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APRIL 2023

SPRING ISSUE

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# CanPKU News



### **Letter from the Editor:**

Springtime is a time of renewal and new beginnings, and the start of a new year is an opportunity to reflect on the past and set goals for the future. As we emerge from the darkness of winter, we can look forward to longer days, warmer weather, and the promise of new growth. Spring is a time of endless possibilities.

As we move into the new year and the spring season, it's important to remember that change takes time and effort. We may stumble along the way, but it's important to stay committed to our goals and remain open to new opportunities and experiences. So let's embrace this new beginning and all the exciting things that it brings.

What are your new goals for your low protein diet?

Warmest regards,

Marjorie Guhl

## **Inside this issue**

[Letter from the Editor](#)

[Update from our  
President](#)

[We have a new logo!](#)

[Spring activity idea](#)

[Welcome: New Board  
members](#)

[Community story:  
Congrats!](#)

[What's new at  
canpku.org?](#)

[Remembering Dr.  
Charles Scriver  
\(1930-2023\)](#)

[DTC Flyer](#)

[Fundraising update:  
Spare for Rare!](#)

[Zoom with us!](#)

[Upcoming Events](#)

[Feature Story](#)

[Drive to Thrive](#)

[Recipes](#)

[Updates and articles  
of interest](#)

[Let's hear from you!](#)

[INFORM RARE](#)

[Canadian News](#)

[CanPKU Sponsors](#)

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## We have a new logo!

CanPKU+/CanPCU+ will be our acronym going forward in an effort to be more inclusive of the other Allied Disorders we represent and assist. The move to adding Denim (Jean/Gene) Blue was to better align ourselves with the traditional colours recognized in various other areas of the globe.



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

Because Knowledge Leads to Better Health  
Parce que la connaissance mène à une  
meilleure santé

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

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## SPRINGTIME ACTIVITY IDEA

Growing a garden with your little ones can be a fun and educational activity for both you and your children. It not only teaches them about healthy eating and discipline but also helps them develop a sense of responsibility and appreciation for the wonderful foods they can enjoy.

Here are some tips for growing a garden with your little ones:

- **Start small:** Start with a small area that your child can manage. It can be a small plot of land or even a container garden. This will help your child feel a sense of accomplishment and encourage them to continue.
- **Choose the right plants:** Choose plants that are easy to grow and maintain, such as herbs, lettuce, carrots, and radishes. These plants grow relatively quickly, which will keep your child engaged and excited about the progress.
- **Involve your child:** Involve your child in every aspect of the gardening process, from choosing the plants to planting, watering, and harvesting. This will help them develop a sense of ownership and responsibility towards the garden.
- **Teach healthy eating habits:** Encourage your child to try the fruits and vegetables they have grown. Explain to them the benefits of eating healthy, low protein foods and how the plants they have grown contribute to their overall health.
- **Practice discipline:** Gardening requires discipline and patience. Use this as an opportunity to teach your child the importance of hard work, perseverance, and delayed gratification.

Enjoy! And if you do start up a garden with your PKU'er, please send us your photos at [newseditor@canpku.org](mailto:newseditor@canpku.org). We'd love to share with the community!

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## Meet Tanya

“ Mom of Jacob, born in 2010 with PKU. She started with CanPKU+ just to learn. She is now



driven by helping our community. Her goal is to do everything she can to make each day with Rare a little easier!



” Tanya Chute Nagy

Vice President and  
Event Planner



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



*Hello,*  
**JÉRÉMIE  
DION-  
LATOUR**

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Jérémie is a young adult with PKU living in Quebec. He will also represent CanPKU's French community as our French Liaison. Jérémie is currently also in university to become a Doctor. Welcome to the team!!

MEET



## Our Team Members

Melanie is mom to Masen, who at age 8 was diagnosed with Classical Homocystinuria on June 25, 2021. He was missed at newborn screening and had to make big changes in his life at the age of 8 years old after this very surprising diagnosis.

Melanie loves to connect with others and is a fierce advocate for her son and the rare disease community.

Melanie and family live in Vancouver, BC in Canada.



*Congratulations!*

Congratulations to Lauren Harrison, from our PKU community, and her team who won Silver at the 2022 Curling Club National Championships that took place from November 21-26 in Edmonton at West Edmonton Mall.

They represented Ontario at the championship.





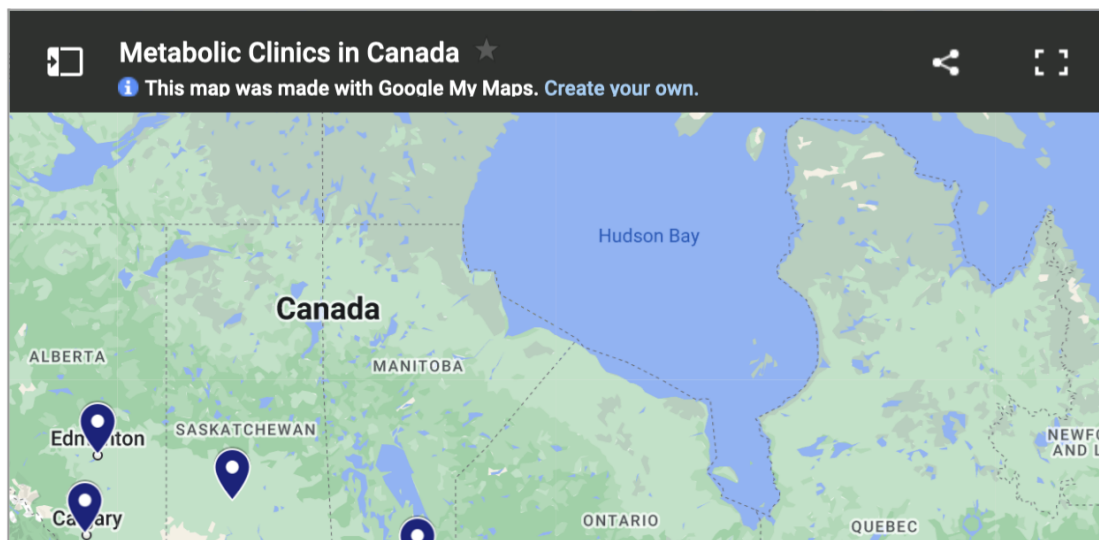
# NEW AT CANPKU.ORG

*See what's new*

Did you know that we now have an interactive map showing all our metabolic clinics as well as patient locations by postal code?

- 📍 Adults and Children
- 📍 Adults Only
- 📍 Children Only

## METABOLIC CLINICS IN CANADA:





## METABOLIC CLINICS IN CANADA:

# CALL FOR NEWSLETTER SUBMISSIONS

NEW

**We would love to hear from you!  
Do you have a recipe, tip/trick, DTC  
success story or even a word of  
encouragement for your fellow PKU'ers?  
Whatever it may be, if you'd like to share,  
please submit to [newseditor@canpku.org](mailto:newseditor@canpku.org).**

We want to thank those who have made themselves available to CanPKU enabling us to translate our English documents and items into French to help provide the same information to both communities. We welcome our new French Chair Jeremie Dion Latour to the team.

We would like to provide Jeremie with a few more names to be able to rely on to help with such translations. If you are bilingual or able to help translate documents please let us know.

