

MAKING EACH DAY POSSIBLE

Annual Report

A Year of Impact: Advancing hope, care and possibility for Albertans affected by ALS

2025

ANNUAL REPORT
alsab.ca

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OUR GUIDING PRINCIPLES

Mission, Vision & Values

Mission

Our mission is to make each day the best possible day for those living with and affected by ALS. We achieve our mission by providing support, facilitating the provision of care, promoting awareness, helping find a cure, and advocating for change.

Vision

A world where no one faces ALS alone; where every person has access to care, support, and hope.

Values

Caring — We demonstrate compassion by listening and providing responsive and practical support.

Accountability — We are responsible for our decisions and actions on behalf of the Society.

Service — We serve the needs of people affected by ALS in a fair and equitable manner.

Passion — We communicate our enthusiasm to encourage others to share in our vision.

Quality of Life — We strive to make each day the best possible day.

Respect — We respect the rights, responsibilities, and uniqueness of all people we work with.



GOVERNANCE

Board of Directors

"Strong governance, strategic leadership, and a shared commitment to our mission continue to guide the ALS Society of Alberta forward."

Working closely with the Executive Director, the Board provides strategic direction, oversees organizational governance and financial stewardship, supports risk management, and helps guide long-term planning. Together, they ensure the Society is well-positioned to meet the evolving needs of Alberta's ALS community while responsibly stewarding the generosity of donors, volunteers, sponsors, and partners.

Through their diverse expertise and shared commitment to our mission, the Board helps strengthen the foundation that allows the ALS Society of Alberta to deliver meaningful impact today while building for the future.



Nancy Lyzaniwski
Board Chair



Andrea Orzech
Treasurer



Nick Poirier
Secretary



Gord Banting
Director



Tom Gee
Director



Willy Grant
Director



Lynn Headley
Director



Kimberly Howard
Director



Pamela Keenan
Director



Terri Kezema
Director



Leslie Ring Adams
Executive Director



Scott Vuylsteke
Director

MESSAGE FROM THE BOARD CHAIR

Building a Stronger Future, Together



As I reflect on 2025, I am filled with gratitude for the extraordinary community that makes the work of the ALS Society of Alberta possible. Every day, I am inspired by the courage and resilience of the Albertans living with and affected by ALS, and by the generosity of the volunteers, donors, sponsors, researchers, healthcare professionals, and staff who stand beside them and our organization.

As a Board, we remain committed to providing strong governance, responsible stewardship, and strategic leadership to ensure the ALS Society of Alberta continues to meet the evolving needs of Alberta's ALS community. Together with Executive Director Leslie Ring Adams and the dedicated staff team, we have focused on strengthening the organization while remaining grounded in our mission of making each day the best possible day for people living with and affected by ALS.

This year marked meaningful progress in advancing ALS research in Alberta. Building on the announcement of the Alberta ALS Research Network (AARN) in 2024, its Steering Committee was established and its Project Manager was hired in 2025. These important milestones laid the foundation for a collaborative provincial research network that will bring together researchers, clinicians, and people with lived experience to accelerate discoveries and improve outcomes for Albertans living with ALS.

At the same time, we made significant investments into the future of the ALS Society of Alberta. Throughout the year, staff, volunteers, and community leaders worked collaboratively to prepare for the 2026 launch of Side by Side for ALS, uniting Alberta's signature ALS fundraising events under one provincial movement while honouring the legacy and local identity of each community event. The team also completed the redevelopment of the Society's website, creating a more accessible, user-friendly digital experience that would launch in early 2026. While much of this work took place behind the scenes, these initiatives strengthen our ability to serve clients, engage supporters, and build awareness for years to come.

Of course, none of this progress would be possible without the unwavering support of our community. Whether you participated in an event, made a donation, volunteered your time, shared your story, or partnered with us in advancing research and care, your contributions have made a meaningful difference in the lives of Albertans living with and affected by ALS.

