
April 2022 Newsletter Template

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 1:27 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](#)

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

[Adult Arena](#)

[Teen Time](#)

[Kids Korner](#)

[Canadian News](#)

[International Events / News](#)

[Recipes/Recettes](#)

[Patient Profile](#) (Board Member Edition)

[Resources](#)

[Your Profile on CanPKU.org](#)

[Further Reading](#)

[Donations](#)

[Sponsors Page](#)

UPCOMING EVENTS

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

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!



When you do nothing you feel overwhelmed and powerless. But when you get involved you feel the sense of hope and accomplishment that comes from knowing you are working to make things better.

- Maya Angelou



www.
canpku.org



Prairies Regional Event

Sunday, May 15, 2022 • Collicutt Centre • Red Deer, AB

Canadian PKU & Allied Disorders welcomes families and individuals to join us for a community educational event! Meet and greet with our sponsors and vendors! Interact and try new products!

Learn about...

- A first-ever Canadian patient registry for PKU and how you'll be able to participate.
- Moving beyond the PKU diet as well as a new treatment from esteemed speakers Drs. Aneal Khan & Jerry Vockley.
- PTC Therapeutics' new pivotal clinical trial available for Canadians with PKU starting from four months of age to adulthood. Coming soon, a significant trial for adults, sponsored by Synlogic, of an engineered enzyme to process Phe in the gastrointestinal tract.
- Calories and eating healthy with PKU with the Saskatchewan clinic.

Register online at www.canpku.org!

Tickets: \$25 for Members

\$50 for Non-Members

Tickets are limited...GET YOURS TODAY!

What To Expect

P - Participate Together

K - Keep Learning

U - Understand More

Meals and snacks will be provided for both traditional as well as low protein diets. Free Childcare will be provided for those 12 and under.



Zoe, Parker & Avery - AB



Marcus - MB



Kayla - AB



Tamara - BC



Lucas & Freya - AB



Victoria - SK



Amanda - BC



Patrick - AB



Rosie - BC

May is PKU Awareness Month!

CanPKU wants to take this opportunity to look back in time and appreciate some of the past that has our PKU community doing so well!

This [four-page article](#), recently published, adds context to the Early History of PKU and how became treatable and brought to light the need for newborn screening.

Click here to watch a video about the discovery of PKU made by Dr. Asbjørn Følling

Click here to watch a video that was created in the '50s to prove to England that Diet can improve PKU. (Child: Sheila Jones)

Click here to watch a video about Sheila Jones story. Anne Green wrote a book called "Unlocking the Treatment for PKU"

Click for: Robert Guthrie and the Trials and Tribulations of Newborn Screening

We thank all those who were early diagnosed for their contributions to where we are today! We also want to give a huge thank you to the companies such as Anjimoto Cambrooke, Vitaflo and Nutricia for making such progress in formula and foods since these times.

Looking Forward:

Click here for an overview of current and upcoming trials available for PKU.

Home Phe Monitor has been a dream for those with PKU for more than a decade. Aptatek Biosciences, Inc. of Princeton, New Jersey has created a prototype.

[NPKUA has offered funding](#) to help continue to move this project included in a total of [4 million seed money!](#)

We thank all those with PKU who participate in trials along with those continuing research in this field.

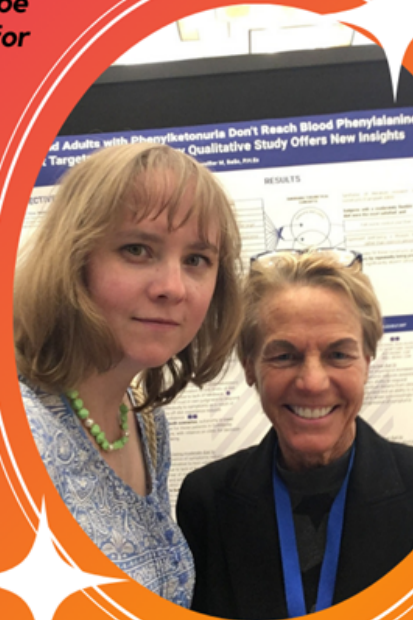
Canadian Adult PKU Patient Researcher Aims to Change the One-Size-Fits-All Diet for PKU



