



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!](#)

Thank You Sponsors!

GOLD

B:OMARIN

SILVER



Greetings!

Well here it is, the 35th issue of CanPKU News,

I hope everyone had plenty to enjoy over the holidays, and now, here is our first CanPKU News Letter of 2019!

We continue to see success stories with the Disability tax credit approval for PKU, a few articles highlighted this quarter. This makes CanPKU 15/15 with appeals to the tax court, the most recent 13 without having to go to trial!

As mentioned before, John worked with our family and our DTC before I became news editor here at CanPKU. We were denied in 2008, and again in 2010. The 3rd application was made with Johns support. We did proceed to tax court, but our appeal was settled successfully without a trial!

If you are considering applying for the DTC, please contact our president John Adams!

I've been encouraged to share an article myself, on some of my experiences with raising a PKU child, its emotional. It would be hypocritical for me to ask me to share your life stories, and not share mine, so its here this issue for your viewing!

2019 Save the Dates have started with TWO Camps this year in TWO locations!

This issue features a few Maternal PKU articles, perfect for spring, and good to save for when you decide to do some PKU family planning of your own!

Speaking of spring, It's cold here in Manitoba, and it feels like the 355th day of winter! I'm dreaming of warm sun and BBQ's. If your with me don't forget to check out the Low Pro Potato salad for your next BBQ!

As always I want to hear from you!! Please don't be shy! You can email me anytime at newseditor@canpku.org if you have questions about the news letter, would like to share a story or photo, or want to join the NEW old fashioned Penpals!

I look forward to hearing from everyone Next quarter!

REMEMBER MAY IS PKU AWARENESS MONTH! Be sure the #weCanPKU your public photos, or submit them directly to me, or our CanPKU social media Pages for feature, and to help spread awareness!!

Sincerely,



Arlene McDonald
Newsletter Editor
Canadian PKU & Allied Disorders Inc



NUTRICIA
Metabolics
Inspiring Futures

BRONZE



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.



2019
Save the Date

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 Adam

The big questions for PKU right now are:

1. Will our frontline therapies (medical formulas and modified foods) be included or left out of the scope of national Pharmacare? Expect this issue to be addressed, or not, in the final report in June of a national advisory council.

Spoke to its Chair earlier this month. Reminded him it is the issue in our CanPKU written submission.

2. When will Kuvan coverage by government drug plans get resolved? It had been nine years since Health Canada approved it as safe and effective (at least for some). Still stuck in red tape of government processes.

3. What are the lessons of Kuvan for Palyngziq coming to Canada? Will BioMarin bring it here if they cannot count in timely coverage by governments or private insurance?

4. Gene therapy: There are signs that the research and development of a PKU cure (as distinct from a therapy) is getting serious. I am going to a scientific meeting in April to learn the latest. I think it is possible that one or more drug developers will apply this year to start the clinical trial research on the first humans. Stay tuned.

5. When I was born, there was no treatment for PKU. I plan to stick around to see its cure, proven and approved.

6. More wins for PKUers applying for the DTC (Disability Tax Credit). In March we had two more wins at the Tax Court of Canada, both without a need for hearings. CRA folded in the days or weeks before the trial date.

7. In May, I will be at the annual conference of Canada's metabolic clinics to update them on CanPKU's work. Will

Join us at a 2019 educational event near you! Learn from the experts, try new products, mingle with friends & families, and have a fun time!

Next up:

BC PKU DAY!

Vancouver, [Sunday 14th, 2019](#)

Camp MagniPHEque

September 6th-8th

Saskatoon Sask.

September 27th- 29th

Douro-Drummer Ontario!

AT PKU Day -

Newfoundland, [End of June/Start of July 2019](#)

More information to follow

Journée PCU Québec

QC PKU Day

- [Information to follow/ informtion encore à venir](#)

Information on up coming events and scholarships can always be found at:

<http://canpku.org/upcoming-events>

Have your say!

[Click here to provide input on what you would like to see the day include!](#)

distribute a handout on how PKU qualifies for the DTC. This Garrod Symposium will be in Toronto.

Tip: If a clinic professional balks at PKU DTC eligibility let me know. Happy to engage in continuing medical education. It is about reading two paragraphs of the Income Tax Act.

8. Won a travel grant to attend a conference in Edmonton in April by the organization which assesses the evidence of cost and benefits for new drugs in Canada (except Quebec).

Representing the Best Medicines Coalition, an umbrella for 27 national patient organizations.

Sincerely,

John Adams.



Message from the Vice President

By: Tanya Chute

Hello All!

Last year, I attended an event held in San Francisco, which was hosted, and paid for by BiOMARIN. It was designed to help bring together patients as well as PKU Associations from across the United States, and included CanPKU, to discuss how better to serve our adults. I am thankful for the chance to do that and love hearing from our adults on how we can help, but more than all of this, upon reflecting on what to write for this newsletter, I was brought back to a statement that was made, and I immediately fell in love. "Alone we are rare, together we are family". Whether you call us a community or family, it's all the same to me. It is the reason I started helping with CanPKU and the reason I continue to pour all that I have into the organization. My son is rare, we belong to a great community. YOU make that community great! Why am I reflecting on that for this newsletter? I also was giving the opportunity to help organize the regional events this year. I am excited to be able to bring together medical professionals, speakers, families and those that are RARE, so for a moment in time, you are not rare. You are part of this community. These events will launch starting in April and continue throughout the year. They are currently in various stages of planning. They are for YOU! In addition to the regional events, we have fundraising events, that are to inspire the feeling of community or PKU Family. Try to get out to a Pins4PKU event if you can! You may just meet others who are "like you". Last year, our local event was attended by 2 PKU Adults and 4 PKU Children, along with friends, grandparents, aunts, uncles, cousins, moms, dads, siblings,... the list goes on. But there PKU was not rare! We are a strong community! It was a great day out just having fun bowling. Being community. The ripple effect of this fun day, was that this was happening across the country on various days, together they raised about \$12,000 to help bring together more community for our regional events including our camps. Don't be alone. Be part of the community. Come out to





Family Camps for All Ages!
OUTDOOR ACTIVITIES!
 Catering to Both Non and PKU Diets!

2 Locations in 2019!

September 6th to September 8th - Saskatoon, SK!
 September 27th to 29th - Douro-Dummer, ON!

