



# CanPku News!

From Canadian PKU & Allied Disorders Inc



March 2018

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## Greetings!

Well here it is, the 36th issue of CanPKU News,

It's that time already!

In this issue of the news letter you will find some fun facts, camp dates, intriguing articles, and updates from our President and VP on what's been happening here at CanPKU!

As a follow up from last issue, I'm SO HAPPY and PROUD to report that the young man who did the "Can You PKU" (also my son) science fair project last issue, went on the regional to receive 3 separate awards, including a bronze overall!

This issue was a difficult one for me! My children are growing and becoming consistently busier and busier! Spring in Manitoba means the snow is melting, and the weather is SUPPOSED to be getting warmer, for our family that means yard clean up, sports activities, and camping season! Our lives get busy when it gets warmer, sometimes making it tricky to find time between work, and activities to check off all those things on my to do list! I appreciate all who volunteer their stories to my email, and save me the time of pestering those on social media to share!

It's usually around this time of year, I find myself SO TIRED at meal time! Sometimes I forget the actual amount of work it takes to cook regular, and LOW PRO meals, 3x every, single, day!

Summer time here means sometimes we sacrifice home cooked meals, for pizza pops, and use the time mom would of spent in the kitchen, to make memories outside, at the beach, the pool, or around a fire in the back yard!

I'm EXCITED, that Cambrooke Therapeutics has come out with the "Broccoli go Pockets". Around 86 PHE each, and my picky PKUER enjoys them! It's awesome to finally have a PKU friendly convenience food my son will eat! A lower PHE quick option he also enjoys is Cambrookes Chicken noodle soup. About 27 PHE per packet. He isn't however a fan of the beef noodle.

My son is nearly 12, and exploring his independence, getting ready to spend some times at home alone. What are some of the first meals you taught your young PKU'er to cook for themselves? Right now he's limited to the kettle, and

the microwave and toaster, but I know I'm going to have to let him spread his wings and start really cooking for himself! I would appreciate any suggestions that are not too complicated!

I Wish you all a warm, and eventful summer full of memories and relaxation!

See you again in September!

*Sincerely,*



Arlene McDonald  
Newsletter Editor  
Canadian PKU & Allied Disorders Inc.

**WE NEED**



## BRONZE



# WE NEED YOU!

We're always on the hunt for new hands to help make a lighter workload! Are you often the loudest at family functions? Maybe advocacy is your calling!  
[Contact us](#) to see how you can help!



### What's John Been up to?

A Message from the President. By: John Adam

- Big disappointment in the federal report recommending national pharmacare; its wording does not include medical formulas or our special foods! So every time you see or communicate with a federal election candidate: why them why are we being overlooked!

- The wording of the Hoskins report says national pharma care should cover "prescription drugs and related products" and later mentions "devices and supplies".

- When I met with the senior official of Health Canada who led the group supporting the Hoskins committee he could only say they did not get down to that level of "granularity".

- By the way, national pharmacare, if it happens, would cover Kuvan because it is a "prescription drug". How unfair!

- Another DTC win at Tax Court for a family with two PKU kids, again without a trail - we are now 16 for 16 on appeals to Tax Court

- Homology Medicines of Boston is starting to recruit adults with classical PKU to volunteer for the first clinical trial of a gene therapy which may cure, not just treat PKU.

Check [www.clinicaltrials.gov](http://www.clinicaltrials.gov) for details. This initial trial will only be at a few clinics in USA. Canadians can apply and travel expenses will be covered. Working with Homology to try to bring follow-up trials to clinics in Canada.

- Working with Synlogic Therapeutics of Boston to try to bring a second round of clinical trials to sites in Canada for its innovative synthetic probiotic to consume Phe in the gut, before it gets into the blood system

- Busy with multiple visits to Ottawa - usually for and paid for by the Best Medicines Coalition (BMC) - on pharmacare, proposed new regulation on drug prices, including meetings with all political parties and many civil servants.

- Personal highlight was at a one-hour meeting with Elizabeth May, Leader of the Green Party, when she reached, touched me on the knee, saying as a newlywed that her new role was as matchmaker for her single female friends, that I seemed to be a good guy, and would I be interested in meeting someone. Reply: I am flattered but I am spoken for.

- Involved in meetings about how to ethically engage with governments, drug developers, doctors, nurses, pharmacists and



## 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).

patient groups; the federal government will pay expenses for three patient representatives to participate in an international meeting about this in Chile in September; I have been chosen as one of the three, in my capacity as board chair of BMC

- Represented CanPKU at scientific meetings of the Society of Inherited Metabolic Diseases (Seattle), Canadian Agency for Drugs and Technology in Health (Edmonton), Garrod Association (Toronto), Canadian Organization for Rare Disorders and Rare Disease International (Toronto) and Abbott Nutrition for metabolic dietitians(Memphis).

- Happy to participate in meeting last week in Ottawa about ethical collaborations in the health sector among government, patients, doctors, nurses, drug and over-the-counter health products developers. I was representing the Best Medicines Coalition of 30 national patient groups. Also representing patients were Connie Cote, CEO of Health Charities Coalition of Canada and Russell Williams, VP Diabetes Canada.

Canada was the first country to adopt a Consensus Statement on Ethical Collaborations. Time to update and upgrade.

Sincerely,

John Adams.



### Message from the Vice President

By: Tanya Chute

It always amazes me how quickly each quarter comes around. Last quarter we saw our educational event in BC; thank you to everyone who attended and made the day a success. It was great to have some folks from clinic out to join us! Before you know it we will be out in Newfoundland for the education event out there. This has been a joint effort between CanPKU and the clinical staff, especially Jill, Crystal and patient advocate (and board member) Brian Quinn. They have so much packed into one day! Be sure to check it out if you are in the area. As summer begins to wrap up, and thought start turning to cooler nights, CanPKU will be firing up TWO Camp

MagniPHEque locations. Saskatchewan will kick off these events with the tremendous help from clinical staff Caroline and Brittany. The weekend events are so exciting! Take a pinch of education, a dash of camping, an ounce of adventures and a pound of friends - will equal one amazing weekend. Following suit, Ontario will wrap up the month with their own camping adventures following a similar recipe in a different area. Quebec, we have not forgotten about you! At the end of October (and sure to be mentioned in the next newsletter) we will head out to meet you in Quebec City. For me, the people will always be the greatest asset of living with a rare disease. Thanks to BioMarin, and their fully funded conference, I was recently able to attend a learning conference on Advocacy and Better Leadership. From it, I took many great ideas, met some new contacts, but mostly, made friends. I love learning from each other, hearing other families share their stories, and getting to know the faces behind other rare disorders. This is a world I never would have chosen, and can't imagine my life without. I am truly a stronger parent, a better person, because of a rare diagnosis. Reach out, share your story, make friends. Alone we are rare, together we are Family.

## Pins 4 PKU 2019

CanPKU is currently seeking energetic, fun, exciting folks (or just someone looking to help out) to organize a bowlathon in your city!

