

# CanPKU News



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

## In This Issue

[Change to Membership Fees](#)  
[Notice of AGM](#)  
[PKU Camp Review](#)  
[Educational Events](#)  
[Advocacy Efforts & Results](#)  
[Disability Tax Credit](#)  
[PKU Around the World](#)

## Quick Links

[Quebec PKU Day](#)  
[About Us](#)  
[Membership Purchase](#)  
[DTC Package Request](#)

## Our Sponsors

BRONZE SPONSORS



SILVER SPONSORS



*family to family*

We hope you are enjoying the return to routines that comes with school, and the September weather in your region.

Here at CanPKU we are busy finalizing details for our Quebec event on October 3rd and doing early planning for our 2016 series. Please [send us an email](#) to let us know what topics you would like to see at the next event in your region - your input is greatly appreciated!

We are also still looking for someone with newsletter experience to take over the role of Newsletter Editor for CanPKU. Or, if you have article ideas, please submit them to [newseditor@canpku.org](mailto:newseditor@canpku.org).

We hope you enjoy this 21st edition of the CanPKU News!

Sincerely,  
Nicole Pallone  
Vice President

John Adams  
President & CEO

**The Canadian PKU and Allied Disorders Inc.  
hereby gives Notice of Annual General Meeting on**

**Monday, September 28, 2015  
7:30-8:30pm, Eastern Daylight Saving Time**

**All members in good standing are entitled to participate by teleconference. Only General Members have voting rights on matters put before the membership.**

**Teleconference information:  
Please use local # where applicable (to reduce cost)  
416-507-9740 Toronto  
or 1-866-512-0904 - rest of Canada**

**You will be asked to enter a Participant Code (8823899) followed by the # key, and then to state your name, followed by the # key. The teleconference will be recorded.**



GOLD SPONSORS

**BIO**MARIN®

### Recipe Corner String Bean Casserole

This recipe is created by **Cook For Love**. To access more great recipes, sign up by [clicking here!](#)



This casserole is great on the Thanksgiving table or any dinner! It can even be assembled ahead of time: Combine the beans and cooled sauce in a baking dish, cover with aluminum foil and refrigerate for up to 24 hours. To serve, heat the casserole in a 350-degree oven for 10 minutes, then add the topping and bake as directed. Store the breadcrumb topping in an airtight container in the refrigerator and combine with the onions just before cooking. Lars own (Larsown.com) imported crispy onions are worth hunting for, if not, substitute with durkee.

**Ingredients**  
**Topping**

## A Trip to the Washington Family Ranch PKU Camp

by Lisa Laing



Although it was a 10 hour drive from Kelowna BC to get to camp, it turned out to be worth the effort. Barb Hill Watts, her son Cole Watts (PKU), my son Connor (PKU) and I all traveled together. We thought that we might win a prize for the furthest

traveled, like at a wedding, but that was not the case. Many of the participants were from the Portland area but we met people from Indiana, New York, Idaho, Montana, and California and all over Oregon and Washington states. Numerous people have attended this camp for 10+ years which I believe speaks to the benefit of gathering as a community drawn by a common bond, PKU.

My 13 year old son, Connor, had this to say: "This was the first year I went to PKU camp and by the first day I was already asking to come back next year. I have a mild case of PKU and I'm a big responder to Kuvan so I was able to eat much of the non-PKU foods (besides meat) but I still found myself eating the low protein food because the camp supplied such a variety of great tasting low protein food. There was so much to do at the camp as well, such as waterslides, Frisbee golf, kickball, whiffle ball, swimming, mini golf, basketball, soccer, ropes course, and lots more! The community of people there were very welcoming and inclusive, I really found it easy being new to everyone and already making friends on the first day."

To my understanding there were approximately 250 campers in total with 50 of the participants having PKU. There were kids of all ages, and some families brought along their extended families. You don't have to have PKU to enjoy PKU camp. There was one family we met from California that traveled over 14 hours with 4 children, 3 with PKU. But the Grandparents came as did two sets of aunts and uncles and their children. Organisers did a good job of including everyone in the group activities, there is plenty to do, and the facility is top notch. The value of the camp is also well worth it. Think about what it would cost to take your family to waterslides for the day; now think about daily waterslides, no line ups, and all you can eat buffets with PKU friendly meals you didn't have to plan for, cook or figure out how to pack!

