



# CanPKU News

Issue No. 15

Canadian PKU & Allied Disorders Inc. Newsletter

March 2014

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## Dear Reader,

Welcome back and thank you for taking the time to read our first newsletter of 2014.

To begin, please forgive us the delay in sending this newsletter out. We have been migrating our contacts over to a different database and this process took a bit longer than anticipated. If you have received this newsletter to the wrong address or have any contact information to be updated, do not hesitate to let us know.

Looking back at previous newsletters, having started on these back in September 2012, I feel that we have come far in advocating and achieving goals for our friends, family and ourselves. It was a rewarding year in many ways and I'm excitedly looking forward to seeing things happen this year as well. I hope this will be the year that all the provinces decide to go with listed drug coverage and full coverage for medical formula and low protein medical foods!

This year we have quite a number of our 'regular' events lined up, starting off with the BC PKU Event on April 5th, 2014, with the rest of the provinces in the months thereafter. Our youngest daughter will be turning two the day before the event. Hopefully the terrible twos' won't arrive within the 24 hours following her birthday or I will feel sorry for the day care staff looking after her. She is already quite a handful!

These are some very busy months ahead of us with events. I hope that you will be able to attend one or more of the various provincial and/or national events in your area!

Sincerely,  
Ruth Appanah  
Editor

CanPKU and Allied Disorders Inc. Newsletter



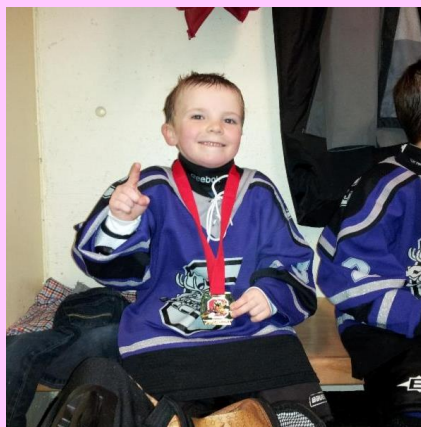
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Innovation in Nutrition

**PKU Profile\***  
**Gabriel Bilodeau**



Gabriel Bilodeau is a six year old bundle of energy. He is very active and loves all sports such as soccer, karate, hockey, baseball, basketball, tennis and cycling.

He is the only member of his family who has PKU, but it does not seem to affect him adversely. Although, one thing that is not easy for him is drinking his formula. It is not

## 2014 Event Series

### Upcoming CanPKU Events:

BC PKU DAY, April-05-14, Vancouver, BC  
BC Childrens Hospital.

[Register now!](#)

ATLANTIC PKU DAY May-03-14,  
Future Inns Hotel & Conference Centre  
Moncton, NB

[Register now!](#)

PRAIRIES PKU DAY, May-17-14,  
Venue : Gaetz Memorial United Church  
Accommodation : Sheraton Red Deer Hotel  
Red Deer, AB

[Register now!](#)

WALKATHON, May 31, 2014, Canada-Wide

ONTARIO PKU DAY, June 1, 2014,  
Venue: CHEO  
Accommodation: Hampton Inn by Hilton Ottawa  
Ottawa, ON

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

We hope to see as many people at their local  
(provincial) event!

Please check our website for more information on each  
of these events as details become  
available. [www.canpku.org/events](http://www.canpku.org/events)

one of Gabriel's favorite things to do because he does not like the way it tastes. However, having a diet and eating differently from his friends in some ways is not an issue for him. This is mostly because his parents manage to find alternatives that he likes.

When he was three, Gabriel took part in a Kuvan clinical trial at the Laval University Hospital in Quebec City.

Unfortunately, he did not respond sufficiently to the drug to remain in the trial and so this was discontinued.

Now six, Gabriel is in kindergarten and is a very bright young boy. He is working on learning how to read. He can already read parts of the nutritional values on food product labels, in particular things such as the amount of protein and daily percentage of vitamins in different items.

Gabriel's favorite part of being in school? Phys Ed. of course! Not surprising given how many sports he likes to participate in!

\* 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!

## Avery's Ride for PKU

If you haven't already heard, this summer we will see an exciting adventure unfold before us when PKU Uncle Kevin Dube cycles across Canada between June 7th and August 17th! We have already been planning for months and Kevin has been training all winter too! As of last week, we have found three generous individuals who will donate large portions of their summer to drive the support vehicle and help ensure Kevin's safety!

