

# CanPKU News



from **Canadian PKU & Allied Disorders Inc.**

## In This Issue

- [Important Dates](#)
- [In the News](#)
- [CanPKU AGM](#)
- [Exciting Announcement: Canadian PKU Camp!](#)
- [Contest: Name the Camp](#)
- [Back to School](#)
- [Quebec Education Event](#)
- [Fundraiser in Vaudreuil Dorion, QC](#)
- [Ouverture de la Clinique metabolique](#)
- [Resignation of Nicole Pallone](#)
- [Advocacy - Please help!](#)

## Quick Links

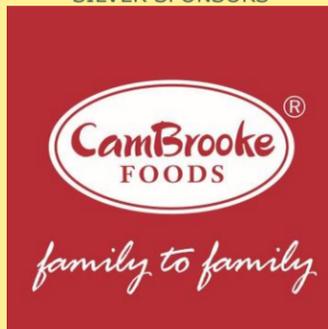
- [Quebec PKU Day](#)
- [About Us](#)
- [Membership Purchase](#)
- [DTC Package Request](#)

## Our Sponsors

BRONZE SPONSORS



SILVER SPONSORS



GOLD SPONSORS



Dear Friend,

Welcome to the 25th issue of the CanPKU newsletter.

Well, the calendar says it's fall, but we are still waiting for Mother Nature to agree, at least in Ontario! Bring on bonfires, cooler nights and hoodies!

Our big news this edition is that we have been busy this summer planning a new initiative (It's pretty exciting!!) You will also find some hints on how to make Back to School smoother and updates on what's going on in Quebec and BC. Our recipe section will fly you around the world to Hungary to try out a popular cultural dish in time for the fall harvest. (Which especially excited our family as our PKUer is part Hungarian). And so much more! Read on!

Our next newsletter will be coming out in December; Please see our request for your input below!

We hope you enjoy this 25th edition of the CanPKU Newsletter!

Sincerely,

Tanya Chute  
Newsletter Editor  
& Secretary

Nicole Pallone  
Vice President

John Adams  
President & CEO

## EXCITING ANNOUNCEMENT FROM CANPKU!!

**Join us for the first annual CanPKU Camp for all ages!**

**Save the dates: Sept. 22-24, 2017 Weekend Camp**



**Mark your calendars: We're extremely excited to announce that we're hosting our first ever camp weekend next September!**

The camp will take place the weekend of Friday evening, September 22 through Sunday midday September 24, 2017, just outside of Peterborough, Ontario.

2017 just happens to be Canada's 150th birthday! What better time to bring our PKU community together than with a national event!

Gather your friends, loved ones and/or yourself - those with PKU and those without - for a weekend full of camp activities, campfires and cabins. Join us for teen and adult cooking demos and low-protein food made by a PKU chef, all weekend long. Lots of camp activities for children of all ages! Much like our Ontario PKU day, we'll also search high and low in the PKU world to find expert speakers to let you know about the latest news and research and provide some new ideas as to how to manage the diet.

Nestled in the heart of the Kawarthas, the campground offers a traditional camp experience, including a scenic and relaxing venue with more than 186 acres of beautiful land with trails, forests and wetlands, and 800 feet of waterfront. Take a break from food preparation and relax near the lake, take in information, and mingle and enjoy others in our extended PKU family!

### Upcoming CanPKU Events:

**October 17, 2016**  
CanPKU AGM

**October 22, 2016**  
Quebec PKU Day in Quebec City

**April 1, 2017**  
BC PKU Day in Vancouver, BC

**June 17, 2017**  
Atlantic PKU Day in Moncton, NB

**September 22-24, 2017**  
First Annual CanPKU Camp!!



Registration opens December 1, 2016 (a great Christmas gift, wink, wink) and is provided on a first-come, first-served basis. Day passes (with meals) will be available for Saturday, September 23, 2017, for those not wishing to stay overnight. The camp is open to families, grandparents and other relatives, adults with PKU, and anyone else affected by PKU. Friends are welcome too!

