



# AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC ANNUAL REPORT 2014-2015



# WHAT IS ALS?

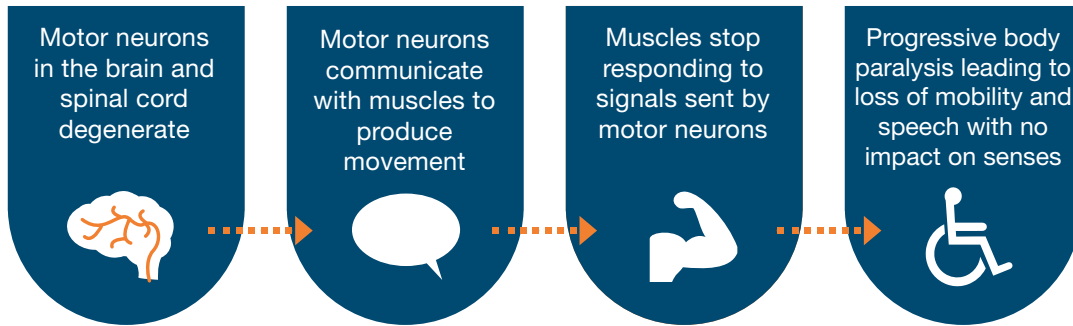
Fatal neurodegenerative disease

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 to people with ALS and their caregivers

Funds cutting-edge research projects in Canada

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

# Stronger Together

## Message from the President and Executive Director

When we share our ideas, energy and philanthropic contributions we create a community that is truly stronger together. Together, we've accomplished a great deal in 2015. We have made sustainable investments in our services and contributed to major research grants. A CROP survey of our members, caregivers and healthcare professionals provided valuable insights into their most pressing needs as well as their appreciation of our services. We were proud to learn there is a 95% overall satisfaction rate with the Society's team and its services (an increase of 12% compared to 2010). The survey highlighted the vital need for respite care while pointing out respite care means different things to different people. We are listening attentively to our community.

In other notable initiatives, we enhanced two financial aid programs designed to support caregivers and children who are significantly impacted when a family member is diagnosed with ALS. The Respite Care Program provides caregivers with additional assistance or an opportunity to take a little time-off from their responsibilities. We also made additional funds available for children's activities. This will allow families to afford extracurricular activities for their children even as the financial burden of the disease increases. Our extensive range of programs and services is designed to support people living with ALS and their families during each stage of the disease.

## Over 30 research studies

While there are no treatments for ALS, we remain very optimistic. Funds raised during the Ice Bucket Challenge are fuelling over 30 research projects from coast to coast. We are hopeful the passionate and dedicated community of researchers will make remarkable discoveries in the coming years.

Everything we have achieved, we have achieved together thanks to our compassionate staff, active board of directors, dedicated volunteers, collaborative health professionals, and valued donors and partners. We are truly stronger together. Thank you for being part of our community.



Luc Vilandr   
Pr sident du comit  ex cutif  
Vice-Pr sident,  
TELUS Solutions en sant 



Claudine Cook  
Directrice g n rale  
Soci t  de la SLA du Qu bec

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# Our Programs and Services for People with ALS, Caregivers and Healthcare Professionals

The Amyotrophic Lateral Sclerosis Society of Quebec is dedicated to improving the lives of people living with ALS and supporting their caregivers. Through our close collaboration with healthcare partners, we are able to offer a variety of programs and services that are complimentary to those offered by other organizations.

The needs of people living with ALS and their caregivers change during all stages of the disease, which is why the ALS Society of Quebec offers many different services. Through documentation, conferences, newsletters and a website, people with ALS, caregivers and healthcare professionals can learn more about issues with regard to ALS. A team of dedicated psychosocial counsellors offers support to each member of the Society: through orientation meetings, support groups, phone support meetings and a toll-free support line. Social and networking activities help reduce social isolation felt by many. Together, the programs and services offered by the ALS Society of Quebec truly make a difference for people touched by ALS.

## INFORMATION



Conferences



Documentation



Newsletters



Resources and Website

## PSYCHOSOCIAL SUPPORT



Listening, orientation and reference



Toll-free support line



Support groups



Teleconference

## TECHNICAL AID AND FINANCIAL AID



Home adaptation Program



Equipment Assistance



Financial Contribution



Respite

NEW



Program for Children

NEW

## SOCIAL AND NETWORKING ACTIVITIES



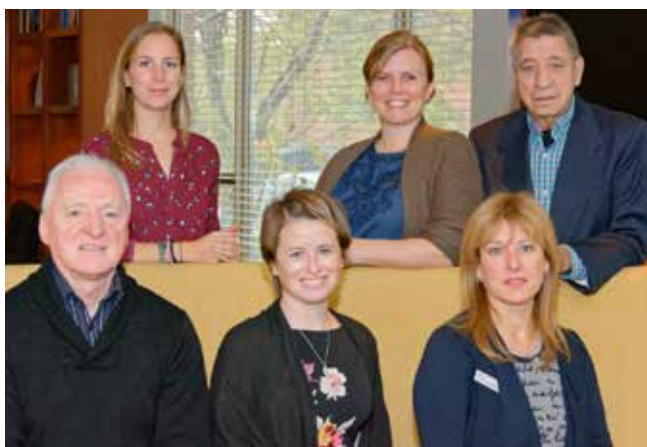
Regional information sessions



Social activities



Online community



Top: Alexandra Sofio, Valérie Neufeld and our amazing volunteer Joseph Roger Marin. Bottom: Yves Lafleur, Leigh Stephens and Diane Tkalec (President of the Programs and Services Committee).



Our members enjoying an apple picking outing.

## Programs & Services: Our Highlights



# Respite Program: Caring for the Caregivers

## For the first time in fourteen years, I was able to take a break.

In 2001, Martin and Anick were planning their lives together, looking forward to great adventures, determined to climb their respective career ladders and to start a family. But fate had decided otherwise. That summer, Martin was plagued by great fatigue, fever, and a loss of muscle strength. The couple learned that he would have to undergo a series of medical exams to determine what was wrong just as they got the news that they were expecting a baby.

"During my pregnancy, we visited many physicians. Some visits were to prepare for the birth of a life. Others – it was always lurking at the back of our minds – to prepare for the end of another life," explains Anick. One month after their daughter, Frédérique, was born, the diagnosis of ALS hit them at their core. "We were told that Martin would never see his daughter grow up."

Fourteen years later, Martin has beaten the odds: the average life expectancy for people with ALS is between two and five years. For Martin, Anick and Frédérique, it has been an emotional and physical roller coaster: love, guilt, happiness, sadness, stress, anxiety, solitude, sleep disorders, moral and physical exhaustion. "None of us had envisioned our lives taking this path. In addition to being 'Mom' to my daughter, I am also a caregiver to Martin."



