

BE AN ALS
**GAME
CHANGER**

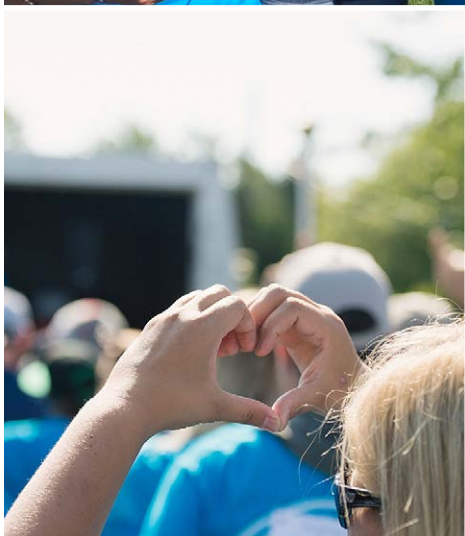
2017-2018 ANNUAL REPORT



JOINING FORCES TO FIGHT ALS

It's hard to win against a tough opponent like Amyotrophic Lateral Sclerosis (ALS), but the actions you took in the past year changed the rules of the game. You changed the lives of families touched by ALS by supporting personalized programs and services for those living with ALS and their loved ones. Your contribution in our awareness initiatives with the general population and government officials was a game changer. Your support also changed the future of ALS by supporting research. We are proud to share the impact you had on the playing field, moving us closer to the goal line.







Some of the Society's board members at the 2018 Ride to Fight ALS. From left to right: Daniel Malandrucolo, Elyse Claude Léveillé, Richard Robitaille, Diane Tkalec, Luc Vilandré, Claudine Cook, Susan Kennerknecht, and Judith Fetzer.

YOU ARE A GAME CHANGER

Without the support and dedication of all our volunteers, donors, and participants, we could never have accomplished so much. This year, thousands of you all across the province took the time to walk, ride, run, and organize fundraisers in your communities, and we are so very appreciative of your efforts.

With your support, we were able to enhance and change the way we provide our services by developing a new virtual learning environment for ALS caregivers and revamping our website.

Available on-demand, these ALS-specific virtual resources have greatly expanded access to our services province-wide.

Your contributions have also allowed us, our partners, and the ALS community to band together to lobby the government on various issues, in particular access to innovative drugs. Thanks to our concerted efforts, Health Canada has approved a new ALS treatment for the first time in 20 years. We will continue to speak up to keep the discussion going.

Lastly, the contributions you've made will be invaluable to ALS research, paving the way for a cure and a better future for everyone touched by the disease. Thanks to your donations, we're proud to have contributed to a \$3 million investment to the ALS Society of Canada's research program. Twelve new research projects are now under way and have become beacons of hope for ALS patients and their families.

The fight against ALS is not over yet. On behalf of the board of directors and the families we support, we would like to thank everyone—researchers, donors, participants, volunteers, healthcare professionals, and partners—for joining us on our mission to make game-changing progress.



Susan Kennerknecht

SUSAN KENNERKNECHT
President of the board of directors
President, Conseil BKK Consulting Inc.

Claudine Cook

CLAUDINE COOK
Executive Director
ALS Society of Quebec

ABOUT AMYOTROPHIC LATERAL SCLEROSIS (ALS)



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

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

2-5 YEARS

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

1:1

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



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



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

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Radio-Canada
Person living with ALS

DIANE TKALEC
Nurse clinician
Former caregiver

DENIS J. VANDAL
Marketing consultant



Lucie Thériault surrounded by her loved ones at Montreal's Walk to End ALS on September 16th, 2018.

CHANGING THE DAILY LIFE OF FAMILIES TOUCHED BY ALS

Offering personalized support across the province

Nothing can prepare someone for living with ALS, but thanks to your donations, our team can maintain and create new ways to support Quebec families touched by ALS throughout the province and at every stage of the illness.

3,518

Members (people living with ALS, caregivers and healthcare professionals)

2,000

Interventions for personalized assistance and support

24

Diversified regional and online conferences for families, as well as, exchange forums for healthcare professionals

272

Requests accepted for varied financial aid

68

Support groups for people living with ALS and their caregivers, including a new group in Gatineau

1,663

Registrants for support activities

INFORMATION

- Regional conferences and information sessions
- Trainings sessions and workshops such as: PDSB (Principles for moving loved ones safely) and First Aid for choking
- Documentation
- Newsletters
- Website, information resources, teleconferences and webinars
- Exchange forums
- New virtual learning environment Taking Care

PSYCHOSOCIAL SUPPORT

- Toll-free telephone line
- Counselling, orientation and referral
- Support groups
- Teleconferences
- Bereavement support

TECHNICAL AND FINANCIAL AID

- Equipment assistance
- Residential adaptation program
- Financial aid
- Respite
- Financial program for children

NETWORKING ACTIVITIES

- Social activities
- Pairing and networking
- Online community
- Presence on Huddol, a virtual network for caregivers and professionals;
- Caregiver Recognition Day and cocktails for caregivers and the bereaved

PROGRAMS AND SERVICES: SUPPORT FOR THE WHOLE FAMILY



48 activities uniquely for caregivers



13 diversified social activities to break down isolation



17 children were able to pursue their extracurricular activities thanks to the collaboration and funding of the Canadian Tire Jumpstart Foundation



21 wishes fulfilled, allowing 176 people to experience and share special moments thanks to the Seize the Day program. Launched with the financial support of the Tenaquip Foundation, the program's goal is to give the gift of memories to families touched by ALS

"A huge thank you to the Tenaquip Foundation and the Society for giving me the opportunity to experience this wonderful hot air balloon flight with my family. This delightful adventure allowed us to literally experience a change of scenery and distract us from our very demanding daily life. We will cherish this wonderful memory."

