



**As we look back on the past year, we are filled with gratitude for the support and generosity of our community. Together, we had a successful Giving Tuesday campaign to wrap up 2022, and for that, we cannot thank you enough.**

**We saw our community come together to support one another in ways both big and small, and we are truly inspired by the kindness and generosity that was shown.**

**We would like to take this opportunity to wish you all a happy and healthy new year. We look forward to continuing to work together to make a positive impact on the PKU community and beyond.**

**Thank you for your continued support and we look forward to a successful 2023.**

**Warmest regards,**

**Marjorie Guhl, CanPKU News Editor**





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INFORM RARE

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CanPKU Sponsors





# 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).**

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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 à la recherche 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 informer.



# volunteers needed

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## NEW!

Welcome to our new Q&A feature. Every month we'll ask for your questions! In the following issue, we'll post the responses we receive.

### January question:

What is your biggest tip/piece of advice when eating out and still sticking to your diet?

## DTC

### **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](http://www.CanPKU.org)**

**Because Knowledge Leads to Better Health**

DTC2022\_10

# 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](http://www.CanPKU.org)**

Parce que la connaissance mène à une meilleure santé

CIPH2022\_10







**Did you know HCU is under Canadian PKU and Allied Disorders umbrella?**

HCU stands for Homocystinuria.

We are looking to meet people who have HCU and are living in Canada.

Tell us about the YOU in #HCYOU

Email [HCU@CanPKU.org](mailto:HCU@CanPKU.org)

**#HCYOU**



**Saviez-vous que PCU et maladies apparentées Canada soutient également les personnes atteintes d'homocystinurie et de leucinose?**

Nous cherchons à rencontrer des personnes vivant au Canada qui ont reçu un diagnostic d'homocystinurie ou de leucinose.

Pouvez-vous nous aider à entrer en communication avec cette communauté?

Courriel  
[HCU@CanPKU.org](mailto:HCU@CanPKU.org)  
[MSUD@CanPKU.org](mailto:MSUD@CanPKU.org)

**#PCUnite**

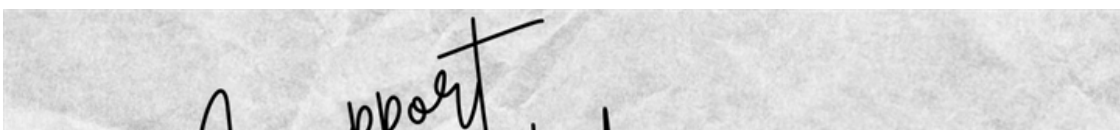
# Fundraising Updates

CanPKU participated in GivingTuesday, which is the world's largest generosity

movement, on November 29th, 2022. This 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 will go directly towards supporting those with PKU and allied rare disorders in Canada. I am blown away by the kindness and generosity that was shown to CanPKU on GivingTuesday. I set a goal of \$500 for this event as it was the first event I had hosted after joining the CanPKU team and I really wasn't sure what to expect. We far exceeded this goal and I 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. I'm looking forward to future fundraising events and supporting the CanPKU community. Please reach out if you have any questions about how you can help with fundraising or if you'd like to host a fundraising event. Keep an eye out for the rebranding of our PINS 4 PKU fundraiser which will be released soon. - Melissa Ferguson, Fundraising Chair.

Le 29 novembre 2022, CanPKU a participé à MardiJeDonne, qui est le mouvement de générosité le plus important au monde. C'était notre première année de participation à MardiJeDonne et nous sommes très fiers de vous annoncer que grâce à la communauté extrêmement généreuse de CanPKU, nous avons ammassé 2795\$! Cet argent sera utilisé pour supporter directement ceux qui ont la PCU et les maladies apparentées au Canada. Je suis épatée par la gentillesse et la générosité qui ont été démontrées à CanPKU lors de la journée MardiJeDonne. J'avais établi un objectif de 500\$ pour cet événement, car c'était le premier événement que j'ai organisé après avoir rejoint l'équipe de CanPKU et je ne savais pas trop à quoi m'attendre. Nous avons grandement dépassé cet objectif et je voudrais dire un énorme MERCI à chaque personne qui a donné, qui a partagé nos publications sur les réseaux sociaux et qui a passé le mot à propos de cette levée de fonds. Si vous avez des questions sur comment vous pouvez aider avec nos collectes de fonds ou si vous aimeriez organiser un événement de levée de fonds, veuillez s'il-vous-plaît nous contacter. Restez aussi à l'affût de la nouvelle image de notre événement PINS 4 PKU qui sera disponible bientôt.