This is the first 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. They will be recruiting Canadian and U.S. adults with PKU for their study in July. Their story begins at Camp MagniPHEque 2017 in the kitchen

Part 1. Canadian Camper with PKU Perspective Sparks Research

Camp MagniPHEque kitchen 2017. Maria Depenweiller, Milton (Ontario patient), was busy unloading her cooler of supplies for a low-protein food demo, while Annie Prince, USA (Oregon dietitian), was assembling low-protein s'mores for the evening bonfire. Their passions about adult PKU diet therapy were remarkably similar and drew them to sharing ideas.



Dr. Bill Hanley, camp guest speaker that year had raised an intriguing research question 10 years before, 'Do all adults with PKU need continual, highly restricted diet therapy?' This was just before the PKU Guidelines for blood phenylalanine became stricter for all adults with PKU. Annie had a chance to reflect on Dr. Hanley's question, while meeting him and talking with Maria and cabinmates (adults with PKU) who expressed varying levels of success in reaching the new guidelines.

The camp experience confirmed Annie's interest to investigate this question. Maria and Annie obtained ethics approval for a small study, recruited, and consented four of the adults Annie met at camp. Together, they developed an interview guide and conducted in-depth interviews. Data analysis suggested that adults vary widely in their response to diet and blood levels and that they have learned on their own the necessary diet steps to take to prevent or reduce symptoms—irrespective of blood levels. They presented their findings, 'Why Adults with PKU Don't Reach Blood Phenylalanine Targets: An Exploratory Qualitative Study Offers New Insights,' at the 2018 Genetic Metabolic Dietitians International Meeting. It was during their presentation that they met two researchers (from Turkey and Denmark) who joined in their quest to individualize and optimize diet management for adult PKU.

Maria and Annie, along with CanPKU, wish to thank Canadians attending

Tanya and Annie, along with CanPKU wish to thank Canadians attending Camp MagniPHEque in 2017 that kicked off this research project!



Stay tuned next issue: Part 2. Improved Symptoms in Single Subject Convince National PKU Alliance to Fund Research

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.

Adult Arena

Our Adult Zooms are starting to grow!

We are excited with all the new participants. If you are 18+ with PKU these are JUST for you.

[May 19th, 2022](#)

[May 28th, 2022](#)

To ensure these events are only attended by adults, settings on your profile may need to be updated. We can help! Email tanya.chute@CanPKU.org if you are unable to register.



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!

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!



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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.

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NUTRICIA
Brought to you by Nutricia North America



Teen Time

Do you or your teen have PKU?

Born between 2004 and 2009?

We need your email!! Please send it to tanya.chute@canpku.org so we can send emails specific to teens.

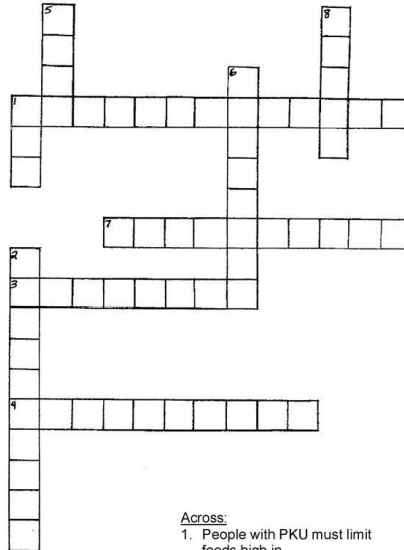


KIDS KORNER

Alicia Alligator's Crossword Puzzle

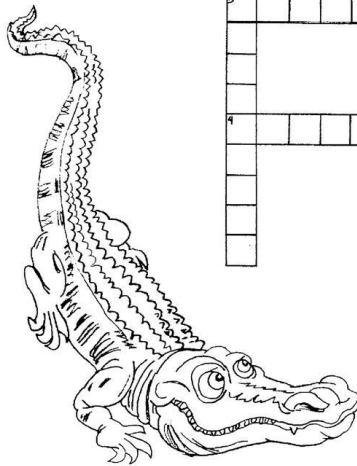
Down:

