



June 8, 2013

2013 AGM

Annual Report 2012-2013

This past February, CanPKU celebrated our 5th birthday. We have accomplished so much in the last five years that we should all be proud of this organization that represents and supports the PKU community in Canada.

In the last fiscal year we continued to grow our database, as well as our membership base which is now over 100 members for the first time ever! Most importantly, we now have an expanded group of dedicated volunteers, as shown on our Organizational Chart. Quarterly newsletters continue to go out and are soon to be regularly available in French. We also keep in touch with our contacts with emails regarding fundraising and advocacy efforts as well as event invitations and reminders. We continue to be active on social media, this year adding regular activity to our Twitter account.

Today marks the last event in our 2013 Event Series which included events in Vancouver, BC; Saskatoon, SK; Halifax, NS; Sherbrooke, QC; here in Vaughan, Ontario and a small patient get together (without speakers) in St. John's, NL. These events were attended by over 260 people including patients, parents, friends, other family, professionals, speakers, politicians and vendors. Local Event Coordinators are recruited whenever possible to help organize these events and we are forever grateful for the time and ideas that they contribute. We invited several new speakers to events this year and look forward to bringing them to other parts of the country to share their expertise!

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. Our unrestricted education grants from Biomarin still represents the majority of our funding but income from other sources such as other corporate sponsorships, donations and membership fees are on the rise. We are also considering further fundraising with merchandise sales available online.

The first National CanPKU Walkathon was held on Saturday, June 1st and was by all accounts a success and a super way to celebrate the end of PKU Awareness Month (May). Born from our experience in hosting walkathons in combination with our BC PKU Days in Vancouver in 2010, 2011 and 2012 (where we raised a combined total of almost \$10,000) we chose to make this a national event for several reasons. Walkathons are a great way to raise awareness: everything from collecting pledges to coverage in local newspapers helps raise the profile of PKU in the area. It is also a fun way to get the PKU community together, and show the local PKU families that they have the support of their hometowns. This year we had five official venues: Vancouver (hosted by Caylee Auge), Kamloops (hosted by Amanda Cosburn) and Sparwood, BC (hosted by Nicole Pallone); Red Deer, Alberta (hosted by Amy Christenson)



and London, Ontario hosted by Jennifer Ballagh. I'm thrilled to report that this event was attended by 107 walkers and raised \$5,991 for CanPKU! We learned that organizing a local walk only take 2-4 hours of time, especially with the toolkit for hosts that was developed and will be improved for next year. We definitely hope to at least double the number of venues next year and also double the awareness and dollars raised, so please mark Saturday, May 31st on your calendar for 2014!

In the fall of 2012 we assembled and shipped 100 new and improved PKU Starter Kits to clinics across the country. 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. The kits have also been simplified so that they are applicable to older patients returning to diet, late-diagnosed patients, and patients with other IEM's requiring dietary management. Many thanks to the patient support committee who worked on this project: Tanya Chute of Peterborough, ON, Heather Shayna of Winnipeg, MB, Tania Legace of Shediac, NB and Nicole Pallone of Sparwood, BC.

We continue to advocate strongly in several provinces, with a particular focus on the BC campaign on the theme of: Getting BC from Worst to First. BC currently provides no funding at all for low protein foods and is the only province to fully review Kuvan, have a process for patient input and decide to not fund it for any PKU patients. We are in discussions with the Newfoundland and Labrador Ministry of Health regarding an expansion of the program: funding currently stops for all patients who turn 18 and even before that only provides coverage of 2 kinds of formulas and staple low protein foods. The Saskatchewan government is aware of our concerns about the lack of clinic access for PKU adults in the province and we have written to an Atlantic Canada private provider of health insurance for prescription drugs about their universal denial of Kuvan funding for the dozen patients who have so far applied. We applaud the decision of Ontario to fund Kuvan for PKU patients, meaning the largest public drug program in the country has agreed on the price of this drug with its manufacturer. But we have also let ON Ministry of Health officials there know that we have grave concerns about the strict and unrealistic restrictions to access that they implemented with their published criteria. ON clinicians have also communicated with that Ministry to express concern about the criteria. There is work to be done in every province, but we have learned to focus our limited resources more conservatively to maximize our effectiveness.

We are pleased that Quebec, which has a very good program to provide formulas and low-protein foods for pku and other inborn errors of metabolism requiring medical diets, has listed Kuvan for PKU pregnancies and opened a door to other PKU patients to apply for exceptional access on an individual basis. We note that Quebec continues to review the possibility of listing Kuvan for other PKU patients.

We have learned of a roadblock to the start of clinical trials in Canada for the second drug therapy for PKU known as Peg-PAL. A European company known as Merck-Serono has the rights to Peg-PAL in



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www.canpku.org | info@canpku.org
Suite 180 - 260 Adelaide Street East, Toronto, ON M5A1N1
1-877-226-7581 | fax 1-877-789-2462

Canada but unlike BioMarin has not committed to moving forward in Canada. We are advocating directly to Merck-Serono to make Peg-PAL available in Canada.

We have added volunteers to our growing operations team, as per our organizational chart. We would also like to thank Tatiana Dociu for her work as co-founder and Secretary and a Director from 2008 to 2012, and welcome our new Secretary and Director, Tanya Chute.

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