



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 33rd issue of CanPKU News, and the 3rd issue for me! We have jam packed this newsletter. If you see a large white space on the right hand side - please look for an option to "view entire message" at the bottom of the email so you don't miss out on some great content.

I'm still making tweaks, and learning the ropes, and I thank you for all the support while I get the hang of it! I know we had some technical issues getting everyone's letter into their inbox last quarter, and we are working hard to resolve that!

I have also been busy soliciting stories on facebook and instagram (again). I am a part of most, of the PKU support groups and have found lots of inspiration from posts there in!

My apologies in advance for next quarter, you may find me lurking in your inbox, asking you to share your personal PKU journeys with the news letter. I will continue to reach out, and attempt to connect our PKU community on a global level. I'm so thankful to have had my PKU child born in the time of technology, where he never has to feel alone in his journey!

That being said, everyone's journey is unique, and individual, at CanPKU news, we understand that. No judgement is passed on your personal stories, and we really do want to hear from you, as you are!

Not one of us is without fault, or struggle, and sometimes it is really nice to know, (especially myself as a parent) , that I'm not alone in my feelings.

I like to hear, that I'm not the only one who feels guilty, or wonders about the state of my child's body, after pumping him full of highly manufactured foods, formulas, medications, and high sugar beverages for calories. It's comforting to see that I'm not the only one who sometimes has to poke a finger, more than once, to fill out the blood spot card. Perhaps the most comforting of all, is to hear from PKU patients, who once had parents, who forced the strict diet and supplements on them. Even when it was hard, or they fought not to comply. To see them as adults, successful, and thankful to their parents, for keeping them healthy, gives me hope, and strength on the days, when PKU brings tears to my child's eyes, and makes his life feel unbearable.

This is why, I'm in your inbox. Why I'm sending reminders to #weCanPKU on your photos. Because, in 2018, no one has to feel alone. I want everyone to feel connected, and validated,



BRONZE



encouraged to stay on diet, even when its hard. If your 40 years old, and still cant poke your own finger, its okay, your not alone. Still add strawberry quick to your formula, in order to stomach it, its okay, your not alone! Are a parent of a PKU child, and feel like the world is crumbling around you, its okay, your not alone!

Please feel free to reach out to me on social media, via the CanPKU page, my personal inbox, or email me at: newseditor@canpku.org if you would like to share something, to help keep our PKU community strong, and connected!

Sincerely,



Arlene McDonald
Newsletter Editor
Canadian PKU & Allied Disorders Inc.



**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.

**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!

2018
Save The Date!

Educational & Networking Events

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

Camp MagniPHEque

Douro-Dummer, ON . September 28-30

Quebec PKU Day



What's John Been up to?

A Message from the President. By: John Adams

Hello from Australia, where I will be speaking four times this coming weekend at the annual conference of the Australia association, which includes all metabolic diet-treated diseases, but of course PKU is the largest group. My topics are PKU history of key families who made a big difference, PKU and the Brain (it is about protecting the brain, not just managing a challenging diet), update on the launch of the Global Association for PKU and a roundtable



Le samedi 13 octobre 2018 de 9 h à 16 h
Saturday, October 13, 2018 from
9:00 AM to 4:00 PM

Sylvan Adams YM-YWHA

Soyez des nôtres pour cet événement plein d'intérêt où vous pourrez apprendre de spécialistes, goûter de nouveaux aliments hypoprotéinés, échanger avec d'autres familles PCU et simplement passer une merveilleuse journée!

Join us at this great event to learn from the experts, try new low protein products, mingle with other PKU families and have a great time!

[Pour plus de détails sur l'événement, cliquez ici!](#)
[For more information, please click here!](#)

Des bourses de voyage sont disponibles - ne laissez donc pas des considérations financières vous priver de cette occasion d'être mieux renseigné ... Parce que la connaissance conduit à une meilleure santé!

Date limite de demande -
Le samedi 22 septembre 2018.