Little by little, Martin has completely lost his autonomy, with his head being the only part of his body that still moves. He requires assistance in every aspect of his life. To feed himself, to brush his teeth, to answer the phone, to scratch himself, to go to the bathroom, to reposition himself about ten times per night, among other things... "For caregivers, everyday requires generosity, patience and acceptance. But we need recognition, support and, more than ever, respite."



With actress Eve Landry at our Celebrity Softball Game

In July 2015, the ALS Society of Quebec responded to that need and launched a Respite program. "For the first time in fourteen years, I was able to take a break. Thanks to the Respite Program, I took some much-needed time for myself while certified home care workers were with my husband."

Since the launch of the program, many caregivers, some even for the first time, took advantage of the Respite Program. This has meant uninterrupted sleep, worry-free errand-running, or squeezing in some much needed social time for people who have dedicated their lives to supporting their loved ones.

# The ALS Society of Quebec is expanding its programs and services dedicated to caregivers.



The ALS Society of Quebec knows that caring for someone diagnosed with a neurodegenerative disease is physically and emotionally demanding. From the outset, the Society's goal has always been to improve the quality of life of caregivers, as well as those diagnosed with ALS, by providing services to support, equip and refer our caregiver members as needed, thus reducing the risk for injuries, exhaustion, depression, anxiety and eventually, pathological mourning. Thanks to numerous partnerships and generous grants, the Society has been able to improve and even add services that support caregivers further in a concrete way, as they provide care for their loved ones during all stage of the disease; in the Montreal and surrounding regions, Montérégie as well as the Quebec region. Based on our team's expertise, the Society is proud to have increased and diversified the following services:

- Personalized and continued accompaniment and support that meets caregivers' specific needs, at the outset of and throughout their journey with ALS
- Information about the disease, referral services, support and respite resources which are available in the healthcare system and through community organizations
- Emotional support and follow-ups through in-person meetings at our offices, home visits, phone contacts and emails (which also breaks isolation and provides answers/information)
- Monthly presence at four important ALS clinics of the region in order to reach and support to caregivers:
  - o Montreal Neurological Hospital
  - o Notre-Dame Hospital
  - o Maisonneuve-Rosemont Hospital
  - o St-Jérôme Hospital
- Information sessions, support groups, informal meetings, cocktails, appreciation days and social activities dedicated to caregivers and the bereaved.
- Conferences, teleconferences and training on subjects such as "The challenge of making it all work", "Adapted travel", "Testimonial from a former caregiver", workshops for caregivers, "Today's caregivers" and "Toward the recognition of a legal status for caregivers", to name a few.

FINANCÉ PAR

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[lappuimontreal.org](http://lappuimontreal.org)



## The Society expands its regional outreach

In 2015, one of the Society's priorities was to extend its outreach to members across the province and to diversify its activities held outside the metropolitan area. As a result during this year, the Society traveled to thirteen administrative regions, organized more support groups outside of Montreal than it had ever done and held thirteen teleconferences.

### New Support Group in Montérégie

When Alexandra Sofio, a psychosocial counsellor at the Society, started her Masters project in early 2015, she had not anticipated that it would lead to a regular support group for people living on the South Shore of Montreal. "From January to April, I met with a small group of caregivers to learn more about their experiences. At the end of the project, it was clear there was a real need for this type of support on a permanent basis."

Today, the group includes both caregivers and people with ALS. "Participants are divided into two groups: the caregivers and those living with ALS. It's important that the caregivers have their own space to focus on their needs and express what they feel openly. It gives them an opportunity to find their voice as a caregiver and as a person," she says. "Their meetings help them see that they aren't alone. They work on problems together and often develop a new sense of hope."

*"Huge thanks to all of you. It's such a pleasure to see everyone at the support group, and we return home with renewed energy. Your support is precious to us."* - A group member

### Regular presence in Quebec City

With the help of dedicated volunteers and facilitators, the Society has also expanded its services in the Quebec City area. Subsequently, twelve support groups and a workshop for caregivers were held. "This kind of support is invaluable and helps caregivers as well as people with ALS. We need this support as we navigate through the different stages of this disease," said one participant. The Society is grateful for the contributions made by our facilitators and volunteers: Line Beauregard, Claudette Brizard, Odette Bussieres, Diane Ferland, Josiane Falardeau and Odette Lacroix.

#### Awareness or support activities in 13 administrative regions

Beaconsfield, Boucherville, Bromont, Brossard, Chambly, Charlevoix, Contrecoeur, Drummondville, Gatineau, Laval, Lennoxville, Longueuil, Lorraine, Montréal, Outaouais, Pointe-aux-Outardes, Pointe-Claire, Québec, Rivière-du-Loup, Saint-Hyacinthe, Saint-Jean-sur-Richelieu, Saint-Jérôme, Saint-Lambert, Saint-Nicolas, Sherbrooke, Saguenay Lac-Saint-Jean, Sorel, Varennes, Verchères.



### Helping a support group grow

Yves Lafleur has worked as a psychosocial counsellor with the Society since 2009 and leads a support group in Lorraine, north of Montreal. "It's a social encounter that greatly benefits everyone," says Yves. "The meetings allow our members to talk about what's on their mind at any given point. The group was founded by Chantal Lanthier, diagnosed with ALS in 2013, and is growing steadily. When new people join us, they really benefit from meeting our longer-term members."

### Support one phone call away

In addition to support groups, the Society organizes conference calls through which it is able to reach people from all across the province. In 2015, 13 conferences have permitted the Society to extend its outreach to people with ALS, caregivers and healthcare professionals. Several experts were able to provide quality information over the phone on various aspects of life with the disease. These conferences are diverse and allow to break the isolation of our members. Moreover, several support meetings also take place on the phone and give rise to twinning between members. These calls create and maintain a contact between members and the Society. According to Mr. Lafleur, "This is a convenient alternative to face-to-face meetings for members living outside of the Metropolitan area or whose mobility is limited."

# Leave your wheelchair on the dock and sail away

## Outing leaves participants in awe



*"Wow, wow, wow!!!! FREEDOM!!! What a terrific day. I've been imprisoned inside my body for years, and I never thought it possible to experience such a feeling of freedom..."* says Ginette Beaudreault, who took part in a sailing excursion organized last summer at the Pointe Claire Yacht Club.

**FREEDOM** was the word of the day for the six members of the ALS Society of Quebec who learned to sail. Paula Stone, who volunteers with the Society and the Association québécoise de voile adaptée (AQVA), organized the outing to the yacht club.

"Most people with mobility challenges are surprised to discover they can learn to sail," says Ms. Stone. "At first, they have concerns: they worry about the boat capsizing and they can't imagine how they will get in and out of the boat. But once you explain everything, you see their eyes light up as they realize they can do it."

