ALS SLA
CANADA

Future.
Focused.

2025 REPORT
TO THE COMMUNITY

GROUNDED IN IMPACT AND SUPPORT TODAY,
FUTURE. FOCUSED. REFLECTS ALS CANADA’S
COMMITMENT TO STRENGTHENING CARE,
AMPLIFYING COMMUNITY VOICES,
ADVANCING RESEARCH, AND BUILDING MOMENTUM
TOWARD A WORLD FREE OF ALS.

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ALS. Focused.

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Accountability. Focused.

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Progress. Focused.

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Community. Focused.

ALS.
Focused.


ALS DOESN'T STOP.
NEITHER WILL WE.
LA SLA NE S'ARRÊTE PAS.
NOUS NON PLUS.
HELPING YOU NAVIGATE YOUR PATH

A MESSAGE TO THE COMMUNITY

In 2025, we remained clear in our direction: Future. Focused.

Being future focused does not mean looking past the needs of today. It means strengthening care and services now while advancing the research and advocacy required to change what comes next.

From across Canada, ALS Canada brought together people living with ALS, caregivers, clinicians, researchers, provincial Societies, and other ALS organizations to define national research priorities. From this alignment, the Canadian Collaboration to Cure ALS was established to accelerate discovery and unify our country's efforts on behalf of people affected by ALS. United, we brought this shared vision to Parliament Hill to advocate for federal investment to establish a national research strategy that reflects both the urgency of the disease and the opportunity before us.

This year also marked a meaningful milestone with Health Canada's approval of Qalsody for people living with SOD1-ALS. This advancement demonstrates that ALS is treatable when research is prioritized and properly funded. Canadian scientists, advanced in part by investments from ALS Canada, helped lay the groundwork that made this progress possible.

At the same time, we remained focused on supporting nearly 4,000 Canadians living with ALS today. Through access to trusted information, community services, and sustained advocacy, we worked to improve quality of life and ensure individuals and families are not navigating this disease alone.

This work is possible because of you. Your generosity strengthens care today and drives the research that will define tomorrow.

Thank you for your continued commitment to a world free of ALS.

Tammy Moore, Chief Executive Officer

Alyssa Barry, Chair, ALS Canada Board of Directors

ALS CANADA 2024–2028 STRATEGIC PLAN

Guided by the voices of the ALS community, ALS Canada's 2024–2028 Strategic Plan outlines our path toward a world free of ALS. Built around four impact goals, it focuses our work on advancing research, improving equitable care, strengthening advocacy, and mobilizing knowledge. This Annual Report highlights the progress we are making toward these goals as we continue to work alongside the ALS community across Canada.

Read ALS Canada's 2024-2028 Strategic Plan

LEAD
DRIVE
MOBILIZE
EMPOWER

STRATEGIC PLAN 2024–2028

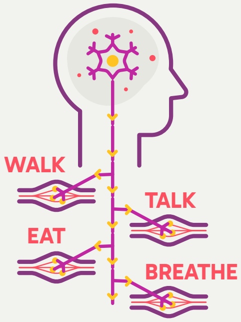
LEAD
Canada's contribution
to **global ALS research**

DRIVE
equitable and timely access to
the best possible standard of care,
treatments, and services

MOBILIZE
collective action to advocate
for maximum impact

EMPOWER
informed decision-making
and recognition of ALS

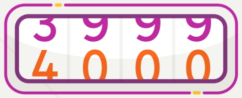
ABOUT ALS



Amyotrophic lateral sclerosis (ALS) is a disease of the motor neurons, the living wires that connect our brain and muscles.

Over time, as their motor neurons die, people living with ALS **lose the ability to walk, talk, eat, and eventually breathe**.

There is **no cure for ALS** and **few treatment options** for most people living with the disease.



Nearly **4,000 Canadians live with ALS**.

Each year, approximately **1,000 Canadians will be diagnosed**, and **1,000 people will die**.

ABOUT ALS CANADA

The ALS Society of Canada is **working to change what it means to live with ALS**, an unrelenting and currently terminal disease.

We respond to the urgent, unmet need for life-changing treatments by **investing in the most promising research** to fuel scientific discovery.

We **advocate for equitable, affordable, and timely access to proven therapies and care**. We **empower informed decision-making** and recognition of ALS.

Nationally, we **ensure people affected by ALS have access to trusted ALS information, education, resources, virtual support groups, and workshops**. In Ontario, **Community Leads** provide **direct support**, helping people **navigate healthcare and community services** and **access equipment**.

VISION

A world free of ALS.

MISSION

We work with the ALS community to improve the lives of Canadians affected by ALS through advancing research, care, advocacy, and information.

FOCUSED ON ALS AT EVERY LEVEL

Grounded in lived experience, ALS Canada's work turns mission and vision into action at every level.

Ontario

We deliver community-based support services and equipment, and advocate at the provincial level to strengthen systems of care. This work helps people living with ALS and their families navigate healthcare and community services, access equipment, and find reliable information when they need it.

National

We focus on access to trusted information that supports informed decision-making. Through education, virtual programs, and specialized expertise, including Canada's first National Genetic Counsellor, we help individuals and families understand genetic risk, testing options, and emerging research.

Global

We lead and collaborate to drive equitable access to therapies and sustained investment in research. By working with partners in Canada and around the world, we help accelerate progress and amplify the voice of the ALS community.

> **"Having someone guide me and give me strength I didn't know I had has been incredible. With ALS Canada's support, I'm not facing ALS alone."**
>
> **Shaleen Latchman,** diagnosed with ALS in 2022

Accountability. Focused.

YOUR GENEROSITY FUELS OUR WORK

The work of ALS Canada is made possible by the generosity of individuals, companies, and foundations who believe in supporting people affected by ALS. Your donations power the programs, advocacy, and research featured throughout this report and ensure this impact can continue.

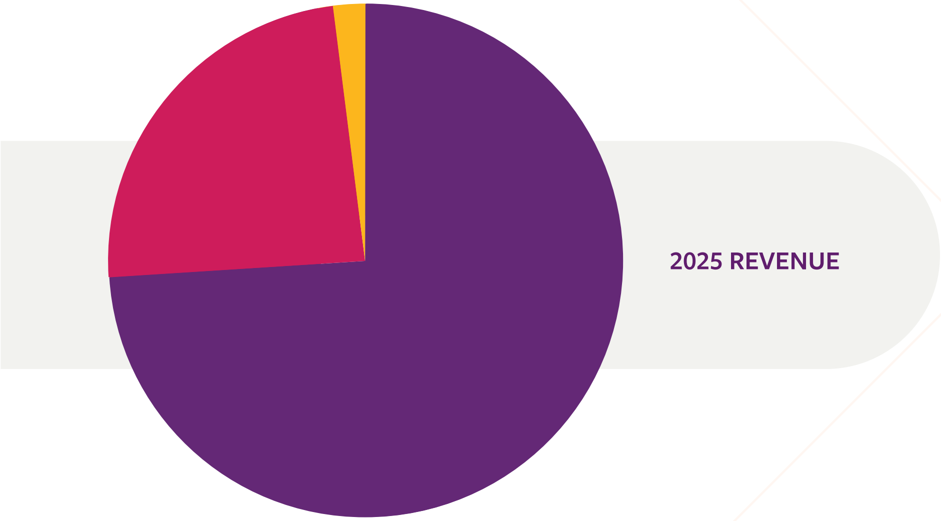
We are deeply grateful for your commitment to this work and for moving it forward with purpose and intention.

