



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC
LOU GEHRIG'S DISEASE

ANNUAL REPORT 2013

What is ALS?

ALS takes...

- Your arms.
- Your voice.
- Your legs.
- Your life.

Amyotrophic Lateral Sclerosis (ALS) is a fatal and rapidly progressing neuromuscular illness. It destroys the neurons of the motor muscles, gradually leading to the total paralysis of the body while leaving mental faculties untouched. Every day, two to three Canadians die of ALS. Every year, more people die from ALS than multiple sclerosis, cystic fibrosis and muscular dystrophy combined. There is currently no known cause or cure for the disease.

THE ALS SOCIETY OF QUEBEC

Mission

Our mission is:

- to provide support and referrals for people living with ALS and their loved ones;
- to raise funds for research and to ensure the maintenance and development of our services and programs;
- to raise awareness of this disease.

Values

Respect

We treat each individual as a person in their own right. We respect their rights and abilities and we avoid causing any harm.

Compassion

We help those in need.

Dedication

We offer services fairly and equitably without expecting anything in return on the personal level.

Accountability and transparency

We take responsibility for our decisions and actions and we exercise high levels of diligence and transparency in our commitments. We work toward the continuous improvement of the Society.

Passion

It is with enthusiasm and sensibility that we make efforts to improve the quality of life of people affected by ALS.

Quality of life

We work toward offering high quality support and services to every person with ALS in Quebec.

Message from the President of the Board and Executive Director

Together we achieve so much

The year 2012-2013 was very successful and we are extremely proud. Whether we are talking about our broad range of services, our contribution towards cutting-edge research or progress made in fundraising and awareness, we are very privileged to share these successes achieved through outstanding teamwork.

In Canada, over 3,000 people including 600 in Quebec are living with ALS. About 250 Quebecers lose their fight each year: it is more deaths than multiple sclerosis, cystic fibrosis and muscular dystrophy combined. When we think of people with ALS, words such as strength, determination, resilience, dignity and inspiration come to mind. They are an incredible source of motivation for us all.

The growth of our fundraising activities is very gratifying and indicates that our efforts to raise awareness are being heard and heeded. By giving their time to the Society, our volunteer event chairpersons, our donors and partners are offering hope to many.

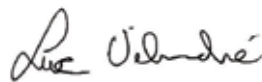
Our supporters also enable us to fund programs and services as well as key research. Canada's world-renowned scientists are leading efforts to develop treatments and to find a cure. Every donation, whether it is a small or a large amount or even your time, helps us improve our services to members and their families, and brings us closer to life-changing discoveries.

Looking forward, we are convinced we are on the precipice of even greater success. By pooling our shared passion, talents and energy we will not only fulfill our mission but we will also move closer to realizing our vision of a world without ALS.

Thank you so much to everyone. Please know YOU are the difference and have a direct impact on the lives of people with ALS.



Claudine Cook
Executive Director
ALS Society of Quebec



Luc Vilandr 
President of the Board
Vice-President, TELUS Health Solutions

Our Board members get involved on every level.
From left to right:
Daniel Malandrucolo,
Guylaine Breault,
Caroline Chartier,
Dominic Delambre,
Diane Tkalec, Claudine Cook,
Kim Holden, Luc Vilandr .
Front: Alain B rard.
Missing: Genevi ve Bertrand,
Boriana Christov,
Angela Genge,
Chantal Lanthier



Board of Directors (2012-2013)

Executive Committee

Luc Vilandr 
President
Vice-President, TELUS Health Solutions

Daniel Malandrucolo
Vice-President
Vice-President, Vast-Auto Distribution Lt e and Groupe MMO Inc.

Dominic Delambre
Secretary-treasurer
Partner, B lisle, Beaudry, Delambre, Gagnon, CA

Administrators

Alain B rard
Manager, Lanxess Inc
Person living with ALS

Genevi ve Bertrand
Managing Director,
Accenture, Montr al

Guylaine Breault
Partner, SPATIUM

Caroline Chartier
Manager, Rolls-Royce Canada

Me Boriana Christov
Lawyer, BCF Business Law

Dr Angela Genge
Neurologist

Kim Holden
Financial Consultant

Chantal Lanthier
Canada Correctional Services
Person living with ALS

Diane Tkalec
Consultant, PERFORM Centre and Pfizer Canada
Former caregiver

Marc and Elyse's journey

ALS Society of Quebec offers invaluable support

The progression of amyotrophic lateral sclerosis (ALS) is as rapid as it is unforgiving. It demands the person living with ALS and the caregiver constantly adapt to rapidly changing conditions. So it was for Marc Lavigne, his caregiver and wife Elyse Léveillé and the couple's two adult children. Marc was diagnosed with ALS in February 2010. He and Elyse first reached out to the ALS Society of Quebec through the internet. Soon, they were participating in different Society conferences that helped prepare them for different facets of their coming journey.



