



FOR WHAT COUNTS

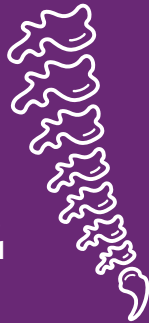
2019 ANNUAL REPORT
TO THE COMMUNITY



What is ALS?



A disease that involves the **brain, spinal cord** and the muscles of the body.



ALS **causes the motor neurons to die**, which means that over time, the brain stops communicating with the muscles, causing gradual paralysis.

What happens to someone when they have ALS?

Someone with ALS will gradually **lose the ability** to walk, talk, eat, move, swallow and eventually breathe.



WALK
TALK
EAT
MOVE
SWALLOW
BREATHE

The disease carries a tremendous burden – emotionally, **mentally, physically and financially**.



Families often face a **\$150,000 to \$250,000 financial burden** over the course of the disease.¹

¹ Gladman et al. Economic burden of amyotrophic lateral sclerosis: a Canadian study of out-of-pocket expenses. Amyotroph Lateral Scler Frontotemporal Degener. (2014) 15: 426-32.

Who is affected?

ALS affects **individuals and families**.



Four out of five people with ALS will **die within five years** of being diagnosed.

An estimated **3,000 Canadians** are living with ALS.

Each year approximately **1,000 Canadians** will be diagnosed and **1,000 will die**.



9 out of 10 people diagnosed **do not have a family history**.

What treatments are available?

There is no cure for ALS.



There are **more than 60 ALS clinical trials** currently in progress, any one of which could be proven effective and become a future therapy.

There are **only two approved treatments for ALS in Canada**, the second of which was approved in 2018, but accessing them is a challenge.



IT'S TIME FOR CHANGE

Each day more than 3,000 people and families throughout Ontario and Canada face the profound emotional, financial and psychological impact of living with ALS. Their collective experience is core to every action we take and decision we make. And each person affected by this devastating disease is reason enough for our work to change the reality of ALS.

By supporting the ALS Society of Canada, you are helping to transform what an ALS diagnosis will mean and create a future where:



1. People affected by ALS receive the best possible standard of care



2. People with ALS have a better quality of life and improved lifespan because of the treatments that are available



3. People with ALS have the information they need to make informed decisions

Creating this reality unites the ALS community – people affected by the disease, donors, fundraisers, volunteers, researchers, clinicians, and partners. Each part of the community brings drive and perspective that is helping to create impact. By working together we can make a future without ALS possible.



“It is a privilege to connect with people and families affected by ALS to support them in their journey. We know more needs to be done – maintaining the status quo is not an option. Thanks to your support, we can work with all of the remarkable and talented people in our community to make change and achieve our shared goal.”

JOSETTE MELANSON
CHAIR, BOARD OF DIRECTORS

Strategic Impact 1

BEST POSSIBLE STANDARD OF CARE

Due to the complex and progressive nature of ALS, the needs of people living with the disease change over time and can evolve rapidly. Yet within the patchwork nature of Ontario's healthcare system, those needs are not always met, and ALS Canada must step in to fill the gaps.

Thanks to you, we can continue to offer health and social system navigation, care coordination, practical advice, and emotional support to people, as well as continue to provide long-term loaned equipment that helps people living with ALS to maintain their dignity, independence, and safety. These supports and services, tailored to each person in our community, are vital in changing the way people living with ALS and their families are cared for in Ontario.



ALS does not define Alan Medcalf, who was diagnosed in 2016. Throughout his adult life, Alan has chosen to work and volunteer with organizations and groups he believes make the world a better place. “In the next part of my journey, I’ll invest some of my energy and experience with the ALS Society of Canada as a volunteer spokesperson, facilitator, or advocate, finding ways to help make a difference in the world we share,” says Alan.

He currently serves on ALS Canada’s Client Services Advisory Council, which provides advice about the services we provide in Ontario, and participates in the Walk to End ALS to raise awareness and funds. He’s also committed to supporting those living with ALS within his own community and is co-facilitating a newly formed peer-to-peer ALS support group in the Brockville area. In facing his ALS diagnosis, Alan has chosen to celebrate the journey and “to help create and sustain hope for those living with ALS, and those around them.”

ALAN MEDCALF
DIAGNOSED WITH ALS IN 2016
MEMBER, ALS CANADA CLIENT SERVICES ADVISORY COUNCIL



SERVICES AND SUPPORT

COMMUNITY CONNECTION:

A pilot **Caregiver Day** in Toronto provided family caregivers a reprieve from daily stresses and connection with others who understand what they're going through to help them develop their resiliency and add to their resources.