*"It was my first time sailing. Initially I hesitated about going, primarily because walking on a dock scares me, let alone rolling on one. Secondly I thought being out in the sun all day would be exhausting. But with the Society hosting the activity, it gave me the confidence to try it,"* says Ms. Beaudreault, who has been living with ALS for 14 years.

Sailing is one of the few sports people with ALS or other physical challenges can take part in, explains Ms. Stone. The AQVA has a fleet of five Martin 16 sail boats designed for those with limited mobility. The Martin 16 is nimble and fun in a breeze, and with a 330 lb. keel, it's impossible to sink. The participant sits low in the boat with a central "joystick" style tiller to steer and control the sails. The boat can be further adapted for those who have limited or no use of their arms. Using a sophisticated straw system called the "sip 'n puff", the sailor uses his or her breath instead of controlling the helm and sails with their hands. By just inhaling or exhaling gently into the straw, the rudder will move left or right and the sails can be let out or drawn in. This allows even those with extremely limited mobility to independently sail the boat.

*"I absolutely adored being at the helm. I highly recommend this activity for anyone with mobility challenges,"* says Ms. Beaudreault.

"As a volunteer with the ALS Society for the last few years, and with the AQVA for 17 years, my reward is when I see the smiles on people's faces when they get back. After all these years, I still get tears in my eyes when I see how happy they are," says Ms. Stone.



Pedro Alfaro enjoying the day



"It felt as if the sky and the water could go on forever!" Kathy Vaux



Paula Stone, volunteer at AQVA and ALS Society

# One weekend to make a difference

*By Chantale Grenon-Nyenhuis, Ride to Fight ALS 2015 participant*

There they were, at the top of that last hill, waiting for me and cheering me on. Once I finally got there, they gave me a chance to catch my breath, reminding me that I "did it!" We all crossed the finish line together.



Chantale with her three boys

When I decided to take part in the Ride to Fight ALS three-day challenge, I had never met any other participant. However, I couldn't have completed 300 km without them, their smiles, their encouragements, their advice and the occasional push up a hill. I am not a cyclist (far from it!), and doing the Ride to Fight ALS was a huge challenge for me. When I found out that Dean Stock, my two youngest boys' hockey coach, had been diagnosed with the disease, I wanted to help. I also wanted my kids to understand that we could make a difference, even if only in a small way. Three of my boys took part in the one-day event on Sunday, and loved their experience.

During this memorable weekend, I got to meet some truly wonderful people who have been cycling and raising funds and awareness for many years, and who are deeply committed to the cause. I learned about those for whom they were riding. I learned more about how the Society supports people living with ALS and their family, as well as about some of the research that is being done to find a treatment for ALS. I really felt like I was part of something larger. When I decided to do the Ride, I told Dean that I would tell everyone I knew about ALS. As I did, I was surprised to see how many people have been touched by the disease, through family members or friends. There is a lot of support out there.

My family and I had the chance to have dinner with Alain Bérard, who was diagnosed with ALS in 2011, and his family on Saturday night. His warm personality and his sense of humour made quite an impression on my boys. And when he thanked me for taking part in the Ride, I knew that, even though my legs were sore and shaky, I would be back next year!

## New important partner

### Welcome and thank you TELUS Health!

The ALS Society of Quebec is thrilled to partner up with TELUS Health as the official presenter of the event for the next three years. Through this partnership, the contribution towards the cause will be increased and the participants' experience will be elevated to another level! TELUS Health's contribution has helped enhance the event by adding a Family Day which rallied over 150 participants of all levels: young athletes, relatives and families. About 90 courageous cyclists conquered 300km over three days in the Eastern Townships. This 8th edition raised over \$238,000, making it the biggest annual fundraising event for the Society. The event is part of a series of three cycling events that collectively gathered 246 cyclists.



Successful experience for those cyclists, for whom it was a first participation.



Our Board members get involved on every level.



We are having fun before hitting the road.

**We are truly grateful to all of our participants and organizers for their efforts and energy invested in our activities!**



**Thanks to the Alouettes for their support throughout the season and at the Montreal Walk in memory of Tony Proudfoot.**



**Our participants have honored their loved ones at one of our 10 walks.**



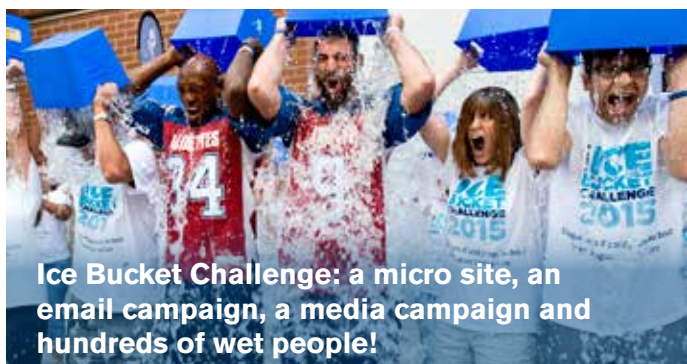
**Unified by our mission: Team Stock helps shutout ALS nationwide and raises over \$118,807!**



**25 female celebrities issued from the artistic, media and sports fields competed during the Celebrity softball game.**



**The Government of Quebec gave us a \$74,491 donation made possible through the 2014 Entraide campaign.**



**Ice Bucket Challenge: a micro site, an email campaign, a media campaign and hundreds of wet people!**



**It's thanks to hundreds of volunteers across the province that we can achieve our mission.**



**67% increase in activities organized by the community.**



**Our members take part in all our events and teach us about strength, courage and determination!**

## Teaming up to raise awareness

2014 was known as the Ice Bucket Challenge year, when ALS benefited from incomparable public attention across the globe. The 2015 Ice Bucket Challenge was dedicated to the people and the cause behind the ice cubes, and less about the viral phenomenon. No efforts have been spared to increase awareness about ALS. We want to applaud our community for their creative initiatives: for example, Martin Lauzon (living with ALS for 14 years) completed an "IBC Marathon" (one ice bucket every day in August)!



Thank you to Jean-Sébastien Francoeur (producer), Evren Boisjoli, Fabrice La Roche, Simran Dewan, Maxime Séguéla, Jeremy Sandor, René Arseneau, Daniel Ho-Tieng, Roland Cody Larocque, Lisa-Marie Charron, Rafael Willits, Simon Allard, Karl de Serres, Cineground, Eve Duranceau and Caroline Chartier.

