



Tanya Chute <tanya.chute@canpku.org>

CanPKU October 2023 Newsletter

Canadian PKU and Allied Disorders <info@canpku.org>
Reply-To: Newseditor - Marjorie Guhl <newseditor@canpku.org>
To: CanPKU Master Account <info@canpku.org>
Cc: CanPKU Master Account <info@canpku.org>

Mon, Oct 16, 2023 at 12:19 PM



I hope this newsletter finds you well and that you had a wonderful Thanksgiving celebration filled with love, laughter, and delicious food surrounded by family and friends.

Warmest regards,

Marjorie Guhl
CanPKU+ Newseditor



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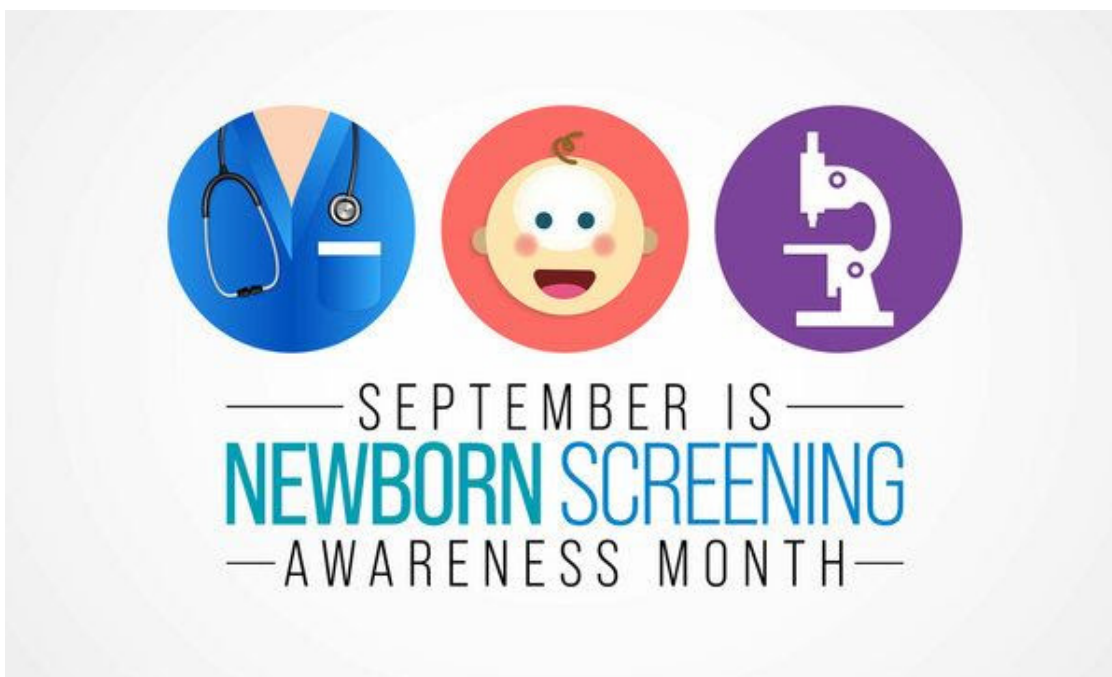
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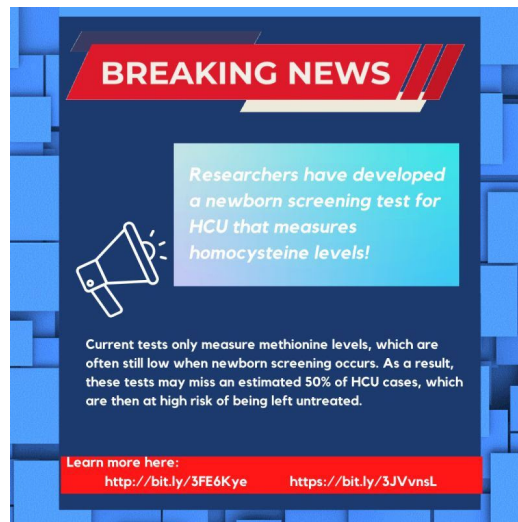


In honour of newborn screening awareness month, we wanted to highlight this news from earlier this year!

"HCU has been included on the on the list of disorders for which newborns should be screened in Canada. However, current tests only measure methionine levels, which are often still low when newborn screening occurs. As a result, these tests may miss an estimated 50% of HCU cases, which are then at high risk of being left untreated.

In order to remedy this situation, the researchers developed a newborn screening test for HCU that measures homocysteine levels. In infants with HCU, homocysteine levels usually rise before methionine levels. They almost always rise during the first few days of life -- the time when newborn screenings are usually performed -- making homocysteine a better early marker of this disease."

➔ Learn more about this exciting breakthrough!
<http://bit.ly/3FE6Kye>
<https://bit.ly/3JVvnsL>





CanPKU+ feels it is important to represent our community using REAL faces of those who are affected by each disorder, where we can. If you would like to be featured on our promotional or educational materials, flyers, website and more here is how!

1. Complete a RARE FACES photo release
2. Grab a favorite photo of the person with Rare in your household
3. Email them both to info@canpku.org

Then keep your eye out and you may just see yourself featured online or in print on our materials!

October is
HCU Awareness Month!



#HCUAwareness2023



HCU
Awareness
AMERICA



Research study by
Science 37

**Remote HCU research
options for you or
family**



CANPKU+ CANPKU+

**October is
HCU Awareness Month!**

How can you spread awareness?

Attend the
CLASSICAL HCU EL-PFDD
October 27, 2023, at 10 am to 3 pm ET
and share your HCU experience!