This event will take the place of our Ontario PKU day for 2017. This first annual camp means we intend to make the camp sustainable and repeat it annually. As for cost, we're currently seeking out new sources of funding to subsidize costs and make it affordable for all (more on that soon!). In the meantime, we're always looking for new ideas: if you have a fundraising idea, we want to hear it! Please contact [camp@canpku.org](mailto:camp@canpku.org).

More to come soon! Check out our website for some FAQs.

### Recipe Corner

When I first heard of a Hungarian Goulash on [PKU - Be Inspired's](#) Facebook page, I was intrigued, over the moon excited, and whipped off an email to get a recipe to share! We are excited to bring this to our table.

**Please note: because this recipe hails from the UK where most fruits and vegetables are considered 'free' foods, there is no phe breakdown for this recipe.**



Yield: 4 servings

You'll need

- 2 tbsp olive oil
- 1 medium onion, sliced
- 3 garlic cloves, crushed
- 2 red peppers, cut into thick slices
- 1 tbsp tomato puree
- 1 tbsp sweet paprika
- 2 tsp hot smoked paprika
- 1kg sweet potatoes, cut into 3-4cm chunks
- 200g button mushrooms
- 1 400g can chopped tomatoes
- 100ml vegetable stock
- Salt to taste

1. Heat the oil in a large pan and fry onion, garlic and peppers until the peppers are starting to soften.
2. Add the tomato puree, the 2 types of paprika, the sweet potato chunks and the mushrooms, then stir well to coat.
3. Add the chopped tomatoes and bring to a simmer.
4. Tip the stew into the slow cooker, add 100ml of hot stock, mix well and cover. Cook on the low setting for 4 hours. Cooking times may vary depending on the brand and size of your slow cooker so always check that the sweet potatoes are cooked through (but still firm) before turning off the slow cooker.

Also check the seasoning and add a little salt if you wish before serving the goulash steaming hot. Eat it on its own or with a side of boiled rice, steamed greens or homemade LP flatbread.

If you have a recipe to share, please submit it to [newseditor@canpku.org](mailto:newseditor@canpku.org).

### What's the name of our camp? Wouldn't we like to know!

Name our camp! Do you have a catchy, clever and/or quirky name for our camp? Submit your ideas to Lisa Olsen, Camp Director, at [camp@canpku.org](mailto:camp@canpku.org) and you could win a free camp registration!

**All submissions must be received by November 1, 2016.**

### Back to School!

DayCare, PreSchool, Kindergarten, Grade One?



It has been a short couple of years since we handed the management of PKU over to the education system in our home. I remember spending HOURS on the internet making what teachers would either love or hate me for... our School PKU Guide. The binder gets updated each year and will travel with him through the school system. Other parents before us have done the same, and many families have their own system. I thought it would be a great time of year to supply you with some of the tools that the CanPKU website provides in this regard.

[The ABC's of PKU](#) was developed by Nicole Pallone when her PKU daughter was entering public school. This 8-page summary of PKU is everything a teacher, daycare provider or babysitter needs to know about PKU, including a final page for you to personalize with your specific information.

[Passing on the Scale](#) is a description of Laura Demchuk Sloan's process of preparing for daycare that you may also find useful. She also wrote [My Baby & PKU](#) to educate daycare staff.

[My PKU Binder](#) also has helpful hints through out its pages. We found it helpful to search the keyword "school or daycare".

[PKU and the Brain](#) is a handy resource which was included for teachers to review for our binder. This is available for free on the website as a download as well as in book form for a small fee.

How does your family prepare for Back to School? Are there any tips you can add to help us update these resources or to help design a How to Guide for those **Heading off to Post Secondary?** from a parent or PKUers point of view?? We are often each others best resources and we would love to hear from those of you who are already at this stage! Email to [newseditor@CanPKU.org](mailto:newseditor@CanPKU.org)

## PKU Profile

Sam is a 21 year old, fun loving, adventure seeking, young adult from Vancouver, B.C. She was diagnosed with PKU at two weeks old and was blessed with parents who strived to raise her to her full potential. When she was young, the doctors told her parents that her brain was in their hands, and if she wanted to do well in school and participate in extra curricular activities, it was up to them.



