ALS QUEBEC

Annual Report 2022-2023

Courage and **Community**

Taking action to end ALS with **COURAGE** and **COMMUNITY** support

Every person living with ALS deserves our support to navigate the overwhelming losses and challenges of this disease.

Together in community, we work tirelessly to ensure that people affected by ALS across the province have the necessary resources, support and opportunities to live their lives to the fullest.

Message from our Chair and Executive Director

Living with ALS means losing the very thing those facing the disease need most: strength.

Yes, physical strength may decrease. But the determination and compassion of the ALS community provide a different type of strength: the courage to take action against ALS.

Your support for ALS Quebec means that no matter where in the province they live, people affected by ALS have access to a community of support that is a source of strength and empowerment. Because of you, we can take action to go further.

Our accomplishments throughout 2022-2023 reflect the many ways we are listening to and responding to the needs of the ALS community. Guided by our strategic plan, we deepened knowledge and support within the ALS community through continued improvement to our support groups, ongoing dialogue with healthcare professionals, and an enhanced website.

We took bold steps to increase our support for ALS research within Quebec and Canada by renewing and expanding our commitment to the ALS Quebec Research Fund which was launched in 2022 with the help of generous donor and funder support.

We advocated for access to new treatments on behalf of the ALS community in Quebec, and our voice was heard.

We created more visibility for ALS by repositioning the organization through a successful rebranding exercise, redesigning our logo and revamping our website to drive awareness for our shared cause.

We are especially proud of:

- Our united team and the compassion that runs throughout the organization.
- Our dedicated volunteers and staff who have worked side-by-side to uphold our common vision.
- Our volunteer Board members, many of whom have a personal connection to ALS, who provide governance oversight to our organization.

And many thanks to all of you for your continuous support. It means the world to us.

Thank you for embodying hope!

Susan Kennerknecht

Chair, Board of Directors
ALS Society of Quebec

Claudine Cook

Executive Director
ALS Society of Quebec

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 – 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, finally, 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 impacts 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.

We are in this together

People living with ALS never need to feel alone with the strength of our community in Quebec. Through our support and resources, families affected by ALS can find a sense of belonging and lean on each other for strength and wisdom. Throughout 2022-23, we deepened our community connections to better respond to the needs of people affected by ALS, whose passion and wisdom guide us every day. And we did this with your vital and ongoing support.

How we support our community

Information

- Documentation
- Educational webinars
- Website and online, on-demand resources
- Newsletters

Psychosocial and Community Support Programs

- Orientation and reference
- Personalized support and toll-free line
- Support groups
- Short-term financial support
- Bereavement support

Awareness, Social and Networking Activities

- Social activities and events
- Online community
- Professional networking activities
- Interaction with ALS research community

Opportunities to Get Involved

- Advocacy
- Volunteer
- Ambassador's club

> “ *ALS Québec is a precious organization, and the counsellors are essential in helping us understand and live with ALS. I salute your great dedication. What you do for people with ALS and their caregivers is priceless! It's wonderful to see the empathy, openness and kindness you show in your approach to people.* ”
>
> - **Alain St-Hilaire,** Living with ALS since 2022

The impact of our community outreach

6,500+
members (persons diagnosed with ALS, caregivers, bereaved loved ones, and healthcare professionals)

560
people living with ALS (30% of them newly diagnosed) registered with ALS Quebec

156
families affected by the death of a loved one with ALS

1,400
people living with ALS, family members, and bereaved people stayed informed and connected through our newsletter

500+
people affected by ALS received timely individualized support and counselling

60%
of support by our counsellors focused on helping caregivers needs in addition to those of the person living with ALS

484
participations in
21 educational webinars

475
participations in
60 support group meetings

193
healthcare professionals joined our new Community of Practice

17
regions in the province had access to resources and support

284
online resources were made available on our **NEW** and improved website

160+
participants attended our research webinars and Q&As

Community support for families and healthcare professionals

ALS can be an isolating disease. Often, families do not know anyone else who has been diagnosed. And as the disease progresses, communication and mobility become more challenging. One of our strengths is in bringing the ALS community together, whether virtually or in person, to find community and courage in shared experiences.

Peer-to-peer support joins kindred spirits

Ginette and Line bonded like sisters from the moment they were introduced through ALS Quebec's Peer-to-Peer Support Program. For seven years, they leaned on each other, comforted by the knowledge that living with ALS gave them a unique understanding of what the other was experiencing. In their silence, they understood each other and had the same vision of things.

They embodied hope together, re-living moments of their youth through music, bursting into song without even the use of their voices, and dancing in their electric wheelchairs like two teenaged girls. Together, they participated in support and fundraising events for ALS Quebec, building precious memories and courageously advocating for their community. After living with ALS for 21 years, Ginette's courageous journey ended in June 2023. Nevertheless, friendship is stronger than ALS. Ginette continues to live within our hearts and to inspire us every day.

Workshop addresses unique needs of young people

The idea behind running a workshop for youth with a family member living with ALS was originated by several young people ranging in age from 7 to 16. In 2023, ALS Quebec collaborated with a youth social services organization, Deuil Jeunesse, to hold its first ALS Youth Workshop which was both educational and provided a safe space to share their personal stories. They raised issues unique to their stage in life, including their role in the family, how to talk about difficult topics, the impact of ALS on their school life and social relationships, managing their emotions, and a growing sense of responsibility as young caregivers.