Travel Scholarships are available so don't let finances stand in the way of your education... Because Knowledge Leads to Better Health!

Application Deadline -
Saturday, September 22, 2018.

panel discussion with lots of questions and answers. Thanks to the Australian association for covering the travel costs. Also spending personal time visiting Sydney and Melbourne.

Will be back home in time for our Camp.

Thanks to VP Tanya, board chair David Brennan, board Secretary Francis Grove and Treasurer Frances Goodfellow for coordinated work to have us ready for our Annual General Meeting on Friday, Sept. 28th.

In early July, represented CanPKU and the biannual conference of the US National PKU Alliance in Atlanta. Amazing meeting. Breath-taking range of research into new treatments and possible cures for PKU. Happy to be part of the public launch of the new global charity for PKU, along with Cristian Baigorria from Canada and colleagues from Argentina, Australia, Brazil, Chile, Mexico, Europe, Turkey and the USA.

Continued work on national Pharmacare, taking part in a patient consultation with the federal Advisory Council and on the steering committee of National Pharmacare Initiative of the Conference Board of Canada and the Best Medicines Coalition. Working to

get PKU (and other metabolic) medical formulas and medical foods included in any national pharmacare.

Hope everyone had a safe and enjoyable summer. Fall will be busy.

Sincerely,
John Adams.



Message from the Vice President

By: Tanya Chute

Hello!!

I hope everyone has had a terrific summer! For our friends on the west coast, we hope you are able to breath a little nicer these days. I was thinking of you and how scary the threat of evacuation must be with PKU. We included a Evacuation package in a previous newsletter. It may be found at <http://canpku.org/wp-content/uploads/2016/03/Newsletter-June-2016.pdf>.

Currently, I am wrapping up the planning for Camp MagniPHEque and counting the days until the event begins. Our family is super

YOU ARE INVITED TO CanPKU 2018 AGM



Friday September 28, 2018 at 8:00pm

Friday September 28, 2018 at 8:00pm
Vendredi 28 septembre à 20h00
heure avancée de l'Est

All members in good standing are entitled to participate by teleconference. Only General Members have voting rights on matters put before the membership. [Become a Member](#)

For the full details [Please click here for the Notice of AGM](#)

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

\$101 - \$200

Debbie St John-De Wit

\$20- \$100

Hayden Knox

Dave and Sherry Johnson

In celebration of Barry and Linda Crooks (PKU Grandparents) Anniversary

Stephanie Hicks

Melissa De Wit

Hali White

Chloe Brown



We would like to acknowledge those who contributed by donation.

PKU Profile

...JACE...

excited and can't wait to see old friends and make new ones. Canoeing, Archery, Wall climbing, crafts, campfires - so many things to do - which will our schedule include? The knowledge that will be shared by professionals (medical ones and every day ones like those living with PKU) will be valuable to all of us.

Looking forward, myself and Brian Quinn (Adult PKUer from NFLD) will be attending a conference "BioMarin's PKU Advocacy Summit and Advisory Board" This will be focusing on Adults with PKU and I personally am looking forward to hearing about ways to better engage with this demographic. This will be my personal goal for 2019. Feel free to send me emails to tanya.chute@canpku.org with any feedback, suggestions, or topics you would like myself on behalf of CanPKU to look at. Your feedback can help us better serve your needs. We are here for everyone in our community. Tell us what you need from us! I would also like to thank BIOMARIN for the funds they provided to include myself and Brian in this event.

Until the next edition,

Tanya.

Back to School

Starting school can be scary for any parent. Nutricia has developed this handy hand out to help introduce PKU to your teacher!

For the full download check out this link <http://www.lowproliving.com/backtoschool/>

What is PKU?

PKU is short for Phenylketonuria (fen-el-key-ton-ur-ia), which is an inherited metabolic condition. People with PKU cannot break down the amino acid phenylalanine (fen-el-al-a-neen) in their bodies. Phenylalanine (PHE) is found in all food that contains protein. PKU is a serious medical condition that is managed with a special PKU formula and a diet low in whole protein and PHE.