### The Ice Bucket

Challenge inspired our first awareness Public Service Announcement (PSA) featuring Dean Stock, his wife Paula and their three children. Like many others, the family accepted the Challenge in August 2014, but for Dean and Paula, the real shock was yet to come: in December, Dean was diagnosed with ALS. "We felt we had to do our part to raise awareness and money to support families touched by ALS, as well as research," says Paula. We are extremely grateful towards the professional team who volunteered their time, energy and expertise to make this PSA. We would also like to thank Cinepool Studio for lending us their studio space and the equipment as well as our media partners for broadcasting the PSA free of charge: Bell Media, Shaw Media, Rogers, CBC, Radio-Canada, VTélé and Télé-Québec. Thank you also to Outfront Media for donating outdoor digital signage across the province



2015 also marked Quebec singer-songwriter Luc Cousineau's media tour about his upcoming projects and the ALS diagnosis he received in 2013. His final album *Tant qu'il y aura une chanson*, is a testimonial of his optimistic outlook despite the disease. Luc Cousineau has also decided to get involved by donating half of the sales proceeds to the Society.

Furthermore, we have made great progress in raising awareness among our provincial representatives. On May 28th, we had an information booth at the Assemblée nationale du Québec to create conversation about our cause. Then on October 29th, we teamed up with the Multiple Sclerosis Society, Muscular Dystrophy Canada as well as Parkinson Quebec to submit a brief centered on improving the quality of life for the thousands of people who count on us. All groups agreed upon some priorities: developing a network for housing accommodation resources that respond to the needs of adults living with a neurodegenerative disease, supporting caregivers as well as providing access to innovative medication. These interventions pave the way for further awareness initiatives in 2016.



Geneviève Chartré, Dr N. Dupré, Claudine Cook, Hon. Pierre Arcand and Diane Tkalec – May 2015



Annie Turcot (Parkinson QC), Nadine Provost (SP), Prime Minister Philippe Couillard, Diane Tkalec (SLA) and Pascale Rousseau (MD) – Oct 2015

# Thank you to our volunteers, we couldn't do it without you!

As volunteers, your contributions make an enormous difference in the lives of those touched by ALS. Your time, advocacy, enthusiasm, dedication and your caring nature all play a crucial role in helping us fulfill our mission.

## Young volunteers carry the torch

A growing number of young philanthropists are getting involved. They are volunteering, organizing events, raising funds and awareness among their friends and at their schools. They are truly our leaders of tomorrow!

### Honour thy father

Since 2005, Sarah Shahani and her mom have participated in the annual Walk for ALS. They formed Team Shahani in memory of Sarah's dad, Dayal Shahani, who succumbed to the disease. "It was really tough but we received tremendous support from the ALS Society of Quebec. That's why I think it's crucial to give back," says the 28-year-old medical student.

To date, Sarah's team has raised over \$30,000. Sarah says the Walk honours those lost to ALS and lets those living with the disease know they aren't forgotten and the Society can support them.



Sarah (front) with other volunteers at the Walk for ALS in Montreal



Justine (2nd) with her friends during her fundraiser

Justine Soles, daughter of CFL and McGill Redmen player Michael Soles, living with ALS since 2005, also got involved for the cause. The 18-year old, along with her friend Taylor, organized a fundraiser "Camp For A Cure". The outdoor event gathered close to a hundred campers and was filled with entertainment: bonfire, dance, games and a barbecue. At the end of the night, Justine, Taylor and their friends raised \$10,000 to support research and families touched by ALS.

### Honour thy mother

Dominique Lavergne completed an internship with ALS Quebec last summer as part of her Bachelor's degree. It was a natural choice since her mom Ginette Leblanc, who died of ALS in 2013, received tremendous support from the Society.



Dominique (2nd) with other volunteers at an event at the Aigles de Trois-Rivière stadium.

Dominique helped with various fundraisers and organized the first Walk for ALS in Trois-Rivières, her mother's hometown, raising an impressive six thousand dollars.

"The cause is dear to me," says the 24-year-old. "Being diagnosed with ALS is devastating both medically and financially. My mom wasn't earning a big salary; she didn't have a lot of savings or insurance. Once she could no longer work, she relied on family and friends to get by. The Society's support is crucial and we need to continue raising money to help those living with the disease."

To read more stories and see our volunteers in action, please visit our website at [als-quebec.ca](http://als-quebec.ca)

Volunteers of all ages take action to help our fight



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

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Kaufman, Stephen  
Kelley, Geoffrey  
King-Doyle, Valerie  
KPMG  
La Gargouille  
La Renaissance des Îles Inc.  
La Villa, Angelo  
Labelle, François

Labrèche, Michel jr	MAR-KIN Foundation	Roberge, François	Thompson, Chirs
Lachance, Carl	Matériaux de Construction D.L. Inc.	Robineau, Guy	Tozza, Mario
Lacroix, Mercedes	Meldrum, Jennifer	Roy, André	Trahan, Sabine
Lant, R. Anthony	Mobilenet Communications Inc.	Royal Canadian Legion, Filiale Pointe Claire - Branch #57	Trahan, Maxime
Laurin, Jacques	Mondou, Francine	Samaras, Joseph C.	Tremblay, Michel
Lauzon, Jean-Claude	Montagano, Jerry	Schatia, David	Tremblay-Dumas, Claude & Francine
Lavigne, Daniel	Monticciolo, Cathy	Schwartz, Joyce & Alan	Ultra Electronics Tcs
Lemieux, André	Morisset, Jean & Claudine	Sekure Merchants	Vaux, Robert
Lemonde, Martine	Neemeh, Alain	Sermatech Power Solutions LP	Vézina, Louis
Lepage, Paul	Paroisse Saint-Côme	Services administratifs VIGI	Vilandr�, Luc
Lepage, Sophie	Perrault, François	Services V&O	Vilandr�, Jos�e
Les Entreprise Etoile Inc.	PF R�solu Canada Inc.	Simard, St�phanie	Vinc, Lisa & Matt
Les Importations Cavan Inc.	Pierre Arco (1980) Lt�e	Soci�t� de Chirurgie Digestive de Qu�bec	VisiPro Inc.
Long, Denis	Power, Ryan	Solareh inc.	Von Richter, Dominique
Loyola High-School Football Program	Promoli, Fred	Soles, Michael	Wait, Richard
M4P Inc.	Prosanto Chaudhury Fund	Srougi, Yacoub	Williams, Eric
Mahony, Patrick	Proudfoot, Janet	Stock, Paula	Wilson, Glen
Manulift EMI, Lt�e	RDTs	Tchervenkov, Jean	Yocum, William
Maple Leaf Lawns LLC	Reed, Wesley	T�d Phone Channel	Zenith Merchant Services
Marcel Naud Family Foundation	Richter, Dominique	The Hudson Yacht Club	Zone Resto Pub
Marianopolis Students Union	Roberge, Danielle		