Cost for staying on site for the weekend:
 Up to five years old = \$50
 Six years and older = \$125

Visit: www.canpku.org/CampMagniPHEque For More Details!

Travel Scholarships Available!

Click [HERE](#) to learn more about travel scholarships!

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

\$501- \$1000

\$101 - \$500

- Mrs. Stephanie Koza... Thank you!
- Mrs. Joyce Swain... Thank you!
- Mrs. Bertha White... Thank you!
- Iron Hawks" c/o "Gene Edwards".
- PKU Poker Run. Thank you!!

\$20- \$100

Ms. Lori Arnott..Thank you!
 Mrs. Michelle McConnell.. Thank you!



events. See what we offer. If we don't offer what you feel you need, then tell me what you need, and we will work to do better! Don't let funds get in the way, we bowl for you! I will never say I don't enjoy or appreciate the travel that comes with the events; I have traveled by car, train and plane. The part I love the most, meeting YOU! Seeing the face of PKU. Making sure that you know you are not alone, you are family/community. Eventually, I hope to get to every region, know every clinic, be part of your PKU Community, but until then, get out there and meet each other!

Tanya.

The CanPKU Report Card of Provincial Coverage



was last updated in 2016. CanPKU is still involved in all kinds of advocacy work to help improve the lives of families living with PKU. From supporting Disability Tax Credit Applications, to trying to secure better coverage of foods and formulas in provinces that need it, to fighting for mandatory labeling of aspartame products and inclusion of rare drugs in a National Pharmacare plan... the battles continue, and supporting documents can often help sway decision-makers in our favour.

Last time we collected information for this Report Card, we went straight to the clinics to gather information about what was covered in each Province/Territory, and what services were available. This time around we have decided to include the voice of the people - this will help us gather more responses and will ensure that public perception is fairly represented. Although it matters what is actually available in your region, what you think is available in your region is equally important! Survey responses will help us update our report card but will also help guide our advocacy efforts by highlighting what is needed most in each region. It is important to realize that this report card is not meant to be a judgment of the clinics, but rather an assessment of how well the government of each Province/Territory takes care of their PKU people.

We invite patients, caregivers and clinicians to all

We would like to acknowledge those who contributed by donation.

participate in the survey. Each person should only do the survey once, although multiple responses from within the same family are perfectly acceptable (don't tell me you and your spouse always agree on these things!) We will be collecting survey responses until March 31st and aim to have an updated Report Card available for publish in the June newsletter. Your voice matters - make it heard!

PKU Profile



Fill out the new survey [Here](#).

Review the 2016 Report Card [Here](#).



My girl....CPKU

She's a rockstar on the Soccer field (plays Forward and usually earns about a 3 minute break each game). She shows beautiful

Texas Longhorns and has started her own ranch brand - Loving All Ranch. She's a straight A student, Cadette in Girl Scouts, TLBT (Texas Longhorn Breeders of Tomorrow) director and she makes money selling longhorn beef. She's made

What the heck is Peg Pal?

Blog post by: JennPKU

Hey all! I've been seeing lots of posts on my PKU groups on Facebook asking about PEG-PAL, so I decided to write a post about my experiences with this PKU wonder-drug. If ever there was a time to have PKU....IT'S NOW. This drug is a REVOLUTION! Here we go:

I'm 25 and currently live in Omaha, Nebraska where the only PKU (metabolic) clinic in the state is located. Even more convenient, I'm a third year medical student at the University of Nebraska Medical Center. I'll be a doctor in a year, yay! So it's fair to say I'm at the hospital fairly frequently.

I tried Kuvan, another FDA-approved Biomarin drug for PKU, and unfortunately didn't respond. Since then, I've been bugging my doc about this PEG-PAL thing and involving Nebraska in one of Biomarin's (the PEG-PAL creators) clinical trials.

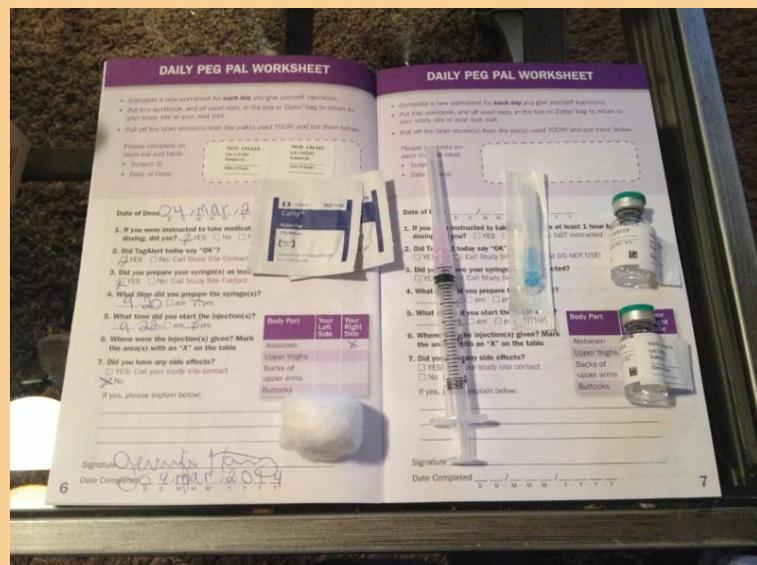
Hallelujah they listened! Last winter I was notified UNMC's proposal to become a study site for the PEG-PAL trials. Side note... props to my physician for making this happen. There's an unbelievably complex time-consuming, tree-killing, paper-dense process sites must go through to become "approved" for such a study. The man-power and time it takes to make this happen is crazy...but that's a whole separate story.

enough money to purchase her own cows and currently owns 7 under her ranch. She tracks her own phe intake (300 mg phe day) using the How Much Phe app. She loves to cook Using recipes from Cookforlove.org and her own creations. She's 12 years old y'all. PKU has not hindered her life at all. It's an annoyance at times, but has taught her that hurdles are meant to be crushed.
 PKU STRONG ☐☐

Submitted By: Michelle Smith

We love to shine the spotlight! To be featured in this column, please submit a photo and paragraph to newseditor@canpku.org.

Read more [Here!](#)



Roll Call!!

Are you a Canadian PKU Parent or Patient? Below is a list of contact information linking you to one on one support, volunteered from our PKU community!