As for PKU educational experience, they offered it too. Cooking classes were well attended, and there were many vendors on site with samples and product give-aways. The speaker's event was also informative with Christine Brown from the PKU community at the National level, Dr. Cary Harding with updates on PEG-PAL, and Terri Oxley from BioMarin.

All in all it was an enjoyable way to spend a few days amongst the PKU community in a beautiful setting at a great facility!

4 slices low protein bread, each slice torn into quarters [84 mg]  
2 tablespoons butter, softened [12 mg]  
¼ teaspoon salt [0 mg]  
¼ teaspoon fresh ground pepper [2 mg]  
50 gm (1/2 cup) Lar's Own Crispy Onions

### String Beans and Sauce

500 gm green beans, ends trimmed and halved [340 mg]  
6 tablespoons butter [36 mg]  
170 gm (1) onion, cut into ¼ inch dice [43 mg]  
110 gm (1) red pepper, cut into ½ inch dice [45 mg]  
180 gm (10) button mushrooms, stems trimmed and quartered [157 mg]  
10 gm (2 cloves) garlic, minced [17 mg]  
1 teaspoon salt [0 mg]  
½ teaspoon fresh ground pepper [4 mg]

2 tablespoons cornstarch dissolved in ¼ cup of the vegetable broth [0 mg]  
360 gm (1½ cups) vegetable broth, preferably Swanson [14 mg]  
120 gm (1/2 cup) heavy cream [122 mg]  
pinch cayenne pepper [0 mg]  
pinch of freshly grated nutmeg [0 mg]

### Instructions

1. FOR THE TOPPING:  
Pulse bread, butter, salt, and pepper in food processor until mixture resembles coarse crumbs, about ten 1-second pulses. Transfer to large bowl and toss with onions; set aside.
2. FOR THE VEGETABLES:  
In a large skillet over medium heat, melt 2 tablespoons butter.

## Journée PCU du Québec Québec PKU Day 2015



Le samedi 3 octobre | Saturday October 3  
Campus de l'Université de Montréal en Mauricie  
Trois-Rivières, Québec

Savez-vous comment obtenir l'argent qui vous revient en crédit d'impôt pour personnes handicapées?  
Savez-vous ce qu'il y a de nouveau pour la PCU?

Do you know how to get the dollars you deserve from the Disability Tax Credit?  
Do you know what's new in PKU?

Soyez des nôtres le mois prochain! Please Join Us Next Month!

**Inscrivez-vous maintenant!**  
**Register Now!**



## Advocacy Efforts Get Results!

by Nicole Pallone & John Adams



### Recent improvements

to various metabolic food programs across the country have made life easier for many PKU patients. In Saskatchewan, an expanded list of approved low protein foods was welcome news. PEI recently saw implementation of a \$3,600 per patient annual subsidy allowing patients to purchase foods from National Food Distribution Center. BC's Metabolic Nutrition Program, as of September 15th, is also run through NFDC meaning that BC patients have coverage of cold ship

items for the first time ever. These follow our previous announcement that Manitoba adult patients now receive coverage, although we are still awaiting details of that program!

**A word of caution:** with the expansion of these programs, it is important to note that while the cost to the patient is decreased, the cost to government is increased. Therefore, it is important that we are all conscious of not wasting these foods. Make sure you have enough room in your freezers, and don't order more than will be consumed before the expiry date!

**Ontario advocacy efforts** continue to be the focus of CanPKU with the hopes of a ripple effect to other provinces. We have been very busy over the summer on a Kuvan advocacy campaign and are ready now to launch our Fall campaign.

During the summer, we learned that the first and only three applications for PKU patients to get Kuvan covered by the provincial government had been rejected. So no PKU patients are getting Kuvan through the governments of ON and SK even though those government listed the drug in 2013.

Add onion and garlic, sauté until it begins to soften, about 4 minutes. Add bell pepper and mushrooms, and cook until softened and most of the liquid has evaporated, about 8 minutes. Season with ½ teaspoon salt and ¼ teaspoon pepper. Set aside to cool.