> *“I’m very grateful to have had the chance to attend a support group adapted for young people. First of all, I appreciated being able to learn more about this disease and having some of my questions answered. What’s more, being able to talk to other young people in the same situation made me feel understood, because even if you talk about it with your friends or family, there’s no one who really knows what emotions you might be feeling, or even how to react when you open up to them.”*
>
> \- **Béatrice Corriveau,**
> Granddaughter of a person living with ALS

ALS Quebec launches new Community of Practice for healthcare professionals

Since 2012, healthcare professionals have met regularly with ALS Quebec staff via conference call and videoconference to discuss issues related to their practice with families living with ALS, a group called the Exchange Forum. In September 2023, ALS Quebec launched a new Community of Practice (CoP), an online forum on Microsoft Teams where healthcare professionals can participate in ongoing conversations, post questions, and share up-to-date information to help establish best practices and expand our collective knowledge on a continuous basis, no longer limited to the Exchange Forum meeting times. To date, nearly 200 members of various professions have signed on!

Most importantly, the CoP was created to offer professionals a supportive environment where they can feel comfortable sharing as part of the larger ALS community that embraces vulnerability, compassion, and the courage we discover when we are there for each other.

‘Seize the Day’ grants 50 families their special wish

Thanks to the Tenaquip Foundation, the “Seize the Day” program allows people living with ALS to create memories with their loved ones. As of today, more than 50 families have gathered to enjoy special events such as sailing, renting cottages, ice fishing, celebrating a wedding, attending a movie and enjoying family picnics! Many wishes have come true and brought joy into the lives of families with ALS.

“ *I was diagnosed with ALS 19 years ago and have been living in a long-term care facility for many years. Before ALS became so physically limiting, I would go to the movies every week. Now, I only watch movies in my room. But thanks to the Seize the Day program, ALS Quebec arranged for me to see* Batman vs Superman *in 2016. Seven years later, the next time I left my room, they took me to see* Avatar 2. *Seeing a movie in a theatre with family and friends is something I cherish and hope to do more often* ”

- **Carlos Botelho,**
Living with ALS since 2004

“ *Receiving dad’s ALS diagnostic last April was like being swept away by a huge tornado. One of the many fears I had was that he wouldn’t be there to walk me down the aisle at my wedding. Organizing the event in a short amount of time on a tight budget felt overwhelming but ALS Quebec came through with a generous financial gift to make our wedding day extra-special for dad and for the whole family. Thank you for a precious day with loved ones we will never forget!* ”

- **Catherine Lespérance LeBouthillier,**
Father living with ALS

“Thank you so much again. It's so much appreciated!

We met at the cottage I was able to rent, thanks to your support.”

Guylaine Larone's family

“You make us so happy! Thank you so much! Since our father is staying far away from his family, we rented a cottage where he could see his children and grandchildren.”

Emanuel Peirera's family

“Once again, thank you for allowing us to experience these wonderful moments as a family!”

Norman Simard's family

We extend a heartfelt thank you to the Tenaquip Foundation for their continuous support of our mission over the past 19 years and for being the driving force behind our ***“Seize the Day”*** program, creating precious moments and lasting memories!

THE **TENAQUIP** FOUNDATION

Raising awareness: Empowering our community

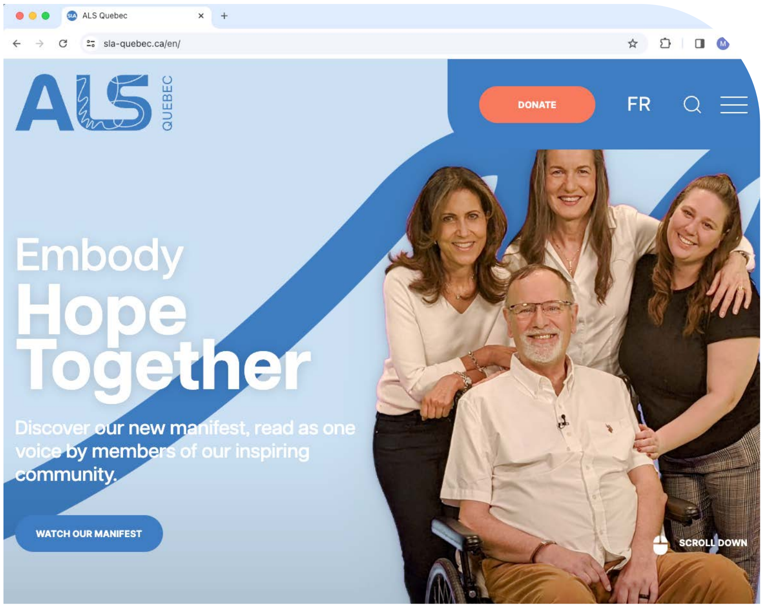
After the shock of an ALS diagnosis, many families affected by the disease are looking for answers and information. ALS Quebec is there to help. As they become more aware of the everyday challenge of people living with ALS, they often choose to raise awareness and advocate for the needs of the ALS community. These acts of courage are essential in the fight against ALS. We empower our community to take action alongside us so that together, we are creating the visibility and influence needed to drive positive change.

Revitalized brand amplifies our message of hope

Last June, we proudly unveiled our new brand identity, featuring a redesigned logo and new tagline to help communicate our message clearly and effectively. Our new logo signifies the fragility of life when ALS disrupts the path of those affected by the disease and their loved ones. But, more importantly, it symbolizes the strength of our support and the courage of our community to overcome ALS, which is the key message in our new tagline, EMBODY HOPE TOGETHER.

