



CanPKU News

Issue N

Canadian PKU & Allied Disorders Inc. Newsletter

December 2014

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Dear Reader,

Seasons Greetings - I hope this issue of the newsletter finds you all well and happy, and not too cold!

This is a the time for CanPKU when the events planned for 2014 are at an end and we are already working on next year's exciting projects! We would like to remind our readers to let us know of any ideas or topics that you would like see in the new year and we will do our best to try and work with these.

Closing out the year can often be a time for reflection for many, what they have accomplished, what they might wish to accomplish next year. We at CanPKU have many goals and action items on our agenda for next year.

Below we summarize what we feel to be interesting and newsworthy to the community as well us update on plans for the new year! There is so much going on that we have also decided to add a section - check out "**What's New**" to find a brief description and links to some topics you may find interesting.

Please also join us on [Facebook](#) and on Twitter (@canpku, @npallone) to stay in touch and help us spread the word when important announcements are in the air!

Thanks for reading and wishing you the best over the holidays!

Sincerely,
Ruth Appanah
Editor
CanPKU and Allied Disorders Inc. Newsletter

Quebec PKU Event

by Helene Dandurand

On Saturday, October 18th, close to 50 people took part in the CanPKU Quebec 2014 Educational Event which was held in Quebec City, at the Four Points Sheraton Quebec Resort.

After the customary welcome and introduction, we opened up the day with Dr. Cary Harding's talk on "What's New in PKU" where he updated us on current therapeutic uses of Kuvan, Peg-Pal development and preclinical efforts with gene therapy. He also outlined why the treatment of PKU needs to evolve to meet the needs of patients as they move ahead in life. A prominent figure in the treatment of PKU, Dr. Harding is a geneticist at the Oregon Health & Science University and an attending physician at the OHSU.

RECIPE CORNER

Low Protein Pulled Pork Sandwiches



Number of servings: 4

Serving size: 1/2 cup (125 ml)

Ingredients

- 1 can (20 oz) green Jackfruit in brine (not in syrup!)
- ½ cup (125 ml) BBQ sauce Trade (Diana chicken ribs removed)
- 1/3 cup (75 ml) water

Preparation

- Drain canned jackfruit. Rinse well and drain again.
- Shred the jackfruit and chop parts that seem a little harder. Place in a sauce pan. Add BBQ sauce and water. Bring to boil. Simmer for 30 minutes.
- Refrigerate overnight if possible, for best flavor absorption.
- Serve on bread of your choice.

Per portion - Phe: 35 mg, Leu 46 mg, protein 1.3 g

Suggestion: garnish sandwich with avocado and/or serve with coleslaw.

*Recipe provided by Genevieve LaFrance from:

www.lowprorecipes.com

HOWMUCHPHE.ORG IN CANADA!

IT'S HERE!

Howmuchphe.org is an online tool for finding phe values of various foods and as of December 15th and it is now

AVAILABLE TO CANADIANS! [Click here](#) to see the announcement.

This online database of phe amounts is the updated version of Virginia Schuett's PKU Food List, and is accessible from any device with internet connection. As a user of this service I can tell you that it is fantastic to have the information at my fingertips when I am visiting

Next, Geneviève LaFrance, a dietitian at the CHUS in Sherbrooke, presented on her low protein recipe Web site that she created and launched in 2014 (see "Low Protein Recipes in French and English" article at left). She was also in the midst of a personal challenge to experiment the PKU diet for two weeks with a restricted PHE amount of 300 mg/day. She compared her experience to that an adult returning to diet and wanted to experiment first hand what it entailed on a daily basis, at home, at work and eating out. She said it was an eye opener - she gained a true insight on life on PKU diet and learned more in this short time than in the past 6 years of counseling!

After a wonderful lunch, appreciated by both PKU and non PKU'ers alike, an informative presentation on Glycomacropeptide (GMP's) was given by Dr. Denise Ney, a Billings Bascom Professor of Nutritional Sciences and a Waisman Center investigator at the University of Wisconsin-Madison. GMP is a natural dietary protein from whey that contains just a trace of PHE and provides an alternative to the traditional amino acid formula. Because it is an intact protein, it is more efficiently utilized by the body. Studies also indicate that it may be beneficial to skeletal and renal health. As it is believed to promote satiety and fight the persistent hunger that PKUers often feel, GMP may improve dietary compliance and metabolic control in PKU.

We closed the day with a dynamic cooking demo by Malathy Ramanujam, owner of Taste Connections and an expert in low protein cuisine. With volunteers from the audience, Malathy prepared tortillas, English muffins and beet burger meat balls in a pop cake machine that was raffled off at the end of day! Tasting was required of all participants.

Lots of laughs, a couple of mishaps (with no need to call the fire department!) and excellent cooking ideas brought us to the end of another great PKU Day in Quebec.

Thanks for joining us... BECAUSE KNOWLEDGE LEADS TO BETTER HEALTH!!

2015 Event Series

by Nicole Pallone

We are in planning mode for our 2015 Education Event Series and are excited about seeing you all at our events next year! We have invited all your Canadian clinicians to present at our five regional events this year, and hope to see a lot of them involved.