What happens?

Since people with PKU cannot break down PHE, too much whole protein in their diet will cause an unhealthy and dangerous build up of PHE in their bodies. High PHE levels are harmful to the brain and can lead to learning problems and other medical conditions if not well managed.

High PHE levels may cause:

- Lack of attention or focus
- Learning disabilities
- An overall tiredness or lack of energy
- Behavior problems
- Anxious feelings
- And more...

To help prevent this, individuals with PKU must follow a special diet low in whole protein and drink their PKU formula throughout the day.

What should I do?

Teach your student as you would anyone else. PHE levels can fluctuate. Your student with PKU may sometimes need additional time or attention to keep pace with the classroom.

Help to make sure your student drinks his/her PKU formula. Peer pressure may cause children to secretly spill out or hide formula. It is important your student has a safe place to consume and store the formula.

Communicate openly with parents and ask questions. Since you spend a good portion of the day with your student, you may be the first to notice PKU-related learning or behavior problems. Bringing this to the parents' attention quickly is very important for successful PKU management.

Helpful Tips

- ✓ Always encourage diet adherence. "Just a taste" can set a bad example that not following the diet at school is acceptable behavior.
- ✓ Treat this child the same as other students. PKU is not an illness and your student is not sick. As long as they follow the special diet and drink PKU formula, your student can be just as successful as the rest of the class.
- ✓ Do not let PKU identify your student. Helping to establish a sense of self outside of PKU is a lesson your student will remember for life.

PKU formula is a critical part of the diet. Since someone with PKU cannot have many foods that contain whole protein they rely on PKU formula to supply special protein. PKU formula is typically consumed several times per day.

**Tobias Hagedorn,
Secretary of the European Society
for Phenylketonuria and Allied
Disorders,
Speaks at NPKUA -Conference in
Atlanta, Georgia (USA).**

"I have a dream, that one day all children will have access to new-born screening and early diagnosis, and to adequate treatment. I have that dream! I have a dream, that one day science will be able to offer us a treatment with minimal impact on our daily life and quality of life. I have that dream! And I have a dream that PKU patients from all over the world will stand up and call health care providers and politicians to listen to them and to guarantee their dignity."

(Taken from Tobias's speech)

[Read The Full Speech Here](#)



Submitted By: Kimberly Santiago

Jace Townsend was born on June 23rd 2016. He enjoys exploring and discovering new surroundings, also spending time watching Moana & Boss Baby, playing with bouncy balls, puzzles, swimming, and going to the park!

He's a happy 2 year old, who was diagnosed at birth with classic PKU.

Jaces's tolerance is 70 mg (not including the phe in his formula, this is just his limit for food) and uses Periflex Junior Plus for his supplement.

His favourite foods are: Country Sunrise chicken patties, Country Sunrise Pancakes, and Mevalias spaghetti with pasta sauce.

Jace is currently in speech therapy due to some frequent high levels from the past causing a delay in

In Lieu of birthday gifts, 11 year old boy collects donations for CanPKU!

Hayden Knox is an 11-year-old boy who has classical PKU. He loves to play soccer and hockey as well as enjoys playing video games like most kids. On his 11th birthday in June 2018, he couldn't think of anything he wanted for his birthday so I brought up the idea of doing a charity birthday party. I have to be honest and say that I borrowed the idea from some very special friends, Chad and Wayne, who have a wonderful son named Grayson who has MSUD (Maple Syrup Urine Disease). I have watched Grayson have similar parties where he has donated so much money to the BC

requent high levels from the past during a delay in his speech. But other than that he is an incredibly smart child with a lot of potential!

Jace lives in Clermont, Florida and he goes to the University of Florida metabolic pediatric care center in Gainesville, for his PKU care.

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



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!

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 Coburn

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.

Children's Hospital.