Our re-branding shines a new light on our core mission so we can amplify our message. At the heart of it all, we remain the same caring organization that provides support to families affected by ALS, raises awareness among the public, engages with health professionals and government authorities, and contributes to important ALS research.

Access to information is easier than ever!



Embody Hope Together

Discover our new manifest, read as one voice by members of our inspiring community.

When reviewing our brand identity, we also reviewed and redesigned our website. The site's user-friendly format and enhanced functionalities allow for easier access to valuable and up-to-date information about ALS as well as useful resources that empower families who live with ALS.

Visitors can also explore the various ways to get involved and inspire people around them to take action and support the cause.

Our new Manifesto: Hope embodied through community action

On Global ALS Awareness Day, we shared our meaningful new Manifesto featuring members of our community. As we Embody Hope Together through our actions and our words, we amplify our voices around a united vision.

Thanks to the entire team who helped to produce our ALS Quebec Manifesto: Louise Michaud and the RDS crew from Bell Media, our amazing community who joined us from across the province to take part, and Atypic for their creative direction. Together, we made this special project a reality.

The Manifesto was part of an awareness campaign that reached 199,137 people across the province.

Our digital footprint is growing

As part of our strategic plan, we focused on raising awareness and invested in reaching out to our community via digital media strategy and integrated communications. We are very pleased with the metrics we have seen so far and we look forward to continuing this momentum in 2024.

Our digital footprint is growing. We raised awareness through campaigns, increased digital engagement with our community, and increased the number of public outreach initiatives by our Ambassadors.

99,000
users on our new website: als-quebec.ca

144
newsletters sent to our community

55
media mentions and articles raising awareness about the *Walks* and the *Ride to End ALS*, resulting in
9 million impressions

8,894
Facebook followers

413,859
Global reach

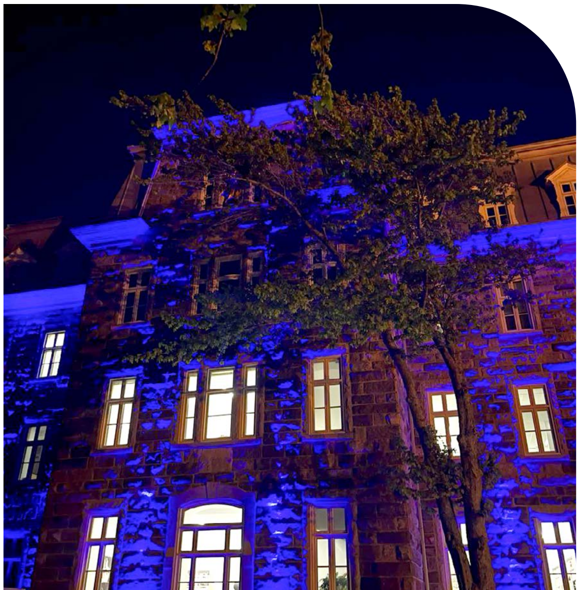
18,194
Interactions (likes, shares, comments)

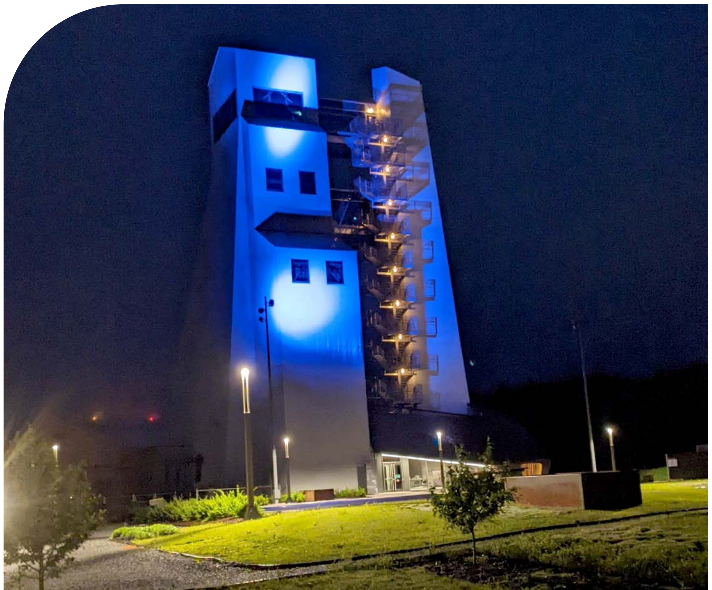
Members of the National Assembly speaks up for our community action

Quebec's National Assembly members, **Michelle Stelakwe** (Member for Mont-Royal-Outremont and Deputy House Leader of the Official Opposition) and **Sylvain Lévesque** (Member for Chauvreau and Second Vice President) addressed the government on behalf of the 600 people in Quebec living with ALS and their families in a call to action to raise awareness about the disease and increase the level of support available. Thank you, Mrs. Setlakwe and Mr. Lévesque, for bringing our cause to the attention of legislators and the public at large.

Blue skies for ALS Awareness Month

To mark ALS Awareness month in June, 16 buildings in 8 cities around the province of Quebec were lit up in blue to help raise awareness about ALS. City halls, churches, stadiums, hotels and other landmark sites in Montreal, Québec City, Trois-Rivières, Alma, Chicoutimi, Montebello, Rivière-du-Loup, Thetford Mines, and La Malbaie were all part of this initiative. Thank you for lighting up our hearts and inspiring us to keep working for positive change together!