Nous tenons à remercier ceux qui se sont engagés à donner du temps pour CanPKU, nous permettant de traduire nos documents et autres éléments de l'anglais au français pour contribuer à offrir la même information aux deux communautés. Nous souhaitons la bienvenue à Jérémie Dion-Latour, notre nouveau directeur francophone. Nous sommes d'autres bénévoles sur qui nous pouvons compter pour de telles traductions. Si vous êtes bilingue ou si vous pouvez aider à traduire des documents, veuillez s'il vous plait nous en



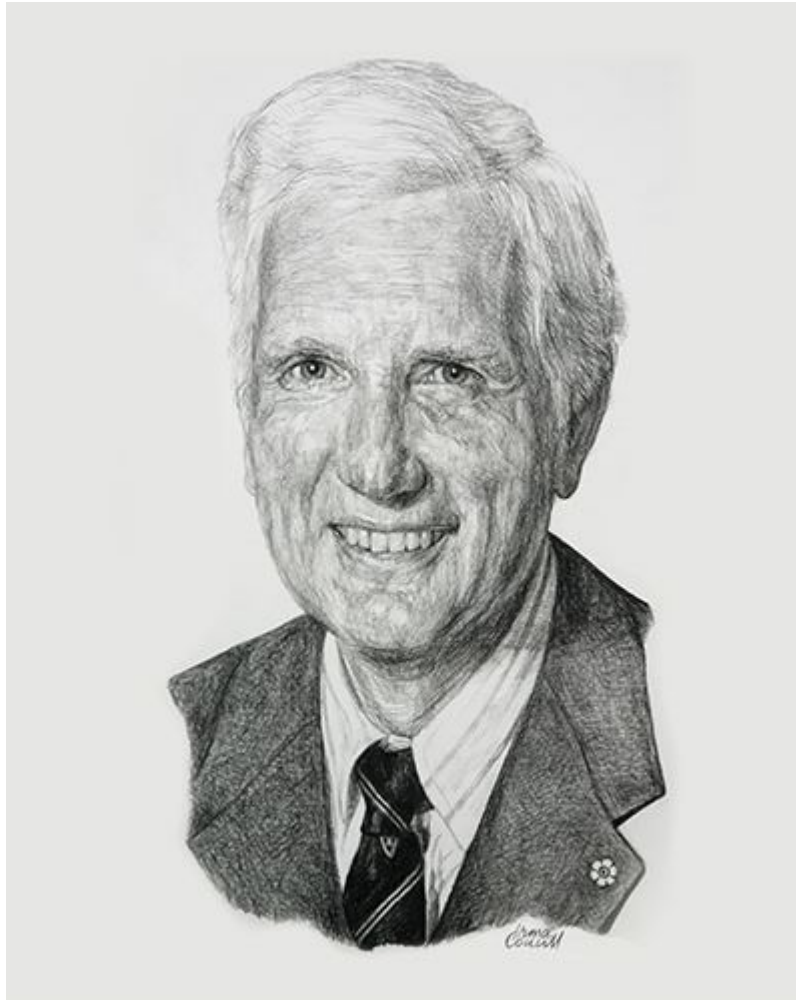
# volunteers needed

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We're on TikTok!

[Click here to find us!](#)



It is with profound sadness that we share the news of Dr. Charles Scriver's death on Friday April 7<sup>th</sup>, 2023. Charles passed in Montreal with his loving family at his bedside. His wife Zipper, his four children Do-Ellen, Peter, Julie and Paul, and several of his grandchildren had come home from all corners of the earth to be with him. He died in the city he loved, in a McGill hospital, at the top of Mount Royal, overlooking his beloved McGill University. He was home.

For those of us who knew him well, the loss will remain ever immeasurable. For the many others whose lives he touched through his work and humanity, he will be remembered as an extraordinary clinician and scientist whose life was dedicated to making his very extensive research and that of others meaningful for patients. He was the epitome of the physician scientist. Charles, who studied at the Dent Lab in London in the early 1960's, brought the techniques he learned to the US and Canada, establishing in North America the study of inborn errors of metabolism. His contributions have had a seminal influence on biochemical genetics.

Charles was a truly warm and caring individual; a renaissance person, deeply knowledgeable not only in science but in the arts - music, poetry, literature, and language. Those of us who heard his beautifully delivered lectures and/or have read his equally beautifully written papers have indeed been fortunate.

The formal obituary will be shared upon publication.

A Celebration of Life will take place on Thursday, April 20th at 3:00 pm at the

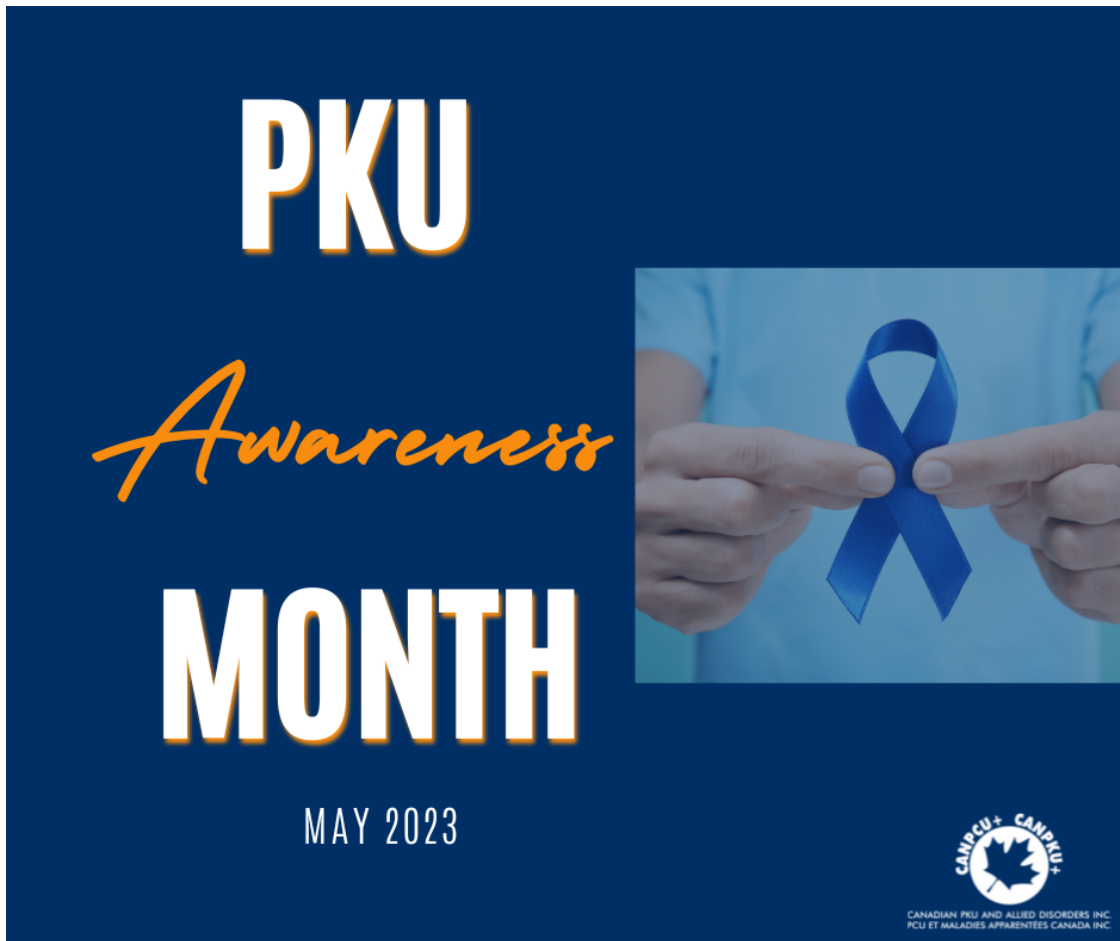
Loyola Chapel, 7141 Sherbrooke Street West, Montreal, H4B 1R6,  
CANADA. All are welcome.

