



CanPku News!

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Canadian PKU and Allied Disorders Inc.



DECEMBER 2019

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DID YOU KNOW?

CanPKU provides our PKU community with 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?

CanPKU is currently 17 wins for 17 appeals to Tax Court of Canada!

Click the "DTC Package Request" link, to start working with CanPKU on your DTC status today!

****Over a life time, the DTC and the seven other potential benefits it enables, can add up to hundreds of thousands of dollars in value, especially when combined with the RDSP!!****



www.canpku.org

Greetings!

Well here it is, the 38th issue of CanPKU News,

I'm excited to have some time to myself this evening to get my little paragraph into the news letter!

This issue talks alot about new and upcoming treatment and therapies for PKU! this is so exciting for me, as in our sons 12 years of life, we went from diet as the only treatment, to now seeing options, and ourselves using Kuvan!

The holidays are coming, and in our house that means lots of basketball practices, Christmas and band concerts, & cooking/ baking Regular and Low Pro versions of favorite treats for the holidays!

Life hack for PKU Parents. Cook in BULK, invest in some good Tupperware and FREEZE meals! These are essential, for last minute activities, (which usually arn't at all last minute, some even planned weeks in advance, I only just hear about them... at the last minute.. I know at least some of you can relate LOL) They are also awesome for kids to reheat themselves, we use stickers to label the total PHE in each container.

We have frozen and reheated many types of pasta, our version of chili, rice dishes, soups/ stews, and even premade "hamburger patties" from the mix, froze and then thrown on the grill!

I have to say I have it pretty easy as a PKU mom when it comes to Christmas. Our 12 y/o doesn't have much of a sweet tooth, and doesn't care to veer too far away from his staple foods.

Most hollidays his treats look something like this:



Thank You Sponsors!

Thank You Sponsors!

GOLD

B:OMARIN®

SILVER

 CAMBROOKE
THERAPEUTICS™

 NUTRICIA
Metabolics
Inspiring Futures



BRONZE

 **Innomar Strategies®**
AmerisourceBergen

However, last year on his birthday, we bought him one of these,



and it is his new favorite! Add frozen fruit and a little sugar (optional) and your pumping out bowls full of sorbet for the whole family! If you haven't finished Christmas shopping for your PKU'er yet, I highly recommend one of these! It has been an awesome, healthier alternative for our non PKU son as well!

With that being said, I also need to finish my Christmas shopping! I'll wrap up my part of the news letter now, so I can get busy wrapping other things!

From all of us here at CanPKU,



See you again in 2020!

Sincerely,





Arlene McDonald
Newsletter Editor
Canadian PKU & Allied Disorders Inc.



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

October:

- Fascinating day at the Supreme Court of Canada in Ottawa of an appeal regarding new federal laws against discrimination on basis of a genetic characteristic. The court decision will take months. Background: CanPKU is a member of the Canadian Coalition for Genetic Fairness which was there defending a law passed by Parliament (without the support of PM Justin Trudea or then Attorney General Jodie Wilson Raybold). That law changed the Canada Human

Rights Code, the Canada Labour Code and the Criminal Code to outlaw genetic discrimination in employment or insurance.

- With CanPKU board member Nicole Pallone, medical geneticist Pranesh Chakraborty and epidemiologist Beth Potter, both of the University of Ottawa, worked by phone and email on a proposal for another 5 year grant for ongoing study of clinical practices and outcomes in metabolic diseases including a special focus on PKU. CanPKU is a participating partner in this project. A decision by the Canadian Institutes for Health Research expected in Q1 2020.

- On behalf of the Best Medicines Coalition (again CanPKU is a member) began working with doctors, nurses, drug and medical device developers, government, & others on refining a set of principles for ethical collaborations

- Presented a webinar on the threat of USA governments arranging for wholesale imports of medicines intended for Canadians. Webinar facilitated by the Canadian Cancer Survivors Network (for BMC).

- Attended a workshop in Philadelphia on "Hard Science Innovation Forum" and got to see a working demo of a home Phe monitor under development by Aptatek BioSciences

- Participated with Brian Goetz and Charles Black, both PKU adults, in a BioMarin patient advisory board focused on outreach to teens and adults with PKU, at expense of BioMarin

- Spoke at our Quebec event in Montreal. That gathering had really good vibes.

November

- at request of Government of Canada and at its expense, presented at a global meeting on general considerations for clinical trials, from the patient group perspective, at the offices of the USA Food & Drug Administration (FDA) representing the Best Medicines Coalition

- spoke as a panelist on issues with federal changes in price controls on



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.



2020 SAVE THE DATE

Education and Networking Opportunities

Join us at a 2020 educational event near you! Learn from the experts, try new products, interact with friends & families, and have a fun time!

Next up:

Ontario Camp MagniPHEque
- Sept 18-20, 2020

Information on upcoming events and travel scholarships can always be found at:

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

The CanPKU volunteer Board Members, have been reviewing our opportunity planning for 2020. We are making some changes that we hope will meet the needs of our membership and beyond to the PKU community. We encourage your feedback for planning in 2021 and beyond.

BC and Prairies Regions - our sister organization, the National PKU Alliance (NPKUA) of the USA, is hosting their once-in-two-years conference "Challenging the Summit" in Vancouver, WA (near Portland, OR). This will take place July 9-12th, 2020. Save the dates! We encourage you to consider attending. We are working with NPKUA to provide partial travel scholarships for adults and/or families to attend this amazing event.

This fun and amazing conference offers Networking, NPKUA Funded Research Updates, Adults, Teens and Parent Breakouts, Kid Zone, distinguished speakers on the latest scientific developments and so much more. It gets rave reviews from those Canadians who have attended.

CanPKU has set aside travel scholarships to help cover up to 50% of the cost of attendance (Registration, travel and accommodation). There is also an opportunity to apply to the NPKUA travel scholarships to assist in covering some costs (where available) Please refer to their website for full details <https://www.npkua.org/News-Events/Conferences/2020-conference>. Registration will open in January 2020.

Ontario

- Camp MagniPHEque 2020 is scheduled for September 18-20 at the same location (Camp Kawartha, Douro Dummer, ON outside Peterborough). Save the dates! We welcome adults and families. Camp scholarships are available to assist with registration and travel costs. Please note, at the time of our planning, it is expected that this event will take a pause in the year 2021. Be sure to join us this year else you may have to wait two years.

