

# CanPKU News



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

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**Dear Friend,**

Welcome to the 24th issue of the CanPKU newsletter.

This exciting time of year has us looking forward to sunshine, school breaks, vacation and hopefully extra family time. This is my favourite time of year!

The past quarter has held many of our regional educational events, including guest speakers, cooking demonstrations, and a chance to meet and mingle. We have launched our new website. Wow! What an improvement. Our newsletter will bring you some highlights!

Alberta faced disaster to Fort McMurray and surrounding areas. These fires continue to burn. They reminded us how important emergency plans are, which we highlight in this edition of the newsletter. British Columbia showed us remarkable results from their 3rd Annual PKU Walkathon held in Kamloops, and we have an article about that too!

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

We hope you enjoy this 24th edition of the CanPKU Newsletter!

Sincerely,

Tanya Chute  
Newsletter Editor  
& Secretary

Nicole Pallone  
Vice President

John Adams  
President & CEO



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## Important Dates



### Upcoming Educational Events:

October 15/22, 2016 - Quebec PKU Day

### Non CanPKU Events:

July 9th, 2016 - 1st Annual PKU Poker Run (See below)

## Emergency Preparedness

**We all know we need to be ready, but do we know what we need to have ready?**



I admit, I think that we are ready to be self-sufficient for quite a while inside our home. I am a little bit over cautious when it comes to making sure his supplies are well stocked. But, what if we had to leave our home? Sure, I could quickly grab a thing or two, and would I forget stuff? Yes, sadly, I'm sure in a panic with a ticking clock we would forget far more than we ever could imagine. Based on the recent events in and around Fort McMurray, this hit me far too hard. So, for this newsletter, I absolutely wanted to highlight this need for all! So, grab a coffee, or a tall glass of your favourite beverage, a pen and paper and start today! I have attached a few "articles" which may help motivate you.

Thank you so much to Amy who with a short deadline wrote up a brief overview of her experience with evacuating from Fort Mac with her family, including a PKUer. Read that article [HERE](#)

PKU Advocate Kevin Alexander did an interview with his metabolic nutritionist, Amy Cunningham, who has since become an advocate for emergency preparedness following Hurricane Katrina. That interview is found by following this link: <http://www.pkulife.tv/2013/08/29/pku-emergency-preparedness/>

My PKU Binder, created by National PKU Alliance, can be accessed on CanPKUs pages with this link: <http://canpku.org/wp-content/uploads/2016/05/2011-NPKUA-Binder.pdf>.

However Chapter 12 is dedicated to Emergency Preparedness and it is located at this link: <http://npkua.org/portals/0/pdfs/pkubinder/PKU%20Binder%202011-Ch12.pdf>

For me... well, I am off to buy a tote or two to stock up and know that we can grab and dash if the need ever arrives!

## Recipe Corner

When we think summer, we think picnics at the zoo or the park, and a feast of KFC. For our PKUer, this meant slides, monkeys, and french fries. NOT ANYMORE! Thanks to Brenda at Cook for Love, Kentucky Fried Cauliflower is on the menu for this summer!



Prep time: 5 mins Cook time: 3 mins Total time: 8 mins  
Yield: 4 servings

### Ingredients:

- \* 250 gm (1/4 head) cauliflower, broken into bite-size nuggets
- \* (1 1/2 Tablespoons) energ egg replacer
- \* (1/3 cup) ice cold water
- \* (1/2 cup) CFL baking mix
- \* 1/4 teaspoon xanthan gum
- \* 1 teaspoon salt
- \* 1 teaspoon Mrs. Dash
- \* 1/2 teaspoon garlic
- \* 1/2 teaspoon sweet paprika
- \* 1/2 teaspoon sugar
- \* 1/4 teaspoon oregano
- \* 1/2 teaspoon parsley
- \* (2 tablespoons) toasted lp breadcrumbs\* see note below
- \* oil for frying