Make your 2026 donation today to strengthen the lives of people affected by ALS and drive progress toward a world free of ALS.

Jason Ritchie, ALS Canada Board Member diagnosed with ALS in 2024, with his two daughters, Olivia and Aleksandra, and his wife, Christina.

2025 FINANCIALS

The audited financial statements of ALS Canada are available on our website. To promote transparency, donor confidence, and informed giving, this report includes financial summaries from 2024 and 2023. A detailed breakdown of revenue and expenses for each year is provided in the appendix.

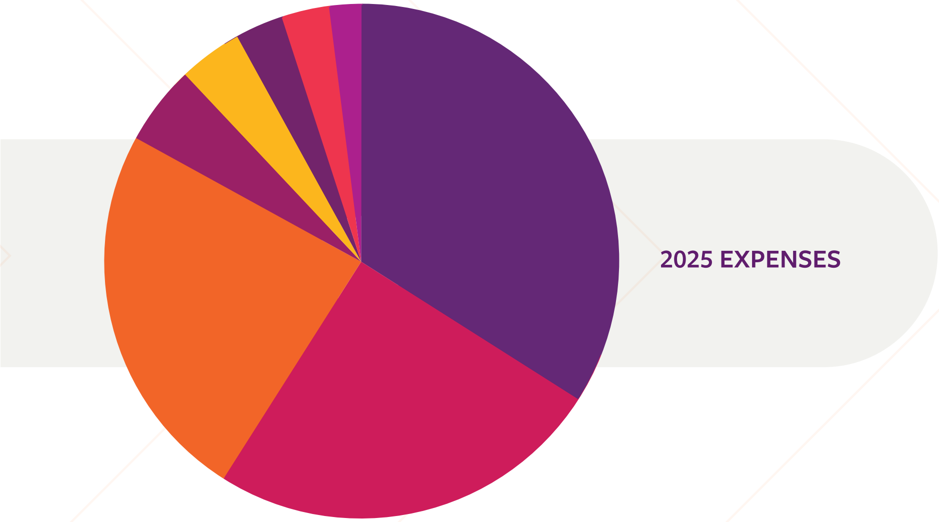


🟪 Fundraising Donations and Other Income	$9,681,177	73.6%
🟥 Ontario Ministry of Health	$3,200,000	24.3 %
🟨 Investment Income	$265,710	2.1%
Total	**$13,146,887**	**100%**

* Participating provincial ALS Societies contribute to the ALS Canada Research Program through 40% of net proceeds of Walk to End ALS events, as follows:

- ALS Society of Manitoba $47,709
- ALS Society of Newfoundland & Labrador $28,636
- ALS Society of Prince Edward Island $19,505
- ALS Society of Quebec $80,000

The ALS Society of Quebec provided an additional $125,000 in support of the ALS Canada Research Program, which included $26,060 on behalf of the Dr. Jean-Pierre Canuel Fund at the ALS Society of Quebec.



🟪 Community Services	$3,995,277	34.3%
🟥 Fundraising	$2,892,261	24.8%
🟧 National Research*	$2,782,234	23.9%
🟪 Advocacy	$608,570	5.2%
🟨 Public Awareness	$426,114	3.7%
🟪 Other Charitable Purpose	$398,781	3.4%
🟥 Administration	$313,900	2.7%
🟪 Governance	$241,818	2.0%
Total	**$11,658,955**	**100%**

* When including matching grant funding of $1,007,500 from Brain Canada, the total research investment is $3,789,734.

Recognition.
Focused.

COLLECTIVE EFFORT BY THE ALS COMMUNITY

The dedication of 340 volunteers and 4,848 event participants played a vital role in advancing ALS Canada's work in 2025, through their time, expertise, and leadership. Their commitment strengthened our reach and responsiveness to people affected by ALS, and we are deeply grateful for the dedication and care they brought to this work.

Visit als.ca/take-action to join the ALS community and empower our vital work.

ALS Canada Walk to End ALS

Twenty-two Walk to End ALS events across Ontario united communities in support and honour of people affected by ALS. In his final advocacy efforts, community member Steven Gallagher published an op-ed urging the community to maintain hope and keep the momentum going, a rallying call that resonated across the ALS community. In Ontario, 433 teams and 4,475 participants raised $2,103,845, demonstrating the power of collective action. A minimum of 50 per cent of funds raised support the ALS Canada Research Program, where investments are matched dollar for dollar by Brain Canada.

Together with participating provincial ALS Societies outside Ontario, Walk to End ALS events generated $568,826 in total fundraising. Of this amount, $175,849.88 was directed to the national ALS Canada Research Program. In these provinces, 40 per cent of Walk funds support the national Research Program, with the remaining proceeds supporting community services in the provinces where funds are raised, including Manitoba, Newfoundland and Labrador, Prince Edward Island, and Quebec.

Giovanni Naccarato, diagnosed with ALS in 2022, crosses the finish line with his family at the Halton Walk to End ALS.

ALS CANADA PULL TO END ALS

ALS Canada Pull to End ALS pulls into Simcoe County

From Toronto to a new Simcoe County location, the ALS Canada Pull to End ALS brought teams together to pull a 42,000-lb transport truck 100 metres, competing for the fastest time and symbolizing the weight of an ALS diagnosis. Across both events, 15 teams and 250 participants raised $213,563, building teamwork, awareness, and hope with every pull.

Team Big Mike giving it their all at the Toronto Pull to End ALS on the campus of York University.

Cyclists line up at the starting line of the ALS Canada Revolution Ride, ready to set out across Niagara's wine country from the event's new location in Jordan, Ontario.

ALS CANADA REVOLUTION RIDE

New roads, same purpose: ALS Canada Revolution Ride

The ALS Canada Revolution Ride rode into Jordan, Ontario, bringing cyclists on scenic 40 km and 90 km routes through Niagara's wine country. Together, 18 teams and 110 participants raised $227,846, including four riders living with ALS who crossed the finish line and inspired everyone along the route.

Community event fundraisers

More than 75 community members across Canada hosted grassroots fundraisers through our Community Events program, raising a combined $405,000 by turning personal milestones and challenges into meaningful action for the ALS community. Among them, Amanda Greenberg travelled from Dollard-des-Ormeaux, Quebec, to participate in the Toronto Waterfront Marathon in honour of her uncle.

> **“What began as a personal challenge grew into a community effort that raised more than $10,000. ALS is devastating and still doesn’t receive the attention it deserves. Every effort matters, and the impact reaches further than you think.”**
>
> **Amanda Greenberg**

Amanda Greenberg celebrates finishing the Toronto Marathon in honour of her uncle.

FEATURE STORY

JBS FOUNDATION’S TEN YEARS OF GIVING, STRENGTHENING CARE AND ACCESS FOR PEOPLE WITH ALS

As a long-standing partner of ALS Canada, JBS Foundation has seen its investments deliver meaningful, lasting change for people affected by ALS. Over a decade, this funding has strengthened ALS Canada's Community Services program, broadening the organization's ability to provide timely, reliable services to people and families navigating the disease.

