

The Power of Community

Annual Report
2023-2024





The Power of Community

The experience of living with ALS is unique to everyone diagnosed and every family member too.

Yet at the heart of every ALS journey is a powerful truth:

Together, we are stronger.

Over the past year, our community has shown the incredible impact of collective action.

Your commitment to our shared cause means that no one with ALS is ever alone.

Message from our Chair and Executive Director

Living with ALS can be a lonely and overwhelming experience for those diagnosed and their loved ones. It is a challenging disease – and no one should have to face it alone.

That's where the power of community comes in. At ALS Quebec, we're proud to be the spark that brings people together – a source of unity, community, hope and action for people affected by ALS in Quebec.

In the past year, our community has shown what our collective efforts can achieve. With compassion and determination, and from the smallest acts of kindness to large-scale initiatives, together we are changing lives.

Because of you, we have re-introduced paused programs, strengthened existing services, and launched new initiatives to meet people where they are at in their ALS journey. Here are just a few highlights:

- Our inaugural YCare Day helped children and teens understand ALS and introduced them to common mobility and communication equipment.
- We launched new programming tailored to the needs of people newly diagnosed with ALS.

- We strengthened our in-person support groups to help people navigate ALS with the empathy and wisdom of their peers.
- We helped to re-launch the Quebec based André-Delambre International ALS Research Symposium after a five-year hiatus.

Through first-time events like United on the Greens to End ALS, annual favorites like the Walks and the Ride to End ALS, and our determined community of supporters who generously donate, raise funds, and volunteer, your generosity has allowed us to build back stronger since the pandemic.

We ended the year on a high note by co-hosting international meetings with the ALS Society of Canada in Montreal, bringing together 1,600 ALS care professionals, researchers, organization representatives, and people with lived experience all working to improve the reality of ALS.

Just like you are, through your support of ALS Quebec.

Together, we're an unstoppable force.

Thank you for being part of our powerful community!



With gratitude,

Susan Kennerknecht

Chair, Board of Directors
ALS Society of Quebec

Claudine Cook

Executive Director
ALS Society of Quebec



The Power of Community

What is Amyotrophic Lateral Sclerosis (ALS)?



Also known as Lou Gehrig's disease, ALS is a fatal neurodegenerative disease with no cure.

1:1

There are 4,000 Canadians living with ALS. Each year, 1,000 people are diagnosed (150 in Quebec). For each person diagnosed, someone dies.



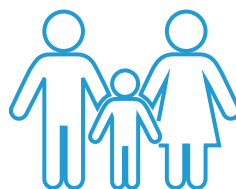
Communication between the brain and the motor muscles is cut off, and people gradually lose their ability to walk, talk, swallow, and breathe.



ALS can affect anyone: 90% of cases are sporadic, 10% are hereditary.

**2-5
Years**

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



ALS affects the whole family on emotional, physical and financial levels.

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 favor.

To **raise awareness and understanding** of the disease and mobilize the public to contribute to the cause.

To **fund** the most promising and relevant research projects that could improve their living conditions and cure the disease.

How you power community

ALS is not a disease to be faced or fought alone.

That's why community is essential – to navigate the realities of the disease, to improve the care people receive, and to end ALS once and for all through research discovery.

Your support of ALS Quebec shows that you believe in the power of community – that together, we can achieve so much more than we can alone.

Did you know?

Your support is helping more than **7,000** people! That's the number of people living with ALS, family members, bereaved loved ones, and healthcare professionals who are registered with ALS Quebec to receive information, services and support.

Here's how you helped them

Information, guidance and referrals



500+

people affected by ALS received timely individualized support and counselling



Our **13** educational webinars had a combined attendance of **312**



More than **75** items were added to our online resource centre



10 children and youth participated in our inaugural YCare program



Patients at two of the province's ALS Clinics can meet with a member of our team during their weekly visits

Professional and peer support

Our **74** support group meetings had a combined attendance of over **500**



In person support groups were offered in Lorraine and St-Hubert

Our Community of Practice gives **200+** registered healthcare professionals a place to share and exchange information to support their ALS patients



50 healthcare professionals attended our webinars

131 families received personalized bereavement support



Our inaugural ALS 101 workshop series for newly-diagnosed families had a combined attendance of

55

Our **3** virtual exchange forums with healthcare professionals had more than **100** attendees collectively

Programs to support daily living

More than **37** families have benefited from the Seize the Day program. Thanks to Tenaquip Foundation, Seize the Day brings joy and delight into the lives of families with ALS by providing financial support to experience a special activity together.



More than **36** families received financial assistance to support their well being as well as their children's healthy development, thanks to a grant from the Fondation Bon départ de Canadian Tire du Québec.

Social activities and events



We held four social activities and events last year, including an adapted sailing excursion supported by accredited sailors and specially designed for people with ALS.

Support for the Whole Family

Hope for a world without ALS

Not so long ago, Yannick Richard was busy building his business. He wasn't yet 50 years old, and his three school-aged children kept him feeling young. He had many projects and dreams to motivate and challenge him.

ALS was not in his plans. But it changed everything.

A routine walk one evening resulted in a sprained ankle, which was the start of an 18-month series of medical appointments. Finally, a neurologist confirmed Yannick's ALS diagnosis.

As his leg strength lessened, Yannick used a cane, then crutches, and finally a wheelchair. He closed his business and became an advocate for people with disabilities.

Yannick is grateful for the ongoing support he receives from ALS Quebec.

"I was immediately reassured and comforted when I realized there was an experienced team to support me through the challenges ahead," he says. "I can confide in them anytime, and I feel understood. Their approach is comforting, attentive, and proactive."

Yannick and his wife enrolled their children in ALS Quebec's YCare day for children and youth.

"Losing independence is a frightening prospect for people with ALS and their families. My wife and I knew the YCare program was a must for our kids. They attended workshops that helped them understand my condition and get familiar with the equipment I'll need."



Yannick's message to ALS Quebec's supporters is focused on the possibilities of the future.

"Because ALS has no cure, we must do everything we can to change that. Donations will help to mobilize as many people as possible around a major goal: to create a world without ALS."

