



# CanPKU News!

From Canadian PKU & Allied Disorders Inc.



March 2018

## In This Issue

[Become a Member](#)

[Important Dates](#)

[In the News](#)

## Quick Links

[About Us](#)

[Membership Purchase](#)

[DTC Package Request](#)

[The ABC's Of PKU](#)

[PKU and The Brain](#)

[HowmuchPHe.org](#)

[Join Our Mailing List!](#)

## Greetings!

Welcome to the 32nd issue of CanPKU news!

Our apologies the letter is coming out a little late! A lot has been happening since our last issue, so many thanks to give, events attended, and with school almost finished and summer on its way, we've all been busy!

In this issue you will find:

CanPKU Attended BC educational day, in addition to the great efforts by the PKU community, organizing and attending our "Pins For PKU" events nation wide during May, PKU awareness month.

This has been our most successful fundraiser yet, HUGE thanks to all who made the events possible nationwide!

Peg-Pal received US FDA approval, as the second treatment available to PKU patients in the USA.

The GMDI conference was held.

CanPKU is continuing to help PKU patients and families achieve disability tax credit status, taking steps forward to disability tax fairness. CanPKU offers services helping families work with the CRA free of charge. (See more under the "Did You Know segment on the right hand side of this article!")

We were thrilled to see the #weCanPKU photos on social media! Don't stop in June, keep up the #'s and we will keep including them in our letter! Also, # your supplement photos for the Supplement Spectacular segment!

Let's keep the PKU awareness alive all year long!!

*Sincerely,*

John Adams    Tanya Chute    Arlene McDonald

President & CEO    Vice President    Newsletter Editor

**Thank You Sponsors!!**

GOLD

**BIOMARIN**<sup>®</sup>

SILVER



NUTRICIA  
**Metabolics**  
Inspiring Futures



BRONZE



**WE NEED  
YOU!**

We're always on the hunt for new hands to help make a lighter workload!

Are you often the loudest at family functions? Maybe advocacy is your calling!

[Contact us](#) to see how you can help!



### What's John Been up to?

A Message from the President. By: John Adams

Where have the last three months gone?

Represented PKUers, directly or indirectly, at the following, so PhePhe travelled a lot

- Best Medicines Coalition conference on national pharmacare
- BioMarin North American summit on patient advocacy
- Canadian Agency for Drugs and Technology in Health symposium (led a panel discussion on what national pharmacare could mean for PKU and other rare disorders)
- Garrod symposium of Canada's metabolic clinicians
- Health Technology Assessment International global conference
- International Alliance of Patient Organizations 8th global patients summit
- National Pharmacare Initiative of the Conference Board of Canada roundtable and its steering committee
- meeting head of the largest government drug program (Ontario)
- Health Canada discussions about PKU/Phe labelling of foods, prescription drugs and over-the-counter medications
- work group of Best Medicines Coalition, Canadian Pharmacists Association and the Health Charities Coalition of Canada which produces a paper of patient-centric principles for any national pharmacare

Continued working with individuals and families on Disability Tax Credit appeals.

Managed to include a vacation in the countryside of Umbria, Italy with my new girlfriend!



Sincerely,

John Adams.



### A Message from the Vice President

By: Tanya Chute

Hey Guys! What an exciting quarter. Happy PKU Awareness month! Whether you educated one person, celebrated it with your own PKUer (even if that is you) or did a fundraising event... KUDOS!! I want to thank each and every person who contributed to Pins for PKU. It was amazing to see a small initiative get offered in one town, and out to the masses - in case someone else wanted to - turn into an event with almost a dozen locations and about \$10,000 raised! This will help so many people get to camp this year. Speaking of camp... time is running out. Are you interested? Have you registered? Don't forget, if funds are holding you back, all these amazing fundraisers lately, are taking care of that need. Send in a scholarship. I was delighted to travel to BC and NS to facilitate the education event and meet so many new faces. I love our community and continue to try and find ways to bridge us all. Please reach out with any new ideas.

Sincerely,

Tanya.



## BECOME A MEMBER!

Signing up for a CanPKU membership is the easiest way to help the organization, and comes with great benefits. Members are eligible for a \$10 off coupon for HowMuchPhe, receive discounts on fees to CanPKU events, receive discounts for low protein products, and more!

General memberships are only \$20 per year!

To sign up, please go to

[www.canpku.org/become-a-member](http://www.canpku.org/become-a-member).



