

ALS DOESN'T STOP. NEITHER DO WE.

2019-2020 ANNUAL REPORT



**ALS DOESN'T STOP.
NEITHER DO WE.**

ALS DOESN'T STOP. NEITHER DOES OUR RESILIENCE.



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ODETTE LACROIX

Volunteer in Charlesbourg, Quebec, for 15 years and former caregiver

Back in 2001, when my husband Pierre was diagnosed with ALS, the outlook for people living with the disease was very different. At the time, there was only one support group in the entire province, so we had to travel to Montreal once a month if we wanted to attend. Fortunately, over the years, the programs and services offered by the ALS Society have multiplied and developed, to the point that we can now get personalized support quickly and close to home. That's how we got through life as a family coping with ALS to the best of our abilities—with the support of the ALS Society of Quebec.

When Pierre passed away, I promised that I would continue to support the families in his honour and his memory, no matter what. Of course, we've had our share of upheavals and challenges over the years, and 2020 is no exception. The COVID-19 pandemic has made it impossible to visit families in person, attend support groups, or walk together in solidarity during the Walk to End ALS. But what's been even harder is not being able to say goodbye to the people whose time has come too soon is already bad enough, but it's even more unbearable when you can't share your pain and sorrow—or your hope for a future without ALS—with family and friends.

WITH CHANGE COMES ADJUSTMENT AND RESILIENCE

Right off the bat, with help from the ALS Society of Quebec, we had to find new ways of connecting virtually, like Zoom calls, in order to spend time together. At 79, wrapping my brain around these new tools was no walk in the park! It was a challenge adjusting to this new way of communicating, which we'd never used before. With change comes adjustment and resilience, and together we've found practical ways to keep our community spirit alive. As proof, one of the last support groups on Zoom was attended by 19 people!

For 2021, I want to wish everyone a year filled with love and compassion. I'm confident that together we'll be able to keep navigating the many challenges that life throws at us. As for me, I'm going to continue keeping my sacred promise by making sure that families touched by ALS across Quebec get the best possible support, day after day, year after year.



OUR MISSION

The ALS Society of Quebec is a non-profit community organization whose mission is to support people touched by ALS and their families through every step of their journey. It also promotes and funds research, while raising awareness of the disease with the public, government and healthcare professionals. The Society survives on donations and **the proceeds** from various fundraising events.

ABOUT AMYOTROPHIC LATERAL SCLEROSIS (ALS)

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



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

1:1

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.



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

2-5
YEARS

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



2019-2020 BOARD OF DIRECTORS OF THE ALS SOCIETY OF QUEBEC



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TELUS

ALS DOESN'T STOP. NEITHER DID WE.

2020 was a challenging year for all of us. In March, as the world came to a halt and we were all navigating through uncharted waters, one thing was certain: ALS doesn't stop and neither could we.

The strength, courage and resilience of our community has always inspired and driven our team to fulfill our mission no matter what obstacles were in front of us. This was so true, more than ever this year. Together, we adapted quickly to our new virtual world by embracing new technology and by focusing on finding sustainable strategies and solutions to continue to support and empower our families. **Our virtual fundraisers kept our community connected, engaged, and motivated to take action, which they did with passion, collaboration and care,** fueling our team, our families and researchers with **the hope** that "Ça va bien aller".

We are truly grateful for the Government Covid Emergency Funding programs, the generosity of many

foundations, partners, donors and volunteers, whose support enabled us to continue to meet our families' growing needs.

We are proud to share our accomplishments in this Annual Report. Along with our Board of Directors and staff, we have an unwavering belief in the work we do and the impact you have on our mission. We would like to take this opportunity to thank you for being an integral part of the ALS Community. Every action you took counts; whether you made a donation, participated in an event, raised your voice or gave your time, YOU are all ambassadors for our cause.

We truly miss seeing you all in person. We do not know what lies ahead, but together, we know we will remain by our families' sides at every stage of their journey with ALS. We will continue to support research and we will raise our voices to affect change. ALS doesn't stop and neither will we. Ever.



Susan Kennerknecht
Chair, Board of Directors



Claudine Cook
Executive Director
ALS Society of Quebec

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TANYA LUTTRELL
Consultant at SISMIK
Culture d'impact



DR. RICHARD ROBITAILLE
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of Neuroscience Université
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DENIS VANDAL
Marketing consultant



NORMAN MACISAAC
Executive Director, Léger
Foundation, retired
Person living with ALS



DIANE TKALEC
Nurse Clinician
Former Caregiver



LUC VILANDRÉ
Former President, TELUS
Health, SLA QC
Co-Founder of the
Ride to Fight ALS

ALS DOESN'T STOP. NEITHER DO OUR PROGRAMS AND SERVICES.

Since it was first founded, the ALS Society of Quebec has supported its members throughout their journey with the disease. The goal of our support work has always been to help our ALS families to develop two important qualities: resilience and agility. Faced with the unexpected events of this year, it was our turn to demonstrate those qualities. Despite the pandemic—and maybe even because of it—we've made great strides, staying focused on our mission to help families, with all the compassion needed to deal with this new reality that's affected us all.

