

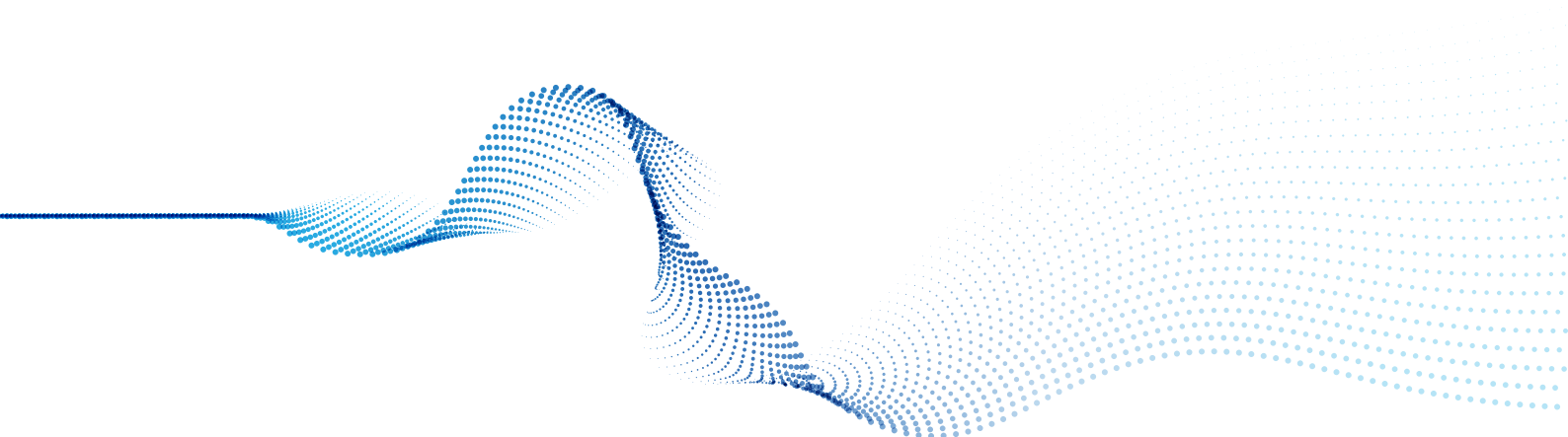


2021-2022 ANNUAL REPORT

A large, abstract graphic consisting of a series of white dots arranged in a wavy, undulating pattern that spans across the middle of the page.

AMPLIFY

Louder together.
Stronger together.



AMPLIFY

ALS can take away the ability to speak. So, we must make our voices louder.
ALS can take away the ability to move. So, we must create our own momentum.
Together, our voices are louder. Together, we can go further.

Together, we can realize our vision:

People affected by ALS have the necessary resources, support and opportunities to live their lives to the fullest.

A UNITED COMMUNITY TAKING ACTION TO MAKE A POSITIVE IMPACT

Time and time again, the ALS community proves that there is strength in numbers and that by working together, we can push further than we could have imagined on our own. That collaborative spirit has been at the heart of ALS Quebec's work in 2021/22. Our accomplishments over the last year reflect the many ways we are listening to and responding to the needs of the ALS community. We are operating in a changing environment that requires stronger advocacy as new therapies emerge. It also requires stable research funding to further fuel scientific discovery – always with a focus on the well-being of Quebecers affected by ALS.

We are especially proud of our united team and the compassion that runs through the organization. Our Board members have collaborated on a new strategic plan that clearly defines our mission and our path forward. Our dedicated volunteers and staff have worked side-by-side to uphold our common vision. Together, we have raised the profile of ALS, increased our full range of support services and extended our reach across the province through in-person

and virtual contact. We have also renewed and expanded our commitment to ALS research by launching the ALS Quebec Research Fund whose goal, with partnerships, is to maintain and nurture research within Quebec and Canada.

This year marks our 40th anniversary. It has been a time to reflect on how we arrived here today, and a time to build toward a promising future. As part of our renewal, we repositioned the organization through a successful rebranding exercise, redesigning our logo and revamping our website to improve communications so we can connect with, advocate on behalf of, and inform our community better than ever before. We also became a proud member of the International Alliance of ALS/MND Associations, a global network joining organizations around the world committed to the fight against ALS.

The momentum that inspires all of us to press on helps foster hope for individuals and families affected by ALS in Quebec. Thank you for helping us lift spirits, raise voices, and move the dial on ALS. We are deeply grateful.



Susan Kennerknecht
**Susan
Kennerknecht**

President, Board of Directors
ALS Society of Quebec



Claudine Cook
Claudine Cook

Executive Director
ALS Society of Quebec

WE CAN GO FURTHER

ALS is not a disease to be faced or fought alone. That's why we believe in the power of the community. By working together, individual efforts are amplified to make today's struggles with the disease less burdensome, and to create a future where an ALS diagnosis does not mean the same thing it does today.

ABOUT AMYOTROPHIC LATERAL SCLEROSIS (ALS)



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

1:1

Each year, 1,000 Canadians are diagnosed with ALS—for each person diagnosed, someone else 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.

We are deepening our resolve to help people affected by ALS in Quebec:

- 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.

2021-2022

BOARD OF DIRECTORS OF THE ALS SOCIETY OF QUEBEC

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
President, Conseil BKK
Consulting Inc.



ANDRÉ FALARDEAU
Former CEO of General
Dynamics Canada
Former caregiver



BENOIT GUINDON, Secretary
Lawyer, Kellner Avocats



TANYA LUTTRELL, Vice-Chair
Consultant at SSMIK Culture
d'impact

ADMINISTRATORS



ISABEL CYR
Director, Government
Relations & Public Affairs,
Lithion Recycling Inc.
Former caregiver



DR. RICHARD ROBITAILLE
Professor
Neurosciences Department,
Université de Montréal



MARIO HUDON
Former sports commentator
living with ALS



VINCENT GAGNÉ
Director, Government
Relations, TELUS



DIANE TKALEC
Nurse Clinician
Former Caregiver



NORMAN MACISAAC
Social activist and author
living with ALS



LUC VILANDRÉ
Former president, TELUS
Health

INCREASING OUR EFFORTS TO BETTER SUPPORT OUR COMMUNITY

Often, the ALS community tells us that our programs and services are a source of strength to them as they navigate the changing reality of the disease. We are proud to help connect the ALS community so they can rally together in shared experience, and also offer a safe space for timely individualized support.

Every opportunity to connect, whether virtually or in person, is inspiring! Our devoted counsellors are part of a cohesive team dedicated to supporting every person affected by ALS within the province. Last year, we enhanced the team by adding a new position, Educational Services and Resources Manager, to better respond to our members increasing need for useful resources and keeping abreast of information about ALS.

Virtual support, offered individually and in group settings, allowed us to continue increasing our outreach, especially for members living in rural areas and those less able to readily leave their homes. The option to return to some in-person meetings provided a welcome space for others, like members of our Lorraine Support Group who gain a deepened benefit from gathering in supportive presence. We expanded our support groups to meet the specific needs of recently diagnosed individuals, to provide more regular contact for bereaved families, and to boost our peer-to-peer

support matching program that pairs individuals and families facing similar circumstances.

