

MOTION

No. 88

Calling on Government to fund treatments available on the formulary for rare disease

Trish Altass gives notice that she will move, seconded by Heath MacDonald the following Motion:

WHEREAS those battling rare diseases often have limited options for life- extending or life-saving treatments;

AND WHEREAS these individuals deserve the same access to formulary funding as individuals who are battling more common diseases;

AND WHEREAS recently an Islander was denied access to a medication that is currently on the provincial formulary and was prescribed by her physician;

AND WHEREAS due to heterogeneity and small patient numbers larger studies are extremely difficult to complete for many rare diseases. The Canadian Agency for Drugs and Technologies in Health (CADTH), therefore, recommends that patients with rare diseases are treated according to more common disease guidelines despite the lack of large randomized studies;

AND WHEREAS the formulary review system in place in PEI does not recognize the CADTH recommendation that, although large randomized studies are very limited for certain types of rare disease, treatments that pose greater benefit to patients than risk should be provided and funded if they are on the provincial formulary and if prescribed;

THEREFORE BE IT RESOLVED that the Legislative Assembly calls on Government to implement a protocol to enable funding for treatments available on the formulary for rare diseases;

THEREFORE BE IT RESOLVED that the Legislative Assembly calls on Government to provide a more transparent and thoughtful response process for formulary requests. Letters, both approvals and denials, should be produced and decisions justified with research.

Signed by: Trish Altass

Signed by: Heath MacDonald

Date: November 12, 2020