 INTERACTIVE LIVE POLLING | TELEPHONE CALL-INS 



HCU Awareness Month Activity List

- Change your social media picture to the HCU Awareness Ribbon
- Start a HCU fundraiser
- Share an infographic about HCU
- Share a patient story
- Share your diagnosis story
- Challenge your friends to the same amount of protein and three normal protein shakes a day #ToastToHCU
- Share a pic of an item that has the same amount of protein you can have
- Share your daily diet record -completed
- Share a low-protein meme
- Share something you wish people understood about HCU
- #HaikuforHCU—Write and share a Haiku describing life with HCU
- Wear jeans for your rare genes #ItsInOurGenes
- Wear your HCU Shirt and share a pic online—#HopeConnectsUs
- #GoBlueforHCU
- #HCUAwareness post in a public place
- Share with a stranger what HCU is and why it's important to you
- #Create4Cure—Create a work of art that brings awareness for HCU— can be a song, dance, a painting—get creative!
- #High5forHCU—List 5 ways HCU makes you a stronger, better person

Share your favorite low protein recipe! Bonus if you cook it and share a pic

Dining out, low protein style. Where do you like to eat?

Share a pic of what your grocery store haul looks like

Real cost of HCU: Grocery Cost Comparison #Medical Nutrition Equity Act. or share some patients with HCU require injectable B12. B12 on average is \$300-400 a month and most insurance companies don't cover it!

Share a picture or video capturing all the medication you take (this includes formula for those who need it).

Share a picture of your first pair of glasses, or a device that helps you navigate or communicate due to lack of vision

All states test for classical HCU, but many are still missed

Share a picture of you and a HCU buddy! Or tag a friend who is of great support

#FacesofHCU—Share a picture of you saying, I am one of the 1 in 200,000 people with HCU

#Hope4HCU—Share 4 things that give you hope and encouragement

Share the HCU timeline—if you know other facts. let us know!

Cutting Edge of HCU: Share about a therapy that is in the works!

To find additional information and resources, visit: <https://hcnetworkamerica.org/hcu-awareness-month/>

SPOTLIGHT ON CLASSICAL HOMOCYSTINURIA

NAMES:

- HOMOCYSTINURIA, HCU, CYSTATHIONINE BETA SYNTHASE (CBS) DEFICIENCY

INCIDENCE:

- 1 IN 200,000

BIOMARKERS:


- HIGH HOMOCYSTEINE AND METHIONINE

SYMPTOMS:

- STROKES, BLOOD CLOTS, LENS DISLOCATION, OSTEOPOROSIS AND MENTAL HEALTH CONCERNS

TREATMENT:

- A COMBINATION OF B6, B12, FOLIC ACID, BETAINE, LOW PROTEIN DIET AND/OR MEDICAL FORMULA



CANPKU BOARD MEMBERS NEWS

At the yearly organizational meeting of the board following the AGM, the Officers of the Board were elected:

David Brennan as Board Chair

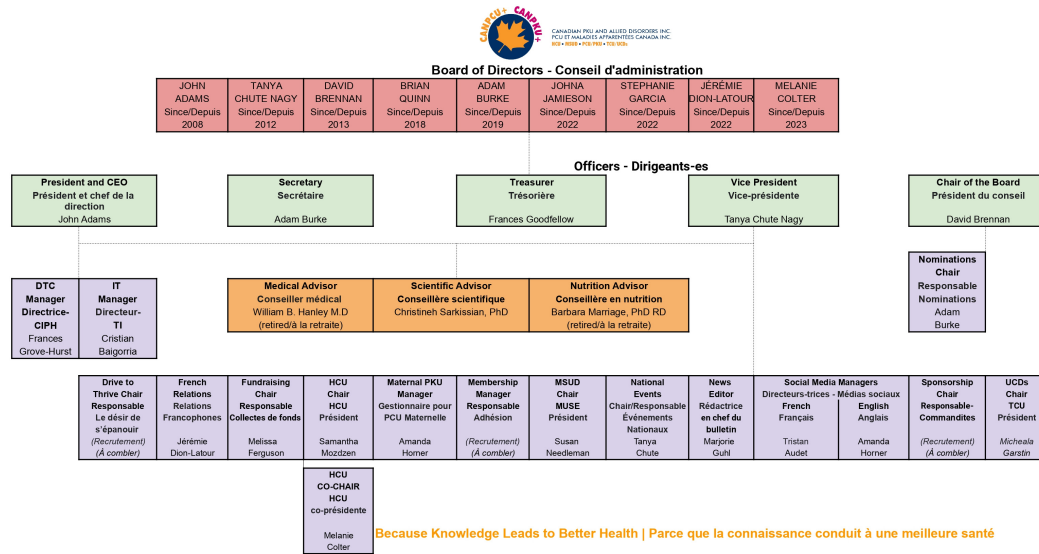
John Adams as President

Tanya Chute as Vice President

Frances Goodfellow as Treasurer

Adam Burke as Secretary

FR/EN - 2023 2024 Organization Chart / Organigramme. Final



Recruiting - Any position showing as recruiting is currently accepting Expressions of Interest. Please submit your interest to info@CanPKU.org and we will forward it for review.
 À combler - Les personnes intéressées peuvent postuler pour tout poste à combler en soumettant leur candidature à info@CanPKU.org; nous la transmettrons pour examen

Révisé le 28 Septembre 2023
 Revised Sept, 28, 2023

180-260 Adelaide St. E
 Toronto, ON M5A 1N1

At the AGM in September, Melanie Colter, an HCU mom from Vancouver, BC was elected as our new co-chair for HCU.

