

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 and we will help you out!

All buttons are clickable to be taken to the registration page

In Person Camp MagniPHEque ~ En personne - Événement régional

2022-09-09 6:00 PM to 2022-09-11 Noon Eastern
[1010 Birchview Road, Douro-Dummer ON K0L 2H0](#)

CanPKU Annual General Meeting (AGM)

2022-09-09 7:00 PM Eastern
[1010 Birchview Rd, Douro-Dummer, ON](#) and Virtual

Quebec - En personne - Événement régional ~ In Person - Regional Event

2022-09-24 10:00 - 4:30 Eastern
Université Laval [2325 Rue de l'Université, Québec, QC G1V 0A6](#)

Atlantic - En personne - Événement régional ~ In Person - Regional Event

2022 -10-15 10:00 - 4:30 Atlantic
Centre Communautaire Moncton Lions Community Centre [473 St George St. Moncton, NB](#)



Inside this issue

[Upcoming Events](#)

[Zooms For You](#)

[Canadian Adult PKU Patient Researcher Aims to Change the *One-Size-Fits-All* Diet for PKU](#)

[Drive to Thrive](#)

[INFORM RARE](#)

[Canadian News](#)

[International Events / News](#)

[Recipes/Recettes](#)

[Patient Profile](#) (Board Member and Management Team Edition)

[Resources](#)

[Your Profile on CanPKU.org](#)

[Donations](#)

[Sponsors Page](#)

.

CanPKU hopes you are all enjoying your summer!

We are still keeping busy here at CanPKU working on gathering some numbers on instances of our Rare in Canada with the help of your clinics. We continue to strive to bring education and support to those in the community. We are busy at work finalizing the plans for the last of our educational events which are coming up in the fall as well as the Annual General Meeting (AGM). You will see some emails coming at you in the next month about the AGM. Please ensure your membership is up to date before this meeting happens so you can have your say in the way that CanPKU will look in the upcoming year. Did you notice this was coming out a bit late? We are super busy with lots on the go, so we apologize for it coming to you a little late! We will be back on track for October! (hopefully) Cheers!



Register for Camp Here

Registration extended for ONE week. Please register by Aug 19th 11:59PM
(Eastern Time Zone - Toronto)

Sorry, Scholarships are now closed.

Samedi 24
septembre 2022 PCU ÉVÈNEMENT RÉGIONAL



SAMEDI 24 SEPTEMBRE
10H00 - 16H30
QUEBEC, QC

CE QUI VOUS ATTEND

- P - Participer ensemble
- C - Comprendre davantage
- U - Unifier nos efforts pour apprendre



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.

Xavier, un jeune athlète récemment médaillé aux Jeux d'été du Canada, nous parlera de la façon dont il parvient à conjuguer sport et PCU! Sa mère nous expliquera aussi le rôle qu'elle a joué dans la réussite sportive de Xavier.

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.

<https://canpku.org/event-4896071>

Saturday,
September 24th
2022 CANPKU REGIONAL EVENTS



SATURDAY SEPT 24TH
10:00 AM - 4:30 PM
QUEBEC CITY, QC

WHAT TO EXPECT

- P - Participate Together
- K - Keep Learning
- U - Understand more



CanPKU welcomes families and individuals to join for a community educational event!

Activities will include information sessions, break out groups and more.

Child care will be provided for those under 12 years old

An athletic youth, Xavier, will chat with us about his ability to juggle his PKU and sports which recently saw him win a medal at the Canadian Summer Games! His mom will also present on the role she played to get Xavier to this point in his career.

PTC Therapeutics will join us to discuss their new trial which will be available in Canada for those with PKU starting from 4 months of age into adulthood. Synlogic also is recruiting for a Phase 3 trial and will be sharing the details of their trial. It's an exciting time to have PKU!

Learn about a first ever Canadian patient registry for PKU and how you will be able to participate.

