

CanPKU News



from Canadian PKU & Allied Disorders Inc.

In This Issue

- [Important Dates](#)
- [2018 NPKUA Conference](#)
- [Fundraising - Schools](#)
- [Have your say](#)
- [Camp MagniPHEque](#)
- [BC Event](#)
- [Prairies Event](#)
- [Proof your input is valuable](#)
- [Starter Kits](#)
- [Fundraising - Paint Night](#)
- [Fundraising - Walk a thon](#)
- [Fundraising - Horse Show](#)

Quick Links

- [About Us](#)
- [Membership Purchase](#)
- [DTC Package Request](#)

Our Sponsors

BRONZE SPONSORS



Dear Friend,

Welcome to the 28th issue of the CanPKU newsletter.

This has been a busy few months, but I am getting used to my role as VP and thank everyone for their support and patience as I transition. A look back on this quarter shows such positive strides for our community. Our events on the west coast brought families together to see a familiar face and maybe meet a new one. Our speakers were delightful and informative. Our bi-annual program of the Starter Kits is in the home stretch with just a few packages left to go out in the mail (more below on this). We cannot thank Ligia and Nicole enough for their help on this project. May, of course was PKU Awareness month, which is one of my favourite months to reflect on when I prepare the newsletter. We really do have the best families on board to make our organization wonderful! Check out below four extremely successful events that happened across our country to not only help financially, but to raise awareness and show we are PKU Proud! Thanks for all the efforts; We are excited to be able to use these funds at camp and to help bring campers from coast to coast to Camp MagniPHEque this year!

It's been a great quarter, with more sunshine on the horizon... who could be happier? Read down to get more information on things that have happened, as well as those coming!

Have a safe and enjoyable summer!

Sincerely,

Tanya Chute
Newsletter Editor
& Vice President

John Adams
President & CEO

SILVER SPONSORS



GOLD SPONSORS



IT'S NOT TOO LATE TO JOIN US THIS SATURDAY (JUNE 17TH) AT ATLANTIC PKU DAY!

Held in Association with Vitalité NB's Annual Clinic Picnic at St. Anselme Rotary Park, Dieppe

11 am to 2 pm - Picnic
2 pm to 5 pm - CanPKU Speaker Series

ADMISSION IS FREE for CanPKU Members

\$10 for Guests/Non-Members



**WE LOOK FORWARD TO SEEING YOU THERE!
TO REGISTER NOW, CLICK HERE!**

HAPPY FATHER'S DAY!



JUNE 18TH



Message from President

By John Adams



In an effort towards advocacy, we have drafted a submission to the Quebec agency on the results of our patient/family survey regarding Kuvan.

Our educational events have been in full swing, and I was fortunate to be able to see families at both the BC event in Vancouver and the Prairies event in Red Deer. I prepared small topics of conversation for presentation on the activities of CanPKU and the Disability Tax Credit application.

It is also important that we represent CanPKU at other organizations conferences. Often we are invited to attend free of charge, and expenses are covered for CanPKU providing we send a representative and provide content. For the first time, in March CanPKU had a display at the Abbott Nutrition Conference. We were also represented at meetings of Best Medicines Coalition in Toronto and Canadian Organization for Rare Disorders in Vancouver and Toronto. We met with the pan Canadian Pharmaceutical Alliance on Kuvan with Drs. Murray Potter and William Hanley and parent John Forstrom whom all participated in a conference on national pharmacare by Health Coalition of Canada in Ottawa. CanPKU was represented at BioMarin PKU Summit in California and the Canadian Agency for Drugs and Technology in a Health symposium in Ottawa. Also in Ottawa, CanPKU was represented at the Newborn Screening symposium in Ottawa.

Bridging borders across the world, a young man with PKU arrived from Ireland to Ontario this quarter. We were able to assist in getting him connected with his new PKU clinic in Toronto.

These activities all fit well into our mission statements and we are very grateful for the continued support of our community by way of membership, volunteering, fundraising and donations, as well as the support of corporate sponsors. Without these funds - none of what we do would be possible. Thank you for your generosity!

Nutricia - Thank you for sponsoring Canoeing at Camp MagniPHEque!



They will be joining us at camp and offering Saturday Dinner Low Pro food Demo, Canoeing and more! Will we see YOU at camp?