It's EASY! We will help!  
As little as a group of friends,  
as big as you can dream!

email [tanya.chute@canpku.org](mailto:tanya.chute@canpku.org)



Can we beat last years #s?

Funds raised help PKUers and families travel to Camp MagniPHEque

All the PINS for PKU Bowlathons have concluded!

Proceeds earned will be going towards Travel Scholarships!

Watch Septembers Newsletter Edition for Grand totals earned in each location!!

Thank you to everyone who held and helped organize events and participated!



Join us at a 2019 educational event near you! Learn from the experts, try new products, mingle with friends & families, and have a fun time!

Next up:

**Camp MagniPHEque**

**September 6th-8th  
Saskatoon Sask.  
September 27th- 29th  
Douro-Drummer Ontario!**

**Atlantic PKU Day -  
Newfoundland, July 5th  
More information to follow**

**Journée PCU Québec  
QC PKU Day**

**- Information to follow/ informtion encore à venir**

**Information on up coming events and scholarships can always be found at:**

**<http://canpku.org/upcoming-events>**

**Have your say!**

**[Click here to provide input on what you would like to see the day include!](#)**

Tanya.

## CRA Fee Cap Called Ruinous



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← Previous

Monday, June 3, 2019



### CRA Fee Cap Called Ruinous

The Canada Revenue Agency in an unprecedented regulation proposes to cap selective fees charged by private accountants and tax advisors at a hundred dollars. Consultants said the rule affecting more than 60,000 firms will drive many out of business.

"If you put in this fee schedule, it eliminates everyone immediately," said Shane Nercessian, managing partner of True North Disability Services of Surrey, B.C. "I have thirty staff. We're a small business. We do not get paid if we are not successful in helping people get a refund."

The Agency in a notice *Disability Tax Credit Promoters Restrictions Regulations* said it would mandate a maximum \$100 fee charged by consultants who file *Disability Tax Credit* applications on behalf of clients. Some 1.3 million Canadians qualify for the credits worth \$1.4 billion a year, by official estimate.

About five percent of new applicants – 12,000 people a year – hire consultants to navigate the claims process. "If you understand how the *Income Tax Act* works, great," said Nercessian. "In our experience – and this is with thousands of people across Canada – we find so many cases where the Canada Revenue Agency has not fairly applied the tax credit and makes mistake after mistake after mistake."

The Agency in 2017 admitted it disqualified claims by Type 1 diabetes patients in all but "exceptional circumstances" and only reversed the policy following protests from MPs. A federal Disability Advisory Committee in a May 24 report *Enabling Access To Disability Tax Measures* cited the Agency for denying claims on grounds that had "no basis in law", and questioned an unexplained 53 percent increase in rejection of applications on the basis of "mental functions".

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[Read full Article Here.](#)

## PhePhe Travels

PhePhe the CanPKU Rare Zebra boarded a plane with CanPKU VP, Tanya Chute and headed to Mill Valley California this month. BioMarin hosted a conference (and covered expenses for them to attend) to help strengthen the knowledge needed to effectively advocate and better leadership skills to better serve our community. It brought together many BioMarin staff along with various advocacy groups (not just PKU related) to engage with each other in being stronger individuals as well as teams. We are thankful for the efforts BioMarin places into ensuring that not only are more treatments becoming a reality in PKU, but we are stronger as a patient group to fulfil the needs of our community. PhePhe was super excited to head to BioMarin Campus and have the chance to thank some of the folks who play a role between when a drug becomes a thought to when it becomes life changing. BioMarin are the makers of Kuvan and Palynziq. Great things are happening in the scientific world when it comes to PKU. PhePhe and CanPKU would like to thank BioMarin for the continued support of our community.



Family Camps for All Ages!  
OUTDOOR ACTIVITIES!  
Catering to Both Non and PKU Diets!

**2 Locations in 2019!**

September 6<sup>th</sup> to September 8<sup>th</sup> - Saskatoon, SK!  
September 27<sup>th</sup> to 29<sup>th</sup> - Douro-Dummer, ON!

Cost for staying on site for the weekend:  
Up to five years old = \$50  
Six years and older = \$125

Visit: [www.canpku.org/CampMagniPHEque](http://www.canpku.org/CampMagniPHEque) For More Details!

**Travel Scholarships Available!**

Click [HERE](#) to learn more about travel scholarships!

Thank you to those who donate to CanPKU.  
You truly make a difference!

**GOLD**

**\$501- \$1000**

**SILVER**

**\$100 - \$499**

Melissa De Witt,  
in honour of Grace and Harrison De Witt



In honour of Grace and Harrison De Witt,  
Thank you!



## BRONZE

\$20- \$99

Mrs Valerie McDougall,  
Mrs. Heather Caldwell,  
Richard Beazley,

In memory of Mildred Giffin, of Amherst N.S, passed on March 14th, 2019, who listed CanPKU as a beneficiary for memorial gifts, in honor of her 2 great-grand daughters with PKU.

Thank you, and sending our greatest sympathy's from CanPKU.



We would like to acknowledge those who contributed by donation.

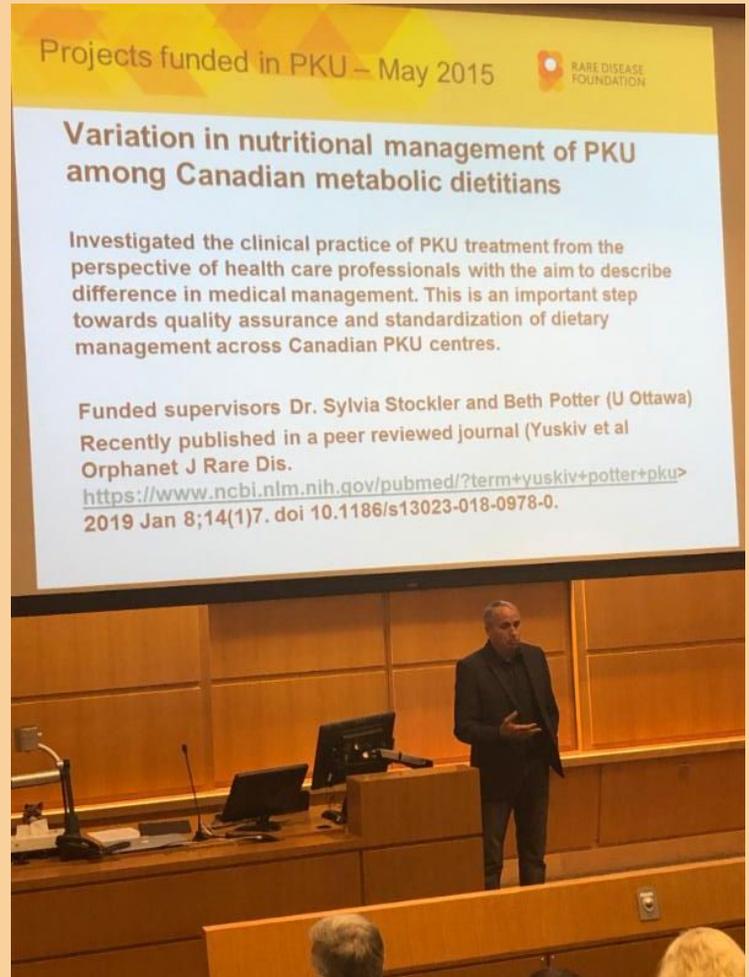
## PKU Profile

## BC PKU Day Event!



The BC PKU day, was held in Vancouver on Sunday April 14th. CanPKU President John Adams, as well as many other important, and valuable speakers came out to celebrate, and educate PKU with patients, friends and families! Below are some photos from the event!

