



CanPKU News

Issue No. 16

Canadian PKU & Allied Disorders Inc. Newsletter

June 2014

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NUTRICIA
Metabolic Nutrition

Dear Reader,

School's out - almost - and the summer is fast approaching. With it, holidays and camping trips have been planned and we are excitedly looking forward to getting away from the big city!

Last year, we had some challenges with getting the calories in on our couple of trips that we had planned. To be honest, we really didn't fully understand the connection of how important it was to keep not only the formula and phe goals on target, but also to make sure our little one was getting enough calories. This year, confident I could do better, we attempted a 3 day trip to Whidby Island just across the Washington/BC border. Never been? I highly recommend it if you live close by - beautiful. Also, very gratifying to see the fresh air and beach-combing sessions clearly gave Alayna a big appetite. This time around, too few calories were really not an issue!

I hope, with some great weather coming up over the summer that all our readers will be able to get away and relax, not letting any dietary restrictions dissuade them!

In this newsletter we have decided to include 2 recipes - you can really never have too many, and these ones use almost exclusively supermarket sourced products - always a bonus to use ingredients you don't have to order in advance!

Plus we have exciting updates from PKU events already held and the first week or so of Avery's Ride for PKU which started off in Victoria on June 7th, and more! I hope you enjoy!

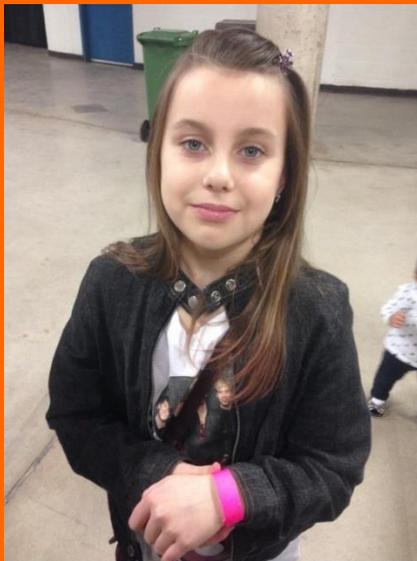
Sincerely,
Ruth Appanah
Editor
CanPKU and Allied Disorders Inc. Newsletter



Innovation in Nutrition

PKU Profile*

Brittney Sykes



Brittney was born eight years ago in Hamilton Ontario with her loving parents and older brother Brady (non PKU) by her side. Days after her birth, her parents received a phone call and diagnosis that would change their life forever - but their dedication, alongside their

2014 Event Series

Upcoming CanPKU Events:

QUEBEC PKU DAY,
October 18, 2014,
Venue and Accommodation:
Four Points Sheraton Québec Resort
Quebec, City, PQ

So with just Quebec PKU Day still to happen on October 18th, our 2014 Event Series is largely behind us. We are still finalizing speakers for our Quebec City event, but we have confirmed that Dr. Denise Ney will be there to educate us all about Glycomacropeptides (a natural protein source low in phe) and Malathy Ramanujam from Taste Connections will be giving a cooking demo that is sure to inspire you.

It will be a great event, bilingual as usual, and we encourage everyone to apply for Travel Scholarships when the time comes. We hope to see you there!

Please check our website for more information as details become available:

www.canpku.org/events

amazing dietician and metabolic doctor at McMaster hospital in Hamilton, made it possible to follow her strict PKU diet.

Brittney is growing up to be an amazing little girl that is always smiling and laughing, never complaining about her special diet. She is lively and energetic and has many interests. In her spare time she loves swimming, skating and playing outside with her cousins. Brittney has also been playing the piano for the past three years and loves attending lessons and performing for audiences small and large.

Brittney says she likes having PKU because "God made her this way to save the animals".

She loves animals and inspires to be a Veterinarian.

With the support and encouragement of a very loving family, close friends, and the PKU community, Brittney can live a life with normal expectations and dreams like any other child.

* Please note that we are always looking for children or adult profiles to highlight with each newsletter. If you would like to contribute your or your child's story please contact the [editor](#)!

BC PKU Event: April 5th, 2014

Every year I enjoy the opportunity to attend the BC PKU event, or have since our youngest daughter was born, and it never fails to disappoint. I think this might have been the best one yet - held April 5th in the Chan Auditorium at BC Childrens' and Womens' Hospital in Vancouver!