- Melissa Ferguson, Présidente responsable des collectes de fonds.

A close-up photograph of a handwritten signature in black ink on a light-colored, textured paper. The signature is written in a cursive style and appears to read 'Melissa Ferguson'. The ink is dark and the paper has a slightly grainy texture.

"I support  
CAMP KU"

"Please give to  
Edmonton PKU.  
Branch In thanks  
for supporting my  
niece."

"For Leni "

"Great  
initiative to  
take part in  
Giving  
Tuesday"

"For Jack"

"SUPPORTING  
OUR  
GRANDSON,  
BEN BURKE  
THANK YOU"

"Thank you for  
your support  
and ongoing  
advocacy for  
people  
experiencing  
PKU.

Your work is  
endlessly  
meaningful"

"Thanks for  
uniting us  
PKU families  
together and  
continuing to  
spread  
awareness for  
our loved  
ones."







# THANKS FOR YOUR HELP!

YOUR HELP IN OUR FUNDRAISING EFFORTS ARE APPRECIATED!



#WeCanPKU #PCUnite



**Thank you to all of our donors!**

Tara Nicholls

Brenda Fuentes

Chad Styre

David Pinault

Susan Wilson

Rebecca Goorts

Rachel Goorts

Rahm Glezos

Greg Weeks

Jennifer Burke

Mari-Lynne Tota

Robert Harris

Herb Guhl

Barbara Marriage

Marjorie Guhl

Charles Black

David Brennan

John Adams

Cali Scott

Paul Pietrkiewicz

Liv Cook

Veronika Moore

Connie Cook

Carol Johnston

Nick Ebbadi-Cook

Bev Goorts

Courtney Graham

Jenna Goorts

Abbey Leimgardt

Tanya Chute Nagy



WOULD YOU LIKE TO HOST A  
FUN BOWLING EVENT AND SUPPORT CANPKU  
AT THE SAME TIME? THEN LET'S TALK ABOUT

**SPARE FOR RARE!**

CONTACT MELISSA AT  
[FUNDRAISING@CANPKU.ORG](mailto:fundraising@canpku.org)  
TO LEARN MORE ABOUT THIS AMAZING  
FUNDRAISING OPPORTUNITY

### 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

Joyce Swain

Adriano Tommasino

[Click to donate](#)

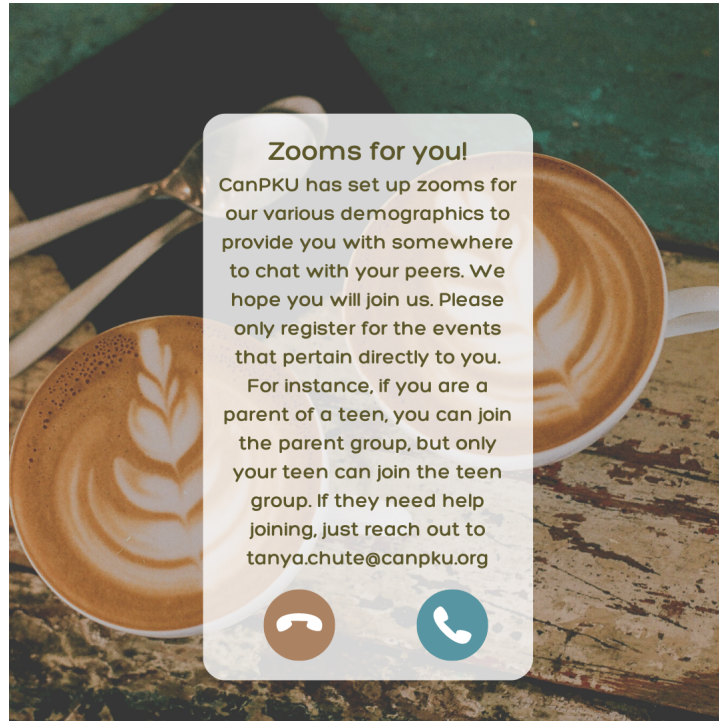
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THANK  
YOU

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# Zoom with us!