Thanks to our donors, Yannick and his family benefited from the following ALS Quebec services:

- Personalized support from professional counsellors
- A free webinar about tax credits available to people with ALS
- Financial assistance for their three children's healthy development
- Seize the Day program to create special memories as a family
- YCare youth education program

Meeting the community where they're at

Responding to the needs of newly diagnosed families

When participation dropped in their support group for newly diagnosed people, the ALS Quebec team wondered: might the idea of a support group feel intimidating to someone still coming to terms with their ALS diagnosis?

The team recognized a huge need for information in the weeks following diagnosis – but their connections with the community suggested that a

different approach might better meet the needs of families early in their journey.

The ALS Quebec team leapt into action. They created a series of **ALS 101 workshops** specifically for newly-diagnosed people and families. Topics included an ALS overview, support options available through the healthcare system and at all levels of government, what to

expect emotionally, pain, resilience-building strategies, and end-of-life.

Offered for the first time in 2024, the ALS 101 series has been a huge success with families just starting to navigate life with the disease. The format enables them to access important information and connect with others in similar situations.



ALS 101 by the numbers

Number of workshops offered: 6

Total participating: 29

Combined workshop attendance: 55 participants

In their own words:

"I really like this dynamic where we can talk to each other about these topics with all of you, thank you for this initiative!"

"Your workshops are extremely constructive and help demystify the disease!"

"Thank you for being there. My family and I are very well-supported."



Creating unforgettable moments

Thanks to Tenaquip Foundation, families can Seize the Day

People diagnosed with ALS and their loved ones face a life-limiting diagnosis that will profoundly change their daily lives.

Most people with ALS can expect to live two to five years after their diagnosis. During this time their muscles will weaken and their ability to move, eat, speak, and

breathe will be affected, a little bit at a time.

That's why each new day becomes so special. And it's why we're so grateful to Tenaquip Foundation for their generosity in supporting the Seize the Day program since 2017.

Through Seize the Day, people living with ALS can enjoy

unforgettable moments with their loved ones and create memories that will last forever.

Last year, 37 community members have had their wishes granted and enjoyed activities like sailing, cottage getaways, ice fishing, movies, family picnics, and destination travel.

Supporting Young Caregivers

Because caregiving affects the whole family

Young people often play a crucial role in caring for a loved one with ALS, but many have questions and feel alone in their experiences.

YCare is a program designed specifically for children and teens, providing them with a hands-on training with ALS care equipment led by a multidisciplinary team that includes physiotherapists, occupational therapists, social workers, respiratory therapists, speech therapists, a neurologist, and more.



YOUTH CAREGIVING: TRAINING, SKILLS, & SUPPORT

ALS Quebec held its first YCare event in 2023-24. Participants aged seven to 14 moved through different stations alongside other peers, fostering support and learning in a positive environment.



Dr. Melinda S. Kavanaugh, professor of social work and licensed clinical social worker specializing in neurological disorders, founded Global Neuro YCare to support young caregivers of family members with neurological disorders. So far, 87 youth have completed the Global Neuro YCare program, with 92% reporting new friendships and feeling less alone, and 75% increasing their care skills and knowledge.



In their own words

“Our little girl really enjoyed the day, as it gave her a better understanding of what her grandfather is going through. She made us laugh as she explained things to her grandfather and little brother. We thought she understood a lot for her age.”

“Our 2 children really enjoyed the day. The thing they liked the most was looking at the screen that used glasses to type which then activated the computer’s voice. They had a lot of fun with the Hoyer lift.”

“My daughter doesn't ask a lot of questions so we don't push -- although twice [since the event], she asked us questions which was a change. She asked my husband what his manual wheelchair will look like so he showed her a picture online. It was a positive change – thank you for your ongoing support.”

This program was made possible in part by an unrestricted grant given by:



Mitsubishi Tanabe Pharma
Canada

Together, our voices are louder

ALS awareness and advocacy across the province and beyond

Support in the National Assembly

To kick off ALS Awareness month in June, Quebec National Assembly member Michelle Setlakwe, who represents Mont-Royal-Outremont, met with members of our ALS community to hear about their lived experience. She also addressed the provincial government with remarks highlighting the work of ALS Quebec and the need for research advancements to improve quality of life and life expectancy for the approximately 600 people in Quebec who are living with ALS right now.

Thank you, Ms. Setlakwe, for your words of support for the ALS community.



Shining a light on ALS

An amazing 11 buildings across the province shone brightly in blue to recognize ALS awareness month in June:

Basilique Notre-Dame de Montréal, Château Frontenac, CHUM, Fairmont Montebello, Grande Roue de Montréal, Hôtel Concorde, ITHQ, Les Gorges de la rivière Magog (Sherbrooke), Maison Alcan, Place Bonaventure, Tour du stade Olympique





Year-round visibility

There may be an entire month focused on ALS awareness, but this disease and our community deserve attention and support year-round! Thank you to our remarkable ALS Ambassadors for your ongoing efforts to help people understand the realities of living with ALS: Dr. Alec Cooper, Norman MacIsaac, Alain Marotte, Yannick Richard, and Amanda Tam.

"It's important to be realistic and aware of your situation, but it's equally important to still find joy and hope in life. TikTok has been a coping mechanism and a form of expression for me."

Montreal-based Amanda Tam in Business Insider. She has also been featured in Self magazine about having ALS at age 23 and is active on Tik Tok to raise awareness.

"I sense a huge mobilization effort underway worldwide. The people who have decided to fight alongside us give me hope, and so does the progress medicine is making."

Yannick Richard

"[ALS] is a disease that affects one's identity because it affects how you interact with the world and people."

Norman MacIsaac was interviewed by CTV News Montreal on the 10th anniversary of the ALS Ice Bucket Challenge in 2024.

Connecting within and beyond our community

As a hub for people affected by ALS in Quebec and an entry point for others to learn about the disease, our website and other digital channels are important ways for us to foster connection, community, and support.



57,000

visits to our website, als-quebec.ca



9,284

Facebook followers



193

newsletters sent to our community



673,800

Global reach



120

media mentions and articles raising awareness of ALS and our fundraising initiatives, resulting in more than

24 million impressions



12,800

Interactions (likes, shares, comments)

Partnering on shared issues



Neuro Partners
Progressive Neurological Diseases

For the past seven years, ALS Quebec has been a member of Neuro Partners, a group of five organizations dedicated to supporting people and families living with degenerative neurological diseases including ALS.