In a jam-packed day attendees heard the first presentation from Chad Farquharson, his personal story of advocating for his son and dealing with the challenges involved with Maple Syrup Urine Disease (MSUD). Following this, Dr. Jerry Vockley from the University of Pittsburgh/Pittsburghs Childrens' hospital gave us updates on the latest research in PKU as did Dr Sylvia Stockler from BC Childrens and Womens with some latest updates on Kuvan and Kuvan response.

After the lunch break Dr. Kendra Bjoraker, a clinical neuropsychologist from Minnesota, spoke about PKU and the brain followed by Dr Denise Ney, from Madison Wisconsin, who spoke about Glycomacroprotein and it's benefits and use in the PKU diet.

Rounding out the day was a great cooking demo - I hope we can have these at the event every year - by Malathy Ramanujam from Taste Connections. Malathy had a booth set up beforehand so we could sample some of her delightful recipes. Quite handy for those of us with young

Recipe Corner

Spring Stir Fry!



1 medium zucchini
1/2 red bell pepper
3 asparagus spears
2 tbsp vegetable oil
1 clove garlic
1/2 tsp salt and 1/2 tsp ground
black pepper

Slice zucchini into thin rounds. Dice the bell pepper. Peel and coarsely chop the asparagus. In a small saucepan bring 1/2 L of water to a boil and add the asparagus for 2-3 min. Drain water and set the asparagus aside. In a large frying pan/wok heat the vegetable oil. Add the zucchini and bell pepper and fry, stirring occasionally. Once the zucchini is browned on one side, add the asparagus and garlic. Season with salt and pepper and continue to cook for another 2-3 min until zucchini is soft.

Serve as a side dish or over low protein pasta/rice.

Optional additions: for more flavor add fresh chopped parsley, green onions and/or basil.

children who would not sit still during the demo! My family advised me that the tortillas were the best they have tasted - ever. The veggie meatball was delicious. Due to multiple requests, we have included this recipe in this issue!

It is difficult in the scope of this newsletter to really do justice in describing the caliber of guest speakers and demos' at these sessions. It was very impressive. I'd like to thank the wonderful guest speakers for making the trip out to talk with us, the organizers of the event, the sponsor/vendors that were able to attend, and also give a big shout out to the day care staff who looked after the little ones so well.

Looking forward to next year!

Because knowledge leads to better health!

Atlantic PKU Event

Atlantic PKU Day was held on Saturday, May 3rd in Moncton, NB.



We had a great turnout of people which included adult, teen and child patients as well as their family members. We also had a bus load of culinary students from the Culinary Institute of Canada in Charlottetown, PEI and we were very excited to see them learning how their love of cooking could ultimately help protect the brains of PKU patients! We are also excited to see what low protein foods they prepare at the Avery's Ride for PKU event happening in Charlottetown PEI on Monday, August 11th!

Ryan Clarke from Advocacy Solutions started the day off with a candid look at how and why we need to be

Makes 4 portions.

Per recipe: 3 g protein, 289 cal

Per portion: 0.7 g protein, 72 cal

Recipe kindly provided by Maria Depenweiller. For more information see [The Wooden Spoon](#).

Bonus Recipe Corner!

By popular request we are featuring 2 recipes in this edition. This one was kindly provided to us by Malathy Ramanujam, who was a guest at the BC PKU Event, holding a demo cooking session.

FABULOUS "BEET" BURGERS



Summertime is always associated with grilling burgers, hot dogs and so on. Living in a grilling-obsessed nation, nobody has to sacrifice the great smoke-flavored patties while being on the special metabolic diet. With the clever infusion of "Liquid smoke flavor" the ordinary Veggie Pattie is transformed into the summer favorite.

This recipe is made using grated vegetables to add color and texture and smoky barbecue sauce and the Liquid smoke (available at Wholefoods Market or any place that sells Barbeque

advocates, and how we can be so much more effective working together towards our goals.

Nicole Pallone was kindly given permission by Dr. Jerry Vockley to share his presentation at this event, and attendees learned about the new PKU Treatment Guidelines and future treatments coming down the pipe.

The keynote speaker of the day was psychologist Dr. Shawn Christ who has done extensive research regarding PKU and the Brain.

