



July 13, 2012

## 2012 AGM

### Annual Report 2011-2012

CanPKU has put another year behind us and at 4 years old we are no longer a 'toddler' and are firmly in the preschool years. As with any preschooler we have much learning and growing still to do but we have accomplished many things in the first four years of which we can all be proud in terms of information-sharing, peer support, education and advocacy.

Our database has grown to well over 500 contacts and we are reaching out to those contacts on a regular basis with our quarterly newsletter, regional event invitations and other emails regarding news or other information that warrant mass communication. We are active on social media with a Facebook page and a Twitter account and are succeeding in reaching out to more of the PKU community on an ongoing basis. We have 85 current members in all four categories and plan to reach out this year to all past members who have not renewed, in an effort to encourage renewal or understand why they have chosen not to be a member of our organization.

We welcomed Brienna Young and Jennifer Ballagh as new members of the board of directors and Frances Goodfellow as Treasurer and Wilma McCormack as Membership Chair. Their volunteer contributions were excellent and allowed us to grow and mature as a young non-profit. Our medical advisor William B. Hanley, MD, continued to provide invaluable support and guidance.

We are still committed to holding an education event in every region (Pacific, Prairies, Ontario, Quebec & Atlantic) each year and those events are running smoother and drawing more attendees than ever before with expert speakers as the primary draw. Securing these experts to speak at our events on a volunteer basis is no small feat and must be credited to our commitment to represent CanPKU at international events and our ability to foster relationships among many professionals in the PKU community.

We continue to focus on diversifying our income and have succeeded in part. We have increased our operating budget and expanded the number of companies who contribute financially as sponsors. While our funding from BioMarin represents about 84% of our overall budget, it is worth noting that it is down from about 93% and we continue to focus on reducing our dependence on a single source of funding.

In that regard, we are in preliminary planning stages for a new national event: The CanPKU National Walkathon. For three years in a row our BC event has shown that a small number of participants – usually less than 10 families participate in the walk portion of the event – can raise large sums of money. This year alone over \$3,000 was raised from the walkathon in Vancouver. A National CanPKU



walkathon, where volunteers across the country agree to host a walkathon in their hometown, could contribute significantly to next year's income. Local hosts would receive instruction, materials and support from CanPKU as to how to organize a successful walk and this national fundraising campaign will double as an awareness campaign.

In line with our purpose of providing the latest, accurate information about PKU to families and clinics, we undertook a special project to publish in plain language a 40-plus page booklet, in English and French, about the recent gains in scientific knowledge about PKU and the Brain. We have distributed copies at education gatherings, posted on our website and are beginning to distribute through the clinics. Families in Saskatoon and Edmonton have already found it helpful in getting schools and school districts to respond to the learning needs of their PKU children. This booklet was originally developed by the US National PKU Alliance and we appreciate their assistance with our project and especially the volunteer contribution of our medical advisor Dr. William B. Hanley in helping us update and adapt it for Canadians.

Another huge success of 2011 was the rollout of our PKU Starter Kits project. Through many hours of work acquiring donations, organizing and assembling materials and shipping kits across the country, new families in Canada diagnosed with PKU now receive the essentials for managing this disorder. We have many ideas how to improve the next round of kits and to possibly expand the project to include other categories of patients. Efforts are underway to organize a Patient Support Committee whose primary focus would be to receive the kit materials, assemble, package and ship the kits off to the various clinics across Canada.

We have had a significant focus this year on advocacy activities across the country, largely due to the decision of four provinces (BC, ON, QC and SK) to review whether or not to fund Kuvan, including new opportunities for patient group input. This has forced us to focus on this area of coverage, although there are multiple coverage and/or clinical service issues in almost every province/territory. We have added a new page to our website called Advocacy, to which we are continually adding province/territory-specific resources that all families can use. With limited personnel and resources, we are not able to advocate for all care and coverage issues with equal force at the same time in 13 jurisdictions and must make strategic choices as to how to have the most positive impact.

Our philosophy in focusing on the Kuvan is multi-faceted: firstly, the provinces that are reviewing Kuvan force us to do the same – it would be negligent of us to ignore their requests for input on Kuvan and bull-headedly focus on other coverage issues; secondly, communicating with the various provincial governments regarding Kuvan allows us to build relationships with key people and bring other concerns to the forefront, which we continue to do regularly; thirdly, it is essential for the Canadian PKU community as a whole to understand that we must ensure public funding of Kuvan for there to be any hope of future treatments and cures, such as PEG-PAL, of coming to Canada; and fourthly, when we campaign for improvements for foods and/or formulas and/or clinical services along with coverage for



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Kuvan, the cost of the drug makes the cost of foods, formulas or clinical services seem modest by comparison (as has been noted by more than one government official). We are happy to discuss our philosophy and decision on our advocacy work with anyone who is interested.

We launched the first-ever PKU Awareness month in May, and plan to continue this major activity in future years, with a national news media outreach and PKU Action Days at the BC and ON Legislatures. In fact, a Bill to officially designate May as PKU Awareness month was introduced in the ON Legislature by the provincial representative of CanPKU Chair Cristian Baigorria. This is the first time this has taken place anywhere in Canada. Working with other volunteers next year we hope to expand this set of activities to include more provinces.

We also hope to create a comprehensive Education package that can be used across the country to help families educate extended family, babysitters, teachers and other caregivers about the specific challenges of living with PKU. Digital media including videos and interactive teaching modules are in the planning stages and we are currently working on organizing an Education Committee to propel these ideas forward.

CanPKU continues to expand our services in regards to advocacy, education and patient support. Our profile in the provincial, national and international communities is growing and well-respected. We are still a young organization with much work to do - and many volunteer opportunities available! We hope you will all continue to show your support by remaining members, attending events and volunteering time when you can.

Sincerely,

Nicole Pallone  
Vice President and Director

John Adams  
President & CEO, and Director