Quebec - We have had discussions with key individuals and families in the Quebec region and established this event will pause just for 2020. Our Atlantic Region event in 2020 will be bilingual for adults and families who are looking for content en

new drugs in Ottawa at the Canadian Association for Healthcare Reimbursement. Two lawsuits against the changes have been filed by 22 drug companies and their trade association. A couple of patient groups are likely to seek status as intervenors. Theme: Each of us has a right to medical assistance in dying (thanks to the Supreme Court of Canada), but doesn't that mean we have a right to medical assistance in living?

- met with a Canadian company specializing in bringing other companies' new therapies to Canada about the state of PKU treatments across Canada
- attended conference on cell and gene therapies of the Canadian Organization of Rare Disorders in Toronto; the future is bright for cures for genetic disorders such as PKU.

Attended conference of the Health Research Foundation in Montreal on the impact of artificial intelligence on health and health research (for the Best Medicines Coalition).

- Met with Health Canada's Assistant Deputy Minister for Regulatory Enforcement and then Chief Regulatory Officer of Health Canada about the threat to Canadians supply of prescription medicines if USA proceeds with plan for wholesale imports of drugs meant for Canadians (for BMC)
- Invited to speak to an all-day update on research about sickle cell disease in Montreal. SCD like PKU is a single gene disorder. And like PKU is on the cusp of a host of new therapies after very little in past 20 years.

December

- Chaired two-day meeting of the Best Medicines in Toronto (CanPKU is a member)
- Testified at a hearing in the State Capitol of Michigan against a bill to enable bulk imports of drugs meant for Canadians (for BMC).
- Briefed by BioMarin on status of plans to provide Kuvan in powder form in packets of 100 & 500 mg. Stay tuned. Ask your clinic.
- Chaired teleconference meeting of the trustees of the Global Association for PKU (GAP)

Sincerely,

John Adams



Message from the Vice President

By: Tanya Chute

Hello CanPKU!

Can't believe another year has come and gone. Can you? We are preparing for the Christmas holidays in our household. Stockings are hung (who am I kidding, we got a puppy this month so our stockings cannot be hung as ALL socks are her favorite snack!!) But they are folded up nicely, awaiting Christmas Eve so they can get put out on the couch where the puppy cannot reach! Reflecting on the year, I would be remiss to not send out some words of Thanks! Thanks to our News Editor who ensures that John and I stay on track so she can deliver the newsletter to everyone out there. Thanks to the board members who continue to volunteer their time and efforts to ensure that this organization continues to move forward. Thanks to our members whose membership means a few extra dollars in the bank to spend towards our goals and who's name adds significant value to our cause as we advocate on your behalf. Thanks to those who attended the events held this year and especially thanks to those who offered to speak or present material for us all to learn from. Lastly, thanks to the

français.

Atlantic - We are in the early stages of planning the Atlantic Region event. We can confirm it will happen in 2020 (likely to pause in 2021). The content will be bilingual (English and Francais). We will provide details as soon as they become available - keep an eye on the next newsletter for more.

What about education? We are looking to provide you with education directly to your home or on the road and at times that suit you! Webinars are becoming more and more popular. Webinars are delivered live and are recorded so they can be posted on our website so you can view them at your convenience. We would love to hear what topics you are interested in hearing/learning about or what type of professionals you would like us to link you to. Are you interested in "chat" options with like-minded PKUers? Let us know! We want to be of great value to you and yours.

What about the networking/social side of things? We will have more scholarships available to help people travel to events this year. To do this, we will also be utilizing funds raised from Pins4PKU - bowlathon local initiatives led by our fantastic community-minded volunteers are popping up around the country over the last two years! We encourage families to create a fun night or evening out. We will help with some of the logistics as well as advertising to families in your area! We will also continue to work with our sponsors to help ensure you are aware of the valuable programs they make available in your area!

Have your say!

[Click here to provide input on what you would like to see these events and webinars include!](#)

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

If you'd also like to make a contribution,

[Click Here to Donate!](#)

GOLD

[\\$501- \\$1000](#)

Mrs. Jennifer Burke Thank You!!

SILVER

[\\$100 - \\$499](#)

Mrs. Melissa de Wit

Thank You!!

clinics, who continue to support those with PKU as well as CanPKU. Special thanks goes out to the NL Clinic and the SK clinic for their added support in the coordination of two of our events this year, the Atlantic Regional Event and Camp MagniPHEque Western held in Saskatchewan. Shortly after the newsletter goes out, I will add this segment of thanks so that you guys can add your thanks to these folks if you feel compelled to do so :) I look forward to 2020 and the new adventures it will bring for our family, the CanPKU family as well as the broader PKU family! Merry Christmas, Seasons Greetings and Happy Holidays to you all!

Cheers!

Tanya Chute

Tanya.



Lettuce Eat... Something Other Than Salad At School & Daycare

(article from pkunews.org)

....

SPECIAL SITUATIONS

Snacks, Treats, Parties

Parties and celebrations that include food are a common occurrence at school. There are a few ways to prepare ahead of time and those ideas can be written into the 504 or IEP. Stock the classroom with a few shelf-stable PKU foods. This could include store-bought items (Synders Gluten Free Pretzels) or Cook for Love Crunchy Granola Bars, CFL or TC cookies.

Ask the teacher to give a 48-hour notice of a classroom event and bring CFL Soft Pretzels or Quick Cinnamon Buns.

Medical formula

Medical formula is a very important part of a PKU student's learning. Taken 2-4 times per day can help blood phe levels stay in a more stable range (versus peaks and valleys). This steady-state will help directly with classroom management and learning. There are a few options to consider and included in the 504 or IEP:

- Drink it in the class
- Go to the nurse's office to drink it
- Request a mini-fridge in the classroom. Might help to offer to share space with the teacher or other students with meal accommodations.
- Request allowance of a cooler or bottle at their desk
- Request the use of the teacher's lounge refrigerator

Medication

For those on Kuvan, it can be scheduled to be taken before and after school.

Mrs. Melissa de WitThank You!!
Mrs. Joyce Swain.....Thank You!!
Mrs. Evonne Grenier.....Thank You!!

BRONZE

\$20- \$99

Mr. Charles Veilleux Thank You!!!

