

CanPKU News



from Canadian PKU & Allied Disorders Inc.

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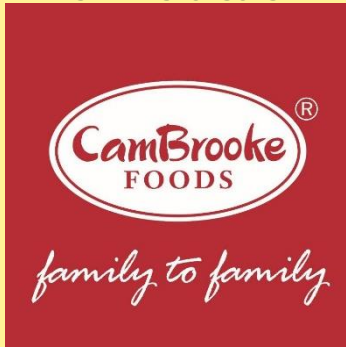
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Dear Reader,

Welcome to the 22nd issue of the CanPKU newsletter, the final edition for 2015 and my first as Editor. I would like to introduce myself and tell you a little about us. Our PKUer is 5 and a half. He loves school (kindergarten), anything with wheels, and most recently is obsessed with Dinosaurs. He amazes me daily with the ability to rattle off scientific names of dinosaurs I have never heard of, but Google confirms their existence! He can tell us facts about each dinosaur, and likes to remind us that he is a herbivore, and we are carnivores. PKU is part of him, but has not slowed him down one bit!

It was about 5 years ago that I read my first CanPKU Newsletter. It had been forwarded to me from a Mom of another PKUer; about the same age as our son. Despite the fact we may never meet face to face, I quickly referred to her as a friend and valued our emails back and forth tremendously. After reading the newsletter, I reached out to CanPKU to see how I could meet more people, attend events, share stories, become more educated in an effort to walk with families who understood the same fears, milestones, excitements, and understanding of the food! I joined as a volunteer, eventually becoming the Secretary for the Board, and am now a Director as well. With time, I learned that CanPKU's support extends much farther than this



newsletter; advocacy for food and formula coverage, outreach to the various levels of government, support to ensure financial programs are obtainable, starter kits, organized events, the list goes on. For me, the home and community is where I am strongest and most passionate about..... and that's ok! We have many people in our organization who do the other things wonderfully! We all work together to try and provide you with the best organization to meet your needs. I aim to provide information on all avenues of what folks want to read about. Saying that, what a great time to review what our newsletter offers and see if we are achieving that goal!

Please take a moment to complete a [survey](#). Your answers matter!

We hope you enjoy this 22nd edition of the CanPKU News! It was fun putting it together!

Sincerely,
Tanya Chute
Newsletter Editor & Secretary

Nicole Pallone
Vice President

John Adams
President & CEO

Important Dates

Between Newsletters



Feb 20th - Please advise by email if you are able to host a walk-a-thon in May

Feb 28th - [International Rare Disease Day](#)

Educational Events:

- April 30, 2016 - Prairies PKU Day ((Winnipeg)
- May 14, 2016 - Ontario PKU Day (London)
- May 15, 2016 - BC PKU Day (Vancouver)
- May 22, 2016 - Atlantic PKU Day (Halifax)
- October 15/22, 2016 - Quebec PKU Day



Recipe Corner

Low Protein Gingerbread Men

Thank you to Brienna Young, mom of Hayden CPKU for sharing her delicious recipe



Ingredients:

- 1 ¾ Cups Baking Mix (Cambrooke foods)
- 1 Cup Wheat Starch
- 2 tsp Baking Soda
- 2 tsp Cinnamon
- 1 ½ tsp Ginger
- 1 ½ tsp Cloves
- ½ tsp Salt
- 1 Cup Butter (162 gr.)
- 1 Cup Brown Sugar (lightly packed)
- ¼ Cup Molasses

Directions:

- 1) Combine 1st 7 ingredients. Mix Well
- 2) Cream Butter, brown sugar and molasses until it is light and fluffy (Using hand held mixer)
- 3) Add dry ingredients gradually to the creamed mixture, mix well. (Using hand held mixer) Chill dough for easy rolling.
- 4) Roll dough out (1/4 inch thick) onto lightly floured (wheat starch) board.
- 5) Cut with cookie cutter and place on greased cookie sheet. Or use parchment paper (which I use).
- 6) Bake at 325-350 degrees for 8-9 mins or until set. Cookies may appear uncooked when you take them out of the oven, but they will set quickly.

A perfectly done cookie will be slightly soft when it is cool.

