



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

LOU GEHRIG'S DISEASE



2015-2016

ANNUAL REPORT

Together we go further

When we share our ideas, energy
and philanthropic contributions
we create a community that is truly
stronger together.

Thank you to our builders

Over the years, many exceptional people put countless efforts in order to further the Society's mission. On August 27, 2016, in front of 400 guests, we celebrated them, our builders, who one chapter at a time helped us grow into the organization we are today. Everyone, in their own way, used a piece of their personal story to raise awareness and funds for ALS, which led to the Society's ability to improve the quality of life of those who are touched by the disease. We are proud to share their stories, and honored that their legacies continue to shine with us at the Society.



Lise Deschesnes

When her husband was diagnosed with ALS, Lise Deschesnes realized that there were no services in Quebec for families touched by the disease. Ms. Deschesnes decided to change this by dedicating herself to the cause, becoming an active member of the Board of Directors in 1997, and then serving as President of the Society for almost 10 years.



André Delambre

In 2002, René Angelil and Céline Dion's trusted advisor André Delambre's world was turned upside down when he learned he had ALS. Faced with adversity, he rolled up his sleeves and created the André-Delambre Foundation to fund research and help families affected by the disease. With his friends and family by his side, he made it his mission to raise public awareness about the disease.



Martin Matte

In 2002, Martin Matte's father lost his battle with ALS. Eager to support the cause, the comedian agreed to step into the role as the Society's spokesperson in 2003 in honor of his father and his friend André Delambre. Martin chose to throw his support behind the Society, a cause largely unfamiliar to the general public. He also chose the Society to support families who are most in need. His involvement has helped to shine a spotlight on the disease.



Vincent Damphousse

In 2007, it was Vincent Damphousse's turn to serve as spokesperson for the Society. The former Habs captain was an active member of the Board of Directors for eight years, and chaired for over six years a benefit golf tournament and poker tournament which raised over \$1M. A shining example of dedication and commitment, he never missed an event or an opportunity to show his support for families touched by ALS.



The Reed Family and the Tenaquip Foundation

In 2005, Tenaquip founder Ken Reed was diagnosed with ALS. After his death, the Reed family fulfilled his wish of giving back to the community by setting up the Tenaquip Foundation, which has provided financial assistance to several organizations, including the Society, for the past 10 years. The Reed family's goal is to ease the burden of the disease as much as possible for other families in the same situation.



Tony Proudfoot and the Montreal Alouettes

After receiving his diagnosis in 2007, former Alouettes player, teacher, and sports commentator, Tony Proudfoot launched himself into creating the Tony Proudfoot Fund at the Society, which provides support to families living with ALS, as well as post-doctoral researchers at the Montreal Neurological Institute wishing to undertake research projects on ALS. Tony raised public awareness for ALS across the country and inspired his Alouettes teammates to get on board Team Proudfoot. Ten years later, several Alouettes players still participate in the Walk for ALS, carrying on Tony Proudfoot's legacy of educating people about the disease.



Patrice Roy, Céline Galipeau and the ICI Radio-Canada team

Following the death of their Téléjournal colleague, Bruno Bonamigo, Céline Galipeau and Patrice Roy shone a light on ALS by doing several feature stories on Bruno's battle with the disease, an initiative that gave a great number of Quebec viewers insight into the ravages of ALS, not only for the patients themselves, but also for their loved ones.

Thank you for being a part of our story

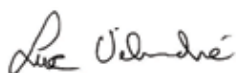
Everyone has a story to tell—a story that helps us to understand where we've come from but, more importantly, where we're headed.

2016 marked an important chapter in our story. In addition to increasing awareness about ALS amongst the public and government officials, posting record fundraising results and expanding our programs and services throughout the province, research developments are leading to promising discoveries that are giving our community cause for hope.

All families touched by ALS across the province inspire us every day to work harder in order to better suit their changing needs. Our goal is to provide the best possible support in collaboration with the healthcare network. As the disease progresses, they have growing needs that must be met in a timely manner. Whether it is an attentive ear and a shoulder to lean on, support groups that encourage participants to open up to others going through similar experiences, a webinar to empower our community with information, specialized equipment to help ALS patients remain independent for as long as possible, financial aid, respite for caregivers, and social activities to combat the isolation - thanks to your support, we're able to offer all of these different services, at each stage of the disease.

Since the Ice Bucket Challenge became a social media phenomenon in 2014, nearly \$20 million has been invested in Canadian ALS research at a time when it has the potential to make the greatest impact. Significant progress in ALS research is being made — researchers now believe that finding effective treatment options for ALS is now a matter of "when," not "if,".

We are proud to share our highlights, our stories and results with you in this Annual Report. Without the support we receive from our dedicated volunteers, generous donors, engaged participants, committed partners, compassionate healthcare professionals and guidance of our Board of Directors, none of it would have been possible. Together, let's write the next, equally memorable, chapter in our story. Let's team up to give people living with ALS and their families the happy ending they so deserve.



Luc Vilandré

President of the Board, ALS Society of Quebec
Vice-President and General Manager, Health Benefits
Management and Payment Solutions - TELUS Health



Claudine Cook

Executive director
ALS Society of Quebec



From left to right:
Susan Kennerknecht,
Dominic Delambre,
Claudine Cook,
Luc Vilandré,
Michel Simard,
Elyse Claude Léveillé,
Diane Tkalec and Daniel
Malandrucolo at the
Ride to Fight ALS 2016.

BOARD OF DIRECTORS (2015-2016)

Executive Committee

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Vice-President and General Manager,
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Person living with ALS

Anis Nazar
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Fasken Martineau

Dr Richard Robitaille, PhD
Professor and researcher
Department of Neurosciences - Université de
Montréal

Diane Tkalec, BScN.
Nurse Clinician
Former Caregiver

WHAT IS ALS?