Growing up, Sam danced, played basketball, volleyball, was great at swimming and was an outstanding student. Now, she plays soccer, piano, guitar, ukulele, and drums. She also leads a group of grade seven girls every week in faith related discussions and activities. She graduated high school with a Youth Ministry scholarship and graduated with her Hospitality and Resort Business Management Diploma in November 2014 with an average of 87%. She has gone on to be a tournament coordinator at an elite golf club.

Sam has classic PKU with a low tolerance, however she has never strayed from her diet and has always had good levels. She reluctantly tried Kuvan and to her and everyone else's surprise, she responded wonderfully. Now that the trial is over, the funding for the drug is non-existent, but her and her family and friends refuse to give up fighting for coverage. Sam loves to travel and is always looking for ways to make her diet easier to handle so she can satisfy her wanderlust.

[Join Our Mailing List!](#)

## In the News

Articles you may enjoy

<http://www.raredr.com/contributor/jennifer-payne/2016/09/driving-microbiome-science-pku-and-probiotics>

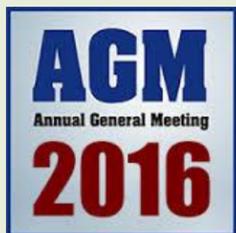
PKU Market - Phenylketonuria Pipeline Therapeutics Landscape 2016 Report -

<http://www.prnewswire.com/news-releases/pku-market---phenylketonuria-pipeline-therapeutics-landscape-2016-report-591395821.html>

[Canadian Patient Group Survey Report 8.29.16 by Ward](#)

[Ontario Launches Working Group to Benefit People Living with Rare Diseases](#)

## CanPKU AGM



**Save the date:**

Monday Oct. 17 at 8:00 pm Eastern time

Please watch your inbox for more information.

Don't forget to be able to vote at the AGM you need to be current in your membership! Be sure to check your status and/or renew if needed!

# Journée PCU du Québec Quebec PKU Day 2016

**Le samedi 22 octobre | Saturday October 22**

Faculté des sciences de l'agriculture et de l'alimentation,  
Université Laval, Québec, QC



**Deux grands événements en un jour!  
Two Great Events In One Day!**

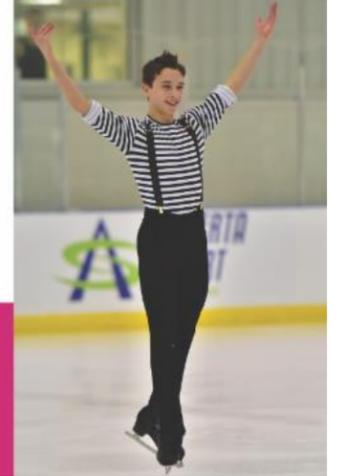
Événement d'information et de réseautage  
et démonstration culinaire commanditée par Cambrooke  
Therapeutics!



Annual Education & Networking Event  
Plus Cooking Demonstration sponsored by Cambrooke Therapeutics!

Soyez des nôtres le mois prochain! Please Join Us Next Month!

**Inscrivez-vous maintenant!  
Register Now!**



## PKU Fundraiser in Vaudreuil Dorion, QC

Sessions guidées de peinture sur toile et artisanat de groupe.



Candace has reached out to CanPKU to advise us of a fundraiser and seek assistance in filling the spaces!