Recipe Corner

STRAWBERRY ORANGE CHILL DRINK



1 3/4 cups orange juice
1/2 cup lemon juice
3 pints strawberries, hulled
1 3/4 cups sugar
1/8 tsp salt

In covered blender, blend all ingredients at high speed until smooth. Pour mixture into a 13x9-inch baking pan. Cover with foil or plastic wrap and freeze until partially frozen (about 4 hours), stirring occasionally. Spoon strawberry mixture into a large chilled bowl and beat with a mixer until smooth but still frozen. Return mixture to pan and freeze until firm, about 3 hours. For easier scooping and serving, remove mixture from freezer and let stand at room temperature for 10 minutes.

Makes 20, 1/2 cup servings.

Per recipe: 141 mg phe, 8.6 g protein
Per serving: 7 mg phe, 0.4 g protein

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

Cambrooke Therapeutics is hosting Bogs and Frogs at Camp MagniPHEque



An activity for our littlest campers to our most curious! Visit a nearby pond with nets and buckets to discover what lives there and how they play a part in the eco system.

Vitaflo needs YOUR vote to pick their camp activity!

Complete a quick one question survey and let us know!



[Click HERE to VOTE!](#)

Do you want to "Climb to New Heights" with Vitaflo or "Hit the Bullseye"?

PKU Profile

Sarah is 10 years old and was born with Classic PKU. She does really well with her diet and formula and is well controlled and is becoming more independent every day. However she hates getting her blood spots taken but we are working on that! She started taking Kuvan 3 years ago and her PHE intake has doubled and is currently allowed 17g of Protein a day. She does struggle with ADHD, anxiety and school and we are working on these issues so she can be successful in life. Sarah is funny, warm hearted and has lots of energy to say the least. She has her moments where she "hates" having PKU but for the most part she doesn't complain too much, she says it just makes her extra special and we love her for that. Her passion in life is animals, especially horses. She started horseback riding (dressage) a little over 3 years ago and decided it was a little too slow paced for her so she has recently moved over to the Hunter/Jumper discipline and seemed to find the place she wants to be. Her goal in life is to have her own barn and riding school when she grows up and we fully support her and will do everything we can to help her make that dream a reality.



We would love to shine the spotlight on your PKUer!
Send a brief intro and photo to newseditor@canpku.org

[Join Our Mailing List!](#)

In the News Articles you may enjoy

[Healthy Bones in PKU](#)

[Global PKU Market](#)

[Ethan's condition means food poses real threat](#)

[Mum of five with rare disorder ...](#)

[Eating meat could give me seizures](#)

[PKU Sphere introduced by Vitaflo USA](#)

[Set up procedures to ensure lab results don't fall through the cracks](#)

[Lifting the limits for PKU](#)

[Synlogic goes public through merger with failed Mirna](#)

[Baby Genes, PKU Alliance Launch Genetic Testing Program](#)

[Research Report On Phenylketonuria \(PKU\)](#)

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>

You asked, we answered! You now have two great ways to enjoy camp!

Join us for a **weekend** (3 days, 2 nights) of fun, knowledge, relaxation, and campfires! Bring the 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 bunkie style cabins, too! Weekend campers will have first priority over selecting activities where necessary. **\$150 per person. Kids 5 and under FREE (this year only).**

Focus on Rare Diseases

'We were devastated' - Parents on discovering their youngest child is battling same rare disease as his brother

For lives at risk, the perfect recipe

Balancing Branched Chain Amino Acids in Medical Foods for Inherited Disorders of Amino Acid Metabolism

Federal Health Minister, Hon. Jane Philpott, Announces PMPRB Consultations

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)

Need some financial help to attend the weekend? Click Here

Can't make the whole weekend, but don't want to miss all the fun? Join us for a **single day (Saturday)**. These campers will participate in the educational component of the day (much like a typical regional event) and also get to take part in camp activities throughout the day! Arrival at 8:30 a.m depart by bedtime. Lunch, supper, snacks activities and camping fun is included for all day SATURDAY in this package! (No over night stay is permitted.) **\$75.00 per person. Kids 5 and under FREE.**

Registration is limited and on a first-come, first-served basis. Spaces are filling fast! You do not want to miss out!

For all those registered, watch your inbox for activity selection and more information coming mid summer.

