



# CanPKU News

from Canadian PKU & Allied Disorders Inc.

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Dear Friend,

Welcome to the 29th issue of the CanPKU newsletter. You will notice this newsletter is coming to you a little off schedule this month. We appreciate your patience.

Hat's off to everyone who participated in Camp this year. It was quite the kick off for this annual event! Thank you to everyone who pitched in and made it successful from those who helped with the planning, to those who ran the dishwasher after meals! Everyone was so happy to make this successful and that you all did! Anyone who is a member of CanPKU please watch your inbox as you will be receiving a email including all the camp recipes. For those who are not members, we have included the "Not Dogs" which were enjoyed on Friday night at camp in this newsletter. As well, for MEMBERS ONLY we will include a bit of the information shared during some of the workshops available at camp. It's not too late to get in on the whole list - simply sign up for a membership THIS month!

Speaking of membership - did you know that by joining as a member you also save \$\$ off registration for the 2018 event schedules? These are currently under way and we are excited to roll them out in the new year!

We hope you enjoy this edition of the newsletter!

All the best,

Sincerely,

Tanya Chute  
Newsletter Editor

John Adams  
President & CEO

& Vice President



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**BIO MARIN**



**Join us at a 2018 educational event near you! Learn from the experts, try new products, mingle with other families, and have a fun time!**

**BC PKU Day . Vancouver, BC . April (TBD)**

**Prairies PKU Day . Saskatoon, SK . July 14**

**Ontario PKU Day . Hamilton, ON . TBA**

**Quebec PKU Day . Montreal, QC . October 13**

**Atlantic PKU Day . Halifax, NS . TBA**

**Camp MagniPHEque**

**Douro-Dummer, ON . September 28-30**

### Recipe Corner

#### Camp Not Dogs

**\*\*Want more camp recipes? Be a member!\*\***



## Message from President

By John Adams



Busy times. Our CanPKU team is actively planning events for 2018.

Thanks to an additional grant provided specifically for this opportunity, I am just back from a long weekend in Hell...a town in Norway, where the conference of the European Society for PKU took place. So if you tell me to go to h..., I will say: been there, done that!

Met with a core group to work on details for founding a global PKU association, which will be incorporated in England and registered there as a charity. Attended with a poster and booth at the once-in-4-years International Conference of Inborn Errors of Metabolism to promote the global initiative.

PKUers can be the victims of discrimination based on the genetic condition so there is good and bad news. We learned this week of a PKU child who family applied for an increase in extended health insurance from a private company and were refused due to the diagnosis of PKU. The good news is an Ontario politician introduced a Bill to make it a human rights violation to discriminate on basis of a genetic characteristic. We must work to get that Bill passed all steps into law. If so, Ontario will be the first province to do this, following a similar federal law enacted earlier this year. Yes we will need to get equivalent legislation in every province and territory. We are working with and are members of the Alliance for Genetic Fairness.

Continuing to monitor the negotiations over Kuvan access ongoing between BioMarin and the consortium of government drug plans. These negotiations, for good or not, will strongly influence whether Pegvalise (old name Peg-PAL) will ever be available in Canada. BioMarin has applied for approval for Pegvalise in the USA and anticipates a decision in late May, 2018.

I have been elected this month as Chair of the Best Medicines Coalition a non-profit umbrella group of 30 patient organizations.

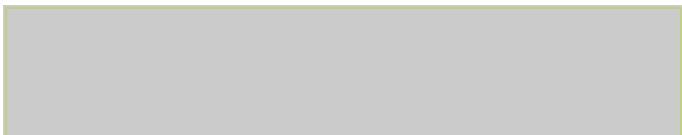
Finally a big shout out to Tanya Chute and her entire family for the fabulous first-ever Camp MagniPHEque last month!

## Help us improve the newsletter.



We would love your input on how to make the newsletter better.

[Please take a minute to complete this quick survey.](#)



Ingredients:

- 2 jars of 4oz carrot baby food (2 x 128 ml Heinz carrots, stage 1)
- 1 ¾ cup (420 ml/175 g) Cambrooke Baking Mix
- ½ Cup (120 ml/48 g) Country Sunrise instant Potatoes, dry mix
- 1 Tbs (15 ml/9g) PaneRiso Egg Replacer
- ½ Tsp Garlic Powder
- 1 Tbs (15 ml/16 g) BBQ sauce

Directions:

- Mix all ingredients together (It will be like play doh)
- Roll out and wrap in Saran Wrap
- Tie off and boil lightly for 10-15 minutes

Be careful to watch that the wrap doesn't split.