To keep everyone safe, follow government recommendations, and relieve some of the additional stress caused by the health crisis, our team had to react quickly to make sure our members continued to get the support they needed. We made adjustments to everyone's roles in order to maintain our services to the community. As an essential service provider, we went online to keep up our support activities and stay informed of the needs of the ALS community. Above all, we wanted to remain a constant presence for our members, as a way of making them feel less isolated and meeting their needs as best possible. That prompted us to move forward with our Taking Care virtual learning platform, adding relevant, up-to-date information and resources that are available on demand.

Over the past few months, we've kept the lines of communication open with our members, through our website, social media, email, and regular mail. We spread the word online about our new support services, while keeping in touch by phone with our members who don't have Internet access. While there have been some changes to our financial program, our commitments all remain the same. Our new community support program aims to help families that are most vulnerable from a social and financial point of view, and those with needs that can't be met by our existing programs. Its goal is to make sure that no one who needs help falls through the cracks.

We want to thank the PES committee, our dedicated professionals and volunteers, and the team at the ALS Society of Quebec, who truly understand the reality facing people living with ALS. We couldn't do what we do without your support. This year, you allowed us not only to adjust our services, but also make them better.



Véronique Pignatelli

Director of Programs and
Support Services
ALS Society of Quebec



Diane Tkalec

Nurse clinician
Formal caregiver
Board member



PES COMMITTEE

- PES Committee Chair: Diane Tkalec (nurse clinician, former caregiver, Board member)
- ALS Society of Quebec team: Véronique Pignatelli (social worker, director of services), Leigh Stephens (social worker, psychosocial counsellor)
- Public-system occupational therapists: Ann-Marie Léporé (CIUSSS-ODIM), Paula Stone (retired, expert in long-term care)
- Other health professionals: Zeldia Freitas (social worker, clinical activities specialist (SAC), CREGÉS-caregivers)
- Person with ALS and caregivers: Prochat Salas (former caregiver/volunteer at ALS clinic) and Patricia Pineault (person with ALS, palliative care nurse)



“HELP WAS JUST A PHONE OR ZOOM CALL AWAY!”

When 2020 began, journalist and radio host Elias Makos had no idea that he'd be facing down not one, but two deadly diseases: On June 29, his 74-year-old mother was diagnosed with ALS. Since then, he's spoken out regularly on *The Elias Makos Show* on CJAD 800 as a caregiver and ALS ambassador to help his mother tackle the disease with hope and optimism—with support from the ALS Society of Quebec.

“Help is only one call away, by phone or by Zoom! Since her diagnosis, and as her disease progresses, the ALS Society of Quebec has been there for my mother and our family. Even in this new, online world, we got the help we needed fast. One call with a psychosocial counsellor and we got all the support, advice, and information about the disease we could possibly need. And it was very reassuring to know we're not alone. The many services they provide, and their role in advancing research into the disease, create something we all need to get through a time like this: hope.”

- Elias Makos, Host of *The Elias Makos Show* on CJAD 800 and caregiver to mother living with ALS

“If we share the burden, the burden becomes lighter for all of us.”

- Suchitra Samanta, caregiver

WE HELP YOU TO BE BETTER INFORMED AND BETTER EQUIPPED AT EVERY STAGE OF THE DISEASE

INFORMATION



Documentation



Conferences



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

* Certain conditions apply.



This year, we've had to tweak the format of our support groups to adjust to the pandemic and continue to provide essential services to our members. Very quickly, the Zoom video conferencing platform became our main way of providing help and support. Using Zoom, we were able to set up virtual support groups by region and by language, for both ALS sufferers and their caregivers, to give people a safe space to talk about the issues that affect them.

We also adapted our virtual interventions to meet the specific needs of our members at all stages of the disease. First, we increased the frequency of the virtual evening events for bereaved loved ones. We also created a new virtual support group especially for families who have received an ALS diagnosis during the pandemic.

We quickly realized the many advantages of using Zoom to communicate with our members. Before COVID, our first contact with the families used to be in person, so video calls are a way for us to maintain that warm and compassionate approach. The chat feature in Zoom also lets people with bulbar ALS be a part of the conversation.

But the main advantage of this shift to online services has been the ability to reach people in geographically isolated areas. One of the challenges in the past has been low numbers of participants in the support groups in certain parts of the province. With Zoom, this is no longer an issue. People with the disease, caregivers, counsellors, and bereaved loved ones from all over can get together and support one another, no matter where they live.

A big thanks to our volunteers in the different support groups! Our virtual support groups would not have been so successful without the dedication and hard work of the volunteer hosts, Odette Lacroix, Maryse St-Gelais, Thérèse Carignan, and Angèle Doucet. Your invaluable support makes all the difference to our community.

Some of our achievements...