For those who cannot attend, the link for the live stream is  
- <https://youtube.com/live/GNDkqZXxWX4?feature=share>

In lieu of flowers, donations can be made to the Scriver Family Prize in  
Genetics at McGill or the Montreal Children's Hospital Foundation, Genetics.

*Christineh Sarkissian and Harvey Levy*

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The poster features a dark blue background. At the top, the word "PKU" is written in large, bold, white letters with a yellow glow. Below it, the word "Awareness" is written in a cursive, orange font. At the bottom, the word "MONTH" is written in large, bold, white letters with a yellow glow. In the center, the text "MAY 2023" is written in a smaller, white, sans-serif font. On the right side, there is a photograph of two hands holding a blue awareness ribbon. In the bottom right corner, there is a circular logo with a white maple leaf and the text "CANPKU+ CANPKU+" around it. Below the logo, the text "CANADIAN PKU AND ALLIED DISORDERS INC." and "PCU ET MALADIES APPARENTÉES CANADA INC." is written in small white letters.

### **Did you know that May is PKU Awareness month?**

Upload photos of any of the following challenges, (or make your own!) for PKU Awareness month on Facebook, TikTok 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 Strong- Achievement (a grade, a sport, stayed on track, etc.)

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## Update from our CanPKU President

Hello from sunny, warm Ajijic, Mexico.

I had a recent health event and wanted to let you all know and share the good news outcome.

In late March, during 8 flights in 7 days (Canada-USA-Canada-USA-Mexico) I began to experience shortness of breath walking long distances in airport terminals. Then I had an episode of acute chest pressure (angina but not pain) during major physical activity. The angina passed within 3 minutes. This had not happened before and called for immediate investigation.

A cardiac stress test prompted a second angina episode. An angiogram confirmed the tentative diagnosis. The main artery nourishing my heart muscle had a severe, 90% blockage. One might say I was a time bomb for a heart attack.

The hospital team of seven was expecting this and ready to intervene. (See photo of operating room.)

They used an innovative procedure of targeted ultrasound to smash up the blockage which was calcified plaque. Kind of like having a kidney stone in that artery. (See diagram of obstructed artery.) They blasted the blockage 30 times to clear it. This procedure is called lithotripsy.

Then they inserted a stent to keep that section of artery wide open. (See diagram of stented artery.)

The angiogram, lithotripsy and stenting together took about one hour. I was awake the entire time and only felt mild pain once when they expanded the stent.

I was kept in hospital overnight for observation and initial healing. The cardiologist said I could fly the next day, if I wished.

A follow-up check-up a week later indicated all is well.

I feel great and in better health than before. When your heart is getting a full supply of blood (& oxygen in particular), life is better.

I want to note and praise the excellent diagnostic work up and interventions I received from cardiologist Dr. Sergio Najjar Lopez and team at Hospital San Francisco de Asis in Cuadelaire. (Cuadelaire is a process of health assistance



Francisco de Asis in Guadalajara. (Guadalajara is a mecca of health sciences for all of Latin America, with 4 medical schools. Dr. Najjar trained in Guadalajara, Mexico City & Madrid.)

It was all of 3 days from first  
have happened so quickly in

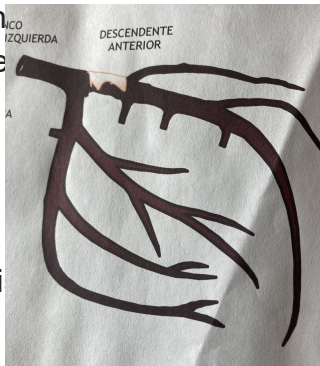


ng. Not sure this would

In a second piece of person  
Sande from BC who has been  
Christmas Day - I dubbed her  
would not forget her name. S

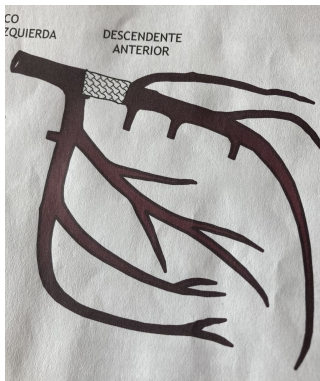
to a fellow Canadian Teresa  
jic. When we first met - on  
Spanish "Santa Teresa" so I  
doctor and specialist.

She was right there at the time of the first angina attack and knew exactly what it was and what to do. She has  
my guardian angel and quite  
is my Santa Teresa.



step of this journey. She is  
th prompt action. She truly

John Adams  
CEO & Co-Founder  
Canadian PKU and Allied Di



**Congratulations on your engagement, John, and we wish you all the best during your recovery!**

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Are you interested in  
hosting a FUN-raiser  
to support CanPKU?

## SPARE FOR RARE

is a fun and exciting bowling fundraiser  
(formerly known as PINS 4 PKU)

Contact our Fundraising Chair,  
Melissa, at [fundraising@canpku.org](mailto:fundraising@canpku.org)  
for more information



**HOW DO I HOST A**   
**"SPARE FOR RARE" EVENT?**

[CONTACT  
CANPKU](#)

[DEVELOP THE  
CONCEPT](#)

- REACH OUT VIA EMAIL TO OUR FUNDRAISING CHAIR, MELISSA AT [FUNDRAISING@CANPKU.ORG](mailto:FUNDRAISING@CANPKU.ORG) FOR MORE INFORMATION AND ASSISTANCE WITH PLANNING THE EVENT

- WILL YOU HAVE A THEME
- WILL THERE BE PRIZES?
- WILL YOU GET THE BOWLING LANES SPONSORED?
- HOW MANY TEAMS/PEOPLE WILL/CAN ATTEND?
- WE CAN HELP!

## FIND A VENUE

- FIND A BOWLING CENTER TO HOST YOUR EVENT
- CHOOSE A DATE THAT WORKS FOR YOU AND THE FACILITY
- CHOOSE A TIME FRAME THAT WORKS ON THE CHOSEN DAY

## SPREAD THE WORD

- POST ON SOCIAL MEDIA
- HAVE FRIENDS AND FAMILY POST ON SOCIAL MEDIA
- PUT FLYERS UP IN LOCAL BUSINESSES
- POST IN LOCAL SOCIAL MEDIA GROUPS
- WE CAN HELP!