As usual we provided a catered lunch, free daycare and access to a variety of metabolic vendors. It was a very informative, enjoyable day!

Prairies PKU Event

Prairies PKU Day was also held on a Saturday in May, in Red Deer, AB.



Even though it fell on a long weekend, that did not stop deter people from attending what so far has been our largest event in 2014! We had 18 kids attend our free daycare service and although we scrambled at the end to find some extra daycare providers in the last few days (please everyone, register early for these events!) it was pure joy to see all those PKU kids and siblings interacting with each other all day!

The adults also enjoyed themselves, listening to renowned PKU physician Dr. Barbara Burton (What's New in PKU), neuropsychologist Dr. Kendra Bjoraker (PKU & the Brain), and Ryan Clarke and Joanne Koskie, both advocacy

necessities). Addition of grated beets adds an authentic pink color to the patties. You could add other vegetables but make sure the correct amount of protein or amino acid values have to be added to the total nutritional information. Make sure the veggies are fresh for a great flavor and grated really fine so there is a homogenous mixture.

Ingredients:

Finely grated raw beet	2 Tbs
Zucchini, grated	½ small
Carrot, peeled and grated	½ small
Granny Smith apple, peeled and grated	1 medium
Onion, minced	2 Tbs (1/4 small)
Fresh garlic, minced	1
Tomato ketchup	1 Tbs
Barbecue sauce	2 Tbs
Liquid smoke	¼ tsp
Canola oil	3 Tbs
Salt and Black pepper	To taste
Low-protein bread crumbs§	½ cup made from 2 slices of low protein bread (TC bread mix)
TC-Multi baking mix	¼ cup or more

If the grated vegetables have lots of water squeeze out excess moisture. In a food processor or in a big bowl blend onions, garlic, ketchup, barbecue sauce, salt,

consultants that have been working with CanPKU on various campaigns.



As usual, the only thing lacking from this event was more time for families to mingle and share their stories and expertise - we will work on that for next year!

Because knowledge leads to better health!

Avery's Ride for PKU

by Nicole Pallone

Today is Father's Day, and I want to take a moment to thank some very special dads out there. Thank you to the PKU dads who weigh and measure phe intake, make or bake special foods, and support your kids' journey through this world of rare disease. To the husbands, fathers, uncles and other men who support those with PKU by doing some or all of the above and more: thank you. To my own father, who volunteered his time to CanPKU and who passed away last October: thank you! You are loved and missed!



Father's Day this year will be a little tough for me, but it will probably be even tougher for Kevin Dube, who will have cycled almost 1,000 km across BC in the previous week, and

pepper, and canola oil until smooth. Add to shredded mixture. Add breadcrumbs and TC-multi-baking mix to bowl with vegetables. Mix thoroughly until everything is blended well. Refrigerate for one hour. With wet hands, shape into 4-6 burgers. Cook 3 minutes on each side on grill lightly brushed with oil. Or you could cook the patties on stove top on a sauté pan or frying pan on medium heat 3 minutes on each side and then finish the cooking on the grill to give the patties grill marks. In order for the burger to cook thoroughly, close the frying pan with a lid initially for a minute and then cook the rest of the time without a lid.

The mixture can be made into hot dogs, by shaping the mixture into hot dogs and cooked on stove top just like the patties.

NUTRIENT INFORMATION (per recipe):

Kcal: 769

Pro(gm): 3.4

PHE(mg) : 99

MET(mg): 37.5

LEU(mg): 130

For other recipes and information please see Malathy's [Taste Connections website](#).

Upcoming Events and Activities!

Please see below for a number of upcoming camps, educational sessions and other events that may be of interest to those in the community.

who will be roughly 4,000km away from his own small children and wife! Challenging as that is, Kevin's maternal grandfather also passed away just a few days before Day 1 of Avery's Ride... may he rest in peace knowing that he left behind an absolutely incredible family.



The amazing sacrifice Kevin is making to help the PKU community still astounds me. His commitment to making a tangible difference has in turn made so many of us open our hearts and doors to support his adventure. CanPKU has spent countless hours helping to plan this great journey, and we are so thrilled with the community support we are seeing in return. We have 3 very dedicated volunteers who are taking care of driving the support vehicle over the 70 day trip. We have had dozens of people step forward to host Kevin and his support team across this vast country. We have received gift cards for gas stations, restaurants and groceries to offset the costs of much needed supplies.

