



CANADIAN PKU AND ALLIED DISORDERS INC.
PCU ET MALADIES APPARENTÉES CANADA INC.
HCU • MSUD • PCU/PKU • TCU/UCD

Draft Minutes of the Annual General Meeting CanPKU+
September 16, 2023, 7:00pm EDT
Via Video Conference and In Person

PRESENT		ABSENT
In Person	Virtual	
John Adams Tanya Chute Frances Goodfellow Barb Marriage Brian Quinn Jeremie Dion Latour Stephanie Garcia Melanie Colter Kate Vinokurov Wilma Allan	David Brennan Christineh Sarkissian Melissa Ferguson Jenn Pino	Adam Burke Johna Jamieson Arlene MacDonald
ITEM		ACTION
Call to Order <ul style="list-style-type: none"> David called the meeting to order with Quorum Introductions were provided by all Board and attending members. 		David
Approval of Agenda In Adam's absence Barb agreed to take notes for Tanya to type and distribute. Motion: Barb moved to approve the agenda. Brian seconded the motion, accepted by all members.		Barb Motion Carried
Approval of Minutes from previous Annual General Meeting: Motion: Barb moved to approve the minutes, Frances seconded the motion. Accepted by all members.		Barb Motion Carried
Report from the Chair of the Board <ul style="list-style-type: none"> David thanked the Board, all volunteers, and all members that have done work or contributed to the community. He is glad that CanPKU+ now includes HCU, MSUD and UCDs Commented on the continued health of the organization and a continued focus on the budget and funding to ensure support going forward. Highlighted the contribution we make with respect to advocacy. Called out a thank you to Francis as Treasurer, Adam as Secretary, Tanya as VP, and John as President of the organization. Wishes everyone a great year to come and continued success with the great work we are doing to make Canada the best place to be to live with our rare disorders. 		David
Annual Report <ul style="list-style-type: none"> John welcomed the individuals from the allied disorders, namely Kate and Melanie both in attendance but also those chairs who could not be with us, Samantha, Susan and Michaela who have been a tremendous help with the launches. Access to clinical research studies continues to be supported by CanPKU+ as seen with our presentations coming at the Ontario event tomorrow on Synlogic Clinical Trial and the PKU Carrier study. We have also supported the Science 37 Natural Health study for HCU and the PTC Therapeutics for their current drug therapy trial. 		John



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<ul style="list-style-type: none"> We continue to help families gain access to needed funding by helping with their applications for their (prevent) Disability Tax Credit, if they are on their treatment plan and fulfill 14 hours of efforts during the week. We have seen strides in the areas CanPKU+ specifically has spoken about (HCU, UCDs, MSUD, PKU) but also TYR. Spoke of the 500 Million dollars which was announced by Health Canada for support of Drugs for Rare Disorders and the goal of CanPKU+ to work to ensure that it will include access to rare drugs including foods and formulas. We currently have 333 active members. This is our highest membership yet. With the change to the database over the pandemic, it allows us to count each family member represented by the membership as opposed to simply one/membership. It also allows us to remove “sponsors” from membership numbers. Overall, this seems like a positive step forward. 	
<p>Financial Report</p> <ul style="list-style-type: none"> Francis provided an update on the annual Financial Statements, including walking through key balance sheet items and highlights from the statement of profit and loss. Financial Statements were distributed previous to the AGM. All those in person have a paper copy. <p>First Motion: Frances moved to approve the 2022-2023 Financial Statements for the fiscal year ending March 31, 2023, Brian seconded the motion. Unanimous approval.</p> <p>Second Motion: Frances asked the Members to approve forgoing an independent financial review for the fiscal year 2023/24 due to the cost versus the size of this non-profit. Cost was \$5000 to audit the last time. Seconded by Tanya. Unanimous approval.</p>	<p>Frances</p> <p>Motion Carried</p> <p>Motion Carried</p>
<p>Appointment of Auditors</p> <ul style="list-style-type: none"> There have been none this year. 	<p>David</p>
<p>Nominating Committee Report</p> <p>In absence of Adam, the chair for the nomination committee, John recommended a slate of the following individuals to each be nominated for a three year term.</p> <ul style="list-style-type: none"> David Brennan Stephanie Garcia Melanie Colter <p>Motion made by John to elect the above 3 named individuals as Directors of the Board each for a three year term 2023-2026. Seconded by Brian.</p> <p>John made an additional remark to thank Arlene MacDonald for her years of service both on the board as well as our News editor.</p>	<p>John</p> <p>Motion Carried</p>
<p>Changes to Bylaws</p> <ul style="list-style-type: none"> David noted no changes to bylaws. 	<p>David</p>
<p>New Business Update</p> <ul style="list-style-type: none"> No new business to highlight. 	<p>David</p>
<p>Adjournment</p> <p>David adjourned the meeting.</p>	<p>David</p>



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