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

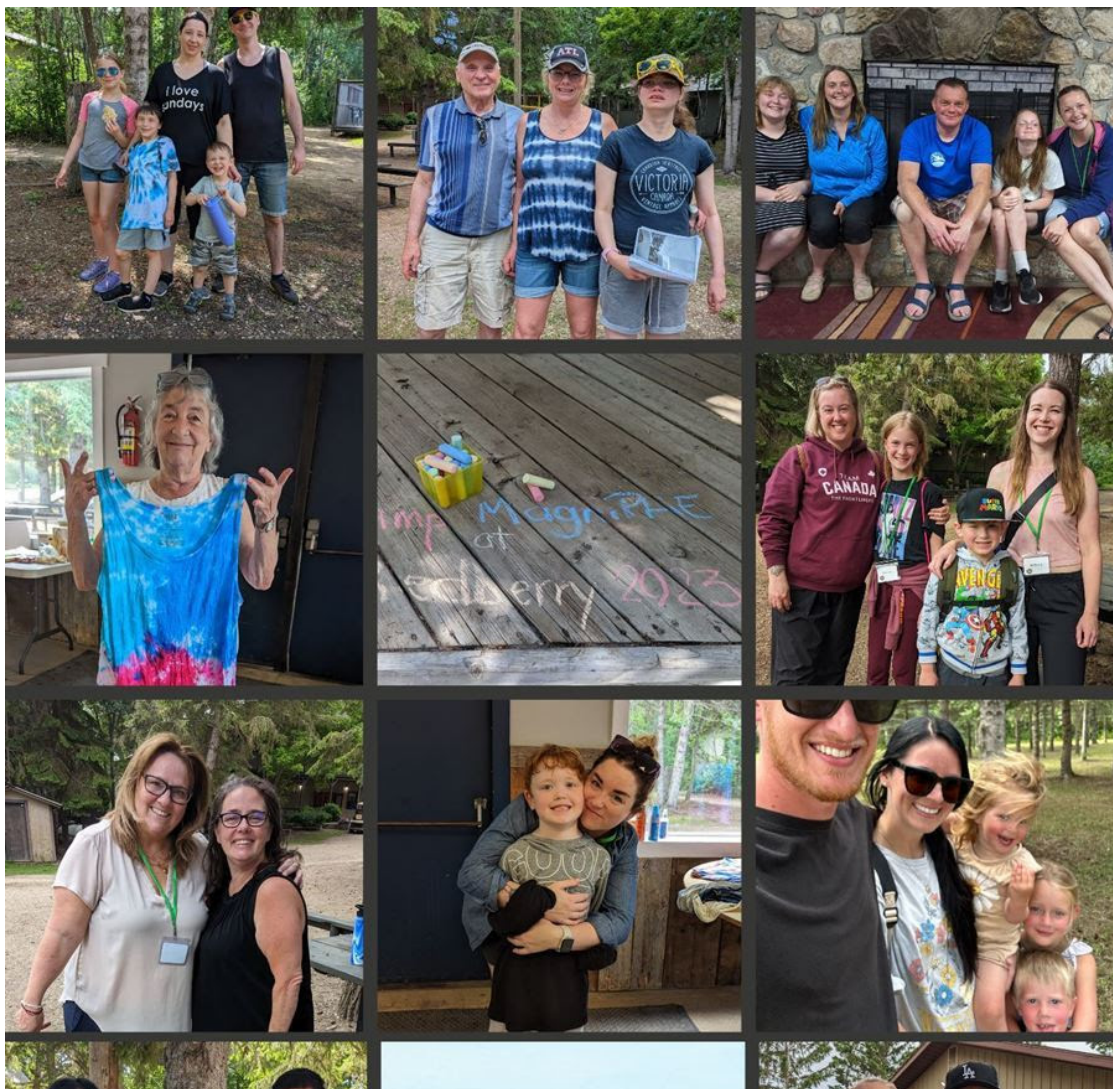
changes in his life at the age of 8 years old after this very surprising diagnosis.

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.



2023 Camp Photo Highlights





HOW MUCH PHE HALLOWEEN CANDY GUIDE

	<p>Airheads Bottlecaps Candy Necklaces Dots Fruit Runtz Fun Dip Gobstoppers Hard Candy*</p>	<p>Jolly Ranchers Hard Candy Laffy Taffy Lifesavers* Mike & Ike Nerds Pez Candy in Dispenser Pixy Stix Ring Pop</p>	<p>Salt Water Taffy Smarties (U.S. version) Sour Patch Suckers/Lolly-Pops/Dum Dums* Swedish Fish SweetARTS classic *Make sure these are not sugar-free & contain only phe-free sweeteners</p>
	<p>PER PIECE Licorice, Bites Marshmallow Ghosts Sugar Daddy, Junior Tootsie Roll Midgees Tootsie Roll Pops, Caramel, Chocolate, or fruit flavors</p>	<p>PER PACKAGE Candy Corn Jelly Beans, all flavors Skittles, all flavors Sprees Chewy Candy Starburst Fruit Chews, all flavors SweetARTS Chewy</p>	
	<p>Hershey Hugs Hershey Kisses Kraft Caramels Red Vines Black Licorice Twists Red Vines Original Red Twists Rolo Caramels in Milk Chocolate Sugar Babies, Fun Pack</p>	<p>Twizzlers Licorice Twists Twizzlers Strawberry Twists</p>	
	<p>MINI CANDY BARS \$100 Grand, 3 Musketeers, Almond Joy, Baby Ruth, Butterfinger, Hershey's Minis, Kit Kat, Milky Way, Mounds, Snickers, Twix</p> <p>PER PIECE York Peppermint Patty Reese's Peanut Butter Cup, miniature</p>	<p>PER PACKAGE Haribo Gummi Bears Jolly Rancher Gummies Junior Mints, regular size Life Saver Gummi Savers M & M's, fun size Malted Milk Balls</p>	<p>Milk Duds, 13 pieces Raisinets, 1.58 oz. bag Sugar Babies, regular size Sugar Daddy, regular size Whoppers</p>