At the end of Day 1 of Avery's Ride we had raised over \$15,000 in Avery's name. Fantastic! Funds raised will be used first and foremost to counter the cost of the ride (equipment, gas, food, accommodation, etc.) and anything above and beyond that will be given back to CanPKU so that we can continue to work on our goals of education, patient support and advocacy.

There are so many ways for you to get involved! A wide variety of events are happening across the country on the route: pub nights, days at the zoo, culinary experiences and more - join us!! We still have places where Kevin needs

2014 NPKUA Conference

Salt Lake City, Utah

July 10th - 13th, 2014

[Registration Information.](#)

Camp PHEver

Burton, Texas

July 13 - 18, 2014

A week long summer camp for children/adolescents with PKU.

[Registration Information.](#)

Camp Sealth - PKU Camp

Vashon Island, WA

July 29th - Aug 2nd, 2014

[Registration Information.](#)

Metabolic Camp at Emory University.

Atlanta, Georgia

June 23rd-28th

Educational Camp for women 12 and older with PKU or MSUD.

[Registration Information.](#)

PKU Camp at South Shore YMCA

Sandwich, MA

Aug 17-22nd

For campers with PKU.

[Registration Information.](#)

Cavitt Kids Foundation

Kamp Courage

Dry Gulch, OK

Aug 13-17th

For Kids with Spina Bifida, Cerebral Palsy and PKU.

[Registration Information.](#)

accommodations, and more gas and food cards are always appreciated. More events can be organized - big or small, to show Kevin support and encourage a sense of community, and could be combined with fundraising efforts. Or you could simply choose to make a donation (and receive a tax receipt for amounts over \$10).

However you choose to become involved, I encourage you to do so - being a part of this incredible journey is a once in a lifetime opportunity that I know you won't regret! To learn more about Kevin, his inspiration, and details of this cross-country campaign, please visit www.rideforpku.ca, or email me (nicole.pallone@canpku.org).

And finally, to Kevin: there are no words to express how honoured we are to be part of such an inspiring event. For your time, your courage, your commitment and your effort: Thank you. And Happy Father's Day!

Hat's Off To...Manitoba!

After meeting with CanPKU in January, the Manitoba Ministry of Health has been telling us that it will begin to cover low protein food for adults with metabolic disorders in the province. This announcement became official at the beginning of June when the Minister's office emailed the Shayna family from Winnipeg, who have also been advocating hard for this coverage. We are on pins and needles awaiting the details and we will be thrilled to announce them to you as soon as we can! Thanks, Manitoba!

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 the annual membership fee for professionals has been reduced to \$25 per year.

Approved at the AGM in July 2011 and subsequently approved by Industry Canada in July 2012, our Membership Categories have been updated as follows. Please note that all members in good standing who have voting rights will be re-classified as General Members so as to retain their voting rights. Please ensure that you choose the

Oregon PKU Family Camp

Antelope, OR

Aug 22-25th

A 3 day event for families with PKU.

[Registration Information.](#)

*If you have an event that you would like us to include please [contact us](#)

Emory University Research Update

Emory University and the Southeast Newborn Screening and Genetics Collaborative (SERC) have a number of projects they are working on that they would like to update the community about.

This includes consensus-based guidelines for the nutritional management of Maple Syrup Urine Disease (MSUD), which are available online to metabolic dietitians and clinicians. As well, they are continuing work on the Newborn Screening Follow-up Data Integration Collaborative (NBSDC) project.

Furthermore, after launching the Newborn Screening patient registry with Phenylketonuria (NBS-PKU Connect), the patient profile for Maple Syrup Urine Disease (NBS-MSUD Connect) has now been phased in.

For more information please see the [NBS-Connect Brochure](#). If you wish to support any of these activities please see the Genetics Project [Pledge form](#).

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 one free issue of National PKU News, courtesy of Virginia Schuett and all members now receive a 5% discount on all Country Sunrise products ordered from PKU Perspectives!

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.*

Becoming a member includes the following benefits to you:

- *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;*
- *Reduced registration fees for all CanPKU events;*
- *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).*

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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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