Nutritional Information: Makes 26 Cookies. 30g each
Per Recipe: 6.30 exchanges (94 mg Phe)
Per 30g Cookie: 0.25 exchanges (<4 mg Phe)

Wheat Starch (1 cup) = 0.50 exch.
Baking Mix (1 ¾ cup) = 0.18 exch.
Butter (162 g) = 4.32 exch.
Cinnamon (2tsp) = 0.40 exch
Cloves (1 ½ tsp) = 0.45 exch
Ginger (1 ½ tsp) = 0.45 exch
In Total: 6.30 exch/recipe

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

What's up CanPKU?

Here at CanPKU all of our 2015 education events are behind us for another year. We are already ramping up for next years events. Please send us an email to info@canpku.org and let us know what topics you would like to see at the next event in your region - your input is greatly appreciated!

Events next year will be held in the following locations:

London, Ontario - May 14, 2016
Vancouver, BC - May 15, 2016
Halifax, NS - May 22, 2016

We hope to have events in the following locations as well but are still looking for suitable venues:

Winnipeg, MB - April 30, 2016
Quebec City, QC - Oct 15 or 22, 2016

If you have information about a community centre, school, church or other inexpensive location that may be suitable, please contact jenn.pino@canpku.org.

PKU Walkathon - May 2016

Coming to your city? (It might be!)



Did you know the PKU Walkathons have raised thousands of dollars over the years for CanPKU? It has the potential to be the biggest fundraiser for us each year. We need your help generating these funds to allow us to continue to work for the PKU Community. And keep in mind, that it does not have to be just a walk! You can ask participants to walk, run, hop, skip, dance, bike or whatever it is that you are passionate about - be creative!

Those who have held a walkathon can let you know its super easy!! The hardest part is picking the date and the place - it can be anytime and anywhere but we suggest the weekend of May 28/29 to finish off May as PKU Awareness Month!

To see just how easy it is, check out our [Walkathon Host Package](#). It gives you step by step instructions and we have other supporting document too. We will be publishing all walkathons planned to help advertise in our next newsletter in March, so please let us know ASAP if you are interested, and have your date and

PKU Profile



Alex is 14 years old and likes playing with his ipod and xbox 360, going places, drawing, and riding his bike. He likes to eat home-made burritos and pizzas - he even likes to invent all kinds of new recipes too! Alex enjoys chatting with his friends, listening to music, reading comic books and playing tricks on his brothers (he's the joker of his family). He's good at mathematics and likes being in school. When Alex grows up, he wants to be involved in the video game industry.

Join Our Mailing List!

New Bronze Sponsor

Innomar Strategies

We would like to send a big "thank you" to Innomar Strategies. Welcome to our family. They have just signed on as a Bronze Sponsor.



Sponsors allow us to continue to support the Canadian PKU and Allied Disorders community.

Toronto Sick Children's Hospital Families

We are aware that Toronto Sick Children's Hospital attempted to reach all families before Valerie's retirement. Should the news be reaching you for the first time, we have outreached on your behalf.

"Two metabolic dietitians will be dividing the PKU patients. If you have any questions or need to reach your dietitian please call Melanie Lameront at 416 813 5753 to be directed to the appropriate person."

location set . Maybe there is another family close by that you don't yet even know about!

Please do not hesitate to host a walk, even if you know that you are the only PKU family in your area! Collecting pledges is easy and is a great opportunity to spread awareness and knowledge about PKU... even if your family is the only family in the area you may be amazed at the amount of support in your community. Even if only small amounts of a couple hundred dollars can be collected, this will contribute significantly to our overall funds raised, and go far towards spreading awareness about PKU in your community!

****Personal Note from your Editor**** I took the leap of faith last year and even thought we didn't have much time to give, we hosted a local walkathon. We simply grabbed a date and planned to "walk the local zoo" together. We were joined by family and friends, as well as a PKU family who was relocating to our city within a few months, currently living about a half hour away. We love the new friends we have made! It's a bonus that we raised over \$100 for CanPKU. Next year we hope to double our attendance and money raised.

Quebec Educational Event

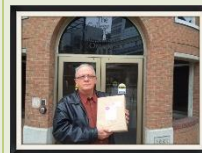
by Helene Dandurand



October 3rd, 2015 was the Quebec Educational Event. Please click this [LINK](#) for an article on the days activities.

Advocacy Ontario

By John Adams



After three years of frustration and bureaucratic run-around regarding access to Kuvan for PKU in Ontario, concerned individuals and families led by CanPKU paid another visit to the provincial Legislature in early December to advocate for changes in the highly restrictive criteria.