As the illness progressed and Marc was no longer able to walk or use his hands and arms, Elyse was able to borrow specialized mobility equipment with the ALS Society's Technical Aid program. She also received financial assistance from the Society to deal with the cost of adapting the family's home for reduced-mobility living and to hire assistants who offer caregivers much-needed respite. Caring for someone with ALS, especially in the later stages of the illness, is a fulltime job. "It's more work than caring for a baby," says Elyse. "When a baby sleeps, you can rest. But with ALS there's the fear of respiratory or other distress even during sleep. There's no letup. The patient requires constant care".

Elyse, who had to leave her teaching job for a year-and-a-half to stay at home with Marc, says as difficult as the situation became, it would have been far more so without the help of the ALS Society of Quebec. "What you do as a primary caregiver, you do with love", says Elyse. "But it's a heavy burden. You run out of energy," she adds.

The assistance Elyse got from the ALS Society of Quebec was more than just financial and material. She also found an extended support network through the Society's ALS Chums Facebook page, where she connected with ALS patients and their caregivers and families.

Marc died this past July. He was only 50.

Elyse has returned to her teaching job in Ste-Julie, on Montreal's south shore and hopes to continue reaching out to help others struggling with ALS.

Our Services

Information for people with ALS, caregivers and healthcare professionals

- Conferences ✓
- Newsletters ✓
- Documentation ✓
- Resources ✓

Emotional support

- Orientation and reference ✓
- Toll-free support line ✓
- Workshops ✓
- Support groups ✓

Social and networking activities

- Regional information sessions ✓
- Social activities ✓

Technical Aid and Financial Assistance

- Residential Adaptation Program ✓
- Equipment Assistance ✓
- Financial Contribution ✓

“Life is beautiful”

ALS slows but doesn't stop Maurice

Maurice Leclerc considers himself 'lucky'. The 84-year old has five children and four grandchildren and numerous close friends. He was married for 25 years to the 'loveliest person' he's ever met. He loved his job so much he worked till age 77.

A year into retirement, Maurice was diagnosed with amyotrophic lateral sclerosis(ALS). The deadly disease is robbing Maurice of mobility. To get around and maintain his balance, he leans heavily on grab bars and walls. His wheelchair breaks his imprisonment granting him the freedom to visit with friends and family.

The disease is slowing him down, but it hasn't stopped him. Not by a long shot.

Maurice is a regular at the Society's monthly Interactive Group Meetings when health professionals provide information and coping tips or those living with ALS talk about their struggles. He is also speaks six or eight times a year at ALS events. He describes his journey with the disease to donors and the newly diagnosed.

The gift of sleep

One thing Maurice struggles with is sleeplessness. Like many living with ALS, Maurice endures tremendous pains in his legs and arms due to muscle cramps. On nights when the pain is unbearable, Maurice makes his way to his reclining rocking chair and finds relief and an extra hour or two of sleep. The Society loaned the recliner to Maurice through its Technical Aid Program which gives those living with ALS access to free equipment that improves their quality of life but is not provided free under the provincial health-care system.

“I have tremendous appreciation for the Society and its staff. When I call they listen. They help me make decisions. It is a form of therapy,” he says. “I have never been told: ‘Sorry, there is nothing we can do for you.’ Even if my problem is complicated, they find the answer or suggest a solution.”

Despite, everything Maurice says, “Life is beautiful. I've been lucky enough to cope with this disease for six years. God is helping me. And with the support of the ALS Society of Quebec, I am winning.”



