



October 16, 2016

2016 AGM

Annual Report – March 31, 2016 Year End

Our annual event series continues to be a pillar of our activities, and we still have our 2016 Quebec event, which will be held next weekend. As always, we ask for feedback on how to improve these events. With the majority of attendees being parents of younger children, our content is perceived at being directed at that audience. Regular feedback shows that adults want content that is more applicable to them, but we struggle with adult registration being low. 2017 events will be held in Vancouver on April 1st, in Moncton on June 17th, and our Saskatoon and Quebec event dates still to be determined.

Our 2017 Ontario event will be replaced with our first every Canadian PKU Camp weekend on September 22-24, 2017! We have actively been planning this and registration will be open before the end of this year. We are very excited for this new adventure and hope that many of you will be able to join us. This new initiative is feasible because PKU mom Lisa Olsen of Waterloo, ON stepped forward to volunteer to lead this activity and our collective vision is to make the Camp sustainable as an annual activity

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.

Quarterly newsletters continue to go out due to the persistence of the CanPKU Executives, but the volunteer position of Newsletter Editor is still open. Please feel free to submit articles to newseditor@canpku.org if you have interesting adventures, recipes or ideas relevant to the PKU community. We'd love to hear from you!

We are also looking for a Fundraising Chair to increase our fundraising activities. We still hope to see the National Walkathon idea build into an annual, major fundraising event, but we have not had the man power required to build this into a national event. Organizing a walk really only takes a few hours and can easily net \$1,000, even from a very small community. The annual walk in Kamloops, BC raised more than \$3,000 this year and saw the participation of local MLA and BC Health Minister Terry Lake. Please consider planning one in your area in May 2017 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 PKU Start Kit project will soon need to start assembling the next round of kits 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. Unfortunately, the struggle for coverage of Kuvan by government drug programs remains. At writing only two patients in Alberta, two indigenous patients in the jurisdiction of Health Canada and eight patients in Quebec have had access to Kuvan through government programs. CanPKU made its second written submission as a patient group to the Common Drug Review in the summer of 2016 as CDR began another review of Kuvan. We again thank the almost 300 people in Canada and the USA who took part in our survey about the patient perspectives on PKU and Kuvan as the survey results formed the basis of our submission. While the CDR recommendation and report are not yet available publically, matters do not look favourable as the drug company has requested a reconsideration of the report, which is under a behind-closed-doors process.

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, a volunteer, PKU mother and professional translator. 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 are thankful to bilingual nurse Lynn Ryan of Moncton, NB for volunteering to help at our 2017 Camp.

We participate in related patient organizations such as the Best Medicines Coalition (BMC) and the Canadian Organization for Rare Disorders (CORD). John has completed ten years of volunteer service on the governing board of CORD and has recently been re-elected for the second year to the governing board of BMC.

It is important to recognize and thank again Nicole Pallone for her six years of outstanding service as Vice-President of CanPKU. We wish her the best as she transitions out of that role by December 31st and we are very happy she will continue on our Board. We anticipate announcing her replacement shortly.

We have a great Board of Directors who are committed to the three key principles of the organization: Advocacy, Education and Patient Support. 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,



Because Knowledge Leads to Better Health

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