I explained to Hayden that In Lieu of

birthday gifts, we kindly ask his friends to instead contribute to his "birthday fund". 50% would go to Hayden, and 50% would go to the Canadian PKU & Allied Disorders Inc. He loved the idea and I was so thrilled. There are so many benefits to doing this sort of birthday. For one, it decreases the amount of birthday present clutter that tends to follow a birthday party. We have all been there - when you go into your child's room and see all the toys they just don't play with anymore. Also, it's a nice treat for the parents of the children attending the party. They don't have to go out to a store and hunt down a present - Just a simple homemade card and monetary donation. Most people gave a \$20 bill, which was simple and easy. We had Hayden put half of his portion in his bank account (savings) and half he could keep in his wallet, or buy himself something special for his birthday. This was a great opportunity to teach him about saving money. Finally, and most importantly, it taught Hayden to think of someone other than himself on his special day.

Hayden was able to raise \$160, of which, \$80 was donated to CanPKU. It may not have been a large donation, but it was massive in the eyes of an 11 year old. After all, it was the lesson he learned from the experience which was Huge!

The look of pride he had on his face when he told the Bank teller why he was donating his money to this particular advocacy group was the cherry on top for me as a mom. He told me afterwards how good it made him feel to donate money to CanPKU because "thanks to them my food is free!". He is referring to CanPKU's long fight with the BC government to help cover the cost of low protein foods. Thanks to CanPKU we now get \$3000/year to purchase special low protein foods. This was a very rewarding

experience for Hayden and I would highly recommend it to anyone.

(submitted by Brianna Young)

CanPKU thanks you very much Hayden and Brianna. We would like to send a very special Happy Birthday to a very special kid!

Arlene
Mother of CPKU Boy, Born 2007
Manitoba, Canada.
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.***

Recipe Corner

Thanks Giving Staple Low Protein Pumpkin Pie!



Ingredients

- 240 gm (1 cup) apple juice [7 mg]
- 8 gm (2 tablespoons) egg [26 mg]



Poker run for PKU

by Angel Edwards

HOW IT ALL STARTED....

In September 2014 chris and angel Krauskopf welcome their daughter Delilah into the world. At five days old Delilah was diagnosed with PKU.

In Celebration of Delilah's first birthday her parents and grandmother Deb Brown; Finance Coordinator with Hamilton Health Sciences



created the PKU FUND. The PKU FUND is specifically to used for patient amenities such as; group celebrations, cooking

demonstrations and resource materials.

- 8 gm (2 tablespoons) agar [26 mg]
- 200 gm low protein graham crackers [92 mg]
- 4 tablespoons (1/2 stick) butter, melted [24 mg]
- 3 tablespoons sugar [0 mg]
- 240 gm (1 cup) So Delicious Coconut Beverage [20 mg]
- 4 gm (2 teaspoons) cinnamon [6 mg]
- 4 gm (2 teaspoons) ginger [9 mg]
- 1 gm (1/2 teaspoon) nutmeg [2 mg]
- dash cloves [0 mg]
- 1/2 teaspoon salt [0 mg]
- 30 gm (2 tablespoons) dark rum, optional [0 mg]
- 2/3 cup brown sugar [5 mg]
- 20 gm (2 tablespoons) kudzu , dissolved in 60 gm (1/4 cup) apple juice [2 mg]
- 425 gm (15 oz. can) canned pumpkin [153 mg]
- 60 gm (1/4 cup) heavy cream [60 mg]
- 2 teaspoons vanilla [0 mg]

