

# BECAUSE OF









*“It’s true that there is strength in numbers. Together, we are a powerful force. Thank you for all you do in support of our shared cause.”*

RON FOERSTER CHAIR, BOARD OF DIRECTORS



## STRENGTH IN NUMBERS

**EVERY DAY, MORE THAN 3,000 PEOPLE AND FAMILIES** throughout Ontario and Canada live with the realities of ALS, a devastating disease that takes away dreams, abilities, and lives. But for all ALS takes, it cannot take away our shared desire for a future without this disease.

By supporting the ALS Society of Canada, you and others like you are part of a powerful community whose momentum is creating real and meaningful change. **Because of you...**

- People living with ALS throughout Ontario can participate more fully in their lives.
- Canadians affected by ALS can have hope for treatments as a result of research funding.
- Work is taking place to advocate for better care, services and access to therapies.

As the vehicle that helps to translate your desire for a future without ALS into meaningful progress and impact, the ALS Society of Canada is grateful for all you do. In fact, many people are surprised to learn that we do not receive any government funding – making the collective impact of your contributions all the more impressive and important.

## THE FACTS ABOUT AMYOTROPHIC LATERAL SCLEROSIS (ALS)



ALS is a disease that involves the brain and spinal cord, the muscles of the body and the motor neurons that send signals between the two. Because the motor neurons are dying, over time, the brain stops communicating with the muscles, causing them to become gradually weaker, and resulting in progressive paralysis including losing the ability to walk, talk, eat, move, swallow and eventually breathe.



9 out of 10 people with ALS **do not have a family history** of the disease.



There is **no cure** for ALS and there are few treatment options for the majority of people living with the disease.



A family living with ALS will face a **\$150,000 to \$250,000** financial burden over the course of the disease due to expenses for treatment, care, and equipment needs as well as lost income.<sup>1</sup>

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



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

About **1,000** Canadians are diagnosed with ALS each year and a similar number die.

<sup>1</sup> “Economic burden of amyotrophic lateral sclerosis: A Canadian study of out-of-pocket expenses,” by Matthew Gladman, Celina Dharamshi and Lorne Zinman, published in *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 2014.

## THE RIGHT HELP AT THE RIGHT TIME



One of the least understood aspects of ALS is why people experience it so differently, both in terms of where symptoms start and move to next, and how quickly they progress. Researchers are working on the answers, but for people living with ALS today the disease can be very much an individual journey: what's needed looks different from person to person and changes over time.

That's why services tailored to the needs of each person and family are so important – and that's what you are making possible. Thanks to you, each family's journey with ALS is made a little easier by enabling ALS Canada to fill gaps within the healthcare system and respond to individual non-medical needs that arise outside of clinic visits and homecare appointments.

### A lifeline to safety and community

Over time, someone living with ALS will need different types of equipment as their muscles weaken. For each person, it can be difficult to predict exactly when physical needs might require the shift from a walker to a wheelchair, for example



Photo courtesy of snap Beaches/Danforth.



**2,600** pieces of equipment were provided to Ontarians living with ALS in 2018 through ALS Canada's equipment program, at a cost of **\$1.3 million**.



**199 donors in Ontario** generously chose to give their gently used equipment to ALS Canada's equipment loan pool so that others could benefit.



**1,300 home visits** took place at which ALS Canada Regional Managers provided personalized connections to people and families living with ALS throughout Ontario.

***“After my sister died from ALS, I started volunteering and fundraising so that other people and families living with ALS can have the equipment and support they so desperately need.”***

JUDITH MALVERN, ALS CANADA VOLUNTEER

– making it expensive and complicated to quickly access the equipment that is vital to living safely and staying connected to family and friends. That’s where ALS Canada’s equipment program comes in for people living with ALS in Ontario: loaned equipment available for longer time periods than the healthcare system provides, delivered at no cost and fully funded by generous donors.

### **Expert advice to navigate challenging terrain**

For a family newly diagnosed with ALS, an ALS Canada Regional Manager is often one of the first people they’ll meet. Providing services to the ALS community in Ontario, Regional Managers are system navigators who are knowledgeable in nearly everything a family will face while living with ALS and can help families on their journey with ALS by answering questions, identifying resources, advocating for care and providing practical advice. In addition to visiting people in their home, Regional Managers offer support groups for people living with ALS as well as caregivers. It’s no wonder they are one of the most valued resources ALS Canada provides.