On behalf of the Board of Directors, thank you for your trust, your generosity, and your belief in our mission. Together, we are building a stronger future for Alberta's ALS community while creating hope for the generations to come.

With gratitude,

Nancy Lyzaniwski
Board Chair, ALS Society of Alberta

MESSAGE FROM THE EXECUTIVE DIRECTOR

Families Need Support Today



One of the greatest privileges of my role is seeing firsthand the resilience of people living with ALS and the compassion of those who support them. Every day our team has the opportunity to walk alongside Albertans during one of the most difficult times in their lives, and that responsibility shapes every decision we make.

In 2025, we remained focused on what matters most: ensuring individuals and families affected by ALS received compassionate support, timely access to equipment, trusted resources, and meaningful connections throughout every stage of their journey. Behind every statistic in this report is a person whose life has been touched by the generosity of our community, whether through equipment that restored independence, a support group that eased isolation, or a conversation that reminded someone they were not alone.

One of our greatest priorities in 2025 was continuing to strengthen the support available to people living with ALS and those who care for them. We expanded opportunities for connection, education, and practical support by growing our client services and creating more ways for individuals and families to engage with one another. Through programs like Compass for the ALS Caregiver, caregivers gained access to guidance, resources, and a supportive community to help them navigate the challenges of their role. We also increased opportunities for clients and caregivers to come together through support groups, educational sessions, and community events, helping reduce isolation and foster meaningful connections. These investments reflect our commitment to ensuring every person affected by ALS has access to compassionate support, trusted information, and a community that understands their journey.

I continue to be inspired by our staff, who approach every conversation with empathy and professionalism. Whether delivering equipment across the province, supporting caregivers through difficult decisions, organizing community events, or ensuring the organization remains financially strong, they consistently put our clients first. While our daily focus remains on serving families, we also continued to strengthen the organization for the future through investments in research, digital services, and our provincial fundraising strategy. Demand for our services continues to grow, reminding us that while progress is being made in research, families need support today. We remain committed to ensuring no Albertan faces ALS alone.

As we move into 2026, we will continue to strengthen our programs, invest in research partnerships, support caregivers, and build the relationships that make this work possible. I am excited about what lies ahead and grateful to everyone who is part of this community.

With appreciation,

Leslie Ring Adams
Executive Director, ALS Society of Alberta

The Year in Numbers

469

Clients supported

5,352

Pieces of equipment provided

6,390

Client touchpoints made

97

Support groups held

11

Educational presentations hosted

10

Walk and Runs for ALS

30

Community fundraisers organized

100%

Of requests for support fulfilled

“Every number represents a life touched, a family supported, and a community strengthened.”

PROGRAMS & CLIENT SERVICES

Supporting Albertans affected by ALS

An ALS diagnosis changes lives in an instant, bringing new challenges, difficult decisions, and uncertainty for individuals and their loved ones. At the ALS Society of Alberta, we are committed to ensuring no one faces that journey alone.

From the moment of diagnosis, our team provides compassionate support, practical resources, and personalized guidance tailored to each individual's evolving needs. Whether connecting families with equipment, offering emotional support through peer groups, providing educational resources, or helping young people continue the activities they love, our programs are designed to make each day the best possible day for people living with and affected by ALS.

Client Services

The Client Services team is often the first point of contact following an ALS diagnosis, providing compassionate guidance and practical support from day one. As the demand for ALS services continues to grow across Alberta, our team remains alongside clients and their families, connecting them with resources, navigating available services, and helping them access the care and equipment they need.

Through one-on-one support, clinic visits, educational presentations, and ongoing communication, we strive to ensure every Albertan living with ALS has access to timely, personalized support throughout every stage of their journey.

Support Groups

Living with ALS can feel isolating, but no one should have to face the journey alone. Our support groups create welcoming spaces where clients, caregivers, and those who have experienced the loss of a loved one can connect with others who understand their experiences. Offered in both virtual and in-person formats, these groups provide opportunities to share knowledge, find encouragement, build meaningful relationships, and receive emotional support throughout every stage of the ALS journey.



