



Voices of Hope

Annual Report
2024-2025



Community at our core. Hope in every voice.

Every voice in our Amyotrophic lateral sclerosis (ALS) community brings experience, perspective, and purpose.

The impact happens when those voices come together – as part of a movement working for better todays and brighter tomorrows.

These are **voices of hope**. And their combined strength cannot be silenced.

Through our work, we carry these voices forward – meeting them with a range of supports for families, amplifying them through advocacy and awareness, and shaping a better future through continued research investment.

Our work isn't finished. But with you by our side, we move forward – with purpose, with community, and always with hope.



Dr. Richard Robitaille, Dr. Alec Cooper, Susan Kennerknecht, Isabelle Lessard, Marie-Hélène Gaudreault, Co-Chair of the ALS Caucus, Sylvie Barma, Dr. Angela Genge and Claudine Cook

Message from our Chair and Executive Director

ALS is a devastating disease. It affects far more than physical strength: it continuously disrupts even the simplest activities of daily life, including how people move, speak, connect, and live. Its progression is relentless, and its impact on individuals and families is profound.

And yet, in the face of these challenges, the ALS community continues to demonstrate the power of hope.

Hope doesn't deny the reality of ALS. It helps us focus. On what it means to live well today. On what compassionate support, connection, and dignity can look like in the midst of uncertainty. And on the future we're working toward: one where those diagnosed have access to better treatments and, ultimately, a cure.

As part of our ALS community, **you are a voice of hope.**

Whether you've shared your story, raised awareness, gotten involved, made a gift, or simply stayed connected – your voice has made our community stronger. Your support helped move hope into action in 2025 in many ways. For example:

- Families gained access to a new, more flexible financial assistance option that better reflects everyday life with ALS.
- People newly diagnosed could turn to our ALS 101 programming, now offered regularly, to ease the emotional and informational overwhelm of a new diagnosis.
- 11 research bursaries were awarded to emerging researchers at the undergraduate, master's, and postdoctoral levels, supporting the next generation of ALS research in Quebec.
- Through advocacy and collaboration, the voices of the ALS community were elevated in the places where change happens.

These accomplishments are part of our collective progress – but they also remind us of the continued need. Every day, people living with ALS and those who care for them face challenges that demand urgent, compassionate responses.

At ALS Quebec, we remain committed to the needs of the ALS community throughout our province and transforming what we hear into meaningful action.

Thank you for being a voice of hope – and for staying with us as we carry that hope forward.

With gratitude,



A handwritten signature in black ink that reads "Susan Kennerknecht".

Susan Kennerknecht

Chair, Board of Directors
ALS Quebec



A handwritten signature in black ink that reads "Claudine Cook".

Claudine Cook

Executive Director
ALS Quebec

Voices of leaders in our community

In 2025, nine members of Quebec's ALS community were awarded the King Charles III Coronation Medal by the ALS Society of Canada. They were among 39 individuals recognized nationwide for their exceptional contributions to advocacy, research, support, and care in the pursuit of a world without ALS.

Through their lived experience, leadership, and compassion, these Quebec recipients have helped elevate the voices of people affected by ALS and inspire meaningful change – both within our province and beyond.

- **Claudine Cook**, Executive Director, ALS Quebec
- **Dr. Angela Genge**, Executive Director, ALS Centre of Excellence for Research and Patient Care; Director, ALS Clinic at The Neuro (Montreal Neurological Institute-Hospital); ALS Canada Board Member
- **Susan Kennerknecht**, ALS community advocate and Chair, ALS Quebec
- **Isabelle Lessard**, Director, Vincent-Bourque Foundation and volunteer, ALS Quebec
- **Norman MacIsaac**, ALS community advocate, ALS Canada Community Ambassador, and Board Member, ALS Quebec
- **Dr. Geneviève Matte**, Clinical Assistant Professor, Dept. of Neurosciences, Faculty of Medicine, Université de Montréal
- **Dr. Richard Robitaille**, Professor, Dept. of Neurosciences, Université de Montréal, and Board Member, ALS Quebec
- **Dr. Guy Rouleau**, Director, The Neuro (Montreal Neurological Institute-Hospital); Chair, Dept of Neurology and Neurosurgery, McGill University Chief, Dept of Neurosciences, McGill University Health Centre (MUHC)
- **Dr. Christine Vande Velde**, Professor, Dept. of Neurosciences, Faculty of Medicine, Université de Montréal



Claudine Cook, Dr. Guy Rouleau, Susan Kennerknecht, Dr. Christine Vande Velde, Tammy Moore, CEO, ALS Society of Canada, Dr. Geneviève Matte, Dr. Richard Robitaille, Charline and Maria Bourque, daughters of Isabelle Lessard

ALS at a glance



A fatal neurodegenerative disease

Also known as Lou Gehrig's disease. There is currently no cure.



4,000 Canadians are living with ALS, including 600 in Quebec

Each year, 1,000 people are diagnosed, including 200 in Quebec. For every diagnosis, someone else dies.



ALS disrupts the brain's ability to control muscles

Over time, people lose the ability to walk, speak, swallow, and breathe.



Anyone can be affected

ALS carries a lifetime risk of 1 in 300 for each of us. Anyone can develop ALS regardless of gender, socioeconomic status, geography, or race. 90% of cases are sporadic. 10% are hereditary.



Progression can be rapid

80% of people diagnosed die within 2 to 5 years.



ALS doesn't just affect the person diagnosed

The disease impacts entire families – emotionally, physically, and financially.

These facts help explain why the disease demands compassion and urgent action.

Our commitment to people affected by ALS in Quebec is:

- To **support** them with a complete range of services adapted to all stages of the disease.
- To **empower** them to improve their living conditions and their current and future environment.
- To **advocate** for their rights with key political actors and bring about change in their favour.
- To **raise** awareness and understanding of the disease and mobilize the public to contribute to the cause.
- To **fund** research initiatives that could improve their living conditions and cure the disease.

Everyone who is part of this community is a voice of hope – a force driving change towards a future where every person affected by ALS can access the support, resources, and opportunities they need to live life to the fullest.

Hope in motion: Judith and Nicolas's story

When her partner Nicolas was diagnosed with ALS almost 2 years ago, Judith knew she couldn't stop the disease – but she could take action in her own way. That's what spurred her and her family to turn their participation into a 12-hour, 96-kilometre fundraiser for ALS Quebec. And at the centre of it? Her partner Nicolas, who lives with ALS, was deeply moved to be able to take part in the relay in an adapted wheelchair.

“It was beautiful to watch his brother, cousin, our daughter, and nieces and nephews take turns carrying him along the route,” Judith says. “And I think it inspired other runners and people cheering from the sidelines, too.”

For Judith, that day reflected the support that has helped to carry them through every stage of ALS.

“ALS Quebec has been a steady voice of hope throughout our journey,” says Judith. “Through webinars and workshops, we've received solid, practical information. Counselling has helped ease isolation. Thanks to personalized support, I've never once felt alone.”



Judith's family raised over \$6,500 through the event – a powerful expression of gratitude, and of hope for the future.

“We know there's no treatment that truly slows ALS. But research is what will get us there.”

Their story is one of resilience, love, and action... and a reminder that every voice in this community has the power to move others.



Thanks to our donors, Judith's family benefited from the following ALS Quebec services:

- Workshops and support groups to understand ALS and prepare for its progression
- Personalized counselling for emotional support and to reduce isolation
- Financial programs, including Seize the Day that provided a memorable cottage experience for the whole family
- Connection to up-to-date research information through our webinars

A journey of support

Over the past year, we walked alongside thousands of people affected by ALS, responding to their questions, needs, and hopes at every stage of the journey. With the support of donors, partners, and the community, people who reached out were met with listening, guidance, connection, and care.

The impact shown below reflects our work in 2025 and shows what is possible with the support and participation of our incredible community.

Together, we reached and supported: 7,300+ people across the ALS community

First Outreach

When people first reach out, they are often overwhelmed. We listen and help them make sense of what's next.

339 people living with ALS and caregivers newly registered with us, who received **500** hours of support and guidance

73 participations from people seeking guidance they could trust with our ALS 101 Workshop series

Learning and Navigating

As questions grow and change, we offer accessible, reliable information in many formats.