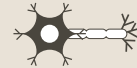
Fatal neurodegenerative disease

Amyotrophic lateral sclerosis, also known as:

Lou Gehrig's Disease



Motor Neuron Disease



Motor neurons in the brain and spinal cord degenerate



Motor neurons communicate with muscles to produce movement



Muscles stop responding to signals sent by motor neurons



Progressive body paralysis leading to loss of mobility and speech with no impact on senses



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 to people with ALS and their caregivers

Funds cutting-edge research projects in Canada

Raises awareness in the general population, government and healthcare professionals.

Offering personalized programs and services to people living with ALS, caregivers and healthcare professionals



"The team at the ALS Society of Quebec knows that ALS can evolve quickly and bring many changes in the lives of people living with ALS and their families. This is the reason we continually strive to give each one of them personalized support, at every stage of the disease."

- Véronique Pignatelli,
Director of programs and support services

Véronique Pignatelli with Maurice Leclerc, 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

Programs & Services: Our Highlights



When technology breaks the silence

Since Guy Provost's diagnosis struck three years ago, his wife Nathalie watched as ALS robbed him of his muscles, then his voice, locking him up in a silence that caused him anguish and anger. Despite the many tools that the mother of two developed to maintain communication with her husband, he simply did not have the strength to respond anymore. "When the law on medical assisted dying was adopted, my husband chose the date on which he wanted to leave this life: December 1st, 2016", says Nathalie.

Today, things are different. Upon discussing Guy's situation with Nathalie, and his urgent need to be able to communicate and socialize again, one of the Society's psychosocial counsellors, Yves Lafleur, took steps with his colleague, Kate Busch, to find a way to help in collaboration with the healthcare system. "I did my job; I was convinced that there had to be a solution. We simply couldn't let this man be deprived of his only means of communication and connection with the outside world."

On September 28, 2016, after many months of silence and absence from the web, Guy received a TOBII computer, which allows him to communicate through the movement of his retina. Since this technology entered his life, Guy has his smile back and found the voice he had long lost. "The world has opened up again for Guy! His TOBII not only allows him to express himself, to share his thoughts and give advice to our teenaged daughters, it also allows him to catch up with his friends on social media. To see his face light up once again has been such a blessing to our family!"



Guy and his wife Nathalie during their visit at the Society to present the TOBII to the team.

A few words from Guy

Guy wants you to know how much he appreciates your support. He sends you this message composed through eye movements using his TOBII:

"I am happy to be able to say once more, I love you! To stay in touch with one's surroundings and loved ones is important. The disease makes us prisoners of our own bodies, but it does not take away our capacity to think or love! "



Keeping in touch with all of our members

In order to be there for all families living with ALS across the province, the ALS Society of Quebec uses technology as a complement to its existing programs and services. In addition to our in-person conferences in the regions, our teleconferences and webinars are adapted to the constraints with which our members live and provide them with a flexibility that is important to them.



"This gives us the opportunity to get to know things, to realize what is happening to us, and most of all to understand where we are going."

- Monique Thivierge Sauriol,
living with ALS, Montérégie

Monique and her husband Roger.

On the other side of the screen

Through a series of thematic webinars, several people living with ALS, their caregivers and health professionals have been able to find answers to their questions related to the disease, while remaining at home. The purpose of these webinars was to explore many issues related to the disease, including planning for end-of-life care, the fears associated with an ALS diagnosis, the legal management of a person's assets, home care and hospice care and, finally, access to adapted touristic and cultural activities. In addition to the webinars, applications such as Facetime or Skype make the work of the Society's staff much easier since they can, just by using their finger tips, contact a member or caregiver who would like to participate in a support group meeting or needs to confide in someone, but whose ALS-related constraints prevent them from leaving their home.

One phone call away

By using teleconferencing as a way to communicate, the Society manages to significantly increase the geographical area over which it can offer its programs and services and can, therefore, provide support to families who live in more remote areas. Whether for the purpose of support group meetings or actual conferences, the teleconferences allow us to share relevant information about ALS and create sense of proximity between the Society and its members, in addition to breaking the sense of isolation that our members may feel when they live outside the Montréal area. According to Yves Lafleur, psychosocial worker with the Society and facilitator of those calls, "this is a convenient alternative to face-to-face meetings for members who live far away and for those whose autonomy and mobility are limited."

In person

It is with the goal of increasing accessibility to resources and information about ALS that the Society has set up regional conferences. These conferences, which this year took place in Granby and Gatineau, allowed people living with ALS in those areas to better know and understand the disease and to identify the resources at their disposal. Also, in the course of those conferences, participants had the opportunity to discuss with health care professionals and to take part, if they felt the need to, in a support meeting where they could share their experience with others. In addition to those regional conferences, support groups in Québec City, in the Montérégie, in the Laurentides and in Montréal allow our staff team to support an important number of families.

Thank you to the Rossy Family Foundation for supporting the well-being of our members through our support groups.



ALS Quebec and “L’Appui pour les proches aidants d’aînés” team up to support caregivers

Caregivers are important pillars of the support network that people living with ALS rely on. Since November 2013, the ALS Society of Quebec and L’Appui pour les proches aidants d’aînés Montreal are working together in order to support these individuals in their complex caregiver role. Among other things, this collaboration has allowed us to develop a training program for caregivers, to establish many social activities dedicated to them and finally, to create a personalized assistance program in order to intervene quickly at every step of the disease.

SUPPORT THAT TAKES MANY FORMS

- > Support groups
- > Personalized individual support
- > Conferences on caregiving
- > Training sessions
- > Caregiver Recognition Day
- > 5@8 for caregivers
- > Evening gatherings for the bereaved

Better trained to better care

This year, caregivers of people living with ALS had the opportunity to have their questions answered and to get new tools, thanks to three training sessions adapted to their reality. First, host Mireille Chamberland, a trainer who specializes in the principles of safe patient transfers, taught participants how to safely accomplish their assisting tasks while avoiding potential injuries using different methods. During the second training session, clinical nurse Jean Bilodeau provided them with precious advice on maintaining their loved one’s respiratory health by using different techniques to improve it. Finally, a third training session with speech language pathologist Martine Barrette allowed participants to identify the effects of ALS on communication as well as communication aids that can improve their exchanges with the person living with ALS. These two training sessions prepared caregivers to face the challenges their loved one’s will go through and therefore reduced a part of their stress.