Key Highlights

More than 1,500 clients served (people with ALS, caregivers, health care professionals)

290 accepted requests for Technical and Financial Aid Programs

More than 25 thematic conferences

Introduction of discussion forums for network professions in partnership with the Island of Montreal ALS Committee

Partnership with the Institut de Planification des Soins for a serie of videoconference on advanced care planning, advanced medical directives and the rights of people experiencing loss of autonomy

Regions visited (information day or social activity): National Capital, Eastern Townships, Lanaudière, Laurentians, Laval, Montérégie, Outaouais, Saguenay

Support groups in the West Island for caregivers in partnership with NOVA West Island

Regular presence of Society's counsellors at the Neuro's and St-Jerome Hospital's ALS clinics

Participation to a working committee on Technologies and ALS

805 participants to conferences and support groups

Events and Awareness

“The spark that will lead us to the cure” - André Delambre



If Dominic Delambre has been involved wholeheartedly in the fight against Amyotrophic Lateral Sclerosis for the past 10 years, it is especially for his father, André Delambre who passed away from ALS in 2006. Dominic refuses to stand idly by this disease which affects about 600 Quebecers at any given time. Secretary-treasurer at the Fondation André-Delambre and at the ALS Society of Quebec as well as co-chair of the benefit-event Ride for ALS with Luc Vilandré, Dominic seizes every opportunity to contribute to the cause, both in the boardroom and in the field.

“Ten years ago in the province of Quebec, this orphan-disease was completely unknown not only to the public but also to many health professionals. Today, I am deeply convinced that the situation has changed and that ALS is better known to the population.” ▶



Participants of the Walk for ALS in Sherbrooke.



Odette Lacroix, coordinator for the Quebec City Walk for ALS with Capi, the mascot for the Quebec's Capitales team.



Patrice Roy and Celine Galipeau, news anchors from Radio-Canada at the Walk for ALS in Montreal.



The second edition of the Walk for ALS in Baie-Comeau was a great success! Many fundraising activities were organized in profit of the Walk.



Members accompanied by their caregiver went apple picking near Mont St. Grégoire.



Alouettes players supported the Tony Proudfoot Fund at the Walk for ALS in Montreal.



Volunteers for the Walk for ALS in Quebec City at work.



Participants of the 4th edition of the Ride for ALS Edition. Among them are actresses Christine Beaulieu, Eve Duranceau and Suzanne Bolduc.



Sugar Shack outings are popular social activities among our members.

◀ Saying that Dominic's efforts are achieving results would be an understatement. For the last six years, the Ride for ALS has contributed \$926,000 towards the cause. "Riding to fight ALS is as enjoyable as it is useful! On top of gathering funds for the cause, I have the pleasure of participating in its organization, as well as riding for three days." There is no doubt that Dominic is proud to contribute to the cause.

"Getting involved in the fight against ALS is simply my contribution to society, but it is also because I firmly believe that one day we will find a solution to this disease. In the meantime, if we can help people with ALS and their families, we will have taken a big step forward..."



113 fearless cyclists faced Mauricie's hilly slopes during the 6th Ride for ALS.



Vincent Damphousse greatly contributed to our cause by chairing a benefit golf tournament for six years and raising a cumulative total of a million dollars.



Many families got together at the Walk for ALS in Montreal.



Isabelle Tremblay, Nascar racer along with Chima Ihekwoaba and Ameet Pall from the Montreal Alouettes at the 4th edition of Spinning for ALS.



We can count on a fantastic team of volunteers and cycling guides to ensure logistics and safety at the Ride for ALS.



Chantal Lanthier organized a benefit brunch which was highly successful. From left to right: Véronique Pignatelli, Yves Lafleur, Chantal Lanthier and Dr. Marie-Josée Langlois.



In July, Lise Laurence and her family conquered the Kilimanjaro after raising funds in memory of their friend Marc Lavigne.



René Petit held three 5-km benefit-races in 2013.



Charlotte Saint-Hilaire, Julie Renald and Frédéric Chauvin all ran the full 15 km of the Super Spartan Race after raising funds for the cause.



Glenn Pratt organized a benefit volleyball tournament in honour of his friend Patrick Scully.



THANK YOU, VINCENT!

Over the last eight years, Vincent Damphousse has been closely associated with the ALS Society of Quebec. As an ambassador and a well known sports personality in the world of hockey, one more time Vincent has scored a hat trick.

For the past few years, the golf tournaments chaired by Vincent in collaboration with Clublink as well as his Poker tournament raised more than \$1M, with the generous support of the Tenaquip Foundation and the Reed Family. By gathering leaders from the business and sports sector, Vincent contributed to raising awareness to this unknown disease. With these funds we have scored a victory in fulfilling our mission.

