

# 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.



## [Up Coming Events](#)

[Click to see event list](#)

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**HOWMUCHPHE.ORG**



## South Of The Border Ground "Meat"

- **1 Tbs vegetable oil**
- **¼ (17.5g) small onion, minced**
- **1 garlic clove, minced**
- **¼ tsp garlic powder**
- **1 tsp ground cumin**
- **½ tsp chili powder**
- **½ tsp smoked paprika**
- **1 tsp brown sugar**
- **2 Cambrooke Burger Patty Mix patties, uncooked (see package instructions)**
- **salt, to taste**

[Read Directions Here!](#)



Help us Keep in Touch with PKUers across Canada

To help us keep in touch with the PKU community country-wide, we have a database and, like all databases, it needs tender, loving care. For example, when people move, change emails or change phone numbers, sometimes they forget to let us know.

Because we don't like to lose touch, we are looking for someone who has a couple hours a week or so to dedicate to helping keep our contacts up to date. This will include emailing and phoning individuals to update addresses, emails, family members, etc.

This is a volunteer position.

Bilingualism (English and French) would be an asset but not necessary.

Happy to answer any questions.

Please send an expression of interest to VP Tanya Chute at [tanya.chute@canpku.org](mailto:tanya.chute@canpku.org).

Thanks for your help.

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



**CanPKU** would like to extend our genuine thanks to all those who donated this quarter!

**\$200**

In Honor of Grace & Harry de Witt

**\$50.00**

Mr. John Feruglio

**\$100**

Bruno Geiger

**\$100**

Ms. Sylvia Healey

**\$100**

In Honor of Grace & Harry de Witt

Click [here](#) to watch videos



“Demandez un échantillon à votre diététiste, en appelant au  
**877 636-2283**  
ou en envoyant un courriel à  
[Canada.CustomerService@nutricia.com](mailto:Canada.CustomerService@nutricia.com).”





## ***\*FEATURED ARTICLE\****

### **Help Scientists Develop a New Treatment Option for PKU!!**

Interested in helping advance a potential new treatment option for PKU?

**Synlogic** is a clinical stage biotech company based in Cambridge, MA, USA whom which working on potential new treatments for PKU.

To guide their development efforts, Synlogic scientists are trying to understand better the daily challenges patients and families living with PKU are facing.

You can participate in this survey if you are a PKU patient or a parent/caregiver of a PKU patient.

For each completed survey Synlogic will make a donation to the CanPKU.

Please take this Patient Survey by using the link below:

#### **For Patients:**

**In English** <https://www.surveymonkey.com/r/PKUPatientCAN>

**In French** <https://www.surveymonkey.com/r/PKUPatientCANFR>

#### **For Parents/caregivers:**

**In English** <https://www.surveymonkey.com/r/PKUParentCaregiverCAN>

**In French** <https://www.surveymonkey.com/r/PKUParentCANFR>

You can find more information on Synlogic here:

- <https://www.synlogictx.com/>

We look forward to your feedback! Together, we are one step closer to achieving a meaningful outcome

for PKU patients and their families.

Thank you,

**The Synlogic PKU Team**

 <https://www.cambrooke.com/>

 <https://www.cambrooke.com/>





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## National Strategy for High-Cost Drugs for Rare Diseases

**The Best Medicines Coalition (BMC)** is a national alliance of patient organizations, together representing millions of patients, with a shared goal of equitable, timely and consistent access to safe and effective medicines that improve patient outcomes.

The BMC strives to ensure that patients have a voice and are meaningful participants in health policy development, specifically regarding pharmaceutical care.

We commend the government as it takes important steps forward to address access to drugs for rare

diseases. As part of our efforts on behalf of patients, we welcome this opportunity to comment on Building a

National Strategy for High-Cost Drugs for Rare Diseases. The BMC and many of its member organizations have also participated in Health Canada's various consultative meetings.

We support a broad approach to a Canadian rare disease strategy, and to that end, the Best Medicines

Coalition supports the development of a comprehensive policy that first and foremost focusses on improving, saving, and transforming patients' lives.

[Read More Here.](#)

## Visit our Sponsors!!



**CanPKU** is grateful & thankful for their continued support!



**\$10,000+**



**\$5000**



**\$3000**



**\$1500**



## *Support in Kind*







## **Another DTC SUCCESS STORY!**

[Click here to read en francias](#)

Several years ago, I attended a CanPKU meeting in Montreal. At this meeting, my husband and I met John Adams, the president and founder of the organization. Already at the time, the group was working.....

[Click here to keep reading in english.](#)

**It is with great excitement that we announce the save the date for CanPKU's Camp MagniPHEque for the Fall of 2021.**

We anticipate the world will be back to somewhat of a normal state with lockdowns ended, people vaccinated and the wrath of Covid 19 to be mostly "old news". We will continue to follow provincial and federal guidelines to provide a safe opportunity for young and young at heart to enjoy camping PKU-Style. Who's ready to start popping bubbles with us?? Save the date!