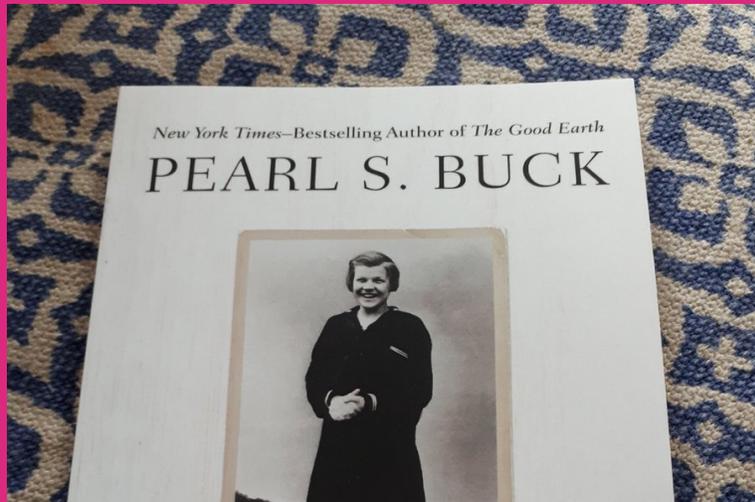
Pat Giffin Thank You!!

Fred and Imelda..... Thank You!
(To Lucas Love Great Grandma & Great Grandpa)



We would like to acknowledge those who contributed by donation.

PKU Profile



[Read the Full Article Here!](#)

Do you support a spouse or common-law partner, or a dependant with a physical or mental impairment? If so, The Canada

Caregiver Credit (CCC), a non-refundable tax credit, may be available to you.



Here's what you need to know about the Canada Caregiver Amount.
Out with the Old

The Canada Caregiver Credit replaces three credits:

- The Caregiver Amount,
- The Amount for Infirm Dependants (18 & older), and
- The Family Caregiver Amount.

The rules for claiming each of these credits were very different from each other. For example, the Caregiver Amount required that the person you were supporting live with you, while the Amount for an Infirm Dependant did not. The Family Caregiver Amount was the only one of the three available for children up to the age of 18. Now, with the Canada Caregiver Credit, figuring out if you qualify for a tax credit is much simpler. There's only one set of requirements; either you qualify or you don't.

Eligibility

You may be able to claim the CCC if you support your spouse or common-law partner with a physical or mental impairment.

You may also be able to claim the CCC for one or more of the following individuals if they depend on you for support because of a physical or mental impairment:

- Your or your spouse's/common-law partner's child or grandchild
- Your or your spouse's/common-law partner's parent, grandparent, brother, sister, uncle, aunt, niece, or nephew (if they were

resident in Canada at any time in the year)

Support

An individual is considered to depend on you for support if they rely on you to regularly and consistently provide them with some or all of the basic necessities of life, such as food, shelter and clothing.

[LEARN MORE HERE](#)

Home Phe Monitor Updates

-National PKU NEWS

Example Color Response vs. Blood Phe

The Child Who Never Grew

A MEMOIR

@emmavardy2 - Via Twitter

This is going to be hard read. But one I feel ready for. Think its important to be able to tell whole story of pku, to know progress that has been made, and recognise progress needed. #pku

Geriatrician at Salford Royal #GDE. Dementia lead SCN GM. Associate Editor QI Age and Ageing. Chair BGS dementia SIG. Mum to daughter with PKU. Own views.

We love to shine the spotlight! To be featured in this column, please submit a photo and paragraph to 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 2012 and Calla (5) diagnosed in 2013.

Hamilton Ontario

Click [HERE](#) to Contact.

Ashley Sulpher

Parent of Anderson, diagnosed in May 2017
Ontario

Click [HERE](#) to Contact.

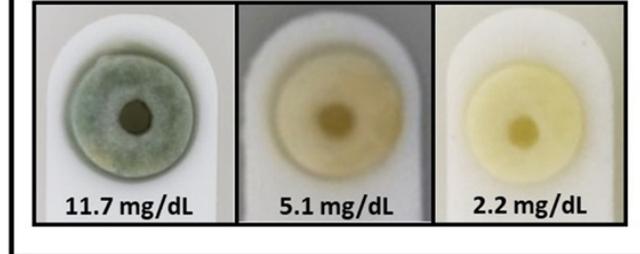
Angel Edwards

Parent of Delilah, diagnosed in September 2014
Ontario

Click [HERE](#) to Contact

Tanya Chute

Parent of Jacob born and diagnosed 2010. Also born as a micro



Ongoing Clinical Trial of a Urine Test for At-Home Blood Phe Monitoring
Robert A. Latour, Ph.D.; McQueen-Quattlebaum Professor
Department of Bioengineering; Clemson University, Clemson, SC
Researchers at Clemson University have been working over the past five years on the development of a urine test as an at-home monitoring method for blood Phe level. Clinical support has been provided by the Greenwood Genetic Center, Greenwood, SC and Dr. Rani Singh's group of the Department of Human Genetics, Emory University, Atlanta, GA. Following initial development and validation, a small one-year clinical trial was begun earlier this year in June, which was coordinated with the assistance of the Tennessee PKU Foundation and the Vanderbilt Children's Hospital in Nashville, TN. We currently have 14 enrolled participants with PKU in this ongoing clinical trial. The clinical trial results are very encouraging with the average difference between the blood Phe levels estimated by the urine test vs. the corresponding laboratory-reported blood Phe levels being less than 1.5 mg/dL. The current prototype test works by dipping a test disc into a sample of urine and placing it under an LED-lit light-control enclosure. A photograph of the disc is then taken using a smartphone after just one minute. The color of the disc from the photograph is then read using an RGB color app to provide a quantitative value of the color response. As shown in the accompanying graphic, the color of the center hole in the test disc becomes darker as blood Phe level increases and is used to provide an estimate of the corresponding blood Phe level. Clemson University is currently negotiating a license agreement for this technology (patent pending) with a major urine-test company, with a target of having a commercially available product for the PKU community by the end of 2020, or the early part of 2021. Funding support contributing to the development of this technology and the ongoing clinical trial has been provided by the National PKU Alliance.

[Read More Here](#)



DID YOU KNOW?

Alot of advancement has been made in the way we manage and treat PKU patients. Here is a Graphic of hunt for new PKU therapies.

preemie at 26 weeks.
Central Ontario

Click [HERE](#) to Contact.

Amanda Cosburn
Maternal PKU/ adult advocate
Diagnosed in 1986
British Columbia
Click [HERE](#) to Contact.

Stephanie Garcia
PKU adult and advocate
Diagnosed in 1987
Ontario
Click [HERE](#) to Contact.