IDEAS FOR HANDLING HALLOWEEN CANDY

- ➡ Set aside higher-phe candy for the "switch witch" who comes & brings a present on Halloween night
- ➡ Trade in higher-phe candy at the dentist or donate it at local firehouses or other organizations
- ➡ Trade higher-phe candy with friends and siblings for lower-phe options



#GIVINGTUESDAY



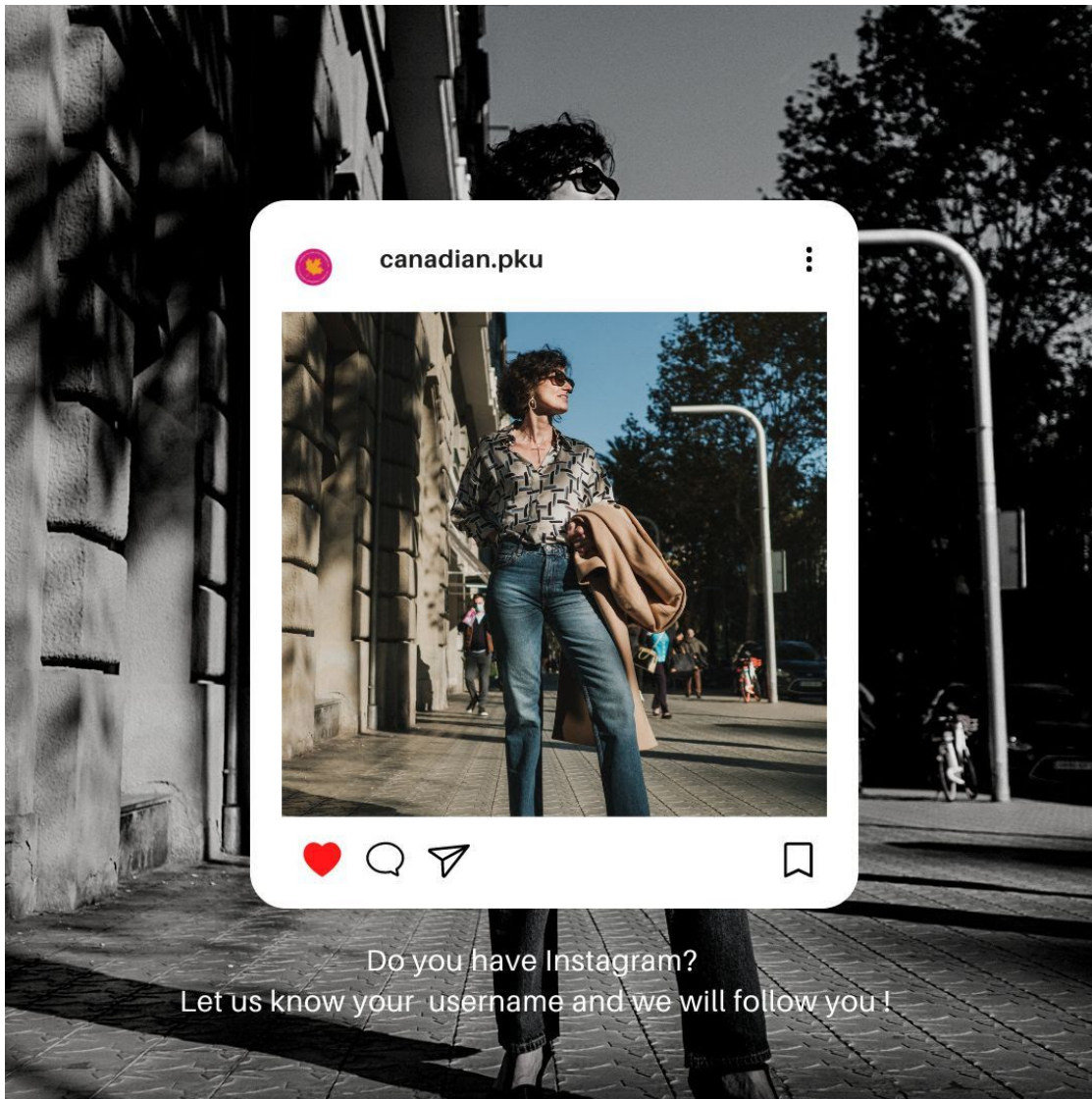
Giving Tuesday 2023!

GivingTuesday is the world's largest generosity movement. 2022 was our first year participating in GivingTuesday and we are absolutely thrilled to report that due to the extremely generous CanPKU community, we raised \$2795!!

This money goes directly towards supporting those with PKU and allied rare disorders in Canada. We were blown away by the kindness and generosity that was shown to CanPKU on GivingTuesday. Our goal was \$500 for this event as it was the first event we had hosted. We far exceeded this goal and want to say a huge THANK YOU to every person who donated, shared our posts on social media, and spread the word about this fundraiser.

Let's make 2023 an even bigger year! Details for Giving Tuesday will be posted to our social media accounts closer to the date (November 28)