## Watch for upcoming dates





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

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

Feb 4th

March 16

April 15

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

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

Feb 15

March 4

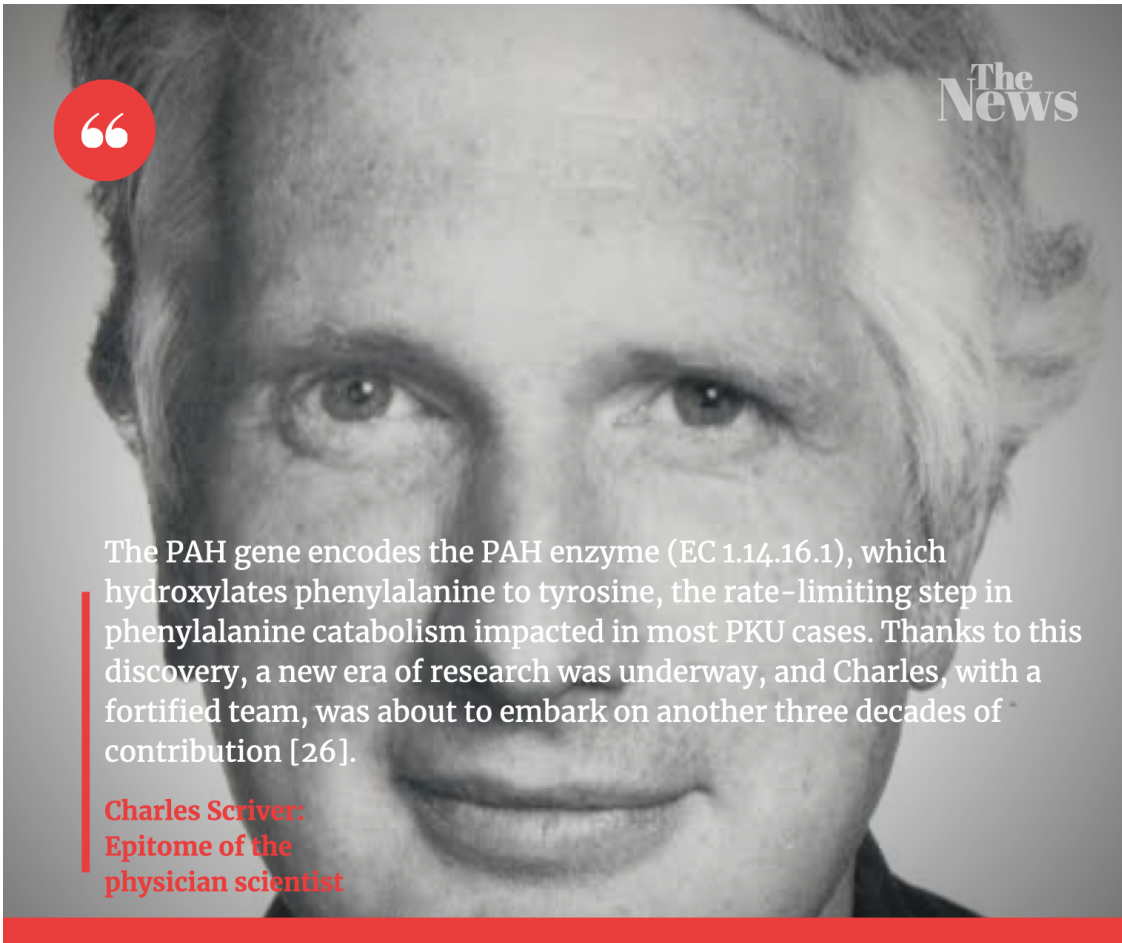
April 4

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

Feb 4

March 4

April 15



The PAH gene encodes the PAH enzyme (EC 1.14.16.1), which hydroxylates phenylalanine to tyrosine, the rate-limiting step in phenylalanine catabolism impacted in most PKU cases. Thanks to this discovery, a new era of research was underway, and Charles, with a fortified team, was about to embark on another three decades of contribution [26].

**Charles Scriver:**  
Epitome of the  
physician scientist

A short biography of Dr. Charles Scriver

[Click for full article](#)

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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.

**Save the Date:**  
**2023 CanPKU Events**

**MAY**

**BC/YUKON EVENT  
(VANCOUVER, BC)**

**13**

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.

**EN PERSONNE - ÉVÉNEMENT RÉGIONAL  
IN PERSON - REGIONAL EVENT**

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

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



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

# CAMP MAGNIPHEQUE

Save the date for June 2-4th, 2023  
Taking place near Saskatoon, SK



#CampMagniPHEque

Everyone welcome! 