Our collaborative efforts included meetings and reception with members of the National Assembly to highlight the importance of simplified research funding and better access to innovative treatments.

Thank you to our ALS Quebec Ambassadors who attended and shared their lived experience.



In November 2024, ALS Quebec and members of our community joined other ALS advocates on Parliament Hill in Ottawa for the ALS Advocacy Reception. Organized by ALS Action Canada, this event focused on the need for better policies and support for people affected by ALS in Canada.

Recognizing leadership in awareness and advocacy

When Mario Hudon was diagnosed with ALS in 2020, he took action to raise awareness about the challenges of the disease. He was a model of courage and an inspiration for the entire ALS community.

To honour Mario who passed away in November 2023, ALS Quebec created the **Mario-Hudon Award** to recognize an outstanding ambassador who advocates for the rights of people living with ALS and raises awareness among

the public and key political figures.

We were pleased to recognize Norman MacIsaac with the inaugural award. Norm became involved with ALS Quebec shortly after his diagnosis in 2014. Soon after meeting Mario, they co-chaired together the ALS Quebec Advocacy Committee and initiatives.

In presenting the award, Mario's spouse Nancy recognized Norm's "outstanding dedication to the cause,



his exemplary leadership that inspires others to act, and his powerful voice that raises awareness and furthers ALS Quebec's mission to improve the well-being of the community."

Congratulations, Norm! And most of all, thank you for continuing to be a great warrior and for inspiring hope for the entire ALS community!

Your support is transforming hope into momentum

Research investments drive discovery and progress in ALS

Thanks to our donors, we've made significant progress with our \$1 million **ALS Quebec Research Fund** with \$458,240 invested in 2023-24. This critical investment fuels scientific discovery, driving ongoing progress towards overcoming ALS.

Our investments strengthen the research community in Quebec, contribute to the best ALS research in the country, and further special initiatives – all with the goal of advancing knowledge, care, and treatment.

Nurturing Quebec's ALS research community



Established in honour of Tony Proudfoot, a beloved Montreal Alouette who passed away from ALS in 2010, the **Tony Proudfoot Training Fellowship in ALS Research** supports outstanding master's and doctoral students or post-doctoral fellows pursuing research training in ALS research at The Neuro.

We're pleased to recognize Dr. Matti Allen, an expert in neuromuscular physiology, as the 2024 fellowship recipient. Over the next two years, Dr. Allen will work alongside ALS clinicians and researchers at The Neuro and Université de Montréal.

Thanks to everyone who has contributed to the Tony Proudfoot Fund at ALS Quebec for making this fellowship possible!



"I would like to express my gratitude to the ALS Society of Quebec, and to Tony Proudfoot and his family. As a life-long lover of football, this award is all the more meaningful to me! I am very excited to be working to better understand ALS and researching promising new treatments for the community."

Dr. Matti Allen, Tony Proudfoot Training Fellowship recipient for 2024

Expanding access to a national research initiative



Together with ALS Action Canada, ALS Quebec provided funding for the ALS Clinic at CHUM to participate in CAPTURE ALS, a national initiative that aims to understand and treat ALS faster.

By collecting biological information and samples from patients with ALS as well as healthy individuals and making this information available for researchers to study, CAPTURE ALS aims to better understand the causes of the disease, its differences from person to person, and the underlying biological patterns that can lead to treatments.

Thanks to donors, ALS patients who receive care at the CHUM clinic now have the ability to participate in CAPTURE and have their biological information and tissue samples collected and studied as part of the overall effort.

"I offered to be a participant of CAPTURE ALS at the Neuro, as a healthy brain participant. I know that the ALS community is generous in giving their time to ALS research, but I realized that it is harder for the research community to find participants without ALS who can act as baselines, so as to compare images of the brain. Participating in this project only required a few hours of my time, and hopefully my participation will help to further our understanding of this devastating illness."

Kate Busch, CAPTURE ALS participant and ALS Quebec staff member



The return of the André-Delambre Research Symposium

The **André-Delambre Research Symposium** returned in December 2024 after a pandemic-induced hiatus. Previously hosted by Dr. Jean-Pierre Julien, the latest edition of the conference brought international ALS researchers to Quebec for the 16th time to exchange knowledge and collaborate.

Thank you to the organizing committee of **Drs. Christine Vande Velde, Richard Robitaille, Angela Genge and Chantelle Sephton** for their work to relaunch this important conference, which ALS Quebec was pleased to sponsor!



Supporting participation in research studies

Participation from the ALS community is essential to much of the ALS research currently underway. Because of our close connection with people and caregivers affected by ALS, we are contacted regularly by students and researchers about opportunities for community involvement in their work.

Throughout the year, we received 26 such requests and were able to support all but two, either by meeting with researchers to provide information, sharing their projects with the community, participating in the research ourselves, or providing guidance and advice.

Demystifying ALS research through hands-on experiences studies

A lot of ALS research currently underway happens in university laboratories where teams put their advanced scientific knowledge to work. Their efforts are essential to making progress in ALS, but aren't always visible to people and families affected by the disease.

That's why we were grateful to Drs. Richard Robitaille, François Gros-Louis, and Chantelle Sephton who donated tours of their labs for our online auction – helping to showcase momentum in ALS research, break down barriers

between researchers and the patient community, and raise funds for our continued research investment.

These actions and many others – like attending our Walks and hosting virtual Q&A sessions – demonstrate the genuine desire of our research community to connect with and be inspired by people affected by ALS. By sharing the work they are doing to create a brighter future, others can be as excited about it as they are.