(Below ) a photo of David Page, He is Executive Director the Rare Disease Foundation, presenting at the BC PKU event!



Larry Blankstein explains Synlogic drug development at BC event!



## Alex Muralles

PKU Patient and Carnegie Mellon University Graduate, majoring in Biological Sciences, minoring in Computational Biology.

At 21 years old, one week before our 1 year wedding anniversary, I gave birth to this sweet boy. We found out ten days later that he had PKU. I was

devastated, confused, angry, scared and overwhelmed. I cried a lot - but never in front of him. We read everything we could about PKU, followed recipes, made best friends with the gram scale, connected with PKU chat rooms, support groups, PKU News...anything that could help us with making sure we did everything right to manage his PKU. After reaching every milestone early, and near perfect blood levels, his genetic doctor told us "not to expect much from him."

Read that last sentence again.

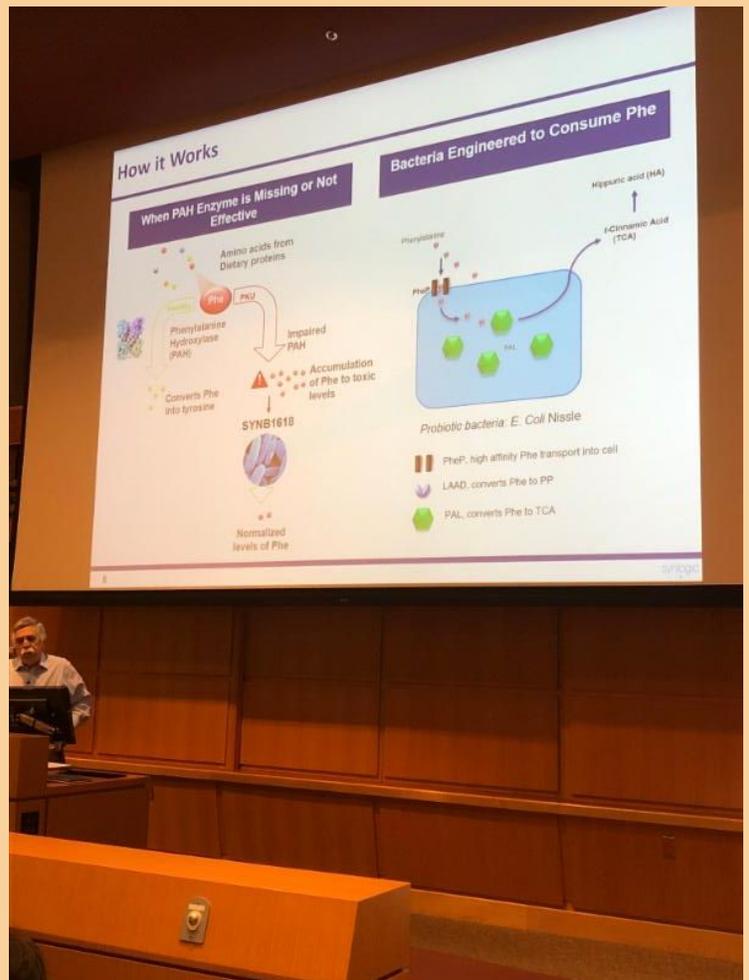
So, we changed clinics. We found the absolute BEST dietician( Helen McCune-who we will FOREVER be grateful to) and continued to learn, love, and advocate for our son. We expected GREAT things from him, always. We expected him to do the very best he could do, always. And he did.

Last weekend Alex Muralles graduated from Carnegie Mellon University with a major in Biological Sciences and a minor in Computational Biology. We are so very proud of him!

Don't EVER let anyone tell you not to expect much from your child because of their PKU. It is a part of who they are, a perfectly designed part of their life and body. It does not define, predetermine or limit their future. It is a part of who they are, and who they were meant to be. ♥☐

Congrats Alex Muralles! We are so very proud of you!

Submitted By: Melissa  
McLaughlin Muralles



Some low Protien Treats made by the children!



We love to shine the spotlight! To be featured in this column, please submit a photo and paragraph to [newseditor@canpku.org](mailto:newseditor@canpku.org).



# Roll Call!!

**Are you a Canadian PKU Parent or Patient?**

**Below is a list of contact information linking you to one on one support, volunteered from our PKU community!**

**Erin Mullings**

Two children with PKU: Aspen (7), diagnosed in April 2012 and Calla (5) diagnosed in November 2013.

Hamilton Ontario

Click [HERE](#) to Contact.

**Ashley Sulpher**

Parent of Anderson, diagnosed in May 2017

Ontario Canada

Click [HERE](#) to Contact.

**Angel Edwards**

Parent of Delilah, diagnosed in September 2014

Ontario Canada

Click [HERE](#) to Contact

**Tanya Chute**

Parent of Jacob born and diagnosed May 2010. Also born as a micropremie at 26 weeks. Ontario Canada

Click [HERE](#) to Contact.

**Amanda Cosburn**

Maternal PKU/ adult advocate

Diagnosed in 1986

Kamloops bc Canada

Click [HERE](#) to Contact.

**Stephanie Garcia**

PKU adult and advocate

Diagnosed in 1987

Hamilton, Ontario

Click [HERE](#) to Contact.

**Arlene**

Mother of CPKU Boy, Born 2007

Manitoba, Canada.

Click [HERE](#) to Contact.

**John Feruglio / Spouse**

Parents of Amy (22)

Regina Sask.

Click [HERE](#) to Contact.

**Brian Quinn**

Adult PKU/ Atlantic Provinces



Lary, John, And Brian with PhePhe!



## Who will speak for the unmet needs of the sick?

*By Nigel S B Rawson and John Adams*

Click [HERE](#) to Contact.

If you're interested in volunteering your time/ Pku experience with others in the PKU community, and would like to be added to the roll call. Please email your information to:

[newseditor@canpku.org](mailto:newseditor@canpku.org)

With subject line "Roll Call"

**\*\*Note:** This is not a replacement for medical advice, your PKU clinic is the best place to have medical questions answered,. These are people with personal experience of PKU diagnosis's, offering to be a sounding board/ friend. Please always check with your clinic before making any changes to your treatment.\*\*



## Happy Birthday Carver!

Thank you



The adorable little girl, (pictured below's) name is Carver, and on May, 22nd Carver Celebrated her second birthday!