## FUNDRAISE

- ASK LOCAL BUSINESSES TO SPONSOR LANES
- HAVE EVENT PARTICIPANTS COLLECT DONATIONS
- YOU COULD CONSIDER HAVING A SILENT AUCTION WITH DONATED PRIZES TO RAISE MONEY AT THE EVENT

## THE EVENT

- THE DAY OF THE EVENT IS A TIME FOR FUN!
- REMEMBER TO ENJOY YOURSELF, YOU'VE WORKED HARD ON THIS!
- TAKE PHOTOS AND VIDEOS TO SHARE WITH CANPKU FOR OUR SOCIAL MEDIA PAGES



# COMMENT HÉBERGER UN ÉVÈNEMENT "REPAIRE POUR RARE"?



## CONTACTER CANPKU

- CONTACTER PAR E-MAIL NOTRE PRÉSIDENTE DE LA COLLECTE DE FONDS, MELISSA À [FUNDRAISING@CANPKU.ORG](mailto:FUNDRAISING@CANPKU.ORG) POUR PLUS D'INFORMATIONS ET DE L'AIDE POUR PLANIFIER L'ÉVÈNEMENT

## DÉVELOPPER LE CONCEPT

- AUREZ-VOUS UN THÈME
- Y AURA-T-IL DES PRIX?
- FEREZ-VOUS SPONSORISER LES PISTES DE BOWLING ?
- COMBIEN D'ÉQUIPES/DE PERSONNES PARTICIPERONT/POURRONT PARTICIPER ?
- NOUS POUVONS AIDER!

## TROUVER UN LIEU

## FAIRE CONNAITRE

- TROUVER UN CENTRE DE BOWLING POUR ACCUEILLIR VOTRE ÉVÉNEMENT
- CHOISISSEZ UNE DATE QUI CONVIENT À VOUS ET À L'ÉTABLISSEMENT
- CHOISISSEZ UNE PLAGE HORAIRE QUI FONCTIONNE LE JOUR CHOISI

- PUBLIER SUR LES RÉSEAUX SOCIAUX
- DEMANDEZ À VOS AMIS ET À VOTRE FAMILLE DE PUBLIER SUR LES RÉSEAUX SOCIAUX
- METTRE DES FLYERS DANS LES COMMERCE LOCAUX
- PUBLIER DANS DES GROUPES DE MÉDIAS SOCIAUX LOCAUX
- NOUS POUVONS AIDER!

## LEVER DES FONDS

- DEMANDER AUX ENTREPRISES LOCALES DE PARRAINER DES VOIES
- DEMANDER AUX PARTICIPANTS À L'ÉVÉNEMENT DE RECUEILLIR DES DONS
- VOUS POURRIEZ ENVISAGER D'ORGANISER UN ENCAN SILENCIEUX AVEC DES PRIX DONNÉS POUR AMASSER DES FONDS LORS DE L'ÉVÉNEMENT

## L'ÉVÉNEMENT

- LE JOUR DE L'ÉVÉNEMENT EST UN MOMENT DE PLAISIR !
- N'oubliez pas de vous amuser, vous avez travaillé dur là-dessus !
- PRENDRE DES PHOTOS ET DES VIDÉOS À PARTAGER AVEC CANPKU POUR NOS PAGES DE MÉDIAS SOCIAUX

**We are super excited to launch our T-shirt Fundraiser! We have shirts for people with HCU, MSUD, PKU, UCDs and those who love them! We have English. We have French. We can't wait to show you what they are...but we want to keep them a secret until we launch!**

**Watch for it, coming soon!!**

**Nous sommes ravis de lancer notre collecte de fonds pour les t-shirts ! Nous avons des chemises pour les personnes atteintes de HCU, MSUD, PCU, TCU et ceux qui les aiment ! Nous avons l'anglais. Nous avons le français. Nous avons hâte de vous montrer ce qu'ils sont... mais nous voulons les garder secrets jusqu'au lancement ! Surveillez-le ! À venir!!**





## **Fundraising Committee**

We are looking for a few energetic people to help out on our fundraising committee. No experience necessary (but we know some of you have talent - we have seen it!) Welcoming those from coast to coast. We will brainstorm as a group, share ideas, encourage others.

Sign up by emailing Melissa at [fundraising@canpku.org](mailto:fundraising@canpku.org)

### **Recently received donations:**

Stephen Schwindt

[Click to donate](#)

THANK  
YOU

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## **UPCOMING EVENTS**

**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](mailto:info@canpku.org) and we will help you out!**

**All buttons are clickable to be taken to the registration page.**

# Zoom with us!

## Watch for upcoming dates

### NEED A CHAT?

JOIN OUR ZOOM CAFE  
MORE INFORMATION AT  
[WWW.CANPKU.ORG/](http://WWW.CANPKU.ORG/)



CanPKU+ offers online cafes where you can join folks like you. Chat about the ups and downs or just the day to day!



**Adults (18+) with PKU  
or Allied Disorder**

(Be sure to also check below  
for Teens and Adults which  
you can attend!)

April 22-2pm est.

**Parents of those with  
PKU (All ages of  
PKU)**

April 22-11am est.



# Save the Date: 2023 CanPKU Events



## EXPLORE CanPKU+

### JOIN US FOR AN OPEN HOUSE - APRIL 17TH

HCU, MSUD, PKU, UCD, TYR



#### Learn about Allied Disorders

CanPKU+ has rebranded with a PLUS SIGN as we are not alone in the world of rare metabolic disorders diagnosed with Newborn Screening. Come meet some of those living with some of the other RARES



#### Come meet those in the same boat as you

Join a break out group that is just for your specific type of Rare. Talk about what you want from CanPKU+ Help us learn more about what you need and who you are!



#### Bring us along for the ride

We are here for you. We are a not for profit patient advocacy group. We want to help you live your best life with your rare condition. Let us tell you what we already have in place!



**JOIN US!**

Register for the zoom at:  
<https://canpku.org/event-5223344>

Questions: [info@canpku.org](mailto:info@canpku.org)

**MONDAY APRIL 17TH, 2023**

**START: 5PM PM/ 6PM MT/ 7PM CT/  
8PM ET/9PM AT/ 930PM NF**

[Click to register-cliquez pour vous inscrire](#)

samedi 13 mai 2023 CANPCU+ EVÉNEMENT ÉDUCATIF



SAMEDI 13 MAI  
9H30 - 16H30  
VANCOUVER, CB

CE QUI VOUS ATTEND

- P - Participer ensemble
- L - L' éducation
- U - Unifier nos efforts pour apprendre
- S - Soutenir les autres
  - HCU, UCDs, HT-1, MSUD, PCU

Où:  
4480, rue Oak, Vancouver CB  
CB Hôpital pour enfants,  
Centre Chan pour l'éducation à la santé familiale



Venez échanger avec les exposants et essayer de nouveaux produits. Découvrez le tout premier registre de patients canadien pour les personnes atteintes de PCU et la façon dont vous pouvez y prendre part.

Parlez à d'autres personnes qui vivent avec Rare. Rosie Pallone (PCU) Melanie Colter (HCU).

Écoutez Erin Mullins, psychologue agréée et mère de l'UCP, passionnée par le développement de l'enfant et la santé mentale.

Visitez le laboratoire de dépistage néonatal

Trouvez plus d'informations  
[www.canpku.org/BCYUKON](http://www.canpku.org/BCYUKON)

PTC Therapeutics se joindra à nous pour présenter son nouvel essai clinique ouvert au phénylcétonuriques de 4 mois et plus au Canada. Synlogic recrute également pour la phase 3 d'un essai clinique dont elle nous fournira les détails. L'avenir est certainement prometteur pour ceux atteints de PCU.

Les repas sont fournis en gardant à l'esprit les régimes pauvres en protéines. Veuillez nous indiquer sur le formulaire d'inscription si des besoins alimentaires supplémentaires doivent être satisfaits. Nous ferons de notre mieux pour vous accommoder.

Un service de garde sera assuré pour les moins de 12 ans.

