



CanPKU News

Issue No. 20

Canadian PKU & Allied Disorders Inc. Newsletter

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Dear Reader,

Our 20th edition of the CanPKU newsletter is here! I hope you can all appreciate that in an organization such as ours that relies so heavily on volunteers, there are times when sticking to our scheduled newsletter release is difficult. 2015 seems to be one of those years!

While we are sad to see Ruth step down as our newsletter editor, we wish her all the best in her new endeavors and are thrilled to have a new volunteer, Kelly Milco, agree to take on the task of newsletter editor. Welcome to the CanPKU team, Kelly!

We hope everyone is having a great summer and enjoys this edition of our newsletter!

Warm regards,
Nicole Pallone
Vice President

We apologize for the delay in sending this newsletter out, and also apologize if you received it twice! Our next newsletter will still come out on September 15th as planned.

2015 Event Series

Since our last newsletter we have held four of our five events, and are looking forward to **Quebec PKU Day on Saturday, October 3rd in Trois Rivieres!** We have had record attendance at some of our events this year and hope that Quebec is the same!

Please 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!



We are already gearing up for our 2016 event series. 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!

If you have suggestions on what topics you would like to see at your next regional event, please [email Jenn Pino](#), our National Events Coordinator. And make sure you attend our events next year, **Because Knowledge Leads to Better Health!**

Disability Tax Credit Information Packages

This is a reminder that CanPKU Members are eligible to receive our DTC Information Package which is intended to help qualified patients receive this important benefit. We have had over 50 requests for these packages and look forward to hearing from families whether or not their applications are successful.

To date, we know there have been successful applicants in BC and Ontario. Please be sure to let us know the outcome of your applications so that we can continue to learn what makes an application successful and how to best approach the appeal process.

TO RECEIVE YOUR COPY OF THE DTC INFORMATION PACKAGE

[CLICK HERE!](#)

HOWMUCHPHE.ORG IN CANADA!

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

CanPKU still 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.

Recipe Corner:

2016 National Walkathon

Next year, we want to make PKU Awareness Month in May a resounding success by hosting walkathons in multiple communities across Canada - and we need your help!

We encourage all of you to take just a few hours out of your life and host an event 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.

Let your imagination run wild - it can be a walkathon, a dance-a-thon, a zumbathon, or any other activity you choose!

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	PDF	
Walkathon Venue Form	PDF	Word
Walkathon Pledge Sheet	PDF	Excel
Tips for Collecting Pledges	PDF	
Walkathon Funds Collected Form	PDF	Word

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

Thai Noodle Salad



Note: The phe calculations for this recipe are done by a volunteer and should be verified by your dietitian.

Yield: This recipe is for a one serving portion, and contains a total of 73mg of phe or 4.85 exchanges.

Ingredients:

- 1 bundle of dried mung bean noodles
- 20g of raw carrots, julienned
- 20g of raw bean sprouts
- 10g of green onions, chopped
- 20g of water chestnuts, sliced into slivers
- 20g of raw red bell peppers, julienned
- few leaves of fresh cilantro or basil

Dressing:

- 1/2 tbsp of Soy Sauce (china lilly)
- 1 tsp of Dietary Specialties Imitation Peanut Butter
- 1/2 tsp lime juice
- 1 tsp red wine vinegar
- 1/2 tbsp red pepper jelly
- 1 tsp sesame oil
- salt, pepper & hot sauce to taste

Preparation:

ADVOCACY UPDATE

CanPKU is in the midst of a major, sustained advocacy focused in Ontario initially to win genuine access to Kuvan for PKU responders from government drug plans.

In May, a delegation of PKU families attended the Ontario Legislature and won a hard-fought battle by persuading Ontario Health Minister Dr. Eric Hoskins to ask his drug plan officials to take a fresh look at the clinical criteria for Kuvan access. Below are links to the extensive, positive news coverage the campaign is getting.

To recap briefly, Health Canada approved Kuvan for sale in 2010 and Ontario and Saskatchewan reached a price agreement with the drug company in 2013. However, more than two years later no PKU patient in either province has access to the medication under provincial drug plans. Ontario PKU doctors wrote the province in 2014 saying the access criteria were written with little or no consultation and make it difficult if not impossible to access the drug.

Quebec is covering Kuvan for some patients and so is Health Canada for one First Nations PKU child. The other provinces so far have declined to cover the drug.

Dr. Andreas Schultze of the Hospital for Sick Children in Toronto received the most recent rejections for three patients and he wrote to CanPKU and his medical colleagues that he believes those patients are Kuvan responders.