4996 Members (people with ALS, caregivers, bereaved loved ones, and health professionals)

Counselling and personalized support for more than **500** families

283 Face-to-face meetings by our team for specialized ALS clinics and resources

900 Participants registered for support activities (lectures and groups)

13 Themed lectures and **3** discussion forums for health professionals

71 Support groups for people living with ALS and their caregivers

New: Bilingual virtual support groups tailored to specific needs

30 Support activities for caregivers

3 In-person social activities and **4** Virtual meetings to counter isolation

265 Families receiving technical or financial aid

1600 Hours of respite offered to 33 families

STATISTICS RELATED TO THE CONSULTATION OF OUR ONLINE RESOURCES:

2670 views of our **YouTube** videos, including information and support capsules, conferences on ALS research and virtual awareness campaigns

6146 inquiries for specialized resources for people with ALS, caregivers, family members and healthcare professionals on our website

7016 views of **207** resources from the Taking Care platform

A total of **13 162** visits to our resource pages available on demand



Forum des Échanges

Since 2013, we've organized the **Forum des Échanges** for health professionals to share information about their practices caring for people with ALS. This year, we held three editions of the Forum, which were attended by some 100 professionals across the province. We took the opportunity during this first virtual meeting to present our recently updated Checklist for health professionals, a list of services and technical aids that an ALS sufferer might need during the course of their disease.



Virtual bilingual conferences and presentations

We organized **virtual bilingual conferences and presentations** on topics of interest to the entire ALS community. During the year, we gave updates on ongoing clinical trials and teleconferences on current research, followed by question periods. We also provided practical information to our members on accessible travel, self-compassion, anticipatory grief, and medical cannabis for the treatment of certain ALS-related symptoms. Thanks to technology, we were able to record some of these lectures and post them on our website. We also restructured our monthly InfoXpress newsletter to highlight key information for our members.



Support for healthcare facilities

Until mid-March, the ALS Society team of Quebec has maintained its presence in various healthcare environments, especially in **multidisciplinary ALS clinics** (Le Neuro, CHUM) and **the Laurentian ALS clinic** (St-Jérôme Hospital). With the confinement measures and teleworking, it was possible to establish contact and offer greater remote support to ALS clinics and other resources across the province.



Partnerships and collaboration

Throughout the year, we continued our **partnerships** and community outreach efforts with L'Appui pour les proches aidants, Kéroul, Haydoun, Nova Montréal and Nova WI, Institut de planification des soins, WIPCR, ALS Canada and Federation Councils, and McGill University's Steinberg Centre for Simulation and Interactive Learning (SCSIL). We also entered into new partnerships with organizations such as Centre de soins palliatifs de Saint-Raphaël, Université de Montréal (CHSLD research project, school of rehabilitation), Telus Health, Location Légaré, and GASO (Groupe des aidants Sud-Ouest). Thank you to all our partners!

ALS DOESN'T STOP. NEITHER DO OUR FUNDRAISING EVENTS.

The Walk to End ALS

Since 2004, the ALS Society of Quebec has held a Walk to End ALS in different cities across the province. This year, our first online edition was held on June 21st, 2020, for Global ALS Awareness Day. Our loyal community was front and centre on our social media platforms and on roads all over the world—from Ontario to Switzerland to Australia. Thank you all for walking with us!



HUNDREDS
OF WALKS HELD
ACROSS THE
PROVINCE.

60%
OF MONEY
RAISED GOES TO DIRECT
SERVICES FOR FAMILIES



40%
OF MONEY
RAISED GOES
TOWARD RESEARCH*



UNITED
DESPITE THE
DISTANCE

*Matched by Brain Canada

RIDE TO FIGHT ALS, POWERED BY TELUS HEALTH



Les Courageux: Most popular team on social media

It's always a joy to see new supporters like Les Courageux—who participated in the Virtual Ride to Fight ALS powered by TELUS Health—join the ALS community. Together, the team members cycled 55 km between Sainte-Martine and Beauharnois for Huguette Fluet, diagnosed with ALS in April 2020. From their presence on social media and family photos, it's plain to see they're a tightly knit team dedicated to advancing our mission of supporting ALS families and ultimately finding a cure for this terrible disease. Thank you, Les Courageux!



David Brazeau's calves of steel

Four hundred and sixty kilometres later, David Brazeau took home the title of "Longest distance covered from August 28-30," the official weekend of the Ride to Fight

ALS powered by TELUS Health. The young cyclist also took to his bike with his sister Maude during the Virtual Walk to End ALS, covering 215 km in honour of their grandmother Fleurette Touchette Simard. Thank you and great job! We're proud to have you as a member of the ALS team. Thank you to all cyclists across the province!

THE SOCIETY'S
FLAGSHIP
EVENT,
POWERED BY
TELUS HEALTH

50 TO
1,000 KM
TRAVELLED
PER CYCLIST
OVER THE
SUMMER!

\$2.45
MILLION
RAISED SINCE
2008

2021 EDITION
STAY TUNED FOR DETAILS!

ALS DOESN'T STOP. NEITHER DOES OUR COMMUNITY.



The generosity of Manon Pépin

Since 2018, Manon Pépin has been one of those dedicated community members who gives and gives back to the ALS Society of Quebec, and this year is no exception. In addition to raising more than \$5,000 with her team of walkers in Ste-Hyacinthe on June 21, Manon raises money all year long by selling books, scarves, DVDs and CDs, and other used items on social media. She's only too happy to donate her time and energy in support of Pierre and Pauline, her clients and friends touched by ALS. Thank you, Manon, for your ongoing generosity!



