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

By: ALS Society of Canada

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Recommendation

- That the Government of Canada invest **$50 million over 5 years** in the **Canadian Collaboration to Cure ALS** to scale four existing, high-impact ALS research initiatives – **CAPTURE ALS, the Canadian Neuromuscular Disease Registry (CNDR), the Canadian ALS Research Network (CALS), and Access ALS** – to unify Canada's ALS research efforts, so that every Canadian living with ALS can 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 ALS with greater precision.

The Issue

Amyotrophic lateral sclerosis (ALS) is a terminal neurodegenerative disease, causing progressive paralysis, robbing people of their ability to walk, talk, eat, swallow, and eventually breathe. Nearly 4,000 Canadians live with ALS, and 1,000 are diagnosed annually. With no cure and limited treatments, 80% of people living with ALS die within two to five years.

ALS strikes people in the prime of life, while raising families, advancing careers, and contributing to society and the economy. Its impact extends far beyond the individual, placing a profound emotional and financial strain on families and communities across Canada.

This burden is even more acute for veterans who have an increased risk of getting diagnosed with ALS when compared to the general population.[1]

From the moment of diagnosis, people living with ALS face a terminal illness where research represents their greatest—and often only—hope for a future where ALS is no longer a death sentence. Despite this reality, Canadians living with ALS face significant barriers to accessing clinical trials and research that could help 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.

Expanding access to research, particularly within high-risk populations like veterans, offers a critical opportunity to help us gain a better understanding of ALS more broadly, providing insights that could benefit patients from all walks of life. It also represents a fiscally responsible approach for government by addressing a disease for which it already bears significant costs through disability benefits and healthcare expenditures, including through Veterans Affairs Canada, which recognizes ALS as an occupation-related disease for Canadian Armed Forces members.[2]

While, the United States and the United Kingdom have recognized this opportunity and committed significant annual funding towards ALS research (over **$315M USD** and **£50M** respectively), Canada has fallen behind peer nations.

To reverse this inequity through a strategic, aligned and effective approach that will directly benefit Canadians affected by ALS, **the Canadian ALS Community is calling for an investment of $50 million over five years in the Canadian Collaboration to Cure ALS – presenting a unique opportunity for Canada to outpace international competitors by integrating its universal healthcare data with its world-class research talent.**

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[1] https://www.neurology.org/doi/abs/10.1212/01.wnl.0000148649.17706.d9

[2] https://veterans.gc.ca/en/about-vac/reports-policies-and-legislation/policies/amyotrophic-lateral-sclerosis-als#101475

The Solution

The Canadian Collaboration to Cure ALS represents a unified, coordinated strategy to help scale four high-impact Canadian initiatives — **CAPTURE ALS, the Canadian Neuromuscular Disease Registry, the Canadian ALS Research Network, and Access ALS** — to unify Canada's ALS research efforts so that Canadians can access, contribute to, and benefit from discoveries that could change the trajectory of their disease.

By unifying and scaling initiatives that are already operational, investment in the Canadian Collaboration to Cure ALS would fund expansion and further integration, while reducing potential duplication throughout the ALS research community.

Pillar 1: Biological Mapping of ALS **$30M 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. ALS has no known cure and impacts every individual uniquely, and while limited treatments can help manage symptoms or modestly slow progression, the disease remains fatal. Investing in research that explores this complexity is a crucial foundation to advancing ALS from a terminal diagnosis to a treatable condition.

CAPTURE (**C**omprehensive **A**nalysis **P**latform **T**o **U**nderstand, **R**emedy, and **E**liminate) **ALS** is an initiative that is transforming our understanding of the disease. It is an open-science platform that revolutionizes our understanding of ALS through the collection of biological data to answer one of the most urgent questions in ALS research: Why does ALS affect each person differently?

Through integrating clinical data, imaging, genomics, and biosamples to uncover the biological factors driving these differences, CAPTURE ALS paves the way towards biomarker discovery and therapeutic targets that will slow disease progression. This is achieved through the utilization of innovative technologies and by fostering national and international collaborative research.

With a federal investment of $30M over 5 years, CAPTURE ALS will

- Expand to 15 locations.
- Allow 1075 participants, 900 people living with ALS and 175 healthy control volunteers, to take part in the platform data submission process.
- Help provide a deeper understanding of the nature of ALS and potential treatments.

Pillar 2: Real World Tracking of ALS **$6M over 5 years**

While biological data and the results of controlled clinical trials are key aspects of research, a comprehensive and coordinated system for tracking ALS in real-world settings is also crucial for advancing research, enhancing clinical care, and informing public policy. The **Canadian Neuromuscular Disease Registry (CNDR)**, established in 2010, serves as Canada's largest national registry for neuromuscular diseases, supporting pan-Canadian clinical sites and capturing data on more than 8,000 individuals, including people living with ALS.

By following people from diagnosis onward, the CNDR collects key demographic and clinical data, including postal code, date of birth, diagnosis timelines, and occupation, to understand how ALS progresses across Canada's diverse populations, and reveals 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 also help 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 $6 million over 5 years for CNDR will:

- Expand capacity to collect, harmonize, and analyze longitudinal ALS data.
- Improve accessibility of de-identified data for research.
- Accelerate the generation of real-world evidence that supports patient care, therapeutic discovery and development, policy decisions, and innovation.
- Expand national ALS data capture to include 2,000 new patients, caregivers, and asymptomatic familial participants.
- Enhance data harmonization and integration between CNDR and CAPTURE systems to enable secure, cross-platform analysis.