We invested in existing and new strategic partnerships to increase our impact, including many regular exchanges with ALS clinic teams, community healthcare professionals, multi-disciplinary experts, researchers and foundations. A new collaboration with Baluchon Alzheimer provides respite for ALS caregivers so they can take time to rest and recharge; and our continuing partnership with Appui helps fund caregiver support so that loved ones and caregivers have a safe space where they can talk about their experiences and receive emotional support.

Last year, we also expanded our volunteer network to reinforce outreach and ongoing dialogue with the community. Our incredible volunteers helped facilitate support groups and networking forums and participated in working committees that ensure the best care practices and services are integrated into our evolving programs.

It is hard to put into words how privileged we feel to be part of such an incredible group of dedicated people. The teamwork, the shared values, and the compassion that is shown day after day form the essence of a beautiful circle of care that just keeps growing.



A handwritten signature in black ink.

Diane Tkalec

Nurse clinician
Former caregiver
Board member



A handwritten signature in black ink.

Véronique Pignatelli

Director of Programs
and Support Services
ALS Society of Quebec

WE ARE BROADENING OUR IMPACT



Your support is changing how people experience an ALS diagnosis.

Imagine being told you have ALS and then being left on your own to process the overwhelming implications and navigate the realities of the disease.

Thanks to your support, no one in Quebec needs to face their ALS diagnosis alone. Through videoconference, telephone, or email, our professional counsellors are available to provide guidance, recommend services and supports, and answer questions. Our online resources are available to help people who prefer to self-serve. And peer support in both one-on-one and group settings is available for those who find comfort in connecting with others in the community.

We provide support and resources to help you stay informed and prepared throughout every stage of the disease

Information

- Documentation
- Educational webinars
- Internet site 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

YOUR IMPACT IN NUMBERS

Support/Programs ■

5000+

Members
(persons diagnosed
with ALS, caregivers,
bereaved loved ones,
and healthcare
professionals)

500+

Families living with
ALS, received timely
individualized support
and counselling by
phone, Zoom or email,
without a wait list

225

Online resources
available

57

support group
meetings,

468

participants

189

Families with a recent
ALS diagnosis, were
welcomed and provided
with emotional support
and accurate,
practical information
and resources

3

Virtual discussion
forums for
healthcare
professionals,

200

participants

50+

Requests -
Programs to
support daily
living

19

Educational
webinars,

429

participants

156

Newly bereaved
members received
a personalized
follow-up support
phone call

Resources
and support
provided in all

17

regions

Research ■

Established the
500K
ALS Quebec
Research Fund

More than
150 participants
attended our
research webinars
and Q&As

Awareness/advocacy ■

Our digital footprint is on the rise: Raised awareness through campaigns, increased digital engagement with our community and increase in testimonials by our Ambassadors

als-quebec.ca
112, 956 users
238,376 pageviews

150
newsletters sent to
our community

f
8564 Followers (+480)
Global reach: 500 398
Paid reach: 322 194
Interactions (likes, shares,
comments): 31 840

"Following my mother's death, my father wanted to encourage your organization to continue its wonderful work with families affected by this unjust and cruel disease. My parents were extremely grateful to have found you along their path. You made a big difference in their daily lives and helped them face this disease with courage and dignity. On my behalf, on behalf of my father and in memory of my mother, I sincerely thank you for being there for them."

– Sylvie Renaud



Our community “Seizes the Day” thanks to the Tenaquip Foundation

In 2018, the Tenaquip Foundation generously supported the launch of Seize the Day, a program that aims to fulfill a special wish for those living with ALS. Since its inception, the program has been a source of comfort and joy, by creating meaningful and lasting memories for families coping with the challenges of this disease. Throughout 2022, the ALS Society played a vital role in helping twelve families affected by ALS to create cherished experiences and special moments.

Thank you, Tenaquip Foundation, for generously granting a special wish to persons living with ALS and their families since 2018, through its **“Seize the Day”** program!

“I want to thank you for the great support! It was a deeply emotional day as I had the privilege of renewing my parents’ wedding vows in front of family and friends. This short moment didn’t last long since dad’s energy level is not strong, but I can tell you that feeling all the affection of people present as well as their support gave us a bit of strength and courage to continue to move forward throughout whatever is ahead of us.” - Karyne Girard and family

“Thank you ALS Quebec for this unforgettable evening at the La Ronde Fireworks! It was a memorable evening and to be able to look at these beautiful pictures is just wonderful.”

- Pauline Mathieu

THE **TENAQUIP** FOUNDATION

AWARENESS AND ADVOCACY

TOGETHER WE CAN TURN UP THE VOLUME

Raising awareness of ALS and advocating for the needs of people affected by the disease is a critical part of our ongoing work as a community.

Through continuous awareness initiatives, we continue to educate the public about the enormous challenges facing families affected by ALS. By means of media interviews, speaking at events, and marking ALS Awareness Month in June of each year, we strive to build understanding about the disease and inspire support.

Working together, we can amplify our voices so that more people understand the difficult realities of the disease and are motivated to take action.

Even as the disease weakens people's voices, together we can get louder to raise awareness and champion access to new therapies.

Never Too Young to Speak Up for Your Cause

Amanda Tam is the youngest person on the ALS Quebec data base. She is a third-year psychology major with a sunny nature and a realistic world view that help her remain positive and unattached to any long-term plans. Today, Amanda is learning to live in the moment and focus on her immediate goal: graduating from McGill in May 2023.

She also wants to help ramp up public awareness and understanding of ALS. Without awareness it is difficult to raise funds for research and support services. Without research, there will never be a cure. Without sustained government funding, people affected by ALS will not be able to access the best quality of care.

"When I say I have ALS," she explains, "I can see people don't really know what it is. They have no clue what is happening to me." Many of Amanda's classmates remember hearing about ALS during the Ice Bucket Challenge, but they don't know much about the disease itself. Amanda wants to change that by sharing her story on social media, participating in awareness campaigns, and spreading the word to anyone who will listen.

Living with ALS at the age of 21 is practically unheard of. Nevertheless, Amanda draws courage from the life of Stephen Hawking who was diagnosed with ALS at the same age. The award-winning film, *The Theory of Everything*, was an eye opener for her, and a reminder not to shy away from her resolve to GET LOUD about ALS.

Speaking out does not come easily, but that isn't preventing Amanda from stepping up to the mic, even if she is naturally inclined to remain quiet about her struggle with ALS. Having this disease has emboldened her. ***"What have I got to lose?" she says, "and there is so much to gain by continuing to raise the volume, one voice at a time."***



Our heartfelt thanks to Norman MacIsaac and Mario Hudon for their invaluable service as co-chairs of the ALS Advocacy Committee and for their unwavering dedication to the ALS community



Norm MacIsaac, a social activist and author, and Mario Hudon, a former radio announcer, have partnered as vocal champions for our cause for the past several years. Working side-by-side with ALS Quebec to increase our collective impact, they have been described as the 'Dream

Team.' "We complement each other in such a way that we've been able to take big strides," says Norm. "It's this team approach that is ALS Quebec's greatest strength."

