



September 26, 2014

2014 AGM

Annual Report 2013-2014

What a remarkable year this has been! Although we continued with our regular operations, we also added a significant project thanks to the ambition and dedication of Kevin Dube. Avery's Ride for PKU was conceived almost a year ago, was planned throughout the year and was executed over the summer with great success. This event raised tons of awareness, brought the PKU community together from coast to coast and also secured additional funding for CanPKU.

In January we started the transition to a new database management software program, called DonorPerfect. This program allows instant access to our current database from anywhere in the world and simplifies much of our updating. Unfortunately we found the training module to be lacking and due to our own time constraints we are not yet utilizing this program to its' full potential. However, given time and correct implementation, this software will allow us to use our volunteer hours more efficiently and hopefully start to increase our membership base.

Quarterly newsletters continue to go out but we would appreciate feedback on the content and format of these. Is it time for a new look? Are the articles interesting? Our newsletters over the last year were opened by 34-40% of recipients and while that may seem low, the industry average for NFP communications is roughly 22%.

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.

Our 2014 Education Event Series continues, with one more event yet to be held in Quebec City in mid-October. The BC, Atlantic, Prairies and Ontario events had a combined total of 200 registrants, so we are thrilled to see that these still offer value to patients and families. As always, we hope to increase our registration and would value feedback on what topics will encourage you to attend.

Diversification of our funding is an ongoing concern, although the success of Avery's Ride for PKU has certainly contributed to our being more financially independent this year! Our regular sponsors are still on board with supporting our goals and we are still encouraging other vendors to become sponsors.



Due to the commitment of hosting Avery's Ride for PKU this summer, walkathons did not happen across the country. We would like to see this as a focus next year, as a way for local PKU communities to come together and to raise funds so that CanPKU can continue working towards our goals.

Although it seems hard to believe, we are once again in need of Starter Kits. This program has proven to be very well received and it is a project that we feel strongly about. Unfortunately the process of collecting items for the kits has fallen behind as other tasks have taken priority. More volunteers to manage or assist projects like these would be greatly appreciated!

Advocacy continues to be a major focus of CanPKU, with every province still needing improvements in the care provided or access to treatments. January 1, 2014 saw the implementation of the BC Low Protein Food Subsidy Program, which was a huge step forward for the BC IEM community. Manitoba has also confirmed that they will begin funding low protein foods for adults soon, and are currently working on the details of how the program will run. We are making headway, but it is slow. If there is one thing we have learned it is that without many of us joining together, our voice is too small to be heard.

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.

Overall, we feel that CanPKU is doing a good job of supporting the Canadian PKU community. We have many ideas for how to expand our reach and hope to see each of you become more involved in the organization. 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