### Instructions:

1. Combine baking mix, xanthan gum, salt, Mrs. Dash (or 1/2 tsp onion, 1/2 tsp garlic, dash cayenne, 1/4 tsp white pepper), garlic, parsley and sugar in a small bowl. Mix, set aside.
2. Combine ener-g egg replacer with ice cold water (the colder the batter, the crispier the cauliflower). Add 2 tablespoons of the CFL seasoned starch to the ener-g egg replacer batter.
3. Add the toasted breadcrumbs to the remaining dry starch mixture.
4. Dip each floret into the ener-g egg replacer batter and then the seasoned CFL mix.
5. Fry in hot oil (375) for about 3 minutes.

Bread crumbs Note: If you do not have toasted LP Breadcrumbs on hands, you can add 10 mg crushed cornflakes or ground up gluten free pretzels - just adjust the phe. It also works with just the seasoned starch, but Brenda prefers it with a little more texture.

Serving size: 4 florets, 80 gm Phe Per Serving: 61 mg  
Mg phe/ Gm food: .76 mg/gm Calories Per Serving: 114  
kcal Phe Per Recipe: 243 mg Calories Per Recipe: 456 kcal

## 3rd Annual Walk-a-thon

Kamloops boasts a successful event!



BC Health Minister Terry Lake supports Kamloops Walk for PKU in May, seen with 4 PKUers who live in Kamloops: Amanda Cosburn carrying her 12-week-old daughter Madelyn (non-PKU), Amanda Jamah, Hayden Knox wearing scooter helmet and Austin Graham. Great turnout, great spirits. PKU Proud! Silent auction raised \$1,500. The event was also attended by counsellor Arjun Singh and approximately 60 walkers!

Special thanks co-organizers Amanda Cosburn and Brienna Wells.

To read more on the event please check out

<https://amandacosburn.wordpress.com/2016/05/28/3rd-annual-kamloops-walk-for-pku/>

## Summer Camp



Summer Camp is part of being a kid! PKU doesn't have to limit your opportunities! Have you or your child attended a successful camp while intergrating your PKU Lifestyle? Send us a message to [info@canpku.org](mailto:info@canpku.org) so we may compile a list for next year's summer season! These camps are offered south of the border, and cater to PKU directly. For more information please click the following link:

<http://npkua.org/Portals/0/PDFs/camps/2016%20Summer%20Camp%20List.pdf?ver=2016-03-31-071854-123>

Brenda also offers a delicious looking dip to go with these. Please see the full recipe including the dip at her site:

<http://cookforlove.org/kfc-kentucky-fried-cauliflower-2/>

You will need to register for this site. Membership is free (donations welcomed but not required). So many delicious ideas the whole family can share!

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

## PKU Profile



As all new parents, we were excited to bring home our baby boy. We received a phone call, several days later, that turned our world upside down. Liam had PKU. How could this be, when just days ago, his doctor said that he was perfect? The next months, even years, have been spent learning as much about PKU as we can.

We are fortunate to have our families nearby, in Charlottetown, Prince Edward Island. Without their support and the guidance from Liam's medical teams, this 'learning curve' would have felt impossible. We have also been blessed with Liam's childcare. We feel that it is important to note that many friends have been made through CANPKU. Some friendships have been made online. It is comforting to chat with other people who have experience with PKU.

Liam is now a six year old bundle of energy who loves playing with his cousins. He takes gymnastics and has just started skating

- **IPAD's PKU Mini Camp for Kids**  
*June 17 - 18, 2016; Salt Lake City, UT*
- **Metabolic Camp Emory University**  
*June 20 - 25, 2016; Atlanta, GA*
- **Camp PHEver**  
*July 10 - 15, 2016; Burton, TX*
- **Camp Knot a Phe**  
*July 28 - 31, 2016; Prescott, AZ (AZ residents only)*
- **Cavett Kids Foundation Kamp Courage**  
*August 17 - 21, 2016; Dry Gulch, OK*
- **Camp Huber**  
*August 19 - 21, 2016; Westminster, MD*
- **PKU Camp at the South Shore YMCA Camp**  
*August 21 - 26, 2016; Sandwich, MA*
- **PKU Northwest Alliance Family Camp**  
*August 25 - 28, 2016; Antelope, OR*
- **Camp Connect**  
*August 26 - 28, 2016; Winder, GA*
- **East Bay Camp**  
*September 23 - 25, 2016; Hudson, IL*

## Hat's off to Pete!

.... and a big thank you as well!