3. **FOR THE STRING BEANS:** Prepare an ice bath: Fill a large bowl with ice and water; set aside. Bring a saucepan of water to a boil. Add beans, and cook until bright green and just tender, 4 to 5 minutes. Drain, and plunge into ice bath to stop cooking. When cooled, toss drained beans with mushroom mixture; set aside.
4. **FOR THE SAUCE:** Melt the remaining 4 tablespoons butter in a medium saucepan over medium-low heat. Add broth and heavy cream. When almost at a boil whisk the cornstarch and water together, then pour into the saucepan and bring to a simmer, about 30 seconds. Stir in cayenne, nutmeg, and the remaining ½ teaspoon salt and ¼ teaspoon pepper. Remove from heat, and let cool to room temperature. Pour over beans and vegetable mix, and toss to combine.
5. Butter a 9-by-13-inch glass or ceramic baking pan. Spread the green-bean mixture over the bottom. Cover with foil, and refrigerate until just before serving.

During the summer, John Adams and our advocacy consultants met individually with the Ontario doctors who treat PKU and who had sent a joint letter in 2014 to the ON government proposing major changes in the highly restrictive criteria for Kuvan for PKU under the Ontario Public Drug program. CanPKU updated the doctors on advocacy to date, government responses and urged the doctors to write a follow-up letter to the government. As you can appreciate, it takes a while to arrange and conduct meetings with Dr. Murray Potter in Hamilton, Dr. Andreas Schulze in Toronto, Dr. Michael Geraghty in Ottawa, Dr. Chitra Prasad in London, Dr. Jennifer MacKenzie in Kingston and Dr. Pranesh Chakraborty in Ottawa. The doctors were and are very supportive and the meetings went well.

At the same time, we kept in touch with the Ontario Government mainly through the office of Health Minister Dr. Eric Hoskins and we continued to talk with an investigator of the Ontario Ombudsman about our official complaint that the government is not administering the drug program properly in regards to Kuvan.

Dr. Hoskins has asked us to meet with Suzanne McGurn, the Assistant Deputy Minister in charge of the Drug program. That meeting is scheduled for October 1. CanPKU is inviting representatives of the Ontario MDs who treat PKU patients to participate in that meeting.

CanPKU is asking for an interim solution to the problem of the restrictive criteria while the drug is to be reconsidered by an inter-provincial evidence review process which will likely take another year to complete including time for further negotiations for listings.

**Ontario PKUers: We need your help, whether or not you are on Kuvan or considering it. It is a sad day when provinces decline to make accessible any new treatment option. Alone, our voices are whispers; together we can be heard! If you want to lend your voice, please [email John Adams](mailto:john.adams@canpku.org).**

Lack of access to Kuvan through government drug plans does not bode well for any future treatments such as Peg-PAL.



6. Preheat oven to 350 degrees. Sprinkle topping and bake until golden brown, about 30 minutes.

#### Nutrition Information

- Yield: 8 serving
- Phe Per Serving: 97 mg
- Calories Per Serving: 142 kcal
- Phe Per Recipe: 778 mg
- Calories Per Recipe: 1132 kcal

Recipe type: Sides  
Prep time: 30 mins  
Cook time: 60 mins  
Total time: 1 hour 30 mins

#### PKU Profile



My name is Julie Sawler-McMullin. I was born March 6, 1974. I am now forty one years old. I have PKU.

My Mom and Dad noticed at an early age that there was something wrong. After lots of visits to the doctors, I was diagnosed with PKU at nine months old. I was put on the PKU diet and it was well controlled.

I had a pretty normal childhood. I was involved in many activities like horseback riding, Brownies, Girls Guides, figure skating,

#### Clinic Sponsored Events

## Save the Date!

Please join us for a day of family fun and hands-on learning

#### When:

Sunday, November 1, 2015  
1:00 pm

#### Where:

To be determined

#### Event Highlights:

- Hands-on low protein cooking workshop lead by Malathy Ramanujam of Taste Connections
  - Free to attend
  - Food tasting will be offered

This event is hosted by BC Children's Hospital and Vancouver General Hospital, and sponsored by Vitaflo USA and Taste Connections.

*Invitation to follow*

*Families from BCCH, contact Barbara Cheng at [bcheng@cw.bc.ca](mailto:bcheng@cw.bc.ca) and patients from VCH, contact Jennifer Branov at [jennifer.branov@vch.ca](mailto:jennifer.branov@vch.ca) with any questions.*

## Disability Tax Credit - Update

As anticipated, there has been a high demand for the Disability Tax Credit Information Package. Since these were first launched in March, we have given out over 50 packages, and our fingers are crossed for some good results!