All applicants must be members of CanPKU to purchase weekend or day passes. Please ensure your membership is up to date. Not sure? Send us a message and we can check.

Questions? Please contact us at camp@canpku.org or info@canpku.org.

Check out our website for some [FAQs](#).

CanPKU British Columbia Event

By John Adams



As you can see from the photo, as always, we had a great turn out in Vancouver for our recent B.C Event. Our speakers were all excited to be there. Our west coast families new and familiar are always a welcoming group! Can't

wait to see you next year!

CanPKU Prairies Event - Red Deer Alberta

By John Adams



Chef Neil of VitoFlo presents low-protein cooking demonstration at Prairies PKU day in Red Deer, AB.

The soup, bread and pizzas were fantastic.

We thank all of the speakers, cooks and families for coming out!

Interested in Bone Health with a PKU diet? This webinar is for you!



Ground Breaking PKU Research
Join us for a 1 hour webinar

June 21, 2017 @ 8pm EST

A one (1) hour webinar for
caregivers and individuals with PKU



Join Denise Ney, PhD, RD, Nutrition Professor
and Researcher who will review:

- The latest evidence on PKU medical formulas made with Glytactin (GMP)
- Why & how Glytactin formulas can benefit your health
 - Bone, muscle and digestive
- Hear first hand testimonials



To register: <http://bit.ly/pku-webinar>



For information on our Glytactin products visit cambrooke.com
or call 866 456 9776, option 2

[CLICK HERE TO REGISTER](#)

Thank you for the feedback received as well:

Thank you CanPKU for an awesome day in Red Deer Alberta Great presentations and food. (Lynn P, [FB page](#) messenger)

Thanks again for putting on the PKU Prairies day 2 weekends ago. We really enjoyed it and found it great to get more information about all of the topics discussed. (Joey M. by email)

Proof your input is valuable!

By Tanya Chute



Remember a while ago, we requested participation in a survey regarding Kuvan. We were asking for input regardless if you were currently on Kuvan, had tried it in the past, or didn't have any interest at all. This information

was then collected and submitted to the Common Drug Review (CDR) as patient perspectives.

CADTH reviewers and the Canadian Drug Experts Committee members thank you for your time and effort!

CanPKU would also like to thank you for helping us work towards our mission statement of helping and advocating for families affected by rare disorders such as PKU. Thanks for voicing your opinion. Your voice is helping make change!

To read the reply from CADTH please click [HERE](#)

Starter Kits

By Tanya Chute



When a family is introduced to an inherited error of metabolism disorder (IEM) such as PKU, MSUD etc, for the first time (a few short days following the birth of their perfect child) or reintroduced (as an adult, taking the steps to return to an IEM diet), it is overwhelming, as many of you may remember.

Nicole Pallone, our former Vice President, took the initiative to make this a little less scary. Her efforts created the concept of a "Starter Kit". It includes the necessary tools to help get on track and a comforting letter welcoming folks to the

CanPKU Family. This kit would not be possible without our wonderful supporters who make it happen! We are excited to announce that the 4th round of starter kits are currently making their way to clinics across Canada.

We would like to take a moment to recognize those that made it happen in 2017!

In no particular order:

We wish to recognize and thank the Specialty Food Shop, located at The Hospital for Sick Children, for covering the cost of shipping the starter kits to clinics across Canada. The Specialty Food Shop provides specialized products and nutrition advice for children and adults across Canada with a variety of special dietary needs, both in-store and online (www.specialtyfoodshop.ca).

[Atlantic Promotions](#) have outdone themselves again this year with providing both a StarFrit measuring scale and formula shaker.

PHENYLADE® 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!



Request A Sample

Coming soon:



sphere™

VitaFlo's first GMP-based medical food for use in the dietary management of Phenylketonuria.

Visit www.VitaFlo.ca to learn more about our medical food options for PKU.

Medical food intended for use under medical supervision.
© Reg. Trademarks of Société des Produits Nestlé S.A.



[Visit Our Sponsor](#)

HowMuchPhe - A comprehensive diet-management system for PKU with phe/pro/exchange and calorie values for more than 7,000 foods has provided a number of baby food books to be included with infant starter kits for PKU diets.

