

NDP Response: ALS Society of Canada

Lisa Marchitto
VP Marketing and Public Affairs
ALS Society of Canada

Dear Ms. Marchitto,

Thank you for taking the time to write to us regarding the unmet needs of Canadians living with Amyotrophic Lateral Sclerosis (ALS).

New Democrats believe that Canada must seize this moment to work towards a cure for ALS, and we must ensure that all Canadians impacted by this devastating disease have access to high-quality treatment and compassionate care.

That's why a New Democratic government will work in partnership with the provinces and territories to establish universal public pharmacare as rapidly as possible – with a target launch date of 2022. We will create an arms-length agency that will be responsible for establishing and overseeing the list of medications and devices covered by pharmacare. The agency will be governed collaboratively by the federal, provincial, and territorial governments and include strong patient representation.

We are very mindful of the need to ensure that Canadians with rare diseases and disorders are well-served and that promising drug therapies are appropriately accessible. We believe that special care must be taken to ensure that formulary listing decisions are responsive to these requirements and future pharmaceutical innovation. Our goal is to construct a broad, comprehensive formulary that all provinces and territories will agree to cover with no direct cost to patients in exchange for dedicated federal transfer payments.

Furthermore, New Democrats believe the federal government has a responsibility to fund research that will accelerate progress towards the development of effective treatments for ALS. The low prevalence of ALS makes competition for CIHR grants more difficult, and funding research less attractive to industry partners. Additionally, without a survivor population, grassroots funding is limited – all resulting in a need for targeted public support. We agree that CAPTURE ALS represents an important investment in ALS research that has the potential to make meaningful and impactful discoveries about the disease.

Again, thank you for your message. For more information, please visit: www.ndp.ca.

Sincerely,

Canada's New Democrats