A third Caregiver Recognition Day

On Sunday, November 6, 2016, approximately 30 caregivers gathered at Andrea Restaurant to take a moment to exchange, catch their breath and learn more about their role as caregivers. They also took part in an interactive discussion on motivation with guest speakers, psychotherapists and social workers Éline Clavet and Maria José Gallo. Many of these caregivers, who are now friends, confided in each other and shared the latest news about their lives, their loved one’s health situation and exchanged tips and tricks to overcome some problems due to the evolution of ALS. “This day allows us to share tools and to see that we’re not alone going through this difficult time”, confided Linda Boucher, who’s been caring for her husband Clarence for over a year now.

Life after caregiving

While it is essential to help caregivers learn their role, it is even more important to support them when they have to learn how to cope with the loss of both their loved one and their caregiver role. To that effect, the Society implemented a new bereavement support program in order to help caregivers get through this last stage of ALS. Evening gatherings for the bereaved, in the form of cocktail evenings, have been organized to give them a moment to open up about their new reality, and share. According to Leigh Stephens, psychosocial counsellor at the Society, this initiative is essential to facilitate the mourning process. “According to our members, the bereavement process when it comes to ALS is very singular. Therefore, the bereavement cocktails give past caregivers the opportunity to share where they are at in their bereavement process with people who know and understand what they went through, to reconnect with people they may have met at past events, to network and learn how others are dealing with this final phase of the illness.” Moreover, our psychosocial counsellors increased the number of bereavement follow-ups in two regions to help caregivers and their families go through this ordeal.

L’APPUÏ POUR LES
PROCHES AIDANTS
D’AÎNÉS
MONTRÉAL

To learn more about L’Appui National or to find an Appui organization in your area, please visit www.lappui.org



Participants of this third Caregiver Recognition Day are raising their glass to celebrate their amazing work.



Leigh Stephens (left), psychosocial counsellor at the Society, with many caregivers during the Caregiver Recognition Day.

Listening to our families

As each case of ALS is different, our members and their needs are unique. Thanks to their feedback, we can adapt our programs and services to their reality. This information is essential in order to provide them with personalized support where and when they need it most.



Our psychosocial counsellors are listening to each of our members and their needs.



Psychosocial support

While visiting family in Peru, Rosa Gamarra de Leyva's health quickly deteriorated. Living with ALS, Rosa, age 85, was no longer able to walk. Rosa's granddaughter Mabel flew down to Peru to bring her home to Montreal.

"It was a very emotional time. I was so grateful to speak 'face-to-face' by Skype with Leigh Stephens, psychosocial counsellor at the ALS Society of Quebec, even though I was very far away. She was so very, very helpful. It was like speaking with a friend. Leigh gave me a to-do list that got me acting rather than leaving me stuck in indecision. She even helped arrange our flight back. I couldn't have done it without her guidance and support."

- Mabel Palomino, caregiver, Montreal



Residential Adaptation Program

When Pierre Michaud was diagnosed with ALS in July 2016, he quickly needed some help from the ALS Society of Quebec to ensure his safety and independence at home.

"Right now, my condition has stabilized, but I'm unsteady on my feet. To prevent a fall, the Society helped pay for a stair railing installed on my home in Gatineau. The Society's Technical Aid and Financial Assistance Program also supplied a medical alert system. If I fall, I just need to press a button to call for help. It is a huge relief to know that, as the disease progresses, the Society will be there to support my wife and me."

- Pierre Michaud, ALS patient, Gatineau



Respite program

For the last eight years, Jean Morisset, PhD, Associate Professor of gastroenterology at Université de Sherbrooke, has been taking care of his wife Claudine, who is living with ALS. He managed to go on a trip for the first time since then, thanks to the ALS Society's respite program.

"I really appreciate the Society's respite program. It helped me hire two caregivers to stay with my wife while I attended a medical conference in Poland last year. Claudine was very happy with the round-the-clock care. Meantime, I was relieved to know she was in good hands while I was away. The Pilot Program is a really terrific service. It gives caregivers a chance to change their daily routine, rest and reenergize. Claudine and I are very grateful."

- Jean Morisset, caregiver, Sherbrooke



Support groups

Living with ALS for a few months now, Gilles Durand regularly takes part in support groups offered by the Society in his area, in the Montérégie. These encounters give him the boost he needs to go through this ordeal.

"It allows me to find answers to my questions, my fears and my distress with psychosocial counsellors who are listening to me. I get to meet people like me, living with ALS, who really understand how I feel since some of them are in more advanced stages of the disease. Participating in this group makes me feel less isolated, I get answers, comfort and encouragement. It gives me energy that helps me get through some steps a little easier."

- Gilles Durand, ALS patient, Saint-Jean-Sur-Richelieu

Volunteers who make a difference

We'd like to extend our deepest thanks to all our volunteers, whose support allows us to advance our cause a little more each day. No matter their age or area of expertise, each one of them plays an important role in allowing us to soar to greater heights.

Odette Lacroix: winner of the 2016 Chantal Lanthier Award



Odette Lacroix and her husband, Pierre.

