



AGM Minutes of the Board of Directors  
 1010 Birchview Road, Douro-Dummer, ON  
 Sunday September 24, 2017 1:00pm EDT

PRESENT	Via Conference Call	ABSENT
John Adams, President/ CEO Tanya Chute, Vice President David Bremnar, Chair Frances Hurst Frances Goodfellow Mary Lou Sukman Wilma Allan	Nicole Pallone	
ITEM		ACTION
<b>Call to Order</b> <ul style="list-style-type: none"> <li>David called the meeting to order at 1:03pm EDT</li> </ul>		David
<b>Confirmation of Quorum</b> <ul style="list-style-type: none"> <li>The AGM bylaw requires 2 people present in the same location to meet quorum. Therefore quorum was confirmed.</li> </ul>		David
<b>Approval of Minutes</b> <b>Motion:</b> To approve minutes from last year's minutes which were circulated in the last Newsletter.		Motion Carried
<b>Chair's Report</b> A few highlights over the last year: we have a new Vice President who has been working out quite well. We are happy the way Tanya Chute has replaced Nicole Pallone in that role. Nicole remains on the board as a director. David the Chairman of the Board his time to renew. <b>Review of Current Officers</b> <ul style="list-style-type: none"> <li>Chairman of the Board - David Brennan (Dad: daughter with PKU)</li> <li>President and CEO -John Adams (Dad son with PKU)</li> <li>Vice President – Tanya Chute (Mom son with PKU)</li> <li>Treasurer – Frances Goodfellow (Mom daughter with PKU)</li> <li>Secretary– Frances Hurst (PKU adult)</li> <li>Charles Black (PKU adult &amp; the first person to be diagnosed in Manitoba after newborn screening began) term expiring, standing for re-election</li> <li>Helene Dandurand (Mom with PKU daughter) served 10 years on the board. Has someone else to take her role.</li> <li>Tanya Campeau (Mom with two PKU sons) term expiring and wishes a break but would like to return down the road.</li> </ul> <b>Review of Board of Directors (9 positions)</b> <ul style="list-style-type: none"> <li>David Brennan (Dad PKU daughter) term expiring, standing for re-election</li> <li>John Adams (Dad PKU son) term continues</li> <li>Tanya Chute (MOM PKU son) term continues</li> <li>Nicole Pallone (Mom daughter with PKU) term continues</li> <li>Amanda Cosburn (PKU adult) term expiring, standing for re-election</li> <li>Charles Black (PKU adult &amp; the first person to be diagnosed in Manitoba after newborn screening began) term expiring, standing for re-election</li> <li>Helene Dandurand (Mom with PKU daughter) served 10 years on the board. Has someone else to take her role.</li> <li>Tanya Campeau (Mom with two PKU sons) term expiring and wishes a break but would like to return down the road.</li> </ul> Other highlights over the last year: (1) Disability Tax Credit (DTC) Many PKU applicants are being declined by the Canada Revenue Agency and recent outcome: first case successful in the Tax Court of Canada. (2) International coalition of PKU we are trying to leverage our Canadian experience and make an expansion to those with PKU all across the globe. (3) Camp has major milestone this year by all accounts it was mad success.in the planning it was a great success. (4) The starter kits went out this year and all of those make it a successful year.		David