## In-Kind Donations

Agropur division Natrel	Fruit d'Or	Le Dindon du Qu�bec	RDTs
Agropur Fromages fins	Galerie du Tapis d'Astous et Fr�res Inc.	Les Producteurs de lait de Montr�gie-Est	Regroupement du baseball f�minin de Montr�al
Appartements-H�tel Trylon	Giovanni Clothes Inc.	Libert�	Rouge FM
astronautes	Globe Multim�dia	Location Pelletier	Soci�t� des alcools du Qu�bec
Centre ADN	GLS Productions	M Manger Traiteur	Spa Scandinave
Centre Montr�gien de r�adaptation	Gogo Quinoa	Magenta Studio Photo	Station Mont Tremblant
Chenail Fruits et L�gumes	Hyundai Gabriel	Marsham International	Studios Cin�pool
ClubLink Entreprises Ltd	IGA	Medicum	Subway Bromont et Cowansville
Compagnie d'embouteillage Coca-Cola	iSM Line	Molson Coors	Ville de Boucherville
Croque ta Vie	Karine Cousineau Communications	Montreal Times	Volcano M�dia
Cycle N�ron	Kin�-Concept	Nissan Granby	West Jet
�cole des M�tiers de l'Horticulture de Montr�al	Krispy Kernel	Optik Athletik	
Fairmont Manoir Richelieu	LCC Vins & Spiritueux	R.M. H�bert	

## Activities organized by the Society's friends

Pratt & Whitney auction (Guy Beauchemin) | Bears of Legend concert (Charlotte B rard) | Dance with the Classics (Roger Boudreau) | Pointe-Claire Oldtimers Hockey Club (Alan Chaif) | Ice Bucket Challenge - Frank The Tank (Fran ois Contant) | Fondation Andr -Delambre Race (Jos e Delambre) | Camilien-Houde Challenge (Dominic Delambre) | Marie- laine Thibert concert (Joanne Dinarzo) | Car wash for Team Stock (Allison Dorval) | Car exposition (Yohan Dunn) | Book sale (Louise Dupont) | Les Soeurs de Saint-Joseph (Marie-Claire Dupont) | Used book sale (Marl ne Flamand) | Pub Azul (Natacha Gaudreault) | Family pic nic (Marcel Gosselin) | Workplace fundraiser - CUPE (Chantale Grenon-Nyenhuis) | Tupperware sale (Bonnie Guertin) | Bromont Ultra (Marc H bert & Gilles Poulin) | McGill University special evening (Kappa Kappa Gamma) | Dance and dinner (Micheline Lajeunesse) | Toronto marathon (David Lauzon) | Ice Bucket Challenge marathon (Martin Lauzon) | Forest Hill Elementary School - Jr. Campus for Team Stock (Lester B. Pearson School Board) | Westwood High School - Sr. Campus for Team Stock (Lester B. Pearson School Board) | Golf tournament (Serge Longtin) | Dek hockey tournament (Philippe Michaud) | Hockey tournament for Team Stock (Peter Miller) | Tony Proudfoot Ergathon (Brian Morin) | Conference on computer security (George- tienne No l) | Golf tournament (Montreal Commissioned Police Officers) | Poker tournament for Team Stock (Opticca Consulting) | Miniature models exhibition (Yvon Perron) | Volleyball tournament (Pratt family) | P tanque tournament (H l ne Renaud) | Spinning for Team Stock (Claudia Romero) | Walk for Alain Rose (Cindy Rose) | Ice Bucket Challenge - Camping St-Polycarpe (Luc & Carole Sabourin) | Ice Bucket Challenge - R tisserie Guay (Lise Samson) | Marymount Academy International (Yubiidsan Senathirajah) | Spaghetti dinner and bazaar (Service des Loisirs St-Elz ar de Laval) | Camp For A Cure (Justine Soles) | Andr  St-Yves bowling tournament (Nancy St-Yves) | Workplace fundraiser - Retirement home (Mario Thiboutot) | Brunch for ALS (Jean-Christophe Topalidis) | Patinothon (Florence Vachon) | St-Lazare Women's Softball league for Team Stock (Martha Wickware) | Pool tournament (Ron Williams) | Banque Scotia 21K and 5K de Montr al