Four young caregivers received financial support to attend a youth retreat in Saskatchewan, where they connected with youth from across Canada and learned coping strategies to support them on their return home.



More than **140 ALS Canada support groups** were held across Ontario for people living with ALS and caregivers to provide a forum for information and an opportunity for peer learning and experience sharing.

PRACTICAL SUPPORT:

2,800 pieces of equipment at a cost of **\$1.6 million** were provided to Ontarians living with ALS in 2019 at no cost through ALS Canada's equipment program, helping to improve quality of life and reduce strain on caregivers.

206 people donated on average **2-3 pieces** of equipment at a value of more than **\$360,000** to the ALS Canada equipment loan pool so other people could benefit.



2,200

Equipment request forms were downloaded from our website more than **2,200 times**.

PERSONAL CONNECTION:

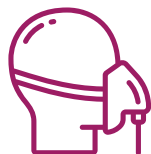
There were **7,203 touchpoints** via phone, text message or email between ALS Canada Regional Managers and people and families living with ALS.



Regional Managers provided **1,491 in-home visits** to people and families living with ALS across Ontario helping people to navigate their journey with the disease – providing practical information and serving as a connection with the healthcare system.

SYSTEM COORDINATION

Championed the need for access to BiPAP in long-term care with the provincial government and participated in a working group on this topic convened by Ontario government bureaucrats so people with ALS can have access to the breathing equipment they require in their long-term care facility.



"ALS Canada was on my side from day one, and for that, I am truly grateful. They have provided me with essential equipment such as a hospital bed, commode, wheelchair, and lift, but more importantly, my Regional Manager provides support. She has been very instrumental in advocating on my behalf to various agencies. I wish every ALS patient in the world had access to a supportive organization like ALS Canada."

ZEHR MADENLI WITH HER HUSBAND SINAN
DIAGNOSED WITH ALS IN 2009

TOOLS TO MEASURE AND IMPROVE CARE

More than 320 people who have received support from ALS Canada responded to a survey about their experience to help us improve the services and support we provide. Ninety-three per cent of the respondents indicated positive impressions of working with their Regional Manager. The equipment program and support for caregivers after they have lost their loved one were identified as priority areas with opportunities for ongoing improvement.



We facilitated the development of best practice recommendations for clinical care by clinicians from across the country, scheduled to be published in 2020. This will become an important resource for standard of care for people with ALS.



Strategic Impact 2

MORE TREATMENTS = LIVING BETTER, LONGER

Because ALS is still a fatal disease – for now, at least – transformative research is needed to better understand the disease and identify pathways to target for developing treatments. ALS Canada is the only consistent, dedicated source of ALS research funding in the country. Your generosity makes it possible for this research to keep happening.

Your support has also enabled us to actively advocate for change in how drugs become available to Canadians – so that as new therapies are developed, people living with ALS can access them in a timely, affordable and equitable way.



Despite the challenges Margot faces daily, she is the kind of person who always pushes through. “I won’t give up and say ‘woe is me,’” she says. Her resilience and determination to make the most of each day help her accept the fact that she can no longer work or get out of the city on weekends like she used to. In turn, Margot is giving back to the community by fundraising for the Walk to End ALS and facilitating ALS support groups at the Sunnybrook ALS Clinic in Toronto. As an active member of ALS Canada’s Client Services Advisory Council and an advocate, Margot also brings forward her own experiences living with ALS through government consultations and meetings, including participating in a roundtable discussion on the implementation of national pharmacare. “The reality of living with ALS reinforces why policy change is so desperately needed to support people today and in the future.”

MARGOT ALGIE
DIAGNOSED WITH ALS IN 2015, ADVOCATE AND MEMBER,
ALS CANADA CLIENT SERVICES ADVISORY COUNCIL

RESEARCH INVESTMENT

Several research studies funded by ALS Canada were published in prestigious academic journals, enabling the findings to be leveraged by other researchers.

\$1.4 million was invested in these leading-edge ALS research grants and awards from across the country, fuelling scientific discoveries to help create a future without the disease.

* in partnership with Brain Canada
** in partnership with La Fondation Vincent Bourque
*** in partnership with Orangetheory Fitness

Dr. Mohan Babu, University of Regina, \$100,000
How do unique protein interactions explain TDP-43 behaviour in different people with ALS?

Dr. Patrick Dion, Montréal Neurological Institute at McGill University, \$100,000
How do environmental marks on RNA play a role in how ALS is caused?

Dr. Matthew Miller, McMaster University, \$100,000
Does prior exposure to common viruses influence ALS onset and disease progression?