SPOTLIGHT ON ALS RESEARCH AND Q&A

10.06.2024



DR. RICHARD ROBITAILLE, PH.D.
Full Professor
Department of Neurosciences,
Université de Montréal



DRE. GENEVIÈVE MATTE
Clinical Assistant Professor
Department of Neurosciences,
Faculty of Medicine, Université
de Montréal, Research
Investigator, CHUM Research
Centre



DR. VINCENT PICHER-MARTEL
Neurologist
Researcher
CHU de Québec, Université Laval



DRE. CHANTELLE F. SEPHTON, PH.D.
Associate Professor
Brain Research Center, Institut
Universitaire en santé Mentale
de Québec, Université Laval



DR. OLIVIER BLANCHARD
Assistant Professor
Department of Neurology
and Neurosurgery, McGill
University Health Center



DRE. CHRISTINE VANDE VELDE, PH.D.
Full Professor
Department of Neurosciences,
Université de Montréal/CRCHUM



Advancing ALS research across the country

The ALS Society of Quebec is proud to have contributed \$255,239 to the national ALS Canada Research Program, which works toward addressing the unanswered questions about the causes and progression of ALS and supports pathways for the development of future therapies.

All projects funded by the ALS Canada Research Program are supported by the generosity of participating provincial ALS Societies, ALS Canada donors, and community-based fundraising efforts, including 40 per cent of proceeds from the Walk to End ALS in Quebec. Before grants are awarded, prospective projects undergo a peer-reviewed grant competition that engages a panel of ALS experts in prioritizing projects grounded in scientific excellence and with the potential to most quickly advance the field of ALS research.

The ALS Canada-Brain Canada Discovery Grant Program included a Dr. Jean-Pierre Canuel Fund – SLA Québec | ALS Canada – Brain Canada Discovery Grant where \$300,000 were awarded to Dr. Christine Vande Velde, Université de Montréal, in collaboration with Dr. Jonathan Watts, UMass Chan Medical School (USA), for the project Relevance of stress granule dynamics to ALS pathogenesis in vivo.

Funding for the project was made possible by the Dr. Jean-Pierre Canuel Fund and ALS Quebec, who generously contributed \$150,000 to ALS Canada, which was matched by Brain Canada through the CBRF*.



Dr. Jean-Pierre Canuel Fund and ALS Quebec are proud to support another project as part of the 2024 ALS Canada-Brain Canada Discovery Grant Program: ***Stress granules neuroprotective or neurotoxic in ALS pathogenesis?*** Dr. Christine Vande Velde, at Centre Hospitalier de l'Université de Montréal – CHUM, in collaboration with Dr. Richard Robitaille, awarded \$300,000 over three years.

For Dr. Jean-Pierre Canuel, who has been living with ALS for 11 and a half years, "these donations to Quebec researchers are an immense source of pride. To have been able to contribute to this financial package is for me an opportunity to demonstrate to all those who support me that one day, it will be possible to cure the terrible disease that is ALS."

Dr. Jean-Pierre Canuel,
Retired physician, living with ALS



The Vincent Bourque Foundation



FONDATION
VINCENT BOURQUE

As part of the 2024 ALS Canada-Brain Canada Trainee Award program, one of the Postdoctoral Awards was supported by Fondation Vincent Bourque.

Agathe Lafont, a postdoctoral fellow supervised by Dr. Richard Robitaille, working at Université de Montréal, was awarded \$165,000 over three years for the project, Exploring vulnerability across NMJs in ALS: transcriptomic and physiological insights.

Funding for Dr. Agathe Lafont's Postdoctoral Fellowship was made possible through a partnership with Fondation Vincent Bourque, who generously contributed \$82,500 to ALS Canada, which Brain Canada matched through the Canada Brain Research Fund (CBRF*).

Over the years, the Fondation Vincent Bourque has supported research programs in the amount of \$480,375

and donated \$260,000 to support families affected by ALS in Quebec. Thank you to Isabelle Lessard and the Foundation for their generous and ongoing support, including Team Joe Bicycle for hitting the pavement and raising vital funds at the Ride to End ALS. Your contributions are a powerful way to carry forward Vincent's legacy and honour his values of generosity and giving back.

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

"Following the advances in research in recent years, we are more motivated than ever to pursue our mission! The Vincent Bourque Foundation is proud to participate in this joint effort with ALS Canada and ALS Quebec. Vincent would have turned 50 this year, and it's for him and for all the families affected that we're all working together towards a future without ALS."

Isabelle Lessard



"ALS Quebec's contributions to the ALS Canada Research Program are a testament to the power of collaboration in driving ALS research forward. Together, we are supporting innovative studies that will hopefully bring us closer to a world free of ALS. We are grateful for their partnership and the generosity of the ALS community."

Dr. David Taylor, Vice-President, Research and Strategic Partnerships,
ALS Canada



Welcoming the global ALS community to Montréal

ALS awareness and advocacy from around the world

From December 2 to 8, 2024, Montréal became a global hub for the ALS community as researchers, clinicians, healthcare professionals, organization leaders, and people with lived experience gathered for a series of meetings focused on the collective goal of a world without ALS.

Co-hosted by ALS Canada and ALS Quebec, the meetings included:

- the Annual Meeting of the International Alliance of ALS/MND Associations, which has 64 member organizations from 38 countries working to address the current challenges faced by people living with ALS today.
- the Allied Health Professionals Forum, which brought together more than 400 allied health professionals to share best practices in the care and support of people living with ALS.
- the International Symposium on ALS/MND, a scientific conference organized by the MND Association, which brought together more than 1,200 researchers, clinicians, and others working in or affected by ALS to share their work and collaborations.

People living with ALS and caregivers attended all meetings, sharing their firsthand experiences as a way to ground the discussions in the realities of the disease and underscore the urgent need for collaboration and innovation to end ALS.

A special message from Céline Dion

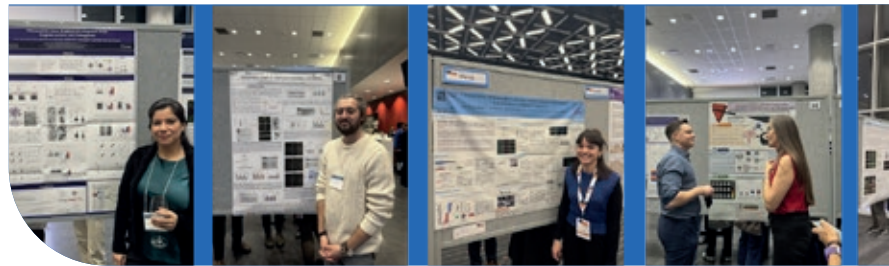
To kick off the international meetings, delegates were welcomed with a surprise video message from Québécoise talent and global superstar Céline Dion. Ms. Dion has seen firsthand the realities of ALS: her dear friend André Delambre was diagnosed with the disease and went on to raise significant funds for research, including the Quebec-based scientific conference that continues to bear his name.