**Carole Paquin, Laval,
beneficiary of the new Seize the Day program**





Occupational Therapist Ann-Marie Léporé during the filming of a four-part video series about safety and home modifications in ALS.

CHANGING THE WAY WE DELIVER OUR SUPPORT

Taking Care, a new virtual learning environment for caregivers of someone living with ALS

Launched with the financial support of L'Appui national pour les proches aidants d'âinés and the collaboration of McGill University's Steinberg Centre for Simulation and Interactive Learning (SCSIL), the virtual education program Taking Care offers caregivers of people living with ALS the opportunity to access on-demand resources provided by experts and health care professionals specialized in ALS.



The Taking Care platform content allows caregivers and people living with ALS across the province to find answers to their questions at the time and place that is best suited to their reality and personal journey.

244 SPECIALIZED ALS RESOURCES IN A VARIETY OF FORMATS



122 TO READ

Including fact sheets, guides, manuals and books of interest.



25 TO LISTEN TO

From teleconferences animated by experts to guided relaxation and meditation exercises.



48 TO WATCH

A new series of 4 videos about safety and home modifications, webinars on a wide variety of topics, in addition to films of interest.



49 INTERNET LINKS

Local and international support programs and information about pertinent government and legal services, research news, innovations and key resource networks that help to better equip families with their changing needs during their journey with ALS.

ANSWERING REAL NEEDS BY SIMULATING THE REALITY OF CAREGIVERS

A four-part video series on safety and home modifications in ALS with Occupational Therapist Ann-Marie Léporé and produced in collaboration with the SCSIL features standardized patients, actors who put themselves in the shoes of someone living with ALS and their caregiver. Strategies to help make the kitchen, bedroom and bathroom safe for everyone are presented.

The four video segments on home modifications in ALS were filmed in a SCSIL simulated apartment.



"Navigating and accessing reliable information and support as a caregiver to someone who has ALS can be very challenging and overwhelming. I remember it being so stressful not to know where to turn for specific information, to be in situations where some allied health care professionals knew less than I did about the illness, or to see information about an upcoming conference that would have been helpful in my caregiver journey if I had received it three months earlier. The aim of the "Taking Care" virtual learning environment is to cover relevant topics that are essential for equipping and inspiring ALS caregivers to maintain and improve their quality of life."

Diane Tkalec

Occupational Therapist Ann-Marie Léporé (left) and Diane Tkalec, the ALS Society of Quebec's Taking Care Project Manager.



TAKING CARE
A virtual learning environment
for caregivers



With the financial support of

L'APPUÏ POUR LES PROCHES AIDANTS D'ÂÎNÉS



McGill



STEINBERG CENTRE FOR
SIMULATION AND INTERACTIVE LEARNING
CENTRE DE SIMULATION ET
D'APPRENTISSAGE INTERACTIF STEINBERG



CHANGING THE GAME FOR FAMILIES TOUCHED BY ALS

Chantal Lanthier (centre) with her spouse, Jocelyn Théorêt, and Denise St-Pierre, Coordinator of the Walk to End ALS in Saint-Hyacinthe.

UNITED IN THE FIGHT AGAINST ALS

Just under two years ago, Chantal Lanthier crossed paths with someone who very quickly became a dear friend: Denise St-Pierre, who's dedicated herself heart and soul over the past few years to supporting the cause of ALS. With a singular commitment, Denise threw all her energy into rallying the troops to keep moving the battle against ALS forward.

*The wonderful friendship I have with Denise began in spring 2017. She'd read my book, **Parce que parfois, la pluie doit tomber**, and was really moved by it. She approached me to ask for more copies to give to her employees at the Centre de conditionnement physique ADN. She wanted them to learn more about ALS ahead of their participation in the two fundraising events that she'd organized: the very first Walk to End ALS in Saint-Hyacinthe in 2015 and the Yoga for ALS evening in 2017. Her goal was to educate her employees, to then have them spread the word to loved ones to generate even more influence and support.*

I was really impressed with her dedication and compassion—two qualities that sparked the chemistry that's existed between us ever

since. Even though she was touched and inspired by my book, she's always felt the need to help people with ALS and their families. She believes she was "destined" to make a difference.