12 education webinars with **417** total participations

39 resources added to our online resource hub, with **350+** resources now available

Connection and Support

We help people find strength through shared experiences and professional guidance, in ways that feel right for them.

65 support groups with **500+** participations

532 people supported individually with counselling support

Living Fully

There is life after an ALS diagnosis. We help people find dignity and reclaim their identity through joyful experiences and practical support.

103 financial assistance requests supported through our Seize the Day, Quality of Life, and Youth Support programs

Inclusive social activities such as our Hobby Club, adapted sailing and holiday musical event

Community, Remembrance and Hope

Our support doesn't end. Many people in our community stay connected as volunteers and advocates.

11 bereavement support groups

116 bereaved caregivers supported individually

Strengthening the journey

Families don't navigate ALS alone, and neither do the professionals who support them. We strengthen care by supporting healthcare professionals with shared knowledge and connection.

- On-site counsellor presence at both Montreal ALS clinics, supporting care teams and patients in real-time
- Individual coaching and one-on-one guidance provided to healthcare professionals
- **200+** professionals engaged in our Community of Practice that fosters shared learning and access to ALS expertise
- **650+** healthcare professionals participated in conferences, webinars, and professional forums, including an international presentation at the Allied Professionals Forum organized by the International Alliance of ALS/MND Associations
- **1,100+** professionals supported with trusted information and resources

Making sense of what comes next

Information, guidance, and referrals

An ALS diagnosis can be overwhelming. At ALS Quebec, we help families affected by ALS feel supported, informed and less alone at every step of the journey.

ALS 101 Workshops: Clear information, at the right

In the early days, people have many questions and need a place to turn. Our ALS 101 Workshops support people living with ALS and their loved ones, whether newly diagnosed or newly ready to receive information. Delivered in a welcoming, compassionate way, these sessions provide a clear understanding of ALS, the healthcare system, and how to access services and equipment.

“ALS 101 has been like a gas station for me, where I come to fill up my tank.”

– ALS 101 participant

Webinars: Staying informed as needs evolve

ALS is a journey, and questions change over time. Our educational webinars ensure information continues to flow throughout the year, in ways that are accessible to as many people as possible. This year, we introduced an online translation platform so both English- and French-speaking participants could fully engage with webinar content. Through 12 webinars offered throughout the year, we welcomed 417 participations.

Website resources: Trusted support, always available

Our online resource centre is an ever-evolving, reliable source of information that families can return to whenever they need it. This year, 39 new resources were added, bringing the total to more than 350 carefully selected tools, guides, and videos.

Where community and expertise meet

In Sherbrooke, we brought together people touched by ALS, caregivers, and healthcare professionals for a local gathering focused on learning, dialogue, and connection, featuring a presentation and Q&A session with Dr. Émilie Lareau-Trudel. These community-based gatherings help strengthen relationships between families and the medical community, address practical concerns, and create space for sharing knowledge and experiences.

Where voices are heard and met

Professional and peer support

ALS affects people differently, and support must be just as flexible. We respond by offering a wide range of professional and peer-based supports that adapt to individual preferences, stages of the disease, and life circumstances. Whether people are seeking shared understanding, expert guidance, or both, they can find support that feels right for them.

Peer support: Shared experience, mutual understanding

People are told ALS is rare. Peer support groups and one-on-one peer support create spaces where people know they are not alone in living this reality. This year, we hosted 65 support group meetings, bringing together more than 250 participants through groups for people living with ALS, caregivers, bereaved caregivers, and anglophones. We also optimized the support group experience by adding structure and supports for volunteer facilitators.

“Support groups have helped me the most in my caregiving role. By connecting with people who are experiencing the same things as me, I’ve felt more understood and less isolated.”

– ALS Quebec support group participant



Connecting care to community

Our staff connect regularly with ALS clinics across the province, helping strengthen collaboration and ensure families have access to trusted support beyond the medical setting. This includes a presence at the two Montréal-based ALS clinics – the Neuro and CHUM – where our team offers information, referrals, and community-based guidance alongside clinical care.

Collaboration beyond the individual

Our support extends to the health professionals who care for families affected by ALS. Whether they work with ALS patients daily or only occasionally, we provide spaces for learning, dialogue, and guidance through individual support, webinars, an Exchange Forum, and a Community of Practice. Together, these efforts help strengthen the network of care that surrounds families across Quebec.

Counselling support: Expertise, reassurance, and guidance

When families need professional support, our psychosocial counsellors provide a listening ear and expert guidance. People come to us with their whole reality – medical, emotional, practical, and personal – and our team helps them navigate ALS within the context of their actual lives. No two journeys are the same, and support is always personalized, flexible, and grounded in expertise. This year, 532 individuals received one-on-one support, with 850 direct support hours provided to help people navigate emotional challenges and complex decisions.

“ALS arrives like a storm, often in a desert of answers. My role is to offer guidance, a human presence, and support at the pace families need it, so they never have to go through this journey alone. I walk alongside them, from the shock of diagnosis through the daily adjustments, adapting to the evolution of their needs at every stage.”

– Ady Proper, ALS Quebec support counsellor



Living fully: Because a diagnosis is not an identity

Programs to support daily living

Living with ALS does not erase identity, dreams, or the need for joy. Our programs bring dignity, fun, and possibility into the everyday, helping people and families experience life beyond the challenges of the disease.

Financial assistance: Support that eases the burden

Financial stress can quickly become overwhelming for families living with ALS. This year, we restructured our financial assistance program to expand access to practical services that support daily well-being, including minor home adaptations and respite services. The program is flexible and tailored to each family’s unique needs, ensuring support can adapt to different realities, priorities, and stages of the ALS journey.

“ALS Quebec’s financial assistance is like a magical gift that provides respite from the difficulties and obstacles of this disease. I hope other ALS patients are benefiting from this program as I have!”

– ALS Quebec support group participant

Social experiences: Connection beyond support groups

Connection takes many forms. Our inclusive social activities help people share experiences outside of a traditional support group setting. These moments foster connection, laughter, and a sense of normalcy. New in 2025, our Hobby Club offers a welcoming space for participants to share their interests and the many facets of who they are, while being among others who understand how ALS can shape, adapt, or transform those hobbies.

“The Hobby Club creates a space where I can focus on what interests me, not on ALS. It’s so meaningful to spend time talking about life, passions, and there here and now.”

– Herman Jacobs, living with ALS for over 20 years and co-founder of the ALS Quebec Hobby Club

Making the extraordinary possible with generous support from the Tenaquip Foundation

Through the Seize the Day program, we help make meaningful experiences accessible to people living with ALS and their loved ones.

By supporting simple but powerful moments – such as sharing breakfast together to break isolation, celebrating a birthday, or spending time in an adapted chalet surrounded by nature – experiences that were once out of reach become lasting memories.

Seize the Day reminds families that joy, connection, and shared experiences remain possible, even in the midst of life with ALS.

In 2025, we granted 37 wishes through the Seize the Day program, generously funded by the Tenaquip Foundation.

When hope feels like home

It was during an ALS support group in Lorraine that long-time outdoor enthusiast Alain Marotte first heard about the Seize the Day initiative. Months later, he found himself back where he felt most at home – surrounded by nature at Oka National Park.

With thoughtful adaptations and the support of those close to him, Alain was able to enjoy a camping trip that reconnected him with a lifelong passion and gave him a chance to feel free, present, and fully himself. Moments like these remind us that life with ALS can still include joy, connection, and meaningful experiences.

“I want to do everything I can within my capabilities... Hearing people having fun around me makes me happy.”

– Alain Marotte, living with ALS



THE TENAQUIP FOUNDATION



Visibility that drives change

ALS Awareness

More than being seen, awareness is about creating the conditions for understanding, solidarity, and change. Through year-round awareness efforts, we bring the realities of ALS into the public space, inviting communities, partners, and decision-makers to stand alongside people affected by the disease.

Grounded in voices of hope, our awareness work helps ensure that lived experiences do not remain invisible, but instead inspire support, engagement, and collective action.