## Special thanks to our volunteers

Allard, Simon | Ansari, Mojgan | Ante, Zharmaine | Aris, L on David | Arnosti, H l ne | Arnosti, Samuel | Arseneau, Ren  | Aub , Nancy | Audy, Huguette | Barakett, Victoria | Beaulieu, Jessica | Beaulieu, Maxime | Beaulieu, No mie | B land, Sabrina | Beljan, Morgan | B rard, Alain | B rard, No mie | Bergeron, Gis le | Bergeron, Marie-Claude | Bertrand, Genevi ve | B rub , Alexandra | Bilodeau, Marie-Claude | Bissonnette, Chantal | Boisjoli, Evren | Boissonneault, Dany | Boisvert, Jo lle | Boivin, Darina | Boivin, Jos e | Boivin, Julia | Boivin, Louise | Bonamit , Sabrina | Bouchard, Lucie | Boulianne, Fran ois | Boulianne, Julie | Bourgoin, Marc-Andr  | Bournival, Julie | Boutin, Carine | Brault, Louis | Brault, Philippe | Brault, Stephan | Breault, Guylaine | Brisson-Hovington, Jennyfer | Brizard, Claudette | Bussi res, Odette | Camirand, Marie-Pier | Carboneau, Lyne | Carey, Catherine | Castonguay,  milie | Chamandy-Cook, Eric | Charron, Lisa-Marie | Chartier, Caroline | Chartrand, Tina | Chouinard, Guylaine | Christof, Boriana Me | Cody Larocque, Roland | Contant, Carmel | Coulombe, Yany | Couture, Nadia | Crosswinds | Dalaire, Janine | Dampousse, Vincent | De Gagn , Jocelyne | de Serres, Karl | Delambre, Dominic | Delambre, Lorraine | Delambre, Nicolas- tienne | Demirjian, Vick | Desparts, Jul | Dewan, Simran | Di Iorio, Linda | Dinarzo, Joanne | Dinarzo, Nicolas | Donovan, Gary | Drouin, Elyse | Dufour, Ginette | Dulude, Fran ois | Dumoulin, Carole | Duranceau, Eve | Duchesneau, Myl ne | Fahey, Kaitlin | Firoozi, Faraz | Fortier, F lix | Fortier, St phane | Fortin, Line | Forzani, Cassandra | Francoeur, Jean-S bastien | Frigault, Diane | Gagn , Vincent | Gagnon, Guy | Garand, Genevi ve | Gaudreau, Marie-Soleil | Gaudreault, Natacha | Gauthier, Laurie | Gauthier, S bastien | Genge, Angela Dr. | Georgiopoulos, Kristina Vasiliki | Germain, Lucie | G vry, Michel | Gilbert, Sylvie | Gills, P l | Gosselin, Julie | Goyette, Sylvie | Grenier, Julie | Grenier, Lorraine | Grenier, Pierrette | Grenier, St phane | Grenon-Nyenhuis, Chantale | Griffin, Marc | Guidote, Julien | Guidote, Kiara | Hammill, Kevin | Hawey, Pierre | Hennelle, Marjorie | H roux, Gaston | Hidalgo, Camilla | Hidalgo, Monica | Hier, Caitlin | Ho-Tieng, Daniel | Hotte, Roger | Houde, Michel | Iorio, Olivia | Jacinto, Jos  | Jaros, Fran ois | Jean, Jovia | J euses de la Ligue en Jupon | Jutras, Catherine | Kambitakis, Maria | Knobble-Heath, Helga | La Roche, Fabrice | Laberge, C line | Labonville, Nathalie | Lacroix, Odette | Lacroix, Sylvie | Lafontaine, M lanie | Landry, Jean | Langis, Mathieu | Langlois, Martine | Lanthier, Chantal | Lapi re, Fernand | Lapointe, Pauline | Lavergne, Dominique | Lavigne, Fernand | Le Mesurier, Pierre | Leblanc, Simon | Leblanc, Nicole | Leclerc, Marie-Mich le | L gar , Jean-Pascal | L gar , Normand | L'Esp rance, Michel | Lessard, Daniel | Lessard, David | L vesque, Gino | Mailhot, Barbara | Mailhot, Pierrette | Mail , Monique | Malandruccolo, Daniel | Maltais, Louise | Marin, Joseph Roger | Martel,  milie | Masson, Carole | McKibbin, Steven | McKibbin, Vincent | Mercer, William | Mercier, Danielle | M thot, Claudette | Michaud, Diane | Michaud-Tremblay, Catherine | Minville, F lix | Moffat, Rick | Moreau, Andr  | Morel, Quentin | Morin, Jean-Paul | Morpeau, Val rie | Nait Abbou, Nada | No l, Georges- tienne | Nozzolillo, Jennifer | Nyenhuus, Christophe | Nyenhuus, Darren | Nyenhuus, Liam | Nyenhuus, Matthew | Nyenhuus, Nicolas-Olivier | Olivier, Carolanne | Paradis, Andr  | Paradis, Eric | Perrault, Guy | Pilette, Gilles | Plamondon, Lucie | Plamondon, St phanie | Poirier, Jeannine | Prince, Rita | Prince, Yves | Proulx, Carole | Proulx, Luc | Provost, Nathalie | Quentin,  ric | Quessy, Anabel Me | Quintal, Gilles | Racine, Dominique | Rafie, Anthony | Ragot, Philippe | R mond, Andr e | R mond, Marie-Claud | Rh aume, Florent | Richoz, Danielle | Robardet, Patrick | Robert, Sylvie | Robineault, Richard | Roy, S bastien | Ruel, Claude | Saillant-Boulinguez, Sarah | Sandor, Jeremy | Segreti, Cindy | S gu la, Maxime | Simard, Elyse | Simard, Michel | Simoneau, Mariette | Simoneau, Nancy | Slayd, Annakin | St-Amant, Odile | St-Fleur, Elsie | St-Laurent, Danielle | St-Onge, Lydia | Strasser, Thomas | Talbot, Val rie | Tessier, Joanne | Tessier, Nancy | Th or t, Maya | Tkalec, Diane | Tremblay, Claudette | Tremblay, Isabelle | Tremblay, Jos e | Tremblay, Monique | Tr panier, Sophie | Vachon, Edith | Valiquette, Louise | Veriepe, Julie | V zina, Louis | Vignola, Lyne | Vilandr , Christiane | Vilandr , Luc | Watter, Marie- ve M. | Weiner, St phanie | Whissel, Jean | Willits, Rafael

# Pushing the Field of ALS Research Forward

*"Thanks to the Arthur J. Hudson Translational Team Grant, three research laboratories from two Quebec universities (Laval and McGill) will work together towards the discovery of biomarkers associated with the progression of ALS and towards the comprehension of therapeutic effect of a new compound extracted from a medicinal plant which targets a neuroinflammatory path. We hope that this translational research project will contribute to a deeper understanding of the disease and will enable us to develop effective treatments for people living with ALS."*

- Jean-Pierre Julien, Ph. D, Professor, Department of Medicine (Psychiatry and Neurology), Université Laval, and a recipient of ALS Canada-Brain Canada Arthur J. Hudson Translational Team Grant

## You are paving the way to make ALS treatable, not terminal.

Everyday we push forward on efforts to elevate the ALS Canada Research Program; investing in the best science that offers the most promise to slow down ALS or even stop it. Research is the only pathway to change the course of ALS. With your continued support, you are helping make ALS treatable, not terminal.

In 2015, because of your generosity coupled with our partnership with Brain Canada, we were able to invest \$15 million in ALS research across Canada. These dollars funded 56 investigators at 15 universities across the country, all of whom are working to uncover such answers as to how can we diagnose ALS earlier; what role do various proteins play to improve treatment options for people living with ALS; and ultimately how can we slow or stop the progression of ALS.

Your donations helped leverage collaborative partnerships amongst the best in the field. The ALS Canada – Brain Canada Arthur J. Hudson Translational Team Grant representing the single, largest ALS research competition in Canadian history, awarded teams of researchers across multiple academic institutions over \$10 million in funding. Also, for the first time, we invested in a research grant aimed at helping manage the symptoms of the disease and improve the lives of Canadians with ALS.

The future of research for ALS is promising. Thank you for your support over the past year and your continued commitment to the ALS Canada Research Program.

## The ALS Canada Research Program by Numbers

- 34 projects funded representing 56 investigators at 15 universities in seven provinces
- First time research carries over to client care with the launch of the new Clinical Management Research Grant
- Launched four unique ALS Canada Research Program monthly webinars
- The 2015 ALS Canada Research Forum broke records with the highest attendance in the history of its 11 years
- \$15 million invested in ALS research across Canada



Dr Angela Genge



Dr Pierre Drapeau



Dr Jasna Kriz



Dr Jean-Pierre Julien



Dr Nicolas Dupré

## Unraveling ALS: TDP-43 and C9ORF72

This year saw promising new leads in understanding the normal functions of arguably the two most important ALS proteins: TAR DNA-binding protein 43 (TDP-43) and C9ORF72. Determining how these normal functions are disrupted in ALS is something that has been sought after for years and has resulted in new lines of potential therapy that will now be tested in laboratory models of the disease with hopes of future effect in humans.

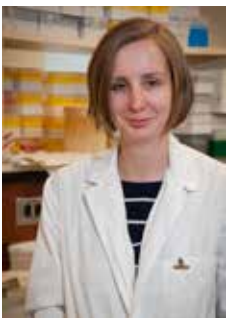
## International Collaboration

In 2015, more genetic causes of ALS were discovered, including TANK binding kinase 1, an intriguing new target that will inevitably help in our understanding of how ALS is caused. Its identification was the result of a multi-national collaboration that provided collective data sufficient to declare it as a bona-fide ALS gene. More and more of these consortia are taking advantage of shared resources and knowledge to work together on solving problems that can't be tackled alone. As our networks expand, our chances of breakthroughs in ALS grow.