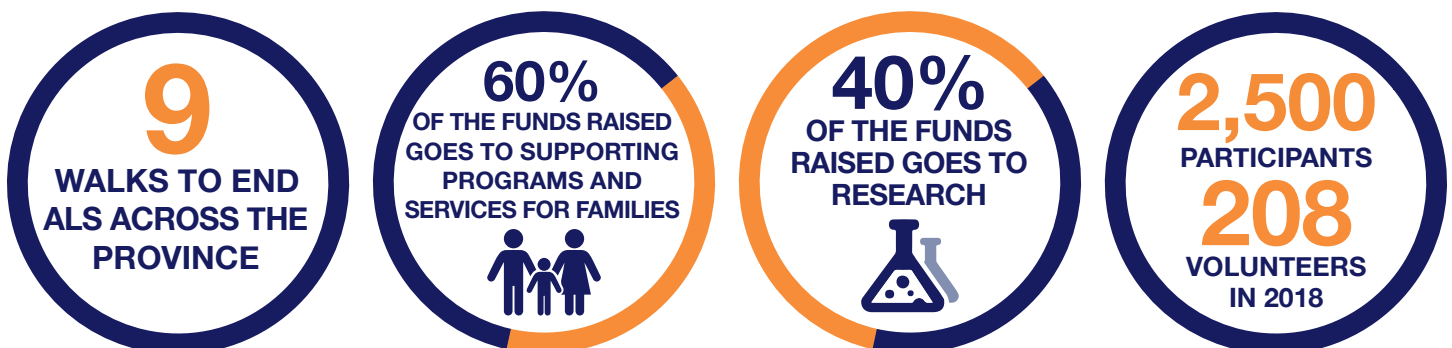
Today, two years later, Denise is still unwavering in her commitment. Her original ideas flow not only from her creativity, but also from her desire to raise awareness about the disease and to make sure donors don't forget about us. Her energy and enthusiasm inspire us to push our limits. As proof, she did an amazing job leading the warm-up sessions for the Ride to Fight ALS and the Walk to End ALS in Montreal.

Our Denise is larger than life, and we thank her from the bottom of our hearts for her dedication to the ALS community in Quebec. Thanks to people like her, the lives of ALS patients and their families are a little brighter.

I love you, my friend.

Chantal xxx

ABOUT THE WALKS TO END ALS





THANKS TO ALL MEMBERS OF THE ALS TEAM WHO ORGANIZED ACTIVITIES TO RAISE MONEY AND AWARENESS ABOUT ALS IN THEIR COMMUNITIES! **EVERY ACTION COUNTS!**

Activities at Hampstead Elementary School (David Lee)

Baie-Comeau committee activities

Benefit dinner (Stéphane Boudreau)

Benefit dinner in honor of Édith Bélanger (Valérie Claing)

Birthday as a gift (Jennifer Shannon)

Book sale - Le vent se lève (Jean Whissel)

Bromont Ultra (Gilles Poulin & Marc Hébert)

Burlesque Fundraiser (Yael Perez)

Camping activities (Nathalie & Caroline Savard)

Caroling night (Meredith H. Hayes)

Choir Vocal 80 (Diane Bouthillier)

Cookie jar sale (Sabrina Joyce-Dupuis)

Culinary arts class (Collège Ville-Marie)

Dance with the Classics (Roger Boudreau)

Défi Everest Premier Tech (Nancy Aubé)

Dek Hockey Tournament (Philippe Michaud)

Door to door (Rose-Aline Rouleau)

Erg-a-thon Tony Proudfoot (Dawson College)

Friday Night Bites (John Misiasz)

Fundraising in honor of Gilles Rousseau (Carole Rousseau)

Garage sale (Marie-Josée Ricard)

Half-Ironman in honor of Roger (Sébastien Picard)

Hot Pepper Challenge (Sébastien Picard)

Information and fundraising booth (Pei-Ching Ho)

Jewelry sale, Fourrure FUR (Suzanne Lachance)

Le Défi des Beaucerons - Team Drouin (Caroline Drouin)

Le Tricheur (Sabrina Cournoyer)

Line dancing event (Micheline Lajeunesse)

Paul Régimbal (Tony Proudfoot Fund)

Personal fundraising (Julie Nault)

Personal online fundraising (Stella Wojas)

Pow Wow in Odanak (Jacques T. Watso)

Race at l'Islet (Linda Morissette)

Ram"mouse"sons Family Day (Louise Champagne & Michel Tremblay)

Returnable containers collect (Amélie Gagnon)

Returnable containers collect (Justin Lavigne)

Reusable Félix Homme bags selling (Sophie Paquette)

Snack Bar for ALS (Jean Whissel)

Softball game (Nathalie Breton)

Spaghetti dinner (Nancy Aubé)

Spaghetti dinner (Pierrette Mailhot & Carole Bordeleau)

Spinning for ALS (Claudia Romero)

Spinning with Joe Bicycles (Isabelle Lessard)

Thrive Through Self Care book launch (Mitzi Perez)

Town fair (John A. Mac Donald)

Tribute show for Gina Gravel (Mario Drouin & Daniel Vaillancourt)

Walk in Repentigny (Alexia Petitclerc)

Yoga for ALS - Centre ADN (Denise St-Pierre)

Zumbathon (Josée Dicaire)



Vincent Bourque surrounded by his family and friends at the 2018 edition of the Ride to Fight ALS.

CHANGING THE CONCEPT OF HOPE FOR FAMILIES TOUCHED BY ALS

In August 2018, Isabelle Lessard and her daughter, Maria, then 14, participated in the Ride to Fight ALS for the first time, a deeply moving experience. Their husband and father, Vincent, was diagnosed with ALS in 2015. Since then, Isabelle has been actively supporting the cause, by co-founding the Vincent Bourque Foundation and through her role as an Ambassador for ALS Quebec.

My husband was diagnosed with ALS in May 2015. Up until then, the illness had been a very private thing for our family. I decided to do the Ride to Fight ALS cycling challenge so that my daughters—our daughters—could experience the full support of the community, and make a difference as well. At the time, Maria was 14, Charline was 10, and Arielle was 9.