Arlene
Mother of CPKU Boy, Born 2007
Manitoba
Click [HERE](#) to Contact.

John Feruglio / Spouse
Parents of Amy (22)
Saskatchewan
Click [HERE](#) to Contact.

Brian Quinn
Adult PKU/ Atlantic Provinces
Click [HERE](#) to Contact.

Kari Anderson
Ontario
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

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.

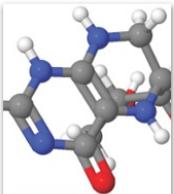
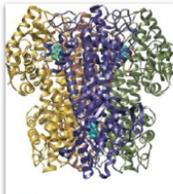
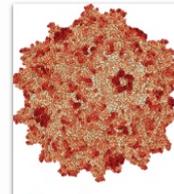
These are people with personal experience of PKU diagnosis, and living with PKU after diagnosis, offering to be a sounding board/ friend. Please always check with your clinic before making any changes to your treatment.***

Recipe Corner



Guacamole & Sweet Potato Fries

Serves: 1 person
Ingredients

 <p>Cofactor therapy</p> <p>Goal: Supply the PAH enzyme cofactor called tetrahydrobiopterin to stabilize certain mutant forms of the PAH enzyme and increase its activity.</p> <p>Companies: BioMarin Pharmaceutical (approved drug Kuvan), Censa Pharmaceuticals</p>	 <p>Enzyme substitution therapy</p> <p>Goal: Supply PAL through subcutaneous injection or oral delivery.</p> <p>Companies: BioMarin Pharmaceutical (approved drug Palyngiq), Codexis, Nestlé Health Science</p>	 <p>Gene editing</p> <p>Goal: Fix the mutation in the PAH gene using CRISPR base editing, or insert a full copy of the PAH gene into liver cells so the body can permanently produce the PAH enzyme.</p> <p>Companies: Homology Medicines</p>	 <p>Gene therapy</p> <p>Goal: Deliver a full copy of the PAH gene to liver cells, using adeno-associated viruses, lentiviruses, or lipid nanoparticles, so the body can permanently produce the PAH enzyme.</p> <p>Companies: American Gene Technologies, BioMarin Pharmaceutical, Generation Bio, Homology Medicines, Pfizer, Sanofi, Ultragenyx Pharmaceutical</p>
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If your interested in learning more about current PKU therapies, [Click Here](#) to read this amazing survey of novel PKU therapies. Simplified, informational, and easy to read!

"The dogma was that PKU treatment had been solved," says Cary Harding, a metabolic disease specialist at Oregon Health & Science University. "But if you came in and started treating patients, it was obvious that things had not been solved."



When Lauren was born, there was just one drug for PKU. Now there are two, both sold by BioMarin Pharmaceutical. The first, called Kuvan, loosens the restrictive diet for a fraction of people with the disease

- 1/2 avocado (Hass)
- 1 sweet potato/ 130g
- 1 tomato
- Juice of half a lime

For this recipe, you will just need olive oil (or your favourite oil), salt & pepper to taste.

Method

- Peel and chop the sweet potato into chips. Place them in a microwavable container and season with salt, pepper and 1/2 tbsp. olive oil. Cover and place in the microwave for 4-5 minutes, stirring them half way through. A few more minutes will be needed if your chunks are thicker.
- To make the guacamole, mash the avocado up in a bowl, and then stir in the chopped tomato and the juice of half a lime.
- Place the fries and guacamole on a plate with a slice of lime.

Nutritional information per serving

- Calories: 353 kcal
 - Protein: 4g
 - Phe: 200mg
- Exchanges: 13

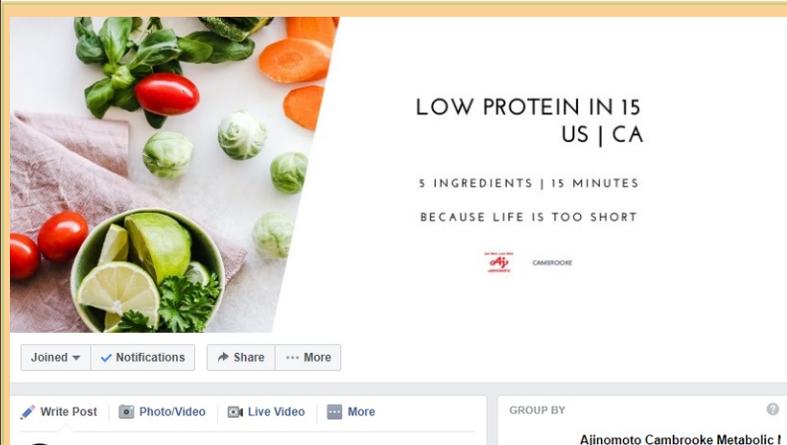
[Click HERE For Step By Step Video!](#)

If you have a recipe to share, please submit it to newseditor@canpku.org.

lessens the restrictive diet for a fraction of people with the disease, including Lauren, allowing them to eat a few extra grams of protein each day. The second, Palynziq, is a daily injection of phenylalanine-degrading enzymes that allow people with PKU to grab whatever they want out of the fridge. But Palynziq is approved only for adults, and the prescription comes with a warning about potentially severe immune reactions that hospitalized some people during clinical trials for the drug.

Soon, people with PKU could have more and better options. Seeing Palynziq's impending approval, a dozen biotech companies began taking nearly every conceivable approach to tackle PKU: once-a-day pills that stabilize the mutant enzyme, cells transformed into phenylalanine-munching machines, and a plethora of gene-therapy approaches promising a permanent cure are all on the table.

[Read Full Article Here](#)



Facebook cooking channel Launched!!

It shows quick 15 minute low protein meals for families or adults, who don't have time to waste. All meals are delicious and nutritious too. Also learn how to prepare some of Cambrooke's most popular food products at home.

Please feel free to join yourself and/or pass along/share with other families who are on low protein diets!

<https://www.facebook.com/groups/lowproteinin15.us.ca/>

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





IN THE NEWS!

Links to articles you may enjoy!

Articles you may enjoy

[The new Canada caregiver credit](#)

[- Censa Pharmaceuticals Announces CNSA- 001 Met Primary and Secondary Endpoints in Phase 2 Trial in Patients with PKU](#)

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

[- Thriving With PKU Youtube](#)

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



"Doctors are experts in medicine, but that doesn't mean they're experts on the Income Tax Act. They can have a poor understanding of what the requirements are and, on a daily basis, we find doctors are providing incorrect advice."

