



CanPKU News

Issue No. 13

Canadian PKU & Allied Disorders Inc. Newsletter

September 2013

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Dear Reader,

September arrives, and with it, the third issue of this years newsletter, as well as the return of many to school/college/university.

Our non-PKU daughter entered grade one this year, which went off mostly without any hitches, to our great relief (and surprise)! It did, however, make us think about if, in a few years time, we would have the same experience with our cPKU daughter. Already, before the first week of school was over, we had the first round of colds enter the house and put the kids out for a few days. We like to think that Alayna is building up a strong immune system now with the exposure to various bugs she gets from her sister bringing them home from school!

So with the return to the school year, and vacations and time off over the summer finished with, we'd like to update you about ongoing activities CanPKU has been busy with as well as upcoming events and items of potential interest to the community. Please read on to see more about the Ontario PKU event, upcoming fundraisers and much more!

Best,

Ruth Appanah

Editor

CanPKU and Allied Disorders Inc. Newsletter



Innovation in Nutrition

PKU Profile*

Tristan Ryker West



Tristan is 5 years old and lives in Grande Cache, Ab. Tristan was born on Sept. 5, 2008 in Campbell River, BC and was diagnosed with PKU at 2 weeks old. He started going to clinic at Vancouver Children's Hospital, until the family decide to move back to Alberta when Tristan was 9 months old. He now goes to clinic once a year at the Stollery Children's Hospital in Edmonton, Ab.

Tristan understands his diet very well. He knows what foods he can't have and the ones he can. He loves helping Mom and Dad weigh out his food and super

2013 Event Series Updates

Ontario PKU Event

Ontario PKU Day

Held on Saturday, June 8th in Vaughan, Ontario this family event included a wonderful, hands-on cooking workshop lead by PKU Chef Gina Valente. Participants learned how to make PKU friendly salsa, tortillas, tacos and Spanish rice while minimizing the low protein foods as much as possible.

After eating this fabulous lunch, the kids enjoyed the onsite daycare and the adults listened to presentations by Dr. Denise Ney ("Glycomacropeptides: A New "Whey" for PKU) and Dr. Rodney Howell (Guidelines for Treating PKU, from the American College of Medical Genetics). Dr Ney discussed the latest research on the nutritional value of the low-phe diet and a new low-Phe dietary option, Glycomacropeptides, and Dr Howell presented the soon-to-be-published American College of Medical Genetics new guidelines for treatment of PKU (which we had also featured in last quarters newsletter).



This fun-filled morning and educational afternoon was followed by our Annual General Meeting. We would like to thank all the volunteers and speakers who made this day possible, and all the families who attended for their participation. We hope to see you all next year!

For more information on CanPKU Events please see [Click Here!](#)

Because Knowledge Leads to Better Health!

juice (his Perifelx Jr. Formula) that he loves to drink. He is currently taking Kuvan to help increase his PHE tolerance. He started taking Kuvan on May 7, 2013 and has responded to the drug, with no adverse side effects. Tristan has gone from a daily intake of 16 exch. (240mg/phe) to 29 exch. (435mg/phe). His levels have stayed stable at 2.0 for the last 4 weeks. His dieticians are constantly challenging that by increasing him by 1 exch. per week when his blood spot results come in. We will find out at the end of this week if we will be increasing his Phe some more.

Tristan has started kindergarten this year and loves his new school and teacher. He is a very energetic little boy who loves to sing and jump around. You will never see him without a smile on his face. His favourite things to do are wrestle and watch wrestling with daddy, learning how to play basketball and playing with all his Thomas and friends trains. His Mom and Dad think Tristan will grow up to be on TV one day as he loves to entertain people with his songs and acting out parts in movies. Tristan is extremely friendly and will say hello to everyone he sees and will always have some sort of story to tell if he stops and talks to you.

* 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!

Traveling with PKU Kids

We see regular questions on facebook groups, listservs and email from PKU parents concerned about traveling with their young kids. A whole lot of trial and error has taught me some good rules of thumb that I am happy to share with you. Each type of travel brings its own unique challenges, so I've broken this up by category.

Camping:

Okay, so camping season is pretty much over in most of the Great White North, but I want to encourage you all to do family camping trips next summer! It is a great way to get in touch with nature, each other, and important for your PKU kids to know that PKU can be managed in many different situations. Yes, it is a little harder but we have learned to cope. There are many different types of camping, from wilderness tent camping to trailer camping complete with water, sewer and electrical hookups. I'm going to focus on wilderness camping for two reasons: one, that's what we do and what I'm familiar with, and two, anything else is easier!