From her personal experience living with an autoimmune condition, Ms. Dion spoke to the importance of research in offering hope for an improved quality of life and solutions. She thanked the researchers and healthcare workers who dedicate their professional lives to supporting families affected by ALS, reminding the community that they are not alone.



Supporting the next generation of researchers in Quebec

ALS Quebec was proud to provide 15 travel grants for early-career researchers in Quebec to attend and benefit from face time with the ALS research community. Supporting the next generation of researchers is crucial because their new ideas and innovations are the future of ALS scientific discovery and clinical care.



Congratulations to Dr. Richard Robitaille!

During the International Symposium on ALS/MND, Dr. Richard Robitaille, Full Professor in the Department of Neuroscience at the Université de Montréal and an ALS Quebec Board member, was recognized with the Drs. Ayeez and Shelena Lalji & Family ALS Endowed Award for Innovative Healing. This global award celebrates excellence in research for an individual or team of investigators who are making transformative breakthroughs in the science of repair and regeneration of neurological function. Congratulations, Dr. Robitaille, on this well-deserved recognition!

Spotlight on our work with healthcare professionals

ALS Quebec team members Kate Busch and Leigh Stephens gave a presentation during the Allied Professionals Forum about our Community of Practice program, an online hub where allied health professionals can connect with one another virtually and share information with the goal of providing their ALS patients with the best possible care.



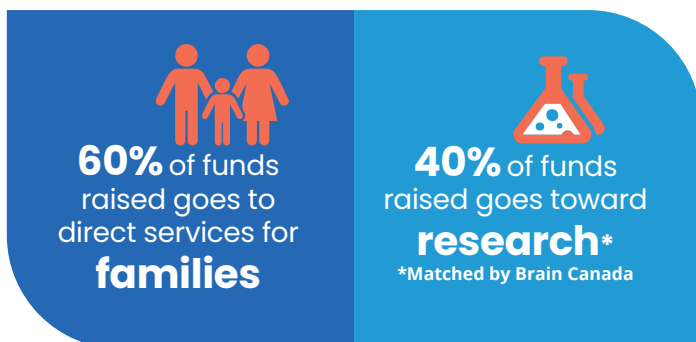


The Walk to End ALS is one of our flagship fundraising events. This popular annual event brings together family and friends to raise funds for research and support.

10 Walk locations across the province



Thank you to everyone who volunteered, participated, donated and fundraised. Together, we can do so much more than when we act alone!



Stepping up to the plate for ALS



Since 2006, MLB broadcaster Rodger Brulotte has taken part in various events we've held over the years. But now, his ALS connection is personal. We would like to thank Rodger for stepping up to the plate as our 2024 Honorary President of our Walk to End ALS events, in

honor of a close family friend who is living with ALS.

Our goal is for Rodger to one day say, "La SLA : Bonsoir, elle est partie!"



Celebrating an ALS milestone

Let Carlos Botelho inspire you! At the 2024 Walk, Carlos celebrated 20 years of living with ALS. To support his fundraising efforts and raise awareness for the cause, he sent a beautiful e-mail to family and friends – even adding a personal touch, his passion for superheroes:

"Put on your favourite superhero T-shirts, get some fresh air with friends and family, and do some good at the same time."



Honouring their mother's final wish

Outdoor activities have always been an important part of the Delorme-Robitaille family's life. The five children grew up running, swimming, skiing and biking alongside their father, Sylvain, and mother, Valérie. So when Valérie was diagnosed with ALS at the age of 54, the many fundraising activities organized by ALS Québec were a natural way for the family to show their support and mobilize their network of friends and family while raising awareness and funds.

Throughout 2024, the five Delorme-Robitaille children, her husband Sylvain, and Valérie's network of friends and

colleagues participated in various combinations of the Ride to End ALS, the Walk to End ALS, the Beneva Marathon and the 10th anniversary of the Ice Bucket Challenge.

One of Valérie's wishes was for her family to participate in the Walk to End ALS, even though she was unable to. The day after her passing, united in their grief, family and friends attended the Walk in Saint-Adèle to pay tribute to Valérie and show her the love and support she had always shown them.



"The support we received from ALS Quebec was greatly appreciated, whether for Valérie, our father, or for us as adult children. It's easy to underestimate the amount of support needed until you experience that need firsthand. ALS Quebec was there for us at each step of the disease."

Melissa Robitaille, Valérie's daughter

Cycling enthusiasts hit the roads for a 17th year



Pushing pedals to pull in big fundraising results

Did you know our annual cycling event has raised more than \$4.2 million to date? Open to all levels and offering a choice of one or two-day routes, the 17th edition of the ALS Quebec RIDE took place in beautiful Salaberry-de-Valleyfield area.

A source of inspiration to all our riders this year was Jean-François Champagne. We met him in 2016 when he accompanied the ALS Quebec RIDE cyclists on his motorbike as part of the EMC (Escortes Motos Cyclistes). Then, in 2023, Jean-François was diagnosed with ALS.

Today, Jean-François can no longer ride his motorbike, but he continues to get involved in the causes that are close to his heart. He was therefore among us this year, supported by his many EMC colleagues.

"When I participated in the ALS Quebec RIDE eight years ago, I did not yet know that my loved ones and I would be affected by ALS and benefit from the work that ALS Quebec does. This year, I returned to the event to show my gratitude as someone living with the disease. I was very moved to see dozens of EMC pilots present for the start and to acknowledge their support."

Jean-François Champagne





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

SLA ALS

En collaboration
avec la collaboration
avec



ALS Quebec was proud to launch a new golf fundraising initiative that quickly became bigger than the sport.

Earlier in 2024, the golf community lost a beloved and passionate advocate, Patrick Rhéaume, who passed away just 15 months after his ALS diagnosis.

Inspired by Patrick, **United on the Greens to End ALS** was born. The fundraiser saw hundreds of golf enthusiasts teeing off at clubs across the province in September. Participants

secured their tee-off times by placing the winning bids in an online charitable auction featuring more than 70 golf packages and other sports-related items donated by participating golf clubs and golf pros.