Let cool slightly and remove wrap let cool the rest of the way.

Tips:

- We have kept wrapper on and fridge/froze - Outcome - Good
- We also poked with "pogo" stick and dipped in Cambrooke's MixQuick and Deep fried (hot grease to start) making a "Pogo"

Nutritional Information provided by retired Sick Kids Dietitian, Valerie Austin

YIELD (from above-mentioned recipe):

Total Weight 556 grams

We make this into 10 equal hot dogs 55-56 grams each (can be made bigger for sausages)

PER 55 G WEIGHT (1 hotdog)

0.5g protein, 19 mg PHE,101 kcal

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



## Camp was awesome! Thanks to all who attended and helped!

For one weekend in September, 108 campers, 31 with PKU, from three provinces, and two countries all came together to make the community of Camp MagniPHEque. It was awesome! We will let the pictures tell the stories!



**PKU Profile**

Maya is a happy and healthy nine year old girl who loves her country life out in New Brunswick. Maya was born with mild PKU and is thriving with life and does not let her PKU diagnosis hold her back!



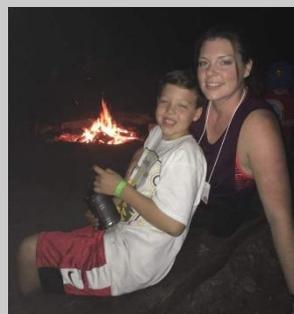
Maya is a Kuvan responder and has been taking it for about three years now with no visible side effects. It has kept her PHE levels nice and low and has allowed her to eat some more natural protein throughout the day. Maya is VERY diligent in taking her pills every day and in drinking her formula -

even though she does not like the taste of the Periflex very much! She understands that her formula is necessary to help her grow up strong and healthy. Maya LOVES McDonald's french fries and her Dad is proud that most of them are made by McCain Foods where he works! She has been very accepting of her diet and life with PKU but like everyone she has some down days where she wishes it was gone!

Maya has such a big heart and is sensitive to the feelings of others. She is a very happy girl who often wears a big wide smile and is usually found giggling and playing with her family and friends. Maya loves to swim, play soccer and other sports, and has recently discovered an interest in Drama - she played an orphan in her school's production of Annie last year! And like many other kids Maya also likes to spend time playing with some fun games and Apps on her iPad!

Maya and her family have adjusted well to life with PKU and it is no longer something that worries them every day. They are all thankful for the medicines and foods that are available today in New Brunswick and are sure that Maya will have a happy, healthy, and blessed life!

Want to be our next spotlight? Send a bio and photo to [newseditor@canpku.org](mailto:newseditor@canpku.org)



Can't wait!

National PKU News has put together this handy handout to help guide you through the spooky maze of

# HALLOWEEN CANDY

Download this guide by clicking here

**IDEAS FOR HANDLING HALLOWEEN CANDY**

- Use one ingredient per candy that you "trust" to eat? (Candy corns & 5 mg or greater low-PHE options)
- Look for higher PHE candy at the store or donate it at your local food bank or other organization.
- Use higher PHE candy for friends and siblings (if known PHE levels).

PKU News

**HAVE A FUN AND SAFE HALLOWEEN!** 🎃 🧛 🎃 🧛

# Save the Date

## September 28 to 30, 2018

### Douro-Dummer, ON

## In the News

### Articles you may enjoy

[FDA Accepts BioMarin's Pegvaliase Biologics License Application \(BLA\) and Grants Priority Review Designation](#)

[Moms and future moms with rare inherited disorder aim for healthy babies](#)

[Flagship-backed Rubius raises \\$120M to take off-the-shelf red blood cell cancer therapeutics into the clinic](#)

[LA resident organizes fundraiser for rare metabolic disease](#)

[The \\$550 smartphone device that can detect diseases like 'a portable laboratory'](#)

[QRCS initiative aids PKU patients in Gaza](#)

[Judge forces NHS England rethink on Kuvan](#)

[NHS should consider protein-control treatment for PKU child](#)

[PKU funding battle: Family wins High Court challenge over drug](#)

[Judge rules against NHS in Kuvan funding case](#)

[Molly's Kids: Indian Land boy living with rare genetic disorder Using Smell to Diagnose in Genetic diseases](#)

