



# CanPKU News

Canadian PKU & Allied Disorders Inc. Newsletter

March 2015

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## Dear Reader,

The time has arrived, after 2 1/2 years of being the editor of this newsletter, where I feel that I need to step down from the position to focus on other personal and work related issues.

Being part of the community and learning about the latest and greatest news events happening with CanPKU in the early stages of their planning has been truly engaging. I have met many people from the community and heard their stories, shared their experiences and valued their contributions to the newsletter.

From my daughters birth in 2012 until now, I have been fortunate to have been working part-time, so that I could devote myself to raising my children as well as having some time to spend working on the quarterly newsletter. However, very soon I shall start a new full-time job at a local University and I feel that my time is going to be stretched too thin to continue with this editorial position. For those of us with young ones with or without PKU, I know you understand how much work it can be.

So this will be my last issue and CanPKU would like to ask for a volunteer who might be willing to step forward to take over this role. It doesn't require a significant amount of time and I guarantee you that you will find it both enjoyable and rewarding. If you think you would be interested in taking this on, please contact [Nicole Pallone](#) or [John Adams](#)

Sincerely,  
Ruth Appanah  
Newsletter  
CanPKU and Allied Disorders Inc.

Editor



### SHARE YOUR PKU EXPERIENCE AND EARN \$\$

[Please click here for more information on this unique opportunity!](#)

### ADVOCACY WINS!

With the leadership of CanPKU, the advice of professionals and the participation of dozens of PKU families across the country, we have seen many success in advocacy over the past few years. These include:

- \*Funding of low protein foods in Saskatchewan;
- \*Public funding of Kuvan in Ontario;
- \*Public funding of Kuvan in Saskatchewan;
- \*Funding of low protein foods in BC;
- \*A verbal commitment to provide funding of LP foods for adults in Manitoba (still to be implemented);
- \*A commitment to provide funding of LP foods for patients in PEI ([click here](#) to read more)

Another exciting success story has recently happened. In March, CanPKU advocated successfully on behalf of a one-year-old boy with PKU who is a newcomer to Ontario and a refugee claimant with his mother from Eastern

*We apologize for the delay in sending this newsletter out, which was due to a technical problem with the Disability Tax Credit Information Package request form being created. Our next newsletter will still come out on June 15th as planned.*

### Disability Tax Credit - A PKU Success Story!

by Nicole Pallone

At one of our events last year, the Dad of a patient asked me if I had applied for the DTC. "No," I replied. I had heard of other PKU patients applying without success and honestly, I do not have a lot of time to waste in my life. **I will also admit that I struggled a bit with the idea of 'labeling' Rosie as disabled.**

However, this Dad had successfully applied and when he talked about the financial benefits... well, frankly, I didn't care much about the label! So, he shared his application with me which included a letter describing the condition and why diet is an essential component of management.

**Our clinic doctor was great about filling out the forms,** I crafted a heartfelt explanatory letter, and we sent our application by mail at the end of May. And we waited. And waited. And waited.

By the time I received a response at the beginning of August, I had almost forgotten about it. But there it was, in my hand: a letter stating that our application had been accepted! The letter stated that we can now claim the DTC until Rosie is 18, and that a reassessment of prior tax years would be forthcoming.

Then, a few weeks later, it happened: **we suddenly had an extra \$3,000 in our bank account.** Cautiously optimistic, I called the CRA for an explanation. I learned that it was an

Europe. In this case, ironically, the PKU infant qualified for the Ontario Drug Plan but did not qualify for the program which provides formula and low-phe foods.

CanPKU brought the boy's medical needs to the attention of the provincial official in charge and in less than 24 hours of CanPKU's outreach, the child was approved for government funding of formula.

**Hats off to Assistant Deputy Minister Suzanne McGurn for her immediate personal interest and attention to this patient's needs.**

CanPKU worked closely with PKU clinic staff at the Hospital for Sick Children on this case and the child's mother signed a consent for CanPKU advocacy.

Individually, we are different. Together we can make a difference! To help with advocacy efforts in your province, all you need to do is email [john.adams@canpku.org](mailto:john.adams@canpku.org) and let us know you are interested. We will keep you up to date on advocacy efforts in your region and coach you through how you can help!

## **Rare Disease Day!**

The last day of February is Rare Disease Day and here at CanPKU we feel it is important to support this international awareness event.

This year, we sent a denim Awareness Ribbon to all our current members as a small token of our appreciation. If you did not receive one, please make sure we have your correct mailing address!

