



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 [Medical Professional's Name],

Date

Re: Advocating for Faster, Broader Access to New Therapies in BC

We trust this email finds you well. We are writing to bring your attention to a crucial advocacy campaign in which Canadian PKU and Allied Disorders (CanPKU+) is partnering with the non-profit coalition Med Access BC to address the pressing issue of medication access in British Columbia. As a valued health care professional, we first wanted to advise you of our participation and second, where possible seek your awareness, understanding, and support which will be vital in driving positive change.

Background:

Access to new medicines in Canada is currently below average on an international scale, with public drug coverage provided for only 21% of new medicines launched globally. According to the Organization for Economic Co-operation and Development (OECD), Canada ranks 26th out of 32 higher-income countries, in the time taken from regulatory approval to first public coverage. This situation varies across the country, in an unfortunate postal code lottery, with patients in some provinces experiencing significant disparities. Unfortunately, British Columbia is listed as the worst province in Canada in terms of very slow access to new treatments.

BC is the third largest province by population, with an estimate of 5.5 million residents, after Ontario and Quebec. Its healthcare spending per person is near the average across the provinces and territories, but this includes expenditures from hospitals, physicians, medications, private insurance, and out-of-pocket costs. However, when we compare expenditures by category, BC spends the least on its public drug plan per person compared to the other provinces. It has remained relatively flat since 2010, while all other aspects of the healthcare sector have experienced growth. Specific data is available on the campaign website at ...

Sadly, from a meeting in November 2023 between the Medicines Access Coalition – BC and members from the BC Assistant Deputy Minister's Office, including the PharmaCare Benefits Branch, it was made clear that BC will not reconsider their decisions for non-covered medicines. Between 2018 and 2023, this includes 31 medications that are covered by most provinces, except BC. By comparison, Ontario only declined coverage for two of the 31 medicines and Alberta for three. This data is available on the campaign website at

Using PKU as an example, Health Canada approved the first drug, Kuvan, in 2010 while BC listed it in 2022, a delay of 12 years. This should not be an exemplar when innovative drugs are



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approved by Health Canada and funded by other provinces. BC also lags behind other large provinces in coverages of medical foods, medical formulas and medical supplements which, as you well know, are often the first-line or only available treatment for inherited metabolic disorders.

Campaign Focus:

Inequities in public drug plans (formularies) persist from coast to coast to coast.

As health care professionals, you are well aware of the impact this can have on patients, forcing them to consider older therapies, make significant lifestyle changes, do without the most effective form of treatment or even contemplate relocation outside BC for access to necessary medicines.

How You Can Help:

- **Raise Awareness:** Share information about this campaign within your clinic and among your colleagues.
- **Encourage Patient Advocacy:** Inform your patients about the campaign and encourage them to participate by contacting their MLAs and sharing their experiences.
- **Social Media Support:** Amplify the campaign message on social media platforms to reach a broader audience, using relevant hashtags.
- **Get Involved:** To learn more about the campaign and how you can contribute, please visit [Campaign Website/Link] or www.canpku.org/MedAccess-BC

Your expertise and influence play a crucial role in creating awareness and advocating for positive change. We appreciate your ongoing commitment to the well-being of your patients and the broader community.

Thank you for your time, and we hope to count on your support in making a meaningful impact through this campaign.

Sincerely,

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



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