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

<https://canpku.org/event-4896071>

Inscrivez-vous ici/Register here

Atlantic Regional
Event

**SAVE
THE DATE**



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

**RÉSERVEZ
LA DATE**

Événement régional de
l'Atlantique

**10
15
22**



CanPKU has set up zooms for our various demographics to provide you with somewhere to chat with your peers. We hope you will join us. Please only register for the events that pertain directly to you. For instance, if you are a parent of a teen, you can join the parent group, but only your teen can join the teen group. If they need help joining, just reach out to tanya.chute@canpku.org

Please note time of events are all listed in Eastern Time Zone (Toronto). Adjust accordingly for your region.

Zooms for YOU!

CanPKU has set up zooms for our various demographics to provide you with somewhere to chat with your peers. We hope you will join us. Please only register for the events that pertain directly to you. For instance, if you are a parent of a teen, you can join the parent group, but only your teen can join the teen group. If they need help joining, just reach out to tanya.chute@canpku.org

Adults (18+) with PKU or Allied Disorder

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

Aug 25th

Sept 24th

Oct 20th

Teen and Adults with PKU or Allied Disorder (13+)

When our teen population grows we will make a separate group for them as well.

Aug 13th

Sept 10th (From Camp!)

Oct 1st

Parents of those with PKU (All ages of PKU)

Aug 13th

Sept 10th (from Camp!)

Oct 1st



Part 2. Improved Symptoms in Single Subject, Convince National PKU Alliance to Fund Maria's Research

Canadian Adult PKU Patient Researcher Aims to Change the One-Size-Fits-All Diet for PKU This is the second in a series of three articles about a Canadian adult with PKU, a U.S. dietitian, and how they joined together to create a funded research study, literally one patient at a time. Maria's story continues at the Society for Inherited Metabolic Diseases, April 2022.

SIMD Conference 2022. Maria Depenweiller (Ontario patient) was presenting a long-awaited poster at one of the largest international conference of metabolic scientists. She was sharing her preliminary findings of a study conducted three years earlier, originally scheduled for presentation when Covid struck the U.S. March 2020. A chance to gain feedback from colleagues about the next logical research step was put on hold.

The 2020 missed opportunity caused Maria and Annie (U.S. dietitian, see Part 1) to consider the prospect of moving directly to putting the poster data into a research grant. Working collaboratively with Dr. Shoji Yano at the University of Southern California and Dr. Kirsten Ahring in Denmark (see photo), they spent one year preparing a grant application due in April 2021. Dr. Yano was one of six investigators who received a 2021 award for the project, "Can Dietary Large Neutral Amino Acids (LNAAs) Improve Care of Adult PKU: An N-of-1 Study." A study Maria and Annie had conducted in one patient would be expanded into a larger clinical trial!

What are LNAAs and how could they improve adult care? LNAAs are a group of amino acids that include Phe and tyrosine. They compete with one another for transport from blood to brain. When one (for example, Phe) is high in blood, the others (for example tyrosine) are unable to enter the brain as efficiently. Tyrosine is essential for making brain chemicals such as dopamine which controls sleep, attention and other functions affected in adults with PKU. Treatment is to lower blood Phe. However, even with the best dietary treatment, blood Phe remains elevated.

In Maria and Annie's original single patient trial, they asked the question, 'If the other blood LNAAs are increased relative to Phe, could this improve symptoms?' They found one willing volunteer, obtained informed consent, and conducted an experiment to quantify symptom changes in response to LNAA supplementation. Six months later, the adult patient's fatigue and difficulty concentrating were absent—with no significant change in blood Phe!

This preliminary trial, along with Dr. Yano's previous work, was sufficient evidence to convince NPKUA to fund the research which aims to improve symptoms and quality of life in adult patients with no blood Phe reduction. The group, led by Dr. Shoji Yano, is now recruiting 6-9 adults with PKU for their study which begins in the fall.

Stay tuned final in this series (next issue): Part 3. Maria's first National PKU Alliance Meeting Experience as a Patient and a Researcher

Check out the scientific poster presented at SIMD (Society of Inherited Metabolic Disorders) conference.



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 to sign up!