[Legal battle for 'life-changing' drug to be given to boy](#)

[What is PKU disease, what are the symptoms of Phenylketonuria and what sort of diet do sufferers need to follow](#)

[In One Ear: Grabbing attention for PKU](#)

[Sixth Annual Creighton Farms Invitational hosted by Jack Nicklaus Raises Record \\$1.4 Million for Children's Health Charities](#)

[Maternal PKU - Why I'm Having A Burrito Delivered To The Labour Ward](#)

[Biomarin Submits BLA for New Phenylketonuria Therapy](#)

## Atlantic PKU Day 2017

Thanks to Lynn and the PKU Clinic in NB for inviting us to share in the PKU day the clinic plans for their members. With combined efforts, amazing results happened. Check out this



great looking group!

## BIG WIN!

by John Adams



Big win for PKUers at the Tax Court of Canada for a federal benefit called the Disability Tax Credit in the case of PKU mom Erin Mullings who challenged the Canada Revenue Agency refusal for her 3-year-old daughter. The court decision came out in July and October 1st was the deadline for the government to appeal. They did not appeal. So the case stands as settled case law and while not binding on another judge, it is a strong guideline. PKUers can be eligible by meeting 3 key criteria: the PKU enzyme deficiency qualifies as a physical impairment, the PKU "diet" qualifies as medical therapy and you (patient and all caregivers) spend at least 14 hours a week, on average, managing the disorder and its therapy. See story in this newsletter about another PKU mom who got 10 years worth of retroactive tax refunds. Total: \$50,000!

I am acting as agent representing six more PKU families also appealing CRA refusals to the Tax Court. More welcome. Also volunteering on the executive of the new Disability Tax Fairness Coalition to advocate for better CRA administration of this tax benefit. We are aligned with organizations representing diabetes, mental health, etc. on this campaign.

## "This means my son graduated from college this year and is going on to university without any debt."



This is the story of how a divorced mother of two children applied for the Disability Tax Credit for her son with PKU, was approved and has received about \$50,000 in tax refunds.

Angela Smail is a small business owner who does bookkeeping and tax returns for individuals, sole proprietorships and small business corporations. She lives in eastern Ontario.

Her son, Quinn Smail, was born in 1997 and diagnosed with PKU through newborn screening, regularly attending clinic at the Children's Hospital of Eastern Ontario in Ottawa. He is on the PKU diet therapy and does not use Kuvan. In early 2015, Angela learned through CanPKU of the successful DTC application of Nicole Pallone of British Columbia for her daughter. So Angela approached her clinic with that new

## Early Screening for Tetrahydrobiopterin Responsiveness in Phenylketonuria

### ASHG honors Edward McCabe with 2017 Advocacy Award

## 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).

**GLYTACTIN BUILD™**  
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• Mix BUILD and a packet of Glytactin RESTORE Lite Powder for a low-calorie high-protein boost.

**On its own**  
• Glytactin BUILD can be consumed on its own by mixing 1 packet into 6 oz of water.  
• Mio™ drops or PKU-friendly flavor enhancers are a great option to build up the flavor.

**Give it a shake**  
• Make a morning shake by adding 1 packet of BUILD, low Phe fruit, water and ice. Blend thoroughly.  
• As an added treat, pour the shake into popsicle cups and have a yummy frozen fruit snack at night!

**Think outside the glass**  
• Add BUILD to your favorite pancake, french toast or waffle recipe for a protein-packed breakfast.  
• Add BUILD to your favorite queso or mix into your low-protein meat or cheese to BUILD up your meal.

**REQUEST A SAMPLE TODAY! 866 456 9776 samples.cambrooke.com**

information and filled out the first page of the DTC application. Dr. Pranesh Chakraborty filled out the other pages required as Quinn's PKU medical specialist.

Angela also included a personal letter outlining the challenges of managing the PKU therapy, adapted to Quinn's circumstances, based on a model suggested by CanPKU.

Dr. Chakraborty then received a six-page, "CONFIDENTIAL" questionnaire from the Canada Revenue Agency (CRA) asking for additional information.

Dr. Chakraborty called CanPKU and we discussed the CRA questions and how best to answer them. This was the first time CanPKU learned about the confidential six-page questionnaire sometimes sent to medical doctors who sign DTC applications. In late 2015, Quinn was approved by CRA for the DTC, without any further reconsiderations, reviews or appeals. The CRA decision is called a Notice of Determination. Quinn was initially approved for the years 2002 to 2020.