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>

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# feature Story

"The purpose of this blog is to provide resources and information about Phenylketonuria, but above all it is a site for sharing ideas, tips and suggestions to facilitate the diet management of active adults."

"Ce blogue a pour objectif de fournir des ressources et quelques informations relatives à la Phénylcétonurie, mais se veut surtout un site de partage d'idées, de conseils et suggestions pour faciliter la gestion du régime pour des adultes actifs."

-Tristan Audet



## TEACHING THE BASICS TO OUR PKU CHILD

"It can be quite a challenge! I myself have a 3-year-old daughter and I have a whole range of lessons to teach her. The importance of vegetables, of eating good foods, of not doing stunts on the couch, etc. Not always easy, especially with her little rebellious mind. What always works best is when what I say is clearly explained, makes sense and above all, is fun."

## APPRENDRE LES BASES À SON ENFANT PCU

Ça peut représenter tout un défi! J'ai moi-même une fille de 3 ans et j'ai toute une panoplie d'apprentissages à lui inculquer. L'importance des légumes, de manger des bons aliments, de ne pas faire des acrobaties sur le divan, etc. Pas toujours facile, surtout avec son petit esprit rebelle. Ce qui fonctionne le mieux, c'est toujours lorsque ce que je dis est clairement expliqué, a du sens et surtout, est amusant.

[Click for full article and more!](#)

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**A Success Story: Turning the Disability Tax Credit into the  
Prevent Disability Tax Credit**



Hello!

My name is Richelle and our family is based out of the greater Vancouver area. My husband and I have two kids, a daughter who is 7 and a son who just turned 6. Both have PKU but it is not slowing them down! They are in competitive swimming and even our little kindergartener son has mastered the 25 meter deep end pool! Our daughter who is in Grade 2 loves reading, she is currently reading at a Grade 4 level. We are so proud of our PKU kids!

Back in 2015 we welcomed our daughter and right before her first birthday, in May of 2016, CanPKU held conference for PKU awareness day. At that conference we met a bunch of amazing families, tried out low protein foods and we learned about the DTC. At that point CanPKU said it was about a 50/50 chance to get approved for the DTC.

A week after we started the application process. My son with PKU was not born yet so this application was for my daughter only.

Our metabolic team at children's hospital helped us at the time and the nurse even saved a previous application of one that got approved. She used it as a template for ours. We were hopeful however we got denied.

I was still optimistic at that time, since I have heard of families who re-apply at an older age and get approved! I was told by someone that it could possibly be because babies require 24/hour care regardless but school age is when it has more of a social impact?

Fast forward to 6 years later and now I have two PKUers in elementary school! I was shocked to learn that younger PKUers were getting approved for the DTC, and the success stats had largely improved. So we decided to re-apply!

I am so thankful for the amazing connections in the PKU community! It was Marjorie, CanPKU's new editor, who reached out and encouraged me to use the resources through the CanPKU and get in touch with John Adams and Frances Grove-Hurst!

Marjorie helped me put together a spreadsheet for the application and then both John and Frances were quick to help me, step by step!

After a long wait (on the governments end) both kids got approved for the DTC!! We later found out that the backpay we received was only for the 3 years and in order to get the rest we had to fill out another form.

After more waiting we received the remaining portions of the DTC!

We are so thankful for all of the help and support from CanPKU during this application process! We cannot express how grateful we are!

If you have previously been denied, please reach out to the wonderful people at CanPKU!!!





Bonjour!

Mon nom est Richelle et ma famille et moi habitons dans la région du grand Vancouver. Mon mari et moi avons deux enfants, une fille de 7 ans et un fils qui vient d'avoir 6 ans. Les deux ont la PCU, mais cela ne les arrête pas! Ils sont en natation de compétition et même notre fils à la maternelle maîtrise déjà la piscine profonde de 25 mètres! Notre fille qui est en deuxième année aime lire, elle est présentement à un niveau de quatrième année. Nous sommes si fiers de nos enfants PCU!

En 2015, nous avons accueilli notre fille et juste avant son anniversaire, en mai 2016, CanPKU a tenu une conférence pour la journée de la sensibilisation à la PCU. À cette conférence, nous avons rencontré plusieurs familles géniales, nous avons essayé des aliments faibles en protéines et nous avons appris sur le CIPH. À ce moment, CanPKU nous a dit qu'il y avait environ 50% de chances que notre demande pour le CIPH soit approuvée.