Email Tanya



GENETIC METABOLIC DIETITIANS INTERNATIONAL, INC (GMDI)

Tanya Chute attended the GDMI Conference held just outside of Vegas, Nevada in May of 2022. This meeting brings together Metabolic Dietitians from all over the world but mostly Canada and USA. The time spent at this event allows for an ability to network and learn from our sponsors and more importantly the Registered Dietitians which you may see in your clinic. This was Tanya's first time attending this event. She had the opportunity to meet some of your clinicians which she had not yet had the chance to meet face to face. She also was able to continue to build relationships with our sponsors that allow us to provide the best possible content to our virtual and in person events.



2022 NPKUA Challenging the Summit.

CanPKU offered travel scholarships to those in Canada who wished to attend the National PKU Alliance conference. It brought together vendors, speakers, doctors, scientists, patients and families. In total we had 5 Canadians in attendance. (Unfortunately, we didn't manage to get a photo of us all at one time). The last evening of the event we did manage to take a walk with three of us down to the waterfront to discuss some of what we captured at the event. It was an awesome event. Congratulations to NPKUA for the successful event. See you in 2 years!

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

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!

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.



Fundraising Committee

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

Sign up by emailing Tanya.Chute@CanPKU.org

(Can you join both committees mentioned in this newsletter - Absolutely!)

CAMBROOKE™

Feel balanced. Feel better.™

20 GLY TACTIN® BUILD Flavors



20g
PE

110
kcal

20mg
Phe

Mix with
4oz
Water

Enjoy our baking mixes!



Visit Cambrooke.com

CanPKU shares information but does not endorse any products.



PKU
sphere®

Vitaflo™

Enhancing Lives Together
A Nestlé Health Science Company



New PKU sphere20 powder flavours,
Banana and Lemon!



Visit
Vitaflo.Ca to
learn more

USE UNDER MEDICAL SUPERVISION

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

All trademarks are owned by Société des Produits Nestlé S.A., Vevey, Switzerland. © 2022 Nestlé.



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 to set up a time to speak at your convenience.

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

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

synlogic

Il n'est jamais trop tard pour reprendre le régime alimentaire PCU ou améliorer son adhésion! Que vous ne suiviez plus le régime alimentaire ou que vous ayez de la difficulté à le suivre, notre kit 'Ma nutrition pour la vie' fournit de l'information sur l'importance du régime alimentaire ainsi que des conseils utiles. [Jetez un coup d'œil à notre livret d'information.](#)

**EST-CE QUE VOUS OU UN PROCHE
REPREND LE RÉGIME ALIMENTAIRE?**

Envoyez-nous un courriel au canada.metabolics@nutricia.com pour recevoir notre kit 'Ma nutrition pour la vie' comprenant un livret d'information, des livres de recettes et plus!



©2022 Nutricia North America.
Tous droits réservés.

NUTRICIA
Présenté par Nutricia North America

It's never too late to improve or return to the PKU diet! Whether you are off-diet or having difficulty staying on your low-protein diet, our 'diet-for-life' kit provides information on the importance of the PKU diet as well as some helpful tips. [Check out our information booklet here:](#)

**ARE YOU OR A LOVED ONE
RETURNING TO DIET?**

Send us an email at canada.metabolics@nutricia.com to receive our "Diet-for-life" kit including an information booklet, recipe books and more!



Available in English and French.

©2022 Nutricia North America.
All Rights Reserved.

NUTRICIA
Brought to you by Nutricia North America

Be part of INFORM RARE!

Join our Youth Advisory Group and have your say in research that is important to you!

What is this about?

INFORM RARE is a network of researchers from across Canada who are conducting research into three rare conditions: mucopolysaccharidoses (MPS), phenylketonuria (PKU), and spinal muscular atrophy (SMA). It is essential that researchers hear what's important to young people like you, who are experts in what it's like to live with these conditions. **We need your input and advice!**

Who can apply?

- Youth aged 12-18 with a diagnosis of MPS, PKU, or SMA
- Those who have a basic understanding of English (la plupart des documents de travail et les réunions se tiendront en anglais, quoiqu'il y aura une facilitatrice bilingue qui s'assurera que vous pourrez communiquer en français)
- Those who have access to the Internet and video conferencing (Zoom)

How will I participate?