Carver's parents asked that guests at her birthday celebration make a donation to CanPKU in lieu of gifts!

CanPKU is honored to have been selected as a recipient in Carvers birthday celebrations!

On behalf on CanPKU, Thank you Carver, and Happy belated Birthday!!



"Some academic authors have criticized pharmaceutical companies for funding patient advocacy groups because they see it as a conflict of interest. Media commentators also tend to take a negative view of industry funding for such non-profit organizations. Although it cannot be proved that funding from pharmaceutical companies influences the policy positions of patient groups regarding whether drugs should receive insurance coverage, the implication, with varying levels of subtleness, is that this is the case.

Authors of these articles and media reports are unlikely to have a child or partner suffering from a major debilitating or life-threatening condition for which the only effective therapy is an innovative costly drug. Otherwise, they might be less judgemental and investigate whether the private health insurance to which they and their employers contribute provides coverage for the required medicine. Since most universities and media corporations contribute to a comprehensive private insurance plan, they might be lucky. If not, they could look to their provincial public drug plan, but the likelihood of gaining reimbursed coverage would be substantially lower, because Canada has a two-tier drug insurance system. "

[Read the Full Article Here.](#)



### Heading to the U.S.A This summer?

The NPKUA has compiled the following list of Summer Camps across the United States that cater to PKU families and adults.

- Camp PHEnomenal: May 3 - 5, 2019, Meridian, Tx
- Camp Knot A PHE: May 24 - 27, 2019, Prescott,



- AZThe Hole In The Wall Gang Camp: May 30 - June 2, 2019, Ashford,
- CTPKU NW Alliance Family Camp: June 6 - 9, 2019, Antelope, OR
- Emory Metabolic Camp: June 17 - 22, 2019, Atlanta, GA
- Camp PHEver: July 7 - 12, 2019, Burton, TX - Camp for ALL
- IPAD's PKU Mini Camp for Kids: July 19 - 20, 2019 Park City, UT
- Illinois Family Camp: July 19 - 21, 2019, Lacon, IL
- Camp Cavett: July 31- August 4, 2019, Adair, OK
- Camp Huber: August 23 - 25, 2019, Westminster, MD
- Camp Connect: September 13 - 15, 2019, Winder, GA

[Click Here to Learn More!](#)

## Ontario Poker Derby for PKU!

### Pins 4 PKU 2019

CanPKU is currently seeking energetic, fun, exciting folks (or just someone looking to help out) to organize a bowlathon in your city!

It's EASY! We will help! As little as a group of friends, as big as you can dream!

email [tanya.chute@canpku.org](mailto:tanya.chute@canpku.org)



Can we beat last years #s?

Funds raised help PKUers and families travel to Camp MagniPHEque

Please contact:

[tanya.chute@canpku.org](mailto:tanya.chute@canpku.org)

to register and get a pledge sheet to ensure that we have enough lanes booked at the center closest to you!

Pledge sheet can also be downloaded [by clicking here.](#)

Current locations (More to come)

**Brantford, ON**

Sunday May 26th 1-3 pm EST. Star Lanes Limited Brantford ON N3S 3B9 Register with [k\\_charlton@live.com](mailto:k_charlton@live.com)

**Kamloops, BC -**



IRONHAWGS 4th Annual PKU Poker Run!!

Over the last few years we have had a great turn out.....this year we want you to stand by our side at the roadside!!

Pm me for more details!!

Come here the ROAR, feel the excitement and embrace the feeling of being PKU STRONG!!!

Tickets are \$20.00 if you plan to ride.

No fee to come and cheer on the riders as they pass by the Oakland Community Centre.

"TOGETHER WE ARE PKU STRONG"

"LOUD AND PROUD"

Kamloops, BC

Sunday May 11th 12-2 pm PST. Falcon Lanes 2020 Falcon Rd, Kamloops, British Columbia V2C 4J3. Register with amandacosburn@gmail.com

Newmarket, ON

- We're working on it. Stay tuned!

Peterborough, ON -

Sunday May 5th 2-4 pm All you can bowl. . Lakeview Bowl, 109 George St. N Peterborough. Please register with tanya.chute@CanPKU.org

Sparwood, BC

- Saturday May 4th 12-2 pm. All you can bowl. Elk Valley Fun Centre 1290 Ponderosa Drive. Sparwood. Only 36 spots available. Please register with npallone@Shaw.ca. Elk Valley Fun Center graciously donated lanes and shoes! Minimum \$20 donation suggested.

[Learn More Here!](#)



### Recipe Corner



## KFC- Kentucky Fried Cauliflower

### Ingredients:

- 2 1/2 c Cauliflower, broken into bite-size nuggets 175mg
- 1 1/2 TBSP Egg Replacer
- 1/3 c Ice cold water
- 1/2 c Cook for Love Baking Mix 38mg
- 1/4 tsp Xanthan Gum
- 1 tsp Salt
- 1 tsp Mrs. Dash Seasoning
- 1/2 tsp Garlic Powder 7mg
- 1/2 tsp Sweet Paprika 6mg
- 1/2 tsp Sugar
- 1/4 tsp Oregano 2mg
- 1/2 tsp Parsley 1mg
- 2 TBSP CFL Toasted Bread Crumbs, \* see note below 19mg
- 4 c Vegetable oil, for frying

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, paprika, oregano and sugar in a small bowl. Mix, set aside

## 85th Anniversary Discovery of PKU story!

2019 marks the 85th anniversary of the landmark discovery of PKU by Dr. Asbjørn Følling. The discovery of PKU was a fundamentally important step forward for the fields of biochemistry, genetics, metabolism, and medicine. It led to subsequent work that has saved the lives of thousands of children born with this rare disease.



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.

6.

For the sauce: 120 gm (1/2 cup) mayonaise [92 mg]; 15 gm (1 tablespoon) yellow mustard [24 mg]; 1/2 tsp. garlic powder [7 mg]; 1 tbsp. apple cider vinegar; 42g (2 tablespoons) honey [4 mg]; Salt and pepper, to taste; Combine above in a small bowl. The dipping sauce is .64 mg/gm

### Notes

If you do not have toasted lp breadcrumbs on hand, you can add 10 gm crushed cornflakes or even ground up gluten free pretzels - just adjust the phe. It also works with just the seasoned starch, but we prefer it with a little more texture.