No refrigeration? No water? Only a one burner stove? Yes, it is totally doable with the PKU diet. We pack our water in, no problem. We cook most of our meals over the fire, so the one burner is all we need. And we have developed a fairly extensive cooler system for foods: we have a dry cooler for dry goods, a cold cooler for items that need refrigeration, and then a third cooler that has a block of ice and crushed ice for those things that MUST be kept cold, like milk, formula (and beer). Plan the meals in advance, and only take the amount you need for each serving. Always have lots of low protein or free items as well as some higher items on hand. When we are camping Rosie tends to have cereal and almond/rice milk for breakfast, sandwiches and/or veggies for lunch, pasta, potatoes and veggies for dinner, and lots of fruit for snacks. Other favorites are the Country Sunrise eggs and Country Sunrise hot dog mix - which, for the record, can be roasted over the fire just like a regular wiener!! End the day with roasted marshmallows or some Jiffy Pop popcorn and you have a very happy PKU camper. Rosie has almost ten camping trips under her little belt and we still make mistakes (including forgetting her formula entirely last time, which I had to drive back for the next morning!) but we've learned that keeping it simple reduces the stress.

Road trips:

Be they long or short, road trips can be troublesome. The same tricks can apply to some extent: have a lunch bag of dry snacks, as well as a cooler for milk, formula, etc. If it is a day trip be careful to pack extra food as accidents, construction or chores

Featured Recipe

Braised Onions



2 onions
2 tbsp white wine
4 tbsp chicken broth
1 tsp ground black pepper

Slice the onions in thick wedges and place them into individual oven-proof ceramic pots. Add a splash of white wine, broth and a bit of freshly ground black pepper. Place in the oven at 350F (180C) for 2 hours and bake with lid on. Ideally let the onions rest overnight in the oven while it cools down. Serve warm or cold with low protein bread.

can add hours to your day. If it is a long road trip, always ask for hotel rooms with mini fridges and microwaves. You can freeze meals beforehand and then just zap them for a quick PKU dinner. We keep lots of fruit and low protein snacks on hand because restaurant meals of salads and French fries add up quickly!

Air Travel:

Think this is what makes parents most nervous but for me it is the easiest of the three - possibly because Rosie has already been on 42 different planes (practice makes perfect!) There are some key things you need to make air travel smooth. A letter from your dietitian, which states explicitly that PKU is a metabolic disorder requiring a severely restricted medical diet and that you will be traveling with prepared formula that must be kept cold, frozen ice packs to keeping formula cold, dry formula, dry foods, and prepared and pre-measured fruits and vegetables or other foods. I have always had this letter with me and it has always made things go very smoothly through security. Once you are on the plane, the key to a smooth flight is your pre-planning and organization: have a small cooler bag with the snacks and formula you will need on the plane. Have all of the other PKU essentials - dry formula, foods, scales, etc. - in a separate carryon that you can store above (never pack it in your checked bags). If you have a baby, the stewards are happy to provide a cup of hot water for warming a bottle (remember to buy a bottle of water after you are through security for mixing the formula, if necessary - the stewards are busy at the beginning of a flight and it is no fun to wait for water with a cranky baby on your lap!) If you are going on an extended vacation, you can often send dry goods ahead of time to the place you are staying - just makes sure you send it quite far in advance so that you can confirm its arrival before you hop on that plane. Finally - don't forget some favorite toys/activities to keep the kids busy on that plane ride!

The most important thing to remember is that it is all doable and it gets easier every time you do it - whatever your vacation plans, don't let the PKU part of it be a stress! There are many of us out there who have been there, done that, and we are all happy to share our experiences and support other PKU families. Happy trails!

Nicole Pallone



Recipe yield: 2 portions
Per portion: protein 1.1g, phe 18mg, calories 45cal

NOTE: for extra flavour add a wedge of smoked bacon to each pot and let it braise with the onions. Then don't forget to remove the bacon and let the other non-PKU members of the family take care of it. Don't worry, all the lovely flavours will stay with the onions.

*From The Wooden Spoon: [click here](#) to see more!

Hat's Off To:

The Saskatchewan Government and the Ministry of Health!

Last week the Government of Saskatchewan and Ministry of Health announced that they had agreed to list Kuvan as a covered benefit for those with PKU who meet the criteria.