**BECAUSE OF YOU:**

Significant updates were made to the comprehensive **ALS guide and fact sheets** that people receive to help them make informed decisions throughout their journey, with the final products to be available in 2019.



ALS Canada offered more than **100 training and information sessions** to organizations, vendors and healthcare providers, helping them be better equipped to respond to the needs of people with ALS.



**6,800**

A total of **150 support group meetings** took place throughout Ontario, enabling caregivers and people living with ALS to receive encouragement, comfort and advice from others with firsthand knowledge of the disease.

There were **6,800 touchpoints** via phone, text message or email between ALS Canada Regional Managers and people and families living with ALS.

Caregivers who have lost someone to ALS will benefit from improved resources, following the successful pilot of a bereavement transition support group in Ottawa that was a direct result of feedback received from clients and caregivers in 2016. **Bereavement transition support groups** are being offered in 3 additional communities in 2019.







STEPHANIE CHRISTIANSEN HALL WITH HER CHILDREN

## CREATING MEMORIES for her children

When you are 29 years old and experience cramping in your legs at night, the last thing on your mind is ALS. For Stephanie Christiansen Hall, a mother of three living with ALS, trying to stay positive and live day by day is tough. “I don’t want my kids not to have me,” she says. “When you’re a young parent, you don’t think your time is limited.”

Taking each day at a time, Stephanie is grateful for the services she has received from ALS Canada. “I got in touch with ALS Canada less than a week after my diagnosis. Because of the generosity of donors, my ALS Canada Regional Manager, Lianne Johnston, is always there to listen, offer support and give information – so my family and I don’t have to go through this alone.”

Facing an uncertain future, Stephanie is determined to do everything in her power to help find effective treatments for ALS. She knows that sustained investment in promising ALS research will lead to new therapies. She is also hopeful that researchers will find a cure within her lifetime.

At the same time, Stephanie is trying hard to be the best mother she can be – despite her physical challenges. “I spend as much time as possible with my kids every day, going out to the park in my scooter, playing games, and doing arts and crafts. I want to focus on creating memories and instilling the values I would like them to grow up with,” she explains. “I can’t take any moment with my family for granted.”

Stephanie defines a hero as “someone who finds the strength to endure overwhelming obstacles.” She is doing exactly that in the face of a horrible disease. And Stephanie’s children don’t have to go far to find a hero in their midst.

***“ALS Canada is always there to listen, offer support and give information – so my family and I don’t have to go through this alone.”***

## REMEMBERING

# Eddy Lefrançois, a champion, advocate and friend



## LET'S ROLL...

Diagnosed with ALS in 1992 with a prognosis of three to five years to live, Eddy Lefrançois became a force within the ALS community, showing the world that he would not be defined by his disease. A rare example of someone who lived well beyond the average life expectancy of someone diagnosed with ALS, Eddy approached each day as an opportunity. He travelled around North America and parts of Europe working on his bucket list, rolling across all terrains into adventures that included a Stanley Cup final game, whitetail deer hunt, and indoor skydiving.

Eddy worked tirelessly to raise awareness of ALS and mobilize others to support the cause. In his words, “I may not control the fact that I have ALS, but I control my actions to make people aware that ALS is a terrible disease to live with... anybody can develop it at any time; we have to work together for a future without ALS.”

Even after the disease took away his ability to speak, Eddy used social media and his personal website to connect with people near and far. He was widely seen as a guiding voice and champion to people living with ALS, often being contacted by those across Canada and around the world to share his perspective and experience, along with his motto “let’s roll...”. We are grateful for all Eddy has done as an ALS Canada Ambassador in support of our shared cause. He will be remembered always.

## A VOICE WITH GOVERNMENT DECISION-MAKERS



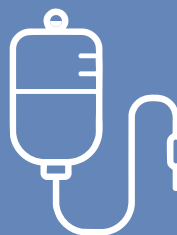
Compared to many other diseases, ALS affects a relatively small number of people, but in a very significant way. Even though the healthcare system provides critical touchpoints for people living with ALS – for example, through ALS clinics and provincially funded homecare – there are still tremendous gaps. At a federal level, the agencies that coordinate drug approval, pricing and access need to be aligned for faster action, and there is no dedicated federal funding for ALS research. For a community that measures time by loss, clearly much more can be done.