I'm so happy to have raised \$3,858 CAD for CanPKU. CanPKU has been so amazing in educating, advocating and making us feel a welcome member of the PKU community ever since we found out our 4 year old daughter Luka had PKU a week after she was born. You can see and share my Marathon Fundraising Campaign at the link below.

<http://chim.pn/1HESCMU>

Ever since I was 5 riding my BMX along side my Dad when he trained for a marathon it's been bucket lister of my own. In doing so, I want to raise awareness for 2 causes that impact people near & dear to me; PKU (Phenylketonuria) which my daughter Luka has and MS which impacts my sister Melissa. I qualified for the 2016 Boston marathon at my maiden marathon attempt in Edmonton in August 2015 with a time of 3:07:06. My BHAG (Big Hairy Audacious Goal) was to try and cross the line in under 3 hours in the Boston Marathon in April 2016. After 4 months of training 5 days a week, and up to 95km/week I crossed the line in 3 hours, 2 minutes and 36 seconds. It was shy of my sub 3 hour goal but conditions considered (it was way hotter than anticipated) I was really happy with the result. Of 31,000 runners I started at ranking 6791 (based upon my qualifying time) and crossed the line in 1777th position. It was such an awesome feeling of accomplishment and very humbling to see the support



lessons. He has already participated in his first triathlon!

Everyone said that the diet will just be second nature to Liam. By the time Liam was 4, we knew that they were right. Liam could read a few words and one of them was 'protein' on a food label. He was sharing a snack one day with his cousins, and was excitedly telling them that it was "zero"! They didn't understand his enthusiasm, but it was a proud moment for us. He's going to be okay with this. Just like the doctor said at his birth, "He's perfect"! Six years later, we still have the proof!

Join Our Mailing List!

## In the News

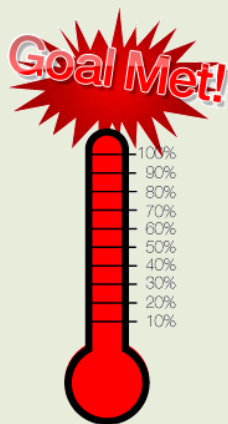
Articles you may enjoy

[http://www.citynews.ca/2016/05/03/video-bill-to-fight-genetic-discrimination-among-life-insurers/?show\\_id=0](http://www.citynews.ca/2016/05/03/video-bill-to-fight-genetic-discrimination-among-life-insurers/?show_id=0)

<http://www.womenofchina.cn/womenofchina/html/features/health/1606/100-1.htm>

[http://www.huffingtonpost.com/tara-shafer/rare-disease-day-mom-make\\_b\\_9344742.html](http://www.huffingtonpost.com/tara-shafer/rare-disease-day-mom-make_b_9344742.html)  
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## Game night fundraiser



***For the second time, BC PKU parent Steve Lemky hosted friends for a games night as a CanPKU fundraiser. This year's event raised \$600 for CanPKU - thanks, Steve!***

*Fundraisers like this provide important contributions to CanPKU*

*and help keep the organization financially*

pour in for the PKU/MS fundraising campaign. I owe a lot to my very patient and support wife, and two girls; Luka (4) and Avideh (2).

Thank you for all the contribution from those volunteers at CanPKU and we look forward to continuing to be an engaged family in the PKU community.

Pete, Lee-Anne, Luka and Avideh.