Saturday May 13, 2023 CANPCU+ REGIONAL EVENT



SATURDAY MAY 13, 2023  
9:30 AM - 4:30 PM  
VANCOUVER BC

WHY ATTEND?

- P - Participate Together
- L - Keep Learning
- U - Understand more
- S - Spreading our wings.
  - HCU, MSUD, UCD, TYR, PKU

At  
BC Children's Hospital  
Chan Center for Family Health Education  
4480 Oak Street, Vancouver BC V6H3N1



Come talk to exhibitors and try new products. Discover the very first Canadian patient registry for people with PKU and how you can take part in it.

Talk to other people who live with Rare. Rosie Pallone (PCU) Melanie Colter (HCU) Michaela Garstin (UCD).

Hear from Erin Mullins, a licensed psychologist and PKU mom who is passionate about child development and mental health.

Find more information  
[www.canpku.org/BCYUKON](http://www.canpku.org/BCYUKON)

PTC Therapeutics will join us in presenting its new open-label clinical trial at 4 months and older in Canada. Synlogic is also recruiting for phase 3 of a clinical trial of which she will provide us with the details. The future is certainly bright for those with PKU.

Meals are provided with low protein diets in mind. Please let us know on the registration form if any additional dietary requirements need to be met. We will do our best to accommodate you.

A childcare service will be provided for children under 12 years old.

Click to register-cliquez pour vous inscrire

Sunday May 7 2023 CANPCU+ REGIONAL EVENT



SUNDAY MAY 7, 2023  
9:30 AM - 4:30 PM  
QUÉBEC, QC

WHY ATTEND?

- P - Participate Together
- L - Keep Learning
- U - Understand more
- S - Spreading our wings.
  - HCU, MSUD, UCD, TYR, PKU

At  
Laval Université  
2305 l'Université St  
Room ADJ-2320 and 2326



Come talk to exhibitors and try new products. Discover the very first Canadian patient registry for people with PKU and how you can take part in it.

A childcare service will be provided for children under 12 years old.

Talk to other people who live with Rare.

Tristan Audet, Solange Lambert, Jérémie Dion-Latour will share their stories with us.

Find more information  
[www.canpku.org/QuebecRegional](http://www.canpku.org/QuebecRegional)

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dimanche 7 Mai 2023 CANPCU+ EDUCATIONAL EVENT



DIMANCHE 7 MAI  
10H00 - 16H30  
QUÉBEC, QC

CE QUI VOUS ATTEND

- P - Participer ensemble
- L - L' éducation
- U - Unifier nos efforts pour apprendre
- S - Soutenir les autres
  - HCU, UCDs, HT-1, MSUD, PCU

Où:  
Université Laval  
la salle ADJ-2320 et 2326  
2305 rue de l'Université,



Venez échanger avec les exposants et essayer de nouveaux produits. Découvrez le tout premier registre de patients canadien pour les personnes atteintes de PCU et la façon dont vous pouvez y prendre part.

Un service de garde sera assuré pour les moins de 12 ans.

Parlez à d'autres personnes qui vivent avec Rare.

Tristan Audet, Solange Lambert, Jérémie Dion-Latour partageront avec nous leurs histoires.

Trouvez plus d'informations  
[www.canpku.org/QuebecRegional](http://www.canpku.org/QuebecRegional)

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Click to register-cliquez pour vous inscrire

## Looking for:

# Child Care Workers

We are looking for 2-3 child care workers to help in our child care area at the upcoming in person event. You will be in charge of activities only. Eating happens with their parents.  
\*Both positions offer a small cash payment.

### 1 LEADER:

- ✓ 16+ Years old
- ✓ Child care experience
- ✓ Basic First Aid helpful

### 1-2 SUPPORT:

- ✓ 13+ Years old
- ✓ Good with children

**Sign Up Now**



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



## En recherche de:

# Travailleurs de la garde d'enfants

Nous cherchons pour 2-3 travailleurs de la garde d'enfants pour aider dans notre zone de garde d'enfants lors du prochain événement en personne. Vous serez en charge des activités uniquement. Manger se passe avec leurs parents.  
\*Les deux positions offrent un petit paiement en espèces.

### 1 CHEF :

- ✓ 16 ans et plus
- ✓ Expérience en garde d'enfants
- ✓ Premiers soins de base utiles
- ✓ Vérification de secteur vulnérable effacée (si disponible)

### 1-2 ASSISTANCE :

- ✓ 13 ans et plus
- ✓ Bon avec les enfants

**S'inscrire maintenant**



plus d'informations:  
[tanya.chute@canpku.org](mailto:tanya.chute@canpku.org)



Atlantic Regional Event

**SAVE THE DATE**

**30  
09  
23**

**RÉSERVEZ LA DATE**

Événement régional de l'Atlantique

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

Click to register-cliquez pour vous inscrire

June 2 - 4, 2023  
Redberry, Saskatchewan

**CAMP  
MAGNIPHEQUE**

International Attendees Welcome  
Meals, bed, activities and fun included  
All Protein restricted metabolic disorders welcome  
All ages welcome  
(Under 18 needs a guardian)

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

 CANADIAN PKU AND ALLIED DISORDERS INC.  
PCU ET MALADIES APPARENTÉES CANADA INC.  
Because Knowledge Leads to Better Health  
Parce que la connaissance mène à une meilleure santé  
[www.CANPKU.org](http://www.CANPKU.org)

[https://www.youtube.com/  
watch?v=Wp403Mll-tA](https://www.youtube.com/watch?v=Wp403Mll-tA)

2-4 juin 2023  
Redberry, Saskatchewan

**CAMP  
MAGNIPHEQUE**

Bienvenue aux participants internationaux  
Repas, lit, activités et amusement inclus  
Tous les troubles métaboliques restreints par les protéines sont les bienvenus  
Tous les âges sont les bienvenus  
(Les moins de 18 ans ont besoin d'un tuteur/ans)

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

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

[https://www.youtube.com/  
watch?v=3VYj5uR5Ycc](https://www.youtube.com/watch?v=3VYj5uR5Ycc)

[Click to register-cliquez pour vous inscrire](#)

**Ne laissez pas les finances vous empêcher de participer. Des bourses sont disponibles.**

**Do not let finances get in the way of attending. Scholarships are available. Please visit our events page for more info and scholarship applications!**

<https://canpku.org/sys/website/?pageId=1075315>

Feature Story

# THE ESSENTIAL CALCULATION



*PCU BLOG: Relevant articles on the management of phenylketonuria on a daily basis.*


*If you follow my blog regularly, you may have read an article a few months ago on nutrition labels. It contains all kinds of essential information to analyze to help you make informed choices for your diet.. This applies to everyone. On the other hand, in the case of phenylketonuria, mathematics need to be included.*


[Click for full article](#)

---

## AMINO ACIDS AND OUR ALLIED DISORDERS


**Natural Protein from Foods**





**20 Amino Acids are found in Food Protein**

**Natural Protein from Muscles and Body Tissues**



**Amino Acids are used to:**

- Grow and repair our body
- Make hormones and brain chemicals, (neurotransmitters, etc).
- Maintain healthy hair, nails and skin
- Have normal digestion
- Boost our immune system
- Provide energy