Words are not enough to describe the tireless work that Odette Lacroix does for the Society, even now, at the age of 75! In recognition of her dedication, we chose Odette to receive the Chantal Lanthier Award, awarded to a volunteer whose remarkable contribution to our mission makes him or her an inspiration to others. From the moment Odette's husband, Pierre Lacroix, was diagnosed with ALS in 2001, the couple rolled up their sleeves and got to work helping as many people as possible where they live in Quebec City. Shortly after Pierre's death in 2011, Odette went back to getting involved for the Society. As a retired nurse, Odette organizes support groups in the area, helps out at the local Walk for ALS and all the social activities, recruits potential participants for clinical trials, and makes sure ALS patients are never alone as they face the end stages of their disease. "I do this because I love it. I enjoy helping the patients, I enjoy working with the Society—I've made beautiful friendships and I have a lot of love for everyone here!"

Volunteer superheroes brightened Carlos Botelho's day as part of a private Batman vs Superman screening.



Many volunteers help us every week by accomplishing administrative tasks. Special thanks to André, Joseph, Kaitlin, Monica, Odile, Phyllis, Rhoda and Roger!



The Desjardins team helped us with the final preparations for the Ride to Fight ALS.



The students from St. George's school enjoyed their visit to the Society as part of a scrapbooking activity with our members.



Many volunteers all across the province contribute to the success of the Walks for ALS!



In addition to furthering our mission, our volunteers even help cyclists from the Ride to Fight ALS up the hill!



“People should ride for ALS because it’s such an incredible feeling to help those who can’t ride and who’d give anything just to be on a bike, riding next to us. People living with ALS are the real superheroes.”

- Simon Tooley, Ride to Fight ALS participant



The Ride to Fight ALS: Together we go further

The 9th edition of the Ride to Fight ALS powered by TELUS Health, including the Society’s very first Evening of Dreams benefit dinner, was held from August 26 to 28, 2016, at Château Vaudreuil, where 650 participants and volunteers gathered to make the cycling challenge an historic success. Backed by the support of our dedicated community, the Ride’s three events—the 3-day challenge, the 1-day challenge, and the Evening of Dreams—raised a combined total of over \$430,000 for the cause, the most money since the event was first held in 2008!

Cycling to save lives

For the second year, the Nouveaux Super-héros team tackled the Ride to Fight ALS challenge. Dressed in the flashy costumes of some of the most popular superheroes, these Montreal-based friends took to their bikes to give hope to people living with ALS. Team captain Simon Tooley is all too familiar with the ravages caused by ALS. His brother, Mark, had the disease. “I don’t want anyone else to have to go through what Mark and our family went through, so that’s why I ride for ALS.” Unfortunately, shortly after doing the Ride, Simon lost his brother to the disease.

Through social media networks, Simon has been able to raise awareness for the disease by talking about his brother’s battle. “Mark was a very private person, but he gave me permission to tell his story so that we could raise more money for research, to one day hopefully find a treatment and maybe even a cure.”



The Nouveaux Super-héros strike a pose before taking the road

An Evening of Dreams to honour the Society’s Builders



Montreal Canadiens legends Guy Carbonneau and Yvon Lambert with members, Yvon Dubé and Sylvie Guilbault.

The Society’s very first benefit dinner, which took place under the theme of an Evening of Dreams and which was attended by close to 400 guests, including Guy Carbonneau, P.J. Stock, Vincent Damphousse, Peter Dalla Riva, and Michael Soles, was the perfect opportunity for it to honour its builders. Martin Matte, whose father succumbed to ALS in 2002, prepared a video message as he was unable to attend. ICI Radio-Canada anchorman Patrice Roy was the evening’s host, and Montréal Canadiens legend Yvon Lambert led the live auction. Thanks to the involvement of our generous donors and participants, the inaugural benefit dinner was certainly one of the highlights of this memorable weekend.



The teams clowning around before the starting gun.



(From left to right) : Colin Bockus and Daniel Lalonde, both living with ALS, were riding alongside Mr Lalonde’s brother Richard and the Society’s president of the board Luc Vilandré.



Participants are having fun on the roads of Vaudreuil-Dorion.

Quebec Walks for ALS

All across Canada, thousands of people gather together and walk for ALS to demonstrate their support and solidarity towards families touched by the disease and Quebec is no exception. From the Outaouais to Rivière-du-Loup and then to Montreal, 10 ALS Walks have taken place across the province to raise a total of more than \$270,000. Thanks to the organizing committees, volunteers, dedicated community members, and donors, each Walk, in its own way, marked a new chapter for the Society.

Rivière-du-Loup Walk exceeds its fundraising goal

Having lost her mother to ALS in 2005, Nancy Aubé didn't hesitate to step back into her role as coordinator of the second edition of the Rivière-du-Loup Walk for ALS. On September 25, 2016, the more than 150 participants who gathered at Parc du Campus and Parc de la Cité raised \$13,000, far more than the organizing committee had expected. "We exceeded our goal, thanks to the hard work of the committee members, who are committed to raising awareness for the cause," Nancy said. Deeply moved by the experience of Léon-David Arias Gonzales, the instigator of the walk and a member of the organizing committee, the Rivière du Loup community walked with him one last time before he passed away three weeks later. "The highlight of my day was Léon-David's beautiful smile. So many great memories come to mind when I think back on that emotional day," Nancy said.

10 Walks for ALS across the province

Montreal, Laval, Quebec City,
Charlevoix, Rivière-du-Loup,
Outaouais, Sherbrooke, Trois
Rivières, Saint-Hyacinthe
and Lennoxville



Nancy Aubé received the distinguished volunteer award.



Sarah Saillant-Boulinguez (middle) enjoying the fun with volunteers from the Quebec City Walk for ALS.

The Caribbean meets Quebec

For the first time this year, Sarah Saillant-Boulinguez headed up the 12th Walk for ALS in Quebec City, with an outstanding organizing committee by her side. Since losing her mother to ALS in 2012, Sarah understands what the disease entails, which is what pushes her to get involved. "I know from personal experience how much damage the disease can do in such a short period of time, so if I can make the patients and their families happy in any way at all, count me in!" And that's exactly what she and her team did by organizing a major Caribbean-themed event where participants could let loose and have fun, and even attend a Capitales de Québec baseball game. "The thing I'm most proud of about this year's Walk is the amazing way that all seven committee members worked together. Everyone brought their strengths to the table, which is what made the event such a resounding success." And that's no understatement: The event raised \$68,000!