It was a huge challenge for Maria and I. We didn't even own bikes! But we decided to make this a family challenge—for a cause that was important to all of us. We wanted to be able to make a difference together. As luck would have it, my brother-in-law was in the process of opening his bike shop called Joe Bicycles: We found our experts! Everything was falling into place for us to sign up for the Ride to Fight

ALS. Slowly, but surely, with Joe Bicycles and the entire community behind us, we completed the challenge, pushing through each kilometre with a smile on our faces.

I'll never forget the sheer joy and the feeling of hope and accomplishment that we shared with my husband, our daughters and our friends at the finish line.

Our goal in tackling this physical challenge was to raise awareness for the cause, to make a difference for my husband and for everyone else affected by ALS. It was also the perfect opportunity to have an exciting adventure with my daughter, in honour of Vincent, because love wins over everything, even ALS.

We had so many people rooting for us, from the bus driver to our hairdresser to teachers and neighbours. The support we got from our family and friends was truly heart-warming. During the event, we also had the unforgettable opportunity to meet other people with ALS and their loved ones. The Ride to Fight ALS is much more than just a physical challenge; it's an event steeped in compassion, support and hope. It's truly an amazing, magical weekend.

ABOUT THE RIDE TO FIGHT ALS

The Society's
flagship event,
powered by
TELUS Health

250
cyclists and
volunteers

1-3
days,
75-
300 km

\$2
million
raised
since 2008

2019
EDITION
Auberge Godefroy
in the Mauricie
region from
August 23-25



REIGNITING THE SPARK OF HOPE

In the very early stages of his disease, my husband said it felt like all the energy in his legs had drained away—like the spark had gone out. That was the first sign of ALS; he had been an amazing athlete. Our goal in doing the challenge was to restore hope to the people touched by ALS. At the closing barbecue, Maria took to the stage to say a few words and then we all lit Bengal lights to “spark new hope for her father” and for everyone suffering from the disease. That was a very emotional moment.

The Ride to Fight ALS was truly remarkable and inspiring to us in so many ways. Our team smashed its fundraising goal by raising \$13,000. The impact of this event is immeasurable. We will cherish the memory of each kilometre we travelled, because with each pedal stroke, we knew how deeply we were loved and supported. And this gave us the boost we needed, during the Ride itself, but also while training for the event and still today.

We were carried forward by a tremendous wave of love, positivity and hope. We met so many dedicated professionals, generous volunteers, and other families like ours. This event brings everyone in the ALS community together and gives them hope and the opportunity to strike a blow at ALS.

Taking part in the Ride to Fight ALS has a direct, concrete impact on the ALS community. So, we'll be back next year—and probably for many years to come—from August 23 to 25 in the Mauricie region with an even bigger team!

Vincent Bourque, surrounded by his spouse Isabelle and their three daughters Arielle, Maria and Charline.



FONDATION VINCENT BOURQUE

ABOUT THE VINCENT BOURQUE FOUNDATION

On November 15, 2018, ALS patient Vincent Bourque and his wife, Isabelle Lessard, launched the Vincent Bourque Foundation with the goal of eradicating ALS by funding research and supporting families touched by the disease at ALS Quebec.

The Vincent Bourque Foundation partnered with ALS Canada and the Brain Canada Foundation to award a \$165,000 Post-Doctoral Fellowship to Dr. Sahara Khademullah, a postdoctoral candidate from Dr. Yves De Koninck's lab at Université Laval. The Foundation has also pledged to sponsor the Annual André-Delambre Research Symposium for the next ten years. This symposium attracts internationally renowned ALS researchers, who share their knowledge and latest discoveries about the disease.

“The boundaries of research are limited only by the amount of funding available. That's why we're proud to contribute to the discovery of new treatments through ALS research by helping researchers who are just starting out in their careers,” explained Vincent Bourque, co-founder of the Foundation, a few days before he passed away on November 20, 2018.

Until a cure is found, the Vincent Bourque Foundation, through the ALS Society of Quebec, will work diligently to improve access to the best care and assistive devices for people with ALS and their families in order to help them maintain their autonomy and quality of life for as long as possible.

The Vincent Bourque Foundation will continue its work in honour of this formidable man, who leaves behind an inestimable legacy for the ALS community.



From left to right: Quebec regional advisor to the Office of the Minister of Health Jamee St-Hilaire, Dr. Angela Genge, MP Francis Drouin, MP Pablo Rodriguez, Nancy Roch, MP Marc Serré, Dr. Richard Robitaille, ALS Quebec Executive Director Claudine Cook, and policy advisor for Health Canada Kate Moussouni. Not pictured: Norman MacIsaac.

CHANGING THE GAME FOR THE ALS COMMUNITY

ENGAGING IN DIALOGUE WITH THE GOVERNMENT AND THE GENERAL PUBLIC

Making game-changing progress means reaching out to Quebecers and government authorities to raise awareness for ALS and the realities and challenges that people touched by the disease have to face.



"I want to urge governments to pledge their support for ALS, once and for all, the same way they do for other, more common neurodegenerative diseases. We're close to finding a cure, but we lack funds. All I want to see is real political will and concrete efforts toward ending this disease, which has claimed thousands of victims. I take life one day at a time, but I never give up hope that one day we'll find a drug to help us live longer and that we'll have quicker access to medicine, which is why I continue to speak up and why I encourage you to do the same."

