

A Community Connected

2017 ANNUAL REPORT TO THE COMMUNITY



Together, we h

... face the day

... find the answers



Have the power to...

... drive change

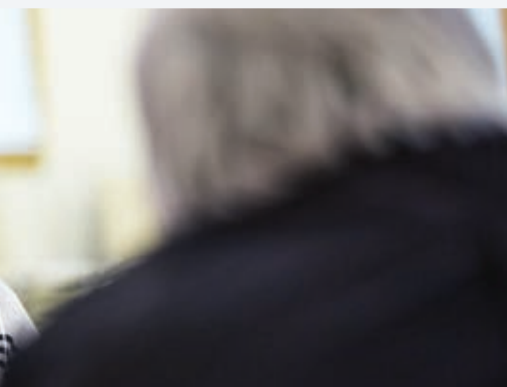
... keep memories alive

...make
change
happen

ALS can be such an isolating disease. It exacts a terrible toll on individuals and their families. Together, we are working to lessen that burden and instill hope. By connecting people to services and support in their community. By collaborating to find research answers. By initiating meaningful dialogue to guide policy. By partnering to raise funds.

This report is ALS Canada's way of saying thank you for all you make possible, and letting you know about the difference you're making.





You make all the difference

This report is to celebrate you, our supporters. In it, you'll meet four extraordinary people – Shelley, Denis, Norm and Beth – each champions of the ALS Canada cause whose stories underscore the passion and commitment driving our community forward. You will also find highlights from 2017 that illustrate the impact you are having and the care and consideration we have given to investing your donor dollars wisely and efficiently.

If you have a personal connection to ALS, you'll know our community is a resilient and hopeful one, filled with incredible people doing their part to create a future without ALS. ALS Canada has the privilege of helping to connect the many people and organizations who share our cause. We know we can accomplish so much more working together – connections that are possible only because of your support.

In Ontario, where we provide community-based support, we made strides to better respond to the needs of people living with ALS. Through thoughtful changes to our geographic coverage informed by feedback from those who receive our services, people living with ALS are now able to have more frequent touchpoints with their local ALS Canada representative, should they desire. We have also been able to put donor dollars to better use by lessening the time our field staff spend on the road ([page 6, Shelley's story](#)).

If you have a personal connection to ALS, you'll know that our community is a resilient and hopeful one, filled with incredible individuals all doing their part to create a future without ALS.

Over the course of the year, we visited ALS clinics and research laboratories across the country to see some of the important work being funded through the ALS Canada Research Program and to meet with some of the volunteers who are participating in clinical trials you are helping to make possible. An additional \$3 million was awarded in 2017 for 12 new research projects – and because the research we fund is vetted by an international panel of experts, you can be confident it is the best ALS research in the country with the greatest potential to slow down or even stop the disease ([page 10, Denis's story](#)).

And because ALS knows no boundaries, international collaborations are important to ensure Canada is represented in initiatives with the potential to make a difference for people living with ALS no matter where they live. We were proud to contribute the first 200 Canadian DNA profiles to Project MinE, an international collaboration that seeks to identify the genetic 'signature' that leads someone to develop ALS, and for which we continue to advocate for federal funding ([page 14, Norm's story](#)). Our partnership with Brain Canada that started during the Ice Bucket Challenge continued with additional funding provided in support of Project MinE, enabling our contribution to go that much further.

While we are focused on the needs of people living with ALS today and the research that will help to create a future without the disease, we are also mindful of how our organization needs to evolve in anticipation of potential new treatments that are widely believed to be on the horizon. We would like nothing more than to put ourselves out of business – but until that day comes, we must consider our role in helping people living with ALS to have the best standard of care; in equitably



accessing new treatments; and in responding to information needs. And of course, to carry out this work we must have the financial resources to successfully navigate a complex, changing, and economically-challenging environment (page 18, Beth's story).

To that end, a major undertaking in 2017 was the development of ALS Canada's new strategic plan to guide our work over the next five years and beyond. This process was grounded in the perspectives of many representatives from our community: people living with ALS, caregivers, donors, researchers, clinicians, our Board, provincial partners, the Canadian and international research community, and other health charities. Their input was essential in helping to shape our shared vision for a future without ALS. Collectively, and with the continued support of generous donors like you, we know that a future without ALS can become a reality.

Ron Foerster, Chair

Tammy Moore, CEO

THE FACTS ABOUT AMYOTROPHIC LATERAL SCLEROSIS (ALS)

ALS is a fatal disease with no cure.

ALS causes the brain to gradually stop communicating with the muscles in the body — taking away the ability to move, speak, eat, swallow, and eventually breathe.

80% of people living with ALS die within 2-5 years of diagnosis.

An estimated 3,000 Canadians are living with ALS.

Every year 1,000 Canadians are diagnosed with ALS and a similar number die.

5 to 10% of ALS cases are hereditary.

The average cost of ALS to a family is **\$150,000 - \$250,000¹**.

Also known as **Lou Gehrig's disease** and motor neuron disease (MND).

¹ Source: "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.

SHELLEY

Everyone living with ALS is burdened with the terrible knowledge that their disease is terminal. Facing each day with optimism is not easy. It wasn't easy for Shelley Sterling, who passed away in May of 2018. But even when ALS had taken her ability to walk and compromised her breathing, Shelley found a way to maintain her sense of humour and her positive outlook.

After a night this past winter when she spent long hours sitting up in bed coughing and "huffing and puffing," Shelley still found a way to bring humour to the situation by asking her ALS Canada Regional Manager, Melissa, "how the Big Bad Wolf did it" when he needed to fill his lungs with air.

Shelley was grateful for many things in her life, especially the loving care she received from her husband, Jim, her children Hollie and Tom, and her big black Newfoundlander, King Arthur, who didn't leave her side the night she was in distress as a result of that serious coughing fit. She also felt lucky for the support she received from ALS Canada and inspired to give back by fundraising for the WALK for ALS.