Your gifts to ALS Canada give people affected by ALS a voice with both federal and provincial (Ontario) governments. With the involvement of the ALS community, ALS Canada's advocacy efforts help decision-makers understand how inefficiencies, inconsistencies and gaps in the healthcare system are leaving people with ALS behind. By highlighting problems and working with government to identify solutions, we can create momentum for meaningful change.



The profile of ALS was raised on Parliament Hill throughout 2018 through:

- 3** meetings of the all-party ALS Caucus chaired by MP Francis Drouin
- 7** meetings between ALS Canada and MPs and policy advisors
- 3** parties made remarks in the House of Commons in recognition of ALS Awareness Month in June



Canada's ALS community was able to voice their experiences and hopes for edaravone, the second ALS drug to be approved by Health Canada and the first in nearly two decades.

More than **550 Canadians** participated in an online survey and focus groups to inform ALS Canada's submission about edaravone to the Canadian Agency for Drugs and Technologies in Health (CADTH), which plays an important role in the decisions provinces make about how drug costs are covered.

Progress was made in advocating for fair access to non-invasive respiratory equipment for people living with ALS in Ontario's long-term care facilities and residential hospices.





THE POWER

## of your Voices



*“It’s important that people who aren’t as familiar with ALS understand the many challenges you face when living with this disease. That’s why I give my efforts to ALS Canada’s advocacy initiatives – to educate and help drive action.”* MIKE RANNIE, DIAGNOSED WITH ALS IN 2017

ALS Canada ambassadors Carol Skinner and Eddy Lefrançois, with further engagement from ALS community champions Denis Blais and Bill Duff, started a letter-writing initiative in late 2018 urging Members of Parliament to hold themselves accountable for Motion M-105, which called upon the federal government to play a leadership role in supporting ALS research, and to support national efforts to find a cure for ALS at the earliest opportunity. We were proud to have assisted this initiative by creating an online tool that helped more than **2,375** Canadians ask the federal government for dedicated ALS research funding.

BECAUSE OF **YOU:**



**PICTURED LEFT:**  
ALS CANADA CEO TAMMY MOORE APPEARS BEFORE THE HOUSE OF COMMONS STANDING COMMITTEE ON HEALTH TO SHARE THE BARRIERS TO TREATMENT FACED BY THE ALS COMMUNITY.

ALS Canada was able to advocate for the needs of Canadians living with ALS during federal consultations on the development of a national pharmacare program, expensive drugs for rare diseases, and treatment barriers for people with rare diseases.



ALS Canada made its first budget submission to the Ontario government, recommending five things the government could do to help Ontarians living with ALS receive the care they need.

*“In the 180 days during Health Canada’s priority review period, 500 Canadians have died of ALS. How many will die awaiting the CADTH decision? After that, how many will have to die while they’re awaiting the availability through a publicly funded drug program? We are dealing with a community that measures time not by calendars but by loss of their own function and the number of members who will die during this process.”*

TAMMY MOORE, ALS CANADA CEO

*“The advancements in research over the past few years have brought a lot of hope to the ALS community that new and effective treatments will soon become available. But if changes are not made now to streamline the approval system, this hope will be gone because we won’t have the physical or financial means to access a therapy that could save our lives. That is why it is so important that the Ontario government put a strategy in place today to reduce the barriers to drug access for people living with ALS.”* MARGOT ALGIE, DIAGNOSED WITH ALS IN 2015 AND FACILITATOR OF A PEER SUPPORT GROUP

# INVESTING IN A FUTURE WITHOUT ALS

The first gene known to play a role in ALS was identified 26 years ago. Research discovery since then has accelerated greatly, to the point that there has been more progress in the last five years than ever before. At its most complex, ALS research is a quest to understand the biological causes and progression of the disease in order to develop therapies that will make it treatable. But at its simplest, ALS research represents hope.