Instructions

1. Soak apple juice and agar in a medium sized pot for at least 10 minutes to soften before heating.
2. Preheat oven to 325 degrees.
3. Process the graham cracker pieces in the food processor to fine even crumbs, about 30 seconds. Sprinkle the butter and sugar over the crumbs and pulse to incorporate.
4. Sprinkle the mixture into a 9 inch pie plate. Using the bottom of a measuring cup, press the crumbs into an even layer on the bottom and sides of the pie plate. Bake until just beginning to brown, 15 to 18 minutes. Cool completely.
5. Heat the apple juice/agar mixture that has been softening to a boil. Reduce heat to simmer, partially cover and cook for 10 minutes to completely dissolve the agar.
6. Add the coconut beverage, spices, sugar, rum and pumpkin to the agar mixture. Raise the heat to medium. As it comes to a boil, reduce heat and add the kudzu mixture. Cook for 3 to 5 minutes.
7. Puree the pumpkin filling in the food processor until smooth, 10 to 15 seconds. With the machine running, pour the heavy cream and vanilla into the feed tube in a steady stream. Process for 15 seconds longer.
8. Pour the pumpkin filling into the baked and cooled pie crust. Refrigerate uncovered until chilled and set, about 5 hours. Serve chilled.

Yield: 10

Serving size: 1 slice

Phe Per Serving: 43 mg

Calories Per Serving: 262 kcal

Phe Per Recipe: 427 mg

Calories Per Recipe: 2622 kcal

The passion continued with Delilah's grandfather Gene Edwards. A member of the IRONHAWKS motorcycle club, collectively the club organized a ride to celebrate PKU patients, families and friends.

Each of the PKU patients, families and friends stand by the roadside waiting in anticipation for the riders to pass by. What a site to see and experience. At the beginning of the ride as the bikers cruise by, they greeted us all the with smiles, waves and honking horns as they continued their journey. That very moment is one that will never be forgotten and we look forward to next year's event.

The first run in July 2016 donated \$2000.00 exclusively to the PKU FUND, McMaster Children's Hospital. In July 2017; CanPKU president John Adams attended the second year with information materials. A donation of \$1000.00 was given to Camp MagniPHEque and a second gift to PKU FUND was donated. In July 2018 the third year was successful yet again. The tradition continued and both CanPKU Camp MagniPHEque and the PKU FUND will receive donations.

We would like to thank CanPKU for supporting the ride with the generous donation of bracelets. If you are interested in riding or being a spectator please look for details in future CanPKU newsletters or on PKU Facebook groups.

Angel, Chris and Delilah
 Delhi, Ontario

Dr. Barbara Burton Receives "HERO OF PKU" Award



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-](https://www.flipgive.com/teams/145032-canadian-pku-and-allied-disorders)

[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>

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!



"Dr. Barbara Burton received the PKU Hero Award for her longtime passionate care of patients with inborn errors of metabolism. She's been director of the PKU clinic at the Ann & Robert Lurie Children's Hospital in Chicago since 1999 and participated in many clinical trials for new drug therapies, including Palyngiq (formerly Pagvalias)."

(Quoted from the [National PKU Alliance Conference in Atlanta](#))

Dr. Burton has spoken to several CanPKU meetings.

CanPKU would like to acknowledge her and her direct connections to helping Canadian families.

Life changed for one family, on October 2, 2007 when Dr. Burton accepted him into her clinic for a clinical trial of Kuvan. This drug was still investigational and had not been approved on any country. His blood Phe level was 824 umol/L - incidentally, the highest level ever recorded. After two days if Kuvan, his Phe was 192, a drop of 75 %. After 4 weks if Kuvan, it was 132. In time they learned that the PKUer was a complete responder to Kuvan and he gradually normalized his intake of natural protein.

In 11 years if Kuvan therapy, his blood Phe has never been over 360 except twice when he had an illness.

Later Burton traveled on her own time to give talks to Canadian PKU families and clinicians about her world-leading experience in treating PKU.

We have gotten to know Dr. Burton well over the years. She was the first doctor in the world to administer Kuvan to a PKU patient and went in to be the first doctor in the world to administer Palynziq to a PKU patient.

She is a remarkable medical doctor who has given freely of her personal time to the PKU communities including speaking in every region of Canada.

Thank you, Dr. Burton.

Canadian families have had truly amazing experiences with US medical care and US biotechnology thanks to you.