**Don't Miss Our 2nd Annual, ALL AGES, Camp!**

Fun Camp Activities, Engaging Speakers, Meeting New Friends, Trying New Products, AND MORE

Weekend, Weekend GLAMPING, Single Day & Weekend Child Passes Available until JULY 31, 2018

**September 28 - 30, 2018**  
Douro-Dummer, ON

Visit [CanPKU.org/CampMagniPHEque](http://CanPKU.org/CampMagniPHEque) For More Details



**Join us at a 2018 educational /  
Networking event near you!  
Learn from the experts, try new  
products, mingle with friends &  
families, and have a fun time!**

**\*\* NEW EVENT\*\***

**Ontario PKU MOTORCYCLE  
POKER RUN**

**July 7th 2-18  
Roadside of the Oakland community  
center.  
Kickstands up at noon!**

**Ontario PKU Day  
Hamilton, ON . TBA**

**Prairies PKU Day  
Saskatoon, SK . July 14  
Kinsman Children's Centre**

**Camp MagniPHEque  
Douro-Dummer, ON . September 28-30**

**Quebec PKU Day  
Montreal, QC . October 13  
Sylvan Adams YM-YWHA**

**Thank you to those who donate to  
CanPKU.  
You truly make a difference!**

**Thank You to:**  
**Ashley Sulpher, Elsie Belise,  
Melissa Tavaras, Amanda Cosburn,  
David Brennan, Kari Anderson,  
Tanya Chute,  
and  
all who took part in the Pins 4  
PKU events!!  
Here are the results of those  
fundraising efforts!**

**Renfrew, ON - \$3200  
St. Isidore, ON - \$1284**



**CanPKU Attended BC Educational  
Day!!**



BC Educational Day was on April 6, 2018. We heard an amazing life journey of Adult PKU Brian Goetz the only Canadian currently on trial (and doing awesome) on the medication Pegvalise.  
(Please check spelling)

It's an incredible story - check out the education event nearest you to hear his speech as he is travelling the country with us this year! Our breakaway sessions and round table were other highlights of the day. The photo shows all the faces of PKU that attended the educational day. We were delighted to see how many adults with PKU joined us this year and hope this is a continued trend. After a day of education, learning, sampling vendors options, and visiting friends - BC Kicked off the first of a series of PINS FOR PKU fundraisers. We covered 3 lanes, raised some money and had a great deal of fun and spirit! "We've got Spirit for PKU, We've got spirit, how bout you?" Check out the video on our [FB page!](#)



St. Isidore, ON - \$1284  
 Newmarket ON - \$4167.63  
 Woodstock NB \$200  
 Brantford ON \$2189  
 Halifax NS \$345  
 Peterborough \$958.56  
 Kamloops BC \$290  
 Richmond BC \$113.50

Total to date: **\$12747.69!**



We would like to acknowledge those who contributed by donation.



**YOU CAN HELP WITH PKU RESEARCH!**

The Canadian Inherited Metabolic Diseases Research Network (CIMDRN) is seeking advisors for a research project they are doing on family-centred care. The researchers are trying to understand the health care experiences of families with children with inherited metabolic diseases.

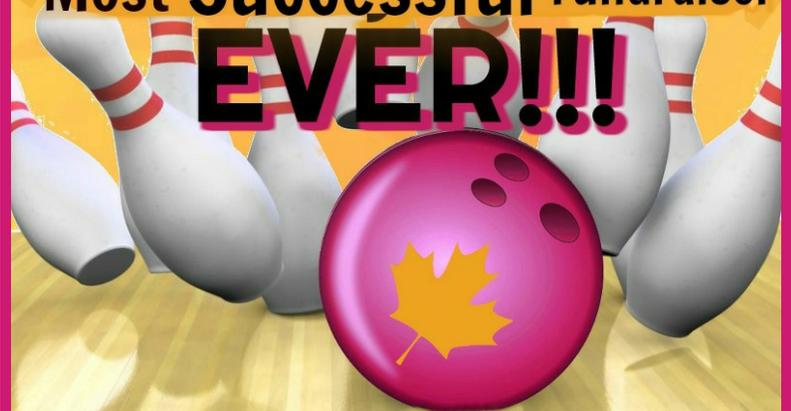
They are looking for 10 advisors to help them as they design the study. Please [CLICK HERE](#) for more details about the project and a description of the advisor role.

The researchers are interested in

# Let's CELEBRATE!

To All Who took Part in the Bowl-a-Thons...

**YOU** made Pins For PKU Most Successful Fundraiser **EVER!!!**



**Thank you participants, bowlers, and donors!!**

Thank you to everyone who helped organize and attended the "Pins for PKU" Events across the country!

Below are some photos of the great fun that was had!!

making sure that they know as much as possible about the wide variety of health care experience that families can have. They are seeking a group of advisors with as much diversity as possible on children's ages, type of inherited metabolic disease, metabolic