ALS Awareness Month: Voices in action

Each June, ALS Awareness Month brings renewed focus to a shared goal: changing the devastating reality of ALS and working toward its end. Throughout the month, communities across Quebec came together through Walk to End ALS events, social media engagement, and fundraising initiatives that support people living with ALS today while advancing advocacy and research for the future.



To mark ALS Awareness Month, Michelle Setlakwe, MNA for Mont-Royal–Outremont, used her voice in the Quebec National Assembly to speak about the realities of ALS and the importance of continued research. We thank her for supporting the ALS community and helping ensure that hope, urgency, and lived experience are reflected in public

Lou Gehrig Day: Hope at the ballpark

Each year on June 2nd, Lou Gehrig Day connects baseball fans across the country in honouring the Hall of Famer and raising awareness of the disease that cut short not just his career, but his life. In Quebec, members of our community took part in the ceremonial first pitch at a Capitals game, sharing this meaningful moment with fans and families – with thanks to Baseball Quebec. Awareness extended to baseball broadcasts through support from RDS. Our thanks to Quebec's baseball community for stepping up to the plate and helping to strike out ALS!



Expanding awareness with eyes on the goal

This year, the Our Eyes are on the Goal awareness campaign helped bring ALS into greater public view. Through billboards displayed during ALS Awareness Month and the year-end holiday season, we shared messages of hope, urgency, solidarity and extended the campaign across our social media channels.

We are grateful to G3 Média and Pattison Media for generously donating the billboard space that helped us to reach new audiences throughout the province.



Amplifying Our Voices

As a trusted reference for people affected by ALS and for anyone seeking information about the disease, ALS Quebec uses its digital platforms and media relations to increase awareness of ALS and share reliable information.

This sustained presence allows us to reach thousands of people across Quebec and keep them engaged within our community.



2,3+ million

views on our social media platforms (Facebook, LinkedIn, Instagram)



67,000+

subscribers to our email communications



11,500+

followers across our social media channels



100,000+

visits to our website sla-quebec.ca, with the most visited pages being:

- What is ALS?
- Symptoms and types of ALS
- Who can be affected?



21 million

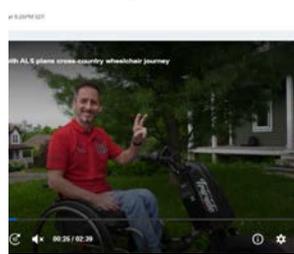
impressions across **60+** media articles and mentions

Amplifying lived experience

Throughout the year, media coverage brought the realities of ALS into everyday conversations. Voices from ALS Quebec representatives and across our community – including Dr. Alec Cooper and Dr. Jean-Pierre Canuel, who did a CBC interview on voice cloning; Chantal Lanthier, who did an interview at Salut Bonjour with her new AI voice; Yannik Richard, whose remarkable journey generated media coverage across the country; and radio coverage of Lou Gehrig Day on June 2nd – helped deepen public understanding of ALS and the need for greater support. We are deeply grateful to everyone who shared their story.



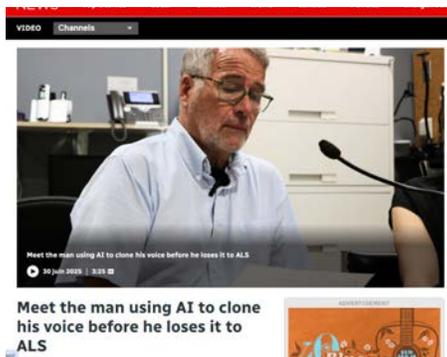
ALS awareness month, Quebec media cross-country wheelchair trek



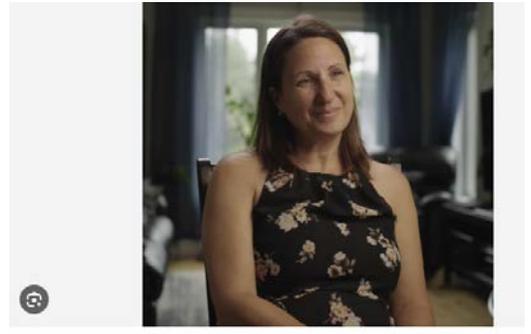
SLA dans Charlevoix: déterminée à trouver une thérapie en l'honneur de son père, de sa grand-mère et de sa tante



La santé publique de l'Estrie confirme l'absence d'excès de cas de SLA dans le Val-Saint-François



«Je suis parti à pleurer»: incapable de parler, elle retrouve sa voix grâce à l'intelligence artificielle



Julie contre la sclérose latérale amyotrophique | Radio-Canada.ca

From the screen to support

In May, members of the ALS Quebec community took part in a special episode of La Poule aux œufs d'or, where Loto-Québec matched each contestant's winnings with a charitable gift. Thank you to contestants Jean-Yves Déry and Rose-Yvette Simard who selected ALS Quebec as their charity of choice, resulting in a \$63,000 donation! Mr. Déry took part in memory of his partner, Réjeanne Duchesne, who had ALS. We also extend our sincere thanks to Yannik Richard, ambassador for ALS Quebec, who was present to represent our team.



From hope to lasting change

Advocacy

Advocacy is how voices of hope are carried beyond individual experiences and into action that shapes care, access, and quality of life. By working alongside partners, policymakers, and the ALS community, we help ensure that lived realities inform decisions that affect people today and create better outcomes for the future.



Stronger together on Parliament Hill

In October, we joined ALS organizations and community members from across the country for a federal advocacy day on Parliament Hill in Ottawa. Members of our team and community met with Members of Parliament to share the realities of living with ALS and to advocate for a \$50 million federal investment in the Canadian Collaboration for a Cure – a national strategy to unite and scale three research efforts already driving progress: CAPTURE ALS, the Canadian Neuromuscular Disease Registry, and the Canadian ALS Research Network. Coming together in this way demonstrated the unity of the ALS community as we pushed for change with a clear, shared voice.



Alicia Dubinski, Mélanie Joly, Minister of Industry and Minister responsible for Canada Economic Development for Quebec Regions, Dr. Richard Robitaille and Dr. Chantelle Sephton



Advancing rights through Neuro Partners

As one of five members of Neuro Partners, we continued advocating in Quebec for stronger government programs that better support people living with neurodegenerative diseases and their caregivers. Through meetings with Members of the National Assembly, open letters, and formal submissions, we called for practical improvements to informal caregiving, home support, care facilities, and treatment access. This work reflects our commitment to ensuring that people who live with ALS have the resources, support, and options they need to live as fully as possible.



Diego Martinez, Executive Director, Quebec Division, MS Canada, Roxane Deschamps-Sonsino, Manager, Philanthropic Development and Government Relations, Quebec Division, MS Canada, Frantz Benjamin, MNA for Viau and Third Vice-President of the National Assembly of Quebec, Marie-Hélène Bolduc, Vice-President, Programs and Services, Muscular Dystrophy Canada and Anaïs Le Bourdon, Director of Communications and Marketing, ALS Quebec

Through Neuro Partners, we work alongside four other organizations supporting people living with neurodegenerative diseases and those who care for them. By joining forces, we strengthen our collective ability to advocate for better policies, services, and supports in Quebec – drawing attention to shared priorities and advancing change that benefits all affected communities.

Translating hope into treatment options

The conditional approval of QALSODY by Health Canada was a milestone for people whose ALS is caused by a mutation in the SOD1 gene. Recognized for its therapeutic value by the Institut national d'excellence en santé et services sociaux (INESSS), this treatment offers hope of slowing disease progression for this rare form of ALS. We remain actively engaged in advocacy efforts to ensure equitable access in Quebec through ongoing consultations with government programs, close monitoring of next steps, and continued efforts to secure timely reimbursement so that hope can translate into real treatment options.

“Instead of thinking that I have a few months to live, I am now thinking that I could have years ahead of me – and that's thanks to my participation in a clinical trial. I advocate so others in the ALS community can have the same opportunities when they stand to benefit from emerging treatments.”

– Yannik Richard, living with ALS



Your voices of hope fuel progress

ALS Quebec Research Fund

From the desk of Dr. Richard Robitaille, Chair, ALS Quebec Research Fund Committee

Research is one of the most important ways ALS Quebec helps turn hope into progress. This past year, we helped Quebec's ALS research community – among the most active in the country – continue to move forward through collaboration, innovation, and shared purpose.