However, we still have some needs and are hopeful that you and/or your friends and family will be able to assist with the following:

- Hosting - to avoid costly hotels and restaurants we are relying as much as possible on the good graces of our PKU community to put up Kevin and/or the support driver when they are in each town. They will also appreciate any home-cooked meals that are offered! We still need accommodations in the following locations: BC (Hope, Merritt, Salmon Arm, Revelstoke); Alberta (Calgary, Lloydminster); Saskatchewan (North Battleford, Grenfell, Moosomin); Manitoba (Brandon, Portage La Prairie, Winnipeg, Prawda); Ontario (Dryden, Ignace, Upsala, Nipigon, Terrace Bay, Wawa, Batchewana Bay, Sault Ste. Marie, Blind River, Espanola, Tobermory, Palmerston, Champlain); Quebec (Montreal, Trois Rivieres, St. Pascal, Quebec City), New Brunswick (Edmunston, Fredericton, Moncton); Nova Scotia (Halifax, New Glasgow, Port Hawksberry, North Sydney); Newfoundland (Argentia, St. John's).

Remember that there are many other ways you can help: organize an event at one of the stop locations; cash in rewards points for gas cards, restaurant gifts certificates or hotel stays; donate [online](#) or simply spread this message to your contacts by email, Facebook or Twitter!

For more information go to [www.rideforpku.ca](http://www.rideforpku.ca).

Let's help this inspiring man reach his goals!

Because Knowledge Leads to Better Health!

## RECIPE CORNER

### Cabbage Burgers



This is a great simple recipe. Cabbage is a great source of fiber, vitamins C, K and folate. Try these burgers as a school or work lunch. They re-heat and freeze well.

3 cups cabbage  
1 cup Loprofin baking mix (or any other baking mix)  
2 tbsp Kingsmill egg replacer  
1 small onion  
2 cloves garlic  
2 tsp ground black pepper  
1 tsp salt  
Vegetable oil for frying

In a food processor mince onion, garlic and raw cabbage until you get smooth fine texture. Transfer minced vegetables into a mixing bowl. Stir in baking mix, egg replacer and salt and pepper. Mix well until you achieve thick dough like consistency. If your cabbage did not give enough juice and mixture seems too dry you may add about one tablespoon of water. Let the mixture rest for about 10min. Spoon the mixture into a frying pan with some hot oil and fry burgers from both sides. Serve hot with your favourite toppings.

\*note that this recipe was kindly provided by Maria Depenweiller. For more recipes and nutrition please visit: [The Wooden Spoon](#)

## Rare Disease Study: Patient Recruitment

The Center of Genomics and Policy at the University of McGill, Montreal, is actively recruiting patients in Calgary, Edmonton and Ottawa for their study: "Preferences and the Value of Whole-Exome Sequencing as a Diagnostic Tool for Rare Diseases." It is part of the CARE for RARE project, a pan-Canadian project promoting the use of a new genetic technology for diagnosing rare diseases.

The aim of the study is to explore and understand the perceptions and opinions of patients with rare diseases regarding the value of obtaining a diagnosis. Part of the study is also to evaluate the benefit of using technologies such as whole-exome sequencing (WES) in providing a clinical diagnosis for patients with rare diseases.

Recruitment of patients for focus groups is ongoing from February-April, and study organizers would like to share information about this study and ask for study participants who are patients with rare metabolic diseases.

This study has received ethics approval by the Universities of Calgary and McGill.

Please see related ads for [adult](#) and [child](#) participants and contact the study coordinator listed below if you wish to have more information or are interested in participating.

#### Contact:

Daphne Esquivel Sada  
Research Assistant  
Centre of Genomics and Policy  
McGill University  
1-855-398-6724

## 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.

### Rare Finds 2014 - A Feast for the Senses

Vancouver, BC  
April 26th, 2014

Click [here](#) for registration, tickets or information.

### Camp John Marc - Camp PKU

Dallas, Texas  
May 2-4

For families who have a child with PKU.

Click [here](#) for more information or to register.

### Camp Knot-A-Phe

Prescott, Arizona  
June 5th - 8th, 2014

Click [here](#) for more information or to register.

### 2014 NPKUA Conference

Salt Lake City, Utah  
July 10th - 13th, 2014

Click [here](#) for more information or to register.

### Camp PHEver:

Burton, Texas  
July 13 - 18, 2014

A one week summer camp for children and adolescents with PKU.

Click [here](#) for more information or to register.

### Camp Sealth - PKU Camp

Vashon Island, WA  
July 29th - Aug 2nd, 2014

Click [here](#) for more information or to register.