Erin Mullings

Two children with PKU: Aspen (7), diagnosed in April 2012 and Calla (5) diagnosed in November 2013.
 Hamilton Ontario
 Click [HERE](#) to Contact.

Ashley Sulpher

Parent of Anderson, diagnosed in May 2017
 Ontario Canada
 Click [HERE](#) to Contact.

Angel Edwards

Parent of Delilah, diagnosed in September 2014
 Ontario Canada
 Click [HERE](#) to Contact

Tanya Chute

Parent of Jacob born and diagnosed May 2010. Also born as a micropremie at 26 weeks. Ontario Canada
 Click [HERE](#) to Contact.

Amanda Cosburn

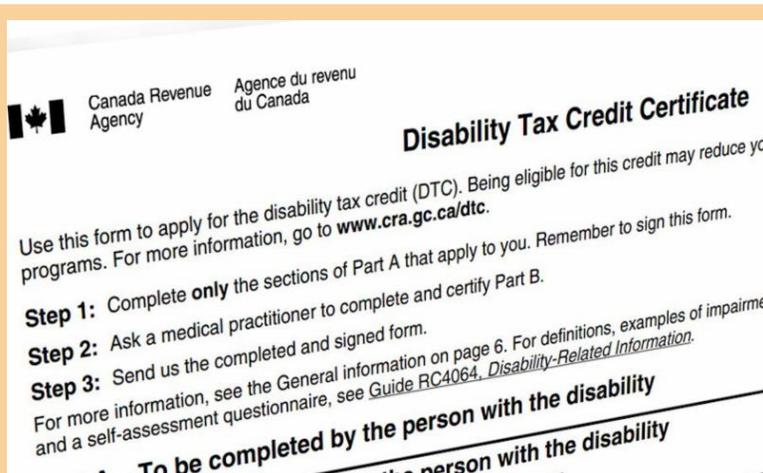
Maternal PKU/ adult advocate
 Diagnosed in 1986
 Kamloops bc Canada
 Click [HERE](#) to Contact.

Stephanie Garcia

PKU adult and advocate
 Diagnosed in 1987
 Hamilton, Ontario
 Click [HERE](#) to Contact.

Arlene

Member of CanPKU since 2007



Another Tax Court decision upholding a disability tax credit for phenylketonuria ("PKU")

Hughes V. The Queen.

Applying for the DTC on behalf of yourself, or a loved one for PKU is not an easy task, however, with each winning case, I believe it becomes easier for the next person.

We have mentioned before that CanPKU will help you with your application to for the DTC, as well as stay with you during any appeal, or objection process.

CanPKU president John Adams, helped news editor Arlene McDonald and her family take their application right through to a formal objection to tax court in 2017.

Mother of CPKU Boy, Born 2007
Manitoba, Canada.
Click [HERE](#) to Contact.

**John Feruglio / Spouse
Parents of Amy (22)
Regina Sask.
Click [HERE](#) to Contact.**

**Brian Quinn
Adult PKU/ Atlantic Provinces
Click [HERE](#) to Contact.**

If you're interested in volunteering your time/ Pku experience with others in the PKU community, and would like to be added to the roll call. Please email your information to:

newseditor@canpku.org

With subject line "Roll Call"

****Note: This is not a replacement for medical advice, your PKU clinic is the best place to have medical questions answered. These are people with personal experience of PKU diagnosis's, offering to be a sounding board/ friend. Please always check with your clinic before making any changes to your treatment.*****

2017.
Arlene had applied on behalf of her son Marcus, twice prior to winning outside of tax court in 2017. Both applications were denied. The second application was appealed with additional information, and then denied.

The CRA Can be intimidating and difficult to navigate, but CanPKU can help you!

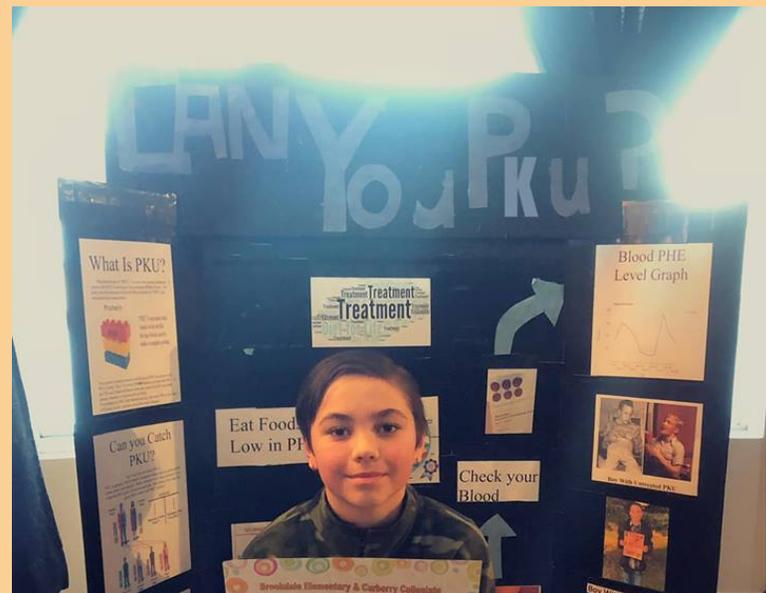
[HERE](#), is an article of yet another DTC for PKU case, that makes a clear point of how PKU qualifies for the DTC under CRA guidelines.



You have only 90 days from a negative CRA decision (Notice of Determination or Notice of Re-determination) to file an objection. Pay attention to the dates on your correspondence from the CRA, regarding your DTC application.

That is the way to preserve your rights as a taxpayer.

Can You PKU?



Pins 4 PKU 2019

CanPKU is currently seeking energetic, fun, exciting folks (or just someone looking to help out) to organize a bowlathon in your city!

It's EASY! We will help!
As little as a group of friends,
as big as you can dream!

email tanya.chute@canpku.org



**Can we beat last years #s?
Funds raised help PKUers and families
travel to Camp MagniPHEque**

**Please contact:
tanya.chute@canpku.org
to register and get a pledge sheet to ensure that
we have enough lanes booked at the center
closest to you!**

Pledge sheet can also be downloaded [by clicking here](#).

