



LEGISLATIVE ASSEMBLY  
of BRITISH COLUMBIA

Honourable John Horgan, MLA  
Premier of British Columbia  
West Annex, Parliament Buildings  
Victoria, B.C.  
V8V 2L8

Honourable Adrian Dix, MLA  
Minister of Health  
Room 337, Parliament Buildings  
Victoria, B.C.  
V8V 2L8

February 15, 2022

Dear Premier Horgan & Minister Dix,

I am writing today to urge you to continue providing support to the ALS Society of BC as they transition into the second phase of their Project Hope, which will enable clinical trials and further research into Amyotrophic Lateral Sclerosis (ALS) here in British Columbia.

As you know, ALS is a serious health issue in our country that impacts thousands of Canadians, with nearly 1,000 people dying each year from the disease. It has profound impacts on those diagnosed, as well as their families who work so hard to care and advocate for their loved ones. For those living with ALS, time is of the essence, as the average prognosis for the disease is between two to five years. Government must play a greater role in the fight against ALS and the search for an eventual cure through continued involvement in trials like those of Project Hope.

The goal of the ALS Society's Project Hope is to establish a world-class ALS centre at UBC, including an ALS Professorship in Research, through which clinical trials can be conducted right here in B.C. This will provide a combination of both research and quality clinical care that is not currently available in our province.

Your government provided support, which in tandem with donations from British Columbians, allowed the Society to reach the goal of \$5.3 million needed to move forward on Phase 1 of the project. A memorandum of understanding has now been signed between the UBC Faculty of Medicine and the ALS Society of BC and the recruitment process to hire a senior ALS Clinician Scientist to champion the project is underway.



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Now, the Society is excited to move forward into the second phase of the project, which will require raising further support to fund the vital research, clinical trials, and clinical care that the centre seeks to provide. A partnership between the government and the ALS Society will be essential in making this goal a reality and I urge your government to commit to supporting the ALS Society in their important, and life-changing work.

We all want a world without ALS, and the only way to get there is through investment in research and clinical trials like those that will be possible if Project Hope comes to fruition.

I hope that government makes supporting this work a priority so that together we can find a cure for ALS.

I look forward to your response.

Sincerely,

Shirley Bond

Leader of the Official Opposition

BC Liberal Critic for Health, Seniors Services and Long-Term Care

MLA, Prince George-Valemount

Cc: Wendy Toyer [w.toyer@alsbc.ca](mailto:w.toyer@alsbc.ca)

Encl: PROJECT HOPE Phase II.pdf



Faculty of Medicine

## ALS Society of BC PROJECT HOPE



We believe we are at the crossroads of unprecedented hope. There are over eighty (80) promising ALS therapies in the late stages of the clinical trials. Tragically the reality is all of this activity has been largely happening outside of Canada. British Columbians diagnosed with ALS must travel, at their own expense, to other provinces and countries to participate in ALS clinical trials. That is their only hope.

The two goals for PROJECT HOPE are:

### #1 Goal

To establish an ALS Research Professorship at UBC which will be held by a Clinician/Scientist to champion and run the program. This will be funded by an endowment investment of \$5.3 Million. This endowed position will exist in perpetuity.

### UPDATE

- ✓ We are extremely grateful for the generous support of PROJECT HOPE and are pleased to announce the \$5.3 Million goal has been achieved! Special thanks to the Province of BC for contributing \$3 Million. The remaining \$2.3 Million was donated by British Columbians.
- ✓ Trust and Gift Agreements between the ALS Society of BC and the University of BC are in place to fund the ALS Society of BC ALS Research Professorship.
- ✓ The recruitment process to hire a senior ALS Clinician Scientist to champion the project is underway.
- ✓ UBC has committed funding through the [President's Academic Excellence Initiative](#) to support the recruitment of a senior ALS clinician-scientist and bring clinical trials to patients with ALS faster.

**“The partnership between the ALS Society and UBC is an historic leap toward meaningful change for all those living with ALS here in BC and beyond,” said Dr. Jon Stoessl, professor and head of UBC’s department of neurology. “Patients are counting on us to improve access to treatment, develop new therapies and move closer to a cure for ALS. Local patient participation in clinical trials will be critical to achieving these bold aims.”**

## **#2 Goal**

The ALS Professorship will strive to create an optimal environment integrating research and clinical care.

### **UPDATE**

- ✓ It is our dream to End ALS through creating a world class ALS Centre at UBC. To that end, the ALS Society of BC has pledged to UBC to raise an additional \$20M to see this come to fruition.
  - ✓ We are requesting the Province of BC to provide a matching grant of \$10M to assist us with our fundraising efforts and to achieve our goal of \$20M as soon as possible.
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