Dr. Minh Dang Nguyen, University of Calgary, \$100,000
Does a substance in gut or oral bacteria influence the disease course of ALS?

Dr. Jeehye Park, Hospital for Sick Children (SickKids) Research Institute, \$100,000
Can a new ALS mouse model provide important information for understanding and treating ALS?

Dr. Richard Robitaille, Université de Montréal, \$100,000
Are the same faulty nerve-muscle connections in ALS mice also occurring in humans?

Dr. Peter St. George-Hyslop, University of Toronto, \$100,000
What is the role of the annexin A11 gene in ALS disease processes?

Dr. Stefano Stifani, Montréal Neurological Institute, \$98,400
Can advanced technology reveal the role of multiple cell types affecting ALS in humans?

Dr. Jocelyn Zwicker and Dr. Christine Watt, Ottawa Hospital, \$55,437
Can earlier palliative care consultation improve patient and caregiver quality of life?

Dr. Yana Yunusova*, Sunnybrook Research Institute, \$100,000**
Can speech-recognition technology help diagnose ALS?

Alicia Dubinski, Université de Montréal, \$75,000
Can an animal model provide new insights into the formation of stress granules?

Myriam Gagné, Université de Montréal, \$75,000**
What is the role of a newly discovered protein in ALS?

Rahul Kumar, Montréal Neurological Institute, \$75,000
Is the loss of normal function of C9ORF72 in a particular cell type a key driver of ALS disease processes?

Marc Shenouda, University of Toronto, \$75,000***
Is an experimental drug that can prevent abnormal protein behaviour in ALS already out there?

Terry Suk, University of Ottawa, \$75,000*
Could newly discovered tags on TDP-43 protein explain its abnormal behaviour in ALS?

Dr. Ulises Rodríguez Corona, Institut de recherches cliniques de Montréal (IRCM), \$165,000
Can new understandings about nuclear speckles lead to new treatment options for ALS?

CAPACITY BUILDING

Seven Canadian ALS researchers received financial support to attend the **International Alliance of ALS/MND Associations** scientific conference in Perth, Australia, where they could learn about and share scientific knowledge with their peers from around the world.



ALS Canada VP Research **Dr. David Taylor is the Chair** of the International Alliance of ALS/MND Associations' Scientific Advisory Council, which provides knowledge translation and updates on science and clinical development to ALS organizations around the world.

200+ Canadian ALS researchers and clinicians attended two days of scientific presentations at the **ALS Canada Research Forum**, sharing knowledge and identifying collaborations for future research initiatives.

ACCESS TO THERAPIES

Leading up to the federal election, more than **2,300 Canadians sent letters** to Canada's federal party leaders, asking them to create a future with equitable, timely and affordable access to proven ALS treatments.



Continued to support Canada's ALS clinics in building capacity to host clinical trials and regularly met with stakeholders along the drug access pathway, including manufacturers, to encourage clinical trials and regulatory approval in Canada.

We participated in the **2019 CADTH Symposium, CORD International Conference**, and the **Canadian Association for Healthcare Reimbursement Conference** to voice that Canada's drug access pathway isn't meeting the needs of the ALS community.



More than **100 people participated in webinars** to start mobilizing advocacy efforts for provincial drug plans to reimburse Radicava.



"With a pipeline of potential therapies, it's time for governments to step up and do more to address the urgent need for access to emerging ALS therapies and the realities of living with a terminal disease."

BETH ROBERTSON
VOLUNTEER AND FORMER CAREGIVER TO HER HUSBAND, TIM, WHO LIVED WITH ALS FOR 13 YEARS

Strategic Impact 3

BETTER INFORMATION, BETTER DECISIONS

Compared to many other diseases ALS affects a smaller number of people but in a very significant way. By helping others to better understand the impact of ALS, we can influence funding, policy and program decisions to create positive change, as well as empower our community to make choices that best meet their individual needs. Each day, people in our community generously and boldly share their experiences with ALS to help highlight the realities of living with the disease.

Thanks to the generosity of donors, our work will continue to be informed by these experiences in order to ensure that information is relevant and responds to the needs of those we exist to support.



Jeff was diagnosed with ALS 12 years ago at the age of 41. First, he lost the ability to walk, then to talk. Today, the only muscles Jeff can fully move are in his eyes, so that's how he communicates – a text-to-speech device gives him the ability to type with his eyes at a rate of about 15 words per minute. That's how he wrote his memoir, *Still Life*, which was released in October 2019. Jeff and his wife Darlene were also the focus of two awareness videos produced by ALS Canada in 2019 that provided a glimpse into their day-to-day life and the love they share for one another.