Angela then exercised her rights as a Canadian taxpayer to ask CRA to reassess her income tax returns going back ten years, which is the maximum allowed by law. Angela received the adjustments for the tax returns 2005 -2014. As Quinn is her dependent while attending post-secondary school she continues to be able to claim the DTC on her taxes until he is no longer a dependent. As a knowledgeable tax preparer, Angela also asked CRA to reassess the Child Tax Benefit (CTB) going back ten years. CRA will only go back 3 years without an additional request.

What does this mean? Below is a table Angela provided which shows her Net Income for the years involved and the value of both the DTC and the CTB:

In 2017, Quinn graduated from a two-year program at Canador College, North Bay, ON in recreational and leisure services. He was accepted into the 2 year Bachelor of Arts in Global Tourism Management. He was admitted into the third year of a program in global tourism at Royal Roads University, in Victoria, BC, which he started earlier this month.

He worked this summer at the Hole in the Wall Gang camp started by the actor Paul Newman for Children and their families coping with cancer and other serious illnesses and conditions, such as PKU, sickle cell disease, cancer, etc. Quinn attended the week-long camp as a child. The camp is located in Ashford, Connecticut. [www.holinthewallgang.org](http://www.holinthewallgang.org)

CanPKU thanks Angela for sharing this information to help benefit other families with PKU. CanPKU is ready, willing and able to assist other families with exercising their rights to apply for these tax benefits for their PKU family members.

Click [HERE](#) to see the Disability tax summary results for Quinn

## New for 2018 at Camp MagniPHEques!



Many of you are already familiar with Brenda Winiarski's amazing recipe site, CookForLove.org. Now, Brenda is teaming up with National PKU News to transform CFL into a community-based site with recipes from Brenda, Virginia Schuett's cook books, Malathy Ramanujam of Taste Connections, and YOU! The content for all recipes will be verified by HowMuchPhe.org. This will be a great resource to share your own recipes and find others that have worked for the community.

## PHENYLADE GMP NOW AVAILABLE IN CANADA!



**DAVID**  
40 years old,  
Classical PKU

"When I tasted the PhenyAde™ 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 PhenyAde flavour profile to aid patient acceptance and support dietary adherence



REQUEST  
A SAMPLE

[Request a Sample](#)

Help design this site by taking Cook For Love's survey here (and enter to win a free recipe adaptation or a year's subscription to HowMuchPhe.org): <https://cookforlove.org/cfl-and-howmuchphe>

## Cookforlove.org news!



Many of you are already familiar with Brenda Winiarski's amazing recipe site, CookForLove.org. Now, Brenda is teaming up with National PKU News to transform CFL into a community-based site with recipes from Brenda, Virginia Schuett's cook books, Malathy Ramanujam of Taste Connections, and YOU! Phe content for all recipes will be

verified by HowMuchPhe.org. This will be a great resource to share your own recipes and find others that have worked for the community.

Help design this site by taking Cook For Love's survey here (and enter to win a free recipe adaptation or a year's subscription to HowMuchPhe.org): <https://cookforlove.org/cfl-and-howmuchphe>

## Did you know PKU gel can be mixed to a spoonable semi-solid or a low volume drink?

PKU gel is a second stage medical food designed to decrease reliance on high volume formula and may promote appetite for regular foods.

For more information or to request a sample, visit [www.VitafloUSA.com](http://www.VitafloUSA.com)



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## Government of Canada wants to know...

A survey for feedback to the Canada Revenue Agency about how its officials handled your application for the Disability Tax Credit.



We know that families are receiving mixed replies regarding the DTC. We are aware of many cases being denied with

others being accepted. There is a great deal of difference between those getting told no, and one family getting towards \$50,000 in back payments. There is also the difference between families hearing yes on the first try and other families having to head to tax court after appeals on application have been denied. The government is asking for feedback on YOUR application to the DTC. If you wish to participate please follow this link : <https://cra-arc-survey-sondage.ca/s/dtc-ciph>

Survey available in English as well as French.

## Grant and Fellowship Opportunities from the National PKU Alliance



The National PKU Alliance (NPKUA) works to improve the lives of individuals with phenylketonuria (PKU) and pursue a cure. The organization provides funding to advance the science of PKU by funding the most promising research that will lead to new therapy discoveries and a cure. Since 2010, the organization has invested close to \$3 million in research that has led to new knowledge, the acceleration of new therapies and supported pilot studies that have been able to leverage larger federal funding.