Une semaine après le début du processus d'application. Mon fils avec la PCU n'était pas encore né, donc l'application était seulement pour ma fille.

Notre équipe métabolique au Children's hospital nous a aidé à ce moment et l'infirmière avait même sauvegardé une application précédente qui avait été approuvée. Elle a utilisé un gabarit pour la notre. Nous étions plein d'espoir, mais la demande a été refusée. J'étais tout de même optimiste à l'époque, puisque j'avais entendu parler de familles qui réappliquaient plus tard et dont la demande était finalement acceptée! Quelqu'un m'a dit que ça pourrait être à cause que les bébés ont besoin d'une attention 24h sur 24 de toute façon, mais à l'âge scolaire les impacts sociaux se font plus ressentir?

Si on avance dans le temps, 6 ans plus tard, j'ai maintenant deux enfants PCU à l'école primaire! J'ai été surprise d'apprendre que des enfants PCU plus jeunes ont été approuvés pour le CIPH, et les chances de succès ont largement augmenté. Nous avons donc décidé de réappliquer!

Je suis si reconnaissante pour les connections incroyables de la communauté PCU! C'était Marjorie, l'éditrice des nouvelles CanPKU, qui m'a contacté et qui m'a encouragée à utiliser les ressources disponibles de CanPKU et à communiquer avec John Adams et Frances Grove-Hurst! Marjorie m'a aidée à créer un tableur pour mon application, puis John et Frances m'ont aidée rapidement, étape par étape!

Après une longue attente (de la part du gouvernement), les deux enfants ont été approuvés pour le CIPH!! Nous avons réalisé par après que l'argent que nous avons reçu était seulement pour 3 ans et que nous devons compléter un autre formulaire pour le reste. Après un peu plus d'attente, nous avons reçu le reste du CIPH!

Nous sommes tellement reconnaissants pour toute l'aide et le support de CanPKU pendant ce processus d'application! Nous ne pouvons exprimer à quel point nous sommes reconnaissants!

Si vous avez déjà été refusé, s'il-vous-plaît contactez les gens merveilleux chez CanPKU!!!





**CanPKU team reports that the application success rate now is running at 100%. Parliament changed the law in 2022 so that time spent on medical formulas and medical foods definitely counts as part therapy for PKU and allied disorders treated by a medical diet.**

**CanPKU has successfully helped +150 adults and families, and counting, to get the DTC.**

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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

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# Ditch the binders!

Being a patient with or a caregiver to someone with a rare disorder can be both mentally and emotionally draining.

From the early days of diagnosis to countless appointments with physicians and various therapists and more, it can be daunting keeping everything organized.

Chronically Simple was built by patients and caregivers for patients and caregivers. The app provides a centralized place to all of your important documents, organized in a way that makes sense for you. Never arrive at an appointment without the information you need again.



## From early childhood to the transition to adulthood, Chronically Simple can help you manage the healthcare of someone you love.



**MEDICAL DOCUMENTS**  
Test and diagnostic results



**APPOINTMENT REMINDERS**  
Synced with medications, documents and questions for the doctors



**SYMPTOM TRACKER**  
Find trends and triggers



**MEDICATION TRACKER**  
Manage complex therapies



**HEALTHCARE PROVIDERS**  
Track which physicians you see and for what reason



**VACCINE TRACKER**  
Vaccine records at your fingertips



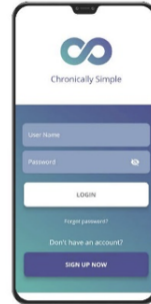
**MULTI-USER FUNCTIONALITY**  
For you and those you care for



**EXPENSES**  
Be prepared for grants, funding, and taxes



**DAY AT A GLANCE**  
Keep on top of today's tasks



[www.chronicallysimple.com](http://www.chronicallysimple.com)

Chronically Simple has been a supporter of CanPKU since 2021 and offers a forever premium subscription to its members. To unlock your complimentary Premium subscription, **use code CanPKU2021 to register online** at [www.chronicallysimple.com](http://www.chronicallysimple.com)



# 11th Annual RareVoice Awards



Congratulations to the 2022 RareVoice Awards recipients. All of our nominees are true rare disease champions.