- We will hold an orientation session (fall 2022) and we expect to have 5-8, 1-hour virtual meetings per year
- In between meetings, we may ask you to give your opinion on a specific issue or question by responding to a short questionnaire
- We will ask you to commit for one year, but you may be interested in staying with the group for an extra 1-2 years

What will I do?

- Share with us which outcomes (such as improvements in your quality of life, your treatments, etc.) are important to you
- Give us advice on creating research materials (such as surveys, information sheets for recruitment) that make it easier for youth to be involved in research that is important to them

What's in it for members of the Youth Advisory Group?

- You will collaborate with other young people across Canada and our research team
- You will learn about the health research process and make a valuable contribution to rare disease research
- You will be compensated \$25/hour for attending meetings, your preparation time, and occasionally responding to requests in between meetings

I'm interested! How do I apply?

- Please fill out this brief survey by **August 17th**: <https://www.surveymonkey.ca/r/SW56GKM>
- Our goal is to form a diverse group (where you live, your age, your condition) so we may not be able to select you at this time. We will let you know about other opportunities to participate later on.

Questions? Email the INFORM RARE team at informrare@uottawa.ca





Canadian News

Big News!

Health Canada approved Palynziq in April although the product monograph is backdated slightly to March 30, 2022. The Canadian approval follows the EMA approval, rather than the FDA original approval, as it includes 16 and 17 year olds, the higher dosage of up to 60 units (3 vials) a day and mentions the phe-regulated diet as one of the goals of therapy.

Biomarin has also initiated a Canadian page <https://www.biomarin.ca/> for Canadians looking for more information on their products in Canada. You will find information on Palynziq as well as Kuvan on this page, along with other drugs in their Rare Disease Portfolio.

In June, Parliament changed the DTC portion of the Income Tax Act to recognize that those on medical formulas and/or medical foods are eligible under "life sustaining therapy" pathway.



International News

E.S PKU (European Society of PKU) Opens registration for their annual conference

Society for the study of inborn errors of metabolism annual symposium opens registration

Homology Medicines Announces FDA Lifted Clinical Hold on pheNIX Gene Therapy Trial for PKU

We thank London Health Sciences for allowing us to use a recipe from their newsletter. To see previous newsletters from this clinic, click [here](#)

The Inherited Metabolic Disorders News

Emmitt's Mug Cake

This is a very delicious low protein addition to any meal or snack.

4 Tablespoons	Cambrooke Mixquick
1 Tablespoon	Brown sugar
3 Tablespoons	Silk Almond Original beverage
1 Tablespoon	Oil
¼ Teaspoon	Cinnamon
1 Teaspoon	Vanilla

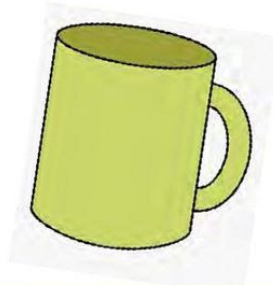


- Spray or grease your mug so that the cake does not stick
- Add all the dry ingredients first, then add the wet. Mix until combined
- Microwave on high for 1 minute
- Enjoy the cake right out of the mug with a spoon

Emmitt has a few suggestions:

- Add your favourite fresh or frozen fruit right before cooking
- Sometimes the cake is a little "raw" on top. If you do not like that, just microwave for another 20-30 seconds. "I like it gooey on top."



1 mug	0.2 g protein	12 mg phenylalanine
-------	---------------	---------------------



RECIPES

Check out this delicious Scone recipe from Cambrooke

Recipes
SCONES



Materials Needed:

- 1 Fork or whisk
- 1 Mixing Bowl
- 1 Greased Cookie Sheet or muffin tin

Time Saving Suggestion: Bake in a larger batch and freeze.

Suggestion: Can be enjoyed as breakfast, toasted or warmed with jam.
At Lunch – as a sandwich base, anytime as a snack or accompaniment with soup, brique or chowder.

2 cups (200g) Cambrooke MixQuick
1/4 Cup non dairy creamer or alternative

Heat oven to 450 degrees F.
Mix ingredients with a fork or whisk until blended.

Spoon onto a greased cookie sheet (or traditional style biscuits) or divide mixture into six greased muffin tins.

