



TOGETHER

2016-2017 ANNUAL REPORT



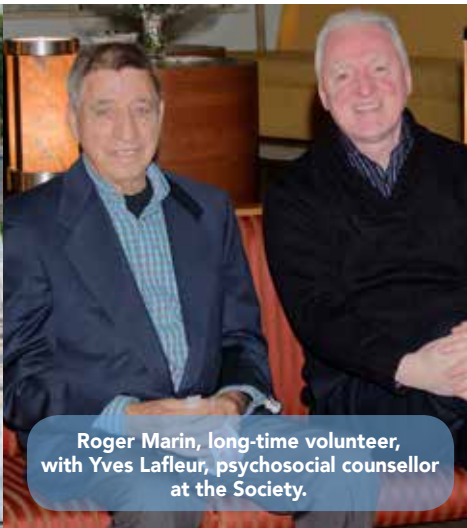
WE ARE PASSIONATE CARING COURAGEOUS



Dr. Jean-Pierre Canuel with Quebec's Walk for ALS organizing committee.



Kathy Vaux glows at the Society's adapted sailing activity at Pointe-Claire Yacht Club.



Roger Marin, long-time volunteer, with Yves Lafleur, psychosocial counsellor at the Society.



Michael Soles (right) had a lot of fun watching Canadian Football League commissioner Randy Ambrosie and Alouettes de Montréal General Manager Kavis take the #IceBucketChallenge, along with Alouette Bruno Heppel, former Alouette Davis Sanchez and radio announcer Rick Moffat.



Valérie Claing (right) took part in the Scotiabank Challenge in honor of her mother Edith, who's living with ALS.



Alain Bérard and his wife Dominique Racine met with Patrick Huard and Mathieu Baron at Bon Cop Bad Cop 2 movie premiere.



Amélie Gagnon collected many returnable containers so she could make a generous donation to Sherbrooke's Walk for ALS.



Line Thiboutot with friends, family members and some of the Alouette's cheerleaders at Montreal's Walk for ALS.



Sébastien Dextraze was proud to take part in Montreal's half marathon thanks to his loyal friends who took turns pushing him towards the finish line. Photo credit: Martin Belleau



Volunteers were ready for Montreal's Walk for ALS.



Ride to Fight ALS team Les Mollets d'acier enjoyed the beautiful roads of Vaudreuil-Dorion.



Steeve Day (center) with his loved ones during a dinner show fundraiser organized in his honor by his friend Pierre Millette.

ENGAGED INSPIRED STRONG COMMITTED



Some of the Society's board members at the 2017 Ride to Fight ALS. From left to right: Daniel Malandruccolo, Susan Kennerknecht, Luc Vilandré, Dominic Delambre, Claudine Cook, Michel Simard, Elyse Claude Léveillé and Diane Tkalec.

TOGETHER, WE STAND UNITED

If there's anything we've learned over the years, it's that we can't do it alone. Together, we're the voice, the heart and the hope of the ALS community. Together, we're able to accomplish great things. Every action, no matter how small, has a direct impact on the life of a family affected by ALS, but also on the advancement of research into a cure.

The first thing we did was to team up with the health network in order to respond quickly to the unique and changing needs of the families we support. Whether it's respite care or helping pay for extracurricular activities, or just someone to talk to, our wide range of services help the hundreds of caregivers, parents and children in Quebec who are touched by ALS to maintain the best quality of life possible, despite the chaos the diagnosis can cause in their daily lives.

We're also proud of our role in making sure our members' voices are heard by the public and the government. Our ambassadors have done a great job of shining the light on the many challenges we face, including access to innovative drugs and the urgent need to fund ALS research. We're convinced that their message will continue to resonate over the coming year, inspiring Quebecers to take action.

We're also very fortunate to have the support of many generous volunteers, donors and participants. This year, thousands of people from all across the province gave money, walked, ran, cycled, and even organized their own fundraising activities in honour or in memory of a loved one. We're infinitely grateful and extremely blessed to have them as part of Team ALS.

Finally, if we can ever hope to talk about ALS in the past tense, it will be thanks to an army of brilliant international researchers who are working hard to unlock the mystery of ALS. Thanks to your donations, we're proud to have contributed to a \$3 million investment in the ALS Society of Canada's research program, resulting in the creation of 12 new research projects and bringing renewed hope to the ALS community.

Thanks to all the researchers, donors, participants, volunteers, health professionals and partners who stand united with us and who, little by little, help us piece together the puzzle that will one day solve the mystery of ALS, defeating it once and for all.



LUC VILANDRÉ
President of the Board, ALS Society of Quebec
Vice-President and Chief Operating Officer,
- TELUS Health



CLAUDINE COOK
Executive Director
ALS Society of Quebec

BOARD OF DIRECTORS OF THE ALS SOCIETY OF QUEBEC

Executive Committee

- LUC VILANDRÉ**, President
Vice-President and Chief Operating Officer,
Health Benefits Management and Payment Solutions -
TELUS Health
- DANIEL MALANDRUCCOLO**, Vice-President
Vice-President, Vast Auto Distribution Ltée. Groupe MMO INC
- DOMINIC DELAMBRE**, Treasurer
Associate
Delambre, Gagnon, CPA Inc.
- MICHEL SIMARD**, Secretary
Management and IT consultant
Michel Simard Services-conseils Inc.
- SUSAN KENNERKNECHT**
President, Conseil BKK Consulting Inc.

Administrators

- ANDRÉ FALARDEAU**
Former caregiver
- JUDITH FETZER**
CEO and co-founder, COOK IT
Former caregiver
- VINCENT GAGNÉ**
Director, Governmental Relations, TELUS
- ELYSE CLAUDE LÉVEILLÉ**
Teacher, English second language
Former caregiver
- NORMAN MACISAAC**
Executive Director, Léger Foundation, retired
Person living with ALS
- ME ANABEL QUESSY**
Attorney
Fasken Martineau
- DR. RICHARD ROBITAILLE**
Professor, Neuroscience department, Université de Montréal
- NANCY ROCH**
Senior Director, Planification grille et diffusion, Radio-Canada
Person living with ALS
- DIANE TKALEC**
Nurse clinician
Former caregiver
- DENIS J. VANDAL**
Marketing consultant



Members of the Society with psychosocial counsellor Yves Lafleur at Ville Lorraine's support group.

SUPPORT AND SERVICES FOR OUR MEMBERS

Improving the quality of life of Quebec families touched by ALS

Learning you have ALS is devastating. The diagnosis stirs up all kinds of emotions -- fear, worry, sadness and anger. From diagnosis to end-of-life care and bereavement support, our dedicated team of psychosocial counsellors and coordinators provide compassionate and knowledgeable support to families living with the disease.

We help empower those living with ALS, their caregivers and family members, by providing them with information about the disease and helping them navigate the health system and community services. To ensure those living with ALS receive the best possible quality of care, we provide free seminars to health professionals so they better understand the disease, its progression and the evolving needs of those in their care.

We know when it comes to a disease like ALS; one size simply does not fit all. Each person's journey with the disease is unique with its own set of symptoms and natural progression.

For this reason, we are committed to providing personalized supportive services, financial assistance and specialized equipment to meet each member's individual needs. We organize a variety of in person and online social activities and networking events to break isolation, and to allow those living with ALS and their caregivers an opportunity to share their stories, worries and frustrations while offering one another emotional comfort and moral support.

Our philosophy is simple: we get to know each family personally and work hand-in-hand, partnering with them to improve their quality of life, enhance their comfort, and alleviate their suffering. We are a friend, an advocate, and a resourceful lifeline that Quebecers touched by ALS rely on and trust.