Advocacy: The courage to speak up

Norm MacIsaac and Mario Hudon: Courageous advocates for our cause

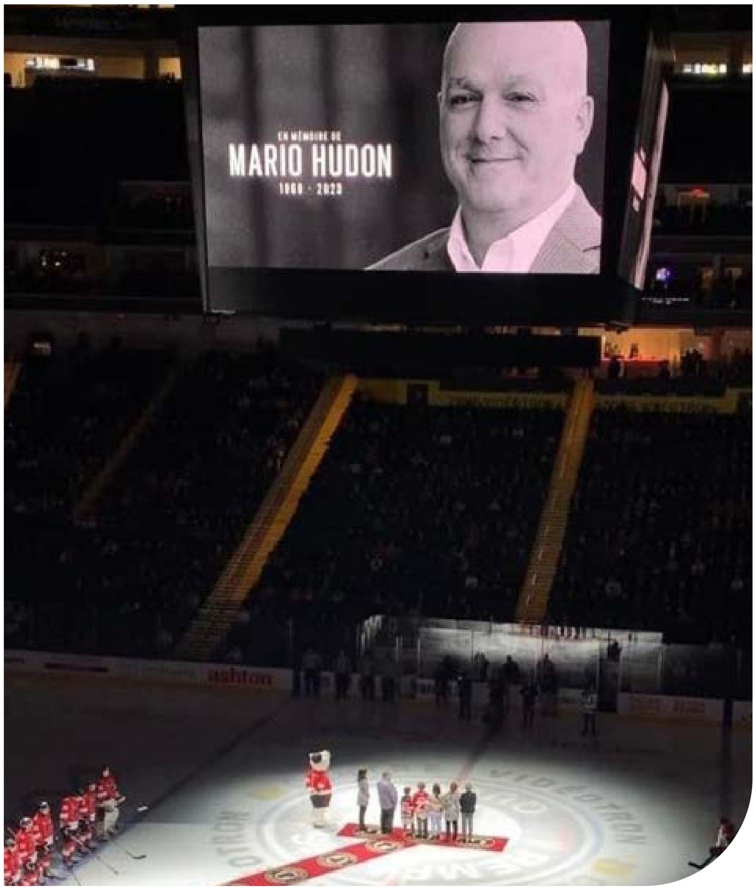
For the past three years, Board members Norm MacIsaac and Mario Hudon co-chaired the ALS Quebec Advocacy Committee with the kind of grit and determination that moves people to action. Despite the monumental challenges of living with ALS, they championed our community on radio and television, on social media, at press conferences and public events, and directly with government. Their courage and perserverence paid off in expanding access to innotaive treatments. There is still much work to do to expand access to this and other treatments, but for now, we celebrate and acknowledge the power of collaboration and the success of our inspired leaders. **Thank you!**

Tribute to Mario Hudon: Former radio announcer never lost his ability to connect

The ALS community lost one of its most courageous and vocal advocates on November 20, 2023. Drawing on his broad network of contacts and friends, many from his professional life as a sportscaster, Mario rallied for the team from the moment he was diagnosed with ALS in 2020. Mario worked tirelessly to bring attention to the devastating realities of living with ALS. He was a model of courage and fortitude and an inspiration to all of us. We will remember you, Mario, as one of the best.

Paying tribute to Mario, Chantal Lanthier, a cherished member of our community, shared these words on her Facebook page:

> *“ Mario is a shining example of strength and courage. As one of the great ambassadors for ALS Quebec, he gave his all to advance our cause. Today, with great sadness, I wish to pay him the respect he truly deserves. Mario, my heart is with you and your family. Thank you for your message of perseverance and the way you love life and cherish people. Your legacy to your children and grandchildren will make them so proud. ”*



Collaboration with Neuro Partners strengthens our collective voices

Neuro Partners
Progressive Neurological Diseases

For the past seven years, ALS Quebec has been partnering with Neuro Partners, a group of five organizations in Quebec dedicated to supporting people living with a degenerative neurological disease. They include the MS Society of Canada (Quebec Division), Parkinson Quebec, Muscular Dystrophy Canada (Quebec Division), the Huntington Society of Quebec, and the ALS Society of Quebec.

Together, we can do more to raise awareness and work in collaboration with elected officials to address issues of importance to our members: home care, housing, support for caregivers, access to innovative treatments and clinical trials. ALS Quebec plays a key role in supporting these efforts, acting as a resource, and volunteering its members to join committees and take part in consultations.

Research is hope

ALS Quebec commits to $1 million research fund

The ALS research community in Quebec is among the best in the country. This active and passionate group of professionals inspires us with their dedication to better understanding and treating ALS. As we continue to build the ALS Quebec Research Fund governed and guided by an esteemed committee to channel donor dollars into the Quebec research community, we continue to contribute to the national ALS research program administered by the ALS Society of Canada to fund the most promising research nationwide. The fund will also support the next generation of ALS researchers through bursaries and travel grants with the goal to maintain and nurture research talent in Quebec and Canada.

