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## NEWS RELEASE

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Ministry of Health

### **People with ALS will benefit from research, clinical trials**

VICTORIA – The Province is providing the ALS Society of BC with \$2 million for PROJECT HOPE to further support patients living with amyotrophic lateral sclerosis (ALS) in British Columbia through research for a cure and clinical trials.

PROJECT HOPE will establish an ALS research professorship in collaboration with the University of British Columbia (UBC). This new, permanent ALS dedicated clinician/scientist will offer patient care and further improve patient outcomes and research, with the goal of increasing access to clinical trials in British Columbia for local patients.

“For the first time in nearly a decade, British Columbians living with ALS will soon have a chance to participate in potentially life-changing research close to home,” said Adrian Dix, Minister of Health. “For 40 years, the ALS Society of BC has been dedicated to providing support to patients and their families and works to improve the quality of life for people living with ALS. Now, through PROJECT HOPE, they are giving more hope to people with ALS by supporting clinical trials right here in B.C.”

Brad MacKenzie, chair, ALS Society of BC Advocacy Committee, said, “As somebody living with ALS, it feels great to know that our needs are recognized by the provincial government and UBC. Now that PROJECT HOPE is successful, British Columbians living with ALS, myself included, should feel proud that we will soon have more local access to cutting-edge, world-class clinical trials for the disease.”

The clinician/scientist will work out of the Djavad Mowafaghian Centre for Brain Health (DMCBH) at UBC. Scientists at DMCBH also work on Alzheimer’s and Parkinson’s research, which provides an opportunity for collaboration between the study of these three neurodegenerative diseases.

“This investment represents an unprecedented opportunity to accelerate the translation of ALS research to patient care, bringing hope to patients and families,” said Dr. Dermot Kelleher, dean of UBC’s faculty of medicine and vice-president of health at UBC.

This provincial investment supports the ALS Society of BC in improving care for people with ALS. In 2020, government provided \$1 million to the ALS Society of BC to support its fundraising efforts. In August 2020, the Ministry of Health also began providing coverage of edaravone, or Radicava, for patients living with ALS. In a clinical trial, edaravone helped slow the worsening of this disease in a select ALS patient subpopulation.

The ALS Society of BC was founded in 1981 by ALS patients, their family members and health-care professionals to meet the physical and emotional needs of people living with ALS and their caregivers. They support families directly, raise funds for patient services and research and

work to increase public awareness and understanding of ALS.

Approximately 400 British Columbians live with ALS. ALS is a fatal neurodegenerative disease where patients typically become unable to move, speak, swallow and breathe as the condition progresses.

**Learn More:**

For more information on the ALS society of BC, visit: <https://www.alsbc.ca/>

For information about ALS services at the G.F. Strong Rehabilitation Centre, visit: [http://www.vch.ca/locations-services/result?res\\_id=1277](http://www.vch.ca/locations-services/result?res_id=1277)

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