In 2016 we hope to have a bigger presence on Rare Disease Day and we welcome your ideas on how to do this!

adjustment to our Child Tax Benefit paid over the last three years. For prior years, we would have to request a review in writing. And the same would happen with our income taxes - they would automatically reassess the last three years, but anything before that we would have to request in writing. So we did.

**The process finally ended in December 2014. More than 6 months after submitting our application everything had been reassessed and we had received a whopping \$25,000 in refunds!**

CanPKU realized right away that we needed to help other Canadians make successful applications, and I am thrilled to announce that **the CanPKU Disability Tax Credit Information Package is now available.** It includes instructions, examples and tips for making a successful application. In addition, we will be hosting a workshop at every one of our regional events this year to help people understand and start the process. Remember that retroactive refunds will vary greatly depending on your income and taxes paid over the years. However, even if you are accepted and don't receive a refund, you will still pay LESS taxes in future years. **Having just completed our 2014 taxes, I can tell you that it increased our refund by approximately \$2,500.**

And yes, both child and adult patients should apply. However, It is important to note that not every IEM patient will qualify - those with high tolerances, either because of Kuvan or without, will likely not be able to satisfy the requirements.

**The key is acknowledging that management of PKU is life-sustaining therapy and illustrating that eligible activities - doing blood tests, tracking phe intake, preparing and administering formula - take 14 hours or more per week.** Preparing meal, purchasing foods, traveling to appointments and the hundred other things we spend time on with this condition are NOT eligible.

If you have suggestions on how we can help raise awareness and support this important day next year, please email:

[nicole.pallone@canpku.org](mailto:nicole.pallone@canpku.org).

## **Because Knowledge Leads to Better Health!**

### **HOWMUCHPHE.ORG IN CANADA!**

We mentioned in the previous issue that [Howmuchphe.org](http://Howmuchphe.org), an online tool for finding phe values of various foods, was made available to Canadians as of December 15th, 2014.

CanPKU has a limited number of one-time use, \$10 off coupons available to our current members!

If you have not yet done so, please email Nicole Pallone directly to request this coupon: [nicole.pallone@canpku.org](mailto:nicole.pallone@canpku.org).

### **Recipe Corner:** **Granola Bars**



**Yield:** 15bars, 3 mg Phe, 5 mg Leu and 191 cal per bar.

#### **Ingredients:**

- 1 cup (250 ml) Wel-Plan or other baking mix
- ½ cup (125 ml) dried cranberries
- ½ tsp (2.5 ml) cinnamon

**Because we have received overwhelming feedback that we need to improve the benefits available to members, and because we anticipate that package recipients may require extra help in navigating this process, we have chosen to make these packages available to members only.** We sincerely hope this packages helps those in need.

**TO RECEIVE YOUR COPY OF THE DTC INFORMATION PACKAGE**

**[CLICK HERE!](#)**

### **2015 Event Series**

**by Nicole Pallone**

Mark your calendar for the following dates and places!

Please also remember that travel scholarships are often available - don't let finances stand in your way of your health and coming out to one of these great events in your area!

<u>2015</u>	<u>Event</u>	<u>Dates:</u>
	Prairies PKU Day - Saskatoon	Saturday April 11
	Atlantic PKU Day - Halifax	Sunday May 3
	BC PKU Day - Vancouver	Sunday May 24
	Ontario PKU Day - Toronto	Sunday June 7
	Quebec PKU Day - Trois Rivieres	Saturday Oct 3

Past attendees have often commented about how great these events are... they enjoy meeting other patients and parents, learning tips and tricks for managing the diet, educating themselves about the current ongoing research and tasting lots of new foods! Make sure you don't miss out, and remember why we do this...

**Because Knowledge Leads to Better Health.**

- 1 tsp (5 ml) baking powder
- 1 box (150 g) Loprofin crackers
- ½ cup (125 ml) Loprofin cereals (or other, such as Lp Flakes)
- ¼ cup (60 ml) brown sugar
- ½ cup (125 ml) canola oil
- ½ cup (125 ml ) honey
- 1 tsp (5 ml) vanilla

#### Preparation:

- Preheat oven to 350F.
- Line a square 8 in cake pan with parchment paper.
- In a large bowl, mix together baking mix, cranberries, cinnamon and baking powder.
- In a large resealable plastic bag, place the crackers and cereals. Seal the bag and remove as much air as possible. With a rolling pin, crush the content of the bag to obtain small pieces.
- Pour content of the bag into the bowl with the baking mix.
- In a measuring cup, stir together sugar, oil, honey and vanilla. Add this mixture to the baking mix mixture. Mix well.
- Pour into prepared baking dish. Press well in the pan.
- Bake for 25 minutes.
- Cool completely before cutting into bars.