"I can't express how grateful I am for the support we received from the ALS Society of Alberta. The number of times that we needed to reach out was unfathomable. I don't know how we would have gotten through this period of time without their support. The rapid decline was so challenging. The ALS Society of Alberta was there for us every step of the way, regularly delivering the next piece of equipment that we needed."

- Caregiver client

INDEPENDENCE, DELIVERED

The Equipment Loan Program

The Equipment Loan Program is one of the ALS Society of Alberta's most vital services, providing essential equipment at no cost to Albertans living with ALS. As needs change throughout the progression of the disease, timely access to specialized equipment helps individuals maintain their independence, comfort, and safety while reducing the physical and financial burden on families.

"The ALS Society was there at every turn to provide the equipment I needed. Whether it was my walker, wheelchair, lift, or communication device, every piece of equipment helped me maintain my independence and quality of life."

- Client

Made possible through the generosity of our donors and supporters, the program ensures clients receive the right equipment at the right time, wherever they live in Alberta. Recognizing that the needs of people living with ALS can change rapidly, our team is committed to responding quickly, often arranging equipment delivery within days of a request, so clients receive the support they need without unnecessary delays.

Mobility

From walkers and wheelchairs to transfer equipment and patient lifts, mobility equipment helps clients remain active, safe, and engaged in daily life while supporting caregivers with safe transfers and mobility assistance.

Communication

Communication technology, including eye-gaze systems, tablets, and other assistive devices, helps clients stay connected with loved ones, participate in conversations, and continue expressing themselves as communication becomes more challenging.

Daily Living

Adaptive equipment such as hospital beds, bathroom safety equipment, lift chairs, and specialized eating aids helps clients maintain comfort, dignity, and independence throughout every stage of their ALS journey.

Caregivers

Equipment also supports caregivers by making transfers safer, reducing physical strain, and helping families keep loved ones at home longer.



YOUTH & FAMILY SUPPORT

Debi Lefaiivre ALS Youth Champions Fund

\$16,174

Dollars awarded

27

Applications supported

The Debi Lefaiivre ALS Youth Champions Fund helps ensure that children and youth affected by ALS can continue participating in the activities they love. Whether it's sports, music, arts, camps, or other extracurricular programs, the fund helps ease the financial pressures many families face following an ALS diagnosis.

By supporting opportunities for connection, growth, and normalcy, the fund allows young people to continue learning, playing, and thriving while navigating the challenges of having a parent or guardian living with ALS.

About Debi



Debra Lefaiivre, affectionately known as Debi, was a beacon of love and strength whose compassion and dedication left a lasting impact on all who knew her. After losing her parents at a young age, Debi embraced the role of family matriarch, offering unwavering support and affection to her 10 siblings and their families. Her empathy and commitment to others extended throughout her remarkable 45-year career at Vecova, where she tirelessly championed the rights and dignity of individuals with disabilities, embodying values of inclusivity and service.

Debi's dedication to making a difference continued through her work with numerous organizations, including the ALS Society of Alberta, where she formed deep connections and generously helped others in Alberta navigate their ALS journeys.

"We are truly grateful to the Debi Lefaiivre ALS Youth Champions Fund for their generous support during a very difficult time in our lives. Our daughter just completed her first season of gymnastics — something she's dreamed of doing — and this was only made possible through the help of this incredible fund. "

- Client

POWERED BY PEOPLE

Celebrating Our Volunteers

The ALS Society of Alberta is powered by an extraordinary community of volunteers whose dedication, compassion, and generosity make our work possible. From our Board of Directors and event committees to support group facilitators, fundraisers, and countless individuals who generously give their time throughout the year, our volunteers play an essential role in supporting Albertans living with and affected by ALS.

Their leadership, expertise, and unwavering commitment strengthen our organization, expand our reach, and help ensure that every dollar raised and every hour volunteered has a meaningful impact. We extend our heartfelt thanks to each volunteer for standing beside Alberta's ALS community and helping make each day the best possible day.