Programs & services: our highlights

- ▶ Over 3,000 clients served (people living with ALS, caregivers, healthcare professionals)
- ▶ 600 persons living with ALS assisted
- ▶ Connected with 1100+ family members and 45 activities dedicated to caregivers
- ▶ Over 560 requests accepted for diversified financial aid, including the new bereavement support financial aid program
- ▶ Over 1,440 interventions for personalized assistance and support
- ▶ 1,322 registrations for support activities
- ▶ 61 support groups for people living with ALS and their caregivers
- ▶ 9 regional conferences and 7 webinars
- ▶ 10 social activities to break isolation
- ▶ 6 exchange forums for healthcare professionals

TOGETHER, WE FIND STRENGTH

"My husband had just turned 40 when he was diagnosed with ALS. At the time, our three children were 6, 7 and 11 years old. We were all very active as a family. Vincent was an avid skier and loved to spend the day on the slopes with our three girls, who were all bitten by the bug from the time they were little. As you know, ALS complicates things, but the Society's youth program makes some of them easier to cope with. For the past three years, our daughters have continued to hit the slopes thanks to this program. Sometimes we all go, and Vincent and I watch the girls practicing their favorite sport. Other times, my husband stays at home with a caregiver and rests. And when the girls get home, he loves to hear all their wacky stories about their day at the ski hill. It's almost as if he was there. When you're living with ALS, each sliver of happiness gives you the boost you need to keep going in the fight against this disease. We'd like to thank the ALS Society of Quebec for giving us back the chance to spend this time with our girls—rosy cheeks, hot chocolate and all!"



ISABELLE LESSARD
Caregiver and life partner of Vincent, who's living with ALS

"When the time came to adapt my house, ALS Quebec helped me out financially. When I could no longer walk, they helped me get a wheelchair and coordinate home care services. When I lost the use of my hands and arms and started feeling isolated, they gave me a head mouse for my computer so I could stay in touch with my friends and family and continue using other technologies that keep me safe and independent. I can tell you that my independence is priceless, so it's definitely the greatest gift you could give someone with ALS."



MARTIN LAUZON
Living with ALS

INFORMATION



Conferences



Documentation



Newsletters



Resources, website and webinars

PSYCHOSOCIAL SUPPORT



Orientation and reference



Bereavement support



Toll-free line



Support groups



Teleconferences

TECHNICAL AND FINANCIAL AID



Residential adaptation program



Equipment assistance



Financial contribution



Respite



Financial contribution for children

SOCIAL AND NETWORKING ACTIVITIES



Regional information sessions



Social activities



Online community



Online caregiver network

WHAT IS ALS?

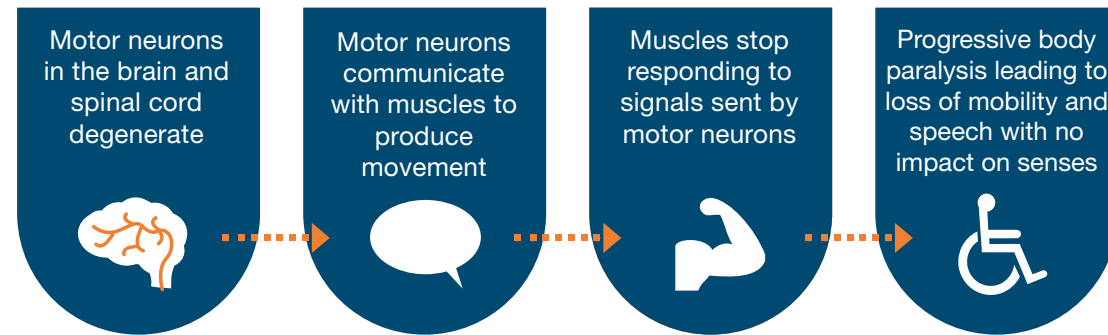
Fatal neurodegenerative disease

Amyotrophic lateral sclerosis, also known as:

Lou Gehrig's Disease



Motor Neuron Disease



Life expectancy **80%** of people die within **2 to 5** years after the diagnosis

In Canada ALS is the most common cause of neurological death in Canada. More people die every year of ALS than of muscular dystrophy, multiple sclerosis and cystic fibrosis combined.

About **3000** people suffer from ALS

Diagnosis Death 1:1

ALS

Can affect anyone:
90% of cases are random
10% of cases are hereditary



Impacts the whole family
on emotional, physical
and financial levels



Unknown causes.
No curative treatment.



The ALS Society of Quebec

Offers programs and services for people with ALS, their caregiver and healthcare professionals

Funds and promotes cutting-edge research projects in Canada

Raises awareness with the general population and government officials

HELPING THOSE WHO HELP OTHERS

Many people tend to think caregivers 'pitch in' from time to time to help a loved one with ALS. In fact, informal caregivers—not health professionals—provide the majority of home care (80%) to those living with ALS.

Caregivers support those living with ALS and their autonomy by helping with everyday activities such as running errands, providing transportation, and cooking meals, to providing more functional support by assisting with clothing, bathing, grooming, administering medications/injections, feeding, scheduling of medical appointments and finances. In some cases, ALS caregivers provide 24/7 complete care and support in the home. Many juggle these tasks while faced with the challenge of balancing work, raising children or taking care of other elderly family members. All the while, caregivers witness their loved one's progressive loss of autonomy and are in a position of having to adapt the level of intensity of their caregiving while trying to maintain their physical and emotional health.



Caregivers at one of the Society's support groups.

Personalized psychosocial support

This is where our committed team comes in. Thanks to funding from l'Appui pour les proches aidants d'âinés, we work arm-in-arm with caregivers. Our goal is to improve their quality of life and reduce their risk of injury, exhaustion, depression and stress. To this end, we provide individualized psychosocial support, interactive and specialized support groups, training, connections to community resources, critical financial support for respite, bereavement and grief counselling. We care for the caregivers so they have the energy, knowledge and ability to help their loved one deal with the devastating and debilitating impact of ALS.

ALS: a disease that affects the whole family

Children and teens are not unaffected when a parent is diagnosed with ALS. As well, to help maintain continuity, we provide financial support for activities such as hockey, music lessons and art classes. We believe the wellbeing of caregivers is paramount, and that the caregiver experience is different for every family living with ALS. We recognize caregivers devote an enormous amount of time, energy, focus and financial resources caring for loved ones with ALS. But, they can't do it alone. They need our support. They deserve our support. They have our support.

Huddol: a new online community for caregivers

In order to expand the offer of support to ALS caregivers throughout the province, the ALS Society of Quebec began collaboration with Huddol, a new online community platform for caregivers. The Huddol platform, and the creation of a dedicated Huddol group named, #ALSCaregivers, aims to give a helping hand to ALS caregivers who would like to have access to webinars, conferences, social activities, share tips, and advice with other caregivers and healthcare professionals with similar interests and information needs.



Participants of the Caregiver Recognition Day are enjoying some board games animated by pub Randolph.

THANK YOU TO L'APPUI NATIONAL AND MONTREAL FOR THEIR GENEROUS SUPPORT!

L'APPUI POUR LES PROCHES AIDANTS D'ÂINÉS



Line Thiboutot, Chantal Lanthier and Ginette Beaudreault opening the first Walk for ALS of the year in Saint-Hyacinthe on May 6, 2017, accompanied by federal MP Brigitte Sansoucy and by event organizer Denise St-Pierre from Centre ADN. Photo credit: Andrée-Anne Rivest

"While taking care of my sister, who has ALS, I also found out that one of my uncles died from the disease and that, oddly enough, there were several cases of ALS in the Mauricie region. Thanks to the Society, my sister was able to get equipment loans and support throughout her eighteen-month battle. After seeing what she went through, I vowed to raise money to make sure that other people would be helped by the many services offered by the Society. Walking together is a great way to rally people behind the cause and to meet kind, brave souls who are filled with hope. It's the perfect opportunity to show them our support and to talk to other people who are going through, or who've been through, the same situation. At the same time, since part of the money raised goes to research, we can hope that there will one day be a treatment or a cure for this terrible disease."



THÉRÈSE CARIGNAN
Trois-Rivières Walk
for ALS coordinator

"I've decided to dedicate the funds my team and I raised as part of Quebec's Walk for ALS to research simply because no money equals no cure. No cure equals no research. No research equals death. Maybe for cases like mine, it will be too late. My hope remains, however, that we'll find a cure for others or even that ALS will be prevented altogether. When you have ALS, you're frozen in a block of ice. It's as if you were a deep sea diver immobilized by your suit or as if your body were encased in concrete or quicksand. In order to break the ice and free ourselves from this terrible disease, we need to find a cure. The key to finding the first treatment is to fund research."



DR JEAN-PIERRE CANUEL
With Jean-Guy Fournier and René Roy,
all 2017 Walk for ALS top fundraisers

TEAM ALS

Fighting ALS, together

ALS Quebec survives on donations and fundraisers done throughout the year.

Our donors, participants, partners and volunteers are passionately committed to helping those touched by ALS to live their best possible lives and to funding research.

