia to present Kristen with her award.

### **Congratulations Kristen!**

### **Hat's Off To...**

#### **Seneca Student Federation**

**Roel Isufflari**, Manager of the Seneca College Student Federation in Markham, ON, contacted CanPKU in mid-November. He indicated that **CanPKU board member Tatiana Radu**, a teacher at the college, had inspired his group of students to raise awareness and funds for CanPKU in an effort to help the families that deal with this disorder. Activities include spreading awareness about CanPKU, collecting donations on our behalf and organizing a luncheon where they will give us any funds raised and provide an

renowned **PKU chef Gina Valente!** Saturday's education event included a passionate talk by **Dr. Barbara Burton**, another well-received presentation by John Adams on the history of PKU treatment, a thorough presentation by **Dr. Siriwardena, Valerie Austin** and the rest of the team at the Toronto for Sick Children clinic. We also heard from adult PKU patient **Brian Goetz**, who is currently studying to become a doctor, about the dangers of going off diet and how to avoid those struggles.

Following the education session, attendees traveled a short distance to the **Pampa Norte Polo Farm** and were thoroughly entertained at the **Polo-4-Kids** event! This fundraiser included world-class exhibition polo games, excellent food (including low-Phe options), various vendors and a fun, party atmosphere! Proceeds raised were donated to the **SickKids Foundation**.

Later that night registrants enjoyed a **PKU-friendly banquet**, followed by some **karaoke and dancing** (especially enjoyed by the younger crowd!) There was lots of time to mingle and people seemed to thoroughly enjoy this relaxed, educational weekend get-a-way. On Sunday we held our **Annual General Meeting** which all members were invited to attend - it truly was a fulfilling weekend!

### **August 27th : Newfoundland & Labrador Event**

The second-ever meeting of PKU families in Newfoundland and Labrador took place in an inviting church hall in St. John's and was organized by **Doreen Quinn**. **John Adams** was the guest speaker, once more sharing his wonderful presentation on the role of families in the history of PKU treatments. We were happy to have metabolic diet **vendors** present with their latest product samples, which is always appreciated by the families in attendance. In the audience was a couple with a **newly-diagnosed newborn** and a mother and her son who had travelled a total of **16 hours**, by car and ferry, from Labrador to attend. We appreciated the continuing help of clinic dietitian **Louise Dalton** with the event. In an effort to reach all individuals in the Atlantic regions, the event in 2012 will be held in **Moncton, New Brunswick**.

### **September 18th: BC PKU Day, Vancouver, BC**



opportunity for us to educate all those in attendance about PKU.

This kind of unsolicited volunteer fundraising makes the world a better place. **We are truly grateful to Roel and the Seneca Student Foundation** for all their efforts, and we look forward to attending the luncheon!

### ASK US!

"Is Aspartame the only artificial sweetener that contains PHE? I think this is correct but still stay away from other sweeteners out of fear that I am wrong."

To answer your question I contacted Melanie Reeves, a dietitian at the metabolic clinic at Alberta Children's Hospital. Ms. Reeves advises that it is just aspartame that is the concern. Other artificial sweeteners such as sucralose (**Splenda**), acesulfame potassium (**Ace K**), and **sugar alcohols** such as **sorbitol** and **mannitol** contain no Phenylalane.

However, she cautions that aspartame has several different brand names: **Equal**, **Sweet N Low**, **Nutrasweet** or **AminoSweet** here in North America and **Candarel** in the UK **need to be strictly avoided**. And there may be other brand names for aspartame too so be careful!

**Bottom line: always read the packaging and the fine print and avoid anything that says 'contains aspartame'!**

**Do you have a PKU related question that you are having**



The weather held and the walkers and silent auction bidders **raised just over \$4,500** for CanPKU on the 3rd annual **BC PKU Day**. Attendees enjoyed a light lunch with PKU options and then listened to recollections from **Dr. Louis Woolf**, developer of the first low-PHE formula, as he recalled the mistakes and happy accidents that contributed to the discovery that PKU was indeed treatable. **Mr. John Adams**, founder and President of CanPKU, followed with his in-depth presentation on the history of PKU treatment. Participants then broke off for mini **workshops including Advocacy, Cooking for PKU, Maternal PKU and Transitioning to Adulthood**. We also had the privilege of honoring **Dr. Louis Woolf** and newly retired dietitian **Carol Hartnett** with **PKU Hero awards**.