Topics will include an adult with PKU speaking about his experiences, dietitians speaking about a new way to manage PKU, how PKU affects the brain, why the Genetic Fairness Coalition matters, an update on current PKU research, GMP formulas, and more!

These events are not only educational, but after gathering feedback we've learned that people want more time to mingle. We'll do our best to work extra time into the program while still providing you with lots of excellent speakers.

relatives, in a restaurant or at the grocery store!

There is a \$45 annual subscription cost for the service, but all **current CanPKU members as of December 31, 2014 are eligible to receive a \$10 off coupon** (one time only) - so sign up today if your membership has lapsed! Current members need to email Nicole Pallone (nicole.pallone@canpku.org) to request their coupon.

Merry Christmas from CanPKU!!

Book Publication by PKU Adult Advocate

-
(*please note this book is not about PKU, but is featured because the author is an adult with PKU, also very active in the community*)

Maria Depenweiller is thrilled to share the news - her new book "Russian Cuisine - traditional and contemporary home cooking" is ready to hit the shelves of the bookstores in January 2015.

Discover the fascinating details and tasty delights of a vast country that spans 11 time zones and brings together more than 180 ethnic groups.

Detailing the evolution and development of traditional Russian cooking, this book gives a better understanding to the foods that are now known as classic Russian dishes.

An all-encompassing cookbook replete with recommended music pairings and suggested readings from Russian literature, Russian Cuisine looks back on Russian history as never before.

From table settings to pantry items, this is a comprehensive guide to Russia's culinary past, and an essential book for savouring the history of Russian food.

Maria Depenweiller is a Professional Home Economist (PHEc), food writer, nutrition specialist and a recipe developer who has PKU. She was born and raised in Moscow, Russia. She started helping around the kitchen at an early age and picked up her culinary skills from her mother and both grandmothers. Maria wrote her first cookbook in a school notebook at the age of twelve, recording the recipes she saw her grandmother make at her summer house. Cooking and writing became her permanent obsessions. She has published three books on

We always include topics that are applicable to PKU patients of all ages, but will include more to encourage adult patients to attend!

Mark your calendar for the following dates and places, and remember that travel scholarships are often available - don't let finances stand in your way of your health!

2015 Event Dates:

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.

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!

Event info: www.canpku.org/events

AGM Meeting Updates

On September 26th at 7:30pm Eastern CanPKU held its Annual General Meeting (AGM) in Toronto. All current members were invited to attend to provide a voice, take part in the process as well as put themselves forward for a number of vacant positions within the group.

As a result of this meeting, a number of new faces have joined and we would like to officially welcome:

David Brennan (Chair of the Board)

Charles Black

Amanda Cosburn

Linda Stewart

Tanya Compeau

These five newcomers join John Adams, Nicole Pallone, Helene Dandurand and Tanya Chute to complete our newly expanded Board of nine members. We look forward to a productive year and would like to thank Cristian Baigorria and Jennifer Ballagh for completion of their recent term.

culinary topics in Russian, including a special collection of low protein recipes for PKU.

After coming to Canada together with her family she got a degree in Food and Nutrition at Ryerson University and became later a professional home economist. Her work background includes working for Nestle as a sensory and nutrition specialist, being a member of the board of directors of the Toronto Home Economics Association, expertise in natural supplements, organization of community cooking workshops, writing for newspapers, media coordination for Ontario Home Economics Association and low protein recipe development.

If interested, the book is now available for pre-order via the following links:

<http://www.chapters.indigo.ca/books/savours-and-flavours-of-russian/9781770502338-item.html?ikwsec=Books&ikwidx=5>

<http://www.amazon.ca/Russian-Cuisine-Traditional-Contemporary-Cooking/dp/1770502335>

By Maria Depenweiller, PHEc

Consider a Donation This Christmas!

This holiday season, why not support something near and dear to your heart? **You can now receive an income tax receipt for donations to CanPKU of \$10 or more by donating at:**

<http://www.corddonate.ca/canpku>.

Your donation will help to ensure that CanPKU can continue doing what we do best: educating, supporting and advocating for Canadian PKU patients young and old. Please help us diversify our funding to ensure our sustainability, and help yourself at tax time too!

Hat's Off To...



**Cristian Baigorria,
Founding Member of CanPKU**

Cristian Baigorria has stepped down after



Save the Date: Rare Disease Day

The Canadian Organization for Rare Disorders has announced that Rare Disease "Day" will be March 5-7th, in Toronto, Ontario at the Marriott downtown Eaton. Strategic planning, research updates, training plus an awards dinner gala are planned for the event. More details can be found on the CORD website at:

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

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 will be participating 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.
2. CanPKU had a useful meeting with two senior officials of Alberta Health's pharmaceutical services in Edmonton on Nov. 19. The discussion of the clinical benefits of Kuvan for PKU responders was well-informed by neuropsychologist Dr. Kendra Bjoraker. Thanks to PKU parent Ciaara Christante of Leduc for joining CanPKU President John Adams and adding to the discussion. It is clear that more advocacy is called for with AB Health - email john.adams@canpku.org if you would like to get involved!
3. Dr. Kendra Bjoraker was the expert speaker on PKU and the Brain at a well-attended meeting of PKU families at the Edmonton children's hospital on the evening of Nov. 19th. This mini event was organized on short notice and CanPKU will always try to expose families to experts who are in Canada on business. Thanks to Dr. Bjoraker for donating three days of her time include travel from and back to Minneapolis.

almost seven years as a Director and the first Board Chair of CanPKU.