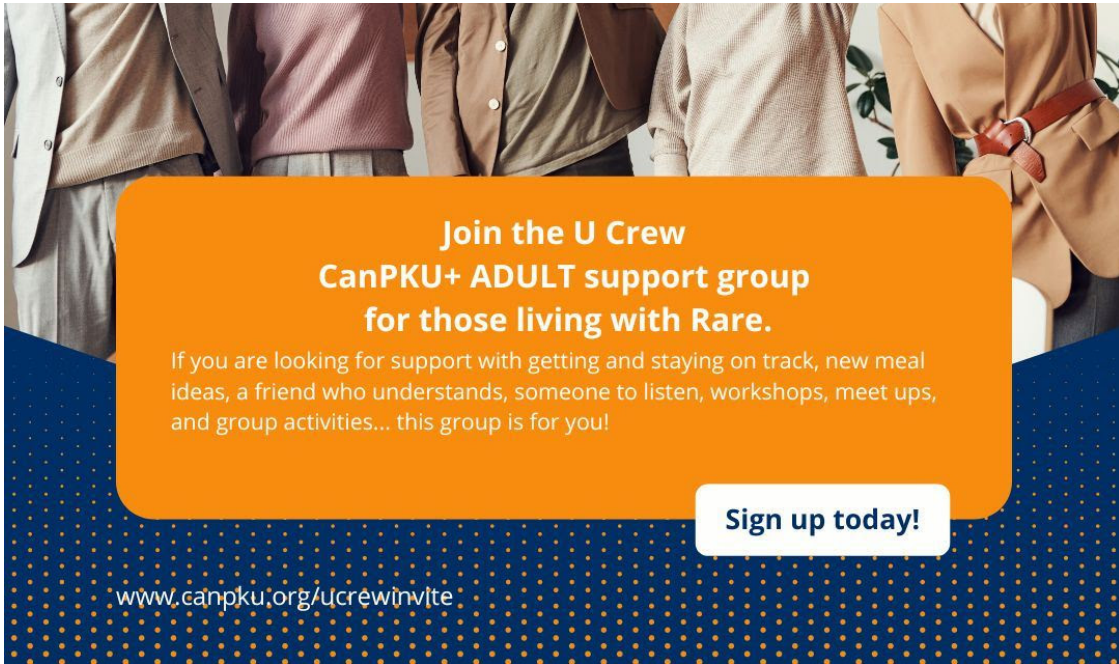
Thank you!



Join the U Crew today at CanPKU+ Open for all adults living with rare who need a listening ear, a place to talk, support each other, learn new recipes, design tools to succeed. All rare disorders are welcome (HCU,MSUD,PKU, UCDs etc)

Link: www.canpku.org/ucrewinvite





Join the U Crew
CanPKU+ ADULT support group
for those living with Rare.

If you are looking for support with getting and staying on track, new meal ideas, a friend who understands, someone to listen, workshops, meet ups, and group activities... this group is for you!

Sign up today!

www.canpku.org/ucrewinvite



We're on TikTok!

[Click here to find us!](#)

Recently received donations:

Joyce Swain

[Click to donate](#)





We hope you are doing well!

Earlier in the summer we shared with our CanPKU+ members an opportunity to participate in an online survey on medical formulas for children/youth with PKU conducted by **INFORM RARE**, a research network led from the University of Ottawa. **INFORM RARE** is planning a research study to test two different kinds of medical formula for children and youth with PKU. Before doing so, they would like to learn more about the medical diet and daily routine of children and youth with PKU, in addition to reasons for or against participating in a future research study on medical formulas. **The survey is still open**, and we invite those who are interested and eligible (see criteria below) to participate **by October 15**. We will not contact you more than 3 times. If you have already participated in this survey, thank you so much, and please disregard this letter.

To be eligible for this survey you must be:

A **child/youth** who is:

- between 12 and 18 years of age;
- diagnosed with PKU;
- currently following or has previously followed a PKU medical diet (partially or fully); and
- receiving care for PKU from a Canadian metabolic clinic

Or

A **caregiver** (e.g., parent, grandparent, foster parent, legal guardian) of a child/youth who is:

- between 4 and 18 years of age;
- diagnosed with PKU;
- currently following or has previously followed a PKU medical diet (partially or fully); and
- receiving care for PKU from a Canadian metabolic clinic

The survey should take you approximately **20 minutes** to complete. Please note that participating in this survey is **completely voluntary** and you can decide to leave at any point. Participating in the survey does not mean you will have to participate in the future study. Your decision to participate in this survey will have **no effect on your relationship with CanPKU+**. **We will not know whether you decide to participate in this survey and will not have access to your individual responses.**

To learn more about the survey and to participate, please click on the following link (recommended browser: Google Chrome): <https://redcap.link/informpku>. If you do not wish to participate, you may simply ignore any invitation that you receive.

Please feel free to circulate this information to anyone within Canada who you think might be interested in participating.

If you have any questions, please email the research coordinator Ammar Saad asaad2@uottawa.ca

Thank you for your time!
John Adams and Tanya Chute, on behalf of CanPKU+

John Adams *Tanya Chute*

Version date: 8-9-2023



Nous espérons que vous allez bien!

Plus tôt au cours de l'été, nous avons partagé avec nos membres de CanPCU+ l'occasion de participer à un questionnaire en ligne sur les formules médicales pour les enfants et les jeunes atteints de phénylcétonurie (PCU) menée par **INFORMER RARE**, un réseau de recherche dirigé par l'Université d'Ottawa. **INFORMER RARE** planifie une étude de recherche pour tester deux types de formules médicales différentes pour les enfants et les jeunes atteints de la PCU. Avant de ce faire, ils aimeraient en savoir plus sur le régime médical et

la routine quotidienne des enfants et des jeunes atteints de la PCU, ainsi que les raisons pour lesquelles ces enfants et jeunes souhaiteraient, ou non, participer à une étude future sur les formules médicales. **Le questionnaire est toujours ouvert** et nous invitons les personnes intéressées et admissibles (voir les critères ci-dessous) à y participer **d'ici le 15 octobre**. Nous ne vous contacterons pas plus de 3 fois. Si vous avez déjà participé au questionnaire, merci beaucoup et veuillez ne pas tenir compte de cette lettre.