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

## Newfoundland and Labrador - lack of coverage for Adults

Many of you may have read the recent [Telegraph](#) article regarding coverage of medical formula for adults with PKU in Newfoundland and Labrador. The recent news coverage on this highlights the inequities in how each province determines where funding in its care system will go, and how this province in particular is failing adults with metabolic disorders.

People such as John Robinson and Andrew Ryan are at risk because the government refuses to provide a standard of care for treatment that is available in every other province in the country.

In fact, both these men have been unable to pay for their medical formula, Phenyl free 2, due to the lack of funding coverage. The average monthly cost of the formula for an adult male is approximately \$900. This is a sum that is difficult, if not impossible, for most individuals and families to afford. The reality is, at this cost, most of these people will not be able to provide themselves with the basic treatment that the rest of Canada gets covered under the health care system.

One of the interviewees in the article suggests that he may have to move to a different province in order to receive the necessary coverage of medical formula.

This is an unacceptable state of affairs and really puts Newfoundland and Labrador with a failing grade in its treatment of it's residents. CanPKU is actively advocating in the the province on behalf of these patients.

But you can also help.

Please visit the [CanPKU](#) webpage for a template letter that can be use to sent to the Ministry of Health in Newfoundland and Labrador urging them to provide the critical coverage that these patients need.

## CORD Petition

The Canadian Organization for Rare Disorders (CORD) has started a petition on Change.org asking the Health Minister to approve the Orphan Drug Regulatory Framework.

Many of you will already know about the Orphan Drug Regulatory Framework (we profiled the [press release](#) in a previous newsletter). This is a regulatory framework created by Health Canada to facilitate better access to new therapies, information and drug treatments for those living with a rare disorder.

The Orphan Drug Regulatory Framework is at the point where it is now ready to be approved by the federal government. If approved, this will allow for quicker, more effective and better access to treatments in Canada.

CORD has been actively working to get the framework approved by the government but feels this process is taking too long - the Health Minister announced the framework in October, 2012. In light of this, and in conjunction with Feb 28th's Rare Disease Day and the Rare Disease Conference held in Ottawa on March 3rd, CORD is asking members to sign the [petition on Change.org](#) in support of those with a rare disorder, to encourage the government to sit up, take notice and finally approve the network.

Please take a moment to consider signing this petition.

## Advocacy Updates

In the last year we have seen many changes in coverage for patients throughout the country - with low protein food coverage being implemented in BC and Kuvan added to the Saskatchewan and Ontario formularies (albeit with criteria challenges that still need to be overcome). CanPKU spends significant time and resources dedicated to advocacy and it is gratifying to see that the Ministers are listening and the situation is starting to change.

Perhaps the recent publication of the [ACMG guidelines](#) and [GMDI dietary guidelines](#) may be a useful tool for use by the provinces to determine how to ensure fair and consistent coverage.

In fact, Alberta Health's ED for pharmaceuticals, recently wrote to John Adams on Twitter that Alberta will look at ACMG guidelines as it considers paying for Kuvan. This is encouraging news for those living in Alberta.

There is no denying that there is still a long way to go in achieving consistent guidelines from each province in terms of services, supplies and medications that will be funded. It is daunting that each province makes these decisions independently from each other because it means that CanPKU needs to advocate for access to treatments ten times instead of once!

Although we are happy with our successes, we are very focused on the work we still need to do. In particular, the short article regarding medical formula coverage for adults living in Newfoundland and Labrador needs our focus. Criteria for coverage of Kuvan in Saskatchewan and Ontario is so strict that no doctors have applied on behalf of their patients. Most Atlantic provinces need expanded resources in terms of food and/or formula coverage and most patients are still without access to Kuvan.

This is why we always ask our readers to help when they are able. We need your voice! There is strength in numbers, and advocacy is no exception.

Please visit our website at [www.canpku.org/advocacy](http://www.canpku.org/advocacy) to see how you can help.

Together we can make a difference!

## Hat's Off To... Brienna Young

CanPKU would like to take their Hat's Off to Brienna Young.

Brie is the mother of a very energetic, soon to be 7 year old son with PKU and served on the CanPKU Board of Directors for 2 ½ years.

Brie stepped down from this role late last year when life just got too busy... being a PKU mom, working as a nurse and planning her wedding is keeping her very busy!

Congratulations to Brienna and Josh on their engagement, and thank you so much for all the time you dedicated to CanPKU!

### Quick Links...

[Our Website](#)

[Our Previous Newsletters](#)

[Our Facebook Page](#)

## 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 please [click here!](#)

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

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.

**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).*

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](http://www.canpku.org).

Sincerely,  
Canadian PKU & Allied Disorders Inc.



Because Knowledge Leads to Better Health

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