Recipe Credit : <https://cookforlove.org/recipes/detail/75580>

## Savory cheese biscuits.



### Wet:

- 3 cups mix quick,
- 1/4 tsp salt,
- 1/2 tsp garlic powder,
- 1 tsp parsley,
- 1 tsp Italian seasoning,
- 3/4 cup shredded low protein cheese (eg daiya cutting board style, CBF etc)

### Dry:

- egg replacer,
- 1/2 cup oil,
- 1 cup water

Preheat oven to 350 degrees. Combine dry ingredients (including cheese). Combine wet ingredients. Combine wet and dry and mix. Spray muffin tin with cooking spray so



My name is Kaisa Haugen and I live approximately a 2-hour drive from Følling, a tiny place in northern Trøndelag. To most people this is an insignificant place in a small rural area in a small Scandinavian country. But to me and to many other people with PKU (or "Følling's disease" as it is sometimes called in Norway) this is a very important place. This is where the doctor who gave us a chance at life came from, a man whose discovery would have a nearly incomprehensible effect on the lives of PKU patients and their families. This place is the hometown of Dr. Asbjørn Følling.

[Click here to Read more!](#)



# DID YOU KNOW?



### Getting It Right for Patients Canada's 1st National Pharmacare Plan

One of the most important items in this year's federal election will be Canada's First National Pharmacare Plan. After a year of consultations, the Canadian public has learned some of the key elements in the proposed plan. The promises are appealing but, as they say, "the devil is in the details". Over the next weeks and months leading up to the election, the Canadian Organization for Rare Disorders and the Consumer Advocare Network will host a number of webinars and implement a number of surveys to engage patients and the public on some of the important "details" they want to see— or absolutely not see—in a National Pharmacare Plan. We hope that all stakeholders will take part.

Please take a few minutes (about 5 - 7) to answer our first survey on Developing a National Formulary (Drug List). It will take only about 5 to 7 minutes to complete. And stay tuned for our first Webinar to be held last week of June.

Survey Link: [https://www.surveymonkey.com/r/Pharmacare\\_Survey1](https://www.surveymonkey.com/r/Pharmacare_Survey1)

Durhane Wong-Rieger  
President & CEO  
Canadian Organization for Rare Disorders  
p: 416-969-7435  
m: 647-801-5176  
[www.raredisorders.ca](http://www.raredisorders.ca)

and dry and mix. Spray muffin tin with cooking spray so they don't stick and divide into 12 muffins. Sprinkle more low protein cheese on top and bake for 20 mins. Tastes great with soup, or a savory snack in a lunch. Phe is dependent on what kind of low protein cheese you use. I estimated this batch to be around 7mg phe per muffin.

Submitted by: *Brianna Young*

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



## IN THE NEWS!

*Links to articles you may enjoy!*

*Articles you may enjoy*

[John Adams talks about accessing drugs for rare conditions](#)

[Thriving With PKU Youtube](#)

[Powerful "My PKU Life" - Carrie Hall Books available for as little \\$2.37!](#)

[Living with PKU, Lessons from the PKU Community](#)

[Take the survey Here!!](#)

## Future looks bright for PKU Patients..



**Homology Medicines Announces FDA Clearance of Investigational New Drug Application for HMI-102 Gene Therapy Candidate for PKU : Homology Medicines..**

- Phase 1/2 pheNIX Trial Would Represent First PKU Gene Therapy to Enter the Clinic -

- Initial Clinical Data Expected by the End of 2019 -

BEDFORD, Mass., April 4, 2019 - Homology Medicines, Inc. (Nasdaq: FIXX), a genetic medicines company, announced today that the U.S. Food and Drug Administration (FDA) has provided clearance for Homology to begin its Phase 1/2 pheNIX clinical trial with HMI-102, a one-time gene therapy candidate for adults with the rare genetic disease phenylketonuria (PKU), an inborn error of metabolism. Homology has been working closely with multiple clinical sites in the U.S. to prepare for potential initiation of the pheNIX trial, which is designed to evaluate the safety and efficacy of the investigational gene therapy in a randomized, concurrently-controlled, dose-escalation study in adult patients with classic PKU.

[Read More Here!](#)

## MAY is PKU AWARENESS MONTH

**\*\*Don't stop in may, keep using #'s all year long for a features in this column !\*\***

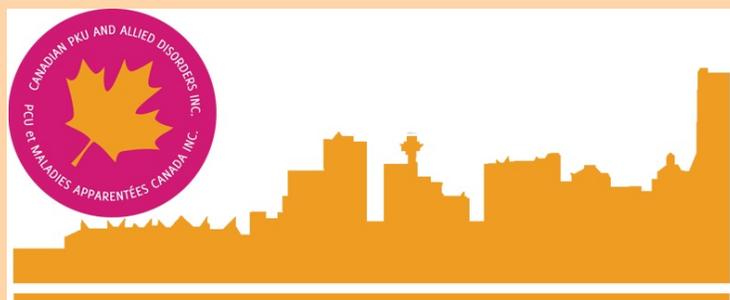
# #WeCanPKU

## #weCanPKU

Upload photos of any of the following challenges, (or make your own!) for PKU Awareness month on Facebook Or Instagram. Use the hashtag #WeCanPKU for a chance to be featured in our next issue!

- Preparing, Weighing, or Eating low protein food
- Fry Day Friday! (include how much phe is in your fries!)
- Eating out, Low Pro
- Delivery Day! (a photo when your low pro food arrives)
- Blood Test day
- Bottoms Up Formula!
- Paint your nails blue for PKU
- Traveling with PKU
- PKU Clinic Day

**Reforming how the Canada Revenue Agency (CRA) responds to applications for the Disability Tax Credit (DTC) by PKUers requires focus, discipline and determination.**



The good news is two-fold:

1. When necessary to appeal CRA negative decisions to the Tax Court of Canada, our CanPKU track record is now 15

-PKU Clinic Day  
-PKU Easter  
-PKU STRONG  
-Achievement (a grade, a sport, stayed on track, ect!)

Tax Court of Canada, our claim to track record is now 15 wins for 15 appeals - with the most recent 13 cases resolved without a trial.

2. Increasingly it is possible to transform an initial no into a yes before having to even start a court appeal, but there is a specific trick!

Here is a summary of a recent case:

It is an example of how quickly a NO can be turned into a YES.

- applied in late December 2018,
- CRA "no" late January 2019,
- Notice of Objection filed first week of February 2019.
- CRA "yes" received late March 2019 with many years of retroactivity for the PKU teenager.

Total time from application submitted to YES: three months and only two month from filing a Notice of Objection. That is the trick!

We have learned a lot in helping with about 50 applications since 2016 in what works and what is a waste of time.