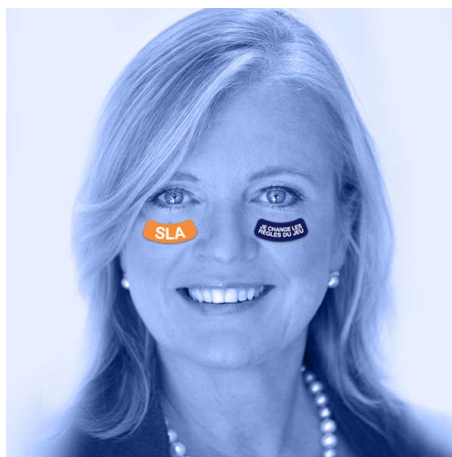
Nancy Roch,
ALS Quebec Ambassador living with ALS since 2017

"I'm all too familiar with ALS—my father died from the disease in 2002, so we know exactly what it entails. Then, André Delambre approached me to become the spokesperson for the ALS Society of Quebec, which helped me learn even more about the cause. When my father had ALS, most people had never heard about it, let alone seen it firsthand. Whenever I'd talk about it, people just didn't get it. Today, it's much better known thanks to the efforts by the ALS Society of Quebec and the work we all do together. I have a soft spot for people with ALS and their families. We can't give up. Concrete actions are the only thing that will help us find a cure for this terrible disease."

Martin Matte, comedian and actor,
and former spokesperson for the ALS Society of Quebec



In a show of support and as part of our ALS Awareness Month campaign, various personalities from the sports and cultural spheres and members of the ALS community got together to talk about what they do to help change the game.



Dr. Angela Genge, neurologist and ALS researcher at the Montreal Neurological Institute and Hospital



P.J. Stock, RDS sports analyst and former NHL player



Sabrina Cournoyer, cultural reporter on TVA's show Salut Bonjour



Marc Griffin, RDS baseball analyst and former player for the Montreal Expos



Dr. Jean-Pierre Canuel, retired doctor living with ALS



Isabelle Giroux, Actress, Ruptures, and honorary spokesperson for Trois-Rivières' Walk to End ALS in 2018

SPEAKING UP IN 2018:

- Instigated by ambassador Nancy Roch, we met with Health Canada and several members of the federal parliament to emphasize the need to put Canada on the same playing field as the USA with the pharmaceutical industry and help accelerate the process for approval of new drugs or treatments, such as Radicava. Nancy also met with the Institut national d'excellence en santé et en services sociaux (INESSS) to stress the urgency for people living with ALS.
- Our advocacy team also met with L'Ordre des infirmières et infirmiers auxiliaires du Québec (OIIAQ) to discuss policies around administering drugs that aren't yet approved by Health Canada, but already available in other countries.
- On-going support to ALS Canada's Advocacy initiatives and attendance at the ALS Caucus meeting in Ottawa by ambassador, Norman MacIsaac.
- Neuro Partners brief entitled "Pistes de solutions pour améliorer la qualité de vie des personnes atteintes d'une maladie neurologique évolutive" submitted to the National Assembly and discussed with various Quebec MPs, testimonial from our ambassador Norman MacIsaac, and meeting with Minister of Health and Social Services Gaétan Barrette.
- Announcement by MPs Pierre Arcand and Pablo Rodriguez highlighting ALS Awareness Month.
- Strong and engaging presence on social media, regular email communications and digital marketing awareness campaigns that keep our cause at the forefront with our stakeholders.

Thank you to our devoted volunteers, tireless participants, loyal partners and generous donors.
Your support fuels the hope of a future without ALS.

THE **TENAQUIP** FOUNDATION

L'APPU POUR LES PROCHES AIDANTS D'AINES

TELUS | Health



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iii HealthPartners



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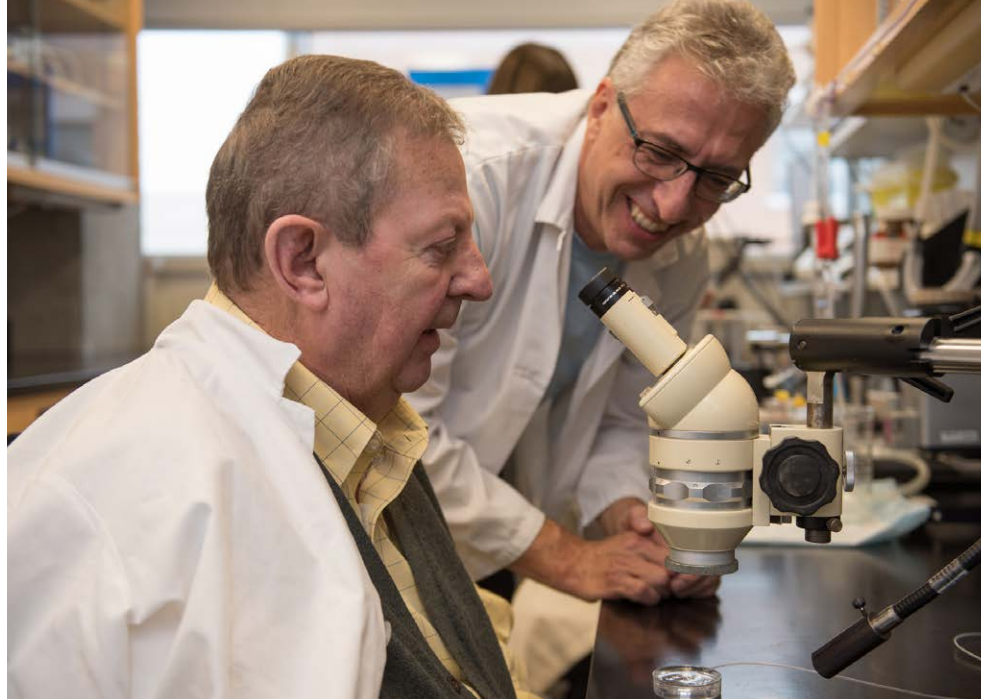
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ALS RESEARCH IN NUMBERS