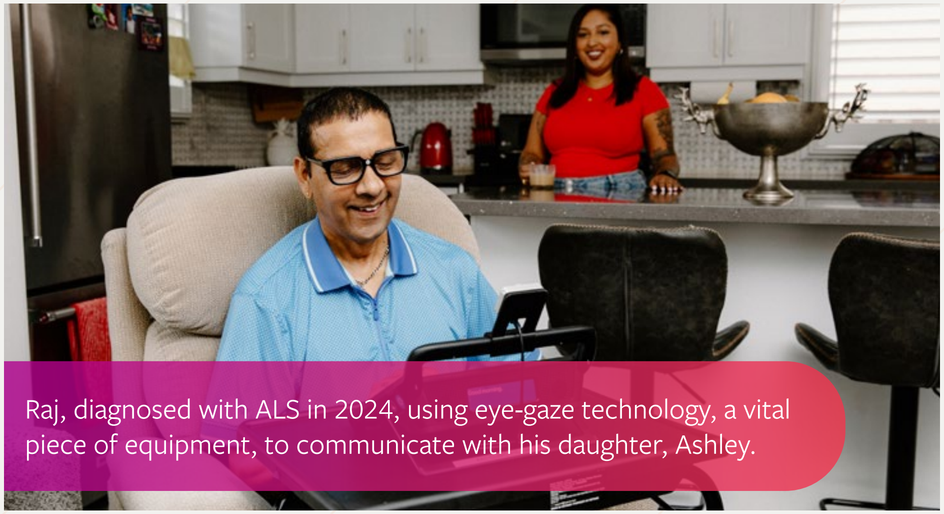
"Living with or caring for a loved one with ALS is a long, hard road, and folks affected by ALS often feel alone. At JBS Foundation, we want to help support those who are undertaking this journey," said Terry Smith, Executive Director of JBS Foundation. "Through our long-term partnership with ALS Canada – built on shared values like accountability, compassion, and collaboration – we have been able to witness the growth and transformation of the services for people with ALS and the impact of investing in services."

Aligned with its commitment to community impact, JBS Foundation has focused on improving access to essential resources. Its investment in the ALS Canada Equipment Program enabled the delivery of critical equipment. It contributed to advocacy efforts that led to the establishment of a government-funded Ontario Provincial ALS Program.

"We are deeply grateful for the sustained commitment of JBS Foundation," said Chris Pon, Vice-President of Fund Development at ALS Canada. "Their investment empowered our organization and the ALS community to advocate for the Ontario Provincial ALS Program, creating lasting access to ALS clinics in Ontario, community services, and equipment that supports safety, independence, and quality of life."

Terry said that he and the JBS Foundation Board have appreciated the opportunities to take active roles in transforming the lives of people with ALS. "Unfortunately, there are no quick fixes. But the longer we invest with ALS Canada, the more we know that we are part of something meaningful and impactful."

> **"Unfortunately, there are no quick fixes. But the longer we invest with ALS Canada, the more we know that we are part of something meaningful and impactful."**
>
> **Terry Smith,**
> Executive Director of JBS Foundation



Raj, diagnosed with ALS in 2024, using eye-gaze technology, a vital piece of equipment, to communicate with his daughter, Ashley.

Progress.
Focused.

STRENGTHENING ACCESS TO CARE AND SUPPORT

Strengthening caregiver mental health

Caring for someone living with ALS can be overwhelming and isolating. With $50,000 from Rexall Care Network, ALS Canada launched a referral program in Ontario, providing 70 caregivers with up to four specialized therapy sessions. Designed to address stress, grief, and complex family dynamics, the program fills a critical gap by offering tailored support beyond group settings and helping caregivers navigate both current and future challenges.

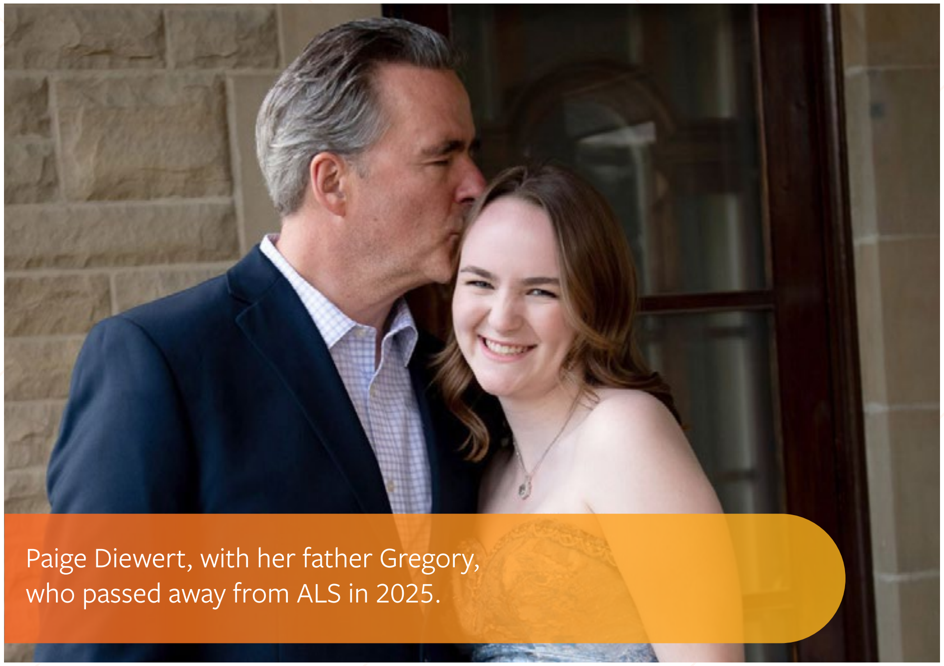
Uniting the global ALS community in the Day in the Life Suite

In December 2025, ALS Canada and the ALS Association co-hosted the International Alliance of ALS/MND Associations Alliance Meeting and Allied Professionals Forum in Toronto, bringing together more than 300 health care professionals from over 30 countries. A highlight was the immersive Day in the Life with ALS Suite, which showcased assistive technologies that enhance accessibility, communication, safety, and independence. The meetings strengthened international partnerships and reinforced a shared commitment to improving quality of life for people living with ALS worldwide.

Kevin Daly's legacy investing in young people's futures

ALS Canada and the Kevin Daly Bursary Fund awarded $2,500 to five students to advance post-secondary studies as part of the ALS Canada Kevin Daly Bursary program. Funded through donations made in honour of Kevin Daly, the bursary celebrates his legacy by investing in young people impacted by ALS. With 12 bursaries awarded to date, totaling $30,000, the program strengthens the ALS community by supporting emerging leaders committed to advancing care, research, advocacy, and a world free of ALS.

> **“Just getting through university is difficult at the best of times, and having a parent with a terminal illness can make it a very isolating experience. I am so grateful to ALS Canada and the Daly family for reminding me that I am not alone in this, and there is a community of people going through similar experiences.”**
>
> **Paige Diewert,**
> recipient of the ALS Canada Kevin Daly Bursary


Paige Diewert, with her father Gregory, who passed away from ALS in 2025.

Enhancing the ALS Canada Equipment Program with provincial investment

With the Ontario government's investment in the Ontario Provincial ALS Program, the ALS Canada Equipment Program improved timely access to equipment recommended by Occupational Therapists. Investments in essential items, including portable, foldable power wheelchairs, have strengthened independence and enhanced quality of life for people living with ALS.

Building foundations for genetic ALS services

In 2025, ALS Canada developed a genetic persona tool to guide the design of community-centred programs and resources for people affected by genetic ALS. Informed by lived experience, the tool reflects the perspectives of individuals, families, and healthcare providers, and guides program planning related to decision making, future considerations, and reproductive planning.

Umayangga Yogalingam, Manager, Knowledge Exchange and Community Information at ALS Canada, participates in the Day in the Life with ALS Suite demonstration at the Allied Health Professionals Forum.