As members of the Board of ALS Quebec and Co-Chairs of the ALS Quebec Advocacy Committee, Norm and Mario have been raising their voices in public, on radio and television, on social media, and at press conferences to magnify the profile of this deadly disease and urge Health Canada to ensure quicker access to new ALS

treatments. People living with ALS can wait years before decisions are made on whether provincial and territorial drug plans will cover the drug – even after federal government approval. Most recently, ALBRIOZA was given the green light from Health Canada in June 2022. To the dismay of everyone in our community, it is still not accessible through public funding anywhere in Canada. "It's the biggest hope for ALS patients in 120 years," says Mario, "and red tape is holding us back. I've been fortunate to access it with financial support from the manufacturer, but for others, it is just too long to wait."

Norm has been living with ALS since 2014. Mario was diagnosed in 2020. As precious days elapse, their physical voices are failing them. Even so, they continue to inspire hope and they model what people can achieve working together, even when the barriers are a mile high. As Norm explains, ***"Collaborating has ensured that I am a warrior, not a victim, and that makes a world of difference in my outlook on my life with ALS. It means I am part of the solution."***

OUR VOICES ARE BEING HEARD

ALS Quebec has been partnering with **Neuro Partners** for the past six years. Neuro Partners encompasses 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.

Neuro Partners aims to represent its community members to Quebec elected officials about issues of importance to its members, such as home care, housing, support for caregivers, access to innovative treatments and clinical trials.



ALS AWARENESS MONTH

ALS requires us to get loud. Even as the disease weakens people's voices, we can together turn up the volume to raise awareness and champion access to new therapies.

JUNE 2

Major League Baseball's first-ever league-wide Lou Gehrig Day took place in 2021 and is now recognized every year.



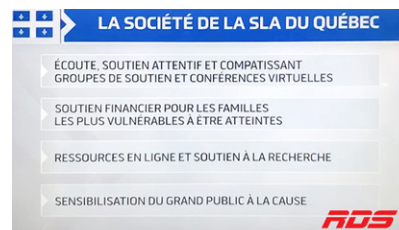
JUNE 2

Thank you to RDS and the broadcast team: Jean-Francois Guilbault (in memory of his wife), Alain Ursereau and Marc Griffin



JUNE 2

Thank you to Les Capitales de Québec for their Lou Gehrig Night

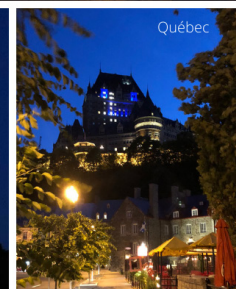
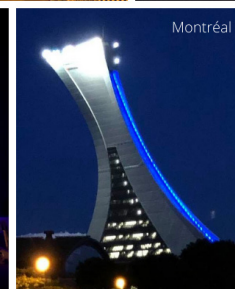
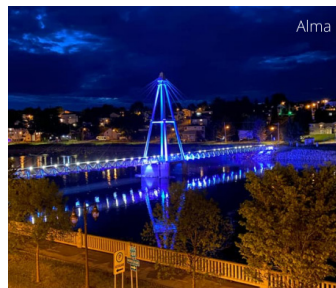


JUNE 21

Global ALS/MND Awareness Day, an initiative of the International Alliance of ALS/MND Associations

Landmark lightings

Across Quebec, buildings are lit in blue to mark ALS Awareness Month. The Olympic Stadium in Montreal, the City Hall in Sherbrooke, La Petite Décharge River footbridge in Alma, Saguenay, the Basilica Sanctuaire Notre-Dame-Du-Cap in Trois-Rivières, and the Fairmont Le Château Frontenac in Quebec City are among the landmarks that have been illuminated over the years to raise awareness for ALS.



We want to express our deep appreciation to Pierre Arcand for his continued recognition of #ALSawarenessmonth in his statements at the National Assembly of Quebec throughout his tenure. We wish him all the best in his retirement!

WE ARE ACCELERATING THE PACE

Research is a source of tremendous hope for the ALS community

Our donors help advance ALS research in numerous ways: by ensuring there is dedicated funding available for ALS research here in Quebec and across Canada, and by fostering strong connections among the ALS research community that calls Quebec home.

ALS Quebec Research Fund

Maintaining and nurturing research talent within Quebec and Canada is the goal of the ALS Quebec Research Fund. Thanks to donor support, the Fund was created in 2022. We are currently developing the strategic roadmap that will guide us in investing these funds in a way that will have maximum impact. Thank you to our Scientific Committee for their leadership and guidance as we create this new approach to research investment that is so critical to our mission:

- **Dr. Richard Robitaille (Chair), Professor, Neurosciences Department, Université de Montréal and member of the ALS Quebec Society's Board of Directors, Chair of the ALS QC Research Committee and Scientific & Medical Advisory Council (SMAC) Committee member.**
- **Dr. François Gros-Louis, Full Professor, Université Laval**
- **Dr. Geneviève Matte, Neurologist, CHUM**
- **Dr. Chantelle Sephton, Associate Professor, Université Laval**



A special thank you to Dr. Richard Robitaille, member of ALS Quebec's Board of Directors and chair of our Research Committee. His commitment and leadership as a board member to finding a treatment and cure and inspiring his students and his lab staff through his research give hope to our community and to all people whose lives have been affected by ALS. His goal of bringing the research community and our families together is imbedded in all his actions: whether they be research overviews and Q&A sessions that rally prominent clinicians and experts at the forefront of ALS research in Quebec, or walking with his lab staff and our families at the Walk to end ALS, or cycling 200-300 km at our annual Ride to Fight ALS.

Five years later, the impact of Vincent Bourque's legacy continues to grow

Before his death from ALS in 2018, Vincent Bourque and his wife, Isabelle Lessard, established the Vincent Bourque Foundation to support families affected by ALS and fund ALS research, adding, "The recent scientific breakthroughs give us hope that we will soon find a treatment that will significantly increase quality of life for ALS patients, and possibly even cure them of the disease." That same year, Vincent passed away at the age of 43.

What is it like to press on in the face of such loss? Isabelle has lived through plenty of threshold moments when she and her three daughters have felt Vincent's absence most deeply: Maria's high school graduation and entrance to university, Charline's gold medal ceremony at the Canadian judo championships, and Arielle's rodeo competitions. These bittersweet occasions have also reminded Isabelle that her children carry the imprint of their father's many qualities as they mature into adulthood. His legacy, through the \$1,200,000 raised on behalf of the Foundation and the hope he inspired in those around him, are visible reminders of his lasting influence.

Taking action, through the Foundation and events like the annual Ride to Fight ALS, helps Isabelle embrace the vicissitudes of life. For all the powerlessness she and her daughters experienced witnessing Vincent's demise, there is a corresponding (and ever growing) feeling of strength

and momentum with every effort to accelerate the fight against ALS. ALS Quebec has been a constant source of motivation and support, and a bridge to the broader community: "The ALS community has been, for us, like the gentle touch of someone's hand on your shoulder, a warm blanket under grey skies," explains Isabelle. "The power of sharing among people affected by ALS filled us with love and amplified our strength and courage in the face of the disease. We are like one big family."