(please note that the image shown was taken by the editor and in these bars we added 40 g of semi sweet mini chocolate chips to the recipe, please adjust the accordingly if you do this).

\*Recipe kindly provided by Genevieve LaFrance from:

[www.lowprorecipies.com](http://www.lowprorecipies.com)

#### Summer Camps - Upcoming for 2015

NPKUA has just listed a number of upcoming summer camps across the US. Some of these may be of interest to our readers, depending

If you are willing to volunteer at the event in your area please contact our National Events Coordinator,

Jenn Pino, at [jenn.pino@canpku.org](mailto:jenn.pino@canpku.org)!

Event info: [www.canpku.org/events](http://www.canpku.org/events)

#### Hat's Off to...

#### RUTH APPANAH



As Ruth mentioned in her opening letter, life has taken her in an exciting new direction that will drastically reduce the amount of free time she has available. Her dedication over recent years to being our Newsletter Editor was greatly appreciated and we will miss working with her! So, we take our Hat's Off to Ruth: thank you for being easy to work with, open to feedback and taking initiative. We knew with the newsletter in your capable hands it would be done on time, and done well (ironically, this newsletter is the first time we have published late in quite some time but it is due technical difficulties!)

If you are interested in stepping into the role of CanPKU Newsletter Editor, please email [nicole.pallone@canpku.org](mailto:nicole.pallone@canpku.org). Successful candidates do not need any experience but the ability to work independently and previous experience using Constant Contact is definitely an asset!



on their proximity and where they might be at the time of the camps.

Please click on the list below for further details!

<http://www.npkua.org/Resources/PKUCamps.aspx>

If any of our readers have an event or item they would like us to highlight, please don't hesitate to let us know by [contacting us](#).

### **Tips for Travelling with PKU, by Maria Deppenweiller!**

I am a PKU adult and a globetrotter. Travelling with PKU is much easier than you think but requires you to plan ahead your trip a little bit more thoroughly. Here are some useful tips on how to get your trip organized and not worry about your diet en route.

#### **Formula:**

It is always the best bet to bring all your formula along with you. If your trip will last longer than a month you can arrange formula shipments overseas with your formula provider/manufacturer or with family. As formula is considered to be a medication in most countries it requires a doctor's prescription and can not be easily bought over the counter.

Put at least 3 day supply of formula in your carry on luggage - in case your checked in suitcase gets lost and you do not receive it right away. If possible keep it all in original intact packaging (i.e. bring an unopened can instead of half-done one) in order to avoid extra questions.

Think of how you prepare your formula, Do you mix it with cold water, or juice, do you need straws or special shakers? In case of water - bottled water can be easily obtained

### **Walkathon!**

Although we took a hiatus to support the journey of Avery's Ride for PKU, this year we would like to continue with our Annual National PKU Walkathon fundraiser!

We encourage all of you to take just a few hours out of your life and host a walkathon in your community - it is a very rewarding experience! This is a great opportunity to raise awareness, bring PKU families together, and offer some financial support to the only PKU patient organization in Canada.

With the goal of raising awareness as well as funds for CanPKU, this event can be as big or small as you like and tons of fun! We have lots of resources to make it easy:

Host Information Package	<a href="#">PDF</a>	
Walkathon Venue Form	<a href="#">PDF</a>	<a href="#">Word</a>
Walkathon Pledge Sheet	<a href="#">PDF</a>	<a href="#">Excel</a>
Tips for Collecting Pledges	<a href="#">PDF</a>	
Walkathon Funds Collected Form	<a href="#">PDF</a>	<a href="#">Word</a>

Please note that these documents will be available from our website soon! We look forward to hearing about your local Walkathon!

### **What's New!**

**by John Adams**

This new section will include information from the PKU community that may be of interest to you. Be sure to click the links for more information!

1. CanPKU is taking part in the annual conference of the Society for Inherited Metabolic Diseases (SIMD) March 28-April 1 in Salt Lake City, Utah. John Adams is representing CanPKU and sharing an exhibit booth with Christine Brown of the US National PKU Alliance.

everywhere but if you need juice and a particular temperature - think of where you will get it. It would make sense to bring along enough for the actual travel time and buy local juice once you have arrived. Always a good idea to bring along your own formula shaker/bottle.