COMMUNITY SERVICES BY THE NUMBERS

Community Leads travelled 90,120 km across Ontario to provide in-person support and resources to people affected by ALS

447 people attended webinars covering **Community Services education sessions** (driving with ALS, voice preservation, organ donation), ALS Research and Clinical Trials 101 Q&A Drop-In, Clinical Trials Unboxed, will and estate planning, and Global ALS Awareness Day

ALS Canada Community Services team hosted **55 education sessions** with **1,650 attendees** in Ontario, primarily long-term care homes, hospices, and Ontario Health atHome organizations

ALS Canada hosted **62 virtual support groups** with **324 attendees**

SUPPORT BY THE NUMBERS

ALS Canada's Community Leads in Ontario supported **1,450 registered clients** in 2025, consistent with 2024. More than **3,000 caregivers** accessed information, care, and resources throughout the year.

3,389 pieces of equipment distributed to people registered with ALS Canada, contributing to **independence and quality of life for people living with ALS**. This is consistent with the previous year.

24%
Walkers, wheelchairs, and scooters

23%
Lift supports, slings, Hoyer lifts, and ceiling tracks

23%
Mattresses and beds

18%
Bathroom equipment

Demographic of clients by age:

17-19 yrs	1%
20-29 yrs	1%
30-39 yrs	2%
40-49 yrs	8%
50-59 yrs	16%
60-69 yrs	31%
70-79 yrs	32%
80-89 yrs	8%
90 plus	1%

- *Age range is 17 years old to 96 years old*
- *1,450 active clients in 2025 and 89 inactive*

Regional Breakdown:

11.7%	South West, Waterloo Wellington
12.5%	Central East and South East
11.2%	Champlain
13.2%	North Simcoe, Muskoka, Central, and Northern Ontario
10.4%	Hamilton, Niagara, Haldimand, and Brant
13%	Toronto
11.7%	Central
16.3%	Mississauga, Halton, and Central West

ADVANCING CANADA’S ALS RESEARCH ECOSYSTEM WITH GLOBAL IMPACT

Community comes together to set national research priorities

In June, the National ALS Research Summit in Toronto brought together 67 stakeholders from across Canada’s ALS ecosystem, including people living with ALS, researchers, clinicians, people affected by ALS, and other ALS organizations. The meeting launched the Canadian Collaboration to Cure ALS, a coordinated strategy to scale CAPTURE (Comprehensive Analysis Platform To Understand, Remedy, and Eliminate) ALS, The Canadian Neuromuscular Disease Registry (CNDR), The Canadian ALS Research Network (CALS), and Access ALS, strengthening Canada’s role in advancing global ALS research.

Building capacity in ALS genetic care

Maya Binet, MSc, was hired as Canada’s first ALS National Genetic Counsellor, based at the University of Calgary. Funded by TD Bank Group, this two-year pilot advances research, education, and national collaboration. Working with ALS Canada, CALS, and international experts, her role strengthens genetic counselling and improves access to trusted genetic information and guidance for individuals and families affected by ALS.

Maya Binet, MSc, Canada’s first ALS National Genetic Counsellor, presenting to ALS Canada’s Community Services team.

Helping families navigate ALS genetics

With Global Neuro YCare, informed by families affected by genetic ALS, and End the Legacy, ALS Canada launched *Talking to Youth about ALS/MND Genetics*, a resource designed to help families have thoughtful, age-appropriate conversations with young people about ALS and genetics, with compassion, clarity, and care.

Sponsoring opportunities for leaders to unite

Through strategic meeting sponsorships, ALS Canada helped to bring clinicians and researchers together at key national and international forums to advance ALS science. Featured events included the International Motor Neuron Society Meeting, Workshop on Phenotype and Biology of ALS Frontotemporal Spectrum Disorders, Gordon Research Conference on ALS and Related Motor Neuron Diseases, and plenary ALS speaker at the Manitoba Neuroscience Network Annual Meeting.

Strategic research investments driving Canadian and Global discovery

Strategic research investments supported national and international collaboration to strengthen data, accelerate discovery, and build research capacity. A total of $606,000 was invested across initiatives, including CAPTURE ALS, CNDR, and new international partnerships with FightMND in Australia and the Packard Center in the U.S., aligning Canadian efforts with global science to advance progress.

Canada’s leadership at international ALS research tables

The priorities of the Canadian ALS community were brought to the global research table, contributing Canadian expertise to international scientific and advisory groups focused on ALS treatments. Through involvement with the GoALS Scientific Review Board, CDMRP ALS Programmatic Review Panel, International ALS/MND Symposium Programme Committee, Biogen Development Network, and more, this work helped shape global partnerships and progress for people living with ALS.

RESEARCH AWARDS

$2,240,000
invested in
ALS research
in 2025

12
research grant awards
to advance ALS
research across
Canada and
globally

10
travel grants awarded
to Canadian ALS
researchers to present
their work at
international ALS
conferences

ALS Canada–Brain Canada Discovery Grants
6 projects funded

Advances ALS research by supporting promising ideas from early discovery through development.
*$750,000 invested, matched by Brain Canada through the Canada Brain Research Fund** (*see page 40*)

2025 ALS Canada Discovery Grant in partnership with the ALS Quebec – Dr. Jean-Pierre Canuel Fund
1 project funded

Supporting research better to understand the causes of ALS, advance treatments, and improve quality of life.
$125,000 invested, matched by the ALS Quebec – Dr. Jean-Pierre Canuel Fund

ALS Canada–Brain Canada Clinical Research Fellowship and Trainee Awards
4 projects funded

Supporting early-career clinicians and researchers advancing expertise and innovation in ALS research.
$257,500 invested, including $37,500 from Fondation Vincent-Bourque, matched by Brain Canada through the Canada Brain Research Fund

The Shionogi Canada Fellowship
1 project funded

Supporting improvements in ALS clinical care and research training.
$50,000 invested

> **“Receiving this award is, above all, a profound mark of trust from the ALS community, one I am proud to honour every day through my work. Together, we are united in the shared goal of ending ALS.”**
>
> **Simon Alvado,**
> PhD student, Université de Montréal, and 2025
> ALS Canada–Brain Canada Trainee Award recipient

FEATURE STORY

FONDATION VINCENT-BOURQUE SURPASSES $500,000 IN DONATIONS, A LEGACY OF HOPE FOR ALS RESEARCH

Vincent Bourque, diagnosed with ALS in 2015, believed the disease was not incurable but understudied. With his wife, Isabelle Lessard, he established a foundation to help support ALS research. Though Vincent died in 2018, his impact has continued. Fondation Vincent-Bourque recently surpassed a significant milestone, donating $500,000 in total contributions to the ALS Canada Research Program.

"Investing in research honours Vincent's legacy and aligns with his optimism and determination," said Isabelle. "It ensures that his story becomes part of the momentum toward breakthroughs, treatments, and ultimately, a cure."

Support from Fondation Vincent-Bourque helped fund seven ALS Canada–Brain Canada Trainee Awards and one ALS Canada Career Transition Award, supporting early-career scientists undertaking innovative projects. Through these awards, Fondation Vincent-Bourque is helping to grow the ALS research ecosystem in Canada, now and in the future.

"The sustained, long-term funding from Fondation Vincent-Bourque has been critical to our support of the best young minds in ALS research," said Dr. David Taylor, Chief Scientific Officer at ALS Canada. "It provides an important confidence in them that we back them and their work as they forge ahead in their career."

Isabelle says the foundation reaching this significant milestone demonstrates the power of people coming together with a shared purpose.

"Every dollar donated to research reflects someone choosing hope over helplessness," she said. "Surpassing this milestone shows that our society believes in research as the path forward and strengthens our commitment to being a meaningful force in accelerating discoveries."

