

# CanPKU News



from Canadian PKU & Allied Disorders Inc.

**Dear Friend,**

Welcome to the 27th issue of the CanPKU newsletter.

March has finally arrived and winter will soon be a distant memory! Did you welcome 2017 in with any new resolutions? Are they still intact? Has cupid pierced you or a loved one with a magical arrow? Are you counting the days until the flowers bloom? (I fall into the last category!) Ready to replace the snow shovel with an umbrella any day!

We are gearing up for the first of our regional education events, taking place in the beautiful province of BC.

Sincerely,

Tanya Chute  
Newsletter Editor  
& Vice President

John Adams  
President & CEO

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## EDUCATIONAL EVENTS

REGISTER TODAY!

2017

**Join us at an educational event near you!  
Learn from the experts, try new low protein  
food, mingle with other families, and have a  
fun time!**

**BC PKU Day . Vancouver, BC . April 1**

[Click Here for More Info](#)

[Click Here to Register](#)

**Prairies PKU Day . Red Deer, AB . May 27**

[Click Here for More Info](#)

[Click Here to Register](#)

## Message from President

By John Adams



Lot's happening! I am thrilled to welcome Tanya Chute-Nagy as our new (and third) Vice President; she continues to lead our Camp MagniPHEque initiative

We are actively recruiting a new Secretary for our Board of Directors and a Newsletter Editor to replace Tanya in these two roles. Interested? Let me or Tanya know.

We feel it's important to keep you up to date on what CanPKU is up to. It helps show you the value in the Membership - as many of these activities have costs associated with them. Your dollars help! (Membership for those with PKU and parents of those with PKU is only \$20!) You truly are making a difference when you spend these dollars as it helps us help others! Continue to read to see what we have been up to this last quarter.

Inspired by fellow patient group activists at the 30th meeting of the Genetic Alliance in Washington, DC March 9 & 10. Francis Collins, head of the US National Institutes of Health predicted a gene-editing cure for life-threatening sickle cell disease within five years. Hope CanPKU will follow soon after.

We are in process of meeting with the pan-Canadian Pharmaceutical Alliance (pCPA) which negotiates for all government drug programs for access to Kuvan for PKU

We are preparing a submission to the Quebec agency which does health technology assessment re Kuvan coverage

With Helene Dandurand, participated with the CanPKU display at a public event in Montreal on Feb. 21 to raise awareness of rare disorders sponsored by the Quebec organization for orphan diseases

We met with PKU clinic staff at the Hospital for Sick Children in Toronto to make plans for Camp MagniPHEque. Tanya joined by phone.

We have had many discussions about fundamentals for patients in any future national pharmacare arrangement through the Best Medicines Coalition, Health Charities Coalition of Canada and Canadian Pharmacists Association

Assisted a family from the Netherlands who were travelling to Canada. Their child is affected by Tyrosinemia, another rare allied disorder. They wanted to travel prepared and we were able to put them in touch with the correct individuals to ensure they would have support and foods available while on holidays to Canada.

We represented Hamilton, ON family at federal Tax Court on Feb. 20 appealing CRA refusal of Disability Tax Credit. Excellent, fair and thorough hearing. The judge reserved decision so we wait for written decision. Nicole Pallone was an effective witness.

We also represented Calgary family at Tax Court hearing March 14 on same issue.

We were thrilled by a overwhelming vote (222-60) in House of Commons in early March to give final approval to a bill outlawing discrimination on basis of genetic characteristics. Opposed by Liberal Cabinet, supported by Liberals,

[Click Here for More Info About a Travel Scholarship](#)

**Atlantic PKU Day . Moncton, NB . June 17**  
[Click Here for More Info](#)

[Click Here to Register](#)

[Click Here for More Info About a Travel Scholarship](#)

### Recipe Corner

#### ZUCCHINI AND MUSHROOM STIR FRY



1 small zucchini, sliced  
1 small carrot, sliced  
3 oyster mushrooms, sliced  
1 onion  
1 tsp black pepper  
½ tsp salt  
1 tsp herbes de province  
4 tbs olive oil

Peel and dice the onion. In a deep frying pan heat the olive oil, add salt, pepper, herbes de province and onion. Sautee until onions become transparent. Add the zucchini, carrot and mushroom and cook on medium heat, constantly stirring until carrots become tender.

Serve as a side dish or over low protein pasta.

Shared with permission from the Wooden Spoon which specializes in low protein recipes. Check them out!  
<http://www.thewoodenspoon.ca/foods/>

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

Conservatives and New Democrats. Outraged later by comments of federal Attorney General Judy.

We look forward to the next Quarter to see how we can work to affect change and support our members!