1. An abbreviation for Phenylketonuria
2. _____ is the most important part of the PKU diet for older children and adults
5. Alicia Alligator got a _____ when she laid under the plants
6. Alicia Alligator had an _____
8. When someone cannot eat a certain food, they must _____ it



Across:

1. People with PKU must limit foods high in _____
3. People with PKU eat low protein foods to stay _____
4. _____ is the most important part of the diet for babies and younger children
7. _____ breads and cereals are an important part of the PKU diet



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195
(206) 685-3015, Toll Free in Washington State 877-685-3015
<http://depts.washington.edu/pku>

Alice Alligator Crossword borrowed from Cristine M. Trahms Program for Phenylketonuria in Seattle for this resource. It can also be found online [here](#)



Riddle me this?

When do you GO at red and STOP at Green?

When you are eating a watermelon

do
THE RIGHT
THING...
EVEN WHEN
no one
IS LOOKING.

**NEED HELP
EXPLAINING PKU TO
GRANDPARENTS?**



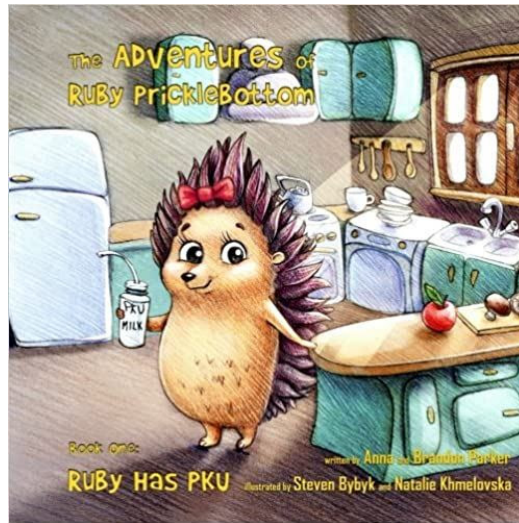
Nutricia's PKU guide provides useful information and diet tips to help grandparents better understand PKU and how they can help.

Available in English and French.



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NUTRICIA
Brought to you by Nutricia North America



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>



Canadian News

CanPKU is happy to announce:

The Macdonald-Laurier Institute Welcomes Newest Senior Fellows, Nigel Rawson and John Adams

OTTAWA, ON (April 11, 2022): We are pleased to announce that Nigel Rawson and John Adams will be joining the Macdonald-Laurier Institute as Senior Fellows.

According to MLI Managing Director Brian Lee Crowley, “MLI is fortunate to have worked with Nigel Rawson and John Adams extensively in recent years; they are precisely the kind of world-class thought leaders that we at MLI aim to attract and cultivate.

“As Canada presses forward with an unnecessary, costly, and counterproductive approach to drug policy, Canadians will depend even more on the warnings that Rawson and Adams have long provided.”

For the full article [click here](#)



International News

Synlogic Announces Data Presentations at the 2022 Genetic Metabolic Dieticians International (GMDI) Conference and Garrod Symposium

CAMBRIDGE, Mass., April 28, 2022 (GLOBE NEWSWIRE) -- Synlogic, Inc. (Nasdaq: SYBX), a clinical-stage biotechnology company developing medicines for metabolic and immunological diseases through its proprietary approach to synthetic biology, today announced that the Company will present data from its phenylketonuria (PKU) program at two upcoming medical congresses focused on inborn errors of metabolism. These include two poster presentations at the Genetic Metabolic Dieticians International (GMDI) Conference being held May 5-7, 2022 in Lake Las Vegas, NV, and a data presentation at the Garrod Symposium being held May 12-14, 2022 in Calgary, Alberta, Canada. Details are provided below.