VitaFlo - Who works in partnership with health care professionals, patients and their families, in order to create products that combine the best of cutting edge research with the lifestyle demands of modern living, ensuring the most acceptable products are available - included measuring tools in all of the kits.

Nutricia - Who believes in the power of nutrition to make a positive and proven difference to health. Every day they are inspired by their purpose: to pioneer nutritional discoveries that help people of every age live longer, healthier lives - included measuring tools to the kits.

Volunteers: In addition to our sponsors, in order to get to your clinic, volunteers fill the need! Merci Beaucoup to Helene Dandurand for translating the printed material for our French community. Thank you to Ligia Simone and family for taking care of packaging and shipping for the Eastern Regions of Canada, to Nicole Pallone and family for taking care of the Central/Western Regions of Canada, to my own family for packaging the clinics in Ontario, and to John Adams and Wilma Allan for doing some hand deliveries to local clinics.

Please note: Not all kits include the same items based on availability of products and clinic clients. These kits are ONLY available at clinic and based on availability. They are reserved for new patients when they have the kits on hand. We recognize from time to time the clinic does not have a supply when a new patient is seen. We are unable to back order. We thank you for this understanding.

It take a village



Event held by Rosie and Nicole Pallone

And this village held a very successful paint event!

Nine year old Rosie Pallone and her Mom, Nicole, have organized several CanPKU Fundraisers over her short life, and this year was no

different. On Sunday May 7th, friends and family from their small community of Sparwood, BC came together at a Paint Day event to support Rosie and the organization. Local artist Sue Hanlon has started a company (www.artbeatactivities.ca) and frequently gives back to the community by donating proceeds of a Paint Day to various organizations.

Message from Mom: Rosie is a budding artist and was thrilled to make this our PKU Awareness Month fundraiser, as we were super excited to have two other PKU patients from nearby communities participate! We had a sold out event with 40 participants and a small silent auction, raising \$1,187.50 in total.

As always, we are thrilled and humbled by the generosity of everyone in our hometown, and this fundraiser was fun for all involved and super easy to organize! In her short life, Rosie has raised over \$12,000 for PKU. This year, she has requested that our donation be used to help PKU families get to the first ever CanPKU camp (Camp MagniPHEque), which will be held this September. We would like to thank everyone who contributed to



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

[Visit Specialty Food Shop](#)

this wonderful event as well as CanPKU, for always being such an amazing support to our family.

Thanks guys!

(The attached photo is the 3 PKUers who attended the event)

5th Annual Kamloops Walk for PKU

By Amanda Cosburn



This year the Annual Kamloops Walk for PKU held by Amanda Cosburn and Brienna Wells. They had a change of venue and it was hosted at Riverside park in downtown Kamloops BC. They had approx 30 guests and raised around \$800 dollars including silent auction items. (Final total still in the works). As always the event was a success and we look forward to next year!

Special thanks to the ladies for their efforts, Costco and Save on Foods (Westside Location) for refreshments and the wonderful people of their

community that continue to support this team!

Did you know?



Be ready for next tax season with the following information:

<http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmptng/ddctns/lns300-350/330-331/dtlxpn-eng.html#trvl80>

Announcing the 2018 NPKUA Conference



The National PKU Alliance will be holding its 5th biennial conference July 5-8, 2018 in Atlanta, GA. Not only will you learn about the latest research but you will have opportunities to mingle with other individuals and families with PKU. The conference will be held at the beautiful Hilton, downtown Atlanta, centrally located within walking distance of many area attractions and

PKU friendly restaurants.

Visit <https://www.npkua.org/News-Events/Conferences> for more information.

What does a horse and PKU have in common?

By Melissa Taveras



Sarah! You will see Sarah featured in the PKU Profile in this edition. Here is more on the how the horse is related:

For PKU Awareness Month we decided to incorporate what Sarah's loves and

hosted a Ride - A -Thon at Wake Robin Farm where she takes her riding lessons. We worked with the owner Kelly Maxwell and was able to organize an Open House that took place May 7th. We set up a info table with raffles that were generously donated by local vendors in our community and thanks to social media were able to spread the word about the event. We did not charge an entrance fee but you were able to pay \$5.00 for a mini riding lesson which was a big hit. You were able to meet and greet all the horses, goats, bunnies and other farm animals. We had a grooming station where you could learn to brush a horse, and then you could visit the craft table and make a craft to take home with you.