> **Investing in research honours Vincent's legacy and aligns with his optimism and determination."**
>
> **Isabelle Lessard,** Director, Fondation Vincent-Bourque
> Pictured on page 25 with her three daughters,
> Arielle, Charline, and Maria.

FROM DISCOVERY TO ACCESS: QALSODY IN CANADA

Scientific leadership in ALS research

The conditional approval of Qalsody (tofersen) in Canada for adults living with SOD1- ALS marks a milestone built on decades of research, with ALS Canada-supported researchers playing a central role in advancing this discovery.

The landmark identification of the first ALS gene, SOD1, was funded by ALS Canada and driven by Canadian researchers, including Dr. Guy Rouleau. Building on this breakthrough, subsequent work by Canadian scientists such as Dr. Neil Cashman, Dr. Heather Durham, and Dr. Denise Figlewicz advanced understanding of how disease-causing variants in the SOD1 gene drive ALS pathology, while reshaping the fundamental understanding of ALS biology and its genetic aspects. Over the years, additional ALS Canada–funded researchers across the country have continued to deepen insights into SOD1 pathology.

Building on this foundational work by Canadians and others around the globe, researchers, working with Ionis Pharmaceuticals, helped establish antisense oligonucleotide therapies (ASOs) as a potential treatment strategy for SOD1-ALS. After years of collaboration and refinement, Ionis partnered with Biogen to advance clinical trials of the ASO named tofersen, which was finally approved under the trademarked name Qalsody. It represents hope that ALS is treatable and shows that sustained investment in research, supported by ALS Canada donors, can translate discoveries into treatments.

Ensuring access and equity

Following Health Canada's conditional approval of Qalsody in 2025, ALS Canada continues to focus on ensuring timely and equitable access for Canadians living with SOD1-ALS.

We submitted input from nearly 600 ALS community members to Canada's Drug Agency, emphasizing urgency, equity, and shared decision-making. Stakeholder feedback helped remove restrictive language around reimbursement eligibility in the draft recommendation, demonstrating the impact of advocacy from patients, clinicians, and ALS Canada.

ALS Canada is also working to enhance equitable access to genetic counselling and testing, ensuring eligible individuals can benefit from targeted therapies. From regulatory approval to reimbursement and system readiness, ALS Canada works to ensure that research progress leads to real-world access for people living with ALS.

"Our family's journey shows that SOD1-ALS is no longer a death sentence, but a treatable disease. If we act quickly and invest in research with a national strategy, we can turn every ALS diagnosis into a story of hope," Ben Webb (pictured below), 17, said during a reception on Parliament Hill. Having witnessed generations of his family affected by SOD1-ALS, he underscored the urgent need for research investment.

MENU

CANADIAN ALS COMMUNITY RECOGNIZED WITH KING CHARLES III CORONATION MEDAL

ALS Canada was selected to present the King Charles III Coronation Medal, recognizing Canadians who have made outstanding contributions toward a world free of ALS. Across the country, 39 individuals received the Medal, including people living with ALS, volunteers, researchers, clinicians, and advocates. Celebration events across Canada brought together recipients, their families, and communities. Read the list of recipients here.

ADVANCING NATIONAL POLICY FOR ALS

Canadian ALS community's Day on the Hill

Members of the ALS community from six provinces, including people living with ALS, caregivers, researchers, clinicians, advocates, and ALS organizations, gathered on Parliament Hill. A total of 49 participants took part in 22 meetings with 28 government officials to call for $50 million over five years to fund the Canadian Collaboration to Cure ALS. The investment would scale CAPTURE ALS, CNDR, CALS, and Access ALS, strengthening national research, expanding access to clinical trials, and accelerating progress toward new treatments.

"ALS is a relentless disease with rapid progression and devastating outcomes, yet we are still far from a cure. Time is not on our side," said Faye Murphy, an ALS Canada Community Ambassador, diagnosed with ALS in 2024. "Without research, ALS remains a death sentence; with it, we can move toward making ALS a treatable disease. We won't have a voice for much longer, which is why federal investment in ALS research is so urgent."

> "
>
> **Without research, ALS remains a death sentence; with it, we can move toward making ALS a treatable disease.**
>
> **Faye Murphy,**
> ALS Canada Community Ambassador, diagnosed with ALS in 2024

ALS community advocates arrive on Parliament Hill to call for a national investment in ALS research.

Strengthening ALS leadership at the federal level

The All-Party Parliamentary ALS Caucus at the federal level was reinvigorated on Parliament Hill under new cross-party leadership by MP Peter Fragiskatos (London Centre) and MP Marie-Hélène Gaudreau (Laurentides—Labelle), with eight MPs participating in the meetings. Working alongside ALS Canada and informed by the Canadian ALS community, the Caucus is helping keep ALS on the federal agenda, building awareness, and advancing priorities such as the Canadian Collaboration to Cure ALS and coordinated national action.

Ilayda Ulgenalp, ALS Canada Senior Manager, Advocacy & Stakeholder Relations; Dr. Erik Pioro; MP Adam Chambers; Faye Murphy; and her husband, Blake, at the Canadian ALS Community's Federal Advocacy Day on Parliament Hill.

ADVOCACY BY THE NUMBERS

2 pre-budget consultations were held with the **federal** and **Ontario governments**

291 Ontario ALS community members and **460 Canadians nationwide** wrote to **elected officials** to advance **ALS priorities**

6 consultations with **Canada's Drug Agency** and **Health Canada** to **amplify the lived experiences** of **people living with ALS**

55 government officials engaged through **40 federal** and **provincial meetings** to **advance access to therapies, research funding,** and **home and community care**

EXPANDING KNOWLEDGE AND UNDERSTANDING OF ALS

Helping families talk about ALS at every age

The ALS Canada Children and Youth Resource Hub launched to help families navigate an ALS diagnosis. Informed by families and experts, it offers age-appropriate tools, including animated videos, activity sheets for adults to support their conversations with children and youth and their mental health. Funded by the CIBC Foundation, this resource fills a critical gap for young people affected by ALS, with 234 resource downloads and 1,356 video views to date.

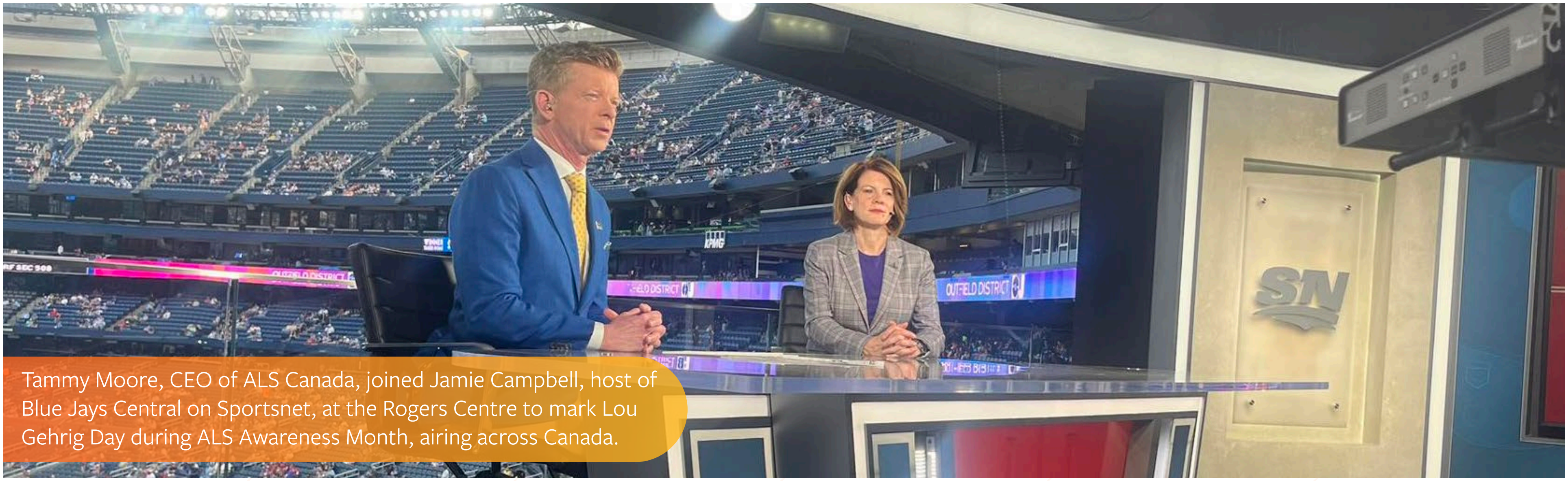
2025 ALS Canada Canadian ALS Learning Institute