**\*Phenylketonuria (PKU)**

**PHENYLALANINE** (Phe)

**ISOLEUCINE** (Ile)

**VALINE** (Val)

**LEUCINE** (Leu)

**\*Maple Syrup Urine Disease (MSUD)**


\*The name of the disorders associated with being unable to process these amino acids properly

**\*Classic Homocystinuria (HCU)**

**METHIONINE** (Met)

**TYROSINE** (Tyr)

**\*Tyrosinemia (TYR Type II or III)**



www.canpku.org


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Parce que la connaissance conduit à une meilleure santé


	CLASSIC HCU	MSUD	TYR	PKU
<b>BLOODWORK:</b>	Increased homocysteine and methionine levels	Increased leucine, isoleucine, valine	Increased methionine, phenylalanine and tyrosine levels	Increased phenylalanine levels and decreased tyrosine levels
<b>THERAPY:</b>	Foods lower in Protein Medical Foods: Betaine Supplements - Methionine B6	Foods lower in Protein Medical Food Medical Formula	Foods lower in Protein Medical Food Medical Formula Pharmaceutical	Foods lower in Protein Medical Food Medical Formula Optional: Pharmaceutical
<b>HOW RARE?</b>	About 1,200,000 births, but the true number of people with the condition is not known due to a 10% false negative rate on NBS	About 1,185,000 births. It occurs more often in the Mennonite community, affecting about 1 in every 300 infants.	About 1,100,000 births in the USA and Europe. It occurs more often in Norway, Finland and in the province of Quebec, Canada.	About 1,100,000 live births. It occurs more often in Caucasians and Native Americans, a lower number in African Americans, Hispanics, and Asians.
<b>EARLY SIGNS &amp; SYMPTOMS:</b>	If undetected via NBS: <ul style="list-style-type: none"> <li>• Lethis dislocation</li> <li>• Severe nearsightedness</li> <li>• Blood clots</li> <li>• Strokes</li> <li>• Tall Stature</li> </ul>	If undetected via NBS: <ul style="list-style-type: none"> <li>• Sweet or Maple Syrup smelling urine, sweat, or ear wax</li> <li>• Other signs may include:               <ul style="list-style-type: none"> <li>• Abnormal muscle movements/twitching</li> <li>• Metabolic Crisis</li> <li>• Lethargy</li> </ul> </li> </ul>	If undetected via NBS: <ul style="list-style-type: none"> <li>• cabbage-like smell to urine or skin</li> <li>• Other signs may include:               <ul style="list-style-type: none"> <li>• Jaundice</li> <li>• Diarrhea and bloody stools</li> <li>• Easy bleeding/bruising</li> </ul> </li> </ul>	If undetected via NBS: <ul style="list-style-type: none"> <li>• Musty body odor</li> <li>• Decreased ability to eat</li> <li>• May not show signs before 6 months old</li> <li>• No alert in learning to sit, crawl, and stand</li> <li>• Developmental Delay</li> <li>• Small head size</li> <li>• Eczema</li> </ul>

NBS = Newborn Screening  
These signs & symptom list are not all inclusive. Only a medical team can make an accurate diagnosis

## LES ACIDES AMINÉS ET LES MALADIES MÉTABOLIQUES


**Protéines naturelles de la nourriture**





**20 acides aminés sont retrouvés dans la nourriture**

**Protéines naturelles retrouvées dans les muscles et les tissus du corps**



**Les acides aminés sont utiles pour:**

- Grandir et réparer notre corps
- Faire des hormones et des substances chimiques du cerveau (neurotransmetteurs, etc).
- Maintenir des cheveux, une peau et des ongles en santé
- Avoir une digestion normale
- Renforcer votre système immunitaire
- Procurer de l'énergie

**\*Phénylcétonurie (PCU)**

**PHENYLALANINE** (Phe)

**ISOLEUCINE** (Ile)

**VALINE** (Val)

**LEUCINE** (Leu)

**\*Leucine (MSUD)**


\*Le nom des conditions associées avec le fait d'être incapable de transformer ces acides aminés correctement.

**\*Homocystinurie classique (HCU)**

**METHIONINE** (Met)

**TYROSINE** (Tyr)

**\*Tyrosinémie (TYR Type II ou III)**



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	HCU CLASSIQUE	LEUCINOSE	TYR	PKU
<b>TESTS SANGUINS:</b>	Niveaux élevés d'homocystéine et de méthionine	Leucine, isoleucine et valine élevées	Niveaux élevés de méthionine, phénylalanine et tyrosine	Niveaux élevés de phénylalanine et niveaux abaissés de tyrosine
<b>TRAITEMENT:</b>	Aliments faibles en protéines Aliments thérapeutiques Formule médicale Bétaine Parfois - vitamine B6	Aliments faibles en protéines Aliments thérapeutiques Formule médicale	Aliments faibles en protéines Aliments thérapeutiques Formule médicale Pharmaceutique	Aliments faibles en protéines Aliments thérapeutiques Formule médicale Options: Pharmaceutique
<b>RARE À QUEL POINT?</b>	environ 1,200,000 naissances, mais le vrai nombre est incertain à cause de nombreux faux négatifs (10% de faux positifs non détectés)	environ 1,185,000 naissances. Plus fréquent dans la communauté mennonite, ce qui affecte environ 1 naissance sur 300.	environ 1,100,000 naissances aux EU et en Europe. Elle est plus présente en Norvège, en Finlande et dans la province de Québec, Canada.	environ 1,100,000 naissances. Elle affecte plus souvent les personnes caucasiennes et les personnes asiatiques, un nombre inférieur chez les personnes afro-américaines, hispaniques et asiatiques.
<b>SIGNES ET SYMPTÔMES PRÉCOCES:</b>	Si non détecté au dépistage néonatal: <ul style="list-style-type: none"> <li>• Détérioration du cristallin</li> <li>• Myopie sévère</li> <li>• Caillots sanguins</li> <li>• AVC</li> <li>• Grande taille</li> </ul>	Si non détecté au dépistage néonatal: <ul style="list-style-type: none"> <li>• Urine, sueur ou crachats qui sent sucré/sauge d'ail</li> <li>• Autres signes:               <ul style="list-style-type: none"> <li>• Raideurs/mouvements musculaires anormaux</li> <li>• Cris métalliques</li> <li>• Lethargie</li> </ul> </li> </ul>	Si non détecté au dépistage néonatal: <ul style="list-style-type: none"> <li>• Urine ou peau qui sent le chou</li> <li>• Autres signes:               <ul style="list-style-type: none"> <li>• Jaunisse</li> <li>• Diarrhée et sang dans les selles</li> <li>• Saignements et entassements blancs</li> </ul> </li> </ul>	Si non détecté au dépistage néonatal: <ul style="list-style-type: none"> <li>• Urine qui sent le moisi</li> <li>• Les enfants ont tendance à grandir plus lentement que les autres</li> <li>• Retard dans l'apprentissage de la marche, de ramper et de se lever seul</li> <li>• Retard développemental</li> <li>• Petite taille</li> <li>• Eczéma</li> </ul>

Les signes et symptômes ne sont pas tous inclus. Seule une équipe médicale peut faire un diagnostic juste.

**LET'S TALK ABOUT MENTAL HEALTH**

SAVE THE DATE

May 3rd, 7.00 - 8.30pm ET

**VIRTUAL WELLNESS**  
Supporting Psychological Well-being:  
Strategies for Success

KENDRA J. BJORAK  
PH.D., L.P.

