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## NEWS RELEASE

For Immediate Release  
2022HLTH0114-000509  
April 6, 2022

Ministry of Health

### **More HOPE on the way for ALS patients**

VICTORIA – The Province is investing \$2 million through the ALS Society of BC for the second phase of PROJECT HOPE to further support British Columbians living with amyotrophic lateral sclerosis (ALS).

"It's an honour to be this year's recipient, and on behalf of government, I thank the ALS Society of BC and Dr. Eisen for their strong commitment to helping people and families affected by an ALS diagnosis," said Adrian Dix, Minister of Health. "This is a team effort, and I'm proud to be on your side in the ongoing search for an end to ALS. That is why our government is pleased to provide funding to the society for their PROJECT HOPE efforts, reaching Phase 2 after success with Phase 1. Keep up the good work. Thank you to all members of the legislative assembly for their support in this project, including MLAs Susie Chant and Shirley Bond."

PROJECT HOPE Phase 2 will see the ALS Society work with the University of British Columbia (UBC) to build a team to lead research and clinical trials and to staff a world-class ALS clinic at the university.

"The ALS Society of British Columbia is very grateful for the new partnership between the society, the Province of British Columbia and the University of British Columbia," said Wendy Toyer, executive director, ALS Society of BC. "We are now in a place to take PROJECT HOPE to the next level. The ALS professorship at UBC will strive to create an optimal environment, integrating research and clinical care. PROJECT HOPE provides the opportunity for people living with ALS in B.C. to participate in clinical trials and to access improved care in their province."

In 2021, the ALS Society of BC's PROJECT HOPE Phase 1 raised more than \$5.3 million to establish an ALS research professorship in collaboration with UBC. This permanent ALS-dedicated clinician-scientist will care for patients and work to improve patient outcomes, conduct research and increase patient access to clinical trials in B.C.

"I am thrilled that our government is supporting PROJECT HOPE," said Susie Chant, MLA for North Vancouver Seymour. "As a nurse, I recognize the profound impact this investment will have in supporting the work of the ALS Society of BC. This work is critical in moving toward, and beyond, ALS becoming a chronic illness rather than a terminal one, supporting clients, families and friends in that journey. Thank you to everyone that contributes to those efforts."

#### **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)

People with ALS can share their thoughts on upcoming drug review processes via the Your Voice survey online: <https://www2.gov.bc.ca/gov/content/health/health-drug-coverage/pharmacare-for-bc-residents/drug-review-process-results/your-voice>

A backgrounder follows.

**Contact:**

Ministry of Health

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## BACKGROUND

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### **Facts on ALS in British Columbia**

- The ALS Society of BC was founded in 1981 by ALS patients, family members and health-care professionals to meet the physical and emotional needs of people living with ALS and their caregivers.
- The society supports families directly and raises funds for patient services and research.
- Approximately 400 British Columbians live with ALS.
- ALS is a fatal neurodegenerative disease that gradually causes patients to lose the ability to move, speak, swallow and breathe.
- In 2020, government provided \$1 million to the society to support fundraising.
- This provincial investment builds on the \$2 million provided in 2021 to support the society's PROJECT HOPE Phase 1.
- In August 2020, the Ministry of Health began providing coverage of edaravone (Radicava) for patients living with ALS.
- In a clinical trial, edaravone helped slow the worsening of the disease in a select patient subpopulation.

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