



# CanPKU News

Issue No. 8

Canadian PKU & Allied Disorders Inc. Newsletter

June 2012

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## Dear Reader,

When I stepped into the role of Vice President back in the fall of 2010 I was immediately impressed with how much our young organization had accomplished in less than 3 years with so few resources. I also had many ideas on how to grow and improve our small Non-Profit.

One of the ideas I was passionate about was reinstating this quarterly newsletter. Some said that quarterly was too ambitious and indeed it does take many hours to write and gather articles, format the newsletter, and update the database for distribution. But I was determined to re-establish this form of communication between us and the PKU community.

We are indeed growing, in terms of membership, core volunteer hours, exposure, outreach and operating budget. This growth is what compels me to hand off the production of this newsletter to someone else so that I can dedicate more of my time to the core functions of the organization while being assured that this important facet of communication with our PKU community will continue.

There are many roles available within CanPKU in many different areas: administration, advocacy, education, awareness, fundraising and more. Please let us know if you are able to volunteer some time to us... even a couple hours a month can make a huge difference!

Sincerely,  
Nicole Pallone  
Vice President & Director

## 2012 Event Series

### Prairies PKU Day

The first of our education events for 2012 was held in Winnipeg, Manitoba on Sunday, May 6th. Volunteer Local Event Coordinator (**LEC**) **Heather Shayna** did a fabulous job managing all the details prior to the event and as a result the



Innovation in Nutrition

### PKU Profile Sydney Strong



Sydney Strong is a happy and vibrant 6 year old currently living in London ON along with her older sister Amelia (11) and her Mom, Jennifer Ballagh. Sydney was born in Ottawa, and was diagnosed at 7 days.

Every parent has a clear memory of that moment after being told

day went off without a hitch. Topics included an update by **Dr. Aziz Mhanni** about treatments for PKU available in Manitoba, a presentation by **Dr. John Mitchell** for the need for Canadian Guidelines for clinics regarding PKU treatment and care, and a discussion about PKU and the Brain including the known neurocognitive problems commonly associated with PKU by **Dr. Jennifer Kwon**. CanPKU VP Nicole Pallone gave an update on the advocacy efforts of CanPKU with a focus on Saskatchewan and Manitoba, and **Dr. Sylvia Stockler** opened the discussion period with a thought-provoking look at the necessity for a nation-wide study on Kuvan to help define clinically significant responses. A favorite speaker among the attendees was **PKU Patient and Mom Kari Kilmer**, from Laramie, Wyoming. Kari will also be speaking at our Alliston, ON event in July so be sure to attend that one if you can!

There were more than 50 people in attendance including patients, families, CanPKU representatives, speakers, local metabolic staff and, for the first time ever, clinic staff from out of province who attended our event in an effort to learn more about managing PKU. A highlight of the day was our presentation of a "**Hero of PKU**" award to **Dr. James C. Haworth**. Dr. Haworth spent many years working with PKU patients in Manitoba and it was an honour to meet him and recognize his efforts. It was a great day full of animated conversation and the sharing of knowledge and experiences. The feedback received from the attendees who filled out our questionnaire showed that the speakers were a hit, the quality of the food surpassed expectations and overall the day was a great success.

#### BC PKU Day

Held on Sunday, June 10th in Vancouver, BC, this day started with a fundraiser walkathon where **\$3,200 was raised** for CanPKU, with more expected to trickle in. These funds help offset the cost of hosting these important Education Events and we truly appreciate everyone who donated and collected pledges. For the first time in CanPKU history, we were able to video tape the meeting... to watch the presentations of our fabulous speakers [CLICK HERE!](#) You won't regret it!

The education session had an exciting lineup that was appreciated by all. **Dr. Shawn Christ** showed fascinating MRI pictures of the differences in brain function and structure between PKU and non-PKU individuals. **Dr. Steven Yannicelli** engaged the audience with a compelling look at what nutrients are lacking from the traditional PKU diet and what problems it can lead to, and **Dr. Cary Harding** updated the

your child has a disorder that will be life long. It is nothing short of overwhelming and worrisome.

For Jennifer, the best way to cope with the learning curve and the implications of what this would mean for day to day life was to be prepared by knowing as much as possible. To continue the momentum on how to best move forward in a positive way, research and education were the key factors.

Becoming involved in the PKU community was not only a source of invaluable information, but also a great emotional support network. "It gives me inspiration to see how other families have managed and continue to maintain that positive attitude" says Jennifer. "Every parent wants the best for their children, having a child with PKU can mean many things, but it no longer means having to limit what the possibilities are for my daughter."

We are so glad to have parents like Jennifer who find time out of their busy lives to contribute to the goals of CanPKU, in a variety of ways. Jennifer leads a very busy life and is a valued member of our Board of Directors... Sydney is obviously in very good hands!