The Disability Tax Credit Promoters Restrictions Act is making waves in the financial services industry. That act received royal assent in 2014, but it, along with the associated Disability Tax Credit Promoters Restrictions Regulations, is not expected to come into force until 2020.

The proposed regulations would cap the fees that tax promoters can charge for helping with both DTC eligibility and disability-related tax refund requests at \$100 per request in each taxation year. The fee would be applied to both federal and provincial DTC requests (except in Quebec, where rules differ). The act defines a "promoter" as a person who directly or indirectly collects a fee related to DTC requests. (The list of examples includes professionals who offer tax help, including financial services providers.)

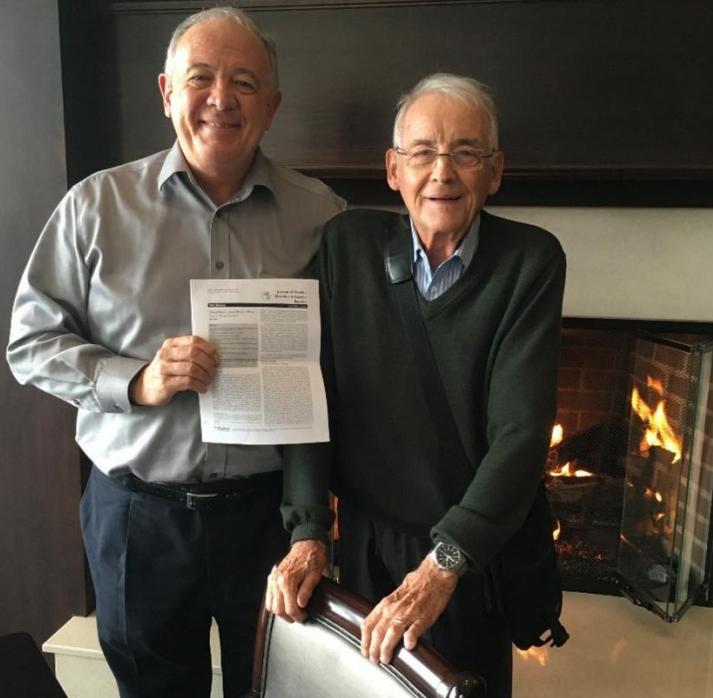
Analysis of the impact of the act, published in June 2019 in the Canada Gazette, states that DTC applications are "relatively straightforward" and take no more than an hour for promoters to complete because doctors do most of the work. (The comment period ended in July.) Therefore, the goal of implementing a low flat fee for promoters is to ensure that income tax refunds generated by disability credits aren't eaten up by "excessive" fees, the analysis states. Refunds should "remain at the disposal of those who are entitled to them, and who need them most," it adds.

The impact analysis includes the views of the federal Disability Advisory Committee (DAC) - a group that was reinstated in 2017 following controversy over the Canada Revenue Agency's (CRA) rejection of DTC applications made by Canadians with Type 1 diabetes. Several fee structures were presented to the DAC by the CRA in 2018, and the committee selected a fixed dollar amount for simplicity. However, the committee voiced concerns over whether it's possible for a fixed rate to simultaneously be affordable for vulnerable populations and high enough to compensate legitimate professionals adequately. Some applications that promoters deal with "might require additional work," the DAC's analysis states.

Peter Weissman, partner at Cadesky and Associates LLP in Toronto, says claiming the DTC can be "pretty simple for [those with] a visible disability" for which the severe and prolonged physical impact of their condition is clear. But, "it's been hard to access the DTC for people with mental infirmities of some sort."

Weissman doesn't provide DTC consulting to clients, but knows people who do. He says, "[There are] people who are not being approved [by the CRA] or who are having difficulty with their claims; that's where

Happy Birthday Dr. Hanley!





*WILLIAM B. HANLEY, MD, FRCPC
 Professor Emeritus University of Toronto
 Honorary Physician &
 Director Emeritus, PKU Programme
 Divisions of Clinical & Metabolic Genetics and Paediatric
 Medicine
 The Hospital for Sick Children
 Clinical Adjunct - Paediatrics/Faculty of Medicine, University of
 Toronto
 Project Investigator, The Research Institute*

Dr. William B. Hanley started to treat PKU patients in 1960 and was the first doctor in Canada to set up a PKU clinic - at the Hospital for Sick Children, Toronto. That was before universal newborn screening began in any part of Canada.

He was born in 1930 and turns **90 on January 19th**.

Dr. Hanley, also volunteers as a medical advisor to CanPKU, was the specialist for hundreds of PKU children including the son of CanPKU president John Adams. He was also a GP for John's son, which meant only needing to see ONE doctor for all medical needs! Quite an amazing service model!

in 2018 Dr. Hanley overcame a bureaucratic barrier for a young PKU man from Ireland who came to Canada on a work permit, so that this PKUer could be seen at the Adult clinic in Toronto! Although Dr. Hanley did not renew his medical licence at the end of last year, he continues his interest in all things PKU, following the latest research and reviewing articles for scholarly publications!

BILL HANLEY IS A LIVING PKU HERO!!

CanPKU would like acknowledge this milestone, and send him our warmest wishes on his birthday in the New year!

consultants provide value." These experts offer services that one hour and \$100 won't cover, he adds. In his view, the proposed act is the result of just a few companies "charging a lot of money, and they sort of ruined it for everyone."

[Continue Reading Here](#)

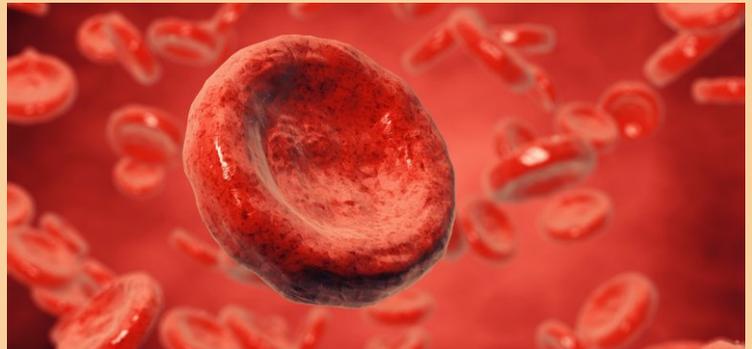


EDUCATION
 webinar series

Alone we are rare. Together we are strong.