He was one of the three founders of CanPKU (with Tatiana Dociu and John Adams) in 2008. There were no national, regional or provincial organizations for PKU and Cristian was integral to giving patients a voice.

Cristian's leadership was no surprise; he was the founding President of the Argentina PKU association before moving his family to Canada. That major relocation was so his late-diagnosed PKU daughter could access expert supports in Canada. We can all be happy that this PKU child is doing very well in school and life.

He and his wife Paola were the moving spirits for several years behind the Polo4Kids annual awareness and fundraiser for CanPKU in partnership with the Hospital for Sick Children Foundation. They live in Mississauga, ON with their three children.

He and his family have been key participants in advocacy with the Ontario government and he provided key advice and Spanish language documents to assist in the creation of the Mexican PKU association.

Cristian is an Information Technology specialist and entrepreneur. He has been master of our website and has kindly agreed to continue in that role.

He is a true leader and consummate professional. In his native language: Muchas Gracias, Señor.

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 as of December 31, 2014 will be eligible to receive a \$10 off coupon for howmuchphe.org. 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

4. PKU was covered in a special report on Global TV Regina and Saskatoon featuring Leah and Steven Creighton of Saskatoon and their three PKU children. This report was part of a series on problems with access to drugs for rare disorders. Thanks to the Creighton family for speaking publicly about the concern that patients who respond to Kuvan must "washout" by not taking the drug for many weeks and then re-qualify under government drug programs, no matter how long they have been on Kuvan or how well it works for them. [Click here](#) to watch the coverage!

5. 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.

6. The CanPKU Board at its most recent meeting decided unanimously to join the Canadian Genetic Fairness Coalition which advocates for laws to ban discrimination on the grounds of genetic characteristics. Two board members shared experiences with a PKU person being denied extended health benefit coverage in one case and life insurance in another case. Information on the Coalition is available at www.ccgf-cccg.ca

7. The [Genetic Fairness Coalition](#) is supporting a Bill in the Senate of Canada which limit the use of genetic information in insurance. The federal government on the recent Throne Speech promised action to end genetic discrimination.

8. Cook for Love, a source of great, creative recipes for PKU diets has relaunched its website. The new site allows you to customize the recipes while recalculating the phe amounts based on your changes, but all users must sign up anew as membership information was not transferred to the new site. To do so, please go to www.cookforlove.org

9. Ironically, Canadians and their government drug programs pay more than double for common generic drugs, according to a recent study. Perhaps this is why government drug plan managers say they cannot afford to cover drugs for PKU and other rare disorders. [Click here](#) to read a news story about this important issue.

10. CanPKU board member Charles Black, an adult with PKU, and President John Adams attended the annual conference of the Best Medicines Coalition in Toronto in mid-November. For more information about this organization please [click here](#).

11. Good news about an expansion of newborn screening: PEI is adding sickle cell disease to its testing program, with another 13 diseases to be added over the next two years. PEI was the first province to start newborn screening for PKU back in 1963 - for more information about the program, please [click here](#).

12. Virginia Schuett's not-for-profit company, National PKU News, now has the online tool howmuchphe.org available to Canadians! See the story on the left for more information.

New Recipe Website: LowProRecipes.com

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 (new in 2014!)

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.*

Our recipe contributor this month is Geneviève Lafrance, a Registered Dietician in the Department of Genetics at the University of Sherbrooke. She has been advising people with various inherited metabolic diseases since 2007.

Recently, Genevieve created the website Lowprorecipes.com site to help people with inherited metabolic diseases in their everyday lives, convinced that a recipe is more than a simple way to prepare food, it is a tool to help accomplish their medical treatment.

Her challenge was to develop simple recipes, visually appealing, tasty and low in protein! She wanted to prove to everyone that following a low protein diet can be easy and delicious.

Detailed nutritional value for each amino acid is available for each recipe of this website. The recipes have been developed with products available in Quebec, at the grocery stores or through companies that manufacture food especially for the treatment of inherited metabolic diseases.

It is the first tool of the sort available in French and English in North America.

The site is always evolving with the addition of a section on products newly spotted in food retail stores that are appropriate for a lopro diet.

Users are also invited to submit their own finds that could be share with the entire community.

Geneviève has invested a lot of her time and effort in this endeavor which, with the help of its sponsors and supporters, could give rise to new projects such as a printed recipe book and cooking demos.

Please visit:

www.lowprorecipes.com

or www.recettesfaiblesenproteines.com

for more information!

Quick Links...

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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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