Lessons:

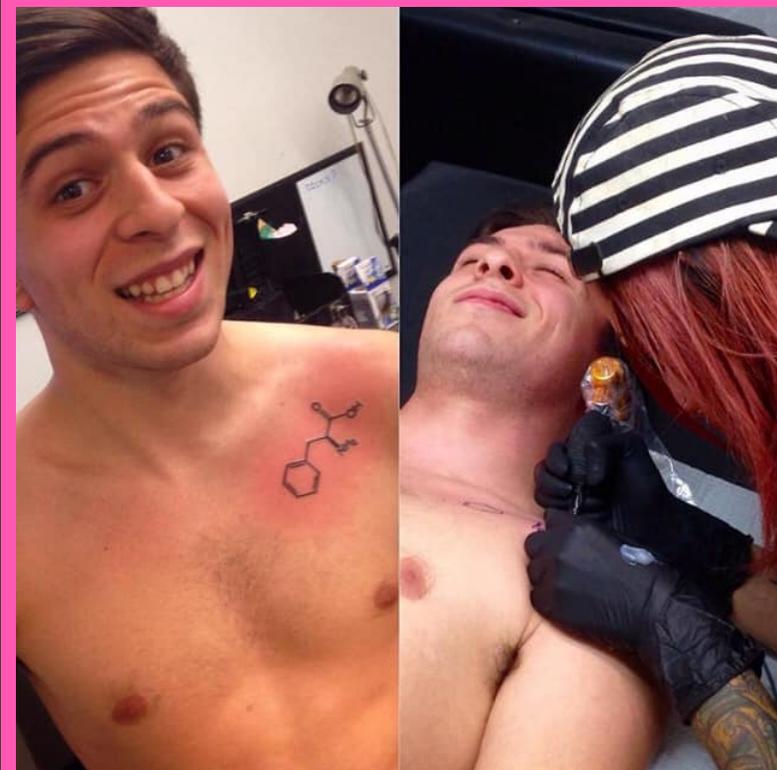
1. submit a spreadsheet with details of the tasks of PKU therapy and times spent on those tasks (got to show at least 14 hours a week on tasks of therapy.)
2. submit a Notice of Objection within days of receiving an initial "no". (The no comes in a Notice of Determination").
3. don't waste time asking for a review, a reconsideration or an appeal internal to CRA, or submitting any additional info.
4. in both the original application and Notice of Objection state that you are relying on two recent Judgements of the Tax Court: Cummings v The Queen 2017 TCC 133 and Hughes v The Queen 2018 TCC 42. Those were the two PKU DTC trials we won.

If you have not done this before, we suggest that you do not try to do this alone.

"Let CanPKU coach you each step of the way"  
-John Adams (President @ CanPKU)



www.  
canpku.org



The Best Medicines Coalition has been actively involved in consultations on pharmaceutical pricing modernization since 2016. Most recently, the BMC has been represented on a Patented Medicines Prices Review Board (PMPRB) Steering Committee by Gail Attara, who has expertly and diligently communicated patient perspectives.

The process has been challenging with broad concerns that proposed regulations if passed will deter the timely introduction of new drugs. As discussed on the BMC National Issues webinar last week, the BMC under Gail's signature, has provided formal input to the Steering Committee again expressing patient positions and issues with the committee process.

The submission to the PMPRB Steering Committee, letters to the Prime Minister and the Treasury Board President asking that the proposed regulations not proceed and requesting meetings to discuss and provide patient perspectives, have been sent.



To the Mother who just received her child's diagnosis, You will be Okay.

-Sarah Lango



Some Matching PKU awareness Tattoos!



Jonah Reeder prepares a special protein shake that helps him manage a metabolic condition called phenylketonuria.



"The day I received my daughters official medical diagnosis is one that will forever stand out in my mind. We had just returned home from running an errand when the phone rang. When you answer to hear the world renown neurologist on the other end of the line, you know the news you are about to receive probably isn't what you want to hear. It was just a few simple words, "The tests results came back and it confirmed the diagnosis we had discussed."

[Read the full article Here.](#)



Photo from BC PKU event.

In photo are PKU adult Brian Quinn on right, CanPKU president John Adams, and Larry Blankstein of Synlogic. All 3 were speakers at the event.

Please Make sure your photos are public, or post them directly on to our CanPKU social media pages, using #weCanPKU to make sure we see them!

## HOME PHE MONITOR SHAPE OF THE FUTURE!

As you may have heard, there has been progress lately on the development of a home-based phe monitor. One company working closely with the FDA toward approval has asked PKU News to help by surveying the community to further refine the features of, and needs for, such a device.

Since a device like this has never been manufactured before, the company needs a little bit of help from the community as they work out how the device will be used.

**That's where you come in.** Take this 5-minute survey and help inform the company's development, which they hope to have in clinical trials in 2019. [Click here to take the survey.](#)

SHARE YOUR OPINION



TAKE THE SURVEY!

As you may have heard, there has been progress lately on the development of a home-based phe monitor. One company working closely with the FDA toward approval has asked PKU News to help by surveying the community to further refine the features of, and needs for, such a device. Since a device like this has never been manufactured before, the company needs a little bit of help from the community as they work out how the device will be used.

## A Gulp Of Genetically Modified Bacteria Might Someday Treat A Range Of Illnesses

Instead of eating a typical breakfast every day, Jonah Reeder gulps down a special protein shake. "The nutrients in it like to sit at the bottom, so I usually have to shake it up and get all the nutrients from the protein and everything," says Reeder, 21, of Farmington, Utah, as he shakes a big plastic bottle.

Reeder was born with a rare genetic disorder called phenylketonuria, or PKU. If he eats meat, drinks milk or consumes other common sources of protein, toxic levels of the amino acid phenylalanine could build up in his body and damage his brain.

So Reeder gets his protein from the shake, which is rich in other amino acids, vitamins and proteins that don't contain phenylalanine.

"It's a really healthy drink," Reeder says. "It's basically protein, except without phenylalanine."

[Click here to Read more!](#)



# DID YOU KNOW?

Most of us know, But a fun fact to share when educating

That's where you come in. Take this 5-minute survey and help inform the company's development, which they hope to have in clinical trials in 2019.

[Click here to take the survey.](#)

others!

## Good Old Fashion..



Would you, or your child be interested in connecting with other PKU Patients around the world?

Do you like receiving good old fashion snail mail?

Send an email to: [newseditor@canpku.org](mailto:newseditor@canpku.org) and let us help connect you with another PKU patient looking for a pen pal!



ALSO...

Small reminder for the fundraising organized by Silicycle, company or Geneviève, the mother of Vincent PCU works.

50% of the donations collected will go to the Genetic Nutrition Fund. This money will allow the purchase of an I-Pad, play table for the consultation room during your visits to CHUL and financial support for the metabolic picnic.

A tax receipt will be provided with any donation of \$ 20 or more. Easy and fast to give online!



## DID YOU KNOW?

CanPKU provides our PKU community with the expertise in understanding, and applying knowledge of PKU to the specifics of the DTC, **FREE** of charge?

Also our CanPKU president

John Adams, Will represent DTC claimants at tax court (if necessary) at no charge?

### DID YOU KNOW:

John Adams represented, Our news editor Arlene McDonald and her family in their appeal, and then objection with the CRA?

Arlene did proceed to tax court, but her appeal was settled successfully without a trial.

A source has informed us that the CRA is currently processing 2 DTC applications for PKU individuals who have



processing 2 DTC applications for PKU individuals who have used a commercial service, which charges 30% of the tax credits received.