Current locations (More to come)

Brantford, ON

Sunday May 26th 1-3 pm EST. Star Lanes Limited
Brandford ON N3S 3B9 Register with
k_charlton@live.com

Kamloops, BC -

Sunday May 11th 12-2 pm PST. Falcon Lanes 2020
Falcon Rd, Kamloops, British Columbia V2C 4J3.

Register with
amandacosburn@gmail.com

Newmarket, ON

- We're working on it. Stay tuned!

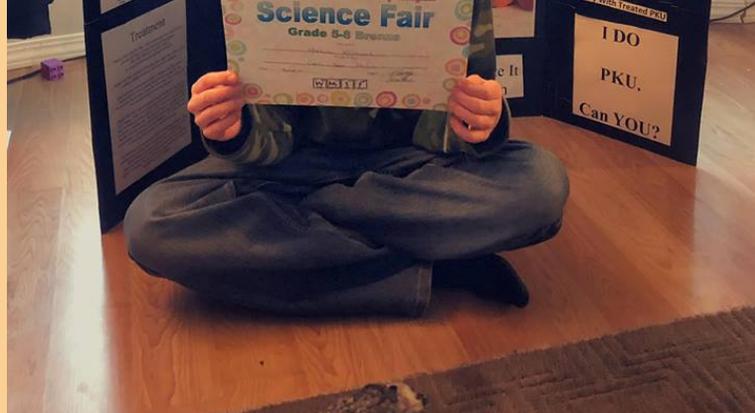
Peterborough, ON -

Sunday May 5th 2-4 pm All you can bowl. . Lakeview
Bowl, 109 George St. N Peterborough. Please register
with tanya.chute@CanPKU.org

Sparwood, BC

- Saturday May 4th 12-2 pm. All you can bowl. Elk
Valley Fun Centre 1290 Ponderosa Drive. Sparwood.
Only 36 spots available. Please register
with npallone@Shaw.ca.
Elk Valley Fun Center graciously donated lanes and
shoes! Minimum \$20 donation suggested.

[Learn More Here!](#)



11 Year old Marcus was diagnosed with PKU at birth in 2007. On March 6th, 2019, he presented his informative science fair project titled, "Can You PKU".

The presentation covered the basics of PKU, how amino acids are building blocks of protein, how recessive genes work, and the importance of the PAH enzyme. Marcus included a working moving diagram of how "Phe" is metabolized in Non PKU people, vs PKU people.

After thoroughly explaining how treatment works, Marcus challenged his teachers, peers, and science fair judges to try a PKU cooler supplement, as well as follow a low protein diet that he had menu planned in detail for 48 hours.

Marcus came home from the science fair with Bronze in his region, and will be taking his presentation to divisional's just in time for PKU awareness month!

Marcus aspires to one day be a geneticist, and help treat and possibly cure children with PKU. In the mean time he is doing a fantastic job advocating, and bringing awareness to the condition, as well as the importance of diet for life!

Congratulations Marcus! Keep up all the hard work!

Recipe Corner

Potato Salad for BBQ Season!



Potato Salad means Summer to Most of us! We even make Potato Salad in a Pita or wrap with lots of lettuce, shredded carrots, thinly sliced radishes and red onions - it is delicious (think low protein Chicken Salad).

Do not overcook the potatoes or you will get a mealy salad.
Cool the potatoes before you add the dressing.



You can substitute Miracle Whip for the mayo which will decrease the phe, but we don't like the tang in our house.

If Molly is craving potato salad and has had a bit too much phe to have a decent portion, I reduce the potato by 1/4 and add cassava (no guest has ever noticed) so you can also reduce the phe that way. Please note that you should keep a little of the mayo/veggie mix on the side and add it to cooked macaroni (Aproten Rigatini) and you have a macaroni salad as a lower side dish.

Ingredients

Unites of measurement: Grams

- 900 g Russet potatoes, peeled & cut into 3/4-inch cubes 636mg
- 30 g Distilled white vinegar
- 50 g Red onion, minced 12mg
- 50 g Celery, chopped fine 10mg
- 51 g Carrots, chopped fine 16mg
- 50 g Red pepper, chopped fine 12mg
- 30 g Dill Pickles or pickle relish, finely diced 5mg
- 30 g Pickle Juice
- 151 g Mayonnaise 101mg
- 10 g Dijon Mustard 28mg
- 8 g Fresh parsley, minced 12mg
- 6 g Salt, to taste
- 1 g Pepper, to taste 2mg

Instructions

1.

Place potatoes in large saucepan and add water to cover by 1 inch. Bring to boil over medium-high heat; add 1 tablespoon salt, reduce heat to medium, and simmer, stirring once or twice, until potatoes are tender, about 8 minutes.

2.

Drain potatoes and transfer to large bowl. Add vinegar and, using rubber spatula, toss gently to combine. Let stand until potatoes are just warm, about 20 minutes.

3.

Meanwhile, in small bowl, stir together onion, celery, carrot, red pepper, pickle, mayonnaise, Dijon mustard, sugar, parsley and salt and pepper to taste. Using rubber spatula, gently fold dressing into potatoes. Cover with plastic wrap and refrigerate until chilled, about 1 hour; serve. (Potato salad can be covered and refrigerated for up to 1 day.)

- Phe Per Serving: 93 mg
- Protein Per Serving: 2.3
- Exchanges Per Serving: 6.2
- Calories Per Serving: 181

Recipe Credit : <http://www.leannebakes.com/2012/11/santa-strawberries.html?m=1>

If you have a recipe to share, please submit it to newseditor@canpku.org.



Congratulations from CanPKU!



CanPKU would like to extend A HUGE Congratulations to Amanda Cosburn, and family, on the announcement of their newest family member, joining them in August of 2019! Amanda is a Board Member of CanPKU, our Social Media Rep, and adult PKU patient and advocate!

Amanda's Blog can be found [HERE](#).

Where you can follow along with her in her Maternal PKU journey. Amanda is also a member of our "Roll Call" section if you'd like to ask any questions, or find out more detailed information on her blog posts!



IN THE NEWS!

Links to articles you may enjoy!