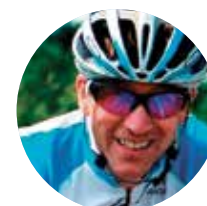
This past year, Quebecers in all four corners of the province turned out to support our Ride to Fight ALS powered by TELUS Health, attended a "Magical evening" with Alain Choquette, and participated in 10 different Walks for ALS and a host of third-party fundraising activities. Not only do the events raise important funds and awareness, the energy they create is also electric, thanks to the tremendous camaraderie, enthusiasm and compassion of our supporters and volunteers.



The 10th Ride to Fight ALS powered by TELUS Health raised over \$400,000.

Marie-Claude Diamant, Ride to Fight ALS participant.

"My brother Pierre was always very courageous. He never felt sorry for himself. When he learned he had ALS, he did everything he could to spend as much time as possible with his family. I then decided to get involved with the Society by putting together the Ride to Fight ALS with Dominic Delambre. There are now over 250 participants and volunteers. If thousands of people got involved, each by putting in a little effort, raising a little bit of money, we could change the world. We would find an answer, we would find a cure. TELUS Health's team is so proud to push this inspiring event forward."



LUC VILANDRÉ
Ride to Fight ALS co-founder and Vice-President
and Chief Operating Officer, Health Benefits
Management and Payment Solutions, TELUS Health

"My team, "Les Pédales à Bob Michaud," and I have been riding in memory of my father since 2011. We participate year after year, first of all, because ALS is a cause that's dear to our hearts, and also because of the great camaraderie at the event, which is always so well organized. The three-day event is a wonderful opportunity to bond with fellow team members and other participants. Of course, we hope that all the money invested in research brings us closer to a cure for this disease, but there's also a crucial need for all the resources that are made available to people with ALS and their families. These funds are needed to help ALS patients cope with the effects of the disease and also to better prepare their loved ones to support them through this difficult time."



PHILIPPE MICHAUD
Ride to Fight ALS participant
and former caregiver



On August 5th, 2017, the Ram "Mouse" sons family day, organized by Louise Champagne and her husband, Michel "Mouse" Tremblay, himself an ALS patient, raised \$29,000 for the cause

A DEDICATED COMMUNITY

The reason the ALS Society of Quebec is able to help so many families across the province is first and foremost because it's backed by a community of people with hearts in hand and heads full of ideas for ways to honour a loved one touched by ALS.

Over the past year, schools, businesses, and sports organizations rallied together to organize some 60 fundraising activities. In addition to providing much-needed financial support for the Society's activities, these personal initiatives also help to draw the attention of many Quebecers to the existence of ALS and the urgent need for a cure.

Invaluable volunteers

The Society is also proud to be able to rely on the 300 volunteers who make up Team ALS. Their talents and skills are what help to get the Society's flagship projects and events off the ground, allowing us to maximize our support and resources for families living with ALS.

Once again this year, the members of Team ALS combined their respective strengths to give a powerful boost to our mission, for which we are most grateful.



Chantale and her son Matthew volunteering at Montreal's Walk for ALS in 2015.

Chantale Grenon-Nyenhuis, recipient of the Chantal Lanthier Award

Chantale Grenon-Nyenhuis decided to get involved with the Society after learning that Dean Stock, her two youngest sons' hockey coach, had been diagnosed with the disease. For the past three years, she has strapped on her bike helmet to take part in the Ride to Fight ALS. A volunteer translator and ambassador for our events, including the Walk for ALS in Montreal, she wears many hats and inspires her family to also do their share. Last summer, she and her four sons hosted a fundraising party for the Society attended by 300 kids. "Volunteering keeps me from getting hung up on life's little inconveniences. It makes me feel like I'm doing something useful and valued." Her dedication has earned her the Chantal Lanthier Award, awarded to a volunteer whose remarkable contribution to our mission makes them an inspiration to others.

TOGETHER, WE MAKE A DIFFERENCE

"When our friend and former employee, Yvan, asked us to step up to the plate for the cause, that's when we decided to raise money for ALS Quebec by running our first marathon. He told us that we couldn't do much to help him, but that we'd be doing a lot for future people living with ALS. Yvan's bravery was an inspiration to us all! We really admire everything the Society does to support people living with ALS, including helping Yvan to adapt his car so he could keep driving for a few months longer. We're also proud that part of our donations goes toward financing research and new treatments for ALS."



STEVE RIOUX AND JEAN-FRANÇOIS RICHARD
Organizers of the fundraising marathon in honour of Yvan Labilloy

"After losing my mother to ALS, not only did I want to give back to the ALS community, I also wanted to keep in touch and get involved to make sure I stayed up to date on the latest developments in research and the disease. I enjoy spending time with the people at the Society, I enjoy helping in any way that I can and doing my part to support the cause. It makes me feel useful. The work done by the volunteers is not only important, it's indispensable, and everyone should get involved in solidarity with the families who are living with this challenge."



MONICA HIDALGO
Volunteer with the Society
since 2013

Thanks to all the members of Team ALS who organized fundraising and awareness-raising activities and gave us their time over the past year! Every action counts!

4 @ 7 - Université de Sherbrooke
(Vincent Cotnoir)

Annual Donation Night
(Pointe-Claire Old Timers Hockey Club)

Art exhibition in honor of Louise
Raymond (Manon Ruffet)

Bake sale (Daniel Bérard)

Book sale "Parce que parfois,
la pluie doit tomber"
(Chantal Lanthier)

Bromont Ultra
(Gilles Poulin et Marc Hébert)

Camping activities (Nathalie Savard)

Car wash (Samantha Coutinho)

Caroling night (Meredith H. Hayes)

Chantal Lanthier softball
tournament (Nathalie Breton)

Country dance and conference
(Micheline Lajeunesse)

Dance and dinner Groupe Réso
St-Hubert (Sylvie Fournier)

Dance with the Classics
(Roger Boudreau)

Dinner show for Steeve Day (Peter Myles)

Erg-a-thon Tony Proudfoot
(Brian Morin)

First marathon ever in honor of
Yvan Labilloy (Steve Rioux and
Jean-François Richard)

Fundraising event (Pierrefonds
Comprehensive High School)

Garage sale (Marie-Josée Ricard)

Garage sale (Zoë Gariépy)

Golf tournament (AQDFL)

Golf tournament (Pierre Pallascio)

Guerre des Clans
(Laurie-Anne Chasles)

Ice Bucket Challenge
(Knights St-Thomas High School
Football Team)

Ice Bucket Challenge
(Chantal Arbour)

Invergie Golf (Colin McTavish)

Jennifer Shannon
(In celebration of her birthday)

Jeux du Commerce (UQAT)

Jeux du Commerce - Université
Laval (Veronica Barahona)

Jeux du Commerce
(École de Gestion de John Molson)

Jeux du Commerce (HEC)

Jeux du Commerce
(Université McGill)

Jeux du Commerce (UQAR)

Jeux du Commerce (UQTR)

Jewelry sale, Fourrure FUR
(Suzanne Lachance)

Le Grand Méchoui
(Richard Létourneau)

Marymount Academy - different
activities (Tharaneea)

Mason jar sale
(Université Sherbrooke)

Miniature model exhibition
(Yvon Perron)

Party for ALS
(The Grenon-Nyenhuis family)

Paul Regimbal
(Tony Proudfoot Fund)

Personal fundraising (Anis Nazar)

Personal fundraising (Stella Wojas)

Personal fundraising
(Suzie Pharand)

Ram "mouse" sons family day
(Michel Tremblay)

Reusable Félix Homme bags selling
(Sophie Paquette)

Seb and Terry run for ALS
(Sébastien Servant)

Spaghetti dinner (Geneviève
Dorion Bélisle et David Maurice)

Spaghetti dinner (Marjerie Plante)

Spaghetti Dinner (Pierrette Mailhot)

Spinning for ALS (Claudia Romero)

Sports challenge at l'École Massé
(Geneviève Parent)

Teen up for ALS (Cassandra Forzani
and Andrew Ratcliff)

St-Lazare au Galop festival

Tool sale (Marc-Antoine Rondeau)

Wine and cheese at Hills hair salon
(Ashley Hill)

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



Members of the ALS Caucus during the ALS Education Day at the Neuro on September 14, 2017. Left to right: Dr. Angela Genge (Neuro), federal MP Marc Serré, Tammy Moore (ALS Canada), Gates Perreault (ALS Canuck), federal MP Francis Drouin, Dr. Heather Durham (Neuro), Claudine Cook (ALS Quebec), and Norman MacIsaac, Society ambassador.