## **EXCITING ANNOUNCEMENT FROM CANPKU!**

**Join us for the first annual CanPKU Family Camp for all ages!**

*Sept. 22-24, 2017 Weekend Camp*

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



**Registration closes July 31, 2017, 12:01 EDT**

**TO REGISTER, CLICK HERE** or visit <http://bit.ly/campmag2017>

Join us for a **weekend** (3 days 2 nights) of fun, knowledge, relaxation, and campfires! Bring the

## PKU Profile

We want to know!

Send us a photo of the PKUer in your family with a brief Biography or achievement.

Newborn? Just learned to make your own milk? Sports or education achievement? Maternal PKU? Two PKU friends spending time together?



We would love to shine the spotlight!

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

[Join Our Mailing List!](#)

## In the News Articles you may enjoy

[On genetic fairness](#)

[Dipharma and Alvogen launch Diterin in South Korea](#)

<https://pku.iamrare.org/>

[From Rare to Great - Forbes](#)

[Evaluation of the Effects of Terminating the Diet in Phenylketonuria](#)

[Not for Profit vs Charitable](#)

## Become A Member

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

**General memberships are only \$20 per year!**  
To sign up, please go to  
[www.canpku.org/become-a-member](http://www.canpku.org/become-a-member).

family from Friday to Sunday. Food will be catered to PKU and non-PKU diets, expert speakers talking about the latest developments surrounding PKU, cooking demos and vendor displays. It's a weekend not to be missed! Bring the whole family along, take a break from food preparation and relax for the weekend. All this, and sleeping in cabins, too!

Registration is limited and filled on a first-come, first-served basis. **Your weekend camp pass includes a free CanPKU Membership for 2017!**

Questions? Please contact us at [camp@canpku.org](mailto:camp@canpku.org) or [info@canpku.org](mailto:info@canpku.org).

Activities are being voted on as this issue is going out! The camp grounds offers Canoeing, Archery, High Ropes, Wall Climbing, Low Ropes, Adventure courses, hiking trails, camp fires and so much more! Which activity is your favorite? Email [camp@canpku.org](mailto:camp@canpku.org) and let us know!

More to come soon! Check out our website for some [FAQs](#).

## Look who is coming to camp!

By Tanya Chute



In addition to the exciting news that we will be joined by members of the Toronto SickKids Medical Team we have also confirmed two special attendees!!

Dr. Bill Hanley, left the PKU clinic at HSC in 1997, 20 years ago. He is going well at the young age of 87. He will be attending camp and is excited to possibly see some of his former patients.

Much of the Toronto PKU community has had their lives impacted by contributions made by now retired, Valerie Austin. Valerie has attended many CanPKU events in the Ontario Region and would be a familiar face to other attendees!

We are excited to have both these iconic individuals attend camp. Will you be joining us too?



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- Optimized formulation to provide advanced nutrition for your health
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- Supports brain and eye development
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[cambrooke.com](http://cambrooke.com) or 866 456 9776, opt 2

## Walk to Camp - Sort of :)

Fundraising for Camperships



May is PKU Awareness Month and when most of the walk a thons tend to happen for CanPKU.

Pick a day in May and plan a walk a thon for your city, neighbourhood and friends! We have lots of resources on the website to help you out!

All funds received from walk a thons this year will help get people to camp! We are hoping to raise enough to provide travel scholarships for camp... Camperships :)

Let us know what you have planned and in what area. We will send out a SPECIAL EDITION Walk a thon newsletter if there is enough walks happening!

Walking not your thing? You can plan other "A-thons" to help raise funds. Rosie and her Mommy (Nicole Pallone) are planning a painting night.

Let us know how we can help!

## PHENYLADE GMP NOW AVAILABLE IN CANADA!



**DAVID**  
 40 years old,  
 Classical PKU

"When I tasted the PhenylAde™ GMP product, it was very easy to drink, it was very smooth, and in comparison to other products in the market, I actually preferred it."

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- Built on the PhenylAde flavour profile to aid patient acceptance and support dietary adherence



REQUEST  
 A SAMPLE

[Request a Sample](#)

## Help Wanted: Newsletter Editor

Ever wanted to be involved with CanPKU?



For the last year the Newsletter has been completed by myself, Tanya Chute, Secretary and Board Member for CanPKU. I have enjoyed gathering the information and sharing it with the PKU Community. Saying that, my new role, will have me completing many other tasks and I would hate to see this be affected.

I would be happy to help transition this position to someone else and teach you all you need to know! I would be available whenever you had questions or concerns regarding the position.

If you have ever wanted to be part of the team, but not have a lot of time to devote, this position may be perfect! Only a few hours every quarter! Please email to [tanya.chute@canpku.org](mailto:tanya.chute@canpku.org) to further discuss the position.

## Help Wanted: Secretary

Want to know the latest happenings in CanPKU?