**Side Note: Sadly, Pete's extraordinary efforts and generosity of spirit have provided us with an important learning opportunity. Both CanPKU and the MS organization he chose to receive these donations are "Not for Profit" groups as opposed to Registered Charities. This is because of the advocacy work the groups do. Only Registered Charities can provide tax receipts for donations, and when Peter chose CHIMP as a vehicle to streamline the collection of donations, he was not aware that funds collected can only be released to Registered Charities. Refunds cannot be given to the donors because tax receipts were immediately sent out to everyone making a donation. Pete did not work this hard to have funds sitting in "limbo", so we continue to work towards a resolution to obtain these funds, to be able to use them the way Pete wished.**

**When you are raising funds for any not for profit group, please keep in mind that only registered charities can issue tax receipts, and be wary of the fine print of online fundraising facilitators and their potential inability to release funds to the organization of your choice. Again, we are absolutely grateful to Pete and his family, and thank him tremendously for not only the financial gain, but the awareness and sense of community he established on his journey!**

sustainable. For more information on how to host an event, please go to [www.canpku.org](http://www.canpku.org).

### Help Fight Genetic Discrimination in Canada.

A federal Bill to protect genetic test information and to ban use of it to discriminate in terms of employment or life and disability insurance is making progress. It has passed the necessary three readings in the Senate and was just introduced in the House of Commons.

CanPKU is an active member of the Canadian Coalition for Genetic Fairness.

For more information, view this link - [http://www.citynews.ca/2016/05/03/video-bill-to-fight-genetic-discrimination-among-life-insurers/?show\\_id=0](http://www.citynews.ca/2016/05/03/video-bill-to-fight-genetic-discrimination-among-life-insurers/?show_id=0)

For more information please following the link: <http://ffb.ca/support-bill-s-201-lend-your-voice-to-stop-genetic-discrimination-in-canada/>

**1st ANNUAL POKER RUN FOR PKU**  
Benefitting PKU Fund at Hamilton Health Sciences Foundation.

WHEN: July 9th, 2016

AREA: Simcoe, Ontario

WHO:

Do you ride Motorcycle and want to join in?  
Do you want to salute those that do ride in appreciation of their efforts?

Contact Angel Edwards for more information at [gentle.life@hotmail.com](mailto:gentle.life@hotmail.com)

**Donations from the run will go to the PKU funds at Hamilton Health Sciences Foundation - McMasters Children's Hospital.**

HOW IT ALL STARTED...

In September 2014 Delilah Krauskopf was born and diagnosed with PKU at 5 days old. Delilah's parents Angel and Chris Krauskopf along with the hard work of her grandmother Deb Brown, Finance Coordinator with Hamilton Health Sciences Foundation, created the PKU

## BC PKU Educational Event



### BC PKU Day

#### Journée PCU de la Colombie-Britannique

Sunday, May 15 - Vancouver, BC

Le dimanche 15 mai - Vancouver, C.-B.

Speakers: Katherine Deming, Jane Gillis, Koen & Keith Kucher, Ramona Salvarinova, Sylvia Stockler, Keiko Ueda

## Atlantic PKU Educational Event



### Atlantic PKU Day

#### Journée PCU de l'Atlantique

Sunday, May 22 - Halifax, NS

Le dimanche 22 mai - Halifax, N.-É.

Speakers: Chad Farquarson, Keith & Koen Kucher, Jerry Vockley

## Prairies PKU Educational Event



### Prairies PKU Day

#### Journée PCU des Prairies

Sunday, June 5\* - Winnipeg, MB

Le dimanche 5 juin\* - Winnipeg, Man.

Speakers: Charles Black, MLA Jon Gerrard, Lisa Olsen, Jerry Vockley

FUND. The PKU FUND is specifically used for patient amenities such as: group celebrations, supplies and resource materials. In celebration of Delilah's 1 st birthday her parents Angel and Chris Krauskopf invited guests to make donations to the fund in lieu of gifts.

