



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

March 12, 2021

Dear Premier Horgan & Minister Dix,

We are writing today to urge you to take immediate action on increasing funding, clinical trials, and research into Amyotrophic Lateral Sclerosis (ALS) here in British Columbia.

ALS is a serious health issue in our country that impacts thousands of Canadians with around 1,000 dying each year from the disease. We know the hard work that goes into raising money to help fund patient services and critical research that, hopefully, will result in a world without ALS.

B.C. lags far behind other provinces in the fight against ALS and the protection of those living with the disease. The ALS Clinic at GF Strong is woefully outdated and under-resourced, all while no dedicated physician care or clinical trials are currently available to ALS patients in our province. Currently, there are over 160 clinical trials that patients do not have access to here in British Columbia. Consequently, ALS patients are forced to travel to other provinces or the United States to participate in these important trials. This should be seen as unacceptable, at any time, but it is indefensible during a global pandemic.

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This disease has serious impacts on those diagnosed with ALS as well as their families who often face great burdens in caring for their loved ones. Time is of the essence, as those living with ALS face an average prognosis of two to five years. It's vital that government play a greater role in the fight against ALS and the search for an eventual cure.

Our BC Liberal Caucus has been in discussions with ALS advocates and we believe it is imperative that your government take swift action to address the lack of resources devoted to ALS research and treatment. This includes securing access and healthcare plan coverage for promising new therapies for ALS patients, funding ALS research, and working with the ALS Society of BC to bring Project Hope to fruition. The goals for Project Hope are to establish an ALS Professorship in Research at UBC, through which clinical trials can be brought to our province, allowing for a combination of both research and quality clinical care. Your government pledged its support in the past to make Project Hope a reality — this kind of investment is needed in B.C. and action is long overdue.

We, and the many families who face an ALS diagnosis each year in this province, look forward to your response.

Sincerely,

Shirley Bond
Leader of the Official Opposition
MLA, Prince George-Valemount

Renee Merrifield
Official Opposition Critic for Health
MLA, Kelowna Mission

CC ALS Action Canada
ALS Society of British Columbia