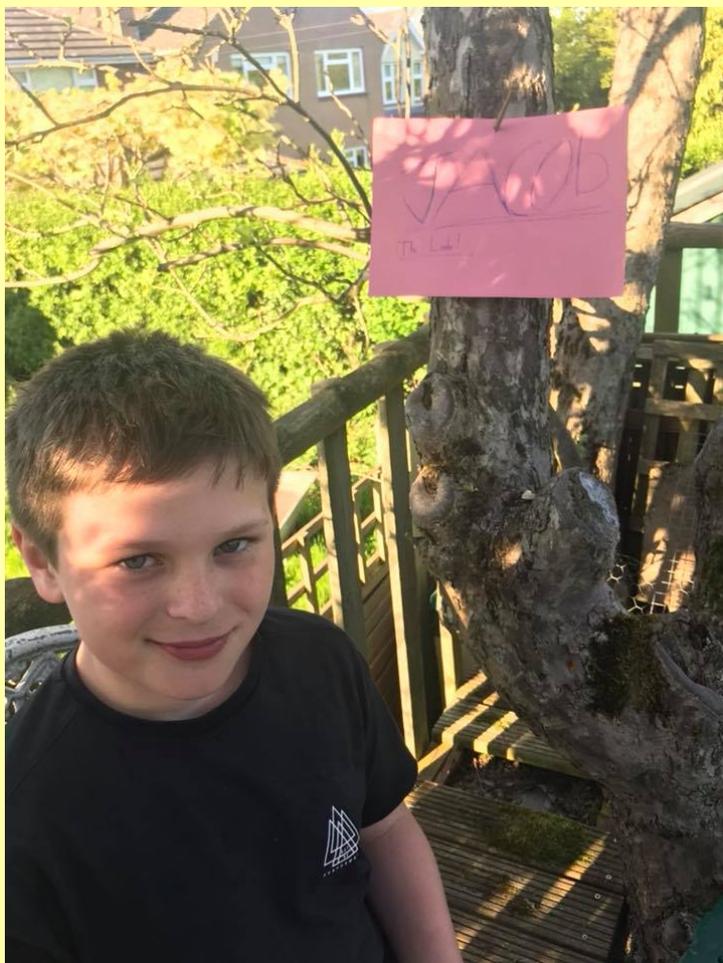
centre where care is received, province/territory, and distance from home to metabolic clinic. No prior research experience is necessary. If there are more applicants than positions, CIMDRN will choose applicants based on creating the most diverse representation possible.

If you are interested in participating, or would like more information, please contact one of the following people:

- Andrea Chow, research associate; [achow@uottawa.ca](mailto:achow@uottawa.ca), 613-562-5800 x4353
- Beth Potter, principal investigator; [bpotter@uottawa.ca](mailto:bpotter@uottawa.ca), 613-562-5800 x8718
- Isabel Jordan, patient/family partner; [isabeljordan@me.com](mailto:isabeljordan@me.com), 604-815-1371
- Nicole Pallone, patient/family partner; [npallone@shaw.ca](mailto:npallone@shaw.ca), 250-910-6426
- Maureen Smith, patient/family partner; [maureen\\_smith@rogers.com](mailto:maureen_smith@rogers.com), 613-230-3619

## *PKU Profile*





PKU Hello! My name is Jacob Newby. I'm 10 years old and have PKU. I live in the United Kingdom.

PKU means that I can't have the phenylalanine in protein. Mostly every bit of protein has phenylalanine in it. This means I can't have meat, most dairy or chocolate- I will explain in more detail about that later.

All of us PKUers are allowed a certain amount of protein every day. We call these 'exchanges' and each exchange equals 1 gram of protein. Most of my friends with PKU are allowed 2 exchanges a day. A lot of food I use for my exchanges are 2 1/2 exchanges! The person with the highest number of exchanges I've met is allowed 25 exchanges- to me that is a lot. I have 13 exchanges a day which for someone with PKU is a pretty good amount!

Don't feel sorry for me. There is loads of free food I can eat. When I say free, I don't mean the price in a supermarket. 'Free' is how we describe food containing '0 exchanges'. I can get lots of exchange free foods on prescription from my Doctor. These are given to me by companies called Vitaflo and Nutricia.

I can have potato, but only a certain amount. 1 exchange of jacket potato is 80 grams for example. It's the same with chocolate- I have to work out what 2 exchange is then weigh it out using my digital scales. I even have to count peas!

We get tonnes of opportunities to try new foods. In England you can go on an activity weekend with other children your age with PKU. At first you don't know anyone, but by the end you've made loads of new friends.

Every 6 months I go to the Evelina Children's Hospital for my check up to see if you're doing well. It's right by the London Underground, so London's a super convenient location. I just



Bowl-a-thon in St-Isidore, ON. Collected \$1284.00!!

Richmond BC was excited to kick off #PinsforPKU after the West Coast Regional Event. Joined by Annette Webber from Nutricia, 4 families and CanPKU's Event Planner Jenn Pino and VP Tanya Chute each bowled a game of Cosmic Bowling. We raised \$200 and had a boat load of spirit and fun during our evening out. Thank you so much to those that came out and supported the event. It was tremendous!



London Eye and the London Aquarium, so sometimes I get to visit these too. For me the best visit is at Easter as we have an Easter party and we get to see Dr Ranj from the TV Show 'Get Well Soon'.

At home you can find me reading, bike riding or sitting watching TV drinking my red coloured supplement that I keep in my own cupboard with my special food in the kitchen. My supplement is a drink that gives me the protein I need to grow and develop normally, but without the phenylalanine part which would damage my brain. I have had this fluid medicine 3 times every day since I was 10 days old. I have one at 7.30am, one at noon and then one at 7pm. When it is school I have my sup at lunchtime break, but I don't mind at all.

Another thing I must do is called 'bloods'. Most people are afraid of it, but I don't mind. In fact, I do it myself and I usually get it right. When the bloods are finished I post them all the way to the Evelina Hospital, then the Doctors make sure they are where my safe levels should be.