The videos can be viewed [here](#).

JEFF SUTHERLAND
DIAGNOSED WITH ALS IN 2007



AWARENESS AND EDUCATION

Held **29 meetings** (18 federal, 11 provincial) with politicians and their staff to advocate for the needs of the ALS community.

Increased government's awareness of ALS by ensuring ALS Awareness Month was acknowledged in the Ontario Legislature and federal House of Commons in June.



Became a **member of Research Canada**, a national alliance dedicated to advancing health research through collaborative advocacy to help elevate the need for ALS research in Canada.



Arranged for major landmarks – the 3D Toronto sign at Nathan Phillips Square, the CN Tower and Niagara Falls to be lit in purple during ALS Awareness Month in June to bring awareness to ALS.

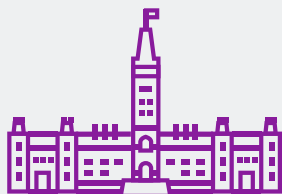
Shared the stories of **30 people affected by ALS** through our blog and other awareness opportunities so people understand the personal impact of the disease.



Launched **two new ALS awareness videos** featuring Jeff and Darlene Sutherland who have been living with ALS since 2007. Combined, the videos generated **58.7K views, 1.9K social reactions** and aired on Rogers Media television stations demonstrating the realities of facing ALS daily.



Participated in **two meetings** of the all-party ALS caucus chaired by MP Francis Drouin to elevate the need for timely and affordable access to therapies and for ALS research funding.



Thank you to the 38 community members – including people living with ALS and personal caregivers – who participated in these awareness initiatives in 2019

ACCESS TO INFORMATION

In 2019, there were **900 downloads** of the ALS guide from the ALS Canada website and more than 250 hard copies were given out to Ontario families and to provincial ALS Societies.



Four research webinars were offered in 2019, with more than 120 people attending.

www.als.ca



There were more than **390,000 visitors** to ALS Canada's website in 2019, including over 5,600 downloads of ALS Canada fact sheets. ALS Canada's fact sheets will be updated in 2020.

COMMUNITY ENGAGEMENT

ALS Canada is informed by people affected by ALS. At a leadership level, three people living with ALS served on our Board of Directors and Client Services Advisory Council in 2019. The majority of Board members had a personal connection as a caregiver, family member or friend.

We worked with members of the ALS community to advance advocacy initiatives relating to access to therapies.



More than **250 people attended the 2019 Inspiration + Impact dinner**, which brought together different members of the ALS community – people living with the disease, researchers, clinicians, donors, volunteers and partners – in support of our shared cause.

13 people with lived experience participated in key informant interviews to create personas, which inform our work. This important initiative will help ALS Canada to strengthen our information resources and services to better respond to the changing needs of people affected by ALS.

"Now that I have my own adversity and as I learn new skills to deal with ALS, I am doing my part to get the message across by getting out in the community and talking openly about ALS. I need people to see what is happening and how I've progressed. ALS doesn't change who I am and what I'm about; it's just something I have to deal with."

ADAM WELBURN-ROSS
DIAGNOSED WITH ALS IN 2018



Strategic Enabler

FUNDRAISING

Donors to ALS Canada collectively gave **\$10,581,764** in 2019, not including interest, investment returns and deferred revenue. Individuals, provincial ALS Societies, foundations, corporations and other organizations giving \$1,000+ in 2019 are acknowledged on our website at www.als.ca/donors.

ALS Societies in each province generously provided a total of **\$746,517** to ALS Canada in 2019, which includes 40% of their net Walk proceeds as well as additional giving.



Walk to End ALS events across Ontario united more over 4,000 people across **33** communities, and raised over **\$2 million** to provide help and hope to people affected by ALS!

*Walk to
End ALS*



Lolo Lam is a passionate advocate for making a future without ALS a reality. After her father died from ALS in 2010, her desire to give back has never been more focussed. “I have a calling now to honour my dad. If I can help in any way possible, then I’m going to give not just my money but also my time,” says Lolo. For seven years running, she has engaged her colleagues at Equitable Bank in creating corporate teams and raising more than \$20,000 in 2019 alone through the annual ALS Canada Plane Pull to End ALS. “I know that by supporting ALS Canada, help is going directly to the people who need it,” she says.

LOLO LAM
PLANE PULL TEAM CAPTAIN AND ALS CANADA SUPPORTER

A record-breaking **\$197,595** was raised at the ninth annual ALS Canada Plane Pull to End ALS. This signature event connects to a corporate audience, providing a unique team-building experience while giving participants the chance to make a difference.