- Support of Quebec ALS Research Network, which aims to create a dialogue with the new generation of researchers
- Support of the 14th Fondation André-Delambre Symposium in Quebec city
- Over \$1.7 million invested in Canadian ALS research through the ALS Canada Research Program, the only dedicated source of funding for ALS research in Canada
- A total of 14 projects funded, including 8 project grants and 6 trainee awards - the most trainee awards granted in a single year
- 170 + Canadian ALS Researchers attended the 14th annual ALS Canada Research Forum, an event that fosters collaboration amongst Canadian researchers, helping to nurture new ideas and build capacity
- 450 + people learned about the latest advancements in ALS research in Canada by participating in research webinars and the 3rd annual Virtual Research Forum



Dr. Richard Robitaille shares his microscope with Guy Aubert, who's living with ALS.
Photo credit: Amélie Philibert

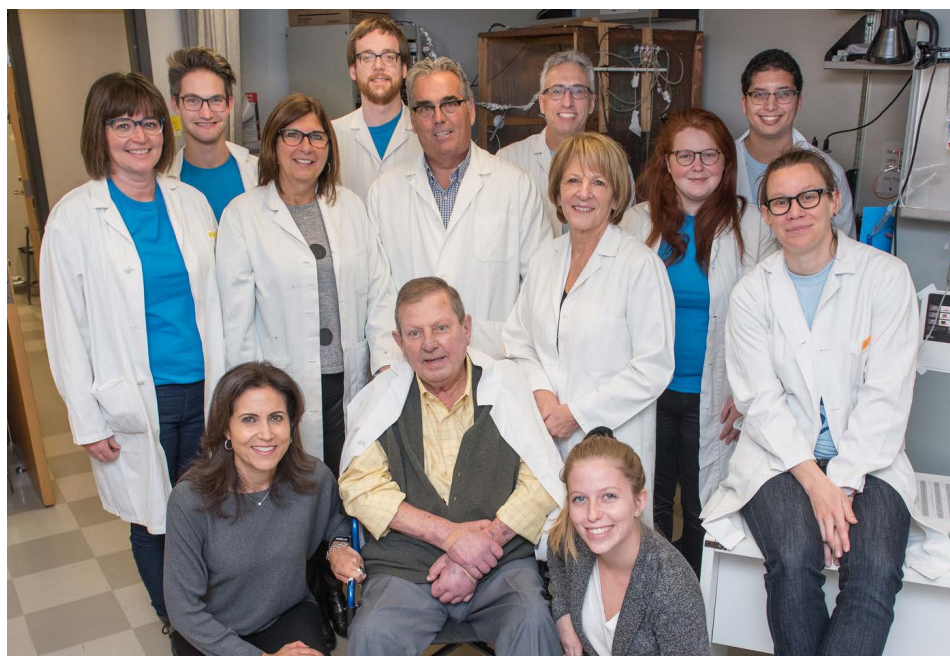
CHANGING THE FUTURE OF ALS

Bridging the gap between families and the research community

Guy Aubert's hope for the future was shaken to the core after he was diagnosed with ALS in March 2018. But the Victoriaville man's hope was restored by Dr. Richard Robitaille and his ALS research team. He and his wife, along with their friends Max and Sylvie, spent the day with Dr. Robitaille at his lab, a unique experience that they'd bid on during he last online auction in support of ALS Quebec.

"Our team was honoured to have Mr. Aubert and his friends visit our lab. The goal of the exercise was, first and foremost, to bridge the divide between the research community and the families touched by ALS who, just like us, survive on hope. Meeting Mr. Aubert really changed our lives by opening up our eyes to his situation and reminded us of why we do what we do."

Dr. Richard Robitaille, full professor, Department of Neuroscience, Université de Montréal, and member of ALS Quebec's Board of Directors



2018 ALS RESEARCH REVIEW

The ALS Society of Quebec is proud to have contributed over \$155,000 to the ALS Canada Research Program, which aims to accelerate research impact by providing funding support for the best ALS projects focused on translating scientific discoveries into treatments for ALS.

In 2018, the ALS Research Program funded more than \$1.7 million in Canadian ALS research to support the next generation of ALS researchers bring forward new and innovative discoveries and to help established researchers further advance our understanding of the disease – all to help create a future without ALS.

Included was a \$1 million investment in eight new research projects that aim to enable the exploration of new therapeutic targets, extend existing research to support further discoveries and help researchers gain a greater understanding about why ALS progresses differently in each individual.

An additional \$720,000 in funding was also provided in partnership with Brain Canada for six new trainee awards to support the next generation of ALS researchers currently pursuing PhDs or postdoctoral research positions, with the aim of sustaining high-quality Canadian ALS research. The investment represents the last of the matched funds from Brain Canada following the Ice Bucket Challenge, as well as a new partnership with La Fondation Vincent Bourque, which we helped to establish shortly before Vincent passed away from ALS, to make one of the trainee awards possible as part of his legacy.