Rubius delays first clinical readout, as crowded PKU field marches on



- Those waiting for the first look at human data from Rubius will have to be patient for a few more months. On Thursday, the Cambridge, Massachusetts-based biotech delayed the timeline for its first clinical readout to early 2020, admitting the trial has yet to dose its first patient.
- The study is testing Rubius' lead therapeutic candidate, RTX-134, in adult patients with phenylketonuria, or PKU. Several other companies, including BioMarin Pharmaceutical, Homology Medicines and Moderna, are also developing therapies to treat the rare inherited disorder.

Rubius has failed to deliver on its first clinical timeline, after setting the expectation throughout 2019 for a readout by year's end. Even after disclosing problems with a contract manufacturer in August, Rubius executives said the situation was under control and reaffirmed the 2019 timeline for data. They lowered expectations for the readout to include just four patients instead of the previously planned five to 10. Rubius now expects to report early Phase 1 results in the first three months of 2020, the company said in reporting its third quarter financial results. Rubius stated it will announce when the first patient is treated, implying the study has yet to dose a patient despite actively recruiting since late September, according to clinicaltrials.gov.

[Read More Here](#)

INTERESTED IN CLINICAL TRIALS?

CLINICAL
 TRIALS
 ONTARIO

DID YOU KNOW? CLINICAL TRIALS:

Quebec PKU Day A Success!



- Are done all across Canada – there are thousands happening right now
- Depend on people to volunteer
- Don't just happen in hospitals or doctors' offices
- Study more than drugs
- Help us learn more about how to treat people and improve their health

WHAT ARE CLINICAL TRIALS?

Clinical trials are studies that involve people and test many types of interventions including drugs, devices, genetic therapies, natural health products, psychotherapies, and lifestyle and preventative care interventions.

WHY ARE CLINICAL TRIALS DONE?

Clinical trials are done to provide research data, or evidence, about the intervention(s) tested. This evidence helps in deciding what therapies or other interventions might work best for people.



CLINICAL TRIALS ANSWER QUESTIONS ABOUT AN INTERVENTION(S) SUCH AS:

- Is it **safe**?
- Can it **improve** or **cure** disease?
- Can it help people **live longer** with the disease?
- Does it help people **feel better**?

TYPES OF HEALTH INTERVENTIONS STUDIED

Clinical trials study treatments or interventions on their own or in combination with each other. These might include:

- Drugs
- Devices
- Surgery
- Radiation Therapy
- Diagnostic Procedures
- Diet and Lifestyle

[Learn More](#)



Is the PKU'er In your life hard to shop for?

Consider giving them the gift of memories and send them to Camp Magnipheque for Christmas!!





Have you been curious about attending
Camp MagniPHEque??

CanPKU offers travel scholarships to help
you get there!

Check out these videos from Camp to see
what you might of missed!

[Click here for the English Video](#)

[Click here for the French Video](#)

Stay tuned for upcoming 2020 Camp dates!

[Click Here](#) to register for Camp
MagniPHEque Ontario

[Click Here](#) to apply for a travel scholarship



EARLY BIRD RATE GOOD UNTIL FEB 29TH!!!



www.
canpku.org

Notice: ONTARIO CAMP MAGNIPHEQUE will take a break next year.

CanPKU is looking at running the this camp every OTHER year, starting in 2020, then the next camp in 2022!

New From Cambrooke, Creamy Hot Vanilla Breakfast cereal!

Learn more [Here!](#)

breakfast
CREAMY HOT CEREAL

Vanilla

Nutrition Facts
24 servings per container
Serving size 1/4 cup (28g)
Amount per serving
Calories 124

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

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 1½ 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.

servings suggestion

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

FLCF10639D

8 04795 10639 4

NET WT 24 OZ (680 G)



Canpku Quebec day, held at Laval University, on October 26th.

Thank you to all participants for the enriching exchanges and beautiful meetings. Thanks to Canpku, it's president John Adams and his volunteers.

Thank you to our precious partners, the representatives of the formulas companies: Nutricia, Ajinomoto Cambrooke and VitaFlo as well as the pharmaceutical company Biomarin.

Photos and thanks borrowed from Facebook

Stay tuned for upcoming 2020 Camp dates!



www.
canpku.org

PKU AWARENESS

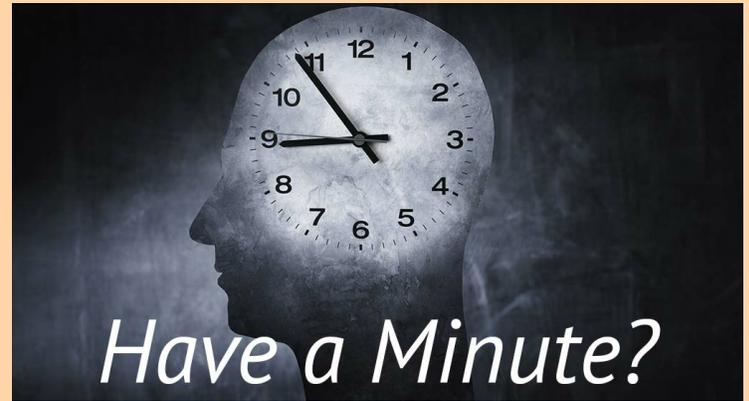
****Don't stop in may, keep using #'s all year long for a features in this column !****

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



18+ Years of age? Diagnosed with PKU?
VITAFLO USA is looking for PKU adults to help create and app that supports YOU!

Help Vitaflo Shape the app by answering a few survey questions [HERE!](#)



The global phenylketonuria treatment market size is expected to reach USD 1.02 billion by 2026 registering a CAGR of 11.0%, according to a new report by Grand View Research, Inc. Rising prevalence of PKU across the world and favorable government regulations are the factors expected to spur the market growth over the forecast period.

For instance, according to the FDA, in 2018, phenylketonuria affected about 1 in 10,000 to 15,000 people in U.S. Furthermore, according to the Orphanet, it was estimated that 1 in 10,000 newborns in Europe is suffering from PKU. The target disease is highly prevalent in European

countries, such as Italy, Ireland, and Turkey. It was estimated that around 1 in 4000 individuals in Turkey were diagnosed with PKU.

Various awareness programs conducted by private and public organizations are also projected to fuel market growth. Some of the organizations conducting such programs are SickKids, Children's Hospital of Wisconsin, CHOC Children's, and Boston Children's Hospital. These programs aim to promote optimal emotional, developmental, and physical health PKU patients.