"Volunteering with the ALS Society has given me a sense of purpose I never expected. Knowing I can make even a small difference in someone's life is incredibly meaningful."



The Alberta ALS Research Network (AARN)

Established in 2024, the Alberta ALS Research Network (AARN) entered an exciting new phase in 2025. With the formation of a multidisciplinary Steering Committee and the hiring of AARN's first dedicated Project Manager, the network strengthened its leadership and governance while beginning to deliver on its mission of advancing ALS research in Alberta.



“AARN is strengthening connections between researchers, clinicians and the ALS community across Alberta, creating new opportunities for collaboration and discovery. By supporting emerging researchers and innovative programs like CAPTURE ALS, we are building momentum toward better treatments and a future without ALS.”

- Dr. Gord Jewett

From Foundation to Action

Throughout the year, AARN announced its first funding opportunities, invested in the next generation of ALS researchers, and welcomed members to its first Research Network Member Meeting, creating new opportunities for collaboration and knowledge sharing across the province.

AARN Research Trainee Awards

In partnership with Mitacs, AARN announced its first-ever Research Trainee Awards, investing in undergraduate, graduate, doctoral, and postdoctoral researchers pursuing ALS research in Alberta. Through Mitacs' Accelerate program, AARN's investment is matched, allowing the network to support more emerging researchers while maximizing every research dollar. The awards help attract and retain talented researchers in Alberta and foster the next generation of ALS research leaders from the University of Calgary and Alberta.

AARN Fund Matching Awards

AARN also launched its first Fund Matching Awards, helping Alberta researchers compete for larger national funding opportunities. By providing matching contributions for major grant applications, AARN enables researchers to leverage a significantly greater research investment from organizations such as Brain Canada. This approach helps bring additional funding into Alberta while strengthening the province's capacity for innovative ALS research.

Why It Matters

Research breakthroughs don't happen in isolation. By investing in students, supporting researchers seeking larger grants, and strengthening collaboration across Alberta, AARN is creating the conditions for new discoveries that will benefit people living with ALS for years to come.

RAISING OUR VOICE

Advocacy in Action

Advocacy is an essential part of creating meaningful change for people living with ALS. Throughout 2025, the ALS Society of Alberta worked alongside researchers, clinicians, caregivers and people with lived experience to advance ALS research and promote equitable access to care and support.

Advocating for the Future: ALS Research

In October 2025, representatives from the ALS Society of Alberta joined researchers, clinicians, people living with ALS, caregivers, and ALS organizations from across the country on Parliament Hill for the Canadian Collaboration to End ALS.

The national delegation called on the federal government to invest \$50 million over five years in Canada's ALS research infrastructure, supporting initiatives that will expand clinical trials, strengthen research networks, and accelerate the development of new treatments. Alberta's leadership through initiatives such as AARN, CAPTURE ALS, and the Canadian Neuromuscular Disease Registry continues to play an important role in this national movement.



ALS Action Canada

ALS Action Canada is a national, patient-led nonprofit advocating for the urgent needs of people living with ALS. Through education, collaboration, and advocacy, they push for faster drug approvals, improved access to treatments, and a coordinated national ALS strategy to ensure no one facing ALS is left behind.



Grace Westbury, Leslie Ring Adams,
Dr. Gerald Pfeffer, Nancy Lyzaniwski,
Glenn Love, Dr. Gordon Jewett

"Collaboration in the ALS community is essential to providing care to patients, loved ones, as well as driving system change. We are proud to be a partner of the ALS Society of Alberta, and to support the vital programs, services, advocacy and research it delivers. I had the opportunity to spend time with the team, patients, families and volunteers at our Courage to Fight ALS night in Edmonton. I was blown away by the kindness and commitment of the Alberta community. Thank you for all you do for ALS." - Leigh Naturkach, ALS Action Canada

Standing up for Equitable Access

The ALS Society of Alberta also advocated for equitable access to COVID-19 vaccinations for people living with ALS following changes to Alberta's immunization program. Recognizing that many individuals living with ALS are medically vulnerable, we called for clear eligibility criteria and accessible vaccination options to ensure those who wished to receive the vaccine could do so without unnecessary barriers. By working with government officials and raising awareness of these concerns, we continued our commitment to advocating for the health and well-being of Alberta's ALS community.