Shelley had a gift for making friends and connecting with people, so it wasn't too surprising that the first year she participated in the WALK for ALS, 120 of her friends showed up and helped raise \$17,000.

After she was diagnosed, Shelley made an effort to meet other people with the disease. When she was first in touch with ALS Canada, her Regional Manager Laurie connected her with others living with ALS. The resulting sense of community was uniquely comforting to Shelley, who received practical tips like purchasing specially-shaped bowls and spoons with curved handles to make eating food easier; using a portable power wheelchair to help get around outside of the house, and listening to webinars hosted by ALS Canada for helpful information.

Shelley spoke highly of the support she received from Laurie – and also Melissa, who became her new Regional Manager in 2017. Shelley said the transition was "seamless," and she talked about how much she valued Melissa's positive attitude, her knowledge, and her willingness to cover any subject. Shelley expressed gratitude for the way Melissa listened to her concerns and for her quick turnaround whenever Shelley had a question that needed further investigation.



Ultimately, the grace and dignity with which Shelley faced her struggle with ALS was a testament to her extraordinary character and an inspiration to everyone who became part of her community.

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MELISSA

Even though she supported Shelley for less than a year, knowing that she makes a difference in the lives of so many families living with ALS – and sharing moments of laughter despite the challenges – keeps Melissa inspired to do the best she can for all the people she supports.

Melissa (pictured below with Jim, Tom and Hollie Sterling) joined ALS Canada in 2017 as one of three new Regional Managers after the organization realigned its service geography to support more regular in-person touchpoints with people across Ontario. Because people living with ALS have such unique needs that are frequently beyond what the health care system is able to provide, Melissa's role involves connecting on a regular basis with about 100 families like Shelley's. In addition to visiting people in their homes on a regular basis, she also stays in contact by phone, email, or through "virtual calls" to answer questions as they arise.

A typical workday for Melissa might include two or three visits. Initially, families are often dealing with the shock and grief of a recent diagnosis. Melissa will help provide education and verify that an intake form has been completed with the local LHIN (Local Health Integrated Network) so that families can have timely access to healthcare professionals such as occupational therapists, speech language pathologists, and social workers in addition to personal support workers to help with daily activities.

While medical advice is beyond the scope of ALS Canada's service offering, Melissa is able to help by making referrals and advocating on behalf of families to receive adequate outside support. She is also there to talk through some of the difficult emotions, often at times when families are feeling particularly isolated and alone in their struggle.

Melissa also plays a vital role helping people access equipment free of charge. She remembers Shelley saying that it would have been hard for her family to manage without this support including a wheelchair, hospital bed, and a power chair on loan from ALS Canada. "The two things I hear most from the families I work with," says Melissa, "is how equipment from ALS Canada has allowed them to continue a quality of life without placing financial strains on them. People often comment on how responsive we are to rapidly changing needs and that it's one less thing they have to worry about."



THE DIFFERENCE YOU MADE IN 2017



PERSONAL CONNECTION

You enabled people living with ALS across Ontario to receive **more frequent and personalized support** with the addition of one new full-time Regional Manager position and two part-time ones. ALS Canada Regional Managers offer home visits to discuss individual and family needs, provide information and education, facilitate support groups, and help fill the gaps in care and support not addressed by our healthcare system.

Community-based Support



"Secura Financial provides ongoing support for ALS Canada through an annual Golf Tournament. The funds raised each year go towards purchasing equipment for people living with ALS in the Kingston area."

Secura Financial,
Corporate Sponsor



1,100

ALS Canada Regional Managers conducted 1,100 family visits to provide personalized support.



184

Support group meetings took place in 15 Ontario communities for people with ALS and their caregivers.



108

Educational sessions were delivered to raise awareness about ALS among healthcare workers and community groups.





REDUCING EQUIPMENT COSTS

Your support helped to further lessen the financial burden on families by **enabling ALS Canada to absorb all costs associated with delivering and returning our loaned equipment.**

The introduction of a personal spending account means that ALS Canada can purchase small bathroom items for people to address their individual safety needs, while saving the time and money that were required in making these items available through our loan pool.



2,987

Pieces of equipment that improve quality of life were delivered free of charge.



"I support ALS Canada because I know what a difference support services can make. When my wife Judith was alive, we desperately wanted to keep her at home for as long as possible. ALS Canada was able to provide a wheelchair and a ceiling lift, both of which were very helpful."

James King

IN TRIBUTE

Remembering Ron Myles, ALS Canada Ambassador, Northern Ontario

Ron Myles worked as a manager in hotels and restaurants for 40 years, and continued to work at Home Depot after retiring at age 60. He was diagnosed with ALS in 2015. Until his death in November 2017, he refused to let the disease slow him down. Instead, he became an advocate for ALS Canada, spreading the word about ALS, sharing his personal journey on social media, telling his story in a fundraising letter to inspire donors to give, and participating in public events to raise awareness.

In June 2016 Ron's message was broadcast online to support ALS Awareness month. He had difficulty speaking because the disease had progressed. He had lost the ability to walk. But he did not lose his desire to embrace life. Ron spoke about precious moments in his day, sitting in his wheelchair enjoying the sunshine on his deck and taking pleasure in the company of his young grandchildren.

Ron chose to "seize the day" by sending positive thoughts out to the world. He couldn't change the course of the disease, but he left us with words of hope and inspiration: "I'm going to die from ALS but it's not going to take my life away."



DENIS' STORY

finding

Denis Blais has a favourite Bob Marley quote: “You never know how strong you are until being strong is your only choice.” Since his ALS diagnosis in 2015, those words have never been more profound. “Having to live with a terminal disease is the toughest challenge life has ever thrown me,” says Denis.