Furthermore, continuous R&D for the disease treatment is estimated to enhance the market growth. For instance, Synlogic, Inc.'s SYN1618 drug is undergoing Phase 1/2a clinical trials and also received fast-track designation from FDA. In addition, other companies, such as Rubius Therapeutics, Inc., Retrophin, Inc., and Homology Medicines, Inc. are also conducting research to develop novel therapies, such as oral, enzyme therapy, gene therapy.

[Learn More Here](#)





Rosie got her Rare Bear today! Such a fun way to celebrate her uniqueness. There are no two teddy bears alike. ☐☐



Group Photo from the Quebec PKU 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!



Will there be clinical trials in Canada??

Pioneer in Phenylketonuria (PKU) Therapies, Submits Clinical Trial Application (CTA) in U.K. for Investigational Gene Therapy for PKU

BMN 307 Represents a Potential 3rd PKU Treatment Option in BioMarin's PKU Franchise
2nd Gene Therapy Program in Product Pipeline

"This clinical trial application marks the latest milestone in BioMarin's 15-plus year commitment to the PKU community. BioMarin has brought the only two approved therapies for PKU to patients around the world," said Hank Fuchs, President, Worldwide Research and Development at BioMarin. "Leveraging our expertise in gene therapy, we are pleased to be adding a new gene therapy product, which is potentially a transformative solution, to build on our current achievements for the PKU community."

[Learn more Here](#)



DID YOU KNOW?

Developments continue regarding the threat of mass importation of drugs to the U.S. from Canada, including current and proposed state legislation and other measures.

Currently BMC Board Chair John Adams is in Washington, D.C. as part of a contingent organized by U.S.-based Partnership for Safe Medicines, meeting with various officials to present a Canadian patient perspective. Meetings are planned with the Department of Health and Human Services, and senior U.S. administration and political staffers. John is also participating in Congressional panel briefings presenting a Canadian patient perspective.

The Canadian government has yet to provide a detailed public statement on plans to deal with this threat to Canada's drug supply.



CANADIAN PKU AND ALLIED DISORDERS INC.
PCU et MALADIES APPARENTÉES CANADA INC.

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 device. 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.

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

NEW FOR PKU!

GET READY FOR A DIFFERENCE YOU CAN TASTE



-  Enjoyable, neutral flavour with a smooth texture for easy drinking
-  Contains glycomacropeptide (GMP), which is made from an intact protein source and is naturally low in phenylalanine
-  Excellent source of both calcium and vitamin D, two nutrients that help build and maintain strong bones and teeth
-  The only ready-to-drink PKU formula with GMP to provide both DHA & EPA, omega-3 fatty acids often missing from a typical PKU diet

Net Wt. 8.5 fl oz/250 mL NO MIXING!

Be among the first to taste the difference! To request a sample, contact your dietitian or call us at **1-877-636-2283**

PhenylAde GMP READY is a specialized formula for the dietary management of Phenylketonuria (PKU). Must be used under medical supervision.

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NUTRICIA



sphere™

A powdered low phenylalanine-free formula with a blend of glycomacropeptide (GMP), essential and non-essential amino acids, carbohydrate, fat (including docosahexaenoic acid – DHA), vitamins and minerals.

PKU sphere is for use in the dietary management of Phenylketonuria (PKU).

USE UNDER MEDICAL SUPERVISION

Your healthcare team will determine which products are appropriate to your diet. Consult your clinician or dietitian to know more about PKU sphere.

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Innovation in Nutrition
A Nestlé Health Science Company

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CHALLENGING THE SUMMIT 2020 NPKUA CONFERENCE

JULY 9-12, 2020 • VANCOUVER, WA

Save the dates are going out this month with information on the upcoming registration for the 2020 NPKUA Conference in Vancouver, WA- July 9-12, 2020. Please join us in Challenging the Summit for PKU! Registration will open on January 2, 2020. We hope that you and your family will take an extended trip to capture some memories by taking in some of the



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

beautiful scenic areas in Oregon, Washington states before, during and after the conference! Find out more about traveling to the destination of the conference - Vancouver USA. <https://www.visitvancouverusa.com/>

Partial conference scholarships will be available again in 2020. More information and the scholarship application will also be available on our website in January.

Plan to book your stay at the Hilton, Vancouver, WA under our group rates. For more information visit the NPKUA website.

[Register on January 2, 2020!](#)

[Learn more on Facebook!](#)



Looking Forward to the Next Issue?

PLEASE SHARE!

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

Send feedback to: newseditor@canpku.org to be published in our July issue!

To read the English version of this article, or learn more, click [HERE!](#)

DISSIPER LE BROUILLARD

Publié 16 octobre 2017 Par Tristandans Articles en français, Mode de vie / Lifestyle

La question que je dois me faire poser le plus souvent au sujet de la phénylcétonurie est probablement par rapport aux effets que je ressens lorsque je ne respecte pas ma diète. Je vais donc en parler ici en vous racontant une petite histoire très personnelle.

Il y a de cela plusieurs années, j'ai commencé à faire quelques recherches dans les médias sociaux (alors tous récents) sur la phénylcétonurie. Je suis tombé par hasard sur quelques pages intéressantes dont l'une organisait un podcast en direct sur le sujet. On pourrait y entendre parler, entre autres personnes, une diététiste américaine qui elle aussi était PCU. Le titre du podcast : Dissiper le brouillard.

J'ai donc écouté ce podcast fort intéressant qui m'a ouvert les yeux sur une réalité très importante. Quand on ne respecte pas la diète, ce n'est pas plusieurs semaines ou mois plus tard que nous pouvons en ressentir les effets, mais plutôt quelques heures ou jours plus tard. En effet, la diététiste expliquait que quand elle commençait à oublier quelques trucs (des détails, comme ses clés) ou avait un peu plus de difficulté à s'organiser, elle prenait un moment pour penser à ce qu'elle avait mangé dernièrement. En général, ce comportement s'expliquait par un régime bâclé dans les jours précédents.

C'est à ce moment que j'ai décidé que je prenais mon régime en main. Définitivement. Et c'est par la suite que j'ai remarqué que le podcast portait effectivement bien son nom.

