

# CanPKU News



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

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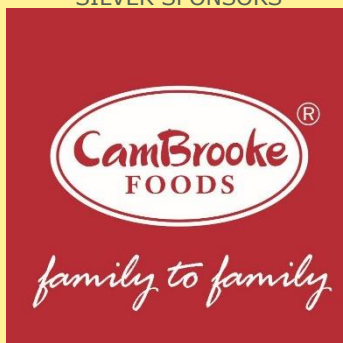
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## Dear Friend,

Welcome to the 26th issue of the CanPKU newsletter.

Time sure flies by and here we find ourselves back at our final newsletter of 2016. Seems like it was just yesterday we were writing the September Back to School issue. Since then however, we have had many changes at CanPKU.

Our AGM has taken place and we thank those who made the call. It's a great time for reflection on the year past and rejuvenation for the coming year. We are always looking for new volunteers and if being part of CanPKU is of interest to any of you please reach out. This can be in many capacities and requires no previous knowledge about any specific area. We are happy to help you along!

Plans are really coming along for the First Annual Camp and you find more details regarding this below in this issue, including the name which was selected by a contest held in the last newsletter. Our Quebec event was held in October. We thank all for attending and making it amazing. Without families attending these events would not happen. Quebec also had a successful fundraiser, peek a little farther down to see what one family with a great idea was able to achieve!

Thanks for reading and we hope you enjoy this 26th edition of the CanPKU Newsletter!

Sincerely,  
 Tanya Chute                      John Adams  
 Newsletter Editor              President & CEO  
 & Secretary

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## 2017 EDUCATIONAL EVENTS

### SAVE THE DATE

APRIL 1ST                      ♦ BC PKU DAY ♦ VANCOUVER

MAY 7TH\*                     ♦ QUEBEC PKU DAY ♦ MONTREAL  
\*(Subject to final dates of GARROD Symposium)

MAY 27TH                    ♦ PRAIRIES PKU DAY ♦ RED DEER

JUNE 17TH                   ♦ ATLANTIC PKU DAY ♦ MONCTON

SEPTEMBER 22ND - 24TH  
♦ 1ST ANNUAL CAMP MAGNIPHEQUE  
♦ OUTSIDE PETERBOROUGH

PLEASE WATCH YOUR INBOX  
FOR MORE INFORMATION!

**WE LOOK FORWARD  
TO SEEING YOU AGAIN!**

### Recipe Corner

#### Chocolate Chip Cookies

There isn't anything much better than the taste of a perfect chocolate chip cookie. Other than perhaps having someone else make them for you! This recipe is being featured as a THANK YOU to a little boy named Brady and his mommy who made these and shared them with our own PKUer. The recipe HAD to be shared! They are so delicious. We also want to thank CookForLove.Org who continues to turn out amazing recipes (including this one) for the PKU community (and their families) to share!

## EXCITING ANNOUNCEMENT FROM CANPKU!!

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

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



Just a 15-20 minute drive East of Peterborough, ON  
in the scenic Kawartha Lakes region of Ontario.

**EARLYBIRD SPECIAL:** Save \$30 if you purchase a  
Weekend Pass

Includes Meals, Activities, and Accommodations for  
\$120.00 CAD Per Person by Tuesday February 28,  
2017! (After March 1, 2017, the Weekend Pass is  
\$150.)

Registration closes July 31, 2017, 12:01 EDT

**TO REGISTER, CLICK HERE** or visit  
<http://bit.ly/campmag2017>

Join us for a weekend of fun, knowledge, relaxation,  
and campfires! The first annual Ontario PKU Camp is  
the traditional camp experience - complete with  
bonfires, camp activities and nature - with a PKU  
twist. With food catered to PKU and non-PKU diets,  
expert speakers talking about the latest  
developments surrounding PKU, cooking demos and  
vendor displays, it's a weekend not to be missed!  
Bring the whole family along, take a break from food  
preparation and relax for the weekend. All this, and  
sleeping in cabins, too!

Registration is limited and filled on a first-come,  
first-served basis.



Yield: 4 servings

#### Ingredients

- 290 gm (2¼ cups) wheat starch [23 mg]
- 1 teaspoon xanthan gum [0 mg]
- 50 gm (1/2 small box) jell-o instant pudding, vanilla flavored [0 mg]
- 1 teaspoon baking soda [0 mg]
- ½ teaspoon table salt [0 mg]
  
- 12 tablespoons (1 ½ sticks) unsalted butter, softened [72 mg]
- ½ cup granulated sugar [0 mg]
- ½ cup brown sugar [4 mg]
- 25 gm (1/2 large) mixed egg [170 mg]
- 15 gm (1 tablespoon) water
- 1 teaspoon vanilla extract [0 mg]
- 50 gm (1/3 cup) semi sweet chocolate chips [120 mg]

