



September 28, 2018

Advisory Council on the Implementation of National Pharmacare Secretariat  
Brooke Claxton Building  
70 Colombine Driveway  
Ottawa, ON K1A 0K9

**Re: ALS Society of Canada Submission to the Advisory Council on the Implementation of National Pharmacare**

Dear Advisory Council for the Implementation of National Pharmacare;

This letter is in support of the recommendations put forward by Health Charities Coalition of Canada (HCCC) in response to the discussion paper *Towards Implementation of National Pharmacare*. The six recommendations for a patient-centred approach to national pharmacare presented within the HCCC response hold true for Canadians living with ALS, yet there are additional considerations unique to this community that still faces a challenging and terminal diagnosis.

Amyotrophic Lateral Sclerosis (also known as ALS, Lou Gehrig's disease, or motor neuron disease) is a disease that gradually paralyzes people because the brain is no longer able to communicate with the muscles of the body that we are typically able to move at will. As the connection with muscles of the body breaks down, someone living with ALS will lose the ability to walk, talk, eat, swallow, and eventually breathe. Approximately 3,000 Canadians are living with ALS at a given time.

Through this letter we aim to highlight the perspective of Canadians living with ALS to ensure the Advisory Council for the Implementation of National Pharmacare understands the importance of equitable access to therapies and the barriers that could inadvertently be put in place if the program is not developed with these considerations in mind. Based on the recommendations provided by HCCC, we ask that the Advisory Council consider the following as it relates to Canadians living with ALS:

- **HCCC Recommendation 3:** *A national pharmacare program needs to ensure that all Canadians have access to prescription medication coverage – including all ages and those with acute, chronic and episodic illnesses, including rare diseases.*
  - **Treatment Administration:** A national pharmacare program must consider that access to prescription medication does not end when patients have the drug in hand and ensure that patients can also have the therapy administered equitably, regardless of where they live or their financial means. As we have seen with the drug Radicava (edaravone), an ALS therapy currently undergoing Health Canada priority review, despite being able to access the drug through Personal Importation or Health Canada's Special Access Program, many in the ALS community faced significant challenges having the therapy administered. Radicava (edaravone) is administered through an IV. As the provinces have different policies and approaches to managing drug infusions, some people living with ALS were able to receive the infusions at no cost, while others had to pay out-of-pocket to have the drug infused by private clinics or nurses. This type of inconsistency is not acceptable as it unfairly and unnecessarily impedes access to therapies.

- **HCCC Recommendation 4:** *A national pharmacare program needs to ensure patients are able to access all drugs approved by Health Canada – if not on the national formulary, then via private insurance plans or through separately adjudicated access programs that consider a patient’s specific circumstances. Reducing access that citizens currently have to prescription medicines is counterproductive and creates uncertainty for all people in Canada.*
  - **Separately Adjudicated Access Programs:** The development of any separate access programs under the national pharmacare program must be done in a manner that ensures the programs are easy to navigate and operate under streamlined timelines. These separate access programs cannot be designed in a way that creates additional challenges and gaps for Canadians who need medication not available on the formulary, especially given those that are most likely to need to access this type of program would include diseases with smaller populations.
  - **Emerging Therapies:** While there is currently no cure and few treatment options available that have a significant impact on the progression of ALS, there is a strong pipeline of emerging therapies that bring hope to the community. For Canadians living with ALS it is vital that a national pharmacare program consider the treatment pipeline and be responsive to new therapies coming to market in order to ensure access in a timely manner.
- **HCCC Recommendation 5:** *Funding pharmacare should be shared across different payers to balance sustainability and affordability with improved access to treatments and patient choice.*
  - **Financial Burden:** As stated in the HCCC response, *any cost-sharing with patients should be simple, straightforward, realistic and reflect the true burden of out-of-pocket spending on individual patients and families.* As demonstrated with the above Radicava (edaravone) example, the out-of-pocket spending can extend beyond the cost of the drug and may include specialized care and equipment to administer the therapy. If drug administration is not covered by a publicly-funded drug program, then the entire cost of drug administration must be considered when determining the true burden of out-of-pocket spending.

The development of a national pharmacare program has significant implications for all Canadians, including those living with ALS. We thank the Advisory Council on the Implementation of National Pharmacare for the continued involvement of patients and patient advocates in its consultation process.

We hope you will take the recommendations put forward by Health Charities Coalition of Canada into advisement, as well as those presented here for people living with ALS and other rare diseases.

Sincerely,



Tammy Moore  
CEO