

# CanPKU News



from **Canadian PKU & Allied Disorders Inc.**

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## Dear Reader,

Welcome to the 23rd issue of the CanPKU newsletter.

Things are getting busy around here with many of our educational events on the horizon. These events are hosted in various regions across the country. They take many months of coordination of details. Events may include cooking demonstrations, product sampling, guest speakers with a range of information to offer. Above these fantastic components, they also allow families to meet or reconnect with each other. All events offer free daycare for those who are in need.

Members receive a discount against the registration fees. This is a great time to review if you have paid your membership fees. You would not want to miss out on the savings for these programs.

Please see elsewhere in this edition regarding the upcoming events happening this year, and mark your calendars!

We hope you enjoy this 23rd edition of the CanPKU Newsletter!

Sincerely,  
Tanya Chute  
Newsletter Editor  
& Secretary

Nicole Pallone  
Vice President

John Adams  
President &  
CEO



*family to family*

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### Important Dates

Between Newsletters

- May 14, 2016 - Ontario PKU Day (London)
- May 15, 2016 - BC PKU Day (Vancouver)
- May 22, 2016 - Atlantic PKU Day (Halifax)
- \*new\* June 5, 2016 - Prairies PKU Day (Winnipeg)

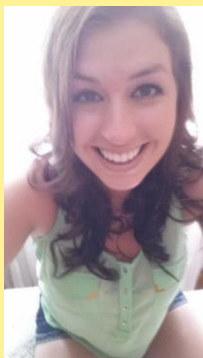
### Upcoming Educational Events:

October 15/22, 2016 - Quebec PKU Day

### Recipe Corner

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

## PKU Profile



Hillary is a 22 year old student at McMaster University. She is currently completing her fourth year in a combined honours program in Economics & Communication Studies. She is an active member of her university community and takes on a variety of leadership roles. She is also a member of MENSA.

Hillary was diagnosed with classical PKU within a few days of being born. She is currently treating her PKU with diet and formula and is restricted to less than 8.5g of protein per day. Like many young adults with PKU, she is going through the process of learning to manage her diet on her own both with everyday meal plans and eating out with friends. However, she does not let her restrictive diet hold her back - Hillary spends her summers working in the Rocky Mountains and living in dorm-style staff housing accommodations.

After suffering a serious spinal injury and being diagnosed with osteoporosis Hillary is committed to a healthy, active lifestyle and is currently learning how the PKU diet affects strength training and fitness. In her free time, Hillary enjoys outdoor recreation and adventure sports. She recently went on a 10 day white-water canoe trip down the Rio Grande, and managed to accommodate her low-protein diet and medical needs in a back-country, desert environment.

Hillary is excited to share her stories with you and hopes to illustrate that PKU does not need to inhibit one from living an adventurous, healthy and successful life.

CanPKU has been fortunate enough to have Hillary speak at our Ontario Event in 2015. She will be speaking at other events this year! Stay tuned.

[Join Our Mailing List!](#)

## What's up CanPKU?

As mentioned earlier, we are getting pretty excited about opening the 2016 education events for CanPKU. Please send us an email to [info@canpku.org](mailto:info@canpku.org) and share your input!!

### Events happening during this newsletter period:

#### Ontario PKU Day

#### Journée PCU de l'Ontario

Saturday, May 14 - London, ON

Le samedi 14 mai - London, Ont.

10 am to 12 pm:

12th Annual Low Protein Cooking Demonstration  
Real Canadian Superstore (825 Oxford Street East)  
Contact Suzanne Ratko 519-985-8500 ext 52469

1 to 4 pm:

Speaker Presentations  
Amphitheatre, London Health Sciences Centre

De 10 h à 12 h :

12<sup>e</sup> démonstration annuelle de cuisine hypoprotéinée  
Real Canadian Superstore (825 Oxford Street East)  
Communiquez avec Suzanne Ratko 519-985-8500,  
poste 52469

De 13 h à 16 h :

Conférences  
Amphithéâtre du London Health Sciences Centre

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#### BC PKU Day

#### Journée PCU de la Colombie-Britannique

Sunday, May 15 - Vancouver, BC

Le dimanche 15 mai - Vancouver, C.-B.

9 am to 5 pm | De 9 h à 17 h

Chan Centre

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#### Atlantic PKU Day

#### Journée PCU de l'Atlantique

Sunday, May 22 - Halifax, NS

Le dimanche 22 mai - Halifax, N.-É.

