



CanPKU 2019 Annual General Meeting Minutes
 1010 Birchview Road, Douro-Dummer, ON
 Sunday September 27, 2019 5:00pm Eastern

<p>PRESENT Onsite Location) John Adams, President Frances Hurst, Secretary, BOD Tanya Chute, VP (in/out) BOD</p> <p>Via Teleconference David Brennan, Chair Frances Goodfellow, Treasurer (Member) Nicole Pallone, BOD Charles Black, BOD Brain Quinn, BOD Amanda Cosburn, BOD</p> <p>Members: Adam Burke, Jon McNerny, Karen Richard, Marie Toll</p>	
ITEM	ACTION
<p>Call to Order</p> <ul style="list-style-type: none"> David called the meeting to order at 5:04pm Eastern Daylight Time 	David
<p>Confirmation of Quorum</p> <ul style="list-style-type: none"> The AGM bylaw requires 2 people present in the same location to meet quorum. John Adams and Frances Hurst are at location on camp site. Therefor, we have quorum. 	David
<p>Approval of Minutes</p> <ul style="list-style-type: none"> David made the motion be made to accept the draft minutes as distributed. <p>Action: Motion: That the draft minutes from of the 2018 AGM be accepted as distributed. Seconded by Amanda</p>	David Motion Carried
<p>Chair's Report</p> <ul style="list-style-type: none"> Thank you everybody for your efforts this past year. Much of what we do is volunteer and is born out of love for all people with PKU. That effort really means a lot to making a difference in their world. So, thank you for everything you've done this year and thanks in advance for all we are going to do next year. As a board, we did good this year just showing up to our quarterly meeting and met quorum for each. We ere able to conduct our business on schedule with no interruptions. CanPKU has continued to build communities. One of our better years with regional events taking place in Newfoundland and some representation from Brian Quin and 2 camps. For the first time CanPKU held a camp in Saskatchewan and the 3rd annual at Camp Kawartha Duoro-Dummer Ontario. DTC has gotten over the hump but John may have something to say about that later. People at Revenue Canada have our attention now and I think they are starting to get to know the drill. We can certainly give ourselves a pat on the back for the assistance for that. Thank you for doing that behind the scenes work. Our newsletter continues and thanks to Arlene Mac Donald News Editor for doing that newsletter. Pins for PKU raising money and Raising awareness for PKU donation coming in Can PKU on Social media, offering support. We are solvent as an organization. Thank you everybody for your help and you volunteer efforts for Can PKU and Allied Disorders. 	David
<p>Introductions: The Board</p> <ul style="list-style-type: none"> <u>David Brennan; Chair</u> is from western NB and has a daughter with PKU who responds to Kuvan. Like to be involved to keep myself up to date. <u>Frances Grove Hurst; Secretary; CanPKU</u>, Adult who PKU, 48, from Port Perry, ON, and manages treatment through diet and also a successful applicant for the DTC. <u>Nicole Pallone</u> from Sparwood, BC. Nicole was introduced to the PKU world when her 	John



daughter Rosie was born 2008 also on Kuvan. Has been on the CanPKU board since 2010 and was Vice President for 6 years and happy to continue to be involved on the board. First PKU family (test case) to be approved for the DTC.

- Amanda Cosburn from Kamloops, BC. is a PKU adult who just had a baby 6 weeks ago. I have been though maternal PKU twice now with phenomenal PHE levels. Treated through diet and formula. Runs own daycare and hosts walk-a-thons and events for CanPKU.
- Brian Quinn: from St. John's, NL, is a PKU Adult. Just got back on diet last September. Its been an interesting ride on PKU.
- Charles Black: PKU adult 55, has been on the board since 2005. Was taken off diet at age 11 and fought to get back on diet with the provincial government and was put back at age 49. Assists with DTC for CanPKU.
- Frances Goodfellow, Treasurer, lives in Bolton just outside of Toronto. Has a daughter 16, with PKU, (on the call as well). Her twin does not have PKU. Have been Treasurer since 2011. I am a CPA and I have the background to do it and happy to contribute something I am familiar with.
- Tanya Chute: mom of son with PKU, age 9. I was just a Mom who wanted to find out how I could help out. So Now I am VP and Camp Coordinator of CanPKU. Lives in Douro-Dummer near Peterborough, ON.