He is the first to profess that he and his husband, Tom, have cried many tears and spent days feeling overwhelmed. But that hasn't stopped him from living in the moment and finding meaning. Today, he focuses on doing what he can to advance ALS research. “We have no choice in the matter,” explains Denis. “We have to raise money for ALS research. Without research, there is no hope for treatments, or for a cure.”

In 2016, when Denis and Tom launched their own Ice Bucket Challenge, they raised \$11,000 in just one week, almost four times their initial goal. They were so encouraged by the response that they did it again the following year. In 2017, they also formed team “Feathers of Hope” for the annual WALK for ALS in downtown Toronto. Denis wanted the team name to reflect the idea that “hope becomes a very important thing in your life” when you have ALS, so he took inspiration from one of his favourite poems by Emily Dickinson, “Hope is a Thing with Feathers.” Securing the commitment of Tom's employer, RBC, contributed significantly to the overall success of the team, but for Denis, what made the day stand out more than anything was the wonderful feeling of connection walking among so many members of the ALS community.





“We must take an active role in spreading awareness and work with ALS Canada to raise money to support the ALS community and ALS research.”

need

Denis’ involvement with ALS Canada doesn’t end with his fundraising efforts. In 2017, he and Tom accepted an invitation to speak at the annual ALS Canada Research Forum that brings together Canada’s ALS research community to share insights and updates as well as opportunities for collaboration. Denis was particularly impressed with how many different angles researchers are taking to try to solve the ALS puzzle, increasing the chances that we will soon find the answers we need to develop new treatments so people with ALS can have a better quality of life and a longer life expectancy.

Last year, Denis also had the opportunity to observe ALS Canada’s peer review process at which research proposals are evaluated by a panel of independent experts. What most impressed him was the amount of time the international panel spent carefully reviewing and discussing all the submissions to ensure that grants are awarded to the projects with the most hope for treatments that will slow or even stop the disease.

“We are the face of the disease,” says Denis. “We must take an active role in spreading awareness and work with ALS Canada to raise money to support the ALS community and ALS research.” That kind of attitude is sure to have a ripple effect that will spread hope and inspire others to keep up the momentum!



Momentum to fuel the next research breakthrough

DEDICATED ANNUAL FUNDING FOR ALS RESEARCH

ALS Canada is the **only dedicated funding mechanism in Canada for ALS research**. Funding decisions are based on a **rigorous peer-review process** that engages a panel of independent experts from around the world.

ALS Canada awarded \$3 million in research grants in 2017. Learn more at www.als.ca/2017research.



"I am fighting for a cure to save my dear friend, Kristine, who has been living with ALS for four years. Seeing the smile on my best friend's face pushes me forward towards finding a cure."

Elizabeth Skelly

Dr. Turgay Akay,
Dalhousie University,
\$125,000

What can we learn from mice that are able to walk almost normally despite significant loss of motor neuron function?

Dr. Flavio Beraldo,
Western University,
\$110,770
Could touchscreen technology help to improve testing for the cognitive impairment that occurs in some cases of ALS?

Dr. Yves De Koninck,
Université Laval,
\$125,000
Could targeting the activity of motor neurons in the spinal cord be a new way to diagnose and treat ALS?

Sonja Di Gregorio,
Western University,
\$50,000
How might misfolded proteins that occur in ALS cause cells to die?

Dr. Heather Durham,
McGill University,
\$1.8 million*
Can a promising drug combination address one of the defining biological characteristics of ALS?

Dr. Derrick Gibbings,
University of Ottawa,
\$125,000
Can microscopic bubbles in our bodies be used to deliver ALS treatments through the bloodstream?

Audrey Labarre,
Université de Montréal,
\$75,000
Will probiotics that improve ALS symptoms in worms also work in mice?

Dr. Marco Prado,
Western University,
\$125,000
Can a protein that becomes toxic in most cases of ALS be protected by adjusting the levels of another, "guardian" protein?

Dr. Richard Robitaille,
Université de Montréal,
\$121,048
Why are eye muscles often more resistant to ALS, and what can we learn about this that could help to preserve the function of other muscles?

Jay Ross, McGill University,
\$75,000
Could whole genome sequencing reveal new areas of genetic mutations that make some people more likely to develop ALS?

Dr. Stefano Stifani,
McGill University,
\$124,930
Could the change in communication processes between motor neurons and the immune cells of the nervous system after an ALS diagnosis help to identify new treatment targets?

Dr. Lorne Zinman,
University of Toronto,
\$124,949
Can image-guided focused ultrasound technology be used safely in people living with ALS as a means of delivering future treatment?

* In partnership with the Brain Canada Foundation through the Canada Brain Research Fund with financial support from Health Canada, following matching funds committed after the Ice Bucket Challenge.



FUELING COLLABORATION WITHIN CANADA AND ABROAD

ALS Canada is spearheading Canada's participation in **Project MinE**, a collaborative, multi-national initiative with more than 15 participating countries. The project will map the full DNA profiles of 15,000 people with ALS and 7,500 control subjects, providing a clearer understanding of how ALS is caused and in turn, accelerating our ability to identify how to treat it.

The first 200 Canadian DNA profiles (of a target 1,000) were contributed to Project MinE with funding from ALS Canada and matching funds from Brain Canada.



"I get really excited to pursue questions and solve problems in a scientific context. I want to understand the underlying mechanisms of ALS so that we can find a therapy."

Sonja Di Gregorio,
Western University



"We hope this new technology will be proven safe and effective in order to move quickly into clinical trials using human volunteers."

Dr. Derrick Gibbings,
University of Ottawa



"This new avenue of research may help to identify future treatments that could slow disease progression and improve quality of life."

Dr. Richard Robitaille,
Université de Montréal



"I support ALS Canada because I lost my father and both my sisters to a hereditary form of ALS. There is a possibility that I, my children, my nieces and nephews will also develop ALS. I feel a sense of gratification knowing that I am contributing in my own way to help find a treatment and hopefully a cure for ALS."