### **Letter from your doctor:**

Although in all my travel history I have been asked only once for such letter at Heathrow airport, it is absolutely necessary to have it with you at all times along with passport and boarding pass. The doctors letter should in brief describe the fact that you have PKU and that you must transport your medication aka formula + low protein food with you at all times. Your Doctors name and contact info should be included as well. A translation into local language (other than English) is helpful too in case the border guards have difficulty understanding English. This document is your permission to transport food and formula regardless of general airport rules (i.e. limits on liquids, powders and other suspicious objects)

### **Low protein foods:**

Depending on your personal phenylalanine tolerance this issue can be solved in several ways and it all depends on the duration of your stay and what is available.

If your trip is going to be short and there will be no access to a kitchen try to minimize the amount of specialty foods that you bring along. A loaf of low protein bread will do. If you plan to stay longer and will have access to a kitchen - low protein pasta is another easily transportable low protein food. Snacks like crackers, cookies etc are also easy to carry and store.

Try to avoid bringing along foods that require much cooking or need refrigeration or spoil quickly.

### **Airplane food:**

Useful conversations are taking place with Canadian PKU-treating doctors including Sylvia Stockler and Clara van Karnebeek of Vancouver, Aneal Khan of Calgary, Chitra Prasad of London, Andreas Schultz of Toronto, Michael Geraghty of Ottawa, Bruno Maranda of Sherbrooke, Nancy Braverman and Grant Mitchell of Montreal.

SIMD is an opportunity to network with clinicians and with vendors such as Cambrooke Nutrition, Nutricia, Vitaflo and BioMarin.

2. Behind the Glass marketing research/education project: on March 28, at the SIMD meeting John Adams was invited to observe a moderated discussion among PKU adults in their 20s and 30s about their experiences living with PKU, targets for phe levels, diet, medical foods and nutrition, mental health assessments and Kuvan therapy. In a separate room, clinicians also observed the 90-minute patient discussions and then the clinicians had their own moderated discussion about what the patients said and what the clinicians had learned from patients.

The project was funded by BioMarin Pharmaceuticals. CanPKU has agreed to work with BioMarin to help organize a similar moderated discussion for patients and parents of PKU children to be held in Vancouver Saturday, May 23. [Click here for details.](#)

3. Here we go again with more bureaucracy over the government funding for Kuvan responders. CanPKU received a letter in February from the Pan-Canadian Pharmaceutical Alliance (PCPA) on behalf of most of the government drug plans across Canada saying that new information about the clinical benefits of Kuvan for PKU would have to be resubmitted by the drug company to the Common Drug Review. If this takes place, it will be the third time that Kuvan has been considered by CDR and its independent expert advisory committee.

John Adams wrote to the CEO of the agency which runs the Common Drug Review to seek

When booking your airplane ticket inquire with the airline directly (not the travel agent!) what choice of specialty meals they have. Some airlines do offer low protein meals, but you have to book them in advance. Vegetarian meals are also a fair deal - you can always remove the peas and beans and eat the rest. Another bonus - specialty meals are typically served before everything else so you get your meal sooner!

Always follow up at check in to make sure that they have indeed booked your special meal. Do not rely on the good memory of airline staff and don't be shy to remind them that you need something.

### **Resorts:**

If you go on vacation and plan to stay in a resort, your best bet is the buffet. If you can not identify the ingredients of a local dish by yourself - feel free to ask the chef for details.

In some places you can bring your own low protein pasta and ask the cook to prepare it for you.

Do not be shy to ask for special requests - like salad without nuts, bigger portion of side vegetables etc.

Some resorts do offer help with special diets, this is something that you have to ask while booking your trip.

All resort rooms typically have a little refrigerator, that allows you to store your own specialty foods (just move those liquor bottles out of the way to make more space).

### **Restaurants:**

When going out to a restaurant in a different country be proactive and ask for a menu before you walk in. A quick glance at the food list will give you an idea if you can find something edible or not.

Do not hesitate to ask right away if restaurant will accept any dietary adjustments (i.e. no cheese on salad, soup with no croutons,

assurance that CanPKU will have the opportunity to make a submission if Kuvan goes back into the process for the third time. If you wish a copy of the PCPA or CanPKU letters in this regard, please email [john.adams@canpku.org](mailto:john.adams@canpku.org)

4. John Adams will meet with representatives of the Pan-Canadian Pharmaceutical Alliance in late April. PCPA represented the provinces and territories to negotiate discounts for bulk purchases of prescription drugs under a mandate from the Premiers.