FUNDRAISING

COMMUNITIES SHOWING UP FOR ALS

From walks and runs to grassroots events, Albertans showed the power of community.

STRENGTH IN NUMBERS

Communities Coming Together for ALS

Across Alberta, communities once again demonstrated the extraordinary power of generosity, compassion, and connection. Whether participating in a signature event, organizing a local fundraiser, or making a personal gift, thousands of Albertans came together to support people living with and affected by ALS.

Every dollar raised helps provide essential equipment, client services, support programs, advocacy, and research, ensuring Albertans affected by ALS receive the support they need while helping advance the search for better treatments and, ultimately, a cure.

Betty's Run for ALS & Walk Together for ALS

In 2025, the ALS Society of Alberta proudly hosted Betty's Run for ALS in Calgary and Walk Together for ALS events in communities across the province. These signature fundraising events brought together participants, volunteers, sponsors, and supporters to honour loved ones, celebrate resilience, and stand alongside those living with ALS.

Together, these events showcased the strength of Alberta's ALS community while raising critical funds to support programs, services, equipment, and research. Throughout the year, planning committees, volunteers, and stakeholders also worked closely with Society staff to prepare for the evolution of these events into Side by Side for ALS, to be officially launched in 2026. This work honoured the legacy of Betty's Run for ALS and Walk Together for ALS while laying the foundation for a unified provincial movement.

\$629,166

Raised through Walk for ALS

\$548,795

Raised through Betty's Run for ALS



GRASSROOTS GENEROSITY

Community-Led Fundraisers

The generosity of Albertans extends far beyond our signature events. Throughout the year, individuals, families, schools, businesses, and community organizations organized their own fundraising initiatives in support of the ALS Society of Alberta.

From golf tournaments and cycling events to brewery partnerships, community celebrations, birthday fundraisers, and creative grassroots initiatives, these events reflected the passion and dedication of people determined to make a difference for Alberta's ALS community.

Each fundraiser tells a story of connection, remembrance, hope, and generosity. Together, these community-led efforts help ensure Albertans living with and affected by ALS continue to receive the support they need.

\$360,983

Raised through Community Fundraisers



Quonset Days



Cycle for ALS



Howard Smith Memorial Team Roping



Dan's Night to Fight

STRENGTHENING OUR REACH

Education & Public Awareness

Education plays a vital role in building understanding and ensuring Albertans have access to reliable information about ALS. Throughout the year, the Society delivered educational presentations, shared resources with healthcare professionals and community organizations, and provided trusted information through our website, publications, and outreach activities.

These efforts help individuals and families navigate an ALS diagnosis while strengthening awareness of the disease across Alberta.

An Evening of Storytelling and Strength



As part of our commitment to fostering understanding and connection, the ALS Society of Alberta welcomed supporters to An Evening of Storytelling and Strength at cSPACE Marda Loop. The event featured an intimate conversation with Kelsie Snow, who shared her family's experience navigating ALS alongside her husband, Chris.

"Joan Didion famously wrote that, “We tell ourselves stories in order to live.” I think we tell other people our stories in order to connect, to feel seen and heard and to reach out across the void to let other people know they aren’t alone.

- Kelsie Snow

Through Kelsie's reflections on caregiving, resilience, grief, and hope, attendees gained a deeper understanding of the realities of living with ALS and the profound impact the disease has on individuals and families. The evening created space for honest conversation, meaningful connection, and community, while inspiring compassion and support for everyone affected by ALS.