Now more than ever before, our community is supporting our cause through monthly giving, which grew to raise a total of **\$228,393 through the generosity of 1,114 donors.**



Legacy planned giving donations totalled **\$1.9 million.**

Community events raised a record **\$378,214** in support of our shared cause.



"Orangetheory Fitness is proud to partner with the ALS Canada Research Program to dedicate funds in support of Canadian ALS research. We hope to continue striving for a cure while supporting scientific discovery that will one day improve the lives of individuals and families who are affected by this rare and yet, terrible disease."

Blake MacDonald
President, OTF Canada Inc

Team ALS runners participating in the Ottawa and Toronto Scotiabank Marathons raised a total of **\$21,473.**

2019 was the **20th Annual Hickory Dickory Decks Golf Tournament**, with **\$120,000+** raised for ALS Canada since 1999.



Volunteers like our 60+ Walk Coordinators across Ontario contributed more than **6,000** hours throughout 2019 to advise the organization, organize fundraising events, provide administrative support and much, much more.



For the third year, through a partnership with Queen's University that is generously supported by an alumni donor, one student joined ALS Canada as summer intern, helping with a range of client services and finance projects, including organizing the first Caregiver Day.



Corporate partnerships raised **\$336,943.** This year, we were the charity of choice for McCormick Canada, as well as long-time partners Orangetheory Fitness, HealthPartners and Federated Health Charities.

Community-organized cycling initiatives **Miles4Matty and Mike's** "Spice up Your Life" ride to end ALS raised a collective **\$19,000.**

YOUR DONATIONS AT WORK

SUPPORT AND SERVICES

To respond to the needs of people living with ALS in Ontario, we spent \$1.3 million providing direct support to people and families living with ALS and an additional \$1.6 million providing equipment.

NATIONAL RESEARCH

In 2019, we awarded \$1.6 million in new research grants including Project MinE and CAPTURE ALS. We accounted for the full financial commitment of these grants in 2019, although most grants will be paid out over multiple years. An additional \$672K was used to support the ALS Canada Research Program and the broader ALS research community in Canada. In November 2019, the Board of Directors approved a plan that would carry the use of the 2019 surplus into 2020, including a commitment of \$1 million to leverage a potential match with Brain Canada for the CAPTURE ALS research project.

FUNDRAISING

Our revenue and the expenses associated with generating donations are analyzed regularly to ensure our cost of fundraising is sustainable within an acceptable range. In 2019, our cost of fundraising was 21%, which considers costs like credit card processing fees and fund development support to generate donations and is well within the Canada Revenue Agency's guidelines for a charity.

PUBLIC AWARENESS

Investments made in 2019 have enabled us to increase awareness of the organization through digital marketing and advertising, and the development of two ALS awareness videos. We also updated the comprehensive ALS handbook, which launched in early 2020 after being last reviewed in 2012.

ADVOCACY

Through our advocacy investments in 2019, we were able to bring forward the perspectives of people living with ALS with government officials to advocate for policy changes that will have a meaningful impact. We also developed infrastructure to support e-advocacy efforts and launched advocacy training initiatives for our community.

OTHER CHARITABLE PURPOSE

This year, we invested additional funds in volunteer development and other national programs.

GOVERNANCE

The Board of Directors met in person 4 times in 2019 in addition to teleconferences and other calls as required. While out-of-pocket expenses for travel and accommodation are reimbursed, no compensation is provided for their generous gifts of time and expertise.

CAPTURE ALS

The solution is in you!

Understanding the heterogeneity of ALS – or why the disease can behave differently in each person – is the next frontier of ALS research and the best hope for developing effective ALS therapies. CAPTURE ALS is a Canadian-led, open science platform that aims to collect and analyze biological data from Canadians living with ALS in order to understand why each person's journey is so unique. Led by a group of world-renowned basic and clinician ALS scientists, and leveraging collaborations and infrastructure built through years of ALS Canada support and funding, CAPTURE ALS will address ALS clinical variability by collecting the most comprehensive biological picture of individuals with ALS ever attempted in the field. In 2019 we invested \$100,000 towards the project management of this innovative platform, which was critical in bringing together the infrastructure for future launch.



"There isn't any time to waste. ALS is a time-sensitive disease. We feel lucky to be in Canada, where research is leading edge. We're excited by the progress that has been made in the last five years and optimistic that in my wife Youtaz's lifetime, we'll see great strides made so that this disease doesn't impact other families the way it has us."