Your support together with our partnership with ALS Societies across Canada, makes possible the country's only dedicated pool of ALS research funding via the ALS Canada Research Program. Without it, there would be no guarantee of ALS research taking place in Canada. You are also enabling Canada's internationally respected ALS research community to stay connected with one another and form new partnerships to help research go further, faster. Your generosity helps bring Canada's ALS researchers together annually at the ALS Canada Research Forum to learn about one another's work and collaborate in ways that might not happen otherwise.

## 2018 Research Grants

### Dr. Gary Armstrong, Montréal Neurological Institute, \$125,000

Cutting-edge gene-editing technology to make new zebrafish models of ALS and accelerate the discovery of new therapies

### Dr. Jasna Kriz, Université Laval, \$125,000

Can a protein that affects immune cells in the brain be reprogrammed to prevent or slow ALS?

### Dr. Ayse Kuspinar and Dr. Vanina Dal Bello-Haas, McMaster University, \$125,000

A first-of-its-kind tool to assess how ALS clinical trials affect quality of life, developed in collaboration with people living with the disease

### Dr. Eric Lécluyer, Institut de recherches cliniques de Montréal (IRCM), \$125,000

A study of the formation of stress granules to better understand a common cause of ALS

### Dr. Janice Robertson, University of Toronto, \$125,000

Is the pathology of ALS different in one part of the brain than another?

### Dr. Ekaterina Rogaeva, University of Toronto, \$125,000

Can environmental factors affecting genes explain why ALS affects people differently?

### Dr. Xavier Roucou, Université de Sherbrooke, \$125,000

Does a unique, hidden protein play a role in ALS?

### Dr. Christine Vande Velde, Université de Montréal, \$125,000

Could a previously unstudied protein play an important role in ALS?



*"As someone living with ALS, when I see the passion and dedication of the Canadian ALS research community, I am hopeful that we will soon find the answers we need to change the lives of people living with this disease. While there has been significant progress in the last few years, there is more work to be done and we must continue to invest in ALS research to bring us closer to a future without ALS."*

DENIS BLAIS,  
DIAGNOSED WITH ALS IN 2015

The ALS Canada Research Program awarded more than **\$1.5 million** in research grants in 2018:



**\$1 million for eight new research projects** focused on scientific discovery to treat ALS.



**\$720,000 for six trainee awards** that will help to create Canada's next generation of ALS researchers. Representing the last of the matched Ice Bucket Challenge funds awarded in partnership with Brain Canada<sup>2</sup>, these awards also represent a new partnership with La Fondation Vincent Bourque.

<sup>2</sup> Supported through the Canada Brain Research Fund with financial support from Health Canada, following matched funds committed after the Ice Bucket Challenge.



**2018 Trainee Awards,**  
in partnership with Brain Canada

**Abdullah Ishaque, University of Alberta, \$75,000**

Can advanced brain imaging techniques help to diagnose ALS at very early stages and predict disease progression?

**Dr. Sahara Khademullah, Université Laval, \$165,000**

*in partnership with La Fondation Vincent Bourque*

Can restoring motor neuron inhibition prevent or stop ALS progression?

**Lilian Lin, University of Toronto, \$75,000**

Is a loss of C9orf72 responsible for the most common protein abnormality in ALS?

**Yasir Mohamud, University of British Columbia, \$75,000**

Does a specific type of viral infection play a role in triggering ALS and its progression?

**Dr. Prateep Pakavathkumar, Université de Montréal, \$165,000**

Can using worm and stem cell models of ALS to screen for new ALS drugs identify a therapy that slows disease progression?

**Dr. Yulong Sun, University of Toronto, \$165,000**

Design a new lab test that may help diagnose people with ALS at the earliest stages of the disease

Grants are awarded following a competitive peer-review process that engages global ALS experts who evaluate a worldwide pool of applications to identify projects grounded in scientific excellence and with the potential to most quickly advance the field of ALS research.

***“People living with ALS have extremely limited options. Every day that I’m at work, my goal is to try to find answers that will help.”***

DR. SAHARA KHADEMULLAH, UNIVERSITÉ LAVAL

***“The progress of research in recent years has brought hope to those living with ALS that life-changing treatments could be possible. We are proud to be helping to build the capacity for future ALS research discovery by supporting Dr. Khademullah’s research as part of Vincent’s legacy.”***

ISABELLE LESSARD,  
WIFE OF VINCENT BOURQUE



**BECAUSE OF YOU:**



**180** Canadian ALS researchers attended the 2018 ALS Canada Research Forum, attending presentations and satellite meetings from Saturday through to Monday. It was inspiring to see a packed room at 8 a.m. on a Sunday morning as a full day of scientific presentations got underway!



