

# ALS SOCIETY OF BRITISH COLUMBIA:

## For Members of the Legislative Assembly of BC

**i** *The ALS Society of BC is a registered nonprofit charity that provides direct support to ALS patients along with their families and caregivers to ensure the best quality of life possible while living with ALS. Through supporting research, we are committed to finding the cause of, and cure for Amyotrophic Lateral Sclerosis.*

### OVERVIEW

**i** *In British Columbia, unless a person has coverage through an extended health plan, the cost that could be incurred per patient over the course of the disease could exceed \$140,000, just for essential medical equipment.*

#### ALS Society of British Columbia: Key 2018 Statistics

- Provided care for 485 people living with ALS and their families' province-wide
- 137 British Columbians were diagnosed with ALS
- 135 British Columbians died from ALS

The ALS Society of BC does not receive direct funds from the Province of BC.

Current funding for ALS patients' treatment through the Government of BC only comes from three programs: The Provincial Respiratory Outreach Program (PROP), Technology for Independent Living Program (BCITS) and the Communications for Youth and Adults Program (CAYA). These agencies receive all or partial funding from the Province of BC.

ALS BC has a contract with CAYA in which \$25,000 is paid annually by ALS BC to ensure ALS patients receive priority due to the incredibly quick progression of ALS.

ALS BC applies for a BC Community Gaming Grant each year. In 2019, \$195,500 was received. The conditions require that these funds must be allocated to the equipment loan program, outreach and public awareness, patient transportation, the Day of Caring program, mobile clinics, support groups, psychological support and kids camp.

### THE OBJECTIVE

**i** *Currently in British Columbia, there is limited capacity to support clinical trial research for patients with ALS. The ALS Centre at GF Strong has limited capacity in terms of staff resources or space to enable BC ALS patients to participate in clinical trials taking place.*

*In order to facilitate the capacity for patients in BC to participate in ALS clinical research:*

- **Need #1:** Two full-time positions are needed: an ALS-dedicated physician to oversee ALS patients and clinical research, and a clinical research coordinator to facilitate the administrative aspects of the trials.
- **Need #2:** Additional space at the ALS Centre at GF Strong.
- **Need #3:** \$1 million in funds from the Province of BC over a five-year period to match the ALS Society of BC contribution.

## OUR PROPOSAL



*The ALS Society of British Columbia to partner with the Province of British Columbia to increase capacity at the ALS Centre to host clinical trials and to foster clinical research.*

*ALS BC has raised through fundraising and a bequest, \$1 million to contribute and has established the ALS Centre of Excellence Fund. We request a matching grant from the Province of BC over 5 years.*

The care currently provided by the ALS Centre team is extraordinary. The Centre located at GF Strong, in Vancouver, provides leading care for patients not only in the Vancouver area but province-wide. The ALS specialists (funded by Vancouver Coastal Health only) provide care to people living with ALS no matter where they live in BC. They also provide mobile clinics to support patients who can no longer travel to Vancouver for appointments at the Centre. The dedication to care for patients is extraordinary and essential for those dealing with ALS. Being a rare disease, many BC healthcare professionals are not equipped or educated to provide quality care for an ALS patient as specialized care is required. The ALS Centre Team is a service not only for patients but also for healthcare workers caring for people living with ALS by sharing training and expertise while in the community (in-service training). The dedication to patient care through, for example, the mobile clinics is something only done in British Columbia. This is funded and coordinated by the ALS Society of BC in partnership with the team at the ALS Centre at GF Strong.

While the care for patients in BC is outstanding for the resources currently available, providing hope for patients with a terminal disease is part of the society's mandate. Last fiscal year, the ALS Society experienced a very successful year in fundraising and received a sizable bequest which enabled the society to allocate \$1 million in an established five-year managed expendable fund. The goal for this money is to expand services to BC ALS patients by providing their access to clinical trials. This is something most Canadians living with ALS already have access to, including clinical trial centres in Alberta, Saskatchewan, Manitoba, Ontario and Quebec and Nova Scotia. The impact on those suffering with ALS in our communities would be not only beneficial for improving research outcomes but also essential in improving patient outcomes.

ALS is a difficult disease, as the diagnosis means no hope of recovery, no significant treatment options and not even the possibility of slowing the disease progression. Enabling ALS patient's province-wide to have access to participate in clinical trials fills a gap in services available to most other Canadians. For several decades, it has been appreciated that specialty ALS clinics increase survival and well-being of patients with ALS.

In 1981, Dr. Andrew Eisen, Professor of Neurology, UBC, established a multidisciplinary ALS Clinic at VGH. This became internationally recognized and was associated with clinical research and clinical trials (and a large and continuing publication record).

**Clinical trials and clinical research are vital to ALS patients, enabling them to participate in their care, which prolongs survival and well-being.**

In 2005, at the time when Dr. Eisen retired from UBC and VGH, the clinic moved to GF Strong. Since then, there has been considerable difficulty in maintaining clinical trials and clinical research. Unquestionably, ALS patients have continued to receive excellent care but are now missing out on the trial and research elements associated with an “excellent ALS Clinic.”

The main reason for this has been the lack of funding for a dedicated full-time ALS physician. As a result, there are now four neurologists seeing ALS patients on a part time basis, with limited time and resources to perform clinical trials and research.

Critically, the proposed Centre of Excellence would aim to attract new talent in British Columbia that is needed. Over the next decade, three of the four doctors in BC who care for ALS patients at the ALS Centre will be retiring, and a critical loss in resources and patient services will occur. The loss of doctors will leave BC in an urgent situation of not being able to care for patients. By creating a centre with the capacity for research, BC would become competitive and desirable for doctors who specialize in ALS. Without such incentive, it is difficult to foresee patient care remaining at current levels.

## CONCLUSION

**i** *The ALS Society continues to advocate for better services for those suffering in BC with ALS. The proposed BC ALS Centre of Excellence is the next critical step for advancing patient care in British Columbia. This will improve patient outcomes and attract top, dedicated, professional talent critically needed over the next decade. The \$1 million funding request to the Province to match the existing dedicated funds from the ALS Society would transform the lives of ALS patients in BC. Your support advancing this to the top of the Government agenda is appreciated.*

We look forward to working with Members of the Legislative Assembly in supporting our efforts to ensure patients in BC suffering from ALS have the best possible care and to improve patient outcomes for those dealing with a devastating disease that usually offers no hope.

Wendy Toyer, Executive Director  
ALS Society of British Columbia  
1233 – 13351 Commerce Parkway  
Richmond, BC V6V 2X7  
P 1-800-708-3228  
W [www.alsbc.ca](http://www.alsbc.ca)  
E [w.toyer@alsbc.ca](mailto:w.toyer@alsbc.ca)



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