RAISING AWARENESS Speaking out together

While a major part of our mission depends on our ability to listen to our members and their needs, our other key objectives include advocating for them, educating the public through various channels, and showing how your donations directly impact the lives of Quebec families living with ALS. In 2017, the Society, its ambassadors and its partners worked hard to paint a picture of the realities facing our community and to inspire others to take up the mantle of ALS by sharing their stories.



Nancy Roch, Yvon Cournoyer, Stella Wojas and Nicole Isabelle are just some of the Society's ambassadors speaking out on behalf of Quebec families touched by ALS.

The ALS community in the spotlight

This year, Quebecers heard from several of the Society's ambassadors, who were front and center in the media, shining a light on the challenges facing the ALS community. Thank you to our ambassadors and to all the families who continue to share their stories with us and the media in order to keep the conversation going.

ALS Quebec and Partenaires Neuro at the National Assembly

On Thursday, October 26, 2017, Partenaires Neuro, a group of five organizations that includes the Society, presented a brief at Quebec's National Assembly entitled "Pistes de solutions pour améliorer la qualité de vie des personnes atteintes d'une maladie neurologique évolutive" (Solutions for improving quality of life for individuals with a progressive neurological disorder). Together, the partners advocated for the needs of more than 200,000 Quebecers living with a progressive neurological disorder. Our goal: To educate the members of the National Assembly about the issues and challenges facing people with one of these incurable diseases, including homecare, better adapted housing, support for caregivers, medical assistance in dying, basic funding, access to care and services, and access to innovative drugs. To read the full brief, please visit partenairesneuro.ca.



Louis Adam (Multiple Sclerosis Society of Canada), Nicole Charpentier (Parkinson Québec), Marie-Hélène Bolduc (Muscular Dystrophy Canada), Claudine Cook (ALS Quebec) and Jean-François Lamarche (Fédération québécoise des Sociétés Alzheimer).

TOGETHER, OUR VOICES ARE HEARD

"After my diagnosis, the Society helped me find my way and deal with the disease. It's a place where people can get together and combine their strengths in the battle against ALS. Agreeing to be an ambassador is a very life affirming action and a way of contributing to the fight for future generations who will be touched by the disease. In the meantime, it does people with ALS a lot of good to talk about it with others. When you have ALS, the last thing you should do is isolate yourself. It's crucial that we educate the public about the disease in order to increase support for programs and services as well as research. It's the only way to defeat ALS once and for all."



NORMAN MACISAAC
Ambassador and member of the Society's Board of Directors, living with ALS

"The Society gives us a great deal of moral and financial support, and whenever I speak to businesses, my goal is always to educate people about our disease and help them understand the importance of backing our cause—something that makes me feel very useful. These days, it's rare to come across people who support our cause, so I'm comforted by the tremendous compassion I always see during these encounters. Telling them my story makes me feel alive."



LINE THIBOUTOT
Ambassador HealthPartners – Quebec, living with ALS

"I decided to write my autobiography "Parce que parfois, la pluie doit tomber" after many people wrote to me or told me that I was an inspiration and that I should share my story. People seemed moved by my bravery in confronting the disease and by my positive outlook on life. I was often asked to write testimonials or share the speeches I gave during fundraising events. When I started losing my voice and the dexterity in my hands, I told myself, it's now or never. I think my story has the potential to inspire people and help them overcome the challenges they're facing."



CHANTAL LANTHIER
Society ambassador and author of the book "Parce que parfois, la pluie doit tomber", living with ALS

"Sometimes people need to be reminded that good health is a privilege. Reading a story like mine brings home a hard truth: life is fragile. We need all the moral and financial support we can get to give people with ALS hope for a brighter future and, until a treatment is discovered, to give them the tools they need to maintain a certain quality of life. So, it seems crucial to me to not only talk about the disease itself, but also about the repercussions it has on the day-to-day lives of patients and their families."



STELLA WOJAS
Society ambassador, living with ALS

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

FONDATION
Québec Philanthrope
INVESTIR POUR DONNER ET PÉRPUÉTER

FONDATION
DE LA FAMILLE
ROSSY
ROSSY
FAMILY
FOUNDATION

iii **HealthPartners**

**MONSIEUR
MUFFLER**
PNEU ET MÉCANIQUE

FONDATION ANDRÉ DELAMBRE

ÉQUIPE PROUDFOOT

TEAMSTOCK.CA

**POWER CORPORATION
OF CANADA**

MEMBER OF
MEMBRE D' **Imagine** Canada

MVP
GROUP AGENCY

**LEAVE A LEGACY™
QUÉBEC**

**MARTIN
PINEAU** CONCEPTION
DESIGN
MULTIMÉDIA
MPCOM.COM

Air Canada
Bell Média
Cycle Néron
Estate of Camille Antaki

Friends of the Neuro
Globe Multimédia
Groupe International Travelway
Groupe Messier

Les Alouettes de Montréal
Les Capitales de Québec
Les entreprises Truck'N Roll Inc.
Les Hôtes de Montréal

Liquid Boardwear (W.L. Activewear)
Mylène Duchesneau, graphic artist
OUTFRONT média Inc.
Restaurante Andrea

DONORS \$2,500+

Association Québécoise de la
Distribution des Fruits
et Légumes
Beaudet, Madeleine B.
Canuel, Jean-Pierre Dr.
Château Vaudreuil

Durand, Gilles
Eric T. Webster Foundation
Fédération des Caisses
Desjardins
Fondation Jeanne Wojas et
Robert Chevrier

Fondation Michel
Raymond Lakah
Fondation Sibylla Hesse
Freedom International
Brokerage Co.
Gestion Sylvain Arsenault Inc.

Gouvernement du Canada
Groupe Jean Coutu (PJC) inc.
Laboratoires Charles River
services précliniques Mtl. inc
Little, Jim
Mathieu, Thérèse

Michaud, Philippe
Pigeon, Jean-Marc
Québecor Média
Roy, René
Trivisonno, Ennio

DONORS \$500+

2810158 Canada Inc.
2810166 Canada Inc.
4411587 Canada Inc.
AEM International
Aéroport de Québec Inc.
Agropur
Alcantar, Emilie
Alègre, Pauline
Alimentation Couche-Tard Inc.
Allard, Martine
AMOCs
André Normand Inc.
Arcand, Pierre
Ascensia - Carl Dionne
Aviva, milieu de vie pour aînés
B.O.H.A. / A.H.A.B. in Trust
Baillargeon, Michel
Bastien, Gaétan
Beaulac, René
Belle, Pierre
Bellemare Couvertures Ltée
Bérubé, Anne
BeSP Inc.
Bloch, Jules
Boisvert, Anne-Marie
Bombardier Aéronotique
Branton, Philip
Bronstetter, Michael
Brunet, Alain
Bulle Groupe
Burns, Robin
Caisse de bienfaisance des
employés et retraités du CN
Caisse Desjardins de Gentilly-
Lévis-Rivière du Chêne
Canuel, Hélène
Caron, Michelle
Caron, Régis

Cenovus Employee
Foundation
Centre d'Outillage L.B. Inc.
Charest, Guy
Charron, Lise
Chasles, Laurie-Anne
Chevaliers de Colomb
Chouinard, Marco
Chrétien, François
Cirino, Roseanna
Coulombe, Nancy
Courteau, Robert
Cumming, Kathleen E.
Dallaire, Gervais
D'Amour, Jean (député)
D'Amours, Pierre
Dandurand, Philippe
Darwish, Michael
Dekalb/SynAgri
Delambre Gagnon cpa Inc
Démolition des Rivières
Di Pietrantonio, Phil
District.Mao
Djoukhadjian, Manouk
Dr Sylvain Faucher Inc.
Dr Yves Turgeon
Duchesne, Ruth
Dufour, Robert
Edger, Marilou
Équipe Alithya