The Régimbalds team up against ALS

When Jacques Régimbald, who was diagnosed with ALS in 2015, and his son, Martin, began raising money for the Walk for ALS in Laval, they had no idea just how big their efforts would pay off. "When we first got started, we were aiming for \$5,000, but after only three weeks, we'd already hit \$4,600. The money kept pouring in, so we upped our goal to \$10,000, then \$12,000," said Jacques, who's convinced that his and his son's network of friends is the reason for their success. Eighty-year-old Jacques didn't let his disease stop him from crossing the finish line with his children, Martin and Nathalie. Martin was both astonished and moved by his father's achievement. "I was very proud of my dad. He did part of the walk in a wheelchair, which was the first time he'd used one since his diagnosis, but at the end he managed to stand up and cross the finish line." Martin hopes that the money raised will help educate more people about the "devastating disease" that is ALS. Meanwhile, Jacques remains hopeful about the research being done into ALS. "All I want is for them to find a cure. If this money can help fund research into the disease and help families, then I'll be happy."



Jacques Régimbald with his son, Martin, and his grandson at the Walk for ALS in Laval.

A dedicated community

The Society is made up of many men and women who dedicate their time and effort by helping us achieve our mission. It is thanks to the commitment and involvement of these active community members that we're able to make an even bigger difference in the lives of people living with ALS.

Ormstown rallies behind Michel "Mouse" Tremblay



Strongman Hugo Girard was among the many participants who came out to support the Tremblay-Champagne family.

On August 6, 2016, the RAM "Mouse" SONS POUR VAINCRE LA SLA family day drew out more than 1,000 participants in Ormstown, in Montérégie, to the astonishment of organizers Michel "Mouse" Tremblay, who has ALS, and his wife, Louise Champagne. "We were completely caught off guard. We'd set a goal to raise \$10,000, maybe \$15,000 at most, but the results were way better than we'd ever imagined. There are no words to describe how we feel. I never thought it was possible to experience so much gratitude. My heart is bursting with it!" said Louise, thrilled with the results of the event, which raised close to \$37,000 for the Society.

4 years of dancing with The Classics!

For the fourth year, Roger Boudreau, Steve Roy and Bruce Mcleod took to the stage to perform the greatest hits from the 50s to the 80s as part of the Dance With The Classics event in support of the ALS Society. It was Roger, along with his bandmates of the past decade, who first got the project off the ground for his good friend, Larry Ayotte. "When I found out that Larry had ALS in 2011, I offered to organize a fundraising dance for the ALS Society of Quebec in his name. My wife and I spent several hours with Larry and his wife, Jacqueline, planning the first edition of the dance." Not only did the event become a huge sensation, raising more than \$17,500 in just four years, it also led to a lasting friendship between the two couples.



(Left to right) Roger Boudreau, Steve Roy and Bruce Macleod have made up The Classics for the past 10 years.



After receiving a liver transplant, 10 year-old Laurent wanted to give back. With the help of ZOO FEST and Poppers Coolers, he organized an Ice Bucket Challenge that managed to raise \$620! "It has exceeded my expectations! I'm so happy to be able to help those who need it!"



In honour of Alain Bérard, living with ALS, three accounting and management graduates, Noémie Bérard, Marie-Christine Lalande and Wafaa Bayi, organized a comedy show in support of the Society that raised an impressive amount of \$11 455.



As part of the Youth and philanthropy initiative program, Nico, Eric and Todd from Selwyn House School did an outstanding presentation on ALS. They've won the competition as well as a \$5 000 donation to the Society.



The 4th edition of the Kenny Rockhead Pool Tournament brought together once again friends and family.



Inspired by Michael Soles, students from Loyola and Sacred Heart Schools raised funds and awareness.



In addition to helping the Society, Marc Hébert is also getting involved with the Adaptive Sports Foundation.

Bromont Ultra goes beyond for the third consecutive year!

October 8 and 9, 2016, marked the third edition of the Bromont Ultra, with courses from 2 to 160 km pushing runners to the limits of their endurance. The event, which raises money for several different charities, attracted more than 1,350 runners and raised an impressive \$29,000 for the Society. It wasn't the first time that Marc Hébert, a member of the Bromont Ultra organizing committee, had gotten involved for ALS. "I first heard about the ALS Society of Quebec six years ago, under very sad circumstances when my good friend, Robert Michaud, was diagnosed with ALS. My two Bromont Ultra companions and I wanted to organize charity events to support causes that have very particular needs but that don't always have enough funding, so that's why I decided to make the Society my priority."

Claude Fortin launches a bold challenge with Pierre Lavoie



Diagnosed with ALS in 2007, Claude Fortin never dreamed that a simple Ice Bucket Challenge issued to his idol, triathlete Pierre Lavoie, would take on such massive proportions. While giving an interview with his wife, Annie, about his disease, Claude Fortin challenged Pierre Lavoie, known for his Grand Défi movement, to pour a bucket of ice water over his head. The triathlete responded to the challenge a few days later and even upped the ante, in true Ironman fashion, by swimming 5 km in the icy waters of the Saguenay River and challenging others to take an ALS Sports Challenge. "I know Claude Fortin well. He's a source of inspiration to a lot of people. Taking up his challenge was my way of honouring the man himself and the athlete he once was," said Lavoie.



Pierre Lavoie showed support to his friend Claude Fortin by swimming 5 km in the cold waters of the Saguenay River.



"You have no idea how happy and excited I am. This speaks to my passion for helping others—I was an outreach worker at the CLSC for more than 20 years. I've set myself a very specific goal to do anything I can to help others," says Claude Fortin, moved to see how many people took up the ALS Sports challenge.