In its inaugural year, United on the Greens raised more than \$80,000 for ALS Quebec. Thank you to Golf Quebec, PGA Quebec, the Association of Golf Courses in QC, the Association of Golf Course Owners of QC, the golf community, partner organizations, sponsors and media partners.



We would like to thank the following golf courses for uniting with us to end ALS:

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Community fundraising

Harnessing the power of many

Across the province, hundreds of people are taking the initiative to fundraise in their own way for ALS Quebec. Your support creates ripples of change that enable our work and help families affected by ALS discover strength, solidarity and hope. Thank you!

The Ice Bucket Challenge turns 10

The summer of 2024 marked the 10th anniversary of the Ice Bucket Challenge, a global movement that united people around the world to raise unprecedented funds and awareness for ALS. This incredible initiative fueled groundbreaking research and powered community support for people living with and affected by the disease.

To mark the anniversary, people across Quebec's ALS community paid tribute to this game-changing movement by getting soaked all over again!



Teamwork for the win!

After being diagnosed with ALS, long-time soccer coach Phil Lalonde decided to marry his passion for the sport with an annual fundraising event. 2024 marked the third year of the Coach Phil Senior Soccer Tournament to End ALS raising over \$161 000!

In recognition of his extraordinary impact, Phil received the inaugural Teresa Dellar Inspiration Prize from the Teresa Dellar Foundation.

“Phil’s journey is a true testament to the power of leadership and perseverance. Despite facing his own battle with ALS, Phil has channeled his energy into uniting the West Island community and raising awareness for ALS research through the Coach Phil Foundation. His tireless commitment to this cause exemplifies the spirit of this award.”

TDC Foundation



Small houses, big impact

Since 2011, Yvon Perron has raised more than \$82,000 for ALS Quebec, including over \$17,000 only in 2024, thanks to his miniature village of houses in the Charlevoix region.



Candles for the cause

Karine Soulières is a neighbour of Yvon Perron. She has taken the initiative to sell candles with proceeds donated to ALS Quebec.



Cheesecake sales

The bakery Si petit soit-il sold lemon-dipped cheesecakes with a portion of proceeds to ALS Quebec, raising \$460.



Softball tournament

Thank you to Mélanie Jolin and the organizing committee involved in the second edition of their benefit softball tournament.



Musical evening

DJ Martin Lavoie, who has ALS, organized a musical evening attended by over 250 people in March in Saint-Aimé-des-Lacs, Charlevoix and raised \$5,130 for ALS Quebec.



Training competition for the cause

Showdown Laval was a three-girl team functional training competition held on May 11, 2024. Gabryelle Lortie decided to add a fundraising element to the competition in tribute to her mother Julie Raymond, who died in July 2023 from ALS.



Michael Soles Bowl

The fourth edition of the Michael Soles Bowl, held in September in Pointe-Claire, brought senior football teams from two high schools – St. Thomas and Loyola – together in competition. This game is a celebration of Michael Soles' contribution to football at St. Thomas High School, John Abbott College, McGill University, the CFL's Edmonton and Montreal teams, and his support of Loyola High School during the years his sons Matthew and Anthony played football for the school.

Michael died in July 2021 after a long battle with ALS.



Corn roast

The Camping Parc de la Péninsule recreation committee organized a corn roast with 100% of the proceeds going to ALS Quebec to support a friend of the campground who has ALS.



Almonds for ALS

Mitzi Perez's family received support from ALS Quebec when her father was diagnosed with ALS. He died in September 2022, and Mitzi donates a portion of her product sales annually to ALS Quebec.

Team ALS Quebec in action

21K Montreal

The 21K de Montréal is the annual spring gathering of the Montreal running community, and 2024 marked the 10th year of ALS Quebec's participation. Two members of our team ran with Richard Gameiro, who participated in honor of his mother-in-law Anna Sforza who passed away from ALS in April 2018. "Since running is one of my passions," he says, "I decided to pay tribute to her in this way, while promoting the cause."



Beneva Marathon

2024 marked ALS Quebec's 3rd participation in the charity component of this event. Léa Dion was very emotional at the start of the race. She decided to take part in the Beneva Marathon in honour of ALS Quebec and her father, whom she lost to ALS six years ago.

Bromont Ultra

Our community was ready for the Bromont Ultra! Three members of the ALS Quebec team also took part in the weekend adventure, which was filled with energy, solidarity and hope!



"I lost my father to ALS. Proud and independent, he lost control of his body because of this disease. That's why, for several years now, I've been raising funds for ALS Quebec through the Bromont Ultra. I've run the 12km, the 25km and even the 55km thinking of him and raising money for you. It's very important to me and I'm very proud to think that I've probably reached or even surpassed the \$10,000 mark on my own. And I intend to keep going! Thank you for doing what you do."

Julie Fortier, daughter of Denis Fortier

The gift is you!

Celebrating our generous and talented volunteers

Giving back is a family affair

One of our support groups in Lorraine took on a celebratory tone in 2024 when the **Chantal Lanthier Volunteer Award** was presented by its namesake to our longtime volunteer and supporter Mylène Boudreault.

Connected to the ALS cause through her sister-in-law Josée, who passed away in 2019 at the age of 52, Mylène has given her time to ALS Quebec in a number of ways. As one of the organizers of the Ondes Positives team that was created to honour Josée and support ALS Quebec, she leads an annual can and bottle drive, holds garage sales, and sells chocolate and other goodies to raise funds. These community-based initiatives have raised more than \$100,000.

In presenting Mylène with her award, Chantal had this to say: "We wish it hadn't taken illness to bring us together, but that's how life goes sometimes. Mylène, you are an angel for all of us. You put a spring in our step; you are like a buttery sun that warms our insides and reaches straight into our hearts. By presenting you with this award, we would like to emphasize that for us and the ALS Society of Quebec, you and your entire team are our volunteer of the year."

Congratulations, Mylène, on this well-deserved recognition! Thank you for your steadfast dedication.