Members

- Karen Richard form Marathon, ON, First grandchild who was just born 2 months ago with PKU. Wants to learn more about PKU and raising awareness.
- Marie Toll Lives in Edmonton, AB. Has a son 23 with PKU. Have had a few rough years and coming around to the other side and wants to do want ever I can for awareness. Really excited to be here. Her son has just got back on diet a few months ago.
- Adam Burke from Toronto. Proud parent of a 5 year old daughter, with PKU and a 3 year old daughter who does not have PKU. A rough go as well in the first couple of years and now ready to contribute PKU and looking forward to seeing everyone at camp tomorrow.
- Jon McNery: from rom Toronto with a son nearly 1 has PKU. Here to learn a bit about what is going on with PKU.
- John Adams: co-founder and President Did not know anything about PKU until we had son now 32. He decided that Mom and Dad should be learning about PKU. He had faced challenges in elementary and high school and university. Now is doing extremely well. He graduated from University and is working as a first responder on Highway 407 around Toronto. Hopefully he will achieve his career goal and start as a Probationary Fire Fighter for The City of Toronto soon. He tried Kuvan on a clinical trial and he has an extraordinary response to it.

Management Report

Appreciation from John Adams, President:

- Tanya Chute deserves a huge hug and thank you. She is a dynamo and does just about everything in this organization. She has done a tremendous job filling remarkably large shoes of Nicole Pallone, as Nicole at did at one time.
- Frances Hurst -Thanks to Frances Hurst. She has been on board for 2 years and for 3 years served as Secretary. Frances has had some changes in her life and is going to pause for a while. It has also created a vacancy on the Board which we will deal with later on this agenda.
- I want to thank everybody who has been on the board huge volunteer and contribution, Thank you very much!
- As mentioned earlier we are solvent. We ask for funding from every one of the manufactures of the treatments in the PKU space. We do get a good response from all of them. Many of them will be at this Camp to interact and socialise and show new products as there are always being updated.
- There has never been a better time to be living with PKU. We are very close to the possibility of a cure – 2 companies who have different version of gene therapy. The first company is Homology, a start up company from Boston area. They are actively recruiting for PKU patients for the first clinical trial. They will have to go thorough 2-3 clinical trails to be sure that it is safe and effective. The second company is **BioMarin** which is the developer of the drug called Kuvan and is also the second drug known as Palynziq. They