Équipe TELUS Bienfaisance,
Investissements
communautaires
Eventus Electric Inc.
Express 57
Externat St-Coeur-de-Marie
Fabi, Jean et Ginette
Famille Rainville
Faucher, Gaston
Fletcher, Ted
Foisy, Marie-Claude
Fondation Marie-Françoise et
Marc Beauchamp
Fondation Robert Sawyer
Fondation St-Hubert
Fondation Suzanne et Jean-
Robert Leclerc
Fonds de Bienfaisance
Bombardier Aéronautique
Fonds Serge Gouin et Denise
Chicoyne
Fontaine, Suzanne
Fréchette, Thérèse
Gagné, Yves
Gagnon, Jean
Gagnon, Jeannine T.
Gauthier, Karine
Gauthier, Martin
Gauthier, Michael
GBN Textiles Inc.
Genfoot Inc.
Genge, Angela Dr.
Gennaoui, Tony
Gestion Constantin Inc.
Gestion Rosaire Dubé
Ghattas, Bahjat
Giguère, Richard
Godbout, François
Gosselin, Julie

Goudreau, Mabel
Gouin, Michèle
Graman Investments Inc.
Gravel, Nicole
Groupe Paramount
Groupe Sourcinc Inc.
Groupe Touchette
Habra, Magdi
Hajji, Gilbert
Harries, Patricia
Hartt, Trudy
Hayes, Meredith H.
Helou, Camille
How, Jocelyne
Hubert, Joseph
Hydro-Flow Filtration Systems
John J. Campbell Co. Inc.
Julien, Guy-François
Julien, Pierre et Helga
Kakebeeke, Jacob L.
Kakebeeke, Jake
Karambatsos Lawyers
Karna, Ajoy
Kaufman, Stephen
Kermack, Delia
Kim, Gene
Kratynski, Ivonna
Ktalysis Inc.
Kwitko Family Foundation
Labbé, François
Labllois, Yvan
Labllois, Yvan
Lalonde, Richard
Landry, Johanne
Laprise, Michel
Laprise, Roger
Larochelle, Lionel
Larouche, Marc

Laurentide Controls
Lavigne, Fernand
Lavoie, Magella
Lemieux, Andrée
Lepage Millwork
Lepage, Paul
Les Céramiques Bonamigo
Les Entreprises Roofmart Ltée
Perras, Evelynne
Pharand-Mantha, Danielle
Picard, Alexandre
Pilon, Claude
Pinsonnault Fund
Pro-Doc Ltée
Promoli, Fred
Prosanto Chaudhury Fund
Proudfoot, Janet
Qualitek
Quart, Joanna
Quimper, Pierre-Luc
Raymond, Louise
RBC Day of Service Grant
Reed, Wesley
Refrabec Inc.
Missionnaires du Sacré-Coeur
Mister Transmission
Montessori School of Pointe
Claire
Morgan, Rick
Morin, Bernard
Morisset, Jean-Alfred
Mosaic Sales Solutions
Canada Operating Co.
Mouvement des Caisses
Desjardins
Nadeau, Steve
Nassibian, Gary
Nazar, Jamil
Neemeh, Alain
Nemay, Marie-Paule

Nguyen, Tuan
Organisme
d'autoréglementation du
Courtage Immobilier du
Québec
Osler, Hoskin & Harcourt
Paquette, Francine
Pelletier et Picard Médecins
Perras, Evelynne
Pharand-Mantha, Danielle
Picard, Alexandre
Pilon, Claude
Pinsonnault Fund
Pro-Doc Ltée
Promoli, Fred
Prosanto Chaudhury Fund
Proudfoot, Janet
Qualitek
Quart, Joanna
Quimper, Pierre-Luc
Raymond, Louise
RBC Day of Service Grant
Reed, Wesley
Refrabec Inc.
Missionnaires du Sacré-Coeur
Mister Transmission
Montessori School of Pointe
Claire
Morgan, Rick
Morin, Bernard
Morisset, Jean-Alfred
Mosaic Sales Solutions
Canada Operating Co.
Mouvement des Caisses
Desjardins
Nadeau, Steve
Nassibian, Gary
Nazar, Jamil
Neemeh, Alain
Nemay, Marie-Paule

Shaheen, Virginia
Silencieux de l'Est
Simard Carrier, Jeannine
Sizons Designs
Smith, Robert L.
Soles, Jane
Someca Immobilier Ltée
Soprema
Sterthal, Jack
Steve Rioux et Jean-François
Richard ph. Inc.
Swieca, Richard
The Chelminski Family
Foundation
Thermo Vision
Toitures Trois Etoiles Inc.
Toniolo, Rod
Trudeau, Stéphane
Trudel Immeubles
Vachon, Daniel
Vachon, Jacynthe Royer
Vachon, Marcel jr
Vachon, Serge
Vallée, Linda
Vanguard Pharma
Vaux, Robert
Vidéotron s.e.n.c.
Vidupré, Emma
Bussière, Catherine
Bussières, Odette
Carey, Catherine
Carignan, Thérèse
Falardeau, André
Fetzer, Judith
Flanagan, Brenda

Shane, Virginia
Silencieux de l'Est
Simard Carrier, Jeannine
Sizons Designs
Smith, Robert L.
Soles, Jane
Someca Immobilier Ltée
Soprema
Sterthal, Jack
Steve Rioux et Jean-François
Richard ph. Inc.
Swieca, Richard
The Chelminski Family
Foundation
Thermo Vision
Toitures Trois Etoiles Inc.
Toniolo, Rod
Trudeau, Stéphane
Trudel Immeubles
Vachon, Daniel
Vachon, Jacynthe Royer
Vachon, Marcel jr
Vachon, Serge
Vallée, Linda
Vanguard Pharma
Vaux, Robert
Vidéotron s.e.n.c.
Vidupré, Emma
Bussière, Catherine
Bussières, Odette
Carey, Catherine
Carignan, Thérèse
Falardeau, André
Fetzer, Judith
Flanagan, Brenda

MAJOR PRODUCTS AND SERVICES DONORS

Action Sports Physio
Agropur Fromages Fins & Division Natrel
Alain Choquette
Association des proches aidants de la
Capitale-Nationale
Authentic Brands Group
Brigitte Sansoucy, Députée de St-Hyacinthe
Bulletin Canada
Centre ADN
Centre dentaire Notre Dame
Centre montérégien de réadaptation
Centre Sheraton Montreal
Centre Typo
Chenail Fruits et Légumes
Christine Tremblay

Cirque du Soleil
Clif Bar
Cobra Puma Golf
Complexe Hockey Bonaventure
Concepts Yvon Lambert
CookAndDate, What's Cooking
Daniel Malandrucolo
Daniel McInnis
Dorel Sports
Émilie Dionne-Lanthier, vidéographe
Étiket
Evenko
Fairmont Le Manoir Richelieu
Flow Water
Freemark apparel Brands inc. (Bench)

Funkins
Gino Lévesque
Groupe Marcelle
Gusta Foods
ISM Line
Juste pour rire
Karine Cousineau Communications
Krispy Kernel
La Boutique Piscine Spa BBQ
La Petite Bretonne
La Sirène de la Mer
La Valse des coureurs
LCC Clos des Vignes
Le Dindon du Québec
M Manger Traiteur

Mint Green Group
Molson Coors
Montreal Times
Morphilm Productions
Nathalie Gauthier
New Balance Athletics
Oatbox
Pittsburgh Penguins
Popeye Suppléments
Productions Feeling Inc.
RDTs
Rick Moffat
Ritz-Carlton
Rosemont-Petite-Patrie
Rouge FM

Sanctuaire Notre-Dame-du-Cap
Santé Physio à domicile (Montréal)
Sierra Flower
Société des alcools du Québec
Squish
St-Clet Design
Tennis Canada
The Classics
Tim Raines
Trudeau Corporation
Ville de Québec
Ville de Rivière-du-Loup
Ville de Sherbrooke
VITALI-T
Zibo! Restaurant

WE THANK ALL OUR DONORS, NO MATTER WHAT AMOUNT IS GIVEN. EVERY DONATION COUNTS!