On behalf of the Board of Directors, persons affected by ALS, their caregivers, their families and friends, a special thanks to Vincent for having dedicated his time and energy to our cause.

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

Estate of the Late Sheila Lyons

Fondation Sibylla Hesse

Health Partners Canada

Intact Assurances

Partenaires Santé - Québec

Power Corporation

The Tenaquip Foundation

Travelway International

W.L Activewear

Telus Health Solutions

Fondation André-Delambre

Tony Proudfoot Fund

Major donors and third party events - \$ 500 +

Dance with the Classics
(Mr. And Mrs. Larry Ayotte)
Tournoi de golf (Lucille Bibeau)
Vente de bracelets (Élodie Boudreau)
Souper spaghetti (Carole Bordeleau)
Spectacle de danse orientale
(Diane Desrosiers)
Tournoi de Hockey (Dane Gilmour)
Course Petit 5km (René Petit)
Volleyball Tournament (Glenn Pratt)
98,5FM
Agropur
Alouettes de Montréal
Andritz Ltd.
Association des Policières et Policiers
Provinciaux du Qc
Association of Catholic Retired Adm.
Au Vieux Duluth Restaurants Inc.
Joel Aubin
Karen Aziz
Bar Onyx
Barbe, Corbeil, Seigny
Comptables Agréés inc
Madeleine B. Beaudet
Pierre Belle
BENCH.
Louise Boivin
Roberto Bomba
Carlo Bonamigo
Bonneterie Richelieu (Intl) inc
Carlos Botelho
François Breton
Michel Brutti
Robin Burns
Canadian Tire - Ste-Jérôme
Caisse de bienfaisance des employés
et retraités du CN
Caisse populaire Desjardins de Lévis
Les Capitales de Québec
Régis Caron
Centre d'Auto Outaouais D.C. inc
Chagall Design
Lise Charron
Andy Chelminski
Chenail Fruits et Légumes
Pierre Chevalier
Robert Chevrier
Marco Chouinard
Cie de pierre Arco (1980) Ltée
CIOT Montreal inc.
CJAD
Clinique Access Med inc
Club Lions Clermont-La Malbaie

Clublink
CM Displays & Events Inc.
Coca Cola
Conseil Général CSQ
Construction St.-Maxim Inc.
Corlab
CTV
Lisa et Fady Debbane
Jean-François d'Entrmont
Desjardins Sécurité Financière
Stephen DiTommaso
Laur-Ann Doiron
Maurice Doucet
René Doucet
Roger Dupuis
Heather Durham
Eric Duteau
Luc Duval
Michelle Elizov
Fidélité Investments
Marc-André Filion
Fondation Laure-Gaudreault
Bombardier Aéronautique
Line Fortin Photographe
Ginette Fournier
Linda Garant
Maryse Gaudreault
Natacha Gaudreault
Yvon Gauvreau
GDG Informatique et Gestion Inc.
Genfoot Inc.
Gestion Eric Ehouarne
GFG-Camint inc
Nathalie Girouard
Karine Gosselin
Great-West Life Assurance Company
Pier-Yves Grenier
GROUPE MMO INC.
Groupe Permacon
H Grégoire
Guillaume Hardy
Pierre Hawey
Meredith Hayes
Jocelyne How
IBM Canada Ltée
Ing Direct
JBMM Entreprises
Bobby et Joanne Julien
Samantha Juraschka
Stephen Kaufman
Fahd El-khoury

Gene Kim
Krispy Kernels
Jean-Claude Kirouac
Kwitko Family Foundation
François Labelle
Mercedes Alcroix
Réjean Lalumière
Lanxess Corporation
LCC Clos des Vignes
Le Fitness Loft inc
Le Marché des Oiseaux Inc
Les courses Tempus Fugit
Les Vannes Dynamique (Canada) inc
Michel Lesage Inc.
Pierre-Paul Letellier
Anne Létourneau
L'Industrielle- Alliance
Denis Long
Loto-Québec
Frances Lowe
Luxtec
Marché au Chalet (1978) Inc.
Marché D'Alimentation Beck inc
Marché Robert Tellier (1990) Inc.
Marché Tellier Beaubien Inc.
Diane Marin
McMahon Distributeur Pharmaceutique Inc.
Philippe Michaud
Robert Miron
Cathy Monticciolo
Guiseppe Monticciolo
Jean-Claude Montpellier
Alexandre Moreau
Rick Morgan
MVP Restaurant & Bar
Dang Khoa Nguyen
Gilbert Normand
Victor J. Pamensky
Patrouille de ski Mont Grand Fonds
Bernard Pepin
Pepsico/Frito Lay Canada
Joel Perrault
Roberto Pietrovito
Placements CI
Pointe-Claire Oldtimers Hockey club
Raymond Poitras
James Popp
Josee Portugais
Gilles Poulin
Lucie Prévost
Proceria Consulting Inc.