#### Instructions

1. Heat oven to 375 degrees. Line two large baking sheets with parchment paper.
2. Whisk wheat starch, xanthan gum, pudding, baking soda, and salt in medium bowl; set aside.
3. In standing mixer fitted with paddle attachment or with hand mixer, beat butter, granulated sugar and brown sugar at medium speed until light and fluffy, about 3 minutes, scraping down sides of bowl with rubber spatula as needed. Add egg, water and vanilla; beat at medium speed until combined, about 30 seconds. Add dry ingredients and beat at low speed until just combined, about 30 seconds, scraping down bowl as needed. Add chocolate chips, stir until combined.
4. Form dough into tablespoon sized 1 -inch balls. Place dough balls on parchment lined baking sheet. If desired, freeze the dough balls on the baking sheet. Once frozen, place in a Ziploc bag for easy delicious homemade cookies in minutes.
5. Bake until cookies are golden brown around edges and just set and very lightly colored in center, about 9 to 12 minutes. If using frozen dough balls, cook for an extra three minutes. Cool cookies on baking sheet about 3 minutes; using wide metal spatula, transfer cookies to wire rack and cool to room temperature.

For the full Nutritional Information please see their website <http://cookforlove.org/chocolate-chip-cookies-3/>

Questions? Please contact us at [info@canpku.org](mailto:info@canpku.org) or [camp@canpku.org](mailto:camp@canpku.org).

More to come soon! Check out our website for some [FAQs](#).



## Help Wanted: Newsletter Editor

Ever wanted to be involved with CanPKU?



For the last year the Newsletter has been completed by myself, Tanya Chute, Secretary and Board Member for CanPKU due to the lack of another interested party.

I would be happy to help transition this position to someone else and teach you all you need to know! I would be available whenever you had questions or concerns regarding the position.

If you have ever wanted to be part of the team, but not have a lot of time to devote, this position may be perfect! Only a few hours every quarter! Please email to [tanya.chute@canpku.org](mailto:tanya.chute@canpku.org) to further discuss the position.

## Rare is Everywhere



A book to help children understand rare.

Rare is Everywhere is a new children's book that helps children embrace differences in themselves and others through depictions of amazing genetically rare animals. By showcasing animals that are different from the ones that children are used to seeing - like white tigers, brown pandas, blue lobsters, pink grasshoppers, and many others - children learn that differences are everywhere - and something to celebrate!

Proceeds from the book will be donated to the Rare Disease Foundation, and the book's author-illustrator, Deborah Katz, has launched a Kickstarter campaign on Monday, October 24th to fund the first print run. She needs our help to make the campaign a success!

Follow this link for more information <http://rareiseverywhere.com/>



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

## PKU Profile

### Introducing Brady!



Brady is an energetic, wonderful soul who is growing to have Daddy's sense of humour more and more every day! He introduced his family to PKU when diagnosed, much like many of our PKUers do! His big brother Noah is a great help and his best friend. Brady likes Paw Patrol and the colour green. He is followed by the team in Toronto at Sick Kids. The family has met another local family thanks to a CanPKU Walk-a-thon held shortly after Brady was born. This friendship has meant a great deal to both families as they are able to share recipes (even the finished products), celebrate milestones, great days/news and help each other with troubling shoot concerns. Brady is absolutely perfect and nothing will slow him down!

#PKUPROUD #ATTENDINGCAMPMAGNIPHEQUE  
#BRADYISAWESOME

[Join Our Mailing List!](#)

### In the News

Articles you may enjoy

<http://www.businesswire.com/news/home/20161107005899/en/Cambrooke-Therapeutics-Announces-Launch-Burger-Patty-Mix>

<http://www.businesswire.com/news/home/20160920005138/en/Cambrooke-Therapeutics-launches-all-new%C2%A0Glytactin%E2%84%A2-Complete-Bar-medical>

## Journee PCU du Quebec/ Quebec PKU Day 2016

Le samedi 22 octobre/ Saturday October 22



## 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).



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- 20g PE/erving
- Supports brain and eye development
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HCU IVA MMA PA MSUD PKU

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- order low protein food  
- try eggs

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

## PKU Fundraiser in Vaudreuil Dorion, QC

By Candace LaPointe



We recently held a Fund raiser for the Canadian PKU & Allied Disorders Association. It was a great success. John

Adams asked me to share with you this wonderful event and how it came to be.

On September 2nd, 2014, our very first, most beautiful, grandson was born, such a joyous event. Within 10 days, he was diagnosed with classic Phenylketonuria. Not only had we never heard of this disorder, but reading of its dire consequences, if left untreated, engulfed our family in heartfelt worry. But thanks to the dedicated staff at the Montreal Children's Hospital and the positive encouragement from the Canadian PKU Association, our grandson is a very healthy little boy.