Genetic Metabolic Dieticians International (GMDI) Conference:

- **Title:** Dietary Management Outcomes During Synpheny-1, a Phase 2 Clinical Trial of a Live Biotherapeutic, SYN1618, for the Management of Phenylketonuria
Author: Nicole McWhorter, MS, RD,
Date and time: May 5, 2022 from 5:30 – 7:00 P.M.
- **Title:** Characterization of Dietary Protein Intake in PKU Patients
Author: Ken Ndugga-Kabuye, MD
Date and time: May 5, 2022 from 5:30 – 7:00 P.M.

Garrod Symposium:

- **Title:** Reduction in Plasma Phenylalanine Levels in Patients with Phenylketonuria with Live Biotherapeutic SYN1618: Interim Analysis from an Ongoing Phase 2 Study (Encore)
Author: Marja Puurunen, MD, PhD
Date and time: May 13, 2022 from 4:30 – 6:00 P.M.

The presentations will be available in their respective sections of the Presentations and Publications page on the Synlogic website on the day of the presentations.

To access the full press release [CLICK HERE](#)

RECIPES

Check out this delicious Banana Bread Recipe from VitaFlo

VitaFlo™ Recipe

BANANA BREAD



Recipe makes
8 slices

Prep time
10 minutes

Bake time
40–45 minutes

NUTRITION INFO PER SERVING
(1/8 recipe)

Calories 190

Protein 0.7 g

Phenylalanine 29 mg

INGREDIENTS

- 1/2 cup (100 g) brown sugar
- 3 bananas, ripe, medium-sized, peeled and mashed
- 1 1/2 cups (165 g) low protein all-purpose baking mix
- 1 tsp baking powder
- 1 tsp vanilla extract
- 1/4 cup coconut milk beverage, original
- 1 1/2 tsp low protein egg replacer

DIRECTIONS

- 1 Preheat oven to 350°F.
- 2 Cream brown sugar and bananas together in a medium-sized bowl.
- 3 Add the rest of the ingredients to the banana mixture and combine.
- 4 Pour mixture into a greased 9 x 5 inch (23 x 13 cm) loaf pan.
- 5 Bake in preheated oven on the middle shelf for 40–45 minutes or until a toothpick inserted into the center of the loaf comes out clean.
- 6 Place on a wire rack and allow to fully cool.

VitaFlo
Enhancing Lives Together
A Nestlé Health Science Company

This recipe is suitable for a protein restricted diet. Be sure to check with your healthcare professional before making changes to your diet.

This recipe was analyzed using HowMuchProtein. The nutrition information could change depending on the brand of the product you choose and should only serve as a guideline. Always check the nutrition label of any product substitution to ensure it is suitable for you. Refer to labels for allergen information and suitability. All trademarks are owned by Société des Produits Nestlé S.A., Vevey, Switzerland. © 2022 Nestlé.

Download

RECETTES

Regardez cette délicieuse recette de pain aux bananes de VitaFlo

Recette VitaFlo™

PAIN À LA BANANE



La recette fait
8 tranches

Temps de préparation
10 minutes

Temps de cuisson
40-45 minutes

INFORMATION NUTRITIONNELLE PAR PORTION
(1/8 de la recette)

Calories 190

Protéine 0.7 g

Phénylalanine 29 mg

INGRÉDIENTS

- 1/2 tasse (125 ml ou 100 g) de sucre brun
- 3 bananes, mûres, de taille moyenne, pelées et écrasées
- 1 1/2 tasse (375 ml ou 165 g) de farine tout usage faible en protéines
- 1 c. à thé (5 ml) de poudre à pâte
- 1 c. à thé (5 ml) d'extrait de vanille
- 1/4 tasse (60 ml) de boisson à base de lait de coco, originale
- 1 1/2 c. à thé (7,5 ml) de substitut d'œufs faible en protéines

PRÉPARATION

- 1 Préchauffer le four à 180°C (350°F).
- 2 Mélanger le sucre brun et les bananes dans un bol moyen.
- 3 Ajouter le reste des ingrédients au mélange de bananes et brasser.
- 4 Verser le mélange dans un moule à pain de 9 x 5 pouces (23 x 13 cm), graissé.
- 5 Cuire au four préchauffé, sur la grille du milieu pendant 40-50 minutes ou jusqu'à ce qu'un cure-dent inséré au centre du pain en ressorte propre.
- 6 Placer sur une grille et laisser complètement refroidir.