SPECIAL THANKS TO OUR VOLUNTEERS

Abdellatif, Mohamed
Asselin, Madeleine
Aubé, Nancy
Aubé, Nathalie
Aubé, Valérie
Bastien, Yves
Beaulieu, Daniel
Beaulieu, Jessica
Beaulieu, Maxime
Beaulieu, Nancy
Beaulieu, Noemi
Beaulieu, Phyllis
Bebbington, Sandra
Bélisle, Daniel
Bergeron, Gisèle
Bergeron, Marie-Claude
Bergevin, Mathieu
Bernier, Caroline
Bernier, Eric
Bernier, Joanie
Bernier, Sylvie
Bernier, Yannick
Bernier-Dion, Daphné
Bernier-Dion, Marianne
Bérubé, Nancy
Bérubé, Nancy
Bilodeau, Jean
Bilodeau, Marie-Claude
Bilodeau, Simon
Bissonnette, Chantal
Boissoneault, Dany
Boisvert, Lise
Boivin, Darina
Boivin, Josee
Boivin, Julia
Boivin, Louise
Boivin, Suzanne
Boivin, Suzie
Bonhomme, Daphney
Bouchard, Angèle
Bouchard, Lucie
Boudreau, Roger
Bouliane, Julie
Brizard, Claudette
Bruno, Côté
Bucher, Theresia
Bussière, Catherine
Bussières, Odette
Carey, Catherine
Carignan, Thérèse
Falardeau, André
Fetzer, Judith
Flanagan, Brenda

Chamandy-Cook, Eric
Chandonnet, Claudia
Chapdelaine, Serge
Charland, Laurie
Charpentier, Anne
Chassé, Alain
Chouinard, Daniel
Cliche, Marie-Michèle
Corbin, Lise
Cosic, Martin
Coss, Angie
Côté, Bruno
Coulombe, Yamil
Coulombe, Yary
Couture, Jocelyne
Couture, Lucie
Dalaire, Janine
D'amato, Carole
de la Durantaye, Laurent
De Turenne, Pénélope
Delambre, Nicolas-Étienne
Delcourt, Annie
Delorme, Karen
Denizon, Yves
Déry, Alexandra
Desaulniers, Line
Descôteaux, Nathalie
Desjardins, Michel
Goyette, Michel
Grand'Maison, Diane
Gravel, Jean-François
Gravel, Josée
Gravel, Nicole
Greenberg, Audrey
Grégoire, Carole
Grenier, Karine
Grenier, Lorraine
Grenier, Pierrette
Grenier, Stéphane
Grenon-Nyenhuis, Chantale
Griffin, Kelly Anne
Guelloz, Medhi
Guillemette, Mélanie
Han, Weilin
Harvey, Paul-Émile
Hébert, Marc
Hébert, Mélynda
Herrera, Nicholas
Hewitt, Jennie
Hidalgo, Monica
Hogue, Kyle
Hogue, Stéphane
Houde, Michel
Inkel, Mariette

Fleury, Zach
Florence, Légraré
Fortin, Line
Fortin, Marilyn
Fortin, Michel
Fournier Létourneau, Olivia
Fournier, Céline
Fournier, Claudie
Fournier, Geneviève
Fournier, Laurette
Fournier, Manon
Fournier, Marie-Pier
Gagné, Patricia
Gagné, Vincent
Gagnon, Amélie
Gagnon, Lisa
Gagnon, Mathilde
Garand, Geneviève
Garant, Linda
Gaudreault, Natacha
Gaudreault, Roger
Gauthier, Louise
Gauthier, Mélanie
Gauthier, Michel
Gauthier, Sébastien
Gélinas, Daniel
Germain, Lucie
Gosselin, Julie
Goyette, Michel
Grand'Maison, Diane
Gravel, Jean-François
Gravel, Josée
Gravel, Nicole
Greenberg, Audrey
Grégoire, Carole
Grenier, Karine
Grenier, Lorraine
Grenier, Pierrette
Grenier, Stéphane
Grenon-Nyenhuis, Chantale
Griffin, Kelly Anne
Guelloz, Medhi
Guillemette, Mélanie
Han, Weilin
Harvey, Paul-Émile
Hébert, Marc
Hébert, Mélynda
Herrera, Nicholas
Hewitt, Jennie
Hidalgo, Monica
Hogue, Kyle
Hogue, Stéphane
Houde, Michel
Inkel, Mariette

Jacques, François
Jasmin, Gabriel
Jean, Jovia
Jean, Sébastien
Johnson, Alexander
Journey Freight International
Julien, Stéphane
Kabbash, Sophie
Kennerknecht, Susan
Labbé, Marie-Claude
Laberge, Céline
Lacroix, Odette
Lafontaine, Mélanie
Lamontagne, Mariette
Landry, Jean
Landry, Mario
Langlais-Riou, Marion
Langlois, Fanny
Langlois, Martine
Larouche, Marc
L'Arrivée, Bernard
Lavigne, Fernand
Lavoie, Audrey
Le Gresley, Jean-Pierre
Le Groupe ÉvoluSoins Inc
Le Mesurier, Catherine
Leblanc, Denise
Leclerc, Maurice
Leduc Pilette, Monique
Lefrançois, Maude
Légaré, Florence
Légaré, Jean-Pascal
Légaré, William
Legault, Diane
Lepage, Denise
Lepage, Marie-Christine
Lépine, Jannie
Lessard, Daniel
Lessard, David
Léveillé, Elyse Claude
Lévesque, Nadia
MacDonald, Denise
MacDonald, John
MacIsaac, Norman
Madoff, Rhoda
Madore, Nathalie
Mailhot (Turcotte), Diane
Mailhot, Barbara
Mailhot, Pierrette
Mailhot, Sonia
Malandrucolo, Daniel
Maltais, Diane
Manneh, Raouf
Marin, Joseph Roger

Marquis, Caroline
Martel, Diane
Martel, Gilles
Martel, Nicole
Mercier Tremblay, Monique
Mercier, Danielle
Michaud-Dinarzo, Joanne
Michaud-Simard, Philippe
Minville, Félix
Miron, Dominique
Moreno, Sofia
Morpeau, Valérie
Nault, Coralie
Noël, Georges-Étienne
Nolin, Amélie
Normandin, Éric
Nozzolillo, Jennifer
Nyenhuys, Christophe
Nyenhuys, Darren
Nyenhuys, Liam
Nyenhuys, Matthew
Nyenhuys, Nicolas
Paradis, Éric
Parisella, Joseph
Pelletier, Jonathan
Pelletier, Marie-Ève
Pelletier, Sandra
Pelletier, Sarah
Perreault, Christine
Perron, Steeve
Perron, Yvon
Perth, Sylvie
Pilette, Gilles
Pilon, Steven
Pineault, Martin
Pineault, Patricia
Pinos, Amalia
Plamondon, Lucie
Plourde, Martin
Poirier, Jeannine
Pomerleau, Claudia
Pouliot, Laurence
Prevost, Jimmy
Prince, Rita
Prince, Yves
Pritchard, Lisa
Proulx, Carole
Quessy, Anabel
Quintin, Isabelle
Rafie, Anthony
Ricard, Marie-Josée
Richoz, Danielle
Rimada, Camila
Roberge, Gabrielle

Robineault, Richard
Robitaille, Richard Dr.
Roch, Nancy
Roseberry, Tommy
Ross, Allan
Roy, Diane
Roy, Micheline
Roy, René
Saillant-Boulinguez, Sarah
Savard, Margot
Shahani, Sarah
Sheink, Nicole
Simard, Michel
Simoes, Philip
Simoneau, Nancy
Sirois, Jenny
Sofio, François
Stone, Paula
St-Onge, Lydia
St-Pierre, Renée
Strasser, Thomas
Nyenhuys, Nicolas
Paradis, Éric
Parisella, Joseph
Pelletier, Jonathan
Pelletier, Marie-Ève
Pelletier, Sandra
Pelletier, Sarah
Perreault, Christine
Perron, Steeve
Perron, Yvon
Perth, Sylvie
Pilette, Gilles
Pilon, Steven
Pineault, Martin
Pineault, Patricia
Pinos, Amalia
Plamondon, Lucie
Plourde, Martin
Poirier, Jeannine
Pomerleau, Claudia
Pouliot, Laurence
Prevost, Jimmy
Prince, Rita
Prince, Yves
Pritchard, Lisa
Proulx, Carole
Quessy, Anabel
Quintin, Isabelle
Rafie, Anthony
Ricard, Marie-Josée
Richoz, Danielle
Rimada, Camila
Roberge, Gabrielle

TOGETHER, WE ARE STRONGER!



After participating in the Fondation André-Delambre's 13th annual research symposium, Canadian and international researchers met with families touched by ALS at the Montreal Walk for ALS.