How could we ever repay these kind people for all their support, was always at the back of our minds. Then one day I noticed, on the PKU website, events that had taken place to raise not only funding, but awareness of this genetic disorder. There were bike rides and marathon runs, that raised thousands of dollars. And then I read of a family who raised \$100.00 with a bake sale and quickly thought, aha! It doesn't have to be thousands of dollars, every little bit helps, and at that moment, our fund raiser came into fruition.

My sister and I started giving guided arts classes this spring. It's a very small business, we'd had four sessions (one a month), roughly 14 participants at each class and everyone always left with their very own 16" x 20" masterpiece and wanting to return. So we put out feelers and realized we could probably get 20 to 30 people to attend a guided painting fund raiser. We would donate \$10.00 from each entrance fee to PKU. Best case scenario, we'd raise \$200.00 to \$300.00.

And so it began. We placed an ad in our local paper's "Things to do about town", and also included an invitation to the Editor to be our Celebrity Guest for the Event. The paper generously responded with a half page article explaining PKU and encouraged people to attend. This publicity gave us instant recognition, opening the door for many local merchants who generously sponsored us with door prizes for our participants.

Relatives and friends who were unable to attend, sent us donations, knowing all monies raised would

## 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



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A SAMPLE**

[Request a Sample](#)

## What has John been up to?

John represents CanPKU at many events.

### SEPTEMBER:

- \* Invited to speak on the role of families in advocating for newborn screening at the International Society for Neonatal Screening in The Hague, Netherlands.
- \* Best Medicines Coalition (BMC), a non profit group of patient organizations including CanPKU, held their AGM. John was reelected as a Director.
- \* Canadian Organization of Rare Disorders (CORD) held their AGM . John completed 10 years as a Director.
- \* John met with founder and President of China PKU Union in their office in Beijing, during a personal visit to China

### OCTOBER:

- \* Participated in an intense 4-day Advocacy Boot Camp run by veteran patient advocates Louise Binder and Gail Attara; usual \$5,000 fee covered by an anonymous sponsor
- \* monitored meeting and follow-up of the expert advisory committee of the Common Drug Review as

be given to the PKU Association for their continued support of children with this disorder and their families.

An artist living in a nearby town contacted us. She was so moved by the Local Journals' article that she donated one of her beautiful wild animal illustrations. She chose lions explaining that people with PKU need to always be strong as they courageously observe their life long, diet restrictions. A local art studio framed the painting for us at no charge!

A couple from our church recognized our picture from the paper and gave us a very generous donation. They explained, that 46 years ago, their firstborn son had to have a lung removed, the day he was born. And they empathized with worried parents and their new born PKU children.

The day of our event we had 20 participants, and with the kindly support of family, friends and our awesome community, we raised \$1500.00

In conclusion, if there are any grandparents out there, who are wondering how they can help their children cope with raising a PKU child, I encourage you to pay it forward...Choose something you love to do and turn it into a fund raising event. You will be amazed at how many people will come to your assistance. People want to help and your fund raising event will give them that opportunity.

The PKU Association is made up of volunteers, let us show them our gratitude for their constant dedication and support of our families and professionals, as they ease the burden of strict diets and help find cures.

## Follow up from September

We asked - We got answered!



Did you know there is a scholarship available for student with PKU who are entering post secondary school? Canadians ARE eligible. Applications for this year's programs are already closed, but keep an eye out for those heading to post secondary programs next year!

<https://pkunews.org/guthrie-koch-scholarship/>

## Have your say...

Looking forward to Next Issue



PLEASE SHARE!

Our next newsletter will be due out March 15th. Hopefully we are seeing signs of spring. In order to have time to include any idea, please share with us things you would like to see at the First National CanPKU Camp - Camp MagniPHEque!



it reconsidered Kuvan for coverage by government drug plans

\* Delivered our annual Quebec PKU Day program in Quebec City.

NOVEMBER:

\* Invited to speak at annual conference of European Society for PKU in Dublin, Ireland on topic of global issues for PKU families and organizations

\* Attended 2-day CORD conference for patient experts on health technology assessment (ie. coverage of new therapies), in Toronto

\* Attended Patient Summit on Drug Pricing Policies , in Toronto

\* Invited to participate in a 2-day Summit of Patient Group Leaders in North America sponsored by Biomarin, in San Francisco

\* Met with Health Canada officials re labelling of Aspartame re Phe and PKU for some foods and drinks and lack of labelling for PKU in over-the-counter and prescription drugs also regulated by HC; included PKU dietician representing Garrod Association in meeting.

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

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.

The content deadline for our March 2017 Issue is March 1st, 2017

**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@canpku.org) and request your coupon today!

**Limited Quantity Availalbe - Sign up now!**

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