Although CanPKU has concerns about the strictness of the

Novel Breath Test Study Ongoing at BC Childrens Hospital PKU Clinic

Dr. Raja Elango, a researcher in the Department of Pediatrics at the University of BC, in collaboration with Dr. Sylvia Stockler, is currently trialing a novel breath test at the BC Childrens PKU Clinic as part of an ongoing study partly funded by the Rare Disease Foundation.

The purpose of the study is to determine more information on how one's body breaks down dietary Phenylalanine (Phe). Participants involved in the study are required to have a breath test to measure the amount of Phe present and see if this can be correlated with patients blood phe levels. If successful, it is hoped that this test could then be used as another tool in PKU management and as a way to accurately monitor how Phe is utilized by the body, in a less invasive manner than current methodology.

Further detail on what is involved in the test procedure is below;

Breath Test for PKU Children - the purpose of this study is to gather information about how your body breaks down dietary phe and involves:

- A 4 hour fast followed by a 2 hour test (which can be done first thing in the morning before breakfast, weekends are ok too).
- Drinking a stable isotope (^{13}C), that is safe and normally present in our food.
- Breathing into a bag, 7 times during the 2 hour test period.
- Also includes 20 minutes under a clear hood to measure breathing rate.
- No blood test involved and participants can eat a snack/meal right after the 2 hour test.

Results so far have been promising. However, the use of further participants would be of significant value to study results so if you would like to be involved, please contact Dr. Elango at relango@cfri.ubc.ca or his Research Dietitian Gayathri Murthy at gmurthy@cfri.ca or your PKU Clinic for further details.

established criteria, and will continue advocating on behalf of patients to ensure Kuvan is accessible, we know this is a great step forward in terms of treatment options funded by the Saskatchewan Ministry of Health.

Thanks to the Ministry of Health in Saskatchewan for making this happen.

*For criteria for eligibility and/or treatment [click here](#).

Advocacy Updates

Throughout the summer CanPKU has continued to work hard by advocating for better care and coverage throughout Canada.

In Atlantic Canada we have several meetings with government officials and an insurance company lined up for September.

In Ontario, we are gathering information about whether patients have been able to access Kuvan now that it is publicly funded (if you have any experience with this, please email us!).

The Saskatchewan government has been assessing whether to fund Kuvan, and we are excited to learn that their decision has been to list the drug for patients who meet responder criteria.

In BC, we continue our high-pressure campaign with a softer approach due to the changes that came with the last election.

Save The Date!

Please consider getting your haircut for PKU on Sunday, October 20th, 2013, if you live in and around the lower mainland area (or might be for this date).

This year the fall Hair 2 Help Cut-a-thon will be directly supporting those with PKU. All proceeds from the Salons participating below will be used to fund PKU research at BC Children's Hospital as well as provide critical funds for CanPKU Advocacy and educational activities.

Participating salons are below.

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BC CHILDREN'S HOSPITAL FOUNDATION

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Save the Date!

For our Fall H2H Hair 2 Help Cut-a-Than supporting Children's Rare Disease - PKU.

Sunday Oct. 20th 2013

Contact a participating Salon near you for further details

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For more information please contact the salon directly or [CanPKU](#) or the [Newseditor](#). **Every cut counts!**

We are hopeful that the new Minister of Health, who has met previously with some of his PKU constituents, will be more supportive of our needs and we hope to hear an update in September.

There is work to do in every province, and we encourage you to help us with our advocacy efforts. Please email us if you are interested in improving the care and coverage of PKU patients in your province!

Mission Statement: to improve the lives of people with PKU and allied disorders and the lives of their families.

CanPKU Penny Drive

Fundraising is an essential part of the activities of CanPKU, required to support all the advocacy and related tasks that the organization undertakes.

Just a reminder that we are still collecting for the CanPKU Penny Drive.

Every little bit can make a difference!

For more details on how to help please [click here!](#)

Your support is greatly appreciated!

Ideas or Suggestions for 2014?

CanPKU always encourages feedback from our readers and members. We would like to hear from you if you have any suggestions or topics that you would like to hear about or see featured in any of the 2014 events that are currently being planned.

Please feel free to email [click here](#) and let us know!

Become a Member!

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! Other benefits include discounts on CanPKU event registration fees, eligibility for CanPKU Travel Scholarships and voting rights at our Annual General Meeting (General Members only).

To become a member go to:

<http://www.canpku.org/become-a-member>.

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.

By becoming a member you are showing your support for CanPKU to accomplish its goals, which include:

- Creating awareness about PKU and other inherited

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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.

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newseditor@canpku.org.

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Dear Reader;

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Sincerely,
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