Pillar 3: Integrated National Clinical Trial Network **$14M over 5 years**

Clinical research is the primary pathway for people living with ALS to access life-changing discoveries, yet two structural issues hinder progress.

First, many Canadian ALS research sites are under-resourced, lacking the specialized staff and infrastructure needed to support consistent trial participation, creating barriers for patient access.

Second, Canada has limited national capacity to conduct Phase 1 trials at scale, excluding many Canadians from the earliest stages of drug development. This gap has significant downstream implications as companies that initiate Phase 1 trials in a given country often continue their clinical programs in that same jurisdiction. As a result, Canada's limited Phase 1 capacity not only restricts early access for patients but also limits participation in later-stage trials and reduces the likelihood of attracting sustained private investment.

It also means that promising Canadian discoveries, originating in our world-class fundamental science ecosystem, often forced to move abroad for early clinical testing, rather than being developed and retained within Canada.

The **Canadian ALS Research Network (CALS)** and **Access ALS**, work collaboratively to help address these gaps, forming the clinical research access pillar of the Canadian Collaboration to Cure ALS.

CALS is the established national ALS clinical research network across Canada who specialize in ALS research and clinical care. With 22 sites across Canada, CALS directly addresses the first barrier to clinical trial access in Canada through supporting best practices in clinical care across the country and strengthening Phase 3 trial capacity nationwide, ensuring that Canada can deliver the large-scale trials that follow early-phase development.

Access ALS is designed to close the critical Phase 1 gap by strengthening Canada's early-stage trial capacity by providing a coordinated framework that streamlines trial start-up, reduces redundancies, and improves efficiency. By enabling Canada to participate in and lead early-phase studies, this model positions the country to attract the full continuum of clinical development, from first-in-human trials through to late-stage studies.

Together, CALS and Access ALS help to build Canada's clinical trial capacity, improving access to clinical care for people living with ALS across the country, while translating biological discovery and real-world evidence into accessible clinical research and therapeutic development, and establishing a robust research pathway that attracts private investments that will benefit the economy.

Alignment with Federal Priorities

Beyond supporting those impacted by ALS now and into the future, the investment in the Canadian Collaboration to Cure ALS will help the federal government make progress in some key priority areas, such as:

- **Health System Efficiency:** Better use of health data across Canada could save an estimated **$2.4 billion**[3] in provincial health budgets by reducing redundant testing and optimizing resource allocation. Canadian Collaboration to Cure ALS builds interoperable data, real-world evidence, and analytics capacity that can be used beyond ALS, and enables participation in research across geography, reducing the "postal code lottery" effects and ensuring public healthcare dollars translate into comparable opportunities and outcomes nationwide.
- **Domestic Data Sovereignty:** Ensuring that Canadian health data remains under national governance, protecting patient privacy while fueling domestic AI and biotech growth. Canadian Collaboration to Cure ALS helps achieve this goal through building and growing a longitudinal national data system, creating a platform for the open exchange of biological data, and increasing collaboration amongst researchers to close clinical research gaps in ALS.
- **Talent Attraction & Retention:** Reinforcing Canada's ability to attract top international researchers, supporting the government's goal to make Canada a top-three global life sciences hub. The Canadian Collaboration to Cure ALS provides the scale, predictability, and infrastructure that leading researchers increasingly require to build their careers in Canada, which will help elevate Canada as a key player in ALS research and attract talent to the country and aid in this goal.
- **Private Sector Investment:** A coordinated and efficient clinical trial network makes Canada a primary destination for global pharmaceutical companies, who currently invest over **$2 billion** in Canadian R&D annually.[4] This private sector investment goes even further towards supporting Canada's competitiveness when you consider that for every $1 spent on health research, $4.71 is invested back into the Canadian economy.[5] Canadian Collaboration to Cure ALS makes Canada a more attractive destination for pharmaceutical sponsors—which brings trial revenue, research jobs, and downstream Phase 2/3 investment that compounds over time. Companies that run Phase 1 trials in a country tend to keep their later stage programs there too.

[3] https://ppforum.ca/publications/mining-canadas-health-data/
[4] https://www.canada.ca/en/health-canada/news/2026/03/new-task-force-to-enhance-canadas-competitiveness-and-improve-access-to-innovative-medicines.html
[5] https://www.afmc.ca/wp-content/uploads/2022/10/Economic_Impact_Study_Report_EN.pdf

Conclusion

The strategic and targeted investments we need for Canadians living with ALS 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. Budget 2026 presents a critical opportunity to extend this success to ALS.

Investing in the Canadian Collaboration to Cure ALS represents a timely, shovel-ready nation-building opportunity that aligns with the federal government's vision for "One Canadian Economy", driving domestic innovation and national integration. It will enable Canada to capture the full value of its world-class researchers, clinics and the infrastructure – delivering meaningful impact for people affected by ALS and also strengthening Canada's competitiveness and generative long-term economic returns.

In Budget 2026, an investment in the Canadian Collaboration to Cure ALS is a clear and actionable opportunity to drive both health and economic outcomes – positioning Canada as a leader in the global effort to end ALS while building a more innovative, integrated, and resilient economy.