The process was pretty simple and we had so much fun planning this event but it didn't end there. We then planned our finale for the next weekend where all students of the riding school signed up for our Mother's Day Horse Show. Riders took pledges for this event and we had more raffles and donations where all the proceeds will be given to CanPKU, which is over \$2100. I cannot thank everyone enough for their support and generosity, it was emotionally overwhelming but extremely rewarding. The moments

Camp Triumph

By Tanya Chute



It's mission is to acknowledge, support, and provide an opportunity for children and youth - whose families are affected by chronic illness or disability - to build confidence, positive self-esteem, and reach their full potential through nurturing qualities of perseverance, respect, and understanding. PLEASE NOTE: They are unable to provide the PKU diet, this camp is not for those with PKU but the siblings or children who live with those affected.

For more information please visit:

<http://www.camptriumph.ca/>

Thanks!



An extra show of our appreciation!

Thank you so much to the Jennifer Burke for your valuable donation. Your dollars truly help us fulfill our mission statements!

National Food Distribution made a generous donation to CanPKU and will be present at each of our education events.

Grandpa Tony from SK, contributed a donation on behalf of his grandson Brayton to help improve the lives of those living with PKU.

Peterborough ON Schools

Both school boards really kicked in to help support Camp MagniPHEque.



Kenner CVI - Held a Coffee House encouraging those who participate in the Arts to spotlight their talents. They sold tickets to the event.

Thank you to Emily C. and student council for raising enough money to sent a child to camp on a camp scholarship. Applications were requested via our Facebook page for this opportunity. They are excited to be able to "sponsor" a little girl from our of province to attend!

Holy Cross Catholic Secondary School held a "Genes for Jeans" day. This is a uniformed school. Once a month the students are invited to pay \$2 to opt out of their uniform and wear jeans to school. All of the months were already booked, but when asked to support this program, the school chaplain, Teresa Cosentino, added an extra date and the school raised over \$700! These funds will go towards making Camp MagniPHEque even better!

Thank you to both of these Peterborough Ontario schools for showing how much they care!

We will look to make Jeans4Genes an annual event - if you have a local uniformed school, or work in an environment that would participate in this program,

that stick out for me, is how many people I spoke to about PKU had the same question, "wow, how did you guys find out that Sarah had it?". When you tell them about the heel prick test, everyone was able to relate to that but no one really knew what that test was. Like me, I thought that once I was discharged from the hospital all the tests that have been conducted had come back fine, they don't tell you that you may get a phone call in 10 days that your baby may have a genetic disorder.

We can't wait for next year to plan our next event and perhaps double this year's proceeds!

(Not to go unmentioned but Sarah's parents place of employment also participated in Jeans4Genes raising just over \$30 - every bit counts!)

PKU Patient Registry

by Eileen Blakely



The National PKU Alliance, a US based national PKU advocacy organization, partnering with the National Organization of Rare Disorders, is excited to announce the successful launch of their PKU Patient Registry in January 2017. This

patient centered registry has great potential to accelerate research and improve outcomes for individuals with PKU. Information gathered and stored in the Registry will help researcher's develop better treatments and continue to work toward a cure.

The Registry has been over three years in planning beginning in Atlanta, Georgia when the NPKUA met with other individuals hosting various rare disease registries and initiatives. The Registry committee, consisting of clinicians and parents worked to create a tool that will help researchers better understand how PKU progresses over time. Unlike other PKU registries, information will be entered by the patient and not by clinic staff. Information, collected via a series of electronic surveys will cover many different aspects of PKU such as diet treatment, insurance coverage, medical and family history and genetics.

Registry enrollment within the first 4 months exceeded 600 individuals thanks to the support and efforts of several partnering PKU agencies and groups. Updates have been shared at recent CanPKU events and more are planned for the summer and fall.

Enrollment in the PKU Patient registry is free and open to any individual with PKU or that individuals' parent or guardian. To date - individuals from three Canadian provinces (Alberta, Ontario and Saskatchewan) have registered and begun entering their information. We hope we can have representation from all provinces by the end of the summer. To learn more or register please visit <https://pku.iamrare.org>. Questions concerning the Registry can be directed to the Registry coordinator, Eileen Blakely, at 715-493-0074 or registry@npkua.org.