In case you missed it, please enjoy the #RareVoice2022 show [here](#)



## RAREVOICE AWARDS 2022 AWARDEES

### **Federal Advocacy by Congressional Staff**

Aisling McDonough, Office of Representative Anna Eshoo (Ensuring Lasting Smiles Act)  
Jay Eberle, Office of Senator John Barrasso (Access to Genetic Counselor Services Act)

### **Federal Advocacy by a Patient Advocate or Organization**

Amy Oliver  
(FEHBP Coverage of Medical Foods)

### **Federal Agency Staff**

Joni Rutter

### **State Advocacy by a State Legislator**

Assemblymember Brian Maienschein of California  
(AB 114, Rare Disease Sequencing for Critically Ill Infants Act)

### **State Advocacy by a Patient Advocate**

Shannah Hudson (Newborn Screening RUSP Alignment in Mississippi)

### **Teen Advocacy**

Owen Maxfield and Claire Oliver  
(Medical Nutrition Equity Act and Utah PKU Formula Program)

CanPKU was happy to award a Hero of PKU Award to Dr. Scriver at a community meeting in Montreal in 2010.

# Feature Recipes



Recipe name: Fast Lower Protein Scalloped Potatoes (Gluten free too!)

Serves: 1-2

Preparation time: 15 min

Cooking time: 30 min

## Ingredients

2 tbsp butter\* (0 grams)

1 garlic clove, minced \* (0 grams)

(\* I cheat and use 2 tbsp garlic spread)

1/2 tsp Kosher Salt (0 grams)

Black Pepper to taste (1/4 tsp?) (0 grams)

1 can of sliced potatoes, rinsed (4.5 gram)

(Option: Trade canned potatoes for

Yuca Potatoes from Cambrooke

1 cup onion (1.8 grams, if not simplified)

2 tbsp cornstarch (0 grams)

1/2 cup non dairy milk (varies)

1/4 cup vegetable broth (varies)

1/4 tsp thyme leaves (fresh or dried)

1/2 cup non dairy cheese

## Preparation

1. Heat oven to 400degrees F. Grease small baking dish with cooking spray. Rinse potatoes under cool water and add to the dish. Set aside.
2. a) If using garlic butter, fry onions in mid sized frying pan until soft.  
b) If using regular butter, fry onions in mid sized frying pan until soft. Add minced garlic and fry for 2-3 more minutes.
3. In a separate bowl, mix milk and cornstarch until well blended. (This will thicken in pan but needs to be mixed cold so it doesn't make lumps!)
4. Add vegetable stock, mix until combined. Add milk, salt, pepper, thyme. Mix until combined. (optional - add half your cheese here). Continue cooking until sauce begins to thicken.
5. Pour this over potatoes and mix well. Add the rest of the cheese on top.

## Notes

6. Cover with tinfoil and bake until potatoes are hot (30 min-ish).



Protein can vary depending on products you purchase.

1/2 cup Non Dairy Silk NextMilk 2% = 0.5 grams

1/4 cup Vegetable Broth Brand: Selection = 0 grams

1/2 cup Non Dairy Cheese Brand: Violife = 0 grams



Nom de la recette : Patates gratinées rapides faibles en protéines (sans gluten)

Portions : 1-2

Temps de préparation : 15 min

Temps de cuisson : 30 min

### Ingrédients

<u>2 c. à table de beurre* (0g)</u>	<u>1 tasse d'oignon (1,8g)</u>
<u>1 gousse d'ail émincée * (0g)</u>	<u>2 c. à table de fécule de maïs (0g)</u>
<u>*ou 2 c. à table de beurre à l'ail</u>	<u>1/2 tasse de lait végétal</u>
<u>1/2 c. à thé de sel kasher (0g)</u>	<u>1/4 tasse de bouillon de légumes</u>
<u>Poivre noir au goût (1/4 c. à thé?)</u>	<u>1/4 c. à thé de feuilles de thym</u>
<u>1 conserve de patates en tranches</u>	<u>1/2 tasse de fromage végétal</u>
<u>(4,5g ou remplacer par les patates</u>	
<u>Yuca de Cambrooke)</u>	<u>(1g) = 1g de protéines</u>

### Préparation

1. Préchauffer le four à 400°F. Graisser un plat à cuisson avec un enduit à cuisson. Rincer les patates à froid et ajouter au plat à cuisson. Mettre de côté.
2. a) Avec du beurre à l'ail, faire revenir les oignons dans une poêle de taille moyenne jusqu'à ce qu'ils soient tendres.  
b) Avec du beurre régulier, faire revenir les oignons dans une poêle de taille moyenne jusqu'à ce qu'ils soient tendres. Ajouter l'ail émincé et faire revenir pour 2-3 minutes supplémentaires.
3. Dans un bol séparé, mélanger du lait et la fécule de maïs jusqu'à ce qu'ils soient bien mélangés; ils vont épaissir dans la poêle mais doivent être mélangé à froid pour éviter le grumeaux!
4. Ajouter le bouillon de légumes et bien mélanger.

