



CanPKU News

Issue No. 9

Canadian PKU & Allied Disorders Inc. Newsletter

September 2012

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Dear Reader,

Welcome to the September edition of the CanPKU newsletter.

I would like to take a moment to introduce myself as the new editor of the newsletter.

Although very new to the community, when Nicole asked for help with the organization, in particular the newsletter, I was very happy to volunteer for this role. As a parent of a recently diagnosed PKU baby, I wanted to find out everything I could about this disorder. In doing so, I quickly realized the best way to do so was to get involved with the community. Taking on responsibility for the quarterly newsletter seemed like an excellent way to get actively involved and learn more about PKU in the process.

As Nicole has indicated, she was passionate about reinstating the newsletter. I too believe it to be an important form of communication to our readers to learn more about what is going on within and external to the community.

I hope that you will find this quarters content informative and useful. If you have any suggestions or comments regarding the newsletter, I invite you to contact me at your convenience using the reply e-mail option.

Sincerely,

Ruth Appanah

Editor

CanPKU and Allied Disorders Inc. Newsletter



Innovation in Nutrition

PKU Profile*

Alayna Brynn Lemky



Alayna Brynn Lemky was born at BC Women's Hospital on April 4th, 2012. Like her older sister, Sienna, she was perfect in every way and completed our family. We took her home and began the next chapter of our lives as a family of four. Children's Hospital called us 6 days later with the shocking news of her diagnosis and we felt the world crashing around us. At first, we thought it must have been a

2012 Event Series

Upcoming CanPKU Events:

Quebec PKU Day:

Saturday, September 22nd in Quebec City, QC

Please check our website for more information on each of these events as details become available. www.canpku.org/events



Ontario PKU Event

Our annual Ontario event in Alliston was a little different this year but still a great success. There was no Polo-4-Kids fundraiser which made room for a longer education session on Saturday. We had 50 people in attendance and were once again honoured to have PKU Chef Gina Valente cater the weekend for us. Speakers at the education event included three PKU patients: Ontario resident and mom of two, Carrie Hall; Applied Nutrition representative Sarah Foster; and Wyoming ranch owner Kari Kilmer, who is also the mom of a PKU baby! These heartfelt and personal accounts of living with PKU were rounded out with presentations by Sick Kids dietitian Valerie Austin and Dr. Georgeanne Arnold, clinic director of medical genetics at the Children's Hospital of Pittsburg. From the opening reception on Friday evening to the Annual General Meeting on Sunday morning, the PKU community of Ontario came together for fun, support and education... Because Knowledge Leads to Better Health!

mistake, but repeat testing confirmed the result and she was admitted that night to the hospital to begin treatment. Like every parent, our journey into educating ourselves about PKU began then and there.

It's been a long 5 months since that first phone call and while the shock has worn off, some things will always stay with us. Certainly, we watch every milestone with happiness and extra attention in a way that we did not with Alayna's older sister. And each week seems to bring with it new worries or challenges - the next one being the introduction of food into her diet! Many readers will no doubt have passed this exciting period already. The knowledge that so many have gone before us, and managed, makes us realize as a family we will also be able to cope with it all. We are also encouraged by all the support available to us through both Children's Hospital and the PKU community as a whole to help us along the way. Knowing this, we are confident that Alayna's life will be normal, happy and productive - with the best possible outcome that she can have. We know she will be able to reach whatever goals she sets for herself and we are looking forward to being there to see it all happen.

* Please note that we are always looking for children or adult profiles to

New Study: Mothers Experiences Feeding Infants with PKU

A recent, as yet unpublished, study from Oregon Health & Science University reveals interesting data on breastfeeding outcomes in mothers from both Canada and the US before and after diagnosis of PKU in their infant.

Researchers at OHSU found that study respondents (recruited from the PKU Listserv) showed statistical differences in breast feeding depending upon whether the mother was Canadian or American. For example, 100% of Canadian mothers who responded to the survey initiated breastfeeding at birth compared with 84% of American mothers. Perhaps not surprisingly the percentage of mothers breastfeeding dropped significantly in the American cohort to 67%, but in the Canadian cohort to only 78% post PKU diagnosis. However, despite these drops, both Canadian and American mums met or exceeded the Healthy People 2020 Breast Feeding objectives for breastfeeding infants at both birth and until 6 months (but not at 12 months).

The research group involved in this study hopes to complete further work to determine factors that enhance or impede the duration of breastfeeding in these mothers who cannot exclusively breastfeed their babies due to PKU.

For more information see: [Breastfeeding Outcomes](#)

For any further questions, or to participate in a study, please contact Sandra Banta-Wright at bantawrs2012@alumni.ohsu.edu.

Advocacy Update: Call to Action!

CanPKU spends significant time and resources dedicated to advocacy. It is up to each province to decide what services, supplies and medications get funded. As such, we have a monumental task in advocating for better care and coverage in the 10 different provincial health care jurisdictions in this country - all of which need to

highlight with each newsletter. If you would like to contribute your or your child's story please contact the editor!