The granting of each award followed a competitive peer review process, which engaged global ALS experts who evaluated a larger pool of applications to identify the projects that are grounded in scientific excellence and have the potential to most quickly advance the field of ALS research in order to develop effective treatments.



Many international ALS researchers joined the 14th Annual Fondation André-Delambre Symposium at Quebec city's Université Laval.



"The ALS Canada Research Program directs donor dollars towards the best ALS research projects in Canada and funds exceptional students and postdoctoral candidates with the goals of creating the next generation of dedicated ALS researchers in the country. The projects funded this year include great new ideas that need pilot funding to gather a foundation of data, ongoing ALS research that is already impacting the global understanding of ALS, and studies that directly affect people living with ALS today. With Brain Canada's commitment of matched funds following the Ice Bucket Challenge now complete, the ALS Canada Research Program will return to its historic funding levels. The generosity of donors and partnerships with provincial ALS Societies across Canada are essential in maintaining the momentum of the last five years and expand to fund even more projects in the future."

**Dr. David Taylor,
VP Research, ALS Canada**

CAN A REVOLUTIONARY GENE-EDITING TOOL CREATE BETTER ANIMAL MODELS FOR STUDYING ALS?

Amongst the researchers being funded is Dr. Gary Armstrong from the Montréal Neurological Institute, who was awarded a \$125,000 project grant. With this grant, Dr. Armstrong will use a revolutionary gene-editing tool called CRISPR-Cas9 to create genetically modified zebrafish that more accurately represent the genetic situation in human ALS. Using specialized techniques to measure the health of motor neurons in these models, Dr. Armstrong hopes to gain new insights into the relationship between muscles and motor neurons in order to better understand how ALS arises. If successful, his project will pave the way for using his innovative CRISPR-Cas9 tool to create accurate models of ALS in other animals in future research.



“Validating our innovative gene-editing tool to make zebrafish models of ALS may help other researchers develop better animal models of ALS, helping to advance promising therapies into clinical trials much faster than current timelines.”

**Dr. Gary Armstrong,
neuroscientist and assistant professor
at the Montreal Neurological Institute, McGill University**

DOES A PREVIOUSLY UNSTUDIED PROTEIN PLAY AN IMPORTANT ROLE IN ALS?

The TDP-43 protein is usually found inside the cell nucleus and is responsible for regulating many cellular processes. In 97 percent of ALS cases and nearly half of frontotemporal dementia ones, scientists have discovered that the TDP-43 protein is misplaced to an area outside the cell nucleus called the cytoplasm.

Dr. Vande Velde recently discovered that reducing the amount of TDP-43 protein in the nucleus caused an ALS gene called hnRNP A1 to be abnormally read, thus creating a new protein that she labeled hnRNP A1B. Dr. Vande Velde suspects this new protein could be a previously undiscovered toxic form. In her work, she will examine how hnRNP A1B functions and whether it plays a role in known mechanisms of ALS pathology. She will conduct cell and mice experiments first and then validate her findings using ALS tissue samples generously donated to the Douglas-Bell Canada Brain Bank in Montréal and through other ALS labs.

“I hope that a better understanding of hnRNP A1B’s function in ALS will reveal it as a potential target for new therapies and biomarkers in the future.”

**Dr. Christine Vande Velde, Ph.D., associate professor,
Department of Neuroscience, Université de Montréal and at the
Université de Montréal CHUM Research Center**



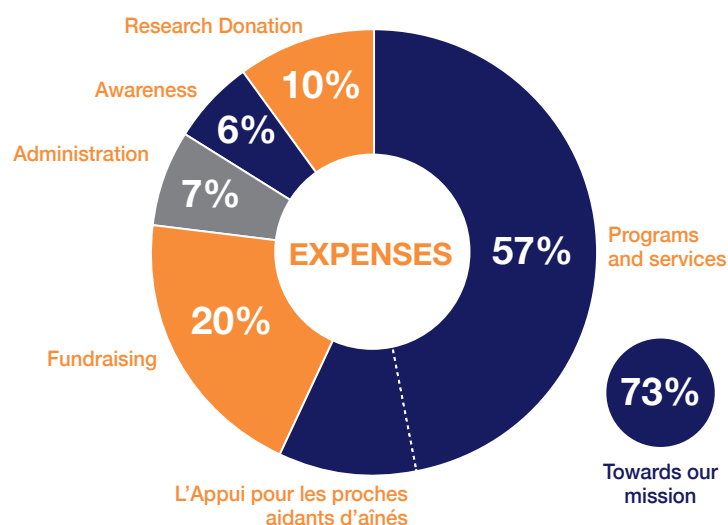
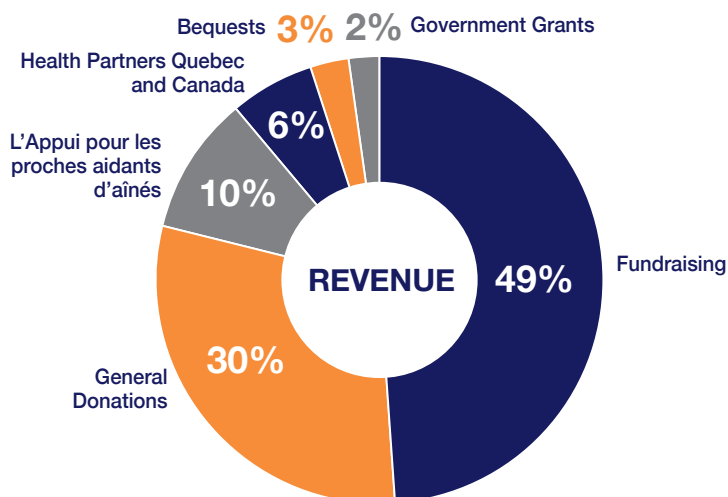
**THANK YOU TO ALL CANADIAN RESEARCHERS FOR FEEDING HOPE OF A FUTURE WITHOUT ALS!
To learn more about the ALS Canada Research program, please visit als.ca and als-quebec.ca**