"There is one goal: to end ALS," says Isabelle. "Since the creation of the Foundation in 2018, we have financed five research projects in collaboration with Brain Canada and ALS Canada. Our researchers are laser-focused... the more answers we find, the closer we will be to a cure. I know this for sure. One day, we will receive that phone call to say, 'We've done it!'"



New Partnership Boosts Innovative ALS Research:

Dr. Jean-Pierre Canuel Fund – SLA Québec | ALS Canada – Brain Canada Discovery Grant



As a family physician, Dr. Canuel encountered ALS with patients. He remembers one very emotional meeting with a nun in her 60's who reached out to him in the late stages of her disease with a request. "I couldn't make out

what she was saying," he explains, "so I told her to rest for a while and that I would return later with the nurse to try to attend to her needs. When I returned, I told her I was very sorry, but I couldn't understand... and all she could do was shed a tear. Seeing her trapped in her body with all her mental faculties intact was heartbreaking."

In 2014, Dr. Canuel received his own ALS diagnosis. He was still enjoying working as a physician after more than three decades. The relatively slow progression of his disease allowed him to stay at his practice for another two years, but eventually he had to retire and give up the many leisure activities that filled his free time with joy: snowmobiling, managing his maple grove, dancing, and being actively involved with his grandchildren.

The personal losses, and the challenges for his family, have taken a huge toll, but they have also galvanized Dr. Canuel to act. The Dr. Jean-Pierre Canuel Fund at ALS Quebec is founded on the simple and powerful idea that we can do more together. The Fund, launched in 2022 and seeded through the generous financial support of Dr. Canuel, is a joint effort with ALS Quebec to channel critical funding towards ALS research. This year, it is part of an even larger collaboration as a sponsor of the 2023 Discovery Grant Program, a partnership between ALS Canada and Brain Canada (with the financial support of Health Canada) which encourages new research focused on determining causes of ALS or identifying new treatments.

Keeping abreast of all the latest news about ALS from his professional lens and from the perspective of his personal wheelchair, Dr. Canuel sums it up like this: ***"The only avenue, the only course of action, remains research – to discover the cause and find treatments that will either stabilize the disease or cure it."*** The Dr. Jean-Pierre Canuel Fund – SLA Québec | ALS Canada – Brain Canada Discovery Grant is one more focused effort to keep moving the research in a positive and hopeful direction. The ALS community thanks you for your deep and meaningful commitment Dr. Canuel!

As part of the 2022 ALS Canada-Brain Canada Trainee Award program, which invests in projects that will build on existing knowledge of the biological processes that lead to the onset and progression of ALS and explore new therapeutic targets and a possible treatment strategy for ALS, the 2022 Postdoctoral Fellowship was supported by Fondation Vincent Bourque.

Funding for the 2022 Postdoctoral Fellowship was made possible by Fondation Vincent Bourque, who generously contributed \$82,500 to ALS Canada, which was matched by Brain Canada through the Canada Brain Research Fund (CBRF)*.

2022 ALS CANADA RESEARCH PROGRAM OVERVIEW

The ALS Society of Quebec is proud to have contributed \$175,000 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.

The ALS Canada Research Program accelerates the impact of high-quality ALS research investments, fills important knowledge gaps in our understanding of ALS, ensures a strong pipeline of ALS researchers, and strengthens Canada's infrastructure for ALS clinical trials.

Each year the Program awards a series of research grants to support areas of research that are expected to have high impact, ensuring that there is a steady pipeline of work underway. ALS doesn't stop and neither does the work taking place in the lab and in the clinic. Each investment made is an investment in a future without ALS.

Through the Discovery Grant Program and in partnership with the Brain Canada Foundation*, the ALS Canada Research Program invests in leading-edge research focused on pursuing innovative new areas of ALS research including genetics, biomarkers, pathways for future therapies and improving quality of life. By fueling scientific discovery and furthering our understanding of ALS, these grants enable ALS researchers across Canada and around the world to collaborate on projects that push the envelope and will one day have a positive impact on people living with ALS and their families, bringing hope for a future without the disease.

The 2022 Discovery Grant Program included the Dr. Jean-Pierre Canuel Fund – SLA Québec | ALS Canada – Brain Canada Discovery Grant whereby \$300,000 was awarded to Dr. Alex Parker, Université de Montréal, in collaboration with Dr. Gary Armstrong at McGill University for their project titled ***“Axonal degeneration as a therapeutic target for ALS.”*** With this award, Dr. Parker will explore whether targeting a specific region of the motor neuron, called the axon, represents a promising treatment strategy for ALS. Our congratulations to Dr. Parker and Dr. Armstrong!

Congratulations to Dr. Richard Robitaille, Professor, Neurosciences Department, Université de Montréal, who was also awarded \$300,000 ALS Canada-Brain Canada Discovery Grant for his noteworthy study - in collaboration with Dr. Danielle Arbour, Dr. Roberta Piovesana at the Université de Montréal, and Dr. Robert Bowser at the Barrow Neurological Institute - of neuromuscular junction proteins that might eventually aid in the development of essential biomarkers.

Dr. Jean-Pierre Canuel Fund – SLA Québec also invested in Project MinE, the largest global collaboration in ALS research with the aim of better understanding the genetic basis of ALS by mapping the full DNA profiles of people with the disease from around the world.

As part of ALS Quebec's ongoing support of the ALS Canada Research Program, contributions are also allocated to ensuring that the ALS research community is connected globally and that we are working collectively toward a future without ALS. In doing so, the ALS research community met once again at the 2022 ALS Canada Research Forum. For information on ALS Canada's Research program: als.ca.



“For decades, Canadian ALS research has been an important contributor to the global effort on understanding and treating ALS, and supporting this work is critical for us to keep moving the needle closer to more effective ways of helping people live longer and better lives. Our team at ALS Canada ensures that donor dollars are utilized to have the maximum Canadian and internationally collaborative impact as we continually strive forward with urgency.”

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



WE ARE CREATING MOMENTUM

You – our donors, partners, volunteers, and program participants – understand that ALS takes so much. And that is why we are thankful for all you choose to give. Thanks to you, Quebecers affected by ALS have a place to receive trusted support and resources as they navigate the impact of the disease and all that it takes.

Thank you for your perseverance in supporting our phenomenal community!

Once again during the past year, our wonderful community organized a host of fundraising events that brought a lot of people together to raise funds for ALS and raise awareness about this terrible disease. As we got back to a new normal, you all showed extraordinary gumption and incredible strength by organizing trans-Canadian bike rides, setting up softball tournaments, coaching soccer teams, riding your motorcycles, running, building miniature villages to attract tourists, or hosting live entertainment events with radio hosts, broadcast teams, anchors, and reporters, all for the cause. Your significant financial contribution allowed us to continue serving families affected by ALS the best way we know how, as well as to contribute to promising research.

We would like to thank each and every one of you, for all the time and effort it took to put together your unique event. You truly showed what it means to be part of a strong and united team building a future without ALS!