Fighting tooth and nail for ALS

For the second year in a row, the Aïsudan de Mont-Laurier kickboxing gala pulled out all the stops to support our mission, donating more than \$10,000 to the ALS Society of Quebec. One of the event organizers, Robert Guay, took to the ring during the first edition of the gala for a fight symbolizing his mother's battle against ALS. Thank you, Robert!



In honour of Denis Asselin

On October 7, 2019, Denis Asselin from Sainte-Sabine, in the Montérégie region, found out that he was the fourth person in 30 years in his town to be diagnosed with ALS. Soon after, he decided to create an online fundraising page to raise awareness for the cause. Sadly, Mr. Asselin passed away on November 11, but thanks to his efforts and those of his wife, Annie Tanguay, his fundraising campaign raised over \$13,000. Our condolences and thanks to his family and friends.



A racer among walkers

In late June 2020, walkers across Canada participated in the Virtual Walk to End ALS—but not Michel Bousquet, who preferred to organize the Tour de Laval à la course! His efforts paid off: He ran 60 km and raised more than \$6,000. Thanks to Michel and all his supporters!



On the move despite the pandemic

It's possible to organize a fundraising event in the midst of a pandemic! On October 17, 2020, runners and walkers from the region gathered in Saint-Eugène-d'Argenteau to support Rémy, who has ALS, and raise over \$6,800. Thank you for your participation and your generosity!

THANKS TO ALL MEMBERS OF TEAM ALS who organized activities to raise money and awareness in their communities. **EVERY ACTION COUNTS!**

Almond sale (Mitzi Perez)

ALS Lac St-Jean 1st Edition (Suzie Bouchard)

Annual fundraising activity in memory of Francine Pharand (Suzie Pharand and Geneviève Lalande)

Bike ride in honour of Fleurette Touchette (Maude and David Brazeau)

Bromont Ultra (Gilles Poulin/Marc Hébert)

Dance workshops (Joanne Vallée)

Epicure sale (Julie Moufrage)

FADOQ bowl-a-thon (Jacynthe Paradis)

Fundraising activity (Antonia Iagallo)

Fundraising activity (Cindy Segreti)

Fundraising activity - Knights of Columbus (Pierre Laprise)

Fundraising activity - Petites Maisons de Cap-aux-Oies (Yvon Perron)

Fundraising activity in honour of Denis Asselin (Denis Asselin and Annie Tanguay)

Honey sale (Susan Kennerknecht)

Kickboxing gala (Robert Guay)

Online sale of used items (Manon Pépin)

Paul Regimbal (Tony Proudfoot Fund)

Refundable bottle drive (Mylène Boudreault)

Stairs challenge (Denis Poulin)

Team Makos (Elias Makos)

Tour de Laval à la course (Michel Bousquet)



Tiny houses, big heart

For 9 years now, Yvon Perron has been part of our big ALS team, donating a generous amount each year, collected from the visitors to his miniature village in Cap-aux-Oies. This year, the craftsman donated over \$6,000, for a total of more than \$28,000 over the years. Thank you so much, Mr. Perron!



Even more bottles for Les Ondes Positives

Pandemic or not, Mylène Boudreault from Team Les Ondes Positives once again this year travelled throughout the Lanaudière region and Montreal's North and South shores collecting refundable bottles from generous donors. This year, more than \$7,000 was raised. Thank you for your dedication, Mylène!



A dose of TLC for our families

The Chair of our Board of Directors, Susan Kennerknecht, also gets involved by selling jars of honey from her beehives to support our families touched by ALS. Thank you, Susan, for being a part of our team!



Almonds for ALS

Selling homemade treats is a great way to raise money for ALS. For the past few years, Mitzi Perez has been selling delicious sugar- and cinnamon-coated almonds for the cause. Thank you, Mitzi, for adding a dash of happiness to the ALS community!



A dedicated member of Team ALS

Year after year, Paul Regimbal continues to raise awareness in his community for the ALS Society of Quebec's mission, through the Tony Proudfoot Foundation and sports-related fundraising events, such as hockey tournaments and the Saturday Night Hockey Fund. Thank you for your efforts, Mr. Regimbal!

SPECIAL THANKS TO OUR VOLUNTEERS

With your help, we can provide the best support and care to a community of people living with ALS. We thank you for giving your time to such an important cause, and help us continue our fight against ALS.