Paula Phillips



SUPPORTING CLINICAL TRIALS

In 2015, following the Ice Bucket Challenge, ALS Canada in partnership with Brain Canada awarded funding for a Phase 2 clinical trial for the drug pimozide. Led by the University of Calgary with nine hospital centres participating across Canada, the trial began recruiting participants in 2017 and will study the safety and effectiveness of pimozide in slowing the progression of ALS in a larger sample of ALS patients than was studied previously. Pimozide, a drug originally used in schizophrenia, has been shown to enhance communication between the muscles and the nerves in laboratory animals born with the equivalent of the human form of ALS.

DEVELOPING CANADA'S ALS RESEARCH COMMUNITY

The Canadian ALS research community is growing. The work of 70 Canadian researchers is predominantly focused on ALS, double the number from 5 years ago.

140

Canadian researchers attended the 13th annual ALS Canada Research Forum supporting knowledge sharing and collaboration among Canada's ALS research community.

HELPING TO KEEP CANADIANS INFORMED

400+

people learned about the latest advancements in ALS research in Canada by participating in ALS Canada's research webinars and Virtual Research Forum.



driving change

Norm McCauley is hoping to carry on the legacy of his younger brother, Chris, who was an outspoken and passionate advocate for the ALS community. “Chris was never one to worry about himself. He didn’t once complain about his disease,” recalls Norm.

Instead, Chris focused his energy on pressing the federal government to move beyond talk with a budget allocation for ALS research, and specifically, for Project MinE. Chris had plans to take his message to Ottawa in person at a meeting with the Minister of Health, but unfortunately, a last-minute scheduling change meant that Chris was too sick to travel once the meeting was rebooked.

Now, Norm (pictured here with brother Tim) is eager to continue fundraising and raising awareness about ALS. “When the advocacy comes from people afflicted by the disease or families who have been through it,” says Norm, “I definitely think the message can be even stronger. And when we have enough voices collectively, it gives us all hope.” Norm talked a lot with Chris about Project MinE, the importance of knowledge sharing across international borders, and the potential for genetic research to provide answers. He is thrilled that ALS Canada raised enough funding in 2017 for the first 200 genetic profiles of people with ALS. He is inspired by the fact that other countries are

continuing to join in this important global effort. Norm also feels hopeful that the research may benefit other related neuromuscular diseases. “That makes it a really good front-end investment for the common good,” he says. “And that’s not going to happen without a strong advocacy voice.”

Not all families can put together a care team like the McCauley’s. Chris’s wife, Maria, Norm’s mother, his three other brothers, and his two sisters all took part. “It would take four of us to lift Chris in his wheelchair to come downstairs,” says Norm. “We made it work, but long-term care wasn’t even an option for Chris because of his breathing assist equipment. More needs to be done at the provincial level to support family caregivers.”

Norm is busy thinking about how he can make the biggest difference through advocacy. As a start, he wrote a letter to the all-party ALS Caucus and invited ALS Canada CEO, Tammy Moore, to speak to his high school students. Every opportunity to get the word out is a chance to bring the message home.

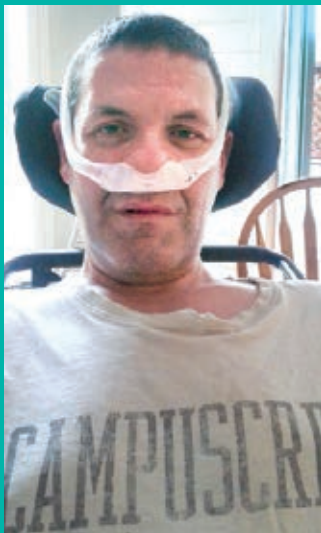


Norm talked a lot with Chris about Project MinE, the importance of knowledge sharing across international borders, and the potential for genetic research to provide answers.



IN TRIBUTE

Remembering Chris McCauley, ALS Canada Ambassador for Project MinE



Chris McCauley was diagnosed with ALS when he was 52, just a short time after celebrating his first wedding anniversary in 2014. He was a talented athlete and played two seasons of pro hockey before establishing his career in social work.

While Chris knew there was little chance of a medical breakthrough that would change his own prognosis, he didn't let that stop him wanting to make a difference. After his ALS diagnosis, Chris immersed himself in knowledge about the research taking place to understand the underlying causes of the disease. As he put it, "I think of others who will come after

me and like me, lose the blossom of their health so insidiously. I want to do something to make it better."

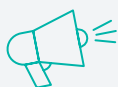
Chris served as ALS Canada's Ambassador for Project MinE until his death in August 2017. He rallied support behind this global research initiative because he saw the potential to answer some of the many unsolved questions about ALS by mapping full DNA profiles of 15,000 people living with the disease. He also recognized Canada's important role in contributing 1,000 DNA profiles, and volunteered to be one of the first Canadians with ALS to participate in the genetic sequencing for Project MinE.



Engaging in meaningful dialogue to influence policy

ADVOCATING FOR THE ALS COMMUNITY ON PARLIAMENT HILL

The ALS Caucus is an all-party group of parliamentarians and senators who have come together to better understand the realities of ALS and opportunities to address them. ALS Canada played a leadership role in spearheading the creation of the ALS Caucus in late 2016.



Your support enabled ALS Canada to attend all three ALS Caucus meetings that took place in 2017, as well as meetings with many other government representatives. Topics included the need for equitable and affordable access to new therapies and the importance of dedicated, ongoing research investment that will help to ensure Canada is an attractive destination for companies to bring clinical trials and emerging therapies.



Introduced by ALS Caucus member Judy Sgro, MP, Motion 105 calling upon the federal government to play a leadership role in supporting ALS research received unanimous approval in the House of Commons.



