



Announcing Avery's Ride for PKU

PKU uncle will cycle across Canada in 71 days this summer to raise awareness and \$25,000

TORONTO – January 31, 2014 - A young father will ride his bicycle more than 7,000 kilometers coast-to-coast this summer to draw attention to a rare, brain-threatening disorder which affects his newborn niece, Avery. The Canadian PKU and Allied Disorders (CanPKU) non-profit association is proud to announce Avery's Ride for PKU. This Ride is the brainchild of Kevin Dube, of Kitchener, Ontario, who learned about PKU when Avery was born and diagnosed in August 2013. This will be the first ride across Canada for PKU.

This exciting event will begin in Victoria, BC on Saturday, June 7th and end in St. John's, NL, on Sunday, August 17th. Mr. Dube will cycle for 71 days through all weather and terrains, determined to make a difference for Avery and all those living with PKU. The route includes every provincial capital and the 16 cities with a PKU-treating clinic. Mr. Dube hopes to raise at least \$25,000 for CanPKU.

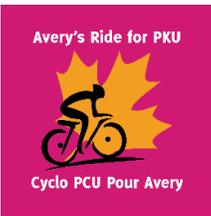
"My wife and I knew that we needed to do something to support our family," says Kevin Dube. "After talking with CanPKU President John Adams, we decided that a cross-Canada bike ride would be a great way to advocate, raise awareness and fundraise for those families living with PKU."

PKU stands for phenylketonuria and affects about 2,000 Canadians. Untreated, PKU can lead to mental retardation and other neurological problems. It is managed by specialized clinics through a challenging diet by severely restricting the intake of all forms of protein containing phenylalanine ("PHE") and replacing missing nutrients through specially-made medical formulas and foods. Low blood-PHE levels and adherence to this extremely strict diet can be more easily attained in about 50% of patients with the aid of Kuvan, the first medication available to treat PKU approved by Health Canada in 2010. Due to differences in provincial health care, where you live has a direct impact on your ability to manage this disorder. Only three provinces publicly fund Kuvan, with extremely strict criteria reducing access, and several provinces still fail to fund the necessary medical foods and formulas sufficiently, especially for adults. PKU can be so devastating that each province and territory tests every newborn baby for PKU and has done so since the 1960s.

"Kevin has been astute in his short exposure to PKU in realizing that there is a lot of work to be done in this country to ensure that every patient living with PKU has access to all the treatments and clinical care and support they need," says John Adams, CanPKU President and CEO, and father of a young man with PKU. "There is not a single province or territory in this country that does not need to improve PKU funding in some major way."

There are several ways that the public can help this initiative and a full list can be found at <http://www.rideforpku.ca/english/how-you-can-help/>. CanPKU needs a support vehicle such as an RV or SUV donated for the cross-country tour, and will need a driver or drivers to help ensure Mr. Dube's safety throughout the route. Donations can be made at <http://www.corddonate.ca/averysrideforpku>. People





can offer food and/or accommodation if they are located near one of the stops by emailing CanPKU at tanya.chute@canpku.org.

“We really hope to see people inspired by Kevin’s selfless act,” says Nicole Pallone, CanPKU Vice President, and mother of young girl with PKU. “Maybe you are retired and have always wanted to drive across this beautiful country, or maybe you have some travel points or miles that you can cash in for a gas card. However you want to contribute, it will help make this project successful, and in turn help everyone who lives with this devastating disorder.”

For more information about the Ride and how you can help, please visit www.rideforpku.ca.

About PKU

PKU (phenylketonuria) is a rare, inherited, brain-threatening metabolic disorder, rendering the body 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. Approximately 1 in 12,000 to 15,000 infants in Canada is born with PKU. All provinces and territories offer newborn screening tests to determine if a child is born with PKU. If PKU is detected, the appropriate, aggressive treatment must be initiated immediately and maintained throughout life to ensure normal brain development.

About Canadian PKU and Allied Disorders Inc.

Canadian PKU and Allied Disorders Inc. is a non-profit association dedicated to providing accurate news, information and support to families and professionals dealing with PKU and similar, rare, inherited metabolic disorders also detected by newborn screening. Our mission is to improve the lives of people with PKU and allied disorders and the lives of their families. For more information, visit www.canpku.org and download our comprehensive resource for patients and families, [PKU and the Brain](#).

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