Here is what she writes:

*We have a 2 year old grandson with PKU, and are very grateful to your PKU Association for helping our family understand and cope with this condition. Your generosity providing starter kits and PKU information updates is so greatly appreciated.*

*My sister and I have a small business that offers inspiring and stress-free, guided painting sessions. All our events are given by a Professional Art Therapist.*

*We provide all the materials: paint, easels, brushes, aprons..., and we strive to assemble a fun and outstanding experience for all participants. And each painter leaves our session with their very own masterpiece.*

*Our company is called Artetvino for adults and Artetartisto for children. For further information about us please visit our website: [www.artetvino.com](http://www.artetvino.com) or email us: [info@artetvino.com](mailto:info@artetvino.com) or friend us on Facebook.*

*On Saturday, September 24th, we are hosting an Artetvino session at Zee Grub. The address is 2970 Route Harwood, Vaudreuil Dorion, QC., J7V 8P2. Class begins at 11:30AM and finishes at 2:00PM. The admission fee is \$35.00 per person. Artetvino will donate \$10.00 of each charge collected to The Canadian PKU & Allied Disorders Inc. We are expecting at least 20 people & can facilitate 40.*

**Let's help them fill the space! The guided art session will be conducted in English with French translation available.**

## Ouverture de la Clinique métabolique à Trois-Rivières, QC



Le projet de faire une spécialisation en médecine métabolique (pédiatrique et adulte) était le centre de mes intérêts depuis que j'ai fini mon cursus général en pédiatrie en 1995.

L'intégration du programme de Biochimie médicale et le fellowship en médecine métabolique à l'Université McGill à

Montréal m'ont permis de réaliser ce projet à mon rythme en prenant le temps de voir des patients de tout âge pour mieux comprendre les enjeux des maladies métaboliques surtout à l'âge adulte. Je me suis rendu compte rapidement qu'il y avait un manque de médecins dans ce domaine et compris qu'il faut agir le plus vite possible pour offrir des soins adéquats et une transition sans douleur du suivi pédiatrique au suivi adulte. Le besoin était bien plus visible à Trois-Rivières qu'à Montréal en constatant que des patients devraient se rendre régulièrement dans une grande ville pour un suivi spécialisé en médecine métabolique.

Depuis que j'ai pris mes fonctions au CHAUR de Trois-Rivières ( Pavillon Ste-Marie), j'ai commencé à bâtir ma propre clinique de médecine métabolique en donnant une série de conférences au Campus de La Mauricie pour mieux me faire connaître et participer à l'organisation de la journée d'information CAN PKU le 3 octobre 2015 en collaboration avec Mr John Adams CEO de CAN PKU ici même au Campus de la Mauricie.

## Become A Member

Signing up for a CanPKU membership is the easiest way to help the organization, and comes with great benefits. Members are eligible for a \$10 off coupon for HowMuchPhe, receive discounts on fees to CanPKU events, receive discounts for low protein products, and more!

General memberships are only \$20 per year! To sign up, please go to [www.canpku.org/become-a-member](http://www.canpku.org/become-a-member).

### It's HERE!

**NEW!**  
**WEBSITE!**

We LOVE feedback! Have you had a chance to review the site? What did you think?

Please provide feedback to [Nicole.pallone@canpku.org](mailto:Nicole.pallone@canpku.org)

[www.canpku.org](http://www.canpku.org)

Cette clinique va donc permettre aux patients de La Mauricie porteurs de maladies métaboliques d'être suivi dans leur propre région sans avoir à se déplacer. Il existe par ailleurs une collaboration avec les grands centres hospitaliers connus pour leur expertise en matière de maladies métaboliques ( McGill, Ste-Justine, CHUS, CHUQ...)  
Contact : centrale des rendez-vous 819-378-9842 Dr Mohsen B Tanfous

## Resignation of CanPKU Vice President, Nicole Pallone:



When my daughter was diagnosed in January 2008, the earth disappeared from beneath my feet. Within six months we knew that we had this; that PKU would be a part of our lives but would not rule our lives. Shortly after that I realized that BC was negligent by not funding the medically required low protein foods. When Rosie was just over a year old, Amanda Cosburn, PKU Adult and now Board member, asked me to help her organize a walkathon in Vancouver, with proceeds going to CanPKU. The rest, as they say, is history. Since October of 2010 I have been the Vice President of this wonderful organization, and it is with mixed feelings that I announce my resignation. I have done two full, three-year terms as VP and my family and career obligations are now such that I can no longer make the same commitment to CanPKU.