[Articles you may enjoy](#)

[Home Blood test Video!](#)

[Thriving With PKU Youtube](#)

[Powerful "My PKU Life" - Carrie Hall Books available for as little \\$2.37!](#)

MAY is PKU AWARENESS MONTH

****Don't stop in may, keep using #'s all year long for a features in this column !****

#WeCanPKU



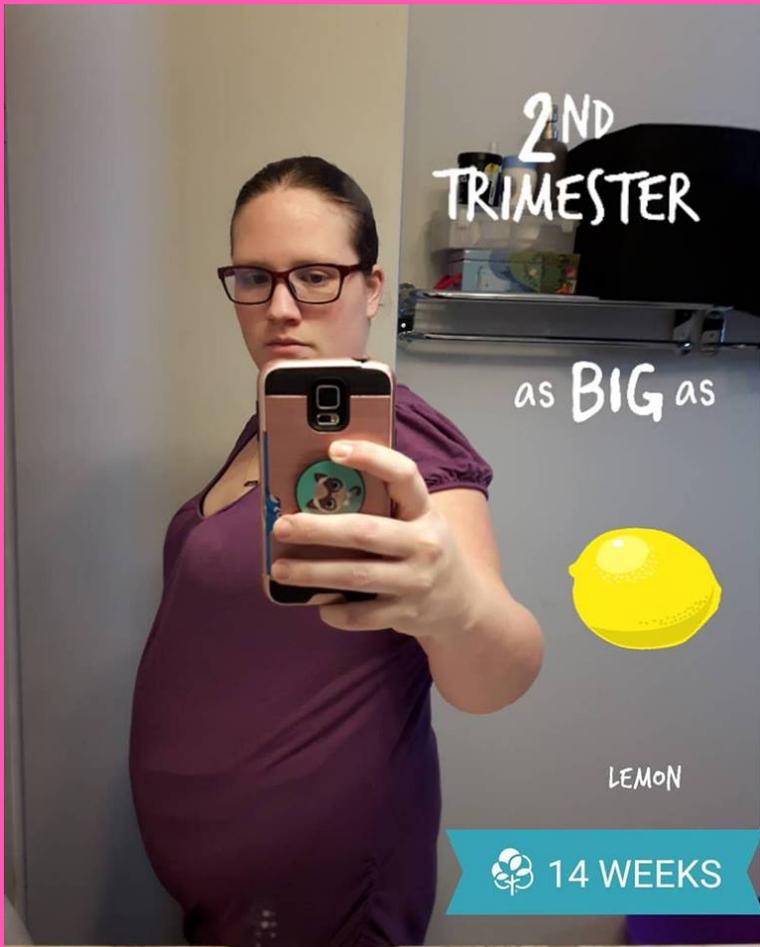
Having Hope

CARRIE C. HALL



The third book in the PKU novel series, written by Carrie, *Having Hope* is a candid look inside her second pregnancy as she shares her private journal entries with her readers.

Carrie's books can be purchased for as little as \$2.79, link for purchasing can be found in our "In the News" Section of the news letter!



Amanda, celebrates the 2nd trimester in her 2nd Maternal PKU Pregnancy, in BC!

Please Make sure your photos are public, or post them directly on to our CanPKU social media pages, using #weCanPKU to make sure we see them!

HOME PHE MONITOR SHAPE OF THE FUTURE!

As you may have heard, there has been progress lately on the development of a home-based phe monitor. One company working closely with the FDA toward approval has asked PKU News to help by surveying the community to further refine the features of, and needs for, such a device.

Since a device like this has never been manufactured before, the company needs a little bit of help from the community as they work out how the device will be used.

SHARE YOUR OPINION



Thank you to VitaFlo VitaFriends for their contribution to the Starter kits. Production of these kits has officially started for 2019!

Starter kits are distributed to all the hospitals in Canada that treat PKU and Allied Disorders. These are organized, prepared, packaged and shipped to be distributed to those newly being diagnosed and/or adults returning to diet (where available).

The Specialty Food Shop in Toronto pays for the postage to get these from CanPKU to the clinics that need them.

Are you someone who has room in their house for some shipments to be stored, time to package them individually and mail them out? CanPKU is still looking for a couple volunteers to help with this project!



That's where you come in. Take this 5-minute survey and help inform the company's development, which they hope to have in clinical trials in 2019. [Click here to take the survey.](#)

TAKE THE SURVEY!



As you may have heard, there has been progress lately on the development of a home-based phe monitor. One company working closely with the FDA toward approval has asked PKU News to help by surveying the community to further refine the features of, and needs for, such a device.

Since a device like this has never been manufactured before, the company needs a little bit of help from the community as they work out how the device will be used.

That's where you come in. Take this 5-minute survey and help inform the company's development, which they hope to have in clinical trials in 2019.

[Click here to take the survey.](#)

Good Old Fashion..



Would you, or your child be interested in connecting with other PKU Patients around the world?

Do you like receiving good old fashion snail mail?

Send an email to: newseditor@canpku.org and let us help connect you with another PKU patient looking for a pen pal

Parenting a PKU Child, Kuvan, and the Hard Days

*Written by: Arlene McDonald
CanPKU News Editor*

**** DISCLAIMER, This information is based on 1 family experience and NOT a replacement for medical advice****

Being a Parent is HARD!

Being a parent of a genetically rare child, adds an additional set of obstacles, some of which you forget, or don't always realize were there.

Once a year, (minimum) PKU will make me cry.

I don't want this to alarm new PKU parents. PKU is manageable, your child's future is bright!

Even within this news letter, you will find tons of examples of PKU adults, who's PKU never held them back!

My point is, its okay, if PKU makes you cry sometimes! The roll call section is a GREAT resource, if you ever feel this way. There are parents of PKUers you can contact, or PKU adults, who will tell you, no matter how mad they may have gotten when they were young, they are thankful for the hard work their parents put fourth to keep them on diet. You can feel assured that the hardest PKU days are worth it!

That being said, I thought this edition, I would share with you, one of my HARDEST PKU Parenting moments. I'm always asking our readers to be vulnerable, share their raw emotions, so it seems only fair, as the news editor, for me to do the same.

MY PKU VS KUVAN experience.

I originally wasn't going to share this. I've shared with my close PKU family, but now that things have settled I feel like our experience may shed light for others, so here it is. I'm not asking for judgment. If you don't like what I say, you don't have too, but I'm not trying to start a feud. (Throwing that out there)

Kuvan. We started our Kuvan trial for our 10 year old in December 2017. We will write off the 1st week as he was super sick.