The most common thing that can raise your levels is a sore throat, headache or anything that makes you feel poorly. I have 2 sisters and a brother. They don't have PKU but they make sure I am OK with everything I eat (although I can do it myself). The best supplement time is at night because I listen to my favourite son artist, Bruno Mars, and then I go to bed.

By Jacob Newby, Age 10

**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).**



Pins For PKU - Newmarket was held on May 12th at Stellar Lanes in Newmarket. They had a very successful event thank you to our 71 bowlers! 13 lanes were booked and out of that 9 of them were sponsored by local establishments in Mount Albert as well family and friends that could not attend or bowl themselves. All bowlers collected pledges as well as we had a several raffle items that were a big hit. They are proud to say they more than doubled last year's Ride A Thon with \$5048, less expenses with a **GRAND TOTAL** of \$4,167.75!

We had 4 PKU'ers attend our event this year and everyone had a blast! I already have some great ideas for next year and hope to double this year's!

### *Recipe Corner*

## Camping Season Is Upon us!





This pasta salad is wonderful to bring to any Barbeque. There is enough dressing and vegetables for 1 pound of pasta, so figure out what portions you need of high and low protein pasta and divide appropriately. The total phe in the recipe (minus the pasta) is 522 mg, so you can figure out how much phe is in your serving size. P.S. If you use canned olives and I find out about it, I am coming to your

house to yell at you.

#### Ingredients

#### Dressing

- 6 tablespoons extra virgin olive oil [0 mg]
- 3 tablespoons red wine vinegar [0 mg]
- 30 gm (2 tablespoons) fresh lemon juice [3 mg]
- 30 gm (1 small) shallot, minced [24 mg]
- 3 gm (1 clove) garlic, crushed [5 mg]
- 5 gm (1 teaspoon) Dijon mustard [12 mg]
- 20 gm (1 cup loosely packed whole leaves) fresh basil, roughly chopped [26 mg]
- 10 gm (1/4 cup) fresh chives, roughly chopped [10 mg]
- 45 gm (3 tablespoons) mayonnaise [35 mg]
- 1 teaspoon salt [0 mg]
- 1/4 teaspoon ground black pepper [2 mg]

#### Salad

- 150 gm broccoli florets [173 mg]
- 125 gm (1/2 large) yellow bell pepper, cut into 1/4-inch-thick strips [51 mg]
- 125 gm (1/2 large) red bell pepper, cut into 1/4-inch-thick strips [51 mg]
- 120 gm (1/2) English cucumber, quartered and cut into 1/4 inch slices [37 mg]
- 120 gm (1/2 small) red onion, halved and thinly sliced [30 mg]
- 60 gm pitted kalamata olives, cut in half lengthwise [20 mg]
- 180 gm (1/2 pint) cherry or grape tomatoes, quartered [43 mg]



Joined by Dan, a representative of Cambrooke, Maggie C. from the clinic in NS, two PKU adults, and family/friends this mighty team in Halifax NS raised \$345. The day saw a few strikes, some spares and lots of gutter balls. Laughs were in no short supply either. Tanya, VP of CanPKU, says that "Candlepin bowling is not to be underestimated - it is not simply 10 pin bowling with a 5 pin ball... much harder than it looks (and way more fun - or maybe that was just because of the company!!) Looking forward to next years social event!

*Thank you #lucky9lanes for hosting our first ever#pinsforpku we made money and memories. Thanks#bcpku for your support!*

## EXCITING ANNOUNCEMENT FROM CANPKU!

*Join us for the Second Annual CanPKU Family Camp for all ages!*

**September 28-30, 2018**  
**But don't wait too long,**  
**registration closes July 31, 2018!**

*Just a 15-20 minute drive East of Peterborough, ON in the scenic Kawartha Lakes region of Ontario.*



Have you heard of "Glamping"?

Perhaps GLAMPING is for you! (Glamorous camping.. not our word.. its a thing!)

Prefer a private, non shared sleeping space? Fresh crisp sheets and maid service while you are out?

We have secured space at a hotel for those who would like a more pampered experience.

Call and book your room at the Village Inn, Lakefield (1-800-827-5678) using "Camp PKU" as a code. Online booking is NOT available. Price for the room is \$119/night based on two nights and can accommodate 2 or 4

- Aprotin Pasta Fusilli (60 gm uncooked per serving) [18 mg]

### Instructions

1. For the dressing: In a blender or food processor, combine vinegar, lemon juice, garlic, shallots, basil and chives. Blend until herbs have been minced. Add Dijon mustard, salt, pepper, and mayonnaise. Blend briefly. With the blender or food processor on, gradually pour in olive oil. You will have a thick, creamy dressing. Set aside.
2. For the salad: Bring 4 quarts of water to boil in a large pot. Stir in 2 tablespoons salt and the pasta and cook until completely tender. During the last minute of cooking throw in the broccoli florets. After 1 minute, remove florets and place in a bowl of ice water. This is called blanching and shocking. It helps maintain a bright green and crisp floret. Reserve ½ cup of the pasta cooking water, then drain the pasta in a colander. Transfer the hot pasta to a large bowl.
3. Stir the reserved pasta water into the dressing. Pour half of the dressing over the pasta and toss to coat. When pasta cools, add all of the vegetables except the broccoli (the vinegar will cause it to turn a dull color).
4. To Store: Cover the pasta salad tightly with plastic wrap and poke several vent holes. Transfer the remaining dressing to an airtight container. Refrigerate the pasta salad for an hour. If you need to make in advance, keep the cooked pasta at room temperature and then combine right before you are serving. The low protein pasta become hard once refrigerated beyond an hour.
5. To Serve: Shake the reserved dressing to recombine, then pour half of the dressing over the salad and toss to combine. Add the broccoli florets and the remaining dressing as needed to keep the salad moist.