9 am to 5 pm | De 9 h à 17 h

IWK Health Centre

## In the News

Articles you may enjoy

<http://www.thespec.com/news-story/6270604-campaign-to-treat-rare-diseases-hits-hamilton/>

<http://www.theglobeandmail.com/opinion/newborn-screening-50-years-of-federal-foot-dragging/article28954561/>

[http://www.huffingtonpost.com/tara-shafer/rare-disease-day-mom-make\\_b\\_9344742.html](http://www.huffingtonpost.com/tara-shafer/rare-disease-day-mom-make_b_9344742.html)

<http://www.irishtimes.com/life-and-style/health-family/no-one-in-school-knows-there-is-anything-wrong-with-charlie-anymore-1.2495623>

<http://www.news-medical.net/news/20160216/Study-could-pave-way-for-new-treatment-strategies-for-PKU.aspx>

<https://globenewswire.com/news-release/2016/02/29/815208/0/en/BioMarin-Announces-BioMarin-RareConnections-TM-Rebranding-and-Consolidating-BioMarin-s-Comprehensive-Support-and-Services-for-Eligible-Rare-Disease-Patients.html>

<http://www.bizjournals.com/boston/blog/bioflash/2015/12/newest-flagship-startup-will-make-redblood-cells.html>

## Help Fight Genetic Discrimination in Canada.



Bill S-201 Needs your help!

From the article below:

"Did you know that Canada is the only G7 country without any legal restrictions to protect the privacy of personal genetic testing results? This needs to change. We need your help to make sure that Canadians' genetic information is protected and private. Now is the time to act. Keep reading to learn how you can express your support."

For more information please following the link:

<http://ffb.ca/support-bill-s-201-lend-your-voice-to-stop-genetic-discrimination-in-canada/>

## Prairies PKU Day

### Journée PCU des Prairies

Sunday, June 5\* - Winnipeg, MB

Le dimanche 5 juin\* - Winnipeg, Man.

\* Please note new date \* Veuillez prendre note de la nouvelle date

9 am to 5 pm | De 9 h à 17 h

ANAVETS Unit 283

## Events which will come after this newsletter period:

### Journée PCU du Québec

### Quebec PKU Day

octobre - Ville de Québec, QC

October - Québec City, QC

À annoncer | To be announced

If you have information about a community centre, school, church or other inexpensive location that may be suitable for Québec City, QC,

please contact [jenn.pino@canpku.org](mailto:jenn.pino@canpku.org)

## HOT OFF THE PRESS!



Our website has been under construction for a while. You may have noticed broken links, and limited updated content. We have been making changes which have come from our Board and our Membership. These will make the site more functional, user friendly, and informative. Stay tuned, these changes are coming soon! We appreciate your patience!

## PKU Walkathon - May 2016

Coming to your city? (It might be!)



We placed a request last issue for people to come forward and let us know if you were able to plan a walk-a-thon in their area.

Thank you to all who have come forward!

For those who are thinking about it, but have not yet committed, it is still not too late! 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.



## CanPKU Starter Kits

By Tanya Chute



It's that time again!

In 2010, CanPKU created a Starter Kit to be sent to the metabolic clinics. Contained in this kit is a letter from CanPKU offering our support and services, as well as some items to help make the diagnosis a little less scary. It has included items such as a food scale and measuring cups. Many items in the kits have been donated from various supporters and sponsors. These kits are given out to parents of newborns identified with newborn screening or adults who are returning to diet for PKU and other allied disorders.

We are hearing back from clinics that they are in need of more kits! We are preparing to facilitate round 3!

We have had wonderful volunteers in the past, and we will reach out to them again to see if they can assist. As the notification we would be starting Round 3 came very close to this edition of the newsletter, we wanted to take this opportunity to reach out and see if anyone else would like to assist with this project. We are looking for a total of 5-6 volunteers to help with the assembly of the kits. The materials will all be arranged by us, and sent to your home. You will be required to store the items until they have all been received, assemble the kits, and prepare them for shipping to the clinics in your region or area.

Whether you would have liked to have received a kit (but your child was born before we started) or you did receive a kit, and would like to help ensure someone else gets the same benefit, or you simply have an unused storage area and some free time -- We would LOVE to hear from you! Please email to [info@canpku.org](mailto:info@canpku.org)

Again, if you previously have helped on this project, we would love to have you assist again! We will be messaging you shortly.

Thanks in advance!

## Confirmed Local Events:

### British Columbia:

**Kamloops** - Date, time and location TBD For more information please contact Coordinator: Amanda Cosburn at [amandacosburn@gmail.com](mailto:amandacosburn@gmail.com)

### Ontario:

**Peterborough** - May 29th. 1-3pm. Riverview Park and Zoo (1230 Water St.) We will meet up in the parking lot Rain or Shine (We proved last year a lil rain can't dampen our fun!) If possible RSVP to receive any updates to [tanya.chute@canpku.org](mailto:tanya.chute@canpku.org) but feel free to surprise us if you find yourself in the area! Coordinator: Tanya Chute

**Toronto** - May 31st. Coordinator: Tammy Dexter - Please contact [newseditor@canpku.org](mailto:newseditor@canpku.org) for more information.

## Advocacy Ontario



John Adams, joined by others, continues to be active on behalf of CanPKU and along side the Canadian Organization of Rare Disease with Advocacy issues concerning our membership.

We have attached a recent document provided by CORD outlining Rare Diseases (not just PKU) click [here](#) to view.