Vérifier auprès de votre professionnel de la santé si cette recette est adéquate pour vous.

La base de données HowMuchProtein a été utilisée pour l'analyse nutritionnelle. Cette recette a été spécialement conçue pour un régime pauvre en protéines. Les informations nutritionnelles peuvent changer selon le marqueur du produit que vous choisissez et il ne devrait servir que de guide directeur. Rappelez-vous que 48gettes pour vérifier les informations sur les allergènes et vous assurer que les produits vous conviennent.

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Enhancing Lives Together
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Board Member Profile

Time to get to know a couple of our Board Members a little bit better.

Meet Charles Black



BOARD MEMBER, MEMBERSHIP CHAIR,
PKU ADULT



As a person with PKU, discovered on my third day of life I have had the good fortune of being caught early. In 1965, I was the first child in the province of Manitoba to be detected through the wonders of newborn screening. Since that auspicious beginning, I was taught that PKU was something that I had to learn to own and advocate for, this is why it was natural for me to align myself with CanPKU and do my part to make the lives of others easier than it was for me. As a director, I have been involved in various capacities helping with the Disability Tax Credit and as a membership coordinator. Over the last 6 years, it has been a pleasure to speak to others who have PKU. However, my greatest sense of accomplishment comes from engaging with other adults lost over the years to outdated approaches to PKU management. This is a lifetime condition and I feel that it is important to do my part however small.

[Email Charles Black](#)

Meet Cristian

Cristian is the dad of a 21 years old PKU lady. He started working with PKU families in 2002, launched "PKU Argentina" and created the first PKU website in Spanish. He moved to Ontario in 2004 looking for better treatment and care for his daughter. In 2008 he co-founded CanPKU, was Chair of the Board and currently working as the IT Manager. Cristian is passionate about helping the PKU community in Canada and Latinamerica.



[Email Cristian](#)



"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

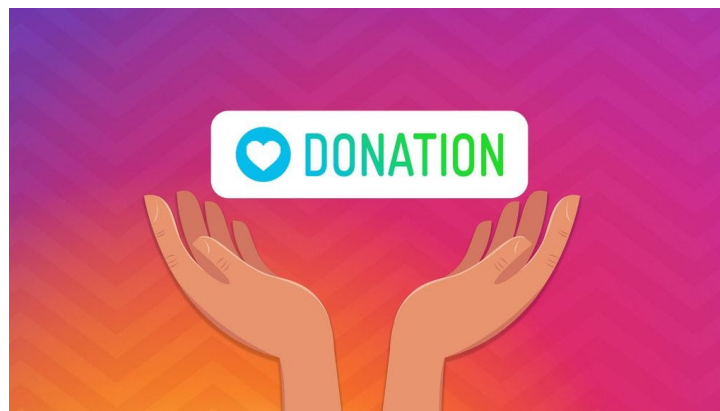
Federal government to announce high-speed internet for low-income seniors, families | CBC News

Special Thanks

Recently Received:

Pineault Family

[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.



CAMBROOKE



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Innomar Strategies

synlogic





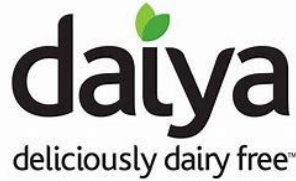
[Click here](#) for more information on
chronically**simple**

Watch the YouTube video here

<https://youtu.be/UCETreIM1HA>



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



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

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