ALS SLA
CANADA

Written Submission for the Pre-Budget Consultations in Advance of the 2025 Federal Budget

By: ALS Society of Canada

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RECOMMENDATION:

- The Government of Canada to invest **$50 million over five years** in **the Canadian Collaboration to Cure ALS** that will scale three existing high-impact ALS research initiatives – **CAPTURE ALS**, **the Canadian Neuromuscular Disease Registry (CNDR), and the Canadian ALS Research Network (CALS)** – to establish a coordinated national research ecosystem through which every Canadian living with ALS can participate in, and benefit from, cutting-edge science that will accelerate discoveries by Canadian researchers, advance understanding of the disease, and enable the development of therapies to treat this devastating terminal illness with greater precision.

The Issue

Amyotrophic lateral sclerosis (ALS) is an unrelenting, terminal neurodegenerative disease that causes progressive paralysis, robbing people of their ability to walk, talk, eat, swallow and eventually breathe. Nearly 4,000 Canadians live with ALS, and approximately 1,000 Canadians are diagnosed each year. With no cure and treatments providing only modest benefits, 80% of people living with ALS die within two to five years of diagnosis.

ALS strikes people in the prime of life, while they are raising families, advancing careers, and contributing to society. Its impact extends far beyond the individual, touching families and entire communities, including veterans, who face a greater risk of being diagnosed with ALS.

From the moment of diagnosis, people living with ALS are forced to confront a terminal illness with limited treatment options and significant barriers to participating in clinical trials and research that could expand our understanding of the disease and offer hope. These limitations are particularly severe for Canadians living in rural, northern, and underserved regions, who have even fewer options to contribute to scientific discovery or access emerging therapies.

As a result, Canadians are being left behind – unable to access or contribute to research that could drive progress toward a cure. This inequity persists not because Canada lacks scientific expertise or infrastructure, but due to chronic underinvestment in ALS research by the federal government and the lack of a coordinated national strategy that has delayed critical progress. In the face of a rapidly progressing disease, continued inaction is measured in missed opportunities and lives lost.

Other countries have recognized this urgency and responded with bold action. The United States passed the ACT for ALS legislation, committing over $100 million annually to improve access to experimental therapies and accelerate research. The U.S Department of Defense also invests $40 million annually into dedicated ALS research aimed at developing new treatments. The United Kingdom has invested £50 million to fund the establishment of an innovative ALS/MND Research Institute.

Strategic investments like these have already demonstrated impact in other disease areas. Coordinated research funding in cancer, Parkinson’s, and multiple sclerosis has improved survival rates, broadened treatment options, and attracted global partnerships. ALS research in Canada has yet to receive comparable investments, despite having the expertise and platforms that are ready to deliver.

Meanwhile, potential cuts to major U.S. health research funding programs, including those for ALS, are creating uncertainty that threatens global progress. In this shifting landscape, Canada has a timely opportunity to lead.

That is why **ALS Society of Canada (ALS Canada) and the Canadian ALS community is calling for an investment of $50 million over five years to invest in the Canadian Collaboration to Cure ALS – a coordinated strategy that will ensure every Canadian can access, contribute to, and benefit from discoveries that could change the trajectory of their disease.**

Solution: The Canadian Collaboration to Cure ALS

Now is the moment for bold federal leadership. Canada is home to world-class ALS researchers, clinics, and the infrastructure needed to become a leader in ALS research. Federal investment is crucial to scaling existing initiatives, unifying efforts nationwide, and accelerating progress.

To determine where such investment would have the most significant impact, ALS Canada brought together clinicians, researchers, people living with ALS, caregivers, and ALS organizations from across the country. This collaborative process resulted in a clear consensus: three existing, high-impact Canadian initiatives, **CAPTURE ALS**, **the Canadian Neuromuscular Disease Registry** (**CNDR),** and **the Canadian ALS Research Network** (**CALS)**, represent Canada's strongest opportunity to lead in the global pursuit of a cure for ALS.

1. Unlocking the biology of ALS $35 million over 5 years

ALS is a heterogeneous disease, meaning it varies from person to person, including where symptoms first appear in the body, age of onset, rate of disease progression, involvement of genetic and environmental factors, and more. Investing in research that explores this complexity is crucial to advancing ALS from a terminal diagnosis to a treatable condition.

There is a significant opportunity to turn this vision into reality through **CAPTURE (Comprehensive Analysis Platform To Understand, Remedy, and Eliminate) ALS**, an initiative that is revolutionizing our understanding of the disease. CAPTURE ALS utilizes innovative technologies and fosters national and international collaborative research efforts to identify and analyze diverse biological characteristics of people living with ALS, focusing on data collection, biomarker discovery and acceleration towards personalized medicine.

A federal investment of $35 million over five years will:

- Expand the platform to 12 ALS research-ready Canadian sites and increase participant enrollment in every province, broadening representation of Canada's diverse population.
- Accelerate the identification of biomarkers and therapeutic targets that will slow disease progression and improve quality of life for people living with ALS.
- Support fundamental ALS research nationwide by providing access to deep phenotyped biosamples and data.
- Position Canada as a global leader in ALS research, attracting top-tier researchers from around the world.

2. Advancing ALS care through real-world data $7.5 million over 5 years

A comprehensive and coordinated system for tracking ALS in real-world settings is crucial for advancing research, enhancing clinical care, and informing public policy. By following people from diagnosis onward, **the Canadian Neuromuscular Disease Registry (CNDR)** collects key demographic and medical data, including postal code, date of birth, diagnosis timelines, and occupation, to understand how ALS progresses across Canada's diverse populations, revealing regional and socioeconomic differences that inform more equitable care.