Week 2 his levels were HIGHER then normal. Week 3 the same thing. No diet change. Only change was Kuvan.

My son is a lot of things to me, but we fight. He is not treated different then his non pku sibling.

During these 2 weeks, we did not fight, it did not take us 1.5 hours of shouting, repeating myself, or needing a "break" from each other to get ready for school. His attitude was in check, and he was pleasant to be around. He did not hate his life, or PKU.

Normally I can tell when his levels are high, because our day to day struggles are amplified, we are both at our wits end. I was SHOCKED when his levels came back high.

Pleasant is not a word I would normally use to describe my son, but for the first time in a LONG time, for 30 days, we enjoyed each other's company. He didn't fight taking his supplement

patient looking for a pen pal!

Have you moved?

Remember to update everyone, including CanPKU, if your mailing address has changed!



each other's company. He didn't fight taking his supplement, we had long deep conversations, about his day, his feelings, and no one got angry.

Due to a lack of reduction in levels, our clinic deemed him a non responder in the 3rd week. I knew something was happening. Something was different, that wasn't being reflected in his levels. I outsourced on facebook support groups, to my PKU community, and got answers from other parents from other clinics. One of the parents, and someone after years of confiding in, i consider a close friend, suggested increasing his calories, as he'd likely become catabolic.

With 1 week left in the trial, I ensured he received 1800-2000 calories a day. And did back to back blood tests. We received those blood tests 1 week after our trial had ended, and he had been OFF of Kuvan. The results? A 35% reduction in levels. Enough to deem him a responder. My clinic was in awe. They didn't seem to understand how this could of happened. Where other clinics knew right away. All that it took was a liter of apple juice a day, and 7 Kuvan tabs.

We will be getting a renewed prescription. However. My clinic had prematurely reported him as a non responder. So we would not receive our Kuvan until the next week.

After a week of fighting every morning. Of loosing privileges, missing activities due to poor attitude and behavior. My son was in his room. Kicking and screaming, throwing things, loosing his mind, hating his life. I was sitting on the couch listening, watching the clock for an acceptable time to open a bottle of wine. After 10 years I know, when he's in this state, he wont hug me, and no amount of calm consoling words will help him. So I sit. And try my best to ignore this, as I know it's late, his adhd meds have worn off, and eventually he will sleep. And we will try again tomorrow. That's when I heard inconsolable crying. It had changed from anger and resentment to utter sadness. Like a break in an anxiety attack, I went to see him.

With some coaxing he let me hug and hold him. Through tear filled eyes, he said to me. "I HATE feeling this way" he went on to tell me he didn't feel normal. That when he was on Kuvan he wasn't overwhelmed or angry ALL the time. That he wanted it back, even if he couldn't eat anything extra.

After crying with him a little and settling him into bed. I realized, PKU is a jerk. Not my son. PKU. He's not ungrateful, full of attitude, or a trouble maker. Even with "safe" levels. His mind functions in a state of constant toxicity that none of us can understand. Like he explained it causes him constant frustration and is overwhelming.

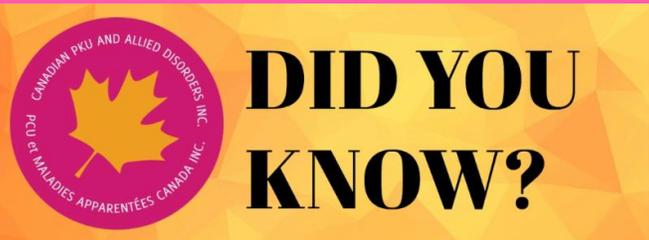
I tried to think of a time I felt this way. I thought back to when he was a newborn. When I ran on 2 broken hours of sleep a night. Trying to manage all his dietary needs and regular newborn stuff that was all new to me. Then I imagined feeling that way at 10 years old.

Our clinic to date, is not up to date with many things PKU related. I strongly suggest everyone look at the top of this page, and read "[PKU and the Brain](#)".

There are side effects to to PKU even on diet with good levels. Something my clinic never acknowledged.

I'm so great-full for these sites and the people I've met, who have helped me through this, and that next week we will have Kuvan back, and he can feel "normal" again.

I'm also SO frustrated that we were days away from never having this opportunity. That we would struggle everyday forever. Because my clinic didn't have or seek all the



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:

John Adams represented, Our news editor Arlene McDonald and her family in their appeal, and then objection with the CRA?

Arlene did appeal to tax court, but her appeal was settled successfully without a trial.

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 so we can continue helping others obtain DTC status without the use of commercial services.

Easy Fundraising?

FlipGive

Want to help us fundraise using the dollars you are already spending?

Do your everyday shopping with [hundreds of great brands](#) and earn cash back for CanPKU with every purchase!

[Join our team](#) and enter our code: BSSCS9

Or find us by clicking on <https://www.flipgive.com/teams/145032-canadian-pku-and-allied-disorders> and JOIN THIS TEAM on the top right.

Share this information with friends and family!

Know someone else who may like to use this tool for fundraising? Use our referral link and both accounts can be credited \$20.00
<https://www.flipgive.com/r/704154>

CanPKU Happy & Honored to be a part, and Co-founder of Disability Tax Fairness Effort.



forever. Because my clinic didn't have or seek all the information available.
To anyone trying Kuvan. Calories are so important. Trust your gut, the doctors don't always know everything.

To parents of / patients that are non responders also struggling. Your doing great. PKU is a jerk. And it's HARD! And you're not alone in your struggles.
That is all.



Another DTC Success Story!!

By Brienna Young, registered nurse, PKU mom and BC resident



I would just like to thank CanPKU for all they have done to assist us in FINALLY getting our 11 year old approved for the Disability Tax Credit! It has taken a few years and multiple denials from the CRA, but thanks to all the hard work of other PKU families, past and present CanPKU members, and especially John Adams, President of CanPKU, we were finally approved!
My son, Hayden, is 11 years old and has CPKU. I applied for the DTC many years ago after going to a CanPKU event in Vancouver, British Columbia. John told us about how to fight the CRA and prove to them why PKU qualifies for the DTC. I heard from other families who had



(Letter from DTFA, "Disability Tax Fairness Alliance")

"We have high hopes and expectations, That the work of the DAC will help reduce and eliminate barriers, to access the DTC for Canadians with severe and prolonged, mental and physical impairments"

- Quote from letter to Minister Leboutheillier

[Read Letter.](#)

I heard from other families who had been successful in their attempts, and I was told not to be discouraged if we received a letter of denial. However, when that original denial letter arrived, it was nearly impossible to not feel discouraged. I told myself I would try again soon, but week after week, month after month, it kept getting put off - until we almost completely forgot about it.