Wonder what is discussed at CanPKU Board meetings? Want the inside scoop?

We are seeking a new Secretary. This role consists of taking minutes at the Quarterly Board Meetings as well as the AGM. You will be guided on what your roles are during the months leading up to the

AGM as well as expectations on taking minutes. Please reach out to [tanya.chute@CanPKU.org](mailto:tanya.chute@CanPKU.org) if this is something that would interest you.

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## Push ups for PKU



We thank Nutricia North America for this program and the community it builds for PKUers everywhere.

We are excited to report this year the program raised \$1,330 for CanPKU.

Thanks to our members, friends and family who supported this 2nd annual event and did their 5 push ups!

To read more see:

<http://www.lowproliving.com/push-ups-for-pku-challenge/> and <http://www.lowproliving.com/push-ups-4-pku-challenge-results/>

## RQMO Annual Rare Disease Show

By Helene Dandurand

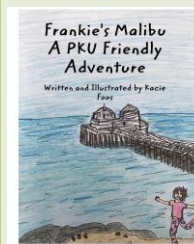


Le Regroupement Québécois des Maladies Orphelines (RQMO) a tenu son premier Salon des des maladies orphelines le 21 février dernier au Complexe Desjardins, au centre-ville de Montréal, dans le but d'accroître la visibilité des maladies rares et orphelines au Québec et d'informer le public sur celles-ci. PCU Canada comptait parmi les vingt associations de patients qui avaient un stand au Salon. Le nôtre a été animé par John Adams, notre président et chef de la direction, et Hélène Dandurand, administratrice, relations avec les francophones. Cet événement d'une journée entière nous a donné l'occasion d'informer des membres du grand public et d'autres exposants sur la nature de la PCU, ses succès et ses défis et les actions de PCU Canada. Notre trousse d'information sur le crédit d'impôt pour personnes handicapées a suscité un intérêt marqué de la part de plusieurs autres associations. Pour plus d'information sur cet événement, visitez le site Web du RQMO à <http://rqmo.org/>

RQMO, Quebec Rare Disease Coalition, held its first Orphan Disease Show on February 21st at Complexe Desjardins, in downtown Montréal, to increase the visibility of rare and orphan diseases in Quebec and inform the general public regarding them. CanPKU was among the twenty patient associations that had a stand. Ours was manned by John Adams, our President & CEO and Hélène Dandurand, director, Francophone relations. This full day event gave us the opportunity to inform members of the public and fellow exhibitors on the nature of PKU, our successes and challenges and the actions of CanPKU. Our Disability Tax Credit Information Package initiative generated quite a bit of interest on the part of other associations. For more information on this event, visit RQMO Web site at <http://rqmo.org/>

## Frankie's Malibu A PKU Friendly Adventure

by Kacie Foos



Kacie Foos is a writer who lives in California with her Husband Mike, and daughter Frankie. When Frankie was diagnosed with PKU at four days old, Kacie searched for children's books to read to her daughter.

There were so few options Kacie was inspired to write a children's e-book series for her daughter and other children to relate to.

"Frankie's Malibu A PKU Friendly Adventure" is her first release in this series.

This first story introduces you to a little girl named Frankie. She lives in Malibu, California with her family, and we travel with her through her wonderful world. Frankie does not live life controlled by her metabolic disease; instead she

## Have your say...

Looking forward to Next Issue



PLEASE SHARE!

Our next newsletter will be due out June 15th. Let us know how you spend your summer!

Send feedback to [newseditor@canpku.org](mailto:newseditor@canpku.org) and we will publish these in our June issue!

celebrates life and her community of Malibu. This book series spreads awareness and opens a conversation to other metabolic diseases in our world.

Kacie will be releasing her next book "Frankie's London A PKU Friendly Adventure" in April 2017. She plans to release four "Frankie E-Books" by June 2017 and will have them out in print by the end of the summer.

Kacie's mission is to spread awareness and continue writing children's books for other metabolic diseases in our world.

The wonderful things about these books are that not only do they educate families about PKU, but also that they are just fun learning books for children.

For example, in Frankie's Malibu, children learn about local wildlife, constellations, nutrition, and reading. Future releases will teach kid's about culture, math, travel, new languages, nutrition, kindness, and so much more.

"Frankie's Malibu A PKU Friendly Adventure" is currently available to download at [Blurb.com](http://Blurb.com) and the Apple Ibooks store.

Links attached below...

<http://www.blurb.com/ebooks/616123-frankie-s-malibu-a-pku-friendly-adventure>

<http://itunes.apple.com/us/book/id1209780039>

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,**

**Tanya Chute**  
**Newsletter Editor & Vice President**

**Canadian PKU & Allied Disorders Inc.**

The content deadline for our June 2017 Issue is June 1st, 2017

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\$10!**

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