Canadian investment is going further and Canadian ALS researchers will have better access to high-quality tools that can improve the quality and pace of ALS research thanks to the ALS Reproducible Antibody Platform, a partnership between ALS Canada, the ALS Association in the US and the Motor Neuron Disease Association in the UK.



Canada’s network of ALS clinicians received administrative resources to **facilitate clinical trial access across Canada** and collaborate on initiatives to improve the quality of care for people living with ALS.



More than **230 Canadians** were able to learn about the latest scientific developments in ALS research through the ALS Canada Virtual Research Forum, a free day of scientific talks available online.



MAHEK KAUR AND HER FATHER CHARANJIT SINGH

## WALKING IN HER

# mother's footsteps

When her dad first suggested holding a Walk to End ALS as a way to fulfill the requirements of a “Passion Project” for school, 14-year-old Mahek Kaur was hesitant. “I thought, ‘There’s no way I can pull it off,’” she says. “I’m too young. I don’t have the knowledge or resources to do it.” Even so, Mahek felt inspired: her mom, Amrit, had died of ALS in 2017 and the Walk would be a way to honour her memory.

“My mom was always giving to others,” Mahek explains. “This was a way I too could help by joining a cause close to my heart.” And so, the Etobicoke Walk took place in April 2018. It raised more than \$30,000 – an amazing result for a first-time event. The success is a testament to the power of a community to support its members and refocus the energy of their grief on giving back.

At first, Mahek found it hard to talk about her family’s struggle with ALS. She didn’t want sympathy, so she tried to keep it to herself. The night before she was scheduled to go on stage to promote the Walk at a high school assembly, she wasn’t sure if she was ready to share her story publicly, but news of her mother’s death had already spread. “If not now – then when?” she thought. “This was an important opportunity to educate people about ALS.”

With her dad’s ongoing encouragement and assistance from teachers, community members and her ALS Canada Regional Manager, Joanna Oachis, Mahek succeeded beyond her wildest dreams. “I learned I’m capable of more than I give myself credit for and that it’s possible to create change at any age,” explains Mahek, now 15. “My mother’s memory inspired me. In turn, I inspired others.”

## DOLLAR BY DOLLAR, YOUR GENEROSITY ADDS UP

Donors to ALS Canada collectively gave **\$7.3 million** in 2018, not including interest, investment returns and deferred revenue. Individuals, provincial ALS Societies, foundations, corporations and other organizations who gave \$1,000 or more in 2018 are acknowledged on our website at [www.als.ca/donors](http://www.als.ca/donors).



Donations left in estates and wills totalled **\$153,323** and large gifts from individuals, corporations and foundations totalled **\$709,563**.

Government employees gave generously in 2018: **\$191,005** from employees in federal government and corporate offices through workplace campaigns led by HealthPartners, and **\$62,148** from Federated Health Charities campaigns in Ontario. Both amounts are reported within the “other fundraising donations and income” section of our revenue.



# Walk to End ALS

**\$4+**  
MILLION

Walk to End ALS events took place in 34 Ontario communities, raising over \$2.1 million of a \$4+ million nationwide total. Of money raised through the Walk in other provinces, 40% of net proceeds were directed to ALS Canada for research grants and initiatives.



ALS Societies in each province generously provided a total of \$829,821 to ALS Canada in 2018 which includes 40% of their net WALK proceeds as well as additional giving.



**\$292,152**

The gently-used equipment generously donated to ALS Canada's equipment loan pool had an appraised value of more than \$292,152 which is reflected as a corresponding expense for the equipment program.



Thanks to new partnerships with Ports Toronto, Billy Bishop Toronto City Airport and Porter Airlines, and returning sponsor Equitable Bank, the Plane Pull to End ALS raised \$92,127 while giving participants a unique experience. Together with Hike to End ALS events in Ottawa and Toronto, these three signature fundraising events raised \$142,076.