## PKU & the brain

attendees on the various PKU-related research projects happening in various locations in an effort to find a cure! **LEC Sally Broadbent** handled all the details and we had another smooth day, and kudos to PKU Mom **Marnie Silveira** who made all the low-protein food for the event! We were also treated to a performance by **PKU teen Sam Balenzano** and the 16 kids in daycare had a blast. BC PKU Day was attended by over 80 people, including for the first time in CanPKU history an MSUD family, and was another great success!

### Atlantic PKU Day

On Saturday, June 16th at Camper City in Moncton, NB, CanPKU partnered with the metabolic clinic for a combination Education Event and PKU Potluck Picnic.

Participants were fortunate to learn from a distinguished roster of speakers. **Cate Vockley** spoke about newborn screening, and living with PKU was discussed by PKU adult **Sarah Foster**. **Dr. Jane Gillis** of the Halifax clinic, **Dr. Elaine Deschenes** of the NB program and a world expert in PKU, **Dr. Jerry Vockley** of Pittsburgh Children's Hospital all discussed the current states of treatment and research for PKU. The sun shone on us that day under the big tent at Camper's World and families from New Brunswick, PEI and Nova Scotia enjoyed a day full of fun activities and friends.

### Upcoming CanPKU Education Events:

#### **Ontario PKU Day & AGM:**

Friday, July 13th to Sunday, July 15th in Alliston, ON

#### **Quebec PKU Day:**

Saturday, September 15 in Saint-Augustin-de-Desmaures, QC

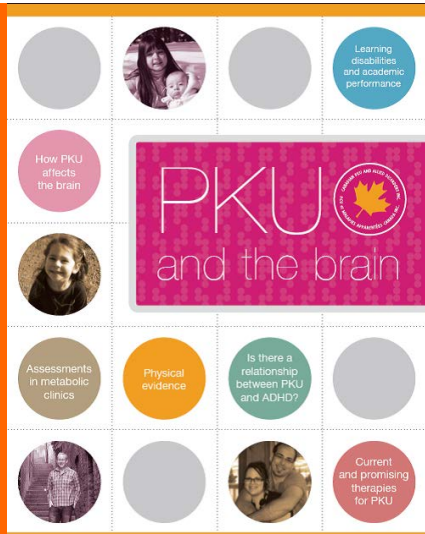
Please check our website for more information on each of these events as details become available.

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

### CanPKU at Conferences

Part of growing an organization like this involves attending professional conferences and establishing relationships with the various doctors, clinicians, researchers, vendors and other patient groups of the PKU community worldwide. These relationships are vitally important for securing sponsorships and retaining volunteer speakers for our regional CanPKU Education Events.

2012 has been a very busy year! The National Institute of Health hosted a two-day conference in Washington DC in late February titled "PKU Scientific Review Conference: State of Science and Future Research Needs". CanPKU President John Adams and Vice President Nicole Pallone both attended this conference and found it to be very informative. Nicole has written a (16 page!)



This brand new publication is an excellent resource for patients, parents, teachers and clinicians alike! Adapted from the NPKUA version by the same name, CanPKU has added the most recent research available and 'Canadianized' some of the language and units of measurement. We have also had the entire document translated into french for our francophone community! It is available [on our website](#) or you can [order a hard copy by email](#).

## RECIPE CORNER

### Chocolate Chip Cookies



Mix together until light and fluffy:

- 1 ¼ Cup Butter
- ¾ cup brown sugar
- ½ cup granulated sugar
- 3 tbl Molasses
- (acts as a binding agent)

summary of the information shared at the conference, which you can find on our website or [by clicking here](#).

In March, Nicole travelled to Rome, Italy to attend the European PKU Group Symposium where she was invited to speak at the Dietitian's Conference about her experience with using Kuvan on a PKU patient under 4 years of age (her daughter, Rosie). This 3 day conference hosted approximately 300 dietitians and doctors and was exclusively geared towards PKU treatment options and guidelines. "It was a tremendous learning experience," says Nicole. "It was 3 whole days of hearing about the newest PKU research - I was in heaven! I strongly recommend to all our Canadian PKU clinicians that they attend this annual event if they can secure funding."

In April, John and Nicole represented CanPKU in New Orleans, LA, at the GMDI (Genetic Metabolic Dietitians International) annual conference. This conference is perhaps one of the most important as it allows us to connect with the front-line clinic staff - the dietitians. The bi-annual conference welcomes several Canadian dietitians each year and allows us to meet in person the many dietitians across the country that we email regularly, and who we rely on to communicate with patients about our existence and education events.

Nicole Pallone has won a travel scholarship to attend the NPKUA bi-annual conference in late July, and will be traveling there with her daughter Rosie. It is not too late to register so for more information go to the [NPKUA website](#).

These conferences are all wonderful opportunities to learn a lot, raise the profile of CanPKU in the international PKU Community and get to know the various clinicians who we are so reliant upon for sharing knowledge with PKU patients in Canada.

## Advocacy Update

Advocacy is verbal support or argument for the purpose of instigating action. It is not activism; it is grounded in logical, rational thought. There are differences between awareness, education, and advocacy - only advocacy is about tangible change.