At the centre of this work is the ALS Quebec Research Fund. Guided by expert oversight through our Committee, the Fund ensures donor contributions are invested with care to strengthen research capacity in Quebec, support national efforts, and nurture the next generation of ALS researchers. In 2025, we invested \$519,901, and our Board remains committed to growing the Fund so we can allocate more to research each year.

Progress is already taking shape. New treatments such as QALSODY, along with clinical trials and initiatives including CAPTURE ALS, are helping to pave the way for future therapies. We were also pleased to support the relaunch of the André-Delambre International ALS Research Symposium that connects Quebec with the global research community.

Equally important, we bring research closer to the people it serves through bilingual, twice-yearly Q&A sessions that connect researchers directly with the ALS community, making science accessible and building trust, understanding, and shared hope.

To our donors and to the ALS community: thank you. Your support fuels this momentum and keeps hope moving forward.

ALS Quebec Research Fund Committee



Dr. Richard Robitaille
Chair;
Full Professor, Neurosciences
Department, Université de
Montréal;
ALS Quebec Board Member;
Scientific & Medical Advisory
Council (SMAC)



François Gros-Louis
Advisor;
Full Professor,
Université Laval



Dr. Geneviève Matte
Advisor;
Neurologist, CHUM



Dr. Chantelle Sephton
Advisor;
Full Professor,
Université Laval



André Besner
Vice President, Quality and
Continuous Improvement,
Trans Canada Forest Products;
ALS Quebec Board member



Dr. Jean-Pierre Canuel
ALS Quebec Board member,
living with ALS since 2014

Shaping the future, with your support

The ALS Quebec Research Fund channels donor support into research that advances understanding, care, and treatment of ALS. Guided by expert oversight and informed by lived experience, it turns collective commitment into tangible progress including the highlights from 2025 that follow.

Research powered by community participation

CAPTURE ALS is a national research initiative that collects clinical data and biological samples from people living with ALS as well as healthy individuals to advance understanding of the disease. By choosing to participate, members of Quebec's ALS community contribute directly to research that may shape future discovery and treatments. To support this collective effort, we committed two years of funding support for a CAPTURE ALS site at the CHUM clinic, in partnership with ALS Action Canada. Going forward, we are proud to provide bridge funding that ensures continued support for all three Quebec-based CAPTURE ALS sites.



“As co-founder of the Vincent Bourque Foundation, along with my late husband Vincent who passed away from ALS in 2018, and as a biologist, I believe scientific engagement in research is essential for the ALS community. Being a control participant in CAPTURE ALS contributes to the collective effort to better understand ALS and honour Vincent's fight in support of the ALS community's shared goal: a future without ALS.”

– Isabelle Lessard, CAPTURE ALS participant (control group)



Investing in the next generation of ALS research

Progress in ALS research depends on sustained investment in people and ideas. This year, we supported emerging researchers at every stage of their journey – funding three summer student bursaries, six master's-level bursaries, and two postdoctoral start-up grants. These investments help young scientists gain hands-on experience, launch independent research programs, and remain engaged in the ALS field. By supporting early-career researchers today, we help ensure that new perspectives, discoveries, and treatments continue to take shape – strengthening the future of ALS research in Quebec and beyond.



“Working in an ALS laboratory is, for me, a way to honour those who, like my grandfather, face the disease with courage. That is why I feel genuine gratitude and strong motivation at the prospect of being able to contribute to discoveries that could improve patients' quality of life.”

– Maika Doré, University of Montreal neuroscience student and recipient of a summer student bursary



“To anyone who has made a donation: thank you. A gift to ALS Quebec enables researchers like me to pursue breakthrough ideas, supports the training of future scientists, and sustains clinical and research programs that advance care and hope. Together, we can change what the future looks like for people living with ALS.”

– Dr. Vincent Picher Martel, neurologist specializing in neuromuscular diseases and recipient of a postdoctoral start-up grant

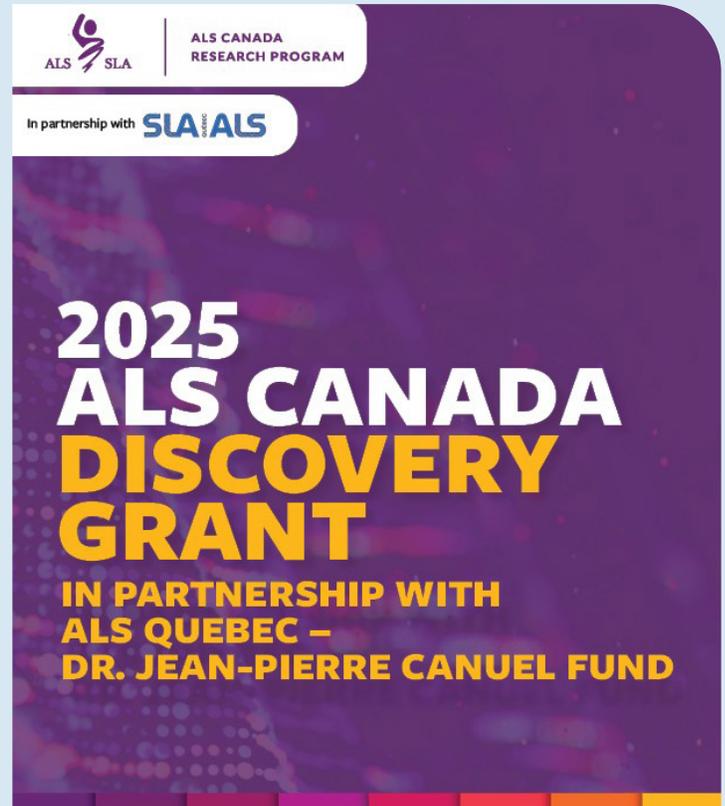
Strengthening research through partnership

Our commitment to research extends beyond provincial borders. Through strategic partnerships, including national collaboration with ALS Canada, we help ensure that promising research receives the scale and coordination it needs to move forward. Over the past five years, we have contributed more than \$1.1 million to ALS Canada's research program – amplifying the impact of local generosity through collective, Canada-wide progress.

In 2025, we are proud to have contributed \$205,000 to the national ALS Canada Research Program, including 40% from Walk to End ALS events.

Through these funds, we are proud to have contributed to research projects as part of a partnered approach, coordinated national investment:

- \$125,000 awarded to Dr. Janice Robertson, in collaboration with Dr. Shreejoy Tripathy (University of Toronto), for *Mapping Alternative Polyadenylation and Splicing in ALS via Single-Nucleus Long-Read Transcriptomics*. Supported through a 2025 ALS Canada Discovery Grant, in partnership with ALS Quebec – Dr. Jean-Pierre Canuel Fund.
- \$300,000 over three years awarded to Dr. Christine Vande Velde (CHUM), in collaboration with Dr. Richard Robitaille, for *Stress Granules: Neuroprotective or Neurotoxic in ALS Pathogenesis?* Supported through the ALS Quebec – Dr. Jean-Pierre Canuel Fund in conjunction with the 2024 ALS Canada-Brain Canada Discovery Grant Program.



“The partnership between ALS Quebec and ALS Canada exemplifies what can be achieved through collaboration. By joining forces, we have been able to support the most impactful ALS research in Canada, no matter where it’s being done. With the shared urgency of supporting work that will accelerate toward a world free of ALS, Canadians will ultimately benefit from new treatments faster through these partnered, national investments. We deeply appreciate ALS Quebec’s mutual commitment to this vital mission and vision.”

– Dr. David Taylor, Chief Scientific Officer, ALS Canada



FONDATION VINCENT BOURQUE

As part of the 2025 ALS Canada-Brain Canada Trainee Award program, one of the Postdoctoral Awards was supported by The Vincent-Bourque Foundation.

Veronica Grybas, a doctoral candidate supervised by Dr. Maxime Rousseaux, working at University of Ottawa, was awarded \$75,000 over three years for the project, *Examining the role of TDP-43 SUMOylation following ALS-relevant stress*.