Pour être admissible au questionnaire, vous devez être :

Un **enfant ou jeune** qui :

- est âgé de 12 à 18 ans
- est diagnostiqué avec la PCU
- suit actuellement ou a suivi un régime médical pour la PCU (partiellement ou totalement)
- reçoit des soins pour la PCU d'une clinique métabolique canadienne

Ou

Un **fournisseur de soins** (par exemple, parent, grand-parent, parent nourricier, tuteur légal) d'un enfant ou d'un jeune qui :

- est âgé de 4 à 18 ans
- est diagnostiqué avec la PCU
- suit actuellement ou a suivi un régime médical pour la PCU (partiellement ou totalement)
- reçoit des soins pour la PCU d'une clinique métabolique canadienne

Il vous faudra environ **20 minutes** pour répondre au questionnaire. Veuillez noter que la participation à cette enquête est **entièrement volontaire** et vous pouvez vous retirer à tout moment. La participation au questionnaire ne signifie pas que vous devrez participer à l'étude future. Votre décision de participer au questionnaire n'aura **aucun effet sur votre relation avec CanPCU+**. **Nous ne saurons pas si vous décidez de participer au questionnaire et n'aurons pas accès à vos réponses individuelles.**

Pour en savoir plus à propos du questionnaire et pour participer, veuillez cliquer sur le lien suivant (navigateur recommandé : Google Chrome) : <https://redcap.link/informpku>. Si vous ne souhaitez pas participer, vous pouvez simplement ignorer toute invitation que vous recevez.

N'hésitez pas à partager cette information à toute personne au Canada qui, selon vous, pourrait être intéressée à participer.

Si vous avez des questions, veuillez envoyer un courriel au coordinateur de recherche Ammar Saad à l'adresse asaad2@uottawa.ca

Nous vous remercions de votre temps!

John Adams et Tanya Chute, au nom de CanPCU+



Date de la version : 8-3-2023












CanPKU+ acknowledges and thanks PKU mom Arlene McDonald of Carberry, MB for her volunteer dedication and service as a Board member and earlier as our newsletter editor and as one of our “warriors” unjustly denied the DTC for her child who successfully appealed to the Tax Court of Canada, paving the way for the pro-metabolic diseases treated by medical diet amendment to the Income Tax Act.

Thank you, Arlene.

DISABILITY TAX CREDIT (DTC) Did you know?

-  We have helped + 150 adults and families with a child or children living with rare disorders to receive the Disability Tax Credit.
-  **No one who followed our advice has been refused!** In the early period, there were some rejections - all successfully appealed.
-  **You don't have to be “disabled” to be eligible.** Most approvals have been for people on a time-consuming therapy, the “medical diet”, under clinic guidance, to prevent becoming significantly impaired, mentally or physically.
-  In mid-2022, 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”.**
-  The DTC opens the door for several other benefits and credits, which vary for children or adults.
-  The DTC can be made **retroactive for up to ten years. You may get a bunch of tax rebates!**
-  Clinics and other patient groups are asking for our help with DTC applications for other conditions... and we are helping them get approved!



**Have you applied for the DTC?
What are you waiting for?
We can help!**



L'autre côté français.

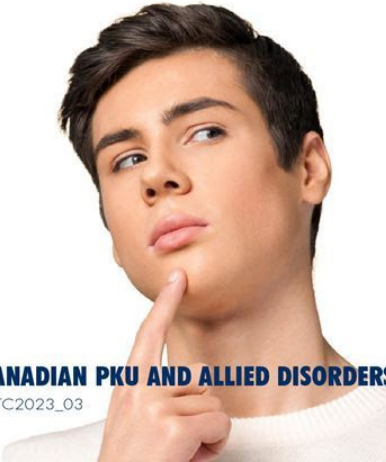
www.CanPKU.org
Because Knowledge Leads to Better Health

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

DTC2023_03

CRÉDIT D'IMPÔT POUR PERSONNES HANDICAPÉES (CIPH) Le saviez-vous ?

- Nous avons aidé plus de 150 adultes et familles avec un enfant ou des enfants vivant avec la PCU à demander et à recevoir le crédit d'impôt pour personnes handicapées.
- **Aucune personne ayant suivi nos conseils n'a été refusée!** La plupart des demandes approuvées concernaient des personnes qui suivent, sous supervision médicale, un régime alimentaire exigeant en temps, qui vise à prévenir les déficiences physiques ou intellectuelles.
- Au milieu de 2022, le Parlement a modifié la partie sur le CIPH de la Loi de l'impôt sur le revenu afin de reconnaître **que les personnes qui consomment des formules médicales et/ou des aliments médicaux sont admissibles dans le cadre de la « thérapie de maintien de la vie ».**
- L'admissibilité au CIPH ouvre la porte à plusieurs autres avantages et crédits qui varient pour les enfants ou les adultes. Le DTC peut devenir **rétroactif jusqu'à dix ans. Vous pourriez bénéficier de nombreuses remises fiscales!**
- Les cliniques et autres groupes de patients demandent notre aide pour les demandes de CIPH pour des personnes souffrant d'autres conditions, et nous aidons à les faire approuver!



**Avez-vous demandé le CIPH?
Qu'attendez-vous?
Nous pouvons aider!**

English on other side.

www.CanPKU.org

Parce que la connaissance mène à une meilleure santé

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

DTC2023_03

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.



The graphic features three vertical panels: a snowman on the left, a forest of tall trees in the center, and a campfire on the right. The text 'CAMP MAGNIPHEQUE' is centered in blue, with 'just got cooler' in a cursive font below it. The event details 'January 12-14, 2024' and 'Ganaraska Forest, Ontario' are at the bottom left. The CanPKU logo and website are at the bottom right.

**CAMP
MAGNIPHEQUE**
just got cooler

January 12-14, 2024
Ganaraska Forest, Ontario

 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

Zoom with us!
Watch for upcoming dates



ONLINE EVENTS

U Crew - Support Group

2023-11-15 6:00 PM

Virtual

Parent of Rare Cafe - Support Group

2023-11-18 2:00 PM

Virtual

Adult/Teen Cafe - Support Group

2023-11-18 3:00 PM

Virtual

Please ensure your CanPKU account indicates if you're an adult or teen with Rare or a parent of Rare.