FINANCIAL SUMMARY

Financial year from November 1st 2017 to October 31st 2018

| REVENUE | 2017-2018 | 2016-2017 |
|--|--------------------|--------------------|
| Fundraising | \$802 385 | \$900 715 |
| General Donations | \$463 650 | \$335 923 |
| L'APPUI pour les proches aidants d'âinés | \$161 720 | \$185 748 |
| Health Partners Quebec & Canada | \$91 619 | \$110 109 |
| Bequests | \$50 000 | \$25 407 |
| Government Grants | \$29 493 | \$25 950 |
| Tony Proudfoot Fund | \$15 036 | \$28 897 |
| Team Stock Fund | \$9 166 | \$41 655 |
| Other | \$3 685 | \$7 611 |
| TOTAL | \$1 626 754 | \$1 662 015 |

| EXPENSES | 2017-2018 | 2016-2017 |
|--|--------------------|--------------------|
| Programs and services | \$816 211 | \$751 640 |
| L'APPUI pour les proches aidants d'âinés | \$170 415 | \$129 182 |
| Fundraising | \$338 990 | \$361 793 |
| Administration | \$121 069 | \$102 520 |
| Awareness | \$109 145 | \$90 880 |
| RESEARCH CONTRIBUTION | | |
| Contribution to research | \$141 374 | \$158 092 |
| Contribution to the Neuro (Tony Proudfoot Fund) | \$7 350 | \$26 678 |
| Contribution to research conferences (Fondation André-Delambre Symposium and ALS Quebec Journal Club) | \$14 089 | \$67 156 |
| | \$162 813 | \$251 926 |
| TOTAL | \$1 718 643 | \$1 687 941 |
| Excess (deficiency) of revenue over expenses | (\$91 889) | (\$25 926) |



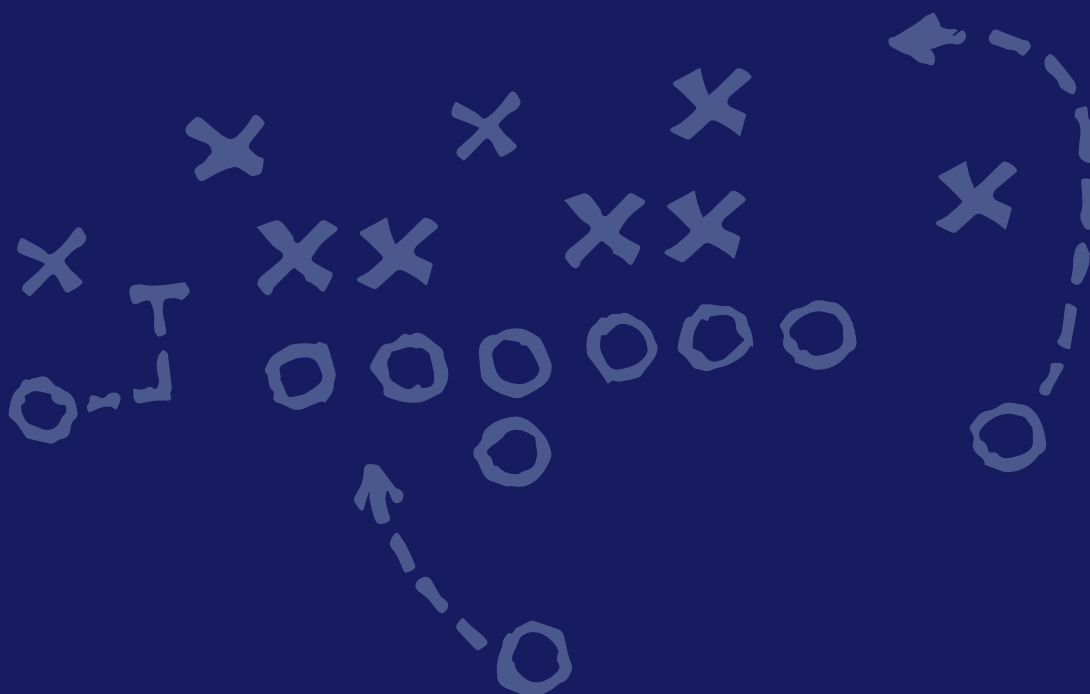
Please visit our website to view a detailed version of our audited statement

THE GAME IS NOT OVER YET

Thank you for being a game changer for the ALS community!
Thank you for giving, walking, riding, running, volunteering or organizing an event and therefore bringing our mission closer to the goal line. Unified in our fight against ALS, every dollar supports Quebec families touched by ALS and bring researchers closer to a cure while sending a strong message of hope. The game is not over yet: please visit als-quebec.ca to learn how you can keep on being an ALS game changer.







AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

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Huddol

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