*Amanda Cosburn presents Dr. Louis Woolf with a PKU Hero Award at BC PKU Day*

All this was followed by a **Q & A session** with professionals and PKU patients, and we were treated to an impromptu performance by talented PKU teen **Sam Balenzano**. It was a

trouble finding the answer to? Send an email to [nicole.pallone@canpku.org](mailto:nicole.pallone@canpku.org) with "Ask Us" as the subject: we'll do our best to find the answer!

## Health Canada creates Patient and Consumer Participation Pool for Health Products and Food Branch

CanPKU encourages you to submit an application to be part of the pool of patients and caregivers who have a voice on issues that matter to those with PKU: health products and food. To read more or apply, [click here](#).



## Care about the Rare!

**February 29, 2012** is global **Rare Diseases Day**. For more information about how you can spread awareness and support those with rare diseases, [click here](#).

If you are in the Ottawa area, consider supporting the **Canadian Organization for Rare Disorders (CORD)** at the "Celebrate the Rare" gala at 6:30pm. For more details go to [the CORD website](#).

## Survey Says...

We recently put out a survey to gather feedback about our events

successful day where registrants were able to meet with vendors of metabolic products and mingle with other PKU patients and clinic staff. Next year we will hold our Vancouver event in June and hope to exceed this year's headcount of 75!

## October 15th: Quebec PKU Day, Montreal, PQ

Our final event of the year was organized by **CanPKU Board Member H el ene Dandurand** and held in Montreal Quebec. Many of the families had attended the year previous and were equally impressed this year with the quality and content of the presenters and their presentations. We were lucky enough to secure yet again **Dr. Jerry Vockley** to speak, with his words ably translated by our own Helene Dandurand into French.

As Scientific Director of the Waters-CHUS Expertise Centre in Clinical Mass Spectrometry and director of the Mass Urinary Screening Program at the CHUS, in Sherbrooke, **Dr. Cristiane Auray-Blais** spoke about the technology, its impact on newborn screening and the follow-up of PKUers.

A lively **Q & A session** followed each of the presentations and though we didn't have as large a turnout as we had hoped for, the families were grateful for the information and the chance to mingle again with other PKU families and have their kids get to hang out together.

**Our 2012 Educational Event Series will take us to Vancouver, Winnipeg, Alliston, Quebec City and Moncton - make sure you keep an eye out for Travel Scholarship opportunities and attend the one closest to you!**

## Advocacy 101

Advocacy is verbal support or argument for the purpose of instigating action. It is not activism; it is grounded in logical, rational thought. There are differences between awareness, education, and advocacy - only advocacy is about tangible change.

in an effort to learn what people really want and increase future attendance. Preliminary results show that content of speakers is the number one priority and we will strive to bring quality presentations to our events in 2012.

We have also learned that the cost of traveling to our events is an issue for many, and we are currently looking for ways to create a sustainable Travel Scholarship Fund so that we can continue to assist families with attending these educational and networking opportunities.

We have had lots of constructive criticism from the comments provided and we appreciate everyone who has taken the time to answer the survey. If you have ten free minutes, please [click here](#) to take the survey!

Whether or not you have attended our events in the past, your feedback is important and will help us create events that you don't want to miss!

### **New Webcast Discussing Current BioMarin PKU Clinical Studies: Peg Pal, PKU 016 & the Blood Phe Monitor System**

Curious about current BioMarin PKU Clinical studies? What is being studied? What progress has been made? Listen to our [latest clinical](#)

In each newsletter we will provide simple tasks that everyone can do to further the cause, and tips on how to be an effective advocate.

Previous suggestions included writing letters to local government officials, including your MLA and Minister of Health, and educating local school staff or work colleagues during a professional development day or staff meeting with a PKU Seminar.

Tips to make it effective include making it personal and keeping it simple. Tell your PKU story: how it has affected you and your loved ones as well as what needs to be done to make life better for you and yours. Explain a little bit about what PKU is, but keep it simple. Make sure your letter is specific to what needs to be done in your province. (For information on this, email us or check out the 'resources' section on our website for a summary of what is covered in each province.)