CanPKU wants YOU to receive your DTC credits, please consider CanPKU before opting to pay commercial services advertising on social media, with 30% of your return.

CanPKU welcomes you to make a donation at [www.canpku.org](http://www.canpku.org) so we can continue helping others obtain DTC status without the use of commercial services.

CanPKU est honoré de partager avec vous PHÉNYLCÉTONURIE QUÉBEC où vous pouvez trouver des articles sur la phénylcétonurie et des idées dans les deux langues officielles du Canada! Pour lire la version anglaise de cet article ou en savoir plus, cliquez ici!

CanPKU is honored to share with you,  
**PHÉNYLCÉTONURIE QUÉBEC,**  
Where you can find PKU support in BOTH of Canada's official languages!  
To read the English version of this article, or learn more, click [HERE!](#)

## LES ÉMOTIONS ET LA PHÉNYLCÉTONURIE

Vous avez sans doute déjà entendu l'expression « manger ses émotions ». C'est un phénomène bien connu qui consiste à tenter d'atténuer le stress, l'anxiété, la peur, la colère, au moyen de la nourriture. Évidemment, c'est une très mauvaise habitude, car on perd toute conscience de ce que l'on mange et ça peut éventuellement mener à des problèmes de santé, surtout quand les aliments ingérés sont à haute teneur en sucre et en calories. Les PCU n'échappent pas à cette réalité. Malheureusement, en plus des calories et du sucre, ils doivent se soucier d'autre chose : les protéines.

La majorité des gens atteints de phénylcétonurie et qui suivent leur régime ont quand même des passages de temps à autres où le régime est moins bien suivi. Nous passons tous à travers ces périodes. Mais j'étais dans une excellente période dernièrement et j'en étais particulièrement fier. Puis, hier est arrivé. Hier était une mauvaise journée. Du début à la fin. Vous savez, ce

genre de journée où tout va de travers. En plus, j'avais faim; l'horaire de cette journée était vraiment tout croche et ne m'aidait vraiment pas à bien gérer mon régime, à prendre des repas au bon moment. Bien sûr, je suis quelqu'un de positif et ces événements n'ont pas réellement entaché ma bonne humeur. Par contre, qu'on soit positif ou non, ce genre d'événements négatifs à répétition, même si ce n'est rien de grave, finissent par tomber sur les nerfs et nous affecter. C'est exactement ce qui est arrivé et à un certain moment, j'ai vraiment eu envie d'envoyer tout paître et de manger plein de trucs que tout bon PCU devrait même éviter de regarder. Je voulais inconsciemment « manger mes émotions ». En fin de compte, je m'en suis plutôt bien sorti, mais cela m'a fait comprendre à quel point ce phénomène est une épée de Damoclès au-dessus des gens et particulièrement de ceux qui ont la phénylcétonurie (ce qui m'a donné l'idée d'écrire cet article). Je vais donc partager avec vous comment je m'en suis sorti. 5 trucs pour éviter de « manger ses émotions » (et éviter les protéines qui viennent avec) :

1. Prendre conscience du problème. Comme je l'écrivais ci-dessus, j'ai vraiment compris à un certain stade que je risquais de dériver. Ce n'est pas toujours facile de prendre conscience de quelque chose d'aussi subtil, mais j'ai pratiqué énormément de visualisation dernièrement (secret de mon succès des dernières semaines) et j'ai le vif sentiment que cela m'a aidé à prendre conscience de la situation.
2. Toujours avoir des collations faibles en protéines sur soi. Une autre bonne habitude que j'ai prise dernièrement. Par chance, j'avais des barres de chocolat et beurre d'arachide « Complete » de Cambrooke sur moi, ce qui m'a permis de tenir le coup jusqu'à ce que je revienne.
3. Identifier des solutions de restauration à faible taux de protéines. Comme j'étais dans un coin que je connais bien de Montréal, je savais où aller me procurer des aliments qui me satisferaient suffisamment, du moins jusqu'à ce que ces sentiments s'atténuent.
4. Notez ce que vous mangez. J'ai pris l'habitude de noter mes

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**Cambrooke Therapeutics' latest breakthrough!**

*The lowest Phe GMP medical food available for PKU!*

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The lowest Phe and lowest calorie complete GMP product available!

- ✓ Lowest Phe
- ✓ Natural!
- ✓ Lowest calorie GMP nutritionally complete formula
- ✓ Low volume
- ✓ Low carbohydrates
- ✓ Zero total sugars
- ✓ No artificial sweeteners, colors or flavors
- ✓ Symbiotic combination of probiotics & prebiotics to support gut health

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

[Learn More](#)

**XPhe minis**

Complete: With all required Micronutrients  
Protein supplement: Phe-free  
Intended for: PKU / HPA  
Suitable: From 7 Years  
In form of: Tablets

metaX

1 sachet = 94 tablets: 10 g protein

Ideal for: School, Work, Travel, Sports

[Learn more on Facebook!](#)

**PHENYLADE®  
GMP MIX-IN**

**NEW!**

[Learn More](#)

**Now available in Canada!  
Phenylade Gmp Mix-In**

Introducing a new GMP-based PKU formula that is tasteless and odorless! Simply mix with water, any flavored drink or current PKU formula. Each single serve pouch provides 10 g PE and 15.3 mg of Phe with only 42 calories! To request a sample, call 1-877-636-2283

[Learn More](#)

## ***PKU Patient Registry***



**Still haven't registered?**  
Click [Here](#), To make A difference!

**Thank you again for your commitment to accelerating PKU research!**



**Looking Forward to the Next Issue?**  
**PLEASE SHARE!**

**Our next newsletter will be due out JULY 15th. Let us know what you think!**

repas dans l'excellente application Lose It (j'en parlerai davantage dans un futur article). Si vous voulez surveiller de plus près la consommation de phénylalanine, vous pouvez aussi essayer l'application de Cambrooke Metabolic Balancer. C'est un excellent moyen de prendre conscience de ce que l'on mange.

5. Ne pas garder ça pour soi. J'ai eu le réflexe de verbaliser mon « flash » à ma conjointe qui m'a immédiatement encouragé à rester sur le droit chemin. C'est probablement ce qui m'a le plus aidé à ne pas dérailler.

Le sentiment de vouloir manger n'importe quoi est malheureusement très fort dans ces situations et c'est l'ensemble de ces éléments qui m'ont aidé à passer à travers. De votre côté, avez-vous déjà ressenti ce besoin de manger des éléments que vous aimez beaucoup, mais auxquels vous n'avez pas droit lorsque tout va mal? N'hésitez pas à m'en parler si c'est le cas (ou même si ce n'est pas le cas).

## **The CanPKU Report Card of Provincial Coverage**



was last updated in 2016. CanPKU is still involved in all kinds of advocacy work to help improve the lives of families living with PKU. From supporting Disability Tax Credit Applications, to trying to secure better coverage of foods and formulas in provinces that need it, to fighting for mandatory labeling of aspartame products and inclusion of rare drugs in a National Pharmacare plan... the battles continue, and supporting documents can often help sway decision-makers in our favour.