Yield: 8 large servings

Phe Per Serving: 83 mg

Calories Per Serving: 380 kcal

Phe Per Recipe: 522 mg + pasta 37 to 55 mg depending upon serving size + phe from pasta

people. Then when reserving your stay with us please book Weekend Glamping. (We have also added this to the 2017 offerings so you can get in on this before Dec 24!) First come first serve on these rooms and they are at risk of selling out before camp registration closes.

There are no day, or one night glamping opportunities available.

More "New" items to come... examples are Sunday Lunch wasn't too popular, so we are instead looking at a Friday Dinner. AGM will also take place at a different time to ensure those who want to participate are able (before we are all tuckered out from the weekend). Stay tuned!

## BUILD 20/20: The Lowest Phe GMP Medical Food Ever!

Cambrooke developed Glytactin in collaboration with researchers at the University of Wisconsin, the cheese capital of the world. The result was a combination of GMP and a balance of critical amino acids, such as leucine, arginine, and tyrosine, which are at low levels in GMP.



- Lowest Phe 20 mg Phe per 20 g PE serving - 30-40% lower Phe than all other GMP products for PKU
- Natural! Natural whole GMP protein supplemented with naturally fermented AAs from Ajinomoto
- Low volume
- Lowest calorie GMP nutritionally complete formula - 108 calories
- Low carb - 5 g/ serving
- Total sugars - 0 g
- No artificial sweeteners or colors
- Neutral taste - no artificial flavors
- Easy to mix in your medical food as a protein booster
- Add to flavored beverages or used with flavor drops (Mio etc.)
- Synbiotic: includes prebiotic GMP plus supplemented probiotics to support gut health

Credit:  
<https://cookforlove.org/pasta-salad-2/>

If you have a recipe to share, please submit it to  
[newseditor@canpku.org](mailto:newseditor@canpku.org).

Learn more [Here!!!](#)



## Receives Standard Approval for Palynziq™ (pegvaliase-pqpz) Injection for Treatment of Adults with Phenylketonuria

The approval of Palynziq in the United States marks an important milestone for adults living with PKU who will now have access to an effective new treatment option for controlling their blood Phe. The approval of Palynziq comes during National PKU Awareness Month. During National PKU Awareness Month, local patient organizations are encouraged to organize events to spread PKU awareness and raise funds for academic research. "BioMarin is thrilled to be able to offer this important new therapy to adults with PKU who are unable to control their Phe levels with existing options.

Read Full Press Article [HERE](#).

## Genetic Metabolic Dietitians International GMDI Conference

Written By: Nicole Pallone

Once every two years, Genetic Metabolic Dietitians International (GMDI) hosts a conference. This is an amazing opportunity for dietitians treating PKU and other metabolic disorders to come together for a few days of focused learning and a chance to network with their peers. It also provides an excellent opportunity for CanPKU representatives to connect with dietitians face to face and to learn what is new in the world of metabolic diets, as well as a chance to meet and mingle with current and potential sponsors.

The GMDI conference is routinely well-attended by Canadian dietitians and this year was no exception. With 410 attendees from 23 different countries, it truly was an international affair and 28 of those attendees were Canadian. The agenda of this three day conference, held April 26-28 in Orlando, Florida, had many topics specific to PKU as well as topics that related to multiple disorders. It was nice to see Dr. Mark Korsen from the Genetic Metabolic Centre for Education speak passionately about the value and desire of patients and caregivers to teach others about the conditions they know. Dr. Rajavel Elango from BC Children's Hospital/University of BC spoke about the protein requirements in Inborn Errors of Metabolism (IEM) patients, indicating that it should typically be 1.14-1.33g/kg/day - higher than that of a regular diet - and roughly 20% of overall dietary intake.

Amy Cunningham (New Orleans) and Kirsten Ahring (Denmark) spoke on PKU Treatment Guidelines and the benefit of finding a consensus worldwide - without question a challenging feat, and one that is even harder to implement even if agreement is reached. Fran Rohr of Boston Children's Hospital has been involved in the Pegvaliase (formerly Peg-Pal, and now Palynziq) and spoke to the nutritional

## 20 Years of PKU

Written By:  
**Chloe Easton,**  
Adult PKU patient of  
South Yorkshire, England.