Coach Phil: Giving hope to the ALS community, one kick at a time

Thanks to Coach Phil and his determined team of volunteers and players, an incredible \$37,125 were raised as part of the first senior soccer fundraising tournament that took place last June 2022 in Pointe-Claire, Quebec, to help support people affected by ALS and fund promising research aiming to find a cure for the disease.

Coach Phil a.k.a. Phil Lalonde was diagnosed with ALS in September 2021. As it turns out, the sobering news about the disease has brought out the very best in him. He drew from his inner strength and resourcefulness and found the motivation to go out and do what he does best: coaching and launching his "Coach Phil Senior Soccer Tournament to End ALS" in support of the ALS Society of Quebec.

Most of all, Coach Phil's goal is to raise awareness about the disease. "I've been coaching soccer for more than 30 years and this tournament is my way to raise awareness and funds for this important cause," said Coach Phil.

His goal to make the tournament an annual event and draw teams from other parts of the Montreal Island has received the green light. Planning for the 2023 event is well underway and he looks forward to exceeding last year's results.

"I believe in keeping a positive attitude no matter what. ALS challenges that every day, but so far, with the help of the ALS Society and my army of family and friends, I'm staying true to myself," concluded Coach Phil.

Jacques Thériault – A celebratory 51 km run to mark his friend's 51st birthday

Jacques Thériault joined his friend Philippe Lasnier, both experienced marathon runners, to run 51 kilometers on the Chambly Canal in support of the ALS Society of Quebec. They invited people to join them along the route to run or walk for the cause. Jacques ran for his wife Joanne Clendenning who has been living with ALS since January 2022. The event helped them raise \$3000.





Hugo Lambert – Cycling 5,000 km across Canada to raise funds for ALS

Hugo Lambert is a cyclist who embarked on an incredible personal challenge to cycle over 4,657 km from Vancouver to Montreal to raise funds in memory of his mother who passed away from ALS in 2020 and in honour of all others living with this disease.

Hugo's project was a resounding success on all levels, not only in terms of the amount raised (over \$43,000), but also with respect to raising awareness and engaging the public by sharing our mission with the communities he met before, during and after his challenge. He has been an inspiration to many people who are affected by the disease in Quebec and in all other Canadian provinces.

We would like to congratulate Hugo once again on his accomplishment and thank him for being part of our team to help defeat ALS.

Roslyn Scott's annual race is out to beat ALS

Roslyn Scott has been running in memory of her husband, Lennox Lewis. This has been the third edition of her Run & Walk fundraiser during the month of June, at the Olympic Park in Pincourt, which has raised more than \$1300.



Transport DSquare's second annual softball tournament hits a home run!

To help support a member of their team affected by ALS, Transport DSquare organized its second annual softball tournament fundraiser in August 2022, with all proceeds going to the cause. They also donated \$1 to the ALS Society of Quebec for every order placed by their customers during the entire month of June 2022, which is ALS Awareness Month. This was a resounding success, as they helped raise more than \$20,000.

Luc Bisaillon organizes bowl-a-thon to strike out ALS

Luc Bisaillon has been living with ALS since 2020. Ever since that fateful day, he has been raising awareness relentlessly about the disease on social media platforms. In addition, he organized a bowl-a-thon last May, which gathered more than 100 supporters and raised more than \$6000 for the cause.



Chantal's Ride in high gear for a third year

Three years ago, as a way of celebrating her life before being diagnosed with ALS in 2013, Chantal Lanthier and her husband Jocelyn Théorêt decided to bring together her long-time friends for a fundraising motorcycle ride in collaboration with BKQCV (Blue Knights Chapitre V) in support of the ALS Society of Quebec. Last year, the third edition of Chantal's Ride raised more than \$8,800 for the cause. Well done, Chantal and Jocelyn!

Capitales de Québec team up to strike out ALS

Last June 3, 2022, Capitales de Québec held a special Lou Gehrig event at the Canac Stadium, as part of their team effort to contribute to a future without ALS. A big thank you to Capitales de Québec for teaming up with us and making this memorable event possible, as well as for all your years of support! We would also like to thank Mario Hudon, Dr. Canuel, Mr. Gauthier, and Odette Lacroix for their attendance!



TSN 690 Party gathers support from the media community

Last September, Billy Bob Productions organized a 20th anniversary celebration for TSN 690 at Fairmont Theatre, which brought together show hosts, broadcast teams, anchors, reporters, insiders, and special guests with live entertainment. The event raised \$ 10,000. All proceeds went to the ALS Society of Quebec's Team Stock Fund in memory of PJ Stock's brother, Dean. Thank you for your continued support!

Les Petites Maisons de Cap-aux-Oies – Miniature replicas make a big impact

For the last fifteen years, retired chef Yves Perron has been building replicas of the Cap-aux-Oies village buildings in miniature and showing them to visitors during the summer. The proceeds collected during the visits are then donated to the ALS Society of Quebec, in memory of one of his friends who died of ALS in 2012. Last year, thanks to his miniature village, he raised more than \$11,200 for the ALS Society, and since the beginning, he raised more than \$49,000.





Charlevoix community steps up to help end ALS

On September 25, 2022, rays of sunshine pierced through a cloudy sky along the shores of the St. Lawrence. For the 200 participants who joined this year's record-breaking Charlevoix Walk for ALS, it was a fitting symbol of hope driven by a passionate community of people affected by ALS. After a two-year hiatus due to the pandemic, the 17th Walk for ALS in La Malbaie successfully raised \$12,500, more than double the original goal.

The event was first organized in 2003 by Elsa Tremblay and other supporters of the cause. Elsa's father and grandmother both died of ALS. Today, Elsa is a doctoral student studying neuroscience at the Université de Montréal where she is focusing on why the connection between the motor neuron and the muscle becomes progressively disconnected in ALS patients. Her goal is to find a therapeutic strategy to correct it. At the start of this year's Walk for ALS, Elsa addressed the crowd

with an inspiring message about supporting ALS research, stressing the need for diverse strategies of inquiry to better understand and treat this very complex and difficult disease.

Denis Villeneuve, who was diagnosed with ALS in October 2020, also spoke about the importance of research to pave the way towards new treatments that will slow the progression of symptoms in ALS patients. Denis knows first-hand that clinical trials can be interrupted due to inconclusive results, but he also reminded the crowd that progress is only possible with sustained and accelerated support for ALS researchers. At his request, Denis' friend, Martin Lavoie (municipal councillor for Malbaie, also living with ALS) arranged to play the song, Hold My Hand, by Lady Gaga, while participants formed a large circle, holding hands, in a beautiful show of solidarity and love. It was a perfect way to head off the event!



It's really a team effort to be able to unravel pathogens and mechanisms in the disease process. So I think funding allows us to have money for various projects. To really diversify the investigation we can do. And this is really the key for this team effort to be successful, and to allow us to find a cure for the disease.

**- Elsa Tremblay PhD student, Université de Montréal
Organizer, Charlevoix Walk for ALS**





The Lussier family rally around their mother in the Ride to Fight ALS

"The Ride to Fight ALS in Saint Hyacinthe last summer was so well organized and fun for everyone," explains David Lussier. "I had a blast!" David rode alongside 20 members of "Team Ooya" in honour of his mother, Diane Thibeault, who attended in her wheelchair to greet each one of her five children, aged 28-38, as they crossed finish line.