Many thanks to our Scientific Committee for their tremendous leadership in helping us form a cohesive and effective plan to support research investment which is such a vital part of our mission:

Dr. Richard Robitaille,
Full professor, Neurosciences Department, Université de Montréal, ALS Quebec Board member and Chair of Research Committee, Scientific & Medical Advisory Council (SMAC) member

Dr. François Gros-Louis,
Full Professor,
Université Laval

Dr. Geneviève Matte,
Neurologist, CHUM

Dr. Chantelle Sephton,
Associate Professor,
Université Laval

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

Dr. Jean-Pierre Canuel,
ALS Quebec Board member, Diagnosed with ALS in 2014

> *“I lost my grandmother to ALS in 2000 and my father in 2004. As part of the ALS research field for more than a decade now, I’ve seen tremendous advances since the ALS Ice Bucket Challenge in 2014. There are promising new treatments, targeted genetic treatments for specific genetic mutations, and many more potentially ground-breaking therapies currently in clinical trials. The future looks promising!”*
>
> \- **Elsa Tremblay**
> PHD Student, Université de Montréal

2023 ALS Canada Research Program overview

The ALS Society of Quebec is proud to have contributed $265,000 to the national ALS Canada Research Program which works towards 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% of net proceeds from the *Walk to End ALS*.

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 was awarded to Dr. Alex Parker, Université de Montréal, for his project titled "*Axonal degeneration as a therapeutic target for ALS.*"

Dr. Jean-Pierre Canuel Fund – SLA Québec will support another project as part of last year's ALS Canada-Brain Canada Discovery Grant Program and an announcement will be made in early 2024.

ALS Québec is proud to partner with donors to help maximize our investments and our impact on ALS research.

As part of the **2023 ALS Canada-Brain Canada Trainee Award program,** one of the Doctoral Awards was supported by the Fondation Vincent Bourque.

Anna Huynh, a PhD student in Dr. Yana Yunusova's lab at Sunnybrook Research Institute, was awarded $50,000 over two years for her project, *Development of a shared decision-making aid for bulbar symptom management in ALS.*

Funding for the 2023 Award was made possible by the Fondation Vincent Bourque, who generously contributed $25,000 to ALS Canada, which was matched by Brain Canada through the Canada Brain Research Fund (CBRF)*.

Over the years, the Fondation Vincent Bourque has supported research programs in the amount of $397,875 and donated $260,000 to support families affected by ALS in Quebec. Thank you to 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*.

**The Canada Brain Research Fund, is an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada*

> "*We are grateful to ALS Quebec and partners for their valuable contribution to our national research initiatives. Our vision of a world free of ALS will be achieved much faster when we work together to fund science that can truly make a difference in our understanding of the disease, and our ability to translate that into urgent treatments that will change people's lives.*"
>
> \- **Dr. David Taylor**
> Vice-President, Research and Strategic Partnerships, ALS Canada

Families and researchers connect face-to-face and virtually

ALS Quebec hosted two successful ALS research conferences in 2023, led by Dr. Richard Robitaille and attended by 160 members of our community. People living with ALS and their families were able to interact with researchers and clinicians during Q&As in person and online. It was an excellent opportunity to learn about the latest developments going on in the labs and to strengthen the bond between families affected by ALS and the scientific community.

RESEARCH OVERVIEW AND Q&A

23 • 02 • 2023

DR. RICHARD ROBITAILLE
Full Professor, Department of Neuroscience, Faculty of Medicine, University of Montréal

DR. ANGELA GENGE
Director, ALS Centre of Excellence for Research and Patient Care, Executive Director, Clinical Research Unit, The Neuro

DR. GENEVIÈVE MATTE
Clinical Assistant Professor, Department of Neurosciences, Faculty of Medicine, University of Montreal, Research investigator, CHUM Research Centre

DR. NICOLAS DUPRÉ
Full professor, Department of Medicine, Faculty of Medicine, Université Laval

DR. CHANTELLE SEPHTON
Associate Professor, Université Laval, CERVO Brain Research Centre

DR. SYLVIE GOSSELIN
Associate Professor, Department of Medicine, Department of Neurology, FMSS, University of Sherbrooke, Neurologist, CIUSSS de l'Estrie-CHUS

Montreal plays host to our global ALS community

Our global community is gathering in Montreal in 2024 for the International Alliance of ALS/MND (Motor Neuron Disease) Associations and the MND Research Symposium which will be co-hosted by ALS Quebec and ALS Canada. More than 1,500 delegates from 40 countries are expected to attend to discuss the latest in ALS research and the best practices in care and support for people affected by ALS. We are excited to come together for this incredible opportunity to share, collaborate and learn together.

Co-hosted by:

SLA QUÉBEC ALS

ALS SLA CANADA

Organized by:

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

mnda motor neurone disease association

New online hub simplifies search for clinical trials

Quick access to information, treatments and clinical trials is essential for people with ALS. Powered by the CATALIS Quebec Network and developed in partnership with the Quebec government, Clinical Trials Quebec (CTQ) is an innovative new information and services hub that makes it easy for individuals all across the province to learn about clinical research and find clinical trials that could prolong their lives. Over the past two years, ALS Quebec proudly took part in the Advisory Committee for this important service to our community.

CAPTURE ALS: A revolutionary platform for ALS research

CAPTURE (**C**omprehensive **A**nalysis **P**latform **T**o **U**nderstand, **R**emedy, and **E**liminate) ALS is a Canadian platform that unites patients, physicians and researchers in academia and industry to study ALS. CAPTURE ALS provides the systems and tools necessary to collect, store, and analyze vast amounts of information about ALS, creating the most comprehensive biological picture of people with ALS. By openly sharing this information with other worldwide ALS initiatives, Canadians will play a major role in the global effort to understand and treat ALS.