PETER WOOD
DIAGNOSED WITH ALS IN 2015

FINANCIAL SUMMARY

Our leadership carefully monitors fundraising revenue and expenses to ensure the organization's needs and goals can be met in a fiscally responsible way that maximizes the use of donor dollars.

- We adhere to generally accepted accounting standards for not-for-profit organizations that comply with the Canada Revenue Agency's requirements. Since 2014 we have used the deferral method of recognizing revenue, which allows us to recognize externally restricted revenue in the period where the future investments in research and client services occur. At December 31, 2019, we had **\$1.9 million** in deferred revenue remaining. These funds are held in secure income-generating investments.
- We invest all funds under the guidelines of an established investment policy approved by the Board of Directors.

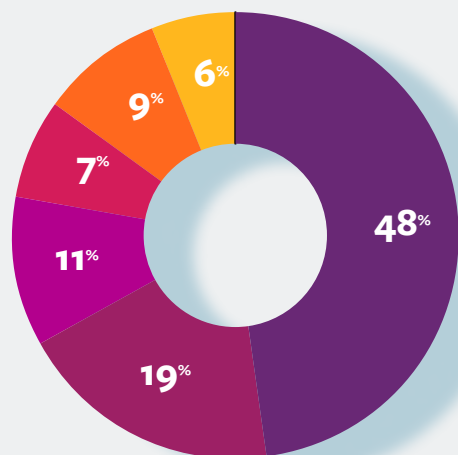
At December 31, 2019, we held **\$5.9 million** in cash and **\$10.5 million** in short and long-term investments of government and corporate bonds, pooled bond mutual funds and other financial instruments.

- We were fortunate to receive two significant unexpected gifts in the later part of 2019. Due to the timing of these gifts, we were not able to utilize these funds in 2019 which has resulted in an operating surplus of **\$2.4 million** when including the unrealized gain on investments. In November 2019, our Board approved a deficit budget for 2020 to utilize these funds in the following year.

- Subsequent to year-end, the global pandemic has had a significant impact on businesses and organizations through the restrictions put in place by the Canadian, provincial and municipal governments. At this time, the extent of the pandemic's impact on ALS Canada is unknown.

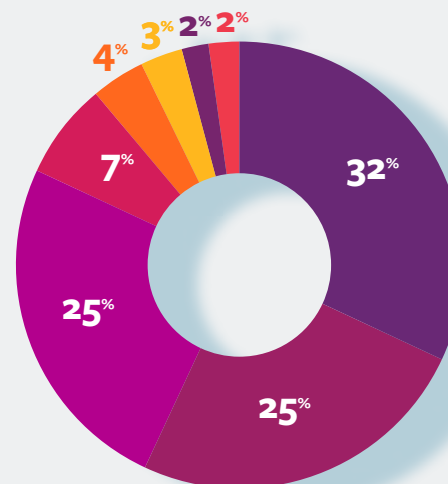
Visit our website to view our audited financials.

2019 Revenue



Other Fundraising Donations and Income	\$5,029,164
Ontario Walk to End ALS	\$2,056,894
Direct Mail	\$1,131,696
From Provincial Societies	\$746,517
Tribute and Monthly Giving	\$981,739
Fundraising Events	\$635,754

2019 Expenses



Support Services	\$2,847,129
National Research	\$2,247,491
Fundraising	\$2,217,788
Public Awareness	\$593,257
Advocacy	\$386,373
Administration	\$252,699
Other Charitable Purpose	\$189,065
Governance	\$180,502

FINANCIAL SUMMARY

STATEMENT OF FINANCIAL POSITION

For the year ended
December 31, 2019

In \$	General Fund	Research Fund	Tim E. Noël Endowment Fund	2019	2018
Assets					
Current assets					
Cash	\$ 4,260,288	\$ 350,674	\$ 1,300,000	\$ 5,910,962	\$ 3,933,526
Short-term investments	302,791	9,107,305	–	9,410,096	9,299,833
Accounts receivable	201,536	177,935	–	379,471	650,972
Prepaid expenses and other assets	144,771	–	–	144,771	124,1467
	\$ 4,909,386	\$ 9,635,914	\$ 1,300,000	\$ 15,845,300	\$14,008,477
Long-term investments	–	1,140,753	–	1,140,753	1,215,173
Capital assets	56,081	–	–	56,081	70,739
Intangible assets	35,960	–	–	35,960	82,107
	\$ 5,001,427	\$ 10,776,667	\$ 1,300,000	\$ 17,078,094	\$ 15,376,496
Liabilities					
Current liabilities					
Accounts payable and accrued liabilities	\$ 545,985	–	–	\$ 545,985	\$ 522,456
Current portion of deferred revenue	403,374	500,000	–	903,374	1,197,347
Current portion of research grants payable	–	3,989,242	–	3,989,242	2,198,877
	\$ 949,359	\$ 4,489,242	–	\$ 5,438,601	\$ 3,918,680
Long-term deferred revenue	\$ 692,956	\$ 266,364	–	\$ 959,320	\$ 608,213
Long-term research grants payable	–	1,635,145	–	1,635,145	4,228,504
	\$ 1,642,315	\$ 6,390,751	–	\$ 8,033,066	\$ 8,755,397
Commitments					
Net assets	\$ 3,359,112	\$ 4,385,916	\$ 1,300,000	9,045,028	\$ 6,621,099
	\$ 5,001,427	\$ 10,776,667	\$ 1,300,000	\$ 17,078,094	\$15,376,496