Diane was diagnosed with ALS in June 2020 in the midst of the Covid pandemic. Her devoted family united around her throughout her illness and extended their embrace to the larger ALS community. By the time the 2022 Ride to Fight ALS rolled around, the Lussier family was already a fundraising force for the cause. Their "Lady Di Team" raised a total of \$40,000 in the 2021 and 2022 Walk to End ALS during June Awareness Month. Later in 2022, David's girlfriend, Matilde, organized a team for the Ride to Fight ALS taking place in August. Her company, Ooya, provided colourful Hawaiian-style team jerseys and free drinks for everyone at the event. The immediate Lussier family, their relatives and their friends raised an additional \$8,000 for ALS Quebec to help fund ALS research and offer support services for people affected by ALS.

The annual Ride to Fight ALS is a signature event for ALS Quebec. It raises much needed funds and fuels a strong sense of community and connection. Even for someone like David who can count on the support of his close-knit family, attending the event helps counter feelings of loneliness and isolation so common among people affected by ALS, particularly in recent years during the Covid pandemic. David was also delighted to talk with ALS Quebec staff on hand and, in his words, "see just how involved and determined they are."

Sadly, Diane passed away in October. Her son, David, has already decided to participate in this year's Ride; ***"Women have a life expectancy of 84 years in Canada. Until the time my mum would have reached that age, I will stay invested in fighting ALS."***



In 2022, we celebrated
15 years of the
Ride to Fight ALS

**Over
10 000 KM**
cycled last
summer

**3.5
millions**
raised since 2008

SPECIAL THANKS TO OUR VOLUNTEERS

Thank you to our devoted volunteers, tireless participants, loyal partners, and generous donors! Your continued support fuels the hope for a future without ALS, while providing the best care for our community.

Ameganvi, Pudio	Gaudreault, Claude	St-Gelais, Maryse	Tessier, Noémie	Duchesneau, Mylène
Carignan, Thérèse	Larouche, Bruno	Bérubé-Poliquin, Alexandra	Bord, Marine	Jutras, Hélène
Gagné, Léo	Robitaille, Richard	Cyr, Isabel	Diep, Ty	Pépin, Manon
Lafontaine, Daniel	Bastien, Yves	Grenier, Stephan	Guruswamy, Revathy	Vilandr�, Luc
Poirier, Jeanine	C��t�, Michael	Luttrell, Tanya	Martineau, Odette	Cardinal, Jacques
Audette, Carole	Gauthier, Michel	St-Pierre, Denise	Tkalec, Diane	Dumas, Pansy
Cloutier, R��jean	Latrache, Diane	Boivin, Louise	Boudreau, Fabienne	Kennerknecht, Susan
Gagn�, Vincent	Salas, Prochat	Delambre, Dominic	Doucet, Ang��le	Peters, Martine
Lanno, Mia	Beaulieu, Maxime	Grenon-Nyenhuis, Chantale	Hudon, Mario	Villeneuve, Alain
Powel Smith, Carol	Couture, ��milie	MacIsaac, Norman	Moreau, Diane	Cardinal, Karina
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Avitso, Annick	Germain, Lucie		Vaudreuil, Jo��lle	
Coll-Cardena, Pepita	L��por�, Ann-Marie		Cantin, Edith	

Facebook Fundraising

Mario Hudon (��ric Martel, Denis Ferland)	Jade Trudel	Mariepierre d'Amour	Daniel Comeau	Danielle Beaulieu
Benoit Michaud	Sophie Crevier	MP Lab	Nicole Chevalier	Jojo Forgues
Haim Masliah	Denis Dessureault	Nathalie Michaud	Julianne Fortin	Maryse M��tivier
Julie Larochelle	Marie-Christine Lepage	Christel de Vries	Annie Galipeau	Michel Gariepy
Luc Bienvenue	Marie-jos��e Landry	Isabel Gilmont	Sonia Martineau	Nicole Hamel
Anne Baril	Keven Garant	Mario Gauthier	Am��lie B��rard	Sarah Th��riaault
Sonia Langlois	St��phanie BC	Mart Rocket-Tanger	��ric Saucier	V��ronique Poirier
David Lussier	Fannie Parizeau	Claudie Villecourt	Kim Le Gruiec	Myriam Gu��rault
Celine Nault	Lamoureux, Sarah KD & Tamara Phaneuf	Olivier Tremblay	Michelle Fredette	Marcel Lambert
Jonathan Champoux	Lise Thibeault	Sandra St-Amand	Lise Locas	M��lanie St-Jacques
Guillaume Bertrand	Jeff Labrie	Andr�� Mass�� & Marc Proulx	Germaine Cousineau	R��al Benoit
Natalie Joron	Marie-Claude Monette	Denis Dubois	Johanne Fiset	Mario Picard
Gaby Bolduc	Genevi��ve Th��riaault	Lise Vinette	Julie Pelletier	Petrouse la frousse
Karl G Deslauriers	Natacha Cha	Mia Godbout-Nadeau	Dominique-Sophie Thomas	Audrey Bernatchez
Sabrina Tremblay	Bernard Lemay	Janie Dallaire	Jos��e Latendresse	Jos��e Villeneuve
Jean-Guy Lafreni��re & Francoise Blais	Laurie Gagnon	Julie Rodrigue	Jos��e Tass��	Isabelle Guindon
Andr�� Denis	Catherine Laurin	Lyne Larose	Alexandre Beaulieu	Vincent Sims��
Muriel Carpentier	Philippe Saucier	Helen Brien	Andrew Luttrell	Cynthia Blake
	Haie Rick Bernat-ch��z	Gab Charrette	Chantal C��t�� Brisson	Kevin Belley
				Raphael Purdy

3rd party EVENTS

Run around the island of Montreal (Anne-Lise Nadeau, Isabelle Desjardins-David, Doudja Mekamcha)	Annual fundraising in memory of Francine Pharand (Suzie Pharand)	Chantal's ride - 3rd Edition (Chantal Lanthier)	Transport Dsquare's Softball Tournament - 2nd Edition (Thanina Bennaceur)
Coach Phil Senior Soccer Tournament (Phil Lalonde)	Auction (Cercle de fermi��re de l'Annonciation)	Mini-Putt (Serge Garneau)	Annual Fundraising - Ondes Positives Team (Myl��ne Boudreault - Catherine Panelli)
Super Bowl LVI - Team B��rard (Alain B��ard)	Shave-a-thon (��tienne Ferland)	Benefit Show (Luce Doucet)	Beers sale for ALS (masoif.com)
Almond for ALS (Mitzi Perez)	R3n RoZ Run (Roslyn Scott)	20th Anniversary - TSN Party (Billy Bob Productions)	Annual fundraising - Miniature houses (Yvon Perron)
Dinner-show Evening (Sarah-Maude Blier)	Viewing of the documentary D'une rive �� l'autre (Phil Laroche and Jean Dussault)	Half Marathon St-Jean-sur-Richelieu (Sabrina Roussy)	Annual fundraising activity (Elias Makos)
Bowl-A-Thon (Luc Bisaillon)	Run for ALS (Jacques Th��riaault)	Half Marathon for ALS (Marie-Michelle Pouliot)	Marathon Beneva
TransCanada 2022 #RideforALS (Hugo Lambert)	Travers��e du Lac Tremblant (Mich��le Ashton)	Michael Soles Bowl 2nd Edition (Randy Burns)	Charity challenge 21k de Montr��al
Workers' Celebration (SFMQ)	Eldorathon to End ALS (Julie B��dard)	Let loose for the cause (Benoit Mayer)	ALS Lac St-Jean - 3rd Edition (Suzie Bouchard)
		Bromont Ultra (Gilles Poulin)	



LES ONDES POSITIVES

Volunteering: A family affair

Josée Martin, Mylène Boudreault's sister-in-law, sadly passed away from ALS on March 6, 2019, at the age of 52, only five and a half months after her diagnosis. Since that day, Mylène has made it her goal to help raise funds for the ALS Quebec mission, to keep her alive in her memory.