Bien que j'avais beaucoup de difficulté à respecter ma diète pendant mes études, ça ne m'a jamais empêché de fonctionner, car j'ai eu la chance d'avoir une mère qui m'a fait suivre la diète aux milligrammes près. (Rappelez-vous toujours qu'il est primordial de suivre à la lettre la diète pour un bébé ou un enfant.) J'imagine qu'il est aussi possible que nous soyons affecté à différents niveaux. (C'est aussi ce que pense Susan Waisbren, psychologue, lorsqu'elle a été interrogée sur le sujet par l'animateur du podcast.) J'ai effectué avec grand succès mes études en sciences pures au cégep, puis mon baccalauréat et ma maîtrise en communication à l'université. Mais lorsque j'ai repris ma diète pleinement en main par la suite, je n'ai pu m'empêcher de remarquer ce que ça m'a fait. C'est littéralement un brouillard qui s'était dissipé. Tout m'est apparu encore plus clair et plus facile que ça ne l'était avant. J'étais tout simplement plus vif, plus rapide, plus calme et plus serein qu'avant.

Pourquoi faut-il poursuivre sa diète une fois adulte? Parce que c'est important pour notre santé, parce que ça nous permet de vivre notre plein potentiel. Parce que si vous trichez en ce moment, vous ne vous rendez tout simplement pas compte de ce que cela vous fait.

Avez-vous des expériences similaires à raconter?

VOTRE SUIVI NUTRITIONNEL pour maladies métaboliques!

- Metabolic formulas
- Metabolic eNewsletter
- Low-protein foods
- Metabolic workshops

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

Website: specialtyfoodshop.ca | Email: sfs.admin@sickkids.ca
Call: 1-800-737-7976 or 416-813-5294 | Fax: 416-977-8394

[Learn More](#)



There is an French App, Available for IOS and Android, to help manage your PKU?
Learn more about it [HERE!](#)



DID YOU KNOW?

PKU Patient Registry



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

Thank you again for your commitment to accelerating PKU research!

usual as possible. If your child is not able to tolerate his or her usual food and formula pattern, offer half-strength formula and juice, and then try to return to a normal formula and food pattern as tolerated.



What about blood draws?
When your child is sick, please contact the PKU Clinic before taking your child in for a blood draw. Since illness can affect blood phe levels, the date for a blood draw may need to be adjusted.

University of Washington PKU Clinic
CHDO - Box 357920, Seattle, WA 98195
(206) 598-1800, Toll Free in Washington State 877-685-3015
<http://depts.washington.edu/jku>
Updated February 2008

Selected Medications that Contain Phenylalanine

For a complete list, see <http://www.pkunews.org>

Over-the-counter Medications

Cold and Allergy

- Alka-Seltzer Plus – some flavors
- Benadryl allergy and sinus fastmelt
- Benadryl allergy chewables
- Childrens PediaCare Multi-Symptom Cold Chewables
- Diabetic Tussin
- Halls sugar free menthol cough suppressant drops
- Ricola Sugar free herb throat drops
- Robitussin sugar free throat drops
- Sudafed childrens chewables
- TheraFlu
- Triaminic softchews
- Walgreens Effervescent Cold Relief Plus
- Wal-Tussin DM Clear (Walgreens brand)
- Valu-Rite Expectorant DM clear cough syrup

Analgesic

- Advil, Childrens chewable tablets grape
- Advil, Junior strength fruit
- Alka-Seltzer PM
- Eccedrin Quick Tabs
- Motrin, chewable tablets
- Non-Aspirin, Childrens soft chewable tablets and Junior strength all flavors (Walgreens brand)
- Tempra quicklets childrens or junior strengths

Electrolyte Replacement

- Pedialyte Freezer Pops
- Kao Lectrolyte electrolyte replenisher

Prescription Medications

Antiemetics

- Zofran, ODT

Antibiotics and Antivirals

- Amoxicillin chew tabs
- Augmentin chewable tablets

Augmentin oral suspension

- Cefzil
- Penicillin V Potassium for Oral Suspension
- Videx chewable tablet (all strengths)
- Viracept powder for Oral Suspension
- Zyvox, 100mg/5ml suspension

Latest Breakthrough in PKU Medical Foods



The Food and Drug Administration (FDA) strongly recommends against the use of over-the-counter (OTC) cough and cold products for infants and children under 2 years of age because serious and potentially life-threatening side effects could occur.

OTC cough and cold products include these ingredients: decongestants (for unclogging a stuffy nose), expectorants (for loosening mucus so that it can be coughed up), antihistamines (for sneezing and runny nose), and antitussives (for quieting coughs). The terms on the label include "nasal decongestants," "cough suppressants," "expectorants," and "antihistamines."

The FDA is reviewing information about use of these medications for children ages 2 to 11 years. The FDA's recommendations for children ages 2 years and older include the following:

- Check the "active ingredients" section of the DRUG FACTS label.

Be very careful if you are giving more than one OTC cough and cold medicine to a child. If you use two medicines that have the same or similar "active ingredients," a child could get too much of an ingredient which may hurt your child.

- Carefully follow the directions in the DRUG FACTS label.
- Only use the measuring spoons or cups that come with the medicine or those made specially for measuring drugs.
- Choose OTC cough and cold medicines with childproof safety caps, when available, and store the medicines out of reach of children.
- Understand that OTC cough and cold medicines do not cure or shorten the duration of the common cold.
- Do not use these products to sedate your child or make children sleepy.
- Call a physician, pharmacist, or other healthcare professional if you have any questions about using cough or cold medicines in children 2 years of age and older.

For more information, see <http://www.fda.gov/consumer/updates/coughcold011708.html>.

Updated February 2008

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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>

Have you moved?

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



Are you living with phenylketonuria (PKU)?

Rubius Therapeutics is conducting a clinical study of an investigational enzyme replacement therapy, called RTX-134, for the potential treatment of PKU.

WE ARE SEEKING:

- Study volunteers who have been diagnosed with PKU
- Men 18 years of age or older
- Women *not* of childbearing potential (not capable of becoming pregnant)
- Study volunteers with Phe levels above 600 $\mu\text{mol/L}$ (10mg/dl) and are on a stable diet

Patients are not eligible to participate if they are currently taking or have previously received treatment with Palynziq® (pegvaliase-pgpz).

Qualified study participants may be eligible to receive reimbursement for time and travel expenses.

For more information, please visit www.rubiustrials.com/pku, email clinicaltrials@rubiustx.com or talk to your doctor.



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Mail
Address

CanPKU Happy & Honoured 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 Lebouthillier

[Read Letter.](#)

Canadian Anti-Spam Law Consent

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