Marc, Age 10. Takes his supplement after Swimming!

The CRA makes life more difficult for people with disabilities

Published July 3, 2018



People with severe disabilities face a number of challenges in everyday life, chief among them financial - including barriers to employment and additional costs to manage their conditions, from mobility devices through to specialized therapy. To ease the burden a bit, governments have created a number of social assistance programs and tax breaks for this growing and evolving demographic group. Arguably, the most important of these is the Disability Tax Credit (DTC).

The credit itself is modest - since it's non-refundable, about two-thirds of people with severe disabilities can't claim it because their incomes are so low they pay no tax - but it opens the door to accessing a host of other programs such as the child disability benefit and the registered disability savings plan.



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!



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:

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

That's why it's essential that eligibility for the DTC be determined in a manner that is simple, fair, consistent and transparent.

Right now, it is anything but.

The application process is onerous, requiring a report from a physician (which often has to be paid for), a 42-step calculation to determine eligibility (which, again, often requires costly professional help) and, finally, a review by the Canada Revenue Agency that too often ends with a seemingly arbitrary rejection.

When medical professionals provide a diagnosis - based on rigid criteria, no less - pencil-pushers in the CRA have no business second-guessing a medical decision unless there is evidence of fraud.

Despite the flaws in the process, people with physical disabilities fare pretty well. The old-fashioned notion that wheelchair = disability still persists.

Those with developmental and psychiatric disabilities face much higher rejection rates when applying for the DTC; people with invisible chronic conditions such as type 1 diabetes and autism have been cut off unjustly and with little explanation.

To make matters worse, people often have to reapply and demonstrate anew that they still have a disability - as if a person with Down syndrome, for example, suddenly sheds their third chromosome 21.

Not to mention that the appeals process is opaque and utterly lacking in compassion.

These problems - which have festered for far too long, in large part because of the lack of leadership from federal Revenue Minister Diane LeBouthillier - came to a head last year.

The Senate standing committee on social affairs, science and technology investigated and exposed these problems in a report titled *Breaking Down Barriers*.

The senators make some sensible recommendations about fixing the DTC and related programs, and even about the treatment of people with disabilities more generally.

The two most important suggestions are that the DTC become a refundable (as opposed to a non-refundable) tax credit so it would benefit the most needy.

Story continues below advertisement

The Senate committee also recommends that everyone in a provincial program for people with disabilities be enrolled automatically in the registered disability savings program. The RDSP is one of the most innovative social programs ever introduced in Canada, a legacy of the late finance minister Jim Flaherty. It allows people with disabilities and their caregivers to set aside money for future care, tax-free (much like an RRSP).

In addition, Ottawa will match private contributions up to \$3,500 annually with a \$70,000 lifetime limit, and provide an additional contribution of \$1,000 a year for low-income participants up to a lifetime maximum of \$20,000.

The RDSP has allowed more than 123,000 Canadians to sock away \$2.5-billion to ensure a little bit of financial security in their future, but it is still woefully underused. No grant or bond should go unused or unclaimed.

While the RDSP was a bold leap back in 2006, the Senate report also reminds us that although it was supposed to be a first step, little progress has been made since then.

There are 1.8 million people in Canada living with severe disabilities.

Drugs for rare disorder

Phenylketonuria hit the market.

July 25, 2018 by Emily Gersema, University of Southern California



"Brady Connolly is an 18-year-old rugby player who can barely eat any protein. No steak, no beans, no peanut butter shakes—none of the foods you'd imagine a young athlete would crave. That's what it's like to live with phenylketonuria (PKU)."

"Since I started taking Kuvan years ago, I've been able to eat a modified vegetarian diet, rather than a complete low protein diet," Connolly explains. "Before Kuvan, I couldn't eat things like breads, rice or pastas. Now, I can at least eat regular carbs with lots of fruits and vegetables. It makes a huge difference."