Looking ahead, ALS Quebec looks forward to supporting the expansion of this important platform in Quebec.

ALS CAPTURE ALS THE SOLUTION IS IN YOU

Community fundraising: Fuelling collective action

ALS takes so much. And that is why we are thankful for all you choose to give. Our donors and volunteers are champions of the cause who are committed to supporting the needs of the ALS community. Your impact is transformational because of how it affects people's lives. Because of you, families affected by ALS can find community and courage at an incredibly difficult time. And in the face of ALS, it is community and courage that fuel our collective action against ALS.

Walks to End ALS raise $280,000: Every step counts!

The *Walk to End ALS* is a signature fundraising event for the ALS community that takes place across Canada. In Quebec, 8 walks were organized with volunteers and supporters.

In Quebec City, members of our community were on the baseball field for a ceremonial first pitch with our long-time sponsor of the Walk to End ALS, the Capitales de Québec.

Louis-Étienne and Emmanuelle Nadeau organized the first Thetford Mines' *Walk to End ALS* to honour their late father, Germain.

Thank you to everyone who participated in the Walks for bringing attention to our cause.

> “*We organized this walk in memory of our father, Germain Nadeau, who was well known in the region. But above all, we're doing it to support the mission of the ALS Society of Quebec. We are convinced that if he was still alive, albeit ill, he would have encouraged us to organize this walk!*”
>
> \- **Louis-Étienne** and **Emmanuelle Nadeau,**
> Father passed away from ALS in 2019

Victoriaville embraces 16th annual Ride

Our 2023 Annual *ALS Quebec Ride* showcased the strength of our ALS community in the Victoriaville region last summer. Co-presidents Nicole Bergeron and Max Sévégny lent their support for this exceptional event in memory of Guy Aubert who passed away from ALS in 2019, raising more than $425,000. Thank you to the SERVIR Foundation for their 5-year financial commitment with the *ALS Quebec Ride*.

Some teams and participants went the extra mile to design their own cycling event closer to home. We would like to highlight the outstanding fundraising effort of Teams Denis MEGA POWER in Charlevoix, and Susan's Angel from Nuns' Island who each raised about $15,000. Thank you for contributing in your own way to this outstanding fundraising effort.

Uphill challenge shows strength of resolve

In February 2023, Jean-François Trudeau achieved an extraordinary physical feat to help raise $33,000 for ALS Quebec at the Centre multisports André-Chagnon in Vaudreuil-Dorion. Though most participants in the Everest Challenge 8848 climbed as a team, Jean-François cycled the equivalent of climbing Mount Everest, 8,848 metres, solo. He did it not once, but twice in only 28 hours! Sadly, his mother-in-law, Mrs. Théorêt, passed away from ALS on January 8, 2024. Humbled by witnessing his mother-in-law's extraordinary courage in the face of ALS, he recently posted on Facebook, **“***I used to think my athletic triumphs made me the most resilient member of the family. But I was dead wrong. What I've endured doesn't hold a candle to what it takes to live with ALS.***”**

Hats off to Hostile Western!

Georges Jr. Hamel is donating proceeds from the sale of its caps, one of his best-selling item, to ALS Quebec. In 2023, Georges raised more than $7,000. That's a lot of caps sold for a good cause! His apparel company, Hostile Western, promotes the cowboy lifestyle, a passion Georges shared with his late father who passed away from ALS.

Let's kick ALS out of the ring!

Organized by Robert Gay in memory of his mother, the 3rd annual Mont-Laurier Kickboxing Gala raised $8,000 to support the mission of ALS Quebec. Congratulations Robert and all the members of your fierce team for throwing a mean punch and kicking ALS where it matters!

Coach Phil scores another big win!

Soccer coach and community organizer Phil Lalonde's second annual Soccer Tournament surpassed even last year's huge success, raising $57,875. The Pointe-Claire community rallied around their beloved coach to show how much they care and how inspired they are to keep moving forward, no matter what it takes.

Travel with purpose: Climbing mountains to end ALS

Anthony Soles turned an idea that started as a travel plan to summit large mountains into something with a much bigger purpose. He wanted to honour the memory of his father, Michael Soles, a former McGill Redmen and Alouettes player who lived with ALS for more than 16 years. Anthony and his friend William Stone-Barney set out to summit and ski Mt. Rainer, Mt. Hood, and Mt. Washington as part of a challenge to raise funds and awareness around the harsh realities of this life-altering disease. Anthony also wanted to share one of the important life lessons his father passed on in a letter to him: **“***Live every day to the fullest and never take the time we have for granted.***”** Thank you, Anthony and William, for raising $20,000 and for helping spread the word.

A race against time

For Andrée-Anne Trépanier, participating in the Marathon Beneva holds special significance. Her father, an avid runner, experienced his first symptoms of ALS as he was about to embark on a new racing season. In 2023, Andrée-Anne and her team raised close to $6,000 in a race against time to beat ALS once and for all. Congratulations to all participants who chose to run for ALS Quebec and who raised in total, more than $12,000.

The Bromont Ultra: Going above and beyond

For the last 10 years, ALS Quebec has been participating in the Bromont Ultra, alongside other organizations who each compete for their own cause. One of this year’s ALS Quebec team captains, Catherine Tellier, rallied her friends and family in honour of her aunt Nicole who is living with ALS. Thank you for transforming your compassion into meaningful action everyone! You proved once again how strong and resilient we are as a community determined to improve the lives of those affected by ALS.

