



## OPINION

# ALS is devastating our military families—it's time to invest in research to find out why

As Ottawa increases military spending, it must also fund research into the diseases linked to military service.

BY TAMMY MOORE

Canada marks June as ALS Awareness Month, formally recognized by Parliament. Every year, Canadians living with ALS, their families, clinicians, researchers, and advocates work to build public understanding of one of the country's most devastating—and least understood—diseases.

Amyotrophic lateral sclerosis, better known as ALS or Lou Gehrig's disease, progressively paralyzes people by destroying the brain's ability to communicate with the muscles we voluntarily control. Over time, people living with ALS lose the ability



Canadians who have served in the Armed Forces have a significantly higher incidence rate of ALS compared to the general population, writes Tammy Moore. *The Hill Times* photograph by Andrew Meade

to walk, talk, eat, swallow, and eventually breathe.

Nearly 4,000 Canadians are currently living with ALS, and approximately 1,000 more are diagnosed each year. The lifetime risk is roughly one in 300. Nine out of 10 people diagnosed have no known family history of the disease. ALS often strikes people in the prime of their lives and carries an average life expectancy of just two to five years after diagnosis.

Yet, despite its severity, we still know remarkably little about why ALS develops, why it progresses differently from one person to another, and why certain populations appear disproportionately affected.

One of the most compelling and under-examined areas of inquiry is the connection between military service and ALS. A growing body of international evidence indicates that former military service is an increased risk factor for developing the disease. Canadians who have served in the Armed Forces have a significantly higher incidence rate of ALS compared to the general population. Recognizing that, Veterans Affairs covers significant medical costs for Canadian Armed Forces members diagnosed with ALS.

Yet, the underlying reasons for this increased risk remain unclear. Understanding why

this risk exists represents an important opportunity not only to better support people who have served, but to also advance our broader understanding of ALS for all Canadians.

The United States has recognized the same troubling correlation, and invests heavily in understanding it. Through the Department of War, America has committed more than US\$300-million toward ALS research to date, including US\$40-million in the last fiscal year alone.

Two countries with similar demographics and military structures. Both face the same unanswered questions around service-related ALS risk. Yet



Tammy Moore is the CEO of ALS Canada. *Handout photograph*

while Canada is significantly increasing defence spending, military-related health research remains largely absent from the conversation.

This needs to change.

Understanding the causal connection between military service and ALS is not simply an academic exercise. It is a pathway toward prevention. Better understanding risk factors could save millions in care costs, improve quality of life for patients and families, and potentially prevent future cases altogether.

As a national health charity, ALS Canada continues to invest significantly in research, largely through philanthropic donations. That generosity matters enormously. But philanthropy cannot be a substitute for sustained public investment in a disease with national reach and implications across Canada's 13 public health systems.

The knowledge gaps remain profound. Researchers are still trying to answer foundational questions: why does one Canadian deteriorate rapidly and die within months while another lives with slower progression for years? Which environmental or biological preconditions contribute to disease onset? Why are some populations more vulner-

able than others? We still lack many of the datasets necessary to answer even these basic questions because the research has not been adequately funded.

And in ALS, time matters enormously.

The first 18 months following onset of symptoms is the critical window for access to clinical trials and early intervention using therapies that have shown meaningful promise in slowing disease progression. Yet many Canadians with ALS are not definitively diagnosed until after that period has passed, making them ineligible for many of the most innovative treatments under development.

Consider the case of Bob, a Canadian Armed Forces veteran and former Hercules pilot. It took nearly two years for him to receive a confirmed ALS diagnosis. By then, he no longer qualified for the clinical trials showing the greatest promise. His experience reflects a broader reality: people living with ALS endure a prolonged and frustrating diagnostic process involving unnecessary surgeries and treatments because ALS symptoms are often mistaken for conditions such as carpal tunnel syndrome or spinal disorders.

That kind of trial-and-error medicine is physically tax-

ing, emotionally devastating, economically disruptive, and deeply costly to families and the healthcare system alike.

Canada already possesses the foundation for a more ambitious national response. The Canadian Collaboration to Cure ALS has brought together researchers, clinicians, and people living with the disease into a co-ordinated national strategy designed to build on established programs to accelerate scientific discovery and improve equitable access to research and clinical trials.

It includes centralized open-science platforms collecting clinical and biological data; patient registries that help understand the population, and guide clinical care and public policy; and expanded clinical trial networks designed to bring emerging therapies to Canadians outside major urban centres.

But this work requires stable and meaningful funding.

It also requires a recognition that geography should not determine whether someone receives access to hope. Today, Canadians living in Toronto, Montreal, or Calgary are far more likely to access leading-edge ALS clinical trials and emerging therapies.

Outside those centres, access drops dramatically. Bridging that

gap is an important step toward ensuring equality of access across the country.

ALS can strike anyone. There is no vaccine, no known lifestyle prevention strategy, and no sufficient demographic profile. For a country that prides itself on universal health care, equality of access, and compassion as guiding public principles, that reality should be unacceptable.

Canada needs a more co-ordinated, strategic, national effort on ALS research to better understand this disease and allow people living with it to better benefit from new therapies. That effort should begin with substantial public investment into researching the still poorly understood connection between military service and ALS. This can begin with meaningful federal support for the Canadian Collaboration to Cure ALS and the broader ecosystem of research, diagnostics, and clinical trials that offer genuine hope to patients and families.

The science is advancing. The opportunities are real. But without public investment, Canada risks watching breakthroughs happen elsewhere while Canadian families continue to wait.

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