The Canadian ALS Learning Institute (CALI) welcomed 19 participants from across Canada, including one from Alberta, four from British Columbia, one from Manitoba, 12 from Ontario, and one from Saskatchewan. Through the program, participants became ALS Canada Community Ambassadors and continue to engage with the organization, strengthening national advocacy and advancing understanding of the research landscape.

Bringing ALS into the spotlight

During ALS Awareness Month in June, ALS Canada was invited by the Jays Care Foundation to a Toronto Blue Jays game at Rogers Centre as part of the team's recognition of Lou Gehrig Day (June 2) and commitment to honouring his legacy. Families were hosted in a suite, ALS awareness videos aired in-stadium, and ALS Canada's CEO, Tammy Moore, participated in an on-air interview during the national broadcast, helping raise awareness across the country.

ALS Canada marked the month with several awareness activities, including a national webinar highlighting all aspects of our work across Canada, and the lighting of community monuments across Ontario, including the CN Tower and Niagara Falls.


Tammy Moore, CEO of ALS Canada, joined Jamie Campbell, host of Blue Jays Central on Sportsnet, at the Rogers Centre to mark Lou Gehrig Day during ALS Awareness Month, airing across Canada.

MENU

KNOWLEDGE EXCHANGE BY THE NUMBERS

2,825 views of **recorded webinars** and **video resources** supported on-demand access to **ALS information** through ALS Canada's YouTube channel

68 original stories and digital content pieces published highlighted the lives of people affected by ALS in Canada and the work being done across the ALS ecosystem

73 community members and staff shared their stories through media interviews, blog posts, social media, and email campaigns

The Jays Care Foundation welcomed members of the ALS community and their families to a Toronto Blue Jays game, hosting them in an accessible box in honour of Lou Gehrig Day.

Chair of the Board, International Alliance of ALS/MND Associations

Tammy Moore, CEO of ALS Canada, assumed the role of Chair of the International Alliance of ALS/MND Associations. As Chair, Tammy provides global leadership rooted in the lived experiences of people living with ALS and caregivers, while strengthening collaboration and impact across the Alliance's international membership.

Leading with IDEA

In 2025, Inclusivity, Diversity, Equity, and Accessibility (IDEA) shaped how we showed up for the ALS community across our programs, research, and engagement efforts. Guided by an internal IDEA working group, we took action to foster belonging and respond to diverse needs. We recognized International Women's Day, Pride Month, National Day for Truth and Reconciliation, World Mental Health Day, and International Day for Persons with Disabilities, while continuing to champion equitable access to care, resources, and research for all people affected by ALS.

Catherine Cummings, CEO of the International Alliance of ALS/MND Associations; Calaneet Balas, CEO and President of The ALS Association and Past Chair of the International Alliance of ALS/MND; and Tammy Moore, CEO of ALS Canada and Chair of the International Alliance of ALS/MND, at the 2025 Alliance Meetings in Toronto.

These goals define ALS Canada's priorities for 2026:

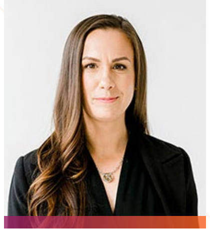
Community Services	ALS Canada's Community Services team will deliver **61 educational sessions**, a **10 per cent year over year increase**, to **strengthen awareness and understanding of ALS** among the community and care partners.
Advocacy	ALS Canada will **meet** with at least **20 federal and provincial government officials** to **advance the priorities of the ALS community**, including through coordinated advocacy days on Parliament Hill and at Queen's Park.
Research	Through **partnerships, committees,** and **knowledge leadership, ALS Canada** will **influence the direction** of more than **$100M towards ALS research** in 2026.
Knowledge Exchange and Awareness	To expand **access to information and resources for all Canadians, ALS Canada** will **increase virtual programming by 20 per cent** over the previous year. We will also continue to **build awareness of the disease across all mission areas by sharing 10 per cent more original media content** on als.ca.

Community.
Focused.

ALS CANADA LEADERSHIP

ALS Canada's Board of Directors provides strategic oversight to ensure the organization remains accountable, resilient, and positioned for long-term impact. Drawing on diverse professional expertise, including the perspectives of people living with ALS who serve on the Board and across ALS Canada's governance structures, the Board helps guide decisions that strengthen care today and advance research and advocacy for tomorrow.

ALS CANADA
BOARD OF DIRECTORS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Past Chair


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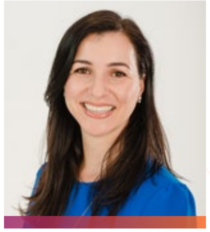
Elizabeth Gandolfi


Dr. Angela Genge


Harry Joosten


Kris Noakes


Sharon Ranalli


Rob Reading


Jason Ritchie


Matthew Rotenberg


Dr. Chantelle F. Sephton


Dr. Christen Shoesmith

ADVISORY COUNCILS AND COMMITTEES

The **Scientific and Medical Advisory Council** guides ALS Canada's research to ensure it aligns with strategic priorities and is conducted with integrity. Comprised of researchers, clinicians, and community members living with or affected by ALS, the Council brings diverse expertise and lived experience to inform our work today and advance progress for the future.

Chantelle Sephton, PhD, Co-chair
David Taylor (staff), PhD, Co-chair, ex officio
Gary Armstrong, PhD
Alyssa Barry – Chair, ALS Canada Board, ex officio
Ari Breiner, MD
Vanina Dal Bello-Haas, PhD, PT
Colleen Doyle (staff), ex officio
Martin Duennwald, PhD
Wendy Johnston, MD
Carolina Jung (staff), ex officio
Tammy Moore (staff), ex officio
Cali Orsulak, BScPharm, BCPS, CDE
Gerald Pfeffer, MD, PhD
Richard Robitaille, PhD
Guy Rouleau, MD, PhD
Michael Spivock, PhD
Paula Trefiak
Christine Vande Velde, PhD

The **Community Services Advisory Council** draws on lived and professional experience to guide our programs and strengthen support for Ontarians affected by ALS.

Matthew Rotenberg, Co-chair
Kim Barry (staff), Co-chair
Vanina Dal Bello-Haas
Andrew Dundas
Lisa Flaifel
Laura Henstock
Dr. Hayley King
Brianna Marbach
Denise Martins
Matthew McNeil – passed away in October 2025
Tammy Moore (staff)
Jennifer Myers
Steve Parker
Paula Rodriguez
Lisa Shepherd
Liza Zanyk

Established in 2020, the **Advocacy Committee** brings professional and lived experience to help advance our federal and Ontario advocacy priorities.

