



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

Because Knowledge Leads to Better Health
Parce que la connaissance mène à une
meilleure santé

www.CanPKU.org

Dear (Individual):

Date

Re: Advocating for Faster & Wider Access to new treatments in BC

Canadian PKU and Allied Disorders (CanPKU+) is a member of Medicines Access Coalition – BC (MedAccess BC). This non-profit brings together local and national patient organizations with an interest in British Columbia to be a unified voice to bring awareness, education, attention and change to improve access to medicines to improve health outcomes for the people of BC.

Together we (CanPKU+ and MedAccess BC) bring your attention to a crucial issue that affects patients and families across British Columbia—access to new medicines. Your voice and advocacy can make a **significant impact**, and we are reaching out to ask for your support in urging your MLAs to act.

Currently, Canada provides public drug coverage for only 21% of new medicines launched globally, ranking 26th out of thirty-two higher-income countries according to the Organization for Economic Co-operation and Development (OECD). Inequity exists in public drug coverage plans (formularies) from coast to coast, with some provinces offering coverage for certain approved medications while others do not. You may be dismayed, as we are, to learn that British Columbia lags all other Canadian authorities in providing access to new treatments. This means that patients in BC are facing the worst challenges in this country about accessing crucial medications, leading to potential health risks and financial burdens.

In the example of PKU, Health Canada approved the first drug, Kuvan, in 2010 and BC started covering it in 2022, a lag of 12 years. BC also lags other large provinces in covering medical foods and medical formulas which are often the primary or only form of therapy for inherited metabolic disorders.

Unfortunately, these denials and delays by BC government leave some patients in BC without coverage for the medications they need, forcing them to consider older therapies, make significant lifestyle changes, go without the more effective treatment for them, or even relocate to other areas of Canada.

Your advocacy can make a difference. By reaching out to your provincial elected representative (MLA), who works for you, and sharing your concerns, and personal



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stories if applicable, you can contribute to raising awareness about the importance of improved medication access in the province. BC must have a provincial election in 2024 so this is a suitable time to reach you.

We encourage you to engage in three ways:

1. Write a Personal Email or Letter:

Express your concerns and experiences with medication access in BC. Share how it has impacted your life or the lives of those you care about. If you wish, you can ask for a meeting with your MLA to discuss these matters.

2. Attend Town Hall Meetings or Virtual Sessions:

Participate in public forums where you can directly address your MLA and fellow constituents about the need for improved medication access.

3. Use social media to Amplify Your Voice:

Share your advocacy efforts on social media platforms, using relevant hashtags and tagging your MLA to ensure your message reaches a broader audience.

To find your MLA and their contact information, please visit

<https://www.leg.bc.ca/learn-about-us/members>.

Your involvement is crucial in advocating for positive change. Together, we can work towards ensuring that everyone in British Columbia has timely access to the medications they need for their health and well-being.

Thank you for your time, support, and commitment to making a difference.

Sincerely,

Sincerely,

Melanie Colter	John Adams
BC Resident, IEM Parent and CanPKU+ Board Member	CoFounder and President of CanPKU+