Claudine Cook, Veronica Grybas, Peter Fragiskatos, Co-Chair of the ALS Caucus, Sylvie Barma, Dr. Alec Cooper and Isabelle Lessard

Over the years, The Vincent-Bourque Foundation has supported \$517,875 in research investment through our partnership with the ALS Canada Research Program and donated \$360,000 to assist families affected by ALS through ALS Quebec.

We extend our sincere thanks to Isabelle Lessard and the Foundation. Their generous and ongoing commitment, which extends beyond financial support to attendance at events and participation in research initiatives, makes them voices of hope for the ALS community.

Bringing research within reach

Each June and December, we host bilingual Research Q&A sessions to bring science closer to the people it serves. These welcoming conversations connect our community directly with ALS researchers and clinicians, creating space to ask questions, share concerns, and better understand emerging progress. With 75 to 100 participants at each session, these exchanges strengthen trust, deepen understanding, and build hope for the future.

Notre panel Our panel



DR RICHARD
ROBITAILLE,
PH.D.
Université de
Montréal



DR GARY
ARMSTRONG,
PH.D.
McGill
University



DR NICOLAS
DUPRÉ
Université
Laval



DRE GENEVIÈVE
MATTE
Centre hospitalier de
l'Université de Montréal



DRE CHANTELLE
F. SEPHTON,
PH.D.
Université
Laval



DR DAVID
TAYLOR,
PH.D.
Société canadienne
de la SLA



DRE CHRISTINE
VANDE VELDE,
PH.D.
Université de
Montréal

Merci à nos commanditaires
Thank you to our sponsors



Voices of hope in action

Behind every moment of progress this year was a powerful community of donors, fundraisers, participants, volunteers, and partners.

Together, you helped make hope happen.

Moving forward, together

Walk to End ALS

Each year, our **Walk to End ALS** events bring communities across Quebec together in a powerful act of solidarity. People walk to honour loved ones living with ALS, to remember those they've lost, and to support families affected by the disease.

This deep personal commitment translates into collective impact that fuels the services we provide and advances research, discovery, and progress. Importantly, it reminds those affected by ALS that they are never alone.

"As long as I have my voice and my legs, I will not stop fighting."

After her ALS diagnosis in June 2024, Carole's world was turned upside down. Already a cancer survivor, she faced fear, anger, and profound uncertainty for herself and her family. With the support of her loved ones, her healthcare team, and ALS Quebec, Carole chose to take back control – by seeking support, participating in research, and getting involved.

Through support groups, workshops, and one-on-one guidance, Carole found reassurance, connection, and the confidence to act. In June, she formed a team for the Walk to End ALS in Québec with her husband Jean. Together, they raised \$6,700.

Today, Carole continues to raise awareness, support research, and live fully – using her voice to help others find strength and hope.



Your impact adds up!

10 Walk locations, as well as virtual participation

60% of funds raised went to services for people affected by ALS.

40% of funds raised went to advance research discovery, with funds matched by Brain Canada for double the impact!



20 years of walking together in Charlevoix

In 2025, the ALS community in Charlevoix celebrated a milestone: 20 years of the Walk to End ALS, reflecting a longstanding commitment to people living with ALS and their families.

Held in La Malbaie, this anniversary edition brought together participants, volunteers, and supporters who have shown up year after year. What began as a local initiative has grown into a lasting tradition of solidarity, awareness, and generosity, reflecting the strength of a community that continues to stand alongside those affected by ALS.



Honouring dedication

Martin Lavoie received the 2025 Mario Hudon Award in recognition of his sustained commitment to raising awareness, funds and support in the region. He shared a powerful message of courage and hope: “I love life so much. Why give up? Life is too beautiful not to live.”

A record-breaking year

The 2025 Walk raised \$45,272, making it the most successful Charlevoix Walk to date.



With thanks to the local organizing team

A heartfelt thank you to Elsa Tremblay, Gilles Martel, Luc Samama, and the many local organizers, volunteers and partners whose dedication and care have sustained the Charlevoix Walk for 20 years. Their commitment continues to bring people together and make a meaningful difference for families affected by ALS.

Two decades of impact

Since 2004, the Charlevoix Walk has raised more than \$300,000 to help families receive needed support and advance ALS research.

Creativity that inspires generosity

Long-time supporter Yvon Perron once again rallied the community through his handcrafted miniature houses initiative, which over the years has raised more than \$100,000 for ALS Quebec.

Beyond the Walk

In 2025, community-led initiatives across Charlevoix – including the Denis Unlimited Power team, Karine Soulières’ candles, and a bowling tournament – generated over \$64,500 for ALS Quebec.



Peddalling towards progress

Ride to End ALS

The **Ride to End ALS** in August 2025 brought cyclists together to push their limits in support of people living with ALS and their families. Participants ride for many reasons: to honour loved ones, to raise awareness, and to help fund support services and research. The Ride shows what's possible when determination, solidarity, and generosity come together on the road.

Riding for those he loves, and for those he's never met

Jean-Francois' story



When Jean-François's wife Laurie was diagnosed with ALS in Summer 2024, life changed overnight for the two of them. The shock was immense, and questions quickly surfaced about navigating what lay ahead, including parenting their five-year-old.

Through ALS Quebec, they found understanding, information, and guidance that helped restore some balance. Amid the uncertainty, there was also hope: Laurie was found to be eligible for a treatment that could slow the progression of her disease.

For Jean-François, cycling became a way to cope – and to act. What started as a personal challenge grew into a team effort raising funds for ALS Quebec. Driven by love, determination, and the belief that our actions matter, Jean-François fundraised for and participated in the Ride to End ALS not just for Laurie and their daughter, but for all families facing ALS.

“Participating in the Ride to End ALS this year was a no-brainer. For me, it was a way to give meaning to what we are going through, to turn helplessness into action. Because of the incredible support of my colleagues, family, and friends, I felt uplifted. In August, I rode for Laurie, for Éléonore, and for all the families who, like us, are learning every day to move forward with ALS. And I continue to move forward with them, with hope.”

– Jean-François Limoges

Thank you to our sponsors



Purpose behind every swing

United on the Greens to End ALS

In September, **United on the Greens to End ALS** brought golf enthusiasts together at clubs across Québec through a unique province-wide fundraising initiative. Participants teed off in small groups at local courses, united by a shared love of the game and a common purpose: supporting people living with ALS and their families.

Funds were raised through an online charitable auction featuring golf packages, exclusive experiences, and special items. Participants secured their tee times by placing winning bids and making donations, transforming friendly competition into collective impact.

Held for the second year in 2025, United on the Greens continued to show what's possible when a community rallies with purpose, creating connection and momentum beyond the fairway.

We extend special thanks to former NHL players Vincent Damphousse, Guy Carbonneau, PJ Stock, Stéphane Fiset, and Simon Gagné for joining this year's event and helping strengthen its reach and spirit.



Thank you for teeing up!

Through province-wide participation, more than \$152,000 was raised through United on the Greens to End ALS!

Special thanks to these community events that translated their love of golf into support for ALS Quebec:

- Golf Boss, organized by Richard Dubé and Dominic Sanche in memory of Richard Dubé's father
- Mike Paquin Showtime Golf Tournament, organized by Luc Miron in memory of Mike Paquin
- Solheim Cup Golf Tournament, organized by Suzanne Bruneau in memory of Mike Paquin



Peter Broome is a proud Quebecer who grew up playing golf in Montreal. After competing locally, he became a member of the PGA of Canada and a Lifetime Honorary Member of the PGA of America. He has been living with ALS since August 2024.

“The ALS family worldwide is a tireless and dedicated community that needs our help with both awareness and funding. Locally, ALS Quebec is a very special team that is making a difference with Quebecers living with ALS... ALS is relentless, but so is the golf community.”

The team at ALS Quebec would like to thank Peter for lending his support as an ally of United on the Greens to End ALS. His journey and the hope he embodies are a source of inspiration for the ALS and golf communities.



**UNIS SUR LES VERTS
POUR VAINCRE LA SLA
UNITED ON THE GREENS
TO END ALS**

SLA QUÉBEC **ALS**

En collaboration avec/In collaboration with



Thank you to Golf Québec, PGA Québec, the Association of Golf Courses in QC, the golf community, partner organizations, sponsors and media partners.