International research collaboration Project MinE continued to be a focus for ALS Canada's federal budget ask, for which we submitted a pre-budget brief. Together with our provincial partners we engaged MPs across the country in voicing their support for federal funding for Project MinE where Canada is poised to play a leadership role.



ALS Caucus Chair Francis Drouin, MP and ALS Caucus Member Marc Serré MP visited ALS research labs in Vancouver, Edmonton, Toronto, Ottawa, and Montreal to see the work the ALS Canada Research Program is investing in. Each visit highlighted the collaboration and sense of community that exists between ALS clinics, research labs, clinical trial participants, and ALS Societies across Canada.



EQUITABLE ACCESS TO NEW THERAPIES

Following the United States Food and Drug Administration's approval of a new ALS therapy, Radicava, ALS Canada was active throughout 2017 in connecting with its manufacturer Mitsubishi Tanabe Pharma America and with Health Canada about the need for Canadians to have equitable access to this drug through the channels within the healthcare system.

With the possibility of a second ALS treatment to be approved by Health Canada – and more potential ALS therapies in the pipeline – ALS Canada has built further capacity for its public affairs function to be able to bring forward the voices of people living with ALS and to navigate the complex environment surrounding drug access and cost reimbursement.



IMPROVING THE STANDARD OF CARE

Until research results in new therapies that profoundly change the way someone experiences ALS, it is important to advocate for better daily living. Donor support enabled ALS Canada to advocate on a number of fronts related to a better standard of care.



ALS Canada made a formal request to the **Ontario government to provide non-invasive breathing devices** for people with ALS in long-term care facilities and residential hospices when they are no longer able to remain at home, and specialized training for the staff working with them.

ALS Canada continued to advocate in support of a palliative care framework provincially as well as federally. Palliative care provides comfort and support to patients and families during a life limiting illness, at the end stages of life, and when dealing with grief and loss. It includes relieving pain and other symptoms; preventing and relieving psychological and spiritual suffering; and improving quality of life.



As a member of the Palliative Care Matters Steering Committee, ALS Canada supported Bill C-277.

Introduced by Marilyn Gladu, MP, it provides for the development of a national palliative care framework and received Royal Assent in December 2017.



Within Ontario, **ALS Canada supported Bill 182, the Compassionate Care Act**, a private member's bill introduced by Sam Oosterhoff, MPP, to introduce a provincial framework on hospice palliative care.

BETH'S STORY

keeping memories

Beth Robertson and her husband, Tim, were always active community members but it wasn't until after Tim was diagnosed with ALS in 2004 that ALS Canada became the focus of their fundraising and volunteering efforts.

Over the years, Beth and Tim, their three children, their parents, and Tim's siblings all rallied behind the cause, returning year after year to support ALS Canada events such as the WALKs, golf tournaments, and the annual Plane Pull.

"Tim's Titans" was the name of the team the Robertson family formed for the Hamilton WALK for ALS in 2004. Two years later, Beth's 16-year-old daughter, Lindsay, founded the Halton Region WALK for ALS. Lindsay has been running the event ever since, including last year's first "In Memory Of" Walk for which Tim's Titans raised a record amount. "I am so proud of Lindsay," says Beth, "and after all this time, she's still all in." The mother and daughter team joined other fundraising walks in the past, but Beth says there's something very special about the WALK for ALS where so many participants have a connection with the disease. "There's a tremendous feeling of togetherness, being surrounded by friends and seeing all the people with ALS who show up at a WALK for ALS despite the hardship."

One of the greatest challenges is finding new sponsors to raise more money for the event every year. "Funding is more important than ever," Beth says. "We're at a crossroads. Treatments will help people live longer like Tim and that means we are going to need a lot more money to meet higher demand for education about ALS,



ries alive



“There’s a tremendous feeling of togetherness, being surrounded by friends and seeing all the people with ALS who show up at a WALK for ALS despite the hardship.”

one-on-one support from Regional Managers, and equipment like shower commodes and wheelchairs.” Beth feels confident ALS Canada is in a strong place today, with dynamic leadership to guide the organization. But she also knows there’s a lot of work ahead to ensure there is adequate funding in place to address new needs as they evolve.

Nowadays, Beth is more involved than ever. She volunteers in the ALS Canada office every week to help with administration, work she recognizes would have been impossible when she was still employed as a teacher and caring for Tim full time. She’s also volunteered to help caregivers attending ALS Canada support groups, and she accepted an invitation last year to share her personal perspective during consultations to inform the strategic planning process at ALS Canada. This year, for the first time, Lindsay is handing over some of the responsibility of running the WALK for ALS to her mom, who is volunteering as a WALK Coordinator. Devoting herself to the cause helps Beth work through her grief and honour Tim’s memory. She finds fulfillment doing something truly meaningful. “It’s what keeps me going,” she says with a big smile.

Donor dollars driving momentum



"I was with my mom when she received her ALS diagnosis – she was frozen with fear so I took her in my arms and we both cried. She was a single mother and she was always there for me. I absolutely adored her. I started fundraising for ALS Canada as a way to honour her memory, spread awareness and raise funds for an organization that was there for me when I really needed the help. I support ALS Canada as a way to give back."

Chris Silva (pictured at left with his brother and mother Darlene)

ALS Canada donors are the lifeblood of our organization. Whether you are an individual donor, corporation, foundation or provincial ALS Society, you are part of making remarkable progress possible. **Thank you!**

We are also grateful to our partners – in particular, Brain Canada which through the Canada Brain Research Fund matched the generosity of Canadians with \$10 million in ALS research funding following the Ice Bucket Challenge. By the end of 2017, nearly all of Brain Canada's \$10 million investment had been allocated to ALS research, along with an additional \$150,000 in matched funds in support of Project MinE.