### Notes

5. Ajouter du lait, le sel, le poivre et le thym. Bien mélanger. (Optionnel: ajouter la moitié du fromage ici). Continuer la cuisson jusqu'à l'épaississement.
  6. Verser sur les patates, mélanger et ajouter tout le fromage sur le dessus.
  7. Couvrir avec du papier aluminium et cuire pendant environ 30 minutes.
- Total évalué par le Conseiller Nutritionnel de CanPKU: 6,35 g prot, ~318mg PHE







# Low Protein Basic Bagel Recipe

Richelle and I met through Instagram and I am so glad we did! We've since met up in person and our PKU'ers have even met! She has two PKU'ers (6 & 7 years old) and clearly has a passion for baking.

Richelle bakes the most beautiful low protein items. She certainly has a knack for it! I am definitely not a baker, but this bagel recipe is fool proof! And let me tell you, they turn out perfectly every time!

-Marjorie, CanPKU News Editor

(Recipe shared from her Instagram account, with permission)



**pkubaby** ✨ PKU ✨

Basic Bagels 🥯



This recipe can be completely customized to the bagel of your preference:

- cinnamon raisin
- everything bagel
- blueberry bagel
- sesame bagel

Or whichever you like!



Recipe

Whisk together well:

- 1 box (500 g) Loprofin Baking Mix by [@nutriciametabolics](#)
- 1 packet (8.5 g) dried instant yeast
- ½ tsp salt
- 1/2 tsp powdered psyllium husk

.

Then add:

- 200mL warm water
- 2 Tbsp vegetable oil
- 120 mL (1/2 cup) unflavored non-dairy creamer\*

.

Knead this mix until it forms a dough. Dust a little extra of low protein flour in the bowl if it is too sticky to handle.

.

Form this dough into a large ball in bowl and cover with plastic wrap.

Let this rise for 30 min. (If you have active dry yeast instead of instant then let it rise for 1.5 hours)

.

Pre-heat oven to 375 degrees

In a large pot bring to a boil:

- ~10 cups of water
- 1 Tbsp brown sugar

Line a baking sheet with parchment paper. Divide the dough

...the remaining sheet with parchment paper. Divide the dough into 8 equal parts. Roll it into flattish balls. Place onto the baking sheet. Use the end of a wooden spoon or your fingers to poke the holes into the dough balls.

Place the bagels one or two at a time into the boiling sugar water for 1-2 min. Remove from the water with a slotted spoon, draining all excess water before returning to the tray.  
\*at this point if you would like to add a topping now is the best time

Brush the bagels with vegetable to improve colour while baking.

Bake in the pre-heated oven for 10 min.  
Broil for another 3-5min to brown them off.  
Enjoy 🍞 💙

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## **NPKUA Conference review**

This is the third 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 NPKUA Conference, July 2022.

In early July 2022 I was lucky to attend the NPKUA conference for the first time ever. I have heard a lot about this event from other PKUers and was hoping to attend it myself one day. Then COVID happened and froze everyone's travel plans and events. So this year slowly emerging from all the confinements and virtual meetings NPKUA announced in person conference.

Annie and I were advised to submit an abstract for the poster session. So we did. Soon we found out that both our submissions – “Adapt diet to lifestyle or lifestyle to diet? Individual choices characterize classical adults” and “Reasons why adult patients accept different degrees of metabolic control than clinicians who care for them” were accepted!

This was my first visit to Oregon and Washington states. Yes I managed to visit both at the same time because the airport is located in Oregon and the hotel where the conference took place was located just across the river – in another state of Washington. A bit of jet lag ensured that I got my early morning free to enjoy the very fresh air and amazing giant sequoias in the park just outside the hotel.

I had the pleasure to meet the CanPKU delegation and spend some time with them at the conference as well.

The Conference schedule was packed with very interesting events, speeches and just enough free time to walk around and meet new people. I was fortunate enough to make some new PKU friends there.

