



September 28, 2015

## 2015 AGM

### Annual Report – March 31, 2015 Year End

As the excitement from Avery's Ride wore off, we settled back into our regular routine but with the momentum of awareness that had been created. In the year since our last AGM we have once again held an Education Event in every region of this vast country – events that are increasing in number and sustainability. For the previous five events, we have had over 250 participants! As always, we welcome input as to how we can make these events better. We are already planning our 2016 event series so if you have ideas about content or format of the next event in your region, now is the time to let us know! 2016 events will be held in Vancouver, Winnipeg, Toronto or London, Quebec City and Halifax.

Quarterly newsletters continue to go out due to the persistence of the CanPKU Executives. More volunteers for this important function would be greatly appreciated! Please feel free to submit articles to [newseditor@canpku.org](mailto:newseditor@canpku.org) if you have interesting adventures, recipes or ideas relevant to the PKU community. We'd love to hear from you!

Social media is a growing avenue of communication for CanPKU. We have a regular presence on Facebook and a growing presence on Twitter. As with all social media, the success is reliant on our members and contacts sharing our posts and tweets. Often this can be done quickly and easily, and we encourage you to help us increase our visibility by including us in your social media experience.

Avery's Ride contributed significantly to our bottom line for the March 31, 2015 year end, with a net profit of \$48,569.45. Incredible! It just goes to show you a huge difference one person can make. We do not think it is a coincidence that since Avery's Ride ended just over 1 year ago, we have seen expansions to food programs in BC, Saskatchewan, Manitoba and PEI! The financial success of Avery's Ride also meant that for the 2015 year end, our Unrestricted Education Grants from Biomarin only represented 46% of our total income. To continue diversifying our income we would like to see the National Walkaton idea build into an annual, major fundraising event. Organizing a walk really only takes a few hours and can easily net \$1,000, even from a very small community. Please consider planning one in your area in May 2016 to celebrate PKU awareness month! With virtually no public reimbursement for Kuvan, our funding from Biomarin is at risk and we must strive for additional income if we want to continue to provide the same level of service to the patients and families of Canada.

The 2015 Starter kit project was completed, although several delays added up to a much longer process than anticipated! Nevertheless, kits were distributed to the PKU clinics across the country and we continue to receive great feedback about this Patient Support project. We will begin assembling the next



round of kits in 2016 with an anticipated delivery date of early 2017. Please feel free to ask your clinic for feedback on whether they are using the kits, low on kits, etc.!

Advocacy, as always, is a major focus of CanPKU. Just two weeks ago, BC's Metabolic Nutrition Program was expanded with patients now allowed to order any foods carried by National Foods within their \$3,000 annual budget. Saskatchewan also saw an expanded list come into effect over the summer, and Manitoba is in the process of implementing a program to provide food coverage for adult IEM patients. In addition, PEI saw an expansion of their food program, with patients now allowed up to \$3,600 per year for foods carried through NFDC. This is all great news that will undoubtedly help many patients, and we are thrilled to have had a positive influence on these government actions. Unfortunately, the struggle for coverage of Kuvan remains. In a nutshell, the provinces have ceased negotiations with both Biomarin and CanPKU, and are insisting that Kuvan go through yet another Common Drug Review. CanPKU is strategizing about how to best present the perspective of patients for the Patient Organization Submission that will be allowed, and in the meantime is urging Ontario to provide revised criteria for coverage of Kuvan on an interim basis. The hope is that other provinces will follow suit if Ontario relaxes the strict criteria that has seen no patients qualify for funding.

CanPKU still struggles with providing support, resources and communications to our French-speaking population (including, ironically, this executive summary!) All of the translations we do manage are done by Helene Dandurand, and we are eternally grateful for her time and dedication. However, for us to become a fully bilingual organization, which has always been a goal, we will require more bilingual volunteers.

We have a great Board of Directors who are committed to the three key principles of the organization: Advocacy, Education and Patient Support. We also have the largest member base in the history of the organization and hope it is a reflection of our improved service to the families living with PKU and other IEM disorders. Please continue to provide your support by purchasing memberships, volunteering time, attending events, supporting us on social media, making donations and organizing fundraisers. We look forward to another successful year at CanPKU!

Sincerely,

Nicole Pallone  
Vice President and Director

John Adams  
President, CEO and Director