**This year I turn twenty one, and honestly I don't know where the time has gone. A lot has changed for me over time, including my PKU. When I was very young I was on four exchanges a day, but last year I was put up to 30. It's been a slow journey to get to where I am today, but now I've reached a point where I am able to live pretty much a normal life.....**

**"When I was about 8 years old we went to our first PKU Conference and I would say this was a huge turning point in my life;"**

**"The PKU Conference really was revolutionary in many ways for us. We saw how to deal with the diet from a whole new perspective,"**

[Read more of Chloe's Story Here.](#)

Or check out her blog at:  
[thenkulife.blogspot.co.uk](http://thenkulife.blogspot.co.uk)

and how Palyzid) and spoke to the nutritional challenges that come along with diets as they are modified to allow for more protein intake. Without question, the role of dietitians will still be essential as PKU patients responding to this new treatment relearn how to balance their nutritional needs.

Lauren Duncan of Virginia gave an interesting presentation comparing the nutritional needs of a maternal PKU patient over the course of two pregnancies - the first time pregnant with a single baby versus the second pregnancy of twins - with the latter requiring significantly more protein. I was also able to attend a workshop on sports nutrition basics and their application to a PKU diet - of particular interest to me as Rosie started entering competitions this past figure skating season. Karen Dolins (New York) and Jennifer Branov (Vancouver) made it clear that PKU athletes need to be very conscious not only of protein and caloric intake, but also of when various dietary needs are consumed.

Beyond all that learning, I was able to connect with representatives from Nutricia, Cambrooke Therapeutics, Vitaflo, Biomarin, Modality Rx, POA Pharma North America, Dr. Schar USA, NPKUA, How Much PHE, and more. I also had a poster presentation showing our slow process transitioning to the Simplified Method and how Rosie's levels stayed stable throughout our approach. As usual, I was honoured to represent CanPKU, share our experience with registered dietitians treating PKU and to meet with sponsors.

## **Potential PKU Treatment Receives FDA Fast Track Designation**

*Written By:*  
**Krista Rossi**

**RareDR**  
Rare Disease Report®



# DID YOU KNOW?

## Cooking an ingredient or vegetable changes it's Phe value?

### Here's Why!

As you cook a vegetable, ect, it can either take on weight while simmering in a liquid or lose its liquid/juice as it cooks. And the cooked weight is never consistent. The length of cooking time, cooking temperature, and the size of the food affect the end weight, which then impacts the mg/g of phenylalanine.

Learn more about cooked Vs Raw [Here!](#)

Article from, ["PKU NEWS"](#)

Written By: [Cook For Love's](#) BRENDA WINIARSKI

Synlogic announced that SYN1618, received the US Food and Drug Administration's (FDA) Fast Track designation for the treatment of phenylketonuria (PKU). Synlogic's president and chief executive officer, JC Gutiérrez-Ramos, PhD, made Rare Disease Report aware that the drug had recently entered the clinic in an exclusive interview last week.

SYNB1618 is designed to carry out a programmed metabolic pathway engineered to consume phenylalanine (Phe) and convert it into harmless metabolites. Trans-cinnamic acid in the blood, which can be further metabolized in the liver and excreted as hippurate in the urine, includes such harmless metabolites. This process provides potentially important biomarkers of SYN1618's activity.

Read More [HERE.](#)



# DID YOU KNOW?

CanPKU provides our PKU community with the expertise in understanding, and applying knowledge of PKU to the specifics of the DTC,

FREE of charge? Also our CanPKU president John Adams, Will represent DTC claimants at tax court (if necessary) at no charge?

**DID YOU KNOW:**

## Cat in the Hat

### SUPPLEMENT SPECTACULAR!

Formula and supplements are an essential part of PKU therapy, but are not always a favorite experience!

Submit a Photo of you or your child taking your PKU supplement to [newseditor@canpku.org](mailto:newseditor@canpku.org), Title: Supplement Spectacular, with your name, and where your taking your supplement, for a chance to be featured here!

Get creative, only a few photos will be selected each issue, so use it as an incentive on those days when it's not your favorite thing to do!



**YOU**  
Take your **Supplement**  
**Here and There...**  
You Take your  
**SUPPLEMENT**  
**EVERYWHERE!**

You are super, That's a fact,  
and the Cat in the Hat Knows  
alot about that!



CanPKU Board member Amanda Cosburn with her bettermilk formula!



John Adams represented, Our news editor Arlene McDonald and her family in their appeal, and then objection with the CRA? Arlene was able to obtain DTC status for her son, without proceeding to tax court.

A source has informed us that the CRA is currently processing 2 DTC applications for PKU individuals who have used a commercial service, which charges 30% of the tax credits received.

CanPKU wants YOU to receive your DTC credits, please consider CanPKU before opting to pay commercial services advertising on social media, with 30% of your return.

CanPKU welcomes you to make a donation at [www.canpku.org](http://www.canpku.org) so we can continue helping others obtain DTC status without the use of commercial services.

## TAX COURT OF CANADA



### Tax credits:

**Proper meaning of word "therapy" in disability tax credit provisions,**  
meant care or treatment of physical or mental condition.

Taxpayer's dependent daughter was born with \_\_\_\_\_, which required following very specific dietary treatment plan to avoid brain damage.

Canada Revenue Agency (CRA) determined that taxpayer was not entitled to claim disability tax credit in respect of her daughter because impairment related to dietary restriction and treatment activities consisted of following dietary regime.



Marcus Takes his Supplement while he shops!  
PKU Cooler 20's!