A new corporate partnership with Orangetheory Fitness raised \$256,244 for the ALS Canada Research Program with generous donations arising from the Augie's Quest campaign.



iii HealthPartners  
PartenaireSanté

We Are Your Neighbours  
Nous sommes vos voisins

## Your gift of time

People affected by ALS know more than most how precious time is. That's why the efforts of ALS Canada volunteers are so valued. In 2018, volunteers like our 60+ Ontario Walk Coordinators contributed more than 9,800 hours to advise the organization, organize fundraising events, provide administrative support and much, much more.







THE PEACOCK FAMILY: BEN, MEGEN, KELSEY AND THEIR MOTHER SUSAN, WITH FRAMED PICTURE OF FATHER AND HUSBAND JEFF

## COURAGE TO LIVE;

## courage to carry on

Shortly before the 2017 Walk to End ALS, Jeff Peacock posted a Facebook message to make a last-minute pitch for donations. He was fully cognitive but physically debilitated by the disease: a BiPAP machine made his breathing more comfortable, a feeding tube provided nutrients, and eye gaze technology made it possible for him to type. Entering each character with a blink of his eyes, the message took days to complete.

Jeff died in August 2018, five years after his ALS diagnosis. “I’ll forever be affected by our journey,” says his wife, Susan. “Living with ALS is unimaginable unless you’ve been there. It’s been an enormous struggle, but ALS also brought us closer as a family and with our friends and community,” she explains.

“Fundraising for the Walk gave us something positive to focus on – and for Jeff, who was reluctant at first, it became one of the most important days of the year.”

Susan says she and her family have been grieving since the day Jeff received his ALS diagnosis. She admits she is often moved to tears thinking about it all, but she also feels motivated and determined to do what she can to help others. “His courage and will to live as long as he did was a true testament to his character.”

Whether it’s talking to someone who is struggling with ALS today, or fundraising for the next Walk, Susan will continue to rally the community in her husband’s honour.

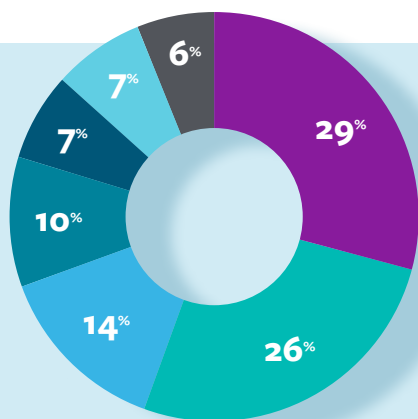


# YOUR DONATIONS AT WORK

- **Support services:** To respond to the needs of people living with ALS in Ontario, we spent \$1,003,007 providing direct service to people and families living with ALS and an additional \$1,299,899 to provide equipment.
- **National research:** In 2018, ALS Canada awarded \$1.5 million in new research grants. We accounted for the full financial commitment of these grants in 2018, although some will be paid out over multiple years. An additional \$671,519 was used to support the ALS Canada Research Program and the broader ALS research community in Canada. Matched funds of \$288,992 from the Brain Canada Foundation and leveraged funds of \$200,000 USD from each of the ALS Association (US) and Motor Neuron Disease Association (UK) for the ALS Reproducible Antibody Platform are reflected on those organizations' financial statements, resulting in a larger research investment than our financials show.
- **Fundraising:** Our revenue and the expenses associated with generating it are analyzed regularly to ensure our cost of fundraising is controlled. In 2018, our cost of fundraising was 27%, which takes into account 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.

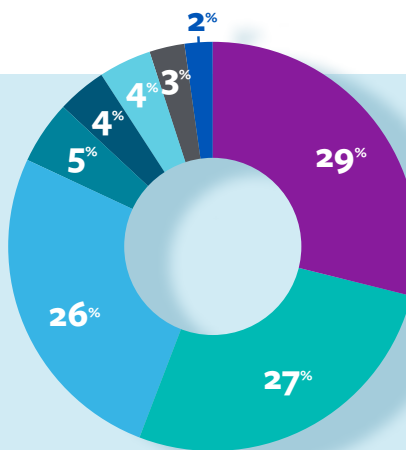
- **Public Awareness:** Investments in 2018 have enabled us to refresh the look of our signature fundraising event, the Walk to End ALS, and to increase awareness through digital marketing and advertising.
- **Advocacy:** Through our advocacy investment, we were able to bring forward the perspectives of people living with ALS to government stakeholders, including input into a study of barriers to access for expensive drugs for rare diseases and CADTH's review of edaravone.
- **Other Charitable Purpose:** This year we invested additional funds in volunteer development and other national programs.
- **Governance:** The Board of Directors met in person four times in 2018 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 the generous giving of their time.