5. One constant challenge for PKU and allied disorders is the need for more tools in the toolbox for clinics and patients to achieve better outcomes.

6. The US Orphan Drug program - which we lack in Canada - is getting great results. In 2014, the US approved 49 new orphan drugs, a 53% increase over 2013. The number of orphan drug designated for development increased 13% to 293. And the number of requests for orphan drug status reached 467, up 35%. All three numbers are records.

However, given that there are more than 7,000 rare disorders with treatments for only about 500 (PKUers are fortunate to have more than one kind of treatment, yet we need more) it is clear that conventional thinking is inadequate to meet unmet medical needs. As a society we are not spending enough on innovative treatments to keep us out of hospitals and reaching our full potentials. There are more than 6,500 rare disorders without any treatments, including the two neurodegenerative diseases which took the life of my wife, Marita, last year.

7. In January, US President Barack Obama and Dr. Francis Collins, Director of the US National Institutes of Health, announced plans to collect genetic data on one million Americans to help develop treatments tailored to individual patients. Called the "precision medicine initiative", this description does make one pause to think that past and current approaches



risotto with no cheese). Typically the fancier the restaurant the more hesitant they are to adjust their dishes to customer's liking.

If you do not see a specific dish that you can eat - ask the waiter to make one up for you - a plate filled with side of vegetables and fried potatoes for example, is typically not listed in the menu but most restaurants will happily put one together for you.

Do not hesitate to ask for details - what are the ingredients in the salad for example (sometimes nasty surprises like nuts or cheese may arrive unannounced).

Some restaurants are willing to cook your pasta. As an option you can bring along a package of low protein pasta and ask them to cook it up for you with their own sauce. But this is something you need to ask in advance when booking a restaurant in order to avoid hassle once you are at the table.

#### **Local foods:**

It is always a great idea to explore local markets for things you may eat. Aside from the cultural and educational benefits you may come across surprising things. For example when I was in Brazil I discovered a local pancake that was made from cassava flour (basically starch) that was super low in protein and widely available everywhere. In Peru fried yucca - a typical side dish proved to be a great replacement for higher phe potatoes.

If you do not speak local language - try to pick foods that you are confident about - butter, fruits, vegetables.

It is always a great idea to learn how "protein" is spelled and pronounced in different languages - that way you will be able to read the labels on most foods and see if it is sufficiently low in protein. Just make sure you check the portion size - some countries go with nutritional info per 100g and some -

to treatments must be based on "imprecise" medicine.

New York Times article:  
<http://mobile.nytimes.com/2015/01/31/us/obama-to-unveil-research-initiative-aiming-to-develop-tailored-medical-treatments.html?referrer=>

8. Update on the fight to end genetic discrimination: The Senate of Canada passed a bill last month to amend the Canada Labour Code to protect employees under its jurisdiction (about 10% of workers) from genetic discrimination in employment. Unfortunately, the Conservative majority in the Senate deleted two major elements which would have prohibited any person from required another person to take a genetic test or to disclose the results and to amend the Canada Human Rights Act to prohibit discrimination based on genetic characteristics. The original version of the Bill was introduced by James Cowan, Leader of the (Liberal) Opposition in the Senate. Senator Cowan noted that Canada is the only major developed country without a law to prohibit genetic discrimination. The watered-down Senate Bill goes to the House of Commons now.

9. The Sickle Cell Disease Association of Canada will present its Patient Care Award of Excellence to John Adams for his advocacy work in promoting expanded newborn screening across the provinces of Canada as a reception on Parliament Hill in Ottawa on May 5.

10. CanPKU will be participated again at a North American meeting of doctors treating PKU and other metabolic disorders. We will again share a booth with our colleagues of the U.S. National PKU Alliance at The Society for Inherited Metabolic Disorders (SIMD). This takes place in Salt Lake City, Utah March 28 - April 1. Dr. Michael Geraghty of Ottawa represents Canadian docs on the SIMD board.

11. Mark your calendars for 2016: the biannual conference of the U.S. National PKU Alliance will next take place July 28-31, 2016 in Indianapolis, Indiana.

per serving size which can be more or less than 100g.

Ask local people about their traditional foods and what ingredients go in it. Sometimes you can stumble across great new low protein foods.

You can find more info about low protein foods and me here:

Twitter: @DepenweillerM

Instagram: earilian

Blog:  
<https://thewoodenspoonblog.wordpress.com/>

Web:[www.thewoodenspoon.ca](http://www.thewoodenspoon.ca)

### Quick Links...

[Our Website](#)

[Our Previous Newsletters](#)

[Our Facebook Page](#)

### In Our Next Issue...



Watch for our June 15th newsletter when CanPKU Vice President Nicole Pallone shares her experience of a family vacation at Disneyland!