RECIPE CORNER

Low Protein Spring Rolls*



Ingredients:

120g shredded or julienned carrots

130g chopped cabbage (I used coleslaw mix)

175g bean sprouts

100g chopped water chestnuts

16g chopped green onion (that is all I had!)

Salt & pepper to taste

2tbsp sesame oil

1pkg vermicelli style white rice noodles

1pkg rice paper wrappers (label said 0.4g of protein each)

Directions:

Lightly sauté the first 5 ingredients in the sesame oil, literally just a few minutes to soften and combine the flavours. Add salt & pepper as desired. Set aside.

Drop the rice noodles in boiling water per package directions until soft, then drain and rinse with cold water.

improve in regards to care and coverage of treatments for PKU!

Newfoundland and PEI both cease coverage of PKU formulas when patients turn 18. Manitoba does not have funding for low protein foods after the age of 18; New Brunswick, Nova Scotia & Newfoundland only cover staple low protein foods and in Newfoundland that coverage stops at age 18; PEI only covers low protein foods for patients on social assistance and BC only covers \$40 per month worth of low protein foods for social assistance recipients who apply for the stipend!

None of the provinces cover Kuvan for PKU patients, with the exception of Quebec which will fund Kuvan for use during preconception and pregnancy. But did you know that every province will pay for Kuvan to treat patients with Bipterin Deficiency? And that some provinces buy Kuvan for use as a diagnostic tool? The governments are willing to pay full price for these uses, but are not willing to accept the best financial package in the world for Kuvan so that PKU patients who respond to Kuvan can live better lives.

We often get asked: why do we spend so much of our time advocating for Kuvan when better formula and low protein food coverage would benefit all patients?

Firstly, we believe that some patients can benefit significantly from this form of treatment. Secondly, the provinces are constantly reviewing various drugs and making decisions on whether or not to fund them publicly; unfortunately, we have no influence over when this process happens for Kuvan. Being a part of this process allows us to build valuable relationships with decision-makers as well as represent PKU patients. Thirdly, we believe that failure to publicly fund Kuvan in Canada may cause companies developing future treatments or cures for PKU to decide against working in Canada. It costs companies a lot to bring new treatments to market and they will not do so if they see Canada as a high-risk venture. Finally, we DO spend time advocating for other things as much as our resources, time constraints and opportunities allow.

Put a plate on your kitchen scale. Set up a pan/bowl of hot water large enough to submerge each rice paper wrapper. For each spring roll, submerge a wrapper until soft and pliable then place on the plate on the scale. Add 30 grams of the vegetable mixture and 15 grams of cooked rice noodles. Wrap per the package instructions and voila! Serve with plum sauce or sweet chili sauce and let the whole family enjoy.

Nutritional Information:

Each spring roll is 3.18 exchanges or 47.7mg of phe. This includes the wrapper which, at 0.4g of protein each was counted as 1.33 exchanges (20mg of phe).

*note that this recipe was kindly provided by Nicole Pallone

NBS Connect

Introducing the NBS Connect patient registry!

NBS Connect has been designed as a resource for those affected by certain disorders included in the newborn screening (NBS) panel. Extensive development of the registry will occur via a phased approach using Phenylketonuria (PKU) as the model disorder, followed by other inborn errors of metabolism.

We have to educate our governments. We need to teach decision-makers that with the limited currently funded treatment options, reaching target blood-phe levels of less than 6 mg/dl (360 μ mol/L) ranges from difficult to impossible. We need them to recognize that there are over 275,000 possible PKU genotypes and therefore no one treatment that works for everyone. Physicians who treat PKU patients also need to have access to all the tools in the toolbox so that each patient can reach their best possible outcomes in life.

We need your voice. Visit our website at www.canpku.org/advocacy. There are updates on various campaigns on that page as well as tools and instructions to make advocating easy. Check the site often for news updates and new tools. It is time to take actions - together we can make a difference!

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 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.

Patients affected with PKU are encouraged to visit the website at www.nbsconnect.org, register and complete their participant profiles. Participants will have access to disorder specific education materials, information on the latest research and clinical trials, recipes, interactive health tracking systems, "Ask an Expert" tools and more. The developers of NBS Connect believe that patients taking advantage of the resources provided will be empowered to make more informed health care decisions.

Organizers also want the registry to be an asset both for forming connections between consumers and for building a qualitative database for future research. From the perspective of those with PKU or family members with PKU, adding to the NBS Connect patient registry will provide valuable information for the community as a whole.

For a brochure please click [NBS Connect Brochure](#).

If you have any questions or comments please email the project coordinator Yetsa Adadevoh at coordinator@nbsconnect.org.

Quick Links...

[Our Website](#)

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).*

Hat's Off To...

National PKU Alliance

The National PKU Alliance recently organized the "Making

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PKU History" conference held in Cherry Hill, NJ, in late July. This conference was a resounding success with over 525 participants attending events, including sponsors and exhibitors. We look forward to their next conference, which is scheduled to be sometime in 2014!

Highlights and information from this years conference, including the conference video and presentations can be found at the following link: [NPKUA Conference](#)

[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.



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