
2022 Q1 44th edition Newsletter

1 message

Canadian PKU and Allied Disorders <info@canpku.org>
Reply-To: Tanya Chute Nagy <tanya.chute@canpku.org>
To: Tanya Chute Nagy <tanya.chute@canpku.org>

Thu, Oct 20, 2022 at 1:13 PM



CanPKU News 2022

Canadian PKU and Allied Disorders Inc. is a non-profit association of volunteers, first organized in the Spring of 2008 based in Toronto, Ontario. We are dedicated to providing accurate news, information and support to families and professionals dealing with phenylketonuria and similar, rare, inherited metabolic disorders.

Our mission is to improve the lives of people with PKU and allied disorders and the lives of their families. By allied disorders, we mean other rare, inherited metabolic disorders also detected by the modern miracle of newborn screening.

La « Canadian PKU and Allied Disorders Inc. » est une association à but non lucratif de bénévoles créée au printemps 2008 à Toronto, en Ontario. Nous nous engageons à fournir des nouvelles, des informations et un soutien précis aux familles et aux professionnels travaillant avec la phénylcétonurie et des troubles métaboliques héréditaires rares similaires.

Notre mission est d'améliorer la vie des personnes atteintes de PCU et de troubles apparentés ainsi que la vie de leurs familles. Par troubles apparentés, nous entendons d'autres troubles métaboliques héréditaires rares, également détectés par le miracle moderne du dépistage néonatal.



Inside this issue

[Upcoming Events](#)

[Adult Arena](#)

[Kids Korner](#)

[Teen Time](#)

[International Events / News](#)

[Recipes](#)

[Patient Profile](#)

[Resources](#)

[Further Reading](#)

[Your website profile](#)

[Sponsors Page](#)



UPCOMING EVENTS

Adult Cafe (And Support Group)

For those Adults 18+ with PKU

2022-02-12 3:00 PM Eastern

Virtual

Adult Cafe (And Support Group)

For those Adults 18+ with PKU

2022-02-24 8:00 PM Eastern

Virtual

Sip Sip Hurray!

An online event that celebrates YOU!

On International Rare Day CanPKU and Necpad (New England Connection for PKU) come together to provide you a unique celebration. Bring along your formula to sip and let's celebrate YOU!

Recruitment for SynPheny (Do not register here)

Current sites are only in the U.S.A

They are accepting Canadians and will pay for costs of travel etc.

[Learn more here](#)

2022 Regional Event - Red Deer, AB

2022-05-15 9 a.m. - 4 p.m. MST

Register for In Person

Register for Virtual/Online

NPKUA's Challenge the Summit 2022 Conference

2022-07-07 to 2022-07-10

Vancouver, Washington, USA

2022 Camp MagniPHEque

2022-09-09 6:00 PM to 2022-09-11 Noon Eastern

[1010 Birchview Road, Douro-Dummer ON K0L 2H0](#)

CanPKU Annual General Meeting

2022-09-09 7:00 PM Eastern

[1010 Birchview Rd, Douro-Dummer, ON](#) and Virtual

* Please note: If you are unable to register for an event that you believe you should have access to, please email to info@canpku.org and we will help you out!



“Start by doing what’s necessary; then do what’s possible; and suddenly you’re doing the impossible.”

– Francis of Assisi



À la recherche d'un nouveau Directeur des relations francophones!

Après une belle aventure de trois ans, j'ai dû quitter mon rôle de Directeur, Relations francophones au sein de CanPKU, un organisme canadien qui vient en aide aux personnes atteintes de phénylcétonurie ainsi qu'à leur famille au Canada. C'est le cœur gros que j'ai pris cette décision, car je laisse derrière moi une magnifique équipe de membres passionnés et très impliqués.

L'organisme est actuellement à la recherche d'une personne qui serait intéressée à prendre le relais et à plonger dans le fascinant monde de la phénylcétonurie au sein du Conseil d'administration. CanPKU souhaite ardemment bonifier son offre francophone, c'est pourquoi ce poste est très important pour les aider à concrétiser ce projet.

Êtes-vous intéressés à vous impliquer? Voici quelques tâches du Directeur, Relations francophones :

- Participer aux rencontres en ligne du Conseil d'administration une fois à tous les deux mois
- Effectuer des traductions de contenus anglophones vers le français
- Participer occasionnellement à des événements francophone dans le domaine de la santé /
- génétique / métabolique dans le but de représenter CanPKU et la phénylcétonurie
- Participer au développement de la section francophone du site Internet de CanPKU

Il est préférable que la personne souhaitant s'impliquer soit bilingue (anglais / français), mais il serait possible de s'arranger dans le cas d'une personne unilingue francophone.

Si vous désirez obtenir plus d'informations, contactez la Vice Présidente et directrice de CanPKU Tanya Chute à l'adresse tanya.chute@canpku.com .

Merci beaucoup pour votre intérêt.

Looking for a new Director of Francophone Relations!