2018 Revenue

Other Fundraising Donations and Income \$2,331,872	From Provincial Societies \$829,821
Ontario Walk to End ALS \$2,101,506	Tribute and Monthly Giving \$581,572
Direct Mail \$1,092,267	Fundraising Events \$517,736
	ALS Ice Bucket Challenge* \$505,595

\* Deferred revenue



2018 Expenses

Support Services \$2,302,906	Advocacy \$326,196
National Research \$2,151,787	Administration \$288,416
Fundraising \$2,098,771	Other Charitable Purpose \$206,354
Public Awareness \$438,593	Governance \$189,541

# FINANCIAL SUMMARY

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

ALS Canada adheres 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, 2018 we had \$1.8 million in deferred revenue remaining. These funds are held in income-generating secure investments.

ALS Canada invests all funds under the guidelines of an established investment policy approved by the Board of Directors. At December 31, 2018, ALS Canada held \$3.9 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. This represents deferred revenue, research grant commitments, and funds available for future investment.

## STATEMENT OF FINANCIAL POSITION

As at December 31, 2018

In \$	General Fund	Research Fund	Tim E. Noël Endowment Fund	2018	2017
<b>Assets</b>					
<b>Current assets</b>					
Cash	\$ 1,043,305	\$ 1,590,221	\$ 1,300,000	\$ 3,933,526	\$ 9,069,316
Short-term investments	310,754	8,989,079	–	9,299,833	4,593,740
Accounts receivable	436,128	214,844	–	650,972	644,977
Prepaid expenses and other assets	124,146	–	–	124,146	49,197
	\$ 1,914,333	\$ 10,794,144	\$ 1,300,000	\$ 14,008,477	\$ 14,357,230
<b>Long-term investments</b>	–	1,215,173	–	1,215,173	2,428,292
<b>Capital assets</b>	70,739	–	–	70,739	86,053
<b>Intangible assets</b>	82,107	–	–	82,107	131,383
	\$ 2,067,179	\$ 12,009,317	\$ 1,300,000	\$ 15,376,496	\$ 17,002,958
<b>Liabilities</b>					
<b>Current liabilities</b>					
Accounts payable and accrued liabilities	\$ 467,358	\$ 55,098	–	\$ 522,456	\$ 465,581
Current portion of deferred revenue	684,847	512,500	–	1,197,347	1,355,353
Current portion of research grants payable	–	2,198,877	–	2,198,877	2,432,902
	\$ 1,152,205	\$ 2,766,475	–	\$ 3,918,680	\$ 4,253,836
<b>Long-term deferred revenue</b>	\$ 354,448	\$ 253,765	–	\$ 608,213	\$ 1,079,111
<b>Long-term research grants payable</b>	–	4,228,504	–	4,228,504	5,006,717
	\$ 1,506,653	\$ 7,248,744	–	\$ 8,755,397	\$ 10,339,664
<b>Net assets</b>	560,526	4,760,573	1,300,000	6,621,099	6,663,294
	\$ 2,067,179	\$ 12,009,317	\$ 1,300,000	\$ 15,376,496	\$ 7,002,958



