



## Outline For MLA Meetings – BC

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 the lack of funding of low protein foods, which are a necessary component of the accepted treatment for PKU. Mention that you will be asking your MLA to write a letter to the Minister of Health about this issue and that you have with you a draft for his/her consideration.
3. Key Messages:
  - a) BC is the only province that does not offer any funding of low protein foods for patients with PKU.
  - 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 each have a program to test every newborn to discover new cases of PKU.
  - d) Low protein foods are essential for good metabolic control of these patients and to improve diet compliance in teens and adults.
4. Tell your MLA a brief version of your personal story and the link you have to a 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 requesting that he immediately provide funding for low protein foods for all PKU patients 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.