



## Outline For MLA Meetings – PEI

1. Introduce yourself and the person(s) with you. REMEMBER - it is important that you always take at least one other person with you. Make sure to note that you live in the riding. If asked if you represent anyone other than yourself, you can mention that you're part of Canadian PKU and Allied Disorders (CanPKU), the non-profit association for families.
2. Explain that you are there to discuss a decision by Health Canada in April 2010 to approve the medication KUVAN for the treatment of people with PKU. Mention that you will be asking your MLA to write a letter to the Minister of Health and Wellness about this issue and that you have with you a draft for their consideration.
3. Key Messages:
  - a) Over two years ago, Health Canada approved the use of KUVAN for patients with phenylketonuria (PKU), a rare and inherited metabolic disorder that results in toxic levels of the amino acid 'Phe' in the blood and brain.
  - b) PKU is a brain-threatening condition that, if not properly managed through a severely restrictive diet, can result in symptoms ranging from mild cognitive impairment to mental retardation and epilepsy.
  - c) All of the provinces and territories in Canada have a program to test every newborn to discover new cases of PKU. PEI began its program in 1963.
  - d) KUVAN is the first and only drug therapy proven to reduce the blood Phe levels in people with PKU (when taken in conjunction with diet), yet it is not accessible through public funding to PKU patients in PEI.
4. Tell your MLA a brief version of your personal story and the link you have to a person with PKU. If you have experience with KUVAN, please mention the impact that the medication has had on the person with PKU.
5. Core Facts - select and mention some of the core facts around PKU (see fact sheet).
6. **Ask - I am asking you to write a letter to the Minister of Health and Wellness requesting that she immediately provide KUVAN as a choice to PKU patients who are responsive to the medication and to enable their health care providers in PEI to more effectively manage this brain damaging disease.**
7. Dialogue - press your MLA until they agree to write the letter and ask if he or she would like a copy of the prepared draft you brought. Remember to ask to be copied on the letter that your MLA sends. If your MLA would like further information about PKU treatments, newborn screening etc., please let them know that you will get it for them and note their request in the report back form.
8. Conclusion - thank your MLA for their time and for agreeing to write the letter. Let them know that you will be following up in the coming days and weeks.