The organization is pleased to release its 2018 Call for Research Proposals and Fellowships to continue our mission and advance PKU research.

## Moving abroad with PKU

Ever wondered what it's like to move to Canada with PKU?



For David, despite all his preparations in advance of his trip across the Atlantic Ocean from Ireland, it was not what he had planned.

Lots of things were new to discover when arriving to Canada, and we are not talking about LoProtein Poutine!

Read about his experience in his own words [here](#).

## Research Grants

This grant program funds pre-clinical, translational and clinical research projects that investigate all aspects of phenylketonuria with a special focus on research that advances the treatment and management with the long term goal of facilitating the development of a cure. The RFP can be found [here](#).

## Post Doc Fellowships

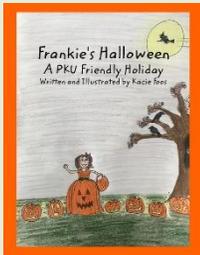
The fellowship program promotes and encourages PKU-related research in young investigators in pre-clinical, translational and clinical research projects that investigate all aspects of PKU. Applicants must have a PhD, MD or equivalent and have an opportunity to hold a full-time fellowship position at an established institution in the U.S. or internationally. Applicants may request \$55,000 per year for two years. The RFP can be found [here](#).

Full proposals should be received no later than November 1, 2017. Award notices will be given by January 31, 2018 with funding to begin on March 1, 2018.

For questions or additional information, please contact Christine S. Brown, Executive Director of the NPKUA, at [christine.brown@npkua.org](mailto:christine.brown@npkua.org).

## A Halloween PKU Friendly Story!

Article Subtitle



Kacie Foos is a writing machine! Based out of the USA she has written a few Frankie ebooks which are all PKU Friendly stories.

Her latest is just in time for Halloween!

(Good thing our newsletter was late and we could tell you about this festive book!)

More information available at <http://survey.constantcontact.com/survey/a07ebrdex0uig9y74dx/start>

## PKU Knows No Borders

## Please click images to view larger

### PKU knows no borders

August 1, 2017

In July 2017, a regional and several country-based PKU patient organizations from around the world made history by agreeing to form the first international association for PKU. This global entity will serve as a supportive umbrella organization to regional and national patient organizations and groups in bridging the gap for PKU worldwide.

The formation of this group is in the early stages. We are pleased to share the following information about the organization at this time.

#### Vision

Our vision is that all people living with PKU, despite their origin, will be able to reach their full potential.

#### Mission

Our mission is to advance PKU as a global health priority and strengthen PKU associations and groups throughout the world.

#### Priorities

As people living with PKU, our priorities are:

- To create a global platform for PKU advocacy that includes ensuring universal access to newborn screening and diagnosis, treatments and comprehensive care;
- To mentor like-minded patient associations and groups and offer best practices and support that are sensitive to their experiences, culture, language(s) and laws;
- To increase collaboration among PKU researchers, scientists, clinicians and patient groups to move basic science and research forward to accelerate new knowledge, treatments, and a cure.

#### The Founding Member Organizations are committed to the formation of this new global entity

- Asociación Mexicana de Fenilcetonuria, AC (Mexico)
- Canadian PKU and Allied Disorders
- European Society for PKU
- Corporación PKU Chile
- Grupos de Padres PKU Asociación Civil de Fenilcetonuria de Argentina
- Metabolic Dietary Disorders Association (Australia)
- National PKU Alliance (USA)
- SAFE Associação Amiga dos Fenilcetonúricos do Brasil
- Turkey PKU Family Association



Organizational tasks have been assigned and plans are progressing for meetings over the next year. The founding members would like to thank Abbott Nutrition, BioMarin Pharmaceuticals Inc., Cambrooke Therapeutics, Dr. Schär Medical Nutrition GmbH, Nutricia Advanced Medical Nutrition, and Vitafo (International) Limited for supporting this initial organizing meeting in Toronto, Canada, to improve the lives of people living with PKU worldwide. During the start-up phase the Canadian PKU and Allied Disorders is acting as financial agent for the global organization.

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**  
**Newsletter Editor & Vice President**  
**Canadian PKU & Allied Disorders Inc.**

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\$10!**

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