

The ALS community is calling on the government to make substantial changes to Canada's drug access process and to better fund ALS research that will lead to effective treatments.

1. HELP CANADIANS ACCESS INNOVATIVE THERAPIES FASTER



a) ENSURE PATENTED MEDICINES PRICES REVIEW BOARD (PMPRB) REFORMS DON'T IMPACT PATIENT ACCESS

Only move forward with proposed changes to PMPRB regulations if the federal government can establish that they will not limit or delay access to innovative medicines for people living with ALS, including the Special Access Programme.



b) FOLLOW THROUGH ON DRUG ACCESS COMMITMENTS

Expedite the establishment of the Canadian Drug Agency so the average approval and reimbursement decision timelines are shortened for therapies for ALS as a rare disease with an unmet need.



c) INCLUDE PEOPLE WITH LIVED EXPERIENCE

Commit to meaningful engagement with the ALS community during the development of the CDA and related initiatives affecting access to ALS therapies.



d) IMPLEMENT HESA RECOMMENDATIONS ON OPEN-LABEL EXTENSIONS

Eliminate the unnecessary Health Canada approval for open-label extensions for drugs proven safe and effective at the end of the clinical trial, as recommended by the House of Commons Health Committee.



In the 6 months during Health Canada's priority review period of a new therapy, 500 Canadians will die of ALS. How many more will die waiting for reimbursement and price setting decisions?

WHY NOW?

In the 2019 federal election all major national party platforms committed to improving access to treatments¹.

There is no time to waste. The timelines associated with how drugs are evaluated and made available in Canada should not be a barrier to accessing future proven treatments. Better access to effective ALS treatments will see the burden of ALS decrease and result in people living longer, with less severe symptoms, and the ability to contribute more productively to society.

DID YOU KNOW?

There are more than 60 ALS drugs in development.

Any one of them could be proven effective and become a future treatment.

2. BE A PARTNER IN FUNDING DEDICATED ALS RESEARCH



Invest **\$35 million over five years** to fund **CAPTURE ALS** (the **Comprehensive Analysis Platform To Understand Remedy and Eliminate ALS**) and **empower Canadians to participate directly in the global fight to end ALS.**



CAPTURE ALS is a Canadian-led open science platform of comprehensive biological data from 1,000 Canadians living with ALS that will enable the study of why ALS progresses differently in people with the aim of **strengthening clinical trials and accelerating life-changing therapy development.**



Led by a group of world-renowned Canadian ALS experts, CAPTURE ALS will be driven academically at four existing ALS centres of excellence across Canada – **Edmonton, Toronto, Montreal, and Quebec City** – with the principal investigator located in **Alberta.**



Through **open science,** the datasets and samples collected through the platform will be rapidly shared with academia, industry and complementary consortia across Canada and the globe.

WHY NOW?

Understanding the differences in ALS progression will lead to the discovery of new therapies, enhance the success of clinical trials, reveal who is ideal for specific treatments, and accelerate marketing approval and access of effective therapies.

Canada's ALS research community is well-positioned for the next landmark medical discovery in ALS and to lead the next generation of global ALS research. **CAPTURE ALS will enable Canada to become a world leader in the study of ALS and will contribute to efforts in the US, UK, Europe and Australia and lead to new discoveries in ALS.**

Did you know? ALS progression is unique in each person and affects people of all ages, genders, and socio-economic groups in different ways.

WHAT YOU CAN DO:

1. Join the ALS caucus
2. Write a letter to the Minister of Health in support of these asks

The ALS Society of Canada (ALS Canada) works with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS. Visit www.als.ca to learn more.

We acknowledge the financial support from the ALS Society of Manitoba and the ALS Society of Saskatchewan to help make these meetings possible.

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