## **PKU Nutrition Management Guideline Now Available!**

GMDI and the Southeast Regional NBS and Genetics Collaborative (SERC) are partnering to develop nutrition management guidelines for treatment of inborn errors of metabolism.

The new guideline for nutrition management of PKU is now ready for viewing!

The PKU guideline can be found at these links:

<http://gmdi.org/Resources/Clinical-Practice-Tools/Nutrition-Guidelines>

[https://southeastgenetics.org/ngp/guidelines\\_pku.php](https://southeastgenetics.org/ngp/guidelines_pku.php)

The Nutrition Guideline project developed an extensive methodology to provide evidence- and consensus-based standard of care guidelines for nutritional management of inborn errors of metabolism. The PKU guideline is the second one of these to be completed. All guidelines will be updated regularly to assure that they continue to reflect reliable and current information from both clinical and research efforts.

Many in academic and clinical arenas, as well as from the consumer community, have contributed to this project. NPKUA, in particular has donated funding to help support this work.

Special thanks goes out to the GMDI members who have committed a significant amount of time and effort as members of the PKU guideline work group:

Amy Cunningham and Shideh Mofidi (Co-Chairs), Debra Hook, Helen McCune, Kathryn Moseley, Beth Ogata, Surekha Pendyal, Jill Skrabal, and Ann Wessel. Rani Singh is project Principal Investigator, Fran Rohr the Co-investigator. Consultants are Dianne Frazier and Pat Splett.

For access: please go to the GMDI home page, [www.gmdi.org](http://www.gmdi.org), and click on "PKU Management Guidelines". To view the official announcement, please go to [NMG Guidelines Announcement](#).

## **Become a Member!**

The more members we have the greater our voice is when advocating for better treatment coverage and care.

To become a member go to <http://www.canpku.org/become-a-member>.

**Please note that all members are eligible to receive a \$10 off coupon for howmuchphe.org while quantities last. To request your coupon, please email [nicole.pallone@canpku.org](mailto:nicole.pallone@canpku.org).**

Please ensure that you choose the appropriate category when you next renew your membership!

- **General Member (GM):** any person diagnosed with PKU or other allied disorder; any person related to a person with PKU or other allied disorder and whose life is directly affected by the diagnosed disorder (such as a parent, grandparent, legal guardian, sibling, spouse or child). Only General Members 18 years of age and older having voting rights.
- **Supportive Member (SM):** any person who supports the vision and mission of CanPKU and is interested in advancing its objectives. Supportive Members have NO voting rights.
- **Professional Member (PM):** any professional (doctors, researchers, nurses, nutritionists, among others) related, interested and/or working on PKU and other genetic and/or metabolic disorders. Professional Members have NO voting rights.
- **Corporate Member (CM):** any corporation interested in helping and supporting CanPKU. Corporate Members have NO voting rights.

**New members will receive a 5% discount on all Country Sunrise products ordered from PKU Perspectives and one free box of VitaBites from Vitaflo.**

Other benefits include:

- Discounted registration rates at all CanPKU events;

- Direct contact from CanPKU regarding newsletters and event invitations;
- Direct access to new information regarding treatments, research and Provincial/Territorial advocacy campaigns;
- Support from other individuals and families who understand;
- Priority access to travel bursaries for CanPKU events, when available;
- Opportunities to volunteer and make a difference;
- Tips on advocacy and creating awareness in your community; and
- Voting rights at Annual General Meetings and Special Meetings (General Members Only).

*By becoming a member you are showing your support for CanPKU to accomplish its goals, which include:*

- *Creating awareness about PKU and other inherited metabolic disorders;*
- *Providing a supportive community for those living with PKU and other inherited metabolic disorders;*
- *Increasing opportunities for PKU families and others to attend educational and networking events;*
- *To improve the lives of people living with PKU and other inherited metabolic disorders;*
- *Promoting and supporting research; and*
- *Advocating for increased treatment coverage across Canada.*

Join Our Mailing List!

Dear Reader;

Please feel free to forward this newsletter on to your contacts. CanPKU is always looking for volunteers, members and corporate sponsors. For more information about our organization and other PKU resources, please visit our website at [www.canpku.org](http://www.canpku.org).

Sincerely,  
Canadian PKU & Allied Disorders Inc.



Because Knowledge Leads to Better Health

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