



Because Knowledge Leads to Better Health

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2015 AGM Minutes - Draft

September 28, 2015 7:30PM ET

Attendance: John Adams, Nicole Pallone, David Brennan, Tanya Chute, Helen Dandurand, Ligona Simones, Amanda Cosburn, and Charles Black,

Call to Order 7:36 Pm ET

Confirmation of Quorum : Two physical people in the same location completed by John Adams and Charles Black at Charles' Residence. Remainder of attendees by phone in.

Approval of Minutes - last AGM distributed by email previous to meeting. Motion to adopt the minutes of the previous AGM as Distributed. Seconded by Nicole Pallone. Adopted by consent

Chair's Report - David Brennan – Little to report. Happy to declare that we have a dedicated team working hard to better the families affected by PKU.

Management Report

John Adams – Verified as distributed.

Nicole Pallone- Last 5 educational events had a total of >250 participants showing a growing attendance trending.

Newsletters continue to go out, social media presence is growing and continues to be an avenue for growth for us. 2014 Avery's Ride is involved in this reporting season. Net Profits from Avery's Ride were \$48,569.45. We would like to see the national walkathon to be a big national event this year. Special thanks to those who helped with starter kits which went out. Advocacy continues to be a focus. Still interested in highlighting Kuvan, but have seen a few provincial gains as well. David Brennan opened the floor to questions and reminded that questions are also welcome via email for those who prefer this method.

Looking forward - A new initiative of "Federal Disability Tax Credit", while it has been a fair amount of work, CanPKU has gained more members than we had in the past, by offering this package to members only. This application is being suggested for those with PKU and MSUD. We have had families receive approval, and we are learning from those who have not received this. We would like to put together an appeal FAQ to guide people through a successful process. Amanda C. advised that she had problems getting people to sign the application. Charles advised it is required to be signed by a specialty clinic, not a GP. CanPKU is unaware of any other family experiencing this challenge. John suggested we consider doing a report to members and metabolic clinicians at the Garrod Symposium. An Ontario family received an approval letter this Saturday. She provided what we suggested, as well



as additional information which she is forwarding to Charles for review. John reminded that the section which PKU qualifies is under life sustaining therapies not under feeding.

We will also be working with interprovincial negotiating process to access medication (listings in Ont/Sask) where no patient has had access to the medication (Kuvan) CanPKU strives to offer peer support, advocacy and patient support.

Introductions - Ligona Simones - has a daughter who has PKU and will be 2 in Nov. They live in Toronto. They wanted to join in and see what goes on. Get some insight on how CanPKU is ran and how we work. Added a special thank you to all who volunteer. She attended both the London and Toronto Events. She is getting a little more involved. Sophia is doing well, a typical toddler. She refuses to eat some days, and eats everything other days! :) David provided a welcome from the board and advised that we are always looking for folks to get involved regardless how little or abundance of time you have.

Treasurer's Report (By Nicole Pallone in absence of Frances Goodfellow) - Financials were distributed earlier by email. *Highlights* - we had an increase in operating income by \$25,000 as a result of Avery's Ride. We had less money from BioMarin (<\$30,000). Fewer expenses in advocacy, as travel was not required as much. Less funds spent on conferences globally. Our event costs (5 educational events) very stable. Expenses for Avery's Ride \$16,000. There is a general breakdown of expenses on page 3. Much is similar to previous years. Fiscal Year - April 14-March 15 Open to questions now, and/or in the future by email. David questioned if John felt secure or concerned regarding the next year financially. John advised that our funds seemed secured for 2016 from BioMarin support. Going forward, this may be questionable. BioMarin is getting a reasonable response from private insurance, but not from Government levels. IF reasonable access is granted, generic medications may be available in approx 5 years, at that time, it is unlikely we will see the same support, if any. Peg Pal is also being worked on in the United States, however, at this time is not being marketed or worked on in Canada.

John moved the motion to adopt the treasurer's report. Charles Black seconded the motion. Adopted by consent.

Motion made by John Adams, on behalf of the members, to seek and retain an auditor review the financials. Helen Dandurand asked if this is required by law. John Adams advised that the new laws, depending on the size of the budget, noting, a review, or a full audit is required. Nicole verified the new not for profit advises at the 5 year mark, or if budget is more than 300,000 the review is mandatory. This is part of the by-law change that was adopted last year. As we are >5 years, we fall under this requirement. Amanda Cosburn seconded the motion. Adopted by consent.

Election of Directors (David Brennan) We had a cut off of last Thursday for accepting names for new directors. No names were brought forward. We have a current director, John Adams, at a two year



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expiration. Vote is not required as there is no competition for the seat. Nicole Pallone motioned we continue John Adams role. This will be for a three year term. Amanda Cosburn second the motion. John Adams graciously accepted the three year term.

The floor was opened for suggestion - none

Changes to Bylaws (David Brennan) - nothing to note at this time

New Business (David Brennan) - no new business was brought forward by email.

Amanda Cosburn addressed many items which were discussed at the strategic planning meeting in 2014. Nicole advised that much of the items which were forecasted and desired, hinge on obtaining our new website. John advised that he had talks with the web-designer months ago which advised the changes were "imminent". This has not come to light. Amanda Cosburn asked if we are considering getting a new "web-designer". John advised it has been reviewed. John suggested that a review of the notes may be required, Nicole reminded that we have to start at the website. This area needs to take priority in resolving. Nicole requested John follow up by phone this week, as emails are unanswered.

John directed questioning to Ligona - How did she find out about PKU. She advised the starter kit. She advised that she read what she could, and signed up for CanPKU right away. When Sophia was first diagnosed, everyone was sending her a number of items, which were not always helpful. It was nice to know that CanPKU was available to support her. She was reminded she is welcome to hang out with us anytime!

Adjournment (David Brennan) - Happy to report we stayed on track and we can adjourn at 8:32PM. David reminded that we have a Board meeting directly following this AGM.