Former racecar driver Bertrand Godin did a 6,7 km rowing machine training in support of those who are touched by ALS.



Claudine Cook, Executive Director of the Society, and Diane Tkalec, board member, also tested their limits.



Radio-Canada anchor Patrice Roy and his friend, Charles Ménard, also took up the ALS Sports Challenge.



Let's break the ice—raising awareness

Raising awareness for ALS is an integral part of our mission. By communicating with the public through a range of different platforms, we succeed in educating and informing people—and, above all, breaking the taboos—about ALS. As with the many other communications released throughout the year, that was the goal of our Let's Break the Ice campaign, launched as part of ALS Awareness Month in June 2016. Thank you to all families who continue to share their stories with us and with the media in order to keep the discussion going.

Chantal Lanthier opens up to *Salut Bonjour*

The moving interview shined a light on the impact that the viral Ice Bucket Challenge campaign had on research and revealed the changes that ALS has had on Chantal and Jocelyn's lives since Chantal's diagnosis in 2013. While the disease continues to march relentlessly on, Chantal is holding on to the things that mean the most to her: "My positive outlook, my family, my friends, and my love for life."



Two years after her first interview on *Salut Bonjour* during the Ice Bucket Challenge campaign, Chantal Lanthier dropped in again on the show's host, Ève-Marie Lortie, with her husband, Jocelyn, and the Society's Executive Director, Claudine Cook.



(From left to right): Nadine Prévost (MS), Nicole Charpentier (Parkinson QC), Louis Adam (MS), Josée-Lisa LeFrançois (Alzheimer QC), and Leigh Stephens (ALS QC) during their visit at the National Assembly.

Neuro Partners submits its brief to the National Assembly

On November 9, 2016, Neuro Partners, a new umbrella group of five organizations, advocated for the interests of more than 200,000 Quebecers living with a progressive neurological disease at Quebec's National Assembly. Along with Parkinson Québec, Muscular Dystrophy Canada, the Federation of Quebec Alzheimer Societies, and the Multiple Sclerosis Society of Canada, the ALS Society of Quebec is very proud to have submitted a brief on ways to improve the quality of life for people living with a progressive neurological disease. Access to innovative medications, adapted housing, and support for caregivers were the central points discussed with the MNAs in attendance.

Love wins against ALS

The Society took advantage of Valentine's Day to launch a communication campaign about the ability of love to conquer all, even ALS. Five Society members and their spouses generously agreed to share their love stories on social media to raise awareness about the impacts that ALS can have on a relationship and how love can sustain a couple through such a devastating ordeal.



Alain Bérard, who has ALS, and his wife, Dominique Racine, generously agreed to be featured in the campaign.



"Don't stop coming to visit us, talk to us, laugh with us, eat and celebrate with us. Don't be afraid of those three little letters, even if you're worried that you won't know what to say"

- Michael Soles,
former Alouette fullback,
diagnosed in 2005

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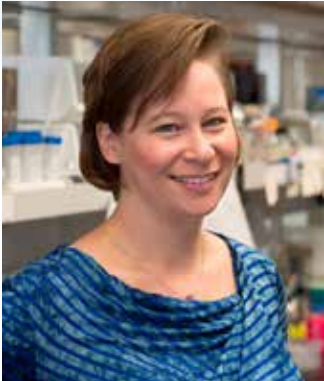
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Carbonneau, Lyne	Firooz, Faraz	Hotte, Roger	Madoff, Rhoda	Quessy, Me Anabel	Vilandrè, Luc
Cardona, Ivan	Fortier, Stéphane	Houde, Michel	Madore, Nathalie	Racine, Dominique	Whissel, Alex
Carey, Catherine	Fortin, Line	Hudon, Isabelle	Mailhot, Barbara	Rafie, Anthony	Whissel, Jean
Carignan, Thérèse	Fortin, Line	Hudon, Isabelle	Mailhot, Pierrette	Ratcliff, Andrew	Whissel, Pier-Luc
CBC Do Crew	Forzani, Cassandra	Hugon, Isabelle	Mailhot, Sonia	Richoz, Danielle	Whissel, Valérie
Chalifoux, Me Danielle	Fournier, Claudie	Jacques, François	Mailhot, Sonia	Rimada, Camila	Wolfe, Réal
Charland, Laurie	Fournier, Geneviève	Jean, Jovia	Malandrucolo, Daniel	Riopel, Sylvie	
Charpentier, Nathalie	Fournier, Jean-Guy	Johnson, Alexander	Maltais, Diane		
Chartier, Caroline	Fournier, Manon	Julien, Stéphane	Manganaro, Christina		
Chiu, Joyce	Fournier, Nicole	Kelen, Sari	Marin, Joseph Roger		
	Frenette, Etienne	Kennernknecht, Susan	Marquis, Caroline		
		Kirouac, Jean-Claude	Martel, Gilles		
			McKibbin, Steven		

We are truly stronger together!

Collaboration behind ALS Research

In the field of research, collaboration is key. Many ALS research projects have resulted in important discoveries, thanks to this interaction. Therefore, the ALS Society of Quebec is proud to support Quebec's initiatives that aim to encourage exchange between today's and tomorrow's researchers, all over the world.



Dr. Christine Vande Velde

Associate Professor in the Department of Neuroscience at Université de Montréal and the Centre hospitalier de l'Université de Montréal (CHUM), Research Centre.

On September 27, 2016, many researchers, clinicians and students gathered in an informal setting in order to share their projects and ideas in ALS research during the very first ALS Research Network meeting, initiated by

Dr. Christine Vande Velde and Dr. Angela Genge. "In the last few years, ALS researchers have been collaborating more and more. As a result, we have made significant findings. I think in my lifetime we will discover a therapy to treat ALS. We'll finally get it. The therapy might not benefit all patients, but it will be a start."



Dr. Jean-Pierre Julien

Professor at the Faculty of Medicine, Université Laval and Neurosciences Director at l'Institut universitaire en santé mentale de Québec.