Volunteers: Inspiring courage and embodying hope

Transforming loss to give hope in community with others

After more than 16 years of service with ALS Quebec, Diane Tkalec can only be described as a “*volunteer extraordinaire.*” Diane has been an unstoppable force for positive change in the ALS community as a board member, advocate, an active participant, volunteer and fundraiser at events to support our mission. She even researched and produced ALS Quebec's Nutritional Guide, an essential resource to help our families.

“*Sometimes in life we see and experience things that make us stop and demand that we take action,*” explains Diane. When she lost her 49-year-old husband (and father to their only daughter) to ALS in 2007, she took what she had learned as a caregiver, professional nurse, and bereaved wife to show her daughter “*that it is possible to face life's challenges with integrity, compassion and altruism, ultimately making a meaningful difference in the community.*” There isn't a day that goes by that Diane isn't conscious of her ability to speak, swallow, write, walk, and breathe. And not a day that goes by that she doesn't renew her commitment to help improve the care and quality of life of those affected by ALS and support research to unlock some of the mysteries of this ferocious disease.

After 10 years of service on the board of ALS Quebec, Diane will be stepping down as an administrator on the Board of Directors and as President of the Client Services and Programs Committee. However, we know we will continue to see her at our events, and she won't be far when we need some guidance and input.

Thank you for your years of service Diane! We are forever grateful.

Special thanks to our volunteers

Thank you to our devoted volunteers, tireless participants and loyal partners! Your continued support gives hope for a future without ALS, while providing the best care for our community. Your time commitment and your compassion forge the bonds that keep our community united behind our common cause.

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3rd party events

4500 m to end ALS (Dominique Forgues)
Annual fundraising - Miniature houses (Yvon Perron)
Annual fundraising activity (Elias Makos)
Annual fundraising in memory of Francine Pharand (Suzie Pharand)
ATV Ride (Stéphane Trottier)
Auction (Line Goulet)
Big Mountains, bigger cause (Anthony Soles & William Stone)
Birthday party (Patrick Rhéaume)
Bowl-A-Thon 2nd Edition (Luc Bisaillon)
Bromont Ultra 10th Edition (Gilles Poulin)
Coach Phil Senior Soccer Tournament (Phil Lalonde)
Comedy show (Laurie Barrette)
Défi Éverest 8848 (Jean-François Trudeau)
Félix Brousseau comedy show (Félix Brousseau)
Golf tournament (Jasmin Dumas)
Harmony Trend' show (Étienne Paquet)
Hockey Pool - Cage aux sports (Phil Laroche)
Hostile Western (George Hamel)
Karl-o-thon (Véronique Privé)
Kickboxing Gala 3rd edition (Robert Gay)
Marathon Beneva 2nd Edition
Michael Soles Bowl 3rd Edition (Randy Burns)
Online fundraising in honor of Jean (Robert Trépanier)
Online fundraising in memory of Richard Aubin (Stéphanie/Katia Aubin)
Pause for the cause (Josiane Dubé)
Photos exhibition (Steeve Baker)
R3NROZ 3rd edition (Roslynn Scott)
Retro benefit evening (Pierre Laprise)
Sale of bracelets (Valérie Boudreault)
Sale of pottery (Francine Bohémier)
Softball tournament (Mélanie Jolin)
Stud' and Ride for ALS (Marine Bord)
The 21K de Montréal Charity Challenge
Véronique colleagues' Fundraising (Marie-Ange de Boutray)
Waitress for a night (Jean-François Brun)


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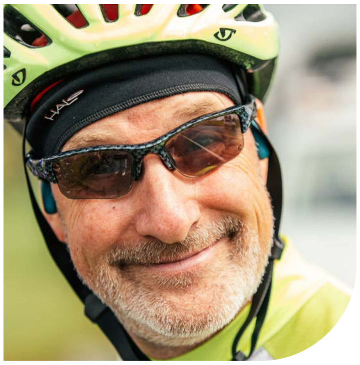


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A special thank you to our donors!

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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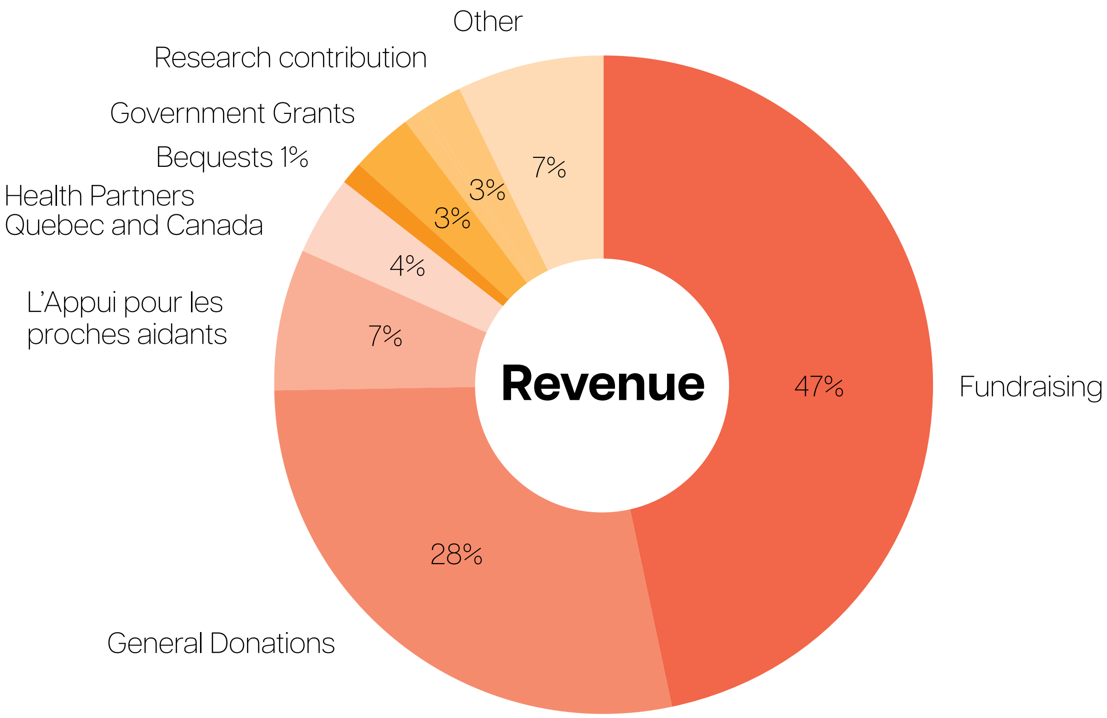
Financial Summary