In an effort to make it even easier for you to become an advocate, we have created an 'Advocacy' tab on our website, which will soon be filled with wonderful province/territory-specific resources. Be sure to check it out! We encourage everyone to set aside an hour or two



1-2 tsp Vanilla

Combine in separate bowl:

- 2 cups CBF Baking mix
- 1 ¼ cup wheat starch
- 2 tsp Baking Soda
- 1 tsp salt
- 2 tsp egg replacer

Add butter mixture to dry ingredients and then add:

- Approx 1 Cup semi-sweet Chocolate Chips (weigh them and add desired amount)

Spoon 1 tbl cookie dough (rolled into ball and squished into flat circle) onto ungreased cookie sheet. Bake at 350 degrees for 8-10 mins. Tip: I found that the hotter the baking sheet (after placing multiple sets of cookies in oven) the worse the cookies looked; and foil worked really well vs. parchment.

#### **Nutritional Information:**

When I made this recipe I used approx 250 grams Butter = 6.6exch

And 77gr of higher protein chocolate chips (milk chocolate) which came to 16 exch.

This batch of cookies came to 23 exchanges and made 70 (2 in x 2 in) cookies = 0.33 exch each!

### **Hat's Off To... Local Event Coordinators**

Without our Local Event Coordinators it would be extremely difficult to organize and run our regional education

every month to write letters and set up meetings with the government officials who make the rules about what treatments are available for your loved ones with PKU.

CanPKU has launched an extensive and intensive advocacy campaign across Canada to improve access to treatments and clinical services for all people living with PKU.

This nation-wide campaign started with the writing and printing of a new publication called "PKU and the Brain", a 44-page booklet available in English and French, which is our effort to translate into plain language the key scientific findings of the last 10 years or so about PKU and its effects on the human brain. It is available [on our website](#) or you can [order by email](#). Families have already found it helpful in getting school officials to understand PKU and how it can effect school performance and behaviours.

The advocacy campaign was also the impetus for the launch of the first-ever declaration of May as PKU awareness month in Canada, which included the introduction of a Bill in the Ontario Legislature and PKU Action Days in the Legislatures of BC and ON. Our campaign continues with meetings with key officials of provincial Health Ministries in Manitoba, Ontario and British Columbia, with plans and hopes for meetings with representatives of other provinces. This campaign included preparation of media kits and outreach to news media across Canada which produced interviews, news stories and features. We successfully recruited support from medical professionals of each clinic we approached. Details of the media kits and media stories are posted on our website under '[News](#)'.

For next year's PKU Awareness month, we are asking for volunteers in every province and territory to work with us to extend the reach of this public and government education effort to every part of Canada. This takes much time and preparation so please let us know you are interested and [email us today!](#)

events smoothly and efficiently. So this quarter, we would like to specifically mention the LEC's that are responsible for our 5 regional events in 2012:

**Prairies: Heather Shayna**

**BC: Sally Broadbent**

**Atlantic: Stewart Landry &  
Sonia Stadler**

**Ontario: Janine Anderton**

**Quebec: Helene Dandurand**

Thank you all so much for the countless hours you put in so that these education events can happen... **Because Knowledge Leads to Better Health!**

This campaign is built on the strong foundation of our annual series of regional community education and networking meetings and CanPKU's proven ability to write compelling submissions and to develop effective working relationships with governments as new treatment options and improvements in clinical services are considered by the provinces and territories.

One measure of the success of this advocacy strategy is that CanPKU has been invited to meet with BC Health Minister Michael de Jong on July 9th to discuss coverage for low-protein foods and Kuvan.

*Please note: CanPKU fully supports each of its members being personal advocates; however, any communications that show affiliation with CanPKU including but not limited to the use of the CanPKU logo, CanPKU letterhead or your title as a CanPKU member means that the communication must be pre-approved by the CanPKU President or Vice-President.*

## **PKU SUMMER CAMPS!**

It is that time of year! Click on the camp name for more information of each PKU Summer camp.

### **Metabolic Camp at Emory University**

June 25-30; Atlanta, Georgia;  
\$325 pp

### **Camp PHEver**

July 8-13; Burton, Texas; \$300 pp

### **Face Forward Project**

July 8-12; Waltham,  
Massachusetts; FREE

### **Camp Sealth**

Aug 7-10 (PKU); Seattle,  
Washington; \$400 to \$525 pp  
depending on age

### **Ohio PKU Camp**

Aug 10-12; Cleveland, Ohio;

### **PKU Camp (YMCA)**

Aug 19-24; Sandwich,

## **Become a Member!**

The more members we have the greater our voice is when advocating for better treatment coverage and care.

**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

Massachusetts; \$735 pp (\$810 for Horseriding camp)

**Oregon PKU Family Camp**

Aug 24-27; Antelope, Oregon;  
\$130 pp

**Maine PKU & AD Family Camping**

Sep 21-23; Nobelboro, Maine;

To search for more events in your area, please go to the

**National PKU Alliance website.**

**Have a Safe & Happy Summer!**

- 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.

To become a member go to

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

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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