You may email info@canpku.org if you are not sure. Email will ONLY go out to those who have identified themselves as this type of connection to rare.



Cheers to a successful ON event! Thank you to all who joined us.



Fall Recipes

This delicious, cozy, fall recipe is from the Cook for Love website.

"Cook for Love is a non-for-profit dedicated to the metabolic community. Our mission is to empower members of our community to improve their health through cooking and education. Our goal is to dispel the myth that, given severe dietary restrictions, people on low protein diets must settle for less."

-Cook for Love website



Prep time: 45 min

Cook time: 45 min

Ready in: 1 hr 30 min

Author: Brenda Winiarski

Carrot Cake is a tradition in our house for Easter and a tie for Strawberry Shortcake for my Mom's favorite birthday cake. I knew I had to get the recipe just right or my Mom would let me know it. This is a super moist and flavorful cake that all of your guests will enjoy. You can use store bought canned cream cheese frosting or make the sour cream one on the site, which is also delicious.

- 60 g Dried cranberries 12mg

- 60 g Orange Juice 7mg
-
- 325 g Cook for Love Baking Mix 190mg
- 10 g Baking Soda
- 5 g Baking Powder
- 3 g Salt
- 6 g Cinnamon, ground 6mg
- 1 g Nutmeg, ground 2mg
- 1 g Ginger, ground 2mg
- 1 g Cloves, ground 1mg
- 43 g Jell-o Instant Vanilla Pudding
-
- 50 g Large Egg 340mg
- 200 g Sugar
- 110 g Brown Sugar 4mg
- 60 g Mayonnaise 40mg
- 113 g Small jar pureed baby food carrots 20mg
- 5 g Vanilla Extract
- 6 g Orange Zest 3mg
-
- 240 g Canola Oil
- 227 g Crushed pineapple in juice, 1 small can
35mg
- 305 g Carrots, raw, whole medium, shredded
67mg

Instructions

Step 1

If you are making the Browned Butter Sour Cream Frosting, brown the butter now and refrigerate.

Step 2

Preheat oven to 350. Grease a 9 x 13 inch pan.

Step 3

Place raisins in a small pot with $\frac{1}{4}$ cup of orange juice (use the orange you will need to zest). Bring to a boil and simmer for a few minutes to plump up the dried cranberries. Set aside.

Step 4

Sift the baking mix, baking soda, baking powder, salt, jell-o pudding and spices using a triple sifter.

Step 5

Place the egg in the large bowl of a mixer. Beat on medium high speed with wire whisk attachment for two minutes, or until light in color and thickened. Add the sugars 1 tablespoon at a time, taking about 4 minutes to add it all. Add the mayonnaise, vanilla, orange zest and baby carrots. Whip for another two minutes.

Step 6

Turn the mixer down to medium. Slowly pour the oil in a steady stream. Beat for one to two minutes until the oil is completely incorporated.

Step 7

Change to a paddle attachment. Add the starch mixture all at once, blending for about 30 seconds on a low speed. Add the pineapple with juice, blend again. Using a spatula, fold in the carrots and raisins. Pour the batter into prepared pan,

smoothing the surface with the spatula.

Step 8

Bake for 50 to 55 minutes. A piece of raw spaghetti should come out clean when inserted in the center. Cool the pan on a rack. After 20 minutes, carefully invert the cake onto a cooling rack (place rack on top of pan and gently flip). When completely cool invert it back to serving plate and frost.



Carrot and squash soup with ginger
Perfect for those days when you need a warm hug of a meal.

Nutrition Information	
Per <i>recipe</i> (5 cups)	
Calories	612 kcal
Protein	8.7 g
Phenylalanine	368 mg
Tyrosine	294 mg

Nutrition Information	
Per <i>serving</i> (1¼ cups)	
Calories	153 kcal
Protein	2.2 g
Phenylalanine	92 mg
Tyrosine	74 mg

Nutrition information does not include GMP MIX-IN.

Recipe and food photography by Akeela Jakhura.

**Do you have a favorite recipe?
Send them to us by filling out the form below.
This can be found [here](#) on our website.**

Recipe name: _____

Serves: _____

Preparation time: _____

Cooking time: _____


Ingredients

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Preparation

Notes









THE CANADIAN PKU REGISTRY

LAUNCHING SOON!

What is a patient registry?

A database that stores information about a group of patients who have the same disease.

www.pkuregistry.ca



What should I expect?

You and your caregiver will complete surveys about your health.

Who can join?

Caregivers sign up on behalf of patients diagnosed with PKU, 18



years old and younger, receiving
healthcare in Canada.
Participation is voluntary.



Postcard Version 1, August 15, 2023 This registry is approved by the CHEO Research Ethics Board

hello

We want to be sure you know about this exciting news and be up to date on everything you need to do in order to participate!

Updates and Articles of Interest

Clinical Trial for Phenylketonuria (PKU)

IRB Approved at the Protocol Level
Apr 3, 2023

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#36849987.1

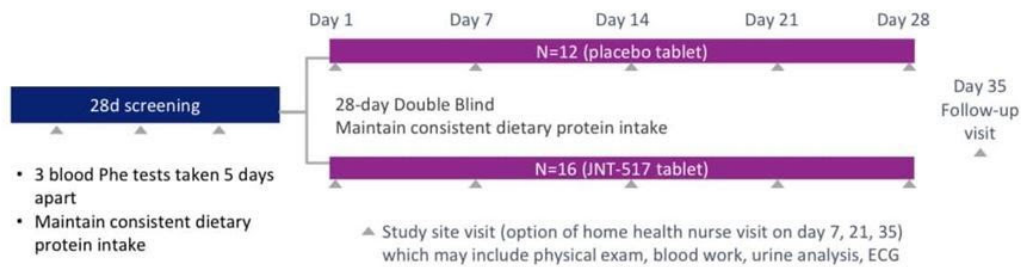


Jnana Therapeutics is developing a novel, orally administered medication for the potential treatment of PKU. SLC6A19 is the neutral amino acid transporter which is responsible for reabsorption of Phe from the proximal renal tubule and absorption of Phe in the small intestine. JNT-517 is an investigational oral small molecule inhibitor of SLC6A19 and is designed to block renal Phe reabsorption resulting in potentially increased urinary Phe excretion.