Initially, she started out fundraising and then came up with the idea of collecting cans and bottles to return them to Ontario to raise money for the Society. This led to the launch of Les Ondes Positives, a family team that saw Mylène and Catherine Panelli (her cousin's wife) come up with a variety of original fundraising ideas.

Before Josée's death, Mylène promised her to continue what they had started together. "I will fight to the end. I will continue until we find a cure for this disease," she says.

Her strong motivation and charisma have won her many supporters for her cause over the years. Above all, Les ondes positives is a tremendous family effort, where everyone can find their

place and make themselves useful, each in their own way: cousins, children, and grandparents. Whether it's a candy box and chocolate almond sale (Catherine Panelli), garage sales (her cousin Nathalie Nadeau), Halloween decorations (her cousin Benoit and his sons) or the "Bowl-a-thon" (Josée's father), they all do their part to raise funds.

What is the secret to this enthusiasm for collecting funds for the ALS cause? **"There are no small donations, only generous donations,"** is her motto. It is very important for Mylène to thank everyone for any donation they make, be it an empty bottle of liquor or 40 cases, a few dollars or \$1000 in donations.

For Mylène, volunteering is not a one-way street, as she also derives a lot from her work. "Giving time to this cause is extremely rewarding for me, both psychologically and physically. It makes me feel useful and above all, it helps raise awareness of this terrible disease, since not many people know about it," she says.

Your generosity makes all the difference! ALS Quebec donors and volunteers 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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et des Canadiens de
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We thank all our donors. Every donation counts!

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FINANCIAL SUMMARY

Financial year from November 1st 2021 to October 31st 2022

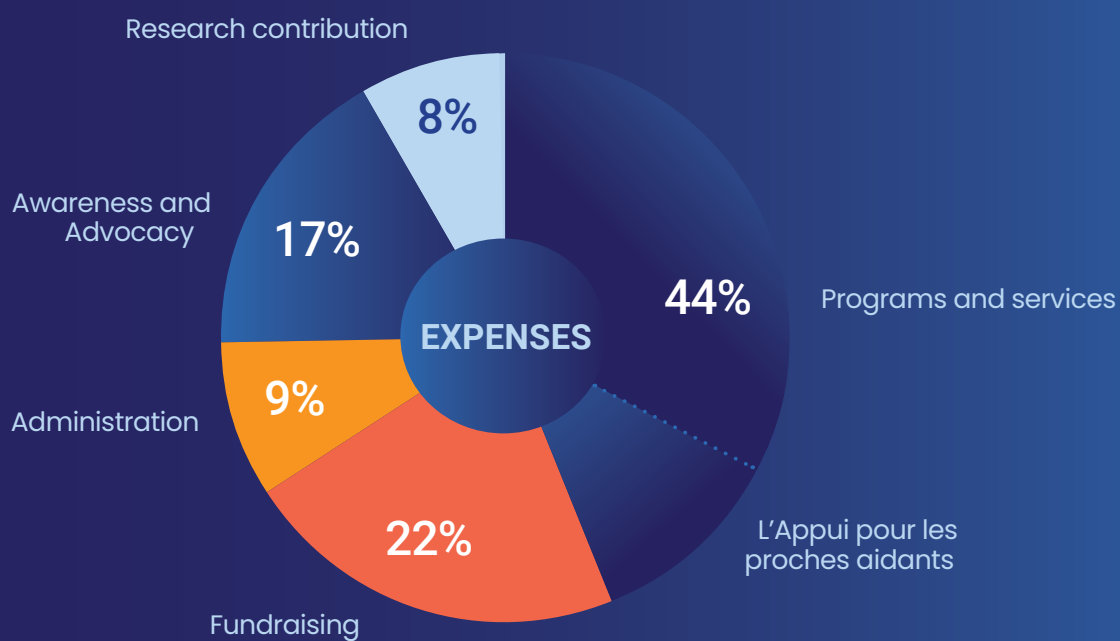
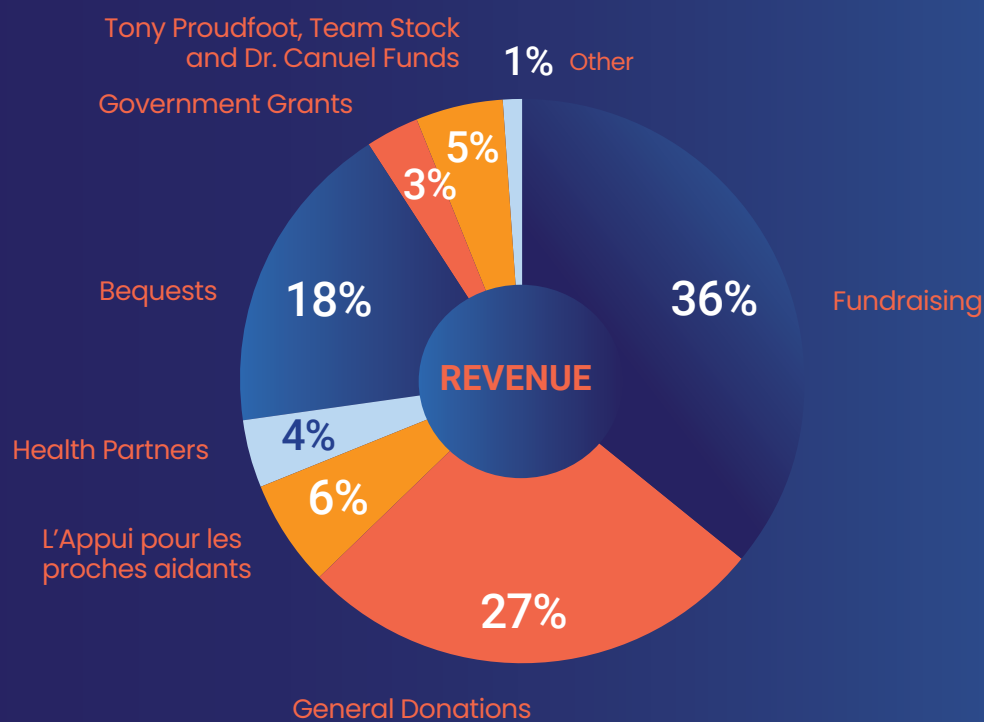
REVENUE

