

CanPKU

2016 Annual General Meeting

Draft Minutes

In Attendance - David Brennan (Chair of the Board), John Adams (President), Nicole Pallone (Vice President), Tanya Chute (Secretary) Helene Dandurand (Francophone Chair), Frances Goodfellow (Treasurer), Lisa Olsen (Camp Director), Bill and Laura Sloan (Parent of PKUer). John Adams located at the home of Bill and Laura Sloan for the meeting to meet two individuals in one location. Everyone else via teleconference. Tanya Compeau (joined at 8:40pm)

Call To Order (David Brennan) 8:07 Eastern Tanya completed Roll call for who she had in attendance and David called the meeting to order. Tanya sent all documents via email to attendees

Confirmation of Quorum (David Brennan) confirmed. Welcomed everyone to the AGM.

Approval of Minutes - last AGM (David Brennan) - Helene Dandurand made motion to accept the minutes as distributed and summarized. Nicole Pallone seconded. Accepted by all.

Chair's Report (David Brennan) - On behalf of the board we have had accomplishments and challenges. CanPKU embarked on a new adventure of a Camp. The regional events, the work on the Disability Tax Credit. We have had some international networking and assistance programs put in place. We worked with the common drug review (Kuvan) and other advocacy work. We have launched and continue to fine tune the new website. Our budget remains solvent. We have experienced a turnover of our VP position and want to thank Nicole for her efforts to date and during the transition. David would like to keep every one refreshed as we move towards the next year to maintain inspiration and steam ahead. As Canadians, our systems and medical communities are respected worldwide and we are in a good position to lead for a better PKU model here and abroad.

Management Report (John Adams, Nicole Pallone) - This report was prepared focused on last year and was forwarded previously on the previous attempt for the AGM. This was also sent out again for this meeting. (See attachments). Verbal Summary: CanPKU started with advocacy, education and patient support. The regional events are pillars of all three of those points. Plans are in place for 2017 regional events kicking off April 1 in Vancouver and wrapping up in September at the Ontario Event doubling as the National Camp. Lisa Olsen will spear head the event. Volunteers will be welcomed for this event. Social media is a growing form of communication as well as Twitter. Our success depends on members and contacts "sharing" our data to increase our visibility. We are always looking to diversify income - including the walkathon. Kamloops saw a successful walkathon this year raising over 3,000. The PKU Starter Kit will be coming around again with a delivery date anticipated early 2017. Health technology assessment has updated the assessment criteria. We are still faced with the price reduction. This continues to be reviewed and worked on. Two PKU families are taking the refusal of Disability Tax Credit to Tax Court (From Alberta and Ontario). We have had acceptances and refusals. We are fully engaged with the parents with Tax Court. We look for more bilingual volunteers to assist Helene Dandurand with her translation of materials on behalf of CanPKU. John also

verbalized a strong gratitude to Nicole Pallone for her efforts over the years in regards to her Vice-President duties with CanPKU. The board is grateful for her remaining on the board. Nicole added under events with attendance the east seems to go down, while the west fluxuates. She isn't sure if that is random, but would like this monitored to see if there is an explanation. The newsletter continues to go out base on the efforts of Tanya Chute in absence of a Newsletter Editor. We seek to fill this position. It is also important to ensure that we continue to the Starter Kits and this will need to be started soon to ensure that they are available for delivery in the new year.

Treasurer's Report (Frances Goodfellow) -Frances delivered her report based on the attached documents. Frances has forwarded the books to a financial auditor. She received a call today to confirm when we need them back by and were advised end of calendar year. Going forward this will be completed systematically. Motion to receive the financial statements by Bill Sloan Second by Helene Dandurand. Accepted by all.

Election of Directors (David Brennan) - David advised he did not receive any expressions of interest. The current board has 9 positions. Nicole Pallone, Linda Stewart, Tanya Chute and Helene Dandurand area all up for renewal of position. Linda Stewart has not expressed interest in renewal. Helene Dandurand no longer feels she is the best Quebec representation on the board - however she also would like to be involved as a volunteer in French. She would like to see someone else as a director. She feels it would be best to have someone who has a young child in the clinical system. Nicole Pallone and Tanya Chute both agreed to stay on for another term. Helene agreed to stay on the board with the condition that CanPKU actively seek a replacement for her. John moved a motion to reelect Helene, Nicole and Tanya to the board. Nicole Pallone seconded the motion. Motion carried by all.

Changes to Bylaws (David Brennan) - Treasurer Frances Goodfellow advises that she is having conflicts when trying to move money electronically. This is due to the fact that our by-law states that we require two signatures however electronically this is not an option. John advised the members need to be notified in advance of the AGM. Frances will need to seek alternate wording for the current by law to make this change. John advised this can then be addressed at the next AGM or a special meeting. This will be reviewed offline and updated as required to the members.

New Business (David Brennan) -There are no items for new business proposed

Adjournment (David Brennan) - Thanked all for time. Bill motioned to adjourn. Helene seconded the motion. Adjourned the meeting at 9:07 Eastern.