Taxpayer appealed. Appeal allowed. Taxpayer spent more than 14 hours weekly on average on treatment and management of daughter's PKU, after some adjustments to taxpayer's calculations.

Some flexibility in precision of hours should be allowed in these cases.

Proper meaning of word "therapy" in disability tax credit provisions meant care or treatment of physical or mental condition.

Scope of qualifying activities in case of PKU was described in another judgment.

Therapy sustained daughter's vital mental functions, as without it, she would have potentially devastating and irreversible damage to her mental functioning.

Daughter's treatment was not simply dietary restriction.

Counting and managing consumption of phenylalanine was more like administering medication than managing diet.

Impairment that limited what person was capable of processing as nutrition without causing severe bodily damage might be considered in giving humane, compassionate and common sense interpretation to requirement of marked restriction in feeding him or herself.

*Hughes v. The Queen (2018), 2018 CarswellNat 1262, 2018 CarswellNat 725, 2018 TCC 42, 2018 CCI 42, Patrick Boyle J. (T.C.C. [Informal Procedure]).*



**RECOUNTING PKU: A LIVING HISTORY PROJECT FOR ADULTS WITH PKU**



**RECOUNTING PKU** is now open for submissions.

Adults (individuals 18 and over) with PKU, please join this online living history project and



Jessica Taylor. 20 Year old with PKU. Drinking phenex 2 at the Future Inns Bayer's Lake!!

share your story about growing up, or living your daily life, with PKU.

This project seeks to not only recognize the changes in PKU treatment (the new foods, treatments, recipes!) but chronicle the lives of adults with PKU.

While the majority of online PKU discussions focus on dealing with a new diagnosis, learning how to follow the diet, and issues parents face on behalf of their children with PKU, adults with PKU are managing on their own, with less community support, and often more complex struggles-bigger appetites, juggling your diets at work, the affects of aging, managing your own diets as well as those of your family-than the younger members of the community.

Your participation can help change the discussion, and lend support and solidarity to the thousands of adults like you.

**JOIN**

**THE PROJECT [HERE!](#)**



**A new PKU Cook Book is Ready for order!!**

**Written by a PKUer for PKUers. Available in hard cover and soft cover. Ships globally through Amazon.**

**Click [Here](#) To check it out!**

#### Letter from the Editor

*As I begin on my second ever edition of the CanPKU news letter, I am once again thankful to everyone who has taken the time, and been willing to share their PKU stories, and advocate for PKU patients across the country! I really do want to hear from you, please don't be shy! My apologies for all those who have received private messages on social media asking to hear your stories, our PKU community is small, but strong!*

*It is my goal to continually bring us all together, sharing personal experiences through the news letter.*

*Before Facebook groups, and #hashtags on Instagram, when my son was first diagnosed, I longed for conversation with someone who understood what PKU was about. Like many new moms I vented my frustrations to my mom friends.*

*"My son has a runny nose, he fed some lunch to the dog and I'm not sure how much, and he wont drink is formula,*

## Articles you may enjoy:

[A BRAMPTON man is to embark on a 100-mile run for PKU](#)

[PKU Women and Husband to adopt 2 PKU children from China!](#)

## PKU Patient Registry



Still haven't registered?  
Click [Here](#), To make A difference!

Thank you again for your commitment to accelerating PKU research!

Did you [#weCanPKU](#) for PKU awareness month?

# Isn't just a number sign anymore! Using [#weCanPKU](#) on your photos on social media allows people to search, and connect with those in our CanPKU community, share ideas, photos, ect!

now his levels are high and i'm not 100% sure the cause!" My mom friends would answer me with, " That sounds really frustrating, today my kiddo had diarrhea, I think that's from teething if it helps. Also, your little guy can have fish right?"

With the technology available to us today, no one HAS to feel like they can't relate to others! Did my short story remind you of a situation you once found yourself in? Do people assume you still eat fish and chicken?

I want to hear about it!

Send me your photos, your frustrations, your triumphs!

With your help and support, we are truly making this country, this planet! A better place, for PKU patients and families.

Sincerely,



Arlene McDonald  
Newsletter Editor  
Canadian PKU & Allied Disorders Inc.



Looking Forward to the Next Issue?

**PLEASE SHARE!**

Our next newsletter will be due out in September.  
Let us know what you think!

Send feedback to:  
[\*\*newseditor@canpku.org\*\*](mailto:newseditor@canpku.org)

## Give it a try!

*Don't stop there! I will continue to watch for your hashtags #''s and will select some to feature here in the newsletter!*

# #weCanPKU

Upload photos of any of the following challenges, (or make your own!) for PKU Awareness month on Facebook Or Instagram. Use the hashtag #WeCanPKU for a chance to be featured in our next issue!

- Preparing, Weighing, or Eating low protein food
- Fry Day Friday! (include how much phe is in your fries!)
  - Eating out, Low Pro
- Delivery Day! (a photo when your low pro food arrives)
  - Blood Test day
  - Bottoms Up Formula!
- Paint your nails blue for PKU
- Traveling with PKU
  - PKU Clinic Day
  - PKU Easter
  - PKU STRONG
- Achievement (a grade, a sport, stayed on track, ect!)



