The needs of PKU families vary by province/territory but one thing is universal: ALL provinces and territories have at least one area of PKU treatment and care that needs improvement. We want patients, families and clinics to have access to all the tools in the PKU treatment toolbox. We have had many successes in our advocacy, but there is still more work to do.  The campaigns have ranged from coverage of low protein foods, to better clinical services and a call on the provincial and territorial governments to publicly fund Kuvan, the first and only drug therapy proven to reduce blood Phe levels in people with PKU. At this time, although all provinces fund Kuvan for BH4-deficiency (which used to be called malignant PKU and is detected by newborn screening through high levels of Phe in blood), only Quebec, Saskatchewan and Ontario fund Kuvan for PKU patients – and the criteria is so stringent that most people don’t qualify.

Kuvan went back to the Common Drug Review (CDR) for the fourth time, in early 2016 and we expect results in the summer of 2016.  If the CDR recommends that provinces Do Not List this medication, then it will be extremely difficult (but not impossible!) to get provincial coverage of this treatment.  If the CDR makes a recommendation that provinces should list this medication, we will likely still need to advocate in several provinces for this to actually happen.  As with all our advocacy efforts, there is strength in numbers and we need your help!

With limited resources, we have focused our efforts based on what we believe will have the biggest impact on the PKU community in Canada in the long term. We must urge decision-makers to provide access to Kuvan for all forms of PKU while governments are actively reviewing whether or not to fund this innovative treatment: their focus on Kuvan has encouraged/required us to do the same and although we recognize that Kuvan will not work for everyone, our philosophy is that patients deserve to have access to all available treatment options. We have many other campaigns that are necessary and important and will continue adding to this website until all the PKU care and treatment issues are addressed.

In 2015, we focused our efforts specifically in Ontario with the belief that if we could make progress there, other provinces would follow suit.  For detailed information about the Ontario campaign, please visit [www.canpkuaction.org.](http://www.canpkuaction.org/)  On that site, there is also a handy email tool that let’s you easily write to the Premier and Minister of Health in your province!

**For more information or to have any questions answered, please contact:**

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