Delilah's grandfather Gene Edwards has organized this event. They are anticipating over 100 riders will attend and hope to continue the run annually.

## PKU Around the World

International PKU Day June 28th.

International PKU Day was launched in 2013 by the E.S. PKU

For more information and to see what events are happening check out the following link:

<http://www.pkuday.org/2016/04/18/pkuday-org-launched/>

**Congratulations and hats off to all involved!**

## 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).

## Ontario Educational Event

A photo was not available at time of publication.

Thank you to all those that attended the event making it successful!

Speakers: [Katherine Deming](#), [Lisa Olsen](#)



**It's HERE!**

We are so excited to introduce you to our new bundle of joy! Please take a moment to check out the new and improved website. It is much easier to navigate, has more information, and is over all more user friendly! Tell us what you think!

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

## Disability Tax Credit - Update

In 2015, CanPKU began a campaign to inform patients and families living with PKU or an allied disorder about likely eligibility for DTC. Our campaign was based on three factors:

1. The public website tools of the Canadian Diabetes Association to help diabetics know how to qualify for DTC,
2. A successful DTC application by a MSUD family,
3. A successful application by a PKU family resulting in tax refunds of almost \$25,000 because the DTC can be applied retroactively for up to 10 years.

These successful applications rely on changes to DTC criteria since 2005, including a new section on life-sustaining therapies, which is crucial in the case of diet-treated aminoacidopathies.

Since we began this campaign, there have been mixed results at/by CRA. About 50% of the applications we know about are successful, most often not requiring any review or appeal.

However, we have seen an issue emerging of inconsistent interpretations of DTC criteria by different reviewers in decentralized CRA offices across Canada. These variable interpretations seem to affect a number of families.

A Member of Parliament in April, raised these inconsistencies in the House of Commons on behalf of a negatively affected constituent and John Adams further wrote to the CRA Commissioner requesting a meeting to review the difficulties generated by inconsistency decision-making and to request guidance by CRA senior management to resolve the inconsistencies.





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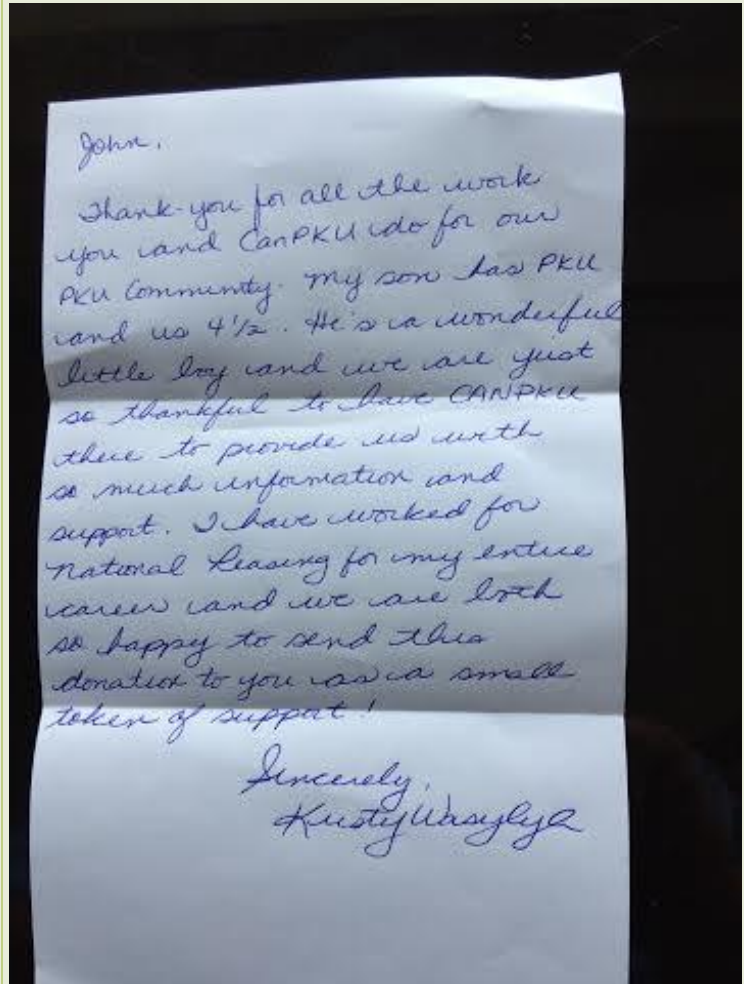
REQUEST  
A SAMPLE