## #weCanPKU Photos!!



# sphere™

Vitaflo's first GMP-based medical food for use in the dietary management of Phenylketonuria.

- ◆ Lower in calories and sugar versus other GMP-based medical foods for PKU per protein equivalent
- ◆ A powdered GMP-based medical food available in pre-measured packets
- ◆ Available in Vanilla and Red-Berry flavors

Visit [www.Vitaflo.ca](http://www.Vitaflo.ca) to learn more about our medical food options for PKU.

Medical food intended for use under medical supervision.  
© Reg. Trademarks of Société des Produits Nestlé S.A.



[Learn More](#)



# PKU Friendly Sloppy Joes!



Current and Previous CanPKU Vice Presidents!  
Tanya and Nicole!



## Cambrooke Therapeutics' latest breakthrough!

The lowest Phe GMP medical food available for PKU!

**20/20** GLYTACTIN BUILD™ 20/20

COMING SOON!

- ✓ Lowest Phe
- ✓ Natural!
- ✓ Lowest calorie GMP nutritionally complete formula
- ✓ Low volume
- ✓ Low carbohydrates
- ✓ Zero total sugars
- ✓ No artificial sweeteners, colors or flavors
- ✓ Synbiotic combination of probiotics & prebiotics to support gut health

The lowest Phe and lowest calorie complete GMP product available!



Request a sample today! [cambrooke.com](http://cambrooke.com) or 866 456 9776, opt 2

[Learn More](#)

## Did you know PKU gel can be mixed to a spoonable semi-solid or a low volume drink?

PKU gel is a second stage medical food designed to decrease reliance on high volume formula and may promote appetite for regular foods.

For more information or to request a sample, visit [www.VitafloUSA.com](http://www.VitafloUSA.com)



Innovation in Nutrition  
A Nestlé Health Science Company

Medical food intended for use under medical supervision. ® Reg. Trademarks of Société des Produits Nestlé S.A.

[Visit Our Sponsor](#)



Jen Pino  
CanPKU National Events Co-Ordinator!



**PHENYLADE®  
GMP MIX-IN**

**NEW!**

[Learn More](#)

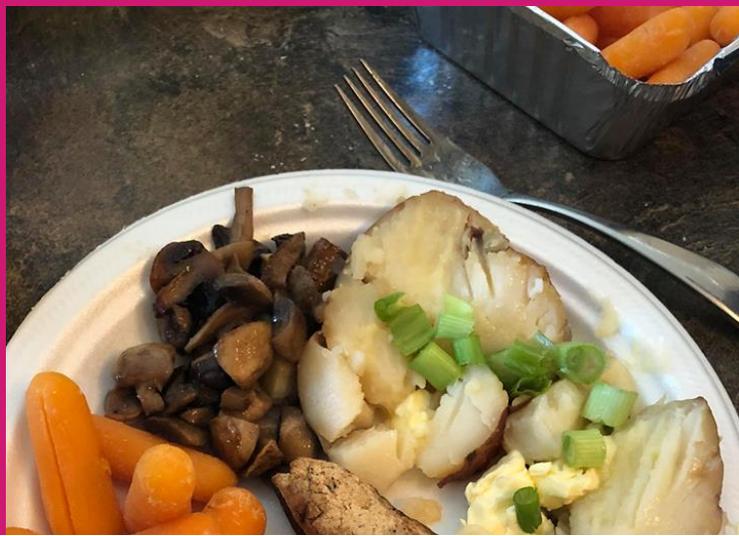
**Now available in Canada!  
Phenylade Gmp Mix-In**

Introducing a new GMP-based PKU formula that is tasteless and odorless! Simply mix with water, any flavored drink or current PKU formula.

Each single serve pouch provides 10 g PE and 15.3 mg of Phe with only 42 calories!

To request a sample , call 1-877-636-2283

[Learn More](#)



GOODS &  
**SPECIALTY  
FOOD SHOP**

Specialty Food Shop offers products and services that meet the dietary needs of metabolic infants, children



## Camping with PKU!

Low Protein Cook out at the lake, garlic fried mushrooms, BBQ'd baked potato and carrots, and a Country sunrise Mushroom burger "Smokie"

### 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 any identifying information to outsiders. For more information, please don't hesitate to contact us.

GUIDANCE

and adults living across Canada.

- Metabolic formulas
- Low-protein foods
- Metabolic eNewsletter
- Metabolic workshops

To hear about low protein products, promotions and events, click [here](#) to sign up for our Metabolic eNewsletter.

Website: [specialtyfoodshop.ca](http://specialtyfoodshop.ca) | Email: [sfs.admin@sickkids.ca](mailto:sfs.admin@sickkids.ca)  
Call: 1-800-737-7976 or 416-813-5294 | Fax: 416-977-8394

[Visit Website](#)

**Save  
\$10!**

Become a CanPKU member and receive many great benefits as well as a \$10 off coupon for [HowMuchPhe.org](http://HowMuchPhe.org)! Already a member? Email [Tanya Chute](mailto:Tanya.Chute) and request your coupon today!

Limited Quantity Available - Sign up now!