Bake 10-12 minutes or until golden brown

Notes:



SERVINGS 6
PER SERVING:
FAT 6 MG
LEU 6 MG
PROTEINE 02.6
CALORIES 160

Download

RECETTES

Découvrez cette délicieuse recette de Scone de Cambrooke

SCONES



Matériel nécessaire :

- 1 fourchette ou fouet
- 1 bol à mélanger
- 1 feuille de biscuits graissée ou bolles à muffins

Suggestion de gain de temps: Cuire en feu en plus grande quantité et congeler.

Suggestion: Peut être enjoyed au petit-déjeuner – grillé ou réchauffé avec de la confiture.
Au dîner – comme base de sandwich.

Ne pas oublier: quand comme sandwich ou accompagnement avec soupe, brique ou chaudière.

Préparation

- Chauffer le four à 450 degrés F.
- Mélanger les ingrédients avec une fourchette ou fouetter jusqu'à ce qu'ils soient mélangés.
- Verser sur une feuille de biscuits graissée (pour des biscuits de style traditionnel) ou diviser le mélange en six moules à muffins graissés.
- Cuire au four 10-12 minutes ou jusqu'à ce qu'ils soient dorés.

Notes:

INGRÉDIENTS

- 1 tasse (100g) MixQuick
- 1/4 tasse – 1 C. à soupe de brasseur facile en poudre (lait d'amande, lait de soj)

PORTIONS 6
PAR PORTION:
FAT 6 MG
LEU 6 MG
PROTEINE 02.6
CALORIES 160

Télécharger

Board Member and Management Team Profile

Time to get to know those who make CanPKU work - a little bit better.

Although Frances is not a board member at this time, she has in the past been part of our board and continues to provide valuable support to our members.



Email Frances



“Volunteers don't get paid. Not because they are worthless, but because they are priceless.”

- Sherry Anderson



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

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



Further Reading:

Timely access for patients to innovative medicines - A policy change overdue: Rawson and Adams for Inside Policy | Macdonald-Laurier Institute

American Gene Technologies Attracts Investment from Ride Wave Ventures

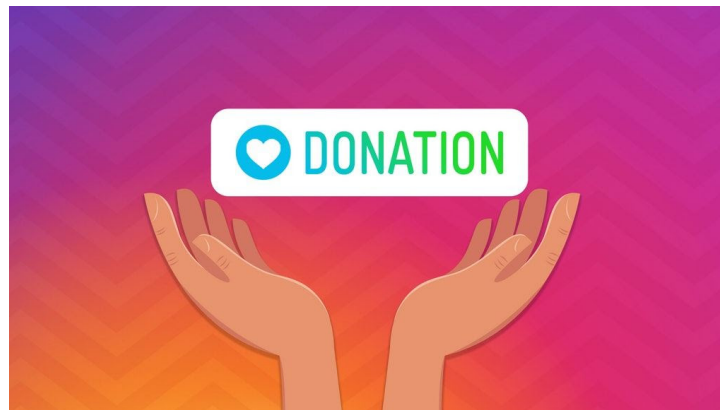
Federal government to announce high-speed internet for low-income seniors, families | CBC News

Special Thanks

Recently Received:

Pineault Family
Melissa Ferguson

[Make a Donation](#)



Visit Our 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.

B:OMARIN[®]

Eat Well, Live Well.
Aj
AJINOMOTO

CAMBROOKE

DANONE
NUTRICIA



rx **meta**
modality INSTITUTE FOR DIETETICS
Crest

**INNOVATIVE
MEDICINES
CANADA**

AmerisourceBergen
Innomar Strategies

synlogic

P/RMA
RESEARCH • PROGRESS • HOPE



 Government of Canada Gouvernement du Canada





[Click here](#) for more information on
chronicallysimple

Watch the YouTube video here

<https://youtu.be/UCETreIM1HA>



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



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.



“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

Canadian PKU & Allied Disorders Inc.

Because Knowledge Leads to Better Health

#180 - 260 Adelaide Street East, Toronto, ON, M5A 1N1, Canada

1-877-226-7581

PCU et maladies apparentées Canada inc.

Parce que la connaissance conduit à une meilleure santé

info@canpku.org

[Unsubscribe](#)