STATEMENT OF OPERATIONS

For the year ended
December 31, 2019

In \$	General Fund	Research Fund	Tim E. Noël Endowment Fund	2019	2018
Revenue					
Fundraising and donations	\$ 7,585,544	\$ 1,864,524	–	\$ 9,450,068	\$ 6,675,144
Direct mail campaign	1,072,135	59,561	–	1,131,696	1,092,267
Interest and investment income	331,072	–	39,000	370,072	229,828
	\$ 8,988,751	\$ 1,924,085	\$ 39,000	\$ 10,951,836	\$ 7,997,239
Expenses					
Research grants	–	\$ 1,575,250	–	\$ 1,575,250	\$ 1,525,268
Other research support	–	672,241	–	672,241	671,519
National programs	125,348	–	–	125,348	116,515
Ontario client support services	2,847,129	–	–	2,847,129	2,302,906
Public awareness	593,257	–	–	593,257	438,594
Advocacy	386,373	–	–	386,373	326,196
Volunteer development	63,717	–	–	63,717	89,838
	\$ 4,015,824	\$ 2,247,491	–	\$ 6,263,315	\$ 5,470,836
Other					
Fundraising	\$ 2,217,788	–	–	\$ 2,217,788	\$ 2,098,771
Administrative	252,699	–	–	252,699	288,416
Governance	90,251	90,251	–	180,502	189,541
Bad debt recovery	–	–	–	–	(45,000)
	\$ 2,560,738	\$ 90,251	–	\$ 2,650,989	\$ 2,531,728
	\$ 6,576,562	\$ 2,337,742	–	\$ 8,914,304	\$ 8,002,564
Excess (deficiency) of revenue over expenses before unrealized gain (loss) on investments	\$ 2,412,189	\$ (413,657)	\$ 39,000	\$ 2,037,532	\$ (5,325)
Unrealized gain (loss) on investments	386,397	–	–	386,397	(36,870)
Excess (deficiency) of revenue over expenses	\$ 2,798,586	\$ (413,657)	\$ 39,000	\$ 2,423,929	\$ (42,195)

STATEMENT OF CHANGES IN NET ASSETS

For the year ended
December 31, 2019

In \$	General Fund	Research Fund	Tim E. Noël Endowment	Total
Balance, December 31, 2017	\$ 650,128	\$ 4,713,166	\$ 1,300,000	\$ 6,663,294
Excess (deficiency) of revenue over expenses	(89,602)	46,938	469	(42,195)
Interfund transfers	–	469	(469)	–
Balance, December 31, 2018	\$ 560,526	\$ 4,760,573	\$ 1,300,000	\$ 6,621,099
Excess (deficiency) of revenue over expenses	2,798,586	(413,657)	39,000	2,423,929
Interfund transfers	–	39,000	(39,000)	–
Balance, December 31, 2019	\$ 3,359,112	\$ 4,385,916	\$ 1,300,000	\$ 9,045,028

ALS CANADA LEADERSHIP

ALS Canada's competency-based Board of Directors provides strategic direction and oversight to ensure donor dollars are maximized to serve the organization's charitable purpose.

These leadership volunteers contribute expertise across a range of disciplines, a genuine passion for the cause, and their strong desire to make a difference.