"Giving time to this cause has done a tremendous amount of good for me, both psychologically and physically. It makes me feel useful and above all it makes the whole world aware of this terrible disease.... I will fight until the end. I will continue until a cure is discovered for the disease."

Mylène Boudreault, volunteer at ALS Quebec; recipient of the 2024 Chantal Lanthier Volunteer Award



Thank you to all our volunteers!

We're grateful to the many people who generously give their most precious asset – their time – to support our mission and the ALS community.

Karen Abitbol	Marie-Christine Chabot	Jocelyn Dorion	Monica Hidalgo	Louis-Étienne Nadeau	Claude Rainville
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Facebook Fundraising

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

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3rd party events

All in for ALS (Tonina Barrata)	Five Three - Clothing's sale (Xavier Brunet)	Marathon Beneva 3 rd Edition	Showdown Laval (Gabryelle Lortie)
Almonds for ALS (Mitzi Perez)	Fundraising - Corn roast (Daniel Sicotte)	Marathon in honour of Coach Pat (Guillaume Lamarre)	Softball Tournament (Mélanie Jolin)
Amazon Awareness Day (Ayman Ibrahim)	Fundraising Fly & Ride Expedition(Rina Labrecque)	Marathon in honour of Coach Phil (William Boivin)	Spaghetti Dinner (Mélanie St-Jacques)
Annual fundraising - Miniature houses (Yvon Perron)	Fundraising in memory of Colette (Mélicha Trottier)	Meka Products (Karen Abitibol)	Tattoo designs for sale (Jorie Brisson)
Annual fundraising in memory of Francine Pharand (Suzie Pharand)	Golf tournament in Mike Paquin's memory (Christian Doiron)	Michael Soles Bowl 4 th Edition (Randy Burns)	The 21K de Montréal Charity Challenge
Annual fundraising- Tony Proudfoot (Paul Régimbal)	Hostile Western (George Hamel)	Musical dance evening (Martin Lavoie)	The Neko Van Project (Marine Maugeais)
Benefit comedy show (Stéphane Trottier)	Invincible Été documentary screening (Yannik Richard)	Ondes Positives (Mylène Boudreault et Catherine Panelli)	Valérie Delorme's memorial fundraising (Marie-Eve Robitaille)
Bromont Ultra - 11th Edition (Gilles Poulin)	Ironman 70,3 Tremblant (Spencer Levine)	Provigo St-Sauveur hot dog dinner (Sandra Lacroix)	Walk for Andée (Florence Auclair)
Cheese cake sale (Mélanie Bouliane)	Italian Open golf tournament (Lino Sabini)	R3NROZ - 4 th Edition (Roslynn Scott)	Walk for Claire Fontaine (Andrée-anne Martel)
Coach Phil Senior Soccer Tournament (Phil Lalonde)	Karl-o-thon (Véronique Privé)	Saint Chrysostome Derby (Cynthia Hébert & Jamie Pouliot)	Women's Golf Tournament in Mike Paquin's memory (Suzanne Bruneau)
DD Tournament 2024 (Samuel Paré)	Kickboxing Gala - 4 th Edition (Robert Gay)	Sale of candles (Karine Soulière)	

A special thank you to our Donors, Partners and Sponsors!

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

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Alouettes de Montréal	Chenail	IGA Famille Jasmin	Microtel Mont-Tremblant	SAQ
Auberge du Lac Saint-Pierre	Club de Hockey Canadien	IGA Jodoïn	Mimi et August	Scandinave Spa Vieux-Montréal
Auberge Godefroy	Défi Évasion	IGA Thetford Mines	Musée de la Civilisation de Québec	Sibéria Spa
Aura Basilique Notre Dame	Discair Productions	Kinipi Spa	Musée Pointe à Callières	Sport Expert - Côte Vertu
Barrfly	Distillerie 3 lacs	La Compagnie Vilandré	Ombrelle	Subway Valleyfield
BioSattva	Domaine du Ridge	La maison hantée de Saint-Étienne	Ooya	Tennis Canada
Birra Fanelli	Enterprise	Lambert	Orange Theory Fitness	Théâtre Denise Pelletier
Blanc ParRouge	Frankie's	Le Trident	Griffintown	Travelway International
BleuFeu	G2G Bar	Les Producteurs de lait	Parc de la Gorge de Coaticook	Trudeau
BotaBota Spa	Germain Hotel Québec	Capitale-Nationale et Côte-Nord	Propur	Volvo
Boutique Guindon	Giant Valleyfield	Manoir d'Youville	PWHL Montréal	Yoga Jeans
Burnbrae	Halte des Pèlerins	Mark Smith	QViva resort - Hotel Azura	Zoo de Granby
Centre des sciences de Montréal	Hotél & Spa Le Germain			Zoo Sauvage St-Félicien



PartenaireSanté Québec

Thanks to our partnership with Partenaire Santé, ALS Quebec benefits from valuable support that enables us to concretely improve the quality of life of people affected by ALS. This support strengthens our ability to respond to the specific needs of the community, by promoting collective and innovative initiatives for a more united and inclusive future.