When he helped spearhead the organization of the first ALS Annual Symposium on behalf of the Fondation André Delambre in 2005, Dr. Jean-Pierre Julien was hoping for an international collaboration to emerge from this event. Twelve years later, he thinks he achieved this goal.

"Since 2005, nearly 300 guest speakers coming from 14 countries have taken part in these encounters. One particular thing about this symposium is that the friendly environment encourages participants to discuss the unpublished results of their research projects. ALS is a complex disease and the collaboration between experts is essential in trying to understand both molecular and cellular mechanisms involved."



Dr. Nicolas Dupré

Associate Professor, Faculty of Medicine, l'Université Laval and Director of the ALS Clinic at Centre hospitalier de l'Université Laval (CHUL).

Dr. Dupré studies the genes linked to ALS and other motor neuron diseases. Mapping these mutant genes will significantly advance treatment that could slow down or stop the disease. "I am very excited by advances in genomic research which is allowing us to create motor

neurons in the lab. By using skin samples from those with ALS we are able to recreate motor neurons with the same genetic background. This is helping us gain a better understanding of the degeneration of motor neurons and will eventually open the door to new therapies and treatments and diagnostic methods for ALS."



Dr. Angela Genge

Director of the Clinical Research Unit and the ALS Research Program at the Montreal Neurological Institute and Hospital (The Neuro).

Dr. Genge's research focuses on testing new ALS treatments in clinical trials to improve the quality of life of people living with ALS. "2017 promises to be a huge year with a variety of new clinical trials. Plus, many medications currently in the review process are showing a lot

of promise. We'll be going to Health Canada for approval soon. Also, the Neuro will be the first Open Science institute in the world. Starting in 2017, research data will move freely between research teams. The aim is to speed up discoveries of all neurological diseases with ALS at the forefront of this initiative."



Dr. Pierre Drapeau

Professor, Department of Neuroscience at Université de Montréal and the Centre hospitalier de l'Université de Montréal (CHUM), Research Centre.

Dr. Drapeau studies zebra fish with mutant TDP-43 or FUS genes that causes them to develop a disease which mimics human ALS. In fact, Dr. Drapeau discovered the drug Pimozide slows down ALS in fish. "We are about to publish the promising results and in early 2017, phase two clinical trials will get underway. Worldwide, a number of clinical trials are underway to test the effectiveness and safety of various ALS treatments. Within a year or two, several new medications should be available. These treatments will improve the quality of life of those living with the disease."

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

2016 ALS Research Review

Investments in ALS research have always been a reason to be hopeful that one day there will be effective treatments for this devastating disease. As a result of generous donor contributions and our partnership with the ALS Society of Canada, we – and you! – helped to fund more than \$6 million in research in 2016 through the ALS Canada Research Program.

Research Highlights

The research investments made in 2016 will fund 20 projects across the country, enabling 31 researchers at eight academic institutions to engage in important ALS research.

These include:

- With co-funding from Brain Canada (with financial support from Health Canada), two large-scale multi-year team initiatives – one of which is using stem cell technology to better understand and potentially treat ALS, while the other is studying in a new way the gene most commonly linked to ALS development (see sidebar).
- \$1.5 million awarded to early-career researchers through three different grant programs that invest in the future of ALS research by developing the next generation of scientists and enabling them to focus their work on ALS.
- \$700,000 to seven smaller studies, co-funded with Brain Canada (with financial support from Health Canada) that enable investigators to explore outside-of-the-box research.
- The first recipients of the ALS Canada Clinical Management Grant. This program funds research focused on avenues to maximize function, minimize disability and optimize quality of life through symptom management and support to families and persons living with ALS. The funding allowed a group of researchers to explore the use of cannabinoids, substances that have demonstrated therapeutic effects including anti-inflammatory, analgesic, and anti-anxiety, for ALS symptom management.



A research team led by Dr. Guy Rouleau of McGill University and the Montreal Neurological Institute was awarded \$2.2 million to study motor neurons and astrocytes created from people living with different forms of ALS via stem cell technology. Dr. Rouleau and his team, which includes other collaborators at McGill University and the Montreal Neurological Institute as well as Université de Montréal and Université Laval, will study the biology of these stem cells to determine if their characteristics in the laboratory can represent different forms of human disease and further develop them as a potential screening mechanism for therapeutics. The tools and tests created in this project will be valuable for both Canadian and global ALS researchers as new resources to understand the disease and find new ways to treat it.



A research team led by Dr. Janice Robertson of University of Toronto was awarded \$1.6 million to understand whether the most common genetic abnormality in ALS, which occurs in the C9ORF72 gene, causes or contributes to the disease through a loss of the gene's normal biological function. The majority of the research community is focusing on how the genetic abnormality in C9ORF72 might lead to an extra, toxic function, but in this five-year study, the team – which includes other collaborators at the University of Toronto as well as Sunnybrook Health Sciences Centre, McGill University and the Montreal Neurological Institute, and the University of British Columbia – will comprehensively analyze the potential damage to motor neurons lacking C9ORF72, and examine if both loss and gain of function mechanisms combine to cause ALS. This knowledge could fundamentally alter how therapeutics are developed for common forms of ALS as well as frontotemporal dementia (FTD), which often occurs with ALS.

The ALS Canada Research Program by numbers

- **6 million dollars** invested in ALS research across Canada in 2016;
- **20 projects** funded representing 31 investigators at 8 universities in seven provinces ;
- **7 studies**, co-funded with Brain Canada (with financial support from Health Canada);
- **3 grant programs** that invest in the future of ALS research by supporting the next generation of scientists



For more information, please visit als.ca

“For those of us with ALS, we keep hoping, every second, that researchers will find a way to extend our lives and ultimately save us.”