The idea of starting over seemed daunting and just 'too complicated'. I cringed at the thought of trying to re-organize and get everything together again for a second attempt. However, my son and I were lucky enough to win a travel scholarship to attend the first CanPKU camp in Ontario in 2017! There, they had a workshop for those interested in learning about the DTC and had some fabulous tips and tricks. It was at that event that I was re-inspired. After talking to John, I felt that I knew exactly what to do now! They gave us information packages with easy-to-follow instructions and models to assist us in creating our own DTC application. I felt confident that CanPKU would be there to support us in our journey, because this time, we had even more information and winning experiences from other families across Canada to learn from.

In fact, earlier that year my son got a new Metabolic Physician, and she told us she didn't believe

PKU qualified so she didn't feel right about signing the form. When I told John Adams, he insisted on calling her. He was able to educate her and explain to her why PKU qualified. She immediately sent us the signed paper work and we were off! Not surprisingly, we received our second denial letter, but I didn't let it get me down. I knew most people were getting denied and we had all the tools in our tool box to fight them. I sent my letter to John and we started the next step in the process, by filing a Notice of Objection. We ended up taking the CRA to the Tax Court of Canada and sending CRA the two recent cases where Canadian families had won in court at a trial. It was no surprise that CRA backed down and approved Hayden for the DTC!! We did not have to go to a trial.

Thank you to everyone who helped pave the way for us! We could not have done it without these inspirational and educational CanPKU events or the one-on-one support that was given to us! Thank you!!

CAMBROOKE THERAPEUTICS

Cambrooke Therapeutics' latest breakthrough!

The lowest Phe GMP medical food available for PKU!

20/20 GLYTACTIN BUILD™ 20/20

COMING SOON!

The lowest Phe and lowest calorie complete GMP product available!

- ✓ 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

Request a sample today! cambrooke.com or 866 456 9776, opt 2

[Learn More](#)

NEW!

PHENYLADE® GMP MIX-IN

PhenylAde GMP MIX-IN

ACCUEIL | HOME | ARTICLES | PKU | PKU - | CANPKU | AIDEZ PKU QUÉBEC | HELP PKU QUÉBEC

CANPKU

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](#)

The new Cook for Love site has launched!

[Check it out here!!](#)

The wonderful work of Virginia Schuett and Dorothy Corry, the talented Malathy Ramanujan of Taste Connections and pastry chef and up-and-coming low-protein rock star Amber Gibson have joined forces with little old me and PKU News/HowMuchPhe.org (HMP) to expand your culinary options.

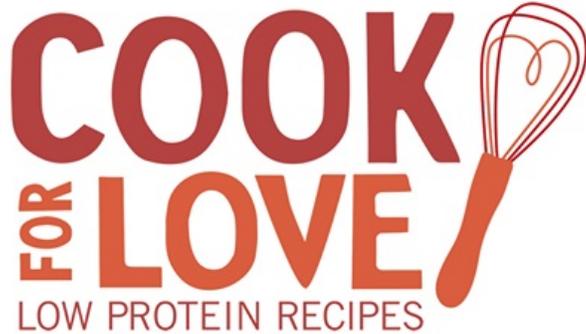
All of the recipes have gone through HMP so you know the phe, protein and calorie counts are accurate, and if values change, the recipes will automatically update.

Search options abound -- pick a chef or a meal type, enter an ingredient, and build a list of your favorites.

In the coming months we'll open up new features including the rating system, comments & questions, sharing your own images and, for HMP users, creating and sharing your recipes with the entire community!

Since CFL originally launched 10 years ago, my goal was to eventually create a community driven recipe site. All of the incredible ideas and recipes that all of you have posted on this Facebook page have cemented that desire. It never could have happened without the technology behind HMP and Sarah Chamberlin's ridiculous work ethic, organizational skills and drive to help this community. Thanks Sarah -- you rock!

As always, access to the site is free. Happy Cooking!



[Looking Forward to the Next Issue?](#)

PLEASE SHARE!

Our next newsletter will be due out JULY 15th. Let us know what

PHÉNYLCÉTONURIE QUÉBEC



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 version of this article, or learn more, click [HERE!](#)

(LET'S TALK ABOUT PHENYLKETONURIA AND BAD MOOD)



POUR EN FINIR AVEC LA PHÉNYLCÉTONURIE ET LA MAUVAISE HUMEUR.

J'étais en train de fureter sur quelques groupes Facebook sur la phénylcétonurie en quête d'inspiration lorsque je suis tombé sur la question suivante : quelle est la pire chose qu'on vous ait dite concernant votre phénylcétonurie? Je peux vous dire qu'il y a toutes sortes de choses qui sont ressorties, des drôles et des moins drôles! Mais une réponse en particulier m'a intéressé.

"Tes niveaux de phénylalanine doivent être hauts parce que ton attitude est nulle."

Le commentaire était suivi de quelques réponses d'autres membres qui ont aussi entendu une phrase similaire. N'oublions pas qu'il est vrai que de hauts niveaux de phénylalanine ont un impact certain sur les émotions, la patience et l'anxiété.

D'un point de vue individuel, ce que je trouve intéressant maintenant que je suis mon régime à la lettre, c'est que lorsque je dévie, je peux ressentir ces différences au niveau de la patience et de l'émotion, j'en suis plus conscient et c'est très bien! C'est extrêmement encourageant de constater qu'on peut faire la différence et ça nous motive à revenir sur le droit chemin très rapidement.

Je comprends donc parfaitement que les gens bien au courant des symptômes d'un régime mal suivi puissent se poser cette question. De temps à autre.

Là où le bât blesse, c'est quand cette question est utilisée comme argument dans une discussion et que ça devient tellement courant que

plusieurs personnes écrivent en commentaire sur Facebook qu'ils se sont fait dire cette phrase. Je sais aussi par expérience que ça ne se limite pas à la phénylcétonurie. J'ai déjà entendu d'autres personnes raconter qu'à la suite d'épisodes difficiles au niveau psychologique, ceux-ci étaient

you think!