A Phase 1b clinical trial (JNT517-101) is being conducted of JNT-517 to assess the safety, tolerability, and effect on urine and blood levels of neutral amino acids (including Phe). The study is enrolling approximately 28 participants with PKU across 14 sites in the U.S. and Australia.

Key eligibility criteria include:

- PKU diagnosis
- Adults (ages 18-65 years)
- At least 2 blood Phe values > 600uM in the past year
- Currently not taking or willing to stop taking any PKU medications (i.e., Palynziq, Kuvan) or large neutral amino acid supplements before participating in the trial
- Not participating in other clinical trials of investigational treatment



To learn more about the study or to refer patients, please see clinicaltrials.gov (NCT05781399) to contact the nearest study site.

For questions, please contact clinicaltrials@jnanatx.com



Version 2 approved 29Mar2023
JNT-517 is an investigational therapy. Safety and efficacy have not been established by any health authority

PTC Therapeutics to Present Recent Data for Sepiapterin at the Society for the Study of Inborn Errors of Metabolism (SSIEM) Annual Symposium

<https://www.prnewswire.com/news-releases/ptc-therapeutics-to-present-recent-data-for-sepiapterin-at-the-society-for-the-study-of-inborn-errors-of-metabolism-ssiem-annual-symposium-301910660.html>

NIH Awards Penn Medicine and Children's Hospital of Philadelphia \$26 Million Grant to Develop Therapies for Rare Newborn Genetic Diseases

<https://www.penmedicine.org/news/news-releases/2023/august/penn-team-seeks-to-create-treatments-for-3-rare-genetic-diseases>



Canadian News

Waiting for new drugs for rare disorders in Canada – part 2, health technology assessment: Nigel Rawson and John Adams for Inside Policy

English Article: <https://macdonaldlaurier.ca/waiting-for-new-drugs-for-rare-disorders-in-canada-part-2-health-technology-assessment-nigel-rawson-and-john-adams-for-inside-policy/>



Synpheny-3, a clinical trial for adults living with PKU, is now recruiting in Canada!

If eligible, people can participate by going to a clinical trial site [OR](#) through a combination of in-person and virtual visits.

Scan the QR code to learn more.

Synlogic Clinical Leadership Team



@Synlogictx

Angela Kurtz,
MS, RD, CDNNeal Sondheimer,
MD, PhD

synlogic

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



so sweet to be
ONE!

We want to celebrate with you!



CAMBROOKE



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PCU ET MALADIES APPARENTÉES CANADA INC.
Because Knowledge Leads to Better Health
Parce que la connaissance mène à une
meilleure santé
www.CANPKU.org

To receive a first years birthday gift
for your little one with Rare
Email to info@canpku.org

Please be sure to include parents name
and email as well as the birthday child's
name and birthday.

*Did we miss their birthday? Let us know. All first birthdays celebrated this year will qualify.



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*Supplemented with amino acids




PRODUCT INFO & INGREDIENTS

Available in Coffee Mocha and Vanilla
 8.5 fl. oz. per carton


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THE NUTRITION THEY NEED, THE TASTE THEY DESERVE



DHA

Includes DHA, a nutrient typically lacking in the PKU diet¹²



FIBERS

Each serving provides 1.5 g of soluble fiber to help meet daily fiber needs.



GREAT TASTE

PKU formula made with GMP are known for their mild taste and may help with feeling full³⁻⁵



EASY TRANSITION

Vanilla or Plain flavor for easy transition from other Nutricia products



Only Nutricia provides GMP-based PKU formula in your choice of can or single-serve pouch

PhenyAde® GMP Drink Mix is a specialized food for the dietary management of Phenylketonuria (PKU) and must be used under medical supervision.
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L'ALIMENTATION DONT ILS ONT BESOIN, LE GOÛT QU'ILS MÉRITENT



ADH

Inclus de l'ADH, un nutriment important souvent manquant dans le régime alimentaire PCU



FIBRES

Chaque portion fournit 1,5 g de fibres solubles pour aider à satisfaire les besoins quotidiens en fibres.



EXCELLENT GOÛT

Préparations pour la PCU contenant des glycomacropéptides (GMP) reconnues pour la douceur de leur goût et pouvant aider les patients à se sentir rassasiés



TRANSITION FACILE

Saveur de Vanille ou Nature (sans arôme) assurant une transition facile à partir d'autres produits Nutricia



Seule Nutricia offre une préparation pour la PCU à base de GMP en boîtes ou en sachets de portion individuelle – À vous de choisir!

PhenyAde® GMP Drink Mix est une préparation spécialisée pour la prise en charge nutritionnelle de la phénylcétonurie (PCU) et doit être utilisée sous supervision médicale.
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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



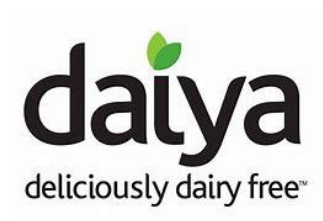
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Our sponsors are listed in the order that they began to support CanPKU's efforts. This order does not represent the dollars they may contribute.





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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*

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