Last time we collected information for this Report Card, we went straight to the clinics to gather information about

what was covered in each Province/Territory, and what services were available. This time around we have decided to include the voice of the people - this will help us gather more responses and will ensure that public perception is fairly represented. Although it matters what is actually available in your region, what you think is available in your region is equally important! Survey responses will help us update our report card but will also help guide our advocacy efforts by highlighting what is needed most in each region. It is important to realize that this report card is not meant to be a judgment of the clinics, but rather an assessment of how well the government of each Province/Territory takes care of their PKU people.

Send feedback to: [newseditor@canpku.org](mailto:newseditor@canpku.org)  
to be published in our July issue!



**Vitaflo's PKU Vision**  
Provide a wide range of PKU specially formulated foods to support you throughout life's journey

Our goal is to continue to develop products that offer you convenient and flexible choices for your diet.

For further information about our products, please consult your healthcare professional.  
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- Metabolic workshops

To hear about low protein products, promotions and events, click [here](#) to sign up for our Metabolic eNewsletter.

Website: [specialtyfoodshop.ca](http://specialtyfoodshop.ca) | Email: [sfs.admin@sickkids.ca](mailto:sfs.admin@sickkids.ca)  
Call: 1-800-737-7976 or 416-813-5294 | Fax: 416-977-8394

[Learn More](#)

## Cat in the Hat SUPPLEMENT SPECTACULAR!

Formula and supplements are an essential part of PKU therapy, but are not always a favorite experience!

Submit a Photo of you or your child taking your PKU supplement to [newseditor@canpku.org](mailto:newseditor@canpku.org), Title: Supplement Spectacular, with your name, and where you taking your supplement, for a chance to be featured here!

Get creative, only a few photos will be selected each issue, so use it as an incentive on those days when it's not your favorite thing to do!

We invite patients, caregivers and clinicians to all participate in this survey. Each person should only do the survey once, although multiple responses from within the same family are perfectly acceptable (don't tell me you and your spouse always agree on these things!) We will be collecting survey responses until March 31st and aim to have an updated Report Card available for publish in the June newsletter. Your voice matters - make it heard!



Fill out the new survey [Here](#).

Review the 2016 Report Card [Here](#).



**DID YOU KNOW?**

**VOTRE SUIVI NUTRITIONNEL** pour maladies métaboliques



There is an French App, Available for IOS and Android, to help manage your PKU?

**Have you moved?**  
Learn more about it [HERE!](#)

Remember to update everyone, including CanPKU, if your mailing address has changed!



**YOU**  
Take your Supplement  
Here and There...  
You Take your  
SUPPLEMENT  
EVERYWHERE!

You are super, That's a fact,  
and the Cat in the Hat Knows  
alot about that!

New From Cambrooke, Creamy Hot  
Vanilla Breakfast cereal!

Learn more [Here!](#)



breakfast  
CREAMY HOT CEREAL

Vanilla



Want to help us fundraise using the dollars you are already spending?

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Or find us by clicking on <https://www.flipgive.com/teams/145032-canadian-pku-and-allied-disorders> and JOIN THIS TEAM on the top right.

Share this information with friends and family!

Know someone else who may like to use this tool for fundraising? Use our referral link and both accounts can be credited \$20.00

<https://www.flipgive.com/r/704154>

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I agree to receive the CanPKU newsletter and related communications from the Canadian PKU and Allied Disorders non-profit concerning matters related to PKU or allied disorders. I may withdraw my consent at any time via SafeUnsubscribe.

**CanPKU Privacy Statement**



### Nutrition Facts

24 servings per container

Serving size 1/4 cup (28g)

Amount per serving  
**Calories 124**

	% Daily Value*
<b>Total Fat</b> 2.1g	<b>3%</b>
Saturated Fat 0.2g	<b>0%</b>
Trans Fat 0g	
<b>Cholesterol</b> 0mg	<b>0%</b>
<b>Sodium</b> 4mg	<b>0%</b>
<b>Total Carbohydrate</b> 14g	<b>5%</b>
Dietary Fiber 1g	<b>4%</b>
Total Sugars 1g	
Includes 0g Added Sugars	<b>0%</b>
<b>Protein</b> 0g	

Vit. D 0mcg 0% • Calcium 5mg 0%  
Iron 0mg 0% • Potas. 49mg 2%  
Phosphorus 11mg 0%

\*The % Daily Value tells you how much a nutrient in a serving of food contributes to a daily diet. 2000 calories a day is used for general nutrition advice.

FLCF10639D



**INGREDIENTS**  
Cassava meal, tapioca, non-dairy creamer (sunflower oil, corn syrup solids, food starch-modified, mono and diglycerides, natural flavor, citric acid, and carrageenan), natural flavors (maltodextrin, capric/caprylic triglycerides, flavors).

**MANUFACTURED BY**  
CAMBROOKE THERAPEUTICS, INC.  
AYER, MA 01432 cambrooke.com  
Manufactured in a facility that uses eggs, milk, nuts, soy and wheat.

**DIRECTIONS FOR USE**  
Stove Top: Mix 1/4 cup cereal with about 1 cup water or non-dairy milk in a small pan. Bring to boil, turn heat down, cover and simmer for 5 minutes. Cereal will be thick. Add additional water or non-dairy milk to reach desired consistency.

Microwave: Mix 1/4 cup cereal and about 1 cup water or non-dairy milk in microwave safe bowl. Microwave on high 2-3 minutes, stirring once at the halfway point and again when finished. Add additional water or non-dairy milk to reach desired consistency. Let stand a few minutes before serving.

Infants and toddlers: Use 1 1/2 Tbs cereal and about 1/2 cup water or non-dairy milk and follow conventional directions above. Be careful that prepared product has cooled sufficiently for child. Discuss introduction of solid foods with child's physician.

Store in a cool, dry place.  
**LOW PROTEIN MEDICAL FOOD**  
For use under medical supervision for conditions such as inborn errors of protein metabolism.

serving suggestion

Amino Acids	per serving
Protein	0.3g
Phenylalanine	7mg
Valine	8mg
Leucine	10mg
Isoleucine	7mg
Methionine	3mg
Tyrosine	4mg
Threonine	5mg

**NET WT 24 OZ (680 G)**

Canadian PKU and Allied Disorders maintains member/participant/registration information for its own use and does not rent, sell or otherwise provide any identifying information to outsiders. For more information, please don't hesitate to contact us.

**CanPKU Happy & Honored to be a part, and Co-founder of Disability Tax Fairness Effort.**



(Letter from DTFA, "Disability Tax Fairness Alliance")

**"We have high hopes and expectations, That the work of the DAC will help reduce and eliminate barriers, to access the DTC for Canadians with severe and prolonged, mental and physical impairments"**

- Quote from letter to Minister Lebouhiller

[Read Letter.](#)

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