## About ALS Canada Research Program

The ALS Canada Research Program aims to accelerate research impact through a comprehensive national program focused on translating scientific discoveries into treatments for ALS and fostering Canada's strong and networked ALS research community to maximize capacity and collaboration. Support for the ALS Canada Research Program is made possible by the generosity of donors and the ALS Societies across Canada.

**To learn more about the ALS Canada Research Program, please visit [als.ca](http://als.ca) and [als-quebec.ca](http://als-quebec.ca)**

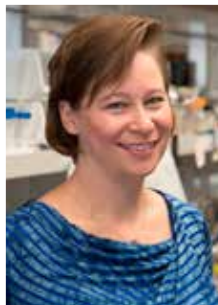


## The Tony Proudfoot Training Fellowship

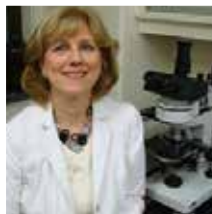
The Tony Proudfoot Training Fellowship in ALS research at the Montreal Neurological Institute and Hospital supports promising young scientists at the master's, doctoral and post-doctoral level who wish to undertake research projects that specifically focus on ALS. This year, the winner of the Tony Proudfoot Fellowship is Dr. Audrey Dangoumau. Audrey recently completed her PhD thesis under the supervision of Pr. Patrick Vourc'h at the University of Tours, in France. Her PhD research revealed the importance of SUMOylation in the formation of aggregates with SOD1 mutation. Currently a postdoctoral fellow under the supervision of Dr. Guy Rouleau at the MNI, Audrey will work on elucidating the death process in motor neurons.



Dr Guy Rouleau



Dr Christine Vande Velde



Dr Heather Durham



Dr Richard Robitaille



Dr Geneviève Matte



Dr Alex Parker

# ALS Canada Research Program National Research Investments

## ALS CANADA – BRAIN CANADA ARTHUR J. HUDSON

### Team Julien

Preclinical and clinical studies with withanolides: therapeutic effects, molecular signatures and biomarkers  
\$2.5 million over 3 years

### Team Kalra

Novel MRI biomarkers for monitoring disease progression in ALS  
\$2.9 million over 5 years

### Team Kong

Selective knockdown of misfolded SOD1 as a therapy for amyotrophic lateral sclerosis  
\$1.6 million over 5 years

### Team Korngut

A randomized controlled trial of pimozone in subjects with ALS  
\$500,000 over 3 years

### Team St George-Hyslop

Discovery of therapeutic targets for FUS-dependent forms of ALS  
\$1.4 million over 5 years

### Team Vande Velde

Regulation of the stress granule proteome and transcriptome by TDP-43 in ALS: biomarkers and therapeutic targets  
\$1.7 million over 5 years

## ALS CANADA – BRAIN CANADA DISCOVERY GRANTS

### Dr François Berthod

Université Laval  
Study of the impact of glycation on ALS using an in vitro tissue-engineered model of spinal cord  
\$100,000 over 2 years

### Dr Martin Duennwald

Western University  
RGNEF modulates protein misfolding in ALS  
\$100,000 over 2 years

### Dr Heather Durham

McGill University  
Epigenetic mechanisms underlying dendritic atrophy in ALS  
\$100,000 over 2 years

### Dr Charles Krieger

Simon Fraser University  
Use of bone marrow cells to deliver single chain antibodies in ALS  
\$100,000 for 1 year

### Dr Blair Leavitt

University of British Columbia  
Muscle-targeted therapy for ALS  
\$100,000 for 1 year

### Dr Peter McPherson

McGill University  
Regulation of endosomal membrane trafficking by C9ORF72 in ALS  
\$100,000 for 1 year

### Dr Pier Jr Morin

Université de Moncton  
Identification of circulating non-coding RNAs with diagnostic relevance to ALS patients using a unique extracellular vesicle capture method  
\$100,000 over 2 years

### Dr Alex Parker

Université de Montréal  
Investigation of the innate immune system and motor neuron degeneration in genetic models of ALS  
\$100,000 over 2 years

### Dr Janice Robertson

University of Toronto  
Characterizing the C9ORF72 protein interactome for identifying novel pathogenic pathways in ALS  
\$100,000 over 2 years

### Dr Fabio Rossi

University of British Columbia  
The role of peripheral inflammation in ALS: an exploratory study  
\$100,000 over 2 years

### Dr Amir Sanati Nezhad

University of Calgary  
Novel microfluidic platform for investigating axonal sprouting in motor neurons  
\$100,000 over 2 years

### Dr Christine Vande Velde

Université de Montréal  
Misfolded SOD1 species in ALS pathogenesis  
\$100,000 over 2 years

### Dr Melanie Woodin

University of Toronto  
Synaptic inhibition in the motor cortex of an ALS mouse model  
\$100,000 over 2 years

## ALS CANADA BRIDGE GRANTS – 2 YEARS

### Dr Neil Cashman

University of British Columbia  
Molecular interactions between TDP-43 and misfolded wild-type SOD1: implications for sporadic amyotrophic lateral sclerosis  
\$200,000 over 2 years

### Dr Avi Chakrabarty

University of Toronto  
Role of TDP-43 in regulation of stress granules in ALS: biomarkers and therapeutic agents  
\$200,000 over 2 years

### Dr Jasna Kriz

Université Laval  
Glia-neuron crosstalk in early amyotrophic lateral sclerosis  
\$200,000 over 2 years

### Dr Victor Rafuse

Dalhousie University  
Characterization of the mechanisms underlying exercise induced strengthening of the neuromuscular junction  
\$200,000 over 2 years

## ALS CANADA – BRAIN CANADA CAREER TRANSITION AWARDS

### Dr Gary Armstrong

(supervisor: Dr Pierre Drapeau)  
Université de Montréal  
Mechanisms of glutamatergic neuronal dysfunction in genetic models of ALS  
\$425,000 over 5 years

### Dr Chantelle Sephton

(mentor: Dr Jean-Pierre Julien)  
Université Laval  
Mechanisms of synaptic dysfunction in amyotrophic lateral sclerosis  
\$315,000 over 3 years

## FELLOWSHIPS 1-3 YEARS

### Dr Marvin Chum

(supervisors: Dr Teneille Gofton, Dr Christen Shoesmith)  
Western University/London  
Health Sciences Centre  
Palliative care and respiratory support of patients with ALS  
\$200,000 over 2 years (clinical research)

### Dr Jacquelyn Cragg

(supervisors: Dr Neil Cashman, Dr Marc Weisskopf)  
University of British Columbia  
Etiology and progression of amyotrophic lateral sclerosis: the role of military service, trauma, and prescription drug use  
\$165,000 over 3 years