50,768

donors helped raise
\$6.9 million.



\$280,000

was the appraised value of new or used equipment donated to ALS Canada. An additional **\$153,389** in equipment was purchased for the ALS Canada loan pool.



117

community-based fundraising events were organized by generous donors across Ontario.



\$2.1M

The WALK for ALS was held in 31 communities across Ontario raising more than \$2.1 million of a more than \$4 million nationwide total.

Thank you



"My grandmother was such an incredible person. She always wanted the best for people and empowered everyone else to be a better person. Every 6-12 months, I host a broadcasting event to raise funds in her memory. This is my way of making the best of even the worst situation."

Fabio Giorno (pictured with his family in the back row at the far right)



"I was diagnosed in October with ALS. I am a 29-year-old mother of three beautiful children, 5, 6, and 7... I cannot stress enough how much donating to the WALK for ALS means to me. Please give me a chance to have more time with my loved ones."

Stephanie Christiansen-Hall

Thank you ALS Canada donors! We are grateful for every gift. Individuals, provincial ALS Societies, foundations, corporations and other organizations who gave \$1,000 or more in 2017 are acknowledged on our website at als.ca/donors.

Thank you ALS Canada volunteers! The hours you dedicated at our office, at fundraising events like the WALK for ALS, in the community and in our leadership contributed immensely to our shared successes in 2017.

FINANCIAL SUMMARY

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

ALS Canada adheres to generally accepted accounting principles that comply with the Canada Revenue Agency's requirements. To accommodate the Ice Bucket Challenge, in 2014 we changed to a deferred method of recognizing revenue, which allows us to set aside money on our balance sheet for future investments in research and client services. At December 31, 2017, we had

\$3.5 million in deferred revenue remaining. These funds are held in income-generating secure investments. As soon as the funds are fully committed, the liability is reflected in our records and the deferred revenue balance decreases accordingly.

ALS Canada invests all funds under the guidelines of an established investment policy approved by the Board of Directors. At December 31, 2017, ALS Canada held \$9.1 million in cash, and \$7 million in short and long-term investments of government bonds, corporate bonds, GICs and other financial instruments.

STATEMENT OF FINANCIAL POSITION

December 31, 2017

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2017 Total	2016 Total
Assets					
Current					
Cash	\$ 1,403,423	\$ 7,665,893	\$ –	\$ 9,069,316	\$ 11,844,337
Short-term investments	314,302	4,001,994	277,444	4,593,740	1,758,892
Accounts receivable	499,432	145,545	–	644,977	619,742
Prepaid expenses and other assets	49,197	–	–	49,197	87,221
	2,266,354	11,813,432	277,444	14,357,230	14,310,192
Long-term investments	–	1,405,736	1,022,556	2,428,292	4,709,847
Capital assets	217,436	–	–	217,436	249,041
	2,483,790	13,219,168	1,300,000	17,002,958	19,269,080
Liabilities					
Current					
Accounts payable and accrued liabilities	464,157	1,424	–	465,581	736,313
Current portion of deferred revenue	660,385	694,968	–	1,355,353	2,119,052
Current portion of research grants payable	–	2,432,902	–	2,432,902	3,294,633
	1,124,542	3,129,294	–	4,253,836	6,149,998
Long-term deferred revenue	709,120	369,991	–	1,079,111	1,422,477
Long-term research grants payable	–	5,006,717	–	5,006,717	5,058,315
	1,833,662	8,506,002	–	10,339,664	12,630,790
Commitments					
Net assets	650,128	4,713,166	1,300,000	6,663,294	6,638,290
	\$ 2,483,790	\$ 13,219,168	\$ 1,300,000	\$ 17,002,958	\$ 19,269,080

STATEMENT OF OPERATIONS

Year ended December 31, 2017

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2017	2016
Revenue					
Fundraising and donations	\$ 4,276,959	\$ 2,567,959	\$ –	\$ 6,844,918	\$ 8,618,482
Direct mail campaign	961,128	88,094	–	1,049,222	1,039,116
Interest and investment income	133,421	71,273	22,777	227,471	243,407
	5,371,508	2,727,326	22,777	8,121,611	9,901,005
Expenses					
Research grants	–	2,062,540	–	2,062,540	3,488,454
Other research support	–	725,775	–	725,775	842,984
National programs	101,155	–	–	101,155	43,705
Ontario client support services	2,404,806	–	–	2,404,806	2,308,098
Public awareness	87,820	–	–	87,820	228,486
Advocacy	234,216	–	–	234,216	112,095
Volunteer development	98,484	–	–	98,484	45,369
	2,926,481	2,788,315	–	5,714,796	7,069,191
Other					
Fundraising	1,808,418	–	–	1,808,418	1,690,974
Administrative	403,129	–	–	403,129	396,130
Governance	200,264	–	–	200,264	172,151
Bad debt expense (recovery)	–	(30,000)	–	(30,000)	75,000
	2,411,811	(30,000)	–	2,381,811	2,334,255
	5,338,292	2,758,315	–	8,096,607	9,403,446
Excess (deficiency) of revenue over expenses	\$ 33,216	\$ (30,989)	\$ 22,777	\$ 25,004	\$ 497,559

STATEMENT OF CHANGES IN NET ASSETS

Year ended December 31, 2017

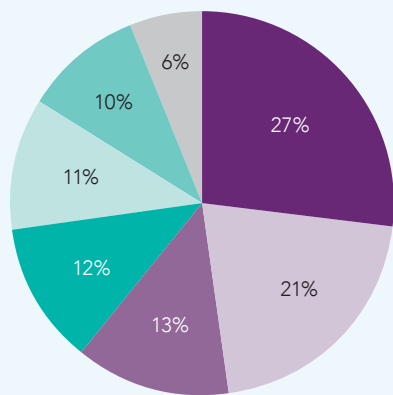
	General Fund	Research Fund	Tim E. Noël Endowment Fund	Total
Balance, December 31, 2016	705,006	4,633,284	1,300,000	6,638,290
Excess (deficiency) of revenue over expenses	33,216	(30,989)	22,777	25,004
Interfund transfers	(88,094)	110,871	(22,777)	–
Balance, December 31, 2017	\$ 650,128	\$ 4,713,166	\$ 1,300,000	\$ 6,663,294