## STATEMENT OF OPERATIONS

For the year ended December 31, 2018

In \$	General Fund	Research Fund	Tim E. Noël Endowment Fund	2018	2017
<b>Revenue</b>					
Fundraising and donations	\$ 4,500,089	\$ 2,175,055	–	\$ 6,675,144	\$ 6,844,918
Direct mail campaign	1,035,353	56,914	–	1,092,267	1,049,222
Interest and investment income	130,962	61,527	469	192,958	227,471
	\$ 5,666,404	\$ 2,293,496	\$ 469	\$ 7,960,369	\$ 8,121,611
<b>Expenses</b>					
Research grants	–	\$ 1,525,268	–	\$ 1,525,268	\$ 2,062,540
Other research support	–	671,519	–	671,519	725,775
National programs	116,515	–	–	116,515	101,155
Ontario client support services	2,302,906	–	–	2,302,906	2,404,806
Public awareness	438,594	–	–	438,594	87,820
Advocacy	326,196	–	–	326,196	234,216
Volunteer development	89,838	–	–	89,838	98,484
	\$ 3,274,049	\$ 2,196,787	–	\$ 5,470,836	\$ 5,714,796
<b>Other</b>					
Fundraising	\$ 2,098,771	–	–	\$ 2,098,771	\$ 1,808,418
Administrative	288,416	–	–	288,416	403,129
Governance	94,770	94,771	–	189,541	200,264
Bad debt recovery	–	(45,000)	–	(45,000)	(30,000)
	\$ 2,481,957	\$ 49,771	–	\$ 2,531,728	\$ 2,381,811
	\$ 5,756,006	\$ 2,246,558	–	\$ 8,002,564	\$ 8,096,607
<b>Excess (deficiency) of revenue over expenses</b>	<b>\$ (89,602)</b>	<b>\$ 46,938</b>	<b>\$ 469</b>	<b>\$ (42,195)</b>	<b>\$ 25,004</b>

## STATEMENT OF CHANGES IN NET ASSETS

For the year ended December 31, 2018

In \$	General Fund	Research Fund	Tim E. Noël Endowment	Total
<b>Balance, December 31, 2016</b>	\$ 705,006	\$ 4,633,284	\$ 1,300,000	\$ 6,638,290
Excess (deficiency) of revenue over expenses	33,216	(30,989)	22,777	25,004
Interfund transfers	(88,094)	110,871	(22,777)	–
<b>Balance, December 31, 2017</b>	\$ 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)	–
<b>Balance, December 31, 2018</b>	\$ 560,526	\$ 4,760,573	\$ 1,300,000	\$ 6,621,099

## ALS CANADA LEADERSHIP



ALS Canada has a skills-based Board of Directors whose strategic leadership ensures donor dollars are maximized to serve the organization's charitable purpose.

### **2018 BOARD OF DIRECTORS**

Ronald Foerster, *Chair*

Josette Melanson, *Vice Chair*

Carol Cottrill

Dr. Heather Durham

Laura Gay

Dr. Angela Genge

Anne Marie Giannetti

Noella LeBlanc

Patrick Merz

Patrick Nelson

Vincent Quinn

Daniel Riverso

Dr. Michael Spivock

Dr. Christine Vande Velde



## 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** ensures that research activities contribute to the strategic priorities of ALS Canada and are carried out with integrity.

Dr. Christine Vande Velde, *Chair*  
Dr. Heather Durham  
Dr. Angela Genge  
Dr. François Gros-Louis  
Dr. Wendy Johnson  
Dr. Charles Krieger  
Dr. Jasna Kriz  
Dr. Colleen O'Connell  
Dr. David Taylor  
Dr. Yana Yunusova

Grounded by personal and professional experience, the **Client Services Advisory Council** helps to improve the journey of people and families living with ALS in Ontario.

Anne Marie Giannetti, *Co-Chair*  
Patrick Nelson, *Co-Chair*  
Ron Black  
Sheldon Crystal  
Tasneem Dharas  
Lisa Droppo  
Vincent Quinn  
Sarah Reedman  
Dr. Christen Shoesmith  
Jane Sosland  
Dr. Michael Spivock  
Dr. Jeff Sutherland  
Darlene Sutherland  
Dr. Anu Tandon  
Danielle Wells

### TOGETHER WE CAN ACHIEVE MORE

**ALS Canada has national responsibilities within the federation of eight provincial ALS Societies across Canada. Together, we advance federal advocacy and 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)  
Health Charities Coalition of Canada (HCCC)  
Palliative Care Matters

#### Provincial:

Canadian Assistive Devices Association (CADA)  
Ontario Neurodegenerative Disease Research Initiative  
Ontario Caregiver Coalition  
Quality Hospice Palliative Care Collation of Ontario

## ALS Society of Canada

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Toll-free 1-800-267-4257  
[www.als.ca](http://www.als.ca)



@ALSCanada

Founded in 1977, the ALS Society of Canada (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.