John



<p>just announced that they are applying in the United Kingdom for authorization of their first clinical trial for their version of gene therapy.</p>	
<p>Global Association for PKU (GAP)</p> <ul style="list-style-type: none"> • John Adams, Christian Baigorria and Tatiana Dociu are the founders of CanPKU that began in 2008. • GAP now is registered in the UK as a charity., known as the Global Association for PKU. John Adams and Christian Baigorria are both Founders of that new organization. It's now in the early stages and hopefully lift off in the next 2 years. We need to bring the advantages of clinical care of newborn screening and clinical therapies to those places without them. 	<p>John</p>
<p>Update on Disability Tax Credit</p> <ul style="list-style-type: none"> • We put a big effort over recent years, thanks to Nicole Pallone and Charles Black to bring to the people's attention that they can qualify for DTC because they have an impaired enzyme function. So far, we have had to go full trials for the first 2 cases and we have to do 14 other appeals to the Tax Court of Canada - all that have been settled without a trial. You are paying too much in taxes if you haven't got your DTC and we can help you fix that. <p>Questions:</p> <ul style="list-style-type: none"> • How do you know if one doesn't qualify for DTC? Would there be a reason why they wouldn't? (asked by Frances Hurst) <p>Answer: Example John's son is currently on Kuvan would not qualify, as he now has no more protein restrictions or formula. Or, if you are not spending 14 hours a week on therapy tasks.. And a Dr. has to sign the application.</p>	<p>John Adams</p>
<p>Financial Report <u>Frances Goodfellow distributed certain financial statements for review.</u></p> <p>Balance Sheet</p> <ul style="list-style-type: none"> • As of March 31st, at the end of our fiscal year, we have a cash balance of around \$73,000. Then under Global accounts, because of us have been financial agent for GAP while it was information, you'll a few numbers that have the global name beside it. That will be removed when we transfer things over to GAP but that has not happened yet. • We had no receivables at the end of the year, and we don't have any fixed assets anymore based on after the audit. The Auditor said it wasn't a big enough value to worry about to have fixed assets. • We have a few payables, around \$600.00. • The differed revenue is Revenue for items DTC- there we have to make sure those numbers are in the proper year. • Prepaid Expenses \$2000.00 are for travel arrangements for conferences that are happening April and May, but we paid them in January. Those will have to be removed out of the overall expenses for the year. They will have to be adjusted back to the next year. • Net income after expenses – overall with all the events, including national events, the bottom line is that we have around \$18,600.00 <p>Profit and Loss Collapsed</p> <ul style="list-style-type: none"> • Overall, we are in a profit position the events at different regional locations are usually around \$5,000 or \$6,000. And those are anticipated expenses because those are educational events. • Based on all the fundraisers the actual account has donations over \$12,000.00 so that had a big impact for the account so it was not in a loss at all, we made \$1200.00 That will be used going forward. <p>Profit and Loss</p> <ul style="list-style-type: none"> • This is a look at the comparison of how you did compared to the year before. It is a summary of all the classes of expenditure and revenue in one column compared to how we did last year • Last year we were in a loss position and this year we are in a profitable position where the fundraising has really had an impact. • John added an explanation on profit and loss year to year comparison. Some of the 	<p>Frances Goodfellow</p>



<p>numbers in the previous year 2017-18 year show a higher number of \$ 227,000, then a reduced income in this year about \$154,000. I believe the difference is largely accounted for by the initial start up activities that ran though our book keeping on behalf of the new Global Association for PKU.</p> <p>Action: Motion: To accept the financial statements for April 2018 to March 2019 as presented. <i>(moved by John Adams, seconded by Nicole Pallone)</i></p> <p>Action: Motion: To authorize a financial review for current fiscal year April 2019 to March 2020 and do without an audit. <i>(moved by John Adams, seconded by Charles Black)</i></p> <p>Discussion: CanPKU is “not-for-profit” but we are not a registered Charity. The new Canada Not for Profit Corporation Act requires us to do this kind of motion at the AGM or the default is we will have to do a full audit. The members at the AGM each year have a choice if they are requiring a financial review or a full audit. A full audit would cost more than \$5,000.00, a financial review is about half that price. The law requires the members to vote for it unanimously, or a full audit must take place.</p> <p>Adam Burke said he could discuss the possibilities with John of having connections that might be able to do the financial review pro bono.</p>	<p>Motion Carried</p> <p>Motion Carried</p>
<p>Election of Directors</p> <ul style="list-style-type: none"> We have one open position and one solid expression of interest. Adam Burke is a Chartered Accountant with 10 years working for auditing and financial institutions. Four years ago Adam joined RBC (Royal Bank of Canada) and has been promoted to the roll of executive overseeing the teams that audit all the finance corporate treasury and tax globally. Having some tougher time with PKU daughter feels now I the time to contribute and give back. <p>Action: Motion: For the members to elect Adam Burke for a 3-year term. <i>(moved by John Adams, seconded by Nicole Pallone)</i></p> <p>Discussion get to know if next year there are more opportunities to come. Question: <i>(from Frances Goodfellow)</i> If there is a board member – even though they have not been present on the board meetings and not doing anything, can the board ask the person to step down? Answer: In our bylaw there is a provision that the board can consider and take action if there is a concern with the performance of a director.</p>	<p>Motion Carried</p>
<p>Changes to By Laws</p> <ul style="list-style-type: none"> No changes proposed - The bylaw is on the website – www.canpku.org 	<p>John</p>
<p>Adjournment: Motion Meeting Adjourned at 6:16pm Eastern Daylight Time.</p>	<p>David Motion Carried</p>