Back row: Daniel Rivero, Carol Cottrill, Patrick Nelson, Dr. Christine Vande Velde, Vincent Quinn, Tammy Moore, Dr. Angela Genge, Dr. Michael Spivock
Front row: Ronald Foerster, Josette Melanson, Laura Gay

2019 BOARD OF DIRECTORS

Josette Melanson, <i>Chair</i>	Jim Mitrakos
Ronald Foerster, <i>Past Chair</i>	Patrick Merz
Norma Beauchamp	Patrick Nelson
Carol Cottrill	Vincent Quinn
Dr. Heather Durham	Daniel Rivero
Laura Gay	Dr. Michael Spivock
Dr. Angela Genge	Dr. Christine Vande Velde
Dr. Wendy Johnston	Tammy Moore (ex-officio)
Noella LeBlanc	

IN APPRECIATION: DR. HEATHER DURHAM

Like most people, Dr. Heather Durham, researcher and professor at McGill University, never expected to be touched by ALS. Her connection to the disease came indirectly and unexpectedly through a patient she met more than 30 years ago as a young investigator at the Montreal Neurological Institute and Hospital. Year after year Dr. Durham's quest to find answers and develop effective treatments has continued to grow, as has her commitment to the cause and active engagement in ALS Canada initiatives. In April 2019, Dr. Durham's terms on the Board of Directors and Scientific and Medical Advisory Council came to an end. Thank you Dr. Durham for your many contributions to the ALS community!



OUR VISION

A future without ALS

OUR MISSION

We work with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS.

ADVISORY COUNCILS

The **Scientific and Medical Advisory Council** provides guidance to ensure that research activities contribute to the strategic priorities of ALS Canada and are carried out with integrity.

Dr. Christine Vande Velde, *Co-Chair*
Dr. David Taylor (Staff), *Co-Chair*
Dr. Aaron Izenberg
Dr. Angela Genge
Dr. François Gros-Louis
Dr. Wendy Johnston
Dr. Jasna Kriz
Dr. Hanns Lochmüller
Josette Melanson (ex-officio)
Tammy Moore (ex-officio, Staff)
Dr. Robin Parks
Dr. Kerri Schellenberg

The **Client Services Advisory Council** contributes personal and professional experience to help to improve the journey of people and families living with ALS in Ontario.

Patrick Nelson, *Co-Chair*
Lisa Droppo (Staff), *Co-Chair*
Margot Algie
Ron Black
Sheldon Crystal
Tasneem Dharas
Heidi Kinnon
Stephanie Mazzei
Alan Medcalf
Josette Melanson (ex-officio)
Tammy Moore (ex-officio, Staff)
Vincent Quinn
Sarah Reedman (Staff)
Dr. Christen Shoesmith
Lisa Sullivan
Sherry Szucsko-Bedard
Dr. Anu Tandon

TOGETHER WE CAN ACHIEVE MORE

ALS Canada has national responsibilities within the federation of eight provincial ALS Societies across Canada. Together, we fund ALS research through the ALS Canada Research Program, to which provincial ALS Societies generously donate 40% of net proceeds from their annual Walk to End ALS events.

The work of ALS Societies across Canada is governed by the Federation Council. Working together we can maximize our impact to make the greatest difference for people living with ALS.

Federation Council Member Societies

ALS Society of Alberta
ALS Society of British Columbia
ALS Society of Canada
ALS Society of Manitoba
ALS Society of Newfoundland and Labrador
ALS Society of Prince Edward Island
ALS Society of Quebec
ALS Society of Saskatchewan

ALS Canada is proud to partner with organizations and associations in Ontario, across Canada and around the world to improve the lives of people living with ALS.

International:

International Alliance of ALS/MND Associations

National:

Canadian ALS Research Network (CALS)
Canadian Assistive Devices Association (CADA)
Health Charities Coalition of Canada (HCCC)
Palliative Care Matters

Provincial:

Ontario Neurodegenerative Disease Research Initiative
Quality Hospice Palliative Care Collation of Ontario

ALS Society of Canada

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Toll-free 1-800-267-4257
www.als.ca



@ALSCanada

Pictured on front cover:

Adam Welburn Ross, with mother Gail Ingersoll
and stepfather Gord Ingersoll (top left);
Selvajothy Manotheepan and Rajaratnam
Manotheepan (top right);
and Peter Wood and daughter Siena
(bottom right).

Amyotrophic Lateral Sclerosis Society of Canada
Charitable Registration Number 10670-8977-RR0002

Founded in 1977, ALS Canada works with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS. We are a registered charity that receives no government funding – all of our services and research are funded through the generosity of our donors.

Through the ALS Canada Research Program, we fund peer-reviewed research grants, foster collaboration and build capacity within Canada's ALS research community and participate in new areas of research where we are well-positioned to have an impact. Within Ontario, ALS Canada has a role similar to that of the provincial ALS societies providing services and support to help meet the needs of people living with ALS. Through advocacy federally and provincially within Ontario, ALS Canada gives voice to the collective experience of people living with ALS to help drive program and system changes for the ALS community.

www.als.ca

The Standards Program
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