**This quarter, focus on someone close to home. If you are the parent of someone with PKU sit down with them and have frank discussions, no matter what age, about the disorder. Explain how important 'diet for life' is and what can happen if they eat the wrong things. I strongly believe that kids are smarter than we think they are. Because of this belief I often talk to my kids as though they are years older than they really are, and then backtrack a little if they seem confused. Usually, they are not. Before my daughter was 3 years old she knew that she had PKU, she had to weigh her food, she couldn't share her food, and that eating high protein food was bad for her brain.**

If you are an adult with PKU pick someone close to you and invite them out for coffee for a mini education session. This can be a spouse, a sibling, your own child, a friend, coworker or even your boss! Explain to them what PKU is, what the diet is like, why 'diet for life' is important. Alert them to the symptoms you experience when you are off diet. Talk about your successes and your frustrations, your fears and any silver linings...

[studies webcast](#) that covers a number of the current clinical studies, including Peg Pal, PKU 016 and an update about the Blood Phe Monitor system.

In the case of the programs noted in this alert, we worked closely with the BioMarin Clinical Operations team to ensure the information presented is complete and accurate. Our belief is that keeping your eye on research is an important way of staying informed. In the webcast above, you'll hear about BioMarin's current PKU studies and, of course, you can always go to [clinicaltrials.gov](http://clinicaltrials.gov) to learn more about any and all studies in PKU.

### PK (Me and) U

by Mark Huddart

Like an assassin it lays quietly,  
Where nobody can see,  
Like a drug in large doses,  
It damages me.

On the surface I'm normal,  
So nobody can tell,  
The effects that I feel,  
Or my minds living hell.

To some I'm the weirdo,  
The short tempered guy,  
But they just don't know,  
That my levels are high,  
It means nothing to you,  
So it mustn't exist,  
But to me things are cloudy,  
I see life through a mist,

From the need to be normal,  
I do what they do,  
They're pleasure is my poison,  
But i just carry on through,

**most importantly, let them ask questions!**

As with any of your advocating efforts, we're here to help. Feel free to call or email us for assistance in this regard.

*Please note: CanPKU fully supports each of its members being personal advocates; however, any communications that show affiliation with CanPKU including but not limited to the use of the CanPKU logo, CanPKU letterhead or your title as a CanPKU member means that the communication must be pre- approved by the CanPKU President or Vice-President.*

### Become a Member!

The more members we have the greater our voice is when advocating for better treatment coverage and care.

**New members will receive one free issue of National PKU News, courtesy of Virginia Schuett!**

By becoming a member you are showing your support for CanPKU to accomplish its goals, which include:

- Creating awareness about PKU and other inherited metabolic disorders;
- Providing a supportive community for those living with PKU and other inherited metabolic disorders;
- Increasing opportunities for PKU families and others to attend educational and networking events;
- To improve the lives of people living with PKU and other inherited metabolic disorders;
- Promoting and supporting research; and
- Advocating for increased treatment coverage across Canada.

Becoming a member includes the following benefits to you:

- Direct contact from CanPKU regarding



Filling myself,  
With my own kryptonite,  
Knowing tomorrow,  
My head will feel shite.

Now I'm sick of feeling drunk,  
And out of the zone,  
So I'm sobering up,  
Knowing I'm not alone,  
For the people on here,  
Understand I'm not drunk  
Just been filling my body,  
With all sorts of junk!

We all have our weakness,  
But you all share in mine,  
The missing part in our puzzle,  
That little enzyme,  
So I haven't touched drugs,  
I committed no crime,  
I just ate some food high in,  
Phenylalanine!

***Mark Huddart is an adult living  
with PKU in Surrey, UK. Thanks for  
sharing, Mark!***

- newsletters and event invitations;
- Direct access to new information regarding treatments, research and Provincial/Territorial advocacy campaigns;
- Support from other individuals and families who understand;
- Reduced registration fees for all CanPKU events;
- Priority access to travel bursaries for CanPKU events, when available;
- Opportunities to volunteer and make a difference;
- Tips on advocacy and creating awareness in your community; and
- Voting rights at Annual General Meetings and Special Meetings.

To become a member go to  
<http://www.canpku.org/become-a-member>.

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Dear Reader;

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Sincerely,  
Canadian PKU & Allied Disorders Inc.



Because Knowledge Leads to Better Health

[www.canpku.org](http://www.canpku.org) | [info@canpku.org](mailto:info@canpku.org)  
Suite 180 - 260 Adelaide Street East, Toronto, ON M5A1N1  
416-207-0064 or 1-877-226-7581 | fax 1-877-789-2462