### Dr Matteo Da Ros

(supervisor: Dr Derrick Gibbings)  
University of Ottawa  
Unbiased determination of pathways affected by ALS-linked stress granules and their elimination by autophagy  
\$165,000 over 3 years

## ALS CANADA BRIDGE GRANTS – 1 YEAR

### McGill University

Dendritic attrition in amyotrophic lateral sclerosis  
\$100,000 for 1 year

### Dr Peter McPherson

McGill University  
Endosomal membrane trafficking in neurodegenerative disease  
\$100,000 for 1 year

### Dr Christopher Pearson

University of Toronto  
Unusual nucleic acid structures in C9ORF72-related ALS/FTD repeat instability  
\$100,000 for 1 year

### Dr Chantelle Sephton

Université Laval  
Effects of amyotrophic lateral sclerosis-linked FUS mutations on synaptic function  
\$100,000 for 1 year

## DOCTORAL RESEARCH AWARD – 3 YEAR

### Éric Martineau

(supervisor: Dr Richard Robitaille)  
Université de Montréal  
Targeting the regenerative function of glial cells at the neuromuscular junction in amyotrophic lateral sclerosis  
\$75,000 over 3 years

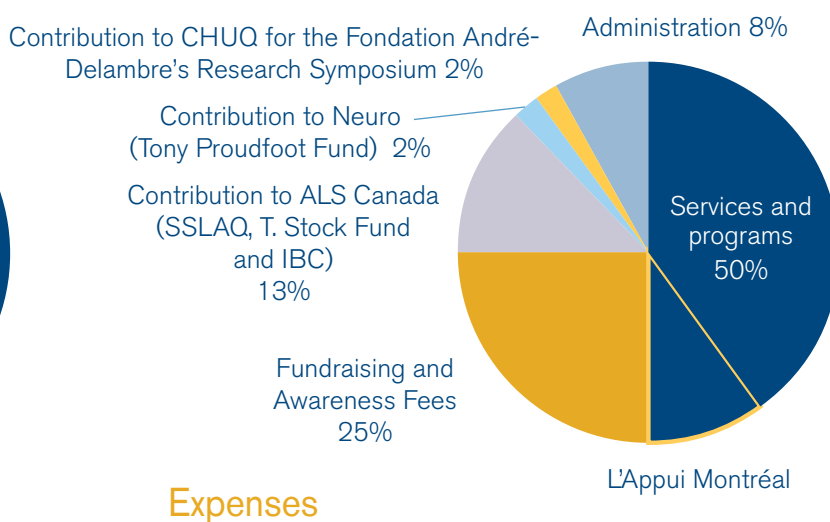
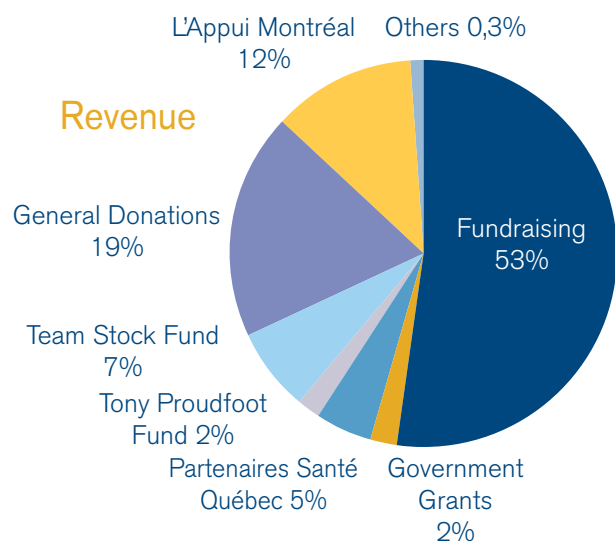
### Maneka Chitiprolu

(supervisor: Dr Derrick Gibbings)  
University of Ottawa  
Mechanisms eliminating stress granules by autophagy  
\$75,000 over 3 years

# Financial summary Financial year from November 1<sup>st</sup> 2014 to October 31<sup>th</sup> 2015

REVENUE	2014-2015	2013-2014 (sans IBC)	2013-2014 (IBC)	2013-2014 Total
Fundraising	\$ 745 291	\$ 682 030	-	\$ 682 030
Ice Bucket Challenge (IBC)	-	-	\$ 2 660 950	\$ 2 660 950
Government Grants	\$ 25 407	\$ 26 086	-	\$ 26 086
Partenaires Santé Québec and Santé Canada	\$ 74 652	\$ 76 307	-	\$ 76 307
Tony Proudfoot Fund	\$ 25 572	\$ 44 885	-	\$ 44 885
Team Stock Fund	\$ 102 961	-	-	-
General Donations	\$ 267 172	\$ 159 989	-	\$ 159 989
Wills and Bequests	-	\$ 26 741	-	\$ 26 741
L'Appui Montréal	\$ 169 865	\$ 103 178	-	\$ 103 178
Others	\$ 3 839	4 614	-	\$ 4 614
<b>Total</b>	<b>\$ 1 414 759</b>	<b>\$ 1 123 830</b>	<b>\$ 2 660 950</b>	<b>\$ 3 784 780</b>

EXPENSES	2014-2015	2013-2014 (sans IBC)	2013-2014 (IBC)	2013-2014 Total
Administration	\$ 122 909	\$ 99 611		\$ 99 611
Services and programs	\$ 651 173	\$ 596 924		\$ 596 924
L'Appui Montréal	\$ 168 654	\$ 103 178		\$ 103 178
Fundraising and Awareness Direct Fees	\$ 179 091	\$ 90 365		\$ 90 365
Fundraising and Awareness Indirect Fees	\$ 227 140	\$ 238 887		\$ 238 887
Ice Bucket Challenge Direct Fees		-	\$ 192 150	\$ 192 150
Research Contribution	\$ 261 434	\$ 170 628	\$ 1 727 427	\$ 1 898 055
Contribution to ALS Canada - Walk & activities	\$ 178 299	\$ 113 948		\$ 113 948
Contribution to ALS Canada - IBC	\$ 25 939	-	\$ 1 727 427	\$ 113 948
Contribution to Neuro (Tony Proudfoot Fund)	\$ 26 760	\$ 19 422	-	\$ 19 422
Contribution to CHUQ for the Fondation André-Delambre's Research Symposium	\$ 30 436	\$ 37 258	-	\$ 37 258
<b>Total</b>	<b>\$ 1 610 401</b>	<b>\$ 1 299 593</b>	<b>\$ 1 919 577</b>	<b>\$ 3 219 170</b>
Excess (deficiency) of revenue over expenses	(\$ 195 642)	(\$ 175 763)	\$ 741 373	\$ 565 601



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



# 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](mailto:info@sla-quebec.ca) [www.sla-quebec.ca](http://www.sla-quebec.ca)

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