2017 ALS RESEARCH REVIEW

ALS Quebec is proud to contribute to the ALS Canada Research Program, which invests in the best ALS research in Canada that will have significant impact on the global effort to create a future without ALS.

In 2017, 12 new research projects totalling \$3 million were funded through the ALS Canada Research Program including a \$1.8 million study of a promising drug combination; three trainee grants that will help to nurture the next generation of Canadian ALS researchers currently pursuing their PhDs; two projects that explore how ALS treatments could be delivered through the bloodstream; and an initiative that seeks to understand why the muscles of the eyes are often unaffected in people living with ALS even

as other muscle groups shut down. All the projects being funded seek to answer questions that will help to move us from greater understanding of ALS to the development of therapies for human use.

Simply put, there is more ALS research to fund than money available – making it necessary to have a proven method for making difficult decisions about which research receives funding. The ALS Canada Research Program awards funding based on a peer review process that is continually evolving and being optimized. Known within the scientific community as the gold standard for assessing all types of research, peer review engages independent experts in evaluating the quality and rigour of research papers and proposals.

TOGETHER, WE GIVE HOPE

We reached several milestones in 2017, from the advancement of clinical trials leading to drugs with beneficial effects to the development of new tools and diversified, modern approaches. These approaches and concerted efforts are slowly starting to break down the wall that is ALS. Even though they're small compared to the ultimate goal, the cracks are still there and the progress we've made is irreversible. Quebec researchers are fully committed to the shared effort of finding a treatment and a cure for ALS. This year also saw ties being forged between researchers, members of the Society, people with ALS and caregivers. From our privileged positions on the Board of Directors, we're able to facilitate discussions and links between the Society and researchers. We also invited ALS patients to participate in the most recent meeting of Quebec researchers (ALS Quebec Journal Club). These ties are very important because, not only do they create relationships, they also motivate and energize researchers, who are given the chance to witness the determination and fighting spirit of those living with ALS.



DR. RICHARD ROBITAILLE
Member of the Society's Board of Directors and ALS researcher in the Neuroscience department at Université de Montréal



ELSA TREMBLAY
Former caregiver studying ALS with Dr. Robitaille as part of her Ph.D. in Neuroscience at Université de Montréal

Research represents hope, which is plain to see from the many recent breakthroughs in the field of ALS therapies. In fact, 2017 was a very inspiring year for research into ALS treatments. First of all, a second drug, Edaravone, was recently marketed in the United States and Japan to treat people with ALS. While it's not yet available to patients in Canada, it represents an important step for research in the field. In terms of clinical trials, two potential drugs merit attention: Masitinib, a drug that targets the significant inflammation that develops during the disease, and NurOwn, an innovative stem-cell therapy that could even improve motor function in ALS patients. Both have successfully passed several steps and are currently at the final phase of the clinical trial process, which bodes very well for the coming year. The initial clinical trial of the neuroleptic drug Pimozide also yielded encouraging results, and a new clinical trial is currently underway in Canada. The community eagerly awaits the results of these numerous trials in 2018.

"ALS is an incredibly complex disease, but the research community is making tremendous headway and has come very far with very little in comparison to annual funding levels of diseases that have treatment options. For the ALS Canada Research Program this has only been possible because of the generosity of donors, partnerships with provincial ALS Societies across Canada, and organizations like Brain Canada, which by matching donations made through the Ice Bucket Challenge has essentially doubled Canada's ALS research investment over the past several years."



DR. DAVID TAYLOR
Vice President Research, ALS Canada

THE ALS CANADA RESEARCH PROGRAM BY THE NUMBERS

- ▶ \$3 million invested in ALS research across Canada in 2017.
- ▶ 12 projects funded, including a \$1.8 million project funded with the Brain Canada Foundation.
- ▶ More than \$300,000 invested in Project MinE, an international research collaboration that is studying the DNA profiles of 15,000 people living with ALS and 7,500 control subjects in order to identify the genetic patterns that might lead to the development of ALS and better target the development of treatments. This research investment included a \$150,000 matching contribution from the Brain Canada Foundation through the Canada Brain Research Fund, with the financial support of Health Canada.
- ▶ 150+ Canadian ALS researchers in attendance at the 13th annual national research forum, an event that supports knowledge sharing and collaboration among Canada's ALS research community.
- ▶ 10+ hours of ALS research content offered to the public during the second annual virtual research forum, which featured 25 speakers.
- ▶ 3 scientific conferences sponsored including the 13th Annual Fondation André-Delambre Symposium.

RESEARCH SPOTLIGHT



DR. HEATHER DURHAM, McGill University / Montreal Neurological Institute

In ALS and many other neurodegenerative diseases, one of the defining characteristics is that proteins can become misfolded and clump together. In many of our body's cells, protective mechanisms increase the production of heat shock proteins that prevent misfolded proteins. But in our motor neurons, the ability to produce heat shock proteins can be impaired, possibly making them more vulnerable to misfolding.

For years, Dr. Heather Durham at McGill University/the Montreal Neurological Institute has been studying drugs that might enhance heat shock protein response in motor neurons. Recently, she has found a particular drug combination that can greatly increase the production of heat shock proteins in motor neurons.

This project sets the stage for researching a promising drug combination that may one day become an important therapy for people with ALS. Dr. Durham and collaborating researchers Dr. Josephine Nalbantoglu, Dr. Richard Robitaille, and Dr. Chantelle Sephton will seek to find the optimal combination of heat shock drugs together with a histone deacetylase drug and then examine the protective capabilities of the best combination in ALS mice. They will also investigate how the drugs work, which could lead to the development of potential biomarkers for human clinical trials in the future. The team will collaborate with multiple biotech and pharmaceutical companies that own the unique heat shock and histone deacetylase drugs. If this project is successful, the next step would be for drug companies to conduct toxicity testing and ultimately clinical trials with human volunteers.

"These drugs have been in development for decades, but a combination approach has never been tested," said Dr. Durham. "ALS is complex... and we haven't been able to make a sufficient impact on it yet."

A \$1.8 million investment, this project is co-funded by the Brain Canada Foundation through the Canada Brain Research Fund (with financial support from Health Canada) through matching funds committed following the Ice Bucket Challenge.



AUDREY LABARRE, Université de Montréal

When you hear the word probiotics, you may automatically think of the digestive benefits of foods such as yogurt. But what if certain probiotics could also play a protective role in ALS?

Audrey Labarre, a doctoral student in Alex Parker's lab at Centre de recherche du CHUM, is using a \$75,000 Trainee Award from ALS Canada to advance some surprising discoveries. In 2016, with an ALS Canada-Brain Discovery Grant, Audrey was able to successfully identify how specific probiotics "rescued paralysis and motor neuron death in ALS worms."

Thanks to the Trainee Award, Audrey will now be able to study if there are similar effects with these probiotics in mice.

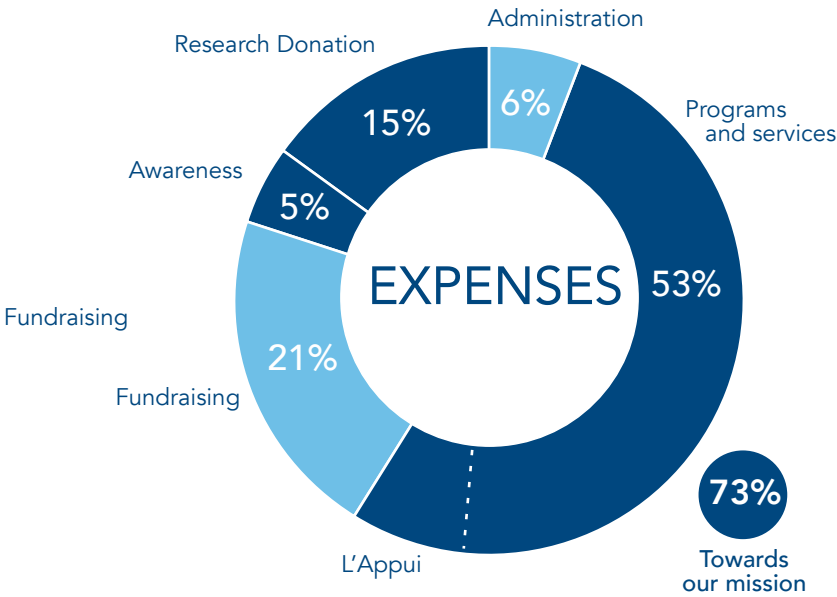
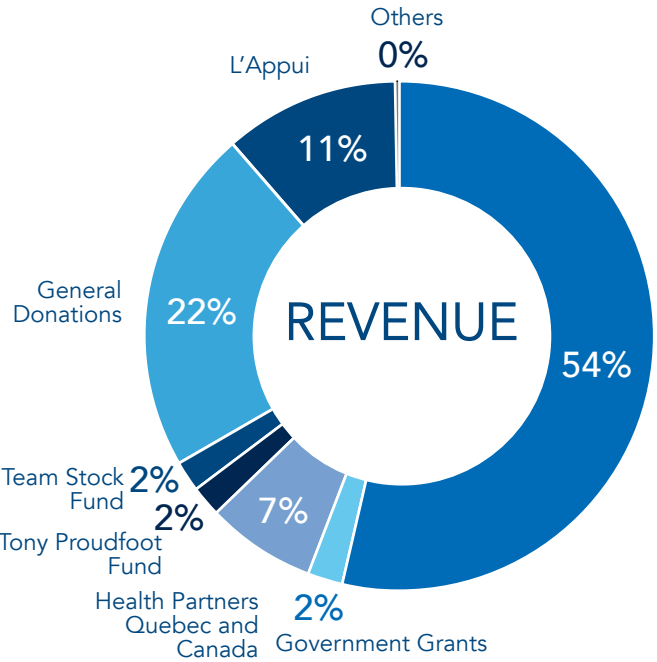
THANK YOU TO ALL CANADIAN RESEARCHERS FOR FUELING HOPE OF A FUTURE WITHOUT ALS!