After a great three-year adventure, I had to leave my role as Director, Francophone Relations at CanPKU, a Canadian organization that helps people with phenylketonuria and their families in Canada. It is with a heavy heart that I made this decision, because I leave behind a magnificent team of passionate and very involved members.

The organization is currently looking for someone who would be interested in taking over and diving into the fascinating world of phenylketonuria on the Board of Directors. CanPKU is eager to improve its French-speaking offer, which is why this position is very important to help them make this project a reality.

Are you interested in getting involved? Here are some of the duties of the Director,

Francophone Relations:

- Participate in online meetings of the Board of Directors once every 2 months
- Translating English content into French
- Occasionally participate in Francophone events in the field of health / genetics /metabolic in order to represent CanPKU and Phenylketonuria
- Participate in the development of the French section of the CanPKU website

It is preferable that the person wishing to get involved be bilingual (English / French), but it would be possible to arrange in the case of a unilingual French-speaking person.

For more information, contact CanPKU Vice President and Director Tanya Chute at tanya.chute@canpku.com.

Thank you very much for your interest.

Adult Arena

We have started adult get togethers on zoom. Some of them will have informational programming, some of them are just a bunch of adults getting together and chatting about what matters. Growing older with PKU. If you are 18+ with PKU - please join us! The next session is set for Feb 24th. [Adult Cafe \(And Support Group\)](#) If you have any trouble registering please email to tanya.chute@canpku.org. To ensure these events are only attended by adults, settings on your profile may need to be updated. We can help!

Whether you are on diet, off diet or somewhere in between - this is a NON JUDGEMENTAL place to come and chat with like minded folks with a great deal in common!

Hope to see you there!



KIDS KORNER

CANPKU

S	R	R	R	L	S	A	L	L	E	S	O	S	A
M	E	A	S	U	R	E	E	L	P	P	A	L	L
U	E	D	O	C	T	O	R	U	P	A	A	M	U
H	S	L	E	V	E	L	Y	N	R	G	O	N	M
A	I	E	E	S	U	C	D	I	L	H	U	A	R
E	H	L	C	E	K	P	N	E	W	E	R	R	O
P	M	S	L	W	P	A	A	T	E	T	C	A	F
E	U	R	V	O	R	W	C	O	I	T	R	T	E
O	S	E	U	O	C	G	A	R	G	I	A	A	A
R	H	E	P	T	I	O	H	P	H	P	C	C	R
A	R	R	O	R	S	A	R	U	L	E	K	U	O
N	O	S	E	I	R	F	W	B	P	A	E	S	E
G	O	I	M	S	E	P	A	R	G	S	R	G	S
E	M	P	D	S	E	O	O	W	N	A	S	K	H

CANDY
FORMULA
CRACKERS
SPAGHETTI
LEVELS
DOCTOR
APPLE
PHE
FRIES
PKU
MEASURE
MUSHROOM
PEAS
GRAPES
WEIGH
BROCOLLI
PROTEIN
ORANGE

Play this puzzle online at : <https://thewordsearch.com/puzzle/3208038/>

What 2 things can you never eat for breakfast?

Answer: Lunch and Dinner



"And will you succeed? Yes indeed, yes indeed! Ninety-eight and three-quarters percent guaranteed!"

- Dr. Suess

Teen Time

Are you a teen with PKU? Do you have a teen with PKU? Do they have their own email? Reach out to tanya.chute@canpku.org. We can set up a profile under the family account and send tailored emails to them!



Calling all gamers!! We are looking to set up a gaming group for teens and adults who play video games! Want to join? Email to tanya.chute@canpku.org

More information once we have enough gamers to proceed.



INTERNATIONAL NEWS

SYNOLOGIC PRESS RELEASE

- On track to initiate Phase 3 for treatment of phenylketonuria (PKU) in H2 2022 -
- Additional milestones include multiple clinical read-outs across programs including enteric hyperoxaluria and homocystinuria (HCU) during 2022 -

<https://investor.synlogictx.com/news-releases/news-release-details/synlogic-announces-progress-toward-2022-clinical-milestones-and>

MDLINX

PTC923 (sepiapterin) lowers elevated blood phenylalanine in subjects with phenylketonuria: A phase 2 randomized, multi-center, three-period crossover, open-label, active controlled, all-comers study

<https://www.mdlinx.com/journal-summary/ptc923-sepiapterin-lowers-elevated-blood-phenylalanine-in-subjects-with-phenylketonuria-a-phase-2/1oeIEI7gGhewHiMTBhgnDT>

All Phenylketonuria Patients in England to be Offered Generic Sapropterin

<https://www.medscape.com/viewarticle/965055>

Undiagnosed PKU Can Exist Everywhere: Results From an International Survey - The Journal of Pediatrics

RECIPES

PKU Caesar Salad

Phe (mg): 56

Ingredients

2 tbsp lemon juice

1 tsp minced garlic

½ tsp minced garlic

¼ tsp Dijon mustard

salt and pepper to taste

¼ cup olive oil, divided

1 cup low-pro croutons (made from ~2 slices
bread, cut into 1" cubes)

CamBrooke home-style

½ head romaine lettuce, torn (8 cups)

Instructions

1. Combine lemon juice, garlic, and Dijon; season with salt and pepper.
2. Drizzle in 3 Tbsp. olive oil, whisking to combine.
3. Sauté bread and garlic in 1 Tbsp. olive oil in a skillet over medium heat until bread is crisp and browned.
4. Season bread with salt and pepper.
5. Toss together romaine, dressing and croutons.