SNAPSHOT OF 2017
REVENUE AND EXPENSES

REVENUE

Excluding the Ice Bucket Challenge deferred revenue and interest / investment income, in 2017 ALS Canada raised \$6.9 million. Our largest source of funds was the WALK for ALS, a national initiative that in 2017 took place in more than 90 communities across Canada, including 31 Ontario communities that raised over \$2.1 million. 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 \$828,781 to ALS Canada in 2017 which includes 40%

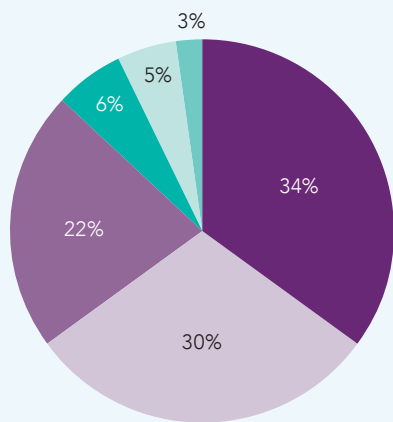
of their net WALK proceeds as well as additional giving. “Other fundraising” includes \$92,293 provided through the generosity of employees in federal government offices across Canada, who gave through workplace giving campaigns led by HealthPartners, as well as the \$280,170 appraised value of equipment that was donated to ALS Canada in 2017 and is included as a corresponding expense for the equipment program. Also included are donations left in estates and wills, which totalled \$264,704, and large gifts from individuals, corporations and foundations totalling \$660,500.



2017 Revenue

- Ontario WALK for ALS
\$2,113,891
- Other fundraising (donations and income)
\$1,677,339
- Direct mail
\$1,049,221
- ALS Ice Bucket Challenge*
\$930,353
- From provincial societies (for research)
\$828,791
- Tribute and monthly giving
\$742,787
- Fundraising events
\$471,566

* Deferred revenue



2017 Expenses

- National research
\$2,788,315
- Support and services
\$2,404,806
- Fundraising
\$1,808,418
- Other charitable purpose
\$521,675
- Administrative
\$403,129
- Governance
\$200,264

EXPENSES

Research

In 2017, ALS Canada awarded \$2.1 million in new research grants. We accounted for the full financial commitment of these grants in 2017, although some will be paid out over multiple years. An additional \$726,000 was used to support the ALS Canada Research Program and the broader ALS research community in Canada.

Our research expenditures do not show an additional \$1 million in matched funds from the Brain Canada Foundation. These funds are reflected in Brain Canada's financial statements rather than ALS Canada's, resulting in the actual amount invested in ALS research in 2017 being greater than our financials show.

Client Services and Support

To respond to the needs of people living with ALS in Ontario, we spent \$1.1 million providing direct service to people and families living with ALS and an additional \$1.3 million to provide equipment.

Other Charitable Purpose

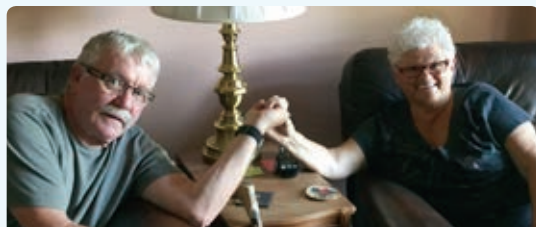
Public awareness, federal advocacy, and volunteer development are part of ALS Canada's charitable work. While the financial results of these efforts can be difficult to quantify, they have an impact that benefits the ALS community.

Fundraising

Our revenue and the expenses associated with generating it are analyzed regularly to ensure our cost of fundraising is controlled. In 2017, our cost of fundraising was 26%, which takes into account costs such as credit card processing fees and fund development support to raise these valuable donor contributions. This amount is well within the Canada Revenue Agency's guidelines for a charity.

Governance

The Board of Directors met in person five times in 2017 in addition to teleconferences and other calls as required. Out-of-pocket expenses for travel and accommodation are reimbursed; however, no compensation is provided for the generous giving of their time. Throughout the year, individual Board and Council members made personal donations to the cause and facilitated donations from their employers. These donations were made to ALS Canada as well as the ALS Society in their province of residence.



"ALS comes like a dark cloud on the horizon that suddenly becomes a tornado; changing everything in your life, ripping at the roots of your foundation and transforming your world into chaos. You sift through the remnants one day at a time and rejoice in the treasures you find left behind. ALS Canada partnered with my husband Randy and I on the journey, providing support, knowledge, direction, and much needed equipment. It is with great pleasure I donate everything I can to say thank you and contribute to their ongoing research in finding a cure."

Grace King



"My best friend was diagnosed with ALS at the age of 39. That's why my partner and I decided that when we pass away, we're going to donate our estate to charity. It goes back to that old adage about how out of something so bad comes something so good. For me, it's all about increased awareness, better education and an expanded understanding of the special needs of ALS sufferers, their families and caregivers."

Richard Ellis

Why your support is still needed

No one could have anticipated the unprecedented success of the Ice Bucket Challenge in 2014. It brought a new level of awareness to ALS. The response from the public was astounding. The generosity of Canadians helped us to leverage matching funds from Brain Canada to invest more than \$20 million in ALS research over a four-year period.



As stewards of this tremendous gift, we have been mindful and deliberate in our decisions about how best to invest the funds to ensure the most benefit to the people we serve. We are proud to say that the Ice Bucket Challenge funds earmarked for research have been nearly fully committed.