We have heard back from a handful of applicants, and unfortunately the news is mostly negative. Remember, if you are declined you can appeal. Sending CanPKU a copy of your application and the rejection letters can help us figure out what common threads are resulting in negative outcomes, and teach us what information needs to be clarified in the appeal process.

But there is some good news. Jodi Walters of Manitoba was one of the first members to receive a package and informed us back in May that her son had been approved! They have already received \$7,000 in refunds and are still waiting for additional reviews to take place. "Canpku was a big help and if it was never mentioned that we could get the DTC I would

ballet, music competition's, rhythm gymnastics and singing. During my school years, I sometimes found it hard to be with my friends who were eating everything while my diet was controlled. I also had trouble in some of my classes, but I was able to learn with the help of tutors. I completed grade 12 Special Needs at Frank Maddock High School, Drayton Valley, Alberta in 1993. I had a wonderful time at graduation and I loved our theme song - It's A Whole New World.

After graduation, I took a course on line to become a Bridal Consultant. I graduated on March 31, 2009 with honors. I am currently married and I enjoy being home taking care of my husband and cats.

My Mom and Dad are amazing parents. They taught me to set goals and believe in myself. Although I struggle daily to control my diet, I continue to believe that I can eventually overcome this challenge.

## Change to Membership Fees

Over a year ago, we changed to a database management system called DonorPerfect to manage our contacts, memberships and more.

We have learned, through trial and error, that it is impossible for this system to differentiate between the different membership types when they are the same price. With General, Supporting and

never have applied as our own social worker said we couldn't because he was on diet and that was preventing him from becoming disabled", says Jodi. "CanPKU is a great community to be a part of with so many resources and so many people wanting to help each other as best they can."

Please [click here](#) to request a copy of the DTC Information Package!



## PERIFLEX® LQ GREAT FOR SCHOOL LUNCH!



## GREAT TASTE

A GREAT WAY TO GET PKU PROTEIN  
WHEN AWAY FROM HOME!

REQUEST A SAMPLE

Get a **FREE Nutricia lunch bag or tote** with your sample request.

\*Only 1 per household. Available while supplies last.

Professional memberships all costing \$25 per year, DonorPerfect was getting confused and labeling all new membership purchases as Professionals.

To solve this problem, the CanPKU Board has approved a change to membership fees. As soon as possible, annual membership fees will be as follows:

General: \$20  
Supporting: \$25  
Professional: \$30  
Corporate: \$100

Being a member comes with a host of benefits, not the least of which is simply supporting the organization.

To learn more about the benefits or purchase a membership, please [click here](#).

[Join Our Mailing List!](#)

## PKU Around the World

Advocacy Works in Australia



### WELCOME NEWS FOR IEM FOOD GRANT RECIPIENTS - GOVERNMENT REVERSES DECISION

Today the 31 July 2015 MDDA welcomed wonderful news that the Federal Government has reinstated the IEM Food Grant for all recipients. This ends the uncertainty for hundreds of families across Australia.

The Minister for Health, Sussan Ley, today confirmed that after completing their consultation and reviewing all the options available, reinstating the IEM Food Grant was the best way to support families with Inborn Errors of Metabolism.

The MDDA would like to thank every family, individual, organisation and stakeholder who committed their time and energy to raise awareness of the impact of the initial decision through writing letters to MPs, speaking to the media, sharing their stories on social media and signing petitions.

We are pleased that the Government has listened to the evidence and our stories, and understood the unique situation that those living with Inborn Errors of Metabolism deal with every day. We are encouraged by the decision and are committed to continuing to raise awareness of this rare, genetic disease.

We'd like to thank the Government for taking the time to genuinely hear our concerns, as well as thanking every individual who took the time to stand up so that their voice could be heard.

You can find more in Minister Ley's statement by [clicking here](#).  
Monique Cooper  
President

Metabolic Dietary Disorders Association

CanPKU is a volunteer-run organization dedicated to improving the lives of PKU patients and their families. By becoming a member, you help support the goals and projects that benefit the Canadian PKU community. Thank you for your support!

**Sincerely,**



NICOLE PALLONE

Canadian PKU & Allied Disorders Inc.

# Save \$10!

Become a CanPKU member and receive many great benefits as well as a \$10 off coupon for HowMuchPhe.org! Already a member? Email [Nicole Pallone](#) and request your coupon today!

**Limited Quantity Available - Sign up now!**