Beaulieu, Phyllis	Cyr, Isabel	Fetzer, Judith	Lessard, Isabelle	Miron, Dominique	Saillant, Sarah
Beaulieu, Nancy	Dallaire, Janine	Freitas, Zelda	Luttrell, Tanya	Morpeau, Valérie	Salas, Prochat
Bekkouche, Nahid	De la Durantaye, Laurent	Gagné, Vincent	MacIsaac, Norman	Normandeau, Guy	St-Gelais, Maryse
Bélanger, Philippe	Delambre, Lorraine	Gentil, Dr. Benoît	Madoff, Rhoda	Parisella, Joseph	St-Pierre, Denise
Berthiaume, Daniel	Denizon, Yves	Gosselin, Julie	Madore, Nathalie	Patten, Dr. Kessen	Stone, Paula
Bérubé, Dr. Maxime	Dion, Odile	Hidalgo, Monica	Madore, Pierre	Pineault, Martin	Tanguay, Michelle
Biljan, Morgan	Doucet, Angèle	JP	Malandruccolo, Daniel	Pineault, Patricia	Taylor, Dr. David
Boivin, Louise	Ducharme, Isabelle	Kennerknecht, Susan	Martineau, Odette	Piotte, France	Tkalec, Diane
Boudreau, Fabienne	Duchesneau, Mylène	Lacroix, Odette	Matte, Dr. Geneviève	Poirier, Jeanine	Tremblay, Marie-Christine
Boudreau, Roger	Dufour, Maude	Lanno, Mia	Messier, Marc	Powel Smith, Carol	Vandal, Denis
Canuel, Dr. Jean-Pierre	Dupré, Dr. Nicolas	Lapointe, Geneviève	Michaud-Dinarzo, Joanne	Robitaille, Dr. Richard	Van Velde, Dr. Christine
Carignan, Thérèse	Falardeau, André	Laverdière, Louise		Roy, Diane	Vilandrè, Luc
Chalifoux, Danielle		Léporé, Ann-Marie			



AS DEDICATED AS EVER TO OUR CAUSE

Since the release last October of his book *The Best of the Worst News: Tales of Inspiration from Around the World* and *My Life with ALS*, our ambassador Norman MacIsaac continues to speak out loud and proud on behalf of the ALS community. In addition to his bilingual blog more-than-als.com, Norman gives interviews and talks on his personal experience with ALS, including a TED Talk he gave last March called *Surviving with ALS: Lessons from International Development*. Most recently, he created a petition at the House of Commons to reduce the delay in obtaining access to innovative Health Canada-approved ALS treatments to a maximum of 3 to 6 months. He is also the administrator of the Facebook group *ALS: Canadian Advocacy / SLA : Défense de nos droits au Canada*. Thank you to Norman and to all our members for your tireless efforts in the defense of our common mission!



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BOXED MEALS THAT GIVE AND GIVE BACK

The ALS Society of Quebec is very proud to have been chosen as one of the 5 recipient causes of Cook it's Star Chef Program! To contribute to this ongoing fundraiser and support the 5 organizations in their social mission, Cook it called upon the generosity of its thousands of subscribers across the province by inviting them to offer their loyalty points (stars) to the cause of their choice with a major awareness campaign. For every donation of 1000 stars, Cook it will donate \$5 to partner organizations to secure a better future for all those in need. A big thank you to Cook it for this great collaboration and a special thank you to Judith Fetzer, president and co-founder of Cook it, who has a family history associated with ALS.



STRENGTH IN NUMBERS IN THE FIGHT AGAINST PROGRESSIVE NEUROLOGICAL DISEASES

On October 27 and 28, 2020, representatives of the group Partenaires Neuro, including the ALS Society of Quebec, the MS Society of Canada, Parkinson Quebec, Muscular Dystrophy Canada - Quebec Division, and the Huntington Society of Quebec, met virtually with members and ministers of the National Assembly. All political parties were represented. The objectives of this meeting were to draw elected officials' attention to the cause of people living with a progressive neurological disease and to discuss topics of interest for them, such as home care and housing. During the meeting, we clearly told the politicians about our desire to contribute to the redefinition of the healthcare system, to ensure a quality living environment for people living with a progressive neurological disease. Thank you for joining us in this conversation, which is so vital for the ALS community and for all the families touched by a progressive neurological disease.



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EFFORTS THAT PAY OFF

At the start of 2020, access to the drug RADICAVA (edavarone) was far from guaranteed. In January and February 2020, our ambassador Mario Goupil spoke out in the press and on social media, advocating for easier access to the treatment for ALS sufferers in Quebec and Canada. In April 2020, RADICAVA was added to the list of medications covered by the RAMQ.

"The negotiations have finally paid off. It was a long, hard battle, but we're finally seeing the rewards," said Mr. Goupil, in an interview with the daily *La Tribune*. *"I'm happy about one thing—that this is going to help a lot of people in the future. There are roughly 600 people in Quebec living with ALS. The next people to be diagnosed with this disease can now hope to suffer a little less and live a little longer. That's the most important thing."*

This small victory would not have been possible without Nancy Roch's documentary *La bataille de Nancy* and her interview on the show *Tout le monde en parle*, in which she lobbied for access to better treatments for ALS. Although Nancy passed away this summer, so many people newly diagnosed with ALS stand to gain from the legacy of her battle. Thank you, Mario and Nancy, for your dedication.

ALS DOESN'T STOP. AND NEITHER DO OUR EFFORTS TO RAISE AWARENESS.

LA SLA N'ARRÊTE PAS.

NOUS NON PLUS.

Textez ACTION au 20222
pour faire un don

ALS DOESN'T STOP.

NEITHER DO WE.

To donate, text ACTION to 20222



Every June, as part of **ALS Awareness Month**, a vast public awareness campaign takes place to educate the public about the disease and raise money for research and essential services for people with ALS and their caregivers.