CAMBROOKE

**SAVE the DATE**  
for a special event for those with Rare Disorders...an invitation to register will be sent out soon

**Your opinion counts!**

We are trying to learn more about what matters most to people with PKU during adulthood and if protein substitutes/medical foods could be improved.

If you have PKU and are 30 years or above, we would like to hear what you think by completing an online survey.

The survey should take around 40 minutes to complete.

To find out more please email Rachel Wilson on:  
[25191233@edgehill.ac.uk](mailto:25191233@edgehill.ac.uk)

We'd like to say thank you by offering an

to the first 100 people who complete the survey.  
Survey will be closed in spring 2023.





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## CanPKU's Drive to Thrive Committee

As mentioned earlier this year, CanPKU is committed to helping those who were previously misguided (with information that at the time was believed to be correct) that it would be ok to come off their medical diet. This may have been as the medical community believed that the brain had developed enough and would not incur further brain damage by lifting the protein restriction. It may be due to the fact some provinces restricted coverage of therapeutic products (and some still do) so it was impossible to maintain the previous "diet" therapy. Lastly, it may be due to the fact the adult opted for their own reasons to come off "diet" and stop therapy.

We now know that this is not the best course of action. We owe it to those who were previously diagnosed, but are now lost to treatment to help them return to clinic and resume treatments (which have dramatically improved since their time on therapy).

To do this, we need your help. We are looking to form a committee that will help locate and support these individuals. You do not have to be an adult with PKU, just a passion to help. We hope to have representatives from many provinces.

Are you up for it? (Can you join both committees mentioned in this newsletter - Absolutely!) Email to [Tanya.Chute@canpku.org](mailto:Tanya.Chute@canpku.org) to sign up!

[Email Tanya](mailto:Tanya.Chute@canpku.org)





I don't know why but Spring always makes me think of delicious baked breads, rolls etc. Perhaps that is because of Easter. Thank you so much to Brienna for sharing this delicious Cinnamon Bun recipe with CanPKU. I will definitely give this a try with my little one.

## Cinnamon Buns

By Brienna Young, PKU Mom



### Ingredients:

- 3 cups CF MixQuick
- $\frac{1}{4}$  cup (30 grams) cake flour

### Mix:

- MixQuick, cake flour, yeast, Metamucil, sugar and salt together.
- Add rice dream and oil. Stir until well blended.
- Add small amounts of wheat starch if dough is still a bit sticky.
- Sprinkle wheat starch onto counter and knead dough until nicely formed.
- Roll out dough into rectangular shape; roll dough until approx  $\frac{3}{4}$  inch thick
- Combine cinnamon, brown sugar, and butter. Sprinkle mixture onto the dough, leaving  $\frac{1}{2}$  inch border.



## Notes



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canpku.org



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TAKE YOUR FORMULA TO THE  
**MAX!**

Power up your day with the help of **delicious and easy recipes** featuring **Maxamum<sup>®</sup>** formulas.

NUTRICIA

Maxamum<sup>®</sup> products are specialized formulas from Nutricia North America for the dietary management of protein homocysteinuria (HCU), maple syrup urine disease (MSUD) and phenylketonuria (PKU) and must be used under medical supervision.  
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[Click here to download the Maximum recipe booklet.](#)

TIREZ LE MAXIMUM DE VOTRE FORMULE  
**MÉTABOLIQUE**

Faites le plein d'énergie pour la journée avec l'aide de **recettes faciles et délicieuses** à réaliser avec les formules **Maxamum<sup>MD</sup>**.

NUTRICIA

Les produits Maxamum<sup>MD</sup> sont des préparations spécialisées de Nutricia North America pour le soutien nutritionnel de l'homocystéinurie (HCU), la leucosé et la phénylcétonurie (PKU) et doivent être utilisés sous surveillance médicale.  
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[Cliquez ici pour télécharger le livret de recettes Maxamum.](#)

**TURN PERIFLEX®  
ADVANCE INTO  
YOUR FAVOURITE  
FLAVOUR!**



**Vanilla**      **Chocolate**      **Strawberry**



Simply add 1-2 tbsp (15-30 mL) of your favourite flavoured syrup.\*

\*Adding flavourings to Periflex Advance may change the phenylalanine (PHE) content. Be sure to read labels or consult your healthcare professional and account for any additional PHE sources.

Periflex Advance is a specialized formula from Nutricia North America for the dietary management of protein phenylketonuria (PKU) and must be used under medical supervision. © 2023 Nutricia North America. All rights reserved.

**NUTRICIA**

[Click here to download the Periflex Advance mixing suggestion handout.](#)

**AJOUTEZ VOTRE  
SAVEUR PRÉFÉRÉE  
À PERIFLEX<sup>MD</sup>  
ADVANCE!**



**Vanille**      **Chocolat**      **Fraise**



Ajouter 1-2 c. à soupe (15-30 ml) de votre sirop aromatisé préféré\*.

\*Ajout de saveurs à Periflex Advance peut modifier le teneur en phénylalanine (PHE) pratiquée. Assurez-vous de lire les étiquettes ou consultez un professionnel de la santé et prenez compte de la PHE des produits supplémentaires.

Periflex Advance<sup>MD</sup> est une préparation spécialisée de Nutricia North America pour la prise en charge nutritionnelle de la phénylcétonurie (PCU) et doit être utilisé sous supervision médicale. © 2023 Nutricia North America. Tous droits réservés.

**NUTRICIA**

[Cliquez ici pour télécharger le document de suggestion de mélange pour Periflex Advance.](#)

## Updates and Articles of Interest

### Adams and Steele: Canada must act to fund drugs for rare diseases

*The U.S. has had legislation on drugs for rare diseases for 40 years, yet Canada can't even come up with a common framework across the country.*

John Adams, Kim Steele

Published Mar 09, 2023 · Last updated Mar 09, 2023 · 3 minute read

[Join the conversation](#)



[Click for full article!](#)



Video Link

"It was a historic day in Montreal with the public launch of the long-awaited federal strategy on drugs for rare disorders.

It was an honour to be invited by Health Minister Duclos to attend and to speak"

-John Adams, CanPKU President

*This event was broadcast live and a recording is available on YouTube.*



## Canadian News



### **BREAKING NEWS: Federal Government Allocates Up to \$1.4 Billion to Improve Access to Drugs for Rare Diseases**

This morning, March 22, 2023, Federal Minister of Health Jean-Yves Duclos announced \$1.5 billion in funding associated with the government's long anticipated national rare disease strategy first announced in 2019.

Most of the funding – up to \$1.4 billion – which is to be allocated over the next three years, is earmarked for bilateral agreements with provinces and territories to expand their drug programs' coverage to include new and existing drugs for rare diseases, and to support early diagnosis and screening for rare diseases.

According to the announcement, federal, provincial and territorial governments will *"jointly determine a small set of new and emerging drugs that would be cost-shared and covered in a consistent way across the country, for the benefit of patients"*. PDCI will continue to monitor and report developments concerning how drugs will be selected by governments for funding under this strategy and whether consultations will be conducted.

The remaining funding will be allocated as follows:

- \$33 million to Indigenous Services Canada's Non-Insured Health Benefits Program to support eligible First Nations and Inuit patients living with rare diseases;
- \$20 million over three years to the Canadian Agency for Drugs and Technologies in

Health (CADTH) and the Canadian Institute for Health Information (CIHI) to improve the collection and use of evidence to support decision-making;

- \$32 million over five years to the Canadian Institutes of Health Research (CIHR) to advance rare disease research with a focus on developing better diagnostic tools and establishing a robust Canadian rare disease clinical trials network; and,
- \$16 million over three years to establish governance structures, and an Implementation Advisory Group, to support the implementation of the Strategy.