Janet Proudfoot
Imran Qureshi
Radio-Canada
RDS
Peter Reed
Paul Regimbal
Restaurant Grec Baie-Jolie
Resto la Banquise
Rotary Club du Vieux-Montréal
Royal Canadian Legion,
Filiale Pointe Claire - Branch #57
Prochat Salas
Services Financiers I.T.A.
Sleeman
Mike Shannon
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Société des alcools du Québec
SOLAREH
St-Edmund PPO/Home&School Ass.
Marie St-Jacques
Nicole St-Pierre
Supermarché Don Quichotte inc
Supermarchés Jacques Daigle inc,
Magasin #8033
Claude Tessier
The Gazette
Alexandrine Thériault
Diane Tkalec
Sabine Trahan
Cindy Tremblay
Yves Tremblay
Truck 'N Roll
Deborah Trudeau
United Way - Centraide Ottawa
United Way of Greater Toronto
Vast-Auto Distribution Ltée
Jean-Pierre Veilleux
Louis Vézina
Vigilance Santé
Luc Vilandré
Josée Vilandré
Ville de Contrecoeur
Ville de Québec
Ville de Saint-Lambert
Éric Vincent
VMsys Informatique Inc.
Eric Williams
William Yocum
Erminio Zappitelli
Zed Graphic Communications

We are thankful towards all of our donors regardless of their contribution. Every donation counts.

Researchers making enormous strides forward

Promising discoveries will open door to new therapies

Research aimed at understanding amyotrophic lateral sclerosis (ALS) has made exceptional strides forward in the past 10 years. Researchers are gaining a better understanding of ALS with Canadian scientists credited with many discoveries and some of the world's top peer-reviewed ALS research.

Major genetic breakthroughs

Advances in genetic research have led to exciting breakthroughs with the identification of numerous additional new genes associated with ALS. "We are getting closer to understanding how the disease occurs which should translate into promising therapies in the foreseeable future that will delay the progression of symptoms," says Dr. David Taylor, Director of Research for the ALS Society of Canada.

Dr. Taylor wishes there was better news about the immediate future of drugs for the 3000 Canadians living with ALS. Those living with the fatal neurodegenerative disease become progressively paralyzed due to degeneration of the upper and lower motor neurons in the brain and spinal cord. Eighty per cent of people with ALS die within two to five years of diagnosis – unable to breathe or swallow. Ten per cent of those affected may live for 10 years or longer.

More clinical trials than ever

Until a cure for a disease is found, it is necessary to continue to search for better, safer, and faster acting treatments. Clinical trials are one way to test these treatments using human volunteers to study the safety and effectiveness in changing the course of health outcomes.

Dr. Taylor notes there are many promising clinical trials currently being tested in Canada and internationally, and he doesn't negate the chance of a serendipitous discovery that will have a major impact on the disease. He also notes that many clinical trials are at Phase II when clinicians will start to find out if they may slow the progression of the disease.

Helping researchers find tomorrow's treatments and cures

Your donations make research possible. In the past year the ALS Society of Quebec contributed \$252 258 to ALS research. Across Canada, a total of \$1.6-million in donations was used to support Canadian scientists as they unravel the mysteries of ALS.