PKU adult John W. Adams read to the news media a letter signed by all the PKU specialists in Ontario unanimously disagree with the government criteria and called for an immediate solution. These specialists had proposed alternate criteria in March 2014. In their current letter, these treating physicians noted that the first three applications for coverage had been rejected and most of the doctors declined to go to the bother of applying because the criteria were virtually impossible to satisfy.

PKU Supplement Program

Health PEI

Health PEI
One Island Health System

If you or your child has been diagnosed with phenylketonuria (PKU), you may be eligible for coverage of approved nutritional supplement costs through the Phenylketonuria Supplement Program.

For more information please following the link: <http://www.healthpei.ca/index.php3?number=1026296&lang=E>

Best Medicine Coalition (BMC)

By John Adams



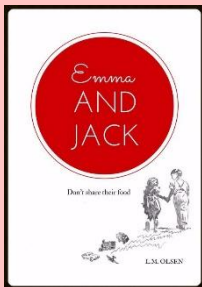
CanPKU President John Adams presented a case study of what has gone wrong with how government drug plans and related agencies are not making Kuvan available to PKU people who respond to it.

The presentation was at a conference in November of a patient advocacy non-profit called the Best Medicines Coalition (BMC). CanPKU is a member of BMC and John was elected to its board of directors earlier this fall.

Here is a link to the slides of his presentation: [Click Here](#)

Emma and Jack Don't Share Their Food.

By Lisa Olsen



As a parent to a small child with PKU, I was running into a problem: how do I explain the concept of sharing and taking turns to my son, but add in that he absolutely cannot share his food? I searched our local library and the internet for books that might help and I kept coming up short. And so I write Emma and Jack Don't Share Their Food. Now, when my son looks curiously at another's plate or a friend offers him food, I always hear his tiny voice confidently say "we don't share food!" And he's okay with it.

Lisa has brought to our attention her book. It is available as a free PDF or for purchase as a hardcopy. For more information check out:

<http://www.lisaolsenwriting.com/#!e-books/vt0www>

PKU Around the World

National Recognition in USA

Dec. 3, 2015 was National PKU Awareness Day for United States of America, as seen [here](#).

Congratulations and hats off to them!

CanPKU also released news that President John Adams had filed a complaint with the College of Physicians and Surgeons of Ontario that the strict criteria meant the government was substituting its opinion for the judgement of medical specialists and thereby practising medicine illegally and preventing highly qualified doctors from doing their jobs.

These advocacy actions generated questions in the Ontario Legislature, news stories in the [Toronto Star](#), [Kingston Whig-Standard](#) and Barrie Examiner and on [CHCH-TV](#) in Hamilton.

The response of the Ontario government to date has been to tell PKU patients who can benefit from Kuvan to wait for one or two more inter-provincial evidence review and negotiation processes, which will most likely take at least another year.

Details of the advocacy campaign, transcript of comments in the Ontario Legislature, and news media coverage are available on our CanPKUAction website at

<http://www.canpkuaction.org/>

Readers are urged to use the email and social media tool on that website to show your support for this campaign. Thank you for your support.

We are always looking to add families to our dedicated team which is taking strides to ensure we are not unheard! Please [email John Adams](#) to join this team.

Disability Tax Credit - Update

We continue to work with members who are looking to apply as well as those who are not having successful applications. We are happy to report that we have had some successes! This is a letter from a family in the Toronto, Ontario area.

Our story begins 9 years ago when we found out that our daughter was born with Classic PKU. As she got older and we needed to start buying foods that were not covered, the extra doctor visits, the extra things you pay for, like parking at Sick Kids, scales, blenders, special formula bottles, when you are on Maternity Leave money is pretty limited and when you have all these extra expenses that you were not prepared for it became very overwhelming. Our daughter started to show signs of anxiety and I had to extend my Maternity Leave with no pay so right out the gate bills were coming in and I was not bring in an income. I had talked to my accountant and he suggested I apply for the DTC. So I

Hat's Off to **NUTRICIA!**



PKU **PUSH-UP** CHALLENGE

From November 2nd to December 3rd 2015



#NutriciaMetabolics & #PushUps4PKU

For every tagged video of 5 push-ups,
Nutricia will donate \$5 to NPKUA / CanPKU

What is PKU?

Phenylketonuria (PKU) is a genetic disorder that a child inherits from both parents. Presently, there is no cure for PKU, which is estimated to affect 1 out of every 10,000 live births¹. However, it can be managed effectively with proper diet and special nutritional formulas designed for persons with PKU. Find out more at www.lowproliving.com.