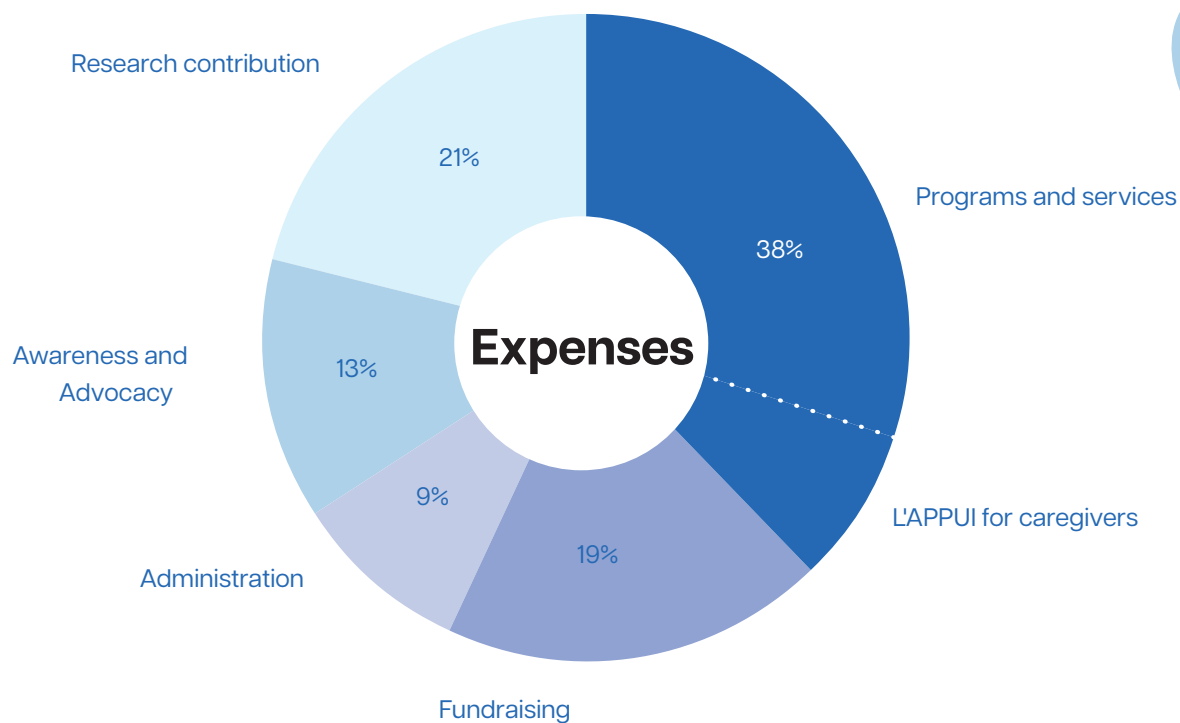
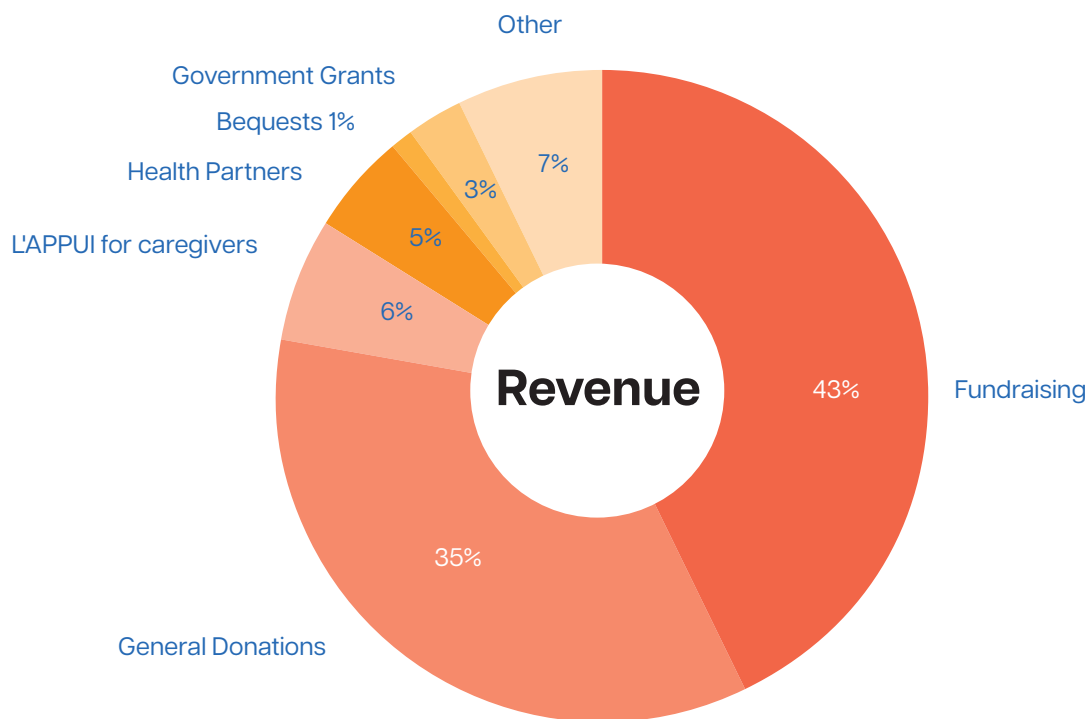
Financial Summary

Financial year from November 1st 2023 to October 31st 2024

REVENUE	2023-2024	2022-2023
Fundraising	\$883,487	\$912,765
General Donations	\$655,021	\$555,847
L'APPUI for caregivers	\$124,179	\$134,201
Health Partners Quebec & Canada	\$94,014	\$78,538
Bequests	\$18,750	\$25,000
Government Grants	\$67,666	\$58,230
Tony Proudfoot Fund	\$10,854	\$11,492
Team Stock Fund	\$1,050	\$2,360
Dr. Canuel Fund	\$38,510	\$30,134
Other	\$145,092	\$141,560
TOTAL	\$2,038,622	\$1,950,127
EXPENSES	2023-2024	2022-2023
Programs and services	\$661,194	\$535,041
L'APPUI for caregivers	\$161,118	\$145,027
Fundraising	\$426,258	\$326,419
Administration	\$188,497	\$138,166
Awareness	\$291,930	\$264,729
Research Contribution	\$458,240	\$273,641
TOTAL	\$2,187,236	\$1,683,023
Excess (deficiency) of revenue over expenses	- \$148,614	\$267,104

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

Breakdown of revenues and expenses



2023-24 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 and HR Committee



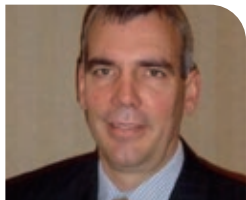
Tanya Luttrell, Vice-Chair
Former caregiver
Consultant at SISMIK
Culture d'impact
HR Committee



André Besner, Vice-Chair
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
Diagnosed with ALS in 2014
Research Committee
Finance Committee



Isabel Cyr
Director, Government Relations
& Public Affairs
Lithion Recycling Inc.
Former caregiver
Advocacy Committee



Vincent Gagné
Director,
Government Relations
TELUS Corp.



Mario Goupil
Retired journalist
Real Estate agent (Estrie)
Former caregiver
Advocacy Committee



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



Ann-Marie Léporé
Occupational Therapist
Programs and Services Committee



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





AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

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This report is also available in French.