<p><b>Management Report</b></p> <ul style="list-style-type: none"> <li>A continues thanks to Tanya Chute on her many roles. As Editor of the newsletter, we continue to have a quarterly newsletter which is the most important way of communication. John pointed out in an extra formal thanks for Tanya's time and effort as Vice President in doing a wonderful job in 'fixing things under the hood' in the car that is CanPKU in terms of integrating and updating the data bases, which needed some major attention and are now properly synced and big thanks to her for doing that!</li> </ul> <p><b>Disability Tax Credit</b></p> <ul style="list-style-type: none"> <li>We actually fought the Canada Revenue Agency at the Tax Court of Canada in 2 separate cases. The first case was about PKU mom with a 3 year old, not on Kuvan. In court she was able to prove that she spent 29 hours on managing the PKU therapy but the CRA has until October 1st to appeal it. Haven't heard anything on that yet. The second case was a PKU Mom with a 17 year old who is on Kuvan which makes a difference on the time on managing PKU. There was an error presented that in the calculations of time spent on tasks of PKU therapy and the government lawyer tripped her up a bit on cross examination. Waiting to hear back if the court will give her a break. There are 5 other cases waiting for hearing dates at the Tax Court of Canada. In each case, John is acting as agent for the family pro bono, with any out-of-pocket expenses for travel reimbursed by CanPKU.</li> <li>The fact that a diet cannot be considered eligible for this tax credit a disability but therapy is eligible. We have to win several cases. John's goal is to flood the courts with many cases to the point that the Chief Judge will complain to the CRA about its inappropriate hardline on PKU cases.</li> <li><u>Below are what are required:</u>        Must prove you spend at least 14 hours per week on the 10 or 11 elements of PKU therapy to prevent becoming markedly restricted in the mental activities of daily living. Ordering, making and consuming the formulas and special low-protein foods, washing formula bottles, plus time to measure PHE in regular foods, frequent blood tests and phone or email consults with clinic and educating alternate caregivers for day care, school, school trips, etc. can be counted towards the 14-hours a week minimum. Also time to Keep track of diet/PHE journal and meeting daily prescribed target amount of phe/protein i.e., 10 g per day.</li> </ul>	<p>John</p>
<p><b>Financial Report</b></p> <ul style="list-style-type: none"> <li>We engaged an accounting firm to do a financial review. Based our income as a not for profit organization, the government regulations say once you reach a certain level of annual budget you need to have an review or an audit. We were still under the wire where we didn't have to have an audit but we did have to have a review. So had the review done by Preston GTA LLP. First page of report read by Frances. Reading of page "1, in the report prepared by Frances herself. The report is emailed attached along with the draft minutes. After the reading of the first page of the report from the audit firm Frances explained that this is a double negative meaning that "we are good".</li> <li>Cash is \$80,000 for the financial year ending March 31<sup>st</sup>, 2017; Assets at 93,000, liabilities 14,000, deferred revenue \$25,000, net assets \$67,821. So what the assets means is for all money we have receive over the years have accumulated and all the expenses we had to pay after we done all of that we have \$67000 that we haven't utilized is extra funds and ideally are for future. That's the way we carry over.</li> <li><i>Statement of Operations:</i>        Overall revenue was \$134,000 compared to \$167,000 the prior year. The difference was mostly as a result of one-time funding to assist us with consulting help to do an online survey and draft our submission to the Common Drug Review about Kuvan for PKU.</li> </ul>	<p>Frances Goodfellow</p>



<ul style="list-style-type: none"> <li>• <i>Expenses</i> Overall are within \$10,000 from year prior. \$5,100 is what we have to pay for the financial review –Deficiency of \$2.700.</li> <li>• <i>Cash flow</i> The most important thing to know is that we still have money in the bank.</li> </ul> <p>It was noted by John that the financial statements as reviewed confirm our status as a tax exempt organization</p> <p><b>Motion:</b> To approve the financial report as accepted.</p>	<p><i>Cont'd</i></p> <p><b>Motion Carried</b></p>
<p><b>Election of Directors</b></p> <p><b>Motion:</b> That David Brennan, Amanda Cosburn and Charles Black re-elected as Directors, each for a term of three years.</p> <p><b>Motion:</b> That Frances Hurst be elected to the Board of Directors for a 3 year term.</p> <p><b>Motion:</b> That the nominations be closed. Which means we will run with one open vacancy for a BOD for the time being.</p>	<p><b>Motion Carried</b></p> <p><b>Motion Carried</b></p> <p><b>Motion Carried</b></p>
<p><b>Changes to Bylaws</b></p> <ul style="list-style-type: none"> <li>• There are no changes to by laws proposed; should anyone want to make any changes to a bylaw in the future get in touch with a board of director and we will add it to a future agenda.</li> </ul>	<p>John</p>
<p><b>Adjournment</b></p> <p><b>Motion:</b> That the meeting be adjourned at 2:14pm</p>	<p>David</p> <p><b>Motion Carried</b></p>