Participating Golf Clubs

Abacoa Golf Club	La Faune Golf Club	Oasis Golf Club
Alpin Golf Club	La Lièvre Valley Golf Club	Old Lennoxville Golf Club
Balmoral Golf Club	La Tuque Golf Club	Owl's Head Golf Club
Beaconsfield Golf Club	La Vallée du Richelieu Academy	Pinegrove Country Club
Boucherville Golf Club	La Vallée du Richelieu Golf Club	Pont-Rouge Golf Club
Club Laval-sur-le-Lac	Lac Champlain Golf Club	Royal Montreal Golf Club
Elm Ridge Country Club	Le Blainvillier Golf Club	Saint-Michel Golf Club
Fred Colgan Golf Academy	Le Maître Golf Club	Saint-Prime Golf Club
Golf Matha	Le Versant Golf Center	St-Jean Ltée. Golf Club
Golf Métropolitain Anjou	Les Rivières Golf Club	Summerlea Golf & Country Club
Golf Royal Laurentien	Lorette Golf Club	Tadoussac Golf Club
Golf Saint-Raphaël	Lotbinière Golf Club	The Griffon des Sources Golf Course
Hawkesbury Golf Club	Milby Golf Club	The Royal Ottawa Golf Club
Islesmere Golf Club	Mont Adstock Golf Club	The Royal Québec Golf Club
Kanawaki Golf Club	Montcalm Golf Club	Trois-Saumons Golf Club
Ki-8-Eb Golf Club	Montmorency Golf Club	Victoriaville Golf Club
L'Oiselet Golf Club	Mount Bruno Country Club	Windmill Heights Golf & Country Club
La Bête Golf Club	Napierville Golf Club	

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When initiative becomes impact

Community fundraising

Across Quebec, individuals, families, and groups are finding their own ways to support us and the ALS community by turning personal ideas, talents, and moments into meaningful action. Each initiative helps strengthen support for families affected by ALS and advances research, while reminding us that hope often begins with one person deciding to act.



Yannik Richard: A great journey of courage and determination

Last autumn, Yannik Richard, a father of three who is living with ALS, set out on an extraordinary journey to travel 4,500 kilometres in just 35 days in his motorized wheelchair. He raised an incredible \$26,110, with half supporting the purchase of an adapted van for his family and half donated to ALS Quebec. Yannik's arrival home was celebrated by loved ones, community members, and leaders who came together to recognize the courage, resilience, and generosity behind this remarkable initiative.



Mont-Laurier Kickboxing Charity Gala: Community strength in action

Organized by Robert Gay, the Mont-Laurier Kickboxing Charity Gala was created in memory of his mother, who died of ALS. Now in its fifth year, the event brings together athletes, supporters, and spectators to raise funds through high-quality competitive bouts. Since its inception, the gala has raised more than \$75,000 for ALS Quebec. Each year, the gala continues to grow in reach and recognition, driven by community pride, dedication, and a shared desire to make a difference.



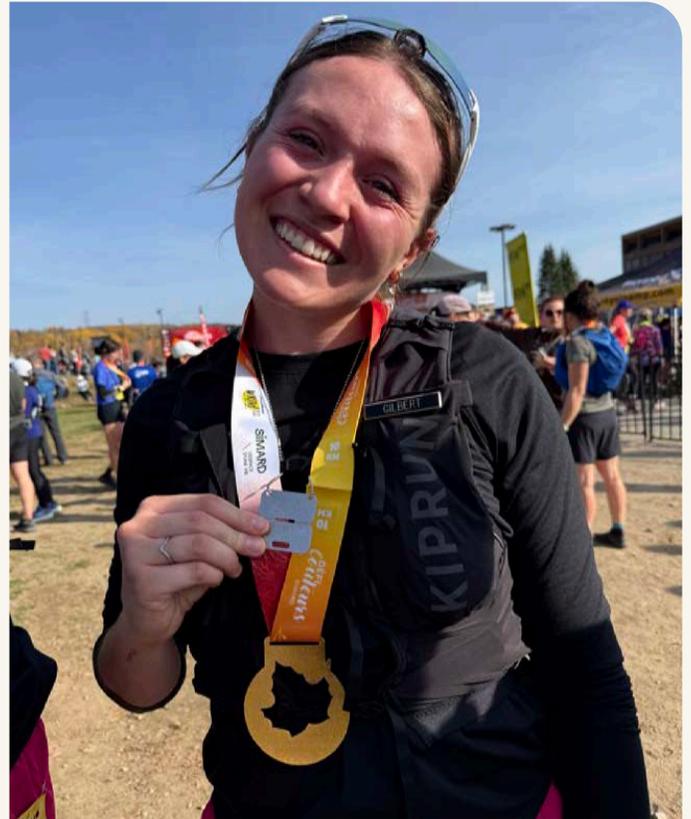
Yoga for the cause: Movement with heart

Idolem Verdun turned weekly wellness into meaningful support for the ALS community. The studio offered a reduced-price hot yoga class every Monday, along with optional cold plunge dips during the month of June, inviting participants to give back in a simple and accessible way. Through these efforts, the initiative raised more than \$3,200 for ALS Quebec. For yoga studio owner Fannie Parizeau Lamoureux, the cause is deeply personal – she lost her mother to ALS.



Hostile Western: Giving back through business

Founded by George Jr. Hamel, Hostile Western is a Quebec-based apparel brand using its platform to support ALS Quebec in a meaningful way. In memory of his father, who died of ALS in 2005, George is donating \$2 from the sale of every cap – the flagship and best-selling product – to ALS Quebec. Over the past three years, they have raised more than \$25,000. Thanks to George and Hostile Western for being a powerful example of how entrepreneurship and personal motivation can create lasting impact!



Défi des couleurs

Océanne Chiasson ran 10 km at the Défi des couleurs at Mont-Sainte-Anne in memory of her husband's father, François Gilbert, raising awareness and support for ALS Quebec.



Simon Lafrenière's training session

Simon Lafrenière and the teams at Paro-Don, Villa – Espace Paro, and Campus – Espace de Formation supported ALS Quebec through their activities, raising more than \$20,000.



Moto, Bières et Terroir

For the second year, the organizing committee of Moto, Bières et Terroir chose to donate event proceeds to ALS Quebec. The 2025 event honoured fellow motorcyclist Nicole Villiard, who is living with ALS, and raised \$8,000.

Facebook fundraising

Thank you to all those who created a fundraiser on Facebook to celebrate a birthday, an anniversary, host an event and more!

Laurence Baker	Lorraine Delambre	Lyse Myette
Stephanie Beaupré-Camirand	Mathieu Delisle	Sophie Mym
Normand Bélanger Dubuc	Léon Demers	Mélanie Ouellet
Jocelyn Belley	Andre Denis	Monia Parent
Lingbert Belotte	Myriam Desjardins	Suzanne Piche
Réal Benoit	Nathalie Desnoyers	Renée Redmond
Real Beriault	Claude Fortin	Alain Rheume
Nancy Bérubé	Annie Galipeau	Julie Rhéaume
Alex Blais	Shaa Gravel	Gabriel Roy
Joanie Blanchard	Katherine Hamelin	Karine Soulière
Helene Blouin	Justine Houde	Kemly Sylvestre
Carole Bordeleau Bergeron	Julie Janvier Allard	Anne-Marie Thiffault
Martine Breton	Catherine Labelle	Pascale Tremblay
Manon Brouillette	Valérie Laberge	Suzie Vallières
Muriel Carpentier	Lucie Lambert	Véronique Vêrousse Deschênes
Benoit Cayer	Jinny Mars-o	Yanina Wilson
Sonia Charest	Angèle McClure	
Caro Côté	Mel Mel	