**SAVE THE DATE**

  
**CAMP  
MAGNIPHEQUE**

**RÉSERVEZ LA DATE**

**SEPTEMBER 24-26  
24 AU 26 SEPTEMBRE  
2021**



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## **MAY Is PKU AWARENESS MONTH!**


**CHECK OUT OUR STORE TO GRAB SOME CanPKU SWAG!**

**Also Check out what our PKU Community is Creating on Etsy!**



 <https://canadianpkuandallieddisorders.wildapricot.org/sys/webstore/?pageId=1075236>

 <https://canadianpkuandallieddisorders.wildapricot.org/sys/webstore/?pageId=1075236>

 <https://canadianpkuandallieddisorders.wildapricot.org/sys/webstore/?pageId=1075236>



# PKU & the Flu Vaccine

*-A Letter from CanPKU President John Adams.*

We received an email from a concerned individual regarding PKU and the FLU Vaccine.

I spoke to Dr. William Hanley before answering,

**#1.** CanPKU cannot provide medical advice, which must come from a qualified health care professional.

**2.** Dr. Hanley gave me permission to share that he strongly encourages everyone - including those with PKU - to get the seasonal flu vaccine each year.

**3.** Dr. Hanley says in his experience of 65 years as a medical doctor he has never had concerns about recommending the flu vaccine to any patient. He gets the flu shot each year for himself.

**4.** Let me add that since founding CanPKU in 2008 I have attended a lot of scientific conferences related to PKU in and outside Canada and spoken with a large number of medical doctors and clinical dieticians about PKU and never once has any of them raised any concern about the flu vaccine for a PKU child or adult.

Hope this helps, those who are wondering this season.





CanPKU est honoré de partager avec vous PHÉNYLCÉTONURIE QUÉBEC où vous pouvez trouver des articles sur la phénylcétonurie et des idées dans les deux langues officielles du Canada! Pour lire la version anglaise de cet article ou en savoir plus, cliquez ici!

CanPKU is honored to share with you,

### **PHÉNYLCÉTONURIE QUÉBEC,**

Where you can find PKU support in BOTH of Canada's official languages!

To read the English versions of his articles, or learn more, click [HERE!](#)

## **IN MEMORIAM, DR LOUIS I. WOOLF, PROFESSEUR ÉMÉRITE**

Source: John Adams, cofondateur, président et chef de la direction, CanPKU & Allied Disorders Inc.

Publié le [Page Facebook de CanPKU](#) le 13 février 2021.

*Vous ne savez peut-être pas grand-chose de Louis Woolf, ou même n'avez jamais entendu parler de lui, mais si vous vivez avec la phénylcétonurie, prenez le temps d'honorer sa mémoire, sa vie et son travail.*

*C'était son idée de créer une formule médicale sans phénylalanine qui a changé le monde, transformant ainsi la phénylcétonurie de condition incurable à traitable. Cela a également transformé la génétique, faisant de la phénylcétonurie la première maladie génétique avec un traitement. Ensuite, il a plaidé pour le dépistage néonatal universel et pas seulement pour la PCU.*

*Il est décédé le 7 janvier 2021 et aurait eu 102 ans en avril. Ce fut un privilège et un honneur de connaître ce gentil géant. CanPKU lui a remis sa plus haute distinction, "Hero of PKU".*

**[Continuez à lire ici](#)**



**We love to shine the spotlight! To be featured in this column, please submit a photo and paragraph to [newseditor@canpku.org](mailto:newseditor@canpku.org)**



# MAXIME

If you really want to demonstrate who the real Maxime is, you will find a picture of Maxime with his football team. Maxime is the one in blue in the middle, with his arms crossed.

This shows that it is not because we do not eat protein, that we cannot practice a sport requiring great athletic qualities and that we cannot be muscular !!!!

The other photo was taken at Christmas where Maxime is surrounded by his parents, his sister Amélie who is 20 years old and who does not have PKU and our cat Tickle.

*Submitted by: Marie-Claude*



Did you see Vitaflow's New recipe?



[Watch Video Demonstration here!](#)



## What's New On The Back Of The Pack?



Noticed some changes on the Nutrition Facts Label? New labels are rolling out, and some of the changes might throw you off. Here's a primer on what's going on:

There are two types of label updates:

- Formatting and content updates dictated by FDA. We're currently seeing new labels based on regulations passed in 2016, which was 20 years after the last label format updates. Manufacturers with less than \$10 million in sales needed up update their labels by 1/1/2021, which is why we're noticing changes now
- Label updates initiated by the manufacturer, when ingredients or recipes change ([more on those below](#))

[Continue reading here.](#)

Throughout the month of May,  
& ALL YEAR LONG,  
Use **#WeCanPKU**  
On your social media posts for a chance for your photos to be featured  
right here, in the news letter!

Remember your posts have to be public for us to see them!

Don't want to change privacy settings?  
No problem!

Email your awareness photos all year to [newseditor@canpku.org](mailto:newseditor@canpku.org) with  
the subject **#weCanPKU !**

Feel Free to Save some of the awareness images located through the  
news letter to help you spread awareness in May!





### **Canadian Anti-Spam Law Consent**

I agree to receive the CanPKU newsletter and related communications from the Canadian PKU and Allied Disorders non-profit concerning matters related to PKU or allied disorders. I may withdraw my consent at any time via SafeUnsubscribe.

### **CanPKU Privacy Statement**

Canadian PKU and Allied Disorders maintains member/participant/registration information for its own use and does not rent, sell or otherwise provide



### **We need your help!!**

Once upon a time, there was a YouTube channel for CanPKU. We want to use this more! But no one knows how to access the original channel. We were able to get the videos all moved over to our new channel. but we lost our subscribers 😞 Come join us! Search "Canadian PKU and Allied Disorders - CanPKU "

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### **CONTACT US**

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