This year, our virtual “ALS doesn’t end, and neither do we” campaign encouraged the members of the ALS community to take concrete steps to achieve our common goal of putting an end to ALS, once and for all. Whether by making a donation, participating in the Virtual Walk to End ALS and/or Ride to Fight ALS, joining in the conversation on social media, or getting involved as a volunteer or ambassador, every action counted toward advancing our common mission. Faced with the reality of having to adjust to the COVID-19 pandemic, we also held a fundraising campaign in which people could easily donate \$5, \$10, or \$25 to the ALS Society of Quebec by texting the word **ACTION** to 20222. Special thanks to **OUTFRONT Media** for donating digital panels across the province and to **Bell Media** for supporting our campaign.



The flagship event of **ALS Awareness Month** was without a doubt the **Virtual Walk to End ALS**, which took place on June 21, 2020, to mark **Global ALS Awareness Day**. Across the country, provincial organizations that support families touched by ALS participated in this huge **walk** in a remote show of solidarity for those struggling to cope with the disease.

BUILDINGS LIT UP IN BLUE FOR ALS

“On the night of June 20-21, 2020, several buildings were lit up in blue to mark **Global ALS Awareness Day** on Sunday, June 21. Thank you to the **Olympic Stadium** in Montreal, the **City Hall** in Sherbrooke, the **Basilique du Sanctuaire Notre-Dame-du-Cap** in Trois-Rivières and the **Fairmont Le Château Frontenac** in Quebec City.

Thanks to our dedicated elected officials



We’re very lucky to have the support of dedicated politicians who raise awareness in their communities about the reality of living with ALS and the concrete actions we can all take to fund research and help Quebec families. Many thanks to **Anthony Housefather** and **Pierre Arcand**, respectively the MP and the MNA for the Mont-Royal riding, for supporting the **ALS Society** during **ALS Month** and throughout the year. Thank you also to all these MPs across Quebec who support the large **ALS** community on a daily basis.

THANK YOU TO OUR DEVOTED VOLUNTEERS, TIRELESS PARTICIPANTS, LOYAL PARTNERS AND GENEROUS DONORS.
YOUR SUPPORT FUELS THE HOPE OF A FUTURE WITHOUT ALS,
WHILE PROVIDING THE BEST CARE FOR OUR COMMUNITY.

LA FONDATION **TENAQUIP**

L'APPU POUR LES
PROCHES AIDANTS
D'AINES



**Gestion
de patrimoine**

TELUS | Health

iii HealthPartners

LES AMIS DU NEURO

FONDATION
Québec Philanthrope
INVESTIR POUR DONNER ET PÉPÉTUER



FONDATION
FÉDÉRATION
DES MÉDECINS SPÉCIALISTES
DU QUÉBEC



ALTRU FOUNDATION

Bourassa Savaria
FONDATION

**ALBERT & FLORENCE AZIZ
FAMILY FOUNDATION**



FONDATION ANDRÉ DELAMÈRE



OUTFRONT

ZED | ZED GRAPHIC COMMUNICATIONS INC.
COMMUNICATIONS GRAPHIQUES ZED INC.



MEMBER OF **Imagine** Canada
MEMBRE D'



COOK IT

GARDAWORLD

CANADA RUNNING SERIES



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A DONATION IN THE NAME OF LOVE AND HOPE

33 YEARS OF LOVE. 28 YEARS WITH ALS.

In October 2020, the ALS Society of Quebec received a large donation in memory of Lorraine Samson, with the goal of paying it forward to families living with the disease.

"Lorraine, my love,

You departed this world on November 22, 2019, after 28 years spent suffering from ALS. Since that day, my life has been turned upside down. Our love story lasted 33 years, and despite all the hardships we faced, we were good together. It wasn't always easy, but your courage, tenacity, and practicality certainly made it easier to bear.

Now more than ever, I realize how much of an impact you had on my life. You were a source of inspiration and comfort to me. We looked out for each other. My only consolation since your passing is knowing that you're no longer in pain. But my greatest regret is that medicine failed you.

I can only hope that this donation to the ALS Society of Quebec will change that and give everyone battling this terrible disease some measure of hope.

I miss you desperately, Lorraine. I love you.

John xx"

ALS DOESN'T STOP. NEITHER DOES RESEARCH.

The ALS Society of Quebec is proud to have contributed to the ALS Canada Research Program, the only dedicated source of ALS research funding in Canada, to address the unanswered questions about the causes and progression of ALS and support pathways for the development of future therapies.

With funds raised in 2020, the ALS Canada Research Program held three peer-reviewed grant competitions that resulted in a \$1.65 million investment in leading-edge ALS research projects. These initiatives are in keeping with the need for Canadians living with ALS to have access to quality care, and an increased understanding of the biology of ALS to identify new treatment targets.

In early 2020, \$650,000 was invested in three initiatives that enhanced the ALS research community's knowledge base needed to develop treatments. Whether it's using wearable technology that enables remote collection of ALS progression data for future clinical trials, studying new imaging biomarkers that could help ALS clinical trials better evaluate the effectiveness of promising new treatments, or searching for new therapies in the lab, the three research initiatives being funded are contributing new knowledge to the field. They are also creating tomorrow's leaders of ALS research and care in Canada by enabling early-career researchers to focus exclusively on ALS and gain experience that will help maintain and strengthen Canada's expertise in ALS and create greater capacity for clinical trials to be offered here.