For more information, please consult the [Government of Canada's news release](#).

**Background:** Federal Budget 2019 initially proposed investing up to \$1 billion over two years, starting in 2022–23, with up to \$500 million per year ongoing to improve Canadians' access to drugs treating rare diseases. Health Canada's 2021 [Discussion Paper](#) and public consultation sought stakeholder feedback on how to build the national strategy, culminating in its report [Building a National Strategy for Drugs for Rare Diseases: What We Heard from Canadians](#).

Please contact **Courtney Abunassar, Associate Director, Market Access and Policy Research** at [courtney.abunassar@pdci.ca](mailto:courtney.abunassar@pdci.ca) for any questions or further information.

## Have you tried the newest formula flavour options from **Vitaflo™**?

### Looking for a GMP\* formula option?

Discover our newest PKU sphere® flavours

#### New Banana & Lemon flavours!

Vanilla • Red Berry  
Chocolate

### Prefer an amino acid-based formula?

Check out our PKU express™ plus line with a new flavor option

#### New Raspberry flavour!

Orange • Tropical  
Lemon • Unflavoured



\* GMP = Glycomacropeptide.

#### FOR USE UNDER MEDICAL SUPERVISION

Be sure to check with your healthcare professional before making changes to your diet.

Not for intravenous use. For enteral use only. Not for use as a sole source of nutrition.  
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Scan the QR code for more mixing inspiration and our recipe ideas



Enhancing Lives Together  
A Nestlé Health Science Company



Eat Well, Live Well.



CAMBROOKE™

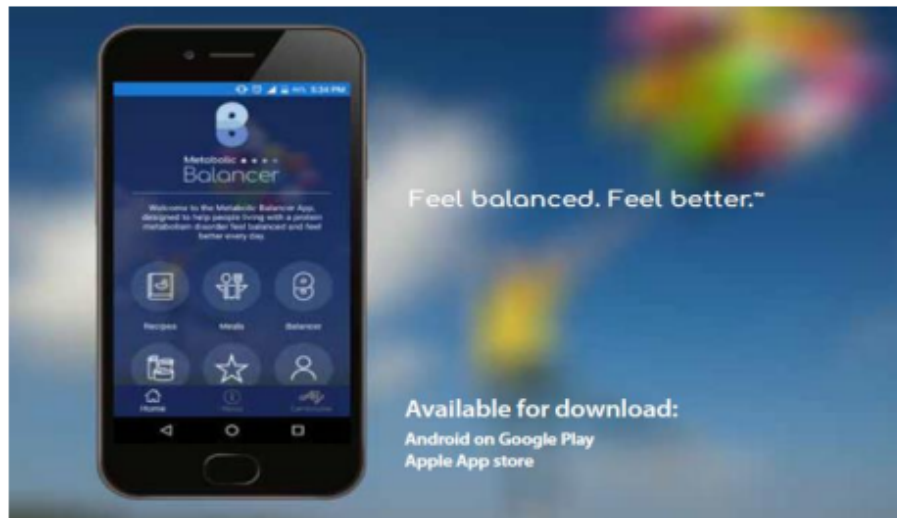
## Metabolic Balancer APP

to help manage PKU

**Metabolic Balancer** is designed to help you manage your PKU diet. This app guides you through your meals, snacks, and formula intake.

### Use Metabolic Balancer to:

- ✓ Discover dietary information for over 7,500 low protein foods and formulas
- ✓ Search and learn the Phe content of your food
- ✓ Track your blood levels
- ✓ Print or email your diet log before clinic visits
- ✓ Record your food over time to make connections between what you eat and feeling well
- ✓ Track your Kuvan intake



Let's hear from you!



**Do you have  
a genetic  
condition?**

**Are you  
between 10-19  
years old?**

## **We'd like to hear about your experiences of being a teenager with a genetic condition**

For more information: [tasha.wainstein@bcchr.ca](mailto:tasha.wainstein@bcchr.ca)

We would like to invite your child (10-19 years old) to participate in a study that aims to explore the experiences of adolescents with genetic conditions. Even if genetic testing did not identify a gene change which explains their medical problems, we are still interested in hearing about their experiences. Participation in this study is voluntary and would involve a ~1 hour virtual interview. During the interview, we will ask some questions about their experiences of living with a genetic condition. They will also be asked to complete three short questionnaires online. We hope this study will help us to design the best possible clinical services for adolescents who have genetic conditions. Your child will receive \$20 for sharing their time and expertise on this important study. For additional information about the study, please contact Tasha Wainstein who will be happy to answer any questions you or your child may have ([tasha.wainstein@bcchr.ca](mailto:tasha.wainstein@bcchr.ca) or 604-875-2000 (ext 6333)).

We believe that the insights of adolescents from your organization will be extremely valuable. If you have any questions about the study, please feel free to contact me

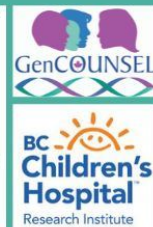
([Carly.pistawka1@bcchr.ca](mailto:Carly.pistawka1@bcchr.ca)) or Tasha  
([tasha.wainstein@bcchr.ca](mailto:tasha.wainstein@bcchr.ca)).

Thank you for your consideration



Participating in this study involves an ~1hr interview with a researcher and answering a few short questionnaires and you'll receive a \$20 gift card!

If you or your caregivers would like more info:  
<https://tinyurl.com/363t23pu>  
or contact: [tasha.wainstein@bcchr.ca](mailto:tasha.wainstein@bcchr.ca)



## Will You Share Your Story?

We are looking for **people living with PKU** to share their story. How does PKU affect your life and what does it mean if potential new treatment options become available? We'd like to hear from everyone,

but especially from **adults who are struggling to meet treatment targets (Phe > 600 umol/L or 10 mg/dL).**

---



If you are willing to **share your story**, please email  
Lori Gorski [lori.mckenna.gorski@synlogictx.com](mailto:lori.mckenna.gorski@synlogictx.com)  
to set up a time to speak at your convenience.

*Your story may be shared outside of Synlogic - but only with your approval.*

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**We are so grateful to you, and to the devoted  
leaders of CanPKU, for their continued  
collaboration and guidance.**

synlogic

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## RESOURCES

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

[www.canpku.org/Downloadable-educational-resources](http://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](http://www.canpku.org/Update-your-Profile) and [www.canpku.org/how-to-use-the-website](http://www.canpku.org/how-to-use-the-website)

View your Profile: <https://canpku.org/Sys/Profile>



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

# CanPKU Sponsors

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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synlogic

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RESEARCH • PROGRESS • HOPE



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 **Canadian  
Red Cross**

**HOMOLOGY™**  
Medicines, Inc.

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



**daiya**  
deliciously dairy free™

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## CanPKU News

**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.



*“Education is the  
passport to the  
future, for tomorrow  
belongs to those  
who prepare for it  
today.”*

*—Malcolm X*

## Privacy Statement:

Please note that CanPKU maintains member/participant/registration information for its own use and does not rent, sell or otherwise provide any identifying information to outsiders.

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



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