



February 22, 2013

Dear Premier Clark:

We write to ask you to make a badly needed investment of \$2.8 million in improving the health of 170 children and adults living with PKU in BC

Since 2009, Canadian PKU and Allied Disorders (CanPKU) has been advocating to the British Columbia Government to raise the standard of care for patients who suffer from the brain-threatening disease, Phenylketonuria (PKU), to national and international standards and best practices.

PKU is a rare, inherited, metabolic disorder, where the body is unable to process phenylalanine (“Phe”), an essential amino acid found in dietary protein. The resulting accumulation of Phe in the blood is toxic to the brain. It is such a serious disease that the B.C. Government has been screening every newborn baby for PKU since the 1960s.

CanPKU has tried to work in an open, accessible and cooperative way with the Ministry of Health for three years to provide better resources to those who suffer from PKU. Yet, after three years, we have not seen **ANY improvement** for PKU patients in this province.

We believe the B.C. Ministry of Health has not only turned its back on PKU patients, but it has engaged in a deliberate and systematic campaign to avoid providing improved treatment for PKU patients in B.C. – the same treatment that other governments in Canada provide their citizens. It is our view that your government is the worst government in Canada in providing treatment for patients who suffer from PKU.

What we need is simple: a \$2.8 million investment by the B.C. government in a **Comprehensive Brain Protection Strategy** to deliver better health outcomes for PKU patients by:

- 1) **Bringing funding for medical foods up to standards comparable to Alberta, Saskatchewan, Quebec and Ontario.**
- 2) **Providing dedicated funding for evidence-based, innovative therapies to treat PKU, including Kuvan which has been approved by Health Canada and which is being funded by Ontario effective February 28, 2013.t.**
- 3) **Adding a full-time psychologist, PKU Clinic Coordinator, nurse and a part-time dietitian to the PKU/metabolic clinic team at B.C. Children’s Hospital.**
- 4) **Re-evaluating the clinician/patient ratio on a bi-annual basis for the adult clinic at Vancouver General Hospital.**
- 5) **Providing for travel costs when patients/families need to travel to Vancouver for clinical services from northern, rural or remote homes.**

Premier Clark, CanPKU seeks only the **minimum standard of care and resources** necessary to protect the brains of the 170 B.C. patients suffering from PKU.

An investment of \$2.8 million is a little more than 0.01 per cent of the \$2.4 billion increase in the Health budget over three years which your Government announced in the 2013 Budget. This investment is not a budget buster.

We urge you to do the right thing and commit to CanPKU's ***Comprehensive Brain Protection Strategy for PKU Patients*** (copy enclosed) to ensure those British Columbians living with this condition have access to the necessary available resources and treatments.

By protecting patients from the devastating health impacts associated with PKU, the related burden on the healthcare system will be significantly reduced, and the ability of people living with PKU to have productive and taxpaying lives will increase.

The time is now to extend your government's stated commitment to "Families First" to PKU families. It is time for BC to stop treating PKU patients as orphans of the healthcare system. We urge you to work with us to bring treatment for PKU patients in British Columbia from worst to first in Canada.

It's simply a no brainer.



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