1. Wockley J, et al. Genet Med. 2014;16(2):188-200.
Nutricia will cap the donation to a maximum of 400 videos during this time period.



We'd like to extend our heartfelt thanks to Nutricia North America for their inspiring **#pushups4pku** initiative! To see a summary of the results, please [click here](#). We are thrilled to receive a part of the \$6,000 that Nutricia is donating to CanPKU and NPKUA. Thanks, Nutricia!

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.

went on line and filled out the forms myself. Of course I was denied and just sort of put it on the back burner. When I heard Nicole's story I was very hopeful and requested the package from CanPKU, and the process began. I followed the sample application and letter that was provided and added some additional medical information. In addition to the PKU, she also has an Anxiety Disorder, a Learning Disorder and ADHD that is common with PKU patients. I had my family doctor fill in the Application and there was a lot of back and forth and changes until I was satisfied. I also included a copy of all of her assessments and letters of diagnosis, reports from her social worker, school, IEP, Occupational Therapist and personal letter like the one similar in the package.

I sent my package off at the of July and just waited and waited. I then started to here that there was a lot of denied applications and started to panic. Well, then in September there it was, my letter from Revenue Canada that she had been approved. I then faxed and also mailed a hard copy to the Tax Revenue Office a copy of the approval letter and sent 2 requests in writing 1) to have my income tax's reviewed and 2) to have my Child Tax Credit to now include the Child Disability Tax Credit. Then I sat and waited again.

Then it happened, the funds began to come in.. October 20th I received \$1200 (last 3 years of Child Benefit), November 5th \$19,000 (Tax Adjustment) and finally on November 20th the final Child Benefit of \$9500. I do not understand why some patients are approved and some are not but I believe you need to work closely with your physician and ensure they have covered everything. The more info and details the better.

Thank so much for sharing your story!



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To sample all Glytactin products, request a Variety Kit.

Please [click here](#) to request a copy of the DTC Information Package! This package is available to any current member of CanPKU.

Happy Retirement to Valerie

By WB Hanley MD



Valerie is retiring - sadly!! She was the PKU Programme Dietitian-Nutritionist @ SickKids for 30 years and treated over 500 patients. She worked long

hours (no overtime pay!) and was usually the last person to leave the department late in the evening. She wouldn't leave until everything was "just right".

The original PKU Clinic in Toronto was housed in the Neurology Department - this was appropriate since most PKU patients (before newborn screening) were profoundly cognitively handicapped and many had refractory seizures. Dr Stobo Pritchard, head of Neurology at the time, realized that there was now a therapy for PKU and it would cease to be a serious neurological problem. He asked me to start up a PKU clinic (in 1963). The first thing we did was to lobby for newborn PKU screening. We were successful due largely to the PKU parent advocacy group who approached Stephen Lewis (MPP) and the news media.

In the early days we pretended to know something about nutrition and our results were "not optimal" (to say the least). Fortunately Valerie came along and taught us how to properly nourish these patients on a restrictive, semi-synthetic low phenylalanine diet. Valerie also participated in a number of PKU research projects including the International (Canada, US and Germany) Maternal PKU study. She was a mentor to many dietitian-nutritionists who went on to treat PKU in other venues.

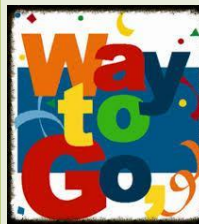
I have always said that over my 35 years as Director of the SickKid's PKU Programme that Valerie did all the work and I got all the credit.

We wish Valerie a wonderful retirement - presumably some of it will be sailing the Caribbean (in the winter) with Brian.

Photo Credit: Thanks to Frances Grove for catching this photo opportunity of Valerie and Dr. Hanley at the Ontario PKU Education Event and sharing it with us for the newsletter.

Regina's Koen Kucher

by John Adams



It is always exciting when we see youth excelling at sports they love. It is even more inspirational when the individual has PKU!

The full article can be found at <http://leaderpost.com/sports/local-sports/reginas-koen-kucher-savouring-a-national-championship>

We are grateful to everyone who has been willing to share their PKU stories and advocate for PKU patients across the country. Together, we have truly made this country a better place for PKU patients and families, and will continue to push for improvements to the various health care plans that we rely upon. Thank you for taking part in these activities, and helping to make Canada a better place.

Sincerely,



NICOLE PALLONE

Canadian PKU & Allied Disorders Inc.

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\$10!**

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