- Michel Tremblay, living with ALS, Montérégie

Making Progress

Since the Ice Bucket Challenge became a social media phenomenon in 2014, nearly \$20 million has been invested in Canadian ALS research at a time when it has the potential to make the greatest impact. Significant progress in ALS research is being made — researchers now believe that finding effective treatment options for ALS is now a matter of “when,” not “if,” and that research discovery is limited only by the amount of funding available to pursue it.

As just one example of a recent development in ALS research, July 2016 saw researchers announcing that the gene NEK1 has been found to play a significant role in the development of amyotrophic lateral sclerosis (ALS). This landmark discovery is the result of an 11-country research collaboration that was funded through the Ice Bucket Challenge. The research team included 3 Canadians, one of whom was directly funded by the ALS Canada Research Program for their work during this discovery. This finding will trigger future studies that focus specifically on the NEK1 gene.

Investing with Integrity

The ALS Canada Research Program invests in the best science in order to pursue our unwavering commitment to make ALS treatable, not terminal. Decisions about which projects to invest in are made through a peer review panel, which is the international standard of excellence for research funding. This process provides an objective assessment on the best science that is most able to advance the field.

Thank you

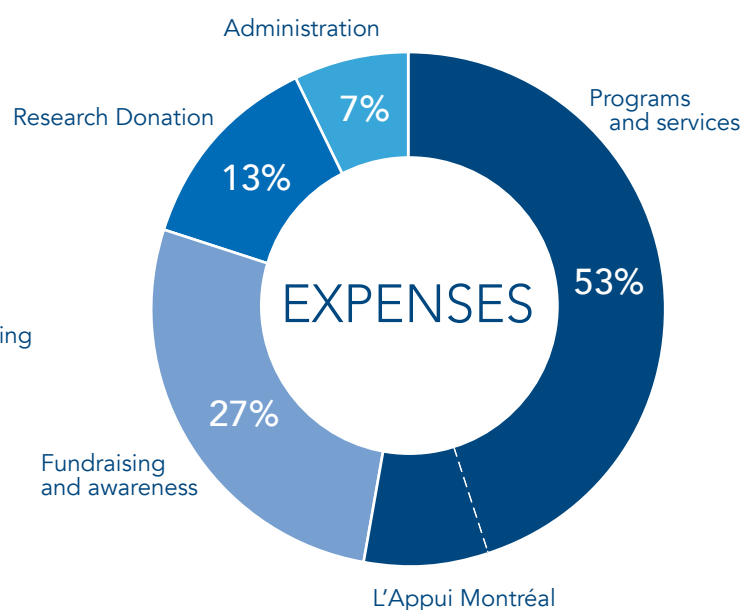
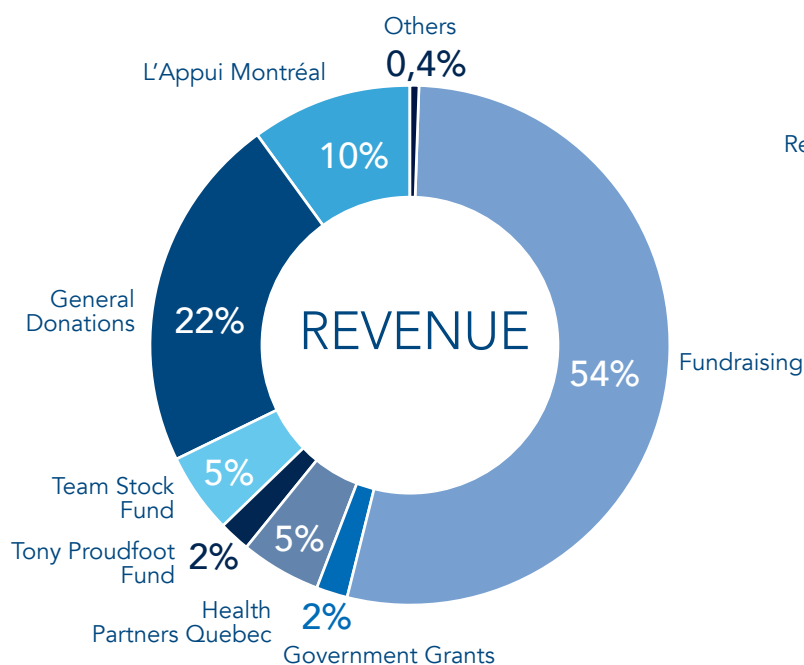
Thank you for your continued support of the ALS Canada Research Program. It is because of your generosity that we can continue to make significant investments in the research that is needed to make ALS treatable, not terminal.

Thank you to all Canadian researchers for feeding hope of a future without ALS!



Financial Summary Financial year from November 1st 2015 to October 31st 2016

REVENUE	2015-2016	2014-2015
Fundraising	\$827 503	\$745 291
Government Grants	\$25 693	\$25 407
Health Partners Quebec	\$76 901	\$74 652
Tony Proudfoot Fund	\$24 594	\$25 572
Team Stock Fund	\$73 403	\$102 961
General Donations	\$332 059	\$267 172
L'Appui Montréal	\$159 312	\$169 865
Others	\$6 607	\$3 839
Total	\$1 526 072	1 414 759\$
EXPENSES	2015-2016	2014-2015
Administration	\$111 453	\$122 909
Programs and services	\$729 149	\$651 173
L'Appui Montréal (SLAppui)	\$133 360	\$168 654
Fundraising and Awareness	\$432 017	\$406 231
Research Contribution	\$201 475	\$261 434
Contribution to ALS Canada – (ALSSQC, T.Stock Fund and IBC)	\$154 700	\$204 238
Contribution to The Neuro (Tony Proudfoot Fund)	\$11 259	\$26 760
Contribution to ALS research conferences (André-Delambre Foundation symposium and others)	\$35 516	\$30 436
Total	\$1 607 454	\$1 610 401
Excess (deficiency) of revenue over expenses	(\$81 382)	(\$195 642)



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



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

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This report is also available in French.

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