BC MINISTRY OF HEALTH: To HARM or PROTECT?

WHY ISN'T THE BC MINISTRY OF HEALTH DOING MORE TO HELP PROTECT THE BRAINS OF 150 PKU PATIENTS?

PKU (phenylketonuria) is a rare, inherited, brain-threatening 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, and if left untreated, symptoms can range from mild cognitive impairment to severe mental retardation.

Newborn screening for PKU

All provinces introduced universal newborn screening for PKU starting in the 1960s, allowing treatment to begin immediately after the condition is detected.

However, many treatment options aren't accessible to PKU patients who need them.

Funding for medical PKU formula

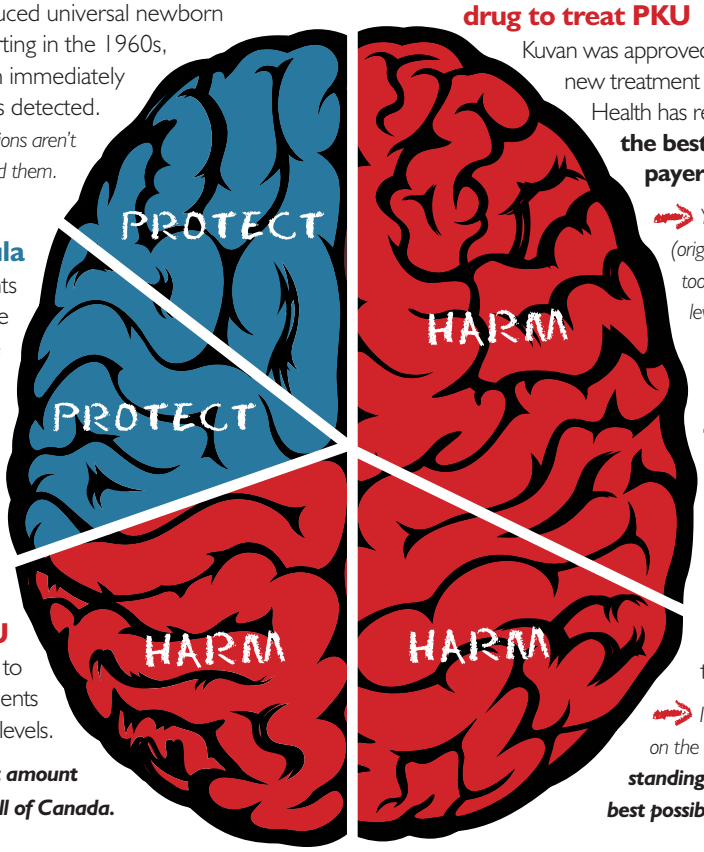
By the 1960s, all provincial governments across Canada had agreed to provide public funding for the synthetic low-Phe formulas that formed the original basis of the lifelong treatment for PKU.

However, many patients on formula and a Phe-restricted diet still experience difficulties controlling their Phe levels.

NO funding for medical foods for PKU

The BC Ministry of Health has refused to fund this critical tool to help PKU patients manage their blood phenylalanine ("Phe") levels.

BC currently provides the least amount of coverage for medical foods in all of Canada.



NO funding for first and only drug to treat PKU

Kuvan was approved by Health Canada in 2010 as the first new treatment for PKU in 60 years, but the BC Ministry of Health has refused to fund it, **despite being offered the best financial terms available to public payers by the manufacturer.**

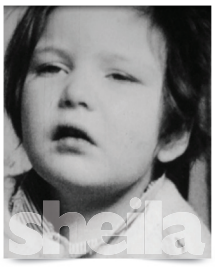
Yet, Kuvan is funded in BC to treat BH4 deficiency (originally called malignant PKU) and as a diagnostic tool to determine whether newborns with high Phe levels have PKU or BH4 deficiency.

NO acceptance of the latest treatment recommendations

Prompted by increasing evidence of suboptimal outcomes in PKU patients managed only with a restrictive diet, recommendations for the use of Kuvan were published by a group of the world's leading PKU experts as a guide to improve the lifelong management of PKU.

In refusing to accept this expert guidance on the use of Kuvan, ***the BC Ministry of Health is standing in the way of appropriate care and the best possible outcomes for patients.***

60 YEARS AGO, Sheila Jones of England was the first PKU patient to be successfully treated with a low-Phe synthetic formula. **If left untreated, symptoms of PKU can range from mild cognitive impairment to severe mental retardation.**



TODAY, the developing brain of four-year-old PKU patient Rosie Pallone of Sparwood, BC is being protected from toxic blood Phe levels. She follows a restricted diet, including synthetic formula and medical foods, and takes Kuvan through a clinical trial. BUT, **the BC Ministry of Health only covers the cost of the formula.**

The BC Ministry of Health must provide immediate funding for all PKU treatments to help protect patients from this brain-threatening disease.

FOR MORE INFORMATION, VISIT WWW.CANPKU.ORG.

A message from Canadian PKU and Allied Disorders Inc.

CANADIAN PKU AND ALLIED DISORDERS INC.