To learn more about the ALS Canada Research program, please visit als.ca and als-quebec.ca.

FINANCIAL SUMMARY

Financial year from November 1st 2016 to October 31st 2017

REVENUE	2016-2017	2015-2016
Fundraising	\$900 715	\$827 503
Government Grants	\$25 950	\$25 693
Health Partners Quebec & Canada	\$110 109	\$76 901
Tony Proudfoot Fund	\$28 897	\$24 594
Team Stock Fund	\$41 655	\$73 403
General Donations	\$361 330	\$332 059
L'Appui	\$185 748	\$159 312
Others	\$7 611	\$6 607
Total	\$1 662 015	\$1 526 072
EXPENSES	2016-2017	2015-2016
Administration	\$102 520	\$95 690
Programs and services	\$751 640	\$729 149
L'Appui	\$129 182	\$133 360
Fundraising	\$361 793	\$383 824
Awareness	\$90 880	\$63 956
Research Contribution	\$251 926	\$201 475
Contribution to ALS Canada – (ALSSQC, T.Stock Fund and IBC)	\$158 092	\$154 700
Contribution to The Neuro (Tony Proudfoot Fund)	\$26 678	\$11 259
Contribution to research symposiums (FAD and others)	\$67 156	\$35 516
Total	\$1 687 941	\$1 607 454
Excess (deficiency) of revenue over expenses	(\$25 926)	(\$81 382)



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



Elyse-Claude Léveillé, Paula Stone and Diane Tkalec, volunteer members of the Society's programs and services committee.



Alain Choquette made us all experience magical moments at the Society's Magical Evening gala and Chantal Lanthier was no exception.



The Bromont Ultra raised over \$235,000 in support of 14 organizations, including the Society.



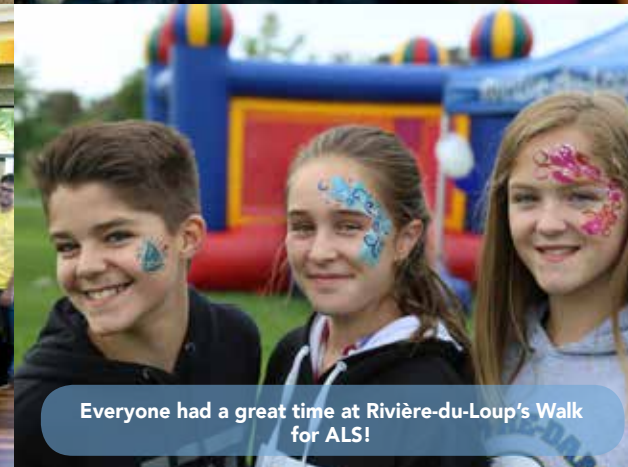
Martin Lauzon with Louise Boivin, volunteer at the Society's support groups in Ville Lorraine.



L'Appui Montréal announced an investment of \$5.2 million for Montreal organizations, including the Society, in the presence of Francine Charbonneau, Minister responsible for Seniors and Anti-Bullying.



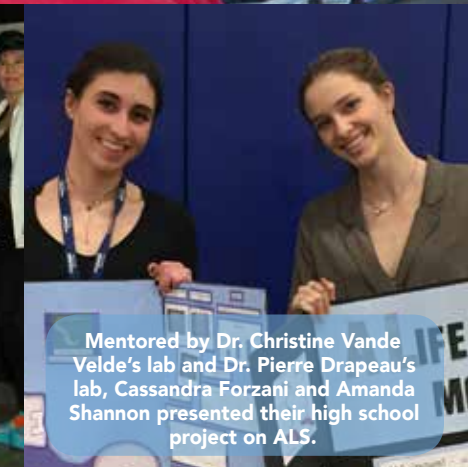
Many volunteers are behind the success of Quebec's Walk for ALS, coordinated by Sarah Saillant.



Everyone had a great time at Rivière-du-Loup's Walk for ALS!



Chantal Lanthier and her husband Jocelyn delivered a touching message to the Society's team at the Holiday Brunch.



Mentored by Dr. Christine Vande Velde's lab and Dr. Pierre Drapeau's lab, Cassandra Forzani and Amanda Shannon presented their high school project on ALS.

TOGETHER, WE WILL GO FURTHER.



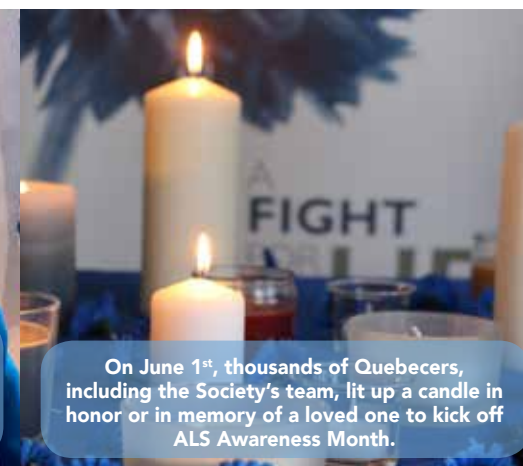
Members of the Society at one of Ville Lorraine's support groups.



Many caregivers enjoyed taking part in the Caregiver Recognition Day.



For the last three years, in memory of her uncle, Jennifer Shannon (now 12 years old) has asked her friends to make a donation to the ALS Society instead of giving her a material gift for her birthday.



On June 1st, thousands of Quebecers, including the Society's team, lit up a candle in honor or in memory of a loved one to kick off ALS Awareness Month.



St-Georges Student leadership initiative with Cassandra Forzani, Andrew Ratcliff and EN ADOS UP students.



Our members enjoyed beautiful weather for the annual sugar shack outing activity.



Lawrence Ayotte (left), his daughter Samantha and his wife Jacqueline appreciated the company of their friends Roger and Fabienne Boudreau at the Society's Holiday Brunch.



Dr. Jean-Pierre Canuel kicked off the Capitales de Québec's game by doing the ceremonial first pitch.



Society's board member Judith Fetzer (left) strikes a pose with her Ride to Fight ALS team En mémoire de Diane B.



In memory of her grandmother, 9 year-old Zoé organized a garage sale with her friend's help to support different charities, including the Society.



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

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

Phone: 514 725-2653 Toll free in Quebec: 1 877 725-7725 Fax: 514 725-6184

Email: info@sla-quebec.ca www.sla-quebec.ca

Registered Charity No: 119153187RR0001

Credits Graphic Design: Mylène Duchesneau Texts: Roxanne Goulet and the ALS Society of Quebec team

Photographs: Nancy Aubé, Daniel Berthiaume, Line Fortin, Daniel Gélinas, Stéphane Hogue, Bernard L'Arrivée, Nathalie Madore, Gilles Pilette et Valérie Whissel Icons: freepik.com



Huddol

This report is also available in French.