Dr Angela Genge



Dr Guy Rouleau



Dr Jasna Kriz



Dr Jean-Pierre Julien



Dr Nicolas Dupr e



Dr Fran ois Gros-Louis



Dr Christine Vande Velde



Dr Heather Durham

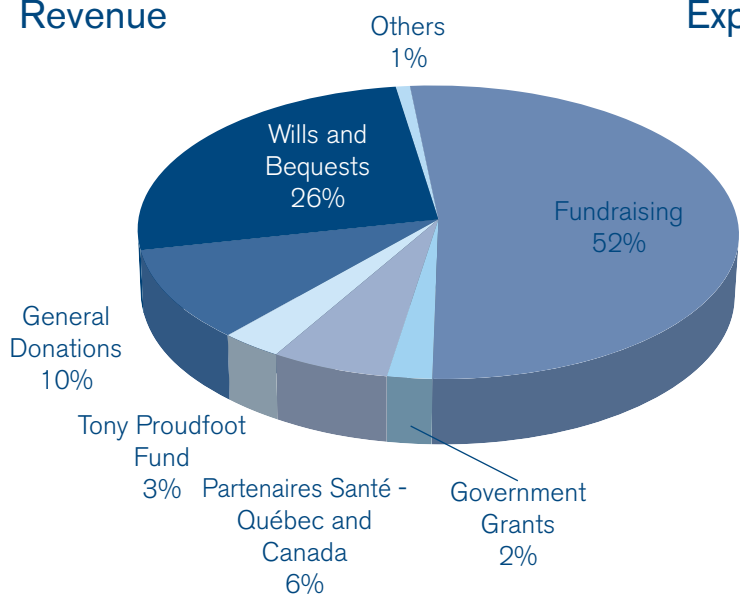
To learn more about the researchers in Quebec looking for treatments and cures for ALS go our new website www.sla-quebec.ca

Result Summary

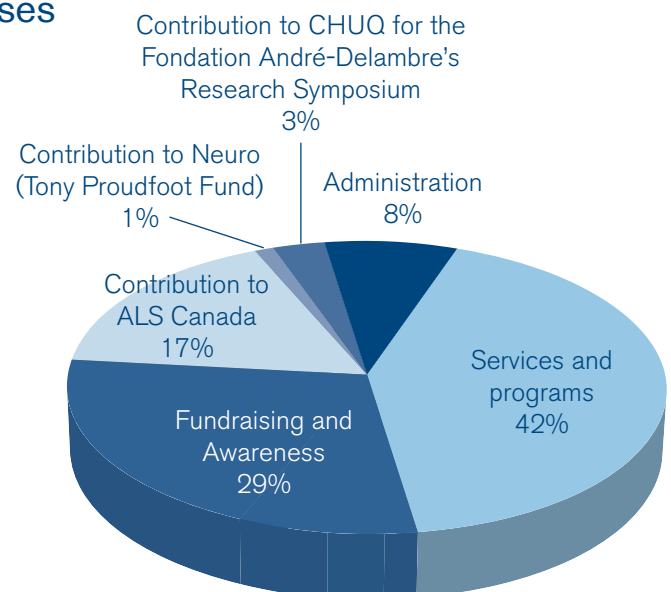
REVENUE	2012-2013 (12 MONTHS)		2011-2012 (12 MONTHS)	
Fundraising	\$ 701 664	52,4%	\$ 663 911	71,2%
Government Grants	\$ 24 625	1,8%	\$ 80 998	8,7%
Partenaires Santé - Québec and Canada	\$ 85 720	6,4%	\$ 78 603	8,4%
Tony Proudfoot Fund	\$ 37 148	2,8%	\$ 26 814	2,9%
General Donations	\$ 136 227	10,2%	\$ 74 581	8,0%
Wills and Bequests	\$ 342 000	25,5%	\$ 7 815	0,8%
Others	\$ 11 709	0,9%	-	0,0%
Total	\$ 1 339 093	100,0%	\$ 932 722	100,0%

EXPENSES				
Administration	\$ 91 645	7,6%	\$ 113 444	10,7%
Services and programs	\$ 511 430	42,5%	\$ 511 611	48,3%
Fundraising and Awareness Direct Fees	\$ 112 603	9,4%	\$ 68 148	6,4%
Fundraising and Awareness Indirect Fees	\$ 235 947	19,6%	\$ 242 946	23,0%
Research Contribution	\$ 252 258	21,0%	\$ 122 345	11,6%
Contribution to ALS Canada	\$ 200 593	16,7%	\$ 64 850	6,1%
Contribution to Neuro (Tony Proudfoot Fund)	\$ 16 408	1,4%	\$ 24 710	2,3%
Contribution to CHUQ for the Fondation André-Delambre's Research Symposium	\$ 35 257	2,9%	\$ 32 785	3,1%
Total	\$ 1 203 883	100,0%	\$ 1 058 494	100,0%
Excess (deficiency) of revenue over expenses	\$ 135 210		\$ (125 772)	

Revenue



Expenses





AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC



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