Send feedback to: newseditor@canpku.org
to be published in our July issue!

PKU Patient Registry



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

Thank you again for your commitment to accelerating
PKU research!

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, 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!

A Healthy Diet for PKU Includes medicinal formula in British Columbia!



la santé d'épisodes dimanches au niveau psychologique, ceux-ci étaient utilisés pour souligner une attitude négative. Cependant, tout le monde a un niveau de patience différent et chacun a le droit d'être de mauvaise humeur ou d'avoir une attitude désagréable de temps en temps, phénylcétonurie ou non. Le contexte des situations que chacun vit est bien plus déterminant. Le régime alimentaire est dur à suivre. Quand un PCU se fait dire que ses taux sont hauts uniquement par prétexte qu'il est de mauvaise humeur alors qu'il est en plein combat pour essayer maintenir des bons taux... ça peut être contrariant. Tout le monde est de mauvaise humeur à un moment donné ou un autre, mais tout le monde n'a pas nécessairement la phénylcétonurie.



Clinical Study Opportunity

Participants Needed

The NPKUA wants to let you know about the following opportunity to impact possible future treatment for PKU.

Synlogic Inc. is conducting a study of an investigational, liquid oral medication in adult subjects with PKU for the possible treatment of PKU. Eligible subjects will receive investigational product in the clinic, and will undergo safety monitoring, evaluations and subsequent follow-up.

The study is currently open for enrollment in Salt Lake City, Utah. Synlogic will cover travel expenses for potential subjects willing to travel to Utah to participate. Additional sites across the US are opening soon.

Volunteers must:

- Be diagnosed with classic PKU
- Have a phe level above 600 µmol/L
- Be an adult between 18-64 years of age
- On a stable diet (including medical formula if used)

PRA Health Sciences is recruiting for this study. For more information, call Kendall Davis at 919-788-6519 or visit ClinicalTrials.gov and search for study NCT03516487.

Thank you for your participation!

Participants Needed!

The NPKUA wants to let you know about the following opportunity to impact possible future treatment for PKU.

Synlogic Inc. is conducting a study of an investigational, liquid oral medication in adult subjects with PKU for the possible treatment of PKU. Eligible subjects will receive investigational product in the clinic, and will undergo safety monitoring, evaluations and subsequent follow-up.

The study is currently open for enrollment in Salt Lake City, Utah. Synlogic will cover travel expenses for potential subjects willing to travel to Utah to participate. Additional sites across the US are opening soon.

Volunteers must:

- Be diagnosed with classic PKU
- Have a phe level above 600 µmol/L
- Be an adult between 18-64 years of age
- On a stable diet (including medical formula if used)

PRA Health Sciences is recruiting for this study. For more information, call Kendall Davis at 919-788-6519 or visit ClinicalTrials.gov and search for study NCT03516487.

Thank you for your participation!



VOTRE SUIVI NUTRITIONNEL pour maladies métaboliques



There is an French App, Available for IOS and Android, to help manage your PKU? Learn more about it [HERE!](#)

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.



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!

[Visit Our Sponsor](#)



Specialty Food Shop offers products and services that meet the dietary needs of metabolic infants, children and adults living across Canada.

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

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

Website: specialtyfoodshop.ca | Email: sfs.admin@sickkids.ca
Call: 1-800-737-7976 or 416-813-5294 | Fax: 416-977-8394

[Learn More](#)

New From Cambrooke, Creamy Hot Vanilla Breakfast cereal!

Learn more [Here!](#)



breakfast
CREAMY HOT CEREAL



Vanilla



serving suggestion

Nutrition Facts

24 servings per container
Serving size 1/4 cup (28g)

Amount per serving		% Daily Value*	
Calories	124		
Total Fat 2.1g		3%	
Saturated Fat 0.2g		0%	
Trans Fat 0g			
Cholesterol 0mg		0%	
Sodium 4mg		0%	
Total Carbohydrate 14g		5%	
Dietary Fiber 1g		4%	
Total Sugars 1g			
Includes 0g Added Sugars		0%	
Protein 0g			
Vit. D 0mcg	0%	Calcium 5mg	0%
Iron 0mg	0%	Potas. 49mg	2%
Phosphorus 11mg	0%		

*The % Daily Value tells you how much a nutrient in a serving of food contributes to a daily diet. 2000 calories a day is used for general nutrition advice.

INGREDIENTS

Cassava meal, tapioca, non-dairy creamer (sunflower oil, corn syrup solids, food starch-modified, mono and diglycerides, natural flavor, citric acid, and carrageenan), natural flavors (maltodextrin, capric/caprylic triglycerides, flavors).

MANUFACTURED BY
 CAMBROOKE THERAPEUTICS, INC.
 AYER, MA 01432 cambrooke.com

Manufactured in a facility that uses eggs, milk, nuts, soy and wheat.

DIRECTIONS FOR USE

Stove Top: Mix 1/4 cup cereal with about 1 cup water or non-dairy milk in a small pan. Bring to boil, turn heat down, cover and simmer for 5 minutes. Cereal will be thick. Add additional water or non-dairy milk to reach desired consistency.

Microwave: Mix 1/4 cup cereal and about 1 cup water or non-dairy milk in microwave safe bowl. Microwave on high 2-3 minutes, stirring once at the halfway point and again when finished. Add additional water or non-dairy milk to reach desired consistency. Let stand a few minutes before serving.

Infants and toddlers: Use 1 1/2 Tbs cereal and about 1/2 cup water or non-dairy milk and follow conventional directions above. Be careful that prepared product has cooled sufficiently for child. Discuss introduction of solid foods with child's physician.

Store in a cool, dry place.

LOW PROTEIN MEDICAL FOOD

For use under medical supervision for conditions such as inborn errors of protein metabolism.

Amino Acids		per serving
Protein		0.3g
Phenylalanine		7mg
Valine		8mg
Leucine		10mg
Isoleucine		7mg
Methionine		3mg
Tyrosine		4mg
Threonine		6mg

FLCF10639D



NET WT 24 OZ (680 G)

Save \$10!

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

Limited Quantity Available - Sign up now!