Yet there is much more to be done. The momentum of the last several years has inspired hope throughout the ALS community. Within the last five years, there has been more progress in ALS research than in the past century. Potential treatment options are on the horizon for the first time ever.

This is a watershed moment filled with promise but also with the sobering awareness of a changing landscape that requires us to prepare for a future reality that is different than what we know today. How will the healthcare system

respond to new therapies, and will Canadians be able to benefit from equitable, timely and affordable access? What resources must we have in place to adequately support the expectations of the community we serve?

To answer these questions we engaged the ALS community within Canada and beyond as part of a strategic planning process to reassess our own role as an organization and determine the best course of action. We heard from people living with ALS, from our provincial partners, from ALS researchers and clinicians, from our counterparts in other countries, and from other health organizations for perspective and insight. The result is a new strategic plan grounded in a vision and mission that reflect where we are headed as a community, and the outcomes we want to see for all Canadians affected by ALS:



a better standard of care; equitable access to new treatments; and timely, credible information to support decision-making.

Now, more than ever, we need to keep ALS front and centre in the hearts and minds of donors and influencers who can help to create a different reality for people living with ALS. Our community is unwilling to accept the status quo and the daily challenges we know all too well. Fueled by the hope that we see in each new research discovery, we envision a different future – one without ALS. Your ongoing support will help to create it.

OUR LEADERSHIP



The **Board of Directors** is a skills-based board from across Canada that provides strategic leadership and oversight for the organization to serve its charitable purpose and make the most effective use of donor dollars.

Ronald Foerster, Chair
Geneviève Bertrand,
Past Chair
Carol Cottrill
Dr. Heather Durham
Nick Egarhos
Laura Gay

Dr. Angela Genge
Anne Marie Giannetti
Dr. Charles Krieger
Josette Melanson,
Treasurer
Patrick Merz
Rick Morgan

Patrick Nelson
Vincent Quinn
Daniel Rivero
Dr. Christine
Vande Velde

The **Scientific and Medical Advisory Council**

provides strategic advice to ensure research activities contribute to the vision and priorities of ALS Canada and are carried out with integrity.

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Vande Velde, Chair
Dr. Heather Durham
Dr. Andrew Eisen
Dr. Angela Genge
Dr. François Gros-Louis
Dr. Sanjay Kalra
Dr. Lawrence Korngut
Dr. Charles Krieger
Dr. Jasna Kriz
Dr. Yana Yunusova
Dr. Lorne Zinman

The **Client Services Advisory Council**

provides input to help improve the journey of people and families living with ALS in Ontario. Members include people with lived experience and those who work with people and families living with ALS.

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Co-Chair
Patrick Nelson, Co-Chair
Ron Black
Sheldon Crystal
Catherine Chater
Tasneem Dharas
Vincent Quinn
Dr. Christen Shoesmith
Jane Sosland
Michael Spivock
Dr. Jeff Sutherland
Dr. Anu Tandon
Danielle Wells

The **Revenue Advisory Council**

supports revenue-generating initiatives that will ultimately help to fund our charitable purpose.

Daniel Rivero, Chair
Jonathan Corber
Carol Cottrill
Geneviève Bertrand
Naguib Gouda
Patrick Nelson

Together, we can achieve more

The ALS Society of Canada is a registered charity dedicated to creating a future without ALS.

We have national responsibilities within a federation of eight provincial ALS Societies across the country. We advance federal advocacy, and we fund ALS research through a national research program that is generously supported by our provincial partners who donate 40% of the net proceeds from their annual WALKs for ALS in addition to other fundraising initiatives. We also play a role similar to our provincial partners by providing community-based support and services to people in Ontario; and we represent Canada's ALS community internationally with global partners like the International Alliance of ALS/MND Associations.

The work of ALS Societies across Canada is governed by the Federation Council, which is comprised of one staff representative and one volunteer representative from each partner organization. Working together, we can maximize our impact to make the greatest difference for people living with ALS, while responding to the variation that exists between provincial healthcare systems where we each play a role in filling gaps.



"Our Federation Partners provide the support that we often need to keep us doing what we do on a daily basis and national research is instrumental to our unified hope that one day we won't have to do what we are doing now."

Cheryl Power,
Executive Director, ALS Society
of Newfoundland and Labrador



"The work of ALS Societies across Canada is that much more impactful because of the strength of our partnerships with one another. Partnerships grounded in the community we serve and support with time, money, professional and personal talents, and unique perspectives. Stronger together, the power of our voices – indeed our offerings – move us toward our ultimate goal of one day beating ALS."

Susan Kennerknecht,
Vice Chair, Federation Council

FEDERATION COUNCIL

Leadership

Briann Smith, Chair
Susan Kennerknecht, Vice Chair

ALS Society of Alberta

Karen Caughey, Executive Director
Jan Desrosiers, Chair, Board of Directors

ALS Society of British Columbia

Wendy Toyer, Executive Director
Vandhana Misri, Past Chair,
Board of Directors

ALS Society of Manitoba

Diana Rasmussen, Executive Director
Micheline Chaput, Vice President,
Board of Directors

ALS Society of Newfoundland and Labrador

Cheryl Power, Executive Director
Tammy Cassell, Board Representative

ALS Society of Prince Edward Island

Bernie Plourde, President, Board of Directors
Cindy Warren, Client Services
Coordinator/Secretary

ALS Society of Quebec

Claudine Cook, Executive Director
Susan Kennerknecht, Chair, Board of Directors

ALS Society of Saskatchewan

Mike Richter, Executive Director
Bernadette Mysko, Board Representative

ALS Society of Canada

Tammy Moore, CEO
Rick Morgan, Board Member



ALS SOCIETY OF CANADA

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 towards a future without ALS.

ALS SOCIETY OF CANADA

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