The last six years have been a time of growth for both the organization and myself. I am honoured to have contributed in any way that helped the organization grow, helped our voices be heard or helped a family feel supported. It has been tremendously rewarding to see pet projects such as the Newborn Starter Kits and the Disability Tax Credit packages benefit other families. It has been a joy to meet each of you who attended a CanPKU event that I hosted, to answer your emails, or get to know you through Facebook. I will forever be grateful for the numerous opportunities I had in my role of VP to attend and present at PKU conferences all over the world, and to then pass on my knowledge and experiences to others.

Taking on the role of Vice President was what allowed me to see some good come out of this diagnosis, and allowed me to always be knowledgeable about new PKU related treatments, management practices and advocacy efforts. If you feel passionate about helping others, have a personal connection to PKU and have some flexibility in your schedule, I strongly encourage you to consider working with this organization. Expressions of interest and resumes can be emailed to John Adams ([john.adams@canpku.org](mailto:john.adams@canpku.org)) by October 3, 2016.

I will continue to be the Vice President of CanPKU until December 31, 2016, and can hopefully overlap some of that time with a new VP to make the transition as smooth as possible. Beyond that, I plan to continue as a member of the Board, and will surely go back to organizing fundraising events that benefit CanPKU! I would like to sincerely thank John Adams, for taking me under his wing, and all of the Canadian PKU families, for allowing me to serve you. It has truly been an honour!



The **first** family of nutritionally complete ready to drink AA based formulas for those with inherited disorders of metabolism!

- Complete nutrition to meet more than your protein needs
- Optimized formulation to provide advanced nutrition for your health
- 20g PE/serving
- Supports brain and eye development
- Less acidity than other Amino Acid formulas
- Great berry taste, with no artificial flavors or colors
- Convenient ready-to-drink cartons



Remember

- order low protein food
- try Eggs

Request a sample today!  
[cambrooke.com](http://cambrooke.com) or 866 456 9776, opt 2

## PHENYLADE GMP NOW AVAILABLE IN CANADA!



**DAVID**  
40 years old,  
Classical PKU

"When I tasted the PhenylAde™ GMP product, it was very easy to drink, it was very smooth, and in comparison to other products in the market, I actually preferred it!"

- Contains Glycomacropeptide (GMP), made from a whole protein source
- Provides 52 mg of DHA in each 10 g PE serving. Helps meet WHO/FAO recommendations for DHA at age appropriate protein equivalent intakes
- Excellent source of Calcium & Vitamin D to help build and maintain strong bones and teeth
- Built on the PhenylAde flavour profile to aid patient acceptance and support dietary adherence



REQUEST  
A SAMPLE

[Request a Sample](#)

## We need YOUR help!



Fellow members of the rare diseases community:

Now is a critical time for our campaign to implement a federal orphan drug regulatory framework and an intergovernmental initiative to help fund rare disease treatments so that no Canadian is left behind.

Attached is a [template letter](#) that we urge you to consider writing to your MP.

We once again need your help and that of your communities - please help spread the word through your networks. Letters to MPs don't require any postage. Simply include all or part of the following messages, and thank you for contributing your voice to this important national effort.

FIRST: Find out who your MP is if you don't already know by entering your postal code at this [WEBSITE](#).

SECOND: either email or send by post (no postage required) a letter like our template attached [here](#). Feel free to add your story or connection with rare disorders, as personalizing the message will help bring home the need for national action!

THIRD: if you get a response, share it with us by sending us a copy [atinfo@raredisorders.ca](mailto:atinfo@raredisorders.ca).

Sincerely,

Durhane Wong-Rieger  
President & CEO  
Canadian Organization for Rare Disorders

## What has John been up to?

John represents CanPKU at many events.



### Sickle Cell Awareness Group of Ontario

In late August, 2016 John delivered a workshop on effective governance for the board and management of the Sickle Cell Awareness Group of Ontario, based on a similar workshop he did for the Sickle Cell Disease Association of Canada earlier this year.