Richard Ellis, Co-chair
Ilayda Ulgenalp (staff), Co-chair
Alyssa Barry – Chair, ALS Canada Board
Steffi Burgi (staff)
Lisa Flaifel
Alan Kagedan – passed away in July 2025
Barbara Kagedan
Tammy Moore (staff)
Kris Noakes
Sharon Ranalli
Jason Ritchie
Marc Roy
Karin Schnarr, PhD, MBA

THANK YOU TO OUR 2025 DONORS

Our impact is made possible by the generosity of our donors and fundraisers. We are grateful to the thousands of individuals, corporate partners, and foundations who supported ALS Canada in 2025 through community events, monthly and annual gifts, planned giving, and in-kind contributions.

Your support strengthens care and services for people affected by ALS, advances research, and sustains advocacy efforts that move us closer to a world free of ALS.

We also thank the ALS Society of Manitoba, ALS Society of Newfoundland and Labrador, ALS Society of Prince Edward Island, and ALS Society of Quebec for their partnership and continued collaboration.

The following list recognizes individuals, foundations, and companies that donated $2,500 or more in 2025 and consented to be acknowledged. Every effort has been made to ensure accuracy.

If you have any questions or corrections, please do not hesitate to contact us at donations@als.ca.

> **“I give monthly to ALS Canada because behind every diagnosis is a person, a family, and a future worth fighting for. It’s my way of standing beside individuals and families affected by ALS every step of the journey, offering hope, compassion, and support when it’s needed most.”**
>
> **Sonila Elezi,**
> monthly donor and Director of Human Resources
> and Volunteer Services at ALS Canada

MENU

Individuals

Alison Mackay
Andrea Baxendale
Arthur Ito
Barbara McIlmoyl
Barry Zimmermann
Brenda Gelowitz
Brennen Chow
Brian Kerr
Brian T. Lahey
Cameron A. McCormick
Cameron and the late Nancy Wood
Carla Wielgoz
Carole Campeau
Christine D. Ritsma
Christine Kincaid
Claire Allen
Colleen O'Connell Campbell
Craig Miller
Cynthia Mannion
Damji Family
Dan Dumond
Dan Wilder
David G. and Priscilla Weir
David Cayley
David Robertson
Deirdre O'Connor
Diana and Louis Provenzano
Donna Rutherford
Ellen L. Singleton
Emily Barbara Bolton
Faye Murphy
Frank Fortino
Frank Lama
Fred Birnbaum
Gale W. Robertson
Garth W. Birney
Gary Envik
Gavin E. Dirom
George and Madeleine Betts
Gerald G. Wyant
Gino Bellisario
Gurpreet Sohi
Harry L. Zheng
Hazen and Janis Gilks
Heidi Attenborough
Hélène and Bernard Marcil
Hugh G. Fraser
Iain McOustra
Ilana Hosios
James R. Pearson
Jamie L. Wiggins
Jamie Levey
Jane McDonell
Janet Jucu
Janet Pounder
Jeff Blake
Jill Fritsch
Joan Yerex
John and Alma Sullivan
John P. Embry
John Saunders
Karen Archer
Kathy Fraser
Katie and Tayler Henderson
Kelly Anderson
Kenneth and Shelia McArthur
Kevin Stucken
Kim McGlade
Kimberly A. Lamb
Kiran Sembhi
Larry Reid
Lee Payne
Lee Williams
Leon Gosselin
Leslie J. Green
Leslie Raenden
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Tim M. Gilchrist
Tina Mola
Verla Talnariu
Vince Dicosimo and Family
Walter Muilwyk
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Wesley B. Lamb
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The Clara Quinn Cup for ALS
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United Way Calgary and Area
United Way Niagara
Yorkville Run

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Cowan Foundation
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Sue Martin & Donald Paul Bush Charitable Foundation
The Andrew Beckerman Fund at the Victoria Foundation
The Catherine and Maxwell Meighen Foundation
The Cohen Kay Family Foundation
The Colwell Ellis Charitable Foundation
The Garron Foundation
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The Hawkey Family Foundation
The Michael J. Beal Fund
The Mifflin Family Foundation
The Patterson Family Fund
The Pottruff Family Foundation
The Read Family Foundation
The Salden Foundation
The W. Muilwyk Fund
Townsend Family Foundation

Estates

Estate of Earl David Johnson
Estate of Fern Rutherford
Estate of Florence Ann Murphy
Estate of Gloria M. Collins
Estate of Irina Ciolan
Estate of Irma Patricia McLeod
Estate of John David Isbister
Estate of John Kuryk
Estate of Kathleen Isadora McFarlane
Estate of Leona Head
Estate of Margaret Alison Beattie
Estate of Marlene Waechter
Estate of Mary E. Gilpin
Estate of Michael Phillip Mutter
Estate of Peter Cornelis Dalm
Kate Mackay Memorial Fund

2025 ALS CANADA RESEARCH PROGRAM AWARDS

The ALS Canada Research Program remains the only national, dedicated source of funding for ALS research in Canada. Through strategic investment in the most promising Canadian research, we support discoveries that improve clinical care today and accelerate the development of effective treatments for tomorrow. This work is made possible by the generosity of donors and participating provincial ALS Societies across Canada, who contribute 40 per cent of Walk to End ALS proceeds, along with additional funding raised through community events, partnerships, and individual giving throughout the year.

Projects supported through the 2025 competitions were selected through a rigorous peer-review process. Applications were evaluated and ranked based on scientific excellence, innovation, and their potential to meaningfully advance ALS research.

All 2025 competitions were awarded in partnership with Brain Canada through the Canada Brain Research Fund*, with the exception of the 2025 ALS Canada Discovery Grant in partnership with the ALS Quebec – Dr. Jean-Pierre Canuel Fund, and The Shionogi Canada Fellowship.

Fondation Brain Canada Foundation

* The CBRF is an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada Foundation, which increases Canadians' support for brain research and expands the philanthropic space for funding brain research to achieve maximum impact.

ALS Canada-Brain Canada Clinical Research Fellowship

TDP-43, SOD1, and FUS proteinopathies in vivo: interrogating prion-like mechanisms and drug rescue in zebrafish and ALS hiPSC-derived neuron xenotransplant models

Dr. Michele DuVal, University of Alberta, $200,000

The Shionogi Canada Fellowship (previously Tanabe Pharma Canada)

Innovative multimodal 7T MR imaging to assess cortical excitability and disease subtypes in ALS

Dr. Pedro Saldanha de Castro, Sunnybrook Research Institute, $100,000

SHIONOGI

Funding for the project was made possible by Shionogi Canada Inc.

ALS Canada Discovery Grant in partnership with the ALS Quebec – Dr. Jean-Pierre Canuel Fund

Mapping alternative polyadenylation and splicing in ALS via single-nucleus long-read transcriptomics

Dr. Janice Robertson, University of Toronto, in collaboration with Dr. Shreejoy Tripathy, $125,000

SLA QUÉBEC ALS

Funding for the project was made possible by the ALS Quebec – Dr. Jean-Pierre Canuel Fund.