## 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 more successes!

We have had 20 families advise of an application and result. 8 of those were approved (42%). Of those, 5 were in BC (2 approvals, 3 denials), 3 were Alberta (1 approved, 2 denied), 2 in Manitoba (1 approved, 1 denied), 9 in Ontario (4 approved, 5 denied) and 1 applicant from New Brunswick, who was approved.

## PKU Around the World

... at the speed of the internet! By Tanya Chute

As some of you may know, CanPKU's President John Adams, frequents Mexico. As a strong advocate where ever John goes, he is involved with clinics in Mexico, and the doctors there are aware of his roles within CanPKU.

Recently, a family of a one month old, received the diagnosis of PKU. The family already had plans of moving to Vancouver, BC, in the months to come. The metabolic physician attending in Mexico was able to provide the family with John's contact information. Once he offered his warm welcome from CanPKU, he was able to provide the family with the contact name of the new metabolic team in Canada who would head up their son's medical care upon arrival. Within hours of the original doctor emailing John, the family had also received a quick hello from the Canadian team, and replied with an email of thanks.

It is so wonderful to be dealing with PKU at a time, where access to support is available. Personally, I am proud of CanPKU and the support it lends to Canadian (and not yet Canadian) families! The family has joined our Facebook page. Hopefully they will be settled enough to be able to attend the BC education event and meet some of our wonderful families, who in our typical Canadian way, will also become a wealth of knowledge!

**Congratulations and hats off to all involved!**

## 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).

We also wanted to use this opportunity to thank a family for going public with their feelings. Please click the following link to review the awareness they are spreading! Thanks again!

<http://www.cbc.ca/beta/news/canada/calgary/calgary-mother-calls-rejection-for-federal-disability-benefits-heartbreaking-1.3476490>

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

## Submission to the CDR



You may recall recently receiving a request to complete a survey for CanPKU in regards to Kuvan. This was requested for those who are and are not on Kuvan. There were two types of surveys, ones for families and one for professionals who manage PKU. The results of these surveys were compiled and submitted to Canadian Agency for Drug and Technologies in Health (CADTH). This agency has before them a resubmission of Kuvan for the treatment of PKU. The Common Drug Review (CDR) does not allow for patient groups to send a speaker, but does allow for a written submission. Results of the survey have been collected and tallied. Our submission has been included by way of the following link for our members to have a chance to see the results as well. THANK YOU TO ALL WHO PARTICIPATED IN THE REVIEW! Sharing your experiences were paramount in this project!

[CanPKU Input to CDR Re: Kuvan March 6, 2106](#)

## Maternal PKU



CanPKU would like to extend a HUGE congratulations to Amanda and Cole on the arrival of their precious pink bundle of joy! Madelyn made her debut this month at 6lb 11oz and 48 cm long! All pregnancies are amazing but we paid special attention to this one! Amanda is a board member of CanPKU, she also has PKU herself. For anyone wondering, Madelyn did have her newborn screening, and tested negative for PKU.

For more information on Maternal PKU check out Amanda's blog where she documented her journey! So inspirational for all our little girls who look forward to being a Mommy some day! Thanks Amanda!

<https://amandacosburn.wordpress.com/>



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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.

**HOPE** should not be as rare as the diseases we treat.

*The Annual*  
**RARE FINDS**  
A FEAST FOR THE SENSES

RARE DISEASE FOUNDATION

Sat., April 23, 2016  
7:00pm | Sheraton Wall Centre  
1088 Burrard St. Vancouver, BC  
RARE COCKTAILS | GREAT FOOD  
RARE AUCTION | ENTERTAINMENT

Experience creations from top Chefs, Mixologists and Brew Masters at our unique event benefiting extraordinary children. Delectable treats expertly prepared by: Chef David Jorge, *S+L Kitchen & Bar*, *MasterChef Canada*, Season 2 winner, Chef Starri Chow, *Sheraton Wall Centre*, Chef Alessandro Vianello, *The Fairmont Waterfront*, Chef Adam Pegg, *La Quercia*, Chef Faizal Kassam, *Gibo Trattoria*, Chef Dan Olson, *Railtown Catering*, Chef Karen McAlly, *Eleanor Chow Waterfall*, *Cadeaux Bakery*, Steve Fecho, *Match*, Chef Max Straczek, *Fable Kitchen*, Chef Jon McCartney, *Peronos Tapas Restaurant & Lounge*, Greg Hoak, *Master Chocolatier*, *Chocolate Arts*, Mark Pennington, *Cacao Barry*, *Steamworks Brewing Company*, *Bomber Brewing*, *Driftwood Brewery*, *Steel & Oak Brewing*, *Jacob Sweetapple*, *Absolut Brand Ambassador*, Eric Scot, *Sheraton Wall Centre*, Amber Bruce, *The Keefer Bar*, Julia Diakow, *Tacofino*

Proceeds benefiting Rare Disease Foundation of Canada For tickets visit [www.rarediseasefoundation.org](http://www.rarediseasefoundation.org)



Click [HERE](#) for ticket purchase information

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