Community events

160 km in memory of Xavier - Bromont Ultra (Nicolas Therrien and Marjolaine Giroux)	Coach Phil Senior Soccer Tournament (Phil Lalonde)	Michael Soles Bowl 5 th Edition (Randy Burns)
Annual fundraising - Miniature houses (Yvon Perron)	Équipe Couture - Nous Vendons Votre Maison - Pierre-Luc Lavoie	Moto, bières et terroir (Nathalie Roy)
Annual fundraising in memory of Demetre (Jim) Mimidakis (Anthis Mimidakis)	Défi des couleurs (Océanne Chiasson)	Move for a cure (Cassidy Reichment)
Annual fundraising in memory of Francine Pharand (Suzie Pharand)	Five Three Apparel (Xavier Brunet)	Celebration in support of France Gauthier (France Gauthier)
Annual fundraising in memory of Xavier Charette - Brousseau (Ian Charette-Brousseau)	Fête du Lac des nations (Julie Dubois)	R3NROZ - 5 th Edition (Roslynn Scott)
Annual fundraising - Tony Proudfoot (Paul Régimbal)	Grand Prix de Trois-Rivières - Loge du président	Softball & Beach Volley Tournament (Mélanie Jolin)
BBQ IGA St-Jérôme (Yannik Richard)	Hope Project - Tri'ing to End ALS (Donna Bartel)	Ste-Madeleine Camping (Isabelle Girouard)
Bowling Tournament La Clairemontaine et QuilleOdon (Martin Lavoie)	Hostile Western (George Jr. Hamel)	Terra Spencer show for Coach Phil (Jeff Steinberg)
Bromont Ultra 12 th Edition	India Rosa - Restaurants (Denis Sodalj)	The ALS Great Journey (Yannik Richard)
Candle sales (Karine Soulière)	J'M'atelle pour Michel (Camille Poirier)	The community class - Idolem Yoga Verdun (Fannie Parizeau Lamoureux)
	Kickboxing Gala - 5 th edition (Robert Gay)	Training session. Villa - Espace paro/Campus - Training space (Simon Lafrenière)
	Les Ondes Positives (Mylène Boudreault et Catherine Panelli)	Zumba Thon to end ALS (Nadine Ladouceur & Karine Janelle)
	Marathon Beneva de Montréal 4 th Edition	
	Meka Products (Karen Abitibol)	

Turning movement into meaning

Community walks and runs

Across Quebec, people are stepping up to turn movement into meaning. By adding a fundraising component to races, walks, and endurance events under the banner of **Team ALS**, they transform personal challenges into shared support for families affected by ALS.

Often inspired by someone they love, these participants act with purpose – raising funds, building awareness, and showing that hope is not just felt, but lived through action. Together, our Team ALS participants reflect the many ways voices of hope take shape when people decide to move, come together, and support one another.

Nicolas Therrien at the Bromont Ultra: Keeping a promise

Friends since childhood, Nicolas and Xavier had promised each other they would one day run a marathon together. But a few months later, Xavier was diagnosed with ALS. Despite his determination, the disease made that shared goal impossible.

To honour his friend's memory and keep his promise, Nicolas took on the Bromont Ultra, a grueling trail run. He ran 160 kilometres: 80 for himself, and 80 for Xavier. Through his participation and fundraising, Nicolas raised more than \$28,500, contributing to more than \$54,700 raised by Team ALS Quebec supporters at the event. His journey shows how personal commitment can transform loss into meaningful action.



Dahlia at the Marathon Beneva de Montréal: Running for her mother

This year, the Marathon Beneva de Montréal was deeply personal for Dahlia Tomassini. She ran in honour of her mother, who was recently diagnosed with ALS. Inspired by her mother's strength and resilience at a time when so much felt uncertain, Dahlia – along with family and friends – chose running and fundraising as a way to demonstrate their support and raised nearly \$20,000. Together with many other committed runners, these efforts contributed to more than \$30,000 raised for ALS Quebec during the Beneva Marathon.



Running for Anna – and for hope

In 2018, Richard Gameiro's mother-in-law, Anna, passed away after a long battle with ALS. His wife lost her mom, and the disease left emotional scars that are still felt today.

Anna's strength and grace left a deep impression on the family, spurring Richard to take action. Ever since, he's been running the 21K de Montréal in her memory. For Anna. For his wife. And for his two sons—so they can grow up understanding the power of empathy and the importance of standing up for something bigger than themselves.

"ALS Quebec was there when we needed them most. Today, I also run for them – and for every family facing this reality. As long as hope exists, I'll keep running."

Giving time. Gaining purpose.

Recognizing the volunteers who help make hope happen



Coach Phil: A volunteer who inspires us all

For much of his adult life, Phil Lalonde has built teams, set goals, and encouraged others to give their best – on and off the soccer field. After being diagnosed with ALS, he chose to keep contributing in a way that felt right for him. From that determination, the Coach Phil Senior Soccer Tournament was born.

Held for the fourth time in 2025, the tournament has raised more than \$235,000 for ALS research and support services. This achievement reflects not only Coach Phil's own commitment and perseverance, but also his gift for bringing people together. True to his coaching roots, he has inspired a dedicated community of volunteers to join him in building something meaningful around a shared vision.

In recognition of his extraordinary achievements, Coach Phil received the Chantal Lanthier Award, which we give annually to an outstanding volunteer in our ALS Quebec community. When presenting the award, Chantal Lanthier and her husband Jocelyn Théorêt described Coach Phil as having “magic at his fingertips and kindness deep in his heart” – words that reflect the teamwork, perseverance, and spirit of generosity he brings to everything he does.

Through his committed involvement, Coach Phil reminds us that hope is built through action, connection, and the choice to keep giving of oneself, even in the face of adversity.



With gratitude to our volunteers

We are deeply grateful to the many individuals who share their time, care, and talents in support of our mission. Each contribution helps strengthen our community and reflects a voice of hope for people affected by ALS.

Carole Adam	Jean-Pierre Canuel	Benjamin Dion	Marie-Pier Grenier	Andréanne Lepage	Annabelle Provençal
Michael Alinauskas	Julian Cardinal	Laura Doulet	Benoit Guindon	Ann-Marie Léporé	Diane Provencher
Samuel Alvado	Thérèse Carignan	Caroline Doré	Claire Guindon	Carmen Lessard	Nicole Provencher
Mélanie Amyot	Manon Carrol	Jocelyn Dorion	Johanne Héroux	Martha Leyva	Nancy Quessy
Carolle Audette	Katherine Chadwick	Angèle Doucet	Debbie Huq	Andrea Lian	Alain Racine
Manon Aumais	Marcel Charrette	Elyse Drouin	Robert Hoffman	Daniel Lussier	Claude Rainville
Lyne Authier	Marcel Charrette	Serge Dubé	Pierrette Isabelle	Tanya Luttrell	Serge Ricard
Jackie Ayotte	Liliana Chávez	Alexis Duchaine	Julie Janvier Allard	Denise MacDonald	Stéphanie Richard
Yves Bastien	Marie-Ève Choquette	Martin Duchaine	Annie Jobin	Norman MacIsaac	Richard Robitaille
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Denis Blanchette	Lorraine Damecour	Michel Gauthier	Yan Laroche	Alexandre Nadeau	Elsa Tremblay
Lucie Bouchard	Lorraine Damecour	Louise Gauthier	Tommy Lavallée	Georges-Étienne Noël	Mylene Tremblay
David Boudreau	Lina Dansereau	Emmanuel Germain	Nancy Lavoie	Nicole Paradis	Chantal Trempe
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Mylène Boudreault	Marie-Hélène Demers	Bob Gingras	Chantal Leblanc	Marjorie Pare	Kelly Veilleux
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	Ty Diep	Lorraine Grenier			

A special thank you to our donors, partners and sponsors!

Your generosity makes all the difference for families across the province by easing the burden of ALS, investing in research that holds promise for treatment and care, and fueling awareness and advocacy efforts.

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Gilles Raymond

Régulvar

Ressources forestières biotiques inc

Aurélien Riou

Melissa Robitaille

Roehampton West

Gaétan Rondeau

Line Roy Bond

Rv Avantages Sociaux

Dominic Sanche

Monika Simon

STC Acoustique 2015 inc.