The registry's real-time insights into treatment decisions, clinical trial participation, and health-service utilization support evidence-based clinical decision-making and facilitate national and international research collaborations.

At the system level, national-level data can guide policymakers in better resource allocation decisions to enhance health outcomes, address care disparities, and plan effectively for future system needs.

A federal investment of $7.5 million over five years will:

- Achieve nationwide coverage, with a goal of enrolling every Canadian diagnosed with ALS into the registry.
- Accelerate the development of new therapies.
- Provide critical data and timely insights for clinical and policy-making decisions.
- Uphold Canadian data sovereignty, ensuring that health data is governed, stored, and used in ways that protect privacy and align with national research priorities.

3. Improving equitable access to ALS clinical trials $7.5 million over 5 years

Participation in clinical trials is often the only opportunity for people living with ALS to access emerging therapies. Yet in Canada, access remains highly uneven. For Canadians living in rural and remote areas, the opportunity to contribute to and benefit from clinical trials is often out of reach.

A significant reason for this disparity is the lack of consistent, well-resourced clinical trial infrastructure across the country. Conducting clinical research requires trained staff, dedicated space, regulatory expertise, and logistical support – resources that many ALS clinics lack. Without this foundation, even interested sites cannot participate in clinical trials, and willing patients are left out.

The Canadian ALS Research Network (CALS) is uniquely positioned to address this gap. CALS is a network of clinicians across Canada who specialize in ALS research and clinical care. It is widely regarded, both nationally and internationally, for its leadership in rapid study recruitment and attracting global trials to Canada. What CALS lacks is the funding required to expand clinical trial capacity across Canada. The network is shovel-ready and prepared to scale across Canada with the right investment.

A federal investment of $7.5 million over five years will:

- Expand clinical trial readiness across the country.
- Support clinical training and research site development.

- Prioritize investments in underserved and remote communities to reduce health disparities.
- Ensure that every Canadian living with ALS can participate in research closer to home.

Rather than operating in isolation, CAPTURE ALS, CNDR and CALS can function as an interdependent system – each enhancing the impact of the others to drive progress:

- CALS provides the national clinical infrastructure and houses the expert clinicians needed to enroll participants into both the CNDR and CAPTURE ALS.
- CNDR offers critical real-world data that informs clinical trial design, tracks health outcomes and supports evidence-based care, made possible through collaboration from CALS sites.
- CAPTURE ALS produces high-quality biosamples and clinical data, which become more powerful when linked to CNDR's longitudinal data tracking, facilitated through CALS.

These infrastructures are already operational, internationally collaborative, and ready to scale, but they require sustained federal funding to reach their full potential.

Now is the time to act. Canada has a pivotal opportunity to transform the ALS research landscape, deliver improved health outcomes, and bring real hope to people and families facing this devastating disease.

Anticipated Outcomes

The federal government's investment of $50 million over five years in a Canadian Collaboration to Cure ALS will unlock the full potential of this national ecosystem and result in:

- Improved access to clinical trials and research for people living with ALS, helping to reduce disparities in care and innovation across the country.
- Accelerated identification of biomarkers and therapeutic targets through real-world data collection and coordinated biological sampling, enabling faster scientific breakthroughs.
- Enhanced clinical decision-making and health system planning, driven by real-time Canadian data that improves efficiency.
- Strengthened capacity to retain and attract top scientific and clinical talent, reinforcing Canada's global leadership in ALS research and supporting the government's ambition to make Canada a hub for innovation.
- Strong protection of Canadian data sovereignty, ensuring that health data remains under national governance and is used ethically and transparently to benefit Canadians.

Alignment with Federal Government Priorities

Investing in the Canadian Collaboration to Cure ALS represents a timely, nation-building opportunity that aligns with the federal government's vision for "One Canadian Economy", driving domestic innovation and national integration. At a time when global scientific leadership is being redefined, Canada has a window of opportunity to lead in an area of high unmet need, positioning our country as a stable and competitive destination for industry investment, independent from, and competitive with, the U.S.

Currently, due to lack of investments, many Canadians living with ALS are enrolled in U.S.-based studies, resulting in research data being collected, governed and stored outside of our borders – undermining Canadian data sovereignty. Without a coordinated, Canadian-led effort, our domestic scientific progress is constrained, and Canadians have fewer opportunities to benefit directly from the research they help advance.

Investing $50 million over five years in the Canadian Collaboration to Cure ALS embodies the federal government's goals of competitiveness and domestic innovation. By supporting Canadian-led science, connecting rural and urban communities, and strengthening a national ALS research infrastructure, this investment will create high-value jobs, improve health outcomes and increase Canada's global influence.

Conclusion

Canada stands at a pivotal moment. The global factors which have previously propelled ALS research forward are now at risk. We have the expertise, infrastructure, and scientific momentum to change the course of ALS, but only if we choose to act. An investment of $50 million over five years through the Canadian Collaboration to Cure ALS in CAPTURE ALS, the CNDR, and CALS will scale Canada's most high-impact research platforms into an integrated and world-leading ecosystem.

With the potential to become a nation-building opportunity and a global contributor, this investment will give Canadians living with ALS, and people yet to be diagnosed, a future with hope, dignity, and meaningful progress.

By acting now, Canada will lead globally in ALS innovation, ensuring that Canadians from coast to coast can participate in and benefit from cutting-edge science and demonstrate what is possible when we take action so no Canadian is left behind, with Canadian research leading the way.