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CanPKU continues to work with families interested in applying for this tax credit and provides support during the process. Please continue to update us with your results so we can continue to assist families.

Please [click here](#) to request a copy of the DTC Information Package! This package is available to any current member of CanPKU.

**With Thanks,**



It was truly a blessing to receive this beautiful note to our President on behalf of himself and all those involved in CanPKU. This kudo goes out to everyone involved and we wanted to share it!

As well, a huge thank you back to the family and their employer who provided a very generous donation to help us continue what we do!

Our community means the world to us, and this not for profit group is made up of some of Canada's finest!!

Hats off to you all!



## Current PKU Research Study

For those that attend BCCH



A current PKU research study called "Etherlipid Metabolism in Patients Treated with Sapropterin Dihydrochloride: an Exploratory study" that is being undertaken in the Department of Pediatrics, Division of Biochemical Disease at BC Children's Hospital.

The purpose of this study is to learn more about the metabolism of etherlipids (fatty substances and fatty acids) in children diagnosed with phenylketonuria (PKU).

Participation in this study requires a donation of a small blood sample by your child after at least 4 hours fasting (same as annual blood work); no food no formula, water is fine.

If you choose not to take part, this will not affect your medical care in any way.

This study is funded by the Department of Pediatrics, Division of Biochemical Diseases and has received ethical approval by the UBC C&W Research Ethics Board.

Please find included in this article, a copy of the Consent form with further information should you want to read more. The blood draw for this study does require it be obtained at BCCH.

If you can /want to participate, the procedure is that you meet with Dr. Nataliya Yuskiv the clinic, go through the consent form, and you will be given your lab requisitions for both your typical blood work as well as this study and you do everything in one poke.

For more information please contact by email [nyuskiv@cw.bc.ca](mailto:nyuskiv@cw.bc.ca)

[Consent](#)

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[Survey Link](#)

As a note - there is no need for the Consent form to be signed this is just to provide information; completed survey is considered as given consent.

## June 28 is 100th anniversary of birth of founder of newborn screening for PKU

Following information is from

[https://en.wikipedia.org/wiki/Robert\\_Guthrie](https://en.wikipedia.org/wiki/Robert_Guthrie)



**Robert Guthrie, MD, Ph.D.** (June 28, 1916 - June 23, 1995) was

an **American microbiologist**, best known for developing the bacterial inhibition assay used to **screen** infants for **phenylketonuria** at birth, before the development of irreversible neurological damage.

<sup>[1]</sup> Guthrie also pioneered the collection of **whole blood** on specially designed filter paper, commonly known as "Guthrie cards"

as a sample medium that could be easily collected, transported and tested. Although Guthrie is best known for developing the test for phenylketonuria, he worked tirelessly to raise awareness of the need to screen for treatable conditions and adapted his method to early screening tests for **galactosemia** and **maple syrup urine disease**.

For more information on Robert Guthrie, MD may we also suggest the following book:

Koch, Jean (1997). *Robert Guthrie: The PKU Story*. Hope Publishing House.

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,**

NICOLE PALLONE

Canadian PKU & Allied Disorders Inc.

## Have your say...



Looking forward to Septembers Issue

PLEASE SHARE! What is your favorite low protein back to school snack?

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

Just in time for back to school!

# 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 Available - Sign up now!**

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