Some I have virtually met before while others I have not seen before. But overall a feeling of a giant family reunion hovered over the conference. Everyone was just one or two hand-shakes away from others.

In my personal experience nothing motivates you stronger to take care of your PKU than mingling with other PKUers and just talk. Sharing peer experiences and building bonds between other rare patients is extremely empowering and make you feel that you belong to this group.

On the big day of the poster presentation I made sure the posters were up early. It was the busiest two hours I could remember in the past decade. Talking non stop, discussing and again meeting new people.

Dr. Yano, Kathryn Mosley and Kirsten Ahring were also presenting other posters so we were all very busy.

It was a very pleasant accomplishment to present the results of many months of research work in front of such a friendly crowd of PKU patients, medical specialists and advocates. I am very grateful to all who made this possible and do hope to attend more PKU conferences in the future.

Maria Depenweiller

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*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)**





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## 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.**

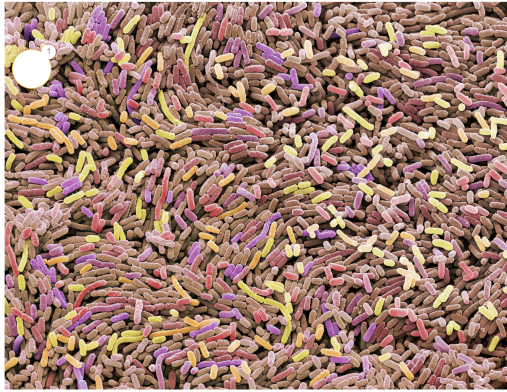
synlogic

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## Updates and Articles of Interest

## This Gulp of Engineered Bacteria Is Meant to Treat Disease

A small study of people with a rare disorder that prevents them from processing protein is an early attempt at creating “living” medicines.



Escherichia coli, or E. coli, bacteria is commonly found in the human gut. PHOTOGRAPH: STEVE GSCHEISSNER/GETTY IMAGES

[Click for full article!](#)

## Synlogic Provides Corporate Update and Outlook for 2023

Good news for both PKU and HCU people that there is positive steps towards new therapies!

[Click for full article!](#)

## Jnana Therapeutics Announces FDA Clearance of IND Application for JNT-517 for the Treatment of Phenylketonuria

Click for full article!

synlogic



Happy New Year from Synlogic! Synlogic ([www.synlogictx.com](http://www.synlogictx.com)) is a biotech company based in Cambridge, MA, that is developing potential medicines for PKU and HCU. The potential PKU medicine, called SYN1934, will soon enter Phase 3, the final stage of clinical trials!

**What is it?** Synlogic will study an investigational medicine in its Phase 3 study. This investigational medicine is made from a probiotic and is a powder that is mixed with a small glass of water, taken with meals.

**What does this mean?** This is important because a Phase 3 study is the final stage before a company may apply for drug approval which may lead to a new treatment option for PKU.

**What can you do? Stay Connected – Sign up [here](#) to receive updates.**

Thank you for your continued support as we kick-off what is sure to be an incredible year.



## Canadian News

Kuvan is now covered in Nova Scotia as of December 1, 2022!

**PKU**  
**sphere<sup>20</sup>**  
**liquid** is getting updated

**PKU sphere<sup>20</sup> liquid is now available in a Tetra Pak<sup>®</sup> reducing the amount of virgin plastic by 76%\***  
\*when comparing each individual plastic bottle to an individual Tetra Pak



1. New recyclable carton
2. Vanilla flavour
3. Lower Phenylalanine (Phe)
4. Reduced cartons per box

Learn more about PKU sphere liquid\* @ [Vitaflo.Ca](https://www.vitaflo.ca)



**Lower Phe for liquid and powder**  
per protein equivalent

FOR USE UNDER MEDICAL SUPERVISION



Thank you to Karen, Stephanie  
and all the staff  
at Ajinomoto Cambrooke!

**Thank you to Cambrooke for the Holiday gifts!**

**If you registered for one, keep your eye on your mailbox. They  
are still arriving!**

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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>



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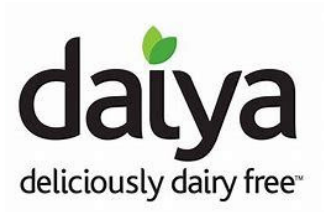
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## CanPKU News

**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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