ALS CANADA-BRAIN CANADA TRAINEE AWARDS

Doctoral Awards

Study of perisynaptic Schwann cells contribution on NMJ reinnervation efficiency in ALS
Simon Alvado, Université de Montréal, $75,000

Examining the role of TDP-43 SUMOylation following ALS-relevant stress
Veronica Grybas, University of Ottawa, $75,000**

Postdoctoral Fellowship

Feasibility RCT of a digital tool for management of bulbar disease in ALS
Dr. Jennifer Soriano, University of Toronto, $165,000

ALS CANADA-BRAIN CANADA DISCOVERY GRANTS

Seed Grants

Mechanisms of intracellular mRNA trafficking in ALS
Dr. Loic Binan, Lady Davis Institute-Jewish General Hospital, in collaboration with Dr. Sali Farhan, $125,000

Multimodal whole-body muscle MRI in ALS, including artificial intelligence (AI)-assisted image processing: Biomarker of lower motor neuron dysfunction
Dr. Ari Breiner and Dr. Jodi Warman-Chardon, Ottawa Hospital Research Institute, in collaboration with Dr. Gerd Melkus, $125,000

Multimodal MRI-derived biomarkers for ALS: insights from large-scale data
Dr. Sanjay Kalra, University of Alberta, in collaboration with Dr. Fabrizio Pizzagalli, $125,000

Developing pathology specific imaging biomarkers in ALS: integrating postmortem neuropathology and multimodal ex-vivo MRI
Dr. Yashar Zeighami, McGill University, in collaboration with Dr. Mahsa Dadar and Dr. Yasser Iturria Medina, $125,000

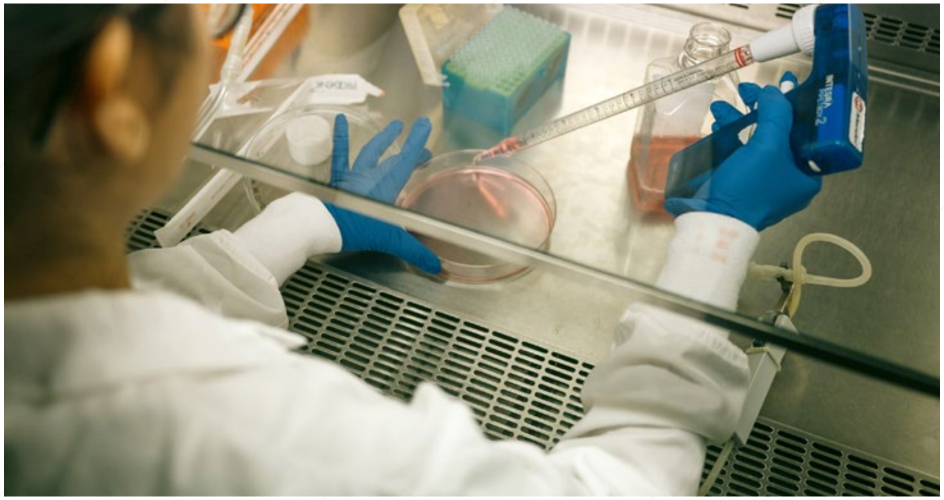
Development Grants

Development of a novel therapy for Amyotrophic Lateral Sclerosis (ALS)
Dr. Jiming Kong, University of Manitoba, in collaboration with Dr. Geoff Tranmer, $500,000

Development of a lead importin-β1 modulator for therapeutic rescue of TDP-43 pathology in ALS
Dr. Janice Robertson, at the University of Toronto, in collaboration with Dr. Joel Watts, $500,000

FONDATION
VINCENT BOURQUE

**Funding for Veronica Grybas' Doctoral Award was made possible through a partnership with Fondation Vincent-Bourque, who generously contributed $37,500 to ALS Canada, which Brain Canada matched through CBRF.



APPENDIX

2024 And 2023 Financial Summaries

As part of our commitment to transparency and accountability, ALS Canada has included our financial information from the previous two years, offering a clear view of how donor contributions are invested to drive impact through community services, research, awareness, knowledge exchange, and advocacy.

The audited financial statements of ALS Canada are available on our website.

2024 REVENUE

🟪	Fundraising Donations and Other Income	$9,779,004*	95.5%
🟥	Investment Income	$457,809	4.5%
	Total	$10,236,813	(100%)

* Participating provincial ALS Societies contribution to the ALS Canada Research Program through 40% of net proceeds of Walk to End ALS events:

- ALS Society of Manitoba $35,899
- ALS Society of Newfoundland & Labrador $23,294
- ALS Society of Prince Edward Island $23,896
- ALS Society of Quebec $105,239

2024 EXPENSES

🟪	Community Services	$3,143,298	30.7%
🟥	Fundraising	$2,627,694	25.6%
🟧	National Research*	$2,619,619	25.6%
🟨	Public Awareness	$485,962	4.7%
🟪	Advocacy	$460,895	4.5%
🟥	Other Charitable Purpose	$394,122	3.8%
🟪	Governance	$281,613	2.7%
🟪	Administration	$237,388	2.3%
	Total	$10,250,591	(100%)

* When including matching grant funding of $1,107,000 from Brain Canada, the total research investment is $3,726,619.

2023 REVENUE

🟪	Fundraising Donations and Other Income	$8,875,547	95.1%
🟥	Investment Income	$457,975	4.9%
	Total	$9,333,522	100.00%

* Participating provincial ALS Societies mainly contribute to the ALS Canada Research Program through 40% of net proceeds of Walk to End ALS events, as follows:

- ALS Society of Manitoba $38,590
- ALS Society of Newfoundland & Labrador $21,597
- ALS Society of Prince Edward Island $27,448
- ALS Society of Quebec $90,005

The ALS Society of Quebec provided an additional $175,000 in support of the ALS Canada Research Program, which included $75,000 on behalf of the Dr. Jean-Pierre Canuel Fund at the ALS Society of Quebec.

2023 EXPENSES

🟪	Community Services	$2,971,167	31.6%
🟥	Fundraising	$2,675,641	28.4%
🟧	National Research*	$2,176,689	23.1%
🟪	Advocacy	$454,796	4.8%
🟨	Public Awareness	$355,558	3.8%
🟪	Governance	$252,198	2.7%
🟥	Other Charitable Purpose	$270,150	2.9%
🟪	Administration	$252,179	2.7%
	Total	$9,408,378	100%

* When including matching grant funding of $1,051,500 from Brain Canada, the total research investment is $3,228,189.

About ALS and the ALS Society of Canada

Amyotrophic lateral sclerosis (ALS) is an unrelenting and currently terminal disease. It progressively paralyzes people because the brain is no longer able to communicate with the muscles of the body that we are typically able to move at will. Over time, as the muscles of the body break down, someone living with ALS will lose the 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. Four out of five people living with ALS will die within two to five years of their diagnosis.

The ALS Society of Canada is working to change what it means to live with ALS. Grounded in and informed by the Canadian ALS community, we respond to the urgent unmet need for life-changing treatments by investing in high-quality research that will fuel scientific discovery and by engaging industry, supporting increased clinical capacity, and advocating for equitable, affordable, and timely access to proven therapies.

Responding to the tremendous need for current and credible ALS knowledge, awareness, and education, we empower Canadians affected by ALS to navigate the current realities of ALS, be informed consumers of ALS information, and advocate effectively for change. In Ontario, we provide direct community services to help people navigate ALS.

Founded in 1977, ALS Canada is a registered charity whose work is powered by generous donors who share our vision of a world free of ALS.

ALS Society of Canada
180 Bloor Street West, Suite 500
Toronto, ON M5S 2V6
als.ca

Cover Image:
Shaleen Latchman, diagnosed with ALS in 2022, with her mother.

Accredited
IMAGINE CANADA

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