Thanks to the support of funding partners la Fondation Vincent Bourque and Mitsubishi Tanabe Pharma Canada, these three research projects were made possible at a time when health research funding is challenged due to the COVID-19 pandemic.

In late 2020, in partnership with the Brain Canada Foundation, the ALS Canada Research Program awarded 8 Discovery Grants totalling \$1 million. Designed to fuel the innovation that will accelerate our understanding of ALS, Discovery Grants identify pathways for future therapies and optimize care to improve the quality of life for people and families affected by ALS. The matched funds contributed by Brain Canada through the Canada Brain Research Fund meant that there was double the amount of funding available for the Discovery Grants in 2020¹.

All projects funded by the ALS Canada Research Program are supported by the generosity of 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 engaged a panel of scientific experts in prioritizing projects grounded in scientific excellence and with the potential to most quickly advance the field of ALS research.

¹ The Canada Brain Research Fund is an innovative partnership between the Government of Canada (through Health Canada) and Brain Canada.





RESEARCHER PROFILE



Dr. Silvia Pozzi

Université Laval – Recipient of a \$250,000 La Fondation Vincent Bourque-ALS Canada Career Transition Award

Dr. Silvia Pozzi, currently a postdoctoral fellow in Dr. Jean-Pierre Julien's lab at the Université Laval CERVO Brain Research Centre, is aiming to develop antibodies that can delay or stop the progression of ALS. Her work will validate how the interaction of two specific proteins can activate a biological pathway that eventually leads to motor neuron death. While she will initially try to prevent this protein interaction in mouse models, if successful, she hopes to determine if similar effects can be seen in humans, which would result in a new target for the development of ALS treatments. This \$250,000 grant is supported in partnership with the Vincent Bourque Foundation.



FONDATION
VINCENT BOURQUE

The Vincent Bourque Foundation aims to eradicate ALS by supporting people living with ALS and their families through the ALS Society of Quebec, in addition to funding important research projects. We want to thank the Vincent Bourque Foundation for their continued support over the years.



"ALS Canada Research Program funding is supporting critical areas of clinical care, biomarker identification and development, clinical trial outcome measures, and identification of new treatment targets, all of which contribute to improved care, treatments and quality of life for people living with ALS. These investments also provide an environment that supports ALS research excellence in Canada which is a critical piece of the global effort to create a future without ALS."

- Dr David Taylor, VP Research, ALS Society of Canada.



WEBINARS SHARING GLOBAL KNOWLEDGE AND RESEARCH ON ALS



ALS Quebec's support of the ALS Canada Research Program contributes to initiatives that keep Canada's world-leading ALS research community connected to new and emerging global research and helps advance research with the potential to benefit Canadians living with ALS.

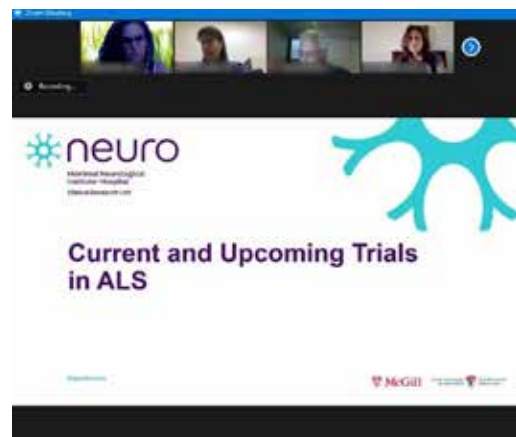
Following the cancellation of the 2020 ALS Canada Research Forum due to the COVID-19 pandemic, industry partner Biogen Canada sponsored a five-part webinar series that enabled the ALS research community to continue to share knowledge virtually.



The webinars engaged researchers from institutions around the world and across Canada, including the Montreal Neurological Institute (the Neuro) and the Université de Montréal, and touched on topics such as ALS clinical trials, animal models, and moving promising basic research closer to clinics.



The ALS Society of Quebec has contributed to the diffusion of the progress of ALS research by offering two online conferences to the ALS community, in February and June 2020. Thank you to Dr. Angela Genge, Dr. Richard Robitaille, PhD, Dr. Geneviève Matte, Dr. Christine Vande Velde and Dr. David Taylor, who participated in one or the other of these conferences and thus contributed to providing information on ongoing clinical trials to families touched by ALS in Quebec.