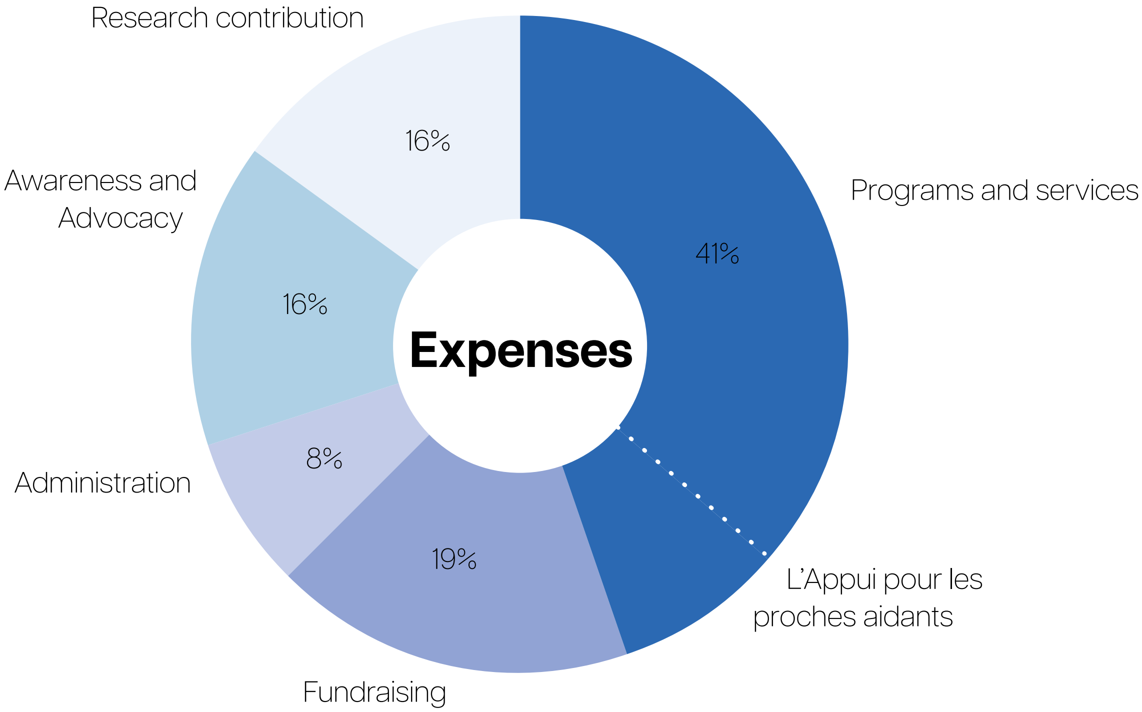
Financial year from November 1st 2022 to October 31st 2023

REVENUE	2022-2023	2021-2022
Fundraising	$912,765	$844,987
General Donations	$555,847	$642,710
L'Appui pour les proches aidants	$134,201	$148,317
Health Partners Quebec & Canada	$78,538	$84,089
Bequests	$25,000	$411,068
Government Grants	$58,230	$79,714
Tony Proudfoot Fund	$11,492	$15,101
Team Stock Fund	$2,360	$11,245
Dr. Canuel Fund	$30,134	$73,163
Other	$141,560	$31,346
TOTAL	**$1,950,127**	**$2,341,740**

EXPENSES	2022-2023	2021-2022
Programs and services	$535,041	$402,662
L'Appui pour les proches aidants	$145,027	$141,709
Fundraising	$326,419	$267,491
Administration	$138,166	$107,769
Awareness and Advocacy	$264,729	$206,514
Research Contribution	$273,641	$108,672
Total	**$1,683,023**	**$1,234,817**
Excess (deficiency) of revenue over expenses	$267,104	$1,106,923

Breakdown of revenues and expenses





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

2022-2023 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.

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Former caregiver to a loved one with ALS

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Diagnosed with ALS in 2014

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Former caregiver

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Neurosciences Department, Université de Montréal
Research Committee

Diane Tkalec
Nurse Clinician
Former caregiver
Programs and Services Committee

Mario Hudon
Former sports commentator, ALS Warrior (December 2020-November 2023)
Advocacy Committee

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

Our inspiring community in action

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This report is also available in French.