Both the NDP and PC Health critics have asked the Ontario Health Minister to report back on changing the criteria.

Meanwhile, the provincial drug plans except Quebec have asked the drug company to submit new information about the usefulness of Kuvan to treat PKU to another interprovincial evidence review process called the Common Drug Review. This will be the third time since 2010 that Kuvan has been considered by the interprovincial process. This latest process will likely take until next summer to complete, which is too long in our opinion.

Now it is more important than ever that our community engage in this advocacy campaign! More information can be found on our special advocacy website:

www.CanPKUAction.org

We thank those of you who have come forward to participate in these efforts, and hope that other families will consider becoming further engaged!

- Boil a small pot of water and cook the mung bean noodles per the directions on the package. Rinse in cold water when done. Set aside.
- Combine dressing ingredients until well blended. Set aside.
- Combine salad vegetables in a mixing bowl. Add cooled noodles and dressing. Toss, and garnish with fresh cilantro or basil. Serve immediately or save for later!

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 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](#).

Update from Nutricia

As part of our Silver and Gold sponsorship packages, sponsors are invited to share company news in our newsletters. This article was written by Nutricia staff.

NUTRICIA Metabolics
Inspiring futures

Introducing Periflex® Junior Plus
Our most advanced PKU formula for juniors now contains DHA and Fiber.

Now Available In Canada!!!

Arming Juniors with the NEXT Generation of PKU Nutrition

Request Sample

Talk to your dietitian today.

As part of Nutricia North America's commitment to provide BEST CARE in specialized nutrition, we are continuing to make improvements across our Periflex family of products, providing

PKU Profile Alex Des Ruisseaux



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 videogame industry.

patients with the best possible nutritional support according to the latest medical and scientific knowledge.

Therefore we are so pleased to offer you the new Periflex Junior Plus family with its four different flavours : Plain , Vanilla , Orange and Berry .
PKU Periflex Junior contains:

- DHA to support brain and eye development in children up to 2 years of age.
- Nutricia's multi-fiber blend to support digestive system.
- Improved levels of calcium and Vitamin D to help build and maintain strong bones and teeth.
- Updated macro- and micronutrients profile to meet current DRI recommendations.

To learn more please visit: <http://www.medicalfood.com/>

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.

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:

PKU in Disneyland!

by Nicole Pallone



As many of you have done before, we spent a week of our spring break in the magical world of Disneyland! This proved to be the best family vacation we've ever had, and included special treats for our PKU daughter.

With a little bit of planning ahead, the PKU diet was quite easy to manage in Disneyland. A few months prior to our trip, I emailed the Disneyland chefs (DLR.Special.Diets@disney.com) to let them know that they would have a PKU guest coming to the resort. I received a quick reply from one of the Disneyland chefs, who advised me of all the restaurants that can provide low protein meals. He then recommended that we make reservations, and advise him of the dates and times.



It took a lot of planning - figuring out what part of the park we would be at during specific meal times was admittedly a challenge - but it was so worth it! Rosie really needed those low protein calories while trekking 5km each day, and it also meant that we enjoyed many of the nice restaurants that are now on the Disneyland grounds! The resort has really stepped up the quality of restaurants and

- 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.*

Quick Links...

[Our Website](#)

[Our Previous Newsletters](#)

[Our Facebook Page](#)

we had some fantastic meals, but be warned - the cost adds up quickly!



In addition to one or two restaurant reservations each day, we also carried in a backpack full of snacks, drinks, formula and scale. This is definitely allowed! They will check your backpack each day when you enter the park to ensure there are no glass items, but this is a great way to ensure that you have appropriate food readily available, and an excellent way to save a few bucks! The resort has also gotten better at having healthier options available... it is not all corn dogs and cotton candy anymore! Street vendors regularly had healthier options that worked with our PKU diet: pineapple spears, pickles, apple juice smoothies, fresh fruit and apple chips!

So, how did we deal with formula? Instead of lugging around ice packs and trying to keep formula cold all day, we decided to use powdered milk. I checked with our dietitian prior to the trip about what amount of powdered milk to use, and divided that and the formula powder into three equal servings (a baby formula dispenser, available at most grocery stores, worked well). Then when it was time for formula, we simply had to mix the powder with some water and it was ready to go! TIP: a wide mouth water bottle for mixing made it easier to pour the dry formula and water into.

It was a great treat for Rosie to be able to order her pasta at a restaurant, and enjoy some low protein Mickey waffles just like the other kids. It all worked wonderfully and we truly had a magical vacation!



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.

Sincerely,
Canadian PKU & Allied Disorders Inc.



Because Knowledge Leads to Better Health

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