FINANCIAL SUMMARY

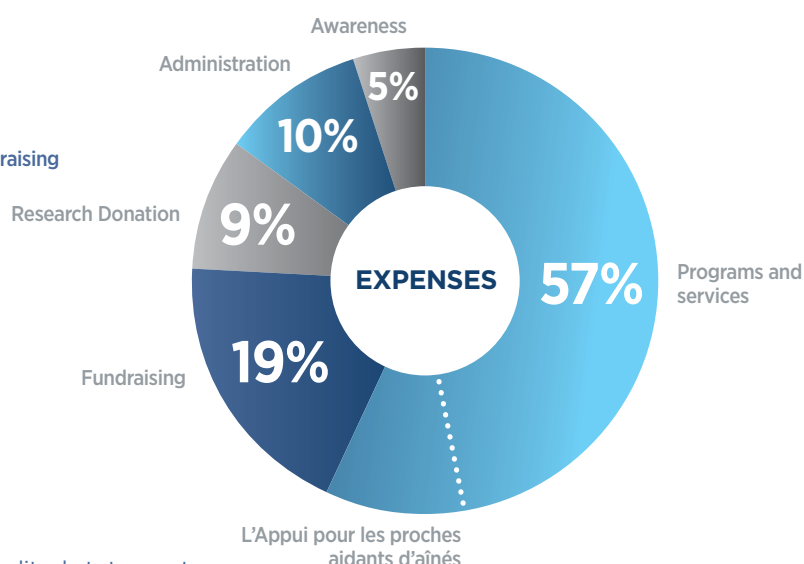
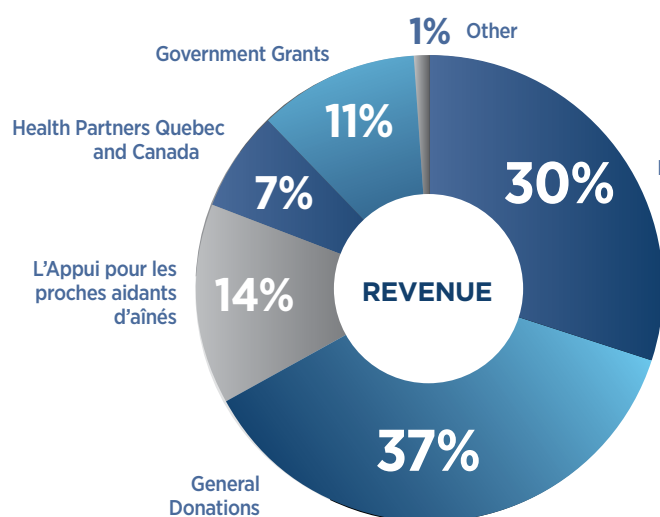
Financial year from November 1st 2019 to October 31st 2020

REVENUE

	2019-2020	2018-2019
Fundraising	\$447 293	\$804 806
General Donations	\$525 935	\$457 993
L'APPUI pour les proches aidants d'âinés	\$206 274	\$159 275
Health Partners Quebec & Canada	\$100 984	\$105 695
Bequests	-	-
Government Grants	\$158 917	\$32 040
Tony Proudfoot Fund	\$13 627	\$17 082
Team Stock Fund	\$1 675	\$18 409
Other	\$10 990	\$10 132
TOTAL	\$1 465 695	\$1 605 432

EXPENSES

	2019-2020	2018-2019
Programs and services	\$493 239	\$783 136
L'APPUI pour les proches aidants d'âinés	\$195 688	\$154 983
Fundraising	\$234 702	\$316 048
Administration	\$125 145	\$117 972
Awareness	\$63 887	\$80 608
RESEARCH CONTRIBUTION		
Contribution to research	\$95 183	\$140 496
Contribution to the Neuro (Tony Proudfoot Fund)	\$6 689	\$8 395
Contribution to research conferences (Fondation André-Delambre Symposium and ALS Quebec Journal Club)	\$1 176	\$20 172
	\$103 048	\$169 063
TOTAL	\$1 215 709	\$1 621 810
Excess (deficiency) of revenue over expenses	\$249 986	\$16 378



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



Joyeuses fêtes à toute l'équipe
et merci pour tout ce que
vous faites pour les personnes
atteintes et leurs proches.

- Diane Roy, bénévole



I can only imagine how
COVID-19 has complicated the
already difficult live of those
tortured with ALS. But thanks to
the dedicated professionals like
yourself the agony is lessened.

- Richard Capstick



I think often of you girls at the
ALS Society of Quebec and
all the help and support you
gave us.

- Cheryl Leonard





Pendant la pandémie, on oublie tout ce que vous faites. Sans vous, la souffrance serait bien plus pénible! Je vous envoie des câlins en attendant d'en faire plus.

- Marie-Hélène Beaudry



It has been an emotional rollercoaster since my diagnosis. The ALS Society of Quebec has been there since day one supporting me every step of the way. The counselors at the society also broke the news of my diagnosis to my kids. No matter what I need they are always there for me. They answer every question I may have. The staff at the society have so much compassion, empathy and knowledge. I am so grateful to have them with me on this horrible disease.

- Antonia lagallo



Un gros merci à l'équipe de la Société de la SLA. Votre aide et vos encouragements ont été réconfortants.

- Carole St-Vil



Merci de transmettre mes remerciements sincères à toute l'équipe de la Société de la SLA, qui fut très présente et d'un précieux support pour notre famille au cours des sept dernières années plus particulièrement. Je leur en serai toujours très reconnaissante. Continuez votre bon travail, qui est essentiel à la survie des proches de cette maladie si difficile.

- Maryse Morin



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

5415 Paré Street, suite 200, Mount-Royal (Quebec) H4P 1P7

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Credits Graphic Design: Mylène Duchesneau

Texts: Audrey-Maude Falardeau, Valerie Neufeld, Diane Tkalec and the ALS Society of Quebec team

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Huddol

This report is also available in French.