### Newborn Screening international conference

John Adams as CanPKU President was an invited speaker at the 25th anniversary conference of the International Society for Neonatal Screening in The Hague, Netherlands Sept. 11-14, 2016 on the topic of the role of patient groups in newborn screening. John is recognized as a subject matter expert in newborn screening and is a published author in scientific journals. He combined that trip to Europe to attend the annual conference of the Society for the Study of Inborn Errors of Metabolism (SSIEM) in Rome Sept. 6-9, 2016. He posted on Facebook about the conferences and trip.

### European Society for PKU (ESPKU)

John has also been invited to speak on international perspectives at the annual conference of the European Society for PKU to take place in Dublin, Ireland on Nov. 2-6, 2016.

### Upcoming Events:

Annual General Meeting of the Best Medicines Coalition (BMC) - Sept. 15, 2016 by teleconference. David Brennan, chair of the CANPKU board, represented CanPKU.

Annual General Meeting of CORD -Sept. 20, 2016 by teleconference. John will represent CanPKU.

Fall Conference of Best Medicines Coalition (BMC) Nov. 16-17, 2016 in Toronto. John Adams and Lisa Olsen will represent CanPKU.

## Have your say...

Looking forward to December Issue



PLEASE SHARE! Any favorite Christmas recipes? Holiday traditions?

Send feedback to [newseditor@canpku.org](mailto:newseditor@canpku.org) and we will publish these in our December issue!

## 2016 Hometown Christmas Parade - Texas.

*Dec 3rd - If you should be in Texas*

The City of Pearland allows My PKU Awareness Foundation each year to have a PKU float to help them raise awareness of PKU.

2015 was their first year building the PKU float and this year they have been blessed to have the talented UH Society of Asian Scientists and Engineers build a mind blowing float.

Help them build their float, walk with them, and help them raise awareness of PKU to change PKUer's lives.

### WHEN

Saturday, December 3, 2016 from 5:00 PM to 10:00 PM (CST)

### WHERE

Old Alvin Road to Pearland Parkway, Pearland, Texas, 77581

To join, view this [link](#)

## Research Survey for all PKU patients/families:



The team of physicians and researchers of British Columbia Children's Hospital Metabolic (PKU) clinic is conducting the survey on your experience with PKU and Kuvan (even if you did not take Kuvan, it is still ok to participate in the survey).

The team would like to know your perspective on treatment and what treatment outcomes are

important to you. The BC Children's hospital team believes that this information might eventually help to inform better care for PKU patients and provide more evidence on treatment guidelines.

The link to the survey is posted several months ago but only one survey has been completed so far. Researchers are asking for your help to get this study done. The survey will take 10-20 minutes to complete and it is anonymous. If you wish to complete the survey, please [click here](#).

We would like to thank you for your support.

Biochemical Genetics Center, Children's Hospital of British Columbia at the University of British Columbia

If you have questions about the survey, please email to [nyuskiv@cw.bc.ca](mailto:nyuskiv@cw.bc.ca)

## Promotion Name

Try phrases like: dramatic savings, clearance, overstocked, reduced rates, buy 1 get 1 free, treat yourself, you deserve it, and don't miss out. Insert a link in the promotion to your website. Because links are tracked, you can see which promotions generate the most interest in your customers.

**Our Price:** \$  
**List Price:**  
**S & H:**\$3.00

Click  to edit

Double-click to **insert** an image

Right-click to **format** image

100 x 100 pixels

We are grateful to everyone who has been willing to share their PKU stories and advocate for PKU patients across the country. Together, we have truly made this country a better place for PKU patients and families, and will continue to push for improvements to the various health care plans that we rely upon. Thank you for taking part in these activities, and helping to make Canada a better place.

Sincerely,

Tanya Chute

Canadian PKU & Allied Disorders Inc.

# Save \$10!

Become a CanPKU member and receive many great benefits as well as a \$10 off coupon for HowMuchPhe.org! Already a member? Email [Nicole Pallone](mailto:Nicole.Pallone) and request your coupon today!

Limited Quantity Availalbe - Sign up now!