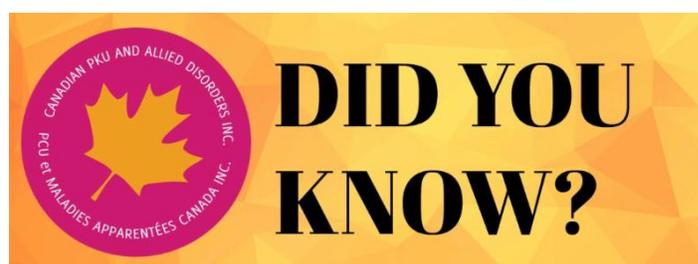
Read More [HERE](#)

The most corrosive and debilitating problem most of them face is poverty, not their underlying physical or mental condition. Accessibility is about much more than ramps, it's about being a full participant in society, economically and otherwise. There is probably no group in society that would benefit more from a guaranteed basic income. As the committee notes in its report, the aspiration for all should be "economic citizenship that ... advances dignity, agency, pride, confidence and self-worth; and eliminates the soul-destroying aspects of welfare." The tax system is not the ideal way to get there, but as long as we are depending on credits, grants and savings plans, they should at least be providing much needed benefits, not creating more barriers.

The last people who should be shaping social policies for the most disadvantaged are anonymous accountants in the Canada Revenue Agency.

Credit:

<https://www.theglobeandmail.com/opinion/article-the-cra-makes-life-more-difficult-for-people-with-disabilities/>



BioMarin has submitted an application to Health Canada for market authorization for Kuvan for PKU in the form of powder in sachet packets.

Each packet contains 100 milligrams of the active ingredient, which is the same quantity as one tablet of Kuvan.

The powder form of Kuvan is a useful alternative for any patient who has difficulty swallowing the tablet form, especially for younger children.

The powder form has been approved in the USA.



Articles you may enjoy

Experimental gene therapies have yielded

"Test the Taste"
- Special Event for PKU Patients: Enjoying Food Thanks to APR Innovative Supplementation.

[Experimental gene therapies have yielded promising results in early trials.](#)

[Living with phenylketonuria in adulthood: The PKU ATTITUDE study](#)

[Thriving With PKU Youtube](#)



APPLIED PHARMA RESEARCH



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



(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 LeBouthillier

[Read Letter.](#)

The initiative, promoted by the APMMC, the Italian patients association of inherited metabolic diseases with the unconditioned support of APR, aimed at gathering genuine feedbacks from PKU patients and their families on the company innovative medical food palatability in a friendly and relaxed setting - a Sunday lunch.

During the lunch, a well-known chef prepared, under medical supervision, a full menu suitable for a PKU diet, made of four dishes - from appetizer to dessert, each of them including APR Phe-free amino-acids.

Learn More [HERE.](#)



Cambrooke Therapeutics' latest breakthrough!

The lowest Phe GMP medical food available for PKU!

20 **20** **GLYTACTIN BUILD™ 20/20**

COMING SOON!

Lowest Phe

#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
- Eat Day Friday! (include how much phe is in your fridge)

- ✓ 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 or 866 456 9776, opt 2

[Learn More](#)

- 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!)



Vitaflo's PKU Vision

Provide a wide range of PKU specially formulated foods to support you throughout life's journey

Our goal is to continue to develop products that offer you convenient and flexible choices for your diet.

For further information about our products, please consult your healthcare professional.
© 2018 Reg. Trademarks of Société des Produits Nestlé S.A.

[Visit Our Sponsor](#)



A PKU Friendly Breakfast in British Columbia!

GMP MIX-IN

[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
GUIDANCE

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](#)

“Have
your
say”

Looking Forward to the Next Issue?
PLEASE SHARE!

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

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



Some PKU Awareness gear in Manitoba!

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!

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.

PKU Patient Registry



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

Thank you again for your commitment to
accelerating PKU research!

**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](#) and request your coupon today!

Limited Quantity Available - Sign up now!