	2021-2022	2020-2021
Fundraising	\$844 987	\$850 842
General Donations	\$642 710	\$676 412
L'Appui pour les proches aidants	\$148 317	\$161 240
Health Partners Quebec & Canada	\$84 089	\$81 897
Bequests	\$411 068	-
Government Grants	\$79 714	\$128 628
Tony Proudfoot Fund	\$15 101	\$61 030
Team Stock Fund	\$11 245	\$1 280
Dr. Canuel Fund	\$73 163	-
Other	\$31 346	\$10 661
TOTAL	\$2 341 740	\$1 971 990

EXPENSES

	2021-2022	2020-2021
Programs and services	\$402 662	\$326 667
l'Appui pour les proches aidants	\$141 709	\$184 201
Fundraising	\$267 491	\$226 594
Administration	\$107 769	\$108 040
Awareness	\$206 514	\$87 879
RESEARCH CONTRIBUTION		
Contribution to research	\$101 688	\$215 541
Contribution to the Neuro (Tony Proudfoot Fund)	\$6 984	\$55 325
Contribution to research conferences	-	\$1 803
	\$108 672	\$272 669
TOTAL	\$1 234 817	\$1 206 050

Excess (deficiency) of revenue over expenses	\$1 106 923	\$765 940
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Please visit our website to view a detailed version of our audited statements.

Highlights of the ALS Society of Quebec's 40 years

In October 2023, ALS Quebec will celebrate its 40th Anniversary. Over the years, we've reached so many remarkable milestones, and here are just a few noteworthy highlights!

1983

The Bercovitch Family establishes the ALS Society of Quebec in honour of their son who had ALS.



2003

Céline Dion headlines concert at the Bell Centre in Montreal raising \$1.3 million, ALS Quebec's first major donation made possible through the André Delambre Foundation.



1999

Mrs. Lise Deschesnes appointed president of ALS Quebec.



2004

First Walk to End ALS takes place outside Montreal and in La Malbaie. The Walk goes on to become a province-wide annual fundraising event.

2006

Former Expos, sports and entertainment celebrities come together to strike out ALS at ALS Quebec's first Celebrity Softball Game that became an annual tradition for over 8 years.

2000

Riluzole is the first ALS treatment to be approved in Canada.



2007

After being ALS QC's spokesperson for over 2 years, Martin Matte passes the puck to 1993 Montreal Canadiens Stanley Cup player, Vincent Damphousse, who lends his name and leadership for 8 years to ALS Quebec's Board of Directors and Annual Golf and Poker Tournament. Both to this day, help support our mission when they can.



2007

Tony Proudfoot mobilizes media across Canada to raise awareness and establishes the Tony Proudfoot Fund to support research fellowships at the Montreal Neurological Institute and to help families affected by ALS in Quebec.

Montreal Alouettes join annual Walk to End ALS to help Team Proudfoot and Soles tackle ALS.



2008

First Ride to Fight ALS, powered by TELUS Health, gathers cyclists to take a stand against ALS. The annual event goes on to become ALS Quebec's signature fundraising event.



2008

The Reed Family, through the Tenaquip Foundation, matches all donations to the annual Vincent Damphousse Golf Tournament and become an annual donor to this day in memory of Kenneth Reed, In addition to supporting families, they helped launch our Seize the Day program.

2013

Quebec singer-songwriter Luc Cousineau, diagnosed with ALS, lends his support to ALS Quebec, donating proceeds from his new album featuring ***Tant qu'il y aura une chanson.***

CBC/Radio-Canada producer, Bruno Bonamigo, is accompanied by colleagues Patrice Roy and Céline Galipeau, document his ALS journey to raise awareness.



2014

The Ice Bucket Challenge goes viral, raising unprecedented awareness around the world. Quebec alone raised a remarkable amount of \$2.67 million and thousands of videos were shared online. An unparalleled contribution of \$10 million to ALS research in Canada was made, matched by Brain Canada, making it a historic milestone.



2013

Beginning of a partnership with Appui for the development of services for caregivers, and thanks to this collaboration, our services have been expanded, made more varied, adapted and accessible.

Hockey Night in Canada joins fight to raise awareness campaign by former Habs player PJ Stock in honour of his brother Dean.

2015

The first regional support group took place in Quebec and is still active, thanks to the determined work of several dedicated volunteers.

2015

2016

Café Rencontre l'Entre-Nous in Lorraine ! The group was initially launched by Chantal Lanthier and her partner Jocelyn in their small kitchen. This group still breaks isolation, meets every 6 weeks and often attracts more than thirty participants.

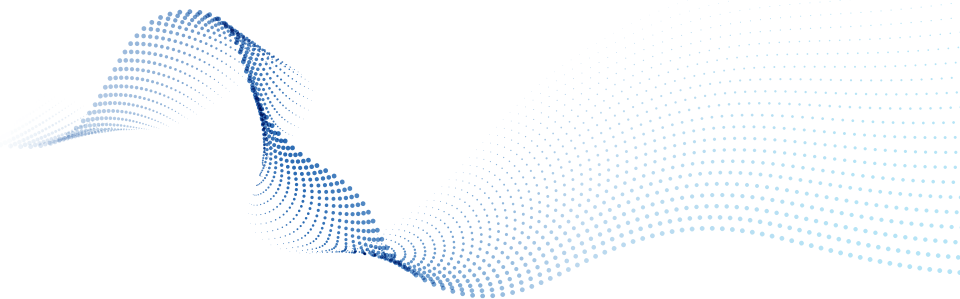
2016

Start of Partenaires Neuro
Partenaires Neuro is a group of five member organizations with a shared mission of supporting and advocating on behalf of individuals living with a progressive neurological condition and their caregivers, in their interactions with political decision-makers.

Appui
proches aidants
Vous êtes là **pour eux**,
nous sommes là **pour vous.**



Neuro Partners
Progressive Neurological Diseases



2018

Edavarone is the 2nd treatment for ALS approved in Canada after relentless advocacy from the ALS Community across the country and ambassadors like Nancy Roch and Mario Goupil in QC.

2022

For the second time in 4 years, a new treatment, Albrioza, becomes the 3rd approved drug to treat ALS in Canada.



2020

Pandemic, quick shift to the virtual world, expanding our reach and staying connected.

2023

INESSS gives a positive recommendation to list Albrioza and Oral Radicava. Although this is positive news, we will continue to advocate for timely and equitable access to treatments and clinical trials.

2023

ALS Quebec launches new rebrand ready to amplify our voices and lead the way for a future without ALS.

Looking forward

As we look towards the future, we are excited to continue building on our progress and pursuing our mission with even greater determination. We are grateful for your continued support and look forward to working together to make a positive impact on our community. Thank you for joining us on this journey.

FOUR STRATEGIC ORIENTATIONS

- An approach centered around people living with ALS
- A new philanthropic Momentum
- A cause that touches Quebecers' hearts
- An additional contribution to research

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

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This report is also available in French.