Making it Possible

Throughout ALS Awareness Month in June, the ALS Society of Alberta’s 2025 Making It Possible campaign shared the personal stories of Albertans living with ALS, their families, volunteers and community supporters. By giving people a platform to speak openly about life with the disease, the campaign helped build understanding, challenge misconceptions and ensure those affected by ALS felt seen and heard across the province.

Kevin Truss	Dan Pubben	David & Judy Webb	MAKING IT POSSIBLE 2025 THANK YOU, ALBERTA!	Bruce Beswick	Alan Widynowski	Conrad Gotzmann
Saz's Soliders	Dave McMaster	Doug Lee		Adishwar Randhawa	Brian Dennis	Mike Oliver
Laurie Ferguson	JoAnn Noffsinger	Quonset Days		Ralph Scott	Rob Markley	Lesley Korman
Monique Nadeau	David MacLean	Hashem Metham		The Backlunds	Richard Broen	Board of Directors
Lori Huolt	Cheryl OshaneK	Stacy Hollister-Rank		Jenna Doll	Willy Grant	

Ensuring Donations are used Responsibly & Effectively



It is my privilege to present my first Treasurer's Report on behalf of the Board of Directors for the year ended December 31, 2025.

Before reflecting on the ALS Society of Alberta's financial results, I would like to extend my sincere thanks to Gord Banting for his many years of dedicated service as Treasurer. His thoughtful stewardship, financial expertise, and commitment to the ALS Society of Alberta have helped build the strong financial foundation that supports our mission today. I am grateful for the opportunity to build on his work and serve our organization in this new role.

The ALS Society of Alberta remains in a strong financial position, guided by strategic stewardship and a continued commitment to ensuring donor contributions are used responsibly and effectively. Throughout the year, we balanced funding for essential

client programs and services with investments in research and strategic initiatives that will strengthen our organization and support Albertans living with and affected by ALS.

The Society ended the year with an excess of revenues over expenses of \$192,317. Total revenue for 2025 was \$3.1 million, reflecting the continued generosity of our donors, event participants, community fundraisers, donors, sponsors and partners. Our signature fundraising events, Betty's Run and Walk Together for ALS, together with third-party community fundraisers and donations, continue to provide the foundation for our programs, services, advocacy, and research initiatives.

In 2025 we also made significant investments in our mission. We increased our commitment to research through the continued development of the Alberta ALS Research Network (AARN), maintained the province's only ALS-specific Equipment Loan Program, delivered vital client services across Alberta, and invested in a new website and rebrand to strengthen the organization for the future. Total expenses for the year were \$2.9 million, reflecting these strategic investments in both current support and long-term impact.

Total net assets at year end were \$4.5 million, reflecting the intentional use of accumulated resources to advance research, strengthen programs and services, and invest in the organization's long-term sustainability. The ALS Society of Alberta remains in a strong financial position, with the resources to continue supporting Albertans living with and affected by ALS for years to come.

On behalf of the Board of Directors, thank you to our donors, sponsors, volunteers, staff, and community partners for your continued trust and generosity. Your support makes every achievement in this report possible and helps us make each day the best possible day for Albertans living with and affected by ALS.

Warmly,

Andrea Orzech
Treasurer, ALS Society of Alberta Board of Directors

2025 Revenue & Expenses

2025 Revenue

Donations	\$797,031
Walk for ALS	\$629,166
Betty's Run for ALS	\$548,795
Third Party Fundraisers	\$360,983
Other	\$757,875
Total	\$3,093,850

2025 Expenses

Equipment purchase & repairs	\$700,003
Administration	\$663,240
Client services	\$422,647
Amortization	\$316,073
Fundraising	\$316,942
Research expense	\$314,003
Awareness	\$128,468
Volunteers	\$40,157
Total	\$2,901,533

\$5,459,007

Total Assets

\$986,190

Total Liabilities

\$4,472,817

Total Net Assets

TOGETHER, NO ONE FACES ALS ALONE.

That's what Making It Possible means — donate at alsab.ca to help make each day the best possible day for Albertans living with and affected by ALS.



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