Marie St-Laurent

Succession Fabienne Barnard

Succession Nicole Beaudoin

Daniel Surbey Bougie

Diane Tkalec

Stéphane Tourigny

Claire Tremblay-Dickey

United Way East Ontario - Centraide Est de
l'Ontario

Nicole Viau

Wesbell Technologies West

Westower

Young Israel of Chomedey

Financial summary

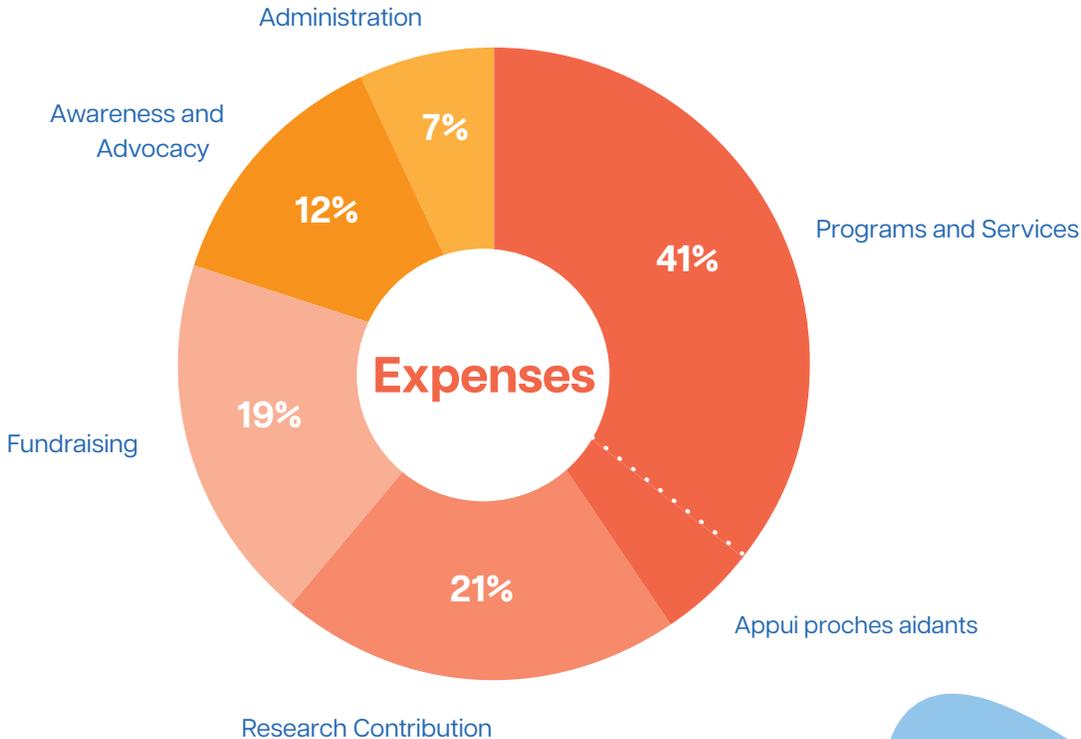
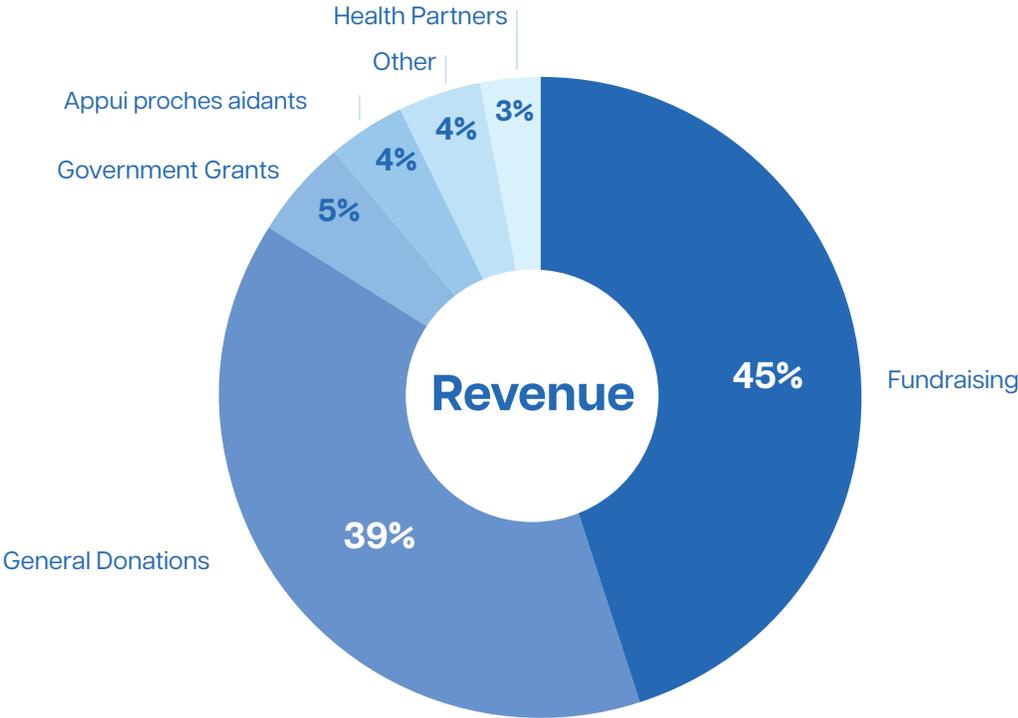
Financial year from November 1st 2024 to October 31st 2025

REVENUE	2024-2025	2023-2024
Fundraising	\$1,054,998	\$883,487
General Donations	\$877,353	\$655,021
Government Grants	\$107,211	\$67,666
Appui proches aidants	\$86,222	\$124,179
Other	\$85,444	\$145,092
Health Partners Quebec & Canada	\$76,803	\$94,014
Dr. Canuel Fund	\$26,060	\$38,510
Tony Proudfoot Fund & Team Stock Fund	\$16,590	\$11,904
Bequests	-	\$18,750
TOTAL	\$2,330,681	\$2,038,622

EXPENSES	2024-2025	2023-2024
Programs and Services	\$897,026	\$661,194
Research Contribution	\$519,901	\$458,240
Fundraising	\$475,576	\$426,258
Awareness	\$323,011	\$291,930
Administration	\$163,484	\$188,497
Appui proches aidants	\$118,270	\$161,118
TOTAL	\$2,497,269	\$2,187,236
Excess (deficiency) of revenue over expenses	-\$166,588	-\$148,614

Please visit our website to view a detailed version of our audited statements.

Breakdown of revenues and expenses



2024-25 Board of Directors

Our volunteer Board members are leaders from the business and health community who provide governance oversight to our organization. Many have a personal connection to ALS.

Executive Committee



Susan Kennerknecht
Chair
Former caregiver
Nominating Committee
HR Committee



Tanya Luttrell
Vice-Chair
Former caregiver
Consultant at SISMILK
Culture d'impact
HR Committee



André Besner
Vice-Chair and Secretary
Vice President, Quality and Continuous Improvement,
Trans Canada Forest Products
Former caregiver
Finance Committee



Benoit Guindon
Secretary
Lawyer, Kellner Avocats
Former caregiver



Daniel Lussier
Treasurer
General Manager, Groupe Bellus Construction Inc.
Former caregiver
Finance Committee

Administrators



Dr. Jean-Pierre Canuel
Retired physician
Living with ALS since 2014
Research Committee
Finance Committee



Dr. Alec Cooper
Retired physician
Living with ALS since 2023
Advocacy Committee
Research Committee



Isabel Cyr
Director of Strategic Partnerships and Public Affairs, ABB Motion Canada
Former caregiver
Advocacy Committee



Vincent Gagné
Director, Government Relations
TELUS Corp.



Johanne Héroux
Public Relations and Communications consultant
Communications Committee



Ann-Marie Léporé
Occupational Therapist
Programs and Services Committee



Norman MacIsaac
Social activist and author living with ALS since 2014
Advocacy Committee



Dr. Richard Robitaille
Full Professor, Department of Neuroscience, Université de Montréal
Research Committee

Our community in action



Our community in action





AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

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Graphic Design: Mylène Duchesneau

Texts: Relate Communications

Photographs: Mathieu Chevalier, Club Photo Joliette, Christian Gingras, Média Photos Charlevoix, Émilie Pelletier, Kevin Sun, Pierre Vignau, Mario Walker



This report is also available in French.