"The purpose of life is to live it, to taste experience to the utmost, to reach out eagerly and without fear for newer and richer experience."

— Eleanor Roosevelt

Patient profile

This patient profile comes to you from the Newsletter of London Health Science Center. We are sharing it with permission from both the clinic as well as Jeanette.

My name is Jeanette and I was born on May 12, 1967. I am 54 years old, and I was diagnosed with PKU at birth. I am the youngest of five children. In October of 1966, it came to pass that all babies born were to have a screening to see if they had PKU, and my screening was positive. My family had never heard of this before, and the doctors had to keep me in the hospital to get my diet and my phenylalanine levels in the normal range. I was in the hospital for about 3 weeks. The doctors needed to test the rest of my family to see if my siblings had PKU. They found out my older sister, Margaret, also had PKU. They were concerned about Margaret's progress due the fact she was almost 3 and had been eating regular protein foods. They immediately put her on the PKU diet.

[CLICK HERE TO CONTINUE READING JEANETTE'S STORY AND SEE WHAT ELSE WAS FEATURED IN THIS AMAZING EDITION OF THEIR NEWSLETTER!](#)



“Take a limitation and turn it into an opportunity. Take an opportunity and turn it into an adventure by dreaming big!

- Jo Franz

RESOURCES

CanPKU has a number of resources which can be downloaded or printed at

www.canpku.org/Downloadable-educational-resources

Getting the most from the CanPKU website and emails!

Did you know you can get tailored emails and event invitations (like a cafe chat between folks like you! That could be a parent of a PKUer, Child, Teen or Adult with PKU!)

To do this we need some help with updating your profile.

Find out how to do this with information found at

www.canpku.org/Update-your-Profile and www.canpku.org/how-to-use-the-website



Further Reading:

[Inform Rare Newsletter Dec 2021](#)

[Prioritisation for therapies based on a disorder's severity: ethics and practicality](#)

THANK
YOU



Our sponsors are listed in the order that they began to support CanPKU's efforts. This order does not represent the dollars they may contribute.

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Sponsorship in Kind. These companies provide assistance other than financial.



Check out what our sponsors are up to!!

Who is PTC Therapeutics?

PTC Therapeutics is a science-driven, global biopharmaceutical company focused on the discovery, development, and commercialization of clinically differentiated medicines that provide benefits to patients with rare disorders.

[Read this article to learn more](#)

What is the SynPheny trial about?

[Read this dialogue between CanPKU's VP Tanya Chute and Nicole McWhorter, a metabolic dietician who has worked in clinics and is currently consulting on this trial.](#)

You can also see the video at

<https://youtu.be/5RkTGWUkzRQ>

Are you looking for new tools to help manage your diet?

Check out our YouTube channel [Nutricia Metabolics Canada](#) for a series of [3 new videos](#) on meal planning and label reading:

1. How to plan your weekly low protein meals
2. How to read a nutrition facts table
3. How to calculate the amount of protein in your portion size

[Click here to watch the videos](#)

Available in English and French
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Eat Well, Live Well.

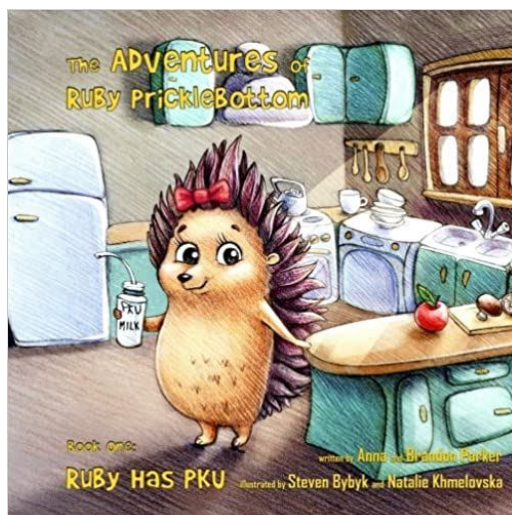


CAMBROOKE™

CanPKU and Ajinomoto Cambrooke teamed up in 2021 to bring the story of "The Adventures of Ruby Pricklebottom" to PKU fans of all ages across our community!

You can view that video at

<https://youtu.be/aDgnto6PCsQ>



[Click here](#) for more information on
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Watch the YouTube video here

<https://youtu.be/UCETrelM1HA>

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